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people with HIV australia

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# **HIV and Ageing in Australia – The New Frontier**

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**April 2019**



*Dedicated to the memory of the HIV-positive men and women from the earlier years of the epidemic who did not have the opportunity to age well with HIV*

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NAPWHA's work on HIV and Ageing – Phase 1 – was supported by a one-off contribution from Queensland Positive People. David Pieper was engaged as Project Officer in Phase 1.

**Published by National Association of People with HIV Australia**

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ISBN: 978-0-9924681-6-3

**Suggested Citation**

Woods, R. 'HIV and Ageing in Australia – The New Frontier', National Association of People with HIV Australia, 2019



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# Executive summary

The life expectancy of Australians living with HIV has been steadily increasing and is approaching that of the general population. Many people living with HIV (PLHIV) are already dealing with the changes and challenges of growing older, and many more will be doing so in coming decades. For them, and for the community organisations that serve and represent them, living simultaneously with HIV and with the consequences of ageing is a 'new frontier'. This report describes and synthesises the work that has been carried out by the National Association of People Living with HIV Australia (NAPWHA) to address this challenge now and into the future.

Research provides an increasingly solid evidence base upon which all stakeholders, including NAPWHA, can base their decision-making and activities. With the success of antiretroviral therapy (ART) since the mid-1990s, there has been dramatic fall in the rate of AIDS-related infections and malignancies. PLHIV, a large proportion of whom are now 50 and older, are increasingly being treated for diseases commonly associated with ageing. Evidence suggests that the prevalence of comorbidities and other age-related conditions is higher amongst PLHIV than in their uninfected peers, and that earlier and more pronounced ageing both have an impact. Geriatric syndromes of particular concern are frailty, arising from the cumulative effects of age-related health deficits; and chronic inflammation, upon which both HIV and ageing have an effect.

The vulnerability to develop physical and mental health problems, as well as the distress caused by symptoms and their impacts on daily functioning, is increased among those who have been living with HIV for many years. This vulnerability reflects the impact of diagnosis in the earlier period of HIV, when prognosis was poor, treatments were less effective and HIV-related trauma and stigma were more pronounced; as well as the increased time living with a chronic disease, including a younger age at HIV diagnosis, and the effects of prolonged HIV treatment or long periods without treatment.

Research adopting mixed qualitative and quantitative methods addresses the lived experiences of older PLHIV, who do not comprise a homogenous group. The experience of ageing with HIV is impacted by factors such

as gender, sexual orientation, socio-economic status and age at diagnosis; consequently older PLHIV deal with the ageing experience in diverse ways. Studies consistently report high levels of self-rated health, active engagement with life, and optimism about the future. On the other hand, mental health problems are also commonly reported; there are fears about whether aged care services are equipped to provide HIV-sensitive care; and financial hardship, housing stress, social isolation, loneliness and an abiding HIV stigma contribute to poorer outcomes for many older PLHIV.

Helpful strategies adopted by older PLHIV themselves include:

- Caring for mind and body through adherence to ART and other treatments, and a focus on diet, exercise and effective stress management.
- Active decision-making in favour of wellbeing-promoting strategies and choices, eliminating negative relationships or environments, and adopting positive attitudes and beliefs.
- Engaging in meaningful activities – such as hobbies, employment or volunteering – that contribute to ongoing learning, maintaining focus and establishing purpose.
- Building and maintaining strong networks of friends, support groups and service organisations.

Of particular relevance to NAPWHA and its communities is the research finding that peer support continues to play a central role in helping PLHIV to achieve positive health and wellbeing outcomes, including peers supporting peers with strategies such as those described above. HIV peer navigators also assist in engaging people in HIV care across the care continuum.

Initiatives to promote successful ageing for PLHIV, including those that support treatment adherence, preserve health and delay disease progression, rely on having in place a strong service delivery framework. Explicit integration of geriatric principles into HIV care, being attuned to age-related issues such as frailty and chronic inflammation, and holistic addressing of the impacts of multiple morbidities and resulting polypharmacy are strategies supported in the literature.



Care should ideally be provided through a coordinated multidisciplinary team in order to avoid fragmentation of care pathways, and this includes addressing loneliness, social isolation, financial hardship and the stigma associated with both HIV and ageing, all of which have an impact upon wellbeing and quality of life. There is value too in incorporating rehabilitation approaches that help to manage the health-related challenges and disabilities associated with HIV.

Keeping informed of, and contributing to, policy debates and initiatives is crucial for organisations such as NAPWHA when striving to achieve the best outcomes for older PLHIV. This document considers developments in Australian policy concerning the increasingly interconnected areas of health care, aged care, informal carers, and the disability sector, and notes several features that hold promise for NAPWHA's constituency: a focus on consumer-directed care; active coordination to promote continuity of care; and stronger recognition, reward and resourcing for informal carers. Demands on health and aged care services are high, and will increase as Australia's population ages. Studies suggest that there is concern about the preparedness of services to adequately address the often complex needs of older PLHIV across the care continuum. In the same way as ageing is uncharted territory for many living with the virus, so does HIV and ageing present an unfamiliar challenge for policy makers and service providers.

As Australia's peak non-government organisation representing community-based groups of people living with HIV, and with the learnings gained in Phase 1 of the HIV and Ageing Project, NAPWHA is well placed to ensure that a focus on HIV and ageing continues through the following:

- **Community organisation** – serve as a peak organisation, provide support to affiliates, mobilise communities, and unite organisations with respect to HIV and ageing
- **Advocacy** – through advocating for the needs of older PLHIV in policy decision-making, maintain a strategic focus on PLHIV at the federal public policy level and serve as a conduit between peer-based community organisations and the Australian Government
- **Peer support** – continue to develop expertise in peer support in the context of HIV, articulate and promote peer support principles and best practices, and apply learnings gained in previous decades to

promote peer support and peer navigation for older PLHIV

- **Networks and partnerships** – foster the networks and partnerships that are essential for developing innovative approaches to addressing the new frontier of HIV and ageing
- **Research and evaluation** – conduct, and participate in, research and evaluation studies that generate understanding, evidence and best practices for improving the lives of older PLHIV
- **Services** – work closely with community-based affiliates to promote innovative and integrated care services that will best meet the needs of older PLHIV

In keeping with this broad approach, recommendations are made for continuing NAPWHA's HIV and Ageing Project in a second phase that will build directly on the work described in this document.



# Acronyms

<b>ACAT</b>	Aged Care Assessment Team	<b>ICSS</b>	Integrated Carer Support Service
<b>ADL</b>	Activities of Daily Living	<b>LGBTIQA+</b>	Lesbian, Gay, Bisexual, Transsexual, Intersex, Queer, Asexual, other diverse sexual orientations and gender identities
<b>AIDS</b>	Acquired Immunodeficiency Syndrome	<b>MSM</b>	Men who have Sex with Men
<b>APPLES</b>	Australian Positive and Peers Longevity Evaluation Study	<b>NAPWHA</b>	National Association of People With HIV Australia
<b>ART</b>	Antiretroviral Therapy	<b>NDIA</b>	National Disability Insurance Agency
<b>ASHM</b>	Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine	<b>NDIS</b>	National Disability Insurance Scheme
<b>BMI</b>	Body Mass Index	<b>NGO</b>	Non-Government Organisation
<b>CD4</b>	Cluster of Differentiation 4 – white blood cells that fight infections	<b>OPAN</b>	Older Persons Advocacy Network
<b>CGA</b>	Comprehensive Geriatric Assessment	<b>PATSIN</b>	Positive Aboriginal and Torres Strait Islander Network
<b>COAG</b>	Council of Australian Governments	<b>PHN</b>	Primary Health Network
<b>COTA</b>	Council on the Ageing	<b>PLHIV</b>	People Living With HIV
<b>DDI</b>	Drug-Drug Interaction	<b>PTSD</b>	Post-Traumatic Stress Disorder
<b>GP</b>	General Practitioner	<b>QoL</b>	Quality of Life
<b>HAND</b>	HIV Associated Neurocognitive Disorder	<b>ROAH</b>	Research on Older Adults with HIV (study)
<b>HALL</b>	HIV and Later Life (study)	<b>SGM</b>	Special General Meeting
<b>HCV</b>	Hepatitis C Virus	<b>SRSA</b>	Self-Rated Successful Ageing
<b>HIV</b>	Human Immunodeficiency Virus	<b>TON</b>	Treataware Outreach Network



# 1 Introduction

## 1.1 Background

The National Association of People with HIV Australia (NAPWHA) is Australia's peak non-government organisation representing community-based groups of people living with HIV (PLHIV).

NAPWHA launched the HIV and Ageing Project in 2017. Supported by Queensland Positive People, ViiV Healthcare

and a Communicable Disease Prevention and Service Grants Fund grant from the Australian Government, the first phase of NAPWHA's HIV and Ageing Project (Phase 1) investigated, consulted and reported on the impact of ageing on PLHIV in Australia. This report builds on the outcomes of Phase 1 and through additional research, summarised in Table 1 below.

## 1.2 Research questions

The following questions guided the data-gathering and analysis, and the writing of this report:

1. What does some of the international and national literature say about the experience of HIV and ageing – especially as regards the role of peer supports but also with reference to the scientific literature on the impacts of ageing with HIV and impacts of living with multiple co-morbid conditions?
2. What are some of the national policy frameworks that impact on ageing with HIV in the Australian context?
3. What is currently known about the cohort of people ageing with HIV in Australia?
4. What are the major HIV and ageing issues for Australia?
5. What are future research activities in which NAPWHA could play a central role in advocating for or coordinating?
6. With reference to comparative international literature and NAPWHA's role as a national advocacy organisation for people living with HIV in Australia, what could be mapped out as NAPWHA's future policy and programmatic activities in this area?
7. What are the risks of doing nothing?

## 1.3 Research approach

Research carried out in order to complete this report is summarised in Table 1.

*Table 1: Methods of data-gathering for this report*

Method	Description	Further reference
<b>Literature review</b>	<ul style="list-style-type: none"> <li>• Systematic reviews of evidence published in peer-reviewed journals in English between 2010 and 2018</li> <li>• Reports of studies relating to HIV and ageing published in peer-reviewed journals in English between 2010 and 2018</li> <li>• Studies of the lived experiences of older PLHIV</li> </ul>	Appendix A (table of evidence)
<b>Document analysis</b>	Desktop review: <ul style="list-style-type: none"> <li>• Australian policy context</li> <li>• Comparative – role of national positive people's organisations</li> </ul>	Appendix D (Australia's health landscape)  Table 4 (comparative organisations)
<b>NAPWHA HIV and Ageing Project Phase 1</b>	<ul style="list-style-type: none"> <li>• A series of consultations and presentations undertaken in 2017 and 2018, underpinned by a review of documentation and literature</li> <li>• A small-scale survey (N=39) of people living with HIV and the organisations representing them</li> </ul>	<ul style="list-style-type: none"> <li>• Highlights from Phase 1 included in this report</li> <li>• Appendix B (consultees)</li> <li>• Appendix C (survey questionnaire)</li> </ul>
<b>Post Phase 1 consultation</b>	The lead author: <ul style="list-style-type: none"> <li>• Worked closely with NAPWHA staff to scope and design the study, consider organisational priorities for addressing HIV and ageing, and strategize Phase 2</li> <li>• Made a presentation on HIV and ageing at the 2018 NAPWHA Annual General Meeting, and obtained additional feedback, especially regarding NAPWHA's addressing of HIV and ageing looking forward</li> </ul>	Appendix E (proposal for Phase 2 of NAPWHA's HIV and Ageing project, including a program logic)





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## 1.4 This report

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The objective of this report is to present the outcomes of the research described above for a wide readership. It provides an evidence-based and policy-informed foundation for NAPWHA to address the ‘new frontier’ of HIV and ageing in the coming years. The content is structured as follows:

- Discussion of the evidence base on HIV and ageing
- Presentation of insights into the lived experiences of PLHIV generated through social research carried out in Australia and internationally
- Description of the dynamic policy context and its current and potential impacts on growing older with HIV in Australia
- Highlighting insights generated through research and the professional literatures on pathways to improved health and wellbeing outcomes for older PLHIV
- Discussion of the role and function of NAPWHA in addressing HIV and ageing
- A synthesis of the study as a whole, structured in such a way as to provide a response to each of the research questions listed earlier.

All literature and documentation used in the study are contained in the reference list; and there are several appendices, whose links to material contained in the body of the report are signposted.

## 2 HIV and ageing: Evidence

The intersection of HIV and ageing is an active field of research and publication. This narrative review of literature published between 2010 and 2018 focuses on topics that are of interest to professional groups, researchers, service providers, policy makers and PLHIV. On the assumption that a literature review is a 'secondary analysis' research technique that seeks, presents, and analyses 'formal knowledge that has been articulated, codified and stored in an accessible format' (Jesson, Matheson and Lacey 2011: 16), the analysis is used to generate new insights, particularly – in consideration of the research questions – insights that contribute to applied policy and practice.

Selected studies are summarised in a 'table of evidence' (Appendix A), following the model of Reychetnik and Frommer (2002). Only literature that comprehensively

describes the conduct and findings of a discrete research study – or systematic reviews of such studies – are included in this table. Studies are analysed and described on the basis of the following criteria:

- Author(s); date; location
- Study objectives, research design and methodology
- Key findings
- Implications, as put forward by the author(s) themselves.

Combined with a wide range of other literature and documentation, listed alphabetically in the reference list, findings are analysed on the basis of a narrative approach to literature review (Rhoades 2011). Doing so assists in establishing the 'state of play' with regard to the identified topics relating to HIV and ageing, and to addressing the research questions.

### 2.1 Demographic shift

Several recent cohort studies have suggested that the life expectancy of PLHIV is likely to 'approach that of the general population, particularly among those who initiated ART [antiretroviral therapy] at earlier disease stages' (Hunt 2014: 2). Consequently, an increasing proportion of PLHIV in Australia are older adults: compared to 5% in 1986, 43% of PLHIV in Australia were aged over 50 years in 2016 (Kirby Institute 2017: 48). This is in keeping with trends in all countries where PLHIV have access to ART. In the USA, for example, the Centre for Disease Control and Prevention estimates that over half of PLHIV are now over the age of 50 years (Gauraldi and Pallela 2017). International studies suggest that, alongside improved survival, more people first being diagnosed at an older age also contributes to an overall increase in cohorts of older PLHIV (Rosenfeld et al 2015: 2).

Jansson and Wilson (2012) made use of innovative demographic modelling techniques to show that the mean age of PLHIV in Australia increases by around half a year (0.49 years) each year. These researchers (from the Kirby Institute) also predicted that prevalence is likely to remain greatest in the inner city areas of the major capital cities, but that, due to internal migration, relative changes would be observed for each jurisdiction regarding the numbers of PLHIV living in the major cities vis-a-vis the rural/regional areas (Jansson and Wilson 2012: 5).

In the most recent modelling carried out by the Kirby Institute, Bretaña et al (2018) make the following predictions:

- Assuming continuation of the current trend in annual notifications, the total number of diagnosed PLHIV in Australia would increase by 38% from 24,646 in 2017 to 34,095 in 2027



- In 2027, the highest proportion of PLHIV will be in the 55-59 age group and the average age will be 52 years.
- If, however, annual HIV notifications declined by 65%, the average age of diagnosed PLHIV in Australia would be 54 years in 2027.

## 2.2 Comorbidities

The overall trend since the mid-1990s among people living with the human immunodeficiency virus (HIV) is of a dramatic fall in the rate of AIDS-related infections and malignancies (Wing 2016). Instead, older PLHIV are being treated for diseases commonly associated with ageing (Escota et al 2018). There is growing evidence that the prevalence of comorbidities and other age-related conditions is higher amongst PLHIV than in their uninfected peers (Negredo et al 2017; Petoumenos et al 2017: 8). These non-infectious comorbidities include, but are not limited to:

- Cardiovascular disease and stroke
- Chronic neurological complications, also described as HIV-associated neurocognitive disorders (HAND)
- Several types of cancer, especially those associated with chronic viral infections
- Osteoporosis and fracture

- Depression
- Diabetes mellitus
- Chronic renal disease
- Chronic obstructive pulmonary disease

(Escota et al 2018; Negredo et al 2017; Wing 2016; Althoff et al 2016)

In older PLHIV, these pathologies may exist simultaneously as 'complex multimorbidities' (Guaraldi and Pallela 2017: S130). Although PLHIV are at greater risk of comorbidities than peers living without the virus, comorbid events do not appear to occur dramatically earlier, but research is continuing (Althoff et al 2016). HAND is one of the comorbidities discussed in the research, and since it has been estimated to occur in 30% to 50% of HIV-infected people (Cohen et al 2015), it is described in greater detail:



### HIV-Associated Neurocognitive Disorders

HIV enters the brain soon after infection through crossing the blood-brain barrier. Prior to the availability of ART, AIDS Dementia Complex occurred in over 20% of HIV-infected people as one consequence of this. The brain continues to be a reservoir for HIV even among patients who receive ART.

In the era of ART and viral suppression, the diagnostic classification of HIV-Associated Neurocognitive Disorder (HAND) has been developed as an alternative to AIDS Dementia Complex. While

not as debilitating as dementia, HAND manifests as impairments of attention and working memory. It has a debilitating impact on executive functioning.

HIV may interact with the ageing brain to affect neurological structure and function, but research has not yet resolved the issue of whether HIV

- directly affects neurocognitive degeneration
- accelerates normal cognitive ageing; or
- contributes to a worsening of other comorbidities.

Rosenfeld et al (2015) write that, as a result of the impact of comorbidities, non-HIV factors become increasingly important to the health and wellbeing of older PLHIV.

A high burden of comorbidities among older PLHIV is directly linked to another health issue frequently raised in the literature, namely polypharmacy (Althoff et al 2017).

## 2.3 Polypharmacy

Edelman et al (2013: 615) point to a growing consensus in the literature that the use of five or more medications is 'a clinically meaningful definition of polypharmacy'. Other definitions include:

- The consumption of excessive, unnecessary or non-indicated drugs
- The use of at least one unnecessary medication
- The use of different thresholds for the number of medications in a patient's drug regime.

(Negredo et al 2017: 4; Edelman et al 2013: 614)

The risk of harms from polypharmacy increases as the number of medications increases (Edelman 2013). Common problems associated with polypharmacy in older people include:

- Inappropriate medication use, including decreased medication adherence, and difficulties managing medication, especially when multiple prescribers are involved
- Adverse drug events, including drug-drug interactions (DDIs), drug toxicity and mortality
- Delirium, falls and fractures
- Impaired elimination and/or drug accumulation linked to loss of the optimal functioning of the liver or kidneys, which may decrease with age.

(Edelman et al 2013; Date 2018; Guaraldi and Rockwood 2017; Negredo et al 2017)

These effects can be exacerbated in older people living with HIV because 'various drug interactions can alter the effectiveness of the antiretroviral regimen and can result in drug toxicity' (Blaycock and Wartmann 2015: 447). ART typically requires the use of at least three different antiretrovirals on a daily basis, and many PLHIV may experience polypharmacy as soon as they begin with ART. In addition, their total time of exposure to polypharmacy is extended compared to the general population, the effects of which are exacerbated in the older years (Edelman et al 2013: 614). As written by Althoff et al (2016: 6):

*... multimorbidity leads to polypharmacy. Polypharmacy can lead to declines in neurocognitive performance, which can contribute to falls and fragility fractures causing pain, additional psychoactive medication, and increased polypharmacy.*

Edelman et al (2013) drew on a comprehensive review of the literature to recommend an intervention for polypharmacy that is specifically suited to the needs of PLHIV (this is summarised in the table of evidence in Appendix A).

## 2.4 Accelerated or accentuated ageing?

In considering the increased longevity of PLHIV, an important question for research has been (see eg

Singh et al 2017; Pathai et al 2014; Hunt 2014): Does HIV accelerate the ageing process, causing age-related



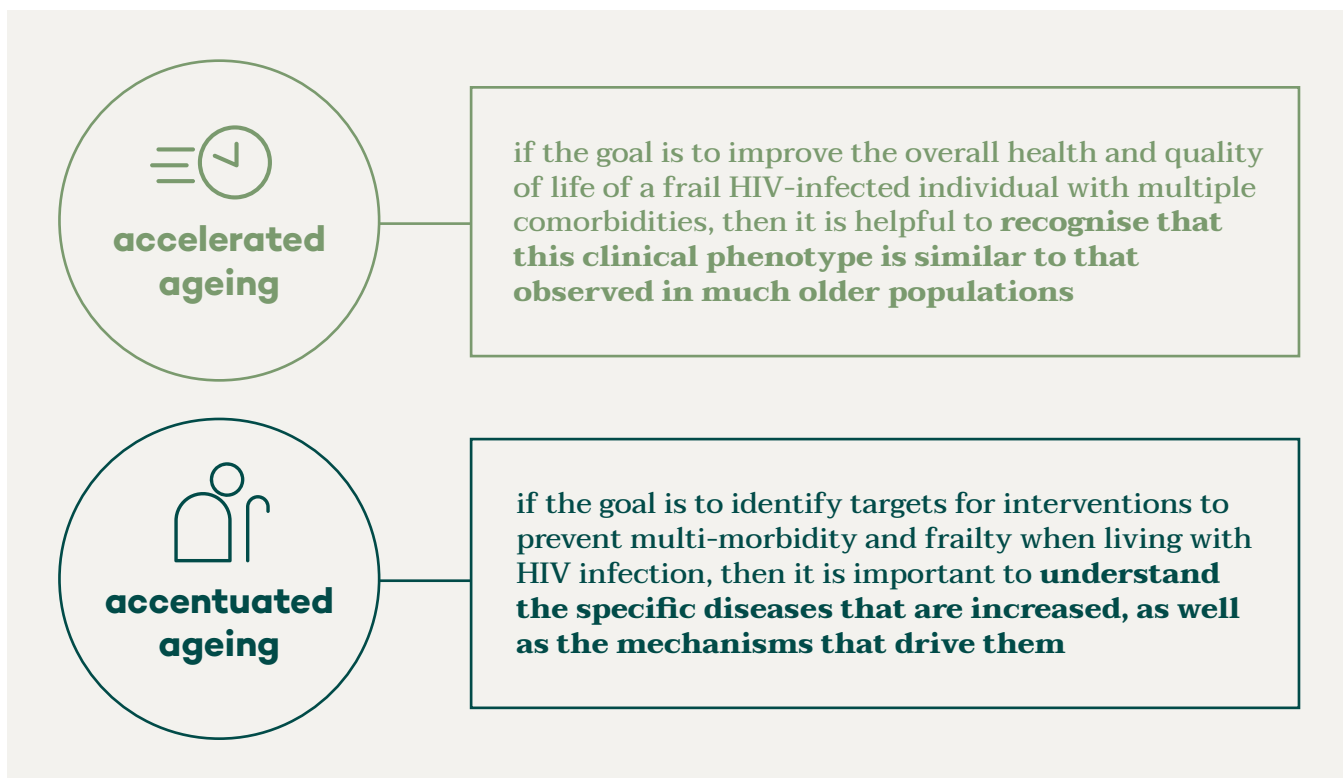
symptoms to appear earlier? Or is it rather the case that HIV presents an additional risk factor for developing chronic conditions at every age, which in the older years serves to accentuate the challenges of ageing?

Studies have provided mixed results, suggesting that both accelerated and accentuated ageing have an impact, with neither by itself providing a complete explanation (Pathai et al 2014: 833). These researchers point out that whether HIV is a model of accentuated or accelerated ageing is probably disease or condition specific. With respect to the immune system, including evidence on ongoing immune

activation (discussed in greater detail below), there is support for accelerated immune senescence/ageing. On the other hand, many illnesses, such as cardiovascular disease and diabetes, appear to be accentuated rather than accelerated in patients living with HIV (Pathai et al 2014).

In similar vein, Sabin and Reiss (2017) write that, although often diagnosed with age-associated non-communicable comorbidities at younger ages, there is insufficient evidence to demonstrate that HIV infection leads to either accelerated or accentuated ageing. Hunt (2014: 3) suggests that 'the framing of the debate depends on one's perspective'. This could be expressed as follows:

Figure 1: Relative focus on accelerated or accentuated ageing influenced by clinical goals



Source: based on Hunt (2014: 3)

In summary, the trend in the literature is to suggest that earlier and more pronounced symptoms of ageing both need to be kept in mind; that some diseases or conditions are accelerated, while others may be accentuated; and

that the framing of the debate may be influenced by differing perspectives guiding service provision. Research is continuing.

## 2.5 Frailty

Frailty is related to the ageing process and is considered to be 'one of the original geriatric syndromes' (Singh et al 2017: 502). As described by Brothers et al (2014: 1170):

*Although people generally accumulate health problems with age, individuals of the same age can experience very different levels of health. Geriatricians introduced the term 'frailty' to describe this variability. Frailty represents the cumulative effects of age-related deterioration in multiple physiological systems and homeostatic mechanisms, resulting in greater vulnerability to stressors.*

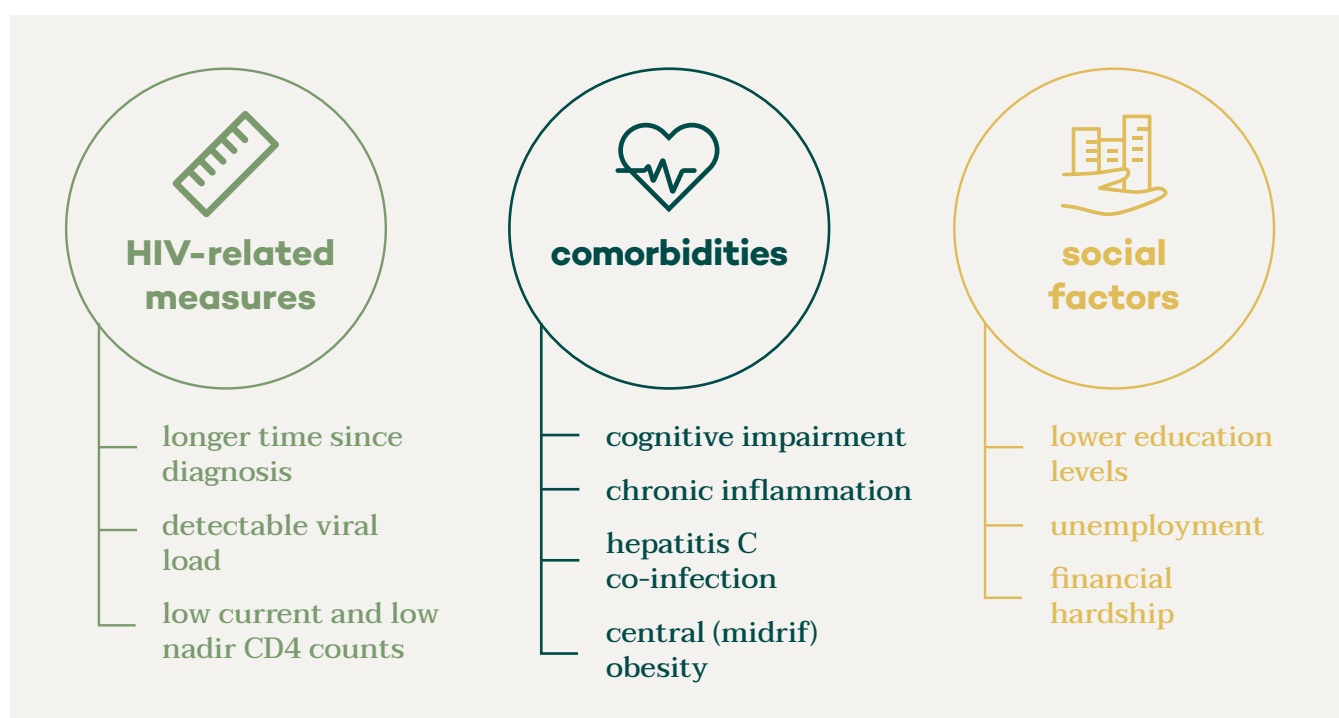
Frailty has been conceptualised as a **physical phenotype**, a clinical syndrome that is distinct from other disease processes, or from ageing itself; or as a **state of vulnerability** arising from an accumulation of non-specific but age-related health deficits (Brothers et al 2014). Irrespective of the model of frailty adopted, commentators agree that it reflects a decline in the body's

physical and psychological reserves and increases the risk that an apparently minor event can precipitate a serious decline in health (Date 2018).

A body of evidence points to PLHIV being more susceptible to becoming frail at earlier ages than the general population, with associated declines in health and functioning (Wing 2014: 64; Brothers et al 2014; Levett et al 2016). According to Brothers et al (2014: 1178), within an overall approach to caring for older people with HIV, the concept of frailty could be 'useful for identifying vulnerable individuals, for organizing care and for comprehensively measuring the impact of illness and treatment on overall health status'. These researchers also point out that many PLHIV are likely to survive to an age where they might become frail in spite of, and not because of, HIV infection (Brothers et al 2014).

Risk factors for PLHIV in developing frailty can be clustered into three groups:

Figure 2: Risk factors for PLHIV in developing frailty



Sources: Brothers et al (2014); Wing (2016)



Several measures are used to identify frailty, ranging from clinical judgment, through measures of a single item (such as speed of walking), to the assessment of multiple domains of health using validated tools (Brothers et al 2014: 1171). The outcomes of an Australian study (Yeoh et al 2018) lend support to the view that whether or not an assessment of frailty is made depends to some degree on the instrument used to measure it: based on a sample of 93 HIV-positive men aged over 50, all using ART, the study found the prevalence of frailty to vary between 10.8% and 22.6%, depending on the instrument.

Despite this lack of consistency, the researchers suggest that 'identifying frailty is the first step in the implementation of a range of interventions to improve the quality of life and HIV care in people living with HIV' (Yeoh et al 2018: 9). Date (2018) argues that the presence of one or more 'frailty syndromes' – falls, immobility, delirium, incontinence, susceptibility to medication side effects – in an older person with HIV should prompt closer monitoring and further investigation, even though it may on its own not necessarily indicate frailty.

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## 2.6 Chronic inflammation

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Inflammation refers to the body's process of fighting against harmful pathogens and manifests as the release of chemicals that trigger a response from the immune system. Chronic inflammation happens when this response lingers, which may have a negative impact on tissues and organs. Compared to older people in the general population, chronic inflammation has been found to be higher in older people living with HIV (Escota et al 2018).

Researchers make the point that changes that occur to the immune system in the process of ageing generally – including T-cell abnormalities – show similarities with processes that occur in untreated HIV infection (Escota et al 2018; Date 2018; Pathai et al 2014). On the basis of a systematic review of the evidence, Pathai et al (2014) found that in many patients living with HIV there is evidence of 'a state of immune senescence characterized by low level, constitutive inflammation, combined with an inability to rapidly mount adequate immune activation upon challenge'.

The presence of 'subclinical chronic inflammation related to HIV infection is...associated with major age-related complications' (Negredo et al 2017: 2). Wing (2016) concludes that elevated rates of inflammation seen in PLHIV are associated with greater risk of disease, including cardiovascular, renal, neurocognitive, oncological and osteoporotic illnesses. The persistent inflammatory state may also interact with health-related behaviours such as smoking, diet, and exercise, and 'may be even more important interventions for HIV-infected patients than the general population' (Hunt 2014: 7).



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## 2.7 The vulnerability of long-term survivors

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People with a longer duration of HIV infection constitute the most vulnerable sub-group among all PLHIV who are ageing. A study carried out by Guaraldi et al (2015) found that the prevalence of comorbidities and age-related chronic diseases was significantly higher amongst HIV-positive groups compared to the general population; and that, amongst the HIV-positive groups, duration of HIV infection was associated with an increased risk of multimorbidity. Put differently, length of time with HIV infection is a greater contributor to morbidity and lower quality of life than chronological age.

A study conducted in the UK (McGowan et al 2017; see Appendix A) found that longer time with diagnosed HIV infection was (independently of age) related to a higher prevalence of all self-rated physical and mental health problems, the distress caused by these symptoms, and health-related functional problems such as mobility, self-care and performance of usual activities. The association between longer time with diagnosed HIV infection and poorer health can be linked to two factors (McGowan et al 2017: 98):

- **Earlier calendar time of diagnosis:** diagnosis at a time when HIV prognosis was poor, treatments were less effective or more complex, HIV-related stigma was greater, and people living with the virus were dealing with often overwhelming grief and loss

- **Increased time living with a chronic disease:** health and social implications, including younger age at HIV diagnosis, the effects of prolonged HIV treatment, or the effect of longer time with untreated HIV infection.

Date (2018) writes that many of the longest-term survivors from the pre-ART era continue to be impacted by the legacy of the early years of the epidemic. She suggests that a diagnosis of complex post-traumatic stress – or even a distinct ‘AIDS survivor syndrome’ – may be more accurate than that of post-traumatic stress disorder (PTSD) in accounting for the psychological and psychiatric symptoms seen in some long term survivors. It may also contribute to finding means of addressing these debilitating conditions.





# 3 Lived experiences of older PLHIV

HIV peer organisations, health and social service providers, governments and researchers are grappling with how to support PLHIV to age well. In reaching for this objective, stakeholders need to better understand what is happening with PLHIV as they age, preferably in their own words, and to apply those understandings to their practices.

Continuing the narrative review approach adopted for section 2 of this document, this section considers published research from Australian and similar jurisdictions internationally – specifically the United Kingdom (UK), Canada and the United States of America (USA) – that sheds light of the lived experiences of older PLHIV.

## 3.1 Australian research

### 3.1.1 Australian Positive and Peers Longevity Evaluation Study (APPLES)

Commencing in 2014, APPLES was a prospectively recruited cross-sectional sample of HIV positive and HIV negative men who identified as gay or bisexual and were aged 55 years and over (Petoumenos et al 2017). Key findings from the study, summarised in Appendix A, include:

- The HIV-positive sample had significantly increased odds for self-reported comorbidities including thrombosis, diabetes, heart disease, neuropathy and bone disease.
- More HIV positive men (42%) had a healthy body mass index (BMI) compared with HIV negative men (33%).
- Evidence of past or current hepatitis C virus (HCV) coinfection was significantly greater among HIV positive men (8%) compared to HIV negative men (1%).

- Increased prevalence of traditional risk factors among HIV positive populations (such as elevated lipids, hyperglycaemia, altered body composition, smoking, and alcohol and recreational drug use) significantly contributed to an increased risk for morbidity.

The researchers suggest that understanding the relative contribution of HIV infection, ART and lifestyle factors to the development of comorbidities would contribute to the development of better screening, prevention and advocacy programs (Petoumenos et al 2017).

### 3.1.2 Qualitative study in regional Queensland

Gardiner (2018) investigated the experience of older PLHIV in regional Queensland (see Table of evidence in Appendix A). Using qualitative methodology, this study found that, in contrast to the ‘third age’ now seen as achievable for most of the baby boomer generation, illness had forced a form of premature retirement on these participants.

Trauma was common in the life experience of the participants: they had faced imminent mortality in early adulthood, and had lost partners and networks of friends. In particular, participants in the study who had been on the Disability Support Pension (DSP) had faced the challenge of finding a non-work-related purpose early in life. While many were on anti-depressants, few had a mental health plan. Most participants felt that the complexities of their lived experiences had given them wisdom that could be applied to the process of ageing (Gardiner 2018).

### 3.1.3 HIV Futures 8

HIV Futures is a repeated cross-sectional and longitudinal study of PLHIV in Australia conducted by the Australian Research Centre in Sex, Health and Society at La Trobe University since 1997. In its eighth iteration, HIV Futures 8 (Power et al 2016), the demographic shift is already evident: the average age of study participants (N=895) was 51 years, and over half (56.3%, n=485) were aged 50 years or more. Almost a quarter of the participants who were 50 years or older (23%, n=51) had been diagnosed with HIV in 2010 or more recently. The majority of participants (60.4%, n=533) reported their overall sense of wellbeing to be 'good' or 'excellent', and there were no significant differences between age groups in this regard. At the same time, older participants were significantly less likely to consider their health to be 'excellent' or 'very good'.

Other findings from this study include (Power et al 2016):

- More than half the participants (51.8%, n=454)

reported that they had been diagnosed with a mental health condition at some point in their life, while 31.9% (n=277) had taken medication for a mental health condition within the past six months.

- 42 participants indicated that they needed regular assistance with daily tasks due to a long-term illness or disability. Despite this, only 12 people indicated that they had received home-based care from a formal provider.
- 197 participants (22.3%) indicated they had been diagnosed with a sexually transmitted infection in the past 12 months.
- 213 participants (24.3%) reported that they smoked on a daily basis, and 323 (36.9%) had previously smoked daily, but had quit. The rate is almost twice as high as for the Australian population as a whole (12.8%).

On the basis of the findings from HIV Futures 8, the researchers conclude, in respect of older PLHIV:

*People who were older were more likely to report poorer physical health, more likely to have co-morbidities and more likely to report limitations in their capacity to undertake daily tasks due to poor health. This points to a need for the HIV sector and the mainstream health and aged care sectors to ensure appropriate services are available to PLHIV. This will require clinical and support staff to have skills in HIV management as well as an understanding of social issues related to HIV, including stigma and discrimination.*

(Power et al 2016: 5)

## 3.2 International research

### 3.2.1 United Kingdom

#### 3.2.1.1 HIV and Later Life (HALL) study

The HALL study was conducted in the UK between 2013 and 2015 (Rosenfeld et al 2015; summarised in Appendix A). Findings from the study suggest that older PLHIV experience challenges that are both similar to those experienced by younger PLHIV, and unique to the later years. These are summarised in Table 2:



Table 2: Challenges identified by participants in the HALL study (UK)

### Challenges similar to younger PLHIV

- HIV-related stigma
- Difficulties of disclosure
- Uncertainties of living with a chronic condition
- The impact of HIV on work, social relations, sexual and romantic relationships, and financial security

### Unique experiences and concerns of the later years

- Ageism intersecting with HIV stigma, and its potential impacts on the quality of long-term care
- Fear or difficulty in disclosing HIV status to their children and grandchildren
- Uncertainties over how HIV, HIV medications, and ‘normal ageing’ intersect to influence physical and mental health
- Dealing with the consequences of career interruptions and the need to reformulate plans for retirement

Source: based on Rosenfeld et al (2015)

Two-thirds of people taking part in the study reported good mental health and QoL. The factors associated with poorer reported mental health and lower QoL were predominantly social (eg poverty), rather than related to physical health. Women’s levels of depression and anxiety were slightly higher than those of male participants. Women were also less satisfied than men were with their QoL, health, and the support they received from friends (Rosenfeld et al 2015).

The researchers concluded that the experience of ageing with HIV is shaped by gender, sexual orientation, culture, income, migration status, and age at diagnosis (Rosenfeld et al 2015). Many study participants also acknowledged that only those living with HIV could fully appreciate what it was like to live and age with the virus.

In a deeper analysis of the HALL study data, Rosenfeld and Anderson (2018) focused on how older PLHIV in the UK seek and secure support, and on what terms. The analysis showed that social support cannot easily be divided into ‘formal’ or ‘informal’ domains and is further complicated by their membership in communities which vary in the openness of discussion of HIV. Participants’ social networks were ‘varied and often robust, including relationships with family, friends, partners, work colleagues, neighbours, and fellow members of churches and other community groups’ (Rosenfeld and Anderson 2018: 8). Many described living with HIV as ‘so complex,

nuanced and, to a great extent, inexpressible and even unknown, that only other PLWH [PLHIV] could comprehend its experience and impacts’ (Rosenfeld and Anderson 2018: 8). This finding has implications for peer support, discussed in greater detail in section 5 of this document.

### 3.2.1.2 National Study of Ageing and HIV (50 Plus)

The 50 Plus study explored the needs and experiences of people living with HIV aged 50 and over in the UK (Terrence Higgins Trust 2017; also see Appendix A). The researchers write:

*Many support needs are not unique to people living with HIV – the welfare and social care systems across the UK are failing many. However, we have found that living with HIV adds an extra level of need – additional necessities that go beyond the ‘standard’ experiences of ageing (Terrence Higgins Trust 2017: 14).*

Based on the assumption that, for all stakeholders, growing older with HIV can be considered ‘unchartered territory’, the researchers concluded that people living with the virus are a diverse group, and cautioned against placing all PLHIV aged over 50 into one category. For

example, the study found that PLHIV reported feeling happier the older they got. Their levels of wellbeing improved, and they had lower levels of HIV self-stigma: altogether, 77% of respondents aged 65 and over rated their wellbeing as 'good' or 'very good', compared to 34% of those aged 50-60. Of individuals aged 50-60, 25% reported their wellbeing as 'bad' or 'very bad', compared to only 5% aged 65 or older. Nearly three times as many 50-60 year olds had the highest score for HIV self-stigma compared to those aged 65 or older (Terrence Higgins Trust 2017: 35-37).

The study highlighted the broader living conditions of PLHIV in the UK and found that many faced social isolation and loneliness. Poverty had a powerful impact, with 58% of survey respondents living on or below the poverty line and 84% of respondents concerned about future financial difficulties. Housing was also a central concern: two thirds (62%) of people who responded to the survey did not own their own home. A third (32%) of those over 50 were solely reliant on benefits to live. An additional 5% relied on benefits as the major source of their income.

### 3.2.1.3 ASTRA study

McGowan et al (2017) report on the ASTRA study – a cross-sectional questionnaire study of 3,258 HIV-diagnosed adults (2,248 men who have sex with men [MSM], 373 heterosexual men and 637 women) recruited from UK clinics in 2011– 2012 (see Appendix A).

Five of the most prevalent symptoms were 'lack of energy' (25.9%), 'difficulty sleeping' (24.4%), 'feeling drowsy/tired' (24.2%), 'muscle aches or joint pains' (20.8%) and 'problems with sexual interest/activity' (19.2%).

Congruent with findings from the 50 Plus study (Terrence Higgins Trust 2017; described above), the ASTRA study found that the prevalence of symptoms of depression and anxiety tended to decrease with age. McGowan et al (2017) suggest that a lower prevalence of anxiety and depression among older compared with younger people living with HIV may reflect stronger adaptation to hardship in older adults, which has been developed through their lifespan; and with regard to older PLHIV, it may be a sign of 'resilience'.

The researchers conclude that a longer time with diagnosed HIV infection may be a more important

factor than chronological age in determining wellbeing among people living with HIV. The study found that a longer time with diagnosed HIV infection was related to a higher prevalence of all self-rated health problems independently of age: symptom distress, depression, anxiety and all of the functional domains, such as basic activities of daily living.

## 3.2.2 Canada

### 3.2.2.1 Living strategies

O'Brien et al (2018) examined the type and frequency of strategies used by PLHIV (N=935). The study found that older respondents were dealing with a greater number of concurrent health conditions than their younger counterparts, but were also more likely to use living strategies to help them deal with the disabilities associated with those conditions. Respondents reported engaging most, or all the time, in living strategies associated with:

- **Maintaining a sense of control** – self-management focusing on the basics such as nutrition and getting enough sleep, and maintaining focus or establishing purpose
- **Adopting positive attitudes and beliefs** – for example, 60% agreed with the statements 'I consider myself healthy living with HIV'; and 'I accept and value who I am, good and bad'; slightly more (61%) acknowledged that health fluctuates, with 'good' and 'bad' days

The researchers concluded that 'understanding how living strategies are used among older and younger adults with HIV can help to identify ways health-care providers can promote positive, timely, and age-appropriate self-management approaches for enhancing health' (O'Brien et al 2018: 2).

### 3.2.2.2 Loneliness

Carter (2018) reports on research that aimed to better understand the prevalence of loneliness amongst PLHIV in Canada, and to examine the risk factors and impacts of loneliness. The study (N=836) found that almost two-thirds (64%) of participants reported loneliness, including 18% who said they were lonely 'quite often', and 46% who were lonely 'some of the time'.

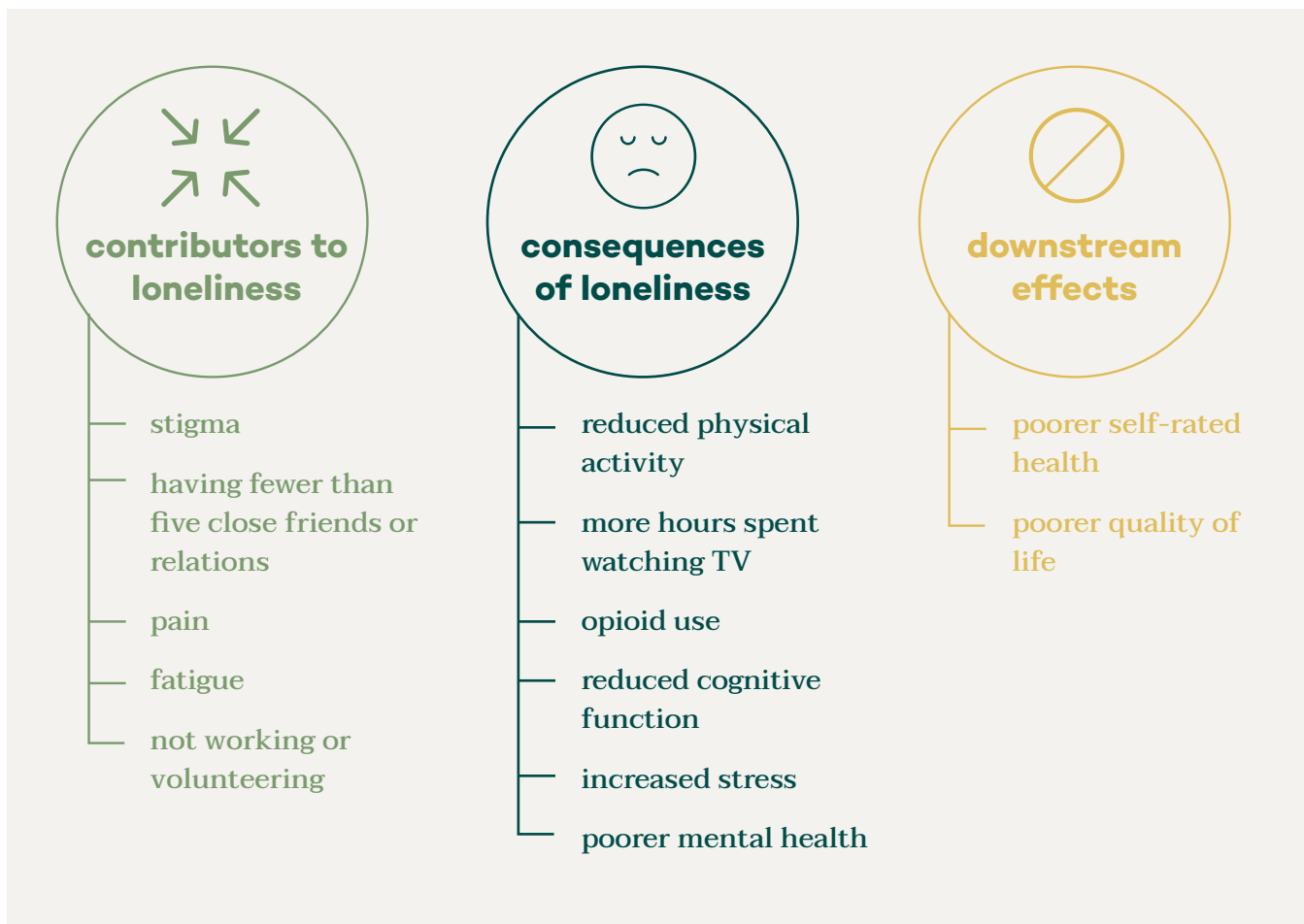


Loneliness was greater in respondents who did not have enough money to meet their basic needs; had a higher number of, and more severe, HIV-related symptoms; identified 'weakness' (frailty) as a symptom; had lung disease; or exhibited lifestyle factors such as reduced physical activity, watching more television and opioid use. Relatively few of the respondents who were often

lonely rated their health as very good or excellent (25.0%), compared to those who were never lonely (61.3%).

On the basis of the study, the investigators generated a model that can be used to better understand the association between loneliness and poorer health outcomes:

Figure 3: Model to conceptualise the association between loneliness and poorer health outcomes in older PLHIV



Source: Based on Carter (2018)

Carter (2018) points out that further research is necessary to determine the direction of the association between loneliness and poorer outcomes.

## 3.2.3 United States of America

### 3.2.3.1 Research on Older Adults with HIV (ROAH) Study

Conducted in San Francisco from 2015 to 2018, the Research on Older Adults with HIV (ROAH) 2.0 Study built on the ground-breaking ROAH study that had been carried out in New York in 2005 (ACRIA 2018; see Appendix A). Findings from this study that provide insights into the lived experiences of older PLHIV include:

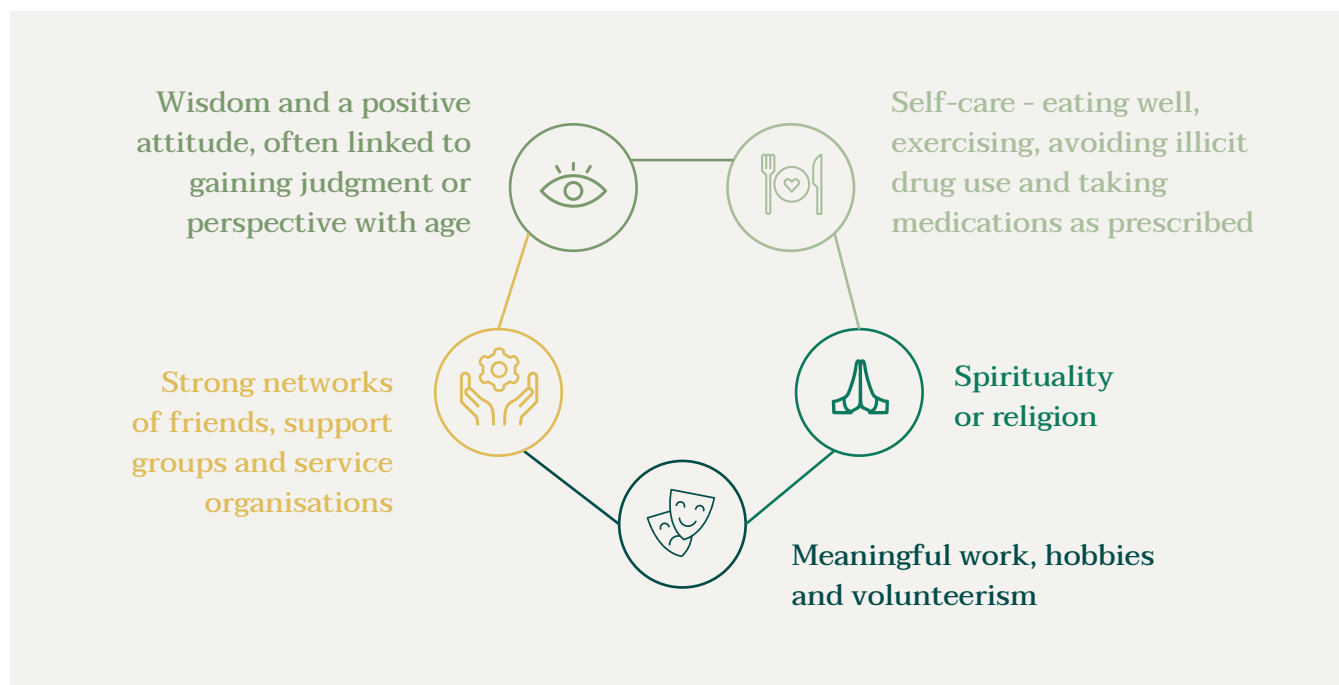
- Self-reported physical health was high (almost 60% of survey participants described their physical health as excellent or good, 96% are receiving ART, and 92% report having an undetectable viral load). There appears to be little association between age and the number of comorbidities among participants.

Polypharmacy was high – respondents on average reported taking over 10 pills a day.

- Well over half of participants reported having dealt with depression (65%) and anxiety (62%) in the year leading up to the survey. Depending on criteria applied, the rate of PTSD among the participants ranged from 35% to 70%.
- 59% of participants had trouble with at least one activity of daily living (ADL). While a few participants felt confident that care would be available to them if they became sick or injured, many were uncertain and afraid of what would happen if they were no longer able to care for themselves. Several expressed reluctance or fear at the prospect of having to rely on mainstream care services.
- Participants exhibited high levels of loneliness.
- Participants were found to be enduring serious financial strain, commonly linked to difficulties in maintaining housing in a city like San Francisco.

The study identified the following as factors that facilitate positive ageing for PLHIV:

Figure 4: Factors facilitating positive ageing for PLHIV



Source: based on ACRIA (2018)





### 3.2.3.2 Exploring the experiences of women

Psaros et al (2015) carried out qualitative research in Boston to explore the experiences of older women living with HIV. The study (N=19) found that most of the women felt better adjusted to living with HIV over time: the experience of growing older caused them to re-examine prior beliefs and a sense of shame, and to make meaning of their diagnosis. At the same time, uncertainties relating to their health, such as running out of treatment options, remained and even intensified with age.

Three subthemes of living successfully with HIV over time emerged:

- Caring for mind and body (nutrition, regular physical activity, effective stress management)
- Changing or eliminating negative relationships or environments, the 'toxic forces' in their lives
- Engaging in meaningful activities, especially participating in HIV-related causes and advocacy; and learning opportunities.

Cognitive processes such as dispelling internalised stigma, acceptance of diagnosis, appreciation of the perspective gained from HIV, and confidence in illness management also contributed to ageing well.

On the basis of the study, the researchers point to the value of peer support, including one-on-one counselling with a trained peer familiar with group norms; and the ability to tailor interventions to address the most pertinent topics, such as substance use, condom use, disclosure, and HIV communication. Long-term survivors may benefit from additional support and knowledge about what to expect as they age further with HIV (Psaros et al 2015).

### 3.2.3.3 Needs assessment study in New York

Brennan et al (2010) report on a study carried out in New York to assess the service utilisation patterns and related issues among older adults with HIV (N=180) who had an existing connection to the HIV/AIDS service network. The majority of participants lived alone, were unemployed, and relied on disability payments for income. It was not surprising, then, that 29% reported inadequate incomes for making ends meet, while 59% reported that they 'just managed to get by' (Brennan et al 2010: 12).

As perhaps one of the first studies to explicitly investigate ADL among older PLHIV, it found that participants had the greatest difficulty with doing housework (35%), followed by shopping and preparing meals (both 20%). The study also found that older PLHIV might not be able to access the support that many people typically derived from family of origin and friends, causing them to become increasingly reliant upon publicly-funded resources. Their use of services was high in all domains, including government, HIV/AIDS services and health and long-term care services.

The study found that HIV/AIDS stigma was still a barrier for many participants, and one-third were afraid that their HIV status would be disclosed to others if they accessed the services they needed. It is also noteworthy that 'in many domains, older women with HIV perceived significantly greater barriers to services than their male peers' (Brennan et al 2010: 47).

# 4 National policy frameworks that impact on ageing with HIV

This section considers Australian policies relating to:

- Aged care
- Health care
- The role of informal carers
- Disability

These areas of public policy are strongly influenced by demographic trends and projections, shifts in public perceptions, and changing political priorities. They are

also substantial components of public expenditure – for example, the Commonwealth of Australia is forecast to spend \$87.9 billion on health and aged care in Australia in 2017–18 (Department of Health 2018). In terms of their impact on HIV and ageing, there is value in ‘keeping a finger on the pulse’ of how policy initiatives and decisions impact on positive people’s lives on a day-to-day basis, and what can be done to help address the gaps, overlaps and concerns they might have within the continuum of care.

## 4.1 Aged care

As with all Australian citizens, PLHIV in their later years are impacted by policies relating to ageing and aged care. The Australian Government initiated a process of reforms to the aged care system in 2012, and these reforms are ongoing at the time of writing. By 2022, the Government’s vision is that Australia’s aged care system will:

- be sustainable and affordable, long into the future
- offer greater choice and flexibility for consumers
- support people to stay at home, and part of their communities, for as long as possible
- encourage aged care businesses to invest and grow
- provide diverse and rewarding career options (Australian Government 2018a).

Key aspects of these reforms are briefly summarised next.

### 4.1.1 Underlying principle

The principle underlying aged care in Australia is ‘consumer-directed care’ (CDC) (Australian Government 2018a). This approach to service provision gives consumers more say in the services they access, how they are delivered, and who will deliver them. Each person needing care works with a service provider to develop an individual care plan which includes:

- Agreement on the level of involvement each elderly person has in managing his or her care package
- Knowing how the package is funded and how the individual budget is spent through the preparation of





- monthly income and expense statements
- The option to be reassessed for a higher level of package or using their own money to purchase top-up services
- The right to change the care plan to suit changing needs (Commonwealth of Australia 2018).

## 4.1.2 Single entry point

‘My Aged Care’ was introduced on 1 July 2013 as a clear entry point to the aged care system (Australian Government 2018a). Making strong use of online technology, and undergoing regular updates and changes since it was introduced, My Aged Care includes:

- Information for consumers, family members, carers and service providers
- Online service finders and an electronic matching and referral capability
- Fee estimators that allow consumers to calculate costs
- A central client record
- Contact centre staff
- The Aged Care Provider Portal, which, amongst others, enables service providers to self-manage information about the services they deliver.

## 4.1.3 Continuum of care

The design of the new system breaks down traditional distinctions between home care, residential care and hospital care; and between the care that is provided by informal unpaid carers and formal service providers.

Strongly in favour of supporting older Australians to remain in their own homes for as long as possible, access to home-based support services for older people and their carers is provided through the Commonwealth Home Support Program (Australian Government 2018a). The My Aged Care Regional Assessment Service conducts face-to-face assessments of people seeking entry level support at home. This implies that consumers have access to the Home Care Packages Program, which provide four levels of support:

- Home Care Level 1 – basic care needs
- Home Care Level 2 – low level care needs
- Home Care Level 3 – intermediate care needs
- Home Care Level 4 – high care needs

The distinction between ‘low level’ and ‘high level’ residential care has been removed (Australian Government 2018a). This means that any person with a permanent residential aged care approval may be admitted to any residential aged care place, subject to availability and the provider’s agreement. Residents may be asked to pay daily fees and contribute to their accommodation costs – fees and payments vary depending on residents’ individual financial circumstances.

Transition care refers to care for older people who have been in hospital and need extra time to recover (Commonwealth of Australia 2018). The care can be provided in the patient’s own home, in hospital, or in a residential aged care home. Depending on needs, eligible services include physiotherapy, podiatry, access to a social worker, nursing support (such as wound care), and personal care (showering, toileting, dressing).

According to Jansson and Wilson (2012), issues such as HIV training and resource provision in the aged care sector will need to be addressed as the population of PLHIV ages. This would include providing access to effective diagnostics and treatments for increasingly complex comorbidities. Increased rates of age-related disease among PLHIV puts increasing demands on healthcare systems, compounded by an increased risk of adverse reactions due to polypharmacy.

## 4.1.4 Single Aged Care Quality Framework

As part of reforms to the aged care system, the government is developing an ‘end-to-end, market-based system with the sector where the consumer drives quality’ (Australian Government 2018b). This includes a Single Aged Care Quality Framework with a set of quality standards for all aged care services. The standards, which serve to emphasise the CDC approach and the continuum of care discussed earlier, are listed in the box below.



## Australian Aged Care Quality Standards

1. Consumer dignity and choice – each consumer is treated with dignity and respect, and their identity, culture and diversity are valued.
2. There is ongoing assessment and planning based on partnership with consumers.
3. Each consumer gets safe and effective personal care, clinical care, or both personal care and clinical care.
4. Each consumer gets safe and effective services and supports for daily living that meet their needs, goals and preferences and optimise their independence, health, wellbeing and quality of life.
5. The service environment is welcoming and easy to understand, and optimises each consumer's sense of belonging, independence, interaction and function.
6. The organisation regularly seeks input and feedback from consumers, carers, the workforce and others, and uses the input and feedback to inform continuous improvements for individual consumers and the whole organisation.
7. The organisation has a workforce that is sufficient, skilled and qualified to provide safe, respectful and quality care and services.
8. There is effective organisation-wide governance.

Source: Australian Government (2018b)

The Australian Aged Care Quality Agency, which accredits Australian Government-subsidised age care homes, will commence assessment and monitoring against the new standards from 1 July 2019. It is also noteworthy

that any person receiving aged care services subsidised by the Australian Government can freely submit their concerns about the services they receive to the Aged Care Complaints Commissioner, whose powers have been strengthened in keeping with the aged care reforms.

## 4.2 Health care

### 4.2.1 Complexity

Australia's complex health care 'landscape' is summarised in an infographic in Appendix D and is briefly described next. The country has a universal health care system that, in its design and implementation, is strongly influenced by having a federal system of government (Glover 2016):

- The Australian Government is primarily responsible for funding the state/territory-delivered health services, including jointly funding the public hospitals. It funds and operates the Pharmaceutical Benefits Scheme (PBS); funds Medicare, the universal health insurance scheme, and with it, subsidies for primary care providers through the Medicare Benefits Scheme (MBS); and provides funds for integrated primary health care and public health services through the establishment of Primary Health Networks (PHNs).
- State and territory governments are primarily responsible for the direct delivery of public health services. This includes the public hospitals, ambulance services, public dental care and



community health services. Acute mental health and psychiatric care provided in hospitals, community-based services, and specialised residential care services are also state/territory responsibilities, and they provide subsidies and incentive payments in the areas of prevention, chronic disease management, and mental health care. They coordinate the Local Hospital Networks.

- Local governments have a limited role in public health measures such as immunisation and the regulation of food standards, and some provision of home care services. Many local governments in remote and very remote Local Government Areas have a stronger involvement in the planning, delivery and coordination of health services.

Intergovernmental collaboration and decision-making occurs through the Council of Australian Governments (COAG), with some shared arrangements detailed in national agreements and strategies (Department of Health 2018). One of these, the *National Disability Strategy 2010-2020*, is discussed in greater detail in section 4.4.1 below.

Private health insurance, strongly promoted and widely available, is intended to offer more choice of providers (particularly in hospitals), faster access to non-emergency

services, and rebates for selected services (Glover 2016). Government policies encourage uptake of private health insurance through a tax rebate and, for people above a certain income, the Medicare Levy Surcharge, which serves as a 'penalty payment' for not having private health insurance (Glover 2016).

## 4.2.2 Eighth National HIV Strategy 2018-2022

The *Eighth National HIV Strategy 2018-2022* (Australian Government 2018c) recognises that the proportion of PLHIV in older age groups is growing, and that this will have implications for the healthcare system and for aged care service provision. While priority areas for action within the Strategy continue to be on education, prevention and HIV management, the document also recognises that 'the ageing of population of people with HIV in Australia is a key issue to be considered in the response (Australian Government 2018c: 28). Consequently key area for actions 13 and 14 in the Strategy are as follows:



### Eighth National HIV Strategy Key Areas for Actions

13: Improve the integration of care provided to people with HIV, including by general practitioners, sexual health physicians, psychosocial support services, community pharmacies, community based nursing, other health services and specialists, and aged care services, particularly in rural and remote locations

14: Identify, implement and evaluate models of care that meet the needs of people with HIV who are ageing and ensure quality of care across services

Source: Australian Government (2018c: 29)

Of significance to peer-based organisations such as NAPWHA, the Strategy affirms the principle that meaningful participation of people living with HIV is

essential to the development, implementation, monitoring and evaluation of programs and policies (Australian Government 2018c).

## 4.2.3 Primary Health Networks

Primary Health Networks (PHNs) became operational on 1 July 2015 as independent organisations within regions/ jurisdictions that are closely aligned to the state and territory Local Hospital Networks or their equivalent (Booth, Hill et al 2016). PHNs are operated by not-for-profit companies and have skills-based boards that receive advice from clinical councils and community advisory committees. They make decisions independent of government, for example, deciding which services or health care interventions should be provided in their regions, and who should provide them. They also work closely with providers to monitor performance and implement change.

PHNs focus on 'how an individual experiences health care – access to care, its efficiency, effectiveness and quality – as well as the degree of connectedness experienced by patients when navigating the health system, whether it is fragmented or seamless' (Booth, Hill et al 2016: 1). The government (Department of Health 2018) agreed to

priority areas for targeted work by PHNs, including aged care. Through adoption of a population health approach in respect of aged care, PHNs would:

- Undertake needs assessments and service planning for their regions in order to accommodate the needs of older Australians and ensure equitable access to appropriate services
- Ensure aged care, disability, community services and health care systems are aligned to enable consumers to seamlessly transition between service systems and receive the care and support that best meets their needs in the most appropriate service setting
- Develop solutions to fill priority gaps in primary care services for older Australians (Australian Healthcare and Hospitals Association 2015).

In terms of their integrative function within the broader healthcare system, focus on local needs, and the inclusion of aged care as a priority area, PHNs would be important partners for HIV community organisations as larger numbers of older PLHIV access – and transition between – healthcare, disability and aged care services, more of which are being delivered in people's own homes and other community-based settings.

## 4.3 Formal and informal care

There are around 2.7 million carers in Australia (Department of Social Services 2018), who 'provide ongoing unpaid support to people who need it because of their disability, chronic illness, mental ill-health, dementia or frail age' (NSW Government 2014: 4). According to ACIL Allen Consulting (2014), several factors contribute to increasing the importance of, and demand for, carers in Australia:

- The increasing proportion of the population that is ageing
- Community preferences
- Policy and practice that encourages and supports people with caring needs to remain in their homes for as long as possible
- The intention of specific policy reforms, such as the aged care reforms discussed earlier.

All of these factors pertain to older PLHIV as well, and suggest that the recognition and role of carers is likely to gain in prominence in coming decades. Features of the policies and systems relating to carers in Australia are briefly summarised next.

### 4.3.1 Carer Gateway

Similar to the single entry point for aged care discussed earlier, the Australian Government operates the 'Carer Gateway' website (<https://www.carergateway.gov.au/>), which, amongst others, enables people to understand legal definitions and recognition of the 'carer' role; obtain information; and find services. It is estimated that around 80% of carers are unclear about, or unaware of, the support and services available to them (Department of Social Services 2018), which suggests that this may also be an issue for carers of PLHIV as well.



## 4.3.2 Financial support for carers

The Australian Government provides a range of payments, benefits and concessions for eligible carers. The two main payments are Carer Allowance and Carer Payment (Department of Social Services 2018).

Carer Allowance is an income supplement available to people who provide daily care and attention in a private home to a person with disability or a severe medical condition. It can be paid in addition to a social security income support payment. Carer Allowance recipients caring for a child under 16 receive a Health Care Card. A \$250,000 family income test threshold was applied to the Carer Allowance payment from 20 September 2018.

Carer Payment is an income support payment for people who are unable to support themselves through substantial paid employment because of the demands of their caring role. Carer Payment is income and assets tested and paid at the same rate as other social security pensions.

## 4.3.3 Integrated Carer Support Service Model

The Integrated Carer Support Service (ICSS) model was launched in October 2018. The ICSS provides carers with

access to early intervention, and preventative and skill-building supports. A new network of Regional Delivery Partners has been set up across Australia to deliver and/or coordinate local and targeted services for carers (Department of Social Services 2018). Also from October 2018, new digital services for carers commenced through the Carer Gateway website including:

- Digital counselling services to help carers manage daily challenges, reduce stress and strain, and plan for the future
- Online peer support, connecting carers with other carers for knowledge and experience sharing, emotional support and mentoring
- Online coaching resources with techniques and strategies for goal-setting and future planning
- Educational resources to increase the skills and knowledge of carers relating to specific caring situations, and to help them to build their confidence and improve their wellbeing.

## 4.3.4 Implications

PLHIV with care needs have benefitted from the supports provided by informal carers since the early years of the epidemic. As significant numbers move into their later years, informal caring is likely to increase in importance. Australia has taken concrete steps in recent years to better recognise, reward and resource carers. Organisations such as NAPWHA can engage with these initiatives so as to promote the interests of older PLHIV and their informal carers.

# 4.4 Disability

As has been evident in the discussion thus far, themes of ‘breaking down silos’ among the health, disability and aged care sectors, of placing more and more decision-making power in the hands of consumers and their carers, and of streamlining service gateways and transitions to ensure continuity of care have featured prominently in recent Australian policy decisions. Key developments in disability policy are discussed next.

## 4.4.1 National Disability Strategy

Since 2010, Australia’s *National Disability Strategy 2010-2020* has guided disability policy across all levels of government (federal, state/territory and local). The

state and territory governments implement the Strategy through their Disability Plans (Department of Social Services 2018). Priority areas for action to improve the lives of people with disability, their families and carers have been:

- Inclusive and accessible communities
- Protection of rights, justice and legislation – for example promulgation of the *Disability Discrimination Act 1992* was part of Australia's commitment to eliminating all discrimination against people with disability (HIV/AIDS was a group accommodated under this Act)
- Economic security
- Personal and community support
- Learning and skills
- Health and wellbeing.

## 4.4.2 Disability Support Pension

The eligibility requirements for the Disability Support Pension (DSP) are:

- Having a permanent and diagnosed disability or medical condition that prevents a person from working
- Aged between 16 and the age pension age
- Meeting Australian residency requirements
- Meeting income and assets tests (Department of Human Services 2018).

Recent changes to the eligibility assessment for the DSP suggests that there is value in focusing on some of the terms:

*Manifest medical eligibility* – having a terminal illness with a life expectancy of less than two years

*Fully diagnosed, treated and stabilised* – the disability or medical condition needs to be fully diagnosed (based on documented medical evidence), fully treated (including having a plan for the next two years) and fully stabilised (the treatment will assist the person to be able to work at least 15 hours a week over the following two years; or there are medical or other reasons why treatment is not possible).

*Work capacity* – applicants undertake the Job Capacity Assessment, which includes a focus on how the disability or medical condition affects his or her ability to work

*Program of Support* – helps people with a disability to prepare for, find and keep a job and includes help with work experience and training, and injury management. The support is provided by accredited Disability Employment Services and Australian Disability Enterprises.

Source: Department of Human Services (2018)

People in receipt of the DSP are able to access services under the National Disability Insurance Scheme (NDIS), discussed next.

## 4.4.3 National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) is a core action under the *National Disability Strategy 2010-2020*

and has been incrementally replacing hitherto models of care. In terms of the NDIS, all Australians under the age of 65 who have a permanent and significant disability are provided with the 'reasonable and necessary' supports they need to enjoy an ordinary life based on individualised packages of support. The National Disability Insurance Agency (NDIA) is the independent Australian Government agency responsible for implementing the NDIS.

Access requirements for the NDIS include: availability of the scheme in a local area; applicant's residency status; disability requirements; and, in some cases, early





intervention requirements.

**Disability requirements** include:

- An impairment or condition that is likely to be permanent (i.e. it is likely to be lifelong)
- The impairment substantially reduces the person's ability to participate effectively in activities, or perform tasks or actions without assistance from other people, assistive technology or equipment (other than common items such as glasses)
- The person cannot participate effectively even with assistance or aides and equipment
- The impairment affects the person's capacity for social and economic participation
- The person is likely to require support under the NDIS for his or her lifetime.

An impairment that varies in intensity, for example

because the impairment is of a chronic episodic nature, may still be permanent, and may be eligible for support under the NDIS.

**Early intervention requirements** may be met if the impairment or condition is likely to be permanent and there is evidence that supports at the current time (early interventions) will help by:

- reducing how much help will be needed to do things in the future
- improving or reducing deterioration of functional capacity
- helping family and carers to keep helping
- being most appropriately funded through the NDIS, and not through another service system.

The reporting on NAPWHA's involvement in the NDIA consultations (Phase 1 of the project) is provided in the box below.

## NAPWHA's contribution to the NDIA consultations in 2018

While HIV is covered by the definition of disability in the *Disability Discrimination Act 1992* (Parliament of Australia 1992), the Australian Government does not consider HIV/AIDS itself to be a disability for the purposes of NDIS assessment.

Because access to NDIS is based on functional impairment, agencies and individuals need to develop skills to reframe needs in terms of functional impairment. NDIA Planners work on a person's goals and aspirations ie what they want to achieve and their immediate and unmet needs. In order to do this properly, they need to have an understanding of how living with HIV affects the person's achievement of goals and aspirations as they age. There is concern that knowledge of the issues around HIV and ageing among NDIA assessors and planners is inadequate and that training may be necessary.

People who meet the NDIS access requirements (called participants) receive funded supports and an individual plan. People with HIV related disability need to meet the access requirements in order to access NDIS. These include: availability of the scheme in their area; residency status; disability requirements. Early intervention requirements may provide access before a person is permanently

impaired if it reduces deterioration of functional capacity or reduces how much help will be needed to do things in the future.

NDIA is developing strategies to support NDIS delivery for particular priority action areas, to ensure they are responsive to the needs of people in those groups. These include strategies for: Aboriginal and Torres Strait Islanders; people who are culturally and linguistically diverse; and LGBTIQ+. A plan for 'hard to reach people' is also planned, which may include people who experience mental health conditions. There are implications for people with HIV in each of these, although HIV is not specifically mentioned in any of the plans, because they are focused on the ways in which people are functionally impaired, rather than the disabling conditions themselves.

NAPWHA was involved in the LGBTIQ+ consultation and found the consultation to be extensive, thorough and representative. NDIA have indicated a commitment toward enacting these strategies through action plans with measurable targets and the interest of people with HIV has been noted in relation to the LGBTIQ+ strategy, the Aboriginal and Torres Strait Islander strategy and the Rural and Remote strategy in particular.

## 4.4.4 Implications for PLHIV and HIV community organisations

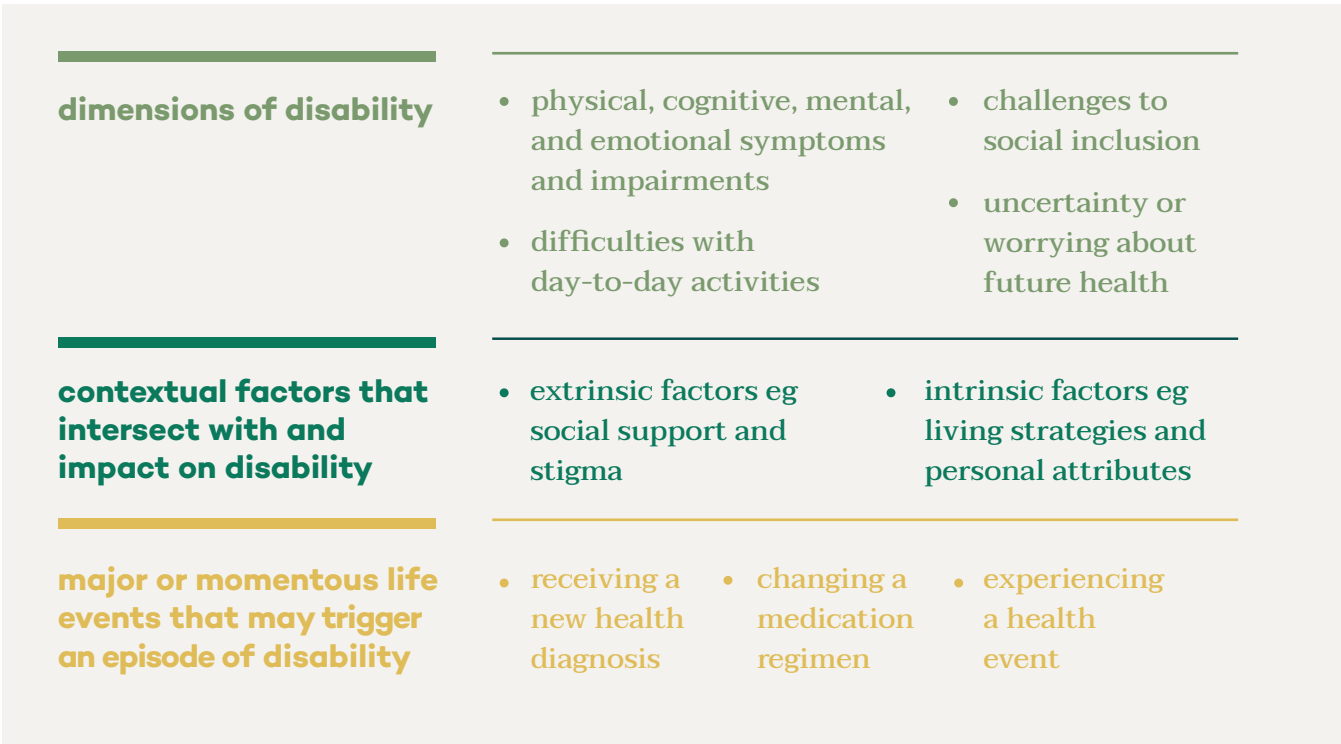
As is evident from the brief discussion above, there is a degree of uncertainty in Australia regarding the definition of disability in the context of HIV, and the implications of this for policy and practice. Consultations and policy reforms are likely to continue taking place, particularly as the NDIS becomes more established and is evaluated. An important function for peer organisations such as NAPWHA is to build networks and partnerships, continue to be informed, contribute to the debates, and advocate in the best interests of PLHIV. In turn, the organisations would contribute to keeping PLHIV informed of policy

developments, especially in light of uncertainties many have (as discussed in section 3 of this report) about services and supports as they move into their later years. One of the unresolved issues is briefly discussed next.

Can living with HIV be regarded as having an ‘episodic disability’? If so, what implications might this have for disability policy? Canada, a country that is similar to Australia in many policy and governance respects, has been focusing on this issue (O’Brien et al 2018). Based on a program of initiatives in that country, disability in the context of HIV has been defined as ‘the combination of multidimensional (physical, cognitive, mental, emotional, and social) health challenges living with HIV including uncertainty or worrying about future health’ (O’Brien et al 2018: 2).

In Canada, the Episodic Disability Framework (Figure 5) has been developed to characterise the multi-dimensional and often fluctuating nature of disability-related challenges for PLHIV:

Figure 5: Episodic disability framework as applied to people living with HIV



Source: based on O’Brien et al (2018: 2)

In keeping with this focus on the disabling aspects of HIV, researchers and practitioners in Canada have also carried out innovative work with regard to rehabilitation approaches that can help older PLHIV to manage the

health-related challenges and disabilities associated with HIV (O’Brien et al 2014). These are included in the discussion on ‘pathways to improvement’, which is the next theme addressed.





# 5 Pathways to improvement

Having considered some of the empirical evidence relating to HIV and ageing, studies on the lived experiences of older PLHIV, and the Australian policy context, discussion now turns to ways in which PLHIV can best be supported as they grow older. Drawing on the literature, this section considers:

- Promoting successful ageing in the context of living with HIV
- Explicit integration of HIV care and geriatric care
- Focusing on wellbeing and quality of life
- Incorporating rehabilitation approaches as needed
- Multidisciplinary and integrated models of care
- Extending and promoting HIV peer support
- Incorporating HIV peer navigators as needed

## 5.1 Promoting successful ageing

Ageing is broadly defined as ‘the time-dependent functional decline that affects most living organisms’ (Wing 2016: 62). According to an often-cited model developed by Rowe and Kahn (cited in Escota et al 2018: 59), ‘successful ageing’ comprises three major criteria:

1. Avoiding disease and disease-related disability, including avoidance of the risk factors for morbidity
2. High cognitive and physical functional capacity – sustaining the physical, mental and emotional aptitude for performing activities
3. Active engagement with life, which includes maintaining productivity and keeping valuable interpersonal relationships.

Research suggests that these criteria are not always congruent with opinions expressed by many older people themselves. Despite having to deal with illness and disability, respondents in studies frequently report that they are ageing successfully. They point to factors such as independence, resilience, coping mechanisms and overall wellbeing as important contributors to this (Escota et al 2018: 59). Some researchers make use of self-rated successful ageing (SRSA) measures, often combined with measures of physical and emotional functioning. They also factor in the influence of psychosocial functioning, such as the availability and use of social supports in

maintaining desired levels of autonomy (Moore et al 2013; see Appendix A). According to McGowan et al (2017: 98), ‘quality of life, autonomy and self-rated health are essential components of successful ageing’.

Focusing on PLHIV in particular, pathways to successful ageing include:

- Early initiation of ART and exploring newly-trialled and available treatment options
- Addressing psychosocial as well as medical issues, which includes maintaining a focus on quality of life (discussed in greater detail below), autonomy and self-rated health
- Interventions to enhance psychological traits such as resilience, a sense of personal mastery and optimism
- Application of primary prevention and screening guidelines
- Early interventions for those who are at risk for becoming frail
- Decision making and action on dealing with modifiable risk factors such as smoking
- Acknowledging and addressing vulnerabilities related to social disadvantage

(Escota et al 2018; Brothers et al 2014; McGowan et al 2017; Moore et al 2013)



Explicit interventions to support successful ageing are strongly indicated for ‘people who have lived with HIV for a long period of time’ (McGowan et al 2017: 98).

An approach to successful ageing that is also worthy of consideration is the ‘life-cycle approach to HIV’, put forward by the Joint United Nations Programme on HIV/AIDS (UNAIDS 2016). At its heart, this approach aims for wellbeing throughout the life-cycle. As the proportion of PLHIV 50 years and older increases (estimated to increase worldwide by 47% from 2000 to 2010), health care

systems will need to be geared up to offer integrated, cost-effective, comprehensive chronic care. Within a life-cycle approach, the wisdom and knowledge of older people living with HIV ‘can be leveraged for both individual and wider community health and well-being’ (UNAIDS 2016: 95). In a study carried out in Queensland, for example, Gardiner (2018) found that the complexities of the lived experiences of the participants in the study (see Appendix A) had given them wisdom that could be applied to the process of ageing.

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## 5.2 Towards integrated HIV and geriatric care

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Several of the studies included in this paper advocate for an integration of HIV care and geriatric care. This would imply shifting to an approach in which the objective is not only disease management and longevity, but also maintaining quality of life for as long as possible – it is about improving both the quantity and the quality of life (Althoff et al 2016).

Geriatric medicine has developed principles and practices that strive to enhance the quality of life of older people through a combined focus on **health/illness and functioning** (Guaraldi and Rockwood 2017: 507; emphases added). Functioning can be further delineated as **basic activities of daily living** such as

dressing, bathing, feeding and transferring; and **higher order functions** (or the instrumental activities of daily living) such as using the phone, shopping, and managing medications and finances (Singh et al 2017: 501). Functioning is a crucial focus for intervention when the elderly, people with disabilities and those living with chronic illnesses are encouraged to delay acute and residential care for as long as possible, as is the case in Australia (see section 4 of this document).

The principles of geriatric medicine (Singh et al 2017: 502) can be summarised as follows:



## Principles of geriatric medicine

- Ageing cannot be defined or measured solely by the presence or absence of disease.
- Syndromes related to ageing are distinct from classic medical syndromes. A syndrome, unlike a disease, is often of unknown aetiology and is defined by a complex and often non-fixed combination of clinical signs and symptoms.
- Geriatric syndromes do not fit into discrete disease categories. They are common, cross organ systems and discipline-based boundaries, and are often defined by a single symptom (such as urinary incontinence). Individual syndromes may have multiple aetiologies. Older patients often have multiple geriatric syndromes at one time.
- The impact of multimorbidity in older patients cannot be deduced by simply adding the impacts of multiple individual comorbidities. Optimal therapy must also take into account patient preferences, prognosis and clinical feasibility.

Source: Singh et al (2017: 502)

With consistent integration of these principles, attention can be given to factors that negatively impact on the ageing process for PLHIV. These factors include ongoing HIV-associated inflammation and immune activation; the effects of chronic exposure to ART (which may lead to organ system injury); polypharmacy; and behaviours that are harmful to health, such as smoking, alcohol and substance abuse (Althoff et al 2016).

Efforts to integrate HIV and geriatric care would need to explicitly address HIV-related stigma. Several of the studies discussed in this report (see section 3) draw attention to its persistence and deleterious consequences for PLHIV; and to the fears older PLHIV may have of having to deal with the additional stigma associated with old age as well. The overlap of HIV and ageing stigma contributes significantly to poor outcomes for older PLHIV and 'may require interventions separate from those used for either individually', including at the institutional and infrastructural levels (Guaraldi and Pallela 2017: S133). Date (2018) writes that when stigma manifests healthcare settings it serves as a significant barrier to 'normalising HIV as a medical condition'.

Within a holistic geriatrics-based approach, geriatric syndromes to consider include:

- Multimorbidity and polypharmacy, which go hand in hand
- Functional impairment, including gait speed and grip strength; these have been associated with low muscle mass and loss of bone density
- Cognitive dysfunction, estimated to affect as many as half of HIV-infected adults
- Frailty
- Falls and fractures (Althoff 2016: 7-8).

Drawing on the literature, elements of a framework for integrating HIV care and geriatric care are summarised in Table 3.

Table 3: Integrating HIV care and geriatric care

Element	Discussion	References
Comprehensive Geriatric Assessment (CGA)	A CGA is a multidimensional and interdisciplinary diagnostic process that aims to determine the medical, psychological, and functional capabilities of an older person. It uses specific criteria including medical comorbidities, psychosocial problems, changes in living situation, and specific geriatric conditions. A CGA can help to determine the risk for illness, residual skills, and the short- and longer-term prognosis.	Singh et al (2017) Negredo et al (2017) Guaraldi and Palella (2017)
Screen for frailty	If not already included in the CGA, there is value in screening specifically for frailty. Indications for referral/screen for frailty syndromes include multiple comorbidities, polypharmacy and functional or mobility decline.  Identifying frailty is an especially important consideration for HIV care in terms of addressing wellbeing and QoL.	Levett and Wright (2017) Yeoh et al (2018)
Personalised treatment plan, implementation and monitoring	The CGA is the basis for a personalised treatment plan. Care is shared by several service providers in a process that includes: <ul style="list-style-type: none"> <li>• Data gathering</li> <li>• Discussion among team members</li> <li>• Development of a treatment plan</li> <li>• Implementation of the treatment plan</li> <li>• Monitoring response to treatment</li> <li>• Revising the treatment plan</li> </ul>	Guaraldi and Palella (2017)
Addressing vulnerabilities specific to older PLHIV	These include: <ul style="list-style-type: none"> <li>• The overlap of HIV and ageing stigma</li> <li>• Vulnerabilities for disability and poorer mental health</li> <li>• High burden of chronic comorbidities</li> <li>• ART in the context of polypharmacy</li> <li>• Modifiable behaviours that are harmful to health</li> </ul>	Guaraldi and Palella (2017) Althoff et al (2016) Edelman et al (2013)
Human resourcing	Defining the role of the geriatrician and ensuring collaboration with HIV primary care providers.  Needs assessment and training of care providers.  Logistic coordination and diverse provider interaction to ensure cross-disciplinary collaboration.  Determination of workflow.	Guaraldi and Palella (2017) Singh et al (2017) Rosenfeld et al (2015)



In summary, Guaraldi and Rockwood (2017: 507-508) write:

*The remarkable progress in HIV/AIDS medicine can benefit from what has been learned in*

*geriatric medicine...Every advance in medicine brings new questions and new opportunities. It is an exciting and welcome challenge now to have to address how best to care for people living with HIV as they enter old age.*

## 5.3 Focusing on wellbeing and quality of life

Several of the studies summarised in Appendix A (amongst others Escota et al 2018; Gardiner 2018; Terrence Higgins Trust 2017) point to the importance of focusing on the wellbeing and quality of life (QoL) of older PLHIV. As Gardiner (2018) writes, a purely 'biomedical' orientation risks neglecting the psychosocial needs of those with a history of trauma, depression and other comorbidities; and, for many people, psychosocial needs are often more difficult to manage than illness.

According to Wing (2016), factors affecting the QoL of older PLHIV include physical and psychiatric disabilities and morbidities; loss of partners and friends (that contribute toward a sense of 'lost community'); social isolation; stigma; unemployment; poverty; and crime. Strong links between wellbeing and socio-economic status are regularly made in studies exploring the lived experiences of PLHIV (see section 3 of this report). The Terrence Higgins Trust (2017: 42) found in the UK, for example, that levels of wellbeing decreased, and social isolation and age-related stigma and loneliness increased, in tandem with lower income levels.

In a Canadian study, O'Brien et al (2018) focused on the

'living strategies' adopted by PLHIV that enable them not only to maintain control over their health, but also to adopt positive attitudes and outlook. Their research (see Appendix A) suggests that, in supporting older PLHIV with their unique living strategies, service providers could fruitfully examine ways of assisting them:

- To maintain a sense of control over life, linked to lifestyle factors such as diet, exercise and sleep, establishing purpose and focus, maintaining life balance, and planning for and anticipating the future
- To address attitudes and beliefs, including outlook on life, faith and spirituality
- To seek social interaction with others, including acquiring knowledge and understanding of HIV, practising selective disclosure of HIV status, and building confidence for employment
- To focus on other aspects of life beyond HIV status (O'Brien et al 2018).

The HALL study conducted in the UK (also summarised in Appendix A) found that achieving good QoL is 'an ongoing project that required active work' (Rosenfeld et al 2015: 2).

## 5.4 Rehabilitation

Drawing in particular on initiatives in Canada, rehabilitation approaches such as physical therapy and occupational therapy have been found to assist older

PLHIV to manage the health-related challenges and disabilities associated with HIV (O'Brien et al 2014; see Appendix A). When rehabilitation is practised, the

intersection between personal attributes (eg worrying about the future) and social attributes (eg difficulties participating in social life) is considered and addressed. Rehabilitation approaches also take into account the broader determinants of health, such as the impacts of poverty, social exclusion and stigma (O'Brien et al 2014).

These researchers recommend that evidence-informed recommendations that are relevant for rehabilitation in the context of HIV should be applied using an individualised approach incorporating the unique values, preferences, goals and needs of the individual (O'Brien et al 2014). For example:

- Aerobic and resistive exercise may be recommended

for comorbidities including bone and joint disorders, cancer, stroke and diabetes

- Cognitive rehabilitation interventions (eg cognitive training, cognitive stimulation and cognitive rehabilitation) may be effective for a wide cross-section of the older PLHIV population.

In support of including rehabilitation into a comprehensive care framework for PLHIV, Guaraldi and Pallela (2017: S133) write that 'robust evidence' exists for the effectiveness of task-sharing that involves occupational, physical therapists, practitioners of physical medicine and rehabilitation practitioners 'particularly in the assessment of age-related physical disability and triaging for geriatric consultation'.

## 5.5 Multidisciplinary and integrated care

A multidisciplinary focus is inherent to rehabilitation practice (discussed above) and is also strongly supported in the literature in respect of all interventions and outcomes for older PLHIV.

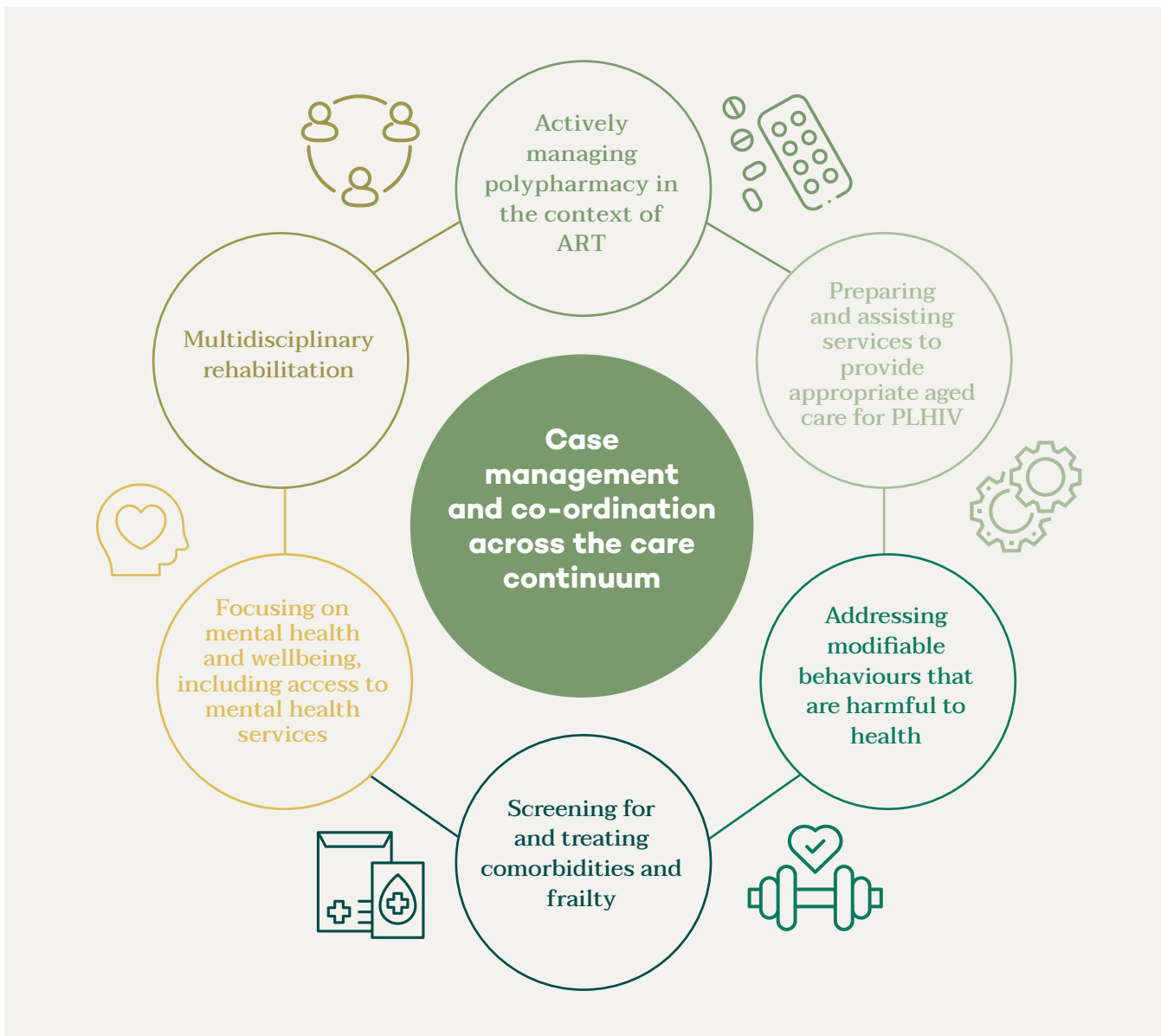
As Edelman et al (2013: 618) write in respect of polypharmacy, 'continuity and integration of care has been identified as a protective factor for minimizing polypharmacy, and silos of care are a risk factor for polypharmacy'. Negredo et al (2017) draw on the research evidence to show that care of the older patient with multimorbidity is best managed through a multidisciplinary team and, in order to avoid fragmentation of care pathways, team co-ordination is required. Date (2018) makes the observation that the management of increasingly complex health and social care issues for older PLHIV often requires specialist input, supporting the need for there to be a concomitant focus on teamwork and coordination.

In keeping with trends in health and social care, as well as with developments in Australian policy (see section 4), integrated and multidisciplinary care also presupposes active involvement of the care recipient and his or her network of informal and community carers. Researchers highlight the importance of involving PLHIV appropriately in all stages of the planning, commissioning and delivery of services; of providing training to workers in the long-term health care sector; and of working collaboratively across professional boundaries (Rosenfeld et al 2015).

Drawing on a wide range of literature, elements of an integrated care model for people ageing with HIV are illustrated in Figure 6:



Figure 6: Elements of an integrated model of care for people ageing with HIV



Sources: based on Wing (2016); Althoff et al (2016); Rosenfeld et al (2015); O'Brien et al (2014)

QoL concerns, the increased need to prioritise medical issues, and end-of-life care grow in importance as the person living with HIV enters their 70s, 80s and beyond (Wing 2016; Rosenfeld et al 2015). Based on research conducted in Ontario, Kendall et al (2017) found that disproportionate utilisation of acute care (as measured in the study) had important implications for older PLHIV, including an increased risk of dying in hospital instead of

at home. There was also the need for a consistent focus on mental health and social needs, including isolation and loneliness, economic hardship and housing instability. These researchers recommended that, to optimise the quality and cost-effectiveness of care, and improve end-of-life experiences for PLHIV, there should be stronger involvement of community-based palliative care services (Kendall et al 2017: e6).



## 5.6 Peer support

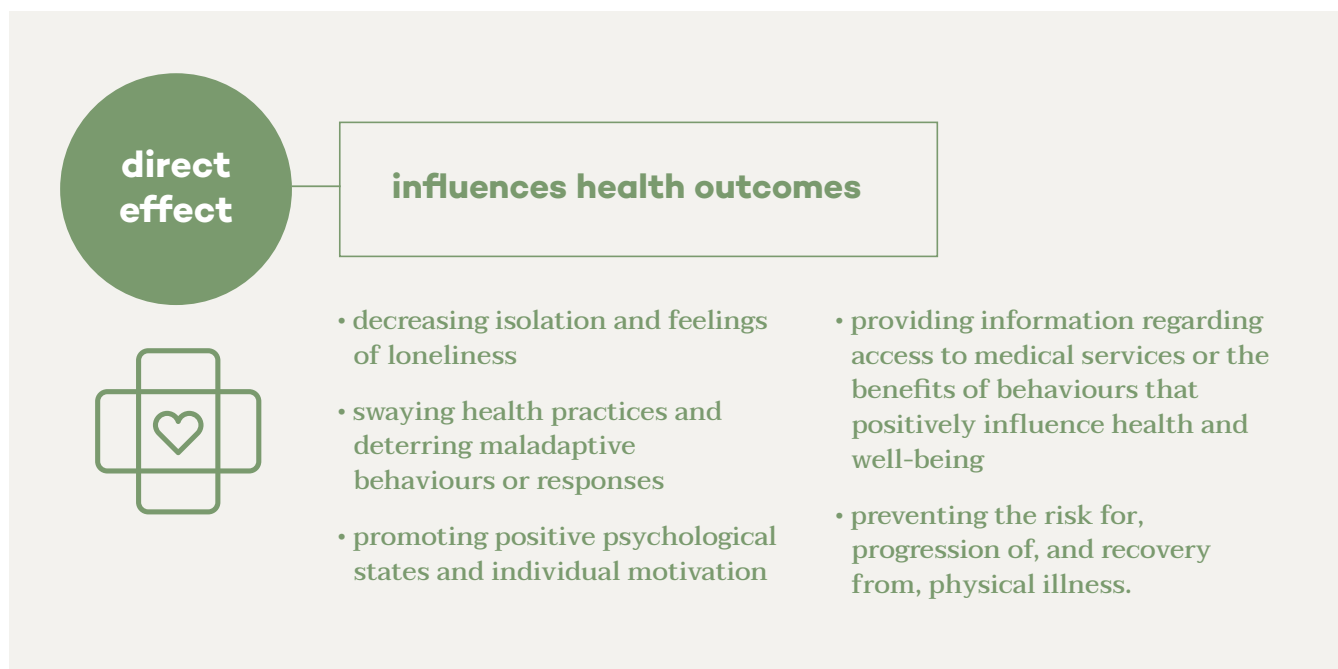
According to Dennis (2003: 329), peer support within a health care context can be defined as ‘the provision of emotional, appraisal, and informational assistance by a created social network member’. Within a peer support relationship, people see each other as equal partners. The focus is on mutual learning and growth that can ‘transform our lives and the lives of our communities for the better’ (Positively UK 2017: 6). Peer networks have led efforts to protect the rights, health and dignity of PLHIV since the start of the epidemic, and they continue to be critical (HIV Caucus 2018). Many commentators argue that any response to HIV should be grounded in the experiences of those living with HIV (see eg Allan et al 2018).

Peers understand situations in a way that ‘naturally

embedded social networks’ may not (Dennis 2003: 329). Research suggests that, in distressing times, broader social networks may not respond positively to health and ill-health issues, partly from an inability to appreciate the stressful nature of the experiences and partly from feeling threatened. Rosenfeld et al (2015) point to the importance of HIV-specific peer support and other voluntary sector organisations and support groups in delivering crucial social support to older PLHIV, especially in terms of the recognised benefit of peer support in enhancing mental health and wellbeing.

Dennis (2003) developed a model – often cited in the literature (see eg Peterson et al 2012) – to conceptualise the means through which peer support achieves positive outcomes:

*Figure 7: Benefits of peer support in contributing to positive health and wellbeing outcomes*





## buffering effect



### protects against the influence of stress on health

- redefining and reducing the potential for harm posed by the stressor
- broadening the number of coping resources
- discussing coping strategies, problem-solving techniques, and counter-responses thereby moderating the initial appraisals of the stressor
- highlighting norms through social comparison which prescribe adaptive behaviour
- inhibiting maladaptive responses, and counteracting the propensity to blame oneself for causing the stressor or adversity

## mediating effect



### peer relationships can indirectly influence health by

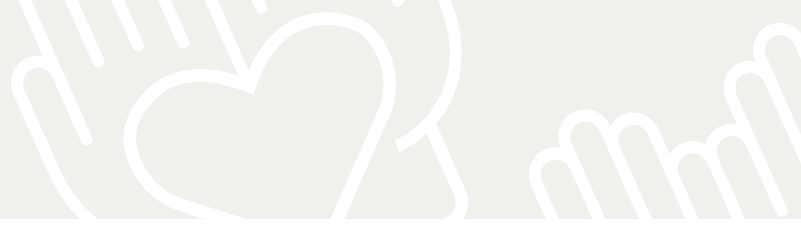
- assisting in the interpretation and positive reinforcement of performance accomplishments
- providing vicarious experience and observational learning through role modelling
- offering opportunities for social comparisons to promote self-evaluations and motivation
- teaching coping strategies and conveying information about ability
- positively interpreting emotional arousal
- encouraging cognitive restructuring through anticipatory guidance

Source: based on Dennis (2003)

As can be seen in this framework, peer support influences health outcomes (direct effect); protects against the influence of stress on health (buffering effect); and indirectly influences health (mediating effect). Research studies (see section 3 of this report) consistently show the value placed by older PLHIV themselves on engaging with and learning from peers. It is only from a peer that that someone living with HIV can hear (as reported by Rosenfeld et al 2018: 105)

*...she told me, 'This is a journey. Never give up. Look at me, I'm surviving. I want you to be a survivor, a role model. Take your tablets, listen to your doctor, your nurses, your consultant, and any group that can help you get the knowledge'... That's what I did, and yes, I'm still surviving.*

A development of the peer support model since the 1990s is 'peer navigation', discussed next.



## 5.7 HIV peer navigation

Peer navigators can be defined as ‘medication-adherent role models living with HIV who share the same experiences and community membership and who are trained to provide effective services that increase the linkage, retention, and medication adherence of the people they serve’ (AIDSUnited 2017: 1). An important distinction from peer support models (discussed above) is that peer navigators are remunerated, rather than being volunteers. As employees, they receive specific training, support and supervision in order to carry out their work, which includes:

- Case finding and community outreach
- Routine appointment reminder phone calls
- Accompaniment to appointments
- Transportation assistance
- Referrals and associated follow-up
- Treatment adherence education and support (AIDSUnited 2017).

Research suggests that peer navigation (also termed ‘health navigation’) can play a role in engaging people in HIV care across the care continuum (Broeckaert and Challacombe 2014; see Appendix A) through reducing the stress, anxiety and depression associated with illness and using the healthcare system; and working with each client to identify the potential barriers they might face, find and implement solutions to those barriers, and over time, build the capacity of the client to manage these barriers themselves.

Based on an evaluation of HIV peer navigation programs throughout the USA, AIDSUnited (2015: 10) put forward a best practice approach for integrating peer navigators into HIV models of care. Features of this model include:

- Design a system that integrates peer navigators into the HIV care team well before the hiring of peer navigators – a standardised title and position for peer navigators is desirable; and protocols and procedures for the program need to be established, including how they will interact with colleagues.

- Identify the specific populations to be served by peers and aim for a good matching of clients with a peer that has an understanding of their barriers and opportunities for optimal health.
- Implement a competency-based training for peer navigators and provide them with consistent administrative and clinical supervision.
- Create a documentation system to describe and monitor peer-client activities that is linked to case management records.

For older PLHIV, especially those dealing with complex multimorbidity and geriatric symptoms, peer support and peer navigation both assume greater significance when they are negotiating complex policy and service frameworks. Central aspects of these frameworks in Australia have been discussed in section 4 of this report. A key area of action in the *Eighth National HIV Strategy* (Australian Government 2018: 32) is to maintain and develop peer support models, including supporting PLHIV to function as peer navigators.



# 6 NAPWHA's role in addressing HIV and ageing

As evident in the Australian and international literature, a wide spectrum of sectors and organisations is already explicitly addressing HIV and ageing, and doing so from diverse scientific, community, professional, service delivery and policy making perspectives. Within this mix, what is the ideal role and function of NAPWHA?

The material in this sections considers this question in light of NAPWHA's peak organisation status in Australia and the scope it has to develop innovative and collaborative approaches to supporting its constituency. The following are discussed:

- Summary of the process and outcomes of the work carried out in NAPWHA's HIV and Ageing Project Phase 1, including a recommended advocacy agenda
- Adoption of a comparative approach in order to explore ways through which positive people's organisations in other jurisdictions address HIV and ageing – the emphasis is on national organisations similar to NAPWHA
- Outline of the priorities according to NAPWHA staff, having themselves drawn upon the outputs and outcomes of Phase 1.

## 6.1 Process and Outcomes from NAPWHA's HIV and Ageing Project Phase 1

### 6.1.1 Consultations

A range of consultations were held in Phase 1. Staff members from state-based PLHIV organisations were contacted to gather insights into the lived experiences of PLHIV in each State. Researchers in the fields of behavioural science, social science and basic science were also contacted to provide input and suggest references (see Appendix B). Consultation occurred at the NAPWHA Special General Meeting (SGM) held on 13 and 14 April 2018. At that meeting, PLHIV representatives of all Australian States and territories were asked to provide

input to NAPWHA's national HIV and ageing advocacy agenda.

The SGM consultation on HIV and ageing aimed to promote awareness of the issues surrounding HIV and ageing and dissemination of information related to service provision. Delegates were asked to consider the advocacy issues presented, the reasons for their importance, and what might be done about them. Topics for discussion included:

- The **legislative and service delivery frameworks for ageing** – structure of disability and aged care service provision in Australia; access to

NDIS and My Aged care for PLHIV; opportunities for PLHIV organisations

- Quantification and qualification of the **data on HIV and ageing** – numbers of people ageing with HIV, where they are located, the comorbidities affecting them, and how they are currently being monitored
- **Analysis of the gaps** – development of an advocacy agenda, pathways and partnerships to pursue, and meeting the challenges of an ageing population of people with HIV

NAPWHA supports a number of national networks to facilitate the engagement of specific sub populations of PLHIV including Femfatales, PATSIN and Poz Action and Treataware Outreach Network. Femfatales (the National Network of Women living with HIV) is an advisory group that is constituted to provide collaboration between those involved in policy and advocacy work for women living with HIV in Australia. With the support of NAPWHA, Femfatales advocates, informs policy and responds to the challenges facing PLHIV, with a focus on women. The specific issues of women ageing with HIV have been raised by Femfatales, noting that there is a distinct lack of research about the effects of ART on women's bodies and the effects that ageing may have on women who live with HIV.

The Positive Aboriginal and Torres Strait Islander Network (PATSIN) is a national membership-based group for Indigenous people living with HIV. PATSIN recognises the diversity of the lived experience of Indigenous people and, supported by NAPWHA, provides advocacy, support and information, underpinned by the provision of culturally appropriate peer support. While the median age of Aboriginal people with HIV is younger than the white Australian population, the lower life expectancy and high rate of health problems among older Aboriginal people means that there is significant interest in the issues of ageing with HIV among Aboriginal PLHIV.

Concerns have been expressed that Aboriginal Community Controlled Health services may currently not be providing adequate care for Aboriginal and Torres Strait Islander people ageing with HIV; this is an issue to investigate further, with the aim of searching for solutions to benefit older PLHIV.

Poz Action is the operational leadership of funded HIV organisations from the State based jurisdictions, which comprise: Living Positive Victoria, Positive Life New South Wales, Positive Life South Australia and Queensland Positive People. PLHIV organisations aim to represent and advocate on behalf of the diversity of people living with HIV, and are founded in a commitment to the involvement and empowerment of the group most affected by HIV — people living with the virus. The issues of HIV and ageing and management of comorbidities have been raised in the Poz Action forum and members have supported NAPWHA's work in this area.

The Council on the Ageing (COTA) was contacted to understand the opportunities to advance the agenda of people ageing with HIV. Researchers in the fields of behavioural science, social science and basic science were also contacted to provide input and suggest references. Appendix B lists the stakeholders that were consulted.

Consultation occurred at the 2018 Annual NAPWHA Treataware Outreach Network (TON) meeting held on 19-20<sup>th</sup> April 2018. At that meeting, professionals from all over Australia who were working together to optimise the overall wellbeing of PLHIV and those affected by HIV were asked to provide input to NAPWHA's HIV and ageing advocacy agenda. Points from the NAPWHA presentation at this meeting are summarised in the box below.



## HIV and ageing

Region	2020	Number of PDHIV > 55 years	Number of PDHIV 65+
Australia	28,422	12,590	4,917
NSW	11,722	5,192	2,027
Sydney	9,082	4,023	
NSW Rural	2,638	1,168	
Victoria	6,959	3,082	1,203
Melbourne	5,841	2,587	
Rural Victoria	1,118	495	
Queensland	5,408	2,395	935
Brisbane	2,697	1,194	
Rural Queensland	2,710	1,200	
South Australia	1,449	641	250
Adelaide	1,218	539	
Rural South Australia	231	101	
Western Australia	2,026	897	350
Perth	1,623	718	
Rural Western Australia	403	178	
Tasmania	294	130	51
Northern Territory	210	93	36
Australian Capital Territory	355	157	61

Activity is happening at all levels of the Australian response to HIV and ageing, particularly at the community level; however, NAPWHA believes that a coordinated enhanced advocacy agenda is warranted and is in the process of developing that agenda.

Findings from a 2015 study carried out by Positive Living NSW were presented, including a table of projections for the numbers of older PLHIV in the various regions of the country:

For older PLHIV, it is important to recognise the difference between chronological ageing (number of years that have passed since birth) and biological ageing (description of an individual's development based on biomarkers) and the influence of comorbidity (two or more diseases that occur in one person at the same time).



Four 'pillars of the HIV response' can be identified as:

1. **Government** – strong focus on promoting an Aged Care Workers Training module on HIV
2. **Research** – several studies occurring in Australia, including the APPLES study (discussed in section 3 of this report)
3. **Health and medical services** – there are several resources currently available including the training module published by ASHM (Hermann and Skinner 2016); ART Guidelines (HIV and the older patient); and ADAHPS
4. **Community** – including work carried out by the Western Australian AIDS Council (eg HIV and Ageing training for community and residential service providers; Victorian AIDS Council (eg Community Support Program providing care coordination, home care workers, social support and medical transport); ACON (eg the Living Older, Visibly and Engaged [LOVE] Project); Positive Life NSW (eg HAND resources, NDIS support); Living Positive Victoria (eg Senior Voices Positive Speakers Bureau); and Queensland Positive People (Positive in Queensland Study; expanding peer navigation).

### Challenges:

- Quantity – it is estimated that approximately 1,000 individuals will need high level care (often linked to HAND), and most services will be delivered in homes, but are there enough providers?
- Quality – Ageing with HIV is a unique experience, changes in aged care provision risk a reduction in clinical understanding/availability.
- Availability – Services outside of metropolitan areas are limited and are also more outside the reach of specialist opportunities for learning and upskilling
- Demand – the recent system change to consumer focus (Consumer-directed care) requires the consumer to be informed about what services are available and what their eligibility is. Consumer focus implies that the consumer has the capacity to self-assess, navigate and advocate within a complex system. At the same time, PWHIV are tired, having borne the additional burden of long-term survival, psychological burden, accelerated or attenuated ageing etc.

Also recognise that, although interconnected in a continuum of care, aged care is distinct from health care; for the vast majority of PLHIV, aged care providers are likely to be from the mainstream; and NDIS could be a potentially confounding factor.

## 6.1.2 Presentations

NAPWHA made presentations at several national events to engage a broader audience in the emerging issues surrounding HIV and ageing.

Attending the 5th National Elder Abuse Conference: Together Making Change, hosted by the Seniors Rights

Service on 19 and 20 February, the HIV and Ageing Project Officer made a presentation on *HIV stigma and discrimination: a perspective on elder abuse*. Key points from the presentation are summarised in the box below.





## HIV stigma and discrimination: A perspective on elder abuse

Abusive behaviour based on stigma and discrimination it is not always recognised as discriminatory by those who perpetrate it. People ageing with HIV should expect to be treated with dignity and respect, and their care to be free from rejection, exclusion, insults and gossip.

Ageing presents challenges in terms of loss, physical deterioration and social sidelining even when one has good health, financial stability and strong supports. Evidence shows that living with HIV can accelerate and accentuate the ageing process, with physical and mental deterioration starting earlier, and lifestyle factors adding to this deterioration. Years of chronic inflammation, with cells on the warpath, and the long-term side-effects of medication, take their toll, making people with HIV even more vulnerable.

People ageing with HIV are entitled to expect a standard of care and compassion from health care staff without abuse. However, abusive behaviour based on stigma and discrimination is not always recognised as discriminatory by those who perpetrate it. Sometimes this is due to lack of knowledge, at other times there are cultural factors at work.

Aged care workers may need to challenge their own beliefs and attitudes towards such issues as sex and sexuality (including same sex relationships, transgender and intersex people), injecting drug use, fears of and knowledge of HIV/AIDS in order to provide the best possible care for people with HIV.

NAPWHA attended the 10<sup>th</sup> Health in Difference 2018 Conference hosted by the National LGBTI Health Alliance from 11 to 13 April 2018. The HIV and Ageing

Project Officer made a presentation on *HIV and ageing: A new frontier for LGBTI advocacy*. Key points from the presentation are summarised in the box below.



## **HIV and ageing: A new frontier for LGBTI advocacy**

By 2020, 50% of all people living with HIV in Australia will be over 50. While HIV is no longer a death sentence, people living with the virus experience ageing differently from their HIV negative peers. Cardiovascular disease, kidney disease and physical frailty can strike people with HIV in their 30s and 40s. Emerging issues such as HAND can result in a significant reduction in functional capacity.

While other marginalised groups, notably Indigenous Australians are now disproportionately affected by HIV, over 80% of people living with HIV in Australia identify as gay men. Research reveals a combination of factors which both accelerate and accentuate ageing for people living with HIV. This may mean that people with HIV need to access ageing and age care services at younger ages than their peers. In recognition of this phenomenon, work at the jurisdictional level to provide services for people ageing with HIV has begun, but a national framework for advocacy is necessary to

ensure the emerging needs of this community are properly recognised and met.

In addition, stigma and discrimination against LGBTI people in age care settings may be increased in the case of people living with HIV. The good work being done in assisting the Government implement and review the National LGBTI Ageing and Age Care strategy provides an opportunity to advocate for the needs of LGBTI people ageing with HIV. It also opens the door for a wider discussion of the needs of all Australians ageing with HIV.

While the public perception of HIV has improved in recent years, PLHIV can still face barriers to receiving services and care, particularly as they age. Sometimes fear of discrimination or negative past experience prevents them from accessing services. Lack of knowledge and experience of HIV among health workers can lead to discrimination and potentially worse health outcomes.

NAPWHA's HIV and Ageing Officer's presentation at the ASHM Conference in September 2018, which summarised the outcomes of Phase 1, is summarised next.



## Outcomes of an investigation into HIV and ageing in Australia

We live in an ageing society and increasing life expectancy is raising many issues. It is not surprising that when NAPWHA asks our member organisations what new areas we should be investigating, the area that has come up with increasing frequency is the issue of HIV and ageing.

In the next few years more than half the HIV population in Australia will be over 50. Around half (6,000) of these people could be considered as long term survivors – who are arguably the most physically and psychologically impacted. The next decade will be about the ageing HIV population, but there is surprisingly little published data on this population in Australia and many questions still to be answered.

A critical question in understand HIV and ageing is whether HIV is an additional risk factor for a wide number of chronic conditions thus *accentuating* the prevalence of disease at every age; or whether HIV is *accelerating* ageing through pathways and mechanisms common to the ageing process? Unfortunately there is no clear answer. Both *accelerated* and *accentuated* ageing seem to occur in people with HIV, but not across all conditions and not for all people. There are few specific biomarkers of ageing in PLHIV, who are impacted by antiretroviral therapy, and a high rate of modifiable lifestyle factors. It is clear that comorbidities are affecting people with HIV as they age, including thrombosis, diabetes, heart disease, neurocognitive issues, bone disease and certain types of cancer. It is also clear that people with HIV are typically dealing with more comorbidities than their HIV negative peers. Frailty measures help to move away from the exceptionalism of HIV in service delivery, which has the potential to be stigmatising for the recipients of that care.

NDIS and My Aged Care are revolutionary ways to deliver services to vulnerable people in our society, but they have their own complexities, including:

- HIV is considered a disability under the *Disability Discrimination Act* but that doesn't mean automatic qualification for NDIS.
- PLHIV face many of the same issues accessing NDIS and My Aged Care as others in the wider community. There is uncertainty about the overlap and gaps between the systems, and criteria are often unclear or not made publicly available. Websites are confusing.
- There is provision for PLHIV to access NDIS at earlier ages if it can be demonstrated that spending money now will avoid future expenditure
- PLHIV can access My Aged Care from age 50 if they need support to live independently in the community, and are on a low income, homeless or at risk of being homeless, or if they are Aboriginal or Torres Strait Islander. Access at earlier ages may also be possible for those are concerned about accelerated ageing with HIV.
- At the same time, assessors have no specialist training and little experience in dealing with HIV; and there is a backlog of 100,000 people waiting for access to care packages

The aged care sector is undergoing significant reform due to pressure from a variety of sources, including initiatives to ensure it is inclusive of LGBTIQ+ people. This will directly and indirectly benefit many people ageing with HIV, even if they are not also part of that community. PLHIV organisations are responding to the needs of their communities as they age – they are ideally placed to understand and respond, although funding is an issue.

NAPWHA's proposed advocacy agenda for HIV and ageing was also put forward.



The proposed advocacy agenda is presented in section 6.1.4 below.

## 6.1.3 Survey

NAPWHA conducted a small-scale survey designed to explore some of the real life concerns regarding ageing with HIV and views people may have on aged care services. NAPWHA's community contacts were invited to complete the survey based on their own concerns or on behalf of communities they work with. Selected individuals with an interest in the subject were also invited to provide responses. The questionnaire used in this survey is provided in Appendix C.

This exploratory study (N=39) found that the top three concerns about ageing with HIV amongst the respondents were social isolation, dealing with comorbidities, and access to services, specifically My Aged Care and NDIS (discussed earlier in this report). Other concerns included stigma and discrimination; finance and housing; and the quality of aged care. A large majority of respondents (92%) believed that their community would be impacted 'very much' or 'quite a lot' by age-related comorbidities. However, only 12% of respondents believed that their community were 'well informed' about growing older with HIV, and a further 28% were 'unsure'.

Peer support programs were felt to be 'extremely important' (51% of respondents) or 'very important' (26% of respondents) in reducing the impact of HIV and ageing. A majority (71%) felt that lifestyle changes (diet, exercise, drug and alcohol use and smoking) can help 'very much' or 'quite a lot' to reduce the impact of comorbidities.

Respondents made suggestions on the kinds of information that would most improve the lives of people ageing with HIV, and these included:

- Information about aged care services
- Healthy lifestyle information to reduce the impact of comorbidities
- Medical information on the impact of HIV on the ageing process
- Information on community support and social services.

Suggested changes to service provision to improve the community's experience of ageing with HIV included:

- Changes to aged care service provision that focus on the specific needs of PLHIV
- More focus on holistic care that effectively integrates HIV concerns with ageing concerns
- More inclusive service provision.

## 6.1.4 Proposed advocacy agenda

Findings from Phase 1 of the NAPWHA HIV and Ageing project, suggest as a whole:

1. A lack of knowledge and understanding of aged care services and how to access them is exacerbating the fears of PLHIV who are ageing.
2. There is a role for PLHIV organisations in running inclusive social programs which tackle isolation and fears about HIV and the ageing process, and about access to aged care.
3. There is work to be done to facilitate the integration of HIV care with geriatric care.

In light of this, and in keeping with the overall objective for Phase 1, an advocacy agenda – a road map which identifies the desired outcomes, explains why it is important and proposes some ways to get there – was put forward. This agenda (summarised in the box below) was also provided in the 'Outcomes of an investigation into HIV and ageing in Australia' report delivered to the Australian Government in September 2018.



### Proposed advocacy agenda following the conduct of NAPWHA's HIV and ageing Project Phase 1

Ensure that agencies and individuals can access non-HIV aged care and disability services that meet the specific needs and concerns of people ageing with HIV.

Funding for research on the incidence, prevalence and impact of comorbidities commonly experienced by Australians with HIV in later life. In particular, we should understand more about HAND and the needs of specific populations like women with HIV.

Improve medical services to address HIV and the ageing process, including developing HIV gerontology as a specialty field.

Ensure PLHIV who are already experiencing comorbidities associated with ageing receive appropriate care to reduce or manage the impact of comorbidities.

Empower PLHIV over 50 to make improvements to their health and wellbeing, based on the provision of detailed and accurate information.

## 6.2 Examples from other jurisdictions

A comparative approach was used in order to explore ways through which HIV positive people's organisations in other jurisdictions address HIV and ageing. Drawing on a desktop review of information available in the public

domain, the emphasis was on national organisations that were similar to NAPWHA. Table 4 summarises the findings of this document analysis.

Table 4: Role of national positive people's organisations: A comparative approach

Country	Organisation, Mission, Objectives	Indicative roles and functions	Specific focus on ageing
→ Canada	<p>Canadian AIDS Society (CAS) is a national voice for people living with HIV/AIDS and represents community-based HIV/AIDS organizations across the country.</p> <p>Its objective is to strengthen the response to HIV/AIDS in Canada and enrich the lives of people and communities living with, and affected by, HIV/AIDS.</p>	<p>Roles of CAS: promoting education and awareness; mobilising communities; advocating at the federal public policy level; and providing information and resources.</p> <p>CAS works with elected officials and senior public servants; leads discussions with key funders; and convenes national and regional meetings with members. It has a role in sector capacity building.</p>	<p>Recognises the new challenges emerging as PLHIV live longer – greater risk of comorbidities, ageing challenges, and adjusting to new prognoses.</p> <p>Produced <i>One Foot Forward: A Greater Involvement of People Living with AIDS</i> training toolkit</p> <p>Produced <i>HIV and Aging in Canada</i>, an updated 2013 HIV and aging fact sheet</p>
→ Netherlands	<p>The HIV Vereniging (association) promotes itself as the 'experts in living with hiv' in the Netherlands.</p> <p>It strives for equal and non-discriminatory treatment of people living with HIV.</p>	<p>The organisation provides information, advocacy, research and support for PLHIV.</p>	<p>Partner in the AGEhIV Cohort Study. Carried out over six years from 2010, the study compared people living with HIV who were older than 45 with a comparable non-HIV positive cohort.</p>



Country	Organisation, Mission, Objectives	Indicative roles and functions	Specific focus on ageing
<b>New Zealand</b>	<p>Body Positive New Zealand (Tinana Ora Aotearoa) is founded and run by and for PLHIV.</p> <p>Body Positive is an associate member of NAPWHA.</p>	<p>Body Positive provides a range of services for PLHIV, aiming to break down the sense of isolation PLHIV often experience, and to build a sense of community. These services include:</p> <ul style="list-style-type: none"><li>• Facilitating or supporting a range of support groups for PLHIV</li><li>• Developing a network of HIV+ peer navigators</li><li>• Facilitating educational events</li><li>• Advocating from an HIV+ perspective in public forums and debates</li><li>• Providing counselling to members via the Positive Health Scheme</li></ul>	<p>Published the booklet <i>Ahead of Time: Growing older with HIV</i> in 2012.</p> <p>Although not specific to the work of Body Positive, the 2018 New Zealand HIV update had the focus: <i>The spectrum of care, from Pre-exposure prophylaxis (PrEP) to HIV in an ageing population</i></p>
<b>Scotland</b>	<p>HIV Scotland is an independent NGO</p>	<p>Operates nationally, addressing policy and practice across Scotland and linkages to national UK bodies.</p> <p>Advocates for people living with HIV, challenges stigma, and encourages engagement in planning and delivering equitable and quality services across Scotland.</p> <p>Focuses on policy, capacity building and campaigning.</p> <p>Unites the third sector by bringing agencies together in support of policy development, information sharing, and joint action.</p> <p>Delivers a strategic and professional contribution.</p> <p>Maintains an overview of HIV-relevant knowledge, research and effective interventions.</p>	<p>There is currently no specific policy or strategy for HIV and ageing in Scotland. However, broader policies on ageing do exist which will have implications for the future care of people living with HIV.</p> <p>HIV Scotland would like to see policy-makers and service providers better recognise the growing numbers of people who are living with HIV into old age. Consideration must be given not just to their health and social care needs but also their financial and emotional needs, diversity, and rights.</p>





Country	Organisation, Mission, Objectives	Indicative roles and functions	Specific focus on ageing
<p>→</p> <p><b>South Africa</b></p>	<p>The National Association for People Living with HIV &amp; AIDS (NAPWA) mobilises infected and affected people to unite against the spread and impact of HIV and AIDS</p>	<p>The organisation carries out its mission by developing and sustaining PLHIV support groups and structures; promoting education that is sensitive and specific to the needs of PLHIV; and providing guidance and support for PLHIV. NAPWA's core programs are:</p> <ul style="list-style-type: none"> <li>• Mobilisation of PLHIV</li> <li>• Treatment, care and support</li> <li>• Advocacy and human rights</li> <li>• HIV prevention</li> <li>• Economic empowerment</li> </ul>	<p>No specific programs focusing on ageing</p>
<p>→</p> <p><b>United Kingdom</b></p>	<p>Positively UK provides peer-led support, advocacy and information to everyone living with HIV to manage any aspect of their diagnosis, care and life with HIV.</p>	<ul style="list-style-type: none"> <li>• Project 100 – aiming to provide all PLHIV in the UK with access to peer support</li> <li>• Take Control, Learn, Connect – a program of interactive workshops for PLHIV, including those recently diagnosed</li> <li>• Focus on particular groups – Women, Gay and Bisexual Men, Young people, Aged 50+</li> </ul>	<p>Campaign – <i>Aged to Perfection</i>: addresses coming to terms with a new diagnosis, managing treatments, dealing with sex and relationships, feeling better about self, or for people who just want someone to talk to</p>



Country	Organisation, Mission, Objectives	Indicative roles and functions	Specific focus on ageing
USA	<p>The HIV Caucus collectively speaks with a unified voice for people living with HIV in the USA.</p> <p>The US PLHIV Caucus is comprised of organisations, coalitions, networks or client groups of people living with HIV, and independent advocates living with HIV.</p>	<p>The US PLHIV Caucus was established in 2011 to live out the directive of the 1983 Denver Principles calling for engagement of PLHIV in all HIV/AIDS related work.</p> <p>It focuses on facilitating meaningful involvement of PLHIV in all aspects of the HIV epidemic, specifically targeting the following:</p> <ul style="list-style-type: none"><li>• National HIV Strategy</li><li>• Program and policy participation</li><li>• International AIDS Conference, serving as the lead body for the USA</li></ul>	<p>By 2014, already 45% of PLWHIV in the USA were 50 years and older.</p> <p>A National HIV/AIDS and Aging Awareness Day is, observed annually on September 18th. It focuses on the issues facing the ageing population with regards to HIV prevention, testing, care and treatment.</p> <p>All HIV organisations in the USA are currently dealing with political changes that have included the ending of the HIV Council and proposed massive cuts to HIV/AIDS prevention and treatment programs in the FY 2018 Federal Budget.</p>

As the analysis above shows, the underlying functions of HIV peer-based organisations, especially those at a national level, include:

- Mobilising communities of people living with HIV and their friends, families and supporters
- Providing or facilitating peer support
- Advocating at the federal public policy level through maintaining a strategic long-term focus on people living with HIV
- Uniting the not-for-profit non-government sector by bringing agencies together in support of policy development, information sharing, capacity building, campaigning and joint action
- Promoting HIV education and awareness, and contributing to HIV prevention

- Providing information and resources
- Maintaining an overview of HIV-relevant knowledge, research and effective interventions, as well as undertaking original research.

Increasing in significance in recent years, a focus on HIV and ageing dovetails well with these functions. Advocacy, partnering in research and providing evidence-based and accessible information are common strategies adopted in jurisdictions similar to Australia. At the same time, there does not as yet appear to be a 'best practice' approach, suggesting scope for Australia to take a lead – as it has so often over the past few decades – in responding to this new frontier in HIV.

## 6.3 Priorities according to NAPWHA staff

In a workshop held at NAPWHA in October 2018, and on the basis of a consideration of evidence from the literature, staff brainstormed what might be priority functions for the organisation in addressing HIV and ageing. Overall, there was support for acknowledging HIV and ageing as a 'new frontier' for PLHIV. Five core functions were agreed upon.

### 6.3.1 Providing a national overview of HIV and ageing

NAPWHA is the only organisation in the country that provides a national overview of HIV and ageing specifically from the point of view of PLHIV. This includes:

- Explicitly demonstrating our organisation's willingness to address PLHIV concerns about ageing
- Gathering, collating and disseminating PLHIV voices
- Placing a focus on health and mental health

### 6.3.2 Taking a cohesive positive voice to Canberra

Closely linked to the first function, this implies:

- Alerting policy makers to the concerns of PLHIV
- Advocating and lobbying for PLHIV, with a particular focus on the intersection of health, ageing and disability
- Interpreting policy and system negotiations and changes for the benefit of PLHIV

A task for the organisation is to continue its strategic

relationship with the Australian Government. This includes being informed of, and taking part in consultations relating to, ageing and aged care policies and strategies.

### 6.3.3 Maintaining an overview of social service system impacts on PLHIV

Working together with partner organisations and service providers, this incorporates a focus on:

- Community-based care and 'ageing in place'
- Residential care
- The overlaps and gaps among the health, ageing and disability sectors.
- Keeping abreast of Australian Government policies and strategies in connection with ageing and aged care – founded on the principle of consumer-directed care – would be essential.

Recent experiences in countries such as the USA suggest that HIV/AIDS organisations need to continue being politically savvy and be prepared to engage directly in political processes.

### 6.3.4 Peer support by and for older PLHIV

NAPWHA has a clear role with regards to peer support for PLHIV in their later years. The research and theory underpinning peer support in a health context has been developing consistently over the past two decades, and this suggests that support from peers who are living with HIV in their later years may contribute directly



and indirectly to positive health outcomes, as well as protecting against the impact of stressors. Strong partnerships with the state-based affiliates would be essential to extending peer support networks throughout the country, with a focus on HIV and the later years. In particular, NAPWHA can take a more active role in delivering peer support to PLHIV living in the smaller States/Territories; and can help to articulate and promote peer support principles and best practices.

## 6.3.5 Research and evaluation

NAPWHA's role in research and evaluation, including partnering with other organisations and engaging in original research, underpins the functions outlined above. Directions for further research are discussed in greater detail in section 7.7 below.

# 7 Synthesis: addressing the research questions

Through responding to the research questions, this final section of the document provides a synthesis of the study as a whole.

## 7.1 HIV and ageing in the literature

**What does some of the international and national literature say about the experience of HIV and ageing – especially in regards to the role of peer supports but also with reference to the scientific literature on the impacts of ageing with HIV and impacts of living with multiple comorbid conditions?**

With the success of ART since the mid-1990s, there has been dramatic fall in the rate of AIDS-related infections and malignancies. PLHIV, a large proportion of whom are 50 years and older, are increasingly being treated for diseases commonly associated with ageing. Evidence suggests that the prevalence of comorbidities and other age-related conditions is higher amongst PLHIV than in their uninfected peers, and that both accelerated (earlier) and accentuated (more pronounced) ageing have an impact. Geriatric syndromes of particular concern are frailty, which increases the risk that an apparently minor event can precipitate a serious decline in health; and chronic inflammation, which is affected by both HIV and ageing.

The enhanced vulnerability of those who have been living with HIV for many years has been identified in several studies: a longer time with diagnosed HIV infection is related to a higher prevalence of all self-rated physical and mental health problems and the distress caused by these

symptoms. It is also related to health-related functional problems with mobility, self-care and the performance of usual activities.

Maintaining viral suppression through the use of ART, together with the treatment of comorbidities such as cardiovascular disease, depression, osteoporosis and chronic renal disease, puts PLHIV at risk of polypharmacy. The risk of harm from polypharmacy increases with the number of medications used. These harms include inappropriate medication use, DDIs, delirium, falls and fractures, and impaired elimination and/or drug accumulation linked to loss of the optimal functioning of the liver or kidneys, which may decrease with age.

The experience of ageing with HIV is shaped by factors such as gender, sexual orientation, socio-economic status and age at diagnosis. Many PLHIV report that only those living with HIV could fully appreciate what it was like to live and age with the virus.



## 7.2 Policy

**What are some of the national policy frameworks that impact on ageing with HIV in the Australian context?**

Breaking down of silos among the health, disability and aged care sectors, placing more decision-making power in the hands of consumers and their carers (consumer-directed care), and streamlining service gateways and transitions to ensure continuity of care have featured prominently in recent Australian policy initiatives. Features such as a single entry point to the aged care system, concrete steps to recognise, reward and resource carers, the NDIS, strong use of online technology, and national standards and complaints procedures all contribute to breaking down traditional distinctions between home care, residential care and hospital care; and between the care that is provided by informal unpaid

carers and formal service providers.

Programs and services such as the Home Care Packages Program, Integrated Carer Support Service and PHNs would be important partners for HIV community organisations as more and more PLHIV access – and transition between – the health care, and community, disability and aged care services. The principle – expressed again in the *Eighth National HIV Strategy* – that meaningful participation of people living with HIV is essential to the development, implementation, monitoring and evaluation of programs and policies is of significance to peer-based organisations, including NAPWHA.

## 7.3 People ageing with HIV in Australia

**What is currently known about the cohort of people ageing with HIV in Australia?**

Research on older Australians living with HIV can be complemented with findings from studies that have been carried out in jurisdictions such as the UK, Canada and the USA. These studies suggest that self-reported sense of wellbeing is high and, indeed, that happiness and reduced self-stigma increase with age. Participants report that the complexities of their lived experiences generate wisdom that could be applied to the process of ageing. While

mental health issues are commonly reported, the severity of the symptoms of depression and anxiety also tends to decrease with age. Helpful strategies adopted by people ageing with HIV include:

- Caring for mind and body through a focus on issues such as treatment adherence, nutrition, regular physical activity and effective stress management

- Adopting self-management strategies associated with maintaining a sense of control, including through lifestyle choices made, eliminating negative relationships or environments, and fostering positive attitudes and beliefs
- Engaging in meaningful activities that contribute to ongoing learning, maintaining focus and establishing purpose
- Building and maintaining strong networks of formal and informal supports.

At the same time, studies also show that older PLHIV are more likely than younger peers and non-infected peers to be dealing with a greater number of concurrent health conditions, and more likely to report limitations in their capacity to undertake daily tasks due to poor health. Many report uncertainty over how HIV, ART and 'normal ageing' would intersect to impact on their overall health and wellbeing. Trauma is common in the life experience of participants in many of the studies and a majority report dealing with a mental health condition at some point in

their life. Concerns about ageing may be exacerbated for long-term survivors, who had faced imminent mortality in early adulthood, had lost partners and networks of friends, and may already be experiencing functional limitations in areas such as housework or mobility.

Using chronological age alone does not account adequately for social and behavioural outcomes observed among older adults with HIV. Financial and housing problems, loneliness and social isolation exacerbate concerns many may have about being able to access the kinds of supports typically derived from family of origin and friends. Some find themselves increasingly reliant upon publicly-funded formal resources. Surveys reveal that many PLHIV are worried about policy and service system changes, and whether ageism intersecting with HIV stigma could create difficulties for them down the track, specifically in relation to the quality of long-term care. Studies suggest that older women with HIV perceive significantly greater barriers to services than their male peers.

## 7.4 Major HIV and ageing issues for Australia

### What are the major HIV and ageing issues for Australia?

#### 7.4.1 The search for pathways to optimise the health and wellbeing of older PLHIV

A key issue for stakeholders is to explore, trial, share and promote pathways that deliver optimal health and

wellbeing outcomes for older PLHIV. Although the predictors of successful ageing in PLHIV are not yet fully established, successful ageing can be promoted through explicit integration of geriatric principles into HIV care, strengthening peer supports, and directly addressing factors that affect individuals' overall wellbeing and autonomy. Within an integrated and holistic approach, the literature provides support for measures that include, but are not limited to:

- A shift from targeted disease-specific management to geriatrics-based models in which the emphasis is on maintaining quality of life for as long as possible
- Managing HIV through early initiation and





maintenance of ART, and exploring newly-trialled and available treatment options

- Addressing polypharmacy
- Early interventions for those who are at risk of frailty
- Control of modifiable risk factors such as smoking
- Acknowledging and addressing vulnerabilities related to social disadvantage.

Understanding the relative contributions of age, HIV infection, ART and lifestyle factors to the development of comorbidities would contribute to the development of better screening, primary prevention and treatment programs, including rehabilitation.

Opportunities to support treatment adherence, preserve health and delay disease progression would rest upon having greater insight into the lived experience of older PLHIV, and acknowledging their engagement with their own wellbeing. It also requires maintaining a strong focus on mental health and psychosocial functioning. This includes screening regularly for depression and anxiety, and making available interventions that would assist older PLHIV to increase resilience, a sense of personal mastery, and optimism. Such interventions are strongly indicated for older PLHIV impacted by issues such as poverty and isolation, and for those who have lived with the virus for a long time.

As an approach to optimise health and wellbeing for PLHIV, peer support has been immensely productive in the Australian context, and at all levels: institutional and decision-making, community, peer support groups and organisations, and one-to-one peer support and mentoring.

There is also a need for ongoing research and making research findings as widely available as possible, including ensuring that findings are made accessible and useful to PLHIV themselves.

## 7.4.2 The need to strengthen the service delivery framework

Increased rates of age-related illnesses and functional problems affecting many older PLHIV will put pressure

on the health, aged care and disability service systems in coming years, and also increase burdens on informal carers. Australian and international research shows that older PLHIV express concerns about ageing that include increased loneliness and social isolation, uncertainty about maintaining independence in light of comorbidities and functional decline, access to services (specifically, in Australia, My Aged Care and NDIS) and the potential impact of unpreparedness and HIV-related stigma on the quality of mainstream service provision. All of these point to a second major HIV and ageing issue for Australia: strengthening the service delivery framework.

Means are already being discussed in the literature to promote appropriate, effective and efficiently delivered and monitored services for older PLHIV. They include developing comprehensive care plans in which the assessment and management of frailty is a priority for care; and promoting models of multidisciplinary and shared care, where HIV may not always be the major pressing condition, but where issues such as PLHIVs' previous experiences with care systems, the overlap of HIV and ageing stigma, and the cumulative effect of multiple comorbidities and polypharmacy need to be addressed.

HIV training and resource provision in the aged care sector and for clinical and support staff will need to be addressed as the population of PLHIV continues to age. This includes:

- Integrated HIV and geriatric care
- Developing understandings of the psychological and social issues related to HIV, and incorporating these learnings into psychosocial interventions
- Providing access to effective diagnostics and treatments for increasingly complex comorbidities
- Developing expertise in multidisciplinary team participation and coordination.



## 7.5 Role for NAPWHA

With reference to comparative international literature and NAPWHA's role as a national advocacy organisation for people living with HIV in Australia, what could be mapped out as NAPWHA's future policy and programmatic activities in this area?

- 1. Community organisation** – NAPWHA serves as a peak organisation for the community of interest – people living with HIV in all parts of the country – and provides support to its affiliates in their efforts to address emerging ageing-related issues, particularly as they are expressed by PLHIV themselves. It mobilises communities of people living with HIV and their friends, families and supporters. With respect to this new frontier for people living with HIV, NAPWHA has a strong role in uniting organisations in support of policy development, information sharing, capacity building, campaigning and joint action.
- 2. Advocacy** – NAPWHA maintains a strategic focus on PLHIV at the federal public policy level and, in keeping with demographic trends, strongly advocates for the needs of older PLHIV in policy decision-making. It provides evidence-based and accessible information especially to PLHIV themselves. It serves as a conduit between peer-based community organisations and government, also in addressing stigma and discrimination.
- 3. Peer support** – NAPWHA continues to develop expertise in peer support in the context of HIV, and applies learnings gained in previous decades to promote peer support for older PLHIV. It generates, gathers and shares data and information, and articulates and promotes peer support principles and best practices. It supports its affiliates to extend peer support networks throughout the country, with a focus on older PLHIV, and may take a more direct role in delivering peer support to older PLHIV living in the smaller jurisdictions that lack state/territory organisations. It advocates for the appropriate use of peer navigators as part of the care continuum for older PLHIV.
- 4. Networks and partnerships** – NAPWHA recognises that fostering networks and partnerships, also at the international level, is essential for developing innovative and collaborative approaches to addressing the new frontier of HIV and ageing.
- 5. Research and evaluation** – NAPWHA conducts and participates in the conduct of research and evaluation studies that increase understandings and generate evidence and best practices for improving the lives of older PLHIV.
- 6. Services** – NAPWHA works closely with its community-based affiliates to promote integrated services that will best meet the needs of older PLHIV. It explores innovative service coordination and/or provision opportunities in light of expressed uncertainties regarding the preparedness of the aged care sector to adequately address the needs of older PLHIV.

In keeping with this broad approach, recommendations are made for continuing NAPWHA's HIV and Ageing Project in a second phase that will build directly on the work described in this report. A draft proposal for Phase 2 is provided in Appendix E.



## 7.6 Risks of doing nothing

### What are the risks of doing nothing?

This question relates closely to the prior two questions. Neglecting to focus on the ageing trend among people living with HIV, including actively involving them in initiatives, could:

- Present lost opportunities for optimising the health and wellbeing of older PLHIV through supporting treatment adherence, delaying disease progression and strengthening the service delivery framework, particularly at this early phase of the ageing trend.
- Jeopardize consumer-directed and continuity of care principles and contribute to service system stress – including over-use of acute services – as the demands for integrated service provision for older PLHIV increase.
- Disempower Australians living with HIV and the community organisations that represent and serve them, contributing to inefficient policy decisions and approaches.
- Compromise opportunities to develop enhanced models of peer support that focus specifically on ageing well with HIV.
- Mean that Australia misses out on participating actively in international initiatives to generate evidence and best practices relating to HIV and ageing.

## 7.7 Directions for future research

### What are future research activities in which NAPWHA could play a central role in advocating for or coordinating?

The analysis contained in the table of evidence (Appendix A) provides insights into current trends in Australian and international research on HIV and ageing. It includes the researchers' discussions of their own findings, their assessments of gaps in evidence, and their recommendations for future research. Drawing upon these insights, suggestions are made for research activities in which NAPWHA could play a central role in advocating or coordinating.

### 7.7.1 Lived experiences of older PLHIV

NAPWHA and its affiliates are uniquely placed to engage in, strongly contribute to, and/or advocate for research that aims to better understand the lived experiences of



older PLHIV in Australia. Research of this nature tends to use mixed qualitative and quantitative methods, and several research designs are possible, including cross-sectional studies (snapshot of a sample of people at a given time), longitudinal studies (following a cohort of people over time) and case studies. O'Brien et al (2018) note that understanding how living strategies are used among older and younger adults with HIV can assist providers to promote positive, timely, and age-appropriate self-management approaches for enhancing health and wellbeing; and address attitudes and behaviours that are less conducive to wellbeing.

McGowan et al (2017) note that grouping older people together in an over-50s age group may miss important differences. There is value in examining older age groups separately, as well as accounting for time since HIV diagnosis in any analyses that are made. Guaraldi et al (2015) suggest that longitudinal studies should take particular consideration of the more vulnerable subset of people ageing with a longer duration of HIV infection. UNAIDS (2016: 95) makes that point that the wisdom and knowledge of older people living with HIV 'can be leveraged for both individual and wider community health and well-being'.

## **7.7.2 Evaluation studies**

HIV and ageing presents novel challenges for all service providers and innovative approaches are being trialled, including with respect to the pathways to improvement discussed in section 5 of this report. These programs and initiatives need to be evaluated so as to contribute to best practice. Means to promote successful ageing in the context of HIV would be a central focus for service provision. Since the predictors of successful ageing for PLHIV are not firmly enough established (Escota et al 2018), this contributes to difficulties for service providers to ensure that the supports they provide are appropriate, effective and efficiently delivered. Moore et al (2013) call for research that focuses on interventions to enhance positive traits in older PLHIV.

Another key issue is the integration of HIV and geriatric medicine and what this means for policy and practice. Innovative combined HIV/aged care programs need to be promulgated and evaluated, as should be the effectiveness

of training programs for HIV care providers in aged care principles, and vice versa.

## **7.7.3 Biomedical research**

The table of evidence (Appendix A), and the discussion provided in section 2 of this document, sheds some light on biomedical research interests and activities relating to the intersection of HIV and ageing. It is a wide-ranging and dynamic field of scientific research, and the evidence base is growing stronger by the year. NAPWHA and its affiliates would be active consumers of the research outputs, while also advocating for more research of this nature to be undertaken, also in Australia.

## **7.7.4 Reviewing and synthesising the literature for the benefit of PLHIV**

A research activity particularly suited to the role and function of NAPWHA is to periodically review the research evidence on HIV and ageing, and the policy context, as has been a focus of this document. Of importance then is to disseminate the outcomes of such reviews in ways that are accessible and useful for PLHIV and the community organisations that represent them.



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# Appendix A:

## Table of evidence

The table below summarises empirical studies relating to HIV and ageing that are published in peer-reviewed journals in English between 2010 and 2018. The studies are listed chronologically by year of publication, with the newest studies up front; and then alphabetically within each year of publication.

Table 5: Table of evidence

Author(s); date; location	Study objectives, research design and methodology
ACRIA Centre on HIV and Ageing (2018)  USA – specifically San Francisco	<p>Study to assess the status of older adults living with HIV in order to inform the development of programs and policies that best address their needs.</p> <p>There are over 10,000 people aged 50 or over with HIV in San Francisco, representing 65% of all PLHIV; hence the choice of location for the study. The study participants were recruited to reflect the age distribution of PLHIV 50 and over in that city: 50-59 (54%); 60-69 (36%); 70+ (8%); age not reported (2%).</p> <p>Data were gathered by means of a survey (N=197) and five focus groups were with five sub-populations (N= 44): male gay and bisexual; African Americans; transgender persons; Asian/Pacific islanders; and Spanish-speaking Latinos.</p>



## Key findings

Almost 60% of survey participants described their physical health as excellent or good, 96% are receiving ART, and 92% report having an undetectable viral load. 67% of participants had been diagnosed before 1996 and 59% reported having received an AIDS diagnosis at some point. There appeared to be little association between age and the number of comorbidities among participants. Respondents reported taking over 10 pills a day on average to deal with a range of health conditions.

Well over half of participants reported past-year depression (65%) and anxiety (62%). Depending on criteria applied, the rate of PTSD among the participants ranged from 35% to 70%. More than half (59%) of participants, had trouble with at least one ADL.

Participants exhibited high levels of loneliness: 43% scoring 'lonely' or 'very lonely'. The perception that services are not available, difficult to find or hard to access, or are not free/too costly, were leading problems.

Focus group participants reported on factors that facilitate positive ageing, including wisdom and positive attitude, self-care, religion/spirituality, meaningful work, hobbies and volunteerism, and strong networks of friends, support groups and service organisations.

## Implications

Access to mental health treatment is a significant problem for some older adults with HIV; the roots of the anxiety, depression and PTSD seen in this population are longstanding; and health providers would do well to adopt a trauma-informed approach.

Offering more occasions for older adults with HIV to come together, whether building on existing programs or creating new ones, may be a worthy aim.

Solutions for easing the financial strain of living on a fixed income in a city like San Francisco with rising housing costs should be considered.

Given high levels of comorbidity and polypharmacy, many PLHIV would likely benefit from care guided by geriatric medicine's precepts and a coordinated care approach. Expanding combined HIV/geriatric care programs and training HIV care providers in geriatric care principles may be worthy avenues for increasing access to this treatment approach.



Author(s); date; location	Study objectives, research design and methodology
<p>Escota et al (2018)</p> <p>International</p>	<p>Review of the evidence relating to successful ageing in PLHIV</p>
<p>Gardiner (2018)</p> <p>Australia (Queensland)</p>	<p>Qualitative investigation of the experiences of older PLHIV living in regional Queensland.</p> <p>31 older gay men living in regional Queensland were interviewed via two semi-structured annual interviews between 2013 and 2015.</p>



Key findings	Implications
<p>Older PLHIV are being treated for diseases commonly associated with ageing. These include: cardiovascular disease (a leading cause of death for those on effective ART); osteoporosis and fracture; infection-related cancers; chronic liver and chronic kidney disease; and frailty and other age-related conditions (eg cognitive impairment, visual impairment, depression).</p> <p>Changes that occur in the immune system with normal ageing show similarities with processes that occur in HIV infection. Chronic inflammation is higher in older people living with HIV.</p> <p>Pathways to successful ageing include:</p> <ul style="list-style-type: none"><li>• Early initiation of ART</li><li>• Use of newer treatment options including new antiretroviral drug formulations and combination therapies</li><li>• Application of primary prevention and screening guidelines</li><li>• Aggressive control of risk factors such as smoking</li><li>• Addressing health disparity by narrowing the gap in health outcomes between different population groups</li></ul>	<p>There is a need for further research into 'successful ageing', both in the general population, and in the HIV-infected population.</p> <p>Predictors of successful ageing in PLHIV are not well known, but should include a focus on psychosocial issues and the impact of vulnerabilities related to disadvantaged social status.</p> <p>There is a need for more research to understand the contribution of chronic inflammation on older PLHIV.</p>
<p>In contrast to the 'third age' now seen as achievable for most of the baby boomer generation, PLHIV experienced a life course that included facing imminent mortality in early adulthood, and losing partners and entire networks of friends. Illness forced a kind of premature retirement on these participants during the years when most people participate in the workforce and accumulate wealth.</p> <p>Participants on the DSP had faced the challenge of finding a non-work-related purpose early in life. Trauma was common in the life experience of the participants and most were on anti-depressants long term, but did not have a mental health plan.</p> <p>Most participants felt that the complexities of their lived experiences had given them wisdom that could be applied to the process of ageing.</p>	<p>A purely 'biomedical' orientation risks neglecting the psychosocial needs of those with a history of trauma, depression and other comorbidities.</p> <p>Psychosocial needs are often more difficult to manage than illness itself.</p>



Author(s); date; location	Study objectives, research design and methodology
<p>O'Brien et al (2018)</p> <p>Canada</p>	<p>The study examined living strategies used by PLHIV, specifically in dealing with episodic disability.</p> <p>Research design – cross-sectional, self-administered, web-based survey (N= 935), using a community engagement approach to survey design and implementation.</p> <p>The median age of participants was 48 and the median year of HIV diagnosis was 2000.</p>
<p>Yeoh et al (2018)</p> <p>Australia</p>	<p>The study compared the prevalence of frailty in older men living with HIV using three different instruments: the Frailty Phenotype, the Frailty Index and the Edmonton Frail Scale.</p> <p>The aim was to compare factors associated with frailty defined by each instrument, and their associations with QoL.</p> <p>Cross-sectional study (N=93)</p>
<p>Kendall et al (2017)</p> <p>Ontario, Canada</p>	<p>Retrospective, population-based study among PLHIV, drawing on the Registered Persons Database to capture all deaths in Ontario from 1 April 2010 to 31 March 2013.</p> <p>Out of 264,754 eligible cases, 570 of the deceased had HIV</p>



Key findings	Implications
<p>Older participants in the study lived with a greater number of concurrent health conditions compared to younger respondents. They also engaged in positive living strategies more frequently.</p> <p>Living strategies aimed at maintaining a sense of control used most or all of the time included getting enough sleep (60%); eating healthily (65%); practising good dental care (76%); and taking medications (92%).</p> <p>Living strategies connected to attitudes and beliefs included developing and maintaining a positive outlook eg accepting that health can fluctuate with good days and bad days (61%).</p>	<p>The concept of ‘living strategies’ can be operationalised as the behaviours, attitudes, and beliefs adopted by people living with HIV to help deal with disabilities associated with HIV and multimorbidity.</p> <p>Understanding how living strategies are used among older and younger adults with HIV can assist healthcare providers to promote positive, timely, and age-appropriate self-management approaches for enhancing health; and address attitudes and behaviours that are less conducive to wellbeing.</p>
<p>The prevalence of frailty in the sample ranged from 10.8% (using the Frailty Phenotype), through 15.1 % (using the Edmonton Frail Scale), to 22.6% (using the Frailty Index).</p> <p>Frail men living with HIV, regardless of the instrument used, have poorer QoL than robust/non-frail men living with HIV.</p> <p>Initiation of ART prior to 1996 was associated with frailty using the Frailty Phenotype.</p>	<p>Identifying frailty is an important consideration for HIV care in terms of ageing and QoL.</p> <p>CD4 T-cell count remains an important marker of immunologic health, but it may have less utility in predicting age-related comorbidities.</p> <p>It will be important to develop a frailty instrument that</p> <ul style="list-style-type: none"><li>• is clinically feasible, which implies that it is straightforward and quick to implement</li><li>• contains objectively measurable variables</li><li>• is a good predictor of clinically significant outcomes.</li></ul>
<p>PLHIV were significantly younger than those without HIV (mean age of death 56.1 years vs. 76.6 years).</p> <p>PLHIV spent a mean of 20.0 days in an acute care hospital in the last 90 days of life compared with 12.1 days for the deceased living without HIV. More PLHIV died in hospital.</p> <p>After adjustment, HIV was associated with 4.5 more acute care days. Mean cost of care in the last year was significantly higher among PLHIV (\$80,885.62 vs. \$53,869.77), mostly attributable to acute care costs.</p>	<p>There are important differences in the end-of-life experience between PLHIV and people living without HIV. PLHIV are still dying much earlier than their non-HIV counterparts, and remain more marginalized, including having lower incomes.</p> <p>Disproportionate acute care use, which also increases the risk of dying in hospital, has important patient-level implications. To optimise the quality and cost-effectiveness of care, patient-centred HIV services should ideally be integrated with community-based palliative care services.</p>



Author(s); date; location	Study objectives, research design and methodology
<p>McGowan et al (2017)</p> <p>UK</p>	<p>Report on the ASTRA study – a cross-sectional questionnaire study of 3,258 HIV-diagnosed adults (2,248 MSM, 373 heterosexual men and 637 women) recruited from clinics in the UK in 2011– 2012.</p> <p>The mean age of participants was 45.</p> <p>Participants completed a self-administered questionnaire on a range of socio-demographic, health, HIV-related and lifestyle issues</p>
<p>Negredo et al (2017)</p> <p>International</p>	<p>The study reviewed the evidence with the objective of integrating the existing guidelines for management of HIV in older patients.</p>





Key findings	Implications
<p>A longer time with diagnosed HIV infection was related to a higher prevalence of all self-rated health problems, independently of age.</p> <p>Most prevalent distressing symptoms were ‘lack of energy’ (25.9%), ‘difficulty sleeping’ (24.4%), ‘feeling drowsy/tired’ (24.2%), ‘muscle aches or joint pains’ (20.8%) and ‘problems with sexual interest/activity’ (19.2%). Depression was measured in 27.1% of participants and anxiety in 21.9%</p> <p>With older age, PLHIV reported a higher prevalence of health-related functional problems, but a lower prevalence of depression and anxiety symptoms. This may be a reflection of better adaptation to hardship in older adults, developed through their lifespan; of facing fewer high-demand situations as a consequence of retirement; of ‘resilience’, which has been found to be high in older HIV-diagnosed people; or of a ‘survivor’ selection effect towards psychological wellbeing.</p>	<p>A longer time with diagnosed HIV infection may be a more important factor than chronological age in determining wellbeing among people living with HIV.</p> <p>Grouping older people together in an over-50s age group may miss important differences. There is value in examining older age groups separately, as well as accounting for time since HIV diagnosis in any analyses that are made.</p> <p>There is a need for increased inclusion of PLHIV over 50 years in clinical trials focusing on comorbidities, polypharmacy, and alterations associated with age.</p>
<p>Non-AIDS-related mortality has eclipsed AIDS-related mortality as the major cause of death in PLHIV who have widespread access to ART.</p> <p>The prevalence of comorbidities and other age-related conditions (functional or neurocognitive or mental problems) is higher in the HIV-infected population than in their uninfected counterparts. In particular:</p> <ul style="list-style-type: none"><li>• Older HIV-infected patients are particularly vulnerable to declines in everyday functioning, mainly in instrumental activities.</li><li>• HIV infection predisposes to several types of cancer, in particular those associated with chronic viral infections, such as Epstein-Barr virus and human papillomavirus.</li><li>• There is consistent evidence that neurocognitive ability is impaired in a significant proportion of HIV-infected patients.</li><li>• Studies continue to demonstrate an association between HIV serostatus and frailty, regardless of the effectiveness of ART.</li></ul>	<p>Ageing is a complex process that is more complicated in combination with a chronic disease, such as HIV infection.</p> <p>Care of the older patient with multimorbidity is best managed through a multidisciplinary team.</p> <p>The principles of geriatric medicine can be drawn upon by HIV medical practitioners, and these include the value of conducting a comprehensive geriatric assessment (CGA) to ascertain health status and individual needs.</p> <p>Since PLHIV tend to use a higher number of concomitant medications, the management of polypharmacy needs to be a key clinical focus.</p>



Author(s); date; location	Study objectives, research design and methodology
<p>Petoumenos et al (2017)</p> <p>Australia</p>	<p>Commencing in 2014, the Positive and Peers Longevity Evaluation Study (APPLES) was a prospectively recruited cross-sectional sample of HIV positive and HIV negative men who identify as gay or bisexual, aged 55 years and over.</p> <p>228 HIV-positive and 218 HIV-negative men were included in the study (N=446). The median age was 63 years.</p>
<p>Terrence Higgins Trust (2017)</p> <p>UK</p>	<p>A National Study of Ageing and HIV (50 Plus) explored the needs and experiences of people living with HIV aged 50 and over in the UK. It was conducted by the Terrence Higgins Trust, Age UK and the Joseph Rowntree Foundation in 2010 and updated in 2016.</p> <p>Peer-led research design model involving a team of 12 volunteer peer researchers from across the UK. Methods included:</p> <ul style="list-style-type: none"> <li>• Survey: N=246, with 22% being women</li> <li>• In-depth interviews: N= 30</li> <li>• Six group workshops: 19 women and 22 men</li> <li>• data summit involving the entire team of peer researchers</li> </ul>



Key findings	Implications
<p>The HIV-positive sample had significantly increased odds for self-reported comorbidities including thrombosis, diabetes, heart disease, neuropathy and bone disease.</p> <p>More HIV positive men had healthy body mass index (BMI) (42%) compared with HIV negative men (33%), and a greater proportion of HIV negative men were obese (HIV negative 24% compared with 14% of HIV positive men).</p> <p>Evidence of past or current HCV coinfection was significantly greater among HIV positive men (8%) compared to HIV negative men (1%).</p>	<p>Understanding the relative contribution of HIV infection, ART and lifestyle factors to the development of comorbidities in older PLHIV can contribute to the development of screening, prevention and advocacy programs.</p> <p>Increased prevalence of traditional risk factors among HIV positive populations (such as smoking, elevated lipids, hyperglycaemia, altered body composition, and alcohol and recreational drug use) significantly contributes to an increased risk for morbidity.</p>
<p>The older a PLHIV got, the happier they felt, the better their wellbeing, and the lower their levels of HIV self-stigma.</p> <p>Many older people with HIV face social isolation and loneliness and poverty has a powerful impact. 58% of survey respondents lived on or below the poverty line and 84% of respondents were concerned about future financial difficulties. 58% of respondents experienced moderate to high levels of self-stigma. Housing was also a key concern. Two thirds (62%) of people who responded to the survey did not own their own home.</p> <p>Social care is not currently meeting the needs of PLHIV – co-ordinated long-term condition management, with support to self-manage, is essential. HIV clinical services are not the ‘one-stop-shops’ they once were and some survey respondents were concerned about what will happen once their HIV consultant retires.</p> <p>Since 2010, the health and social care system in the UK has become ‘unrecognisable’ due to austerity and restructuring.</p>	<p>For all stakeholders, growing older with HIV can be considered uncharted territory.</p> <p>There is a need for someone, possibly a GP, to take on a coordination clinical support role to ensure PLHIV receive the long-term condition management they need.</p> <p>PLHIV aged 50 and over need to be central to discussions, policy change and structural change. Many support needs are not unique to people living with HIV – the welfare and social care systems across the UK are failing many. However, living with HIV adds an extra level of need, additional necessities that go beyond the ‘standard’ experience of ageing.</p> <p>Public health institutions should actively increase awareness of older PLHIV among the general population.</p>



Author(s); date; location	Study objectives, research design and methodology
<p>Althoff et al (2016)</p> <p>International</p>	<p>Systematic review of evidence-based strategies to address the complexity of care for those ageing with HIV</p> <p>The researchers are experts based at a range of Schools of Medicine and Public Health – Johns Hopkins University, Imperial College London, University of Amsterdam and Yale University.</p>
<p>Cohen et al (2015)</p> <p>International</p>	<p>Review of the literature on the effects of HIV infection on neurocognitive dysfunction</p>
<p>Guaraldi et al (2015)</p> <p>Italy</p>	<p>The study compared the prevalence of, and risk factors for, comorbidity between HIV patients with a longer duration of infection and those who seroconverted at an older age.</p> <p>The study made use of a case-control study design. HIV-Ageing (n=404) and HIV-Aged (n=404) participants were matched with participants sampled from the general population (n=2,424).</p>



Key findings	Implications
<p><b>Factors influencing ageing with HIV</b> include ongoing HIV-associated inflammation and immune activation; the effects of chronic exposure to ART, leading to excess organ system injury; and harmful health behaviours such as tobacco, alcohol and other substance abuse.</p> <p>PLHIV are at <b>greater risk of comorbidities</b> than peers living without the virus, although comorbid events do not appear to occur dramatically earlier. Key comorbidities include cardiovascular disease; certain types of non-AIDS cancers, especially those that are virally associated; liver disease; renal insufficiency; pulmonary disease; and depression.</p> <p><b>Geriatric syndromes</b> to consider include multimorbidity and polypharmacy, which go hand in hand; functional impairment, including gait speed and grip strength; cognitive dysfunction, estimated to affect as many as half of HIV-infected adults; frailty; and falls and fractures.</p>	<p>Integrated care for those ageing with HIV would include:</p> <ul style="list-style-type: none"><li>• Earlier HIV diagnosis and treatment</li><li>• Earlier HCV diagnosis and treatment</li><li>• Screening for and treating comorbidities</li><li>• Proactively managing weight gain after ART initiation</li><li>• Emphasising the importance of physical activity</li><li>• Eliminating substance use</li><li>• Actively managing polypharmacy</li><li>• Using tools (calculators and indexes) which assist in knowing when to intervene</li><li>• Preparing care facilities to be able to offer the best care to PLHIV</li><li>• End of life planning</li><li>• Testing and adapting models of care</li></ul>
<p>Prior to the availability of ART, AIDS dementia complex occurred in over 20% of HIV-infected people. In recent years, the diagnostic classification of HIV-associated neurocognitive disorder (HAND) has been developed as an alternative.</p> <p>HAND continues to occur in 30% to 50% of HIV-infected people, and while not as debilitating as dementia, it manifests as impairments of attention, working memory and executive functioning.</p>	<p>HIV enters the brain soon after infection, and the brain continues to be a reservoir for HIV even among patients who receive ART. HIV interacts with the ageing brain to affect neurological structure and function.</p> <p>Research has not yet resolved the issue of whether HIV directly affects neurocognitive degeneration or accelerates normal cognitive ageing; or whether HAND contributes to a worsening of other comorbidities.</p>
<p>People ageing with HIV are heterogeneous in terms of their health.</p> <p>The prevalence of comorbidities is significantly higher amongst people with HIV compared to the general population.</p> <p>People with longer duration of HIV infection show a higher probability of multimorbidity than people who seroconverted at older ages.</p> <p>People with a longer duration of HIV infection constitute the most vulnerable sub-group among PLHIV who are ageing.</p>	<p>Studies which investigate differences among groups of people ageing with HIV can yield greater insights into the relationships between age, HIV duration, and health, and help identify patients that may be more vulnerable. Preventative interventions could be directed at the identified patients.</p> <p>Longitudinal studies should take particular consideration of the more vulnerable subset of people ageing with a longer duration of HIV infection.</p>



Author(s); date; location	Study objectives, research design and methodology
<p>Psaros et al (2015)</p> <p>USA – specifically Boston Massachusetts</p>	<p>Qualitative study (N=19) conducted in Boston exploring the experiences of women over 50 living with HIV to better understand how they make sense of their diagnosis and cope with their illness over time and during the ageing process.</p> <p>47% of the women identified as African American and 37% as White.</p>



Key findings	Implications
<p>Most of the women felt better adjusted to living with HIV over time. The experience of growing older caused women to re-examine prior beliefs and a sense of shame, and to make meaning of their diagnosis.</p> <p>Health uncertainties (running out of treatment options, bodies ‘giving out’, and general uncertainty about health status) remained and even intensified with age.</p> <p>Three subthemes of living successfully with HIV over time emerged:</p> <ol style="list-style-type: none"><li>1. Caring for mind and body (nutrition, regular physical activity, effective stress management)</li><li>2. Changing or eliminating negative relationships or environments, the ‘toxic forces’ in their lives</li><li>3. Engaging in meaningful activities, especially participating in HIV-related causes and advocacy; and learning opportunities.</li></ol> <p>Also facilitative to successful ageing were cognitive processes such as dispelling internalised stigma, acceptance of diagnosis, appreciation of the perspective gained from HIV, and confidence in illness management.</p>	<p>Women such as those included in the study are the first to live with HIV over time. Answers that may help them to deal with ongoing uncertainties they have about their health may still elude service providers at this time.</p> <p>Peer-support interventions have been used with some success and include one-on-one counselling with a trained peer familiar with group norms; and tailoring of the interventions to include the most pertinent topics (such as substance use, condom use, disclosure, and HIV communication).</p> <p>Long-term survivors may benefit from additional support and knowledge about what to expect as they age further with HIV.</p> <p>A model of coping with HIV (beginning with experience at the time of diagnosis to successful coping over time, and including consideration of facilitators and barriers) can be tested in further studies.</p>





## Author(s); date; location

## Study objectives, research design and methodology

Rosenfeld et al (2015)

UK

Report on the HIV and Later Life (HALL) study carried out between 2013 and 2015. The study's research questions:

- What are the personal histories, concerns, social circumstances, relations, resources, and support systems of older people living with HIV in the UK?
- What is the mental health and quality of life of this older group?
- What are the relationships between social support, mental health and QoL, and how do these impact on the QoL of people ageing with HIV in the UK?

Methods:

- 17 stakeholder interviews
- three focus groups with older PLHIV (23 participants)
- 76 life-history interviews with older PLHIV
- 100 surveys with older PLHIV

Half of the study's interviewees and survey participants were aged 50-56 and half were aged 57-87 years.



Key findings	Implications
<p>The experience of ageing with HIV is shaped by gender, sexual orientation, culture, income, migration status, and age at diagnosis. Participants reported many of the same challenges as those faced by younger people living with HIV such as HIV-related stigma, the difficulties of disclosure, uncertainties of life with a chronic condition, and the impact of HIV on work, social relations, sexual and romantic relationships, and financial security.</p> <p>Unique experiences and concerns that are specific to later life include:</p> <ul style="list-style-type: none"><li>• Ageism intersecting with HIV stigma to further stigmatize older people living with HIV, and specifically in relation to the quality of long term care</li><li>• Fear or difficulties in relation to disclosure of their HIV status to their children and grandchildren</li><li>• Uncertainties over how HIV, ART, and ‘normal ageing’ intersect to influence physical and mental health</li><li>• Romantic prospects being undermined by virtue of other older people being particularly ignorant about the realities of HIV</li><li>• The consequences of interruptions to professional careers and the need to reformulate plans for later years, for example with regard to retirement</li></ul> <p>Two-thirds of people taking part in the study had good mental health and QoL. Factors associated with poor mental health and QoL were predominantly social (eg poverty) rather than medical. Participants felt that only those living with HIV could fully appreciate what it was like to live and age with the virus.</p> <p>Women participants’ levels of depression and anxiety were slightly higher than those of male participants. Women were also less satisfied than men were with their QoL, health, and support from friends.</p>	<p>To enhance the mental health and wellbeing of PLHIV, better understanding and support is needed of the role of HIV-specific peer support and other voluntary sector HIV provider organisations.</p> <p>Older people living with HIV should be appropriately involved in all stages of planning, commissioning and delivery of services.</p> <p>Agencies and service providers must be alert to the high proportion of older people living with HIV who are parents. Awareness of the complexities, including the ability to provide ongoing support to children, and if and how to disclose, are areas of concern.</p> <p>In anticipation of increasing numbers of people living with HIV entering their 70s, 80s and beyond, the long-term care sector will require training in the care needed by older people living with HIV.</p> <p>The complexity and potential for fragmentation of care pathways for this population requires providers to work collaboratively across boundaries for best outcomes.</p> <p>Mental health services are essential to many older people living with HIV.</p>



Author(s); date; location	Study objectives, research design and methodology
<p>Wing (2016)</p> <p>USA and Western Europe</p>	<p>Review (secondary analysis) of published studies focusing on the epidemiology of ageing, the question of accelerated ageing, comorbidities, geriatric syndromes and frailty, and management and psychosocial issues.</p>
<p>Broeckaert and Challacombe (2014)</p>	<p>Review of the evidence relating to health or peer navigation and its impact on care coordination.</p> <p>In the search for literature the emphasis was on systematic reviews published from 2010 to 2014.</p>



Key findings	Implications
<p>There is great heterogeneity in life expectancy of people living with HIV, based on factors such as virological suppression, CD4 nadir, time of diagnosis and IV drug use. The overall trend since 1996 is a dramatic fall in the rate of AIDS-related infections and malignancies.</p> <p>The controversy over whether HIV accelerates ageing has not been resolved.</p> <p>Patients with HIV have an increased number of comorbidities compared to those without HIV. These include cardiovascular disease and stroke; osteoporosis and fracture; chronic renal disease; chronic neurological complications, often described as HIV-associated neurocognitive disorders (HAND); cancer-related mortality; and geriatric syndromes, including frailty.</p> <p>Factors that can affect PLHIV quality of life include physical and psychiatric disabilities and morbidities; loss of partners and friends (a sense of lost community); social isolation; stigma; unemployment; poverty; and crime.</p>	<p>Management of the older HIV patient includes an emphasis on early diagnosis and treatment, preventative measures for comorbidities and avoiding polypharmacy. The latter suggests the need for a regular review of all medications, with a focus also upon drug interactions.</p> <p>Since elevated rates of inflammation seen in PLHIV are associated with greater risk of disease, including cardiovascular, renal, neurocognitive, oncological and osteoporotic disease, these conditions may present a major challenge for older HIV patients.</p> <p>The issue of quality of life, prioritization of medical issues and end of life care become increasingly important as the patient grows older.</p> <p>Appropriate geriatric care needs to be discussed, planned, provided and monitored.</p>
<p>Navigation impacts on care coordination and health outcomes through improving screening rates and rates of confirmatory testing, earlier diagnosis, access to care, and treatment outcomes.</p> <p>Reducing stress, anxiety and depression associated with illness and using the healthcare system may improve the likelihood that clients will stay in care.</p> <p>There is currently no standard model of health navigation in the literature.</p>	<p>Many people living with HIV are not optimally engaged in care. Health navigation can play a role in engaging people in HIV care across the care continuum.</p> <p>Navigators can work with each client to identify the potential barriers they might face, find and implement solutions to those barriers, and over time, build the capacity of the client to manage these barriers themselves.</p>



Author(s); date; location	Study objectives, research design and methodology
<p>Brothers et al (2014)</p> <p>International</p>	<p>Review of the evidence on frailty in people ageing with HIV</p>
<p>Hunt (2014)</p> <p>International</p>	<p>Review of evidence relating to HIV and ageing with a focus on the unresolved issues that need to be addressed through research.</p>
<p>O'Brien et al (2014)</p> <p>Canada</p>	<p>Review of the research evidence specific to HIV, rehabilitation and ageing.</p> <p>165 studies met the inclusion criteria.</p> <p>Recommendations were generated from the literature and sent to PLHIV and health professionals to comment upon (external endorsement).</p>



Key findings	Implications
<p>In their assessments of frailty, published studies of frailty in PLHIV tend to make use of scales composed of a limited number of specific health measures. Factors associated with frailty can be clustered into:</p> <ul style="list-style-type: none"><li>• HIV-related measures, such as longer time since diagnosis and a detectable viral load</li><li>• Comorbidities, including HCV coinfection, cognitive impairment and inflammation</li><li>• Social factors, especially lower education levels, unemployment and low income in the past year.</li></ul> <p>The implications of incorporating frailty concepts into HIV care are as yet unknown.</p>	<p>The concept of frailty could be useful as a tool to measure and communicate the complexity of ageing and vulnerability in PLHIV, to inform the development of therapies and to guide the delivery of care.</p> <p>Healthy ageing with HIV may be promoted through early intervention for those at risk of becoming frail.</p> <p>Many PLHIV are likely to survive to an age where they might be frail in spite of, not because of, HIV infection.</p>
<p>As the HIV epidemic ages, the impact of HIV on multi-morbidity and premature mortality is likely to take on increasing public health importance.</p> <p>The persistent inflammatory state of treated HIV infection is likely to be an important determinant of morbidity and mortality.</p> <p>Smoking cessation, diet and exercise may be even more important interventions for HIV-infected patients than the general population.</p>	<p>Future research could focus on:</p> <ul style="list-style-type: none"><li>• Better understanding the root causes of the persistent inflammatory state in treated HIV infection</li><li>• Developing more effective interventions for chronic inflammation</li><li>• Establishing consensus on the most appropriate biomarkers to use for surrogate outcomes in pilot trials of immune-based interventions.</li></ul>
<p>The literature suggests that there is a clear role for rehabilitation professionals in helping older PLHIV deal with complex comorbidities. Multidisciplinary rehabilitation has a role to play across the continuum of care for PLHIV.</p> <p>A rehabilitation approach should include a comprehensive assessment of physical, neurocognitive and mental health impairments.</p> <p>Rehabilitation professionals need to consider the role of extrinsic contextual factors such as stigma and ageism, HIV disclosure, and emotional and practical social supports on the health and well-being of PLHIV.</p>	<p>Evidence-informed recommendations that are relevant for rehabilitation in the context of HIV should be applied using an individualised approach incorporating the unique values, preferences, goals and needs of the individual:</p> <ul style="list-style-type: none"><li>• Aerobic and resistive exercise may be recommended for comorbidities including bone and joint disorders, cancer, stroke and diabetes.</li><li>• Cognitive rehabilitation interventions (eg cognitive training, cognitive stimulation and cognitive rehabilitation) may be also be recommended.</li></ul>



Author(s); date; location	Study objectives, research design and methodology
<p>Pathai et al (2014)</p> <p>International</p>	<p>Extensive literature review to examine the ways in which HIV is similar and dissimilar from natural ageing, and to assess the validity of HIV as a model of premature ageing.</p>
<p>Edelman et al (2013)</p> <p>International</p>	<p>The study aimed to draw on the findings from available literature to suggest how existing interventions with regard to polypharmacy might be adapted to those ageing with HIV.</p> <p>Comprehensive review of the HIV-specific literature relevant to polypharmacy.</p>





Key findings	Implications
<p>Multimorbidity, frailty and chronic inflammation are common in HIV-infected patients.</p> <p>Inflammation and the activation of coagulation pathways are central to the pathophysiology leading to morbidity and mortality among older PLHIV.</p> <p>Co-infection with cytomegalovirus (CMV) is a significant contributor to senescence.</p> <p>Many of the T-cell abnormalities associated with ageing are similar to those observed in untreated HIV infection.</p>	<p>The answer as to whether HIV is a model of accentuated or accelerated ageing is probably disease or condition specific. With respect to the immune system, including evidence on ongoing immune activation, there is support for accelerated immune senescence. Many illnesses such as cardiovascular disease and diabetes appear to be accentuated rather than accelerated.</p> <p>There is a need for validated biomarkers of ageing in the context of HIV, suggesting the need for well-designed studies of PLHIV that would enable a better understanding of the mechanisms that lead to ageing and age-related diseases.</p>
<p>Polypharmacy among people living with HIV is common.</p> <p>Polypharmacy is strongly associated with non-adherence in the general population, but the effects of polypharmacy on ART and non-ART adherence are only beginning to be examined. It is also linked to both under-prescribing and over-prescribing, although research has not yet generated validated tools to assess for inappropriate medication use among PLHIV.</p> <p>There is strong evidence that polypharmacy increases the risk of adverse drug events and geriatric syndromes (falls, fractures and dementia).</p> <p>Factors contributing to polypharmacy's harms for patients with HIV include pre-existing organ injury; DDIs; and substance use</p>	<p>An intervention to address polypharmacy in HIV-infected populations would include:</p> <ul style="list-style-type: none"><li>• A comprehensive process of medication reconciliation, including an honest discussion with the patient about their level of adherence and sense of associated symptoms.</li><li>• Assessment of substance use, including non-medical use of controlled substances.</li><li>• Assessment and ranking of each medication according to risks and benefits.</li><li>• Prioritising a plan with the patient – which medications will be stopped and which ones started, how medication effectiveness will be monitored for therapeutic and adverse effects, and when additional changes might be considered.</li><li>• Incorporate the use of clinical decision support systems.</li></ul>



Author(s); date; location	Study objectives, research design and methodology
<p>Moore et al (2013)</p> <p>USA</p>	<p>The study aimed to understand the risk and protective factors associated with self-rated successful ageing with HIV.</p> <p>A cross-sectional, case-controlled study was carried out in San Diego, California, with 83 community dwelling PLHIV and 83 demographically matched HIV negative individuals; mean age 59 years.</p> <p>Two-thirds of the PLHIV subjects had a diagnosis of AIDS.</p>
<p>Sankar et al (2011)</p> <p>International</p>	<p>Systematic critical content review of peer-reviewed social and behavioural research on ageing and HIV.</p> <p>58 publications met the inclusion criteria</p>



Key findings	Implications
<p>Neither age nor HIV disease status was associated with self-rated successful ageing (SRSA). Despite worse physical and mental functioning and greater psychosocial stress among the HIV+ participants, the two groups had comparable levels of optimism, personal mastery, and social support.</p> <p>Higher SRSA was significantly associated with better physical and mental functioning as well as lower depressive symptoms, greater happiness, resilience, optimism, and personal mastery, better attitudes towards own ageing, and lower perceived stress.</p>	<p>Since HIV infection does not appear to impact the relationship between positive psychosocial factors and SRSA, this study suggests that successful psychosocial ageing is possible in older PLHIV.</p> <p>Positive traits such as resilience, optimism and sense of personal mastery have a stronger relationship with SRSA than the duration of HIV infection or the severity of HIV disease.</p> <p>Research is needed that focuses on interventions to enhance positive traits in older PLHIV.</p>
<p>Several reviewed studies focused on subgroups and their specific situations and needs and found significant differences among ethnic groups in living with HIV in later life and also differences among older people when groups were defined by mode of transmission.</p> <p>Older adults with HIV often reported high rates of depression. Older women with HIV were more likely to live alone than younger women with HIV, and financial concerns plagued their lives.</p> <p>Using chronological age alone did not account adequately for the social and behavioural outcomes of older adults with HIV.</p>	<p>Constructs from gerontology may contribute to clarifying how later life, life course stage, and psychological development intersect with, influence, and are influenced by HIV disease and long-term ART.</p>

# Appendix B: Expert informants consulted in Phase I of the project

**Cory Irlam**, Director Advocacy and Government Relations, Council on the Ageing

**Samantha Edmonds**, Silver Rainbow - National Project Manager (LGBTI Inclusive Ageing and Aged Care), National LGBTI Health Alliance

**Samantha Edwards**, Director, Grants Analysis Section, Ageing and Sector Support Branch, Australian Government, Department of Health

**Bernard Gardiner**, School of Public Health, University of Queensland

**Limin Mao**, Associate Professor, Centre for Social Research in Health

**Lance Feeney**, Consultant, Positive Life NSW

**Kathy Petoumenos**, Associate Professor, Biostatistics and Databases Program, The Kirby Institute

**Liz Crock**, CNC HIV, Bolton Clarke (formerly Royal District Nursing Service Melbourne)

**Denise Cummins**, Clinical Nurse Consultant, Community Nursing Service, Community Health SLHD

**Lucette Cysique**, NHMRC Research Fellow, NeuRA, Senior Lecturer, UNSW

**Clovis Palmer**, Head, Palmer Laboratory, Adjunct Senior Lecturer, Monash University, Department of Infectious Diseases

**Elvis Caus**, Client Services Manager, Bobby Goldsmith Foundation



# Appendix C: NAPWHA's survey questionnaire

**\* 1. To what extent do you think that age related comorbidities will impact your community's ageing with HIV?**

- ☐ Not at all
- ☐ A little
- ☐ Unsure
- ☐ Quite a lot
- ☐ Very much

Comment (please provide more detail)

**\* 2. How confident are you that making changes to diet, exercise, drug and alcohol use, and smoking will assist in reducing the impact of comorbidities as your community gets older?**

- ☐ Not at all
- ☐ A little
- ☐ Unsure
- ☐ Quite a lot
- ☐ Very much

Comment (please provide more detail)

**\* 3. How confident are you that available medication could reduce the impact of comorbidities as your community gets older?**

- ☐ Not at all
- ☐ A little
- ☐ Unsure
- ☐ Quite a lot
- ☐ Very much

Comment (please provide more detail)

**4. How important are peer support programs to assist in reducing the impact of HIV and ageing?**

- ☐ Extremely important
- ☐ Very important
- ☐ Somewhat important
- ☐ Not so important
- ☐ Not at all important

Other (please provide more detail)

**\* 5. What are your community's top three concerns about living with HIV as they get older?**

- 1
- 2
- 3

**\* 6. How well informed would you say your community is about getting older with HIV?**

- ☐ Not at all
- ☐ A little
- ☐ Unsure
- ☐ Quite well informed
- ☐ Very well informed

Comment (please provide more details)

**7. What sort of information do you think would most improve the lives of people ageing with HIV?**

**8. What changes to service provision would most improve your community's experience of ageing with HIV?**

**9. Contact details (optional) Bottom of Form**

# Appendix D: Graphic illustration of Australia's 'health landscape'

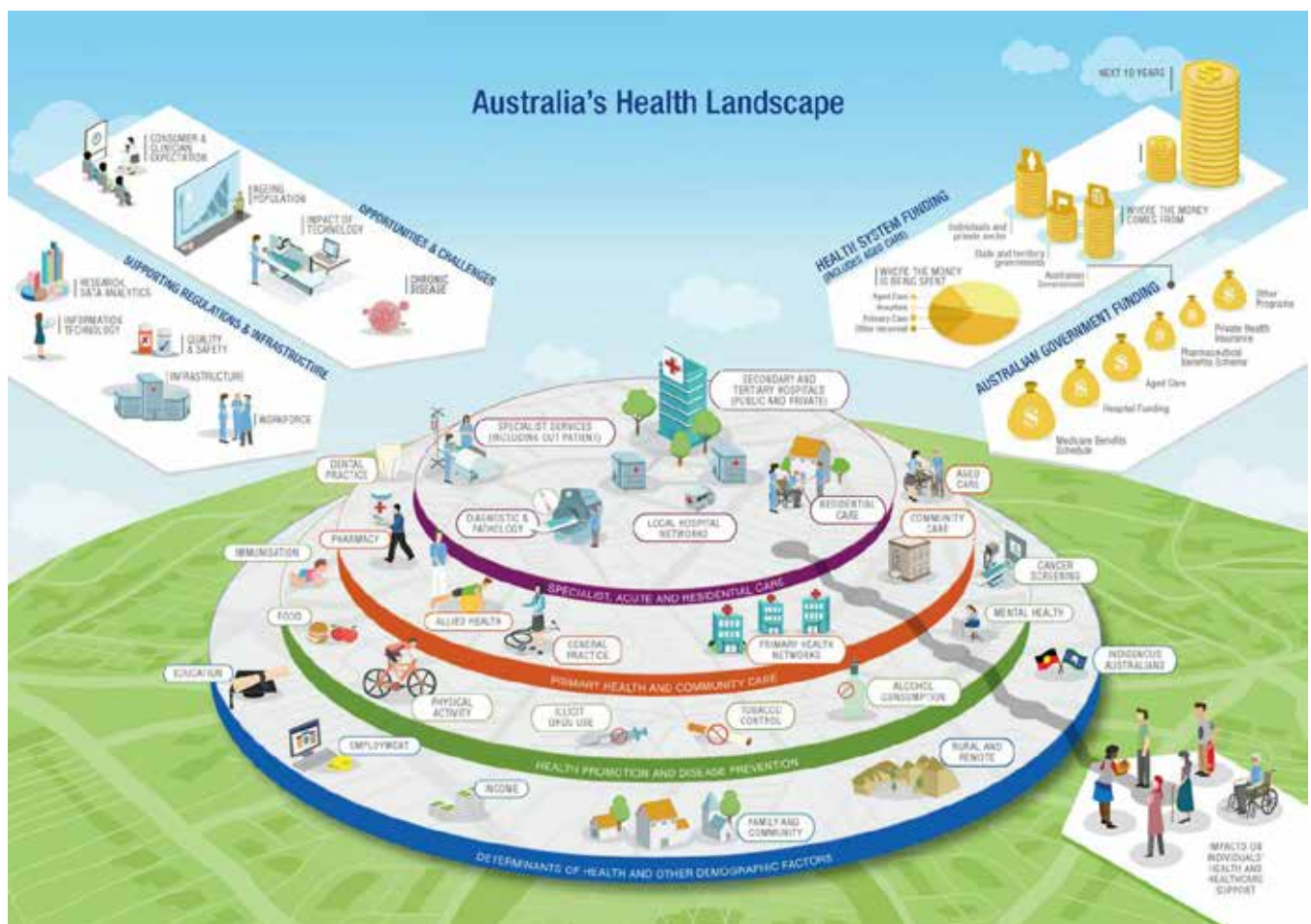


Figure 8: Australia's health landscape infographic

Source: Department of Health (2018)



# Appendix E: Proposal for Phase 2 of NAPWHA's HIV and Ageing Project

A proposal to build upon the work carried out in NAPWHA's HIV and Ageing Project Phase 1 is put forward.

**Recommended timeframe:** from January 2020 to December 2020

**Recommended budget:** 1.5 FTE Community Services Worker Level 6, plus administrative, travel and publication costs

Reporting: quarterly process reports; Long-term Survivors Case Study Report delivered by November 2020; Project Evaluation Report delivered by December 2020

## Long-term outcomes:

1. Younger PLHIV are better equipped to plan for their futures, and older PLHIV have a greater ability to age well in place and to avoid or delay hospitalisation and residential care.
2. Older PLHIV receive quality peer support that contributes to treatment adherence, adoption of health preservation attitudes and behaviours, and the delay of disease progression.
3. The service delivery framework for older PLHIV in Australia is strengthened through the adoption of evidence-based approaches built upon partnerships.
4. Long-term HIV survivors adhere to antiviral treatment regimes, maintain independent living, and delay ageing and HIV-associated disease progression. In keeping with these objectives, Phase 2 would have a four-pronged approach:
  1. Nationwide Outreach and Health Promotion Campaign
  2. Development of training materials
  3. Collaboration on promoting models of HIV geriatric care
  4. Reaching out to long-term survivors

Each is discussed in greater detail next.

## **Initiative I: Growing Older with HIV – Nationwide Outreach and Health Promotion Campaign**



### **Rationale**

As Australia's peak non-government organisation representing community-based groups of PLHIV, NAPWHA is well-placed to continue its tradition of health and education initiatives and outreach on a national level through a focus on growing older with HIV, which in many respects is the 'new frontier' for our constituency. PLHIV, including those younger than 55, would benefit from having evidence-based understandings of HIV and ageing, including greater knowledge of common HIV comorbidities and the ageing process, healthy living and the choices and steps that can be taken to promote their mental health and wellbeing into the older years. This would enable younger PLHIV to have greater confidence and be better equipped to plan for the future, and contribute to older PLHIV ageing well in place and avoiding or delaying hospitalisation and residential care.



### **Proposal**

With the active involvement of PLHIV community-based groups throughout Australia, NAPWHA would plan and organise a *Growing Older with HIV – Nationwide Outreach and Health Promotion Campaign*. The campaign would take the form of a well-publicised 'roadshow' involving a series of public health outreach and education workshops in all capital cities, including at least two regional centres. Each event would include:

- Advertising and promotion of the Roadshow in each locality
- Facilitated workshops focusing both on hearing the experiences of people ageing with HIV as well as providing evidence-based information on issues such as comorbidities, healthy living and access to aged care services
- Discussion of the potential for the establishing 'healthy ageing with HIV' working groups in each centre that can become part of the activities of the local community groups.

While a standard approach to each roadshow event would be prepared and planned in advance by NAPWHA staff, the program would be attenuated to the circumstances and needs of each locality, drawing on the insights of the local community-based HIV support organisations. The processes and outcomes of these workshops would be summarised in a NAPWHA publication that would be made accessible to community-based groups and service providers.



### **Recommended timeframe**

March 2020 to December 2020





## Initiative II: Healthy ageing peer support – development of training materials



### Rationale

Peer support and mentoring has been a prominent form of support for PLHIV since the 1980s. Currently, for example, Queensland Positive People trains and supervises people with HIV to become Peer Navigators, who provide a time limited, peer-based intervention to allow people newly diagnosed with HIV in order to explore social, health and emotional issues, and promote the benefits of treatment. In Victoria, the Ageing with HIV Peer Support Network is a monthly informal peer support group run by Living Positive Victoria for people in Melbourne and regional Victoria. Drawing upon these models, a nationwide peer support approach is put forward as a means to promote healthy ageing in PLHIV in order to complement the care and support they receive from formal service providers as well as from family members, friends and partners.



### Proposal

NAPWHA will devise a training program – incorporating a set of teaching/learning materials and resources – for PLHIV who wish to become volunteer peer supporters/mentors. The functions of these peer mentors would include, but are not limited to:

- social and emotional support to assist older PLHIV to remain motivated to focus on their health and wellbeing
- sharing experiences with regard to personal health behaviours and interactions with service providers, and inviting discussion on these issues with their mentees
- keeping older PLHIV engaged in the ongoing management of HIV infection and comorbidities over time, especially after incidences of acute illness.

These materials and the training program would be piloted in south-east Queensland and evaluated. On the basis of this evaluation, the materials would be revised. The model and its associated materials and documents would be made available to community-based support organisations throughout the country, particularly in online mode.

Discussion of peer support and support networks would be included in the nationwide Roadshow described above.



### Recommended timeframe

March 2020 to December 2020

## Initiative III: Collaboration on promoting models of HIV geriatric care



### Rationale

The cumulative effect of multiple comorbidities, including mental ill-health, often presents the most challenges for PLHIV. This suggests that, as PLHIV grow older, they may require access to disability and aged care supports and services at earlier ages (accelerated ageing) and at a higher level (accentuated ageing) than their non-HIV positive peers. Organisations and professionals in the health, aged care and disability sectors would benefit from having access to up to date knowledge pertaining to HIV and the ageing process, including models of care in HIV geriatrics (Guaraldi and Palella 2017), the addressing of stigma and potential discrimination (Gardiner 2018), and the range of evidence-based, multi-faceted interventions that can contribute to improved health and wellbeing outcomes for older PLHIV (Herrmann and Skinner 2016).



### Proposal

NAPWHA will work with the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) to promote models of HIV geriatric care that can be shared with service providers. Building upon a long tradition of successful partnership, a Memorandum of Understanding (MoU) would be proposed that would bring the resources of the two organisations together to promote models of HIV geriatric care in the Australian health and ageing service systems.

The 2016 publication *HIV and Ageing: Management Guidelines* (Herrmann and Skinner 2016) would form the basis of a recommended professional development program, and it would be complemented by measuring, monitoring and addressing frailty in older PLHIV (Brothers et al 2014; Levett and Wright 2017); as well as models of care in HIV geriatrics (Guaraldi and Palella 2017).



### Recommended timeframe

January 2020 to December 2020



## Initiative IV: Reaching out to long-term survivors



### Rationale

Many older PLHIV in Australia are long-term survivors, who continue to be impacted by the legacy of the early years of the epidemic. They may be dealing with ongoing financial insecurities, social isolation and complex comorbidities that have a negative impact on their quality of life. They may be uncertain about the impact that HIV has on the ageing process, including the impacts of long-term use of treatments, contributing to concerns for the future and their ability to remain independent. The fear of ending up in mainstream nursing homes, where they may not receive adequate treatment and may be stigmatised or discriminated against because of their sexuality and/or HIV status, may also be very prominent for those who do not have family members or other people to care for them should they become very ill and lose their functionality for daily living.

All of these factors may contribute to poorer mental health outcomes for older people with HIV, with associated negative outcomes such as increased social isolation, despair and the discontinuing of HIV treatment. A focus on long-term survivors is in keeping with evidence (McGowan et al 2017; Guaraldi et al 2015) that longer duration with HIV infection is more important than chronological age itself in contributing to poorer health and psychosocial outcomes.



### Proposal

NAPWHA will explore and operationalise means through which to reach out to long-term survivors at risk of poor health and psychosocial outcomes. This will include strengthening partnerships with physicians and HIV/AIDS services. With a strong focus on respect, solidarity and dignity, and being open and listening to their concerns, the aim is to develop on a case by case basis greater insights into long-term survivors' needs, fears, experiences and preferred service choices. This approach is also in keeping with the Aged Care Quality Standards (Australian Government 2018b) which will apply to all aged care services from 1 July 2019. Subject to Parliamentary approval, these Standards include 'Consumer Dignity and Choice' and the consumer outcome: *I am treated with dignity and respect, and can maintain my identity. I can make informed choices about my care and services, and live the life I choose* (Australian Government 2018b: 6).

NAPWHA will produce a case study report on this initiative, where the 'case' is defined as long-term HIV survivors in Australia at risk of accentuated poorer health and psychosocial outcomes.



### Recommended timeframe

March 2020 to December 2020

A program logic underpins the above proposal. Central to the program logic approach is putting forward an outcomes hierarchy, which shows the assumed cause-and-effect relationships between program outcomes, from immediate and short-term impacts to long-term

outcomes. Doing so provides the basis for thinking about how the program needs to function to achieve the desired outcome (NSW Health 2017). There is a range of models available, but common elements include:

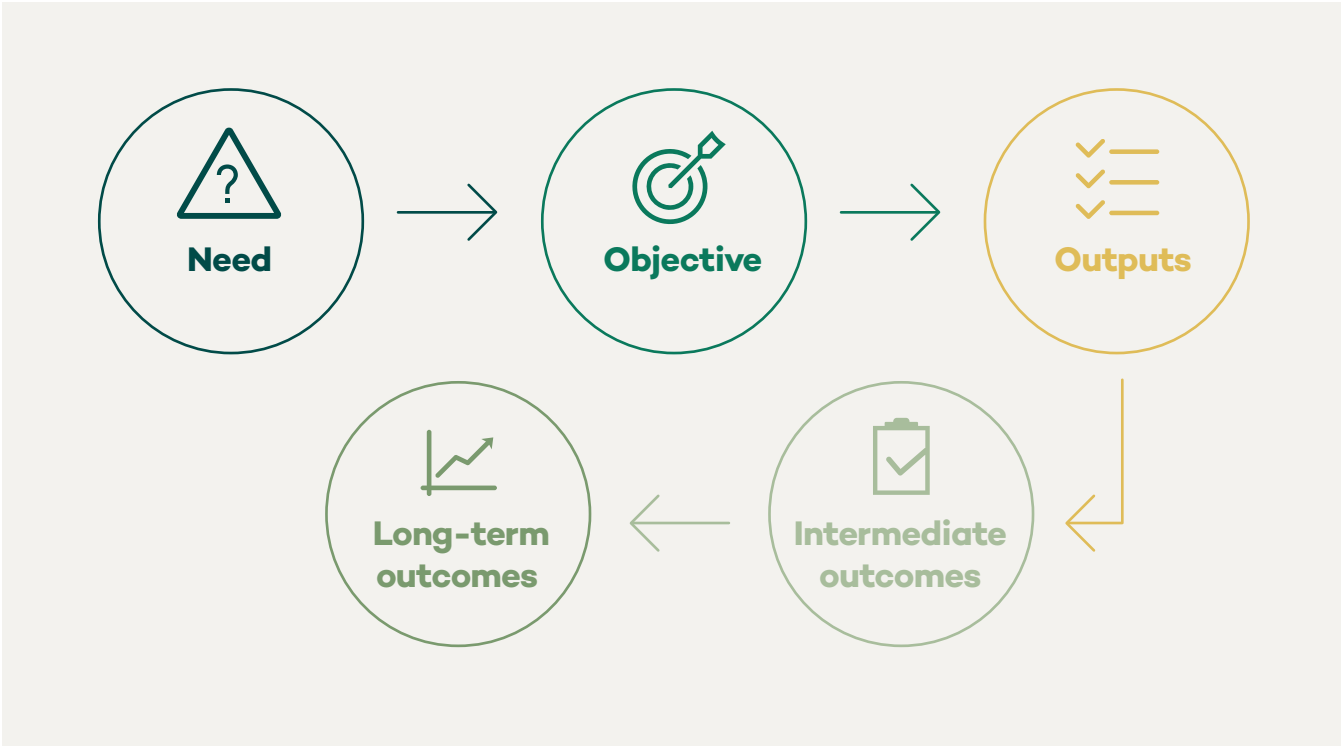


Figure 9: Program logic model

Use of a program logic model contributes significantly towards more effective management, measurement and accountability. In particular, it encourages evaluation to

be built into the program, and resourced, from the outset.

Table 6 puts forward a proposed program logic for Phase 2 of NAPWHA’s HIV and Ageing Project.



Table 6: Program logic: NAPWHA HIV and Ageing Project Phase 2

Initiative	Need	Objective	Outputs	Outcomes
Nationwide Outreach and Health Promotion Campaign	As the age demographic of people living with HIV increases due to the success of antiretroviral therapy, more PLHIV are dealing with issues common to the ageing process, often in the absence of evidence-based understandings of HIV and ageing.	To conduct a <i>Growing Older with HIV</i> – <i>Nationwide Outreach and Health Promotion Campaign</i> that takes the form of a well-publicised ‘roadshow’ involving a series of public health outreach and education workshops	<ul style="list-style-type: none"><li>• State-based community organisations engaged</li><li>• Ten ‘roadshow’ events planned, organised and held</li><li>• PLHIV provided with up to date and accurate information on HIV and the ageing process, healthy living and the choices and steps that can be taken to promote their mental health and wellbeing</li><li>• Several ‘Healthy ageing with HIV’ working groups established</li><li>• NAPWHA report on the Campaign made accessible to community-based groups and service providers</li></ul>	<i>Intermediate outcome:</i> Australian PLHIV are better informed about HIV and ageing  <i>Long-term outcome:</i> Younger PLHIV are better equipped to plan for their futures, and older PLHIV to have a greater ability to age well in place and to avoid or delay hospitalisation and residential care.
Peer support training materials focusing on the intersection of living with HIV and ageing	Volunteer PLHIV mentors need up to date and evidence-based information and training on approaches and methods that will enable them to provide support to their peers who are ageing.	To design a peer training program, incorporating a set of teaching/learning materials and resources, for PLHIV who are, or who wish to become, peer supporters for older PLHIV.	<ul style="list-style-type: none"><li>• State-based community organisations engaged</li><li>• Older PLHIV peer training program devised</li><li>• Training model piloted in south-east Queensland and evaluated</li><li>• Peer training model revised on the basis of evaluation</li><li>• Resources produced and distributed nationwide</li></ul>	<i>Intermediate outcome:</i> Peer support for older PLHIV is enhanced through the development and trialling of a training model and associated resources  <i>Long-term outcome:</i> Older PLHIV receive quality peer support that contributes to treatment adherence, adoption of health preservation attitudes and behaviours, and the delay of disease progression.

Initiative	Need	Objective	Outputs	Outcomes
Promoting models of HIV geriatric care in Australia	As PLHIV grow older, they may require access to disability and aged care supports and services at earlier ages and at a higher level than their non-HIV positive peers.	To promote the wider adoption of models of geriatric HIV care in the Australian service system, with a specific focus on addressing frailty in older PLHIV	<ul style="list-style-type: none"> <li>• MoU established between NAPWA and ASHM</li> <li>• Scoping of opportunities to extend HIV geriatric care models within the service delivery system</li> <li>• Service providers alerted to the value to older PLHIV of a focus on frailty</li> <li>• Pilot program initiated, carried out and evaluated at St Vincent's Hospital, Sydney</li> <li>• Findings disseminated</li> </ul>	<p><i>Intermediate outcome:</i> As a voice for PLHIV, NAPWA assumes an active role in promoting HIV geriatric care models in Australia</p> <p><i>Long-term outcome:</i> The service delivery framework for older PLHIV in Australia is strengthened through the adoption of evidence-based approaches built upon partnerships.</p>
Reaching out to long-term HIV survivors	Having lived for most of their adult lives with HIV infection, many older PLHIV continue to be impacted by the legacy of the early years of the epidemic, are weighed down by years of socio-economic insecurity, have renewed concerns about the loss of their independence, and may consider mainstream aged care services with trepidation.	To reach out to long-term survivors at risk of poor health and psychosocial outcomes, including disengagement from the community and service sectors, treatment cessation, and the onset of preventable comorbidities	<ul style="list-style-type: none"> <li>• Means identified of reaching out to, and engaging with, long-term survivors, drawing upon enhanced partnerships with the community sector, physicians and disability and aged care service providers</li> <li>• Relationships established with long-term survivors based on respect, solidarity and dignity</li> <li>• Greater insights developed into long-term survivors' needs, fears, experiences and preferred service choices</li> <li>• Case study report, where the 'case' is defined as long-term survivors at risk of frailty, and poor health and psychosocial outcomes</li> </ul>	<p><i>Intermediate outcome:</i> Long-term survivors engage better with the HIV community sector and the aged care service systems</p> <p><i>Long-term outcome:</i> Long-term HIV survivors adhere to antiviral treatment regimes, maintain independent living, and delay ageing and HIV-associated disease progression.</p>



**napwha** national association of  
people with HIV australia

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**HIV and Ageing in Australia – The New Frontier**