

# Profiles of PLHIV in Australia



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## Understanding the complexity of needs and capacity to access health and support

### Introduction

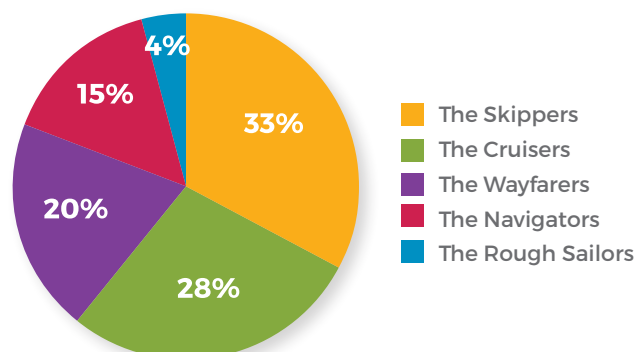
Supporting people living with HIV (PLHIV) to manage their health, treatments, and quality of life requires an understanding of their diverse experiences.

This study has analysed a sub-sample from the HIV Futures 8 survey (a national survey of health and wellbeing of Australian PLHIV), to identify a set of broad profiles of PLHIV in Australia with different health status and capacity to access clinical services.

We used Latent Profile Analysis (LPA) to identify naturally forming groups based on a range of measures including: health and wellbeing, current HIV treatment experience, treatment for comorbidities, time since diagnosis, and health literacy. We then compared the groups on further measures such as experiences with the healthcare system, and financial, psychological and geographical barriers to healthcare access.

We found five broad profiles that we have named:

- **The Skippers** – experts in their own good health (33% of the HIV Futures 8 respondents)
- **The Cruisers** – cruising with their health but insecure with health systems (28% of respondents)
- **The Wayfarers** – having complex health needs not always met (20% of respondents)
- **The Navigators** – confidently managing complex health (15% of respondents)
- **The Rough Sailors** – facing significant barriers to good health (4% of respondents)



On the following pages, we have described these broad groups, detailing their experience and circumstances, and highlighting their potential clinical and support needs.

The profiles are not intended to be representative of individuals, but are meant to highlight how different experiences, perspectives, barriers and health outcomes for PLHIV tend to group together.

The aim of this study is for clinicians and the HIV health and community sector to draw on these profiles to support their considerations of the diversity of PLHIV in Australia with respect to health needs and capacity to access and engage with services.

We believe this will assist the understanding of, and tailoring services to, the diversity of PLHIV in Australia.

Please note that, consistent with the general pattern of the HIV epidemic in Australia, the HIV Futures 8 sample was predominantly Anglo-Celtic, male, and gay. We did not find any significant differences with respect to ethnicity, gender, or sexuality between the identified groups.

# THE SKIPPERS

## Experts in their own good health

Skippers are highly knowledgeable and confident when it comes to their health care. Most Skippers are well-educated inner-city dwellers, enjoy an above-average income, and have private health insurance.

For the most part, Skippers feel they have the resources to choose health care providers according to their needs and preferences. Skippers will engage confidently with health care providers – asking questions, seeking information and taking a lead in their health care choices.

Skippers are generally in good physical health and are unlikely to be experiencing side effects from HIV medication. However, around half will be taking medication for at least one condition other than HIV, most commonly hypertension, cardiovascular disease, or asthma. This may be related to age for some Skippers. One in six Skippers are taking medication for a mental health condition.

Skippers cope well with HIV-related stigma and have a high level of resilience. Very few Skippers report that they have experienced discrimination in a healthcare setting.

Skippers also tend to have strong support networks and be well connected to their communities.

### Clinical and support needs

Skippers are highly literate experts in their own health so support them to lead the way and be prepared to engage in honest discussions about treatment options and health care needs. Skippers will most likely instigate an HIV treatment review if they feel their current regimen is not working for them or if they become aware of new or simpler regimens that might suit them better. However, Skippers will probably appreciate you recommending resources or the latest clinical information where appropriate. Amongst this group are the people who are likely to be early adopters and role-models for other PLHIV.

## KEY STATISTICS

**33% of the sample**

**Average age: 52**

**21% diagnosed with HIV within the past 5 years**

	SCALE RANGE	AVERAGE SCORE	
Physical health	0-100	78	HIGH
Emotional wellbeing	0-100	82	HIGH
Feeling supported by health providers	1-4	3.75	HIGH
Perceived ability to engage with health providers	1-5	4.92	HIGH
Capacity to navigate the healthcare system	1-5	4.67	HIGH



# THE CRUISERS

## Cruising with their health but insecure with health systems

Cruisers are doing well with their health and, for the most part, have uncomplicated health needs but some may be disengaged from their health providers and healthcare needs. Most Cruisers live in inner-city areas, are well educated, have above-average incomes, and private health insurance.

Cruisers do not always feel confident engaging with healthcare providers. They feel only moderately satisfied with their previous healthcare experiences (although are unlikely to have experienced discrimination) and many are not sure that they will be able to find a provider who adequately meets their needs. Their contact with healthcare providers for HIV-related treatment is less frequent than for other PLHIV.

Cruisers are unlikely to be experiencing side effects from the HIV medication and only a few will be taking medication for other health conditions. The most common conditions are similar as in other groups: hypertension, asthma and cardiovascular disease.

Basically, most Cruisers are doing fine health-wise right now, but if they do become unwell or develop more complex health needs they might need support to more actively engage with their healthcare options and communicate with providers.

Compared to other groups, Cruisers may be less connected to other PLHIV. But they have reasonable levels of social support otherwise and report higher than average levels of resilience.

Cruisers tend to be younger and more recently diagnosed than other groups of PLHIV.

### Clinical and support needs

Be aware that good physical health may mask insufficient support received by some Cruisers. Referral to HIV peer support services may be helpful. Young people and those who are newly diagnosed will be less experienced managing HIV and will likely have had less need to pay close attention to their health in the past. As such, they may not have had a chance to develop the resources, knowledge or skills to advocate and communicate their own health needs. Taking time to talk through options and processes for HIV treatment and management may be important – perhaps also initiating periodic treatment reviews as they may not feel confident to do so, or not realise this is an option.

## KEY STATISTICS

**28% of the sample**

**Average age: 49**

**28% diagnosed with HIV within the past 5 years**

	SCALE RANGE	AVERAGE SCORE	
Physical health	0-100	70	HIGH
Emotional wellbeing	0-100	74	HIGH
Feeling supported by health providers	1-4	3.14	MEDIUM
Perceived ability to engage with health providers	1-5	3.97	MEDIUM
Capacity to navigate the healthcare system	1-5	3.76	MEDIUM

# THE WAYFARERS

## Having complex health needs not always met

The Wayfarers often have complex health needs and often struggle to ensure these needs are met within the health system. Many Wayfarers feel unsupported by their healthcare providers and many report past experiences of HIV-related discrimination in healthcare settings.

Around half of Wayfarers live in inner city areas, while the other half live in the outer suburbs or regional/rural areas.

Wayfarers have low levels of education and income compared to other PLHIV. Around 60% are reliant on social security as their main source of income.

Wayfarers are more likely than other groups to be experiencing side effects of their HIV treatment. They are also more likely to have negative views on antiretroviral treatment, with many feeling that it is harmful to their overall wellbeing. Many Wayfarers have been living with HIV for a long time and their health may have been affected as a result.

Wayfarers report experiencing physical and mental ill-health and are likely to be taking medications for at least one condition other than HIV, including hypertension, asthma and arthritis. Around 20% of Wayfarers are regular users of cannabis/marijuana and 15% report regular use of non-prescription sleeping pills, analgesics or other painkillers.

Wayfarers find it difficult to negotiate health systems. Many are seeing multiple providers and close to 60% have had difficulty accessing specialist medical services for non-HIV

health conditions – this may be related to living outside of cities and low income.

Wayfarers report high levels of internalised stigma related to HIV, have low levels of resilience and limited social and support networks.

### Clinical and support needs

Wayfarers have high clinical and support needs relative to other PLHIV. In some cases, they may struggle to find appropriate services within their local areas and they may need to travel long distances to access health care providers. As such, Wayfarers may need support to identify appropriate healthcare providers and, in some cases, financial or practical assistance to get to appointments. Good communication between providers will help to enhance care and ensure continuity of care across different services. Clinicians will need to work closely with Wayfarers to ensure they are on the best HIV treatment regimen for them and initiate treatment reviews where necessary. Wayfarers are relatively isolated socially and may benefit from peer support programs or other services that bring them into contact with other PLHIV.

## KEY STATISTICS

20% of the sample

Average age: 51

15% diagnosed with HIV within the past 5 years

	SCALE RANGE	AVERAGE SCORE	
Physical health	0-100	39	LOW
Emotional wellbeing	0-100	48	LOW
Feeling supported by health providers	1-4	3.05	MEDIUM
Perceived ability to engage with health providers	1-5	3.60	MEDIUM
Capacity to navigate the healthcare system	1-5	3.44	MEDIUM



# THE NAVIGATORS

## Confidently managing complex health

Navigators are experienced in managing the health system and confident in advocating for their health needs. However, relative to other PLHIV, they are likely to have complex chronic health issues and needs.

Navigators tend to live in urban areas – the inner city or suburbs. They have an average level of education and may be experiencing financial stress as around half of the Navigators rely on social security as their main source of income. Around 40% have private health insurance, although most report having access to a bulk billing clinic for their HIV care.

Navigators are likely to be currently experiencing side effects from HIV treatment. In addition, as many Navigators have been living with HIV for many years, they are also likely to have had experiences with HIV treatment side effects and a longer history of ill-health. Navigators are likely to be taking medications for one or more conditions other than HIV, most commonly asthma, hypertension, arthritis and other conditions related to ageing. Navigators are more likely than other PLHIV to be regular users of non-prescribed sleeping pills, analgesics or other painkillers – around 30% report regular use of these drugs.

Navigators are confident and experienced users of health systems. They are likely to have had more satisfactory experience and more opportunity to build trust and rapport with healthcare professionals than other PLHIV. They know a lot about HIV and about their own health needs. They are comfortable and resourceful when choosing healthcare providers and they will likely know what questions to ask.

Navigators are likely to be seeing multiple healthcare providers for different conditions, thus will appreciate providers who are cognisant of this fact and maintain clear records to ensure coordination of care.

Navigators have quite good social support networks and feel connected to other PLHIV, but physical and mental ill-health can be a barrier to social engagement for some Navigators which, in turn, can reduce support and lead to isolation.

### Clinical and support needs

Navigators are resourceful and confident when it comes to managing their health and meeting their care needs. However, since their health needs are often complex they may struggle financially. Many Navigators have been living with HIV for a long time and may have had long periods of ill health. They may also be managing more than one chronic health condition. A strong and respectful relationship with their HIV doctor will be essential to good management of their health. This will be reinforced by effective communication and coordination of care across multiple providers. Navigators often have strong support networks and a good circle of friends, but they may need extra support at times when ill-health makes it more difficult for them to stay in touch with others or socialise. They may also need financial support at times.

## KEY STATISTICS

**15% of the sample**

**Average age: 53**

**13% diagnosed with HIV within the past 5 years**

	SCALE RANGE	AVERAGE SCORE	
Physical health	0-100	44	LOW
Emotional wellbeing	0-100	54	MEDIUM
Feeling supported by health providers	1-4	3.83	HIGH
Perceived ability to engage with health providers	1-5	4.85	HIGH
Capacity to navigate the healthcare system	1-5	4.38	HIGH



# THE ROUGH SAILORS

## Facing significant barriers to good health

While not many PLHIV fall into the Rough Sailors group, this is an important group to be aware of. The Rough Sailors have complex chronic healthcare needs and many are struggling to maintain their physical and emotional health.

Rough Sailors are more likely than other PLHIV to be living in regional/rural areas (around 40%). Rough Sailors are less likely than other groups to have a university education and more likely to rely on social security as their main source of income.

Compared to other PLHIV, the Rough Sailors have been living with HIV for a relatively short time. Many report that side effects of HIV treatment are interfering with their everyday life.

The Rough Sailors are less likely than other groups to be in regular contact with healthcare providers, even though they are more likely to report experiencing ill-health and HIV treatment side effects. Many Rough Sailors are taking medication for conditions other than HIV, including hypertension and gastrointestinal problems. Around 20% of Rough Sailors report regular use of non-prescribed sleeping pills, analgesics or other painkillers.

The low level of contact with healthcare providers among Rough Sailors may in part be due to their lack of confidence accessing health services. Many Rough Sailors feel unsupported by healthcare providers and incapable of navigating health systems. Close to half of Rough Sailors report past experiences of discrimination within healthcare settings.

Difficulties with health services and experiences of discrimination may also be related to geography and income:

Many Rough Sailors live outside of inner city areas and/or rely on social security, and may thus have limited options when it comes to access to health providers.

Rough Sailors report very low levels of social support and connection and very limited support from other PLHIV.

### Clinical and support needs

Rough Sailors may be dealing with side effects from HIV medication, but what really stands out with this group is their social isolation and a relatively low level of emotional wellbeing. Rough Sailors are often isolated from friends and family and may have very limited contact with other PLHIV. This may contribute to high levels of internalised stigma observed in this group. Rough Sailors are more likely to be newly diagnosed than other PLHIV (although this does not mean all newly diagnosed people are Rough Sailors). As such, Rough Sailors may need support to come to terms with their diagnosis and treatment management. A simple treatment regimen and emphasis on social/emotional support is likely to be an appropriate way to approach healthcare for Rough Sailors. In addition, it may be important to be aware that referral to multiple providers may cause stress to Rough Sailors due to fear of stigma or discrimination. Peer support programs and specialist social services/social workers could be highly beneficial for this group.

## KEY STATISTICS

4% of the sample

Average age: 47

27% diagnosed with HIV within the past 5 years

	SCALE RANGE	AVERAGE SCORE	
Physical health	0-100	41	LOW
Emotional wellbeing	0-100	48	LOW
Feeling supported by health providers	1-4	2.06	LOW
Perceived ability to engage with health providers	1-5	1.93	LOW
Capacity to navigate the healthcare system	1-5	1.88	LOW





## HIV Futures 8 data

The HIV Futures 8 was a national survey of 895 Australian PLHIV, conducted between July 2015 and June 2016. The survey was open to people aged 18 years or older who were currently living in Australia. The survey instrument included approximately 250 items relating to: health and wellbeing; treatment use; testing and diagnosis; sex and relationships; and use of, and access to, community and clinical services. Participants came from all states and territories in Australia.

Full details regarding the HIV Futures 8 study protocol and method are available on the ARCSHS website: [latrobe.edu.au/arcschs](http://latrobe.edu.au/arcschs)

## Analysis

The HIV Futures 8 data were analysed with the use of Latent Profile Analysis (LPA), which allowed us to group respondents into probability-based profiles where individuals grouped within a profile scored similarly across multiple measures: health and wellbeing, current HIV treatment experience, treatment for comorbidities, time since diagnosis, and health literacy. The final sub-sample from HIV Futures 8 used in the analysis was limited to 762 participants who provided answers to all questions forming the basis of the profile grouping.

To identify the model with the best fit to the data, we tested a set of models with an increasing number of latent profiles (1-8 profiles). The 5-profile model was selected based on the model fit (estimated with Bayesian Information Criterion; BIC),

profile size, and model parsimony considerations. Subsequently, respondents were assigned to profiles based on the probability estimates. We then compared how the five profiles differed on the variables forming the grouping. We also tested for differences on a range of additional variables including access and use of health services, use of illicit drugs and socio-demographic background.

Full details of the methodology and results will be described in a forthcoming journal paper. For further details, please contact Dr Gosia Mikołajczak ([m.mikolajczak@latrobe.edu.au](mailto:m.mikolajczak@latrobe.edu.au)).

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