

# HIV Services Review

## **Building the next generation of HIV care**

The Alfred's response to community feedback



# HIV Services Review:

## The community helping to build the future of HIV care

In early February 2021, we started a conversation with our HIV community about the future of HIV care.

So much had changed for the better in the world of HIV care in the past decade and we wanted to understand the priorities of people living with HIV.

Home to the Victorian HIV service, it is important we know where to best place our resources when delivering care especially with the increasingly diverse experiences and needs of people living with HIV.

Working with our partner organisations – Living Positive Victoria, Positive Women, Thorne Harbour Health – along with the Department of Health, we reached out to the HIV community and specialists and asked for their help.

We used social listening, digital platforms, specialist media, and traditional face-to-face conversations to reach as many in the community as possible.

Close to 230 people took part in surveys and discussions, providing us with detailed responses and insights that will help us shape the next generation of HIV care.

Thank you to those who generously gave of their time to provide this feedback.

This report summarises the feedback received as well as our response.

You can provide comments to our response at: <https://redcap.link/1y72pi5o>

## How many people did we reach?



30,062

Alfred Health  
social media reach



345

consultation page,  
unique visits



641

comments



70,000

social listening  
reach



227

surveys



6

kitchen table  
attendees

# Who did we hear from?



88% Male



12% Female



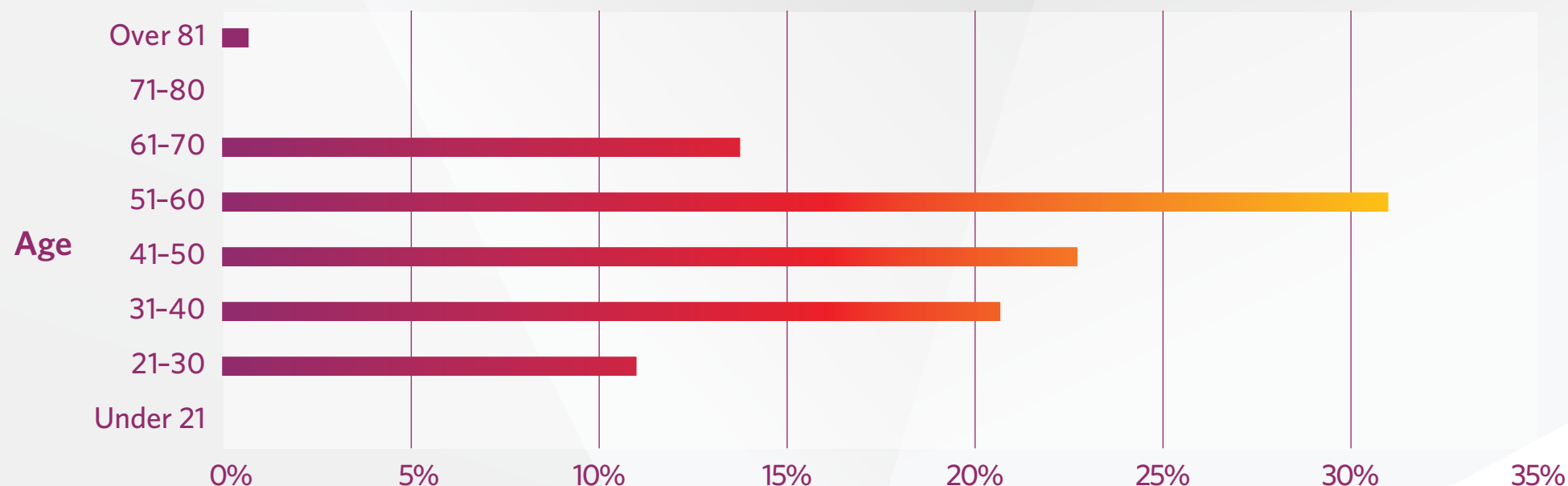
1% Non-binary



2 Aboriginal  
and Torres Strait  
Islanders



Residence:  
87% Metro vs  
13% Regional/  
rural



## Who did we hear from?

Preferred language  
other than English  
3%

Time since diagnosis  
– earliest: 3 months  
– longest: 37 years  
– average: 17 years

## Where are respondents accessing care?



- Alfred HIV service
- MSHC HIV service
- Other HIV service provide
- Does not access specialist HIV services
- Other

Other HIV service providers included: Monash ID, Northside, Prahran Market, Centre Clinic

## We asked you:

- 1.** What are some of the worries or challenges that you anticipate when thinking about your future healthcare?
- 2.** Do you feel HIV services meet your current needs?
- 3.** What matters most to you when staying in hospital?
- 4.** What are some of the worries or challenges when thinking about your future generally?

## What did you tell us?

Worries or challenges when thinking about future health.

### Key themes

HIV and ageing

Long term impacts of treatment

Mental Health

Stigma – amongst health professionals

Availability and cost of medication

I worry about costs and choice.

Accelerated ageing due to HIV.

Ageing is occurring rapidly ... I can see myself having to access aging supports ... Any help or easing into these ageing supports would be helpful.

Premature deterioration of health.

Is medication always going to be cheap?

Stigma – interaction with Healthcare providers often involves stigma.

The antiretroviral medication I take doesn't interfere with other treatments I may need.

Long term drug affects.

I am concerned with my mental health. I was initially overwhelmed by my diagnosis.



## We heard ...

### Ageing

People are concerned about ageing, their future and the long-term impacts of HIV.

Ageing is occurring rapidly ... I can see myself having to access aging supports ... Any help or easing into these ageing supports would be helpful.

## Our response ...

### Continuing to build our current work:

- HIV Outward Program Nursing Home model – education and training to nursing homes where people are placed, ongoing HIV care coordination and medication provision to several health services.
- HIV Assist in-reach into nursing homes for psychosocial support and ability to support community access where appropriate.

### Future responses:

- A new Statewide HIV and Ageing Multidisciplinary Clinic, incorporating the HIV neurocognitive clinic.
- With community organisations, Alfred Social Work to share information and updates on NDIS and aged care services.
- Care co-ordination to facilitate efficient multi-specialist review, reduce multiple appointments.



## We heard ...

### Chronic disease management

People are concerned about the burden of having chronic, complex health needs.

Managing comorbidities such as blood pressure and inflammation. Being able to continue managing my health conditions with the physicians. Longer term it is fragility, physical and psychological health and well being.

## Our response ...

### Continuing to build on our current work

- Expansion and further development of the model for the HIV Complex Metabolic clinic, providing multi specialist review in one clinic (HIV, Endocrinology, Renal, General Medicine, Nutrition, Pharmacy).
- Enhanced promotion of the clinic to other hospitals and GPs.

### Future responses

- Expansion of the clinic in an outreach location in Inner North to provide better access.
- Care co-ordination to facilitate efficient multi-specialist review, reduce multiple appointments.

## We heard ...

### Mental health

People highlighted Mental Health concerns and need for services when and where they need them.

I am concerned with my mental health. I was initially overwhelmed by my diagnosis.

I think it will be important to have specialists in a range of disciplines related to ... mental health, and of course the other specialist that already work collaboratively with HIV services.

## Our response ...

- Expanded HIV Outward program and building presence in acute hospitals across Melbourne
- Partner with peak bodies and support community
- Education and Resource Centre training HIV and mental health
- Expand Outpatient Psychiatry access with a multi-disciplinary model
- Ensure we keep abreast of planned changes in mental health services at State and Federal level. Maximise knowledge and access points for PLHIV.

## We heard ...

### Access to medication

People wanted to ensure access to medication – free/low cost.

I worry about costs and choice.

Is medication always going to be cheap?

## Our response ...

### Review HIV medication access

#### Current:

- Free HIV medication via MSHC, co-payment at community pharmacies and Alfred.

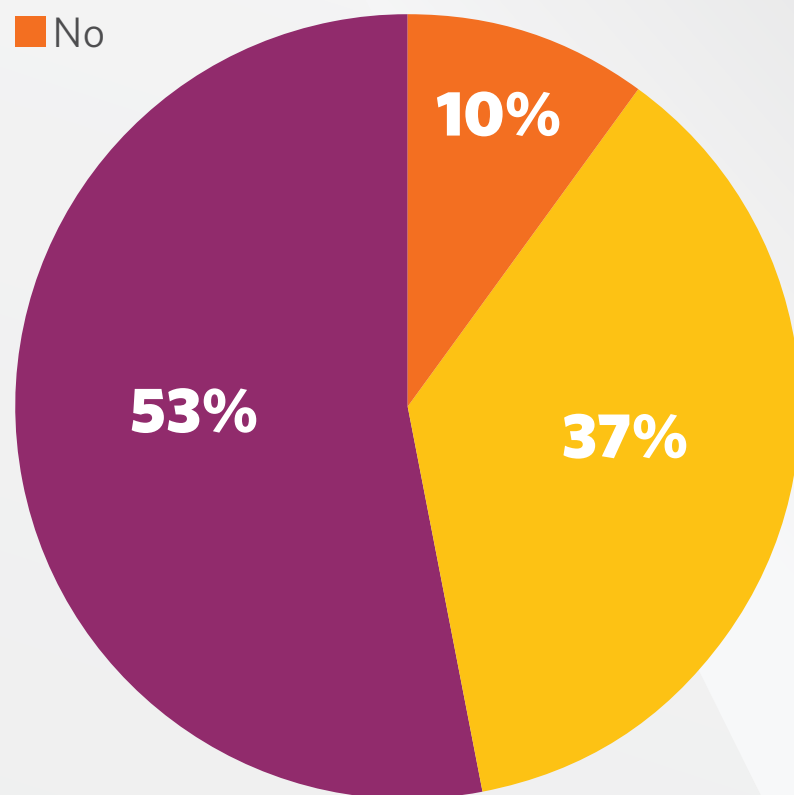
#### Future:

- Review to determine a consistent future model.

## What did you tell us?

Do you feel HIV services meet your current needs?

- Yes, completely
- Yes, to some extent
- No



### Key themes

Continuity of care

Compassionate care

Access

Availability of services for regional/rural patients

Continuity of care, seeing the same ID specialists/staff, feeling safe, listened too and understood were all strong themes from respondents that indicated services were meeting their needs.

At Alfred Health more patients were satisfied with only 6% saying that services did not meet their needs.

When respondents indicated services don't meet needs fully, access was the strong theme and this was due to availability of services for regional and rural patients.

## We heard ...

### Access

People identified access and equity issues for rural and regional Victoria.

I would prefer better regional services rather than having to travel to Melbourne, but during lockdown I was given telephone consultations and had meds posted to me.

I live in rural Victoria, appointments don't usually take into account the 7 hour round trip.

## Our response ...

### Increasing the reach to rural and regional Victoria

- Develop formal linkages and clinical partnerships with rural and regional hospitals, Sexual Health Centres and GPs.

## We heard ...

### Specialist HIV Care

People wanted to know they are receiving the best care from trained staff.

While HIV in Australia is becoming more manageable, there still need to be more education and awareness of healthcare professional to appropriately care for people living with HIV. Especially in a non-HIV specific health care setting.

## Our response ...

Leading the quality of HIV care across the state through the Victorian HIV Clinical Care Network

### Continuing

- GP education and HIV case conferences at HIV high case load clinics.

### Future response

- Currently working on a project to measure and report on key quality of life indicators across HIV clinical services in Victoria.

## We heard ...

### Care continuity

People want to know they are getting the best care through their GP.

People wanted to make sure GPs were up to date and trained.

## Our response ...

### Continuing our role educating and supporting S100 GPs\* and hospital services

- Expansion of educational and mentoring support for the current HIV workforce and new HIV workforce (medical, nursing and allied health practitioners).

\* S100 GPs are General Practitioners who provide are able to prescribe HIV medications



## We heard ...

### Awareness

People wanted to know more about the HIV statewide program and the different services available.

How about letting the gay community, especially people who are HIV+ actually know about the specialist services available ... I have no idea what they are.

## Our response ...

### Increase service promotion and awareness of services

Enhance the service profile through:

- the Alfred Health website
- links with partner organisations
- GP Health Pathways, Infectious Diseases and HIV networks.

Strengthen the branding of Victorian HIV service through:

- profiles of staff
- services in community organisation newsletters, videos, regular guest spots community radio.

## What did you tell us?

What matters most when staying in hospital

### Key themes

Respect and privacy

Confidentiality

Private rooms

Staff education/capability

I have found the peace and quiet of a single room at FH a curative and restful recipe from recovering from major illness – cancer etc. I gather it might be closed soonish. If so I would want some kind of step down care provided.

Being respected and treated just like everyone else in the hospital. I am not a boogie monster or HIV zombie!

Privacy, empathy and being treated as anyone else would be, with no stigma.

Being discreet when I am in a room with other patients. I have had this happen and they were not exactly discreet and a nurse disclosed to a stranger.

Fairfield is where I receive the best care. Not due to a single room, but the care I receive is second to none. The staff know me and are incredibly knowledgeable on HIV and the issues that come along with it.

FH\* Fairfield House is a ward in The Alfred where people with HIV have been cared for over the past 20 years.

## We heard ...

### Staying in hospital

People highlighted the importance for post acute recovery care, step down care from the acute environment and a model of chronic disease management.

They identified the culture of care, support and familiarity as being very important along with privacy.

11 consumer/community respondents mentioned the care in Fairfield House.

## Our response ...

### Important to continue inpatient care at The Alfred especially for people with:

- complex care needs as part of their transition to home from acute care
- chronic or advanced disease requiring health reviews and multiple specialist assessment work ups

### The reduced demand for inpatient beds means care can be housed in a new modern facility:

- continue the philosophy of care from Fairfield House
- 3-5 bed facility separate from acute wards

### Evolve models of care especially for people with acute needs.

## What did they tell us?

Worries or challenges when thinking about the future generally.

### Key themes

Future finances

Housing

Stigma – from wider population

Social isolation

My concerns for the future all revolve around what happens if I get employment and then my health deteriorates, what would I do?

Health insurance may become unaffordable for me and I fear losing choice and control over my specialist care.

Future income as I have very little superannuation.

I have a fear of becoming homeless and what that would mean for me.

I live with the constant concern that people will find out about my illness and judge and discriminate against me.

## We heard ...

### Stigma

People are concerned about the impact and existence of stigma – within healthcare setting but also in the broader community.

I live with the constant concern that people will find out about my illness and judge and discriminate against me.

## Our response ...

### Health service

- Staff education/awareness, strengthening our culture around diversity and inclusion
- Respect in action campaign

### Community

- Partner with peak bodies and support community

## How did responses differ between groups?



### Gender – female

- Family planning
- Pregnancy



### Location – rural

- Access to specialist services
- Access to GP

<50

### Under 50 years of age

- Stigma from within gay community
- Mental health as current/future concern

>50

### Over 50 years of age

- Long term impacts of treatment
- Fairfield House – 11 participants

## What did health professionals have to say?

Sub-acute care is essential and needs to continue.

Patients report to their health professional experiencing stigma when accessing care in other parts of the health service.

An HIV service all under the one roof would help to create a truly comprehensive and collaborative service environment for clinicians and service users.

Psychosocial – importance of access to NDIS funding for HIV patients with neurocognitive concerns.

42 surveys    122 comments

Infectious Disease and Sexual Health Specialists, HIV nurses, Allied Health professionals, Ward Clerks



## Our next steps

- ✓ Co design this model of care and facility with our community
- ✓ Developing and continuing the Fairfield House philosophy
- ✓ Achieving integrated care that wraps around the patients

We would like to hear your comments on our response and plans for the next stage of HIV care. You can provide your comments here <https://redcap.link/1y72pi5o>