

Victorian HIV Service: Partnering with the community to design the future of HIV care

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Acknowledgement of Country

Alfred Health acknowledges the Boonwurrung/
Bunurong and Wurundjeri Woi Wurrung peoples
of the Eastern Kulin Nation as Traditional
Owners and Custodians, and pays respect to
their Elders past, present and emerging.

We acknowledge and uphold their continuing
relationship to lands and waterways and extend
our respect to all Aboriginal and Torres Strait
Islander peoples.



AlfredHealth

The Soul of Country

Artwork by Jarra Karalinar Steel

Declaration of competing interests

No-one is paid to give this presentation

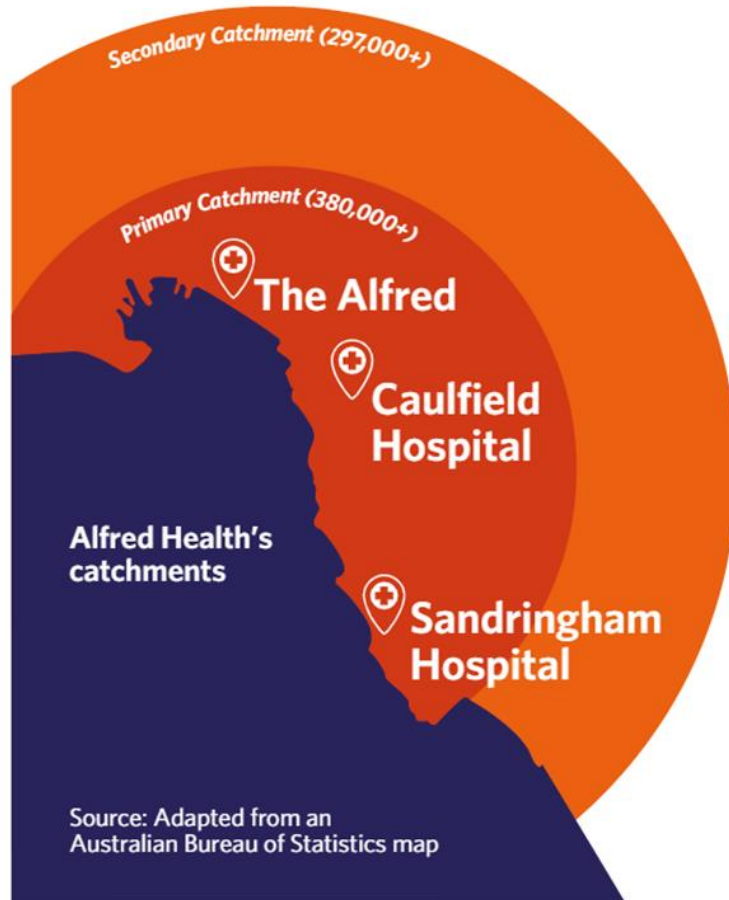
No-one has previously paid for our advice

No research funding

No conflicts of interest

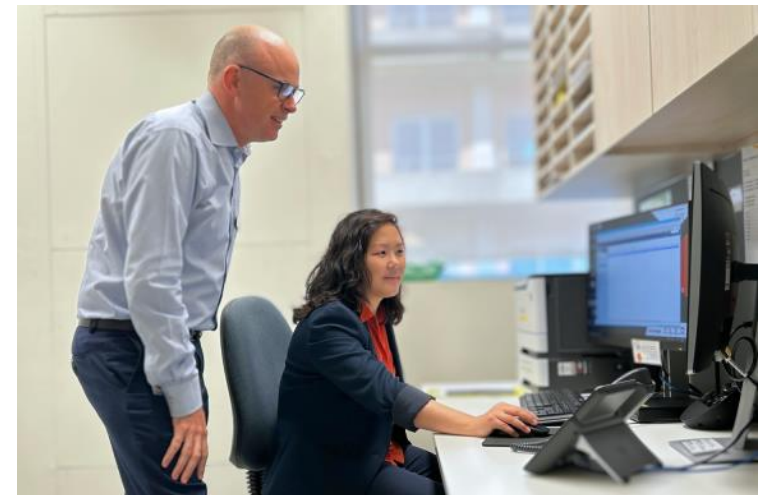
No shareholdings in pharmaceutical or other companies have paid for attendance

About Alfred Health



18 state-wide services, including the Victorian HIV Service

Victorian HIV Service



Patients Come First Strategy



Empower
 Consumers lead the planning, design, development and evaluation of services/projects

Co-design
 Consumers partner with us from development phase to design, implement and evaluate services/projects

Collaborate
 Consumers are represented on committees/working groups etc and can provide advice and recommendations

Consult
 Consumers are invited to provide feedback on their experiences, perspectives and ideas for improvements

Inform
 Consumers receive information about Alfred Health projects and improvement initiatives

HIV Services Advisory Group

Alfred Health's HIV Services Advisory Group (HSAG) has been helping Alfred Health plan for future services and identify community needs and future trends in HIV care since 2014.



HSAG member David Menadue OAM

I have always been happy to be involved as a consumer on the Alfred Health's HIV Services Advisory Group because I know that the organisation takes consumer representation and our perspectives seriously.

To have senior staff who care for people with HIV in the service involved in this Advisory Group has meant that current issues can be addressed promptly and services improved where necessary.

Why now?



Co-design

Consumers partner with us from development phase to design, implement and evaluate services/projects

To learn what services and facilities are required to support our patients into the future, Alfred Health wanted to begin a conversation with our HIV community.

This would give us a deeper understanding of patient needs, and help identify the best way to deliver HIV services into the future.

Guiding principles

Principles

- Do this together
- Recognise what has gone before
- Be responsive
- Communicate 'in language'
- Bring people along
- **Be transparent**



What we set out to achieve

Objectives

- Connect with the community through acknowledging the history of long term survivors and the importance of Fairfield House
- Enable the community to connect with the conversation
- Use co-design principles to create an ongoing conversation with our HIV community working with our clinical partners
- Gather quality information that enables Alfred Health to develop a proposal for care development
- **Engage seldom heard people**
- Contribute to improving the future care of people with HIV
- Create basis for ongoing dialogue and connection with HIV community

Two-staged approach to consultation

Stage 1 - Pre-position forming engagement

A needs analysis process to understand the current and future needs of the HIV community. Sharing the results with the community and double checking that we have it right.

Stage 2 - Post-position forming engagement

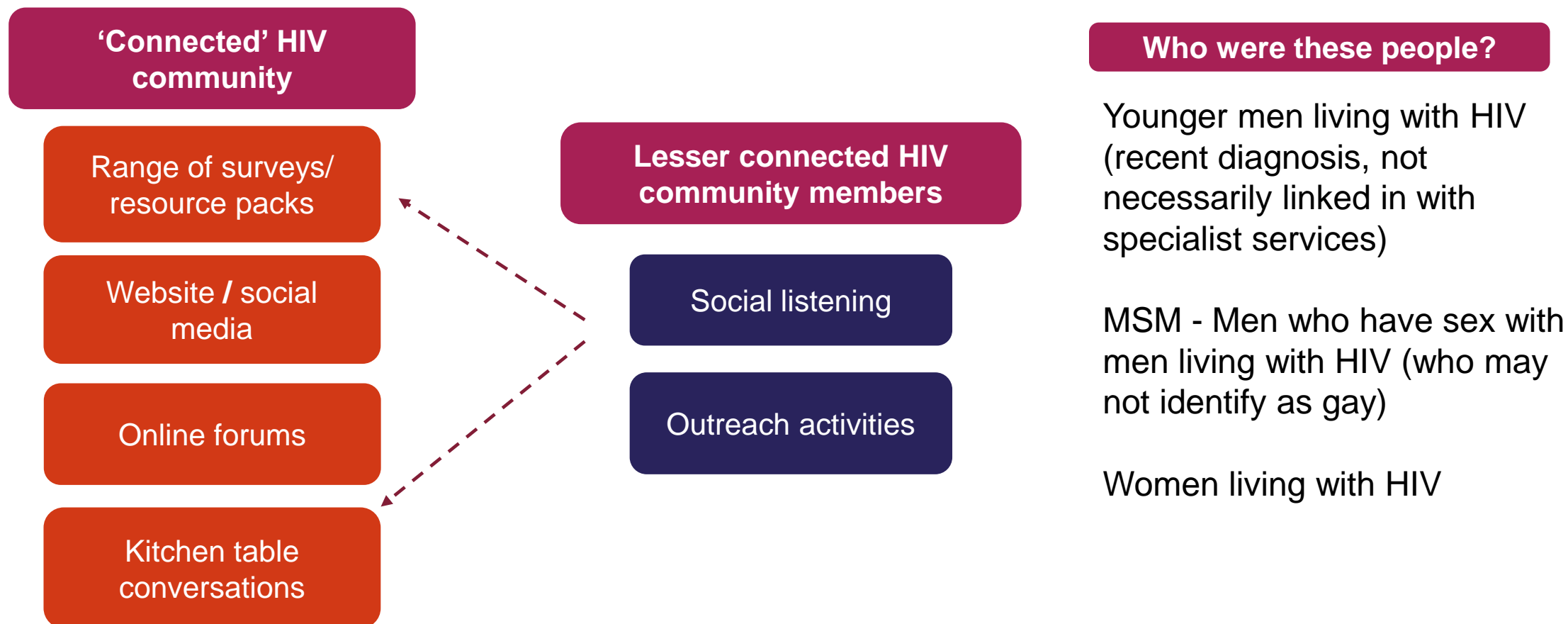
Develop a proposal for the development of future services and facilities with the HIV community based on feedback from Stage 1. Check in with the HIV community to check that we have it right.



Challenging embedded engagement methods



How to connect with the broader HIV community



Consultation summary – what we did

Stage 1



Surveys

Main survey - digital

Short survey – digital and paper

Kitchen table conversations

Facilitated by HIC at Positive Living Centre

Social listening



Facebook, Instagram, Grindr - Short survey

- Utilise social media algorithms
- Proactive
- Use ads to target groups



Social listening

Stage 1

Don't judge me by my HIV		Will HIV outlive me?	
			
Ad Name: Don't judge me by my HIV		Ad Name: Will HIV outlive me?	
Link clicks	Impressions	Link clicks	Impressions
313	25,088	122	13,035

Images and provocations

- Used the codesign group to select the most appropriate images
- Provocations: tested different statements with the consumer/community members. Which ones would make a person stop scrolling?

How many people did we reach?

30,062

Alfred Health
Social
media reach

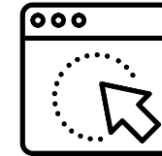


70,000



Social
listening
reach

345



Consultation page,
unique visits

227 surveys



641 comments

6 Kitchen table
attendees



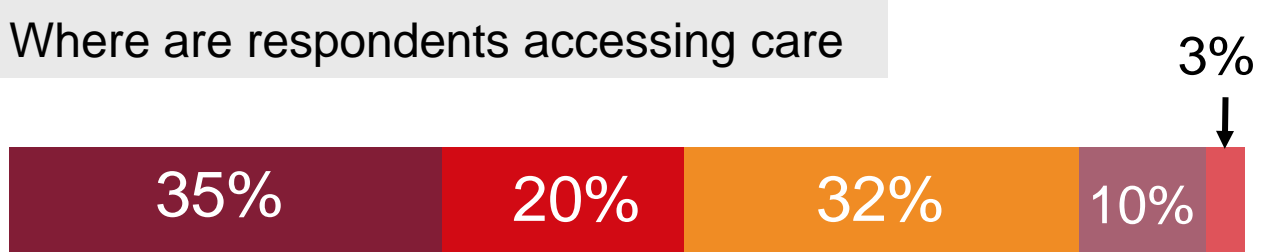
11 Zoom forum
attendees



Who did we hear from?

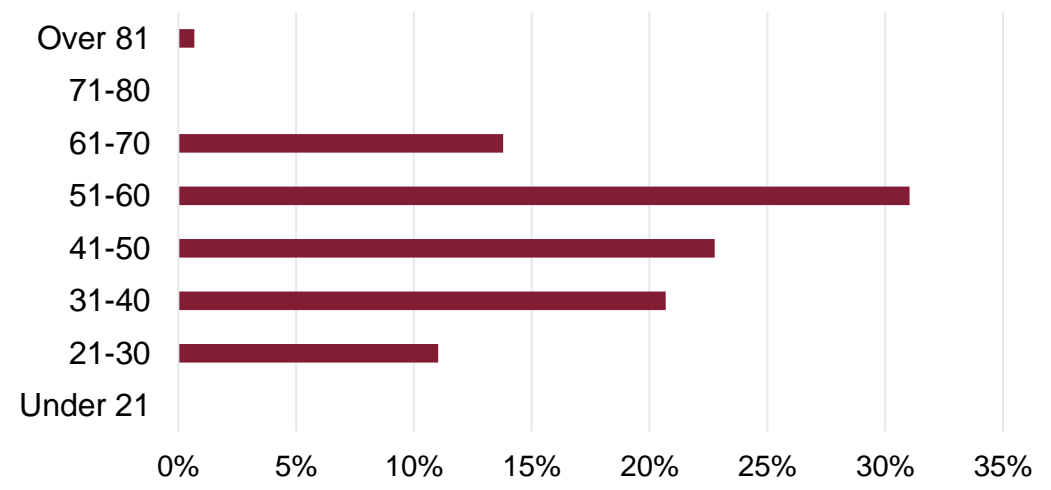
Preferred language other than English **3 %**

Time since diagnosis
Earliest - 3 months Longest - 37 years
Average – 17 years



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

Age



Gender

Male 88% - Female 11% - Non-binary 1%

Residence

Metro 87% vs Regional/rural 13%

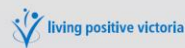
We asked, we heard, we propose

Stage 2

HIV Services Review

Building the next generation of HIV care

The Alfred's response to community feedback



AlfredHealth

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.

Co-designing the new facility

Stage 2

Phase 1 – Deliberative forum



Develop design brief for new facility

Phase 2 – Consumer partnership

Consumers partner with staff and architects as part of User Design Group to develop schematics and detailed design

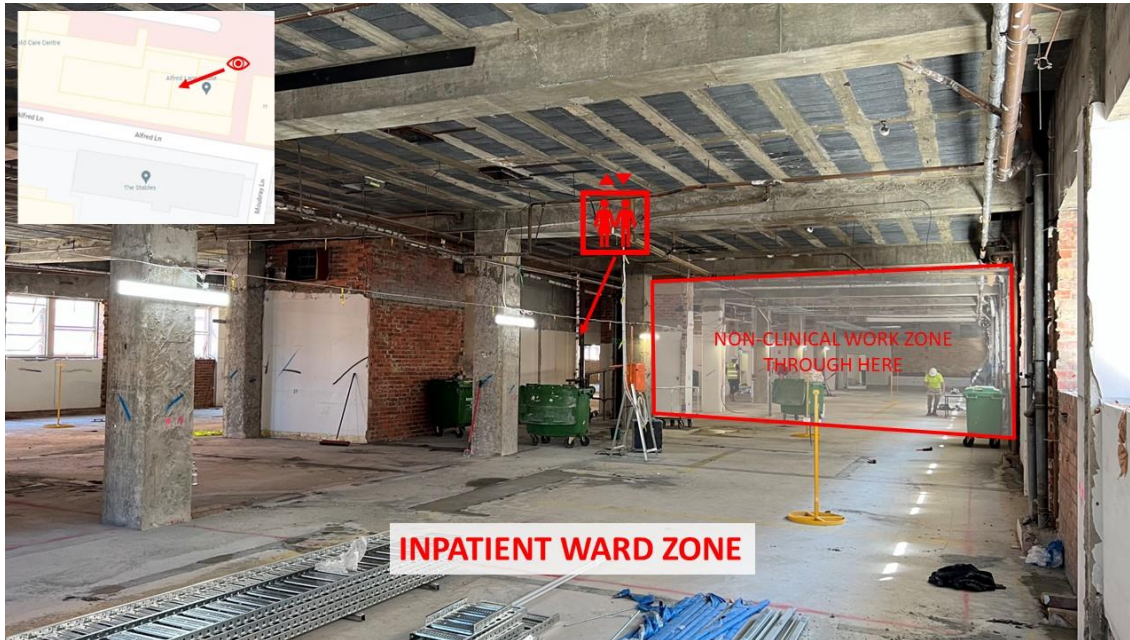
Phase 3 – Wider consultation

Community asked to provide feedback on schematics and detailed design



Co-designing the new facility

Stage 2



Where to next?

Key learnings

- Co-design from the very beginning. Develop shared principles and objectives.
- Managing stakeholder expectations
- Feel the fear and do it anyway
- Test and the flexibility to adapt
- Hearing from a small group of seldom heard voices can be incredibly valuable

Thank you to our partners...



- Prof. Andrew Way, AM, CEO Alfred Health
- Prof. Jenny Hoy, AM, Director HIV Medicine, Alfred Health
- Ursula McGinnes, Executive Director, Public Affairs and Communication, Alfred Health
- Tim Chestney – Patient Experience Officer, Alfred Health
- Danny Vadasz, Former CEO HIC

Further information - www.alfredhealth.org.au/hiv-future-care

Contact – comparticipation@alfred.org.au

Questions and answers session – over to you

