

The research is being carried out by the following researchers		
Role	Name	Organisation
Principal Investigator	Dr Dean Murphy	Australian Research Centre in Sex, Health and Society, La Trobe University
Co-investigator	Dr Jeanne Ellard	Australian Research Centre in Sex, Health and Society, La Trobe University
Co-investigator	Dr Dion Kagan	Australian Research Centre in Sex, Health and Society, La Trobe University
Co-investigator	Professor Adam Bourne	Australian Research Centre in Sex, Health and Society, La Trobe University
Research funder	Commonwealth Department of Health and Aged Care	

### 1. What is the study about?

This study is investigating the experiences of people recently diagnosed with HIV in Australia. The project will focus on experiences of HIV infection, diagnosis, treatment, and living with HIV.

Information gathered through this project will be used to improve HIV clinical care and support services and inform the development of new strategies to reduce HIV transmission.

The project is supported by the National Association of People With HIV Australia (NAPWHA), the national peak community organisation representing people living with HIV. The project also has an advisory board that provides advice to the research team on recruitment, analysis, and implications of the study's findings.

### 2. Do I have to participate?

Being part of this study is voluntary. If you want to take part, we ask that you read the information below carefully, and we are happy to answer any questions you have.

You can read the information below and decide at the end that you do not want to participate. If you decide not to participate this will not affect your relationship with La Trobe University.

### 3. Who is being asked to participate?

You are invited to take part in this research if you have been diagnosed with HIV within the past 12 months, are 18 years or older, and are currently residing in Australia.

### 4. What will I be asked to do?

If you decide to participate in this research, you must give us your 'consent'. This means that you have freely chosen to be involved and that you give us your permission to interview you. If you choose to give us your consent and participate, you will take part in a semi-structured interview of between 1- and 1.5-hours duration. The interview will be conducted via a video conferencing platform such as zoom or via phone depending on your preference. Interviews conducted via video conferencing platforms will be both audio and video recorded as the software in these platforms records both audio and video files. However, we will delete the video file at the end of the interview and only store the audio file. The external transcription service will not receive a copy of the video file.

The focus of the interview will be on the event/s related to your HIV infection; experiences of diagnosis, HIV treatment and monitoring; care and support; experience of living with HIV; sex and relationships; previous HIV and sexual health testing history; community and social networks; and basic demographic information (e.g., age, country of birth, cultural-ethnic background, occupation, education level).

All the information we collect from you is confidential. If you are not comfortable answering any question/s during the interview, you can decline to answer. If you do choose to participate you will be compensated for your time and contribution to the research with a \$100 digital retail gift card. The total time commitment for participating in the project is 1.5 hours.

**5. What are the benefits?**

Your participation will contribute to better and more targeted HIV prevention strategies, a reduction in barriers to accessing HIV services, including testing, among priority groups, and improved pathways into HIV care and treatment. These outcomes will significantly benefit people at-risk of – or diagnosed with – HIV, and society more broadly.

**What are the risks?****6.**

With any research there are (1) risks we know about, (2) risks we don't know about and (3) risks we know about but don't expect.

As part of this study, we will ask you to reflect on the circumstances you believe led to your HIV infection, and your experience of HIV diagnosis. We have carefully crafted our questions to minimise the risk of distress to you, but there is a chance that reflecting on these experiences could cause you some minor discomfort. In the event of discomfort, during the interview you can ask to take a break or to discontinue the interview. The interviewed will be conducted by qualified interviewer, with experience discussing potentially sensitive issues about sex and HIV and will bring the interview to a close if you experience distress beyond discomfort. We also encourage you to contact one of the counselling services listed below if you experience distress after the interview.:

the interview:

**ACON**

Intake Officer (for counselling services)

Telephone 1800 063 060

**HIV Info Line**

(Monday to Friday 10am–5pm AWST) – Telephone 1300 56 52 57 NSW only

**Thorne Harbour Health (Vic)**

Client Liaison/Duty Worker (for counselling services)

Telephone 03 9865 6700 (10:00am to 4:00pm, Monday to Friday) Rural (free call) 1800 134 840

**Lifeline**

(Free national telephone crisis support 24 hours/7 days a week)

Telephone 13 11 14

Website [www.lifeline.org.au](http://www.lifeline.org.au)

**Beyond Blue**

(Free national telephone support 24 hours/7 days a week)

Telephone 1300 224 636

Website [www.beyondblue.org.au](http://www.beyondblue.org.au)

**QLife**

(Free national telephone and web counselling for LGBTI people 3pm–12am daily)

Telephone 1800 184 527

Website [Qlife.org.au](http://Qlife.org.au)

**Black Dog Institute**

Telephone 02 9382 2991

**The Gender Centre (NSW)**

Telephone 02 9519 7599

9:00am to 4:30pm, Monday to Friday

**Rainbow Door (Vic)**

Telephone 1800 729 367

Text 0480 017 246

Email [support@rainbowdoor.org.au](mailto:support@rainbowdoor.org.au)

WAAC (WA)

(Counselling for people living with HIV)

Appointments can be booked online:

<https://www.waac.com.au/what-we-do/counselling/for-people-with-hiv/>

or by phone 08 9482 0000

As part of this study, we will ask you about your sex life and relationships since your HIV diagnosis. While disclosure of HIV status to sexual partners is no longer mandatory in any jurisdiction in Australia, there are state and territory laws related to recklessly putting another person at risk of contracting HIV. We will take great care to protect your identity, however if subpoenaed by the courts to provide identifying information about an individual, the research team would be obliged to do so.

We also encourage you to contact the research team after the interview if you experience something that you aren't sure about, or you want to discuss the interview or any other concerns you have related to participating in the research.

Name	Organisation	Position	Telephone	Email
Dr Dean Murphy	Australian Research Centre in Sex, Health and Society, La Trobe University	Principal Investigator	(03) 9479 8717	D.Murphy@latrobe.edu.au

## 7. What will happen to information about me?

When reporting research findings, we will refer to you by a false name so there is little risk that your identity will be discovered through the research reporting process. Only the principal investigator and research team for this project will have access to the project's raw data. We will use Rev an external transcription service to transcribe your interview, the service has strict privacy and confidentiality procedures in place and your data will be deleted once the transcription is completed. Data collected from you as part of this research project may be used for future research purposes or shared with other researchers. If data are shared, it will be for related research purposes (as determined by the study team) and only if ethics approval has been granted for the proposed research project. The research team will only provide data to other researchers in a de-identified format (meaning that your name and identity has been removed from the data)

Everything you say in the interview will be kept confidential. Any information gathered in the interview will be protected in order to protect your identity. Any hard copy transcripts will be kept in a securely locked cabinet accessible only to the researchers. Audio recordings and electronic copies of transcripts will be kept in a password-protected folder on a secure University computer. The audio recording will be kept for seven years after the research has been published, and then destroyed.

## 8. How will my identity and privacy be maintained?

We will protect the confidentiality of the information we collect from you. We will take great care to remove any information about you from the interview transcript (for example names, places of residence). In addition, when using excerpts of interview transcripts in publications and presentations, the research team will be careful to remove any contextual information that may identify any individual participants.

We will keep your interview audio recording for seven years after the project is completed. After this time, we will destroy the audio recordings, consent form and any contact details that we have for you that will reveal who you are.

We may retain the de-identified interview transcripts for 'extended' use, meaning for use in future research projects. Specifically, we are seeking to retain the de-identified data from this project to contribute to an archive that could be used to research the history of HIV seroconversion in Australia. Data from this study will only be used for this purpose if ethics approval has been granted for the proposed research project.

The storage, transfer and destruction of your data will be undertaken in accordance with the Research Data Management Policy <https://policies.latrobe.edu.au/document/view.php?id=106/>.

The personal information you provide will be handled in accordance with applicable privacy laws, any health information collected will be handled in accordance with the Health Records Act 2001 (Vic). Subject to any exceptions in relevant laws, you have the right to access and correct your personal information by contacting the research team.

**9. Will I hear about the results of the study?**

You will be offered the opportunity to receive the annual summary reports. You can send an email to Jeanne Ellard [j.ellard@latrobe.edu.au](mailto:j.ellard@latrobe.edu.au) to request a copy of the summary report(s). Alternatively, you can request a copy of the summary report(s) by completing a form on the study's webpage <https://www.latrobe.edu.au/arcshs/xxxxxx>

**10. What if I change my mind?**

You can choose to no longer be part of the study at any time. You can let us know by:

1. Completing the 'Withdrawal of Consent Form' (provided at the end of this document);
2. Calling us; or
3. Emailing us.

Your decision to withdraw at any point will **not** affect your relationship with La Trobe University or any other organisation listed. If you withdraw, we will stop asking you for information. Any identifiable information, including the audio recorded interview, transcript and consent form will be withdrawn from the study. However, once the results have been published, we can only withdraw information such as your name. If results haven't been published, you can choose whether we use those results or not.

**11. Who can I contact for questions or want more information?**

If you would like to speak to us, please use the contact details below:

Name	Organisation	Position	Telephone
Dr Dean Murphy	Australian Research Centre in Sex, Health and Society, La Trobe University	Principal Investigator	(03) 9479 8717

**12. What if I have a complaint?**

If you have a complaint about any part of this study, please contact:

Ethics Reference Number	Position	Telephone	Email
HEC23423	Senior Research Ethics Officer	+61 3 9479 1443	<a href="mailto:humanethics@latrobe.edu.au">humanethics@latrobe.edu.au</a>

### Consent Form – Declaration by Participant

I (the participant) have read (or, where appropriate, have had read to me) and understood the participant information statement, and any questions have been answered to my satisfaction. I agree to participate in the study. I know I can withdraw at any time following the collection of my data. I agree information provided by me or with my permission during the project may be included in presentations, published in academic journals and websites, and in a report on the condition that I cannot be identified.

- I agree to have my interview audio recorded.
- I would like to receive a copy of the results via email or post. I have provided my details below and ask that they only be used for this purpose and not stored with my information or for future contact.
- I agree to have my interview data used for future studies that are closely related to this research project.
- I agree to be contacted for future, related projects.

Yes, participants will be provided with an option to have their interview data used for this study only and not future studies. I agree, we will seek consent to be contacted for future, related projects. We have added this option to the consent form.

Name	Email (optional)	Postal address (optional)

#### Participant Signature

- I have received a signed copy of the Participant Information Statement and Consent Form to keep

Participant's printed name	
Participant's signature	
Date	

#### Declaration by Researcher

- I have given a verbal explanation of the study, what it involves, and its risks. I believe the participant has understood
- I am a person qualified to explain the study, the risks and answer questions

Researcher's printed name	
Researcher's signature	
Date	

\* All parties must sign and date their own signature

### Withdrawal of Consent

I wish to withdraw my consent to participate in this study. I understand withdrawal will not affect my relationship with La Trobe University of any other organisation or professionals listed in the Participant Information Statement. I understand the researchers cannot withdraw my information once it has been published.

**I understand my information will be withdrawn as outlined below:**

- ✓ Any identifiable information about me will be withdrawn from the study
- ✓ The researchers will withdraw my contact details so I cannot be contacted by them in the future studies unless I have given separate consent for my details to be kept in a participant registry.
- ✓ The researchers cannot withdraw my information once it has been analysed, and/or collected as part of a focus group.

I would like my already collected and unanalysed data:

- Destroyed and not used for any analysis.  
 Used for analysis.

**Participant Signature**

Participant's printed name	
Participant's signature	
Date	

**Please forward this form to:**

Name	Organisation	Email	Telephone
Dr Dean Murphy Principal Investigator	Australian Research Centre in Sex, Health and Society La Trobe University Building NR6 Bundoora Victoria 3086 Australia	D.Murphy@latrobe.edu.au	(03) 9479 8717