Models of HIV Care Participant Information Statement and Consent Form for People Living with HIV

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 Thomas Norman	Australian Research Centre in Sex, Health and Society, La Trobe University
Co-investigator	Professor Graham Brown	Australian Research Centre in Sex, Health and Society, La Trobe University
Co-investigator	Dr Skye McGregor	Kirby Institute, University of NSW
Co-investigator	Professor Claire Vadjic	Kirby Institute University of NSW
Research funder	Medical Research Future Fund	

1. What is the study about?

This study is investigating understandings of HIV survivorship, and experiences of healthcare and quality of life for people living with HIV (PLHIV) including awareness and use of HIV shared care plans. The project will also investigate the role of HIV peer navigators in the healthcare management of PLHIV and the experiences of clinical service providers in delivering care to PLHIV.

Information gathered through this project will be used to improve HIV shared care in Australia and to optimise models of HIV care and support to equitably meet the diverse needs of PLHIV, HIV peer navigators and clinical care providers.

The Models of HIV Care project is part of a larger program of work, *Maximising survival and quality of life for people living with HIV in Australia*. The program is led by the Kirby Institute, University of NSW and funded by Medical Research Future Fund. This program of work was developed in partnership with the National Association of People with HIV Australia (NAPWHA), the national peak community organisation representing people living with HIV, Health Equity Matters, the national federation for Australia's leading HIV organisations and ASHM, the national organisation representing healthcare professionals in HIV, blood-borne viruses, and sexual and reproductive health.

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, The University of New South Wales or any other organisation collaborating with us.

3. Who is being asked to participate?

You are invited to take part in this research if you have been diagnosed with HIV, currently live in Australia and are aged 18 or over. The project aims to recruit 40 PLHIV.

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 60-minute semi-structured interview and complete a chain diagram (journey map) prior to the interview that will take you 30 minutes to complete. The interview will be conducted via a video conferencing platform such as Zoom. If you live in Sydney or Melbourne, you can also choose to do a face-to-face interview. The chain diagram will be sent to you via mail.

Interviews conducted via video conferencing platforms will be both audio and video recorded as the software in these platforms record 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 Rev.com will not receive a copy of the video file.

The focus of the interview will be on your health and quality of life since HIV diagnosis and your experiences of accessing healthcare. During the interview we will explore treatment history; comorbidities; experiences of clinical care (including shared care plans); understanding of HIV as a chronic illness; wellbeing and quality of life (physical wellbeing, social relationships, emotional wellbeing, functionality, and feelings about the future); resources and resilience; and understandings of survivorship.

Interview data will be supplemented by a chain diagram where we will ask you to plot three significant events related to HIV diagnosis, clinical care, and health and wellbeing on a timeline. We will send you the chain diagram to complete prior to the interview via mail. We will ask you to complete it prior to the interview. Once you have completed the diagram, we will ask you to use your phone to photograph it and then send it as an email attachment or text attachment to the interviewer. If you do not have access to a phone, we will provide you with a pre-paid envelope to return the diagram in. The diagram will supplement the interview by providing a visual representation of the significant events and experiences that have shaped your experience of living with HIV overtime.

You will not be offered the opportunity to review or edit your interview transcript, but the transcript will be based on the verbatim recording of the interview and will be an accurate account.

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 $60 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 improvements in HIV models of care with the aim of maximising the quality of life and health outcomes for the diversity of PLHIV in Australia.

6. What are the risks?

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 your quality of life, health and experiences of living with HIV over time. We have carefully crafted our questions to minimise the risk of distress to you, but there is

a chance that reflecting on these topics and 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 interview will be conducted by a qualified interviewer, with experience discussing potentially sensitive issues about HIV and they 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.

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

Beyond Blue
(Free national telephone support 24 hours/7 days a week)
Telephone 1300 224 636
Website 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

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

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

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 the research team for this project will have access to the project's raw data. We will use Rev.com 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.

Everything you say in the interview will be kept confidential. Any information gathered in the interview will be protected. 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.

8. How will my identity and privacy be maintained?

We will protect the confidentiality of the information we collect from you. We will 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 remove any contextual information that may identify any individual participants.

We will keep your consent form and contact details for 7 years after the project is completed. After this time, the documents will be destroyed.

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 information about publications based on the findings of the study including any publications that are available through open access or published through PLHIV community media. There are three ways in which you can access study outcomes:

1) Provide your contact details in the consent form to receive copies of any available publications or outputs.
2) You can send an email to Jeanne Ellard j.ellard@latrobe.edu.au to request that you are sent copies of available publications and outputs.

3) You can access study outcomes by completing a form on the study's webpage Models of HIV of care , Australian Research Centre in Sex, Health and Society, Our work, Blood-borne viruses and other stigmatised conditions, La Trobe University

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
HEC26340	Senior Research Ethics Officer	+61 3 9479 1443	humanethics@latrobe.edu.au

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 complete the chain diagram.
☐ 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 to send me any results of the research.

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 unless using verbal consent.

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, The University of NSW or 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 about future studies unless I have given separate consent for my contact details to be stored.
- ✓ The researchers cannot withdraw my information 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.

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