

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM (PISCF)

Positively Women: A research project using art to express what it means to be a woman living with HIV in Australia
Dr Allison Carter, Kirby Institute, UNSW

1. What is the research study about?

You are invited to take part in a community-based research study led by the Kirby Institute and collaborating research and community organisations. The aim of this study is to understand how the creation of images and narratives by women living with HIV about their lives, relationships, and sexual and reproductive health can empower and transform, both the women and those who view their work. The study has two stages. First, we will conduct an **online art workshop** with women living with HIV over Zoom, involving a range of reflective at-home activities like drawing, painting, meditation, gentle movement, and storytelling. Interviews will be conducted at the end of workshop. Second, the art produced in this workshop will be shared in a **public art exhibition** (and other publications). You must agree to both phases, and you will be consulted on how and where the artwork may be used. Our aim is for the project to help strengthen peer networks, support access to peer-to-peer art and information, and challenge stereotypes about HIV in society.

Your confidentiality, autonomy and wellbeing are important to us. Therefore, you will be encouraged to participate in this research at a level that is comfortable for you. In each stage of the research, you will be given the opportunity to identify the level of confidentiality you require and the amount of information about yourself you want to share publicly. For instance, you can remain anonymous by using an alias throughout the project and you can have the camera off during the workshop. You can change your mind about anything at any point.

2. Who is conducting this research?

The study is being carried out by the following researchers:

Principle Investigator: Dr Allison Carter, Kirby Institute, UNSW

Chief Investigators: Jane Costello, Positive Life NSW
A/Prof Christy Newman, Centre for Social Research in Health, UNSW
Dr Asha Persson, Centre for Social Research in Health, UNSW
Prof Katherine Boydell, Black Dog Institute, UNSW
Adjunct Prof Deb Bateson, Family Planning NSW

Research Manager: Dr Patricia Morgan, Kirby Institute, UNSW

Research Funder: Australian Government Department of Health

In partnership with a national Community Advisory Board:

Katherine Leane, President, Positive Life SA, Femfatales National Association of People with HIV Australia

Dr Kirsty Machon, Executive Director, and Heather Ellis, Positive Women Victoria

Sarah Feagan, Peer Navigator, Living Positive Victoria

Marcus Bogie, Manager HIV & Client Services, Meridian

Rebekah Lamb, Women's Care & Support Coordinator, Northern Territory AIDS & Hepatitis Council

Kim Oatley, Queensland Positive People

Diane Lloyd, Positive Organisation Western Australia

Jeanne Ellard, Senior Research Advisor, Australian Federation of AIDS Organisations

Michelle Tobin, Chair, Positive Aboriginal Torres Strait Islander Network

And others who wish to remain anonymous.

3. Am I eligible?

The research study is open to people who meet the following criteria:

- Woman (self-identified);
- Living with HIV (self-identified);
- 18 years of age or older;
- Living in Australia;

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- Able to communicate in English;
- Access to the internet and a computer or smartphone for videoconferencing;
- Willing and able to provide voluntary, informed consent.

No experience in art-making is required.

4. Do I have to take part in this research study?

Participation in this research study is voluntary. Before deciding whether or not to take part, please read this information carefully and ask us questions about anything that you do not understand or want to know more about. A member of the research team will talk you through what is involved before you sign up. If you decide you want to take part in the research study, you will be asked to:

- Provide consent for both phases of the project: 1) art workshop and 2) art exhibition.
- Keep a copy of this Participant Information Statement and Consent Form (PISCF).
- Participate in a way that is comfortable for you, including taking breaks if needed and not doing any activities that you find uncomfortable.

5. What does participation in this research require?

If you agree to take part in this research, you will be invited, along with 6-12 other women living with HIV, to participate in an online art workshop using Zoom. The workshop starts in October 2020 and runs across 5 weeks. You will have the option to attend a workshop during the week in the evening or during the day in the weekend; a group decision on a day and time will be made that most suits the participants. If for whatever reason you cannot attend the introductory workshop session, please let us in advance so that we can allocate your spot to a woman on the waiting list. For this workshop you will need access to the internet, a smart phone, tablet or computer, and a quiet space to work in. The workshop will be led by a professional artist, Patricia Morgan and co-facilitated by Jane Costello and Allie Carter, who have extensive experience in research and community-based advocacy with women living with HIV.

In the first four weeks, you will participate in a group art session, 3 hours weekly. In each session, you will be introduced to easy meditation and art practices such as drawing, pastels, photography, collage, colour mixing, mark making, and poetic writing. You will then spend some time working on your art (with Zoom running in the background so that we can stay connected as a group), using these techniques to express your thoughts and feelings about life with HIV, including your identity as a woman, your body, relationships, sexual and reproductive health, and the society in which you live. Art practices will be scaffolded starting with simple exercises and building up to more complex practices. Each session will also include reflection, storytelling, and group discussion. This will lead to the creation of a meaningful final artwork, expressing significant aspects of your life.

Across the first four weeks of the workshop, you will be asked to keep a visual diary of your experiences to capture symbols, personal imagery, photography, and free-flowing reflection.

You will also be asked to share your thoughts and experiences with fellow participants on a private Facebook group between each session, and to send pictures of your art to the research team (email: positivelywomen@kirby.unsw.edu.au). If you do not have Facebook or prefer not to use it, that is okay; you will also have a chance to speak about your work during each Zoom call.

At the end of the workshop, in week 5, you will be invited to participate in a semi-structured individual interview lasting 60 minutes over Zoom or via phone to understand your experiences of the workshop and your analysis of the imagery you create.

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The results of this workshop that you are happy to share publicly (e.g., the artworks you create, the documentation of your experiences, photographic and video images, segments of interviews and discussions) will be appear in art exhibitions and other publications. The art exhibitions may occur through an online project website and/or in-person at a community art gallery. The other publications (some of which are pending funding) may include: research and community publications, a project website, a proposed book, social media and news media, and educational material for similar workshops with other communities. As mentioned, you will decide the level of privacy and confidentiality you are comfortable with. You will also decide whether to have your work published or displayed. Please keep in mind that it will not be possible to withdraw an image from say a published book or article.

Other important information about your participation in this research:

- You can refuse to have your artworks, stories, and images exhibited, answer any questions, or withdraw from the study at any time.
- The workshop sessions and semi-structured interviews will be video- and audio-recorded using Zoom. The facilitators will also take field notes. This is important to ensure accurate data collection and analysis. Only the person who hosts the meeting (i.e. the facilitator) is able to download the recordings by using their UNSW staff number and password.
- There are parts of the workshop where you will be taking photographs – for these parts, you may choose to work with a friend who understands the issues of confidentiality in this project who can help you document your work with photography and/or video. However, do NOT allow anyone to be around you during the group discussions and interviews to ensure confidentiality and privacy for all participants.
- Confidentiality is an important aspect of this research study. Thus, for any public-facing activities like art exhibitions, you will be offered the opportunity to contribute anonymously and use a graphic to represent yourself, or to use your real name and photo. Your level of confidentiality is completely your choice. Please respect others' confidentiality during and after the workshop as well, by not discussing anything that happens in the workshops with people outside of it.
- Art materials will be posted to you for your use in this research study. Personal computers, smartphones, and internet access are not provided. We will also provide pre-paid postage for you to mail your artworks to the research team who will have them temporarily so they can be documented and used in the art exhibitions and publications. When this is done, your artworks will be returned to you.

6. Are there any risks involved?

The meditative and creative practices in the workshop can be enjoyable, healing, and useful for gaining self-awareness, though it is possible that you may become upset or find that the discussions are stressful or embarrassing. If you experience discomfort or any feelings of distress while participating in the research, you can stop participating at any time. You can access support by contacting a member of the research team. A peer support worker and two psychologists will be on-call and can be accessed directly by you or via a member of the research team. Their contact details are on page 6. Alternatively a list of support services are provided on pages 6 and 7.

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There are also potential risks to sharing your stories and artwork in exhibitions and publications. For example, viewers may post negative comments, or if you share a story with your real name it may impact on your personal or professional life. It is completely your choice if, how, and what you share. We encourage every woman to consider six questions before sharing their story publicly: 1. Why do you want to share your artwork or stories? 2. What might happen to it? 3. Who might see it? 4. How would you feel if your family, friends, partners, or colleagues read it? 5. Could it hurt you now or in the future? 6. How will you feel about having shared it in a day? A year? 10 years?

There can be a risk when working online that confidentiality can be compromised. Because of this you will be given the opportunity to use an alias throughout the course of the workshop. The workshop will start with participants being asked to commit to maintaining confidentiality in and after the workshop and this forms part of the informed consent process. The online platforms used for this online workshop (Zoom and private Facebook chat) are private and secure, and only participants and workshop facilitators will have the permissions needed to access the platform and therefore anything that is shared online. Your safety and wellbeing matters to us. We will continue to discuss any concerns or questions you have throughout the process, and to debrief and support one another.

7. What are the possible benefits to participation?

There are several benefits of participating in this study. Firstly, the mediation and art practices in the online art workshop can be enjoyable and provide heightened self-awareness and understanding. It is possible that some participants may even wish to continue these practices after the project (there are many free meditation resources to assist with this such as insighttimer.com). Secondly, spending time with a group of peers offers the opportunity to share feelings and experiences and strengthen your support networks and friendships. Thirdly, a professional artist will facilitate the workshop and help you gain new art skills. Fourthly, your artworks will provide positive and empowering images of living with HIV, which through their public exhibition can offer new ways for individuals and organizations to understand women's lives, relationships, experiences and HIV. Finally, you will get to keep your artworks after the exhibition. In addition to these main benefits, you will be provided with an honorarium of \$200 when you have finished the 5-week workshop in recognition of your time and participation.

8. What will happen to information about me?

By signing the consent form, you agree to the research team collecting and using the information you provide for the research study. As a reminder, this includes the artworks you create, the documentation of your experiences, photographic and video images, segments of interviews and discussions. These will appear in art exhibitions and other publications (in person and online).

Screening forms, consent forms, and audio-files of your verbal agreement to participate in this study will be stored in a locked filing cabinet in a secure location at the Kirby Institute. The artwork that you send to us will also be stored on the secure premises of the Kirby Institute – they will be kept in a separate locked filing cabinet, unconnected to the consent forms.

Research data (e.g. audio and video recordings, photography, documentation, field notes, and images of your artwork) will be stored in UNSW OneDrive. This is a secure, password protected, storage platform. It is only accessible to the approved research investigators. In accordance with ethics guidelines for human research, all information will be stored for a minimum of 5 years after the completion of the research.



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The artwork you create is owned by you, but the Kirby Institute retains the right to be the first organization to exhibit or publish (materially or virtually) the stories and artwork, without charge, in the exhibitions/publications, in print or online. However, you as the creator of the artwork retain all rights and ownership over the artwork and can exhibit or republish it elsewhere after the Kirby Institute has published it. We simply ask that you do so AFTER the exhibitions/publications have been completed.

The information you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further information on how the University protects personal information is available in the UNSW Privacy Management Plan: <https://www.legal.unsw.edu.au/compliance/privacy/mgtplan.html>

9. How and when will I find out what the results of the research study are?

With your permission, you will be informed via email about the results of the research study, including exhibitions of your artworks, publications, and a possible book and website. If you would like to be notified of these activities and outputs, please let us know by inserting your email or postal address in the consent form. We will only use these details to inform you the results of the research.

10. What if I want to withdraw from the research study?

You may withdraw from the research study at any time. You can do so by completing the 'Withdrawal of Consent Form' at the end of this document or you can call or email the project's Research Manager (Patricia Morgan) or Chief Investigators (Allison Carter, Jane Costello) using their contact details below to tell them you no longer want to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney or any of the organisations involved in this research. If you decide to leave the research study, the researchers will not collect additional information from you. You can request that any identifiable information about you be withdrawn from the research project. We will delete all information that has been collected from you up to that point, unless you say that you want us to keep it. However, as some group discussions in the workshop will also be documented, and as they are interactive in nature (i.e. what a participant says may affect how other participants respond in the discussion), you have to be mindful that it will not be possible to delete individual responses from the discussion. It will also not be possible to remove material that is already published.

11. What if I have a complaint or any concerns about the research study?

If you have a complaint regarding any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

Position	UNSW Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
HC Reference No.	HC200344

12. What should I do if I have further questions about my involvement in the research study?

If you have further questions regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

Name	Patricia Morgan
Position	Research Manager

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Telephone	+61 2 9385 9018
Email	p.morgan@unsw.edu.au
Name	Allison Carter
Position	Chief Investigator
Telephone	+61 2 9385 9018
Email	acarter@kirby.unsw.edu.au
Name	Jane Costello
Position	Chief Investigator
Telephone	61 2 92062177
Email	janec@positivelife.org.au

13. If at any stage during the project you become distressed or require additional support from someone not involved in the research, please call:

For counselling support:

Ruth Hennessy
Psychology Unit Manager/Senior Clinical Psychologist
[The Albion Centre, 150 Albion Street Surry Hills NSW 2010](#)
Email: Ruth.Hennessy@health.nsw.gov.au
Ph: 9332 9645

Shiraze Bulsara
Senior Clinical Psychologist
[The Albion Centre, 150 Albion Street Surry Hills NSW 2010](#)
Email: Shiraze.Bulsara@health.nsw.gov.au
Ph: 9332 9646

Katherine Leane
Peer Counsellor
President, Positive Life SA
Femfatales National Association of People with HIV Australia
Email: katherineleane@gmail.com
Ph: 0410 707 923.

Community resources:

Organisation 1	Beyond Blue
Telephone	1300 224 636
Website	http://www.beyondblue.org.au/
Organisation 2	Mental Health Access Line
Telephone	1800 011 511
Website	http://nswlhd.health.nsw.gov.au/about/mental-health-services/
Organisation 3	1800RESPECT (domestic violence and sexual assault counselling)
Telephone	1800737732 (toll free)

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Website	https://www.1800respect.org.au/
Organisation 5	ACON Counselling Services (for LGBTIQ+ people)
Telephone	1800 063 060 (toll free)
Website	http://www.acon.org.au/lgbti-health/mental-health/#lgbti-counselling
Organisation 6	Positive Life NSW
Telephone	02 9206 2177
Website	https://www.positivelife.org.au/
Organisation 7	Positive Life SA
Telephone	0410 707 923
Website	http://www.positivelifesa.org.au/
Organisation 8	Positive Women Victoria
Telephone	(03) 9863 8747
Website	https://positivewomen.org.au/
Organisation 9	AIDS Action Council of the ACT
Telephone	(02) 6257 2855
Website	https://www.aidsaction.org.au/
Organisation 10	Northern Territory AIDS & Hepatitis Council
Telephone	Darwin: 08 8944 7777; Alice Springs: 08 8953 3172; Palmerston: (08) 8931 3676
Website	https://www.ntahc.org.au/
Organisation 11	Queensland Positive People
Telephone	(07) 3013 5555
Website	https://www.qpp.org.au/
Organisation 12	Positive Organisation Western Australia
Telephone	0431905338
Website	http://positivewa.org/
Organisation 13	Positive Lives, Tasmania
Telephone	0478 909 949
Website	https://positivelivestasmania.org.au/
Organisation 14	QLife (for LGBTIQ+ people)
Telephone	1800 184 527
Website	https://qlife.org.au

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Consent Form #1 – Online Art Workshop

Please note that you can change your mind through the course of the research study and revise your consent form. To do so, please contact the project's Research Manager (Patricia Morgan) or Chief Investigators (Allison Carter, Jane Costello) using the contact details on page 5.

Declaration by the participant

I understand that:

- I am being asked to participate in an online art workshop and exhibition. The purposes, study tasks, data collection and risks of this project have been clearly explained to me.
- My participation in the art workshop will be documented through audio, video, photography, art works, and interviews and groups discussions (all of which are now known as 'materials' of the workshop).
- Some of the materials of the workshop will be shared with my permission in art exhibitions (online and in-person) and other publications including research and community publications, a website proposed book, social media and news media, and educational material for similar workshops with other communities (all of which are now known as 'outputs' of this research study).
- I will be given an opportunity to review any imagery, text, video or audio that identifies me and make corrections before these materials are shared publicly in the research study's output. I will not be asked to review non-identifying information.
- I am free to withdraw consent for the use of my artwork, images of me, sections of my interview in the research study's outputs. However, this has limits (for example, an already published book). Withdrawing consent will not affect my relationship with any of the named organisations and/or research team members.
- I own the artworks I create but the Kirby Institute retains the right to be the first organization to exhibit or publish them, without charge, in the research study's outputs. As the creator of my artworks, I retain all rights and ownership over them and can exhibit or republish them elsewhere after the Kirby Institute has exhibited/published them.
- Confidentiality in this workshop is important. I commit to keeping all information shared in the course of the workshop and exhibition confidential.
- I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or team members. However, data that has already been used in a publication will not be able to be removed.
- I have read the Participant Information Statement and Consent Form, or someone has read it to me in a language that I understand.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I agree:

- To participate in this research study as described.
- To have my artwork and stories collected for the purpose of this research study as described.
- To be audio and video recorded for the purposes outlined above.
- To keep all personal or identifying information shared with me by other participants in the course of this research study confidential.
- To use my real name and images of me in the research study's outputs OR contribute anonymously and use a graphic to represent myself (**please circle one**).
- To being given a copy of this document to keep.
- To be notified about exhibitions and publications via email, phone or postal address. I have provided



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my contact details below and understand that they will only be used for this purpose.

Email: _____

Phone: _____

Postal address: _____

Participant Signature

Name of Participant (please print)	
Signature of Research Participant	
Date	

Please note: Because this study is online, we will record verbal consent over the phone and complete the written form on your behalf, recording date, time, and who has recorded it. We will keep these brief audio files as evidence of consent, in an encrypted folder. These will be stored separately from research data files to protect your confidentiality. Thus, a signature is not required. We will email and/or mail a hard copy of this form with the art materials to you before the workshop so that you have a copy.

Declaration by Researcher*

I have given a verbal explanation of the research study; its study activities and risks and I believe that the participant has understood that explanation.

Researcher Signature*

Name of Researcher (please print)	
Signature of Researcher	
Date	

*An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study.



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Consent Form #2 – Exhibition and Publication of Artwork

Declaration by the participant

- I grant the Kirby Institute and those acting with the Kirby Institute’s authority and permission, the right and permission to use and publish my artwork, stories, and images collected through the online art workshop in the project outputs below:
 - Art exhibitions
 - Research and community publications
 - Project website
 - Social media and news media
 - Book
 - Educational material
- I am aware that these exhibitions and publications are accessible to the general public. I understand that they may be disseminated across Australia and, possibly around the world, in print and on the Internet.
- I understand that I will be given an opportunity to review any imagery, text, video or audio that identifies me and make corrections before these materials are shared publicly. I will not be asked to review non-identifying information.
- I own the artworks I create. However, I agree that the Kirby Institute retains the right to be the first organization to exhibit or publish my artworks, without charge. There will be no payment to me for this material. As the creator of my artworks, I retain all rights and ownership over them and can exhibit or republish them elsewhere after the Kirby Institute has exhibited/published them.
- I understand that I can refuse to consent, or withdraw consent, if I am not comfortable with a proposed use of the art.
- I have read all of the information in this document and agreement, and I confirm that I fully understand it.

Participant Signature

Name of Participant (please print)	
Signature of Participant	
Date	

Please note: Because this study is online, we will record verbal consent over the phone and complete the written form on your behalf, recording date, time, and who has recorded it. We will keep these brief audio files as evidence of consent, in an encrypted folder. These will be stored separately from research data files to protect your confidentiality. Thus, a signature is not required. We will email and/or mail a hard copy of this form with the art materials to you before the workshop so that you have a copy.



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Declaration by Researcher*

- I have given a verbal explanation of the research study; its study activities and risks and I believe that the participant has understood that explanation.

Researcher Signature*

Name of Researcher (please print)	
Signature of Researcher	
Date	

*An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study.



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Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales and any institutes involved in the study. If required see Point 10 of this document for further information. You may also withdraw consent by calling this project's Chief Investigator Dr Allison Carter on 02 93850900.

Participant Signature

Name of Participant (please print)	
Signature of Research Participant	
Date	

The section for Withdrawal of Participation should be forwarded to:

Chief investigator:	Allison Carter
Email:	acarter@kirby.unsw.edu.au
Phone:	61 2 9385 0900
Postal Address:	Kirby institute, Wallace Wurth Building, UNSW Sydney