



Positively Women

A RESEARCH PROJECT USING ART TO EXPRESS WHAT IT MEANS TO BE A
WOMAN LIVING WITH HIV IN AUSTRALIA

Participant Guide | October 2020

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1. WELCOME LETTER

On behalf of the entire team, we warmly welcome you to 'Positively Women: A research project using art to express what it means to be a woman living with HIV in Australia.'

Our aim with this project is to help strengthen peer networks, support access to peer-to-peer art and stories of lived experience, and challenge stereotypes about women and HIV in society. We are excited to collaborate with you on these goals.

For this workshop, you will need access to the internet, a smart phone, tablet or computer, and a quiet and confidential space to work in. Everything else that you will need is provided in this package.

Included in this package is:

- Participant guide, including the consent form that you have already completed verbally via phone
- Art design kit, including a visual diary to reflect on your experiences throughout the workshop
- Visual library, which provides ideas of artistic techniques you may wish to try
- Stamped addressed envelope for mailing us your artworks

At the end of the workshop, you will choose which artworks and visual diary entries you want to send us for the exhibition and post it to us in the stamped addressed envelope. We 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. Here is our address for mailing purposes:

Attn: Patricia Morgan
UNSW Mail Centre
Mathews Building F23 Dock
Gate 11, Botany Street,
Kensington, NSW 2033

Please feel free to phone or email us at positivelywomen@kirby.unsw.edu.au at any time with questions and for support and guidance. We greatly look forward to getting to know you better and to working with you on this project.

Warmly,

Patricia, Allie, & Jane

2. OVERVIEW

2.1 TWO PARTS TO THE WORKSHOP

The art workshop will begin in October (the date/time will be determined by group consensus and the schedule will be provided to you via email).

The workshop is online and has two parts:

- 1) Four 3-hour group art and discussion sessions on Zoom that run every week for 4 weeks. Each session will include gentle meditative art practices and group discussions.
- 2) On the 5th week, there will be a 1-hour interview with each participant on Zoom. This will be about your life with HIV, your artworks, and your experience of the workshop.

In the week before the workshop begins, we will have a **‘Welcome and Q&A’ meeting**. This will include an introduction to the workshop and each other, the creation of group guidelines, and a chance to ask questions. It will also allow everyone to become familiar with Zoom before we begin.

These activities will be led by a professional artist, community developer and academic, 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.

It is important that everyone tries their best to attend all sessions so that we can support one another, build a strong community, and progress in the art practices at the same time. If you think you may have to miss a session, please let us know in advance.

2.2 MAIN POINTS TO KEEP IN MIND

Being Comfortable: One of the most important aspects of this workshop is that you are comfortable. While we encourage you to do the practices as we present them, please feel free to change them so you are comfortable, and if you like to experiment and be creative. Please set up the space you are going to work in so that it is comfortable and private. If you feel as though you need a break at any time during the workshop sessions, please take one. Or if you are feeling uncomfortable in the sharing circles, please feel free to say you do not want to share – simply say something like ‘pass’ when it is your time to share. If you start to feel uncomfortable during a session, please take a break and come back when you feel ready. Also, just do the practices as best as you can without feeling as though you have to push to achieve something beyond what is comfortable for you.

Debriefing and support: If you feel uncomfortable or distressed during the workshop, please let the facilitator know by typing a private message in the Zoom chat function. You will then have the option to move into a private online room to speak with a facilitator and/or leave the session. Then, when it is convenient for you, there is: a peer support person, 2 psychologists and support services who you can contact for help (their contact details are in section 2 as well as in the consent form).

Process art: The art-making you’ll experience in the workshop is Process Art. As it sounds, this is about the process of art-making - that is what you feel and understand as you make the art, rather than producing a particular kind of art ‘product’.

Gentle meditation and movement practice: We will be doing these types of practices in the workshop. Please feel free not to do them or modify them in a way that suits you, though we encourage you to try them, as being in calm gentle meditative state will help with your art-making.

Remaining Non-judgmental: It is important that you do the practices 'just as best as you can' – directed by your inner voice and feelings. Pushing or striving for something you think you should be doing, and self-judgement can get in the way. As best as you can, please let go of any ideas you have about art making and what it means to be an artist. You also may like to watch this 19 minute video on self-compassion before the workshop starts: <https://www.youtube.com/watch?v=IvtZBUSplr4&t=154s>

3. CONTACT LIST

3.1 RESEARCH TEAM

The general study email is positivelywomen@kirby.unsw.edu.au

To contact us directly:

Researcher Manager	Patricia Morgan, Kirby Institute, UNSW Sydney
Telephone	+61 448 801 929
Email	p.morgan@unsw.edu.au
Principle Investigator	Allie Carter, Kirby Institute, UNSW Sydney
Telephone	+61 2 9385 9018
Email	acarter@kirby.unsw.edu.au
Chief Investigator	Jane Costello, Positive Life NSW
Telephone	+61 2 9206 2177
Email	janec@positivelife.org.au

3.2 COUNSELLING SUPPORT

It is important for participants and team members to reach out when they need support. If at any stage during the project you become distressed or require additional support, please feel free to contact the individuals and organisations below.

To speak with a psychologist, contact:

The Albion Centre (150 Albion Street Surry Hills NSW 2010) via phone ([02 9332 9600](tel:0293329600)) or email (reception@thealbioncentre.org.au). You can request to speak with either: Ruth Hennessy or Shiraze Bulsara, Senior Clinical Psychologists.

Available: 9:00am-6:00pm during weekdays. Please say that you are with the Positively Women study. Both Ruth and Shiraze are aware of the study. If they are not available, the call will get through to their intake psychologist and they will decide whether to wait for them or to potentially speak with you themselves. Please be aware that sometimes the intake psychologist won't be a woman.

To speak with a peer counsellor, contact:

Katherine Leane
Femfatales National Association of People with HIV Australia
President, Positive Life SA
A woman who has been living with HIV for 33 years
Email: katherineleane@gmail.com, Phone: [0410 707 923](tel:0410707923)

Available whenever needed, including weekends. Kath may have to ring back up if she misses your call. Over the 5 weeks of the project, she will touch base with each woman, just to connect and see how you are going.

All conversations with counselling support are confidential.

3.3 COMMUNITY RESOURCES

Organisation 1	Lifeline
Telephone	Call 13 11 14 (all hours) or Text 0477 13 11 14 (12pm to 12am AEST)
Website	https://www.lifeline.org.au/131114/
Organisation 2	Beyond Blue
Telephone	1300 224 636
Website	http://www.beyondblue.org.au/
Organisation 3	Mental Health Access Line
Telephone	1800 011 511
Website	http://nswlhd.health.nsw.gov.au/about/mental-health-services/
Organisation 4	1800RESPECT (domestic violence and sexual assault counselling)
Telephone	1800737732 (toll free)
Website	https://www.180orespect.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 LGBTQIQ+ people)
Telephone	1800 184 527
Website	https://qlife.org.au

4. SAFETY AND WELLBEING

4.1 THE POWER OF STORYTELLING

There are a lot of benefits of storytelling through art, from enhancing creativity and connection to igniting social change in the world.

This project is designed to create empowering stories about what it means to be a woman living with HIV in Australia. We hope that this workshop enables you to learn more about your health and relationships, gain insight from the experiences of other women, and advocate for social change.

Our work is very much focused on bettering the lives of women living with HIV, including their freedom to determine their own physical, mental, sexual and reproductive health and happiness, not constrained by social and cultural mandates.

In creating your own stories through art, you are able to represent your own experiences. This can have a powerful effect on yourself and on our communities.

4.2 MINIMIZING RISKS

While sharing stories and imagery about living with HIV with others can be healing and inspiring, it can also be challenging and have unintended impacts on our health and well-being. Participating in this research may bring up strong emotions, such as anger, hurt, trauma, and frustration.

Sharing your art work online also brings certain risks with it. We might regret sharing something or encounter negative and unpleasant comments. Sharing things online comes with additional concerns around privacy, confidentiality, and the fact that what we post online is available to others forever.

Bearing this in mind, we will do our best to minimize any risks associated with this research study. We take very seriously our responsibility to ensure that all participants and team members are doing well, have full power and control over their participation, and are treated with respect and dignity.

4.3 PROMOTING SAFETY AND WELLBEING

- a) **You have autonomy:** It is completely your choice if, how, and what you want to share.
- b) **Participation is voluntary:** It is important to recognize that sharing and publishing narratives and images is 100% voluntary and at any time you can request to remove your work from this research project and any art exhibitions.
- c) **Consent is an on-going process:** We think of consent as a process that occurs in repeated steps and over time. At the start of the project, you must review and agree to the information contained within two consent forms: one to participate in the art workshop (including group discussions and individual interviews), and another related to the exhibition of workshop documentation and the images participants create (and other publications). These forms provide a plain language description of the project and the risks of sharing images and narratives. Only after you are fully informed about the research and have agreed to participate will we proceed with the research activities. Throughout the research, you will be reminded that all activities are voluntary, you do not

have to answer any questions or complete any activities that make you feel uncomfortable. You are also welcome to stop participating at any time.

- d) **Communication is essential:** You will participate in weekly Zoom sessions throughout the course of the art workshop to facilitate communication, debriefing, and support. As part of these sessions, we will regularly engage in reflexive discussions about all aspects of the project, consistent with our views of consent as a process.
- e) **Confidentiality is paramount:** You can choose to use your real name and imagery that identifies you in the exhibition, or to be anonymous. Personal information will not be published or shared with others without expressed written consent.
- f) **Personal check-ins and self-care are valued:** We fully support and encourage you to engage in personal check-ins and self-care throughout the life of the project.
- g) **Self-care during, between, and after the workshop is important:** If at any time you feel upset during the workshop please just stop what you are doing and take some time out. You might like to let the facilitator know by using the chat function in Zoom that you are taking a break or that you would like to go into a private breakout room and speak with one of the facilitators. We understand that may already have many techniques you use to calm and support yourself such as breathing and meditative practices and please use these whenever you need to.
- h) **Mental Health Support and Resources are available** (please see our list of supports).

4.4 OTHER TIPS FOR PROTECTING OURSELVES ONLINE

- You can share images and narratives anonymously. If you do, it is very important that you review every name, word, scenario, etc., for anonymity.
- Ask yourself: Why do I want to share my story? 2. What might happen to it? 3. Who might see it? 4. How would I feel if my family, friends, partners, or colleagues read it? 5. Could it hurt me now or in the future? 6. How will I feel about having shared it in a day? A year? 10 years?
- Ask yourself: What do I feel comfortable sharing? What do I NOT feel comfortable sharing?
- Ask yourself: Do I prefer to be anonymous versus disclose my identity?
- Reflect on what you feel comfortable sharing before you write/make art.
- Spend time with your images and thoughts. Reflect on them before sharing.
- Think about your audience: How will different readers, with different views, interpret this?
- Create boundaries. If something does not feel right, feel free to stop or seek support at any time.
- Debrief difficult experiences with a member of our team, close friend, or counsellor.
- For any art exhibitions, whether in-person or online, we will have community guidelines that encourage supportive comments.

5. ZOOM

5.1 LOGGING INTO ZOOM

We will be using Zoom over the course of the art workshop. If you don't already have Zoom, it is free software that allows you to have video calls with anyone in the world.

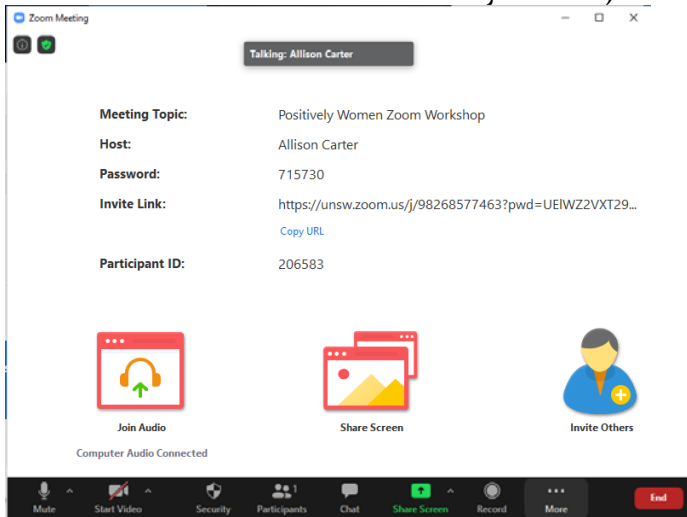
Before the workshop begins, please download Zoom here: <https://zoom.us/download> Click on the **Download** button under “**Zoom Client For Meetings.**”

Then all you need to do is click on the link below and enter a password (we will provide this link to you in email). Please do this a few minutes before the session starts as it can take time for Zoom to open.

Link: <https://unsw.zoom.us/j/98268577463?pwd=UElWZ2VXT29MYXlpUk5RNVZYMEdSUT09>
Password: 715730

This link will be the same for each week. Please do NOT share this link with other people.

Here is what it Zoom looks like when you have joined the meeting:



5.2 HELPFUL HINTS FOR USING ZOOM

Communicating on Zoom is different than communicating in person and here are some hints to help with that:

- If you hover your mouse at the bottom of the Zoom screen you will see a number of different icons that you can use; for example the chat button is there and icons for video and sound that you can turn on and off.
- Please mute yourself when you're not speaking as background noise can be distracting. Hover your mouse at the bottom of the Zoom Screen and you will see a little microphone icon, just click on that.
- There is a chat function in Zoom that you can use for a number of different reasons for example you can use it to let the facilitators know if you need to take a break. If you hover your mouse at the bottom of the screen you will see the chat, when you see it just click on it and a side panel on the right of the screen will appear. You have the choice to type in a message to everyone, or just to one person which others won't see

WEEK 2

Theme: *What Sustains Me, What Gives Me Pleasure and Strength?*

Overview: Week Two involves drawing and painting using photographs that describe what sustains you and gives you pleasure and strength. You started on this before the workshop by sending us photos.

Time: 3 hours

Agenda:

- Welcome and acknowledgement of country (5 mins)
- Storytelling circle where we talk about our experiences and the week between (30 mins)
- Art practices (110 mins)
- Group discussion about our artwork, the workshop & time to ask questions (20 mins)
- Brief introduction to next week's practices (5 min)
(There will be two 5 min breaks during the Zoom session.)

Art practices:

- Prior to this session, you were asked to take photographs to represent what sustains you and gives you strength and pleasure. You sent them to us to photocopy in different sizes and we have sent them back to you in time for this session.
- The practice will start with a gentle breath focusing practice and then move into working with the photographs you have taken and the Visual Library (see page 38, simplifying images).
- You will also be introduced to a design practice where images are simplified. This symbolic imagery will be used along with your photographs to create three works about: *What Gives Me Strength and Pleasure and What Supports Me In My Life*.
- The practice ends with poetic writing about the practice and your experiences.

Before the session, please remember to:

- Follow the general instructions on page 13, '6.3 Preparing for the workshop each week'
- Before the session begins, please prepare two large sheets of paper (size A3) by drawing grids on them using a ruler and graphite pencil (not the white one). You will be gluing your photographs onto these pages and the grid will help you place the pictures evenly. Pencil your grids lightly, as you may want to rub the lines off when finished. **See page 16 for 'instructions for drawing grids.'** If these instructions are unclear, feel free to email us or wait for the workshop.

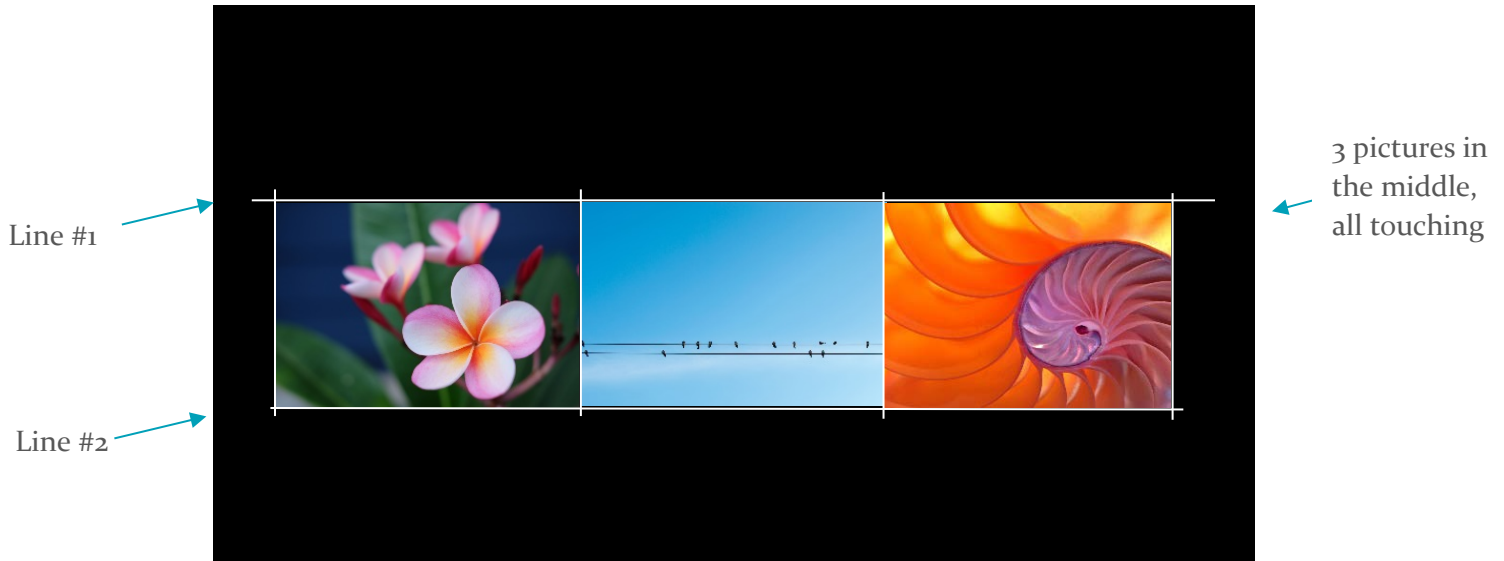
After the session, please remember to:

- Finish any of your artworks
- Work in your visual diary
- Share your art work and experiences via our Private Facebook group

Instructions for drawing grids:

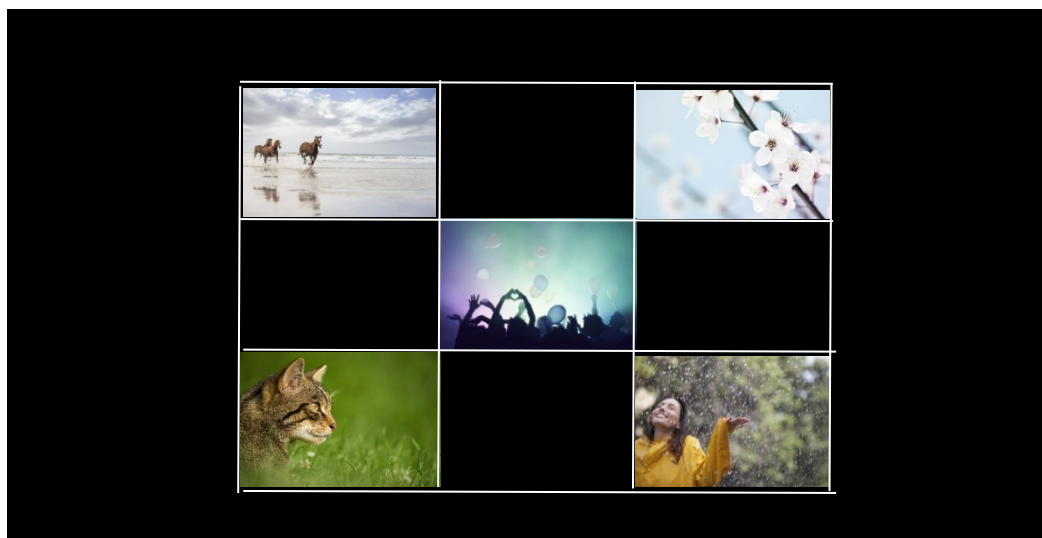
Get one large piece of black paper (size A3):

- This will be for your 3 middle sized photographs that represent pleasure, strength and support.
- Draw a 6-box grid with your pencil with two lines at the top and bottom - the space in-between the lines needs to be big enough to hold the middle-sized photocopies.
- Once your lines are drawn, place the 3 middle-sized photographs on the page so that the images are butted together – i.e., there are spaces top and bottom but no spaces between the images.
- During the workshop, you'll glue the photos to the page & erase the pencil markings.



Get a second large piece of paper (size A3) - this could be black or white, whichever you prefer:

- This will be for your 5 smallest photographs that represent pleasure, strength and support.
- Draw a 9-box grid with your pencil - the space in-between the lines need to be big enough to hold the 5 smallest photographs.
- During the workshop, you'll glue the photos to the page & erase the pencil markings.



WEEK 3

Theme: *Re-Working Imagery from the Past*

Overview: Week Three focuses on images from the past and on ways to rework this imagery in the present. You started on this before the workshop when you spent time reflecting on the past to choose images from the time of your diagnosis. There is a tradition of reworking imagery to comment on it, for some artists this has been about highlighting social and political issues including racism and sexism. There are examples of this in the Visual Library starting on Page 70. On page 71 you will see two photographs, one of an aboriginal man taken in the early 20th century and the aboriginal and queer artist Brook Andrews' reworking of that image. The original photograph would have been postcard size and sold to tourists. Andrews blew the image up so that the viewer confronts this man one-on-one, rather than holding the image in their hand. Andrews added Mandarin words that translate as something like: 'Mischievous girl', he added color, painted out the background and broke the image down. He has also given his art work the title "Sexy and Dangerous". There are a number of layers to this art work with for example the breaking down of the image, which fragments the aboriginal man's body suggesting the brutal history of colonialization. In the works by Betty Tompkins, on page 72 of the Visual Library, derogatory words often used about women are repeatedly written over famous paintings of women to comment on sexism. In Week Three you will be using these ideas to rework the images you have chosen to comment on the ways HIV has been depicted or the ways it has impacted you.

Time: 3 hours

Agenda:

- Welcome and acknowledgement of country (5 mins)
- Storytelling circle where we talk about our experiences and the week between (30 mins)
- Art practices (110 mins)
- Group discussion about our artwork, the workshop & time to ask questions (20 mins)
- Brief introduction to next week's practices (5 min)
(There will be two 5 min breaks during the Zoom session.)

Art practices:

- Prior to this session, you will be asked to identify and send us images from the past related to HIV that are meaningful for you. These images should express something about the early days of your diagnosis, how you felt, what you saw and so on. These may be photographs of you from around the time you were first diagnosed, or images/posters you saw in health clinics you attended or images you saw on TV, in the media, in popular culture, or art works.
- In this week's session you will be introduced to design ideas regarding the manipulation of imagery, and how such manipulation provides a means to critique that imagery.
- In this session you will also be able to use the imagery of nature, animals and mythical beings that you worked with in Week Two, and then incorporate into a final drawing, painting or collage.
- The practice ends with poetic writing about the practice and your experiences.

Before the session, please remember to:

- Follow the general instructions on page 13, '6.3 Preparing for the workshop each week'

After the session, please remember to:

- Finish any of your artworks
- Work in your visual diary
- Share your art work and experiences via our Private Facebook group

WEEK 4

Theme: *Bringing it Altogether to Create a Meaningful Self-Portrait*

Overview: In Week Four, you will reflect on what you have done in weeks 1-3 to create a self-portrait. As you will see from the examples of self-portraits in the Visual Library, starting on page 84, there are many ways for you to do this, from semi-realistic to abstract. You will be using color and mark making, symbols created from simplifying images, poetry and using words as a part of image making, ideas and images from the photographs you took in Week Two, reflections, sketches and words from your visual diary and ideas from Week Three where you reworked imagery. If you have the time you may like to do some sketches or writing about the self-portrait you'll create before the Week Four session.

Time: 3 hours

Agenda:

- Welcome and acknowledgement of country (5 mins)
- Storytelling circle where we talk about our experiences and the week between (30 mins)
- Art practices (110 mins)
- Group discussion about our artwork, the workshop & time to ask questions (20 mins)
- Brief introduction to the 1-on-1 interviews to be conducted next week (5 min)
(There will be two 5 min breaks during the Zoom session.)

Art practices:

- We will gather all of our artworks from the previous sessions and starting with a gentle breath focused exercise spend time reflecting on what each of us has done.
- This will then lead to an extended practice where you use elements of your previous work and any medium you like to work with to create an abstract self-portrait.
- The practice ends with poetic writing about the practice and your experiences.

Before the session, please remember to:

- Follow the general instructions on page 13, '6.3 Preparing for the workshop each week'

After the session, please remember to:

- Finish any of your artworks
- Work in your visual diary
- Share your art work and experiences via our Private Facebook group

WEEK 5

In the week following the workshop, at a time that is convenient for you, we will do a one-hour one-on-one interview. In this interview, via Zoom, we will discuss your life with HIV, your artworks, and your experience of the workshop.

Please also remember to mail us your artworks and visual diary using the stamped addressed envelope that we provided in your package. We 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. Here is our address for mailing purposes:

Attn: Patricia Morgan
UNSW Mail Centre
Mathews Building F23 Dock
Gate 11, Botany Street,
Kensington, NSW 2033

What happens after week 5?



We hope to share the art works and stories created this workshop in a public art exhibition and other publications, as outlined in the consent form. We are currently working to secure funding for this. Before anything is exhibited online or in-person, we will contact you to confirm which of your art works and stories you give permission to exhibit. This will begin in 2021, and we will use the email you provided in the consent form to contact you.

Thank you for your time and energy!

We hope you enjoy the workshop and find it interesting and helpful. We very much appreciate your participation as we believe it will support deeper understandings of using the arts in HIV-research and the development of positive and empowering imagery for women living with HIV.

7. APPENDIX

7.1 PARTICIPANT INFORMATION AND CONSENT FORM

	
PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM (PISCF) <i>Positively Women: A research project using art to express what it means to be a woman living with HIV in Australia</i> 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;
- 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.

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.

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.

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
Telephone	+61 448 801 929
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
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13. If at any stage during the project you become distressed or require additional support from someone not involved in the research, please call:

Counselling support:

It is important for participants and team members to reach out when they need support. If at any stage during the project you become distressed or require additional support, please feel contact the individuals or organisations below.

To speak with a psychologist, contact:

The Albion Centre (150 Albion Street Surry Hills NSW 2010) via phone (02 9332 9600) or email (reception@thealbioncentre.org.au). You can request to speak with either: Ruth Hennessy or Shiraze Bulsara, Senior Clinical Psychologists.

Available: 9:00am-6:00pm during weekdays.

Please say that you are with the Positively Women study. Both Ruth and Shiraze are aware of the study. If they are not available, the call will get through to their intake psychologist and they will decide whether to wait for them or to potentially speak with you themselves. Please be aware that sometimes the intake psychologist won't be a woman.

To speak with a peer counsellor, contact:

Katherine Leane
Femfatales National Association of People with HIV Australia
President, Positive Life SA
A woman who has been living with HIV for 33 years.
Email: katherineleane@gmail.com
Ph: 0410 707 923

Available whenever needed, including weekends.

She may have to ring back up if she misses your call. Over the 5 weeks of the project, she will touch base with each woman, just to connect and see how you're going.

All conversations with counselling support are confidential.

Community resources:

Organisation 1	Lifeline
Telephone	Call 13 11 14 (all hours) or Text 0477 13 11 14 (12pm to 12am AEST)
Website	https://www.lifeline.org.au/131114/
Organisation 2	Beyond Blue
Telephone	1300 224 636
Website	http://www.beyondblue.org.au/
Organisation 3	Mental Health Access Line
Telephone	1800 011 511
Website	http://nswlhd.health.nsw.gov.au/about/mental-health-services/
Organisation 4	1800RESPECT (domestic violence and sexual assault counselling)

Telephone	1800737732 (toll free)
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

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

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.

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.

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.

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

7.2 RELEASE LETTER FOR FRIENDS/FAMILY

	
GENERAL RELEASE / PERMISSION LETTER <i>Positively Women: A research project using art to express what it means to be a woman living with HIV in Australia</i> Dr Allison Carter, Kirby Institute, UNSW	

This is a general release / permission letter for friends/family/loved ones who may be in photographs used by participants in the Positively Women art workshop and exhibition. These photographs can only be used with your permission. Please read the following, tick all of the boxes that are applicable and sign the form.

I grant the Kirby Institute and those acting with the Kirby Institute's authority and permission, the right and permission to use and publish photographs of me as part of artwork created for the Positively Women art-research study.

I understand the materials that my image could be in are:

- 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 pertaining to me before these materials are shared publicly.

I understand that I can refuse to consent, or withdraw consent at any time, if I am not comfortable with a proposed use of any imagery pertaining to me. However, this has limits (e.g., an already published book).

I understand that there will be no payment to me for this material.

Name	
Signature	
Email	
Phone	
Date	

Your contact details will only be used to communicate with you regarding the use of your image.

Addendum for minors

I hereby certify that I am the parent/or guardian of _____ a child under the age of eighteen (18) years. I hereby consent that any photographs may be used by Kirby for the purposes set forth in the form above signed by the child model, and the form shall have the same force and effect as if executed by me.

Name	
Signature	
Email	
Phone	
Date	