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| **The research is being carried out by the following researchers** |
| **Role** | **Name** | **Organisation** |
| Principal Investigator | Professor Suzanne Fraser | La Trobe University |
| Chief Investigator | Dr Jeanne Ellard | La Trobe University  |
| Chief Investigator | Dr Adrian Farrugia | La Trobe University |
| Chief Investigator  | Dr Renae Fomiatti | La Trobe University  |
| Research funder | The Victorian Department of Health and Human Services |

1. **What is the study about?**

This research project uses a co-design approach to develop a new stigma and discrimination intervention toolkit to reduce stigma and discrimination associated with blood-borne viruses (BBV) and sexually transmissible infections (STI) in health service settings. Co-design is broadly defined as designing research, services, solutions to problems, or products by collaborating with people and organisations directly involved in an issue, place, or process.

This research project will collaborate with healthcare professionals currently working in the BBV and STI health service sector in Victoria and representatives of advocacy and community organisations to gather information on the strengths and weaknesses of available stigma and discrimination reduction tools and initiatives relevant to these settings. This research project will also gather information about ways to address the institutional arrangements that may inadvertently enable stigma and discrimination related to BBV and STI in health service settings.

You are invited to take part on the basis of your professional experience working in the BBV and STI health service sector in Victoria.

1. **Do I have to participate?**

Participation is voluntary. If you want to be part of the study we ask that you read the information below carefully. We are happy to answer any questions you have.

You can read the information below and decide at the end if you do not want to participate. If you decide not to participate this won’t affect your relationship with La Trobe University or any other listed organisation.

1. **Who is being asked to participate?**

You are invited to take part on the basis of your current professional experience working in the BBV and STI health service sector in Victoria. We are also inviting other professionals working in these sectors to participate.

1. **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 participate in data collection for this research project. If you choose to give us your consent and participate, you will be asked take part in two rounds of focus group discussions, approximately three months apart. You will also be asked to take part in a third round of data collection in which you will be asked to review the draft toolkit and provide written feedback. The total time commitment for participating in the project is 4.5 hours.

While the co-design approach of this project is most effective when participants complete all three rounds of data collection, the voluntary nature of participation means you can leave the project at any phase of data collection.

The data collected will only relate to your opinions and experiences with respect to addressing stigma and discrimination in healthcare service settings, you will not be asked questions about your personal life or experiences outside of your professional work.

Focus groups will be facilitated by experienced researchers with expertise in focus group

discussion with professional staff.

**Round one focus group** (this one): We will ask you to participate in a group interview/discussion with a specific disease focus i.e., sexually transmissible infections, HIV, hepatitis C or hepatitis B. The focus group will be 90 minutes. You will be allocated a group based on your expertise and experience with one these disease areas. The round one focus group will ask you questions about the strengths and limitations of available tools and initiatives designed to reduce stigma in relation to the particularities of the disease, the affected communities, and the practices and behaviours associated with the disease.

**Round two focus group**:We will ask you to participate in a group interview/discussion where you will review key findings from the first round of data collection. The focus group will be 90 minutes. The discussion will focus on how findings from the first focus groups can be used to address stigma and discrimination in BBV and STI health service settings. You will be invited to collaborate with the researchers and other participants in the production of a stigma and discrimination toolkit relevant for the BBV and STI health sectors.

Focus group participants are requested to uphold confidentiality and not disclose the responses of other participants to others. Each focus group will run for up to 90 minutes and will be conducted online using a video conferencing service, such as Zoom.

**Round three** **written feedback** **on the draft toolkit:** We will ask you review the draft stigma and discrimination toolkit and complete a short written feedback form. We anticipate that this will take up to 90 minutes to complete. You will be emailed a copy of the draft toolkit and the feedback form and asked to comment on the presentation style, perceived quality, feasibility and suitability for use in a health service context.

*This Participant Information Statement and Consent Form is for the Round one Focus Group. You will be asked to complete a separate consent form for each data collection round.*

1. **What are the benefits?**

Your participation will allow you the opportunity to directly contribute to the development of a stigma and discrimination reduction toolkit that you will be able to use in your own work practice. Additionally, your participation has the potential to improve the health outcomes of people living with or affected by BBV and STI more broadly. The toolkit will also have the potential to be adapted for use in other disease areas and health care settings.

1. **What are the risks?**

With any study there are (1) risks we know about, (2) risks we don’t know about and (3) risks we know about but don’t expect. If you experience something that you aren’t sure about, please contact us immediately so we can discuss the best way to manage your concerns.

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| **Name/Organisation** | **Position** | **Telephone** | **Email** |
| Professor Suzanne Fraser | Lead Investigator and Director, Australian Research Centre in Sex, Health and Society | (03) 9479 8813 | s.fraser@latrobe.edu.au |

When reporting research findings, we will refer to you by a false name so there is little risk that your identity will be discovered through the research reporting process.

Only the principal investigator and research team for this project will have access to the project’s raw data. Other bona fide researchers approved by the principal investigator may be given access to the data, but only in its de-identified form.

Everything you say in the focus group discussions will be kept confidential. Any information gathered in the focus groups will be protected in order to protect your identity.

Any hard copy transcripts will be kept in a securely locked cabinet accessible only to the researchers. Audio recordings and electronic copies of transcripts will be kept in a password protected folder on a secure University computer. The material will be kept for five years after the research has been published, and then destroyed.

1. **How will my identity and privacy be maintained?**

We will **collect** information in ways that **will** reveal who you are.

We will **store** information in ways that **will** reveal who you are.

We will **publish** information in ways that **will not** be identifiable in any type of publication from this study.

We will **keep** your information for five years after the project is completed. After this time we will destroy all of your data.

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/) <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.

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

If you would like to receive the Research Broadsheet with the key finding from first round of focus group discussions or the Final Toolkit, we can record a preferred contact method such as your email address or phone number. We will arrange to send you a copy of the Broadsheet and Toolkit once they are complete.

1. **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.

When you withdraw we will stop asking you for information. Because of the way in which the focus group discussions are recorded, and the interactive nature of a group interview the research team will not be able to withdraw or destroy individual participant responses, but we will not use your individual responses in the analysis or in any publications. We will withdraw your individual written feedback on the draft toolkit. 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.

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

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

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| --- | --- | --- | --- |
| **Name/Organisation** | **Position** | **Telephone** | **Email** |
| Dr Jeanne Ellard, La Trobe University | Research Fellow | 0400855038 | j.ellard@latrobe.edu.au |

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

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

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| --- | --- | --- | --- |
| **Ethics Reference Number** | **Position** | **Telephone** | **Email** |
| HEC21394 | 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 a presentations, published in journals, in a published research Broadsheet and in a Toolkit on the condition that I cannot be identified.

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| [ ]  I do | [ ]  I do not | consent to participating in an online focus group that will be audio recorded. |

[ ]  I would like to receive a copy of the results via email or post. I have provided my details below and ask that they only be used for this purpose and not stored with my information or for future contact.

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| **Name** | **Email (optional)** | **Postal address (optional)** |
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**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 the risks and I believe the participant has understood;

[ ]  I am a person qualified to explain the study, the risks and answer questions

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| --- | --- |
| Researcher’s printed name |  |
| Researcher’s signature |  |
| Date |  |

\* All parties must sign and date their own signature

**Withdrawal of Consent**

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

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

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

I would like my already collected and unanalysed data

[ ]  Destroyed and not used for any analysis

[ ]  Used for analysis

**Participant Signature**

|  |  |
| --- | --- |
| Participant’s printed name |  |
| Participant’s signature |  |
| Date |  |

**Please forward this form to:**

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| --- | --- |
| CI Name | Dr Jeanne Ellard |
| Email | j.ellard@latrobe.edu.au |
| Phone | 0400855038 |
| Postal Address | Australian Research Centre in Sex, Health and SocietyLa Trobe UniversityBuilding NR6Bundoora Victoria 3086Australia |