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PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM - ONLINE VERSION

Sex in translation: Understanding concepts of health and relationships among Chinese people in Australia

Dr Allison Carter Kirby Institute, UNSW

[What is the research study about?

You are invited to take part in this research study. The research study aims to:

- To document the process of translating the questionnaire of the Australian Study of Health and Relationships into Simplified Chinese, and the process of training and debriefing the bilingual interviewers.
- 2) To examine the linguistic, social, and conceptual issues around sexual meanings and values raised in the translation process, through pre-testing a translated survey with Mandarin-speaking participants.

1. Who is conducting this research?

The study is being carried out by the following researchers:

Chief Investigator: Dr Allison Carter, Kirby Institute, UNSW

Co-Investigators: A/Prof Limin Mao, Centre for Social Research in Health, UNSW

A/Prof Christy Newman, Centre for Social Research in Health, UNSW

A/Prof Catherine O'Connor, Kirby Institute, UNSW

Dr Horas Wong, Kirby Institute, UNSW Erin Ogilvie, Kirby Institute, UNSW

Dr Yingli Sun, School of Humanities and Languages, UNSW

Dr Cathy Vaughan, Centre for Health Equity at the University of Melbourne

Dr Daniel Vujcich, School of Public Health, Curtin University Dr Pan Wang, School of Humanities and Languages, UNSW

Student investigator: Ye Zhang, Kirby Institute, UNSW

Defeng Jin, Centre for Social Research in Health, UNSW

Research Funder: This research is being funded by the Australian Government Department of Health.

2. Inclusion Criteria

- Aged between 18 and 69 years; and
- · Being able to read and understand the simplified Chinese script; and
- Being able to speak and understand Mandarin Chinese;
- Living in Australia (e.g. citizens, permanent residents, people on working or student visas, etc.)

Anyone who does not meet the inclusion criteria, and those who are not able to provide informed consents, and those who do not consent for audio recording will be excluded. Short-term visitors (such as tourists and short-term business visitors) will also be excluded.

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

Participation in this research study is voluntary. If you don't wish to take part, you don't have to. Your decision to participate, or not to participate, will not affect your relationship with the research team or with the institutes involved in the study.

This Participant Information Statement and Consent Form tells you more about the research study. It explains the research tasks involved. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information form carefully. Please ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you may want to talk about doing so with a relative or friend. If you decide you want to take part in the research study, you will be asked to:

- Sign the consent form
- Keep a copy of this Participant Information Statement (should you wish)

4. What does participation in this research require?

If you agree to participate, you will be invited to a focus group discussion. You will be asked to provide some basic information (age, gender, and sexuality) so that we can ensure participants share similar characteristics, and a contact number or email, and a list of days and times for which you are available for the discussion. The number or email you provide will **solely be used for arranging the discussion**, and they will not link to any study data. They will be destroyed once the group discussion is completed.

We will arrange a convenient date and time, and a place where the discussion can take place (e.g. a meeting room at UNSW). About two weeks before the interview, we will contact you via phone or email to confirm your participation and details of the meeting date, time, and place. However, until the COVID-19 situation has been resolved and all restrictions lifted, all focus group discussions will be conducted virtually via Zoom. Please see "For focus groups that are conducted via Zoom" section below for further information regarding Zoom focus groups.

Each focus group will have a maximum of 8 participants. It will be conducted in Mandarin and will take approximately 2 hours. In each session, you will be given a hard copy of the Chinese version of *the Australian Study of Health and Relationships* survey to comment on. The survey covers a range of topics such as demographics (e.g. age, sex, occupation, family situations), sexual and reproductive health (e.g. sexual experiences, sex education, contraception, sexual difficulties, and sexually transmitted diseases) and knowledge of and attitudes towards sex. **You are not required to answer the survey.**

Two moderators will guide the group to discuss participants' views towards and understandings on the terms and concepts used in the questionnaire. During group discussion, <u>you are not required to disclose your own personal experiences towards specific survey questions</u>. For example, some

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questions in the survey are about sexual experience. Instead of asking you to talk about your own sexual experience, we will ask the group to discuss questions such as 'if you were going to design this survey, what is a better way to ask Chinese people about sex?'

If the COVID-19 situation has been resolved and all restrictions have been lifted, we will continue to conduct face-to-face focus groups:

For face-to-face focus groups

We will audio record the group discussion. The moderators will also take field notes during the process. The field notes are used to record important non-verbal data collected in the groups (e.g. participants' gestures, eye contact, etc.), and for the moderators to jot down any ideas or important point that come to mind that may assist data analysis.

You do not have to answer any questions that make you feel uncomfortable, and you can withdraw from the study at any time. <u>The study does not collect any personal identifiable</u> data (e.g. your real name, name of workplace or school).

If you do not consent to be audio recorded before the focus group begins, you will be regarded as not consenting to participate and will not be included in the group.

If you decide to withdraw from the study altogether, we will try to 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 group discussions 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 the research team may not be able to delete individual responses from the discussion. If this happens, we will discuss with you to find the most appropriate way to deal with the data.

However, until the COVID-19 situation has been resolved and all restrictions lifted, in order to minimise person to person contact, all focus group discussions will be conducted virtually via Zoom.

For focus groups that are conducted via Zoom

About two weeks before the interview, we will contact you via phone or email to confirm your participation and details of the meeting date, time, and the link and password to a Zoom meeting. You will only be provided with the link to the meeting if you agree the meeting to be recorded.

Before the day of the Zoom meeting, you will receive a copy of the Chinese version of *the Australian Study of Health and Relationships* survey by email, fax or post (depending on your preference). The survey covers a range of topics such as demographics (e.g. age, sex, occupation, family situations), sexual and reproductive health (e.g. sexual experiences, sex education, contraception, sexual difficulties, and sexually transmitted diseases) and knowledge of and attitudes towards sex. **You are not required to answer the survey.**

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On the day of the Zoom meeting, you will receive another reminder by email regarding the time, the link and password to the meeting. You can join the focus group by clicking on the link and enter the password at the meeting time. You do **NOT** need to turn on your video camera if you do not wish to.

Each focus group will have a maximum of 8 participants. It will be conducted in Mandarin and will take approximately 2 hours.

Two moderators will guide the group to discuss participants' views towards and understandings on the terms and concepts used in the questionnaire. During group discussion, <u>you are not required to disclose your own personal experiences towards specific survey questions</u>. For example, some questions in the survey are about sexual experience. Instead of asking you to talk about your own sexual experience, we will ask the group to discuss questions such as 'if you were going to design this survey, what is a better way to ask Chinese people about sex?'

During the online focus group, you are required to follow the below rules for online etiquette:

- 1. Find a quiet and private space to attend the focus group by yourself only.
- 2. Do not allow anyone (e.g. family members, flat mates, etc.) to be around you during the discussion. Preferably, please use a headset or earphones for the discussion.
- 3. Do not take any screenshots or make a record of the focus group
- 4. Be respectful and patient, especially when other participants are experiencing internet connection difficulties
- 5. Do not share your screen to the group, or having private chat with other participants (e.g. using the Zoom chat function).

If a participant is found violating any of the above rules, the moderator will stop the interview and recording immediately. The participant may be requested to leave the group and they will not get the incentive.

The focus group meeting will be video-recorded. The moderators will also take field notes during the process. You do not have to answer any questions that make you feel uncomfortable, and you can withdraw from the study at any time. **The study does not collect any personal identifiable data** (e.g. your real name, name of workplace or school).

In order to protect your confidentiality, you do **NOT** need to turn on your video camera if you do not wish to. You do not need to enter your real name in Zoom. If you do not consent to be video recorded before the focus group begins, you will be regarded as not consenting to participate and will not be included in the group.

All video recordings will be recorded directly on the Australia's Academic and Research Network (AARNet) CloudStor. AARNet is a not-for-profit company that provides ultra-high-speed Internet and communications services only to Australia's research and education sector since 1989 (for more information about AARNet, please visit https://www.aarnet.edu.au/about-us). Only the person who hosts the meeting (i.e. the facilitator) is able to download the recordings by using UNSW staff number and password.

If you decide to withdraw from the study altogether, we will try to 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 group discussions are interactive in nature (i.e. what a participant says may affect how other participants

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respond in the discussion), you have to be mindful that the research team may not be able to delete individual responses from the discussion. If this happens, we will discuss with you to find the most appropriate way to deal with the data.

5. Are there any risks involved?

We do not expect that there will be any risks or costs associated with taking part in this study, besides giving up your time. However, it is possible that some participants may feel that some of the questions we ask are upsetting or embarrassing. If you do not wish to answer a question, you may skip it and go to the next question, or you may take a short break or end your participation. The Interview will only be continued if you want to do so.

You could also arrange another interview date, or withdraw directly from the study (See point 5 above for more information about how your data will be managed after withdrawing from the study).

If you become upset as a result of your participation in the research project, the research team will be able to provide information for referral to counselling or other appropriate support. Alternatively, a number of free contactable support services are included at section 12 below. Any counselling or support will be provided by qualified staff who are not members of the research team.

6. What are the possible benefits to participation?

You will receive a payment of AU\$50 after the focus group to compensate you for your time [either cash or a supermarket e-voucher, TBD by the finance dept of the Kirby Institute]. There will be no other direct benefit beyond this payment. We do though hope to use the information we get from this research to improve our understandings of health and relationships for Mandarin-speaking people in Australia and therefore, enhance health promotion and services.

7. What will happen to information about me?

By signing the consent form, you consent to the research team collecting and using the information you provide for the research study. Your information will only be used for the purpose of this study and it will only be disclosed with your permission. All information will be stored in re-identifiable format where any identifiers such as your name and address will be replaced with a unique code.

Information collected from you in an electronic format stored on a UNSW password protected OneDrive only accessible to the approved research investigators. Information collected from you using paper-based measures (e.g. field notes, consent forms) will be stored in the Kirby institute, Wallace Wurth Building, UNSW Sydney, and only the approved research investigators will have access to this information. Audio recordings will be stored on a UNSW password protected OneDrive only accessible to the approved research investigators.





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For Zoom video recordings, all recordings will be recorded directly on the Australia's Academic and Research Network (AARNet) CloudStor. AARNet is a not-for-profit company that provides ultra high-speed Internet and communications services only to Australia's research and education sector since 1989 (for more information about AARNet, please visit https://www.aarnet.edu.au/about-us). Only the person who hosts the meeting (i.e. the facilitator) is able to download the recordings by using UNSW staff number and password. As Zoom automatically stores video and audio recordings separately, only the audio recordings will be downloaded. The video recordings will be deleted immediately. This can ensure that any identifiable information such as faces or names that are captured in the videos will not be saved. The audio files will be stored on the UNSW server in a password-protected folder. The audio files will then be transcribed.

All information will be stored for a minimum of 5 years after the completion of the research.

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.

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

It is anticipated that the results of this study will be published and/or presented in a variety of forums, reports and journals. In any publication and/or presentation, we may use some quotations from the interviews – if we do, then any personal details will be removed or changed to ensure maximum level of confidentiality of you and the people around you.

If you would like to receive a report of the study you can let the research team know by inserting your email or mailing address in the consent form. We will only use these details to send you the results of the research.

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

If you do consent to participate, you may withdraw at any time. You can do so by completing the 'Withdrawal of Consent Form' which is provided at this link [https://unsw.au1.qualtrics.com/jfe/form/SV_56CiSnVkw1YIGm1] or you can ring the research team directly and tell us 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.

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10. 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:

Complaints Contact (Please contact TIS National on 131 450 if you need an interpreter.)

Position	UNSW Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
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11. What should I do if I have further questions about my involvement in the research study?

The person you may need to contact will depend on the nature of your query. If you require further information 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	Horas Wong	
Position	Research Coordinator	
Languages	English, Mandarin and Cantonese	
Telephone	61 2 9385 0900	
Email	horas.wong@unsw.edu.au	

Name	Allison Carter	
Position	Chief Investigator	
Telephone	61 2 9385 0900	
Email acarter@kirby.unsw.edu.au		

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

(Please contact TIS National on 131 450 if you need an interpreter.)

Organisation 1	Beyondblue
Telephone	1300 224 636
Website	http://www.beyondblue.org.au/
Organisation 2	Mental Health Access Line
Telephone	1800 011 511
Website	http://nnswlhd.health.nsw.gov.au/about/mental-health-services/
Organisation 3	1800RESPECT (domestic violence and sexual assault counselling)
Telephone	1800737732 (toll free)
Website	https://www.1800respect.org.au/
Organisation 4	Mensline Australia (for men)
Telephone	1300 78 99 78
Website	https://mensline.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/#lbgti-counselling

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