

Appendix 7

Consent Forms for Consumer Participants

Approval No: UNSW (08073)

THE UNIVERSITY OF NEW SOUTH WALES

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM **For consumers in drug treatment services (round one data collection)**

Treatment Service Users Project Phase 2 (TSU2)

Participant Selection and purpose of the study

You are invited to participate in a research study into the suitability and impact of consumer participation in drug treatment services. The drug treatment service where you work has been selected through an expression of interest process to conduct a demonstration consumer participation project. The project is being conducted as a partnership between the National Centre in HIV Social Research and The Australian Injecting & Illicit Drug Users League (AIVL). We hope to learn from this study what model of consumer participation will be most suitable for the drug treatment sector, the impact of consumer participation on service delivery, communication between providers and consumers and on health outcomes for consumers. Ultimately, we hope to use the findings of this study to develop a nationally agreed definition of consumer participation that can be used to guide consumer participation across the drug treatment sector. You were selected as a possible participant in this study because you are a consumer at one of the drug treatment services that is conducting a demonstration consumer participation project and you indicated that you might be interested in participating.

Procedures

If you decide to participate in this research, we will ask you to take part in either a discussion group with other consumers and/or an interview, of one to one and half hours in length, at a time and place convenient to you. It will however be your choice as to whether you participate in an interview and/or a focus group. The study will have two data collection rounds, one at the beginning of the demonstration project and one at its completion. This information and consent form is for round one data collection. Agreement to participate in this first round of data collection will not mean who are required to take part in the second round of data collection. If you are interested in being considered for the second round of data collection please provide your contact details on the form provided on page 5 of this document. The peer interviewer will re-contact you a few weeks prior to the round two data collection to check your availability and continuing interest.

We would like to digitally audio-record your voice during the research so we do not miss any important points. If you feel uncomfortable about that, you can ask at any time for the tape recorder to be turned off.

During the focus groups and interviews we will discuss consumer satisfaction with service delivery, levels of communication between consumers and providers, awareness of existing consumer participation activities and attitudes to consumer participation. We will also ask you a few questions about your background so we can describe who participated in the research.

Appendix 7 —Consent Forms for Consumer Participants cont...

THE UNIVERSITY OF NEW SOUTH WALES

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM (continued)

(For consumers in drug treatment services round one data collection)

Treatment Service Users Project Phase 2 (TSU2)

Confidentiality and disclosure of information

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission, except as required by law. If you give us your permission by signing this document, we plan to publish the most important results in academic journals, an evaluation report published by the Australian Injecting & Illicit Drug Users League, community-based magazines and online at www.aivl.org.au and <http://nchsr.arts.unsw.edu.au>. A number of measures will be put in place to ensure participant confidentiality. Following the interview or discussion group all your contact details will be removed from our records, except if you agree to be re-contacted in relation to the second round of data collection. If you agree to be recontacted your details will be removed either when you decline to participate in the second round or after round two data collection. Following transcription of the interview your real name will be replaced with a pseudonym (or nickname). In addition, all other details you mention that might identify you or others will be changed (e.g. the name of your workplace, friends, colleagues, drug treatment services and venues attended). The digital audio recordings will be destroyed as soon as they are transcribed and the de-identified transcripts will be kept in a locked filing cabinet to which only the researchers will have access. In any publication, information will be provided in such a way that you cannot be identified.

Recompense to participants

In recognition of your contribution to this study and the effort you made to attend this interview or focus group, we will recompense you with AUD twenty-five dollars for travel expenses.

Complaints

Complaints may be directed to the Ethics Secretariat, The University of New South Wales, Sydney, 2052, Australia (phone 9385 4234, fax 9385 6648, email ethics.sec@unsw.edu.au). Any complaint you make will be investigated promptly and you will be informed of the outcome.

Feedback to participants

A plain language summary of results will be available on the AIVL www.aivl.org.au and NCHSR <http://nchsr.arts.unsw.edu.au> websites at the completion of the evaluation process and distributed to participating services. Upon completion of the project, data will be analysed and an evaluation report written. The findings will also be published in academic articles for peer-review. The results will also be presented at conferences. An overview of the demonstration projects will be written up and the findings of the evaluation will be discussed at a nationally convened workshop hosted by AIVL.

Your consent

Your decision whether or not to participate will not prejudice your future relations with The University of New South Wales or your health service provider. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without prejudice.

If you have any questions now, please feel free to ask the researcher. If you have any additional questions later, please contact Dr. Jeanne Ellard on (02) 9385 6406, or email j.ellard@unsw.edu.au.

You will be given a copy of this form to keep.

Appendix 7 —Consent Forms for Consumer Participants cont...

THE UNIVERSITY OF NEW SOUTH WALES

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM (continued)
(For consumers in drug treatment services round one data collection)

Treatment Service Users Project Phase 2 (TSU2)

You are making a decision whether or not to participate. Your signature indicates that, having read the information provided above, you have decided to participate.

.....
Signature of Research Participant

.....
Signature of Witness

.....
(Please PRINT name)

.....
(Please PRINT NAME)

.....
Date

.....
Nature of Witness

Appendix 7 —Consent Forms for Consumer Participants cont...

THE UNIVERSITY OF NEW SOUTH WALES

Treatment Service Users Project Phase 2 (TSU2)

REVOCAION OF CONSENT

I hereby wish to **WITHDRAW** my consent to participate in the research proposal described above and understand that such withdrawal **WILL NOT** jeopardise any treatment or my relationship with the University of New South Wales.

.....
Signature

.....
Date

.....
Please PRINT Name

The section for Revocation of Consent should be forward to Dr Jeanne Ellard, National Centre in HIV Social Research, The University of New South Wales, Sydney, 2052, NSW.

Appendix 7 —Consent Forms for Consumer Participants cont...

THE UNIVERSITY OF NEW SOUTH WALES

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM (continued)
(For consumers in drug treatment services round one data collection)

Treatment Service Users Project Phase 2 (TSU2)

If you would like to be contacted about participating in round 2 data collection please fill out this form.

Name (which can be just a first name)

Contact details:

Email:

Phone:

(H) _____

(W) _____

Please be assured that we will exercise discretion in making contact with you. We will not mention anything about the study or the name of the Centre to any person other than you who may answer the phone in either your home or workplace. If there is a specific time of day you would prefer us to call please let us know.

Thank you for your interest
Dr Jeanne Ellard
National Centre in HIV Social Research
j.ellard@unsw.edu.au
(02) 9385 6406

Appendix 7 —Consent Forms for Consumer Participants cont...

Approval No (08073)

THE UNIVERSITY OF NEW SOUTH WALES

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM **For consumers in drug treatment services (round two data collection)**

Treatment Service Users Project Phase 2 (TSU2)

Participant Selection and purpose of the study

You are invited to participate in a research study into the suitability and impact of consumer participation in drug treatment services. The drug treatment service where you work has been selected through an expression of interest process to conduct a demonstration consumer participation project. The project is being conducted as a partnership between the National Centre in HIV Social Research and The Australian Injecting & Illicit Drug Users League (AIVL). We hope to learn from this study what model of consumer participation will be most suitable for the drug treatment sector, the strengths and weaknesses of the demonstration project, the impact of consumer participation demonstration project on service delivery, communication between providers and consumers and on health outcomes for consumers. Ultimately, we hope to use the findings of this study to develop a nationally agreed definition of consumer participation that can be used to guide consumer participation across the drug treatment sector. You were selected as a possible participant in this study because you are a consumer at one of the drug treatment services that is conducting a demonstration consumer participation project and you indicated that you might be interested in participating.

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Appendix 7 —Consent Forms for Consumer Participants cont...

THE UNIVERSITY OF NEW SOUTH WALES

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM (continued) **(For consumers in drug treatment services round two data collection)**

Treatment Service Users Project Phase 2 (TSU2)

During the focus groups and interviews we will discuss the impact of the demonstration projects on staff and consumers, service delivery, communication between consumers and providers, attitudes to consumer participation, the suitability of the chosen model of consumer participation, changes in health and treatment outcomes and changes in skills and capacity amongst consumers and service providers in relation to consumer participation. We will also ask you a few questions about your background so we can describe who participated in the research.

Confidentiality and disclosure of information

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission, except as required by law. If you give us your permission by signing this document, we plan to publish the most important results in academic journals, an evaluation report published by the Australian Injecting & Illicit Drug Users League, community-based magazines and online at www.aivl.org.au and <http://nchsr.arts.unsw.edu.au>. A number of measures will be put in place to ensure participant confidentiality. Following the interview or discussion group all your contact details will be removed from our records. Following transcription of the interview your real name will be replaced with a pseudonym (or nickname). In addition, all other details you mention that might identify you or others will be changed (e.g. the name of your workplace, friends, colleagues, drug treatment services and venues attended). The digital audio recordings will be destroyed as soon as they are transcribed and the de-identified transcripts will be kept in a locked filing cabinet to which only the researchers will have access. In any publication, information will be provided in such a way that you cannot be identified.

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Treatment Service Users Project Phase 2 (TSU2)

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Signature of Research Participant

.....
Signature of Witness

.....
(Please PRINT name)

.....
(Please PRINT NAME)

.....
Date

.....
Nature of Witness

Appendix 7 —Consent Forms for Consumer Participants cont...

THE UNIVERSITY OF NEW SOUTH WALES

Treatment Service Users Project Phase 2 (TSU2)

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Signature

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Date

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Please PRINT Name

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