



Participant Information Sheet

For clients of Wellington Early Intervention Services or their support/whānau

Study title:	Co-designing a healthy lifestyle programme for people experiencing first episode psychosis	
Principal investigator:	Name: Dr Matthew Jenkins Department: Psychological Medicine Position: Senior Research Fellow	Contact phone number: 0221740904

Introduction

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate.

If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the aim of this research project?

Young people living with first episode psychosis face challenges in maintaining healthy lives away from the diagnosis itself. We are aiming to understand the experiences of people living with psychosis in terms of staying healthy, including any challenges to this and the things that make it easier to lead a healthy lifestyle.

From understanding these experiences, we want to work with you to design a healthy lifestyle programme, which will hopefully lead to positive health outcomes for yourself and people experiencing psychosis in the future.

Who is funding this project?

This research is funded by a Lotteries Health Research Grant.

Who are we seeking to participate in the project?

We are looking for people who are clients of Wellington Early Intervention Services that have experienced first episode psychosis (FEP) or are supporting someone who has experienced FEP (e.g., family/whānau members).

You are eligible to take if you are either:

A client of Early Intervention Services, Wellington, experiencing first episode psychosis who is 16 years old or over. If you are currently experiencing an acute episode of psychosis, you will not be eligible.

or

A whānau/family member of a client of Early Intervention Services who is experiencing first episode psychosis, or someone who supports a client.

If you have any questions about whether or not you are eligible, you can email the lead researcher, Matthew Jenkins, at matthew.jenkins@otago.ac.nz.

If you participate, what will you be asked to do?

You will be asked to attend three workshops from September to November 2022. The exact dates of these workshops are not yet determined. The workshops will be held at Te Whare Tipu, Hania Street, Wellington City. If travelling to the workshops from Kapiti Coast or Hutt Valley districts, we will organise free transport for you.

These workshops aim to understand your experiences in maintaining your health since experiencing an episode of psychosis, or in supporting someone experiencing psychosis.

Workshops will last around two hours each.

If you wish, you may be interviewed instead of participating in the workshops. These interviews will have the same objectives as the workshops – to understand your experiences of living with psychosis or supporting someone living with psychosis. A family member or case worker can be present if you choose this option.

Participation is voluntary. You are completely free to choose not to participate, and this will not affect your usual healthcare/that of the person you are supporting.

You will be offered a \$20 petrol or grocery voucher for participating in this research.

Is there any risk of discomfort or harm from participation?

No discomfort or harm is expected as a result of participating in this research.

Mental health professionals and cultural advisors will be available should you wish to talk to anybody before, during or after the workshops.

What data or information will be collected, and how will they be used?

We will collect data in a few ways. First, we will collect data as we go in the form of 'data walls', which are simply notes that are kept on the walls (e.g., using sticky notes) or on whiteboards at

the workshop. We will also record audio. We will use both the data walls and audio recordings to understand your experiences. If you participate in an interview, we will audio record this and this recording will be transcribed in full (i.e., all words will be recorded in writing).

Finally, we will ask you to complete a brief survey to understand your experiences of the co-design workshops. This might include questions about your satisfaction with the workshops.

All of the data will be kept confidential. If we communicate any of it outside the workshop, we will ensure, unless we have your permission otherwise (e.g., for a podcast or video recording).

All of this data will be kept in a secure, password-protected, encrypted database that is only accessible to our core research team. Your personal details will not be passed on to anybody else, nor will they be reported in any articles that we produce as a result of this project. Where we might use your stories or quotes, we will not use your real names, or any other potentially identifying information. (The exception to this is if you wish to be part of the documentary/podcast that we will be developing as part of this project - see below).

Additional recording

There will also be times when some of the workshops will be recorded on video or audio (sound) for the purpose of creating a documentary and/or podcast about the research. You can tell us whether you want to or don't want to appear in any pictures, video, or audio (podcast) on the attached consent form. None of this content will contain sensitive information. Participation in the documentary and/or podcast are completely voluntary. If you do not wish to be a part of the documentation, we will take steps to ensure your anonymity (e.g., by blurring participants' face). They are not a part of the project itself and not participating will have no consequences for you.

What about anonymity and confidentiality?

Audio recordings will be transcribed using a secure and automated online service. Any content recorded for the purpose of research will be de-identified, meaning that you will remain anonymous. When analysing the data, participant names will be replaced with numbers. A secure document will be kept that will link participant names to assigned participant numbers. Only the lead researcher will have access to this document.

When discussing the workshops and/or interviews outside of the research, you are reminded to maintain confidentiality as much as possible.

If you agree to participate, can you withdraw later?

You may withdraw from participation in the project before its completion.

Any questions?

If you have any questions now or in the future, please feel free to contact either:

Name Matthew Jenkins	Contact phone number:
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Position Senior Research Fellow	0221740904
Department Psychological Medicine, Wellington	
Name Tracey Gardiner	Contact phone number:
Position Assistant Research Fellow	+64 4 918 5263
Department Psychological Medicine, Wellington	

This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.



Co-designing a healthy lifestyle programme for people experiencing first episode psychosis

Principal Investigator: Dr Matthew Jenkins

matthew.jenkins@otago.ac.nz

CONSENT FORM FOR PARTICIPANTS: Clients and whānau/support

Following signature and return to the research team this form will be stored in a secure place for ten years.

Name of participant:.....

1. I have read the Information Sheet concerning this study and understand the aims of this research project.
2. I have had sufficient time to talk with other people of my choice about participating in the study.
3. I confirm that I meet the criteria for participation which are explained in the Information Sheet.
4. All my questions about the project have been answered to my satisfaction, and I understand that I am free to request further information at any stage.
5. I know that my participation in the project is entirely voluntary, and that I am free to withdraw from the project before its completion (*i.e.*, July 2023).
6. I know that as a participant I will participate in two to three workshops, where I will be expected to discuss my experiences of physical health (where comfortable or appropriate), or my experiences as someone who supports a family member who is experiencing first episode psychosis. I will also be expected to complete a brief survey at the end of the project.
7. I know that the workshops will explore physical health while experiencing first episode (or supporting someone who is) and that if the workshop topics develop in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question, and/or may withdraw from the project without disadvantage of any kind.
8. I understand the nature and size of the risks of discomfort or harm which are explained in the Information Sheet.
9. I know that when the project is completed all personal identifying information will be removed from the paper records and electronic files which represent the data from

the project, and that these will be placed in secure storage and kept for at least ten years.

10. I understand that the results of the project may be published and be available in the University of Otago Library, but that either (i) I agree that any personal identifying information will remain confidential between myself and the researchers during the study, and will not appear in any spoken or written report of the study or (ii) I agree to be named or identified in the study and will sign a waiver form.
11. I understand that some aspects of this project will be video and audio recorded for the purpose of producing a video documentary or a podcast. If this occurs, I will be required to provide separate informed consent. I will have the option of having my anonymity preserved at all times (e.g., through blurring my face on video or being omitted altogether).
12. I know that there I will be offered a \$20 petrol or grocery voucher for participating in this study, and that no commercial use will be made of the data.

Signature of participant:

Date:

Name of person taking consent

Date:



Participant Information Sheet

For people working with or within Early Intervention Services

Study title:	Co-designing a healthy lifestyle programme for people experiencing first episode psychosis	
Principal investigator:	Name: Dr Matthew Jenkins Department: Psychological Medicine Position: Senior Research Fellow	0221740904

Introduction

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate.

If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

What is the aim of this research project?

Young people living with first episode psychosis face challenges in maintaining healthy lives away from the diagnosis itself. We are aiming to understand the experiences of people living with psychosis in terms of staying healthy, including any challenges to this and the things that make it easier to lead a healthy lifestyle.

We want to understand young people's experiences, as well as those of their whanau/support, to be able to develop an effective healthy lifestyle programme. However, we also want to ensure that any programme is feasible within the context of Wellington Early Intervention Services, and so require your valuable input as mental health care providers and community partners.

Who is funding this project?

This research is funded by a Lotteries Health Research Grant.

Who are we seeking to participate in the project?

We are looking for people who work or volunteer for or with Wellington Early Intervention Services, specifically with young people that have experienced first episode psychosis (FEP).

If you have any questions about whether or not you are eligible, you can email the lead researcher, Matthew Jenkins, at matthew.jenkins@otago.ac.nz.

If you participate, what will you be asked to do?

You will be asked to attend three workshops, in September, October, and November 2022. The exact dates of these workshops are not yet determined, but will be decided in July 2022. The workshops will be held at Te Whare Tipu, Hania Street, Wellington City.

These workshops aim to understand not only young people's experiences in maintaining health while experiencing FEP, but also the context of early intervention services, so that we can co-develop a feasible and effective healthy lifestyle programme.

Workshops will last around two hours each. The September workshop will explore the experiences of clients/whanau in leading/supporting healthy lifestyles. The October and November workshops will use these experiences, and ideas coming from clients/whanau, to develop a healthy lifestyle programme.

If you wish, you may provide written feedback on the material covered by the workshops rather than attending in person. However, we emphasise that the workshops are the preferred method of engagement.

Participation is completely voluntary, and you are free to withdraw from the project at any point without any disadvantage to yourself.

Is there any risk of discomfort or harm from participation?

No discomfort or harm is expected as a result of participating in this research.

What data or information will be collected, and how will they be used?

We will collect data in a few ways. First, we will collect data as we go in the form of 'data walls', which are simply notes that are kept on the walls (e.g., using sticky notes) or on whiteboards at the workshop. We will also record audio.

All of the data will be kept confidential. If we communicate any of it outside the workshop, we will ensure your anonymity, unless we have your permission otherwise (e.g., for a podcast or video recording).

All of this data will be kept in a secure, password-protected, encrypted database that is only accessible to our core research team. Your personal details will not be passed on to anybody else, nor will they be reported in any articles that we produce as a result of this project. Where we might use your stories or quotes, we will not use your real names, or any other potentially identifying information. (The exception to this is if you wish to be part of the documentary/podcast that we will be developing as part of this project - see below).

Additional recording

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What about anonymity and confidentiality?

Audio recordings will be transcribed using a secure and automated online service. Any content recorded for the purpose of research will be de-identified, meaning that you will remain anonymous. When analysing the data, participant names will be replaced with numbers. A secure document will be kept that will link participant names to assigned participant numbers. Only the lead researcher will have access to this document.

When discussing the workshops and/or interviews outside of the research, you are reminded to maintain confidentiality as much as possible.

If you agree to participate, can you withdraw later?

You may withdraw from participation in the project before its completion.

Any questions?

If you have any questions now or in the future, please feel free to contact either:

<p>Name Matthew Jenkins Position Senior Research Fellow Department Psychological Medicine, Wellington</p>	<p>Contact phone number: 0221740904</p>
<p>Name Tracey Gardiner Position Assistant Research Fellow Department Psychological Medicine, Wellington</p>	<p>Contact phone number: +64 4 918 5263</p>

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Co-designing a healthy lifestyle programme for people experiencing first episode psychosis

Principal Investigator: Dr Matthew Jenkins

matthew.jenkins@otago.ac.nz

CONSENT FORM FOR PARTICIPANTS: Advisory group

Following signature and return to the research team this form will be stored in a secure place for ten years.

Name of participant:.....

1. I have read the Information Sheet concerning this study and understand the aims of this research project.
2. I have had sufficient time to talk with other people of my choice about participating in the study.
3. I confirm that I meet the criteria for participation which are explained in the Information Sheet.
4. All my questions about the project have been answered to my satisfaction, and I understand that I am free to request further information at any stage.
5. I know that my participation in the project is entirely voluntary, and that I am free to withdraw from the project before its completion (*i.e.*, July 2023).
6. I know that as a participant I will participate in two to three workshops, where I will be expected to discuss my experiences of working within early interventions services, specifically with regards to supporting the physical health of young people experiencing first episode psychosis.
7. I know that if the workshop topics develop in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question, and/or may withdraw from the project without disadvantage of any kind.
8. I understand the nature and size of the risks of discomfort or harm which are explained in the Information Sheet.
9. I know that when the project is completed all personal identifying information will be removed from the paper records and electronic files which represent the data from

the project, and that these will be placed in secure storage and kept for at least ten years.

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Signature of participant:

Date:

Name of person taking consent

Date: