**Protocol: Co-designing a healthy lifestyle programme for FEP patients**

**Research aims**

1. To understand the lived experiences of young people experiencing FEP with regards to improving or maintaining their health.
2. To co-design a healthy lifestyle programme for young FEP clients.

**Methodology**

***Participants***

*FEP clients and their* support

The community of people experiencing FEP is heterogenous with regards to cultural background, gender, and education. We will be working closely with Wellington Early Intervention services to identify participants that are representative of these demographic characteristics as much as is feasible. In terms of sample size, approximately 125 clients are engaged with early intervention FEP services. We aim to recruit approximately 24 clients, plus any support (members of their whānau) that they wish to accompany them. $20 petrol or supermarket vouchers will be offered to FEP clients and, separately, their support as acknowledgement of their time (maximum of two vouchers related to any FEP client).

*Inclusion criteria:*

Participants must be current FEP clients or whānau members *or* someone supporting a current FEP client.

*Exclusion criteria:*

Participants will be excluded if they are experiencing an acute psychotic episode, as determined by their assigned mental health professional.

*Early intervention service (EIS) advisory group*

A group of experienced EIS providers will be identified to form an advisory group for the project. These will include psychiatrists, clinical psychologists, mental health nurses, case workers, and service managers. This group will also include cultural advisors that identify as Māori and Pasifika.

We aim to identify and recruit approximately 15 service providers members from across a range of roles to form this group.

*Inclusion criteria:*

Participants must be either working within early intervention services and working direcrly with FEP clients (i.e., as mental health professionals or case workers).

**Procedure**

An iterative co-design process will be used to understand the health issues that FEP clients face and find workable solutions to address these issues. An iterative approach is an important in allowing for participant reflection and hypothesis testing of prototype solutions (Dawda et al., 2020; Hardt et al., 2021). The process will consist of five key phases: 1) Contextual inquiry (understanding the context, including issues faced by participants and contextual constraints); 2) participatory design (working with participants to come up with initial solutions); 3) product (programme) design (working with the advisory group to develop a programme based on participatory design outcomes); 4) prototype as hypothesis (asking FEP participants to approve or provide comment on the programme); and 5) final programme revision. Following these phases, the final programme will be presented to all stakeholders and an audit conducted to identify resources required to deliver and evaluate the programme. Further details on these components can be seen on pages 3-8.

**Workshop group size and locations**

To facilitate meaningful engagement and experience sharing, and to minimise anxiety for participants, we aim to run groups containing between 6 and 10 participants.

Wellington Early Intervention Services serve clients across three main areas: Kapiti Coast, Hutt Valley, and Wellington City.

Depending on take-up from clients in the satellite sites (Kapiti, the Hutt Valley), the workshops will be held either at locations close to these sites, or participants will be offered free transport to Wellington City. This might result in multiple workshops per stage. If this is the case, the research team will work to collate the results for the purpose of designing programme components, while highlighting any site-specific differences.

**Workshop facilitators**

The research team responsible for organising and facilitating the workshops include: Dr Matthew Jenkins, Dr Victoria Chinn, Ms Tracey Gardiner, and two research assistants. In addition, Toi Tangata – a Māori-led and Māori-focused health promotion agency with expertise in co-design – will assist in workshop facilitation. Between the research team and Toi Tangata, there is extensive experience in terms of supporting health behaviour change, working with people living with serious mental illness, and putting co-design principles into action.

**Data collection and analysis**

Data will be collected in the form of ‘data walls’ within the workshops, in which visual tools (e.g., post-it notes, mind maps) are used to create real-time data. This approach is effective in allowing for continuous member-checking and grouping of themes.

Interviews will be offered to FEP clients who wish not to participate in a group session. If this option is taken, these interviews will be audio-recorded and transcribed.

Thematic analyses will be conducted on workshop and interview data pertaining to the lived experiences of young people experiencing FEP.

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| **Workshop 1: Contextual inquiry (Part 1) and participatory design (Part 2)** | |
| *Time* | Two hours (approx.) |
| *Participants* | FEP clients and their support, early intervention services advisory group (optional).  FEP clients and their support will be the main stakeholders, while the early intervention services advisory group will be asked to attend to understand the needs of FEP clients and assist in co-designing the first iterations of workable solutions and initial feedback will be sought on these potential solutions. |
| *Objective(s)* | To understand factors relating to the health of FEP clients in terms of barriers and facilitators (Part 1).  To initially devise ways in which barriers can be addressed and facilitators optimised (Part 2). |
| *Process* | *Part 1: Contextual inquiry*  The following topics will be explored with FEP clients and their whānau/support:   * What does health mean to you? What does a healthy life look like? * What are the perceived health problems that FEP clients face (aside from FEP itself)? * What are the barriers and facilitators to overcoming these health problems? (Framed from an individual to a structural/systems level e.g., lack of health education, lack of localised facilities.)   *Part 2: Participatory design*  FEP clients and their whānau/support will work with EIS service providers to create a programme that aims to address the issues identified in Part 1.  Key questions:   * What might a healthy lifestyle programme look like? This will consider programme length, components, facilitators. * Examples of existing similar lifestyle programmes will be presented (e.g., RUFIT, Next Level Health). Which aspects of these programmes might work for this group, or what could be modified to suit?   The findings from both Part 1 and Part 2 will be summarised (written report) and will provide the basis for Workshop 2. |
| *Data source(s)* | Data wall, group transcriptions.  Live note-taking using a whiteboard will occur as the session progresses (undertaken by research assistants). |

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| **Workshop 2: Programme design** | |
| *Time* | Two hours (approx.) |
| *Participants* | EIS advisory group. |
| *Objective(s)* | To develop Version 1 of the healthy lifestyle programme. |
| *Process* | The EIS advisory group, Toi Tangata, and the core research team will work together to design a feasible healthy lifestyle programme based on the outcomes of Workshop 1 that consider the requested programme components and would be feasible within the constraints of early intervention services.  A summary of findings from Workshop 1 will be verbally presented and in writing. A facilitated discussion will then focus on the following key questions:   * Which co-designed components are feasible within the context of early intervention services and the specific population? * How can not immediately feasible changes be made? * What compromises need to be made, what are these?   Consensus will be sought for each of the individual programme components or features (e.g., programme length). As a result, Version 1 of the programme will be developed. |
| *Data source(s)* | Rating of components in terms of feasibility. |

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| **Workshop 3: Prototype as hypothesis** | |
| *Time* | Two hours (approx.) |
| *Participants* | FEP clients and their support. |
| *Objective(s)* | To collect feedback on Version 1 of the healthy lifestyle programme with regards to programme acceptability. |
| *Process* | Participants will be presented with the programme via a combination of written materials and verbal presentation.  Where components in Workshop 1 were not included, the rationale behind this exclusion will be clearly explained (autonomy support).  Participants will be asked to provide feedback on the suggested programme with regards to feasibility, accessibility, and appeal, in the form of verbal or written feedback (participants’ preference).  Participants will also be asked to provide suggestions for the name of the programme.  FEP clients and whānau/support will be asked to complete a modified version of the Healthcare climate questionnaire (HCCQ; see Appendix A) to ascertain perceived autonomy support and participant satisfaction throughout the co-design process. |
| *Data source(s)* | Data wall, interview transcriptions (for participants not wanting to participate in workshop). |

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| **Workshop 4: Programme revision** | |
| *Time* | Two hours (approx.) |
| *Participants* | EIS advisory group. |
| *Objective(s)* | To create a final revision of the programme that considers any suggested changes within Workshop 3. |
| *Process* | Feedback on Version 1 of programme as a result of Workshop 3 will be summarised and presented (verbally, written) to participants.  All suggested changes will be listed, and a facilitated discussion regarding each change and any revisions will be made revision of the programme based on this feedback to create Version 2.  Key questions regarding each potential change:   * Is the change viable, both in isolation and in combination with ? * Does the change align with the overall programme aims? * Can the changes be implemented with current resources, or are further resources required?   The reason for accepting or rejecting each change will be recorded, to provide sufficient rationale to clients (i.e., autonomy support). |
| *Data source(s)* | Rating of components in terms of feasibility. |

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| **Programme presentation / dissemination hui** | |
| *Time* | Two hours (approx.) |
| *Participants* | All stakeholders, including clients, whānau members, EIS advisory group, other service providers, and health service management. |
| *Objective(s)* | To disseminate project findings, resultant programme, and obtain final feedback from FEP clients. |
| *Process* | All project stakeholders will be invited to a presentation of the results of the project and the resulting programme.  FEP clients will be asked to indicate their approval of the programme with regards to the previously stated needs and requested features (relative to the contextual constraints) via a short survey.  Modifications are not expected to be made at this stage, although any minor changes will be considered. |
| *Data source(s)* | Questionnaires (FEP clients/whānau/support) |

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| **Final consultation and audit of current resources** | |
| *Time* | Two hours (approx.) |
| *Participants* | EIS advisory group, EIS research partners |
| *Objective(s)* | 1) To identify resources immediately available and create a minimal viable programme that can be delivered using these resources, and 2) to identify and write a grant application to deliver the full programme. |
| *Process* | The final project stage is a formal audit of what is required to deliver and evaluate the programme (e.g., contracting of exercise professionals or nutritionists to deliver sessions, venue hire) conducted.  A minimal viable programme will be constructed that can realistically and pragmatically be delivered with resources already available within WEIPS (with regards to staffing, logistics, equipment etc.).  Those resources that cannot be provided directly by WEIPS will be included in a research project grant that will be submitted in 2023 to deliver and evaluate the co-designed programme (e.g., HRC Emerging Research First Grant). This future grant will also include cost effectiveness analysis. |

**Dissemination**

**Videography**

A documentary or documentary series will be produced in conjunction with Frank Productions (<https://www.frankproductions.co.nz/>). This will mainly consist of interviews with:

* Clients and their families
* Toi Tangata
* Clinicians
* Researchers

For anyone that might be featured, appropriate permissions will be sought beforehand (via a section on the study informed consent form).

**One in Four podcast**

The research project will be featured on One in Four in an episode that explores the physical health of people living with serious mental illness.

**Proposed research papers**

* Lived experience of young people experiencing FEP (qualitative)
* Co-design process (implantation paper)

**Project reports for Lotteries Health and CCDHB**

* Completed as per provided templates.

**Appendix A: Questionnaires and surveys**

**Healthcare Climate Questionnaire**

Purpose: To assess the effectiveness of the co-design process in terms of giving participants autonomy in their healthcare (within a framework of self-determination theory).

Note - The original scale contains the word ‘physician’, which has been replaced here by ‘workshop facilitators’.

7-point Likert scale from 1 (strongly disagree) to 7 (strongly agree)

1. I feel that the workshop facilitators has provided me choices and options

2. I feel understood by my the workshop facilitators.

3. I am able to be open with the workshop facilitators at our meetings.

4. The workshop facilitators convey confidence in my ability to make changes

5. I feel that the workshop facilitators accept me.

6. The workshop facilitators have made sure I really understand about my condition and what I need to do.

7. The workshop facilitators encourage me to ask questions.

8. I feel a lot of trust in the workshop facilitators.

9. The workshop facilitators answer my questions fully and carefully.

10. The workshop facilitators listen to how I would like to do things.

11. The workshop facilitators handle people's emotions very well.

12. I feel that the workshop facilitators care about me as a person.

13. I don't feel very good about the way the workshop facilitators talks to me. (reverse-scored)

14. The workshop facilitators try to understand how I see things before suggesting a new way to do things.

15. I feel able to share my feelings with the workshop facilitators.

**Brief co-design acceptability survey**

1. Were there any aspects of the workshops that you particularly liked or disliked? If so, what were they?
2. On a scale of 1 to 10, how much do you feel that your opinion was heard during the workshops?
3. Do you have any other comments about this project?