



Australian
National
University



Join the conversation

**Evaluating the effectiveness
of experience-based co-
design in improving the
client experience of mental
health transition across
health sector interfaces**

Kate Cranwell

Professor Terence V. McCann

Meg Polacsek

AUTHOR DETAILS

Kate Cranwell, Community Services, Western Health, Victoria

Professor Terence V. McCann, Centre for Chronic Disease, College of Health and Biomedicine (Discipline of Mental Health Nursing), Victoria University, Melbourne, Victoria

Meg Polacsek, Community Services, Western Health, Victoria

ACKNOWLEDGEMENTS

This research is a project of the Australian Primary Health Care Research Institute, which is supported by a grant from the Australian Government Department of Health. The information and opinions contained in it do not necessarily reflect the views or policy of the Australian Primary Health Care Research Institute or the Australian Government Department of Health.

We would like to thank the consumer participants who were involved in the different phases of the project for sharing their experiences of mental health services and for contributing to the efforts to improve consumer experiences of transitions across services.

We also gratefully acknowledge the following contributors and participants:

Dr Gayelene Boardman, Centre for Chronic Disease, College of Health and Biomedicine (Discipline of Mental Health Nursing), Victoria University

Linda Kensington, Chief Operating Officer, South Western Melbourne Medicare Local

Lebe Malkoun, Director of Community Services, Western Health

Jenny Orr, Manager of Community Access Programs, Western Health

Staff of the Western Health Mental Health Hospital Admission Reduction Program and Mid West Area Mental Health Service



This work is licensed under a [Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License](https://creativecommons.org/licenses/by-nc-sa/4.0/).

Cranwell, K., McCann, TV and Polacsek, M. Join the conversation: Evaluating the effectiveness of experience-based co-design in improving the client experience of mental health transition across health sector interfaces. 2015. APHCRI.

Kate Cranwell

Western Health

Gordon St

Footscray 3011

Australia

T +61 4 1144 0728

E Kathryn.cranwell@wh.org.au

CONTENTS

Background.....	5
POLICY CONTEXT	5
REGIONAL CONTEXT	5
AIMS	5
LITERATURE REVIEW	6
Method.....	8
EXPERIENCE-BASED CO-DESIGN	8
TARGET GROUPS AND RECRUITMENT	8
Consumers	8
Health provider staff	9
RESEARCH TEAM.....	9
PROGRAM LOGIC MODEL	9
DEFINITIONS.....	10
DATA COLLECTION AND ANALYSIS	10
Consumers	10
Health provider focus groups and interviews	10
Data analysis	10
Joint workshop	11
Surveys.....	11
Database audits	11
Results.....	12
IMPLEMENTATION OF EBCD	12
Consumers	12
Health provider focus groups	13
Joint workshop	14
EFFECTIVENESS OF EBCD PROCESS	15
Consumer participants	15
Health provider staff participants	16
IMPACT OF IMPROVEMENTS	16
Surveys.....	16
Database audits	17
Discussion.....	19
Key findings	23
THE CONSUMER PERSPECTIVE.....	23
Experience-based Co-design	23
CREATING RESPONSIVE SERVICES	24
Fragmentation of services	24
Next steps.....	25

References.....26
Appendix 1: Program logic model.....28
Appendix 2: Verbatim transcript of consumer film.....29

Background

POLICY CONTEXT

This research project was informed by the goals of the current Australian health policy environment and reflects the key aims of:

- > Improving the quality of care for people with severe and persistent mental illnesses
- > Strengthening service models for the delivery of primary mental health care
- > Improving quality, accountability and innovation in mental health services.¹

The strong focus of this project on involving consumers in service improvement aligns with national and state policies of supporting greater consumer participation in the health care system. This commitment is articulated in several policy statements, including the Australian Government's agenda for collaborative government action in mental health¹, the Victorian Government's Doing it with us not for us policy² and the Partnering with Consumers Standard contained in the National Safety and Quality Health Service Standards.³

REGIONAL CONTEXT

The western region of Melbourne is one of Victoria's fastest growing and most diverse regions. Health demands are increasing and will continue to grow rapidly, fuelled by a high burden of disease, socio-economic disadvantage and population diversity.⁴ Mental health issues have been prioritised as a high need area by health services in the region.⁴ Also emphasised is the need to break the cycles of repeated crisis intervention and fragmented care experienced by people with complex mental, medical and social health care needs.¹

The project was led by Western Health, in collaboration with Victoria University, and endorsement from South Western Melbourne Medicare Local and Macedon Ranges and North Western Melbourne Medicare Local. Its focus was to work with consumers of mental health services to improve their experience as they transition from tertiary to primary care services and self-management support. By gathering the experiences of consumers, their families and those who work in the industry, the aim of the project was to promote service system integration and to provide a vehicle to plan locally responsive mental health services to streamline transitions between services and sectors. As such, particular attention was given to the transitions that occur when a consumer transfers between services and at the interface between acute and community care. In this context, 'transition of care' refers to the actions taken to coordinate and enable continuity of care for consumers as they transfer between different locations or levels of care within the same location.⁵

The project was endorsed by the Better Health Plan for the West.⁴ As the lead agency, Western Health's collaboration with other services in Melbourne's western suburbs aligned the project with one of the Plan's three health priorities (mental health) and three of its objectives, namely to:

- > Deliver services that are inclusive and culturally appropriate
- > Provide services that are well coordinated, easy to access and navigate
- > Develop a research program focused around health priority areas.⁴

AIMS

The overall aim of this project was to use EBCD to improve consumers' experiences of mental health services as they transition through tertiary services to primary care and self-management support. The specific aims of the project were to:

- > Understand the experiences of consumers as they transition through tertiary services to primary care and self-management support
- > Identify opportunities for service redesign and integration, to improve consumers' service transitions
- > Develop, trial and evaluate service redesign initiatives aimed at improving consumer experiences of transitions
- > Promote greater understanding of services, more integrated care across the system, and more effective communication between stakeholders.

LITERATURE REVIEW

In Australia, mental health care is provided by public and private sector services, general practitioners and non-government organisations. Service contexts range from hospitalisation and other residential care, to hospital-based outpatient services, community mental health care services, and general practitioners or specialists.⁶ Many consumers need a range of supports, which are provided directly by state / territory governments or through partnerships with non-government organisations.⁷ The Australian Government's principal role in delivering mental health services is to support primary care, which provides education and promotion, as well as early intervention, treatment and referral.⁷

Mental health is one of the eight streams of National Health Reform in Australia. Australia's National Mental Health Strategy has guided mental health reform since 1992, and aims to reduce the prevalence and severity of mental illness.⁸ The National Mental Health Strategy explains the range of psychosocial and environmental factors that affect mental health, such as income, employment, education and access to community resources.⁸ As such, a wide spectrum of interventions, from mental health promotion and mental illness prevention through to recovery, are required to address mental health problems.

However, data show that health services, including mental health services, tend to be fragmented and slow to respond, leading to poor health outcomes for consumers.⁹⁻¹¹ The Fourth National Mental Health Plan recommends improving coordination between primary care and specialist mental health services, and suggests that emergency and community services develop protocols that support care transitions between services.¹ In acknowledging that these improvements depend on collaboration between services as well as integrated models of service delivery, another recommendation of the Fourth National Mental Health Plan is that health provider staff should engage actively with consumers at all levels, including research, policy development and service delivery.¹

Nowadays, consumer participation is generally accepted as part of healthcare research.¹² Involving consumers in planning, delivery, implementation and evaluation of activities has been shown to have significant benefits for consumers and health providers.^{13,14} Consumer participation in mental health services enhances social inclusion, which is considered integral to the recovery process,¹⁴ and enables health providers to gain new insights and build positive relationships with consumers.¹²

Engaging consumers and health provider staff in evaluating and developing services creates more responsive services and a workforce that better meets the needs of consumers and the broader community.^{12,14} While involving consumers in service improvements is well established, the methods used have been limited mostly to surveys, audits or attendance at meetings or events, and are not necessarily focused on understanding consumer experiences.¹⁵ There is increasing evidence suggesting that these approaches are often poor at allowing consumers to express what really matters to them.^{15,16}

One way of bridging this gap with consumers is to adopt a co-design approach. While still an emerging social practice,¹⁷ co-design refers to partnership and shared leadership between consumers and professionals.¹⁸ Rather than health providers just listening and responding

to consumers, co-design brings groups of stakeholders together to collaboratively produce new understandings and design service improvements.¹⁷ One such co-design process is Experience-based Co-design.¹⁹

EBCD was developed by The King's Fund for the National Health Service in the United Kingdom and was first piloted in a head and neck cancer service in England in 2005.²⁰ EBCD has been implemented in a range of settings in several countries, but is relatively new in its application to the Australian setting.¹⁸ Interest in the use of EBCD in the mental health setting is increasing, with several recent studies showing promising results in community and in-patient settings.^{19,21}

As a participatory action research approach, EBCD is user-centred (experience-based) and leads to collaborative change (co-design) between consumers and health providers.¹⁹ EBCD is a phased process in which consumers and health provider staff capture and then seek to understand their lived experiences of healthcare services.²² They then work together to improve the service based on this shared understanding, and, subsequently, evaluate the effects of changes to the service.²² As such, EBCD gives consumers an active role in identifying, implementing and evaluating improvements to healthcare services.²⁰ By reconceptualising the role of consumers, the approach provides a structured process for their participation in the quality improvement process.²⁰ In so doing, EBCD enables a shift in focus from routine collection of patient data to embedding co-design practices and values in healthcare organisations.²⁰ When used effectively, EBCD enables health providers to:

- > Understand what is currently working well
- > See where consumer and care experiences can be improved
- > See where workforce skills need to improve
- > Change organisational systems to improve consumer care and experiences.¹⁹

However, the discovery phase involving consumer interviews and health provider staff focus groups – on which quality improvement activities are based – is often lengthy and costly, which may present a barrier to the adoption of EBCD.^{23,24} Although evidence to date supports EBCD as a rigorous methodology, previous experience of using EBCD at Western Health has found that, although effective, it is a time and resource intensive process. As such, there is a need to further evaluate the effectiveness of EBCD in producing sustainable change to consumer experiences.^{17, 23-25}

Method

EXPERIENCE-BASED CO-DESIGN

EBCD involves gathering experiences from consumers and health provider staff through in-depth interviewing, observations and group discussions; identifying key ‘touch points’ (emotionally significant points) and assigning positive or negative feelings. A short edited film is created from the consumer interviews. The film is shown at a joint workshop of consumers and health provider staff, conveying in an impactful way how consumers experience the service. Consumers and health provider staff then identify jointly areas for redesign and work together to make improvements to the service and care pathways. As such, EBCD differs from other consumer experience methodologies because consumers and health provider staff work collaboratively to identify, design and implement service improvements.²⁵

Detailed information, guidelines and templates about EBCD are publicly available from The Kings Fund website²⁶; however, the EBCD approach adopted in this project is summarised in Figure 1.

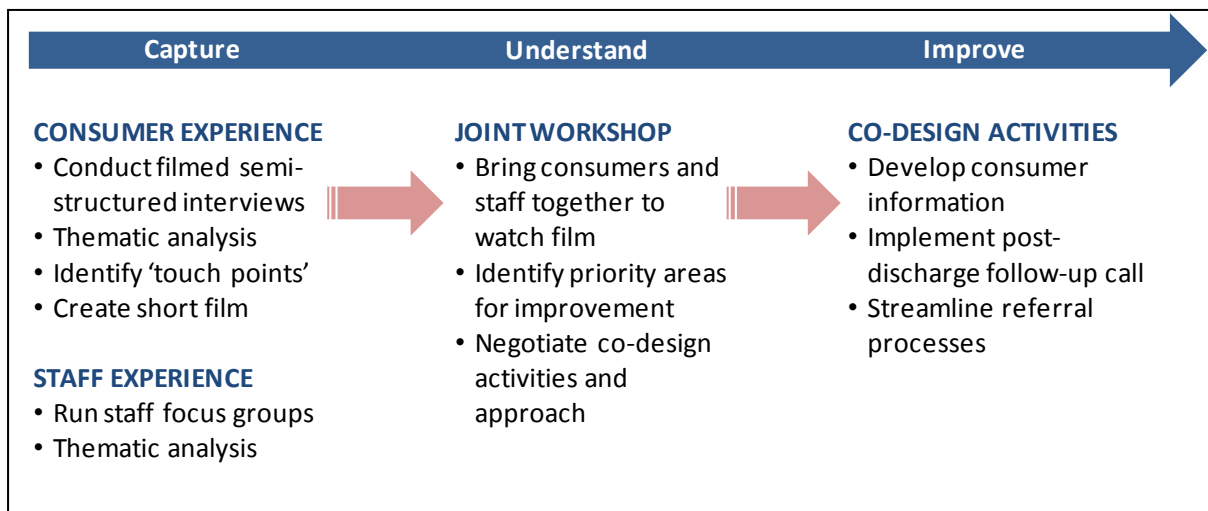


Figure 1: EBCD implementation [Adapted from 27]

TARGET GROUPS AND RECRUITMENT

Ethical approval to conduct the project was given by Melbourne Health Human Research Ethics Committee and Western Health Office for Research. Inclusion and exclusion criteria applied to participants. All participants were required to provide written consent at different stages of the project.

Consumers

Consumers with mental health and complex health care needs, who were frequent presenters to the emergency departments and high users of health care, were targeted for inclusion in the project. They were recruited through the Mental Health Hospital Admission Reduction Program (MH HARP) at Western Health.

MH HARP is a pilot initiative funded by the Victorian Government Department of Health that provides coordinated community-based care to people with a mental illness who present frequently to hospital emergency departments, seeking treatment for urgent and/or non-urgent issues.²⁸ MH HARP is being piloted in three health services in the Melbourne metropolitan area over a five-year period, from 2013. The entry criteria for MH HARP is people who have two or more emergency department presentations within 12 months and

have a mental health issue, or complex health and psychosocial needs, and who could benefit from a period of intensive care coordination to link them with suitable community services and build their self-management capacity. MH HARP provides intensive care coordination and support for up to six months. Typically, case managers make referrals to short-term clinical treatment and community-based services and supports, stabilising and building clients' capacity to self-manage.

The project aims and approach were explained to potential participants, who could then make informed decisions about their participation. The number of eligible consumer participants to interview was less than anticipated, mainly due to the relative newness of MH HARP, which commenced as a pilot program in July 2013, and the need for consumers to have been discharged from the service before being approached to participate. However, the research team had a good success rate with consumers who were invited to participate, with over half those approached consenting to take part in the video-recorded interviews. As such, 16 consumers agreed to participate, comprising:

- > Twelve 'patients' (nine women and three men)
- > Four carers
- > Average participant age of 60.2 years, ranging from 24 to 86
- > Two participants - one patient and one carer - from a culturally and linguistically diverse background.

Health provider staff

Participants were recruited from MH HARP, two regional mental health services and broader community services programs at Western Health. Most participants were involved in front-line work with consumers, although they worked across several different services and organisations.

General practitioners (GPs) were also invited to participate, with notices published in Medicare Local newsletters and invitations sent to a list of GPs whose patients were identified in the MH HARP data.

RESEARCH TEAM

The project research team provided expertise and advice on consumer and health provider staff engagement, data collection and analysis, and implementation and evaluation of improvement activities. The team also provided clinical expertise about their perceptions of the experiences of consumers with complex mental, medical and social health care needs. The team met regularly throughout the project and consisted of researchers from three institutions:

- > Western Health: Kate Cranwell (Lead Researcher), Meg Polacsek (Project Manager) and Dr Jo Silva (Associate Researcher)
- > Victoria University: Professor Terence V. McCann (Principal Researcher) and Dr Gayelene Boardman (Associate Researcher)
- > South Western Melbourne Medicare Local: Linda Kensington (Associate Researcher).

PROGRAM LOGIC MODEL

A program logic model was developed to graphically depict the resources, activities, outputs and outcomes of the project (Appendix 1).

DEFINITIONS

For the purposes of this research project, the term 'consumer' refers to both patients and carers associated with the Western Health MH HARP service.

DATA COLLECTION AND ANALYSIS

Data collection took place between March and August 2014. To address the research aims, data collection and analysis were organised in three phases:

- > Implement EBCD to obtain consumer and health provider staff views, and to identify priority areas for improvement
- > Evaluate the effectiveness of the EBCD process in increasing consumer involvement in service re-design and improving consumer experiences of transitions
- > Evaluate the impact of the improvement activities implemented as a result of the EBCD process.

Data were collected from health provider focus groups, filmed consumer interviews, a joint consumer / health provider staff workshop, surveys and database audits.

Consumers

Filmed interviews were conducted over a three-month period in 2014. Interviews took place in consumers' homes and lasted from 45 to 60 minutes. The project manager conducted each interview, supported by a colleague who managed the technical aspects of the interview, such as monitoring the camera and microphone. All interviews were conducted in English without the need for interpreter support.

Health provider focus groups and interviews

Two focus groups were conducted in March 2014 to capture the views of 17 health provider staff members.

Semi-structured, individual face-to-face interviews were also conducted with four regional GPs between May and July 2014.

The focus groups and GP interviews were audio-recorded, with verbatim transcription conducted by an independent service provider.

Data analysis

The footage from the video-recorded interviews was reviewed by the research team, who identified, coded and organised the data into meaningful themes and sub-themes, with key 'touch points' selected from each interview.

Smith and Osborn's method was used to analyse the data gathered from health provider interviews and focus groups, as follows:

- > Transcribed data were read and re-read to obtain a broad appreciation of consumer participants' experiences of transitioning through services
- > Manual coding of the raw data was undertaken using NVIVO software
- > Codes were grouped together and, from these, themes were identified
- > Themes were grouped into groups of themes and sub-themes
- > Data reduction occurred concurrently, omitting themes that were insufficiently grounded in the data.²⁹

A more intense analytical arranging of themes then took place, encompassing rearranging and refining themes and abstracting them to a higher level.²⁹

Video clips and key quotes that best illustrated the themes were then selected. Participants were given the opportunity to view, discuss and provide consent for the use of the edited clips from their particular interviews. A story-board of consumer film clips, staff quotes, voiceover files and images was compiled and sent to an external production house, which created a 20-minute film that depicted mental health consumer experiences. Use of a professional editor and production house ensured that the footage flowed and moved seamlessly from one speaker to the next, grouped by theme.

Joint workshop

A joint consumer and health provider staff workshop was held in August 2014, bringing together seven of the 16 consumers who took part in the filmed interviews, six of the staff who participated in focus groups and one of the GPs who had been interviewed previously. The workshop was facilitated by Professor Terence V. McCann, who has extensive experience in running focus groups. Participants watched the film, discussed the footage and identified priority areas for improvement through a process of facilitated discussion.

Surveys

Consumer and staff participants were asked to complete surveys on their experiences and views of the effectiveness of the EBCD process. These surveys, adapted from the EBCD patient feedback forms produced by The King's Fund,¹⁹ included five quantitative (closed) and three qualitative (open-ended) questions, and provided opportunity for comment. The closed questions about the filmed interviews produced responses that could be categorised and counted according to the options selected by the respondents. This enabled a clear understanding of participants' views on particular aspects of the project, such as their understanding of the aim of the project and the experience of being filmed. In analysing responses to the open-ended questions on participants' views of what was done well or could have been done better, consistencies and differences were listed and analysed, to explore connections and relationships (if any) between responses.

Database audits

An audit of information captured on a routine basis by MH HARP was conducted to identify response times and patterns of referrals to and between services for a baseline and post-implementation period.

Results

The overall aim of this research project was to improve consumer experiences of mental health services as they transition through tertiary services to primary care and self-management support. Consistent with the approach used to collect and analyse data, the results are presented under:

- > Implementation of EBCD
- > Effectiveness of EBCD process
- > Impact of improvements.

The results are outlined below and discussed in the following section.

IMPLEMENTATION OF EBCD

EBCD was used as a qualitative means to understand consumers' experiences, identify opportunities and implement initiatives to improve their experiences of service transition, and to promote greater understanding of services, more integrated care and more effective communication.

Consumers

The themes highlighted in the consumer interviews are shown in Table 1.

Table 1: Summary of themes – Consumer interviews

Theme	Illustrative quotes
Views on the service	I haven't got to where I am now without her helping me, because I was just a cot case
	It was good ... yeah ... it was good because I could talk to him about how things were going and staying out of the hospital, rather than going back into it
Connecting with the MH HARP service	I was a bit perplexed when they come to see me ... because I didn't know really what they were going to do
	Very nervous to begin with, 'cause I thought, 'Here's a complete stranger, coming into my life, and I have to tell them everything'
Overall experience	Pretty intimidating, actually ... yeah, I felt intimidated because I wasn't asked. I was told what was going on, rather than asked what was going on.
	Some of them don't listen. I say, 'You're not listening to me. I don't want that. I'm telling you how I feel'
Personal insights	At the time I was really worried about my kids, not being able to ... you know, who's going to take them to school?
	I lost all my friends, because I developed something that I didn't know was happening to me
Moving between services	There was no follow-through once I got home, I got sort of forgotten again
	The communication was difficult ... You ring up and say 'Where is he?' and they've gone on holidays. This kind of thing ...
	It was, 'Everything going alright?' She talked it over with me and she said, 'You think you're right to handle it?' And she said, 'Any time you need to, you can get in touch with me'.
Confusion	There was a bit of confusion there, like with the services. There's so many. And at the time, you know, you're a bit confused already, and then make it even more confused.

Theme	Illustrative quotes
	It was basically cut off from one and that's about it sort of thing, rather than putting you onto another and putting you onto another.
Carers	It's very confronting having to make that choice for them ... And if not all the information is there and stuff's missed, it just causes so much more trauma and stress. We've met a lot of people over the last few years, far too many. There's no need for that. There's no consistency, you know, there's no sort of goal. It's just endless at the moment.
Opportunities for improvement	Someone that could come and check that you're alright, even if it's only a phone call, it's good. Even if someone does quit the service, or you stop seeing someone for some reason, that you follow up to see that they've got someone else, that they've gone with another program, get another program to be in contact with them. What I needed back then was someone to guide me, to help me. Because I didn't know which service to go to ... there's so many. A package or something, you know, that has information for carers that's simple and easy to read, and someone to say, 'Here's my phone number. If you're having trouble, give me a call and we'll see how we can help you.'

A verbatim script of the film is provided in Appendix 2.

Health provider focus groups

Seventeen health provider staff attended one of two facilitated focus group sessions. The responses elicited from the focus groups and individual interviews with four GPs are shown in Table 2.

Table 2: Summary of themes – Health provider focus groups and GP interviews

Theme	Issue	Illustrative quotes
Perceptions of consumers' emotional responses to services	Not heard	They feel they're not heard by the system
	Fearful	Scared would be one of the words that I would use
	Confusion	Their understanding can be quite confusing ... where we fit into the system and not fully really understanding the system to begin with
	Frustration	There's a lot of frustrations when they're being moved around
What health providers felt consumers thought they did well	Availability	Being able to sit down with the person
	Advocacy	There's someone there that can have involvement with the different services
	Assessment	We spend considerably more time with them and get a far better picture of actually what's going on
	Coordination	The coordination of all those appointments and all those waiting lists
What the service could do better	Provide support	For some people, they will say it's the first time I've been able to say this in my own language
	Attitude	They often have a pre-conceived idea about why they're coming in
	Better medical coverage	It would be useful to have a general doctor or someone in the clinic

Theme	Issue	Illustrative quotes
	Training	[General] staff lack the mental health training and confidence in treating patients with mental health conditions
	Better service delivery	There's long waits. Then they'll have to go to other areas, which is difficult for them.
Service provider perspectives of what the service does well	Follow-up	Ensuring people get follow-up after they leave
	Talking and listening	I think we're good at talking to people ... they feel that they've been heard
	Being responsive	We can be responsive when we need to be
	Continuity and support	We know what the long-term plan is ... and we're there to follow that through
Family involvement	Benefits	I think they're very central, they're the keys to the continuity of care, really
Collaboration	Communication	We have daily communication ... and then discuss referrals and pick up referrals
	Technology	I just wish there was a more streamlined communication system we could use
Opportunities for improvement	Streamlining services	So that they don't have to talk to different people and keep telling your story
	Sharing common resources	A single point of referral
	Promotion	Raising the profile of services ... so that we're all aware of what each other does

Joint workshop

At the joint workshop, participants watched the film, discussed the footage and identified priority areas for improvement through facilitated discussion. Key themes identified through this process are shown in Table 3.

Table 3: Summary of themes – Joint workshop

Theme	Sub-theme
Access and pathways	Accessing the system through different pathways, often with long waiting times Duplication of assessments and/or referrals not picked up Falling through the gaps.
Early engagement	Lack of information and communication Not informed of what to expect from services or other options Help to navigate the system.
Continuity and follow-up	Increase information transfer across services Provide long-term case management Follow up to ensure transition to a new service has occurred.
Relationships and engagements	Promote connection with care manager Assist with service navigation and access.

Theme	Sub-theme
Carers	Greater involvement, particularly in goal setting and discharge planning Need more information on carer support.
Crisis-based service orientation	Services are crisis-focused, but then not ongoing.

The three main co-design initiatives selected for implementation are summarised in Table 4.

Table 4: Summary of co-design initiatives

Co-design initiative	Status
Design and develop consumer information on MH HARP	A new brochure explains the MH HARP service, including information on who the service is for, how it works and how it can help A direct contact number is included on the brochure The brochure is provided to all new clients referred to the service.
Design, implement and evaluate a consistent post-discharge follow-up process	MH HARP clinicians now contact clients within four weeks of their discharge from the program, to ensure that the arrangements made at the time of discharge have supported their continuity of care Consumers are now also asked to share any feedback on the service, which is included as a standard item on team meeting agendas.
Increase awareness and understanding of the role of MH HARP	Meetings have been held with key stakeholders, to establish opportunities to improve communication and streamline referral between MH HARP and regional mental health service providers At the time of reporting, this work is ongoing.

Taking into account the scope and timeframes of the project, these co-design initiatives were seen as achievable and of immediate benefit to both groups. The development of consumer information about MH HARP, for example, was something practical and tangible that engaged staff during the development process and would be immediately useful to future service users.

EFFECTIVENESS OF EBCD PROCESS

Surveys containing quantitative and qualitative questions were used to evaluate the effectiveness of the EBCD process.

Consumer participants

In a telephone survey conducted after the individual filmed interviews, all 16 consumer participants reported that:

- > They felt comfortable sharing their views and experiences
- > They had the opportunity to ask questions
- > They were glad to have the opportunity to share their experiences and provide feedback
- > EBCD is a good way for health providers to gather consumer feedback.

In response to a question about the usefulness of EBCD to obtain consumer feedback, verbatim quotes from consumers during the telephone survey indicated they valued the approach adopted in the project:

- > 'Talking to someone is much nicer than writing it down on a piece of paper'
- > 'It made me feel like I have a voice'
- > 'I think its [EBCD] the only way to do it'.

In a survey administered after the joint workshop, consumers indicated that their experiences of seeing the film were 'excellent' or 'good', although several noted that 'there was not enough group involvement'. All consumers felt that they had received appropriate information and support to enable their attendance at the workshop.

Health provider staff participants

Of the 17 staff who participated in the focus groups, nine completed and returned evaluation surveys. Their responses indicated that they either 'strongly agreed' or 'agreed' that:

- > It was useful to hear the views and experiences of colleagues at the focus group
- > Staff were able to express their views in the focus group.

There were mixed views about the composition of the focus groups, with some participants valuing the 'good mix of clinicians from other areas', while others indicated that it was not useful to have a mixed group of staff. Several suggested that they could have prepared better for the workshop if the questions had been sent to them before the session.

In a follow-up survey distributed after the joint workshop, staff indicated that they felt that consumers may not understand the complexities relating to the different functions, funding models or organisational boundaries of different mental health services and how they interact. The view of mental health services as siloed, complicated by different auspicing arrangements between health providers, was seen to make any efforts aimed at improving consumer experiences particularly challenging.

IMPACT OF IMPROVEMENTS

Surveys

Seven out of 16 consumers (43.8%) chose to continue their involvement in the project and nominated their preferred means of participation. These consumers shared their views on the improvements that had been implemented within MH HARP, and on the experience, effectiveness and sustainability of the EBCD process. In a second telephone survey conducted with consumer participants (n=7) after improvements had been made:

- > All reported that the new brochure would have improved their understanding, and would be useful to new clients, of the service
- > All reported that a post-discharge follow-up telephone call would have been useful, although one consumer raised the need to consider how the service would be able to re-admit a client, if the arrangements made for ongoing support at discharge had not been successful

- > All felt that EBCD was an effective approach to involving consumers to identify and develop improvements.

Two improvement activities were implemented within three months of the joint workshop, while efforts to progress the third improvement initiative continue. In a follow-up survey three months after the improvements were implemented, MH HARP clinicians indicated that more time would be needed to evaluate the impact, effect and sustainability of improvements.

Database audits

An audit of information captured on a routine basis by MH HARP indicated that the referral process between the emergency department and MH HARP had been enhanced, with more appropriate referrals being made and consumers accessing the service sooner.

Comparisons between a baseline period (September to November 2013) before the project improvements were implemented and a post-implementation period (September to November 2014) demonstrate an increase from 33 to 55 per cent of new consumers seen within one week of being referred to the program (Figure 2). Clinicians expected that this improvement was due to greater understanding of the service and its referral criteria, which had been identified as an area for improvement.

Following the implementation of service improvement initiatives, additional fields were added to the database to facilitate accurate data capture and reporting in future.

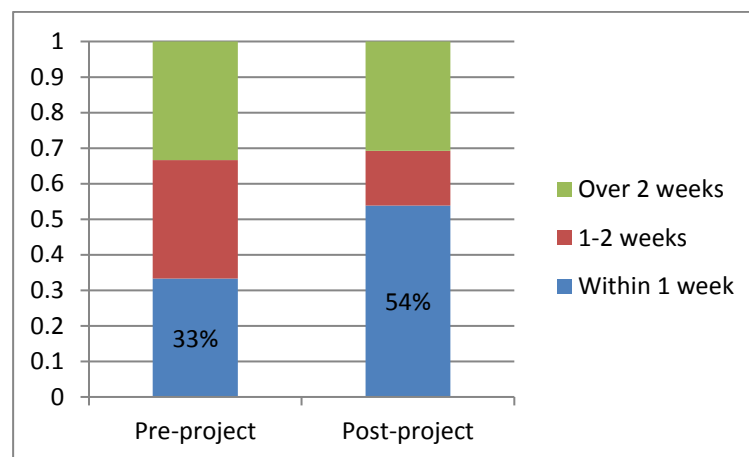


Figure 2: Responsiveness from referral to assessment

An audit of the frequency of post-discharge follow-up telephone calls made for the same time period revealed an increase in clients receiving a post-discharge follow-up call (Figure 3).

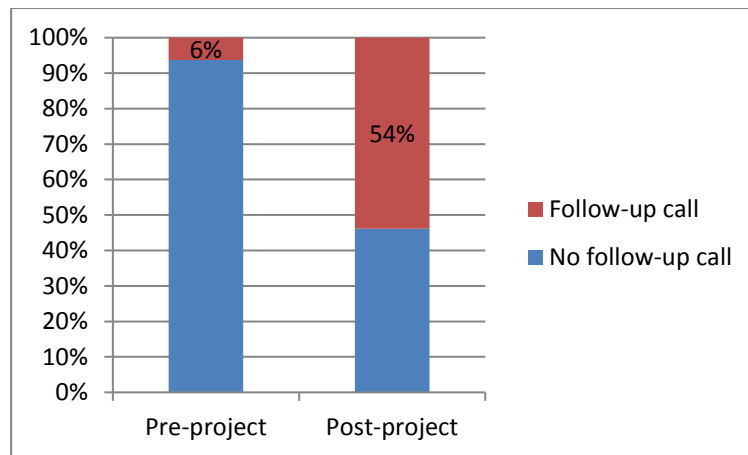


Figure 3: Improvement activity – Post-discharge follow-up telephone calls

Due to the number of different services and organisations typically involved in supporting each client, there is no single data source that captures the client’s overall transition across the continuum of care in the mental health system. However, an audit of deidentified MH HARP client data for the pre- and post-project review periods revealed an increase from 33 to 50 per cent of clients being referred to or linked in with a greater number and range of appropriate support services in the post-implementation period. This improved focus on referrals to and linkages with other health providers, as well as the new practice of conducting individual follow-up calls, seek to ensure that transitions are occurring as planned. Anecdotal comments from staff suggest that this may be attributable to an improved understanding of the particular needs of consumers and the importance of the role of MH HARP in supporting these consumers as they transition across or between different services.

We are cautious, however, in attributing these improvements to the EBCD project alone, given that processes and services continue to be influenced by several factors, including broader organisational change, the functional nature of MH HARP and the fact that mental health services are delivered in silos and not streamlined as a continuous, comprehensive journey.²² As such, the transferability of findings from this research project is limited.

Discussion

EBCD is intended to engage consumers and health provider staff in a collaborative approach.¹⁷ New understandings and behaviour depend on all stakeholders being prepared to actively participate in the process.¹⁷ By bringing together internal and external stakeholders who previously had limited joint input into service design and delivery, the EBCD approach adopted in the present project provided a forum in which consumers and staff collaborated to generate service improvements.^{16,17} The results of this project support EBCD as an effective means of capturing consumer and staff experiences, as it provided a framework for understanding the impact of duplication and fragmentation of care. The results provide valuable insights into the experiences of consumers with complex mental, medical and social health care needs.

The success of this research project is seen in consumers' high level of interest and active engagement in the EBCD approach. Despite a relatively small pool from which to recruit potential participants, the research team was successful in recruiting 50 per cent of consumers who were invited to participate in the project. Follow-up surveys with consumers elicited positive statements about their experience of having had the opportunity to share their stories and participate in service improvements. This positive response to the consumer experience of EBCD is consistent with findings of other EBCD projects, which indicate the success of this particular methodology in engaging consumers effectively.¹⁸

While several consumers indicated their interest in participating in future service improvement activities at Western Health, this project also provided the impetus to identify opportunities for clients to provide feedback on an ongoing, less formal basis. For example, the guidelines for post-discharge follow-up calls include a prompt to elicit general feedback on the service, or suggestions for how the service could be improved. Under this new process, consumer feedback and suggestions will be addressed in regular team meetings of frontline staff and used to inform continuous service improvement.

Those involved in filming, reviewing and editing the consumer interviews also reported how powerful it was to be directly involved in capturing consumers' experiences and seeing them as 'real people'.

However, the effectiveness of any methodology depends on the staff applying it and their sense of ownership of change opportunities and processes.²² In this regard, we encountered several challenges. Several staff who attended the joint workshop, for example, reported that it had been confronting to see the film for the first time. While the main purpose of the film in EBCD is to trigger discussion,¹⁸ the result on this occasion was that most staff participants at the workshop spoke very little during the post-film discussion. The facilitator's ongoing efforts to position the purpose of the film and workshop in a manner that was consistent with the EBCD toolkit had little impact on staff participation. The consumer participants, however, remained engaged with the facilitator and members of the project team who were present. Towards the end of the workshop, consumers and members of the project team agreed that the co-design activities would be addressed through individual consultation with consumers and additional meetings with staff. This adaptation to the usual EBCD process of structured joint working groups was in response to consumers' preference to be visited at home or contacted by telephone, due to their chronic mental and physical health issues. The project team also recognised that this flexibility might provide additional opportunity to re-engage with staff who had found the joint workshop confronting.

Shortly after the joint workshop, a follow-up meeting was held with the MH HARP team to show the film again and to confirm the priority areas for improvement and the approach to implementing co-design strategies. At this forum, the team reflected on their initial reactions to the film and reported that the experience of seeing the film for the second time was less confronting as it had been in the joint workshop.

The lower than expected level of staff participation in several aspects of the project, in particular in the joint workshop, should be seen in the light of several mitigating factors. Finding themselves in new roles in a new mental health service, for example, members of the MH HARP team were focused on providing a new service to newly referred consumers. More broadly, they also faced several challenges at the organisational and system levels, which may have influenced their beliefs about opportunities and scope for change. These included:

A restructure of Western Health's Community Services, announced soon after the project commenced.

The developmental nature of the MH HARP service, which had only been in place for approximately three months before the project commenced. This meant that recruitment, policies and procedures were still being refined and embedded when the project commenced. It also meant that it was difficult to enlist somebody within the service to actively drive the implementation of ideas.

Western Health relies on a partnership arrangement with two regional mental health service providers to support consumers with mental health and complex health care needs who present frequently to its emergency departments. Furthermore, at the time the project commenced service and individual role delineation across the different services were still being negotiated and streamlined.

The lack of a single data source that captures episodes of care across a consumer's transition through the mental health system. While a customised data collection tool was developed for the purposes of the MH HARP trial,²⁸ it was not always possible to link the data collected through this method to individual client records.

Despite government legislation, structural changes in mental health systems and advocacy for recognising its significance, consumer participation is still a challenging issue for some frontline staff.³⁰

The nature of staff participation is known to affect project outcomes and effectiveness, and several EBCD projects have reported challenges in engaging staff.^{18,22} That said, staff often become more engaged as a project progresses or when they realise a project's usefulness and purpose.¹⁸ To some extent, these challenges match those documented by other similar projects, which have found that the change process raised issues in relation to staffing, power relations, time and resources.^{17,18,25,31} Despite additional efforts to inform and engage staff through ongoing communication and encouragement, this meant that the research team could push ideas, but that the staff were not pulling those ideas forward.²²

Notwithstanding these difficulties, three co-design initiatives were identified, developed and implemented following the joint workshop in this project. Consumer participants in the project reported that the improvements outlined above would have been of assistance to them when they accessed MH HARP. However, staff indicated that more time is needed before the effectiveness and sustainability of the improvements could be evaluated properly. Notwithstanding the time and resource parameters of the project, indications are that the particular difficulty in engaging key staff had an adverse impact on the implementation and sustainability of improvements.

Like consumers, staff are rarely involved in determining the research agenda, proposing research questions or providing interpretation of results. Involving staff in identifying and developing the research brief, defining and setting standards of care, and supporting active leadership at the service level may facilitate the sustainability of any improvements or changes.¹¹ Future projects might benefit from engaging consumers and front-line staff in the development of the project, not just during implementation. It may also have been beneficial to have frontline staff members within MH HARP itself who were committed to the project, rather than a separate research team being seen to impose the project on the service.

On a service level, real improvement is more likely when co-design activities apply across consumer transitions from admission to recovery. However, the range of services, different funding sources and mechanisms, approaches to treatment and service cultures create duplication and gaps, resulting in a system that is fragmented and difficult for consumers to navigate.³³ These challenges also apply to research projects that seek to understand and improve the consumer experience, and future projects should consider carefully whether or how to tailor EBCD to suit particular settings.²⁵ At this point in the project, it might have been useful to have some information or guidelines on whether or how the typical EBCD process could be adapted without its integrity being compromised. Indeed, an approach that more deliberately combines service design and change management may have produced better results, with commitment (rather than compliance) by all parties supporting the sustainability of improvements.³³

With mental health care being provided by public and private sector services, general practitioners, as well as non-government organisations, improved service integration requires structural and cultural change at the local, organisational and system levels. In an attempt to address these challenges, representatives from all partner organisations were included on the project's research and steering groups, providing an opportunity to share information across several organisations. However, despite their initial endorsement of the project, there were different levels of engagement across partner organisations. It also may have been beneficial to engage with policy makers at the project planning and design stage, to support the concept of a 'community of solutions' to facilitate the uptake of research findings to improve health care outcomes.⁵ A partnership approach between consumers, health providers and policy makers may be more effective in enabling sustainable change that improves care coordination and reduces service fragmentation.^{12,33} This is particularly true in the mental health sector, given the complex mix of planning, culture and policy change, levels of care, and service and funding models that are needed to better coordinate and integrate services.¹⁰

Despite the challenges discussed above, key lessons from this project are being shared across Western Health. The successes and challenges experienced in this research project are being used to inform a broader consumer engagement approach at Western Health, whereby consumers could be actively involved in service improvement and design. It is expected that these initiatives will take consumer participation beyond consultation, to an ongoing process of representation, partnership and co-design. These activities reflect the aim of Standard 2 (Partnering with Consumers) of the National Safety and Quality Health Service Standards of supporting consumers to actively participate in improving their experiences of services.³

Furthermore, the experience of using EBCD as a consumer engagement methodology is informing the development of a framework for increasing consumer participation in service redesign more broadly across the organisation. For example, several other departments have sought information and advice from the research team on consumer participation opportunities and strategies. Over and above aligning with the regulatory requirement to partner with consumers,¹⁻³ these efforts to adopt elements of EBCD into other service improvement initiatives and to integrate the broader concept of EBCD into everyday practice reflect a genuine commitment by the organisation to support active consumer participation in service improvement and design.

Opportunities for knowledge exchange with other stakeholders, identified throughout the course of the project, are also being used to support the effectiveness and sustainability of the outcomes and outputs outlined in the program logic model (Appendix 1). The film has been shown in several forums, while two shorter films of some seven minutes' duration have been developed, highlighting consumer views on hospital and inpatient experiences, and ambulance and emergency department experiences. The two shorter films were developed on the suggestion of local quality improvement coordinators, who recognised the value of presenting the consumer experience to staff of specific services during shorter professional

development activities. Given that the main purpose of these films is to trigger discussion,¹⁸ the project team has developed speaking notes that introduce and contextualise the films. The aim is that films shown in different settings will be presented and positioned in a way that is appropriate to the audience and respectful of the consumers who originally provided insights into their experiences in relation to a particular service and for a specific purpose.^{20,34}

In the rapidly growing western region of Melbourne, additional factors to be considered include a high burden of disease, socio-economic disadvantage and population diversity.⁴ While the cultural demographics of the participants in this research project were not necessarily reflective of the region's diversity, it is unclear how well EBCD may be embraced by different cultures. For example, some cultural groups prefer to share their experiences through story-telling, rather than participating in filmed interviews.³⁵ As such, models of enquiry and research to inform service planning should be adaptable to different contexts.

Policy implications from this project span local, national and international systems and sectors. Coordination and continuity of care is possible and beneficial, but is dependent on effective leadership, governance and funding models.¹⁰ As a starting point, it is important to define the concepts of care coordination and integration at the policy level. Similarly, appropriate outcome measures should be established in order to assess elements of continuity of care, care transition and improvement in coordination.¹⁰ More in-depth research over a longer period of time may be useful in this regard.

One of the real strengths of this project in general, and EBCD in particular, is that it allowed consumer participants to feel that their views had been heard. While more time is needed to determine whether tangible and sustainable improvements to service delivery and integration have been achieved through this project, it provided real impetus to expand and support consumer involvement in future service improvement and planning.

Key findings

The overall aim of this project was to use EBCD to improve consumers' experience of mental health services as they transition through tertiary services to primary care and self-management support. Our key findings are summarised as follows:

THE CONSUMER PERSPECTIVE

- > Effectively involving consumers in planning, delivery, implementation and evaluation of services has the potential to deliver significant benefits to consumers and health providers.
- > Understanding the impact of duplication and fragmentation of care from the consumer perspective provides a powerful impetus for developing strategies that promote service integration and responsiveness.
- > Giving mental health consumers the opportunity to participate in service improvement and development activities enhances their sense of social inclusion, considered integral to the recovery process.
- > Follow-up surveys with consumers who participated in this research project elicited positive statements about the opportunity for them to share their experiences and participate in service improvements. This outcome adds to the body of knowledge that demonstrates the value in involving consumers in service improvement and design.

Experience-based Co-design

- > EBCD aims to engage consumers and health provider staff in a collaborative approach, with new understandings and behaviours depending on stakeholders being prepared to actively participate in the process.
- > While it is a time and resource intensive process, EBCD has demonstrated success in engaging consumers effectively.
- > Three co-design initiatives were initiated through the EBCD process:
 - Development of consumer information on MH HARP
 - Design and implementation of a consistent post-discharge follow-up process
 - Work continues on improving communication and referral between MH HARP and regional mental health services, with a view to facilitating service integration across the mental health system.
- > A survey conducted as part of this project revealed that all consumer participants were pleased to have the opportunity to share their experiences, suggestions and feedback, and felt that EBCD was a good way for health providers to obtain consumer feedback.
- > We experienced several challenges in the project with health provider staff engagement and commitment. These challenges are not a reflection on the EBCD methodology as such, but, rather, were the result of organisational and system level issues, including a restructure of Western Health Community Services, announced soon after the project commenced and the developmental nature of the MH HARP service that was at the centre of the project.

CREATING RESPONSIVE SERVICES

- > Involving consumers and health provider staff in evaluating and developing services has the potential to create a more responsive service that better meets the needs of mental health consumers.
- > While preliminary findings suggest that service improvement initiatives identified through this project may positively influence consumers' experiences, more time is needed to evaluate their effectiveness and sustainability.
- > The project has led to an increased focus on referrals to and linkages with other health providers, and follow-up to ensure that transitions occur as planned.
- > Consumer participants in the project reported that the improvements implemented through EBCD would have been of assistance to them when they accessed MH HARP.
- > A broader culture change approach is needed in services to embed consumer participation in service improvement and design activities.
- > As with any methodology, the effectiveness of EBCD depends on the nature of staff participation and application. Close attention should be given to the roles, responsibilities and commitment of the project team, frontline staff and the broader management hierarchy.
- > On a service level, real improvement is more likely when co-design activities apply to consumer transitions from admission to recovery.
- > The range of services, different funding sources and mechanisms, approaches to treatment and service cultures create duplication and gaps, resulting in a system that is fragmented and difficult for consumers to navigate. Our experience suggests that these challenges also apply to conducting research projects that seek to understand and improve the consumer experience.

Fragmentation of services

- > Our experience indicates that funding structures and governance arrangements currently limit the ability of consumers and staff to work together in a co-design approach across different services and the continuum of care.
- > A partnership approach between consumers, health providers and policy makers may be more effective in enabling sustainable change that improves care coordination and reduces fragmentation of services.
- > Health services, including mental health services, tend to be fragmented and slow to respond. Efforts should continue to focus on developing an organised and systemic approach that breaks the cycles of repeated crisis intervention and fragmented care experienced by people with complex mental, medical and social health care needs.

Next steps

Potential directions for further investigation include:

- > Initial evaluation of the brochure and post-discharge telephone call was favourable. However, further evaluation is required to evaluate the impact of these measures on consumers as they transition through tertiary services to primary care and self-management support.
- > Develop and trial adaptations to EBCD to meet the needs of participants from different culturally and linguistically diverse backgrounds.
- > Identify more effective approaches to engaging staff, with a view to improving participation and supporting the sustainability of subsequent improvements.

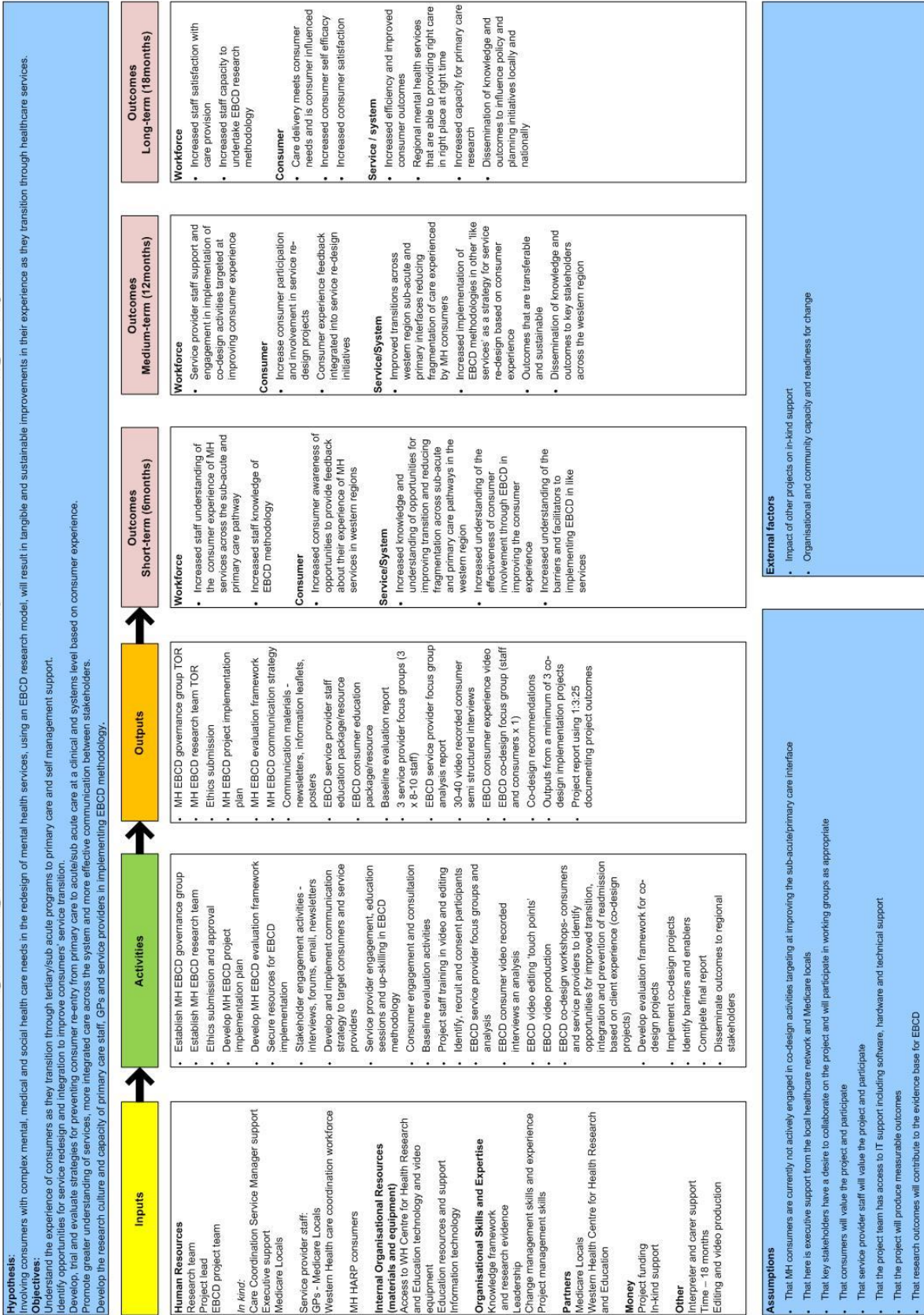
References

1. Commonwealth of Australia. *Fourth National Mental Health Plan: An agenda for collaborative government action in mental health 2009-2014*. Canberra. 2009.
2. Victorian Government Department of Health. *Doing it with us not for us: Strategic direction 2010-13* [Internet]. 2011. [Cited 2014-15]. Available from: <http://health.vic.gov.au/consumer/policy.htm>
3. Australian Commission on Safety and Quality in Health Care. *Safety and Quality Improvement Guide Standard 2: Partnering with Consumers*. Sydney. 2012.
4. *Better Health Plan for the West* [Internet]. 2011. [Cited 2013-15]. Available from: <http://www.westernhealth.org.au/AboutUs/BHPW/Pages/default.aspx>
5. Primary Health Care Research and Information Service. *Maximising the influence of your research on policy* [Internet]. 2014 [cited 2015 January]. Available from: <http://www.phcris.org.au/>
6. Australian Institute of Health and Welfare [Internet]. Canberra: Commonwealth of Australia; 2014 [cited 2015 March]. Available from: <http://mhsa.aihw.gov.au/home/>
7. Commonwealth of Australia. *The roadmap for national mental health reform 2012-2022*. Canberra. 2012.
8. Commonwealth of Australia. *National Mental Health Policy 2008*. Canberra. 2009.
9. Ning L. Building a 'user driven' mental health system. *Advances in Mental Health*. 2010; 9 (2): 112-115.
10. Banfield M, Gardner K, Yen L, McRae I, Gillespie J, Wells R. Coordination of care in Australian Mental Health Policy. *Australian Health Review*. 2012; 36: 153-157.
11. Davison S, Yauck Y, Martyr P, Rock D. How mental health clinicians want to evaluate the care they give: A Western Australian study. *Australian Health Review*. 2013; 37: 375-380.
12. Ning L, Weavell W, Woodhouse S. Consumer participation in research. *New Paradigm*. 2010; 66-68.
13. Minogue V, Girdlestone J. Building capacity for service user involvement in research: The implications and impact of best research for best health. *International Journal of Health Care Quality Assurance*. 2010; 23 (4): 422-435.
14. National Mental Health Consumer and Carer Forum [Internet]. Advocacy brief: Consumer and carer participation - Key issues and benefits. 2010. [Cited 2014-15]. Available from: <http://www.nmhccf.org.au/>
15. Bates P, Robert G. Experience-based design: From redesigning the system around the patient to co-designing services with the patient. *Quality and Safety in Health Care*. 2006; 15 (5): 307-10.
16. Tollyfield R. Facilitating an accelerated experience-based co-design project. *BJN*. 2014; 23 (3): 136-141.
17. Iedema R, Merrick E, Piper D, Britton K, Gray J, Verma R, Manning N. Codesigning as a discursive practice in emergency health services: The architecture of deliberation. *JAB*. 2010; 46 (1): 73-91.
18. Donetto S, Tsianakas V, Robert G. *Using Experience-based Co-design to improve the quality of healthcare: Mapping where we are now and establishing future directions*. National Nursing Research Unit, King's College London. 2014.
19. The Kings Fund. *Improving NHS care by engaging staff and devolving decision-making: report of the review of staff engagement and empowerment in the NHS*. [Internet]. 2014. [Cited 2013-15]. Available from: <http://www.kingsfund.org.uk/>

20. Robert G, Cornwell J, Locock L, Purushotham A, Sturme y G, Gager, M. Patients and staff as co-designers of healthcare services. *British Medical Journal*. 2015; 350: g7714.
21. Callander R, Ning L, Crowley A, Childs B, Brisbane P, Slater T. Consumers and carers as partners in mental health research: Reflections on the experience of two project teams in Victoria, Australia. *International Journal of Mental Health Nursing*. 2011; 20: 263-273.
22. Bowen S, McSevery K, Lockley E, Wolstenholme D, Cobb M, Dearden A. How was it for you? Experiences of participatory design in the UK health service. *CoDesign*. 2013; 9 (4): 230-246.
23. Pierri P. *Designing a better experience for patients* [Internet]. 2012. [Cited 2013-15]. Available from: <http://medlove2012.blogspot.com.au/2012/09/designing-better-experience-for-patients.html>
24. Locock L, Robert G, Boaz A, Vougioukalou S, Shuldham C, Fielden J, Ziebland S, Gager M, Tollyfield R, Pearcey J. Testing accelerated experience-based co-design: a qualitative study of using a national archive of patient experience narrative interviews to promote rapid patient-centred service improvement. *Health Services Delivery Research*. 2014;2 (4).
25. Piper D, Iedema R, Gray J, Verma R, Holmes L, Manning N. Utilizing experience-based co-design to improve the experience of patients accessing emergency departments in New South Wales public hospitals: an evaluation study. *Health Services Management*. 2012; 25: 162-172.
26. *Experience-based Co-design Toolkit* [Internet]. London. The Kings Fund. 2013. [Cited 2013-15]. Available from: <http://www.kingsfund.org.uk/projects/ebcd>.
27. Wolstenholme D, Cobb M, Bowel S, Wright P and Dearden A. Design-led service improvement for older people. *American Medical Journal*. 2010; 3(8): 465-470.
28. Deloitte Access Economics. *Evaluation Framework: Mental Health Hospital Admission Reduction Program*. Barton. 2013.
29. Smith J, Osborn M. Interpretative phenomenological analysis. In *Qualitative psychology: A practical guide to research methods*, 2nd edn. (Smith JA ed.). Sage, London, pp. 51-80. 2008.
30. McCann T, Baird J, Clark E, Lu S. Mental health professionals' attitudes towards consumer participation in inpatient units. *Journal of Psychiatric and Mental Health Nursing*. 2008; 15: 10-16.
31. Toolbox.Com [Internet]. *Assessing organizational readiness for change*. 2008. [Cited 2015 January]. Available from: <http://it.toolbox.com/blogs/enterprise-solutions/assessing-organizational-readiness-for-change-22869>
32. Eagar K, Pirkis J, Owen A, Burgess P, Posner N, Perkins D. Lessons from the National Mental Health Integration Program. *Australian Health Review*. 2005; 29 (2): 189-200.
33. Lin M, Hughes B, Katica M, Dining-Zuber C, Plsek P. Service design and change of systems: Human-centred approaches to implementing and spreading service design. *International Journal of Design*. 2011; 5 (2): 73-86.
34. Costa L, Voronka J, Landry D, Reid J, McFarlane B, Reville D, Church K. Recovering our stories: A small act of resistance. *Studies in Social Justice*. 2012; 6 (1): 85-101.
35. Bessarab D, Ng'andu B. Yarning about yarning as a legitimate method in Indigenous research. *International Journal of Critical Indigenous Studies*. 2010; 3 (1): 37-50.

Appendix 1: Program logic model

Program Logic Model for Mental Health Experience-Based Co-Design Project



Appendix 2: Verbatim transcript of consumer film

Voiceover	<p>The western region of Melbourne is one of Victoria's fastest growing and most diverse regions. With health demands on the rise, service providers have identified mental health as a high need area.</p> <p>For this project, we asked mental health consumers to share their experiences. Speaking to people who had accessed Western Health's Mental Health HARP service, we specifically wanted to understand their experiences of moving between services ... the transitions from one service to another. We also asked staff to share their views. It's part of our commitment to engaging consumers in evaluating and improving services.</p> <p>This short film is a summary of the key points raised by consumers and staff. Western Health's Mental Health HARP team supports people with complex physical and psychosocial needs.</p>
SLIDE	Mental Health HARP Service
Voiceover	Overall, our interviews with consumers showed how they valued the support offered by the Mental Health HARP team.
RV	It was good to have some people who were there for me.
AR	She would talk to me about my issues, talk to me about my problems, and then she would help me try and strategise ways of improving things or getting better, that sort of thing. So that was really helpful.
KS	It was very easy to talk to them, they were very easy people to talk to.
HV	He was really nice, take the time to talk to me and calm me down, even send someone to talk to me right away to calm me down at that time ... it was really great service.
JM	It was good ... yeah ... it was good because I could talk to him about how things were going and staying out of the hospital, rather than going back into it.
MJB	She came a few times and that was really good.
NC	Just talked and listened to me, and gave me different ideas.
MC	It was something that he looked forward to every week.
SA	I haven't got to where I am now without her helping me, because I was just a cot case ... they could have scooped me up and carried me away. And it didn't happen, and I'm sure it was because she was coming at that stage every week.
SLIDE	Connecting with the Mental Health HARP service
Voiceover	But we heard mixed accounts of how they initially connected with the service. Some people did not know they would be getting a call, or what the service could offer them. They also had mixed feelings about talking to someone new.
MJB	I didn't really realise, you know, that she was going to come for that, because nobody had said anything ... and then she rung me.
HV	And then the next day I got a phone call from the Mental Health HARP ... and I said, "How did you get my number?" She said, actually, her coordinator from the service contacted them ... they didn't have time, I think, at the time, so they contacted the department, so she called and I agreed for them to come.
AR	She just said, "We're from Sunshine Hospital, from the Mental Health HARP team. You've been referred to us by one of the doctors here". And I just went,

	"Oh, okay ... [laughs]".
JLS	I was a bit perplexed when they come to see me, because I was thinking they were going to sort of ... maybe I expected more of them ... I don't know ... because I didn't know really what they were going to do .
AR	Very nervous to begin with, 'cause I thought, "Here's a complete stranger, coming into my life, and I have to tell them everything" ...that sort of thing. So it made me very anxious, very nervous to begin with.
RV	I was feeling anxious because I didn't know what it was all about, and so I was taking notes and I was interviewing her, in effect, and trying to find out what the service was that she provided and what the organisation provided.
SLIDE	The overall experience
Voiceover	Looking at general experiences – not just the Mental Health HARP service – we heard mixed reports on how information was shared, how staff engaged with consumers, how decisions were made, how people were treated and how it made them feel.
JM	Pretty intimidating, actually ... yeah, I felt intimidated because I wasn't asked. I was told what was going on, rather than asked what was going on.
JLS	I wasn't consulted about that. They just did it. Nobody told me anything about it, they didn't ask, they didn't explain ... so I was disappointed there.
LP	Sometimes, although they treat you, you get sarcasm. Yes, I've had sarcasm used against me. I'm not dumb and I'm not deaf. I'm not blind. I mightn't say anything at the time, but I hear things, I see things.
NC	Some of them don't listen. I say, "You're not listening to me. I don't want that. I'm telling you how I feel".
DW	I keep telling people I'm not depressed. Or I don't think I'm depressed. What is depression? You know, I said to them, "What is depression?" How do you say, "Well, she's depressed"? Well, I don't feel depressed.
AR	Maybe it's possible to not be so blatantly judgmental right off the bat ... They owe a duty to their patients to still treat them like people.
AW	It was a lot like, you know, for them it was just a normal everyday thing. They go through it every day. They've watched this kind of behaviour in other patients all the time. But for the person who's looking after that family member, and trying to do the right thing by that family member, more compassion and empathy needs to come from the staff.
Voiceover	Staff also identified with this. <i>They feel they're not heard by the system. That their issue is important ... they feel not heard.</i>
SLIDE	Personal insights
Voiceover	Some people shared more personal views or experiences of the impact of a mental health condition on their lives.
HV	At the time I was really worried about my kids, not being able to ... you know, who's going to take them to school? And after my husband's gone to work.
LYP	I lost all my friends, because I developed something that I didn't know was happening to me, and obviously I was coming off like bad people, and I didn't realise that was happening.

LP	I didn't choose to be this way. I had the parents that just ignored it, and I had to bring myself up, I even helped bring three sisters and a brother up with what I was dealing with. I worked, I've had a family. Maybe I didn't do all the best, all the right things, but I never deliberately went out to hurt anybody.
SLIDE	Moving between services
Voiceover	When we asked consumers about their overall experiences of moving between different services, we learned more about how they were discharged from a service or referred to another. For some, this worked well, but for others it didn't.
AR	I found all of them to be really helpful at the same time, to be honest. My psychologist, for example, would give me things to do or strategies to use, or things like that, and then my psychiatrist would handle my medication. And then [she] would come along and would sort of solidify what the psychologist had been telling me, and helping me to process all of that. So, it was really good having all of them together.
KS	It was, "Everything going alright?" She talked it over with me and she said, "You think you're right to handle it?" And she said, "Any time you need to, you can get in touch with me". I've got the number, so no problems that way.
RL	The communication was difficult and one of the things that used to be difficult, perhaps for example, the social worker who's about to go on holidays. "I'm going on holidays, but I'll see you next week", and you ring up and say "Where is he?" and they've gone on holidays. This kind of thing ...
SA	But then he was sick himself and needed time off work, and so I lost that, and that went for quite a few months, with me just floundering around, thinking "Well, he said somebody would contact me", and they didn't. And that really put me right down. I was really in a mess then. I just sat and cried all day, because I didn't know what to do.
MC	They just discharged him. They never discussed with us what's the follow-up plan, so we were a bit confused. We thought that maybe he should have acted a bit more psychiatrically unwell ... like, you know, threatening to harm himself or talk a bit more. But he was just a bit timid. He wasn't like one of those aggressive type of suicidal person, he's more passive.
JLS	There was no follow-through once I got home, I got sort of forgotten again.
LYP	So it's kind of confusing, because the person that came to see me said that I should try, if I'm going to the northern suburbs to stay with my mum for a little while, try and get into the Broadmeadows one. So I tried to get into the Broadmeadows one, but they said I can't, because I don't live there. Like I kept getting told all these different things, and days and then a week would go by, and then I'd have to wait until the next week when he was working, and this and that, and I was actually ringing and trying to find out what was going on.
Voiceover	We also heard about confusion about services, gaps, fragmented services, long waiting times and the lack of some services. Staff recognised these frustrations. <i>We know that the breakdown usually is through multiple services. There're long waits ... and then they have to go to other areas, which is difficult for them.</i>
HV	There was a bit of confusion there, like with the services. There's so many. And at the time, you know, you're a bit confused already, and then make it even more confused.

JM	It was basically cut off from one and that's about it sort of thing, rather than putting you onto another and putting you onto another. You were just cut off.
LYP	I don't have enough information about where you've got to go from here to there, and everything, and your doctors can only take you so far.
MC	They just keep passing us around, you know. And it's really annoying, because they all need a doctor's certificate from his GP or psychiatrist, with the title of the organisation on it. So every time I go to a new organisation, I've got to say, "You know, Dr ... our family doctor ... I need another one, because the other one didn't work out. This is a new one I'm looking to get him into." So she just keeps writing the same email, like 10 times.
RL	It's like everything is kept in this little bubble, and every time the bubbles complete it's just [released]. There's no sort of follow-up of anything, really.
RV	They tried to facilitate me to get the pension, the disability support pension, and I must say that their involvement, although it was well meaning, it sort of hindered, rather than helped the process, because they said they had contacts, but we were getting mixed messages from those contacts.
RS	Those appointments are usually few and far between. They stretch them out. "We'll make an appointment for you, we'll contact you", and then two or three weeks later, sometimes longer, they'll come for one visit. There's not a lot of support, until it comes to the crunch.
SA	So there are problems with the services being available. And also it's the waiting lists. You wait. Like, I've waited to do this rehabilitation class I'm going to be doing ... I've waited since last year ... so yeah, you wait.
SLIDE	Carers
Voiceover	When we looked at the role and experience of carers, we found that sometimes their needs were not being addressed, although staff valued their involvement. <i>I think we would all use the family where we could.</i> <i>At the end of the day, we pull out and it's that carer and family who are left with the ongoing care.</i>
AW	It's very confronting having to make that choice for them. And then having to sift through all the information. And if not all that information is there and stuff's missed, it just causes so much more trauma and stress, and already you're up to here with stress and anxiety.
RL	I think you just think so much more is going to become of it. And then, in the end, every time you've been engaged with something like that, you've wasted your time, because you could have been off doing something else, or ringing another service, or getting something in the community for yourself. But you keep on being taken up ... it's almost like a wasting of energy or resources, because people aren't getting to the nitty gritty, if you know what I mean.
RS	We've met a lot of people over the last few years, far too many. There's no need for that. There's no consistency, you know, there's no sort of goal. It's just endless at the moment. There're no targets. It's just "patch up and run".
MC	Her target client was my mother, but she doesn't speak Chinese and my mother doesn't speak English. She's a trained family therapist. She came a few times and we discussed as a family. It was really enjoyable. She said that "I only have a limit, I can only come two or three times". Again, it was like, do I have to magically get a happy family within two visits? You know, it's really not probable.

SLIDE	What improvements can we make?
Voiceover	So, what do patients and carers need, and what do they think could be done better?
SA	For me personally ... I know everyone might not like it ... but a big bus that came around occasionally and scooped everybody up and took them somewhere where they could have a day of doing things, or just chatting with each other. Someone that could come and check that you're alright, even if it's only a phone call, it's good. And more sessions, more sessions with psychologists, where you could really have a one-on-one chat, instead of "You've got four, here you are".
LYP	It'd be good if someone could just come and say, "Alright, this is what we've got to do today. Have you done this? Have you done that? Oh, that's great." Or say, "Next week, we'll try and do this, this and this". And if they come next week, "How about we do this together?" Even if someone does quit the service, or you stop seeing someone for some reason, that you follow up to see that they've got someone else, that they've gone with another program, get another program to be in contact with them.
HV	What I needed back then was someone to guide me, to help me. Because I didn't know which service to go to ... there's so many.
LP	I enjoyed Rob coming that much, I wanted it to continue.
AR	It was a bit of a shame that it was so short. A little longer would've been nice, but that's how they work so, I can't turn around and say, "Give me more time!" [laughs]
RS	He needs to be doing things. He needs to be out with people, he needs to be back in the community, not, you know, spending hours and hours in his room, sleeping 12, 14 hours a day.
RL	I think a relationship with somebody that is there for the longer haul would be really helpful, someone that could take him out on an activity, or engage him in a pool comp, even a poker club ... whatever ... something that fits the individual.
MC	All he ever wants was just what they call a personal helper. Just someone who comes in every once a week or two times a week, just be a friend, talk to him. You know, make him have something to look forward to. But they can't even offer it. I asked them, "I'm not asking for much, I just want this. And you have that, so why can't you give it to us?" I think it would be more helpful, even towards the end of [his] treatment with Mental Health HARP, if they could have linked us, rather than me contacting Norwood again ... if they can contact them and find out is he even suitable for [him]? Rather than me getting another letter from the doctor, again, and then go to Norwood, knock on the door again, saying "I've done this two years ago. It didn't work out. I don't think this will work either". I spend the entire afternoon there, filling in paper after paper after paper ... and we still get the same result. It's not only annoying and time consuming, but it's really discouraging.
AW	A package or something, you know, that has information for carers that's simple and easy to read, and someone to say, "Here's my phone number. If you're having trouble, give me a call and we'll see how we can help you. Getting them trained in understanding, you know, do some role play, put yourself in their shoes, be the patient, be the carer, and talk about these issues, and put them

	on the table and say, “These are the issues” and talk about it, and do something about it. It can’t be that hard [laughs].
Voiceover	Staff also had some suggestions, including ... <i>Continued education and training to help staff understand the needs of mental health consumers.</i> <i>More information on family networks or support ... something for them to follow up themselves.</i> <i>A single point of referral and sharing common resources.</i> Let’s use this information to work towards improving the experience of consumers – the patients and their carers – and the staff who work with them.
RV	What was very good ... and they were complex issues.
SA	So I think everything ... needed everything I’ve got.
AW	Do something about it, you know ... it can’t be that hard [laughs].