Received: 11 June 2020 | Revised: 7 October 2020 | Accepted: 26 October 2020

DOI: 10.1111/medu.14411

RESEARCH APPROACHES

A research approach for co-designing education with healthcare consumers

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Funding information
This research example reported in this paper was supported by the Western Australian Health Promotion Foundation (Healthway) Exploratory Research Funding under Grant number 32737.

Abstract

Context: Community and consumer involvement in health professions education (HPE) is of growing interest among researchers and educators, particularly in preparing health care graduates to effectively learn from, and collaborate with, people with lived experience of health issues. However, to date there has been limited direction on methodological approaches to engage health care consumers in the research and co-design of HPE.

Approach: In this paper, we describe the background to our work with health care consumers including the five core principles for successful co-design (inclusive; respectful; participative; iterative; outcomes focused) and how they can be applied as a research approach in HPE. We introduce the use of arts and humanities-based teaching methodologies including engagement, meaning-making and translational education strategies to illustrate how this research approach has been applied to reframe mental health education and practice in Australia. Furthermore, we share some reflective insights on the opportunities and challenges inherent in using a co-design research approach in HPE.

Conclusions: For the consumer voice to be embedded across HPE, there needs to be a collective commitment to curriculum redesign. This paper advances our understandings of the educational research potential of working with health care consumers to co-design rich and authentic learning experiences in HPE. Co-design research approaches that partner with and legitimise health care consumers as experts by experience may better align education and health professional practice with consumers' actual needs, an important first step in transforming hierarchical health care relationships towards more humanistic models of care.

1 | INTRODUCTION

Where is the patient's voice in health professions education (HPE)? The notion of 'Nothing about us without us' is endorsed by the World Health Organization framework on integrated person-centred health services[1] that emphasises the importance of co-development between health care professionals and the people using health services. This has resulted in a change of relationship between patients and health care professionals from traditional paternalism towards shared decision making that involves active and equal health care partnerships.[2] This trend towards patient and community involvement in health care was further extended in the 2015 Vancouver

statement to ensure the involvement of patients across all health and social care professional education.[3] This is an important formative step in preparing health care graduates to effectively learn from, and collaborate with, people with lived experience of health issues. This is in comparison, to the biomedical model that focuses on problems, deficits and symptoms and maintains power imbalances and reinforces the notion that expertise lies within professionals. Involving patient's voice (hereby consumer—see Table 1), one that represents a different kind of knowledge, is of growing interest among health professions educators, particularly in research approaches to co-designing education.

A search of the literature revealed two recent systematic literature reviews that explore consumer involvement in education of mental health professionals.[4,5] Both reviews found that if adequately prepared both health professional learners and consumers gain valuable insight and learnings from each other. However, the spectrum of consumer involvement in education varies from informing (eg delivering guest lectures) to the recent move to create consumer academic positions[6] to design and deliver mental health education[7] in the university sector. Although there is practice guidance on the continuum of consumer and researcher engagement in health research,[8] to date there has been limited direction on methodological approaches to engage with health care consumers in the research and co-design of HPE.

In addition to actively involving consumers in HPE, the benefits of integrating arts and health humanities research into professional education is also emerging.[9,10] So, given the clear need for consumers' voice in HPE, this paper describes the participatory action research (PAR) approach used to work with health care consumers, including how it was effectively applied to co-design a series of educational visual narratives (hereby vignettes). Finally, we will discuss some of the opportunities and challenges inherent in co-designing HPE.

TABLE 1 Definitions of key terms relevant to the Australian context

Key term	Definition
Patient	A person who is or has received health care
Consumer	Patients and potential patients, carers, family members, support people and people who use health care services.
Carer	Carers are people who provide care and support to family members and friends who need help, generally in an unpaid capacity.
Consumer/carer participant	A person who is specifically invited to bring an individual consumer, family, carer or community perspective to a discussion and/or decision making on a certain topic (eg mental health issues).
Consumer advocate	A consumer representative/advocate is someone who has undergone training to provide advice and/or advocate for consumer-centred health care.
Consumer engagement	Reflects an approach that involves developing meaningful, mutually respectful relationships with a shared focus.
Consumer and community involvement	Refers to the active partnership between consumers and/or the community in research and health care improvement projects.
Consumer storytelling	Is when consumers impart their first-person experiences of diagnosis, living with symptoms and/or health service use.
Consumer Involvement in Education	Active involvement of people who use health and social services in the education of current and future health professionals[3]
Lived experience educator/academic	A person who is an expert by experience and uses their lived experience of health and/or health care to educate others.

2 | WHAT IS CO-DESIGN?

Co-design is a PAR approach, derived from the field of education [11] which aims to build authentic understandings of a phenomenon and use these to inform and change programmes, services and policies as part of practice.[12] Co-design is a PAR method that has predominately been used to engage health service users, including health care consumers, health practitioners and service planners, in collaboratively designing services and resources to improve and optimise user experience.[13] Incorporating diverse and end user perspectives is essential in health care and service co-design. In Table 2, we present an outline of five core principles for successful co-design in social services[14] and how they can be applied as a research approach in HPE.

3 | THE ARTS AND HUMANITIES-BASED EDUCATION

The use of arts and humanities-based teaching methodologies is gaining momentum in HPE curricula as a potent educational strategy for fostering engagement, meaning-making and translation to health care professional learning and practice.[9] This is not a new concept, educational philosopher John Dewey describes art as an experience that evokes new possibility[15] through sensitively shaping our learning experiences through reflection. Depth of Field is a programme of research that draws on arts and humanities-based teaching methodologies to embed consumer voice into HPE. Previous research includes the use of photographic storyboards, video vignettes and MRI images infused with poetry[16] and documentary style photographs and narratives of older adults[17] which was found to foster nursing[18] and medical students'[19] empathy, insight and reflection on ageing. Other humanities-based education includes narratives using doctor and patient stories to promote more patient or relationship-focused care,[20] and consumer storytelling in mental health education,[21] including memoirs which have the potential to create the 'emotional pull to surprise learners and reawaken empathy and compassion'.[22(p.71)] Research-based and theatre arts strategies are

TABLE 2 Co-design in HPE

	Core co-design principles	Co-design in HPE
1	Inclusive	Key industry stakeholders (including health care consumers) are involved from initial proposal design, development and framing of learning focus to final educational outcome and delivery.
2	Respectful	Health care consumers are considered 'experts by experience', and all input is equally valued in design, development and delivery of education (including payment and co-authorship).
3	Participative	The research process is open, responsive and empathetic with the main aim of co-creating education: to generate new understandings of health and health care experiences.
4	Iterative	This is a cyclic, collaborative process that takes time and embraces movement towards a shared education vision (includes being adaptive, reflective and trialling new and creative pedagogy at the risk of failure).
5	Outcomes focused	The focus is on achieving a shared educational outcome that is not predetermined but co-created during the co-design process.

also being used,[23-26] which Rossiter and colleagues[27] assert is an underutilised medium for the interpretation, translation and dissemination of research findings. In addition, rich pictures[28] and visual thinking strategies (VTS) are increasingly being used as student-centred learning methods in HPE. Developed by Housen and Yenawine, VTS aim to foster aesthetic development, reflective observation and empathetic understandings through careful and collaborative looking at visual art.[29] This method has been found to improve interprofessional health care students' observation, visual literacy and communication skills,[30] teamwork, collaboration and an awareness of multiple perspectives, including interpretation and critical thinking skills[31] and enhanced tolerance of ambiguity/uncertainty.[32]

4 | APPROACH

So, what does co-designing health humanities research and education look like? Drawing on the principles of HPE co-design (Table 2) below, we present the research approaches used to co-design a series of vignettes with mental health consumers. First, the research team, which includes a consumer advocate who has lived experience of mental health issues and recovery (CS), regularly met with representatives from mental health organisations to explore education/training gaps in order to identify those mental health conditions that are poorly understood and/or stigmatised in mainstream health care (Inclusive). A high proportion of health-based research lacks relevance due to researchers' lack of consultation with end users when prioritising an area of research.[33] We found it was essential to involve consumers in the preliminary research proposal development to clearly demonstrate a desire for our research to be 'relevant and important to the needs of the people (the) research is about'.[34(p.17)]

It is important to follow guidelines and consider ethical conditions for working with health care consumers. For instance, in this project, all research participants must have undergone recovery storytelling training (offered through external mental health organisation) that encompasses knowledge, skills and practice in self-care strategies, including informed choice and consent in disclosure. This is essential to mitigate potential vulnerability from the act of recalling/retelling mental illness narratives of experiences.[21] Following ethics approval from The University of Western Australia Human Research Ethics Committee (RA/4/20/4536), consumer participants were recruited through purposeful sampling. This was achieved through partner organisations (see acknowledgements) which were important in establishing rapport and trust with consumers and to ensure data were collected in a supportive and safe environment. Interested mental health consumers were approached by the first author to explain the purpose and process of the project, gain written consent and discuss remuneration for their time (Respectful) and expertise which is guided by organisations policy and guidelines.[35]

Over the following two years, first author (GB) met with consumers in various locations both face to face and via videoconference for a series of in-depth (Participative), audiorecorded reflective conversations (transcribed verbatim for analysis) as they recounted the raw reality of what life is like living and recovering from mental health issues, including interactions with health professionals and services. Open-ended questions using authentic interview principles[36] were used to facilitate maximum exploration and retrieve 'thicker, richer' life descriptions,[37] and were built around a reflective conversational approach.

Throughout the co-design process, the data analysis was not fixed, but grounded in an organic reciprocal analysis approach (Iterative) that sought to clarify experiences and events and develop shared understandings.[38] Narrative techniques including open dialogic conversations were also used whereby stories and interpretations were exchanged, recounted and reconstructed reciprocally.[39] This collaborative method of analysis allowed the research process to be emergent, participative and reflective (between researchers and consumers) in order to refocus and/or reframe activities and thus strengthen educational research outcomes.[12] This approach differs from traditional research approaches whereby the analysis and theorisation occur in the academic world after collecting the data.

The emerging narrative was also complemented by asking consumers to bring along personal humanities-based artefacts (Respectful and Participative) that included fine art, sculpture, music, literature, historical records, clinical notes, letters to the editor and mind maps. Based on object-elicitation interviewing concept,[40]

collecting artefacts as a data collection technique was utilised in two ways. First to help consumers conceptually represent their reality and second to explore how we could use the artefacts in the final vignette as multi-sensorial 'triggers' for 'emotional education'[41] that embodied both affective and cognitive components of experiential learning.[42]

Subsequent conversations focused on further exploring and refining the main themes, drafting the learning outcomes, content and design (Iterative). During this time, the vignette drafts were regularly shared with the research team and partner organisation representatives to ensure accuracy of the qualitative analysis process. In order to communicate research (consumers lived experiences), we infused the narratives and artefacts into humanities-based teaching methodologies so health professional learners may better understand the day-to-day lived experiences and 'therefore cope with issues in practice that are complex, interpersonal, emotional, and embodied'.[27(p.132)]

Finally, the consumers met with medical and fine art portrait photographer (SW) to visually and metaphorically represent the main themes which formed the basis of each educational vignette (Outcomes focused). Collaborating with professional and experienced artists enriches experiences in medical humanities education.[43] The subjective nature of creating visual narratives infused with personal artefacts was used to convey meanings and emotions that are often difficult to portray in traditional education methods. This is beautifully articulated in Wikstrom's description[44] of the power of art dialogues to transport 'participants out of the real world and into a magic world of symbols and images' that challenges literal and concrete thinking.[9] The final themed portraits include Katherine: Borderline Warrior (Borderline personality disorder)[45]; Rosalie: Speak from the Heart (exploring Indigenous intergenerational trauma); Donna: Naturally Tough (Schizophrenia); Shannon: Holding Hope (Anorexia); Clinton: Hope & Renewal (seven mental illness diagnoses), and Pamela: The Artist's Mother who cares for her son Tom who had been diagnosed with schizophrenia 23 years ago. The six visual narratives can be viewed here https://vimeo.com/385779412

5 | PAMELA—THE ARTIST'S MOTHER

Here, we present part of a co-authored (PG) vignette in which Pamela shares her story of caring for her son Tom, a talented and prolific artist who experiences psychosis. In order for the learners to explore and deepen their understanding of the impact a mental illness diagnosis has on family members and/or carers, VTS[29] were used to promote reflective exploration and interpretation of her visual narrative: 'The Artist's Mother' (Figure 1). In small groups, learners are asked: What is going on in this photographic portrait? What makes you say that? What is the mood or feeling? What message is Pamela trying to convey? Further probing questions included: What do you wonder? If you could ask Pamela a question, what would you ask? Why?

Following discussions, learners listen to Pamela's audiorecorded narrative of her all-encompassing feeling of being: 'Claustrophobic, with no exit or escape, surrounded and overwhelmed'. However, her message as she looks directly into the camera is one of steadfast stoicism as she shares with the learner her insights:

> When you look into the eyes of someone who is psychotic it is difficult to connect with them. …as he is trying to make sense of his world. In a similar way, I use mind maps to make sense of my world. At any time when I focus on his art it is a way that I am honouring him as a person.

Next, learners are asked to list the 'textbook' emotional, cognitive, physical and social signs that indicate a person is relapsing into psychosis. This is then contrasted with Pamela's visual mind map (Figure 2) that she titled 'Triggers to worry' which will be infused with a self-portrait of Tom, artefacts and verbatim quotes collected during conversations, including video footage of Tom's room:

> In 2015 he was searching for ways to reassess his life and his art. One of the ways he did this was by painting disturbing murals on the walls.

Additionally, theatre arts strategies are employed as learners are asked to read out loud and discuss clinical notes of Tom's multiple

FIGURE 1 The Artists mother

mental health service interactions juxtaposed with Pamela's handwritten personal diary entries to engage and educate learners in empathy and emotion[46]:

> 1997 – A private psychiatrist admitted Tom to East Wing at * Hospital and then he was discharged to the Early Intervention Centre.
>
> *He is hearing voices. He doesn't want to leave me alone. He wrote me a note and handed it to me today – it was his story, about the voices. I am terrified.*
>
> 2002 – Admitted to * Acute Mental Health Ward when suitable services could not be found for him during his stay in rural Australia.
>
> *As a mother I never get over the worry. My wish is for someone to take the responsibility away – that's not right. Its surprising – nobody wants to know about the difficult things.*
>
> 1 month later
>
> *Tom was discharged today under the responsibility and care of his GP – He doesn't have a GP!*

This includes a letter to the editor of a local newspaper (artefact) titled 'No sane sense':

> So, for 18 years, I have had to wait and watch till he reaches rock bottom and exhibits severe psychotic symptoms before the mental health professionals can implement the Mental Health Act…

These educational strategies[9] were used to enhance learners' engagement in content (signs of psychosis) and stimulate meaning-making that opens learners' awareness to author PG's perspectives. This carer's perspective acknowledges the difficult choices and the tacit knowledge family/carers bring to inform health care interactions and treatments. Finally, learners are invited to brainstorm how they can embed hopefulness, dignity, respect and working in equal partnership with individuals and families and are presented with PG's three take home messages as a translational strategy to influence professional practice.[9] An example of the learning outcomes, artefacts used, educational strategies and humanities-based teaching methodologies are presented in Table 3.

6 | OPPORTUNITIES AND CHALLENGES OF CO-DESIGN IN HPE RESEARCH

Drawing on co-design methodologies, this research approach honours and legitimises consumers as experts of their own lives and draws on this expertise to enhance health professions learning and practice. The experiential knowledge consumers bring is important in helping health professions educators, researchers and learners acknowledge 'multiple realities and meanings' that offers an alternate perspective to the medical descriptions of illness found in the clinical textbook. However, for the consumer's voice to be embedded across health and social professional education[3] there needs to be a commitment to change through significant curriculum redesign and opportunities for lived experience educators as living examples of recovery.

Paradoxically, the core principles inherent in the co-design process present both the greatest opportunity (powerful educational outcome) and some fundamental challenges.

The inclusive nature of this approach necessitates that it is both cyclic and iterative with collaborative data collected and analysed over a prolonged period of time which can contrast with our limited personal and professional timeframes. However, as in all qualitative research, rushing the analysis process would risk the preservation and richness of the contextual details of the consumers' stories.[47] We suggest being realistic, prolonging time frames and taking a narrative pedagogy, life history and/or learning approach that focuses on 'research collaboration which helps locate each unique story in a broader frame - providing wider historical insights for the life storyteller and the broader audience for whom the story is recounted'.[39(p.40)]

Co-design education research approaches are not linear, there is no guidebook or predetermined educational outcome, so being open, reflective and adaptive is essential. As a diverse research team, we were exposed to multiple realities and truths which emerged during the co-design research/education partnerships, challenging our health professional, researcher, educator and consumer identities in different ways, a reflexive learning process described as a 'rereading of the world'.[48]

For consumer co-author PG, the long-form interview process helped her gain confidence in finding the truth in her experiences, a way to articulate and hear her voice, which has clarified her thinking. For research team consumer advocate and co-author CS, it was the first time her lived experience of mental health issues was valued as 'legitimated expertise' on a research project.[7] For first author GB, the experience has profoundly changed how she sees mental health through surfacing and shifting mental illness deficit discourse to more inclusive strengths-based, recovery-oriented language and practice. This is one of the key opportunities for involving consumers as co-designers in HPE as it has the potential to highlight and rebalance traditional pedagogical power relationships towards more active and collaborative consumer roles in education, including teacher, assessor and/or curriculum developer.[3]

Maintaining ethical awareness and reflexivity is essential in co-design approaches with health care consumers, including being mindful of mental health as a recovery process. Recovery in this context means 'being able to create and live a meaningful and contributing life in a community of choice with or without the presence of mental health issues'.[49(p.2)] Over the course of 2 years, we

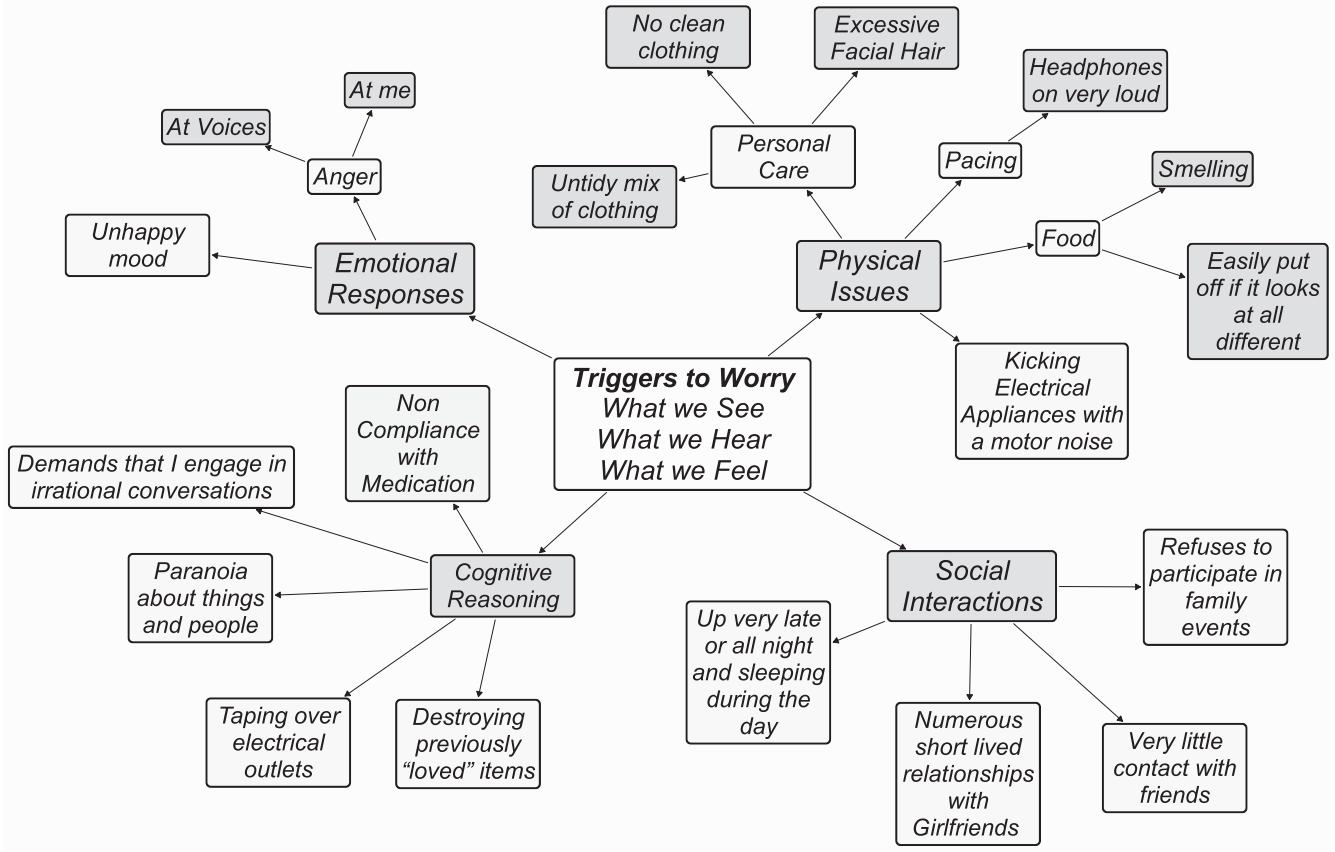

FIGURE 2 Triggers to worry

TABLE 3 Pamela Griffiths (PG): The artists mother vignette

Learning Outcome	Object-elicitation interviewing[40] & Artefacts	Educational strategies[9]	Humanities-based Teaching Methodologies (Small group work)
Explore and deepen your understanding of the impact a mental illness diagnosis has on family members and/or carers.	Figure 1: The artists mother visual narrative & PG son Tom's fine artwork	Engagement strategy	visual thinking strategies,[29] reflective questioning prompts & consumer storytelling
Describe and discuss the emotional, cognitive, physical, and social signs family members/carers may witness if their loved ones are relapsing into psychosis. Discuss and reflect on potential emotions and feelings family members/carer may experience.	Figure 2: PG's Triggers to worry mind maps PG's clinical & personal diary and letter to the editor	Meaning-making strategy	Visual mind maps, Theatre arts strategies[23-26]
List three ways you can interact with family members and/or carers which promote hope, dignity and respect.	3 Take home messages	Translational strategies	Brainstorming in small groups

witnessed the consumers' recovery shifting, therefore each time we met a 'check in' and verbal consent was obtained. Inherent in the co-design process is maintaining the integrity of the shared education outcomes, through remaining respectful of the consumers' lived experiences. Transparent conversations and thoughtful judgements about how to balance the vignettes with both the positive and negative reality of what life is really like living and recovering with mental health issues was challenging.

In relation to drawing on arts and the humanities in co-designing HPE, we found the subjectivity of the arts offers a unique opportunity to embed consumer voice. For example, the themed portraits are both ambiguous and complex so together with visual thinking strategies (VTS)[29] they encourage learners to actively search and construct their own meanings, including an openness to others' perspectives and multiple interpretations in small group work. This contrasts with traditional empirically driven HPE that focus on

definitive, right or wrong answers and lies at the heart of increasing health professionals' tolerance of uncertainty/ambiguity, which refers to the way we perceive and process information when confronted by an array of unfamiliar, complex, or incongruent clues.[50] Recent evidence has shown that health care education can either hinder or foster uncertainty tolerance[51] and should be included in all HPE to prepare health professional learners for 'real-world' clinical uncertainties in an evolving health care system.[52]

7 | CONCLUSION

This paper advances our understandings of the educational research potential in working with health care consumers to co-design HPE. In addition, the power of the arts in HPE to facilitate rich learning experiences, including engagement, meaning-making and translational education strategies,[9] is highlighted. Co-designing HPE with consumers warrants further exploration, especially in its capacity to provoke reflection and empathetic behaviours in clinical practice which Levett-Jones and Cant[53] describe as the responding stage on the empathy continuum. Furthermore, co-design research approaches that partner and legitimise health care consumers as experts by experience may help better align education and health professional practice with consumers' actual needs, an important first step in transforming hierarchical health care relationships towards more humanistic model of care.

ETHICS APPROVAL

This research received ethics approval from The University of Western Australia Human Research Ethics committee RA/4/20/4536.

ACKNOWLEDGEMENTS

The authors extend their gratitude to the six mental health consumers who co-designed the educational vignettes for the Depth of Field resource. We would also like to acknowledge Healthway for funding this research and our partner organisations, including Consumer and Community Involvement Program (CCIP), Richmond Wellbeing (RW), Armadale Kalamunda & Royal Perth Bentley Group, Western Australia Association for Mental Health (WAAMH), Consumers of Mental Health WA (Inc) and the WA Mental Health Commission.

CONFLICT OF INTEREST

The authors report no conflict of interest. The authors alone are responsible for the content and writing of this article.

AUTHOR CONTRIBUTIONS

Associate Professor Gabrielle Brand, PhD, MN, BN, is Associate Professor in School of Nursing & Midwifery at Monash University and the creator of Depth of Field reflective learning methodologies. Mrs Carli Sheers, Cert IV in TAE; Cert IV in MH; Cert 3 CS; Cert 3 MBO; BBus is a lived experience educator who is passionate about reducing mental health stigma and discrimination. Her lived experience has been valued as 'legitimised expertise' on the research team. Mr Steve Wise APP BEnvDes RBI MPhotogIII is an accredited Medical and Professional Photographer. He works as both a Medical and Creative Photographer in Perth, Western Australia. Dr Liza Seubert is the Head of the Division of Pharmacy and Deputy Head of the School of Allied Health in the Faculty of Health and Medical Sciences. Professor Rhonda Clifford is the Head of School, Allied Health at The University of Western Australia. Ms Pamela Griffiths BA Dip Ed (UWA) is an educator who is passionate about advocating for family members to help navigate the mental health system for their loved ones. Associate Professor Christopher Etherton Beer MBBS GradCertHPEd PhD FRACP is Associate Professor in the Medical School, University of Western Australia, and a Medical Co-Director at Royal Perth Bentley Group.

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How to cite this article: Brand G, Sheers C, Wise S, et al. A research approach for co-designing education with healthcare consumers. *Med Educ*. 2020;00:1–8. https://doi.org/10.1111/medu.14411