

DR. JENNIFER O'BRIEN (Orcid ID : 0000-0001-8227-6788)

DR. VICTORIA PALMER (Orcid ID : 0000-0001-7212-932X)

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A Scoping Review of the use of Co-design Methods with Culturally and Linguistically Diverse Communities to Improve or Adapt Mental Health Services.

Jennifer O'Brien (BOT, MOT, MBA)

MPhil candidate, Department of Occupational Therapy

Monash University,

Lecturer, School of Occupational Therapy,

Australian Catholic University

Jennifer.obrien@acu.edu.au

Professor Ellie Fossey, PhD, MSc (Health Psychol), DipCOT (UK)

Head, Department of Occupational Therapy

School of Primary and Allied Health Care

Monash University

Associate Professor Victoria J Palmer, PhD (Applied Ethics)

Lead, Integrated Mental Health Research Program & Co-Design Living Lab

Department of General Practice, Melbourne Medical School, The University of Melbourne

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Abstract:

Mental health services are increasingly encouraged to use co-design methodologies to engage individuals and families affected by mental illness in service design and improvement. This scoping review aimed to identify research that used co-design methods with Culturally and Linguistically Diverse (CALD) communities in mental health services, and to identify methodological considerations for working with this population. In October 2019, we searched 5 electronic databases (CINAHL, PsycINFO, EMBASE, MEDLINE, Web of Science) to identify papers published in which people from CALD backgrounds were engaged in the co-design of a mental health service or program. Searches were limited to peer-reviewed articles published in English in the last 25 years (1993-2019). The search identified 9 articles that matched the inclusion criteria. Using a scoping review methodology, the first author charted the data using extraction fields and then used qualitative synthesis methods to identify themes. Data was grouped into themes relevant to the research question. The two key themes relate first, to improving the experience for CALD communities when

engaging in co-design research and second, to the development of co-design methods themselves. These findings support the need for further research into the transferability of co-design tools with CALD communities, particularly if co-design is to become a best practice method for service design and improvement. This scoping review identified methodological and practical consideration for researchers looking to use co-design with CALD communities for mental health service design, re-design or quality improvement initiatives. Further research is required to explore experiences of co-design methods, including documented protocols such as Experience-Based Co-Design, with CALD communities. This review indicates that explanatory models of mental health, community, and co-design impact partnerships with CALD communities, and need to be understood to optimize the quality of these relationships when using co-design methods.

Keywords:

Community-based research, ethnicity and health, mental health services, minority ethnic clients, service user involvement, service delivery and organisation

What is known about this topic and what this paper adds:

What is known:

- Culturally diverse consumers experience barriers to accessing mainstream mental health services
- Co-design methodology has been put forward as a method to involve people in re-design efforts in order to decrease these barriers and improve access to services
- Little is known about engaging CALD communities in co-design methods within mental health services

What this paper adds:

- The quality of the relationship between the researcher and CALD community impacted on CALD community's experience and engagement
- The explanatory models of mental health, community, and co-design in CALD communities need to be understood to optimize collaborative relationships when using co-design methods with these communities
- Further research investigating how CALD communities experience co-design methods, including documented protocols (such as Experience-Based Co-Design), is required

Introduction

Mental health system reform has been actively working to improve mental health services in order to ensure that they are equitable, accessible and inclusive of the diversity of all Australians (Mental Health Commission, 2018). Diversity refers to all the differences between people in how they identify on grounds including age, caring responsibilities, disability, gender, sexual orientation, indigenous, cultural and socio-economic backgrounds (O'Leary, Russel & Tilly, 2015). This is of particular importance for Australia as one of the most diverse, multicultural societies in the world, with census data indicating that over 26% of Australians were born overseas and projections that this will increase to 32% by 2050 (Australian Bureau of Statistics, 2016; Minas et al., 2013).

Research indicates that people from culturally and linguistically diverse (CALD) backgrounds experience barriers in accessing and engaging with mental health services due to a multitude of factors (Wohler & Dantas, 2017). People from CALD backgrounds may be dealing with an increased risk of experiencing psychological distress due to low proficiency in English, separate cultural identity, loss of close family bonds, stresses of migration and adjustment to a new country, limited knowledge of the health system, trauma exposure before migration, and limited opportunity to appropriately use occupational skills (Gorman, Brough, & Ramirez, 2003; Minas et al., 2013). While it is difficult to accurately assess the rate of mental health disorders within CALD populations, these barriers result in delayed treatment, or a complete lack of treatment and inadequate or less than satisfactory services (Baker, Procter, & Ferguson, 2016; Minas, Klimidis, & Kokanovic, 2007).

With the rate of overseas born Australians set to increase, the identification of access barriers for people from CALD backgrounds is increasingly important, as is the need for inclusive mental health services and practices based on better experiences for CALD groups. Inclusion and intersectionality refer to processes that allow a diversity of people to feel valued and respected, including all aspects of identity, having opportunities and resources so they can contribute their perspectives and talents to improve services (Diversity Council of Australia, 2018; Victoria Government, 2019). Mental health services are developing 'diversity and inclusion frameworks' to strategically identify, engage and work with people from CALD backgrounds to optimize inclusion (Mind, 2018; Neami National, 2018). Yet, to achieve inclusive mental health services and practices, cultural responsiveness must be at the core of all service design and improvement (Minas et al., 2007; Indigenous Allied Health Australia, 2019). Therefore, along with a cultural responsiveness framework, service design and quality improvement projects must use methods that ensure the voices of people who access services are central to re-design efforts (World Health Organization, 2013).

Historically, researchers have utilized participatory research frameworks to enable greater voice and increase social change when working with CALD populations

through engaging in a cyclical approach of doing, researching, doing (Greenwood, 1998). In particular, participatory action research (PAR) and community based participatory research (CBPR) approaches have predominantly been used when working with CALD populations (Evans et al., 2014; Khanlou & Peter, 2005; Michael, Farquhar, Wiggins, & Green, 2008; Stacciarini, Shattell, Coady, & Wiens, 2011). Participatory research approaches aim to shift the philosophical approach in research, recognizing the need for the community whom the research is focused on to fully participate in all aspects of the research, and to exercise power and control in identifying solutions that lead to sustainability (Attwood, 1997). This cyclical approach aims to engage with communities in researching, acting, and reflecting, which leads to further inquiry and action for social change (Minkler, 2000). Service design and quality improvement projects that collaboratively involve all stakeholders have been shown to improve service participation outcomes (Evans et al., 2014). This includes evidence that when active participation is embedded throughout the entire process, it increases the project's relevance and outcomes (Evans et al., 2014; Gilbody, Bower, Fletcher, Richards, & Sutton, 2006).

CBPR builds on participatory research principles as it is a collaborative approach that involves community partners and researchers working together to address health disparities in the community (Minkler & Wallerstein, 2003). It emphasizes community engagement and social action to build on existing strengths and resources within the community, promoting co-learning, and system development through a longer-term partnership process (Minkler & Wallerstein, 2003; Wallerstein & Duran, 2010). A previous scoping review looking at how CBPR has been used with minority populations in mental health services identified that, despite aiming to engage the community to promote co-learning, CBPR researchers tended to use traditional methods rather than co-creating innovative solutions (Stacciarini et al., 2011). These authors also noted that a lack of documented standardized methods for CBPR makes it difficult to compare and evaluate studies. Therefore, researchers and mental health services are increasingly looking for innovative methods to promote inclusion and ensure that participation of all stakeholders is achieved (Palmer et al., 2019; Tandem, 2018; VMIAC, 2006).

The recent cultural and political shift in participation, particularly within healthcare, has prompted a philosophical shift in promoting shared-decision making in treatment and more broadly healthcare design and quality improvement (Palmer et al., 2019). In response, co-design methodologies have been adopted within service design, quality improvement initiatives and research to ensure end user participation. Co-design is an approach used by designers to co-create products, experiences and services, which has gained popularity as a framework for use in quality improvement in healthcare in developed countries over the recent decade for service evaluation and improvement (Robert et al., 2015). For instance, several mental health services in Australia have recently adopted this approach within their policies (Mind, 2018; Neami National, 2018; Tandem, 2018). Within the health and community sector, co-design has been used to co-develop service experiences with designers and users at the centre, thereby differing from CBPR that focuses on participatory research partnerships with a community (Bate & Robert, 2007; Stacciarini et al., 2011). Broadly speaking, co-design is an approach that attempts to actively involve all stakeholders (e.g. employees, clients, carers) in the design process, so as to help ensure the product/service meets the end user's needs (Bessant & Maher, 2009; Robert et al., 2015). Co-design is further described as "identifying and creating an entirely new plan, initiative or service, that is successful, sustainable and cost-effective, and reflects the needs, expectations and requirements of all those who participated in, and will be affected by the plan" (National Mental Health Consumer & Carer Forum, 2017 p.1). A recent explanatory theoretical model of change for co-design and co-production identified the importance of narrative theory, dialogical ethics and cooperative and empowerment theory for understanding processes for change (Palmer et al., 2019) with the values of openness, respect, collaboration and empowerment at its core (Australian Centre for Innovation, 2019).

As co-design can be applied in various ways, there remains an element of conceptual confusion and a lack of clarity within literature about what co-design methods actually involve. Researchers have advocated for greater clarity in processes by

documented protocols and more attention to the direct links between co-design impact and outcome (Palmer et al., 2019; Palmer, et. al 2017). One co-design approach that has developed specific methods is Experience-Based Co-Design (EBCD) (Bate & Robert, 2007). Initially adopted within the National Health Service within the UK in 2006 to involve service users in quality improvement (Bate & Robert, 2006; Point of Care Foundation, 2018), it utilizes end user's narratives through in-depth interviews, videos, e-technology, observations and group discussions with the aim to identify key 'touch points'. This then guides the overall design process. From here end-users and stakeholders work with the areas for improvement in order to co-create solutions (Bate & Robert, 2007; Hackett, Mulvale, & Miatello, 2018).

This scoping review aimed to identify the published literature on the use of co-design methodology with individuals and communities of CALD backgrounds in mental health service projects. The aim was to explore the utility of co-design methodology with CALD communities and to guide future research into how best to design and improve mental health services for these communities. The broad research question was: What are the methodological considerations for using co-design methodology when engaging CALD communities in a service design or quality improvement project within mental health services?

Methods

This scoping review followed Arksey & O'Malley's (2005) framework based on six iterative processes: (i) identifying the broad question; (ii) searching for studies; (iii) selecting the relevant studies; (iv) extracting data; (v) summarising and reporting; and an optional stage of (vi) consultation. The PRISMA extension for scoping reviews was used to ensure that the steps taken followed best practice methods (Tricco et al., 2018).

In October 2019, the researchers searched 5 electronic databases (CINAHL, PsycINFO, EMBASE, MEDLINE and Web of Science) using a key search strategy that was developed through an iterative process to ensure that terms were reflective of terms used in the literature. Key terms included CALD, NESB, "Culturally and

linguistically diverse”, Ethnic, “Non-English” Codesign, “Participatory Design”, “participatory research”, “action research”, “co-production”, “EBCD” and “mental health services” “mental health” “mental health programs” “counselling”. MeSH headings were utilised to ensure that data captured literature in broad research domains. Searches were limited to peer-reviewed articles published in English in the last 25 years (1993-2019). No studies that utilised experience-based co-design with a CALD population in mental health services were identified. For this reason, articles that utilised participatory research, coproduction, community based participatory research, action research and community development methodologies with this population were considered relevant to answering the broad research question and so these terms were added to the search. For the search history, see Appendix 1.

A two-phase selection and data extraction process was then undertaken. All titles and abstracts were reviewed to identify articles relevant to the research question. Articles were excluded if they referred to co-design and the CALD population but did not focus specifically on how people with CALD backgrounds experienced engagement or direct participation in mental health service co-design research. Those studies that did not clearly articulate a co-design methodology were also excluded as the focus of the scoping review was to identify lessons learned from co-design.

The full text of each included article was then read to assess if the participatory research methods were similar to co-design processes and outcomes. Inclusion criteria included any study that engaged people of CALD background in a mental health service design, re-design or quality improvement project. The methodology needed to articulate the use of participatory research design processes and therefore studies including CBPR, co-production, co-design, or action research were included. Those studies that did not clearly articulate a methodology were excluded. Reference lists of all included articles were also reviewed to identify additional studies that might have been missed in the database searches. The full-text screening process was completed by the primary author. The other authors then reviewed it and where queries or differences of view arose, all three authors read

the full article in question, discussed its content and reviewed the search criteria to reach consensus about its inclusion or exclusion.

The included articles were then reviewed according to the PRISMA extension for scoping review recommendations (Tricco et al., 2018) in order to extract data relevant to answering the research question. For each of the included research articles, the first author charted the data using the extraction fields proposed for scoping reviews (Arksey & O'Malley, 2005), with additional details added to enrich our understanding (e.g. participants' characteristics, methodological approaches, conceptual approaches to co-design, research implications).

The extracted data was then used to undertake a qualitative synthesis whereby researchers engaged in a process of grouping data into themes relevant to the research question in three iterative stages (Daudt, van Mossel, & Scott, 2013; Levac, Colquhoun, & O'Brien, 2010). This involved firstly listing findings from studies verbatim, then codes were developed based on content, research methodology and conceptual approaches to co-design. Second, similarities and differences between codes and themes were compared and grouped into descriptive categories. Third, overarching themes were developed to best define each category (Daudt, Van Mossel, & Scott, 2013). The primary author took the lead role in coding the data and discussed the theme development as this progressed at regular intervals with the other authors. A draft summary of themes was then reviewed and agreed upon by all three authors.

Results

Nine articles met the inclusion criteria for this review (see Figure 1.)

Figure 1. Flow Diagram of Literature Search and Selection Process

Insert Figure 1 here

Of these, four were mixed method studies and five were qualitative studies (see table 1). Five of the studies specifically used a community based participatory

research design, with the other four using action research methods; all studies were focused on service development, improvement or re-design of mental health services. Geographically, the studies were located in the USA or the UK; no Australian studies were identified. Two studies engaged and worked with American Indian populations, three other US studies engaged Black, Hispanic, Latino and African communities. The other four studies engaged Black and Minority Ethnic (BME) communities within the UK.

Table 1. Key methodological details and results of included studies (n=9)

Insert Table 1 here

Overview of key themes

The key themes are presented according to the chronological nature of engaging in co-design research, commencing with considerations for engaging a CALD community before starting co-design research; then working together during co-design research; and ending a co-design research project.

Key themes are described in Table 2 below.

Table 2. Key themes identified through qualitative synthesis process

Insert Table 2 here

Before starting co-design research

All the identified studies used approaches consistent with culturally responsive practice, yet only one study noted the importance of cross-cultural training for all researchers before engaging with CALD communities (Kurtz & Street, 2006). Five of the nine studies identified the importance of developing a long-term relationship when working with a CALD community and reported this as important in their success (Doornbos et al., 2018; Dowrick et al., 2013; Kurtz & Street, 2006; Langdon et al., 2016; Lwembe, Green, Chigwende, Ojwang, & Dennis, 2017). One study reported that when using co-design methods with CALD populations, broad community engagement principles need to be present in order to develop

meaningful and participatory relationships (Thomas, Seebohm, Henderson, Munn-Giddings, & Yasmeen, 2006).

Before starting co-design research, further important considerations relate to the explanatory models of both 'mental health' and 'community' within CALD communities.

Explanatory models of mental health

Five studies reported that the explanatory models of mental health within CALD communities impacted on how they adapted evidence-based practices in co-developing culturally accepted and relevant programs/services with CALD communities. For example, evidence based mental health interventions were adapted to include culturally acceptable elements in two studies with North American Indians by co-developing interventions that involved engaging with the land and using traditional cultural practices considered to improve mental health alongside evidence based mental health interventions (Langdon et al., 2016; Novins et al., 2012). In three UK studies, physical exercise was included in mental health interventions for BME clients to better align the intervention with the cultural explanatory model of depression for this population (Dowrick et al., 2013; Lwembe et al., 2017; Thomas et al., 2006).

Explanatory models of community

In four studies, researchers reported that explanatory models of community impacted how they set up their co-design research and influenced how the service/program was developed and delivered (Langdon et al., 2016; Lwembe et al., 2017; Mance, Mendelson, Byrd, Jones, & Tandon, 2010; Novins et al., 2012). Differences in how individuals, families and communities engage and connect with each other result in varying understanding of what a community is. CALD communities with strongly held models of community inter-connectedness were thought more likely to engage with researchers if they too were from the same community (Langdon et al., 2016; Novins et al., 2012). In two studies engaging North American Indian communities, the researchers not only developed long term relationships with these communities but were also thoughtful about the makeup of

their research teams in order to improve engagement throughout the entire project (Langdon et al., 2016; Novins et al., 2012). When engaging with Lumbee (American Indian) youth, researchers reported that equitable partnerships, group dynamics and how conventional evidence-based practice approaches can be meaningfully adapted to fit within other cultural approaches should be taken into account (Langdon et al., 2016). To develop equitable partnerships, this research team involved Lumbee representatives (both workers and the youth themselves) at all levels and set up a collaborative study team, including a community advisory board and a Lumbee co-investigator. Similarly, when working with a North American Indian community, Novins et al., (2012) firstly formed a steering committee consisting of clinicians, administrators, and researchers along with young people, parents and elder/cultural experts from the community before commencing the design process.

Depending on their explanatory models and understanding of community, different communities reported valuing different ways of receiving mental health care. Five of the studies recruited and involved peer workers as a more culturally acceptable way to co-deliver mental health interventions and improve engagement (Langdon et al., 2016; Lwembe et al., 2017; Mance et al., 2010; Novins et al., 2012; Thomas et al., 2006). Similarly, group settings were chosen to provide supportive psychotherapy and psychoeducation in a more culturally acceptable way for ethnically diverse women who reported they were more likely to engage in groups than if this was delivered individually (Kelly & Pich, 2014). Likewise, Lwembe et al., (2017) indicated that, in many different cultures, people expect to be treated with their families and do not understand the typical individual approach to treatment. In this study, the researchers found that when community members perceived that they could be seen with other family members, they were more likely to reach out for help.

Three studies also identified the need to explicitly discuss co-design approaches and how these may or may not align with the ways in which CALD communities operate before beginning research (Langdon et al., 2016; Lwembe et al., 2017; Novins et al., 2012). These studies identified that it is important to consider how CALD communities operate as they may be set up and organized differently to those of the

researcher. In particular, the difference between individualistic and collectivist communities are noted as demonstrating community values in significantly different ways.

During Co-design Research: Quality of the relationship

The quality of relationship between researchers and CALD communities was the most frequently reported methodological consideration within all nine studies.

Aspects identified as important to improving the quality of the relationship between the researchers and the CALD communities included: consideration of the setting context, accessibility, communication, trust, confidentiality and power differentials.

Effective communication is a central issue when working with individuals from different cultural and language backgrounds in co-design. This was highlighted in two studies as a key consideration for the researchers (Dowrick et al., 2013; Kelly & Pich, 2014). Despite this, one study with participants with post-traumatic stress disorder (PTSD) from ethnically diverse backgrounds reported that it was more important that they felt a sense that the therapist/researcher cared about them than needing congruent language and culture (Kelly & Pich, 2004). Language and communication were identified as basic considerations in co-design activities since interpreters may be required. Yet, one identified issue can be that when multiple community groups come together, the sheer number of different languages and cultures may result in an unwieldy number of interpreters (Kelly & Pich, 2004).

Four studies in particular identified trust as an inherent issue in using co-design methods with CALD communities (Doornbos et al., 2018; Langdon et al., 2016; Lwembe et al., 2017; Novins et al., 2012). Working with a BME community in the UK, Lwembe et al., (2017) engaged peer workers as a way to build trust with the community and found that having groups co-led by a community member with experience of mental health problems encouraged trust, safety and hope that they too could become better. Similarly, Novins et al., (2012) and Langdon et al., (2016), who worked with North American Indians, spent considerable time engaging peer workers and representatives for community advisory boards to ensure that trust was

built within the research. The studies that engaged consumers with lived experience as co-facilitators reported increased sense of trust within the project, as well as improved access to services (Langdon et al., 2016; Lwembe et al., 2017; Mance et al., 2010; Thomas et al., 2006; Novins et al., 2012). Despite this, no studies identified clearly whether these co-facilitators were paid for their involvement.

Three of the studies specifically raised access issues as a factor that impacted their research (Kurtz & Street 2006; Thomas, et al., 2006; Kelly & Pich 2014). Lwembe et al., (2017) intentionally designed their co-design research by ensuring that it was led not only by researchers but by representatives from the community, which improved the perceived access to their project. Similarly, Kelly & Pich, (2014) considered context and setting as highly important. To engage with ethnically diverse women with PTSD, they recognized the need to consider issues impacting the women's available time, such as childcare, competing demands and other economic issues, and are barriers to research participation for CALD communities (Kelly & Pich, 2014).

Furthermore, Lwembe et al., (2017) highlight confidentiality as another potential barrier to engagement within close CALD communities. For them, this was a factor making engagement more difficult in working with a tightly knit BME community, in which there were complex stereotypes and stigma about mental health and suspicion of the mental health services.

Ending co-design research

Five of the nine studies highlighted the implications of long-term relationships with CALD communities for ending the co-design process. These studies noted that when co-design processes ended, these relationships did not and that these ongoing partnerships were important in their success (Lwembe et al., 2017; Kurtz & Street, 2006; Doornbos et al., 2018; Dowrick et al., 2013; Langdon et al., 2016). For example, Doornbos et. al (2018), who engaged ethnically diverse women with PTSD in a co-designed supportive psychotherapy and psychoeducation, reported that participants' mental health symptoms did not improve immediately but did over a six-month period. The researchers suggest that their ongoing relationship was

important as it encouraged the women to sustain their use of psychoeducation strategies and gain improvements over time.

Discussion

To the authors' knowledge, this is the first scoping review to focus on methodological considerations for using co-design methods with CALD communities in mental health service design and improvement projects. No studies were identified that had used EBCD methods with CALD communities within mental health services, and so this review explored what has been learnt from research using co-design methods more generally with this population to guide research directions. Consistent with literature in the co-design field, varying co-design methods were used in the nine reviewed studies. The lessons learned from these studies provide methodological considerations that can guide researchers in understanding how EBCD may be adapted to improve cultural relevancy for this CALD communities.

Two overarching issues across the phases of co-design have been identified through this research, relating to:

- 1) The quality of the relationship between the researcher and CALD community impacted on CALD community's experience and engagement.
- 2) Methodological considerations arising from the explanatory models of mental health and community held within CALD communities and their impacts on co-design models.

First, this review identifies methodological considerations for improving the experience for CALD communities engaging in co-design research. This highlighted the need to consider trust, power differentials, confidentiality and communication, all which have been shown to impact the quality of relationships developed between researchers, service users and communities (Mulvale et al., 2016; Stacciarini et al., 2011). These considerations are present when using co-design with all end users, but are of increased significance for minority populations, such as CALD communities, since these factors impact significantly on access and participation in service engagement and are echoed in methodological challenges when using co-design

methods (Baker et al., 2016; Minas et al., 2013; Minas et al., 2007; Procter, Babakarkhil, Baker, & Ferguson, 2014). The magnitude of these barriers needs to be considered when using co-design research, so as to ensure that these barriers are adequately addressed to enable participation of all the relevant stakeholders. Co-design protocols within policy frameworks would benefit from explicitly documenting the need to consider these methodological issues when engaging CALD communities to ensure that researchers are taking extra steps towards addressing the power relations, and thereby improving the likelihood that co-design with CALD communities is genuinely open, respectful, collaborative and empowering (Australian Centre for Innovation, 2019).

Second, this review identifies methodological considerations arising from the explanatory models of mental health and community held within CALD communities and their impacts on co-design models. Drawing upon findings from the reviewed studies, co-design protocols would benefit from additional steps to generate discussion about these explanatory models between the researchers and community involved. These discussions will allow researchers to identify how their own explanatory models of mental health, community and co-design might not only differ from those of the community involved, but also how they may impact the research design process. Similarly, this step may create opportunities for researchers and CALD communities to develop a shared explanatory model for use within the co-design process and inform the kind of co-design tools and techniques used within projects (Dimopoulos-Bick et al., 2019). This may in turn more closely reflect the particular CALD community's experiences and views of the world, thus improving the quality of the co-design process and the likelihood that the end service or product meets the needs of the users.

Explanatory models of mental health differ across various cultural backgrounds (Minas et al., 2013; Kleinman, 1988), including in some CALD communities with people with mental health issues presenting with increased physical and somatic complaints (Minas et al., 2007). Not surprisingly then, adapting evidence-based interventions to include physical, somatic and other cultural approaches, including

spiritual practices, can increase intervention acceptability (Langdon et al., 2016; Novins et al., 2012; Lwembe et al., 2017; Dowrick et al., 2013; Thomas et al., 2006). Acknowledging and discussing these differences with a CALD community may support the development of a shared understanding of mental health between researchers and CALD communities, therefore improving the likelihood that the solutions are designed by the people who will use the service. This will address issues highlighted within CBPR research that researchers tend to use known methods, rather than co-creating innovative solutions with end users (Stacciarini et al., 2011).

Explanatory models of community also impact on research design. Therefore, consideration of how a particular community works and who to engage in the co-design project needs to take place. For instance, it may be apparent that to improve outcomes for a CALD community, a broad cross section of the community needs to be represented so as to reflect the collectivist nature of that community, or that specific elders or community members need to be invited to engage in order to truly represent 'participation' for a community (Langdon et al., 2016; Lwembe et al., 2017; Mance et al., 2010; Thomas et al., 2006; Novins et al., 2012). This is supported by research findings that when CALD community members are embedded throughout the entire research process, this increases the project's relevance and outcomes (Evans et al., 2014; Gilbody et al., 2006). Similarly, engaging with a CALD community and building relationships before starting a co-design research project also improved the likelihood of success (Lwembe et al., 2017; Kurtz & Street, 2006; Doornbos et al., 2018; Dowrick et al., 2013; Langdon et al., 2016). Of course, to do any of this, researchers require skills in cultural responsiveness (Kurtz & Street, 2006).

Finally, this review has identified that culture impacted on understandings of co-design in communities and therefore this too requires attention. As co-design is about collective effort and a relational approach to service design (Palmer et al., 2019; Bates & Robert, 2007), it is driven by values such as openness, empowerment, collaboration and respect (ACI, 2019). Some authors therefore acknowledged that, due to differences in culture and ways that communities operate, conventional

approaches to co-design may need to be re-considered and adapted to fit the particular community context (Lwembe et al., 2017; Langdon et al., 2016; Novins et al., 2012). Co-design protocols used within the dominant culture of a developed country may not necessarily translate to working effectively with a CALD minority community, particularly if the researchers themselves are not from this community. The experience that a CALD community group has of being 'other' implies an implicit difference between community and service. An important consideration then that was not evident in any of the reviewed studies is what practices are already present in the CALD community that drive change from within. It is likely that many CALD communities will have particular community processes that impact on how community members participate and interact. Embedded culturally acceptable participatory processes to support change need to be revealed in order to ensure that community improvements are made from within (Staccariani et al., 2011). It is therefore important for researchers to consider how co-investigators can be identified, where and how to engage a community, and to ensure that logistical issues such as location, confidentiality and economic barriers are all addressed to enable participation. Interestingly, none of the studies identified whether financial remuneration for services was provided for CALD co-investigators. Is it truly possible to collaborate with openness and empowerment when there are economic differences in remuneration? Therefore, using co-design models that are underpinned by detailed explanatory theoretical models will improve dialogue and relational processes that co-design relies upon (Palmer et al, 2019).

This review provides specific information about how research design may be improved to guide future research directions. We suggest that additional steps are warranted when using co-design protocols with a CALD population in order to address the methodological issues identified. The mental health experience co-design MHECO tool kit is one example of an Australian co-design resource developed for use in the mental health setting (Tandem, 2018; Richard et al., 2017; Cooper et al., 2016) that shows promise and may be used with this population. Future research should firstly review existing co-design protocols, such as MHECO and EBCD, with CALD communities in order to understand CALD communities' experience of

engaging in this process. From here, adapting existing protocols to include steps to engage in discussions about explanatory models of mental health and community may address the existing tensions and gaps identified, as well as improving the cultural acceptability of co-design methods.

Review Limitations

The limitations of this scoping review relate in part to the lack of research on this topic, making it difficult to compare studies and study designs. A specific critical appraisal checklist was not used, and this is another limitation. Additionally, conceptual confusion and the multiple ways of defining co-design mean there may be studies that used the concept and theory of co-design, which were not identified by the search terms used in this scoping review. Further, services that engage in co-design processes with CALD populations for service design or improvement may be less likely to publish these activities within academic peer reviewed journals.

Consequently, since grey literature was not included in this review, some examples of co-design with CALD communities for mental health service design and improvement may have been missed. Since the reviewed studies were conducted primarily in the UK with Black and Minority Ethnic (BME) communities and in the USA with Black, Hispanic and Latino communities, its applicability for co-designing mental health services for CALD populations in other multicultural societies should be considered cautiously and needs further research.

Conclusion

The results of this study support the notion that if co-design is put forward in policy as a best practice method for service design and improvement, then further research into the transferability of co-design tools with CALD communities is required. This review provides information for researchers about methodological consideration for using co-design with CALD communities for mental health design, re-design or quality improvement initiatives. Specifically, the need to consider explanatory models of mental health, community and co-design is essential to optimally engage CALD communities in collaborative research. There may be benefit in applying an existing explanatory theoretical model of change to consider the conditions and

mechanisms of action that can support co-design, and indeed, to consider whether further adaptations of the model may be needed in light of the findings of this scoping review. The review provides information about the importance of the quality of the relationship between researcher and the CALD community and the need to consider how to purposefully end a co-design research process.

Further research investigating how CALD communities experience existing co-design methods, and adaptations that may have been made, including documented protocols such as EBCD, is required. This study adds to the literature by identifying that explanatory models of mental health, of community and of co-design impact how co-design methodologies are used in CALD communities. These explanatory models therefore need to be understood to optimize the quality of the collaborative relationships between researchers and CALD communities.

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#	Query	Limiters/Expanders	Last Run Via	Results
S12	S3 AND S6 AND S9	Limiters - Date of Publication: 19930101-20191231; English Language Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	163
S11	S3 AND S6 AND S9	Limiters - Date of Publication: 19930101-20201231 Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	167
S10	S3 AND S6 AND S9	Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	175
S9	S7 OR S8	Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	272,370
S8	(MH "Counseling") OR (MH "Mental Health Services") OR (MH "Mental Health")	Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	102,704
S7	TI (counselling OR counseling OR "mental health") OR AB (counselling OR counseling OR "mental health")	Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	227,644

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S6	S4 OR S5	Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	47,647
S5	MH "Health Services Research") OR (MH "Community-Based Participatory Research")	Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	40,615
S4	TI (codesign* OR "co-design*" OR "participatory design*" OR "participatory research" OR "action research" OR "co-production*") OR AB (codesign* OR "co-design*" OR "participatory design*" OR "participatory research" OR "action research" OR "co-production*")	Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	9,900
S3	S1 OR S2	Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	186,608
S2	TI ("culturally and linguistically diverse" OR CALD OR Ethnic* OR "non-english" OR NESB) OR AB ("culturally and linguistically diverse" OR CALD OR Ethnic* OR "non-english" OR NESB)	Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	141,297
S1	MH "Cultural Diversity") OR (MH "Ethnic Groups")	Expanders - Apply equivalent subjects Search modes - Find all my search terms	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - MEDLINE Complete	70,915

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Table 1 - Key methodological details and results of included studies (n=9)

Research	Aims/Purpose	Focus Population	Study Methodology	Results	Type of service design/quality improvement initiative	Co-design methodological approach and considerations	Themes Identified
Doornbos et al., (2018)	<p>Purpose of this study was to research the effectiveness of the group that was called Women supporting Women. A co-designed psychoeducation and support group for women from CALD communities with anxiety and depression.</p>	<p>Seventy-two women aged between 17–88 years in 3 different underserved communities (US)</p>	<p>Quasi-experimental, non-equivalent comparison group, pretest/post-test design in order to evaluate an education/support group for women 18+.</p>	<p>Lower anxiety and depression results were identified following participating in co-designed groups</p>	<p>A psychoeducation and support group was developed and co-designed by the participants.</p>	<p>CBPR - The process engaged the women in identifying the problems as well as the design and implementation of the intervention. Discussion included emphasise on quality of relationship with the CALD community in developing the intervention.</p>	<p>1) Increased engagement = improved outcomes. 2) Trust - reciprocity important 3) Power needs to be shared 4) Long term follow up important for change</p>

Table 1 - Key methodological details and results of included studies (n=9)

Dowrick et al., (2013)	Study objectives were to clarify the mental health needs of people from underserved groups; identify relevant evidence-based services and barriers to, and facilitators of, access to such services; develop and evaluate interventions that are acceptable to underserved groups; establish effective dissemination strategies; and begin to integrate effective and	Four disadvantaged localities were included in this study. 2 of these localities had high rates of minority ethnic populations. (UK)	Quasi-experimental design with a no-intervention comparator for each element, we tested the model in four disadvantaged localities, focusing on older people and minority ethnic populations.	The patients receiving the developed interventions found the content and delivery of the interventions acceptable.	Researchers developed a culturally sensitive well-being intervention with individual, group and signposting elements and tested its feasibility and acceptability for ethnic minority and older people in an exploratory randomised trial.	Community development principles highlighted as main theoretical approach. Emphasised need to consider how to adapt intervention for cultural acceptability.	1) Increased engagement = improved outcomes 2) Complex diagnostic presentations include mix of psychological and physical symptoms 3) Western MH constructs (explanatory models) inherently different 4) Communication issues
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Table 1 - Key methodological details and results of included studies (n=9)

	acceptable interventions into primary care.						
Kelly & Pich (2014)	Feasibility study for a PTSD program for ethnically diverse women who experienced intimate partner violence.	22 ethnically diverse women who experienced intimate partner violence participated in the group. (US)	Feasibility study, using intervention pretest/post-test qualitative and quantitative data post-test qualitative and quantitative data. Data taken at 2 weeks in to group, 3 months post	Improvement in participant's mental health were found over the 6 months	Intervention developed which was 6-10 weekly sessions focussing on supportive psychotherapy, psychoeducation and self care strategies.	CBPR is used as the research framework. This aided researchers to engage the population group in their developed intervention. The intervention was designed by researchers and altered after consultation with the participants.	1) Communication issues 2) service context (logistics) important 3) Diagnosis/experience can draw people together despite different cultural backgrounds

Table 1 - Key methodological details and results of included studies (n=9)

			and 6 months post				
Kurtz & Street (2006)	Aimed to identify perception of Black and Minority Ethnic (BME) young people and examine initiatives designed to improve access, acceptability of these services.	Four areas were selected: one in London with a large multicultural ethnic population; one in Wales, and one in each of the Midlands and the north of England with large BME communities and specific	A mixed methods approach, including a literature review, national service mapping, in-depth interviews and focus groups in four sample areas and action research in preparing	Research concludes that there is a need to improve awareness of mental health and information about services among BME communities. This requires mental health services and communities to explore ways in which acceptable and	Developed psychoeducational material within larger action research methods study. This is only a small part of this study and was not clearly described in depth.	Action research approach to study. Co-production of psycho-education materials. The specific co-design part of this study was embedded within a broader action research project. The discussion emphasises that there is firstly a need for understanding the population and then secondly strategically placing services within	1) Increased engagement = improved outcomes. 2) Cultural competence training. 3) Strategic context of service required

Table 1 - Key methodological details and results of included studies (n=9)

		developments within the local CAMHS (UK).	materials designed by BME young people	appropriate mental health expertise can be made more readily available		formal and informal settings. Staff need a level of cultural competence in order to embark on co-design projects.	
Langdon et al., (2016)	Describes success and challenges of using a community-based participatory research (CBPR) mixed method project with American Indian Youth	American Indian youth (from the Lumbee community in North Carolina, (US)	Focus groups were conducted with the Lumbee youth, these themes were used to support development of the intervention. Intervention was co-	The CBPR mixed methods project was successful in laying the groundwork for developing a program for American Indian Youth	Develop, implement and evaluate a culturally rich program which was a form of a suicide prevention program. Engaged with community at all stages. Collaborative	Community based participatory research methods. This is approach does not have specific steps rather underlying principles. Considerations need to be taken into account for cultural/spiritual explanatory models of mental health,	1) Explanatory models of mental health 2) Power dynamics and Trust important in quality of relationship 3) Underpinning models of community/participation impact design 4) increased engagement = improved outcomes 5) Interventions need to be culturally relevant

Table 1 - Key methodological details and results of included studies (n=9)

	Author Manuscript		developed with the culture class instructors using the data from phase 1, with a Community advisory board overseeing the whole project.		study team, Lumbee coinvestigator, community advisory board, community members working with the youth and youth themselves were on the community advisory board.	equitable partnerships, group dynamics, how Western EBP can be adapted to be culturally acceptable and meaningful.	
Lwembe et al., (2017)	Evaluation of a pilot cross-sector initiative that used co-production approaches to	BME clients in mental health services (UK)	Evaluation of a pilot service. Qualitative research methods,	Positive results. Focus group reported positives were having the	The intervention was a group that was co-led by a psychological	Co-production. Important considerations; level of engagement of stakeholders (the co-	1) Increased engagement = improved outcomes 2) Co-led = improved outcomes 3) Confidentiality 4) Explanatory model of

Table 1 - Key methodological details and results of included studies (n=9)

<p style="writing-mode: vertical-rl; transform: rotate(180deg);">Author Manuscript</p>	<p>deliver a mental health service to meet the needs of BME clients.</p>		<p>including semi-structured interviews and focus groups, were used to collect data to examine the use of co-production methods used in designing and delivering an improved mental health service.</p>	<p>group co-led by a community member, facilitators were culturally competent and friendly, the group was run in community setting and participants felt that support would be given to family members that weren't eligible for the group improving access.</p>	<p>therapist and a consumer. These interventions were to be both psychologically based as well as involving physical exercise.</p>	<p>led element of this group improved outcomes), setting for where intervention is implemented is important, family/systems approach to treatment improved perception of access. Confidentiality and stigma also impacted on study</p>	<p>community 5) Confidentiality important 6) Interventions need to be culturally relevant 7) Explanatory models</p>
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Table 1 - Key methodological details and results of included studies (n=9)

Mance et al., (2010)	Describes the use of a CBPR approach to adapt a mental health intervention for urban adolescents and young adults disconnected from school and work.	African American adolescents and emerging adults from an urban neighbourhood in East Baltimore (US)	Describes the CBPR process undertaken to modify the mental health intervention	CBPR approach found to be effective in adapting a mental health intervention for CALD communities.	Developed a culturally appropriate intervention to prevent the worsening of depressive symptoms and increase adaptive.	CBPR. CBPR used to ensure community partners participated jointly in all phases of the adaptation process. Co-learning process was inherent within CBPR approach and proved valuable for this project as young people were peer leaders in this intervention. Competing demands for peer leaders was an issue which leads to consideration of power, equity and payment for co-production services.	1) Increased engagement = improved outcomes 2) Explanatory models of community impact research design 3) Power issues in quality of relationship important
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Table 1 - Key methodological details and results of included studies (n=9)

Novins et al., (2012)	Descriptive paper detailing the co-design process and development of a program for Native American Indian Youth	Native North American Adolescents (US)	Describes the CBPR process undertaken to create the mental health intervention	Increased coping strategies identified post engaging in program	Developed a program for Native American Indian youth with the aim of addressing and reducing substance abuse	CBPR. Clear description of logic model for development of the intervention; Foundations, Concepts, Intervention and Outcomes are described. This highlights the need for considering explanatory models of community and mental health within CALD community engaged with.	1) Explanatory model of MH, 2) explanatory model of community 3) Explanatory model of co-design needs to be considered before starting research 4) Trust, power important in relationship 5) Culturally adapted interventions required

Table 1 - Key methodological details and results of included studies (n=9)

<p>Thomas et al., (2006)</p>	<p>Participatory action research study with BME community in UK. This descriptive paper aimed to identify what kind of help do BME participants want and what was the capacity of the community development process to help Bradford's statutory services to understand and respond to these views.</p>	<p>Bradford BME community (UK)</p>	<p>Descriptive paper using participatory action research design</p>	<p>Positive results from engaging with CALD community.</p>	<p>Sharing voices Bradford used a community development framework in order to co-create a group which engaged BME clients by using spiritual, creative, fitness, social and learning activities alongside traditional mental health approaches.</p>	<p>Participatory action research using community development principles within co-design process. Methodological considerations identified as need to consider context and culturally appropriate interventions when developing interventions to ensure access and suitability.</p>	<p>1) Context - setting of interventions important 2) Increased engagement = improved outcomes 3) Post engagement important to maintain positive results</p>
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Table 2. Key themes identified through qualitative synthesis process

	Dowrick et al., (2013)	Kurtz & Street (2006)	Lwembe et al., (2017)	Thomas et al., (2006)	Doornbos et al., (2018)	Kelly & Pich, (2014)	Langdon et al., (2016)	Novins et al., (2012)	Mance et al., (2010)
Main theoretical approach	Community development principles	Action research	Co-production	Action Research	Community based participatory research	Community based participatory research	Community based participatory research	Community based participatory research	Community based participatory research
Pre Co-Design: Cultural and Theoretical Paradigms									
Community engagement is important before working with a community to co-design a project	X	X	X	X	X		X		X
MH diagnoses present differently within multicultural groups which need to be considered						X			
Explanatory models of community impact the way researchers/clinicians should engage. Peer workers recruited in this study			X				X	X	X
Explanatory models of mental health impact the way that mental health services are delivered	X		X			X	X	X	
Cultural competency/responsiveness training needed for staff/researchers first		X							
explanatory model of co-design approach needs to be considered before starting project (steering committee, level of engagement in co-design methodology)			X				X	X	
During Co-design Research; Quality of Relationship									
Trust			X		X		X	X	
Power issues					X		X	X	X
Communication confidentiality	X		X			X			
Logistics/context		X		X		X			
Co-lead service/program improves outcomes			X						
Intervention adaptation needs to involve culturally appropriate interventions			X				X	X	
Post Co-Design Research: Exiting co-design research									
Important to engage in long term Community engagement even after co-design project ends to ensure									
MH project was useful and required				X	X				

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Figure 1. Flow Diagram of Literature Search and Selection Process

