ENGAGING EQUITY-DESERVING POPULATIONS IN CO-CREATION

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LAY ABSTRACT

Refugee families in Canada often face mental health challenges and have difficulty getting the help they need. Despite this, their voices are rarely included in how mental health services are designed. One way to change this is through co-creation, a method that brings people with lived experience together with service providers and researchers to design solutions that work better for everyone.

This study looked at how co-creation can be done in ways that truly include people from equity-deserving groups, like refugee families. This is achieved by reviewing existing research and learning from the *Thriving Together* project, where refugees help co-design mental health supports. I found that successful co-creation needs to be flexible and respectful of different cultures and experiences. Key values like inclusion, shared benefits, and cultural respect were essential for meaningful engagement with refugee families. These values must be turned into real actions, like good communication and building strong relationships.

ABSTRACT

Background: Refugee families in Canada experience significant mental health challenges and face heightened barriers to accessing mental healthcare services, yet their voices remain underrepresented in the design of those services. A co-creation approach offers a way to meaningfully engage those equity-deserving populations by centering their experiences and perspectives. However, limited research has specifically examined how to engage refugee families in co-creation processes. This study aimed to review the literature on engaging equity-deserving groups in co-creation and to develop a tailored engagement strategy as part of the *Thriving Together* co-design project.

Methods: A two-phase approach was used. Phase one involved a structured narrative review guided by Arksey and O'Malley's framework. Three databases (PubMed, Web of Science, and Scopus) were searched, along with grey literature and citation searches. A total of 45 studies were included in the review, and findings were charted across definitions, guiding principles, theoretical frameworks, phases of co-creation, engagement methods, barriers, and enablers. Phase two synthesized these findings with field insights from the *Thriving Together* project to inform a context-specific engagement strategy.

Results: The included studies, primarily from high-income countries, focused on equity-deserving populations and revealed inconsistent terminology but recurring emphasis on key engagement principles, such as trust, power-sharing, and flexibility. Common phases of co-creation included preparation, discovery, ideation, and implementation, with frequent use of creative methods like storytelling and visual tools. Reported barriers included power imbalances and logistical challenges.

These findings and the practical insights informed the engagement strategy, which is conceptualized as a journey, guided by principles, structured around clear phases, supported by practical tools, and designed to proactively address barriers and promote meaningful participation.

Conclusion: More research is needed to advance co-creation with refugee populations. Achieving equitable and impactful engagement relies on operationalizing guiding values such as reflexivity, adaptability, and authentic partnership with the communities involved.

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Table of Contents

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

CCGHR – Canadian Coalition for Global Health Research

CIHI – Canadian Institute for Health Information

CIHR – Canadian Institutes of Health Research

COMPASS Tool – **CO**- production, supporting **M**anagers, preparing **P**articipants, building **A**ffinity, and fostering **S**ensitivity and create relational **S**afety.

EBCD – Experience-Based Co-Design

EqCC – Equity-based Co-Creation

EDGs – Equity-Deserving Groups

GRIPP2 – Guidance for Reporting Involvement of Patients and the Public

HIREB – Hamilton Integrated Research Ethics Board

IAP2 – International Association for Public Participation

NIHR – National Institute for Health and Care Research

PCORI – Patient-Centered Outcomes Research Institute

PI – Principal Investigator

PICO – Patient or Problem (P), Intervention (I), Comparison (C), and Outcome (O)

PPEET – Public and Patient Engagement Evaluation Tool

PRISMA – Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PRODUCES Framework – **P**roblem, **O**bjective, **D**esign, (end-) **U**sers, **C**o-creators, **E**valuation, and **S**calability

SDG – Sustainable Development Goal

SWIFT framework – Strengths, Weaknesses, Individuality, Fixes, and Transformation

WHO – World Health Organization

DECLARATION OF ACADEMIC ACHIEVEMENT

The following is a declaration that the content of the research in this document has been completed by Alshaymaa Ali and recognizes the contributions of Dr. Amanda Sim, Dr. Deborah DiLiberto, and Dr. Bahar Amani in both the research process and the completion of this thesis.

Chapter 1: Introduction

1.1 Background & Rationale

Mental health is essential to overall well-being. It is a fundamental human right that allows individuals to manage life's challenges, achieve their full potential, contribute to society, and thrive in their personal and professional lives (World Health Organization, 2022a). According to the WHO mental health report, in 2019, 970 million people worldwide (1 in 8) are living with a mental disorder, mainly anxiety and depression (World Health Organization, 2022b). While mental healthcare access is a challenge for all Canadians (CIHI Canadian Institute for Health Information, 2023), evidence suggests that immigrants and refugees underutilize mental health services compared to individuals born in Canada (Ng & Zhang, 2021; Thomson et al., 2015).

Canada has a strong history of welcoming refugees, with over 200,000 admitted as permanent residents between 2016 and 2021 and representing a significant portion of the over 1.3 million immigrants who arrived in Canada during this period (Statistics Canada, 2022). While refugees are influenced by the same social determinants of mental health as the general population, their experiences are further shaped by the distinct challenges of the forced migration process (Hynie, 2017). Factors such as pre-migration trauma, challenging post-migration conditions, and racialization and discrimination can significantly impact mental health (Beiser & Hou, 2016; Elshahat et al., 2021; Hynie, 2017; Sim et al., 2023b).

Despite facing numerous risk factors, many refugees demonstrate remarkable resilience (Sim et al., 2023b). Yet, this resilience is often strained by the difficulties of resettlement, including language barriers, discrimination, financial instability, and the stress of adapting to a new culture (Beiser & Hou, 2016; Hynie, 2017; Sim et al., 2023b). Health systems in host countries often fall short of meeting the distinct sociocultural needs of immigrants and refugees due to factors such as

limited cultural competency among providers, language barriers, inadequate interpretation services, and unfamiliarity with the healthcare system (Babatunde-Sowole et al., 2020; Donnelly et al., 2011; Sim et al., 2023a).

The mental health challenges faced by refugee families are not only a matter of individual and community well-being but also of global significance. The United Nations Sustainable Development Goal (SDG) 3 (*Good Health and Well-Being*), specifically target 3.4, focuses on promoting mental health and wellbeing for all, including marginalized and displaced populations (World Health Organization, 2015). Addressing the mental health needs of refugees is essential to achieving this goal, as untreated psychological distress undermines broader health outcomes (World Health Organization, 2011).

To ensure culturally relevant and effective support, the voices of impacted equity-deserving groups such as refugee families must be prioritized in the development of mental health policies and programs (Government of Canada, 2017; Kostiuk, 2019; Sim et al., 2023a). There has been a growing emphasis on participatory research in recent literature, particularly related to co-creation (Masterson et al., 2022; Zogas et al., 2024). Co-creation has gained recognition for its potential to empower both service users and providers to collaboratively design solutions that enhance the quality and relevance of health and public services (Moll et al., 2020).

Co-creation fosters shared ownership and more responsive, effective interventions by actively involving communities and service users in decision-making (Bovaird, 2007). This approach is especially critical when working with equity-deserving populations, as it ensures that solutions are not only contextually meaningful but also empowering. Their engagement enables more tailored responses to specific needs, helps address systemic disparities, and promotes a stronger sense of agency and inclusion (Moll et al., 2020; Mulvale et al., 2019b; Mulvale et al.,

2024). Moreover, co-creation approaches that center equity and inclusivity align with the Sustainable Development Goals' (SDGs) commitment to "leave no one behind" (United Nations Sustainable Development Group, n.d).

To fully appreciate the role of co-creation in advancing health equity, it is essential to examine the populations most impacted by systemic exclusion and how their participation is framed. Co-creation is increasingly used as a strategy to involve communities that have historically experienced systemic oppression which restrict their participation in shaping and assessing health and social services. These populations are frequently referred to as vulnerable; this label, despite being widely used, is subject to debate (Phoenix et al., 2024). Critics argue that such language can inadvertently pathologize individuals by framing vulnerability as an inherent trait, rather than acknowledging the societal structures and historical legacies that produce and perpetuate inequity (Phoenix et al., 2024). In this context, the term equity-deserving groups (EDGs) is used to more accurately reflect the systemic barriers faced by these populations (Phoenix et al., 2024). Equity-deserving groups (EDGs) are populations whose experiences are shaped by intersecting local and global social, historical, political, economic, and cultural factors. These groups are often marginalized by systemic inequities, resulting in limited access to critical services and resources, as well as enduring structural disadvantages (Phoenix et al., 2024).

These populations encounter systemic barriers rooted in ongoing discrimination, oppression, and exclusion. Such barriers lead to persistent disparities in health outcomes and access to services. These issues are not coincidental; they are built into institutional frameworks and policy systems that reflect and reinforce wider social inequities (Phoenix et al., 2024).

Addressing the needs of EDGs requires more than tokenistic or superficial forms of inclusion. It demands the critical examination and reform of existing diversity, equity, and

inclusion practices. This includes establishing and implementing standard operating procedures that prioritize their authentic participation and actively work to dismantle power imbalances (WHO, 2023). Meaningfully engaging EDGs in co-creation leads to more effective, contextually appropriate, and sustainable outcomes.

However, the concept of co-creation encompasses a wide range of practices, its definitions are fluid and its boundaries are often blurred with related approaches, such as co-production and co-design (Albert et al., 2023; Masterson et al., 2022; Pearce et al., 2022; Zogas et al., 2024). Masterson et al. (2022); Zogas et al. (2024) suggested that rather than focusing on rigid definitions, researchers should clearly describe how the core principles and values of their work are enacted in practice (Masterson et al., 2022; Zogas et al., 2024), and to share adaptable resources that others can modify and apply creatively in their own contexts (Greenhalgh et al., 2019; Hickey et al., 2018; Zogas et al., 2024).

In this thesis I follow Pearce's definition of co-creation as the broader term that includes four collaborative processes: (1) co-ideation, (2) co-design, (3) co-implementation, and (4) co-evaluation, and Vargas's definition of co-design as the process of collaboratively designing solutions to pre-defined problems. A more detailed discussion of these concepts and related definitions will be provided in the literature review chapter.

Mangai and De Vries (2018) positioned co-creation at the highest levels of an adapted version of Stewart's continuum of engagement (Stewart, 2009), which includes the following levels: information, consultation, deliberation, partnership, and participatory governance delegation. These stages are cumulative with each one building upon the previous stage. For example, co-creation encompasses information, consultation, deliberation, and partnership,

emphasizing a layered participatory approach that culminates in shared decision-making (Gheduzzi et al., 2020).

Recognizing co-creation as a process that integrates multiple layers of participation highlights the importance of engaging stakeholders in ways that are ethical, inclusive, and effective. This is especially crucial when working with equity-deserving populations, where failure to address systemic barriers, risks sustaining existing inequalities (Mulvale et al., 2019b). According to World Health Organization (2020), community engagement involves building relationships that empower stakeholders to collaborate in addressing health issues and promoting well-being, ultimately aiming to improve health outcomes.

Meaningful engagement is particularly important when working with refugee families who may have experienced marginalization (Radl-Karimi et al., 2018). Research highlights significant challenges in fostering and sustaining co-creation with equity-deserving populations, including power imbalances and difficulties in building trust with communities, shaped by histories of trauma and discrimination (Acha et al., 2021; Goedhart et al., 2021). Barriers such as language, literacy, digital access, transportation, and competing responsibilities often limit participation (Acha et al., 2021; Gheduzzi et al., 2021; Goodyear-Smith et al., 2015; Moll et al., 2020; Parnes et al., 2024). Moreover, without visible outcomes and long-term commitment, co-creation risks becoming tokenistic or extractive, ultimately weakening the empowerment it aims to foster (Acha et al., 2021). While co-creation approaches have been successfully applied to some mental health interventions, few have examined how they can be adapted for refugee families, who have unique settlement and mental health needs and face structural barriers to meaningful engagement and participation in co-creation.

This study aims to explore how to optimize the engagement of equity-deserving populations, particularly refugee families, in the co-design of mental health interventions. It is part of a larger project, "Thriving Together," which aims to co-design and evaluate a culturally responsive family-based intervention to improve the mental health of refugee children and their caregivers (PI: Dr Amanda Sim, McMaster University).

1.2 Research Objectives

The objectives of the study are to:

1. Conduct a literature review on engagement in co-creation to identify key definitions, theoretical frameworks, guiding principles, methods, barriers, and best practices for engaging equity-deserving groups.
2. Develop a strategy for optimizing participants engagement in co-designing a mental health intervention, as part of the *Thriving Together* project.

1.3 Philosophical Orientation

The philosophical orientation that underpins this study is pragmatism. A pragmatic perspective employs “what works,” using diverse approaches and valuing objective and subjective knowledge (Colin Robson, 2016; Held, 2019). Pragmatism focuses on the practical implications of research and the importance of generating knowledge that can be used to address real-world problems (Weyant, 2022). This aligns with the study goal to develop a strategy for optimizing participant engagement in co-designing a mental health intervention. The study not only seeks to understand the nature of participant engagement but also aims to produce an actionable strategy to enhance it. This is achieved through a combination of literature review and insights gained from

direct involvement in the *Thriving Together* co-design project. The selection of these methods, along with the focus on real-world applicability, reflects the core principles of pragmatism.

1.4 Thriving Together Project

The Thriving Together project aims to co-design and evaluate a culturally responsive, family-based mental health intervention for refugee families, in partnership with Wesley, a leading settlement service provider. Conducted in Hamilton, Ontario, which has a significant refugee population, the project builds on Wesley's strong community trust and cultural competence. It seeks to reduce health disparities and inform the development and scaling of sustainable mental health interventions for refugee families across Canada. This initiative builds on prior research that explored the mental health needs and preferred forms of support among refugee families in Hamilton (Sim et al., 2023a; Sim et al., 2023b) (PI: Dr Amanda Sim, McMaster University).

1.5 Thesis Structure

This thesis opens with Chapter One, which provides the background to the study, introduces the research topic and aim. Chapter Two describes the methodology, detailing the approach taken to conduct the research. Chapter Three presents a review of the existing literature, which serves as a foundation for the development of the engagement strategy discussed in Chapter Four. Chapter Four also incorporates insights drawn from participation in the *Thriving Together* project. Finally, Chapter Five discusses the study's findings and concludes with directions for future research and implementation.

Chapter 2: Methodology

This study employed a structured narrative literature review and insights from participating in *The Thriving Together* project (PI: Dr Amanda Sim, McMaster University), to inform the development of an engagement strategy focused on optimizing engagement among equity-deserving populations in co-creation processes. In this chapter I will discuss the methodology for the literature review and my participation in the co-design project.

2.1 Literature Review

The structured narrative literature review (Greenhalgh et al., 2018; Sukhera, 2022) followed the key methodological components of Arksey and O'Malley's (2005) framework, originally developed for scoping reviews. These stages include: (1) identifying the research question, (2) identifying relevant studies, (3) selecting studies, (4) charting the data, and (5) collating, summarizing, and reporting the results (Arksey & O'Malley, 2005). A detailed protocol is discussed in the following sections.

2.1.1 Step One: Identifying the Research Question

This research was guided by the following research question:

What insights can be drawn from existing literature regarding the key terminologies, guiding principles, theoretical frameworks, methods, and best practices for developing a strategy to optimize equity-deserving populations' engagement in the co-creation of mental health intervention?

To address this question, a structured approach was undertaken to identify, screen, and synthesize relevant literature across health and mental health domains.

2.1.2 Step Two: Identifying Relevant Studies

2.1.2.1 Literature Search Strategy and Search Terms

The search strategy was designed to identify studies that discuss engagement processes in the context of co-creation, co-design, and co-production, with a focus on vulnerable or equity-deserving populations. Keywords were developed iteratively, drawing on prior exploratory searches and aligned with the core concepts of the research question. The final search terms included variations of:

engag* AND (co-design* OR co-creat* OR co-prod* OR codesign* OR cocreat* OR coprod*) AND (vulnerable OR refugee) AND (health OR “mental health”)

Wildcards were used to capture different word forms (e.g., "engagement," "engaging"), and Boolean operators, parentheses, and quotation marks were employed to ensure comprehensive and relevant coverage of the literature.

2.1.2.2 Electronic Database Search

Three major databases were searched: PubMed, Web of Science, and Scopus, chosen for their robust indexing of interdisciplinary health and social science literature. In addition to peer-reviewed articles, a grey literature search was conducted via Google search engine using the same search terms without wildcards, parentheses, or quotation marks, to include practice guidelines and toolkits that may not be captured in traditional databases. A citation search was also undertaken by reviewing the references of key articles and identifying new sources through forward and backward citation tracking. The search was conducted between February and June 2025.

2.1.3 Step Three: Eligibility Criteria & Study Selection

2.1.3.1 Eligibility Criteria

Studies were included if they met the following criteria:

- Addressed engagement processes within co-creation, co-design, or co-production initiatives.
- Focused on theoretical frameworks, guiding principles, methods, or best practices for engagement.
- Were situated in health, mental health, or social service contexts.
- Included primarily equity-deserving or marginalized groups, such as refugees, racialized communities, 2SLGBTQ+ individuals, youth, or people living on low incomes (Phoenix et al., 2024).
- The search included articles written in the English language only.

The review incorporated a range of study types, including qualitative studies, methodological and conceptual papers, literature reviews, and grey literature, to capture diverse perspectives on engagement practices. While the review emphasized marginalized populations, some studies and grey literature involving the general population were included if they offered particularly valuable insights or methodological contributions relevant to engagement. Studies involving participants with cognitive disabilities were excluded, as their engagement needs and contexts are distinct from the study population.

2.1.3.2 Study Selection Process

The initial database search yielded the following results: 445 articles from PubMed, 182 from Web of Science, and 55 from Scopus. After reviewing titles for relevance, 58 studies were retained from PubMed, 49 from Web of Science, and 14 from Scopus. Additionally, 41 papers were identified through citation searching and grey literature search.

After title screening, 162 articles were imported into Covidence, a systematic review management platform, and 32 duplicate records were removed. Abstract screening led to the exclusion of 58 studies, and full-text screening resulted in a further 27 exclusions for not meeting the inclusion criteria. In total, 45 studies were included in the review (Figure 1: PRISMA Flow Diagram).

2.1.4 Step Four: Charting the Data

2.1.4.1 Data Extraction

Data from the included studies were extracted using a structured Excel spreadsheet. Key information collected included the citation, population, type of co-research, setting, theoretical frameworks, guiding principles, process phases, activities, and tools, and identified barriers and facilitators to engagement. This systematic extraction allowed for comparison across studies and supported a thematic synthesis of findings. A condensed charting Table is included in Appendix B.

2.1.5 Step Five: Collating, Summarizing and Reporting Results

The extracted data were then collated, summarized, and organized according to recurring categories, methodological insights, and practical strategies relevant to participant engagement. These findings are presented in the literature review chapter and directly informed the development

of the engagement strategy, alongside insights from participating in *The Thriving Together* Co-design Project.

2.2 Participation in the Co-Design Process

In addition to synthesizing findings from the literature review, I participated in *The Thriving Together Co-design Project*, a series of interactive workshops aiming to co-design a culturally responsive, family-based mental health intervention with and for refugee families. The co-design team is made up of refugee caregivers, refugee youth, and service providers (Wesley staff). To date, we have conducted six workshops, during which the team identified key issues, co-ideated potential solutions, and reached a consensus on which solutions to pursue. We have now begun the design phase to develop these selected solutions in detail. My role in this process included supporting participant recruitment, contributing to workshops planning, and assisting in facilitation. This hands-on involvement provided opportunities to observe group dynamics, design engagement activities, witness the exchange of diverse perspectives, and adapt facilitation techniques in real time to ensure inclusivity and accessibility.

Participation in the co-design process grounded findings from the literature review in lived experience. This combined approach facilitated the identification of a wide range of insights, from foundational theoretical concepts to practical, actionable strategies, which contributed to a more inclusive and responsive approach to engagement within co-creation processes. Conducting a literature review in tandem with participation in a co-design project provided a unique dual perspective, deepening my understanding of co-creation not just as a theoretical construct but as a lived, relational, and context-driven process.

2.3 Reflexivity

Central to this experience was the practice of reflexivity, which is an ongoing critical self-reflection on personal biases, assumptions, and interactions with participants (Olmos-Vega, 2023). Reflexive practice promotes transparency and enhances research quality by centering humility, a foundational principle of Global Health Research (CCGHR, 2015).

My positionality as a healthcare professional and Arabic-speaking immigrant significantly shaped how I engaged with participants. These shared cultural and linguistic ties fostered trust, facilitated communication, and enhanced the cultural sensitivity of the process. Sharing the experience of being an immigrant and newcomer reinforced for me that vulnerability is a shared human condition, something everyone encounters at different points in their lives.

At the same time, I recognize that this proximity may have introduced potential biases, including assumptions based on perceived commonalities. To address this, I employed reflexive strategies throughout the research process, such as keeping detailed notes, engaging in peer debriefing, and consulting with supervisors, to critically examine and mitigate these influences.

2.4 Ethics Approval

Ethics approval for *the Thriving Together Project* was obtained from The Hamilton Integrated Research Ethics Board in Health Sciences (HIREB) (Appendix A).

Chapter 3: Results: Literature Review

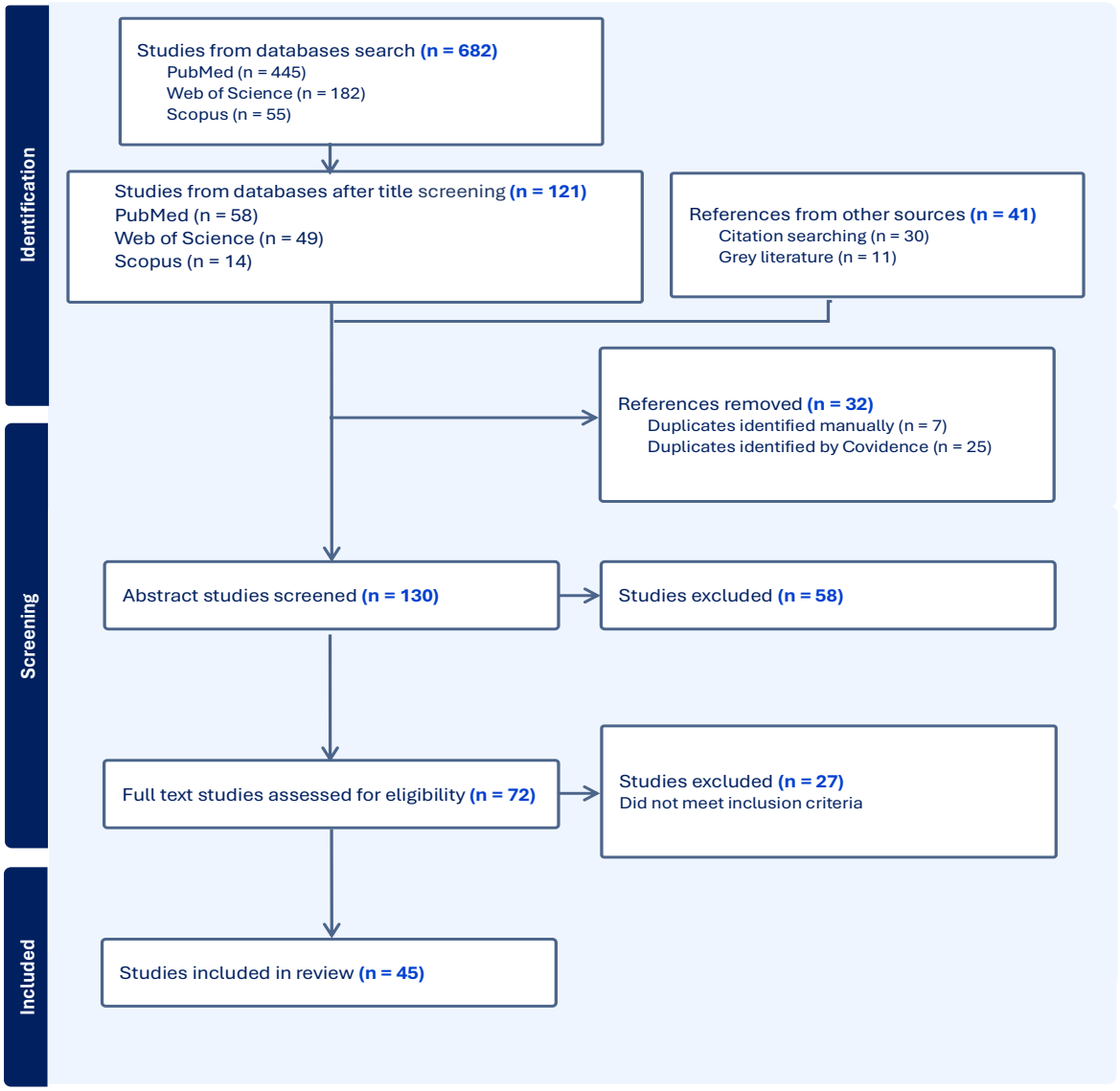
Engaging Equity-Deserving Populations in Co-Creation

3.1 Description of Literature

The 45 included studies comprised 8 literature reviews, 7 grey literature sources (e.g., frameworks, guides, and toolkits), 8 methodological studies, 2 conceptual papers, and 19 qualitative studies (including case studies and descriptive designs), along with 1 study protocol. The studies originated from Europe (15), Canada (14), the United States (6), Australia (6), New Zealand (1), and China (1), along with one WHO report, and one literature review focused on high-income countries. The populations represented included equity-deserving groups (32 studies), patients in healthcare settings (7 studies), general population (2), and Veteran patients (1). In addition, 3 studies specifically focused on refugees, asylum seekers, and newcomers. Among the 32 equity-focused studies, 8 included youth, and 2 included newcomers and immigrants.

This chapter begins by outlining the key definitions and concepts relevant to the study. It then examines the engagement of equity-deserving groups in co-creation, starting with the theoretical frameworks and guiding principles that underpin the process. The discussion then turns to the phases of the co-creation journey, exploring how guiding values are operationalized through strategies that support engagement, and the barriers and enablers of meaningful participation. The chapter concludes by highlighting gaps in the literature and discussing the implications for developing an effective engagement strategy.

Figure 1: PRISMA Flow Diagram



3.2 Definitions and Key Concepts

3.2.1 Engagement, Co-Creation, Co-Design, and Co-Production

Community engagement is a foundational concept in health services and implementation research, and it is recognized for its role in improving health outcomes across diverse settings (Erwin et al., 2024; Vargas et al., 2022; Zhang et al., 2024). World Health Organization (2020) defines community engagement as "a process of developing relationships that enable stakeholders to work together to address health-related issues and promote well-being to achieve positive health impact and outcomes" (p. vii). Frameworks such as Arnstein's Ladder outline levels of engagement, illustrating a spectrum of citizen participation that ranges from manipulation and tokenism at the lower end to full citizen control at the highest level (WHO, 2020).

Although **co-creation, co-design, and co-production** are frequently treated as synonymous, each term has a distinct meaning that helps define its specific role within health and implementation science (Vargas et al., 2022). However, these meanings vary across the literature. According to Pearce et al. (2020); Vargas et al. (2022), co-creation refers to the comprehensive, collaborative generation of ideas, solutions, and strategies involving a diverse set of stakeholders across all phases of an initiative, from ideation to evaluation. Co-design, by comparison, focuses more specifically on collaboratively designing solutions to pre-defined problems. It is grounded in the creative engagement of stakeholders to produce models, prototypes, or service concepts (Vargas et al., 2022). Co-production, on the other hand, relates to the operational phase, involving the implementation of agreed-upon solutions and the active participation of stakeholders in the delivery and assessment of services (Vargas et al., 2022).

In the context of research, however, "co-production" takes on a more expansive meaning. Erwin et al. (2024) defined it as a broad term encompassing co-creation, co-design, and other

participatory approaches. They view co-produced research as the explicit involvement of stakeholders in both the planning and conduct of health research. This means stakeholders are involved in every stage, from identifying research priorities to disseminating results. Research co-production is also defined by Kothari et al. (2017) and Graham et al. (2019) as "a model of collaborative research, where researchers work with knowledge users who identify a problem and have the authority to implement the research recommendations" (Graham et al., 2019, p. 2).

Mulvale et al. (2024) position co-creation as a deliberate collaboration between professionals and individuals with lived experience, where experiential knowledge is valued equally. This framing highlights the importance of shared learning and power and treating different types of expertise as equally valuable.

A persistent challenge in this domain is the lack of terminological consistency. The interchangeable and often imprecise use of terms like co-creation and co-design can result in confusion, misaligned expectations, and inefficient use of resources in program planning and delivery (Pearce et al., 2020). In response to this issue, Pearce et al. (2020) proposed a standardized definition of co-creation:

> The generation of new knowledge that is derived from the application of rigorous research methods embedded into the delivery of a program or policy by researchers and a range of stakeholders, through four collaborative processes: (1) co-ideation, (2) co-design, (3) co-implementation, and (4) co-evaluation. (p. 11)

This definition is anchored in three key principles: the production of new knowledge through robust scientific methods, the integration of these methods into real-world settings, and the continuous engagement of stakeholders across all four phases of the process (Pearce et al., 2020).

Evidence increasingly supports the idea that consistent and meaningful engagement across the co-creation process strengthens stakeholder partnerships, enhances the relevance and contextual fit of interventions, and improves the real-world uptake and sustainability of research outcomes (Pearce et al., 2020). Clarifying terminology is an essential step toward improving the effectiveness and outcomes of collaborative methods in health research and implementation (Pearce et al., 2020).

3.3 Theoretical Frameworks and Key Guiding Principles

This section examines the theoretical frameworks and guiding principles of co-creation discussed in the literature. The literature identifies the frameworks and principles that underpin ethical, inclusive, and effective engagement in co-creation. These foundations guide the design and implementation of engagement processes, and influence the quality, sustainability, and impact of co-creation outcomes.

3.3.1 Theoretical Frameworks

Co-creation approaches are informed by a variety of theoretical frameworks, reflecting their multifaceted and interdisciplinary nature; these frameworks are summarized in Table 1. For instance, Mulvale et al. (2019a), draw on Narrative Theory, Learning Theory, and Design Thinking to emphasize the relational dimensions of co-creation, particularly trust, power-sharing, vulnerability, and empathy. Similarly, Wahi et al. (2023) employ a Socio-Ecological Model to highlight the complex interconnections between individual, community, and systemic factors.

In their literature review, Messiha et al. (2023) identify a wide range of theoretical frameworks used across co-creation, co-design, and co-production studies. Empowerment Theory, for example, positions co-creation as a pathway for enhancing individual and community agency,

particularly in marginalized settings. It functions as both a design principle and an evaluative lens, capturing how participatory methods build local capacity and resilience (Messiha et al., 2023).

Communication-focused theories like Social Learning and Narrative Theory inform interventions by promoting observation, storytelling, and peer-to-peer engagement, supporting both knowledge exchange and behavior change (Messiha et al., 2023).

Other frameworks shed light on how co-creation processes unfold in real-world settings. Symbolic Interactionism and Interactional Ritual Change Theory explore the relational and emotional dynamics that shape belonging and inclusion. Meanwhile, Normalization Process Theory and the Realist Evaluation Framework help to explain how interventions become embedded and sustained in everyday practice (Messiha et al., 2023).

Social Innovation Theory views co-creation as a tool for fostering locally tailored, collaborative responses to complex social and health challenges. Finally, Amartya Sen's Social Justice Framework positions co-creation as both a means and an end, centering equity, participation, and democratic values in both process and outcome (Messiha et al., 2023).

Table 1: *Theoretical Frameworks in the Literature*

Theory	**Theory summary**
Empowerment Theory	Individuals gain control over personal and societal aspects of life by building skills, knowledge, and collaborating with professionals rather than being directed by them (Anselma et al., 2020; Cueva et al., 2017; Messiha et al., 2023).

Social Learning Theory	People learn behavior through observation and modeling, often using real-life or structured scenarios (Koops van 't Jagt et al., 2016; Messiha et al., 2023).
Narrative Theory	Storytelling enhances engagement and learning by creating relatable experiences and role models (Messiha et al., 2023).
Symbolic Interactionism Theory	Human actions are shaped by the meanings developed through social interactions, which are constantly interpreted and adapted (Handberg et al., 2019; Messiha et al., 2023).
Social Effectiveness of Interventions Theory	Interventions are effective when they create shared understanding and restructure relationships through exchange processes (Hoeeg et al., 2019; Messiha et al., 2023).
Realist Evaluation Framework	Assesses the effectiveness of interventions by exploring how specific contexts, underlying mechanisms, and resulting outcomes are connected through a process of interpretation and understanding (Garton et al., 2022; Messiha et al., 2023).
Normalization Process Theory	Explains how new practices become routine, focusing on coherence, participation, collective action, and ongoing evaluation (Duke et al., 2020; Messiha et al., 2023).
Interactional Ritual Change Theory	Social norms and beliefs are sustained and changed through repeated, meaningful interactions (Clarke et al., 2019; Messiha et al., 2023).
Social Innovation Theory	Emphasizes collaborative, local-level problem-solving to create co-produced, impactful social change (Farmer et al., 2018; Messiha et al., 2023).

Amartya Sen's Social Justice Framework	Views co-creation as a democratic and inclusive process, valuing participation, empowerment, and fairness in interventions (Latulippe et al., 2020; Messiha et al., 2023).
The Socio-Ecological Model	Explains that health issues result from multiple interacting factors (individual, social, community, and societal), offering a comprehensive framework to understand these complex influences (Wahi et al., 2023).
Design Thinking	Emphasizes user-centered approaches. It engages both service users and providers collaboratively, focusing on users lived experiences to guide the design process (Mulvale et al., 2019a).

Note. Table content summarized and synthesized from multiple sources, including *Systematic Review of Contemporary Theories Used for Co-creation, Co-design and Co-production in Public Health* (Messiha et al., 2023, *Journal of Public Health*, 45(3), 723–737, https://doi.org/10.1093/pubmed/fdad046), and additional studies cited in the text.

3.3.2 Guiding Principles

The literature identifies a core set of guiding principles as essential for meaningful engagement. Two studies reported co-developing these principles with participants (Albert et al., 2023; Caperon et al., 2023). Although the terminology and emphasis of these principles vary across sources, there is clear convergence around several foundational themes: building relationships, sharing power, fostering inclusion, promoting reciprocity, maintaining adaptability, practicing self-reflection and cultural humility, and ensuring safety and well-being,

1. Building Relationships: Trust and Empathy

Most engagement frameworks in the literature begin with relational foundations such as building trust and cultivating empathy, which are critical components of meaningful involvement, particularly when working with equity-deserving groups (Albert et al., 2023; Benz et al., 2024; Denford et al., 2024; Mulvale et al., 2019b; Roche et al., 2020; Taccone et al., 2023; World Health Organization, 2023). While relationship-building is a cornerstone of all research, co-creation emphasizes a more active and reciprocal model. Rather than simply consulting participants, co-creation fosters equal partnerships where stakeholders and researchers collaboratively shape research goals, processes, and outcomes. This approach marks a shift from one-way knowledge dissemination to collaborative knowledge generation, grounded in strong relationships and mutual trust (Moll et al., 2020).

2. Sharing Power and Equity-Centered Practice

Power-sharing is another recurring principle in the literature; it involves rebalancing traditional hierarchies by valuing lived experience equally alongside academic and professional expertise. This requires intentional co-leadership, shared decision-making, and continuous reflexivity. It is especially important when working with marginalized communities (Albert et al., 2023; Amann & Sleigh, 2021; Health Quality Ontario, n.d.; Mulvale et al., 2019a; NIHR, 2024; NSW Regional Health Partners, n.d.).

3. Inclusion and Accessibility

Inclusion is another consistent principle in the literature. Operationalizing inclusion requires removing structural, cultural, and logistical barriers to participation. This includes covering transportation costs, translation services, accessible formats and flexible timelines (Albert et al., 2023; CIHR, 2014; Erwin et al., 2024; Mulvale et al., 2024). Some frameworks

emphasize the need to meet people in their own spaces and to create welcoming, adaptable environments for engagement (Albert et al., 2023; Moll et al., 2020; Phoenix et al., 2024). Inclusivity also means accounting for intersectionality and the diversity of stakeholders. Intersectionality recognizes that individuals hold multiple, overlapping identities shaped by both privilege and marginalization (Crenshaw, 1989). Meaningful engagement must acknowledge this complexity, ensuring inclusivity by considering the diverse social, health, and contextual factors that influence lived experience (Health Quality Ontario, n.d.; WHO, 2023). For example, McKeon et al. (2024) highlighted that concerns related to privacy and appropriate attire (modesty) had been identified as barriers to women's participation in physical activity. They addressed this by creating women-only spaces, which led to increased participation.

4. Reciprocity and Co-learning

Reciprocity is another emphasized principle in the literature (Denford et al., 2024; Mulvale et al., 2019b; Zogas et al., 2024). Engagement is most ethical and impactful when framed as reciprocal and mutual learning. This entails shared knowledge creation and recognizing the unique expertise of both lived experience and professional training (CIHR, 2014; NIHR, 2024; PCORI, 2021). Authentic engagement requires a two-way exchange, where communities are not just sources of information but beneficiaries of meaningful value. These benefits can take many forms, such as financial compensation, expanded social networks, increased confidence, and the acquisition of new skills and knowledge. Reciprocity may also be reflected in receiving thoughtful feedback, being included in decision-making, or experiencing personal fulfillment through knowing one’s contributions may positively impact others (Albert et al., 2023; Denford et al., 2024; Erwin et al., 2024; Mulvale et al., 2019b; NIHR,2024; Roche et al., 2020). Ultimately, reciprocal relationships foster deeper trust and promote shared ownership.

5. Adaptability, Iteration, and Creative Process

Co-creation literature often highlights flexibility, creativity, and iteration as core elements of engagement (Acha et al., 2021; Albert et al., 2023; Amann & Sleigh, 2021; Sanders & Stappers, 2014). Unlike other research approaches that follow fixed, linear protocols, co-creation is inherently dynamic and evolving. It requires researchers to adapt to the local context, respond to the rhythms and needs of the community, and continuously refine their methods based on ongoing input. This iterative process supports innovation and fosters more responsive and relevant outcomes (Albert et al., 2023; Blackwell et al., 2017; Erwin et al., 2024; Mulvale et al., 2019b; Pearce et al., 2022; Vargas et al., 2022).

6. Practicing Self-Reflection and Cultural Humility

The literature emphasizes that working with equity-deserved population requires researchers to continuously examine their own assumptions, stereotypes, and cultural norms. By stepping back and asking critical questions, they can avoid allowing unconscious biases to shape their judgments. Engaging in this kind of reflection, paired with a willingness to learn about different cultures, helps reduce power imbalances and fosters mutual respect (Mulvale et al., 2024; Phoenix et al., 2024; Radl-Karimi et al., 2018; Roche et al., 2020).

7. Safety and Well-being: Trauma-Informed Practice

Psychological and emotional safety are foundational to meaningful engagement, particularly when working with equity-deserving groups. Participants must feel safe, respected, and supported, to share openly and contribute authentically (Amann & Sleigh, 2021; Mulvale et al., 2024). Creating a psychologically safe environment requires responsiveness to participants' needs and attentiveness to emotional and relational dynamics (Mulvale et al., 2021; Radl-Karimi et al., 2018).

Trauma-informed practice plays a critical role in this process. It emphasizes the creation of safe, predictable, and empowering spaces, especially for individuals and communities who may carry the weight of historical and ongoing trauma, such as colonialism, racism, displacement, and systemic exclusion (Hawke et al., 2024; Mulvale et al., 2024; Roche et al., 2020). A trauma-informed lens invites researchers to acknowledge these realities explicitly yet sensitively, to avoid re-traumatization (Roche et al., 2020).

3.4 The Process

Understanding engaging equity-deserving groups in co-creation requires examining how the process is structured across each phase. Co-creation is typically described as iterative and flexible, but it is also structured by common stages that guide how stakeholders are brought in, how their voices shape decisions, and how accountability is maintained. This section outlines how engagement unfolds throughout the co-creation journey, grounded in the guiding values discussed earlier.

3.4.1 Frameworks

A variety of frameworks have been developed or applied in the literature to guide the co-creation process. For instance, Albert et al. (2023) utilized the asset-based Appreciative Inquiry 5D model (Define, Discover, Dream, Design, Deliver) to structure their approach. Similarly, Leask et al. (2019) employed the **PRODUCES framework (Pr**oblem, **O**bjective, **D**esign, (end-) **U**sers, **C**o-creators, **E**valuation, and **Sc**alability) which offers a systemic structure for co-creation following the example of Cochrane (PICO) process. The **COMPASS tool (CO-** production, supporting **M**anagers, preparing **P**articipants, building **A**ffinity, and fostering **S**ensitivity and create relational **S**afety) contributes by addressing the relational dynamics involved in co-creation (Mulvale et al., 2021).

Other models place a strong focus on equity and inclusivity. For example, the Equity in Engagement Framework developed by Health Quality Ontario (n.d.), promotes equitable engagement through a tree metaphor: with engagement principles as the roots, internal preparation and partnerships as the trunk, and the engagement process as the branches. Likewise, the Valuing All Voices Framework takes a trauma-informed and inclusive stance, encouraging critical reflexivity while prioritizing justice, equity, and safety in the context of health research (Roche et al., 2020).

3.4.2 Phases

While specific terminology varies across literature, most co-creation models follow a phased approach: preparation, discovery, ideation, implementation, and feedback. Engagement strategies are adapted at each stage to support trust-building, inclusion, and shared ownership.

3.4.2.1 Preparation

The process begins with a preparation, during which the foundational conditions for ethical and inclusive engagement are established. This includes building the team, securing institutional and community support, mapping key stakeholders, setting clear goals and expectations, and initiating early relationship-building efforts. Recruitment strategies are context-specific and may involve peer-led outreach, community-based posters, and informal briefings to ensure accessibility and relevance (Mulvale et al., 2019a; Pearce et al., 2022).

To effectively recruit equity-deserving groups, it's important to build trust, engage community insiders, and connect through existing networks and informal spaces. Flexible participation options help ensure the process is inclusive and responsive to participants' needs (Amann & Sleigh, 2021; Mulvale et al., 2019b). Informal pre-engagement-meetings are often used to build rapport, introduce co-design principles, and clarify roles (Mulvale et al., 2021).

3.4.2.2 Discovery

The discovery step focuses on exploring services using various methods such as literature reviews, observation, narrative interviews and storytelling to capture emotional touchpoints (emotionally significant points) and uncover systemic barriers or opportunities for improvement (Albert et al., 2023; Benz et al., 2024; Moser & Korstjens, 2022). Observational techniques are also employed to capture real-time interactions in service environments. They offer insight into workflows, barriers, and user needs. These findings are critical for informing subsequent phases and for tailoring facilitation techniques, especially in navigating the relationship dynamics between equity-deserving groups and service providers (Blackwell et al., 2017; Moser & Korstjens, 2022; The Point of Care Foundation, n.d.). In Experience-Based Co-Design (EBCD), participant narratives are sometimes transformed into "trigger films" or animations (particularly for sensitive topics) (Hawke et al., 2024; Mulvale et al., 2019a). These edited videos highlight key moments in users' experiences and are presented at the beginning of co-creation sessions to center user perspectives, cultivate empathy, and initiate dialogue around shared priorities for change (Hawke et al., 2024; McKeon et al., 2024; Mulvale et al., 2019a).

3.4.2.3 Ideation

The ideation and co-design phase builds on these insights, inviting stakeholders to prioritize challenges and collaboratively generate solutions. Workshops and design sessions often use structured facilitation techniques, including small-group activities, brainstorming, consensus tools, and creative catalysts such as videos or visual prompts (Benz et al., 2024; Mulvale et al., 2019a; Taccone et al., 2023). Tools such as experience maps or storyboards create shared understanding of complex experiences (Mulvale et al., 2019a; Parnes et al., 2024). Ideas are usually developed into prototypes or mock-ups, enabling participants to envision and test tangible

outputs. These sessions are iterative, allowing for continual refinement based on group feedback and reflection (Hawke et al., 2024; Mulvale et al., 2019a; Sanders & Stappers, 2014). Supportive facilitation and creative engagement methods are essential to fostering empowerment and meaningful participation among equity-deserving groups (Gheduzzi et al., 2020; Mulvale et al., 2019a).

3.4.2.4 Implementation and Feedback

In the feedback, evaluation, and implementation phase, participants are actively involved in validating findings and co-assessing the feasibility of proposed solutions (Hoeeg et al., 2019). This phase often includes pilot implementation, validation by participants (Bird et al., 2021; Pearce et al., 2022; Roche et al., 2020; Zogas et al., 2024), as well as process and outcome evaluations (Wahi et al., 2023; Zhang et al., 2024). Actively engaging equity-deserving groups during this stage strengthens the quality and relevance of the outcomes and fosters a sense of ownership and empowerment. Many projects conclude with a celebratory or recognition event, underscoring the importance of relational closure and honoring participants' contributions (Amann & Sleigh, 2021; Moser & Korstjens, 2022; Mulvale et al., 2019a; Parnes et al., 2024; The Point of Care Foundation, n.d.).

3.5 Strategies and Methods That Support Engagement Across the Process

Effective engagement relies on creating conditions that make participation sustainable and impactful. This section examines strategies designed to foster and support such engagement.

3.5.1 Inclusivity and Representation

Diverse stakeholder inclusion is essential, and the meaningful involvement of equity-deserving groups requires careful attention to accessibility, power dynamics, and representation. Purposeful and maximum variation sampling is often used to capture a broad range of demographic

and experiential perspectives (Leask et al., 2019; Vargas et al., 2022; Zhang et al., 2024). Purposeful sampling involves selecting participants based on their ability to provide rich, relevant information aligned with the study's objectives. Maximum variation sampling, a type of purposeful sampling, seeks to capture a wide range of perspectives by including participants with diverse characteristics and experiences (Palinkas et al., 2013). Engagement approaches are also adapted to meet different linguistic, cultural, and cognitive needs through translation, interpretation, the use of visual tools, culturally sensitive methods, and clear language formats (McKeon et al., 2024; Moser & Korstjens, 2022; Mulvale et al., 2019b; Radl-Karimi et al., 2018).

3.5.2 Capacity-Building and Support

Stakeholders can be supported throughout the process with training, mentorship, and peer-based learning. Community members may receive orientation in co-design principles, while professional stakeholders are guided in cultural humility (Acha et al., 2021; Amann & Sleigh, 2021; Mulvale et al., 2019b; Radl-Karimi et al., 2018). Logistical supports, such as honoraria, transportation, childcare, and digital access, are key to reducing barriers and sustaining engagement over time (Boyd et al., 2010; Domecq et al., 2014; Mulvale et al., 2019b). These supports need to be adaptable throughout the process to ensure continued inclusion and emotional safety of equity-deserving groups.

3.5.3 Governance and Power-Sharing

Co-creation engagement efforts increasingly incorporate variable governance models, such as advisory groups (multisector individuals representing diverse cultural groups, service users, providers, payers, and organizations), steering groups (diverse representation provides oversight and guidance), community sounding boards (any community member interested in sharing feedback), and co-leadership models, to support transparency and participant ownership (Albert et

al., 2023; Benz et al., 2024; Erwin et al., 2024; Parnes et al., 2024; The Point of Care Foundation, n.d.).

3.5.4 Evaluation and Accountability

Evaluation and reporting are embedded throughout the engagement lifecycle. Several quantitative and qualitative methods are used, such as interviews, focus groups, observational notes, surveys, digital feedback tools, and co-assessment workshops, to measure both the engagement and outcomes (Leask et al., 2019; Pearce et al., 2022; Zhang et al., 2024). Validated tools such as Public and Patient Engagement Evaluation Tool (PPEET) (Faculty of Health Sciences & Patient Engagement, 2021) and Guidance for Reporting Involvement of Patients and the Public (GRIPP2) (Staniszewska et al., 2017), support structured reporting and transparency (Benz et al., 2024; Bird et al., 2021; Taccone et al., 2023), while the International Association for Public Participation (IAP2) Spectrum is often used to define levels of stakeholder engagement (Roche et al., 2020).

Evaluation examines how equitable and inclusive the engagement process was, which is an important aspect with all research populations but particularly vital when working with equity-deserving groups that may have experienced marginalization or susceptible to harm or tokenistic involvement (Mulvale et al., 2024).

3.5.5 Engagement Methods and Modalities

Effective co-creation engagement relies on cultivating relationships and creating space to share perspectives. This section describes a range of methods and modalities used in co-creation literature to foster equitable and inclusive engagement.

Dialogue-Based Methods: Workshops and Focus Groups

Workshops and focus groups are among the most used modalities for fostering dialogue between diverse stakeholders. In co-creation, these methods move beyond eliciting opinions to creating shared understanding and generating solutions.

Workshops are typically structured around co-creation activities such as experience mapping, solution generation, or prototype testing. Their interactive design helps address power asymmetries by enabling iterative, collective reflection rather than expert-driven decision-making (Mulvale et al., 2019a; Zhang et al., 2024). Focus groups in co-creation are often used to gather community perspectives on emerging priorities or to test the acceptability of proposed ideas. When facilitated effectively, they provide an opportunity to explore divergent viewpoints and align around shared values (Health Quality Ontario, n.d.).

Facilitators play a key role in both formats especially with EDGs, helping to equalize participation, encourage less-heard voices, and adapt in real time to group needs (Gheduzzi et al., 2024). Methods such as experience mapping (visually charting a participant's journey through a service or system), concept mapping (converting complex qualitative data into visual representations that clearly illustrate the connections between ideas), trigger videos (short films that present real user experiences to prompt emotional and reflective dialogue), and prototype creation (developing models or mock-ups of potential solutions) can help participants articulate both explicit and latent needs, those that may not be immediately apparent or easily expressed in words (Bird et al., 2021; Mulvale et al., 2019a; Papoulias, 2018; Windsor, 2013).

Narrative Methods: Interviews and Storytelling

Interviews and storytelling are used in co-creation to center lived experience as legitimate expertise. These methods are particularly important for surfacing emotional, relational, or systemic "touchpoints."

- **Semi-structured interviews** give individuals space to reflect on their experiences, motivations, and perceptions of engagement itself (Hawke et al., 2024).
- **Storytelling**, especially when community-led or facilitated in groups, can reveal shared barriers, strengths, and aspirations. These stories often form the basis for co-design artifacts such as experience maps, journey timelines, or trigger films (Mulvale et al., 2019a; Mulvale et al., 2019b).

Embedded Observation

Observation in co-creation is used to jointly interpret lived environments and understand how systems function. Participatory or embedded observation builds early relational trust, helps facilitators understand unspoken social dynamics, and surfaces barriers that may not be explicitly articulated by participants (The Point of Care Foundation, n.d.). By involving stakeholders in analyzing these observations, the method becomes an entry point for collaborative understanding and systems redesign.

Arts-Based and Visual Methods

Creative and arts-based methods are increasingly used to make co-creation more accessible, inclusive, and emotionally resonant for participants especially EDGs. These approaches reduce reliance on technical language and enable expression through multiple modes such as visual, tactile, and performative. One commonly used method in literature is the trigger film. These films are often shown at the start of co-design sessions to center user voices and prompt

reflective, empathetic dialogue (Blackwell et al., 2017; Hawke et al., 2024; McKeon et al., 2024; Mulvale et al., 2019a; Papoulias, 2018).

Similarly, photovoice projects invite participants to use photography to document aspects of their lives or service experiences. These visual narratives are then used to spark discussion, uncover insights, and identify priorities for change (Wahi et al., 2023; Wang, 1999).

Other techniques identified in the literature include the use of storyboards and comics, which help visualize service journeys, unmet needs, or aspirational futures in ways that are accessible across literacy levels (Parnes et al., 2024; Young et al., 2022). Participatory theatre and role-play are also used to explore real-life scenarios and rehearse different possibilities for change, often allowing participants to embody and reflect on complex dynamics in a safe, facilitated space (Hawke et al., 2024).

These approaches are particularly effective in addressing barriers faced by participants with low literacy, different linguistic backgrounds, or histories of trauma. They also foster empathy, emotional connection, and deeper engagement, especially in groups with power differentials or diverse identities (Hawke et al., 2024; Moser & Korstjens, 2022; Mulvale et al., 2019a).

Digital and Hybrid Modalities: Expanding Access and Reach

Several studies have explored digital engagement through fully online approaches (e.g., Zogas et al. (2024) and hybrid models that blend in-person and digital elements (e.g., Albert et al. (2023); Zhang et al. (2024). Digital tools have expanded the possibilities for inclusive participation, allowing for greater flexibility and reach across geographies and time zones. However, they also introduce risks related to digital exclusion, fatigue, and misaligned expectations (Denford et al., 2024; International Association of Public Participation Canada, 2022).

- **Virtual workshops** use tools such as shared digital whiteboards, co-facilitation, and breakout rooms to support synchronous collaboration. Asynchronous methods (e.g., surveys, feedback tools, shared documents) allow for extended reflection and accommodate diverse schedules and energy levels (IAP2 Canada, 2022).
- **Hybrid models** can foster relationship building through face-to-face interactions while enhancing accessibility for EDGs who face mobility, caregiving, or scheduling constraints (Albert et al., 2023; Zhang et al., 2024).

Effective digital engagement requires thoughtful design; onboarding support, digital literacy training, and technology troubleshooting must be integrated from the start. When grounded in relational principles and guided by co-creation values, these tools can foster meaningful engagement and co-ownership (IAP2 Canada, 2022).

3.5.6 Communication

Communication and facilitation are widely recognized as core components of inclusive and equitable engagement, particularly when working with equity-deserving groups. In the literature, they are framed not only as practical tools but also as expressions of deeper values such as cultural humility and psychological safety (CIHR, 2014; Gheduzzi et al., 2020).

Clear and consistent communication helps ensure participants feel informed, prepared, and engaged. Strategies such as sharing agendas in advance, using accessible language, and providing regular updates promote transparency and inclusion (Taccone et al., 2023; Zogas et al., 2024). Accessible communication also plays a role in reducing perceived power imbalances. For example, avoiding technical jargon and adopting a conversational tone can foster a more approachable and equitable dynamic (Mulvale et al., 2021).

Trust-building is central to this work. Transparent discussions about project goals, roles, and confidentiality lay the groundwork for respectful collaboration, particularly when working with individuals who have experienced marginalization or trauma (Mulvale et al., 2021). Effective engagement with multicultural and marginalized communities calls for communicative responsiveness and cultural humility. Approaches such as validating participants' understanding of key messages, recognizing diverse cultural perspectives, and adapting communication practices accordingly help minimize misunderstandings and foster more equitable participation (Mulvale et al., 2024; PCORI, 2021).

Similarly, effective facilitation is essential to fostering safe and collaborative environments. Trauma-informed facilitation practices, such as monitoring emotional cues, offering mental health resources, and allowing breaks, help participants navigate sensitive topics while feeling supported (Gheduzzi et al., 2020; Mulvale et al., 2019a; Vargas et al., 2022). Structured turn-taking, non-verbal participation options, and flexibility in engagement levels support participants' autonomy and inclusion (Gheduzzi et al., 2020).

3.6 Barriers to Meaningful Engagement

The literature identifies a range of barriers to engagement in co-creation, especially with equity-deserving groups.

Process-Level Barriers

- Tokenistic Approaches: Engagement processes that are superficial, extractive, or overly shaped by institutional goals often erode trust and reinforce existing inequities. When stakeholders feel their input is solicited merely to fulfill procedural requirements, the authenticity of engagement is compromised (Acha et al., 2021; Moll et al., 2020; Mulvale et al., 2024; Zhang et al., 2024).

- Language and Communication Barriers: Differences in language, literacy levels, and communication styles significantly hinder meaningful participation. Technical jargon, inaccessible materials, and a lack of responsive feedback mechanisms can alienate participants. Without culturally and linguistically responsive facilitation, engagement processes risk becoming exclusionary (Acha et al., 2021; Gheduzzi et al., 2021; Goodyear-Smith et al., 2015; Moll et al., 2020; Parnes et al., 2024).
- Conflicts: Differences in communication styles, strong personalities, and cultural misunderstandings can lead to interpersonal tensions that disrupt collaboration. These dynamics often stem from underlying differences in values, interests, power relations, and lived experiences, all of which are shaped by cultural and communicative diversity (Gheduzzi et al., 2021; Hoeeg et al., 2019; Zogas et al., 2024). While conflict in public participation can be challenging, it also offers opportunities for deeper dialogue and the development of more inclusive and resilient solutions, provided it is navigated with skilled facilitation and a constructive approach (IAP 2 Canada, 2016).
- Power Imbalances: Structural and historical inequalities often manifest in engagement settings, limiting the participation of marginalized communities. These imbalances can suppress genuine collaboration and hinder the potential for equitable co-design (Acha et al., 2021; Albert et al., 2023; Boyd et al., 2010; Mulvale et al., 2021).
- Emotional Labor and Trauma: Engagement can be emotionally taxing, particularly for individuals with lived experiences of trauma or systemic injustice. Participants may be asked to revisit distressing experiences, advocate for change, or navigate institutional hierarchies—often without adequate emotional support. Trauma-informed facilitation that centers care,

autonomy, and psychological safety is essential (Amann & Sleigh, 2021; Mulvale et al., 2019a).

- Digital Exclusion: The growing reliance on virtual platforms introduces new inequities. Individuals without reliable internet access, technological fluency, or private, safe spaces may be excluded from digital engagement opportunities. These challenges must be addressed, especially as hybrid models become more prevalent (Denford et al., 2024; Moser & Korstjens, 2022; World Health Organization, 2023).
- Lack of Clarity and Follow-through: Unclear expectations and inconsistent feedback loops can undermine trust and discourage future participation. When participants are not informed about how their input will be used, or do not receive updates on project outcomes, they may feel disempowered. Transparent communication and clear accountability mechanisms are vital for sustaining engagement (Pearce et al., 2022).
- Facilitation Dilemma: Hoeeg et al. (2019) identified a facilitation dilemma in their co-design process, where early proactive facilitation by researchers generated initial momentum but ultimately reduced stakeholder ownership. As stakeholders grew accustomed to structured guidance, the researchers' attempt to step back and encourage participant leadership, led to confusion and unmet expectations. This shift contributed to friction and role confusion (Hoeeg et al., 2019).

Community and Trust Barriers

- Lack of Trust: Historical and ongoing experiences of exploitation and marginalization contribute to deep-seated mistrust toward institutions and researchers. This mistrust can significantly inhibit engagement, especially in underrepresented communities (Acha et al., 2021; Goedhart et al., 2021).

- Cultural Distance and Discomfort: Cultural mismatches, stigma, and emotional vulnerability, particularly around sensitive topics, can make participants reluctant to engage fully. Building culturally safe and affirming spaces is essential to mitigate these challenges (Goedhart et al., 2021).
- Competing Priorities and Structural Inequities: Socioeconomic challenges such as poverty, unstable housing, and mental health burdens often take precedence over engagement in research activities. These structural issues can severely limit the capacity for sustained participation (Goedhart et al., 2021).
- Tax Implications: Compensation may be subject to taxation, so it's important to provide clear guidance to ensure participants understand their potential tax obligations and avoid confusion or legal issues (Canadian Institutes of Health Research (CIHR), 2014).

Institutional and Policy Barriers

- Rigid Research Protocols: Institutional norms that favor fixed methodologies and predefined outcomes can clash with the participant-led nature of meaningful engagement. This rigidity limits responsiveness and innovation (Amann & Sleigh, 2021; Goedhart et al., 2021). The literature also highlights challenges in ethical approval processes, especially when working with vulnerable children and young people. The unpredictable and fluid nature of co-creation with these groups can complicate the navigation of institutional review systems, which are often designed for more traditional, linear research methodologies (Erwin et al., 2024). This procedural rigidity may inadvertently exclude or limit the participation of those whose voices are most needed in intervention design.
- Funding and Resource Constraints: A lack of sustainable funding, administrative support, and the time-intensive nature of relationship-building and recruitment can weaken

engagement efforts. Without long-term investment, initiatives may struggle to maintain momentum (Acha et al., 2021; Goodyear-Smith et al., 2015).

- Logistical Complexities: Limited staffing, constrained timelines, and complex coordination needs further complicate engagement processes. These constraints disproportionately affect efforts to engage marginalized or hard-to-reach populations (Acha et al., 2021; Moser & Korstjens, 2022).

3.7 Enablers Identified in the Literature

- Strong Partnerships and Community Networks: Robust partnerships provide critical resources, expertise, and support for navigating resistance within traditional service systems (Acha et al., 2021; Goodyear-Smith et al., 2015). They are especially effective in addressing barriers such as limited community trust, cultural disconnect, and can also enhance participant recruitment by leveraging established relationships and local credibility.
- Iterative and Flexible Co-creation: Co-creation processes that adapt continuously in response to stakeholder feedback enhance cultural relevance and responsiveness, improving both engagement and outcomes (Mulvale et al., 2019b; Pearce et al., 2022; Vargas et al., 2022). This adaptive approach can help overcome common barriers, including differences in language, literacy levels, communication styles, accessibility, and competing priorities.
- Support and Empowerment: Supporting participants through skill development, clearly defined roles, and transparent processes helps address barriers such as power imbalances, and fosters self-efficacy (CIHR, 2014; Health Quality Ontario, n.d.; Mulvale et al., 2019b; Vargas et al., 2022).
- Cultural and Contextual Adaptation: Tailoring methods to align with local contexts, cultural norms, and community-specific needs build trust and strengthens engagement (CIHR, 2014;

Moser & Korstjens, 2022; Radl-Karimi et al., 2018). And help overcome barriers such as cultural distance and discomfort.

- Conflict Management: Effective conflict management requires treating all participants with equal respect, grounding discussions in shared values, and aiming for mutual understanding rather than full consensus. International Association for Public Participation Canada (2016) distinguishes between task-related and interpersonal conflict, each of which requires specific strategies. Their report highlights practical methods, such as Circles (a relationship-centered approach that uses storytelling, respectful dialogue, and shared values), Deliberative Participation (a structured dialogue method that promotes equality, active listening, and shared decision-making), Gamification (the use of game elements and collaborative challenges to make participation engaging, encourage cooperation, and drive constructive problem-solving, and Dramatic Problem Solving (an interactive, role-play–based method that creates a safe, semi-fictional space for participants to collaboratively explore conflicts). These methods can foster collaboration, reduce power imbalances, and promote inclusive, empathetic dialogue in support of sustainable decision-making (IAP2 Canada, 2016).
- Advancing Accessibility: Actively designing engagement processes to welcome all voices and prioritize meaningful participation. This involves addressing multiple dimensions of accessibility, including physical, financial, linguistic, and psychosocial needs, to address structural barriers to engagement (Mulvale et al., 2019b; Mulvale et al., 2024).

3.8 Gaps in the Literature

Despite the growing recognition of the value of participatory and co-creation approaches, notable gaps remain in the literature, particularly with respect to refugee populations, who are underrepresented in such studies. One significant gap is the limited operationalization and

standardization of meaningful engagement practices, especially for equity-deserving groups. While meaningful engagement is increasingly acknowledged as a core principle, there is still a lack of consensus on how to systematically embed these practices within mental health and public health initiatives (WHO, 2023). Moreover, there is considerable inconsistency in how engagement strategies are developed: some studies report co-developing approaches with stakeholders, others rely on prior experience or existing literature, and several do not describe their engagement design at all. Additionally, inconsistent terminology and the vague use of terms like co-creation and co-design, can lead to confusion and misaligned expectations during program planning and implementation (Pearce et al., 2020). This lack of standardization can hinder the translation of participatory ideals into consistent, actionable strategies and knowledge across diverse settings.

3.9 Implications for Engagement Strategy

Engagement is not just a sequence of activities, but a reflective, ethical, and iterative practice that centers lived experience, challenges traditional hierarchies, and fosters collaborative change. When rooted in robust frameworks and supported by inclusive structures, co-creation offers a pathway not only to improved services but also to more equitable and responsive systems. This literature review informs the development of our engagement strategy for *The Thriving Together* project (PI: Dr. Amanda Sim), which aims to meaningfully involve refugee families and service providers in the co-design of a mental health intervention. Guided by established frameworks and practical tools, the strategy seeks to translate participatory principles into context-sensitive, actionable practices.

Chapter 4: The Engagement Strategy

4.1 Background

This engagement strategy was informed by a literature review and key insights from participating in *The Thriving Together* co-design process (PI: Dr Amanda Sim, McMaster University).

4.2 Meaningful Engagement: A Road Map

I have conceptualized the engagement strategy as a journey (Figure 2), one that is intentional, inclusive, and grounded in shared values. At the heart of this journey is our **Navigation System,** a set of guiding principles that keep us oriented and aligned throughout the co-design process. These values include Building Trust and Relationships, Valuing All Forms of Knowledge, Inclusion, Mutuality and Reciprocity, Flexibility and Responsiveness, Self-Reflection and Cultural Humility, and Psychological Safety and Well-Being. They shape every decision, interaction, and activity. More than just ideals, they serve as operational anchors that ensure our approach remains respectful and equity driven.

Complementing and operationalizing these values are the **Resources and Tools** we use. These include strong communication practices, skilled facilitation, elicitation techniques, and engagement tools. In addition, funding, training, and support help remove barriers and enable meaningful participation from all involved.

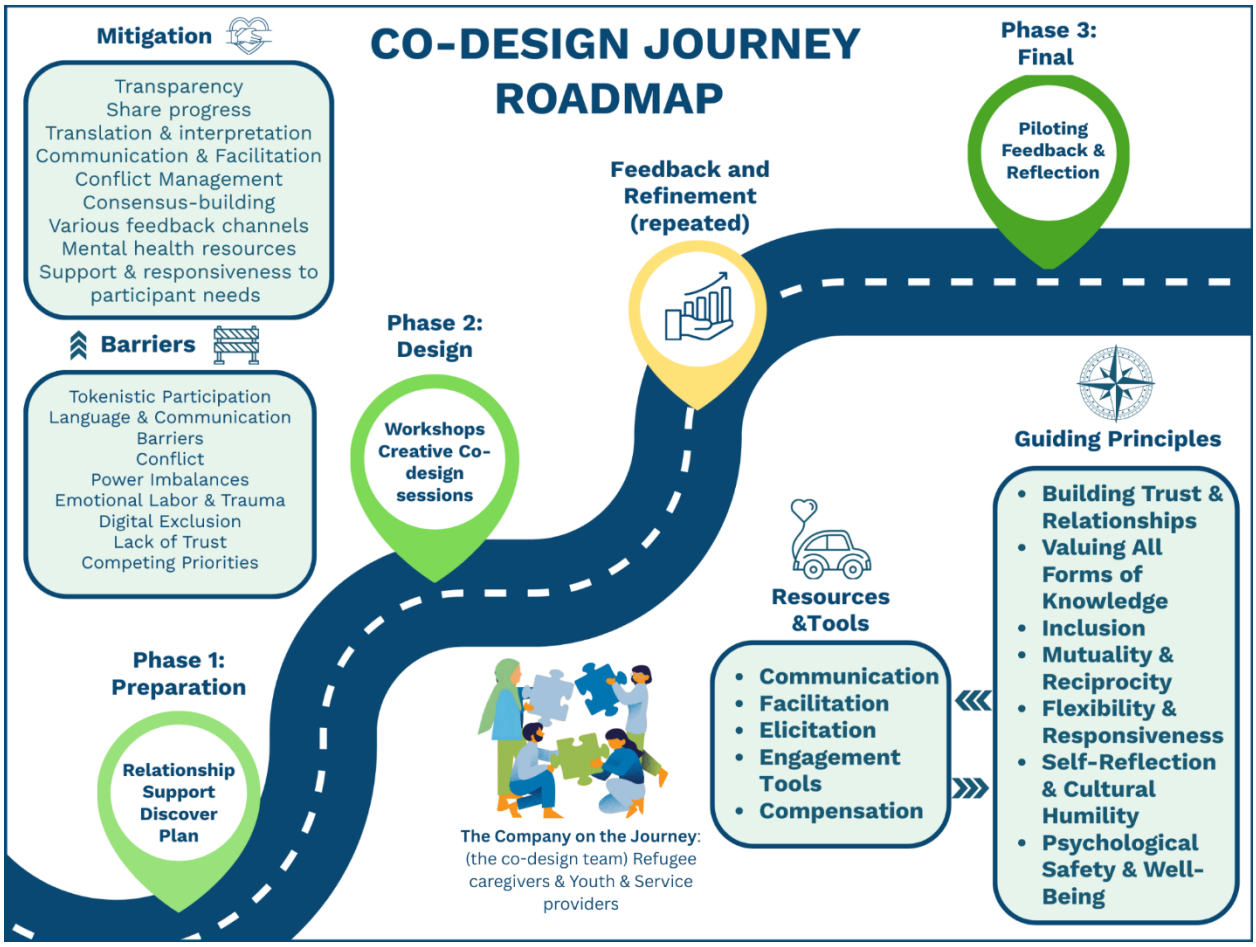
The **Company** on this journey is a diverse and collaborative group of stakeholders, each bringing unique expertise and insight. **Refugee youth, caregivers, and service providers** contribute lived experience to develop a family-based intervention to improve the mental health of refugee families. Researchers guide the process, maintain methodological rigor, and support inclusive co-design. Community partners and organizations help ensure that ideas are not only

implemented but also sustained and scaled within broader systems. Together, this team ensures the process is informed by multiple perspectives, making the outcomes more relevant, responsive, and impactful.

With our principles guiding us, our resources in hand, and our team in place, we embark on a shared journey marked by clear **Stops and Phases**, each designed to build connection, foster creativity, and co-create sustainable solutions.

Naturally, this journey is not without its **Barriers**. We may encounter challenges such as tokenistic participation, language & communication barriers, conflict and tension, power imbalances, emotional labor & trauma, digital exclusion, lack of trust, competing priorities. To address these, we are equipped with a **First Aid Kit** of **mitigation strategies**: transparency, translation & interpretation, communication strategies & facilitation techniques, conflict management techniques, consensus-building tools, various feedback channels, mental health resources, compensation & support. Together, these elements form a thoughtful, flexible, and values-driven strategy for meaningful engagement, which centers community voice, supports co-creation, and builds toward long-term impact.

Figure 2: Co-design Engagement Roadmap



4.3 Key Participants (The Co-Design Team)

The Thriving Together project has partnered with Wesley to recruit refugee caregivers, youth, and service providers as members of the co-design team. To ensure effective interpretation and translation support throughout the co-design process, recruitment efforts focused on two of the most spoken languages among Wesley's clients: Arabic and Dari.

4.4 Theoretical Framework

Empowerment and design thinking theories were chosen as the foundation for this engagement strategy because they offer a complementary and practical framework for fostering

meaningful, inclusive, and sustainable change within complex systems. Empowerment theory supports the creation of equitable spaces where individuals and communities can develop agency, voice, and ownership over decisions that affect their lives. This approach is especially critical when working with refugee populations (Messiha et al., 2023; Palmer et al., 2019). Design thinking focuses on user-centered design principles. This approach emphasizes the service user's perspective, fostering collaboration between users and providers in the co-design process (Mulvale et al., 2019a). Together, these theories challenge traditional hierarchies by distributing power and enabling diverse perspectives. Both theories emphasise the importance of turning ideas into action so that engagement is not just symbolic but results in visible, valued change.

4.5 Guiding Principles

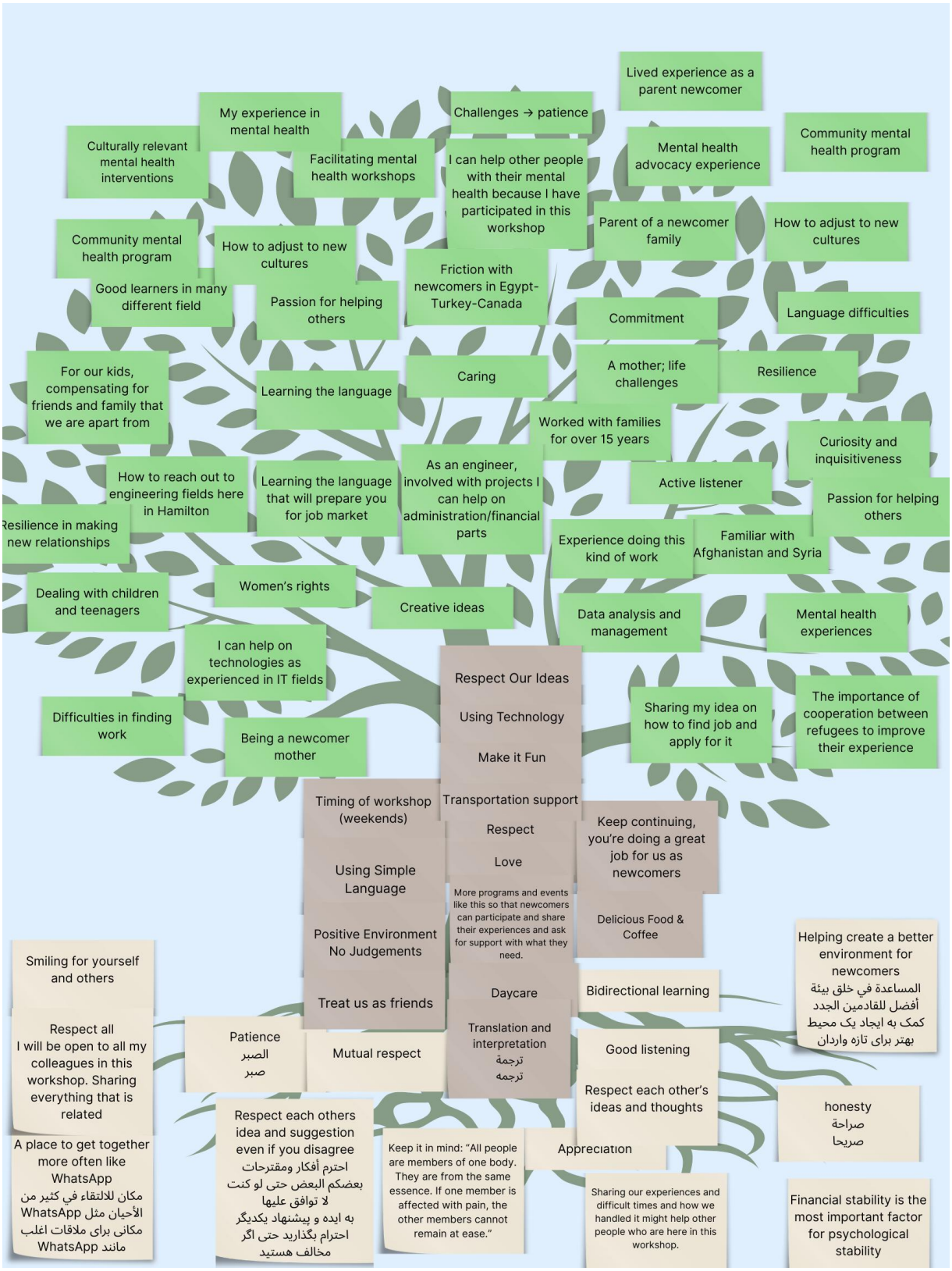
These guiding principles were developed through a combination of literature review and careful consideration of the project's context and goals, helping to shape our engagement practices throughout the process. They were informed not only by existing evidence but also by participants' feedback and suggestions. For example, we facilitated a collaborative "Working Together Tree" activity. In this activity, participants were invited to share the strengths, knowledge, and experiences they bring to the project, along with the values and behaviours we should uphold during our time together. The visual metaphor of the tree supported this reflection: the leaves represented individual strengths and lived experiences; the trunk illustrated what the research team can do to create a meaningful and supportive experience; and the roots symbolized the foundational ways we aim to work together, including how we communicate and treat one another (Figure: 3).

The input shared by participants when it comes to what they need from the research team "the trunk," reflected both logistical needs and relational values. On a practical level, they requested support such as daycare, transportation assistance, translation and interpretation, the use

of simple language, and scheduling workshops on weekends to accommodate their schedule. These highlighted the importance of reducing barriers to participation.

Equally important were the Relationship and Mutuality values participants wished to be upheld within the project. They emphasized respect, including "respect our ideas," along with love, a positive environment free from judgment, "Bidirectional learning" and being treated as friends. They also expressed appreciation and encouragement: "Keep continuing, you are doing a great work for us newcomers." Others asked for more opportunities to connect and contribute, noting: "More programs and events like this so that newcomers can participate, share their experiences, and ask for what they need." Finally, participants expressed that joy and comfort are vital to engagement, suggesting we "make it fun" and provide "delicious food and coffee." Together, these reflections underscored that meaningful engagement requires attention to both structural supports and relational dynamics.

Figure 3: “Working Together Tree” Activity



Informed by the literature review and the participants' input, the following guiding principles emerged: Building Trust and Relationships; Valuing All Forms of Knowledge; Inclusion; Mutuality and Reciprocity; Flexibility and Responsiveness; Practicing Self-Reflection and Cultural Humility; and Psychological Safety and Wellbeing.

4.5.1 Building Trust and Relationships

Trust develops over time through transparency, empathy, and mutual respect (Patient-Centered Outcomes Research Institute (PCORI), 2021). It is both a value and a practice, as emphasized by Pearce et al. (2022) and Moll et al. (2020). This foundation of trust is closely linked to relationship-building. Meaningful relationships often begin well before formal co-design sessions, taking shape through early conversations and informal gatherings that foster authentic connection (Mulvale et al., 2021).

Simple acts such as friendly conversations, sharing meals that feature participants' cuisines and participating in enjoyable activities, as requested by youth participants, can go a long way in building rapport and reducing power imbalances. Attending cultural celebrations such as Eid, joining community newcomer events, and taking the time to listen to participants' stories and lived experiences further strengthens these relationships. Providing regular, transparent updates on the research process also reinforces trust. Throughout the project, the research team acknowledged mistakes, sought input early, and acted on participants' feedback. These consistent practices helped affirm participants as valued partners in the research process and contributed to an environment of mutual trust.

4.5.2 Valuing All Forms of Knowledge

Knowledge gained through formal education or paid work is often given more weight than knowledge derived from lived experience or cultural traditions. This creates a power imbalance where some voices are heard more than others, and their contributions are taken more seriously. In co-creation, all forms of knowledge, including academic, lived, cultural, and practice-based, are valued equally. These diverse perspectives should be integrated throughout the co-design and delivery of research (Mulvale et al., 2024; NSW Regional Health Partners, n.d.; Palmer et al., 2019).

For example, the co-design team includes refugee caregivers, youth, and service providers, and we saw how these diverse perspectives enriched the process. The "Working Together Tree" activity done at the beginning encouraged everyone to think about how their unique strengths, experiences and perspectives, contribute to the process. Decision-making in our process is collaborative, with each voice and vote carrying equal weight. This ensures that academic and practice-based perspectives do not overshadow community knowledge, reinforcing equity, mutual respect, and shared ownership throughout the process.

4.5.3 Inclusion

Inclusion means more than inviting people in, it means transforming how we work together. This principle emphasizes recognizing and accommodating diverse identities, communication styles, and lived experiences. It calls for eliminating physical, linguistic, financial, and emotional barriers (Mulvale et al., 2024). World Health Organization (2023) and Canadian Institutes of Health Research (CIHR) (2014) highlight that inclusive practices require continual learning and adaptation.

In practice, our strategy puts this into action by hosting sessions in familiar and accessible community spaces, offering childcare and transportation support, providing interpretation and translation services, and honoring participants' cultural and religious holidays and planning around them. These efforts help create welcoming environments where all participants feel respected, valued, and empowered to contribute fully.

4.5.4 Mutuality and Reciprocity

Research teams should aim to ensure that all participants benefit from co-creation efforts. These benefits include financial compensation as well as expanded social connections with both the project team and the Advisory Group. Reciprocity should also be felt through meaningful feedback, a sense of personal fulfillment from contributing to positive change, and a growing sense of ownership over the process and outcomes (Denford et al., 2024; Erwin et al., 2024; Mulvale et al., 2019b; Zogas et al., 2024).

For example, participants are compensated for their time and expertise throughout the project. At the final celebratory event, they are invited to present the co-designed prototype, receive recognition through certificates, and connect directly with policymakers through participation in the project's Advisory Group, which can create opportunities for further influence and engagement beyond the research itself.

4.5.5 Flexibility and Responsiveness

Standardized, one-size-fits-all approaches are often inadequate when working with diverse participants. Effective engagement strategies must be adaptable to participants' unique needs, lived contexts, and changing circumstances. Building flexibility into the process enhances both accessibility and responsiveness, allowing the approach to remain relevant and inclusive as the

project evolves (Acha et al., 2021; Blackwell et al., 2017; Canadian Institutes of Health Research (CIHR), 2014; Erwin et al., 2024).

Participants play an active role in shaping and adjusting the engagement strategy. Their feedback after each workshop, is used to help ensure that support and methods of involvement are culturally appropriate, meaningful, and aligned with their preferences and capacities. For example**,** participants' feedback informed the selection of guiding principles, the scheduling of sessions to better fit their routines, and the preferred form of childcare support. They also requested the inclusion of fun activities and their preferred type of coffee, small but meaningful adjustments that contributed to a more welcoming and engaging environment. This participatory approach reinforces shared ownership, trust, and long-term commitment to the project.

4.5.6 Practicing Self-Reflection and Cultural Humility

To work effectively with EDGs, researchers need to approach engagement with openness, curiosity, and self-awareness. This involves actively questioning their own perspectives and remaining alert to the influence of bias and cultural norms. Committing to ongoing learning about different worldviews and lived experiences supports more equitable relationships and promotes mutual understanding and respect (Mulvale et al., 2024; Radl-Karimi et al., 2018).

To support this process, researchers invested time in learning about the cultural backgrounds of participants and actively consult with peer researchers who share those backgrounds and lived experiences. Keeping reflective journals and taking notes throughout the project to document personal reactions, evolving assumptions, and emotional responses, which can help researchers remain accountable and adaptive as they build more equitable and respectful relationships. Our research team included a wide range of cultures, languages, and lived experiences, including diverse ethnic backgrounds, newcomers, immigrants, refugees, and second-

generation individuals. This diversity enriched our communication and relationship-building, while also deepening our practice of self-reflection. The research team met weekly, creating space to debrief, reflect, and plan for upcoming activities and adaptations in response to emerging needs and insights.

4.5.7 Psychological Safety and Wellbeing

Safety and wellbeing are essential to meaningful engagement, particularly when working with refugees who may have experienced trauma before or after migration. A trauma-informed approach supports the creation of safe, welcoming, and empowering spaces where individuals feel respected and heard (Goodyear-Smith et al., 2015; Hawke et al., 2024; Mulvale et al., 2024; Roche et al., 2020).

In our work, we implemented several strategies to support that, such as listening with empathy, being attentive to emotional needs, using trauma-informed communication and offering access to a break room and mental health resources (Amann & Sleigh, 2021; Mulvale et al., 2021; Mulvale et al., 2024; The Point of Care Foundation, n.d.).

4.6 Resources and Tools

In this section, I describe the range of resources and tools we used throughout the process. These include communication-related strategies such as facilitation techniques, as well as feedback mechanisms, elicitation methods, and diverse engagement tools.

4.6.1 Communication

Effective communication is essential for successful engagement in co-design processes. For participants from equity-deserving groups, accessibility, trust, and psychological safety depend on intentional and adaptable communication strategies. This includes using inclusive language and

adopting flexible facilitation methods. Careful attention to how language is used can empower participants to contribute meaningfully. Additionally, providing opportunities for continuous feedback, using various methods tailored to different communication preferences, ensures that all voices are heard and respected throughout the process.

4.6.1.1 Communication Strategies

Clear, accessible, and culturally sensitive communication fosters an environment in which participants feel safe, heard, and valued. Key strategies include:

- Use of Plain Language: Ensuring the clarity and accessibility of communication is essential for equitable engagement. To help reduce perceived power imbalances, we avoided technical jargon, used first names, and maintained an informal tone throughout our interactions (Mulvale et al., 2021; Zhang et al., 2024). Incorporating visual aids (e.g., diagrams, timelines) and creative, art-based methods further supported comprehension and participation, particularly for individuals with varying literacy levels or cognitive styles (Mulvale et al., 2021; Papoulias, 2018; Parnes et al., 2024).
- Being mindful of subtle interaction dynamics: The structure of interactions, such as turn-taking, how people acknowledge each other, and the depth of engagement, this can significantly influence the quality of collaboration and inclusivity (Mulvale et al., 2021). For example, it was important to observe how service users and service providers engage with each other during discussions about services, to identify and address potential tensions early, without compromising participation or trust.
- Emotional and Psychological Safe Communication: Facilitators should remain attentive to participants' emotional cues and be aware of potential triggers (Mulvale et al., 2021). Trauma-

informed facilitation is especially important when discussions involve emotionally charged topics (Acha et al., 2021; Amann & Sleigh, 2021; Mulvale et al., 2024).

- Communication Styles: Adapting communication to suit different interpersonal styles, through active listening, assertiveness, and clarifying questions, enhances understanding and responsiveness. This flexibility ensures participants feel respected and engaged regardless of their preferred communication approaches (Patient-Centered Outcomes Research Institute (PCORI), 2021). During the process, participants were offered multiple ways to express themselves, including open dialogue and written comments. These adaptations contribute to a more inclusive and equitable engagement process.
- Culturally Sensitive Communication: Engaging with multicultural communities requires communicative responsiveness and cultural humility. Acknowledging diverse cultural perspectives, taking time to understand and appreciate the knowledge each participant brings to the team, and adapting communication styles accordingly can help prevent misunderstandings and promote inclusivity (Mulvale et al., 2024; NSW Regional Health Partners, n.d.; PCORI, 2021). Throughout the process, we use culturally sensitive language and acknowledge holidays and occasions that hold significance for participants from diverse cultural backgrounds. For example, offering flowers on Mother's Day, planning activities around holidays, and sending greetings during Ramadan (Muslim holy month) and Nowruz (Afghan cultural day), are gestures that are especially meaningful for newcomers. These practices help foster mutual respect and strengthen rapport and cohesion within the team.
- Procedural Clarity: Consent forms, recording procedures, compensation tax regulations, and formalities that are unfamiliar or intimidating are explained clearly, to ensure participants

feel informed and comfortable throughout the process (Canadian Institutes of Health Research (CIHR), 2014; Denford et al., 2024; Erwin et al., 2024; Goedhart et al., 2021).

- Note-taking and Sharing: The research team documents the workshops by taking detailed notes and photographs of participants' work and ideas. These materials are then synthesized and presented in subsequent workshops to demonstrate continuity, validate participants' contributions, and emphasize that the outputs are the direct result of their efforts (Taccone et al., 2023; Zogas et al., 2024). Prior to each workshop, participants receive an agenda and pre-reading materials, including summaries of work completed to date. Following each session, a draft summary of the discussions and emerging outputs is circulated to ensure that participant contributions are accurately captured and reflected. This process allows all team members to monitor progress in real time and continuously provide feedback (Bird et al., 2021; Taccone et al., 2023).
- Respecting Participants Time: by limiting the communication in between workshops, to avoid engagement fatigue (Zogas et al., 2024).

Thoughtful and adaptive communication strategies not only support inclusion but also strengthen the quality and integrity of the co-design process.

4.6.1.2 Facilitation Strategies

Effective facilitation is important to enabling inclusive, creative, and collaborative co-design processes. Facilitators play a key role in guiding discussions, synthesizing ideas, and supporting diverse participants, particularly those from equity-deserving groups (EDGs), to articulate ideas, share experiences, and contribute to solution development (Gheduzzi et al., 2020).

Also, it is important to keep in mind the way interactions are structured during facilitation, such as turn-taking and levels of engagement (Gheduzzi et al., 2020). These approaches allow

facilitators to adapt their techniques based on the needs of the group and the flow of discussion. Enabling diverse participation by providing non-verbal response cards (e.g., “Yes,” “No,” and “In between”) or digital tools to accommodate different communication preferences and ensure all co-designers can contribute comfortably (Benz et al., 2024).

Gheduzzi et al. (2020) identified several key facilitation strategies for effective engagement. First, setting the stage by clearly explaining the purpose and expectations of the process, using relatable examples to foster understanding. Second, guiding the process requires facilitators to actively support participants through each stage, encouraging deeper contributions while keeping discussions focused, and intervening when conversations become off-track. Third, supporting idea development through summarizing key points and organizing emerging insights to clarify thinking and promote reflection. Facilitators may also introduce new concepts based on prior sessions or recurring issues to inspire creativity and encourage further input.

4.6.1.3 Feedback and Check-ins

To ensure the engagement process remains responsive, inclusive, and participant-driven, the research team conducts frequent check-ins with participants throughout the project. This helps in monitoring emerging needs and addressing any concerns in real time (Mulvale et al., 2021; Pearce et al., 2022; Taccone et al., 2023). Continuous feedback is gathered using a variety of feedback mechanisms, including short surveys, informal verbal check-ins, and a confidential suggestions box available at all in-person sessions. This multi-method approach allows participants to share their thoughts in ways that feel safe and accessible, supporting a dynamic and iterative co-design process.

4.6.2 Elicitation Techniques

Elicitation techniques serve as critical tools in participatory design, enabling participants to explore, and prioritize lived experiences and shared meanings. They help create an emotional and cognitive entry point for deeper discussion and ideation (Moser & Korstjens, 2022; Mulvale et al., 2019a).

Elicitation strategies, such as concept mapping (converting complex qualitative data into visual representations that clearly illustrate the connections between ideas) (Windsor, 2013), experience mapping, prototype co-design, trigger videos or animations (which can help reduce stigma in sensitive contexts) (Hawke et al., 2024; Mulvale et al., 2019a), and the presentation of neutral statements of touchpoints (Palmer et al., 2019), are used to engage participants in a collaborative process of identifying key touchpoints (emotionally significant points) and co-developing solutions. These approaches help reconnect participants to real-world experiences and spark discussions (Gheduzzi et al., 2020; Moser & Korstjens, 2022; Mulvale et al., 2021; Mulvale et al., 2019b).

The prioritization of touchpoints ensures that the most pressing and emotionally significant issues are addressed. This helps to ground co-design efforts in authentic lived experiences and fosters participant ownership of the process (Moser & Korstjens, 2022; Mulvale et al., 2019a; Mulvale et al., 2019b; Palmer et al., 2019).

Together, these techniques support the emergence of trust, empathy, and collaboration within co-design groups and ensure that the resulting improvements are grounded in the realities of those with lived experience.

4.6.3 Engagement Tools

When I began developing this engagement strategy, I found it challenging to identify suitable activities and tools. To address this, I compiled a variety of tools and activities that can be selected and applied throughout the process, depending on the needs of each phase. These tools are typically visual and hands-on, helping to actively engage participants in brainstorming, idea generation, and collaborative problem-solving:

- Arts-Based Methods (such as clay, and Lego, crafts and photographs) can encourage participants to move beyond conventional forms of interaction and expression, supporting inclusion and creative engagement and helping to bridge language differences (Mulvale et al., 2021; Mulvale et al., 2019b).
- Consensus-building tools: we used the Fist-to-Five Agreement, where participants raise 0 to 5 fingers to express their level of agreement or support, which helped gauge group alignment by shifting the emphasis toward those who disagree, encouraging them to voice concerns and engage in dialogue with the majority (International Association of Facilitators, 2016; Taccone et al., 2023).
- Whiteboards or Charts were used for collaborative brainstorming and real-time co-working, enabling ideas to be captured and refined visually (Taccone et al., 2023).
- 10×10 Ideation which is a rapid ideation technique where participants generate 10 ideas in 10 minutes, promoting quick thinking and creativity (Taccone et al., 2023; Weprin, 2020).
- Storyboard as a visual design tool used to translate research evidence into accessible information for participants and community engagement (Parnes et al., 2024).

- Quick Design Prototype is an early version or rough draft of an improvement idea. Prototypes can take many forms, from a simple verbal explanation to a detailed mock-up (Boyd et al., 2010).
- Stakeholder Needs Table which highlights the needs of different stakeholders and identifies improvements that benefit multiple groups (Boyd et al., 2010).
- The SWIFT framework (Strengths, Weaknesses, Individuality, Fixes, and Transformation) is another method for refining improvement ideas in the co-design phase. It involves assessing each idea's strengths and weaknesses, identifying what makes it unique, proposing fixes for its shortcomings, and transforming it into a stronger version (Boyd et al., 2010).
- Additional tools include scenarios (realistic descriptions of how a service functions) and personas or role-playing, which represent typical users or clients, and can help capture the experiences and variable perspectives of stakeholders even those who may not be represented in the process (Boyd et al., 2010; Hawke et al., 2024).

4.7 Compensation

Compensating participants in research is essential for acknowledging their contributions, promoting equity, encouraging sustained engagement, and reducing barriers to participation (Moll et al., 2020; Richards et al., 2018). Compensation is offered transparently, allowing participants to make informed and voluntary decisions without any impact on their ability to participate. Participants receive $100 for each 3-hour workshop, a rate that fairly reflects their time, effort, and lived experience, and aligns with professional standards and institutional guidelines, as recommended by frameworks such as (PCORI, 2021) and (CIHR, 2014). To further reduce barriers and support accessibility, public transit passes, and childcare compensation were also provided.

These practices reflect the implementation of the principles of *Mutuality and Reciprocity* and *Valuing All Forms of Knowledge.*

4.8 Phases

Co-design is often described as a structured but flexible and iterative process (Sanders & Stappers, 2014; Vargas et al., 2022; Zogas et al., 2024). While the literature varies in terminology and the number of stages, most co-design approaches follow a phased process. In our work, I structured the process into three key stages: preparation, design, and a final phase.

In this section, I outline each phase of the process, describing the tools used at each step and illustrating how the *Guiding Principles* were applied. These are also summarized in Table 2. While some tools align with multiple principles, they are categorized in the Table under the one most relevant to their primary function for the sake of clarity and simplicity.

Table 2*: Operationalized Guiding Principles*

Phase	Operationalized Guiding Principle	Resources and Tools
Preparation Phase	*Building Trust & Relationship*	• Attending community events • Holding co-planning sessions with organizations • Transparency about goals and concerns • Introductory guide • Clear and transparent communication • The Advisory Group
	Valuing All Forms of Knowledge	• Create trigger video • Create concept maps
	Inclusion	• Diverse research team • Language interpreters and cultural insiders
	Flexibility & Responsivity	• Flexible plans
	Self-Reflection & Cultural Humility	• Research team training
	Psychological Safety and Wellbeing	• Gather data on participants mental health challenges
Design Phase	*Building Trust & Relationship*	• In person workshops • Ice breaking activities (e.g. Human Bingo) • Fun and enjoyable activities • Using first names • Providing support to participants needs • The Map Introductory Activity • Food from participants' diverse cuisines • Procedural clarity: consent forms & compensation
	Valuing All Forms of Knowledge	• Working Together Tree Activity • The Fist to Five consensus building tool • Carousel format • Concept maps • Trigger video • Prototype • Storyboard • The SWIFT framework
	Inclusion	• Collecting accessibility requirements • Collecting dietary restrictions • Translation & interpretation

		• Participants' cultural music • Transportation support • Childcare support
	Mutuality & Reciprocity	• Financial compensation • Sharing documents and progress • Post-workshop follow-up
	Flexibility & Responsivity	• Adapting schedule for participants convenience • Co-planning of agendas and future sessions • Facilitation strategies • Hybrid approach • Whiteboards • Virtual breakout rooms • Variety of feedback mechanisms
	Self-Reflection & Cultural Humility	• Culturally sensitive language • Culturally sensitive activities • Research team weekly meetings and debriefing
	Psychological Safety and Wellbeing	• Trauma-informed communication and facilitation • Quiet break room • Mental health resources
Final phase	*Building Trust & Relationship*	• Follow-up emails
	Valuing All Forms of Knowledge	• Acknowledging participants contributions (e.g. certificates)
	Mutuality & Reciprocity	• Outcome evaluation • Presenting and testing the co-created prototypes • Celebration event
	Self-Reflection & Cultural Humility	• Final reflection co-assessment workshop

4.8.1 Preparation Phase

Purpose of the Preparation Phase: To secure support, prepare the team, plan, prepare introductory material, gather data to inform the co-design process and recruit participants.

4.8.1.1 Securing Support

To lay the groundwork for meaningful collaboration, the research team began *Building Relationships* early in the process by holding planning sessions with partner organizations. These

sessions initiated the formation of an Advisory Group and provided a space for open dialogue about project goals, capacity, and timelines. Transparency about potential challenges and anticipated benefits has been essential in fostering trust. By aligning the project with organizational priorities and promoting a culture of openness and shared purpose, we have established a strong and collaborative foundation for the initiative's success (Acha et al., 2021; Goedhart et al., 2021; Goodyear-Smith et al., 2015; Mulvale et al., 2021; Mulvale et al., 2019a).

4.8.1.2 Building the Research Team

Integrating individuals with relevant lived experience and cultural backgrounds into the research team enhanced the authenticity and community relevance of the work, while also starting the practical application of the principle of *Building Trust* and *Relationships.* Their perspectives and cultural insights help ensure that co-creation efforts are deeply grounded in real-world experiences and are more responsive to the cultural contexts of the communities involved (Benz et al., 2024). Our research team includes individuals who share cultural and linguistic backgrounds with participants, as well as lived experiences of being newcomers, first- or second-generation immigrants, and refugees.

Additionally, the research team received co-creation training which was essential to equip members with the knowledge and skills needed to identify, connect with, and meaningfully engage equity-deserving groups in co-design (Acha et al., 2021; CIHR, 2014).

4.8.1.3 Planning

The team began by developing the overall process framework and addressing logistical considerations, while leaving room for specific activities to be planned collaboratively as the process unfold. Key planning steps include setting goals, clarifying roles, outlining how results will be shared, and securing essential resources, such as language interpreters. These efforts

support meaningful engagement and help reduce barriers to participation (Goodyear-Smith et al., 2015; Roche et al., 2020).

4.8.1.4 Maintain Flexibility

Planning is important, but even with careful preparation, circumstances can change. To address this, we are designing our engagement plans with adaptability in mind, anticipating potential challenges and preparing strategies to respond effectively (Acha et al., 2021; PCORI, 2021). This flexible approach allowed us to remain responsive to the evolving needs of the co-design team, effectively operationalizing the principle of *Flexibility and Responsiveness.*

4.8.1.5 Create Introductory Materials

Developing a guide that outlines the project's objectives, methodology, expected timelines, and roles, helped align expectations and keeps everyone informed and on track (PCORI, 2021). The guide is part of the onboarding process and is designed to introduce team members to the project. It is tailored to participants through translation, accessible language and design (PCORI, 2021).

4.8.1.6 Gathering Data

Based on data collected in the previous phase of the *Thriving Together* project (Sim et al., 2023a; Sim et al., 2023b), along with a review of the literature on the mental health challenges faced by refugee families and the services available to them, key touchpoints were identified. These touchpoints were used to develop "Challenges and Strengths" concept maps, which served as starting points for discussion (Bate & Robert, 2006; Moser & Korstjens, 2022; Palmer et al., 2019; PCORI, 2021; Wahi et al., 2023). Narrative interviews collected in the earlier phase of the project were adapted into a short video (trigger film). These serve as powerful tools to spark dialogue and foster deeper mutual understanding between service users and providers (Benz et al.,

2024; Mulvale et al., 2019a). It was important for the research team to gain insight into participants lived experiences and mental health needs to ground the process in empathy and *Psychological Safety and Well-being.*

4.8.1.7 Participants' Recruitment:

4.8.1.7.1 Service Providers Recruitment

Service providers (Wesely staff) recruitment begins with identifying internal champions: individuals who are respected and trusted by their peers. These champions play a vital role in generating interest, building credibility, and encouraging wider staff participation (The Point of Care Foundation, n.d.).

Clear and transparent communication from the outset is essential, as it lays the foundation for *Building Trust and Relationships*. Staff are informed that their involvement is part of a collaborative process rather than a top-down initiative being imposed on them. Participation should feel empowering and voluntary, not performative, or tokenistic. Emphasizing the project's focus on continuous improvement, rather than service critique or blame can help foster a positive and open atmosphere. Clearly communicating that the project provides a meaningful opportunity for staff to share their insights reinforces their role as valued contributors in shaping and enhancing services (The Point of Care Foundation, n.d.).

4.8.1.7.2 Service Users Recruitment

Recruiting service users for collaborative research and co-design involved intentionally seeking participants from diverse backgrounds, including variations in age, ethnicity, gender, and other dimensions of identity. The aim is not statistical representation, but rather the depth and richness of insight. When care is taken to include a broad range of voices, contributions can be powerful and transformative (Leask et al., 2019; Moll et al., 2020; The Point of Care Foundation,

n.d.; Vargas et al., 2022; Zhang et al., 2024). This approach reflects the operationalization of the principles of *Valuing all Forms of Knowledge* and fostering *Inclusion.*

We considered ideal participants to be those who had moved beyond the initial phase of accessing services and were able to engage constructively. Their insights, while grounded in personal experience, were shared with a degree of emotional and cognitive distance that supported meaningful dialogue and collaborative problem-solving (The Point of Care Foundation, n.d.). At the same time, we were careful to avoid over-reliance on "super users," or individuals who frequently participate in research. While their perspectives can be valuable, they may not fully represent the broader spectrum of service users (Goedhart et al., 2021; Moll et al., 2020; The Point of Care Foundation, n.d.).

4.8.1.7.3 Diversity and Relationships

Engaging a diverse range of participants helps broaden perspectives and enhances the relevance, quality, and impact of co-design efforts (Taccone et al., 2023; Vargas et al., 2022). Equally important is mapping participants' relationships, values, and roles, particularly among service users and providers, to better understand the dynamics of influence within the group. This type of relational mapping helps identify areas of alignment or tension, clarify underlying power structures, and support more informed, equitable decision-making throughout the process (Mulvale et al., 2021; Vargas et al., 2022).

4.8.1.7.4 Recruitment methods

We used posters and community outreach through organizations to support recruitment efforts (The Point of Care Foundation, n.d.). The literature highlights the importance of using varied and inclusive recruitment methods (The Point of Care Foundation, n.d.), and emphasizes

that engaging informal networks, social media, peer-led groups, and community organizations can help broaden reach, particularly among underrepresented groups (Denford et al., 2024).

4.8.2 Design Phase

The following section outlines the design phase, starting with key elements of pre-workshop preparation, including the introductory process, cultural and linguistic considerations, logistics and accessibility, equity in participation, and post-workshop communication. This is followed by an outline of the process steps and the overall workshops' structure.

4.8.2.1 Pre-Workshop Preparation

Preparation for co-design workshops focuses on creating inclusive, accessible, and culturally responsive spaces that encourage meaningful participation. Planning activities to be fun and enjoyable is important for engaging participants and creating a positive experience (Denford et al., 2024; McKeon et al., 2024), a point emphasized by our participants, particularly youth. Incorporating cultural music and food from participants' diverse cuisines also helped bring the principles of *Inclusion* and *Cultural Humility, Relationship Building* to life. To support participants' *Psychological Safety and Well-being*, a quiet break room was made available for anyone needing a pause, and mental health resources were provided throughout the workshops.
Key components of this preparation include:

4.8.2.1.1 Introductory process

The research team contacted participants individually before the first workshop to confirm interest, collect availability, and explain what to expect. This one-on-one orientation *Builds Relationships* and helps participants feel more prepared for the workshop experience (Benz et al., 2024; Zogas et al., 2024). Each co-designer is also asked in advance about accessibility requirements, dietary restrictions, and any additional support needs. This information enables

researchers to design *Inclusive* sessions that accommodate individual needs and foster a safe, respectful environment (Benz et al., 2024). Also, before each workshop participants receive a clear agenda and included breaks of the day, to help them know what to expect (Mulvale et al., 2021; Zogas et al., 2024).

4.8.2.1.2 Cultural and Linguistic Considerations

All communication materials, including workshop agendas, are translated into participants' preferred languages. These translations are reviewed by research team members who speak the respective languages to ensure accuracy and cultural appropriateness. Activities and language used are designed with cultural sensitivity to ensure they are relevant and appropriate for diverse groups (Benz et al., 2024; Zogas et al., 2024). During the workshops, we employed the communication and facilitation strategies previously described, adapting them to the specific cultural and contextual needs of each group. Additionally, researchers provided real-time interpretation for participants who preferred to communicate in their native language or were not fluent in English. These practices reflect our commitment to operationalizing the principles of *Cultural Humility and Inclusion.*

4.8.2.1.3 Logistics and Accessibility

Workshops are scheduled with consideration for participants' availability and convenience. All logistical details, such as transportation, childcare and venue access, are provided and communicated in advance. The workshop venue is selected for its convenience and familiarity to participants, with their input actively sought and incorporated into the decision-making process (Benz et al., 2024; Domecq et al., 2014; Phoenix et al., 2024; World Health Organization, 2023). These practices reflect our commitment to implement the principles of *Valuing All Forms of Knowledge*, *Mutuality and Reciprocity*, *Flexibility and Responsiveness*, and *Inclusion*.

4.8.2.1.4 Equity in Participation

Equity in participation involves creating a welcoming, inclusive, and non-hierarchical environment where all voices are valued equally. Practices such as using first names help reduce formal barriers and foster a sense of mutual respect (Mulvale et al., 2021). Service providers are encouraged to participate alongside others without dominating discussions, ensuring balanced contributions. Collaborative planning of agendas and future sessions promotes transparency and shared ownership of the process (Leask et al., 2019; Mulvale et al., 2021; Zogas et al., 2024). Empowerment is further reinforced by assigning participants meaningful roles, such as peer facilitators or advisory group members, which enhances their confidence, agency, and investment in outcomes. Together, these approaches operationalize the principles of *Building Relationships, Valuing All Forms of Knowledge*, *Mutuality and Reciprocity*, and *Inclusion*. (Mulvale et al., 2021).

4.8.2.2 Post-Workshop Message

Following each workshop, participants receive a thank-you message, and the team checks in with those who were unable to attend. A feedback survey is also shared to gather input for improvement. To respect participants' time between sessions, communications are kept minimal and purposeful (Zogas et al., 2024).

4.8.2.3 Process Steps and structure

4.8.2.3.1 Establishment of Co-Design Groups

Participants collaborate in smaller groups during workshops. These are organized by language, role (e.g., caregivers, youth, or service providers), or mixed, depending on the discussion topic and evolving group dynamics. Power dynamics, language, and diverse perspectives are carefully considered (Benz et al., 2024).

4.8.2.3.2 Workshops

The co-design team engages in a structured sequence of workshops, beginning with an Initial Workshop, followed by an Identify the Problems Workshop, a Brainstorm Solutions Workshop, and concluding with a series of Prototype Co-Design Workshops:

4.8.2.3.2.1 Initial Workshop

The co-design journey starts with an event that brings together service users, providers, and the research team. This session is designed to break the ice through fun *Relationship-Building* activities such as Human Bingo (Benz et al., 2024), explore timelines and roles, share experiences and strengths and establish collaboration norms through the "Working Together Tree" activity. The focus is on building mutual understanding and laying the foundation for ongoing, meaningful collaboration (CIHR, 2014; Palmer et al., 2019; Zogas et al., 2024). We opened the workshop with a "Map Introductory Activity" in which every team member, including researchers, introduced themselves and placed a pin on a map to indicate their home country or place of origin. This interactive exercise encouraged participants to learn about one another and helped foster a sense of *Inclusion* and *Relationship Building*.

Additionally, we provided participants with clear information about consent forms and compensation process, including the potential tax implications, to promote transparency and informed participation.

4.8.2.3.2.2 Identify the Problems Workshop

The co-design process began by presenting existing research findings on the mental health and well-being of refugee families in Canada for validation and identifying any gaps. This included both the challenges they face and the sources of strength and resilience they draw on through

concept maps and a trigger video were used as elicitation techniques to prompt reflection and discussion.

Participants were then invited to add to this knowledge by sharing their lived experiences, and common difficulties in how services are currently delivered, then prioritize the most pressing problems that the project should address, using (the Fist to Five) consensus building tool and facilitation strategies discussed earlier (Gheduzzi et al., 2024; Mulvale et al., 2019b; Taccone et al., 2023; Vargas et al., 2022). The process was grounded in the principles of *Psychological Safety and Well-being* and guided by trauma-informed facilitation practices.

4.8.2.3.2.3 Brainstorm Solutions Workshop

Using a carousel format, participants are divided into mixed groups and rotate through ideation stations to brainstorm potential solutions for each identified issue. This collaborative approach involves setting shared goals, mapping possible solutions, considering required resources, and discussing how to evaluate success (Mulvale et al., 2019b; Pearce et al., 2022; Pearce et al., 2020; Vargas et al., 2022). This process fostered creativity, strengthened collective ownership, and enabled participants to build on one another's ideas to develop more refined solutions. It also put into practice the principles of *Inclusion* and *Valuing All Forms of Knowledge.*

4.8.2.3.2.4 Prototype Co-Design Workshops

In the final design phase, small mixed-stakeholder groups work together to co-design prototypes of their proposed solutions in a series of workshops, to bring the solutions to life. Facilitators may again use the carousel method to allow participants to engage with and contribute to multiple concepts, grounded in *Inclusion* and *Valuing All forms of Knowledge* principles and enriching the overall design with diverse perspectives (Benz et al., 2024; Leask et al., 2019; Mulvale et al., 2019a; Wahi et al., 2023).

At this stage, we will use hybrid workshops to support convenient, flexible, and focused small group work. Smaller group settings allow for more in-depth discussion and deeper exploration of potential solutions, fostering meaningful engagement among participants.

While digital tools offer expanded access, they also present challenges, including digital exclusion and fatigue (Denford et al., 2024; International Association of Public Participation Canada, 2022). A hybrid approach helps address these risks by combining the accessibility of virtual engagement with the relational benefits of in-person interaction, creating a more *Inclusive* and adaptable environment grounded in *Flexibility and Responsiveness* principle (Albert et al., 2023; Zhang et al., 2024).

To support the digital sessions, we will incorporate a range of strategies, including virtual whiteboards and shared documents to enable real-time collaboration, breakout rooms to facilitate small group discussions, surveys and digital feedback tools to gather input over time, onboarding and digital literacy support to reduce technology barriers and flexible scheduling to accommodate diverse needs and capacities (IAP2 Canada, 2022).

At this stage, various engagement tools (discussed in detail earlier) are also applied, such as prototypes (early versions or rough drafts of the intervention), storyboards to translate ideas into accessible visual formats, and the SWIFT framework to guide the structured refinement of ideas.

4.8.3 Final phase

The final phase of the process is designed not only to implement change but also to ensure the credibility and emotional payoff of collaborative work (Pearce et al., 2022).

4.8.3.1 Co-Implementation and Co-Evaluation

This stage is guided by the principles of *Mutuality and Reciprocity* and *Self-Reflection*. It involves testing the prototype in real-world settings while remaining open to continuous

improvements. As Hoeeg et al. (2019); Vargas et al. (2022) note, the realization phase is iterative, with implementation refined in response to feedback, barriers, and emerging needs. Trial sessions with the co-design team will gather feedback to guide iterative refinement. Additionally, Zogas et al. (2024) describe an innovative approach in which an external audience tested the prototype, allowing designers to observe others reactions, gain fresh perspectives, and validate the team's collective achievement. Finally, outcome evaluation will assess the relevance, usability, and effectiveness of the final deliverables (Benz et al., 2024; Leask et al., 2019; Zhang et al., 2024).

4.8.3.1.1 Support for Implementation

Organization's managers play a crucial role in demonstrating commitment to the co-design process. Managers can support iterative learning and adaptation throughout implementation, to help ensuring sustainability and responsiveness of service improvements (Acha et al., 2021; Mulvale et al., 2021). In our co-design process, the organization has been actively involved from the beginning, through regular planning meetings, ongoing feedback, and collaboration in key decision-making. This early and continuous engagement helps build a shared sense of ownership over outcomes.

4.8.3.2 Celebration and Closure

The final stage of co-design, reflection and celebration, serves both practical and symbolic purposes. Events are held to review the process and accomplishments, share outcomes, and recognize the contributions of all participants (Bate & Robert, 2006; Moser & Korstjens, 2022). A final reflection and co-assessment workshop provides a space for process evaluation, examining how inclusive, equitable, and collaborative the co-design journey has been, and outcome evaluation, which assesses the relevance, usability, and effectiveness of the final outputs (Leask et

al., 2019; Zhang et al., 2024). This workshop also creates an opportunity to review feedback and discuss potential adaptations for future implementation.

Following this, a celebration event showcases the co-created prototypes and acknowledges participants through handwritten cards, certificates, or personalized messages. These gestures foster emotional connection and a sense of closure while also putting into practice the principle of *Mutuality and Reciprocity* (Zogas et al., 2024). Communication should not end with the last workshop, follow-up emails sharing progress updates and next steps help maintain transparency, reinforce participants' contributions, and sustain *Relationships* (Taccone et al., 2023).

As highlighted by (CIHR, 2014), successful engagement means involving stakeholders in shared decision-making, *Mutual Learning,* and *Valuing Experiential Knowledge* as evidence. It requires mechanisms for *Inclusive* participation, *Flexibility*, *Building Relationships, Cultural Humility* and recognizing outcomes as legitimate and meaningful. Finally, the impact of co-design is not just about outputs, it's about relationships formed, capacity built, and a shared sense of purpose achieved (NIHR, 2024; The Point of Care Foundation, n.d.).

4.9 Barriers and Mitigation Strategies

Acknowledging and anticipating barriers to engagement in co-design can support more effective planning and mitigation strategies.

- Tokenistic Participation: When engagement is superficial or driven only by institutional agendas, it undermines trust and reinforces inequity (Acha et al., 2021; Moll et al., 2020; Mulvale et al., 2024; Zhang et al., 2024).

  Mitigation: Maintain transparency and share workshop progress and outcomes with participants (Benz et al., 2024; Parnes et al., 2024; Taccone et al., 2023; The Point of Care Foundation, n.d.).

- Lack of Trust: Past harms and systemic marginalization often result in deep-rooted mistrust, particularly in underrepresented communities (Acha et al., 2021; Goedhart et al., 2021).

  Mitigation: Build strong, long-term partnerships and community networks (Acha et al., 2021; Goedhart et al., 2021; Goodyear-Smith et al., 2015; Mulvale et al., 2021; Mulvale et al., 2019a)..

- Language & Communication Barriers: Language differences, literacy levels, and inaccessible materials can exclude participants, especially without culturally responsive facilitation (Acha et al., 2021; Gheduzzi et al., 2021; Goodyear-Smith et al., 2015; Moll et al., 2020; Parnes et al., 2024).

  Mitigation: Use translation, interpretation, plain language, visual tools, and facilitation strategies outlined in the Tools and Resources section (McKeon et al., 2024; Moser & Korstjens, 2022; Mulvale et al., 2019b; Parnes et al., 2024; Radl-Karimi et al., 2018).

- Conflict: Cultural differences, strong personalities, and value-based disagreements may disrupt collaboration (Gheduzzi et al., 2021; Hoeeg et al., 2019; Zogas et al., 2024).

  Mitigation: Apply respectful, skilled facilitation grounded in shared values and mutual understanding (Gheduzzi et al., 2020). Use conflict management participatory methods (e.g., Circles, Gamification, Deliberative Participation) to navigate conflict constructively (IAP 2 Canada, 2016).

- Power Imbalances: Historical and systemic inequities can silence marginalized voices and limit genuine participation (Acha et al., 2021; Albert et al., 2023; Boyd et al., 2010; Mulvale et al., 2021).

Mitigation: Use consensus-building approaches that value all perspectives equally, build trusting relationships, foster openness and psychological safety and create various feedback channels (Bird et al., 2021; Pearce et al., 2022; Taccone et al., 2023).

- Emotional Labor & Trauma: Engagement may require participants to revisit painful experiences, especially those with lived experience of injustice (Amann & Sleigh, 2021; Mulvale et al., 2019a).

  Mitigation: Adopt trauma-informed facilitation that prioritizes care, autonomy, and psychological safety (Acha et al., 2021; Amann & Sleigh, 2021; Mulvale et al., 2024). Provide a break room where participants can step away discreetly if needed, and ensure that mental health resources are available (Mulvale et al., 2021; The Point of Care Foundation, n.d.).

- Digital Exclusion: Reliance on virtual platforms can exclude those without reliable internet, digital skills, or safe private spaces (Denford et al., 2024; Moser & Korstjens, 2022; World Health Organization, 2023).

  Mitigation: Provide alternatives and support for digital access, including onboarding assistance, digital literacy training, and technology troubleshooting (IAP2 Canada, 2022).

- Competing Priorities & Structural Inequities: Challenges like poverty, housing instability, or health burdens may limit engagement capacity (Goedhart et al., 2021).

  Mitigation: Provide appropriate compensation, and responsiveness to participant needs (Mulvale et al., 2021; Pearce et al., 2022; Taccone et al., 2023).

Chapter 5: Discussion & Conclusion

5.1 Discussion

This research explored how equity-deserving populations are engaged in co-creation processes by combining a structured literature review with active participation in a co-design project. Insights from both informed the development of a comprehensive engagement strategy tailored for refugees.

5.1.1 Themes from the Literature Review

The literature consistently emphasizes that co-creation does not follow a universal model. Rather, successful approaches are those that remain flexible, iterative, and responsive to the unique cultural and contextual dynamics of each setting (Boyd et al., 2010; Goedhart et al., 2021). Pearce (2022) reinforces this view by characterizing co-creation as inherently non-linear and often "messy," underscoring the need for adaptability over rigid methods. This perspective directly influenced our own approach, encouraging continuous reflection and adaptation as new insights and circumstances emerged.

Another recurring theme in the literature is the importance of foundational principles such as inclusion, power-sharing, reciprocity, and cultural humility. In some studies, these values were not simply imposed but developed collaboratively with stakeholders themselves (Albert et al., 2023; Caperon et al., 2023). For example, Caperon et al. (2023) adopted a "test and learn" approach to apply the co-created guiding principles, allowing for real-time adaptation and learning throughout the process.

Inclusive communication is also consistently highlighted as both a practical necessity and an ethical responsibility in co-creation. Strategies such as interpretation services, multilingual

summaries, visual materials, and the use of simplified, jargon-free language help ensure accessibility across diverse literacy levels and cultural contexts. Transparency, consistency, and clear communication are essential for building and maintaining trust, which is an essential foundation for meaningful engagement. Additionally, the literature recommends the use of culturally sensitive, trauma-informed facilitation to foster safe and supportive spaces for participation, especially when working with EDGs such as refugees, who have experienced forced displacement and related trauma (CIHR, 2014; Gheduzzi et al., 2020; Mulvale et al., 2019a; Taccone et al., 2023).

While co-creation processes are flexible, they often follow a loosely structured sequence of phases: preparation, discovery, ideation, implementation, and feedback. Across these phases, the literature offers a variety of tools and methods, such as storyboards, consensus-building activities, and visual mapping, that support collaboration and engagement.

Finally, while engagement evaluation varies widely, several studies describe using formal tools such as PPEET (Faculty of Health Sciences & Patient Engagement, 2021), alongside qualitative methods like interviews, focus groups, and observational notes. These examples reinforce the importance of ongoing evaluation, although they reveal inconsistencies in how such evaluations are designed and reported.

5.1.2 Gaps in the Literature

The literature reveals several notable gaps in the current understanding and application of co-creation, particularly in relation to engaging refugee populations. One of the most significant gaps is the limited focus on co-creation with refugees, especially within mental health and family-

based interventions. As a result, there is little guidance on how to adapt co-creation principles to the distinct cultural, social, and structural contexts of refugee communities.

Another gap lies in the scarcity of practical, adaptable tools. Although the theoretical foundations of co-creation are well documented, many studies fall short of providing concrete examples, replicable methods, or flexible tools that can be tailored to diverse settings.

In addition, there are inconsistencies in how engagement processes are designed. While some studies reported co-developing their engagement strategies with stakeholders (Bird et al., 2021; Taccone et al., 2023; Zhang et al., 2024), others relied on prior experience or existing literature (Zogas et al., 2024), and some did not report their design approach at all.

Furthermore, inconsistent terminology and the vague use of terms like *co-creation* and *co-design*, can lead to confusion and misaligned expectations during program planning and implementation (Pearce et al., 2020). This lack of standardization can hinder the translation of participatory values into consistent, actionable strategies and knowledge across diverse settings.

Finally, evaluation practices vary widely. While some projects employed validated tools such as PPEET (Faculty of Health Sciences & Patient Engagement, 2021), others used qualitative methods like interviews, focus groups, observational notes, surveys, digital feedback tools, and co-assessment workshops (Leask et al., 2019; Pearce et al., 2022; Zhang et al., 2024). However, several studies did not report any evaluation at all, making it difficult to compare outcomes or draw firm conclusions about effective practices across different contexts.

5.1.3 Development of the Engagement Strategy

Our engagement strategy was shaped by both the insights drawn from the literature and the lived experiences shared by participants. The literature helped us identify and articulate key

principles to guide our approach, including building trust and relationships, valuing different forms of knowledge, promoting inclusion, mutuality, and reciprocity, being flexible and responsive, practicing cultural humility and self-reflection, and psychological safety and well-being. These principles aligned closely with the values expressed by participants during the Working Together Tree activity, where stakeholders collectively articulated what meaningful collaboration meant to them.

These principles were rooted in a relational approach, which is foundational to co-creation and differs from traditional positivist paradigms that emphasize objectivity, neutrality, and researcher detachment. Rather than positioning the researcher as a distant, neutral observer, a relational approach centers trust, reciprocity, and care within researcher–participant relationships (Groot et al., 2022; Knowles et al., 2021; Soklaridis et al., 2024). This perspective challenges epistemic hierarchies by valuing experiential and lived knowledge alongside academic expertise, thereby addressing power imbalances that have historically silenced marginalized voices.

In this study, adopting a relational stance involved being responsive to participants' needs and requests for assistance as they emerged, and remaining attentive and flexible, rather than maintaining rigid boundaries in the name of "objectivity." These acts of responsiveness and care were fundamental to building trust. This was particularly important when working with equity-deserving participants, as it helped foster psychological safety, mutual respect, and a sense of shared ownership, which are recognized as essential for meaningful co-creation.

Informed by common phase-based structures described in the literature, we designed a flexible strategy that could be adapted throughout the process. Each phase, from early relationship-building to iterative feedback loops, was tailored to our participants' cultural contexts and logistical needs. We also adapted practical tools such as storyboards, mapping activities, and consensus-

building exercises to be visual, hands-on, and culturally accessible. This ensured that participants with varying language and literacy skills could engage meaningfully throughout the process.

Addressing gaps in the literature required us to draw on other sources of cultural knowledge. Given the scarcity of refugee-focused co-design studies, we leaned on the expertise within our team to shape culturally appropriate engagement practices. This included practical adaptations such as scheduling sessions around Ramadan, providing culturally familiar meals, and incorporating activities that acknowledged and celebrated participants' cultural identities.

By grounding our engagement strategy in both the evidence base and the lived realities of participants, we developed an approach that was not only theoretically sound but also contextually grounded, adaptable, and sustainable.

5.1.4 Recommendations

Rather than rigid frameworks, it is more effective to co-create guiding principles with stakeholders from the outset (Caperon et al., 2023). This approach ensures contextual relevance, fosters participant ownership, and strengthens collaborative relationships.

Persistent barriers, such as language, expectations, and resource limitations, can significantly limit engagement if not proactively addressed. Designing co-creation activities that intentionally reduce these barriers is critical to fostering inclusive engagement. Cultural characteristics should not be considered barriers; the process should adapt to accommodate them and leverage the diversity into points of strength.

Self-reflection by researchers is vital for improving inclusive engagement practices. Focusing on honest analysis and shared learning helps uncover systemic barriers and enables

continuous improvement (Goedhart et al., 2021). Documenting both successes and missteps contributes to a more transparent and adaptive co-creation landscape.

Future research should aim to clarify terminology and develop flexible yet structured outline that support broader application, scalability, and effective evaluation of co-creation. This includes a clear call for transparency and detailed documentation of methods. Standardized language and conceptual clarity are essential for building a coherent and transferable body of knowledge. The development of a curated set of activities, tools, and methods which are anchored in guiding principles, could support researchers in designing more intentional and context-sensitive co-creation processes.

Future research should also include longitudinal studies to explore the durability of co-creation outcomes. While existing evidence suggests that co-creation enhances participant experience and intervention acceptability, its long-term effects on service delivery, health equity, and systemic transformation remain underexplored (Moser & Korstjens, 2022; Taccone et al., 2023). Clarifying how co-creation contributes to sustainable change will be crucial for advancing the field.

In sum, equitable engagement strategies in co-creation require a thoughtful blend of flexible frameworks, reflective practice, and context-sensitive methodologies. When integrated intentionally, these elements support sustainable co-creation and foster long-term, trust-based partnerships.

5.1.5 Study Strengths and Limitations

A strength of this study lies in its integration of theoretical insights with practical experience. By combining a structured literature review with active participation in an ongoing

co-design project, the analysis bridges in-depth theoretical understanding with practical, real-world application. The inclusion of diverse source types, such as qualitative studies, methodological papers, systematic reviews, and grey literature, contributes to a comprehensive and multidimensional understanding of co-creation. Moreover, the use of a systematic search strategy adds rigor and enhances the credibility of the findings.

At the start of reviewing the literature to inform the engagement strategy, I found few tools or activities, and only a limited number of studies provided details about the activities they had implemented. This gap motivated me to develop a pool of activities and tools through my research to support others seeking practical resources for implementing engagement in co-creation effectively.

However, several limitations must be acknowledged. The literature review was limited to English-language publications and conducted using only three databases. As a result, relevant studies published in other languages or indexed in alternative sources may have been missed. Nonetheless, the search strategy produced a diverse set of studies spanning multiple contexts, populations, and engagement approaches, which facilitated the identification of consistent themes. While the co-design project offered valuable real-world insights that helped contextualize the engagement strategy, evaluating the longer-term implementation and effectiveness of the strategy was beyond the scope of this study. This evaluation will be undertaken in future phases of the broader *Thriving Together* project.

5.2 Conclusion

This research examined how equity-deserving populations are engaged in co-creation processes. There is a need for more research focused on refugee populations. Engagement

strategies need to be developed with, not just for, communities, anchored in co-developed guiding principles. While flexibility is a hallmark of co-creation, structure is necessary to ensure ethical practice and alignment with intended goals. A persistent barrier to progress in this field remains the lack of standardization in both terminology and process frameworks. Addressing this gap is vital for improving scalability, facilitating robust evaluation, and enhancing knowledge-sharing across co-creation practice and research. Finally, achieving equitable and impactful engagement relies on operationalizing the guiding values of the process such as reflexivity, adaptability, and authentic partnership with the communities involved.

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Appendices

Appendix A: Letter of Research Ethics Approval

HiREB
Hamilton Integrated Research Ethics Board

Date: Sep-06-2024

Local Principal Investigator: Dr Amanda Sim

Participating HiREB Centre(s): McMaster University

Project ID: 17695

Project Title: Thriving Together: Co-design of a culturally responsive and family-based mental health intervention for refugee children and families

Review Type: Delegated

Date of Final Approval: Sep-06-2024

Ethics Expiry Date: Sep-06-2025

The Hamilton Integrated Research Ethics Board (HiREB) Panel A has reviewed and approved the above-mentioned study.

The following documents have been approved:

Document Name	Document Date	Document Version
Appendix A2 Terms of Reference Advisory Group_V1_20240523	May-23-2024	1
Appendix B2 Terms of Reference Co-Design Team_V1_20240523	May-23-2024	1
Data collection form_V1_20240523	May-26-2024	1
Study Key_v2_07072024	Jul-07-2024	2
Appendix A3 Advisory Group Informed Consent Form_V3_20240707_clean	Jul-07-2024	3
Appendix B3 Co Design Team Informed Consent Form_V3_20240707_clean	Jul-08-2024	3
Study Protocol_V3_20240707_clean	Jul-07-2024	3
Co-design data collection activities	Jul-09-2024	1
Appendix A1 Advisory Group Recruitment Script_V3_20240904_clean	Sep-04-2024	3
Appendix B1 Co-Design Team Recruitment Script_V3_20240904_clean	Sep-04-2024	3

The following documents have been acknowledged:

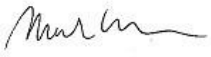
Document Name	Document Date	Document Version
Sim_2021_tcps2_core_certificate	Apr-27-2024	1
Budget_v1_26052024	May-26-2024	1
Wesley LOS	Apr-22-2024	1

While HiREB has reviewed and approved this application, the research must be conducted in accordance with applicable regulations and institutional and/or public health requirements.

We are pleased to issue final approval for the above-named study until the expiry date noted above. Continuation beyond that date will require further review and renewal of HiREB approval. Any changes or revisions to the original submission must be submitted on a HiREB amendment form for review and approval by the Hamilton Integrated Research Ethics Board.

REB members involved in the research project do not participate in the review, discussion or decision.

The Hamilton Integrated Research Ethics Board (HiREB) provides ethical review and ongoing ethical oversight on behalf of Hamilton Health Sciences, St. Joseph's Healthcare Hamilton, Research St. Joseph's-Hamilton, the Faculty of Health Sciences at McMaster University and Niagara Health. HiREB operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans (TCPS 2); The International Conference on Harmonisation of Good Clinical Practices Guideline (ICH GCP); Part C Division 5 of the Food and Drug Regulations, Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations. For studies conducted at St. Joseph's Healthcare Hamilton, HiREB complies with the Health Ethics Guide of the Catholic Alliance of Canada. HiREB is qualified through the Clinical Trials Ontario (CTO) REB Qualification Program and is registered with the U.S. Department of Health and Human Services (DHHS) Office for Human Research Protection (OHRP). Sincerely,



Dr. Mark Inman, MD, PhD
Chair, Hamilton Integrated Research Ethics Board

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Appendix B: Condensed Data Charting Table

Citation	Title	Country	Type of Paper	Type of Co-research	Population	Summary &Key Findings	Definitions of co-research
Acha et al., 2021	Engaging People and Co-Producing Research with Persons and Communities to Foster Person-Centred Care: A Meta-Synthesis.	High-income countries	Literature Review	Co-production, Healthcare.	Vulnerable groups: discriminated, marginalized, or excluded communities	This meta-synthesis identifies various definitions, guiding principles, theoretical frameworks, engagement phases, activities, methods, tools, and challenges and facilitators related to co-production engagement in healthcare research, particularly concerning vulnerable populations.	N/A

Albert et al.,2023	Nothing about us without us: A co-production strategy for communities, researchers, and stakeholders to identify ways of improving health and reducing inequalities.	United Kingdom	Empirical Qualitative– Co-production	Co-production, Healthcare.	Vulnerable population in impoverished areas.	Outlines the co-production of a co-production strategy for the ActEarly multistakeholder preventative research program, aimed at improving children's health and reducing inequalities in deprived areas of the UK. The strategy was developed through an Appreciative Inquiry (AI) process, identifying nine guiding principles and three core values for effective co-production.	"Co-production: While acknowledging the term's 'slippery, woolly and muddled' nature, the paper highlights that co-production is increasingly seen as best practice for improving research and service delivery quality, relevance, and effectiveness. It is also described as a collaborative process involving researchers, practitioners, decision-makers, and the public working together, sharing power and responsibility. Co-research: This serves as an umbrella term encompassing various approaches like 'participatory,' 'emancipatory,' and 'inclusive' research, reflecting a move towards involving communities in knowledge production. It aims to empower participants by giving them greater control over the research process and opportunities for learning and reflection."

Amann, J., & Sleigh, J. (2021).	Too Vulnerable to Involve? Challenges of Engaging Vulnerable Groups in the Co-production of Public Services through Research.	Switzerland	Systematic literature Review	Co-production, Public services.	Vulnerable population (those individual whose ability to provide voluntary consent in research may be compromised, and those who may be at greater physical risks in research)	Reviews the challenges and solutions involved in engaging vulnerable groups in the co-production of public services through research.	"Co-production (general): Historically, defined as 'the mix of activities that both public service agents and citizens contribute to the provision of public services'. Co-production of public services through research: Considered inextricably linked to the co-production of knowledge in research. It describes 'the active and voluntary involvement of members of the public at different stages of the research process aimed at developing or improving a public service'."
Benz et al., 2024.	Community-based participatory-research through co-design: supporting collaboration from all sides of disability.	Australia	A case study- Co-design	Co-design, to produce telepractice model, Healthcare.	People with disability	This document describes the application of co-design, focusing on a telepractice redesign project. It highlights the benefits and challenges encountered, offering recommendations for future co-design initiatives. The core idea is to involve people with lived experience in the design and improvement of services.	"Co-design: Defined as designing with, not for, people. In the context of this article, co-design delineates the collaborative process of discovery, creating, ideating, and prototyping to design or redesign an output. Co-production: An overarching approach to conducting research that requires complementary methods like co-design to achieve its aims. It encompasses co-planning, co-

							discovery, co-design, co-delivery, and co-evaluation.”
Bird et al., 2021	A generative co-design framework for healthcare innovation: development and application of an end-user engagement framework.	Canada	A methodological framework article.	Co-design, Healthcare.	Children with medical complexities and their families.	Introduces a generative co-design framework developed to enhance healthcare innovation by deeply involving end-users. The framework, called 'A Generative Co-Design Framework for Healthcare Innovation,' aims to bridge the gap between postulated benefits of health innovations and their actual outcomes in practice, which often fall short due to insufficient end-user involvement. It emphasizes the importance of creativity in the design process and provides a structured approach to transform creative ideas into specific	N/A

						products, systems, or services. The framework is divided into three main phases: Pre-Design, Co-Design, and Post-Design, each with distinct steps and activities designed to elicit and incorporate end-user viewpoints and practical considerations for healthcare innovation and design.	
Blackwell et al., 2017	Using Experience-based Co-design with older patients, their families, and staff to improve palliative care experiences in the Emergency Department: A reflective critique on the process and outcomes.	USA	Descriptive, Experience-based Co-design (EBCD)	Co-design, Healthcare.	Older patients with palliative needs and their family caregivers	This paper critically examines the application and adaptation of Experience-based Co-design as a quality improvement methodology within a complex healthcare setting, specifically an Emergency Department providing palliative care to older patients and their families. The study aimed to facilitate high levels of participation to gather evidence about palliative care needs in the ED, leading to collaborative working between vulnerable patients, their families, and staff.	"Experience-based Co-design (EBCD): A partnership-based approach and a form of Participatory Action Research (PAR) that enables staff and patients (or other service users) to co-design services and/or care pathways together in partnership. It is a practical and rigorous process for exploring and improving experiences with the full involvement of both service providers and users."

Boyd et al., 2010.	Boyd H, McKernon S, Old A. 2010. Health Service Co-design: working with patients to improve healthcare services.	New Zealand	Co-design guide and toolkit	Co-design, Healthcare.	Patients and service providers, in healthcare.	This guide/toolkit focuses on improving healthcare services by actively involving patients in the design process. It provides a structured approach to co-design, offering various tools and methods to engage patients and staff collaboratively.	"Co-design: A way of improving healthcare services with patients, focusing on understanding and improving patients' experiences of services as well as the services themselves."
Caperon et al., 2023.	Voice, Choice, and Power: Using co-production to develop a community engagement strategy for an ethnically diverse community.	United Kingdom	Descriptive, co-production process	Co-production, Healthcare.	Pregnant women and families with children aged 0-4 years living in an ethnically diverse area	Describes a co-production process undertaken with a diverse community in Bradford, UK, during the COVID-19 pandemic, as part of a review of ongoing community engagement work within the Better Start Bradford Programme.	"Co-production: A collaborative and inclusive process involving service users in the design and delivery of services. It aims to broaden and deepen public services, shifting from professional control to shared responsibility, building a multi-faceted network of mutual support. It also helps ensure health research benefits users and improves implementation and impact of community projects."

Canadian Institutes of Health Research, 2014.	Strategy for patient-oriented research (SPOR): Patient engagement framework.	Canada	Framework	Patient engagement, in health research.	Patients in health research.	This framework, developed by the Canadian Institutes of Health Research (CIHR) for Canada's Strategy for Patient-Oriented Research (SPOR), aims to integrate patients as active partners in health research.	"Patient Engagement: Defined as meaningful and active collaboration in governance, priority setting, conducting research, and knowledge translation. Depending on the context, it may also involve people representing the collective voice of specific, affected communities."
Denford et al., 2024.	Engagement in rapid public health research among young people from underserved communities: maximising opportunities and overcoming barriers.	USA	An empirical qualitative study	Co-production, public health.	Young people from underserved communities	This research explores the barriers and facilitators to engaging young people from underserved communities in rapid public health co-production, particularly within short timeframes for emergency responses.	"Co-production: While defined in various ways, it generally refers to researchers and members of the public working together to achieve a shared outcome, such as developing intervention materials."

Erwin et al., 2024.	Co-production of health and social science research with vulnerable children and young people: A rapid review.	United Kingdom	A rapid review.	Co-production of health and social science research.	Vulnerable children and young people	Synthesizes existing literature on co-production in health and social science research involving vulnerable children and young people (CYP). It identifies various approaches, activities, methods, and tools used, alongside the challenges encountered and facilitators that support successful engagement.	"Co-production (specific definition for this review): Defined as 'involvement of CYP in an explicitly described role contributing to the planning and/or conduct of [health] research.' This includes all aspects and stages of research, from identifying priorities to disseminating results. Co-creation: Often refers to systems-based approaches focused on innovation. Co-design: Defined as 'meaningful end-user engagement in research design,' with engagement levels varying from passive to highly involved across research stages."

Hawke et al., 2024.	Experience-based co-design of mental health services and interventions: A scoping review.	Canada	A scoping review	Experience-based co-design, Mental healthcare.	People with mental health or substance use challenges.	Summarizes the application of Experience-Based Co-Design (EBCD) in mental health and substance use (MHSU) settings, highlighting its utility for quality improvement and intervention development. It details the process, common adaptations, and perceived impacts, while also addressing the unique considerations and challenges within the MHSU sphere.	"Experience-based co-design (EBCD): A structured yet flexible methodology for healthcare quality improvement that brings together individuals with lived experience of a condition (including families or carers) and healthcare service providers. Its aim is to collaboratively design health interventions that are feasible and appropriate, emphasizing a participatory and narrative approach to explore the experience of care from all relevant stakeholders' perspectives."

Health Quality Ontario, n.d.	Equity in engagement framework.	Canada	An Equity in Engagement Framework	Engagement, Cancer Care.	Diverse marginalised populations: LGBTQ, Newcomers, Youth.	Outlines an Equity in Engagement Framework designed to promote equitable engagement and provide tools for organizations to connect with diverse marginalized populations in Ontario. The framework is structured like a growing tree, with engagement principles forming the roots, internal preparation and collaborative partnerships as the trunk, and the engagement process as the branches.	N/A

Hoeeg et al., 2019.	Co-Designing an Intervention to Prevent Overweight and Obesity among Young Children and Their Families in a Disadvantaged Municipality: Methodological Barriers and Potentials.	Denmark	A case study	Co-design process, an intervention to prevent childhood overweight and obesity.	Families in a rural and disadvantaged municipality.	Explores the co-design process, specifically Design-Based Research (DBR), in developing an intervention to prevent childhood overweight and obesity within a disadvantaged municipality. The study found that while DBR fostered a sense of equal partnership and led to innovative tools, the iterative nature of DBR often clashed with municipal organizational structures and stakeholder needs, leading to friction and misunderstandings.	"Design-Based Research (DBR): An innovative methodology for co-creation, particularly suitable for creating innovative programs that address complex challenges. It is a human-centered approach widely used in education research, focusing on designing artifacts and developing theoretical insights. DBR is characterized by continuous participant input, making them co-participants in both design and analysis. It is an iterative process involving repeated loops of designing, enactment, analysis, and redesign, and is context focused."

Gheduzzi et al., 2020.	Facilitating co-production in public services: Empirical evidence from a co-design experience with family caregivers living in a remote and rural area.	Italy	An empirical qualitative case study.	Co-production in public services.	Family caregivers of elderly citizens in rural and remote area in northern Italy.	Investigates the facilitation of co-production in public services, particularly focusing on a co-design experience with family caregivers in remote and rural areas. The study identifies key strategies for facilitators and providers to enhance co-production, emphasizing the importance of balancing power dynamics and managing interactions effectively.	“Co-production is defined as 'a process through which inputs from individuals who are not "in" the same organization are transformed into goods and services'.”

Gheduzzi et al., 2021.	How to prevent and avoid barriers in co-production with family carers living in rural and remote area: an Italian case study.	Italy	Case study	Co-production in Social Care.	Family carers of elderly patients living in rural and remote areas.	Investigates the complexities of co-production in social care, particularly focusing on identifying and interpreting barriers that arise during the co-production of new social services with vulnerable populations, such as family carers in rural and remote areas. It uses a single case study, the Place4Carers project in Italy, to explore how co-destruction processes can be understood and mitigated.	"Co-production: This concept has been widely recognized as a means to reduce citizen dissatisfaction, service provider inefficiency, and conflicts. It involves substantial contributions from citizens in designing and implementing new services. However, its effectiveness has been questioned, and it can be taken for granted without delivering effective results. Co-creation: This refers to processes where participants collaboratively create value."

Gheduzzi et al., 2024.	Exploring Interactions in the Co-Production of Social Care Services with Vulnerable Citizens.	Italy	An empirical, qualitative case study	This paper investigates the dynamics of co-production in social care services, particularly when involving vulnerable citizens.	Family caregivers of elderly citizens in rural and remote area in northern Italy.	investigates the dynamics of co-production in social care services, particularly when involving vulnerable citizens. It highlights the importance of understanding these interactions to make co-production more sustainable and effective, especially given the challenges posed by vulnerable participants. The study emphasizes the crucial role of expert facilitators and proposes communicative strategies to support their efforts in achieving successful co-production outcomes.	"Co-production is a core element of public service delivery in which citizens are involved in the prioritization, design, delivery and assessment of public services."

Goedhart et al., 2021.	Engaging citizens living in vulnerable circumstances in research: a narrative review using a systematic search.	The Netherlands	A narrative (qualitative) review.	Co-research, health and social care research.	Populations living in vulnerable circumstances: people with a low socioeconomic position, those with an ethnic minority background or people with mental health issues	A narrative review of strategies, tools, and methods to support the inclusion of citizens living in vulnerable circumstances in health research and policymaking. It critically analyzes concerns and corresponding strategies, using the socioecological model as an analytical framework.	"Vulnerable Circumstances: The paper purposefully avoids the term 'vulnerable groups', instead using 'citizens living in vulnerable circumstances'. This is based on the belief that vulnerability is not an inherent characteristic of an individual or group, but rather a position created by context. It refers to groups of individuals whose circumstances mean they are often overlooked in engagement practices or are difficult to reach. Examples include citizens with a low socioeconomic position, those with an ethnic minority background, or individuals with mental health issues."

Goodyear et al., 2022.	Development of an Evidence-Informed and Codesigned Model of Support for Children of Parents with a Mental Illness—"It Takes a Village" Approach.	Austria	Empirical Study, Qualitative	Co-design, Mental Healthcare.	People with lived experience of mental illness.	Details the development of an evidence-informed and codesigned model, named 'It Takes a Village,' aimed at improving support for children of parents with a mental illness. The model focuses on early identification and prevention, enhancing existing service systems and informal supports through a collaborative, strength-based approach that integrates local wisdom, lived experience, and international research.	"Co-design: A participatory research approach where researchers work with key stakeholders (including those with lived experience) to co-create new products, practices, or solutions, benefiting from shared knowledge across disciplines and contexts to enhance usability and social relevance."
Leask et al., 2019.	Framework, principles, and recommendations for utilising participatory methodologies in the co-creation and	United Kingdom	Methodological, derived from reflection on literature and three case studies.	Co-creation, Public health.	Case 1: Older adults. Case 2: Older adults Case 3: Adolescent schoolgirls	Presents a framework, principles, and recommendations for systematically applying participatory methodologies in the co-creation and evaluation of public health interventions.	"Co-creation: Defined as 'collaborative public health intervention development by academics working alongside other stakeholders.'"

	evaluation of public health interventions.						
McKeon et al., 2024.	Co-designing a Physical Activity Service for Refugees and Asylum Seekers Using an Experience-Based Co-design Framework.	Australia	Descriptive, Qualitative	Experience-Based Co-Design (EBCD), Public health.	Refugees and asylum seekers.	This study utilized an Experience-Based Co-Design (EBCD) framework to develop a physical activity service for refugees and asylum seekers, incorporating various elements to ensure its effectiveness and cultural appropriateness. The methodology involved a comprehensive approach, from initial project development to evaluation, addressing specific challenges and leveraging facilitators to enhance engagement.	"Co-design: This is defined as a values-led process centered around five key principles: Equal partnership from the beginning, Openness to working together towards a shared goal, Respect for different views, experiences, and diversity, Working together through all stages of the project."

Moll et al., 2020.	Are you really doing 'codesign' ? Critical reflections when working with vulnerable populations.	Canada	A critical reflection methodology paper	Co-design, Health research.	Vulnerable population: groups experience significant health and healthcare disparities linked to intersecting vulnerabilities such as poverty, language barriers, age, disability, minority status, and stigmatized conditions.	discusses the concept of 'codesign' within health research, particularly when engaging vulnerable populations. It emphasizes the need for clear principles and practices to ensure meaningful engagement, addressing the lack of clarity and variation in how codesign is applied. The authors prompt critical reflection on the nature of codesign research, covering planning, implementation, and outputs, while identifying risks, tensions, and offering a tool for reflexivity.	"Codesign: This term, along with 'coproduction' or 'patient engagement,' is increasingly common in health research literature. It refers to the application of user-centric research and service/systems development approaches to solve problems or challenges. It is described as a dynamic, creative approach that embraces partnership with the community, focusing on systems change and improving human experience."

Moser & Korstjens, 2022.	Series: Practical guidance to qualitative research. Part 5: Co-creative qualitative approaches for emerging themes in primary care research: Experience-based co-design, user-centred design, and community-based participatory research.	The Netherlands	Methodological	Three co-creative qualitative approaches: experience-based co-design (EBCD), user-centred design (UCD), and community-based participatory research (CBPR), Primary care research.	Patients and family carers in primary care.	Provides practical guidance on three co-creative qualitative approaches for primary care research: experience-based co-design (EBCD), user-centred design (UCD), and community-based participatory research (CBPR). It outlines their definitions, core principles, goals, stakeholders, engagement phases, activities, methods, tools, and challenges, aiming to help researchers and general practitioners apply these methodologies effectively.	"Co-creation: An iterative and non-linear process that involves the collaborative generation of knowledge by academics and stakeholders throughout the research continuum. It aims to define research problems, develop and implement interventions, and evaluate outcomes in partnership with various stakeholders. Experience-based co-design (EBCD): Seeks to understand how people experience a healthcare process or service. It is a form of action research that captures and understands subjective, personal feelings of patients, family carers, the public, and professionals to identify 'touchpoints' that shape overall experience. The goal is to facilitate collaborative work to improve the quality of care."

Mulvale, Moll, Miatello, Murray-Leung et al., 2019a.	Co-designing Services for Youth with Mental Health Issues: Novel Elicitation Approaches.	Canada	Qualitative study	Experience-Based Co-Design (EBCD) in improving health and social services for youth with mental health issues.	Youth who experience mental health problems.	Explores the application of Experience-Based Co-Design (EBCD) in improving health and social services for youth with mental health issues, focusing on novel elicitation approaches. It highlights the theoretical underpinnings, practical implementation, and the challenges and facilitators encountered in engaging vulnerable populations in co-design processes.	"Experience-based co-design (EBCD) is an innovative, evidence-based approach to health and social system change based on principles of participatory action research, narrative and learning theory, and design thinking. Unique elicitation strategies such as experience mapping, trigger videos, and prototype development are used in EBCD to engage service users and service providers in a collaborative process of identifying touchpoints and solutions to system-level problems."

Mulvale, Moll, Miatello, Robert et al., 2019b.	Codesigning health and other public services with vulnerable and disadvantaged populations: Insights from an international collaboration.	Canada	A modified case study approach	Co-designing, Health, and other public services.	Australia case: (1) Adults with mental health problems. Scotland: (2) Adults with mental health problems. England: (3) Adults with personality disorders. Canada: (4) Youth with mental disorders. Canada: (5) Young workers with mental health issues. England: (6) Survivors of domestic violence. England: (7) Young	Explores the challenges and facilitators of codesigning health and other public services with vulnerable and disadvantaged populations. It synthesizes insights from an international symposium involving practitioners, academics, and service users, drawing on eight case studies across three countries.	"Coproduction: This concept, originating in the 1970s, refers to the involvement of public service users in the design, management, delivery, and/or evaluation of public services. It is based on the understanding that service users possess assets that can improve services, rather than being passive recipients. Codesign: Arising partly from the service design literature and the broader coproduction movement, codesign recognizes service users as 'experts of their experiences.' It aims to utilize this expertise to improve and develop health and community services based on user needs. Experience-based codesign (EBCD): A systematic approach to applying service codesign, initially developed in the UK health sector, that combines a user-centred orientation with a participatory, collaborative, and creative change process underpinned by service design thinking."

					offenders. Canada: (8) Indigenous populations.		

Mulvale et al., 2021.	A COMPASS for Navigating Relationships in Co-Production Processes Involving Vulnerable Populations.	Canada	Qualitative with a reflective/ methodological component.	Co-production, Mental healthcare.	Equity-deserving population: groups facing social and structural barriers to full participation in health services and co-production activities.	Introduces a 'COMPASS' heuristic tool designed to guide researchers in navigating co-production processes, particularly those involving vulnerable populations like youth with mental health issues. It emphasizes the critical role of the research team in managing power imbalances and fostering relational safety throughout the engagement process.	“Co-production: Defined as 'the provision of services through regular, long-term relationships between professionalized service providers (in any sector) and service users or other members of the community, where all parties make substantial resource contributions'. It is founded on the belief that both service providers and users possess unique knowledge to contribute to service improvements. Experience-based Co-design (EBCD): A co-production approach that centers lived experience to improve public services. It involves patients, family members, and service providers collaborating to translate experiences into tangible service redesign.”

Mulvale et al., 2024.	Co-creating a new Charter for equitable and inclusive co-creation: insights from an international forum of academic and lived experience experts.	Canada	A participatory methodology paper	Equity-based Co-Creation (EqCC) Charter, developed from insights gathered at an International Forum.	Equity-Deserving Groups (EDGs): Includes Black, Indigenous, and people of colour; disabled, Mad, 2S/LGBTQIA+ and Deaf communities; and other minoritized groups.	Introduces the 'Equity-based Co-Creation' (EqCC) Charter, developed from insights gathered at an International Forum in August 2022. The Charter aims to foster a new era of co-creation that prioritizes equity and inclusivity, particularly for marginalized groups, by addressing structural inequities and historical harms within public and institutional spaces. It emphasizes power-sharing and collaboration between service providers and users, recognizing the unique insights each group brings to improve health and other public services.	"Co-creation: any collaborative activity involving experience experts (i.e., people who develop expertise arising from their experiences interacting with public services, often referred to as service users, patients, families, etc.) and staff/professionals (e.g., service providers) working together on an even playing field, that is inclusive of the lived experience from all perspectives. Equity-based Co-Creation (EqCC): A new goal for co-creation theory and practice, coined by Hub members. At its core, EqCC involves intentionally working with members of Equity-Deserving Groups (EDGs) to recognize and overcome structural barriers to their participation and impact through co-creation activities. It promotes dialogue about intersecting systems of oppression within health and other public services."

National Institute for Health and Care Research, 2024.	Guidance on co-producing a research project.	United Kingdom	Guidance document.	This guidance document from the National Institute for Health and Care Research (NIHR) provides a foundational understanding of co-producing research projects.	Patients, potential patients, carers, health & social care service users, org reps for service users and people with lived health condition experience.	Provides a foundational understanding of co-producing research projects. It outlines key principles, features, and challenges, emphasizing a collaborative approach where researchers, practitioners, and the public work together to share power and responsibility throughout the research lifecycle.	"Co-producing a research project is an approach in which researchers, practitioners, and members of the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge. The assumption is that those affected by research are best placed to design and deliver it and have skills and knowledge of equal importance."

Palmer et al., 2019.	The Participatory Zeitgeist: an explanatory theoretical model of change in an era of coproduction and codesign in healthcare improvement. *Medical Humanities*, *45*(3), 247-257. https://doi.org/10.1136/medhum-2017-011398	Australia	A theoretical paper that proposes a conceptual framework	co-production and co-design, Mental healthcare.	Service users and carers in Mental healthcare.	Explores the 'new Zeitgeist' of participation in healthcare improvement, focusing on co-production and co-design. It introduces the Mental Health Experience Co-design (MH ECO) model as a case study to develop an explanatory theoretical model of change. The paper identifies eight mechanisms of change and ideal relational transitions, drawing on interdisciplinary theories to understand the underlying processes that impact outcomes in co-production efforts.	"Co-production: Historically, referred to 'citizens as co-producers' of public goods and services, where citizen engagement in service use and delivery created public benefit or value. More recently, it applies to clients or service users engaging in co-producing goods and services, with value largely private to the client and organization. Co-creation, Co-design, Co-innovation: Related practices that coalesce around the concept of co-production, increasingly used in healthcare improvement."

Parnes et al., 2024.	Translating research evidence into youth behavioral health policy and action: using a community-engaged storyboard approach.	USA	Descriptive, Qualitative	Co-design, Mental health.	Youth from historically disenfranchised communities. (parent peers, community health workers, youth peers)	Details a case study on using a community-engaged storyboard approach to translate research evidence into youth behavioral health policy and action. It highlights the process of fostering research-practice-policy partnerships, particularly in the context of addressing the nationwide shortage of child and adolescent behavioral health providers and disparities in care for historically disenfranchised communities.	"Co-design: A participatory strategy that combines research synthesis with stakeholder expertise in policy and practice to facilitate partnerships and engage end-users in program/policy design processes."

Patient-Centered Outcomes Research Institute (PCORI), 2021.	Best practices in engaging stakeholders.	USA	Guidance document	Stakeholders' engagement in research.	General Population	Outlines best practices for engaging stakeholders in research, drawing guidance from the PCORI Engagement Rubric. It emphasizes the importance of collaboration, communication, and building strong relationships among researchers and stakeholders throughout all phases of a research study.	N/A

Pearce et al., 2020.	What is the Co-Creation of New Knowledge? A Content Analysis and Proposed Definition for Health Interventions.	Australia	Literature review to define co-creation	Co-creation, Health interventions.	Service users within the context of health interventions.	Addresses the conceptual ambiguity surrounding 'co-creation of new knowledge' within health interventions. It proposes a standardized definition and framework based on a content analysis of existing literature, aiming to improve consistency in research and practice.	"Co-creation: The generation of new knowledge that is derived from the application of rigorous research methods that are embedded into the delivery of a program or policy (by researchers and a range of actors including service providers, service users, community organisations and policymakers) through four collaborative processes: (1) generating an idea (co-ideation); (2) designing the program or policy and the research methods (co-design); (3) implementing the program or policy according to the agreed research methods (co-implementation), and (4) the collection, analysis and interpretation of data (co-evaluation)."

Pearce et al., 2022.	Co-creation of new knowledge : Good fortune or good management?	Australia	A case study	Co-creation, Mental health.	People who had attempted suicide.	Explores the application of a co-creation framework for generating new knowledge, particularly within the context of public health interventions in third-sector organizations (TSOs). It uses a case study of an Australian psychoeducational program called Eclipse, designed for individuals who have attempted suicide, to examine the practical implementation of co-creation and the perspectives of researchers and stakeholders involved. The study highlights the 'messiness' and non-linear nature of co-creation, emphasizing the importance of trust, good fortune, and good management in collaborative relationships. It also proposes revisions to the initial co-creation framework based on insights gained from the case study.	"Co-creation: This approach involves the formation of collaborative partnerships among researchers, service providers, and service users (those with lived experience) to work together across the research cycle. The goal is to co-create knowledge that is both actionable and usable. It is considered an underutilized but complementary framework for research translation, aiming to reduce research waste and maximize impact."

Phoenix al., 2024.	Advancing a collective vision for equity-based cocreation through prototyping at an international forum.	Canada	A methodological paper.	Equity-based co-creation (EqCC), Health, and social services.	Equity-deserving groups: populations that, due to varying socio-historic, political, economic, and cultural contexts, are more likely to experience systemic oppression through population-level barriers to health and well-being, and limitations in accessing services. Examples include Black, Indigenous, racialized, disabled,	This paper details the CoPro2022 international forum, which aimed to develop a collective vision for equity-based cocreation (EqCC) through participatory engagement and prototyping. It highlights the importance of including equity-deserving groups (EDGs) in cocreation processes to address systemic inequities and foster transformative change. The forum's activities led to the identification of four cross-cutting themes for EqCC: 'go to where people are,' 'nurture relationships and creativity,' 'reflect, replenish, and grow,' and 'promote thriving and transformation.	"Cocreation, Codesign, and Coproduction: These terms refer to knowledge generation projects where individuals with lived and living experience are recognized as knowledge experts. They contribute to the research process beyond a mere participant role, using creative and relational methods tailored to local contexts to effect change in systems and governance."

					and 2SLGBTQI + people.		

Radl-Karimi et al., 2020.	Under what circumstances can immigrant patients and healthcare professionals co-produce health? - an interpretive scoping review.	Denmark	A scoping review	An interpretive scoping review that investigates the circumstances under which immigrant patients and healthcare professionals can successfully co-produce health.	Immigrant and refugee patients, Health.	Presents an interpretive scoping review that investigates the circumstances under which immigrant patients and healthcare professionals can successfully co-produce health. It identifies key factors facilitating this co-production and highlights the challenges and facilitators involved in such engagements. The review emphasizes that successful co-production requires a system and professionals who are interested and prepared, recognizing immigrant patients as valuable sources of information and powerful co-producers of their own health.	"Co-production: This concept refers to the collaborative creation of valuable healthcare services for the patient. From a service management perspective, all public service is inherently co-produced in a holistic and dynamic service system, where value is created in a process that is intrinsic to the nature of public service. It recognizes that all individuals possess resources like knowledge, skills, habits, and community support that can aid their health and well-being. In healthcare, co-production is the shared work of making a service between the patient and the healthcare professional."

Roche et al., 2020.	Valuing All Voices: refining a trauma-informed, intersectional, and critical reflexive framework for patient engagement in health research using a qualitative descriptive approach.	Canada	Descriptive, Qualitative study	Co-development of patient engagement framework, in health research.	Participants identifying as Inuit; refugee, immigrant, and/or newcomer; and/or as a person with lived experience of a mental health condition.	Introduces and refines the Valuing All Voices Framework, a trauma-informed, intersectional, and critical reflexive approach to patient engagement (PE) in health research. The framework aims to provide guidance for research teams to conduct PE with a social justice and health equity lens, improving safety and inclusivity in health research. It was developed in response to identified gaps in current PE strategies, particularly the exclusion of voices traditionally less heard, and the lack of consideration for the role of trauma in lived experience.	"Patient Engagement (PE): Defined as the meaningful and active involvement of people with lived experience (including caregivers, families, friends, and members of the public) across all stages of the research process, from governance to knowledge translation. The goal is to create opportunities where all forms of knowledge, especially experiential knowledge, are equally valued."

Sanders & Stappers, 2014.	Probes, toolkits, and prototypes: three approaches to making in codesigning.	USA	A conceptual methods paper	Co-design, Research.	General Population	Explores the evolving role of 'making' in the design process, particularly within co-designing, by examining three key approaches: probes, toolkits, and prototypes. It highlights how these methods enable both designers and non-designers to collaboratively engage in making sense of and shaping the future. The paper traces the shift from traditional design where making occurs later in the process to a contemporary view where making is integral across all design phases, from early exploration to evaluation. It also introduces a framework that positions these approaches within different design mindsets (designing for and designing with) and timeframes (world as it is, near future, speculative future).	N/A

Soklaridis et al., 2024.	A balancing act: navigating the nuances of co-production in mental health research.	Canada	A Case study	Co-production, in mental health research.	People with lived expertise of accessing mental health services.	Explores the complexities of co-production in mental health research, using a participatory action research (PAR) project as a case example. It delves into the nuances of co-production by highlighting four key values embraced by the authors' team: navigating power relations together, multi-directional learning, slow and steady wins the race, and connecting through vulnerability. The authors aim to operationalize co-production principles through a case study, emphasizing authentic and equitable collaborations within hierarchical academic and health systems. Offering insights into how to manage tensions between different perspectives on co-production to foster meaningful and productive relationships.	"Co-production in Mental Health Research: This involves collaboration among people with lived expertise (PWLE) of accessing mental health services, those with professional or academic expertise, and individuals possessing both perspectives. They work together to design and actualize research initiatives. Authentic co-production goes beyond a consultation model, recognizing PWLE as equal partners from the outset."

Taccone et al., 2023.	Co-creation of a patient engagement strategy in cancer research funding.	Canada	Descriptive, Qualitative study	Co-creation, Cancer research.	Patient partners with cancer experiences	Details the co-creation of a patient engagement strategy for cancer research funding by the Canadian Cancer Society (CCS). It outlines the process, methods, and lessons learned from developing a multi-faceted strategy aimed at meaningfully and systematically engaging patients, survivors, caregivers, and researchers in research funding and activities.	"Patient Engagement: patient engagement refers to the inclusion of patients in research activities or in the funding process as contributors and/or decision-makers. This involves patients contributing their lived experiences, perspectives, and knowledge to shape research, intending to improve its relevance, impact, and eventual translation to patient populations."

The Point of Care Foundation, n.d.	EBCD: experience-based co-design toolkit. The Point of Care Foundation.	United Kingdom	Toolkit	Experience-based co-design, Healthcare.	Patients	This toolkit gives a step-by-step guide to improving patient experience of health care using a technique called experience-based co-design (EBCD). The toolkit originally stemmed from the Patient-Centred Care Project that was carried out within King's College London, King's College Hospital NHS Foundation Trust and Guy's and St Thomas' NHS Foundation Trust.	"Experience-Based Co-Design (EBCD): An approach that enables staff and patients (or other service users) to collaboratively design services and/or care pathways. It involves gathering experiences, identifying 'touch points' (emotionally significant moments), and using these insights to develop and implement service improvements."

Vargas et al., 2022.	Co-creation, co-design, co-production for public health – a perspective on definitions and distinctions	Australia	Literature review.	Co-creation, co-design, and co-production, public health.	Stakeholders in public health.	Provides a comprehensive perspective on the definitions, distinctions, and relationships between co-creation, co-design, and co-production, particularly within the context of public health initiatives. It highlights that while these terms are often used interchangeably, they have essential distinctions related to stakeholder roles, engagement timing, and the extent of participation. The paper proposes co-creation as an overarching guiding principle that encompasses both co-design and co-production, serving as a framework for designing, implementing, and evaluating effective public health initiatives.	"Co-creation: This refers to a collaborative approach to creative problem-solving involving diverse stakeholders at all stages of an initiative, from problem identification and solution generation to implementation and evaluation. It emphasizes the creation of value through continuous feedback and interaction among stakeholders. Co-design: This describes active collaboration between stakeholders in the design of solutions for a pre-specified problem. It promotes citizen participation to formulate or improve specific concerns, such as service or product improvements or better prevention activities. Co-production: This involves implementing previously determined solutions to an agreed problem, with a focus on the most efficient use of existing resources and assets. It typically occurs after the initiative has been designed, at the point of implementation."

Wahi et al., 2023.	Strengthening Community Roots: Anchoring Newcomers in Wellness and Sustainability (SCORE!): A protocol for the co-design and evaluation of a healthy active living program among a newcomer community in Canada.	Canada	A study protocol paper	Co-design, Public Health.	Newcomer children and families, living in Hamilton, Ontario.	Outlines the protocol for Strengthening Community Roots: Anchoring Newcomers in Wellness and Sustainability (SCORE!), an academic-community research partnership. The project aims to co-design and evaluates a healthy active living (HAL) program for newcomer children and families in Hamilton, Ontario, Canada, focusing on nature-based physical activity. The initiative addresses the significant public health issue of childhood obesity and cardiometabolic risk factors among newcomer Canadians, particularly those in lower socioeconomic circumstances.	N/A

World Health Organization, 2023.	WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions.	WHO	Guide	Engagement, Co-creation and co-design, Health and Mental Health.	Individuals with lived experience of noncommunicable diseases (NCDs), and mental health and neurological conditions.	This framework, developed by the World Health Organization (WHO), outlines a comprehensive approach to meaningfully engaging individuals with lived experience of noncommunicable diseases (NCDs), and mental health and neurological conditions. It emphasizes co-creation of policies, programmes, and services to improve health outcomes and address health inequities, building on participatory approaches and human rights principles.	"Meaningful Engagement: Defined as the respectful, dignified, and equitable inclusion of individuals with lived experience in various processes and activities within an enabling environment, where power is transferred to people. It values lived experience as a form of expertise and applies it to improve health outcomes."

Zhang et al., 2024.	Co-creation and community engagement in implementation research with vulnerable populations: a co-creation process in China.	China	A descriptive and evaluative paper.	Co-creation, Health.	Men who have sex with men (MSM).	Details the successful adaptation and implementation of a four-stage co-creation process for a sexually transmitted disease (STD) testing intervention among men who have sex with men (MSM) in China. It highlights how this approach fostered community leadership, engagement, and resulted in practical adaptations and implementation strategies, particularly for vulnerable populations in low- and middle-income settings.	"Co-creation: Defined as the 'collaborative approach of creative problem solving between diverse stakeholders at all stages of an initiative, from the problem identification and solution generation through to implementation and evaluation'. In this context, program beneficiaries are considered experts due to their lived experience and serve as equal members of the design team alongside researchers. It aims to create a shared leadership role for program beneficiaries in the development and implementation of programs, encouraging early and deep involvement of community members."

Zogas et al., 2024.	Strategies for engaging patients in co-design of an intervention. Patient Education and Counseling.	USA	A narrative review that synthesizes co-design principles and combines this synthesis with the authors' practical experience	Co-design, Health	Veteran patients	Provides practical guidance on engaging patients in co-design to create patient-facing interventions, drawing from the authors' experience with five Veteran patients in the U.S. Department of Veterans Affairs (VHA). It synthesizes co-design principles and literature, detailing a 12-week process conducted via video conference to co-design materials for improving patient-centered care coordination. The paper outlines the principles, stages, strategies, techniques, challenges, and facilitators of co-design, emphasizing its role as a feasible methodology for health services research teams aiming to intensify patient engagement.	"Co-design: This is a specific approach to participatory research where researchers and end users share ownership of the research process and its end products, such as research protocols, interview guides, or interventions. While highly heterogeneous, it is characterized by collaborative research between academic researchers and end users."