Patient Engagement in Adolescent Mental Health Intervention Design and Development

by

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Abstract

Meaningful development and evaluation of mental health care services requires the involvement of individuals who use the services. However, the lived experiences of children and adolescents with mental health concerns as well as their parents/caregivers are seldom considered in studies seeking to improve child and adolescent mental health care. The aim of this thesis was to conduct research focused on patient engagement in child and adolescent mental health care. A scoping review (study 1) was conducted to identify approaches to engagement used in studies focused on child and adolescent mental health care design, development, or evaluation, and to summarize study-reported barriers, constraints, and facilitators to engagement. This review demonstrated that in the majority of studies an explicit framework, such as experience-based co-design (EBCD), was not used to guide engagement of children, adolescents, and their parents/caregivers. Constraints and barriers such as time restrictions limiting prolonged engagement/study progress, difficulties with recruitment, and limited generalizability of study findings were commonly reported by study teams. A mixed-method study (study 2) was conducted in two phases using the principles of EBCD and the Capability, Opportunity, Motivation, Behavior (COM-B) model. In phase 1, two discharge communication interventions for pediatric mental health care in the emergency department (ED) were co-designed with a team of parents/caregivers and ED clinicians: a brochure for families and clinicians to use together during the ED visit, and a text-messaging system for families after the visit. In phase 2, the usability of these interventions was tested by a sample of clinicians, parents, and youth. There was high engagement satisfaction in phase 1, and high user satisfaction in phase 2. Usability testing feedback was used by the co-design team to improve the final intervention versions. Taken together, the two studies demonstrated the importance of engaging patients in mental health research and highlighted important considerations for researchers to consider when conducting intervention-based mental health studies.

Preface

This is an original work by Amber Ali. The mixed-method study, which forms a part of this thesis, received ethics approval from the University of Alberta Research Ethics Board, Project Title “Partnerships to co-design and test a discharge communication intervention for pediatric mental health care in the emergency department”, Pro00102111, September 22, 2020.

Chapter 2 of this thesis is under peer review as A.Z. Ali, B. Wright, J.A. Curran, and A.S. Newton, “Patient engagement in child, adolescent, and youth mental health care research: A scoping review”. *Child and Adolescent Mental Health*. Alongside A.S. Newton and B. Wright, A.Z. Ali conceptualized the review and conducted title, abstract, and full text screening. A.Z. Ali was responsible for data extraction and analysis, submission, and response to edits from peer reviewers. A.Z. Ali drafted the initial manuscript with important contributions from A.S Newton, and editorial input from B. Wright and J.A Curran.

Chapter 3 of this thesis is in preparation for publication as A.Z. Ali, B. Wright, J.A. Curran, J. Fawcett-Arsenault, and A.S. Newton, “Discharge communication for mental health visits to the pediatric emergency department: A mixed-method study”. All authors contributed to conceptualization and defining methods for this study. Alongside B. Wright and J. Fawcett-Arsenault, A.Z. Ali assisted in participant recruitment. A.Z. Ali was responsible for coordinating the study, data collection and analysis, and drafting the initial manuscript. A.S Newton contributed to manuscript composition and edits at various stages of manuscript construction. Editorial contributions were provided by B. Wright, J.A Curran and J. Fawcett-Arsenault.

Dedication

I dedicate this thesis to my parents, for their wholehearted support and constant encouragement to pursue my passions in life.

Also, to my friends, for being there when I needed them the most, and always cheering me on.

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This experience was extremely rewarding, and full of challenges, growth, and lessons learned. I want to acknowledge my supervisors, Drs. Mandi Newton and Bruce Wright, who gave me the opportunity to be part of an amazing project. None of this would be possible without their constant support, encouragement, and guidance over the last two years. I want to especially thank Dr. Newton for her mentorship, and for her dedication to helping me become a better writer and researcher. I would also like to thank Dr. Janet Curran. It was an honor to have her as my committee member, and her support and guidance on conducting patient engagement research and the mixed methods study was invaluable.

Additionally, I would like to thank Joelle Fawcett-Arsenault for her guidance and expertise on recruiting and working with patients and families, and for her role in facilitating co-design team meetings in the mixed methods study. I am also extremely grateful to all the parents, youth, and clinicians that shared their lived experiences and input in the mixed methods study.

Lastly, I would like to acknowledge the generous financial support provided over my graduate program by Dr. Mandi Newton, the Department of Pediatrics, Faculty of Graduate Studies and Research, and Women and Children’s Health Research Institute (WCHRI).

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Study 1: Scoping Review

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List of Abbreviations

APEASE	Affordability, Practicability, Effectiveness, Acceptability, Side-effects/safety, and Equality
BCW	Behavior Change Wheel
COM-B	Capability, Opportunity, Motivation, Behavior
EBCD	Experience-based Co-design
ED	Emergency Department
GRIPP2-LF	Guidance for Reporting Involvement of Patients and the Public 2 Long-Form
METER	Medical Term Recognition Test
MheC	Mental health eClinic
NR	Not Reported
PAR	Participatory Action Research
PiiAF	Public Involvement Impact Assessment Framework
PPEET	Patient and Public Engagement Evaluation Tool
PPI	Patient and Public Involvement
PRISMA-ScR	Preferred Reporting Items for Systematic Reviews and Meta-Analysis: extension for Scoping Reviews
SD	Standard Deviation
SMS	Short Message Service
SRS	Severity Ranking Scale
SUS	System Usability Scale

Chapter 1:

Introduction

1.1. Background

Unmet Mental Health Needs

Mental illnesses are a leading cause of health-related disability, with up to one in eight children worldwide experiencing a mental health problem (Barican et al., 2022; Collishaw, 2015; Hossain et al., 2022). It is currently estimated that 70% of mental illnesses have their onset in childhood or adolescence (Youth Mental Health Canada, 2019); although illnesses usually emerge during childhood, they can continue into adulthood (Collishaw, 2015). Mental illnesses have wide-ranging impacts as they are associated with broader health impacts such as developing subsequent medical conditions (Momen et al., 2020), functional impairments (McKnight & Kashdan, 2009) as well as death by suicide (Bertolote & Fleischmann, 2002).

Over the past decade, mental health care access and quality issues have been highlighted in several studies including data that show less than 20% of children with mental illness receive adequate care (Gill et al., 2017; Kataoka et al., 2002; Perou et al., 2013), and that adolescents with mental illness receive reduced quality of care compared to other age groups (Quinlan-Davidson et al., 2021) and also experience illness-associated stigma (Gulliver et al., 2010; Liu et al., 2014; Radez et al., 2021). Further, a parent/caregiver may not even recognize their child's unmet mental health needs (Gill et al., 2017; Reardon et al., 2017), have difficulty accessing community mental health services for their child (Mapelli et al., 2015; Reardon et al., 2017), lack the knowledge on how to access services (Reardon et al., 2017), and/or be hesitant to discuss their concerns with a primary care physician (Gill et al., 2017). Taken together, these circumstances and experiences may result in mental health crises with parents/caregivers accessing mental health care resources and support for their children in an emergency department (ED) (Liu et al., 2014; Lo et al., 2020). A significant proportion of children and adolescents who visit the ED with their parents/caregivers for mental health concerns—up to 50%—have received no prior outpatient mental health care, making the ED a first point of contact with the mental health care system for many families (Gill et al., 2017; Saunders et al., 2018).

Mental Health Care in the Emergency Department

EDs serve a vital role in de-escalating a mental health crisis and supporting families during the crisis (Saunders et al., 2018). Currently, however, these departments are unideal care settings due, in part, to a lack of evidence-based tools, guidelines, and policies for mental health care (Cappelli et al., 2019). Children and adolescents seeking ED-based mental health care also experience long wait times before care is received, receive inadequate mental health evaluations, and are regularly treated by clinicians and staff that lack mental health care training (Chun et al., 2015; Cree et al., 2021). Most children and adolescents who receive ED care for mental health concerns are discharged to their home after a visit; 32–48% of these children and adolescents may not receive any discharge instructions on what to do after the crisis (Cappelli et al., 2019). Inadequate care provided in the ED and poor discharge practices can result in adverse events including return visits to the ED (Chen et al., 2022; Curran et al., 2019). Up to 39% of children and adolescents presenting to the ED with a mental health crisis can have three or more ED visits for the same concern (Rosic et al., 2019).

Discharge Interventions in the Emergency Department

ED discharge interventions facilitate the transition from acute care to community care by addressing anticipated needs and concerns (Braet et al., 2016; Chen et al., 2022). Discharge interventions should summarize the diagnosis and care given in the ED, address patient questions, teach patients how to care for themselves after the visit, provide information on referrals for follow-up care, and may also involve care coordination before leaving the ED (Hoek et al., 2020; Samuels-Kalow et al., 2012). Interventions can be provided verbally or in written or video-based form, or may involve follow-up calls by telephone after the ED visit (Chen et al., 2022; John Hopkins University, 2014). It is important, however, that discharge instructions of known effectiveness be provided as patient understanding of diagnosis, treatment, and follow-up plans are often poor (Akinsola et al., 2017; Gutman et al., 2018). For example, a recent systematic review of pediatric and adult ED studies highlighted differences in correct recall of discharge instructions: 47% for patients who received verbal information, 58% for patients who received written information, and 67% for patients who received video-based information (Hoek et al., 2020). A multi-faceted approach such as providing written discharge instructions alongside verbal instructions has the potential to improve discharge communication and the correct recall of instructions (Akinsola et al., 2017; Hoek et al., 2020; Taylor, 2000), if the written instructions match the patient's/family's health literacy levels (Powers, 1988; Siegrist et al., 2021; Williams et al., 1996).

High quality discharge instructions enhance the overall quality of care, reduce post-discharge complications, and increase patient and caregiver satisfaction (Newnham et al., 2017). At this time, however, policies and guidelines are lacking for discharge communication in EDs, including pediatric EDs where high quality, specialized pediatric care is expected (Akinsola et al., 2017; Curran et al., 2020). As a result, pediatric mental health discharge interventions vary significantly, with a lack of clear direction (Murphy et al., 2018). Current ED discharge practices often lack crucial information, are difficult for patients and family members to understand, and their provision is frequently rushed (Curran et al., 2020; Newnham et al., 2017). This approach results in poor quality discharge communication (Al-Harthy et al., 2016; Chen et al., 2022). Despite these concerns, and over 80% of pediatric mental health ED patients being discharged home, there is limited literature available detailing the conceptualization and development of discharge instructions for youth with mental disorders (Murphy et al., 2018). Priorities for improving discharge instructions for pediatric emergency mental health care not only include addressing these limitations, but also ensuring adequate evaluation is conducted to understand how and why specific approaches to mental health care discharge instructions are useful for clinicians, and impactful for patients and their families (Murphy et al., 2018).

Patient Engagement and Experience-based Co-design

Parents/caregivers, pediatric patients, and health care providers play a significant role in the discharge communication process; however, traditionally, they have not been involved in developing discharge interventions (Curran et al., 2020). The involvement of children/adolescents and parents/caregivers in the development of discharge inventions for mental health care could improve access to treatment and services after the ED visit and increase the quality and appropriateness of discharge interventions provided in the ED (Bombard et al., 2018; Vojtila et al., 2021).

Patient engagement is a term used to describe a meaningful and active partnership between clinicians, researchers, and patients when conducting research, setting priorities, and translating study findings (Crockett et al., 2019). The term ‘patient’ typically includes people with health conditions, their caregivers, and/or family members (Manafo et al., 2018). In recent years, there is a growing consensus about the vital role of engaging patients in research (Domecq et al., 2014). Research suggests that patient engagement can help to improve the efficiency, effectiveness, and quality of health care services (Bombard et al., 2018). To date, most engagement initiatives have been limited to engaging either patients and parents/caregivers, or health care providers, rather than both (Fucile et al., 2017). To overcome this oversight in traditional patient engagement methods, experience-based co-design (EBCD) is being utilized (Fucile et al., 2017).

EBCD is a qualitative framework, which can be used to evaluate and improve health care services through direct patient engagement (Cooper et al., 2016). EBCD initiatives are considered the best practice for leading improvements in health care (Fucile et al., 2017). The framework supports patients and clinicians collaborating to co-design health care improvement initiatives (Kynoch & Ramis, 2019), and consists of 6 stages: (1) project set-up and observations, (2) engage staff and gather experiences, (3) engage patients/caregivers and gather experiences, (4) joint co-design event, (5) design and implement solutions, and (6) celebration event and review service improvements (Bate & Robert, 2007; Point of Care Foundation, 2020). At this time, the EBCD framework has been largely used in physical health care settings; there are limited published studies using EBCD in mental health care settings (Cooper et al., 2016).

1.2. Personal Interest

Individuals with mental health concerns are not often given the opportunity to provide their input and expertise in research. Although it may require more planning and resources, it is essential to involve these individuals in the design and development of interventions to improve our current mental health care system. I was thrilled to be given the opportunity to work alongside individuals with lived mental health experiences to conduct my master's research. My research interests lie in EBCD because of the importance it places on collaboration throughout a research project, and I value the structured approach to co-design, which is helpful when learning to conduct research.

1.3. Research Aims and Objectives

The aim of my graduate research was to conduct research focused on patient engagement in child and adolescent mental health care. My first project (Study 1) involved conducting a scoping review to understand how other researchers have approached patient engagement in mental health intervention research. I applied the knowledge generated from this review to conduct a mixed-method study (Study 2). The objective of this study was to co-design and test the usability of discharge communication interventions with parents, adolescents (aged 10–19 years)/youth (aged 16–24 years), and clinicians to improve mental health care provided in the Stollery Children's Hospital ED, in Edmonton, Alberta.

1.4. Thesis Outline

This paper-based thesis includes two studies. The outline of the thesis is as follows:

Chapter 1 provides a background summary on mental illness, mental health care in pediatric emergency departments, discharge interventions, patient engagement, and experience-based co-design. An outline of the thesis and objectives is also included.

Chapter 2 presents the manuscript of a scoping review on child, adolescent, and youth mental health engagement in research, which informed my understanding of conducting an experience-based co-design project.

Chapter 3 presents the manuscript of a mixed-method study reporting the process of co-designing and testing pediatric mental health discharge communication interventions.

Chapter 4 provides a summary and discussion of study findings, personal reflections, an overview of study limitations and strengths, and a discussion of the implications of my research, as well as recommendations for future directions of research in this area.

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Chapter 2:

Study 1 – A Scoping Review

Title: Patient engagement in child, adolescent, and youth mental health care research: A scoping review

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2.1. Abstract

Background: Youth and children's lived experiences are rarely considered in studies seeking to improve or evaluate their mental health care. We conducted a scoping review to identify approaches to child, adolescent, and youth engagement in mental health studies as well as study-reported barriers, constraints, and facilitators to engagement.

Method: We systematically searched six electronic databases for literature. We included studies of mental health care service design, development or evaluation that involved engagement of children, adolescents, and/or youth with mental disorders or who intentionally self-harm. Studies could be of any design as long as patient engagement was used at any point during its design and/or conduct. Engagement could include co-designing health services/interventions and/or participating as a co-researcher. We assessed the reporting of patient engagement using the Guidance for Reporting Involvement of Patients and the Public 2 Long-Form (GRIPP2-LF) checklist, and used the experience-based co-design (EBCD) framework to guide data extraction and analysis.

Results: Sixteen articles were included in the review. Most studies used engagement to develop or adapt a mental health service (75%) and utilized a participatory or co-design approach (69%). Participants were namely adolescents and youth (aged 10-24 years) with some studies including young adults (up to 29 years old). Most studies followed less than 50% of the EBCD framework, and the commonly reported study barriers were related to aspects addressed in EBCD: time restrictions, recruitment, and generalizability. Frequently reported study facilitators included study methodology, youth engagement, and having a diverse participant sample.

Conclusions: Findings from this review suggest that the EBCD framework is not commonly used to guide patient engagement in studies of mental health care services. Future initiatives

should consider following the framework to ensure meaningful evaluation and improvements to youth and childrens's mental health care services.

2.2. Introduction

To meaningfully evaluate and improve health care services, health researchers need to involve individuals who use the services in their research (Cooper, Gillmore, & Hogg, 2016). ‘Patient engagement’, also termed ‘patient involvement’, is an active partnership between researchers, health care leaders, and health care service users during the design, conduct, and dissemination of research (Boivin et al., 2018; Crockett et al., 2019; Frank et al., 2015; McCarron et al., 2021), as well as during quality improvement initiatives in health care (Baker et al., 2016; Kim et al., 2018; Morassaei, Campbell, & Di Prospero, 2021). In this partnership, the terms ‘patient’ and ‘patient partner’ refer to engagement with individuals who have personally experienced a health issue, their caregivers, and/or guardians (Patient-Oriented Research Curriculum in Child Health, n.d.).

Patients and patient partners can become meaningfully involved in health care related projects in various ways, such as by acting as project committee members, contributing to question development and co-designing the project’s methods, and helping develop recruitment strategies for under-represented or hard-to-reach populations of health service users (Canadian Institutes of Health Research, 2019; McCarron et al., 2021; Morassaei et al., 2021). Ethical and methodological benefits have been shown to result from engaging health service users in roles such as these. These benefits include improved readability and accessibility of research materials and the inclusion of relevant patient-reported outcomes and experiences and improved recruitment. Such benefits serve to improve a study’s overall quality and potential impact on health care services (McCarron et al., 2021).

Child, adolescent, and youth engagement is an important subset of patient engagement that involves partnerships to address and make decisions about issues that are important to, or affecting children, adolescents, and youth (Bell, 2015; Knowledge Institute on Child and Youth Mental Health and Addictions, n.d.; Mawn et al., 2015). Youth engagement (engagement with individuals aged 15–24 years) (United Nations, n.d.) is more commonplace in research at this time, and has been shown to make research more feasible, easier to implement, and produce results that are more likely to be used and sustained over time (Checkoway & Richards-Schuster, 2003; Hawke et al., 2020). Youth engagement has been reported for a wide range of health research studies with particular inclusion in studies that are community-based (Jacquez, Vaughn, & Wagner, 2013), focused on developing mobile health (mHealth) interventions (Hightow-Weidman et al., 2021), and aimed at improving mental health and substance use interventions (Dunne et al., 2017; Valdez et al., 2020). Across these studies, various frameworks have been used to guide project design and engagement (e.g., participatory action research [PAR], experience-based co-design [EBCD]), and strategies within or outside of guiding frameworks used to promote project involvement and remove constraints to participation (e.g., flexible dates, times, and ways to be involved). As there are currently no formal standards for child, adolescent and youth engagement, the engagement approaches adopted by researchers can vary.

Despite the benefits of patient engagement, there are limited published studies involving children, adolescents, or youth with lived experience with mental disorders in mental health research. This may be due to a lack of information accessible on best practice in involving children, adolescents, and youth in mental health research (Faithfull et al., 2019). It may also be because of a historical minimization and muting of the voices of young people with mental disorders (Kaushik, Kostaki, & Kyriakopoulos, 2016; Mawn et al., 2015; Telesia, Kaushik, & Kyriakopoulos, 2020) rather than seeing value in their lived experience.

Our team was interested in identifying the extent of child, adolescent, and youth engagement in mental health care studies, and in particular, how engagement was fostered throughout a study. A scoping review approach is particularly useful for identifying and mapping the available evidence, as well as for reporting on how research is being conducted (Munn et al., 2018). Using scoping review methodology, our objectives were to: 1) identify the approaches to engagement in studies focused on mental health care design, development or evaluation; 2) summarize study-reported barriers, constraints, and facilitators to engagement and the strategies recommended to overcome or address these issues; and 3) provide recommendations for mental health researchers who want to incorporate patient engagement into the design and conduct of a study.

2.3. Methods

Study Design

The scoping review was conducted using the framework developed by Arksey and O'Malley (2005) with modifications as recommended by Levac, Colquhoun, & O'Brien (2010). We followed five steps of the framework: (1) identify the research question; (2) identify relevant studies; (3) study selection; (4) chart the data; (5) collate, summarize, and report results. Reporting of the review adheres to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis: extension for Scoping Reviews (PRISMA-ScR) checklist (Tricco et al., 2018).

Search Strategy

We developed and executed the search strategy in collaboration with a health sciences librarian. Six databases were searched: Ovid Medline ALL, Embase (Ovid Interface), APA PsycINFO (Ovid interface), CINAHL Plus with Full Text (EBSCOhost interface), Scopus, and ProQuest Theses and Dissertations Global. The search combined subject headings (where possible) and keywords for mental disorders and co-design of research. The search strategy was adapted for each database for optimal performance. The strategy was not limited by study design but was limited to English language studies published from January 2005 to June 2021, as 2005 was the year that publications began to appear in patient engagement and EBCD in mental health research. The reference lists of any review articles that were identified by the search strategy were reviewed to identify additional relevant studies. The search strategy for Medline is provided in Table S2.1.

Criteria for Including Studies in the Review

We included primary studies of mental health care focused on mental health care design, development or evaluation. To be included in this review, studies could be of any design (e.g., qualitative, PAR, quantitative) as long as patient engagement was used at any point during its design and/or conduct. Engagement could include co-designing health services/interventions and/or participating as a co-researcher (e.g., actively collaborating in study governance, knowledge translation, overseeing the conduct of different stages of a study). Patient engagement needed to involve children (aged < 10 years), adolescents (aged 10–19 years), and/or youth (aged 15–24 years) with mental disorders or who intentionally self-harm (lived experience). Studies that included participants over the youth age cut-off were included if the study was focused on youth mental health care (e.g., a study involving participants aged 15–25 years with a focus on improving mental health services for youth). We included studies that did not report an age range if age could be ascertained by the terminology used to describe participants (e.g., use of the term ‘youth). Any studies that did not meet these criteria were excluded. We also excluded studies that focused on improving quality of life for children, youth or young people, but did not involve studying mental health care for mental disorders. Studies focused on health care for neurodevelopmental disorders were also excluded.

Screening for Eligibility

We organized and screened the search results using Covidence systematic review software. Three reviewers (authors AZA, ASN, and BW) independently screened titles and abstracts, classifying the relevancy of each as ‘yes’ ‘maybe’ or ‘no’ using the pre-determined inclusion and exclusion criteria. The full text of studies assessed as relevant or maybe relevant were independently evaluated by three reviewers (authors AZA, ASN, and BW). Any discrepancies in screening decisions were resolved by consensus between the reviewers. For full text studies not accessible online, we contacted primary authors to inquire if full text information was available through them.

Data Extraction

We used the EBCD framework (Bate & Robert, 2007; Point of Care Foundation, 2020) to guide data extraction. This framework is based on four domains—participatory action research, user-centered design, learning theory, and narrative-based approaches to change (Locock et al., 2014). It has six stages that can be adapted or modified to suit individual project resources and needs (Point of Care Foundation, 2020).While the framework has been traditionally used to evaluate and improve health care services through direct patient engagement (Cooper et al., 2016; Kynoch & Ramis, 2019), we used the framework to guide how we understood the process and strategies that were used in mental health care studies involving patient engagement. An outline of the framework is presented in Table 2.1.

Data were extracted using standardized forms, entered into Excel by one reviewer (author AZA), and verified for accuracy and completeness by two reviewers (authors ASN and BW).

Discrepancies were resolved via consensus by reviewers (authors AZA, ASN, and BW). Extracted data included study and population characteristics, descriptions of patient and public involvement strategies, identified barriers (issues that could not be overcome), constraints (issues that could be overcome) and facilitators to patient engagement, and strategies recommended to overcome constraints encountered. Data regarding use of the EBCD steps were extracted using the EBCD framework.

Table 2.1. The six-stage experience-based co-design (EBCD) framework (Bate & Robert, 2007; Point of Care Foundation, 2020)

EBCD Stage	**Steps**
Stage 1: Project set-up and observations	• Set up project steering group and recruit facilitator • Pick aspects of the service that are practical to observe and observe patient experience to achieve insight on how the service works and the perspectives of staff and patients. • Identify and invite suitable patients and staff to participate in the project
Stage 2: Engage staff and gather experiences	• Interview variety of staff regarding their experiences of working within the mental health service of concern • Transcribe and thematically analyze staff interviews • Host joint staff meeting to review themes discovered from staff interviews and identify priorities of staff for service improvements.
Stage 3: Engage patients/carers and gather experiences	• Interview patients and potentially guardians • Ask patients to identify key touch points (crucial moments – good and bad – that shape a patient's overall experience) in interview • Produce a 35-minute trigger film* which represents all the key touch points
Stage 4: Joint co-design event	• Host joint meeting involving the patients and staff and view the trigger film together • Identify three to four target areas for service improvement
Stage 5: Make the changes	• Create co-design groups of patients and staff to design and implement solutions to target areas identified in stage 4
Stage 6: Celebrate and review	• Measure resulting service improvements • Host celebration event for everyone involved to thank participants and report back on achievements

*Trigger films are short films created from the video recordings of patient interviews, focusing on highlighting the emotional touchpoints that were discussed by patients.

Study Reporting of Patient Engagement

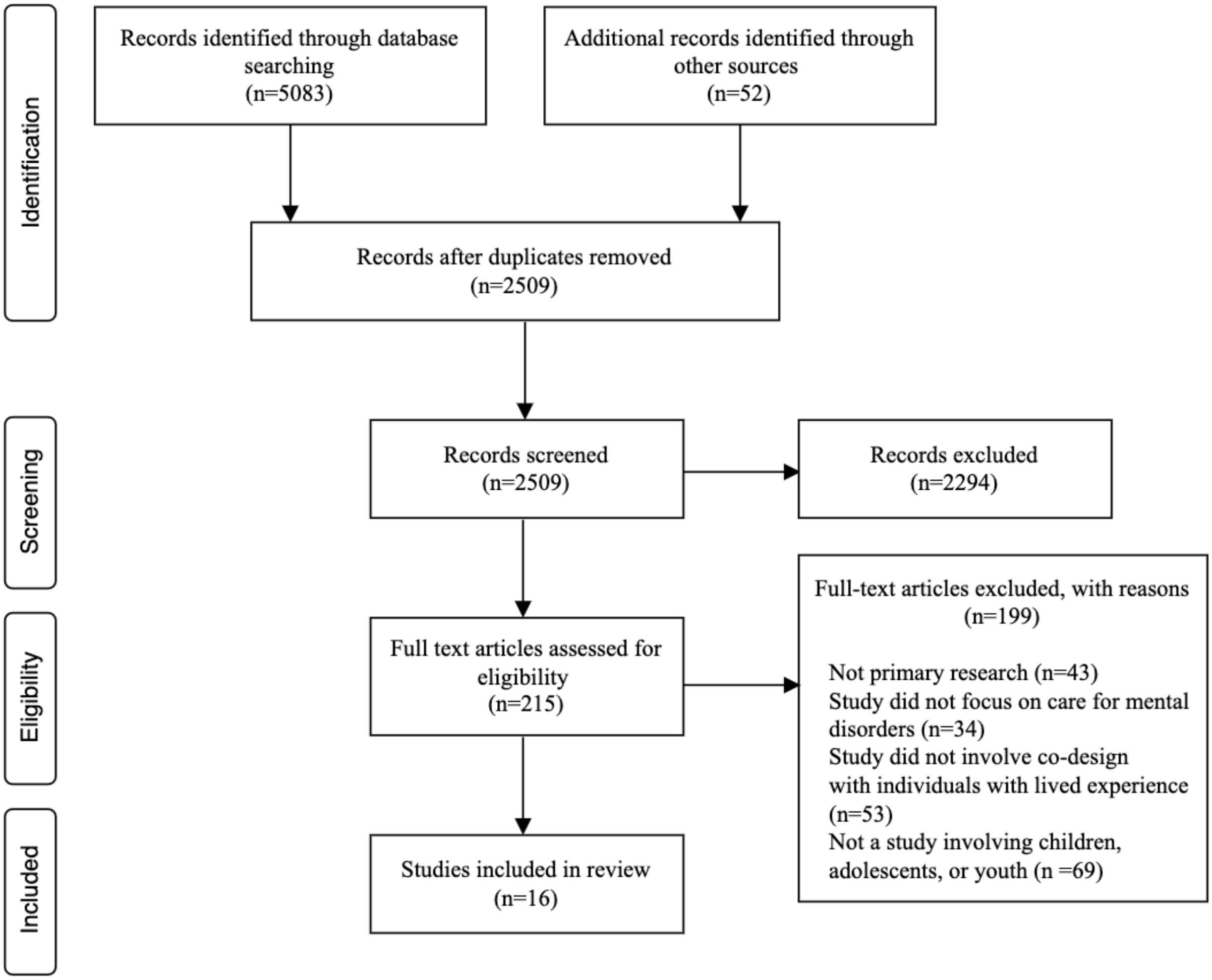
The reporting of patient engagement in studies was assessed using the Guidance for Reporting Involvement of Patients and the Public 2 Long-Form (GRIPP2-LF) checklist (Staniszewska et al., 2017). For each study, we looked for the report of items under the key domains of the GRIPP2-LF checklist (Abstract, Background, Aims, Methods, Capture/Measurement of Patient and Public Involvement (PPI) Impact, Economic Assessment, Study Results). The use of this adapted checklist was important because it provided us with a standardized way to understand patient engagement across a range of studies in child, adolescent, and youth mental health research.

2.4. Results

Literature Search and Selection

The search strategy identified 5,083 articles. Of these articles, 215 remained after title and abstract screening (Figure 2.1). After full-text review, 16 articles met eligibility criteria and were included in the review (Aggarwal et al., 2021; Alderson et al., 2019; Cheng et al., 2021; Cleverley, Lenters, & McCann, 2020; Cwik et al., 2016; Dewa et al., 2019; Dunn, 2017; Graham et al., 2014; Hackett, Mulvale, & Miatello, 2018; Hetrick et al., 2018; Onnela et al., 2014; Ospina-Pinillos et al., 2018, 2019; Realpe et al., 2020; Sundram et al., 2017; Thummathai et al., 2018).

Figure 2.1. Flow diagram depicting study selection for the review



Description of Included Studies

The characteristics of the 16 included studies are presented in Table 2.2. Over half of the studies were conducted in England (31.3%) or Australia (25%), and all studies were published in 2014 or later. The majority of studies involved a qualitative design (n=11; 68.8%), with the remaining studies involving a mixed-method approach. Seven studies (43.8%) did not report the setting in which engagement activities were conducted. Of the studies that reported on setting, most activities were conducted in mental health care settings where individuals were receiving services. All studies involved individuals with a previous history of a mental health disorder or lived experience. The age range of individuals involved in patient engagement activities varied between studies with seven studies involving adolescents and youth (aged 10–24 years) and six studies involving youth and some young adults (age range 16–29 years). No studies involved children. The age range of participants was not reported in three studies. Only 25% of studies (n=4) included information regarding the race or ethnicity of individuals.

Table 2.2. An overview of study features

First author Study design (year, country)	Aim	Setting	Participants	Lived experiences of child, adolescent, and youth participants		
				Age range, years	Experience	Race/ ethnicity
Aggarwal mixed method (2021, India)	Determine contents and delivery approach for a self-harm intervention	Mental health service	24 youth, 4 caregivers, 10 health care providers	15–24	Self-harm attempt	NR
Cheng qualitative (2021, Australia)	Develop recommendations for mental health information technology	Mental health service	75 youth, 7 youth support persons, 21 health care providers	12–25	Mental health service user	NR
Realpe qualitative (2020, England)	Adapt and design a virtual-based intervention for psychosis	NR	20 youth	NR	Mental health service user	NR
Cleverley qualitative (2020, Canada)	Identify expectations and experiences with mental health service transitions	Mental health services	2 youth co-researchers, 21 youth participants	16–19	Mental health service user	Caucasian (62%)
Ospina-Pinillos mixed method (2019, Australia)	Design and culturally adapt and test the MheC	NR	10 young people, 7 health care providers	17–29	Mental health service user	2 Chilean, 8 Colombian
Dewa qualitative (2019, England)	Explore acceptability and feasibility of wearables, social media and other technologies	Mental health service	7 youth co-researchers, 16 youth participants	18–25	Mental health difficulties or diagnosed disorder	Co-researchers:1 Asian, 1 Black, 5 Caucasian
Alderson qualitative (2019, England)	Adapt two substance abuse interventions	NR	32 adolescents, 17 caregivers, 15 health care providers	12–20	Current or previous substance abuse	NR

Hackett qualitative (2018, Canada)	Develop quality indicator tool to improve service experiences	NR	36 youth, 22 caregivers, 24 health care providers	16–24	Mental health service user	NR
Hetrick qualitative (2018, Australia)	Codesign an app for self-monitoring of mood	Mental health services	11 youth, 16 health care providers	18–25	Mental health service user	NR
Ospina-Pinillos mixed method (2018, Australia)	Develop a Web-based mental health clinic	Mental health service	23 youth, 14 health care providers	16–25	Mental health service user	NR
Thummathai qualitative (2018, Thailand)	Develop a depression risk assessment tool	NR	20 adolescents, 3 parents, 7 teachers	10–14	Depressive experiences	NR
Sundram qualitative (2017, New Zealand)	Develop and implement an electronic monitoring tool for depression in primary care settings	Mental health services and schools	29 adolescents, 50 health care providers	12–19	Mental health service user	NR
Dunn qualitative (2017, England)	Co-produce a mental health service transition preparation programme	Mental health foundation trust	17 youth, 30 health care providers	17–22	Had transitioned, or were approaching transition, from child and adolescent mental health services	NR
Cwik mixed method (2016, United States)	Adapt a suicide intervention for American Indian adolescents	NR	NR for youth, caregivers, health care providers	NR	Suicide attempt	NR
Onnela qualitative (2014, Finland)	Develop a professional practice model for mental health interventions in schools	NR	NR for students, caregivers, school staff, health care providers	NR	NR	NR

Graham mixed method (2014, England)	Develop user-generated quality standards for mental health problems in primary care	College, University, Research Institute, Hostel	12 youth co-researchers, 50 youth participants	16–25	Sought help for a mental health problem within the last 5 years or self-reported mental health problems	Youth participants (percent unknown): Black, Caucasian, Indian, Irish, Pakistani, Bangladeshi, Spanish, Kosovan, Guyanese, Burmese

MheC: Mental health eClinic; NR: not reported

Study Reporting of Patient Engagement

The findings from the GRIPP assessment of patient engagement in research are presented in Table S2.2. Half of the studies in this review reported the definition used for patient involvement (Cheng et al., 2021; Dunn, 2017; Hackett et al., 2018; Onnela et al., 2014; Ospina-Pinillos et al., 2018, 2019; Realpe et al., 2020; Thummathai et al., 2018). Almost all studies reported in detail the methods of patient involvement (n=15; 93.8%) (Aggarwal et al., 2021; Alderson et al., 2019; Cheng et al., 2021; Cleverley et al., 2020; Dewa et al., 2019; Dunn, 2017; Graham et al., 2014; Hackett et al., 2018; Hetrick et al., 2018; Onnela et al., 2014; Ospina-Pinillos et al., 2018, 2019; Realpe et al., 2020; Sundram et al., 2017; Thummathai et al., 2018), including who was involved, and the stages and nature of involvement.

Of the studies included in this review, only one study reported explicitly measuring the impact of patient involvement (Dunn, 2017). None of the studies conducted an economic assessment of engagement, which would have involved reporting information on the costs and/or benefits of involvement. Contextual or process factors that enabled or hindered the process of patient involvement were discussed in 46.7% of studies (Alderson et al., 2019; Cheng et al., 2021; Cleverley et al., 2020; Dewa et al., 2019; Dunn, 2017; Hetrick et al., 2018; Realpe et al., 2020). All of the studies reported the outcomes of patient involvement, discussing how it influenced the study. As well, 75% of the studies identified and/or discussed the positive and/or negative impacts that patient involvement had on the study (Alderson et al., 2019; Cwik et al., 2016; Dunn, 2017; Graham et al., 2014; Hackett et al., 2018; Hetrick et al., 2018; Onnela et al., 2014; Ospina-Pinillos et al., 2018, 2019; Realpe et al., 2020; Sundram et al., 2017; Thummathai et al., 2018). Lastly, all of the studies commented critically on the study, reflecting on things that went well and those that did not.

Study Approaches to Patient Engagement

Table 2.3 presents details on the patient engagement approaches used in the studies. The majority of studies (n=11; 68.8%) used a participatory design or co-design approach; the EBCD framework was followed in one study. Most studies (n=9; 56.3%) used more than one method to engage adolescents and youth. The predominant strategies used were interviews, workshops, and focus groups. All the studies involved adolescents or youth with 43.8% of studies (n=7) also involving caregivers, and health care providers. Compensation for study participation was not commonly reported, with only 31.2% of studies (n=5) reporting compensation using gift cards or cash. Of these studies, less than half (n=2; 40%) reported how much compensation was given.

Table 2.3. An overview of each study's patient engagement approach

First Author	Patient engagement strategy		
	Framework	**Approach to engagement**	**Compensation**
Aggarwal	Co-design	Interviews, workshops	NR
Alderson	Co-design	Interviews, focus groups, workshops	NR
Cheng	Participatory design	Workshops	Gift card ($23 USD)
Cleverley	Participatory action research	Co-research role, interviews	NR
Cwik	Participatory action research	Focus groups	NR
Dewa	Co-design	Co-research role, interviews	NR
Dunn	Participatory design	Workshops	NR
Graham	Participatory design	Interviews, focus groups	Paid (value NR)
Hackett	Experience-based co-design	Interviews, focus groups, mobile app	NR
Hetrick	Participatory design	Focus groups, workshops	Paid ($30/hour AUS)
Onnela	Participatory action research	Workshops	NR
Ospina-Pinillos (2018)	Participatory design	Workshops	Gift card (value NR) + reimbursement for travel-related expenses
Ospina-Pinillos (2019)	Participatory design	Workshops	Gift card (value NR)
Realpe	Co-design	Focus Groups, Workshops	NR
Sundram	Co-design	Focus Groups	NR
Thummathai	Participatory action research	Interviews, Focus Groups	NR

AUS: Australian dollars; NR: not reported; USD: United States dollars

Barriers, Constraints and Facilitators to Patient Engagement, and Recommended Strategies to Address them

Facilitators

Nine studies identified facilitators of patient engagement with facilitators varying between studies. Two studies credited study methodology for helping engage participants and enhancing the generation of ideas (Hackett et al., 2018; Ospina-Pinillos et al., 2019). Another two studies identified youth engagement as a facilitator of research relevancy and data integrity (Cleverley et al., 2020; Dewa et al., 2019), and three studies identified a diverse participant sample as also being a facilitator (Aggarwal et al., 2021; Dewa et al., 2019; Graham et al., 2014). To facilitate participation, one study held multiple workshops at different sites and conducted workshops in familiar environments (Alderson et al., 2019), while a workshop facilitator was used in another study (Cheng et al., 2021). Ensuring time to build trust and rapport with youth co-researchers was identified as a facilitator to participation in one study (Dewa et al., 2019). Facilitators reported during data collection included using different methods to gather data and having a workshop facilitator (Alderson et al., 2019; Dunn, 2017).

Barriers and Constraints

Of the 16 included studies, 11 identified barriers/constraints to patient engagement. The constraints most commonly reported in studies related to recruitment (Alderson et al., 2019; Cheng et al., 2021; Graham et al., 2014) and small number of participants or under representation, which may limit applicability of study findings to other adolescents and youth (Dewa et al., 2019; Dunn, 2017; Ospina-Pinillos et al., 2018; Realpe et al., 2020; Thummathai et al., 2018). Depending on the study context, recruitment and participant involvement may be barriers (e.g., there are limited numbers of children, adolescents, and/or youth with lived experience that can participate) or a constraint (e.g., study inclusion criteria is narrow allowing only certain children, adolescents, and/or youth to participate). In one study, the limited number of youth was reported as restricting engagement activities (Dunn, 2017), while in another study it was felt to limit input throughout the design process (Realpe et al., 2020). Issues that were reported to impact youth participation included stigma around mental health (Hetrick et al., 2018), power imbalances between participants (youth, caregivers, and health care providers) (Cheng et al., 2021), and the location of activities (Cleverley et al., 2020). Time constraints were described as limiting prolonged engagement (e.g., during all parts of the design process) (Cleverley et al., 2020; Sundram et al., 2017), and time-consuming governance and engagement procedures were felt to impact study progress (Dunn, 2017; Graham et al., 2014). Other barriers that were reported included difficulty managing youth expectations of project outcomes (Graham et al., 2014), and not being able to verify data interpretations with adolescents (Sundram et al., 2017).

Strategies Used/Recommended to Overcome Constraints

Twelve studies reported constraints, with four recommending strategies to overcome them. To address issues of recruitment and generalizability, the authors of one study suggested expanding the eligibility criteria for those who could engage in the study (Alderson et al., 2019), while another author group suggested recruiting specifically from populations of interest (Cheng et al., 2021). Strategies recommended to increase participation included conducting interviews outside of mental health settings (Cleverley et al., 2020), and providing adequate support to participants to ensure comfort in communication (Cheng et al., 2021).

Alignment with the EBCD Framework

The extent to which studies used engagement strategies from the six stages of the EBCD framework is presented in Table 2.4. Overall, none of the studies incorporated all 6 stages of the EBCD framework. One study incorporated 64% of EBCD components across the 6 stages (Hackett et al., 2018), with all other studies incorporating less than 60% of components.

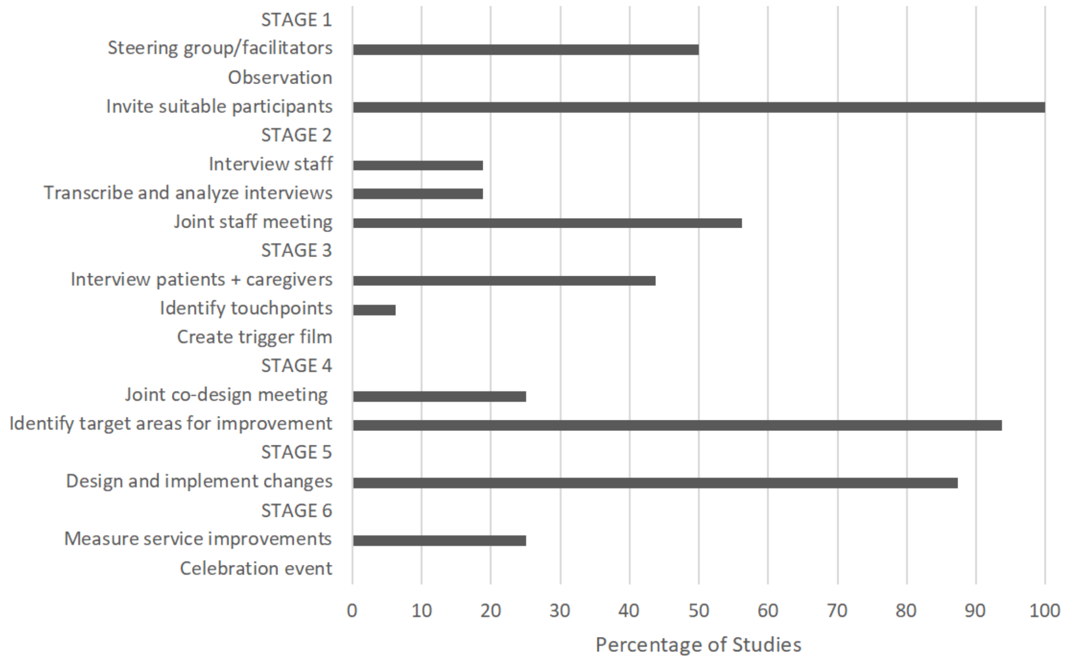
Table 2.4. Study use of the components of EBCD stages

Author(s)	Stage 1			Stage 2			Stage 3			Stage 4		Stage 5	Stage 6		% included
	Steering group/facilitator	Observation	Invite suitable participants	Interview staff	Transcribe and analyse interviews	Joint staff meeting	Interview patients + caregivers	Identify touchpoints	Create trigger film	Joint co-design meeting	Identify target areas for improvement	Design and implement changes	Measure service improvements	Celebration event	
Hackett	✓		✓	✓	✓		✓	✓		✓	✓	✓			64%
Thummathai	✓		✓	✓	✓	✓	✓				✓	✓			57%
Alderson			✓	✓	✓	✓	✓				✓	✓			50%
Onnela	✓		✓			✓				✓	✓	✓			43%
Ospina-Pinillos (2018)	✓		✓			✓				✓	✓	✓			43%
Sundram	✓		✓			✓					✓	✓	✓		43%
Aggarwal			✓			✓	✓				✓	✓			36%
Cheng	✓		✓							✓	✓	✓			36%
Dunn	✓		✓			✓					✓	✓			36%
Graham	✓		✓				✓				✓	✓			36%
Ospina-Pinillos (2019)			✓			✓					✓	✓	✓		36%
Cwik			✓								✓	✓	✓		29%
Hetrick			✓			✓					✓	✓			29%

Realpe			✓								✓	✓	✓		29%
Cleverley			✓				✓				✓				21%
Dewa			✓				✓								14%

The overall percentage of studies that incorporated each component in each stage of the EBCD process is presented in Figure 2.2. The components omitted in all studies were observation (Stage 1), co-creating and viewing a trigger film (Stage 3), and a celebration event (Stage 6). Inviting suitable participants (Stage 1) was the only component that was incorporated in all studies. Other commonly incorporated components were identifying target areas for improvement (93.8% of studies), designing and implementing changes (87.5% of studies), engaging staff in a joint meeting (56.3% of studies), and including a steering group or facilitator (50% of studies). All other components were incorporated in less than 50% of studies.

Figure 2.2. Percentage of studies that included components from each stage of the EBCD framework



2.5. Discussion

In this scoping review, our use of the GRIPP2 checklist and EBCD framework allowed us to comprehensively examine how researchers have approached patient engagement with children, adolescents, and youth in studies of mental health care design, development, and evaluation. We found that: 1) while most studies reported in detail the methods of patient involvement, they did not capture or measure the impact of patient involvement in research; 2) key engagement issues identified by research teams related to recruitment, time restrictions, and small numbers of participants or under representation; and 3) most studies used less than 50% of the engagement strategies outlined in the EBCD framework, and only one study used the framework to guide study design and conduct. However, this framework may help to prevent or mitigate patient engagement issues highlighted by research teams.

Our use of the GRIPP2 checklist provides a unique, but important perspective related to how engagement with children, adolescents, and youth is reported in mental health studies. We found that most studies consistently reported details of the methods used for engagement, but only one study reported capturing or measuring the impact of engagement on the research process or outcomes. This finding is consistent with previous literature which highlights the lack of robust evidence that currently exists on the impact of patient involvement in research (Staley, 2015; Staniszewska et al., 2011). It is essential to assess how well child, adolescent and youth engagement is being incorporated into studies, and the influence this engagement has on mental health research outcomes. Not doing so undermines the purpose of engaging with these young people. Robust measurement of the extent of patient engagement impact could also provide more information to understand what works in patient engagement and for whom. It is especially important to demonstrate the impact of engagement considering the extra time and funding that is required to support and facilitate patient engagement (Domecq et al., 2014), as health researchers and health care decision-makers may be more receptive to meaningfully engaging patients if the benefits will outweigh the potential costs. In future mental health care research, qualitative and/or quantitative instruments for assessing the impact of patient involvement should be developed, or existing frameworks should be utilized and reported in detail, such as the Public Involvement Impact Assessment Framework (PiiAF) (Popay, Collins, & PiiAF Study Group, 2014). This framework was created to assist researchers in developing a plan to assess the impact of public involvement in research.

To date, use of the EBCD framework to guide and support patient engagement has largely been restricted in health care settings to promote collaboration and consultation around health service design (Fucile et al., 2017). EBCD is considered a best practice for leading improvements in health care (Fucile et al., 2017). Only one study in our review followed this framework. Our use of the framework to understand patient engagement activities is based on the perspective that activities that promote EBCD may mitigate or remove constraints to patient engagement as well as improve the quality of mental health research being conducted and reduce stigma for children, adolescents, and youth by valuing their lived experience (Vojtila et al., 2021).

In this review, we found that the steps of the EBCD framework or its activities were not commonly utilized to conduct research in mental health care. Without a framework to guide child, adolescent and youth engagement, uncertainty on why and how to involve them (and their caregivers) could lead to tokenistic engagement and engagement that does not consider the child/adolescent/youth’s needs and preferences (Ocloo & Matthews, 2016). The EBCD framework can limit tokenism by ensuring involvement in all stages of the research and bringing together patients and health care professionals as active partners in a co-design event, a central tenant of the EBCD approach (Gustavsson & Andersson, 2019). While we found that most studies did engage both patients and mental health care providers, the majority of studies did not bring participants together in a co-design meeting. This meeting is considered an essential component to sustaining the changes that are made through co-design, as health care providers and patients may have different perspectives on how to improve care. By allowing health care providers and patients to collectively select target areas for improvement, it is more likely that the resulting changes to care will be realistic and sustainable over time.

A novel contribution from this review relates to our synthesis of study-reported barriers, constraints, and facilitators to engagement. While patient engagement in mental health research has been reviewed before (Mulvale et al., 2016), these important factors relating study conduct and quality have not been reviewed to date. Knowledge of these aspects are essential, however, to improve the quality of mental health research conducted—researchers can use this information to plan for, and better navigate, engagement obstacles, including making contingency plans prior to commencing a study.

In our review, research teams leading the studies most commonly reported recruitment, time restrictions, and small numbers of participants as key barriers and constraints to patient engagement. The EBCD framework provides a structured approach to patient engagement that can reduce uncertainty during the research process and promote efficient and effective use of time and resources. For example, none of the teams from the studies in our review mentioned observing patient experiences prior to beginning research. This activity is critical in the EBCD framework because it gives researchers the opportunity to meet, and learn from, individuals with lived experience (Point of Care Foundation, 2020). This activity may help prevent recruitment issues by providing researchers the opportunity to understand the needs and preferences of potential participants. As qualitative studies often have small numbers of participants, it is critical to recruit a representative sample of participants and report in detail participant characteristics to allow readers to make decisions regarding transferability. Additionally, the EBCD framework is flexible; researchers can adjust stages when needed due to time or resource constraints. Another option is to utilize the accelerated EBCD approach, in which pre-existing patient interviews are used to create the trigger film. Accelerated EBCD allows researchers to save time by not having to conduct and film new patient interviews. This approach significantly decreases the time and budget required to incorporate EBCD into projects, while still generating comparable engagement activities (Locock et al., 2014).

2.6. Limitations

This review has several limitations. First, various terms are used in the published literature to describe the involvement of children, adolescents, and youth mental health service users in research. This includes patient engagement, partners, co-design, patient involvement, etc. There are also various definitions of these terms, which can lead to multiple interpretations. Although we tried to include as many terms as possible in our search, due to the ambiguity in terms and definitions used in studies, and the evolution of patient engagement over the last decade, our search was likely not able to capture all mental health care studies that involved children, adolescents or youth in a co-design or engagement role. Additionally, the terms 'patient engagement and 'patient and public involvement' are often used interchangeably in the literature. In this review, we chose to use the term 'patient engagement', as we only included studies that engaged patients with lived experience, and this terminology is more commonly used in the medical literature. Second, it was challenging to synthesize a body of research based on different approaches taken to patient engagement. However, our use of the GRIPP2 checklist and the EBCD framework allowed us to look for commonalities and differences and better understand how researchers approached patient engagement in research. Third, we did not search grey literature in this review and therefore review findings may not fully reflect the nature of child, adolescent and youth engagement in mental health research including quality improvement initiative reports. Finally, we limited our search to English language studies only, and those recently published (post 2005). It is possible that if we did not have these limitations and also searched the grey literature, additional studies may have been identified.

2.7. Conclusions

Child, adolescent, and youth engagement in mental health research is an evolving approach that has the potential to make studies of mental health care easier to implement, and produce higher quality, sustainable results. In this review, we found that the stages or strategies from the EBCD framework were not commonly used to engage adolescents and youth in mental health care research. However, use of this framework may help to address constraints to engagement and ensure that a tokenistic approach to engagement is not used. Lastly, the impact of patient involvement in research was rarely reported, but should be a standard component of any mental health care study involving patient engagement.

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Supplementary Content

Table S2.1. Detailed search strategy for MEDLINEI conducted on June 15, 2021.

1	Mental Health/
2	mental disorders/ or exp anxiety disorders/ or exp “bipolar and related disorders”/ or exp “disruptive, impulse control, and conduct disorders”/ or exp dissociative disorders/ or anorexia nervosa/ or binge-eating disorder/ or bulimia nervosa/ or food addiction/ or exp mood disorders/ or exp motor disorders/ or anxiety, separation/ or “attention deficit and disruptive behavior disorders”/ or child behavior disorders/ or mutism/ or reactive attachment disorder/ or schizophrenia, childhood/ or stereotypic movement disorder/ or tic disorders/ or exp neurotic disorders/ or exp paraphilic disorders/ or exp personality disorders/ or exp “schizophrenia spectrum and other psychotic disorders”/ or exp somatoform disorders/ or exp substance-related disorders/ or exp “trauma and stressor related disorders”/
3	(mental health or mental wellness or mental* ill* or psychiatric* or depression or depressive or anxiety disorder* or psychoses or psychosis or psychotic* or 51uicide* or compulsive disorder* or OCD or bipolar or mania or adjustment disorder* or traumatic stress or panic disorder* or mood disorder* or ptsd or ptsi or intellectual* disab* or ((stimulant* or substance* or opioid* or marijuana or cannabis or cocaine or heroin or illicit-drug* or fentanyl) adj3 (“use” or user* or usage or abuse* or misuse* or addict*))).mp
4	1 or 2 or 3
5	(co-design* or co-creation or co-production or coproduction or codesign* or experience based design* or EBCD or participatory action research or ((patient engagement or patient involvement or PPI or public involvement) adj6 (research or study or trial))).mp.
6	4 and 5
7	limit 6 to yr=”2005 -Current”

Table S2.2. Assessment of study reporting of components included in each study using the Guidance for Reporting Involvement of Patients and the Public Long-Form (GRIPP2-LF) checklist.

Author and Year	**1. ABSTRACT**	**2. BACKGROUND**	**3. AIMS**	**4. METHODS**	**5. CAPTURE OR MEASUREMENT OF PPI IMPACT**	**6. ECONOMIC ASSESSMENT**	**7. STUDY RESULTS**	**8. DISCUSSION & CONCLUSIONS**
Aggarwal et al. (2021)	1a: Aim ✓ 1b: Methods ✓ 1c: Results ✓ 1d: Conclusions ✓ 1e: Keywords ✗	2a: Definition ✗ 2b: Theoretical underpinnings ✗ 2c: Concepts and theory development ✓	✓	4a: Design ✓ 4b: People involved ✓ 4c: Stages of involvement ✓ 4d: Level or nature of involvement ✓	5a: Qualitative evidence of impact ✗ 5b: Quantitative evidence of impact ✗ 5c: Robustness of measure ✗	✗	7a: Outcomes of PPI ✓ 7b: Impacts of PPI ✗ 7c: Context of PPI ✗ 7d: Process of PPI ✗ 7e: Theory development ✗ 7f: Measurement ✗ 7g: Economic assessment ✗	8a: Outcomes ✓ 8b: Impacts ✗ 8c: Definition ✗ 8d: Theoretical underpinnings ✗ 8e: Context ✗ 8f: Process ✗ 8g: Measurement and capture of PPI impact ✗ 8h: Economic Assessment ✗ 8i: Reflections/critical perspective ✓
Alderson et al. (2019)	1a: Aim ✓ 1b: Methods ✓ 1c: Results ✓ 1d: Conclusions ✓ 1e: Keywords ✗	2a: Definition ✗ 2b: Theoretical underpinnings ✗ 2c: Concepts and theory development ✗	✓	4a: Design ✓ 4b: People involved ✓ 4c: Stages of involvement ✓ 4d: Level or nature of involvement ✓	5a: Qualitative evidence of impact ✗ 5b: Quantitative evidence of impact ✗ 5c: Robustness of measure ✗	✗	7a: Outcomes of PPI ✓ 7b: Impacts of PPI ✓ 7c: Context of PPI ✓ 7d: Process of PPI ✗ 7e: Theory development ✗ 7f: Measurement	8a: Outcomes ✓ 8b: Impacts ✓ 8c: Definition ✗ 8d: Theoretical underpinnings ✗ 8e: Context ✗ 8f: Process ✗ 8g: Measurement and capture of PPI impact ✗ 8h: Economic Assessment ✗ 8i:

							✗ 7g: Economic assessment ✗	Reflections/critical perspective ✓
Cheng et al. (2021)	1a: Aim ✓ 1b: Methods ✓ 1c: Results ✓ 1d: Conclusions ✓ 1e: Keywords ✗	2a: Definition ✓ 2b: Theoretical underpinnings ✗ 2c: Concepts and theory development ✓	✓	4a: Design ✓ 4b: People involved ✓ 4c: Stages of involvement ✗ 4d: Level or nature of involvement ✓	5a: Qualitative evidence of impact ✗ 5b: Quantitative evidence of impact ✗ 5c: Robustness of measure ✗	✗	7a: Outcomes of PPI ✓ 7b: Impacts of PPI ✗ 7c: Context of PPI ✗ 7d: Process of PPI ✗ 7e: Theory development ✗ 7f: Measurement ✗ 7g: Economic assessment ✓	8a: Outcomes ✓ 8b: Impacts ✗ 8c: Definition ✗ 8d: Theoretical underpinnings ✗ 8e: Context ✓ 8f: Process ✓ 8g: Measurement and capture of PPI impact ✗ 8h: Economic Assessment ✗ 8i: Reflections/critical perspective ✓
Cleverley et al. (2020)	1a: Aim ✓ 1b: Methods ✓ 1c: Results ✓ 1d: Conclusions ✓ 1e: Keywords ✓	2a: Definition ✗ 2b: Theoretical underpinnings ✗ 2c: Concepts and theory development ✗	✓	4a: Design ✓ 4b: People involved ✓ 4c: Stages of involvement ✓ 4d: Level or nature of involvement ✓	5a: Qualitative evidence of impact ✗ 5b: Quantitative evidence of impact ✗ 5c: Robustness of measure ✗	✗	7a: Outcomes of PPI ✓ 7b: Impacts of PPI ✗ 7c: Context of PPI ✗ 7d: Process of PPI ✗ 7e: Theory development ✗ 7f: Measurement ✗ 7g: Economic assessment ✗	8a: Outcomes ✓ 8b: Impacts ✗ 8c: Definition ✗ 8d: Theoretical underpinnings ✗ 8e: Context ✓ 8f: Process ✓ 8g: Measurement and capture of PPI impact ✗ 8h: Economic Assessment ✗ 8i: Reflections/critical perspective ✓
Cwik et al. (2016)	1a: Aim ✓ 1b: Methods	2a: Definition ✗ 2b: Theoretical	✓	4a: Design ✓	5a: Qualitative evidence of impact ✗	✗	7a: Outcomes of PPI ✓	8a: Outcomes ✓ 8b: Impacts ✗

	✓ 1c: Results ✓ 1d: Conclusions ✓ 1e: Keywords ✗	underpinnings ✗ 2c: Concepts and theory development ✓		4b: People involved ✗ 4c: Stages of involvement ✗ 4d: Level or nature of involvement ✗	5b: Quantitative evidence of impact ✗ 5c: Robustness of measure ✗		7b: Impacts of PPI ✓ 7c: Context of PPI ✗ 7d: Process of PPI ✗ 7e: Theory development ✗ 7f: Measurement ✗ 7g: Economic assessment ✗	8c: Definition ✗ 8d: Theoretical underpinnings ✗ 8e: Context ✗ 8f: Process ✗ 8g: Measurement and capture of PPI impact ✗ 8h: Economic Assessment ✗ 8i: Reflections/critical perspective ✓
Dewa et al. (2019)	1a: Aim ✓ 1b: Methods ✓ 1c: Results ✓ 1d: Conclusions ✓ 1e: Keywords ✗	2a: Definition ✗ 2b: Theoretical underpinnings ✗ 2c: Concepts and theory development ✓	✓	4a: Design ✓ 4b: People involved ✓ 4c: Stages of involvement ✓ 4d: Level or nature of involvement ✓	5a: Qualitative evidence of impact ✗ 5b: Quantitative evidence of impact ✗ 5c: Robustness of measure ✗	✗	7a: Outcomes of PPI ✓ 7b: Impacts of PPI ✗ 7c: Context of PPI ✗ 7d: Process of PPI ✗ 7e: Theory development ✗ 7f: Measurement ✗ 7g: Economic assessment ✗	8a: Outcomes ✓ 8b: Impacts ✗ 8c: Definition ✗ 8d: Theoretical underpinnings ✗ 8e: Context ✓ 8f: Process ✓ 8g: Measurement and capture of PPI impact ✗ 8h: Economic Assessment ✓ 8i: Reflections/critical perspective ✓
Dunn (2017)	1a: Aim ✓ 1b: Methods ✓ 1c: Results ✓ 1d: Conclusions ✓	2a: Definition ✓ 2b: Theoretical underpinnings ✗ 2c: Concepts and theory development ✓	✓	4a: Design ✓ 4b: People involved ✓ 4c: Stages of involvement ✓	5a: Qualitative evidence of impact ✓ 5b: Quantitative evidence of impact ✗ 5c: Robustness of measure ✗	✗	7a: Outcomes of PPI ✓ 7b: Impacts of PPI ✓ 7c: Context of PPI ✗ 7d: Process of	8a: Outcomes ✓ 8b: Impacts ✓ 8c: Definition ✗ 8d: Theoretical underpinnings ✗ 8e: Context ✓ 8f: Process ✓

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Graham et al. (2014)	1a: Aim ✓ 1b: Methods ✓ 1c: Results ✓ 1d: Conclusions ✓ 1e: Keywords ✗	2a: Definition ✗ 2b: Theoretical underpinnings ✗ 2c: Concepts and theory development ✓	✓	4a: Design ✓ 4b: People involved ✓ 4c: Stages of involvement ✓ 4d: Level or nature of involvement ✓	5a: Qualitative evidence of impact ✗ 5b: Quantitative evidence of impact ✗ 5c: Robustness of measure ✗	✗	7a: Outcomes of PPI ✓ 7b: Impacts of PPI ✗ 7c: Context of PPI ✗ 7d: Process of PPI ✗ 7e: Theory development ✗ 7f: Measurement ✓ 7g: Economic assessment ✗	8a: Outcomes ✓ 8b: Impacts ✓ 8c: Definition ✗ 8d: Theoretical underpinnings ✗ 8e: Context ✗ 8f: Process ✗ 8g: Measurement and capture of PPI impact ✗ 8h: Economic Assessment ✗ 8i: Reflections/critical perspective ✓
Hackett et al. (2018)	1a: Aim ✓ 1b: Methods ✓ 1c: Results ✓ 1d: Conclusions ✓ 1e: Keywords ✓	2a: Definition ✓ 2b: Theoretical underpinnings ✗ 2c: Concepts and theory development ✓	✓	4a: Design ✓ 4b: People involved ✓ 4c: Stages of involvement ✓ 4d: Level or nature of involvement ✓	5a: Qualitative evidence of impact ✗ 5b: Quantitative evidence of impact ✗ 5c: Robustness of measure ✗	✗	7a: Outcomes of PPI ✓ 7b: Impacts of PPI ✓ 7c: Context of PPI ✗ 7d: Process of PPI ✗ 7e: Theory development ✗ 7f: Measurement	8a: Outcomes ✓ 8b: Impacts✓ 8c: Definition ✗ 8d: Theoretical underpinnings ✗ 8e: Context ✗ 8f: Process ✗ 8g: Measurement and capture of PPI impact ✗ 8h: Economic Assessment ✗

							✗ 7g: Economic assessment ✗	8i: Reflections/critical perspective ✓
Hetrick et al. (2018)	1a: Aim ✓ 1b: Methods ✓ 1c: Results ✓ 1d: Conclusions ✓ 1e: Keywords ✗	2a: Definition ✗ 2b: Theoretical underpinnings ✗ 2c: Concepts and theory development ✓	✓	4a: Design ✓ 4b: People involved ✓ 4c: Stages of involvement ✓ 4d: Level or nature of involvement ✓	5a: Qualitative evidence of impact ✗ 5b: Quantitative evidence of impact ✗ 5c: Robustness of measure ✗	✗	7a: Outcomes of PPI ✓ 7b: Impacts of PPI ✗ 7c: Context of PPI ✗ 7d: Process of PPI ✗ 7e: Theory development ✗ 7f: Measurement ✗ 7g: Economic assessment ✗	8a: Outcomes ✓ 8b: Impacts ✓ 8c: Definition ✗ 8d: Theoretical underpinnings ✗ 8e: Context ✓ 8f: Process ✓ 8g: Measurement and capture of PPI impact ✗ 8h: Economic Assessment ✗ 8i: Reflections/critical perspective ✓
Onnela et al. (2014)	1a: Aim ✓ 1b: Methods ✓ 1c: Results ✓ 1d: Conclusions ✓ 1e: Keywords ✗	2a: Definition ✓ 2b: Theoretical underpinnings ✓ 2c: Concepts and theory development ✓	✓	4a: Design ✓ 4b: People involved ✓ 4c: Stages of involvement ✓ 4d: Level or nature of involvement ✗	5a: Qualitative evidence of impact ✗ 5b: Quantitative evidence of impact ✗ 5c: Robustness of measure ✗	✗	7a: Outcomes of PPI ✓ 7b: Impacts of PPI ✗ 7c: Context of PPI ✗ 7d: Process of PPI ✗ 7e: Theory development ✗ 7f: Measurement ✓ 7g: Economic assessment ✗	8a: Outcomes ✓ 8b: Impacts ✓ 8c: Definition ✓ 8d: Theoretical underpinnings ✓ 8e: Context ✗ 8f: Process ✗ 8g: Measurement and capture of PPI impact ✗ 8h: Economic Assessment ✗ 8i: Reflections/critical perspective ✓
Ospina-Pinillos et	1a: Aim ✓ 1b: Methods	2a: Definition ✓ 2b: Theoretical	✓	4a: Design ✓	5a: Qualitative evidence of impact ✗	✗	7a: Outcomes of PPI ✓	8a: Outcomes ✓ 8b: Impacts ✓

al. (2018)	✓ 1c: Results ✓ 1d: Conclusions ✓ 1e: Keywords ✓	underpinnings ✗ 2c: Concepts and theory development ✓		4b: People involved ✓ 4c: Stages of involvement ✓ 4d: Level or nature of involvement ✓	5b: Quantitative evidence of impact ✗ 5c: Robustness of measure ✗		7b: Impacts of PPI ✗ 7c: Context of PPI ✗ 7d: Process of PPI ✗ 7e: Theory development ✗ 7f: Measurement ✗ 7g: Economic assessment ✓	8c: Definition ✗ 8d: Theoretical underpinnings ✗ 8e: Context ✗ 8f: Process ✗ 8g: Measurement and capture of PPI impact ✗ 8h: Economic Assessment ✗ 8i: Reflections/critical perspective ✓
Ospina-Pinillos et al. (2019)	1a: Aim ✓ 1b: Methods ✓ 1c: Results ✓ 1d: Conclusions ✓ 1e: Keywords ✓	2a: Definition ✓ 2b: Theoretical underpinnings ✗ 2c: Concepts and theory development ✓	✓	4a: Design ✓ 4b: People involved ✓ 4c: Stages of involvement ✓ 4d: Level or nature of involvement ✓	5a: Qualitative evidence of impact ✗ 5b: Quantitative evidence of impact ✗ 5c: Robustness of measure ✗	✗	7a: Outcomes of PPI ✓ 7b: Impacts of PPI ✗ 7c: Context of PPI ✗ 7d: Process of PPI ✗ 7e: Theory development ✗ 7f: Measurement ✗ 7g: Economic assessment ✗	8a: Outcomes ✓ 8b: Impacts ✓ 8c: Definition ✗ 8d: Theoretical underpinnings ✗ 8e: Context ✗ 8f: Process ✗ 8g: Measurement and capture of PPI impact ✗ 8h: Economic Assessment ✗ 8i: Reflections/critical perspective ✓
Realpe et al. (2020)	1a: Aim ✓ 1b: Methods ✓ 1c: Results ✓ 1d: Conclusions ✓	2a: Definition ✓ 2b: Theoretical underpinnings ✗ 2c: Concepts and theory development ✓	✓	4a: Design ✓ 4b: People involved ✓ 4c: Stages of involvement ✓	5a: Qualitative evidence of impact ✗ 5b: Quantitative evidence of impact ✗ 5c: Robustness of measure ✗	✗	7a: Outcomes of PPI ✓ 7b: Impacts of PPI ✗ 7c: Context of PPI ✗ 7d: Process of	8a: Outcomes ✓ 8b: Impacts ✓ 8c: Definition ✗ 8d: Theoretical underpinnings ✗ 8e: Context ✗ 8f: Process ✓

	1e: Keywords ✓			4d: Level or nature of involvement ✓			PPI ✗ 7e: Theory development ✗ 7f: Measurement ✗ 7g: Economic assessment ✗	8g: Measurement and capture of PPI impact ✗ 8h: Economic Assessment ✗ 8i: Reflections/critical perspective ✓
Sundram et al. (2017)	1a: Aim ✓ 1b: Methods ✓ 1c: Results ✓ 1d: Conclusions ✓ 1e: Keywords ✗	2a: Definition ✗ 2b: Theoretical underpinnings ✗ 2c: Concepts and theory development ✓	✓	4a: Design ✓ 4b: People involved ✓ 4c: Stages of involvement ✓ 4d: Level or nature of involvement ✓	5a: Qualitative evidence of impact ✗ 5b: Quantitative evidence of impact ✗ 5c: Robustness of measure ✗	✗	7a: Outcomes of PPI ✓ 7b: Impacts of PPI ✓ 7c: Context of PPI ✗ 7d: Process of PPI ✗ 7e: Theory development ✗ 7f: Measurement ✗ 7g: Economic assessment ✗	8a: Outcomes ✓ 8b: Impacts ✗ 8c: Definition ✗ 8d: Theoretical underpinnings ✗ 8e: Context ✗ 8f: Process ✗ 8g: Measurement and capture of PPI impact ✗ 8h: Economic Assessment ✗ 8i: Reflections/critical perspective ✓
Thummathai et al. (2018)	1a: Aim ✗ 1b: Methods ✗ 1c: Results ✗ 1d: Conclusions ✗ 1e: Keywords ✗	2a: Definition ✓ 2b: Theoretical underpinnings ✗ 2c: Concepts and theory development ✗	✗	4a: Design ✓ 4b: People involved ✓ 4c: Stages of involvement ✓ 4d: Level or nature of involvement ✓	5a: Qualitative evidence of impact ✗ 5b: Quantitative evidence of impact ✗ 5c: Robustness of measure ✗	✗	7a: Outcomes of PPI ✓ 7b: Impacts of PPI ✓ 7c: Context of PPI ✗ 7d: Process of PPI ✗ 7e: Theory development ✗ 7f: Measurement	8a: Outcomes ✓ 8b: Impacts ✓ 8c: Definition ✗ 8d: Theoretical underpinnings ✗ 8e: Context ✗ 8f: Process ✗ 8g: Measurement and capture of PPI impact ✗ 8h: Economic Assessment ✗

							✗ 7g: Economic assessment ✗	8i: Reflections/critical perspective ✓

Chapter 3:

Study 2 – Mental Health Discharge Communication Interventions

Title: Discharge communication for mental health visits to the pediatric emergency department: A mixed-method study

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3.1. Abstract

Objectives: Discharge communication is essential to convey information regarding care provided and follow-up plans, but it can be lacking for visits for pediatric mental health crises. Our objectives were to improve pediatric mental health discharge communication by co-designing and testing the usability of new discharge communication interventions.

Methods: The study was conducted in two phases using the principles of experience-based co-design (EBCD). In phase 1 (Sep 2021 to Jan 2022), five meetings were conducted with a co-design team of parents, clinicians, and researchers to co-design discharge communication interventions for pediatric mental health care in the ED. The team used the Capability, Opportunity, Motivation, Behavior (COM-B) model to identify strategies to support the delivery of the interventions. After meeting five, team members completed the patient and public engagement evaluation tool (PPEET) to evaluate the co-design experience. In phase 2 (Apr to Jul 2022), intervention usability and satisfaction were evaluated by a new group of parents, youth, and ED physicians and nurses (n=2 of each). Usability feedback was used by the co-design team to finalize the interventions and delivery strategy.

Results: Two discharge communication interventions were created: a brochure for families and clinicians to use together during the ED visit, and a text-messaging system for families after the visit. There was high engagement satisfaction in phase 1 (mean PPEET score = 4.5/5), and in phase 2, with both interventions there was high user satisfaction (mean clinician score = 4.4/5, mean caregiver score = 4.1/5). Usability feedback included in final intervention versions included instructions on use (brochure and text-messaging) and ensuring texts are sent within 12-24 hours of discharge.

Conclusions: The interventions produced by this study have the potential to address gaps in current discharge practices. Future testing is required to evaluate the impact on patients, caregivers, and health care system use after the ED visit.

3.2. Introduction

Emergency department (ED) health care providers have an integral role in mental health assessment, acute mental health care, and referral to specialized services (Dolan & Fein, 2011; Emerson et al., 2022; Freedman et al., 2020). There is, however, considerable variation across these clinical practices owing to a lack of policy and guidelines to standardize practices (Cappelli et al., 2019). This includes most EDs not requiring the use of pediatric-specific mental health tools to guide assessments or having patient-centred procedures in place for care and referral practices (American Academy of Pediatrics et al., 2013; Leon et al., 2013; U.S. Department of Health and Human Services et al., 2019). This clinical context can result in ED health care providers feeling inadequately trained, unprepared, and uncomfortable when caring for mental health patients (Dolan & Fein, 2011; Suen et al., 2018).

Most children and adolescents who visit the ED for a mental health crisis will be discharged home (Cappelli et al., 2019; Murphy et al., 2018; Sheridan et al., 2015), making discharge communication a critical component of the ED visit (Hoek et al., 2020; Murphy et al., 2018). Before leaving the ED, pediatric patients and their parents/caregivers should understand findings from mental health assessments, the ED care provided, and know if follow-up recommendations include the need for specialized services (and why). Parents/caregivers have also reported wanting information on how to help their child deal with the next crisis, and how to support themselves (Suen et al., 2018). Past research has indicated, however, that between 32% to 48% of families do not receive any discharge instructions (Cappelli et al., 2019), and when instructions are provided, they are often briefly explained with crucial details missing (Curran et al., 2020), and they may not be well understood by patients or their parents/caregivers (Hoek et al., 2020; Suen et al., 2018). The aim of this study was to improve pediatric mental health discharge communication in the ED by co-designing and testing the usability of new discharge communication interventions that would address known gaps in care.

3.3. Methods

Design

The study was mixed-method in design and conducted in two phases (Curran et al., 2019). In phase 1, a co-design team of parents/caregivers and ED health care providers developed the discharge communication interventions. This phase was based on the experience-based co-design (EBCD) framework to ensure the quality and appropriateness of the interventions (Blackwell et al., 2017; Bombard et al., 2018; Vojtila et al., 2021). In phase 2, a group of youth, parents/caregivers, and ED health care providers evaluated the usability of the interventions with feedback used by the co-design team to finalize them.

The study was based out of the Stollery Children's Hospital ED in Edmonton, Alberta, Canada, which has approximately 1800 annual visits by children aged 5–16 years for mental health concerns. The study was approved by the University of Alberta Research Ethics Board.

Participants

Recruitment for both phases involved purposeful sampling to include participants with the experiences and expertise necessary for the study (Bradshaw et al., 2017). In phase 1, the target size of the team was ~7 participants, in keeping with other mental health intervention co-design studies (Hetrick et al., 2018; Mathias et al., 2019; Neill et al., 2021). We recruited 6 parent/caregiver participants with lived experience in pediatric ED mental health visits through the Stollery Family-Centered Care Council, and two ED health care providers with experience in providing care for pediatric mental health concerns (one ED nurse, one ED physician) through a staff listserv email and staff meetings. The demography of team participants is presented as supplementary content (Table S3.1). We had wanted to recruit one or two adolescents/youth with lived experience, but none expressed interest in participation.

The target sample size for phase 2 was ~8 participants per usability testing round (Fortuna et al., 2017; Newton et al., 2020; Storm et al., 2021). While other usability studies have reported that three to four participants are adequate to find 80% of design usability problems (Nielsen, 1995), we wanted to include adolescents/youth, parents/caregivers, and health care providers in testing. We recruited 8 participants for one round of testing. Although multiple testing rounds can be used to improve intervention usability, we only needed to conduct one round given the nominal usability issues that were identified. Usability participants were two youth (aged 16–24 years) and two parents/caregivers, all with lived experience, who were recruited through emails sent to the Stollery Youth Advisory Council and posters in the Stollery ED waiting room. ED health care providers were two physicians and two mental health nurses who did not participate in phase 1, but expressed interest in the study. Usability participant demography is presented as supplementary content (Table S3.2).

All participants provided informed consent. The time and lived experiences of parents/caregivers and youth was recognized by providing them with gift cards of their choice (phase 1 participants: $50 CAD per meeting; phase 2 participants: $25 CAD).

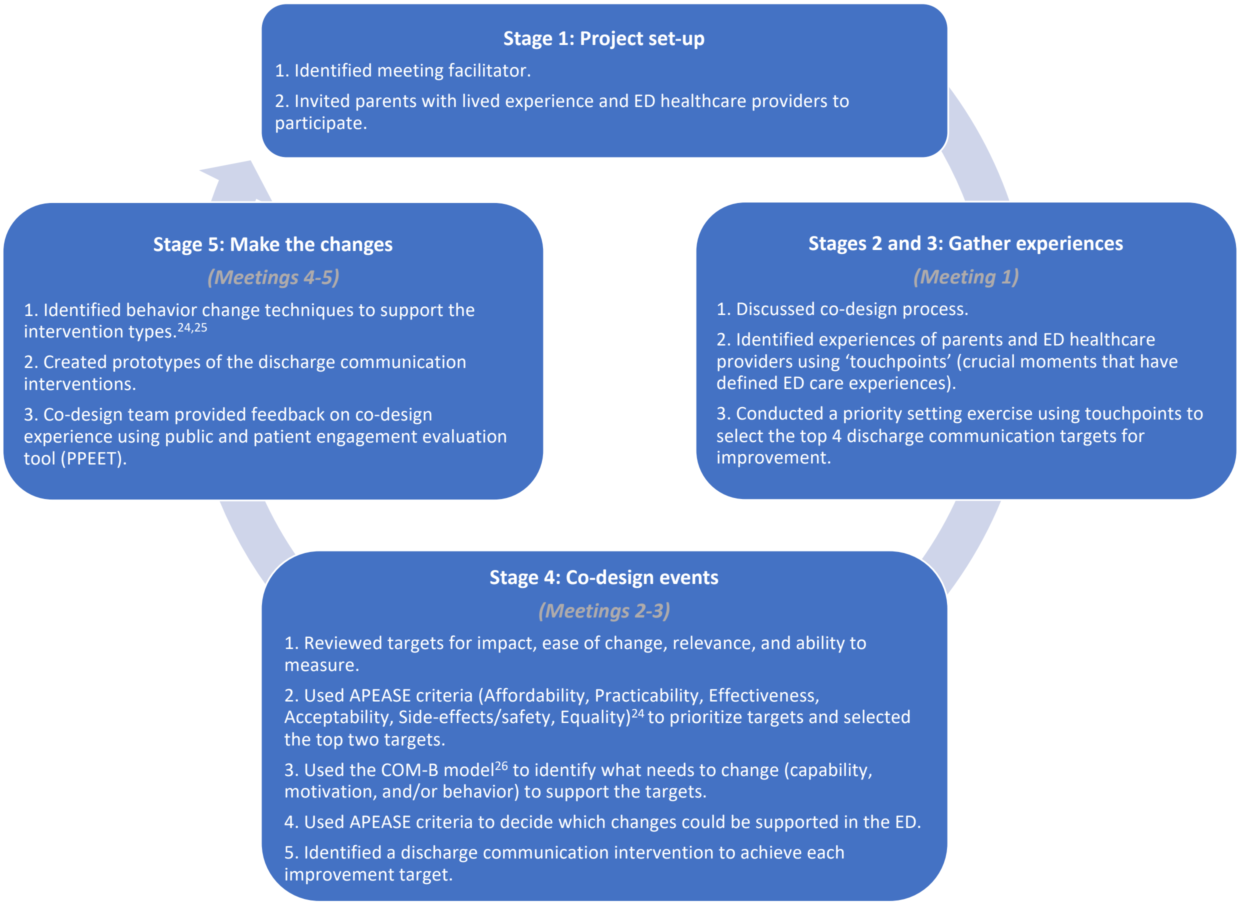
Phase 1 Methods

We developed the discharge communication interventions over five, virtually held, co-design team meetings. Meetings were co-led by two research team members (first author AZA and co-author BW) with input from the patient and family-centred care coordinator from the hospital (co-author JFA). Meetings were recorded to facilitate data analysis and recordings were utilized to create a log. The log was maintained by one research team member (AZA) to document attendance, length of meetings, discussion related to intervention design and discharge communication features (touchpoints, improvement targets, etc.), and the presence of decisional conflicts.

Figure 3.1 outlines the EBCD process including key actions and decision points for the team. Team members used their lived experiences (touchpoints) to identify discharge communication improvement targets, and the APEASE criteria—affordability, practicability, effectiveness, acceptability, side-effects/safety, and equality— to prioritize targets (Michie et al., 2014). The team used the Capability, Opportunity, Motivation, Behavior (COM-B) model and APEASE criteria to specify, for the top two ranked targets, who needed to be involved, what needed to be done (and how often), what changes were needed for the target to be achieved, and how to support change in clinical practice (Mangurian et al., 2017; Michie et al., 2013, 2014). Based on this work, prototypes for two discharge communication interventions were developed.

Parents/caregivers evaluated their co-design team experiences by completing the long-term engagement questionnaire from the Public and Patient Engagement Evaluation Tool (PPEET), a tool developed to assess the quality and impact of engagement activities (Abelson et al., 2016; McMaster University, n.d.). The questionnaire consists of 21 items on processes, outputs, and perceived impacts of engagement activities; 13 questions are scored on a 5-point Likert scale from 1 (strongly disagree) to 5 (strongly agree), and 7 questions are open-ended for comment on scaled items.

Figure 3.1. Stages of experience-based co-design incorporated in Phase 1.



Stage 1: Project set-up

1. Identified meeting facilitator.
2. Invited parents with lived experience and ED healthcare providers to participate.

Stages 2 and 3: Gather experiences

(Meeting 1)

1. Discussed co-design process.
2. Identified experiences of parents and ED healthcare providers using ‘touchpoints’ (crucial moments that have defined ED care experiences).
3. Conducted a priority setting exercise using touchpoints to select the top 4 discharge communication targets for improvement.

Stage 4: Co-design events

(Meetings 2-3)

1. Reviewed targets for impact, ease of change, relevance, and ability to measure.
2. Used APEASE criteria (Affordability, Practicability, Effectiveness, Acceptability, Side-effects/safety, Equality)[24] to prioritize targets and selected the top two targets.
3. Used the COM-B model[26] to identify what needs to change (capability, motivation, and/or behavior) to support the targets.
4. Used APEASE criteria to decide which changes could be supported in the ED.
5. Identified a discharge communication intervention to achieve each improvement target.

Stage 5: Make the changes

(Meetings 4-5)

1. Identified behavior change techniques to support the intervention types.[24,25]
2. Created prototypes of the discharge communication interventions.
3. Co-design team provided feedback on co-design experience using public and patient engagement evaluation tool (PPEET).

Phase 2 Methods

Usability testing was conducted virtually and recorded to facilitate data analysis. Individual participant sessions took ~ 1-hour to complete and were co-led by two research team members (first author AZA and co-author BW). Parent/caregiver and youth participants completed the medical term recognition test (METER) (Rawson et al., 2010) prior to usability testing to understand the health literacy of those evaluating the interventions.

Sessions were structured according to the think-aloud approach (Yu et al., 2014), whereby participants were asked to say aloud their thoughts, feelings, and observations as they first viewed the intervention. We also used an interview guide consisting of three open-ended questions (initial impressions, main purpose, usefulness, and/or timing of delivery), one scenario-based question (how the intervention could be used), and asked participants to pick 5–10 words from a list that they felt best described the intervention as they used it. The same approach was used with all participants, but the scenario-based question was tailored to each participant group (parent/caregiver, youth, health care provider). The session concluded with the participant completing a validated user satisfaction survey scoring questions on a 5-point Likert scale from 1 (strongly disagree) to 5 (strongly agree) or 1 (very poor) to 5 (very good) (Gibson et al., 1991). Health care providers responded to 27 items related to appearance, content, usefulness, and delivery. Parents/caregivers and youth responded to 15 items related to appearance, content, and usefulness. Results from usability testing sessions were presented to the co-design team for intervention refinement.

Data Analysis

We used descriptive statistics to report co-design engagement, participant demographics, and user satisfaction (SPSS, version 23). AZA identified co-design process themes and subthemes from the meeting log using thematic analysis (Braun & Clarke, 2006). These themes and subthemes were used to interpret the PPEET ratings (e.g., instances of decisional conflicts were reviewed to better understand a low rating on the PPEET). We transcribed usability testing feedback and used thematic analysis (Braun & Clarke, 2006) to categorize usability issues identified in the testing sessions.

3.4 Results

Improvement targets for discharge communication

Three, common lived experiences with discharge communication were identified by parent/caregiver co-design team members: 1) confusion about the process of triage and what to do after being discharged, 2) being in shock and forgetting information that was discussed, and 3) not feeling engaged by health care providers in creating a discharge plan for their child. These targets were validated by the healthcare provider co-design team members. The team used these experiences to set two improvement targets for discharge communication.

Target one was an interactive discussion between the physician or mental health team member and family before discharge. Its purpose was to ensure engagement when discussing the discharge plan. For this target to be achieved, the team felt health care providers needed to know the process for engaging families in a conversation about discharge (psychological capability), see other health care providers engage with families in a discharge conversation (social opportunities), have dedicated time and resources to engage families in a conversation about discharge (physical opportunities), and have established routines and habits for engaging families in the discharge process (automatic motivation). The team proposed a brochure-based intervention for this target and identified behavior change techniques to support education, enablement, and environmental restructuring (Michie et al., 2013), which were considered important for the target to be achieved (Table 3.1).

Target two was improved communication after the ED visit. For this target to be achieved, the team felt there needed to be a consistent and efficient system to communicate with families after ED visit (physical opportunity), and established routines for communicating with families after the ED visit (automatic motivation). The team proposed a text message-based intervention for families after ED discharge that would facilitate support, information, and/or guidance depending on the patient/family's needs. To enhance the uptake of this intervention, the team identified the need for environmental restructuring and enablement (Michie et al., 2013), and proposed specific behavior change techniques to support intervention use (Table 3.1).

A detailed overview of the process used by the co-design team to refine details for the two discharge communication targets is presented as supplemental content (Tables S3.3 and S3.4). Final versions of the brochure and text message-based interventions are visually depicted in Figure 3.2.

Table 3.1. An overview of the areas of focus to support behavior change, specific behavior change techniques to facilitate change, and the proposed interventions to help facilitate change.

Area of focus	COM-B components addressed by area of focus	Behavior change technique*	Proposed discharge communication intervention
Target behavior 1: Interactive discussion between the physician or mental health team member and family before discharge			
Education **Enablement** **Environmental restructuring**	Psychological capability Physical opportunity Social opportunity Automatic motivation	Add object to the environment	A brochure to be provided to families in the ED. *Mode of delivery:* face-to-face
		Prompts/cues	The brochure will contain prompts/cues to help families be engaged during discharge process. ED care providers will be educated on how to use the prompts/cues to engage families during discharge process.
Target behavior 2: Improve communication after the ED visit			
Enablement **Environmental restructuring**	Physical opportunity Automatic motivation	Add object to the environment	Set up a system through which automated text messages can be sent to families after their ED visit. The message will ask if families need further support or resources and connect them with such if needed. *Mode of delivery:* virtual

*Michie et al., 2013, 2014

Figure 3.2 Visual depictions of the two discharge communication interventions. (A) Brochure designed to guide engagement during ED visit and creation of discharge plan. (B) Text messaging system developed to support families with resources after discharge from ED

A)

EMERGENCY DEPARTMENT (ED) VISIT GUIDE

What now?
We'll show you how

GETTING THE MOST OUT OF YOUR ED VISIT

IT CAN HELP TO PREPARE AND WRITE DOWN QUESTIONS FOR YOUR CARE TEAM. SOME COMMON QUESTIONS ARE:

- WHO WILL WE SEE AND WHY?
- WHAT ARE SOME STRATEGIES OR RESOURCES WE COULD USE IN TIMES OF CRISIS?
- IF WE'RE CONFUSED ABOUT WHAT IS RECOMMENDED, WHAT CAN WE DO?

OUR QUESTIONS:

2

HAND IN HAND, LET'S MAKE A PLAN

From one family to another, it is okay to not be okay right now. Moments of high stress might not bring out the best in us. There is no shame in asking for help. With your care provider, use the next two pages to create a plan for after your visit.

1. *Questions after seeing the mental health team*
2. *Our plan for after the ED visit*
3. *Self-care: what do I need to do to take care of myself?*
   As a caregiver, what do I need to do to take care of my child?

3

WHAT SHOULD YOU EXPECT AFTER YOUR ED VISIT?

DATE OF VISIT: ______

USE THE SPACE BELOW TO WRITE DOWN WHAT YOU ARE EXPECTING TO OCCUR IN THE NEXT 12-72 HOURS:

APPOINTMENTS AND /OR FOLLOW-UP CALLS:

OTHER: ______

IF YOU HAVE ANY FURTHER QUESTIONS, PLEASE CONTACT THE MENTAL HEALTH CRISIS TEAM FOR CHILDREN AND YOUTH AT 780-407-1000
Available 8:00 am -11:30 pm

4

MENTAL HEALTH RESOURCES

FOR IMMEDIATE CRISIS SUPPORT:

ALBERTA COMMUNITY RESOURCES: CALL 211

MENTAL HEALTH CRISIS TEAM FOR CHILDREN AND YOUTH: 780-407-1000

THE SUPPORT NETWORK, EDMONTON DISTRESS LINE: 780-482-HELP (4357)

KIDS HELP PHONE: 1-800-668-6868

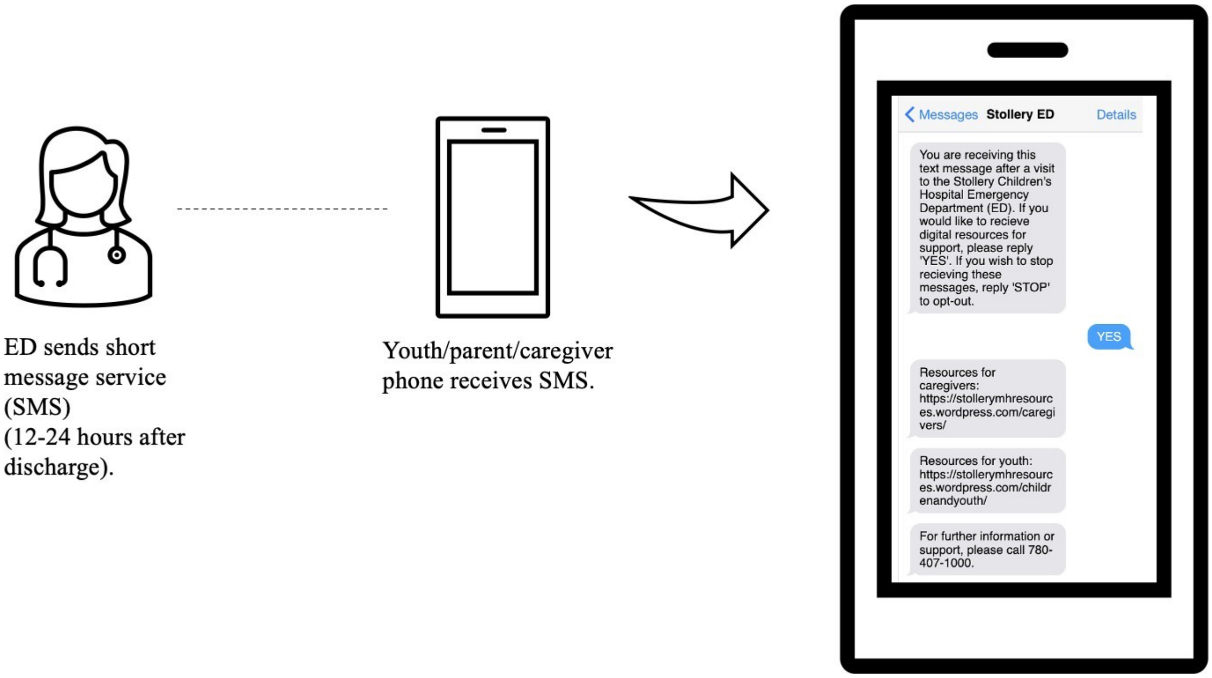
IF IN AN EMERGENCY, CALL 911 OR RETURN TO ED

INFORMATION FOR CAREGIVERS:

INFORMATION FOR YOUTH:

5

B)



ED sends short message service (SMS) (12-24 hours after discharge).

Youth/parent/caregiver phone receives SMS.

You are receiving this text message after a visit to the Stollery Children's Hospital Emergency Department (ED). If you would like to recieve digital resources for support, please reply 'YES'. If you wish to stop recieving these messages, reply 'STOP' to opt-out.

YES

Resources for caregivers: https://stollerymhresources.wordpress.com/caregivers/

Resources for youth: https://stollerymhresources.wordpress.com/childrenandyouth/

For further information or support, please call 780-407-1000.

Co-design engagement evaluation

All co-design team members attended at least one of the five co-design meetings: six members attended meetings 1, 2, and 5, and four members attended meetings 3 and 4. Seven co-design team members (2 healthcare providers, 5 parents) evaluated their experiences using the PPEET with scores ranging from 4.0 to 4.9 (mean score, 4.5). Highest rated engagement experiences related to being able to express views freely, feeling heard, and understanding the objectives of the project. Lowest rated engagement experiences related to feeling better informed about mental health care through this project, and a broad range of perspectives being represented (see Table S3.5, for additional results related to engagement). Meeting log notes indicated that clarification was needed regarding the discharge process at the Stollery ED (7 instances) and research process for the study (7 instances); decisional conflicts occurred in 6 instances, where all opinions could not be incorporated into intervention design due to practicality reasons (per APEASE criteria). Themes from open-ended questions were feeling grateful (opportunity to participate, provide valuable lived experience), learning from other perspectives, and feeling heard. Team members felt the co-design meetings were conducted in a comfortable and collaborative environment; they suggested having more meeting times available and the opportunity to explore other ED needs as areas of improvement.

Intervention testing

The average participant METER score was 37.3/40 (standard deviation [SD], 4.2), indicating high health literacy. All usability testing participants identified that the main purpose of the brochure was to help patients and families collaborate on a plan with the care team and provide resources for after discharge. Usability issues for the brochure related to appearance, mental health resources, and instructions for use. The most common words used to describe the brochure were ‘helpful, ‘useful’, and ‘clear’. All usability testing participants identified that sending a follow-up text with resources or further support would be a helpful, practical way to support families after discharge. Participants did not select words to describe the text messaging system as could not be used during testing. Anticipated usability issues identified for the text messaging system were timing and phrasing of the messages. Issues identified by participants and changes made to the interventions are outlined in Table 2.

Participants completed user satisfaction surveys for the brochure (see Table S3.6, for complete findings), but not the text message intervention as this intervention was not yet developed for use; participants reviewed a demonstration of the proposed text-message process. Parent/caregiver and youth user satisfaction scores ranged from 3 to 5 (mean score, 4.1). Lowest scores related to appearance, while highest scores related to brochure usefulness, understanding, and importance. Health care providers scores ranged from 2 to 5 (mean score, 4.4). Lowest scores related to storing the brochure for occasional use only, and color aesthetics, while highest scores related to brochure understanding, usefulness, and content.

Table 3.2. Summary of feedback provided during usability testing cycle.

Brochure feature and feedback	Impact on design
Aesthetics	
Participants wanted the brochure to be in color, not black and white.	No changes made, as not feasible to print in color at ED.
Resources	
Provide options for walk-in resources for youth to access.	Added walk-in therapy session information in QR code links.
Include operating hours for mental health crisis team number.	Added information on hours of operation on brochure.
Instructions	
Provide instructions (written/verbal) on which sections of brochure to fill out independently vs. with health care provider.	Added written instructions on brochure for sections to be filled out with health care provider.
Provide instructions on which parts of brochure to fill out after being seen by health care provider.	Added written instructions on brochure for section to be filled out after being seen by health care provider.
Text messaging system feature and feedback	**Impact on design**
Timing	
Send out text message 12-24 hours after visit, and during daytime hours.	Text message will be sent out 12-24 hours after discharge from ED.
Phrasing	
Participants expressed that the phrasing of the text message was misleading, as it implied new resources are being provided.	Text message phrasing was revised to make it clear that digital resources are being provided, if required.

3.5. Discussion

Most children and adolescents who come to the ED for a mental health crisis will be discharged home. While comprehensive discharge practices and understandable discharge instructions are important for families in the post-crisis period (Cappelli et al., 2019), this approach to discharge communication is not routinely provided (Murphy et al., 2018). If discharge communication is provided, patients and families may have poor recall and understanding of follow-up plans (Akinsola et al., 2017; Gutman et al., 2018). This study sought to address these clinical care issues by co-designing new interventions in partnership with parents and healthcare providers to improve mental health discharge communication.

The Importance of Co-Design

An important feature of this study was the co-design approach. Traditionally, patients and their parents/caregivers have not been involved in creating new approaches to ED care. This is particularly the case with mental health care (Curran et al., 2019). Given that high quality, effective mental health discharge communication requires the involvement of patients, parents/caregivers, and health care providers (Owens et al., 2011; Wozney et al., 2022), it was important for us to involve parents/caregivers and health care providers in intervention development and evaluation. We were mindful of the need to avoid 'tokenistic engagement' (e.g., limited influence over defining concerns or solutions) (Rose et al., 2003), and chose to follow the EBCD framework. EBCD is a best-practice approach to engaging patients in mental health care quality improvement (Hackett et al., 2018), to ensure meaningful engagement throughout the study. This approach can also result in realistic interventions that will be sustainable in clinical practice over time (Shen et al., 2017).

The EBCD framework guided us in comprehensively exploring lived experiences of parents/caregivers through touchpoints and allowed all team members to collectively select target areas for improvement. The co-design team reported high engagement satisfaction and expressed feeling heard and listened to, further highlighting the benefits of utilizing a framework designed to ensure meaningful engagement. Low engagement ratings and suggested areas for improvement—more flexible meeting times, exploring other ED needs, incorporating more diverse perspectives—are important areas for future projects conducted by our team and others. Some areas for improvement can be readily addressed in future projects such as opening the focus of a project to any area of ED care, not just discharge communication; other areas such as schedule may continue to be a challenge. Despite our best efforts, all co-design team members were not able to attend all meetings due to scheduling conflicts.

Contributions of Usability Testing

Usability testing was also a critical component of this study. Without this method, we may not have identified issues with acceptability, usability, or identified issues that can be used as part of an implementation strategy to support routine intervention use (Kushniruk & Patel, 2004). We believe that the interventions developed in this study can support discharge communication for a mental health visit. The brochure aims to guide the conversation between pediatric patients, parents/caregivers, and ED health care providers, and provides a place to document, during their visit, important concerns and treatment and follow-up plans. The text messaging intervention aims to support families in the post-crisis period. Questions or concerns that emerge after the ED visit, or the need to clarify discharge instructions, can be addressed through this intervention. Because the text messaging system has yet to be developed, additional usability testing is required once the system is ready for use. Testing should include rating experiences with the System Usability Scale (SUS) and/or Severity Ranking Scale (SRS) to understand usability of this technology (Nielsen, 1994). The SUS has published cut-points for interpreting usability (acceptable, not acceptable) and the SRS serves to rate concerns with any features of the technology (none, cosmetic, minor, major, catastrophic). Future studies are also needed to test the impacts of these interventions on patient and family outcomes and experiences (e.g., anxiety, stress, care satisfaction), as well as the impact health care system use after the ED visit (e.g., follow-up visit rates, ED re-visits) to understand the potential value of these new interventions.

Understanding Behavior Change

Our use of an evidence-based, behavior change framework in this study allowed us to address all aspects that affect change (motivation, capability, and opportunity) as well as establish, recognize, and describe the pathways or mechanisms underpinning the discharge communication interventions (Michie et al., 2014). While we have yet to test the impact of the two new interventions, our approach to intervention development will allow us to test not only the effects of the discharge intervention on patient care and outcomes (intervention effectiveness), but the effects of strategies used to support intervention use (implementation strategy effectiveness) (Michie et al., 2015). Hybrid effectiveness-implementation studies for pediatric care have been conducted in ED settings (Knighton et al., 2022; Mello et al., 2018), providing important information on both intervention impacts and how to optimize intervention use.

Limitations

There are several limitations to this study. First, the targets for change and design of the discharge communication interventions were conceptualized from a small sample of parents and health care providers from one children's hospital, which may limit applicability of study findings to other ED settings. Second, we were unable to recruit adolescents or youth to join our co-design team, which would have allowed us to incorporate the patient perspective into the design of the interventions. Third, although the co-design process was collaborative, team members could not attend all meetings due to scheduling conflicts, which limited the perspectives that contributed to intervention design and development.

3.6. Conclusions

The interventions produced by this study have the potential to address gaps in current discharge practices. Our study included several important frameworks and methods—EBCD, usability testing, and behavior change—to design and initially test two, novel discharge communication interventions. This approach resulted in interventions that meet the needs and preferences of health care users/deliverers, and have the potential to improve current discharge practices. Future testing is required to evaluate the impact on patients, caregivers, and health care system after the ED visit.

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Supplementary Content

Table S3.1. Characteristics of co-design team members (n=8).

Characteristic	n (%)
Gender	
Male	2 (14.3)
Female	6 (85.7)
Age, years	
<25	1 (12.5)
35-40	2 (25.0)
41-46	2 (25.0)
47-51	3 (37.5)
Perspective brought to the project	
Family member/caregiver	6 (75.0)
Staff member	2 (25.0)
Group membership	
Visible minority	1 (12.5)
LGBTQ community	1 (12.5)
Person with disabilities	0
Indigenous peoples of Canada	0
Recent immigrant to Canada	0
Not a member	6 (75.0)
Education (highest level completed)	
Some post-secondary (college, university, technical training)	1 (12.5)
Completed college	2 (25.0)
Completed university	1 (12.5)
Post-graduate profession or graduate degree	4 (50.0)
Worked for pay in a health care profession	
Yes	4 (50.0)
No	4 (50.0)

Table S3.2. Characteristics of usability testing participants (n=8).

Characteristic	**n (%)**
Gender	
Male	2 (25.0)
Female	6 (75.0)
Age, years	
16-24	2 (25.0)
25-35	2 (25.0)
36-45	0
46-55	2 (25.0)
56-65	2 (25.0)
Perspective brought to the project	
Parent/caregiver	2 (25.0)
Youth	2 (25.0)
Nurse	2 (25.0)
Physician	2 (25.0)
Race/ethnic group membership	
Caucasian	5 (62.5)
Arab	2 (25.0)
Black or African	1 (12.5)
Parent/caregiver/youth education (highest level)	
High school diploma	1 (25.0)
College	1 (25.0)
University	1 (25.0)
Post-graduate degree	1 (25.0)
Health care providers: years in practice	
<5	1 (25.0)
5-10	1 (25.0)
11-19	0
>20	2 (50.0)

Table S3.3. Behavioral analysis of improvement targets using the COM-B model.

COM-B component	What needs to happen for the target to take place?	Is there a need for change?
Target behavior 1: Interactive discussion between the physician or mental health team member and family before discharge		
Physical capability	Have the physical skills to engage families in a conversation about discharge.	No change needed as care providers have these skills.
Psychological capability	Know the correct process of engaging families in a conversation about discharge.	Change needed as sometimes nurses do not know if patients are ready for discharge and are therefore hesitant to engage families in a discharge conversation.
Physical opportunity	Have the dedicated time and resources to engage families in a conversation about discharge.	Change needed as there are no resources available to ensure families are engaged, and a lack of time to develop relationships with patients and families.
Social opportunity	See other health care providers engage families in a conversation about discharge.	Change needed as most care providers do not do this consistently.
Reflective motivation	Hold beliefs that engaging families is important to discharge process.	No change needed as care providers do hold these beliefs.
Automatic motivation	Have established routines and habits for engaging families in discharge process.	Change needed to establish routine and habit formation.
Target behavior 2: Improve communication after the ED visit		
Physical capability	Have the physical skills to communicate with families after the ED visit.	No change needed as care providers have these skills.
Psychological capability	Know the correct procedure for communicating with families after the ED visit.	No change needed as care providers know the current procedure and are capable of learning a new procedure.
Physical opportunity	Have a consistent and efficient system set-up to communicate with families after ED visit.	Change needed as there is currently no consistent system set-up.
Social opportunity	See other care providers or staff reaching out to families after ED visit.	No change needed as care providers/staff already see this.
Reflective motivation	Hold beliefs that communication with families is important after an ED visit.	No change needed as care providers hold these beliefs.
Automatic motivation	Have established routines for communicating with families after the ED visit.	Change needed to establish routine and habit formation.

Table S3.4. Use of the COM-B model and APEASE criteria to refine details for the two discharge communication targets.

Target	Potential strategy to support behavior change (COM-B model)	Does the potential strategy meet APEASE criteria?
Target 1: Interactive discussion between the ED physician or mental health team member and family.	Education	Yes
	Training	Not practicable; not enough time or resources to train all staff.
	Enablement	Yes
	Restriction	Not practicable; no options to restrict in this context.
	Environmental restructuring	Yes
	Persuasion	Unlikely to be effective in an ED setting.
	Incentivization	Not practicable in an ED setting.
	Coercion	Not practicable in an ED setting.
	Modelling	Not practicable in an ED setting.
Target 2: Improve communication after the ED visit.	Persuasion	Unlikely to be effective without resources and time.
	Incentivization	Not practicable in an ED setting.
	Coercion	Not practicable in an ED setting.
	Training	Unlikely to be effective without a system set-up to communicate through.
	Environmental restructuring	Yes
	Modelling	Not practicable in an ED setting.
	Enablement	Yes
	Restriction	Not practicable; no options to restrict in this context.

Table S3.5. Score (5-point scale) and response distribution of PPEET items.

PPEET item	Mean (SD)
I have a clear understating of the purpose of the discharge communication project.	4.7 (0.5)
The supports I need to participate in the co-design meetings for the discharge communication project are available (e.g., internet access).	4.3 (0.5)
I have enough information to be able to carry out my role.	4.3 (0.5)
I am able to express my views freely.	4.9 (0.3)
I feel that my views are heard.	4.9 (0.3)
A wide range of views on discussion topics is shared.	4.3 (0.7)
The individuals participating in the co-design team for the discharge communication project represent a broad range of perspectives.	4.0 (0.8)
The discharge communication project is achieving its stated objectives.	4.6 (0.5)
I am confident that the feedback provided during our co-design meetings is taken into consideration.	4.6 (0.5)
I think that the work of our co-design meetings makes a difference to the work of the discharge communication project.	4.6 (0.5)
As a result of my participation in the co-design meetings for the discharge communication project, I am better informed about mental health care provided at the Stollery Emergency Department (team members, discharge, and follow-up process).	4.0 (0.5)
Overall, I am satisfied with this engagement initiative.	4.3 (0.5)
This engagement initiative is a good use of my time.	4.6 (0.5)

Table S3.6. Score (5-point scale) and response distribution of user satisfaction surveys. (A) Parent/youth satisfaction survey. (B) Health care provider satisfaction survey.

A. User satisfaction item (Parents/Youth)	**Mean (SD)**
At first glance the brochure attracted my attention.	3.0 (0.8)
The brochure held my attention.	3.3 (0.5)
The brochure is useful.	4.8 (0.5)
I like the illustrations on the brochure.	3.0 (1.4)
I believe what the brochure has to say.	3.8 (1.3)
I would recommend the brochure to a friend or relative to use if they presented to the emergency department for a mental health crisis.	4.5 (0.6)
The brochure is easy to understand.	4.5 (0.6)
What the brochure says is important.	4.5 (0.6)
The brochure reminds me of some things I would need to think about if I/ my child presented to the emergency department for a mental health crisis.	4.3 (1.0)
The brochure would give me some new things to think about if I/my child presented to the emergency department for a mental health crisis.	4.5 (0.6)
The brochure changes some of my thinking.	3.3 (0.5)
The brochure could change how I do things.	3.5 (0.6)
Overall, I recommend that emergency department care providers use this brochure in the emergency department with children/youth experiencing a mental health crisis and their families.	5.0 (0.0)
Overall, I am the right person to get this brochure from an emergency department care provider.	4.8 (0.5)
Overall, this brochure accomplishes its main purpose.	4.8 (0.5)
B. User satisfaction item (Health Care Providers)	**Mean (SD)**
The brochure is designed to:	
Reinforce information.	4.8 (0.5)
Provide new information.	4.3 (1.0)
Stimulate behavior change.	3.5 (1.9)
At first glance the brochure attracted my attention.	4.3 (0.5)
The brochure held my attention.	4.3 (0.5)
Overall appearance.	4.5 (0.6)
Quality of illustrations.	4.5 (0.6)
Use of color.	3.0 (0.0)
Type face (large enough, attractive, etc.).	4.8 (0.5)

Highlighting of major concepts.	4.8 (0.5)
The content of the brochure:	
Up to date.	4.8 (0.5)
Scientifically accurate.	4.7 (0.6)
Adequate scope for objective(s).	4.5 (0.6)
Overall organization.	4.5 (0.6)
Logical flow of ideas.	4.3 (1.0)
Needed background given to enable understanding.	4.0 (1.0)
Summary(ies) given when needed.	5.0 (0.0)
Fair presentation given (e.g., avoids sexism, ethnic bias, ageism, etc.)	5.0 (0.0)
The brochure is useful for its intended audience.	4.8 (0.5)
The brochure is believable.	4.5 (0.6)
The brochure is understandable.	4.8 (0.5)
The brochure requires little or no explanation.	4.0 (0.8)
Overall, I would recommend that emergency department care providers use this brochure with children/youth presenting with a mental health crisis and their families.	4.8 (0.5)
Overall, this brochure meets its objectives.	4.8 (0.5)
Brochure placement:	
The brochure should be given to patients and families in the ED waiting room.	4.8 (0.5)
The brochure should be given to patients and families in the assessment room.	4.0 (1.4)
The brochure should be stored for occasional use.	2.0 (0.8)

Chapter 4:

Discussion and Conclusions

4.1. Summary of Findings

The focus of my graduate research was examining patient engagement in adolescent mental health care. Specifically, in the studies presented in this thesis, I aimed to 1) synthesize evidence on the current approaches to child, adolescent, and youth engagement in mental health care studies; and 2) co-design discharge communication interventions with parents, adolescents/youth, and clinicians to improve mental health care provided in the Stollery Children's Hospital ED.

Scoping Review

Study 1, a scoping review, revealed that majority of studies involving children, adolescents, and youth in mental health service development or adaptation did not utilize an explicit patient engagement framework, such as EBCD (Bate & Robert, 2007), to guide the involvement of patients in research. This study also revealed time restrictions, recruitment, and generalizability as common barriers and constraints to engaging patients in research. These findings highlight the importance of using a framework such as EBCD to address and/or resolve them. Further, as majority of studies did not attempt to capture or measure the impact of patient engagement on the research process or outcomes, this approach is essential in future studies to understand how well engagement is being incorporated into studies and being carried out.

Mixed-method Study

Study 2, a mixed methods study, utilized the EBCD framework (Bate & Robert, 2007) and COM-B model (Michie et al., 2014) to co-design two pediatric discharge communication interventions with a team of clinicians and parents/caregivers. In this study, parents/caregivers identified common experiences with pediatric discharge communication—confusion about what to do after being discharged, forgetting information that was discussed, and not feeling engaged when creating a discharge plan for their child. To address these concerns, two interventions were co-designed: a brochure for families and clinicians to use together during the ED visit, and a text messaging system to support families after the visit. Co-design team members reported high engagement satisfaction, but suggested more flexible meeting times, incorporating more diverse perspectives, and exploring other ED needs as areas of improvement. The usability of the two interventions was evaluated by parents, youth, and ED clinicians, and there was high user satisfaction with both interventions. This study resulted in interventions that have the potential to improve current discharge practices for mental health care.

Taken together, my studies provide an understanding on the current practices of engaging patients in mental health research, and demonstrate how to incorporate important frameworks/models and methods—EBCD, COM-B, and usability testing—to co-develop discharge communication interventions.

4.2. Personal Reflections

On Conducting Study 1 – A Scoping Review

During my first year of graduate studies, I enrolled in a reading course (PAED 567), which was extremely helpful in providing me with the foundational knowledge required to conduct my scoping review. In this course, I learned about the approaches used to conduct patient engagement research, ethical considerations when involving patients in research, how to evaluate patient engagement in research, and how to design and carry out a scoping review. Through this course, I identified gaps in the literature on child, adolescent, and youth engagement in mental health intervention research, which helped me select a topic for the scoping review. I created the protocol for the scoping review as part of this course and received feedback from Drs. Newton. Wright, and Curran, which helped me improve the protocol prior to conducting the review.

Conducting a scoping review on the approaches to engaging children and adolescents in mental health research was extremely helpful in preparing to conduct my mixed-method study. For the scoping review, I initially reviewed several EBCD studies to understand each component of the EBCD framework. Reviewing studies on mental health intervention design and development helped me become more familiar with the way this type of research is conducted and reported. The knowledge that I gained ensured that I integrated components of EBCD into my mixed-method study. As I found that majority of studies did not assess or report patient engagement satisfaction, I made sure to assess patient engagement and highlight the results of the PPEET survey (Abelson et al., 2016; McMaster University, n.d.) in my mixed-method study. The background literature I read on patient engagement also made me aware of the prevalence of tokenism and power imbalances in studies involving patients. I conducted further research on strategies to limit or prevent tokenism and power imbalances prior to beginning phase 1 of the mixed-method study.

If I were to conduct this review again, I would spend more time reviewing recruitment strategies that studies in the review utilized, as most studies included in this review had large numbers of adolescent/youth participants. Reviewing their recruitment strategies may have helped me identify new strategies for recruitment and learn how to utilize these strategies to recruit this population to be part of the co-design team in the mixed methods study.

On Conducting Study 2 – A Mixed-Method Study

Using a virtual platform

Due to the global COVID-19 pandemic, all phases of the mixed-method study were conducted virtually via Zoom. Although the original plan was to hold meetings in-person, there were several benefits to a virtual approach. First, it was more convenient for parents and clinicians to meet virtually as the meetings were often held during evening hours, which made it easier to schedule meetings consistently. Second, the casual environment of a Zoom meeting, and having the ability to turn cameras off when needed, may have allowed parents/caregivers to be more open to sharing their experiences and reduced power imbalances. Third, I was able to utilize features on Zoom, such as the whiteboard feature and polling options, to keep team members engaged during the meetings. One drawback to conducting meetings online, however, was that co-design team members would often not show-up, leave early, or arrive late, although this may have also occurred with in-person meetings.

If I were to conduct this study again on a virtual platform, I would schedule two separate meeting times for the last two co-design meetings (intervention design meetings) and bring together design ideas generated in each meeting afterwards. Using this approach could have potentially increased meeting attendance and participation. Additionally, for meeting 3, in which COM-B components were discussed, I would have utilized the breakout rooms feature on zoom to separate parents and clinicians into separate rooms, and later present a summary of the discussion to the entire team. This would have been feasible as Dr. Wright and I co-led meetings, therefore we could have each facilitated one breakout room discussion. As parents and clinicians discussed the COM-B components from their own perspective, it was not necessary to do this together, and resulted in a longer meeting.

Using an EBCD approach

Using an EBCD approach provided several benefits to my project. First, it provided me with a more structured, systematic approach to engaging parents/caregivers. In meeting 1, exploring team member experiences using touchpoints was especially helpful, as this gave parents/caregivers the opportunity to share their thoughts and immediately highlighted common concerns that they experienced in the ED discharge process. Several times during this meeting, parents/caregivers mentioned being grateful to share their experiences in this manner, as they had previously not been given the opportunity to do so. This allowed me to build rapport and help parents/caregivers feel more comfortable and open to sharing their thoughts. Second, having co-design meetings with both parents and clinicians present was extremely beneficial to study progress. There were multiple instances in which clinicians were able to provide feedback to identified changes in discharge communication that parents were interested in. This helped parents/caregivers realize that some identified changes were not feasible or realistic and as such parents/caregivers were able to focus on designing interventions that were realistic, and more likely to be implemented in EDs in the future.

If I were to conduct this study again, I would integrate more components of EBCD stages into the study. Prior to beginning the study, I would observe patient experiences in the Stollery Hospital ED to become more familiar with how the ED discharge process works, and use this as an opportunity to recruit adolescents/youth to be part of the co-design team. Additionally, I would create a trigger film to highlight key parent/caregiver touchpoints. Although creating a trigger film requires more time and resources, I believe it would be impactful for clinicians to view the trigger film and understand patient experiences through a different lens.

Using a behavior change framework

Using the COM-B model (Michie et al., 2014) was integral to my project in helping identify the necessary changes needed to improve discharge communication. However, due to the complex nature of the behavior change literature, it was extremely important to provide the co-design team members a simplified overview of the theory behind the model. As well, to avoid technical jargon, we provided practical examples of each intervention function to co-design team members. Taking these extra steps helped us save time in the co-design meetings and kept team members engaged and informed throughout meetings.

If I were to conduct this study again, I would ask the co-design team to identify how the areas of focus (e.g., education, enablement) for each discharge communication intervention could be supported by policy categories in the Behavior Change Wheel (BCW), a framework that can be used alongside the COM-B model. This additional step would be helpful in creating a more stringent plan to support implementation of the interventions in the ED.

4.3. Limitations and Strengths

Limitations

Scoping review

When conducting the search for my scoping review, the lack of consistency and my lack of understanding of the terms in the literature used to describe the engagement or involvement of patients in research was a limitation. As involvement can have multiple interpretations, it was difficult to initially define what type of involvement I was interested in, which resulted in a large number of studies to screen. After I developed a better understanding of the methods used to involve patients in research, I adjusted the review inclusion criteria accordingly. This action resulted in me having to screen several studies multiple times to determine their eligibility for the review.

If I were to conduct the review again, I would address these limitations by reading more literature on patient engagement, the terminology used to describe the involvement of patients in research, and methods used to involve patients in research. I would then utilize this knowledge to create a more informed literature search, which may have resulted in less full text studies to screen. I would also use this knowledge to create a more stringent inclusion/exclusion criteria, which would prevent having to screen studies multiple times.

Mixed-method study

For the mixed-method study, there were several limitations. Firstly, recruitment of adolescents/youth was especially challenging. Although the initial plan was to include them in the development and design of the discharge interventions, I was unable to recruit any adolescents or youth with lived experience of mental health concerns. However, as most adolescents/youth present to the ED with a parent/caregiver, parents/caregivers on the co-design were able to discuss pediatric mental health discharge communication from their own perspective, as well as provide input on the experiences of their adolescents/youth. Additionally, due to the global COVID-19 pandemic, recruitment and meetings for this study occurred online. This may have impacted the ability to recruit more diverse participants, as participants needed internet access to be part of this study. Second, scheduling design meetings with co-design team members was challenging as it was difficult to find times when all members were available. For several meetings, many members did not show up, or had to leave the meeting early. This limited the perspectives that we were able to incorporate into the design of the interventions and led to us having to re-visit meeting topics multiple times for members who could not attend. Additionally, at times it was difficult to manage expectations of parents to fit the scope of this project. For example, although our focus was on improving discharge communication, parents were interested in also discussing other ED concerns (ex. patient-physician interactions, mental health room location, etc.). As part of EBCD is providing participants the opportunity to share their stories, we spent time discussing topics that were not directly related to the scope of the project, which resulted in us having to hold an additional meeting to finish intervention design and development.

If I were to conduct this study again, I would review more research on approaches used to recruit vulnerable populations, such as adolescents/youth with mental health concerns, into research project teams. Also, for design meetings which did not require parents and clinicians to meet together, I would hold two separate meetings for the parent group and clinician group. This strategy would provide co-design team members with more options for meeting times, and could limit or prevent issues with attendance. Lastly, in co-design meeting 1, I would have made it more clear to design team members that this project is focused specifically on improving discharge communication, and other ED issues, although important, do not fit the scope of the study. This would have provided co-design team members with more clarity on what we are able to accomplish, and result in less time spent on discussing topics not related to discharge communication.

Strengths

For the scoping review, utilizing the EBCD framework as a guide to compare engagement activities across the studies was especially helpful. Despite the variation in study designs and approaches used, I was able to bring the studies together in a meaningful manner by finding similarities and differences through the EBCD framework and GRIPP2 checklist (Staniszewska et al., 2017). Specifically, assessing study components against the EBCD framework helped me compare studies with different designs, methodologies, and engagement strategies. Similarly, the GRIPP2 checklist helped me assess the ways in which patient engagement is reported in studies and notice gaps and areas of improvement in the reporting of studies which I may have otherwise not come across. As well, although there is the inconsistency in the terminology used to describe patient engagement, my collaborating with a health sciences librarian to develop the search strategy resulted in a well-informed, inclusive search. To ensure consistency of terminology and eligibility criteria, all studies were independently evaluated by three reviewers (myself and my co-supervisors, Drs. Newton and Wright).

For the mixed-method study, the greatest strength of the study was the ability to capture and incorporate the input of co-design team members into the design of the interventions. The use of the EBCD framework was critical, as it helped guide the involvement of team members, resulting in high engagement satisfaction at the end of the project. The design of this study also prioritized involving all relevant stakeholders (youth, parents/caregivers, and clinicians) in the project, a common gap in other patient engagement studies. Additionally, utilizing an evidence-based behavior change framework allowed me to work with the co-design team to understand which components of behavior change (capability, motivation, and/or opportunity) are important to address in order to meet the suggested changes in current discharge communication practices. Addressing each of these components resulted in interventions that are more likely to be implemented in clinical care. Lastly, intervention usability testing helped highlight important improvements that could be made before using the interventions in clinical care. Usability testing and incorporating the suggested improvements was important to ensure the interventions are practical to use in a clinical setting, easy for families to use, and helpful for improving discharge communication between clinicians and families.

4.4. Future Directions

Despite being the end users of mental health interventions, patients are rarely meaningfully involved in research. This was made evident from my scoping review, in which I found only 16 mental health intervention design or development studies that involved children, adolescents, or youth with lived experience. Additionally, many of these studies did not utilize a framework to engage patients. To meaningfully involve patients in research and avoid tokenistic forms of engagement, future researchers should consider integrating the EBCD framework into study design, and prioritize assessing and reporting engagement satisfaction with established tools, such as the PPEET (Abelson et al., 2016; McMaster University, n.d.). My scoping review also highlighted the lack of reporting and measurement of the impact of patient involvement in mental health intervention research. Assessing engagement satisfaction and the impact of engagement on research is essential as there is currently limited evidence on how the involvement of patients makes a difference to health research outcomes (Brett et al., 2014; Evans et al., 2014). Research teams leading mental health intervention studies should incorporate existing patient engagement tools, such as the PiiAF (Popay et al., 2014), into study designs to assess the influence that engagement has on the study and its outcomes.

The discharge communication interventions developed in my mixed-method study have the potential to address several gaps in current discharge communication practices, such as poor patient understanding of diagnosis, treatment, and follow-up plans (Akinsola et al., 2017; Gutman et al., 2018). The brochure is designed to help engage families during discharge communication and ensure the documentation of treatment and follow-up plans. The text messaging system is designed to help support families with resources in the post-discharge period. As the text messaging system is not yet developed for clinical use, additional testing including rating experiences with the SUS and/or SRS (Nielsen, 1994) is critical to understand the usability of this technology. Furthermore, despite initial usability testing indicating high clinician, youth, and parent satisfaction with the interventions, future studies are required to test the impact of these interventions. Specifically, studies should assess the impact of these interventions on health care system use, particularly ED re-visit and follow-up visit rates. The impact on patient and family outcomes and experiences should also be evaluated such as the comprehension and recall of discharge plans, satisfaction with the care received, and satisfaction with follow-up plans or referrals. Additionally, although youth participated in the usability testing of interventions, the design and development of the interventions did not incorporate input from children, adolescents, or youth. Given that they are important end users of these interventions, future studies focused on improving pediatric discharge communication should prioritize incorporating this population in intervention design.

4.5. Concluding Remarks

My graduate research contributes to understanding the current approaches to patient engagement in adolescent mental health research and demonstrates how to meaningfully involve patients in mental health intervention design and development. The discharge communication interventions produced in the mixed-method study have the potential to address gaps in current discharge practices. Future research should focus on testing the impact of these interventions on patient care and outcomes, as well as the effects of strategies used to support intervention use.

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Appendix A

Complete scoping review search strategy (2005 – Present)

Ovid MEDLINE(R) ALL <1946 to Present> Searched June 15, 2021 (Citations = 865)

1	Mental Health/
2	mental disorders/ or exp anxiety disorders/ or exp "bipolar and related disorders"/ or exp "disruptive, impulse control, and conduct disorders"/ or exp dissociative disorders/ or anorexia nervosa/ or binge-eating disorder/ or bulimia nervosa/ or food addiction/ or exp mood disorders/ or exp motor disorders/ or anxiety, separation/ or "attention deficit and disruptive behavior disorders"/ or child behavior disorders/ or mutism/ or reactive attachment disorder/ or schizophrenia, childhood/ or stereotypic movement disorder/ or tic disorders/ or exp neurotic disorders/ or exp paraphilic disorders/ or exp personality disorders/ or exp "schizophrenia spectrum and other psychotic disorders"/ or exp somatoform disorders/ or exp substance-related disorders/ or exp "trauma and stressor related disorders"/
3	(mental health or mental wellness or mental* ill* or psychiatric* or depression or depressive or anxiety disorder* or psychoses or psychosis or psychotic* or suicid* or compulsive disorder* or OCD or bipolar or mania or adjustment disorder* or traumatic stress or panic disorder* or mood disorder* or ptsd or ptsi or intellectual* disab* or ((stimulant* or substance* or opioid* or marijuana or cannabis or cocaine or heroin or illicit-drug* or fentanyl) adj3 ("use" or user* or usage or abuse* or misuse* or addict*))).mp.
4	1 or 2 or 3
5	(co-design* or co-creation or co-production or coproduction or codesign* or experience based design* or EBCD or participatory action research or ((patient engagement or patient involvement or PPI or public involvement) adj6 (research or study or trial))).mp.
6	4 and 5
7	limit 6 to yr="2005 -Current"

Embase <1974 to 2021 April 25> (Citations = 900)

1	mental health/
2	addiction/ or exp drug dependence/ or mental disease/ or exp anxiety disorder/ or exp behavior disorder/ or exp dissociative disorder/ or emotional disorder/ or exp mood disorder/ or exp personality disorder/ or exp psychosexual disorder/ or exp psychosis/ or exp psychotrauma/ or exp schizophrenia spectrum disorder/ or neurosis/ or anxiety neurosis/ or tic/ 3. (mental health or mental wellness or mental* ill* or psychiatric* or depression or depressive or anxiety disorder* or psychoses or psychosis or psychotic* or suicid* or compulsive disorder* or OCD or bipolar or mania or adjustment disorder* or traumatic stress or panic disorder* or mood disorder* or ptsd or ptsi or intellectual* disab* or ((stimulant* or substance* or opioid* or marijuana or cannabis or cocaine or heroin or

	illicit-drug* or fentanyl) adj3 ("use" or user* or usage or abuse* or misuse* or addict*))).mp.
3	(mental health or mental wellness or mental* ill* or psychiatric* or depression or depressive or anxiety disorder* or psychoses or psychosis or psychotic* or suicid* or compulsive disorder* or OCD or bipolar or mania or adjustment disorder* or traumatic stress or panic disorder* or mood disorder* or ptsd or ptsi or intellectual* disab* or ((stimulant* or substance* or opioid* or marijuana or cannabis or cocaine or heroin or illicit-drug* or fentanyl) adj3 ("use" or user* or usage or abuse* or misuse* or addict*))).mp.
4	1 or 2 or 3
5	(co-design* or co-creation or co-production or coproduction or codesign* or experience based design* or EBCD or participatory action research or ((patient engagement or patient involvement or PPI or public involvement) adj6 (research or study or trial))).mp.
6	4 and 5
7	limit 6 to (english language and yr="2005 -Current")

APA PsychINFO <1806 to June Week 1 2021> (Citations = 689)

1	mental health/
2	mental disorders/ or exp anxiety disorders/ or exp bipolar disorder/ or exp dissociative disorders/ or exp eating disorders/ or exp paraphilias/ or exp personality disorders/ or exp psychosis/ or exp somatoform disorders/ or exp "stress and trauma related disorders"/ or exp "substance related and addictive disorders"/ or exp attention deficit disorder/ or exp behavior disorders/ or neurosis/ or tics/
3	(mental health or mental wellness or mental* ill* or psychiatric* or depression or depressive or anxiety disorder* or psychoses or psychosis or psychotic* or suicid* or compulsive disorder* or OCD or bipolar or mania or adjustment disorder* or traumatic stress or panic disorder* or mood disorder* or ptsd or ptsi or intellectual* disab* or ((stimulant* or substance* or opioid* or marijuana or cannabis or cocaine or heroin or illicit-drug* or fentanyl) adj3 ("use" or user* or usage or abuse* or misuse* or addict*))).mp.
4	1 or 2 or 3
5	(co-design* or co-creation or co-production or coproduction or codesign* or experience based design* or EBCD or participatory action research or ((patient engagement or patient involvement or PPI or public involvement) adj6 (research or study or trial))).mp.
6	4 and 5
7	limit 6 to (english language and yr="2005 -Current")

CINAHL Plus with Full Text (EBSCOhost interface) Searched June 7, 2021 (Citations = 839)

S1	(MH "Tic+") OR (MH "Mental Health") OR ((MH "Anxiety Disorders+") OR (MH "Dissociative Disorders+") OR (MH "Substance Use Disorders+") OR (MH "Psychotic Disorders+") OR (MH "Paraphilias+") OR (MH "Reactive Attachment Disorder") OR (MH "Separation Anxiety") OR (MH "Social Anxiety Disorders") OR (MH "Somatoform Disorders+") OR (MH "Neurotic Disorders+") OR (MH "Child Behavior

	Disorders+") OR (MH "Attention Deficit Hyperactivity Disorder") OR (MH "Personality Disorders+") OR (MH "Mental Disorders")) OR ((MH "Bipolar Disorder+") OR (MH "Anorexia Nervosa") OR (MH "Binge Eating Disorder") OR (MH "Bulimia Nervosa") OR (MH "Night Eating Syndrome") OR (MH "Eating Disorders"))
S2	(mental health or mental wellness or mental* ill* or psychiatric* or depression or depressive or anxiety disorder* or psychoses or psychosis or psychotic* or suicid* or compulsive disorder* or OCD or bipolar or mania or adjustment disorder* or traumatic stress or panic disorder* or mood disorder* or ptsd or ptsi or intellectual* disab* or ((stimulant* or substance* or opioid* or marijuana or cannabis or cocaine or heroin or illicit-drug* or fentanyl) N3 ("use" or user* or usage or abuse* or misuse* or addict*)))
S3	S1 OR S2
S4	(co-design* or co-creation or co-production or coproduction or codesign* or experience-based-design* or EBCD or participatory-action-research or ((patient-engagement or patient-involvement or PPI or public-involvement) N6 (research or study or trial)))
S5	S3 AND S4

SCOPUS Searched June 14, 2021 (Citations = 1592)

TITLE-ABS-KEY (mental-health OR mental-wellness OR mental*-ill* OR mental-disorder* OR psychiatric* OR depression OR depressive OR anxiety-disorder* OR separation-anxiety OR attachment-disorder* OR psychoses OR psychosis OR psychotic* OR neurotic-disorder* OR suicid* OR compulsive-disorder* OR personality-disorder* OR dissociative-disorder* OR schizophreni* OR somatoform-disorder* OR adhd OR attention-deficit OR eating-disorder* OR anorexia-nervosa OR bulimia-nervosa OR ocd OR obsessive-compulsive OR oppositional-defiant OR behaviour-disorder* OR behavior-disorder* OR bipolar-disorder* OR mania OR adjustment-disorder* OR traumatic-stress OR panic-disorder* OR mood-disorder* OR ptsd OR ptsi OR intellectual*-disab* OR tic-disorder* OR paraphil* OR ((stimulant* OR substance* OR opioid* OR marijuana OR cannabis OR cocaine OR heroin OR illicit-drug* OR fentanyl) W/3 ("use" OR user* OR usage OR abuse* OR misuse* OR addict*))) AND TITLE-ABS-KEY (co-design* OR co-creation OR co-production OR coproduction OR codesign* OR experience-based-design* OR ebcd OR participatory-action-research OR ((patient-engagement OR patient-involvement OR ppi OR public-involvement) W/6 (research OR study OR trial))) AND (LIMIT-TO (LANGUAGE , "English")) AND (LIMIT-TO (PUBYEAR , 2021) OR LIMIT-TO (PUBYEAR , 2020) OR LIMIT-TO (PUBYEAR , 2019) OR LIMIT-TO (PUBYEAR , 2018) OR LIMIT-TO (PUBYEAR , 2017) OR LIMIT-TO (PUBYEAR , 2016) OR LIMIT-TO (PUBYEAR , 2015) OR LIMIT-TO (PUBYEAR , 2014) OR LIMIT-TO (PUBYEAR , 2013) OR LIMIT-TO (PUBYEAR , 2012) OR LIMIT-TO (PUBYEAR , 2011) OR LIMIT-TO (PUBYEAR , 2010) OR LIMIT-TO (PUBYEAR , 2009) OR LIMIT-TO (PUBYEAR , 2008) OR LIMIT-TO (PUBYEAR , 2007) OR LIMIT-TO (PUBYEAR , 2006) OR LIMIT-TO (PUBYEAR , 2005))

Proquest Dissertations and Theses Global Searched June 14, 2021 (Citations=197)
noft((mental-health OR mental-wellness OR mental*-ill* OR mental-disorder OR psychiatric OR depression OR depressive OR anxiety-disorder OR separation-anxiety OR attachment-disorder OR psychoses OR psychosis OR psychotic* OR neurotic-disorder OR suicid* OR compulsive-disorder OR personality-disorder OR dissociative-disorder OR schizophrenia OR schisophrenic OR somatoform-disorder OR adhd OR attention-deficit OR eating-disorder* OR anorexia-nervosa OR bulimia-nervosa OR ocd OR obsessive-compulsive OR oppositional-defiant OR behaviour-disorder OR behavior-disorder OR bipolar-disorder* OR mania OR adjustment-disorder OR traumatic-stress OR panic-disorder* OR mood-disorder OR ptsd OR ptsi OR intellectual-disability OR intellectually-disabled OR tic-disorder OR paraphilia OR paraphilic OR ((stimulant OR substance OR opioid OR marijuana OR cannabis OR cocaine OR heroin OR illicit-drug OR fentanyl) NEAR/3 ("use" OR user OR usage OR abuse OR misuse OR addict)))) AND noft((co-design* OR co-creation OR co-production OR coproduction OR codesign* OR experience-based-design* OR ebcd OR participatory-action-research OR ((patient-engagement OR patient-involvement OR ppi OR public-involvement) NEAR/6 (research OR study OR trial))))

Appendix B

Ethics Forms for Study 2

STUDY INFORMATION LETTER AND CONSENT FORM
(Youth with Decision Capacity, Health Care Providers, and Parents)

Title: Partnership to design communication instructions for mental health visits to the pediatric emergency department

Sponsor: Women and Children's Health Research Institute

Investigator: Dr. Bruce Wright, Director of Pediatric Emergency Medicine and Dentistry, Faculty of Medicine and Dentistry, University of Alberta; Phone: (780) 248-5575; Email: bruce.wright2@ahs.ca

Background

You are being invited to participate in a study so we can improve discharge communication during pediatric mental health visits to the emergency department. You are being invited to be in this study because you are either: 1) a youth; 2) a parent; or 3) an emergency department care provider at the Stollery Children's Hospital. This form provides information about the study, such as the purpose of the study, the risks and benefits, and what you will be asked to do. Before you decide if you would like to take part in the study, it is important that you understand the study details. A staff member for our research team is available to answer any questions you have about the study. You do not have to take part in this study; taking part is entirely voluntary (your choice). You will receive a copy of this form for your records.

What is the purpose of this study?

Children and youth often visit emergency departments when they need mental health care. Reasons include depression, anxiety, thoughts of suicide, or behaviour problems. For children, youth, and their families, these crises are stressful, can be overwhelming, and leave the family vulnerable. Youth and their families experience lack of communication from care providers on what to expect during and after the emergency department visit and care providers can feel unprepared caring for patients with mental health concerns, and resources to improve the care they provide are in high-demand. The purpose of the study is to improve discharge communication during pediatric mental health visits to the Stollery Children's Hospital.

What would you have to do?

If you agree, you will be part of the team of youth, parents, and emergency department care providers to help design and refine discharge communications for child/youth mental health concerns for use in the emergency department. You will be asked to meet with the team six times via Zoom (a secure video conferencing application) over 18-24 months and each meeting will last ~1.5 hours. The researchers will send you the Zoom link ahead of time via email and will set up a secure meeting password and enable the waiting room feature for added security. You have the option of keeping the Zoom video function off and only using the audio function if you would prefer. The discharge communications will be developed over the first four meetings by identifying potential strategies to increase behavior change in the emergency department, limit the number of strategies, and create the initial discharge communications. The initial discharge communications will then be refined over the last two meetings by asking you to test how easy the discharge communications are to use by completing simple tasks and identifying any issues. We may also need to contact you in the future regarding research questions that may be discovered from the data collected in this study.

What are the risks?

The meetings that will be completed in this study will ask you questions about what's most important to include in discharge communications. We don't anticipate you will experience any risks, but if you have experience with mental health concerns or experiences (either good or bad) in the emergency department with health care providers or patients, discussing the best way to communicate discharge instructions may be uncomfortable. This may be especially uncomfortable as the team will consist of youth, parents, and health care providers. However, you may refrain from answering or participating in any tasks and our team will be present to moderate the meetings to ensure you feel comfortable. It is important to note that because you will be discussing things as a group, your anonymity is not guaranteed. Please note that there is a small risk with any external platform such as Zoom of data that is collected falling outside the control of the research team. Please talk to the researcher if you have any concerns.

Are there any benefits to participating in this study?

If you agree to participate in this study, there may or may not be a direct benefit. The information we get from this study may help us to provide better emergency department visits in the future for other patients.

Do I have to participate?

You may decide not to take part in this study, or may stop participating at any time. This decision will not affect your participation on any Council you belong to or your employment if you are an emergency department care provider. If you would like to stop participating, you can let us know by contacting the study team.

May we contact you for future studies related to mental health?

Please circle your answer: **Yes** **No**

Will we be paid for participating, or do we have to pay for anything?

Being in this study will not cost you anything.

Will my records be kept private?

Everything you do in this study will be kept private and confidential. Information, such as your name and your contact information will be kept confidential and known only by the research team. All your personal information will be stored in a secure, password-protected database for at least five years. After that time, your information will be destroyed. At no time will your name be linked to anything you say in the meetings.

<u>If you suffer a research-related injury, will you be compensated?</u>
In the event that you suffer injury as a result of participating in this research, no compensation will be provided to you by the Women and Children's Health Institute, the University of Alberta, Alberta Health Services, or the Researchers. You still have all your legal rights. Nothing said in this consent form alters your right to seek damages.

<u>Consent</u>
By consenting, you are indicating that you have understood to your satisfaction the information regarding your participation in the research project and agree to your participation as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time. If you have further questions concerning matters related to this research, please contact:

Research Coordinator: Nicole Gehring at (780) 394-0066

Investigator: Dr. Bruce Wright at (780) 248-5575

If you have any questions concerning your rights as a possible participant in this research, please contact the University of Alberta Health Research Ethics Board at (780) 492-0459.

Would you like to take part in this study?

☐ Yes, I will be in this research study. ☐ No, I don't want to do this.

Name	Signature and Date

The University of Alberta Health Research Ethics Board has approved this research study (Pro00102111). A signed copy of this consent will be given for you to keep for your records and reference.

STUDY INFORMATION LETTER AND CONSENT FORM
(Youth with Decision Capacity, Health Care Providers, and Parents)

Title: Partnership to design communication instructions for mental health visits to the pediatric emergency department

Sponsor: Women and Children's Health Research Institute

Investigator: Dr. Bruce Wright, Director of Pediatric Emergency Medicine and Dentistry, Faculty of Medicine and Dentistry, University of Alberta; Phone: (780) 248-5575; Email: bruce.wright2@ahs.ca

Background

You are being invited to participate in a study to improve discharge communication during pediatric mental health visits to the emergency department. Our team co-developed discharge communications with families and we want to test them to make sure they are acceptable before using them as part of routine care in the emergency department. You are being invited to be in this study because you are either: 1) a youth or parent of a youth who visited the Stollery Children's Hospital emergency department in the past six months for mental health care; or 2) are a nurse or physician at the Stollery Children's Hospital who care for children and youth in the emergency department. This form provides information about the study, such as the purpose of the study, the risks and benefits, and what you will be asked to do. Before you decide if you would like to take part in the study, it is important that you understand the study details. A staff member for our research team is available to answer any questions you have about the study. You do not have to take part in this study; taking part is entirely voluntary (your choice). You will receive a copy of this form for your records.

What is the purpose of this study?

Children and youth often visit emergency departments when they need mental health care. Reasons include depression, anxiety, thoughts of suicide, or behaviour problems. For children, youth, and their families, these crises are stressful, can be overwhelming, and leave the family vulnerable. Youth and their families experience lack of communication from care providers on what to expect during and after the emergency department visit and care providers can feel unprepared caring for patients with mental health concerns, and resources to improve the care they provide are in high-demand. The purpose of the study is to improve discharge communication during pediatric mental health visits to the Stollery Children's Hospital.

What would you have to do?

If you agree to take part in this research, you will be asked to meet with the research team to test the discharge communications we developed. The sessions will take 30-45 minutes and will be audio recorded. The session will ask you to perform certain tasks with the discharge communications. As you perform the tasks, you will be asked to 'think aloud'. Youth and parents will work through tasks related to interpreting and discussing discharge instructions while care providers will complete tasks related to communicating and answering questions related to the discharge instructions. We will also ask you some information about yourself (e.g., age, gender, socioeconomic status, and if you are a parent of youth the reason for visiting the emergency department). We will work with you to find time/date options that fit in with your life commitments. We may also need to contact you in the future regarding research questions that may be discovered from the data collected in this study.

What are the risks?

The session will ask you to complete certain tasks and think aloud while you are doing them. We don't anticipate you will experience any risks, however voicing your ideas and concerns out loud in front of other people may be uncomfortable. A member of the research team will help guide you through the tasks to ease any discomforts and you may refrain from participating in any tasks you don't want to complete.

Are there any benefits to participating in this study?

If you agree to participate in this study, there may or may not be a direct benefit. The information we get from this study may help us to provide better emergency department visits in the future for other patients.

Do I have to participate?

You may decide not to take part in this study, or may stop participating at any time. This decision will not affect any care you may receive at the Stollery Children's Hospital if you are a parent or youth. If you are an emergency department care provider, your decision not to take part in the study will not affect your employment at the Stollery Children's Hospital. If you would like to stop participating, you can let us know by contacting the study team.

May we contact you for future studies related to mental health?

Please circle your answer: **Yes** **No**

Will we be paid for participating, or do we have to pay for anything?

Being in this study will not cost you anything. If you take part in this study, you will be given a token of appreciation for your time (i.e., a $25 gift card).

Will my records be kept private?

Everything you do in this study will be kept private and confidential. Information, such as your name, age, and contact information will be kept confidential, separate from your audio recorded responses, and known only by the research team. All your personal information will be stored in a secure, password-protected database for at least five years. After that time, your information will be destroyed.

If you suffer a research-related injury, will you be compensated?

In the event that you suffer injury as a result of participating in this research, no compensation will be provided to you by the Women and Children's Health Institute, the University of Alberta,

Alberta Health Services, or the Researchers. You still have all your legal rights. Nothing said in this consent form alters your right to seek damages.

Consent

By consenting, you are indicating that you have understood to your satisfaction the information regarding your participation in the research project and agree to your participation as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time. If you have further questions concerning matters related to this research, please contact:

Research Coordinator: Amber Ali at (780) 902-2077

Investigator: Dr. Bruce Wright at (780) 248-5575

If you have any questions concerning your rights as a possible participant in this research, please contact the University of Alberta Health Research Ethics Board at (780) 492-0459.

Would you like to take part in this study?

☐ Yes, I will be in this research study. ☐ No, I don't want to do this.

Name	Signature and Date
Investigator/Delegate's Name	Date

The University of Alberta Health Research Ethics Board has approved this research study (Pro00102111). A signed copy of this consent will be given for you to keep for your records and reference.