**Patient and Clinician Perspectives on**

**Patient Portal Use in the Mental Health Context**

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## Abstract

Patient portals facilitate patients' access to their electronic health care records, and may also include features such as patient-clinician messaging, prescription renewal, and educational resources. There is evidence that portals support patient empowerment, therapeutic communication, adherence to treatment, and satisfaction with care. Nonetheless, patient portals are underutilized in mental health settings, with policies in some health care organizations restricting all access to mental health records through patient portals. A qualitative evidence synthesis was conducted to explore the perspectives of clinicians and patients on portal use in the mental health care context represented in the current literature. A systematic search of relevant databases, followed by citation and article screening, yielded 24 qualitative and mixed-methods studies for inclusion, and a thematic synthesis was performed. The synthesis yielded five themes: impacts to the efficiency of mental health care delivery; effects on therapeutic relationships between clinicians and patients; changes to the patient-clinician power balance; the suitability of patient portals for patients with mental illness; and the complexities of information management in mental health care. Ultimately, both clinicians and patients acknowledged numerous potential benefits of patient portals, but there were also concerns about their use specific to the mental health context. These concerns were voiced primarily by clinicians, and originated in part from concern for patient safety, but also from stigmatizing attitudes and the perceived threats of portals to clinicians' workloads and control over the record. This systematic review of qualitative studies highlights opportunities for organizations to support their clinicians through the implementation of recovery-oriented initiatives like patient portals, and to support patients with mental illness by ending discriminatory policies limiting access to their records.

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# Chapter 1: Introduction

Over the past twenty years, there has been a rapid proliferation of digital health innovations made possible by increasing societal comfort with the Internet, mobile technologies, and social applications involving information exchange. It is imperative that nurse researchers investigate these digital interventions: firstly, to determine their suitability for enhancing health care, and secondly, to ensure equitable access to their benefits by vulnerable patient populations.

According to the Mental Health Commission of Canada (MHCC), one in five Canadians live with a mental health problem or mental illness in any given year, and by the age of 40, fifty percent of Canadians have had, or currently have, a mental health problem or mental illness (MHCC, 2013). Mental health problems and illnesses pose significant risks to a person's quality of life; they may negatively impact one's emotional experiences, cognitive functioning, and the ability to participate in social and occupational activities. Additionally, individuals with mental illness comprise a population that is vulnerable to health care inequities. They experience higher rates of poverty, incarceration, homelessness, chronic health conditions, and suicide than the general population. Overall, mental health problems and mental illness are significant sources of personal and societal distress (MHCC, 2013; World Health Organization, 2013). Inadequately managed mental health conditions and comorbid medical conditions also generate significant monetary costs to the health care system through frequent emergency service use and hospitalizations, as well as to the economy through unemployment, absenteeism, and lost productivity (Canadian Alliance on Mental Illness and Mental Health, 2016; MHCC, 2013). Clearly, it is important to explore interventions that might improve the quality of care for those with mental illness, who are underserviced and stigmatized (Canadian Mental Health Association, 2018).

One such intervention is the patient portal (Canadian Medical Association & Ipsos, 2019; Irizarry et al., 2015). Patient portals are Internet-based software applications designed to facilitate patients' access to their health care records. They also include numerous other potential functions, such as appointment booking, prescription requests, self-assessments, communication between patients and clinicians, and provision of educational resources (Irizarry et al., 2015; Mayhew et al., 2018). These functions represent opportunities to improve health care by fostering patients' engagement and collaboration with their clinicians, as well as providing broader access to health information and health services. Emerging evidence suggests that portal use may positively impact patient outcomes, such as patient empowerment, adherence to treatment, satisfaction with care, and therapeutic communication with clinicians (Ammenwerth et al., 2019; Canada Health Infoway & Social Research and Demonstration Corporation [SRDC], 2018; Delbanco et al., 2012; de Lusignan et al., 2014; Otte-Trojel et al., 2014; Sarkar et al., 2014; Shah & Liebovitz, 2017).

## Purpose

While the effectiveness of an intervention is important, one must also consider the usefulness or meaningfulness of it for the people it is intended to help. An initial search of the literature produced several qualitative studies exploring patient and clinician views on patient portal use in various contexts, including mental health care. This initial search demonstrated that, while promising, portals are new and evolving, and research about their use and effectiveness is nascent (Ammenwerth et al., 2019; de Lusignan et al., 2014; Goldzweig et al., 2013). Furthermore, individual qualitative studies, though valuable, are limited because of their small sample sizes and specific contexts (Houghton et al., 2017). One way to offset these limitations is to synthesize findings across studies using a rigorous systematic review methodology. This

facilitates an in-depth understanding of a phenomenon and allows for the identification of common patterns of experience from which useful conclusions can be drawn (Houghton et al., 2017). The purpose of this Master's thesis is to synthesize the findings of existing qualitative studies exploring patient and clinician perspectives of portal use in mental health care, which have not yet been subject to any formal synthesis.

## Research Question

The research question addressed in this qualitative evidence synthesis is 'What are the perceptions, attitudes, and/or experiences of patients and clinicians with regard to patient portal use in the mental health context?'

## Personal Impetus

I am a registered nurse who has worked in mental health care settings for most of my career. Currently, my role is dedicated to advancing nursing education and professional practice at a tertiary mental health centre. As a nurse in this field, as well as someone who has experienced mental illness myself, I am driven to explore innovations for the betterment of mental health care. When patient portals began to be implemented in Ottawa hospitals, I commenced a brief literature review to contribute to their implementation at my facility. I thought my interest would end with this quality improvement project; however, I came across the following line in The Ottawa Hospital's MyChart patient portal website: "You will not be able to see: Psychology, Psychiatry, Mental Health, Social Work, or Spiritual Care documentation." (section 6, The Ottawa Hospital, n.d.). My curiosity was piqued. When I contacted The Ottawa Hospital's MyChart support team to inquire about this, I received the following response:

"There is currently no plan in the future to release this documentation to MyChart. Most of these decisions are steered by a committee that consists of members of the health care team, as

well as input from members of the community who actively use our portal. I believe this questions [sic] has been brought up previously for review, but thus far there is no intention to change" (The Ottawa Hospital, personal communication, February 18, 2020).

As I discovered during my quality improvement project research, this policy is by no means unique to The Ottawa Hospital; rather, exclusion of mental health records appears to be common practice when implementing patient portals. I could not help but wonder what drives these decisions; what are the perspectives of the health care teams, and members of the community, that inform these policies?

This systematic review will illuminate the perspectives of mental health clinicians and patients (and perhaps some who, like me, have experiences on both sides). Hopefully, the study findings will contribute to an improved understanding of patient portal use in this context that informs future policy and practice in Ottawa health care facilities and beyond.

## Paradigmatic Stance

The constructivist paradigm is useful in qualitative mental health nursing research because it places focus on the lived experiences of individuals within their real-world contexts, and from their perspectives (Appleton & King, 1997). The constructivist approach assumes that all perspectives are valid and representative of individuals' differently experienced realities (Appleton & King, 1997).

Constructivism holds an ontological position of relativism. Constructivism asserts that there is no one true reality but instead multiple realities inseparable from the interpretations of those experiencing them (Guba & Lincoln, 1994). There is an underlying assumption that people cannot be considered apart from their contexts and environments, and so the focus of research becomes the lived experiences of those being researched (Weaver & Olson, 2006).

Epistemologically, constructivism asserts that knowledge is subjective, and frequently changes as people and their contexts change (Guba & Lincoln, 1994). There are aspects of personal realities that will naturally overlap between individuals; knowledge consists both of these areas of consensus and coexisting, sometimes conflicting interpretations. (Appleton & King, 1997; Guba & Lincoln, 1994). The purpose of constructivist research is not only to understand and describe these realities, but to explore and interpret the meanings people have ascribed to their experiences (Appleton & King, 1997; Creswell, 2009; Guba & Lincoln, 1994; Weaver & Olson, 2006). Constructivists value individuals being studied as knowledgeable experts on their experiences (Creswell, 2009).

Patients requiring mental health care frequently experience stigma and comprise a vulnerable population with historically poor health outcomes (Canadian Mental Health Association, 2018; Henderson et al., 2014; World Health Organization, 2013). Thus, it is integral to provide a space within research for these patients to use their voices, which are often overlooked (Bracken-Roche et al., 2016; Griffiths et al., 2004; Happell, 2008). It is also important to hear the perspectives and concerns of mental health clinicians; this facilitates understanding of the challenges faced in providing care so that barriers can be evaluated and surmounted. Finally, a comparison of the perspectives between patients and clinicians can provide valuable insight into aspects of the intervention that are viewed as problematic (or sound) by each group and jointly.

Although I situate myself and this research within the constructivist paradigm, I conducted this review with the knowledge that the various qualitative studies included in the review might be conducted using methodologies that align with other paradigms. This plurality

of philosophical underpinnings and the potential tensions between them is addressed in the methodology and results chapters.

## Format of the Thesis

This thesis is formatted in a traditional monograph style and is divided into five chapters (including this one). Chapter 2 provides an overview of the current literature through an exploration of concepts embedded in my research question: mental health and mental illness, mental health care, mental health clinicians, and patient portals. It also includes an examination of concepts that are peripheral to my research question, but nonetheless relevant to the mental health context and/or patient portals: recovery-oriented practice, stigmatization, competency and capacity, and patients' right of access to health information. Chapter 3 outlines the methodological approach and the methods used to answer my research question. Chapter 4 contains the results of the systematic review, including the themes extracted during the meta-analysis and direct quotations to support my findings. Finally, Chapter 5 includes an integrated discussion of findings and their implications for nursing research, education, practice, and policy, as well as the strengths and limitations of the study.

# Chapter 2: Literature Review and Conceptual Foundations

Using the existing literature, I conducted a review to explore key concepts embedded in my research question: mental health, mental illness, mental health care, and patient portals. The following is a discussion and critique of the definitions found in the literature, on which the operational definitions and eligibility criteria in this study are based. The literature review on patient portals also includes a summary of what is already known in this field, in order to establish the role of this study in advancing knowledge about patient portals in the context of mental health care.

In this chapter, I also address additional concepts and theories relevant to my research question that informed my approach to the topic of patient portals in the mental health context. The four core concepts examined in this chapter are: recovery-oriented practice, stigmatization, competency and capacity in mental illness, and patients' right of access to health records. While my research was inductive, and data analysis was not structured using a theoretical framework, I thought it prudent to reflect on pertinent concepts and their relation to my research question prior to data analysis for the sake of transparency and reflexivity.

## Central Concepts: Mental Health and Mental Illness

### Two Conceptual Models

Mental health and mental illness are concepts for which there are numerous, sometimes conflicting, definitions. Traditional models presented these concepts as polar opposites, while more recent literature posits that these concepts are distinct, but related, dimensions of a person's experience, and that they are not mutually exclusive (Iasiello & van Agteren, 2020).

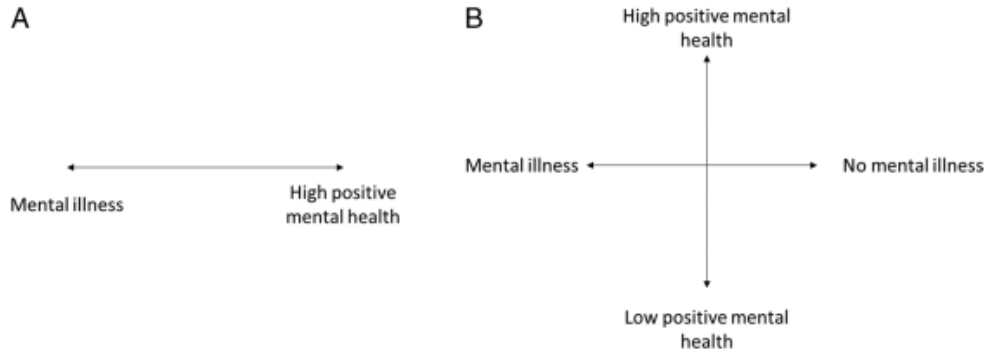
The traditional conceptualization situates the concepts of mental health and mental illness at either end of a single continuum; this ensures that mental health is defined by the absence of

mental illness. In this model, mental health care focuses on reducing or eliminating the symptoms of mental illness as the primary approach to achieving mental health (Iasiello & van Agteren, 2020). However, in the dual continuum model, mental health and mental illness are presented as existing along two separate continua – mental health and mental illness. The mental health continuum indicates the degree to which mental health is present, while the mental illness continuum indicates the degree to which mental illness is present, such that health and illness may co-exist at different levels in the same person. (Iasiello & van Agteren, 2020; Westerhof & Keyes, 2010). A visual depiction of these models is presented in Figure 2.1.

The dual continuum model better explains the experiences of individuals who may have no diagnosable mental disorder but who, nonetheless, struggle with their wellbeing and may seek out support. It also better describes the experiences of people with chronic mental illness who also experience positive mental health. The dual continuum conceptualization of mental health and mental illness is also reflected in the explanation of mental health given by the Canadian Mental Health Association (CMHA): "Mental health isn't simply the absence of mental illness and living with a mental illness doesn't mean you can't have good mental health. Just like someone with diabetes, for example, can live a healthy life, so can somebody with a mental illness" (CMHA, 2020, para. 6). Similarly, the World Health Organization (WHO) includes mental wellbeing in its definition of the broader concept of health and indicates that health is more than the absence of illness: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 2018, para. 1).

**Figure 2.1**

*Models of Mental Health and Mental Illness*




*Note.* The traditional model (A) and the dual continuum model (B). From Iasiello & van Agteren (2020).

### *Hedonia and Eudaimonia*

If mental health (or mental wellness or wellbeing) is more than the inverse or absence of mental illness, what is it? Historically, research on the idea of wellbeing has focused on two core philosophical approaches: the hedonic tradition, which emphasizes a sense of happiness or pleasure as the ultimate expression of wellbeing, and the eudaimonic tradition, which focuses on a person's functioning and the achievement of one's full potential (Keyes, 2014). The World Health Organization (WHO) (2018) has defined mental health as "a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community" (para. 2). This definition aligns with both the hedonic and eudaimonic traditions by referring to both positive affect and positive functioning (Galderisi et al., 2015).

### *Internal Equilibrium*

While widely cited, the WHO's definition of mental health, and the traditions in which it is rooted, have also been subject to criticism. Galderisi et al. (2015) argued that the conceptualization of mental health as a state of wellbeing, which is characterized by the presence

of positive feelings and optimal functioning, presents several problems. For one, it risks pathologizing negative emotions such as sadness and anger, which while unpleasant, are not unhealthy; rather, they are part of the normal human emotional spectrum. For another, optimal functioning is highly influenced by cultural values and individual contexts and resists any attempt at universal definition (Galderisi et al., 2015). Galderisi et al. (2015) critiqued the WHO's conceptualization of optimal functioning as the ability to 'work productively and fruitfully'. They argued that this definition precludes the classification of those who are unable to work (due to age, physical disability, or numerous environmental and social factors) as 'mentally healthy' (Galderisi et al., 2015; Palumbo & Galderisi, 2020). In light of these criticisms, they proposed a different definition allowing for the diversity of emotions and functioning experienced by mentally healthy people:

> Mental health is a dynamic state of internal equilibrium which enables individuals to use their abilities in harmony with universal values of society. Basic cognitive and social skills; ability to recognize, express and modulate one's own emotions, as well as empathize with others; flexibility and ability to cope with adverse life events and function in social roles; and harmonious relationship between body and mind represent important components of mental health which contribute, to varying degrees, to the state of internal equilibrium. (Galderisi et al., 2015, pp. 231-232.)

In recognition of the cultural impact on the historical conceptualization of mental health, and in an effort to exclude culture-bound components, this definition references the universal values of society. Galderisi et al. (2015) explained that these are "respect and care for oneself and other

living beings; recognition of connectedness between people; respect for the environment; respect for one's own and others' freedom" (pp. 232).

Similarly, the Public Health Agency of Canada (PHAC) has defined mental health as "The capacity of each and all of us to feel, think, and act in ways that enhance our ability to enjoy life and deal with the challenges we face. It is a positive sense of emotional and spiritual well-being that respects the importance of culture, equity, social justice, interconnections and personal dignity" (PHAC, 2006, p. i). This definition also reflects hedonic ("ability to enjoy life"; "positive sense of emotional and spiritual well-being") and eudaimonic ("deal with the challenges we face") traditions, while acknowledging the social and cultural factors influencing mental health. Manwell and colleagues (2015) found that this definition was preferred by both researchers and persons with mental health problems. This preference may be due to the broader definition of functioning as being inclusive of coping skills and addressing challenges, rather than focusing on work and productivity (Palumbo & Galderisi, 2020).

***Social Autonomy and Agency***

Upon further exploration of the definitions of mental health proposed in the literature, Palumbo & Galderisi (2020) asserted that the inclusion of the concept of universal values in the definition of mental health is counterproductive and unnecessarily binds a person's mental health to an adherence to cultural norms and values - even so-called universal values, which may not exist. However, rather than offering a wholly new definition, they reinforced some of the basic components of mental health present in the definition proposed in Galderisi et al. (2015): basic cognitive and social skills; the ability to recognize, express and modulate one's own emotions, and flexibility in the face of life changes. When addressing the cultural aspects of the concept of mental health, they referenced the above-mentioned study by Manwell and colleagues (2015), in

which participants (mental health experts, including those with lived experience of mental illness) placed emphasis on autonomy and agency as core features of mental health. Based on their survey, Palumbo and Galderisi (2020) proposed that "mentally healthy individuals are socially connected through meaningful participation in social valued roles (i.e., in family, work, etc.), but … mental health may involve being able to disconnect by choice, as opposed to being excluded" (p. 9). Defining mental health in this way acknowledges the potential influence of engagement in social and cultural roles on mental health. It also acknowledges the notion that healthy individuals should be free to participate in social roles (or not) based on their preferences.

Palumbo & Galderisi (2020) concluded their review by stating that the development of the concept of mental health is ongoing, and that future efforts to refine the conceptualization will require input from persons with firsthand experience of both mental health and mental illness. My own experiences with mental illness have led me to appreciate and embrace the conceptualization of mental health as a state of internal equilibrium, where negative thoughts and emotions are recognized as natural human responses to life circumstances that are managed through individual coping mechanisms as well as chosen social supports.

**Defining Mental Illness**

Mental illness goes by many names, among them mental disorder, mental disability, psychiatric disorder, and psychopathology (Bergner & Bunford, 2017). Mental illness can be rudimentarily defined as a condition involving disturbances in emotion, cognition, or behaviour, resulting in distress and/or functional impairment (American Psychiatric Association [APA], 2018; PHAC, 2022; WHO, 2019). However, just as there is no consensus on a definition for mental health, there is no universally accepted definition of mental illness. Furthermore, there is

no agreement on whether a clear-cut threshold exists between mental illness and 'normal' reactions to life's difficulties, and if so, where it lies (Bergner & Bunford, 2017; Iasiello & van Agteren, 2020). This is unsurprising given that the conceptualization of mental illness is historically rooted in diverse social, cultural, and religious contexts (Fernando, 2014; Kirmayer & Bhugra, 2009).

### *Diagnostic Classification*

As explained in one of the primary classification manuals of mental illness, the *Diagnostic and Statistical Manual of Mental Disorders, 5th edition, text revision* (DSM-5-TR), "the boundaries between normality and pathology vary across cultures… thresholds of tolerance for specific symptoms or behaviors differ across cultures, social settings, and families. Hence, the level at which an experience becomes problematic or pathological will differ" (APA, 2022b, Impact of Cultural Norms section, para. 1). Diagnostic criteria outlined by the DSM-5-TR may include that the emotional responses or behaviours exhibited are socioculturally deviant (APA, 2022b; Bergner & Bunford, 2017); however, "socially deviant behavior (e.g., political, religious, or sexual) and conflicts that are primarily between the individual and society are not mental disorders *unless* [emphasis added] the deviance or conflict results from a dysfunction in the individual" (APA, 2022b, Definition of a Mental Disorder section, para. 2). Additionally, the essential criteria for mental disorders generally include a subjective sense of suffering or distress on the part of the person diagnosed, as well as some level of impaired functioning (APA, 2022b).

The fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) was published in 2013 (APA, 2013), and its text revision (DSM-5-TR) was published in 2022 (APA, 2022a). It is worth noting that the DSM, over its several editions and revisions, has been subject to much criticism and controversy which is beyond the scope of this review. Among

other critiques, there are those who argue that the DSM pathologizes natural human emotional responses and behaviours, that there was undue influence in its development by pharmaceutical companies, and that there was a lack of transparency in the revision process (Hoff, 2009; Welch et al., 2013).

The DSM-5-TR, used primarily in the United States and Canada, is not the only manual used for the identification and categorization for mental illness. The World Health Organization (WHO) publishes the *International Statistical Classification of Diseases and Related Health Problems* (ICD) which is more frequently used than the DSM-5-TR outside of North America (WHO, n.d.). The categorizations and diagnostic criteria outlined in the two manuals do not always align. The authors of the DSM-5, and its text revision, DSM-5-TR, attempted to align the manual with the 11th edition of the ICD, which took effect January 1, 2022 (APA, 2013; APA, 2022a). However, conflicts in the revision schedule made this impossible, and harmonization efforts remain incomplete (APA, 2022b).

### *Mental Health Problems vs. Mental Illness*

The term ‘mental health problem’ is often found in the literature, grouped with the definition of ‘mental illness’. The boundary between these two concepts is not well-defined. In its national mental health strategy document, *Changing Directions, Changing Lives,* the Mental Health Commission of Canada (MHCC) stated: “This Strategy does not attempt to draw a firm line between ‘problems’ and ‘illnesses,’ or to resolve all of the controversies surrounding the choice of terminology” (MHCC, 2012, p. 14). In a separate report published in 2013, the MHCC stated, “The phrase ‘mental health problems and illnesses’ represents the range of behaviours, thoughts and emotions that can result in some level of distress or impairment” (MHCC, 2013, p. 4), and indicates that mental health problems and illnesses may or may not be accompanied by a

diagnosis. The MHCC acknowledged that there are mental health problems that cause distress but do not fulfil diagnostic criteria for ‘mental illness’. These are sometimes described as subclinical or subthreshold (Ji, 2012).

Both the DSM-5-TR and ICD-11 also acknowledge the presence of mental health problems (while not naming them precisely as such). In these diagnostic manuals, problems with mental health not meeting diagnostic criteria for mental illness are identified using of the term ‘unspecified’. As an example, someone with depressive symptoms not meeting the full criteria for major depressive disorder may be described as having an unspecified depressive disorder (APA, 2022c). Additionally, the DSM-5-TR recognizes that there are mental health problems and social and economic circumstances that may exacerbate mental illness. The manual defines these as “conditions and psychosocial or environmental problems that may be a focus of clinical attention or otherwise affect the diagnosis, course, prognosis, or treatment of an individual’s mental disorder” (APA, 2022d, para. 1). Examples of these mental health problems include stress related to employment, schooling, relationship conflicts, etc., as well as difficulties adjusting to life transitions.

Conceptualizations of the nature and range of mental health problems and mental illnesses are also reflected in how data on mental health and illness are collected and published. The above-mentioned report from the MHCC (2013) outlines the findings of a study undertaken by Smetanin and colleagues (2011). This is the source for the widely cited Canadian statistic that one in five Canadians experience mental health problems or mental illness in any given year. Given the broad definition the MHCC provides for mental health problems and mental illness, one might expect this statistic to include those with both diagnosed illness, as well as subclinical mental distress. However, this study was intended to measure major mental illness (Smetanin et

al., 2011), a concept which is discussed below. For the purposes of their study, Smetanin and colleagues (2011) included only mood disorders, anxiety disorders, schizophrenia, attention deficit/hyperactive disorder, oppositional defiant disorder, conduct disorder, substance use disorders, and dementia. This operational definition excludes subclinical conditions; in fact, it excludes a substantial number of the DSM-5-TR and ICD-11 categories. Based on this data, the prevalence of all mental illness in Canada, as well as mental health problems, is likely much greater than 20 percent. This further underscores the need for research into best practices for mental health care.

### *Mental Illness vs. Serious Mental Illness*

The terms serious mental illness, severe mental illness, major mental illness, and severe and persistent mental illness (SPMI) are often used interchangeably in the study of mental illness. These terms distinguish mild or moderate mental illness from mental illness that is typically chronic and has debilitating effects on the individuals who experience it (Zumstein & Riese, 2020). Some researchers base the severity of mental illness on the level of impairment experienced; for example, the United States National Institute of Mental Health (NIMH) defines serious mental illness as “a mental, behavioral, or emotional disorder resulting in serious functional impairment, which *substantially interferes with or limits* [emphasis added] one or more major life activities” (NIMH, 2022, para. 4). The United States Substance Abuse and Mental Health Services Administration (SAMHSA) defines serious mental illness similarly, and in their report on national measures of mental health, ‘substantial interference' was measured using the Global Assessment of Functioning (GAF) scale, with any score less than or equal to 50 considered substantial (SAMHSA, 2020). Of interest, the DSM-5, published prior to SAMHSA’s

report, eliminated the GAF and moved to the WHO Disability Assessment Schedule, Version 2 (APA, 2013).

Other researchers define serious, severe, or major mental illness based on diagnostic categories. For example, in their systematic review on non-psychiatric health service utilization by those with severe mental illness, Ronaldson and colleagues (2020) asserted that severe mental illness "generally refers to illnesses associated with psychosis" (p. 3); they therefore included bipolar disorder, schizophrenia, and schizoaffective disorder, but not major depressive disorder. By contrast, other researchers using the terms 'serious mental illness' or 'major mental illness' have used definitions including psychotic disorders, bipolar disorder, and major depressive disorder (Hunt et al., 2019; Lawrie, 2019; Olmos-Ochoa et al., 2019; Penney et al., 2016). Finally, as outlined previously, the study performed by Smetanin et al. (2011) for the MHCC defined major mental illness as inclusive of mood disorders, anxiety disorders, schizophrenia, attention deficit/hyperactivity disorder, oppositional defiant disorder, conduct disorder, substance use disorders, and dementia.

**Summary**

There is clearly no universally accepted definition of either mental health or mental illness. An analysis of the concept of severe and persistent mental illness conducted by Zumstein & Riese (2020) acknowledged the inconsistencies in terminology throughout the literature and noted that the concept has been defined variously using the dimensions of diagnosis, duration of illness, and level of disability. They cautioned against efforts to produce a universal definition, acknowledged the context-dependent nature of mental health and mental illness, and encouraged researchers to operationalize the concept for their contexts using these dimensions as a guide. In this study, these terms are operationalized in the form of eligibility criteria as outlined in Chapter

3 (Methodology). They are also framed in the context of mental health care delivery, which is discussed next.

## Central Concept: Mental Health Care

### Defining Mental Health Care

The term health care is used to describe services to promote health and treat illness in individuals, families, and communities, and involves processes including health promotion, illness prevention, screening and diagnosis, treatment of disease, health maintenance and monitoring, and palliation (Bergman et al., 2011; Health Canada, 2019). These services are provided by one or more health care professionals, and often within interdisciplinary teams consisting of regulated professionals such as physicians, nurses, and allied health professionals, as well as unregulated care providers such as personal care assistants (Health Canada, 2019).

Mental health care includes health care services provided to those with mental health problems and to those with both mild, moderate, and severe mental illness. Additionally, mental health care can and should include preventative care and health promotion initiatives for the advancement of positive mental health. However, many mental health promotion interventions are broad-scale population-focused campaigns established by the public health sector (Canadian Public Health Association [CHPA], 2021). Examples include public education, suicide prevention initiatives, and advocacy campaigns addressing systemic inequities impacting mental health (CHPA, 2021; PHAC, 2022). These activities are not documented in any individual record of care accessible via patient portals; therefore, for the purposes of this study, these population-focused health promotion interventions were not included under the definition of mental health care. However, individualized health promotion interventions documented in health care records were included.

### *Mental Health Care Service Classifications*

Health care services are commonly classified as primary, secondary, or tertiary care services, and mental health care is provided at all levels. Primary care services, such as offices and clinics run by family physicians/nurse practitioners, are the most broadly accessible, act as the first points of contact with the health care system, and often involve care coordination and referral to specialized services (Health Canada, 2019; Sampson et al., 2015). Primary care services are able to provide basic mental health counselling services and prescription medications to alleviate distress, but patients are referred to secondary and tertiary services for emergent and/or complex care needs (Brien et al., 2015; Canadian Mental Health Association [CMHA], 2018; Health Canada, 2019; Sampson et al., 2015). These services include outpatient mental health clinics or individual specialists' offices, residential addictions treatment centres, emergency departments, acute mental health units in general hospitals, tertiary mental health care centres, and community outreach services (Brien et al. 2015; Canadian Institute for Health Information [CIHI], 2019; Wasylenki et al., 2000). Finally, patients may also receive medications and procedures as part of research studies at quaternary care centres. Quaternary care is the least accessible and the most specialized and complex level of care and includes experimental medicine and procedures; facilities providing quaternary care are often associated with universities (Sataloff, 2019). In Ottawa, quaternary care is provided by the Institute for Mental Health Research, a facility jointly run by The Royal Ottawa Health Care Group and the University of Ottawa (Royal Ottawa Health Care Group, n.d.-a).

### *Mental Health Care Providers*

For the purposes of this study, mental health care is used as an umbrella term for all services provided by a variety of health care providers that address mental health and mental

illness. It should be noted that the terms ‘psychiatry’ or ‘psychiatric care’ and ‘mental health care’ are often used interchangeably; for example, some use the term ‘psychiatric nursing’ to describe nursing care relating to mental health and mental illness (Canadian Nurses Association, n.d.; College of Nurses of Ontario [CNO], 2019b). However, here I will use ‘psychiatry’ and ‘psychiatric care’ to refer to the practice of psychiatrists only.

**Physicians.** Physicians of all specialties and at all levels of care encounter patients with mental health care needs. Primary care physicians (e.g., family or general practitioners) may directly diagnose and treat individuals with mental health care needs. However, they may also refer patients to psychiatrists (Brien et al., 2015). Similarly, in Canadian acute care hospitals, emergency physicians and hospitalists who encounter patients with mental health care needs may consult psychiatrists or advanced practice nurses specializing in mental health care, while themselves focusing on the physical health needs of the patient (Brien et al., 2015).

Psychiatrists are physicians who are specialized in psychiatry. Psychiatry is defined by the American Psychiatric Association as “the branch of medicine focused on the diagnosis, treatment and prevention of mental, emotional and behavioural disorders” (APA, n.d.). Psychiatrists may, among other competencies, diagnose mental illness, prescribe medications, and provide psychotherapy.

**Nurses.** Nurses may provide mental health care in any of the settings identified above. Nurses conduct mental health assessments, provide individual or group education, and administer medications, among other competencies outlined in the *Canadian Standards for Psychiatric-Mental Health Nursing*, *4th edition,* published by the Canadian Federation of Mental Health Nurses (CFMHN, 2014).

However, it should be noted that the level of preparation for mental health care varies dependent on the nurse's licensure and jurisdiction. In some regions, there are nurses trained specifically in mental health (in Western Canada, these are registered psychiatric nurses). In other regions, including Ontario, mental health care is one of many areas of practice in which licensed nurses are employed. These generalist classifications include registered practical nurses (RPNs), licensed practical nurses (LPNs), and registered nurses (RNs), among others (College of Nurses of Ontario [CNO], 2019a). However, in Ontario, the entry-to-practice competencies outlined for RPNs make no direct mention of mental health care (CNO, 2020b), whereas the RN entry-to-practice competencies include the provision of recovery-oriented nursing care, mental health promotion, harm reduction for substance use, and suicide prevention (CNO, 2020a).

Advanced practice nurses, such as clinical nurse specialists and nurse practitioners, also provide mental health care in many different care settings. These advanced practice nurses provide comprehensive care and consultation services for patients with complex needs, as well as leading research, policy development, and educational initiatives. In Ontario, nurse practitioners, unlike nurses in other classifications, are permitted to diagnose mental illness and prescribe medication (Canadian Nurses Association, 2019; CNO, 2021). In some regions (for example, the United States and Quebec), nurse practitioners may specialize in mental health care (McGill University, n.d.; Tracy & O'Grady, 2019).

**Allied Health.** Allied health professionals commonly involved in mental health care include, among others, psychologists, pharmacists, social workers, occupational therapists, recreational therapists, vocational therapists, and behavioural therapists (Brien et al., 2015; CIHI, 2019). Collectively, allied health professionals contribute to the holistic care of patients by providing a broad range of services. These professionals may, for example, assist with

coordinating care and locating community supports; liaise with family members; assess patients' ability to function independently; provide one-to-one psychotherapy or counselling; and facilitate group psychotherapy or other therapeutic activities (Brien et al., 2015; CMHA, 2018).

**Unregulated Care Providers.** Unregulated care providers such as patient care assistants, personal support workers, and orderlies provide auxiliary support in mental health care settings such as assistance with personal care/activities of daily living and monitoring for safety (Royal Ottawa Health Care Group, n.d.-b). Additional unregulated care providers include peer support workers, who are workers with lived or living experience of mental illness who provide counselling and support as part of an organization's mental health services (Peer Support Canada, 2019). These unregulated care providers, by definition, are not registered health care professionals with professional standards (including documentation standards); therefore, they were not included as clinicians in this review (CNO, 2013).

**Community and Social Supports.** It is important to recognize that the informal care provided by family members, social contacts, and community members is a significant contributor to the wellbeing of many individuals with mental health problems or mental illness (CMHA, 2018). Peer support and advocacy organizations unaffiliated with health care institutions also provide many essential services helpful in recovery, such as counselling (CMHA, 2018). However, these informal care givers do not document in the care record, and they were not included as clinicians in this study.

### *Mental Health Care Approaches*

Recent approaches to health care have endeavored to move away from the traditional medical model, which has been criticized for being paternalistic, prescriptive, and over-focused on the treatment of disease rather than treating a person as a whole (Fix et al., 2018). Today's

health care aims to be holistic and person-centred by meeting the unique needs of each individual, honouring their values, perspectives, and experiences, and empowering them to make decisions about their care (Fix et al., 2018; McMillan et al., 2013).

In mental health care, the traditional medical model has emphasized treating mental illness by way of symptom reduction or elimination, without adequate attention to the promotion of positive mental health (Iasiello et al., 2019; Mead et al., 2001; Pilgrim & McCranie, 2013). The definition of recovery from mental illness in the medical model embraces the idea of 'curing' mental illness, which includes complete symptom remission and a return to societally prescribed definitions of function. For many individuals with mental illness, these parameters are neither achievable nor desirable (Mead et al., 2001; Pilgrim & McCranie, 2013). This definition of recovery resulted in a pervasive belief that mental illness was fundamentally incurable and that efforts to treat mental illness were often futile (Bird et al., 2014; Mead et al., 2001). As explained by Iasiello and colleagues (2019), "It has been argued that health care systems designed this way risk providing 'reactive' health care and creating avoidance, fear, and stigma of the pathology" (p. 227). The medical model of mental health care has also been associated with coercion, compulsory treatment, dehumanization, and institutionalization (Henderson et al., 2008; Henderson et al., 2009; Slade et al., 2014).

One response to the criticisms of the medical model has been the development and implementation of recovery-oriented care models (MHCC, 2015; Waldemar et al., 2016). Recovery-oriented models involve movement from traditional, paternalistic mental health care models to more collaborative models of care focused on achieving patients' self-defined recovery goals (Slade et al., 2012; Slade et al., 2014). The concept of recovery-oriented care and its relationship to the medical model is further explored later in this chapter.

## Central Concept: Patient Portals

In order to foster a recovery orientation, patients must be empowered to make care decisions that align with their goals, which cannot be achieved without access to appropriate information and tools that facilitate decision making (MHCC, 2015; Waldemar et al., 2016).

### Defining Patient Portals

Patient portals are Internet-based software applications designed to facilitate patients' access to their health care records, a function also referred to in the literature as patient-accessible electronic health records (PAEHRs) or Open Notes. Patient portals may also include other functions, such as appointment booking, prescription requests, self-assessments, communication between patients and clinicians, and provision of educational resources (Irizarry et al., 2015; Mayhew et al., 2018).

Patient portals must be distinguished from a related term: personal health records. Personal health records allow for patients to enter and maintain their own health data for personal use or sharing with health care providers. Patient portals might include a personal health record function, in which case they can be referred to as 'tethered' personal health records. 'Tethered' refers to the connection to the electronic health record maintained by clinicians. Personal health records that are not 'tethered' do not include data entered by clinicians (Heath, 2017).

### Impact of Patient Portals on Health Care Outcomes

The development oSf patient portals has coincided with shifting priorities in health care policy, such as a focus on patient empowerment and engagement, both central principles of patient-centred care (Castro et al., 2016). In a survey by the Canadian Medical Association and Ipsos (2019), 75% of Canadians indicated being interested in using patient portals, including

68% of people aged 55 years or older. Reasons cited for interest included easier access to their information and to medical services.

Emerging evidence suggests that portal use may positively impact patient outcomes, such as patient empowerment, adherence to treatment, satisfaction with care, and therapeutic communication with clinicians (Ammenwerth et al., 2019; Delbanco et al., 2012; de Lusignan et al., 2014; Otte-Trojel et al., 2014; Sarkar et al., 2014). Further, research shows that patient portals improve patient safety, in part due to the opportunities they present for patients to correct errors in their health care records, thus avoiding incidents such as adverse drug events (Canada Health Infoway & SRDC], 2018; de Lusignan et al., 2014; Otte-Trojel et al., 2014; Shah & Liebovitz, 2017). Finally, studies reveal that patient portals reduce health care expenditures by decreasing unnecessary in-person visits and phone calls and reducing the volume of requests for information (Baker et al., 2005; Canada Health Infoway & SRDC, 2018; de Lusignan et al., 2014; Martínez Nicolás et al., 2019).

## Patient and Clinician Perspectives on Patient Portals

An initial search of the literature produced numerous qualitative studies exploring patient and clinician views on patient portal use in various contexts outside of mental health care such as primary care and oncology. These studies highlighted both positive experiences with patient portal use, as well as numerous concerns.

### *Patient Perspectives*

**Positive Aspects of Patient Portals.** Studies on patient portals reveal that patients feel more prepared for appointments with their clinicians, as well as more informed and involved with their care overall when they have access to a patient portal (Alpert et al., 2019). Patients describe how, through the use of their portal, they feel more able to be assertive and to advocate

for themselves (Alpert et al., 2019), and they also express a greater appreciation for the role of clinicians in interpreting and explaining results (Alpert et al., 2019). In some contexts, notes captured within portals are a primary method by which patients learn about their health, allowing for better formulation of questions during their health care interactions (de Lusignan et al., 2014). Finally, patients describe improvements in communication and collaboration, stating that they are better able to coordinate their care with multiple clinicians because of direct messaging, scheduling functions, and access to their information (Alpert et al., 2019).

**Negative Aspects of Patient Portals.** Research also shows that some patients prefer not to receive certain information via a patient portal, such as information related to serious or potentially fatal diagnoses (Alpert et al., 2019). Further, some patients have voiced concerns about the privacy and security of patient health information when using patient portals due to the potential for data breaches when transmitting information over the Internet (Collins et al., 2017; Delbanco et al., 2012).

### *Clinician Perspectives*

**Positive Aspects of Patient Portals.** Research exploring clinician perspectives of patient portals shows that clinicians find patients to be more engaged in their health care and better informed prior to their visits, which facilitates better awareness of their care options and more sound decision-making (Alpert et al., 2019; Delbanco et al., 2012; Grünloh et al., 2016). Portals also enhance patient-clinician communication (Alpert et al., 2019; de Lusignan et al., 2014). In one study about open clinician notes in a primary care setting, physicians "frequently commented about strengthened relationships with some of their patients including enhanced trust, transparency, communication, and shared decision making" (Delbanco et al., 2012, p. 466). In another study, oncologists felt that they initiated communication with patients more readily

because of the portal (Alpert et al., 2019). Finally, clinicians in some settings have noted that documentation practices improve with the use of patient portals (Delbanco et al., 2012), and others have begun adding health promotion messages in their notes because they know patients read them (Grünloh et al., 2016).

**Negative Aspects of Patient Portals.** Research into clinician views of patient portals has also identified concerns about and barriers to their use. These negative aspects are related to the potential for miscommunication, workload and documentation changes, and the challenges of advances in health care technology.

***Miscommunication.*** Clinicians are worried that patients may not be able to understand the information in their health records due to its complexity and the use of jargon and abbreviations (Alpert et al., 2019; Grünloh et al., 2016). Further, they are concerned that patients might become anxious when they cannot understand and interpret their information, or if they are unable to discuss the implications of the information immediately (Alpert et al., 2019; Grünloh et al., 2016). Clinicians do not want patients ascertaining significant changes in their condition through lab results or other diagnostic tests without being able to discuss the findings in person, which is integral to the therapeutic relationship and patients' wellbeing (Alpert et al., 2019; Grünloh et al., 2016). Finally, clinicians indicate that information about potentially serious or fatal diagnoses should not be communicated via a patient portal and that portals should not replace face-to-face therapeutic interactions (Alpert et al., 2019).

***Workload and Documentation Changes.*** Research also reveals that many clinicians have concerns about an increased workload and subsequent need for more resources due to patient portals (Alpert et al., 2019; Grünloh et al., 2016). Nurses, in particular, tend to be apprehensive about training and the increased time needed to educate patients about the portal (Collins et al.,

2017). Physicians appear to be concerned about time spent managing elements of the portal, such as messaging and responding to inquiries, or increased documentation (Alpert et al., 2019; Collins et al., 2017; Grünloh et al., 2016). Finally, physicians are worried that patients may begin to expect more rapid or frequent communication than what is required or feasible (Alpert et al., 2019; Grünloh et al., 2016).

Some clinicians report that using patient portals necessitates a change in their documentation practices (Collins et al., 2017; Delbanco et al., 2012; Grünloh et al., 2016). Specifically, they feel obliged to change their documentation to make it more comprehensible for laypeople (Collins et al., 2017; Grünloh et al., 2016) and thus less likely to elicit negative reactions (e.g., anxiety or offense). Some clinicians feel a sense of ownership over the patient record, describing it as their work tool. They report that portals should facilitate communication between multiple clinicians, not between patients and clinicians (Grünloh et al., 2016).

***Challenges of Health Care Technology.*** Clinicians express concern that patient portals might introduce further health disparities in situations where patients have no (or unreliable) internet access or difficulty using the internet generally (Alpert et al., 2019; Collins et al., 2017; Delbanco et al., 2012). Further, they note that the security of patient information stored in patient portal databases might be problematic (Collins et al., 2017; de Lusignan et al., 2014). Finally, some clinicians express frustration with electronic medical systems generally, and feel that preoccupation with the technology overshadows patient care (Grünloh et al., 2016).

## Patient Portals in the Mental Health Context

### *Current Use of Patient Portals in Mental Health and Canada*

While patient portals are used by many health care organizations in Canada and the United States (Canada Health Infoway & SRDC, 2018; United States Government

Accountability Office, 2017), implementation in mental health contexts has been slower, and many facilities avoid providing patients with access to their mental health information (Pisciotta et al., 2019). This is reflected locally, where both The Ottawa Hospital and the Queensway Carleton Hospital grant access to many patient records through their respective portals, but not mental health records (The Ottawa Hospital, n.d.; Queensway Carleton Hospital, personal communication, June 2020). In terms of tertiary mental health centres in Ontario: Ontario Shores Centre for Mental Health Services in Whitby established a patient portal in 2014 (Kipping et al., 2016); the Royal Ottawa Health Care Group launched theirs in October of 2020 (Royal Ottawa Health Care Group, n.d.-c), and researchers at the Centre for Addiction and Mental Health (CAMH) in Toronto have conducted research on patient portals, but the organization has yet to broadly implemented the technology for patient use (CAMH, n.d.; Strudwick et al., 2018)

***Preliminary Literature Review***

A preliminary search of the current literature on patient portal use in mental health services produced a small number of survey studies. In the United States, Klein and colleagues (2018) conducted a survey study in which patients with mental health diagnoses accessing primary care services reported positive experiences with patient portals, such as engaging in better self-care, feeling more in control of their health care, and having a better understanding of their health; however, they also reported concerns about information privacy. In Canada, researchers at CAMH have also conducted survey studies. Leung and colleagues (2019) surveyed patients receiving mental health care at CAMH; 79% of these patients were interested in accessing their records via a patient portal, and many were also interested in appointment scheduling functions (Leung et al., 2019). This study further revealed that only 50% of the

patients surveyed were aware of their legal right to access their health records (Leung et al., 2019). Another survey study at CAMH by Strudwick and colleagues (2018) focused on the attitudes of mental health clinicians toward patient portals and found that some clinicians were uncomfortable with patients having access to their health records. Psychiatrists reported being concerned about the changes they believed they would have to make in their documentation practices, and psychiatrists were more likely to be uncomfortable with patient access than nurses or allied health clinicians (Strudwick et al., 2018).

The preliminary search also revealed qualitative studies on patient portal use in mental health with similar methodologies that provided numerous illustrative quotes from patients and clinicians, making them amenable to meta-synthesis. The initial review of the studies suggested that, while there are several similarities between the clinician participants working in mental health settings and their counterparts working in other domains, there are important considerations warranting attention when using patient portals in mental health care. This initial review formed the foundation of this study, which involved a systematic search for any other relevant qualitative literature, followed by a thematic synthesis.

## Summary of Central Concepts

Patient portals, one of many emerging innovations in health care, permit patients to access their health care records more readily. They may also include functions allowing for communication with health providers, scheduling appointments, and accessing educational materials, among others. This technology has been adopted in many health care contexts due to its potential for improved patient outcomes and health care cost savings.

Patient portals have not, however, been as broadly implemented in mental health care contexts, and some organizations with patient portals explicitly exclude mental health records

from their platforms. This has illustrated a need for investigating the phenomenon of patient portal use in the mental health care context, as there are numerous unique considerations for patient portals in this context. Thus, the concepts of mental health, mental illness, mental health care, and patient portals are central concepts embedded in the research question. This review of concepts informed the development of the operational definitions and eligibility criteria described in Chapter 3 to ensure the search strategy and systematic review would be rooted in the literature.

## Related Concept: Recovery-Oriented Practice

Recovery-oriented practice is a central concept in modern mental health care and nursing practice (Mental Health Commission of Canada [MHCC], 2015; Waldemar et al., 2016). The concept of recovery-oriented practice emerged in the late 1980s and 1990s amid the deinstitutionalization of mental health care in the 1960s/1970s and the psychiatric rehabilitation movement of the 1980s (Anthony, 1993; Deegan, 1988). Conceptualizations of recovery and recovery-oriented practice began with research exploring the experiences of persons with physical disabilities, for whom, like those with mental illness, the traditional medical conceptualization of recovery (or 'cure') meant complete elimination of symptoms and restored function, and inadequately reflected their experiences (Anthony, 1993). The concept of recovery was adopted and translated into the mental health literature and care approaches partially in response to the activism of mental health service user advocacy groups and the communication of lived experiences of mental illness (Anthony, 1993; Deegan, 1988; MHCC, 2015; Piat et al., 2009; Pilgrim, 2008).

### Defining Recovery

The literature on recovery-oriented practice is broad and multidisciplinary, and there is no consensus on the definitions of either recovery or recovery-oriented practice, though there are patterns reflected within the literature. This variability in conceptualization is unsurprising given that recovery is often described as 1) individual and unique to each person experiencing it (Anthony, 1993; Leamy et al., 2011; Resnick et al., 2004; Slade et al., 2014), and 2) a process, rather than a static entity or the ultimate end-result of health care interventions (Anthony, 1993; Deegan, 1988; Leamy et al., 2011; Mancini, 2005; Piat et al., 2009). Anthony (1993) provides the following widely cited definition:

> Recovery is described as a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic events of mental illness. (p. 15)

## Conceptualizations of Recovery

### *Recovery From or Recovery In?*

In their review of literature exploring lived experiences of recovery, Davidson and Roe (2007) described two conceptualizations of recovery: recovery *from* and recovery *in.* These conceptualizations are described as complementary and not mutually exclusive. Recovery *from* mental illnesses "involves the amelioration of symptoms and the person's returning to a healthy state following the onset of illness" (p. 463). This is sometimes referred to as clinical recovery in the literature (Lorien et al., 2020) and is associated with the traditional biomedical model (Davidson & Roe, 2007). For some, this sense of recovery may not resonate, or may not be achievable within the near future, or at all. For these people, the concept of recovery *in* – also

known as personal recovery (Lorien et al., 2020) – may resonate. Davidson and Roe's (2007) conceptualization of this mode of recovery is based on the experiences of persons with addiction (who would refer to themselves as being 'in recovery'), however they broadened to include anyone experiencing any mental illness. Recovery in "refers to the process of living one's life, pursuing one's personal hopes and aspirations, with dignity and autonomy, in the face of the ongoing presence of an illness and/or vulnerability to relapse" (p. 464); this definition is in alignment with how recovery is generally defined in the recovery movement and recovery-oriented care.

***Recovery from What?***

Pilgrim (2008) describes three complementary conceptualizations of recovery. The first form is recovery from illness, most associated with the traditional biomedical model, where recovering means symptom elimination and full restoration of function; this is aligned with clinical recovery or the 'recovery from' described by Davidson and Roe (2007). This type of recovery also aligns with the traditional single spectrum model of mental health discussed earlier in this chapter, wherein health and illness lie at opposite ends of a spectrum, and as one recovers, one moves toward health while leaving illness behind (Iasiello & van Agteren, 2020). The second type of recovery described by Pilgrim (2008) is recovery from impairment, wherein recovery involves reduction of symptoms and regaining function to levels where a person can participate in typical occupational and social roles. This aligns with the rehabilitative model of mental health care that emerged in the 1980s (Anthony, 1993), as well as with several definitions of mental health and mental illness in the current literature that identify functioning as one of the indicators of health (American Psychiatric Association [APA], n.d.; PHAC, 2006.; World Health Organization [WHO], 2019). Finally, Pilgrim (2008) describes the concept of recovery from

invalidation, wherein the person with mental illness regains autonomy, dignity, and self-determination and survives the consequences of stigmatization of their mental illness by society and by the health care system. Anthony (1993) also alluded to this last mode of recovery when he stated:

> Recovery from mental illness involves much more than recovery from the illness itself. People with mental illness may have to recover from the stigma they have incorporated into their very being; from the iatrogenic effects of treatment settings; from lack of recent opportunities for self-determination; from the negative side effects of unemployment; and from crushed dreams. (p. 15)

**Recovery and Empowerment**

There have been several studies attempting to capture the components of the recovery process. For example, Resnick et al. (2004) described four domains of recovery: hope, empowerment, knowledge, and life satisfaction. Provencher et al. (2002) indicated that the components of recovery include self-redefinition, improved relationships, empowerment, and hope for the future. Finally, the MHCC (2015) outlined six dimensions of recovery, one of which is affirming autonomy and self-determination.

As evidenced by its presence in numerous models and conceptualization, empowerment is a central component of the recovery process. Mead and Copeland (2000), both individuals with lived experienced of mental illness, conceptualized this empowerment as having the right to make choices in their treatment and their lives, as well as receiving enough information about their options and support from clinicians to do so. Notably, they made explicit mention of access to health records as integral to the recovery process, demonstrating that recovery is essential concept when exploring the phenomenon of patient portals in the mental health context.

## Related Concept: Stigmatization

Stigmatization is a social phenomenon in which a person experiences devaluation based on a condition, attribute, or identity (the "stigma" itself) that is considered inferior, of which mental illness is one example (Goffman, 1963; Pescosolido & Martin, 2015).

### Early Theoretical Works on Stigmatization

The work of Goffman (1963) has laid the foundation for much of the exploration of stigma in the literature. Goffman defined stigma as an "attribute that is deeply discrediting" that causes the bearer to be transformed in the eyes of others "from a whole and usual person to a tainted, discounted one" (p. 3). He described three types of stigmatized conditions: tribal stigma (based on affiliation with a social group or status), abominations of the body (which included physical deformities), and blemishes of individual character (criminality and mental illness, among others). Goffman (1963) viewed stigmatization as a relational and societal process wherein non-stigmatized persons convince themselves of their superiority and the danger posed by the stigmatized persons, and therefore react with hostility.

Another theory of stigma and stigmatization is Weiner's attribution theory. Weiner (1988) explained how the beliefs of individuals about the nature of a person's condition (or stigma) influence their behaviours towards the stigmatized person. He explained that people make attributions about what has caused a stigmatized person's condition, and whether or not that condition is within their control. From there, conclusions are drawn about the person's responsibility for their condition. When a person's condition has been caused, or is worsened, by circumstances perceived to be in the person's control, the person is deemed responsible for their condition, and this creates emotional reactions of anger. When the cause of the person's condition is perceived to be out of their control, this creates an emotional reaction of pity. When

people feel pity towards stigmatized persons, they are more likely to respond with helping behaviours, whereas those who feel anger are more likely to withhold helping behaviours or engage in hostility.

**Interpersonal and Public Stigmatization**

At the turn of the century, research on stigmatization began to intersect with research on the processes of discrimination, which, until that point, was associated with work on societal racism and sexism (Corrigan et al., 2004; Pescosolido & Martin, 2015). For example, Corrigan et al. (2003) conceptualized stigmatization in the general population (public stigma) as consisting of three components: stereotypes, prejudice, and discrimination. Stereotypes are widely held assumptions about social groups and their members. For example, stereotypes of those with mental illness include that they are violent, dangerous, unpredictable, or incompetent; that they will never recover; and that they are responsible for having caused their own illness (Arboleda-Flórez & Stuart, 2012). Prejudice is the adoption of such stereotypes into one's belief system and the subsequent negative evaluation of the social group. Discrimination is the harmful behaviour enacted on members of the social group as a result of prejudicial attitudes, such as coercion, withholding help, avoidance, and frank hostility (Corrigan et al., 2003).

In the mental health care context, patients often report encountering this interpersonal prejudice and discrimination from mental health clinicians, many of whom are unaware of their own stigmatizing behaviours (Arboleda-Flórez & Stuart, 2012; Tyerman et al., 2021). Patients report that some mental health clinicians assume them to be incapable of making decisions (about their treatment or in life generally), withhold important information about their treatment, speak to them as if they are children, communicate a lack of optimism for their recovery, and threaten coercive treatment, leaving patients feeling dehumanized, dismissed, punished, and

patronized (Arboleda-Flórez & Stuart, 2012; Farrelly et al., 2014; Knaak et al., 2017; Kokanović et al., 2018).

**Structural and Institutional Stigmatization**

Early work on stigmatization focused heavily on stigmatized persons themselves and on their attributes, rather than on the people acting on prejudicial attitudes or the power dynamics inherent in the stigmatization process. Additionally, early theories were focused on interactions between individuals, rather than on the broad-scale processes enabling widespread stigmatization (Corrigan et al., 2004; Link & Phelan, 2001). These macrosocial processes constitute structural (or institutional) stigmatization, in which organizations create and maintain legislation and or/policies that affect the opportunities of stigmatized groups and put them at a social disadvantage (Corrigan et al., 2004; Henderson et al., 2014; Link & Phelan, 2001). These laws and policies include restriction of rights (to vote, to rent, to marry, to have custody of children, to make decisions about medical treatment, etc.), as well as decisions about resource access and allocation that favour the non-stigmatized (Corrigan et al., 2004; Deegan, 1992; Link & Phelan, 2001).

Institutional stigmatization is manifested in the health care system in poor resource investment and poor standards of care for patients with mental illness, inadequate preparation of clinicians for mental health care provision during their education, as well as other laws, policies, and organizational cultures that promote paternalistic and coercive treatment over recovery-oriented practices (Corrigan et al., 2004; Henderson et al, 2014; Knaak et al., 2017; MHCC, 2015; Pescosolido & Martin, 2015).

**Self-stigmatization**

Self-stigmatization occurs when a person internalizes societal stereotypes about their own identity or status; it is a process in which the person becomes aware of stereotypes, begins to agree with the stereotypes, then finally applies the stereotypes to themselves, causing shame, reduced self-esteem and self-efficacy (Corrigan, 2016). In the case of mental illness, self-stigmatization can prevent individuals from seeking mental health care (Corrigan, 2004) and limit their willingness or ability to advocate for themselves (MHCC, 2015). Self-stigmatization may also obstruct progress toward personal goals and the pursuit of opportunities because the stigmatized individuals have internalized beliefs that they are, and always will be, incompetent (MHCC, 2015). Corrigan (2016) refers to this as the 'why try' effect.

**Benevolence Stigma**

Much stigma research has focused on behaviours causing overt harms, such as avoidance and hostility. However, a more subtle form of stigmatization described by Corrigan (2005) is benevolence stigma, which can manifest as a component of self, interpersonal, or structural stigmatization. As outlined earlier, the attribution theory of stigma posited by Weiner (1988) explains that beliefs about a person's responsibility for their illness may create either anger or pity, and pity generates helping behaviours. This pity and the subsequent helping behaviours are typically framed as positive phenomena; for example, when the public feels pity for those with mental illness, they are more likely to support the allocation of funds toward mental health services (Corrigan, 2016; Fominaya et al., 2016). However, pity is not always a welcome or helpful emotional reaction. Pity is for the pitiful; when those with mental illness are pitied, they can be seen as fundamentally helpless and incompetent, and the helping behaviours resulting from pity are often paternalistic and coercive in nature (Corrigan, 2016; Fominaya et al., 2016).

When society – both the public, and institutions such as the government and health care systems – collectively reacts with pity, this results in policies and practices that appear helpful, but which ultimately obstruct the movement toward recovery-oriented care (Corrigan, 2016; Fominaya et al., 2016). If these beliefs about helplessness and incompetency are internalized through self-stigmatization, a person's ability to work towards increased competence may be impaired due to reduced self-esteem and self-efficacy. Corrigan (2016) argues that parity – equitable treatment of persons experiencing mental illness – is preferable to pity.

## Related Concepts: Competency and Capacity

### Mental Illness and the Incompetency Stereotype

It is a common stereotype that people with mental illness are in some way incompetent, that is, they lack the skills to function well and independently (Arboleda-Flórez & Stuart, 2012; Campbell, 1994; Henderson et al., 2014). The stereotype of incompetency extends to numerous areas of a person's life; a person with mental illness may be considered incompetent in activities such as employment, managing finances, or maintaining healthy relationships (Campbell, 1994; MHCC, 2015). Another major dimension of competency that is often questioned in persons with mental illness is decision-making capacity, especially with regards to decisions about their health care (O'Brien, 2010; Okai et al., 2007). However, while mental illness can affect a person's cognitive functioning, insight, and judgement, it does not always (or even usually) do so to the extent that it impairs their ability to make reasonable decisions (Corrigan et al., 2004; Okai et al., 2007; Steinert, 2017).

Historically, mental capacity was viewed as all-encompassing; that is, those with impaired capacity were presumed incapable in all dimensions of functioning and decision-making (Candia & Barba, 2011). Individuals with mental illness were often presumed incapable

as a matter of course, and this was true especially for people with psychotic disorders, such as schizophrenia (Appelbaum & Grisso, 1995; Campbell, 1994; Candia & Barba, 2011; Deegan, 1992). However, it is now known that individuals may be capable with regard to some decisions and incapable for others, and that decision-making capacity may fluctuate dependent on situational factors (Appelbaum & Grisso, 1995; O'Brien, 2010; Okai et al, 2007). People who do lose decision-making capacity are more likely to do so in the acute phase of mental illness, and many recover their decision-making capacity (Maxmin et al., 2009). Finally, it should go without saying that diagnostic labels do not determine an individual's capacity (Candia & Barba, 2011; Okai et al., 2007).

**Ontario Laws Regarding Decision-Making Capacity**

Under Ontario's Health Care Consent Act, 1996 (HCCA), all patients are presumed capable with regards to making treatment decisions, except when explicit conditions are met. These conditions are that: a) the person is unable to understand the nature of their illness, and b) that they are unable to comprehend the consequences of receiving or not receiving treatment. When one or both of these conditions are met, a person may be declared incapable with respect to treatment by a physician. When a person is declared incapable with respect to treatment, informed consent must be obtained by someone else, known as a substitute decision maker (usually, but not always, a family member), who is charged with making decisions based on what they believe the person being treated would want if they were capable (Ontario Hospital Association [OHA], 2016).

While the HCCA applies to all patients, there are additional regulations for patients receiving mental health care. Under Ontario's Mental Health Act of 1990, a physician may declare a person incapable with respect to consenting to psychiatric treatment; with respect to

managing property and finances; or with respect to consenting to the collection, use, and disclosure of their health information by health information custodians (OHA, 2016). These assessments of incapacity and their legal consequences (often involuntary detainment and treatment) are ostensibly in place for the protection of either society at large, where the patient is considered to pose a risk to others, or protection of the patient's wellbeing during a period in which they are unable to do so themselves (Appelbaum & Redlich, 2006; OHA, 2016). In recognition of the potential for capacity to fluctuate, physicians are expected to review a patient's incapacity finding on a regular basis to determine if capacity has been regained and their right to consent to (or refuse) treatment can be restored (OHA, 2016).

It is important to note here that a declaration of incapacity to consent to the collection, use, and disclosure of health information does not include any restriction to a patient's access to their own personal health information. Rather, this pertains to the patients' capacity to provide consent for health care organizations to collect, use, and disclose health information to parties *other* than the patient (e.g., family members, other health care organizations, insurance companies, researchers, etc.). There is no legal recognition of incapacity to access one's own health information in Ontario (OHA, 2016).

**Consequences of the Incompetency Stereotype**

Despite research evidence and progressive trends in legislation, the stereotype that people with mental illness are incompetent persists in society at large and in the health care system (both generally and in mental health settings). Patients report being treated as if they are incapable even when they have not been declared so legally. Patients describe being spoken to as if they were children, receiving inadequate information about their treatment, and being excluded from treatment decisions (Arboleda-Flórez & Stuart, 2012; Farrelly et al., 2014; Knaak et al., 2017;

Kokanović et al., 2018). Meanwhile, some clinicians persist in believing that patients requiring mental health care are incapable of making reasonable or realistic decisions about their care or in their lives in general (Farrelly et al., 2016; Kokanović et al., 2018; Magliano et al., 2017; Rivera-Segarra et al., 2019). Furthermore, Deegan (1992) asserts that the traditional paternalistic model of mental health care (which has by no means now been eliminated) perpetuates incompetency by cultivating learned helplessness and dependence. As outlined in the earlier discussion on stigma, the assumption that those with mental illness are incompetent (in any dimension of life) can be internalized through the process of self-stigmatization. This leads to reduced efficacy of functioning as the person with mental illness incorporates ideas about their own incompetency into their belief system, reducing their self-esteem and motivation (Corrigan, 2016; Deegan, 1992). Finally, the stereotype of incompetency might also be reflected in attitudes about granting patients access to their mental health records through patient portals, an act which recognizes patients' capacity to understand their health information and actively participate in their care.

## Related Concept: Patient Right of Access to Health Information

### History of Health Records and Patient Access Laws

Historically, health records were primarily kept by physicians for the purposes of recording and transmitting medical knowledge. The first records kept by health care institutions in the United States were established in the late 18th century; they included simple data such as admissions and discharges. Record-keeping became more detailed over the course of the late 19th century in response to the need for legal documentation for medical insurance and malpractice cases, but these were not used for patient care (Gillum, 2013). The proliferation of health care documentation at the bedside was driven by the need for data to advance medical research and the development of teaching hospitals in the 20th century (Gillum, 2013). Rudimentary electronic

health record-keeping of certain hospital and patient data began during the rise of computing from the 1960s and 1970s; this was developed further using Internet-based functions in the 1980s. It was not until the 2000s, however, that health care institutions began to fully adopt electronic health records (Boothe et al., 2019; Doyle-Lindrud, 2015).

Patients' rights of access to the information in their health records have not always been recognized. In the early 1970s, only nine states in America had laws granting patients any right to view their own health records, and three of these states permitted access only by a patient's lawyer (Helfman et al., 1973). Furthermore, despite the existence of these laws, many patients were refused access and were forced to go to court in order to enforce their rights (Shenkin & Warner, 1973; Helfman et al., 1973; Westin, 1977). It was only in the 1990s, amid patient advocacy movements, that granting patients the right of access to their health information began to be established as standard legislation in Western countries, though case law favoured right of access in most jurisdictions until that point (Bruce, 1984; Davies, 1996; Westin, 1977).

It is worth noting that the English literature on the history of health records and patient access thereof is much focused on the Western world, and especially English-speaking jurisdictions such as the United Kingdom, Australia, the United States, and Canada. I would like to acknowledge that other jurisdictions' historical traditions and practices may differ. For example, Holmes (1974) explains:

> Though this seems a revolutionary concept in our sophisticated data-oriented society, I can report that patients have been the sole custodians of their own medical records in parts of the world for many years. As a former medical missionary in East Africa, I am constrained to describe the "cheti" or "vyeti" system in common use there. At each outpatient visit the patient is given a blank

> scrap of paper stamped with the date and the name and location of the clinic. The doctor or medical assistant writes a few words of history of the present illness and pertinent physical findings on this paper… the patient takes this paper, now a "cheti", to the dispenser or nurse, from whom he receives the prescribed treatment, and then pins the "cheti" to the top of his lifetime collection of these documents, plural "vyeti". He carefully preserves them, usually on his person. The next time he is seen at a clinic he hands the sheaf of papers, vyeti, to the doctor to review. (p. 287)

**Legal Access Restrictions in Mental Health Care**

In much of the historical literature on patients' rights of access to their health information, there is frequent discussion of special considerations and limitations with regards to mental health records. Even Westin (1977), a legal scholar who otherwise advocated for free patient access rights, cautioned against a policy of automatic patient access to records in mental health care:

> Where that part of the medical record is involved in which the health professional's working notes … are sensitive judgments about the patient's emotional condition that might unduly upset the patient to see … a procedure should be afforded that gives the physician an opportunity to explain to the patient why access would not be desirable, or to suggest disclosure to another physician of the patient's choice; but if the patient is not persuaded by these counsels, a right of access should be provided to patients in either chronic and acute care. Where psychiatric care is involved, disclosure of the record directly to the patient over the advice of the psychiatrist would require an order from a civil court. (p. 25)

The literature references laws in some jurisdictions specifically outlining the treatment of some or all mental health records separately from physical health records (Bruce, 1984; Rosenman, 1998), some of which, including federal laws such as America's Health Insurance Portability and Accountability Act (1996), remain in force to this day. However, as discussed later, Ontario law makes no direct mention of mental illness when outlining restrictions of access to health records.

## Historical Perspectives on Patient Access to Health Records

### *Clinician Views*

Given the Western world's history of the health record as a private tool used by physicians for private recordkeeping, education, and research, it is, perhaps, not surprising that the notion of patient access to records has been contentious among clinicians. This is in keeping with the early paternalistic health care delivery models in which physicians made all decisions about patient care and provided only what information they felt the patient needed to know (Michaels, 1989; Shenkin & Warner, 1973; Westin, 1977). This attitude is demonstrated in this statement by the president of the American Medical Association, Richard Bergen, in 1974: "It is our position that a physician has both a right and a duty to withhold information to circumstances in which he reasonably determines that it would not be in the best interest of the patient (Bergen, 1974, as cited by Westin, 1977). In Ontario, these sentiments were echoed by the College of Surgeons and Physicians of Ontario in 1979:

> The medical profession has serious misgivings about the free and open access… If taken out of context and without the benefit of explanation, the physician's records would very likely be misinterpreted by the patient to his own detriment, and undermine the relationship of trust between the physician and patient" (as cited in Michaels, 1989, p. 1077).

The literature from the 1970s and 1980s indicates that clinicians in varied settings felt that disclosure of records would not be in the best interest of patients. They felt the records would confuse or alarm patients, especially without the presence of a physician to explain the information (McShane & Rowe, 1994; Michaels, 1989; Sergeant, 1986). They explained that adding explanations or verbally explaining records would be too time-consuming, and that they would have to change the way they kept records in order to make them 'palatable' for patients or to avoid malpractice suits (Michaels, 1989; Shenkin & Warner, 1973; Westin, 1977). Some mental health clinicians felt that they would be less likely to document honest, but potentially unflattering observations about a patient should the patient have access, which could impact the integrity of the record (McShane et al., 1992) - others feared patients might use the records to pursue legal action against them (Seitz et al., 1978). Nonetheless, some clinicians viewed patient access to their records as positive, believing that they would increase patient knowledge about their health, increase patient autonomy, ensure better continuity of care, increase treatment adherence, and improve the clinician-patient relationship through clearer communication (Annas et al., 1982, as cited in McQuoid-Mason, 1996; Michaels, 1989; Shenkin & Warner, 1973; Stein et al., 1979)

***Patient Views***

There is, unfortunately, a dearth of literature directly exploring patient perspectives on access to health records from the time period prior to the establishment of right of access by law, in mental health settings or otherwise. Much of what is available comes from records of case proceedings of patients seeking access to their records. Of note, Davies (1996) analyzed cases across jurisdictions and found that patients' motivations for these proceedings included a desire for a better understanding of oneself and one's experiences, accessing information on previous

treatments to better understand their health conditions, and to have all information necessary to make future health care decisions. As Davies (1996) explained, “Far from wishing to ‘rummage about’ in files, [patients] perceive their records to be a unique source of valuable information which relates to the innermost core of their being” (p. 193). Other summaries of the patient position in the debate indicate that patients are interested in accessing records to: 1) better understand their health conditions and health care; 2) participate in treatment decisions; 3) choose their providers and evaluate if they were meeting their needs; 4) ensure the continuity of their health records between providers (thereby reducing repeated assessments); and 5) verify the accuracy of their records prior to releasing them to third parties like insurance companies (Shenkin and Warner, 1973; Westin, 1977).

Four studies were found that explore the perspectives of patients in mental health care settings on access to their records. Seitz et al. (1978) interviewed forensics patients at a federal mental health care facility and found that motivations for access to their health records included, for some, desiring information to support their release, but that many patients were simply curious about the contents, and others were not interested in viewing their record whatsoever. Stein et al. (1979) conducted a study in which patients on the psychiatric unit of a general hospital were permitted to view their charts; the majority of these patients reported that access to these records helped them understand their illness and participate more actively in treatment. Parrott et al. (1988) found that patients were motivated to view their records to gain a better understanding of the assessment process, to remember and reflect on the progression of their recovery, and to get a sense of the staff’s view on their prognosis. Parrott et al. (1988) explained that patients felt that reading the notes might be upsetting, but not harmful, and felt they should have the right to make decisions about whether reading the record would be in their best interest.

Finally, Kosky & Burns (1995) found that while some patients expressed great interest in accessing their records, there were some who felt it would not be helpful to them and preferred to "leave it to the doctors" (p.88).

**Current Laws and Regulations for Patient Access to Health Records in Ontario**

In Canada, access to health information is regulated under provincial legislation. Under Section 52 of Ontario's Personal Health Information Protection Act, 2004 (PHIPA), health care facilities have a legal obligation to provide patients access to their health information. PHIPA indicates that while health institutions own the files or systems in which the records are recorded, with regards to the information therein, they are simply custodians, and the patient is the true owner of the health information. Additionally, a recent addition to PHIPA in 2020, Section 52 (1.1) states: "the right to access a record of personal health information includes the right to access the record in an electronic format," which pertains to records accessed through patient portals.

Clause 52 (1) of PHIPA states that patients may be prevented from accessing their health records only in certain circumstances, including if the clinician determines that access would pose a risk to a patient's treatment or recovery, or if it is expected that access would result in serious harm to the patient or another person. Notably, this clause makes no mention of mental illness, so this restriction is not legally associated with mental health records. Therefore, there is no legal rationale for restricting access to all mental health records or treating them separately from other health records at all.

## Summary of Related Concepts

The core concepts of mental health, mental illness, mental health care, and patient portals must be understood in the context of several related concepts: recovery-oriented care, stigmatization, competency and capacity, and the patient right of access to health care records.

The literature review of these interdependent concepts is intended to illuminate the necessity of research into patient portals as an opportunity to investigate improvements to mental health care. While the courts have recognized that patients have the right of access to their health records for many years, health care providers and institutions have not yet aligned their policies with the legal and ethical principles of patient right of access, and barriers to health record access are especially evident in mental health care.

The traditional reasons given for limiting access to mental health records have revolved around concerns over whether releasing information to patients may cause harm to the patient or to another person, or that the patient may be incapable of managing emotions arising from access to their records. This reasoning is reflective of the common stereotypes that people with mental illness are inherently dangerous, unpredictable, and incompetent. The ongoing stigma of mental illness may influence clinicians' views on patient portals, which have the potential to increase patient autonomy and emphasize the role of patients in decision-making. This also has implications for the delivery of recovery-oriented mental health care, in which patients must be empowered to make care decisions that align with their goals. This cannot be achieved without access to their health care information.

Ultimately, patient portals are powerful tools for accessing health information that may support recovery-oriented practice and reduce stigmatization. Research into perceptions of

patients and clinicians on their use can provide valuable insights into how best to leverage portals for improved care and outcomes.

# Chapter 3: Methodology

## Research Question

The research question addressed in this review is 'What are the perceptions, attitudes, and experiences of patients and clinicians with regards to patient portal use in the mental health context?'

## Design

I conducted a qualitative evidence synthesis focusing on the perceptions, attitudes, and experiences of patients and mental health clinicians with regards to patient portal use in the mental health context. Qualitative evidence synthesis involves a systematic review of qualitative data. Systematic reviews were traditionally a method used for quantitative studies; however, as qualitative research has become more prevalent in health sciences and nursing, so too have methods for systematic review and synthesis of their findings (Thomas & Harden, 2008; Tong et al., 2016).

The choice of methodology was informed by Booth and colleagues' (2016a/b) guidance on qualitative systematic reviews as well as Thomas and Harden's guidance on thematic synthesis of qualitative research (2008). The Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols (PRISMA-P) by Moher and colleagues (2015) also informed the development of the study protocol, and the 'enhancing transparency in reporting the synthesis of qualitative research' (ENTREQ) framework developed by Tong and colleagues (2012) was used to ensure trustworthiness, as discussed later in this chapter.

**Paradigmatic Stance**

As I outlined in Chapter 1, my personal paradigmatic stance aligns most closely with constructivism, which upholds the validity of all experiences of reality and emphasizes the role of participants and researchers in co-creating knowledge.

Qualitative evidence synthesis sometimes requires synthesizing data from studies of diverse qualitative methodologies. This poses a challenge, and there is no agreement in the literature about how best to address findings from what some view as 'competing' philosophical perspectives. Some qualitative data synthesis approaches (such as those using early meta-ethnography and grounded theory) include only studies using similar methodologies, while others, such as thematic synthesis, accept a diversity of methodologies for inclusion (Barnett-Page & Thomas, 2009; Soilemezi & Linceviciute, 2018). This is in line with the constructivist approach that recognizes the validity of varied perceptions of reality, and the usefulness of analyzing areas of intersection and discrepancy. This is why I chose to use thematic synthesis.

Additionally, constructivism emphasizes the importance of context in qualitative data. Without an understanding of the contexts in which data were produced, the relevance and transferability of findings between contexts cannot be determined. The patterns of intersection and discrepancy between the perceptions of reality of individuals in different contexts also cannot be analyzed (Guba & Lincoln, 1994; Tong et al., 2016). Thomas and Harden (2008) explain that some researchers do not believe that qualitative evidence should be subject to synthesis at all, and that findings produced in one context are not transferable to other contexts. However, much as clinicians reading primary qualitative studies examine the setting of a study to determine if the findings apply to their clinical settings, researchers conducting thematic

qualitative evidence syntheses can examine the context of each study to determine if, and how, concepts can be synthesized (Thomas & Harden, 2008).

When describing their approach for thematic synthesis, Thomas and Harden (2008) also include methodology as part of a study's context. The approach taken by the researchers in collecting, analyzing, and describing their findings, and the philosophical underpinnings of these approaches, must be considered as a part of the study context alongside other contextual factors such as setting, timeline, etc. This is also in alignment with constructivism, which recognizes that researchers are instruments in the research process and their interpretation and analysis will inevitably have an impact on the findings of a study; there is no way of truly divorcing the researchers' philosophical inclinations from the results.

**Eligibility Criteria and Definitions**

The eligibility criteria and subsequent search strategy were shaped using the SPIDER tool (Cooke et al., 2012). SPIDER stands for Sample, Phenomenon of Interest, Design, Evaluation, and Research type. This tool was developed to facilitate the formulation of research questions addressed by qualitative evidence syntheses as an alternative to the traditional use of the PICO (Patient/Population, Intervention, Comparison, Outcomes) tool in systematic reviews. See Table 3.1 for an outline of how the eligibility criteria were structured using the SPIDER tool.

Research articles were included in the review based on the following inclusion criteria: (S) patient or clinician perspectives, (PI) focus on patient portals the mental health care context, and (DER) inclusion of any primary qualitative data from focus groups, interviews, or free-text surveys, including qualitative data collected in mixed-methods studies. Other inclusion criteria were that the studies were published the English language, and that the full article text was available. Studies excluded from the review included non-English language papers, those whose

full text was unavailable, conference abstracts, grey literature, quantitative studies, systematic reviews, software usability studies, and anything published prior to the dates indexed by the databases.

The definitions of the core concepts embedded in the research question (patient portals, patients with mental illness, mental health care, and mental health clinicians) were formulated as discussed in the literature review (Chapter 2). These definitions are summarized in Table 3.2.

**Search Strategy**

The search strategy outlined in Appendix A was developed with the assistance of the librarian assigned to the University of Ottawa School of Nursing, Marie-Cécile Domecq, and peer-reviewed by Sascha Davis, librarian at The Royal Ottawa Health Care Group. The search strategy was designed with the guidance of the SPIDER tool (Cooke et al., 2012) using synonyms and related terms associated with the intervention and the sample population, as well as relevant thesaurus terms available in the databases. Search terms for research type and design were not included as qualitative studies are not typically well-indexed in databases (Booth, 2016a). See Table 3.1.

A systematic literature search was conducted on September 12, 2021, with the aim of casting a wide net so as not to miss any relevant articles. The databases included were CINAHL, PubMed, PsycINFO, ProQuest Nursing and Allied Health Database, Embase, Scopus, and Web of Science (see Appendix B for information about the databases). The ProQuest Dissertations & Theses Global database was used in the initial database search; however, grey literature sources were ultimately excluded from the final review given that the number of primary qualitative research articles identified for inclusion was larger than expected at the outset of the study. In addition to the initial literature search, I hand-searched the reference lists of eligible articles, as

well as the reference lists of three systematic reviews that were produced by the search and underwent full-text review.

**Table 3.1**

*Using the SPIDER Tool to Structure the Eligibility Criteria*

| SPIDER Category | Research Question Component | Example Search Terms and Subject Headings |
|---|---|---|
| Sample (S) | Patients in mental health care<br>Mental health clinicians | Patients: Psychiatric patients<br>Clinicians: nurse, physician, doctor, psychiatrist, psychologist, therapist, clinician, health care provider |
| Phenomenon of Interest (P and I) | Use of patient portals in the mental health context | Patient portals: patient portal, patient accessible electronic health record (PAEHR), web portal, patient access to records<br>Mental health context: psychiatry, psychology, mental health, mental illness |
| Study designs (D) searched for | Qualitative methods such as focus groups and interviews | Not applicable; Researcher to screen independently |
| Evaluation (E) | Qualitative data on the perceptions, attitudes, and experiences of mental health patients and clinicians | Health personnel attitudes<br>Patient attitudes |
| Research type (R) to be included | Qualitative studies or, mixed-methods studies from which qualitative data can be extracted | Not applicable; Researcher to screen independently |

*Note:* The SPIDER tool is described by Cooke et al. (2012).

**Table 3.2**

*Definitions of Concepts Embedded in the Research Question*

| Concept | Definition |
|---|---|
| Patient portals[a] | Internet-based software applications through which patients may access their mental health care records via computers or mobile devices, and which may include other functions such as appointment booking, prescription requests, self-assessments, communication between patients and clinicians, and provision of educational resources (Irizarry et al., 2015; Mayhew et al., 2018). |
| Patients with mental illness[b] | Those who receive mental health care to address mental illness or mental health problems, or who receive individual mental health promotion interventions documented in a care record.<br><br>Mental illness is defined as any disorder encoded in either the DSM-5-TR or ICD-11 (or the earlier, corresponding versions for studies published prior to the version updates). |
| Mental health care[c] | Formal services offered by mental health care clinicians that is documented in a health care record as defined by PHIPA (2004). |
| Mental health clinicians[d] | Regulated care providers who document health information in a health record. |

[a] Studies on applications providing these secondary functions without the primary function of access to clinician care notes and other health records (often, applications known as electronic personal health records) were excluded from the review.

[b] The experiences of mental health and mental illness are inherently subjective. However, systematic reviews involve searching the medical literature, which primarily relies on DSM-5-TR and ICD-11 definitions.

[c] Informal care by family members or peers is not included because this care is not typically formally documented in patient records or patient portals. Population-based mental health promotion interventions were also not included as they are not documented in health care records. Individual mental health promotion interventions documented in care records were included.

[d] Unregulated care providers (e.g., personal support workers, orderlies) have been excluded because their contribution to the patient chart and interaction with the patient portal is currently very limited. They are also not bound in the same way as regulated care providers to college standards regarding documentation practices. Peer support workers, also unregulated care providers, were excluded from the eligibility criteria as well. However, when their perspectives were provided in studies, these data were included as patient perspectives given their lived/living experiences with mental illness.

**Selection Process**

I used Covidence, a browser-based systematic review software, to complete the citation screening process. Covidence is endorsed by The Cochrane Collaboration, an organization devoted to evidence-based health research, as a tool for efficient screening of abstracts and full texts (The Cochrane Collaboration, 2020). The 1519 citations generated from the database search were first downloaded from the databases to EndNote, and then uploaded to Covidence, a process through which 2 invalid and 554 duplicate citations were removed. I then used Covidence to screen the remaining 963 records using a two-step process. First, titles and abstracts were screened according to the eligibility criteria (these were screened together because the nature of the research could not always be gleaned from the title alone). All citations meeting eligibility, as well as those without enough information to determine eligibility, were retained; these totaled 61 citations. I then reviewed the full texts of the retained citations to determine their final inclusion in the review. All reasons for exclusion were documented for articles not kept after screening the full texts. Dr. Vandyk screened the citations a second time to ensure accuracy, and any discrepancies were resolved through discussion. These screening processes produced 24 studies published across 26 articles for inclusion in the review.

The results of the search strategy and screening process has been summarized in Chapter 4 (Results) using a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram (Moher et al., 2009).

**Quality Appraisal**

Each article was appraised using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist (2018) in Appendix C. The CASP checklist is a 10-item checklist that contains questions focused on evaluating what elements of a study's design were reported as well

as the justification and appropriateness of the study design for the research question addressed. While there is no consensus on the best approach or tool for appraising qualitative studies, the CASP checklist is the most widely used for qualitative evidence syntheses and is considered the most user-friendly for novice researchers (Majid & Vanstone, 2018).

The critical appraisal did not affect the eligibility of studies for inclusion in the review; however, a discussion of the strengths and limitations of the studies is included in the review.

## Data Extraction and Analysis

### *Data Items and Extraction*

Data were extracted using a data extraction tool of my own design (see Appendix D). I pilot-tested the tool with the first included study and reviewed the process with my supervisor. Minor adjustments were made to the tool following pilot-testing to ensure all relevant data were captured. Demographic data were extracted into a dedicated Microsoft Excel spreadsheet whereas patient/clinician experiences were extracted into Microsoft Word.

**Participant Characteristics.** The data extracted regarding patient characteristics include: the number of participants in each study, their sociodemographic characteristics, their professions (for clinicians) or their diagnoses (for patients), as well as any other available clinical characteristics provided. There was no consistent set of sociodemographic characteristic data that were collected for every study.

**Study Characteristics.** Data on the study settings/contexts, timelines, and research methods used were extracted.

**Patient Portal Characteristics.** The names and features of the patient portals (i.e., portal functions such as messaging and scheduling) examined in each study were extracted.

**Philosophical Underpinnings.** Author references to concepts, theories, frameworks, or philosophical paradigms used to inform or underpin the studies were recorded. In addition, the professions/fields of studies of the first two authors of each study were recorded in a dedicated Excel spreadsheet.

**Patient and Clinician Experiences.** The qualitative findings about patient or clinician perceptions, attitudes, and experiences of patient portals were extracted, including direct patient or clinician quotations from focus groups, interviews, or surveys with narrative responses, and the authors' summaries thereof.

It must be noted that a small number of studies included in this review contained minimal qualitative data and lacked supporting quotations. This includes Åkerstedt et al. (2018), Dobscha et al. (2016) and Johansen et al. (2019). Additionally, Blease et al. (2021) included many supporting quotes from diverse participants but did not identify which quotes belonged to patients or clinicians. The corresponding authors for these studies were all contacted via e-mail, inviting them to share their original data. Contact was made only with the first author of Dobscha et al. (2016a) and the original data for this study were obtained through a Freedom of Information Act request (Dobscha et al., 2016b).

### *Data Synthesis*

The data extracted were analyzed using methods appropriate to the nature of the data, as detailed below. All data have been compared across studies to determine commonalities and patterns, and the implications of these findings have been discussed between myself and my thesis supervisor.

**Participant, Study, and Portal Characteristics.** Data on participant, study, and patient portal characteristics are displayed in summary tables in Chapter 4 and reported using frequencies and percentages.

**Philosophical Underpinnings.** The intent at the outset of this project was to include all methodologies, and to consider the methodology and underlying philosophical paradigm of each study as part of the overall study context during the data synthesis process. As it turned out, the qualitative studies included in this review did not frequently report their philosophical alignments (see Chapter 4), and the full diversity of qualitative methodologies were not represented, limiting the need for intensive examination of conflicting paradigms.

**Patient and Clinician Experiences.** The qualitative data were analyzed using thematic synthesis as described by Thomas & Harden (2008), who developed this method specifically for qualitative evidence syntheses in the absence of any other published methods available at the time. Their thematic synthesis is an inductive three-stage process involving, first, free line-by-line coding of the qualitative study data, then clustering of the codes into descriptive themes, and subsequently development of analytical themes based on the reviewers' interpretations. The thesis committee was consulted during the coding and interpretation and any disagreements were discussed and resolved.

## Ensuring Trustworthiness

The findings of the review are reported in Chapter 4 according to the "enhancing transparency in reporting the synthesis of qualitative research" (ENTREQ) framework developed by Tong and colleagues (2012), which is located in Appendix E. This will ensure that those reading the research will understand the measures taken to ensure the trustworthiness of the review, which are outlined below.

The five dimensions of trustworthiness in qualitative research studies are credibility, confirmability, dependability, transferability, and authenticity. The four original dimensions (authenticity came later) were established by Lincoln and Guba (1985) and have been since been refined and further developed (Polit & Beck, 2017).

Credibility refers to the accuracy of the data as well as how well the data answer the research question (Polit & Beck, 2017; Tong et al., 2016). The systematic nature of the search strategy using the SPIDER tool enhances credibility (Cooke et al., 2012). In addition, data were extracted independently by more than one researcher and disagreements were settled through discussion (Polit & Beck, 2017).

Confirmability refers to the assurance that the published findings are reflective of the participants' experiences rather than the researchers' perspectives (Polit & Beck, 2017). Within the constructivist paradigm, it is not completely possible to separate the participants' and researchers' views because the data are created together within a dialogue (Guba & Lincoln, 1994). This is perhaps amplified in an evidence synthesis given that data from qualitative articles already contain participants' views interpreted through the lens of the original researchers, which are then subjected to meta-synthesis by those doing the systematic review. However, to increase confirmability, researchers can use the strategy of reflexive bracketing, which involves having the researchers reflect on their own attitudes and experiences and how these may have affected the interpretation of results (Polit & Beck, 2017). In this study, this took the form of a written reflective journal, an explanation of my personal impetus for the research study (Chapter 1), and as well as research team discussions.

Dependability refers to whether the data are reproducible by other researchers (Polit & Beck, 2017). The reproducibility of findings is one of the cornerstones of scientific evidence. As

a constructivist, I would argue that one could never entirely reproduce another qualitative systematic review due to the inherently interpretive nature of analysis. However, I have kept an audit trail of the search strategy including databases, search terms, and dates of the searches, as well as any decisions regarding the categorization of data, and this facilitates an understanding of how the findings were produced (Polit & Beck, 2017).

Transferability refers to the ability to apply the data in other situations. Individual qualitative studies are not intended to be generalizable, but their findings may be useful within certain contexts (Polit & Beck, 2017). The process of evidence synthesis allows for recognition of patterns and commonalities between contexts to determine what may be transferable between contexts (Tong et al., 2016). Demographic data and description of the participants and context of each of the studies and their contexts have been reported in Chapter 4 and will be part of any published results so that readers may determine if the findings are transferable to their contexts of interest (Polit & Beck, 2017).

Finally, the review maintains authenticity, or fidelity to the participants' realities and the authors' interpretations (Polit & Beck, 2017) by including original quotations in Chapter 4.

# Chapter 4: Results

The systematic search of databases yielded several studies with qualitative data on the perspectives of patients and clinicians on patient portal use in the mental health context, and these data were extracted and synthesized. This chapter outlines the results of this database search and provides a summary of the characteristics of the studies included for synthesis, the demographic data of their participants, and an overview of the findings published. The results of a quality appraisal of these studies are also presented. Finally, this chapter includes the results of the thematic synthesis with direct participant quotes to illustrate findings.

## Search Results

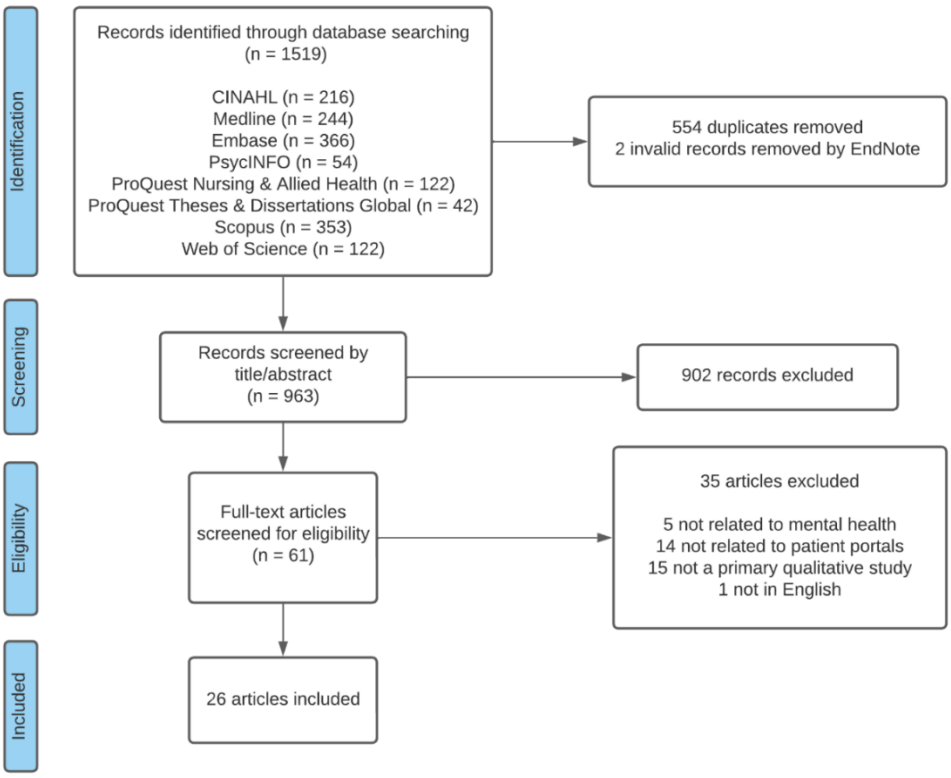
A total of 1519 citations were generated from the database search. Following the removal of duplicate citations, as well as one 'invalid'/incomplete citation generated from a database error, 963 citations underwent title and abstract screening, yielding 61 citations for full-text review. Of these 61 citations, 35 were excluded: five did not pertain to the mental health context, 14 were not about patient portals, and one was not in English. Additionally, there were 15 articles on-topic that did not meet the inclusion criteria because they were not primary qualitative studies. These articles included two study protocols (whose full studies were included), seven editorials or topical reviews, four quantitative studies, and one systematic review. In sum, 61 articles underwent full text review, which yielded 26 articles for inclusion. The search strategy and screening process are summarized in Figure 4.1.

While the final set of articles included for synthesis totaled 26, these represented 24 studies. There were two sets of three grouped articles; that is, articles linked to the same study or study population. Three articles (Erlingsdóttir et al. (2019), Petersson and Erlingsdóttir (2018a), and Petersson and Erlingsdóttir (2018b)) were published to cover the results of a single study with the bulk of the qualitative analysis captured in Erlingsdóttir et al. (2019). Therefore, all

results from this study are reported under Erlingsdóttir et al. (2019). Three other articles (Cromer et al. (2017), Denneson et al. (2017), and Pisciotta et al. (2019)) used the same pool of study participants but published separate qualitative analyses with differing methodologies. Cromer et al. (2017) published patient data, Denneson et al. (2017) published clinician data, and Pisciotta et al. (2017) incorporated data from both sets of participants. These are reported as separate studies, given that each published different sets of data. Any identical quotes extracted were only included once for synthesis, but this overlap was rare (only six quotes were published in more than one study). It is possible that the inclusion of all three articles resulted in overrepresentation of this study's population in the final synthesis; this is addressed in Chapter 5.

**Figure 4.1**

*Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Flow Diagram*




*Note*. The PRISMA flow diagram was created using a template published in Moher et al. (2009).

## Study Characteristics

The characteristics of the 24 studies included in the synthesis are captured in Table 5.1; data are shown for study settings (country and health care setting), participant classifications, methods (data collection and analysis), and any philosophical underpinnings or theoretical frameworks cited by the authors.

### Study Settings

#### *Years Published*

One study was published in 2009 (Fisher et al.), one was published in 2013 (van Dooren et al.), and 22 studies were published between 2016 and 2021.

#### *Countries*

One of the studies (Blease et al., 2021) was conducted in multiple countries. The remaining 23 studies were conducted in one of seven countries: the United States (n=10 studies), Canada (n=5 studies), Australia (n=2 studies), Sweden, (n=2 studies), the Netherlands (n=1 study), New Zealand (n=1 study), Norway (n=1 study) and England (n=1 study).

#### *Health Care Institutions*

Studies were set in various health care institutions, with the majority conducted in single institutions providing a broad range of inpatient and outpatient mental health services: Veterans Affairs mental health services (n=5 studies), tertiary mental health care services (n=6 studies), and studies conducted in hospitals that provided both physical and mental health care services to the general population (n=2 studies). There were also a number of specialized settings represented, including a psychotherapy service embedded in a medical outpatient care centre (n= 2 studies), an outpatient mental health service (n=1 study), an opioid treatment centre (n=1 study), a post-secondary clinic (n=1 study), and a residential care service for those with intellectual disabilities (n=1 study). Finally, there were two studies conducted in primary care

clinics for the general population, two studies were held across settings and included participants from any mental health care setting, and one study included any adult mental health care setting, excluding forensics.

**Participant Classifications**

Eight of the included studies involved patient participants only, ten included clinician participants only, and six included data from both; sociodemographic data are presented later.

**Qualitative Data Collection**

Of the 24 studies, 13 were qualitative only and 11 were mixed-methods. Seven of the qualitative-only studies used individual interviews for data collection, one used a focus group, and four used both interviews and focus groups. In one qualitative study, researchers used a survey as the primary data collection strategy. For the mixed-methods studies, nine employed surveys for qualitative data collection, one used individual interviews, and one used focus groups.

**Qualitative Data Analysis**

The most commonly reported data analysis methods were content analysis and thematic analysis. There were three studies in which there was no full content or thematic analysis published with illustrative quotes. In Åkerstedt et al., 2018, repeated topics found in the data were listed without further analysis. In Johansen et al., 2019, the response data were quantified and reported by number of responses falling into identified categories, without providing the quotes under each category. The same is true for Dobscha et al. (2016); however, the participant quotes were obtained via personal communication with the first author for analysis in this study.

**Table 4.1**

*Summary Characteristics and Contexts of Included Studies*

| First Author & Year | Country | Setting(s) | Participants | Study Design | Qualitative Data | Analysis Method | Paradigms, Methodologies, or Frameworks |
|---|---|---|---|---|---|---|---|
| Åkerstedt 2018 | Sweden | Hospital setting (somatic and MH services) | C | MM | S | Listed repeated topics | Sandman's outrage theory |
| Blease 2021[a] | Multiple | Any MH services | P, C | Q | S | Descriptive content analysis | Use of Delphi polling methodology; qualitative description |
| Chen 2021 | USA | Office-based opioid use disorder treatment | P | Q | I | Stratified thematic analysis | - |
| Chimowitz 2020 | USA | MH services within OP general medical centre | C | Q | I, F | Thematic analysis | - |
| Cromer 2017[b] | USA | VA MH services | P | Q | I | Constant comparative analysis | Aspects of grounded theory methodology |
| Denneson 2017[c] | USA | VA MH services | C | Q | I | Thematic analysis | - |
| Dobscha 2016 | USA | VA MH services | C | MM | S | Counted number of comments by content | - |
| Erlingsdóttir 2019 [d] | Sweden | Any adult MH services excluding forensics | C | MM | S | Abductive content analysis | Informed by Heald's theory of transparency |
| Fisher 2009 | England | General primary care clinic | P | Q | I, F | Content analysis | - |
| Gasteiger 2020 | New Zealand | Student primary care clinic | P,C | Q | I, F | Thematic analysis | Use of Action Research methodology |
| Johansen 2019 | Norway | Hospital setting (somatic and MH services) | C | MM | S | Counted number of comments by content | - |
| Kariotis 2019 | Australia | Primary care | C | Q | I | Deductive thematic analysis | Qualitative description |

| First Author & Year | Country | Setting(s) | Participants | Study Design | Qualitative Data | Analysis Method | Paradigms, Methodologies, or Frameworks |
|---|---|---|---|---|---|---|---|
| Kipping 2016 | Canada | Tertiary MH services | P | MM | S | Thematic analysis | - |
| Leung 2019 | Canada | Tertiary MH services | P | MM | S | Thematic analysis | - |
| Mayhew 2018 | Canada | Tertiary MH services | C | Q | I | Inductive conventional content analysis | Qualitative descriptive approach |
| O'Neill 2019 | USA | MH services within OP general medical centre | C | MM | I | Thematic analysis | - |
| Peck 2017 | USA | OP MH services | P, C | MM | S | Review and selection of illustrative quotes | - |
| Pisciotta 2019[e] | USA | VA MH services | P, C | Q | I | Rapid review deductive analysis | - |
| Strudwick 2018 | Canada | Tertiary MH services | C | MM | S | Inductive content analysis | Qualitative description |
| Strudwick 2020[f] | Canada | Tertiary MH services | P | Q | F | Inductive content analysis | Qualitative description |
| Turvey 2021 | USA | Any MH services | P, C | MM | S | Review and selection of illustrative quotes | - |
| van Dooren 2013 | Australia | OP and residential care for intellectual disability | P, C | Q | I | Thematic analysis | - |
| van Rijt 2021 | Nether-lands | Tertiary MH services | C | Q | I, F | Abductive thematic analysis | Normalization process theory (NPT) |
| Whealin 2016 | USA | VA MH services | P | MM | F | Content analysis | FITT framework |

*Notes.* An en-dash (-) indicates data not reported in the published study. P=Patients. C=Clinicians. S=Survey. I=Interviews. F=Focus groups. Q=Qualitative. MM=Mixed methods. VA=Veterans Affairs. MH=mental health. OP=Outpatient. IP=Inpatient. FITT=Fit between Individual, Task, and Technology.

[a] International experts were recruited from the United States, United Kingdom, Canada, Norway, Sweden, and Estonia.
[b, c, e] Cromer et all. (2017), Denneson et al. (2017), and Pisciotta et al. (2019) each published analyses on the same study population.
[d] This study was published over three papers including Erlingsdóttir et al. (2019), which included illustrative quotes, Petersson & Erlingsdóttir (2018a), in which no qualitative data were published, and Petersson and Erlingsdóttir (2018b) which reported counts of comments by topic.

### Paradigms, Methodologies, or Frameworks

Few studies openly endorsed a particular philosophical or methodological alignment; for the most part, these were not explicitly stated. The most reported methodological approach was qualitative description (n=5 studies), and other reported methodologies included Delphi polling (n=1 study) and Action Research (n=1 study). Additionally, one study described using constant comparative analysis, which is borrowed from grounded theory.

Four studies included theoretical frameworks: these included Sandman's outrage theory, Heald's theory of transparency, normalization process theory (NPT), and the Fit between Individual, Task, and Technology (FITT) framework.

## Methodological Quality Appraisal

The 24 studies included in this review were appraised using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist (CASP, 2018). Answers to the first nine questions ('yes', 'no', or 'can't tell') for each of the 24 studies are documented in Table 5.2.

All 24 studies met criteria for the first three questions of the CASP Qualitative Checklist: 1) the aims of the research are clearly communicated, 2) a qualitative approach was appropriate to meet these aims, and 3) the research designs were well-described, were appropriate to meet the aims of the research, and authors justified the selection of the design.

The criteria for the remaining CASP questions were intermittently met. Specifically, 21/24 studies had an appropriate recruitment strategy, 21/24 had data collection methods that adequately addressed the research question, 15/24 studies demonstrated rigorous data analysis, and 23/24 had a clear statement of their findings. In only 1/24 studies did the authors adequately report on the researcher-participant relationship; the rest were marked 'can't tell' as this was not explicitly discussed in these articles. However, 22/24 studies met the criteria for addressing other ethical issues. The final question of the CASP Qualitative Checklist asks about the value of the

research and its contribution to the field. It is not a ‘yes/no’ question and is therefore not included in Table 4.2. I consider all of the studies valuable despite their limitations, especially given the novel and emerging nature of this field.

**Table 4.2**

*Quality Appraisal using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist*

| First Author & Year | Clear Research Aims | Qualitative Methodology Appropriate | Research Design Appropriate | Recruitment Strategy Appropriate | Data collection addressed research question | Researcher-Participant Relationship Considered | Ethical Issues Considered | Rigorous Data Analysis | Clear Statement of Findings |
|---|---|---|---|---|---|---|---|---|---|
| Åkerstedt 2018 | ✓ | ✓ | ✓ | ? | ? | ? | ✓ | ✗ | ✗ |
| Blease 2021 | ✓ | ✓ | ✓ | ✗ | ✓ | ? | ✓ | ✓ | ✓ |
| Chen 2021 | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ✓ | ✓ |
| Chimowitz 2020 | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ✓ | ✓ |
| Cromer 2017 | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ✓ | ✓ |
| Denneson 2017 | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ? | ✓ | ✓ |
| Dobscha 2016 | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ✗ | ✓ |
| Erlingsdóttir 2019[a] | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ✓ | ✓ |
| Fisher 2009 | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ? | ✓ |
| Gasteiger 2020 | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ✓ | ✓ |
| Johansen 2019 | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ? | ✗ | ✓ |
| Kariotis 2019 | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ✓ | ✓ |
| Kipping 2016 | ✓ | ✓ | ✓ | ✓ | ? | ? | ✓ | ✗ | ✓ |
| Leung 2019 | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✗ | ✓ |
| Mayhew 2018 | ✓ | ✓ | ✓ | ✗ | ✓ | ? | ✓ | ✓ | ✓ |
| O'Neill 2019 | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ✓ | ✓ |
| Pisciotta 2019 | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ✓ | ✓ |
| Peck 2017 | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ? | ✓ |
| Strudwick 2018 | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ✓ | ✓ |
| Strudwick 2020 | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ✓ | ✓ |
| Turvey 2021 | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ? | ✓ |
| van Dooren 2013 | ✓ | ✓ | ✓ | ✓ | ? | ? | ✓ | ✗ | ✓ |
| van Rijt 2021 | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ✓ | ✓ |
| Whealin 2016 | ✓ | ✓ | ✓ | ✓ | ✓ | ? | ✓ | ✓ | ✓ |

*Notes.* ✓ = Yes ? = Can't Tell ✗ = No. See Critical Appraisal Skills Programme (2018) for the checklist used for this appraisal (Appendix C).

[a] Erlingsdóttir et al. (2019), Petersson and Erlingsdóttir (2018a), and Petersson and Erlingsdóttir (2018b) were a sequence of papers published on the same study with the bulk of qualitative analysis presented in Erlingsdóttir et al. (2019).

## Participant Demographics

The most frequent demographic data reported in the studies are summarized in Table 4.3 (patient participants) and Table 4.4 (clinician participants).

### Patient Demographics

Patients were sampled in 13 studies. The most frequent demographic data published in studies including patient participants were gender (n=11 studies), age (n=9 studies), race/ethnicity (n=8 studies), level of education (n=7 studies), and mental health diagnoses (n=5 studies). Other demographic data were reported in two or fewer studies and are not included in the summary table. These include marital status, employment, housing status, annual household income, number of comorbid medical conditions, and access to a computer with Internet.

In those studies where race and/or ethnicity were reported, patient participants were mostly Caucasian (80%). In studies where level of education was reported, 71% were identified as having at least some post-secondary education. There were more participants who self-identified as women than men and ages ranged from 19-81, with average ages reported to be in the 40s and 50s. When diagnoses were provided, the most common were mood disorders, including mild and atypical depression, with a total of 48%. The second most common diagnoses were trauma- or stressor-related disorders, including adjustment disorder and post-traumatic stress disorder, with a total of 26%.

### Clinician Demographics

Clinicians were sampled in 16 of the 24 studies. The most frequent demographic data reported for clinician participants were professional designation (n=17), gender (n=13), and age (n=6). Other demographics were reported in two or fewer studies and are not included in the summary table. These include race and/or ethnicity, location/program of practice, years practicing, hours/week in direct care, and years in current role/facility.

There was a wide range of professional designations represented in these studies; the most common were physicians (n=11 studies), psychologists (n= 7 studies), nurses (n=12 studies), and social workers (n=9 studies). In the 11 studies with physicians, nine included psychiatrists, two included primary care physicians, and four reported ‘other’ physician involvement. In the 12 studies that included nurses, nine included ‘nurses’ generally, two included ‘assistant nurses’, four included ‘nurse practitioners’, and one included ‘clinical nurse specialists’.

**Table 4.3**

*Patient Demographic Data*

| First Author & Year | n | Gender | Age (yrs.) | | Race and/or Ethnicity | Education | Mental Health Diagnoses |
|---|---|---|---|---|---|---|---|
| | | | Range or SD | Mean | | | |
| Blease 2021[a] | 70 | 35 M (1 trans)<br>35 F | 11.52 (SD) | 49.87 | 6 Asian<br>1 Black, African, or Caribbean<br>59 White<br>2 other<br>2 NR | 24 PhD | - |
| Chen 2021 | 17 | 12 M<br>5 F | 27-68 | 42.71 | 1 Black<br>3 mixed race<br>13 White | 6 recent school or less<br>8 Some college<br>3 college degree | 17 opioid use disorder |
| Cromer 2017 + Pisciotta 2019[b] | 28 | 16 F | 30-69 | 47 | 24 White, non-Hispanic | 8 college degree<br>5 graduate degree | 19 major depression<br>19 PTSD<br>2 schizophrenia<br>5 bipolar disorder |
| Fisher 2009[c] | 43 | 2 M<br>8 F | 20-71 | 42 | 11 other ethnic groups<br>30 White British<br>2 NR | - | - |
| Gasteiger 2020 | 9 | 1 M<br>8 F | 19-33 | - | - | All undergraduate or graduate students. | - |
| Kipping 2016[d] | 65 | - | - | - | - | - | - |
| Leung 2019 | 103 | 53 M<br>40 F<br>2 non-binary<br>8 NR | - | - | - | - | - |
| O'Neill 2019[e] | 96 | 20 M<br>65 F | 20-81 | 53.8 | 1 Asian<br>14 Black<br>3 Hispanic/Latino<br>60 White<br>7 other | 19 high school to 2-year degree<br>25 4-year degree<br>31 graduate degree<br>10 NR | 23 major depression or bipolar disorder<br>27 mild/atypical depression<br>11 anxiety disorders<br>11 adjustment disorders or PTSD<br>13 other |

| First Author & Year | n | Gender | Age (yrs.) | | Race and/or Ethnicity | Education | Mental Health Diagnoses |
|---|---|---|---|---|---|---|---|
| | | | Range or SD | Mean | | | |
| Peck 2017 | 52 | - | - | - | 1 Asian<br>3 Black<br>1 Hispanic/Latino<br>43 White<br>4 NR | 1 elementary<br>2 high school<br>11 some college or 2-year degree<br>14 4-year degree<br>20 graduate degree<br>4 NR | - |
| Strudwick 2020[f] | 23 | 6 M<br>17 F | - | - | - | - | - |
| Turvey 2021 | 168 | 70 M<br>94 F<br>4 NR | 68 age 20-39<br>75 age 40-59<br>25 age 60+ | | *Race:*<br>2 Asian or Pacific Islander<br>8 Black or African American<br>151 White<br>3 more than one race<br>5 NR<br>*Ethnicity:*<br>7 Hispanic/Latino<br>158 non-Hispanic/Latino<br>3 NR | - | - |
| van Dooren 2013 | 4 | 2 M<br>2 F | Mid-to-late 30s | | - | - | 4 mild intellectual disability |
| Whealin 2016 | 10 | 7 M<br>3 F | 3.8<br>(SD) | 57.4 | 2 Hispanic<br>7 White, non-Hispanic<br>2 other, non-Hispanic | 6 some college<br>4 college degree or more | 10 PTSD |

*Notes.* n = mental health patient participants in qualitative study components, except as identified below. An en-dash '-' indicates data were not reported in the published study. NR= not recorded (data not provided by participants). SD = standard deviation. M = male. F = female. PTSD = post-traumatic stress disorder.

[a] Demographic data reported for all 70 participants including patients/patient advocates, peer support workers, clinicians, and other experts (e.g., informaticians).
[b] Cromer et al. (2017) and Pisciotta et al. (2019) report on the same sample; however, there is a discrepancy in the ages reported (30-69 or 30-60). Partial demographics were reported, such as number of female participants, White participants, and college-educated participants; these partial demographics are reported as published by the authors, without assumptions about the remainder.
[c] 43 total participants; 10 were in the mental health group. Gender reported for the mental health group; age and race reported for the full group.
[d] Demographics were reported for all patient portal users in the organization, but not specifically for the 65 participants providing qualitative data.
[e] There was total of 96 participants; 85 participated in the survey and 11 in interviews. Interview participants were not included in the survey. Demographics were reported for survey participants only.
[f] Demographic data were reported for the full mixed group of 23 participants (12 patients, 5 peer support workers, and 6 family members/caregivers).

**Table 4.4**

*Clinician Demographic Data*

| First Author & Year | n | Gender | Age (yrs.) | Profession[f] |
|---|---|---|---|---|
| Åkerstedt 2018 | 91 | 32 M<br>58 F<br>1 NR | - | 35 nurses<br>48 assistant nurses<br>8 other |
| Blease 2021[a] | 70 | 35 M (1 trans)<br>35 female | 11.52 (SD)<br>Mean 49.87<br><br>1 age 20-29<br>19 age 30-39<br>14 age 40-49<br>19 age50-59<br>17 age 60+ | 46 clinicians (psychiatry, primary care, social work, nursing, hospitalist, radiology)<br>24 non-clinicians (including 5 patient advocate/person with lived experience) |
| Chimowitz 2020 | 24 | - | - | 24 social workers |
| Denneson 2017 + Pisciotta 2019 | 28 | 16 female<br>12 other or NR | - | 7 psychiatrists<br>5 psychologists<br>3 mental health nurse practitioners<br>3 nurses<br>10 social workers |
| Dobscha 2016 | 208 | 31.3% M<br>56 % F<br>1% other<br>11.5% NR | - | 14.7% psychiatrists<br>18.8% psychologists<br>4.6% nurse practitioners<br>18.8% nurses<br>41.7% social workers |
| Erlingsdóttir 2019[b] Pre-portal survey | 871 | 223 M<br>628 F<br>20 NR | - | 133 doctors (including psychiatrists)<br>91 psychologists<br>228 nurses<br>182 assistant nurses<br>57 social workers<br>16 physical therapists<br>17 occupational therapists<br>76 medical secretaries<br>53 other<br>18 NR |
| Erlingsdóttir 2019[c] Post-portal survey | 699 | 154 M<br>492 F<br>53 NR | - | 97 doctors (including psychiatrists)<br>63 psychologists<br>191 nurses<br>164 assistant nurses<br>45 social workers<br>17 physical therapists<br>18 occupational therapists<br>35 medical secretaries<br>28 unit managers<br>15 NR |
| Gasteiger 2020[d] | 8 | 1 male<br>7 female | Range 25-63 | 1 doctor<br>3 nurses<br>3 counsellors<br>1 administrative staff member |

| First Author & Year | n | Gender | Age | Profession |
|---|---|---|---|---|
| Johansen 2019[e] | 457 | "As many as" 77.7% F | 10.7% < 30<br>24.10% 30-39<br>24.30% 40-49<br>29.3% 50-59%<br>11.6% 60+ | 17.9% doctors/psychiatrists<br>29.5% nurses<br>1.8% physiotherapists<br>1.3% ergotherapists<br>0.9% radiographers<br>13.6% other clinical positions<br>27.4% administrative positions<br>7.6% NR |
| Kariotis 2019 | 11 | 1 M<br>10 F | - | 7 general practitioners<br>4 psychologists |
| Mayhew 2018 | 5 | - | - | 5 clinical nurse specialists |
| Peck 2017 | 15[f] | - | - | 12 psychiatrists<br>1 nurse practitioner<br>2 social workers |
| Strudwick 2018 | 250 | - | 108 < 39<br>107 40-59<br>13 not recorded | 61 psychiatrists<br>69 nurses (e.g., RNs, RPNs, NPs)<br>75 allied health (e.g., OTs, SWs)<br>45 other (e.g., pharmacists, psychologists) |
| Turvey 2021 | 80 | 25 M<br>53 F<br>2 NR | 29 20-39<br>32 40-59<br>18 60+<br>1 NR | 29 psychiatrists<br>3 physician assistants<br>6 other physician or provider<br>25 psychologists<br>15 social workers<br>2 nurses |
| van Dooren 2013 | 2 | 1 M<br>1 F | - | 2 residential support workers |
| van Rijt 2021 [g] (interviews) | 20 | 7 M<br>13 F | Range 27-61 | 4 psychiatrists<br>3 psychologists<br>3 nurse practitioners<br>1 psychotherapist<br>3 'team leaders'<br>6 non-clinicians |

*Notes.* n = mental health clinicians in qualitative study components, except as identified below. An en-dash '-' indicates data not reported by the authors. Where percentages are reported, these are taken directly from the articles; counts were not calculated due to risk of inaccuracies from rounding. NR= not recorded (data not provided by participants). SD = standard deviation. M = male. F = female.

[a] Age/sex/gender data reported for the full group of 70 participants. In this mixed group, 46 indicated they were currently engaged in clinical practice. Quotes included were from clinicians only.
[b, c] Erlingsdóttir et al. (2019) sample data reported in Petersson & Erlingsdóttir (2018a) and Petersson & Erlingsdóttir (2018b).
[b, c, d, e] These studies included medical administrative personnel within their clinician samples. Data were not excluded on this basis as the quotes extracted pertained to direct care, and only one quote was directly ascribed to an administrative staff member.
[e] Data are shown for the full sample of 457 health care workers from both psychiatric and somatic health care. Only data pertaining to mental health care settings were extracted.
[f] There were 15 clinician participants, but only 12 completed the full study; it is unknown which 3 left the study.
[g] Focus groups included clinicians and non-clinicians; 1 overlapped with interview group. Gender and age are reported for the full group. Quotes included were from clinicians only.

## Patient Portal Characteristics

For the purposes of this study, a patient portal was defined as an Internet-based software application through which patients access their mental health care records, at times including secondary functions, such as appointment booking or patient-provider messaging. The portals and the features explored in each study are summarized in Table 4.5.

Seventeen studies were performed at institutions with established portals, whereas two were performed across multiple settings with no specific portal identified and three were performed in institutions where portals were not yet established. Of the studies exploring established portals, six studies included portals unique to single institutions, five included portals associated with a multi-site health system (i.e., MyHealth*e*Vet for Veterans Affairs), and six were about national patient portals available as part of a country's public health care system.

All studies included portals with the potential functionality of patient access to clinician notes, in keeping with the definition established in the eligibility criteria. However, in the clinic setting described by Gasteiger et al. (2020), this access was turned off. This study was, nonetheless, included because patient participants in this study discussed note access as a potentially useful feature.

The availability of secondary portal functions varied. The most common secondary functions discussed were messaging between clinicians and patients (n=11 studies), access to test results (n=10 studies), medication history (n=13 studies), and prescription renewals (n=8 studies). One portal, Australia's MyHealthRecord described by Kariotis et al. (2019) and van Dooren et al. (2013), was designed so that patients can choose what documentation is uploaded into the record.

In the three studies where a portal was not yet established (Mayhew et al., 2018, Strudwick et al., 2018, and Strudwick et al., 2020), authors explored patient and/or clinician perspectives on portals prior to their implementation, and the discussion of these secondary features was hypothetical in nature. These studies occurred at the same tertiary mental health care centre in Ontario, Canada, which was in the planning phase for portal implementation at the time. For these three studies, a checkmark in Table 4.5 indicates that participants discussed the feature as being desirable.

**Table 4.5**

*Features of Patient Portals Reported in Included Studies*

| First Author & Year | Portal Name | Portal Category | Access to Clinician Notes | Access to Test Results | Education/ Resources | Messaging | Medication History/List | Medication Refills | Booking or Viewing Appoint-ments | Patient Data Entry | Patient-Controlled Record Upload |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Åkerstedt 2018 | Journalen | National | - | - | - | - | - | - | - | - | - |
| Blease 2021 | M, U | - | ✓ | - | - | - | - | - | - | - | - |
| Chen 2021 | U | - | ✓ | ✓ | - | ✓ | ✓ | ✓ | - | - | - |
| Chimowitz 2020 | PatientSite | Single-site | ✓ | - | - | - | - | - | - | - | - |
| Cromer 2017[a] | MyHealth*e*Vet | Multi-site | ✓ | ✓ | - | ✓ | ✓ | ✓ | - | - | - |
| Dobscha 2016 | MyHealth*e*Vet | Multi-site | ✓ | ✓ | - | - | - | - | - | - | - |
| Erlingsdóttir 2019[b] | Journalen | National | ✓ | ✓ | | - | - | - | - | ✗ | - |
| Fisher 2009 | U | - | ✓ | ✓ | ✓ | - | ✓ | - | - | - | - |
| Gasteiger 2020 | ManageMyHealth | National | ✗ | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | - |
| Johansen 2019 | Journalen | National | ✓ | - | - | - | - | - | - | - | - |
| Kariotis 2019 | MyHealthRecord | National | ✓ | - | - | - | ✓ | - | - | ✓ | ✓ |
| Kipping 2016 | HealthCheck | Single-site | ✓ | - | - | ✓ | ✓ | - | ✓ | ✓ | - |
| Leung 2019 | HealthCheck | Single-site | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | - |
| O'Neill 2019 | PatientSite | Single-site | ✓ | - | - | - | - | - | - | - | - |
| Peck 2017 | PatientSite | Single-site | ✓ | - | - | - | - | - | - | - | - |
| Turvey 2021 | M, U | - | ✓ | ✓ | - | ✓ | - | ✓ | ✗ | - | - |
| van Dooren 2013 | MyHealthRecord | National | ✓ | - | - | - | ✓ | - | - | - | ✓ |
| van Rijt 2021 | Helsenorge | National | ✓ | - | - | - | - | - | - | ✓ | - |
| Whealin 2016 | MyHealth*e*Vet | Multi-site | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | - | - |
| Portals not yet implemented | | | | | | | | | | | |
| Mayhew 2018 | - | - | ✓ | ✓ | - | ✓ | ✓ | - | ✓ | ✓ | - |
| Strudwick 2018 | - | - | ✓ | ✓ | - | ✓ | ✓ | - | ✓ | - | - |
| Strudwick 2020 | - | - | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | - |

*Notes:* ✓ = feature present, OR feature hypothetically discussed as being desirable (in those studies where portals were not yet implemented); ✗ =feature absent (-) = feature not discussed in the study M = multiple settings. U = unknown portal. For those studies where portals were not yet implemented, discussion of features was hypothetical. While some studies were conducted in settings using the same patient portal, not all studies reported on or discussed the same features.

[a] Cromer et al. (2017), Denneson et al. (2017), and Pisciotta et al. (2019) were published analyses on the same study; data are presented here under Cromer 2017.

[b] Erlingsdóttir et al. (2019), Petersson & Erlingsdóttir (2018a), and Petersson & Erlingsdóttir (2018b) were published analyses on the same study; data are presented here under Erlingsdóttir 2019.

## Extracted Data: Illustrative Quotes and Author-Identified Themes

### Participant Quotes

A total of 492 participant quotes were extracted from the published articles and their supplements. Of the 492 published quotes, 41% were from patients and 59% were from clinicians. The total quotes extracted from each study are summarized in Table 4.6; numerical counts of quotes are presented for the purpose of illuminating the process of extraction.

### Themes

The themes identified by the authors of the 24 studies are listed in Appendix F. Each of the studies included published findings on the qualitative data, but these varied in terms of detail. In 20 studies, authors conducted a content analysis or thematic analysis and illustrated the themes/categories with participant quotes. In three studies (Åkerstedt et al., 2018; Dobscha et al., 2016a; Johansen et al., 2019), they analyzed their data more simply and counted how many comments fell into a certain theme, without publishing illustrative quotes for each theme.

### Data Anomalies

Nine of the 24 studies included at least one quote that either did not pertain to patient portals, did not pertain to mental health care, or was not identified as originating from a clinician or patient. These quotes were not extracted nor included in the synthesis; however, they were sometimes used by authors to illustrate their findings – this is indicated in the footnotes of Appendix F.

I received a set of 164 clinician quotes from Dobscha et al. (2016b) via personal communication with the first author. This created an imbalance between studies in the amount of data available per study and between the numbers of quotes from clinicians compared to patients. Therefore, although these additional quotes were recorded in Table 5.6, they were not included in the calculated totals of published quotes, nor included in my initial coding during the process

of synthesis for this study. Instead, they were compared to my preliminary codes once formed to determine if additional codes were required. No additional codes were produced from this comparison; rather, the data in Dobscha et al. (2016b) were readily categorized using codes already produced from the published data. Several quotes from Dobscha et al. (2016b) have been used to illustrate the themes synthesized in this study.

Furthermore, five of the quotes from Strudwick et al. (2020) were provided by peer support workers. These workers have a dual role in that they are both people with lived or living experience of mental illness and are employed by health care organizations to provide counselling and support as part of the organization's mental health services. Their data were published in the context of the patient perspective; therefore, they were counted as patients for the purposes of this study. Finally, six of the quotes from Pisciotta et al. (2019) were partial or full duplicates of quotes from the related study, Cromer et al. (2017); this is noted and accounted for in Table 4.6.

**Table 4.6**

*Quotes Extracted from Included Studies*

| First Author & Year | Total Quotes | # Patient Quotes | # Clinician Quotes | % Patient Quotes | % Clinician Quotes |
|---|---|---|---|---|---|
| Patient-only studies | | | | | |
| Chen 2021 | 20 | 20 | - | 100% | - |
| Cromer 2017[a] | 51 | 51 | - | 100% | - |
| Fisher 2009 | 3 | 3 | - | 100% | - |
| Kipping 2016 | 10 | 10 | - | 100% | - |
| Leung 2019 | 9 | 9 | - | 100% | - |
| O'Neill 2019 | 30 | 30 | - | 100% | - |
| Strudwick 2020[b] | 25 | 25 | - | 100% | - |
| Whealin 2016[c] | 15 | 15 | - | 100% | - |
| Clinician-only studies | | | | | |
| Åkerstedt 2018[d] | - | - | - | - | - |
| Chimowitz 2020 | 20 | - | 20 | - | 100% |
| Denneson 2017[e] | 55 | - | 55 | - | 100% |
| Dobscha 2016[f] | (164) | - | (164) | - | 100% |
| Erlingsdóttir 2019 | 46 | - | 46 | - | 100% |
| Johansen 2019 | 1 | - | 1 | - | 100% |
| Kariotis 2019 | 10 | - | 10 | - | 100% |
| Mayhew 2018 | 61 | - | 61 | - | 100% |
| Strudwick 2018 | 17 | - | 17 | - | 100% |
| van Rijt 2021 | 27 | - | 27 | - | 100% |
| Studies with patients and clinicians | | | | | |
| Blease 2021 | 1 | 1 | NR | 100.0% | NR |
| Gasteiger 2020 | 18 | 10 | 8 | 55.6% | 44.4% |
| Pisciotta 2019[g] | 28 (-6)* | 13 (-6)* | 15 | 46.4% | 53.6% |
| Peck 2017 | 26 | 10 | 16 | 38.5% | 61.5% |
| Turvey 2021 | 19 | 10 | 9 | 52.6% | 47.4% |
| van Dooren 2013 | 6 | 1 | 5 | 16.7% | 83.3% |
| **TOTAL INCLUDED** | 492 | 202 | 290 | 41.1% | 58.9% |
| **TOTAL REVIEWED** | 656 | 202 | 454 | 30.8% | 69.2% |

*Notes*. # = number. % = percent. NR = not reported. These included only published quotes where the speaker was identified as a patient or clinician, and when the quote pertained to patient portals in the mental health context.

[a, c, e] These studies included quotes contained in supplements published as appendices.

[b] Strudwick et al. (2020) includes data from patients and peer support workers, who hold a dual role as persons with lived experience who are also employed by the hospital. For the sake of simplicity, these have been counted as patient quotes.

[d, f] These studies did not contain quotes in their published studies. Quotes obtained from the author (Dobscha et al., 2016b) included 164 quotes from clinicians which are not present in the "total included" but are in the "total reviewed".

[g] Six of the 13 patient quotes in this study were partial (four) or full (two) duplications of quotes from Cromer et al. (2017), which is accounted for in the totals in the final line.

## Thematic Synthesis

Synthesizing the extracted data from the studies resulted in a total of five themes, each with two or three subthemes. Table 4.7 lists the themes and subthemes. A supplemental table (Appendix G) identifies which studies included data pertaining to each synthesized theme, to illustrate the representation of the themes across studies.

**Table 4.7**

*Synthesized Themes and Subthemes*

| Themes | Subthemes |
|---|---|
| 1: Efficiency of mental health care | • Accessibility to services<br>• Effects on clinician workload<br>• Continuity of care |
| 2: Therapeutic relationships | • Clinician documentation and its effects on therapeutic relationships<br>• Changes in documentation practices to preserve therapeutic relationships |
| 3: The patient-clinician power balance | • Supporting patient rights through empowerment<br>• Decreasing clinicians' power |
| 4: Suitability of portals for patients with mental illness | • Symptoms of mental illness that impact portal use<br>• Social vulnerabilities that impact portal use<br>• Risk of harm to self or others |
| 5: Mental health information management | • Information sensitivity<br>• Unintentional disclosure<br>• Intentional lack of disclosure |

**Theme 1: Efficiency of Mental Health Care**

Theme one is about the efficiency of mental health services and the ways patient portals either positively or negatively impact this efficiency. Participants discussed how portals create greater accessibility and convenience for patients, as well as opportunities to improve continuity of care between clinicians. Clinician participants, however, indicated that portals add to an already high clinician workload, reducing the efficiency of their care delivery. This theme was reflected in 21 of the 24 included studies.

***Sub-theme: Accessibility to Services***

Participants (both patients and clinicians) in eight studies indicated that certain portal functions, such as appointment booking, messaging features, and prescription renewals enable greater access to mental health services:

> Being able to connect with my provider through the portal and skip a lot of the hurdles including waiting on hold sometimes for up to 45 min is really a different way of life and I appreciate it more and more every day. (Turvey et al., 2021, p. 5).

Patient participants explained how the portal facilitates access to services and reduces stress, particularly when urgent care needs arise: "…if you don't make your appointment you're OUT [of medication] ... So I was stressed, but I used the patient portal to contact [the nurse] and she had my prescription faxed down to a pharmacy down there" (Chen et al., 2021, p. 3). Clinician participants similarly appreciated the convenience of patient portal messaging, with participants in one study explaining that they use messaging when they have difficulty establishing contact through more traditional means:

> When we get patients that you are very concerned about, we get in touch with them every couple of days or once a week, something like that, and keep in contact with them. And you can't always get hold of them over the phone, you can't always leave a message, and I think it'd be more straightforward to reach them over ManageMyHealth. (Gasteiger et al., 2020, p. 6).

Patient participants specifically valued the convenience of accessing their mental health records through the portal, a service previously available only through formal records requests to their institutions: "MyHealth eVet… was a good program in order to find information. There was a lot of information that I could use...and I could do it from home" (Whealin et al., 2016, p. 10).

***Sub-theme: Effects on Clinician Workload***

There were variable perspectives from clinicians on the potential effects of portals on their workload. When discussing the impact of patient access to records, clinicians in seven studies noted that "more valuable worktime is likely to be spent on record keeping" (Erlingsdóttir et al., 2019, p. 4). These clinician participants noted that mental health records must house information to fulfill several requirements, such as billing, insurance, legal requirements, and communication between clinicians. With the use of portals, clinicians explained how the addition of a patient audience required them to rework their approach to record keeping:

> Who are we writing these notes for? Is this a record for billing purposes or is this a record for communication with other providers …? Often we're taught to document things in a particular way in order to cover ourselves for legal concerns and adding the layer of actually having the client also reading these

> notes just adds an additional layer of complexity to what you have to think about and how you have to phrase things in your documentation. (Denneson et al., 2017, p. 4).

Clinicians were also concerned about the increased time spent explaining the contents of the record and resolving misunderstanding when patients were able to view their notes via the portal: "They disagree with something I wrote or misinterpret something I wrote. … [this] takes more time over other [tasks] and eventually burdens the system with more red tape and transfers of care." (Dobscha et al., 2016b, p. 7). Despite this increased work, some clinicians appreciated this opportunity to reflect on their documentation:

> It wouldn't increase my workload. I mean maybe by 10 seconds because I probably will read over some things with multiple lenses before I submit, but that wouldn't be a reason for me not to do it. (Chimowitz et al., 2020, p. 162)

Messaging functions were discussed by clinicians in only one study, with varying views. Some clinicians stated that messaging "ridiculously increased our non-compensated time… the time and anxiety around the endless e-messaging will ultimately be the major driver of when I decide to retire" (Turvey et al., 2021 p. 7). Others reported that messaging was "much more efficient than phoning and an unintended consequence is a more efficient workflow'' (Turvey et al., 2021, p. 6).

***Sub-theme: Continuity of Care***

The final sub-theme related to efficiency of care delivery is *continuity of care*. When continuity of care is achieved, there is a seamless flow of health care information between providers in the health care system, allowing for fewer delays,

repetitious interventions, and/or errors. There were eight studies in which participants described how portals could improve the continuity of mental health care between different providers, either within or between institutions. In one such study, patient participants noted that continuity of care was enhanced when institutions used the same (or interoperable) portals, so that the health records were automatically transferred between them: “I currently use my chart and am in [town] so every provider in my area that I go to utilizes it and again it’s just phenomenal” (Turvey et al., 2021, p. 5). Patient and clinician participants also described how portals could establish greater continuity of care between mental and physical health care services. Participants highlighted the fragmentation of services in clinics where patient portal functions were available for physical health care but not mental health care: “At the moment, there's two kinds of separate streams. There's the doctor, and then there's the counseling… considering like, they're in the same service, it would be helpful if they were linked better” (Gasteiger et al., 2020, p. 5).

Patient participants spoke about how they use portals to keep track of their own information, thus ensuring their records are not lost between providers, whereas clinician participants indicated that they were less likely to include as much detail in their notes when patients can read them. They felt this compromised quality of record-keeping, communication between clinicians, as well as continuity of care: “I will provide less clinical information, which will likely disrupt continuity of care with other providers” (Dobscha et al., 2016b, p. 10).

**Theme 2: Therapeutic Relationships**

The second theme, identified in the findings of 16 of the included studies, is the connection between patient portal use and the therapeutic relationship between clinicians and patients, which is a foundational element of mental health care.

***Sub-theme: Clinician Documentation and its Effects on Therapeutic Relationships***

Clinician and patient participants in 14 studies indicated that therapeutic relationships can be compromised when a patient perceives a disconnect between what they understood from in-person communication/interactions and what was written in the chart.

Patient participants reported that they found information, including diagnoses, in the record that were not discussed with them: "I was reading things that were not told to me ... You wrote the diagnosis of the problem right here in black and white, but yet you turn and tell me a whole different story" (Chen et al., 2021, p. 4). This caused a loss of trust in their clinicians. Conversely, they explained that when clinicians ensured their notes were consistent with verbal discussions, this improved the therapeutic relationship: "You read something and then if it's pretty much what they were telling you then it builds that trust... So, it's a good relationship builder between you and your doctor" (Chen et al., 2021, p. 4).

Patient participants also felt that they were misunderstood or misrepresented by their clinicians, and this had negative consequences: "It was a couple items that were put down differently than they were discussed… And that upset me because the way they were reworded is not the way that I said it" (Cromer et al., 2017, supplement p. 5). Patients explained that when they felt heard or validated, this bolstered the

therapeutic relationship: “I always appreciate how well my therapist captures what I’ve said and how I’m feeling. … I felt confident I was getting understood” (O’Neill et al., 2019, p. 532).

Clinician participants in ten studies recognized - and feared – the impact on the therapeutic relationship when patients feel misrepresented or unheard through their notes:

> I am most afraid that a misunderstanding or an unpleasant feeling when reading can, in the blink of an eye, destroy a relationship between the patient and myself that we have built up over several years with some difficult patients. That would be a shame! (Erlingsdóttir et al., 2019, p. 6).

Some clinician participants questioned whether miscommunications were always a result of errors in clinician documentation or communication. They stated that patients often misinterpret or misunderstand their notes, and that “some clients, regardless of how kindly, objectively, generously something is shared in the chart, will take exceptions and will take a lot of support to understand the context of it” (Mayhew et al., 2018, p. 319).

Patient participants described times when it was clear that the clinician made an error in documentation, such as a mistake in their demographic data or medical history. Patients reported feeling upset and that they trusted their clinicians less when they found these more concrete, factual errors in their charts: “I reamed her out about making a mistake. I didn’t ream her out, but I was not happy. So I think we’re in a trust building stage; so she’s writing her notes carefully and I’m reviewing them carefully” (Cromer et al., 2017, supplement p. 2).

When patient participants discovered documentation that caused a breach in trust, they were less willing to be open and forthcoming in conversations, and they described changing the way they interacted with their providers: “I felt uncomfortable that she told me one thing yet I read something else in the note. I don’t know that I would see her again due to this” (O’Neill et al., 2019, p. 532). For some participants, breaches in trust could also cause patients to disengage from mental health care entirely.

Clinician participants also described situations where their patients were no longer interested in engaging in care because they perceived to be misrepresented in their notes: “[The patient] was so angry about the mismatch between what he felt was going on and his diagnosis of schizophrenia that he stopped his psychiatric medications despite it being very stabilizing for him” (Dobscha et al., 2016b, p. 9). Some clinician participants felt this risk outweighed the benefit of allowing open access to health records via portals: “patients will become distrustful of health care and not seek care again when they really need it” (Erlingsdóttir et al., 2018, p. 6).

To mitigate the risks of misunderstandings and lost trust, clinician participants in eight studies not only encouraged patients to review their notes, but actively engaged patients in conversations about their documentation. They saw this as an opportunity to establish transparency of communication and create trust: “I think the process of being open to having the conversation and seeing their concerns is often more powerful than whatever is in the record or they want to change” (Pisciotta et al., 2019, p. 68). Patient participants agreed that conversing directly about the notes and receiving clarification for any misunderstandings was a valuable component of their

care: “The way forward for the patient and clinician is through open dialogue. Maybe … every now and then we just chat about the notes and the impressions so there is no misunderstanding. (Pisciotta et al., 2019, p. 67)

### *Sub-theme: Changing Documentation Practices to Preserve the Therapeutic Relationship*

Clinician participants in nine studies indicated that documentation practices change in response to patient portals. These changes are intended to preserve the therapeutic relationship and prioritize accuracy of information: “When you know that other people are looking at the work that you do, particularly the people who it directly pertains to, then you want to make sure it’s the best, it’s the most accurate” (Denneson et al., 2017, supplement p. 5). Specifically, clinician participants spoke about how some terminology and phrasing are stigmatizing or judgmental, which might affect a patient’s recovery. For example, clinicians “might be more conscious of what they are documenting, and if they start typing in a sentence and feel like it’s a judgmental statement, they may not put it into the health record” (Mayhew et al., 2018, p. 318). Clinicians also add more details about their patients’ strengths and recognition of their progress: “If I’m working with someone and they are presenting with a problem, try to think of including in the note something positive that they’re doing …So maybe some hope and some validation” (Pisciotta et al., 2019, p. 68).

Of note, clinician participants in five studies explained how efforts to preserve the therapeutic relationship through their notes results in poorer quality documentation. These participants noted that in order to maintain rapport with their patients, they

deliberately made their notes vague and omitted details that they would otherwise include:

> I'm now writing a note that either does not document certain things, that is opaque, is bland and is innocuous … I don't want to harm the patient and yet there's certain obligatory aspects to being a provider that you're in a rock and a hard place. You have to document certain minimum things, so you fill it up with crap. (Denneson et al., 2017, supplement p. 7)

**Theme 3: The Patient-Clinician Power Balance**

A third theme, present in 22 studies, is the impact of patient portals on the power balance between clinicians and patients. Both patient and clinician participants described how portals empower patients. Clinicians also described the ways portals affect their control over the health record.

***Sub-theme: Supporting Patient Rights through Empowerment***

Patient participants were inconsistently aware of their rights regarding access to their health records, whereas clinician participants understood patients owned their health information:

> Patients have a right to access their medical records, and have ever since I've been involved in health care - the only difference I see is that now they can do it rapidly, whereas before they had to fill out an ROI [request of information]. (Dobscha et al., 2016b, p. 14)

By having access to their records, both patient and clinician participants agreed that patients were better informed about their care and prepared to make health care decisions, thus becoming partners in care rather than being subjected to a clinician-driven process: "health care decision making… moving in the direction of a patient-

centeredness. As opposed to a clinician having all of the information" (Denneson et al., 2017, supplement p. 1).

Patient participants in ten studies described feeling empowered by having access to their health information: "Just having my own access has given me freedom as a patient" (Kipping et al., 2016, p. 6). They described how portals could be a tool "where it gives [them] a voice" (Strudwick et al., 2020, p. 401). They explained how having this access enabled them to have more control in the care relationship: "I do read my notes. And, you know, I'm like, either you guys work with me or you don't. It's your choice" (Cromer et al., 2017, supplement p. 2).

***Sub-theme: Decrease in Clinicians' Power***

Clinician participants described a shift in power resulting from the implementation of patient portals. In five studies, clinicians sensed a loss of ownership of the record. They viewed patient portals as movement away from the original purpose or "foremost function" (Erlingsdóttir et al., 2019, p. 6) of mental health records. They lamented no longer being able to use the chart to keep personal notes, record preliminary findings, and communicate with other providers, stating that "the notes become watered down and fall short in their function as a tool for the profession" (Erlingsdóttir et al., 2019, p. 5). Clinicians also felt that their autonomy was threatened when patients attempted to dictate what was entered as part of their documentation: "What I'm noticing is that, and I've directly had patients say this to me, '...don't write that in my notes.' ...It's just like they're trying to dictate their care and we're trying to provide care...I feel like I'm on the defense" (Denneson et al., 2017, p. 3).

Finally, clinician participants described losing control over access to the record with the advent of patient portals: "I think the way it was done many years ago when the … practitioner could be involved in the decision to release notes was preferable" (Dobscha et al., 2016b, p. 11). They wanted restrictions in place, such as approval processes, limited access for certain patients, delayed release of notes, or supervised viewing of notes.

**Theme 4: Suitability of Portals for Patients with Mental Illness**

When discussing patient portals in a mental health context, participants in 22 studies spoke about the impacts of portals on patients with mental illness due to the symptoms, risks, and vulnerabilities considered characteristic of this population. They reported how patients with mental illnesses are perceived as having certain characteristics that affect the use and suitability of portals for them.

***Sub-theme: Symptoms of Mental Illness that Impact Portal Use***

Patients with mental illness experience varied symptoms, such as impaired insight, cognitive difficulties, anxiety, and paranoia, among many more. Participants – primarily clinicians – expressed concerns regarding how these symptoms might influence portal use. In four studies, clinician participants directly questioned whether patients with mental illness benefitted from portals because of their lack of insight. They proposed that it was possible – or even likely – that there would be discrepancies between patients' understandings and clinician notes because patients lacked insight into their illnesses:

> The population I work with is often literally in my program because they have limited capacity to accept, understand, or have insight into their illness. In

> order to effectively communicate with other providers without alienating my clients, I will need to find alternative ways to communicate with other providers. (Dobscha et al., 2016b, p. 4).

Clinicians also reported that some patients with mental illness would have difficulty using portals because of cognitive deficits related to their illnesses: "This population [has] more difficulty understanding and processing information [and] that would require more time [to help them use the portal]" (Mayhew et al., 2018, p. 318). They asserted that certain proposed uses of portals, such as charting collaboratively with patients, were not feasible when working with patients with mental illness:

> [We are told] 'You have to write [in the medical record] together with your patient, use the last ten minutes of your consultation.' However, that does not work with our patients. They are completely overstimulated after half an hour, they cannot immediately reflect on what happened. (van Rijt et al., 2021, p. 7).

In ten of the included studies, clinician and patient participants indicated that anxiety symptoms create circumstances where portal use was challenging, such as facing uncertainty and confusion when interpreting the notes. Clinicians indicated that when reading their health record, "[the patient may] start getting a panic attack or anxiety with no support around, in the middle of the night," and wondered, "What kind of resources do [patients] have to deal with that anxiety?" (Strudwick et al., 2020, p. 402). They questioned the ethics of providing access to potentially anxiety-inducing materials without support: "Lack of knowledge and ability to understand the content in the notes can result in increased worry and unnecessary anxiety. Is it ethically right to

leave the patient on his or her own to try and interpret the meaning of the notes?" (Erlingsdóttir et al., 2019, p. 8). Furthermore, clinician participants were concerned that use of the portal would cause worsening paranoia and persecutory delusions: "If someone is exhibiting [symptoms] of paranoia, I am unlikely to add this to the note because reading that I think they are paranoid may make them more paranoid" (Dobscha et al., 2016b, p. 5).

While most findings about the effect of mental illness symptoms on portal use painted them as barriers, clinician participants in four studies suggested that portals could transform the record into a therapeutic tool and educational resource: "[The notes] could be more of a tool for re-explaining …for someone who needs to review information in a different way or see where they are at in their treatment. (Pisciotta et al., 2019, p. 69). They emphasized that this would be especially beneficial to patients experiencing cognitive or emotional symptoms:

> Especially when you're working with people who either have a cognitive disorder or are caregivers and are very emotionally taxed and physically taxed . . . there's too much that happens in session . . . and so I think having access to the notes from a practical standpoint is helpful. (Chimowitz et al., 2020, p. 162)

Interestingly, the above perspectives were echoed by patient participants, who reported that portals were beneficial when they experienced cognitive or emotional difficulties because the notes could be used as a reference or memory aid: "When you come to [the hospital], there's a lot to take in and it can be overwhelming, so the portal can help" (Leung et al., 2019, p. 269) and "I don't think I that I could participate [in my care] if I didn't have access to the notes. Because I wouldn't remember" (Cromer et

al., 2017, supplement p. 3). Finally, there were participants who believed that portals could be helpful to patients in developing insight. According to these participants, portals could be used as tools for self-reflection: "They could look at documentation about themselves… hopefully learn about themselves when they leave the hospital" (Mayhew et al., 2018, p. 319). For example:

> Sometimes it's not clear to me just how often I'm making the same complaints until I see it in writing. I do… mention a lot of the same problems and bring up a lot of the same issues and probably should be doing more about that. (O'Neill et al., 2019, p. 532)

***Sub-theme: Social Vulnerabilities that Impact Portal Use***

Clinician participants in five studies indicated that patients with mental illness are part of a vulnerable population with lower rates of computer literacy and access. They explained that these factors likely influence the suitability of portals for this population. Clinicians were concerned about how portals create inequalities in health care. The following example highlights how computer literacy creates advantages for some and barriers for others:

> We have a particular triage for identifying the most urgent and booking them in straight away, and if we opened up a portal to all, it might be that students who are the most organized or were the best at technology would get the appointments. (Gasteiger et al., 2020, p. 4)

Clinician participants indicated that portals would be challenging to implement, and questioned their value given the large number of clients with low computer literacy or no access to the Internet:

> We have quite a high proportion of clients who have very low literacy… who are homeless or very low income or itinerant… they often don't have internet access or phone contact so again that would be a difficult group for that to be used. (Kariotis et al., 2019, p. 69)

***Sub-theme: Risk of Harm to Self or Others***

Much of clinician participants' concern about access to portals surrounded risk management. In six studies, they reported how they often had patients who experience crisis situations involving self-harm and suicidal ideation. They considered that patients might become upset in response to reading their notes and be more at risk of harming themselves. Because they felt a responsibility for patients' safety, they reacted to this risk with anticipated guilt: "It's going to be that one time, that one [patient] is going to read something and is going to hurt themselves. And then I'm going to feel like I have to live with that" (Denneson et al., 2017, supplement p. 5).

Expanding on their concerns regarding patient safety, clinician participants also explained their apprehensions about messaging functions in portals, stating that patients might try to use this to reach out during a crisis. If this occurred, they would not be able to provide support in a timely manner and they questioned how they could fulfil their duty of care for patients in these circumstances: "If the client is in a crisis, how do you follow up with that at that point if you don't get the message right away?" (Mayhew et al., 2018, p. 318). Conversely, patient participants indicated that access to the portal would be particularly useful for managing crises; the information in the portal could be used as a coping tool in the moment and reduce the risk of a crisis escalating: "[My notes] came in handy when I had a really bad breakdown. I walked

through all the steps that [my clinician] taught me" (O'Neill et al., 2019, p. 532); however, this was reported in one study only.

Like patient safety, clinician participants explained their concerns about managing the risk of violence; they believed that patients might react with hostility and violence to the content of their notes. They linked this risk of violence to the emotional dysregulation sometimes experienced as a symptom of mental illness:

> As a former outreach social worker going to visit homeless people, I have omitted words that I felt client [*sic*] would find offensive such as 'delusion' for my own safety in subsequent visits... I think providers who are outside the safety of a medical facility should have special consideration for notes as they are frequently alone with people with significant mental health problems who may be emotionally disregulated [*sic*].' (Turvey et al., 2021, p. 4)

**Theme 5: Management of Mental Health Information**

The fifth theme, represented in 15 studies, is that information management and communication practices in mental health care are more complex than in other health care contexts. Sharing information about mental health care with clinicians, patients, and families was described as an activity that is laden with risk and that needs to be performed with great caution and sensitivity. Patient portals, as transparent and less controlled means of storing and sharing information, were seen as potentially disruptive to care in the mental health context.

***Sub-theme: Information Sensitivity***

In eight studies, clinician and patient participants reported that mental health information (including information about stigmatized disorders, traumatic events, or

stressors) is inherently more sensitive than many other types of health care information: “There are different tiers of information sensitivity … a blood pressure reading...is not as sensitive as the disclosure of childhood sexual abuse” (Kariotis et al., 2019, p. 68). They explained that when considering mental health records, it is important to demonstrate “that we take MH care serious [*sic*] and we protect it even more than the ‘regular’ medical record” (Dobscha et al., 2016b, p. 17). Mental health information was viewed by patients as “private and very personal” (O’Neill et al., 2019, p. 532), and differently documented than physical health content in the health record:

> I only want my visits with my mental health care provider to be between me and the provider. I see no reason for them to be for everyone to read. … If I am having a side effect from the medication then I would feel differently about the sharing of notes. (Peck et al., 2017, p. 313).

***Sub-theme: Unintentional Disclosure of Mental Health Information***

Participants in six studies explained that negative outcomes could occur through unintentional disclosure of mental health information, such as when data security is compromised, or information is shared with someone it is not intended for. Considering its sensitivity, both patient and clinician participants discussed the importance of data security with mental health information being published online. There was an acknowledgement of the vulnerability of online applications to security breaches. Clinician participants reported having patients who were concerned about these potential breaches, stating they “fear that unauthorized people will be able to read about them” (Erlingsdóttir et al., 2019, p. 7). Meanwhile, patient participants

varied in terms of their concern about portal security. In one study, patient participants stated: “I just hope that patient site is very, very secure” (Peck et al., 2017, p. 313), whereas patient participants in another study dismissed security concerns, stating: “Anything online is at risk for hacking. … I don’t see this one as any worse than other privacy concern in the hospital” (O’Neill et al., 2019, p. 532).

Rather than focusing on security breaches from hacking, patient participants more often expressed worry about data security when they learned about notes being shared between clinicians: “I strongly oppose to have these notes available to anyone who has authorization to read them… this is not my idea of therapy” (Peck et al., 2017, p. 313). Hacking was also not the primary concern for clinician participants, who worried about the possibility of portals creating situations where patients were pressured or manipulated into sharing their data with others (such as employers, intimate partners, or family members). Clinician participants reported that there is a “great risk for privacy violations when notes not only can be read by the patient, but also spread within and outside of the health care system to people who can misuse the information” (Erlingsdóttir et al., 2019, p. 7).

***Sub-theme: Intentional Lack of Disclosure***

In four studies, clinicians described situations where mental health care information is deliberately kept from patients. For some of the included clinicians, the ability to withhold information from patients is a foundational element of their mental health care, thus portals challenge their entire practice: “[Patient access to documentation] really is antithetical to the way that many of us have been, literally, trained and learned to think about our field” (Denneson et al. 2017, p. 3). Clinicians

explained that, as part of the therapeutic process, information is withheld in the hopes that patients independently gain insight into their circumstances. According to these clinical participants, portals compromise this goal:

> What's lost–I think there's a loss of mystique, the mystery… when somebody reads the notes it's essentially pulling the curtain and seeing what's really there, and I think it damages that process… In saying 'hey there are attachment issues, difficult relationship with mother and abuse, has harmed his ability to connect to his wife in this way.' It's that assessment that usually in psychotherapy you want to help the patient come to that conclusion on his or her own. You don't just say 'here's the script and here's the ending'. I think it interferes with that process. (Denneson et al., 2017, supplement pp. 2-3).

Another example of information that is traditionally withheld from patients is collateral information from friends or family members. This is information collected about the patient, sometimes without their knowledge or cooperation, to better understand how the patient's symptoms are affecting their lives in the community. The following quote illustrates how the disclosure of the collateral information could create unnecessary risks to those providing it:

> [I] have had specific issues related to safety where including information in chart would put people in danger. One example is someone with a delusional disorder that engaged in threatening behavior- acquaintance called me to report information and was scared for his safety should the information communicated be placed in the chart." (Dobscha et al., 2016b, p. 4)

There are also situations in mental health care where patients are confined and treated involuntarily, typically due to imminent risk of harming themselves or others. Clinicians described how open access to documentation regarding plans to admit a patient on an involuntary basis could cause distress: "… during meetings we discuss whether an admission to the ward would be an option. If you write down that you consider this, he [the patient] might get upset or deteriorate" (van Rijt et al., 2021, p. 6). These clinician participants hypothesized that access to portals could inadvertently provide patients advance warning of plans for involuntary admission, creating a safety risk: "It is possible that when he [the patient] reads this and thinks: "Hey, they are on my doorstep tomorrow [for an involuntary admission], you know what, I will end it [his life] before they arrive" (van Rijt et al., 2021, p. 6).

# Chapter 5: Integrated Discussion

This chapter includes a summary of the systematic review and its findings, followed by a discussion of three key points in the context of the extant literature, including clinician workload concerns, stigmatization of individuals with mental illness, and changes to the patient-clinician power balance. I then outline the implications of the study for nursing clinical research, practice, education, and policy. Finally, I discuss the strengths and limitations and provide conclusions.

## Summary of Findings

The research question for this qualitative evidence synthesis was 'What are the perceptions, attitudes, and/or experiences of patients and clinicians with regards to patient portal use in the mental health context?' A systematic search of 8 relevant healthcare databases and subsequent review of citations yielded a total of 26 articles published on 24 qualitative or mixed-methods studies, whose qualitative data were extracted and synthesized. Findings reflected five themes:

(1) Patient portals impact the **efficiency** of mental health care delivery. There were clinician and patient participants who felt portals improved efficiency through creating greater access and promoting continuity of care; however, some clinicians explained how the added workload related to using portals is burdensome and negatively affects care.

(2) Patient access to clinical documentation through portals affects **therapeutic relationships** between clinicians and patients. Clinicians described how they changed their documentation practices to preserve their therapeutic relationships.

(3) Patient portals alter the balance of **power** between clinicians and patients. Portals support patients' right to self-determination and autonomy in health care, whereas clinicians lose ownership over the care record and control over who can access it.

(4) The **suitability of patient portals for patients with mental illness** is debated. Some participants – mostly clinicians, but also some patients – expressed concerns that mental illness symptomatology and experiences (anxiety, paranoia, limited insight, and risk for harm to self or others) interfere with the use of portals. Conversely, there were clinicians and patients who felt that the potential benefits of portals, such as increased patient engagement, assistance with accessing and processing information, and increased insight, are particularly beneficial for patients with mental illness.

(5) **The culture of information management in mental health care is complex**. The introduction of patient portals in the mental health context adds to that complexity and disrupts the traditional means of sharing information.

## Discussion Points

### Introduction

This review included studies published primarily in the last six years, which reflects the novelty of patient portals, especially in mental health settings. Key findings were related to the impacts of patient portals on efficiency, therapeutic relationships, power dynamics, and information exchange in mental health care, as well as the suitability of patient portals for meeting the needs of patients with mental illness. The focus of most findings was on the primary function of portals: patient access to their health care records.

Although patient portals are a relatively new tool, access to health records is not a new concept. Access to mental health records has been discussed in the literature before – primarily in the 1970s-1990s, the period just prior to the widespread enactment of laws upholding health information access rights in Western countries (Davies, 1996). When comparing the findings of this review to historical studies on the topic, there are several similarities. In this section, I

discuss key findings of this review in relation to historical perspectives on patients' right of access to their health record. Specifically, I speak to my findings on clinician workload, benevolence stigma, and changes in power distribution, and how these contribute to clinician resistance to patient portal adoption.

**Clinician Workload**

One of the findings of this review was that clinicians felt patient portals would (or did) increase their workloads and reduce their efficiency. At times, these concerns were related to the anticipated, rather than experienced, effects on their work.

Concerns about increased workload related to patient portals are also shared by clinicians in other health care contexts (e.g., internal medicine, emergency medicine, primary care, and oncology). These clinicians reported they did not have enough time for educating patients about the portal or contents of their records, managing patient messages in the portal, or modifying their documentation (Alpert et al., 2019; Collins et al., 2017; Grünloh et al., 2019).

This theme is also found in the literature on mental health care records from the 1990s and earlier, during the initial movement toward upholding patients' right of access to their health records. Clinicians in studies conducted in this period were concerned that permitting patients to access their mental health records would create additional demands on their time (Parrott et al., 1988; McShane & Rowe, 1994). Their concerns were largely about the time required to review notes with patients, as well as for the administrative tasks like processing requests and editing and photocopying documentation (McShane & Rowe, 1994).

Patient portals, by virtue of their digital design, simplify patient access to health care records by eliminating the need for formal requests, as well as photocopying, scanning, or formatting of files (Dobscha et al., 2016b; Irizarry et al., 2015; McShane & Rowe, 1994).

Patients can sign up for an account electronically in order to be granted access, or do so through clinical records departments; clinicians are not necessarily involved with the process of access requests (The Ottawa Hospital, n.d., Royal Ottawa Health Care Group, n.d.) However, clinician participants explained that portals increase their workload in other ways that offset this saved time. They expressed concerns about the time required for educating patients about portals, discussing the content of care notes with patients, as well as performing administrative tasks, such as editing documentation for patient viewing and answering patient messages via portals.

Evidence on the actual impact of portal use on clinician workloads is limited, with few studies evaluating this outcome directly. What evidence exists is mixed, with some studies pointing to increased healthcare efficiencies and others to ongoing clinician concerns about extra work (Irizarry et al., 2015; Laukka et al., 2020; Schwarz et al., 2021; Tapuria et al., 2021; Zhang et al., 2021). Referring to the findings of my review, clinician participants of studies where portals were implemented and a regular part of their practice, reported mixed effects on their workloads. Some indicated there was no change, whereas others reported excessive time spent documenting, discussing notes, or answering messages sent via the portal. In the quantitative component of one included study, Petersson and Erlingsdóttir (2018a/b) found important differences in clinician perspectives on workload. While 40.6% (n=845) of the mental health clinicians surveyed prior to portal implementation believed they would spend more time addressing patient questions outside of appointments, only 18.0% (n=588) reported this post-implementation. Similarly, 35.1% (n=852) of clinicians surveyed pre-implementation believed portal access would prolong appointments, whereas only 14.5% (n=594) of clinicians reported appointments taking longer post-implementation. Finally, 41.5% (n=848) of clinicians believed their time spent on documentation would increase, but only 17.7% (n=662) of clinicians

continued to report this post-implementation (Petersson & Erlingsdóttir, 2018b). Overall, these authors found that the percentage of clinicians concerned about workload was reduced by approximately half after they embedded portals into their practice. Interestingly, the percentage of clinicians who believed that patients would be more engaged, better prepared for their appointments, and have better understanding of their care was also reduced by half post-implementation. The authors proposed that the reduced concerns about workload reflected patients' low uptake of portals, rather than the portal's effect on workload (Petersson & Erlingsdóttir, 2018b).

Although current literature does not reflect many comparisons of post-implementation changes to workload between clinicians in different health care contexts, Kristiansen and colleagues (2019) found that mental health clinicians do spend more time on tasks related to portals than clinicians in other domains. Specifically, they found that 38.6% (n=813) of mental health clinicians spent more time documenting and 20.2% (n=718) spent more time explaining documentation. In comparison, 26.1% (n=2897) of clinicians in other healthcare contexts reported increased time spent documenting and 11.3% (n=2614) spent more time with patients to explain documentation post portal implementation. The authors suggested that their findings were related to clinicians' perspectives that patients with mental illness were more likely to be harmed by information in their care records, and that clinicians were more likely to expect threats and violence from patients. Clearly, clinicians in both mental health care and other health care contexts have anticipatory apprehensions about the additional workload associated with patient portals, which may or may not be reflective of the true workload impacts.

However, any clinician concerns about additional workload should not, especially considering the current health care climate, be taken lightly or dismissed. Clinicians are already

facing high workloads and staff shortages. In 2021, overtime rates for healthcare occupations in Canada were the highest they have been in over a decade (Canadian Institute for Health Information [CIHI], 2022), and vacancy rates in the health care and social assistance sectors doubled between 2020 and 2022 – reaching an all-time high of 126 000 open positions (Statistics Canada, 2022a). Furthermore, 74.6% of clinicians report having an increased workload than before the COVID-19 pandemic (Statistics Canada, 2022b). The negative effects of excessive clinician workload on both clinicians and patients are well-documented. For example, clinicians who are overburdened with responsibilities experience stress-related health consequences, including fatigue and difficulty concentrating. Expectations to assume excessive workloads long-term lead to symptoms of burnout (Farid et al., 2020; West et al., 2018). These stress-related health outcomes not only cause personal distress, but they decrease the quality of care that clinicians are able to provide and are also associated with higher rates of medical errors (Farid et al., 2020; West et al., 2018). On a system level, stress and burnout are associated with high levels of absenteeism and may cause clinicians to change jobs or leave their professions entirely (Farid et al., 2020; Statistics Canada, 2022b; West et al., 2018).

In their systematic review on supporting patient portal implementation in mental health settings, Zhang and colleagues (2021) acknowledged the challenges of incorporating portals into health care workflows, including resource allocation and training requirements. They emphasized that organizations aiming for successful implementation need to appropriately address these challenges to ensure that clinicians are supported. Likewise, in their systematic reviews of portal outcomes, both Irizarry and colleagues (2015) and Laukka and colleagues (2020) recommended that organizations should involve clinicians in the development of patient portals, and account for time spent using portals when managing clinician resources.

Organizational support of clinicians in managing their workload can only benefit patients, who are the people most affected when clinicians are overburdened with work; high workloads and stress levels are associated with increased medical errors and adverse patient outcomes, and reduced quality of care and patient satisfaction (Farid et al., 2020; West et al., 2018).

**Benevolence Stigma and Patient Access Restrictions**

A second key finding of this review was that clinician participants believed that providing access to mental health records could cause patients harm in several ways. They explained how their notes might cause offense and breaches of trust and, in some cases, cause patients to disengage from their care. Clinicians reported employing a number of strategies to mitigate these perceived risks and argued that organizations should have policies in place that limit patient access to records without clinician approval and, in some cases, supervision. These clinicians demonstrated a hesitation to permit patients to access information on their own initiative or acknowledge that they may be able to understand their care records without immediate support and guidance from a clinician. Essentially, clinicians reported that patients lack the capacity to independently access the information in their records because of the symptoms of their mental disorders.

These concerns are echoes of those expressed by clinicians in the literature in the 1990s and prior, when access to mental health care records was first explored. In the study by Parrott et al. (1988), the authors described clinician concerns that patients with mental illness are "too disturbed" (p. 522) to read or engage meaningfully with their health care records. Like clinicians in my review, their participants believed patients with mental illness often do not have the requisite insight or knowledge to benefit from reading their records and may be unable to cope with resultant negative emotions. To mitigate these concerns, participants considered omitting

details in their documentation (McShane & Rowe, 1992; McShane & Rowe, 1994; Sergeant, 1986). Clinicians in this period also shared the fears that patients may behave violently towards themselves or others because of the information found within their health record (McShane & Rowe, 1994; Sergeant, 1986).

In today's context, for studies in health care settings outside mental health, there are similarities, but also important differences. Some clinicians in these settings do believe that access to health records through patient portals will cause patients confusion, anxiety, and distress, yet their reasons differ (Alpert et al., 2019; Grünloh et al., 2016; Tapuria et al., 2021). They explain how it is possible that records containing life-threatening diagnoses are better communicated sensitively in-person, and that or medical information may be too complex for laypeople to accurately interpret (Alpert et al., 2019; Grünloh et al., 2016; Tapuria et al., 2021). Therefore, unlike mental health clinicians, health care providers in other contexts do not generally associate the inappropriateness of portal access with traits perceived as inherent to patients or their illnesses. Instead, they assume universal lack of medical knowledge.

As evidenced by the findings of this review, some clinicians who oppose patient portal implementation espouse the idea that patients with mental illness are inherently impaired with respect to managing negative emotions or processing uncomfortable information. They report that this 'impairment' interferes with their capacity to meaningfully participate in interventions designed to increase their autonomy, like patient portals. In essence, clinicians explained that these 'impairments' are severe enough that the restriction of patient rights is justified for their protection. When clinicians justify the restriction of patients' rights of access to their mental health records in order to protect them, this is a manifestation of benevolence stigma, a phenomenon also known as 'beneficence-induced paternalism' (Corrigan, 2016). Although

clinicians rightly feel a duty of care to their patients, they wrongly assume patients with mental illness require their protection because they are fundamentally incompetent and helpless.

As discussed in Chapter 2, Weiner's (1988) attribution theory addresses differences in stigmatization of individuals with disorders considered to be of their own making, compared to individuals with disorders for which they are not considered responsible. Over the course of the last thirty years, significant education efforts have resulted in the widespread acceptance of mental illnesses as brain disorders for which people are not responsible; however, this has had unintended negative consequences (Corrigan, 2016). Weiner's attribution theory posits that when individuals experience an illness for which they are not responsible, this generates pity and leads to helping behaviours as a social response. Pity, though, is not always helpful; instead, it may perpetuate the stereotype that people with mental illness are inherently incompetent, and reinforce patients' feelings of inferiority, low self-worth, and lack of motivation in a process known as self-stigmatization (Corrigan, 2016; Deegan, 1992; Fominaya et al., 2016).

There is insufficient evidence available about the harms to patients caused by patient portals; in the studies included in this review, there were a small number of anecdotal, but unsubstantiated, reports (Dobscha et al., 2016b; Erlingsdóttir et al., 2019). While some patients might not benefit from record access, there is no evidence to support widespread harm to patients to a degree that justifies policies restricting access to all mental health records, such as those in place in several Ottawa-area hospitals (The Ottawa Hospital, n.d; Queensway Carleton Hospital, personal communication, June 2020). These policies are a form of institutional discrimination against patients with mental illness, and the findings of my review suggest that this discrimination is driven, at least in part, by benevolence stigma (Corrigan et al., 2004; Henderson et al., 2014; Link & Phelan, 2001).

There is, on the other hand, ample evidence that stigma and the resultant discrimination are harmful to patients; people who have experienced mental illness report that their experiences of stigmatization are often more damaging than the illness itself (Mental Health Commission of Canada [MHCC], 2015). For example, patients explain that encountering manifestations of benevolence stigma, such as assumptions of their incompetence in decision-making, exclusion from care planning, and withholding of health care information, leads to several negative consequences, including emotional distress, a sense of dehumanization and infantilization, distrust of clinicians, and disengagement from health care (Arboleda-Flórez & Stuart, 2012; Ewart et al., 2016; Farrelly et al., 2014; Knaak et al., 2017; Kokanović et al., 2018; Tyerman et al., 2021). It seems reasonable to extrapolate that the restriction of access rights, as another manifestation of stigma, could result in similar harms. While research so far has focused on patients' experiences of portals after having been provided access, it would be worth exploring the experiences of patients receiving mental health care at institutions where their access to portals is denied.

As Corrigan (2016) argues, we should be striving for parity, or the equitable treatment of persons experiencing mental illness, over pity. Patients with mental illness do experience symptoms, such as anxiety, paranoia, reduced insight, and impairments in cognitive functioning (American Psychiatric Association, 2022a). However, we also know that patients experiencing these symptoms cannot be assumed to be incapable of making decisions and participating in their healthcare in meaningful ways (Appelbaum & Grisso, 1995; Corrigan et al., 2004; O'Brien, 2010; Okai et al., 2007; Steinert, 2017).

As a deeply rooted sociocultural phenomenon, stigma can be difficult to change despite significant attempts at intervention. The most effective means of addressing stigma are not yet

established, though there are several key elements, including education, social contact, and role modelling by leadership (Corrigan et al., 2016; Knaak et al., 2017). Clinicians and organizations must critically examine the underlying assumptions on which any blanket personal or policy decisions to restrict access to mental health care records are based. They must ensure their practices or policies reflect evidence on the positive effects of patient portal access, the negative impacts of stigmatization, and the ethical obligation to provide equal access to care, including record access, to all patients regardless of diagnosis.

## Changing Power Balance and Recovery-Oriented Care

The third discussion point is pertaining to the changes to the power distribution between patients and clinicians as a result of portal use.

### *Patient Empowerment*

In my review, participants in both categories stated that portals empowered patients by affirming and facilitating their right to access their own health information and participate in their care. They agreed, too, that access enables patients to be more informed and prepared to make care decisions, rather than being passive recipients of clinician care. Patient participants valued the increased sense of control in the care relationship.

The theme of shifting the power balance between clinicians and patients is also present in the literature in other contexts; for example, in the pre-1990s literature on access to mental health records. In Parrott et al. (1988), patients expressed that they did not believe accessing records would be harmful, but even if it were, they wanted the right to make that decision for themselves, because reading their notes provided "a sense of security and authority" (p. 521). Additionally, this sense of empowerment is shared by patient participants in non-mental health settings. Participants in several qualitative studies indicated that patient portal access gives them more

control over their own health, facilitates decision-making, and allows them to act as advocates for themselves (Alpert et al., 2019; Marsh et al., 2020). There are also studies in these health care contexts in which clinicians describe how portals support patient empowerment and health care decision-making (Alpert et al., 2019; Elers & Nelson, 2018; Grünloh et al., 2016; Grünloh et al., 2018; Nøst et al., 2021), and an acknowledgement that "it is the patient's record" (Nøst et al., 2021, p. 4).

As discussed in Chapter 2, empowerment is one of the foundational elements of recovery, and recovery-oriented practice is of primary importance in mental health care (MHCC, 2015; Pilgrim, 2008; Provencher et al., 2002; Resnick et al., 2004; Waldemar et al., 2016). Patients may be disempowered through several mechanisms, including stigmatization and self-stigmatization, where patients with mental illness incorporate the stereotype of incompetence into their self-concept, causing reduced motivation to act on their goals and reduced confidence in making decisions (Corrigan, 2016; Deegan, 1992). Powerlessness is a risk factor for the degradation of both mental and physical health; conversely, when patients are empowered, this is associated with increased quality of life (Fitzsimons & Fuller, 2002; Vauth et al., 2006). Empowerment, as patient participants experienced using portals, is an important mechanism for increasing patients' overall wellbeing, resilience, self-esteem, self-efficacy, and ability to cope with difficulties (Fitzsimons & Fuller, 2002; Grealish et al., 2017; Vauth et al., 2006).

There is, however, another aspect of this shift in power balance to consider: does increased autonomy and control also include a shift in responsibility, wherein the patient assumes responsibility for their own mental health care? In some models of recovery-oriented care, individual responsibility for one's own life and health is emphasized, and this is framed as being in alignment with the principles of autonomy and empowerment (American Psychological

Association, 2012; Copeland, 2015; MHCC, 2015). However, if patients are held wholly "responsible for their own self-care and journeys of recovery" (American Psychological Association, 2012, para. 10), there is a risk that health care organizations, governmental entities, and society at large abdicate their responsibility to address the socioeconomic inequities contributing to mental illness, which are outside any one individual's control (Lakeman, 2016; Smith, 2022). In light of this, it seems possible that the expectation for patients to use portals could be experienced as a burden rather than a boon, given the already significant distress caused by mental illness and systemic inequity (MHCC, 2013; World Health Organization, 2013). While the studies in my review do not include any patient data illustrative of this perspective, it is important to note that these studies only included patient participants who had experiences using a portal, which may have led to sampling bias toward those in favour of portals. Future research should include the perspectives of patients who do not use patient portals when given the opportunity, in order to understand their motivations and determine whether portals are perceived as burdensome.

Ultimately, it may be that patient portal access empowering only inasmuch as it is presented as a choice, rather than a responsibility. Given that individuals with lived experience of mental illness have emphasized autonomy and agency as central to mental health (Manwell et al., 2015), if portal use becomes an imposed expectation, rather than an option, patients may not experience empowerment. This is similar to the idea of social autonomy described as a component of mental health as discussed in Chapter 2: meaningful social roles are considered vital, but only insofar as they are by choice, rather than compulsory. Individuals should have the autonomy to "disconnect by choice, as opposed to being excluded" (Palumbo & Galderisi, 2020). Portals and record access should be presented the same way – as services provided to patients as

an option, but also not imposed on them. Certainly, they should not be used to reinforce personal responsibility in lieu of societal responsibility for addressing the social determinants of health.

***Decreasing Clinicians' Power***

Clinician participants in my review described experiencing a loss of power and control in the care relationship because of patient portal implementation. They described losing their sense of ownership over the content and purpose of the health care record, losing authority over which patients could access the care record, and losing, overall, autonomy in their practice decisions. While some saw changes introduced by portals as positive, others felt threatened and spoke of experiencing anxiety and frustration as a result.

In an earlier review of the state of patient access to their analog mental health records, Schwartz and Rachlin (1985) stated that mental health clinicians believed advocacy for access to the health record represented a "fundamental misunderstanding of the purpose of record keeping" (p. 84). These clinicians, like those in my review, felt that the record was intended for their own use as a memory and communication tool, and was never meant to have patients as an audience. Schwartz and Rachlin (1985) found that clinicians recognized the necessity of providing their patients with information but felt that this should be achieved in other ways that did not include sharing 'their' records. Smith (1978) argued that clinicians' autonomy is threatened by patient access because it creates restrictions in documentation; similarly, Seitz and colleagues (1978) found that clinicians believed patients wishing to access records did so in order to influence staff documentation practices, which challenged their authority over the record. These historical findings align with those of my study, in which clinicians reported feeling a sense of ownership and control over the record and feeling threatened when patients would try to 'dictate' their practice.

The theme of changes in power distribution is also found in studies in health care settings outside of mental health. Clinicians in these settings express concerns about unrestricted access to care records and believe clinicians should maintain some control over the process, such as dictating when and how records are released and approving access (Collins et al., 2017; Nøst et al., 2021; Grünloh et al., 2016; Grünloh et al., 2018). Certain clinician participants in these settings also claim ownership over the health record and its contents, which includes authority over how to best document care (Grünloh et al., 2016; Grünloh et al., 2018). However, it is interesting to note that when Johansen and colleagues (2019) compared mental health clinicians with clinicians in other contexts, they found comments related to denying access to the record only from clinicians in mental health. This suggests that clinician resistance to losing control over the record is likely a more pronounced issue in the mental health context.

Clinician participants in my review described several methods of maintaining some of their control over their practice and reducing the impact of patients having access to the record. Clinicians described limiting their documentation to the bare essentials or being purposefully vague to avoid transparency. There were also clinicians who described keeping records outside of the official electronic health record (Dobscha et al., 2016b; Johansen et al., 2019; van Rijt et al., 2021), or finding ways of communicating with other clinicians that circumvented the record (Dobscha et al., 2016). Notably, participants reported these changes in practice as being ongoing; it seems they were able to alter their practice without any immediate consequences. This raises the question of whether these clinicians have actually lost any autonomy.

While clinicians typically framed these efforts as means of keeping patients safe, this is, as discussed, a manifestation of stigma. As explained by Corrigan (2003), the process of stigmatization involves a power differential; one of the components of stigmatization is

discrimination, in which a more powerful social group (clinicians) can impose actions on a less powerful, stigmatized group (patients with mental illness). Efforts to shift the balance of power threaten the social standing of clinicians as authority figures, creating resistance to change (DuBose & Mayo, 2020; Link & Phelan, 2001). It may be that the stigmatization of mental illness, and its role in keeping clinicians in positions of power, is in part responsible for the more pronounced resistance to patient portals in the mental health context.

However, clinicians are also subject to health care organizations and government entities, which control the resources available to provide care (MHCC, 2013). As discussed, clinicians themselves may be burdened by responsibilities over which they have no control, such as high workloads, which are perceived to be worsened by patient portals (Al-Dweik et al., 2015; West et al., 2018). Clinicians who experience powerlessness and lack of autonomy within their practice environments also suffer negative effects: when clinicians feel unable to control their practice or are excluded from decisions made about their practice by health care organizations, they are more likely to experience demotivation, job strain, compassion fatigue, and burnout (Al-Dweik et al., 2015; West et al., 2018). These, in turn, are associated with reduced quality of patient care (Al-Dweik et al., 2015; West et al., 2018).

***Summary***

Patient autonomy is valued as an essential component of recovery (MHCC, 2015; Pilgrim, 2008; Provencher et al., 2002; Resnick et al., 2004), and clinicians and have an ethical and professional obligation to respect patient autonomy (College of Nurses of Ontario, 2019a; College of Physicians and Surgeons of Ontario, 2021). While clinicians are in positions of greater power than patients, they may also experience negative effects from any loss of autonomy or control within their practice environments, especially in the context of excessive

workloads. Are there ways, then, to account for both patient and clinician needs? Is it possible, for example, to empower and support clinicians in the use of patient portals so that they may empower their patients? There is evidence that when organizational leaders engage with their members during change processes, listen to their objections, and demonstrate that they value their perspectives as authorities in their areas, this mitigates resistance to change (Khaw et al., 2022). It would be beneficial for future researchers to evaluate the effectiveness of these and other strategies used to address clinicians' concerns about patient portals and other tools for enhancing patient autonomy.

**Summary of Discussion Points**

Access to mental health records has been discussed in the literature published prior to two major societal advancements: first, the broad-scale enactment of laws granting rights of access to health records, and now, the implementation of patient portal access in mental health care. Clinicians have varied in their responses to the introduction of patient portals in mental health settings, and these responses are echoes of those heard during the transition in the late nineteenth century allowing access to analog mental health records.

It begs the question: why are clinicians acting as if this is something new? One explanation might be that there has historically been a low rate of access requests in both physical and mental health care contexts, despite patients' professed interest in the opportunity for access (McShane & Rowe 1994; Ross & Lin, 2003). Thus, while patients have been the legal owners of their health information for the past few decades, access to the record is not a routine and expected part of care and is perceived as a change in practice. Additionally, accessing physical copies of records can be a burdensome, time-consuming, bureaucratic process. Patient portals, on the other hand, are designed to increase record access; they are a more independent,

unmonitored, convenient means of record access that is often outside the clinician's control, and with fewer administrative barriers (Dobscha et al., 2016b; Irizarry et al., 2015; McShane & Rowe, 1994). Portal access is also initiated by institutions, rather than patients; that is, institutions actively promote and invite patients to use portals (The Ottawa Hospital, n.d.; Royal Ottawa Health Care Group, n.d.-b). As shown, some clinicians interpret increased record access as a threat to their wellbeing through increased workload; to their patients, due to benevolence stigma; and to their practice, by reducing their control over the record. These perceived threats generate anxiety and resistance (DuBose & Mayo, 2020; Khaw et al., 2022).

However, it is not yet clear if the introduction of patient portals will actually increase rates of patient access to their health records. The literature indicates that patient portals are infrequently accessed, both within and outside of the mental health context (de Lusignan et al., 2014; Etingen et al., 2019; Kipping et al., 2016; Zhang et al., 2021). In Etingen et al. (2019), only 13.7% of mental health patients using the Veterans Affairs service (n=159 581) were registered as users of the patient portal. There is limited research available on the implementation of patient portals, especially in mental health care. A review by Zhang and colleagues (2021) outlines critical success factors for portal implementation such as clinician endorsement, patient education, user-friendliness of portal design, and the presence of valued features, but few studies in mental health settings were included. Ultimately, the reasons behind the limited uptake of portals by patients receiving mental health care has not been adequately explored and is an important area for future research.

A final point: as mentioned, Zhang and colleagues (2021) found that clinician endorsement or resistance of portals has an impact on patient enrollment, with clinician resistance being associated with lower enrollment rates. The authors frame this resistance as a

hurdle to be overcome in order to successfully implement patient portals. This framing of resistance to change as an obstacle is not uncommon; however, recent analyses on organizational change instead frame this resistance as an opportunity for leaders to engage with clinicians, to improve processes and address shortcomings based on their feedback, and to motivate clinicians to be an active part of the change process (Dubose & Mayo, 2020; Khaw et al., 2022). As a nursing leader, I intend to incorporate this optimism into my own practice.

## Nursing Implications

### Research

This systematic review revealed gaps in the current literature, which is not surprising given the novelty of the field. Below I discuss implications related to demographic reporting, qualitative data collection and analysis, and underrepresented populations and contexts in the literature.

#### *Demographic Reporting*

Demographic data were inconsistently reported in both patient-oriented and clinician-oriented studies. Additionally, many of the studies were mixed-methods and did not report demographics separately between the quantitative and qualitative components, especially in survey studies. Because of this, it is difficult to draw conclusions about the nature of the participants that provided data across the included studies. Sociodemographic data about study participants can be useful in analyses of qualitative data because it provides information about participants' backgrounds that may inform their experiences and perspectives. Future research in this area could be enhanced by more comprehensive collection and reporting of this data. Given the perceived impacts of socioeconomic status and mental illness diagnosis on access to and use of portals, and the underrepresentation of certain patient populations in the literature (discussed

further below), these data should include indicators related to level of income, education, race and/or ethnicity, and mental illness diagnosis.

### *Qualitative Data Collection and Analysis*

There is an overall need for more in-depth qualitative studies on the topic of patient portals in mental health. The analysis of qualitative data collected in the mixed-methods studies was generally more superficial than that of the data in wholly qualitative studies. Given that only 13 of the 24 studies yielded in this review were fully qualitative, there is room for more studies that employ comprehensive qualitative analyses, particularly of data collected through interviews and focus groups.

The potential for researcher bias during analysis is not discussed in most of the articles included in this review. The restrictions placed on article length by publishing houses often do not permit the inclusion of every detail of the research process. However, given the potential influence of researcher perspectives on the interpretation of results, it is useful to know how researchers understand and address this potential influence, as a matter of ethics and of philosophical and methodological coherence (Clinical Appraisal Skills Programme, 2018; Polit & Beck, 2017; Thomas & Harden, 2008). Of note, only five studies openly endorsed a particular philosophical or methodological alignment; for the most part, these were not explicitly stated. Ultimately, as this area of research progresses, the inclusion of researchers' philosophical stances and their analyses of the potential bias and/or influence of their perspectives would be beneficial. When researchers include this information, they are providing information about the contexts of their studies just as they are when providing information about the study settings and participants (Thomas & Harden, 2008).

### *Underrepresented Participants and Contexts*

Several populations are underrepresented in the existing literature on patient portals. First, the majority of patient participants in the included studies were Caucasian and highly educated (i.e., with at least partially completed secondary education). This limits the transferability of these findings to underrepresented patient populations, such as racialized persons and those with lower levels of education or socioeconomic status. This is especially relevant given the concerns expressed by clinicians about access to the Internet and computers by the populations they serve.

Second, the most common diagnoses reported by patient participants were anxiety disorders, mood disorders, or trauma- and stressor-related disorders; patients with psychotic disorders were underrepresented. However, clinician participants in this review expressed particular concerns about access to care records by patients with limited insight and psychotic symptoms such as paranoia. Given that the perspectives of patients in this population are underrepresented in the current literature, it is possible that these clinician concerns are based on stereotypes or paternalism rather than evidence. Additional research including the perspectives of patients with psychotic disorders is essential for understanding whether they truly experience portals and record access differently from patients with other disorders.

Third, there is a need for more studies incorporating the perspectives of patients who choose not to engage with patient portals. Most of the studies involving patient participants recruited patients who were familiar with an existing patient portal. Given that the views of patient participants across the literature are generally in favour of portal use, it might be that that we are missing counter perspectives. The perspectives of those who do not use portals would be of particular value in understanding why relatively few patients with mental illness access their records (paper or digital) even when access is granted (McShane & Rowe 1994; Petersson &

Erlingsdóttir, 2018b; Ross & Lin, 2003). Future studies should elicit the views of patients who do not use portals, so that we better understand the rationale behind decisions not to access records, or else barriers preventing access.

Fourth, although some of the settings of the included studies provided inpatient mental health care, the perspectives elicited from participants were typically focused on access to the records by outpatients, and no patients who were admitted to an inpatient unit at the time of the study were sampled. From my own experience, as nurses outnumber other clinicians represented in inpatient settings, nurse researchers may be best positioned to explore perspectives of participants in this context. Furthermore, there are aspects of inpatient care that would impact the perspectives of both clinicians and patients on the use of patient portals in this setting, such as acuity of illness and involuntary detention and treatment.

**Clinical Practice**

There are several ways in which the findings can be applied to the clinical practice of mental health nurses. One of the main implications of these findings is that nurses, alongside other clinicians, must examine their documentation practices to determine if they are keeping the patient in mind as an 'audience'. The Canadian Federation of Mental Health Nurses (CFMHN) includes in their competencies that a nurse "pursues opportunities to reduce stigma" (CFMHN, 2014, p. 12). One such opportunity for nurses is to respond to patients' voiced concerns about documentation through reflective practice and communication with patients about their documentation. Nurses should continually examine their documentation to determine if they are using judgmental or stigmatizing language, if they are using abbreviations or phrases that are unclear (i.e., jargon), if they are documenting not only about the patient's difficulties but about their strengths and progress, and if they are ensuring the accuracy of what they are entering in the

patient record. Nurses should also consider beginning the practice of collaborative documentation in order to involve patients, and initiate discussions about the care notes to allow space for patients to ask questions. The findings of this review demonstrate that patients are reluctant to start these conversations and nurses can play an integral role in creating safe spaces to facilitate this information sharing (College of Nurses of Ontario [CNO], 2006).

The CFMHN (2014) nursing competencies include that a nurse "assists, educates, and empowers clients to select choices which support informed decision-making" (p. 9). Given the impact of patient portals on patient empowerment, as well as their ability to support decision-making through the provision of information, mental health nurses must be prepared to support patients in using patient portals. The CNO entry-to-practice competencies for registered nurses (RNs) in Ontario indicate that a nurse must assist patients to "access, review, and evaluate information they retrieve using information and communication technologies" (CNO, 2020a, p. 8), which is a competency demonstrated when educating patients about accessing and interpreting their health information using patient portals. Additionally, the competency documents for both RNs and registered practical nurses (RPNs) emphasize that nurses must facilitate patients' access to their health information in accordance with relevant legislation (CNO, 2020a/b).

**Education**

To support patients in using patient portals, nurses and other clinicians will need to receive education themselves. The participants in the included studies voiced a need for organizational support and guidance about how to document in light of patient portal access. It will also be necessary to explore any fears about risks and deliver education where these fears arise from stigma. There is evidence that education programs focused on increasing mental

health literacy and dispelling myths about mental illness, in combination with 'contact' approaches in which learners connect with individuals with mental illness in social contexts, can reduce stigmatizing attitudes (Griffiths et al., 2014; Knaak et al., 2017; Mehta et al., 2015; Maranzan, 2016). Staff and students should be provided anti-stigma education to address some of the attitudes underlying concerns that clinicians have about patient portals. As explained by Zhang et al. (2021), clinician attitudes impact patient uptake of the portal; organizations (and the education teams within these organizations) hoping for a successful implementation of portal must address the concerns raised by clinicians and may use the findings of this review as a guide.

The nursing profession would be best supported long-term by ensuring that nursing school curricula includes information about patient portals, and more information about patient access to records in general. In my own experience, nursing school classes addressing documentation focused on legal liability, as well as ensuring information was clear for other clinicians. We did not discuss patient access or how our notes might look to the patient; we discussed legal proceedings and how the notes might look to the court. When we spoke about patient rights, the focus was on patient privacy and confidentiality, not on patient ownership of the information in the record or right to access it. As such, I was frankly ill-prepared to address patient's inquiries into their records. Upon reviewing two of the most up-to-date introductory textbooks on Canadian mental health nursing, I found only brief mentions of patients' right of access to records, whereas there are several paragraphs about the importance of privacy and confidentiality (Austin & Kent-Wilkinson, 2023; Pollard, 2023). Additionally, the health care record is described only as means of communication between care providers, legal documents, and as resources for quality improvement (Lasiuk, 2023; Pollard, 2023).

When knowledge generated during research is not translated adequately into practice, nurses are not able to fulfil their professional and ethical requirements to practice based on current evidence, and patients are unable to reap the benefits of innovations in care (CNO, 2002; Youngbult & Brooten, 2001). My hope is that advancements in research on patient record access in mental health will inform updates to nursing textbooks and nursing school curricula over the course of the next few years.

**Policy**

One of the roles of the nurse, according to the CNO's entry-to-practice documents for RPNs and RNs, is advocacy (CNO, 2020a/b). Nurses are expected to advocate for the empowerment of patients and for the protection of their rights. The CNO indicates that nurses can advocate for patients by supporting evidence-informed practices and health care policies that create health equity (CNO, 2020a/b).

In light of the findings of this review, nurses should advocate their health care institutions to adapt their policies regarding documentation. These policies should recognize patients as an expected and welcome audience of the information in their mental health care records - patients in this review identified this practice as empowering and useful for their recovery. Clinicians require institutional support and guidance regarding their documentation (Denneson et al. 2017; Erlingsdóttir et al., 2019), and while part of this support must include education, institutions must also create structural supports in terms of policy changes, electronic health record design, and adequate resource allocation in light of any workload consideration. (Al-Dweik et al., 2022; DuBose & Mayo, 2020; Zhang et al., 2021).

Nursing organizations can incorporate the findings of this study by reviewing their policies and practice standards. For example, the CNO practice standard for documentation has

not been updated since 2008, before patient portals were established -- and, in fact, prior to the implementation of electronic health records in many facilities (CNO, 2008). There is no guidance within this practice standard about how nurses should chart considering patient access to the record through patient portals (or at all). The standard indicates that nurse documentation "reflects the client's perspective" (p. 3) but provides no further direction as to how this can be achieved. Development of a revised documentation practice standard that addresses open patient access and use of their records is necessary to support nurses in their practice.

Perhaps the most important implication of these findings for policy is that healthcare institutions should be abolishing any policies that restrict access to records solely on the basis that they pertain to mental health care. In order to support evidence-based, recovery-oriented practice, organizations must respect the rights of patients and empower them to access their health care records through patient portals should they so choose.

## Study Strengths and Limitations

### Strengths

As discussed in the methods section, several strategies were employed to ensure this study's credibility. The research question was developed using the standard SPIDER tool (Cooke et al., 2012). Two librarians (Marie-Cécile Domecq of the University of Ottawa and Sascha Davis of The Royal Ottawa Health Care Group) assisted with the development of the search strategy and reviewed it to ensure we found as many relevant studies as possible. Abstracts and full-text article screening were performed independently by two researchers (CC and AV) using Covidence software. Disagreements on screening, coding, extraction, and synthesis were clarified and resolved through discussion between CC and AV. Results of the synthesis are supported by participant quotations to ensure authenticity and fidelity of findings to the participants' experiences.

**Limitations**

This study has a number of limitations to consider, most regarding the inclusion and exclusion criteria. For example, only literature in the English language was included; this means that there may have been studies published in other languages, and in non-English-speaking regions, with useful findings that were excluded. Another limitation is the omission of grey literature, which might house patient or clinician perspectives on patient portals that have not been captured in peer-reviewed articles.

Another limitation of this research is that analyses of contextual elements of the data, such as participant demographics, are constrained by data reporting in the included studies. Demographic information was typically reported for entire samples, even in mixed-methods studies where some participants may not have contributed to qualitative aspects (e.g., in free text components of survey studies). This may have led to a misrepresentation of the demographics of those contributing to the qualitative data.

A noteworthy limitation of not only this study, but review procedures generally, is the way in which first-level screening of titles and abstracts might inadvertently omit on-topic articles if authors do not include pertinent details in their titles, abstracts, or keywords. Specifically, I excluded all articles that did not mention mental health care in the title or abstract. Over the course of my Master's, I incidentally came across one such study (Bernaerdt et al., 2021) that included relevant data on patient experiences with portals in mental health contexts (as well as other contexts). Upon finding the article, I explored how it was missed by my search, and discovered that it was excluded during the screening process due to the absence of any mention of mental health in its title or abstract. This highlights the importance of ensuring that titles and abstracts contain an accurate and thorough picture of the study, as well as the

importance of thorough database indexing. Fortunately, when reviewing the article, there were no themes outside of what was already reflected in my findings.

## Conclusion

Patient portals, the primary feature of which is tethered access to the electronic health care record, are increasingly being adopted by healthcare facilities. However, implementation in mental health settings has not kept pace with other health care settings. This qualitative evidence synthesis sought to explore clinician and patient perspectives of portals in the mental health context. Synthesis of the 24 articles found produced five themes and thirteen sub-themes, many of which are also present in the extant literature published on mental health record access in the 1990s and earlier, as well as contemporary literature in non-mental health contexts.

Ultimately, the findings of this review show that both clinicians and patients in this context have experienced or are aware of potential benefits of portals, but there are also several concerns about portals specific to the mental health context, voiced primarily by clinicians. Clinician resistance to patient portals, while often framed as concern for patient safety and wellbeing (whether due to direct harms or due to inefficiencies in mental health care delivery), also stems from threats to clinicians' own wellbeing and social status. While clinicians should use this information to reflect on their own practice, the responsibility for change does not lie only with individual providers. It is vital that organizations ensure that patients with mental illness are not unjustly excluded from the benefits of portals in response to clinician resistance, and at the same time, they must provide clinicians with the support, education, and the resources needed for successful portal adoption.

The findings of this review also highlighted the need for ongoing research in this context, especially focusing on the experiences of thus-far underrepresented groups: racialized persons,

those with lower socioeconomic status, patients diagnosed with psychotic disorders, and patients who do not use portals. The perspectives of these patients are invaluable for developing a well-rounded understanding of this technology and its implications for practice. Additionally, further research into the most effective interventions for reducing mental illness stigma and facilitating change management during portal implementation would be beneficial for advancing care.

My hope is that the knowledge generated through this qualitative synthesis will be used to inform educational initiatives, policy updates, and the everyday practice of clinicians and organizations in mental health care – whose commitment to patients can be demonstrated by advocating for equal rights of access to patient portals.

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# Appendix A

## Search Strategy

**Search Strategy for CINAHL (EBSCO) – 216 results**

S24 S17 AND S18 AND S23

S23 S21 OR S22

S22 S19 AND S20

S21 S15 OR S16

S20 S13 OR S14

S19 S11 OR S12

S18 S7 OR S8 OR S9 OR S10

S17 S1 OR S2 OR S3 OR S4 OR S5 OR S6

S16 (patient* n5 (experience* or perspective* or attitude* or view* or perception* or survey* or questionnaire* or interview*)).

S15 (MH "Patient Attitudes+")

S14 (attitude* or experience* or perception* or survey* or view* or questionnaire* or interview*)

S13 (MH "Attitude of Health Personnel+")

S12 (nurs* OR psychiatrist* OR physician* OR doctor* OR psychologist* OR clinician* or therapist* or (social n2 worker*) or (healthcare n2 worker*) or (health n2 care n2 worker*) or (healthcare n2 professional*) or (health n2 care n2 professional*) or (healthcare n2 provider*) OR (health n2 care n2 provider*))

S11 (MH "Health Personnel+")

S10 ((patient n2 portal*) OR OpenNotes OR (Open n2 Notes) OR PAEHR OR (patient n2 accessible n2 electronic n2 health n2 record*) OR PCEHR OR (personally n2 controlled n2 electronic n2 health n2 record*) OR (web n2 portal*) OR (personal n2 medical n2 record*) OR (personal n2 health n2 record*))

S9 (MH "Patient Access to Records+")

S8 (MH "Medical Records, Personal+")

S7 (MH "Patient Portals+")

S6 (psych* OR (mental w1 health) OR (mental w1 illness*))

S5 (MH "Psychiatric Patients+")

S4 (MH "Psychology+")

S3 (MH "Psychiatry+")

S2 (MH "Mental Health Services+")

S1 (MH "Mental Disorders+")

**Search Strategy for Medline (Ovid) – 244 results**

22 16 and 17 and 21

21 15 or 20 (patient attitudes OR clinician attitudes)

20 18 and 19 (clinicians + attitudes)

19 13 or 14 (clinician attitudes)

18 11 or 12 (clinicians)

17 8 or 9 or 10 (patient portals)

16 1 or 2 or 3 or 5 or 6 or 7 (mental health/illness)

15 (patient* adj5 (experience* or perspective* or attitude* or view* or perception* or survey* or questionnaire* or interview*)).tw,kf

14 (attitude* or experience* or perception* or survey* or view* or questionnaire* or interview*).tw,kf.

13 exp Health Personnel Attitudes/

12 (nurs* OR psychiatrist* OR physician* OR doctor* OR psychologist* OR clinician* OR therapist* or (social adj2 worker*) or (healthcare adj2 worker*) or (health adj2 care adj2 worker*) or (healthcare adj2 professional*) or (health adj2 care adj2 professional*) or (healthcare adj2 provider*) OR (health adj2 care adj2 provider*)).mp.

11 exp Health Personnel/

10 ((patient adj2 portal*) OR OpenNotes OR (Open adj2 Notes) OR PAEHR OR (patient adj2 accessible adj2 electronic adj2 health adj2 record*) OR PCEHR OR (personally adj2 controlled adj2 electronic adj2 health adj2 record*) OR (web adj2 portal*) OR (personal adj2 medical adj2 record*) OR (personal adj2 health adj2 record*)).mp.

9 exp Patient Access to Records/

8 exp Health Records, Personal/

7 (psych*).tw,kf

6 (psychiatr* OR (mental adj2 health) OR (mental adj2 illness*)).mp.

5 exp Mental Disorders/

4 exp Mentally Ill Persons/

3 exp Psychology/

2 exp Psychiatry/

1 exp Mental Health Services/

**Search Strategy for Embase (Ovid) - 366 results**

| | |
|---|---|
| 21 | 8 and 15 and 20 (patient portals + mental health/illness + patient attitudes OR clinician attitudes) |
| 20 | 18 or 19 (patient OR clinician attitudes) |
| 19 | 16 and 17 (clinicians + attitudes) |
| 18 | 13 or 14 (patient attitudes) |
| 17 | 11 or 12 (clinician attitudes) |
| 16 | 9 or 10 (clinicians) |
| 15 | 1 or 2 or 3 or 5 or 6 or 7 (mental health/illness) |
| 14 | (patient* adj5 (experience* or perspective* or attitude* or view* or perception* or survey* or questionnaire* or interview*)).tw. |
| 13 | exp Patient Attitude/ |
| 12 | (attitude* or experience* or perception* or survey* or view* or questionnaire* or interview*).tw. |
| 11 | exp Health Personnel Attitude/ |
| 10 | (nurs* OR psychiatrist* OR physician* OR doctor* OR psychologist* OR clinician* OR therapist* or (social adj2 worker*) or (healthcare adj2 worker*) or (health adj2 care adj2 worker*) or (healthcare adj2 professional*) or (health adj2 care adj2 professional*) or (healthcare adj2 provider*) OR (health adj2 care adj2 provider*)).mp. |
| 9 | exp Health Personnel/ |
| 8 | ((patient adj2 portal*) OR OpenNotes OR (Open adj2 Notes) OR PAEHR OR (patient adj2 accessible adj2 electronic adj2 health adj2 record*) OR PCEHR OR (personally adj2 controlled adj2 electronic adj2 health adj2 record*) OR (web adj2 portal*) OR (personal adj2 medical adj2 record*) OR (personal adj2 health adj2 record*)).mp. |
| 7 | (psych*).tw. |
| 6 | (psychiatr* OR (mental adj2 health) OR (mental adj2 illness*)).mp. |
| 5 | exp Mental Disorders/ |
| 4 | exp Mentally Ill Persons/ |
| 3 | exp Psychology/ |
| 2 | exp Psychiatry/ |
| 1 | exp Mental Health Services/ |

**Search Strategy for PsycINFO (Ovid) – 54 results**

21 8 and 15 and 20 (patient portals + mental health/illness + patient attitudes OR clinician attitudes)

20 18 or 19

19 16 and 17 (clinicians + attitudes)

18 13 or 14 (patient attitudes)

17 11 or 12 (clinician attitudes)

16 9 or 10 (clinicians)

15 1 or 2 or 3 or 5 or 6 or 7 (mental health/illness)

14 (patient* adj5 (experience* or perspective* or attitude* or view* or perception* or survey* or questionnaire* or interview*)).tw.

13 exp Client Attitudes/

12 (attitude* or experience* or perception* or survey* or view* or questionnaire* or interview*).tw.

11 exp Health Personnel Attitudes/

10 (nurs* OR psychiatrist* OR physician* OR doctor* OR psychologist* OR clinician* OR therapist* or (social adj2 worker*) or (healthcare adj2 worker*) or (health adj2 care adj2 worker*) or (healthcare adj2 professional*) or (health adj2 care adj2 professional*) or (healthcare adj2 provider*) OR (health adj2 care adj2 provider*)).mp.

9 exp Health Personnel/

8 ((patient adj2 portal*) OR OpenNotes OR (Open adj2 Notes) OR PAEHR OR (patient adj2 accessible adj2 electronic adj2 health adj2 record*) OR PCEHR OR (personally adj2 controlled adj2 electronic adj2 health adj2 record*) OR (web adj2 portal*) OR (personal adj2 medical adj2 record*) OR (personal adj2 health adj2 record*)).mp.

7 (psych*).tw.

6 (psychiatr* OR (mental adj2 health) OR (mental adj2 illness*)).mp.

5 exp Mental Disorders/

4 exp Psychiatric Patients/

3 exp Psychology/

2 exp Psychiatry/

1 exp Mental Health Services/

**Search Strategy for ProQuest (Nursing and Allied Health Database) – 122 results**

S4 S1 AND S2 AND S3

S3 su(medical personnel) OR su(employee attitude) OR su(patient satisfaction) OR noft (nurs* OR psychiatrist* OR physician* OR doctor* OR psychologist* OR clinician* or therapist* or (social near/2 worker*) or (healthcare near/2 worker*) or (health near/2 care near/2 worker*) or (healthcare near/2 professional*) or (health near/2 care near/2 professional*) or (healthcare near/2 provider*) OR (health near/2 care near/2 provider*))

S2 su(web portals) OR su(electronic health records) OR noft((Patient near/1 portal*) OR OpenNotes OR PAEHR OR (patient near/1 accessible near/1 electronic near/1 health near/1 record*) or PCEHR OR (personally near/1 controlled near/1 electronic near/1 health near/1 record*)OR (Web near/1 portal*) OR (personal near/1 medical near/1 record*) OR (Personal near/1 health near/1 record*))

S1 su(psychiatry) OR su(psychiatrists) OR su(psychiatric-mental health nursing) OR su(mental disorders) OR noft(psych* OR (mental near/1 health) OR (mental near/1 illness*))

**Search Strategy for ProQuest (Dissertations and Theses Global) – 42 results**

S4 S1 AND S2

S2 su(web portals) OR su(electronic health records) OR noft((Patient near/1 portal*) OR OpenNotes OR (Open near/1 Notes) OR PAEHR OR (patient near/1 accessible near/1 electronic near/1 health near/1 record*) or PCEHR OR (personally near/1 controlled near/1 electronic near/1 health near/1 record*)OR (Web near/1 portal*) OR (personal near/1 medical near/1 record*) OR (Personal near/1 health near/1 record*))

S1 su(psychiatry) OR su(psychiatrists) OR su(psychiatric-mental health nursing) OR su(mental disorders) OR noft(psych* OR (mental near/1 health) OR (mental near/1 illness*))

**Search Strategy for Web of Science – 122 results**

#5: #1 AND #2 AND #3 AND #4

#4: TS=(experience* OR perspective* OR attitude* OR view* OR perception* OR survey* OR questionnaire* OR qualitative OR interview*)

#3: TS=(nurs* OR psychiatrist* OR physician* OR doctor* OR psychologist* OR clinician* or therapist* OR “social worker*” OR “healthcare worker” OR “health care worker*” OR “healthcare professional*” OR “health care professional*” or “healthcare provider*” OR “health care provider*” OR patient* OR client*)

#2: TS=(psych* OR “mental health” OR “mental illness*”)

#1: TS=("patient portal*" OR OpenNotes OR “Open Notes” OR PAEHR OR “patient accessible electronic health record*” OR PCEHR OR “personally controlled electronic health record*” OR "personal health record*" OR "personal medical record*" OR "web portal*")

**Search Strategy for Scopus – 353 – Sept 12, 2021**

#1 TITLE-ABS-KEY ( "patient portal*" OR OpenNotes OR "Open Notes" OR paehr OR "patient accessible electronic health record*" OR "personally controlled electronic health record*" OR "web portal*" OR "personal medical record*" OR "personal health record*" ) **AND**

#2 TITLE-ABS-KEY ( psych* OR "mental health" OR "mental illness" ) **AND**

#3 TITLE-ABS-KEY ( experience* OR perspective* OR attitude* OR view* OR perception* OR survey* OR questionnaire* OR qualitative OR interview* ) AND TITLE-ABS-KEY ( patient* ) ) **AND**

#4 ( TITLE-ABS-KEY ( experience* OR perspective* OR attitude* OR view* OR perception* OR survey* OR questionnaire* OR qualitative OR interview* ) AND TITLE-ABS-KEY ( nurs* OR psychiatrist* OR physician* OR doctor* OR psychologist* OR clinician* OR therapist* OR "social worker*" OR "healthcare worker*" OR "health care worker*" OR "healthcare professional*" OR "health care professional*" OR "healthcare provider*" OR "health care provider*" ) )

# Appendix B

## Table B1

*Research Databases for the Literature Search*

| Database Title | Definition/Scope |
|---|---|
| Cumulated Index to Nursing and Allied Health Literature (CINAHL) | "CINAHL is the authoritative resource for nursing and allied health professionals, students, educators and researchers. This database provides indexing for 2,928 journals from the fields of nursing and allied health. The database contains more than 1,000,000 records dating back to 1981." (p. C) |
| PubMed (Medline) | "The National Library of Medicine's search service providing access to MEDLINE, PREMEDLINE and other related databases, with links to participating online journals." (p. P) |
| American Psychiatric Association PsycINFO | "Includes journal articles, books, book chapters, dissertations and government reports in psychology and related disciplines." (p. A) |
| Nursing and Allied Health Database | "Provides full text journals, evidence based resources, and dissertations to support the study of the many aspects of nursing or the allied health professions, including physical therapy, rehabilitation radiography, dietetics, dental hygiene, and the clinical laboratory sciences." (p. N) |
| Excerpta Medica database (Embase) | "The Excerpta Medica database (EMBASE) is a major biomedical and pharmaceutical database indexing over 3,500 international journals." (p. E) |
| Scopus | "Scopus is a multidisciplinary database including scientific journals, books and conference proceedings. The research areas covered are science, technology, medicine, social sciences, arts and humanities." (p. S) |
| Web of Science | "This database includes conference papers and articles from key research journals in Science, Engineering, Medicine, Social Sciences, and Humanities. It also offers additional features that allow to discover the impact a paper or other published item has had on current research." (p. W) |
| ProQuest Dissertations & Theses Global | "Provides bibliographic information and abstracts for doctoral dissertations and Masters [*sic*] theses from accredited North American, UK and Irish universities. From 1957 to present, dissertations with appropriate copyright permissions may be downloaded at no charge." (p. P) |

*Note:* Definitions per University of Ottawa Library (2020).

# Appendix C

## Figure C1

*The CASP Qualitative Checklist*

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:

6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration?

| | |
|---|---|
| Yes | |
| Can't Tell | |
| No | |

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

| Comments: |
|---|
| |

8. Was the data analysis sufficiently rigorous?

| | |
|---|---|
| Yes | |
| Can't Tell | |
| No | |

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

| Comments: |
|---|
| |

| | | |
|---|---|---|
| 9. Is there a clear statement of findings? | Yes ☐<br>Can't Tell ☐<br>No ☐ | HINT: Consider whether<br>• If the findings are explicit<br>• If there is adequate discussion of the evidence both for and against the researcher's arguments<br>• If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)<br>• If the findings are discussed in relation to the original research question |

Comments:

Section C: Will the results help locally?

| | |
|---|---|
| 10. How valuable is the research? | HINT: Consider<br>• If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature<br>• If they identify new areas where research is necessary<br>• If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used |

Comments:

*Note.* This checklist was reproduced from the Critical Appraisal Skills Program (2018) document.

# Appendix D

**Table D1**

*Data Extraction Form*

| CATEGORY | DATA |
|---|---|
| Date form completed | |
| Study title | |
| Author(s) and professional designations | |
| Year | |
| Research question | |
| Philosophical alignment/methodology | |
| Theories, concepts, and/or frameworks | |
| Setting and context | |
| Patient portal name and features | |
| Sampling/recruitment strategy | |
| Participants (description/number) | |
| Data collection method | |
| Length of study | |
| Analysis method | |
| Themes identified by author analysis | |
| Self-identified study limitations | |

**Qualitative Data for Analysis:**

| QUOTATIONS | AUTHOR COMMENTS |
|---|---|
| | |

# Appendix E

**Table E1**

*Enhancing Transparency in Reporting the Synthesis of Qualitative Research: The ENTREQ Statement – STRENGTHS, REVIEW*

| No. | Item | Guide and description |
|---|---|---|
| 1 | Aim | State the research question the synthesis addresses. |
| 2 | Synthesis methodology | Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology. |
| 3 | Approach to searching | Indicate whether the search was pre-planned (*comprehensive search strategies to seek all available studies)* or iterative (*to seek all available concepts until they theoretical saturation is achieved)*. |
| 4 | Inclusion criteria | Specify the inclusion/exclusion criteria. |
| 5 | Data sources | Describe the information sources used*)* and when the searches conducted; provide the rationale for using the data sources. |
| 6 | Electronic Search strategy | Describe the literature search. |
| 7 | Study screening methods | Describe the process of study screening and sifting. |
| 8 | Study characteristics | Present the characteristics of the included studies. |
| 9 | Study selection results | Identify the number of studies screened and provide reasons for study exclusion. |
| 10 | Rationale for appraisal | Describe the rationale and approach used to appraise the included studies or selected findings |
| 11 | Appraisal items | State the tools, frameworks and criteria used to appraise the studies or selected findings. |

| No. | Item | Guide and description |
|---|---|---|
| 12 | Appraisal process | Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required. |
| 13 | Appraisal results | Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale. |
| 14 | Data extraction | Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? *(e.g. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software).* |
| 15 | Software | State the computer software used, if any. |
| 16 | Number of reviewers | Identify who was involved in coding and analysis. |
| 17 | Coding | Describe the process for coding of data. |
| 18 | Study comparison | Describe how were comparisons made within and across studies. |
| 19 | Derivation of themes | Explain whether the process of deriving the themes or constructs was inductive or deductive. |
| 20 | Quotations | Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation. |
| 21 | Synthesis output | Present rich, compelling and useful results that go beyond a summary of the primary studies. |

*Note.* This table is a reproduction of Table 1 in Tong et al. (2012).

# Appendix F

## Table F1

*Author-identified Themes in Included Studies*

| First Author & Year | Participants | Themes Identified |
|---|---|---|
| Åkerstedt 2018[a] | Clinicians | 1. Fear of being targeted by dissatisfied patients accessing the clinician access log<br>2. Potential benefits of access to patient portal including patient sense of control and security<br>3. Patient characteristics such as lack of impulse control and insight creating perceived risk of violence associated with portal access<br>4. Record access already exists in judicial contexts |
| Blease 2021[b] | Both | 1. Clarify about provider policies on exemptions*<br>a. Permitted exclusions*<br>b. Clinician discretion*<br>2. Providing patients with basic information about open notes<br>a. Accessing the notes*<br>b. Reading mental health notes<br>3. Clinician training in writing mental health notes*<br>a. Writing understandable notes*<br>b. Documenting sensitive information*<br>4. Managing patient-clinician disagreements about mental health notes*<br>a. Instructing clinicians*<br>b. Soliciting patient collaboration* |
| Chen 2021 | Patients | 1. Portal use facilitates and reinforces opiate use disorder and other treatment goals<br>2. Portal use improves health care participation<br>3. Portal use enables monitoring and addressing health concerns beyond substance use disorder<br>4. Portal use has mixed impacts on patient-provider trust |
| Chimowitz 2020 | Clinicians | 1. Open notes can help patients remember<br>2. Open notes can be reassuring to patients<br>3. Writing open notes encourages providers to be more candid<br>4. Patient concerns about notes can improve patient-provider communication<br>5. Why providers may not discuss open notes with patients<br>6. Why patients may not discuss open notes with providers<br>7. Some therapists saw no need to change documentation style<br>8. Some therapists spent a little more time<br>9. Some therapists thought writing open notes improved their workflow<br><br>Non-participating therapists<br>1. Concerns about privacy<br>2. Concerns about impact on note writing<br>3. Concerns about impact on therapeutic relationship<br>4. Potential benefits for patients |
| Cromer 2017 | Patients | 1. The therapeutic relationship and trust<br>2. Transparency<br>a. Strengthening patient-clinician relationships<br>b. Straining patient-clinician relationships<br>3. Respect<br>a. Strengthening patient-clinician relationships<br>b. Straining patient-clinician relationships |

| First Author & Year | Participants | Themes Identified |
|---|---|---|
| Denneson 2017 | Clinicians | 1. Shifting patient-clinician power distribution<br>2. Therapeutic relationship<br>3. Adjusting practice in the context of OpenNotes |
| Dobscha 2016[c] | Clinicians | 1. Impacts of OpenNotes:<br>a. Result in better documentation,<br>b. Improve patient participation in care<br>c. Increase collaboration<br>d. Comments that were generally positive<br>2. Experiences of specific negative consequences of OpenNotes:<br>a. Disagreements about note content<br>b. Disruptions in the therapeutic relationship or trust<br>c. Patients being upset or disagreeing with a diagnosis<br>d. Increased clinician burden<br>e. Patient expressed suicidal or homicidal ideation<br>f. Other |
| Erlingsdóttir 2019 & Petersson 2018b[d] | Clinicians | In Erlingsdóttir et al. 2019 – themes per Heald's transparency framework:<br>1. Effectiveness<br>2. Trust<br>3. Accountability<br>4. Autonomy and control<br>5. Confidentiality, privacy, and anonymity<br>6. Fairness<br>7. Legitimacy<br>In Petersson et al. 2018b:<br>1. Patient groups/diagnoses for which Open Notes may be an asset<br>2. Patient groups/diagnoses for which Open Notes may be problematic<br>3. Suggestions to improve Open Notes |
| Fisher 2009 | Patients | 1. Participation in care<br>2. Quality of care<br>3. Enhancing self-care |
| Gasteiger 2020[e] | Both | 1. Perceptions of the patient portal<br>a. Usefulness<br>b. Ease of use<br>2. Considerations for successful extension into counseling services<br>a. Ability to triage<br>b. Software capability/barriers<br>c. Counselor hopping<br>d. Capacity to seek help<br>e. Fragmented services<br>f. Waiting times<br>g. The stigmatization of mental health<br>3. Opportunities regarding extension<br>a. Extension into low-risk services<br>b. Extension into all services<br>c. Patient-counselor contact<br>d. Increased access and help-seeking<br>e. Aligns with students' communication preferences<br>f. Opening patient notes |

| First Author & Year | Participants | Themes Identified |
|---|---|---|
| Johansen 2019[f] | Clinicians | 1. Not suitable for any mentally ill patients<br>2. Not suitable for all patient groups<br>3. Patients should only be able to access parts of the EHR<br>4. Patients might misunderstand<br>5. Need to deny access<br>6. Omit information<br>7. Write a hidden journal<br>8. Suggest delaying the information<br>9. Complicates their work<br>10. Worry for their own security<br>11. Skeptical of the new logging functionality |
| Kariotis 2019 | Clinicians | 1. Mental health information<br>a. Sensitive information<br>b. Completeness of record<br>c. Information needs<br>2. Mental health information<br>3. Other barriers and benefits to MHR (My Health Record) use<br>a. Access to MHR<br>b. Technology concerns |
| Kipping 2016 | Patients | 1. E-views<br>a. Autonomy<br>b. Personal health information not up to date<br>2. E-requests<br>a. User friendly<br>b. Helpful<br>c. Satisfaction<br>3. E-visits<br>a. Efficiencies<br>b. Satisfaction |
| Leung 2019 | Patients | 1. Patients' readiness and needs<br>2. Patient perceptions of the portal |
| Mayhew 2018 | Clinicians | 1. Implementation strategies<br>a. Advertising,<br>b. Training/teaching strategies<br>c. Client characteristics<br>2. Nurse likelihood to recommend<br>a. Understanding the benefits<br>b. Resistance<br>3. Impact on nursing practice<br>a. Helpful assessment<br>b. Collaboration and engagement<br>c. Increased workload<br>d. Introducing risk,<br>e. Changes in documentation practice<br>4. Perceived influence on patients<br>a. Concerns<br>b. Opportunity for learning |

| First Author & Year | Participants | Themes Identified |
|---|---|---|
| O'Neill 2019 | Patients | 1. Potential benefits of note reading<br>a. Validation<br>b. Use in treatment<br>c. Therapeutic relationships<br>2. Potential risks/harms of note reading<br>a. Feeling judged<br>b. Worry<br>c. Inconsistencies between note and session<br>d. Privacy |
| Peck 2017 | Both | 1. Perceived benefits<br>2. Perceived risks |
| Pisciotta 2019 | Both | 1. Writing notes that maintain the therapeutic relationship<br>a. Be professional and respectful<br>b. Include the right amount and type of detail<br>c. Highlight patient strengths and progress<br>2. Communicating with patients about their note<br>a. Be transparent about note content<br>b. Be open to discussing notes<br>3. Utilizing clinical notes as a patient resource to enhance care<br>a. Write notes knowing the patient will read and use the information<br>b. Write "collaborative notes" |
| Strudwick 2018 | Clinicians | 1. Influence on therapeutic relationship<br>2. Influence on documentation<br>3. Workload<br>4. Agreement/disagreement with the patient portal<br>5. Desire for educational support<br>6. Case by case identification of patients to use the portal<br>7. Patient response<br>8. Technology access/assistance for patients<br>9. Patient access to health information<br>10. Security<br>11. Suggestions |
| Strudwick 2020[g] | Patients | 1. Outcome indicators<br>a. Engagement and empowerment<br>i. Knowledge and awareness of health condition<br>ii. Communication & collaboration<br>b. Consumer experience and satisfaction<br>c. Quality of care and consumer outcomes<br>2. Process indicators<br>a. Privacy and security*<br>b. Portal usage<br>c. Usability<br>3. Barriers and facilitators<br>a. Ease of use<br>b. Privacy and security*<br>c. Availability/type of information and support<br>d. Current health status<br>e. Consumer-health professional relationship<br>4. Desired functionality themes:*<br>a. Access to health information*<br>b. Support*<br>c. Communication with health professionals*<br>d. System interoperability* |

| First Author & Year | Participants | Themes Identified |
|---|---|---|
| Turvey 2021 | Both | 1. Secure messaging – patient and provider perspectives<br>2. Record access – patient and provider perspectives |
| van Dooren 2013[h] | Both | 1. Diversity of abilities and commitment to understanding health<br>2. Complex circumstances, busy lives<br>3. Medical relationships<br>4. Keeping track of health information<br>5. Incoming information as an event |
| van Rijt 2021[i] | Clinicians | 1. Appraising the effect on the patient-professional relationship<br>2. Appraising the challenge of sharing and registering sensitive information<br>3. Appraising patient vulnerability<br>4. Redefining consultation routines and registration practices<br>a. Solution 1: Draft notes for colleagues*<br>b. Solution 2: Making personal notes visible for colleagues*<br>c. Solution 3: Discussing information with patients before registration<br>d. Solution 4: Registering information together with the patient<br>e. Solution 5:Introducing patients to web-based access at the beginning of treatment |
| Whealin 2016[j] | Patients | 1. Interactions with social support<br>a. Receiving support*<br>b. Providing mutual support*<br>c. Obtaining support to cope with symptoms or crisis<br>d. Deterring social support*<br>2. Condition management<br>a. Using web-based tools to manage symptoms*<br>b. Providing a sense of safety and security*<br>c. Signaling reminders<br>3. Access to and communication with providers<br>a. Facilitating accurate reports of pressing or sensitive issues<br>b. Promoting timely communication between veterans and their providers<br>c. Increasing service access for disabled veterans*<br>4. Information access<br>a. Increasing access to trustworthy health information<br>b. Obtaining information from peers*<br>c. Identifying opportunities to improve means of obtaining health information<br>5. Coordination of care<br>a. Improving care coordination across providers and facilities<br>b. Identifying opportunities for improved care coordination |

[a, c, d, f] The published studies did not include analyses with illustrative quotes for each theme, but either outlined repeated comments in their discussion/results or counted comments by theme. For those studies including both somatic and mental health care, only themes related to mental health care are reported here.

[b, g, h, i] These studies included data from participants who were not patients or clinicians/health care staff. Data were only included for synthesis when the person quoted was identified as a patient or clinician. Any themes that were not illustrated by quotes clearly ascribed to patients or clinicians/health care staff are marked with an asterisk *.

[d, e, f] These studies included medical secretaries/administrative personnel within their samples as clinicians/members of the health care team. Only one quote was directly ascribed to an administrative staff member.

[j] Data were only included for synthesis when the quote pertained to patient portals (rather than other eHealth). Those themes that were not illustrative of attitudes toward patient portals are marked with an asterisk *

# Appendix G

## Table G1

*Representation of Synthesized Themes across Included Studies*

| First Author & Year | Participants | Theme 1: Efficiency | Theme 2: Therapeutic Relationships | Theme 3: Power Balance | Theme 4: Suitability for Patients with Mental Illness | Theme 5: Mental Health Information Management |
|---|---|---|---|---|---|---|
| Åkerstedt 2018 | Clinicians | - | - | ✓ | ✓ | ✓ |
| Blease 2021 | Both | - | - | - | ✓ | - |
| Chen 2021 | Patients | ✓ | ✓ | ✓ | - | - |
| Chimowitz 2020 | Clinicians | ✓ | ✓ | - | ✓ | ✓ |
| Cromer 2017 | Patients | ✓ | ✓ | ✓ | ✓ | ✓ |
| Denneson 2017 | Clinicians | ✓ | ✓ | ✓ | ✓ | ✓ |
| Dobscha 2016 | Clinicians | ✓ | ✓ | ✓ | ✓ | ✓ |
| Erlingsdóttir 2019[a] | Clinicians | ✓ | ✓ | ✓ | ✓ | ✓ |
| Fisher 2009 | Patients | ✓ | - | ✓ | - | - |
| Gasteiger 2020 | Both | ✓ | - | ✓ | ✓ | - |
| Johansen 2019 | Clinicians | ✓ | ✓ | ✓ | ✓ | - |
| Kariotis 2019 | Clinicians | ✓ | - | - | ✓ | ✓ |
| Kipping 2016 | Patients | ✓ | - | ✓ | - | - |
| Leung 2019 | Patients | ✓ | ✓ | ✓ | ✓ | ✓ |
| Mayhew 2018 | Clinicians | ✓ | ✓ | ✓ | ✓ | ✓ |
| O'Neill 2019 | Patients | ✓ | ✓ | ✓ | ✓ | ✓ |
| Pisciotta 2019 | Both | - | ✓ | ✓ | ✓ | ✓ |
| Peck 2017 | Both | ✓ | ✓ | ✓ | ✓ | ✓ |
| Strudwick 2018 | Clinicians | ✓ | ✓ | ✓ | ✓ | ✓ |
| Strudwick 2020 | Patients | ✓ | ✓ | ✓ | ✓ | - |
| Turvey 2021 | Both | ✓ | ✓ | ✓ | ✓ | - |
| van Dooren 2013 | Both | ✓ | - | ✓ | ✓ | ✓ |
| van Rijt 2021 | Clinicians | ✓ | ✓ | ✓ | ✓ | ✓ |
| Whealin 2016 | Patients | ✓ | - | ✓ | - | - |

*Notes:* ✓ = The theme is present in the study's qualitative data. (-) = The theme is not present in the study's qualitative data. Only data pertaining to patient portals in the mental health context from patients or clinicians are included.