“A Neglected Topic”: The Culture of Cancer Screening for People with Significant Mental Health Difficulties.

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Abstract

Background: Individuals with significant mental health difficulties (SMHD) are 2.5 times more likely to die from cancer than those without SMHD. Lower uptake of organised cancer screening programmes in one proposed contributing factor. This thesis addressed two research aims: (1) The systematic review sought to synthesise the existing empirical evidence on interventions aimed at improving cancer screening uptake, knowledge and attitudes among individuals with SMHD; (2) An empirical study investigated the culture of cancer screening (i.e. the beliefs and attitudes that influence screening practices and behaviours) for individuals with SMHD within community mental health and general practice services in Ireland.

Methods: (1) A systematic search across four databases was conducted and a narrative approach was used to synthesise data from the included studies. (2) Semi-structured interviews were conducted with 15 participants including psychiatrists and mental health nurses working in community mental health services and general practitioners and practice nurses working in general practice in Ireland. Data were analysed using thematic analysis.

Results: The systematic review identified six empirical examinations of interventions. The qualitative study reported that mental illness stigma, the recovery model of care, poor knowledge and awareness of screening were among the factors contributing to a lack of focused efforts to address poor cancer screening uptake among those with SMHD in Irish services.

Conclusions: Results highlight the need for more rigorous and longitudinal research examining interventions to increase screening uptake. There is also initial evidence to suggest a need for urgent action from policy makers and governmental bodies to address cancer screening uptake for this patient group through improved screening and mental health education, increased resources, and policy development to clarify roles and responsibilities relating to the physical health care of individuals with SMHD.

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Thesis Overview

This thesis aims to explore disparities in cancer screening participation for individuals with significant mental health difficulties (SMHD).

Chapter one will outline the rationale for the subsequent empirical studies described in chapters two and three. This introductory chapter presents a concise summary of literature relating to the inequities experienced by individuals with SMHD in terms of premature mortality, cancer related mortality and cancer screening uptake. This chapter highlights the need for, and importance of, the systematic review and empirical qualitative study that will follow.

Chapter two presents a systematic review synthesising the available empirical evidence for interventions to increase cancer screening uptake, knowledge, and attitudes for individuals with SMHD. It has been prepared for submission to the Psycho-oncology journal.

Chapter three presents an empirical qualitative study exploring the culture of cancer screening (i.e. the beliefs and attitudes that influence cancer screening practices and behaviours) for individuals with SMHD from the perspective of professionals working in community mental health and general practice services in Ireland.

The final chapter will provide a summary of the findings of this thesis and highlight the implications of this work.

Chapter One - Introduction

1.1 Defining Significant Mental Health Difficulties

As a first step, it is important to consider how significant mental health difficulties (SMHD) are conceptualised in this thesis. Although varying terminology is used in the literature to describe similar constructs, such as 'serious mental illness', we will use the term SMHD to align with previous research in the field (e.g. D'Alton et al., 2021; Leahy et al., 2021). While there is no universally agreed upon definition of SMHD, a comprehensive review of definitions proposed it to include schizophrenia spectrum disorders, bipolar disorder and major depression (Ruggeri et al., 2000). This proposed definition is also in keeping with previous literature on cancer and SMHD, likely due to the significant impact on functioning typically associated with these conditions (Günther et al., 2022; Happell et al., 2012; Irwin et al., 2014). As such, for the purposes of this thesis, SMHD will refer to schizophrenia spectrum disorders, bipolar disorder and major depression.

1.2 Premature Mortality for Individuals with SMHD

Research has consistently shown that mortality rates for individuals with SMHD are excessively high, approximately two to three times greater than for individuals without SMHD (Toender et al., 2018). This translates to a reduced life expectancy of 15 – 20 years (Grassi & Riba, 2020; Liu et al., 2017; Nordentoft et al., 2013; Walker et al., 2015). Despite common misperceptions, only a minority of these deaths are attributable to unnatural causes, such as suicide and accidents. Rather, research shows that as much as 80% of premature deaths for those with SMHD are due to comorbid physical illnesses such as cancers, cardiovascular, respiratory and infectious diseases and diabetes (Correll et al., 2017; Jayatilleke et al., 2017). Factors such as unhealthy lifestyle habits and side effects of long-

term antipsychotic medication have been suggested as increasing the risk of developing and dying from these diseases (Laursen et al., 2014). However, that does not capture the full story.

Advancements in research, medicine and healthcare have led to improvements in quality of life and life expectancy generally, but not all individuals have benefitted equally. Individuals with SMHD continue to experience reduced life expectancy compared to those without SMHD, and some research even suggests that this mortality gap is widening over time (Hayes et al., 2017; Tanskanen et al., 2018). For example, a longitudinal Danish study by Nielsen and colleagues (2013) found that over a 30-year period, the average life expectancy for men and women without SMHD increased by 5.7 years and 6.5 years respectively, while life expectancy for men and women with SMHD decreased by 0.7 years and 0.8 years respectively. This pattern was shown to exist independent of intentional self-harm as cause of death. The mortality gap experienced by individuals with SMHD does not appear to be going anywhere and has been described as a "public health scandal" that warrants urgent attention worldwide (Fiorillo & Sartorius, 2021).

1.3 An Overview of Cancer and SMHD

Globally, the burden of cancer is significant and growing (Smith & Oeffinger, 2020). The International Agency for Research on Cancer (IARC) estimates that in 2022, there were 20 million new cases of cancer and 9.7 million deaths (World Health Organisation [WHO], 2024). These numbers are expected to soar over the coming years, with estimates suggesting there will be over 32 million new cases of cancer in 2045 (WHO, 2024). Most recent statistics available from WHO state that 334 million people are living with a SMHD; 280 million are experiencing depression, 40 million are living with bipolar disorder and 14 million have a schizophrenia diagnosis (WHO, 2022). These data are even more concerning when we

consider the immense suffering experienced by those with both cancer and SMHD, and it constitutes a major practical and ethical challenge to healthcare systems globally (Howard et al., 2010).

1.3.1 SMHD and Cancer Comorbidity

The issue of cancer incidence among people with SMHD is not straight forward, with conflicting findings as to whether it differs from the general population. For example, a recent meta-analysis by Anmella et al. (2021) found that having a bipolar disorder diagnosis was associated with a 24% increased risk of any cancer, with that risk increasing to 34% for breast cancer when compared to the general population. Conversely, in a UK-wide matched cohort study that included almost 70,000 patients with SMHD, rates of all cancer diagnosis for that patient group were significantly reduced when compared to those without SMHD (Launders et al., 2022). Li and colleagues (2018) also reported a lower incidence of cancer in individuals with schizophrenia, although the effect size was small and varied by cancer site. Methodological factors such as cohort characteristics, low statistical power, duration of study follow-up and challenges in controlling for the many variables at play in cancer risk (e.g. familial and genetic vulnerability, health service contexts) are thought to contribute to the inconsistency in these findings (Grassi et al., 2023).

1.3.2 SMHD and Cancer Mortality

Despite the lack of consensus regarding incidence rates, it is well acknowledged that those with SMHD who develop cancer unequivocally suffer a worse prognosis than those without SMHD. Research suggests that they are up to 2.5 times more likely to die from cancer than the general population, with some variation noted according to gender, type of mental health need and cancer site (Grassi & Riba, 2021a; Launders et al., 2022; Plana-Ripoll et al., 2019).

Various factors contribute to these increased cancer related mortality rates, with internalised and externalised stigma suggested to play the biggest role in inequitable care across the continuum of cancer care (i.e. prevention, early detection, diagnosis and treatment, palliative care and survivorship) (Grassi et al., 2023). Individuals with SMHD are less likely to seek help for physical ailments (Kisely et al., 2013). When they do, the presence of their mental health difficulties may overshadow their somatic complaints (a concept known as 'diagnostic overshadowing'), resulting in cancers being diagnosed at a later stage (Cunningham et al., 2015). Once diagnosed, those with SMHD are less likely to be allocated to guideline treatments and receive specialist care (Dalton et al., 2018; Kisely et al., 2013). For example, in a study of almost 50,000 patients with prostate cancer, those with SMHD were significantly less likely to receive surgery, radiation and hormone treatment than those without SMHD (Fried et al., 2019). It has also been suggested that this cohort may be less able to engage with, and adhere to, intensive treatment routines, are more likely to be excluded from clinical trials, and that the high prevalence of comorbid physical illness could also contribute to the higher mortality rates (Irwin et al., 2014). In light of these factors, the need for improved early detection and timely treatment of cancer for those with SMHD is of utmost importance.

1.4 An Overview of Cancer Screening and SMHD

Cancer screening is a point early on the continuum of cancer care and is one form of early detection. Its purpose is to identify pre-cancer or early-stage cancer in symptom-free individuals so that prompt diagnosis and treatment can be provided, thus improving the outcomes for the affected individual (WHO, 2022). The European Code against Cancer outlines the importance of taking part in organised cancer screening programmes for bowel, breast and cervical cancers, to reduce cancer risk (Schüz et al., 2015). Literature also

supports the positive impact of organised cancer screening programmes on both incidence and mortality rates. For example, a review of 60 European cohort and case control studies found that participation in a formal breast cancer screening programme is associated with a significant reduction in breast cancer mortality in all European locations included, with rates varying from 12 – 58% depending on the region (Zielonke et al., 2020).

1.4.1 Disparities in Cancer Screening Uptake for Individuals with SMHD

Despite the potential cancer screening holds to save lives, uptake of cancer screening is substantially reduced for those with SMHD when compared to the general population (Aggarwal et al., 2013; Mitchell et al., 2014). A study by Public Health England (2021) found that those with SMHD were significantly less likely to participate in all three national cancer screening programmes compared to those without SMHD: with reported reductions of 18% for breast screening, 20% for cervical screening and 31% for bowel screening. Kerrison and colleagues (2023) analysed this data further and found that participation was lowest in those with SMHD living in socioeconomically deprived areas and those with SMHD and of a Black ethnicity, emphasising the significant impact of intersectionality. Such findings have been replicated internationally also. For example, a large meta-analysis involving over 4.5 million participants worldwide (except Africa), reported that uptake of breast, cervical and prostate screening was significantly lower for those with SMHD compared to those without (Solmi et al., 2020). These findings did not extend to bowel screening and disparities were particularly pronounced for women with schizophrenia. It is important to note however, the publications included in this review involved mental health difficulties outside of our definition of SMHD, such as anxiety and eating disorders, suggesting that the disparity may vary based on definition of mental illness.

Reduced uptake of cancer screening is thought to contribute to the higher likelihood of individuals with SMHD to receive a cancer diagnosis at a later stage when the disease has metastasised and prognosis is poor (Charlesworth et al., 2023). Thus, disparities in cancer

screening uptake represent an important target when considering how to address the significant mortality gap facing those with SMHD.

1.4.2 Reasons for Reduced Cancer Uptake in SMHD

The Social Ecological Model (SEM) provides a useful theoretical framework to consider the various factors at different levels that influence health and health behaviours, such as participation in cancer screening (McLeroy et al., 1988). It posits that health behaviours both shape and are shaped by factors at an intrapersonal, interpersonal, organisational, environmental, and public policy level. Informed by this model, Irwin and colleagues (2014) proposed that interrelated patient-, provider-, and system- level factors, influenced by stigma, may help account for the inequities experienced by those with SMHD at various points on the continuum of cancer care (i.e. prevention, detection, diagnosis, treatment, palliative care or survivorship). Much of the subsequent research into the barriers to cancer screening for this marginalised population have conceptualised their findings according to this model (e.g. Leahy et al., 2021).

At the patient level, recent systematic reviews of the literature have highlighted the following barriers to cancer screening uptake for those with SMHD: poor awareness of cancer screening eligibility and procedures; cognitive symptoms that may impact on an individual's ability to understand the risks and benefits of screening; uncontrolled psychiatric symptoms that may cause individuals to be poorly motivated or paranoid regarding screening; personal experiences of trauma and/or stigma leading to a distrust of healthcare systems; and practical challenges such as lack of transport make attending appointments more difficult (Irwin et al., 2014; Leahy et al., 2021; Tuschick et al., 2024). At the provider and system-level, fragmentation of primary care, mental health care and cancer care services has led to uncertainty about who holds responsibility for promoting cancer screening, and poor communication between services compounds this further (Clifton et al., 2016). The negative impact of stigmatising attitudes among healthcare professionals towards individuals with

SMHD has also been widely documented as a barrier (Tuschick et al., 2024). For example, some medical professionals doubt whether cancer screening is necessary for those with SMHD (Lindamer et al., 2006). While this literature provides much needed insight into the factors contributing to reduced screening participation among individuals with SMHD, it is noteworthy that much of this research has been conducted in North America. Given that health service structures vary greatly throughout the world, caution is warranted in generalising these findings outside of North America.

1.5 Cancer Screening Programmes in Ireland

In line with European Union recommendations, there are currently three national cancer screening programmes operating in Ireland that screen for breast, cervical and bowel cancers. BreastCheck invites women aged 50 – 69 years for a mammogram every two years. CervicalCheck is available to women aged 25 – 60 years. Those eligible can arrange to have their cervical screening completed at their GP practice every 3 years (if aged 25 – 29) or every 5 years (if aged 30 -65). BowelScreen is available every two years to men and women aged 60-69 years. They must ensure they are on the register and will be sent a home screening kit to collect a sample and send off for testing. All three screening programmes are free of charge.

1.6 Rationale for the Current Thesis and Study Objectives

This thesis is composed of two independent studies that contribute to the international literature focused on understanding and addressing reduced cancer screening uptake for individuals with SMHD. It also aims to contribute specifically to Irish research, where there is currently little available research or policy on the topic.

The first study, discussed in chapter two, is a systematic review of interventions aiming to increase cancer screening uptake, knowledge, and attitudes for individuals with SMHD. Given that poor rates of cancer screening uptake are considered a potential pathway to increased risk of cancer mortality for those with SMHD, it is not surprising that advocates in the field are calling for interventions to address these disparities (Grassi & Riba, 2020). Furthermore, the growing literature documenting the barriers and facilitators to screening uptake, provides a solid foundation from which interventions can be developed and adapted to meet the unique needs of this patient group. To our knowledge, only one previous systematic review exists on this topic in which Barley and colleagues (2013) found no studies meeting their inclusion criteria. However, their inclusion criteria were limited to randomised control trial designs only and the review is now over 10 years old. It is hoped that by providing an up-to-date review that includes all study designs, study one can provide a critical synthesis of the empirical evidence available for interventions that will help to inform those seeking to address this disparity in screening uptake.

The second study, detailed in chapter three, aims to describe the culture of cancer screening for individuals with SMHD within mental health and general practice services in Ireland. More specifically and in accordance with Schein's (1985) definition of culture, this will involve an exploration of the underlying beliefs and attitudes that guide screening practices and behaviours in community mental health and general practice services in Ireland. This is a qualitative study, exploring the views of psychiatrists and mental health nurses working in community mental health teams, and general practitioners and practices nurses working in general practice in Ireland. There are several reasons why this research topic is considered important. Firstly, and as already mentioned, most of the research examining barriers to cancer screening uptake for those with SMHD has been conducted in North America. Although this provides valuable information internationally, variation in national health services, the implementation of national cancer screening programmes and

general cultural differences, limits the generalisability of these findings to other contexts. Similarly, if the development of interventions has been based on these studies, caution needs to be exercised if considering implementing such interventions outside North American settings. Thus, before measures can be taken to address screening uptake for those with SMHD in Ireland, it is critical that the current culture of cancer screening is better understood.

Chapter Two - Interventions to improve cancer screening uptake for people with significant mental health difficulties: A Systematic Review

2.1 Abstract

Objectives: Cancer is one of the leading causes of premature death among people with significant mental health difficulties (SMHD). Although cancer screening could save lives, uptake of routine cancer screening programmes in this group are low. The current systematic review sought to identify and synthesise the existing empirical evidence on interventions aimed at improving cancer screening uptake, knowledge, and attitudes among individuals with SMHD.

Methods: We conducted a systematic search across four databases in March 2023 and updated this in February 2024. A narrative synthesis approach was used to synthesize data from the included studies.

Results: We identified six studies eligible for inclusion in the systematic review. Three studies reported experimental investigations of interventions, specifically designed to target a particular type of cancer screening, and three observational studies assessed the association between models of care provision and cancer screening uptake. Four common components within the six interventions were identified: education, supported decision making, patient navigation and integration of physical and mental health care services.

Conclusion: Although these findings show potential promise, there was vast variation in the cancer screening type targeted, interventions used, methodologies and analyses applied. In light of this, together with the limited amount of available evidence, we warrant caution in making further inferences. Our findings highlight the imperative need for more rigorous, longitudinal, and controlled investigations internationally, of interventions that target the cancer screening at a patient, provider and systems level.

2.2 Background

People with significant mental health difficulties (SMHD), die up to 20 years earlier than the general population (Nordentoft et al., 2013). In keeping with previous research, SMHD includes psychotic disorders, bipolar disorder and major depression as these are typically linked with a severe functional impairment (Evans et al., 2016; Irwin et al., 2014). The disparity in life expectancy for those with SMHD has been largely linked to treatable physical health conditions, with cancer cited as one of the leading causes of premature death (Olfson et al., 2015). Evidence is conflicting as to whether cancer incidence differs between those with SMHD and the general population (Anmella et al., 2021). However, once diagnosed with cancer, those with SMHD are up to three times more likely to die from the disease (Nordentoft et al., 2013). This heightened risk of cancer mortality remains, even after controlling for other contributing factors such as gender and geographical location (Zhuo et al., 2017). While a variety of factors appear to contribute to the increased cancer mortality rates including poorer standard of care, limited access to specialised treatments and comorbidities that complicate treatment (Crump et al., 2013), one important and potentially modifiable factor relates to the reduced uptake of cancer screening among those with SMHD (Ross et al., 2021).

Cancer screening has the potential to detect the disease at an earlier stage and has been estimated to prevent anywhere from 15% to 70% of cancer related deaths, depending on the cancer and screening type (Landy et al., 2016; Myers et al., 2015). Unfortunately, uptake of cancer screening is significantly lower among those with SMHD than the general population, leading to advanced disease stage and metastasized disease at diagnosis, and an overall poorer prognosis (Charlesworth, 2023). A recent study in the UK reported that those with SMHD were up to 31% less likely to participate in national breast, cervical and bowel cancer screening initiatives when compared to those without SMHD (Public Health England, 2021). Globally, a meta-analysis of almost 4.5 million participants found that those with

SMHD were nearly 25% less likely to receive any breast, cervical and prostate cancer screening (Solmi et al., 2020). The type of cancer screening, nature of mental health difficulty and other sociocultural factors can also impact on uptake rates. For example, those with psychotic disorders, living in poverty and unstable housing, are thought to be particularly vulnerable to be missed from screening (Hwong & Irwin, 2020; Kerrison et al., 2023). In a recent call to action, Grassi & Riba (2021) have emphasised the urgent need to address the inequalities faced by those with SMHD in relation to cancer screening.

In addition to the typical barriers faced by the general population (e.g. poor awareness), there are unique challenges experienced by individuals with SMHD at a patient-, provider- and systems-level that make participation in routine cancer screening less likely (Irwin et al., 2019; Leahy et al., 2021). At an individual level, uncontrolled psychiatric symptoms, trauma history, fear, and embarrassment are just some of the factors that have been identified in the literature (Clifton et al., 2016; Linz & Jerome-D'Emilia, 2022). At a healthcare provider level, stigma towards those with SMHD, physician bias and poor awareness about cancer screening are among the factors thought to further drive the disparity (Clifton et al., 2016; Tuschick et al., 2024). Lastly, at a wider system-level, poor integration of physical health and mental health care services, as well as social circumstances (e.g. limited access to education, poverty, homelessness and poorer social integration) contribute a further layer of challenges (Clifton et al., 2016).

Given the high mortality rates of cancer, the reduced participation in cancer screening and the crucial role of screening in saving lives, there is a clear need for evidence-based interventions aimed at increasing cancer screening uptake for those with SMHD. While such evidence exists within the general population and shows good efficacy (Agide et al., 2018; Brouwers et al., 2011; Dougherty et al., 2018), these interventions need adaptation to meet the unique needs and challenges facing those with SMHD (Solmi et al., 2020). To our knowledge, there is only one existing systematic review of interventions to increase cancer

screening uptake in this group (Barley et al., 2013). In that review, the authors focused on randomised controlled trials (RCTs) only and found that no trials met their inclusion criteria. Given the potential of interventions to improve screening uptake and therefore reduce mortality rates, and that no systematic review has been conducted since 2013, it is imperative to obtain an updated synthesis of existing evidence for interventions aiming to improve cancer screening uptake for individuals with SMHD.

2.3 The Present Study

The current systematic review aimed to: Identify and synthesise the existing empirical evidence on interventions aimed at improving cancer screening uptake, knowledge, and attitudes among individuals with significant mental health difficulties.

2.4 Methods

This systematic review followed the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (Page et al., 2021). The protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO, registration number: CRD42023370446).

2.4.1 Search Strategy

The following databases were first searched in March 2023 and an updated search was completed in February 2024: PubMed, PsycINFO, EMBASE and CINAHL. Key terms for the search strategy were developed based on knowledge of the topic, comparing existing systematic reviews on similar topics and on preliminary searches. The final key terms used for the search were: (cancer AND screening) AND (schizophrenia OR depression OR psychosis OR bipolar disorder OR serious mental illness OR psychiatric disorder) AND (increas* OR improv* OR interven* OR encourag*). No language or year limits were applied. The reference lists of all studies included for full-text review were also hand searched to identify any further potential studies for full-text screening.

2.4.2 Eligibility Criteria

To be included in this review, studies were required to meet the following inclusion criteria:

1. Population: Interventions must be directed at individuals with SMHD and/or their family/caregivers and/or their healthcare providers. SMHD is defined according to previous research as psychotic disorders, bipolar disorder or major depression (Happell et al., 2012; Irwin et al., 2014).
2. Intervention: Studies must be investigating any type of intervention aimed at improving cancer screening uptake and/or knowledge and/or attitudes among people with SMHD.

3. Comparison: All study designs will be included, so there are no limits on comparison groups.
4. Outcome: Studies must report on the impact of the intervention on cancer screening uptake and/or attitudes towards cancer screening and/or knowledge of cancer screening.

No restrictions were placed on the type of cancer screening studied, the study setting or year of publication. Those with SMHD and comorbid mental, physical or substance abuse difficulties were also eligible for inclusion in the review. Studies were excluded if data relating to the population or outcomes of interest could not be isolated and extracted.

2.4.3 Study Selection

All studies retrieved via the search process were uploaded to Covidence systematic review software (Veritas Health Innovation, n.d.). Any duplicates were automatically removed, and all title and abstracts were screened for eligibility for full text review. The full texts of all remaining papers were subsequently reviewed against the predefined eligibility criteria and a decision was made to include or exclude the study. The reference lists of papers included in the full-text review were also hand-searched and any potentially relevant papers were added to the screening process. During this process, a decision was made to include studies that recruited individuals with serious mental illness, without explicitly stating the type of mental illness. Reasons for exclusion at full text review were documented. All stages of the title and abstract screening and full-text review were completed independently by two authors for 100% of the papers. This resulted in 97% agreement for the abstract and title screening and 84% agreement for the full text screening. Any disagreements were resolved through discussion with a third author. The PRISMA flow diagram is presented in Figure 1.

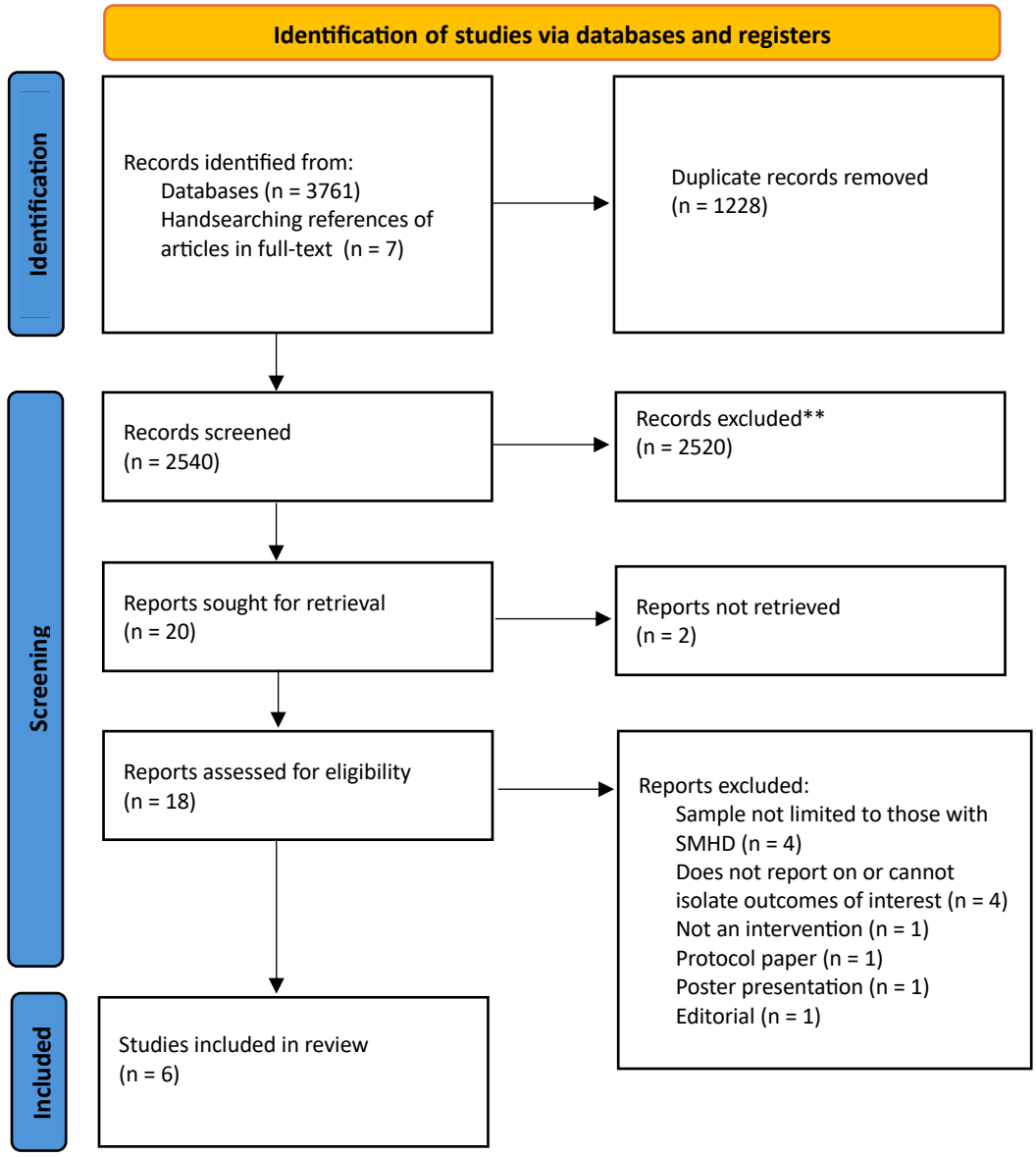

Figure 1. PRISMA Flow Diagram

2.4.4 Data Extraction

A data extraction form was developed, and data were extracted under the following headings: author, year of study, country, study design, description of sample, description of intervention, outcomes and measures, and key findings. Two reviewers independently completed the extraction process for all eligible studies. The extracted data were compared, and any discrepancies were resolved through discussion with a third author.

2.4.5 Quality Assessment

Quality assessment was performed on each study included in the final review using the Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018). This tool was developed for appraising the methodological quality of qualitative, quantitative, and mixed-method studies which was deemed appropriate given the varied designs of the studies included in this review. As a first step, the MMAT includes two initial screening questions that must be passed to proceed with the quality assessment. The questions are: 1) Are there clear research questions? and 2) Do the collected data allow to address the research question? If passed, studies are then categorised into one of five groups according to their design and the related criterion are applied. Each criterion is rated as 'yes', 'no' or 'cannot tell'. Each of these steps were completely independently by two authors for 100% of the studies. Disagreements were resolved through discussion with a third author. The authors of the MMAT discourage from calculating an overall score and instead encourage providing a more detailed presentation of the ratings for each criterion per study.

2.4.6 Data Synthesis

Given that there was significant heterogeneity among the study designs, interventions and outcome measures, a meta-analytical approach was deemed inappropriate. Instead, a narrative synthesis approach (Popay et al., 2006) was used to produce a textual summary of similarities and differences across interventions and their outcomes.

2.5 Results

2.5.1 Study Identification

The PRISMA flow chart in Figure 1 presents the outcomes at each stage of the systematic review search process. A total of 2540 articles were screened by title and abstract against the pre-determined inclusion criteria. From this, a total of 18 full-text articles were assessed for eligibility and six of these met criteria to be included for narrative synthesis.

2.5.2 Study Characteristics

Descriptive information for the six studies is displayed in Table 1. Despite no limitations being placed on year of publication, all papers that met inclusion criteria were published from 2015 onwards. One study took place in Japan and the remaining five in the USA. Most studies (n=4) were quantitative and two used a mixed-method approach from which the quantitative data was extracted (Flores et al., 2021; Weinstein et al., 2019). Half of the studies were experimental (Flores et al., 2021; Fujiwara et al., 2021; Weinstein et al., 2019), using either a randomised controlled trial (n=1), single arm pilot trial (n=1) or mixed-method exploratory sequential (n=1) design to trial an intervention and assess its effect on cancer screening uptake and/or changes in knowledge of cancer screening or attitudes. The remaining 50% (Grove et al., 2021; Murphy et al., 2020; Xiong et al., 2015) were observational and used a retrospective cohort or cross-sectional design to examine associations between various models of care provision and cancer screening uptake for people with SMHD.

In total, 29,989 participants took part in the six studies with wide variation in the individual sample sizes which ranged from 15 (Flores et al., 2021) to 17,556 (Grove et al., 2021). Of the total number of participants included, 3,713 received an intervention of some form and the remaining 25,276 formed a comparison or control group. All participants had a diagnosis of a SMHD which included schizophrenia, schizoaffective disorder and other psychotic disorders, bipolar disorder, and major depression. One study recruited women

with serious mental illness but this was not further defined (Weinstein et al., 2019). Five of the six studies were conducted within primary and secondary care health services, while one focused on women living in supportive housing (Weinstein et al., 2019). Race was not reported in every paper, but studies included Caucasian, American Indian or Alaskan Native, Asian, Black, African American and Hispanic/Latino participants.

With regard to the type of cancer screening studied, the experimental studies each focused on one specific type (breast= 1, colorectal = 1, lung = 1), while the observational studies were typically focused on multiple types.

2.5.3 Study Quality

All studies passed the initial screening questions of the MMAT and thus were retained for quality analysis. Results of the analysis are detailed in Table 2. Only one study, the RCT by Fujiwara et al. (Fujiwara et al., 2021) met all five criteria of the MMAT. Of the three non-randomised quantitative studies, all of them met four criteria. In all studies, it was difficult to assess whether the exposure had occurred as intended as this was not reported in any of the papers. With regard to the two mixed-methods studies, both of these also only met four criteria on the MMAT, as they failed to adhere to the quality criteria of each tradition of the methods involved. For example, Weinstein et al (Weinstein et al., 2019) did not account for confounders and the measures used by Flores et al (Flores et al., 2021) to assess outcomes had not been tested for reliability and validity.

Table 1: Characteristics of included studies

Author & Year	Methodology & design	Country and setting	Sample description	Mental health diagnosis	Quality Rating (# of criteria met)
Flores et al., 2021	Mixed Methods Sequential exploratory design	USA Community mental health clinic	N = 15 F = 6, M = 9 Mean age = 61.3 Race: White = 13, American Indian or Alaska Native = 2	Treatment resistant schizophrenia or bipolar disorder (breakdown not reported)	4/5
Fujiwara et al., 2021	Quantitative Randomized parallel group trial	Japan Psychiatric outpatient clinic	Total N = 170 F = 84, M = 86 Median Age = 53 No details reported on race	Schizophrenia=100 %	5/5
Grove et al., 2021	Quantitative Retrospective cohort study	USA Primary care setting	Intervention N = 160 F = 33% Mean Age = 42±15 Race: American Indian=0.63%, Asian = 1.9%, Black = 64%, >1 race = 1.3%, Unknown = 4.4%, White = 28% Comparison 1 N = 1433 F = 48% Mean Age = 45±15 Race: American Indian = 0.35%, Asian = 2.2%, Black = 70%, >1 race = 1.1%, Unknown = 5%, White = 21% Comparison 2 N = 16,053 F = 48% Mean Age = 46±15 Race: American Indian = 1.2%, Asian = 0.66%, Black = 52%, >1 race = 1.1%, Unknown = 4.2%, White = 40%	Schizophrenia OR schizoaffective disorder (breakdown not reported)	4/5
Murphy et al., 2020	Quantitative Retrospective cohort study	USA Behavioural health home (BHH)	Intervention N = 3,298 F = 44.9% Mean Age: 43.7 Race: Black = 45.6%, White = 47.3%, Other = 7.1% Comparison N = 8,878 F = 60.9% Mean age = 40.5 Race: Black = 59.6%, White = 35.5% Other = 4.9%	Schizophrenia = 63.6%; Bipolar disorder = 23.8%; Major depression = 11.8% Comorbid substance use disorder = 21.7% Schizophrenia = 36.4%; Bipolar disorder = 36.2%; Major Depression = 26.4% Comorbid substance use disorder = 27.6%	4/5
Weinstein et al., 2019	Mixed methods Single arm trial with qualitative interviews	USA	N = 21 F = 100% Mean age = 53.19 Race: African American = 76%, White = 14%, Other/unknown = 10%	Serious mental illness, not specified = 100%	4/5
Xiong et al., 2015	Quantitative Naturalistic,cross-sectional study	USA Integrated behavioural health primary care (IBHPC)	Total N = 350 F = 61% Mean Age = 46.3 Race: Caucasian = 46%, African American = 20%, Hispanic/Latino = 12%, Asian = 10%, Other = 13%	Schizophrenia = 16% Depression = 42% Bipolar disorder = 32% Other = 9%	4/5

Table 2: MMAT Appraisal of Included Studies

Study	Screening Questions		Qualitative					Quantitative randomised controlled trials					Quantitative non-randomised					Quantitative descriptive					Mixed-methods				
			Q1	Q2	Q3	Q4	Q5	Q1	Q2	Q3	Q4	Q5	Q1	Q2	Q3	Q4	Q5	Q1	Q2	Q3	Q4	Q5	Q1	Q2	Q3	Q4	Q5
Flores et al 2021	√	√																					√	√	√	√	X
Fujiwara et al 2021	√	√						√	√	√	√	√															
Grove et al 2021	√	√											√	√	√	√	—										
Murphy et al 2020	√	√											√	√	√	√	—										
Weinstein et al 2019	√	√																					√	√	√	√	X
Xiong et al 2015	√	√											√	√	√	√	—										

√ = Criterion met, X = Criterion not met, - = Can't tell

2.5.4 Interventions

Three of the six studies trialled a novel intervention designed to increase participation in and/or knowledge of, a particular type of cancer screening among individuals with SMHD (Flores et al., 2021; Fujiwara et al., 2021; Weinstein et al., 2019). The remaining three studies (Grove et al., 2021; Murphy et al., 2020; Xiong et al., 2015) assessed the impact of receiving care via an integrated mental and physical health service on cancer screening uptake rates. Table 3 details the interventions, target screening type and comparison groups used in each study.

2.5.4.1 Experimental investigations of targeted interventions

The three experimental interventions studies included a decision support and navigation intervention for mammography (DSNI) (Weinstein et al., 2019), a case management approach for colorectal cancer screening (Fujiwara et al., 2021) and an educational intervention for lung cancer screening, all targeted toward individuals with SMHD. There were three common components described across these three interventions: education; support with decision making; and patient navigation. Two studies (Fujiwara et al., 2021; Weinstein et al., 2019) used all three components, while Flores et al (Flores et al., 2021) used only education.

Education was a component in all three interventions and typically incorporated information on the importance of cancer screening and the screening process specific to the type being studied. One intervention also included education on health promotion behaviours i.e. smoking cessation in relation to lung cancer (Flores et al., 2021). The individuals providing education varied across studies but included thoracic radiologists and mental health clinicians for the lung cancer intervention (Flores et al., 2021) and case managers (nurses, psychiatric social workers or psychologists) (Fujiwara et al., 2021). The provider of the educational component was not clear in the third study (Weinstein et al.,

2019). Support with making a decision regarding screening participation was provided by the case manager in one study during the initial education session (Fujiwara et al., 2021) and by the research assistant formally trained as a decision counsellor in conjunction with a computer-based decision counselling program (Weinstein et al., 2019). The final component to these two studies was patient navigation. This consisted of in-person or telephone follow-up. These check-in's provided opportunities to see if participants had progressed with the screening, troubleshoot any difficulties they may have encountered and recap on the education provided. It also involved logistical support, such as helping schedule screening appointments and arranging transport.

2.5.4.2 Observational studies of care provision models

The remaining three studies included in the review assessed the association between a unique model of care provision and cancer screening uptake (Grove et al., 2021; Murphy et al., 2020; Xiong et al., 2015). The care models included an integrated behavioural health primary care (IBHPC) (Xiong et al., 2015), a behavioural health home (BHH) (Murphy et al., 2020) and enhanced primary care (EPC) (Grove et al., 2021). Common to all of these care models was the integration of physical and mental health care for individuals with SMHD. However, details on how this was achieved, and other features of each model was very limited. One study (Grove et al., 2021) detailed the support given to healthcare providers working with individuals with SMHD in terms of training, allowing for longer appointment times to build rapport with patients and regular communication between primary care providers and behavioural health providers. No other studies detailed support provided to healthcare staff.

Table 3: Intervention details and results

Study	Intervention (N)	Comparator (N)	Target cancer screening type	Outcomes and measurement tools	Key results
Flores et al., 2021	Lung cancer screening educational intervention (N = 15)	N/A	Lung cancer	1. Feasibility assessed by enrolment and completion rates 2. Acceptability assessed by responses to a 1-item Likert scale ("Overall, I was satisfied with the educational session") 3. Attitudes towards lung cancer and lung cancer screening measured by changes on pre- and post- non-standardised questionnaires	1. 50% enrolment rate deemed feasible. 2. 14/15 expressed satisfaction with the intervention. 3. Significant change in participants' worry about developing lung cancer post- intervention (*d* = .53)
Fujiwara et al., 2021	Case management + TAU (N = 85)	TAU only (N = 85)	Colorectal cancer	1. Colorectal cancer screening uptake measured using municipal records 2. Uptake of other cancer screening measured using municipal records	1. Colorectal screening participation significantly higher in intervention +TAU vs TAU only (*p* = <.0001, risk difference 35.3%). 2. Lung screening significantly higher in intervention + TAU vs TAU only (*p* = 0.0051, risk difference 18.8%). 3. No significant differences between groups in screening rates for gastric, breast and cervical cancer.
Grove et al., 2021	Enhanced primary care (N = 160)	Two clinics providing usual primary care (N = 17,486)	Not specific	1. Receipt of colorectal cancer screening 18months post initial primary care visit	1. Enhanced primary care had no significant effect on the probability of colorectal cancer screening receipt (treatment effect = 0.045)
Murphy et al., 2020	Behavioural health home (BHH) (N = 3,298)	Those in psychiatric rehabilitation programs, not enrolled in BHH (N = 8,878)	Not specific	1. Receipt of a Pap smear for cervical cancer screening' mammography for breast cancer screening' and colonoscopy, sigmoidoscopy, or fecal occult blood test (FOBT) for colorectal cancer screening according to Maryland Medicaid administrative claims data.	4. BHH enrolment was associated with an increase in the likelihood of receiving cervical cancer screening (odds ratio [OR]=1.20, 95% confidence interval [CI]=1.07–1.35; p=0.002), breast cancer screening (OR=1.30, 95% CI=1.06–1.59; p=0.01) and not associated with the likelihood of colorectal cancer screening, compared with no BHH enrolment
Weinstein et al., 2019	Decision support and navigation intervention (N = 21)	N/A	Breast cancer	1. Feasibility and acceptability assessed by tracking process measures of the intervention and interviews at baseline and follow-up with participants. 2. Cancer screening intention and utilisation assessed using an Adapted Preventive Health Model (Sifri et al., 2010; Tiro et al., 2005).	1. 100% completion rate 2. 67% uptake of mammography post-intervention 3. Significant decrease in Decision Conflict Scale from baseline to 1 month post-intervention (p = .01, 95% CI 2.00-15.38) 4. No significant change detected on the PHM.

				3. Changes to breast cancer knowledge and decision conflict measured using the Decisional Conflict Scale (Linder et al., 2011).	
Xiong et al., 2015	Integrated behavioural health primary care (IBHPC) (N = 132)	Two existing community mental health programs (N = 218)	Not specific	1. Participation in mammogram within past 2 years; Pap test within 3 years; PSA or digital rectal exam within 1 year; colonoscopy within 5 years assessed via self-report.	1. Of those eligible for each screening: 67% reported having an up to date Pap test, 52% a mammogram, 11% a PSA/rectal exam and 44% a colonoscopy. These numbers were consistently lower when compared to the two mental health care comparison groups.

2.6 Measures and Outcomes

The primary outcome of interest was uptake of one or more types of cancer screening (n=5). Secondary outcomes included acceptability and feasibility of intervention (n= 2) and changes in attitudes/knowledge about cancer screening (n=2). Table 3 provides key findings while a summary of intervention components and outcomes can be found in Table 4.

2.6.1 Acceptability and Feasibility of Interventions

Of the two papers that examined the feasibility and acceptability of the studied intervention, both reported positive findings (Flores et al., 2021; Weinstein et al., 2019). Flores et al. (Flores et al., 2021) outlined a very clear criterion to determine feasibility (i.e. ≥50% enrolment among eligible participants and at least 75% intervention completion among those who enrolled) and acceptability (i.e. ≥75% overall satisfaction with the intervention as assessed in the post-intervention survey). Conversely, Weinstein et al. (Weinstein et al., 2019) were less clear on criteria for feasibility and used feedback from participants during the interview as evidence for acceptability.

3.5.2 Effect of interventions on cancer screening uptake

Where participation in cancer screening was measured (n=5), three studies utilised administrative data to gather this information (Fujiwara et al., 2021; Grove et al., 2021; Murphy et al., 2020), while two studies used participant self-report data (Weinstein et al., 2019; Xiong et al., 2015). The statistical analyses used to examine effects varied greatly as did the comparison groups that they were measured against as highlighted in Table 3.

3.5.2.1 Cervical Screening

Three studies measured cervical screening outcomes with only one (Murphy et al., 2020) reporting a positive effect that enrolment in a behavioural health home (BHH) was associated with an increase in the likelihood of receiving cervical cancer screening compared with those not enrolled in a BHH.

3.5.2.2 Breast Screening

Of the four studies that measured breast screening outcomes (Fujiwara et al., 2021; Murphy et al., 2020; Weinstein et al., 2019; Xiong et al., 2015), 50% reported a positive effect. The BHH studied by Murphy et al. (Murphy et al., 2020) was associated with an increased likelihood of receiving breast screening, while Weinstein et al 2019 reported that 67% of women enrolled in a decision support and navigation intervention who were not up to date on screening at baseline, self-reported having attended breast screening at post-intervention.

3.5.2.3 Colorectal Screening

Four studies reported on uptake of colorectal cancer screening (Fujiwara et al., 2021; Grove et al., 2021; Murphy et al., 2020; Xiong et al., 2015). Enhanced primary care (Grove et al., 2021), BHH (Murphy et al., 2020) and IBHPC (Xiong et al., 2015) were not shown to impact on colorectal cancer screening when compared to the comparators in each study. The case management approach examined by Fujiwara et al. (Fujiwara et al., 2021) specifically targeting colorectal cancer screening was shown to have a significant effect on screening uptake when compared to treatment as usual.

3.5.2.4 Lung, Gastric and Prostate (PSA) Screening

Outcomes on lung and gastric screenings were reported as a secondary outcome in one study (Fujiwara et al., 2021). The case management approach was shown to significantly increase lung cancer screening uptake when compared to TAU, while the same intervention

had no effect on gastric screening. PSA screening uptake was reported to be lower among participants involved in IBHPC intervention compared to the two comparison mental health treatment clinic groups (11% vs 15% and 21% respectively) (Xiong et al., 2015).

2.5.3 Effect of interventions on cancer knowledge and attitudes towards screening

Two studies measured the impact of the intervention on knowledge/attitudes towards a specific type of cancer and associated screening program using non-validated brief questionnaires designed for each study (Flores et al., 2021; Weinstein et al., 2019). Participants in the lung cancer education intervention, who were long-time smokers, reported significantly higher worries about developing lung cancer post-intervention (Flores et al., 2021). In contrast, the decision support and navigation intervention study found no change in breast cancer knowledge or orientation toward screening (Weinstein et al., 2019). Decisional conflict decreased significantly from baseline to post-intervention for this group, which authors reported was suggestive of a decrease in concerns related to mammography.

Table 4: Summary of intervention components and outcomes

Study	INTERVENTION COMPONENTS					OUTCOMES								
	Education	Decision Support	Patient Navigation	Integrated physical + mental health care provision model	Training for healthcare staff	Cervical screening participation	Lung screening participation	Breast screening participation	Bowel/ colorectal screening participation	Gastric screening participation	PSA screening participation	Changes in knowledge/ attitudes	Feasibility	Acceptability
Flores et al., 2021 (Flores et al., 2021)	√											[+] change in patient worry about developing lung cancer	[+]	
Fujiwara et al., 2021(Fujiwara et al., 2021)	√	√	√			[o]	[+]	[o]	[+]	[o]				
Grove et al., 2021 (Grove et al., 2021)				√	√				[o]					
Murphy et al., 2020 (Murphy et al., 2020)				√		[+]		[+]	[o]					
Weinstein et al., 2019 (Weinstein et al., 2019)	√	√	√					[+]†				[o] no change in breast cancer knowledge or orientation toward screening [+] less concerns re mammography	[+]	[+]
Xiong et al., 2015 (Xiong et al., 2015)				√		[o] †		[o] †	[o] †		[o] †			

[+] = statistically significant increase, [-] = statistically significant decrease, [o] = inconclusive or no evidence, †based on descriptive statistics only

2.6 Discussion

This systematic review provides a synthesis of the existing empirical literature examining interventions aimed at improving cancer screening uptake, knowledge, and attitudes among people with significant mental health difficulties. It builds on one previous review that focused solely on RCT investigations and yielded no results (Barley et al., 2013), by placing no restrictions on study design. Results of the current review identified six studies, thus highlighting the considerably limited research on this topic. However, all studies were published from 2015 onward, which suggests that this is still an emerging area of interest.

The included studies were broadly grouped into two categories: 1) experimental examinations of interventions designed to target a specific cancer screening type; and 2) observational examinations of the association between models of care provision and uptake of various cancer screenings. The narrative synthesis highlighted vast heterogeneity in terms of the types of interventions studied and the targeted cancer screening types. Furthermore, the methodologies and analyses used also varied greatly. Thus, we cannot conclude that any one type of intervention is superior, however the findings of this review provide some valuable insights into the current state of research in this area and offer important considerations for future research.

Education, patient navigation, supported decision-making and integrated physical and mental health care services were among the components that made up the interventions identified in this systematic review, showing promising results. These findings support previous research in the general population that report patient navigation and decision support aids respectively to be effective at increasing participation in cancer screening programmes (Gabel et al., 2020; Mosquera et al., 2023). Flores et al., (Flores et al., 2021) studied education alone as an intervention but did not measure outcomes on cancer screening uptake. While education should likely be a core component to any intervention

targeting screening uptake, its use in isolation is open to questioning given the various practical and systemic barriers, such as transport issues and stigma, faced by those with SMHD that education alone cannot target (Clifton et al., 2016). The integration of mental and physical health care services has been shown to facilitate more frequent visits to primary care and improve screening and monitoring of cardiovascular-related conditions for individuals with SMHD (Murphy et al., 2018). However, no standardised format or protocol for implementing these types of services exists and details contained within the papers included in this systematic review were limited. Thus, it is difficult to ascertain the exact mechanisms that supported improvement in cancer screening uptake.

2.7 Study Limitations

There are limitations that should be taken into account when considering the findings of the present systematic review. Firstly, the majority of included studies come from the USA and half examined the effect of national models of care provision, which greatly limits the applicability of interventions and generalisability of results to other health systems, cultures and settings. Of the three studies that examined targeted interventions, two were limited by very small sample sizes and lack of a comparison group (Flores et al., 2021; Weinstein et al., 2019) and in the case of one of these studies, no statistical analysis of effect on cancer screening uptake (Weinstein et al., 2019). While the three remaining studies, focused on care provision models, involved much larger sample sizes and used control groups, their observational design and a poor ability to control for confounding factors limits any assessment of effectiveness. Finally, as all six studies only reported on cancer screening uptake at one point in time, it is not possible to deduce whether any reported improvements are sustained over time. This is not a challenge unique to this area of research, as it has been highlighted in previous reviews of general physical health screenings for this population

(Lamontagne-Godwin et al., 2018). There is a clear need for more rigorous, well-controlled and longitudinal studies.

The present review has a number of strengths, primarily related to the systematic and thorough approach that was used to synthesise existing empirical evidence. Given that this area of research is still in its infancy and evidence is limited, the broad search strategy and criteria employed aided the identification of studies of interest. However, as there is no internationally recognised definition of SMHD (Gonzales et al., 2022), there was some variation in how SMHD was conceptualised across studies and it sometimes included conditions outside of our predefined criteria such as anxiety. When not possible to extract the data relevant to our population of interest, studies were excluded from the review. While this may have led to the omission of potentially relevant interventions, maintaining strict criteria likely added to the integrity of the current review.

2.8 Clinical Implications and Recommendations for future research

Barriers to cancer screening occur at patient-, provider- and system-levels (Irwin et al., 2019). The components that made up the experimental study interventions (i.e. education, patient navigation and supported decision making), could be conceptualised as addressing barriers at the patient and provider level (Weinstein et al., 2016). Although limited details are provided on the specifics of the care provision models examined in the observational studies, they appear to primarily target system level challenges such as the well documented fragmentation between mental and physical health services (Leahy et al., 2021). While all of these individual components have been highlighted as essential to any effective intervention (Garcia-Alcaraz et al., 2023), it has been suggested that interventions incorporating elements at all levels of patient-, provider- and system-level factors hold more promise, but this requires investigation (Strunz et al., 2022).

The majority of the included studies were based in the USA which is not surprising given that much of the foundational research into the barriers and facilitators to cancer screening has also been conducted there. In a recent review, 80% of the twenty included studies examining barriers to cancer screening for those with SMHD were conducted in North America (Tuschick et al., 2024). While these findings have international implications, it is important to note the variation in national health services and cancer screening programmes, as well as differences in cultural norms and expectations. As such, it is important that researchers and policy makers first understand the state of cancer screening in their locality, prior to trialling any type of intervention.

Finally, as research continues to grow in this field, it is critical that best efforts are made to engage people with lived experience of SMHD in research as collaborators throughout the process, rather than just study participants (Domecq et al., 2014). For example, two studies in this review involved members from the population of interest (i.e., individuals with SMHD) in the development of the respective interventions (Flores et al., 2021; Weinstein et al., 2019), but such involvement can and should extend to research study design and conduct. In addition to this being an ethical responsibility for researchers, it will also improve the validity and relevance of any research findings (Faulkner & Chambers, 2021).

2.9 Conclusion

Individuals with SMHD are significantly less likely to receive routine cancer screening, leading to higher mortality rates than those in the general population. This systematic review identified six studies of interventions aimed at improving cancer screening uptake, knowledge, and attitudes among this population group. Although our findings show potential promise, given the variation in cancer screening type targeted, interventions used,

methodologies and analyses, together with the limited amount of available evidence available, we warrant caution in making further inferences. There is an imperative need for more rigorous, longitudinal, and controlled investigations internationally, of interventions that target the barriers of cancer screening at a patient, provider, and systems level.

Chapter Three – The Culture of Cancer Screening for Individuals with Significant Mental Health Difficulties: Exploring Health Professional Perspectives.

3.1 Abstract

Objective: Individuals with significant mental health difficulties (SMHD) are up to 2.5 times more likely to die from cancer than those without SMHD. One reason for this may be reduced rates of cancer screening uptake within this group. Currently, much of our understanding about the reasons why screening uptake is lower is based on research completed in North America, which may not be generalisable outside of that context. Thus, the current study explored the culture of cancer screening (i.e. the beliefs and attitudes that influence screening practice and behaviour) for individuals with SMHD in community mental health and general practice services in Ireland.

Method: Semi-structured interviews were conducted with 15 participants, including psychiatrists and mental health nurses working in community mental health teams, and general practitioners and practice nurses working in general practices services in Ireland. Data were analysed using inductive thematic analysis.

Results: Findings indicate that cancer screening for those with SMHD may be an under-prioritised topic in clinical settings. Exploration of the underlying attitudes and beliefs contributing to this highlighted the influence of stigma, the recovery model of care and lack of knowledge and awareness about screening and the inequities facing those with SMHD.

Conclusions: Although these results are based on a relatively small number of participants and do not infer generalisability to all services within Ireland, they offer support to previous international studies and also add some novel contributions. Research, clinical and policy implications are discussed.

3.2 Background

Survival and quality of life have greatly improved for people with cancer due to advancements in cancer detection and treatment, however not all patients have benefited equally (Fond et al., 2019). People with significant mental health difficulties (SMHD), such as schizophrenia spectrum disorders, bipolar disorder and major depression, have a substantially greater risk of cancer mortality than the general population (Nordentoft et al., 2021). This is despite there being no clear evidence to suggest differences in cancer incidence rates between the groups (Anmella et al., 2021; Weinstein et al., 2016). Worryingly, this mortality gap inequality continues to widen over time (de Mooij et al., 2019; Grassi & Riba, 2020), and addressing the disparity in cancer survival for those with SMHD has become a global issue (Yamada et al., 2023).

Individuals with SMHD experience inequities across the continuum of cancer care, from cancer prevention through to palliative care, that impact on their chances of survival (Yamada et al., 2023). Cancer screening is a point early on that cancer continuum and is one form of early detection that holds the potential to prevent up to 70% of cancer related deaths, depending on the type of cancer and screening (Landy et al., 2016; Myers et al., 2015). While strategies to increase uptake of cancer screening in the general population have shown good efficacy (Camilloni et al., 2013), those with SMHD are still up to 31% less likely to take part in national bowel, breast and cervical screening when compared to the general population (Public Health England, 2021). As a result, these individuals are more likely to present with advanced stage cancer or metastatic disease when diagnosed, lessening their chances of survival (Davis et al., 2020; Kisely et al., 2013). Thus, understanding and addressing the disparity in cancer screening uptake within this group is of critical importance (Grassi & Riba, 2021).

Informed by the Social Ecological Model, Irwin et al (2014) defined multi-level patient, provider and system barriers to cancer screening for those with SMHD. Such barriers

include uncontrolled psychiatric symptoms, limited understanding and awareness of screening programmes, stigma and fragmentation of mental health and physical healthcare systems (Leahy et al., 2021; Tuschick et al., 2024). These findings have facilitated an emerging interest in the development of interventions aiming to increase cancer screening uptake for those with SMHD. While this research is still in its infancy, initial examinations of case management (Fujiwara et al., 2021), decision support and navigation (Weinstein et al., 2019), and integrated physical and mental health care service provision models (Xiong et al.,2015; Murphy et al., 2020) have shown positive effects. Although promising, these studies are limited by small sample sizes and lack of longitudinal follow-up; there is a clear need for further research.

To date, most of this research into both the barriers faced by those in accessing cancer screening, and the subsequent interventions to address this disparity in uptake, has been conducted in North America. A recent systematic review conducted by Tuschick and colleagues (2024) reported that just four of the twenty included studies examining barriers to cancer screening for those with SMHD were conducted outside of the USA and Canada. To our knowledge, only one intervention targeting cancer screening uptake for this group has been conducted outside of the USA, in Japan (Fujiwara et al., 2021). This has significant implications in terms of the generalisability of any results, given the vast differences in health organisations and screening policies across the world (Ross et al., 2021).

3.3 Rationale for the Current Study

In Ireland, there is currently no official policy outlining what professionals hold overall responsibility for the physical health of individuals with SMHD (Collins et al., 2021), although community mental health teams (CMHTs) and General Practitioner's (GP's) are the most frequent points of healthcare contact for this patient group (Butler et al., 2020).

Furthermore, to date, no research has been conducted to understand current protocols, procedures and attitudes relating to cancer screening for individuals with SMHD in an Irish context. Addressing this gap in knowledge is an essential first step in reducing the inequity faced by those with SMHD within the Irish health service.

3.4 Objectives of the Current Study

The current qualitative study will aim to explore the culture of cancer screening for individuals with SMHD in community mental health and general practice services in Ireland. More specifically and in accordance with Schein's (1985) definition of culture, this will involve an exploration of the underlying attitudes and beliefs that influence screening practices for people with SMHD within community mental health and general practice services in Ireland.

3.4.1 Context: Cancer Screening Programmes in Ireland

In line with European Union recommendations, there are currently three national cancer screening programmes operating in Ireland that screen for breast, cervical and bowel cancers. BreastCheck invites women aged 50 – 69 years for a mammogram every two years. CervicalCheck is available to women aged 25 – 60 years. Those eligible can arrange to have their cervical screening completed at their GP practice every 3 years (if aged 25 – 29) or every 5 years (if aged 30 -65). BowelScreen is available every two years to men and women aged 60-69 years. They must ensure they are on the register and will be sent a home screening kit to collect a sample and send off for testing. All three screening programmes are free of charge.

3.5 Methods

3.5.1 Study Design

As the current study sought to explore the culture of cancer screening for individuals with SMHD, a qualitative approach was taken to allow for a deeper understanding of participant's experiences, beliefs, and attitudes.

This study adopted a critical realist approach to inform the design, methodology and analysis. This approach proposes that a knowable reality exists, and while observation might enable us to be more confident about what exists, existence itself is not reliant on observation (Sayer, 2000). Unobservable structures and underlying mechanisms cause observable events, and a critical realist approach strives to identify these underlying causal factors at a deep level. Importantly, it also acknowledges the fallibility of our knowledge of the world, as it consists of subjective interpretations that are formed by the context within which a researcher operates (McEvoy & Richards, 2006). This approach aligns well with the aims of this research; to understand the culture of cancer screening, exploring the underlying factors influencing practices at a deep level. This search for causation has been suggested to lead to the development of practical policy recommendations to address social issues (Fletcher, 2017); an outcome hoped for this research.

3.5.2 Participants

The target population for recruitment included: 1) General practitioners (GP's) and practice nurses (PN's) currently practising in general practice services in Ireland; and 2) Psychiatrists and mental health nurses (MHN's) currently working in CMHT's in Ireland.

The recruitment process involved disseminating approved invitations via existing professional networks (e.g. Irish General Practice Nurses Educational Association, UCD School of Medicine Research Network, Community Mental Health Team leads). Given slow

recruitment rates, a snowball sampling method was also used, in that existing participants identified future participants from among their professional circle and referred them to the study. When potential participants contacted the researcher, they were provided with an information sheet and consent form (Appendices A and B).

Regarding sample size, Braun and Clarke (2021) posit that there is no absolute way to estimate or justify sample sizes in reflexive thematic analysis (TA). They have critiqued the idea of data saturation (i.e. the point at which data stops generating new codes or themes) that has dominated qualitative research to date and recommend instead that researchers consider the information richness of their dataset and whether it meets the aims and requirements of the study. In light of these recommendations, a number of factors influenced the research team's decision to complete recruitment. Firstly, by December 2023 at least three representatives from each profession had taken part in the study and it was the belief of the research team that the data gathered to date would permit an in-depth exploration of the research question. Secondly, as this project was being completed as part of a Doctorate degree, time considerations were also taken into mind.

Table 5 presents the demographics of participants that were recruited and took part in the study. The total of 15 participants was comprised of 4 GP's, 3 PN's, 3 Psychiatrists and 5 MHN's. Sixty percent were female. The number of years of clinical experience ranged from 6 – 40 years (M = 18.67, SD = 9.76). All participants worked in services located in urban areas of Ireland.

Table 5: Demographic Characteristics of Participants

Participant	Gender	Profession	Years of Clinical Experience
1	m	GP	17 years
2	f	GP	12 years
3	m	GP	13 years
4	f	GP	13 years
5	m	Psychiatrist	21 years
6	m	MHN	6 years
7	f	MHN	20 years
8	m	MHN	32 years
9	m	MHN	11 years
10	f	MHN	40 years
11	f	Psychiatrist	16 years
12	f	Psychiatrist	15 years
13	f	PN	26 years
14	f	PN	31 years
15	f	PN	7 years

3.5.3 Procedure

Recruitment and data collection took place from November 2022 – December 2023. Semi-structured, individual interviews were conducted with all participants, lasting from 33 to 72 minutes. All interviews were conducted over Zoom to facilitate access to participants across Ireland and to aid convenience for participants. The interview schedule (Appendix C) was developed based on existing literature in the field and was also guided by the Theoretical Domain Framework (TDF; Francis et al., 2012). The TDF is a tool that consolidates 33 theories of behaviour change into 14 construct domains. It has been widely used in research seeking to identify the factors impacting on the uptake of evidence-based practices in healthcare settings, including those that impact on cancer screening uptake within a population with SMHD (Clifton et al., 2016). All interviews were guided by this schedule, however the semi-structured nature granted the researcher flexibility to delve deeper into participant's responses when appropriate. The interview schedule was tested on a member of the research team, which highlighted feedback for the interviewer to incorporate into future

study interviews. The lead researcher (CC), a female psychologist in clinical training with experience in research and clinical interviewing, conducted the interviews. She had no relationship with participants prior to interviews.

3.5.4 Data Analysis

The data were analysed using reflexive TA (Braun & Clarke, 2006, 2019). This method of analysis was selected for a number of reasons including its theoretical flexibility as a method. It is applicable to a wide range of topics and phenomena (Braun & Clarke, 2019). Secondly, a central component of RTA is the acknowledgment of the researcher as an active part of the researcher. This was particularly important to the primary researcher given her role as a psychologist in clinical training, which integrates a high level of reflection on the impact of our own assumptions, beliefs, and values into clinical practice. Lastly, RTA aligns with the critical realist approach in that it enables researchers to gain a rich and nuanced understanding of participant's perceptions, experiences, and meanings, facilitating in-depth exploration of data. Although the TDF guided the initial inquiry by ensuring that a number of behaviour change domains were systematically covered during the interviews, an inductive approach to data analysis was used which allowed for the discovery of unexpected themes that may not fit within the framework. This flexibility was considered crucial for capturing the complexity of the participants' experiences and perspectives on a topic that is relatively understudied.

Interviews conducted via Zoom were audio recorded and transcribed automatically. The researcher verified the accuracy of these transcripts against the audio recordings and then uploaded transcripts to NVivo 14, a qualitative data analysis software. Based on prior research in this area (e.g. Clifton et al., 2016) and on the researcher's experience of conducting the interviews, it was expected that themes would vary according to each participant group, thus the data for each participant group was analysed separately. The data were analysed according to Braun and Clarke's (2006) six steps: 1) Data familiarisation;

2) Generating initial codes; 3) Generating initial themes; 4) Reviewing themes; 5) Defining and naming themes; and 6) Writing up the report.

The researcher began the analytic process by listening to the interviews, verifying the transcripts, re-reading the data and taking note of any initial ideas. The second step involved identifying meaningful segments of text, relevant to the research question, and provisionally labelling them with a brief description and grouping them together for future analysis. Next, the different codes were sorted into potential themes and relevant coded data extracts were collated within the identified theme. Then, candidate themes were checked against the data to assess whether they accurately addressed the research question. Given that codes and themes are generated by a researcher based on their interpretation of the data, there is no expectation that they will be reproduced by a second coder (Byrne, 2022). Instead, a second coder (PD) was used in a reflexive manner, to discuss ideas and explore assumptions and interpretations of the data. As a final step, themes were named and written up into a comprehensive report. The Consolidated Criteria for Reporting Qualitative Research (COREQ; Tong et al., 2007) was used as a reporting framework (Appendix D).

3.5.5 Ethical Approval

The current study received ethical approval from St Vincent's Hospital Group Research Ethics Committee (Ref No: RS22-033) (Appendix E) and an exemption from full ethical review was granted by the UCD Office of Research Ethics (Ref No: HS-LR-22-99-Cullen-Dalton and HS-LR-23-84-Cullen-dAlton) (Appendix F).

3.5.6 Reflexivity

Reflexivity is a crucial ingredient in qualitative research as it highlights the researcher's active role in knowledge production (Berger, 2015). It requires the researcher to be sensitive to the ways in which their assumptions and experience may shape the collection, analysis and interpretation of data throughout the research process (Birks et al., 2014). These

considerations are also in accordance with the COREQ framework. As the primary researcher, I (CC) acknowledge several considerations about myself, my beliefs, attitudes and experiences that potentially influenced this research process, some of which are summarised below.

Key considerations include being Irish and female, my role as a psychologist in clinical training, having no professional experience of cancer screening and holding a strong sense of social justice, particularly for marginalised groups. For example, I frequently reflected on the impact of my position as a psychologist in clinical training working in the public health service. In that work, I view clients' mental health difficulties as stemming from a complex interplay of social, psychological, and biological factors. When interviewing mental health professionals, my experience of working in the mental health system allowed for a mutual understanding of the nature and demands of that work. It's likely that this elicited more honest and in-depth reflections from these participants. However, this may have posed a challenge when interviewing general practitioner professionals. As GP's and PN's are predominantly trained and working within a medical model, at times their beliefs about individuals with SMHD and the nature of their difficulties varied greatly from mine. I found it important to reflect on this and be aware of my reactions in those moments, so that I could remain open, respectful, and curious to their perspective. Without this conscious reflection and effort, there was a risk that participants would not feel comfortable providing more detailed and honest responses.

The reflexive process was supported by keeping a reflective journal and bringing some of these accounts to supervision for discussion.

3.6 Results

3.6.1 Overview of themes

A total of six themes were identified during the thematic analysis of interviews. As evidenced in Figure 2 below, three of these themes were unique to the mental health professional group, two were unique to the general practice professional group and one theme was common across both groups.

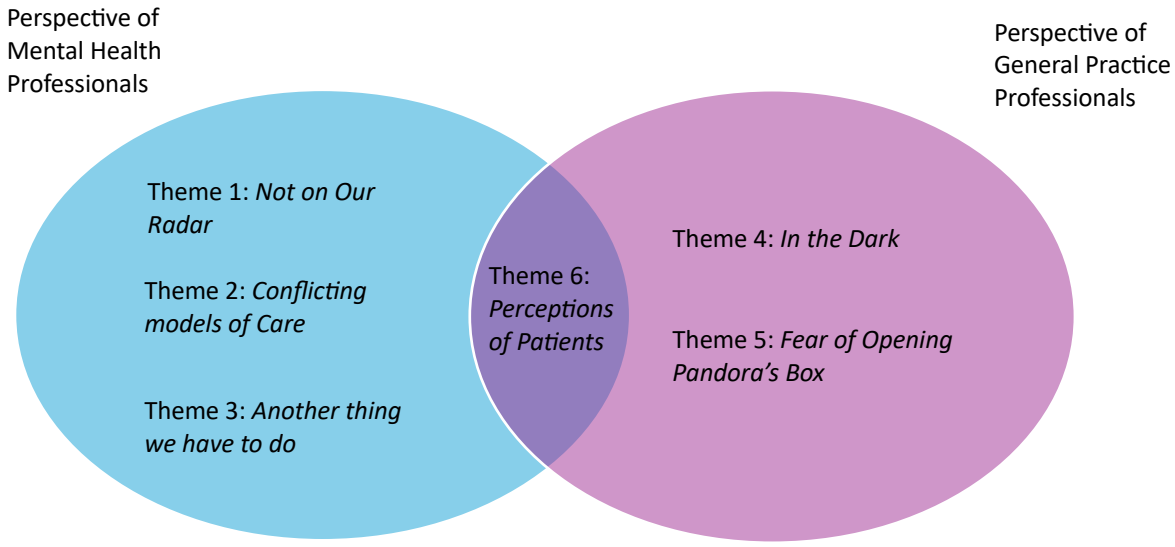

Figure 2. Visual representation of themes identified for each group

To introduce the basic concepts of the themes, Table 6 below provides a brief overview of the characteristics of each theme. A more in-depth description with illustrative quotes from the data will follow.

Table 6: Descriptive overview of themes

Participant Group	Theme	Brief Overview
Mental Health Professionals	*Not on Our Radar*	Limited involvement in cancer screening. Poor knowledge and awareness of cancer screening programmes or the disparity in screening uptake.
Mental Health Professionals	*Models of Care*	The influence of conflicting guiding care principles on how professionals support patients to participate in cancer screening.
Mental Health Professionals	*Another thing we have to do*	Hesitancy to do more with regard cancer screening, partly due to limited resources.
General Practice Professionals	*In the Dark*	Lack of consistent protocols and poor communication leaving GP's and PN's unclear about who is due / overdue for screening.
General Practice Professionals	*Fear of Opening Pandora's Box*	Fear of the potential fallout from decline in mental health of patients and professional ability to manage that.
Mental Health & General Practice Professionals	*Perceptions of Patients*	Attitudes towards this patient group, including stigmatised views, that impact discussing screening.

3.7 Perspective of Mental Health Professionals

3.7.1 Theme 1: Not on Our Radar

The theme **Not on Our Radar** portrays the idea expressed by mental healthcare providers of cancer and cancer screening as something that is not within their scope of attention, consideration or awareness.

Many participants reported having limited knowledge of the national cancer screening programmes generally: what they are, who is eligible for them, or how to access them. Within a professional capacity, there was a sense from participants that it is a topic that is rarely ever considered or spoken about with colleagues or patients.

> *"I'll start off by saying, I wouldn't know screening programmes so I suppose there's a lack of wider knowledge out there. I knew there was breast and cervical maybe, but I suppose it would never come up in my workplace"* – MHN2

> *"This is actually probably one of the first times that I'm even thinking about the topic"* – PSY2

This limited awareness also extends to the disparity faced by individuals with SMHD in terms of cancer screening being one of the leading causes of mortality, and this group being significantly less likely to attend cancer screening than the general population. Some participants acknowledged that these statistics are probably not widely known, while others expressed a sense of denial and questioned the reliability of such reports.

> *"What you said at the beginning about cancer screening being a leading cause of death.. I would guess that most people on the ground don't actually know that"* – PSY2

> *"I'd be really interested to see that study [reporting disparity in cancer screening uptake] because I'm surprised it's that high'* – MHN3

From a physical healthcare point of view, psychiatrists and mental health nurses highlighted that their only focus is on managing the side effects of any psychiatric medication they have prescribed to patients.

> *"As part of the side effects of some of these drugs, they can cause these problems [diabetes, obesity]. So if we feel responsible for causing it, then we're going to monitor it…. Whereas, cancer screening is just another world"* – PSY1

> *"I suppose it [cancer screening] probably gets a short shrift because when we talk about physical health, what everyone is focused on is your antipsychotic making you fat, is your antipsychotic making you diabetic, that is where people's minds are more at. They're not necessarily thinking of cancer"* – PSY2

As a result, prevention and early detection of all other health conditions such as cancer, receive little to no attention within community mental healthcare settings. Participants emphasised clear boundaries that all other medical matters are not their responsibility. Instead, it is their perspective that these fall under the remit of general practice. There was a strong feeling from participants that automatic deferral of physical health concerns to the GP maintains boundaries and avoids roles becoming *"too blurry"* (MHN2).

> *"Normally we'd leave the physical bits and bobs to the GP and hope that they would do it and like I said, most of the time and I don't think I'm alone in this, we wouldn't even think about it. We'd think that's for the GP and that's their remit and we have mental health and probably that's enough actually."* – MHN5

> *"I keep my mental health hat on. Don't get too involved that's what we've been told, or else things get too blurry you know. So go to your GP and I'll document it but that's about it to be honest"* – MHN2

3.7.2 Theme 2: Conflicting Models of Care

This theme aims to capture the influence of the principles that guide care provision within mental health services. It endeavours to describe the conflicting ways in which participants

interpret these principles, and how this may impact on the support professionals could provide to patients engaging in cancer screening.

Participants alluded to the prevailing influence of care models on how they would consider supporting a patient in accessing cancer screening. One MHN with many years of experience, described the conflict she experiences as models of service provision in Ireland have moved away from paternalistic care towards a recovery model framework that promotes the independence of patients.

> *"You can become conflicted because years ago we were doing that you know, going to places with service users and now the recovery has come in and we're encouraged I suppose to encourage our service users to do everything on their own"* – MHN5

This MHN acknowledged that this is not always conducive to best outcomes for patients and stated that she is willing to exercise flexibility with these guidelines, and ultimately support patients in whatever manner she can.

> *"At the end of the day, I suppose you do what you have to do. Like I'd go with them for a first assessment or whatever they were going for"* – MHN5

For most other clinicians, there was an overarching acceptance of the recovery ethos into daily practice, that appeared to be an almost unconscious, unquestioned process. For them, this ethos involves promoting patients to do things and make decisions for themselves, regardless of the context.

> *"It's kind of getting the patient to take responsibility as well by going to the GP so there's a little bit of that as well. Anything they can do themselves, you'll try to get them to do themselves"* – MHN3

> *"I think the onus has to be on the individual to take some personal responsibility for themselves so I'm not sure if you can bring a step in there [to bridge the gap between cancer screening education and attendance].. The way it has gone with the whole*

recovery ethos and accountability you know kind of taking personal responsibility I think it's up to the person too whether or not they want to do it." – MHN4

3.7.3 Theme 3: Another thing we have to do

This theme strives to capture the predicament many participants alluded to in terms of wanting to do more to increase cancer screening uptake for their patients, but ultimately feeling that the presence of various systemic factors inhibits them.

Participants described an intent to do more with regard to the promotion of cancer screening with their patients. This intent appeared to be largely driven by the increased awareness of cancer related disparity during our discussions, and subsequent feelings of sadness and guilt as they reflected on potential past *"missed opportunities"* (PSY2).

"Thanks for bringing it up.. as I said, I had never thought about it and now that you put the idea in my head, I'll be much more aware of it and wouldn't be afraid to ask somebody" – MHN5

In exploring what more could be done on their part, there was a sense of hesitation expressed by participants. While many agreed to leave information pamphlets and posters in clinical waiting rooms and possibly mention it to patients, there was a sense of reluctance to go beyond that.

"It's just a matter of perhaps some pamphlets in the clinics and just as easy either hand it to the person when you visit them or the whole service could just send it out to people if they wanted" – MHN3

"I don't mind mentioning it in conversation but actually being actively involved in it, I don't think that is within our scope of practice. You know, where does the door shut then? Absolutely, I'll give them leaflets or whatever and advise them but I'm not going to chase up." – MHN3

In delving deeper, participants disclosed various barriers to their ability to actively promote and encourage cancer screening. There was an overarching sense of feeling burdened, working within pressured services where priorities constantly change and feeling unskilled to be providing physical health care or advice to patients.

> *"I suppose if I'm being radically honest, this is another thing that we have to do… If I say it to our nurses 'would you do this' sometimes I get a response of 'oh here's another thing they're asking me to do'"* – PSY2

> "*I don't feel confident. When you're in psychiatry you do get de-skilled in terms of physical health… professional insecurity, I might feel a bit ill-equipped at the moment to bring these things up you know, I have a bit of an information deficit and I need to know a bit more."* – PSY1

Ultimately, many participants felt that this could warrant a separate role, such as the introduction of a physical health nurse to the community mental health team. The idea being that that individual's scope of practice would lay purely in the promotion and monitoring of physical health. A number of participants referenced how this has been implemented effectively in other services, both abroad and in Ireland.

> *"I probably would put in a role of a clinical nurse specialist for physical health. You know, kind of monitoring the physical health of patients and still have ever member of the MDT with the role of doing the education piece, but you also have somebody full-time who is looking at physical health"* – MHN1

3.8 Perspective of General Practice Professionals

3.8.1 Theme 4: In the Dark

GP's and PN's described a lack of consistent protocols for identifying patients eligible for screening, knowing whether they have received an invite for screening and if they have taken part, frequently leaving them **in the dark.**

All GP and PN participants acknowledged cervical screening as the only screening programme they are actively involved with and responsible for. For a small number of participants, this has led to the development of robust clinic specific protocols for identifying and inviting eligible patients to attend for cervical screening.

> *"I personally feel it's a really important service so we're very proactive about getting people registered, getting a plan into their files and then when we see they are overdue smears, they get three text reminders, a phone call and then they get a letter"* - GP4

For other general practice clinicians, such identification protocols or systems do not exist. As a result, GP's and PN's reported that they are reliant on opportunistically catching patients when they attend for other health related matters.

> *"I think our practice, or all practices are limited because we don't actually know who is due or isn't due unless they're in the practice, unless they're actually coming into me and I ask them, are you due a smear test? I wouldn't have a proper recall system where I can see all of those women"* - PN2

> "*There's no tracking. So if they're not being tracked, then you know, the lady who comes in with schizophrenia, you know has she even been asked if she's sexually active?"* – GP3

With regard to bowel and breast cancer screening, participants alluded to that being a very different entity, one that is managed by the National Screening Service with little to no integration with their daily clinical practice.

> *"As regards breast cancer, we pretty much rely on the national screening program to call and recall people…with bowel screening, I would say we don't really get involved in that at all"* - PN3

Participants expressed a sense of being left in the dark or feeling helpless, often not knowing if patients are even registered on national screening systems, if they have missed their screening or how to link them in with screening services.

> *"How do we reach them? Well, we currently don't have a way of linking a person into a national screening program if we know they haven't attended, other than telling them please go and do it. There's no back road in for us."*- GP1

> *"We don't really have communication for those who opted out or never attended mammogram so we don't know what's going on. We certainly receive information when they have attended and had their mammogram, particularly when something is detected but we certainly don't get communication saying they didn't attend"* – GP4

These struggles experienced by GP's and PN's are further compounded by the demanding nature of general practice, limited resources, and non-prioritisation of cancer screening within the wider healthcare system.

> *"I suppose general practice nowadays is just so busy and so manic, and you're trying to keep all these balls in the air to try and remember to advise people to register or come or follow up or whatever it might be for cancer screening*" - PN3

> *"I hate to say but time is tight, we are firefighters with the kids, the coughs the colds the crisis presentations that need to be seen day to day, so cancer screening gets put down the list until the government decide to prioritise"* – GP4

3.8.2 Theme 5: Fear of Opening Pandora's Box

The theme ***Fear of Opening Pandora's Box*** speaks to the cautious approach adopted by GP's and PN's when discussing or conducting cancer screening with patients with SMHD, largely due to fears of causing upset, rupturing the therapeutic relationship, and their perceived ability to manage any potential fallout.

GP and PN participants acknowledged the traumatic life experiences many of their patients with SMHD have been through. As a result, GP's and PN's alluded to the importance of building a good relationship with these patients as the first and foremost consideration, before any discussion about cancer screening can be brought up.

> *"People with serious mental health issues have often had dreadful life experiences. This is not the time to be going in with strong health promotion on the first interview. You're going to be pretty gentle at the beginning. You're going to strike a rapport and you spend a bit more time doing that"* - GP1

However, participants also reported that the establishment of trusting relationships does not always facilitate open discussions about cancer screening. One GP expressed the internal dilemma he faces when considering how patients will respond to his recommendation of cancer screening, with worries that he will lose their engagement.

> *"I have a lower threshold for taking an opportunity when somebody with a significant mental health issue presents. I have a few quite severe schizophrenic patients that have built a level of trust with me but are still difficult to engage and it's always a fine line between, will they actually do what I want? Will they comply, or will they jack-knife at some point and not follow up? You do open a Pandora's box"* - GP3

For others, PN's in particular, the fear of bringing up the topic of cancer screening is more related to their perceived inability to manage any potential negative reaction that might be evoked in patients. When faced with these kinds of situations, PN's expressed a fear of saying or doing the wrong thing and the wider impact that may have on the patient.

> *"It's hard enough to manage them in the time frame that you have to see them for whatever they've come in for. To bring another topic in [like screening] would start a whole cascade of manic behaviour. Sometimes you'd go, am I ready for that? And then go, yeah no don't... I'm not getting involved here for fear, Oh my God, I don't undo somebody else's therapeutic role"* -PN1

> *"I would say that overall, it can sometimes become very difficult if they're uncontrolled, if they're unpredictable, sometimes when they do have a mental breakdown and we have that in the clinic, it can be very hard, dealing with them because we're not specifically skilled like the GPs are."* – PN2

Nevertheless, the importance of screening and needing to adapt the approach to both discussing cancer screening and carrying out cervical screening was highlighted by participants.

> "*So I would be very careful to read body languages and also to adapt. I would be more conscious about my body language to not come over as aggressive or forceful"- PN2*

A minority of GP's and PN's expressed a level of confidence in working with this patient group, which they attributed to their many years of experience and close physical proximity to mental health services for additional support.

> *"I don't feel like I'm ill equipped because I think I have enough experience to be able to do it now. And I also have my colleagues down the corridor [community mental health] if I'm really coming to a stumbling block or I'm not quite sure what to do, I can go and get some advice from them. But not everybody is as lucky as that"* – PN3

3.9 Shared Perspectives

3.9.1 Theme 6: Perceptions of Patients

Perceptions of Patients was the only theme common to both participant groups. It aims to capture the impression mental healthcare and general practice professionals have of people with SMHD and how this might impact on both their professional approach and patient's participation in cancer screening programmes.

To begin, there was a wide acknowledgement from participants that patients with SMHD cannot always be grouped together. Participants reported that patients and their needs differ from individual to individual.

> *"I suppose everyone is individual as well. You'll have patients that are completely on top of things as well that would be going for their screening"* - MHN2

Some participants expressed the view that not all SMHD's (i.e. psychosis, bipolar disorder and major depression) could be viewed equally in terms of their impact on the individual's engagement with cancer screening.

> *"So I think there's three groups in there. There's bipolar, there's major depression and there's schizophrenia, and for some reason they're called serious mental illness which is true, but they're very different starting points, you know"* – PSY1

When it comes to bringing up the topic of cancer screening with patients, both mental health and general practice professionals highlighted the importance of timing. They described the current state of patient's mental health, physical health and social circumstances as key factors in deciphering whether it's appropriate to promote screening.

> *"If they're in an acute depressive phase or if they're manic that day, it's not the appropriate time to address this [screening]. If they're having an exacerbation of their illness, it would not be a good idea. Or if they're acutely unwell, if they happen to have a really bad chest infection or something, that's not the time to be talking to people about things like that* – PN3

Both groups of participants spoke about paranoia, anxiety and lack of motivation, symptoms they associated with this patient group, as perceived barriers to patients attending cancer screening.

> *"I guess somebody's in a really bad place and you know, chronic severe depression. They have no interest, you know. I mean to get out of bed sometimes is enough, you know"* – GP3

> *"I suppose this is quite rare, but I have some patients with a psychotic level of denial even around physical illness thinking no that's not possible, that won't happen to me and it can be very fixed and very concrete about it"* – PSY2

There was also an idea expressed by participants that this patient group are juggling a lot in their lives, from mental health struggles, to attending various appointments, managing crises and difficult social circumstances. They reported that this has an impact on patients' capacity to manage any additional demands. Participants felt this leads to non-prioritisation of physical health, avoidance of screening invitation letters and not attending appointments.

> *"If you're grappling with your mental health difficulties, I'm sure there is a pile of letters building up as they come through the letterbox"* – PSY3

> *"A lot of the time, they're dealing with immediate crises or struggles. So that ability to think ahead, to be motivated, to prioritise something like that just might not be there"* – PN1

3.10 Discussion

This study is the first to explore the culture of cancer screening for individuals with SMHD within community mental health and general practice services in Ireland. As a reminder, within this study culture refers to the beliefs and attitudes that influence screening practices and behaviours (Schein, 1985). A total of fifteen participants including psychiatrists, mental health nurses, GP's and PN's were interviewed. The results suggest that screening for this patient group may be an overlooked topic, with no population specific procedures in place to support those with SMHD to learn about or access cancer screening. The results also shed light on some of the underlying factors contributing to the under-prioritisation of cancer screening for this group and offer important considerations for potential next steps to address this inequity.

Results of this study highlight the limited involvement of mental health professionals in the promotion of cancer screening for individuals with SMHD. In keeping with previous research (Clifton et al., 2016; Howard & Gamble, 2011), mental health professionals described a poor knowledge of national cancer screening programmes. Furthermore, participants in the current study also reported a lack of awareness of the disparity faced by those with SMHD with regard to cancer screening uptake and cancer mortality rates compared to the general population. Taken together, these gaps in knowledge likely reinforce the non-prioritisation of cancer screening in their work with this patient group. These findings are consistent with previous reports of a lack of training for mental health nurses with regard to physical health care (Howard & Gamble, 2011), ambivalence among mental health nurses in terms of promoting physical health (Happell et al., 2012) and suggestions that physical health is generally under prioritised in mental health care (Gray & Brown, 2017). The non-involvement of mental health professionals in cancer screening promotion may represent a missed opportunity, particularly given the frequency with which these patients attend their community mental health teams and how this could lend itself to the

development of strong therapeutic relationships that allow for open discussions about screening. In fact, Garcia-Alcaraz and colleagues (2023) reported that patients expressed a preference for cancer screening interventions to be led by mental health providers.

Comments from participants working in general practice suggested difficulties in identifying patients overdue for any of the three screenings, due to a lack of clinic protocol or poor information sharing with screening programmes. Such fragmentation of services within healthcare systems is not unique to the Irish system and has been documented as a barrier to screening uptake in previous research (Flores et al., 2019). Without clear protocols and procedures that allow for the identification of patients eligible or overdue for screening, and communication from national screening programmes about their non-attendance, opportunities for GP's and PN's to encourage and follow-up with patients are non-existent.

Despite both participant groups expressing a desire to do more when it comes to increasing cancer screening uptake for those with SMHD, they also acknowledged the demanding nature of their respective services and the limited resources available to them as additional factors that hinder their ability to promote and follow up on patient participation in cancer screening. Time, pressurised services with high workloads and the competing needs of complex cases are frequently cited as barriers to recommending screening with patients, not only those with mental health needs but also within the general population too (Leahy et al., 2021; Rubio-Valera et al., 2014).

The perceptions mental health and general practice professionals hold of patients with SMHD emerged as another important underlying factor that may contribute to the apparent lack of cancer screening prioritisation. For example, in the current study some participants expressed a view that of this patient group as not prioritising their physical health, while others reported that symptoms of paranoia, anxiety and apathy not only pose a barrier to individuals taking part in screening, but may also prevent professionals from bringing the topic up for discussion. Previous research has noted the presence of stigma

among healthcare professionals towards individuals with SMHD and highlighted the negative impact it has on patient engagement with cancer screening and treatment too (D'Alton et al., 2021; Leahy et al., 2023). Furthermore, comments from some general practice professionals highlighted a lack of confidence and a level of anxiety in working with this patient group. Such fears have been associated with poor mental health knowledge and training, leading to negative attitudes, lower quality of care and poorer patient outcomes (Knaak et al., 2017). Deficiencies in the healthcare training tailored to manage mental illnesses can only be corrected with improved mental health education (Riffel & Chen, 2020).

The influence of the recovery-oriented model of care that guides mental health services in Ireland was a novel and interesting finding that emerged. Although recovery is a central focus in national health policy in many countries, there is great variability in how each health service interprets and implements the concept (Cruwys et al., 2020; Swords & Houston, 2020). In the current study, it appeared that mental health professionals viewed recovery as including the promotion of personal responsibility and independence. While this represents progress from the antiquated paternalistic approach of the past, it may bring some inadvertent challenges specific to cancer screening participation. Practical issues, such as difficulties with scheduling and attending screening appointments, have been well documented as barriers to screening uptake for those with SMHD (Leahy et al., 2021; Tuschick et al., 2024). Thus, it is important that careful consideration is given to the meaning of recovery and whether it facilitates or disables patients' capacity to engage with physical health screenings, such as cancer. For example, individualised support in the form of arranging transport to screening appointments and regular check-in's to follow-up on screening progress have been identified as essential components to any intervention aiming to improve screening uptake (Garcia-Alcaraz et al., 2023).

3.11 Strengths, limitations, and future research directions

Significant efforts were made to maximise the rigour and credibility of this research. These included regular reflection and acknowledgment of the researcher's role throughout the research process. Such reflections were documented in a reflective diary and brought for discussion with the supervisor. In addition, the study was reported in accordance with COREQ framework. To the author's knowledge, this is the first study aiming to explore the cancer screening for those with SMHD within an Irish context. Although this may limit the generalisability of results, it provides much needed context specific information that can inform recommendations relevant to the Irish health system.

Most notably, this study was limited by the lack of representation from individuals with SMHD. Patient and public involvement (PPI) in research is increasingly recognised as best practice, leading to improved validity and relevance of research findings (Faulkner & Chambers, 2021; Gray-Burrows et al., 2018). Despite efforts made by the research team to involve individuals with SMHD in an advisory capacity during study development and to recruit as participants in the study to share their views on cancer screening, we were unsuccessful to do so in the timeframe available to the research team. Individuals with SMHD have often experienced stigma and discrimination within healthcare systems and can struggle to engage with treatment (Dixon et al., 2016; Tranberg et al., 2023). In light of this, and combining it with the double stigma of cancer, it is not surprising that engaging this group in research presents a challenge. The current research team are conducting a number of additional projects that explore the disparity faced by those with SMHD at various points along the cancer trajectory. In conjunction with a number of mental health advocacy groups, they are actively developing a PPI panel to ensure that the voice of this marginalised group can be included with respect and sensitivity. Understanding the perspectives and needs of those with SMHD is of utmost importance before more specific interventions targeting cancer screening at the patient level can be recommended.

Finally, although not intended in the design of this study, all participants in this study reported working in mental health and general practice services situated in urban areas. We know that modes of care delivery in urban areas differ greatly from the modes used in more rural, less populated regions (Teljeur & Kelly, 2008). Future research should seek to include the perspectives of those working in rural areas, as cancer screening practices and the mechanisms influencing them might vary.

3.12 Clinical and Policy Implications

As this research presents an in-depth understanding from the perspective of a relatively small number of professionals in Ireland, it's important to recognise that we are not inferring generalisability nationwide as a result. Potential future research may include a national audit of cancer screening as it applies to individuals with SMHD. Nonetheless, results of the current study allow us to make some tentative suggestions for future clinical and policy work.

Importantly, this research suggests cancer screening for individuals with SMHD may be an overlooked topic within clinical practice. As an immediate action, there is a need to educate mental health and general practice professionals on the inequities in cancer screening and cancer mortality faced by this patient group, as well as on the details of national cancer screening programmes. It is hoped that this will not only increase their awareness, but that it will also increase their confidence in terms of promoting physical health measures for those with SMHD. Given the influence of stigmatising attitudes on cancer screening promotion and uptake, we also recommend more education surrounding mental illness for healthcare professionals (D'Alton et al., 2021). Professional healthcare training programmes should also consider incorporating a greater emphasis on mental health education going forward (Riffel & Chen, 2020).

Culture is something that is taught to employees, with beliefs and attitudes often filtering down from leadership and manifesting into behaviours and practices (Martin, 2006). In Ireland currently, there is no policy clarifying who holds responsibility for monitoring, detecting and managing the physical health of individuals with SMHD (Collins et al., 2021). It's plausible that this ambiguity at a leadership and policy level is linked to the lack of awareness, knowledge and prioritisation of cancer screening for those with SMHD that was identified by participants in the current study. Policymakers and governmental bodies need to prioritise addressing the disparity in cancer screening for individuals with SMHD. Notably, this study adds to existing literature identifying resource issues as a barrier to healthcare providers promoting cancer screening to patients with SMHD (Butler et al., 2020). Thus, when developing and implementing new policies and strategies, it's critical that adequate resources are in place.

3.13 Conclusion

This qualitative study is the first to explore the culture of cancer screening within community mental health and general practice services in Ireland. Results suggest that generally, cancer screening is under-prioritised within these clinical settings for individuals with SMHD. This appears to be influenced by a variety of underlying attitudes such as stigma towards SMHD, the recovery model of care, lack of knowledge and awareness of the disparities facing this group and limited resources. Although these findings are based on the views of a relatively small number of participants and are not intended to be generalised nationally or internationally, they highlight important areas for future clinical, research and policy focus. Further research involving individuals with SMHD is required before targeted interventions at a patient-level can be recommended. Furthermore, there is a clear need for urgent action from leadership, policy makers and governmental bodies to address cancer screening for this

patient group through improved screening and mental health education, increased resources and policy development to clarify roles and responsibilities relating to the physical health care of individuals with SMHD.

Chapter Four - Discussion

4.1 Overview of Thesis Rationale, Aims and Objectives

There is clear evidence to suggest that individuals with SMHD are significantly more likely to die from cancer, than those without SMHD (Grassi & Riba, 2021b; Launders et al., 2022; Plana-Ripoll et al., 2019). This is despite there being no conclusive evidence to suggest that a difference in disease incidence exists between the two groups (Anmella et al., 2021; Launders et al., 2022). While various factors might contribute to this increased risk of cancer related mortality, such as inequitable care and the high prevalence of comorbid physical illnesses, one important and potentially modifiable factor relates to the reduced uptake of cancer screening within this patient population (Ross et al., 2021). This is thought to lead to later stage and metastasised disease at diagnosis, lending to poorer outcomes (Charlesworth et al., 2023). While factors at a patient-, provider- and systems- level have been proposed to account for lower screening participation, much of this research has been conducted within a North American context (Tuschick et al., 2024), restricting its generalisability to health services and cultural contexts elsewhere. Furthermore, in order to address the disparities faced by those with SMHD in terms of screening uptake, there is a clear need to assess the evidence available for interventions targeting this issue. Thus, this thesis aimed to contribute to the international literature focused on understanding and addressing reduced cancer screening uptake for individuals with SMHD. It also aimed to contribute specifically to understanding within an Irish context, where there is currently very little research available.

Specifically, this thesis aimed to meet the following two objectives:

1. To identify and synthesise the existing empirical evidence on interventions aimed at improving cancer screening uptake, knowledge, and attitudes among individuals with SMHD.

2. To explore the culture of cancer screening for individuals with SMHD in community mental health and general practice services in Ireland. More specifically and in accordance with Schein's (1985) definition of culture, this involved an exploration of the underlying attitudes and beliefs that influence screening practices in community mental health and general practice services in Ireland.

4.2 Summary of Key Findings

Chapter two systematically reviewed the available empirical evidence on interventions aimed at improving cancer screening uptake, knowledge, and attitudes among individuals with SMHD. Results identified only six studies, highlighting the considerably limited research on this topic. The included studies were grouped into two categories: 1) experimental examinations of interventions designed to target a specific cancer screening type; and 2) observational examinations of the association between models of care provision and uptake of various cancer screenings. Four common components were identified across the interventions including: education, patient navigation, supported decision-making and integrated physical and mental health care services. Each intervention comprised at least one of these elements, while some comprised several of them. Although interventions showed promising results in terms of increasing cancer screening uptake, knowledge and attitudes, many of the studies were limited by small sample sizes, lack of comparison groups and absence of longitudinal data. Furthermore, the narrative synthesis highlighted vast heterogeneity in terms of the types of interventions studied, cancer screening types targeted, and type of methodologies and analyses used. Taken together, caution is warranted in concluding the superiority of any one intervention and the need for larger, more rigorous, and longitudinal investigations of interventions is needed.

The second study, described in chapter three, sought to qualitatively explore the culture of cancer screening for people with SMHD within community mental health and general practice services in Ireland. A total of 15 participants were interviewed, consisting of psychiatrists and mental health nurses working in community mental health teams (CMHTs) and GP's and practice nurses working in general practice. It is important to note that the results of this study are based on a relatively small sample of professionals and are not suggested to be representative of all CMHTs and general practice services in Ireland. Nonetheless, results reported a lack of population specific procedures in place to support those with SMHD to learn about or access cancer screening. Furthermore, analysis revealed that factors such as mental illness stigma, interpretation of the recovery model of care, lack of awareness about cancer-related disparities for those with SMHD, poor understanding of cancer screening programmes and limited resources, may contribute to the apparent under-prioritisation of cancer screening for individuals with SMHD in these services. While much of these findings provide support for other international reports, the influence of the recovery model of care offers a new consideration.

4.3 Implications for theory, practice, policy and future research

Overall, this thesis highlights cancer screening for individuals with SMHD as an under-prioritised topic within clinical and research settings. The systematic review presented in chapter 2 outlined a very limited evidence base informing the use of interventions to increase cancer screening uptake, leaving policymakers and clinicians with limited choice in considering how to address these inequities. More specifically within an Irish context, the qualitative study reported that factors such as stigma, the recovery model of care, lack of awareness about disparities in cancer screening and limited resources may contribute toward a lack of focused efforts to ensure those with SMHD are participating in screening.

Implications of these findings in terms of theory, practice, research and policy are addressed below.

Results from this thesis align with previous literature in highlighting that mental illness stigma among healthcare providers may contribute to inequities in cancer screening and care for those with SMHD (Irwin et al., 2014). Moreover, the double stigma of both SMHD and cancer, adds an additional layer of complexity (Howard et al., 2010) and may be one of leading reasons for the paucity of evidence-based interventions in the literature and limited focused clinical efforts aimed at supporting those with SMHD to engage with cancer screening. Such a focus on mental health symptoms and lack of prioritisation of physical health of those with SMHD could be considered diagnostic overshadowing, a phenomenon that has been highlighted in previous research looking at physical health inequities for this group (Cunningham et al., 2015). Furthermore, it is also plausible that the difficulties described in relation to PPI for this thesis is also linked to the stigma experienced by this group. In line with previous research, we echo recommendations for more education concerning mental illness for healthcare professionals (D'Alton et al., 2021) and suggest that healthcare training programmes consider incorporating a greater emphasis on mental health education moving forward (Riffel & Chen, 2020). Notably, none of the identified interventions discussed in chapter 2 detailed measures to address stigma among healthcare providers. This is an important component that future interventions may wish to consider. Finally, given that other converging forms of stigma, such as gender, social economic status and ethnicity (otherwise known as intersectionality) have been shown to further reduce screening participation rates in SMHD (Kerrison et al., 2023), these groups may require additional attention to understand and address screening disparities.

Findings of this thesis also have implications for how recovery-oriented models of care are conceptualised both in the Irish health system and internationally. While the core principles of the recovery model as defined in Ireland, including empowerment and self-

determination (HSE, 2018), represent an important shift from the outdated and paternalistic approach, it is important that adequate attention is given to its conceptualisation and implementation. Results of the qualitative study in chapter 3 discuss how the interpretation and implementation of this model may cause a further barrier to screening participation for those with SMHD. For example, interpretation of the recovery-model as 'promoting personal responsibility' as found in our study, can mean that individuals with SMHD are left to make a decision about, and arrange screening on their own. Considering that cognitive and practical difficulties, such as remembering information and arranging transport, have already been identified as challenges to screening participation (Irwin et al., 2014), this may unintentionally reinforce those barriers. Examination of the components of promising interventions in chapter 2 also provide initial evidence for the use of patient navigation and supported decision making in increasing screening uptake. Thus, both policy makers and healthcare providers need to remain mindful of the impact of models of care and attune to the specific needs of individuals with SMHD regarding cancer screening. This novel finding also makes a noteworthy and new contribution to Irwin et al (2014) model identifying various factors at patient, provider and system levels that impact screening participation.

At a broader level, results of this thesis highlight an outstanding question: who assumes responsibility for the physical health care of patients with SMHD? Half of the interventions discussed in the systematic review involved either a designated professional to support participants with SMHD to participate in cancer screening; the other half highlighted the integration of physical and mental health care into one. Currently, Ireland does not have a policy stating who should take overall responsibility for the physical health, including the promotion of cancer screening, to patients with SMHD (Collins et al., 2021). Such ambiguity about roles has been documented in other international settings and is thought to be a source of confusion for professionals and patients, and ultimately leads to these patients falling through the cracks in terms of physical healthcare (Butler et al., 2020; NHS, 2024).

While there is a clear need and well documented evidence for better integration and sharing of information between primary care, mental health and cancer screening services, it is also necessary that clinical accountability and responsibility are established for physical health care of these patients. Although there is a movement among policy makers to include mental health professionals in the general monitoring of the physical health of their patients, our study adds to the literature identifying resource issues as a significant barrier to this (Butler et al., 2020). There is an urgent need for policymakers and governmental bodies to consider potential solutions to this and ensure that the adequate resources are in place to address the inequities in physical care faced by those with SMHD, including cancer screening. Suggestions from participants in study two included embedding a physical health nurse within each CMHT for example. Although there appears to be little research examining the efficacy of such a pathway, this might be a promising avenue for future researchers and policymakers to explore. This thesis provides sufficient data to suggest a national evaluation or pilot of such a care pathway.

4.5 Strengths and Limitation

As the strengths and limitations of each study are documented in chapters 2 and 3 respectively, this section seeks to capture the overarching strengths and limitations to the thesis as an overall piece.

A key strength of this thesis is its emphasis on understanding and addressing a topic that is under-researched and under-prioritised. The updated systematic review was rigorous and systematic in its approach, providing policymakers and clinicians with an up-to-date synthesis and critical appraisal of existing evidence for interventions aimed at increasing cancer screening uptake for those with SMHD. The qualitative study is the first to explore cancer screening practices and attitudes within an Irish context, and the

design of the study allowed for the development of in-depth and rich data. The research team consulted with colleagues at the Irish National Cancer Control Programme throughout the research process, to ensure that results would be meaningful and relevant. As a result, this research makes a significant and novel contribution to international literature and theory, while also offering important considerations for practice and policy specific to the Irish context.

The most notable limitation of this thesis is the lack of patient input into both the conceptualisation and design of the systematic review and qualitative study, and as participants in the qualitative study. Although the research team went to great efforts in contacting PPI organisations, receiving ethical approval to include patients and orchestrating recruitment drives with colleagues, these attempts were unsuccessful. Due to delays in obtaining ethical approval, little success in recruiting patients and the fact this project was being completed as part of a Doctorate with associated time constraints, a decision was made to stop recruitment. However, as noted in Chapter 3, this is an important goal in future research and the research team are actively developing a PPI panel to support future research in the area of cancer and SMHD.

The lack of a universally accepted definition of SMHD has been acknowledged as a major methodological flaw in research on cancer screening and applies to this study also. For example, a meta-analysis synthesising the effect of pre-existing SMHD on cancer stage at diagnosis found that varying definitions of SMHD influenced effect sizes (Davis et al., 2020). Such variation in conceptualisations could mean that the results of our systematic review were limited based on the specific definition we adhered to. Furthermore, the applicability of our findings in the qualitative study may not extend to those with other mental health needs such as anxiety disorders, that are sometimes encapsulated in other definitions of SMHD. Despite this, the fact that this thesis provided and justified a definition of SMHD from the outset is also a strength, given that it is not common practice. For

instance, a content analysis of 788 studies that characterised participants as having 'SMI' found that only 15% of these studies actually defined the term (Gonzales et al., 2022).

4.6 Conclusion

This thesis comprises two independent pieces of research: a systematic review synthesising the available empirical evidence for interventions aimed at increasing cancer screening uptake, knowledge, and attitudes for individuals with SMHD; and a qualitative study exploring the culture of cancer screening for individuals with SMHD within mental health and general practice services in Ireland. Results highlight this as an under prioritised topic a small evidence base to support the use of targeted interventions to increase screening uptake. Within an Irish context, findings suggest that stigma, attitudes towards the recovery model of care, limited awareness of screening and the related disparities faced by those with SMHD may be among some of the factors contributing to the lack of focused effort addressing screening for those with SMHD. Taken together, the results of this thesis offer a meaningful contribution to the international literature and theory, while also outlining potential next steps for future research, practice and policy in Ireland.

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Appendices

Appendix A: Participant Information Sheet

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PARTICIPANT INFORMATION SHEET

STUDY TITLE: The Culture of Cancer Screening for those with Significant Mental Health Difficulties: A Patient and Healthcare Provider Perspective

NAME OF PRINCIPAL INVESTIGATOR: Dr. Paul D'Alton, Associate Professor, School of Psychology, UCD.

You are being invited to participate in a research study. Thank you for taking time to read this information leaflet.

WHAT IS THE PURPOSE OF THIS STUDY?

Research suggests that individuals with significant mental health difficulties (i.e. major depression, bipolar disorder and schizophrenia) are less likely to take part in routine cancer screening programs, leading to later diagnosis and poorer outcomes. This study aims to understand the culture (beliefs, behaviours, barriers and facilitators) surrounding cancer screening for this group of individuals from a patient and healthcare provider perspective.

WHY HAVE I BEEN ASKED TO TAKE PART?

You have been invited to take part in this research because:

- You are currently practicing as either (a.) a mental health professional or (b.) a GP or practice nurse in Ireland.
- You are consenting and able to participate in English.

WHAT WILL HAPPEN IF I VOLUNTEER?

Your participation is entirely voluntary. If you initially decide to take part, you can change your mind at any time without difficulty. This will not impact any current or future relationship you may have with UCD.

If you agree to participate, you will be requested to:

- Read a consent form and review it with a member of the research team via Zoom. This will give you an opportunity to seek any clarification you need about the study. If you consent to take part, the member of the research team will fill out the consent form on your behalf.

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- Complete an individual interview with a member of the research team. The interview will last approximately 45mins and will take place over Zoom. During this interview, you will be asked to share your thoughts and experience of promoting or conducting cancer screening among individuals with significant mental health difficulties.
- With your consent, Zoom will automatically transcribe the interview. To ensure the transcription is accurate, the interview will also be recorded. You will have the option to turn your camera off so that only audio will be recorded, or keep it on so that both audio and video will be recorded.

WHAT WILL HAPPEN TO MY DATA?

Zoom generated transcripts and recordings will be saved directly to the researcher's computer in a password protected file. Immediately following the interview, the transcript will be reviewed against the recording by the researcher to ensure accuracy and the recording will then be deleted. All identifying information in the transcripts will be redacted, and transcripts will be uploaded to an encrypted site with original copies deleted from the computer. Results of this study will be presented in a thesis and submitted for publication in scientific journals. You will not be identifiable in these documents. As per UCD guidelines, the transcripts will be securely stored for a period of 10 years before being securely disposed of.

WHO WILL HAVE ACCESS TO MY DATA?

Only members of the research team will have access to your data.

ARE THERE ANY BENEFITS FROM MY PARTICIPATION?

You will not benefit directly from taking part in this study but the results of this research may contribute to improving access to cancer screening programs for individuals with significant mental health difficulties.

ARE THERE ANY RISKS INVOLVED IN PARTICIPATING?

There is minimal risk associated with this study. It is possible that you may become uncomfortable while reflecting on your experiences during the interview. Should this happen, you may choose to take a break, decline to answer particular questions or stop the interview at any time you wish.

WHAT HAPPENS IF I DO NOT AGREE TO PARTICIPATE?

Should you choose not to participate in this study, it will not impact any current or future relationship you may have with UCD or St Vincent's University Hospital.

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CONFIDENTIALITY

Your identity will remain confidential. A study number will identify you. Your name will not be published or identifiable in any presentations or papers, or disclosed to anyone.

WHO IS ORGANISING AND FUNDING THIS RESEARCH?

This study is being organised by St. Vincent's University Hospital and University College Dublin.

HAS THIS STUDY BEEN REVIEWED BY AN ETHICS COMMITTEE?

The UCD Ethics Committee have reviewed and approved this study.

CONTACT DETAILS

Should you have any questions regarding the research now, or at a later date, please do not hesitate to contact the researcher or her supervisor via the information below.

Researcher: Clare Cullen **E-mail:** clare.cullen@ucdconnect.ie

Supervisor: Dr Paul D'Alton **E-mail:** paul.dalton@svgh.ie

Appendix B: Participant Consent Form

UCD School of Psychology
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Áras John Henry Newman
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www.ucd.ie/psychology

PARTICIPANT CONSENT FORM

STUDY TITLE: The Culture of Cancer Screening for those with Significant Mental Health Difficulties: A Patient and Healthcare Provider Perspective

PRINCIPAL INVESTIGATOR: Dr. Paul D'Alton, Associate Professor, School of Psychology, UCD.

Consent Statement

- I have read the Information Sheet and have had adequate time to consider it.
- I have had an opportunity to speak with a member of the research team and all questions have been answered to my satisfaction.
- I voluntarily agree to be part of this research study.
- I understand I am under no pressure to participate in the study, and **I understand that I may withdraw from the study at any time** if I wish. This will not impact any current or future relationship I may have with UCD.
- I consent to having my interview recorded *with/without* (please select one) video.

Has the Information Sheet and Consent Form been discussed with the named participant below? YES / NO (please circle one)
Based on the above statement, does the named participant provide consent to participate in the study? YES / NO (please circle one)

_____
Name of Participant (print)

_____ _____
Name of Person Obtaining Consent (print) Date and time

_____
Signature of Individual Obtaining Consent

Appendix C: Interview Schedule

Interview Guide – Mental Health Professionals

Introduction:

Thank you again for taking the time to participate in this study. We are really interested in hearing your views on routine cancer screening for individuals with significant mental health difficulties, by this we are primarily referring to those that experience schizophrenia, bipolar disorder and major depression. Before we begin do you have questions?

Demographics:

Age:
Sex:
Race:
Highest level of education obtained:
Profession:
Number of years working in that profession:

Knowledge

- Have you had any experience of cancer screening with your patients?
- Can you tell me what you know about the national cancer screening programmes? (Prompts: different types, eligibility, how it is accessed).
- Do you have experience of promoting this with your patients with serious mental health difficulties?
- As you may be already be aware, individuals with significant mental health difficulties are significantly less likely to avail of these screening programs than the general population. I'm curious if you have any thoughts on why this might be the case?

Social/Professional Role and Identity

- As a mental health professional, do you feel that cancer screening promotion fits within your role?
- Are there other care providers you think are equally or better positioned to take on this role?

    - If so, do you feel you can consult with these care providers and include them in the process or ask for support?

Skills

- Do you feel confident in discussing and promoting physical health measures with your patients? What about supporting them in gathering more information, arranging appointment etc?
    - Have you had any relevant training that has helped / would help in this regard?

Optimism

- Based on your experience, when you talk about cancer screening or other health promotion strategies with these patients, are you optimistic that they'll engage? What about their ability to follow through with treatment if needed?

Beliefs about consequences

- Do you worry about the outcome of cancer screening for these patients in particular, and their ability to manage a potential diagnosis (prompts: the possibility of the stress worsening their mental health, their ability to attend appointments)?
    - What would that mean for you? (prompts: increased workload, crisis management)

- Would these potential challenges outweigh the advantages of screening in your opinion?

Reinforcement

- From your past experience, would it make you more or less likely to promote it with your clients?

Intentions

- As you're aware, the patients we are talking about often have a complex range of needs. Do you believe, health promotion initiatives such as cancer screening is a priority in your work? What about for them, is a priority of theirs?

Goals

- Is this something you would like to do more in your work with clients?

- If there was one thing you could change to address this, what would it be?

Memory, Attention and Decision Processes

- How do/would you decide whether to promote cancer screening with a patient? (Prompts: severity of mental health needs, presence of other unmet needs e.g. housing)

Environmental Context and Resources

- Are there any standard procedures for promoting cancer screening in your workplace? (Prompts: how would you be aware that they are eligible, is there an established process for arranging screening)

Social Influences

- Do you and your colleagues ever talk about cancer screening for patients? What is the general thinking among your colleagues?

Emotion

- How does it make you feel when you think about promoting cancer screening with your patients? (Prompts: apprehensive, nervous, feeling burnt out)

Behavioural Regulation

- What would help you manage those feelings? (prompts: having a standard procedure in the workplace, being better informed, access to a physician)

Other

- Thank you for sharing your time and opinions today. Before we finish up, is there anything else you would like to say on this topic?

Appendix D: Consolidated criteria for reporting qualitative studies (COREQ)

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Inter viewer/facilitator	Which author/s conducted the interview or focus group?	48
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	48
3. Occupation	What was their occupation at the time of the study?	48
4. Gender	Was the researcher male or female?	48
5. Experience and training	What experience or training did the researcher have?	48
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	49
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	50 and 51
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	46
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	46

11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	46
12. Sample size	How many participants were in the study?	47
13. Non-participation	How many people refused to participate or dropped out? Reasons?	N/A
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	48
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	N/A
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	47 and 48
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	48
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	N/A
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	49
20. Field notes	Were field notes made during and/or after the inter view or focus group?	51
21. Duration	What was the duration of the inter views or focus group?	48
22. Data saturation	Was data saturation discussed?	47

23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	50
25. Description of the coding tree	Did authors provide a description of the coding tree?	N/A
26. Derivation of themes	Were themes identified in advance or derived from the data?	49
27. Software	What software, if applicable, was used to manage the data?	49
28. Participant checking	Did participants provide feedback on the findings?	N/A
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	53 - 64
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31. Clarity of major themes	Were major themes clearly presented in the findings?	53 - 64
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	N/A

Appendix E: Ethical Approval – St Vincent's University Hospital

ST. VINCENT'S UNIVERSITY HOSPITAL
Elm Park

St. Vincent's University Hospital
Elm Park, Dublin 4,
D04 T6F4, Ireland

T +353 1 221 4000
www.stvincents.ie

Dr Paul D'Alton,
Head of Department of Psychology & Principal Clinical Psychologist,
St. Vincent's University Hospital
Elm Park
Dublin 4.

28th April 2023

Ref No: RS22-033
The Culture of Cancer Screening for those with Significant Mental Health Difficulties: A Patient and Healthcare Provider Perspective
Documents: Consultant Letter - V1 1July22; Agenda REC Meeting 07.09.2022; GCP 2; GCP; Patient Debriefing Sheet v1 1July22; Patient Information Letter v1 - 1July22; Research-Study-Checklist-Declaration-Signatory-1 v1 1June22; Standard-REC-Application-Form v1 1June22; Study Protocol V1 1June22; (RS22-033) Culture of Cancer Screening for those with Significant Mental... (2); PIL-Combined-with-Data-Confidentiality-Agreement v1 29Sep2022; Service User Interview Guide - Bowel Screening V1 26Sep2022; Service User Interview Guide - Breast Screening V1 26Sep2022; Service User Interview Guide - Cervical Screening v1 26Sep2022; Standard-REC-Application-Form v1 29Sep2022; REC Response Letter 1March23;

Dear Dr Paul D'Alton,

Following review of the responses and clarifications received, this study has been granted full Ethics approval.

Please note, it is the responsibility of the Principal Investigator to retain full file copies of all documentation submitted and received in respect of this application.

Yours sincerely,

[redacted]

Dr David Murphy
Deputy Chairperson
SVHG Research Ethics Committee

Appendix F: Ethical Approval – UCD

HS-LR-22-99-Cullen-DALton Low Risk Study External Inbox ×

exemptions.ethics@ucd.ie 4 Aug 2022, 09:54
to me, Paul

Dear Clare

Thank you for your low risk-study submission to the Human Research Ethics Committee – Humanities (HREC-HS) which meets the criteria for a low-risk study. Should the nature of your research change and thereby alter your low risk status please inform the committee. Please note for future correspondence regarding this low-risk study that your Research Ethics Reference Number is: **HS-LR-22-99-Cullen-DAlton.**
This Low-Risk Study is being approved by the HREC on the condition that you observe the following:

- We note that this ethics approval is for the participants in Groups 2 and 3 as described in your application form.
- **External REC Approval and/or Permission to Access/Recruit Human Participants/or their Data:** *(if applicable)* Please be aware that recruitment of participants or data collection should not begin until written permissions to access them are secured from external organisations/individuals.
- **Researcher Duty of Care to Participants:** please ensure that ethical best practice is considered and applied to your research projects. You should ensure that participants are aware of what is happening to them and to their data whether a study is de-identified or not. All researchers have a duty of care to their participants who have the right to be informed, the right to consent to participate and the right to withdraw from the study.
- **Please note** that HREC no longer process **insurance cover** on behalf of the researcher. Researchers are required to complete a self-assessment form from the UCD SIRC office – please see www.ucd.ie/sirc/insurance

Any additional documentation should be emailed to research.ethics@ucd.ie quoting your assigned reference number (provided above) in the subject line of your email.

All Low-Risk Studies are subject to a Research Ethics Compliance Review.
Regards
Jan

HS-LR-23-84-Cullen-dAlton Low Risk Study External Inbox ×

exemptions.ethics@ucd.ie Wed, 3 May 2023, 16:13
to me, Paul

Dear Clare

Thank you for your low risk-study submission to the Human Research Ethics Committee – Humanities (HREC-HS) which meets the criteria for a low-risk study. Should the nature of your research change and thereby alter your low-risk status please inform the committee.

Please note for future correspondence regarding this specific submission that your Research Ethics Reference Number is: **HS-LR-23-84-Cullen-dAlton.**

This Low-Risk Study is approved by the HREC on the condition that you observe the following:

- **External REC Approval and/or Permission to Access/Recruit Human Participants/or their Data:** *(if applicable)* Please be aware that recruitment of participants or data collection should not begin until written permissions to access them are secured from external organisations/individuals. **We note that you have provided approval from the St Vincent's University Hospital REC.**
- **Researcher Duty of Care to Participants/and or their data:** please ensure that ethical best practice is considered and applied to your research projects. You should ensure that participants are aware of what is happening to them and to their data whether a study is de-identified or not. All researchers have a duty of care to their participants who have the right to be informed, the right to clear and specific consent to participate and the right to withdraw from the study.
- **Please note** that HREC no longer process **insurance cover** on behalf of the researcher. Researchers are required to complete a self-assessment form from the UCD SIRC office – please see https://www.ucd.ie/sirc/insurance/humanresearchinsurance/

Any additional documentation should be emailed to research.ethics@ucd.ie quoting your assigned reference number (provided above) in the subject line of your email.

All Low-Risk Studies are subject to a Research Ethics Compliance Review.
Regards
Jan

Janette Stokes
Research Ethics Officer
Office of Research Ethics (ORE)
W. www.ucd.ie/researchethics