A Transdiagnostic Approach to Fears of Recurrence and Progression in People with Mental Health Conditions

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Statement of Originality

This is to certify that to the best of my knowledge the content of this thesis is my own work. This thesis has not been submitted for any other degree or purposes.

I certify that the intellectual content of this thesis is the product of my own work, and all the assistance received in preparing this thesis and the sources has been acknowledged.

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Authorship roles are specified according to the Contributor Role Taxonomy (CRediT), developed by the National Information Standards Organization. For all empirical chapters listed below (Chapters 2 to 5), the author of this thesis, Daelin Coutts-Bain, is credited with conceptualization, data curation, formal analysis, investigation, methodology, visualisation, writing the original draft, and review/editing of writing. The roles of secondary authors are listed for each chapter individually below. Generative AI was not used in this research or in preparation of the thesis. This research was supported by an Australian Government Research Training Program Scholarship.

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List of Abbreviations

AMOS	Analysis of Moment Structures
BTMS	Bodily Threat Monitoring Scale
COREQ	Consolidated Criteria for Reporting Qualitative Studies
COSMIN	Consensus-based Standard for the selection of health status Measurement Instruments
CRediT	Contributor Role Taxonomy
CBM-I	Cognitive Bias Modification of Interpretation
CBT	Cognitive Behavioural Therapy
CFA	Confirmatory Factor Analysis
CFI	Comparative Fit Index
DASS-21	Depression Anxiety Stress Scales (21-item version)
DSM	Diagnostic and Statistical Manual of Mental Disorders
EFA	Exploratory Factor Analysis
EMA	Ecological Momentary Assessment
EMDR	Eye Movement Desensitisation and Reprocessing
FCR	Fear of Cancer Recurrence
FoDRQ	Fear of Depression Recurrence Questionnaire
FOP	Fear of Progression
FORP	Fears of Recurrence and Progression
FORP-MHQ	Fears of Recurrence and Progression about Mental Health Questionnaire
FoRSe	Fear of Recurrence Scale
GAD-7	Generalised Anxiety Disorder-7
ICC	Intra-class Correlations
ICD	International Classification of Disease
IES-R	Impact of Event Scale – Revised
IPQ-R	Illness Perception Questionnaire – revised

ISMI	Internalized Stigma of Mental Illness Inventory
MARS-5	Medication Adherence Rating Scale – 5-item version
MHAI	Mental Health Anxiety Inventory
NICE	National Institute for Health and Care Excellence
OCD	Obsessive-compulsive Disorder
PANAS-X	Positive and Negative Affect Scale (extended version)
PCL-5	Post-traumatic Stress Disorder Checklist for DSM-5
PHQ-9	Patient Health Questionnaire-9
PTSD	Post-traumatic Stress Disorder
QUAD	Questionnaire on Anticipated Discrimination
RMSEA	Root Mean Square Error of Approximation
SAQ	Self-Appraisal Questionnaire
SCID-5-RV	Structured Clinical Interview for DSM-5 Research Version
SCID-5-PD	Structured Clinical Interview for DSM-5 Personality Disorders
SPSS	Statistical Package for Social Sciences
SRMR	Standardised Root Mean Squared Residual
TLI	Tucker-Lewis Index
WAMHQ	Worries About Mental Health Questionnaire
WARPS	Worries About Recurrence and Progression Scale

Thesis Abstract

Fears of recurrence and progression (FORP) are a normal and expected response to chronic illness, but they can become distressing and disabling. In cancer survivors, FORP is well-understood, with many survivors experiencing persistent worry that their cancer will come back or get worse. In contrast, despite its clear conceptual relevance, there is a paucity of research on mental health-related FORP in people with mental health conditions. Moreover, this comparatively small literature is mostly limited to fear of psychosis relapse in people with schizophrenia, where this fear is known to predict a shorter time to relapse. Hence, this thesis investigates whether mental health-related FORP is also relevant to those with non-psychotic conditions, and whether it represents a distinct construct that can be modelled and measured transdiagnostically. Chapter 2 presents a mixed-method systematic review and meta-synthesis of the existing literature. Meta-synthesis of qualitative literature was used to develop a preliminary model of mental health-related FORP that was demonstrable relevant to those with and without a history of psychosis. Further, narrative review of the quantitative literature demonstrates that FORP is associated with worse psychological outcomes, poorer quality of life, and disturbances in health behaviours, such as increased medication adherence, across diagnoses. Chapter 3 extends this model using qualitative interviews of people with psychotic and non-psychotic conditions (n = 18), and further demonstrates that FORP has transdiagnostic relevance. This chapter also reports on findings from a cross-sectional survey (n = 269) which provides preliminary quantitative support for the model. To facilitate further research on mental health-related FORP, Chapter 4 describes the development and validation of a novel questionnaire assessing FORP in people with mental health conditions (n = 905). This measure demonstrates strong psychometric properties, discriminant validity from related constructs, including mental health anxiety, and measurement invariance across groups with varying clinical histories, including those with and without a history of psychosis or mania. This provides preliminary evidence that mental health-related FORP can be measured transdiagnostically. Chapter 5

employs this measure in a 14-day ecological momentary assessment study (*n* = 68), capturing four daily observations to examine predictors of FORP. Results indicate that intrusive memories of being mentally unwell, shame, and negative appraisals of mental state fluctuations, rather than attentional focus, predict subsequent FORP, lending empirical support to key components of the theoretical model developed in Chapters 2 and 3. Together, the empirical chapters of this thesis provide robust evidence that mental health-related FORP is a distinct, measurable, transdiagnostic construct. Chapter 6 discusses the broader clinical and theoretical implications of these findings. Considering evidence to suggest that FORP may predict relapse of mental health conditions, it is proposed that further clinical research on FORP is needed.

Chapter 1: General Introduction

1.1 Living with Illness and Fears of Recurrence and Progression

Illness is a universal part of the human experience. Indeed, all individuals will have to contend with the personal experience of illness throughout their lives. However, for those who develop a chronic, or otherwise more serious, illness, this experience can be far more profound. Phenomenological accounts of illness have drawn attention to how the changes to one's life that accompany serious physical and mental health conditions can fundamentally alter one's sense of self (Carel, 2016; Svenaeus, 2000a, 2000b). This is unsurprising, as chronic illnesses can be associated with substantial impairments that prevent people from being able to engage in valued activities, and some illnesses can even be life-limiting. As a result, worry about whether an illness will lead to disability, or even death, is natural. However, rates of chronic illness are increasing as the global population ages, and advances in treatment are providing better health outcomes but increased uncertainty. That is, people are living longer, but often with chronic illnesses where the course of illness is intermittent and unpredictable. As such, an increasing problem in health is that people are living with the threat of illness recurrence or progression looming over them for years, or even decades. A particularly prominent example of this is cancer, where due to advances in treatment, such as personalised medicine, cancer survivors are living longer (Passaro et al., 2024). Hence, nowhere within psychology is this concept more studied than in fear of cancer recurrence (FCR).

In recent decades, FCR, often defined as a "fear, worry, or concern relating to the possibility that cancer will come back or progress", has come to be understood as an expected and natural part of adjusting to diagnosis and treatment of cancer (Lebel et al., 2016, p. 3165). Given the threat to life and the unpleasant physical and social changes that often accompany cancer and its treatment, this is unsurprising. Indeed, having some degree of FCR is near ubiquitous amongst cancer survivors (Simard et al., 2013). When levels of FCR are mild, this may be adaptive, as fear may motivate survivors to monitor for signs of

recurrence, attend routine screening, and make healthy lifestyle choices (Lee-Jones et al., 1997). Nevertheless, FCR can become chronic, distressing in and of itself, and has been shown to be unrelated to the objective risk of recurrence or progression (Simard et al., 2013). Critically, this is not a rare phenomenon. Longitudinal research using group-based trajectory modelling has consistently found that whilst most cancer survivors report moderate or high FCR that spontaneously improves with time, approximately 1-in-4 survivors will report high FCR that remains stable up to five years following successful cancer treatment (Custers et al., 2020; Manne et al., 2017; Schapira et al., 2022). Corroborating this, a recent meta-analysis has demonstrated that 19% of all cancer survivors have severe FCR warranting specialised psychological intervention (Luigjes-Huizer et al., 2022).

These high rates of clinically significant FCR are concerning given that FCR has been consistently associated with greater psychiatric morbidity (Simard & Savard, 2015), and symptoms of depression and anxiety (Podina et al., 2023). FCR is also consistently associated with functional impairment and poorer quality of life (Simard et al., 2013). Moreover, high levels of FCR are associated with increased use of primary and secondary healthcare services, including unscheduled visits to general practitioners and emergency rooms, which may occur as fearful cancer survivors seek reassurance regarding their health status (Williams et al., 2021). Hence, FCR not only places a burden on individual cancer survivors, but also the broader healthcare system. Hence, it is unsurprising that support for managing FCR is one of the most commonly reported unmet needs of cancer survivors (Lisy et al., 2019; Miroševič et al., 2019; Tan et al., 2021).

Since FCR is characterised by anxiety about one's own health, and is associated with health-related reassurance seeking, one might question whether FCR is distinct from established psychiatric diagnoses that share these features, namely illness anxiety disorder, somatic symptom disorder (American Psychiatric Association, 2022), or health anxiety (World Health Orgainization, 2019). It should be noted that illness anxiety disorder was primarily developed for otherwise healthy people, and somatic symptom disorder for those

with mild, largely unexplained symptoms, who were concerned about an illness they do not have and are unlikely to experience. In contrast, cancer survivors have lived experience of the illness they fear, and must live with the real and present threat of recurrence or progression even after treatment. Hence, it has been proposed that FCR is distinct from these diagnoses, and that these diagnoses are inappropriate within the cancer context (Herschbach & Dinkel, 2014). Indeed, an international Delphi study of experts on FCR found that a majority of those with clinical expertise did not endorse diagnoses of illness anxiety disorder, somatic symptom disorder, or health anxiety for those with clinically significant FCR (Mutsaers et al., 2020). Corroborating this, empirical research using structured diagnostic interviews has demonstrated that many of those with clinical FCR do not meet diagnostic criteria for any of these disorders (Dinkel et al., 2014; Simard & Savard, 2015). Hence, although FCR shares some clinical features with existing psychiatric diagnoses, there is both conceptual and empirical evidence that indicates FCR is a construct distinct from health anxiety.

As the significance of FCR has gained recognition, research on this construct has proliferated, particularly over the last decade (Butow et al., 2019). To accompany this increase in interest, existing models of anxiety were adapted to the context of cancer to explain what causes and perpetuates FCR. This led to the rise of several cognitive-behavioural models that have different, but complimentary, foci. Firstly, Fardell et al.'s (2016) cognitive processing model draws on the self-regulatory executive function model of anxiety to explain the development of FCR (Wells & Matthews, 1996). Fardell et al.'s (2016) model proposes that intrusive thoughts about cancer are normal, given that receiving a cancer diagnosis is a life-threatening event. However, the natural dissipation of these normal cancer-related intrusions is prevented by metacognitive beliefs that worry, and intrusions, are especially important. These metacognitions activate a cognitive attentional syndrome, characterised by biased attention towards threat-related information, worry, and cognitive avoidance, which are common in anxiety disorders, but in this case perpetuates FCR.

Alternatively, Simonelli et al (2017), while acknowledging these same cognitive components, propose that existential concerns, such as death anxiety, are the central factor underlying FCR. Drawing on terror management theory (Pyszczynski et al., 1999), they note that the increased awareness of one's own mortality following cancer diagnosis may drive avoidant coping strategies which perpetuates FCR. Lastly, Heathcote and Eccleston (2017), drawing on cognitive bias research, propose that because pain may indicate the recurrence of some cancers, sensations of pain demand interpretation in cancer survivors. Hence, biased interpretation of pain sensations as inherently threatening, i.e., indicative of cancer recurrence, increases attention towards ambiguous somatic cues, identifying more potentially threatening sensations, thereby driving FCR.

The development of theoretical models like these has led to the development of novel psychological interventions specifically designed to reduce FCR, such as Conquer Fear (Butow et al., 2017). Importantly, the most recent meta-analysis on the efficacy of psychological interventions for FCR demonstrated that psychological interventions are effective at reducing FCR (Tauber et al., 2019). Critically, as FCR is associated with increased use of healthcare services, these interventions may not only alleviate the individual burden of FCR, but also be a cost-effective means to reduce the associated systemic strain on healthcare systems (Williams et al., 2021). Hence, as researchers have studied FCR and developed FCR-specific interventions, substantial progress has been made in reducing the burden of FCR on cancer survivors and wider society.

While FCR has been very thoroughly investigated in recent years, the idea that a person might worry about their health condition getting worse is not just relevant to cancer survivors. The same concept, often called fear of progression (FOP), has been applied to those that live with other physical chronic illnesses, including diabetes, arthritis, and multiple sclerosis (Herschbach & Dinkel, 2014). Just like cancer, these illnesses can cause significant disability, and even be life-limiting. Just as in FCR, FOP is a normal, and potentially adaptive, response to lived experience of chronic illness. Indeed, a meta-

synthesis of qualitative research on FOP in chronic illness found substantial overlap between accounts of FOP in non-cancer illnesses and accounts of FCR reported elsewhere in the literature (Sharpe et al., 2022a). Given these similarities, the authors argue that FCR and FOP are manifestations of the same underlying construct. This study also included a meta-analytic component that demonstrated FOP was associated with poorer quality of life and worse symptoms of anxiety and depression, just like FCR. Ultimately, these findings corroborate the notion that FCR and FOP are essentially equivalent manifestations of the same transdiagnostic construct (Herschbach & Dinkel, 2014; Smith et al., 2024).

In summary, both FCR and FOP are important phenomena in understanding the lived experience of people with chronic physical illnesses. While they are normal, and at mild levels are potentially adaptive reactions to living with the real threat of death or disability, they are distinct from health anxiety and other established psychiatric diagnoses. Nevertheless, these fears are often a source of clinically significant distress and impairment that places a substantial burden on individuals and healthcare systems. Recognition of the significance of FCR and FOP has led to increased research attention, resulting in the development of theoretical models which have gone on to inform psychological interventions that have proven efficacy. Hence, it is now possible to reduce clinically significant FCR and FOP with psychological interventions and thus reduce the overall burden of chronic physical illnesses on individuals and society more broadly. However, could fears of recurrence and progression (FORP) also be relevant to people with lived experience of mental health conditions?

1.2 Fears of Recurrence and Progression in Mental Health

There is a paucity of research on FORP in relation to mental health conditions. This is surprising for several reasons. Firstly, like chronic physical health conditions, mental health conditions have a significant impact on health, functional capacity, and quality of life

(Vigo et al., 2016). Hence, there is a substantial cost associated with a deterioration in one's mental health. Worryingly, the global burden and prevalence of mental illness is continuing to increase, especially in young people, where mental illness is a leading cause of disability and death (GBD 2019 Mental Disorders Collaborators, 2022; McGorry et al., 2024). Indeed, in Australia, suicide is the leading cause of death for those between the ages of 15 and 44 (Australian Institute of Health and Welfare, 2025). Considering the substantial costs associated with mental health conditions, it is reasonable to expect people to fear deteriorations in their mental health. Secondly, mental health conditions often become chronic or follow a relapsing-remitting course, as physical health conditions do. As an example, obsessive-compulsive disorder and anorexia nervosa have relatively low rates of remission even with appropriate treatment (Bloch et al., 2013; Eisen et al., 2013; Zipfel et al., 2015). Other conditions which remit more reliably are nevertheless characterised by high rates of relapse, such as anxiety conditions, mania, and depression (Fagiolini et al., 2013; Oud et al., 2016; Richards, 2011; Yonkers et al., 2003). Indeed, the 'revolving door' phenomenon, where people tend to represent to mental health services after successful treatment due to relapse or the development of a new condition, is a major problem for people who experience mental illness and health services alike (Menzies et al., 2024a). Hence, it may be reasonable to anticipate future deteriorations in one's mental health, even if one no longer meets criteria for a disorder. Lastly, it is possible that, just like FCR and FOP, FORP may be adaptive and may motivate people to be appropriately vigilant for early signs of mental health deterioration, and precipitants of deterioration, thereby identifying opportunities to take preventative action. Indeed, monitoring of early signs of relapse is often recommended in clinical practice for a range of mental health conditions, including schizophrenia-spectrum and bipolar conditions (Birchwood & Spencer, 2001; Goodwin, 2003). For these reasons, we would expect people with lived experience of mental health conditions to worry about recurrence or progression, even whilst relatively well. However, despite the conceptual relevance of FORP to the mental health context it has received very

little empirical attention, especially compared to FCR. Moreover, much of this nascent literature is limited to fear of psychosis relapse in people with schizophrenia.

Fear of psychosis relapse was identified as a phenomenon as early as several hundred years ago. In an essay on the prevention of “insanity”, psychiatrist and surgeon George Hill wrote that those who recover from such illness often “dread an attack of insanity [and] have generally horrid apprehensions at the thought of being incarcerated in a lunatic asylum” (Hill, 1814, p. 381). However, it was not until far more recently that fear of psychosis relapse was studied empirically. To our knowledge, Herz and Melville (1980) were the first to study fear of psychosis relapse when they found that people with schizophrenia who had recently been hospitalised retrospectively reported “fear of going crazy” as a prodromal symptom that predicted their acute psychotic relapse. It has since been theorised that this fear of relapse leads one to over-interpret early warning signs of psychosis, like hearing voices, as inherently indicative of acute relapse, thereby increasing anticipatory distress which accelerates incipient psychosis (Birchwood, 1996). For this reason, Birchwood (1996) postulated that excessive fear of relapse might limit the efficacy of monitoring oneself for early warning signs by driving hypervigilance towards fluctuations in mental state and exacerbating distress.

Since then, the ways in which fear of psychosis relapse may constrain interventions for psychosis has been further elaborated upon. Recently, Gumley et al. (2020) proposed the cognitive-interpersonal model of early warning signs. This model describes how the stigma of psychosis, and anticipation of coercive treatment, leads people to attempt to cope with their fear of relapse by avoiding healthcare providers. This avoidance may then be interpreted by healthcare providers as evidence of increased risk, leading to increased monitoring of the service user, inadvertently reinforcing the service users’ negative expectations of themselves and the service. Hence, fear of psychosis relapse may accelerate incipient psychosis not only by perpetuating anxiogenic cognitive processes, i.e., hypervigilance and interpretation biases, but also by reducing service engagement. This is

significant as acceleration toward relapse reduces the window during which preventive treatment can be provided, thereby increasing the duration of untreated psychosis, leading to poorer outcomes (McGorry et al., 2008). Although these proposed mechanisms have not been empirically tested, there is evidence that fear of psychosis relapse does predict a shorter time to relapse, as hypothesised, even when controlling for early warning signs of psychosis (Gumley et al., 2015). Hence, FORP appears to be an important construct in predicting, and potentially preventing, acute psychotic relapse.

Beyond predicting psychotic relapse, there is some evidence that fear of psychosis relapse is associated with other clinically relevant outcomes. For instance, the only existing systematic review on mental health-related FORP prior to the research reported in this thesis is a recent review of fear of psychosis relapse in people with schizophrenia and their carers. The review demonstrated that fear was associated with greater suicidal ideation, depressive symptoms, and poorer self-esteem (Zukowska et al., 2022). This review also synthesised the existing qualitative literature on fear of psychosis relapse and found some evidence that this fear may lead to social withdrawal as people try to cope with shameful memories of being unwell. Theoretically, this social withdrawal and avoidance limits engagement with healthcare services, consistent with the cognitive-interpersonal model of early warning signs (Gumley et al., 2020). However, more broadly, withdrawal and avoidance reduces access to positive social experiences which may go on to protect against the development of depression or social anxiety secondary to psychosis (Gumley et al., 2010).

Despite these findings, which provide preliminary evidence of the clinical importance of FORP, the available literature on fear of psychosis relapse is limited. For instance, Zukowska and colleagues' (2022) systematic review only included five quantitative studies, four of which were cross-sectional. This makes it difficult to establish the directionality of the relationships between fear of psychosis relapse and depression, suicidality, and low self-esteem. Similarly, their meta-synthesis of qualitative research was derived from just four studies, all of which explored fear of psychosis relapse in relation to other constructs. As

none of their included studies intended to examine fear of psychosis relapse, their meta-synthesis may be lacking the depth and breadth of detail required to draw reliable conclusions about the construct. This issue is exacerbated by their exclusive focus on people with schizophrenia, which meant that their review did not include relevant research on fear of psychosis relapse in other conditions, such as post-partum psychosis or bipolar disorder (e.g., McGrath et al., 2013). Indeed, mental health-related FORP is rarely considered outside the context of psychosis generally, and schizophrenia specifically. This paucity of empirical research is consistent with the absence of theoretical models accounting for FORP in the mental health context. Although researchers' have proposed that fear of psychosis relapse may be important to mental health outcomes in psychosis (Birchwood, 1996; Gumley et al., 2020), to our knowledge there is no theoretical account of how FORP is developed or maintained in relation to any mental health condition. This is significant as it means little is known about the construct of FORP itself, and whether the experiences and factors associated with FORP manifest similarly in those with non-psychotic mental health conditions.

1.2.1 The Benefits of a Transdiagnostic Approach

Despite the conceptual relevance of FORP to other mental health conditions, there is almost no research on the construct outside the context of psychosis. This is a major limitation for several reasons. Firstly, schizophrenia-spectrum conditions make up a minority of mental health diagnoses. Forty-two percent of Australians will meet diagnostic criteria for at least one mental health condition in their lifetime (Australian Bureau of Statistics, 2023), but only 1% will experience acute psychosis (Moreno-Küstner et al., 2018). Hence, most of the people we might expect to experience mental health-related FORP are not being studied, if it is confirmed that FORP is a major issue in other mental health conditions. Secondly, most of those who develop a mental health condition will go on to accumulate additional diagnoses, mostly in a different diagnostic category to the initial condition (Caspi

et al., 2020; Menzies et al., 2024a). Hence, we would expect that someone who worries about recurrence and progression of one condition, such as psychosis, may also be worried about a recurrence or progression of co-occurring conditions, such as depression. For this reason, diagnosis-specific approaches to FORP may not adequately capture comorbidity experiences which commonly occur in clinical practice. Lastly, there is increasing evidence that mental health conditions are best conceptualised as dimensional spectra, such as in the Hierarchical Taxonomy of Psychopathology (HiTOP) model, rather than as discrete categories, such as in the DSM-5-TR (Kotov et al., 2017, 2021). There is some variability in the structure of these dimensional spectra identified between studies due to differences in sampling and measurement. However, in general, an overarching 'general psychopathology' factor accounts for broad internalising, externalising, and thought disorder spectra, which gives rise to different syndromes, e.g., eating pathology, post-traumatic stress, phobias, which cross-load to varying degrees (Forbes et al., 2017, 2021; Kotov et al., 2021). Indeed, the most recent Lancet Commission on mental illness notes that the binary, categorical approach to diagnosis fails to adequately capture the complexity of mental health (Patel et al., 2018). The more contemporary, dimensional understanding of psychopathology draws attention to the transdiagnostic basic psychological processes which have been proposed to underlie mental health conditions, such as perfectionism, cognitive biases, and death anxiety (Egan et al., 2011; Hirsch et al., 2016; Menzies et al., 2024b). Conceptually, we expect that FORP may be one such transdiagnostic construct. Hence, expanding the study of FORP to people with non-psychotic mental health conditions and exploring whether FORP would be suitable within a transdiagnostic framework is important.

1.2.3 Distinguishing between Recurrence and Progression

Aside from the limitations of taking a diagnosis-specific approach to the study of FORP, there is also a limitation to focusing on a fear of an acute and discrete recurrence of symptoms, such as fear of psychosis relapse, in the context of schizophrenia. Although the

positive symptoms of psychosis, such as hallucinations and delusions, can have a substantial deleterious impact on people, the same is true of negative symptoms, such as avolition, and cognitive symptoms, such as social cognition deficits (Carbon & Correll, 2014). In general, the positive symptoms of psychosis tend to respond well to treatment, whereas negative and cognitive symptoms tend to be more persistent (McCutcheon et al., 2020, 2023). Hence, although someone with schizophrenia may fear acute psychotic relapse, they may also fear progression of their negative or cognitive symptoms, or even residual positive symptoms, which are also common (Schennach et al., 2015). The occurrence of residual symptoms, even during or after effective treatment, is not just relevant to psychosis. Residual symptoms are also common in those with remitted mood (Conradi et al., 2011), obsessive-compulsive (Simpson et al., 2006), trauma and stressor-related conditions (Larsen et al., 2019), and disordered eating conditions (Tomba et al., 2019). Therefore, it is important to consider the possibility that individuals may worry about progression of their residual symptoms, as well as an acute recurrence of a particular symptom or disorder. For this reason, we adopt a definition of FORP, similar to the consensus definition of FCR, that is, a fear, worry, or concern, that one's mental health condition will come back *or* get worse (see Lebel et al., 2016).

In light of this proposed definition of FORP, one may question whether it is appropriate to conflate worries about recurrence and progression by conceiving of them as a single construct. Indeed, there has been debate within psycho-oncology as to whether FCR and FOP are equivalent constructs, as those with active disease who fear their cancer growing or metastasising may theoretically differ from those who are in remission and primarily concerned with recurrence (Butow et al., 2019). Nevertheless, empirical examinations of this question have demonstrated that FCR and FOP, in the cancer context, are highly related and even empirically equivalent (Coutts-Bain et al., 2022; Smith et al., 2024). However, this question of equivalence between fears of recurrence and progression is far more complex in relation to mental health conditions. Firstly, unlike cancer, there are

no biomarkers with clinical utility in identifying or predicting the occurrence, recurrence, or progression of any mental health condition (Abi-Dargham et al., 2023; García-Gutiérrez et al., 2020). Instead, diagnosis is determined by subjective clinical judgement based on analysis of identifiable symptoms and contextual factors. Hence, it is not possible to objectively distinguish between recurrence and progression, or remission and ongoing residual psychopathology, as it is in cancer. Indeed, how to best define a relapse of psychosis remains fiercely debated (see Moncrieff et al., 2020).

Secondly, many mental health conditions are characterised by biased cognitive processing which can lead one to draw overly negative or threatening conclusions about themselves, their future, and the world (Beck, 1979; Hirsch et al., 2016; Livet et al., 2020). Hence, one may question whether mental health-related FORP is simply a manifestation of existing mental health conditions, particularly for those with clinically significant residual anxiety. However, this potentially makes FORP more problematic. If FORP is more likely amongst those who have more symptoms, then the chance of FORP triggering a full relapse or progression of symptoms becomes more likely than in those with chronic physical health conditions, like cancer. Moreover, it is not clear whether FORP is distinct from mental health anxiety, that is, worry about the possibility that one will develop a mental health condition that one has *not* previously experienced. An example of this would be a person with generalised anxiety or obsessive-compulsive disorder being concerned about developing schizophrenia (Commons et al., 2016). Given the paucity of research examining mental health-related FORP, these critical conceptual questions have heretofore remained unanswered. Previous research has demonstrated that FCR and FOP are distinct from health anxiety and related diagnoses in the context of cancer (Dinkel et al., 2014; Mutsaers et al., 2020; Simard & Savard, 2015). However, it is not clear whether mental health-related FORP is a distinct construct as fear itself is a non-specific symptom of many mental health conditions. Although one could argue that FORP is a conceptually distinct, given that lived experienced of the feared condition means one must contend with a very real risk of

recurrence or progression, questions of construct overlap must be examined empirically (Hodson, 2021).

1.3 The Present Thesis

In summary, FORP is well understood as a natural, but nevertheless potentially distressing and impairing, response to living with a chronic physical illness that is understudied in people with mental health conditions, despite being conceptually relevant to this population. There is preliminary evidence that mental health-related FORP is associated with clinically relevant outcomes, most notably in its potential to predict a shorter time to psychosis relapse in people with schizophrenia (Gumley et al., 2015). However, there remains a paucity of research on mental health-related FORP, especially in those with experience of more common, non-psychotic, mental health conditions. Hence, little is known about the nature of the construct, or the full extent of its impact across the population. Specifically, it is not known whether FORP is relevant to those with non-psychotic mental health conditions, or whether FORP is a truly distinct construct separable from mental health anxiety. Moreover, the diagnosis-specific approach to FORP which has heretofore characterised the FORP literature has limited ecological validity, as lifetime comorbidity of mental health conditions is extremely common. Hence, the present thesis aims to address these gaps in the literature by examining FORP within a transdiagnostic framework.

Specifically, the present thesis is guided by the following overarching questions: (1) Is FORP relevant to people with lived experience of non-psychotic mental health conditions? (2) Can a transdiagnostic model explain FORP across different mental health conditions, including psychotic and non-psychotic conditions? (3) Is FORP an empirically distinct construct and can it be measured transdiagnostically? By answering these questions, this thesis intends to provide basic research which elucidates the nature of mental health-related

FORP, and provides a strong theoretical foundation, and measurement tool, that can guide future research and clinical practice on FORP.

To meet these overarching aims, the present thesis presents a series of empirical studies: (1) Chapter 2 presents a mixed-method systematic review which aims to meta-synthesise the qualitative research on mental health-related FORP across psychotic and non-psychotic conditions, and review the quantitative research on the relationship between FORP and psychological outcomes, quality of life, and health behaviours. This allows for a preliminary examination of the relevance of FORP across different mental health conditions, as well as the evaluating whether FORP manifests similarly in people with psychotic and non-psychotic conditions. (2) Chapter 3 presents a mixed-method study which aims to develop a theoretical model of mental health-related FORP based on primary data through a series of qualitative interviews of people with different mental health conditions, and examine some tenets of the proposed model cross-sectionally in a large survey of people with mental health conditions. This chapter extends the findings of Chapter 2 by developing a theoretical model from primary data, allowing for a more in-depth examination of the construct of FORP, its development, and its potential consequences. (3) Chapter 4 draws on the qualitative research of the prior chapter to develop a novel transdiagnostic questionnaire for assessing mental health-related FORP, and validates this questionnaire in a large sample of people with different mental health conditions. The validation of this questionnaire allows for quantitative examination of critical empirical questions, that is, is FORP a distinct construct separable from mental health anxiety, and can a questionnaire measure FORP transdiagnostically across those with experience of psychotic and non-psychotic conditions. (4) Lastly, Chapter 5 uses the questionnaire validated in Chapter 4 to determine whether FORP is predicted by intrusive memories of being mentally unwell, shame, attention to, and interpretation of, fluctuations in mental state, using ecological momentary assessment. This longitudinal study allows for a rigorous test of several core tenets of the transdiagnostic theoretical model of FORP proposed in Chapter 4.

Chapter 2: Fears of Recurrence and Progression in People with Mental Health Conditions: A Mixed-Method Systematic Review and Meta-synthesis

The following chapter is a reproduction of material contained within the following published article, with slight changes to make the formatting consistent across the broader thesis:

Coutts-Bain, D., Sharpe, L., Techakesari, P., Forrester, M. A., & Hunt, C. (2023). A mixed-methods review and meta-synthesis of fears of recurrence and progression in people with mental health conditions. *Clinical Psychology Review*, 102342.

Daelin Coutts-Bain completed the systematic review registration, literature search, title and abstract screening, full-text review, quality assessment, data extraction, quantitative and qualitative data analysis, data visualisation, and wrote the original manuscript.

Professor Louise Sharpe screened all titles and abstracts, co-coded the qualitative data for the meta-synthesis, and provided review and editing of the original manuscript, while supervising the research.

Pirathat Techakesari completed the full-text review, and provided review and editing of the original manuscript.

Madeline Anne Forrester completed the quality assessment, and provided review and editing of the original manuscript.

Professor Caroline Hunt provided supervision, and review and editing of the original manuscript.

2.1 Introduction

It is perhaps unsurprising that a person in recovery from an illness may fear that their illness will recur or get worse. Whilst such a statement might be self-evident, the issue of what is a relapse in mental health is far from straightforward. For example, some illnesses have residual symptoms, even when the person is relatively well, while others may have more distinct periods of being symptom free and then acutely unwell. Moreover, some mental health conditions progress over the course of the condition without periods of clear improvement. As such, for the purposes of this review, we adopt a definition of fear of recurrence or progression, similar to that in the cancer literature (Lebel et al., 2016), such that FORP is the fear that symptoms of a mental health condition will recur or become worse in the future.

The fear of recurrence has been recognised in the cancer context with fear of cancer recurrence (FCR) receiving substantial research attention in recent years (Butow et al., 2019). Indeed, FCR has become known as a near ubiquitous part of adjusting to life beyond cancer (Simonelli et al., 2017). FCR is an understandable reaction to living with the threat of ill health and death, and may even drive adaptive coping or health behaviours (Almeida et al., 2019; Lee-Jones et al., 1997). However, FCR can become severe, and severe FCR is associated with anxiety, depression, poorer quality of life, psychiatric morbidity, and disturbances in health behaviours, irrespective of the objective risk of cancer recurrence (Simard et al., 2013). Beyond cancer, there is a growing literature on fear of progression related to other chronic physical illnesses, such as multiple sclerosis, diabetes, or cardiovascular disease. In these cases, people may fear the progression of their disease leading to a loss of functioning or independence (Sharpe et al., 2022a). Similar to FCR, fear of progression in other chronic physical illnesses is related to worse anxiety, depression and quality of life. However, whether a person with a history of psychological conditions might fear a future deterioration of their mental health has received substantially less empirical and theoretical attention.

The paucity of research on fears of recurrence and/or progression (FORP) in people with a history of mental health conditions is surprising for several reasons. Firstly, like physical conditions, mental health conditions also carry a significant risk to the health, functioning, and quality of life of those who experience them (Vigo et al., 2016). Hence, there is a substantial personal and social cost associated with poor mental health. Secondly, symptoms of mental disorders often fluctuate over time (Wittchen et al., 2000), thus we would expect that people would worry about their illness getting worse even when they are well. Lastly, some mental disorders are characterised by a potential for chronicity and relatively low rates of remission following treatment, such as in obsessive-compulsive disorder (Bloch et al., 2013; Eisen et al., 2013). Whereas other disorders, despite somewhat reliably remitting with treatment, are nevertheless characterized by high rates of relapse, such as anxiety disorders, and (hypo)mania and depression in bipolar or unipolar mood disorders (Fagiolini et al., 2013; Oud et al., 2016; Richards, 2011; Yonkers et al., 2003). In light of this evidence, it would be surprising if people with a history of mental health conditions did not experience FORP, even after effective treatment.

Whilst the FORP literature remains small, interest in FORP among people with schizophrenia has grown over the past decade. Recently, FORP has been theorised to have key implications for the monitoring of early warning signs of acute psychotic relapse in people with schizophrenia. The cognitive-interpersonal model of early warning signs (Gumley et al., 2020) suggests that fear of relapse stems from prior traumatic experiences of hospitalization. FORP is argued to drive anxiety, shame, and avoidance which, in turn, leads to reduced help-seeking behaviours in people with schizophrenia. They argue that care providers interpret this avoidance as an indication of increased risk, resulting in increased monitoring and suspicion toward the service user. Increased surveillance affirms peoples' negative expectations of mental healthcare and FORP. Hence, FORP may constrain the efficacy of monitoring early warning signs, which is recommended as an approach to managing psychosis (Birchwood & Spencer, 2001). Whilst the cognitive-interpersonal model

has not been tested, some of its tenets are consistent with a systematic review of nine studies on fear of relapse in schizophrenia and carers of those with schizophrenia (Zukowska et al., 2022). That is, FORP is associated with trauma associated with previous episodes, as well as depression and anxiety.

Whilst the review by Zukowska and colleagues' (2022) emphasizes the relevance of FORP to people with schizophrenia, there is currently no systematic reviews of FORP related to mental health conditions other than schizophrenia. The absence is likely due to the preponderance of studies on FORP and schizophrenia. Consequently, little is known about whether FORP relates to other mental health conditions, such as depression or anxiety. This focus on fear of acute psychotic relapse in schizophrenia is also reflected in descriptions of FORP used in the literature, including fear of going crazy (e.g., Herz & Melville, 1980), fear of madness (Bassett et al., 2009), fear of relapse (e.g., Gumley et al., 2015), and fear of illness recurrence (e.g., Jamalamadaka et al., 2020). However, there is evidence that after first-episode psychosis some people experience significant social and cognitive functional decline (Chang et al., 2018; Hodgekins et al., 2015). Hence, one could imagine how someone who is at ultra-high risk for psychosis or has had psychosis may fear this functional decline associated with negative and cognitive symptoms, not just an acute psychotic episode. Similarly, a person who is depressed, but is no longer at their lowest mood may best describe their fear as a progression or worsening of existing depression, rather than as a fear of recurrence or relapse. As such, we adopt the term FORP as we believe it better captures the range of potential concerns a person with a history of mental health conditions may experience.

The extension of FORP to non-psychotic illnesses is important as some recent studies have found that people with non-psychotic mental health conditions also experience FORP. One study compared fear of recurrence amongst people in recovery from psychosis or anxiety disorders and found that these two samples did not differ in degree of fear of recurrence (Sired et al., 2021). Another study found that whilst people in recovery from non-

psychotic mental health conditions reported less fear of recurrence than those in recovery from psychosis, they nevertheless reported fear of recurrence (Jamalamadaka et al., 2020). These studies provide early evidence that FORP may be a significant concern across a spectrum of mental health conditions. This corroborates prior qualitative research, which identified FORP as a recurring theme and source of distress in the lives of people with ongoing or past depression (Coyne & Calarco, 1995). Together, these findings raise the possibility that FORP is associated with poorer psychological outcomes in people across a spectrum of different mental health problems, such as depression and anxiety, as well as schizophrenia (Zukowska et al., 2022). Additionally, the degree to which the severity, predictors, or consequences of FORP vary between those with different diagnoses, or whether the construct can be captured transdiagnostically remains unknown.

Identifying whether FORP is a transdiagnostic construct is critical for several reasons. Firstly, comorbidity of mental health conditions is very common (Kessler et al., 2011). A person with schizophrenia may also experience intermittent depression and may worry both about recurrence in either psychosis and/or depression to varying extents. A transdiagnostic model of FORP would allow for clinicians and researchers alike to understand these co-occurring fears and how they may interact within a single framework. Secondly, whilst the content of FORP related to psychosis may differ from FORP related to depression, the psychological processes underlying these fears may be more similar than different. In people with physical health conditions, it has been shown that people with different chronic health issues vary in prognosis and nature still tend to report similar fears of recurrence and progression (Sharpe et al., 2022a).

The present review is novel as it aims to synthesise existing quantitative and qualitative research on FORP in people with current or past mental health conditions, not just in psychosis. Quantitative studies will be reviewed narratively, and, if there are sufficient studies, meta-analysed to elucidate the associations between FORP and psychological outcomes, quality of life, and health behaviours, with exploratory analyses of FORP's

relationship with age and gender. It is expected that FORP will be associated with worse psychological outcomes and quality of life, and disturbances in health behaviours, both adaptive and maladaptive, dependent on the particular health behaviour under investigation. Given sufficient studies, the qualitative literature will be meta-synthesised to generate a transdiagnostic model of FORP in people with mental health problems to serve as a hypothesis-generating framework to guide future research.

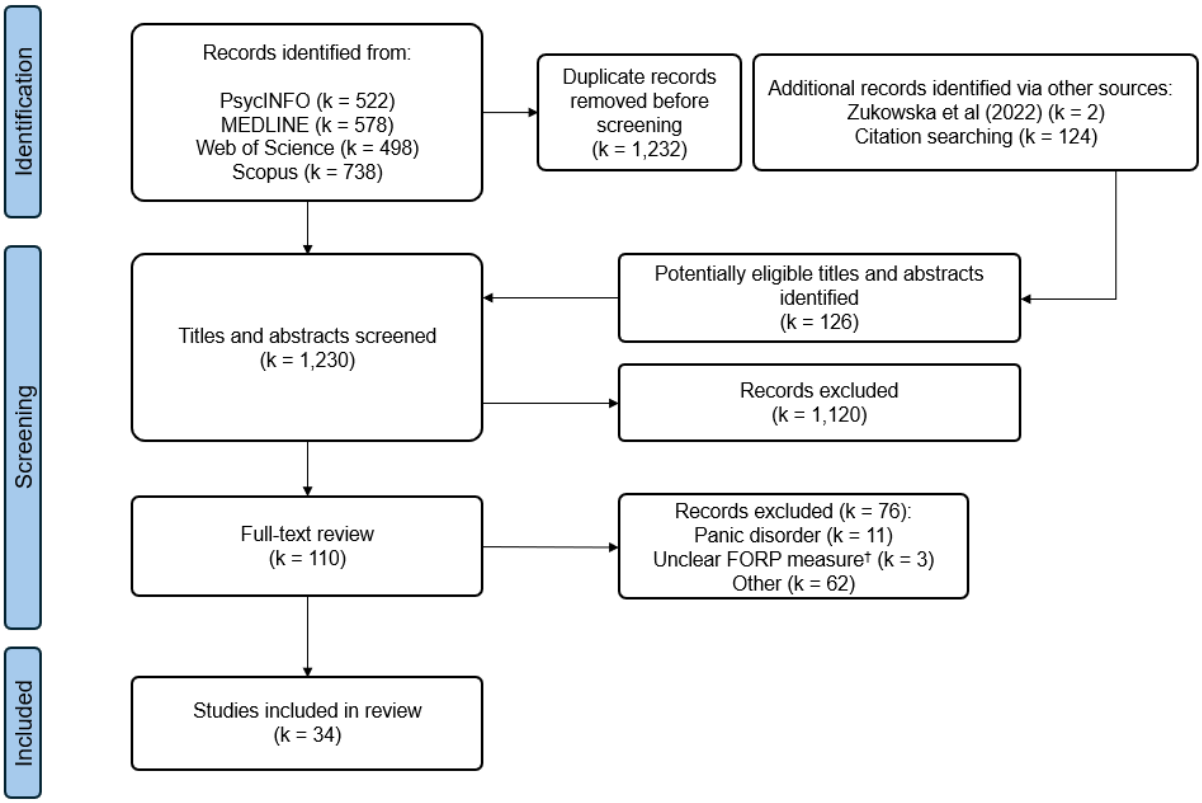
2.2 Method

A systematic search was conducted on the 27th of June 2023 across four databases (PsycINFO, MEDLINE, SCOPUS, Web of Science) to identify studies that reported on FORP in people with current or past mental health conditions. The review was registered prospectively in PROSPERO (CRD42021287692; Appendix A1)

2.2.1 Search Strategy

We conducted systematic searches of the following databases: PsycINFO, MEDLINE, Web of Science Core Collection, and Scopus. We borrowed from the definition of FCR (Lebel et al., 2016, p. 3165), “the fear, worry or concern that cancer may come back or progress” to develop search terms related to FORP. We explicitly excluded a number of common physical disorders (e.g., NOT cancer), but we did not use terms for any psychological condition to ensure that we identified relevant papers for all psychological conditions (Appendix A2). Backwards citation searching of reference lists from studies eligible for inclusion and Zukowska and colleagues' (2022) were screened to identify further studies (Figure 2.1).

Figure 2.1 Flowchart of the Study Inclusion Process.



Note. † refers to studies that did not directly assess FORP but measured it strictly in relation to some other variable, for example, a single item such as 'to what extent are you concerned that your condition will worsen due to social isolation caused by a COVID-19 lockdown?'

2.2.2 Selection of Studies

We included quantitative and qualitative English-language studies that sampled adults who reported having been diagnosed with a mental health condition, if they were published in peer-reviewed journals. Quantitative studies were included if they assessed FORP in relation to the participants' mental health, and/or analysed how FORP related to quality of life, mental health symptomology, health behaviours or relapse or progression. Qualitative studies were included if FORP emerged as a theme or subtheme in the analysis, or if FORP emerged in participant quotes related to some other construct.

2.2.3 Data Extraction

For all included studies, we extracted data pertaining to: authors and year of publication, country of research, participant age, participant gender, study design, diagnoses and method of diagnosis. Further, for quantitative research we extracted, method of FORP assessment, degree and distribution of FORP, and data that assessed the association between FORP and demographic, clinical, or mental health outcomes. For qualitative research, participant quotes, contextualized with researcher interpretations, were extracted if they were related to FORP. For studies that contained quantitative and qualitative data pertaining to FORP, both forms of data were extracted. Lastly, for studies with missing data of interest, and where current corresponding author details could be identified, additional data pertaining to FORP and its relationship to demographic and clinical variables was requested.

2.2.4 Data Synthesis

2.2.4.1 Quantitative Data: Planned Analyses. Correlations, means, and standard deviations were to be analysed using Comprehensive Meta-analysis. Where there was missing data, corresponding authors were contacted to request the relevant data. If sufficient data was available, subgroup analyses were planned for different diagnostic categories. Given that we are investigating FORP across a range of disorders, we would expect considerable heterogeneity and therefore employed a random effects model. Risk of publication bias was to be assessed using funnel plots, Rosenthal's fail-safe N, and Duval and Tweedie's trim and fill method.

2.2.4.2 Quantitative Data: Changes From Published Protocol. At the data extraction stage, there were only 16 studies. Within these studies, there were 10 different measures of FORP, 9 samples of differing mental health conditions, 16 different measures of mental

health outcomes, 2 measures of quality of life, and 5 different measures of health behaviours. Hence, it was not conceptually reasonable to meta-analyse this data given the degree of heterogeneity. Hence, a narrative style review was performed using both originally reported and requested data following the principles of the synthesis without meta-analysis guide (Campbell et al., 2020).

To ensure consistency in reporting of extracted data the following decisions were made. Where multi-subscale measures were used to assess FORP the subscale most relevant to FORP was used. If this data was not available or if no one subscale appeared to capture FORP most clearly, the total scale score was used. When reporting on relationships between FORP and other factors, correlations were reported to maximise comparability between studies, if this data was not available other associative data was reported. When reporting on requested data on FORP in relation to categorical variables, such as gender, means and standard deviations were used to facilitate comparisons. When reporting on demographic or diagnostic factors in longitudinal studies, only baseline data was reported.

2.2.5 Qualitative Data

A meta-synthesis can occur at two levels. Where there is sufficient data, themes and subthemes can be analysed to create an over-arching model. Alternatively, a meta-synthesis can be conducted by extracting all published quotes within each study and analysing these to develop themes and subthemes (Finfgeld-Connett, 2018). This is useful where there is a paucity of data, which was expected given that a previous review of FORP in schizophrenia only identified four qualitative studies (Zukowska et al., 2022). Hence, to conduct the meta-synthesis, extracted qualitative data was independently coded line-by-line by two authors (DCB and LS) to identify concepts across studies. From this coding, descriptive themes and subthemes were established. The two authors then discussed and agreed upon the

identified themes and subthemes, and synthesized a model that accounted for these themes (Finfgeld-Connett, 2018).

2.2.6 Assessment of Study Quality

The Joanna Briggs Institute critical appraisal tools for qualitative and quantitative research, were used to assess study quality in the present review (Lockwood et al., 2015; Moola et al., 2017; Tufanaru et al., 2017). However, the present review included an observational longitudinal study which is a design that the Joanna Briggs Institute does not provide an appraisal tool for. Hence, the authors used an alternative quality checklist specifically designed for this type of study (Tooth et al., 2005). Quality ratings were made by two independent assessors (DCB and MF).

2.3 Results

2.3.1 Study Selection

The search of databases and other sources identified 2,462 studies, 1,230 after removal of duplicates. Of these, 1,120 were excluded after screening titles and abstracts against the inclusion criteria. The remaining 110 articles were read by PT and DCB, who independently assessed their eligibility for inclusion with substantial agreement (Cohen's Kappa = .77). Disagreements were settled by consensus and review by an independent author (LS). This process left 45 papers that were deemed eligible for inclusion after the full text review. However, 11 of these papers were exclusively concerned with panic disorder and had been included as they assessed fear of going crazy. The research team discussed these papers at length, and although fear of going crazy could be interpreted as referring to a fear that one's symptoms of panic could worsen, we elected to exclude these studies as fear of going crazy is a specific symptom within panic disorder (American Psychiatric

Association, 2022). As such, it could be argued that the presence of ‘fear of going crazy’ was a diagnostic confound. To be conservative, we excluded these studies, which left a total of 34 included studies (Figure 2.1).

2.3.2 Study Characteristics and Quality

Of the 34 included studies, 20 reported qualitative findings, and 16 reported quantitative findings (i.e. two studies included both quantitative and qualitative studies). On average, the qualitative studies met 7.2 out of the 10 quality appraisal criteria. Whilst almost all studies appropriately represented the voices of their participants using appropriate analyses to draw conclusions, relatively few studies provided an explicit statement on their epistemology, theoretical, or cultural position within the research. The two quantitative intervention studies both met 9 out of 13 appraisal criteria. Whilst both studies were randomised with appropriate trial designs and outcome measurement, there were significant differences between treatment groups at baseline. The two quasi-experimental studies both met 6 out 9 appraisal criteria. Whilst both studies used appropriate outcome measurements and analyses, neither included a control group. On average, the 10 cross-sectional studies met 5.9 out of 8 appraisal criteria. Whilst most studies used appropriate measurement and analyses of study variables and identified confounds, few used statistical strategies to control for potential confounds. The one observational longitudinal study met 17 out of 31 applicable criteria. Further information on quality ratings is available in Appendix A3. Further study characteristics of qualitative and quantitative studies are provided in Tables 1 and 2, respectively.

Table 2.1. Summary of Qualitative Studies Included in the Meta-synthesis

Reference	Participant Demographics	Diagnoses	Nature of the Sample	Quality Rating
Allan et al (2019)	N = 12 25% female Australia	Mixed substance use disorders	Attendees of a voluntary rehabilitation service	7/10
Baier (1995)	N = 6 66.7% female United States	Schizophrenia	Attendees of a day treatment center for psychosis	5/10
Baker (1995)	N = 15 33% female Canada	Schizophrenia	Attendees of a range of different psychiatric institutions	8/10
Carrick et al (2004)	N =25 48% female United Kingdom	Schizophrenia, schizoaffective disorder, other psychotic illnesses, and borderline personality disorder	People prescribed anti-psychotic medication under the care of a psychiatrist or a day treatment center	9/10
Coyne and Calarco (1995)	N = 17 58.8% female United States	Depression	Community recruitment	6/10
Dyson et al. (2023)	N = 5 100% female United Kingdom	Tobacco use disorder	Users of a stop-smoking health service	8/10
Eveleigh et al (2019)	N = 16 69% female Netherlands	Anxiety, depression	Ongoing prescription for anti-depressants without indication (according to Dutch guidelines)	6/10
Forde et al (2019)	N = 21 100% female United Kingdom	Post-partum psychosis	Recruitment across a mother and baby unit, community perinatal mental health team, and a charity for postpartum psychosis	8/10
Grime & Pollock (2003)	N = 32 71.9% female United Kingdom	Depression	Members of a volunteer self-help organization for depression	5/10
Irawani et al. (2022)	N = 8 37.5% female Indonesia	Schizophrenia	Attendees of a community health center	6/10
Kondoni & Kouimtsidis (2017)	N = 10 30% female United Kingdom	Opioid use disorder	Ongoing opioid substitution therapy	5/10
Leydon et al (2007)	N = 17 58.8% female United Kingdom	Depression	People prescribed anti-depressants for ≥12 months in the community	6/10
McGrath et al (2013)	N = 12 100% female United Kingdom	Puerperal psychosis, or post-partum depression with psychotic features	Mother-and-baby unit and community recruitment	10/10
Nagle et al (2002)	N = 8 25% female Canada	Schizophrenia, schizoaffective disorder	Hospital-based psychosocial rehabilitation program	6/10
Notley et al (2015)	N = 27 33.3% female United Kingdom	Opioid use disorder	People enrolled in opioid substitution therapy for ≥5 years.	8/10
Peindl et al (1995)	N = 268 100% female United States	Mixed post-partum disorders (predominantly depression)	Members of a volunteer-led self-help organization for post-partum disorders	NA*
Robertson & Lyons (2003)	N = 10 100% female Canada	Puerperal psychosis and mania	Subsample of participants from a genetic study on puerperal psychosis	7/10
Sandhu et al (2013)	N = 8 37.5% female United Kingdom	Schizophrenia with post-schizophrenic depression	Participants in an early intervention service for psychosis	10/10
Van Geffen et al (2007)	N = 18 72.2% female Netherlands	Anxiety, depression.	Obtained a prescription for an SSRI in the previous 4 months that was used for a minimum of 2 months.	6/10
Varela et al (2007)	N = 38 40% female United States	Mixed substance use disorders, with mixed comorbid diagnoses (predominantly mood disorders and schizophrenia)	Ongoing treatment for HIV/AIDS, alongside a prescription for psychoactive medication for treating a mental health diagnosis.	4/10

Note. *mixed method study appraised as a cross-sectional quantitative study as that was its primary focus.

2.3.3 Meta-synthesis

In total, 20 of the reviewed studies used qualitative methodology (see Table 2.1). Six of these studies recruited people with a schizophrenia-spectrum disorder (Baier, 1995; C. Baker, 1995; Carrick et al., 2004; Irawani et al., 2022; Nagle et al., 2002; Sandhu et al., 2013). Five studies were in depression or anxiety (Coyne & Calarco, 1995; Eveleigh et al., 2019; Grime & Pollock, 2003; Leydon et al., 2007; Van Geffen et al., 2011). Four studies were on people with a post-partum disorder, including three on post-partum psychosis (Forde et al., 2019; McGrath et al., 2013; Robertson & Lyons, 2003), and one on a mixed, but predominantly depressive, post-partum sample (Peindl et al., 1995). Four studies were in substance use disorders (Allan et al., 2019; Dyson et al., 2023; Kondoni & Kouimtsidis, 2017; Notley et al., 2015). Lastly, one study used a mixed sample of people with psychotic, non-psychotic, and substance-related diagnoses (Varela et al., 2007). Synthesis of participant quotes revealed several key themes and subthemes which are summarised below. The relationships between these components are summarised in Figure 2.2.

1. Fears of recurrence and progression (FORP)

FORP was reported by a range of people, including those with a history of psychosis, opioid addiction, depression, anxiety, mania, and post-partum mental health disturbances. For them, now that they were beyond the worst of their experience, there was a strong fear that these issues could worsen or resurface sometime in the future. Although some people adopted strategies to prevent deterioration, there remained a pervasive sense of uncertainty regarding their future mental health.

> Person with a depressive disorder: *"Even when I'm okay or relatively okay, I feel there is no way I can predict if I'm going to stay that way for two days or two years…"* (Coyne & Calarco, 1995)

> Person with a substance use disorder *"I'm getting a bit anxious, knowing that I'm going. I've been here, wrapped in cotton wool for two months, and being released back into the big, wide world, I'm scared that I'm going to relapse."*
> (Allan et al., 2019)

Across the synthesised studies, there appeared to be four key subthemes underlying FORP: fear of symptoms, loss of progress, fear of death and traumatic experiences.

1.1 Fear of symptoms

Across a range of presentations, people tended to fear a specific set of symptoms that they felt characterised their own periods of mental ill health. Notably, this did not seem to involve speculation that they may develop new symptoms. Instead, people reflected on their previous experiences, and wondered how old symptoms would impact their lives if they were to recur in the present moment, or if existing symptoms were to worsen.

> Person with opioid use disorder: "*I will panic, I am afraid of the symptoms. I will become manic and depressed like the last time where I ended up in hospital. I have a fear of going back and do drugs*." (Kondoni & Kouimtsidis, 2017)

1.2 Loss of progress

Irrespective of their current symptoms, or current difficulties in meeting their goals or personal recovery, people felt they were no longer at the worst of their functional capacity or mental health. Hence, whether it was due to the passage of time or treatment, there was a sense that movement had been in their recovery. For many people, recurrence, or further deterioration of their mental health, represented a loss of progress that was frightening. Some people spoke about this in absolute terms and were distressed at the possibility of going back to "square one" if their mental health were to worsen.

> Person with opioid use disorder: "*I hate to think about it – I would be in such fear and trepidation as to what really could happens; the pitfalls where I could end up and back to square one. It is frightening.*" (Notley et al., 2015)

1.3 Fear of death

For some people, the possibility that they might die because of a deterioration in mental health was a significant worry. For some, there was concern that returning to an unstable mental state would put them at risk of dying by suicide. For others, there was a sense that intense mental experiences could overwhelm a person to the extent that they would simply die, as a result of declining mental health.

> Person with a schizophrenia-spectrum disorder: "*[psychosis] almost cost me my life and it has impressed on me very strongly that I shouldn't allow things to get so out of control*." (Baker, 1995)

1.4 Traumatic experiences of mental ill health or treatment

People in these studies had all lived through intensely distressing experiences related to their mental health. In their quotes, it was clear how distressing these memories remained when invoked in discussions about fears of recurrence and progression. For some, the difficult or traumatic memories were centred on the intensity or severity of their mental illness. Whereas, for others, there was trauma grounded in experiences of undergoing involuntary, coerced, or distressing treatment or hospitalisation.

> Person with a post-partum mental health condition: "*I almost killed my son. I don't think my husband ever forgave that. I don't want to hurt any more children. I was afraid it would happen again. It's been almost fifteen years, but you remember how it felt, the terrible agony of thinking you're crazy and feeling that there can't possibly be hell after death because that was hell pure and simple*." (Peindl et al., 1995)

> Person with psychotic post-partum mental health condition: "*…the shocking departure out of my own home with police and ambulance and the whole street out… it's very traumatic to process, particularly you know, if you're able to, you know, have been, quite, you know, well-functioning up until now."* (Forde et al., 2019)

2. Low-risk, low-reward lifestyle

To manage FORP, people with a range of conditions, from psychosis to depression, reported adopting a conservative, low-risk, low-reward lifestyle that served to avoid precipitants of poor mental health (Figure 2.2). This is an understandable, and potentially adaptive, response to living with a mental health condition. Indeed, it also seemed to underlie adherence to treatment, especially medication, which may maintain mental wellness. However, across the synthesised studies, this approach also led people to avoid potentially enjoyable life experiences, such as having relationships, or to curtail certain employment opportunities. Hence, individuals who adopt a highly avoidant low-risk, low-reward lifestyle may inadvertently make themselves more vulnerable to worse mental health. For example, avoiding relationships can increase loneliness and reduce social support, both of which are potentially protective of deteriorations in mental health (Figure 2.2).

> Person with a depressive disorder: *"I'm afraid to move out to take a risk or go someplace else or take positions that will challenge me more because I don't know if it will trip me into a depression and then I will fail completely… so I structured my life as carefully as possible."* (Coyne & Calarco, 1995)

Across the synthesised studies, there were three manifestations of this lifestyle, which were coded as subthemes: limiting relationships; limiting life goals, and fears of changing treatments.

2.1 Limiting relationships

Some people consciously decided to limit their interactions with other people to avoid the stress that could precipitate recurrence or progression. Interestingly, this avoidance extended to all forms of relationships, including those platonic, romantic, and familial, and those both fleeting and meaningful. This approach seemed to acknowledge the inherent stresses associated with building and maintaining relationships, and how these might negatively impact one's mental health. These anticipated stresses could lead to outright avoidance, such as not pursuing a romantic relationship or talking to people generally, but also a tendency to avoid sharing one's feelings and a preference for superficial relationships. However, these self-imposed limits were sometimes in tension with peoples' desires, such as women with a history of post-partum psychosis who chose to forgo having another child despite a desire to grow their family (Peindl et al., 1995).

> Person with a depressive disorder: "*It has strongly affected my attitude about relationships. It makes me afraid of being in them because I'm afraid they will precipitate something.*" (Coyne & Calarco, 1995)

> Person with a schizophrenia-spectrum disorder and depression: "*I always think I'm gonna get unwell again and again, that's maybe another reason why I don't go out, I don't wanna talk to people 'cause I'm thinking last time, when I had an episode, it was public… that kind of scared me… I'm thinking what if I get unwell again, what if that same thing happens again?*" (Sandhu et al., 2013)

2.2 Limiting occupational/life goals

Similarly, people noted a desire to leave their comfort zone and pursue valued experiences, such as re-entering the workforce, seeking more responsibility, or travelling. However, for those adopting a low-risk, low-reward lifestyle, these valued experiences were

avoided or postponed because of real or perceived threats to their mental health. For many people, although they desired greater independence or responsibility, there was a concern that they would be unable to manage it, or that they lacked sufficient external supports to prevent recurrence or progression, if they were to pursue these goals.

> Person with a depressive disorder: "*It really makes you think twice about what kind of work you're doing. I mean I want to go to the Third World and work, but you think "great" so what happens if I'm over there and you know, it happens*" (Coyne & Calarco, 1995)

2.3 Fear of changing treatment

Many people directly linked their desire to persist with their current mental health treatment, particularly medication regimens, to FORP. For these people, their current treatment plan was identified as an important part of maintaining mental wellness. Whilst medication adherence is often helpful, many people expressed a desire to cease or taper their pharmacotherapy, which they reported they did not pursue due to FORP. Importantly, intention to persist with medication was also found in those who, according to Dutch guidelines, were no longer indicated to be using anti-depressants (Eveleigh et al., 2019). Hence, FORP seemed to elicit greater adherence to one's current treatment, even if the current regiment may no longer be the most appropriate for them.

> Person with an anxiety or depressive disorder: "*Well, I'm feeling very well, I am very stable. I'm in harmony, I don't have any mood swings or anything. I don't think I could feel any better than I do now. Also, mentally. So, I won't risk [ceasing antidepressant medication]. I won't attempt it, maybe it would be successful, but I won't dare to try.*" (Eveleigh et al., 2019)

3. Inability to trust oneself

Many people noted that when mentally unwell, their understanding and insight into themselves and their world was disturbed. Importantly, this was not limited to those with a history of delusions or psychosis. As an example, people with a history of depression noted a tendency toward negative appraisals and thoughts that they would not ordinarily endorse. For some, knowledge of these disturbances made it difficult to trust their assessment of their own mental health during periods of relative mental wellness. Moreover, some had a lack of confidence in their ability to cope with stressors that might worsen their mental health.

> Person with post-partum psychosis: "*…when [my partner] would say things like 'are you feeling ok?'…or you know just look at me really concerned… it just made me feel like it would always, like really shook me, because I'd be like 'oh gosh, am I not ok?'… maybe something's wrong with me again' and I just can't even tell.*" (Forde et al., 2019)

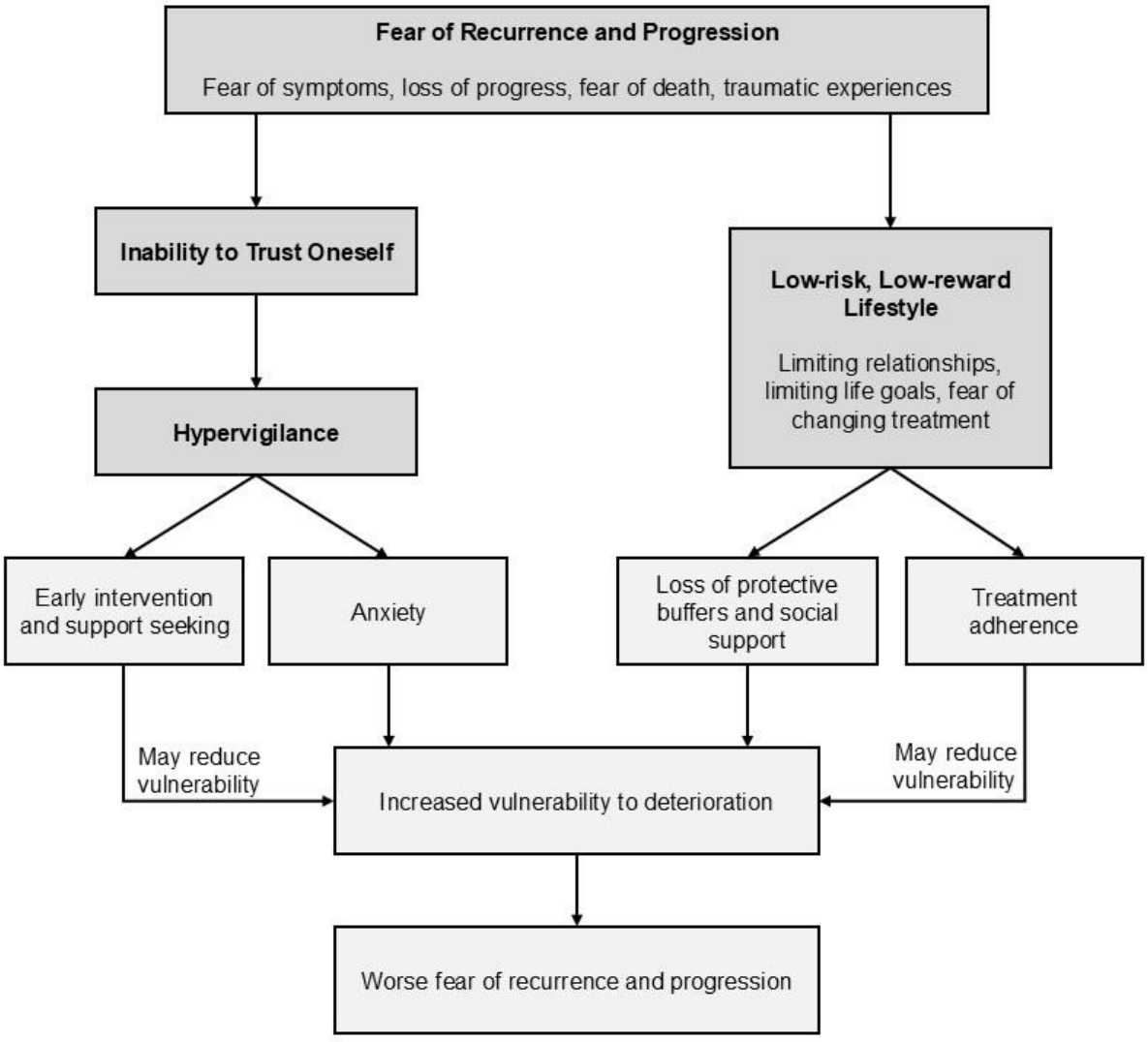
> Person with a depressive disorder: "*When you're depressed, you don't have the distance... you start to believe the negative thoughts... later they seem almost humorous*" (Coyne & Calarco, 1995)

4. Vigilance-Hypervigilance

To resolve this lack of self-trust, many people consciously chose to be vigilant towards symptoms of mental health (Figure 2.2). This vigilance was an important strategy for managing their mental health in recovery, as it helped people to identify early warning signs of deterioration, and thus seek early intervention or further support. However, it was clear that for some, this self-monitoring was a stressful and inadvertently anxiogenic strategy, as normal fluctuations in physiological and psychological state, such as those in irritability, sleep, and low mood, could be perceived as threatening.

Person with post-partum psychosis or mania: "*You can have an off day and think you're really ill again but you're not, you're just having an off day, it took about two years to realize they were normal highs and lows, other people have them but it's like you can't have normal ups and downs.*" (Robertson & Lyons, 2003)

Figure 2.2 Transdiagnostic Model of FORP in People with a History of Mental Health Conditions



Given the large proportion of qualitative studies strictly concerned with psychosis (Table 2.1). We re-analysed our model (Figure 2.2) in the nine studies with predominantly non-psychotic samples (Allan et al., 2019; Coyne & Calarco, 1995; Eveleigh et al., 2019;

Grime & Pollock, 2003; Kondoni & Kouimtsidis, 2017; Leydon et al., 2007; Notley et al., 2015; Peindl et al., 1995; Van Geffen et al., 2011; Varela et al., 2007). When we excluded quotes from studies with predominantly psychotic samples, across the remaining studies concerned with depression, anxiety, and substance use disorders, all themes and subthemes (with one exception) were still identified. The only exception was fear of dying – this subtheme was only identified for those with a history of psychosis.

2.3.4 Quantitative Literature

Of the 16 studies included in the quantitative analyses, the largest number of studies focused on schizophrenia-spectrum disorders (k = 11), the remainder were on depression (k = 2), substance use (k = 1), bipolar (k = 1), and post-partum mental health conditions (k = 1). Five of the 16 studies reported on multiple types of mental health conditions (Table 2.2).

2.3.4.1 Measures of FORP. The most utilized measure of FORP was the Fear of Recurrence Scale (k = 7; FoRSe; Gumley & Schwannauer, 2006). This questionnaire measures three subscales, including a specific fear of relapse subscale. If data on this subscale was not available, data related to the total FoRSe score was reported. The next most common measure of FORP was the Self-Appraisal Questionnaire (k = 2; SAQ; Coyne & Calarco, 1995). Where data on the fear of recurrence subscale was not available, data related to the imposition of limits composite was reported. The next most common measure of FORP was the Worries About Mental Health Questionnaire (k = 2; WAMHQ; Bassett et al., 2009). This questionnaire contains preoccupation, distress, and conviction subscales. As no one subscale was more related to FORP than any other, data related to the total WAMHQ score was reported when available. The remaining studies used different single items to measure FORP (k = 5). Table 2.2 reports which studies used which measures.

Table 2.2 Characteristics of Studies Reporting Quantitative Data Related to FORP

Studies concerned with Mental Health Outcomes, Quality of Life, Age, and Gender					
Study	**Participants**	**FORP Measure**	**Outcome measures**	**Associations with FORP (*r*, unless otherwise stated)**	**Quality Rating**
Allan et al. (2023)	N = 25 Schizophrenia-spectrum disorder	Single item	Single item – anxiety Single item – paranoia	Partial *r* = .07 – .15 Partial *r* = .11	17/31
Bassett et al. (2009)	N = 25 Schizophrenia-specturm disorder	WAMHQ subscales	Psychotic Symptom Rating Scale (PSYRATS; Haddock et al., 1999) Delusion preoccupation amount Delusion preoccupation duration Delusion conviction Delusion distress amount Delusion intensity Beck Anxiety Inventory (BAI; Beck et al., 1988) Penn State Worry Questionnaire (PSWQ; Meyer et al., 1990)	 .13 – .15 .38 – .50 .07 – .04 .49 – .53 .38 – .50 .30 – .43 . 58 – .64	7/8
Braehler et al. (2013)	N = 40 Schizophrenia-spectrum disorder	FoRSe fear of relapse	Beck Depression Inventory (BDI; Beck et al., 1996)	.52	9/13
Collett et al. (2016)	N = 21 Schizophrenia-spectrum disorder	WAMHQ total	BDI Beck Scale for Suicidal Ideation (BSS; Beck et al., 1979)	.72 .48	7/8
Gumley et al. (2015)	N = 169 Schizophrenia-spectrum disorder	FoRSe fear of relapse	Calgary Depression Scale (CDS; Addington et al., 1993) Early Signs Scale (Birchwood et al., 1989)	.51 .73	9/13
Jamalamadaka et al. (2020)	N = 121 Schizophrenia-spectrum and non-psychotic disorders	FoRSe total	Mental Health Anxiety Inventory (MHAI; Commons et al., 2016) Work and Social Adjustment Scale (WSAS; Mundt et al., 2002)	.76 .70	6/8
Ryan et al. (2021)	N = 55 Schizophrenia-spectrum disorder	FoRSe total	Age Gender	-.04 *d* = .06	6/9

Sired et al. (2021)	N = 110 Schizophrenia-spectrum and anxiety disorders	FoRSe fear of relapse	Patient Health Questionnaire (PHQ-9; Kroenke et al., 2001)	.71	4/8
			Generalized Anxiety Disorder 7 (GAD-7; Spitzer et al., 2006)	.70	
			MHAI	.72	
			Recovering Quality of Life (Keetharuth et al., 2017)	-.71	
			WSAS	.51	
			Age	-.11	
			Gender	*d* = .04	
White and Gumley (2009)	N = 27 Schizophrenia-spectrum disorder	FoRSe fear of relapse	Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) depression subscale	.55	7/8
			HADS anxiety subscale	.63	
			Clinician-administered Posttraumatic Stress Disorder Scale for people with Schizophrenia (CAPS-S; Gearon et al., 2003)	.61	
			Impact of Event Scale (IES-R; Weiss & Marmar, 1997)	.73	
			Number of psychiatric hospital admission	.40	
			Age	.01	
			Gender	*d* =.80	

Studies concerned with Medication Adherence and Health-related Behaviors					
Study	**Participants**	**FORP Measure**	**Outcome measures**	**Associations with FORP**	**Quality Rating**
Adams and Scott (2000)	N = 39 Affective or schizophrenia-spectrum disorder	Single item	Evaluated as highly adherent to medication	OR = 9.63	5/8
Bentzley et al. (2015)	N = 69 Opioid dependence	Single item	Greater intended length of buprenorphine maintenance treatment (< 1, 1 – 6, 6 – 12, 12 – 24, >24 months)	OR = 7.71	7/8
Coyne and Calarco (1995)	N = 17 Major depressive disorder	SAQ fear of recurrence	One lifetime depressive episode vs recurrent depression	*d* = .05	4/8

Devulapalli et al. (2010)	N = 140 Bipolar disorders	Single item	Evaluated as adherent to medication	OR = 7.8	7/8
Eisner et al. (2019)	N = 18 Schizophrenia-spectrum disorder	FoRSe fear of relapse	Use of psychosis symptom monitoring smartphone app	ρ = -.58	6/9
Kirk et al. (2000)	N = 25 Depressive and anxiety disorders	SAQ fear of recurrence	One lifetime depressive episode vs recurrent depression	*d* = 1.28	7/8
Peindl et al. (1995)	N = 268 Post-partum mental disorders	Single item	Action undertaken to prevent further pregnancy (e.g., adoption, sterilization, abortion)	OR = 1.77	4/8

Note. Participant characteristics only reported for those with a current or past mental health issue, healthy control group data is not reported here. Measures of mental health outcomes and quality of life if there is available on their association with the study's respective FORP measure. For purposes of brief sample categorization, schizophrenia-spectrum disorder includes people diagnosed with an affective disorder with psychotic features.

2.3.4.2 Age and Gender. All three studies with available data on the relationship between FORP and age found that age was not significantly associated with FoRSe fear of relapse in samples of people with schizophrenia, psychosis, or anxiety, r = -.112 – .006, p > .05, median r = -.035 (Ryan et al., 2021; Sired et al., 2021; White & Gumley, 2009). Similarly, within these studies, FoRSe fear of relapse did not differ between men and women, d = -.059 – .796, p > .05, median d = -.041.

2.3.4.3 Diagnoses. Only three studies reported data on FORP across different mental health conditions. One study found that people with a self-reported history of psychotic mental health conditions reported significantly greater total FoRSe than those with non-psychotic mental health conditions, d = .363 (Jamalamadaka et al., 2020). Conversely, another found that those with a self-reported history of psychosis do not differ from those with anxiety in terms of total FoRSe, d = .270, p > .05, (Sired et al., 2021). Lastly, for people who had recovered from a major depressive episode, SAQ fear of recurrence was not significantly greater in those with a comorbid anxiety disorder, d = .768, p > .05 (Kirk et al., 2000).

2.3.4.4 Relapse. Based on two studies in people with schizophrenia, FORP appeared to be associated with psychotic relapse cross-sectionally and longitudinally. Firstly, the number of lifetime psychiatric admissions to hospital was significantly associated with FoRSe fear of relapse, r = .395, p < .05 (White & Gumley, 2009). FoRSe fear of relapse was a significant predictor of shorter time to psychotic relapse, even when controlling for early signs and symptoms of psychosis, exp(β) = 1.20, p < .05 (Gumley et al., 2015).

Two cross-sectional studies compared FORP in those with a history of a single episode of depression to those with recurrent depression. One study found no difference in SAQ fear of recurrence between such groups, d = .05, p > .05 (Coyne & Calarco, 1995).

Conversely, another study found that whilst SAQ fear of recurrence was unrelated to time since last major depressive episode, those with recurrent major depression reported greater SAQ fear of recurrence than those with a single lifetime major depressive episode, $d = 1.28$, $p < .05$ (Kirk et al., 2000).

2.3.4.5 Medication Adherence and Health Behaviours. Despite heterogeneity in participant characteristics, diagnoses, and assessment of FORP, all three studies that provided relevant data found that FORP was positively associated with medication adherence. In opioid dependent people, concern that one might relapse after a reduction in buprenorphine dose was associated with a longer intended duration of buprenorphine use, OR = 7.71 (Bentzley et al., 2015). People with a severe mood disorder or schizophrenia who were independently deemed highly adherent to their current medication regimen rated fear of re-hospitalization as a stronger influence on their adherence compared to those that were deemed partially adherent, OR = 9.63 (Adams & Scott, 2000). Similarly, in people with a bipolar disorder, fear of relapse was more likely to be endorsed by those that were medication adherent compared to non-adherent, *OR* = 7.8 (Devulapalli et al., 2010).

However, the two studies that explored the relation between FORP and other health behaviours found mixed results. One study used weekly self-reported symptom monitoring via a smartphone app to assess for the risk of psychotic relapse in people with a schizophrenia-spectrum disorder and found that FoRSe fear of relapse was significantly correlated with poorer completion of weekly monitoring, $\rho = -.58$, $p < .05$ (Eisner et al., 2019). Lastly, one study explored the relationship between FORP and family planning decisions made by women with a history of postpartum mental illness, predominantly postpartum depression. Women who took action to prevent further pregnancy by abortion, adoption, or sterilization of themselves or their partner were more likely to report fear of recurrence than those that did not take action to prevent further pregnancy, OR = 1.77 (Peindl et al., 1995).

2.3.4.6 Quality of Life. Two studies administered assessments of FORP and quality of life to participants. They found that higher FORP was associated with poorer quality of life, with large relationships, $r = 0.514 – 0.71$, $p < .05$, median $r = .696$ (Jamalamadaka et al., 2020; Sired et al., 2021).

2.3.4.7 Mental Health Outcomes. For people with a schizophrenia-spectrum or anxiety disorder, which was the only outcome data available, all five studies found a significant positive association between depression and FORP, $r = .51 – .72$, $p < .05$, median $r = .547$ (Braehler et al., 2013; Collett et al., 2016; Gumley et al., 2015; Sired et al., 2021; White & Gumley, 2009). Overall, five studies explored anxiety in relation to FORP. Two studies that used the FoRSe found a significant positive association between anxiety and FORP, $r = .633 – .695$, $p < .05$ (Sired et al., 2021; White & Gumley, 2009). Two studies found a significant positive association between anxiety about mental health and FORP, $r = .724 – .763$, $p < .05$ (Jamalamadaka et al., 2020; Sired et al., 2021). One study found anxiety was significantly associated with WAMH-Q preoccupation (r = .427) but not conviction or distress ($r = .300 – .369$) (Bassett et al., 2009). Across all these anxiety studies median association with FORP was $r = .633$. Similarly, propensity to worry was significantly positively associated with all WAMH-Q subscales, $r = .577 – .635$, $p < .05$ (Bassett et al., 2009). In addition to these studies, a longitudinal network analysis study found that FORP was significantly positively associated with anxiety at the same time point, $r = .15$, $p < .05$, and it predicted anxiety the next day, $r = .07$, $p < .05$, even when controlling for all variables in the network, including paranoia, hearing voices, negative affect, confidence, perceived support, and sleep changes (Allan et al., 2023).

One study explored the relationship between FORP and symptoms of trauma arising from psychosis-related events. They found that in people with schizophrenia, FORP was significantly positively associated with clinician rated and self-reported posttraumatic symptoms, $r = .61 – .728$, $p < .05$ (White & Gumley, 2009). They also found who were

experiencing post-psychosis post-traumatic stress disorder reported greater FORP than those that did not (d = 1.55, p < .05).

Three studies assessed the relationship between FORP and clinician-rated symptoms of psychosis in people with a schizophrenia-spectrum disorder. One study found that FORP was not significantly associated with the time spent preoccupied with a persecutory delusion or their conviction in the delusion, but was significantly positively associated with distress related to the delusion, r = .488 – .534, p < .05 (Bassett et al., 2009). Two studies explored the relationship between overall positive symptoms and FORP, one found a significant positive correlation, r = .51 (Gumley et al., 2015), whereas the other found a non-significant correlation, r = .279 (White & Gumley, 2009). Conversely, both these studies found overall negative symptoms to be positively associated with FORP, r = .18 – .472, p < .05. A longitudinal network analysis study found that FORP was significantly positively associated with hearing voices, r = .11, p < .05, but not hearing voices the next day, nor was it associated with paranoia in the same time window or the next day, when controlling for all variables in the network, including anxiety, negative affect, confidence, perceived support, and sleep changes (Allan et al., 2023).

2.4 Discussion

The present review aimed to synthesize existing qualitative research on FORP in people with mental health conditions, and review the quantitative associations between FORP and psychological outcomes, quality of life, health behaviours, age, and gender. Overall, FORP was identified in people with a lived experience of a range of conditions, including schizophrenia-spectrum, bipolar, depressive, anxiety, and substance use disorders. In qualitative analyses, FORP was associated with an inability to trust oneself and hypervigilance to symptoms of deterioration, which both increased anxiety but promoted early identification of deterioration and support seeking. Similarly, people with a history of

mental illness often reported adopting a “low-risk, low-reward” strategy. As with hypervigilance, the low-risk low-reward strategy had adaptive functions, such as reducing stress and promoting medication adherence. However, at the same time, the low-risk, low-reward strategy also led people to be less likely to have social supports and to limit choices that may have bolstered their quality of life. Although in the qualitative analyses, FORP appeared to have benefits and disadvantages, in quantitative analyses, there were moderate to large associations between FORP and depression, anxiety, other mental health outcomes, and poor quality of life. Lastly, although there was a paucity of quantitative research in non-psychotic mental health conditions, FORP appeared to be associated with greater medication adherence across different mental health conditions.

2.4.1 Qualitative Findings

Fear of recurrence or progression was reported by people with lived experience of a variety of different mental health conditions. Qualitative analyses identified a number of subthemes reflecting the specific concerns about FORP that people raised: 1) *Fear of symptoms,* 2) *loss of progress*, 3) *fear of death*, and 4) *traumatic experiences*.

In reaction to these fears, many people explicitly adopted a cautious, low-risk but low-reward lifestyle that they believed would prevent deterioration of their mental health. This approach involved: 1) avoidance of real and perceived triggers of recurrence and progression, such as drug misuse or stressful situations, 2) adherence to ongoing treatment, even when that treatment was no longer indicated; and 3) avoidance of valued and desired, yet nevertheless anxiogenic, opportunities for independence, responsibility, and social connection. This low-risk approach is understandable, especially considering the serious and complex mental health conditions faced by many of the participants. However, it was clear that for some this avoidant and conservative approach to recovery and ongoing mental

health care interfered with the attainment of personal goals and desires, and even restricted one's access to protective buffers, such as social support (Figure 2.2).

Many of the behaviours described within the quotes related to the low-risk, low-reward lifestyle could be conceptualised as safety behaviours. These are behaviours which temporarily alleviate anxiety by seemingly preventing a feared outcome, in this case mental health deterioration, but which inadvertently maintain or exacerbate anxiety in the long-term by preventing habituation to anxiety and disconfirmation of exaggerated threat expectancies (Craske et al., 2008). However, in clinical practice it can be difficult to distinguish between a safety behaviour and an adaptive safety precaution, especially in people with prior experience of, and greater susceptibility to, a feared outcome. This is the case in many chronic physical conditions, where safety behaviours may not just maintain or exacerbate anxiety but may actually worsen an underlying condition (Sharpe et al., 2022b). Sharpe and colleagues' (2022b) propose that in contrast to safety behaviours, safety precautions will: 1) promote approach of a feared situation rather than avoidance, 2) are based on a realistic, rather than overestimated, threat, 3) are proportional to the threat, 4) are able to mitigate or control the risk of the feared outcome, and 5) allow for engagement in valued activities. These principles may also be useful to determine when behavioural responses to FORP are a maladaptive safety behaviour, or an adaptive safety precaution. This suggests that for some, FORP, at least at milder levels, may be adaptive and promote sensible safety precautions to be adopted.

Similarly, due to prior experience of relapse, or an awareness of how mental illness may alter one's appraisals of various situations or experiences, some people felt unable to trust their own appraisal of their mental health. These people perceived a significant risk for deterioration, and a poor capacity to cope with stressors. Hence, they relied on a strategy of hypervigilance towards early warning signs of ill mental health to reassure themselves of safety and identify the need for further support. This hypervigilance appeared to be exacerbated amongst those who had experienced mental health related trauma, which is

consistent with hypervigilance being a known consequence of trauma (Weiss, 2007). Hence, while vigilance may be helpful and adaptive, by identifying early warning signs and thus enabling early intervention, the boundary between vigilance and hypervigilance was difficult to navigate for many people. Hypervigilance was reported to provoke anxiety, which in turn exacerbates hypervigilance, potentially creating a positive feedback loop that increases the chance mental health deterioration. Hence, like safety precautions within the low-risk, low-reward lifestyle, some vigilance to early warning signs may be one effective strategy in reducing risk of relapse, such as in bipolar disorders (Morriss et al., 2007).

2.4.2 Quantitative Findings

The present review found that FORP was consistently associated with several important mental health outcomes and related behaviours. Firstly, all available studies found that FORP was moderately to highly associated with symptoms of depression, with similar associations between FORP and anxiety. Moreover, in schizophrenia, FORP was generally associated with positive psychotic symptoms and distress, as well as negative, and post-psychotic trauma symptoms. The consistent magnitude of these findings speaks to the robustness of the relationships. Secondly, all studies that assessed the relationship between FORP and intended or actual medication adherence found those with higher FORP reported greater adherence, with strong effects based on reported odds ratios. Importantly, this relationship was found across people with a range of different presentations, including affective conditions, opioid dependence, and the schizophrenia-spectrum. Although there were only a few studies exploring this association, the findings were remarkably consistent across disorders and medications. Lastly, in the two studies that examined FORP in relation to quality of life, FORP consistently predicted impaired functioning and poorer quality of life. These findings are consistent with fear of cancer recurrence (Simard et al., 2013) and fear of progression in other chronic illnesses (Sharpe et al., 2022a).

Conversely, it was difficult to draw any conclusions about the relationship between FORP and other health-related behaviours, largely because most health behaviours were assessed in single studies only. Non-medication related health behaviours appeared to have relationships with FORP that may indicate avoidance of distressing thoughts or stimuli. For instance, FORP was associated with non-adherence to weekly psychotic symptom monitoring using a smartphone app, which may indicate avoidance (Eisner et al., 2019). This is consistent with other research that has demonstrated that people with a substance use disorder are less likely to quit smoking if they believe cessation of smoking will increase their risk of illicit substance use relapse, even when controlling for nicotine and illicit substance dependence (Xie et al., 2021). Here, FORP is associated with a decreased likelihood of engaging with an adaptive health behaviour. However, avoidant changes in health behaviour are arguably best exemplified by women who feared the recurrence of a postpartum mental health issue choosing to avoid further pregnancies by undergoing medical procedures, or adopting another child (Peindl et al., 1995). Although there was a paucity of research on non-medication related behaviours, health behaviours and their association with FORP are worthy of further examination, particularly because those health behaviours can have enormous impacts on people's lives.

There was only a single prospective study that examined FORP as a predictor of future relapse in psychosis. This study found that FORP predicted a shorter time to relapse, even when controlling for early warning signs of psychosis (Gumley et al., 2015). This is supported by the finding elsewhere that higher FORP predicts higher FORP the following day, even when controlling for some early warning signs (Allan et al., 2023). Lastly, one other study in people with psychosis found cross-sectional relationships between FORP and number of lifetime psychiatric admissions (White & Gumley, 2009), but the causal direction of that relationship is unclear. Further in depression, only one of two cross-sectional studies demonstrated that those with recurrent depression reported greater FORP than those with a lifetime single episode of depression (Kirk et al., 2000). However, longitudinal research

determining whether high levels of FORP are a risk factor for mental health relapse is needed.

Interestingly, no study with available data reported a significant association between FORP and gender. This is surprising given that women, on average, report and demonstrate higher levels of fear and anxiety than men, particularly after gendered socialization factors begin to differentially affect people (McLean & Anderson, 2009). Similarly, age had no relationship with FORP. However, the age distributions of these three studies indicate that few older adults (those aged over 65) were sampled. Hence, variance in FORP due to age may emerge in future research that samples those aged under 18 and those over 65.

2.4.3 Convergence Between Qualitative and Quantitative Findings

Overall, the quantitative findings are congruent with the model developed through meta-synthesis. Specifically, higher levels of FORP are associated with distress and poorer mental health outcomes, including increased anxiety and post-traumatic stress symptoms. There was also quantitative evidence to support the notion that FORP leads to a low-risk, low-reward lifestyle. There was clear evidence of increased medication adherence in those with higher FORP, which may be adaptive or maladaptive depending on the context. However, there was quantitative evidence of avoidance of situations that may be triggering but are nevertheless valued, such as expanding one's family, which are consistent with the low-risk, low-reward lifestyle (Peindl et al., 1995). Further, FORP was associated with potentially adaptive behaviours, such as monitoring early-warning signs of psychosis (Eisner et al., 2019). There was strong evidence that higher FORP was associated with worse quality of life, which would be expected if FORP was associated with impairment in functioning across physical, mental, and social domains.

2.4.4 Theoretical Implications

From the current qualitative study, we developed a transdiagnostic framework, described above, to understand FORP. Our model shares a number of similarities with the schizophrenia fear of relapse framework (Zukowska et al., 2022). Specifically, both models note the role of past trauma within mental healthcare settings as a major trigger for the fear of future traumatization. Similarly, both models note that concerns about loss of function, and the resulting social avoidance, triggered by FORP, may inadvertently increase vulnerability to mental health deterioration. Furthermore, our model is also congruent with the cognitive-interpersonal model of early warning signs of psychosis which proposes that hypervigilance and avoidance may be used to cope with fear of psychotic relapse (Gumley et al., 2020). However, the present review extends these previous frameworks. Both the schizophrenia fear of relapse framework and the cognitive-interpersonal model are psychosis-specific models, whereas the current model is proposed to be transdiagnostic. Aside from fear of death, all themes and subthemes were accounted for by studies of people without psychosis, as well as those with psychosis, supporting the likely transdiagnostic nature of the observed constructs.

Moreover, the present meta-synthesis identified ways in which some level of FORP may be adaptive for people with a history of mental health conditions, which differs from Zukowska and colleagues' (2022), but has long been acknowledged in the fear of cancer recurrence literature (Almeida et al., 2019; Lee-Jones et al., 1997). For FORP in mental health, increased adherence to medication appears to be one such potentially adaptive consequence of FORP, which was borne out in both qualitative and quantitative analyses. Similarly, vigilance towards early warning signs of deterioration, such as sleep disturbances, anhedonia, and irritability, may facilitate early intervention, even though when vigilance becomes hypervigilance it can exacerbate anxiety and have negative impacts. Despite this, the quantitative analyses were clear that more severe levels of FORP were associated with increased depression, anxiety and poorer quality of life for people with a range of different

disorders. This raises questions about where on a continuum of FORP the level that might be optimally associated with benefits, and whether this is dependent on the context (e.g. the severity of mental health issue), the time since last episode (e.g. likelihood of relapse) or other factors (e.g. the personal values of the individual). Nevertheless, the data linking high levels of FORP and negative psychosocial outcomes support the view that FORP is unhelpful when severe.

Given the relevance of FORP to a range of mental health conditions, the present review raises questions about how other theoretically related constructs may overlap with FORP. For instance, most contemporary conceptualisations of substance use disorders distinguish between a lapse, such as an abstinent person consuming one beer, and a relapse, the resumption of regular uncontrolled drinking. The abstinence violation effect (Marlatt & Gordon, 1985) could be viewed as a cognitive and affective response to having a lapse, based on the belief that a lapse is tantamount to a relapse. This abstinence violation effect has been found to predict relapse in people who smoke cigarettes (Curry et al., 1987), socially drink (Collins & Lapp, 1991), and binge eat (Grilo & Shiffman, 1994). It seems plausible that FORP may predict the abstinence violation effect. That is, those most fearful of a relapse are those most likely when confronted by a lapse, to believe that a relapse is inevitable. That fear may drive continued drinking, substance use, or binging behaviour. It remains possible that a similar process may account for the finding that FORP predicts actual relapse in people with a schizophrenia-spectrum disorder, even when controlling for early signs and symptoms of psychosis (Gumley et al., 2015).

The present review was exclusively focused on FORP within people who have lived experience of a mental health condition. However, fears of recurrence may also be experienced by carers and loved ones who have not themselves been diagnosed with the condition. Caregivers of people with cancer are known to also report FCR, and may even report greater FCR than the patients they care for (Braun et al., 2021). A recent systematic review of qualitative research on FCR in carers found that whilst the experience of FCR was

similar to that of survivors, the carers' experience was uniquely characterized by their assumed role as a 'protector' of the person they cared for (Webb et al., 2022). Just like in cancer, there is evidence suggesting that friends and family of those with a mental health condition also experience FORP. Research on the family of people who recovered from first episode psychosis found that FORP was a common concern of carers, and that they had little confidence in their ability to identify and cope with future relapses (Lal et al., 2019). Similarly, carers of people with a schizophrenia-spectrum disorder reported FORP and a sense of responsibility over the individual's medication adherence (Kelly et al., 2021). Lastly, family members of women with post-partum psychosis also report FORP and vigilance towards signs of relapse, and that FORP was a factor in family planning decisions regarding future pregnancy (Forde et al., 2019).

Beyond caregivers, mental health professionals involved in the care of those who experience mental health conditions may also worry about recurrence or progression. Whilst some processes, such as (hyper)vigilance, may still be a factor for them, FORP is likely to be experienced and manifest in ways unique to that role, as with carers (Webb et al., 2022). Qualitative research has found that in community mental health settings the different perspectives of psychosis patients, carers, and mental health professionals informs the way they monitor and respond to early warning signs of psychosis (Allan et al., 2020). Whilst all parties are concerned with preventing relapse, some patients may privilege autonomy and reduction in side effects over clinical stability, in contrast to the priorities of some mental health professionals. This has implications for treatment decision making and the application of enforced treatment, which may also be relevant to other conditions where there is high risk for involuntary or coercive treatment, such as in high suicidality, mania, or anorexia nervosa. However, the role of mental health professionals, and thus the interactions between them, carers, and service users with regards to FORP, may differ in clinical settings where this is less of a concern. Whilst the experience of carers and mental health professionals was beyond the scope of the present review, research on these groups and the interactions

between them remains an important avenue of future research and may present opportunities for systemic interventions for FORP and shared clinical decision making.

2.4.5 Clinical Implications

Based on the findings of this mixed-methods review, it is evident that some people with lived experience of a mental health issue experience FORP. Importantly, these fears are not limited to people with a history of psychosis. People with a range of different diagnoses experience FORP, and thus, may also experience increased distress and an impact on their quality of life, even when they are technically recovered. Indeed, there was some evidence of health-related behaviours, such as reproductive decision-making, that were impacted long after the mental health illness had abated and when the risk of recurrence was objectively low – there is some evidence that prophylactic medication use can decrease the risk of post-partum mania and psychosis (Bergink et al., 2012). Whilst this review cannot establish the direction of causality, it is evident from those findings, and the findings of the meta-synthesis, that FORP is associated with significant distress. Hence, the risk of FORP negatively impacting the lives of people after intervention should be considered in clinical practice, particularly during discharge planning, when one might expect FORP to be high. Indeed, it may be that explicitly addressing FORP as part of relapse prevention would be very useful therapeutically.

Despite this, there is a paucity of research on interventions for FORP. The authors are aware of three studies that reported on interventions that purportedly targeted fear of relapse in people with a schizophrenia-spectrum disorder, only one of which significantly reduced FORP. Both a 16-session group compassion-focused therapy program with integration of mindfulness skills (Braehler et al., 2013), and an 8-session early warning signs and emotion regulation group program (Ryan et al., 2021) did not significantly reduce FORP between baseline and end of treatment. Whilst Braehler and colleagues' (2013) compared

compassion-focused group therapy with treatment-as-usual, Ryan and colleagues' (2021) lacked any control group and still did not demonstrate a reduction in FORP despite a reduction in clinician-rated psychotic symptoms. Hence, neither approach is likely efficacious for treating FORP in people with schizophrenia. To our knowledge, only one study has successfully demonstrated a reduction in FORP in people with schizophrenia. Gumley and colleagues' (2022) compared EMPOWER, an intervention that combined peer and clinician support with self-reported daily early warning signs monitoring via a smartphone app, to treatment-as-usual in a RCT over 12 months and found a moderate reduction in fear of relapse in the EMPOWER group compared to treatment-as-usual.

However, such interventions need to be sensitive to any potential benefits that may be associated with some level of FORP. Increased medication adherence was associated with FORP in both quantitative and qualitative studies in the present review. It has also been reported that medication adherence can be a response to fear of chronic physical illness progression (Sharpe et al., 2022a). In many situations, adherence to psychotropic medication is protective. As an example, anti-psychotic medications are generally effective at reducing the symptoms of schizophrenia, especially positive symptoms and the risk of psychosis relapse (Haddad & Correll, 2018; Leucht et al., 2012). However, these drugs are associated with significant side effects, including cardiac disease, tardive dyskinesia, and diabetes (De Hert et al., 2012). Hence, people with a schizophrenia-spectrum condition may weigh the perceived positive effects (e.g., relapse prevention) against the perceived deleterious effects (e.g., metabolic syndrome), with many reluctantly accepting long-term medication despite endorsing a desire to reduce or cease anti-psychotic medication with professional support (Crellin et al., 2022). This is important as long-term use of anti-psychotic medication is intended to prevent relapse. However, a systematic review of relapse definitions used in randomized-controlled trials of anti-psychotics in people with a schizophrenia-spectrum condition found that these definitions varied greatly and may capture false positives (Moncrieff et al., 2020). There was no consensus for when symptom

change constitutes a psychotic relapse, most trials in the review did not specify a minimum duration of symptoms, and/or did not require the presence of positive symptoms alongside functional decline. This, alongside the potential for rebound psychosis or a withdrawal syndrome following cessation of anti-psychotic medication (Chouinard et al., 2017), may confound estimates of relapse prevalence and consequently overestimate the utility of long-term anti-psychotics for reducing relapse risk. Similarly, a Cochrane review of randomised controlled trials comparing discontinuation and continuation of antidepressants in people with depressive or anxiety disorders who have recovered found that there is a lack of evidence to support long-term continuation of antidepressants, as they may not prevent relapse (Van Leeuwen et al., 2021). All medications have side-effects, and even newer anti-depressants are associated with a myriad of potential side-effects (Carvalho et al., 2016). If medication is being continued “just in case”, many individuals will be experiencing side effects without any clear benefit of continued medication. Indeed, one of the studies included in the present review found that FORP was the most significant barrier to discontinuation of antidepressants in people who were, but are no longer, indicated to be using them (Eveleigh et al., 2019). In clinical practice careful consideration of FORP and the ways in which it positively and negatively impacts psychosocial outcomes and adherence is important, and intervening with FORP could improve quality of life, as long as the complexities are considered.

While the data in this review provides a strong case for the need for clinical intervention for those with a higher degree of FORP, based on the literature, there is limited evidence for interventions that can reliably reduce FORP, especially outside the schizophrenia-spectrum, in the context of mental health. Tauber and colleagues (2019) conducted a meta-analysis of treatment trials to reduce fear of cancer recurrence. They found both traditional cognitive-behavioural therapy (CBT) and contemporary CBT (e.g., mindfulness, acceptance and commitment therapy) were efficacious in the management of FCR, although contemporary CBT resulted in larger gains than traditional CBT. Given some

similar constructs observed in FORP in the context of mental health in the current review, adapting contemporary CBT approaches may be a worthwhile approach for future research.

2.4.6 Limitations

Firstly, due to the heterogeneity of the included studies, it was not possible to conduct a meta-analysis. Studies varied in the nature of the sample (e.g., type of mental health condition), measure of FORP, and measures of psychosocial outcomes. Indeed, some of the correlations between variables, such as measures of FORP and depression or anxiety were very high (e.g., Sired et al., 2021). This raises the question of whether available measures of FORP conflate the fear of progression or recurrence with its consequences, such as distress; or whether some of the constructs, such as anxiety about mental illness, are measuring very similar constructs. The most commonly used measure (i.e. FoRSe), is psychosis-specific and there is currently not a transdiagnostic measure of FORP in the context of mental health, as there is for physical health (i.e., FOPQ; Herschbach et al., 2005). Future research which developed a psychometrically robust measure of FORP in the context of mental health would be welcome. Future research should also investigate the degree of conceptual overlap between similar constructs.

Secondly, none of the identified qualitative studies explicitly aimed to explore FORP. In all included studies, FORP emerged as a theme or subtheme, or could be interpretated from participant quotes, in relation to another construct. The fact that there were no qualitative studies focusing explicitly on FORP meant that we were unable to provide a meta-synthesis of previously identified themes, rather we had to provide a meta-synthesis at the original quotation level. Whilst these results demonstrate the relevance of FORP to people with current or past mental health conditions, as FORP emerged spontaneously from a range of different studies and participants, it may mean that some elements of the impact and nature of FORP were not uncovered within the studies themselves. Hence, future

qualitative research explicitly concerned with FORP will be required to attain a richer understanding of the phenomena and provide corroborating evidence for the transdiagnostic model proposed in the current review. Similarly, future research should consider if and how FORP may differ between people with lived experience of different mental health conditions. As a result, while we have proposed a theoretical model of FORP in the context of mental health, further research is required to test the major tenets of the model.

Lastly, the present review sought to explore fears of recurrence *and* progression, consistent with the prevailing definition of fear of cancer recurrence (Lebel et al., 2016). Most of the included studies identified participants who were expressly concerned with fear of acute relapse in the context of schizophrenia-spectrum, post-partum, or puerperal disorders. However, some participants may have had residual symptoms, as Baker (1995) noted that one interviewee declined to be audiotaped due to ongoing paranoia. It is possible that someone with residual symptoms may fear progression of their illness, whereas someone in recovery may be more likely to fear recurrence. This debate between the conceptual overlap of the constructs of fear of progression and fear of recurrence is ongoing in the psycho-oncology literature. It is only recently that this conceptual question has been empirically tested, where fears of cancer recurrence and progression were found to be related but distinct constructs (Coutts-Bain et al., 2022). Future research in FORP in the context of mental health should bear these important conceptual issues in mind.

2.4.7 Conclusions

Notwithstanding these limitations, the present review possessed several notable strengths. It is the first systematic review to explore FORP in mental illnesses beyond schizophrenia. We included both qualitative and quantitative analyses, which allowed us to capture a larger number of studies than earlier reviews (e.g. 32 included studies vs nine, Zukowska et al., 2022). The mixed-method approach also allows for a more complete

synthesis of available evidence. Hence, this novel, and comprehensive, review provides a foundational body of evidence that answers several key questions regarding FORP and draws attention to clinically relevant gaps in the literature.

The present review has demonstrated that FORP is experienced by a range of people with a history of different mental health conditions. FORP encapsulates fears of symptoms, loss of progress, fears of death and retraumatisation. These fears give rise to two key responses: (1) the adoption of a low risk, low reward approach to life; and (2) mistrust of one's own assessment of one's mental health which in turn gives rise to hypervigilance. FORP was strongly associated with worse mental health symptomology and quality of life in all studies. However, FORP also was associated with increased medication adherence and may be adaptive under certain circumstances. Critically, the identified themes were not just a concern of people with psychosis, all but one of the themes and subthemes were also identified in those with non-psychotic mental health problems. The consistency of themes lends weight to the view that FORP is a transdiagnostic issue.

Chapter 3: A Transdiagnostic Model of Fears of Recurrence and Progression in People with Mental Health Conditions

The following chapter is a reproduction of material contained in a manuscript presently under review, with slight changes to make the formatting consistent across the broader thesis:

Coutts-Bain, D., Sharpe, L., & Hunt, C. (2025). A transdiagnostic model of fears of recurrence and progression in people with mental health conditions. *Under review*.

Daelin Coutts-Bain conducted, transcribed, and coded all qualitative interviews, collected quantitative data, and completed all quantitative and qualitative analyses, as well as data visualisation, and wrote the original manuscript.

Professor Louise Sharpe independently coded a subset of qualitative interviews to establish a preliminary coding framework, and was involved in refinement of the framework and emerging theoretical model. She also supervised the research and provided review and editing of the original manuscript.

Professor Caroline Hunt provided supervision, and review and editing of the original manuscript.

3.1 Introduction

The idea that a person with lived experience of an illness could worry about that illness recurring or getting worse is not novel. For example, fear of cancer recurrence (FCR) is a near ubiquitous response to living with the ongoing threat of cancer (Lee-Jones et al., 1997). Whilst some FCR is helpful in motivating adaptive health behaviour, FCR can become severe and is associated with poorer quality of life, psychiatric morbidity, and maladaptive disturbances in health behaviours, irrespective of the objective risk of recurrence (Almeida et al., 2019; Simard et al., 2013). This concept has been extended to other chronic physical illnesses, and a recent meta-analysis found that fear of disease progression in people with different chronic physical illnesses is also associated with greater depression, anxiety, and poorer quality of life (Sharpe et al., 2022a). However, comparatively little research exists on fears of recurrence and progression (FORP) in people with mental health conditions.

Many mental and physical health conditions have residual symptoms that persist even when the affected person is relatively well. Conversely, some people experience distinct asymptomatic periods before becoming acutely unwell again. Diagnostic systems, like the DSM-5-TR (American Psychiatric Association, 2022), define remission as a specified period of reduced or absent symptoms. However, the specified durations are arbitrary and symptom thresholds for relapse and remission can be contentious, particularly in psychosis (Moncrieff et al., 2020). Hence, for this study, our construct of interest was FORP, rather than fear of recurrence, where FORP is the fear that a mental health condition and its symptoms will recur *or* worsen in the future.

In Chapter 2, we found that in people with mental health conditions FORP is associated with poorer quality of life, worse symptoms of depression and anxiety, but greater medication adherence (Coutts-Bain et al., 2023a). That review also developed a model of FORP derived from a meta-synthesis of 19 qualitative studies, which identified four subthemes underlying FORP (*fear of symptoms*, *loss of progress*, *fear of death*, and

traumatic experiences). In addition, there were three themes related to FORP, which were: *inability to trust oneself*, *hypervigilance*, and a *low-risk low-reward lifestyle*, which was comprised of three subthemes (*limiting relationships*, *limiting life goals*, and *fear of changing treatment*). According to the model, some degree of FORP is a normal part of adjusting to life with a mental health condition that may motivate vigilance towards warning signs of deterioration, medication adherence, and avoidance of stressors that precipitate deterioration. However, at more severe levels of FORP, excessive avoidance, and adherence to unnecessary treatment, restricted an individual's capacity to attain personal goals and maintain protective social buffers. Similarly, higher levels of FORP may lead individuals to interpret normal mental state fluctuations as indicative of deterioration, and thus threatening, leading to anxiogenic hypervigilance. Hence, while some degree of FORP may form an adaptive response to lived experience of a mental health condition, it can be distressing, and may inadvertently increase the risk of deterioration.

In contrast to earlier research, which focused on diagnosis-specific manifestations of FORP, predominantly fear of psychosis relapse, this model proposed that FORP was a transdiagnostic construct and that the processes underlying FORP were not unique between conditions (Coutts-Bain et al., 2023a). However, the data underlying this model had several limitations. Firstly, about half the included studies pertained to fear of psychosis relapse, and thus more common conditions, such as depression and anxiety, were underrepresented. Moreover, no included study intended to explore FORP a priori. That is, FORP emerged in qualitative analyses in relation to other constructs of interest. These limitations may have precluded the meta-synthesis from capturing all factors that account for FORP and any factors that might distinguish FORP between psychotic and non-psychotic conditions.

Since the development of the preliminary model (Coutts-Bain et al., 2023a), we identified only one qualitative study that intended to explore FORP (Gumuchian et al., 2024). This study on adults remitted from major depressive disorder found that fear of depression recurrence led to potentially adaptive and maladaptive responses, including hypervigilance

towards symptom fluctuations, increased support seeking, engagement with healthy behaviors, and reduced risk-taking. Overall, these findings are congruent with the preliminary FORP model proposed in Chapter 2. However, there is yet to be a primary exploration of FORP in other mental health conditions, such as disordered eating, or anxiety conditions. Hence, it remains to be seen whether the processes underlying FORP across a range of different mental health conditions can be accounted for by transdiagnostic processes, and whether the preliminary model arising from the meta-synthesis in Chapter 2 provides a comprehensive account of FORP.

To address this gap in the literature, this study had two aims: 1) develop a theoretical model of FORP from interviews with adults diagnosed with different mental health conditions, and qualitatively evaluate its transdiagnostic applicability, and 2) conduct exploratory quantitative analyses to evaluate whether FORP is associated with theoretically derived variables in adults diagnosed with mental health conditions.

3.2 Method

3.2.1 Design

Two related studies were conducted. Study 1, a semi-structured qualitative interview study based on grounded theory (Glaser & Strauss, 2017), and Study 2, a cross-sectional online survey study designed to quantitatively evaluate some of the theoretical relationships described by the model developed in Study 1. The study was approved by the University of Sydney Human Research Ethics Committee.

3.2.2 Population and Sample

Individuals could participate if they were at least 18 years old, living in Australia, and reported being diagnosed with any mental health condition irrespective of severity.

Participants were not excluded if they had been diagnosed with a neurodevelopmental condition, such as autism or ADHD, but such diagnoses were not sufficient to meet inclusion criteria.

Between January and December 2023, Study 1 participants were recruited via the University of Sydney Psychology Clinic and social media advertising using Facebook and Instagram advertisements. The clinic offered psychological assessment and intervention to the community provided by student psychologists enrolled in a post-graduate clinical psychology degree. Clinic attendees who consented to be contacted about research were contacted via email after treatment and discharge. These participants voluntarily gave access to their clinic diagnostic record and were interviewed for Study 1 but did not take part in Study 2. After conducting several interviews and establishing a preliminary coding framework, recruitment was expanded to the wider community via social media advertising to enhance the clinical diversity of the interviewee sample. Community members were eligible to participate if they self-reported being diagnosed with a mental health condition by a psychologist or doctor and entered these diagnoses into a free response box for data collection. The quantitative data from this online survey was used exclusively for Study 2. After completing this online survey about FORP, they could express interest in being interviewed and were strategically sampled for qualitative interviews based on their diagnostic information to ensure a broad sample of people. Therefore, the remaining 10 participants in Study 1 also took part in Study 2. To ensure that this subset of shared participants was not inflating the relationships between both studies, we also performed the analyses without participants from Study 1, and the pattern of results remained identical.

Study 1 interviewees from all recruitment sources were strategically sampled based on demographic and clinical factors to ensure a diverse range of experiences were represented, for example including both common and complex mental health conditions. Interviewees received a $30 gift voucher, and all survey participants were eligible to enter a $100 gift voucher draw.

3.2.3 Procedure

The interviewer conducted one-to-one, semi-structured interviews, in-person or via Zoom, depending on participant preference. See Appendix B1 for the basic interview guide. Recorded interviews were transcribed by DCB and analysed using thematic and framework analysis (Gale et al., 2013; Glaser & Strauss, 2017). The first four transcripts were independently analysed by the interviewer and LS, a female experienced clinical and health psychologist, to develop a preliminary coding framework, with discrepancies resolved through discussion between the coders. All discrepancies were resolved without the need for a third independent coder. In light of substantial coding agreement, all subsequent interviews were coded by DCB. The coding framework was refined with each subsequent interview, transcription, and coding session. This process was managed within Excel and discussed in regular meetings between DCB and LS. This continued until thematic saturation was achieved, indicated by the absence of new codes identified in four consecutive interviews. See Appendix B2 for the final basic coding framework. The interviewer, DCB, was a male postgraduate clinical psychology student. The final model was evaluated by DCB, LS, and CH, another female experienced clinical psychologist. Finally, interviewees were invited to provide feedback, as a part of member checking procedures (Glaser & Strauss, 2017), on the model after all interviews were coded and the proposed final version of the model had been developed.

The research team was likely influenced by their clinical experience as both LS and CH had more than 30 years' experience, as well as previous research on FORP. While Chapter 2 proposed a preliminary theoretical account of FORP, the interviewer and coders were aware that the interviewees experience may differ from existing literature, given the novelty of the study design and sample. Hence, coding and framework analysis employed both inductive and deductive reasoning (Gale et al., 2013). The interviewer and coders practiced personal reflexivity and discussed coding decisions and applications reflexively. Hence, although not conducted in isolation from our knowledge of prior models, effort was

made to ensure thematic development was guided by analysis of our primary data, consistent with a grounded theory methodology. The interviewer was not known to any of the interviewees. Reporting of methodology was guided by the consolidated criteria for reporting qualitative studies (COREQ) (Tong et al., 2007).

To facilitate exploratory analyses in Study 2, several variables identified in the preliminary coding framework (Study 1), or hypothesized to be related to FORP, were assessed using valid and reliable questionnaires, see Variables.

3.2.4 Variables

3.2.4.1 Study 1. Variables of interest in Study 1 were codes, subthemes, and themes, emerging from analysis of transcribed interviews, as per grounded theory (Glaser & Strauss, 2017). Participant recruitment source, lifetime psychiatric diagnoses, and history of psychiatric inpatient admission were considered within framework analysis to explore potential inter-participant differences in themes and subthemes (Gale et al., 2013).

3.2.4.1 Study 2. The revised Impact of Event Scale assessed intensity of intrusive thoughts about past episodes of being mentally unwell (α = .79) (Weiss & Marmar, 1997). The Internalized Stigma of Mental Illness Inventory (ISMI) alienation (α = .79) and withdrawal (α = .80) subscales assessed participants' degree of internalized stigma, whereas the experienced discrimination subscale (α = .75) assessed personal experience of mental health-related discrimination (Ritsher et al., 2003). The Questionnaire on Anticipated Discrimination assessed anticipation of encountering mental health-related discrimination in different settings (α = .86) (Gabbidon et al., 2013). Depression Anxiety Stress Scales (DASS-21) assessed symptoms of depressive (α = .91), anxiety (α = .81), and stress (α = .89) in last fortnight (Lovibond & Lovibond, 1995). Participants' belief that their mental health

conditions were caused by biological factors were assessed with two items previously used in the literature (Lebowitz et al., 2013).

To assess FORP, we asked participants two questions related to fear of recurrence and fear of progression of their mental health concerns. Participants indicated whether they worried that the “mental health conditions I no longer experience will come back” or that “those I currently experience will get worse” on a scale ranging from 0 (not at all) to 4 (a great deal). The two scores were summated to give a total score.

3.2.5 Data Analysis

3.2.5.1 Study 1: Qualitative. Transcribed interviews were analysed using framework analysis (Gale et al., 2013), within grounded theory (Glaser & Strauss, 2017). To evaluate the robustness of identified themes and subthemes, framework analysis was used to group and analyse quotes by participant characteristics.

3.2.5.2 Study 2: Quantitative. Our analyses were exploratory, and thus the relationships between specific variables were not pre-specified. However, we intended to use correlational analyses to evaluate relationships purported within the model developed in Study 1. In addition, we used hierarchical regression to evaluate which variables contributed most strongly to FORP, after first controlling for clinical factors related to FORP, and residual psychological symptoms.

3.3 Results

3.3.1 Study 1: Qualitative Results

Strategic sampling ensured the final sample was roughly split amongst attendees of the University of Sydney Psychology Clinic and services in the community. Eighteen participants were interviewed (characteristics in Table 3.1). Mean interview duration was 61 minutes (range: 49-76 minutes). Interviewees were aged between 18 and 62 years old (M = 35.5, SD = 12.37).

Table 3.1. Interviewee Characteristics

		Psychology Clinic (*n* = 8)	Community (*n* = 10)	Total (n = 18)	
		n	*n*	*n*	%
Gender	Man	1	4	5	27.8
	Woman	6	4	10	55.6
	Non-binary	1	1	2	11.1
	Genderfluid	0	1	1	5.6
Diagnoses	Unipolar mood	2	4	6	33.3
	Bipolar mood	1	4	5	27.8
	Anxiety	7	4	11	61.1
	Obsessive-compulsive	1	0	1	5.6
	Anorexia nervosa	1	2	3	16.7
	Schizoaffective	0	3	3	16.7
Diagnosis of primary concern[a]	Unipolar mood	2	3	5	27.8
	Bipolar mood	1	4	5	27.8
	Anxiety	4	0	3	22.2
	Obsessive-compulsive	1	0	1	5.6
	Anorexia nervosa	1	0	1	5.6
	Schizoaffective	0	3	3	16.7
>1 lifetime diagnoses		5	7	12	66.7
Neurodevelopmental diagnoses[b]		0	1	1	5.6
Source of diagnosis[c]	Psychologist	8	4	12	66.7
	Psychiatrist	0	9	9	50
	General practitioner	0	3	3	16.7
History of inpatient admission		1	7	8	44.4
Currently taking medication		2	9	11	61.1
Ethnicity[d]	Oceanian	0	5	5	27.8
	North-west European	2	3	5	27.8
	South-east Asian	0	1	1	5.6
	People of Americas	2	0	2	11.2
	North-east Asian	1	0	1	5.6
	Other	1	1	2	11.2
	Southern and Central Asian	1	0	1	5.6
Education	High school	0	2	2	11.2
	Certificate III, IV, or (advanced) diploma	1	2	3	16.7
	Undergraduate	3	3	6	33.3
	Postgraduate	4	3	7	38.9

Note. [a] One participant identified both OCD and AN as their primary concern. [b]Participants with co-occurring neurodevelopmental condition/s. [c]Multiple options selectable. [d]One participant's ethnicity data unavailable.

Six themes were identified, some with 2-3 subthemes. All participants were diagnosed with a mental health condition and had undergone treatment. At the time of their interview, all participants believed they were relatively well but nevertheless endorsed some degree of FORP.

1. In Retrospect. Even when relatively well, all participants reflected on their mental health at its worst. In retrospect, some people took a self-compassionate perspective that oriented them towards recognizing their strengths in recovery. However, memories of their behaviour or functional impairments were nevertheless imbued with feelings of shame or horror. Participants extrapolated expectations for their future based on this retrospective analysis of their experience, and in doing so, maintained sometimes unhelpful beliefs about themselves.

"It can be great because I'll go, oh, look how bad that was, you're so much better than that now, it's not going to happen like that again… But the times when it's bad, when I don't see it that way, I see it as, oh, that's something you're capable of repeating."

Woman. Unipolar mood and anxiety disorders. Clinic.

The nature of "in retrospect" could be broadly divided into two subthemes: *traumatic memories*, and an *inability to trust oneself*.

1.1. Traumatic Memories. Memories of being unwell were often described as traumatic. These became distressing reminders of the unpredictability of their conditions and the ever-present threat of recurrence. Hence, there was a universal vulnerability associated

with their experiences. For those with greater FORP, this perceived vulnerability tended to overpower a strengths-based interpretation.

"*I was just alone in my room, you know, and then the thoughts just popped in. The memories of those times… the traumatic moments, like a day where I was rushed to the hospital… everything was just like hell for me that day.*"

Man. Bipolar disorder. Community.

1.2. Inability to Trust Oneself. Many participants recalled being unable to tell how unwell they were during their worst periods, particularly for those with psychosis or mania. In hindsight, this was disturbing, and participants questioned whether they should trust their own appraisal of their mental state, even when relatively well.

"[During mania I] kind of was a different person… that's scary when you so wholeheartedly believe something and you're kind of told growing up like, oh, trust your instincts… No one really warns you about, oh, actually, sometimes you shouldn't do that, sometimes you're actually really wrong… That's what's scary."

Woman. Bipolar disorder. Community.

2. Fear of Recurrence and/or Progression. All participants worried that their conditions might recur or progress. However, their underlying fears were idiosyncratic and related to their previous negative experiences whilst unwell. For example, some feared coercive psychiatric treatment, whereas others worried about encountering discrimination, functional impairments, or dying by suicide or misadventure. These fears were greater in

those unable to trust their own judgements of their mental state as they perceived their mental health as more precarious.

"I just know what has happened in the past to me. And I fear that, you know, without certain treatment or just general life events, that something might trigger that and that I'll get to a place where I can't cope again."

Woman. Schizoaffective disorder. Community.

The underlying fears of participants could be organized as three subthemes: *fear of being harmed*, *fear of harming others*, and *fear of isolation*.

2.1. Fear of Being Harmed. All participants were aware of how a deterioration in their mental health could harm them. In some cases, harm referred to reduced functional capacity associated with deterioration. However, other participants were concerned with being subjected to discrimination, dying at the hands of others, or suicide.

"If somehow I do end up falling through the cracks of the system and I do get worse… It's not exactly as if I'm going to have society rally around me to help me get on my feet. I'm going to be having photos taken of me. I'm going to be that one guy that gets stabbed on a train because they were acting insane."

Woman. Schizoaffective disorder, anorexia nervosa, PTSD. Community.

2.2. Fear of Harming Others. Many participants worried that deterioration of their mental health would harm others, most often friends, family, or romantic partners. Some

worried about physically harming people, particularly those with a history of mania or psychosis. Conversely, others were more concerned with burdening people as they became unable to fulfil their roles and responsibilities, or inadvertently distressing them.

"[My biggest fear is] not so much about dying, it's more about not being here for my son. I'm okay with death, but just not being here… to be a mother, that's what hurts."

Woman. Anorexia nervosa, OCD. Clinic.

2.3. Fear of Isolation. For many participants, isolation was a prevailing fear. For some, this was the worst possible outcome of recurrence or progression.

"Most of [my friends] met me in my stable phase, so I don't know how many would actually stick around if I were to go crazy again'."

Woman. Schizoaffective disorder, anorexia nervosa, PTSD. Community.

3. Better Safe than Sorry. Due to FORP, participants consciously adopted a 'better safe than sorry' approach to manage their conditions. That is, they chose to take a cautious or conservative approach toward life to keep their mental health issues at bay.

"*I think maybe being overly cautious in that is not such a bad thing. I'd rather take the overly cautious route than not.*"

Non-binary person. Bipolar disorder, PTSD. Community.

This approach could be divided into three subthemes: *vigilance-hypervigilance*, *reassurance seeking*, and a *low-risk low-reward lifestyle*. Almost all participants engaged with each to some degree, and while these strategies could be adaptive, they could inadvertently perpetuate distress and increase vulnerability to relapse or progression.

3.1. Vigilance-hypervigilance. All participants reported being vigilant to their thoughts, emotions, and somatic sensations to identify early signs of deterioration. This vigilance created opportunities to implement individual strategies, or seek external support, to manage their conditions.

"I have to be more conscious to keep track of my mental status maybe compared to a regular bloke… there's people that have to keep track of their blood pressure, and I have to keep track of my mind."

Woman. Anxiety disorder. Clinic.

However, due to FORP, many participants interpreted ambiguous fluctuations in mental state as potentially indicative of relapse. Some became hypervigilant and thus noticed additional mild or ambiguous symptoms, creating a positive feedback loop of FORP. Symptom fluctuations were often related to mood, but also included somatic sensations (e.g., fatigue), changes in thought form (e.g., tangentiality), and thought content (e.g., self-criticism). These biases persisted despite being well for many years.

"I got home and it was like 6:30 and I was exhausted and on its own it's like, okay, you just had a busy day, but I was like, oh no, what if this is me going back into that?"

Woman. Unipolar mood and anxiety disorders. Clinic.

"I have had backslides… It feels like all the work I've done is gone out the window and I'm right back there… It's not a full backslide in retrospect… But at the time when in disaster brain, I'm like, it's all fucked!"

Non-binary person. Unipolar mood and anxiety disorders. Clinic.

3.2. Reassurance Seeking. When people were vigilant to symptom changes, they sometimes sought reassurance to manage the resulting fear. Although some sought out mental health professionals, most turned to trusted friends and family who reassured them that their experiences were normal, resulting in short-term alleviation of FORP. However, by diffusing the responsibility for symptom appraisal to others, this reinforced the belief that they could not trust themselves to know whether a symptom was of concern, perpetuating FORP.

"It reduces the fear of relapse for sure because if I tell someone what I'm experiencing and they say that's a normal thing, then I don't have to worry… Whereas, like, if I don't say anything to anyone, then I can't know the truth."

Genderfluid person. Schizoaffective and anxiety disorders. Community.

3.3. Low-risk, Low-reward Lifestyle. Many participants carefully structured their lives to avoid precipitants of deterioration. Sometimes this involved abstinence from alcohol and other drugs, or avoidance of stressful situations that could trigger deterioration. In doing so, many participants avoided stressful, but nevertheless valued and desired activities, including forming new relationships, having children, travelling, or occupational opportunities,

such as taking a promotion. Others made major life decisions, such as forgoing children, because, even if it might not precipitate deterioration, it could increase the cost of deterioration. In some cases, this low-risk low-reward lifestyle inadvertently reduced social or personal buffers that may protect against relapse or progression.

"Fear of relapse, it's kind of a limiting thought in a way because you think if I get a job and then I get unwell again, I'm letting them down. So, should I take a job?... I've just recently started a new job… But I haven't worked in a proper job for five years so something I've been thinking about a lot, like, should I take a risk of doing something that I really want to do? Or should I stay with what's comfortable and just try and live the most simple life possible so there's less chance that I would get stressed?"

Genderfluid person. Schizoaffective and anxiety disorders. Community.

Similarly, FORP could drive a conservative approach to maintenance treatment, as participants described reluctance to taper or cease psychiatric treatment even after long relapse-free periods, unpleasant side effects, or preference for non-pharmacological management. Long-term adherence to treatment can be indicated, particularly in psychotic or manic conditions, but in some instances this may lead to unnecessary use of medication.

"Even now when I think about, you know, I've been well now for [10 years]... should I at some stage think about stopping [SSRI]? And the fear of relapse just takes over. It's almost like, why would I take that risk?"

Man. Unipolar mood disorder. Community.

4. Avoidance. Alternatively, some participants managed FORP and related distress by explicitly avoiding thoughts and reminders of relapse and progression altogether.

"[FORP] sort of hovers around the surface as if it's wondering, 'should I come out for a bit of a look'. And, on the outside is a hand which will just knock it back in if it ever decides to rear its head… I try and repress everything so that I can function."

Man. Bipolar and anxiety disorders. Clinic.

Overall, these attempts at avoidance tended to either describe *suppression and distraction*, or *metacognitions that perpetuate FORP*.

4.1. Suppression and Distraction. When FORP became overwhelming, some participants attempted to reduce distress by thought suppression and distraction, which is likely to provide immediate relief but perpetuate FORP in the longer term.

"I'll go back to some bad habits, like, you know, have a drink or, you know, do something like that... I do try to escape or, you know, push [FORP] away sometimes."

Woman. Anxiety disorder. Clinic.

4.2. Metacognitions that Perpetuate FORP. Some participants endorsed positive and negative beliefs about worrying about getting worse, which may perpetuate the worry itself. For instance, some participants believed that FORP could become "self-fulfilling", and thus worried that FORP was dangerous. Conversely, others believed worry would prepare

themselves for an inevitable deterioration and/or motivate health protective behaviors, thereby perpetuating FORP by encouraging worry.

"I try not to [worry about relapse] because I feel like it's almost like a self-fulfilling prophecy, like if I worry too much about it, it will become that way."

Woman. Unipolar mood and anxiety disorders. Clinic.

"*[FORP is] good if it helps you catch things early and gives you a realistic sort of outlook."*

Woman. Schizoaffective disorder, anorexia nervosa, PTSD. Community.

5. Biological Beliefs and Prognostic Pessimism. Another factor that could exacerbate FORP was a belief that a genetic predisposition, neural abnormality, or biochemical imbalance caused or mediated one's mental health conditions. For some, these biological beliefs led to the assumption that their conditions were permanent and thus uncontrollable or incurable. Whilst this could absolve self-blame for having a mental health condition and challenge stigma, it led some participants to assume that relapse and/or progression were inevitable, exacerbating FORP.

"*I always just figure something probably wrong with my neural connection… I'm treating it like a chronic disease… it will [recur] it's just how it is.*"

Woman. Anxiety disorder. Clinic.

"I see [bipolar] as an inevitable chronic illness where I'm going to relapse at some point... it's a big thing to have hanging over you... it feels more hopeful to not be so fixed on this is entirely biological."

Non-binary person. Bipolar disorder, PTSD. Community.

6. Shame and Perceived Inferiority. Feelings of shame permeated expressions of other themes and subthemes, thus we observed shame and inferiority as an overarching theme. Many participants denied feeling ashamed that they had a mental health condition, per se. However, many felt ashamed that they sometimes experienced deteriorations in their mental health despite accrued treatment and experience of self-management.

This shroud of shame was most visible when participants remembered past episodes of poor mental health, which made the memories, and thus anticipation of deterioration, more distressing. Similarly, some felt guilty about using avoidant strategies, such as a low-risk, low-reward lifestyle or suppression, as they recognized how these might become problematic or limiting. Lastly, shame could create a motivational context for the adoption of biological beliefs that resulted in prognostic pessimism.

"My mom was feeding me… she'd shower me and like do stuff like that for me [when I was unwell]… I feel infantilized and humiliated that I required that, and I think that's probably self-stigma… I had an orthopaedic surgery three years ago and after that I also needed help with showering… there was no shame in that or in asking for help."

Non-binary person. Bipolar disorder, PTSD. Community.

3.3.1.1 Summary. Drawing on grounded theory, we developed a theoretical model to account for FORP. This model proposes that memories of negative, and sometimes

traumatic, experiences associated with being mentally unwell leads to negative expectations of future mental health deteriorations, including fear of being harmed, harming others, and becoming isolated. In retrospect, some people attribute being unable to accurately appraise their own mental state while unwell to the cognitive or perceptual distortions associated with their condition. This realization can be disturbing, as internal indicators of safety and mental wellbeing, such as euthymia, cannot be trusted. Hence, people perceive their mental state as more precarious, exacerbating FORP.

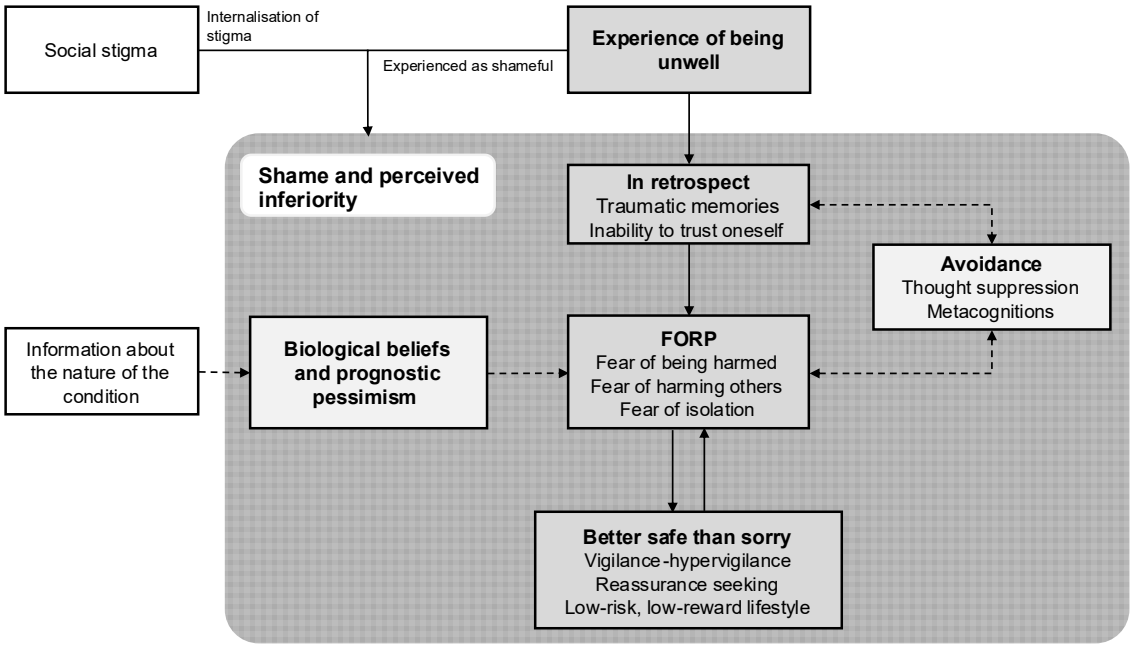
To alleviate FORP, people attempted to reduce their risk of deterioration with a “better safe than sorry” approach towards relapse prevention. This included appropriate vigilance towards mental state, facilitating identification of warning signs and early intervention. However, people may overinterpret mild or ambiguous mental state fluctuations as predictive of deterioration. This threat-related interpretation bias drives hypervigilance towards one’s own mental state, uncovering more threatening cognitive, emotional, or somatic phenomena, creating an anxiogenic feedback cycle. Due to FORP, individuals report threatening mental state fluctuations to trusted people. However, this may become reassurance seeking, alleviating FORP in the short term but inadvertently perpetuating their fear as they are reassured that the threatening fluctuation is not indicative of significant deterioration. Moreover, this behaviour perpetuates an inability to trust oneself, as responsibility for monitoring and interpreting their own mental state is diffused to those perceived as more objective. Lastly, FORP drives adoption of a low-risk, low-reward lifestyle that aims to prevent future mental health deterioration. To do this, people avoid potential precipitants of deterioration, and more rigidly adhere to maintenance treatment. However, this can inadvertently prevent engagement with stressful but nevertheless personally valued activities, and prolong potentially unnecessary medication use, respectively. Hence, this lifestyle may impair one’s capacity to access and maintain protective buffers, such as social connection, and occupational achievement.

Aside from mental state fluctuations, FORP may be elicited by memories of being mentally unwell that arise intrusively from internal or external reminders. However, in the moment, it may not be possible to manage FORP-related distress with “better safe than sorry” strategies. Hence, individuals attempt to avoid these reminders, and suppress traumatic memories or worries about the future. Although this may reduce FORP in the short-term, it ultimately perpetuates FORP by preserving the beliefs underlying their worry and preventing the processing of traumatic memories.

Another factor that may perpetuate FORP is a belief that the condition one fears recurring or progressing has a biological basis. Such beliefs may lead one to assume that their condition is permanent or beyond their control. Understandably, these assumptions exacerbate FORP by increasing the perceived risk of deterioration.

Finally, those more fearful of deterioration were more likely to feel ashamed of their experiences of being unwell, often in reference to their out of character behaviour or impaired functioning. In addition, people felt ashamed of their ‘failure’ to maintain stable mental health despite having received treatment and accrued experience of mental health management. Hence, feelings of shame may arise when people experience FORP intensifying the negative emotional experience of FORP (Figure 3.1).

Figure 3.1 Transdiagnostic Model of FORP in People with Mental Health Conditions



*Note. S*olid paths represent the central causal path of FORP. Dashed paths represent important auxiliary factors maintaining FORP.

To conduct our framework analysis, quotes were grouped and thematically analysed by participant characteristics. This analysis demonstrated that all themes and subthemes were represented irrespective of recruitment stream, history of inpatient admission, and the nature of their mental health condition/s. Interviewees were invited to give feedback on a lay summary of the model. All respondents endorsed the model without corrections.

3.3.2 Study 2: Quantitative Results

3.3.2.1 Demographic and Clinical Factors. Analyses were based on 269 participants, aged between 18 and 76 (*M* = 37.92, *SD* = 13.40). Demographic and clinical history frequencies are reported in Table 2. FORP scores ranged between 0 and 8 with a slight negative skew (*M* = 5.7, *SD* = 1.73). To ensure our 2-item measure was reliable, we recruited an independent sample of 59 people with different mental health conditions and

administered both the 2-item measure, and a more recently developed measure, the FORP-MHQ (Coutts-Bain et al., 2025), which is discussed in Chapter 4. The 2-item brief measure was strongly correlated with the FORP-MHQ (r = .721, p < .001), indicating sufficient reliability for the purposes of this study. Age, gender, whether one was born in Australia, and education were not associated with FORP (Table 3.2). However, significantly greater FORP was found amongst those currently using medication to manage their conditions, $F(1,267)$ = 5.264, p = .023, d = .28, those with a history of psychiatric inpatient admission, $F(1,267)$ = 7.780, p = .006, d = .35, and those with multiple diagnoses, $F(1,267)$ = 8.500, p = .004, d = .40. These variables were included in the regression analyses.

Table 3.2. Survey Respondent Characteristics

Characteristics		Total *N* = 269 *n*	%	Test statistic examining relationship to FORP	*p*
Gender	Man	50	18.6	F(3,265) = .211	.888
	Woman	192	71.4		
	Non-binary	24	8.9		
	Genderfluid	1	<1		
	Gender non-conforming	1	<1		
	Demigirl	1	<1		
Diagnoses	Unipolar mood	180	66.9		
	Bipolar mood	40	14.9		
	Anxiety	178	66.2		
	Obsessive-compulsive	22	8.2		
	Eating disorder	33	12.3		
	Schizophrenia-spectrum	15	5.6		
	Trauma and stressor-related	102	37.9		
	Personality disorder	48	17.8		
	Dissociative	6	2.2		
	Somatic symptom	3	1.1		
	Substance use	2	<1		
Primary diagnosis	Unipolar mood	107	39.8		
	Bipolar mood	32	11.9		
	Anxiety	58	21.6		
	Obsessive-compulsive	5	1.9		
	Eating disorder	9	3.3		
	Schizophrenia-spectrum	12	4.5		
	Trauma and stressor-related	26	9.7		
	Personality disorder	18	6.7		
	Dissociative	2	<1		
Number of lifetime diagnoses	>1 diagnosis	205	76.2	*F*(1,267) = 8.500	.004
Neurodevelopmental diagnosis[a]		36	13.4	*F*(1,267) = .902	.343
Source of diagnoses[b]	Psychologist	189	70.3		
	Psychiatrist	178	66.2		
	General practitioner	148	55		
	Pediatrician	1	<1		

History of inpatient admission		113	42	$F(1,267) = 7.780$	.006
Currently receiving therapy		172	63.9	$F(1,267) = 1.199$	.274
Currently taking medication		170	63.2	$F(1,267) = 5.264$	.023
Born in Australia		211	78.4	$F(1,267) = .554$	.457
Ethnicity	Oceanian	107	39.8		
	North-west European	102	37.9		
	Other	16	5.9		
	Southern and Eastern European	13	4.8		
	South-east Asian	10	3.7		
	People of Americas	7	2.6		
	North-east Asian	6	2.2		
	Sub-saharan African	4	1.5		
	Southern and Central Asian	3	1.1		
	North African and Middle Eastern	1	0.4		
Educational achievement	Did not complete high school	19	7.1	$F(4,264) = 1.904$	.110
	High school	35	13		
	Certificate III, IV, or (advanced) diploma	78	29		
	Undergraduate	87	32.3		
	Postgraduate	50	18.6		

Variables	*M*	*SD*	Cronbach's alpha (α)	Correlation with FORP (*r*)	*p*
Age	37.92	13.40	-	.049	.422
Biological beliefs	10.80	2.57	-	.225	< .001
Intrusive thoughts	16.43	7.46	.898	.460	< .001
ISMI Alienation	16.95	3.69	.801	.389	< .001
ISMI Withdrawal	15.88	3.76	.830	.342	< .001
ISMI Experienced discrimination	12.48	3.40	.840	.301	< .001
Anticipated discrimination	35.98	7.71	.898	.256	< .001
Depression	10.89	5.64	.916	.454	< .001
Anxiety	7.33	4.36	.839	.324	< .001
Stress	10.92	4.90	.860	.399	< .001
FORP	5.70	1.64	-	-	-

Note: [a]Participants with co-occurring neurodevelopmental condition/s. [b]Multiple options selectable.

3.3.2.2 Correlational Analyses. FORP was significantly correlated with all variables of interests, $p < .001$ (Table 3.2). Full correlation matrix is available in Appendix B3. FORP was significantly associated with having experienced mental health-related discrimination ($r = .301$), anticipating future discrimination ($r = .256$), intrusive thoughts about being unwell ($r = .460$), stronger beliefs that one's mental health conditions are biological ($r = .225$), and internalized mental health stigma ($r = .342$-$.389$). FORP was also significantly associated with current symptoms of depression ($r = .454$), anxiety ($r = .324$), and stress ($r = .399$). All these variables were normally distributed, aside from biological beliefs and FORP which had a small negative skew. However, as regression analyses are generally robust to slight violations of normality (Knief & Forstmeier, 2021), parametric analyses proceeded as planned.

3.3.2.3 Regression Analysis. In step 1 of the hierarchical regression to predict FORP, lifetime history of more than one diagnosis and inpatient psychiatric admission were significant predictors. Conversely, current medication use was not. Step 1 accounted for 6.4% of variance in FORP. In step 2, symptoms of depression, anxiety, and stress were added. However, only current medication use and depressive symptoms significantly predicted FORP. Step 2 accounted for 26% of variance in FORP. In step 3, all other variables of interest were added. However, only depressive symptoms ($\beta = .201$, $p = .012$), intrusive thoughts of being unwell ($\beta = .293$, $p < .001$), and biological beliefs ($\beta = .157$, $p = .005$) significantly predicted FORP. Overall, step 3 accounted for an additional 8.3% variance in FORP, with the final model accounting for 34.4% of total FORP variance (Table 3.3).

Table 3.3. Hierarchical regression predicting FORP.

Variables	FORP											
	Step 1				Step 2				Step 3			
	B(SE)	*β*	R^2	ΔR^2	*B*(SE)	*β*	R^2	ΔR^2	*B*(SE)	*β*	R^2	ΔR^2
>1 diagnosis	.552(.229)*	.148	.064	.064***	.288(.207)	.077	.260	.196***	.260(.204)	.070	.344	.083***
Inpatient history	.452(.204)*	.139			.227(.185)	.070			.198(.181)	.061		
Medication use	.369(.208)	.111			.398(.186)*	.120			.321(.182)	.097		
Depression					.086(.021)***	.304			.057(.022)	.201*		
Anxiety					.036(.025)	.096			.015(.025)	.041		
Stress					.044(.028)	.123			.005(.028)	.013		
Intrusions									.063(.015)	.293***		
Biological beliefs									.098(.034)	.157**		
ISMI Alienation									.046(.037)	.105		
ISMI Withdrawal									-.012(.038)	-.028		
ISMI Experienced discrimination									.003(.036)	.005		
Anticipated discrimination									-.003(.015)	-.016		

Note. $N = 255$, as missing-date was deleted listwise. *$p \leq .05$, **$p \leq .01$, **$p \leq .001$.

3.4 Discussion

The present study aimed to develop a model of FORP in people with mental health conditions from qualitative data, and to test some purported relationships between FORP and other constructs. FORP was reported by people diagnosed with numerous different mental health conditions, including psychotic and non-psychotic conditions. Drawing on grounded theory, we developed a model of FORP for this population. This model proposed that due to social stigma, people retrospectively viewed their experience of being unwell through a lens of shame. Traumatic memories of being unwell were extrapolated into fears for the future, leading to worry about being harmed (including functional impairment and death), harming others, and becoming isolated should deterioration occur. Some individuals also believed they should not trust their own appraisal of their mental state, which exacerbated FORP. To ameliorate FORP by reducing the risk of deterioration, people adopted a better safe than sorry approach characterized by vigilance to mental state fluctuations, support seeking, avoidance of stressors, and adherence to maintenance treatment. However, excessive application of these strategies, including hypervigilance, reassurance seeking, or adoption of a low-risk low-reward lifestyle which limited access to protective buffers, was common, inadvertently perpetuating FORP and increasing vulnerability to deterioration. In the shorter term, cognitive avoidance was used to rapidly relieve distress, inadvertently perpetuating FORP. FORP was also elevated amongst those who believed their conditions had a biological basis, as this could elicit prognostic pessimism. Generally, quantitative analyses supported relationships between FORP and factors identified in interviews. That is, FORP was associated with internalized mental illness stigma, discrimination, intrusive memories of being unwell, biological beliefs, and symptoms of depression, anxiety, and stress.

3.4.1 Qualitative Findings

According to the model, FORP is an expected response to lived experience of mental health conditions that can be distressing. Although FORP may simultaneously drive adaptive and maladaptive health behaviours, our findings indicate that those with greater FORP tend to be more distressed and reliant on strategies to prevent recurrence or progression which inadvertently perpetuate FORP and increase the risk of deterioration. Overall, these findings are congruent with the preliminary model of FORP proposed in Chapter 2. Indeed, all major elements of this model were identified in the present study, including traumatic experiences, inability to trust oneself, vigilance-hypervigilance, and the low-risk, low-reward lifestyle. However, the present study extends this preliminary model by integrating previously unidentified factors, such as pervasive shame, biological beliefs, and cognitive avoidance. Moreover, it elaborates on the recurring themes, such as the role of avoidance in perpetuating not just FORP but also the underlying traumatic memories, based on rich primary data from a more clinically diverse sample.

Critically, the framework analysis demonstrated all themes and subthemes were identifiable even when participants were grouped by lifetime history of diagnostic category and re-analysed separately (Gale et al., 2013). In addition, neither recruitment, nor inpatient admission history, were uniquely associated with any theme or subtheme. Together, these findings demonstrate the robustness of the model across disorders of varying severity and provide strong evidence of transdiagnostic applicability. Based on the present study, we propose that FORP is a transdiagnostic construct, as has been proposed in chronic physical illness (Herschbach & Dinkel, 2014; Sharpe et al., 2022a).

3.4.2 Quantitative Findings

Correlational analyses evaluated patterns of relationships identified in the qualitative model. This demonstrated that, as described in the model, greater FORP was associated

with intrusions about being unwell, stronger beliefs that one's mental health conditions were biological in nature, internalized mental illness stigma, experienced and anticipated mental health-related discrimination, and symptoms of depression, anxiety, and stress. In addition, FORP was also associated with current use of medication, consistent with the low risk, low reward subtheme.

The hierarchical regression analysis demonstrated that it was stronger intrusions and biological beliefs that were individually predictive of FORP, even when controlling for background factors and symptoms of depression, anxiety, and stress. Conversely, internalized mental health stigma, in terms of alienation and social withdrawal, as well as experienced and anticipated discrimination, were no longer associated with FORP. We did not measure shame, cognitive avoidance, metacognitions, or the better safe than sorry strategies, and so further research is needed to further test the predictions of the model.

3.4.3 Convergence between Qualitative and Quantitative Findings

Overall, the qualitative and quantitative findings were consistent. The results highlight the importance of aversive experiences during episodes of poor mental health, and the almost universal intrusive re-experiencing thereof. Indeed, post-traumatic stress symptoms following psychosis is associated with FORP in people with schizophrenia (White & Gumley, 2009). This is consistent with the negative experiences described by interviewees, including hospitalization and discrimination, which reportedly led to FORP. Together these findings suggest a central role of traumatic and negative memories of being unwell in contributing to FORP.

Qualitative analyses indicated that shame was an over-arching theme that coloured the experience of FORP. Internalized mental illness stigma was associated with FORP in univariate analyses, but ceased to predict FORP in the hierarchical regression equation once other variables were included. This may appear surprising, as shame was prominent in

our interviews. However, shame is not internalized stigma, per se. Internalized stigma, in relation to mental illness, is a process whereby an individual with a mental health condition endorses stereotypes about people with mental health conditions, applies these stereotypes to themselves, and feels devalued (Livingston & Boyd, 2010). Shame is just one emotional response invoked by this process. Secondly, the Internalised Stigma of Mental Illness scale is predominantly concerned with negative feelings toward *having* a mental health condition (Ritsher et al., 2003). Most interviewees denied feeling ashamed of their mental health conditions, as such, but nevertheless were ashamed of perceived failures in managing their conditions. We included internalized stigma to reflect the experiences of shame described by early interviewees, but a direct measure of shame may have yielded different results. While this is possible, one of the major sources of shame in the interviews were the memories of the person at their most unwell. It is possible that the shame emanated from the traumatic experiences and, hence, when re-experiencing phenomena were accounted for, internalized mental health stigma was no longer significant.

In contrast, believing that one's mental health conditions had a biological cause was associated with FORP in both qualitative and multivariate analyses. According to the model derived in this study, prognostic pessimism mediates this relationship. Although we did not measure prognostic pessimism in this study, this is consistent with experimental research that found when people with mental health conditions are shown biological accounts of their condition, they report poorer prognostic expectations. Similarly, telling individuals they are genetically predisposed to major depressive disorder causes them to recall more depressive symptoms in the preceding weeks (Lebowitz & Appelbaum, 2019). This has implications for FORP, as prognostic pessimism and cognitive biases towards symptoms were described as important in perpetuating FORP. Indeed, recent research has demonstrated that beliefs that mental health conditions are permanent, prone to recurrence, and unresponsive to treatment, are known to be associated with FORP (Coutts-Bain et al., 2025).

Critically, the quantitative analyses confirmed that some identified phenomena (i.e., intrusions and biological beliefs) predicted FORP over and above psychological symptoms. Not only does this support the qualitative findings in relation to these predictors, but it provides evidence that FORP is a distinct construct not wholly accounted for by psychological symptoms.

3.4.4 Theoretical Implications

Theoretical research on psychosis has identified ways that FORP may increase vulnerability to psychotic relapse. Seminal research on monitoring early warning signs of psychosis noted how fear of relapse may enhance attention to, and worry about, the meaning of mental state changes, thereby driving dysphoria and withdrawal which accelerates relapse (Birchwood, 1995). The cognitive-interpersonal model of early warning signs elaborates on how this might further constrain the efficacy of psychosis symptom monitoring by affecting service user and provider dynamics (Gumley et al., 2020). Within this theory, FORP drives anxiety and shame which elicits hypervigilance, and avoidance of mental healthcare services. These coping strategies are interpreted by healthcare providers as evidence of increasing risk of relapse, prompting further monitoring of the service user, thereby corroborating users' negative expectations of services and self, exacerbating FORP. The results of this study are broadly consistent with this theory, but extends it in meaningful ways.

Our model proposes that these processes are not solely related to schizophrenia-spectrum conditions but are broadly applicable across different diagnostic categories. This was observed in both qualitative and quantitative analyses. Although shame and trauma have previously been associated with FORP, empirically and theoretically (Gumley et al., 2020; White & Gumley, 2009), the present study elaborates on the potential mechanisms of how these factors drive FORP. According to participants, traumatic experiences whilst

mentally unwell led to ongoing intrusions. These traumatic memories led to an inability to trust one's own appraisal of their mental state, and simultaneous hypervigilance and avoidance to alleviate distress. In the longer term, people adopted a better safe than sorry attitude that prioritized safety, sometimes over valued activities and lifestyles. Importantly, our model also highlights non-professional interpersonal dynamics, such as the role of friends, family, and partners in support and reassurance seeking. Further, FORP enhanced potentially helpful healthcare utilization, including medication, rather than leading solely to avoidance. Interestingly, many of the complex relationships identified in the present study, including both over- and under-utilization of health care, have been identified in research on FCR (Thewes et al., 2012). It is probable that some of the models of FCR are also relevant to FORP.

The most well-known theories of FCR are complementary cognitive-behavioural models which have distinct foci (Fardell et al., 2016; Heathcote & Eccleston, 2017). The novel cognitive processing model of FCR proposes that all individuals experience intrusive thoughts about illness following a life-threatening diagnosis, but that those who interpret these intrusions as especially important develop cognitive biases which prevent these intrusions from naturally dissipating over time, perpetuating FCR (Fardell et al., 2016). Elements of this cognitive attentional syndrome (Wells & Matthews, 1996) were associated with FORP in people with mental health conditions. Indeed, our qualitative analyses indicate that unprocessed aversive memories are central to the development of FORP. Similarly, the Cancer Threat Interpretation model provides a framework consistent with some findings of this study (Heathcote & Eccleston, 2017). According to this model, because pain can predict cancer recurrence, cancer survivors must interpret painful sensations as potentially indicative of recurrence. This drives body-orientated hypervigilance and perpetuates FCR. In the case of mental health conditions, it is fluctuations in cognitive, emotional, *and* somatic symptoms that may indicate recurrence or progression, and thus which demand attention and interpretation (American Psychiatric Association, 2022).

Despite overlap between models of FCR and FORP, there were notable differences. The present study identified shame as a salient feature of mental health-related FORP. In contrast, a meta-synthesis of 87 qualitative studies on FCR found that shame rarely arose as a theme, and that fear, distress, and sadness were more characteristic of FCR (Almeida et al., 2019). This difference in the identification of shame, a more interpersonally grounded emotion, may reflect that although cancer-related stigma does exist, it is less pervasive than mental health-related stigma (Corrigan et al., 2000). Finally, the low risk, low reward lifestyle has not been identified in relation to FCR. It may be that the propensity for lifestyle choices, and stress, to exacerbate mental health deterioration is greater than in cancer, reducing the need to adopt a low risk, low reward lifestyle to manage FCR.

3.4.5 Clinical Implications

As the present study was exploratory in nature, it is not possible to make any recommendations for how excessive FORP may best be treated psychologically. However, our model suggests that future FORP-related interventions must be sensitive to the adaptive and maladaptive effects of FORP. For instance, a desired reduction in FORP may inadvertently decrease motivation to use appropriate better safe than sorry strategies. Conversely, psychoeducation that encourages vigilance to mental state may inadvertently exacerbate FORP. Hence, we recommend that future clinical research on FORP interventions monitor iatrogenic effects, including both outcome, such as relapse, and mechanism, such as poorer medication adherence and self-monitoring. Critically, this issue of iatrogenic effects is not insurmountable. EMPOWER, an app for self-monitoring early signs of psychosis, is a relapse prevention intervention sensitive to FORP (Gumley et al., 2020). In a feasibility trial, EMPOWER reduced FORP compared to treatment-as-usual (Gumley et al., 2022). Hence, there is preliminary evidence that FORP can be reduced without compromising appropriate self-monitoring.

3.4.6 Limitations

The findings of the present study must be qualified by some limitations. Firstly, we were only able to attain confirmed diagnosis from University of Sydney Psychology Clinic interviewees. However, there is evidence that people are reasonably reliable at self-reporting their own mental health diagnoses (Vieira et al., 2022). Similarly, we were unable to identify which our participants were presented in remission from their feared conditions and thus could not determine whether FORP differed between those in remission and those who were not. However, themes and subthemes closely related to the findings of Study 1 have been identified in prior qualitative research on people with remitted depressive conditions (Gumuchian et al., 2024). Secondly, we used a brief, individually developed measure of FORP for the quantitative study. This was because there are no validated FORP questionnaires, except one specific to schizophrenia (Gumley et al., 2015). In addition, we began data collection for the quantitative study whilst continuing to iterate upon the qualitative coding framework. Hence, some aspects of the model emerged in later interviews and thus were not assessed (e.g., cognitive avoidance, shame). There were also no validated measures of certain constructs (e.g., better safe than sorry, and inability to trust oneself). Therefore, future research should more stringently test the model.

3.4.7 Conclusion

Notwithstanding these limitations, the present study possessed several notable strengths. It is the first study to report on qualitative interviews explicitly designed to understand FORP across a diverse array of mental health conditions, including psychotic and non-psychotic conditions. In addition, the present study synthesizes primary qualitative data to rigorously develop a theoretical model and triangulate the results in a relatively large sample of people with prior mental health conditions.

The present study demonstrates that FORP is a clinically relevant construct for people with lived experience of different mental health conditions. FORP arose from aversive, sometimes traumatic, experiences of being mentally unwell that become ongoing intrusions. Due to FORP, people try to keep themselves well by keeping vigilant to fluctuations in their mental state, seeking support, avoiding stressful stimuli, and adhering to maintenance treatment. However, those with higher FORP became hypervigilant, reassurance seeking, avoidant of valued activities, and adherent to treatments that may be unnecessary. This could be particularly true of those who believe their mental health conditions are biological in nature, and those ashamed of their conditions or their perceived capacity to manage them. It is evident that FORP is a transdiagnostic construct with significant relevance to the mental health and wellbeing of people who have lived with mental health conditions and warrants further research.

Chapter 4: Validation of a Transdiagnostic Measure of Fears of Recurrence and Progression about Mental Health Conditions

This chapter is based upon the following published article, with slight changes to make the formatting consistent across the thesis.

Coutts-Bain, D., Sharpe, L., Hunt, C. (2025). Validation of a transdiagnostic measure of fears of recurrence and progression about mental health conditions. *British Journal of Clinical Psychology*, 1-16.

Daelin Coutts-Bain designed the survey, collected participant data, conducted all data analyses, and wrote the original manuscript.

Professor Louise Sharpe designed the survey, and provided review and editing of the original manuscript, while supervising the research.

Professor Caroline Hunt provided review and editing of the original manuscript, while supervising the research.

4.1 Introduction

Some people with lived experience of chronic illness worry about the possibility that their illness could recur or worsen over time (Sharpe et al., 2022a). This concept is particularly well-studied in relation to cancer, where fear of cancer recurrence is understood as a natural and potentially adaptive response to having lived with cancer (Lee-Jones et al., 1997). Nevertheless, fear of cancer recurrence can become chronic, distressing, and when severe is associated with poorer psychological outcomes and maladaptive disturbances in health behaviours (Simard et al., 2013). Fears of recurrence and progression (FORP) are also relevant to those who live with other chronic illnesses and is similarly associated with poorer psychological outcomes and quality of life (Sharpe et al., 2022a). However, research on FORP in relation to people with mental health conditions is comparatively nascent. Drawing on the prevailing definition of fear of cancer recurrence (Lebel et al., 2016), we define mental health-related FORP as a fear, worry, or concern that one's mental health conditions may recur or worsen with time.

In Chapter 3, a transdiagnostic model of FORP in people with mental health conditions was proposed based on a grounded theory study. The resulting model postulates that intrusive aversive memories of being mentally unwell fuel expectations for the future, leading to increases in FORP. In addition, these memories remind people of the cognitive and perceptual distortions associated with being mentally unwell. These reminders elicit an inability to trust one's own appraisal of their mental status, even if relatively well, further exacerbating FORP. In response to FORP, people adopt a 'better safe than sorry' approach to managing their mental health conditions which may involve: 1) interpreting ambiguous or mild fluctuations in their mental state as predictive of deterioration, and thus threatening, thereby driving vigilance towards them, 2) asking others whether these fluctuations indicate mental deterioration, and 3) avoiding life stressors and other precipitants of deterioration whilst adhering to treatment. These strategies may be adaptive, but they can also result in hypervigilance, reassurance seeking, and avoidance of stressful but nevertheless valued

personal and social activities, respectively. These factors then inadvertently perpetuate FORP and increase the risk of deterioration by causing distress and reducing access to protective buffers.

In Chapter 3, we tested some of these proposed relationships in a large sample (*N* = 269) finding evidence to support them. Furthermore, the findings of the most recent systematic review of FORP in relation to mental health were generally consistent with the full model (see Chapter 2). Specifically, FORP was associated with poorer psychological outcomes, including greater depression, anxiety, and symptoms of post-traumatic stress, as well as increased medication adherence. Additionally, one study demonstrated that FORP predicts a shorter time to psychosis relapse in people with a schizophrenia-spectrum condition, even when controlling for early warning signs of psychosis (Gumley et al., 2015). Hence, there is emerging evidence that FORP is an important construct in understanding the overall burden of lived experience of mental health conditions, and in predicting relapse.

However, further study of FORP in people with mental health conditions is presently limited by a paucity of appropriate measurement tools. In Chapter 2, we briefly reported on the different measures of FORP they were identified in the literature. Many of these were unvalidated single-item measures, and most FORP questionnaires, including the Self-Appraisal Questionnaire fear of recurrence subscale (Coyne & Calarco, 1995), and the Worries About Mental Health Questionnaire (Bassett et al., 2009), were not well-validated and had not undergone structural validation through factor analysis. Hence, the degree to which these questionnaires are valid and reliable measures of FORP is unknown. The only FORP questionnaire with a published validation study was the Fear of Recurrence Scale (FoRSe; Gumley & Schwannauer, 2006), which was designed to assess fear of psychosis relapse in people with schizophrenia-spectrum conditions, although this only involved exploratory factor analysis and did not confirm the factor structure in a second sample (Gumley et al., 2015). Hence, to the authors' knowledge, there are no demonstrably valid and reliable measures of FORP for people with more common, but nevertheless potentially

serious, non-psychotic conditions. This is a significant gap in the literature as people with disordered eating, anxiety, obsessive-compulsive, and mood conditions also experience FORP (Coutts-Bain et al., 2025a; Gumuchian et al., 2024).

The paucity of well-validated measures of FORP also draws attention to a significant conceptual issue, that is, the potential overlap between FORP and mental health anxiety – defined as worry about developing a condition one has not previously experienced (Rachman, 2012). A similar distinction has previously been drawn between fear of cancer recurrence and health anxiety (Mutsaers et al., 2020). However, if FORP and mental health anxiety are essentially equivalent constructs, research treating FORP as distinct may obscure the true relations between variables of interest and unnecessarily consume resources as researchers retread old ground. To avoid such construct redundancy, we must ensure that newly proposed psychological constructs are distinct from previously established constructs (Hodson, 2021). Conceptually, one might expect that lived experience of being mentally unwell makes FORP potentially qualitatively different from mental health anxiety. Those with conditions that are marked by frequent recurrences, such as those with bipolar conditions, depression or schizophrenia, contend with a lifelong increased risk of recurrence and the possibility of worsening residual symptoms (McCutcheon et al., 2020; McIntyre et al., 2020). Whilst typically transitory conditions, such as major depression, are similarly associated with increased risk of recurrence even after treatment (Wojnarowski et al., 2019). Despite this conceptual argument, whether two constructs can be distinct in measurement remains an empirical question (Hodson, 2021), one that is yet to be answered as the only published validation of a FORP questionnaire, i.e., the FoRSe, did not examine discriminant validity with mental health anxiety (Gumley et al., 2015). This raises concerns about potential construct redundancy, particularly as the FoRSe is strongly correlated with mental health anxiety (Coutts-Bain et al., 2023a).

The present study aimed to address these gaps in the literature by developing and validating a new transdiagnostic measure of FORP suitable for individuals diagnosed with

both psychotic and non-psychotic mental health conditions; the Fears of Recurrence and Progression About Mental Health Questionnaire (FORP-MHQ). The initial FORP-MHQ item pool was intended to assess FORP. We aimed to conduct an exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) to assess the structural validity of the FORP-MHQ. We expected that the FORP-MHQ would possess good convergent validity (i.e., strong correlations with other measures of FORP), good discriminant validity (i.e., a non-redundant association with mental health anxiety), and good concurrent validity (i.e., associations with theoretically-related variables, such intrusive memories of being mentally unwell, belief that one's condition is permanent and difficult to control, depression, and anxiety). Measurement invariance analyses were conducted to determine whether the FORP-MHQ was measuring FORP invariantly across those with and without a history of psychosis/mania, and those with and without diagnoses spanning multiple diagnostic categories, to further explore transdiagnostic applicability. Lastly, analyses to evaluate the internal consistency and 28-day test-retest reliability were conducted to assess the reliability of the FORP-MHQ.

4.2 Method

4.2.1 Phase I: Development of Items

Development of the FORP-MHQ was informed by the COSMIN Study Design checklist for patient-reported outcome instruments (Mokkink et al., 2019). The initial FORP-MHQ item pool was derived from prior interviews of people with lived experience of mental health conditions, both psychotic and non-psychotic, who experienced FORP, reported in Chapter 3. Quotations from these interviews were analysed by two researchers, one of whom was a clinical psychologist with expertise in clinical health psychology, the other a recent graduate of a clinical psychology program. This analysis was used to draft 40 prospective FORP-MHQ items (see Appendix C1). Seven of the interviewees were then

reinterviewed to solicit feedback on the items and questionnaire instructions. This feedback was used to improve the clarity of several items, assess the appropriateness of instructions, items, and response options, and set the recall period to one month. All interviewees stated this timeframe allowed them to give the most accurate assessment of their experience of FORP. According to the SMOG readability criteria (McLaughlin, 1969), this version of the FORP-MHQ was readable by people with an eighth-grade reading level.

4.2.2 Phase II: Validation of the FORP-MHQ

4.2.2.1 Inclusion Criteria. We recruited participants by advertising on social media between June and July 2024. Individuals were eligible to participate if they were at least 18 years old, were proficient in English, currently living in Australia, and self-reported being diagnosed with a mental health condition. We considered the possibility of recruiting based on diagnostic interviews, but this was not practical given the large number of participants required for questionnaire validation. Hence, we recruited based on self-report as there is evidence that people can self-report psychiatric diagnoses reasonably reliably (Vieira et al., 2022) they had received from clinicians, to avoid participants reporting self-diagnoses. Moreover, given our interest in the transdiagnostic applicability of the measure, we were primarily concerned with the presence of a diagnosis, rather than the particular diagnosis, per se. Participants diagnosed with neurodevelopmental conditions, such as autism, were not excluded so long as they had also been diagnosed with a mental health condition in addition to their neurodivergence. Participants were excluded if they failed at least one of two instructional manipulation checks, e.g., “Please select ‘Extremely’ for this item” (Oppenheimer et al., 2009). We also examined participant responses for duplicate responding, impossibly fast completion times, as well as extreme responding. This study was approved by The University of Sydney human research ethics committee.

4.2.2.2 Measures. Participants were administered demographics questionnaires and the 40 initial items of the FORP-MHQ, including self-reporting which mental health conditions they had received from mental health professionals. To assess convergent validity, the FoRSe (Gumley et al., 2015), and the Worries About Recurrence and Progression Scale (WARPS; Sharpe et al., 2024), a FORP measure validated in people with physical chronic illnesses, were administered. To assess concurrent validity, the following measures were used: revised Impact of Event Scale (IES-R) was used to assess intrusive memories of being unwell, avoidance, and hyperarousal (Weiss & Marmar, 1997). The Generalised Anxiety Disorder-7 (GAD-7) to assess symptoms of anxiety (Spitzer et al., 2006). The Patient Health Questionnaire-9 (PHQ-9) to assess depressive symptoms (Kroenke et al., 2001). The revised Illness Perception Questionnaire (IPQ-R) to assess perceived chronicity, cyclical nature, consequences of condition, personal control, and treatment control over one's condition/s (Moss-Morris et al., 2002). In addition, participants who indicated that they were currently using medication to manage their mental health conditions also completed the short-form Medication Adherence Rating Scale (MARS-5) to further examine concurrent validity (Chan et al., 2020). To assess discriminant validity, mental health anxiety was measured with the Mental Health Anxiety Inventory (MHAI; Commons et al., 2016). As all the participants had lived experience of mental health conditions the instructions of the MHAI were modified to be appropriate to this context and to ensure it assessed anxiety about conditions individuals had not been diagnosed with. These modifications were as follows: 1) the following instruction was added "this question refer to mental illnesses you have not been diagnosed with", 2) we added additional instructions for items 15 to 18, "think about what it might be like if you had a serious mental illness [added] *that you do not currently* have". Participants that completed this baseline survey were able to opt in to be contacted regarding a follow-up survey in 28 days which re-administered the FORP questionnaires. Participants were eligible to gain one entry into a draw to win one-of-three $150 gift cards for each survey they completed.

4.2.2.3 Analyses. We randomly selected half the participants (*N* = 432) from the overall sample to conduct an exploratory factor analysis using SPSS (version 29) software. Factors were extracted using maximum-likelihood extraction with direct oblimin rotation. The number of factors to extract was determined by parallel analysis at the 95th percentile of random eigenvalues bootstrapped using 5000 samples, and examination of the scree plot (O'Connor, 2000). In the remaining half of the sample (*N* = 433), we conducted a confirmatory factor analysis using AMOS (version 29) software. To evaluate model fit, the following fit index cut-offs were applied: Good fit was indicated by CFI ≥ .95, TLI ≥ .95, SRMR ≤ .08, and RMSEA ≤ .06, with values closely approaching these cut-offs deemed indicative of acceptable fit (Hu & Bentler, 1999).

To determine whether the FORP-MHQ is measuring FORP equivalently between those with different clinical histories, we conducted two tests of measurement invariance using multi-group CFA to compare: 1) those diagnosed within a single diagnostic category and those with diagnoses across multiple categories, and 2) those with and without a history of mania/psychosis. The first comparison was selected to determine whether the FORP-MHQ was measuring FORP equivalently between those who may fear multiple different conditions recurring or progressing. The second comparison was selected given the existing literature has largely focused on FORP in the context of psychosis, in contrast to the relative lack of research on FORP in non-psychotic conditions, and in light of the overlapping nature of psychosis and mania (Kotov et al., 2021). Lastly, to determine whether the FORP-MHQ is measuring FORP equivalently between those identifying as men and women, we conducted tests of measurement invariance. To evaluate measurement invariance, we used Cheung and Rensvold's (2002) cut-off criteria, i.e., ΔCFI ≤ .01 as indicating invariance.

After the structural validation of the FORP-MHQ, we assessed others facets of validity and reliability using the complete sample (*N* = 865). To evaluate discriminant validity, we modelled the latent factors underlying the FORP-MHQ and MHAI with a CFA in AMOS. We then constrained the variances of the latent variables, FORP and mental health anxiety,

to one, thereby making the covariance of the latent factors equivalent to their correlation. We then assessed discriminant validity by examining the upper limit of the 95% confidence interval of this correlation. For this procedure, an upper limit correlation estimate of $r < .80$ has been proposed to demonstrate good evidence of discriminant validity (Rönkkö & Cho, 2022). This procedure provides a more stringent assessment of discriminant validity than those based on correlations between observed scores as it prevents measurement error from suppressing the magnitude of the correlation. Lastly, to assess reliability we examined internal consistency with Cronbach's alpha, and test-retest reliability by correlating FORP-MHQ at baseline with the FORP-MHQ administered 28 days later.

4.3 Results

4.3.1 Participants

Nine-hundred and five participants were recruited. Forty participants were excluded for failing an instructional manipulation check (4.6% of participants). Hence, the final overall sample consisted of 865 participants. On average, participants were 38.82 years of age (*SD* = 14.44, range = 18 – 82), identified as women (75.1%), most had North-west European ethnicity (64.2%), and a lifetime history of 2.54 mental health condition diagnoses (*SD* = 1.16). See Table 4.1 for further demographic and clinical information. See Appendix C2 for demographic and clinical information for the EFA and CFA subsamples.

Table 4.1. Demographic and clinical factors

Variables		*N*	%
Gender	Man	137	15.7
	Woman	650	75.1
	Non-binary	73	8.4
	Gender fluid	4	<1
	Intersex	1	<1
Born in Australia		734	84.9
Ethnicity †	Oceanian	300	34.7
	North-west European	555	64.2
	Southern and Eastern European	82	9.5
	North-east Asian	25	2.9
	South-east Asian	29	3.4
	Southern and Central Asian	9	1.0
	People of the Americas	18	2.1
	Sub-saharan African	6	<1
	North African and Middle Eastern	13	1.5
	Other	6	<1
Educational achievement	Did not complete high school	64	7.4
	High school	152	17.6
	Certificate III, IV, or (advanced) diploma	239	27.6
	Undergraduate	223	25.8
	Postgraduate	187	21.6
Diagnoses †	Schizophrenia-spectrum	53	6.1
	Bipolar mood	124	14.3
	Unipolar mood	595	68.8
	Anxiety	617	71.3
	Obsessive-compulsive	92	10.6
	Trauma-stressor related	367	42.4
	Dissociative	30	3.5
	Somatic symptom	3	<1
	Feeding and eating disorders	65	7.5
	Substance use disorder	5	<1
	Personality disorder	133	15.4
Source of diagnoses †, ‡	Psychologist	588	68
	Psychiatrist	593	68.6
	General practitioner	476	55
Neurodevelopmental diagnoses †	Autism	127	14.7
	ADHD	224	25.9
	Specific learning disorders	25	2.9
History of chronic physical illness		471	54.5
History of psychiatric inpatient admission		339	39.2
Not currently using medication		226	26.1
Current medication †	Antipsychotics	191	22.1
	Mood stabilisers/anti-convulsants	146	16.9
	SSRIs	271	31.3
	SNRIs	193	22.3
	Tricyclic antidepressants	41	4.7
	Tetracyclic antidepressants	47	5.4
	MAOIs	5	<1
	Benzodiazepines	98	11.3
	Alpha and beta blockers	36	4.2
	Medical cannabinoids	18	2.1
	Others	164	19.0

Note: † Multiple options selectable. ‡ Refers to diagnosis of mental health conditions, not neurodevelopmental conditions.

4.3.2 Exploratory Factor Analysis

Firstly, the item-total correlations of the initial 40 items were examined. Thirteen items possessed correlations < .40, and were thus removed, as per recommendations (Clark & Watson, 1995). The communalities of the remaining 27 items were evaluated, two of which were removed as they possessed communalities < .50. Following this, 11 items demonstrated ceiling or floor effects that necessitated their removal. Lastly, the Kaiser-Meyer-Olkin measure of sampling adequacy was .919 and Bartlett's test of sphericity was statistically significant (X^2 = 4640.90, *df* = 120, *p* < .001), indicating that the sample data for the remaining 16 items was suitable for factor analysis (Tabachnick et al., 2013). Parallel analysis of the 16 FORP-MHQ items based on the 95th percentile of random eigenvalues, and an analysis of the scree-plot, both indicated a three-factor structure (see Appendix C3).

A three-factor EFA was conducted using maximum-likelihood extraction with direct oblimin rotation. Based on item content and factor loadings, these factors represented: 1) FORP severity, 2) vigilance towards fluctuations in mental state, and 3) a conservative approach to treatment, respectively. No cross-loadings >.30 were observed. Together, these factors accounted for 71.06% of variance in participant responses to the FORP-MHQ. The factors representing vigilance and a conservative approach to treatment were positively correlated (*r* = .239). Conversely, the factor representing FORP severity was negatively correlated with the factors representing vigilance (*r* = -.350) and a conservative approach to mental health treatment (*r* = -.370). However, as the items loading on factors two and three loaded negatively, they are describing the negative poles of these constructs, i.e., no vigilance and a non-conservative approach to mental health treatment. This is an artifact of rotation, and thus these negative factor correlations indicate positive relationships between FORP severity, vigilance, and a conservative approach to treatment. See Appendix C3 for the full results of the 16-item EFA.

However, both vigilance and conservative approach subscales were comprised of three items each, which may be too few to form a reliable factor, as five or more items with

strong factor loadings is considered desirable (Costello & Osborne, 2019). Moreover, conceptually, both vigilance and a conservative approach to treatment are theoretically downstream effects of FORP, they are not FORP per se. This is important as including the consequences of a primary construct of interest in a questionnaire can create conceptual confusion as to what precisely is being assessed, particularly when the total score of a questionnaire may be used in clinical or research settings (Costa et al., 2016). Hence, on both psychometric and conceptual grounds, these two subscales were deleted, resulting in a final 10-item version of the FORP-MHQ which purely assessed FORP severity (Table 4.2). Excluding more marginal factors in this manner can be appropriate to ensure a questionnaire is parsimonious, reliable, and more conceptually coherent (Tabachnick et al., 2013). Item inter-correlations and item-total statistics for the 10-item FORP-MHQ are available in Appendices C5 and C6, respectively.

Table 4.2. 10-item EFA of the final FORP-MHQ items

		Factor loadings
	Items	**I**
1	I worry that I will become unwell again	**.749**
2	I am disturbed by thoughts or images about becoming unwell again	**.796**
3	When I imagine what could happen if I become unwell again, I feel quite distressed	**.766**
4	I can't stop thinking about, or imagining, becoming unwell again	**.829**
5	When I worry about becoming unwell again it's hard to focus on what I am doing	**.778**
6	Worrying about the consequences of getting unwell again takes over my mind	**.811**
7	I find myself thinking about the terrible things that might happen if I get unwell again	**.828**
8	If I got unwell again, I fear it would be worse than it was before	**.727**
9	When I get upset about becoming unwell again, becoming unwell and what might happen afterwards, seems like one of the worst things that could possibly happen	**.748**
10	I feel anxious when I think about the possibility of getting unwell in the future	**.772**
	Eigenvalues	6.487
	% of variance accounted for	64.873

Note. Factor loadings with an absolute value >.30 are indicated in bold.

4.3.3 Confirmatory Factor Analysis

A CFA was conducted in the remaining sample (*N* = 433), using the final 10-item FORP-MHQ. Multiple fit indices were triangulated to assess the single factor structure of the FORP-MHQ. The following indices demonstrated good fit: $X^2(35) = 173.036$, $p < .001$, $X^2/df = 4.944$, CFI = .95, and SRMR = .04. Other indices demonstrated acceptable fit: TLI = .93, RMSEA = .096 (90%CI: .082 – .110) (Hu & Bentler, 1999). Hence, overall, there is evidence to indicate that the FORP-MHQ measured one factor – severity of FORP.

4.3.4 Reliability

Cronbach's alpha was used to assess to the internal consistency of the FORP-MHQ. This demonstrated excellent internal consistency (α = .939). Three-hundred and thirty-five participants responded to the optional 28-day test-retest questionnaire (38.7% participation rate). Six participants were excluded for failing an attention check, with a further four being excluded for duplicate responding (3.0% exclusion rate), leaving a final sample of 325 participants. Four-week test-retest reliability was *r* = .727.

4.3.5 Construct Validity

The FORP-MHQ, which measures the magnitude of FORP, was strongly positively correlated with the FoRSe fear of recurrence subscale (*r* = .706) and the WARPS (*r* = .728), providing good evidence of convergent validity. The FORP-MHQ was also correlated with theoretically-related constructs as expected. Higher FORP was associated with higher IES-R intrusions about being mentally unwell (*r* = .648), avoidance (*r* = .455), and hyperarousal (*r* = .591). Stronger beliefs that one's conditions are chronic (*r* = .241), prone to recurrence (*r* = .263), have significant consequences (*r* = .451), and cannot be controlled by personal action (*r* = -.244) or treatment (*r* = -.321), as measured by IPQ-R subscales, as well as symptoms

of anxiety (*r* = .538) and depression (*r* = .569), measured by the GAD-7 and PHQ-9, respectively. The FORP severity subscale was also positively correlated with the perceived likelihood that a future deterioration in mental health would be "about as bad as it was before" (*r* = .330) and "worse than it has ever been" (*r* = .531), but not that a future deterioration would be "not as bad as it has been before". Conversely, FORP-MHQ severity was not significantly correlated with the belief that one's mental health conditions were caused by biological factors. In those that were currently using medication to their mental health conditions, FORP severity was also associated with poorer medication adherence (*r* = -.135). Correlations reported in Table 4.3.

Table 4.3. Correlations between FORP-MHQ subscales and variables of interest

		α	FORP-MHQ
FoRSe	Fear of relapse	.87	.706*
	Awareness	.80	.208*
	Intrusiveness	.90	.591*
WARPS		.93	.728*
MHAI		.87	.666*
IES-R	Avoidance	.81	.455*
	Intrusions	.89	.648*
	Hyperarousal	.83	.591*
IPQ-R	Chronicity	.84	.241*
	Cyclical	.75	.263*
	Consequences	.78	.451*
	Personal control	.83	-.244*
	Treatment control	.80	-.321*
Biological causes		.75	.022
MARS-5		.79	-.135*
GAD-7		.90	.538*
PHQ-9		.87	.569*
Perceived risk of deterioration	Not as bad as it's been before	-	.006
	About as bad as it's been before	-	.330*
	Worse than it's been before	-	.531*

Note. *, $p < .001$. Cronbach's Alpha indicated by α.

FORP-MHQ severity scores were strongly correlated with scores on the MHAI (r = .666). To further examine discriminant validity, we modelled the FORP-MHQ severity subscale and the MHAI in a structural equation model to correlate their latent factors (Appendix C7). The factors underlying these questionnaires, FORP and mental health anxiety, were correlated at r = .764 (95%CI: .729 – .797). As the upper limit of this confidence interval did not exceed .80, this demonstrates good evidence of discriminant validity (Rönkkö & Cho, 2022).

4.3.6 Measurement Invariance

A multi-group CFA was conducted to assess measurement invariance in the FORP-MHQ between those with and without a history of psychosis and/or mania. Results provided evidence of configural invariance (X^2 = 335.019, p < .001; CFI = .950, TLI = .936, RMSEA = .069, SRMR = .378). Based on the cut-off of ΔCFI ≤ .01, proposed by Cheung and Rensvold (2002) invariance held when constraining factor loadings to be equal between groups, i.e., metric invariance (X^2 = 365.306, p < .001; CFI = .950, TLI = .943, RMSEA = .065, SRMR = .371), when constraining intercepts to be equal between groups, i.e., scalar invariance (X^2 = 373.876, p < .001; CFI = .950, TLI = .949, RMSEA = .061, SRMR = .381), and when constraining residual variance between groups, i.e., residual invariance (X^2 = 392.998, p < .001; CFI = .948, TLI = .953, RMSEA = .059, SRMR = .387). Hence, there is evidence that the FORP-MHQ possesses strict measurement invariance between those with and without a history of psychosis and/or mania.

Multi-group CFA analyses were conducted to assess measurement invariance in the FORP-MHQ between those with conditions within a single diagnostic category and those with diagnoses spanning multiple categories. Results provided evidence of configural invariance (X^2 = 348.11, p < .001; CFI = .950, TLI = .935, RMSEA = .068, SRMR = .036). Based on the cut-off of ΔCFI ≤ .01, proposed by Cheung and Rensvold (2002), invariance

held when constraining factor loadings to be equal between groups (X^2 = 355.11, p < .001; CFI = .950, TLI = .943, RMSEA = .064, SRMR = .040), when constraining intercepts to be equal between groups (X^2 = 383.776, p < .001; CFI = .947, TLI = .946, RMSEA = .062, SRMR = .047), and when constraining residual variance between groups (X^2 = 408.692, p < .001; CFI = .944, TLI = .949, RMSEA = .060, SRMR = .060). Hence, there is evidence that the FORP-MHQ possesses strict measurement invariance between those with and without a diagnostic history spanning multiple diagnostic categories. Those with diagnoses across multiple categories (M = 26.02, SD = 8.03) reported greater FORP than those without (M = 22.27, SD = 9.19, t(863) = -5.204, p < .001, d = .454.

A multi-group CFA was conducted to assess measurement invariance in the FORP-MHQ between those identifying as men and women. Results provided evidence of configural invariance (X^2 = 323.899, p < .001; CFI = .953, TLI = .939, RMSEA = .068, SRMR = .339). Based on the cut-off of ΔCFI ≤ .01, proposed by Cheung and Rensvold (2002) invariance held when constraining factor loadings to be equal between groups (X^2 = 335.671, p < .001; CFI = .952, TLI = .946, RMSEA = .064, SRMR = .344), when constraining intercepts to be equal between groups (X^2 = 364.656, p < .001; CFI = .948, TLI = .947, RMSEA = .063, SRMR = .343), and when constraining residual variance between groups (X^2 = 381.959, p < .001; CFI = .947, TLI = .951, RMSEA = .061, SRMR = .350). Hence, there is evidence that the FORP-MHQ possesses strict measurement invariance between those identifying as men and women. Men (M = 24.45, SD = 9.21) and women (M = 25.52, SD = 8.24) did not significantly differ in terms of FORP, t(785) = -1.349, p = .089, d = -.127.

4.4 Discussion

The present study aimed to develop a novel transdiagnostic measure of FORP for people with mental health conditions. The initial 40 items were reduced to a final 10-item version of the FORP-MHQ which assessed FORP severity. See Appendix C9 for the final

version of the FORP-MHQ with full instructions. Although initial analyses suggested a three-factor structure, including FORP severity, vigilance, and a conservative approach to treatment, both vigilance and conservative approach factors were comprised of three items each, which is a number small enough to impair content validity and reliability. Moreover, both these factors did not measure FORP per se, which was the intended aim of the FORP-MHQ. Hence, these marginal factors were excluded on both statistical and conceptual grounds, leaving a parsimonious 10-item questionnaire assessing the severity of FORP. None of the included items had ceiling or floor effects, allowing them to capture good variability in responses. The FORP-MHQ was positively associated with alternative measures of FORP, but was empirically distinct from mental health anxiety, demonstrating good evidence of both convergent and discriminant validity. Overall, FORP severity was correlated with theoretically-related constructs as expected, including positive association with intrusive memories of being mentally unwell, avoidance of those memories, and related symptoms of hyperarousal, as well as symptoms of anxiety and depression. It was also associated with beliefs that one's conditions are chronic, recurring, highly consequential, and cannot be effectively controlled by personal behaviour or treatment. Additionally, FORP was not associated with one's perceived risk of a "not as bad as it was before", i.e., mild, deterioration, but was associated with the perceived likelihood of deterioration that would be as, or more, severe than previously experienced. However, unexpectedly, FORP severity was not associated with the belief that one's condition had a biological origin, and was associated with poorer medication adherence. Lastly, the FORP-MHQ possessed strict measurement invariance between those with and without diagnoses across multiple diagnostic categories, those with and without a history of psychosis and/or mania, and identifying as men and women.

The finding that FORP severity was not significantly associated with the belief that one's conditions were caused by biological factors was surprising. However, FORP severity was associated with beliefs about mental health conditions that theoretically mediate this

relationship. The biological accounts of illness are known to predict beliefs that said illnesses are permanent or chronic, likely to recur, and respond more poorly to treatment (Lebowitz & Appelbaum, 2019). In the present study, FORP severity was associated, as expected, with these beliefs. Yet, the present study was unable to examine this potential indirect relationship between biological beliefs and FORP as beliefs about the nature and cause of mental health conditions were only assessed cross-sectionally. Another unexpected finding was that FORP severity had a small association with poorer medication adherence. This contrasts with the most recent review on mental health-related FORP, where FORP was consistently associated with greater adherence in those with schizophrenia-spectrum, mood, and opioid use conditions (Chapter 2). One possible account of this discrepancy is that prior quantitative research finding a positive association between FORP and adherence examined specific populations and their FORP, in relation to a particular class of medication, for example, people with bipolar and adherence to mood stabilising medication (Devulapalli et al., 2010). Conversely, in the present study, different conditions and classes of medication were analysed in aggregate. Hence, this may have obscured these stronger, and positive, associations that have previously been identified. Moreover, as different medications have different efficacies, side effect profiles, indications, and dose regimens, it is possible that adherence to some are not related to FORP, or are even negatively associated. Future research should examine these relationships between FORP and medication adherence separately for different medications and indications to elucidate these complexities. Another factor that may have obscured our expected findings was that the sample of the present study reported being highly adherent on the MARS-5. Indeed, we observed a ceiling effect where the modal response was perfect adherence, this will have reduced the variability of the adherence measure, and thus our findings related to the MARS-5 should be interpreted with caution.

Although FORP severity was not associated with the perceived likelihood of a milder mental health deterioration, it was associated with the perceived likelihood of more severe

deteriorations, particularly a deterioration that was “worse than it was before”. This indicates that those with higher levels of FORP tend to expect that future deteriorations in their mental health will be severe and potentially catastrophic, rather than that deteriorations will occur in general. This is comparable to findings from cancer survivors, where quantitative and qualitative research indicates that those with higher levels of fear of cancer recurrence are more concerned with death (Coutts-Bain et al., 2023b; Thewes et al., 2016). This is important as it demonstrates FORP is not simply an index of one’s perceived risk of deterioration, and is instead related to more complex expectations related to prior experiences of being mentally unwell.

Compared to existing measures of mental health-related FORP, the FORP-MHQ possesses several significant advantages. Firstly, it is the only questionnaire to be validated in people with a range of different conditions, not just schizophrenia-spectrum conditions, as is the FoRSe (Gumley et al., 2015). Hence, the FORP-MHQ has utility in assessing FORP in the wider population of those living with mental health conditions, including those with mood, anxiety, disordered eating, and obsessive-compulsive conditions, in whom FORP is especially understudied (see Chapter 2). Moreover, our measurement invariance analyses demonstrate that the FORP-MHQ is measuring FORP equivalently in those with and without a history of psychosis or mania, allowing for direct comparisons between clinical groups, and providing further evidence of the transdiagnostic applicability of FORP and the FORP-MHQ. Interestingly, our analyses demonstrate that those with lived experience of psychosis and mania do not experience greater FORP than those with experience of arguably less complex and severe conditions. This highlights the potential for people diagnosed with more common conditions, like depression and anxiety, to be distressed and impacted by FORP. This is important as FORP is known to be associated with important clinical outcomes, such as a shorter time to psychotic relapse in schizophrenia (Gumley et al., 2015), medication adherence in people with schizophrenia, bipolar, and opioid use conditions, and poorer quality of life (Chapter 2). In addition, qualitative research has indicated that higher levels of

FORP can underlie decisions to avoid pursuing occupational and relational goals, such as seeking employment, romantic relationships, and having children (Chapters 2 and 3). However, given a paucity of appropriate measurement tools it has not been possible to quantitatively examine the impact of FORP in people with lived experience of more common mental health conditions. Hence, the development and validation of the FORP-MHQ represents an advance in the field of mental health-related FORP, one which can facilitate more rigorous future research.

Moreover, our analyses which demonstrate the FORP-MHQ is invariant between those with and without diagnoses spanning multiple diagnostic categories means that the FORP-MHQ is a valid measure of FORP in those that may worry about the recurrence or progression of multiple conditions. Indeed, our analyses demonstrate those with diagnoses spanning more than one diagnostic category, i.e., those with lifetime comorbidity across varying conditions, endorse greater FORP (d = .454). This is important as, on average, people living with a mental health condition will have experienced more than one condition over the course of their life, either concurrently or sequentially (Kessler et al., 2005; Menzies et al., 2024a). To our knowledge, the FORP-MHQ is also the only mental health-related FORP questionnaire to be demonstrably distinct from a measure of mental health anxiety in a stringent discriminant validity analysis. However, the two constructs are highly related and future research would benefit from clarifying the relationship between the two constructs and other related variables.

The FORP-MHQ is the only mental health-related FORP questionnaire to have demonstrated measurement invariance between men and women, providing further evidence of the robustness of the measure. Overall, the psychometric strengths, and transdiagnostic applicability, of the FORP-MHQ make it a good candidate for future research intending to elucidate unclear or complex relationships between FORP and other variables. This may include known gaps in the literature, such as clarifying how FORP is related to

clinical factors such as the number of prior recurrences, and health behaviours (Coutts-Bain et al., 2023).

Nevertheless, the present study must be qualified by some limitations. Firstly, participants self-reported what mental health condition diagnoses they had received. However, there is evidence that such self-reports are reasonably reliable when compared to diagnostic interviews (Vieira et al., 2022). Moreover, on average, the sample of the present study reported 2.54 lifetime mental health condition diagnoses, which is congruent with a recent meta-analysis of diagnostic interviews that demonstrated on average people diagnosed with a mental health condition have received 2.57 lifetime diagnoses (Menzies et al., 2024a). This suggests that it is unlikely that participants are over reporting symptoms and syndromes as diagnosable conditions.

4.4.1 Conclusion

Notwithstanding these limitations, the present study had several notable strengths. Firstly, the present study's sample was clinically diverse. Overall, we saw good representation of most DSM-5-TR diagnostic categories, making this the first FORP questionnaire to be validated in people with experience of non-psychotic mental health conditions. The sample was also characterised by a high rate of comorbidity, participants both with and without a history of psychiatric hospitalisation, and rates of autism and ADHD comparable to those found in psychiatric outpatient services (Adamis et al., 2022; Nyrenius et al., 2022; Takara & Kondo, 2014). These complexities are common in community mental health settings, and validation of the FORP-MHQ in a sample with these characteristics demonstrates the robustness and ecological validity of the questionnaire for people with a range of different conditions and clinical histories. We aim for the FORP-MHQ to be a catalyst for future research to confirm associations that have been found in people with schizophrenia between FORP and subsequent time to relapse. Clinically, it would be useful

to administer at the end of treatment, or transitions between services, as a part of relapse prevention to identify fears that could be targeted in interventions designed to reduce FORP.

In conclusion, the FORP-MHQ is a valid and reliable measure of FORP severity in a clinically diverse sample that is relatively brief and freely accessible. Hence, this newly developed questionnaire can be used to advance research on FORP in people with lived experience of mental health conditions, including more common, non-psychotic conditions, where FORP is understudied.

Chapter 5: Shame, Intrusions, and Interpretation Biases Predict Fears of Recurrence and Progression in People with Mental Health Conditions

5.1 Introduction

Mental health conditions can have devastating impacts on the quality of life and functional capacity of the individuals who experience them (Vigo et al., 2016). In addition, they often follow a relapsing-remitting course, or can become chronic and worsen over time, even after having received treatment (Gignac et al., 2015; Richards, 2011; Yonkers et al., 2003). Given the real possibility of distress and impairment, it is reasonable to expect people with lived experience of these conditions to worry about the possibility that their conditions will recur or progress over time to some degree. Despite this, there is relatively little empirical research on these fears of recurrence and progression (FORP) in people with mental health conditions. Nevertheless, systematic reviews of this nascent literature have demonstrated that FORP is associated with greater symptoms of anxiety and depression, increased suicidality, poorer quality of life, and post-traumatic stress (Coutts-Bain et al., 2023a; Zukowska et al., 2022). Perhaps most significantly, longitudinal research has demonstrated that fear of psychosis relapse predicts a shorter time to relapse in people with schizophrenia, even when controlling for early warning signs of psychosis (Gumley et al., 2015). Hence, there is some evidence that FORP may be an important construct in predicting relapse, at least in schizophrenia.

To account for the development, and subsequent impact, of mental health-related FORP, a theoretical model of FORP was proposed in Chapter 2 on the basis of existing literature and expanded in Chapter 3 through a series of qualitative interviews. This model proposed that aversive or traumatic experiences which occur whilst mentally unwell, such as discrimination, coercive treatment, harm to self and others, social isolation, and loss of functional capacity, may lead to recurrent intrusive memories of being mentally unwell. These intrusions are then extrapolated into fears for the future, driving greater FORP. Notably, due to internalised mental health stigma, such memories of being unwell, and

anticipation of future deteriorations, are associated with feelings of shame, which may exacerbate FORP. In response to this fear, people adopt a ‘better safe than sorry’ approach to managing their mental health, which is characterised by vigilance to mental state fluctuations, seeking support, and avoiding stressors. However, excessive FORP may lead to overapplication of these potentially adaptive strategies. This may result in hypervigilance towards mental state and biased interpretation of ambiguous mental state fluctuations as threatening, reassurance seeking, or adopting a ‘low-risk, low-reward’ lifestyle which limits access to protective social buffers and interferes with meeting long-term recovery goals. Inadvertently, such strategies perpetuate FORP and increase vulnerability to deterioration. Similarly, other factors, including cognitive avoidance of FORP, and prognostic pessimism, may also contribute to greater FORP.

Although there remains a paucity of research on mental health-related FORP, there is some quantitative evidence which corroborates aspects of the model. For instance, fear of psychosis relapse in people with schizophrenia is associated with intrusive memories of being unwell (White & Gumley, 2009), and poorer self-esteem (Collett et al., 2016). Moreover, in mixed clinical samples comprised mostly of people with non-psychotic mental health conditions, FORP has been associated with intrusive memories of being mentally unwell, avoidance of these memories and their triggers, internalised mental health stigma, and prognostic pessimism (Chapters 3 and 4). However, all this research was cross-sectional, and thus the directionality of the relationships between FORP and these variables remains unknown. This is important as the expanded theoretical model proposed in Chapter 3 makes several directional hypotheses. For instance, intrusive memories of being mentally unwell are thought to be extrapolated into fears for the future, and thus they induce, or at least exacerbate, FORP. In addition, the model proposes that shame is bidirectionally associated with FORP. In the interviews, reported on in Chapter 3, interviewees’ shame about their mental health and capacity for independent management of their conditions was thought to both exacerbate FORP, as it made the perceived cost of deterioration greater. At

the same time, shame was also reported to be a response to FORP, as participants felt ashamed of their level of distress related to FORP and their avoidant behaviours responses to FORP. However, longitudinal research is needed to determine whether the directionality of these observed cross-sectional associations between FORP, shame, and intrusive memories aligns with the transdiagnostic theoretical model.

The paucity of longitudinal research on mental health-related FORP is not just restricted to shame and intrusive memories. To our knowledge, there has been no quantitative research exploring the relationship between FORP, attention towards mental state, and negative interpretations of mental state fluctuations. An individual's mental state is not static, thus fluctuations in mental state, such as changes in one's thought form, thought content, and affect, are a normal and expected part of life. However, for people with lived experience of mental health conditions, these fluctuations may indicate the possibility of recurrence or progression (Birchwood & Spencer, 2001; Goodwin, 2003). For instance, a person with a history of psychosis may interpret day-to-day changes in paranoia, or increasingly noticing tangential connections between external stimuli or events, as potentially indicative of psychotic relapse. Similarly, a person with a history of depression may perceive changes in mood as indicative of increased relapse risk. Indeed, appropriate vigilance towards early warning signs of recurrence or progression is often recommended in clinical practice because it may create opportunities for health-protective action and early intervention (Birchwood & Spencer, 2001; Goodwin, 2003). Nevertheless, hypervigilance towards such fluctuations can be anxiogenic. Theoretically, interpreting mental state fluctuations as inherently predictive of recurrence or progression may increase anticipatory distress, and increase self-monitoring of mental state fluctuations, thereby leading to the identification of more mental state fluctuations, further increasing FORP (Birchwood, 1996; Coutts-Bain et al., 2025). Of concern is that the induced fear can actually contribute to an increased likelihood of relapse. However, while longitudinal research has demonstrated that threatening interpretations of somatic symptoms account for the relationship between these

symptoms and fear of cancer recurrence or progression (Pradhan et al., 2021, 2022), interpretation biases have never been examined with respect to mental health-related FORP. Hence, it is not known whether key theoretical cognitive and affective predictors of mental health-related FORP proposed by Coutts-Bain et al. (2025a) in Chapter 3, namely shame, intrusive memories, as well as interpretation and attentional biases, predict FORP over time.

Rigorous longitudinal research is critical for assessing the directionality of relationships between psychological variables; thus, it is critical for testing theoretical models that propose causal relationships. In this respect, ecological momentary assessment (EMA) may be a particularly advantageous method of conducting longitudinal research on psychological processes (Stone & Shiffman, 1994). EMA involves frequent repeated measures sampling of participants while they are in their real-world environments. This is advantageous because high frequency sampling minimises recall biases by examining small periods of time and current feelings, and collecting data from participants while they are outside the laboratory, going about their normal routine, allows for more ecologically valid observations (Shiffman et al., 2008). This is particularly useful for research on psychological processes, where cognitions and affect may vary continuously over the course of a single day in response to external and internal stimuli. Therefore, EMA allows for ecologically valid examination of temporal relationships between variables which may occur over short periods of time, such as the relationships between intrusive memories, FORP, feelings of shame, as well as biased attention toward, and interpretation of, mental state fluctuations.

Hence, the present study aims to test several core processes of the transdiagnostic theoretical model of FORP, proposed in Chapter 3, by sampling people with lived experience of mental health conditions four times per day over 14 days using EMA. Specifically, we will examine the relationships between FORP, shame, intrusive memories of being unwell, as well as attention and interpretation biases toward fluctuations in mental state, and identify whether these variables predict FORP at the next measurement occasion. We hypothesize

that: 1) intrusive memories of being mentally unwell will predict FORP, 2) shame will predict FORP, 3) there will be a bidirectional relationship between FORP and shame, such that FORP also predicts shame, 4) threat-related interpretations of mental state fluctuations will predict FORP, and 5) attention toward mental state fluctuations will predict FORP. Lastly, we will conduct an exploratory analysis where all significant predictors of FORP are included simultaneously in one model to determine which constructs uniquely account for FORP.

5.2 Method

5.2.1 Procedure

Between March and April 2025, participants were recruited from a research pool for those who are interested in participating in research and who had consented to receive email contact regarding future FORP-related studies. The pool consisted entirely of people who had previously participated in the psychometric validation of the Fears of Recurrence and Progression about Mental Health Questionnaire (FORP-MHQ), reported on in Chapter 4 of the present thesis. All members of the research pool, who had agreed to be contacted for future research, were e-mailed a participant information statement describing the present study, and were able to complete an initial survey confirming their eligibility and collecting baseline demographic variables. Participants were eligible to participate if they were at least 18 years old, fluent in English, currently living in Australia, reported being diagnosed with a mental health condition, and had access to a mobile phone with an internet connection. Eligible participants were then contacted and began the EMA phase of the study. Participants received four text messages at 8.30am, 11.30am, 2.30pm, and 5.30pm, every day, for 14 days. Each text message contained a link to a brief online survey, hosted on REDCap, which participants were only able to access for 90 minutes before the survey became inaccessible. Participants were asked to complete each survey as soon as possible, and complete as many of the 56 surveys as possible, over the 14-day study period.

Following the collection of the EMA data, a subsample of participants were contacted via e-mail to arrange a structured diagnostic interview for the purpose of examining the reliability of self-reported diagnoses within the present sample. Participants who responded to this further contact, and who consented to undergo this interview were administered the Structured Clinical Interview for DSM-5 Research Version (SCID-5-RV; First et al., 2015a), as well as the interview schedule for personality disorders (SCID-5-PD; First et al., 2015b) if participants reported being diagnosed with a personality disorder. All interviews were conducted by a psychologist (DCB, author of the present thesis) who had previously received training in administering such diagnostic interviews. These diagnostic interviews were conducted online, via videoconferencing software. This study was approved by the University of Sydney Human Research Ethics Committee.

5.2.2 Baseline Variables

In their initial survey, before beginning the EMA phase, participants provided demographic and clinical history information, including their self-reported mental health condition diagnoses. In addition, participants completed baseline questionnaires which assessed FORP, and residual symptoms of depression and anxiety, to further characterise the sample. As reported in Chapter 4, the FORP-MHQ is a valid and reliable measure of FORP, and thus this was used to assess baseline FORP in the present study. Further, the Generalised Anxiety Disorder-7 (GAD-7) questionnaire was used to assess baseline symptoms of anxiety (Spitzer et al., 2006), and the Patient Health Questionnaire-9 (PHQ-9) was used to assess baseline symptoms of depression (Kroenke et al., 2001).

5.2.3 EMA Variables

Each online EMA survey used single-item measures to assess different constructs of interest. Single-item measures were chosen because of the planned intensive sampling

paradigm, i.e., four surveys per day for 14 days, which necessitated minimising the survey length to reduce the burden of the study on our clinical sample, and maximise response rates. Although single-item measures cannot demonstrate internal consistency, by definition, single-item measures can demonstrate good criterion validity in comparison to multi-item measures of the same constructs in EMA study designs (Song et al., 2023). Hence, five single-item measures of the five primary constructs of interest were used in the present study. These items were adapted from valid and reliable measures, and are described below. These adaptations were necessary to ensure the items were suitable for both the mental health context, repeated delivery via EMA, and had consistent response options. All participants used a slider to indicate their score on each item, ranging from 0 (“not at all”) to 100 (“extremely”). For the below items, italics indicate changes from the original item. The same items were presented to participants in all 56 EMA surveys.

5.2.3.1 FORP. FORP was measured with a single item adapted from the FORP-MHQ (“*Since you last responded,* how much have you been thinking about the terrible things that might happen if you get unwell again?) (Chapter 4). This item was selected as it possessed the highest item-total correlation of all the individual FORP-MHQ items in the initial FORP-MHQ validation study (r = .800). Similarly, within the present study, analysis of the baseline FORP-MHQ scores indicates that, at baseline, this item correlates strongly with total FORP-MHQ score (r = .865).

5.2.3.2 Intrusive Memories of Being Mentally Unwell. Intrusive memories of being mentally unwell were assessed with a single item adapted from the posttraumatic stress disorder checklist for DSM-5 (PCL-5) (Blevins et al., 2015). This item asked “*Since you last responded*, how much are you being bothered by repeated, disturbing, and unwanted memories *of being mentally unwell*?”, rather than asking about “unwanted memories of the

stressful experience", to ensure it specifically assessed memories of being mentally unwell. A recent systematic review of the psychometric properties of the PCL-5 demonstrated that it is a valid and reliable self-report questionnaire developed to assess DSM-5 PTSD symptoms (Forkus et al., 2023). However, the item adapted for the present study was selected as it is the only PCL-5 item which specifically assesses intrusive memories (Blevins et al., 2015), and is the sole item used to assess intrusions in the abbreviated 4-item version of the PCL-5 (Price et al., 2016).

5.2.3.3 Shame. Momentary shame was measured with a single item asking "How ashamed do you feel right now?". Use of the word 'ashamed' to assess feelings was shame was taken from the extended version of the Positive and Negative Affect Scale (PANAS-X; Watson & Clark, 1994).

5.2.3.4 Attention and Interpretation Biases. In the absence of validated measures for assessing attention and interpretation biases towards fluctuations in mental state, items used in the present study were adapted from the bodily monitoring and bodily threat appraisals subscales of the Bodily Threat Monitoring Scale (BTMS; Heathcote et al., 2023). The BTMS has been validated for assessing people's propensity to monitor their own somatic sensations and to interpret ambiguous sensations as threatening, and has been found to correlate with both fear of cancer recurrence and fear of progression in cancer survivors (Heathcote et al., 2023). Attention bias towards fluctuations in mental state was assessed with a single-item asking "*Since you last responded*, how much have you been monitoring your *mental state* for signs that something is wrong?". This item was adapted from the item that loaded the highest on the bodily monitoring subscale (.893) in the initial validation of the BTMS, "I monitor my body for signs that something is wrong" (Heathcote et al., 2023).

Interpretation of ambiguous fluctuations in mental state as threatening was measured with a single-item asking "*Since you last responded*, how much have you been worrying about a lot of different *mental sensations* (*e.g., emotions, thoughts, feelings*)?". This item was adapted from an item that loaded highly on the bodily threat appraisals subscale (.899) in the initial validation of the BTMS, "I worry about a lot of different bodily sensations" (Heathcote et al., 2023). In the initial validation of the BTMS, there were two items that loaded slightly higher on the bodily threat appraisals subscale, these were "Worrying about something being wrong with my body often stops me from enjoying myself" (.957) and "I worry about bodily sensations even when I've been reassured that there isn't anything wrong" (.904). However, the content of these items appears to relate more specifically to the impact of these threat appraisals, and responses to reassurance seeking, respectively. Hence, the next highest loading item was adapted for the present study.

***5.2.3.5 Filler Items*.** In addition to the above items, several other items were included in the EMA surveys. These included: "How happy do you feel right now?", "How relaxed do you feel right now?", and "Since you last responded, how much have you been thinking about your resilience and your skills in managing your mental health?". These items were included to ensure participants completing the EMA surveys were not purely being exposed to negatively valenced items to mitigate against any risks that the surveys could negatively impact the mood or wellbeing of the participants. Therefore, these items have not been used in the analyses.

5.2.4 Analysis Plan

5.2.4.1 Power analysis. Power analysis for multi-level modelling is highly complex. In multi-level models, statistical power is a function of numerous parameters, including: the number of participants, number of observations within participants, size of the estimated

effects, the distribution of variance across the within and between-person variables, and the reliability of each predictor variable. Hence, best practice for power analysis of multi-level models involves making a priori assumptions about these parameters, based on the prior literature, and use these assumed values to run power-analysis simulations (Nezlek & Mroziński, 2020). However, to our knowledge, this is the first study to collect data on the relationships between FORP and our variables of interest using an intensive longitudinal design, i.e., four daily measurement occasions over 14 days, in a clinical sample, and analyse that data within a multi-level model. Moreover, although we have carefully selected and adapted our single-item measures for use in this study, they have not been used, in their current state, in the literature before. Hence, we were not, a priori, able to confidently estimate several key parameters necessary for conducting a priori multi-level modelling power analysis, and thus a complex a priori power analysis was not conducted. However, to provide a rough approximation of the minimum number of observations required, G*Power, version 3.1, was used to conduct a linear multiple regression power analysis. Based on this analysis, to detect a small fixed effect (f^2 = .01) of two predictors (independent variable and dependent variable autocorrelation) on a dependent variable, at α = .05, and power = .90, a minimum of 1,269 observations were required. Assuming 56 observations per participant, that is equivalent to 23 participants. However, this analysis is likely to underestimate the required sample size as it does not account for non-independence of observations, or our interest in time lagged effects. Moreover, it is highly unlikely all participants would provide a 100% response rate. Hence, we aimed to double this estimated minimum sample size by recruiting at least 46 participants.

5.2.4.2 Baseline Characteristics and Data Preparation. SPSS, version 29, was used to analyse baseline survey data, and to create lagged variables within the EMA dataset. Lagged variables were created by lagging participant responses to the EMA survey by one measurement occasion. A significant association between a lagged variable and a

non-lagged variables demonstrates that the lagged variable predicts the non-lagged variable at the next measurement occasion. To minimise the influence of missing survey responses, which may introduce noise into the data by increasing the time between lagged survey responses, participants who responded to fewer than 39 of 56 (less than 70%) EMA surveys were excluded.

5.2.4.3 Multi-level Modelling. In EMA research, participants provide multiple responses to the same survey items over time. Due to individual differences, each participant's survey responses are likely to be more similar to each other, compared to responses from different participants. Hence, data from the EMA surveys is hierarchically nested, i.e., responses to EMA surveys are dependent on each individual participant. This violates independence of observations, thus standard regression analyses may not be appropriate for analysing the EMA data collected within the present study (Tabachnick et al., 2013). To handle non-independence of observations, and partition within and between-person variance, we used multi-level modelling where responses to EMA surveys (Level 1) are clustered by participant ID (Level 2). Jamovi, version 2.6.26, with the General Analyses for Linear Models add-on, version 3.5.1, was used to analyse data from the EMA surveys in a series of linear mixed-effects models. In all analyses, lagged versions of continuous variables, i.e., responses to EMA survey items, were entered as predictors of non-lagged dependent variables. This allowed us to examine directionality of observed effects.

To confirm whether the EMA data is clustered as expected, null/variance components models with random intercepts were conducted to calculate the intra-class correlation coefficient (ICC), and determine the proportion of variance occurring within-participants and between-participants. These analyses were conducted for all variables, including FORP, shame, intrusive memories, interpretation bias, and attention bias. If the null models demonstrate that the data is indeed clustered within-participants, as evidenced

by ICCs larger than .10, we will conduct a series of multi-level analyses (Snijders & Bosker, 2011).

Each hypothesised predictor of FORP, i.e., shame, intrusive memories, interpretation bias, and attention bias, were individually entered into separate models predicting FORP, with lagged FORP as a covariate. The inclusion of the lagged dependent variable allows us to determine whether our hypothesised predictors predict change in the dependent variable while controlling for the autoregression between the dependent variable at the previous measurement occasion. Following this, these models were re-run with the directionality reversed so that FORP is a predictor of shame, intrusive memories, interpretation bias, and attention bias, while including a lagged version of each respective dependent variable. By examining both possible directions of effect, e.g., whether shame predicts FORP and whether FORP predicts shame, we will be able to determine whether any observed effects are unidirectional or bidirectional. Finally, all significant predictors of FORP were entered simultaneously into a linear multi-level model to determine which variables, if any, uniquely predicted FORP, while controlling for the FORP autoregression. For the above analyses, EMA survey responses were clustered within participants, and all predictor variables were mean-centred within individual participants. To calculate a standardised estimates of effect size, model variables were Z-standardised within-persons allowing for estimation of standardised effect size estimates (β). Based on common rules of thumb, β values of .10, .30, and .50 can be interpreted as small, medium, and large effects, respectively (Cohen, 2013).

5.3 Results

5.3.1 Participants

Sixty-eight participants began the EMA phase of the study. Eighteen of these 68 participants (26.5%) were excluded because they responded to fewer than 70% of the EMA

surveys, leaving 50 participants for final analyses. Of the 18 participants that were excluded, six had fewer than five responses to the EMA surveys (<9% response rate), one had 10 responses (18% response rate), three had responses rates between 38-43%, the remaining eight had response rates between 52-66%. To determine whether the exclusion of the eight participants who had response rates over 50% affected the results, sensitivity analyses with these participants included were conducted.

Within the remaining 50 participants, the average proportion of EMA surveys responded to was 85.4% (47.8 of 56 surveys). Within this final sample, participants age ranged from 19 to 69 years old (M = 40.90, SD = 13.44). The number of self-reported lifetime diagnoses ranged from 1 to 6 (M = 2.76, SD =1.12). Most participants identified as female (78%), and were ethnically north-west European (68%). As the lowest possible score of the FORP-MHQ was 0 and participant scores ranged from 8 to 38 all participants reported experiencing FORP to some degree at baseline. All other participant demographics are reported in Table 5.1, and baseline questionnaire scores are reported in Table 5.2. At baseline, on average, participants were experiencing a mild-moderate degree of anxiety symptoms, and a moderate degree of depressive symptoms (Kroenke et al., 2001; Spitzer et al., 2006).

Table 5.1. Demographic and Clinical Characteristics

Characteristics		Final Sample (*n* = 50)	
		n	%
Gender	Woman	39	78
	Man	8	16
	Non-binary	2	4
	Other (unspecified)	1	2
Born in Australia		33	66
Ethnicity[a]	Oceanian	14	28
	North-west European	34	68
	Southern and Eastern European	3	6
	North-east Asian	2	4
	South-east Asian	3	6
	Southern and Central Asian	1	2
	People of the Americas	3	6
	North African and Middle Eastern	1	2
Education	Did not complete high school	2	4
	High school	9	18
	Certificate III, IV, or (advanced) diploma	15	30
	Undergraduate degree	11	22
	Postgraduate degree	13	26
Diagnoses[a]	Schizophrenia-spectrum	3	6
	Bipolar mood	8	16
	Unipolar mood	36	72
	Anxiety	37	74
	Obsessive-compulsive	4	8
	Trauma-stressor related	30	60
	Dissociative	4	8
	Eating disorders	3	6
	Personality disorders	9	18
Primary fear[b]	Schizophrenia-spectrum	3	6
	Bipolar mood	7	14
	Unipolar mood	19	38
	Anxiety	13	26
	Obsessive-compulsive	1	2
	Trauma-stressor related	16	32
	Dissociative	3	6
	Eating disorders	1	2
	Personality disorders	8	16
>1 lifetime diagnoses		44	88
Diagnosis source[a,c]	Psychologist	35	70
	Psychiatrist	37	74
Neurodevelopmental diagnoses[a]	Autism	6	12
	ADHD	12	24
	Specific learning disorders	5	10
History of inpatient admission		23	46
Currently using medication		41	82

Note. [a]Multiple options selectable. [b]Participants indicated which of their diagnoses they were most concerned about recurring or progressing, and a small number of participants identified multiple diagnoses as their primary fears. [c]Refers to the diagnosis of mental health conditions, not neurodevelopmental conditions.

Table 5.2. Baseline Questionnaire Scores

Baseline Variables	*M*	*SD*	Range	Cronbach's alpha (α)
FORP-MHQ	25.48	8.07	8 – 38	.932
GAD-7	11.74	5.19	0 – 21	.872
PHQ-9	13.76	6.43	2 – 27	.878

Twenty-one participants were administered the SCID-5-RV, and SCID-5-PD, to assess the accuracy of their self-reported lifetime mental health conditions diagnoses. All these participants are included in the final analysed dataset (n = 50). These diagnostic interviews found that 17 of the 21 participants (81%) reported their lifetime history of diagnoses completely accurately, i.e., the interviews found that they had met diagnostic criteria for all their lifetime self-reported diagnoses. In the remaining four participants (19%), the interviews found that they had not met diagnostic criteria for one of their self-reported diagnoses, but had met criteria for all other reported conditions. All participants that were interviewed met diagnostic criteria for at least one mental health condition, which they had self-reported accurately, over the course of their life. See Appendix D1 for the results of the diagnostic interviews.

5.3.2 Multi-level Models

EMA surveys (Level 1, n = 2,487 surveys) were clustered within participants (Level 2, N = 50). Analysis of ICCs emerging from the null models demonstrates that there was sufficient clustering of variables within each participant to justify multi-level modelling, i.e., ICCs > .10 (Snijders & Bosker, 2011). ICCs, along with other descriptive statistics, are reported in Table 5.3.

Table 5.3. Descriptive Statistics for EMA Variables

Variables	ICC	*M*	$SD_{between}$	SD_{within}
FORP	.531	36.69	22.3	21.0
Intrusive memories	.538	37.53	23.2	21.5
Shame	.640	30.79	24.0	18.0
Interpretation bias	.506	45.81	22.0	21.7
Attention bias	.555	43.04	23.5	21.1

Note. ICC reflects the proportion of variance in a variable attributable to between-person differences. Higher ICC values indicate more between-person variance, relative to within-person variance. *M* refers to the grand mean, averaged across all 2,487 responses to the EMA surveys.

A series of linear mixed-effects models were conducted in Jamovi to determine the relationship whether intrusive memories, shame, interpretation biases, and attention biases were predicts of FORP at the next measurement occasion, and vice versa. In each model, a time lagged version of the dependent variable was included as a predictor to control for the autoregression of the dependent variables (Table 5.4). Based on these analyses, intrusive memories, shame, and threat-related interpretations of mental state individually predicted small increases in FORP, even when controlling for the FORP autoregression (Cohen, 2013). To determine whether exclusion of the eight participants with response rates greater than 50% affected the results, these analyses were re-run with these eight participants included. Based on these analyses (n = 58), the pattern of results did not change (Appendix D2).

Table 5.4. Results of Multi-level Models for Determining Direction of Effect between FORP and Other Variables

Dependent variable											
FORP						Intrusions					
Predictors	*b*	*SE(b)*	*p*	95%CI	*β*	Predictors	*b*	*SE(b)*	*p*	95%CI	*β*
Intercept	36.638	3.192	<.001	[30.379, 42.896]	-	Intercept	37.502	3.312	<.001	[31.007, 43.998]	-
Intrusions $_{t-1}$	.146	.027	<.001	[.094, .198]	.146	FORP $_{t-1}$	.011	.028	.705	[-.044, .066]	.054
FORP $_{t-1}$	.071	.027	.009	[.018, .124]	.083	Intrusions $_{t-1}$	.1813	.027	<.001	[.128, .235]	.162
FORP						Shame					
Predictors	*b*	*SE(b)*	*p*	95%CI	*β*	Predictors	*b*	*SE(b)*	*p*	95%CI	*β*
Intercept	36.637	3.192	<.001	[30.379, 42.896]	-	Intercept	30.968	3.433	<.001	[24.236, 37.701]	-
Shame $_{t-1}$	.140	.024	<.001	[.093, .187]	.112	FORP $_{t-1}$	.063	.018	<.001	[.028, .098]	.095
FORP $_{t-1}$	.142	.021	<.001	[.102, .183]	.141	Shame $_{t-1}$	.133	.021	<.001	[.092, .174]	.141
FORP						Interpretation bias					
Predictors	*b*	*SE(b)*	*p*	95%CI	*β*	Predictors	*b*	*SE(b)*	*p*	95%CI	*β*
Intercept	36.637	3.192	<.001	[30.378, 42.900]	-	Intercept	45.719	3.162	<.001	[39.519, 51.919]	-
Interpretation bias $_{t-1}$	.101	.023	<.001	[.056, .146]	.098	FORP $_{t-1}$	.036	.024	.135	[-.011, .084]	.077
FORP $_{t-1}$	.116	.024	<.001	[.070, .163]	.122	Interpretation bias $_{t-1}$	.216	.024	<.001	[.170, .262]	.179
FORP						Attention bias					
Predictors	*b*	*SE(b)*	*p*	95%CI	*β*	Predictors	*b*	*SE(b)*	*p*	95%CI	*β*
Intercept	36.637	3.192	<.001	[30.379, 42.896]	-	Intercept	42.694	3.381	<.001	[36.064, 49.324]	-
Attention bias $_{t-1}$	.036	.023	.122	[-.010, .081]	.087	FORP $_{t-1}$	.036	.023	.119	[-.009, .082]	.095
FORP $_{t-1}$	.155	.023	<.001	[.109, .201]	.129	Attention bias $_{t-1}$	.150	.023	<.001	[.105, .195]	.152

Note. This table provides the fixed effects for the listed variables. Variables with (t-1) are variables that have been lagged by one measurement occasion. The 95% confidence intervals and *p*-values are calculated for unstandardised estimates, i.e., *b*.

5.3.2.1 Intrusive Memories and FORP. Intrusions memories of being mentally unwell significantly predicted FORP at the next measurement occasion (β = .146, p < .001), even when controlling for the significant FORP autoregression (β = .083, p = .009). Conversely, FORP did not significantly predict intrusive memories at the next measurement occasion (β = .054, p = .705), when controlling for the significant intrusions autoregression (β = .162, p < .001).

5.3.2.2 Shame and FORP. Shame significantly predicted FORP at the next measurement occasion (β = .112, p < .001), even when controlling for the significant FORP autoregression (β = .141, p < .001). Similarly, FORP significantly predicted shame at the next measurement occasion (β = .095, p < .001), even when controlling for the significant shame autoregression (β = .141, p < .001).

5.3.2.3 Interpretation Bias, Attention Bias, and FORP. Threat-related interpretations of mental state fluctuations significantly predicted FORP (β = .098, p < .001), even when controlling for the significant FORP autoregression (β = .122, p < .001). Conversely, FORP did not significantly predict threat-related interpretations of mental state fluctuations (β = .077, p = .135), when controlling for the significant interpretation bias autoregression (β = .179, p < .001). Attention towards mental state fluctuations did not significantly predict FORP (β = .087, p = .122), when controlling for the significant FORP autoregression (β = .129, p < .001). Similarly, FORP did not significantly predict attention towards mental state fluctuations (β = .095, p = .119)., when controlling for the significant attention autoregression (β = .152, p < .001).

***5.3.2.4 Simultaneous Prediction of FORP*.** Next, the variables found to be significant predictors of FORP were entered simultaneously into a final multi-level model to

determine whether they uniquely predicted FORP (Table 5.5). The results of this analysis demonstrated that intrusive memories (β = .115, p < .001), shame (β = .091, p < .001) , and interpretation biases (β = .055, p = .013) were statistically significant predictors of FORP at the next measurement occasion. However, lagged FORP no longer predicted FORP at the next measurement occasion.

Table 5.5. Simultaneous Prediction of FORP in a Multi-level Model

	FORP				
Predictors	*b*	*SE(b)*	*p*	95%CI	*β*
Intercept	36.637	3.192	<.001	[30.379, 42.896]	-
Intrusions $_{t-1}$	.114	.028	<.001	[.060, .168]	.115
Shame $_{t-1}$	.121	.024	<.001	[.074, .169]	.091
Interpretation bias $_{t-1}$	.059	.024	.013	[.013, .106]	.055
FORP $_{t-1}$	.033	.028	.239	[-.022, .089]	.046

Note. This table provides the fixed effects for the listed variables. Variables with (t-1) are variables that have been lagged by one measurement occasion. The 95% confidence intervals and *p*-values are calculated for unstandardised estimates, i.e., *b*.

5.4 Discussion

The present study aimed to determine the relationships between FORP and several theoretical predictors of FORP, including intrusive memories of being mentally unwell, shame, threat-related interpretations of mental state fluctuations, and attention to mental state fluctuations, in people with mental health conditions, using EMA. In the present study, as hypothesised, intrusive memories of being mentally unwell predicted greater FORP at the next measurement occasion. However, FORP did not predict intrusive memories, indicating that this was a unidirectional effect whereby intrusions were associated with increased FORP over time. Consistent with our hypothesis, shame predicted greater FORP at the next measurement occasion, and FORP predicted greater shame, indicating a bidirectional relationship between FORP and shame. As hypothesised, threat-related interpretations of fluctuations in mental state predicted greater FORP at the next measurement occasion. However, FORP did not predict threat-related interpretations, indicating this was another unidirectional effect, whereby interpreting fluctuations in mental state as indicative of

potential recurrence or progression led to subsequent increases in FORP. Contrary to our hypotheses, greater attention towards fluctuations in mental state did not predict FORP at the next measurement occasion, nor did FORP predict changes in attention. When the three statistically significant predictors of FORP, i.e., intrusive memories, shame, and threat-related interpretations of mental state fluctuations, were included simultaneously into a single model predicting FORP at the next measurement occasion, all three predictors retained a statistically significant effect. This suggests that FORP is predicted by multiple factors, with intrusive memories, shame and threat-related interpretations all leading independently to subsequent increases in FORP.

The finding that intrusive memories of being mentally unwell predicts greater FORP is consistent with the transdiagnostic theoretical model of mental health-related FORP proposed in Chapter 3. This model proposes that prior aversive or traumatic experiences of being mentally unwell give rise to intrusive memories, these memories are then extrapolated into expectations for the future, increasing FORP. Although prior research has consistently demonstrated that intrusive memories, and related symptoms of post-traumatic stress, are associated with FORP (Coutts-Bain et al., 2025a; Coutts-Bain et al., 2025b; White & Gumley, 2009), the present study is the first to demonstrate that these intrusions directly predict future FORP.

Similarly, the finding that shame has a positive bidirectional relationship with FORP was also consistent with the theoretical model of mental health-related FORP proposed in Chapter 3. According to this model, shame can emerge during recollection of aversive memories of being mentally unwell and increase the perceived cost of future deteriorations, increasing FORP. Simultaneously, people may feel shame about continuing to experience FORP or deteriorations in mental health, and engaging in the FORP-related avoidant behaviours. Although prior research has demonstrated that constructs related to shame, such as internalised stigma of mental illness, and low self-esteem, are associated with FORP (Collett et al., 2016; Coutts-Bain et al., 2025a), the present study is the first to

examine the emotion of shame specifically. Aside from being experienced as unpleasant, shame is a complex social emotion that can motivate a range of avoidant behaviours (Gilbert & McGuire, 1998). Indeed, our finding of a bidirectional relationship between FORP and shame is consistent with the cognitive-interpersonal model of early warning signs for people with a history of psychosis (Gumley et al., 2020). This model proposes that fear of psychosis relapse leads to feelings of shame, and that avoidant coping strategies, such as avoidance of healthcare providers, leads to healthcare providers increasing risk-orientated monitoring of service users, confirming services user's negative expectations of self and fears for the future, exacerbating fear of psychosis relapse. Conceptually, we might expect these processes to also be relevant for those with non-psychotic mental health conditions, especially if they have prior experience of involuntary psychiatric hospitalisation. Although the finding of a bidirectional relationship between FORP and shame in the present study, in a sample largely without a history of psychosis, supports this notion, future research will be needed to examine whether these FORP-related avoidance behaviours occur as theorised.

Contrary to our hypothesis, increased attention toward fluctuations in mental state did not predict FORP. Conversely, interpretating fluctuations in one's mental state as threatening was found to predict FORP. Indeed, prior research examining daily EMA data of people with schizophrenia has found that common early warning signs of psychosis, specifically paranoia, hearing voices, anxiety, negative affect, and changes in sleep did not significant predict fear of psychosis relapse the next day (Allan et al., 2023). Considering the findings of the present study, it appears that it is not fluctuations in mental state, nor the attention given to them, that predicts mental health-related FORP, but rather an individual's interpretation of these fluctuations as threatening, i.e., dangerous and predictive of deterioration. This is consistent with research on fear of cancer recurrence, where threat-related interpretation of ambiguous somatic symptoms accounts for the relationship between these symptoms and fear of cancer recurrence (Pradhan et al., 2021, 2022).

Overall, the identification of intrusive memories, shame, and threat-related interpretations of mental state fluctuations as predictors of mental health-related FORP provides empirical support for the theoretical model of FORP, proposed in Chapter 3. According to Cohen's (2013) rules of thumb for interpreting effect size these relationships may be labelled as small (β = .098 – .146). However, these blanket rules of thumb have received substantial criticism from statisticians who note that effect size must be interpreted in context (Funder & Ozer, 2019). For instance, within the present study, these β values represent the estimated effect of the predictor on FORP at the next measurement occasion, which could be as short as four hours. Hence, we would expect these predictors to have a larger cumulative effect on FORP over time, as intrusions, shame, and threat-related interpretations occur frequently over a single day, week, or month. Moreover, these effects emerged from a series of analyses that were quite robust. Specifically, time-lagged analyses which yield causally meaningful effects, particularly when controlling for autoregression of the dependent variable. In addition, by demonstrating that intrusions, shame, and threat-related interpretations all independently predict FORP, even when controlling for prior FORP, cumulatively these variables predict a larger amount of variance in FORP. Therefore, based on the findings of the present study, these predictors are likely important in accounting for higher levels of FORP.

5.4.1 Clinical Implications

Although the literature on mental health-related FORP is nascent, empirical research has demonstrated that FORP may be an important clinical issue for people with lived experience of mental health conditions. Aside from being associated with greater distress and suicidality (Collett et al., 2016; Coutts-Bain et al., 2023a), there is evidence that FORP may predict a shorter time to acute psychosis relapse in people with schizophrenia (Gumley et al., 2015). Although it remains to be empirically demonstrated that FORP predicts a shorter time to mental health deterioration in those with non-psychotic conditions,

theoretically we might expect this to be the case, as per the model reported in Chapter 3. Hence, reducing higher levels of FORP may not only reduce distress, but it may also reduce relapse rates. High rates of relapse contribute significantly to both the individual burden of mental health conditions, as well as the burden of mental illness on wider society and healthcare systems (Vigo et al., 2016). Therefore, psychological interventions for reducing mental health-related FORP may reduce the overall burden of mental health conditions on the individual's that experience them, and broader healthcare systems.

To our knowledge, there are no psychological interventions which have been designed to address mental health-related FORP. However, the present study draws attention to intrusive memories, shame, and interpretation biases as predictors of FORP. Therefore, these may be potentially modifiable therapeutic targets. By adapting existing psychological interventions known to effectively modify these factors, it may be possible to reduce higher levels of FORP. For instance, due to the significance of intrusive memories of aversive experiences, and shame, in driving FORP, adapting trauma-focused interventions may have utility in reducing FORP. Although post-traumatic stress disorder was historically understood as a fear-based condition, it is now understood that more complex emotions, including shame, are key factors in accounting for the condition and its impact (López-Castro et al., 2019). Hence, future clinical research on FORP may wish to examine interventions which have been shown to be effective in reducing intrusions, such as trauma-focused CBT and eye-movement desensitization and reprocessing therapy. These interventions may have utility in processing aversive memories of being unwell and constructing more adaptive, less shame-inducing, self-beliefs (Mavranezouli et al., 2020). Alternatively, compassion-focused therapy, which was specifically designed to target shame transdiagnostically, may also have utility in addressing mental health-related FORP (Gilbert, 2009).

Another potential target is the way people interpret fluctuations in their mental health, as there is consistent evidence to demonstrate that threat-related interpretations biases can be reduced with cognitive bias modification interventions (Martinelli et al., 2022). These

interventions typically involve training an individual away from making threat-related interpretations of ambiguous information. For people with lived experience of a mental health condition, the belief that mental state fluctuations may predict recurrence or progression is not irrational and may be adaptive, e.g., interpreting changes in mood as early warning signs of depression or mania (Goodwin, 2003). However, cognitive bias modification for interpretation biases reduces the automaticity with which these cognitions are activated (MacLeod & Mathews, 2012). In theory, this could increase the threshold at which fluctuations in mental state trigger the assumption that these fluctuations are indicative of recurrence or progression. For those with very high mental health-related FORP, cognitive bias modification could be a useful intervention for reducing over-interpretation of normative mental state fluctuations, such as feelings of sadness, excitement, or pattern recognition, as predictive of imminent deterioration.

5.4.2 Limitations

The present study must be qualified by several limitations. First, participants in this study were included based on their self-reported diagnoses, which is less reliable than attaining diagnoses via structured clinical interviews. However, there is evidence that people with mental health conditions are reasonably reliable at self-reporting their diagnostic history (Vieira et al., 2022). Moreover, administering a structured diagnostic interview to a subset of participants in the present study (42%) allowed us to demonstrate that our sample was similarly reliable. Importantly, we wanted a sample of people with mental health problems and every participant who was interviewed was confirmed to have accurately reported on their primary mental health condition. Second, although the findings of the present study provide support for the theoretical model of mental health-related FORP proposed in Chapter 3, we did not test all aspects of the model. Notably, we did not test whether prognostic pessimism predicts FORP over time, or whether there is a bidirectional relationship between FORP and ‘low-risk, low-reward’ behaviours, such that FORP predicts

avoidance of desired, but nevertheless stressful, behaviours, such as seeking employment, or establishing new platonic or romantic relationships, and vice versa. The reason for not examining these variables in the present study was pragmatic. To examine core feature of our model, specifically intrusive memories, momentary feelings of shame, and interpretations of mental state fluctuations, it was necessary to implement an intensive longitudinal design that could capture within-day variation in these variables. However, prognostic pessimism, that is, beliefs about the fundamental nature of one's conditions as permanent, recurrent, and unresponsive to treatment, are unlikely to vary in this manner. Similarly, although we believe the 'low-risk, low-reward' lifestyle is an important factor in understanding FORP, the behaviours associated with this lifestyle are likely to be relatively uncommon, e.g., not pursuing a job opportunity, and therefore do not lend themselves to exploration via EMA. Hence, these other features of the theoretical model, namely prognostic pessimism and the 'low-risk, low-reward' lifestyle, would be best examined with an alternative longitudinal design, and over a longer period of the time than the present study.

5.4.3 Conclusion

Notwithstanding these limitations, the present study possessed several notable strengths. Firstly, this is one of the few empirical studies to examine mental health-related FORP longitudinally rather than cross-sectionally. Moreover, by analysing intensively sampled data using time-lagged multi-level modelling, the present study can provide a stringent and rigorous account of the directionality between FORP and its theoretical predictors, i.e., shame, intrusive memories, and threat-related interpretations. Secondly, the sample of the present study was clinically diverse and reflects complexities that are common in real-world clinical settings. Many of the participants in the present study had a history of psychiatric hospitalisation, and lifetime comorbidity of multiple mental health conditions was the norm. Indeed, the mean number of lifetime diagnoses was comparable to the mean number of lifetime diagnoses found in a recent meta-analysis of diagnostic interviews, 2.76

vs 2.57, respectively (Menzies et al., 2024a). Similarly, the rates of autism and ADHD we observed in the present study are similar to those previously found in studies conducted in outpatient psychiatry services (Adamis et al., 2022; Nyrenius et al., 2022; Takara & Kondo, 2014). These sample characteristics, in conjunction with data collection via EMA, increase the ecological validity of the present study. Hence, there is good evidence to suggest that our findings can be generalised to the wider population of those with lived experience of mental health conditions.

In conclusion, intrusive memories of being mentally unwell, feelings of shame, and interpreting fluctuations in one's mental state as threatening predicts mental health related-FORP, in people with lived experience of different mental health conditions. These findings are consistent with the transdiagnostic theoretical model of mental health-related FORP, proposed in Chapter 3. Moreover, intrusive memories, shame, and interpretation biases can be modified by psychological interventions. Hence, future research should explore whether trauma-focused interventions, and psychoeducation on mental state fluctuations, can be adapted to target these proximal predictors of mental health-related FORP, and thus reduce the distress and increased risk of relapse associated with FORP.

Chapter 6: General Discussion

6.1 Overview of Research Aims and Findings

For people with lived experience of serious or chronic illnesses, FORP is a normal and expected response to living with the real possibility that one's illness will recur or worsen over time. Although some degree of FORP may be necessary to motivate appropriate health-protective action, there is clear evidence that this fear can be a significant source of distress, disability, and, surprisingly, may be associated with maladaptive coping strategies that predict poorer health outcomes. Historically, FORP has mostly been examined in cancer survivors, i.e., fear of cancer recurrence, and people with other chronic physical illnesses. However, there is a paucity of research on mental health-related FORP in people with lived experience of mental health conditions. Given the substantial impairments associated with mental health conditions, as well as their potential to follow a chronic or recurrent course, we would expect people to worry about the recurrence or progression of their conditions. Yet, little is known about the relevance and impact of mental health-related FORP, which may affect the 42% of people who will experience a mental health condition in their lifetime (Australian Bureau of Statistics, 2023). Moreover, the small existing literature on mental health-related FORP was predominantly focused on fear of psychosis relapse in people with schizophrenia (Zukowska et al., 2022), thus far less was known about FORP in those with more common, non-psychotic, conditions.

To address these gaps in the existing literature, the present dissertation had the following overarching aims: 1) determine whether FORP is relevant to those with lived experience of non-psychotic mental health conditions, 2) establish a theoretical model of FORP and determine whether FORP can be accounted for transdiagnostically across those with different conditions, and 3) determine whether mental health-related FORP is an empirically distinct construct, and whether it can be measured transdiagnostically. Hence, we aimed to elucidate the nature of mental health-related FORP, and establish a theoretical foundation and measurement tool which can facilitate further research on FORP in people

with mental health conditions. To meet these aims, the present dissertation presents the findings of several empirical studies.

Following systematic retrieval and synthesis of existing research on mental health-related FORP, Chapter 2 demonstrated that FORP was relevant to those with experience of both psychotic and non-psychotic mental health conditions. Meta-synthesis of 19 qualitative studies, nine of which were in psychosis, found that fear of symptoms, loss of progress, and traumatic experiences, were common subthemes underlying FORP in people with and without a history of psychosis – with fears of death only being identified in those with psychosis. Similarly, FORP was related to an inability to trust oneself, hypervigilance towards mental state, and a low-risk, low-reward lifestyle characterised by avoidance of relationships and desired life goals, as well as fear of changing treatment, in those with and without psychotic conditions. Substantial heterogeneity between quantitative studies precluded meta-analysis, thus 16 studies, 11 of which focused on psychosis, were reviewed narratively. This review demonstrated that FORP was strongly associated with poorer quality of life, as well as greater symptoms of depression, anxiety, and psychosis, in people with a history of psychosis. In this population, FORP was also associated with poorer engagement with smartphone-based symptom monitoring, avoiding conception of children, and medication adherence. Although there were only 5 studies on FORP in non-psychotic conditions, FORP was associated with greater medication adherence across mood, anxiety, and substance dependence conditions, where it had been investigated.

Synthesis of these qualitative and quantitative findings demonstrated that FORP is a source of distress for people with a range of different mental health conditions, and provides preliminary evidence that it is associated with clinically significant outcomes. However, this review drew attention to several significant gaps in the FORP literature. Aside from the general paucity of research on non-psychotic mental health conditions, none of the identified qualitative studies intended to examine FORP a priori, thus it was probable that the meta-synthesis did not completely capture the experience of FORP as this was not the focus of

the included studies. Hence, further research was required to gain a deeper understanding of mental health-related FORP, and to determine whether a theoretical model could account for FORP transdiagnostically.

Chapter 3 addressed these gaps in the existing literature by using grounded theory methodology to construct a theoretical model of mental health-related FORP from a series of qualitative interviews. Critically, framework analysis of interview transcripts determined that the model had transdiagnostic relevance for people with lived experience of unipolar mood, bipolar mood, anxiety, obsessive-compulsive, disordered eating, and schizophrenia-spectrum conditions. This model proposed that aversive, or outright traumatic, experiences that occur whilst mentally unwell lead to recurrent intrusive memories of being unwell, which are extrapolated into fears for the future. These memories drive mental health-related FORP, especially for those with internalised mental illness stigma who may experience said intrusive memories, or anticipated future deteriorations, as shameful. To cope with FORP, people adopt a ‘better safe than sorry’ approach to management of their mental health, characterised by vigilance to early warning signs, seeking support, adherence to treatment, and avoidance of stressors. However, excessive FORP may lead to excessive application of these adaptive strategies. This may result in hypervigilance towards mental state and biased interpretation of normal or mild fluctuations as indicative of recurrence, reassurance seeking, and adoption of a ‘low-risk, low-reward’ approach to life, which is characterised by avoidance of stressful, but nevertheless desired, activities, relationships, and occupational goals. Although these are an attempt to preserve one’s mental health, inadvertently they are anxiogenic, and may increase vulnerability to deterioration by reducing access to protective social buffers. Similarly, cognitive avoidance of FORP and related intrusive memories, as well as beliefs that one’s mental health conditions are permanent, recurrent, and beyond personal control, may contribute to greater mental health-related FORP. Although several of these themes and subthemes emerged in the meta-synthesis in Chapter 2, this research expanded upon them and identified additional themes related to FORP, namely shame,

internalised stigma, cognitive avoidance, and prognostic pessimism. Moreover, the one thematic element that did not emerge transdiagnostically in Chapter 2, i.e., fears of death, was identified across diagnostic groups. Hence, the model presented in Chapter 3 can be thought of as a necessary expansion of the earlier preliminary model. Critically, all themes and subthemes in this model were represented in participants with unipolar mood, bipolar mood, anxiety, obsessive-compulsive, disordered eating, and schizophrenia-spectrum conditions. Therefore, the model appeared to have transdiagnostic applicability.

Although grounded theory methodology is useful for constructing theoretical models, empirical validation of a model requires large-scale quantitative research that can be generalised. To evaluate whether mental health-related FORP was related to several psychological variables identified from early qualitative interviews, a cross-sectional survey of 269 people with different mental health conditions was also reported in Chapter 3. Using an ad hoc measure of mental health-related FORP, this study demonstrated FORP was associated with theoretical predictors of FORP, including intrusive memories of being mentally unwell, internalised mental illness stigma, prior and anticipated discrimination, and beliefs that one's conditions had a biological cause, and residual symptoms of depression, anxiety, and stress. In addition, FORP was associated with current use of medication to treat mental health conditions, consistent with the model. However, when these theoretical predictors were entered into a hierarchical regression model, only intrusive memories and biological beliefs significantly predicted FORP over and above residual symptoms and background clinical factors. Although internalised stigma was no longer associated with FORP once other variables were accounted for, this may have been due to the stigma questionnaire focusing on negative feelings towards *having* a mental health condition (Ritsher et al., 2003), rather than negative feelings about one's capacity for self-management which commonly arose in interviews. Moreover, use of an ad hoc measure of FORP, and the cross-sectional nature of the study which precluded any examination of causality, means these findings must be considered tentatively. A more rigorous test of the

theoretical model would require these variables be examined longitudinally, and that FORP be measured with a rigorously validated questionnaire. The absence of such a measure was a major barrier to further research on mental health-related FORP.

After the research described in Chapter 3 was completed, the only validated measure of mental health-related FORP that had been published was the FoRSe (Gumley et al., 2015). This questionnaire was specifically designed to examine fear of psychosis relapse in people with schizophrenia-spectrum conditions, and had not been validated for other clinical populations. Hence, to rigorously test the theoretical model described in Chapter 3, it was necessary to develop a novel questionnaire designed to assess mental health-related FORP generally. To address this gap, we reported on the development and validation of the FORP-MHQ in Chapter 4. Drawing on the qualitative interviews from Chapter 3, a pool of 40-items related to FORP were drafted and piloted in prior interviewees. Following this, these items were administered to 905 people diagnosed with different mental health conditions. Using factor analysis, this item pool was reduced to a structurally valid 10-item questionnaire that assessed the severity of mental health-related FORP. The FORP-MHQ was found to reliably measure FORP, as demonstrated by excellent internal consistency and good 28-day test-retest reliability. The questionnaire also possessed good construct validity, as demonstrated by strong convergent associations with other measures of FORP, concurrent associations with theoretically-related variables as hypothesised, and good discriminant validity as demonstrated by sufficient empirical distinction between FORP and mental health anxiety. Considering these findings, there is good evidence that mental health-related FORP, as measured by the FORP-MHQ, is an empirically distinct construct.

Chapter 4 also explored whether mental health-related FORP could be measured transdiagnostically across people with lived experience of different conditions. Measurement invariance analyses demonstrated that the FORP-MHQ was measuring FORP equivalently in those with and without a history of psychosis or mania, and those with and without a lifetime history of multiple conditions. Critically, this does not mean that these populations

are expected to have equal scores on the FORP-MHQ, instead this means the FORP-MHQ is measuring the underlying construct of FORP equivalently between these groups. From an empirical standpoint, this means that the FORP-MHQ can be used to meaningfully examine FORP magnitude, and the relationship between FORP and other variables, in those with psychotic and non-psychotic conditions, and those who experience FORP in relation to one or multiple different conditions. This demonstrates further evidence that FORP is relevant to those with psychotic and non-psychotic conditions, and provides preliminary evidence that the FORP-MHQ can measure FORP transdiagnostically. Hence, we developed a measure of FORP appropriate for people with a range of different mental health conditions that can facilitate further research on FORP.

With the development of a questionnaire to assess transdiagnostic mental health-related FORP, it was now possible to conduct a more rigorous test of the theoretical model described in Chapter 3. In this endeavour, Chapter 5 reported on a longitudinal study using EMA to examine the directionality of the relationships between FORP, and intrusive memories, shame, as well as attention to, and interpretation of, mental state fluctuations. As predicted, intrusive memories of being mentally unwell, and threat-related interpretations of mental state fluctuations, predict mental health-related FORP over time. In addition, there was a bidirectional relationship between FORP and shame over time, consistent with our theoretical model. Contrary to our hypotheses, attention toward fluctuations in mental state did not predict FORP. When intrusions, threat-related interpretations, and shame were entered into a single model, they were all independent predictors of FORP in people with mental health conditions. Hence, Chapter 5 provided empirical support for some core aspects of the theoretical model proposed to account for mental health-related FORP.

Overall, the research reported in this dissertation has achieved its stated aims. We found robust evidence to support the relevance of mental health-related FORP to people with lived experience of non-psychotic conditions. A transdiagnostic theoretical model accounting for FORP was proposed across Chapters 2 and 3. The development of a

transdiagnostic questionnaire in Chapter 4 also allowed us to demonstrate that mental health-related FORP is a distinct construct, separable from mental health anxiety. This questionnaire then allowed us to test the theoretical model from Chapters 2 and 3, in Chapter 5. With the development of an empirically supported theoretical model, and a valid and reliable questionnaire, the present dissertation provides a strong foundation for further research on mental health-related FORP.

6.2 Methodological Considerations: Strengths, Limitations, and Future Directions

The empirical research presented in Chapters 2 to 5 is methodologically diverse, relying on a range of different designs and sophisticated approaches to data analysis. The various strengths and limitations of these methodologies have been considered within each studies' respective chapter. Nevertheless, some broader strengths and limitations are discussed below, as well directions for future research that may address the limitations of this dissertation.

6.2.1 Self-reported Diagnoses

Across Chapters 2 to 5, participants were asked to self-report their lifetime mental health conditions. As discussed within these empirical chapters, self-reported diagnoses may be a less reliable means of assessing clinical history than structured diagnostic interviews. This is not so much a problem for determining eligibility to participate, where the main concern is identifying who has been diagnosed with a mental health condition, not what their exact conditions are. However, the reliability of diagnoses must be considered when said data is used to characterise a sample, and when conducting analyses pertaining to transdiagnostic applicability. Research has demonstrated that self-reported diagnoses of mental health conditions (Vieira et al., 2022), and schizophrenia-spectrum conditions specifically (Woolway et al., 2024), are generally reliable. Hence, for research relying on

large samples, or where over-burdening of participants with mental health conditions is a concern, such as in Chapters 3 and 4, self-report appears to be a reasonable means of collecting diagnostic data. To examine this issue more closely, with respect to the present thesis, diagnostic interviews were conducted in a subsample of participants from Chapter 5 to evaluate the reliability of self-reported diagnoses. This data demonstrated that 81% of the subsample were perfectly reliable in their self-reported lifetime diagnoses, with the remaining 19% being inaccurate only regarding one of their respective diagnoses. This has important implications for the present thesis. All participants in Chapter 5 had previously participated in the validation of the FORP-MHQ (Chapter 4), and the recruitment source for this validation study was the same as in Chapter 3, i.e., paid social media advertisements on Facebook and Instagram. Indeed, demographic and other clinical history variables are generally consistent between these studies. Hence, our finding of good self-report reliability in the Chapter 5 subsample is somewhat suggestive of good diagnostic reliability across all studies within the present thesis.

Nevertheless, future research on mental health-related FORP should remain mindful of diagnostic reliability, particularly when examining transdiagnostic applicability. It is likely that research comparing measurement, models, or treatment effects in clinical trials, across diagnostic groups will rely on quantitative analyses that require large samples, where it may not be practical, or even possible, to administer diagnostic interviews to all participants. Hence, future research should examine diagnostic reliability using alternative approaches. This may include using diagnostic interviews in a subsample of participants to estimate reliability, as described in Chapter 5. Alternatively, researchers with access to health service data, such as the National Health Service in the United Kingdom, or state public health services in Australia, could use case note diagnoses to collect diagnostic data, as an alternative to relying on self-report.

6.2.2 Psychometric Validation of the FORP-MHQ

Chapter 4 reported on the development and validation of a questionnaire designed to measure mental health-related FORP. Since the publication of the FORP-MHQ, another measure of FORP, specifically for those with depressive conditions, has been published (Gumuchian et al., 2025). Hence, there are now three validated questionnaires for assessing FORP in people with mental health conditions, including: the FORP-MHQ, the FoRSe, which was the designed to assess fear of psychosis relapse (Gumley et al., 2015), and the Fear of Depression Recurrence Questionnaire (FoDRQ) (Gumuchian et al., 2025), which as the name suggests measures FORP in relation to depressive episodes. Overall, all these questionnaires possess good psychometric properties. However, closer examination of these validation studies indicates that the FORP-MHQ may be psychometrically superior for measuring mental health-related FORP (Table 6.1).

Table 6.1. Psychometric Properties of Mental Health-related FORP questionnaires

Questionnaire characteristics	Questionnaires		
	FORP-MHQ	FoRSe fear of relapse subscale	FoDRQ severity subscale
Initial validation study	Chapter 4	Gumley et al (2015)	Gumuchian et al (2025)
Total sample size (*n*)	**865**	162	552
Reliability			
Internal consistency (*α*)	**.94**	.85	.86
Test-retest reliability (*r*)	**.73**	.66	.68
Test-retest period	28 days	14 days	28 days
Structural validity			
Good fit within CFA	**Yes**	No CFA conducted	**Yes**
Alignment of EFA and CFA	**Yes**		**Yes**
Construct validity			
Convergent validity with measures of FORP (*r*)	**.71 – .73**	Not examined	Not examined
Discriminant validity	**Yes, separable from mental health anxiety**	Not examined	Yes, separable from self-efficacy and gratitude
Concurrent validity	**Yes**	**Yes**	**Yes**
Predictive validity	No, cross-sectional design	**Yes, predicts shorter time to relapse**	No, cross-sectional design
Measurement invariance			
Men and women	**Yes**	Not examined	**Yes**
With and without comorbidity	**Yes**	Not examined	Not examined
Psychotic and non-psychotic conditions	**Yes**	N/A	N/A

Note. Comparing across the three questionnaire validation studies, superior evidence for the different facets of reliability and validity is bolded.

Although the FORP-MHQ, FoRSe, and FoDRQ all have good evidence of reliability, comparing their initial validation studies suggests that the FORP-MHQ may have slightly superior internal consistency and test-retest reliability. However, the most significant differences in psychometric properties emerge when examining construct validity. Firstly, only the validation of the FORP-MHQ examined convergence with other measures of mental health-related FORP. Convergent validity can be difficult to assess when a phenomenon is understudied and there is a paucity of measurement tools to assess convergence. Nevertheless, convergent validity of at least $r = .70$ is critical to ensuring that the magnitude of empirical relationships are due to the underlying construct and not questionnaire-related idiosyncrasies (Carlson & Herdman, 2012). Another issue pertaining to construct validity is that, unlike the FORP-MHQ, the FoRSe and FoDRQ have not been subjected to a rigorous test of discriminant validity. Regarding the FoRSe, discriminant validity was not considered during validation (Gumley et al., 2015). This is particularly problematic considering that the FoRSe correlates very highly with mental health anxiety in independent samples ($r = .72 – 76$) (Jamalamadaka et al., 2020; Sired et al., 2021). Conversely, validation of the FoDRQ only weakly considered discriminant validity by demonstrating separability from measures of self-efficacy and gratitude (Gumuchian et al., 2025). Self-efficacy and gratitude are very different constructs to FORP, and thus the distinction of the FoDRQ from self-efficacy and gratitude questionnaires is hardly a stringent test of discriminant validity. Given the scientific risks posed by redundant constructs and measurement tools, tests of discriminant validity should focus on constructs which are conceptually closest to the construct of interest (Hodson, 2021). For mental health-related FORP, this demands examination of separability from mental health anxiety. Moreover, latent variable modelling to prevent measurement error from suppressing correlations between questionnaires is considered best practice for evaluating discriminant validity (Hodson, 2021), and of the three mental health-related FORP questionnaires this has only been performed for the FORP-MHQ. Due to these analyses, the FORP-MHQ possesses the strongest evidence for construct validity, when compared to the FoRSe and FoDRQ.

It is also important to consider the appropriateness of a questionnaire for the population it will be administered to. The FoRSe and FoDRQ were designed to assess FORP in specific populations, that is people with schizophrenia-spectrum conditions and remitted major depression, respectively. However, when these questionnaires are administered in clinical samples, they will invariably be answered by people with a broader range of experiences. Longitudinal birth-cohort research has demonstrated that up to 98% of people with a thought disorder, like psychosis, have also met criteria for an internalising or externalising disorder by age 45 (Caspi et al., 2020). Similarly, research on the temporal sequences of mental health conditions has demonstrated that depression is commonly diagnosed secondary to other conditions, such as anxiety conditions (De Graaf et al., 2003; Menzies et al., 2024a). Moreover, people without a diagnosis of major depressive disorder may still be concerned with the recurrence of depressive phenomena. Numerous symptoms of depression, including mood disturbances, are non-specific, and feature in the diagnostic criteria of anxiety, trauma- and stressor-related, somatic symptom, feeding and eating, substance-related, and personality disorders (Forbes et al., 2024). Hence, people with a history of psychosis or depression may also experience FORP in relation to the other mental health conditions they have likely experienced. Indeed, these fears may interact, as Chapter 4 demonstrated that people with diagnoses across multiple diagnostic categories scored higher on the FORP-MHQ than those without (d = .454). However, whether the FoRSe or FoDRQ can capture these interactions remains unclear. This is especially the case for the FoRSe, which contains items that refer to specific psychotic phenomenon, e.g., “the world has seemed more vivid and colourful” (Gumley et al., 2015).

Nevertheless, it is possible that the experience of mental health-related FORP varies somewhat depending on which syndrome or condition is feared most. For instance, people who are fearful of psychosis recurrence may be more concerned about being hospitalised, whereas those fearful of depression recurrence may be more concerned about becoming suicidal. Assuming these differences in FORP content are significant and clinically

meaningful, there may be some circumstances where a syndrome-specific measure of FORP is useful. If such questions are guiding the research, illness-specific measures can be suitable and represent the best fit for purpose. However, a generic measure of FORP with transdiagnostic applicability may be advantageous in other circumstances because it allows for direct comparisons across different clinical populations, can assess FORP for common comorbidities, and allows for examination of transdiagnostic processes, such as the relationship between FORP and clinical outcomes, like relapse. Hence, the FORP-MHQ is a psychometrically strong, and flexible, measurement tool that can be used to advance research on mental health-related FORP. Although whether the FORP-MHQ is sensitive to change remains to be seen, it may be a strong candidate for future clinical research.

Despite this, it is important to recognise that psychometric validation is an iterative process. Aside from the need to replicate the factor structure of the FORP-MHQ in different populations, there is scope for future research to further evaluate the validity of the measure. Most notably, validation of the FORP-MHQ was unable to examine predictive validity, that is, whether the questionnaire predicts expected outcomes over time, because the study was cross-sectional. At present, only the FoRSe has demonstrated predictive validity, as FoRSe scores predict a shorter time to psychotic relapse even when controlling for early warning signs of psychosis (Gumley et al., 2015). To evaluate the predictive validity of the FORP-MHQ, and to further examine the potential impact of mental health-related FORP, future research should aim to replicate this finding using the FORP-MHQ in a clinically diverse sample.

6.2.3 Future Research on Predictors and Outcomes of FORP

The theoretical model of mental health-related FORP initially developed in Chapter 2, and extended in Chapter 3, describes a range of psychological variables proposed to predict FORP, as well as several theoretical outcomes of FORP. Although empirical evidence for

these proposed associations has been examined across Chapters 2 to 4, the most rigorous test of this model came in Chapter 5. To closely examine the relationship between FORP, intrusive memories, shame, as well as attention to, and interpretation of, mental state fluctuations, intensive longitudinal sampling was used to identify within-day fluctuations in these variables. However, focus on a within-day time scale precluded examination of predictors and outcomes which might be associated with FORP over the longer term. Hence, Chapter 5 was only a partial test of the theoretical model.

Over the longer term, believing one's mental health conditions to be chronic, recurrent, severe, and beyond individual control, i.e., prognostic pessimism, are theorised to predict mental health-related FORP. Indeed, Chapters 3 and 4 these cognitive factors are associated with FORP cross-sectionally. Although endorsement of prognostic beliefs can be modified by exposure to relevant information (e.g., Lebowitz & Ahn, 2018), which might be provided during diagnosis or treatment, endorsement is not likely to vary significantly day-to-day. Similarly, an inability to trust oneself to notice and appropriately act on early warning signs reflects beliefs about self-efficacy that are likely to be more stable than intrusions and feelings of shame. Theoretically, we might expect prognostic pessimism and an inability to trust oneself to vary during critical periods, like diagnosis, treatment, or after a period of acute deterioration or relapse. Therefore, future research which aims to explore the relationship between these cognitive factors and mental health-related FORP should examine change over a longer period of time and attempt to capture moments when change is these beliefs is expected to occur naturalistically.

This principle also applies to future research on the theorised outcomes of mental health-related FORP. Most notably, this applies to research on the 'low-risk, low-reward' lifestyle that is expected to affect people with higher levels of FORP. As first noted in Chapter 2, and expanded upon in Chapter 3, people concerned about recurrence and progression reported avoidance of stressful, but nevertheless desired, activities which they suspect might precipitate mental health deterioration, or increase the perceived cost of

deterioration. Often this involved people forgoing travel, independent living, occupational opportunities, starting new relationships, and having children, despite their desire to explore these possibilities. Contemporary understandings of recovery, with respect to mental illness, draw attention to the importance of pursing personal goals that imbue one's life with meaning and fulfilment, beyond the need for symptom reduction (Davidson & Roe, 2007). Considering this, it becomes evident that high levels of mental health-related FORP may interfere with the process of recovery, worsening quality of life, and potentially increasing vulnerability to acute relapse.

In general, people with mental health conditions, including those with more severe and complex conditions, want to engage in work they consider meaningful (Harvey et al., 2013). In line with recovery principles, work may allow for positive social contact, independence, expression of values, and improved self-esteem, as well as financial benefits. More directly, a meta-review of systematic reviews on the mental health benefits of employment demonstrated that work can be beneficial to mental health (Modini et al., 2016). Nevertheless, there is evidence that work can precipitate deteriorations in mental health when conditions are poor or unjust (Harvey et al., 2017). People with mental health conditions may be intuitively aware of this, and thus may avoid taking on more demanding work, or avoiding employment altogether, despite their desires and goals to the contrary. Indeed, this was reported by our interviewees in Chapter 5. Assuming FORP predicts this avoidant behaviour, FORP may be part of the reason why rates of competitive employment in people with mental health conditions is lower than the general population, especially for those with a history of psychosis (Jefferis et al., 2011; Waghorn et al., 2012). Given the potential impact of FORP on occupational outcomes, and the potential for occupational avoidance to inadvertently reinforce FORP, future research should examine the relationship between these variables longitudinally. Future research would likely require sampling over an extended period, potentially years, to examine the effect of FORP on occupational outcomes given that attaining desired employment can be protracted process. It would be

important that a diverse array of occupational outcomes is considered in this research. For instance, FORP may be a barrier to paid employment, but it also may lead to underemployment, when additional work hours, or a different, but desired job, is perceived as risky for one's mental health.

As with work, people with mental health conditions value meaningful social connections and relationships. This is true of people in general, but relationships may be especially important to recovery for those with mental health conditions. Mental illness can be a catalyst for the loss of important platonic, familial, and romantic relationships (Baker & Procter, 2015; McCarthy-Jones et al., 2013). Indeed, in Chapter 3, this was also reported by our interviewees. Hence, maintaining relationships and connection to community is often regarded as a key component of the recovery process (Leamy et al., 2011). Such relationships may be a source of support, assist with early warning signs monitoring and help-seeking, or simply provide a sense of self-esteem through reciprocal support. Indeed, there are clear bidirectional effects observed between relationships and mental health. For instance, good mental health predicts entry into romantic relationships, whilst being in a supportive romantic relationship simultaneously predicts better mental health (Braithwaite & Holt-Lunstad, 2017). This is even the case for people with more severe mental illnesses, such as psychosis, where being in a romantic relationship is associated with fewer psychotic symptoms and better psychological wellbeing (White et al., 2021a). Nevertheless, relationships, particularly romantic ones, can be a source of distress when relationship quality is low, or when conflict or abuse occurs (Mirsu-Paun & Oliver, 2017). Hence, people experiencing FORP may avoid seeking out new relationships, particularly romantic ones, despite their desires to the contrary. Related to this, people may be concerned about, or even forgo, having children if they anticipate being unable to cope with the stress of parenthood, or believe relapse would put their children at risk. This is especially pertinent for women with a history of psychosis or mania, who may be fearful of post-partum psychosis, particularly those who are treated with teratogenic medication that may need to be ceased

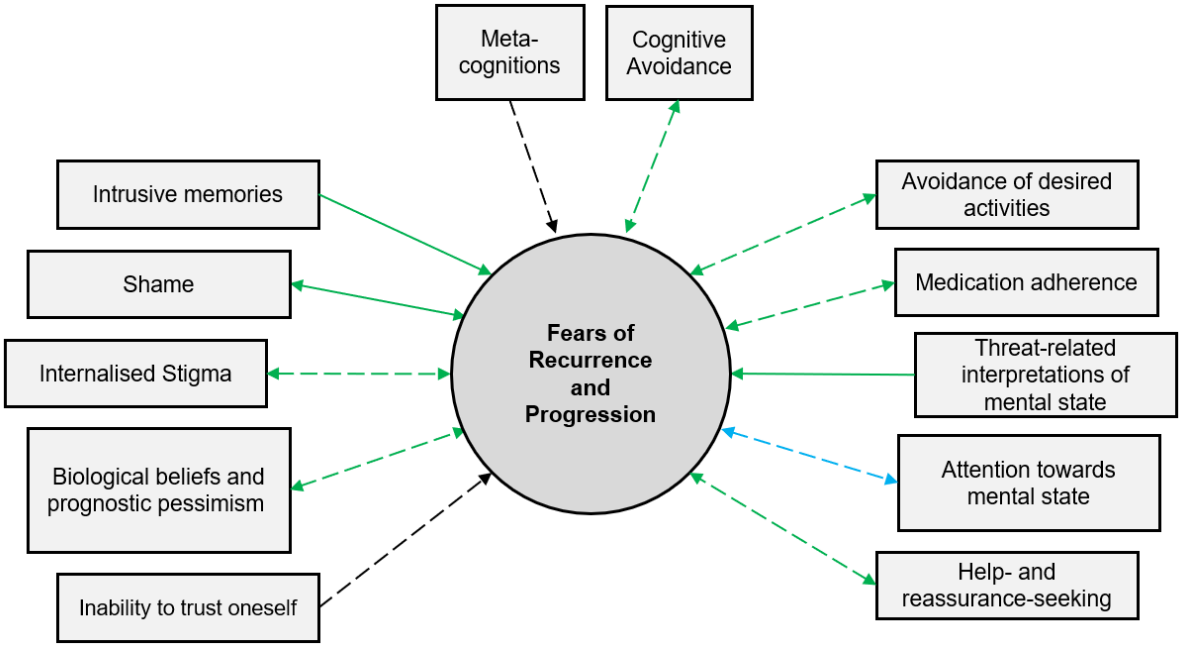
prior to pregnancy (Fabiano et al., 2024; White et al., 2021b). Indeed, there is cross-sectional evidence that fear of post-partum relapse is associated with avoiding conception via abortion, sterilisation surgery, or adoption (Peindl et al., 1995). Given the potential impact of FORP on relationship seeking and family planning, future prospective research should aim to clarify the directionality of these relationships and evaluate the extent of the impact of FORP on these key relational outcomes that may be important to personal recovery.

Evidently, there is a need for further longitudinal research to test Chapter 3's theoretical model of mental health-related FORP. Nevertheless, the findings of this dissertation, in conjunction with the broader literature, provide support for most aspects of the model. In brief, Chapter 5 demonstrated that shame, intrusive memories of being mentally unwell, and threat-related interpretations of mental state predict subsequent FORP. Other factors, such as internalised mental illness stigma, prognostic pessimism, biological beliefs about mental health conditions, and cognitive avoidance, are associated with FORP cross-sectionally (Chapters 3 and 4). Furthermore, recent research has corroborated the finding that FORP is associated with avoidance, as fear of depression recurrence is associated with experiential avoidance, even when controlling for residual depressive symptoms and the number of the prior depressive episodes (Gumuchian et al., 2025). Therefore, the only theoretical predictors of FORP that remain unexamined are maladaptive metacognitions about the importance of FORP, and an inability to trust one's own appraisal of their mental state. To our knowledge, there no validated measures of the latter of these predictors. Hence, while metacognitions could be relatively easily measured in the context of FORP, a new measure of one's ability to trust oneself may be needed to fully test the proposed model.

In terms of theoretical outcomes of mental health-related FORP, Chapter 5 demonstrated that attention towards mental state did not predict subsequent FORP, contrary to our expectations. However, the quantitative systematic review in Chapter 2 demonstrated that across a range of different mental health conditions FORP was associated with

increased medication adherence. Corroborating this, Chapter 3 found that current medication use was also associated with FORP. Although the present dissertation did not quantitatively examine avoidance of desired activities and help- or reassurance-seeking, FORP has been associated with avoidance of conceiving children in those that want children (Peindl et al., 1995), and seeking help from mental health professionals (Gumuchian et al., 2025). See Figure 6.1 for a summary of existing evidence for the theoretical model.

Figure 6.1 Summary of Available Evidence for the Theoretical Model of FORP



Note. Green arrows indicate a relationship that is supported by at least one empirical study. Dashed green arrows indicate cross-sectional evidence, whereas solid green arrows indicate longitudinal evidence. The arrow heads represent directionality of the relationship depending on the available evidence. Blue arrows indicate relationships that have been examined but appeared non-significant. Black dashed arrows indicate relationships that remain unexamined.

6.2.4 Does FORP Predict Relapse in Non-psychotic Conditions?

According to the theoretical model of mental health-related FORP proposed in Chapter 3, high levels of FORP may drive anxiogenic cognitions and behaviours that could increase vulnerability to mental health deterioration. This outcome has been demonstrated in people with schizophrenia-spectrum conditions, where fear of psychosis relapse predicted a shorter time to relapse of positive symptoms, even when controlling for typical early warning signs of psychosis (Gumley et al., 2015). This finding clearly demonstrates the clinical significance of mental health-related FORP, at least in people with a history of psychosis. However, it remains to be seen whether FORP predicts relapse of other, non-psychotic, conditions.

There are many ways to operationalise relapse in psychiatric research (de Zwart et al., 2019; Khalsa et al., 2017; Olivares et al., 2013). However, relapse is most often defined by a clinically significant increase in symptoms on clinician-administered scales, or by using contact with mental health services, often hospitalisation, as a proxy for relapse. Given the divergent nature of psychotic and non-psychotic conditions, this may make prospective research aiming to predict non-psychotic relapse particularly challenging. After treatment for first episode psychosis, approximately 30% of people experience a relapse of positive symptoms within 12-months (Alvarez-Jimenez et al., 2012). Moreover, the time between the early and acute stages of relapse can be abrupt, often occurring just over a matter of weeks (Emsley et al., 2013). This means that prospective research determining psychotic relapse via clinician assessment can be adequately powered over relatively short periods of time. Indeed, Gumley et al. (2015) found that 34.3% of their participants experienced psychotic relapse over a 6-month period, based on clinician assessment of symptoms. Given the high cost associated with psychotic relapse, and its potentially abrupt onset, mental health services and people with a history of psychosis often carefully monitor for early signs of relapse. Moreover, when relapse is not detected early it is likely to be observed in the community, resulting in involuntary hospitalisation (Walker et al., 2019). Hence, prospective

research can feasibly use contact with mental health services to naturalistically identify psychotic relapse. However, this is not necessarily the case for non-psychotic conditions.

Although relapse rates for non-psychotic mental health conditions are high, they tend to recur over periods longer than 12 months. Following a complete course of CBT, 12-month rates of relapse in anxiety disorders are lower than those found following treatment of first episode psychosis (Lorimer et al., 2021). Moreover, these relapse rates may even be as low as 14% if diagnostic remission is achieved during treatment (Levy et al., 2021). Hence, prospective research examining whether FORP predicts relapse may need to take place over several years, to be adequately powered. This may be less of an issue for research intending to predict a relapse of depression, where approximately one third of people who undergo psychological treatment experience relapse over a 12-month period (Kuyken et al., 2016; Wojnarowski et al., 2019). Nevertheless, long-term prospective research aiming to predict relapse of a depressive or anxiety condition may still be challenging due to potential difficulties in identifying relapse. Research has found the average time delay between disorder onset and initial treatment contact is up to several years for depressive conditions, and close to a decade for anxiety conditions (ten Have et al., 2013; Thompson et al., 2008). Conversely, duration of untreated first episode psychosis tends to be shorter, often just several months (Anderson et al., 2010). Although the delay between recurrence and subsequent treatment contact is likely shorter for those who have already undergone treatment, these long delays reflect that common depressive and anxiety conditions often result in less impairment and less observable distress than in psychosis. Indeed, non-psychotic conditions are less likely to result in hospitalisation compared to psychosis (Walker et al., 2019). Moreover, relapse or deterioration may occur more gradually in depressive and anxiety conditions, compared to psychosis (Emsley et al., 2013; Thompson et al., 2008). Hence, prospective research aiming to predict relapse of depressive or anxiety conditions may require regular mental state assessment over several years, rather than using naturalistic contact with mental health services as a proxy for relapse. Nevertheless, such

research will be critical to conduct to determine the extent to which mental health-related FORP is implicated in relapse transdiagnostically.

6.2.5 Mental Health-related FORP in Young People

Chapters 3 to 5, which involved the collection of primary data, used social media advertising to recruit adults living in Australia with a range of mental health conditions. However, a notable limitation of this recruitment strategy is the exclusion of adolescent participants. This is a systemic issue across the mental health-related FORP literature. The systematic review reported in Chapter 2, which did not exclude child and adolescent research, identified no research on FORP in these populations, and to our knowledge no such research has been published since. The decision to focus on adults in Chapters 2 to 5 was both pragmatic, as recruiting adolescents in large numbers can be burdensome as it necessitates more complex consent and safety monitoring procedures, and conceptual, as we expected FORP to be most relevant to those with prolonged experience of the waxing and waning nature of mental health conditions. However, consequently, little is known empirically about the significance of FORP in young people with lived experience of mental health conditions.

Despite this, there is reason to believe FORP may be an important construct for young people. Increases in the global prevalence of mental health conditions is largely driven by an increase in adolescent onset conditions (McGorry et al., 2024). In Australia alone, the 12-month prevalence of mental health conditions in 16 to 24-year-olds rose from 26% in 2007 to 39% in 2021 (Australian Bureau of Statistics, 2023). Aside from a greater prevalence of mental health conditions leading to an increase in the number of people living with FORP per se, FORP may be especially relevant to those being discharged from, or transitioning between, adolescent and adult mental health services. In Australia, the United Kingdom, and other parts of the world, many child and adolescent mental health services

have an upper age boundary of 18 years. As might be expected, qualitative research on youth describes the transition between adolescent and adult services as challenging. Young people report concern about disrupted continuity of care, increases in fees, inability to access appropriate adult services, lack of preparedness, as well as a worry that gaps in service could negatively impact their mental health (Cleverley et al., 2020). In addition, although many early psychosis services have a higher upper age boundary, often 25 years of age, young people transitioning out of early intervention report similar concerns, as well as fear of relapse (Loughlin et al., 2019; Milton et al., 2022). As FORP is known to predict a shorter time to acute psychotic relapse in people with schizophrenia-spectrum conditions (Gumley et al., 2015), this may increase relapse rates during what is already a vulnerable period. Conceptually, we do not have reason to believe that the fundamental nature of mental health-related FORP differs in youth. Nevertheless, adolescents with lived experience of mental health conditions may be at particular risk of FORP during these transitional periods. Hence, future research on mental health-related FORP should examine youth experiences of FORP, especially during transitions out of adolescent or early intervention services where there may be a stepping down in care.

6.2.6 Is Support for Managing Mental Health-related FORP an Unmet Need?

The present dissertation has provided robust evidence that mental health-related FORP is a source of distress, one that may pose a barrier to engagement with desired activities. Hence, some people likely experience high levels of FORP as detrimental to their quality of life. However, the prevalence of these concerns, and whether support for managing FORP is a significant unmet need of people with mental health conditions, remains unexplored. People living with and beyond mental health conditions report a range of different needs, which may or may not be presently met. For instance, Australian research demonstrated that most people with a history of psychosis have their needs regarding medication, housing, and information about their condition, met (Migliorini et al., 2022).

However, most people also reported that their needs for socialising, working or engaging with hobbies, and counselling, were not being adequately met and they required further support. Aside from these unmet needs potentially being related to FORP, it is unclear where FORP itself would rank in this hierarchy of unmet needs. Hence, future research should explore the unmet needs of people with mental health conditions, and whether the relative importance of FORP varies between different conditions. This data would provide greater clarity regarding the extent and prevalence of FORP, as well as identify key populations where further research is needed.

6.3 Clinical Implications and Future Directions

Chapters 2 to 5 of this dissertation describe the theoretical and clinical implications of each respective study, as well as outlining directions for future research. However, the following section provides a broader discussion of the clinical implications of the dissertation in its entirety.

6.3.1 Clinical Interventions for Mental Health-related FORP

Globally, mental health conditions are highly prevalent. Approximately one billion people are expected to meet diagnostic criteria for at least one condition in the last 12-months (GBD Mental Disorders Collaborators, 2022). Consequently, the global economic loss attributable to mental illness is rising, exceeding USD$5 trillion dollars in 2019 (Arias et al., 2022). Worryingly, despite advances in our understanding of mental health conditions and innovation in treatment, the prevalence and burden of mental illness continues to increase (Patel et al., 2018). Although several reasons have been proposed for this, one factor potentially underlying this problem is that people who have already received treatment often represent to clinical services with a similar or different condition – the so-called ‘revolving door’ phenomenon (Iverach et al., 2014). Even after treatment reduces symptoms,

mental health conditions often worsen over time if residual symptoms remain, or recur in the case of remission (Eisen et al., 2013; Fagiolini et al., 2013; Richards, 2011; Yonkers et al., 2003; Zipfel et al., 2015). Similarly, the development of new, previously unexperienced conditions is common (Caspi et al., 2020; Menzies et al., 2024a). This places a tremendous cost on the individual who is unwell, as well as on services which are already struggling with the increase in demand for mental health care (McGorry et al., 2024). Dimensional approaches to psychopathology (e.g., HiTOP; Kotov et al., 2017) provide an account of this 'revolving door' by drawing attention to the interconnected nature of mental health syndromes, and the transdiagnostic processes which underlie them. Drawing on the present thesis and wider literature, there is evidence that mental health-related FORP may be one such transdiagnostic process that might partly account for the 'revolving door' of mental illness.

The transdiagnostic theoretical model of mental health-related FORP developed in Chapter 3 identifies FORP as a source of distress that may motivate a range of cognitive, affective, and behavioural responses. Although some of these responses may be adaptive, other responses may increase a person's vulnerability to recurrence or progression. For instance, FORP is thought to exacerbate anticipatory anxiety when one experiences possible symptoms of their condition, leading to a distress cascade which may accelerate an incipient relapse or increase the likelihood that a mild deterioration becomes an acute relapse (Birchwood, 1996; Coutts-Bain et al., 2025a). In addition, FORP may motivate avoidance of stressful, but nevertheless desired, activities which build social connection and self-efficacy, such as maintaining relationships, and pursuing occupational goals. Such avoidance could reduce access to protective buffers, thereby inadvertently increasing the likelihood of future deteriorations. Although longitudinal research in this area is lacking, cross-sectional research has corroborated this aspect of the model (Figure 6.1). Hence, theoretically, we might expect high levels of FORP to increase the risk of relapse. Indeed, this has already been demonstrated in people with schizophrenia-spectrum conditions,

where FORP predicts a shorter time to acute psychotic relapse (Gumley et al., 2015). Considering this research, psychological interventions which reduce high mental health-related FORP may in turn reduce rates of relapse for people with a history of psychosis, and, potentially, other mental health conditions. Hence, FORP interventions may be a novel angle from which to address the 'revolving door' phenomenon.

To our knowledge, there are no psychological interventions that are specifically designed to reduce mental health-related FORP. Nevertheless, Chapter 5 of this thesis identified several psychological variables which predict higher mental health-related FORP over time, i.e., intrusive memories of being mentally unwell, feelings of shame, and threat-related interpretations of mental state fluctuations. Critically, intrusions, shame, and interpretation biases are responsive to psychological intervention. Hence, by adapting established psychological interventions that target these modifiable risk factors, it may be possible to reduce FORP, and thus partly reduce the substantial burden of mental illness on the individuals who experience them, as well as on broader society.

6.3.1.1 Trauma-based Interventions. With respect to psychopathology, our collective understanding of intrusive memories of traumatic experiences has mostly developed from research on PTSD. Indeed, PTSD is a response to traumatic events which is characterised by, among other things, intrusive re-experiencing of events (Ehlers & Clark, 2000). Disruptions in memory encoding and storage during and after the trauma are understood to cause intrusive memories and sensorial re-experiencing of events. As such, the content of intrusions are often associated with memories of the trauma onset, or the traumatic moments with the greatest emotional intensity (Ehlers et al., 2004). Historically, PTSD was understood as a fear-based condition. However, it is now understood that more complex emotions, including shame, are key factors in accounting for the condition and its impact (López-Castro et al., 2019). The neural circuitry associated with shame differs from that of fear (Lanius et al., 2010), and, from an evolutionary perspective, may have evolved

specifically as an affective signal of social threat, warning a person that their capacity to be perceived positively by others has been lost or weakened (Gilbert & McGuire, 1998). Indeed, while traumatic intrusions can increase the perception of external threat, e.g., the trauma will happen again, negative appraisals of the trauma and aftermath, e.g., it was my fault or, this makes me a bad person, can induce shame (Ehlers & Wild, 2022). Corroborating this, negative self-appraisals following trauma exposure are the strongest cognitive predictor of developing PTSD (Beierl et al., 2020; Ehring et al., 2008).

Numerous psychological interventions for PTSD have been developed, but trauma-focused CBT (e.g., Ehlers et al., 2005), and eye-movement desensitisation and reprocessing therapy (EMDR; Shapiro, 1989), have been demonstrated to be the most efficacious in a recent network meta-analysis (Mavranezouli et al., 2020). Trauma-focused CBT involves systematic exposure to one's own memories of their traumas, alongside other cognitive-behavioural techniques, such as cognitive restructuring, to modify the trauma-related cognitions which may be perpetuating PTSD (Ehlers & Wild, 2022). While EMDR also involves exposure to traumatic memories, this process is more associative and includes side to side eye movements, or other dual-attention stimuli, such as vibrations or audio cues, to purportedly enhance memory processing and cognitive restructuring (Shapiro & Maxfield, 2002). Beyond a general reduction in PTSD symptoms, these interventions reduce the frequency and intensity of intrusive symptoms, and negative trauma-related cognitions (Kleim et al., 2013; Shapiro, 1989). Indeed, both interventions place considerable emphasis on processing the memories that underlie intrusions, and constructing more adaptive, and less negative, beliefs about the self (Ehlers & Wild, 2022; Shapiro & Maxfield, 2002). Importantly, both trauma-focused CBT and EMDR are flexible interventions which have been successfully adapted for diverse clinical populations, including those with a history of psychosis (Mueser et al., 2008; van den Berg et al., 2015).

As trauma-focused CBT and EMDR target intrusive memories and trauma-related shame-inducing cognitions, adapted versions of these interventions may have utility in

treating mental health-related FORP. In the qualitative interviews reported on in Chapter 3, participants described a diverse range of intrusive memories that triggered their FORP. These included memories of discrimination, coercive treatment, physical harm, and functional incapacitation whilst unwell. Often, these memories were sources of shame, as people believed themselves to be a burden, dangerous, responsible for harming others, or incapable of managing their own mental health. By re-processing these memories, and constructing more adaptive, less shame inducing, beliefs about oneself, it may be possible to reduce the high levels FORP that predict relapse. Hence, future research should examine the efficacy of trauma-focused CBT and EMDR for treating mental health-related FORP, as a potential way to reduce any additional risk of relapse.

6.3.1.2 Cognitive Bias Modification. As people navigate life, they rarely have complete information or knowledge about the situations they encounter. For instance, when a person's heart begins to race this could be the result of exercise, excitement, nervousness, or an impending heart attack. This ambiguity must be resolved so that it can be responded to appropriately. Following the above example, should a racing heart be interpreted as a symptom of a heart attack one is likely to experience distress. Indeed, while cognitive biases are common in the general population, there is evidence that people with anxiety and depression are prone to negatively interpreting ambiguous events (Hirsch et al., 2016). Threat-related interpretation biases have even been proposed to underlie the development of chronic fear of cancer recurrence in cancer survivors. Given the real threat that cancer poses to health, ambiguous somatic cues, like pain, are interpreted as evidence of a potential recurrence, which provokes hypervigilance toward bodily sensations (Heathcote & Eccleston, 2017). Supporting this theory, cancer survivors with more somatic symptoms do experience greater fear of cancer recurrence, and this relationship is moderated by one's propensity to interpret ambiguous health-related information as threatening, i.e., threat-related interpretation bias (Pradhan et al., 2021, 2022). Similarly, people with schizophrenia-spectrum conditions have more negative interpretations of psychosis-like symptoms

compared to those with non-psychotic anxiety conditions and those without mental health conditions (Sired et al., 2021). This research also found this is not a psychosis-specific effect, as people with non-psychotic anxiety conditions had more negative interpretations of anxiety symptoms than those with no diagnostic history. Expanding on this, Chapter 5 demonstrated that negative interpretations of mental state fluctuations predict subsequent FORP. Hence, interventions which reduce threat-related interpretation biases may have utility in reducing high levels of mental health-related FORP.

Cognitive bias modification of interpretation bias (CBM-I) is an intervention with demonstrated efficacy is reducing threat-related interpretation biases (Martinelli et al., 2022). Critically, there is evidence that these reductions have clinically meaningful effects, as CBM-I has also been shown to reduce symptoms of anxiety and depression in clinical samples (Fodor et al., 2020). CBM-I involves presenting ambiguous information to a person, allowing them to interpret that ambiguity, and then providing corrective feedback or reinforcement to progressively train them toward a particular style of interpretation – often away from negative interpretations. The most common paradigm for administering CBM-I is the ambiguous scenarios task, where a participant is asked to read an incomplete ambiguous scenario and provide an interpretation that 'completes' it (e.g., Blackwell & Holmes, 2010). In the case of mental state fluctuations, an ambiguous scenario would present a cognition, affect, or behaviour that could feasibly be interpreted as an early warning sign of deterioration, or something benign. As an example, a person might be presented with the following sentence, "You choose to not get out of bed in the morning. You are…". They are then asked to complete the sentence by selecting a word from an array of illness-related or benign options, e.g., "depressed" or "relaxing". In theory, this does not modify the content of one's beliefs, e.g., "low mood may indicate risk of relapse", instead it reduces the automaticity with which these beliefs are activated (MacLeod & Mathews, 2012). Therefore, when a person experiences an ambiguous mental state fluctuation, they may be less likely to interpret that internal sensation catastrophically.

CBM-I interventions have already been found to be effective at reducing threat-related interpretations of somatic sensations, and fear of cancer recurrence, in cancer survivors (Lichtenthal et al., 2017). So, as negative interpretations of mental state fluctuations predict mental health-related FORP, it is feasible that CBM-I may have utility in reducing activation of these fears for people with mental health conditions. Hence, future clinical research should examine whether CBM-I can be adapted to train people away from a tendency to make negative and catastrophic interpretations of potentially normal fluctuations in symptoms of mental state. One advantage of CBM-I compared to trauma-focused CBT and EMDR is its brevity, and the fact that it can be delivered remotely without therapist input, should it prove to be efficacious.

In summary, intrusive memories of being mentally unwell, shame, and threat-related interpretation of mental state fluctuations predict mental health-related FORP. Hence, trauma-focused CBT, EMDR, and CBM-I may have utility in reducing high levels of FORP by directly targeting these modifiable risk factors. This may reduce rates of relapse in people with schizophrenia-spectrum conditions (Gumley et al., 2015). If, as theoretically proposed, mental health-related FORP also increases vulnerability to relapse in people with non-psychotic conditions, then so to might these interventions further reduce the risk of relapse in those with non-psychotic conditions. Considering the impact of the ‘revolving door’ on people with mental health conditions, their communities, and the services that provide care for them, it is critical we consider novel approaches that may go towards addressing this issue (Menzies et al., 2024a). Indeed, the most recent Lancet commission into mental health called for further research into transdiagnostic treatments to address these challenges (Patel et al., 2018). However, as we look toward future clinical research, we must consider the possibility for interventions to do more harm than good.

6.3.2 The Risk of Adverse Effects

There is no shortage of evidence that psychological interventions can be effective in treating a wide range of mental health conditions. However, the potential for psychological interventions to cause adverse effects is rarely considered systematically in clinical research, despite the risk of harm being commonly acknowledged by clinicians (Barlow, 2010). Indeed, a recent review of adverse effect reporting in randomised-controlled trials of psychological interventions found that such reporting was not routine, and although outcomes like unplanned hospitalisation or increases in suicidality are sometimes considered, most often reporting of adverse effects is limited to participants discontinuation rates (Honkalampi et al., 2025). This means that the potential for post-treatment adverse effects is rarely considered, such as whether the cognitive and behavioural restructuring caused by the intervention is associated with negative outcomes in the long-term. This is particularly relevant for interventions designed to reduce mental health-related FORP. In theory, FORP may motivate adaptive lifestyle changes, appropriate self-monitoring, and help-seeking behaviours. Hence, the development of said interventions, and the research which evaluates them, must consider the risk that they will inadvertently increase vulnerability to relapse.

As previously discussed, trauma-focused interventions may have utility in reducing mental health-related FORP by decreasing the intensity of frequency of distressing intrusive memories, and shame-inducing cognitions. As per the theoretical model of FORP from Chapter 3, these targeted reductions would likely reduce distress, but there is a risk that the consequential reductions in FORP itself might increase vulnerability to relapse. Indeed, mental health-related FORP is associated with the tendency to seek support from mental health professionals (Gumuchian et al., 2025), and medication adherence (Chapter 2). Moreover, a reduction in FORP may make people less motivated to avoid stressors or potential relapse triggers, such as recreational substance use. Similarly, as CBM-I may reduce the automaticity with which ambiguous mental state fluctuations activate negative interpretations, CBM-I may *increase* the threshold at which an early warning sign triggers

appropriate help-seeking. This is important because deteriorations in mental health cannot be predicted or identified with the same level of accuracy as in physical health, where routine monitoring of biomarkers has real clinical utility (Abi-Dargham et al., 2023; García-Gutiérrez et al., 2020). Hence, appropriate self-monitoring, interpretation, and action taking, is a core component of staying well for those with mental health conditions. This is especially important for those with a history of mania or psychosis, where identification of early warning signs facilitates changes in medication that may have an acute stabilising effect (Haddad & Correll, 2018; Scherk et al., 2007). Therefore, while mental health-related FORP may be a valuable treatment target, any intervention must ensure that people remain appropriately vigilant and responsive to their early warning signs. In this endeavour, it may be useful to consider how relapse prevention is approached in relation to substance use.

Marlatt and George's (1984) cognitive-behavioural model of relapse provides a framework for understanding the process of relapse in addictive behaviours, alongside a set of strategies to reduce the likelihood and severity of relapse. This model emphasises the importance of avoiding and managing high-risk contexts, whether environmental (e.g., conditioned drug cues) or internal (e.g., negative affect, withdrawal) cues, which may lead to craving, increasing the likelihood of substance use. Importantly, beliefs about the causes and meaning of a smaller ‘lapse’, when they occur, may increase the likelihood of a sustained return to the addictive behaviour, i.e., relapse. If a person attributes a lapse to stable internal factors, such that relapse is an inevitable personal failure, they may experience negative affect and guilt which increases the likelihood of relapse (Marlatt & Gordon, 1985). This reaction, referred to the abstinence violation effect, has been found to predict relapse of alcohol use (Collins & Lapp, 1991), tobacco use (Curry et al., 1987), and cannabis use (Stephens et al., 1994). Hence, effective relapse prevention interventions must incorporate strategies for monitoring internal cues and avoiding external substance use triggers, while also normalising lapses with cognitive restructuring to minimise the abstinence violation effect (Marlatt & Gordon, 1985). These interventions demonstrate that it

is possible to modify maladaptive beliefs about the threat of recurrence or progression, while still encouraging appropriate awareness of early warning signs, and avoidance of relapse triggers. Indeed, relapse prevention interventions guided by these principles are effective in reducing substance use (Bowen et al., 2014).

These relapse prevention principles are also relevant to a range of mental health conditions and behaviours including depression, anxiety, disordered eating, self-harm, and psychosis (Witkiewitz & Marlatt, 2011). With respect to mental health-related FORP, there is also some evidence that FORP can be reduced while maintaining appropriate vigilance to relapse. A recent RCT compared the feasibility and safety of a smartphone-based early warning signs monitoring program (EMPOWER) to treatment as usual, in people with a schizophrenia-spectrum condition (Gumley et al., 2022). Aside from supporting early signs monitoring, the EMPOWER intervention was explicitly designed to normalise fluctuations in psychotic symptoms. Although not an explicitly intended outcome of the trial, fear of psychosis relapse decreased in the EMPOWER group, relative to the treatment-as-usual control (d = -.51), over a 12-month period. Potential mediators of this reduction were not examined empirically. Nevertheless, normalisation of fluctuations in psychotic symptoms may have reduced the degree to which small or ambiguous fluctuations in mental state were interpreted as threatening, thereby reducing FORP significantly over time. This does not demonstrate that reductions in mental health-related FORP have no adverse effects, but it does show that appropriate relapse prevention strategies, such as monitoring early warning signs, are not inherently incompatible with reductions in FORP. Indeed, the trauma-focused and CBM-I interventions that may have potential in addressing FORP would not challenge the validity of using such strategies, but they would, in theory, decrease the likelihood that relapse and associated its associated risk factors, like fluctuations in mental state, are interpreted catastrophically.

To reduce the risk of adverse effects, psychological interventions for mental health-related FORP may benefit from supporting appropriate mental health-protective strategies,

including early warning signs monitoring, medication adherence, and avoidance of stressors. So long as they function as appropriate safety precautions, rather than avoidant safety behaviours that perpetuate anxiety with minimal or little adaptive function (see Sharpe et al., 2022b). Indeed, many existing psychological interventions already include such strategies to prevent relapse. Yet, it is commonplace for CBT treatment protocols to only address relapse prevention in the last one or two sessions (e.g., Foa et al., 2012). This may be insufficient to effectively normalise 'lapses' and challenge maladaptive cognitions about the meaning and nature of relapse, particularly for those with more entrenched negative attributions about relapse. Nevertheless, even if psychological interventions are expressly designed to reduce the risk of adverse effects, it will be critical that post-intervention negative outcomes, like relapse, and changes to proximal protective factors, like medication adherence, and early warning signs monitoring, are measured prospectively.

6.3.3 FORP Interventions in the Australian Context

When considering the design of clinical interventions, it is vital to ensure they are fit for purpose. This means interventions should not only be effective and safe, but that they should also adequately meet the needs of the population it is designed for, in the context they exist within. As the global prevalence and burden of mental health conditions continues to increase, more and more people are living with and beyond mental illness. However, Australia has some of the highest prevalence of mental health conditions worldwide, far exceedingly the global average (GBD Mental Disorders Collaborators, 2022). In Australia, 42% of the population has met diagnostic criteria for a mental health condition in their lifetime (Australian Bureau of Statistics, 2023). Using the latest population data, this means over 11.5 million people in Australia might experience mental health-related FORP (Australian Bureau of Statistics, 2025). Although we would not expect all these people to have clinically significant FORP, meta-analytic research has demonstrated that 19% of all cancer survivors report severe fear of cancer recurrence necessitating psychological

intervention (Luigjes-Huizer et al., 2022). Even if severe mental health-related FORP were less prevalent than this, it could still be an issue affecting millions of people in Australia – and many more globally.

Worryingly, accessing adequate mental health care in Australia is becoming an increasingly difficult task. The reasons for this are complex, but a key issue in understanding the current state of things is the phenomenon of the 'missing middle' (Menssink et al., 2025). The missing middle refers to systematic gaps in mental health care provision that prevent adequate and appropriate care, including: 1) a service gap for those whose needs exceed services designed for mild illnesses but who may not be eligible for services designed for acute and severe mental illness, 2) inflexibility of services, such as the rigid age boundaries between youth and adult services, and 3) services whose treatment has limited availability, suitability, or duration. Although the 'missing middle' is typically used to describe systemic issues in youth mental health care, these issues are broadly and increasingly relevant to adult mental health services (Orygen, 2021).

Due to the absence of public mental health services suitable for many adults, particularly for those not in acute or severe phase of illness, many people in Australia access mental health care through the Better Access to Psychiatrists, Psychologists and General Practitioners initiative (Pirkis et al., 2022). Commonly referred to as Better Access, this scheme was launched nationwide in 2006. Better Access subsidises a limited number of private mental health-related services within each calendar year. Critically, these sessions are rarely free, and often require the service user pay a portion of the fee out-of-pocket, which can result in barriers to access. Nevertheless, for people wanting to access psychological therapy, this scheme initially subsidised 12 to 18 sessions per year. However, in 2011, this was reduced to 10 sessions for most cases. This limited provision of Better Access sessions does not allow for the recommended number of treatment sessions established in evidence-based treatment guidelines for OCD (National Institute for Health and Clinical Excellence [NICE], 2005a), PTSD (NICE, 2005b), depression (NICE, 2022), or

generalised anxiety (NICE, 2020). Hence, people living with mental health conditions in Australia who are not acutely and severely unwell, and who thus may not be eligible for specialised public mental health services, must either pay out-of-pocket or forgo appropriate psychological treatment. Indeed, in 2013 approximately 44% of Australian adults with a mental health condition had forgone care due to the associated out-of-pocket cost (Callander et al., 2017). However, this is likely an underestimate of the present situation as costs associated with mental health services have continued to increase, with the average out-of-pocket cost for psychology services almost doubling since 2013 (Rosenberg et al., 2022).

Finding solutions to these structural problems is beyond the scope of this thesis. However, these issues have significant implications for how interventions for mental health-related FORP should be implemented. Within the current Australian context, an intensive psychological intervention for FORP requiring multiple sessions may not be feasible. Publicly funded hospital- or community-based mental health services are unlikely to offer an intensive intervention on top of the interventions they already provide due to demand-side pressures which encourage discharging current service users to meet growing community need. Conversely, intensive interventions delivered in private practice may be unaffordable. This is especially the case for people with a mental health condition who have already undergone private psychological intervention within the calendar year, and thus who may not have access to additional sessions subsidised by Better Access. Therefore, to best meet community need, mental health-related FORP interventions should be highly scalable and low-cost so that, should they be effective, they can have a significant population-level impact. In this context, there are two approaches to FORP intervention which may be most feasible: brief interventions, and low-intensity digital interventions.

As previously discussed, both EMDR and trauma-focused CBT could be adapted to address mental health-related FORP. Critically, both therapeutic modalities can be effective when delivered briefly. For instance, the standard EMDR treatment protocol has been adapted into single and two-session interventions that can reduce post-traumatic stress in

people exposed to traumatic events, including those exposed to natural disasters and wartime conflict (Jarero et al., 2011; Shapiro & Laub, 2015; Yasar et al., 2021). Similarly, imagery rescripting, a therapeutic technique that can be implemented within trauma-focused CBT, can be delivered in one to three sessions and still effectively address the aversive memories and maladaptive cognitions associated with PTSD (Morina et al., 2017). Given the brevity of these interventions, they could be delivered prior to discharge from mental health services as a part of the relapse prevention phase of treatment. Alternatively, they could be delivered several months after active treatment for those who still experience significant FORP, similar to how 'booster sessions' following psychological intervention are used to reduce the likelihood of relapse (Whisman, 1990).

Alternatively, low-intensity interventions requiring little to no therapist contact, delivered digitally via the internet, may be another way to widely and cost-effectively disseminate interventions to the community. Indeed, one notable example of this is the Australian mental health service, MindSpot. MindSpot is a publicly funded online service that provides brief mental health assessments and internet-delivered CBT for depression, anxiety, OCD, and PTSD, for people living in Australia (Titov et al., 2015). Each of these eight-week interventions contain four to six online modules with accompanying therapeutic 'homework' tasks, automated digital reminders to prompt therapeutic activities, and brief weekly email or phone contact with a therapist. In a series of randomised-controlled trials, these interventions were found to be effective in reducing symptoms relative to wait-list controls (Dear et al., 2015; Spence et al., 2014; Titov et al., 2014; Wootton et al., 2013). However, since being opened to the public, the MindSpot project has continued to be effective (Titov et al., 2020). Between 2013 and 2020, after a brief online assessment with MindSpot, 21,745 people began one of the online interventions, with 14,503 completing treatment (67% completion rate). Intention-to-treat analyses of outcome data found large and sustained reductions in symptoms of depression (d = 1.40) and anxiety (d = 1.42) from baseline to a three-month follow-up. These findings demonstrate that low intensity, but highly

scalable, digital interventions can be effective in meeting the mental health needs of many people, when publicly funded. Hence, future research should consider scalable low-intensity interventions, like those found on MindSpot, as a potential means to address mental health-related FORP. Indeed, the digital PTSD intervention presently available on MindSpot represents a proof-of-concept for the adaptation of trauma-focused CBT to a more scalable format (Spence et al., 2014).

Another potential intervention for FORP that can be delivered digitally at a low cost is CBM-I. CBM-I requires no therapist contact, and can be delivered remotely using common survey hosting platforms, like Qualtrics (e.g., Sharpe et al., 2023). This is a significant advantage over other interventions, with respect to scalability and cost. In addition, CBM-I can be delivered over a small number of brief sessions, potentially only taking 15 minutes each (Martinelli et al., 2022). Hence, CBM-I is unlikely to pose a significant burden to the people undertaking it, and it could feasibly be delivered as adjunct to other treatments, such as low intensity trauma-focused CBT.

Lastly, when considering how best to address mental health-related FORP at the population level, it is worthwhile considering how high levels of FORP might be prevented, rather than treated. The present dissertation has demonstrated that intrusive memories of aversive, or outright traumatic, events underlie FORP. Critically, some of these aversive experiences, like discrimination and coercive treatment in mental health services, may be preventable. At times, inpatient admission, or involuntary admission, to a psychiatric hospital is unavoidable or necessary, due to acute safety concerns or a person's complex needs. Hence, it is critical that these environments, and the process of admission, are safe, respectful, and as therapeutic as possible. A meta-review of the literature on inpatients perception of psychiatric admission found that stronger rapport between staff and inpatients, and shared decision-making about treatment, was associated with more positive experiences of coercive or restrictive measures, and a reduced sense of inferiority and internalised stigma (Modini et al., 2021). Indeed, the necessity of reducing negative or

traumatic experiences of hospitalisation has long been recognised as important for improving mental health outcomes (Patel et al., 2018). However, given that intrusive memories of aversive experiences and shame predict FORP, efforts to improve the care provided by inpatient services may reduce the likelihood that high levels of FORP develop, and thus reduce the risk of subsequent relapse. Although interventions for changing staff conduct and practice in psychiatric inpatient settings can be challenging to implement (Lorien et al., 2020), this may be another means to address mental health-related FORP.

Given the profound challenges facing Australia's mental health services (Menssink et al., 2025; Orygen, 2021), the aphorism that 'an ounce of prevention is worth a pound of cure' is particularly salient. Should mental health-related FORP be found to predict relapse in non-psychotic illness, as it does in psychosis, addressing FORP must become a public health priority. This will require not only targeted psychological interventions, but also systemic reforms aimed at reducing the conditions under which high levels of FORP emerge in the first place.

6.4 Conclusion

FORP is well-understood in the context of cancer, yet it remains largely neglected in the context of mental health, especially among those with more common, non-psychotic, conditions. This dissertation directly addresses that oversight, presenting robust evidence that mental health-related FORP is a distinct, transdiagnostic construct relevant across the spectrum of psychiatric conditions. It also provides both a theoretical framework and validated questionnaire of mental health-related FORP, laying a strong foundation for future research in this emerging field of study. Despite these advances, key questions remain. Most notably, the extent to which mental health-related FORP influences relapse, and whether tailored FORP-specific psychological interventions are warranted. Nevertheless, preliminary findings suggest that FORP may be a 'silent' factor partly explaining the 'revolving door' of relapse often seen in clinical practice. Hence, we hope that the broader

fields of clinical psychology and psychiatry draw on the findings of this dissertation to further explore, and ultimately address, the burden of mental health-related FORP. With further study, mental health-related FORP may come to be recognised as a natural, yet potentially distressing and impairing, part of living with and beyond mental illness, just as fear of cancer recurrence came to be understood as central to the experience of cancer survivorship several decades ago.

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Appendix A

Appendix A provides additional materials relevant to Chapter 2, including:

Appendix A1.	PROSPERO record
Appendix A2.	Search terms for the systematic review
Appendix A3.	Quality ratings of included studies.
Appendix A4.	Published manuscript

Appendix A1. PROSPERO record.

NIHR | National Institute for Health and Care Research

PROSPERO
International prospective register of systematic reviews

"What if it comes back, or gets worse?" A Mixed-Methods Review of Fears of Recurrence and Progression in People with a History of Mental Health Issues

Daelin Coutts-Bain, Louise Sharpe, Caroline Hunt, Rachel Menzies, Peter Pirathat Techakesari, Poorva Pradhan

Citation
Daelin Coutts-Bain, Louise Sharpe, Caroline Hunt, Rachel Menzies, Peter Pirathat Techakesari, Poorva Pradhan. "What if it comes back, or gets worse?" A Mixed-Methods Review of Fears of Recurrence and Progression in People with a History of Mental Health Issues. PROSPERO 2024 Available from https://www.crd.york.ac.uk/PROSPERO/view/CRD42021287692

REVIEW TITLE AND BASIC DETAILS

Review title
"What if it comes back, or gets worse?" A Mixed-Methods Review of Fears of Recurrence and Progression in People with a History of Mental Health Issues

Review objectives
It is well documented that people diagnosed with physical diseases, such as cancer, may fear a recurrence or progression of their disease (Herschbach et al., 2005; Koch et al., 2013). Although this fear can be adaptive by motivating positive health behaviours, such fear can become maladaptive if it becomes distressing, chronic, and impairing. As an example, fear of cancer recurrence is associated with anxiety, depression, worse quality of life, and healthcare overuse (Champagne et al., 2018; Simard & Savard, 2013; Lebel et al., 2013). Some recent research has explored the relevance of fear of recurrence to people in recovery from psychosis (e.g., Jamalamadaka et al., 2020; Sired et al., 2021). However, whether this notion of 'fear of

recurrence' is relevant to other mental health issues or is transdiagnostic across different mental health problems is not well known. The present review aims to identify the degree to which fear of recurrence and progression is relevant to a range of mental health problems.

Keywords
fear of madness, fear of progression, fear of recurrence, fear of relapse, mental health

SEARCHING AND SCREENING

Searches
The searches will be conducted in English in the following databases: PsycINFO, MEDLINE, Scopus, and Web of Sciences Core Collection. These searches will be re-run before the final analyses and any further identified studies assessed for inclusion.

Study design
The review will include qualitative and quantitative English-language research papers that have been published in peer-reviewed journals. Quantitative studies to be included are those that sampled adults and include: 1) assessment of fear of recurrence or progression as it relates to adult participants' mental health, and/or 2) analyses of how fear of recurrence or progression relates to the participants' quality of life, mental health symptomology, health behaviours, and actual relapse or progression. Qualitative studies to be included are those that involved adults and feature: 1) a specific exploration of fear of recurrence or progression related to mental health problems, and/or 2) fear of recurrence or progression as a significant theme related to some other construct.
The review will exclude (i) reviews, (ii) dissertations and conference presentations, and (iii) research concerned with fear of recurrence or progression related to physical health conditions (e.g., fear of cancer recurrence).

ELIGIBILITY CRITERIA

Condition or domain being studied
The domain being studied is the notion that one may fear a recurrence of a previously experienced mental health issue or the progression of a current mental health issue.

Population
Adults aged 18 and older with a current or historically diagnosed or self-reported mental health issue, including but not limited to: schizophrenia, psychosis, bipolar I and II, depression, substance related and addictive disorders, eating disorders, anxiety, and depressive disorders.

Intervention(s) or exposure(s)
The present review is not explicitly concerned with the effects of any interventions or exposures.

Comparator(s) or control(s)
The review will not assess control conditions.

OUTCOMES TO BE ANALYSED

Main outcomes

The main outcomes are the presence and severity of fear of recurrence or progression in relation to mental health issues, and the relationships between these fears and quality of life, mental health symptomology (e.g., depression, anxiety, panic attacks), actual rates of relapse or progression, health behaviours (e.g., reluctance to cease treatment, medication compliance), and demographic factors (e.g., age).

Additional outcomes

Not applicable.

DATA COLLECTION PROCESS

Data extraction (selection and coding)

Titles and abstracts of studies retrieved using the search strategy will be independently screened by two review authors to identify papers potentially eligible for inclusion. The full text of potentially eligible studies will be extracted and independently assessed for inclusion by two review authors. The authors will then screen the reference lists of the included papers and conduct a citation search to identify additional studies that may meet the inclusion criteria. Any disagreement between the authors over the eligibility of a study will be discussed between those authors, if consensus cannot be reached, a third author will independently assess the disputed paper.

Data eligible for extraction will include information pertaining to the participants' degree of fear of recurrence or progression, the relationships between these fears and mental health symptomatology, and actual recurrence or progression. Additional information to be extracted includes location of the study, the study population and participant demographics, diagnoses and method of diagnoses (e.g., structured clinical interview), how fear of recurrence or progression were assessed, and information to assess the risk of bias. Additionally, for qualitative studies, data eligible for extraction will include first order constructs (participants' quotes), and second order constructs (researcher interpretations) that pertain to fear of recurrence of mental health disorders.

Risk of bias (quality) assessment

To assess risk of bias, two assessors will rate each study using a Joanna Briggs Institute (JBI) critical appraisal tool appropriate for the identified study design (Joanna Briggs Institute, 2021). The JBI has checklists that are appropriate for assessment of risk of bias in qualitative, case, cross-sectional, quasi-experimental, and randomised-controlled studies (Ma et al., 2020). Where agreement cannot be achieved, a third reviewer will resolve the discrepancy.

Risk of publication bias will be assessed with funnel plots and statistical analyses (e.g., Duval and Tweedie's Trim and Fill procedure, Rosenthal's fail-safe N). Study heterogeneity will also be assessed statistically. In the event of significant heterogeneity, effect sizes will be determined by a random-effects model.

PLANNED DATA SYNTHESIS

Strategy for data synthesis

Results will be reported according to PRISMA guidelines. Extracted quantitative data will be analysed using Comprehensive Meta-analysis software. Where the necessary data is not

available, the authors of the included paper will be contacted. Quotes from qualitative research will be extracted and coded into themes and sub-themes.

Analysis of subgroups or subsets

For quantitative studies, if sufficient data is available, meta-analyses and subgroup analyses will be conducted for: 1) different DSM-IV and DSM-V disorder categories (e.g., depressive disorders, bipolar and related disorders), 2) and specific DSM-IV and DSM-V diagnoses (e.g., psychosis, anorexia nervosa), and 3) between psychotic and non-psychotic mental health problems. For qualitative studies, if sufficient data is available, we will conduct a meta-synthesis by thematic analysis of all published participant quotes, with consideration of how sample characteristics, such as the nature of the participant's mental health issues (i.e. attributes), may have influenced emergent themes and sub-themes.

REVIEW AFFILIATION, FUNDING AND PEER REVIEW

Review team members

- Mr Daelin Coutts-Bain, The University of Sydney
- Professor Louise Sharpe, The University of Sydney
- Professor Caroline Hunt, The University of Sydney
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Funding source

No funding.

Named contact

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TIMELINE OF THE REVIEW

Review timeline

Start date: 01 November 2021. End date: 31 May 2022

Date of first submission to PROSPERO

26 October 2021

Date of registration in PROSPERO

26 November 2021

CURRENT REVIEW STAGE

Publication of review results 1 change

The intention is to publish the review once completed.The review will be published in English

DOI: 10.1016/j.cpr.2023.102342

Stage of the review at this submission 1 change

Review stage	Started	Completed
Pilot work	✓	✓
Formal searching/study identification	✓	✓
Screening search results against inclusion criteria	✓	✓
Data extraction or receipt of IP	✓	✓
Risk of bias/quality assessment	✓	✓
Data synthesis	✓	✓

Review status
The review is completed.

ADDITIONAL INFORMATION

PROSPERO version history

- Version 1.2 published on 17 Jan 2024
- Version 1.1 published on 26 Nov 2021
- Version 1.0 published on 26 Nov 2021

Review conflict of interest
None known

Country
Australia

Medical Subject Headings
Fear; Humans; Mental Health; Surveys and Questionnaires

Revision note 1 change
Updating status of the record - the review has now been published.

Disclaimer
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Any enquiries about the record should be referred to the named review contact

Appendix A2. Systematic Review Search Terms.

The complete list of search terms used in the systematic review:

(“fear of relapse*” OR “fear of recurrence*” OR “relapse fear*” OR “recurrence fear*” OR “worry about relapse*” OR “worry about recurrence*” OR “relapse anxiet*” OR “recurrence anxiet*” OR “concern about relapse*” OR “concern about recurrence*” OR “relapse concern*” OR “recurrence concern*” OR “fear about relapse*” OR “fear about recurrence*” OR “anxiet* about relapse*” OR “fearing relapse*” OR “fearing recurrence*” OR “fear of illness recurrence*” OR “fear of illness relapse*” OR “worry about illness relapse*” OR “anxiet* about illness recurrence*” OR “concern about illness recurrence*” OR “concern about illness relapse*” OR “anxiet* about illness recurrence” OR “anxiet* about illness relapse” OR “fearing illness recurrence*” OR “fearing illness relapse” OR “fear of progression” OR “fear of deterioration” OR “progression fear*” OR “deterioration fear*” OR “progression anxiet*” OR “deterioration anxiet*” OR “worry about progression” OR “worry about deterioration” OR “concern about progression” OR “concern about deterioration” OR “fear about progression” OR “fear about deterioration” OR “progression concern” OR “deterioration concern” OR “fearing progression” OR “fearing deterioration” OR “illness uncertainty” OR “uncertainty in illness” OR “fear of madness” OR “fear of going crazy”) NOT (“cancer*” OR “neoplasm” OR “multiple sclerosis” OR “diabetes”)

Appendix A3. Quality Ratings for Studies Included in the Systematic Review

Quality Ratings for Qualitative Studies.

Studies	1	2	3	4	5	6	7	8	9	10	Total
Allan et al (2019)	?	+	+	+	+	-	-	+	+	+	7
Baier (1995)	-	+	?	+	+	-	-	+	?	+	5
Baker (1995)	+	+	+	+	+	?	+	-	+	+	8
Carrick et al (2004)	+	+	+	+	+	-	+	+	+	+	9
Coyne & Calarco (1995)	-	+	?	+	+	-	+	+	?	+	6
Dyson et al (2023)	-	+	+	+	+	-	+	+	+	+	8
Eveleigh et al (2019)	-	+	?	+	+	-	+	+	?	+	6
Forde et al (2019)	-	+	?	+	+	+	+	+	+	+	8
Grime & Pollock (2003)	-	-	?	+	+	-	-	+	+	+	5
Irawani et al (2022)	?	+	?	+	+	-	-	+	+	+	6
Kondoni & Kouimtsidis (2017)	-	+	?	+	+	-	-	+	-	+	5
Leydon et al (2007)	-	+	?	+	+	-	-	+	+	+	6
McGrath et al (2013)	+	+	+	+	+	+	+	+	+	+	10
Nagle et al (2002)	-	+	?	+	+	-	+	+	?	+	6
Notley et al (2015)	+	+	+	+	+	-	-	+	+	+	8
Robertson & Lyons (2003)	+	?	-	+	+	+	+	+	?	+	7
Sandhu et al (2013)	+	+	+	+	+	+	+	+	+	+	10
Van Geffen et al (2011)	-	+	-	+	+	-	-	+	+	+	6
Varela et al (2007)	?	-	+	+	?	-	-	+	-	+	4

Note. +, yes; ?, unclear; -, no.

Items: 1 = congruency between philosophical perspective and methodology, 2 = congruency between methodology and aims, 3 = congruency between methodology and data collection, 4 = congruency between methodology and data collection, 5 = congruency between methodology and interpretation of results, 6 = cultural and theoretical statement, 7 = influence of researcher addressed, 8 = representation of participant voices, 9 = ethical considerations, 10 = appropriate conclusions.

Quality Ratings for Cross-sectional Studies.

Studies	1	2	3	4	5	6	7	8	Total
Adams & Scott (2000)	+	+	+	+	-	-	+	-	5
Bassett et al (2009)	+	-	+	+	+	+	+	+	7
Bentzley et al (2015)	+	+	+	+	+	+	-	+	7
Collett et al (2016)	+	+	+	+	+	-	+	+	7
Coyne & Calarco (1995)	+	-	+	+	-	-	+	?	4
Devulapalli et al (2010)	+	?	+	+	+	+	+	+	7
Jamalamadaka et al (2020)	+	+	+	-	+	-	+	+	6
Kirk et al (2000)	+	-	+	+	+	+	+	+	7
Peindl et al (1995)	-	+	-	+	+	-	?	+	4
Sired et al (2021)	+	-	-	-	+	-	+	+	4
White & Gumley (2009)	+	+	+	+	+	-	+	+	7

Note. +, yes; ?, unclear; -, no.

Items: 1 = clear inclusion criteria, 2 = subjects and setting described, 3 = valid and reliable measurement of exposure, 4 = objective measurement of condition, 5 = confounding factors identified, 6 = strategies to deal with confounding factors, 7 = valid and reliable outcome measurement, 8 = appropriate statistical analysis.

Quality Ratings for Intervention Studies.

Studies	1	2	3	4	5	6	7	8	9	10	11	12	13	Total
Braehler et al (2013)	+	+	-	-	NA	+	-	+	+	+	+	-	+	9
Gumley et al (2015)	+	+	-	?	?	+	+	?	+	+	+	+	+	9

Note. +, yes; ?, unclear; -, no; NA, not applicable as intervention delivery could not be blinded.

Items: 1 = random group assignment, 2 = concealed group allocation, 3 = baseline group equivalency, 4 = participants blinded, 5 = treatment delivery blinded, 6 = outcome assessors blinded, 7 = groups treated identically aside from intervention of interest, 8 = adequate follow-up analyses, 9 = intention-to-treat analyses, 10 = consistent outcome measurement between groups, 11 = reliable outcome measurement, 12 = appropriate statistical analyses, 13 = appropriate trial design.

Quality Ratings for Quasi-experiments.

Studies	1	2	3	4	5	6	7	8	9	Total
Eisner et al (2019)	+	+	?	-	+	?	+	+	+	6
Ryan et al (2021)	+	+	-	-	+	?	+	+	+	6

Note. +, yes; ?, unclear; -, no.

Items: 1 = clarity between proposed causes and effects, 2 = participants equivalent within comparisons, 3 = participants treated identically aside from intervention of interest, 4 = control group, 5 = pre and post measurements of outcome, 6 = adequate follow-up analyses, 7 = consistent outcome measurement, 8 = reliable outcome measurement, 9 = appropriate statistical analyses.

Quality Rating for Observational Longitudinal Study

Tooth et al (2005) Criteria	Allan et al (2023)
1. Objectives stated	+
2. Target population defined	+
3. Sampling frame defined	-
4. Study population defined	+
5. Study setting stated	+
6. Study dates stated	+
7. Eligibility criteria stated	+
8. Consideration of selection bias	-
9. Justification of sample size	-
10. Proportion of participants meeting eligibility criteria stated	-
11. Reasons for ineligibility stated	-
12. Number of participants that did not consent stated	-
13. Reasons for not providing consent stated	-
14. Comparison between consenters and non-consenters	-
15. Total number of participants in first stage of data collection stated	+
16. Description of data collection methods	+
17. Reliability of collection methods stated	-
18. Validity of collection methods stated	-
19. Confounding variables described	+
20. Statement of numbers at each follow-up point	N/A
21. Reasons for loss to follow-up quantified	-
22. Missingness of data items at each wave mentioned	+
23. Description of analysis methods	+
24. Use of longitudinal analysis methods	+
25. Absolute effect sizes reported	+
26. Relative effect sizes reported	N/A
27. Loss to follow-up taken into account in analyses	+
28. Confounders accounted for in analyses	+
29. Missing data accounted for in analyses	-
30. Qualitative assessment of the impact of biases	+
31. Quantitative assessment of the impact of biases	-
32. Authors related results back to target population	+
33. Discussion of generalizability beyond target population	-
Total	17 / 31

Note. +, yes; -, no; N/A, not applicable to ecological momentary assessment.

Appendix A4. Published manuscript.

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Review

A mixed-methods review and meta-synthesis of fears of recurrence and progression in people with mental health conditions

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ABSTRACT

A fear that one's physical illness will recur or worsen has received substantial research attention over the past decade, most notably as fear of cancer recurrence. Indeed, such fear is known to be associated with poorer quality of life, adjustment, and psychopathology. However, fear of a recurrence or progression (FORP) of mental health conditions has received comparatively little study. The present review aimed to, 1) systematically review quantitative research on FORP in mental health regarding its association with age, gender, quality of life, mental health outcomes, and health behaviours, and 2) meta-synthesize qualitative research related to FORP to construct a transdiagnostic model. A qualitative meta-synthesis of 19 studies identified four subthemes underlying FORP (*fear of symptoms*, *loss of progress*, *fear of death*, and *traumatic experiences*). The three themes related to FORP were: *inability to trust oneself*, *hypervigilance*, and a *low-risk low-reward lifestyle* which was comprised of three subthemes (*limiting relationships*, *limiting life goals*, and *fear of changing treatment*). A quantitative systematic review of 15 studies found that FORP was strongly associated with worse quality of life, and greater depression, anxiety, psychotic symptoms, and medication adherence, but was not associated with age or gender. Hence, FORP can be understood transdiagnostically, and is generally associated with poorer mental health outcomes but may also predict adaptive health behaviours, such as appropriate medication adherence.

It is perhaps unsurprising that a person in recovery from an illness may fear that their illness will recur or get worse. Whilst such a statement might be self-evident, the issue of what is a relapse in mental health is far from straightforward. For example, some illnesses have residual symptoms, even when the person is relatively well, while others may have more distinct periods of being symptom free and then acutely unwell. Moreover, some mental health conditions progress over the course of the condition without periods of clear improvement. As such, for the purposes of this review, we adopt a definition of fear of recurrence or progression (FORP), similar to that in the cancer literature (Lebel et al., 2016), such that FORP is the fear that symptoms of a mental health condition will recur or become worse in the future.

The fear of recurrence has been recognised in the cancer context with fear of cancer recurrence (FCR) receiving substantial research attention in recent years (Butow et al., 2019). Indeed, FCR has become known as a near ubiquitous part of adjusting to life beyond cancer (Simonelli, Siegel, & Duffy, 2017). FCR is an understandable reaction to living with the threat of ill health and death, and may even drive adaptive coping or health behaviours (Almeida, Elliott, Silva, & Sales, 2019; Lee-Jones, Humphris, Dixon, & Bebbington Hatcher, 1997). However, FCR can become severe, and severe FCR is associated with anxiety, depression, poorer quality of life, psychiatric morbidity, and disturbances in health behaviours, irrespective of the objective risk of cancer recurrence (Simard et al., 2013). Beyond cancer, there is a growing literature on fear of progression related to other chronic physical illnesses, such as multiple sclerosis, diabetes, or cardiovascular disease. In these cases, people may fear the progression of their disease leading to a loss of functioning or independence (Sharpe, Michalowski, Richmond, Menzies, & Shaw, 2022). Similar to FCR, fear of progression in other chronic physical illnesses is related to worse anxiety, depression and quality of life (Sharpe, Michalowski, et al., 2022). However, whether a person with a history of psychological conditions might fear a future deterioration of

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their mental health has received substantially less empirical and theoretical attention.

The paucity of research on FORP in people with a history of mental health conditions is surprising for several reasons. Firstly, like physical conditions, mental health conditions also carry a significant risk to the health, functioning, and quality of life of those who experience them (Vigo, Thornicroft, & Atun, 2016). Hence, there is a substantial personal and social cost associated with poor mental health. Secondly, symptoms of mental health conditions often fluctuate over time (Wittchen, Lieb, Pfister, & Schuster, 2000), thus we would expect that people would worry about their illness getting worse even when they are well. Lastly, some mental health conditions are characterized by a potential for chronicity and relatively low rates of remission following treatment, such as in obsessive-compulsive disorder (Bloch et al., 2013; Eisen et al., 2013). Whereas other conditions, despite somewhat reliably remitting with treatment, are nevertheless characterized by high rates of relapse, such as anxiety disorders, and (hypo)mania and depression in bipolar or unipolar mood disorders (Fagiolini et al., 2013; Oud et al., 2016; Richards, 2011; Yonkers, Bruce, Dyck, & Keller, 2003). In light of this evidence, it would be surprising if people with a history of mental health conditions did not experience FORP, even after effective treatment.

Whilst the FORP literature remains small, interest in FORP amongst people with schizophrenia has grown over the past decade. Recently, FORP has been theorised to have key implications for the monitoring of early warning signs of acute psychotic relapse in people with schizophrenia. The cognitive-interpersonal model of early warning signs (Gumley et al., 2020) suggests that fear of relapse stems from prior traumatic experiences of hospitalization. FORP is argued to drive anxiety, shame, and avoidance which, in turn, leads to reduced help-seeking behaviours in people with schizophrenia. They argue that care providers interpret this avoidance as an indication of increased risk, resulting in increased monitoring and suspicion towards the service user (Gumley et al., 2020). Increased surveillance affirms peoples' negative expectations of mental healthcare and FORP. Hence, FORP may constrain the efficacy of monitoring early warning signs, which is recommended as an approach to managing psychosis (Birchwood & Spencer, 2001). Whilst the cognitive-interpersonal model has not been tested, some of its tenets are consistent with a systematic review of nine studies on fear of relapse in schizophrenia and carers of those with schizophrenia (Zukowska, Allan, Eisner, Ling, & Gumley, 2022). That is, FORP is associated with trauma associated with previous episodes, as well as depression and anxiety.

Whilst the review by Zukowska et al.' (2022) emphasizes the relevance of FORP to people with schizophrenia, there is currently no systematic reviews of FORP related to mental health conditions other than schizophrenia. The absence is likely due to the preponderance of studies on FORP and schizophrenia. Consequently, little is known about whether FORP relates to other mental health conditions, such as depression or anxiety. This focus on fear of acute psychotic relapse in schizophrenia is also reflected in descriptions of FORP used in the literature, including fear of going crazy (e.g., Herz & Melville, 1980), fear of madness (e.g., Bassett, Sperlinger, & Freeman, 2009), fear of relapse (e.g., Gumley et al., 2015), and fear of illness recurrence (e.g., Jamalamadaka, Griffith, Steer, & Salkovskis, 2020). However, there is evidence that after first-episode psychosis some people experience significant social and cognitive functional decline (Chang et al., 2018; Hodgekins et al., 2015). Hence, one could imagine how someone who is at ultra-high risk for psychosis or has had psychosis may fear this functional decline associated with negative and cognitive symptoms, not just an acute psychotic episode. Similarly, a person who is depressed, but is no longer at their lowest mood may best describe their fear as a progression or worsening of existing depression, rather than as a fear of recurrence or relapse. As such, we adopt the term FORP as we believe it better captures the range of potential concerns a person with a history of mental health conditions may experience.

The extension of FORP to non-psychotic illnesses is important as some recent studies have found that people with non-psychotic mental health conditions also experience FORP. One study compared fear of recurrence amongst people in recovery from psychosis or anxiety disorders and found that these two samples did not differ in degree of fear of recurrence (Sired, Griffith, Jamalamadaka, & Salkovskis, 2021). Another study found that whilst people in recovery from non-psychotic mental health conditions reported less fear of recurrence than those in recovery from psychosis, they nevertheless reported fear of recurrence (Jamalamadaka et al., 2020). These studies provide early evidence that FORP may be a significant concern across a spectrum of mental health conditions. This corroborates prior qualitative research, which identified FORP as a recurring theme and source of distress in the lives of people with ongoing or past depression (Coyne & Calarco, 1995). Together, these findings raise the possibility that FORP is associated with poorer psychological outcomes in people across a spectrum of different mental health problems, such as depression and anxiety, as well as schizophrenia (Zukowska et al., 2022). Additionally, the degree to which the severity, predictors, or consequences of FORP vary between those with different diagnoses, or whether the construct can be captured transdiagnostically remains unknown.

Identifying whether FORP is a transdiagnostic construct is critical for several reasons. Firstly, comorbidity of mental health conditions is very common (Kessler et al., 2011). A person with schizophrenia may also experience intermittent depression and may worry both about recurrence in either psychosis and/or depression to varying extents. A transdiagnostic model of FORP would allow for clinicians and researchers alike to understand these co-occurring fears and how they may interact within a single framework. Secondly, whilst the content of FORP related to psychosis may differ from FORP related to depression, the psychological processes underlying these fears may be more similar than different. In people with physical health conditions, it has been shown that people with different chronic health issues vary in prognosis and nature still tend to report similar fears of recurrence and progression (Sharpe, Michalowski, et al., 2022).

The present review is novel as it aims to synthesize existing quantitative and qualitative research on FORP in people with current or past mental health conditions, not just in psychosis. Quantitative studies will be reviewed narratively, and, if there are sufficient studies, meta-analysed to elucidate the associations between FORP and psychological outcomes, quality of life, and health behaviours, with exploratory analyses of FORP's relationship with age and gender. It is expected that FORP will be associated with worse psychological outcomes and quality of life, and disturbances in health behaviours, both adaptive and maladaptive, dependent on the particular health behaviour under investigation. Given sufficient studies, the qualitative literature will be meta-synthesised to generate a transdiagnostic model of FORP in people with mental health problems to serve as a hypothesis-generating framework to guide future research.

1. Method

A systematic search was conducted on the 27th of June 2023 across four databases (PsycINFO, MEDLINE, SCOPUS, Web of Science) to identify studies that reported on FORP in people with current or past mental health conditions. The review was registered prospectively in PROSPERO (CRD42021287692).

1.1. Search strategy

We conducted systematic searches of the following databases: PsycINFO, MEDLINE, Web of Science Core Collection, and Scopus. We borrowed from the definition of FCR (Lebel et al., 2016), "the fear, worry or concern that cancer may come back or progress" to develop search terms related to FORP. We explicitly excluded a number of common physical disorders (e.g., NOT cancer), but we did not use terms for any psychological condition to ensure that we identified relevant papers for

all psychological conditions (see supplementary materials for full search terms). Backwards citation searching of reference lists from studies eligible for inclusion and Zukowska et al. (2022) were screened to identify further studies.

1.2. Selection of studies

We included quantitative and qualitative English-language studies that sampled adults who reported having been diagnosed with a mental health condition, if they were published in peer-reviewed journals. Quantitative studies were included if they assessed FORP in relation to the participants' mental health, and/or analysed how FORP related to quality of life, mental health symptomology, health behaviours or relapse or progression. Qualitative studies were included if FORP emerged as a theme or subtheme in the analysis, or if FORP emerged in participant quotes related to some other construct.

1.3. Data extraction

For all included studies, we extracted data pertaining to: authors and year of publication, country of research, participant age, participant gender, study design, diagnoses and method of diagnosis. Further, for quantitative research we extracted, method of FORP assessment, degree and distribution of FORP, and data that assessed the association between FORP and demographic, clinical, or mental health outcomes. For qualitative research, participant quotes, contextualized with researcher interpretations, were extracted if they were related to FORP. For studies that contained quantitative and qualitative data pertaining to FORP, both forms of data were extracted. Lastly, for studies with missing data of interest, and where current corresponding author details could be identified, additional data pertaining to FORP and its relationship to demographic and clinical variables was requested.

1.4. Data synthesis

1.4.1. Quantitative data: planned analyses

Correlations, means, and standard deviations were to be analysed using Comprehensive Meta-analysis. Where there was missing data, corresponding authors were contacted to request the relevant data. If sufficient data was available, subgroup analyses were planned for different diagnostic categories. Given that we are investigating FORP across a range of disorders, we would expect considerable heterogeneity and therefore employed a random effects model. Risk of publication bias was to be assessed using funnel plots, Rosenthal's fail-safe N, and Duval and Tweedie's trim and fill method.

1.4.2. Quantitative data: changes from published protocol

At the data extraction stage, there were only 16 studies. Within these studies, there were 10 different measures of FORP, 9 samples of differing mental health conditions, 16 different measures of mental health outcomes, 2 measures of quality of life, and 5 different measures of health behaviours. Hence, it was not conceptually reasonable to meta-analyse this data given the degree of heterogeneity. Hence, a narrative style review was performed using both originally reported and requested data following the principles of the synthesis without meta-analysis guide (Campbell et al., 2020).

To ensure consistency in reporting of extracted data the following decisions were made. Where multi-subscale measures were used to assess FORP the subscale most relevant to FORP was used. If this data was not available or if no one subscale appeared to capture FORP most clearly, the total scale score was used. When reporting on relationships between FORP and other factors, correlations were reported to maximise comparability between studies, if this data was not available other associative data was reported. When reporting on requested data on FORP in relation to categorical variables, such as gender, means and standard deviations were used to facilitate comparisons. When reporting on demographic or diagnostic factors in longitudinal studies, only baseline data were reported.

1.4.3. Qualitative data

A meta-synthesis can occur at two levels. Where there is sufficient data, themes and subthemes can be analysed to create an over-arching model. Alternatively, a meta-synthesis can be conducted by extracting all published quotes within each study and analyzing these to develop themes and subthemes (Finfgeld-Connett, 2018). This is useful where there is a paucity of data, which was expected given that a previous review of FORP in schizophrenia only identified four qualitative studies (Zukowska et al., 2022). Hence, to conduct the meta-synthesis, extracted qualitative data were independently coded line-by-line by two authors (DCB and LS) to identify concepts across studies. From this coding, descriptive themes and subthemes were established. The two authors then discussed and agreed upon the identified themes and subthemes, and synthesised a model that accounted for these themes (Finfgeld-Connett, 2018).

1.5. Assessment of study quality

The Joanna Briggs Institute critical appraisal tools for qualitative and quantitative research, were used to assess study quality in the present review (Lockwood, Munn, & Porritt, 2015; Moola et al., 2017; Tufanaru, Munn, Aromataris, Campbell, & Hopp, 2017). However, the present review included an observational longitudinal study which is a design that the Joanna Briggs Institute does not provide an appraisal tool for. Hence, the authors used an alternative quality checklist specifically designed for this type of study (Tooth, Ware, Bain, Purdie, & Dobson, 2005). Quality ratings were made by two independent assessors (DCB and MF).

2. Results

2.1. Study selection

The search of databases and other sources identified 2462 studies, 1230 after removal of duplicates. Of these, 1120 were excluded after screening titles and abstracts against the inclusion criteria. The remaining 110 articles were read by PT and DCB, who independently assessed their eligibility for inclusion with substantial agreement (Cohen's Kappa = 0.77). Disagreements were settled by consensus and review by an independent author (LS). This process left 45 papers that were deemed eligible for inclusion after the full text review. However, 11 of these papers were exclusively concerned with panic disorder and had been included as they assessed fear of going crazy. The research team discussed these papers at length, and although fear of going crazy could be interpreted as referring to a fear that one's symptoms of panic could worsen, we elected to exclude these studies as fear of going crazy is a specific symptom within panic disorder (American Psychological Association, 2013). As such, it could be argued that the presence of 'fear of going crazy' was a diagnostic confound. To be conservative, we excluded these studies, which left a total of 34 included studies (Fig. 1).

2.2. Study characteristics and quality

Of the 34 included studies, 20 reported qualitative findings, and 16 reported quantitative findings (i.e. two studies included both quantitative and qualitative studies). On average, the qualitative studies met 7.2 out of the 10 quality appraisal criteria. Whilst almost all studies appropriately represented the voices of their participants using appropriate analyses to draw conclusions, relatively few studies provided an explicit statement on their epistemology, theoretical, or cultural position within the research. The two quantitative intervention studies both met 9 out of 13 appraisal criteria. Whilst both studies were randomised with appropriate trial designs and outcome measurement, there were

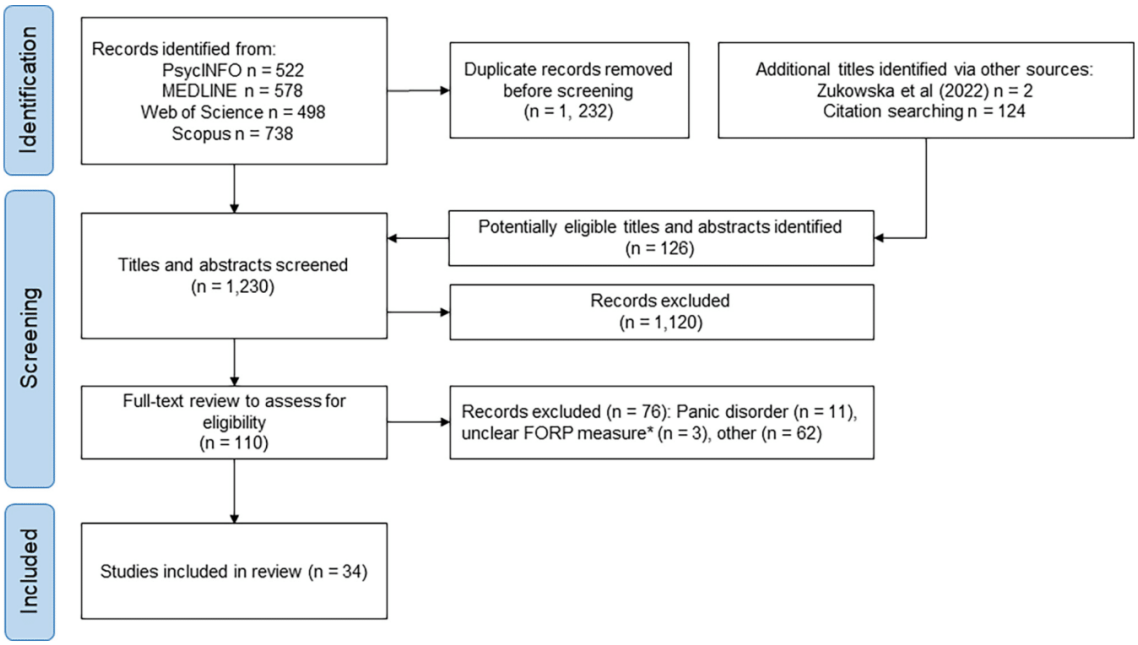

Fig. 1. Flowchart of the study inclusion process.
Note. * refers to studies that did not directly assess FORP but measured it strictly in relation to some other variable, for example, a single item such as 'to what extent are you concerned that your condition will worsen due to social isolation caused by a COVID-19 lockdown?'

significant differences between treatment groups at baseline. The two quasi-experimental studies both met 6 out 9 appraisal criteria. Whilst both studies used appropriate outcome measurements and analyses, neither included a control group. On average, the 10 cross-sectional studies met 5.9 out of 8 appraisal criteria. Whilst most studies used appropriate measurement and analyses of study variables and identified confounds, few used statistical strategies to control for potential confounds. The one observational longitudinal study met 17 out of 31 applicable criteria. Further information on quality ratings is available in Supplementary Materials. Further study characteristics of qualitative and quantitative studies are provided in Tables 1 and 2, respectively.

2.3. Meta-synthesis

In total, 20 of the reviewed studies used qualitative methodology (see Table 1). Six of these studies recruited people with a schizophrenia-spectrum disorder (Baier, 1995; Baker, 1995; Carrick et al., 2004; Irawani et al., 2022; Nagle et al., 2002; Sandhu et al., 2013). Five studies were in depression or anxiety (Coyne & Calarco, 1995; Eveleigh et al., 2019; Grime & Pollock, 2003; Leydon et al., 2007; Van Geffen et al., 2011). Four studies were on people with a post-partum disorder, including three on post-partum psychosis (Forde et al., 2019; McGrath et al., 2013; Robertson & Lyons, 2003), and one on a mixed, but predominantly depressive, post-partum sample (Peindl et al., 1995). Four studies were in substance use disorders (Allan et al., 2019; Dyson et al., 2023; Kondoni & Kouimtsidis, 2017; Notley et al., 2015). Lastly, one study used a mixed sample of people with psychotic, non-psychotic, and substance-related diagnoses (Varela et al., 2007). Synthesis of participant quotes revealed several key themes and subthemes which are summarised below. The relationships between these components are summarised in Fig. 2.

2.3.1. Fears of recurrence and progression (FORP)

FORP was reported by a range of people, including those with a history of psychosis, opioid addiction, depression, anxiety, mania, and post-partum mental health disturbances. For them, now that they were beyond the worst of their experience, there was a strong fear that these issues could worsen or resurface sometime in the future. Although some people adopted strategies to prevent deterioration, there remained a pervasive sense of uncertainty regarding their future mental health.

> Person with a depressive disorder: *"Even when I'm okay or relatively okay, I feel there is no way I can predict if I'm going to stay that way for two days or two years…"*
>
> (Coyne & Calarco, 1995)

> Person with a substance use disorder *"I'm getting a bit anxious, knowing that I'm going. I've been here, wrapped in cotton wool for two months, and being released back into the big, wide world, I'm scared that I'm going to relapse"* (Allan et al., 2019).

Across the synthesised studies, there appeared to be four key subthemes underlying FORP: fear of symptoms, loss of progress, fear of death and traumatic experiences.

2.3.1.1. Fear of symptoms. Across a range of presentations, people tended to fear a specific set of symptoms that they felt characterized their own periods of mental ill health. Notably, this did not seem to involve speculation that they may develop new symptoms. Instead, people reflected on their previous experiences, and wondered how old symptoms would impact their lives if they were to recur in the present moment, or if existing symptoms were to worsen.

> Person with opioid use disorder: "*I will panic, I am afraid of the symptoms. I will become manic and depressed like the last time where I ended up in hospital. I have a fear of going back and do drugs.*" (Kondoni & Kouimtsidis, 2017).

2.3.1.2. Loss of progress. Irrespective of their current symptoms, or current difficulties in meeting their goals or personal recovery, people felt they were no longer at the worst of their functional capacity or

Table 1
Summary of qualitative studies included in the meta-synthesis.

Reference	Participant Demographics	Diagnoses	Nature of the Sample	Quality Rating
Allan, Collings, and Munro (2019)	*N* = 12 25% female Australia	Mixed substance use disorders	Attendees of a voluntary rehabilitation service	7/10
Baier (1995)	*N* = 6 66.7% female United States	Schizophrenia	Attendees of a day treatment center for psychosis	5/10
Baker (1995)	*N* = 15 33% female Canada	Schizophrenia	Attendees of a range of different psychiatric institutions	8/10
Carrick, Mitchell, Powell, and Lloyd (2004)	*N* = 25 48% female United Kingdom	Schizophrenia, schizoaffective disorder, other psychotic illnesses, and borderline personality disorder	People prescribed anti-psychotic medication under the care of a psychiatrist or a day treatment center	9/10
Coyne and Calarco (1995)	*N* = 17 58.8% female United States	Depression	Community recruitment	6/10
Dyson, Skinner, Crick, and Crooks (2023)	*N* = 5 100% female United Kingdom	Tobacco use disorder	Users of a stop-smoking health service	8/10
Eveleigh, Speckens, van Weel, Oude Voshaar, and Lucassen (2019)	*N* = 16 69% female Netherlands	Anxiety, depression	Ongoing prescription for anti-depressants without indication (according to Dutch guidelines)	6/10
Forde, Peters, and Wittkowski (2019)	*N* = 21 100% female United Kingdom	Post-partum psychosis	Recruitment across a mother and baby unit, community perinatal mental health team, and a charity for postpartum psychosis	8/10
Grime and Pollock (2003)	*N* = 32 71.9% female United Kingdom	Depression	Members of a volunteer self-help organization for depression	5/10
Irawani, Asniar, & Marthoenis (2022)	*N* = 8 37.5% female Indonesia	Schizophrenia	Attendees of a community health center	6/10
Kondoni & Kouimtsidis (2017)	*N* = 10 30% female United Kingdom	Opioid use disorder	Ongoing opioid substitution therapy	5/10
Leydon, Rodgers, and Kendrick (2007)	N = 17 58.8% female United Kingdom	Depression	People prescribed anti-depressants for ≥12 months in the community	6/10
McGrath, Peters, Wieck, and Wittkowski (2013)	N = 12 100% female United Kingdom	Puerperal psychosis, or post-partum depression with psychotic features	Mother-and-baby unit and community recruitment	10/10
Nagle, Cook, and Polatajko (2002)	N = 8 25% female Canada	Schizophrenia, schizoaffective disorder	Hospital-based psychosocial rehabilitation program	6/10
Notley, Blyth, Maskrey, Pinto, and Holland (2015)	*N* = 27 33.3% female United Kingdom	Opioid use disorder	People enrolled in opioid substitution therapy for ≥5 years.	8/10
Peindl, Zolnik, Wisner, and Hanusa (1995)	*N* = 268 100% female United States	Mixed post-partum disorders (predominantly depression)	Members of a volunteer-led self-help organization for post-partum disorders	NA*
Robertson and Lyons (2003)	N = 10 100% female Canada	Puerperal psychosis and mania	Subsample of participants from a genetic study on puerperal psychosis	7/10
Sandhu, Ives, Birchwood, and Upthegrove (2013)	N = 8 37.5% female United Kingdom	Schizophrenia with post-schizophrenic depression	Participants in an early intervention service for psychosis	10/10
Van Geffen et al. (2011)	*N* = 18 72.2% female Netherlands	Anxiety, depression.	Obtained a prescription for an SSRI in the previous 4 months that was used for a minimum of 2 months.	6/10
Varela, Montbach, and Shipe (2007)	*N* = 38 40% female United States	Mixed substance use disorders, with mixed comorbid diagnoses (predominantly mood disorders and schizophrenia)	Ongoing treatment for HIV/AIDS, alongside a prescription for psychoactive medication for treating a mental health diagnosis.	4/10

*Mixed method study appraised as a cross-sectional quantitative study as that was its primary focus.

mental health. Hence, whether it was due to the passage of time or treatment, there was a sense that movement had been in their recovery. For many people, recurrence, or further deterioration of their mental health, represented a loss of progress that was frightening. Some people spoke about this in absolute terms and were distressed at the possibility of going back to "square one" if their mental health were to worsen.

> Person with opioid use disorder: "*I hate to think about it – I would be in such fear and trepidation as to what really could happens; the pitfalls where I could end up and back to square one. It is frightening*" (Notley et al., 2015).

2.3.1.3. Fear of death. For some people, the possibility that they might die because of a deterioration in mental health was a significant worry. For some, there was concern that returning to an unstable mental state would put them at risk of dying by suicide. For others, there was a sense that intense mental experiences could overwhelm a person to the extent that they would simply die, as a result of declining mental health.

Table 2
Characteristics of studies reporting quantitative data related to FORP.

Study	Participants	FORP Measure	Outcome measures	Associations with FORP (*r*, unless otherwise stated)	Quality Rating
Studies concerned with Mental Health Outcomes, Quality of Life, Age, and Gender					
Allan et al. (2023)	N = 25 Schizophrenia-spectrum disorder	Single item	Single item – anxiety Single item – paranoia	Partial r = 0.07–0.15 Partial r = 0.11	17/31
Bassett et al. (2009)	N = 25 Schizophrenia-specturm disorder	WAMHQ subscales	Psychotic Symptom Rating Scale (PSYRATS; Haddock, McCarron, Tarrier, & Faragher, 1999) Delusion preoccupation amount Delusion preoccupation duration Delusion conviction Delusion distress amount Delusion intensity Beck Anxiety Inventory (BAI; Beck, Epstein, Brown, & Steer, 1988) Penn State Worry Questionnaire (PSWQ; Meyer, Miller, Metzger, & Borkovec, 1990)	0.13–0.150 .38–0.500 .07–0.040 .49–0.530 .38–0.50 0.30–0.43 . 58–0.64	7/8
Braehler et al. (2013)	*N* = 40 Schizophrenia-spectrum disorder	FoRSe fear of relapse	Beck Depression Inventory (BDI; Beck, Steer, & Brown, 1996)	0.52	9/13
Collett, Pugh, Waite, and Freeman (2016)	N = 21 Schizophrenia-spectrum disorder	WAMHQ total	BDI Beck Scale for Suicidal Ideation (BSS; Beck, Kovacs, & Weissman, 1979)	0.72 0.48	7/8
Gumley et al. (2015)	*N* = 169 Schizophrenia-spectrum disorder	FoRSe fear of relapse	Calgary Depression Scale (CDS; Addington, Addington, & Maticka-Tyndale, 1993) Early Signs Scale (Birchwood et al., 1989)	0.51 0.73	9/13
Jamalamadaka et al. (2020)	*N* = 121 Schizophrenia-spectrum and non-psychotic disorders	FoRSe total	Mental Health Anxiety Inventory (MHAI; Commons, Greenwood, & Anderson, 2016) Work and Social Adjustment Scale (WSAS; Mundt, Marks, Shear, & Greist, 2002)	0.76 0.70	6/8
Ryan et al. (2021)	*N* = 55 Schizophrenia-spectrum disorder	FoRSe total	Age Gender	−0.04 d = 0.06	6/9
Sired et al. (2021)	*N* = 110 Schizophrenia-spectrum and anxiety disorders	FoRSe fear of relapse	Patient Health Questionnaire (PHQ-9; Kroenke, Spitzer, & Williams, 2001) Generalized Anxiety Disorder 7 (GAD-7; Spitzer, Kroenke, Williams, & Löwe, 2006) MHAI Recovering Quality of Life (Keetharuth et al., 2017) WSAS	0.71 0.70 0.72 −0.71 0.51−	4/8
White and Gumley (2009)	N = 27 Schizophrenia-spectrum disorder	FoRSe fear of relapse	Age Gender Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) depression subscale HADS anxiety subscale Clinician-administered Posttraumatic Stress Disorder Scale for people with Schizophrenia (CAPS-S; Gearon, Kaltman, Brown, & Bellack, 2003) Impact of Event Scale (IES-R; Weiss & Marmar, 1997) Number of psychiatric hospital admission Age Gender	0.11 d = 0.04 0.55 0.63 0.61 0.73 0.400 .01 d = 0.80	7/8
Studies concerned with Medication Adherence and Health-related Behaviours					
Adams and Scott (2000)	*N* = 39 Affective or schizophrenia-spectrum disorder	Single item	Evaluated as highly adherent to medication	OR = 9.63	5/8
Bentzley, Barth, Back, Aronson, and Book (2015)	*N* = 69 Opioid dependence	Single item	Greater intended length of buprenorphine maintenance treatment (< 1, 1–6, 6–12, 12–24, >24 months)	OR = 7.71	7/8
Coyne and Calarco (1995)	N = 17 Major depressive disorder	SAQ fear of recurrence	One lifetime depressive episode vs recurrent depression	d = 0.05	4/8
Devulapalli et al. (2010)	*N* = 140 Bipolar disorders	Single item	Evaluated as adherent to medication	OR = 7.8	7/8
Eisner et al. (2019)	N = 18 Schizophrenia-spectrum disorder	FoRSe fear of relapse	Use of psychosis symptom monitoring smartphone app	ρ = −0.58	6/9
Kirk, Haaga, Solomon, and Brody (2000)	N = 25 Depressive and anxiety disorders	SAQ fear of recurrence	One lifetime depressive episode vs recurrent depression	d = 1.28	7/8

(*continued on next page*)

Table 2 (*continued*)

Study	Participants	FORP Measure	Outcome measures	Associations with FORP (*r*, unless otherwise stated)	Quality Rating
Peindl et al. (1995)	N = 268 Post-partum mental disorders	Single item	Action undertaken to prevent further pregnancy (e.g., adoption, sterilization, abortion)	OR = 1.77	4/8

Participant characteristics only reported for those with a current or past mental health issue, healthy control group data is not reported here. Measures of mental health outcomes and quality of life if there is available on their association with the study's respective FORP measure. For purposes of brief sample categorization, schizophrenia-spectrum disorder includes people diagnosed with an affective disorder with psychotic features.

Person with a schizophrenia-spectrum disorder: "*[psychosis] almost cost me my life and it has impressed on me very strongly that I shouldn't allow things to get so out of control*" (Baker, 1995).

2.3.1.4. Traumatic experiences of mental ill health or treatment. People in these studies had all lived through intensely distressing experiences related to their mental health. In their quotes, it was clear how distressing these memories remained when invoked in discussions about fears of recurrence and progression. For some, the difficult or traumatic memories were centred on the intensity or severity of their mental illness. Whereas, for others, there was trauma grounded in experiences of undergoing involuntary, coerced, or distressing treatment or hospitalization.

Person with a post-partum mental health condition: "*I almost killed my son. I don't think my husband ever forgave that. I don't want to hurt any more children. I was afraid it would happen again. It's been almost fifteen years, but you remember how it felt, the terrible agony of thinking you're crazy and feeling that there can't possibly be hell after death because that was hell pure and simple.*" (Peindl et al., 1995).

Person with psychotic post-partum mental health condition: "*…the shocking departure out of my own home with police and ambulance and the whole street out… it's very traumatic to process, particularly you know, if you're able to, you know, have been, quite, you know, well-functioning up until now.*" (Forde et al., 2019).

2.3.2. Low-risk, low-reward lifestyle

To manage FORP, people with a range of conditions, from psychosis to depression, reported adopting a conservative, low-risk, low-reward lifestyle that served to avoid precipitants of poor mental health (Fig. 2). This is an understandable, and potentially adaptive, response to living with a mental health condition. Indeed, it also seemed to underlie adherence to treatment, especially medication, which may maintain mental wellness. However, across the synthesised studies, this approach also led people to avoid potentially enjoyable life experiences, such as having relationships, or to curtail certain employment opportunities. Hence, individuals who adopt a highly avoidant low-risk, low-reward lifestyle may inadvertently make themselves more vulnerable to worse mental health. For example, avoiding relationships can increase loneliness and reduce social support, both of which are potentially protective of deteriorations in mental health (Fig. 2).

Person with a depressive disorder: *"I'm afraid to move out to take a risk or go someplace else or take positions that will challenge me more because I don't know if it will trip me into a depression and then I will fail completely… so I structured my life as carefully as possible."* (Coyne & Calarco, 1995).

Across the synthesised studies, there were three manifestations of this lifestyle, which were coded as subthemes: limiting relationships; limiting life goals, and fears of changing treatments.

2.3.2.1. Limiting relationships. Some people consciously decided to limit their interactions with other people to avoid the stress that could precipitate recurrence or progression. Interestingly, this avoidance extended to all forms of relationships, including those platonic, romantic, and familial, and those both fleeting and meaningful. This approach seemed to acknowledge the inherent stresses associated with building and maintaining relationships, and how these might negatively impact one's mental health. These anticipated stresses could lead to outright avoidance, such as not pursuing a romantic relationship or talking to people generally, but also a tendency to avoid sharing one's feelings and a preference for superficial relationships. However, these self-imposed limits were sometimes in tension with peoples' desires, such as women with a history of post-partum psychosis who chose to forgo having another child despite a desire to grow their family (Peindl et al., 1995).

Person with a depressive disorder: "*It has strongly affected my attitude about relationships. It makes me afraid of being in them because I'm afraid they will precipitate something.*" (Coyne & Calarco, 1995).

Person with a schizophrenia-spectrum disorder and depression: "*I always think I'm gonna get unwell again and again, that's maybe another reason why I don't go out, I don't wanna talk to people 'cause I'm thinking last time, when I had an episode, it was public… that kind of scared me… I'm thinking what if I get unwell again, what if that same thing happens again?*" (Sandhu et al., 2013).

2.3.2.2. Limiting occupational/life goals. Similarly, people noted a desire to leave their comfort zone and pursue valued experiences, such as re-entering the workforce, seeking more responsibility, or travelling. However, for those adopting a low-risk, low-reward lifestyle, these valued experiences were avoided or postponed because of real or perceived threats to their mental health. For many people, although they desired greater independence or responsibility, there was a concern that they would be unable to manage it, or that they lacked sufficient external supports to prevent recurrence or progression, if they were to pursue these goals.

Person with a depressive disorder: "*It really makes you think twice about what kind of work you're doing. I mean I want to go to the Third World and work, but you think "great" so what happens if I'm over there and you know, it happens*" (Coyne & Calarco, 1995).

2.3.2.3. Fear of changing treatment. Many people directly linked their desire to persist with their current mental health treatment, particularly medication regimens, to FORP. For these people, their current treatment plan was identified as an important part of maintaining mental wellness. Whilst medication adherence is often helpful, many people expressed a desire to cease or taper their pharmacotherapy, which they reported they did not pursue due to FORP. Importantly, intention to persist with medication was also found in those who, according to Dutch guidelines, were no longer indicated to be using anti-depressants (Eveleigh et al., 2019). Hence, FORP seemed to elicit greater adherence to one's current treatment, even if the current regiment may no longer be the most appropriate for them.

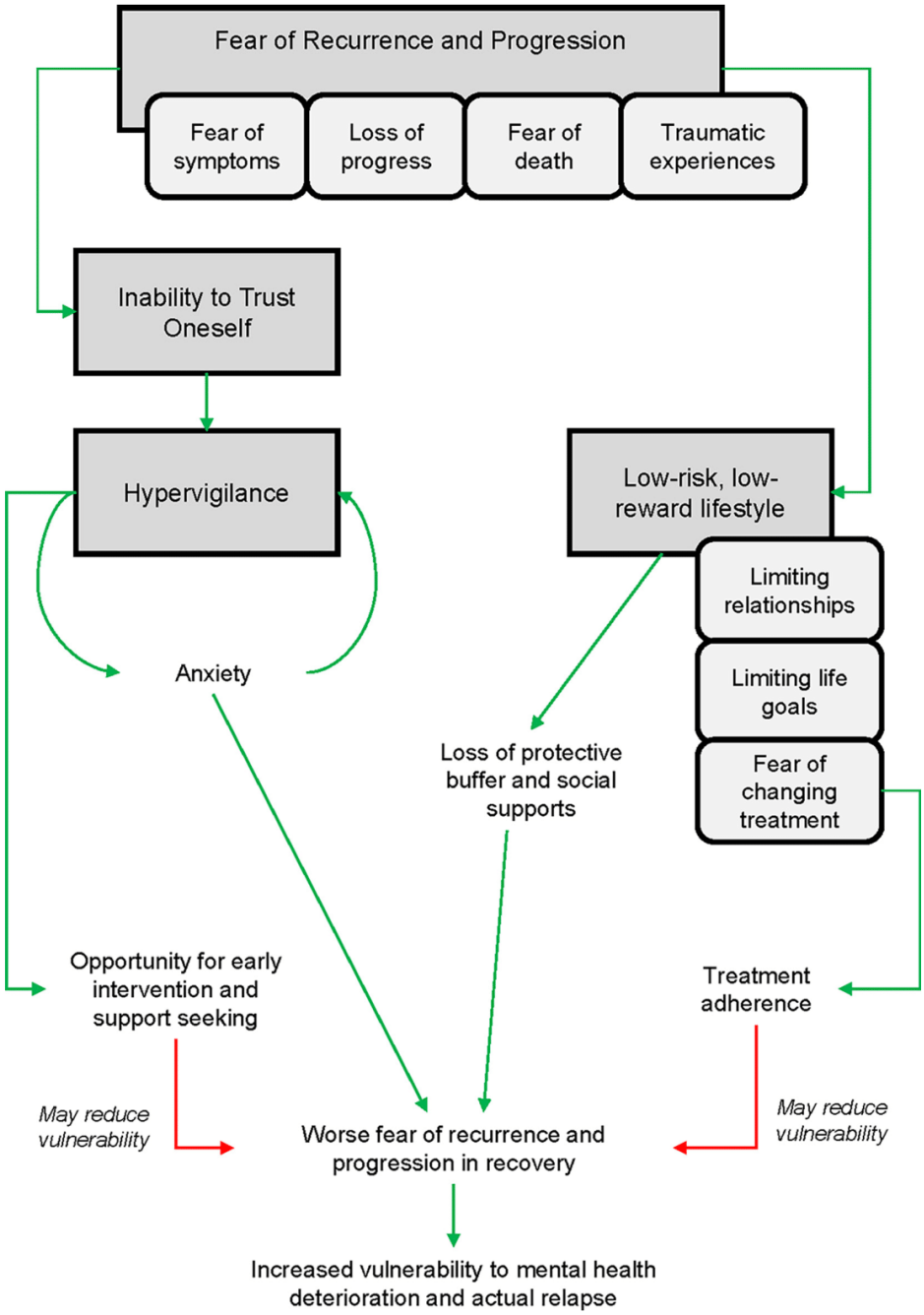

Fig. 2. Transdiagnostic model of FORP in people with a history of mental health conditions.

Person with an anxiety or depressive disorder: "*Well, I'm feeling very well, I am very stable. I'm in harmony, I don't have any mood swings or anything. I don't think I could feel any better than I do now. Also, mentally. So, I won't risk [ceasing antidepressant medication]. I won't attempt it, maybe it would be successful, but I won't dare to try.*" (Eveleigh et al., 2019).

2.3.3. Inability to trust oneself

Many people noted that when mentally unwell, their understanding and insight into themselves and their world was disturbed. Importantly, this was not limited to those with a history of delusions or psychosis. As an example, people with a history of depression noted a tendency towards negative appraisals and thoughts that they would not ordinarily endorse. For some, knowledge of these disturbances made it difficult to trust their assessment of their own mental health during periods of

relative mental wellness. Moreover, some had a lack of confidence in their ability to cope with stressors that might worsen their mental health.

> Person with post-partum psychosis: "*…when [my partner] would say things like 'are you feeling ok?'…or you know just look at me really concerned… it just made me feel like it would always, like really shook me, because I'd be like 'oh gosh, am I not ok?'… maybe something's wrong with me again' and I just can't even tell.*" (Forde et al., 2019).

> Person with a depressive disorder: "*When you're depressed, you don't have the distance… you start to believe the negative thoughts… later they seem almost humorous*" (Coyne & Calarco, 1995).

2.3.4. Vigilance-Hypervigilance

To resolve this lack of self-trust, many people consciously chose to be vigilant towards symptoms of mental health (Fig. 2). This vigilance was an important strategy for managing their mental health in recovery, as it helped people to identify early warning signs of deterioration, and thus seek early intervention or further support. However, it was clear that for some, this self-monitoring was a stressful and inadvertently anxiogenic strategy, as normal fluctuations in physiological and psychological state, such as those in irritability, sleep, and low mood, could be perceived as threatening.

> Person with post-partum psychosis or mania: "*You can have an off day and think you're really ill again but you're not, you're just having an off day, it took about two years to realize they were normal highs and lows, other people have them but it's like you can't have normal ups and downs.*" (Robertson & Lyons, 2003).

Given the large proportion of qualitative studies strictly concerned with psychosis (Table 1). We re-analysed our model (Fig. 2) in the nine studies with predominantly non-psychotic samples (Allan et al., 2019; Coyne & Calarco, 1995; Eveleigh et al., 2019; Grime & Pollock, 2003; Kondoni & Kouimtsidis, 2017; Leydon et al., 2007; Notley et al., 2015; Peindl et al., 1995; Van Geffen et al., 2011; Varela et al., 2007). When we excluded quotes from studies with predominantly psychotic samples, across the remaining studies concerned with depression, anxiety, and substance use disorders, all themes and subthemes (with one exception) were still identified. The only exception was fear of dying – this subtheme was only identified for those with a history of psychosis.

2.4. Quantitative literature

Of the 16 studies included in the quantitative analyses, the largest number of studies focused on schizophrenia-spectrum disorders (k = 11), the remainder were on depression (k = 2), substance use (k = 1), bipolar (k = 1), and post-partum mental health conditions (k = 1). Five of the 16 studies reported on multiple types of mental health conditions (Table 2).

2.4.1. Measures of FORP

The most utilized measure of FORP was the Fear of Recurrence Scale (k = 7; FoRSe; Gumley & Schwannauer, 2006). This questionnaire measures three subscales, including a specific fear of relapse subscale. If data on this subscale was not available, data related to the total FoRSe score was reported. The next most common measure of FORP was the Self-Appraisal Questionnaire (k = 2; SAQ; Coyne & Calarco, 1995). Where data on the fear of recurrence subscale was not available, data related to the imposition of limits composite was reported. The next most common measure of FORP was the Worries About Mental Health Questionnaire (k = 2; WAMHQ; Bassett et al., 2009). This questionnaire contains preoccupation, distress, and conviction subscales. As no one subscale was more related to FORP than any other, data related to the total WAMHQ score was reported when available. The remaining studies used different single items to measure FORP (k = 5). Table 2 reports which studies used which measures.

2.4.2. Demographic and clinical factors

Age and Gender. All three studies with available data on the relationship between FORP and age found that age was not significantly associated with FoRSe fear of relapse in samples of people with schizophrenia, psychosis, or anxiety, $r = -0.112$–0.006, $p > .05$, median $r = -0.035$ (Ryan et al., 2021; Sired et al., 2021; White & Gumley, 2009). Similarly, within these studies, FoRSe fear of relapse did not differ between men and women, $d = -0.059$–0.796, $p > .05$, median $d = -0.041$ (Ryan et al., 2021; Sired et al., 2021; White & Gumley, 2009).

Diagnoses. Only three studies reported data on FORP across different mental health conditions. One study found that people with a self-reported history of psychotic mental health conditions reported significantly greater total FoRSe than those with non-psychotic mental health conditions, $d = 0.363$ (Jamalamadaka et al., 2020). Conversely, another found that those with a self-reported history of psychosis do not differ from those with anxiety in terms of total FoRSe, $d = 0.270$, $p > .05$, (Sired et al., 2021). Lastly, for people who had recovered from a major depressive episode, SAQ fear of recurrence was not significantly greater in those with a comorbid anxiety disorder, $d = 0.768$, $p > .05$ (Kirk et al., 2000).

Relapse. Based on two studies in people with schizophrenia, FORP appeared to be associated with psychotic relapse cross-sectionally and longitudinally. Firstly, the number of lifetime psychiatric admissions to hospital was significantly associated with FoRSe fear of relapse, $r = 0.395$, $p < .05$ (White & Gumley, 2009). FoRSe fear of relapse was a significant predictor of shorter time to psychotic relapse, even when controlling for early signs and symptoms of psychosis, exp.(β) = 1.20, $p < .05$ (Gumley et al., 2015).

Two cross-sectional studies compared FORP in those with a history of a single episode of depression to those with recurrent depression. One study found no difference in SAQ fear of recurrence between such groups, $d = 0.05$, $p > .05$ (Coyne & Calarco, 1995). Conversely, another study found that whilst SAQ fear of recurrence was unrelated to time since last major depressive episode, those with recurrent major depression reported greater SAQ fear of recurrence than those with a single lifetime major depressive episode, $d = 1.28$, $p < .05$ (Kirk et al., 2000).

2.4.3. Medication adherence and health behaviours

Despite heterogeneity in participant characteristics, diagnoses, and assessment of FORP, all three studies that provided relevant data found that FORP was positively associated with medication adherence. In opioid dependent people, concern that one might relapse after a reduction in buprenorphine dose was associated with a longer intended duration of buprenorphine use, OR = 7.71 (Bentzley et al., 2015). People with a severe mood disorder or schizophrenia who were independently deemed highly adherent to their current medication regimen rated fear of re-hospitalization as a stronger influence on their adherence compared to those that were deemed partially adherent, OR = 9.63 (Adams & Scott, 2000). Similarly, in people with a bipolar disorder, fear of relapse was more likely to be endorsed by those that were medication adherent compared to non-adherent, *OR* = 7.8 (Devulapalli et al., 2010).

However, the two studies that explored the relation between FORP and other health behaviours found mixed results. One study used weekly self-reported symptom monitoring via a smartphone app to assess for the risk of psychotic relapse in people with a schizophrenia-spectrum disorder and found that FoRSe fear of relapse was significantly correlated with poorer completion of weekly monitoring, $\rho = -0.58$, $p < .05$ (Eisner et al., 2019). Lastly, one study explored the relationship between FORP and family planning decisions made by women with a history of postpartum mental illness, predominantly postpartum depression. Women who took action to prevent further pregnancy by abortion, adoption, or sterilization of themselves or their partner were more likely to report fear of recurrence than those that did not take action to prevent

relative mental wellness. Moreover, some had a lack of confidence in their ability to cope with stressors that might worsen their mental health.

> Person with post-partum psychosis: "*…when [my partner] would say things like 'are you feeling ok?'…or you know just look at me really concerned… it just made me feel like it would always, like really shook me, because I'd be like 'oh gosh, am I not ok?'… maybe something's wrong with me again' and I just can't even tell.*" (Forde et al., 2019).

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further pregnancy, OR = 1.77 (Peindl et al., 1995).

2.4.4. Quality of life

Two studies administered assessments of FORP and quality of life to participants. They found that higher FORP was associated with poorer quality of life, with large relationships, $r = 0.514–0.71$, $p < .05$, median $r = 0.696$ (Jamalamadaka et al., 2020; Sired et al., 2021).

2.4.5. Mental health outcomes

For people with a schizophrenia-spectrum or anxiety disorder, which was the only outcome data available, all five studies found a significant positive association between depression and FORP, $r = 0.51–0.72$, $p < .05$, median $r = 0.547$ (Braehler et al., 2013; Collett et al., 2016; Gumley et al., 2015;Sired et al., 2021 ; White & Gumley, 2009). Overall, five studies explored anxiety in relation to FORP. Two studies that used the FoRSe found a significant positive association between anxiety and FORP, $r = 0.633–0.695$, $p < .05$ (Sired et al., 2021; White & Gumley, 2009). Two studies found a significant positive association between anxiety about mental health and FORP, $r = 0.724–0.763$, $p < .05$ (Jamalamadaka et al., 2020; Sired et al., 2021). One study found anxiety was significantly associated with WAMH-Q preoccupation ($r = 0.427$) but not conviction or distress ($r = 0.300–0.369$) (Bassett et al., 2009). Across all these anxiety studies median association with FORP was $r = 0.633$. Similarly, propensity to worry was significantly positively associated with all WAMH-Q subscales, $r = 0.577–0.635$, $p < .05$ (Bassett et al., 2009). In addition to these studies, a longitudinal network analysis study found that FORP was significantly positively associated with anxiety at the same time point, $r = 0.15$, $p < .05$, and it predicted anxiety the next day, $r = 0.07$, $p < .05$, even when controlling for all variables in the network, including paranoia, hearing voices, negative affect, confidence, perceived support, and sleep changes (Allan et al., 2023).

One study explored the relationship between FORP and symptoms of trauma arising from psychosis-related events. They found that in people with schizophrenia, FORP was significantly positively associated with clinician rated and self-reported posttraumatic symptoms, $r = 0.61–0.728$, $p < .05$ (White & Gumley, 2009). They also found who were experiencing post-psychosis post-traumatic stress disorder reported greater FORP than those that did not ($d = 1.55$, $p < .05$).

Three studies assessed the relationship between FORP and clinician-rated symptoms of psychosis in people with a schizophrenia-spectrum disorder. One study found that FORP was not significantly associated with the time spent preoccupied with a persecutory delusion or their conviction in the delusion, but was significantly positively associated with distress related to the delusion, $r = 0.488–0.534$, $p < .05$ (Bassett et al., 2009). Two studies explored the relationship between overall positive symptoms and FORP, one found a significant positive correlation, $r = 0.51$ (Gumley et al., 2015), whereas the other found a non-significant correlation, $r = 0.279$ (White & Gumley, 2009). Conversely, both these studies found overall negative symptoms to be positively associated with FORP, $r = 0.18–0.472$, $p < .05$. A longitudinal network analysis study found that FORP was significantly positively associated with hearing voices, $r = 0.11$, $p < .05$, but not hearing voices the next day, nor was it associated with paranoia in the same time window or the next day, when controlling for all variables in the network, including anxiety, negative affect, confidence, perceived support, and sleep changes (Allan et al., 2023).

3. Discussion

The present review aimed to synthesize existing qualitative research on FORP in people with mental health conditions, and review the quantitative associations between FORP and psychological outcomes, quality of life, health behaviours, age, and gender. Overall, FORP was identified in people with a lived experience of a range of conditions, including schizophrenia-spectrum, bipolar, depressive, anxiety, and substance use disorders. In qualitative analyses, FORP was associated with an inability to trust oneself and hypervigilance to symptoms of deterioration, which both increased anxiety but promoted early identification of deterioration and support seeking. Similarly, people with a history of mental illness often reported adopting a "low-risk, low-reward" strategy. As with hypervigilance, the low-risk low-reward strategy had adaptive functions, such as reducing stress and promoting medication adherence. However, at the same time, the low-risk, low-reward strategy also led people to be less likely to have social supports and to limit choices that may have bolstered their quality of life. Although in the qualitative analyses, FORP appeared to have benefits and disadvantages, in quantitative analyses, there were moderate to large associations between FORP and depression, anxiety, other mental health outcomes, and poor quality of life. Lastly, although there was a paucity of quantitative research in non-psychotic mental health conditions, FORP appeared to be associated with greater medication adherence across different mental health conditions.

3.1. Qualitative findings

Fear of recurrence or progression was reported by people with lived experience of a variety of different mental health conditions. Qualitative analyses identified a number of subthemes reflecting the specific concerns about FORP that people raised: 1) *Fear of symptoms,* 2) *loss of progress*, 3) *fear of death*, and 4) *traumatic experiences*.

In reaction to these fears, many people explicitly adopted a cautious, low-risk but low-reward lifestyle that they believed would prevent deterioration of their mental health. This approach involved: 1) avoidance of real and perceived triggers of recurrence and progression, such as drug misuse or stressful situations, 2) adherence to ongoing treatment, even when that treatment was no longer indicated; and 3) avoidance of valued and desired, yet nevertheless anxiogenic, opportunities for independence, responsibility, and social connection. This low-risk approach is understandable, especially considering the serious and complex mental health conditions faced by many of the participants. However, it was clear that for some this avoidant and conservative approach to recovery and ongoing mental health care interfered with the attainment of personal goals and desires, and even restricted one's access to protective buffers, such as social support (Fig. 2).

Many of the behaviours described within the quotes related to the low-risk, low-reward lifestyle could be conceptualised as safety behaviours. These are behaviours which temporarily alleviate anxiety by seemingly preventing a feared outcome, in this case mental health deterioration, but which inadvertently maintain or exacerbate anxiety in the long-term by preventing habituation to anxiety and disconfirmation of exaggerated threat expectancies (Craske et al., 2008). However, in clinical practice it can be difficult to distinguish between a safety behaviour and an adaptive safety precaution, especially in people with prior experience of, and greater susceptibility to, a feared outcome. This is the case in many chronic physical conditions, where safety behaviours may not just maintain or exacerbate anxiety but may actually worsen an underlying condition (Sharpe et al., 2022). Sharpe, Todd, et al. (2022) propose that in contrast to safety behaviours, safety precautions will: 1) promote approach of a feared situation rather than avoidance, 2) are based on a realistic, rather than overestimated, threat, 3) are proportional to the threat, 4) are able to mitigate or control the risk of the feared outcome, and 5) allow for engagement in valued activities. These principles may also be useful to determine when behavioural responses to FORP are a maladaptive safety behaviour, or an adaptive safety precaution. This suggests that for some, FORP, at least at milder levels, may be adaptive and promote sensible safety precautions to be adopted.

Similarly, due to prior experience of relapse, or an awareness of how mental illness may alter one's appraisals of various situations or experiences, some people felt unable to trust their own appraisal of their mental health. These people perceived a significant risk for deterioration, and a poor capacity to cope with stressors. Hence, they relied on a strategy of hypervigilance towards early warning signs of ill mental

health to reassure themselves of safety and identify the need for further support. This hypervigilance appeared to be exacerbated amongst those who had experienced mental health related trauma, which is consistent with hypervigilance being a known consequence of trauma (Weiss, 2007). Hence, while vigilance may be helpful and adaptive, by identifying early warning signs and thus enabling early intervention, the boundary between vigilance and hypervigilance was difficult to navigate for many people. Hypervigilance was reported to provoke anxiety, which in turn exacerbates hypervigilance, potentially creating a positive feedback loop that increases the chance mental health deterioration. Hence, like safety precautions within the low-risk, low-reward lifestyle, some vigilance to early warning signs may be one effective strategy in reducing risk of relapse, such as in bipolar disorders (Morriss et al., 2007).

3.2. Quantitative findings

The present review found that FORP was consistently associated with several important mental health outcomes and related behaviours. Firstly, all available studies found that FORP was moderately to highly associated with symptoms of depression, with similar associations between FORP and anxiety. Moreover, in schizophrenia, FORP was generally associated with positive psychotic symptoms and distress, as well as negative, and post-psychotic trauma symptoms. The consistent magnitude of these findings speaks to the robustness of the relationships. Secondly, all studies that assessed the relationship between FORP and intended or actual medication adherence found those with higher FORP reported greater adherence, with strong effects based on reported odds ratios. Importantly, this relationship was found across people with a range of different presentations, including affective conditions, opioid dependence, and the schizophrenia-spectrum. Although there were only a few studies exploring this association, the findings were remarkably consistent across disorders and medications. Lastly, in the two studies that examined FORP in relation to quality of life, FORP consistently predicted impaired functioning and poorer quality of life. These findings are consistent with fear of cancer recurrence (Simard et al., 2013) and fear of progression in other chronic illnesses (Sharpe, Michalowski, et al., 2022).

Conversely, it was difficult to draw any conclusions about the relationship between FORP and other health-related behaviours, largely because most health behaviours were assessed in single studies only. Non-medication related health behaviours appeared to have relationships with FORP that may indicate avoidance of distressing thoughts or stimuli. For instance, FORP was associated with non-adherence to weekly psychotic symptom monitoring using a smartphone app, which may indicate avoidance (Eisner et al., 2019). This is consistent with other research that has demonstrated that people with a substance use disorder are less likely to quit smoking if they believe cessation of smoking will increase their risk of illicit substance use relapse, even when controlling for nicotine and illicit substance dependence (Xie et al., 2021). Here, FORP is associated with a decreased likelihood of engaging with an adaptive health behaviour. However, avoidant changes in health behaviour are arguably best exemplified by women who feared the recurrence of a postpartum mental health issue choosing to avoid further pregnancies by undergoing medical procedures, or adopting another child (Peindl et al., 1995). Although there was a paucity of research on non-medication related behaviours, health behaviours and their association with FORP are worthy of further examination, particularly because those health behaviours can have enormous impacts on people's lives.

There was only a single prospective study that examined FORP as a predictor of future relapse in psychosis. This study found that FORP predicted a shorter time to relapse, even when controlling for early warning signs of psychosis (Gumley et al., 2015). This is supported by the finding elsewhere that higher FORP predicts higher FORP the following day, even when controlling for some early warning signs (Allan et al., 2023). Lastly, one other study in people with psychosis found cross-sectional relationships between FORP and number of lifetime psychiatric admissions (White & Gumley, 2009), but the causal direction of that relationship is unclear. Further in depression, only one of two cross-sectional studies demonstrated that those with recurrent depression reported greater FORP than those with a lifetime single episode of depression (Kirk et al., 2000). However, longitudinal research determining whether high levels of FORP are a risk factor for mental health relapse is needed.

Interestingly, no study with available data reported a significant association between FORP and gender. This is surprising given that women, on average, report and demonstrate higher levels of fear and anxiety than men, particularly after gendered socialization factors begin to differentially affect people (McLean & Anderson, 2009). Similarly, age had no relationship with FORP. However, the age distributions of these three studies indicate that few older adults (those aged over 65) were sampled. Hence, variance in FORP due to age may emerge in future research that samples those aged under 18 and those over 65.

3.3. Convergence between qualitative and quantitative findings

Overall, the quantitative findings are congruent with the model developed through meta-synthesis. Specifically, higher levels of FORP are associated with distress and poorer mental health outcomes, including increased anxiety and post-traumatic stress symptoms. There was also quantitative evidence to support the notion that FORP leads to a low-risk, low-reward lifestyle. There was clear evidence of increased medication adherence in those with higher FORP, which may be adaptive or maladaptive depending on the context. However, there was quantitative evidence of avoidance of situations that may be triggering but are nevertheless valued, such as expanding one's family, which are consistent with the low-risk, low-reward lifestyle (Peindl et al., 1995). Further, FORP was associated with potentially adaptive behaviours, such as monitoring early-warning signs of psychosis (Eisner et al., 2019). There was strong evidence that higher FORP was associated with worse quality of life, which would be expected if FORP was associated with impairment in functioning across physical, mental, and social domains.

3.4. Theoretical implications

From the current qualitative study, we developed a transdiagnostic framework, described above, to understand FORP. Our model shares a number of similarities with the schizophrenia fear of relapse framework (Zukowska et al. (2022). Specifically, both models note the role of past trauma within mental healthcare settings as a major trigger for the fear of future traumatization. Similarly, both models note that concerns about loss of function, and the resulting social avoidance, triggered by FORP, may inadvertently increase vulnerability to mental health deterioration. Furthermore, our model is also congruent with the cognitive-interpersonal model of early warning signs of psychosis which proposes that hypervigilance and avoidance may be used to cope with fear of psychotic relapse (Gumley et al., 2020). However, the present review extends these previous frameworks. Both the schizophrenia fear of relapse framework and the cognitive-interpersonal model are psychosis-specific models, whereas the current model is proposed to be transdiagnostic. Aside from fear of death, all themes and subthemes were accounted for by studies of people without psychosis, as well as those with psychosis, supporting the likely transdiagnostic nature of the observed constructs.

Moreover, the present meta-synthesis identified ways in which some level of FORP may be adaptive for people with a history of mental health conditions, which differs from Zukowska et al. (2022), but has long been acknowledged in the fear of cancer recurrence literature (Almeida et al., 2019; Lee-Jones et al., 1997). For FORP in mental health, increased adherence to medication appears to be one such potentially adaptive consequence of FORP, which was borne out in both qualitative and

quantitative analyses. Similarly, vigilance towards early warning signs of deterioration, such as sleep disturbances, anhedonia, and irritability, may facilitate early intervention, even though when vigilance becomes hypervigilance it can exacerbate anxiety and have negative impacts. Despite this, the quantitative analyses were clear that more severe levels of FORP were associated with increased depression, anxiety and poorer quality of life for people with a range of different disorders. This raises questions about where on a continuum of FORP the level that might be optimally associated with benefits, and whether this is dependent on the context (e.g. the severity of mental health issue), the time since last episode (e.g. likelihood of relapse) or other factors (e.g. the personal values of the individual). Nevertheless, the data linking high levels of FORP and negative psychosocial outcomes support the view that FORP is unhelpful when severe.

Given the relevance of FORP to a range of mental health conditions, the present review raises questions about how other theoretically related constructs may overlap with FORP. For instance, most contemporary conceptualisations of substance use disorders distinguish between a lapse, such as an abstinent person consuming one beer, and a relapse, the resumption of regular uncontrolled drinking. The abstinence violation effect (Marlatt & Gordon, 1985) could be viewed as a cognitive and affective response to having a lapse, based on the belief that a lapse is tantamount to a relapse. This abstinence violation effect has been found to predict relapse in people who smoke cigarettes (Curry, Marlatt, & Gordon, 1987), socially drink (Collins & Lapp, 1991), and binge eat (Grilo & Shiffman, 1994). It seems plausible that FORP may predict the abstinence violation effect. That is, those most fearful of a relapse are those most likely when confronted by a lapse, to believe that a relapse is inevitable. That fear may drive continued drinking, substance use, or binging behaviour. It remains possible that a similar process may account for the finding that FORP predicts actual relapse in people with a schizophrenia-spectrum disorder, even when controlling for early signs and symptoms of psychosis (Gumley et al., 2015).

The present review was exclusively focused on FORP within people who have lived experience of a mental health condition. However, fears of recurrence may also be experienced by carers and loved ones who have not themselves been diagnosed with the condition. Caregivers of people with cancer are known to also report FCR, and may even report greater FCR than the patients they care for (Braun, Aslanzadeh, Thacker, & Loughan, 2021). A recent systematic review of qualitative research on FCR in carers found that whilst the experience of FCR was similar to that of survivors, the carers' experience was uniquely characterized by their assumed role as a 'protector' of the person they cared for (Webb et al., 2022). Just like in cancer, there is evidence suggesting that friends and family of those with a mental health condition also experience FORP. Research on the family of people who recovered from first episode psychosis found that FORP was a common concern of carers, and that they had little confidence in their ability to identify and cope with future relapses (Lal et al., 2019). Similarly, carers of people with a schizophrenia-spectrum disorder reported FORP and a sense of responsibility over the individual's medication adherence (Kelly et al., 2021). Lastly, family members of women with post-partum psychosis also report FORP and vigilance towards signs of relapse, and that FORP was a factor in family planning decisions regarding future pregnancy (Forde et al., 2019).

Beyond caregivers, mental health professionals involved in the care of those who experience mental health conditions may also worry about recurrence or progression. Whilst some processes, such as (hyper)vigilance, may still be a factor for them, FORP is likely to be experienced and manifest in ways unique to that role, as with carers (Webb et al., 2022). Qualitative research has found that in community mental health settings the different perspectives of psychosis patients, carers, and mental health professionals informs the way they monitor and respond to early warning signs of psychosis (Allan et al., 2020). Whilst all parties are concerned with preventing relapse, some patients may privilege autonomy and reduction in side effects over clinical stability, in contrast to the priorities of some mental health professionals. This has implications for treatment decision making and the application of enforced treatment, which may also be relevant to other conditions where there is high risk for involuntary or coercive treatment, such as in high suicidality, mania, or anorexia nervosa. However, the role of mental health professionals, and thus the interactions between them, carers, and service users with regards to FORP, may differ in clinical settings where this is less of a concern. Whilst the experience of carers and mental health professionals was beyond the scope of the present review, research on these groups and the interactions between them remains an important avenue of future research and may present opportunities for systemic interventions for FORP and shared clinical decision making.

3.5. Clinical implications

Based on the findings of this mixed-methods review, it is evident that some people with lived experience of a mental health condition experience FORP. Importantly, these fears are not limited to people with a history of psychosis. People with a range of different diagnoses experience FORP, and thus, may also experience increased distress and an impact on their quality of life, even when they are technically recovered. Indeed, there was some evidence of health-related behaviours, such as reproductive decision-making, that were impacted long after the mental health condition had abated and when the risk of recurrence was objectively low – there is some evidence that prophylactic medication use can decrease the risk of post-partum mania and psychosis (Bergink et al., 2012). Whilst this review cannot establish the direction of causality, it is evident from those findings, and the findings of the meta-synthesis, that FORP is associated with significant distress. Hence, the risk of FORP negatively impacting the lives of people after intervention should be considered in clinical practice, particularly during discharge planning, when one might expect FORP to be high. Indeed, it may be that explicitly addressing FORP as part of relapse prevention would be very useful therapeutically.

Despite this, there is a paucity of research on interventions for FORP. The authors are aware of three studies that reported on interventions that purportedly targeted fear of relapse in people with a schizophrenia-spectrum disorder, only one of which significantly reduced FORP. Both a 16-session group compassion-focused therapy program with integration of mindfulness skills (Braehler et al., 2013), and an 8-session early warning signs and emotion regulation group program (Ryan et al., 2021) did not significantly reduce FORP between baseline and end of treatment. Whilst Braehler et al. (2013) compared compassion-focused group therapy with treatment-as-usual, Ryan et al. (2021) lacked any control group and still did not demonstrate a reduction in FORP despite a reduction in clinician-rated psychotic symptoms. Hence, neither approach is likely efficacious for treating FORP in people with schizophrenia. To our knowledge, only one study has successfully demonstrated a reduction in FORP in people with schizophrenia. Gumley et al. (2022) compared EMPOWER, an intervention that combined peer and clinician support with self-reported daily early warning signs monitoring via a smartphone app, to treatment-as-usual in a RCT over 12 months and found a moderate reduction in fear of relapse in the EMPOWER group compared to treatment-as-usual.

However, such interventions need to be sensitive to any potential benefits that may be associated with some level of FORP. Increased medication adherence was associated with FORP in both quantitative and qualitative studies in the present review. It has also been reported that medication adherence can be a response to fear of chronic physical illness progression (Sharpe, Michalowski, et al., 2022). In many situations, adherence to psychotropic medication is protective. As an example, anti-psychotic medications are generally effective at reducing the symptoms of schizophrenia, especially positive symptoms and the risk of psychosis relapse (Haddad & Correll, 2018; Leucht et al., 2012). However, these drugs are associated with significant side effects, including cardiac disease, tardive dyskinesia, and diabetes (De Hert,

Detraux, Van Winkel, Yu, & Correll, 2012). Hence, people with a schizophrenia-spectrum condition may weigh the perceived positive effects (e.g., relapse prevention) against the perceived deleterious effects (e.g., metabolic syndrome), with many reluctantly accepting long-term medication despite endorsing a desire to reduce or cease anti-psychotic medication with professional support (Crellin et al., 2022). This is important as long-term use of anti-psychotic medication is intended to prevent relapse. However, a systematic review of relapse definitions used in randomised-controlled trials of anti-psychotics in people with a schizophrenia-spectrum condition found that these definitions varied greatly and may capture false positives (Moncrieff, Crellin, Long, Cooper, & Stockmann, 2020). There was no consensus for when symptom change constitutes a psychotic relapse, most trials in the review did not specify a minimum duration of symptoms, and/or did not require the presence of positive symptoms alongside functional decline. This, alongside the potential for rebound psychosis or a withdrawal syndrome following cessation of anti-psychotic medication (Chouinard et al., 2017), may confound estimates of relapse prevalence and consequently overestimate the utility of long-term anti-psychotics for reducing relapse risk. Similarly, a Cochrane review of randomised controlled trials comparing discontinuation and continuation of anti-depressants in people with depressive or anxiety disorders who have recovered found that there is a lack of evidence to support long-term continuation of antidepressants, as they may not prevent relapse (Van Leeuwen et al., 2021). All medications have side-effects, and even newer anti-depressants are associated with a myriad of potential side-effects (Carvalho, Sharma, Brunoni, Vieta, & Fava, 2016). If medication is being continued "just in case", many individuals will be experiencing side effects without any clear benefit of continued medication. Indeed, one of the studies included in the present review found that FORP was the most significant barrier to discontinuation of antidepressants in people who were, but are no longer, indicated to be using them (Eveleigh et al., 2019). In clinical practice careful consideration of FORP and the ways in which it positively and negatively impacts psychosocial outcomes and adherence is important, and intervening with FORP could improve quality of life, as long as the complexities are considered.

While the data in this review provides a strong case for the need for clinical intervention for those with a higher degree of FORP, based on the literature, there is limited evidence for interventions that can reliably reduce FORP, especially outside the schizophrenia-spectrum, in the context of mental health. Tauber et al. (2019) conducted a meta-analysis of treatment trials to reduce fear of cancer recurrence. They found both traditional cognitive-behavioural therapy (CBT) and contemporary CBT (e.g., mindfulness, acceptance and commitment therapy) were efficacious in the management of FCR, although contemporary CBT resulted in larger gains than traditional CBT. Given some similar constructs observed in FORP in the context of mental health in the current review, adapting contemporary CBT approaches may be a worthwhile approach for future research.

3.6. Limitations

Firstly, due to the heterogeneity of the included studies, it was not possible to conduct a meta-analysis. Studies varied in the nature of the sample (e.g., type of mental health condition), measure of FORP, and measures of psychosocial outcomes. Indeed, some of the correlations between variables, such as measures of FORP and depression or anxiety were very high (e.g., Sired et al., 2021). This raises the question of whether available measures of FORP conflate the fear of progression or recurrence with its consequences, such as distress; or whether some of the constructs, such as anxiety about mental illness, are measuring very similar constructs. The most commonly used measure (i.e. FoRSe), is psychosis-specific and there is currently not a transdiagnostic measure of FORP in the context of mental health, as there is for physical health (i.e., FOPQ, Herschbach et al., 2005). Future research which developed a psychometrically robust measure of FORP in the context of mental health would be welcome. Future research should also investigate the degree of conceptual overlap between similar constructs.

Secondly, none of the identified qualitative studies explicitly aimed to explore FORP. In all included studies, FORP emerged as a theme or subtheme, or could be interpretated from participant quotes, in relation to another construct. The fact that there were no qualitative studies focusing explicitly on FORP meant that we were unable to provide a meta-synthesis of previously identified themes, rather we had to provide a meta-synthesis at the original quotation level. Whilst these results demonstrate the relevance of FORP to people with current or past mental health conditions, as FORP emerged spontaneously from a range of different studies and participants, it may mean that some elements of the impact and nature of FORP were not uncovered within the studies themselves. Hence, future qualitative research explicitly concerned with FORP will be required to attain a richer understanding of the phenomena and provide corroborating evidence for the transdiagnostic model proposed in the current review. Similarly, future research should consider if and how FORP may differ between people with lived experience of different mental health conditions. As a result, while we have proposed a theoretical model of FORP in the context of mental health, further research is required to test the major tenets of the model.

Lastly, the present review sought to explore fears of recurrence *and* progression, consistent with the prevailing definition of fear of cancer recurrence (Lebel et al., 2016). Most of the included studies identified participants who were expressly concerned with fear of acute relapse in the context of schizophrenia-spectrum, post-partum, or puerperal disorders. However, some participants may have had residual symptoms, as Baker (1995) noted that one interviewee declined to be audiotaped due to ongoing paranoia. It is possible that someone with residual symptoms may fear progression of their illness, whereas someone in recovery may be more likely to fear recurrence. This debate between the conceptual overlap of the constructs of fear of progression and fear of recurrence is ongoing in the psycho-oncology literature. It is only recently that this conceptual question has been empirically tested, where fears of cancer recurrence and progression were found to be related but distinct constructs (Coutts-Bain et al., 2022). Future research in FORP in the context of mental health should bear these important conceptual issues in mind.

4. Conclusions

Notwithstanding these limitations, the present review possessed several notable strengths. It is the first systematic review to explore FORP in mental illnesses beyond schizophrenia. We included both qualitative and quantitative analyses, which allowed us to capture a larger number of studies than earlier reviews (e.g. 32 included studies vs nine, Zukowska et al. (2022). The mixed-method approach also allows for a more complete synthesis of available evidence. Hence, this novel, and comprehensive, review provides a foundational body of evidence that answers several key questions regarding FORP and draws attention to clinically relevant gaps in the literature.

The present review has demonstrated that FORP is experienced by a range of people with a history of different mental health conditions. FORP encapsulates fears of symptoms, loss of progress, fears of death and retraumatisation. These fears give rise to two key responses: (1) the adoption of a low risk, low reward approach to life; and (2) mistrust of one's own assessment of one's mental health which in turn gives rise to hypervigilance. FORP was strongly associated with worse mental health symptomology and quality of life in all studies. However, FORP also was associated with increased medication adherence and may be adaptive under certain circumstances. Critically, the identified themes were not just a concern of people with psychosis, all but one of the themes and subthemes were also identified in those with non-psychotic mental health problems. The consistency of themes lends weight to the view that FORP is a transdiagnostic issue.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

No data was used for the research described in the article.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.cpr.2023.102342.

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Appendix B

Appendix B provides additional materials relevant to Chapter 3, including:

Appendix B1:	Basic interview guide
Appendix B2:	Basic coding framework
Appendix B3:	Correlations between FORP and variables of interest
Appendix B4:	Ethics approval.

Appendix B1. Basic interview guide

Interview Questions to Guide the Semi-structured Interviews

To allow the interviewer to be responsive to the context of the interviewees, and their prior responses within the interview, these questions were not asked verbatim. In addition, follow-up questions, not provided here, were asked by the interviewer to clarify meaning and to ensure a deeper understanding of their experience.

- What does fear of recurrence and fear of progression mean to you?
- When did you first notice that you were worried about past mental health conditions coming back, or current conditions getting worse?
- To what extent do you worry about a past mental health condition coming back, or a current condition getting worse?
- How do these fears impact your day-to-day life?
- Is there anything that reduces your fear of recurrence and progression? Is there anything that exacerbates the fear?
- What is the most important thing to understand about fears of recurrence and progression?
- Are there any important things about your fears of recurrence and progression we have not discussed yet?

Appendix B2. Basic coding framework

Theme	Subtheme	Codes
Fear of Recurrence and Progression	Fear of Being Harmed	Discrimination/stigma
		Suicide or self-harm
		Unpleasant or coercive treatment
		Reduced functional capacity
		Being a victim of violent crime
	Fear of Harming Others	Distressing others
		Burdening others
		Physically harming others
	Fear of Isolation	Anticipating loneliness or social isolation
		Loss of existing relationships
In Retrospect	Traumatic Memories	Traumatic memories
		Aversive memories
		Intrusions
	Inability to Trust Oneself	Remembering perceptual disturbances
		Remembering cognitive distortions
		Uncertainty in appraisal of mental wellbeing
Better Safe than Sorry	Vigilance-hypervigilance	Vigilance for mental state fluctuations
		Interpretation of mental state fluctuations
	Reassurance Seeking	Uncertainty in appraisal of mental state fluctuations
		Contacting formal supports (e.g., psychiatrist)
		Contacting informal supports (e.g., family)
	Low-risk, Low-reward Lifestyle	Abstention from alcohol and other drugs
		Avoidance of close relationships
		Changes to family planning
		Avoidance of travel
		Avoidance of occupational opportunities
		Conservative approach to psychological intervention
		Conservative approach to psychiatric intervention

Avoidance	Suppression and Distraction	Suppressing fears of recurrence and progression Suppressing intrusive aversive memories of being unwell Avoidance of stimuli associated with aversive memories
	Metacognitions that Perpetuate FORP	Negative beliefs about worry/FORP Positive beliefs about worry/FORP
Biological Beliefs and Prognostic Pessimism		Drawing analogy to chronic physical illnesses Biochemical imbalance basis Genetic basis Neural basis Perceived lack of personal control Perceived lack of treatment efficacy Perceived inevitability of becoming unwell again
Shame and Perceived Inferiority		Perceived failure in managing mental state Guilt about recurrent relapses despite treatment Expressed shame Upward social comparison

Appendix B3. Correlations between FORP and variables of interest

Variables		1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
1. FORP		-									
2. Biological beliefs		.225**	-								
3. Intrusive thoughts		.460**	.024	-							
ISMI	4. Alienation	.389**	.137*	.430**	-						
	5. Withdrawal	.342**	.089	.478**	.728**	-					
	6. Experienced discrimination	.301**	.065	.432**	.559**	.644**	-				
7. Anticipated discrimination		.256**	.103	.367**	.527**	.616**	.610**	-			
DASS	8. Depression	.454**	.047	.518**	.603**	.547**	.411**	.341**	-		
	9. Anxiety	.324**	.028	.479**	.373**	.370**	.313**	.274**	.464**	-	
	10. Stress	.399**	.111	.554**	.470**	.448**	.403**	.327**	.646**	.596**	-

Note. *p < .05, **p < .001. N = 255

Appendix B4. Ethics Approval.

THE UNIVERSITY OF SYDNEY

Research Integrity & Ethics Administration
HUMAN RESEARCH ETHICS COMMITTEE

Monday, 19 September 2022

Prof Louise Sharpe
Psychology; Faculty of Science
Email: louise.sharpe@sydney.edu.au

Dear Louise,

The University of Sydney Human Research Ethics Committee (HREC) has considered your application.

I am pleased to inform you that after consideration of your response, your project has been approved.

Details of the approval are as follows:

Project No.:	**2022/604**
Project Title:	**Fear of Recurrence and Progression in People with a History of Mental Health Issues Expression of Interest and Interview**
Authorised Personnel:	**Sharpe Louise; Coutts-Bain Daelin; Hunt Caroline;**
Approval Period:	**19/09/2022** to **19/09/2026**
First Annual Report Due:	**19/09/2023**

Documents Approved:

Date Uploaded	Version Number	Document Name
02/09/2022	Version 2	Survey printout v2
02/09/2022	Version 2	Participant Information Statement v2
02/09/2022	Version 1	Interview Guide
02/09/2022	Version 2	Recruitment E-mail v2
02/09/2022	Version 2	Consent Form v2
29/07/2022	Version 1	Phone script and email template for post-EOI contact

Note

- Remember to insert the ethics protocol number (2022/604) into the final paragraph of the participant information statement, and in the footer of any documents (participant information statement, consent form, etc.) that participants can download or receive electronically or in paper copy.

Condition/s of Approval

- Research must be conducted according to the approved proposal.
- An annual progress report must be submitted to the Ethics Office on or before the anniversary of approval and on completion of the project.
- You must report as soon as practicable anything that might warrant review of ethical approval of the project including:
  - Serious or unexpected adverse events (which should be reported within 72 hours).
  - Unforeseen events that might affect continued ethical acceptability of the project.
- Any changes to the proposal must be approved prior to their implementation (except where an amendment is undertaken to eliminate *immediate* risk to participants).

THE UNIVERSITY OF SYDNEY

- Personnel working on this project must be sufficiently qualified by education, training and experience for their role, or adequately supervised. Changes to personnel must be reported and approved.
- Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, as relevant to this project.
- Data and primary materials must be retained and stored in accordance with the relevant legislation and University guidelines.
- Ethics approval is dependent upon ongoing compliance of the research with the *National Statement on Ethical Conduct in Human Research*, the *Australian Code for the Responsible Conduct of Research*, applicable legal requirements, and with University policies, procedures and governance requirements.
- The Ethics Office may conduct audits on approved projects.
- The Chief Investigator has ultimate responsibility for the conduct of the research and is responsible for ensuring all others involved will conduct the research in accordance with the above.

This letter constitutes ethical approval only.

Please contact the Ethics Office should you require further information or clarification.

Sincerely,

[redacted]

Associate Professor Carolyn Maccann
Chair
Psychology Review Committee (Low Risk)

The University of Sydney of Sydney HRECs are constituted and operate in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2018) and the NHMRC's Australian Code for the Responsible Conduct of Research (2018)

Appendix C

Appendix C provides additional materials relevant to Chapter 4, including:

Appendix C1:	Initial item pool
Appendix C2:	Demographics of the EFA and CFA sub-samples
Appendix C3:	Parallel analysis and scree plot
Appendix C4:	16-item EFA
Appendix C5:	Item inter-correlations for the 10-item FORP-MHQ
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Appendix C1. Initial item pool

1. I worry that I will become unwell again.
2. I am disturbed by the possibility that my symptoms will get worse over time.
3. I am disturbed by thoughts or images about becoming unwell again.
4. When I imagine what could happen if I became unwell again, I feel quite distressed.
5. When I remember the times where I have been unwell, I become fearful of becoming unwell again.
6. I can’t stop thinking about, or imagining, becoming unwell again.
7. When I worry about becoming unwell again it’s hard to focus on what I am doing.
8. Worrying about the consequences of getting unwell again takes over my mind.
9. I find myself thinking about the terrible things that might happen if I get unwell again.
10. If I got unwell again, I fear it would be worse than it was before.
11. I worry that getting unwell again will ruin my life, or the life of other people.
12. When I get upset about becoming unwell again, becoming unwell and what might happen afterwards, seems like one of the worst things that could possibly happen.
13. I feel anxious when I think about the possibility of getting unwell in the future.
14. Fear of becoming unwell again lingers in the back of my mind.
15. I pay close attention to my symptoms and other signs of getting unwell.
16. I can't help but notice my symptoms and signs, even when they are barely noticeable.
17. I treat certain thoughts, emotions, and feelings in my body as potential signs of being unwell, even if they might be nothing.
18. I carefully monitor my mental state to avoid becoming unwell.
19. I am vigilant to my early signs of becoming unwell.
20. I am vigilant toward things that might cause me stress and make me get unwell.
21. When I notice myself thinking things that I thought when I was unwell, I treat those thoughts as suspicious.

22. When I feel things that I felt while I was unwell, I worry that I am getting unwell again.
23. I notice changes in my mental state before anyone else does.
24. After I am done worrying that I am getting unwell, in hindsight it seems like it was not as bad as I thought.
25. When I notice that I might be getting unwell, I check with others to see what they think.
26. When I notice a change in my symptoms or warning signs, I don't know how worried to be until I ask someone else about them.
27. When I worry about getting unwell again, I keep it to myself.
28. If I'm ever unsure, I rely on people I trust to tell me if I am getting unwell.
29. When I think I might be getting unwell, I ask people who are more objective than me to monitor me or tell me what to do.
30. Other people reassure me that I'm not getting unwell, even when I worry that I am.
31. When I worry about getting unwell again, I ask other people if they are worried about me too.
32. When I notice a warning sign, or change in symptoms, I quickly tell the people that I trust.
33. When I want to do something, but I think it might lead to me getting unwell, I put it off or delay it (this may include getting a job, volunteering, making new relationships, travelling, having children).
34. Even when I want to do something, if it might lead to me getting unwell, I avoid it entirely (this may include getting a job, volunteering, making new relationships, travelling, having children).
35. I do things that I enjoy or that are important to me, even if there is a risk that it might make me unwell.
36. I think it is better to avoid something that might be fun or important to me if it could be so stressful that it might make me unwell.

37. I rely on my treatment plan (e.g., therapy, medication, ECT) and would be very reluctant to change it even if I had been well for a long time.
38. If I think about changing my treatment plan, I get too worried about getting unwell to go through with it.
39. I worry too much about getting unwell again to think about changing my treatment plan.
40. It is not worth the risk of changing my treatment plan or medication dose, even if changing it is what I want.

Appendix C2. Demographics of the EFA and CFA sub-samples

Variables		EFA Group (*N* = 432)		CFA Group (*N* = 433)		Tests of differences
		N	%	N	%	
Gender	Man	70	16.2	67	15.5	X^2 = 2.012, *df* = 3, *p* = .570
	Woman	323	74.8	327	75.5	
	Non-binary	35	8.1	38	8.8	
	Gender fluid	3	<1	1	<1	
	Intersex	1	<1	0	0	
Born in Australia		367	85	367	84.8	X^2 = .006, *df* = 1, *p* = .936
Ethnicity †	Oceanian	150	34.7	150	34.6	X^2 = .001, *df* = 1 , *p* = .980
	North-west European	278	64.4	277	64.0	X^2 = .014, *df* = 1, *p* = .907
	Southern and Eastern European	45	10.4	37	8.5	X^2 = .883, *df* = , *p* = .347
	North-east Asian	15	3.5	10	2.3	X^2 = 1.042, *df* = 1, *p* = .307
	South-east Asian	13	3	16	3.7	X^2 = .314, *df* = 1, *p* = .575
	Southern and Central Asian	3	<1	5	1.2	X^2 = .110, *df* = 1, *p* = .740
	People of the Americas	11	2.5	7	1.6	X^2 = .917, *df* = 1, *p* = .338
	Sub-saharan African	3	<1	3	<1	X^2 = 0, *df* = 1, *p* = .998
	North African and Middle Eastern	5	1.2	8	1.8	X^2 = .696, *df* = 1 , *p* = .404
	Other	2	<1	4	<1	X^2 = .667, *df* = 1, *p* = .414
Educational achievement	Did not complete high school	34	7.9	30	6.9	*Mann-Whitney U* = 90016 *Z* = -.983, *p* = .326
	High school	70	16.2	82	18.9	
	Certificate III, IV, or (advanced) diploma	118	27.3	121	27.9	
	Undergraduate	108	25	115	26.6	
	Postgraduate	102	23.6	85	19.6	
Diagnoses †	Schizophrenia-spectrum	28	6.5	25	5.8	X^2 = .188, *df* = 1, *p* = .664
	Bipolar mood	61	14.1	63	14.5	X^2 = .032, *df* = 1, *p* = .857
	Unipolar mood	300	69.4	295	68.1	X^2 = .174, *df* = 1, *p* = .676
	Anxiety	314	72.7	303	70	X^2 = .776., *df* = 1, *p* = .378
	Obsessive-compulsive	50	11.6	42	9.7	X^2 = .799, *df* = 1, *p* = .371
	Trauma-stressor related	196	45.4	171	39.5	X^2 = 3.059, *df* = 1, *p* = .080
	Dissociative	19	4.4	11	2.5	X^2 = 2.229, *df* = 1, *p* = .135
	Somatic symptom	1	<1	2	<1	X^2 = .332, *df* = 1, *p* = .564
	Feeding and eating disorders	27	6.3	38	8.8	X^2 = .1.985, *df* = 1, *p* = .159
	Substance use disorder	4	<1	1	<1	X^2 = 1.817, *df* = 1, *p* = .178
	Personality disorder	54	12.5	79	18.2	X^2 = 5.485, *df* = 1, *p* = .019
Source of diagnoses †, ‡	Psychologist	294	68.1	294	67.9	X^2 = .002, *df* = 1, *p* = .960
	Psychiatrist	295	68.3	298	68.8	X^2 = .029, *df* = 1, *p* = .865
	General practitioner	237	54.9	239	55.2	X^2 = .010, *df* = 1, *p* = .921

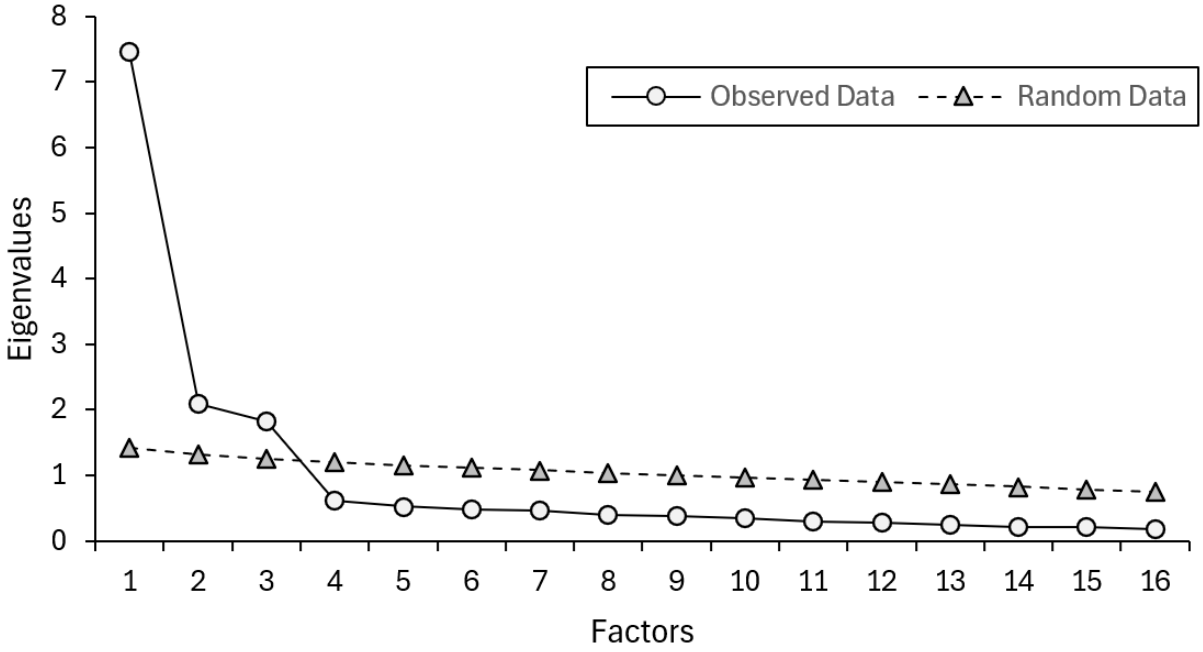
Variables		EFA Group (*N* = 432)		CFA Group (*N* = 433)		Tests of difference
		N	%	N	%	
Neurodevelopmental diagnoses †	Autism	62	14.4	65	15	X^2 = .075, *df* = 1, *p* = .784
	ADHD	108	25	116	26.8	X^2 = .361, *df* = 1, *p* = .548
	Specific learning disorders	8	1.9	17	3.9	X^2 = 3.315, *df* = 1, *p* = .069
History of chronic physical illness		250	57.9	212	49	X^2 = 4.069, *df* = 1, *p* = .044
History of psychiatric inpatient admission		167	38.7	172	39.7	X^2 = .103, *df* = 1, *p* = .748
Not currently using medication		113	26.2	113	26.1	X^2 = 0, *df* = 1, *p* = .984
Current medication †	Antipsychotics	86	19.9	105	24.2	X^2 = 2.370, *df* = 1, *p* = .124
	Mood stabilisers/anti-convulsants	77	17.8	69	15.9	X^2 = .538, *df* = 1, *p* = .463
	SSRIs	144	33.3	127	29.3	X^2 = 1.776, *df* = 1, *p* = .183
	SNRIs	99	22.9	94	21.7	X^2 = .164, *df* = 1, *p* = .685
	Tricyclic antidepressants	22	5.1	19	4.4	X^2 = .225, *df* = 1, *p* = .635
	Tetracyclic antidepressants	15	3.5	32	7.4	X^2 = 6.702, *df* = 1, *p* = .010
	MAOIs	1	<1	4	<1	X^2 = 1.824, *df* = 1, *p* = .177
	Benzodiazepines	50	11.6	48	15.2	X^2 = .041, *df* = 1, *p* = .839
	Alpha and beta blockers	19	4.4	17	3.9	X^2 = .121, *df* = 1, *p* = .728
	Medical cannabinoids	10	2.3	8	1.8	X^2 = .222, *df* = 1, *p* = .637
	Others	82	19	82	18.9	X^2 = 0, *df* = 1, *p* = .987

Note: † Multiple options selectable. ‡ Refers to diagnosis of mental health conditions, not neurodevelopmental conditions.

In regards to age, the EFA group (mean = 39.46, SD = 14.943) and CFA group (mean = 38.19, SD = 13.912) did not significantly differ, $t(863) = 1.293$, $p = .108$.

In regards to the number of lifetime diagnoses, the EFA group (mean = 2.58, SD = 1.187) and the CFA group (mean = 2.50, SD = 1.135) did not significantly differ, $t(863) = 1.012$, $p = .840$.

Appendix C3. Parallel analysis and screen plot



Note. Parallel analysis suggests factors should be retained when the observed data eigenvalue is greater than the corresponding random data eigenvalue.

Appendix C4. 16-item EFA

	Items	Factor loadings		
		I	II	III
1	I worry that I will become unwell again	**.798**	.085	.039
2	I am disturbed by thoughts or images about becoming unwell again	**.790**	-.001	-.018
3	When I imagine what could happen if I become unwell again, I feel quite distressed	**.744**	-.053	-.007
4	I can't stop thinking about, or imagining, becoming unwell again	**.835**	.041	-.026
5	When I worry about becoming unwell again it's hard to focus on what I am doing	**.732**	-.078	-.041
6	Worrying about the consequences of getting unwell again takes over my mind	**.801**	.003	-.022
7	I find myself thinking about the terrible things that might happen if I get unwell again	**.839**	-.022	-.051
8	If I got unwell again, I fear it would be worse than it was before	**.784**	.115	.036
9	When I get upset about becoming unwell again, becoming unwell and what might happen afterwards, seems like one of the worst things that could possibly happen	**.699**	-.077	-.060
10	I feel anxious when I think about the possibility of getting unwell in the future	**.713**	-.141	-.026
11	I can't help but notice my symptoms and signs, even when they are barely noticeable	.282	**-.514**	-.085
12	I carefully monitor my mental state to avoid becoming unwell	-.017	**-.907**	-.010
13	I am vigilant to my early signs of becoming unwell	-.062	**-.916**	.045
14	If I think about changing my treatment plan, I get too worried about getting unwell to go through with it	-.016	.004	**-.823**
15	I worry too much about getting unwell again to think about changing my treatment plan	-.019	.000	**-.912**
16	It is not worth the risk of changing my treatment plan or medication dose, even if changing it is what I want	.019	.026	**-.847**
	Eigenvalues	7.451	2.099	1.819
	% of variance accounted for	46.568	13.119	11.371
	Factor correlations	I	II	III
	I	-		
	II	-.350	-	
	III	-.370	.239	-

Appendix C5. Item inter-correlations for the 10-item FORP-MHQ

	Inter-correlations between items									
	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.
1. I worry that I will become unwell again	-	.678	.578	.625	.529	.551	.634	.567	.534	.590
2. I am disturbed by thoughts or images about becoming unwell again		-	.624	.702	.564	.603	.638	.587	.601	.593
3. When I imagine what could happen if I became unwell again, I feel quite distressed			-	.619	.578	.558	.629	.563	.609	.659
4. I can't stop thinking about, or imagining, becoming unwell again				-	.663	.702	.669	.626	.596	.572
5. When I worry about becoming unwell again it's hard to focus on what I am doing					-	.742	.627	.511	.576	.637
6. Worrying about the consequences of getting unwell again takes over my mind						-	.714	.568	.577	.613
7. I find myself thinking about the terrible things that might happen if I get unwell again							-	.628	.615	.624
8. If I got unwell again, I fear it would be worse than it was before								-	.541	.543
9. When I get upset about becoming unwell again, becoming unwell and what might happens afterwards seems like one of the worst things that could possibly happen									-	.643
10. I feel anxious when I think about the possibility of getting unwell in the future										-

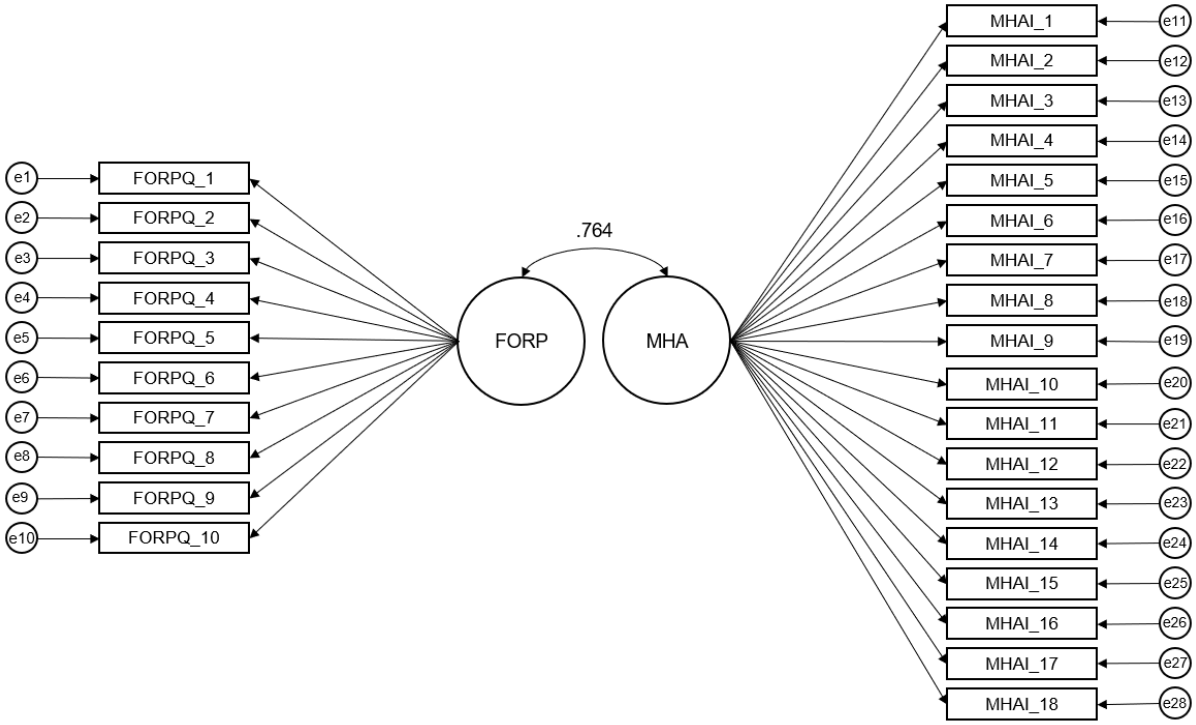
Note. Analyses conducted in the EFA sub-sample (N = 432).

Appendix C6. Item-total statistics for the 10-item FORP-MHQ

	Corrected Item-Total Correlation	Cronbach's Alpha if item deleted
1. I worry that I will become unwell again	.722	.934
2. I am disturbed by thoughts or images about becoming unwell again	.768	.932
3. When I imagine what could happen if I became unwell again, I feel quite distressed	.742	.933
4. I can't stop thinking about, or imagining, becoming unwell again	.800	.930
5. When I worry about becoming unwell again it's hard to focus on what I am doing	.750	.932
6. Worrying about the consequences of getting unwell again takes over my mind	.780	.931
7. I find myself thinking about the terrible things that might happen if I get unwell again	.800	.930
8. If I got unwell again, I fear it would be worse than it was before	.701	.935
9. When I get upset about becoming unwell again, becoming unwell and what might happen afterwards seems like one of the worst things that could possibly happen	.725	.934
10. I feel anxious when I think about the possibility of getting unwell in the future	.752	.932

Note. Cronbach's alpha for the 10-item FORP-MHQ is α = .939. Analyses conducted within the EFA sub-sample (*N* = 432).

Appendix C7. Discriminant validity analysis in AMOS



Note. The latent factor of fears of recurrence and progression (FORP) was assessed with the FORP-MHQ severity subscale. The latent factor of mental health anxiety (MHA) was assessed with the MHAI. The 95% confidence interval of the correlation between the FORP and MHA latent factors was .729 – .797.

Appendix C8. Final version of 10-item FORP-MHQ

Final version of the FORP-MHQ

Instructions:

It is natural for people who have lived with mental health issues to worry that they may come back or get worse. However, some people worry about it more than others.

Below is a list of statements related to your mental health and worries you might have about issues recurring, relapsing, or getting worse in the future. Please indicate how much each statement has applied to you over the past month.

Some of the statements below refer to being or becoming “unwell”. In this questionnaire, "unwell” refers to your mental health getting worse because of a relapse, recurrence, or progression of the issues.

Items:

1. I worry that I will become unwell again
2. I am disturbed by thoughts or images about becoming unwell again
3. When I imagine what could happen if I become unwell again, I feel quite distressed
4. I can’t stop thinking about, or imagining, becoming unwell again
5. When I worry about becoming unwell again it’s hard to focus on what I am doing
6. Worrying about the consequences of getting unwell again takes over my mind
7. I find myself thinking about the terrible things that might happen if I get unwell again
8. If I got unwell again, I fear it would be worse than it was before
9. When I get upset about becoming unwell again, becoming unwell and what might happen afterwards, seems like one of the worst things that could possibly happen
10. I feel anxious when I think about the possibility of getting unwell in the future

Response options:

0 (Never), 1 (Rarely), 2 (Sometimes), 3 (Often), 4 (Very Often)

Appendix C9. Published manuscript.

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ARTICLE

Validation of a transdiagnostic measure of fears of recurrence and progression about mental health conditions

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Abstract

Objectives: Fears of recurrence and progression (FORP) in people with mental health conditions are understudied despite predicting poorer psychological outcomes and increased rates of relapse. However, there are no well-validated questionnaires that assess FORP in people with non-psychotic conditions. Moreover, it is not known whether FORP is empirically distinct from mental health anxiety.

Design: Online survey collected data at two time points.

Method: A 40-item FORP About Mental Health Questionnaire (FORP-MHQ) was derived from lived experience interviews. Analyses were conducted with a sample of 865 people with different mental health conditions. Exploratory factor analysis in a randomly split subsample ($N = 432$) yielded a 10-item, single-factor structure that measures FORP severity. Confirmatory factor analysis on these items was conducted in the remaining sample ($N = 433$). Discriminant and convergent validity, and reliability, analyses were conducted in the complete sample. Measurement invariance was assessed between men and women, those with and without a history of psychosis or mania, and those with and without diagnoses across different diagnostic categories.

Results: The 10-item FORP-MHQ demonstrated good structural, convergent and concurrent validity, internal consistency, and test–retest reliability. It was also empirically distinct from mental health anxiety with good discriminant validity. The FORP-MHQ was invariant between men and women, those with and without a history of psychosis or mania, and those with and without diagnoses across diagnostic categories.

Conclusion: The FORP-MHQ is a valid and reliable tool to assess FORP in people with a range of different mental health conditions, both psychotic and non-psychotic.

KEYWORDS
fear of progression, fear of recurrence, mental health, questionnaire, validation

BACKGROUND

Some people with lived experience of chronic illness worry about the possibility that their illness could recur or worsen over time (Sharpe et al., 2023). This concept is particularly well-studied in relation to cancer, where fear of cancer recurrence is understood as a natural and potentially adaptive response to having lived with cancer (Lee-Jones et al., 1997). Nevertheless, fear of cancer recurrence can become chronic, distressing and, when severe, is associated with poorer psychological outcomes and maladaptive disturbances in health behaviours (Simard et al., 2013). Fears of recurrence and progression (FORP) are also relevant to those who live with other chronic illnesses and are similarly associated with poorer psychological outcomes and quality of life (Sharpe et al., 2023). However, research on FORP in relation to people with mental health conditions is comparatively nascent. Drawing on the prevailing definition of fear of cancer recurrence (Lebel et al., 2016), we define mental health-related FORP as a fear, worry or concern that one's mental health conditions may recur or worsen with time.

Recently, a transdiagnostic model of FORP in people with mental health conditions was proposed based on a grounded theory study (Coutts-Bain et al., 2025). The resulting model postulates that intrusive aversive memories of being mentally unwell fuel expectations for the future, leading to increases in FORP. In addition, these memories remind people of the cognitive and perceptual distortions associated with being mentally unwell. These reminders elicit an inability to trust one's own appraisal of their mental status, even if relatively well, further exacerbating FORP. In response to FORP, people adopt a 'better safe than sorry' approach to managing their mental health conditions which may involve: (1) interpreting ambiguous or mild fluctuations in their mental state as predictive of deterioration, and thus threatening, thereby driving vigilance towards them; (2) asking others whether these fluctuations indicate mental deterioration and (3) avoiding life stressors and other precipitants of deterioration whilst adhering to treatment. These strategies may be adaptive, but they can also result in hypervigilance, reassurance seeking and avoidance of stressful but nevertheless valued personal and social activities, respectively. These factors then inadvertently perpetuate FORP and increase the risk of deterioration by causing distress and reducing access to protective buffers.

Coutts-Bain et al. (2025) tested some of these proposed relationships in a large sample ($N = 269$) finding evidence to support them. Furthermore, the findings of the most recent systematic review of FORP in relation to mental health were generally consistent with the model (Coutts-Bain, Sharpe, Techakesari, et al., 2023). Specifically, FORP was associated with poorer psychological outcomes, including greater depression, anxiety and symptoms of post-traumatic stress, as well as increased medication adherence. Additionally, one study demonstrated that FORP predicts a shorter time to psychosis relapse in people with a schizophrenia spectrum condition, even when controlling for early warning signs of psychosis (Gumley et al., 2015). Hence, there is emerging evidence that FORP is an important construct in understanding the overall burden of lived experience of mental health conditions and in predicting relapse.

However, further study of FORP in people with mental health conditions is presently limited by a paucity of appropriate measurement tools. In their systematic review, Coutts-Bain, Sharpe, Techakesari, et al. (2023) briefly reported on the different measures of FORP they had identified in the literature. Many of these were unvalidated single-item measures, and most FORP questionnaires, including the Self-Appraisal Questionnaire fear of recurrence subscale (Coyne & Calarco, 1995) and the Worries About Mental Health Questionnaire (Bassett et al., 2009), were not well validated and had not undergone

structural validation through factor analysis. Hence, the degree to which these questionnaires are valid and reliable measures of FORP is unknown. The only FORP questionnaire with a published validation study was the Fear of Recurrence Scale (FoRSe) (Gumley & Schwannauer, 2006), which was designed to assess fear of psychosis relapse in people with schizophrenia spectrum conditions, although this only involved exploratory factor analysis and did not confirm the factor structure in a second sample (Gumley et al., 2015). Hence, to the authors' knowledge, there are no demonstrably valid and reliable measures of FORP for people with more common, but nevertheless potentially serious, non-psychotic conditions. This is a significant gap in the literature as people with disordered eating, anxiety, obsessive–compulsive and mood conditions also experience FORP (Coutts-Bain et al., 2025; Gumuchian et al., 2024).

The paucity of well-validated measures of FORP also draws attention to a significant conceptual issue, that is, the potential overlap between FORP and mental health anxiety – defined as worry about developing a condition one has not previously experienced (Rachman, 2012). A similar distinction has previously been drawn between fear of cancer recurrence and health anxiety (Mutsaers et al., 2020). However, if FORP and mental health anxiety are essentially equivalent constructs, research treating FORP as distinct may obscure the true relations between variables of interest and unnecessarily consume resources as researchers retread old ground. To avoid such construct redundancy, we must ensure that newly proposed psychological constructs are distinct from previously established constructs (Hodson, 2021). Conceptually, one might expect that lived experience of being mentally unwell makes FORP potentially qualitatively different from mental health anxiety. Those with conditions that are marked by frequent recurrences, such as those with bipolar conditions, depression or schizophrenia, contend with a lifelong increased risk of recurrence and the possibility of worsening residual symptoms (McCutcheon et al., 2020; McIntyre et al., 2020). Whilst typically transitory conditions, such as major depression, are similarly associated with increased risk of recurrence even after treatment (Wojnarowski et al., 2019). Despite this conceptual argument, whether two constructs can be distinct in measurement remains an empirical question (Hodson, 2021), one that is yet to be answered as the only published validation of a FORP questionnaire, that is, the FoRSe, did not examine discriminant validity with mental health anxiety (Gumley et al., 2015). This raises concerns about potential construct redundancy, particularly as the FoRSe is strongly correlated with mental health anxiety (Coutts-Bain, Sharpe, Techakesari, et al., 2023).

The present study aimed to address these gaps in the literature by developing and validating a new transdiagnostic measure of FORP suitable for individuals diagnosed with both psychotic and non-psychotic mental health conditions: the Fears of Recurrence and Progression About Mental Health Questionnaire (FORP-MHQ). The initial FORP-MHQ item pool was intended to assess FORP. We aimed to conduct an exploratory factor analysis (EFA) and confirmatory factor analysis (CFA) to assess the structural validity of the FORP-MHQ. We expected that the FORP-MHQ would possess good convergent validity (i.e. strong correlations with other measures of FORP), good discriminant validity (i.e. a non-redundant association with mental health anxiety) and good concurrent validity (i.e. associations with theoretically related variables, such intrusive memories of being mentally unwell, belief that one's condition is permanent and difficult to control, depression and anxiety). Measurement invariance analyses were conducted to determine whether the FORP-MHQ was measuring FORP invariantly across those with and without a history of psychosis/mania, and those with and without diagnoses spanning multiple diagnostic categories, to further explore transdiagnostic applicability. Lastly, analyses to evaluate the internal consistency and 28-day test–retest reliability were conducted to assess the reliability of the FORP-MHQ.

METHOD

Phase I: Development of items

Development of the FORP-MHQ was informed by the COSMIN Study Design checklist for patient-reported outcome instruments (Mokkink et al., 2019). The initial FORP-MHQ item pool was derived from prior interviews of people with lived experience of mental health conditions, both psychotic and

non-psychotic, who experienced FORP (Coutts-Bain et al., 2025). Quotations from these interviews were analysed by two researchers, one of whom was a clinical psychologist with expertise in clinical health psychology, the other a recent graduate of a clinical psychology programme. This analysis was used to draft 40 prospective FORP-MHQ items. Seven of the interviewees were then reinterviewed to solicit feedback on the items and questionnaire instructions. This feedback was used to improve the clarity of several items; assess the appropriateness of instructions, items and response options; and set the recall period to 1 month. All interviewees stated that this timeframe allowed them to give the most accurate assessment of their experience of FORP. According to the SMOG readability criteria (McLaughlin, 1969), this version of the FORP-MHQ was readable by people with an eighth-grade reading level.

Phase II: Validation of the fears of recurrence and progression in mental health questionnaire (FORP-MHQ)

Inclusion criteria

We recruited participants by advertising on social media between June and July 2024. Individuals were eligible to participate if they were at least 18 years old, were proficient in English, currently living in Australia and self-reported being diagnosed with a mental health condition. We considered the possibility of recruiting based on diagnostic interviews, but this was not practical given the large number of participants required for questionnaire validation. Hence, we recruited based on self-report as there is evidence that people can self-report psychiatric diagnoses reasonably reliably (Vieira et al., 2022). In addition, participants were instructed to only list diagnoses they had received from clinicians, to avoid participants reporting self-diagnoses. Moreover, given our interest in the transdiagnostic applicability of the measure, we were primarily concerned with the presence of a diagnosis, rather than the particular diagnosis, per se. Participants diagnosed with neurodevelopmental conditions, such as autism, were not excluded so long as they had also been diagnosed with a mental health condition in addition to their neurodivergence. Participants were excluded if they failed at least one of two instructional manipulation checks, for example, 'Please select "Extremely" for this item' (Oppenheimer et al., 2009). We also examined participant responses for duplicate responding, impossibly fast completion times, as well as extreme responding. This study was approved by The University of Sydney human research ethics committee (2024/HE000454), and all participants provided informed consent.

Measures

Participants were administered demographics questionnaires and the 40 initial items of the FORP-MHQ, including self-reporting which mental health conditions they had received from mental health professionals. To assess convergent validity, the FoRSe (Gumley et al., 2015) and the Worries About Recurrence and Progression Scale (WARPS) (Sharpe et al., 2024), a FORP measure validated in people with physical chronic illnesses, were administered. To assess concurrent validity, the following measures were used: revised Impact of Event Scale (IES-R) was used to assess intrusive memories of being unwell, avoidance and hyperarousal (Weiss & Marmar, 1997). The Generalized Anxiety Disorder-7 (GAD-7) to assess symptoms of anxiety (Spitzer et al., 2006). The Patient Health Questionnaire-9 (PHQ-9) to assess depressive symptoms (Kroenke et al., 2001). The revised Illness Perception Questionnaire (IPQ-R) to assess perceived chronicity, cyclical nature, consequences of condition, personal control and treatment control over one's condition/s (Moss-Morris et al., 2002). In addition, participants who indicated that they were currently using medication to manage their mental health conditions also completed the short-form Medication Adherence Rating Scale (MARS-5) to further examine concurrent validity (Chan et al., 2020). To assess discriminant validity, mental health anxiety was measured with the Mental Health Anxiety Inventory (MHAI) (Commons et al., 2016). As all the participants had lived

experience of mental health conditions the instructions of the MHAI were modified to be appropriate to this context and to ensure it assessed anxiety about conditions individuals had not been diagnosed with. These modifications were as follows: (1) the following instruction was added 'this question refer to mental illnesses you have not been diagnosed with', and (2) we added additional instructions for items 15 to 18, 'think about what it might be like if you had a serious mental illness [added] *that you do not currently* have'. Participants who completed this baseline survey were able to opt in to be contacted regarding a follow-up survey in 28 days which re-administered the FORP questionnaires. Participants were eligible to gain one entry into a draw to win one-of-three $150 gift cards for each survey they completed.

Analyses

We randomly selected half the participants ($N = 432$) from the overall sample to conduct an exploratory factor analysis using SPSS (version 29) software. Factors were extracted using maximum-likelihood extraction with direct oblimin rotation. The number of factors to extract was determined by parallel analysis at the 95th percentile of random eigenvalues bootstrapped using 5000 samples and examination of the scree plot (O'Connor, 2000). In the remaining half of the sample ($N = 433$), we conducted a confirmatory factor analysis using AMOS (version 29) software. To evaluate model fit, the following fit index cut-offs were applied: Good fit was indicated by CFI ≥ .95, TLI ≥ .95, SRMR ≤ .08 and RMSEA ≤ .06, with values closely approaching these cut-offs deemed indicative of acceptable fit (Hu & Bentler, 1999).

To determine whether the FORP-MHQ is measuring FORP equivalently between those with different clinical histories, we conducted two tests of measurement invariance using multi-group CFA to compare: (1) those diagnosed within a single diagnostic category and those with diagnoses across multiple categories, and (2) those with and without a history of mania/psychosis. The first comparison was selected to determine whether the FORP-MHQ was measuring FORP equivalently between those who may fear multiple different conditions recurring or progressing. The second comparison was selected given the existing literature has largely focused on FORP in the context of psychosis, in contrast to the relative lack of research on FORP in non-psychotic conditions, and in light of the overlapping nature of psychosis and mania (Kotov et al., 2021). Lastly, to determine whether the FORP-MHQ is measuring FORP equivalently between those identifying as men and women, we conducted tests of measurement invariance. To evaluate measurement invariance, we used Cheung and Resvold's (2002) cut-off criteria, that is, ΔCFI ≤ .01 as indicating invariance (Cheung & Rensvold, 2002).

After the structural validation of the FORP-MHQ, we assessed others facets of validity and reliability using the complete sample ($N = 865$). To evaluate discriminant validity, we modelled the latent factors underlying the FORP-MHQ and MHAI with a CFA in AMOS. We then constrained the variances of the latent variables, FORP and mental health anxiety, to one, thereby making the covariance of the latent factors equivalent to their correlation. We then assessed discriminant validity by examining the upper limit of the 95% confidence interval of this correlation. For this procedure, an upper limit correlation estimate of $r < .80$ has been proposed to demonstrate good evidence of discriminant validity (Rönkkö & Cho, 2022). This procedure provides a more stringent assessment of discriminant validity than those based on correlations between observed scores as it prevents measurement error from suppressing the magnitude of the correlation. Lastly, to assess reliability we examined internal consistency with Cronbach's alpha and test–retest reliability by correlating FORP-MHQ at baseline with the FORP-MHQ administered 28 days later.

RESULTS

Participants

Nine hundred five participants were recruited. Forty participants were excluded for failing an instructional manipulation check (4.6% of participants). Hence, the final overall sample consisted of

865 participants. On average, participants were 38.82 years of age ($SD = 14.44$, range = 18–82), identified as women (75.1%), most had North-west European ethnicity (64.2%) and a lifetime history of 2.54 mental health condition diagnoses ($SD = 1.16$). See Table 1 for further demographic and clinical information.

Exploratory factor analysis

First, the item-total correlations of the initial 40 items were examined. Thirteen items possessed correlations <.40 and were thus removed, as per recommendations (Clark & Watson, 1995). The communalities of the remaining 27 items were evaluated, two of which were removed as they possessed communalities <.50. Following this, 11 items demonstrated ceiling or floor effects that necessitated their removal. Lastly, the Kaiser–Meyer–Olkin measure of sampling adequacy was .919, and Bartlett's test of sphericity was statistically significant ($X^2 = 4640.90$, df = 120, $p < .001$), indicating that the sample data for the remaining 16 items was suitable for factor analysis (Tabachnick et al., 2013). Parallel analysis of the 16 FORP-MHQ items based on the 95th percentile of random eigenvalues and an analysis of the scree plot both indicated a three-factor structure (see Data S1).

A three-factor EFA was conducted using maximum-likelihood extraction with direct oblimin rotation. Based on item content and factor loadings, these factors represented: (1) FORP severity, (2) vigilance towards fluctuations in mental state and (3) a conservative approach to treatment, respectively. No cross-loadings >.30 were observed. Together, these factors accounted for 71.06% of variance in participant responses to the FORP-MHQ. The factors representing vigilance and a conservative approach to treatment were positively correlated ($r = .239$). Conversely, the factor representing FORP severity was negatively correlated with the factors representing vigilance ($r = -.350$) and a conservative approach to mental health treatment ($r = -.370$). However, as the items loading on factors two and three loaded negatively, they describe the negative poles of these constructs, that is, no vigilance and a non-conservative approach to mental health treatment. This is an artefact of rotation, and thus these negative factor correlations indicate positive relationships between FORP severity, vigilance and a conservative approach to treatment.

However, both vigilance and conservative approach subscales were comprised of three items each, which may be too few to form a reliable factor, as five or more items with strong factor loadings is considered desirable (Costello & Osborne, 2019). Moreover, conceptually, both vigilance and a conservative approach to treatment are theoretically downstream effects of FORP, they are not FORP per se. This is important as including the consequences of a primary construct of interest in a questionnaire can create conceptual confusion as to what precisely is being assessed, particularly when the total score of a questionnaire may be used in clinical or research settings (Costa et al., 2016). Hence, on both psychometric and conceptual grounds, these two subscales were deleted, resulting in a final 10-item version of the FORP-MHQ which purely assessed FORP severity (Table 2). Excluding more marginal factors in this manner can be appropriate to ensure a questionnaire is parsimonious, reliable and more conceptually coherent (Tabachnick et al., 2013).

Confirmatory factor analysis

A CFA was conducted in the remaining sample ($N = 433$), using the final 10-item FORP-MHQ. Multiple fit indices were triangulated to assess the single-factor structure of the FORP-MHQ. The following indices demonstrated good fit: X^2 (Tabachnick et al., 2013) = 173.036, $p < .001$, $X^2/df = 4.944$, CFI = .95 and SRMR = .04. Other indices demonstrated acceptable fit: TLI = .93, RMSEA = .096 (90%CI: .082–.110) (Hu & Bentler, 1999). Hence, overall, there is evidence to indicate that the FORP-MHQ measured one factor – severity of FORP.

TABLE 1 Demographic and clinical factors.

Variables	*N*	%
Gender		
Man	137	15.7
Woman	650	75.1
Non-binary	73	8.4
Gender fluid	4	<1
Intersex	1	<1
Born in Australia	734	84.9
Ethnicity[a]		
Oceanian	300	34.7
North-west European	555	64.2
Southern and Eastern European	82	9.5
North-east Asian	25	2.9
South-east Asian	29	3.4
Southern and Central Asian	9	1.0
People of the Americas	18	2.1
Sub-saharan African	6	<1
North African and Middle Eastern	13	1.5
Other	6	<1
Educational achievement		
Did not complete high school	64	7.4
High school	152	17.6
Certificate III, IV or (advanced) diploma	239	27.6
Undergraduate	223	25.8
Postgraduate	187	21.6
Diagnoses[a]		
Schizophrenia spectrum	53	6.1
Bipolar mood	124	14.3
Unipolar mood	595	68.8
Anxiety	617	71.3
Obsessive–compulsive	92	10.6
Trauma-stressor related	367	42.4
Dissociative	30	3.5
Somatic symptom	3	<1
Feeding and eating disorders	65	7.5
Substance use disorder	5	<1
Personality disorder	133	15.4
Source of diagnoses[a,b]		
Psychologist	588	68
Psychiatrist	593	68.6
General practitioner	476	55
Neurodevelopmental diagnoses[a]		
Autism	127	14.7
ADHD	224	25.9

(Continues)

TABLE 1 (Continued)

Variables	*N*	%
Specific learning disorders	25	2.9
History of chronic physical illness	471	54.5
History of psychiatric inpatient admission	339	39.2
Not currently using medication	226	26.1
Current medication[a]		
Antipsychotics	191	22.1
Mood stabilizers/anti-convulsants	146	16.9
SSRIs	271	31.3
SNRIs	193	22.3
Tricyclic antidepressants	41	4.7
Tetracyclic antidepressants	47	5.4
MAOIs	5	<1
Benzodiazepines	98	11.3
Alpha and beta blockers	36	4.2
Medical cannabinoids	18	2.1
Others	164	19.0

[a]Multiple options selectable.

[b]Refers to the diagnosis of mental health conditions, not neurodevelopmental conditions.

TABLE 2 10-item EFA of the final FORP-MHQ items.

		Factor loadings
	Items	I
1	I worry that I will become unwell again	**.749**
2	I am disturbed by thoughts or images about becoming unwell again	**.796**
3	When I imagine what could happen if I become unwell again, I feel quite distressed	**.766**
4	I can'not stop thinking about, or imagining, becoming unwell again	**.829**
5	When I worry about becoming unwell again it is hard to focus on what I am doing	**.778**
6	Worrying about the consequences of getting unwell again takes over my mind	**.811**
7	I find myself thinking about the terrible things that might happen if I get unwell again	**.828**
8	If I got unwell again, I fear it would be worse than it was before	**.727**
9	When I get upset about becoming unwell again, becoming unwell and what might happen afterwards, seems like one of the worst things that could possibly happen	**.748**
10	I feel anxious when I think about the possibility of getting unwell in the future	**.772**
	Eigenvalues	6.487
	% of variance accounted for	64.873

Note: Factor loadings with an absolute value >.30 are indicated in bold.

Reliability

Cronbach's alpha was used to assess the internal consistency of the FORP-MHQ. This demonstrated excellent internal consistency ($\alpha = .939$). Three hundred thirty-five participants responded to the optional 28-day test–retest questionnaire (38.7% participation rate). Six participants were excluded for failing an

attention check, with a further four being excluded for duplicate responding (3.0% exclusion rate), leaving a final sample of 325 participants. Four-week test–retest reliability was $r = .727$.

Construct validity

The FORP-MHQ, which measures the magnitude of FORP, was strongly positively correlated with the FoRSe fear of recurrence subscale ($r = .706$) and the WARPS ($r = .728$), providing good evidence of convergent validity. The FORP-MHQ was also correlated with theoretically related constructs as expected. Higher FORP was associated with higher IES-R intrusions about being mentally unwell ($r = .648$), avoidance ($r = .455$) and hyperarousal ($r = .591$). Stronger beliefs that one's conditions are chronic ($r = .241$), prone to recurrence ($r = .263$), have significant consequences ($r = .451$) and cannot be controlled by personal action ($r = -.244$) or treatment ($r = -.321$), as measured by IPQ-R subscales, as well as symptoms of anxiety ($r = .538$) and depression ($r = .569$), measured by the GAD-7 and PHQ-9, respectively. The FORP severity subscale was also positively correlated with the perceived likelihood that a future deterioration in mental health would be 'about as bad as it was before' ($r = .330$) and 'worse than it has ever been' ($r = .531$), but not that a future deterioration would be 'not as bad as it has been before'. Conversely, FORP-MHQ severity was not significantly correlated with the belief that one's mental health conditions were caused by biological factors. In those that were currently using medication to their mental health conditions, FORP severity was also associated with poorer medication adherence ($r = -.135$). Correlations reported in Table 3.

FORP-MHQ severity scores were strongly correlated with scores on the MHAI ($r = .666$). To further examine discriminant validity, we modelled the FORP-MHQ severity subscale and the MHAI in a structural equation model to correlate their latent factors (see Data S1). The factors underlying these questionnaires, FORP and mental health anxiety, were correlated at $r = .764$ (95% CI: .729–.797). As the upper limit of this confidence interval did not exceed .80, this demonstrates good evidence of discriminant validity (Rönkkö & Cho, 2022).

Measurement invariance

A multi-group CFA was conducted to assess measurement invariance in the FORP-MHQ between those with and without a history of psychosis and/or mania. Results provided evidence of configural invariance ($X^2 = 335.019$, $p < .001$; CFI = .950, TLI = .936, RMSEA = .069, SRMR = .378). Based on the cut-off of ΔCFI $\leq .01$, proposed by Cheung & Rensvold (2002), invariance held when constraining factor loadings to be equal between groups, that is, metric invariance ($X^2 = 365.306$, $p < .001$; CFI = .950, TLI = .943, RMSEA = .065, SRMR = .371), when constraining intercepts to be equal between groups, that is, scalar invariance ($X^2 = 373.876$, $p < .001$; CFI = .950, TLI = .949, RMSEA = .061, SRMR = .381), and when constraining residual variance between groups, that is, residual invariance ($X^2 = 392.998$, $p < .001$; CFI = .948, TLI = .953, RMSEA = .059, SRMR = .387). Hence, there is evidence that the FORP-MHQ possesses strict measurement invariance between those with and without a history of psychosis and/or mania.

Multi-group CFA analyses were conducted to assess measurement invariance in the FORP-MHQ between those with conditions within a single diagnostic category and those with diagnoses spanning multiple categories. Results provided evidence of configural invariance ($X^2 = 348.11$, $p < .001$; CFI = .950, TLI = .935, RMSEA = .068, SRMR = .036). Based on the cut-off of ΔCFI $\leq .01$, proposed by Cheung & Rensvold (2002), invariance held when constraining factor loadings to be equal between groups ($X^2 = 355.11$, $p < .001$; CFI = .950, TLI = .943, RMSEA = .064, SRMR = .040), when constraining intercepts to be equal between groups ($X^2 = 383.776$, $p < .001$; CFI = .947, TLI = .946, RMSEA = .062, SRMR = .047), and when constraining residual variance between groups ($X^2 = 408.692$, $p < .001$; CFI = .944, TLI = .949, RMSEA = .060, SRMR = .060). Hence, there

TABLE 3 Correlations between FORP-MHQ subscales and variables of interest.

		α	FORP-MHQ
FoRSe	Fear of relapse	.87	.706*
	Awareness	.80	.208*
	Intrusiveness	.90	.591*
WARPS		.93	.728*
MHAI		.87	.666*
IES-R	Avoidance	.81	.455*
	Intrusions	.89	.648*
	Hyperarousal	.83	.591*
IPQ-R	Chronicity	.84	.241*
	Cyclical	.75	.263*
	Consequences	.78	.451*
	Personal control	.83	−.244*
	Treatment control	.80	−.321*
Biological causes		.75	.022
MARS-5		.79	−.135*
GAD-7		.90	.538*
PHQ-9		.87	.569*
Perceived risk of deterioration	Not as bad as it's been before	—	.006
	About as bad as it's been before	—	.330*
	Worse than it's been before	—	.531*

Note: Cronbach's alpha is indicated by α.

*$p < .001$.

is evidence that the FORP-MHQ possesses strict measurement invariance between those with and without a diagnostic history spanning multiple diagnostic categories. Those with diagnoses across multiple categories ($M = 26.02$, $SD = 8.03$) reported greater FORP than those without ($M = 22.27$, $SD = 9.19$, $t(863) = -5.204$, $p < .001$, $d = .454$).

A multi-group CFA was conducted to assess measurement invariance in the FORP-MHQ between those identifying as men and women. Results provided evidence of configural invariance ($X^2 = 323.899$, $p < .001$; CFI = .953, TLI = .939, RMSEA = .068, SRMR = .339). Based on the cut-off of ΔCFI ≤ .01, proposed by Cheung & Rensvold (2002), invariance held when constraining factor loadings to be equal between groups ($X^2 = 335.671$, $p < .001$; CFI = .952, TLI = .946, RMSEA = .064, SRMR = .344), when constraining intercepts to be equal between groups ($X^2 = 364.656$, $p < .001$; CFI = .948, TLI = .947, RMSEA = .063, SRMR = .343), and when constraining residual variance between groups ($X^2 = 381.959$, $p < .001$; CFI = .947, TLI = .951, RMSEA = .061, SRMR = .350). Hence, there is evidence that the FORP-MHQ possesses strict measurement invariance between those identifying as men and women. Men ($M = 24.45$, $SD = 9.21$) and women ($M = 25.52$, $SD = 8.24$) did not significantly differ in terms of FORP, $t(785) = -1.349$, $p = .089$, $d = -.127$ (Cheung & Rensvold, 2002).

DISCUSSION

The present study aimed to develop a novel transdiagnostic measure of FORP for people with mental health conditions. The initial 40 items were reduced to a final 10-item version of the FORP-MHQ which assessed FORP severity. See Appendix 1 for the final version of the FORP-MHQ. Although

initial analyses suggested a three-factor structure, including FORP severity, vigilance and a conservative approach to treatment, both vigilance and conservative approach factors were comprised of three items each, which is a number small enough to impair content validity and reliability. Moreover, both these factors did not measure FORP per se, which was the intended aim of the FORP-MHQ. Hence, these marginal factors were excluded on both statistical and conceptual grounds, leaving a parsimonious 10-item questionnaire assessing the severity of FORP. None of the included items had ceiling or floor effects, allowing them to capture good variability in responses. The FORP-MHQ was positively associated with alternative measures of FORP, but was empirically distinct from mental health anxiety, demonstrating good evidence of both convergent and discriminant validity. Overall, FORP severity was correlated with theoretically related constructs as expected, including positive association with intrusive memories of being mentally unwell, avoidance of those memories and related symptoms of hyperarousal, as well as symptoms of anxiety and depression. It was also associated with beliefs that one's conditions are chronic, recurring, highly consequential and cannot be effectively controlled by personal behaviour or treatment. Additionally, FORP was not associated with one's perceived risk of a 'not as bad as it was before', that is, mild, deterioration, but was associated with the perceived likelihood of deterioration that would be as, or more, severe than previously experienced. However, unexpectedly, FORP severity was not associated with the belief that one's condition had a biological origin and was associated with poorer medication adherence. Lastly, the FORP-MHQ possessed strict measurement invariance between those with and without diagnoses across multiple diagnostic categories, those with and without a history of psychosis and/or mania, and identifying as men and women.

The finding that FORP severity was not significantly associated with the belief that one's conditions were caused by biological factors was surprising. However, FORP severity was associated with beliefs about mental health conditions that theoretically mediate this relationship. The biological accounts of illness are known to predict beliefs that said illnesses are permanent or chronic, likely to recur, and respond more poorly to treatment (Lebowitz & Appelbaum, 2019). In the present study, FORP severity was associated, as expected, with these beliefs. Yet, the present study was unable to examine this potential indirect relationship between biological beliefs and FORP as beliefs about the nature and cause of mental health conditions were only assessed cross-sectionally. Another unexpected finding was that FORP severity had a small association with poorer medication adherence. This contrasts with the most recent review on mental health-related FORP, where FORP was consistently associated with greater adherence in those with schizophrenia spectrum, mood and opioid use conditions (Coutts-Bain, Sharpe, Techakesari, et al., 2023). One possible account of this discrepancy is that prior quantitative research finding a positive association between FORP and adherence examined specific populations and their FORP in relation to a particular class of medication; for example, people with bipolar and adherence to mood-stabilizing medication (Devulapalli et al., 2010). Conversely, in the present study, different conditions and classes of medication were analysed in aggregate. Hence, this may have obscured these stronger and positive associations that have previously been identified. Moreover, as different medications have different efficacies, side effect profiles, indications and dose regimens, it is possible that adherence to some is not related to FORP or is even negatively associated. Future research should examine these relationships between FORP and medication adherence separately for different medications and indications to elucidate these complexities. Another factor that may have obscured our expected findings was that the sample of the present study reported being highly adherent on the MARS-5. Indeed, we observed a ceiling effect where the mode response was perfect adherence; this will have reduced the variability of the adherence measure, and thus our findings related to the MARS-5 should be interpreted with caution.

Although FORP severity was not associated with the perceived likelihood of a milder mental health deterioration, it was associated with the perceived likelihood of more severe deteriorations, particularly a deterioration that was 'worse than it was before'. This indicates that those with higher levels of FORP tend to expect that future deteriorations in their mental health will be severe and potentially

catastrophic, rather than that deteriorations will occur in general. This is comparable to findings from cancer survivors, where quantitative and qualitative research indicates that those with higher levels of fear of cancer recurrence are more concerned with death and dying, compared to those with lower levels (Coutts-Bain, Sharpe, & Russell, 2023; Thewes et al., 2016). This is important as it demonstrates FORP is not simply an index of one's perceived risk of deterioration and is instead related to more complex expectations related to prior experiences of being mentally unwell.

Compared to existing measures of mental health-related FORP, the FORP-MHQ possesses several significant advantages. Firstly, it is the only questionnaire to be validated in people with a range of different conditions, not just schizophrenia spectrum conditions, as is the FoRSe (Gumley et al., 2015). Hence, the FORP-MHQ has utility in assessing FORP in the wider population of those living with mental health conditions, including those with mood, anxiety, disordered eating and obsessive–compulsive conditions, in whom FORP is especially understudied (Coutts-Bain, Sharpe, Techakesari, et al., 2023). Moreover, our measurement invariance analyses demonstrate that the FORP-MHQ is measuring FORP equivalently in those with and without a history of psychosis or mania, allowing for direct comparisons between clinical groups and providing further evidence of the transdiagnostic applicability of FORP and the FORP-MHQ. Interestingly, our analyses demonstrate that those with lived experience of psychosis and mania do not experience greater FORP than those with experience of arguably less complex and severe conditions. This highlights the potential for people diagnosed with more common conditions, like depression and anxiety, to be distressed and impacted by FORP. This is important as FORP is known to be associated with important clinical outcomes, such as a shorter time to psychotic relapse in schizophrenia (Gumley et al., 2015), medication adherence in people with schizophrenia, bipolar and opioid use conditions, and poorer quality of life (Coutts-Bain, Sharpe, Techakesari, et al., 2023). In addition, qualitative research has indicated that higher levels of FORP can underlie decisions to avoid pursuing occupational and relational goals, such as seeking employment, romantic relationships and having children (Coutts-Bain et al., 2025; Coutts-Bain, Sharpe, Techakesari, et al., 2023). However, given a paucity of appropriate measurement tools, it has not been possible to quantitatively examine the impact of FORP in people with lived experience of more common mental health conditions. Hence, the development and validation of the FORP-MHQ represent an advance in the field of mental health-related FORP, one which can facilitate more rigorous future research.

Moreover, our analyses, which demonstrate that the FORP-MHQ is invariant between those with and without diagnoses spanning multiple diagnostic categories, mean that the FORP-MHQ is a valid measure of FORP in those who may worry about the recurrence or progression of multiple conditions. Indeed, our analyses demonstrate that those with diagnoses spanning more than one diagnostic category, that is, those with lifetime comorbidity across varying conditions, endorse greater FORP ($d = .454$). This is important as, on average, people living with a mental health condition will have experienced more than one condition over the course of their life, either concurrently or sequentially (Kessler et al., 2005; Menzies et al., 2024). To our knowledge, the FORP-MHQ is also the only mental health-related FORP questionnaire to be demonstrably distinct from a measure of mental health anxiety in a stringent discriminant validity analysis. However, the two constructs are highly related, and future research would benefit from clarifying the relationship between the two constructs and other related variables.

The FORP-MHQ is the only mental health-related FORP questionnaire to have demonstrated measurement invariance between men and women, providing further evidence of the robustness of the measure. Overall, the psychometric strengths and transdiagnostic applicability of the FORP-MHQ make it a good candidate for future research intending to elucidate unclear or complex relationships between FORP and other variables. This may include known gaps in the literature, such as clarifying how FORP is related to clinical factors such as the number of prior recurrences and health behaviours (Coutts-Bain, Sharpe, Techakesari, et al., 2023).

Nevertheless, the present study must be qualified by some limitations. First, participants self-reported what mental health condition diagnoses they had received. However, there is evidence that such self-reports are reasonably reliable when compared to diagnostic interviews (Vieira et al., 2022). Moreover, on

average, the sample of the present study reported 2.54 lifetime mental health condition diagnoses, which is congruent with a recent meta-analysis of diagnostic interviews that demonstrated on average people diagnosed with a mental health condition have received 2.57 lifetime diagnoses (Menzies et al., 2024). This suggests that it is unlikely that participants are overreporting symptoms and syndromes as diagnosable conditions.

CONCLUSION

Notwithstanding these limitations, the present study had several notable strengths. Firstly, the present study's sample was clinically diverse. Overall, we saw good representation of most DSM-5-TR diagnostic categories, making this the first FORP questionnaire to be validated in people with experience of non-psychotic mental health conditions. The sample was also characterized by a high rate of comorbidity, participants both with and without a history of psychiatric hospitalization, and rates of autism and ADHD comparable to those found in psychiatric outpatient services (Adamis et al., 2022; Nyrenius et al., 2022; Takara & Kondo, 2014). These complexities are common in community mental health settings, and validation of the FORP-MHQ in a sample with these characteristics demonstrates the robustness and ecological validity of the questionnaire for people with a range of different conditions and clinical histories. We aim for the FORP-MHQ to be a catalyst for future research to confirm associations that have been found in people with schizophrenia between FORP and subsequent time to relapse. Clinically, it would be useful to administer it at the end of treatment, or transitions between services, as a part of relapse prevention to identify fears that could be targeted in interventions designed to reduce FORP.

In conclusion, the FORP-MHQ is a valid and reliable measure of FORP severity in a clinically diverse sample that is relatively brief and freely accessible. Hence, this newly developed questionnaire can be used to advance research on FORP in people with lived experience of mental health conditions, including more common, non-psychotic conditions, where FORP is understudied.

AUTHOR CONTRIBUTIONS

Daelin Coutts-Bain: Conceptualization; methodology; writing – original draft; visualization; formal analysis; data curation; investigation. **Louise Sharpe:** Conceptualization; writing – review and editing; supervision; methodology; validation. **Caroline Hunt:** Writing – review and editing; supervision; conceptualization; methodology.

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CONFLICT OF INTEREST STATEMENT

The authors declare that they have no conflicts of interested related to the work reported in this paper.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Coutts-Bain, D., Sharpe, L., & Hunt, C. (2025). Validation of a transdiagnostic measure of fears of recurrence and progression about mental health conditions. *British Journal of Clinical Psychology*, *00*, 1–16. https://doi.org/10.1111/bjc.12536

APPENDIX 1

Final version of the FORP-MHQ

Instructions

It is natural for people who have lived with mental health issues to worry that they may come back or get worse. However, some people worry about it more than others.

Below is a list of statements related to your mental health and worries you might have about issues recurring, relapsing or getting worse in the future. Please indicate how much each statement has applied to you over the past month.

Some of the statements below refer to being or becoming 'unwell' In this questionnaire, 'unwell' refers to your mental health getting worse because of a relapse, recurrence or progression of the issues.

Items

1. I worry that I will become unwell again.
2. I am disturbed by thoughts or images about becoming unwell again.
3. When I imagine what could happen if I become unwell again, I feel quite distressed.
4. I cannot stop thinking about, or imagining, becoming unwell again.
5. When I worry about becoming unwell again, it is hard to focus on what I am doing.
6. Worrying about the consequences of getting unwell again takes over my mind.
7. I find myself thinking about the terrible things that might happen if I get unwell again.
8. If I got unwell again, I fear it would be worse than it was before.
9. When I get upset about becoming unwell again, becoming unwell and what might happen afterwards seem like one of the worst things that could possibly happen.
10. I feel anxious when I think about the possibility of getting unwell in the future.

Response options

0 (Never), 1 (Rarely), 2 (Sometimes), 3 (Often), 4 (Very Often).

Appendix C10. Ethics approval.

THE UNIVERSITY OF SYDNEY

RESEARCH INTEGRITY
& ETHICS ADMINISTRATION

HUMAN RESEARCH ETHICS APPROVAL

The University of Sydney confirms that this project meets the requirements of the National Statement on Ethical Conduct in Human Research.

Project identifier:	2024/HE000454
Project title:	Fear of Recurrence and Progression Questionnaire Validation
Version:	0.02
Chief Investigator:	Professor Louise Sharpe
Authorised project team:	Professor Caroline Hunt
	Mr Daelin Coutts-Bain
Date of approval:	Tuesday, 4 June, 2024
Project end date:	04 Jun 2028

Provisos *(if applicable)*

Project summary

For people with mental health conditions, worry that their conditions might recur or progress is an understandable response to lived experience of mental illness. However, it can be distressing, and is associated with poorer psychological outcomes and quality of life. Despite the importance of this construct, there are no well validated questionnaires to assess these worries. The proposed study aims to evaluate the psychometric properties of a newly developed questionnaire to measure these worries in people with mental health conditions, the Fears of Recurrence and Progression Mental Health Questionnaire (FORP-MHQ). This will involve recruiting participants who have been diagnosed with mental health conditions and asking them to complete two online surveys. Use of advanced statistical analyses will allow us to use this survey data to evaluate the validity and reliability of the newly developed FORP-MHQ. Therefore, this research will produce a questionnaire that can facilitate future research.

Documents approved

Document type	File name	Document version	Application version
Change Tracking	2024_HE000454 v0_01 - v0_02 Changes.pdf	1	0.2
Application	Application Form.docx	2	0.2
Participant Consent Form (PCF)	FORPMHQ_Consent.docx	1	0.1
Other	FORPMHQ_SurveyReminder.docx	1	0.1
Other	FORPMHQ_LinkToSurvey2.docx	1	0.1
Recruitment or advertising material	FORPMHQ_Facebook.pdf	1	0.1
Application Attachment	HREC-project-description-FORP-MHQ.docx	1	0.1

Recruitment or advertising material	FORPMHQ_InstagramPost.pdf	1	0.1
Recruitment or advertising material	FORPMHQ_InstagramStory.pdf	1	0.1
Participant Information Statement (PIS)	FORPMHQ_PIS.docx	1	0.1
Survey or questionnaire	FORPMHQ_Survey.docx	1	0.1
Other	FORPMHQ_SurveyTable.docx	1	0.1
Recruitment or advertising material	FORPMHQ_AdTxt.docx	1	0.1
Participant Information Statement (PIS)	FORPMHQ_PIS_TrackedChanges.docx	1	0.2
Project description / Protocol	HREC-project-description-FORP-MHQ_TrackedChanges.docx	1	0.2
Survey or questionnaire	FORPMHQ_SurveyTrackedChanges.docx	1	0.2

Conditions of Approval

- Research must be conducted according to the approved proposal.
- An annual progress report must be submitted on or before the anniversary of approval and a final report on completion of the project.
- You must report as soon as practicable anything that might warrant review of ethical approval of the project including:
  - Serious or unexpected adverse events (which should be reported within 72 hours).
  - Unforeseen events that might affect continued ethical acceptability of the project.
- Any changes to the proposal must be approved prior to their implementation (except where an amendment is undertaken to eliminate *immediate* risk to participants).
- Researchers working on this project must be sufficiently qualified by education, training, and experience for their role, or adequately supervised. Changes to the project team must be reported and approved.
- Researchers must disclose any actual, potential of perceived conflicts of interest, including any financial or other interest or affiliation, as relevant to this project.
- Research data and primary materials must be retained and stored in accordance with relevant legislation and University guidelines.
- Ethics approval is dependent upon ongoing compliance of the research with the *National Statement on Ethical Conduct in Human Research*, the *Australian Code for the Responsible Conduct of Research*, applicable legal requirements, and with University policies, procedures, and governance requirements.
- If your research project is a clinical trial and is being sponsored by the University or is to be conducted on a University of Sydney site, you must comply with additional University governance requirements prior to commencing your Clinical Trial.
- The University may conduct audits on approved projects.

- The Chief Investigator has ultimate responsibility for the conduct of the research and is responsible for ensuring all others involved will conduct the research in accordance with the above.

Ethics Office

On behalf of the University of Sydney

The University of Sydney HRECs are constituted and operate in accordance with the National Statement on Ethical Conduct in Human Research and the Australian Code for the Responsible Conduct of Research (NHMRC). All personnel named on the project should be acquainted with these documents.

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Appendix D

Appendix D provides additional materials relevant to Chapter 5, including:

Appendix D1: Results of diagnostic interviews.

Appendix D2: Sensitivity analysis (*n* = 58).

Appendix D3: Ethics approval.

Appendix D1. Results of diagnostic interviews.

Interviewee #	Self-reported Diagnoses	Diagnoses Identified by Interview
1	MDD	✓
2	BPD	✓
	GAD	✓
	Dysthymia	
3	Bipolar II	✓
	PTSD	
4	MDD	✓
	GAD	✓
	Dysthymia	✓
5	MDD	✓
	GAD	✓
	Dysthymia	✓
6	Bipolar II	✓
7	MDD	✓
	GAD	✓
	PTSD	✓
8	MDD	✓
	PTSD	✓
9	MDD	✓
	GAD	✓
	PTSD	✓
10	MDD	✓
	GAD	✓
	PTSD	✓
	OCD	✓
11	GAD	✓
	Bipolar II	✓
12	MDD	✓
	GAD	✓
13	MDD	✓
	SAD	✓
	PTSD*	✓
14	Bipolar II	✓
	PTSD	✓

15	MDD	✓
	GAD	✓
	PTSD	✓
16	BPD	✓
	GAD	✓
	PTSD*	✓
17	Bipolar I	✓
	PTSD	✓
	GAD	✓
18	Bipolar I	✓
	OCD	✓
19	MDD	✓
	SAD	✓
	PTSD*	✓
20	MDD	✓
	GAD	
21	MDD	✓
	SAD	✓
	PTSD	✓
	OCD	✓
	Bipolar II	

Note. Listed diagnoses refer to lifetime diagnoses. The SCID-5-RV and SCID-5-PD were used to assess lifetime history of self-reported diagnoses. BPD = borderline personality disorder; GAD = generalised anxiety disorder; OCD = obsessive-compulsive disorder; MDD = major depressive disorder; PTSD = post-traumatic stress disorder; SAD = social anxiety disorder. Tick marks indicate that the diagnostic interviews corroborated the self-reported diagnosis. Some participants with a recorded diagnosis of PTSD identified with, and reported receiving, a diagnosis of complex PTSD. As the SCID-5-RV does not include an interview schedule for complex PTSD, PTSD was assessed instead. Where participants reported receiving a diagnosis of complex PTSD, their diagnosis of PTSD is marked with a '*'.

Appendix D2. Sensitivity analyses (*n* = 58).

Dependent variable									
	FORP					Intrusions			
Predictors	*b*	*SE(b)*	*p*	95%CI	Predictors	*b*	*SE(b)*	*p*	95%CI
Intercept	38.607	3.098	<.001	[32.531, 44.682]	Intercept	39.538	3.189	<.001	[33.285, 45.791]
Intrusions $_{t-1}$	.153	.026	<.001	[.007, .110]	FORP $_{t-1}$	<.001	.027	.991	[-.053, .053]
FORP $_{t-1}$	.058	.027	.026	[.103, .203]	Intrusions $_{t-1}$	.186	.026	<.001	[.134, .238]
	FORP					Shame			
Predictors	*b*	*SE(b)*	*p*	95%CI	Predictors	*b*	*SE(b)*	*p*	95%CI
Intercept	38.606	3.098	<.001	[32.531, 44.682]	Intercept	32.005	3.293	<.001	[25.548, 38.462]
Shame $_{t-1}$	.132	.023	<.001	[.088, .176]	FORP $_{t-1}$	.066	.017	<.001	[.032, .100]
FORP $_{t-1}$	.137	.020	<.001	[.098, .175]	Shame $_{t-1}$	.157	.020	<.001	[.118, .196]
	FORP					Interpretation bias			
Predictors	*b*	*SE(b)*	*p*	95%CI	Predictors	*b*	*SE(b)*	*p*	95%CI
Intercept	38.606	3.098	<.001	[32.531, 44.682]	Intercept	47.515	2.992	<.001	[41.649, 53.380]
Interpretation bias $_{t-1}$	.106	.023	<.001	[.062, .151]	FORP $_{t-1}$	.031	.023	.186	[-.015, .077]
FORP $_{t-1}$	.106	.022	<.001	[.063, .149]	Interpretation bias $_{t-1}$	.218	.022	<.001	[.174, .261]
	FORP					Attention bias			
Predictors	*b*	*SE(b)*	*p*	95%CI	Predictors	*b*	*SE(b)*	*p*	95%CI
Intercept	38.606	3.098	<.001	[32.531, 44.682]	Intercept	44.059	3.138	<.001	[37.907, 50.210]
Attention bias $_{t-1}$	.042	.022	.054	[-.001, .084]	FORP $_{t-1}$	.038	.023	.093	[-.006, .082]
FORP $_{t-1}$	.145	.022	<.001	[.102, .188]	Attention bias $_{t-1}$	.148	.022	<.001	[.105, .191]

Note. This table provides the fixed effects for the listed variables. Variables with (t-1) are variables that have been lagged by one measurement occasion. The 95% confidence intervals and *p*-values are calculated for unstandardised estimates, i.e., *b*.

Appendix D3. Ethics approval.

THE UNIVERSITY OF SYDNEY

RESEARCH INTEGRITY
& ETHICS ADMINISTRATION

HUMAN RESEARCH ETHICS APPROVAL

The University of Sydney confirms that this project meets the requirements of the National Statement on Ethical Conduct in Human Research.

Project identifier:	2024/HE001639
Project title:	Ecological Momentary Assessment of Fears of Recurrence and Progression
Application version:	0.03
Chief Investigator:	Professor Louise Sharpe
Project team:	Professor Caroline Hunt Professor Carolyn MacCann Mr Daelin Coutts-Bain
Project start date:	06 Mar 2025
Project end date:	05 Mar 2029
Date of issue:	Thursday, 6 March, 2025

Note:

- Please note 'Version B' of the recruitment email (containing alternative artwork) should be used.

Project summary

For people with lived experience of mental health conditions, worry that their conditions might recur or progress is a common response to experience of having been mentally unwell. However, this fear can be distressing, and is associated with poorer psychological outcomes and quality of life. Despite the importance of this construct, little is known about the psychological processes that underlie poorer outcomes. Although theoretical accounts have been proposed, they are yet to be tested empirically. The proposed study aims to recruit people who have been diagnosed with mental health conditions and ask them to complete multiple brief online surveys about fear of recurrence and progression each day over two weeks. Hence, this research will identify the clinically relevant psychological processes driving fears of recurrence and progression, some of which may be potential targets for psychological treatment.

Documents approved

Document type	File name	Document version	Application version
Survey or questionnaire	EMA_Surveys.docx	2	0.02
Recruitment or advertising material	RecruitmentEmail_Initial_v3_Clean.docx	3	0.03
Survey or questionnaire	FORP-ScreenerSurvey2.docx	2	0.02
Participant Consent Form (PCF)	ParticipantConsentForm2.docx	2	0.02
Participant Information Statement (PIS)	ParticipantInformationStatement_v3_Clean.docx	3	0.03

Application Attachment	ProjectDecription_FORP_EMA_v3.docx	3	0.03
Recruitment or advertising material	RecruitmentEmail_Reminder_v3_Clean.docx	3	0.03
Other	SCID 5-RV Trimmed2.pdf	2	0.02

Conditions of Approval

- Research must be conducted according to the approved proposal.
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- The University may conduct audits on approved projects.
- The Chief Investigator has ultimate responsibility for the conduct of the research and is responsible for ensuring all others involved will conduct the research in accordance with the above.

Ethics Committee Representative

Chair
On behalf of the University of Sydney

The University of Sydney HRECs are constituted and operate in accordance with the National Statement on Ethical Conduct in Human Research and the Australian Code for the Responsible Conduct of Research (NHMRC). All personnel named on the project should be acquainted with these documents.

THE UNIVERSITY OF SYDNEY

Human Ethics Approval certificate

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