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Superusers' Engagement in Online Mental Health Forums: A Qualitative Exploration

CATHERINE LIBERTY BSc (Hons), PGCert, MSc

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Faculty of Health and Medicine

Division of Health Research

Lancaster University

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Abstract

Background

Online forums are increasingly utilised by people experiencing mental health problems as they offer accessible, anonymous, and immediate access to peer support. Forum users generally fall into three categories: observers (who read but do not engage), contributors (who engage intermittently), and superusers (who engage at a high frequency). Despite accounting for just 1% of forum users, superusers are crucial to forum stability. However, little is known about their impacts, experiences, motivations and support needs. This thesis aimed to respond to these knowledge gaps by asking (1) What is known about the bidirectional impacts of superusers and online health forums, and (2) What are the engagement experiences of superusers in online mental health forums?

Methods

Two research approaches were employed. First, an integrative literature review utilising Framework Synthesis synthesised thirty-one sources that focused on (1) the impacts superusers have on online health forums and/or (2) the impacts online health forums have on their superusers. Second, Reflexive Thematic Analysis was used to analyse seventeen semi-structured interviews with self-identified mental health forum superusers from the UK. These interviews explored superusers' engagement experiences, motivations and challenges. Both approaches were rooted in critical realism, which allowed exploration of observable facets together with the ability to infer underlying generative mechanisms.

Results

The integrative literature review resulted in the development of a novel conceptual framework and five bidirectional themes. Three themes centred on the impacts superusers have on online health forums, including their roles in enhancing forum engagement, cultivating emotionally supportive environments, and fostering cohesive, proactive communities. Two themes encapsulated the impacts forums have on superusers, encompassing effects on physical and psychological health, in addition to social connection and validation.

The Reflexive Thematic Analysis generated five themes centred around superusers' mental health forum engagement experiences. These themes highlighted the evolving nature of superusers' engagement over time; superusers' deployment of strong interpersonal and intrapersonal boundaries; experiences of belonging and shared identity; the adoption of primarily help-giving roles that provide purpose; and the challenge of navigating perceived otherness.

Conclusion

As research into superusers remains in its infancy, this thesis makes a significant contribution to knowledge by providing a foundational understanding of the bidirectional impacts of superusers and online health forums, as well as insight into mental health forum superusers' motivations, challenges and overall engagement experiences. These insights highlight superusers' emotional investment, time commitment and vital roles in sustaining peer-led mental health communities. Insights from this thesis encourage critical reflection on digital peer support, ethical forum design, and future directions for research, practice and policy. Moving forward, the evolution of relational dynamics within forums warrants further exploration, and longitudinal studies would be particularly useful here. Regarding practice, digital forum providers should prioritise psychologically safe, inclusive spaces that support their superusers without restricting their autonomy. Regarding policy, new frameworks must formally recognise superusers' essential roles and introduce safeguarding structures that protect their wellbeing. Participatory approaches to forum design and governance are also essential if ethical and effective spaces for superusers are to be assured within online forums.

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List of Abbreviations

BPS	British Psychological Society
CMHC	Common mental health condition
COVID-19	Coronavirus disease 2019
GP	General Practitioner
GT	Grounded theory
IPA	Interpretive Phenomenological Analysis
iPOF	Improving Peer Online Forums
JBI	Joanna Briggs Institute
JMIR	Journal of Medical Internet Research
MHF	Mental health forum
NHS	National Health Service
OHF	Online health forum
ONS	Office of National Statistics
PICO	Population, intervention, comparison, outcome
PPI	Patient and Public Involvement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RTA	Reflexive Thematic Analysis
SHaRON	Support Hope and Recovery/Resource Online Network
SMI	Serious mental illness
SPICE	Setting, perspective, intervention, comparator, evaluation.
SPIDER	Sample, phenomenon of interest, design, evaluation, research type
UK	United Kingdom
WHO	World Health Organisation

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I dedicate this thesis to my mum, Rosemary (Mother Beast) and my dad, Thomas (Buddy). I like to imagine that somewhere, somehow, you can both see all I have gone on to achieve.

Author's Declaration

I declare that this PhD thesis comprises my own work and has not been submitted for the award of a higher degree at any other institution.

The author of each chapter of this thesis was the PhD candidate, Catherine Liberty (CL). The lead supervisor for this thesis was Professor Fiona Lobban (FL). The thesis was also supervised by Dr Caroline Swarbrick (CS) and Dr Paul Marshall (PM). Supporting the systematic literature review were postgraduate researcher Hayley Lawther-Payne (HL-P), postgraduate student Jill Fitzpatric (JF), specialist librarian John Barbrook (JB), and Cochrane information specialist Lynn Hampson (LH). Contributions for each chapter are detailed below.

Chapter 1: Introduction and Background

CL conducted all background research and chapter writing. FL provided feedback on the final chapter draft.

Chapter 2: The Impacts of Superusers in Online Health Forums: An Integrative Review and Conceptual Framework

FL, CS and PM contributed to the chapter conceptualisation. CL conducted all database searches, article screening, data extraction, data analysis, and chapter writing. LH and JB advised on database searching and provided feedback on multiple iterations of search terms. HL-P and JF acted as additional screeners, double-screening (10% and 10% respectively). PM provided feedback on the initial chapter draft, and FL provided feedback on the final chapter draft.

Chapter 3: Methodology

CL wrote the chapter in its entirety. FL, CS and PM provided feedback on the initial chapter draft. FL provided feedback on the final chapter draft.

Chapter 4: Analysis

CL conducted and wrote the whole chapter. FL, CS and PM provided feedback on the analysis. CS provided feedback on the initial chapter draft. FL provided feedback on the final chapter draft.

Chapter 5: Discussion

Cl drafted the chapter in its entirety. PM provided feedback on the initial chapter draft. FL provided feedback on the final chapter draft.

Catherine Liberty

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Chapter 1: Thesis Introduction and Background

1.1 Chapter Introduction

This introductory chapter provides the broader contextual grounding for the research included in this PhD thesis. It begins by introducing key background information and statistics related to mental health, including its prevalence, known risk factors and wide-ranging impacts on both people with mental health problems and their family members (i.e. informal caregivers). Next comes a discussion of the economic consequences of mental health problems, in addition to details on the growing demand for mental health services and the disparities in service provision that prevail. Following this, the chapter explores barriers to help-seeking, centring on mental health stigma as a significant challenge. This key background information lays the foundation for the discussion of alternative forms of mental health support that follows, where attention is given to the rise of internet-based approaches to mental health support and, in particular, the rise of online peer-based support. Peer support is discussed in terms of its historical and traditional offline context, and mental health forums (MHFs) are discussed regarding their potential risks and benefits. Following this, the concept of the MHF superuser is introduced and examined in relation to other types of forum users. Key terminology and concepts relevant to the thesis are integrated throughout. Building on the background context, the rationale for the PhD thesis is presented in terms of its contribution to existing knowledge gaps and congruence with current digital policies and agendas within the United Kingdom (UK). The overarching thesis aims follow, before the chapter concludes with an overview of the thesis structure moving forward.

1.2 Mental Health Overview

Globally, almost one billion people experience mental health problems, and mental health conditions are a leading cause of disease burden and disability worldwide (World Health Organisation [WHO], 2023). Since the COVID-19 pandemic, incidents of psychological distress have increased, and common mental health conditions (CMHCs), including depression and anxiety disorders, which rose by more than 25% at the height of the pandemic, remain elevated (WHO, 2022). According to the Adult Psychiatric Morbidity Survey: Survey of Mental Health and Wellbeing, England, 2023/4 (National Health Service [NHS] Digital, 2024), one in five adults in England (20.2%) have a CMHC while Public Health England (2018) suggest approximately 1% adults in England are living with a serious mental illness(SMI) such as bipolar disorder or schizophrenia (NHS England, 2024b). In 2023, suicide rates in England were the highest in almost 25 years (Office of National Statistics [ONS] 2024), signalling a stark increase in individual suffering. Additionally, a significant number of people experience subclinical mental health symptoms, which, despite falling below diagnostic thresholds, still result in psychological distress and functional challenges (MIND, 2024).

1.3 Mental Health Risk Factors

Mental health problems do not discriminate, meaning anyone of any age and background at any stage of their life can be impacted. That said, several factors increase the likelihood of experiencing a mental health problem. For example, there are socioeconomic and regional disparities in mental health problems, and in England, the prevalence of mental illness is highest in the most deprived areas (NHS Digital, 2024). Adverse life experiences, including poverty, trauma, violence, disability and inequality, can also increase someone's risk of developing a mental health condition, as can the experience of racism, which is a causal factor of mental distress (MIND, 2024). Gender also plays a role, with the prevalence of CMCHs higher in women than men (24.2% versus 15.4%; NHS Digital, 2024). Although suicide rates for women recently reached their highest levels in over two decades, men, whose suicide rates also peaked to their highest levels in recent years, still account for around three-quarters of all suicide deaths registered in England (ONS, 2024). Additionally, mental health outcomes are significantly worse for transgender, non-binary, and gender diverse populations when compared to cisgender men and women (Newcomb et al., 2020; Watkinson et al., 2024). A global meta-analysis found that 29% of transgender people report a lifetime suicide attempt, which is approximately 6 to 10 times higher than in the general population (Kohnepoushi et al., 2023). Such disparities are driven by a complex interplay of social, psychological and structural factors that centre on stigma, discrimination and social exclusion in addition to barriers in accessing affirming and inclusive mental health care (Cronin et al., 2025).

The experience of physical illness, activity-limiting health conditions, and long-term health conditions also plays a significant role in mental health. For example, one longitudinal study of 7,673,978 people, which took into account nine broad categories of physical disease (cancer, neurological, cardiovascular, respiratory, endocrine, gastrointestinal, urogenital, musculoskeletal and haematological disorders), concluded that most physical diseases are associated with an elevated risk of subsequent mental ill health (Momen et al, 2024).

Regarding activity-limiting conditions (i.e. musculoskeletal disorders, chronic pain, chronic respiratory illness, and neurological conditions), the Adult Psychiatric Morbidity Survey (NHS Digital, 2024) found that 32.9% of people with such conditions experience CMHCs compared to just 12.6% of those without. Furthermore, for people with long-term health conditions (defined as chronic conditions that are managed over years or decades with the use of medication and/or other therapies but for which there is no known cure; NHS Digital, 2022), of which more than one-third of the global population are estimated to be living with two or more of (Spiers et al., 2023), there is a two-to-three-fold higher risk of experiencing mental health problems when compared with general population (UK House of Commons Library, 2024).

1.4 The Impact of Mental Health Problems

Mental health problems significantly impact people's daily functioning, negatively affecting relationships and often hindering their ability to work (MIND, 2024). Such impacts can lead to poverty, social exclusion, discrimination, stigma and human rights violations (Boardman, 2011; WHO, 2023), which, as noted above, are mental health risk factors that also arise as consequences of mental health problems. For people with SMI, there can be periods of debilitating psychological problems that may cause them to experience altered reality and fluctuating cognitive capacity that severely limits their ability to engage in every day and occupational activities (Public Health England, 2018). Moreover, those with mental health problems, and in particular, those with SMI, have significantly reduced life expectancy; around 15-20 years shorter when compared with the general population (WHO, 2022).

Mental health problems can also transcend individual experience, as family members of those impacted often take on informal caregiving responsibilities. The informal caregiving role can place a substantial burden on carers as they almost always lack both practical and emotional preparedness and capacity for taking on this role (Cham et al., 2022). What’s more, caregivers of those with mental health problems face unique challenges when compared to carers of those with physical health conditions due to having to care for family members who may experience erratic and unpredictable emotions in addition to suicidal ideation (Ntsayagae et al, 2019). As a result, becoming an informal carer for a family member with mental illness can lead to financial strain, social burden (due to the stigma and discrimination experienced not only by the person with the mental health problem but also the carer themselves [Nenobais et al 2019]), social isolation (Phillips et al., 2023) and feelings of unhappiness and dissatisfaction in life that significantly reduce their quality of life, health, and ability to function effectively and productively in their everyday lives (Cham et al., 2022). These consequences can be especially pertinent for female spousal carers, who, due to a sense of duty, are less likely to reach out for support themselves and therefore more likely to experience higher levels of distress and caregiver burden in comparison to their male counterparts (Phillips et al., 2023). The chronic stress that informal carers experience (Rayland & Andrews, 2023) often leads to maladaptive coping methods, which further impact their own physical and mental health (Bademli et al., 2017).

Despite the burden associated with caregiving, there can be benefits for some people taking on this informal role. For example, caregivers may become more compassionate, tolerant, hopeful and resilient, and some may even experience profound shifts in how they understand the world and their place in it, which in turn spurs posttraumatic growth (Chiba et al., 2025). Furthermore, in acquiring new knowledge and insight into mental health conditions, caregivers may experience decreased stigma and ultimately stronger family relationships (Chiba et al., 2025). However, any potential benefits appear to be mediated by factors such as the caregiver's personality (with extroverts more likely to experience benefits), level of social support and religiosity, meaning benefits are not always applicable (or even possible to attain) for all informal caregivers (Phillips et al., 2023).

1.5 Economic Consequences of Mental Health in the UK

Regarding economic consequences, a 2022 report on the economic and social costs of mental ill health estimated that mental health problems cost the UK economy at least £117.9 billion per year (McDaid & Park, 2022); this cost equates to double the NHS's budget for England that same year. While a more recent claim within MIND's Big Mental Health Report (2024) suggests the cost of poor mental health in England is calculated at £300 billion a year. While funding for mental health treatment has increased over the past few years, the number of people needing treatment has increased far more, meaning it remains insufficient. For example, there were more than 6.4 million referrals to NHS talking therapies and other mental health services in England in 2021/22, with over 2 million people on the waiting list for support in England alone (MIND, 2024). Furthermore, funding that is available is not always used in the most effective way and due to stringent rules. As a result, due to institutional and resource constraints, doctors cannot always provide the level of care they believe is best for their patients (British Medical Association, 2024). Compounding this are challenges within the mental health workforce. For example, in September 2023, 28,663 (19%) of mental health workforce posts in England were vacant and many workers who were in post reported being unwell due to work-related stress. In fact, 42% of mental health staff said they had experienced sickness due to work-related stress (MIND, 2024).

1.6 Demand for Mental Health Services

Demand for mental health services continue to exceed available resources (Rayland & Andrews, 2023), and although NHS England has widely implemented shorter waiting list standards via the introduction of the Improving Access to Psychological Therapies program for CMHCs and appears to be largely meeting these standards (i.e. 89.3 % of those waiting for treatment were seen within 6 weeks in 2022/23 which is above the target of 75% within 6 weeks), there are regional disparities in average waiting times. For example, adults waiting for initial appointments in Gloucestershire waited less than a week, while those in Southport and Formby waited more than 11 weeks (Baker & Kirk-Wade, 2024). Furthermore, in certain areas of England, the time between the first and second appointment could be up to two months (NHS England, 2024a). As funding fails to meet demand, waiting times are even longer for children and young people in need of mental health support in the UK (Rethink Mental Illness, 2024). In 2023/24, 78,577 children and young people referred to CAMHS waited more than a year for treatment (YoungMinds, 2024), while in 2024 it was reported that nearly 40000 children experienced waits of at least two years (Children's Commissioner for

England, 2024). Furthermore, in 2023/24, 171,134 of these children and young people had their referral closed before accessing any support (YoungMinds, 2024).

While on NHS waiting lists, mental health symptoms can become exacerbated, and negative or irrational beliefs that further intensify mental health problems (e.g. “I’m never going to get help, so why help myself?”) can emerge (Punton et al, 2022). Long-term delays can also lead to an increase in emergency interventions, hospital admissions and the development of a general distrust of mental health services, which makes it harder to engage with treatment once it is offered (Rethink Mental Illness, 2024). These systemic mental health treatment limitations and barriers are further complicated by personal help-seeking barriers, one of the most prominent being feelings of stigma-born shame, which impede individuals’ motivation and ability to seek the help that they need (McManus et al., 2016).

1.7 Stigma as a Barrier to Mental Health Help-Seeking

A recent report by UK mental health charity MIND (2024) sheds light on a troubling trend: initial improvements in the public's understanding and attitudes towards mental illness achieved in the past decades have begun to reverse, and as a result, the stigma that surrounds mental illness is increasing (MIND, 2024). Additionally, the charity discovered that more than one in ten people surveyed believed people should feel ashamed of their mental health problems (MIND, 2024). First conceptualised by Goffman (1963), stigma relates to an attribute of self (e.g. a mental health problem) that is stereotypically appraised as “deeply discrediting”. Stigma in modern-day psychology builds on this understanding, defining it as a complex phenomenon that encompasses multiple related dimensions (Link et al., 2004).

Mental health stigma is considered a prominent barrier to help-seeking (Lawlor & Kirakowski, 2014). Regarding the association between mental health-related stigma and active help-seeking, a systematic review and meta-analysis established four distinct facets of stigma that can impact help-seeking: (1) perceived public stigma (individuals perceptions of societies negative stereotypes and subsequent discrimination towards people with mental health problems); (2) personal stigma (individuals own negative attitudes towards mental health problems and subsequent drive to distance themselves socially from those deemed mentally ill) (3) self-stigma (also known as internalised stigma whereby a person with mental health problems devalues themselves and anticipates social rejection) and (4) attitudes towards help seeking (a person's openness to seeking mental health help that encapsulates their perceived need, tolerance for stigma and belief in positive treatment outcomes) (Schnyder et al., 2017). Self-stigma in particular can lead to a negative impact on self-esteem, self-efficacy, hope and empowerment and lead to an increase in severity of mental health symptoms (Livingston & Boyd, 2010).

Given the extent of these independent but interrelated stigma-born barriers to help-seeking, and the fact that many people with mental health problems describe the experience of stigma as being worse than the impact of the mental health problem itself (Thornicroft et al., 2022), it is not surprising that three in five people living with mental illness do not seek support due to concerns about how others would perceive them (Rethink Mental Illness, 2023), and instead try to handle their problems on their own (Jennings et al., 2015).

1.8 Online Help-Seeking as a Response to Mental Health Stigma

Over recent decades, the internet has increasingly offered people with mental health problems an alternative pathway to mental health support. Thanks to factors including perceived anonymity, online help-seeking can help to mitigate the feared, perceived and actual stigma that would otherwise prevent people from accessing support (Naslund et al., 2016; Wallin et al, 2018). Seeking help via the internet, for some, can work to reduce prominent facets of stigma. For example, self-stigma can be challenged through largely anonymous disclosure in MHFs, which can in turn break down shame (Lawlor & Kirakowski, 2014), and perceived public stigma can be tested in a way that requires only minimal emotional exposure due to a largely concealed identity (Buck et al., 2020).

1.9 Online Mental Health Support

Mental Health support-seeking via the internet is a multistep process (Cornally & McCarthy, 2011) where individuals may seek information, resources and/or emotional support in response to emotional distress and symptoms of mental ill health (Kaess et al., 2019). Regarding accessibility, statistically speaking, 96% of households in the UK have internet access, and 89% of UK adults access the internet daily (ONS, 2020). However, those with mental health problems are at risk of increased socio-economic inequalities and subsequent digital exclusion (Greer et al., 2019), often referred to as “digital poverty” (Kalckreuth et al., 2014). Still, individuals with mental health problems, including those with SMI, do access online support at relatively high rates (Kalckreuth et al., 2014; Thomas et al., 2017).

Furthermore, given the recent digital revolution in mental health support (Bucci et al., 2019) and widespread shifts in service delivery to online platforms post-pandemic, more people with mental health problems are turning to the internet for support than ever before (Sorkin et al., 2021).

When seeking help online, there are several options to choose from. For example, individuals may choose to engage remotely with traditional mental health professional services, connecting with online counsellors or CBT-trained professionals, approaches which show little to no difference in effectiveness across a wide range of mental health problems, whether delivered remotely or in person (Zandieh et al., 2024). People may also choose to access self-help interventions, online therapeutic tools, and/or psychoeducation. Many may also access readily available psychometric tests to understand more about their experiences (van Ballegooijen et al., 2016). Yet despite the multitude of support options available online, a large majority of people with mental health problems turn to peer support (Merchant et al., 2022).

1.10 Peer Support & Online Peer Support Forums

Mental health peer support is a recovery-oriented approach whereby individuals with lived experience of mental health problems provide support to others navigating similar challenges (Cooper et al., 2024). Peer support has always existed at a community level (Bond & Ahmed, 2016). Rooted in the 1970s UK service user movement, built upon a user-led ethos and upheld by principles of mutual respect and reciprocity, peer support involves the exchange of stories, knowledge, and emotional support (Iliffe & Thompson, 2019). Peers are experts through experience who provide compassionate insight, empathy, and encouragement to those with shared difficulties (Lloyd-Evans et al., 2014). In the UK, there is growing advocacy for peer support in mental health care (Shalaby & Agyapong, 2020). Multiple well-established psychological theories and health-based models provide frameworks for understanding the processes and mechanisms via which peer support may promote positive psychosocial outcomes. For example, the Helper Therapy Principle (Reissman, 1965), which suggests beneficial boosts to self-esteem, self-efficacy and motivation to recover are produced via a self-help effect. Self-Determination Theory (Deci & Ryan, 1985), which helps to explain how peer support can promote recovery by fulfilling individuals' needs relating to autonomy, competence and relatedness. The Health Belief Model (Rosenstock, 1966), which can help to explain the effectiveness of peer support, showing that when people realise the severity of their mental health problems and also believe that peer support will help, they will derive meaningful benefits. Social Learning Theory (Bandura, 1977), which shows that people gain confidence and ultimately improve their coping skills and health behaviours by observing peers successfully managing similar challenges. While peer support is not designed to replace professional mental health interventions and traditional healthcare services, it can complement these services or act as a bridge to accessing them (Lyons et al., 2021; McCosker, 2018).

In terms of online mental health peer support, MHFs provide immediate ways for individuals experiencing psychological distress to engage in reciprocal emotional and informational support (Lyons et al., 2021; McCosker, 2018). MHFs typically support anonymous, asynchronous textual communication, which, in offering a space to write down thoughts, feelings and experiences, can be both an emotionally cathartic and empowering experience (Dean et al., 2016; Glossop et al., 2025). Examples of MHFs include NHS-hosted forums (e.g. “Support Hope and Recovery/Resource Online Network” [SHaRON]), charity-based forums (e.g. "Side by Side" at MIND), mental health social networking groups (e.g. Facebook groups such as “Living with Psychosis”), health-related groups on discussion-oriented websites (e.g. "r/depression" on Reddit) and health-focused groups on other servers (e.g. "The Therapy Centre" on Discord).

Primary motivations for accessing MHFs and Online Health Forums (OHFs) in general stem from the drive to access or exchange health information and emotional support (Liffe & Thompson, 2019; Naslund et al., 2016). For example, individuals with a recent health diagnosis generally have limited time to discuss this with health professionals, especially as, due to high demand and limited resources, standard General Practitioner (GP) appointments in the UK last for only ten minutes (NHS, 2023). Therefore, OHFs provide the opportunity to discuss their diagnoses and experiences in more depth (Bhamrah et al., 2015; Farnood et al., 2022). Similarly, those in a health crisis may seek signposting information via OHFs and/or connect with like-experienced others for the purpose of therapeutic unburdening (Hargreaves & Bath, 2019). While OHFs are favoured by those who lack in-person social support, conversely, they are also preferentially accessed by those from close-knit communities where in-person social support may be abundant, but the opportunity for anonymity scarce (Farmer et al., 2020).

Those using MHFs may experience multiple benefits (Prescott et al., 2020; Suresh et al., 2021), including increased feelings of connectedness (Smith-Merry et al., 2019), hope, empowerment (Naslund et al., 2016), and social support (Zhang, 2017). Interacting with peers in MHFs has been found to reduce depression (Naslund et al., 2016), isolation (Zhang, 2017) and stigma (Chan et al., 2016). Online MHF engagement also appears to be of particular benefit to individuals experiencing serious mental illnesses, including bipolar disorder, schizophrenia, and psychosis (Bauer et al., 2013; Highton-Williamson et al., 2015; Spinzy et al., 2012). For families and carers of those with mental health problems, MHFs can provide essential information and opportunities to access support (Jones et al., 2022), which is significant as online social support can act as a buffer against the negative health impacts associated with caregiving (Daynes-Kearney & Gallagher, 2023).

Regarding physical health and long-term conditions, OHFs hold significant value for their users (Greene et al., 2011; Lian & Nettleton, 2015) as traditional in-person support networks often struggle to connect those with shared lived experiences. OHFs, however, given their extensive reach, provide opportunities for people to connect (Bond & Ahmed, 2016). OHFs also support those whose health conditions limit or complicate access to in-person support (Gupta & Schapira, 2018). Forum participation for those with physical health conditions can facilitate empowerment (Brady, 2015) and symptomatic relief (Teasdale et al., 2020) while improving overall health and survival rates (Joglekar et al., 2018). Families and carers of those with physical health conditions can also benefit significantly from the information and support accessed via OHFs, as it can assist with everyday problem-solving (Kinnane & Milne, 2010) and provide new insight that improves the caregiving relationship (McKechnie et al., 2014). That said, the idea of discussing personal issues online may not be appealing to some people, and OHF use may not always be a positive or helpful experience, especially in forms that are not adequately moderated (Daynes-Kearney & Gallagher, 2023).

Individuals can also risk exposure to misleading health information and upsetting content online (Bizzotto et al., 2023; Hargreaves & Bath, 2019); this may be of particular concern for carers, who can experience confusion and distress when seeking information online (Sillence et al., 2016). A randomised controlled trial exploring the effect of digital psychoeducation and peer support on the mental health of family carers supporting individuals with psychosis concluded there were few positive and significant impacts on their mental health (Sin et al., 2022). Additionally, discourse around mental health within MHFs can sometimes contribute to stigma rather than reducing it (Horwood et al., 2023), and a small minority of forum users may feel worse after visiting MHFs (Mokkenstorm et al., 2019). Furthermore, a systematic review examining the effectiveness of online peer-to-peer support for younger people with mental health problems (Ali et al., 2015) identified only two randomised controlled trials that reported statistically significant positive outcomes (including improvements in symptoms and increased perceived support), when compared to control groups post-intervention.

Still, despite potential risks, online MHFs are often more accessible than in-person support (Newman et al., 2019), and those using MHFs tend to value the comfort, normalcy and consistency of online forum interactions (Hargreaves & Bath, 2019). Furthermore, the balance between potential risks and benefits of MHF use may be mediated by the forum environment itself. As Marshall et al. (2024) found, online MHF use offers significant benefits, including reduced isolation, validation and normalisation of mental health experiences, mutual encouragement and enhanced mental health self-efficacy but only in contexts where individuals experience psychological safety, active participation and protection of their well-being through effective forum moderation and assurance of anonymity. The anonymity OHFs provide is often acknowledged as a critical factor in their use, as it fosters disclosure among those embarrassed by their illness and provides a sense of safety (Rains, 2014). This may be especially true for those with mental health problems, who, due to stigma, are particularly concerned with ensuring their experiences remain confidential and separate from their offline lives (Marshall et al., 2025). This sense of safety, in turn, supports more uninhibited expression of self (Andalibi & Flood, 2021; Smith-Merry et al., 2019).

While several theories and models that illuminate the mechanisms of traditional peer support were noted in the previous section of this chapter, there is not yet enough evidence to conclude whether such models apply to MHFs in terms of their explanatory power (Rayland & Andrews, 2023). Still, new models that focus on online peer support have begun to emerge. For example, Naslund et al (2016) proposed a conceptual model depicting how online peer support contributes to positive mental health outcomes by enabling people to challenge and reduce stigma, increase self-management and gain access to supportive interventions. Their model outlines key mechanisms such as shared lived experience, reciprocal support and digital social connection as being central to the promotion of recovery-focused outcomes. In addition, Marshall et al. (2024) developed an explanatory framework based on a realist synthesis, showing how facets such as psychological safety, relevant content and supportive forum moderation interact and result in mechanisms that help to reduce isolation, normalise mental health experiences, and foster mental health self-efficacy. However, such models are yet to be widely tested.

1.11 Types of User Engagement in Online Health and Mental Health Forums

Given the fact that there is limited research focusing specifically on user engagement within MHFs, this section draws on broader literature from both MHFs and OHFs more generally, in order to explore common patterns of user engagement. Existing research indicates that the users of OHFs are diverse in terms of how they choose to engage within the forums they use and that for some people, there are more benefits from their engagement style and interactions than for others (Fullwood et al., 2019). One systematic review of user participation styles within OHFs (which also encompassed 6 MHFs) uncovered 41 unique user participation styles across the OHFs, which ranged from highly visible and proactive engagement styles such as influential users, community leaders and frequent initiators to more niche participation styles such as “topic-specific responders” (Carron-Arthur et al., 2015). Yet despite evidence for such participation diversity, users in OHFs (including MHFs) typically fall into one of three overarching participation categories: (1) forum observers, (2) forum contributors and (3) forum superusers (van Mierlo, 2014).

Forum observers (sometimes referred to as ‘lurkers’) passively engage in forums by reading other members' posts without contributing content. Reasons for passive engagement range from concerns over privacy and feeling that they do not belong to innate challenges in expressing personal feelings and experiences (Fullwood et al., 2019). Some may also avoid contributing to MHFs as they fear distressing others (Marshall et al., 2024). Yet observers may still benefit by fulfilling informational needs and taking inspiration from others' experiences. This, in turn, may reinforce continued observation and a reduced need for active participation as goals are being met through “lurking” (Fullwood et al., 2019). Statistically speaking, observers account for around 90% of all users within OHFs (van Mierlo, 2014). Forum contributors, on the other hand, who contribute intermittently, make up approximately 9% of users. Intermittent participation may be driven by a higher level of selectivity where these users only engage with posts that align with their own experiences or needs (Carron-Arthur et al., 2015).

Then there are forum superusers who, despite representing the smallest proportion of users within OHFs (1%), are highly active members who post around 75% of all content (van Mierlo, 2014). Superusers may spend up to 20 hours each week engaging in OHFs (De Simoni et al., 2020) and are essential to the stability and success of forums, with network analysis and simulation models showing that their removal would lead to fragmentation of online communities and subsequent collapse (Joglekar et al., 2018). The imbalance in participation between forum observers, contributors, and superusers is a phenomenon referred to as the “1% rule” (van Mierlo, 2014).

1.12 Research Gap and Thesis Rationale

Superuser research is in its infancy, and preliminary literature searching indicates that while there is some emerging literature on the bidirectional impacts (i.e. how superusers influence forum communities and conversely how forums affect superusers themselves) between superusers and OHFs in general, this literature remains both limited and largely fragmented across disciplines. For example, while a growing body of research has investigated the impact of OHFs on their users (see Chapter 2 for a more detailed review of this literature), the impact of OHFs on superusers specifically has rarely been explored. While some studies, such as De Simoni et al. (2020), have offered insights into such impacts through examining superusers' motivations and online behaviours, it is important to note that exploration of these impacts was not the primary focus. Additionally, while some discussion on the impacts superusers themselves have on forums is evident within the published literature (e.g. De Simoni et al., 2020; Gopalsamy et al., 2017; Healey et al., 2014; Joglekar et al., 2018; Panzarasa et al., 2020; van Mierlo, 2014; Wang et al., 2021), to date, this body of existing literature has not been systematically reviewed.

Bringing together existing but fragmented research is important because, otherwise, knowledge of the bidirectional impacts of forum super use remains limited in its scope. For example, where health-based research has explored the impact of online forum super use regarding peer support dynamics (e.g. De Simoni et al., 2020), other research has centred on online network analysis, focusing on structural patterns and the subsequent impact of high frequency user influence (e.g. Joglekar et al., 2018) yet as things stand these findings remain isolated due to their lack of integration. Accordingly, a systematically conducted integrative literature review of the literature, which brings together disconnected but related strands of research such as these, is essential in order to understand the broader context of those bidirectional impacts (see Chapter 2 for an extended rationale).

In addition, despite the central role that superusers play in sustaining MHFs, very little is known regarding their lived experiences of engagement. As a result, key questions regarding the overall engagement experiences of MHF superusers, in addition to what motivates such high levels of engagement and what challenges or burdens are encountered as a result of this level of forum use, remain unanswered. Answers to such questions are important because, with little insight into superusers' experiences and support needs, MHFs risk potentially losing and/or harming these crucial users, whereas with more understanding of these bidirectional impacts, forum hosts can ensure they design forums and forum policies that care for their superusers. Some recent studies have acknowledged this research gap and have called for the exploration of OHF superusers' experiences, motivations and support needs (De Simoni et al., 2020; Joglekar et al., 2018; van Mierlo, 2014).

Research exploring both the bidirectional impacts of OHF super use and forum superusers' engagement experiences is opportune, given a recent commitment by the NHS to enhance peer support services (NHS England, 2019). This research will also address a top priority for digital technology in mental health care as set out by the James Lind Alliance: "What are the benefits and risks of delivering mental health care through technology?" (Hollis et al. 2018).

Additionally, this research reflects the Department of Health and Social Care Outcome Delivery Plan (2021-2022), which aims to improve support for people with mental health conditions via digital reform (Department of Health and Social Care, 2021). Furthermore, this research is necessary because, at present, organisations like the NHS are increasingly prioritising their digital agendas and investing in the creation of online peer forums (Bucci et al., 2019; Merchant et al., 2022). However, online peer support forums can only thrive if they support, retain and safeguard their superusers (Joglekar et al., 2018; Panzarasa et al., 2020). The research this thesis comprises has the potential to create new knowledge that can guide the organisations that design and maintain MHFs on how best to involve, support and safeguard the superusers of their online forums.

1.13 Overarching Thesis Aims

This PhD thesis aims to address the critical knowledge gaps noted above by conducting two pieces of research:

(1) A comprehensive synthesis of existing literature on the bidirectional impacts of forum super use within the broader context of OHFs. This includes reviewing literature on how superusers influence OHF environments and functioning, in addition to how OHFs impact their superusers, and the development of a new conceptual model to better understand these impacts.

(2) A qualitative exploration of the engagement experiences of MHF superusers. This involves inviting superusers of MHFs to share their experiences of forum engagement, including their motivations for sustained engagement and any challenges or burdens they face as a result of their super use, to generate new

insights into their experiences while identifying potential generative mechanisms underpinning their super use to inform future policy and practice.

The rationale for combining a literature review with a qualitative study is that each contributes distinct yet complementary insights into OHF/MHF super use. The literature review synthesises existing knowledge, linking previously disconnected strands to create a coherent picture of the impacts of super use across a diverse range of OHFs, while also identifying evidence gaps and research priorities. The qualitative study then builds on this by generating rich experiential insights into superusers' engagement in MHFs specifically. Together, they create an iterative dialogue between existing research and new experiential data, generating knowledge that is both theoretically original and practically significant, with implications for policy and practice.

1.14 Thesis Overview

Chapter 1 presented a broad contextual background for this PhD, outlining mental health, help-seeking, peer support, and online peer-led forums, with a focus on superusers. This chapter identified prominent knowledge gaps and offered initial rationale for the research that follows.

Chapter 2 presents an integrative literature review on the bidirectional impacts of superusers and OHFs. In doing so, it builds on the background knowledge presented in Chapter 1 by broadening the scope of the research landscape to include a focus on a wide range of OHFs (including MHFs) while also narrowing the topic to centre specifically on superusers. The chapter outlines the review's rationale, methodology, and provides rationale for key methodological choices. Findings are presented alongside a novel conceptual framework, developed via framework synthesis.

Chapter 3 presents the methodology for the qualitative Reflexive Thematic Analysis (RTA) study of superuser engagement experiences in MHFs. It provides the research rationale, research questions, and a critical discussion of methodological decisions, including philosophical foundations, theoretical considerations, and practical aspects such as sampling, data collection, and analysis. The chapter concludes with reflections on the integration of PPI including its role in shaping the research design.

Chapter 4 presents findings from the RTA study of superusers' engagement experiences in MHFs, beginning with an overview of the study participants, including key demographic characteristics and self-reported reasons for engaging in high-frequency MHF use. A thematic map outlines the generated themes and their relationships, followed by detailed analytic narratives exploring the five main themes.

Chapter 5 presents a critical discussion of the research findings, integrating insights from both the literature review of the bidirectional impacts of superusers and OHFs and the RTA study of superuser engagement experiences in MHFs. It situates findings within existing literature and theoretical frameworks, including the novel conceptual framework created as part of the literature review, and addresses research strengths, limitations, and future directions, as well as implications for practice and policy. The chapter concludes with the overarching thesis conclusion.

Chapter 2: The Impacts of Superusers in Online Health Forums: An Integrative Review and Conceptual Framework

2.1 Chapter Introduction

This chapter builds on the background established in Chapter 1 by narrowing the research area focus and presenting an integrative conceptual literature review on the bidirectional impacts of superusers and OHFs. These bidirectional impacts encompass (1) how superusers impact the functioning and therefore the community environment of OHFs and (2) how OHFs impact superusers themselves. The chapter begins by introducing key facets of existing knowledge on OHFs and superusers before presenting the review aims, questions, and rationale. Details of philosophical positioning and stakeholder involvement come next. The systematic search strategy is then outlined alongside comprehensive details of its development and testing. Next, the eligibility criteria are presented, the PRISMA flow diagram is outlined, and the review approach and rationale for its selection are discussed. The chapter then details data extraction, quality appraisal, and quality assurance approaches before outlining the synthesis approach and conceptual framework development. Review results are presented narratively, tabularly, and via a refined conceptual framework. Findings are discussed in depth, and strengths and limitations are highlighted. The chapter concludes by detailing implications for future research and practice.

2.2 Background

OHFs are widely accessible, web-based platforms that help those impacted by health conditions, along with their carers, to connect. As noted in chapter 1, OHFs have seen a significant increase in use since the onset of the COVID-19 pandemic, reflecting both improved digital literacy and access, in addition to a growing reliance on and normalisation of online peer-based support (NHS England, 2023; Balabaskaran et al., 2024). While most people access OHFs for emotional or informational purposes, not everyone who engages with forums does so in the same way, with OHF users typically being considered forum observers, forum contributors, or forum superusers according to their levels of engagement (van Mierlo, 2014). What's more, someone may be considered an observer of one forum but a superuser of another, as OHF users do not necessarily exhibit consistent engagement patterns or levels of activity across different online platforms (Fullwood et al, 2019). Still, those identified as superusers, sometimes referred to as "high frequency" or "influential" users, play a pivotal role in sustaining online communities by catalysing engagement. They do this by creating the majority of new forum content and therefore providing more information than other contributing forum members (Dias et al., 2012). Additionally, superusers tend to show a preference for providing support over soliciting it, which likely contributes to fostering a supportive online environment (Carron-Arthur et al., 2016a). While little is known regarding the characteristics, traits and experiences that lead individuals to become superusers of OHFs, emerging research indicates altruism and attempts to satisfy psychological needs associated with relatedness, competency, and autonomy may drive such use (De Simoni et al., 2020).

Systematic reviews exploring the impact of OHFs on their users are abundant, exploring (1) how cancer forums impact the well-being, mental health and quality of life of their users (van Eenbergen et al., 2017); (2) the impact of MHFs on depression (Griffiths et al., 2009); (3) the relationship between OHFs and patient empowerment (Johansson et al., 2021); (4) how OHFs impact the daily lives of those with chronic illness (Kingod et al., 2017); and (5) the impact of OHFs on mental health symptomology and recovery outcomes (Ali et al., 2015; Lyons et al., 2021). However, to date, the impact of OHFs on different types of forum users (e.g. superusers) has not been explored. Additionally, as noted in Chapter 1, there is ongoing discussion on the impacts superusers have on the functioning of OHFs within current literature (e.g. De Simoni et al., 2020; Gopalsamy et al., 2017; Healey et al., 2014; Joglekar et al., 2018; van Mierlo, 2014), but to date, this research has not been reviewed.

The purpose of this review is to synthesise existing literature on the bidirectional impacts of OHFs and superusers, that being: (1) the impacts superusers have on the functioning of OHFs and (2) the impacts OHFs have on superusers themselves. As policy frameworks worldwide are increasingly highlighting the importance of online peer-led forums, and given the widespread use of OHFs and the increasing integration of OHFs into healthcare systems, a review of this nature will allow practitioners, policymakers, and organisations like the NHS, who are increasingly prioritising their digital agendas (Bucci et al., 2019; Merchant et al., 2022), to better understand how to support, safeguard and utilise the superusers of OHFs (Joglekar et al., 2018; Panzarasa et al., 2020). Additionally, gaining insight into the theoretical frameworks and models applied to literature in this area may help to illuminate the underlying mechanisms of online peer support, an understanding of which is essential in order to fully understand how peer support works and why it is effective (Rayland & Andrews, 2023). While

Chapter 1 highlighted preliminary research gaps based on initial and informal scoping of the literature, the outcomes of this review will help to establish additional priorities for future research.

2.3 Review Questions

This literature review aims to address the primary review question:

1. What is known about the bidirectional impacts of superusers and OHFs?

Given the emerging nature of superuser research, the review will also explore the secondary questions:

2. How does existing literature conceptualise online health forum superusers?
3. What theoretical frameworks and methodological approaches have been used in existing literature on superusers and OHFs?

Gaining insight into how existing literature conceptualises OHF superusers is crucial to understanding who superusers are, how they engage within forums and the nature of their influence within forums. A clear understanding of superusers will also provide context for interpreting their impacts within OHFs and vice versa.

Regarding exploring the theoretical approaches and methodological frameworks used within existing OHF superuser research, a greater understanding of these choices will provide a clear overview of how the phenomena has been studied so far and the range of theory employed. This will help to establish a comprehensive knowledge base that can inform the use of appropriate psychological theories and methodologies in future research.

2.4 Review Approach

This literature review employs Whittemore and Knafl's (2005) five-step integrative review process: (1) identifying the problem, (2) searching the literature, (3) evaluating the data, (4) analysing the data, and (5) presenting the findings. While there are numerous ways to conduct integrative literature reviews (Beyea & Nicoll, 1998; Cronin & George, 2023; Cooper, 1984; Russell, 2005; Souza et al., 2010), Whittemore and Knafl's (2005) approach is the most widely applied approach within health research.

Integrative reviews are valuable in the context of emerging research topics, as is the case with health forum superuser research, as they permit the amalgamation of a variety of sources, including empirical research (quantitative, qualitative or mixed methods studies), methodological literature (analysis of research designs and methodologies employed in different studies), theoretical literature (review of theories) and grey literature (documents not controlled by commercial publishers [Adams et al., 2016]) (Whittemore et al. 2014). Bringing together research rooted in different paradigms is challenging as it requires reconciling and integrating evidence underpinned by different methodological approaches and philosophical assumptions (Toronto & Remington, 2020). However, this integration can result in more comprehensive understandings and new perspectives (Berry & Colorafi, 2019; Cronin & George, 2023). Additionally, while approaches such as scoping reviews are suitable for emerging research topics (Munn et al., 2018), a further advantage of an integrative review is its ability to lead to the generation of novel conceptual frameworks (Lubbe et al., 2020).

Furthermore, while scoping reviews may guide future research, integrative review findings can directly inform evidence-based practice (Cronin & George, 2020) and policy-based decision-making (Rand et al., 2019; Garside, 2014).

2.5 Philosophical Positioning

This integrative literature review is grounded in critical realism (Bhaskar, 1975). Accordingly, the reviewer acknowledges reality as stratified, independent of thoughts, beliefs, and experience. Additionally, the reviewer recognises that the social world can only be fully understood within the context of its underlying generative mechanisms. It is not common to state the philosophical grounding of literature reviews (Schryen et al., 2015). However, the reviewer does so here to support the reader in gaining insight into the nature of the knowledge sought via this review (de los Santos et al., 2022), that being contextually sensitive, explanatory knowledge that takes into account experiences, observations and underlying causal powers but presumes understanding of reality is fallible and inevitably limited by individual perception (Roberts, 2014) (see Chapter 3 for a more detailed discussion of critical realism).

2.6 Patient and Public Involvement

While planning this literature review, the reviewer met with a group of three PPI advisors (two OHF users and one self-identified health forum superuser) to discuss perceptions of superusers of OHFs and research priorities. PPI members highlighted a need to know and understand the "impacts" of OHFs on superusers' well-being, as collectively the group pondered and discussed forum super use from a safety and harm prevention perspective. Questions on how much forum use might be “too much” were raised, and concerns about the potentially detrimental impact of forum use on mental health centred. However, these questions were also countered by comments on the potential beneficial impacts of heightened forum use, especially for those with limited social and work lives due to their mental health problems. Superusers felt there may be many beneficial impacts, but that it was important to explore the spectrum of those potential impacts. As a result, this priority directly informed the primary review question and helped to shape the initial conceptual framework utilised within this review (see "Conceptual framework development" for further details).

2.7 Methods

2.7.1 Search Strategy

Table 1 shows how the reviewer utilised the SPICE (Setting, Perspective, Intervention, Comparator, Evaluation) framework (Booth, 2006) to define search criteria aligned with the primary review question. While other frameworks such as PICO (Population, Intervention, Comparison, Outcome; Richardson et al., 1995) and SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type; Cook et al., 2012) are commonly applied within literature reviews, SPICE was chosen as it is more adaptable to reviews that seek to incorporate a broader range of study designs and outcomes. PICO, for example, is largely quantitative aligned and is not appropriate for a large variation in evidence types (Booth et al., 2019). While the SPIDER framework may have also been applicable, the inclusion of "design" and "research type" within SPIDER can be restrictive, potentially excluding relevant studies and creating a challenge in balancing the specificity and sensitivity as the inclusion of study design may bring back a large number of inappropriate search hits) (Methley et al., 2014). SPICE, in contrast, focuses on only the key conceptual elements of research.

Table 1

Application of the SPICE framework

Framework Component	Application
Setting	Online health forum.
Perspective	People with health conditions or mental health problems, or their carers.
Intervention	Active participation in online health forums.
Comparator	Frequency of forum use.
Evaluation	Impact(s) of forum use on superusers or impact(s) of superusers on forum functioning.

With support from a specialist librarian for Health and Medicine at Lancaster University (JB) and a Cochrane information specialist (LH), the reviewer developed a highly sensitive search strategy based on insights derived from the SPICE framework. Three overarching concepts guided the search strategy: (1) "Online", (2) "Forum/Community", and (3) "Superuser". Free-text terms incorporating synonyms, acronyms, abbreviations, variations in spelling, medical terminology, and lay language related to the main concepts were utilised. Table 2 outlines the primary search concepts with their alternative free-text terms.

Table 2

Key Concepts and Free-Text Terms

Concept 1: "Online"	Concept 2: "Forum/Community"	Concept 3: "Superuser
online OR digital OR web* OR internet* OR computer* OR electronic OR virtual OR OHC OR e-health OR ehealth OR eintervention* OR e-intervention* OR mhealth OR m-health	communit* OR forum* OR message* OR discuss* OR network* OR group* OR support OR advocacy OR "OHC" OR "peer" OR "peer-to-peer"	superuser OR super-user OR superusers OR champion OR high-frequency OR experienced OR expert OR influential OR senior OR key OR long-term OR longterm OR top OR engag* OR member* OR contribut* OR participa* OR influencer OR elder

To ensure comprehensive searching (Thielen et al., 2016), the reviewer searched the EBSCO-hosted databases MEDLINE, CINAHL, PsycINFO, and Academic Search Ultimate and the non-EBSCO-hosted databases Scopus (Elsevier), Web of Science (Clarivate), and Embase (Ovid). This database combination reflects Bramer et al.'s (2017) guidelines on effective searching, which suggests using a mix of multidisciplinary and subject-specific databases to improve search sensitivity. Subject terms were selected from databases using controlled vocabulary (i.e. the predefined dictionary of search terms or keywords found in some online databases) where available, and expanded (i.e. selecting predefined checkboxes that then include related or synonymous terms automatically in the search) , when appropriate (i.e. when the researcher felt suggested expansion terms were relevant and therefore likely to enhance the search comprehensiveness). Free-text and subject terms were combined using

Boolean operators, with proximity indicators and truncation utilised where feasible (Shaw et al., 2004). The reviewer translated the search strategy for each database according to individual database nuances. Such nuances included (1) the availability and applicability of subject headings, (2) the need to use unique search abbreviations, (3) the applicability of proximity indicators, and (4) the pragmatic need to establish a balance between sensitivity and specificity (see Appendix A).

2.7.2 Search Strategy Testing

During initial literature scoping using the terms "online”, "forum", and "superuser" in Google Scholar, the reviewer selected five studies (Carron-Arthur et al., 2015; Carron-Arthur et al., 2016a; De Simoni et al., 2020; Joglekar et al., 2018; and van Mierlo, 2014) for search strategy testing. These studies were selected based on (1) relevance to the review questions, (2) explicit use of the term “superuser” or “super user”, and (3) alignment with review eligibility criteria. Performing the search ("S1" AND "S2" AND "S3" AND "Test Paper Title") in Medline for each paper yielded all five results, therefore confirming effective literature retrieval.

2.7.3 Backward Citation Searching

Backward citation searching enables reviewers to discover relevant publications not uncovered during the original search (Brown University Library, 2021). The reviewer employed backward citation searching via manual exploration of the reference lists of included publications, reviewing titles and abstracts via Google Scholar. Where reference lists were not explicitly provided (e.g. in one grey literature publication), the reviewer explored embedded article hyperlinks. The reviewer retrieved and screened the full texts for potentially relevant articles. While forward citation searching is commonly employed alongside backward citation searching, it was not employed in this instance due to time constraints (Briscoe et al., 2019).

2.7.4 Grey Literature Searching

Including grey literature can provide valuable information not found in traditional scholarly sources (Bonato, 2018). Accordingly, the reviewer sought to include:

1. Research studies and reports (including theses and dissertations),
2. Government policy documents (including reports, surveys, white papers, and green papers with no geographical constraints).
3. Research and reports compiled by charities and other third-sector organisations.
4. Research and reports compiled by the NHS and other public sector organisations.
5. Expert opinion articles.

The reviewer sought grey literature via EThOS, Embase, Overton, TRIP, and Google Scholar. The Google Scholar "verbatim" option was employed to counter replicability issues (Bonato, 2018). Given the infeasibility of exploring all Google Scholar results, the reviewer explored the first 100 records (Haddaway et al., 2015).

2.7.5 Clinical Trials Registry Searching

Publication bias threatens the validity of literature reviews. However, searching clinical trial registries allows reviewers to become aware of any relevant clinical trials that remain unpublished (Hunter et al., 2021). Accordingly, the reviewer also searched for applicable clinical trials via the International Clinical Trials Registry.

2.7.6 Inclusion and Exclusion Criteria

The reviewer sought to create a list of comprehensive eligibility criteria for study selection with transparency and replicability in mind (McCrae & Purssell, 2015). Table 3 details the inclusion and exclusion criteria.

Table 3

Inclusion and Exclusion Criteria

Inclusion criteria	Description
Design	Permitted publication types: (1) Peer-reviewed academic research (all research designs, including reviews, theoretical literature, research protocols, opinion pieces, letters, and editorials). (2) Non-peer-reviewed academic research (theses, studies, conference abstracts and non-peer-reviewed opinion pieces, letters, and editorials). (3) Government documents (reports, surveys, white papers, and green papers). (4) Research and reports conducted by charities and other third-sector organisations. (5) Research and reports compiled by the NHS and other public sector organisations.

Setting/context	All online health forum settings centring peer-to-peer communication (see "concept: online health forum"). No geographical constraints.
Concept: “impact(s)”	A marked effect or influence. Impact(s) may be positive or negative. Impact(s) may be intentional or unintentional. Impact(s) may be referred to explicitly or implicitly. Include literature examining: (1) The impact(s) superusers have on how OHFs function. (2) The impact(s) of OHFs on superusers themselves.
Concept: "Online forum"	An internet-based platform facilitating text-based communication between users with shared health experiences. For this review, OHFs include: (1) NHS-hosted forums (2) Charity-based forums (3) Other health-oriented forums (4) Health-related groups hosted on social networking platforms (5) Health-related groups hosted on discussion-oriented websites (6) Health-related groups hosted on other group-chatting platforms (7) OHFs with both a positive focus (e.g. recovery-focused) and a negative focus (e.g. anti-recovery/promotes harm). (8) OHFs may include moderated and unmoderated platforms. (9) OHFs may or may not have input from professionals or employed peer workers.
Concept: "Health"	For this review, "health" within the context of online forums refers to: (1) All physical health conditions and diseases, whether acute or chronic/long-term. (2) Hereditary conditions and diseases. (3) Reproductive health (including pregnancy). (4) Degenerative diseases. (5) Infectious diseases. (6) Deficiency diseases.

	(7) Lifestyle-related conditions and diseases. (8) Mental health problems/conditions. (9) Mental health symptomology (without focus on specific diagnosis). (10) Addictions and addictive behaviours.
Concept: “Superuser”	(1) Studies must distinguish between forum user types, acknowledging users with a high frequency of forum use (superusers). (2) The term "superuser" does not need to be stated. (3) Superusers may be individuals with health conditions or their carers.
Publication date	Publications from 1994 to June 2023 (date searches were conducted) *Online forums first emerged in 1994 following the first World Wide Web conference (Reimer, 2024). Therefore, this timeframe reduces the likelihood of irrelevant literature retrieval.*
Language	Published in English or with an existing English translation available. *Given the self-funded nature of this PhD, it was not possible to consider enlisting translation services.*
Exclusion criteria	
Design	Exclude: (1) Visual and audio-based publications (including podcast episodes, documentaries, TED Talks, other academic and non-academic talks, other video-based sources, and graphics). (2) Article retractions, corrections, or reviews. (3) Books (or book chapters) or their reviews. *These exclusions limit the likelihood of duplicate data, focus on text-based publications, and consider time and resource limitations.*
Population	Exclude studies with an exclusive focus on participants under 18. Where age data isn't available or implied, assume forums contain adult participants.

	Children and adolescents' cognitive and emotional development differ from those of adults, meaning the impacts of superusers in OHFs may also vary among these populations.
Concept: "online forum"	Exclude: (1) Focuses exclusively on well-being (without an overarching mental or physical health focus). (2) Focuses on neurodivergence (without a mental or physical health focus). (3) Focuses on learning disabilities (without a mental or physical health focus). (4) Primarily focuses on video or image-based content (e.g. TikTok, YouTube). (5) Primarily focuses on synchronous communication (e.g. real-time chat rooms). (6) Social media platforms that do not explicitly acknowledge the use of a private community group within that platform (e.g. Facebook but not a Facebook group).

2.8 Data Extraction

The reviewer designed a data extraction table that considered the review questions and the heterogeneous nature of included publications (Torraco, 2005). Extracted data included: (1) title and DOI, (2) journal/place of publication, (3) funding and conflicts, (4) design and methodology, (5) health forum focus, (6) population, (7) theoretical/conceptual framework, (8) superuser definition/conceptualisation (9) impact measure and type, (10) key findings, (11) study limitations and (12) pertinent notes/reflections. The reviewer and second reviewer (JF) piloted data extraction using a random sample of five test papers (Büchter et al., 2020). The reviewer then extracted data from each eligible study, and a second reviewer (JF) validated 10% of the extracted data to ensure accuracy (see Appendix B).

2.9 Quality Appraisal

Due to the diverse nature of publications included in integrative reviews, the use of several quality checklists is common (e.g., Mullen et al., 2022). However, evaluating the quality of a body of evidence becomes challenging and time-consuming when employing multiple checklists (Sirriyeh et al., 2012). Therefore, the reviewer selected the quality appraisal for diverse studies (QuADS; Harrison et al., 2021) checklist to appraise included publications wherever possible. While checklists are limited in their ability to consider the paradigmatic underpinnings and coherence of research (Morse, 2021), the QuADS tool has shown strong reliability when applied to health-based reviews that include heterogeneous literature (Harrison et al., 2021). The tool uses 13 reporting criteria to assess study quality across several methodological dimensions with ratings for each item range from 0 to 3, with higher scores indicating higher quality (See Appendix C for full criteria). In one instance where the QuADS tool was not applicable as the publication was a web-based article, the reviewer utilised the Joanna Briggs Institute (JBI) Checklist for Textual Evidence: Expert Opinion appraisal checklist (McArthur et al., 2020). The JBI checklist consists of 6 questions that assess the quality and legitimacy of the option presented. The questions elicit a binary response (yes/no) to help reviewers determine the publication's overall quality (see Appendix D). For all appraisals, to reduce errors, the reviewer conducted quality assessments independent of data extraction (Barnett-Page & Thomas, 2009; Toronto & Remington, 2020).

Reviewers may exclude low-quality literature from reviews (Hannes & Macaitis, 2012). Still, this process is subjective (Thomas & Harden, 2008), and while lower-quality studies may introduce bias, they can also offer value (Mays & Pope, 2000; Morrow, 2005), especially in new research areas (Garside, 2014). The creators QuADS advise against using a cut-off quality score (Harrison et al., 2021). Accordingly, all publications were included.

2.10 Quality Appraisal in Action

To enhance screening quality, the reviewer and a second reviewer (JF) first assessed 20 titles and abstracts against the eligibility criteria, comparing results (Polanin et al., 2019); this process led to the clarification of language around eligibility criteria, to enhance the likelihood of including relevant literature (Meline, 2006). Two reviewers (JF & HL) double-screened 20% of the retrieved titles and abstracts (Waffenschmidt et al., 2019), resolving conflicts via discussion. To improve accuracy, reduce ambiguity, and assure transparency (Moher et al., 2009; Sarkis-Onofre et al., 2021) when reporting review insights, the reviewer used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 guidelines (Page et al., 2021). A literature review protocol was also published in the PROSPERO database (Schiavo, 2019).

2.11 Data Synthesis

There is little guidance on the best approach to data synthesis in integrative reviews (Noyes et al., 2014), and published integrative reviews generally provide only surface-level details (Dwyer, 2020). Integrative reviews commonly utilise content analysis, thematic analysis and, increasingly, framework synthesis (Brunton et al., 2020; Toronto & Remington, 2020). After discussing approaches with a second reviewer (JF), the reviewer selected framework synthesis (Oliver et al., 2008) for this review.

Framework synthesis, originating from framework analysis (Miles & Huberman, 1984; Pope et al., 2000; Ritchie & Spencer, 1994), is a flexible, pluralistic approach that transcends disciplinary and epistemological boundaries (Brunton et al., 2020; Michelson et al., 2022). It is, therefore, particularly suited to (and increasingly utilised within) health-focused integrative literature reviews (e.g. Michelson et al., 2022; Jackimowicz et al., 2017; Kennedy et al.,2019; Orth & van Wyk, 2022). Framework synthesis is compatible with the critical realist foundations of this thesis (Brunton et al., 2020), as it enables researchers to theorise the causal mechanisms underpinning conceptual models (e.g. Demain et al., 2015; Gough et al., 2012). Furthermore, within the context of integrative reviews, framework synthesis has led to findings that have directly informed research and policy (e.g. Barnett-Page & Thomas, 2009; Petticrew et al., 2013).

2.11.1 The Stages of Framework Synthesis

The reviewer incorporated Oliver et al.’s (2008) five-stage framework synthesis process into this integrative literature review:

1. Familiarisation: this stage involved becoming familiar with the research landscape. The researcher informally scoped the literature on superusers and OHFs by searching "online”, "forum", and "superuser" in Google Scholar to gain an overview of existing OHF superuser research.
2. Initial framework construction: this stage involved creating an initial framework based on background knowledge. Pertinent data from background studies was

inductively coded and clustered to capture concepts. Key concepts were also taken from the review questions and PPI discussions. The researcher sketched several frameworks on paper before creating a digital version in Microsoft Word. To maintain a clear, focused framework, the reviewer deliberately centred the framework around concepts relevant to the primary research question only. This framework served as a provisional, flexible starting point (see Appendix E for further details of this process).

3. Data indexing: after systematically seeking and screening the literature (see section 2.7 of this chapter), indexing involved extracting pertinent study characteristics and findings relevant to the review questions into a custom-designed table in Microsoft Excel. The table included extracted data on the study authors, year of publication, journal of publication, author conflicts, study design and methodology, study aims, OHF type and focus, study population, theoretical/conceptual framework use or creation, superuser definition or conceptualisation, impact(s) (including measure and type), key findings and study limitations.
4. Data charting: this stage involved comparison of key characteristics and findings by coding these facets according to observed patterns. Codes were then clustered into overarching themes (Brunton et al., 2020). The researcher initially manually coded data within an Excel document before extracting these codes into tables, where they were rearranged and clustered. From this process, eleven unique codes relating to the impacts of superusers on OHFs were generated, resulting in three overarching themes. Additionally, sixteen

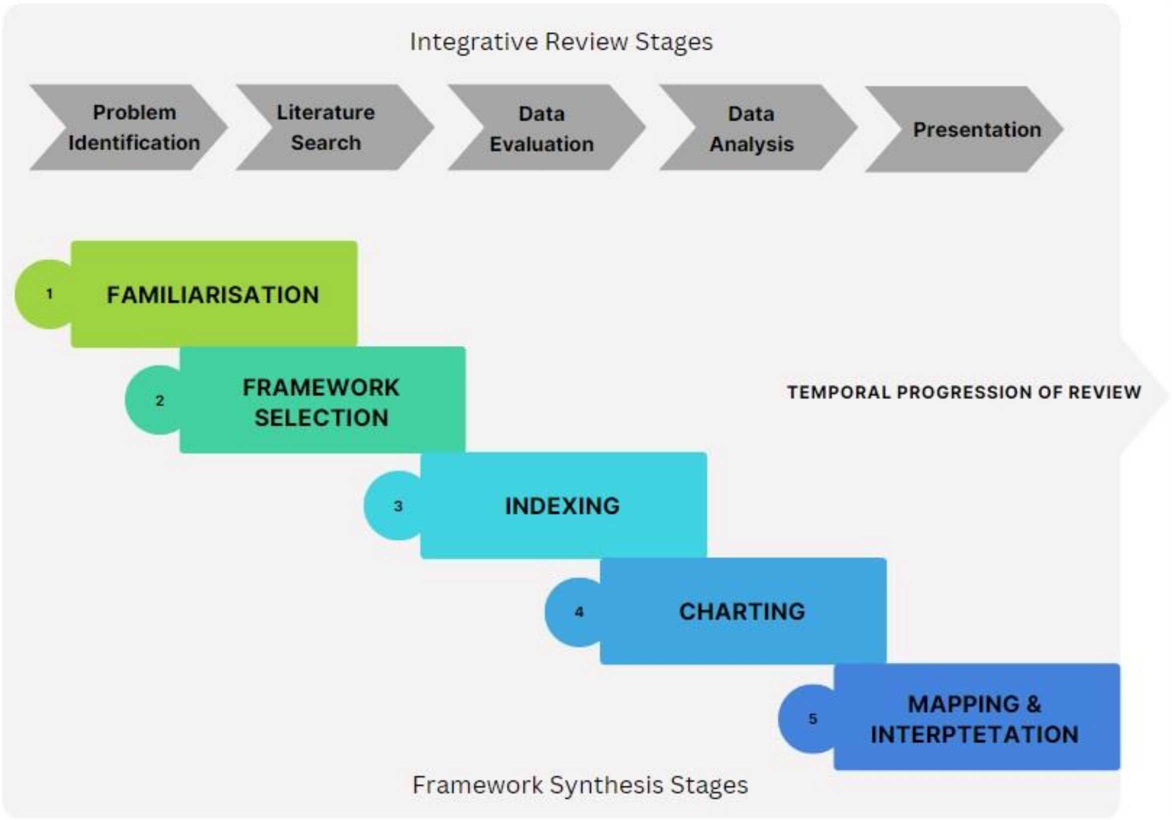
codes relating to the impacts of OHFs on superusers themselves were generated, resulting in two overarching themes (see appendix F for full details).

5. Mapping and interpreting findings: this stage involved considering themes within the context of the review questions, presenting and discussing the findings textually, tabularly and graphically via a refined conceptual framework (See section 2.5 of this chapter).

Figure 1 presents an overview of the five stages of framework synthesis to show how they relate to the integrative review process.

Figure 1

Application of framework synthesis within the integrative review process



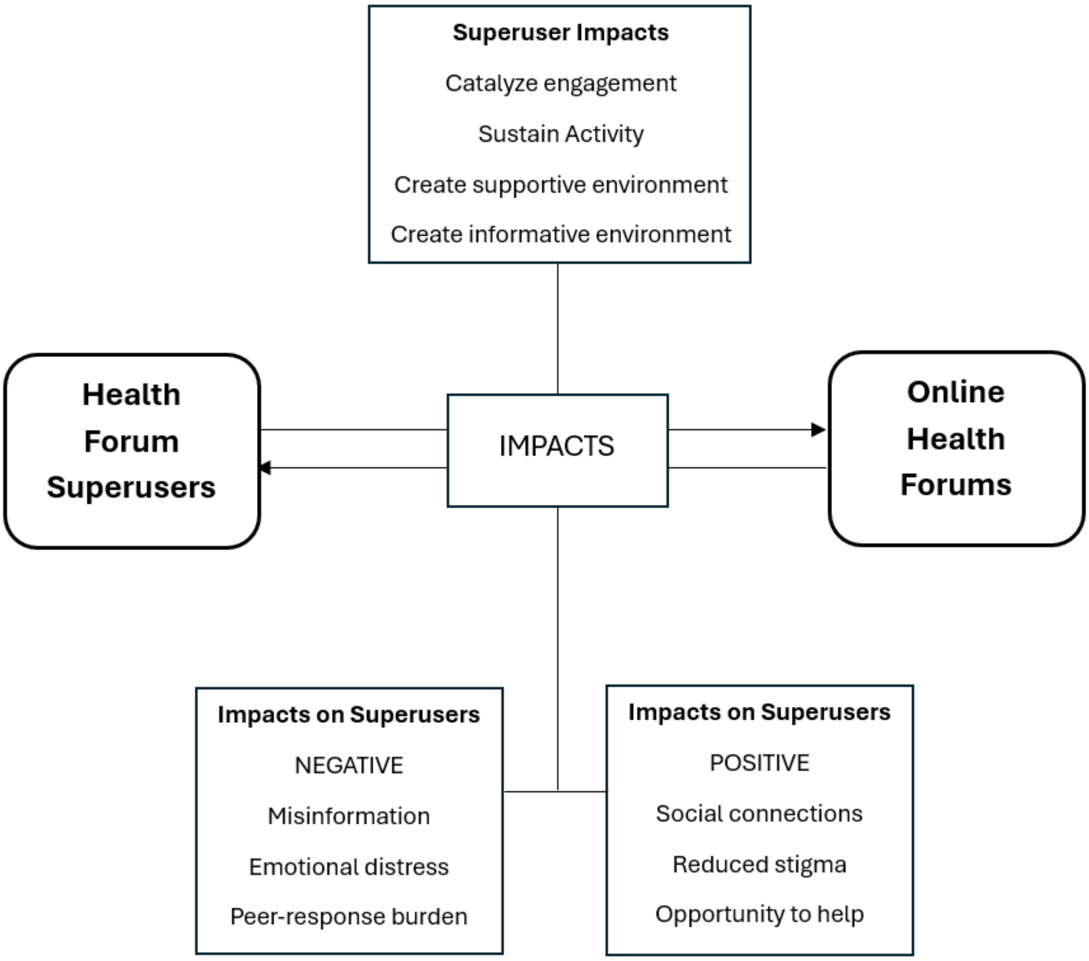
(Adapted from Brunton et al., 2020)

2.12 Conceptual Framework Development

Figure 2 presents the initial conceptual framework that provided a flexible foundation for data organisation (Michelson et al., 2022; Dixon-Woods, 2011). The framework depicts the reviewer's initial understanding of potential key concepts and their presumed relationships (Luft et al., 2022).

Figure 2

Initial Conceptual Framework



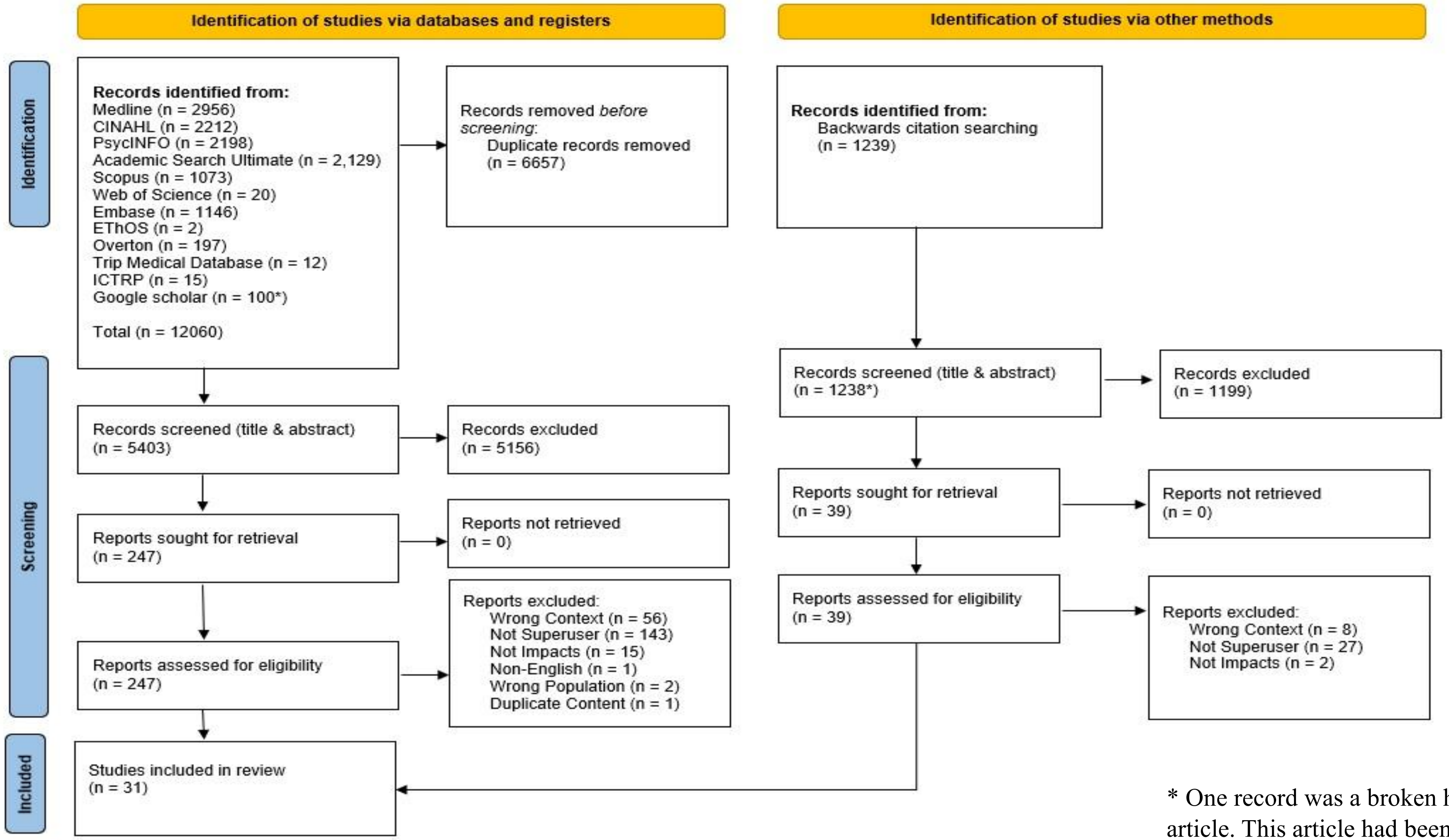
2.13 Results

2.13.1 Overview

This review includes 31 publications comprising 17 quantitative primary research papers, six qualitative primary research papers, four mixed methods primary research papers, a systematic review of quantitative studies, a review of grey literature, a master's degree thesis and an expert opinion article. Almost one-third of the research papers were published in journals from the Journal of Medical Internet Research (JMIR) family, including the main JMIR and its sub-journals JMIR Mental Health and JMIR Diabetes. While most publications did not focus on forum superusers exclusively, all touched on the bidirectional impacts of superusers and OHFs in some way. Publications were of moderate to high quality. QuADS scores ranged from 14 to 36 (M = 27; SD = 4.95), with common methodological strengths including clear reporting of study aims, appropriate use of design choice, well-designed data collection procedures and transparency of results reporting. An additional publication appraised using the JBI NOTARI scoring system received the highest possible appraisal score, indicating strong methodological practice across all measured aims. Almost all publications (n = 30) focused on OHFs promoting recovery or symptom management, while one focused on an anti-recovery forum. Figure 3 presents the PRISMA diagram for this review, while Table 4 outlines pertinent publication characteristics, including the various methodological approaches taken.

Figure 3

Prisma 2020 Flow Diagram



* One record was a broken hyperlink to an online article. This article had been permanently deleted from its host website and therefore could not be screened.

Table 4

Characteristics of Included Publications

First author, year and country	Design and data collection	Setting and sample	Key Findings	Quality appraisal
Batenburg & Das. (2014). Netherlands	Two-wave longitudinal study. Online questionnaires.	Breast cancer. N = 133.	Patients who were highly active in the OHF and scored low on emotional approach to coping experienced increased emotional well-being.	33 (QuADS)
Bayen et al. (2021). France	Prospective observational study. Netnography.	Parkinson's disease. N = 70.	Forum leaders monopolise discussions, launch new themes, detailing scientific facts and answer directly to users, referring to them by name.	26 (QuADS)
Biyani et al. (2014). USA	Observational study. Machine learning.	Cancer survivors. N = 5516.	Influential members provide significantly more emotional support than other forum members.	25 (QuADS)
Carron-Arthur et al. (2015). Australia	Systematic review of quantitative papers.	Smoking cessation, cancer, mental health, diabetes,	A total of 8 studies that made a unidimensional categorisation classified users	27 (QuADS)

		multiple sclerosis, and social innovation in health care. N = 77-49552.	into a "high-engaged" participation style. Associated metrics included posting frequency, thread initiation, thread participation, level of in-degree/out-degree, reading of posts, time logged in, and friendship.	
Carron-Arthur et al. (2016a Australia	Topic modelling. Computer-aided content analysis.	Mental health. N = 2932.	Superusers serve the role of emotionally supportive companions.	36 (QuADS)
Carron-Arthur et al. (2016b). Australia	Social network analysis.	Mental health. N = 2652	Highly active users were key to early-stage forum development. They communicated with new users regardless of shared characteristics and sustained forums over time.	29 (QuADS)
Chen et al. (2020). China	Cross-sectional. Online questionnaire and 1-1 interviews.	Diabetes. N = 1241	Participants with high self-efficacy had a greater degree of forum interaction.	29 (QuADS)

			The frequency and intensity of online interaction might positively affect self-efficacy and, by implication, diabetes self-management.	
Cobb et al. (2010). USA	Modern network analysis.	Smoking cessation. N = 7569	Key players had high levels of connection within the entire forum, which could allow for more rapid and efficient information dissemination.	21 (QuADS)
De Simoni et al. (2020) UK	Asynchronous web-based study using structured interviews.	Asthma. N = 17	Superusers provide help, refer users to healthcare professionals, act as moderators and understand the limits of their help. Most healthcare professionals are unaware of superusers, leaving them unsupported.	32 (QuADS)
De Simoni et al. (2018) UK	Expert opinion online article.	N/A	Superusers generate content, spread information, facilitate discussions, and	6 (JBI)

			provide support and advice. OHFs, led by superusers, are a powerful resource for helping people manage their health.	
Deccache et al. (2019) France	Systematic review of grey literature.	Diabetes, weight loss, cancer, fibromyalgia, depression, polycystic ovary syndrome, cardiovascular disease, lupus, multiple sclerosis, and unspecified chronic diseases.	Hyperactive users drive forum growth by generating new topics and responses, maintaining forum stability through consistent activity, and strengthening community connections by fostering a sense of belonging.	15 (QuADS)
Dias et al. (2012) Norway	Social network analysis.	Diabetes. N = 30000	Key actors were central and highly connected to other users, had a tendency to connect with new users, and disseminated more information.	23 (QuADS)
Feldhege et al. (2021) Germany	Longitudinal observational study.	Pro eating disorder N = 1170	Activity levels were associated with weight loss. More active users lost more weight	27 (QuADS)

			regardless of baseline.	
Geramita et al. (2018) USA	Post hoc analyses of a RCT.	Depression and anxiety. N = 302	Engagement was more broadly distributed than predicted by the 1% rule. Highly engaged users showed notable improvements in anxiety and quality of life. White college-educated female participants were more likely to be top contributors.	28 (QuADS)
Gopalsamy (2017) USA	Longitudinal observational study.	Heart disease, diabetes, substance abuse, fitness, depression, heart rhythm, and anxiety. N = 159000	There is a causal relationship between user engagement and forum growth. Higher engagement encourages lurkers to become more active in forums ("delurking").	32 (QuADS)
Griffiths et al. (2017) Australia	Prospective observational study.	Mental Health. N = 2932	A small minority of active users sustain and grow OHFs. Frequent posters engaged	27 (QuADS)

			longer. There was a trend of fewer posts from rural and remote residents than in cities.	
Healey et al. (2014) New Zealand	Retrospective observational study. Machine learning.	Smoking cessation. N = 2062	Highly engaged users are prolific and persistent contributors who provide responses, foster engagement and are connected to many other users across the engagement spectrum.	25 (QuADS)
Heather et al. (2014) USA	Cross-sectional study. Online survey.	Pregnancy N = 288	Highly supportive community members act as information bridges. Superusers preferentially communicate with poorly connected users. Participants who provided more support also sought more information from friends and other online resources.	24 (QuADS)
Joglekar et al.	Longitudinal network analysis.	Lung health N = 23182	As users became more active, they shifted from	30 (QuADS)

(2018) UK	Machine learning.		seeking help to giving help. Removing users with the most connections caused the largest component to collapse. Both OHFs had a low rich-club coefficient, indicating that highly connected superusers communicated more with poorly connected users.	
Lawless et al. (2022) Australia	Observational study. Netnography. Ethnography combined with grounded theory.	Long-term conditions (older adults). N = 322	Individuals used the OHF to address unmet emotional, informational, physical, or psychosocial support needs. Influencing members provided information, referred others to help sources, moderated by removing inappropriate posts, and welcomed new members.	31 (QuADS)

Litchman et al. (2018) USA	Cross-sectional study. Online survey.	Diabetes N = 183	Engagement was a strong predictor of A1c, reducing the odds of having an A1c ≥7% by 33.8% for every point increase in diabetes online community engagement (0-5).	24 (QuADS)
McCosker. (2018) Australia	Mixed methods study. Digital ethnographic observation. Interviews. Content analysis.	Mental health. N = 1140	Health influencers build non-professional expertise, shape mental health and recovery practices, and create cohesion through impact and feedback cycles. Health influencers focus on interaction modulation and shaping conversations.	23 (QuADS)
O’Neill et al. (2014) UK	Observational cross-sectional study. Online survey.	Non-specific OHFs. N = 1000	Superusers shape the health information others access and are more likely to have their health behaviours influenced by online information.	27 (QuADS)

Van Mierlo. (2014) Canada	Observational study.	Alcohol, depression, panic disorder, and smoking cessation. N = 63990	Superusers accounted for a weighted average of 74.7% of content and generated the vast majority of posts within the OHFs. These findings match the criteria of the 1% rule.	35 (QuADS)
Van Mierlo et al. (2012). Canada	Observational cross-sectional study. Mixed methods: online data analysis and qualitative interviews.	Smoking cessation. N = 219	Minimal correlations between posting behaviour and demographics among superusers. Superusers play powerful roles in social network traffic, with some communicating only within certain cliques. Significant correlation between posting behaviour and years smoked.	28 (QuADS)
Van Uden-Kraan et al. (2009) Netherlands	Retrospective study. Online survey.	Breast cancer, fibromyalgia, arthritis. N = 528	High-frequency posters offered help to others more often.	24 (QuADS)

Vydiswaran et al. (2019) USA	Temporal pattern analysis. Machine learning.	Non-specific OHF. N = >12000000	Peer experts enhance community health with their expertise and willingness to share knowledge. These users augment professional healthcare services with emotional and informational support in OFS.	24 (QuADS)
Willis. (2016) USA	Online ethnography. Discourse analysis.	Arthritis. N = 6578	Opinion leaders are the most influential forum members, facilitating much of the online conversation, engaging in verbal persuasion, convincing others to engage in self-management behaviour, checking in on members, disseminating information, and encouraging bravery.	29 (QuADS)
Wu et al. (2016) CHINA	Network analysis. Exponential	Diabetes N = NR	High-activity individuals prefer to have supportive	14 (QuADS)

	random graph model.		forum conversations. Lurkers may benefit from superusers' conversations.	
Yang et al. (2019) USA	Social network analysis. Mixed-method quality evaluation.	Cancer survivors. N = 66246	More active users often provide emotional and informational support, encouraging other members to interact.	31 (QuADS)
Zhao et al. (2014) USA	Observational study. Text mining. Sentiment analysis.	Cancer survivors. N = 27173	A novel metric, the number of influential responding replies, effectively identifies influential users. Superusers influence forum sentiment, positively reinforcing the community atmosphere. Supporting others likely boosts members' self-esteem.	27 (QuADS)

2.13.2 Health Forum Types

Each publication focused on one or more health forums. Regarding physical health, publications most frequently explored forums on diabetes support (n = 8), cancer support (n =7) and smoking cessation (n = 4). Other forums included lung health (n = 2), arthritis (n = 2), cardiovascular health (n = 2) and multiple sclerosis (n =2). Health topics explored in singular instances included Parkinson's disease, pregnancy health, fibromyalgia, polycystic ovary syndrome, lupus, cystic fibrosis and unspecified chronic diseases. Three publications framed OHFs vaguely, describing them as forums for long-term conditions, those concerned about the same health issue, and those seeking medical information. Regarding mental health, included publications centred on multi-topic MHFs (n = 3), depression or anxiety forums (n = 4), substance abuse forums (n = 2), a panic disorder forum, and a pro-eating disorder forum.

2.13.3 Methodologies and Theoretical/Conceptual Frameworks

The publications included in this review employed a wide range of methodological approaches and therefore varied underpinning ontological and epistemological stances, reflecting diverse existing approaches to OHF superuser investigation despite the relative infancy of this phenomenon. As detailed in Table 4, quantitative research approaches were the most common and included but were not limited to designs utilising longitudinal analyses, cross-sectional surveys, and social network analyses, with some incorporating data-driven approaches such as machine learning and topic modelling. The quantitative studies did not explicitly state their ontological and epistemological stances; however, their methodological choices suggest ontological realism (situating OHF super use as a measurable phenomenon) and epistemological post-positivism (positioning knowledge as measurable yet fallible and likely influenced by researcher positionality and bias). Qualitative approaches employed approaches such as netnography, interviews, online ethnography and discourse analysis, implying largely interpretivist or social constructivist stances where context and meaning making were centred. Mixed-methods studies combined approaches to link OHF use patterns with participants' experiences, often reflecting pragmatic stances.

Most publications (n = 17) did not employ or refer to existing theoretical or conceptual frameworks. Those that did drew on a range of theories, including The Network Effect, used to describe forum engagement and growth (Gopalsamy, 2017; Healey et al., 2014), Social Network Theory, used to create a new metric for identifying forum superusers (Zhao et al., 2014) and Activity Theory, used to explain motivations for communication in OHFs (Wu et al. 2016). Only one study used the 1% Rule of OHFs as a framework to analyse OHF participation (Van Mierlo et al., 2012), but six additional studies referenced this theory (Carron-Arthur et al., 2015; Carron-Arthur et al., 2016b; De Simoni et al., 2018; De Simoni et al., 2020; Geramita et al., 2018; Joglekar et al., 2018). Two studies employed conceptual frameworks to guide their analysis; the first drew on concepts of autonomy, relationship-centred care and Apomediation Theory to explore online self-care support (Lawless et al., 2022), and the second drew on elements of cultural intermediary theory to identify forum superusers (Mcosker, 2018).

Additional publications discussed their findings in relation to social theories, referencing Homophily (Carron-Arthur et al., 2016b), Preferential

Attachment Theory (Dias et al., 2012) and Cooperative Game Theory (Gopalsamy, 2017). Further studies applied psychological theories of varying scope in their discussions. These theories included self-determination theory, used as an interpretive lens for superusers' forum engagement (De Simoni et al., 2020); Bandura's social cognitive theory, used to describe the role of self-efficacy concerning self-management health behaviours in OHFs (Willis, 2016); and the Helper Therapy Principle, used to explain health-related attitudes online (Heather et al., 2014). A further study discussed the Apomediation Model in relation to the use of OHFs (Deccache et al., 2019), and one remaining study employed the overarching concept of empowering processes to explore the impacts of forum participation on users (Van Uden-Kraan et al., 2009).

2.13.4 Health Forum Superusers

Understanding the different ways in which superusers are defined is important because definitions shape the participants who are sought for research studies, influence the focus and interpretation of their behaviours within OHFs, and also impact (whether limiting or enhancing) the comparability of findings across different studies. Included publications defined superusers of OHFs in numerous ways, often using multiple terms within the same study. More than a third used the term “superuser” or “super user” (Carron-Arthur et al., 2015; Carron-Arthur et al., 2016a; Carron-Arthur et al., 2016b; Cobb et al., 2010; De Simoni et al., 2018; De Simoni et al., 2020; Geramita et al., 2018; Gopalsamy, 2017; Joglekar et al., 2018; O'Neil et al., 2014; Van Miero 2014; Van Miero et al., 2012). In some instances, publications acknowledged superusers' elevated social status, referring to them as leaders (Willis, 2016), influential users (Zhao et al., 2014), health influencers (McCosker, 2018), and peer experts (Vydiswaran & Reddy, 2019). Some publications also encapsulated superusers' central value, referring to them as core users (Carron-Arthur et al., 2016b), key players (Cobb et al., 2010), key actors (Dias et al., 2012) and key informants (Mcosker, 2018).

Most publications did not provide demographic information for superusers, and those that did highlighted stark contrasts and used conflicting methods to establish this information. For example, in their network analysis of a smoking cessation OHF, Cobb et al. (2010) found superusers were predominantly female (80.0%) and older than other types of members (i.e. the average age of superusers was 49 years old while the average age of the least active forum members was 42 years old). In contrast, O'Neill et al. (2014), who conducted a survey of internet users in the UK who had accessed user-generated online health content, indicated superusers were predominantly male (67.2%) and younger (16-24 years). Some publications explored personal characteristics and suggested that superusers are likely highly altruistic (De Simoni et al., 2020; Vydiswaran & Reddy, 2019), while another examined psychological constructs and found that superusers exhibit higher health-related self-efficacy than other users (Chen et al., 2020). Only one paper (De Simoni et al., 2020) explicitly explored superusers' motivations, concluding that superusers' high-frequency use is motivated in part by a drive to fulfil psychosocial needs associated with relatedness, competence and autonomy.

Regarding roles within OHFs, superusers were described as providers of information (n = 6), emotional support (n = 5) and general advice (n = 3) who initiate threads (n = 8), provide responses (n = 6) and are highly socially connected online (n = 6). While most publications (n = 20) considered superusers “high-frequency” forum users, there was little consensus regarding the conceptualisation of high-frequency use. For example, sometimes high frequency was conceptualised in terms of post count, but thresholds varied substantially, ranging from 5.8 posts (Geramita et al., 2018) to >60 posts per month (Healey et al., 2014). The included publications also provided little insight regarding how many hours of forum use constitute super use. Furthermore, sometimes high-frequency use included passive use metrics like forum visit duration (n = 3), time spent reading posts (n = 2) and frequency of logins (n = 1).

2.14 The Bidirectional Impacts of Superusers and Online Health Forums

The reviewer synthesised five themes relating to the bidirectional impacts of superusers and OHFs (see appendix F).

2.14.1 Theme 1: Superusers are Integral to Forum Engagement and Growth

By creating new discussion topics (Van Miero et al., 2012), responding to existing discussion threads (Bayen et al., 2021; Healey et al., 2014) and fostering relationships between old and new forum members (Dias et al., 2012; Healey et al., 2014; Yang et al., 2019), superusers are integral to forum engagement, activity and growth (Carron-Arthur et al., 2016b; Decache et al., 2019). Superusers actively engage with new forum members (Dias et al., 2012), have a unique ability to stimulate and maintain impactful conversations by posting frequently but by sustaining dialogue across multiple threads (Gopalsamy, 2017) and are highly likely to respond to existing discussion threads (Joglekar et al., 2018; Van Uden-Kraan et al., 2009).

Despite accounting for 1% of all forum users (Van Miero et al., 2014), superusers' ability to catalyse engagement (which they achieve via generating a disproportionately high volume of posts) is of great value to OHFs (Carron-Arthur et al., 2015) as high engagement is essential for both early-stage community development (Carron-Arthur et al., 2016b) and long-term growth and success (Deccache et al., 2019; Van Miero, 2014). While superuser research is in its infancy, one study has already established causal relationships between higher levels of superuser engagement and forum growth. Drawing on Cooperative Game Theory (which looks at how groups of people contribute collectively to shared outcomes), Gopalsamy (2017) established that superusers make disproportionate contributions to overall forum activity when compared to other users. Then, through causal inference modelling (a statistical approach that allows researchers to distinguish between correlation and causation), Gopalsamy demonstrated forum growth was directly driven by superuser engagement. Additionally, research employing sensitivity analysis (a method that tests how changes to variables impact a systems outcomes) of forum network structures (i.e. the interactions between users which shows who the central users are and how they communicate) confirmed that the removal of superusers from OHFs would cause them to collapse (Joglekar et al., 2018).

2.14.2 Theme 2: Superusers Create Emotionally Supportive and Informative Online Environments

In their drive to help others, Superusers serve to “activate” welcoming online communities rich in emotional and informational support (McCosker, 2018). Superusers proactively welcome forum members and initiate conversations with those who have fewer online connections (Lawless et al., 2022). Superusers are more likely to contribute empathetic, understanding, and affirming posts (Biyani et al., 2014) and regularly check in with others (Willis, 2016) thereby becoming “emotionally supportive companions” (Carron-Arthur et al., 2016a).

Superusers also ensure OHFs become rich hubs of information by signposting others to traditional services (De Simoni et al., 2020), sharing lived experience (Lawless et al., 2022), and acting as “information bridges” (Heather et al., 2014), efficiently disseminating information from its source (Cobb et al., 2010). Due to the frequent sharing of non-professional expertise including contributing personal insights and practical advice related to condition management, and information that helps others to understand and interpret medical information and advice (Joglekar et al., 2018; McCosker, 2018; Vydiswaren & Reddy, 2019), superusers significantly shape health information in OHFs (O’Neill et al., 2014).

This theme embraces two key impacts of superusers on OHFs already outlined by the initial framework: (1) “creates supportive environment” and (2) “creates informative environment” and further contributes to the framework's evolution by highlighting the multifaceted nature of emotional and informational support.

2.14.3 Theme 3: Superusers Drive Community Cohesion and Proactive Health Environments

Superusers facilitate community wholeness (Joglekar et al., 2018) by actively engaging with other members and responding empathetically to the experiences of others. This engagement creates a positive environment where supportive interactions encourage further participation, thereby enhancing community members' sense of belonging (McCosker, 2018). While some evidence suggests superusers preferentially communicate with those who have similar forum use timelines (Van Miero et al., 2012), other evidence suggests shared characteristics are not significant motivators for communication (Carron Arthur et al., 2016b). Thanks to a drive to connect with others across a spectrum of experiences (Healey et al., 2014), together with the use of communication techniques such as referring to other members by name (Bayen et al., 2021) and remembering information shared by others (Willis, 2016), superusers create a “sense of belonging and mutual support” (Decache et al., 2019) in OHFs that goes beyond mere engagement. Furthermore, superusers strive to unify online communities by flagging inappropriate posts (Lawless et al., 2022).

In connecting with others positively (Biyani et al., 2014), superusers appear authoritative (McCosker, 2018) which can influence the emotions and attitudes of others (Zhao et al., 2014). For example, superusers may persuade others to “be brave” in their recoveries (Willis, 2016) and may also encourage forum observers to become contributors through leading by example and creating a sense of support (Wu et al., 2016). Additionally, by sharing their experiences and normalising proactive health behaviours, superusers can motivate others to implement health behaviours (Lawless et al., 2022; Zhao et al., 2014) and, by extension, encourage proactive health environments on the whole. This theme expands on the original conceptual framework by introducing two new elements: (1) community cohesion and (2) proactive health environment.

2.14.4 Theme 4: Forum "Super Use" can Impact Superusers' Psychological and Physical Health

Online forum use, and particularly its "super use", can impact the psychological and physical health of superusers (De Simoni et al., 2018; Heather et al., 2014). For example, high-intensity participation in online forums can increase emotional well-being over time for those who usually struggle to feel and process their emotions (Batenburg & Das, 2014). As noted by Batenburg and Das, this increase may be explained by the fact that frequent online participation can compensate for the negative effects associated with not approaching emotions, in addition to the fact that these users may benefit from the support of peers, empowerment via information, and normalisation of their experiences thanks to shared lived experiences. Improved mental well-being for some users would also make sense, given that active participation in online forums can contribute to a sense of belonging and social connectedness, which in turn improves mental health outcomes (Smith-Merry et al., 2019).

Superusers may also experience increased self-esteem (Zhao et al., 2014), confidence and overall health motivation (De Simoni et al., 2020) thanks to high-frequency forum use; benefits achieved through empowerment gained via knowledge sharing, recognition of helpful contributions within the OHF, the development of supportive relationships and an increased sense of purpose derived from helping others. When it comes to mental health conditions, the impacts of super use on superusers themselves likely vary according to the condition. For example, superusers have shown measurable improvements in their own anxiety levels following six months of high-level forum use but no change in depression (Germita et al., 2018). The authors did not offer any suggestions as to why this may have happened.

Regarding physical health, one study exploring super use of a diabetes-based forum found that the higher superusers' activity levels were in OHFs, the lower their A1C levels (i.e. measures associated with average blood sugar levels, which can be indicative of disease like diabetes) became (Litchman et al. 2018), alluding to the impact forum super use can potentially have on physical health markers. This association appears to be supported by mechanisms including enhanced access to health information and subsequent improved health literary (Van Uden-Kraan et al., 2009). Social support also appeared to play a role, with the authors suggesting a sense of connectedness can encourage altruism, may enhance peer-based knowledge exchange that further supports self-care implementation (Litchman et al. 2018). While this study does not claim a causal link, these factors still suggest possible pathways through which super use can positively influence physical health.

Some research suggests forum super use does not negatively impact health (Batenburg & Das, 2014). However, superusers are more likely to have their health behaviours, treatment decisions, or self-care affected by online information (O'Neill et al., 2014). Superusers may, therefore, be more susceptible to adverse health outcomes depending on their forum of use. For example, Feldhege et al. (2021) found superusers of an online pro-eating disorder forum lost more weight over time than non-superusers, even when they had extremely low baseline weights. Superusers may also experience greater increases in stress during challenging conversations or when they are unable to follow up with other previously distressed members (De Simoni et al., 2020).

2.14.5 Theme 5: Forum "Super Use" Increases Social Connections and Status

Superusers are intrinsically motivated to share their knowledge and lived experience when they believe doing so will help others (De Simoni et al., 2020; Lawless et al., 2022; Vydiswaren & Reddy, 2019). When superusers engage in high levels of conversation, they form impactful relationships that provide mutual support, trust and belonging (McCosker, 2018). In doing so they expand their online social circles (as measured through social network analysis) (Cobb et al., 2010) and increase their level of engagement (as determined by engagement metrics) (Healey et al., 2014), which users have self-reported as enhancing well-being (Van Uden-Kraan et al., 2009).

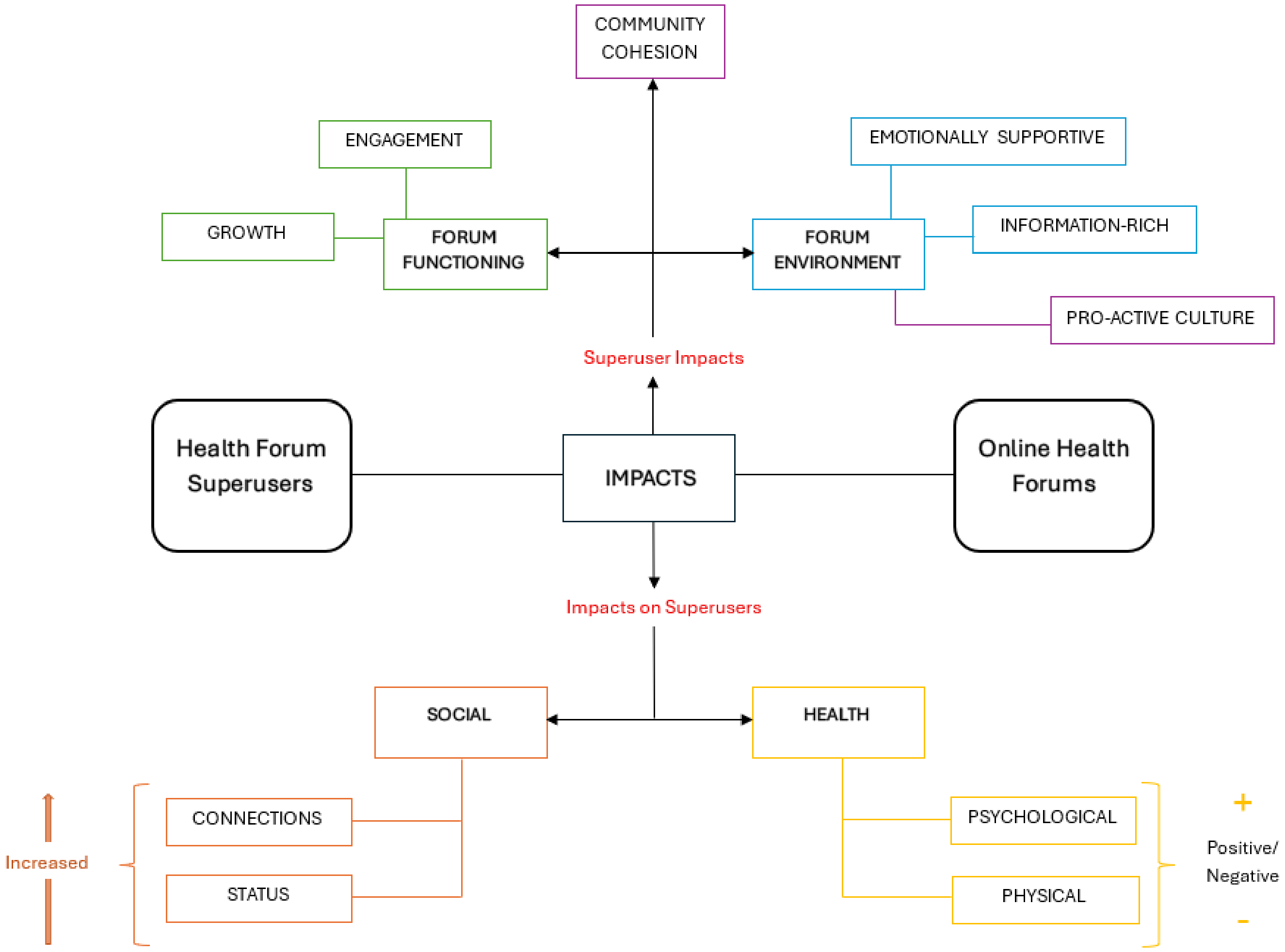
Thanks to their confidence, experience, and online social connections, superusers are often recognised as role models, experts (Vydiswaren & Reddy, 2019) and health influencers (McCosker, 2018) by their peers. Accordingly, superusers tend to adopt leadership roles within OHFs (Bayen et al., 2021; Deccache et al., 2019; Willis, 2016; Zhao et al., 2014). Superusers appreciate the recognition they receive in forums (Van Uden-Kraan et al., 2009), which can further strengthen their involvement in OHFs over time (Zhao et al., 2014). This finding introduces a new concept of elevated social status (see ‘conceptual framework development’ section for further details).

2.15 Conceptual Framework Refinement

Following literature synthesis, the reviewer refined and expanded the initial conceptual framework. Figure 4 presents the final iteration of the conceptual framework.

Figure 4

Conceptual Framework (final iteration)



2.16 Discussion

This review synthesised a relatively new but growing body of evidence on the bidirectional impacts of superusers and OHFs in addition to examining how OHF superusers have been defined and conceptualised within existing literature and the methodological, theoretical and conceptual approaches employed in existing research.

Regarding the question “How does existing literature conceptualise online health forum superusers?” the synthesis highlighted a lack of consistency in the terminology used to describe forum superusers, an issue common across health research (Cooke et al., 2012). The review findings also drew attention to the varied definitions and conceptualisations of superusers that exist in current publications. Data analysis also raised questions on the metrics used to measure high-frequency forum use and whether it is appropriate or helpful to include both active and passive measures of use. Still, the impacts of superuser activity likely vary according to engagement intensity, with benefits potentially plateauing or perhaps becoming negative at extremely high levels of forum use. That said, establishing and disentangling these patterns is challenging given the inconsistent definitions across studies. Furthermore, the absence of an agreed-upon definition of OHF superuser and consensus around what constitutes core measures of superuser activity ultimately makes it challenging to fully understand who superusers are. While a single universal superuser definition may not be appropriate, explicitly working towards a boarder consensus (i.e. agreed-upon facets of super use) would enhance clarity and potentially result in more useful research.

Regarding the question “What theoretical frameworks and methodological approaches have been used in existing literature on superusers and OHFs?” as highlighted in the results section, a wide range of methodological approaches were employed, and most studies did not employ psychological theory. Those that did not employ theory allowed for more flexible, inductive exploration of the bidirectional impacts of superusers and OHFs, while studies that did employ psychological theory were often able to interpret impacts in more conceptually grounded ways, which has broader implications in terms of generalisability (Maxwell, 2013). Furthermore, where theory was applied only to guide discussion, its inclusion sheds light on the potential for existing theory to enrich understanding while avoiding limiting inductive discovery, thereby enabling researchers to remain close to the truth of the findings as opposed to potentially focusing on details of less significance or “telling a story that is not true” (Garvey & Jones, 2021). While mapping the use of theoretical and conceptual frameworks is of value, the decision to adopt theory depends on research questions and aims. Nevertheless, the theories and conceptual models identified here offer a useful starting point for future research.

Regarding the bidirectional impacts of superusers and OHFs, the literature synthesis illuminates superusers' integral roles in shaping OHFs and driving forum success. Their engagement appears to be a key factor in sustaining active communities and even encouraging participation from otherwise silent observers. Superusers shape the OHF environments while OHFs shape superusers' health behaviours and health outcomes. However, it is also likely that individual superuser characteristics (e.g. extraversion versus introversion, level of “real world” social isolation and offline responsibilities) influence how they impact OHFs and how the OHFs, in turn, affect them.

Regarding the impacts of high-frequency health forum use on superusers themselves, the synthesised evidence and resulting conceptual framework provide initial insight into associated health and social impacts. High-frequency engagement appears to impact superusers' own psychological, social and health outcomes, with evidence indicating active participation can enhance social connections, self-esteem and health-promoting behaviours. Still, these effects may also be shaped by the context and unique environment of the OHF itself, including the cultural context, with existing research indicating that differences in the use of online MHFs, including general forum participation and reciprocal help-giving, are shaped by cultural context (Pendse et al., 2019). Furthermore, cross-cultural differences can shape mental health expressions online, and what is considered an appropriate or expected reciprocal health response can vary by culture (Rai et al., 2024). Given that most of the evidence included in this review comes from largely white, western populations, some behaviours associated with super use (e.g. proactively welcoming new users) may not be interpreted in the same positive light and therefore may even lead to negative impacts in some cases.

Given the critical realist underpinnings of this review, together with the growing nature of the review topic, it is essential to recognise the limits of the knowledge presented here and to understand that all findings are context-dependent, presumed to be incomplete, and fallible by nature. Therefore, as research continues, it is reasonable to assume many of the findings presented here will evolve. Still, this review contributes meaningfully to the growing evidence base by highlighting the variability of bidirectional impacts reported across the included studies. Additionally, while care must be taken to avoid overstating conclusions, it is notable that some reported findings are supported by high-quality evidence (QuADS scores >30) and methodologically rigorous quantitative approaches. For example, research has established causal relationships between superuser engagement and forum growth (Gopalsamy, 2017), and sensitivity analysis shows OHFs cannot function without their superusers (Joglekar et al., 2018). Such evidence offers compelling support for the finding that superusers are integral to forum engagement and growth.

Other findings, such as the impact forum super use has on psychological and physical health, must be interpreted with caution as it is based on a limited body of evidence and appears largely dependent on health contexts and conditions. For example, while forum super use has the potential to boost well-being (Batenburg & Das, 2014; Van Uden-Kraan et al., 2009), it may not lead to improvements in all mental health conditions or symptomatology in the same way (Geramita et al., 2018). Additionally, it is reasonable to assume that superusers, like other forum users, may only experience such benefits of forum use when certain conditions, such as psychological safety, relevant content and supportive moderation, are met (Marshall et al., 2024). Furthermore, some types of forum super use can increase exposure to harmful norms that reinforce disordered behaviours, leading to negative health consequences (Feldhege et al., 2021).

While the underlying motivations and generative mechanisms driving the bidirectional impacts of superusers and OHFs outlined here are not directly observable, some inferences relating to the deeper social structures and mechanisms that influence them can be drawn (Michelson et al., 2022). For example, based on the finding that super use increases social connections and status, it is reasonable to suggest that isolation and lack of in-person social support (already found to drive certain forms of forum use [Rice et al., 2016; Zhang, 2017]) may motivate some forum superusers to take on their superuser role. Furthermore, as many people with physical health conditions and mental health problems experience a sense of social disconnect and loneliness (Mushtaq et al., 2014), this finding alludes to potential psychosocial structures that may precede this inherent sense of isolation and aloneness (e.g. the societal norms and values that contribute to the feelings of stigma many people with mental health problems face [Chan et al., 2016; Smith-Merry et al., 2019] or the failure of society to provide adequate support for people with limiting health conditions.

2.17 Strengths and Limitations

There are several notable strengths associated with this literature review. Firstly, two additional reviewers, a specialist librarian and a highly experienced Cochrane information specialist, supported it, bringing collaborative expertise that likely enhanced the number of relevant studies identified (Buscemi et al., 2006). In addition, a comprehensive literature search across OHFs for all health conditions was conducted, ensuring the broader scope of health forum super use was captured. Furthermore, the synthesis of findings from this wide-spanning evidence base led to the development of a novel conceptual framework which offers a structured lens through which future research may explore the bidirectional impacts of OHF super use.

This integrative review included publications that covered a wide range of OHFs. While this was an appropriate decision given the infancy of superuser research, it is also a potential limitation given that the impacts of forum super use likely differ across health conditions. Refining the review's focus to consider only physical or mental health-based forums or focusing on forums for singular health conditions, diagnoses, or experiences may have allowed for a more comprehensive, nuanced exploration of forum super use and its bidirectional impacts. Additionally, a high number of papers were ultimately excluded during the screening process, which in hindsight suggests a more specific search strategy may have been appropriate. Finally, while the eligibility criteria did not impose explicit geographical constraints, the review only included English-language publications. Given the global nature of OHFs, this decision likely excluded potentially relevant publications (Walpole et al., 2019) and prevented identification of cross-cultural facets (Pendse et al., 2019).

2.18 Conclusion and Implications

This literature review is the first to explore the impacts of superusers and OHFs. Due to its integrative nature, this review allowed for the synthesis of disconnected strands of literature from multiple disciplines, and the creation of a novel, multidimensional conceptual framework. Examination of the literature uncovered significant gaps and conflicts regarding who OHF superusers are, their roles within OHFs, and what “high frequency” forum use entails. Future research should, therefore, prioritise establishing clear definitions in these areas while exploring the possibility of differences across various health condition forums and cross-cultural populations. Additionally, while the findings have illuminated superusers' impacts on the functioning and success of OHFs, little is known regarding superusers' experiences, motivations and support needs. Given superusers' pivotal role in OHFs, future research would benefit from qualitative exploration of their experiences to address these prominent knowledge gaps.

The findings of this review also have implications for healthcare organisations, including public sector organisations like the NHS, charities and other third-sector organisations, private healthcare providers, and any other stakeholders invested in the creation, functioning, and overall success of OHFs. Firstly, the findings establish a clear need for OHFs to attract and retain superusers if they are to be successful. Consequently, organisations should develop ways to identify and engage with naturally emerging forum superusers to uncover and address immediate concerns or support needs. Secondly, the findings highlight the need for organisations to find ways to utilise, nurture and protect superusers of OHFs in ways that reduce potential harms associated with high-frequency forum use. For organisations involved in creating and maintaining OHFs, this may include implementing initial superuser safeguarding policies and providing additional support resources for high-frequency users. Ultimately, by establishing and addressing the unique needs of superusers of OHFs, organisations will protect their users' well-being while ensuring their forums' effectiveness and sustainability.

2.19 Additional Information

PROSPERO. Registration number [CRD42023417287]

Chapter 3: Methodology

3.1 Chapter Introduction

This chapter presents a critical discussion of methodological decisions made in relation to the qualitative RTA study. Despite being titled “methodology,” it also details the methods employed. The decision to integrate the research methodology and methods within one chapter reflects the deeply intertwined relationship between methodological justifications and subsequent methods employed. The chapter begins with an overview of the research purpose and aims before introducing and advocating for the critical realist ontological and epistemological foundations by establishing their relevance and compatibility with the research questions and study aims. An exploration of psychological theory in the context of superusers of OHFs comes next. The implications of applying a priori psychological theory are discussed, and an inductive approach is justified. The chapter then transitions from broader methodological discussion to detail specific choices made regarding the research methods. Where appropriate, comparisons to alternative approaches are made, limitations highlighted, and choices justified. The following sections of this chapter then return to methodological discussion with a focus on data sufficiency, approaches to quality assurance, and reflexive practice. The chapter concludes by outlining the ethical commitments made and summarising how PPI advisors have contributed to the research.

3.2 Overview of Research Purpose

As detailed within the introductory chapter of this thesis and expanded upon in the integrative literature review (Chapter 2), superusers presence is critical to forum stability and success. However, little is known about their engagement experiences and motivations to engage in MHFs, together with the types of challenges they may face when doing so. The purpose of this study is to bridge this knowledge gap by interviewing self-identified MHF superusers about their engagement experiences in MHFs. The term "engagement experiences" reflects the fact that this study focused primarily on the interactive and participatory aspects of connecting with others in MHFs (i.e. posting to elicit connection and reading, interpreting and replying to other MHF members' contributions

This study links to a larger research project at Lancaster University (Improving Peer Online Forums; iPOF), which seeks to understand how online peer forums function to provide evidence for new tools to improve them. As the iPOF study did not focus on superusers, the research outlined here aims to contribute to this evidence base and generate new insights that may potentially inform policy and practice, particularly when it comes to organisations that design and run MHFs to involve. The research addressed the following questions:

1. What are the engagement experiences of superusers in online MHFs?
2. What motivates superusers to engage in online MHFs?
3. What challenges do superusers face when engaging in online MHFs?

3.3 Philosophical Positioning

Philosophical assumptions are critical elements of research paradigms that denote the researcher's worldview (Aliyu et al., 2015) and make fundamental assertions regarding ontology (what constitutes reality) and epistemology (the nature of knowledge) (Willig & Rogers, 2017). Qualitative research separates itself from positivist paradigms that ignore the value of subjective experience (Vincent & O'Mahoney, 2016) and embraces interpretivist, constructionist and constructivist paradigms that emphasise constructed reality (Levers, 2013).

In seeking to explore superusers' subjective experiences of online MHFs, this research embraces knowledge as individually constructed. Given the sociocultural elements of mental health (Alegría et al., 2018; Bhugra et al., 2012) and the historical roots of mental health attitudes and beliefs (Link & Stuart, 2017), this research concurrently views knowledge as contextually, socially and historically bound. Furthermore, this research embraces the "real world" impact of online MHFs and their superusers (that being the observable and tangible effect, or potential effect, on superusers experiences, behaviours and mental health outcomes) while also drawing upon a post-positivist perspective (which posits that reality exists independently of our perceptions, while our understanding of it is always fallible as it is mediated by context and human interpretation). This convergence of values and combination of post-positivist and interpretive facets resulted in the decision to employ a critical realist paradigm (Bhaskar, 1978), which combines ontological realism with an epistemology that acknowledges the interpretive yet fallible nature of knowledge (Sayer, 2020).

3.4 Ontological Realism

Ontological realism is compatible with the concept of knowledge construction (both individually and socially); it simply states this construction occurs within a "real" world (Crotty, 1998), thus separating ontology and epistemology and avoiding epistemic fallacy which reduces questions regarding what exists (ontology) to questions about knowledge (epistemology) (Bhaskar, 1975; Collier, 1994). Critical realism stratifies reality into three domains: “the empirical”, “the actual”, and “the real” (Bhaskar, 1975). The empirical level of reality relates to the events we can observe, experience, or measure. In other words, the facets of our human perception. Although these events are always mediated by human experience and interpretation (Fletcher, 2017). The actual level of reality includes all real-world events that occur, whether or not we experience and interpret them. In other words, these events are “true occurrences” that are not filtered by the human experience (Fletcher, 2017). The real level of reality is the deepest layer in the sense that it pertains to the underlying causal structures and generative mechanisms that catalyse and underpin all events; these structures and mechanisms exist independently of our perceptions of them (Bhaskar, 1978; Haigh et al., 2019; Sayer, 2020).

Embracing this multilevel reality when exploring the engagement experiences of superusers in MHFs allowed for linguistic reductionism (oversimplifying or reducing complex experiences to what is said alone) to be avoided (Pilgrim, 2015), instead paving the way for a more nuanced understanding of subjective yet “real-world” experiences. . Furthermore, grounding this research in ontological realism and within the broader critical realist paradigm allowed for greater insight into the complex social dynamics and generative mechanisms underpinning individuals' experiences, thus strengthening the ability of the findings to inform practice moving forward (Pilgrim, 2020).

3.5 Epistemological Position

This research study is underpinned by a critical realist epistemology, which sees knowledge as fallible and transitive and therefore always open to revision (Bhaskar, 1975; Haigh et al., 2019). Drawing on interpretive traditions such as symbolic interactionism, hermeneutics and phenomenology, the critical realist epistemology supports the aim of understanding how people make sense of their socially embedded and culturally bound experiences (Denzin & Lincoln, 2011; Khalifa, 2019). While much literature describes critical realism as being epistemically relativist (e.g. McEvoy & Richards, 2003), which holds truth in the sense that critical realism accepts epistemic relativism (i.e. the view that the world can only be known through existing descriptions or discourses), to say critical realist research is epistemologically relativist lacks nuance. Yes, critical realism embraces social influence and the tentative nature of knowledge; however, it rejects judgmental relativism (i.e. the view that one cannot judge between different discourses and decide that some are better than others) (Sayer, 2000). Therefore, the epistemological stance of critical realism is not fully relativist in the constructionist sense because it does not treat all knowledge as inherently equal. With critical realism, judgemental rationality can be applied to appraise knowledge in order to determine its credibility (Willig, 2013).

Therefore, while different epistemological approaches such as constructivism or constructionism could have underpinned this research (although granted these would not align with the critical realist paradigm itself), critical realism, in its rejection that all knowledge claims hold equal importance and validity and acknowledgement of the fallible and socially influenced nature of knowledge, offered distinct appeal. Through its stratified ontology (as outlined in the previous section), critical realism supports the notion that knowledge, though provisional, can provide plausible and practical insights about the real world. From a critical realist perspective, this approach is considered to offer grater explanatory power when compared to other paradigms, as it encompasses the mechanisms and structures underlying observable phenomena, thereby being better positioned to inform practice and policy (Fletcher, 2017; McEvoy & Richards, 2003). This explanatory potential allows researchers to move beyond surface-level descriptions and towards the identification of causal mechanisms, which in turn better positions study findings in their ability to contribute to meaningful change (Fletcher, 2017). Accordingly, this epistemological stance aligned with the overarching aim of this study: to gain insight into MHF superusers' unique and multifaceted engagement experiences, while also facilitating causal analysis to inform future practice and policy.

3.6 Psychological Theory

Inductive approaches to qualitative inquiry remain dominant (Spencer et al., 2014). However, deductive approaches utilising psychological theory to guide phenomena exploration (Imenda, 2014) or as an interpretive lens (Braun & Clarke, 2022) may help to uncover etic insights and generative processes that inductive routes would leave unacknowledged (Macfarlane & O'Reilly-de Brún, 2012). Therefore, the choice as to whether an inductive or deductive approach is taken depends on its alignment with the study aims and context.

The integrative literature review presented earlier (see Chapter 2) noted a range of theories and conceptual models related to the bidirectional impacts of forum super use which are potentially applicable in guiding the exploration of superusers' engagement experiences. They included The Helper Therapy Principle (Riessman, 1965) which Heather et al., (2014) used to explain online pro-social helping behaviours; Self Determination Theory (Ryan & Deci, 2000) used as an interpretive lens to explain motivations and engagement in forums by De Simoni et al. (2020) and Social Learning Theory/Social Cognitive Theory (Bandura, 1977, 1986) applied by Willis (2016) to describe the relationship between OHF users self-efficacy and their self-managed health behaviours. However, these theories are not specifically theories of superuser behaviour, rather they are higher level theories of general behaviour. Additionally, two conceptual models presented by Lawless et al. (2022) and McCosker (2018) are detailed in that chapter. However, while linked with OHF super use and inclusive of concepts such as autonomy and social identity, which may apply to superusers' engagement experiences and motivations in MHFs, these conceptual models were primarily designed to explore superusers' functions and impacts rather than their engagement-related personal experiences.

In addition, as noted in the background information Chapter 1 of this thesis, Naslund et al (2016) generated a novel conceptual framework illustrating how MHF engagement facilitates empowerment, enhanced social connections, shared understanding and coping strategies. Still, Naslund et al.'s model does not centre on MHF superusers or make distinctions between levels of use at all. Furthermore, a novel conceptual framework was created as part of the integrative literature which may hold significance for MHF superuser experiences (see Chapter 2). Yet, despite its potential applicability, together with the potential applicability of the noted psychological theories to deductively guide exploration of superusers MHF experiences and/or as a lens of analysis, given the infancy of superuser research, the fact that most other studies used psychological theory only as an interpretive lens rather than a guiding framework, and the fact that the conceptual framework while likely holding relevance took into account the broader landscape of OHFs as opposed to taking a more narrow focus on MHFs, the researcher decided to select an inductive approach capable of capturing broader theoretically interesting factors (Braun & Clarke, 2022). While some argue that critical realist research is more suited to largely deductive approaches (Fletcher, 2017), this is not a methodological requirement (Danermark et al., 2019). Subsequently, the data generated from this study was primarily interpreted inductively (i.e. with no guiding theoretical lens), abductively (i.e. by describing the generated data using relevant theoretical concepts and frameworks where inferred) and via the retroductively (i.e. by inferring the underlying causal mechanisms that may explain the observed patterns) where appropriate (Bhaskar, 1979; Fletcher, 2017).

3.7 Research Study Design & Method Selection

This study explored superusers' engagement experiences in, therefore, a qualitative approach applicable to lived experience research and compatible with critical realism was required. Three primary approaches, Interpretative Phenomenological Analysis (IPA; Smith et al., 2009), Grounded Theory (GT; Glaser & Strauss, 1967) and RTA Braun & Clarke, 2006, 2022), were considered.

IPA combines elements of Husserl’s phenomenology and Heidegger’s hermeneutics into an idiographic approach that centres how people make sense of experiences (Smith et al., 2009). IPA is philosophically congruent with critical realism in acknowledging that experiences are grounded in real-world processes beyond individual experience (Smith et al., 2009). Furthermore, IPA promotes inductive inquiry (Smith et al., 2009). However, whereas critical realism encourages exploration of underlying generative mechanisms and causal explanations, IPA remains largely focused on exploring participants’ lived experiences and the meanings they attribute to those experiences.

GT, a leading approach in health research, enables researchers to employ inductive reasoning to generate theories from data that can directly impact policy and practice (Harris, 2015). GT is grounded in symbolic interactionism, and its original conceptualisation (Glaser & Strauss, 1967) established it within a philosophical framework comprised of ontological critical realism and epistemological objectivity (Levers, 2013). Charmaz (2006), however, reenvisioned GT through a constructionist lens (Levers, 2013), and in doing so emphasised that knowledge is socially constructed. While this approach aligns with aspects of critical realism, the constructionist ontology Charmaz employs (that reality itself is socially constructed) does not. A unique facet of GT is its sampling approach. Unlike IPA, which supports purposive sampling, GT uses theoretical sampling, recruiting participants based on emerging theoretical insights (Conlon et al., 2020). However, theoretical sampling is a time-intensive process which poses significant challenges within the timeframe of a PhD project (Thomson, 2011; Wu & Beaunae, 2014).

RTA is a philosophically and theoretically flexible approach to qualitative research analysis that allows researchers to interpret patterns (themes) of meaning across datasets (Braun & Clarke, 2022). RTA separates itself from other forms of thematic analysis (e.g., coding reliability/codebook approaches) by emphasising meaning-making and interpretation (Byrne, 2022) and the researcher's role in constructing knowledge (Braun & Clarke, 2019a). RTA is especially suited to research exploring lived experiences within broader sociocultural contexts (Belotto, 2018). Additionally, RTA is argued to have more direct implications for practice than IPA and GT as thematic statements allow complex qualitative research to be transformed into concise actionable steps that can readily inform both practice and policy (Braun & Clarke, 2021a) which makes it an appealing choice, as this research aims to generate findings that help organisations understand how best to involve, train and support superusers of their online forums. Furthermore, RTA allows for inductive reasoning, semi-structured interviewing, and purposive sampling techniques.

There is rarely one correct methodology or method for qualitative research, and there is potential for similar findings, whether employing methodologies like IPA and GT or methods like RTA (Braun & Clarke, 2022). Still, the researcher selected RTA due to its consistent alignment with the research questions, aims, methods and overall design (Willig, 2013) and its ability to encourage the exploration of superusers' experiences beyond surface-level meaning (Braun & Clarke, 2022). RTA’s emphasis on reflexive practice aligns with the studies' interpretive but fallibilist epistemological stance (i.e. a stance that recognises interpretations are not absolute truth and may change).

3.8 Approach to Reflexive Thematic Analysis

For this study, the data analysis process is considered inductive. Still, purely inductive or deductive approaches are rare and while the researcher deliberately avoided applying psychological theory to create an a priori coding framework, they still brought with them knowledge and assumptions, which inevitably influenced interpretation (Braun & Clarke, 2022). Furthermore, despite the largely inductive analysis approach, some elements may appear partially deductive as the analysis was guided by the three research questions, directing the researcher's attention primarily towards facets of data relating to them. Still, this is congruent with the application of inductive RTA, as Braun and Clarke (2022) emphasise that approaches should be viewed as existing on a continuum. Data was coded at both semantic and latent levels, helping the researcher to identify explicit patterns of meaning generated across participants' accounts while also interpreting underlying assumptions and structural mechanisms.

3.9 Method

3.10 Sampling Approach

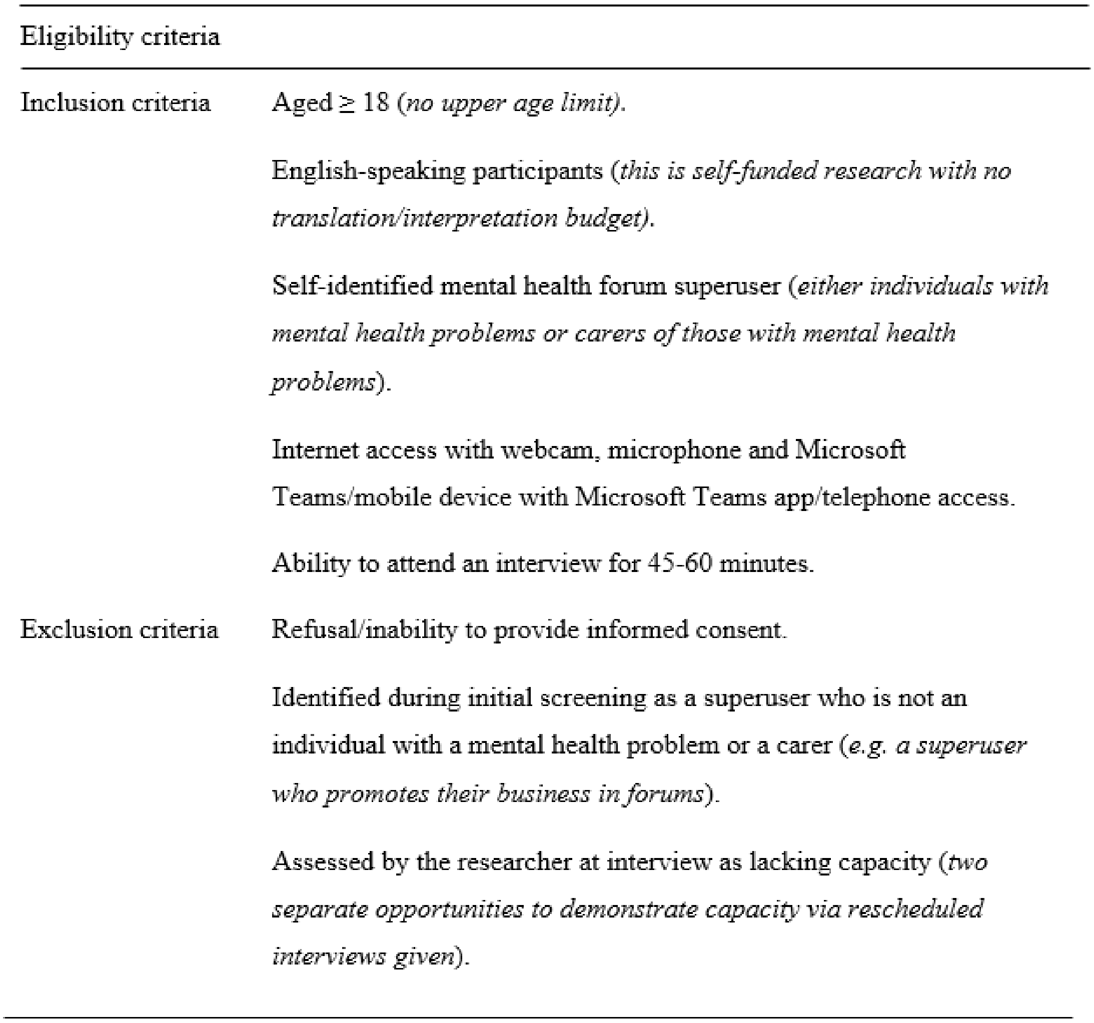
The researcher recruited a homogeneous sample of participants (i.e. self-identified MHF superusers) via typical case purposive sampling. Purposive sampling ensures participants have the lived experience required to share experiences that will address the research questions (Creswell, 2013), enhancing the study rigour (Campbell et al., 2021). The researcher drew on insights from background reading (Carron-Arthur et al., 2015; Carron-Arthur et al., 2016a; De Simoni et al., 2018; Joglekar et al., 2018; van Mierlo, 2014) to create a tentative superuser description that participants could use to self-identify with:

"Superusers spend a lot of time (at least 1 hour each week) talking to other people in online forums. Some superusers provide information, advice, and support to their peers by creating new forum posts. Other superusers help people to feel connected by responding to existing posts. Some superusers go out of their way to make new forum members feel welcome."

The provision of this description may have cued participants about what they went on to talk about in interviews; however, including some form of superuser description, given it is not a widely known term, was necessary to support meaningful self-identification. Other inclusion criteria were kept to a minimum to ensure adequate recruitment (see Table 5).

Table 5

Participant Eligibility Criteria



Eligibility criteria	
Inclusion criteria	Aged ≥ 18 (*no upper age limit).*
	English-speaking participants (*this is self-funded research with no translation/interpretation budget).*
	Self-identified mental health forum superuser (*either individuals with mental health problems or carers of those with mental health problems*).
	Internet access with webcam, microphone and Microsoft Teams/mobile device with Microsoft Teams app/telephone access.
	Ability to attend an interview for 45-60 minutes.
Exclusion criteria	Refusal/inability to provide informed consent.
	Identified during initial screening as a superuser who is not an individual with a mental health problem or a carer (*e.g. a superuser who promotes their business in forums*).
	Assessed by the researcher at interview as lacking capacity (*two separate opportunities to demonstrate capacity via rescheduled interviews given*).

3.11 Recruitment Pathways

The researcher primarily utilised connections with the iPOF study to facilitate recruitment by (a) requesting contact first names and email addresses for self-acknowledged “high frequency” forum users and (b) contacting these forum users via email to share the study flyer (Appendix G). All potential participants provided consent to be contacted for further research via iPOF. The researcher also shared the study recruitment leaflet via their Twitter Account using targeted hashtags (#mentalhealth, #mentalhealthresearch, #forum #research

#researchparticipantsrequired) and attached a request to retweet the post twice (Appendix H).

3.12 Recruitment Process

Upon receipt of expressions of interest, the researcher responded via email (Appendix I) to arrange a short 5–10-minute video call or telephone call (according to potential participant preference) to assess eligibility (Appendix J). If eligibility was confirmed and the potential participant was happy to proceed, the researcher emailed them an information sheet (Appendix K). The researcher then gave potential participants time to consider the research information and encouraged them to ask questions. Only when participants confirmed they were happy to proceed did the researcher send a link to Qualtrics via email, where they completed the consent form (Appendix L). Participants were given pseudonyms upon receipt of consent forms.

3.13 Data Collection

This research utilised semi-structured interviews, positioning participants as discussion leaders (Bryman, 2016), allowing flexible interviewing (DeJonckheere & Vaughn, 2019) and the opportunity for improvisation (Kallio et al., 2016). While alternative methods (e.g. surveys, focus groups and asynchronous web-based discussions) have generated rich qualitative data on online health-based forum use (De Simoni et al., 2020; Prescott et al., 2019; Stawarz et al., 2019), semi-structured interviews can enhance rapport (Morris, 2015) and may be more ethical when recruiting potentially vulnerable populations (Bryman, 2016; Drabble et al., 2016). Interviews lasted between 35 minutes and 1 hour (average =45 minutes) and were conducted via telephone (n=11), Microsoft Teams video call (n=5) and Microsoft Teams audio call (n=1). One researcher (CL) conducted the interviews. The interview topic guide (Appendix N) comprised: (1) forum engagement experiences, (2) motivations for forum use and (3) challenges faced when engaging.

The interview topic guide was piloted with a PPI advisor to test the flow and elicit feedback on appropriateness and relevance. Feedback was largely positive but also identified issues with questions (not always open-ended) and prompts (insufficient depth and frequency). Upon receiving this feedback, the researcher (1) arranged additional practice sessions with a fellow postgraduate student, (2) read more about qualitative interviewing and (3) made slight amendments to the topic guide.

3.14 Data Management & Storage

All data associated with this research was managed in accordance with the Lancaster University Research Data Management Policy (Lancaster University, 2015) and the General Data Protection Regulations (GDPR, 2018). Qualtrics was used to share the information sheet and collect consent and demographic details (Parker, 2019). Data was stored in a password-protected OneDrive folder, accessible only to the researcher and supervisory team (Parker, 2019). A separate password-protected master list was created to link participant names to pseudonyms (Stucky et al., 2014). The interviews were audio-recorded with an encrypted Dictaphone secured in a locked cabinet (Knight, 2018). Transcripts were deidentified (Stucky et al., 2014), and recordings overwritten and permanently deleted after transcription (Ölvecký & Gabriška, 2018). At the end of this study, the researcher will arrange the storage of anonymised data in Lancaster University's institutional data repository, Pure. The researcher will then overwrite and permanently delete all data stored in the OneDrive folder.

3.15 Data Sufficiency

A critical methodological decision in qualitative research concerns what constitutes a sufficient sample size (Young & Casey, 2018). While pragmatic and normative decisions influence sample size decisions in PhD research (Mason, 2010), ensuring enough rich data to address the research questions is essential for high-quality, meaningful research (Stenfors et al., 2020). Still, determining sample size a priori is a positivist approach (Sim et al., 2018); therefore, data saturation and sufficiency concepts were utilised instead.

Aiming for data saturation, the point where no new information "emerges" from data (Saunders et al., 2018), can ensure data sufficiency, and saturation is a concept that could work with the philosophical underpinnings of this research (Constantinou et al., 2017). However, saturation implies that meaning is inherent in (and inevitably exhausted from) data, a stance that conflicts with RTA, the analysis method used in this research. RTA says new interpretations of data are always possible (Braun & Clarke, 2022). Accordingly, the concept of data sufficiency was deemed more appropriate (Braun & Clarke, 2021b).

Data sufficiency (in terms of information power) (Malterud et al., 2016) encourages sample size to be determined according to (1) breadth of study aims, (2) specificity of participant experience, (3) presence of psychological theory, (4) quality of interview dialogue, and (5) analysis approach. This research had three clearly defined but broad questions, did not apply a priori psychological theory and conducted analysis across cases, factors which indicate a larger sample size is needed. In contrast, individuals with experience highly specific to the research questions were recruited, and feedback from interview piloting suggested dialogue was of high quality in terms of ease, rapport and researcher knowledge, factors which allude to the need for a smaller sample size (Malterud et al., 2016).

Comparisons were made with existing superuser research (De Simoni et al., 2020) and a baseline recruitment range (n=15-20) established. The final sample size was decided following initial analysis and discussions with the supervisory team, where it was concluded that enough contextually rich and nuanced data had been gathered to ensure data sufficiency in terms of information power.

3.16 Quality Assurance

While quantitative research conducted within positivist paradigms focuses on long-established “conventional” quality criteria, including reliability, validity and generalizability (Mays & Pope, 2000), due to the diverse paradigmatic and epistemological assumptions underpinning qualitative research (Finlay, 2006), there is a lack of consensus surrounding how to assure and assess its quality (Braun & Clarke, 2022). Therefore, when considering the application of quality assessment tools and quality assurance frameworks throughout this PhD thesis, its critical realist foundations, together with its unique paradigmatic choices (e.g., the use of qualitative interviews and the application of RTA), were considered (Morrow, 2005).

One of the most widely applied criteria for ensuring quality in qualitative research is Guba and Lincoln’s (1985) multi-dimensional concept of trustworthiness (Elo et al., 2014; Stenfors et al., 2020). However, this conceptualisation and its associated facets (credibility, transferability, dependability, and confirmability) are more applicable to constructivist research, which assumes ontological relativism (Guba & Lincoln, 2001), not ontological realism, so transparency, rigour and reflexivity were centred instead (Dada et al., 2023).

3.16.1 Transparency

For research to be transparent, it must counter ambiguity at all stages (Hiles & Cermak, 2007; Tuval-Mashiach et al., 2017). Accordingly, the researcher sought to uphold three dimensions of transparency: (1) data transparency, (2) analytic transparency and (3) production transparency (Moravcsik, 2019). To protect research participants' anonymity, it was not feasible to make all interview data public (Moravcsik, 2019). Instead, including verbatim quotes enabled readers to assess the shared patterns of meaning reported during analysis (Tuval-Mashiach et al., 2017). Verbatim quotes also contributed to analytic transparency, as did explicit reporting of interpretive stages (Moravcsik, 2019).

3.16.2 Rigour

The concept of rigour derives from positivist research (Patterson et al., 2023) and is often considered inflexible and inhibitory to creative qualitative processes (Baillie, 2015; Sandelowski, 1993). However, it is possible to conceptualise it in terms of transparency (Johnson et al., 2020; Steltenpohl et al., 2022), theoretical rigour (e.g., methodological consistency) and interpretive rigour (Fereday & Muir-Cochrane, 2006). In ontologically critical realist research, theoretical rigour enhances quality by increasing the likelihood of identifying generative mechanisms (Kempster & Parry, 2023; Levers, 2013), while interpretive rigour ensures findings have evidential grounding (Fereday & Muir-Cochrane, 2006).

The researcher established theoretical rigour by prioritising methodological transparency and congruence (including detailed methodological descriptions and justifications for decisions made) (Steltenpohl et al., 2022), employing purposive sampling (Campbell et al., 2021), and systematically documenting the data collection and analysis processes (Johnson et al., 2020). The researcher established interpretive rigour by fully immersing in the data before transcription and conducting multiple readings post-transcription (Braun & Clarke, 2022). The researcher also prioritised detailed descriptions, orthographic transcription (detailing tone and non-verbal elements) and transparent data coding and theme generation to ensure interpretive rigour (Fereday & Muir-Cochrane, 2006). Additionally, the researcher sought to further increase rigour via Braun and Clarke's (2006) 15-point checklist for RTA.

3.16.3 Reflexivity

Reflexivity involves researchers critically examine their values, beliefs and biases (Shaw, 2010) and their active role in generating knowledge (Braun & Clarke, 2019a). Reflexivity is an ongoing evaluation of self (Finlay, 2008). For research to be transparent and rigorous, paradigmatically informed reflexive practice must be integrated throughout (Engward & Goldspink, 2020; Finlay, 2008; Steltenpohl et al., 2022). To support a critically reflective approach, the researcher regularly engaged with the questions “What do I know?”, “How do I know what I know?”, “What influences my perspective?” and "From what voice and position do I share my perspective?” (Patton, 2015). These questions guided reflexive journaling (Yardley, 2000), supervisory discussions (Campbell et al., 2021), and data analysis (Dodgson, 2019) as they reflect the subjectivity of “truth” while acknowledging a multilayered reality. This questioning process also enabled the researcher to build awareness of unacknowledged personal assumptions and intersubjective dynamics (Biggestaff & Thompson, 2008; Willig, 2008) potentially influencing the research.

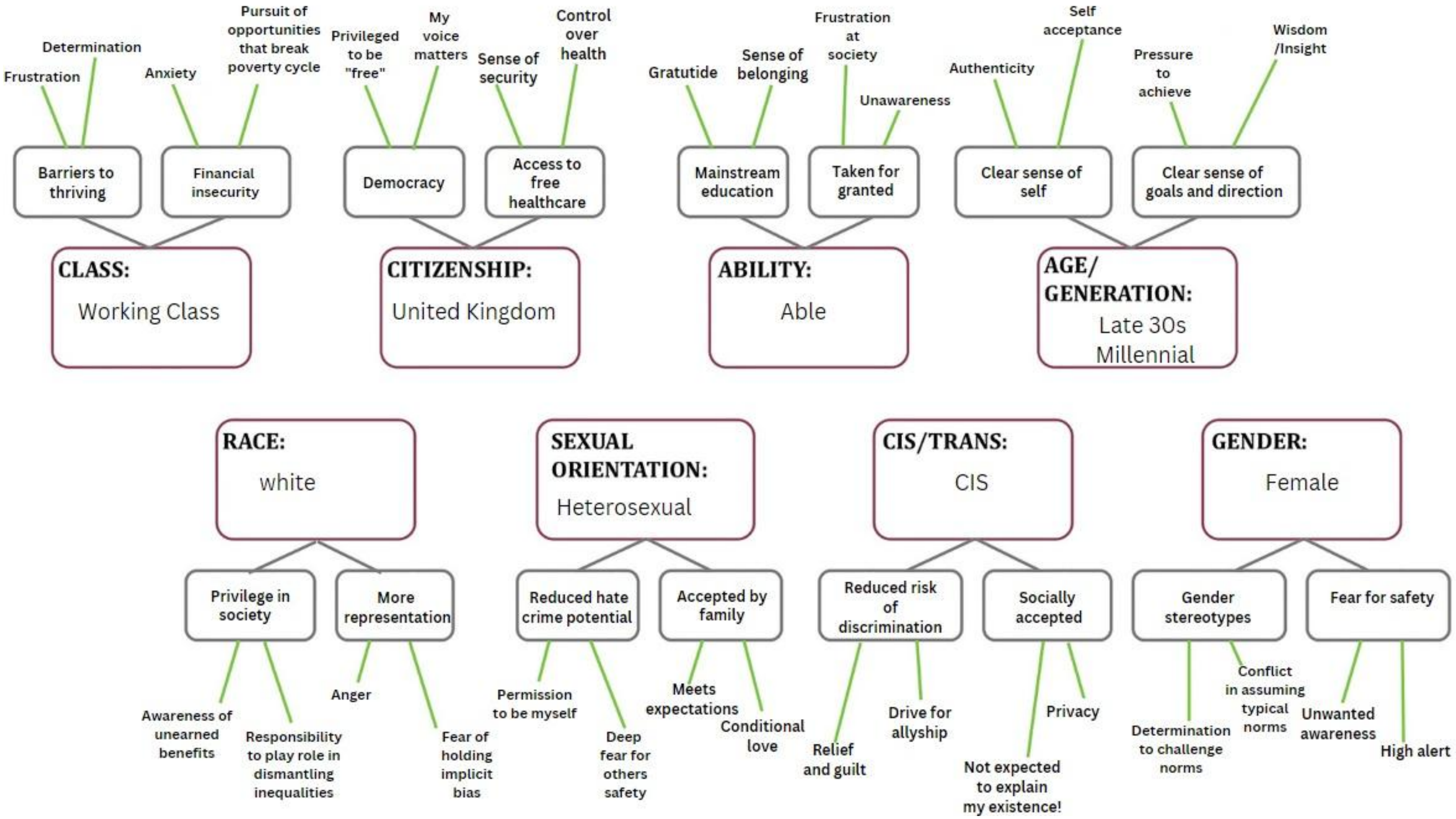
As noted, reflexive journaling was a key element of the reflexive process used throughout the research process. This critical reflection is akin to Schön’s (1983) concept of “reflection on action”, which allows for heightened visibility of subjective bias. Reflexivity was also centred throughout the analysis and when reporting and discussing the study results via reflective memo-writing, frequent comparison with the data, ongoing discussions with supervisors to challenge potential bias and the use of participant quotes to illustrate themes, thus ensuring interpretations remained consistent with participants accounts.

3.17 Researcher Social Identity Mapping

The researcher utilised Jacobson and Mustada's (2019) social identity map. The map comprises three tiers: (1) border elements of social identity, (2) acknowledgement of how these elements impact life, and (3) identification of emotions tied to social identity. While positionality is fluid (Folkes, 2022), the social identity map facilitated reflection on potential researcher–participant power dynamics (Jacobson & Mustada, 2019) and further informed discussions of assumptions potentially influencing data interpretation (Vaandering & Reimer, 2021). Figure 5 presents the map.

Figure 5

Social identity map



(Jacobson & Mustada., 2019)

3.17.1 Positionality Statement

I am a 38-year-old white working-class woman from a socio-economically deprived city in the northwest of England. As a woman, I have experienced oppression due to patriarchal social structures. I have also experienced significant privileges due to my race, citizenship, and ability. Due to my socially accepted sexual orientation and gender identity, I have avoided oppression and discrimination that marginalised groups face. Growing up in community with few expectations of academic achievement, education has been an act of rebellion and empowerment. I hold an undergraduate degree in psychology, a postgraduate certificate in social work and a master’s degree in health psychology.

3.18 Reflexive Practice During Data Collection and Analysis

To fully facilitate effective discussion and evaluation of reflexive practice during this PhD thesis, in this section, I shift away from the conventional third-person academic writing style and instead adopt first-person pronouns. This is a deliberate choice given this section engages with facets of my identity and positionality as a researcher, enabling transparency, authenticity and depth of reflection (Davies, 2012).

While I sought to integrate reflexivity throughout each stage of the research process (Engward & Goldspink, 2020), and my positionality ultimately influenced every decision I made from research inception to data interpretation (Wilson et al., 2022), reflexive practice holds particular significance during data generation and analysis. These research phases are where my identity, including race, ethnicity and age, class and inherent values and subsequent overall positionality intersect with those of the participants and in doing so inevitably shape the co-generation of data and its subsequent interpretation (Kim, 2024). Given the previously noted facets of my social positionality, I remained mindful of how perceptions of shared and differing backgrounds could impact participants' willingness to share their experiences. In particular, I was conscious of how visible and undeniable differences (e.g. gender, age and race) influenced the dynamics of interviews. For example, when interviewing older male participants, being a relatively younger female researcher prompted me to be conscious of imbalances in life experiences and subsequent uneven power distribution and how these facets can inform openness, narrative framing and personal disclosure. Likewise, when interviewing participants whose racial backgrounds and cultures differed from my own, I held awareness of how my own racial identity and its associated privileges likely shaped rapport and influenced how participants chose to engage with me. In response to these reflections, I took particular care to emphasise confidentiality and to create a respectful and non-judgmental atmosphere. I also remained critically aware that for some people, their gender and/or cultural background can result in heightened stigma around mental health and, therefore, heightened challenges in talking about their experiences. To address this, I focused on allowing participants to guide both the pace and depth of disclosure during discussion, and while I did use gentle prompts to encourage further sharing when appropriate, I equally remained attentive to signs of resistance to find the right balance.

My positionality and life experiences also shaped the direction of this research. For example, my initial interest in researching MHF superusers stemmed from both personal and professional experiences. Throughout my early 20s, I used a MHF to access peer support, an experience that positively and profoundly transformed my life. Professionally, I have provided internet-based mental health support for the past 13 years. These experiences encouraged me to be critically aware of potential biases that may have influenced the data interpretation processes. For example, my experiences of online forums were exceptionally positive, while others' experiences may not be. I also firmly believe the internet helps reach those who would otherwise never access support, which, despite having some evidential basis (e.g., Rickwood et al., 2007), I was careful to ensure I did not hold as a universal truth.

My positionality comprises both insider and outsider dimensions (Ademolu, 2023). However, disclosing my MHF experiences was not part of the PhD study, meaning participants likely acknowledged my outsider status both regarding power status (i.e. researcher versus participant) and lived experience (i.e. lack of acknowledgement of a shared lived experience). The researcher–participant relationship holds inherent power inequalities (Kaaristo, 2022), and perceived outsider status can inhibit the construction of knowledge (Muhammad et al., 2015). This critical positionality awareness, therefore, informed trust-enhancing strategies (e.g., informal chats before interview), rapport building (via ongoing email exchange and ice breakers before interview), and a focus on participant ease (e.g., compassionate, inclusive language) that sought to ensure nonmaleficence, sensitivity and participant autonomy (Beauchamp & Childress, 2013; Engward et al., 2022).

3.19 Ethical Considerations

Ethical research practice in the UK is rooted in utilitarianism (a moral framework that prioritises collective wellbeing [Khan, 2016]) and upholds the principles of nonmaleficence, beneficence and autonomy (Beauchamp & Childress, 2013). These ethical obligations have historical foundations in the Nuremberg Code (1947), the World Medical Association's Helsinki Declaration (1964) and the Belmont Report (1979) (Hammersley & Traianou, 2012; Tseng & Wang, 2021). As this research involved interviewing potentially vulnerable participants and exploring internet-based forums, ethical decisions reflected utilitarian-informed guidance from the British Psychological Society (BPS; 2021a; 2021b; Oates et al., 2021) and the Association of Internet Researchers (Franzke et al., 2020). The Lancaster University Research Ethics Committee granted ethical approval for this research in February 2022. The following sections outline how key ethical issues were addressed.

3.19.1 Voluntary Participation

Voluntary participation originates from the Nuremberg Code (Ignacio & Taylor, 2013) and states that research participants must not be unduly influenced or coerced (Fırat & Kılınç, 2017). Accordingly, the voluntary nature of participation (including the right to withdraw) was detailed in recruitment materials, discussed during screening, and revisited at interview. A prominent ethical concern was the influence of payment on autonomous decision-making. The researcher, therefore, ensured payments aligned with similar research payments (Warnock et al., 2022) and confirmed participants knew they would be paid even upon withdrawing from the study.

3.19.2 Informed Consent

The Nuremberg trials established informed consent as an ethical imperative (Hammersley & Traianou, 2012). However, participants can only provide informed consent if research aims, requirements, and use of data are understood (Anderson et al., 2017). Participant understanding was prioritised via rigorous and transparent detailing of all research stages. Participants were provided with information sheets, opportunities to ask questions, detailed consent forms, and assessed for understanding before interviews commenced.

3.19.3 Minimising Harm

Minimising harm to participants is essential if nonmaleficence and beneficence are to be assured (Hammersley & Traianou, 2012). As participants reflected on their experience of using online MHFs, there was potential for emotional distress. Participants were, therefore, signposted to support services before the interview as part of the information sheet. Distress protocols (participant and researcher; Appendix O) were designed based on academic literature, supervisory team input, and ethics committee feedback. Additionally, participants were sent a debriefing email including reiteration of the signposting materials following interview (Appendix P).

3.20 Patient and Public Involvement

Patient and public involvement (PPI) involves collaboration between researchers and individuals with experiential knowledge of research phenomena (Turner et al., 2020). Considered experts through experience (Di Lorito et al., 2020), PPI advisors provide unique layers of insight that may exceed researchers' understanding (Turner et al., 2020). Including PPI advisors in research balances power (Frith, 2023) and ensures researchers move from conducting research “about” people to conducting it “with” them (Price et al., 2022; Råheim et al., 2016). PPI is an ethical imperative (Gladman et al., 2023) and a core element of this PhD research. The researcher recruited a subset of three PPI advisors with experience using MHFs (one of whom identified as a superuser) via the iPOF study PPI group. Recruiting PPI advisors via the iPOF study reduced recruitment time (Joseph et al., 2016) and meant they could be paid via iPOF funds. PPI advisors gave input on:

(1) Research questions

Shared decision-making at early stages enhances research relevance (Kallio et al., 2016), strengthening the subsequent evidence base (Frith, 2023).

(2) Recruitment plans

PPI advisors are crucial in identifying potential recruitment barriers (Rayment et al., 2017). The advisors provided feedback on recruitment materials, resulting in the streamlining of flyers and simplification of wording.

(3) Interview piloting

PPI involvement in topic guide development enhances relevance and integrity (Chenail, 2011; Kallio et al., 2016). Additionally, interview piloting improves researchers' communication skills (Moult et al., 2023).

(4) Discussion of findings

Study findings will be discussed with PPI advisors to better consider their implications and how they might be best positioned to inform policy and practice.

Due to time constraints, these discussions had not yet taken place at the time of writing.

(5) Dissemination

Involving PPI advisors in the creation of dissemination materials will involve the co-creation of a lay summary presenting prominent insights from the study. As noted above, due to time constraints, these dissemination activities have not yet taken place and are expected to occur following the PhD viva.

Chapter 4: Findings

4.1 Chapter Introduction

This chapter presents the generated insights from the RTA study of the engagement experiences of superusers in online MHFs. While the creators of the RTA method, Braun and Clarke, caution against the use of “findings” to describe such outcomes, as it implies the passive discovery of knowledge, the use of “findings” as the chapter title is consistent with the critical realist foundations of this research. From a critical realist perspective, the themes presented here are interpretations of real experiences shaped by deeper, often unseen social structures and generative mechanisms and the term “findings” is used to reflect this.

The chapter begins with an overview of the study participants, which details key demographics and reasons for MHF super use. This overview also includes details on the participants' feelings towards the term “superuser”, having self-identified as this type of high-frequency forum user, to take part in the study. A participant characteristics table comes next, which includes demographic data in addition to data on time spent reading and writing messages in MHFs and how this has evolved. This information is presented to provide context for the findings that follow, helping to situate the participants' experiences within their diverse backgrounds and patterns of MHF engagement. Following this overview, five themes are presented via a thematic map and then via detailed analytic narratives that explore and unpack each theme one by one, offering rich interpretive accounts together with participant quotations, which are used as examples of how these accounts are solidly grounded in the data. Each of the five themes offers a nuanced understanding of different aspects of superusers' engagement in online MHFs.

4.2 Participant Overview

A total of 17 superusers (m=2; f=15) of MHFs participated in this study. The participants were UK-based, ranged in age from 18-74 years old and were predominantly white British (n = 11). Participants disclosed a variety of employment statuses. Almost half (n=8, 47%) were either in full or part-time employment. Others were students (n=2; 12%), retired (n=2; 12%), or unemployed (n=4; 24%), with one participant declining to answer. Reasons for forum super use varied. Some participants became superusers because they had personal experience of mental health problems now or in the past (n=9;53%), because they cared for others with mental health problems now or in the past (n=2;12%), or due to a combination of both (n=6;35%).

The study participants self-identified as forum superusers according to the simple definition provided in the recruitment leaflet: “superusers spend a lot of time (at least 1 hour each week) talking to other people in online forums”. However, of those asked, most had not heard of the term before, and some felt the term superuser had negative connotations that made them question their forum use. For example, one participant said the term “makes you sound like you’re obsessed with it”, while another noted “it kind of almost put me off a bit” (in terms of taking part in the research study), and a third stated that it sounded “bizarre”. While these opinions were not relevant to the research questions, they were gathered as part of icebreaking or the interview winding-down period and given the emerging nature of superuser research, and previous criticisms of the naming of certain types of forum users (e.g. “lurkers”), such opinions felt of value to report.

Regarding time spent using MHFs, participants reported a wide range of hours spent reading forum posts initially (i.e. upon first joining MHFs), ranging from less than one hour per week to more than 25 hours weekly. Time spent writing posts initially ranged from less than one hour per week to up to four hours. When asked how much time they were spending reading and writing forum posts in the present day, some participants noted that they maintained similar usage patterns over time, while for others, there was a substantial increase in forum engagement both in terms of time spent reading posts and writing posts. A small subset of superusers also showed more extreme shifts in engagement over time, with one participant increasing their weekly writing time from four to five hours initially to over 20 hours per week after six years of forum use. An important factor to consider when interpreting these results is that each superuser had spent different lengths of time using MHFs, ranging from two years to over 20 years. Table 6 presents a more detailed overview of the participant characteristics, including additional demographic insights and full data relating to the frequency of use of MHFs.

Table 6

Participant Characteristics

Gender	Age range	Ethnicity	Education	Employment	Mental health condition(s)	Stage of recovery	Forum type(s)	Length of use (years)	Time spent reading posts initially (hours per week)	Time spent reading posts currently (hours per week)	Time spent writing posts initially (hours per week)	Time spent writing posts currently (hours per week)
Female	25–34	White British	Postgraduate	Full time	Undisclosed (carer)	Active mental health problem	Multi-topic mental health	3	<1	>5	<1	>5
Female	45–54	Indian	A-Level	Unemployed	Bipolar Disorder	Active mental health problem	(1) Bipolar disorder (2) General multi-topic mental health	8	1-2	2-3	<1	4-5
Female	55–64	White British	Undergraduate	Unemployed	Bipolar Disorder	Active mental health problem	Bipolar disorder	20	>10	>20	3-4	>15
Male	45–54	Mixed	Undergraduate	Unemployed	Anxiety Disorder	Active mental health problem	Multi-topic mental health	5	2-3	3-4	3-4	2-3
Female	25–34	White British	Undergraduate	Full time	Bipolar Disorder	Active mental health problem	Multi-topic mental health	2	>25	>10	1-2	1-2
Female	35–44	Chinese	Postgraduate	Rather not say	Depression	Previous mental health problem	Depression	3	4-5	<1	<1	1-2
Female	18–24	African	Undergraduate	Student	Schizophrenia (carer)	Active mental health problem	(1) Schizophrenia (2) multi-topic mental health	3	>5	>5	<1	1-2
Female	25–34	Mixed	Undergraduate	Full time	Anxiety & depression	Active mental health problem	(1) Anxiety (2) Depression (3) Trauma	3	>15	>5	3-4	>5
Male	45–54	White British	Undergraduate	Student	Anxiety, Depression & Post Traumatic Stress Disorder	Active mental health problem	(1) Post-traumatic stress disorder (2) Borderline personality disorder	7	3-4	1-2	<1	1-2

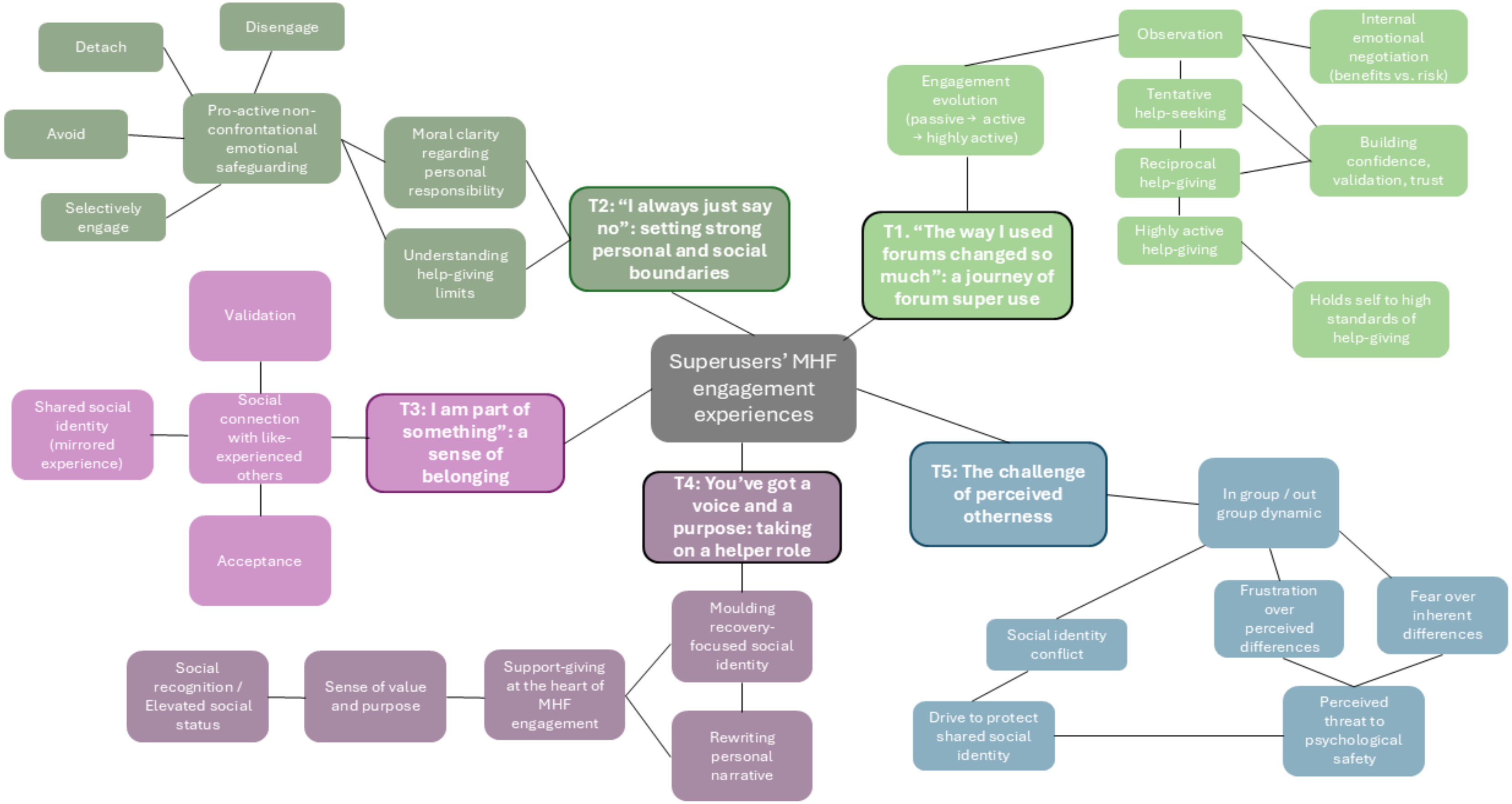
Female	65–74	White (other)	Undergraduate	Retired	Bipolar disorder	Active mental health problem	Bipolar disorder	2	1-2	1-2	<1	1-2
Female	25–34	White British	Undergraduate	Part time	Eating disorder	Active mental health problem	Eating disorder	3	2-3	2-3	<1	4-5
Female	45–54	White British	Undergraduate	Retired	Undisclosed (multiple)	Previous mental health problem	Multi-topic mental health	6	4-5	>30	4-5	>20
Female	55–64	White British	Secondary	Part time	Undisclosed	Active mental health problem	Multi-topic mental health	7	>5	2-3	2-3	1-2
Female	65–74	White British	Undergraduate	Full time	Undisclosed (multiple, trauma-associated)	Active mental health problem	Multi-topic mental health	5	1-2	1-2	1-2	1-2
Female	45–54	White British	Undergraduate	Full time	Eating disorder	Previous mental health problem	(1) Multi-topic mental health (2) Eating disorder	3	1-2	2-3	<1	1-2
Female	25–34	White (other)	A-Level	Full time	Anxiety, Depression & Complex Post Traumatic Stress Disorder	Active mental health problem	(1) Anxiety (2) Depression (3) Complex PTSD	4	>15	>30	3-4	2-3
Female	55–64	White British	Undergraduate	Unemployed	Anxiety, Depression & Borderline Personality Disorder	Active mental health problem	(1) Anxiety (2) Depression (4) BPD	10	>5	1-2	1-2	1-2

4.3 Thematic Diagram

Figure 6 presents a thematic diagram outlining the five themes generated in this study. Each theme captures a different aspect of superusers' engagement experiences and broadly aligns with the central focuses of the research questions: overall engagement experiences (green boxes), motivations for engagement (purple boxes) and challenges (blue boxes) while engaging. The diagram also breaks down each theme into key components; these components are not sub-themes, but rather, they show specific elements that comprise the theme. The decision to avoid breaking themes down into sub-themes was made as each facet of the themes was considered to be of equal importance to the meaning of the overall theme. Braun and Clarke (2019) note that subthemes should be used only in instances where they serve to highlight an aspect of an overarching theme that is especially distinctive or salient. In this analysis, all facets were interpreted as holding comparable significance.

Figure 6

Thematic Diagram



4.4 Generated Themes

4.4.1 Theme 1: "The Way I Used Forums Changed So Much": A Journey of Forum Use

This theme establishes how many MHF superusers come to adopt highly communicative roles within online spaces over time. At its core, this theme centres on the overarching experience of engagement evolution, establishing that many individuals who ultimately become superusers do not exhibit high levels of active forum engagement initially. Instead, most superusers experience a gradual and somewhat linear shift from passive to active use: a shift underpinned by evolving feelings of confidence, validation and trust.

This transition often begins with immersing themselves in the MHF through extensive reading, followed by tentative attempts at help-seeking, which, when met positively, provides a sense of validation and acceptance that encourages ongoing contributions that lead to reciprocal support over time. For example, many of the superusers in this study described how their journey of forum use started with an initial period of intense observation where they learned about their conditions from the experiences of those with similar lived experiences. As one superuser noted:

“I was very, very scared about writing anything at first, and for a long time I would just go and read people's comments” (Charlotte)

Underlying emotions such as anxiety, fear of social rejection and concerns about whether they legitimately belonged in these spaces appeared to be at the heart of this reluctance to engage initially. While not named explicitly as fear, there were instances where participants described needing time to get to a place where they felt “brave” enough to begin engaging with others in the forums:

“So for a whole month I was just observing… then I went well, I got to slowly get brave to put in my own input…what makes me felt brave to post for the first time that day was… I was having a bad experience at home with some people; they were trying to advise me that we shouldn’t talk and shouldn’t go into any mental health issue.” (Zoe)

Here, the decision to engage in MHFs is presented as an internal emotional negotiation. As the participant had not received a welcoming response when trying to talk about their mental health problems at home, here they weigh the benefits of participation and sharing these experiences in the MHF against the fear of vulnerability. Therefore, while initial passive forum use appears to be an inactive process, it is likely that those who go on to become superusers are investing heavily from an emotional point of view, spending time observing others, learning the rules of engagement and calculating the risks of making themselves known within these spaces perhaps especially so when they have received negative and unhelpful responses regarding their mental health problems in their offline lives.

Still, most users described a clear benefit to this observation period, both regarding gaining insight and meeting certain psychological needs. As one participant shared:

“so, I’ve been reading up on trying to find people with that and [erm] seeing the how they well how they cope with the diagnosis or how they understand what that is... they've got a lot of information out there when you read that it just makes you feel so much better" (Mei)

Here, passive access to mental health information and, in particular, other people's accounts of coping with their mental health diagnosis, is centred as a beneficial resource, and it is through exploration of such resources that superusers described a newly forming sense of connection. As a second participant described:

"Reading people's stories, you just sort of [erm] suppose feel less isolated" (Lavanya)

Here, through passive engagement (observation), the foundations of belonging begin to form (see Theme 3 "I am part of something": a sense of belonging, for extended discussion on this).

Following a period of observation, several superusers talked about a specific moment in time that marked a change for them and encouraged active engagement. In one striking instance, a superuser shared how receiving a formal mental health diagnosis encouraged their initial forum use:

"Because I was like pre-diagnosis, so I was sort of just reading what other people were saying... later on, when I did get my diagnosis, I did dive on in... it felt like I was [erm] worthy of being a part of the group... after the diagnosis, I felt like okay, there is my community" (Lavanya)

For this superuser, a sense of worthiness was crucial for the development of their engagement. Once formally diagnosed, they found themselves instilled with a new level of confidence built on the trust that they were like the others in the forum and would therefore be accepted. This account shows an important transition in forum engagement from passive observation to claiming space through engagement. Here, the diagnosis appeared to offer not only validation and a confidence boost that catalysed a new engagement style but also alludes to a sense of belonging that may reflect a deeper shift in their illness identity (e.g. a psychological shift from an “outsider” to an “insider” status).

Still, not every superuser followed the same trajectory. Where previously a sense of internal negotiation was present, one superuser noted her eagerness to communicate immediately:

“I was actually looking for people⋯ and I talk to them straight away, it just happened, yeah” (Helena)

For Helena, there was no passive use of forums, as her eagerness to connect with other people encouraged her immediate communication within the forum.

Still, for most superusers, once they had built confidence and further established a sense of belonging (see Theme 3 for further discussion on this), they described taking on more communicative roles where they shared their mental health experiences:

"I now feel able to post where initially I was reluctant to post, or I was only reading and writing reply comments, but now I feel like I can write posts about my experience" (Emily)

This increase in communication was often underpinned by a need for help from others:

“I was going through a really, really hard time, so they were very supportive of me” (Rose)

When sharing their experiences and seeking support in this way, the majority of superusers reported an outpouring of support:

“When I did reach out for help, I was surrounded by support and people telling me we’re here for you, we’ve been through this, or we’re going through this, and it won’t be like this forever” (Charlotte)

A pattern across participants' experiences established that initial fears of speaking up in forums were soon squashed thanks to the considerate and helpful responses that superusers were given. However, this was not a universal experience. As one superuser described:

“At the beginning, I was a bit more open about my experiences and mental health, but then I realised quite a lot of people were just using the forums to find out what they could apply for what they had to do in certain assessments.” (Joseph)

For Joseph, what had started as a process of integration and reciprocal sharing of mental health experiences soon turned into an isolating experience where he did not build confidence and contribute more as other superusers in this study had described. Instead, he began to question the motives of other forum users and became less open with them as a result.

Still, the majority of superusers in this study did note evolving levels of confidence and feelings of building trust and validation within the online forums they used, with several reflecting on the importance of help-giving, even when seeking help themselves. As one participant described:

"I'd look at them for emotional support, but then when you're looking sometimes you see some things and you think you might as well just say something, I guess" (Amelia)

While another reflected on the importance of reciprocity:

"I need to feed the forum as well as just taking" (Lena)

For many of the superusers in this study, as forum engagement evolved from largely passive observation to active help seeking and eventual reciprocal help-giving, so too did their growing sense of responsibility, as not only did they begin to feel a need to give back, but also there was a drive to do so in meaningful and socially responsible ways. For example, one superuser acknowledged:

"I learned a lot through mistakes, people would say, 'Well, I don't think that was very kind to say there'. I may have said something not inappropriate, but I may have posted a comment which I thought was funny, obviously not [err] sarcasm is not appreciated... I've learned over the years and with political correctness that it's even more important online" (Emily)

Here, a strong sense of learning online social norms is evident, and it is implied that in doing so, superusers then fine-tuned their communication style over time, thus holding themselves to higher standards. Another superuser discussed the care and diligence behind their MHF responses:

“When you’re writing something of that nature, I like to prepare for that and to know so people won’t find mistakes” (Zoe)

While a third explained how they even add a disclaimer to the end of their posts:

“I end up putting a disclaimer sort of on all of my posts... I say if you can't understand clearly what I am trying to say, you can reach out to me, and I'll explain further” (Nicole)

These reflections illustrate how superusers, within their accounts, show a strong awareness of the challenges inherent to online communication, particularly the ways tone and context may be misconstrued in the absence of visual and verbal cues. Through their deliberate communication choices, superusers reflect emotional literacy and a strong commitment to playing a role in maintaining balanced, helpful online communities. Therefore, through these communication efforts, superusers appear to place community and the maintenance of a positive, helpful group dynamic in their engagement. In this sense, they may be positioning themselves as invested community members over solitary individuals (this experience is expanded upon in theme 3: “I am part of something”: a sense of belonging).

A pattern established across many superuser accounts centred on expressions of trust and belief in positive benefits associated with MHFs; facets that appeared to encourage superusers further on their journeys of forum use. As one superuser described:

“I knew very early on that this was going to be something that was going to help me… I’ve took hope and inspiration in the forums from people who ARE like me, and I feel like it was that belief [laughter] more than any one step, you know” (Charlotte)

The sense of belief and inherent optimism in the helpfulness of MHFs echoes the experiences of a number of participants. For example:

“I’m going to go online because I learn more online… I didn’t learn anything about my illnesses from any doctor, not one doctor have I ever ever learnt anything from” (Mei)

The above quote also captures a sense of moving away from traditional help-seeking approaches, such as medical or clinical advice, due to past negative experiences. It suggests that offline opportunities and options for mental health support (or lack thereof) may shape the belief that online spaces offer a different and potentially more valuable source of support, in some cases.

What was clear for most superusers is that after periods of observation, learning, active help-seeking and reciprocal help-giving, there was a very clear shift in their journey of use towards highly active help-giving (as presented in theme 4 “you’ve got a voice and a purpose: taking on the helper role” explores help-giving as a unique facet of superuser motivation). While this help-giving did involve reciprocal benefits at times (see Theme 4), the more time superusers spent in forums, the more they established their sense of identity around helping and guiding others. One superuser described this transition:

“I’m finding and have found these forums quite helpful and useful for me first as a a user but then as a [erm] in an advisory sort of role” (Thomas)

Overall, superusers appeared acutely aware of their changing roles and participation styles over time, in many cases, acknowledging how learning more about mental health and how to support themselves led to this natural progression towards supporting others:

“So much has changed, and I know a lot, and I find myself supporting other people more” (Nicole)

But again, the experience was not universal or indeed positive for all superusers. As one superuser went on to say:

“I used to look and read all the comments and look at the posts and look at the links and try to connect with people posting by responding, but now if something pops up… I’ll literally just be shaking my head because the forums just seem to have got worse and worse. (Joseph)

Despite continuing to identify as a forum superuser, Joseph describes how he went from being open to connecting with others by responding to their posts to becoming disillusioned with forum posts and shaking his head rather than choosing to engage. For Joseph, limited opportunities for satisfactory reciprocal help-giving appear to have inhibited any path towards highly active help-giving (again, despite his acknowledgement of continued high levels of activity within forums).

In summary, this theme establishes how, for many superusers, their engagement experiences evolve from initial observations to active contribution, to guiding and helping others. This journey appears to be both linear and cumulative in the sense that each interaction serves to catalyse higher levels of engagement over time. Still, there are exceptions to this journey, from skipping any initial observation stage to withdrawing help based on the perception of group content. Ultimately, the overarching insight this theme provides is that many superusers may not arrive at MHFs and immediately engage at high frequencies. Instead, while certain traits or experiences may predispose them to higher levels of engagement, super use itself may largely (but not exclusively) develop within the MHF context through a dynamic interplay of lived experience and interaction with like-experienced others. Over time, exposure to like-experienced others has the potential to permit, shape and inform engagement frequency and style and for most superusers, this results in an increase in engagement and engagement style (i.e. help-giving). Given the vital role superusers play in MHFs, this new insight is especially useful for the creators of such online spaces, as through understanding the complex and multifaceted journey of use, superusers navigate to become high-frequency users; they will be in a stronger position to ensure this evolution of engagement is encouraged (See Chapter 5 for further discussion on this).

Given the somewhat linear path of increasing forum engagement that most superusers within this study described following, it might seem that these highly communicative users actively engage with most other MHF members. However, the data generated here goes on to tell a very different story; one that comprises both selective and highly boundaried engagement. Theme 2 “I always just say no": setting strong personal and social boundaries” explores this in more depth.

4.4.2 Theme 2: "I Always Just Say No": Setting Strong Personal and Social Boundaries

This theme explores how many of the superusers in this study discussed engaging in the process of creating and maintaining strong intrapersonal and interpersonal boundaries to successfully navigate the emotional complexities associated with engaging in MHFs. These boundaries appeared to arise from a need to establish balance between supporting others while respecting personal capacity and thus safeguarding emotional well-being. The personal and social boundaries superusers described setting were non-confrontational, comprising aspects of avoidance, emotional detachment, selective engagement and disengagement. Furthermore, many of the detailed boundaries were underpinned by moral clarity regarding the limits of personal responsibility in online spaces. Strong personal and social boundaries were a central facet of the majority of the participants' engagement experiences in MHFs, speaking to the lengths these superusers felt they must go to in order to protect their psychological well-being.

Across many participant accounts, a pattern relating to self-protection via the use of boundaries was evident. Some superusers described employing boundaries to protect themselves against potentially emotionally triggering topics (i.e. those that would pose a threat to their emotional stability):

“If I see something that I thinks going to be a wee bit triggering, I’ll leave that for someone else who’s a wee bit stronger to help” (Thomas)

Particularly illuminating here is the way this participant's response reflects an implicit trust that someone else in the forum will step in to help. This account suggests that help-giving is perceived as a community responsibility, shared amongst users, which in turn may serve as a mechanism of permission that enables superusers like Thomas to set communicative boundaries that prioritise their needs above others.

This clear drive to prioritise psychological safety was discussed by several superusers in the context of respecting their emotional limits:

” You’ve got to know where you are because if you try to help everybody, you’re just going to burn out, you know” (Arina)

This comment outlines online communication as a balanced and carefully informed action where introspection is necessary to understand limits and subsequent boundaries. Arina also went on to talk more about burnout, saying:

“I can burn out sometimes, so I have to be very careful” (Arina)

Her experience of sometimes burning out speaks to times when boundaries have not been deployed effectively and adds an extra layer of understanding here: that while many superusers are successful in maintaining strong intrapersonal and interpersonal boundaries, this is not something experienced by all superusers at all times. That said, a strong pattern across the superuser accounts in this study was the importance of being mindful of weak boundaries and understanding where to draw the line regarding emotional investment within forums. Another superuser reflected on the dangers of becoming heavily invested in MHFs:

“I’ve seen people who get in my personal life who are emotionally attached to those forums, and they’re very into it, and I see that becoming very unhealthy.” (Lena)

Here, a story of becoming emotionally attached to MHFs is presented as a cautionary tale, something to avoid to remain healthy. For Lena, as a superuser, this shows an underlying tension in her view of forum engagement in the sense that, although she is highly active in MHFs, she is suggesting that she maintains emotional distance. This suggests a belief that it is possible to engage intensively (time-wise) while remaining emotionally detached. Her perspective may also reflect a broader concern about emotional burden in MHFs.

Despite high frequency forum use, multiple superusers described selectively engaging with others, not just in accordance with emotional capacity but also according to the degree of shared lived experience. As one superuser explained:

“With a forum, you can put the brakes on as much as you want, you can ignore three things that are posted, and then you see the fourth one and you go Oh yes, I ca— I can relate to that” (Samira)

Such selective engagement was given further context by this participant as she went on to describe the feelings of inadequacy and uncertainty in not fully grasping the lived experience of another:

“There are a lot of things I don’t respond to because they’re outside my sphere of knowledge” (Samira)

This superuser also described a situation where her boundaries were tested, but she remained strong in her commitment to prioritise her boundaries and thus her well-being:

“I have had people who are quite unwell asking for my email address, and I always just say no” (Samira)

This account reflects how some superusers draw firm boundaries around contact beyond the MHF. Although the reasoning for this decision is not made explicit here, Samira's acknowledgement of saying no to “people who are quite unwell” suggests that boundary setting may be context dependent. This interpretation is supported by her admission that she has also made some “really, really good friends” in MHFs with whom she has connected outside of MHFs (e.g. “I had a two-hour [video call] [err] yesterday.)

In another instance, in finding themselves out of their depth in a support-giving conversation, one superuser said:

“I stopped the conversation because I didn't know what to say or do” (Lavanya)

In MHFs, it appears superusers see ending a conversation abruptly as an acceptable and often necessary step to take with one superuser, even commenting on the ease of this practice:

“That was the easiest thing to do, just stop the conversation” (Lavanya)

In online spaces, users often have the freedom to end conversations that challenge or overwhelm them without facing the same social penalties they might encounter offline. This practice may be considered a unique facet of the online disinhibition effect, but here, instead of talking more candidly, the choice is made to say nothing more at all. For superusers, given their high levels of MHF use, the ability to "just stop" a conversation therefore holds even more significance due to the likely frequency at which they experience such interactions and may be one explanation as to why the majority of superusers in this study were able to practice boundary setting more often and build up strong boundaries in the process (Chapter 5 introduces supporting literature on this topic and discusses this interpretation in more depth).

Still, despite the predominant pattern across this theme being one of strong boundary setting, boundaries were not always fixed. Instead, at times, they were tested and sometimes managed only after an unwanted experience. As one superuser described:

"I did befriend someone ... but then I was like okay I'm not liking this ... so I restricted them." (Arina)

In addition to avoidance-grounded boundaries, within the dataset, there were two striking accounts of emotional shielding. In the first, the superuser spoke of employing emotional distancing:

"If you wanna be distant, cause that helps you to cope, then you're gonna be more distant" (Julia)

While in the second, the superuser described a process of conscious compartmentalisation:

“I think when I go on those forums, I think I go in with only half a brain, so I can just detach myself quite quickly” (Lena)

These accounts of emotional shielding were striking due to their pre-emptive nature and may speak to boundaries learned as a result of initial emotional overwhelm during early use of MHFs.

For some superusers, boundaried engagement was more absolute. When they needed to emotionally shield, they chose to disconnect completely, as these three accounts detail:

“Sometimes I’ll just step away from the computer” (Emily)

”I think that when I said enough is enough, I just put my phone down and that is it” (Helena)

” If it’s too much… if it’s too [erm] what’s the word, draining emotionally draining then I’ll stay off it for a while” (Jane)

When superusers set these types of boundaries, they do so without expression of guilt; instead, they are content with decisions to prioritise their own needs, thanks to a strong sense of moral clarity regarding what is and isn’t their responsibility within MHFs. As one superuser shared:

“I try not to get drawn into into the emotional side because I don't really want to make new friends or have somebody come to me really on there because I'm that's not my responsibility” (Emily)

Even when other users exhibited high levels of distress, superusers rationalised their boundaries:

“I find that well, it should be a qualified person that reaches out and not randomers” (Lena)

This comment was especially illuminating as the participant in question did not use MHFs where any “qualified person” (e.g. a therapist or trained professional) was known to be present. Still, the choice not to reach out to some was regarding responsibility:

“It wasn't my [pause] place to say anything” (Lavanya)

Even those who had not found themselves needing to establish social boundaries had strong and clear boundaries in mind should the need arise:

“I would be like, actually, I’m not your therapist, I’m not really there for you as such, I mean I’m happy to discuss it and whatever, but I’m not going to dedicate a huge amount of time to to be with you to help you because I’m not qualified to” (Jane)

Suggesting an integrated community experience and belief that superusers hold about themselves that they should not take on the emotional labour that mental health professionals or those “qualified” to help others should. Regarding the differences between being supportive on a peer level and offering support which may be regarded as “qualified”, when describing someone she knew “who was without a doubt killing themselves”, one superuser, Samira, reflected on the limits of what she could offer:

"You can be a friend, but it's outside of your control, and so in the end I decided, well, I will be a friend, you know I'll continue to be friendly as long as he continues to come here, but you [err] I have no control over the situation whatsoever" (Samira)

Here, Samira's account shows a form of boundary-setting that allowed her to continue engaging without taking on the emotional or practical responsibility that may be assumed of those "qualified" to do so.

There were also instances where some superusers described difficulty in gauging interpersonal boundaries, as is evident in this account:

"I was it was me overstepping the lines where I was disappointed then because they did seem interesting, but well, if it was me, I'd probably say no too if it was someone doing that to me" (Emily)

Here, Emily acknowledges her own difficulties in maintaining certain boundaries as she describes overstepping personal limits. This account reveals the complex, multilayered nature of boundary management within online forums, where superusers (and in fact all types of forum users) must continually negotiate with what boundaries feel right and acceptable for themselves while also working to acknowledge and respect the boundaries of others. This example helps to highlight how one individual's perception of what constitutes an appropriate boundary can differ from another's

In summary, this theme offers a new perspective on the engagement experiences of superusers in MHFs by revealing the extent to which many superusers employ both interpersonal and intrapersonal boundaries when engaging online. On the surface, the boundaries superusers set in MHFs can at times appear abrupt, but ultimately, they are born from a need to respect personal emotional capacity. Boundaries were not always deployed in appropriate ways, as detailed within the theme; sometimes they were tested and adjusted as needed, while at other times there were struggles with judging the acceptability of others' boundaries within the complex online social environment. This theme holds importance for creators of MHFs as it illuminates the emotional demands superusers face in protecting themselves online. It raises crucial questions surrounding who is (and who should be) responsible for establishing MHFs that facilitate peer-to-peer support in a way that does not require such intense emotional investment and calculated use (this point is expanded upon in Chapter 5).

Themes 1 and 2 have established some of the key engagement experiences of MHF superusers. Still, to fully understand these experiences, it is important to know what drives superusers. The two themes that follow focus on critical motivators of MHF super use.

4.4.3 Theme 3: "I am Part of Something": A Sense of Belonging

The theme "I am part of something": a sense of belonging, explores how many superusers experience a sense of validation, acceptance, and shared identity in MHFs. Patterns across superusers' experiences within this study show how MHFs tend to provide superusers with a platform to overcome the loneliness and social disconnect they experience in their offline lives due to mental health stigma, social isolation and daily challenges associated with living with mental health problems.

For many superusers, MHFs are not just spaces for learning and reciprocation of help-giving but also spaces in which they can establish a strong sense of belonging and experience mirrored representations of their own lived experience; experiences that are often unacknowledged, shamed or stigmatised in their offline lives. The sense of belonging that many of the superusers in this study described experiencing through their engagement with like-experienced others was a key factor in motivating and maintaining their high-frequency forum use. Still, as with all experiences, there were divergences from this for some users, where forum use did not lead to the same strong sense of belonging. Still, this theme offers insight into a key pattern in the data around the aspects of forum use that sustain and motivate superusers' engagement in MHFs over time.

A pattern across many participant accounts related to the way in which many of them told emotion-laden stories detailing how MHFs allowed them to bridge the social disconnect they often felt due to their own or their loved ones' mental health problems. Many superusers described experiences of being cut off from their everyday offline social worlds as a result of stigma and limitations imposed by their mental health problems. However, this disconnection did not extend to online spaces. This loneliness comprised both emotional and physical disconnect from an offline social world that appeared to carry on without them:

“I was still alone in my house while the rest of the world was going on around me, but you know I was also connected to that world” (Charlotte)

This account highlights a tension between physical isolation in the offline world and a form of digital social connection found in online spaces. For superusers, this online connection may fill a social void and therefore become a key experience that supports the development of high-frequency forum use.

For some, facets of social identities, such as age, combined with mental health problems, magnified the sense of disconnect:

“They’re really valuable, we have to keep them going because for a lot of people nowadays, particularly when you’re getting older, it’s a very isolating world where I live”(Brigitta)

For some participants, MHFs were lifelines for connection. A similar sentiment of loneliness was expressed by superusers who no longer worked due to their mental health:

“Feeling lonely because I do live on my own… where you do feel like I say lonely or isolated… when everyone else is at work and things like that and you’re just on your own”(Lavanya)

This account reflects how Lavanya experiences a strong sense of disconnection from the everyday social world and, particularly the routine of being at work. Here she expresses how she feels separate and disconnected from “everyone else”. MHFs may help to bridge this social gap by providing connection during times when other forms of connection are not available (e.g. “when everyone else is at work”) and therefore also help to counter feelings of isolation that come from not being able to participate in typical work-life patterns.

Another participant goes on to discuss the necessity of these social bonds for mental health recovery:

“A big thing for mental health recovery is actually socialising and social connection, there are [err] a lot of people that maybe can’t get out of the house, and so they either have an online forum or they’re not communicating at all” (Emily)

In contrast to in-person, socially demanding spaces, MHFs are centred here as alternative, accessible platforms where people who would otherwise struggle to connect due to their mental health problems can form bonds. As a result, for many superusers, MHFs become a legitimate option to negate or at least reduce the sense of loneliness that they feel in their everyday offline lives:

“That’s always taken that loneliness away, so I don’t feel lonely anymore” (Mei)

As Mei details, the social connection facilitated via MHFs has a strong impact on her feelings of loneliness, and this experience may support her and other superusers' frequent and sustained engagement.

In seeing elements of themselves in others, the majority of superusers in this study described how they quickly established the foundations of belonging. As one superuser noted:

“You’re not just talking to somebody hoping they might get what you’re talking about, you’re actually going to a specific site where people have the same problems as you” (Thomas)

That said, forum use did not lead to a strong sense of belonging for all of the superusers in this study. For some, despite going to a specific site, a lack of interaction disrupted any opportunity of a sense of belonging:

“I give up really quickly because I have a feeling like there is no one there besides a therapist moderator… I even text the mail to them a couple of times to ask them is there any out there who will talk, and they said Oh yeah, I know it’s really quiet … I really give up after that” (Helena).

For Helena, despite attempting to connect, the forum environment was not supportive of this, given its quietness. This suggests that forum activity levels are crucial for paving the way to a sense of belonging.

While for another superuser, despite ample opportunities to connect with others, there was a struggle to find any true sense of connection or common ground:

“It was it was to hopefully try and connect to somebody or… find someone who I could talk to who knew… about my illness, my mental health and if not my disability… unfortunately that didn’t happen.” (Joseph)

Joseph's account helps us to see that shared experience is not always the same as emotional resonance and that actually, there are many factors that may inhibit a superuser's ability to integrate themselves within an online community and forge a strong sense of belonging.

While a third superuser noted a challenge in establishing a strong sense of belonging, despite shared experience, the forum environment felt too overwhelming due to others' depth of personal disclosure:

“I just found it too much and left the group because I just couldn’t cope because of how people were and just things they were saying, I just couldn’t I couldn’t deal with it because I’m quite my counsellor says I’m quite empathetic”. (Arina).

Arina’s account sheds light on how individual emotional sensitivity can make it a challenge to connect with like-experienced others, suggesting that forums with clearer guidelines on disclosures or trigger warnings may better support some users to find their place and thus establish a sense of belonging.

Yet despite the challenges some superusers faced, for the majority of the superusers in this study, through shared experience and seeing themselves in others, they found the courage to be emotionally vulnerable:

“I felt myself open up to them, because I felt like someone was there who knew me” (Zoe)

Here, initial layers of fear (discussed in theme 1) are peeled away as superusers begin trusting that they are safe to express their authentic self. This sense of being known is interesting within the context of an anonymous MHF, especially considering the superusers in this study appeared deeply aware of the double-edged sword of anonymity online. As one superuser noted:

“Being anonymous, you know, I think it’s a pro and a con... you know somebody can be really nasty and nobody would be able to do anything about it” (Joseph).

Still, the notion of anonymity was framed in a positive light by most:

“That sort of anonymity does help you to speak much more frankly” (Samira)

It appears psychological safety was enhanced by anonymity, as it became easier to be authentic, and this new level of ability to reveal previously hidden parts of experience allowed superusers to continue to build upon the foundations of belonging.

Further boosting a sense of belonging was the belief, for some, that MHFs are fundamentally altruistic environments:

“at the same time, you know people are coming from you know a place of [erm] a good place mentally and intentionally, as you know people aren’t there to upset you... they’re coming from compassion and there’s no ulterior motive, they just want the best for everyone... they’ve been very respectful to each other, they have been caring... people tend to be so empathetic too because they know what it’s like” (Thomas)

While this optimism and belief in the goodness of MHFs was only expressed directly in a handful of accounts, for some superusers, this added a further perceived layer of emotional safety, which was central to forming a sense of belonging.

Many of the superusers in this study felt other MHF users were inherently good people (e.g. “very respectful… caring… empathetic” as noted in Thomas’s account above) and felt driven to connect with that goodness, a process that often led to the formation of friendships.

Still, some of the superusers alluded to a sense of caution and awareness needed when making deeper connections and friendships online. As one superuser noted:

“You don’t know who’s using a forum. You know, you may feel that you know, you know, at the end of the day… you have to be a pretty good darn judge of character… you need to be quite careful, I say” (Samira)

Still, shared experiences appeared to serve as strong foundations for connecting with others, as Thomas went on to note:

“You know it’s like what Bob Dylan said, that isn’t it strange how people that suffer [err] together are all closer than people who have went through contented times… and that really [err] there’s a camaraderie, a trust, a bond, an unspoken thingy” (Thomas)

Here, friendships appear to play an important role for some superusers when it comes to developing a sense of belonging and aspects of MHFs themselves appear to enhance friendship building:

“I really feel especially forums that are quite small and intimate, I’ve really got to know people… I recognise most of the people who post there… regularly and I like that it gives a sort of intimacy” (Samira)

This account suggests that familiarity enhances connection and trust for some superusers, and thus the ability to form friendships that instil a sense of belonging. In really getting to know people, superusers may become emotionally invested in the space and repeatedly engage over time:

“As time has gone on… I’ve got so close to the people there… we’re interacting totally as friends” (Samira)

Having online friends and a feeling of belonging causes some superusers to experience emotional shifts in how they experience their place in the world:

“I was like, well, actually the world is for me, there’s people just like me, all these people” (Charlotte)

No longer pushed aside by a society unwilling and incapable of accepting them, this superuser found themselves surrounded by like-minded people and, in turn, found their place amongst this community:

“I say quite a lot it’s… my little weirdo community… you’ve got a voice and you feel you belong” (Emily)

And as another superuser expressed:

“I am a part of something”- Nicole

As the superuser accounts presented here demonstrate, for many superusers, a sense of belonging develops in stages, first through countering loneliness and social disconnect, then via mechanisms of being understood and friendship forming and finally through the realisation that the MHF is a safe space to be oneself. Then, for many superusers, belonging to a community of like-experienced others provides a shared experience that extends beyond their individual struggles and fosters a sense of collective identity that motivates them to repeatedly engage with other forum members. However, this is not a straightforward or indeed universally shared experience for all superusers, as some found the forum environment and their perception of other users disrupted the path to building any sense of belonging. This theme is important because it raises questions regarding the onus of responsibility for enabling pathways to belonging (discussed further in Chapter 5).

While this theme presented a sense of belonging as a key motivator of engagement for many superusers of MHFs, it was not the only motivator. Once superusers have established this sense of belonging, many describe finding further motivation by stepping into a help-giving role. Theme 4, “You’ve got a voice and a purpose: taking on a helper role”, explores this motivation.

4.4.4 Theme 4: You’ve Got a Voice and a Purpose: Taking on a Helper Role

This theme explores how MHFs provide platforms for those who are stripped of their social power in everyday society due to mental health problems to establish new identities and experience a new sense of self-worth through helping others. For superusers who adopt it, the help-giving role is not just about supporting others; it is also about establishing purpose. While help-giving is central to the theme, this theme also encompasses several broader processes. These include the rewriting of personal narratives (where superusers begin to reinterpret their mental health experiences in ways that promote recovery, resilience and well-being), the moulding of social identities (as participants describe how they shape their sense of self within online communities), the experience of increasing social status (by gaining recognition and respect from their peers thereby increasing feelings of value and worth) and the experience of inherent joy in establishing a valued place in the world. Accordingly, the central organising concept of this theme is not help-giving but empowerment: a psychological state in which superusers feel capable, confident and permitted to use their experiences to help others, thus establishing an inherent sense of purpose as a result.

Having established a strong sense of belonging in MHFs (see theme 3), several superusers in this study express feelings of deep gratitude for how others supported them early on in the MHF use. This gratitude often goes hand in hand with empathy for others:

"There has just been so much understanding about it, how my [sibling] was given the diagnosis, and I keep feeling how I like to be there for someone going through that as much as possible, the way the forums were there for me” (Nicole)

Here, a clear drive to give back in the form of emotional reciprocity is evident, and this is something that was interpreted across multiple superuser accounts. As a second superuser described:

"You’re even more conscious now because you remember how you were when you came on, so you want to say something that’s supportive" (Thomas)

This process of putting themselves in the shoes of others and holding strong empathy was echoed by a third superuser:

"I can see myself in them, and I can remember how it was for me when I first came to the forums for help" (Nicole)

These accounts show how the help-giving role many superusers take on is born through empathetic reflections on their own journey within the forum. Many superusers described seeing themselves reflected in others, which establishes help-giving as an even more meaningful practice. Interestingly, one superuser saw stepping into help-giving roles as a natural transition:

"Then, because you've learned so much knowledge from them that you end up being a top contributor because you've absorbed all of that information" (Mei)

Here, help-giving is seen as a process via which Mei was able to pass on the knowledge and insight they have acquired. In taking on the role of knowledge conveyors, Mei positioned themselves as a valuable member of their online community, thereby laying the foundations of purpose by establishing an online helper identity. For Mei, there was also a sense that helping others was a moral obligation for those with mental health problems:

"a lot of people with mental health issues, especially [mental health condition] [err] are more kind of like I like to say pay it back" (Mei)

In this context, the notion of a collective helping identity was formed, where helping others was an expectation.

The drive to help others may even be reinforced through observing other helpers receiving validation in MHFs. As one superuser noted:

“They are the most [tut] [err] [erm] the most thankful type people that you will come across because they really do recognise when someone is helping them or is at least trying to help them” (Thomas)

In this account, appreciation from others is framed as a reward for helpful others. It is also of interest how this superuser positions themselves in relation to others, seeing a distinct difference between helpers and those being helped and inviting in an “us” and “them” dynamic (explored further in theme 5).

A pattern established across many of the participants' accounts was that helping others appeared to boost their emotional well-being. As one participant explained:

“you feel like it was worth posting because it's actually been of use to somebody… it is a feel-good thing” (Lavanya)

In a world where many people with mental health problems may feel isolated and disconnected from “everyone else” (see theme 3), MHFs offer a space where self-worth can be affirmed through help-giving. Many superusers in this study described how their time felt worthwhile in the sense that they were making a difference, thereby conceptualising help-giving not only as a selfless act but also one with emotional benefits for the giver, as this superuser described:

“which is actually a a nice thing to use your experience to help people… it actually helps your own [erm] self-development of [err] you know how to help people but also how to help yourself… it feels really good to think you’ve maybe helped somebody and made a difference”(Thomas)

Here, help-giving is framed as a reciprocally beneficial process that allows superusers to meet important psychosocial needs:

"It feels very good, you know, I feel like [tut] I have an impact and effect on other people's lives... There are so many things I learnt along the way on that journey with my [sibling] that I get to pass on... I am a part of something, and maybe sometimes I am there for people to look up to" (Nicole)

In Nicole's account, helping others is framed as something that reinforces purpose, identity and personal growth. For her, helping others strongly connects with broader psychosocial rewards, a facet of use that may help to encourage continued super use.

A sense of reciprocity was also a foundational element of some superusers' accounts, helping to illuminate the fact that help-giving is not necessarily unidirectional even for those who have considered themselves forum superusers for multiple decades (as is the case with this superuser):

"I might say ... 'I'm sick and tired of this forum' ... and then people will say you know what's wrong ... and that's how ... most of it is just general chit chat." (Rose)

Here, Rose shows the fluctuating nature of forum super use and how days of empowerment, purpose and helping others may intertwine with days of heightened need and attempts to elicit help from others.

For one superuser, the positive emotional impact and social rewards of being valued and “a part of something” regarding her connection with a community gave her purpose. As this especially powerful and emotional account describes:

“I’m especially drawn to people who need help, you know… they gave me a way to function in the real world that I hadn’t had before because it’s hard talking to people in real life… I just feel like I’m doing something worthwhile now… it gives me a real boost you know I can sleep easy at the end of the day knowing that I’ve put a lot of my time every day to good use to help people you know…offering other people support feels so I guess fulfilling [pause] it feels like exactly what I’m supposed to be doing with my life you know… these experiences and how it feels to use what I’ve been through to help other people [voice cracking] it makes me quite emotional really [erm] [soft cry] [sign] [pause] it just feels really really really good [laughter] ” (Charlotte)

This in-depth account shows how MHFs provide a transformative sense of purpose for their users in a world where society's ignorance, inaccessibility and lack of care for people with mental health problems have failed them. MHFs become gateways to becoming someone important and a way to attribute new meaning to (and find a new level of acceptance for) mental health struggles. In this sense, the experience of helping is both emotionally fulfilling and identity-affirming.

Interestingly, when asked about the challenges involved in online super use and forum engagement, the superusers in this study who had assumed help-giving roles did not report any sense of burden associated with this role. Instead, they largely shared details of strong boundaries (see theme 2) and uplifting encounters:

“I just come away feeling so much better” (Mei)

With one simple but powerful statement summing up the heart of this theme:

“You’ve got a voice, and you feel you belong” (Emily)

As with all of the themes presented here so far, nuances and exceptions were evident within superusers' accounts. For example, while many superusers described helping others as a central facet of their online experience and something that gave a sense of purpose, others also reflected on withdrawing from help-giving:

“Sometimes I just blank them out… when it’s just the same questions over and over again people don’t search.. I just get bored of correcting them and pointing them in the right direction” (Lena)

Here, Lena depicts help-giving as something that is conditional on her willingness to help others, ultimately mediated by factors such as the perceived effort of others and the novelty of the conversation or request.

Still, it is clear from the superusers' accounts in this study that many MHFs offer unique spaces for those who may otherwise be marginalised, stigmatised or ignored by larger society to develop agency through helping others; something that is not otherwise an option for them when offline. While many different types of MHF users are likely to engage in help-giving exchanges online, the significance of this finding for superusers is that this is a process of deep transformation, where, thanks to their high-intensity forum inputs, new social identities are formed and maintained. By adopting help-giving roles, many of the superusers here detailed how they become purpose-driven, elevate their social status and become valued community members, thereby transforming their personal mental health narratives and perception of their sense of self and place in the world. The significance of this theme lies in its illumination of the psychological and social needs superusers meet through the active process of help-giving, as this insight can help organisations that run MHFs to better consider how to support these users while still providing them with the autonomy and sense of agency their help-giving provides (see Chapter 5 for further discussion of this point).

Help-giving is often associated with altruism, and it is clear from the data generated in this study that many of the superusers involved are deeply caring people who are willing to give their time, knowledge and understanding to others, but who also, at times, still need help from others too. Still, for many, the process of connecting with others and providing support is further complicated by perceived otherness within MHFs. Theme 5, "Perceived Otherness, explores this in more depth.

4.4.5 Theme 5: The Challenge of Perceived Otherness

The theme "the challenge of perceived otherness" is rooted in the concept of 'otherness', which speaks to the fundamental differences superusers perceive within MHFs. This theme offers crucial insight into the superuser experience (and consequently how organisations responsible for MHFs may support them) as it shows how, despite shared lived experience, many of the superusers involved in this study would actively strive to differentiate themselves from other MHF users in ways that elevate their social status, guard their sense of self and even at times undermine the sense of connection and psychological safety MHFs otherwise provide. While the concept of otherness can be considered ambivalent in the sense that otherness may be perceived as positive (e.g. curiosity or interest), negative (e.g. fear or threat) or neutral (e.g. an acknowledgement of otherness but no strong emotional response), many (but not all) participants in this study perceived otherness as having a largely negative skew, linking it to challenges and negative emotions such as frustration and fear that occur when striving to belong alongside other members of MHFs whom appear inherently different from themselves in terms of personal and social identity as well as illness experience and identity.

Patterns of otherness were interpreted where superusers framed this concept in various ways. For example, some discussed otherness regarding gender, where frustrations were aired when elements of others' identity were not in alignment with their own. When talking about sharing mental health experiences online, one superuser discussed how discouraged they became due to the predominant female demographic in the MHF they used:

“Men have specific issues that men need to talk to men about”(Thomas)

In contrast, a female superuser shared their disbelief that men would even be present in certain MHFs:

“Everybody was on it like men”.- Arina

Here, it is evident that some superusers experience unease when they do not find others who share their identity facets or, indeed, when they encounter those they did not expect. However, discussions of the challenges of perceived otherness became more emotion-laden for superusers when encountering differences centring on religion, ethnicity, mental health symptomology and recovery approach. For example, when reflecting on the influence of religion in MHF discussions, one superuser told of how they interjected into a conversation to question its relevance:

"You know there was one actually actually only one example I've ever seen of that and it's around religion somebody said [erm] [tut] I'll pray for them… it was a Muslim against a Christian and they were and [err] I actually I actually responded and I said I thought this was supposed to be helping people not having a well a centuries old argument about what you believe in and all of this…" (Thomas)

Here, Thomas expresses discomfort with religion entering help-giving spaces because this diverges from his expectations of MHFs. In saying "I thought this was supposed to be about helping people", Thomas appears to be holding the belief that religion is not an appropriate topic in this context, thus indicating a preference for more practical and secular mental health peer support. While the topic of religion was not a prominent pattern across the participants' accounts, there was a second powerful religion-related discussion from another superuser:

"there's one of those and and I don't go on that one anymore now [erm] that was there was a lot of [people from another country] you know oh saying like God be with you and for the good of grace… so that's why I didn't go there again because it was too many people like that I thought oh I can't be listening to that it's not my thing… I'm not overly religious, so if they start to talking about God, I'm off."- (Mei)

Here, perceived differences appeared to threaten this superuser's sense of social belonging as their views did not align with those centring God in their recoveries, and as a result, she disconnected from the MHF.

For others, the challenge of otherness came not from an aversion to difference but from the fear of miscommunication:

"Well, we started to get [erm] what do you call it [a different ethnicity] [erm] [a different ethnicity] people starting to come in, which we never had before, so I'm a little bit weary of how I talk because I'm not sure how I [pause] should be… I'm not equipped enough, you know [sigh]" (Arina)

For this superuser, taken-for-granted cultural norms around communication were challenged in such a way that their confidence to engage was diminished as they no longer saw their experiences mirrored in others. This fear of inadequacy when communicating with people from different cultures and backgrounds was framed differently when discussed by this superuser:

"because of the international element of a forum as well [err] to see different approaches… people will tell you that you know about splashing the cold water in your face and then all of a sudden Scandinavians will say 'well we've been doing that for centuries'" (Thomas)

Here, Thomas reflects on the diversity of perspectives and experiences in MHFs and how some recovery advice may be more common amongst certain cultures but unknown to others. Although not explicit, this quote may allude to an underlying apprehension around sharing recovery advice or insights that feel valuable due to a fear they may already be common knowledge for some users. This links back to a feature of theme 1 where several participants noted the high standards they hold themselves to when communicating online (e.g. the content they choose to share and the diligence taken when sharing that content).

Still, the perception of otherness across cultures was not always perceived as a challenge, but instead it was framed as a valued source of connection. As one superuser commented:

“There’s loads of people, but it’s worldwide, so that’s what I like about it, you can talk to everybody all over the world on that one.” (Mei)

Mei’s comment here draws attention to the truth that perceiving otherness is not always a negative experience, as for her, being among those who she considered different to herself was not experienced as a challenge but rather an opportunity for connection. Mei’s experiences show that while many superusers do find the experience of perceiving otherness to be a challenge, there are ways this may be negotiated and understood as a positive experience. A second superuser also draws on this:

“In my circles you can’t talk about mental health at all … in my culture especially … it’s not really accepted or discussed.” (Nicole)

For superusers like Nicole, encountering those who were “different” regarding cultural background and, therefore, their potential openness around discussing mental health problems was not problematic, but rather an actively sought-after aspect of the forum. In such cases, otherness again is highly valued.

These accounts of valuing perceived otherness show how, in some contexts, the perception of otherness could be situated as a positive opportunity; still, they do not negate the broader pattern of challenge described by many of the superusers in this study.

In addition to the challenge of differing facets of identity, several superusers also noted the challenge of engaging with those experiencing different mental health symptoms and those at different stages of recovery. Some by discussing their disinterest in MHF threads made by those with seemingly less disruptive mental health problems:

"I know that's about mental health too, but it's sort of mental health on the lower scale where I'm not there." (Arina)

Here again, otherness is centred and asserted by drawing a distinction between levels of mental health severity, which in turn caused this superuser, and several others like them, to question differences between themselves and others. For the superuser, separating themselves from those on “the lower scale” of mental health severity helps to reinforce their sense of identity and social standing in the forum in the context of a social hierarchy of mental health experience. While some superusers framed the challenge of otherness gently, others were blunt in their discussions:

"Some of the people who are in the low mood and some of the people who are in the high mood... it was so annoying... isolating." (Rose)

Here, despite being in a forum intended to unite like-experienced others, this superuser found clashing types of symptomologies encouraged feelings of isolation. In a separate account, another superuser spoke of the challenge of encountering other users with specific symptoms:

"Sometimes you do get a lot of people on there that are so depressed it's quite negative" (Mei)

This comment hints at superusers' empathetic thresholds and ties back into the need to protect their well-being when using forums by staying away from posts that feel too emotionally overwhelming or triggering (explored in theme 2). In fact, when it came to perceived coping styles and the methods through which others sought to elicit support, several superusers expressed discomfort with their accounts, implying that not all forms of help-seeking are viewed equally. For example, Helena described how certain expressions of distress appeared both performative and excessive:

“I had the feeling like there was like many people who start moaning like Oh my God, I am so small and worthless and the rest of them, like a hundred persons, said no no you are perfect, you are fine for me, it feels like [erm] pause too much attention seeking”(Helena)

Here, Helena situates herself away from those she sees as “attention seeking”, which suggests a tension between empathy and the perceived authenticity of others' distress within MHFs. While her hesitation and pause before saying “attention seeking” suggest potential discomfort in making this judgment, she makes it nonetheless. Similarly, Joseph framed some MHF posts as repetitive, superficial and almost trend-like:

“When I see a post now, I’m like, oh God… it just seems to be like it’s flavour of the week” (Joseph)

Again, echoing Helena’s focus on the style of help-seeking and suggesting frustration in negative perceptions of others' styles of communication within forums. These accounts highlight how superusers navigate complex social landscapes in MHFs and often make their own judgements on what constitutes acceptable forms of communication and help-seeking. These judgements may also reflect internalised stigma, particularly stigma that centres on expressions of distress or perceived need to depend on others, which may, at some level, also be directed inward towards those same traits within themselves. Furthermore, such negative appraisals of others may have a somewhat functional purpose for some superusers. It is possible that by creating distance from certain types of posts or users, superusers are better able to manage emotional overwhelm within forums.

This theme establishes a striking truth: even when purposefully seeking out those who have shared lived experiences of mental health problems (which may include the same symptomology, diagnosis and associated daily challenges), the MHF superusers in this study remain attuned to and vigilant towards the fundamental differences they perceive between themselves and others. Ultimately, this theme therefore speaks to the complexities of human differences, revealing how often perceived differences and an in-group out-group dynamic can disrupt superusers' sense of belonging and identity, making it challenging to engage. On the surface, by avoiding those with different help-seeking styles, or those who do not share prominent personal facets (e.g. gender and religious affiliation), it could be interpreted that superusers are seeking perfectly mirrored representations of the self in MHFs, experiencing and projecting internalised stigma when these expectations do not meet reality. Yet under the surface, it appears the superusers involved in this study seek what all MHF users likely do: a sense of psychological safety and connection with like-experienced others.

While negative experiences of “otherness” are likely experienced by all types of MHF users, the impact of otherness is undoubtedly magnified for superusers due to their high levels of frequency engagement. This high engagement means they will face increasing exposure to these challenges over time. As a result, this theme has established the experience of otherness as a prominent and previously unacknowledged challenge for MHF superusers that organisations who create and maintain MHFs must build awareness of if they are to effectively support and retain their most valuable contributors (Chapter 5 provides extended discussion on this point).

In summary, the five themes presented in this chapter provide a rich and interpretive account of the experiences of superusers in MHFs, providing new insight into how these individuals are shaped as a direct result of their forum engagement, what motivates this engagement over time and challenges faced that may threaten ongoing high-frequency engagement.

Chapter 5: Discussion & Conclusion

5.1 Chapter Introduction

This chapter begins with a summary of the overarching thesis aims, central research questions, and key insights generated from the data. These insights are then critically discussed in relation to existing literature to evaluate how they contribute to, expand upon, or challenge established knowledge on OHF and MHF super use. These insights are then further examined through the lens of relevant psychological concepts, constructs and theoretical frameworks. Following this, the strengths and limitations of the research are considered. Then recommendations for future research are outlined, and implications for practice and policy are discussed.

5.2 Summary of Thesis Aims, Questions, and Findings

The overarching aim of this thesis was to qualitatively explore superusers' engagement experiences in MHFs in order to develop new insight into their overarching experiences, motivations for high-frequency use, and challenges faced when engaging with others, thus creating a new knowledge base for organizations who create and run MHFs to tap into, so they have a more solid understanding of how to encourage, support and retain these essential forum users. Two central pieces of research facilitated this exploration: (1) an integrative literature review on the bidirectional impacts of superusers of OHFs and (2) a RTA of the engagement experiences of MHF superusers.

The integrative literature review (Chapter 2) sought to address the primary question, "What is known about the bidirectional impacts of superusers and OHFs?" In addition to the secondary questions: (1) How does existing literature conceptualise OHF superusers? And (2) What theoretical frameworks and methodological approaches are applied in existing literature on superusers and OHFs? This literature synthesis led to the generation of five themes relating to these bidirectional impacts, in addition to a novel conceptual framework that encapsulated them. Table 7 provides a reminder of these themes.

Table 7

Themes from the literature review (reminder summary)

Theme	Meaning
1. Superusers are integral to forum engagement and growth	Established the key role superusers play in both the initial development and ongoing growth of OHFs
2. Superusers create emotionally supportive and informative online environments	Highlighted how superusers foster welcoming communities by balancing emotional support with the provision of information and practical advice
3. Superusers drive community cohesion and proactive health environments	Showed how superusers promote a sense of shared belonging through mutual support and encouragement of collective adherence to community rules and norms
4. Forum super use can impact both psychological and physical health	Suggested highly frequent forum engagement can catalyse positive health behaviours and outcomes while also highlighting potential risks in specific forum contexts
5. Forum super use increases social connections and status	Established how OHF super use leads to recognition and appreciation from other users which elevates superusers social status

The literature review also established how forum superusers had been conceptualised in existing literature, highlighting various descriptive facets relating to their social status, influence and value, in addition to commenting on their central roles as emotional supporters, advice-givers and information sharers. While most existing research agreed that superusers are high-frequency forum users, literature synthesis suggested there was little consensus regarding the operationalisation of high frequency. Additionally, the literature review shed light on the methodological approaches and theoretical frameworks used in studies exploring OHF super use to date (see Chapter 2; Table 4), revealing a wide range of methodological approaches with little similarities across studies. Most publications did not apply existing theoretical frameworks within their studies, and among those that did, there was little alignment.

The RTA of the experiences of MHF superusers (see Chapter 3 for methodology and Chapter 4 for data analysis) addressed three research questions: (1) What are the engagement experiences of superusers in online MHFs? (2) What motivates superusers of online MHFs? And (3) What challenges do superusers face when engaging in online MHFs? The data generated for this study led to the construction of five themes. Table 8 provides a reminder of these themes.

Table 8

Themes from the RTA (reminder summary)

Theme	Meaning
1. The way I used forums changed so much": a journey of forum use	Established how many superusers of MHFs gradually adopt these roles over time depending on the quality of the forum environment and its associated community dynamics
2. "I always just say no": setting strong personal and social boundaries	Highlighted how many superusers navigate the complexities of MHF engagement by establishing strong interpersonal and intrapersonal boundaries in their forum use.
3. I am part of something": a sense of belonging	Explored how mirrored representations of the self in MHFs enable some superusers to experience feelings of belonging
4. You've got a voice and a purpose: taking on a helper role	Showed how in providing support to other users, many MHF superusers established a sense of purpose and new social identities
5. The challenge of perceived otherness	Centred on the difficulties many superusers faced upon encountering other MHF users who did not share key facets of their personal, social and illness identities.

While an in-depth discussion of the literature review findings was provided in Chapter 2, this overarching thesis discussion chapter revisits key insights from the literature review in order to engage in a deeper critical discussion of the data generated via, and interpretations derived from, the RTA study.

5.3 Towards a Definition of Superuser

Insights from the literature review (Chapter 2) highlight a lack of consensus and existing guidance regarding what constitutes forum super use, revealing that facets of “high-frequency” forum use are determined in various ways and are often dependent on the study focus itself. This supports findings by Carron-Arthur et al (2015), who in their systematic review of participation styles in OHFs noted highly engaged users had been classified in various ways across studies, including metrics such as time logged in, number of friendships and time spent reading. Even when there was agreement across multiple studies on core metrics of super use (e.g. post count; Geramita et al., 2018; Healey et al., 2014), there was no consensus on the operationalisation of this metric. The literature synthesis (Chapter 2) established a picture of super use that centres forum superusers as largely recovery-focused, proactive, emotionally supportive, information providers who tend to play central roles in the community cohesion that drives engagement and growth. The RTA study offered further meaningful insight into superuser characteristics, time spent using forums regarding reading and writing, how superusers perceived their roles and their thoughts on the “superuser” label itself; factors which have important implications for the development of a more coherent, agreed-upon definition of the term.

Regarding their characteristics, most superusers recruited for the RTA study that is part of this PhD thesis (88.2%) identified as female and more than half (59%) were over the age of 45. Given that the majority of recruited superusers were female, this raises questions regarding gendered patterns of engagement within MHFs and supports some existing evidence that indicates MHFs tend to be female-dominated spaces (Glossop et al., 2025) and that women may benefit more from supportive online networks (Shin & Park, 2023). Interestingly, this gender and age distribution closely reflects findings from a large-scale network analysis of smoking cessation forum superusers (Cobb et al., 2010) who found that 80% of OHF superusers were female and that most superusers were in their mid to late forties. Still, these superuser characteristics do conflict with some other existing research (e.g. O'Neill et al, 2014), which found most superusers were younger males. It may be that differences in study design, such as the use of broad population surveys versus forum-specific samples, influence demographic patterns. Additionally, it is probable that superuser demographics change in accordance with specific health forum topics and associated nuances around issues like attached stigma. For example, while anonymity and the online disinhibition effect encourage people to talk about challenging topics (like mental health problems) that they may not talk about in person (Marshall et al., 2025), and those who experience higher levels of mental health stigma can show a preference for online support (Wallin et al., 2018) internalised mental health stigma, while a universal experience, can be particularly challenging for men and therefore remains a persistent challenge for many men due to the way in which it inhibits both help-seeking and disclosure (McKenzi et al, 2022) thus potentially limiting their online engagement and super use of MHFs but perhaps not of other OHFs. Furthermore, facets of online environments and user norms may factor in here. For example, forums hosted via Reddit are likely to have more male users (Connell, 2025); therefore, it would not be surprising to see a shift towards more male superusers in these spaces. Ultimately, these findings suggest caution when making inferences regarding the "typical" characteristics of OHF and MHF superusers, as such traits are likely highly context dependent.

Regarding time spent engaging in forums, participants in the RTA study followed somewhat similar trends in use to that of the asthma forum superusers studied by De Simoni et al (2020), but with more extreme upper limits of use. For example, while De Simoni et al established superusers in their study spent between 1-3 hours writing posts and 1-20 hours reading posts each week, the superusers in the RTA study reported time spent reading posts ranged from less than 1 hour to over 30 hours per week and time spent writing posts ranged from 1 hour to more than 20 hours per week. The more extreme patterns of use exhibited by some MHF superusers may relate to the distinct emotional support needs of those with mental health problems who often experience chronic, ongoing, life-limiting symptoms and heightened social stigma and isolation (Naslund et al., 2016).

Arising from superusers' self-reported time spent in online forums is a crucial yet largely unexplored dimension of forum super use, which is the time they report spending reading in online forums. While, of course, those who use online forums would be expected to spend some time reading others' posts, within the literature, reading is often associated with passive forum use and user types (e.g. the "lurking/lurker" user type; Gopalsamy, 2017; van Mierlo et al, 2014; Wu et al., 2016). Yet substantially high amounts of time spent reading appear central to super use. In fact, within the RTA study associated with this PhD thesis, reading was not only central to the journey toward becoming a superuser (see Chapter 4, Theme 1) but also remained a prominent facet of super use once superuser status had been established (as evident in the participant characteristics reported in Chapter 4). These findings highlight the variability of forum super use and allude to a spectrum of super use that encapsulates both passive and active engagement. Accordingly, this suggests that superusers cannot be defined by their active contributions alone. Furthermore, the term "superuser" itself may require some rethinking, as despite its application in other contexts (e.g. healthcare utilisation; Rosenthal, 2013), data generated during interviews as part of the RTA study established largely negative perceptions of the term.

5.4 Superusers Overall Engagement Experiences

5.4.1 The Evolution of MHF Use for Superusers

While existing literature on forum superusers predominantly characterises them as highly engaged, prolific and persistent posters (Healey et al., 2014) who are highly connected to other forum users (Dias et al., 2012) and are responsible for posting more than two-thirds of all forum content (Carron-Arthur et al., 2015), it offers little insight into how these users come to take on such roles. Therefore, within the existing literature landscape, superusers are largely conceptualised as a distinct forum user type, who comprise just 1% of all forum users and are largely distinct when compared to almost 40 other types of forum users regarding their participation styles (Carron-Arthur et al., 2015). Given how superusers are situated within the existing literature, it could be reasonable to assume that much like those who are more vocal, social and connected within the offline world, superusers, perhaps due to a combination of personality traits, innate communication styles or altruistic motivation to help those whose lived experiences reflect their own, enter forums and immediately step into the superuser role. However, insights from the RTA study challenge this assumption. In the context of MHFs, superuser status, for most, appears to be one that emerges over time thanks to a series of key engagement experiences underpinned by both relational and environmental conditions. Although, as noted in Chapter 4, there were some superuser accounts that were exceptions to this, where the superuser chose to begin communicating immediately within forums at somewhat high frequencies. While mapping the road to super use was not a central research aim of this thesis, a key research question did relate to the exploration of the engagement experiences of superusers. When addressing this research question, an undeniable facet of superusers' engagement experiences is centred on the journey to super use and the evolving nature of engagement that ultimately culminates in it.

The journey to becoming a superuser for most involved intense and focused periods of forum observation. While reasons for inactivity were multifaceted, as detailed in Chapter 4, they appeared to stem from worries that the community would not be the right place for them and an underlying feeling that they might not fit in or belong (Fullwood et al., 2019). (see section “sense of belonging” for discussion on its role as a motivator for MHF super use). During these initial periods of observation, those who would ultimately go on to become superusers spent time learning the social norms and unwritten rules of MHFs, a process that closely aligns with Bandura's (1977) Social Learning Theory. Social Learning Theory suggests that individuals learn not only via direct experiences but also by observing behaviours and consequences experienced by others. Social Learning Theory is already a prominent theory in traditional peer support (see Chapter 1) and here it illuminates a process through which observing peers engaging within MHFs and perhaps also managing their mental health within the context of a supportive online community, can foster confidence in the forum itself and in positive social expectations, thus promoting the evolution of active engagement for the superuser. This first step of the superuser journey for many superusers may also reflect what Merolli et al (2014) describe as the therapeutic affordance of online "exploration". In their study, Merolli and colleagues note how social media users seeking health-based support initially engage in what they consider to be low-risk information-seeking behaviours before taking steps to connect with others and share their experiences, which mirrors this early observational phase forum superusers were found to engage in. In this sense, during the observational phase that precedes high-frequency forum use for many users, they also begin to assess the psychological safety of MHF participation and form expectations on how their participation may be received. As Marshall et al (2024) found, perceptions of psychological safety are essential to engagement in MHFs, and therefore, it may be that positive perceptions of this help to catalyse more active roles and thus the journey of engagement.

While existing research shows superusers are more likely to provide support than they are to ask for it (Carron-Arthur et al., 2016a), the RTA study shows the road to super use typically begins with help-seeking, during which the acknowledgement, validation and connection the users receive becomes the foundation upon which more frequent and sustained engagement and subsequent shift to help-giving is built. Crucially, this initial phase of help-seeking and reciprocity of help-giving appears to be especially transformative for emerging superusers. While many different types of forum users likely succeed in alleviating social disconnect thanks to MHF use, for superusers, this experience appears to have a profound effect and serves as the catalyst for forming bonds that result in higher frequency engagement. In this way, reciprocity is not simply a facet of human engagement but a central mechanism for the evolution of superuser engagement. This interpretation aligns with Dias et al.'s (2012) use of the concept of Preferential Attachment from Network Theory, which explains how users who are already well-connected within online forums tend to become increasingly central to their functioning as a direct result of this. So, in the case of superusers within the RTA study, trust and visibility gained through early reciprocal interactions with other forum members appeared to further encourage their "connectedness", fostering a cycle of reinforcement that situated them as central figures, aka, superusers. That said, superusers in the RTA study did not engage freely but rather in highly boundaried ways.

5.4.2 Highly Boundaried MHF Engagement

The RTA study established that for superusers, engaging with others in MHFs appears to be a somewhat risky endeavour as unregulated engagement potentially poses a threat to their psychological well-being. This was especially true when it came to engaging with other community members due to the potential for them to invite exchanges that were emotionally intense, unhelpful or unwanted. Additionally, there was a risk that superusers would be called upon by other MHF users to provide a level of support (whether emotional or informational) that they were not comfortable or equipped to offer. Whereas formally trained peer support workers (who are different but still somewhat comparable to regarding the peer support they provide) receive guidance on boundary setting so that they can avoid emotional overwhelm, deal with inappropriate support requests and avoid emotional burnout (Lenox et al., 2021), many of the superusers involved in the RTA study had independently learned important boundary-setting practices to counter these potential risks (or indeed learned those boundaries through facing challenges with engagement) and thus safeguard their emotional wellbeing.

For many superusers, at the surface level, it seemed that many boundaries (e.g. distancing themselves from particular posts through disengagement and response refusal) were employed as a direct result of perceived topic relevance. In other words, if forum content and discussions were not relevant to their own experiences, they were reluctant to engage. This aligns with recent research highlighting relevance as a key factor in sustaining engagement in MHFs (Marshal et al., 2024). However, on a deeper level, boundaries reflected a more nuanced psychological awareness of their emotional states and capacities. In this sense, superusers, without conscious awareness, constantly monitored their internal states in order to assess stress, fatigue, emotional capacity and overall emotional load (sometimes even pre-empting these factors) to make decisions on when to engage, continue conversations that had already started, or step back and disconnect. This self-monitoring aligns with Self-Regulation Theory (Baumeister & Vohs, 2004) in the sense that superusers exhibited self-control over their behaviours in order to achieve a goal, that goal being maintained, or further enhanced, emotional well-being. On the other hand, the boundaries set by superusers can be viewed through the lens of Self Determination Theory (Deci & Ryan, 1985; Ryan & Deci, 2000). Self-Determination Theory defines autonomy as a person's experience of being able to live and act in accordance with their personal values and conceptualises it as a fundamental psychological need that underpins well-being. In the RTA study, superusers exercised their autonomy by regulating their engagement within MHFs through a process of self-determined boundary setting. This boundary setting reflected a need to maintain control over participation in order to sustain a level and reach of participation that protected their well-being.

There were also clear elements of the online disinhibition effect (i.e. the tendency for people to say or do things online that they would not typically say or do offline; Suler, 2004) in many of the boundaries superusers employed. For example, superusers often practised social avoidance, emotional detachment and even abruptly disengaged from conversations that did not serve them at times: all boundaries that, while helpful in online contexts, would not be socially accepted or used without consequence in their offline lives. The superusers in this study also demonstrated enhanced moral clarity regarding what was their responsibility and what was not regarding helping others. While those in more formal peer-support roles are taught to make this distinction (Lenox et al., 2021), for superusers, this distinction developed naturally. They recognised their positions as peers, not professionals, and thus they set boundaries without guilt, although again this may have been moderated by feelings of online disinhibition, as it may be easier to “just say no” online than it is in offline environments.

One interesting additional insight is that the boundaries employed by superusers were somewhat context-dependent, as they sometimes described providing more support or using more flexible boundaries when engaging with certain others. This flexibility with boundaries reflects a nuanced approach to the intrapersonal boundaries superusers set. Additionally, as overly rigid boundaries have been suggested to inhibit peer support (Gillard et al, 2013), this explains how superusers were still able to form strong interpersonal connections across MHFs while maintaining stricter boundaries when needed. Given the effectiveness with which superusers appear to employ boundaries within MHFs, it may be that the individuals who ultimately become forum superusers possess a natural ability to accurately self-monitor their emotional states and that they are not only more attuned to these emotions but also more proactive in their responses to them, implementing boundaries as needed. Either way, to fully understand the engagement experiences of superusers, it is important to also discuss the drivers of super use.

5.5 Motivations Driving Superuser Engagement

While isolation and lack of in-person social support have been found to drive online forum use (Rice et al., 2016; Zhang, 2017) and are undoubtedly significant factors motivating early forum use for most users (including those users who go on to become superusers), the RTA study within this PhD thesis sought to uncover motivations specific to high-frequency forum use and in doing so established that the drive to create a sense of belonging and striving to help others were two crucial motivations driving superuser engagement.

5.5.1 A Sense of Belonging

To feel a sense of belonging is a core human need (Maslow, 1970) and an essential foundation of a meaningful life (Tajfel and Turner, 1979). Yet lack of community acceptance and social support is a common experience for those with mental health problems. As a result, people with mental health problems can experience social disconnect, a diminished sense of relatedness and intense loneliness in their everyday lives (Balkir et al., 2013; Mushtaq et al., 2014). It is not surprising, then, that those with mental health problems often seek a sense of belonging in other ways, such as via MHFs, and for the superusers within the RTA study, the need to establish a sense of belonging was a core initial motivation underpinning their high-frequency forum use. This supports findings by De Simoni et al (2020), who, in conducting the only focused investigation to include exploration of superusers' motivations to date, discovered that a drive to experience relatedness (in addition to autonomy and competence) was a key intrinsic motivator associated with Self-Determination Theory (Deci & Ryan, 1985) for superusers within an OHF. In other words, superusers were driven by an innate need to establish strong bonds and connections with like-experienced others.

Superusers' motivations to establish a sense of belonging may also be viewed through the lens of Social Identity Theory (Tajfel & Turner, 1979). Social Identity Theory explains how individuals derive part of their sense of self and their social identities from their place in social groups. Here, “in-group” identification, whereby superusers perceive themselves to share distinct characteristics and facets of experience with others, allows them to feel a strong sense of validation and thus establish a sense of belonging within the community (Thompson et al., 2022). This echoes findings by Marshall et al (2024), who found that through the process of sharing lived experiences, forum users receive validation through the normalisation of these experiences. Once their need to belong is fulfilled, insights from the RTA study suggest superusers' motivations for high-frequency engagement then often evolve further to include finding a sense of purpose via the adoption of help-giving roles.

5.5.2 Taking on a Helper Role

While insights from the RTA study show how superusers begin their active forum use as help-seekers, ultimately, in assuming superuser roles, findings here show superusers situate themselves primarily as help-givers, who tend to offer more help than they ask for. This reflects findings by Carron-Arthur et al. (2016a), who situate superusers as “emotionally supportive companions” who provide more support than they solicit, and Van Uden-Krann et al. (2009), who established that superusers provide more help within online communities than other types of users. One explanation as to why superusers fall into help-giving roles is that there is an innate psychological reward associated with help-giving, a phenomenon outlined by the Helper Therapy Principle (Riesman, 1965). The Helper Therapy Principal details how the act of helping others can generate significant psychological benefits for the helper through various mechanisms, including “self-persuasion through persuading others”, in other words, allowing superusers to improve their own mental health directly by encouraging others to do the same. Accordingly, it is not that superusers do not still need help and support themselves, as they are still living with the mental health problems that brought them to MHFs in the first place. Instead, it is that the process of help-giving is extremely beneficial and perhaps even more so than the receipt of direct support (Salem et al., 1997). Superusers in the RTA study appeared to enhance their self-esteem and overall psychological well-being and went on journeys of personal growth where they took charge of their personal narratives and constructed new versions of self within the MHFs, further reflecting facets of the HTP.

Additionally, via help giving, it was evident that the superusers in the RTA study felt they had found a purpose, an extension of belonging, that resulted in elevated feelings of competence and social usefulness (Gartner & Reissman, 1977). In being recognised as role models and experts in their own right (Vydiswaren & Reddy, 2019), superusers in turn assumed a sense of elevated social status within MHFs. This encapsulates a key impact of OHF use on superusers established in the literature review (Chapter 2) whereby super use not only increases social connections but also perceived social status within the online community.

Insights relating to help-giving as a motivator of MHF super use may also be considered in accordance with Self-Determination Theory (Ryan & Deci, 2000). For example, for superusers, it is likely that helping others fulfils additional innate needs for relatedness (as mentioned previously) while also providing a sense of competence in help-giving that reinforces self-efficacy and enhances their feeling of mastery. Furthermore, being able to help others in voluntary, self-directed ways undoubtedly supports superusers' sense of autonomy, that is, their experience of acting in accordance with their own choices and innate values, which are fundamental facets of intrinsic motivation (Ryan & Deci, 2000). The data presented in Chapter 4 highlights this further by showing how superusers' experiences of autonomy within MHFs are deeply connected with their social identities and sense of purpose, whereby taking on a help-giving role becomes a means for reclaiming agency "lost" in the offline world due to the impacts of mental illness and societal judgements and stigma. Autonomy, as an underpinning driver of super use, is supported by findings from De Simoni et al. (2020), who, through the application of Self-Determination Theory as a lens during data analysis, highlighted the central motivational role autonomy plays in sustaining superuser OHF engagement.

As acknowledged in Chapter 4, many superusers appear to understand and acknowledge that through helping others, they experience psychological benefits. This aligns with findings from Marshall et al. (2024), who, while not centring their research on superusers, reported that in certain contexts, MHF users gain a psychological boost from knowing that their posts have been helpful for others. The psychological benefits associated with this autonomously occurring role may only occur due to the largely subconscious and natural nature of the help-giving role (Riesman, 1965). Still, it would be naïve to assume that help-giving is a given and that superusers are willing to help all members of their online communities, as insights from the RTA study show, help-giving is not only highly boundaried but also primarily directed towards the most relatable others; a factor discussed in the next section.

5.6 The Challenges Superusers Face

As many superusers appear to go on to predominantly adopt help-giving roles within MHFs that require emotional labour in the absence of structured support, it is reasonable to question whether they face similar challenges to other forms of peer supporters, such as emotional exhaustion or distress (Kane et al., 2023). While existing research on the challenges superusers face when engaging in MHFs is scarce, there are some notable insights from wider health research. For example, De Simoni et al (2020) established that OHF superusers, in dedicating a significant amount of time to helping others, often experienced stress, worry and overall emotional burden, especially following interactions with distressed others. While De Simoni et al highlight the emotional burden experienced by OHF superusers, the RTA study offers a related but different perspective on potential stress and burden-inducing challenges for superusers. In the RTA study, while most superusers were reluctant to overtly disclose any sense of emotional burden relating to the help-giving nature of the role, one pattern of challenge that was established for many of them related to experiences of perceived otherness within MHFs.

"Otherness" is a concept with philosophical roots. For example, it is central to Hegel's dialectical view of self-consciousness, where the self develops only through recognising what is different from itself (Ferro, 2013; Geniusas, 2008). In this sense, otherness is a multifaceted social phenomenon that encapsulates beliefs about the self, society, social context and interpersonal relationships. Otherness encourages individuals to assess and evaluate their sense of self against perceptions of differences in others (Doubková et al., 2024).

One explanation for the challenging nature of perceived otherness, many superusers expressed here, is that the sense of community cohesion (and innate sense of belonging) is challenged by the threat of difference within the MHF. For example, when superusers struggled to relate to others due to personal, social or cultural differences, including gender, religion and ethnicity and also factors such as symptomology, mental health experience and help-seeking behaviours, it often resulted in unwanted feelings (e.g. annoyance) and purposeful distance, perceived isolation and forum disengagement (see Chapter 4 for full details). This ties back to Social Identity Theory (Tajfel & Turner, 1979) discussed earlier, in the sense that any perceived differences may be amplified and even internalised as a source of threat to the idealised social group (Daynes-Kearney & Gallagher, 2023). Furthermore, this may help to explain why, in perceiving otherness, many superusers further employed interpersonal and intrapersonal boundaries (as discussed previously) and modified their engagement to ensure they still engaged highly but only with selected others. This would support research that has shown social identity processes are apparent within peer-to-peer support groups (Daynes-Kearney & Gallagher, 2023). Additionally, it may be that the bias of otherness and clear separation of self from perceived “others” served as a mechanism to protect superusers' deliberately constructed social identities; identities that rely on the relatability and assumed safety of deeply connected lived experiences. While the connection between perceived otherness and challenges in engagement spanned across multiple facets of personal characteristics including age and culture, the challenge of perceived otherness was especially apparent in the RTA study when superusers expressed disillusionment in relation to those who were less proactive in their recovery attitudes and efforts as well as those who appeared to be "attention seeking" due to communication approaches taken (see Chapter 4 for further details).

Within MHFs, the superusers in this study demonstrated a high degree of proactivity in terms of their recovery behaviours. Yet when faced with otherness, particularly regarding recovery approach, symptomology and help-seeking behaviours, this manifestation of otherness placed a significant challenge upon many superusers and their ability and desire to connect with perceived others. In such instances, empathetic resonance was limited and motivation to engage with others diminished. From the perspective of Self-Determination Theory, superusers' experience of otherness here may be viewed as frustration due to a lack of relatedness and a lack of competence from others (i.e. the superusers in this study largely felt focused and proactive in their recovery efforts, while they perceived the opposite in some other users). There were of course complexities to this experience, as evident in Chapter 4, as for a small number of superusers, perceived difference was valued, welcomed and even at times specifically sought after (as was the case for one superuser in particular who sought to connect with those outside of her own culture due to the cultural taboo that surrounded mental health within her own circles). This illuminates the deeper contextual factors that may underpin the difference between negative and positive experiences of otherness within MHFs.

Still, the insight that many superusers perceived a heightened sense of otherness, negatively appraised this, and chose to not communicate with other “different” MHF users, appears to diverge somewhat from findings by Carron-Arthur et al. (2016b), who drew on the concept of homophily (the innate tendency individuals have to bond with those who are similar to themselves) to examine communication preferences in OHFs. Where Carron-Arthur et al. (2016b) found homophily was generally important in shaping interaction patterns across OHFs, they found this was not the case for superusers, who they concluded were more likely than other users and especially new forum users, regardless of shared characteristics. It also diverges from findings in similar contexts where superusers were found to be more likely to connect with those who had fewer online social connections, regardless of shared facets of identity (Lawless et al, 2022).

The challenge of perceived otherness and its connection to engaging with other forum users is likely not unique to MHFs. However, it may be that within MHF contexts, internalised mental health stigma is a factor which otherness perpetuates, mediating who some superusers choose to connect with and increasing feelings of burden. For example, when people with mental health problems internalise ignorant public sentiment on mental health (Lawlor & Kirakowski, 2014) (e.g. convincing themselves that societal prejudices about the maintaining factors of mental health problems are true), they may form thoughts such as "I have depression because I am lazy" (Rizzo et al., 2025). Therefore, when building new social identities within MHFs, gaining agency, increasing self-esteem, and rewriting these illness narratives within the confines of MHFs, some superusers may actively seek to distance themselves from those who, through echoes of this historic internalised stigma, they view as lazy, unproductive, “complaining” or “attention seeking” (direct quotes from the RTA study).

Ultimately, these insights on the challenges superusers face when engaging with others in MHFs speak to an inherent truth of MHF use: the fact that shared illness experiences (e.g. being diagnosed with the same mental health problem as others) are not always enough to encourage positive relational dynamics, especially between MHF superusers and other forum users. These findings also provide further grounding and context for the original conceptual model presented in Chapter 2, specifically in relation to the negative psychological impacts associated with super use, which, based on outcomes from the RTA, should also be considered to include the emotional impacts of perceived otherness.

5.7 Strengths and limitations

5.7.1 The Integrative Literature Review

While the strengths and limitations pertaining to the conduct of the integrative review have previously been explored in depth (see Chapter 2), there are several noteworthy strengths and limitations pertaining to the literature review within the context of the overall thesis that have not yet been examined. Regarding strengths, the decision to focus more broadly on the bidirectional impacts of superusers and OHFs (rather than more narrowly focusing on MHFs only), allowed for a broader mapping, synthesis and evaluation of the full landscape of existing superuser research which in turn provided a more comprehensive understanding of the emerging area of superuser research than would have been possible with a more narrow forum-specific focus (Whittemore & Knafl, 2005) and thus laid the groundwork for the more focused qualitative exploration of superusers experiences in MHFs that followed. Still, despite this strength, reviewing superuser literature across all OHFs may have limited the depth and nuance of insight into the roles superusers play within MHFs specifically. This broad integrative approach also resulted in the creation of a conceptual framework that was more applicable to the wider context of health forum superusers as opposed to mental health-specific communities, meaning its application when discussing and interpreting findings in this chapter was somewhat limited.

5.7.2 Study Sampling

Given the lack of consensus on any existing superuser definition, the description used on recruitment materials was intentionally broad, which led to a heterogeneous sample in terms of forum use (e.g. many superusers reported using forums for 1 hour per week, while others reported use of 20> hours per week). Heterogeneity within the overall sample is valuable since maximum variation increases the applicability of findings across diverse contexts and reduces subgroup bias (Patton, 2015). This sampling approach can therefore be considered a strength as it allowed for the recruitment of a demographically diverse participant group regarding age, ethnicity, employment status, length of time using MHFs, reasons for MHF use and span of forum use. However, the wide variation in time spent online among superusers in the RTA study does bring up some unanswered questions. For instance, it is reasonable to assume that those engaging with forums for 1-2 hours per week may have markedly different experiences from those engaging for 20-30 hours per week, yet findings here do not extend to this distinction. Furthermore, it is also important to acknowledge that those who agreed to participate in this study may represent a particular subset of superusers, for example, those who feel very positively about their forum super use and who were therefore motivated to share their experiences of helping others.

This means there are perspectives that are absent from this study, specifically relating to any superusers who may engage more critically within forums or who perhaps use anonymity to disrupt community dynamics and cohesion. As a result, the study sampling approach may have inadvertently led to a somewhat idealised view of superuser forum engagement, which must be considered as a potential limitation.

An additional factor relating to study sampling that may be considered a limitation, is the notably high education level among the study participants. For example, across England and Wales, just over 33% of people over the age of 16 have a level four qualification (i.e. a higher national diploma, bachelor's degree or postgraduate qualification) (Office for National Statistics, 2023). However, a little over 82% of the participants in this study had a level four qualification, meaning the recruited sample was substantially more highly educated than the general UK population. This high education level is particularly interesting given that many of the recruited participants noted having a serious mental illness, which has often been associated with lower educational attainment (Mojtabi et al., 2015). That said, as discussed in the background of this study, despite known barriers, those with mental health problems, including serious mental illnesses, have been found to access the internet at similar rates to the general population. However, questions remain as to why participants in this sample were so highly educated and what this means for the generalisability and transferability of the study findings. While education level is not always found to strongly predict research participation (Scanlon et al., 2021), it can directly impact digital literacy and subsequent understanding of information within online environments (van

Deursen & van Dijk, 2013). However, evidence on the impacts of education on internet use remains mixed as while some research shows a strong link between education and internet use with those who are more highly educated being significantly more likely to use the internet, and at a higher frequency (Perrin & Duggan, 2015), while other research suggests that those with lower levels of education are more likely to spend longer using the internet each day (van Deursen & van Dijk, 2013). Nevertheless, education and associated online literacy may influence how individuals navigate and make use of online environments (Jin et al., 2021). In the context of this study, where participants were superusers of MHFs, the significantly high education level of the sample raises questions regarding whether the findings related to motivations, experiences and challenges of MHF super use reflect those of other MHF superusers on a broader scale. It may be that superusers with lower educational attainment bring different motivations, experience super use differently, and ultimately face different challenges when online. Therefore, it is important to note that the findings presented here may not fully capture the diversity of experiences of MHF superusers, and findings should therefore be interpreted in light of this.

A further limitation relating to study sampling is the fact that only a small number of male participants (n=2) were recruited. This may be explained, in part, by known gender differences in mental health help-seeking behaviours. For example, existing research suggests women are more likely to seek mental health support both in person and via the internet (Jia et al, 2021) and given the findings presented here suggest information-seeking is often the first step towards forum super use, this could help to explain, at least in part, the gender imbalance of participants; a pattern that is also apparent in some other existing superuser research (e.g. De Simoni et al., 2020).

That said, it is important to avoid interpreting this participant gender imbalance based on evidence of online help-seeking demographics and early super user research alone, given that this evidence is currently limited and emerging. Instead, additional factors such as sampling bias and the potential influence of the researcher's gender on study design, implementation and recruitment must also be considered. For example, some existing research notes that female researchers tend to recruit higher levels of female participants within their studies (Jankelowitz et al, 2025), which may occur as female participants feel more comfortable volunteering for a female-led study, but also due to how the study itself is designed and advertised to potential participants. Upon reflection, the researcher acknowledges that recruitment materials used within this study employed images that may have appealed to female participants and that, therefore, may not have been inclusive of potential male participants.

In addition, challenges with recruiting male participants to health-related research are widely documented (Barr et al., 2024; Borg et al., 2024), and overrepresentation of female participants is an ongoing issue (Polit & Beck, 2013). Within mental health research in particular, it may be that the stigma surrounding mental health problems, together with the social influence of traditional masculine norms, pose further barriers for male participation (Knox et al., 2023). For example, research shows men are more likely to frame mental health problems as weaknesses (Judd et al., 2008; Lynch et al., 2018), making them more likely to prefer self-reliance, which limits help seeking, and discourages taking part in research (Addis & Mahalik, 2003; Vogel et al., 2006).

The lower level of male participants within this study may therefore be a result of a combination of the above factors, and as such, it is important to acknowledge that the findings presented here largely reflect the motivations, experiences and challenges faced by female superusers. As a result, caution is advised when considering the extent to which these findings may represent the experiences of male MHF super users.

5.7.3 Forum Context

A further study limitation relates to the contextual information collected in relation to the forums that the study participants were superusers of. When designing the demographic and forum use questionnaires for this study, while the researcher decided to ask participants about the general topic area of the forum(s) they used at a high frequency (e.g. anxiety-based forum, multi-topic general mental health forum, etc.), a decision was made to avoid asking for specific forum details such as the names of the forums used. Any mention of specific forums during interview was also redacted during transcription. Given the relatively small sample size of this study and the fact that superusers make up just 1% of all users within a forum, this decision was made to further promote participant confidentiality, as it was felt that it may have been easier to identify some of the superusers from this study, especially if the forums they used had low user numbers. That said, the researcher acknowledges that the lack of additional forum-specific information gathered, such as the forum name and size, hosting organisation or platform, and presence and role of moderators, may be considered a study limitation given the barriers the lack of this information places in terms of fully contextualising the findings. Such contextual factors may well influence how forums function, how superusers emerge and how their motivations, experiences and challenges change over time. Accordingly, in the absence of this information, all findings presented here must be considered with these contextual limitations in mind.

5.7.4 Data Analysis

A key strength of the data analysis was the commitment to allowing just one researcher to guide the process. While positivist-oriented researchers may prioritise inter-rater reliability and the use of multiple coders to ensure objectivity, this approach is incongruent with many qualitative approaches, including RTA. In this research, the use of an individual researcher for data analysis fully aligns with the critical realist foundations and inherent principles of RTA. This is because both recognise researcher subjectivity as an analytic resource rather than a source of bias to be controlled. Critical realist-informed research posits researcher subjectivity as an inevitable part of the research process but not a barrier to knowledge, as researcher subjectivity does not imply epistemological subjectivism (Bhaskar, 1975). Instead, when engaging with the data, the subjectivity of the researcher can serve as a resource for accessing enhanced layers of meaning (Hanly & Hanly, 2001), provided that reflexivity is centred (Braun & Clarke, 2022; Yardley, 2008), as was the case with the research associated with this PhD. Still, steps were taken to extend analytic insight and to illuminate potential areas of analytic interest that may have initially not been recognised by the primary researcher, thereby deepening reflexive engagement with the data (Braun & Clarke, 2022). To support this process, PM independently coded two of the interview transcripts, offering a second perspective that was used not to confirm the original coding but rather to enrich the interpretive process.

5.8 Future research

There are several areas where future research would be valuable. Firstly, it will be important for future research to explore and challenge existing assumptions within the literature that highly active and passive forms of engagement represent distinct and separate types of users. Instead, future research should seek to consider the journey towards super use and the multiple participation styles a superuser may engage in even after their superuser status has been achieved. Additionally, future research should consider that super use will likely look different across different MHFs and platforms and will always be the result of users' idiosyncratic journeys. This is important because a more in-depth and nuanced understanding of the ways superusers engage with different online communities can inform online support approaches within forums that better acknowledge, support and safeguard these invaluable members. Additionally, the term “superuser” itself may require some rethinking as the term received largely negative feedback from RTA study participants.

While the research presented in this thesis explored a prominent research priority relating to the experience, motivations and challenges that superusers face when engaging in MHFs, further research should seek to build on this foundational knowledge through the exploration of emotional labour and unmet support of superusers. This knowledge, via the provision of crucial insight into how to safeguard the well-being of superusers, could then inform the design and management of more effective and sustainable MHFs that actively seek to reduce harm to their most frequent users. Additionally, while facets of relatedness, competency, and autonomy appear central to superuser engagement, future research would benefit from exploring how these communication drivers and sustainers differ, if at all, cross-culturally. For example, in countries where individual needs are prioritised over group or community needs (e.g., the UK), autonomy may be valued more than relatedness (Balkir et al., 2013).

To effectively address and work towards mitigating the challenges faced by MHF superusers, greater emphasis must be placed on exploring the relational dynamics within forums, alongside the development of methods and interventions that foster connection, understanding and empathy across perceived differences. On that note, it would be interesting to explore how relational dynamics evolve via longitudinal research approaches. Finally, future superuser research could benefit from centring The Helper Therapy Principle and/or Self-Determination Theory within deductive design approaches, as these theories have demonstrated particular relevance for understanding the engagement and motivation experiences of superusers. Additionally, forum data analysis could complement future research of this nature, provided it is conducted ethically with consent and awareness of anonymity (Lobban et al., 2025).

5.9 Implications for Practice

The knowledge generated here offers a particularly valuable resource for public sector organisations such as the NHS, third-sector organisations such as mental health charities and other private-sector health companies involved in the creation and maintenance of online peer-led health-oriented forums, especially as they increasingly centre the provision of accessible, effective and ethically safe peer-led platforms.

For example, the knowledge that many superusers do not arrive at forums as naturally high-engaging users but rather develop this participation style over time, it is essential for organisations involved in OHF creation to embed reflective and responsive structures. Such structures may involve clearly detailed processes guiding superusers on how to privately engage with MHF moderators, signposting and easy to access self-care resources from trusted partners, advice and support on how to engage in the forum in healthy ways, guidance on how to set boundaries and how to navigate personal information sharing and anonymity while using the forum and explicit steps to take when upset, overwhelmed or triggered by forum content. Embedding such structures and resources would encourage psychologically safe environments that encourage personal disclosure, reciprocity of help-giving and thus long-term connections and participation. This is important because sustained participation is critical in building resilient communities that, in turn, provide their users with improved health and mental health outcomes. While these structures can benefit all forum users, they are particularly crucial for superusers due to the fact that they invest significantly more time and emotional energy in forums and are therefore more profoundly impacted by the forum environment than more casual users or observers.

Crucially, in striving to address the challenges and support needs of OHF superusers, organisations should avoid limiting or regulating their forum contributions, as such contributions are driven intrinsically and result in the experience of inclusion and purpose. Therefore, restricting or mediating such contributions (beyond acceptable online norms pertaining to respect for others and limiting triggering content) could undermine superusers' engagement and thus the stability of the forum. Additionally, caution is advised when seeking to identify and define members who are superusers within forums, as explicit acknowledgement of this may undermine the organic nature of superuser engagement and could potentially threaten the psychological benefits superusers gain from their high-frequency use. Instead, organisations should strive to support their high-frequency users via the provision of thoughtfully designed, well-moderated, psychologically safe spaces which acknowledge the complex, ever-evolving interplay between superusers' agency and the structural factors shaping their experiences and balance rule enforcement with sensitive moderator interventions (Marshall et al., 2025).

Furthermore, given that superusers are increasingly exposed to the experience of “otherness”, organisations must determine ways to foster both acceptance and emotional connection across different social, cultural and illness or symptom difference. It is important for such organisations to realise that, as in the offline world, online, shared illness identities alone are not enough to forge cohesive communities. Accordingly, it may be useful to work to reduce stress associated with perceived otherness via the integration of social identity-based strategies (Steffens et al., 2021). Such strategies may include refining experiential groupings within MHFs to promote shared experiences (for example, refining subgroup discussion areas by symptomology), highlighting that group membership is central to MHF use (e.g. referring to people as community members rather than users in MHF wording), placing extra emphasis on language that promotes in-group identity when possible “e.g. “we”, “us”, “our”), and providing lived experience–oriented educational resources that help to unite MHF community members from diverse backgrounds and cultures. By humanising the experience of mental health problems across cultural lines and highlighting shared struggles and strengths, such approaches could encourage focusing less on differences and more on the things that can unite people through their shared mental health experiences. When social identity is shared by group members, health conditions have been found to improve (Frenzel et al., 2022), and this may hold true in online spaces too.

Finally, as superusers may experience both positive and negative health impacts due to their high-frequency forum use, there should be added emphasis on filtering potentially triggering content and encouraging mindful engagement to help mitigate overwhelm. This will reduce the need for superusers to actively (and sometimes pre-emptively) employ strict interpersonal and intrapersonal boundaries, thereby reducing the cognitive effort required to manage emotions while navigating MHFs.

5.10 Implications for Policy

Without superusers, OHFs are not sustainable, yet it is evident that superusers undertake exceptionally high levels of emotional labour within online forums, often with minimal recognition or safeguarding. Therefore, as online peer-led support forums are increasingly recognised and promoted by the NHS (NHS England, 2023), embedded within NHS trusts (e.g. Berkshire Healthcare NHS Foundation Trust, 2025), and integrated into the broader digital healthcare agendas of charities and other third-sector agencies (e.g. MIND, 2025; Togetherall, 2025), it is essential that the contributions of organically evolving forum superusers are formally acknowledged as sustaining elements of OHFs and that their engagement, safety and support needs are explicitly incorporated into policy frameworks. Accordingly, it would be important for policies within all sectors to mandate the inclusion of safeguarding guidelines specific to peer roles that require significant emotional investment within OHFs, as is the case with forum superusers. Such safeguarding guidelines may cover what to do when someone uses the forum “too” frequently in the sense that it is perceived to be a detriment or even harm to themselves or the community as a whole. Additionally, it is vital that digital policymakers adopt participatory approaches (e.g. user advisory groups and/or regular consultation with MHF community members via discussion threads or other data collection methods such as surveys) in the creation of OHF policies to ensure they are meaningful and impactful.

Given the value superusers have not only in forum infrastructure but also in terms of shaping the health behaviours, attitudes and well-being of other users (McCosker, 2018; Lawless et al., 2022; Zhao et al., 2014), their encouragement, retention and care must be established as central priorities of digital agendas focusing on peer-led online support forums. This may be achieved through a rewards and recognition system that aligns with superusers' intrinsic motivations (e.g. badges or titles that recognise the quantity and quality of support given to others in forums), evolving service support options that promote sustained engagement (e.g. providing superusers with unique access to advanced support from moderators), and proactive moderation strategies that foster emotionally supportive environments.

5.11 Thesis Conclusion

Via the synthesis of existing research on the bidirectional impacts of superusers in OHFs, this thesis first established the broader landscape of OHF super use and its implications for both OHFs and superusers themselves. The literature showed that superusers can benefit from the enhanced social connections and elevated social status that high-frequency OHF engagement provides. Additionally, literature synthesis showed high-frequency forum use has implications for both the psychological and physical health of the superuser, although whether this is positive or negative may be mediated by the forum environment itself. Regarding the impacts of superusers on OHFs, literature synthesis showed superuser engagement is responsible for shaping cohesive, information-rich, supportive, proactive communities; all elements that play a central role in OHF stability and growth. Additionally, the qualitative exploration of superusers' experiences of MHFs centred the voices and lived experience of MHF superusers and, in turn, revealed the complex, dynamic and highly boundaried reality of their high-frequency forum engagement, illuminating the largely intrinsic motivations that underpin it and the emotional challenges that often accompany it.

Given the relative infancy of superuser research, the insights generated throughout this PhD thesis make a significant contribution to knowledge by offering new foundational understanding of the bidirectional impacts of superusers and OHFs and the experiences of superusers in MHFs. These findings highlight the emotional investment, time-intensive labour and critical role that superusers play in online health-based communities while encouraging broader reflection on digital peer support, the ethics of online health communities and important directions for future research. As a result, this thesis also helped to establish priorities for future research, practice and policy that highlighted the need to recognise and support superusers by creating psychologically safe and inclusive OHFs, as well as the adoption of participatory approaches in both future research and policy development.

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Appendices

Appendix A: Search Strategies

Medline (EBSCO Host)

Medical Subject Headings (MeSH)

Concept: Online

(MH "Online Systems") OR (MH "Internet-Based Intervention") OR (MH "Online Social Networking") OR (MH "Health Information Systems") OR (MH "Internet") OR (MH "Internet Use") OR (MH "Social Media") OR (MH "Digital Technology") OR (MH "Telemedicine+")

Concept: Community/Forum

(MH "Social Media") OR (MH "Peer Group+") OR (MH "Group Structure") OR (MH "Interpersonal Relations") OR (MH "Interpersonal Psychotherapy") OR (MH "Social Support") OR (MH "Psychosocial Support Systems") OR (MH "Social Interaction") OR (MH "Social Networking") OR (MH "Online Social Networking") OR (MH "Patient Advocacy")

Concept: Superuser

(MH "Peer Influence") OR (MH "Community Participation")

Free Text Search String

Concept: Online

"online" OR "digital" OR "web*" OR "internet*" OR "computer*" OR "electronic" OR "virtual" OR "e-health" OR "ehealth" OR "eintervention*" OR "e-intervention*" OR "mhealth" OR "m-health"

Concept: Community/Forum

((health OR patient*) N5 (communit* OR forum* OR message* OR discuss* OR network* OR group* OR support OR advocacy)) OR "OHC" OR "Facebook" OR "Reddit” OR “Discord” OR “peer" OR "peer-to-peer"))

Concept: Superuser

((“superuser*” OR “super-user” OR “champion” OR ((high-frequency OR experienced OR expert OR influential OR senior OR key OR long-term OR longterm OR top) N5 (user* OR member* OR contribut* OR participa* OR engag*)) OR “influencer” OR “elder”))

CINAHL (EBSCO Host)

Medical Subject Headings (MeSH)

Concept: Online

(MH "Internet") OR (MH "Digital Technology") OR (MH "Online Services")

Concept: Community/Forum

(MH "Social Media") OR (MH "Peer Group") OR (MH "Support Groups+") OR (MH "Online Social Networking")

Concept: Superuser

(MH "Social Participation") OR (MH "Peer Counseling")

Free Text Search String

Concept: Online

"online" OR "digital" OR "web*" OR "internet*" OR "computer*" OR "electronic" OR "virtual" OR "e-health" OR "ehealth" OR "eintervention*" OR "e-intervention*" OR "mhealth" OR "m-health”

Concept: Community/Forum

(health OR patient*) N5 (communit* OR forum* OR message* OR discuss* OR network* OR group* OR support OR advocacy) OR "OHC" OR "Facebook" OR "Reddit” OR “Discord” OR “peer" OR "peer-to-peer")

Concept: Superuser

(“superuser*” OR “super-user” OR “champion” OR ((high-frequency OR experienced OR expert OR influential OR senior OR key OR long-term OR longterm OR top) N5 (user* OR member* OR contribut* OR participa* OR engag*)) OR “influencer” OR “elder”)

PsycINFO (EBSCO Host)

APA Thesaurus of Psychological Index Terms

Concept: Online

DE "Online Social Networks" OR DE "Internet"

Concept: Community/Forum

DE "Social Media" OR DE "Social Networks" OR DE "Online Community" OR DE "Online Social Networks"

Concept: Superuser

DE "Participation" OR DE "Peer Counseling"

Free Text Search String

Concept: Online

"online" OR "digital" OR "web*" OR "internet*" OR "computer*" OR "electronic" OR "virtual" OR "e-health" OR "ehealth" OR "eintervention*" OR "e-intervention*" OR "mhealth" OR "m-health”

Concept: Community/Forum

(health OR patient*) N5 (communit* OR forum* OR message* OR discuss* OR network* OR group* OR support OR advocacy) OR "OHC" OR "Facebook" OR "Reddit” OR “Discord” OR “peer" OR "peer-to-peer")

Concept: Superuser

(“superuser*” OR “super-user” OR “champion” OR ((high-frequency OR experienced OR expert OR influential OR senior OR key OR long-term OR longterm OR top) N5 (user* OR member* OR contribut* OR participa* OR engag*)) OR “influencer” OR “elder”)

Academic Search Ultimate (EBSCO Host)

Subject Terms

Concept: Online

DE "Internet"

Concept: Community/Forum

DE "ONLINE chat" OR DE "ONLINE chat -- Social aspects" OR DE "INTERNET forums" OR DE "ONLINE chat" OR DE "ONLINE comments" OR DE "SOCIAL media"

Concept: Superuser

DE "PEER communication"

Free Text Search String

Concept: Online

"online" OR "digital" OR "web*" OR "internet*" OR "computer*" OR "electronic" OR "virtual" OR "e-health" OR "ehealth" OR "eintervention*" OR "e-intervention*" OR "mhealth" OR "m-health”

Concept: Community/Forum

(health OR patient*) N5 (communit* OR forum* OR message* OR discuss* OR network* OR group* OR support OR advocacy) OR "OHC" OR "Facebook" OR "Reddit” OR “Discord” OR “peer" OR "peer-to-peer")

Concept: Superuser

(“superuser*” OR “super-user” OR “champion” OR ((high-frequency OR experienced OR expert OR influential OR senior OR key OR long-term OR longterm OR top) N5 (user* OR member* OR contribut* OR participa* OR engag*)) OR “influencer” OR “elder”)

Scopus (Elsevier)

Concept: Online

("online" OR "web*" OR "internet*" OR "e-health" OR "ehealth" OR "mhealth" OR "m-health")

Concept: Community/Forum

((health OR patient*) W/3 (communit* OR forum* OR network* OR support OR advocacy)) OR "OHC" OR "Facebook" OR "Reddit" OR "Discord" OR "peer-to-peer"

Concept: Superuser

(("superuser" OR "champion" OR ("influential" W/3 (user* OR member* OR contribut* OR participa* OR engag*))) OR "influencer" OR "elder")

5.11.1 Web of Science (Clarivate)

Concept: Online

("online" OR "web*" OR "internet*" OR "e-health" OR "ehealth" OR "mhealth" OR "m-health")

Concept: Community/Forum

((health OR patient*) NEAR/3 (communit* OR forum* OR network* OR support OR advocacy)) OR OHC OR Facebook OR Reddit OR Discord OR "peer-to-peer"

Concept: Superuser

(("superuser" OR "champion" OR ("influential" NEAR/3 (user* OR member* OR contribut* OR participa* OR engag*))) OR "influencer" OR "elder")

Embase (Ovid)

EMTREE Subject Headings

Concept: Online
internet/

Concept: Community/Forum

online social network/ or online support group/ social media/

Concept: Superuser

peer group/

Free Text Search String

Concept: Online

"online" OR "web*" OR "internet*" OR "e-health" OR "ehealth" OR "mhealth" OR "m-health"

Concept: Community/Forum

((health OR patient*) ADJ3 (communit* OR forum* OR network* OR support OR advocacy)) OR "OHC" OR "Facebook" OR "Reddit" OR "Discord" OR "peer-to-peer"

Concept: Superuser

(("superuser" OR "champion" OR ("influential" ADJ3 (user* OR member* OR contribut* OR participa* OR engag*))) OR "influencer" OR "elder")

Grey Literature Databases (Ethos, Overton, Trip, NHS Digital)

Concept: Online

(online OR internet)

Concept: Community/Forum

(community or forum)

Concept: Superuser

(superuser OR "super user" OR user).

Ethos

Online AND Community AND superuser

Superuser (alone)

Overton

online AND community AND superuser

TRIP

online AND community AND superuser

International Clinical Trials Registry

online and forum and participation

Google Scholar

Online or internet AND community or forum AND superuser

Appendix B: Data Extraction Matrix

Author(s)	Year	Title & DOI	Journal	Funding/ author conflicts	Study design/methodology	Study aim(s)	Forum type & focus	Population	Theoretical/ conceptual framework	Superuser definition/ conceptualisation	Impact(s) (measure / type)	Key findings	Study Limitations	Notes/ reflections	Quality Appraisal
Batenburg, A. & Das, E.	2014	Emotional approach coping and the effects of online peer-led support group participation among patients with breast cancer: a longitudinal study. https://doi.org/10.2196/jmir.3517	Journal of Medical Internet Research.	**Funding**: The Network Institute of the VU University Amsterdam. **Conflicts:** No conflicts declared.	Quantitative: Two wave longitudinal study utilising questionnaires.	To assess whether intensity of online participation and well-being might be moderated by emotional coping style.	Breast cancer forum. (Netherlands).	133 Dutch patients with breast cancer. Average age (n=48). Most had higher education (86/132, 65.2%) and over half (79/133, 59.4%) were employed. Approximately 67.5% reported no current cancer presence, and slightly more than half (68/133, 51.1%) were undergoing treatment, while the rest (65/133, 48.9%) were not in treatment or were under physician monitoring.	None stated.	"Highly active patients". Intensity of participation assessed by frequency of visits, average length of visits, contribution (i.e., reading, responding, starting new topics or questions), and frequency of posts.	**Psychological Wellbeing**: Increase in emotional wellbeing over time for high intensity participants who approach their emotions less actively.	**(1)** Online support group participation increased emotional well-being over time for patients who scored low on emotional approach coping at baseline, provided that they were highly active online. **(2)** Patients who were highly active online with a high score on emotional approach coping reported no change in sense of well-being. **(3)** Findings showed no negative effects of intense support group participation.	**(1)** One-time measurement of emotional approach coping (likely fluid). **(2)** Self-reported data.	N/A	QUADS SCORE: 33
Bayen, S., Carpentier, C., Baran, J., Cottencin, O., Defebvre, L., Moreau, C., Devos D. & Messaadi,N.	2021	Parkinson's disease: content analysis of patient online discussion forums. A prospective observational study using Netnography. https://doi.org/10.1016/j.pec.2021.01.028	Patient Education and Counseling.	**Funding:** No funding declared. **Conflicts:** No conflicts declared.	Qualitative: A prospective observational cohort study (longitudinal) employing netnography.	Assess users' characteristics, discussion contents, and the atmosphere of virtual peer communities.	Four Parkinson Disease forums (France).	70 People with parkinsons disease and their carers. Average age (n=49), 70% females. 87% people with parkinsons disease.	None stated.	"Leaders". Leaders monopolize discussions, launch new themes, detailing scientific facts regarding PD and answer directly to users, referring to them by name. Female (n=13) Male (n=2). 21%.	**Sense of community:** monopolized discussions, launched new themes, answered directly to users, referring to them by names:	Five user profiles appeared: leader, follower, expert, mixed, and undetermined.	**(1)** Difficult to detail characteristics due to anonymity. **(2)** Data loss as unable to collect private posts.	N/A	QUADS SCORE: 26
Biyani, P., Caragea, C., Mitra, P. & Yen, J.	2014	Identifying emotional and informational support in online health communities. https://aclanthology.org/C14-1079/	Proceedings of COLING 2014, the 25th International Conference on Computational Linguistics: Technical Papers.	**Funding:** National Science Foundation Grant. **Conflicts:** No conflicts declared.	Quantitative: observational research study using machine learning-based data analysis of user messages.	Classify and differentiate emotional and informational support in regular and influential user messages.	Cancer Survivors Network of The American Cancer Society. (USA)	Adults with cancer, adults who have overcome cancer and their friends and families. Dataset included 250, 868 messages posted by 5516 users and then explored a random sample of 240 messages.	None stated.	"Influential members" identified by community managers using an unknown method.	**Impact on online community:** Influential members bring positivity and answer concerns effectively. Their presence results in an increased number of messages grounded in emotional support.	**(1)** Influential members provide more emotional support (providing caring/concern, understanding, empathy, sympathy, encouragement, affirmation and validation) than regular members. IMs posted significantly more emotional support than regular members. **(2)** As the number of messages posted increases, both regular members and influential members tend to post more emotional support suggesting a positive correlation between activity level and providing emotional support in the community.	**(1)** Did not consider messages posted by thread discussion starters as they were presumed to be asking for support. **(2)** Did not describe influential user characteristics. **(3)** Did not list own study limitations.	N/A	QUADS SCORE: 25
Carron-Arthur, B., Ali, K., Cunningham, J. Alastair. & Griffiths, K. M.	2015	From help-seekers to influential users: a systematic review of participation styles in online health communities. https://doi.org/10.2196/jmir.4705	Journal of Medical Internet Research.	**Funding:** Australian Postgraduate Award - Young and Well CRC PhD Scholarship - Australian National Health and Medical Research Council (NHMRC) Research Fellowship. **Conflicts:** No conflicts declared.	Quantitative: Systematic review	Determine if any patterns are apparent in user participation across online health communities.	26 different OHCs. smoking cessation (n=7), cancer (n=6), mental health issues (n=6), diabetes (n=5), multiple sclerosis (n=1), and social innovation in health care (n=1).	Samples ranged in size from 77 to 49,552 people. Most included between 1000 and 10,000 people; however, one group of 5 OHCs included more than 140,000 people between them.	None stated	The top 1% of users whose frequency of posts was greatest were deemed to be superusers. Also referred to as "high-engaged users". 8 studies that made a unidimensional categorization classified users into a participation style that we call high-engaged users. Metrics associated with "high-engaged users" included: posting frequency, thread initiation, thread participation, level of in-degree/out-degree, reading of posts, time logged in, and friendship	**Facilitated engagement:** Highly engaged users (according to posting frequency) were regarded by all but one of the studies as being valuable to the OHC because they sustained activity levels and in doing so facilitated the engagement of others.	A total of 41 different participation styles were identified. There was little overlap in participation styles identified across OHCs for different health conditions or within OHCs for specific health conditions apart from high-frequency users.	May not have included all relevant studies, as the search terms may not have encompassed all the different terms used to describe participation styles at this early stage of research.	N/A	QUADS SCORE: 27
Carron-Arthur, B., Reynolds, J., Bennett, K., Bennett, A. & Griffiths, K. M.	2016	What's all the talk about? Topic modelling in a mental health Internet support group. https://doi.org/10.1186/s12888-016-1073-5	BMC Psychiatry.	**Funding:** Australian Postgraduate Award, Australian National Health and Medical Research Council (NHMRC) Research Fellowship. BlueBoard funding: the Australian Department of Health. **Conflicts:** K.M. Griffiths established BlueBoard; and K.M. Griffiths, J. Reynolds, K. Bennett and A. Bennett are responsible for the provision of the BlueBoard service. None of the authors derives personal financial benefit from the operation of the service.	Quantitative: topic modelling using computer aided content analysis to identify topics and sentiment.	Gain new insight into the nature of engagement in internet support groups, including the role of super users and their possible effect on other users.	**Mental Health** Online Forum BlueBoard (blueboard.anu.edu.au). BlueBoard is predominantly used for peer-to-peer discussion about Depression (38.8% of content). It also includes forums on Bipolar Disorder (18.4%), Generalised Anxiety Disorder (5.0%), general discussion (22.1%) and other topics (15.7%)	All posts generated between 1st October 2008 and the 23rd May 2014 (n = 131,004 by 2932 members)	None stated	"super users" (the top 1 % of users by posting frequency)	**Emotional support:** Super users serve the role of emotionally supportive companions.	The findings suggest that super users serve the role of emotionally supportive companions (active helpers in companionship and emotional support) with a focus on topics broadly resembling the consumer/carer model of recovery. Superusers are relatively less inclined than other users to write content about clinical topics such as medication and treatment.	Dichotomisation of users according to their posting frequency (super user vs other users) provides a limited framework for defining the nature of a user's participation in an ISG.	Superusers modify their content to actively help others, but their support may not match what is sought. The study suggests a discrepancy in preferred content between superusers and other users. If this stems from differing perceptions of recovery, super users might be better suited to supporting each other rather than other users.	QUADS SCORE: 36
Carron-Arthur, B, Reynolds, J, Bennett, K, Bennett, A, Cunningham, J. A & Griffiths, K. M.	2016b	Community structure of a mental health Internet support group: Modularity in user thread participation. https://doi.org/10.2196/mental.4961	Journal of Medical Internet Research Mental Health.	**Funding:** Australian Postgraduate Award - Australian National Health and Medical Research Council (NHMRC) Research Fellowship (BlueBoard is supported by funding from the Australian Department of Health). **Conflicts:** Kathleen Griffiths established BlueBoard; and Kathleen, Julia, Kylie, and Anthony are responsible for the provision of the BlueBoard service.	Quantitative: social network analysis	Determine the characteristics of users associated with the community structure so a greater understanding of the factors which lead to user interaction can be gained.	Mental Health Online Forum BlueBoard (blueboard.anu.edu.au). BlueBoard is predominantly used for peer-to-peer discussion about Depression (38.8% of content). It also includes forums on Bipolar Disorder (18.4%), Generalised Anxiety Disorder (5.0%), general discussion (22.1%) and other topics (15.7%)	Posts dated between October 1, 2008, and May 23, 2014 were included in this study and were in a thread with posts given by two or more users (n=130,582 by 2652 users). Age data was grouped into three categories (<25, 25–34, >34) to avoid singularities in the Hessian matrix caused by low counts in brackets above 60 years. Each category contained about one-third of the users.	None explicitly stated. Brief reference to homophily.	(Terms used: Superusers - highly active members - influential members - core users). Measured superuser status using posting frequency and eigenvector centrality aka the most active and central users.	**Sustaining the community:** Superusers (highly active users) played a key role in sustaining the community over time. **Developing the community:** Superusers were essential for community development at early stages.	**(1)** Several highly active users communicated with many other new users who registered at the same time regardless of whether they had similar characteristics (as measured in this study) or not. **(2)** These core users played a key role in sustaining the community over time. **(3)** The observed pattern of highly active and central members registering early in each group in the study is consistent with research which suggests that these users play a vital role in the development of the community at an early stage.	**(1)** BlueBoard is mainly used for depression discussions, so these findings may not apply to MHISGs with more balanced topic distributions. **(2)** Measured superuser status using posting frequency and eigenvector centrality only.	Results suggest that people who join the forum may communicate most with those who register around the same time. While this is not surprising, an important finding is the fact that registration date takes precedence over other factors such as demographic characteristics and type of mental health issue in predicting group membership. It raises the possibility that the social interactions in forums are not largely affected by these characteristics. Homophily suggests that people who communicate frequently tend to share common characteristics. In MHISG, this may result in subgroups of users with similar traits, making homophily a key factor in its	QUADS SCORE: 29

Chen, Z.., Zhang, C. & Fan, G.	2020	Interrelationship between interpersonal interaction intensity and health self-efficacy in people with diabetes or prediabetes on online diabetes social platforms: An in-depth survey in China. https://doi.org/10.3390/ijerph17155375	International Journal of Environmental Research and Public Health.	**Funding:** The Ministry of education of the National Educational Science Planning Project. Medical research fund of Guangdong Province. Clinical teaching research project of the Ministry of Education. General program of Guangdong Natural Science Foundation. Soft science project of Guangdong science and technology plan. Shantou science and technology plan's medical and health category project. Nursing research program of Shantou University Medical College. **Conflicts:** No conflicts declared.	Mixed methods: cross sectional study using questionnaires and 1-1 interviews.	Investigate participation in an online health community among people with diabetes, with a focus on how online interaction influences self-efficacy in the course of coping with diabetes.	Used network platforms, such as QQ, WeChat, Tieba, forums, and diabetes-related apps. (China)	People with diabetes or prediabetes who were active in a diabetes online health community. most respondents were from 34 provinces, autonomous regions, and municipalities in China, with most coming from Guangdong province, and 12 respondents lived outside of China. Most respondents were 31–40 years old, holders of graduate or undergraduate qualifications, and urban residents (accounting for 63.1% of participants). 20.1% frequently (>10 times a day) posting information on the group.	None stated	The most common (33.0% of all respondents) frequency of interaction with the group was 11–30 times per day. High frequency users have high self-efficacy and adopted a greater variety of interaction modes. Respondents with higher self-efficacy were more likely to live in urban areas, and be married, and tended to spend more time paying attention to group information, have a higher frequency of viewing group information, and have a higher frequency of interaction with group members.	**Self efficacy:** measured using modified "diabetes self-efficacy scale" (Lorig et al) and "diabetes self-efficacy scale" (Grinslade et al).	**(1)** Participants with high self-efficacy tended to spend more time paying attention to group information, spend more time viewing group information, and have a greater degree of interaction with group members. **(2)** The frequency and intensity of online interaction might positively affect self-efficacy and, by implication, diabetes self-management. most of the respondents think that online social networking sites have a positive impact on diabetes self-management,	Did not differentiate findings between platforms (e.g. "we chat" and actual forums).	People with diabetes have better self-care when engaging in online health communities than from hospital treatments. Online interactions provide valuable information, a sense of belonging, and improved self-efficacy, encouraging more participation. Frequent interactions with group members predict higher self-efficacy, reduce loneliness, and aid in decision-making.	QUADS SCORE: 29
Cobb, N. K., Graham, A. L. & Abrams, D. B.	2010	Social network structure of a large online community for smoking cessation. https://doi.org/10.2105/AJPH.2009.165449	American Journal of Public Health.	**Funding:** National Cancer Institute of the National Institutes of Health and by the National Heart, Lung, and Blood Institute. **Conflicts:** No conflicts declared.	Quantitative: modern network analysis	**(1)** Characterize the social network and participants of the community. **(2)** Describe its structure and establish that it shared characteristics with other known online networks. **(3)** Identify subgroups whose existence and characteristics might inform the design of cessation interventions.	QuitNet: online community for smoking cessation	7569 QuitNet participants who met the inclusion criteria; these members had 103 592 ties. Most participants (72.0%) were female, and 34.3% reported that they had already quit smoking at the time of registration.	None stated.	Superusers formed an "influential subgroup" derived from the "strongly connected core of actors group"- referred to as "key players", defined as: a set of actors with high levels of connection to the entire community. These individuals were more likely to be female (80.0% vs 71.9%) and older (49.3 vs 42.3 years).	**Connection:** key players had high levels of connection within the entire community. **Information provision:** high levels of connection could allow for more rapid and efficient dissemination of information.	**(1)** Connection: key players had high levels of connection within the entire community which could allow for more rapid and efficient dissemination of information.	(1) Used a limited selection of ties to define the network. (2) Traditional network metrics may have overestimated the diffusion capacity of the network.	N/A	QUADS SCORE: 21
De Simoni, A., Shah, A. T., Fulton, O., Parkinson, J., Sheikh, A., Panzarasa, P., Pagliari, C., Coulson, N. S. & Griffiths, C. J.	2020	Superusers' engagement in asthma online communities: asynchronous web-based interview study. https:/doi.org/10.2196/18185	Journal of Medical Internet Research.	**Funding:** Barts Charity, Queen Mary University of London, Asthma UK, the Medical Research Council, and Health Data Research UK. **Conflicts:** The authors have affiliations with Asthma UK, AstraZeneca, TEVA Life Effects, The Mighty, and WEGO Health.	Qualitative: asynchronous web-based study using structured interviews	Explore superusers' motivation to actively engage in OHCs, the difficulties they may face, and their interactions with health care professionals.	Asthma UK forum & Facebook groups	There were 17 superusers recruited for the study (14 patients with asthma and 3 carers); the majority were female (15/17). The age range of participants was 18 to 75 years. They were active in forums for 1 to 6 years and spent between 1 and 20 hours per week reading and 1 and 3 hours per week writing posts. Of the 17 users, 10 participated in 2 or more forums: 15 out of 17 in Asthma UK HealthUnlocked community and 10 out of 15 in Facebook groups.	Pragmatically driven however the interpretation draws on self-determination theory.	Superusers (users who are in the top 1%-5% in terms of messages posted to the forums)	**Seeking information/support (validation):** Reading others conversations increased engagement. **Helping others:** sustained superuser motivation to engage. **Rewards of engagement:** positive for the superusers, gained confidence, recognition, boosted motivation. **Support provision:** Provide behavioural and emotional support. **Signposting:** Referring community members to medical health professionals input. **Challenges with conversations** - conversations wanting to just complain. worry/stress worry about not being able to follow up with people in distress.	**(1)** Superusers are both patients with asthma and carers of a wide age range, tend to take part in more than one OHC, and spend considerable time in a role sometimes similar to that of moderators **(2)** Superusers showed awareness of the complexity of coping with asthma and the limits of their advice, provided emotional and behavioural self-management support, and had at times to direct users to HCPs for medical queries. **(3)** The superuser role appears to be acquired by users as they deepen their asthma-related knowledge and become accustomed to web-based communication and the dynamics of group-based anonymous interaction, turning into expert patients, acquiring some of the characteristics of the second generation of e-patients. **(4)** Although the superuser role could be stressful at times, most HCPs were unaware of superusers' engagement with OHCs and therefore unable to provide support	(1) The currently limited literature about superusers in online health forums, the lack of a formal identification of superuser status in online health forums, and the a posteriori definition of superusers (i.e., superusers as the top 1% active users over a 10-year period) make it difficult to judge the response rate in this study. (2) The self-selective nature of recruitment may have introduced a subjective bias, as less altruistic superusers with different characteristics may not have responded to the invitation.	Before the study, participants had been active in OHCs for 1 to 6 years, spending 1 to 20 hours/week reading and 1 to 3 hours/week writing posts. Most (11 out of 17) read ≥2 hours/week, and 7 out of 17 wrote ≥1 hour/week. Participation increased over time for 14 out of 17 superusers, driven by a desire to learn more about asthma, changes in asthma conditions or treatments, and increased familiarity with OHC members.	QUADS SCORE: 32
De Simoni, A., Taylor, S. J. C., Griffiths, C. J, Panzarasa, P. & Sheikh, A.	2018	Online "superusers" as allies of the health care workforce. https://catalyst.nejm.org/doi/full/10.1056/CAT.18.0052	NEJM Catalyst Digital Platform.	**Funding**: No funding declared. **Conflicts:** No conflicts declared.	Grey literature: Expert opinion article.	Outline three proposed steps for integrating peer-driven online health communities with traditional services to improve health outcomes for people with chronic conditions.	Not focused on any one type but mentions online health communities of people with chronic conditions, such as asthma, cystic fibrosis, and diabetes, in discussion.	No explicit population details provided.	None stated.	Superusers are defined as individuals who are disproportionately active in online health communities, representing the top 1% of all active users based on the number of contributing posts. They are typically lay volunteers who spontaneously emerge as communities grow larger. They play a central role in generating content, spreading information, facilitating discussion and connections, and providing support, advice, and direction to other members.	**Engagement/Cohesion:** Keep the community engaged and cohesive over time. **Healthcare Allys:** that online peer-peer support can enhance disease self-care, reduce health care utilization, and improve a variety of health outcomes that may also result in both direct and indirect health care cost savings. **Community building:** work to ensure that new members connect with more established users, that discussions do not run dry, and that egregious online behaviours are promptly stopped.	**(1)** Superusers play a central role in generating content, spreading information, facilitating discussion and connections, and providing support, advice, and direction to other members. **(2)** Online health communities, led by their superusers, represent a powerful and largely untapped resource to support people in effectively self-managing their long-term illnesses.	N/A	Modelling the targeted removal of users, starting from the most connected ones (i.e., superusers), induced the two networks to quickly collapse. Ten superusers can sustain a community of 1,000 users. The health care system needs to acknowledge and enhance superusers' central role in sustaining online health communities. Superusers promoting self-management could be seen as an extension of British Expert Patients.	JBI CRITICAL APPRAISAL FOR TEXT AND OPINION: HIGH QUALITY Responses were all positive (either "Yes" or "No" as per the design of the question). Article received the highest appraisal possible.

Deccache, C., Hamon, T., Morsa, M., Andrade, V., Albano, M. G. & Gagnayre, R.	2019	Helping patients to learn: characteristics and types of users and uses of independent online forums on health problems and chronic conditions. https://doi.org/10.1051/tpe/2019008	Therapeutic Patient Education.	**Funding:** The Public Health Research Institute (IReSp), Paris. **Conflicts:** No conflicts declared.	Mixed methods: Literature review of grey literature	Explore the characteristics and types of users in online health forums for health problems and chronic conditions.	Included studies focused on: : diabetes (n=6), weight loss (n=4), cancer (n=2), fibromyalgia (n=1), depression (n=1), polycystic ovary syndrome (n=1), cardiovascular disease (n=1), lupus(n=1), multiple sclerosis (n=1) and unspecified chronic diseases (n=2).	Six publications described the population (adult women, n=4; middle-aged women, n = 1; adolescents, n = 1; men, n = 1). However, no further details reported in this review.	The "apomediation model" is discussed but not applied or directly related to superusers.	Superusers are defined as "consumer-producers" or "hyperactive users" who post 50-70% of all forum messages. They are conceptualized as people who trigger shorter discussions and are seen as leaders.	**Forum growth:** Hyperactive users contribute significantly to the forum's content, stimulating growth by generating new topics and responses. **Forum stability:** Consistent activity helps maintain forum stability, ensuring ongoing participation and engagement from other users **Community connections:** hyperactive users help build and strengthen connections within the community, fostering a sense of belonging and mutual support	**(1)** Users are categorized into roles such as advisors, hyperactive users, agitators, and lurkers based on their activity level and type of contribution. **(2)** 10% of users post 50-70% of the messages, indicating a small group of highly active users. **(3)** Hyperactive users and advisors are particularly impactful in triggering discussions and sustaining the forum's activity.	Studies were not included in this review unless they explicitly used the term "health forum".		QUADS SCORE: 15
Dias, A., Chomutare, T. & Botsis, T.	2012	Exploring the community structure of a diabetes forum. https://doi.org/10.3233/978-1-61499-101-4-833	Studies in Health Technology and Informatics.	**Funding:** The Research Council of Norway. **Conflicts:** No conflicts declared.	Quantitative: social network analysis using a web data extraction script (Python 2.6) and four standard community detection algorithms	Identify the key actors (users) and their role (their primary activities) in user communities in an online diabetes forum.	Diabetes forum	Public data of a diabetes forum that has over 30,000 registered users and over 200,000 posts.	Discussion suggesting forum growth is based on the preferential attachment principle.	"Key actors" or "top users" were identified based on how central and connected they are within the network.	**Connection**: new forum users had a tendency to connect to the superusers (key actors) of the forum. **Dissemination of information:** top users disseminated more information.	**(1)** The degree centrality of the network followed a power law distribution, showing that only a few users were key actors in the forum. **(2)** New users tended to connect with these key actors, reflecting the growth and preferential attachment typical of scale-free networks. **(3)** All top users had high inverse closeness centrality values, indicating their central and important roles in the forum.	Didn't process or attempt to extract any additional personal information so we know nothing of superusers demographics.	The central users on the top community of each algorithm were relatively or highly "experienced" (≥2 years after diagnosis). Although, a few "inexperienced" users (<2 years after diagnosis) did play a central role in some of the mid-sized communities.	QUADS SCORE: 23
Feldhege, J., Moessner, M., Bauer, S.	2021	Detrimental effects of online pro-eating disorder communities on weight loss and desired weight: longitudinal observational study. https://doi.org/10.2196/27153	Journal of Medical Internet Research.	**Funding:** The Open Access Publishing Fund of Ruprecht-Karls-Universität Heidelberg. **Conflicts:** No conflicts declared.	Quantitative: longitudinal observational study exploring user generated data with linear growth models.	Investigate the connection between extent of participation in a pro eating disorder community and impact on body weight.	Pro Eating Disorder Reddit Community.	Data on 1170 users and the unsolicited weight information they shared with the pro-ED community were collected over a period of 15 months (between August 15, 2017, and November 14, 2018).	None stated	More active users/users above mean activity levels.	Superuser weight loss: the level of activity in the r/proed community was associated with weight loss.	**(1)** Activity in the r/proed community was linked to weight loss. **(2)** More active users lost more weight. **(3)** Higher baseline BMI users experienced greater weight loss. **(4)** Even users with very low baseline weight (BMI <17 kg/m2) lost weight. **(5)** Increased activity in the pro-ED community led to more weight loss over time. **(6)** More active users are at greater risk of unhealthy weight loss.	Could not determine whether individuals were active with more than one Reddit account during the period of the study. The observational study design does not allow to conclude causality.		QUADS SCORE: 27
Geramita, B. H., Abebe, K. Z., Rothenberger, S. D., Rotondi, A. J. & Rollman, B. L.	2018	The association between increased levels of patient engagement with an internet support group and improved mental health outcomes at 6-month follow-up: Post-hoc analyses from a randomized controlled trial. https://doi.org/10.2196/10402	Journal of Medical Internet Research.	**Funding:** The National Institute of Mental Health and the National Center for Advancing Translational Sciences of the National Institutes of Health. **Conflicts:** No conflicts declared.	Quantitative: RCT (post hoc analyses)	Apply the 1% rule to categorize patient forum engagement and identify whether any patient subgroups benefitted from forum use.	Depression and anxiety moderated forum created using WordPress specifically for the RCT.	302 patients randomized to the ISG as: superusers (3/302, 1.0%), top contributors (30/302, 9.9%), contributors (108/302, 35.8%), observers (87/302, 28.8%) and those who never logged in (74/302, 24.5%). Mean age n=42.6 years, 81.1% (245/302) were female, and 47.7% (144/302) had at least a college education.	None stated	Superusers were conceptualised using the 1% rule. As only 3 were identified they were grouped with 30 "top contributors" for analysis. On average, this "highly engaged subgroup" posted 5.8 times per month, which averaged approximately 1 post per log-in.	**Improved mental health outcomes.** Compared to participants who never logged in, the combined superuser + top contributor subgroup (n=33) reported 6-month improvements in anxiety (PROMIS: –11.6 vs –7.8; P=.04) and HRQoL (SF-12 MCS: 16.1 vs 10.1; P=.01) but not in depression.	**(1)** Patient engagement with the ISG was more broadly distributed than predicted by the 1% rule. **(2)** The 11% of participants with the highest engagement levels reported significant improvements in anxiety and HRQoL **(3)** Participants who were female, white, and college educated were more likely to be in the superusers + top contributors subgroup (e.g., ≥4-year college education: 70%, 23/33 superusers + top contributors vs 36%, 27/74 of the never log-ins).	The ISG was limited in size. Quantified engagement using a simple measure of post counts, did not include a content analysis of posts or examine the impact of post content on outcomes. All participants had access to the cCBT program, therefore it cannot be excluded that the overall improvements we observed could be attributed to the cCBT program.	Superusers created 42.3 % (630/1488) of posts (median 246), top contributors created 34.6% (515/1488). No other subgroup reported significant symptom improvements.	QUADS SCORE: 28
Gopalsamy, R.	2017	Engagement-based analyses of the growth of online health forums. https://liverpool.idm.oclc.org/login?url=https://www.proquest.com/dissertations-theses/engagement-based-analyses-growth-online-health/docview/1983447334/se-2?accountid=12117	ProQuest Dissertations Publishing. Masters Degree Thesis.	**Funding:** No funding declared. **Conflicts:** No conflicts declared.	Quantitative: longitudinal study . Longitudinal analyses were conducted by evaluating forum engagement over time.	Analyse the relationship between engagement and health forum growth over time.	The health forums specified in the study are from MedHelp.org and include "Heart Disease," "Diabetes," "Substance Abuse," "Fitness," "Depression," "Heart Rhythm," and "Anxiety"	Collected data from 7 OHFs posted between the years 1999 and 2016. No explicit population details provided (there is a breakdown of users per forum but not relating to posting activity).	The Network Effect Hypothesis cooperative game theory employed for measuring engagement capacity.	Superusers referred to as the most important, or influential, users of pro-health platforms integral to the OHF growth, as they willingly provide continuous support, advice and information to other users. Also talked about at the top 1% to generate content. Enhances existing definitions of superusers - Superusers, recognized through the lens of the engagement metric, can now be viewed as users having an innate ability to engage others.	**Engaging others/sustaining:** superusers play a critical role in sustaining the forum's activity by engaging others and encouraging participation. Their engagement capacity is a measure of their ability to attract responses and stimulate conversation. This engagement can implicitly motivate lurkers to become active participants by providing interesting and engaging content.	**(1)** There is a causal relationship between user engagement and the growth of the forum. **(2)** Increased user engagement increases the reach of forums (e.g. more people find out about the forum and join). **(3)** Higher engagement encourages lurkers to become more active in forums ("delurking").	Demographic details of the forum users are not provided. There is an excessive focus on metrics which means other factors in user behaviour are not taken into consideration in relation to forum growth. All of the forums are from a single platform (MedHelp.org) which may reduce	This thesis provides a comprehensive background for the paper Gopalsamy, R., Semenov, A., Pasiliao, E., McIntosh, S. & Nikolaev, A. (2017). To avoid redundancy, the published paper is not included.	QUADS SCORE: 32

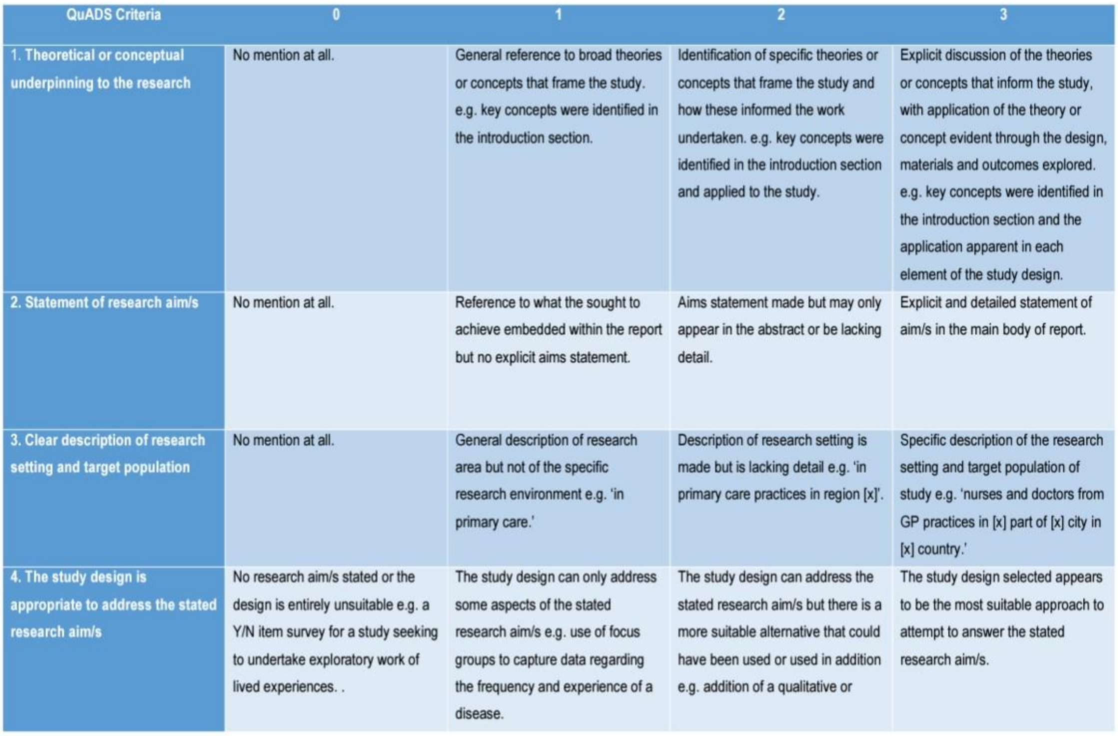
Griffiths, K. M., Carron-Arthur, B., Reynolds, J., Bennett, K. & Bennett, A.	2017	User characteristics and usage of an open access moderated internet support group for depression and other mental disorders: a prospective study. https://doi.org/10.1016/j.invent.2016.11.003	Internet Interventions.	**Funding:** NHMRC Fellowship and Australian Postgraduate Award. BlueBoard was supported by funding from the Australian Department of Health**.** **Conflicts:** KG established BlueBoard and KG, JR KB and AB were responsible for the provision of the BlueBoard service. None of the authors derived personal financial benefit from the operation of the service.	Quantitative: prospective study. Data collected from the database of peer interactions. Predictors of post frequency and retention on the board were examined using logistic regressions.	Evaluate the attributes of a publicly accessible forum for depression and other mental disorders	BlueBoard comprises 10 forums including: (1) Eight condition forums each focused on a different mental disorder (depression, bipolar disorder, generalised anxiety, social anxiety, panic disorder, obsessive compulsive disorder, borderline personality disorders and eating disorders). Each of the condition forums comprised two sub-forums: “Living with [condition, e.g., depression]” and “Taking care of our ourselves”; (2) A carer forum (“Caring for someone with a mental health problem”) comprising four sub-forums: “General”, “Depression and Bipolar disorder”; “Anxiety disorders” and “Other	2932 users contributed 131,004 posts to the ISG. The majority were female, aged 20 to 34 years, and mental health consumers. 19% resided in rural or remote regions. Frequency of posts and retention on the board varied across users, with a moderate association between retention and number of posts. Two-thirds of users were women and the majority were consumers. Although the Board was used by older people including some aged over 75 years, the majority of users were aged between 20 and 34 years. Users resided in 76 different countries, with most living in Australia	None stated	Referred to as ‘active users’ (each contributing between 19 and 11,994 posts) a group distinct from one off users (one post) and multiple users (2-18 posts).	Sustainability and growth of the group.	**(1)** A small minority of active users are sufficient to ensure the sustainability and growth of an online mental health ISG. **(2)** Multivariate analyses confirmed consumers posted more often and engaged with the board for longer, and that young people (under 20) posted less often and engaged over a shorter period than some older age groups. **(3)** A trend towards lower posts among rural and remote residents compared with their city counterparts. **(4)** Gender was not a predictor of multiple compared to one-off posts.	Limited range of personal characteristics were measured at registration. The current study did not examine the relationship between user characteristics or usage and outcomes, either positive or negative		QUADS SCORE: 27
Healey, B., Hoek, J., Edwards, R. & Shahab, L.	2014	Posting behaviour patterns in an online smoking cessation social network: implications for intervention design and development. https://doi.org/10.1371/journal.pone.0106603	PloS One.	**Funding:** University of Otago, Dunedin, New Zealand. **Conflicts:** No conflicts declared.	Quantitative: Retrospective analysis using Python 2.7 web crawler for metadata extraction.	Identify patterns in aggregate posting behaviour over time; explore whether network growth alters user engagement; and examine the feasibility of identifying low-engagement users early in their cessation attempt.	Smoking cessation (Quitblogs). Moderated.	133,096 posts from 2,062 unique users.	The Network Effect Hypothesis.	Superusers are defined as "Highly Engaged Users" (HEUs) - those contributing 180 or more posts or comments (items) within any three month period during a calendar year. Therefore, superusers had high network activity (high post count).	**Engagement:** HEU's are prolific and persistent contributors who provide responses and foster engagement and were connected to many other users across the engagement spectrum. **Retention:** Many HEUs had extended longevity in the network; **Contributions:** they contributed frequently	**(1)** A small number of users contributed disproportionately to network activity. Specifically, 69 Highly Engaged Users. **(2)** The proportion of Highly Engaged Users increased with network growth. **(3)** Many HEUs remain prolific and persistent contributors to the network over at least the medium term.	Did not have access to total current Quitline user registration information over time for analysis. The OCSN we examined was part of a multi-component cessation intervention that included other optional treatment components such as NRT and telephone counselling HEU definition was based on arbitrary based on absolute thresholds that were likely to be useful.		QUADS SCORE: 25
Heather, H. J., Murphy, S. T. & Valente, T. W.	2014	It's better to give than to receive: the role of social support, trust, and participation on health-related social networking sites. https://doi.org/10.1080/10810730.2014.894596	Journal of Health Communication.	**Funding:** No funding declared. **Conflicts:** No conflicts declared.	Quantitative: Internet-based survey.	Examine how participation on a social networking group about pregnancy influenced members’ health-related attitudes and behaviours.	8 popular pregnancy-related sites.	114 pregnant participants. Caucasian (n=88%) mean age (m=29 years) (SD ¼ 5.04). 69% of participants had visited a social networking site every day.	Introduction centres on social support. Discussion highlights Helper therapy principle.	Referred to in text as "highly supportive/highly involved community members" (separate from a "time spent" measure of forum use)	**Information provision:** "highly supportive community members may act as information bridges, seeking information from other sources and relaying it back to the online community." **Encouraging participation:** a low rich-club coefficient suggests superusers preferentially communicated with poorly connected users. **Information seeking:** "participants who provided more support also sought out more information from other sources, such as their friends and other online resources."	**(1)** Spending time on the site was not significantly associated with any outcomes. **(2)** Of the predictor variables, providing social support was associated with the most outcomes, including members being more likely to seek information from other sources and being more likely to follow recommendations posted on the site. **(3)** Qualitative measures of engagement, such as trust, are better indicators of how much impact participation on a site will have on its members, as opposed to a more quantitative measure, such as time. **(4)** The more highly involved support providers are, the more they benefit (but this is not linked to the "time spent" measure).	Time spent measure: Authors discuss disparity between their findings and other findings that show "time spent" is positively associated with network size. Other studies looked at "time spent communicating within online support groups" but in this instance, "time spent" literally meant time spent on site following log in, not specific about activities. Self selection bias. Mainly well educated white women therefore findings may vary with other populations and other health issues.		QUADS SCORE: 24
Joglekar, S., Sastry, N., Coulson, N. S., Taylor, S. J. C., Patel, A., Duschinsky, R., Anand, A., Evans, M. J., Griffiths, C. J., Sheikh, A., Panzarasa, P., & De Simoni, A.	2018	How online communities of people with long-term conditions function and evolve: network analysis of the structure and dynamics of the Asthma UK and British Lung Foundation online communities. https://doi.org/10.2196/jmir.9952.	Journal of Medical Internet Research.	**Funding**: Wellcom Trust. **Conflicts:** MJE is the cofounder, and chief medical officer of HealthUnlocked and AA is a research officer at HealthUnlocked.	Quantitative: Longitudinal network analysis using Python to analyse the structure and dynamics of the networks connecting users who write posts over time.	Uncover and understand how these communities function and evolve, and the role that some users have in maintaining integration and cohesion.	Health Unlocked: Asthma UK and the British Lung Foundation (BLF).	BLF: 19,837 users and 875,151 posts (over 4 years). Asthma UK: 3345 users and 32,780 posts (over 10 years)	None stated.	Superusers are those who write a disproportionally large number of posts and represent 1% of the overall populations. Superusers were defined according to their cumulative activity over the entire observation period.	**Community structure:** interactions were held together by very few superusers, who posted frequently and regularly, 65% of them at least every 1.7 days in the BLF community and 70% every 3.1 days in the Asthma UK community. **Community Cohesion:** posting activity indirectly facilitated tie formation between other users. **Expertise:** transition from help seeking to help giving suggests superusers not only play a topologically important role in the communities, but they are also likely to provide the expertise needed to answer queries.	**(1)** The more active users became, the more likely they were to reply to other users 'posts rather than to write new ones, shifting from a help-seeking to a help-giving role. This might suggest that superusers were more likely to provide than to seek advice. **(2)** Asthma UK superusers made a lower number of connections than BLF ones. **(3)** Sensitivity analysis showed that the removal of users with the largest number of connections caused the largest component to collapse. **(4)** The Rich-Club Effect: Both Asthma UK and BLF communities were characterized by a low rich-club coefficient, which suggests that in both communities highly connected superusers preferentially communicated with poorly connected ones or, alternatively, that superusers tended to avoid each other and instead communicated with those who were only connected with very few others.	No demographic data collected. Did not explore differences in use levels between forums but hypothesised (heart forum used for regular management, asthma forum used after attack).		QUADS SCORE: 30

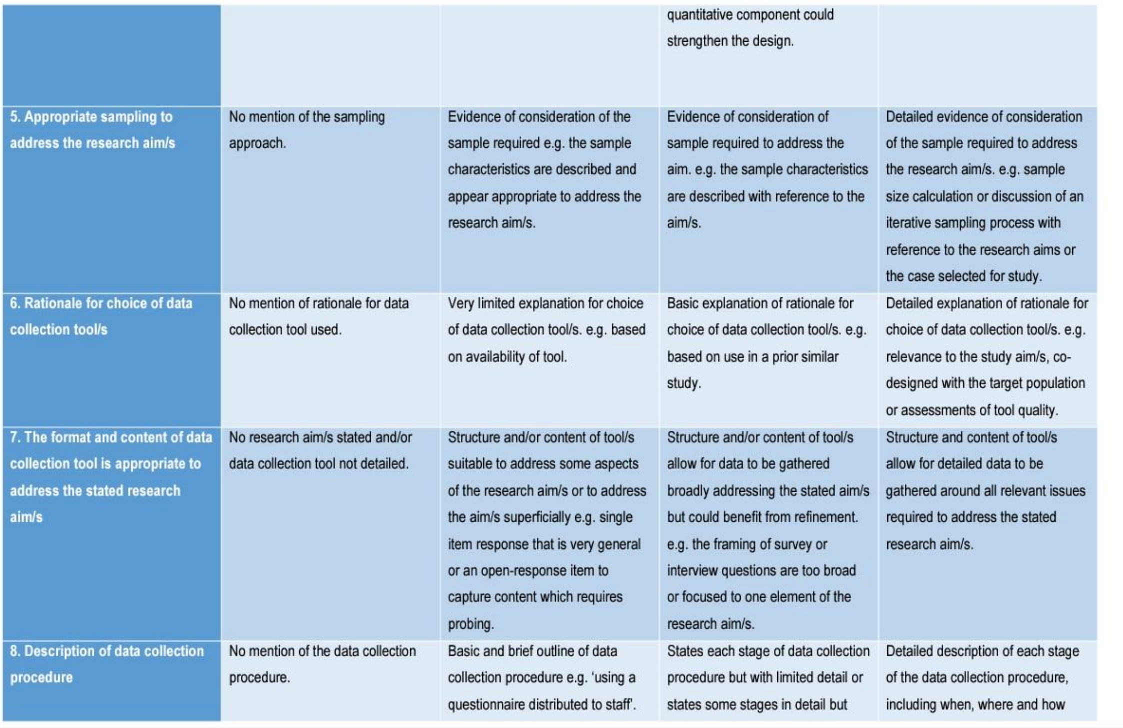
												connected with very few others.			
Lawless, M. T., Hunter, S. C., Pinero de Plaza, M. A., Archibald, M. M. & Kitson, A. L.	2022	"You are by no means alone": a netnographic study of self-care support in an online community for older adults. https://doi.org/10.1177/10497323221124979	Qualitative Health Research.	**Funding:** Flinders University Caring Futures Institute. **Conflicts:** No conflicts declared.	Qualitative: Observational netnographic using online qualitative ethnographic methodology combined with a Straussian grounded theory approach.	Identify and analyse posts in a publicly accessible online community designed for older people.	Older adults' health and self-care for long term conditions forums on a publicly accessible UK-based entertainment and lifestyle website and social network.	181 threads. 659 individual posts. 322 unique community members. All posts and replies posted in the general health forum and forums for specific topics including diet and healthy eating, exercise, cancer, and diabetes.	Broadly, concepts of relational autonomy, relationship-centred care, apomediation theory (i.e., the theory that peer supporters are pivotal in guiding individuals to relevant and credible health information), and a positive psychosocial model of health and well-being in older adulthood underpin this research.	Superusers were not explicitly defined but were acknowledged in the identity type: "The influencing Self". This identity type is characterized by the provision of advice for future action, often based on established personal experience, authenticity, and past engagement patterns in the community (i.e., contributing a high frequency of posts),	**Advice provision:** Provided advice for future action, often based on established personal experience. Ability to influence others and, by extension, health behaviours. **Information and signposting provision:** The influencing self was engaged in the processes of providing information to other users, referring others to sources of help or information. **Forum Moderation:** moderating the forum by flagging or removing offensive or inappropriate posts. Welcoming environment: welcoming new members.	**(1)** Found three self-identities and related processes that were repeatedly involved in the elicitation and provision of support: the support seeking self; the empathizing self; and the influencing self (each associated with distinct interaction styles). **(2)** Movement between identities was fluid and, at times, community members exhibited aspects of multiple identities as they responded to emerging problems and situations. **(3)** Individuals appeared to use the online community because of an unmet need for emotional or informational support relating to condition-specific, physical (e.g., activities of daily living), or psychosocial care needs (this does not relate to superusers specifically).	No socio-demographic information was collected about individual community members, which limits the ability to draw specific inferences Conducted during covid may have influenced results. No formal measures of super use.		QUADS SCORE: 31
Litchman, M. L., Edelman, L. S., & Donaldson, G. W.	2018	Effect of diabetes online community engagement on health indicators: cross-sectional study. https://doi.org/10.2196/diabetes.8603	Journal of Medical Internet Research Diabetes.	**Funding:** No details provided. **Conflicts:** No details provided.	Quantitative: cross-sectional survey-based study.	Survey adults with diabetes who participated in the diabetes online community to better understand and describe who is using the diabetes online community, how they are using it, and whether the use of the diabetes online community was associated with health indicators.	Diabetes.	183 adults participated in this study. Participants were mostly female (71.6%, 131/183), white (95.1%, 174/183), US citizens (82.5%, 151/183), had type 1 diabetes (69.7%, 129/183), with a mean age of 44.7 years (SD 14) and diabetes duration of 18.2 years (SD 14.6).	None stated.	No explicit mention of superuser. However, community engagement was measured on a 5 item scale tool developed by the authors. Higher scores indicated more engagement. Highly engaged users had higher scores and measurable outcomes (see impacts).	**Measurable health:** Diabetes online community engagement was a strong predictor of A1c, reducing the odds of having an A1c ≥7% by 33.8% for every point increase in diabetes online community engagement (0-5).	**(1)** Participants had higher diabetes self-care and better health-related quality of life when compared with norms for diabetes. **(2)** Diabetes online community engagement was a strong predictor of A1c, reducing the odds of having an A1c ≥7% by 33.8% for every point increase in diabetes online community engagement (0-5). **(3)** Study participants are oftentimes (67.2%, 123/183) not informing their healthcare providers about their diabetes online community use even though most (91.2%, 161/181) are seeing their healthcare provider on a regular basis. **(4)** Engagement scores were higher for those who had told their healthcare providers about their DOC use and were unsure if they were supported or felt supported than for those who had never told their healthcare providers about their forum use at all.	Self selection bias. Participants were largely white, college-educated females which is not representative of the entire diabetes community population. Self reporting of health levels may impact reliability of data.		QUADS SCORE: 24
McCosker, A.	2018	Engaging mental health online: insights from beyondblue's forum influencers. https://doi.org/10.1177/1461444818784303	New Media and Society.	**Funding:** Swinburne University Faculty Research Grant. **Conflicts:** No conflicts declared.	Mixed-methods: initially applied digital ethnographic observation to identify key informants. Then combined interviews with quantitative and qualitative content analysis of a sample of forum data.	Characterise the participants and the pathway from expertise to influence in online forums.	BeyondBlue (Mental Health Forum).	Beyondblue does not collect personal information or display any information for a forum user other than a pseudonym. (5 sub forums, 14 threads, 1140 posts).	Conceptual framework draws on Smith, Maguire and Matthews's (2012) key elements of cultural intermediary to examine (a) expertise, (b) framing and (c) influence (Cultural intermediary theory).	Superusers were not explicitly defined but were described as key informants, prominent, influential forum participants and health influencers. They are likened to social media influencers "microcelebrities" and "ordinary celebrities"	**Authority/legitimacy:** health influencers act in beyondblue's mental health forums in ways that establish authority and legitimacy. **Cohesion:** frame and re-frame actions through empathy practices and in doing so stimulate cohesion-generating cycles of impact and feedback among forum participants. **Connection:** activating supportive mental health environments and sustain impactful connections with peers.	**(1)** Effective health influencers build demonstrable non-professional expertise and authority, play an active role in framing and re-framing mental health and recovery practices, and stimulate cohesion-generating cycles of impact and feedback among forum participants. . **(2)** Peer mentors and health influencers do not have a direct role in content moderation, which is the domain of content filters and beyondblue's community manager, but rather in interaction modulation, shaping conversations and framing practices in the forums.	The authors list no limitations.		QUADS SCORE: 23
O'Neill, B., Ziebland, S., Valderas, J. & Lupiáñez-Villanueva, F.	2014	User-generated online health content: a survey of internet users in the United Kingdom. https://doi.org/10.2196/jmir.3187	Journal of Medical Internet Research.	**Funding:** The Institute for Prospective Technological Studies and the European Commission Directorate General for Communications Networks, Content and Technology. **Conflicts:** No conflicts declared.	Quantitative: online survey-based study,	Explore access and production of user-generated health content among UK Internet users and to investigate relationships between frequency of use and other variables.	Non-specific online health forum use.	1000 UK-based participants.	None stated.	Superusers (7.5%, 58/778) are defined as people who accessed and shared content on a daily basis. Superusers were more likely to be male and to be employed but there were no differences between the groups with respect to educational level. Respondents in the youngest age category (16-24 years) are more likely to be superusers They are also acknowledged as "frequent prolifent posters" and key players, active users and caretakers. The paper also references the 1% rule.	**Shape health information:** superusers are likely to shape the health information that others access.	**(1)** Superusers are likely to shape the health information that others access. **(2)** Superusers are more likely to have their health behaviours, decisions about treatments or self-care, and eating or exercise habits affected by the information they access online.	The primary focus of this study is not exclusively online forum use but the access of information overall.		QUADS SCORE: 27
Van Mierlo	2014	The 1% rule in four digital health social networks: an observational study. https://10.2196/jmir.2966	Journal of Medical Internet Research.	**Funding:** No funding declared. **Conflicts:** Trevor van Mierlo is the CEO & Founder of	Quantitative: observational research study	The aim was to determine if the 1% rule applies to moderated Digital Health Social Networks (DHSNs)	Alcohol, depression, panic disorder & smoking cessation forums.	63,990 "actors" (forum users).	The 1% rule, or 90-9-1 principle.	Superusers are "actors" who frequently generate content and facilitate discussions. In this study they are defined as the top 1% of "actors" (forum users) according to post frequency.	**Forum value and growth:** Superusers generate network value and growth. Forum sustainability: social network sustainability requires fresh content and	**(1)** Superusers accounted for a weighted average of 74.7% of content and generated the vast majority of posts within the four DHSNs. These findings match criteria of the 1% rule and may be comparable to the	Only data from registered users were examined.		QUADS SCORE: 35

		https://10.2196/jmir.2966		is the CEO & Founder of		Networks (DHSNs)				frequency.	sustainability requires fresh content and	1% rule and may be comparable to the			
Van Mierlo, T., Voci, S., Lee, S., Fournier, R., & Selby, P.	2012	Superusers in social networks for smoking cessation: analysis of demographic characteristics and posting behaviour from the Canadian Cancer Society's smokers' helpline online and StopSmokingCenter.net. https://doi.org/10.2196/jmir.1854	Journal of Medical Internet Research.	**Funding:** Schering Canada, Johnson & Johnson Consumer Health Care Canada; Pfizer Inc, Canada; Sanofi-Synthelabo, Canada; GSK, Canada; Genpharm and Prempharm, Canada; CTI; Evolution Health Systems Inc., Canada; Health Canada; Smoke-Free Ontario; and Canadian Institutes of Health Research. **Conflicts:** Trevor van Mierlo is the CEO of Evolution Health Systems Inc.	Mixed methods: observational cross-sectional quantitative data sets containing posting behaviours and demographics and qualitative interviews with social network educators.	Analyse data from two large but distinct Web-assisted tobacco interventions to help gain insight into superuser demographic characteristics and how they use social networks.	Two smoking cessation forums.	Forum 1 (SHO) registrants who made at least one post: 7.90% (n = 1670)and forum 2 (SSC) registrants who made at least one post: 14.25% (n = 1627). 219 unique superusers across both forums.	None stated.	Superusers are collectively defined as users who include: key players, posters, active users, or caretakers. Superusers were the top 100 posters (ranked according to their total number of posts), thread starters (ranked according to the total number of threads they started), and clique members (ranked according to the number of threads they participated in). Health educator and social network managers indicated that, based on their years of experience, three distinct types of superusers existed: (1) superusers who cumulatively authored the greatest number of posts (posters), (2) superusers who mainly initiated threads (thread starters), and (3) superusers who only communicated with certain members (clique members), and that management styles differed for each of these superuser subgroups.	**Content:** superusers are responsible for the majority of posts. **Discussions:** superusers initiate many new threads. **Cliques:** some superusers only communicated with certain members. (Here clique communication showed a statistically significant correlation between posting behaviour and years smoked).	**(1)** There were minimal correlations between posting behaviour and demographic characteristics in all of the superuser groups analysed. **(2)** Superusers play powerful roles within social network traffic. **(3)** While SHO and SSC superusers accounted for only 0.4% and 1.1% of total program registrants, they were responsible for 34.78% and 46.22% of social network content. **(4)** Different types of superusers (and superuser subgroups) frequently exist.	Used the term superuser and the three superuser subgroups (posters, thread starters, and clique members) without validating these participatory patterns.	The 95 SHO and 124 SSC superusers accounted for 0.4% and 1.1% of total program registrants and 5.7% and 7.6% of all active social network members.	QUADS SCORE: 28
Van Uden-Kraan, C. F., Drossaert, C. H. C., Taal, E., Seydel, E. R. & Van de Laar, M. A. F. J.	2009	Participation in online patient support groups endorses patients' empowerment. https://doi.org/10.1016/j.pec.2008.07.044	Patient Education and Counseling.	**Funding:** Netherlands Organisation for Health Research and Development (ZonMw), the Dutch Arthritis Association, and Comprehensive Cancer Centre Noord Oost (IKNO). **Conflicts:** No conflicts declared.	Quantitative: retrospective online survey-based study	Explore the extent to which patients feel empowered by their participation in online support groups and with which frequency empowering processes occur.	Online groups for breast cancer (n=7), fibromyalgia (n=6) and arthritis (n=6). (Netherlands)	528 participants, 1% had the diagnosis of breast cancer, 22% had the diagnosis of fibromyalgia, and 23% of the respondents indicated to have arthritis. The other respondents (14%) indicated to have more than one of these three diagnoses. Women (94%). Average age (44). Low level education (33%), Medium level education (41%), high level education (26%). Unemployed (56%).	No explicit framework but study conducted with an overarching reference to "empowering processes".	Superusers are not explicitly defined, however, referred to in passing as "high-frequency posters."	**Support provision:** high-frequency posters offered help to others more often. **Patient empowerment:** including being 'better informed' and 'enhanced social well-being'.	**(1)** Participation in online support groups can make a valuable contribution to the empowerment of patients. **(2)** High-frequency posters indicate helping other participants more often. **(3)** Motivation for using forums: Almost all participants mentioned that 'recognition' was the main reason for them to participate in an online support group.	The respondents are probably the most active participants of the online support groups and therefore not representative.		QUADS SCORE: 24
Vydiswaran, V. G. V., & Reddy, M.	2019	Identifying peer experts in online health forums. https://doi.org/10.1186/s12911-019-0782-3	BMC medical informatics and decision making.	**Funding:** University of Michigan's MCubed grant and departmental funds. Qatar Foundation. **Conflicts:** No conflicts.	Quantitative: temporal pattern analysis and machine learning	Study peer expertise in online health forums and determine how to identify peer experts.	"Medhelp", a general health forum.	The dataset includes the user profiles of all active registered users (Over 12 million registered users).	None stated.	Superusers are not explicitly referred to. However, the paper defines "peer experts" as distinguished from other users based on their activity levels (a "significant amount of time") and impact of involvement (among other measures). Peer experts represent a very small fraction of users. The ratio of peer experts to the total number of users is about 0.15%. Peer experts are said to be altruistic in their interactions, highly motivated and passionate about sharing expertise.	**Provide emotional support:** assisting other users in improving their health. **Advice/information provision:** sharing valuable advice and vital information that might be of potential use to other users (including replying to questions). **Act as role models:** by sharing lived experience.	**(1)** Peer experts could be a great resource to the community because of their topical expertise and willingness to share their knowledge and improve the overall health of the community. **(2)** Peer experts could augment the professional healthcare services with emotional and information support in online health communities. (3) Identifying peer expertise could potentially help improve the perceived reliability and trustworthiness of information in community health forums/		"Silent users" is a nice alternative to lurkers.	QUADS SCORE: 24
Willis, E.	2016	Patients' self-efficacy within online health communities: facilitating chronic disease self-management behaviours through peer education. https://doi.org/10.1080/10410236.2014.950019	Health Communication.	**Funding:** No funding declared. **Conflicts:** No conflicts declared.	Qualitative: online ethnography and discourse analysis	Identify factors of self efficacy related to self-management behaviours found in computer mediated communication shared by people with arthritis in online health communities.	Four arthritis forums.	No explicit population details provided.	Social cognitive theory. Bandura's factors of self-efficacy	Superusers within this study are referred to as "opinion leaders". Opinion leaders are community cheerleaders and gatekeepers. They started threads, responded to posts, checked in on members, disseminated information, and encouraged others to take care of their body, mind, and spirit. They played a crucial role in engaging and persuading members to adopt self-management behaviours.	**Help giving:** superusers (opinion leaders) given the opportunity to help others and played a crucial role in engaging and persuading members to adopt self-management behaviours. **Content/cohesion:** opinion leaders engaging other community members by facilitating most conversations. **Motivating environment:** telling others to "be brave" and sharing lived experience.	**(1)** Opinion leaders are the most influential forum members who facilitate much of the online conversation. **(2)** Opinion leaders always seemed to be engaging in "verbal persuasion," or convincing other members to engage in self management behaviour. **(3)** The opinion leaders acted as gatekeepers within the community, "checking in" on members, asking "how did it go," disseminating information (e.g., website links, news stories), and encouraging other members to "be brave." **(4)** Members in the online communities shared their successes and failures in self-management strategies, providing vicarious experiences for others. This study supports the idea that online health communities can enhance members' self-efficacy in practicing arthritis self-management behaviours.	This qualitative research and cannot be generalized outside of the four online health communities examined. Only examined arthritis. The information presented here is based on community members' self-reported behaviours.		QUADS SCORE: 29
Wu, B., Jiang, S., & Chen, H.	2016	Effects of individuals' motivations on communications in online health forums. https://doi.org/10.2224/sbp.2016.44.2.299	Social Behavior and Personality.	**Funding**: Non stated. **Conflicts**: Non stated.	Quantitative: exponential random graph model (models of network structure that allow insight into the variety of factors that drive individuals to form	Analyse the effects of individuals' motivations, specifically reciprocity, experience, activity, and emotion, on their communications in an online health forum.	Diabetes forum (global)	No explicit population details provided however high activity individuals made up approximately 22% of the population studied.	Small reference to Activity Theory (Allen, Karanasios, & Slavova, 2011).	Referred to as "high activity individuals" superusers were individuals with activity levels greater than the mean activity levels for all users. They were also people who prefer to have supportive forum interactions and post above-average-length messages.	**Passive benefits:** " a large number of lurkers [may] benefit from overhearing the conversations of high-frequency users in the forum. **Support provision**: " length of a message can be considered an indication of a user's effort in contributing a new message or responding to previous	**(1)** High activity individuals prefer to have supportive forum conversations. **(2)** Lurkers may benefit from superusers conversations. **(3)** 22% of users were considered high activity.	Authors do not list study limitations however a primary limitation is how high frequency users have been defined. Another limitation is that they were not the primary focus on this study.		QUADS SCORE: 14

Yang, D., Kraut, R. E., Smith, T., Mayfield, E., & Jurafsky, D.	2019	Seekers, providers, welcomers, and storytellers: Modeling social roles in online health communities. https://doi.org/10.1145/3290605.3300574	Proceedings of the SIGCHI Conference on Human Factors in Computing Systems.	**Funding:** NIMH grant R21 MH106880–01 and a grant from Google to Robert Kraut. Diyi Yang was supported by Facebook Fellowship. **Conflicts:** No conflicts declared.	Mixed methods: quantitative evaluations to cluster user behavioural patterns/qualitative approach to explore role dynamics and their impact on long-term community participation. Mixed-methods (quantitative/qualitative) criteria for evaluating the quality of derived roles.	Cluster behavioural patterns of users in a cancer support community into specific functional roles and investigate how these roles change over members' lifecycles and predict long-term participation in the community.	Cancer Survivors Network of The American Cancer Society. (USA)	66,246 registered users.	None stated.	Superusers are not explicitly referred to but may be considered users who start a significant number of threads and make high levels of comments (therefore being the most frequent users). Superusers may fall into one of several "roles" examined in this study: motional Support Provider, Informational Support Provider, Welcomer, and Story Sharer.	**Community support:** more active users often provide emotional and informational support, which are critical for the community. **Community cohesion:** being support-providers to others encourages members to interact with other members time after time, developing stronger relationships. **Evolving dynamics:** While the roles remained quite stable over time, some roles (e.g. support providers), increased (likely due to the contributions of superusers).	**(1)** Socially positive roles such as support providers and newcomer welcomers were associated with staying longer at the forum. **(2)** Members' patterns of activities and roles can influence their contribution and commitment to the community. **(3)** Being support-providers to others encourages members to interact with other members time after time, developing stronger relationships. **(4)** 9 distinct roles and types of engagement are identified but shown to change over time. The more time spent on a forum the more likely a user is to take on an active supportive role.	Does not have self-reported evaluations from forum members about their perceived roles. While the study makes correlative descriptions of members' role occupation and their engagement in the forum, findings are not causal.		QUADS SCORE: 31
Zhao, K., Yen, J., Greer, G., Qiu, B., Mitra, P. & Portier, K.	2014	Finding influential users of online health communities: a new metric based on sentiment influence. https://doi.org/10.1136/amiajnl-2013-002282	Journal of the American Medical Informatics Association.	**Funding:** the American Cancer Society and Pennsylvania State University. **Conflicts**: No conflicts declared.	Quantitative: text mining and sentiment analysis.	Improve understanding of social influence and identify influential users in OHCs by attempting to assess how online support affects OHC members' emotion dynamics.	Cancer Survivors Network of The American Cancer Society. (USA)	27 173 unique members who are cancer survivors or caregivers.	Reference to classic social network theories that focus on social network structures and have been developed along two lines: centrality metrics and influence model.	Superusers are referred to as influential users (IUs) who have the power or capacity of causing an effect in indirect or intangible ways.	**Sentiment change:** superusers influence the sentiment of other forum members - this impact can be positive in a sense that it reinforces community atmosphere. **Sense of leadership:** assuming the superuser role in this study can strengthen their involvement further. **Self-esteem:** Members who support others likely experience some improvement in their self-esteem	**(1)** A novel metric—the number of influential responding replies is highly effective in identifying influential users. **(2)** When superusers provide support through responding replies, it often leads to positive sentiment changes among recipients.	The research is limited in its ability to establish causal relationships. Factors influencing sentiment changes (e.g. other dynamics within the forum or users' external lives) cannot be isolated or controlled for.		QUADS SCORE: 27

Appendix C: QuADS Scoring System

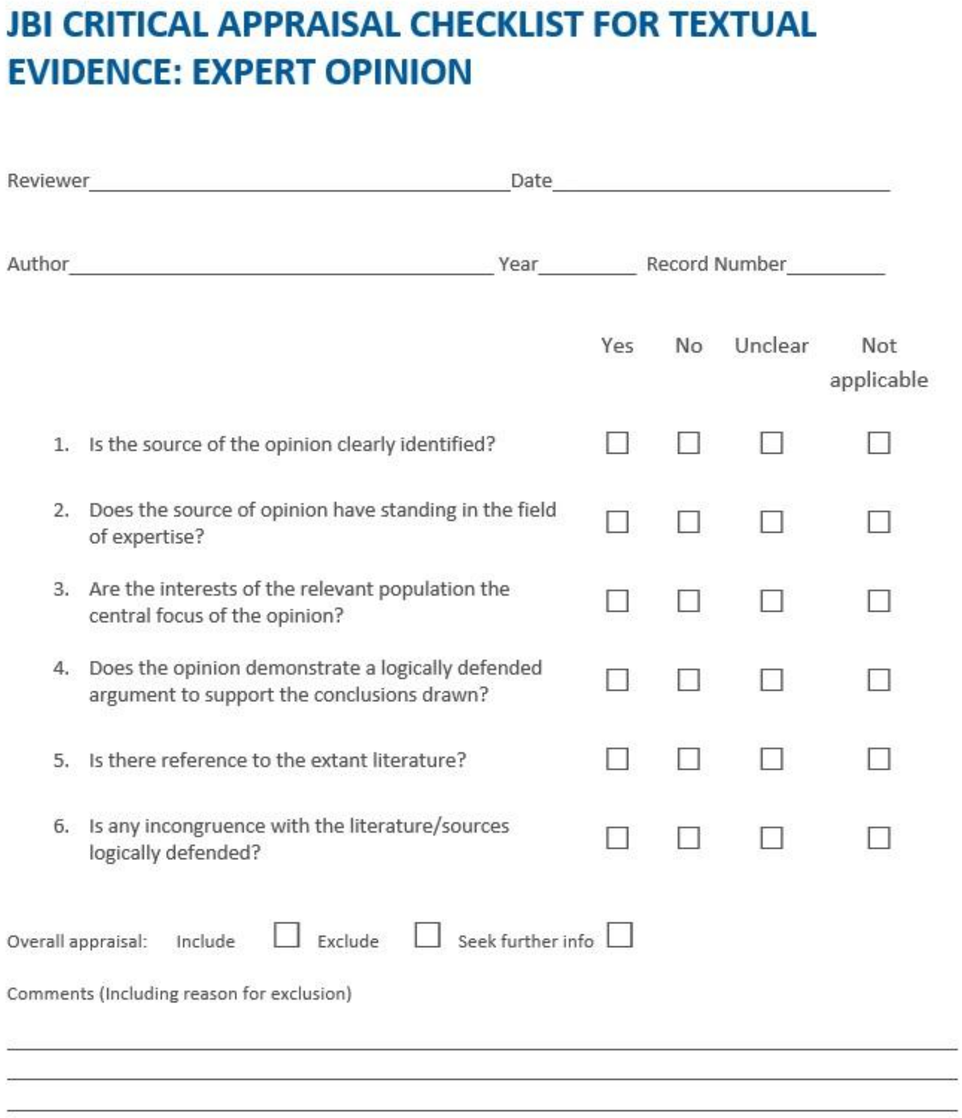




QuADS Criteria	0	1	2	3
1. Theoretical or conceptual underpinning to the research	No mention at all.	General reference to broad theories or concepts that frame the study. e.g. key concepts were identified in the introduction section.	Identification of specific theories or concepts that frame the study and how these informed the work undertaken. e.g. key concepts were identified in the introduction section and applied to the study.	Explicit discussion of the theories or concepts that inform the study, with application of the theory or concept evident through the design, materials and outcomes explored. e.g. key concepts were identified in the introduction section and the application apparent in each element of the study design.
2. Statement of research aim/s	No mention at all.	Reference to what the sought to achieve embedded within the report but no explicit aims statement.	Aims statement made but may only appear in the abstract or be lacking detail.	Explicit and detailed statement of aim/s in the main body of report.
3. Clear description of research setting and target population	No mention at all.	General description of research area but not of the specific research environment e.g. 'in primary care.'	Description of research setting is made but is lacking detail e.g. 'in primary care practices in region [x]'.	Specific description of the research setting and target population of study e.g. 'nurses and doctors from GP practices in [x] part of [x] city in [x] country.'
4. The study design is appropriate to address the stated research aim/s	No research aim/s stated or the design is entirely unsuitable e.g. a Y/N item survey for a study seeking to undertake exploratory work of lived experiences. .	The study design can only address some aspects of the stated research aim/s e.g. use of focus groups to capture data regarding the frequency and experience of a disease.	The study design can address the stated research aim/s but there is a more suitable alternative that could have been used or used in addition e.g. addition of a qualitative or quantitative component could strengthen the design.	The study design selected appears to be the most suitable approach to attempt to answer the stated research aim/s.
5. Appropriate sampling to address the research aim/s	No mention of the sampling approach.	Evidence of consideration of the sample required e.g. the sample characteristics are described and appear appropriate to address the research aim/s.	Evidence of consideration of sample required to address the aim. e.g. the sample characteristics are described with reference to the aim/s.	Detailed evidence of consideration of the sample required to address the research aim/s. e.g. sample size calculation or discussion of an iterative sampling process with reference to the research aims or the case selected for study.
6. Rationale for choice of data collection tool/s	No mention of rationale for data collection tool used.	Very limited explanation for choice of data collection tool/s. e.g. based on availability of tool.	Basic explanation of rationale for choice of data collection tool/s. e.g. based on use in a prior similar study.	Detailed explanation of rationale for choice of data collection tool/s. e.g. relevance to the study aim/s, co-designed with the target population or assessments of tool quality.
7. The format and content of data collection tool is appropriate to address the stated research aim/s	No research aim/s stated and/or data collection tool not detailed.	Structure and/or content of tool/s suitable to address some aspects of the research aim/s or to address the aim/s superficially e.g. single item response that is very general or an open-response item to capture content which requires probing.	Structure and/or content of tool/s allow for data to be gathered broadly addressing the stated aim/s but could benefit from refinement. e.g. the framing of survey or interview questions are too broad or focused to one element of the research aim/s.	Structure and content of tool/s allow for detailed data to be gathered around all relevant issues required to address the stated research aim/s.
8. Description of data collection procedure	No mention of the data collection procedure.	Basic and brief outline of data collection procedure e.g. 'using a questionnaire distributed to staff'.	States each stage of data collection procedure but with limited detail or states some stages in detail but	Detailed description of each stage of the data collection procedure, including when, where and how

			omits others e.g. the recruitment process is mentioned but lacks important details.	data was gathered such that the procedure could be replicated.
9. Recruitment data provided	No mention of recruitment data.	Minimal and basic recruitment data e.g. number of people invited who agreed to take part.	Some recruitment data but not a complete account e.g. number of people who were invited and agreed.	Complete data allowing for full picture of recruitment outcomes e.g. number of people approached, recruited, and who completed with attrition data explained where relevant.
10. Justification for analytic method selected	No mention of the rationale for the analytic method chosen.	Very limited justification for choice of analytic method selected. e.g. previous use by the research team.	Basic justification for choice of analytic method selected e.g. method used in prior similar research.	Detailed justification for choice of analytic method selected e.g. relevance to the study aim/s or comment around of the strengths of the method selected.
11. The method of analysis was appropriate to answer the research aim/s	No mention at all.	Method of analysis can only address the research aim/s basically or broadly.	Method of analysis can address the research aim/s but there is a more suitable alternative that could have been used or used in addition to offer a stronger analysis.	Method of analysis selected is the most suitable approach to attempt answer the research aim/s in detail e.g. for qualitative interpretative phenomenological analysis might be considered preferable for experiences vs. content analysis to elicit frequency of occurrence of events.
12. Evidence that the research stakeholders have been considered in research design or conduct.	No mention at all.	Consideration of some the research stakeholders e.g. use of pilot study with target sample but no stakeholder involvement in planning stages of study design.	Evidence of stakeholder input informing the research. e.g. use of pilot study with feedback influencing the study design/conduct or reference to a project reference group established to guide the research.	Substantial consultation with stakeholders identifiable in planning of study design and in preliminary work e.g. consultation in the conceptualisation of the research, a project advisory group or evidence of stakeholder input informing the work.
13. Strengths and limitations critically discussed	No mention at all.	Very limited mention of strengths and limitations with omissions of many key issues. e.g. one or two strengths/limitations mentioned with limited detail.	Discussion of some of the key strengths and weaknesses of the study but not complete. e.g. several strengths/limitations explored but with notable omissions or lack of depth of explanation.	Thorough discussion of strengths and limitations of all aspects of study including design, methods, data collection tools, sample & analytic approach.

Appendix D: JBI Checklist for Textual Evidence: Expert Opinion



JBI CRITICAL APPRAISAL CHECKLIST FOR TEXTUAL EVIDENCE: EXPERT OPINION

Reviewer______________________________________Date_______________________________

Author_______________________________________ Year_________ Record Number_________

	Yes	No	Unclear	Not applicable
1. Is the source of the opinion clearly identified?	☐	☐	☐	☐
2. Does the source of opinion have standing in the field of expertise?	☐	☐	☐	☐
3. Are the interests of the relevant population the central focus of the opinion?	☐	☐	☐	☐
4. Does the opinion demonstrate a logically defended argument to support the conclusions drawn?	☐	☐	☐	☐
5. Is there reference to the extant literature?	☐	☐	☐	☐
6. Is any incongruence with the literature/sources logically defended?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

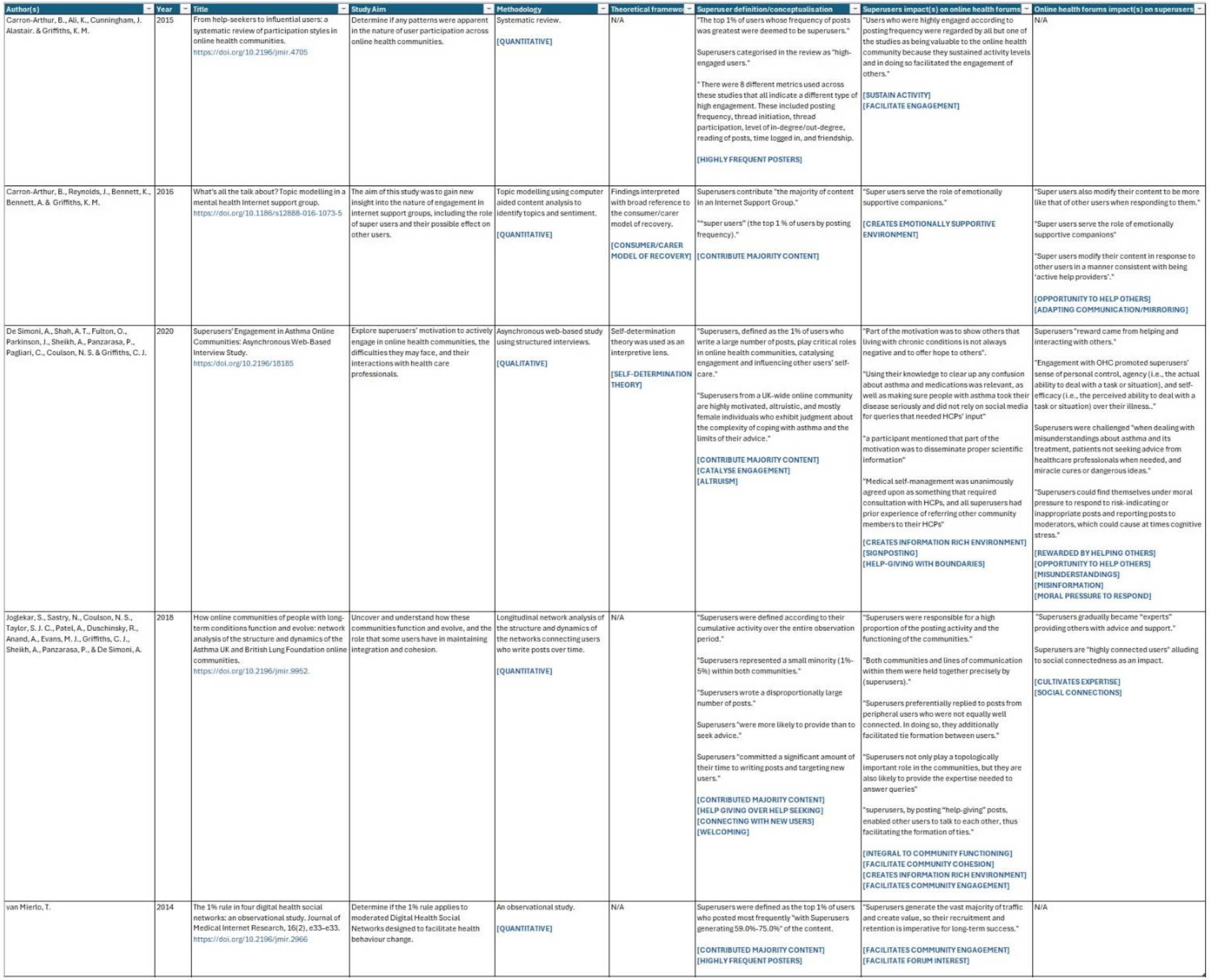
Appendix E: Initial Data Charting

Step 1: Extraction and coding of data from key background studies

Table 1 contains pertinent data extracted from the five key background studies (Carron-Arthur et al., 2015; Carron-Arthur et al., 2016; De Simoni et al., 2020; Joglekar et al., 2018 & van Mierlo, 2014). This data was inductively coded using latent and semantic terms (codes are detailed in bold blue text within the table) while keeping the primary review question: “What is known about the bidirectional impacts of superusers and OHFs?” and the secondary review question: “How are superusers of OHFs conceptualised in existing literature?”. While this review will explore and report findings on a third (secondary) review question: “What theoretical frameworks and methodological approaches are used in existing health forum superusers literature?” a decision to report these findings separately from the conceptual framework was made in order to ensure the framework does not become overcomplicated.

Table 1

An example of relevant data from five key background studies (including initial coding)



Author(s)	Year	Title	Study Aim	Methodology	Theoretical framewo	Superuser definition/conceptualisation	Superusers impact(s) on online health forums	Online health forums impact(s) on superusers
Carron-Arthur, B., Ali, K., Cunningham, J. Alastair. & Griffiths, K. M.	2015	From help-seekers to influential users: a systematic review of participation styles in online health communities. https://doi.org/10.2196/jmir.4705	Determine if any patterns were apparent in the nature of user participation across online health communities.	Systematic review. [QUANTITATIVE]	N/A	"The top 1% of users whose frequency of posts was greatest were deemed to be superusers." Superusers categorised in the review as "high-engaged users." " There were 8 different metrics used across these studies that all indicate a different type of high engagement. These included posting frequency, thread initiation, thread participation, level of in-degree/out-degree, reading of posts, time logged in, and friendship. [HIGHLY FREQUENT POSTERS]	"Users who were highly engaged according to posting frequency were regarded by all but one of the studies as being valuable to the online health community because they sustained activity levels and in doing so facilitated the engagement of others." [SUSTAIN ACTIVITY] [FACILITATE ENGAGEMENT]	N/A
Carron-Arthur, B., Reynolds, J., Bennett, K., Bennett, A. & Griffiths, K. M.	2016	What's all the talk about? Topic modelling in a mental health Internet support group. https://doi.org/10.1186/s12888-016-1073-5	The aim of this study was to gain new insight into the nature of engagement in internet support groups, including the role of super users and their possible effect on other users.	Topic modelling using computer aided content analysis to identify topics and sentiment. [QUANTITATIVE]	Findings interpreted with broad reference to the consumer/carer model of recovery. [CONSUMER/CARER MODEL OF RECOVERY]	Superusers contribute "the majority of content in an Internet Support Group." ""super users" (the top 1 % of users by posting frequency)." [CONTRIBUTE MAJORITY CONTENT]	"Super users serve the role of emotionally supportive companions." [CREATES EMOTIONALLY SUPPORTIVE ENVIRONMENT]	"Super users also modify their content to be more like that of other users when responding to them." "Super users serve the role of emotionally supportive companions" "Super users modify their content in response to other users in a manner consistent with being 'active help providers'." [OPPORTUNITY TO HELP OTHERS] [ADAPTING COMMUNICATION/MIRRORING]
De Simoni, A., Shah, A. T., Fulton, O., Parkinson, J., Sheikh, A., Panzarasa, P., Pagliari, C., Coulson, N. S. & Griffiths, C. J.	2020	Superusers' Engagement in Asthma Online Communities: Asynchronous Web-Based Interview Study. https:/doi.org/10.2196/18185	Explore superusers' motivation to actively engage in online health communities, the difficulties they may face, and their interactions with health care professionals.	Asynchronous web-based study using structured interviews. [QUALITATIVE]	Self-determination theory was used as an interpretive lens. [SELF-DETERMINATION THEORY]	"Superusers, defined as the 1% of users who write a large number of posts, play critical roles in online health communities, catalysing engagement and influencing other users' self-care." "Superusers from a UK-wide online community are highly motivated, altruistic, and mostly female individuals who exhibit judgment about the complexity of coping with asthma and the limits of their advice." [CONTRIBUTE MAJORITY CONTENT] [CATALYSE ENGAGEMENT] [ALTRUISM]	"Part of the motivation was to show others that living with chronic conditions is not always negative and to offer hope to others". "Using their knowledge to clear up any confusion about asthma and medications was relevant, as well as making sure people with asthma took their disease seriously and did not rely on social media for queries that needed HCPs' input" "a participant mentioned that part of the motivation was to disseminate proper scientific information" "Medical self-management was unanimously agreed upon as something that required consultation with HCPs, and all superusers had prior experience of referring other community members to their HCPs" [CREATES INFORMATION RICH ENVIRONMENT] [SIGNPOSTING] [HELP-GIVING WITH BOUNDARIES]	Superusers "reward came from helping and interacting with others." "Engagement with OHC promoted superusers' sense of personal control, agency (i.e., the actual ability to deal with a task or situation), and self-efficacy (i.e., the perceived ability to deal with a task or situation) over their illness.." Superusers were challenged "when dealing with misunderstandings about asthma and its treatment, patients not seeking advice from healthcare professionals when needed, and miracle cures or dangerous ideas." "Superusers could find themselves under moral pressure to respond to risk-indicating or inappropriate posts and reporting posts to moderators, which could cause at times cognitive stress." [REWARDED BY HELPING OTHERS] [OPPORTUNITY TO HELP OTHERS] [MISUNDERSTANDINGS] [MISINFORMATION] [MORAL PRESSURE TO RESPOND]
Joglekar, S., Sastry, N., Coulson, N. S., Taylor, S. J. C., Patel, A., Duschinsky, R., Anand, A., Evans, M. J., Griffiths, C. J., Sheikh, A., Panzarasa, P., & De Simoni, A.	2018	How online communities of people with long-term conditions function and evolve: network analysis of the structure and dynamics of the Asthma UK and British Lung Foundation online communities. https://doi.org/10.2196/jmir.9952.	Uncover and understand how these communities function and evolve, and the role that some users have in maintaining integration and cohesion.	Longitudinal network analysis of the structure and dynamics of the networks connecting users who write posts over time. [QUANTITATIVE]	N/A	"Superusers were defined according to their cumulative activity over the entire observation period." "Superusers represented a small minority (1%-5%) within both communities." "Superusers wrote a disproportionally large number of posts." Superusers "were more likely to provide than to seek advice." Superusers "committed a significant amount of their time to writing posts and targeting new users." [CONTRIBUTED MAJORITY CONTENT] [HELP GIVING OVER HELP SEEKING] [CONNECTING WITH NEW USERS] [WELCOMING]	"Superusers were responsible for a high proportion of the posting activity and the functioning of the communities." "Both communities and lines of communication within them were held together precisely by (superusers)." "Superusers preferentially replied to posts from peripheral users who were not equally well connected. In doing so, they additionally facilitated tie formation between users." "Superusers not only play a topologically important role in the communities, but they are also likely to provide the expertise needed to answer queries" "superusers, by posting "help-giving" posts, enabled other users to talk to each other, thus facilitating the formation of ties." [INTEGRAL TO COMMUNITY FUNCTIONING] [FACILITATE COMMUNITY COHESION] [CREATES INFORMATION RICH ENVIRONMENT] [FACILITATES COMMUNITY ENGAGEMENT]	"Superusers gradually became "experts" providing others with advice and support." Superusers are "highly connected users" alluding to social connectedness as an impact. [CULTIVATES EXPERTISE] [SOCIAL CONNECTIONS]
van Mierlo, T.	2014	The 1% rule in four digital health social networks: an observational study. Journal of Medical Internet Research, 16(2), e33–e33. https://doi.org/10.2196/jmir.2966	Determine if the 1% rule applies to moderated Digital Health Social Networks designed to facilitate health behaviour change.	An observational study. [QUANTITATIVE]	N/A	Superusers were defined as the top 1% of users who posted most frequently "with Superusers generating 59.0%-75.0%" of the content. [CONTRIBUTED MAJORITY CONTENT] [HIGHLY FREQUENT POSTERS]	"Superusers generate the vast majority of traffic and create value, so their recruitment and retention is imperative for long-term success." [FACILITATES COMMUNITY ENGAGEMENT] [FACILITATE FORUM INTEREST]	N/A

Table 2 shows the overarching concepts derived from the five key background papers that are used in the initial conceptual framework. The preliminary codes that informed these overarching concepts are also listed to aid decision transparency. Coding collation was an iterative process and was conducted with the understanding that the initial framework would evolve several times as the literature review data was synthesised.

Table 2

Overarching concepts derived from the five key background papers

Preliminary Codes	Overarching Concept
Concept: Health Forum Superuser	
Self-determination theory	Seeks Autonomy, Seeks Competence, Seeks Relatedness.
Help giving over help-seeking; rewarded by helping others; Altruism.	Altruism
Concept: Health Forum Superuser Impacts on Online Health Forums	
Catalyses engagement; facilitates engagement; facilitates forum interest.	Catalyse engagement
Contribute majority content; integral to community functioning; sustain activity.	Sustain activity
Welcoming; Facilitates community cohesion; Connecting with new users; Adaptive communication/mirroring; Consumer/carer model of recovery.	Create supportive environment
Highly frequent posters; Signposting; Help-giving boundaries	Create informative environment

Concept: Online Health Forum Impacts on Health Forum Superusers	
Positive: Social connections	Social connections
Positive: Opportunity to help others; Cultivates expertise	Opportunity to help
Negative: Misinformation	Misinformation
Negative: Misunderstandings	Emotional distress
Negative: Moral pressure to respond	Peer-response burden

Step 3: Additional elements of the conceptual framework originating from a PPI group meeting

Some elements of the conceptual framework were informed through discussion with PPI members on (1) the priorities for superuser research, (2) what makes someone a superuser, and (3) what PPI members believed to be the benefits and challenges facing such users. Table 3 details these additional overarching concepts and provides further information on how those concepts were selected. Please note: Some of the initial concepts were informed by both the key background literature and input from PPI advisors.

Table 3

Additional elements of the conceptual framework originating from a PPI group meeting

Notes From PPI Meeting Discussion	Overarching Concept

Concept: Health Forum Superuser	
PPI advisors collectively believed people may become superusers because they seek discussions with people who understand them and their experiences.	Seeks Relatedness
One PPI advisor suggested that the stigma of health and mental health conditions could push someone to become an online forum superuser.	Stigma
PPI advisors collectively agreed that a lack of social support at home and in the community could contribute to someone becoming an online forum superuser.	Inadequate social support
PPI advisors collectively discussed how lived experience of a physical or mental health condition would likely be the primary factor in someone becoming a health forum superuser.	Health condition
One PPI advisor talked about how health conditions isolate you from those around you, and the group collectively agreed that isolation is likely a critical factor in someone using health forums to the point that they are considered a superuser.	Isolation
Concept: Online Health Forum Impacts on Health Forum Superusers	
The PPI advisor who suggested stigma could push someone to become an online forum superuser also suggested that engaging with peers frequently in online forums could help to reduce the stigma felt. This comment resonated with the other PPI advisors.	Reduced stigma
Two PPI advisors discussed how their own use of online health forums had sometimes felt triggering and that certain content, comments and conversations could be very upsetting. This discussion led to the	Emotional distress

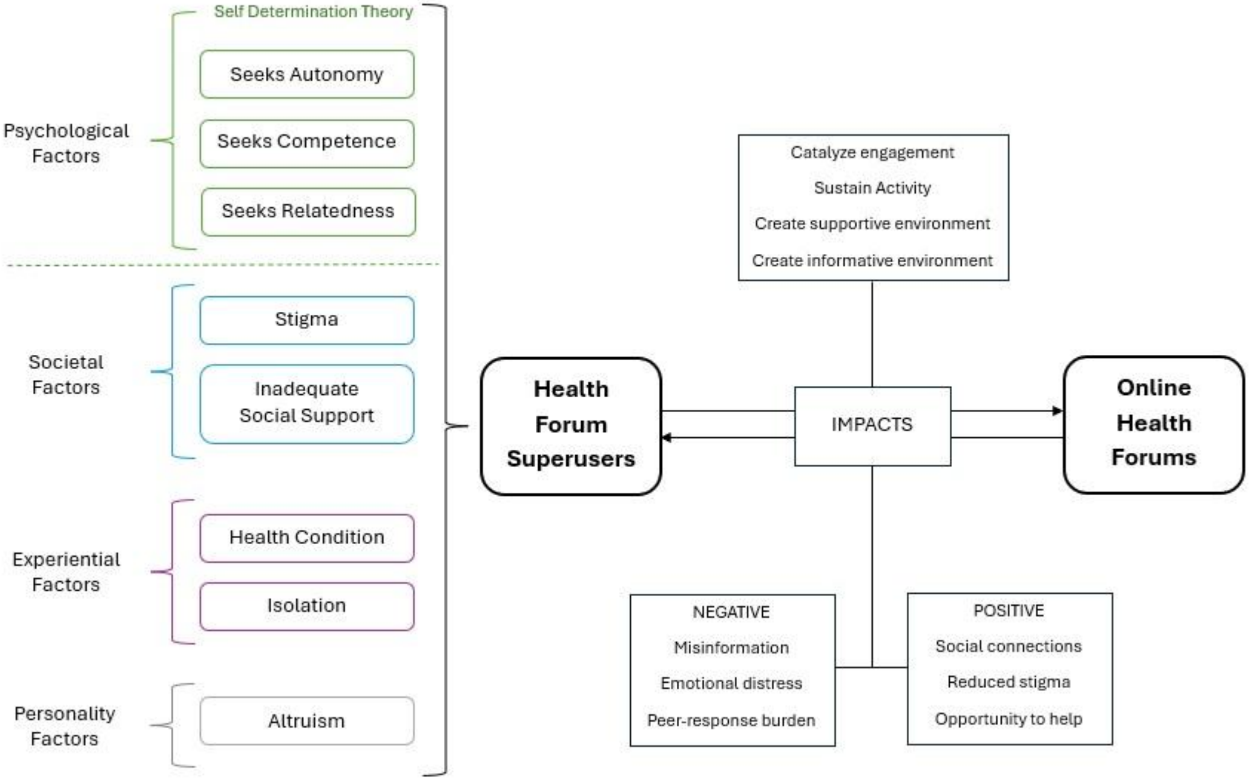
suggestion that people who spend a lot of time in online health forums might sometimes risk feeling more emotional distress. One PPI advisor suggested that some superusers might sometimes feel a sense of duty to respond to their peers, especially if they are distressed. While the members of the PPI group did not relate to this experience personally, all agreed that it could be a challenge for some frequent forum users.	Peer-response burden

Step 4: Creating the initial conceptual framework

Figure 1 presents an early iteration of the conceptual framework that combines insights from the key background papers and PPI advisor insights.

Figure 1

An early iteration of the conceptual framework

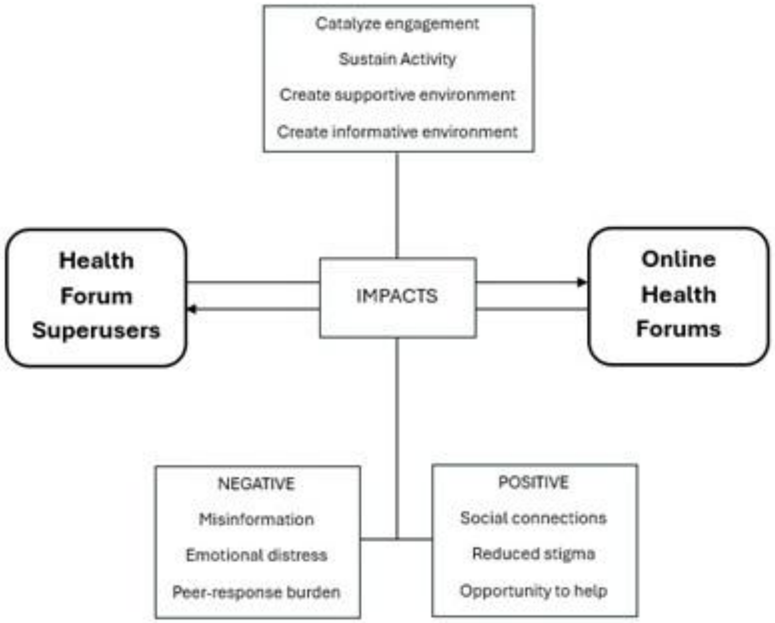


Step 5: Refining the initial conceptual framework

After contemplation and discussion with a second reviewer (JF), a decision was made to refine the initial conceptual framework and frame its focus on the primary review question: “What is known about the bidirectional impacts of superusers and OHFs?” While the two secondary review questions will be fully addressed within the results section of the review, this change will allow for a more comprehensive and nuanced exploration of the bidirectional impacts of superusers and OHFs within the framework itself without the risk of over-complication. Figure 2 presents the refined early iteration of the conceptual framework.

Figure 2

A subsequent early framewor



Appendix F: Data Charting, Coding and Theme Generation

During the data charting stage, the primary reviewer compared key study characteristics and findings and coding them according to the patterns, similarities and differences found. Codes were then clustered into distinct categories, and themes were derived from these categories.

Superusers Impact on Health Forums

Based on data extracted from the publications on the bidirectional impacts of superusers and online health forums, the reviewer established a total of eleven unique codes relating to superusers' impacts on health forums. Table 1 details the code names, definitions, and publications within which the codes are grounded.

Table 1

Codes relating to the impact of superusers on health forums

Code	Definition	Literature grounding
Responsible for forum cohesion	With high levels of connection to new and existing forum members, superusers bring people together and strengthen community relationships.	Cobb et al., 2010 De Simoni et al., 2018 Deccache et al., 2019 Healey et al., 2014 Joglekar et al., 2018 McCosker., 2018 Yang et al., 2019 Zhao et al., 2014
Creates an emotionally supportive environment	Superusers contribute more emotionally supportive messages than other forum members, fostering a sense of support.	Biyana et al., 2014 Carron-Arthur et al., 2016 De Simoni et al.. 2020 Deccache et al., 2019 McCosker 2018 Van Uden-Kraan et al., 2009 Vydiswaran & Reddy 2019 Willis 2016 Yang et al 2014

Creates informative environment	By providing high levels of information within health forums, superusers shape the health information accessed by others and ensure rapid and efficient dissemination.	Cobb et al., 2010 De Simoni et al., 2020 Dias et al., 2012 Heather et al., 2014 Lawless et al., 2022 O'Neill et al., 2014 Wu et al., 2016 Yang et al., 2019
Catalyse engagement	Superusers encourage, facilitate and maintain the participation of other users within the forum.	Carron-Arthur et al 2015 De Simoni et al 2018 Deccache et al 2019 Gopalsamy 2017 Healey et al 2014 Willis 2016 Yang et al 2019
Sustains forum activity	Superusers ensure consistent participation by providing frequent and regular forum content.	Carron-Arthur et al., 2015 Carron-Arthur et al., 2016b Deccache et al., 2019 Gopalsamy 2017 Griffiths et al., 2017 Joglekar et al., 2018 Van Mierlo et al., 2012
Creates welcoming environment	In communicating with new and poorly connected forum users, superusers ensure more members feel welcome within health forums.	De Simoni et al., 2018 Dias et al., 2012 Healther et al., 2014 Lawless et al., 2022
Majority content generation	Superusers are responsible for the majority of posts on health forums; these posts include starting new threads and responding to existing ones.	Deccache et al., 2019 Healey et al., 2014 Van Mierlo et al., 2012
Encourages a proactive health community	Superusers play crucial roles in persuading other forum members to adopt health behaviours, which helps create health communities focused on	De Simoni et al., 2018 Lawless et al., 2022 Vydiswaran & Reddy 2019 Willis .,2016

	health management or recovery.	
Stimulates forum growth	As superusers grow in numbers, contributing content and engaging with other members, forums become more valuable and attract more users.	Deccache et al. 2019 Griffiths et al., 2017 Van Miero., 2014
Enforces rules/social norms	While forum superusers and forum moderators are different, superusers often intervene to flag inappropriate posts and stop unwanted behaviours.	De Simoni et al., 2018 Lawless et al., 2022
Integral to early community development	Superusers play important roles in the early development of online forums due to their high activity levels and central social roles.	Carron-Arthur et al., 2016

A total of three themes were derived from these codes. Table 2 below details how original codes were clustered together to create the themes.

Table 2

Themes relating to the impact of superusers on health forums

Original codes	**Theme**
Catalyses engagement Majority content generation Sustains forum activity Stimulates forum growth Integral to early community development	Superusers are integral to forum engagement and growth
Creates a welcoming environment Creates an emotionally supportive environment Creates an informative environment	Superusers create emotionally supportive and informative online environments
Enforces rules/social norms Responsible for forum cohesion	Superusers drive community cohesion and motivate proactive health behaviours

Encourages a proactive health community	

Health forums' impact on superusers

The reviewer established a total of sixteen unique codes relating to the impacts online health forum use has on their superusers. Table 4 details the code names, definitions, and publications within which the codes are grounded.

Table 4

Codes relating to the impact of online health forums on superusers

Code	**Definition**	**Literature grounding**
Opportunity to help	Health forums provide their superusers with a unique opportunity to help those with shared lived experience.	Bayen et al., 2021 Biyani et al., 2014 De Simoni et al., 2020 Deccache et al., 2019 Healey et al., 2014 Van Uden-Kraan et al., 2009 Vydiswaran & Reddy 2019 Willis 2016 Wu et al., 2016 Yang et al., 2014
Social connections	Health forums allow their superusers to build strong relationships with their peers and to become socially supportive companions in the process.	Bayen et al., 2021 Cobb et a., 2010 Carron-Arthur et al., 2016 De Simoni et al 2018 Dias et al., 2012 Healey et al., 2014 McCosker 2018 Van Uden-Kraan et al., 2009
Opportunity to be a role model	Health forums provide superusers with a platform to provide advice and guidance to others based on their own lived experiences and acquired knowledge.	De Simoni et al. 2018 Lawless et al., 2022 McCosker 2018 Vydiswaran & Reddy 2019 Yang et al., 2019
Leadership role	Health forums enable superusers to take on leadership roles where they	Carron-Arthur et al., 2016b De Simoni et al 2018 Joglekar et al., 2018

	direct the tone and quality of conversations and provide guidance to others that is respected.	McCosker 2018 Zhao et al., 2014
Opportunity to share lived experience	Health forums enable their superusers to share their lived experience of a health condition with their peers.	Lawless et al., 2022 Vydiswaran & Reddy 2019 Willis 2016
Gains validation	Through conversations in online forums, superusers gain support and understanding from others, which validates their experiences.	De Simoni et al. 2020 McCosker 2018
Gains recognition	Other users acknowledge the authority and legitimacy of superusers' forum contributions, thereby giving them a sense of recognition.	Van Uden-Kraan et al, 2009 McCosker, 2018
Gains insight	Through their use of online health forums, superusers seek information that allows them become better informed.	De Simoni et al 2020 Van Uden-Kraan et al 2009
Positive health outcomes	The high-frequency use of online health forums can impact measurable health outcomes for superusers.	Geramita et al., 2018 Litchman et al., 2018
Gains confidence	Superusers of online health forums increasingly acquire confidence.	De Simoni et al., 2020
Increased self-esteem	The more superusers support others, the more likely they are to experience increases in self-esteem.	Zhao et al. 2014
Increased emotional well-being	Superusers who were less active in processing and expressing emotions are more likely to experience increased emotional well-being associated with high-frequency forum use over time.	Batenburg, 2014.
Negative health outcomes	Superusers may experience more negative health	Fledhege et al., 2021

	outcomes when they are high-frequency users of forums that promote an anti-recovery stance.	
Peer response burden	Superusers may experience more stress and worry following interactions with other members experiencing emotional distress.	De Simoni et al., 2020
Exposure to negativity	Superusers of online health forums are more frequently exposed to negative messages online.	De Simoni et al., 2020
High self-efficacy	Superusers of online health forums can have higher self-efficacy than other users. However, it is not apparent whether high-frequency use improves self-efficacy or if self-efficacy leads to high-frequency use in the first place.	Chen et al., 2020

A total of 2 themes were derived from these codes. Table 5 details how original codes were clustered together to create the themes.

Table 5

Themes relating to the impact of health forums on superusers

Original codes	**Theme**
Increased emotional well-being Increased self-esteem Gains confidence High self-efficacy Positive health outcomes Negative health outcomes Exposure to negativity Peer response burden	Forum “super use” can lead to impacts in both physical and psychological health.

Social connections Opportunity to help Opportunity to share lived experience Gains insight Leadership role Gains validation Gains recognition Opportunity to be a role model	Forum “super use” increases social connections and status

Appendix G: Participant Recruitment Flyer

Are You an Adult Who Regularly Uses Online Mental Health Forums?

SEEKING PARTICIPANTS FOR MENTAL HEALTH PHD RESEARCH STUDY

"Superusers Engagement Experiences in Online Mental Health Forums"

⇒ The **PURPOSE** of this study is to learn more about forum superusers' overall experiences, motivations, and support needs.

⇒ The **FINDINGS** from this study can help organisations, like the NHS and other third-sector organisations, understand how best to involve, train and support superusers in the mental health forums they create.

Are you a forum Superuser?

Superusers spend a lot of time (at least 1 hour each week) talking to other people in online forums.

Some superusers provide information, advice, and support to their peers by creating new forum posts.

Other superusers help people to feel connected by responding to existing posts.

Some superusers go out of their way to make new forum members feel welcome.

Study Participation

Participation involves a 60-minute conversation via Microsoft Teams or Telephone. Each participant is paid a £30 "Love2Shop" voucher for their time.

Get in Touch!

To learn more about taking part in this study, please contact Catherine Liberty:

c.liberty@lancaster.ac.uk

What is an online forum? This might be a websites message board, a charity-based online community, a discussion-focused website (e.g., Reddit), or a group hosted by a social network (e.g., Facebook Groups).

Health & Medicine | Lancaster University

Appendix H: Twitter Template

I'm looking for adults who regularly use online mental health peer support forums to take part in my PhD research. If you're happy to be interviewed on your experiences, please get in touch! :)

#mentalhealth, #mentalhealthresearch, #forum #research #researchparticipantsrequired

(Recruitment flyer from Appendix G attached as image)

Appendix I: Email Response to Initial Expressions of Interest

Dear (Name),

Thank you for your email.

I am so happy to hear that you are considering participating in my research study on the experiences of superusers in online mental health forums.

You are suitable to participate in this study if you are:

1. An adult over the age of 18.
2. Someone who identifies as a mental health forum superuser (according to the description you read in the recruitment leaflet).
3. Someone who uses mental health forums because they have a mental health problem (or had a mental health problem in the past) or care for someone who has a mental health problem (or had a mental health problem in the past).

So we can determine if this research is a good fit for you, I'd like to invite you to attend a quick 5-10-minute screening chat with me. During this chat, I will talk a little about the study requirements and ask you to confirm your eligibility.

If you are happy to proceed:

1. To arrange a mutually convenient time to chat, please respond to this linked "Doodle Poll" to let me know which times and dates work for you?

2. Please let me know if you are happy for our chat to happen via Microsoft Teams or prefer a telephone-based chat?

In the meantime, if you have any further questions about this research study or the interview process, please do not hesitate to contact me via email.

Best wishes,

Catherine Liberty | She/Her/Hers | Postgraduate Researcher

www.lancaster.ac.uk

Appendix J: Eligibility Screening Protocol

Introduction

Hi (Name), it's nice to meet you today. I'm Catherine Liberty, a postgraduate researcher at Lancaster University, undertaking my PhD in mental health.

I'm so happy to hear that you're interested in participating in my study on Superusers' Experiences in Online Mental Health Forums. I appreciate your interest and your time.

Today's video chat/telephone call (delete as appropriate) will be brief, just around five to ten minutes, and the purpose of this chat is to see if my study is a good fit for you, given your personal experiences with using online mental health forums.

We won't be recording anything today. I will not be making notes or collecting any data from you. So, you can think of this more as an informal chat. You can leave this screening anytime, skip questions, pause, or stop altogether. And at the end, if it does seem you meet the eligibility criteria to take part in my study, you still have a choice as to whether you go ahead.

Do you have any questions about what I've just said?

So, I'd like to run through five basic questions to help me see if this study is right for you. Is that okay with you?

1. Can you please confirm your age?
2. Do you regularly use online mental health forums?
3. How often would you say you use online forums? (Hours/days per week)
4. Without giving names or details, what types of forums are you using? (e.g., website message boards, charity-based communities, Facebook Groups, Sub-Reddit).
5. Do you use these forums because you or someone you support is experiencing or have previously experienced mental health problems?

According to responses:

1. **Eligible.**
   Based on your answers, it sounds like you would be an excellent fit for this study. With your permission, I would like to send you some information on this study that you can read in your own time to decide whether you'd like to participate. Do you permit this to be sent?

   Thank you very much for your time today (Name). If you have any questions, please do reach out via email. Are you happy for us to end the call at this time?

2. **Not Eligible**
   Based on your answers today, it sounds like this research isn't a great fit for you. This is because…

(Example responses according to question)

1. Participants must be over the age of 18.
2. You shared that you only use online mental health forums infrequently/ you shared that the forums you use regularly are not mental-health oriented.
3. You have indicated you use online mental health forums for less than one hour each week, which unfortunately does not fit in with the needs of this study.
4. While you shared you are using the internet for support, you mentioned that this is not specifically via an online forum.
5. You mentioned using forums for a reason other than seeking personal support or support as a carer of someone with mental health problems. Unfortunately, this means the study is not a good fit for you.

While I am sorry we cannot move to the next stage, I want you to know I appreciate your time and interest today. Do you have any further questions or comments (name?) Are you happy for us to end the call at this time?

Appendix K: Participant Information Sheet

Participant Information Sheet

Superusers' Engagement in Online Mental Health Forums: A Reflexive Thematic Analysis

Thank you for showing an interest in participating in this study. My name is Catherine Liberty, and I am conducting this research as a postgraduate student in the Mental Health PhD programme at Lancaster University, Lancaster, United Kingdom.

Before you decide to participate in this study, it is important that you understand the purpose of this research and what participating will involve. Please read the following information and think about whether you would like to take part. If you have any questions or need any further information, you can contact me directly via email: cliberty@lancaster.ac.uk

What is the study about?

This research will explore the experiences of superusers in online mental health forums. The aim is to learn more about what motivates people to become superusers of online health forums. I am also interested in finding out how superusers can be supported in their roles. I am hoping to interview a range of different people who identify as mental health forum superusers.

Why have I been approached?

You have been approached because you responded to a recruitment leaflet, indicating that you fit the description of an online mental health forum superuser.

Who can take part in this study?

Anyone who identifies as a superuser of a mental health forum (according to the description provided in the recruitment leaflet) can take part in this study as long as you are:

(1) An adult over the age of 18
(2) Use online mental forums because you experience a mental health problem (or have experienced a mental health problem in the past) or care for someone with a mental health problem (or who has experienced a mental health problem in the past).
(3) Understand what is being asked of you and can explain this in simple terms at the start of your interview.

Do I have to take part?

No. It's entirely up to you to decide whether or not to participate. If you choose to participate now, you can still change your mind later. Even if you attend an interview, you will have one week to withdraw your data from the study. However, after this point, your data will be anonymised, analysed and incorporated with other participants' responses so it can no longer be removed.

What will I be asked to do if I take part?

If you decide to take part in this research, first, you will be asked to complete an online form where you provide your consent to participate. You will also be asked to complete an online demographic questionnaire, which asks some questions about your personal characteristics. Then, you will be invited to attend a one-off interview with me (Catherine Liberty). You can choose whether this interview occurs via Microsoft Teams or via telephone. Your interview will be audio-recorded and later transcribed and analysed as part of my PhD Research. Your interview will NOT be video recorded, even if we connect via video call using Microsoft Teams. During the interview, you will be asked to answer questions about your general experiences as an active online mental health forum user. You will also be asked what motivates you to use online peer forums and what challenges you may face in this role.

Will my data be identifiable?

The data collected for this study will be stored securely in the university-approved secure cloud storage area that complies with UK data protection laws. All data files on the computer will be encrypted, and computers will be password protected. Only me and my research supervisors will have direct access to this data.

- Your consent form and demographic questionnaire will be collected via Qualtrics, which is a password-protected secure online platform.
- Interviews will be audio recorded using an encrypted and password-protected digital voice recorder.
- Audio recordings will be destroyed as soon as a typed version of your interview has been created.
- The typed version of your interview will be made anonymous by removing any identifying information, including your name.
- Direct quotations from your interview may be used in the reports or publications from the study, but your name will not be attached to them.
- All your personal information will be stored on Lancaster University’s secure cloud servers in a separate folder from your interview data.
- All your personal information will be destroyed at the end of the study.
- Your personal information will remain confidential. I will only break this confidentiality if you tell me something during our interview that suggests you pose an immediate risk of harm to yourself or others around you. If this happens, I will immediately inform my supervisory team and encourage you to contact the emergency services and/or a helpline or service in your area.
- Following data collection, you will have one week to withdraw your data from the study. After this point, your data will be anonymised, analysed and incorporated with other participants' responses so it can no longer be removed.

- In line with Lancaster University policy, your anonymous interview transcript will be saved on secure cloud servers at Lancaster University for up to 10 years. Under the General Data Protection Regulation (EU GDPR), you have the right to access personal data held about you, you can object to your personal information being processed, and you can amend inaccurate data. You also have the right to have data about you erased. However, these rights only apply in certain circumstances. If you would like to learn more about your rights regarding your personal data, please contact me via email to discuss this further.

Please note: Microsoft Teams uses an advanced level of software security and is suitable for discussing personal and sensitive topics. While no video conferencing software can prevent all phishing attempts and malware or ransomware attacks, data confidentiality breaches using Microsoft Teams are unlikely (but not impossible).

Will I be paid for my time?

You will be paid £30 in the form of a "Love2Shop" voucher for your time. This voucher will be emailed to you after you attend the interview. As you have read in this information sheet, you can decide to withdraw your data for up to one week after the interview takes place. Please note that withdrawing your data does not impact your payment. You will still be paid even if you choose to withdraw from the study.

What will happen to the results?

The results will be summarised and reported in a PhD thesis and will be submitted for publication in an academic journal. The results may also be shared in online articles and blog posts, presented at conferences and shared via social media accounts. No identifiable data will be included.

Are there any risks?

There are no immediate risks anticipated with participating in this study. However, sometimes talking about very personal experiences can cause emotional distress. If you experience any distress during or following participation, you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

While there are no direct benefits, you may find participating empowering as your insight can be used to help to support other people who use online forums. You may also find it cathartic to reflect on your experiences of becoming a forum superuser, and you may gain new insight into your experiences.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the primary researcher:

Catherine Liberty
Email: cliberty@lancaster.ac.uk
Tel: +44 7754166627
Alternatively, you may wish to contact the research supervisor:

Professor Fiona Lobban
Email: f.lobban@lancaster.ac.uk
Tel: +44 1524 593752

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Fiona Lobban
Email: f.lobban@lancaster.ac.uk
Tel: +44 1524 593752
Division of Health Research
Lancaster University
Lancaster
LA1 4YG

You can also contact:
Dr Laura Machin (Chair of the Faculty of Health and Medicine Research Ethics Council)
Email: l.machin@lancaster.ac.uk
Tel: +44 (0)1524 594973
Faculty of Health and Medicine
(Lancaster Medical School)
Lancaster University
Lancaster
LA1 4YG

Thank you for taking the time to read this information sheet.
Please take some time to consider the above points before deciding if you would like to participate.

Please reach out to the primary researcher if you have any questions or if there is anything you are not sure of. If you are happy to proceed, please email the primary researcher, who will inform you of the next steps.

What to do and who to contact in the event of distress

Should you feel distressed before, during or after taking part in this research, the following information can help:

- If you need somewhat urgent help and are already in contact with mental health services in your area, please contact them directly.
- If you are not in contact with mental health services, you may be able to receive assistance from your GP (UK) or primary care doctor.
- **If you face serious and immediate risk, please call the emergency services in your area.** For example, 999 in the UK, 112 in Europe, 911 in the USA or Canada, and 000 in Australia. If you do not know the emergency service number in your area, you can locate it via this link.

If you are in the United Kingdom

- If you are not in contact with mental health services, you may be able to receive assistance from your GP practice, your local out-of-hours GP or the accident and emergency department at your local hospital. You can visit http://www.nhs.uk to locate these services.
- If you are unsure of what help you need, you can call 111 to receive advice from the NHS.
- For someone to talk to over the phone: call Samaritans on 116 123
- To talk with someone via email: email jo@samaritans.org
- If you'd prefer support via text message: text the word "SHOUT" to 85258.

If you are in Another Part of the World

- You can find free, confidential support from a helpline, hotline, online chat service or text messaging service near you by searching at: https://findahelpline.com/
- You can also search for additional mental health resources in your area by searching at: https://checkpointorg.com/global/

Mental Health Support Websites

Mind - https://www.mind.org.uk

Rethink - https://www.rethink.org

Sane - https://www.sane.org.uk

Inspirited Minds - https://www.inspiritedminds.org.uk

Beat - https://www.beateatingdisorders.org.uk/

Bipolar UK – https://www.bipolaruk.org

Hearing Voices - https://www.hearingvoices.org

Black Minds Matter UK - https://www.blackmindsmatteruk.com

Making Space - https://www.makingspace.co.uk

The Canadian Mental Health Association (CMHA) - https://cmha.ca/

American Foundation for Suicide Prevention (AFSP) - https://afsp.org/

Family Caregiver Support - https://www.family-caregiver-support.eu

Carer Support Websites

Carers Federation - https://www.carersfederation.co.uk

The Carers Trust - https://www.carers.org

Carers UK - https://www.carersuk.org

Chill4 Us Carers - https://www.chill4uscarers.co.uk

Eurocarers - https://eurocarers.org/

Appendix L: Participant Consent Form

Participant Consent Form (to be digitised on Qualtrics for online access)

Participant Consent Form Lancaster University

Superusers' Experiences in Online Mental Health Forums: A Reflexive Thematic Analysis

Participant First Name:

Participant Initial of Surname:

Date:

Please read the following statements and click on the statements you agree with:

○ I have received and understood the study information about the project: "Superusers' Engagement in Online Mental Health Forums: A Reflexive Thematic Analysis."

○ I was given time to consider the research information sheet and have been able to ask questions about the study and received satisfactory answers.

○ I understand that my participation is voluntary and that I am free to withdraw at any time during this study. I also know that I can still withdraw my data from this study up until one week after my interview. If I withdraw from this study, my data will be removed.

○ I understand that I am free to stop participating in the study at any time without giving a reason.

○ When interviewed, I understand that I can also refuse to answer a question and ask to stop taking part at any time without having to explain.

○ I understand that my interview will be audio-recorded and transcribed and that data will be protected on encrypted devices and kept secure.

○ I understand that I will be paid for my time in the form of a £30 "Love2Shop" voucher that will be sent to me via email following the interview.

○ I understand that any decision to withdraw my data will not impact my payment.

○ I understand any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the researcher may need to share this information with their supervisor at the university and/or the police.

○ I understand that any information given by me may be used in future reports, academic articles, publications or presentations by the researcher, but my personal information will not be included, and all reasonable steps will be taken to protect my anonymity.
○ I understand that my anonymised data may be shared with other researchers involved in this study.
○ I understand that anonymised data will be kept according to University guidelines for a minimum of 10 years after the end of the study.
○ I understand that personally identifying information, including my name, address, phone number, and email address, will be stored securely and separately from the information I provide as part of this study.
○ I understand that personally identifying information will be permanently deleted once I am sent a debriefing email following the interview unless I request to receive a research summary, in which case my email address will be retained until the end of the project.
○ I confirm I am an adult over the age of 18.
○ I confirm that I use online mental health forums because I experience mental health problems or have experienced mental health problems in the past, or I care for someone who experiences mental health problems or who has experienced mental health problems in the past.
○ I agree to take part in the above study.
○ I agree to receive a summary of the research findings.

Signed: Please type your name into this box to confirm.

Name of researcher: Catherine Liberty

I confirm that the participant was allowed to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability.

I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Signed: (electronic signature)

Appendix M: Interview Scheduling

Email With Interview Time, Date & Method Details

Dear (Name),

Thank you for letting me know the times and dates that would work best for you to meet. (SPECIFIED DAY, DATE, TIME) would work great for me too.

Thank you for letting me know you are happy for our interview to take place via Microsoft Teams. I have sent you a calendar invite directly via Microsoft Teams. This invite will appear in your email inbox, and you can click "accept" via your email notification. If you are new to Microsoft Teams, you can view their started guide here:

https://support.microsoft.com/en-us/office/get-started-with-microsoft-teams-b98d533f-118e-4bae-bf44-3df2470c2b12

On the day of our interview, you'll need to join the meeting via your Microsoft Teams Calendar. If this process is new to you, this page on how to join a meeting will help:

https://support.microsoft.com/en-us/office/join-a-teams-meeting-078e9868-f1aa-4414-8bb9-ee88e9236ee4

Please ensure you have enough time (approximately 45-60 minutes) and a private space to connect to Microsoft Teams. You will also need access to a working microphone and webcam (or a suitable mobile device and the Microsoft Teams app).

OR

Thank you for letting me know the times and dates that would work best for you to meet. (SPECIFIED DAY, DATE, TIME) would work great for me too.

Thank you for letting me know you would prefer for our interview to happen over the telephone.

On the day of our interview, please ensure that you have enough time (approximately 45-60 minutes) and a private space to receive my phone call. I will call you on the phone number you have provided and said is suitable to contact you in your demographic questionnaire.

If you need to change the phone number that I contact you on, please email me the updated contact details.

If, for any reason, I can not get through at our scheduled interview time, I will try to call again five minutes after and ten minutes after our scheduled time.

If you have any further questions, please do not hesitate to get back in touch.

Kind regards,

Catherine Liberty | She/Her/Hers | Postgraduate Researcher

www.lancaster.ac.uk

Appendix N: Interview Topic Guide

Introduction

Hi (Name), thank you for agreeing to be interviewed on your experiences as an online mental health forum superuser today. I'm so happy to have you here! As you know from our previous correspondence, my name is Catherine Liberty, and I'm a postgraduate researcher at Lancaster University, where I am undertaking a PhD in mental health.

The Research Purpose

This study aims to learn more about forum superusers' experiences, motivations and support needs. The findings from this study can help organisations like the NHS, mental health charities and other organisations that have online forums to understand how best to involve, train and support forum superusers in the future.

What Will Happen Today

Today, if you're still happy to proceed with the interview, I would like to talk with you for around 45-60 minutes about your general experiences using online mental health forums. I'd like to ask you what motivates you to use forums, and I'd love for us to talk a little about what types of challenges you might experience in this superuser role.

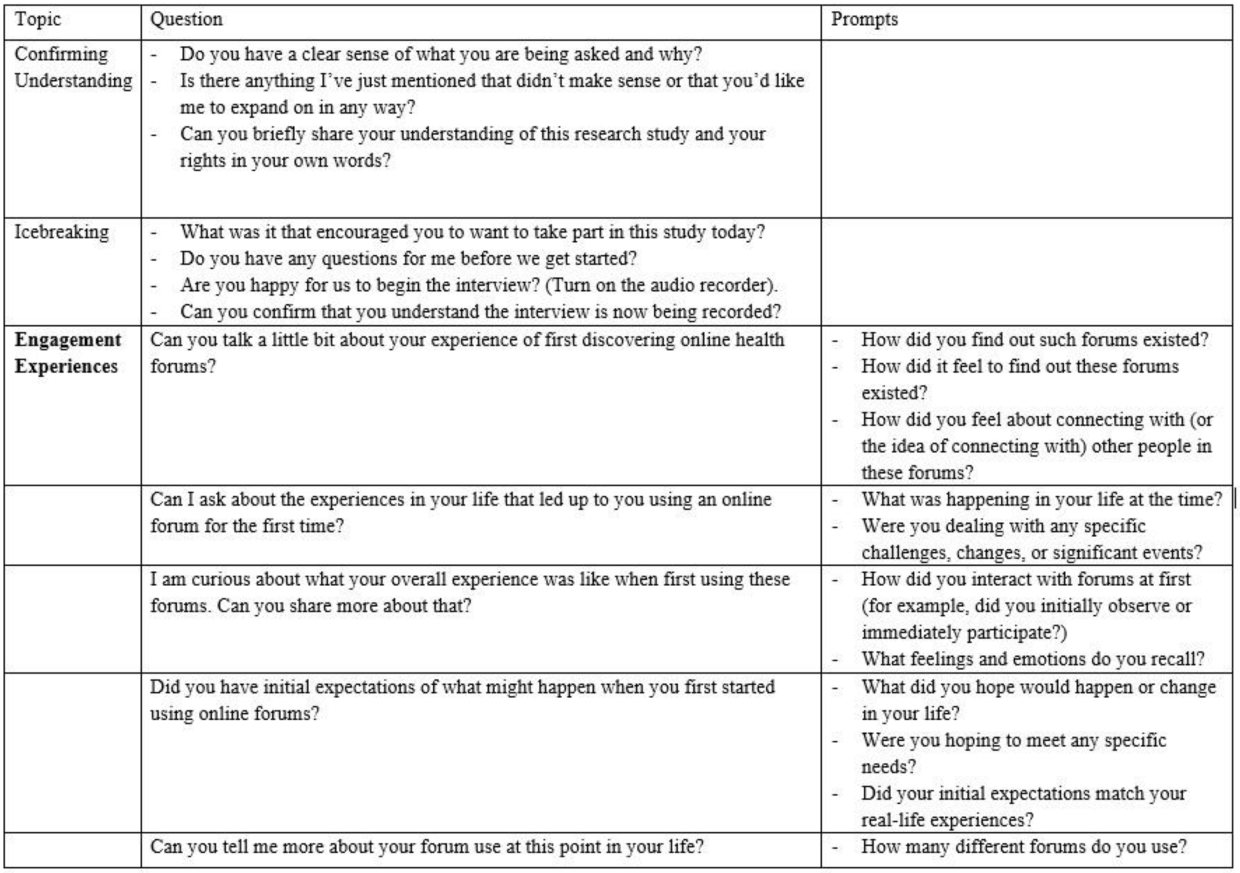
Participants Rights

Through the interview, please remember that you are here voluntarily. During the interview, you can ask to pause, you can request to stop, and you can refuse to answer a question without needing to give me an explanation. While we are talking to each other, I will record the audio from this discussion using a password-protected and encrypted audio recorder (if the interview is via video call, the recording device is shown to the participant at this point). Anything we talk about today will be kept confidential and anonymous. The only exception is if you were to tell me something that indicated you were at risk of harm to yourself or someone else, in which case I would need to share details of what you have said with my supervisory team.

The things you share with me today will be used in future reports, academic articles, and presentations, but there will be no way for anyone to link the things you share with me back to you personally. You will be paid a £30 "Love2Shop" voucher for your time today. This voucher will be sent to you via email. Once the interview is finished, you can still withdraw your data from this study until one week after your interview. And you will still be paid for your time, even if you do withdraw your data. After one week, your data will be anonymised, analysed and incorporated with other participants' responses so it can no longer be removed.

When Connecting via Microsoft Teams

Finally, we are using Microsoft Teams to connect today. Microsoft Teams uses an advanced level of software security and is suitable for discussing personal and sensitive topics. While no video conferencing software can prevent all phishing attempts and malware or ransomware attacks, data confidentiality breaches using Microsoft Teams are unlikely (but not impossible). If this makes you uncomfortable, please know you can withdraw from this research.



Topic	Question	Prompts
Confirming Understanding	- Do you have a clear sense of what you are being asked and why? - Is there anything I've just mentioned that didn't make sense or that you'd like me to expand on in any way? - Can you briefly share your understanding of this research study and your rights in your own words?	
Icebreaking	- What was it that encouraged you to want to take part in this study today? - Do you have any questions for me before we get started? - Are you happy for us to begin the interview? (Turn on the audio recorder). - Can you confirm that you understand the interview is now being recorded?	
Engagement Experiences	Can you talk a little bit about your experience of first discovering online health forums?	- How did you find out such forums existed? - How did it feel to find out these forums existed? - How did you feel about connecting with (or the idea of connecting with) other people in these forums?
	Can I ask about the experiences in your life that led up to you using an online forum for the first time?	- What was happening in your life at the time? - Were you dealing with any specific challenges, changes, or significant events?
	I am curious about what your overall experience was like when first using these forums. Can you share more about that?	- How did you interact with forums at first (for example, did you initially observe or immediately participate?) - What feelings and emotions do you recall?
	Did you have initial expectations of what might happen when you first started using online forums?	- What did you hope would happen or change in your life? - Were you hoping to meet any specific needs? - Did your initial expectations match your real-life experiences?
	Can you tell me more about your forum use at this point in your life?	- How many different forums do you use?

		- What caused you to gravitate towards these specific forums? - Is there anything, in particular, you looked for before joining these forums? - Can you describe a typical week of peer forum use?
	Thinking about the time you spend talking with others online, can you tell me more about your conversations?	- What types of issues do you like to talk about? - Does the type of forum impact the kinds of conversations you have? - Does the presence of a moderator influence what conversations you have? - Do any past experiences impact the types of conversations you have? - What types of things encourage you to post in a forum? - What types of things discourage you from posting in forums?
	Can you talk about any differences between the amount of support you provide to others in forums and the amount of support you receive?	- Do you tend to start new forum topics or reply to existing ones? - How does it feel to ask for support from others? - How does it feel to provide support to others?
Motivations	What would you say motivates you the most to spend time in forums?	- What do you find most rewarding about connecting with others in forums?
	Can you talk about how spending time in online forums impacts your emotional well-being?	- How is your mood impacted? - How is your sense of belonging impacted? - Can you talk a little about how you balance forum use with self-care?

		- What's the best part about being a superuser?
	Can you think of a time when your forum involvement has changed or directed the conversation?	- Do you think your posts help others in any way? If so, how?
	Could you share an example of a particularly memorable or meaningful experience you've had in an online forum?	- How did this experience impact you? - How did this experience impact others? - Do you think this experience has impacted your posting behaviours since? If so, how?
	Some people have suggested superusers have very important and influential roles in forums. What do you think of that?	- What do you think of the term "superuser"?
Challenges	What would you say is the most challenging part of being a superuser?	- Is there anything particularly demanding about your regular interactions? - What emotional challenges have you faced when using forums?
	Could you share an example of a challenging experience you've had in an online health forum?	- Examples might include miscommunications, emotionally charged conversations, people seeking crisis support, dealing with misinformation, heated debates, hostility, rude comments and discussions around sensitive or triggering topics. - How did this conversation come about? - How did this conversation impact you and your relationship with others in the forum? - Do you think this conversation has impacted your posting behaviours? If so, how?
	Are there any times when you've felt overwhelmed by the responsibilities or obligations of being such a frequent forum user?	- Are there any specific parts of forum interaction that can cause you to feel overwhelmed?

		- Is it easy to notice when you're starting to feel overwhelmed? - Have you ever changed how you use forums because of feeling overwhelmed? - What have you found helps when you feel overwhelmed?
	What do you think about the support forums give their users, particularly their superusers?	- What types of support have you noticed? - What types of support are lacking/could help? - Have you ever reached out to forum moderators or other users for support? - If you run an online forum, what would you do, change or prioritise to make sure superusers users felt supported?
	If you ran your own online forum, what would you do to support your superusers?	- What type of impact do you think this could have?
Closing Questions	- Is there anything that came to mind through this interview that you'd like to talk about before we finish here today? - Were there any questions you felt you didn't get to address fully that you'd like to talk more about now? - I have asked you a lot of questions today. Are there any questions you would like to ask me?	
Closing Comment	We've reached the end of our interview; I want to thank you for your time. By sharing your experiences with me today, you've given me such important insight into the experiences of forum superusers. Once I have completed all of my interviews with forum superusers, I hope we can gain some really powerful insights into your experiences, motivations, and support needs so that future superusers can be supported in their roles.	
What happens next	Now I will take some time to analyse the things you shared with me in this interview, along with the interviews of other mental health forum superusers. I will look for shared themes, write up the information I find for publication and submit it as part of my PhD thesis.	

Research summary	Would you like to be sent a summary of the research findings? If so, I'll need to keep your email address until the summary is ready. Can you let me know if this is okay with you?
Ending	Thank you very much for your time today. Are you happy for us to now end the interview?

Appendix O: Participant and Researcher Distress Protocols

Participant Distress Protocol

Indication of distress	- The participant verbally indicates that they are experiencing psychological distress. - The participant exhibits non-verbal behaviours (e.g., crying, shaking, avoiding eye contact, changes in vocal tone) that indicate distress.
Stage 1 response	- Immediately announce that the interview is being paused. - Verbally affirm acknowledgement of distress (e.g., “You mentioned that you’re feeling… or “I noticed that you were showing signs of distress because…” - Gently invite the participant to discuss their feelings (e.g., “How are you feeling right now?” “What types of thoughts are coming up for you?”
Review	- If the participant says they are happy to continue, the interview may be resumed. - If the participant says they are not happy to continue or if they are unsure, announce that the interview is over and follow “stage 2 response”. - If the participant has disclosed something that indicates they pose an immediate danger to themselves or others, follow the “emergency disclosure” response.
Stage 2 response	- Explain to the participant that they will be withdrawn from the study for their safety and wellbeing. - Allow time for ongoing discussion of feelings. - Encourage the participant to access the support resources provided. - Remind the participant a follow-up debriefing email will be sent later that day. - End the video call only when the participant says they are ready.
Follow up	- Provide a follow-up email and support resources later that day.
Emergency Disclosure Response	- Announce that the interview is over. - Listen carefully to what is being said and reflect back on key phrases of what's been said to check understanding. - Offer immediate support and reassurance by encouraging the participant to access emergency support resources (encouraging them to call emergency services in their area or an emergency mental health hotline). - Immediately contact a member of the supervisory team via Microsoft Teams call to disclose what has happened and seek further advice. - Supervisory team to send follow-up debriefing email.

Researcher Distress Protocol

Before data collection	- Reflect on the potential psychological impact of hearing participants' lived experiences. - Decide how many interviews can be conducted each week (considering the potential for emotional exhaustion). - Complete reflexive journal. - Discuss plans and any concerns with the supervisory team.
During data collection	- Schedule supervision meetings following each interview. - Access external help if required (e.g. “Let’s talk” at Lancaster or a private counsellor).
Following data collection	- Arrange a debriefing session with the supervisory team if required. - Complete reflexive journal. - Access external help if required (e.g. “Let’s talk” at Lancaster or a private counsellor).
During data analysis	- Attend regular supervision meetings. - Access external help if required (e.g. “Let’s talk” at Lancaster or a private counsellor).

Appendix P: Participant Debriefing Email and Signposting

Dear (Name),

Thank you very much for meeting with me today to share your experiences as a forum superuser. Your insight is invaluable to this research project and will go a long way in ensuring future forum superusers have the support needed to flourish in their roles.

If taking part in the interview caused you to feel distressed in any way, you may find it helpful to reach out to the following sources of support: (additional details removed according to participants' location and whether they are an individual with lived experience of mental health problems or a carer).

- If you need somewhat urgent help and are already in contact with mental health services in your area, please contact them directly.
- If you are not in contact with mental health services, you may be able to receive assistance from your GP (UK) or primary care doctor.
- **If you face serious and immediate risk, please call the emergency services in your area.** For example, 999 in the UK, 112 in Europe, 911 in the USA or Canada, and 000 in Australia. If you do not know the emergency service number in your area, you can locate it via this link.

If you are in the United Kingdom

- If you are not in contact with mental health services, you may be able to receive assistance from your GP practice, your local out-of-hours GP or the accident and emergency department at your local hospital. You can visit http://www.nhs.uk to locate these services.
- If you are unsure of what help you need, you can call 111 to receive advice from the NHS.
- For someone to talk to over the phone: call Samaritans on 116 123
- To talk with someone via email: email jo@samaritans.org
- If you'd prefer support via text message: text the word "SHOUT" to 85258.

If you are in Another Part of the World

- You can find free, confidential support from a helpline, hotline, online chat service or text messaging service near you by searching at: https://findahelpline.com/
- You can also search for additional mental health resources in your area by searching at: https://checkpointorg.com/global/

Mental Health Support Websites

Mind - https://www.mind.org.uk

Rethink - https://www.rethink.org

Sane - https://www.sane.org.uk

Inspirited Minds - https://www.inspiritedminds.org.uk

Beat - https://www.beateatingdisorders.org.uk/

Bipolar UK – https://www.bipolaruk.org

Hearing Voices - https://www.hearingvoices.org

Black Minds Matter UK - https://www.blackmindsmatteruk.com

Making Space - https://www.makingspace.co.uk

The Canadian Mental Health Association (CMHA) - https://cmha.ca/

American Foundation for Suicide Prevention (AFSP) - https://afsp.org/

Family Caregiver Support - https://www.family-caregiver-support.eu

Carer Support Websites

Carers Federation - https://www.carersfederation.co.uk

The Carers Trust - https://www.carers.org

Carers UK - https://www.carersuk.org

Chill4 Us Carers - https://www.chill4uscarers.co.uk

Eurocarers - https://eurocarers.org/

If you find that you have any further questions or any concerns regarding your participation in this research, you can contact me via cliberty@lancaster.ac.uk, or you can contact my supervisor Professor Fiona Lobban directly if you would prefer at f.lobban@lancaster.ac.uk

As you have opted to receive a summary of the research project findings, you can expect to hear from me again around July-August 2024. After that point, I will permanently delete your email address to maintain your privacy.

OR

As you have not opted to receive a summary of the findings of this research project, I will now permanently delete your email address from my account, ensuring your ongoing privacy is protected.

Finally, please remember you will have one week from today to withdraw your data from the study. After this point, your data will be anonymised, analysed and incorporated with other participants' responses so it can no longer be removed.

Thank you again for sharing your valuable time to participate in this study. I greatly appreciate your involvement.

Kind regards,

Catherine Liberty | She/Her/Hers | Postgraduate Researcher

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