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## SOCIAL MEDIA, EATING DISORDERS AND RECOVERY

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## **Summary of the MRP portfolio**

**Section A** critically reviews relevant literature on the use of online communities in people recovering from an eating disorder. Research findings are presented thematically. Clinical and theoretical implications are discussed, including a discussion of the ways in which online communities may promote or hinder recovery from an eating disorder. Research gaps are identified, and directions for future research are presented.

**Section B** presents a thematic analysis of 15 participant's experiences of using social media during the process of recovering from an eating disorder. Data was collected from two sources: semi-structured interviews, and a sample of social media posts that participants identified as being helpful and unhelpful for their recovery. Four key themes were identified: motivating recovery, a supportive space to share and be open, maintains difficulties, and navigating social media. Results suggest that social media can promote or hinder recovery from an eating disorder in a variety of ways. Findings contribute to an emerging body of literature on the benefits and dangers of using social media.

**Section C** is an appendix of supporting material.

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## **ABSTRACT**

Online communities have the potential to support recovery from an eating disorder (ED). From a search of 4 electronic databases (Assia, PsycInfo, Pub Med and Web of Science), this review evaluated 23 studies on the use of online communities for people recovering from an ED. A number of online communities were identified in the literature, ranging from moderated online support groups to open social media platforms. Findings indicate that online communities can support recovery in a variety of ways: providing a platform for social support, promoting an identity centred around recovery, enhancing empowerment and agency in the recovery process, providing a medium to document recovery and track progress, and raising awareness about EDs in the wider population. It was also found that online communities may pose threats to recovery at times. Methodological quality varied and a large proportion of the studies were observational; future research should adopt alternative research designs, including experimental studies measuring the impact of using online communities, and qualitative research exploring experiences of interacting online with others recovering from an ED. There is also a need for further research exploring social media use in people with EDs, and how this may promote or hinder recovery.

Keywords: online community, online support group, social media, eating disorder, recovery

## INTRODUCTION

### **A brief introduction to eating disorders**

Eating disorders (EDs) are characterised by problematic eating behaviours, concern about body weight or shape, and high levels of distress and impairment (Murphy, Straebl, Cooper, & Fairburn, 2010). The prevalence of EDs is highest in females, often developing during adolescence or young adulthood (Stice, Marti, & Rohde, 2013). EDs have high rates of chronicity, associated physical health difficulties and sometimes death, due to medical complications and suicide (Wentz, Gillberg, Anckarsäter, Gillberg, & Råstam, 2009). Of all mental health difficulties, EDs have the highest rates of mortality (Mitchell & Crow, 2006).

Anorexia nervosa (AN) is characterised by the pursuit of maintaining a significantly low body weight, fear of eating and gaining weight, and body image distortion (American Psychiatric Association; APA, 2013). Bulimia nervosa (BN) is characterised by periods of binge eating (eating a large amount of food within a short time period, whilst feeling out of control), followed by extreme compensatory behaviours including vomiting, using laxatives, and excessive exercise (APA, 2013). These behaviours are often done in secret, creating feelings of shame and guilt (Fairburn & Harrison, 2003). Binge eating disorder (BED) is characterised by episodes of binge eating, which is not followed by extreme compensatory behaviours but, as with BN, is accompanied by feelings of guilt and distress (APA, 2013). When a person's symptoms do not fully fit the diagnostic criteria for AN, BN or BED, a diagnosis of 'other specified feeding or eating disorder' (OSFED; APA, 2013) may be given.

It is estimated that approximately 1.25 million people in the UK have an ED (Beat, 2017), and that 6.4% of adults in the UK exhibit some ED-related symptoms (Health & Social Care Information Centre, 2007). Lifetime prevalence rates for women, that is the proportion of women who have had an ED during their lifetime, are estimated at up to 4% for AN, 2% for

BN, 2% for BED, and 7.6% for OSFED (Micali et al., 2017; Smink, van Hoeken & Hoek, 2013). Although the majority of those with an ED diagnosis are female, estimates suggest that between 10 and 25% of EDs occur in males (Sweeting et al., 2015), and there is now increasing recognition that the experiences of males with EDs have been overlooked (Strother, Lemberg, Stanford, & Turbeville, 2012). Whilst EDs are found globally, they have been identified for longer within Western cultures and they were historically characterised as primarily affecting Caucasian individuals (Striegel-Moore & Smolak, 1996). However, there is little evidence that demographic factors (for example ethnicity, socioeconomic status or sexuality) specifically increase risk for an ED (National Institute for Clinical Excellence; NICE, 2017; Jacobi, Hayward, De Zwaan, Kraemer, & Agras, 2004). Nevertheless, cultural factors do play an important role in help-seeking and recognition of EDs, and professionals may be less likely to identify an ED if the person does not fit the stereotype for such cases (e.g., non-Caucasian or male; NICE, 2017).

National UK clinical guidelines promote psychological approaches for the treatment of EDs (NICE, 2017). Psychological interventions aim to reduce risk, encourage weight gain and/or healthy eating, reduce ED symptoms and related distress, and improve quality of life. A range of evidence-based interventions are recommended, including Cognitive Behavioural Therapy and family interventions (NICE, 2017). There is also an emphasis on early recognition, assessment and intervention for EDs, in order to optimise chances of full recovery and to prevent the ED from becoming chronic and enduring (NICE, 2017). Despite this, however, treatment of EDs remains a challenge and recovery rates are low, with approximately 50% of sufferers recovering after 5-10 years (Abbate-Daga et al., 2013; Bandini et al., 2006; DeJong, Broadbent, & Schmidt, 2012).

## **Eating Disorder Recovery**

The term ‘clinical recovery’ is used to describe clinically relevant changes in ED symptoms, often measured as failing to meet diagnostic criteria and/or improvement on self-report questionnaires (Bardone-Cone et al., 2010). Distinction is made between physical recovery (restoration of body weight and menstruation, and/or cessation of bingeing and purging) and psychosocial criteria for recovery (such as improved self-esteem and self-acceptance, reduced preoccupation with eating, weight and shape, and improved social relationships and social functioning (Bardone-Cone et al., 2010; Emanuelli, Waller, Jones-Chester, & Ostuzzi, 2012)). However, a lack of consensus on what constitutes recovery has led to inconsistencies in the literature and difficulties in measuring recovery and evaluating treatments (Noordenbos, 2011). There is also a distinction between ‘remission’ and ‘recovery’, with recovery typically used to describe sustained remission of symptoms over time (Kordy et al., 2002).

Qualitative studies exploring the personal experience of recovery highlight several important factors in the recovery process. Supportive relationships are often perceived as a driving force in recovery (Hsu & Crisp, 1992; Linville, Brown, Sturm, & McDougal, 2012). Self-acceptance, personal growth, resilience, autonomy, and positive relationships have been identified as fundamental criteria for ED recovery, in addition to a decrease in ED-related thoughts and behaviours (de Vos et al., 2007). Stockford, Kroese, Beesley and Leung (2018) reviewed 14 studies on the experience of recovering from AN, highlighting the process of identity change and self-acceptance. Many people with AN report feeling powerless, experiencing a diminished sense of self, and describe AN as taking over their life and identity. The process of recovery included developing insight into this and the consequences of AN, whilst committing to recovery. Supportive relationships, through which one felt

validated and accepted, enabled individuals to develop a sense of value, worth and identity that was separate from AN (Stockford et al., 2018).

### **Social identity, eating disorders and recovery**

Social identity theory proposes that a person's self-concept is developed through group identification, and that positive social identities are developed and maintained by favourably comparing one's in-group against an out-group (Tajfel, 1978; Tajfel & Turner, 1979). EDs have been explored within a social identity framework, considering the role of social identity in either promoting or hindering recovery (Ison & Kent, 2010). Many people with EDs hold on to a positively-valued illness identity, for example seeing the ED as a way to lose weight, feel in control, and receive protection from the outside world (Schmidt & Treasure, 2006).

Positive illness identity is particularly common with AN but applies to other EDs too (Serpell & Treasure, 2002). Responses from significant others, for example, positive comments about early weight loss, or care and concern from close others, may reinforce this positively-valued identity through promoting social acceptance or reducing feelings of isolation (Schmidt & Treasure, 2006; Marzola, Abbate-Daga, Gramaglia, Amianto, & Fassino, 2015). However, as the ED becomes more entrenched a perceived lack of understanding from others and/or the stigma that can be attached to EDs may motivate sufferers to seek support from alternative environments, including online pro-ED communities (Rich, 2006). Such connections can perpetuate ED behaviours through mutual social influence and identity-based support (Rich, 2006; Rodgers, Skowron, & Chabrol, 2012)

Ison and Kent (2010) proposed that a person's social identity can change during recovery from an ED. The ED is often perceived to bring pros and cons, with positive illness associations being more pronounced early on and negative perceptions of one's ED (e.g., physical health problems and psychological consequences) becoming more pronounced with

time. Furthermore, perceived stigma and negative out-group perceptions, including negative portrayals of EDs, may threaten the ED social identity and contribute to a corresponding shift in social identity that builds motivation to change, willingness to recover and access to treatment (Ison & Kent, 2010; Rich, 2006). Research suggests that recovery from an ED can be supported by successfully moving away from the illness identity and developing a new recovery-focused identity (Espindola & Blay, 2009; Federici & Kaplan, 2008). This involves developing alternative beliefs and values and renouncing disordered eating behaviours (Abbate-Daga, Amianto, Delsedime, De-Bacco, & Fassino, 2013; Bowlby, Anderson, & Willingham, 2015).

### **The social identity model of recovery**

The social identity model of recovery (Best et al., 2016) proposes that a sense of shared identity with others in recovery can facilitate the transition towards a recovery-focused identity. Originally applied to substance misuse, this model frames the process of recovery as a social identity transition; one's core identity shifts from being defined by a group membership whose values and norms centre around substance misuse to being defined by recovery. A shared sense of identity with others transitioning to a 'recovery' identity protects wellbeing through appropriate social support, sharing of coping strategies, and the collective development of an identity focused on recovery (Best et al., 2016; Dingle et al., 2015; Frings & Albery, 2015). Successfully adopting this new identity, whilst moving away from the illness identity, is associated with positive outcomes including improved engagement with treatment (Beckwith, Best, Dingle, Perryman, & Lubman, 2015) and reduced rates of relapse (Buckingham, Frings, & Albery, 2013).

Whilst there is initial support for the social identity model of recovery for EDs, research is in its early stages and the model is yet to be validated within the ED population. Although

relationships with similar others could be helpful, relying on such identities may keep individuals within the world of mental health and ED-related difficulties, preventing a full recovery (Best et al., 2016). Additional interpersonal factors are important to consider, for example the importance of maintaining and/or repairing close relationships with friends and family. At the intrapersonal level, the importance of promoting autonomy and building internal motivation to change (Casasnovas et al., 2007; Ryan & Deci, 2000; Prochaska & DiClemente, 1986) are also considered important factors in the treatment and recovery process. Recovery from an ED is often conceptualised as a personal journey, and remaining aware of this, whilst also considering the social identity processes which may be at play, is important to consider when thinking about the complexities of ED recovery.

### **Online communities**

Porter (2004, p. 1) describes an online community as “an aggregation of individuals who interact around a shared interest, where the interaction is at least partially supported and/or mediated by technology and guided by some protocols or norms”. Since online communities tend to form around a particular topic, they have the potential to develop around the topic of recovering from an ED, therefore providing a possible source of recovery identity. Active engagement with such communities could provide opportunities for social support, facilitate access to information and resources, and promote agency and motivation for recovery (Best et al., 2016; Read, Morton, & Ryan, 2015).

### **Pro-eating disorder online communities**

Research into online ED communities has tended to focus on how online connections with similar others maintains ED behaviours rather than promotes recovery (Riley, Rodham, & Gavin, 2009; Rodgers, Lowy, Halperin, & Franko, 2016). Pro-ED communities, often referred to as ‘pro-ana’ (pro-anorexia) or ‘pro-mia’ (pro-bulimia), promote a positive view of



EDs and endorse the illness as a lifestyle choice, thereby promoting a positively-valued illness identity (Dias, 2003; Giles, 2006). Such websites often include thin-ideal images referred to as ‘thinspiration’, and tips in the form of extreme weight loss behaviours and ways to conceal symptoms from others (Borzekowski, Schenk, Wilson, & Peebles, 2010; Juarascio, Shoaib, & Timko, 2010).

In a review of pro-ED websites, Rouleau and von Ranson (2011) concluded that although such websites have harmful aspects, social support is perceived as a key function. Reasons for visiting pro-ED websites are often a desire for support and understanding, which can help people with EDs relieve the loneliness they experience (Ransom, La Guardia, Woody & Boyd, 2010; Yeshua-Katz & Martins, 2013). It therefore feels important to explore how these same desires and benefits can be facilitated in a healthy, positive and recovery-focused way.

### **Recovery-focused online communities**

In contrast to pro-ED communities, those with EDs may also choose from a number of recovery-focused online support groups. Such groups may offer a powerful social intervention tool, allowing a network to develop that is centred around support and sharing of useful information and experiences (Ransom et al., 2010), thereby promoting a recovery-focused identity. Engagement in recovery-focused communities also has the potential to promote empowerment and to allow individuals to take responsibility for their lives and the management of their illness (McAllister, Dunn, Payne, Davies, & Todd, 2012). A range of empowering outcomes were experienced by patients with breast cancer, fibromyalgia and arthritis who participated in online patient support groups (Van Uden-Kraan et al., 2008), including feeling better informed, increased confidence in treatment, greater acceptance of their illness, increased optimism and sense of control, and improved self-esteem and social well-being. Computer-mediated communication is easy to access and often available 24/7; it

provides a level of anonymity which makes it an attractive platform for people with mental health difficulties as barriers against self-disclosure are reduced (Joinson, 2001; McKenna & Bargh, 2000).

The exponential rise in social media in the recent decade has also enabled the formation of social media communities centred around mental health and recovery (Berry et al, 2017; Lachmar, Wittenborn, Bogen, & McCauley, 2018). Social media platforms are more open and accessible than traditional websites due to the large number of public accounts and can therefore be difficult to moderate (Ging & Garvey, 2016). Such platforms are also more visual, including pictures and videos, and provide users with instant communication and feedback in the form of ‘likes’ and comments (Boyd & Ellison, 2007). Their relative recency and continued growth means that research in this area is still evolving.

### **Summary and aims**

Online communities for people with EDs have the potential to promote an identity centred around recovery and provide a platform for social support; this fits with social identity theory. The literature to date has tended to focus, however, on how online communities may maintain ED behaviour rather than promote recovery. The current review aimed to synthesise literature on the types of online communities used by people recovering from an ED. Specific questions were:

1. What types of online communities are identified in the literature as being available to support people during recovery from an ED?
2. How can these online communities support recovery from an ED?

## **METHOD**

### **Information sources**

A scoping exercise was carried out to get a sense of the literature and to identify key search terms. Electronic databases Web of Science, PsychINFO, Pub Med and ASSIA were searched using advanced search options. Additional papers were identified through hand searching references and through a Google scholar search.

### **Search terms**

The following search terms were used: ("eating disorder\*" OR anorexia OR bulimia OR "binge eating disorder") AND (online OR technology OR internet OR website OR forum OR blog\* OR "social media" OR "social networking site") AND (recovery OR "pro-recovery" OR "social support").

The search was limited to papers published in English. To maximise scope, the search was not filtered by time period. The search took place in October 2018.

### **Eligibility criteria**

#### ***Inclusion criteria***

Studies were included if they offered insight into how online communities may influence recovery from an ED. This included websites, online discussion forums or support groups, blogs, and social media platforms that had a focus towards recovery and support (i.e. not pro-ED). Studies were included if they examined the content of information within online communities, and/or if they explored the benefits, function, impact and dangers of using online communities for people recovering from an ED. To maximise scope, studies comparing recovery-focused communities to pro-ED communities were included.

### ***Exclusion criteria***

The following types of studies were excluded:

- Research solely focused on pro-ED or ‘thinspiration’ communities, as these are not considered recovery-focused
- Research not focused on how online communities are used by people with EDs
- Research solely investigating the use of online interventions, online self-help, or specialised ED smartphone applications for self-management (for example, online interventions that involved interaction with a computerised interface), as these are not focused on interacting with other individuals

### **The search**

The search results and screening process is illustrated in Figure 1. Following the search process, 23 papers were selected to be included in the review.

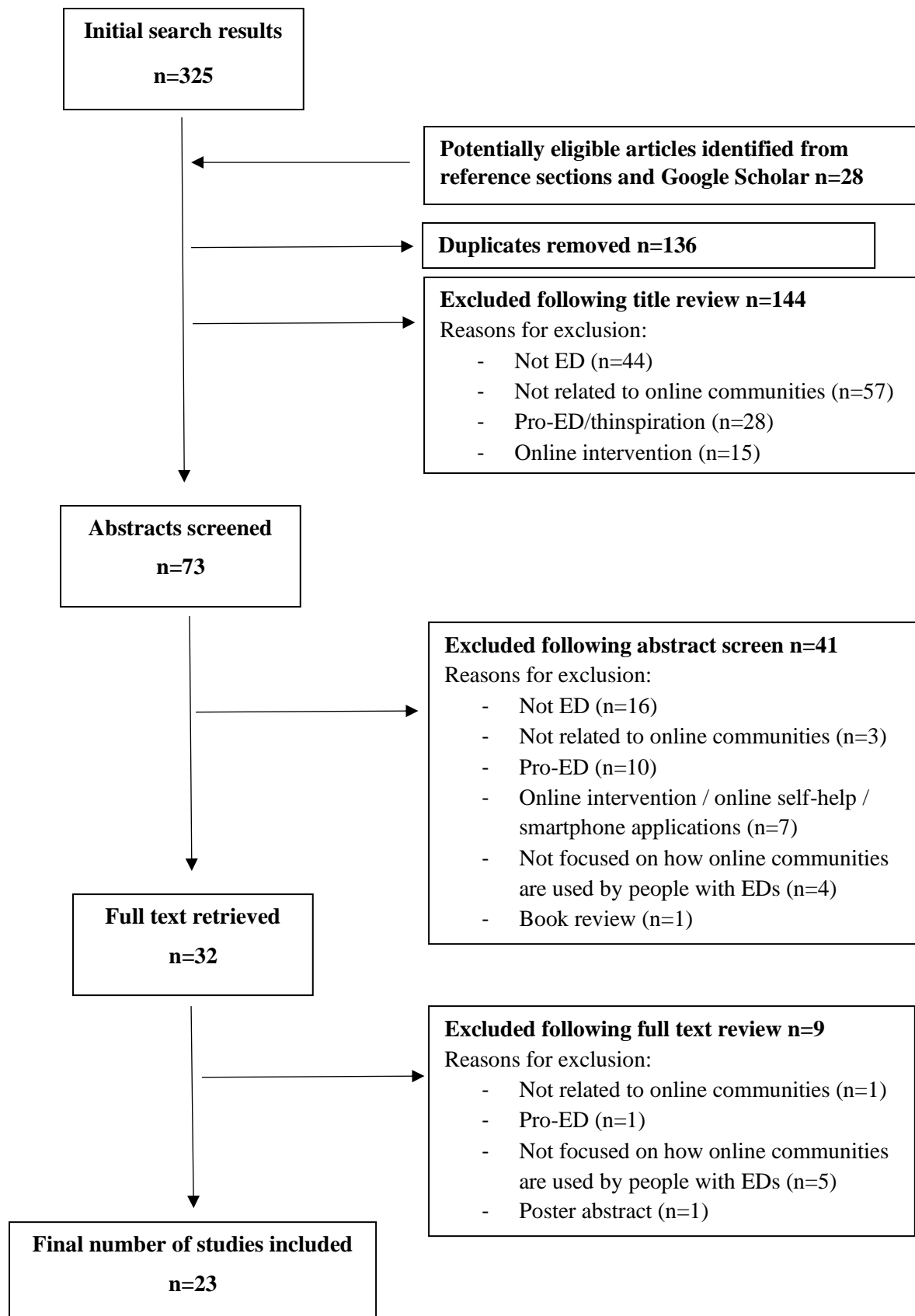


Figure 1. Flow Chart of the Search Process.

## **LITERATURE REVIEW**

The findings of the 23 studies, summarised in Table 1, will be described in relation to the two key questions this review sought to answer. Consideration of the methodological strengths and weaknesses of the studies are presented throughout, in order to synthesise the quality of the findings and to identify literature gaps.

Critical appraisal checklists were used to evaluate methodological quality: the National Institute of Health (NIH, 2014) quality assessment tool for observational cohort and cross-sectional studies, and the Critical Appraisal Skills Programme (Public Health Research Unit, 2006) checklist for qualitative research (Appendix A). A subset of the papers (20%) were cross-checked by a co-supervisor, which were in 97% agreement.

### **Q1. What types of online communities are identified in the literature as being available to support people during recovery from an ED?**

Three main categories of online ED communities were identified in the selected studies: moderated communities (some of which were closed); open access, unmoderated communities; and open, easily accessible social media platforms. These categories will be presented, followed by discussion of the methodological issues related online communities identified in the literature.

#### **Moderated online eating disorder communities**

Four studies focused on moderated online ED communities. Kendal et al. (2015) analysed a moderated online ED discussion forum for young people, located within a pro-recovery ED charity website. The forum stated that its aims were to facilitate peer support between young people who had eating concerns and were looking towards recovery. The forum was moderated by charity employees and was accessible 24/7. Inappropriate content was blocked,

for example, content containing triggers such as weight or foods. People were known by a Username only, and users were unable to contact each other privately, although a moderator who had concerns about a user could attempt to make contact by email. Aardoom, Dingemans, Boogaard, and Furth (2014) studied the website and e-community Proud2Bme, which was launched as a healthy alternative to pro-ED websites, aiming to provide a safe, positive and recovery-focused environment. It offered a range of information, personal stories and experiences, and a platform for interacting with others. Users could connect with peers, psychologists, dieticians and ‘expert’ recovered patients. Weekly moderated group chats focused on different topics took place, and all posts were moderated by employees. McNamara and Parsons (2016) and Hastings et al. (2016) also explored the use of moderated online ED support groups, where moderated, secure 90-minute online sessions were conducted weekly.

As summarised in Table 1, these online communities offered benefits for users and provided a platform for social support. Speculatively, moderated forums have advantages in that positive, recovery-focused communication is promoted and potentially harmful content limited. Users may, however, be aware of the censored nature of the forum and therefore feel less able to share experiences and open up if they know content may be removed. There is limited research into the effects of moderation, although there are indications that it promotes engagement (Syred, Naidoo, Woodhall, & Baraitser., 2014; Wise, Hamman, & Thorson, 2006). None of the above studies evaluated the impact of moderation; it is therefore unclear how moderation influenced what people posted or how they might have benefited from it.

### **Open, unmoderated online eating disorder communities**

Eight studies analysed the use of open-access, unmoderated online communities and support groups for people with EDs (Eichorn, 2008; Flynn & Stana, 2012; Keski-Rahkonen & Tozzi,

2005; McCormack & Coulson, 2009; Riley, Rodham, & Gavin, 2009; Walstrom, 2000; Wesemann & Grunwalk, 2008; Winzelberg, 1997). These online communities often had ‘bulletin boards’ or ‘threads’ related to different diagnoses or topics of discussion and were free to access without membership.

Unmoderated online groups have advantages in that communication takes place in a naturalistic setting that is not subject to censorship or moderation, thereby enabling users to talk freely about their experiences and the challenges of recovery. Despite being unmoderated, some support groups had explicit or implicit rules adhered to by members, for example, a ban on posting numbers or ‘tips’ (Riley et al., 2009), which were confronted by members when breached (Wesemann & Grunwalk, 2008). There were associated risks with unmoderated groups, however; some revealed content that overlapped with pro-ED content, which may have been experienced as ‘triggering’ of ED symptoms and unhelpful towards recovery (e.g. Eichorn, 2008).

### **Social media**

Online communities centred around recovering from an ED were also identified on various social media platforms, including Twitter, Facebook, Instagram, YouTube, Tumblr, Reddit and Flickr. Eleven studies focused on social media communities.

Facebook, the most popular social media platform worldwide (Statista, 2018), contains public or semi-public profiles where users can share information (posts, likes, comments) with other users with whom they share a ‘friendship’ connection. Facebook ‘groups’ can also be created with users who share a common interest. Teufel et al. (2013) identified a range of AN-related groups on Facebook, including pro-ana groups, as well as recovery-oriented groups that provided education and self-help, and groups that opposed the pro-ana mentality. Saffran, Kass, Taylor, and Trockel (2016) explored Facebook use in individuals who had received ED



treatment in a group setting (e.g. inpatient, day patient, outpatient group). Participants reported being 'Facebook friends' with an average of 10-19 treatment peers, and spending up to 30 minutes per day interacting with others from treatment or ED-related organisations.

Twitter allows users to create profiles from which they can 'tweet' text and follow the feeds of others' tweets, thereby creating an interconnected social network. A larger tweet conversation can be created by adding a hashtag to a key term, creating a community based on a shared topic of interest. Recovery-focused ED communities may therefore form on Twitter through the use of shared hashtags (Branley & Covey, 2017; Tan, Keuk, Goh, Lee, & Kwok, 2016).

Instagram is an image-based social media platform. Users share images with captions and/or hashtags with other users and can interact with others by 'liking' or commenting on photos. Several studies note how Instagram can be used to form recovery-focused communities where users document their experience of recovering from an ED and seek support from similar others (Eikey & Booth, 2017; LaMarre & Rice, 2017; Tan et al., 2016). Flickr is also an image-based platform, where users can post public and private data and 'favourite' images (Yom-Tov, Fernandez-Luque, Weber, & Crain., 2012). Tumblr is a microblogging service, which allows users to post text and multimedia content to a short-form blog (Branley & Covey, 2017; De Choudhury, 2015; Tan et al., 2016). YouTube is a video-based platform, where users can upload and view videos, and interact through liking, sharing and commenting (Holmes, 2017; Pereira et al., 2016). Reddit promotes 'throwaway accounts' and pseudonyms to enable anonymous discourse (Wang, Brede, Ianni, & Menazakis, 2018).

ED-related communities on social media are often dichotomised in the literature, as either pro-recovery or pro-ED (Branley & Covey, 2017; De Choudhury, 2015; Wang et al., 2018; Yom-Tov et al., 2012). Given the unmoderated nature of social media, the reviewed studies

suggest that pro-recovery and pro-ED communities often sit side-by-side, but that interaction tends to take place within and not between communities (Wang et al., 2018). However, De Choudhury (2015) notes how the pro-recovery community on Tumblr attempts to educate the pro-ana community of the health risks of AN. Nonetheless, Yom-Tov et al. (2012) suggest that pro-ana users who are exposed to pro-recovery content on Flickr are less likely to cease posting pro-ana information than those who do not receive such comments, therefore suggesting that pro-recovery users' attempts to communicate with pro-ana users are counterproductive, as it engrains pro-ana users in their stance.

### **Methodological considerations**

Overall, 18 of the 23 studies used an observational design to characterise online ED communities, for example analysing the content of messages or images within specific online communities. Whilst this type of research has its strengths, as it allows the observation of behaviour in a naturalistic setting, it also comes with several limitations. Many of the studies noted that it was difficult to confirm clinical characteristics or demographic details of users posting the content. It was therefore not clear to what extent individuals accessing these communities met clinical criteria for an ED, or what stage of recovery they were at. However, Darcy and Dooley (2007) found that users of online support groups demonstrated clinical characteristics comparable to and/or greater than samples diagnosed with an ED, suggesting that the people who show interest in online support groups are the very people for whom they are intended.

A common approach for collecting social media data was using filters to identify users who post content containing keywords related to EDs. However, it is difficult to characterise a community based on a small set of keywords, as individuals may use a wide range of vocabulary to express the same content online (Weng & Menczer, 2015). A more

sophisticated approach was the use of computerised techniques to detect and characterise ED communities on social media (Wang et al., 2018); although these computerised methods may classify communities with higher precision, they too remain open to misidentifying populations.

Ethical considerations are also raised around this type of data, such as consideration of informed consent to use information posted online. It is often accepted that if data is public, as opposed to private, users posting the data acknowledge that information may be viewed and used for a variety of reasons (Eysenbach & Till, 2001). However, this limits the data to online communities which are publicly accessible, which excludes private communities.

Of the 23 studies, 8 focused exclusively on online communities used by people with AN. Whilst this may reflect the types of communities that are most visible online, there appears to be a bias towards research focusing solely on AN at the expense of other diagnoses. One study focused on BN, and none on BED. In other studies that claimed to investigate all EDs, there was a bias towards samples with the majority of participants experiencing AN (e.g. Pereira et al., 2016; Saffran et al., 2016) or using terminology that primarily related to AN (Branley & Covey, 2017).

Although some studies did not report gender profiles, as it can be difficult to ascertain gender from the content of messages, the studies that did report gender showed a bias towards females. Whilst this is consistent with the overall incidence rates of those diagnosed with an ED (Striegel-Moore et al., 2009), there is now increasing recognition that the experiences of males with EDs have been overlooked (Strother et al., 2012). Importantly, one study focused on the use of an online forum specifically for men with EDs (Flynn & Stana, 2012), which was a helpful addition to the female-biased literature.

## **Q2. How can online communities support recovery from an eating disorder?**

The following section will outline themes identified within the studies, related to how online communities can support recovery from an ED. Methodological considerations are presented throughout, in order to discuss the quality of the themes.

### **Social support**

Twelve studies highlighted the opportunities for social support and interaction provided by online communities. Ten of these studies were observational and analysed the content of information online. Interpretations were made regarding how people with EDs use and interact with others based on the content of discussion and observable online interactions.

Kendal et al. (2015) explored how a moderated online discussion forum facilitates support for young people with EDs. Through a thematic analysis of messages on the forum, the authors identified several themes related to social support. The online forum was experienced as a safe space; a trusted environment for people to talk about difficult experiences in a supportive, accepting atmosphere. There was a strong sense of companionship within the forum, offering emotional support and facilitating encouragement for recovery and relapse prevention. Users valued being able to support and mentor others, whilst flexibly responding to the needs of people at different points in their recovery. The authors concluded that the moderated online support forum facilitates mutual support for young people with EDs and promotes engagement in personal recovery. Whilst this study made an important contribution to the literature, it should be noted that data were limited to observations retrieved at a particular point in time; content was collected over a 4-month period which limits the reproducibility of the results (for example identifying any seasonal trends).

Several studies distinguished between the different types of social support exchanged by participants in online communities (Eichorn, 2008; Flynn & Stana, 2012; McCormack &

Coulson, 2009; Winzelberg, 1997). *Informational support* was often sought and provided, such as the provision of information in terms of diagnosis and treatment. Eichorn (2008) found that informational support was the most frequent form of social support provided on online ED support groups, which suggests that many people with EDs seek social support that is grounded in problem-solving. *Emotional support* included expressions of empathy, understanding and compassion towards others, as well as encouragement to keep going and praise for doing well, which was present across many of the studies (Eichorn, 2008; Flynn & Stana, 2012; Kendal et al., 2015; McCormack & Coulson, 2009; Winzelberg, 1997). *Self-disclosure* was also identified as a type of social support, which included the sharing of personal experiences and suggestions. This enabled users to feel connected, particularly when experiences were shared. Self-disclosure was the most frequent type of social support found in an online discussion forum for men with EDs (Flynn & Stana, 2012). Given the societal stigma that prevents many men from disclosing an ED and seeking help (Räsänen & Hunt, 2014), this suggests that online forums may provide a safe space to allow men with EDs to share their experiences and seek support from others. Video testimonials (videos in which users share their experience of having an ED) were described as a form of self-disclosure-based social support (Pereira et al., 2012). These videos provided support to both the poster and viewers; posters were able to express their feelings about their ED and challenges related to recovery, and viewers could respond by offering support, whilst relating to the experiences and finding their own inspiration to seek help.

Flynn and Stana (2012) differentiated between direct and indirect social support provided and received in online communities. *Direct support* was received by asking for help and receiving direct feedback, whilst *indirect support* was received through the emotional expression of others who may not have intentionally offered support, but through sharing similar thoughts and experiences, support was indirectly provided. The authors suggest that the many potential

‘lurkers’ who may have viewed posts but not posted themselves may have received indirect support; such support would be difficult to obtain offline. Using an observational methodology, however, makes it difficult to measure the presence of ‘lurkers’, as observed data only consists of measurable interactions in the form of messages/posts, likes and comments.

Creating a communicative context of safety (Walstrom, 2000), a safe space where users could talk about difficult experiences, was noted as a key component to creating successful social support. Walstrom (2000) suggests how the virtual nature of online support groups can reduce accountability concerns and decrease evaluation anxiety, particularly judgements related to physical appearance. In a micro-level discourse analysis of 3 exchanges of communication, the author illustrates how a communicative context of safety is co-constructed between users, creating a safe space for coping with ED-related difficulties. Whilst this study used a thorough analysis of communication exchanges, the very small sample size compromises the generalisability of the results.

Many studies also highlight the opportunities for increased social interaction and emotional support provided by social media (Eikey & Booth, 2017; LaMarre & Rice, 2017; Pereira et al., 2016; Saffran et al., 2016; Teufel et al., 2013; Wang et al., 2018).

Whilst social support was identified as a key benefit of engaging in online communities, based on the observational design used in many of these studies, it is unclear if users actually perceived these communities as supportive, and it is difficult to interpret why people with EDs chose to seek support online. One study used a qualitative design to explore experiences of using Instagram in people with EDs: Eikey and Booth (2017) found that participants used Instagram as a platform to receive support and provide support to others, which offered a sense of community. People with EDs often feel alone in their illness, but social media

appears to provide a platform for individuals to seek support, understanding, and a sense of belonging. This was the only study that explored experiences of using social media from the perspective of those that use it. The study focused solely on Instagram, however; there is therefore a lack of literature on the experiences of using other social media platforms.

### **Social identity**

In addition to social support, 4 studies highlighted the social identity processes that facilitate recovery in online communities. McNamara and Parsons (2016) conducted a theoretical thematic analysis of online support sessions in an ED forum, using a social identity framework to explore how a sense of shared identity in the online support forum helped individuals with EDs to manage their illness and promote recovery. Results suggested that the ED illness identity initially enabled similar others to connect. For those hoping to recover, identity-based support was perceived to be more helpful than support found outside the group. Interacting online with others working towards recovery promoted a shared recovery-oriented social identity which, compared to the illness identity, promoted group norms of sharing experiences and engaging with treatment.

Hastings et al. (2016) also used a social identity framework to explore the role of social identities in the management of and recovery from ED and co-morbid type 1 diabetes (referred to as ‘diabulimia’). Online focus groups were conducted with 13 members of a diabulimia online support group. A unique diabulimic identity was identified as acting as a barrier to offline support, whilst a shared identity with similar others online was found to promote recovery. Participants felt accepted and validated by the online diabulimic community, and the group allowed members to learn how to manage their condition from others. Family, friends and health professionals were also key to recovery. These relationships were enhanced by the recovery-focused social identity which allowed one to

feel validated, provided encouragement to disclose the illness to close others, and provided support and information to facilitate positive engagement with professionals. The use of online recruitment and procedure was a strength of this study, as it engaged participants using the same means of communication as the topic of interest, enabling a method of interaction comparable to their familiar interactions. However, this recruitment strategy may have also created a bias in selecting ongoing members who were most likely to report positive experiences; those with negative experiences of the group may have not remained active in order to respond to the advert.

Riley et al. (2009) explored how identities associated with weight and body management (referred to as ‘body talk’) were negotiated within online ED communities. Comparing a pro-ana and recovery website, the researchers concluded that body talk functioned to support a group identity. Group members made the body visible online, allowing users to demonstrate their right to belong to the site and to make an identity claim. On the pro-ana site, bodily descriptions provided evidence of being thin. On the recovery website, users’ descriptions showed that they had genuinely suffered from an ED but were now working towards recovery, although still endorsing a thin ideal. For the recovery group, narratives of moving into recovery constructed the users’ recovery as a tentative, ongoing, challenging process, but functioned to support a recovery identity where support could be received. This study again used an observational design, and data were collected on 3 days over Christmas, which may not be representative of usage at different times of the year.

Wang et al. (2018) also suggested how the formation of communities on social media, with like-minded followers and supportive interactions, appeared to assist the construction of a shared identity centred around recovering from an ED.



## **Empowerment**

The concept of empowerment in relation to being part of online communities was discussed in 2 studies. Kendal et al. (2015) suggested that a young person's decision to use a moderated online AN discussion forum could be construed as proactive self-care, facilitating agency and engagement in personal recovery, whilst feeling empowered to support and mentor others.

Aardoom et al. (2014) studied experiences of empowerment in 311 users of Proud2Bme, who completed a series of self-report questionnaires including measures of eating psychopathology, a measure of empowering processes and outcomes as a result of visiting the website, and a measure of general empowerment status. Results suggested that visiting Proud2Bme was associated with actively managing one's ED. Sharing information and experiences, finding recognition and feeling better informed were the empowering processes most often reported. Visiting the website was associated with increased help-seeking behaviour, a greater sense of optimism and control over one's future, and an improved therapeutic relationship and confidence in treatment. Furthermore, lower levels of general empowerment status were significantly associated with higher levels of reported empowering processes and outcomes as a result of visiting Proud2Bme, which suggests that it particularly empowered those who needed it the most (i.e. less empowered individuals). The cross-sectional design of this study offered a strength, in that diagnostic information could be measured and verified. The design did not allow causation to be inferred however, as external factors could have promoted patient empowerment and longitudinal relationships were not assessed. Similar to Hastings et al. (2016), there was also a risk of selection bias, as the sample may not have been representative of all users visiting the website. It is possible that only those who perceived the website as empowering completed the survey, or that those who visited the website frequently enough to see the study advertised experienced the website as

empowering. The retrospective nature of the study also risked recall bias, which could have resulted in over or under-representation of true patient empowerment.

### **Documenting recovery**

Two studies focused on social media explored how social media could be used as a platform to document recovery and to track progress. In a qualitative study involving semi-structured interviews with women with EDs who used Instagram, Eikey and Booth (2017) note that Instagram can be used to chart progress in recovery. Participants kept track of their meals, which was often helpful when sticking to a meal plan or exploring alternative foods to eat. They also posted photos of themselves or activities that highlighted their progress and allowed them to celebrate recovery achievements. The focus on tracking things that exemplified healthy behaviours seemed to be helpful towards recovery; participants liked seeing how they had improved over time, which promoted motivation to continue. However, the qualitative nature of this study, and the small sample size, limits the generalisability of these results.

LaMarre and Rice (2017) also suggest that Instagram can be used to document recovery and monitor progress. Through a thematic analysis of images related to ED recovery, the authors reported that many of the images were of food, documenting ‘healthy’ or ‘indulgent’ food choices whilst noting why this was challenging but significant for recovery. Images of bodies were also common, displaying a narrative of overcoming, for example, through ‘before and after’ posts with images of emaciated and normative bodies. The researchers suggest that Instagram provides a forum for people with EDs to explore their experiences, chart progress and interact with others, whilst making the struggles and challenges of ED recovery visible.

### ***Raising awareness and challenging stigma***

Three studies highlight the wider societal benefits that online communities can promote.

Social media, in particular, was used as a platform to raise awareness about EDs in the wider

population and to challenge associated stigma. Participants in Eikey and Booth (2017) study spoke of using Instagram as a platform to boost awareness about EDs and reduce the stigma associated with them. In a content analysis of communication about EDs on Twitter and Tumblr, Branley and Covey (2017) found two shared motivations among users sharing anti-ana (opposing the pro-ana mentality) and pro-recovery posts. The first was to raise awareness about EDs amongst the general population, for example, sharing content from media articles, television documentaries and charity organisations. The second motivation was to challenge social norms and to highlight the need for systemic change for EDs, by expressing frustration with sociocultural pressures to be thin. Examining video testimonials uploaded to YouTube, Pereira et al. (2016) suggest that social media provides a level of anonymity and safety, which helps people to open up and share feelings which they may not have shared in person before, thereby increasing the visibility and transparency of EDs in the wider population. Social media is a constantly changing medium, however, which could make replicating these studies difficult.

### ***Threats to recovery***

Whilst online communities could prove useful in the recovery process, six studies also noted how they could pose threats to recovery from an ED. Eikey and Booth (2017) report how Instagram could be used to maintain EDs, by providing users with ways to restrict their food intake and affirmation to continue with their ED. Some participants spoke about how the visual nature of Instagram provided a way to experience food without eating anything. Participants also reported comparing themselves with others, which left them feeling inadequate and pressured to eat less. Hastings et al. (2016) also noted how an online diabulimia support group could pose threats to recovery at times. Despite the group experience being generally positive, group interactions could have a negative impact at times,

for example negatively affecting one's mood, which led users to regulate their contact with the group.

Keski-Rahkonen and Tozzi (2005) analysed the process of recovery on a Finnish-language ED discussion group, based on the stages of change model (Prochaska & DiClemente, 1986). The researchers suggest that such groups may be helpful in the early stages of recovery, for example providing peer support and disseminating awareness about EDs when individuals were not yet actively engaged in treatment. However, in the later stages of recovery internet discussion groups may impede recovery. Later recovery is associated with ceasing to identify with the ED and searching for meaning and relationships outside of the illness; remaining a group member later may therefore delay recovery. The authors suggest that in the later stages of recovery, moving away from online support groups and reaching out for alternative activities should be encouraged.

Tan et al. (2016) used a cross-sectional design using self-report questionnaires to investigate social media and smartphone application ('app') usage in participants who presented with an ED in Singapore. 41.8% participants felt that apps (social media apps, as well as apps designed to help the user calculate calories and/or monitor activity levels) helped them in continuing with their ED, for example by maintaining motivation to sustain weight loss or by promoting comparison to others. Participants who used apps to continue their ED scored higher on measures of ED symptoms and were younger than participants who did not use apps to continue their ED. Saffran et al. (2016) used a similar design and found that, after discharge from group ED treatment, comparison to treatment peers on Facebook was frequent and was associated with greater ED psychopathology and related impairment. Online communities, particularly social media, may therefore promote unhelpful comparisons towards others, which may be detrimental for recovery. It should be noted, however, that the use of questionnaires in both of these studies captures self-reported rather than objective

social media usage. The questionnaires were developed for the purpose of the studies; whilst analyses support initial psychometric validity, they would benefit from additional validation. The researchers also administered validated measures of ED symptoms (EDE-Q; Fairburn & Beglin, 1994) and ED-related impairment (Clinical Impairment Questionnaire (CIA); Bohn & Fairburn, 2008), from which associations with social media/internet usage were made. The cross-sectional design, however, means that directions of causality cannot be inferred. Both studies also risk selection bias, as participants elected to take part in the study and may therefore be more likely to report positive results.

LaMarre and Rice (2017) note how many of the images related to ED recovery on Instagram overlap with ‘clean eating’, fitness or health discourses. The authors suggest that a dominant narrative of ‘how to be recovered’ permeates the platform, often depicted as achieving a fit and lean physique (with a narrow zone of acceptability between too thin and too fat) and perfectly balancing the demands of health and recovery. The authors argue that Instagram perpetuates stereotypical representations of who gets EDs and what recovery looks like, which may not fit with many people’s actual experiences of recovery. Many potential users may therefore be alienated from engaging with this recovery community, or those who do must conform to ideals about what recovery can and cannot look like.

Table 1. *Summary of the Studies Selected for the Review.*

Author/s and date	Aim(s)	Design, method and analysis	Sample	Online community	Key findings
<b>Aardoom, Dingemans, Boogaard, and Furth (2014)</b>	To explore experiences of empowerment in a pro-recovery focused e-community	Quantitative; cross-sectional (self-reported questionnaires); correlations, T-tests and ANOVAs	311 participants	Proud2Bme	<ul style="list-style-type: none"> <li>- Visiting Proud2Be was associated with actively managing one's ED</li> <li>- Empowering processes and outcomes were: exchanging information, finding recognition, sharing experiences and feeling better informed</li> <li>- Visiting the website was associated with increased help-seeking, sense of optimism and control over one's future, and confidence in treatment and therapeutic relationship</li> </ul>
<b>Branley and Covey (2017)</b>	To compare how people communicate about EDs on two popular social media platforms	Qualitative; observational; thematic and content analysis	190 social media posts	Twitter; Tumblr	<ul style="list-style-type: none"> <li>- Three types of content (pro-ana, anti-ana, and pro-recovery) were posted on each platform</li> <li>- Anti-ana and pro-recovery posts were more common than pro-ana</li> <li>- Motivations behind anti-ana and pro-recovery posts were: raising awareness about EDs in the wider population and challenging societal norms</li> </ul>
<b>De Choudhury (2015)</b>	To identify characteristics of pro-ana and pro-recovery communities on social media	Quantitative; observational; computerised text analysis	55,334 posts from 18,923 users	Tumblr	<ul style="list-style-type: none"> <li>- Triggering pro-ana is common on Tumblr</li> <li>- The pro-recovery community attempted to educate the pro-ana community of the health risks of AN</li> <li>- Pro-ana communities expressed greater negative affect, higher cognitive impairment, and greater feelings of social isolation and self-harm compared to pro-recovery communities</li> </ul>
<b>Eichorn (2008)</b>	To explore the strategies used by people with EDs to solicit social support, and the frequent themes discussed	Qualitative; observational; content analysis	490 posts	Top 5 Yahoo! ED discussion boards	<ul style="list-style-type: none"> <li>- Over half the messages provided and/or solicited some type of social support</li> <li>- Informational and emotional support were the most frequent types of social support provided</li> <li>- Shared experience was the most frequent soliciting strategy for social support</li> <li>- The primary theme within the messages was positive affect (providing feedback and encouragement to another member) followed by coping with weight</li> </ul>
<b>Eikey and Booth (2017)</b>	To explore how women with EDs use	Qualitative; semi-structured interviews;	16 women, aged 18-23, with a self-	Instagram	<ul style="list-style-type: none"> <li>- Instagram can support recovery from an ED by helping women learn about the recovery process, track their own recovery, learn about healthy foods and exercises, reduce stigma, increase awareness and create a community for social support</li> </ul>

<b>Flynn and Stana (2012)</b>	Instagram in relation to the ED/ recovery To identify the types of social support present and the various functions each serve for members of a men's online ED forum	thematic analysis Qualitative; observational; deductive thematic analysis	reported ED 358 messages by 89 members	Online ED support group for men	<ul style="list-style-type: none"> <li>- Instagram could also be used to maintain/exacerbate ED symptoms and promote comparisons</li> <li>- Types of social support present were: personal disclosure, emotional support, informational support, advice, emotional expression, and gratitude</li> <li>- Five themes were identified: direct/indirect; online/offline; providing/seeking content; the impact (or lack thereof) of masculinity norms; creating a positive culture</li> <li>- Online forums may prove useful in supporting men with EDs, helping them to feeling confident to disclose their ED and obtain support from similar others</li> </ul>
<b>Hastings et al. (2016)</b>	To explore how a sense of shared identity with similar others online enhances wellbeing and promotes recovery for people suffering from ED and type 1 diabetes	Qualitative; focus groups; theoretical thematic analysis	13 participants	Online ED and diabetes support group	<ul style="list-style-type: none"> <li>- Four themes were identified: not like everyone else; shared identity online promotes recovery; threats to recovery; recovery outside the online group</li> <li>- Clinical interventions should include strengthening important group memberships that promote recovery</li> </ul>
<b>Holmes (2017)</b>	To explore videos on YouTube which present narratives of recovery from AN	Qualitative; observational; discursive textual analysis	35 videos	YouTube	<ul style="list-style-type: none"> <li>- Narratives positioned the visibly emaciated body as existing at the core of AN</li> <li>- AN was framed within a medical, individualistic model</li> <li>- 'Selfies' functioned as a means of self-surveillance and expression; allowing girls to scrutinise and check their bodies, whilst informing the viewer of physical deterioration</li> </ul>
<b>Kendal et al. (2015)</b>	To explore how an online forum facilitates support for young people with EDs	Qualitative; online ethnographical approach; thematic analysis	420 messages	A youth-orientated moderated, online ED discussion forum run by an ED charity	<ul style="list-style-type: none"> <li>- Five themes were identified: taking on the role of the mentor; the online forum as a safe space; friendships within the online forum; flexible help; peer support for recovery and relapse prevention</li> <li>- A young person's decision to use this forum can be construed as pro-active self-care which facilitated agency and engagement in personal recovery</li> </ul>
<b>Keski-Rahkonen</b>	To explore the process of recovery in an ED discussion group	Qualitative; observational; constant	685 messages	Finnish language ED	<ul style="list-style-type: none"> <li>- Users' views of recovery changed according to their current stage of change</li> <li>- The internet discussion group was perceived as helpful in the early stages of change, but as impeding recovery in the later stages</li> </ul>

<b>and Tozzi (2005)</b>		comparative method		discussion group	- Internet discussion groups could be helpful in promoting awareness about EDs and providing peer support during the early stages of recovery when individuals are not actively engaged in treatment
<b>La Marre and Rice (2017)</b>	To analyse images relating to ED recovery on Instagram	Qualitative; observational; thematic analysis of images	1056 images	Instagram	- Four themes were identified: a feast for the eyes; bodies of proof; quotable; imperfection - Documenting recovery online allowed one to chart their progress and interact with similar others - Recoveries presented on Instagram resembled stereotypical representations of EDs
<b>McCormack and Coulson (2009)</b>	To examine the nature and types of social support exchanged between participants of an online AN discussion forum	Qualitative; observational; deductive thematic analysis	325 messages	Online ED support group	- The primary function of the group was encouraging and praising others, providing informational support, and sharing personal experiences and suggestions - Users expressed their emotions and frustrations; they commented on how being able to vent their feelings helped them
<b>McNamara and Parsons (2016)</b>	To explore how a sense of shared identity in an online support forum helps individuals with EDs manage their condition and promote recovery	Qualitative; observational; theoretical thematic analysis	18 online support sessions with 75 participants	Online ED support group	- Illness identity formed the basis for communication with similar others - For those in recovery, identity-based support was perceived to be more effective than support found outside the group - Online interactions facilitated the construction of a recovery identity which promoted illness disclosure and treatment engagement
<b>Pereira, Quinn, and Morales (2016)</b>	To quantify and describe content of and responses to ED testimonial videos uploaded to YouTube	Qualitative; observational; content analysis	50 videos	YouTube	- Many users actively sought support for their ED on YouTube, and offered support to others - Viewers responded with more supportive comments compared to negative comments
<b>Riley, Rodham, and Gavin (2009)</b>	To explore how pro-ana and recovery identities are developed and	Qualitative; observational; discourse analysis	212 contributions by 70 users	Two internet discussion forums (pro-	- Three types of body talk were identified: descriptions of doing something with the body; descriptions of the body; bodily experiences - Body talk reproduced the thin ideal and demonstrated claims of group membership



managed in online ED communities

ana and recovery)

<b>Saffran, Kass, Taylor, and Trockel (2016)</b>	To explore Facebook use in individuals with a history of receiving treatment for an ED in a group setting	Quantitative; cross-sectional (self-report questionnaires); correlations, multiple regression analyses, MANOVA	415 participants who self-reported receipt of ED treatment in a group setting	Facebook	<ul style="list-style-type: none"> <li>- Participants averaged 10-19 Facebook friends from treatment and spent up to 30 minutes per day interacting with others with EDs on Facebook</li> <li>- Greater comparison to treatment peers on Facebook was associated with greater ED psychopathology and ED-related impairment</li> <li>- Positive interaction with treatment peers on Facebook was associated with lower ED psychopathology and ED-related impairment</li> <li>- Individuals who had been in treatment longer, on more occasions, and more recently had more Facebook friends from treatment and ED-related organisations and spent more time in ED groups on Facebook</li> </ul>
<b>Tan, Kuek, Goh, Lee, and Kwok (2016)</b>	To investigate social media and smartphone application usage in participants who presented with an ED in Singapore	Quantitative; cross-sectional (self-report questionnaires); descriptive analysis	55 participants with a diagnosis of an ED	Facebook; Instagram; Tumblr; Twitter	<ul style="list-style-type: none"> <li>- 30.9% had viewed content related to EDs on Facebook, 12.7% had visited a Facebook group related to EDs</li> <li>- 41.8% felt that apps contributed to maintaining their ED (social media apps, and apps designed to help the user calculate calories/monitor activity levels)</li> <li>- 32.7% felt that apps were helpful towards recovery (within this 73.7% identified social media apps as being helpful towards recovery)</li> <li>- Participants who used apps to continue their recovery had higher EDE-Q, CIA and EAT scores</li> </ul>
<b>Teufel et al. (2013)</b>	To analyse the content and culture of AN-related communication on Facebook	Quantitative; observational; content analysis	118 AN groups	Facebook	<ul style="list-style-type: none"> <li>- Groups were coded into 5 categories: education; anti pro-ana; self-help; professional help; pro-ana</li> <li>- Facebook groups were found in all categories except professional help</li> <li>- Pro-ana groups were the most active, organised, and offered the highest levels of social support</li> <li>- Social support was present across all groups</li> </ul>
<b>Walstrom (2000)</b>	To explore interaction in an online ED support group	Qualitative; observational; micro-level discourse analysis	3 exchanges of communication	Online ED support group	<ul style="list-style-type: none"> <li>- Two processes were evidenced: the exchange of support group resources for coping with an ED, and the co-construction of a communicative context of safety</li> </ul>

<b>Wang, Brede, Ianni, and Menazakis (2017)</b>	To explore social interactions in social media ED communities	Quantitative; observational; computerised content analysis and social network analysis	4247 posts and 34118 comments by 3029 users	Reddit	<ul style="list-style-type: none"> <li>- Two communities were identified: a large community reinforcing ED behaviour, and a smaller community supporting recovery</li> <li>- Users tended to interact with others within the same community, with limited interactions across communities</li> <li>- Users in the 2 communities displayed distinctive social behaviours and psychological characteristics</li> </ul>
<b>Wesemann and Grunwalk (2008)</b>	To identify fundamental structures of an online discussion forum for BN	Mixed methods; observational; grounded theory and quantitative comparisons	2072 threads, 14,903 postings	Pro-recovery BN forum	<ul style="list-style-type: none"> <li>- Three types of thread were identified: problem-oriented (79%); communication-oriented (15%); meta-communication (3%)</li> <li>- Topics related to active management of the disorder received great attention in pro-recovery forums</li> </ul>
<b>Winzelberg (1997)</b>	To analyse the discourse that occurs on an electronic ED support group	Qualitative; observational; discourse analysis	306 messages	Online ED support group	<ul style="list-style-type: none"> <li>- The most common message content involved self-disclosure (31%), requests for information (23%), and emotional support (16%)</li> <li>- Six themes were identified: coping with increased weight during recovery; coping with external pressures from family and friends; reactions to the cultural pressures to be thin and the standard of beauty portrayed in the media; reminiscence of the psychological symptoms of bingeing, purging and starvation; negative affect; recommendations for psychological treatment and reflections on the benefits members had received from such treatment</li> <li>- Members with longer recovery periods served as role models and offered suggestions for coping</li> </ul>
<b>Yom-Tov, Fernandez-Luque, Weber, and Crain (2012)</b>	To explore AN-related communities on Flickr	Quantitative; observational; content analysis	242,710 images from 491 users	Flickr	<ul style="list-style-type: none"> <li>- Pro-ana and pro-recovery communities interacted more amongst themselves than what was expected from the distribution of contacts</li> <li>- Pro-recovery users employed similar words to pro-ana users to describe their photos</li> <li>- Pro-ana users who were exposed to pro-recovery were less likely to cease posting pro-ana photos than those who do not receive such comments</li> </ul>

## DISCUSSION

This review examined the current literature on online communities for people recovering from an ED. Several online communities were identified, ranging from online support groups moderated by professionals, to open, easily accessible social media platforms. These online communities can support recovery in a variety of ways: providing a platform for social support, promoting an identity centred around recovery, enhancing empowerment and agency in the recovery process, and providing a medium to document recovery and track progress. Online communities, particularly within social media, may also offer wider societal benefits, promoting awareness about EDs in the wider population and challenging stigma. Despite the helpful aspects of online communities, it was found that they may pose threats to recovery and can be used to maintain or exacerbate symptoms. The positive and negative aspects of online communities are important to consider together, particularly when thinking about how the helpful aspects of online communities can be promoted and harmful aspects limited.

Findings offer support for the social identity model of recovery (Best et al., 2016). A sense of shared identity with others online was suggested to promote recovery, allowing users to move away from a positively-valued illness identity and towards an identity centred around recovery and support. Social support was offered and received, enabling users to feel connected with similar others. Social relationships amongst people with EDs are often discouraged due to the risk of disorder maintenance (Vandereycken, 2011), however this review suggests that a sense of shared identity with others in recovery can support the recovery process. The association with the stages of change model (Prochaska & DiClemente, 1986) is an interesting finding, suggesting that online communities may serve a helpful function at a particular point in one's (early) recovery. As recovery progresses, however, engaging with these communities could impede recovery (Keski-Rahkonen & Tozzi, 2005). Experiences of empowerment as a result of visiting online communities is also

significant, adding insight into how online communities can promote engagement in personal recovery outside of traditional healthcare services.

The majority of the studies were observational and analysed the content of information online, for example, analysing the content of messages or images posted within specific online communities. Whilst this type of research allows for the study of behaviour in a naturalistic setting, it also comes with several limitations. It was difficult to characterise demographic and clinical information of users posting the content, and it was therefore not clear if individuals using these communities met clinical criteria for an ED or where in their recovery journey they were. Observational research also makes it difficult to interpret how users actually perceive online communities (i.e. whether they experience them as supportive), and why they choose to access them. Three studies used a cross-sectional design using self-report questionnaires. This allowed clinical characteristics and demographic information to be measured and verified, however they risk selection bias as samples may not have been representative of all users visiting the communities. Two studies employed qualitative designs using semi-structured interviews or focus groups to explore experiences of participating in online communities, which added an important qualitative contribution to the literature. Many of the studies focused on females and on those with AN, which seemed to reinforce stereotypical representations of EDs (LaMarre & Rice, 2016).

### **Areas for future research**

Given the large number of observational studies in this area, there is a need for further research using alternative research designs. Experimental designs could be useful in evaluating the effectiveness of recovery-focused online communities, for example, randomly assigning individuals to wait-list control groups, face-to-face-groups and online support groups/recovery-focused communities. Longitudinal research could measure the impact of

using online communities over time, to add further understanding to how interacting online actually influences recovery and changes in attitudes or behaviour. There is also a need for further qualitative research exploring experiences of using online communities, and perceived benefits and drawbacks.

Given the exponential rise in social media in the recent decade (Statista, 2018), there is a need for further research focusing on the formation of communities on social media.

Research on social media tends to be dichotomised as either ‘pro-ED’ or ‘pro-recovery’, considering either the positive or the negative impact of social media, but has rarely explored how social media can be used in fluid ways that aid *and* hinder recovery. Further research is needed on the potential duality of interactions and outcomes provided by social media.

Other research areas could include investigating the difference between moderated and unmoderated online communities, including the impact of moderation on users; the effect of passively viewing content, as opposed to posting and interacting; and the experiences of males who use online communities, including any differences between males and females in the use of online communities. Finally, additional research could explore online communities for people recovering from BED, which was absent from the literature.

### **Clinical implications**

Online communities may provide a useful tool to aid recovery from an ED. Clinicians should incorporate discussions about online communities into their conversations with service users; they should not only be considered as a risk but also valued as an additional resource.

Clinicians could reflect with service users on the potential benefits and risks of engaging online, in order to promote positive online use. ED charities and third sector organisations could also work towards raising awareness about the types of online communities available and promote positive engagement with such communities. The cost-effectiveness of online

communities is also important to consider, particularly in the current NHS climate, with the potential to support a wide number of people recovering from an ED.

Social media, in particular, has become a huge part of modern-day life. The positive and negative effects of social media should be considered when working with clients and incorporated into the assessment and therapeutic process. If individuals are using social media to learn about recovery, document their progress and interact with supportive others, discussions about these experiences could be helpful in setting, monitoring and working towards goals in recovery. Services could consider running groups (or incorporating within existing groups) that talk about informational quality, risks and benefits of social media, and service users' experiences with technology. The newly developed First Episode and Rapid Intervention for Eating Disorders (FREED) service model highlights the importance of early intervention, alongside adapting services towards the needs of young people with EDs, which includes understanding and working with social media use (Brown et al., 2018). This is supported by the current review, but there is a need for further research and understanding to support working with people with EDs who use social media.

Šmahelová, Čevelíček, Nehybková, Šmahel, & Čermák (2017) explored how health professionals addressed technology use in people with EDs. A large number of professionals reported that they did not enquire about technology use because they did not see it as important for treatment. During the semi-structured interviews, however, some professionals realised that digital technology usage was important to specifically address, and were somewhat surprised by this realisation. This implies the importance of supporting clinicians to engage in these conversations with clients; for example, it may be helpful to provide information and training on the types of content found online, and guidelines on how to approach and explore these issues with service users.

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Section B:

Experiences of using social media in people working towards recovery from an eating disorder.

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## **ABSTRACT**

Social media use is rapidly increasing; whilst the dangers of using social media have been highlighted by previous research, less attention has been paid to the positive influences of social media. This study aimed to explore experiences of using social media in people recovering from an eating disorder (ED). Objectives were to understand how people with EDs use social media in relation to their ED and recovery, and the perceived helpful and unhelpful aspects of using social media during their recovery. In depth interviews with 15 adults (aged 19-40) recovering from an ED were thematically analysed. Participants also shared examples of social media posts that were helpful and less helpful in their recovery, which were included in the thematic analysis. Four key themes were identified: motivating recovery, a supportive space to share and be open, maintains difficulties, and navigating social media. Participants' social media use appeared to change dependent on their level of motivation and stage of recovery. Findings have important implications for clinical practice, working alongside, not against, social media use in those with EDs. Further research is needed in order to greater understand the role that social media plays during the recovery process.

**Keywords:** Social media, eating disorder, anorexia nervosa, bulimia nervosa, recovery

## INTRODUCTION

### Eating disorders

Eating disorders (EDs) are serious, potentially life-threatening conditions, characterised by concern about eating, weight and shape (Murphy, Straebl, Cooper, & Fairburn, 2010). The EDs include anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED) and other specified feeding or eating disorder (OSFED; American Psychiatric Association; APA, 2013), all of which are associated with significant distress and impairment. AN is categorised by maintaining a significantly low body weight through restrictive eating, intense fear of gaining weight or becoming fat, and a disturbance in the way one's body weight and shape are perceived. BN is characterised by repeated episodes of bingeing (eating a large amount of food whilst feeling out of control of eating) and extreme compensatory behaviours including self-induced vomiting, laxative use or excessive exercise. Repeated bingeing also characterises BED, but this is not followed by regular compensatory behaviours. A diagnosis of OSFED may be given when concerns about eating, body weight and shape are present, but when full diagnostic criteria for AN, BN or BED are not met (APA, 2013).

Current estimates suggest that 1.25 million people in the UK have an ED (Beat, 2017), with 6.4% of adults in the UK exhibiting some ED-related symptoms (Health & Social Care Information Centre, 2007). The lifetime prevalence amongst women is estimated at up to 4% for AN, approximately 2% for BN and BED respectively, and 7.6% for OSFED (Micali et al., 2017; Smink, van Hoeken & Hoek, 2013). Whilst the incidence of EDs is greater in females, there has been a noticeable increase in identification of men with EDs in recent years.

Estimates suggest that between 10-25% of EDs occur in males (Strother, Lemberg, Stanford, & Turbeville, 2012; Sweeting et al., 2015). Historically, EDs have been characterised as primarily affecting Caucasian individuals (Striegel-Moore & Smolak, 1996). However, the

specificity of association between ethnicity and EDs has not been well studied (Jacobi, Hayward, De Zwaan, Kraemer, & Agras, 2004). Cultural factors do play a role in help-seeking and recognition of EDs, and professionals may be less likely to identify an ED if the person does not fit the stereotype for such cases (e.g., non-Caucasian or male; National Institute for Clinical Excellence; NICE, 2017).

### **Eating disorder recovery**

Individuals with EDs are often ambivalent about their symptoms and recovery; the ED may be perceived as a burden but also valued (Schmidt & Treasure, 2006; Serpell & Treasure, 2002). Related to this, poor engagement with treatment is common and recovery rates are low (e.g., 50% recovered after 5-10 years; Abbate-Daga et al., 2013; Bandini et al., 2006; DeJong, Broadbent, & Schmidt, 2012). Understanding this ambivalence and enhancing motivation and readiness to change are considered important factors in the treatment and recovery process (Casasnovas et al., 2007; Knowles, Anokhina, & Serpell, 2013).

The recovery approach to mental health endorses five key processes of recovery: connectedness; hope and optimism for the future; having a sense of purpose; identity development; and experiencing empowerment (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). Connecting with others who have similar difficulties, sharing skills and resources, and actively choosing recovery are emphasised by this approach, which fits with many peoples' experience of recovery from an ED (de Vos et al., 2017). Positive relationships with others, self-acceptance, personal growth, resilience and autonomy have been identified as important criteria for ED recovery, in addition to a decrease in ED-related thoughts and behaviours (de Vos et al., 2017). Despite inconsistencies in the literature on what constitutes ED recovery, and how it is defined (e.g. physical versus psychosocial criteria for recovery (Bardone-Cone et al., 2010; Emanuelli, Waller, Jones-Chester, & Ostuzzi, 2012;



Noordenbos, 2011)), supportive relationships through which one feels validated and accepted are consistently reported as an important element of the ED recovery process (Hsu & Crisp, 1992; Linville, Brown, Sturm, & McDougal, 2012; Stockford, Kroese, Beesley, & Leung, 2018).

### **Social identity and recovery**

Social identity theory (Tajfel, 1982; Tajfel & Turner, 1979) is also relevant for understanding the process of recovering from an ED. According to social identity theory, one's sense of self is derived from a perceived membership in a relevant social group (Tajfel, 1982; Tajfel & Turner, 1979). Whilst the literature has predominantly focused on how connections with similar others maintains disordered eating behaviour (Vandereycken, 2011), there is also evidence to suggest that social relationships with similar others can promote recovery from an ED (Ison & Kent, 2010; Hastings, McNamara, Allen, & Parsons, 2016; McNamara & Parsons, 2016).

The recovery process is described by the social identity model of recovery (Best et al., 2016) as a social identity transition, where one's social identity shifts from being defined by a group membership centred around the illness to being defined by recovery. Alongside receiving and offering social support, the recovery group identity guides motivation and offers a sense of purpose (Beckwith, Best, Dingle, Perryman, & Lubman, 2015; Buckingham, Frings, & Albery, 2013; Dingle et al., 2015; Frings & Albery, 2015). McNamara and Parsons (2016) explored how a sense of shared identity with others in an online ED support group could promote recovery from an ED. The ED illness identity initially acted as a social identity that provided the basis for connecting with similar others. However, for those hoping to recover, online interactions promoted the development of a new shared recovery-oriented identity. Group norms of self-disclosure, sharing experiences and engaging with treatment were

endorsed; this promoted motivation and engagement with recovery, and enabled individuals to feel able to cope with the challenges of recovery (Hastings et al., 2016).

## **Social media**

Social media use has expanded exponentially over the last decade. According to the Statistics Portal (Statista, 2018), approximately 66% of the UK population are active social media users, with 2.62 billion users worldwide. Facebook is the most popular site, followed by Twitter, Pinterest and Instagram (Statista, 2018).

Social media platforms are 'web-based services that allow individuals to construct a public or semi-public profile within a bounded system' (Boyd & Ellison, 2007, p. 211). Key characteristics include uploading and sharing images, text or videos, personal information such as name, age and a 'profile picture', and a list of 'followers' or 'friends' to indicate one's connections within the social network (Robards & Bennett, 2011). Users can interact by writing public messages, sending private messages, or by using functions that allow them to react to content (e.g. the 'like' button). Social media differs from traditional media and websites in terms of its accessibility, its interactive nature, and its ability to enable immense control over self-presentation (Perloff, 2014; Rodgers, 2016).

Social media has the potential to support recovery from an ED, in keeping with social identity theory. Recovery-oriented ED communities have been identified on platforms such as Facebook, Instagram, Twitter and Tumblr (Branley & Covey, 2017; LaMarre & Rice, 2016; Teufel et al., 2013). There is emerging evidence to suggest that social media use may have some benefits during the recovery process – providing a platform for social support, inspiring recovery, raising awareness and challenging stigma (Branley & Covey, 2017; LaMarre & Rice, 2016). The majority of this research to date, however, is observational (describing the content of information on social media); little is known about the experience of using social

media from the perspective of those who use it, and how this may promote or hinder recovery. The relative recency and continued growth of social media means that research in this area is ever developing and evolving.

In non-clinical samples, the literature points to several positive influences of social media, including enhanced peer relationships (Kraut et al., 2002), broadened opportunities to connect with others (Markstrom, 2011), and increased opportunities for sharing and self-disclosure (Valkenburg et al., 2011). Several dangers have also been identified, including unhealthy social comparisons and the potential for negative feedback (Holland & Tiggemann, 2016). Research has identified a positive correlation between social media use and body image dissatisfaction (Fardouly & Vartanian, 2015). Low self-esteem and body image difficulties have also been related to higher levels of gratification-seeking from social media, for example turning to social media for reassurance and validation regarding appearance and attractiveness (Perloff, 2014).

Within current UK policy, there is no specific advice or guidance regarding the role of social media in understanding and working with EDs (NICE, 2017). However, the newly developed First Episode and Rapid Early Intervention in Eating Disorders (FREED) service model (Brown et al., 2018) highlights the importance of early intervention for EDs, along with adapting evidence-based interventions towards the needs of young people. This includes incorporating social media use into the assessment, formulation and intervention process. Given that social media has become such a force in people's lives, greater understanding of the benefits and dangers of social media use is needed in order to successfully work alongside people with EDs who use it.

## **The current study**

Given the limited research into the role of social media in ED recovery, the current study aimed to explore experiences of using social media in people working towards recovery from an ED. Thematic analysis (Braun & Clark, 2006) was used to identify themes within people's experiences, in relation to the research questions.

Specific questions were:

1. What are the experiences of using social media in people who are working towards recovery from an ED?
2. What are their perceptions of the influence of social media use on recovery from an ED?
3. What are the types of social media posts that people with EDs experience as being helpful and unhelpful for their recovery?

## METHOD

### Design and procedure

A qualitative design was used to explore experiences of using social media in people working towards recovery from an ED. A critical realist epistemological stance suited this design, whereby positivist assumptions about an objective reality separate from human consciousness were made, whilst acknowledging the social construction of this understanding (Maxwell, 2012). The perspective adopted was that objective factors about social media exist, but that social and cultural factors influenced how participants made sense of their experiences of using social media (Willig, 2013).

The qualitative design involved collecting data from two sources:

1. Semi-structured interviews: experiences of using social media were explored in semi-structured interviews. For part of the interview, participants simultaneously viewed their social media profiles – here, a photo elicitation method (Mannay, 2013) was employed, which involved using visual methods to generate verbal discussion and evoking memories and emotions.
2. Social media posts: participants were asked to identify a sample of social media posts that were helpful and less helpful for their recovery, which were sent to the researcher after the interview.

The semi-structured interview included a flexible schedule that was adapted as information arose. The interview schedule addressed questions relating to social media use, perceived positive and negative effects of using social media, and perceived influence of social media on recovery from an ED (Appendix B). When developing the interview schedule, a focus group was carried out with 4 individuals with EDs who were not related to the project to

discuss suitability of the interview questions, and adjustments were made accordingly. Each interview lasted between 50 and 60 minutes and was recorded with a Dictaphone.

## **Measures**

Participants completed a demographic questionnaire (Appendix C) and the Eating Disorder Examination Questionnaire (EDE-Q; Fairburn & Beglin, 2008; Appendix D). This is a 28 item self-report measure that assesses the core cognitive, emotional and behavioural symptoms of EDs. This measure was used to describe the sample of participants. The scale has good reliability and validity, and is widely considered a preeminent ED assessment tool (Berg, Peterson, Frazier, & Crow, 2012). It yields a Global score and 4 subscale scores (Restraint, Shape Concern, Weight Concern, Eating Concern), although the factor structure of the 4 subscales has not been widely supported (Allen, Byrne, Lampard, & Watson, 2011; Peterson et al., 2007). Scores can range from 0-6, with higher scores indicating greater severity of symptoms. Global scores above 2.77 are considered to be in the clinical range (Sweeting et al., 2015).

## **Participants**

### ***Recruitment***

The study was advertised through a National Health Service (NHS) ED outpatient service and through the UK ED charity Beat. Potential participants responded to the advert via email and were sent further information regarding the study. If they met the inclusion criteria, they were invited to attend an interview with the researcher at the NHS ED outpatient service in London.

### ***Inclusion/exclusion criteria***

Participants were included if they had a current or previous (up to 5 years) diagnosis of an ED (AN, BN, BED or OSFED). Given the variability noted in the field on what constitutes recovery (Noordenbos, 2011), participants were included if they self-identified as ‘working towards recovery’, placing no restrictions on what recovery entailed. Participants had to be currently using social media and between 18 – 65 years of age.

Participants were excluded if they were unable to participate in a 60 minute interview, unable to speak English, had significant communication difficulties, posed a risk under the lone worker policy, were experiencing a psychotic episode, or were currently receiving inpatient treatment.

### ***Sample***

Fifteen participants took part in the study, in line with guidelines for the sample size recommended for qualitative research. The generation of new themes is suggested to reduce after 15 interviews, when using a homogenous sample who take part in a focused, structured interview (Guest, Bunce, & Johnson, 2006). All participants were female, aged between 19 and 40 ( $M=26$ ,  $SD=5.68$ ). Twelve participants had a diagnosis of AN, 1 had a diagnosis of BN, and 2 had a diagnosis of OSFED. Demographic details and EDE-Q scores are shown in Table 1. As shown, the degree of current ED symptomatology varied across the sample and 7 of the 15 participants had EDE-Q Global scores within the clinical range.

### **Data analysis**

Data were analysed using thematic analysis, informed by the method of Braun and Clark (2006). This is a systematic approach to identifying, analysing, describing and reporting themes within data. As research in this area is in its infancy, thematic analysis was deemed

appropriate to explore themes within the data, before developing further theory or understanding (Braun & Clark, 2013). Consistent with the critical realist stance, data were not purely analysed objectively; deeper interpretation of participants' responses and social media posts were made, based on contextual and individual factors (Willig, 2013). An inductive approach was adopted, with codes identified directly from the data. However, during the code and theme development, reference to relevant research was made, as a truly inductive approach is not feasible once the literature has been engaged with. Using a hybrid deductive and inductive approach therefore offered a more robust analysis (Boyatzis, 1998; Braun & Clark, 2006; Fereday & Muir-Cochrane, 2006).

The method was informed by Braun & Clarke's (2006, 2013) 6 step guide:

1. Familiarisation with the data: interview recordings were listened to and transcribed using NVivo software. The interview and social media data were familiarised with through repeated reading/viewing and noting initial ideas. Social media posts that linked with interview data (i.e. posts that were spoken about in the interview and shared with the researcher afterwards for analysis) were familiarised with together, which added additional layers of meaning and validity and depth to the data.
2. Initial generation of codes: data were systematically analysed. Descriptive and interpretive codes were noted on the interview transcripts. Coding of the social media posts was guided by frameworks for thematically analysing images (Kędra, 2013; Shanahan, Brennan, & House, 2019), which involved describing and interpreting the content of the images and how users described the images (e.g. in captions/comments, and/or how they spoke about the posts in the interview), exploring the feelings evoked by the post and the message(s) that the image portrayed. Codes were reviewed and refined, with some being combined, discarded or replaced.



3. Themes were searched for: codes were analysed, and broad themes relevant to the research questions and patterns of meaning were identified.
4. Themes were reviewed: broad themes containing insufficient data were discarded. Themes were checked against the entire data set and between participants to identify patterns. Supervision was used to discuss the themes until a consensus on the final themes and subthemes was reached.
5. Themes were named and defined.
6. The report was produced: a detailed report was produced for each theme.

Appendix E, F and G outline additional detail regarding the coding and analysis process.

### **Ethical considerations**

Ethical approval was granted by an NHS ethics board (Appendix H and I). Informed consent to take part in the study was obtained from all participants (Appendix J and K). All participants and the ethics board received a feedback summary of the results (Appendix L and M).

Whilst the interview was focused on recovery, it had the potential to become distressing and participants were aware that they could stop the interview at any time. Should they have become distressed, participants would have been signposted to appropriate mental health services and third sector organisations (e.g. Beat). Guidance on managing distress or ethical concerns was available to the interviewer at any time, from a qualified Clinical Psychologist.

For the social media posts that were shared with the researcher, participants were asked to share posts that were their own or that were accessible within the public domain, consistent with the Data Protection Act (2018). All identifiable information was removed from the data.

## **Quality assurance**

Inter-rater reliability: a secondary coder independent of the study coded a subset of the data (20%). A proportion of the data and codes (40%) were reviewed and checked by supervisors. The final themes and included quotes were discussed and agreed with supervisors.

Reflexivity: A research diary (Appendix N) was kept to reflect on the interviews, and to note what surprised the researcher and challenged assumptions. The researcher's own experiences of using social media, and its perceived benefits and drawbacks, were discussed in formal and peer supervision. The researcher's joint role as a Trainee Clinical Psychologist and researcher in an ED service may have also influenced pre-conceptions about what was helpful and unhelpful about using social media during recovery from an ED; supervision spaces were again used to discuss this. The researcher sought to remain as curious as possible about the experiences of participants.

Table 1. *Participant Demographic Details and EDE-Q (Fairburn & Beglin, 2008) Scores.*

Pseudonym	Age	Gender	Ethnicity	Diagnosis	Duration of illness (years)	Currently in treatment	EDE-Q Global score*	Self-reported BMI
Alice	23	Female	White European	AN	9	Yes	3.56	18.9
Jemimah	23	Female	White British	AN	2	Yes	4.63	15.4
Beth	21	Female	White British	AN	3	No	2.69	19.4
Holly	29	Female	Japanese	BN	10	No	1.62	21.3
Jan	24	Female	White British	AN	2	No	1.67	22.6
Laura	31	Female	White British	OSFED	14	No	3.96	Not reported
Lisa	20	Female	White British	AN	6	Yes	1.80	15.6
Lizzie	22	Female	White British	AN	4	Yes	3.70	18.1
Hattie	40	Female	White British	AN	25	Yes	2.26	18.1
Emma	26	Female	White British	OSFED	8	No	2.08	Not reported
Rachel	19	Female	White British	AN	6	No	1.57	20.9
Elsa	23	Female	White British	AN	10	No	2.89	Not reported
Kylie	33	Female	White British	AN	15	Yes	3.80	21.2
Kara	30	Female	White British	AN	15	No	5.33	19.1
Jen	26	Female	White British	AN	13	No	1.46	22.7
<b>Mean (SD)</b>	<b>M=26 F = 15</b>			<b>AN = 12</b>	<b>M=9.47</b>	<b>Yes = 5</b>	<b>2.87 (1.23)</b>	<b>19.44</b>
	<b>(5.68)</b>			<b>BN = 1</b>	<b>(6.24)</b>	<b>No = 10</b>		
				<b>OSFED =</b>				
				<b>2</b>				

\*Scores >2.77 are considered within the clinical range on the EDE-Q (Sweeting et al., 2015)

## RESULTS

Facebook, Instagram, Twitter and Tumblr were the most frequently used social media platforms identified by the sample. All participants reported to use social media at least daily.

A total of 4 main themes and 13 subthemes were identified. Example quotes and social media posts have been included to illustrate the themes and codes.

Table 2. *Themes and Subthemes.*

Theme	Subthemes
1. Motivating recovery	1.1 Managing my own recovery 1.2 Inspiration 1.3 Promoting self-acceptance 1.4 Life outside the eating disorder
2. A supportive space to share and be open	2.1 Social support 2.2 Sharing experiences 2.3 Increasing awareness and reducing stigma
3. Maintains difficulties	3.1 Comparisons and competition 3.2 Maintains eating disorder thoughts and behaviour
4. Navigating social media	4.1 Tension between the helpful and the less helpful aspects of using social media 4.2 Anonymity, confidentiality and privacy 4.3 Managing the less helpful aspects 4.4 Changing use of social media at different stages of recovery

## **Theme 1: Motivating recovery**

Social media was experienced as a motivating resource that promoted empowerment and engagement in personal recovery. Within this theme, 4 subthemes were identified: managing my own recovery, inspiration, promoting self-acceptance, and life outside the ED.

Participants were able to use social media to take recovery into their own hands, find inspiration from others, move towards self-acceptance, and build up their life and identity away from the ED - all of which motivated them further towards recovery.

### ***Subtheme: Managing my own recovery***

Participants used social media to manage their own recovery; to learn about the recovery process, access informational support, and to document and reflect on their progress. This promoted feelings of empowerment and enabled participants to take personal responsibility for their recovery. Jen spoke of how she used social media to learn how to begin to make changes to her eating:

*“I also used it in recovery to look at constructive ways to find diets that would be baby steps towards actually ‘I’ll be ok with this’, ‘I can handle this’, and then I can move up. Because you can’t just go to eating full roast dinners every day. So yeah, I used it a lot for nutritional advice, and ways to sort of reframe my view I guess.”*

Other participants spoke of how they learned from others, which normalised the challenges of recovery. Viewing others’ progress allowed participants to learn about unfamiliar and often anxiety-provoking aspects of ED recovery. Jemimah found it helpful to normalise the physical changes her body was going through:

*“She posted one of a massive food baby, and was like bloating, which is something that I couldn’t get used to in recovery. So that really helped, because when I’m feeling*

*like that I relate back to that post and I'm like, it's normal... it's completely normal, it's because I'm in recovery."*

Social media was used as a platform to document one's recovery journey, and to reflect on progress and achievements in recovery. Hattie started *"to open up about things that [she] was trying to challenge [herself] with food wise"*. Participants were motivated by seeing how they had changed over time; social media allowed them to celebrate often small but important milestones in recovery. Lisa shared the below post, to document her progress in relation to food, reflect on the challenges of recovery, and communicate her motivation to keep going:



### ***Subtheme: Inspiration***

Social media provided a source of inspiration and hope for recovery. Following others who were making progress in recovery allowed participants to feel inspired in their own recovery:

*"Hearing other people's stories can be really inspiring, and kind of how they've managed to recover and move on with their lives." (Lisa)*

Beth used social media to share inspiration with others that recovery is possible:

*“Letting people realise that you can get to a point where you look back and you realise a lot has changed, even through like small steps. And it doesn't matter; you can get there if you trust in yourself.”*

Lizzie found it motivating to view others' progress; to see them move towards recovery and to reach a point of happiness with themselves and their body. She shared this post from one of her followers, which she found particularly inspiring:



Rachel found food inspiration on social media helpful, which motivated her to explore alternative foods and to challenge herself with her eating:

*“I was seeing all these recovery accounts and they were like ‘ooh went to this bakery and got doughnuts and cookies’ and I was like ‘oh wow’, so then... that kind of motivated me, because I wanted to go out and do those things.”*

### ***Subtheme: Promoting self-acceptance***

Social media supported the process of self-acceptance with oneself and one's body.

Following accounts that promoted a positive body image was particularly helpful, moving away from the unrealistic 'beauty ideals' that often dominate social media:

*"I follow a lot of positive body image Instagrams and stuff... And I don't follow like gym ones or anything like that anymore." (Holly)*

*"Ones that focus on acceptance of you, regardless of anything. I don't know if they're called something like 'real women' ... they just make me feel a lot more reassured I supposed, where you get pictures of what they say 'real women' just posting pictures that are not airbrushed or anything." (Laura)*

Rachel shared the below post, which focuses on moving away from appearance and noticing other strengths and qualities:

What makes someone beautiful is their kindness, compassion, creativity, their words, actions and emotions.

🌟🌈💖💖💖

Starving yourself, shrinking yourself, being overly self critical and burning yourself to the ground is the worst solution to our low self-esteem problems. We must work to grow our self-esteem and encourage back the joy, sparkle and freedom within our eyes. You are unique, different, beautiful, one of a kind and a special part of the universe.

Be proud, accept and love yourself as yourself 🌙

#beyourself #acceptyourself #loveyourself  
#forwho you are #youareabadass #youareamazing

### ***Subtheme: Life outside the eating disorder***

Participants used social media to build up their life outside the ED. Exploring interests and hobbies helped participants to move away from the focus on eating, weight and shape. Beth spoke of the importance of having a balance between 'recovery' and things 'outside the ED':

*"Things that we're doing outside of the ED, so like, if we both like art, have you seen*



*this person's post? Or have you tried this sort of thing? So trying to keep it like balanced, so it's not all one sided on recovery.”*

Jemimah posted the following picture of her enjoying a date with her partner:



Keeping connected with friends and family on social media was helpful for many, which allowed them to maintain their life outside the ED:

*“I think social media really supported that sort of process of reconnecting with friends, and really simple things like photographs after doing things with friends and chatting to people and planning parties or events or whatever we were going to do.”*

*(Jen)*

## **Theme 2: A supportive space to share and be open**

The second theme related to the supportive nature of social media; it provided a supportive space to share and be open about one’s ED and the challenges of recovery. This allowed participants to create a community where they could both receive support and provide support to others. Many also spoke of the wider societal benefits of being open about one’s

experiences, challenging stigma and increasing awareness and understanding of EDs. By creating this type of community, users felt supported, understood, and less alone in their experiences. Within this theme, 3 subthemes were identified: social support, sharing experiences, and increasing awareness and reducing stigma.

***Subtheme: Social support***

Social support was seen as a key benefit to using social media. Many participants reported feeling a sense of loneliness and isolation, and a lack of understanding from others (e.g. friends and family members). Social media offered the opportunity to connect with similar others, and to feel understood and supported by people with similar difficulties:

*“It was helpful in a way that you knew that you weren't alone, because it felt quite isolating. And kind of, to check in and have that support from other people that don't necessarily know you but they knew how difficult it was when parents or friends and family might have not understood, which was really good.” (Beth)*

Kylie spoke of the benefits of relating to others with similar experiences:

*“It's quite nice if you follow something and you come across something that somebody else has posted that relates to you, or like that you can resonate with, then that's quite nice.”*

Many participants received comments from others, offering support, praise and validation for their efforts in recovery:

*“I was just posting something as well and this girl messaged me out of the blue, saying I'm really proud of how far you've come and you've really inspired me, and that made me feel so good.” (Jan)*

Hattie shared the below comment, an example of the support she received from others:

mentioned you in a  
comment: Thank you- this  
message was lovely and  
reassuring. I'm still bricking it  
today but I'm trying to chill out  
and take it easy. It's honestly  
been so lovely and helpful  
having you cheerlead along the  
way- you've been encouraging  
and supporting me with this  
process for months and I am so  
verv thankful ❤️



55m

### ***Subtheme: Sharing experiences***

Many participants spoke of the benefits of self-disclosure and sharing difficult experiences online; it allowed them to open up and to be honest about their experiences. Lisa spoke of how sharing on social media allowed her to stand up to her ED ‘bully’:

*“I felt like I'd finally stood up to the bullies... like my eating disorder bully. I know that sounds really odd, but I felt like a release from it, and I just felt so much more confident I guess in myself. It hasn't been like the magic switch that has made my recovery like really easy or anything, but it's definitely like a really good point for me.”*

For some, social media provided a first step towards talking about their ED with others. Social media allowed Lizzie to open up and to let others know what she’d been through when she had to leave university:

*“I did a post, because I had to leave uni, and I know lots of people were like where has she gone, because I didn't tell anyone. So then I did a post and then, like I got such a good response...”*

Self-disclosing on social media enabled users to feel connected, particularly when experiences were shared. This enabled others to open up and appeared to create a safe space for talking about personal experiences:

*“Since then people have said ‘I suffer from this’ or ‘I have this’, and it’s just nice that people can open up and like talk about it and things like that, and not just be like keeping it to themselves.” (Emma)*

Showing the reality of recovery was an important aspect of sharing. Many participants connected with the notion of being ‘real’ – positive whilst connecting with the struggle of recovery:

*“And that’s when I started thinking there’s something in this. Of being real, honest, and starting talking about what it feels like to go through that process. Whether you’re still struggling, whether you’re on the journey to recovery, or whether you’re at recovery and you still have to fight. Rather than, or alongside those kind of pictures of ‘I’m doing well, I’m doing great’, I think people often need to feel the connection to the struggle.” (Kara)*

### ***Subtheme: Raising awareness and reducing stigma***

Opening up about difficult experiences also allowed participants to raise awareness and understanding about EDs in the wider population. Lisa shared on social media to challenge the stigma and shame that often surrounds mental health and EDs:

*“I’ve said that I suffer from an eating disorder. I don’t have to be ashamed of it, like I don’t have to be ashamed about saying that I have one. It’s not an illness which is, it shouldn’t be regarded as any more, you know something to be ashamed of as like a broken leg or something, because it’s a mental illness and you don’t choose it.” (Lisa)*

Laura shared information on social media to promote awareness about EDs, which she hoped would enable her followers to notice and support others with EDs:

*“I find it helpful to share some of those posts, that's actually what I use Facebook mostly for, a lot of the time, to promote awareness. So if there's, for example an article about the top ten things that were most useful that somebody said to me that were useful in my recovery, I might then re-share that, so then hopefully other people would read it and then get an idea of maybe what would be a good idea to say to somebody, if they knew somebody.”*

The below quote by Kylie, and post by Rachel, are examples of how participants found it helpful to challenge stereotypical representations of what EDs look like on social media:

*“Yeah, I think it's, because you have the stereotype of what anorexia is and stuff, but I think if you kind of see other people who don't follow that stereotype at all, it's quite nice.”*



### **Theme 3: Maintains difficulties**

Whilst social media could be helpful, it could also be used to maintain difficulties and to

‘serve’ the ED at times. Two subthemes were identified within this theme: comparisons and competition, and maintains ED-related thoughts and behaviours.

***Subtheme: Comparisons and competition***

Participants struggled with the comparisons and competition that social media promoted. Appearance-based comparison was particularly common; participants followed ‘fitness accounts’, models, and other users with EDs, which often made them feel bad about themselves and inadequate by comparison:

*“I guess just like those fitness accounts and stuff, they're not always recovery ones, but I guess it overlaps with the clean eating ones like people who post pictures of like their body and like, because then if like I compare myself to it.” (Alice)*

Many participants spoke of finding ‘transformation pictures’ (pictures comparing differences in body shape, often from a very low weight to a healthier weight) unhelpful because of the comparisons they promoted:

*“I find transformation pictures in a sense can be really unhelpful. I mean I hate them pretty much full stop and I hate the fact that newspapers use them all the time as well. But, I think I don't mind people posting, but when you have like 2 photos side by side, and if someone's in a bad place on one side and really underweight and ill, but it's more the fact that a lot of the pictures that would be posted are body checks. So it's not them sat down with some friends and they're underweight, it's more like purposefully checking their body, so I don't find that helpful at all” (Beth)*

Comparing food and exercise was another form of social comparison which participants found difficult to manage:

*“If I eat something and I'm comparing it to what other people eat then I'm really like oh is this the right amount, or is this too much, which is like I don't know, it just makes it a bit more like obsessive in my head.” (Alice)*

Others reported being pulled in to comparing the severity of their illness with others:

*“I think there is definitely a bit of competitive competition in terms of, it's not like anyone wants to be ill, but there's definitely that kind of level of oooh who's 'iller', or who's 'illest', or who's been in hospital X times, or who's been on a tube X times or something.” (Lisa)*

***Subtheme: Maintains eating disorder-related thoughts and behaviours***

Social media could also be used to maintain ED-related thoughts and behaviours, keeping participants trapped in thinking about food, weight and shape. Participants spoke about social media keeping them pre-occupied with their ED, which held them back from recovering:

*“It's not normal to post that much about your food. It's like the motive behind it is good and you want to recover, but actually it's probably holding you back because it's still that obsession with food and remembering what you've eaten and things like that.” (Lisa)*

Kylie used social media as a way to avoid eating; scrolling through photos and videos of food allowed her to virtually consume foods without actually eating, which enabled her to continue to restrict:

*“If I wanted to eat like I'd watch a video instead of eating.”*

Many participants reported coming across ‘triggering’ information on social media.

Information related to weight loss, exercise, and thin ‘body ideals’ often triggered ED-related

thoughts and pushed participants towards restricting their food and/or exercising. Holly spoke of finding information related to extreme weight loss:

*“There would be like fitness things which aren't really fitness things, like do this many sit-ups and this many squats, that kind of thing. Go to bed earlier, go for a walk instead of eating...”*

Jan shared an example of a triggering post that was unhelpful:



#### **Theme 4: Navigating social media**

The final theme relates to how participants navigated social media throughout their recovery. There was a tension between the helpful and unhelpful aspects of social media that participants grappled with. Concerns about anonymity, confidentiality and privacy were also present. Many participants were finding ways to manage the less helpful aspects of social media, and used it differently during different stages of their recovery.



***Subtheme: Tension between the helpful and unhelpful aspects of social media***

Conflicting views on whether social media was helpful or not were present across the interviews. Many participants reported that social media could be helpful sometimes, but were also aware of its dangers and the negative impact it could have. Hattie was torn between whether social media was helpful or not:

*“I don't feel that it's helpful in terms of recovery anymore. I don't know whether, yeah, I'm really undecided whether it does help people or not. I think my account did help some people, and my comments and my support did help some people, and I'm almost quite proud of some of the feedback that I got, but I'm wary about it.”*

For many, there was a temptation to look at less helpful content:

*“There's also the different hashtags that you come across and sometimes you do see sort of pro-ana type stuff, which I try to avoid, but sometimes I just get too tempted to look and then it makes me feel bad, but I like try to make myself not seek it out but then sometimes I do get really obsessed with stuff and looking stuff up and I can't help myself, then it makes me feel bad and like I'm too fat or whatever.” (Alice)*

The openness and unpredictability of social media also meant that unhelpful content could come up unexpectedly, which was difficult to manage:

*“You have no control over what you're going to see, so seeing something like that could be really helpful, but then someone might post something about how they'd succeeded with a certain diet that day, and they hadn't eaten in three days, and it would just take you straight back again.” (Jen)*

***Subtheme: Anonymity, confidentiality and privacy***

Issues relating to anonymity and confidentiality were present across the interviews. For some, the anonymous nature of social media was helpful, whereas for others, concerns about confidentiality and the risk of people ‘finding out’ about their ED held them back from sharing. Hattie had an anonymous account to protect her from being identified:

*“I didn't put anything identifiable about myself, I was very careful not to post where I was from in the country. I didn't post photos of anything other than food.”*

Elsa spoke of how the anonymous nature of social media provided a level of distance from others, creating a safer space online than in person:

*“It's totally anonymous... so if it all goes horribly wrong I can be like well I'm not talking to you again. Whereas if it's face to face, you have to live with that. Umm, I mean yes, also no-one can say that you don't look like you have an eating disorder, because they don't necessarily see you. I guess when it helped me most of all was when I was bingeing and purging a lot. I was so ashamed of it, but being able to talk about it online was really helpful.”*

Others reported concerns of putting their ED ‘out there’, and how it would be perceived, particularly from friends, family and colleagues:

*“Once you put it on social media it's out there. Even sharing something that's like, not related to me, is like nerve-wracking, in case anyone makes a connection.” (Kylie)*

A theme across many of the interviews was having separate ‘recovery’ and ‘personal’ accounts, with different followers, privacy settings, and types of content. Beth shared how this felt like she was separating the different parts of her:

*“It was like separated this is the recovery part of me and this is the like personal part, and then, it was weird to have that contained.”*

***Subtheme: Managing the less helpful aspects***

Participants were aware of the less helpful aspects of social media and had developed strategies to help them to manage this. This included avoiding less helpful social media, limiting time spent on social media, curtailing unstructured browsing, unfollowing unhelpful accounts, and distancing oneself from triggering content. Beth spoke of setting boundaries around her social media use:

*“I'm kind of learning to set boundaries, and as harsh as it might sound like cut people out if they're not helpful.”*

Others developed cognitive strategies to help manage unhelpful social comparisons, remembering that what you see on social media is not always real life:

*“I think you've also just, always got to remember that what you see on social media is not real life... They might look one way on the internet, but they can actually look really different in real life... You know like, filters and now, things like that, you can put on loads of effects and things like that, you've just really got to remember that what you see on social media is not like real life, and you like can forget that sometimes.” (Lisa)*

Emma also began to stop comparing herself to others on social media:

*“I just thought the best thing to do is stop trying to compare myself to everyone else on social media because it's not helping me and I don't want to be involved in it.”*

***Subtheme: Changing use of social media at different stages of recovery***

Participants' journeys through recovery reflected changes in their use of social media; they used social media differently depending on their stage of motivation to recover. For some, social media was particularly helpful during the start of recovery, when they were just beginning to make changes. Early on in Lizzie's recovery, social media was particularly helpful; she started following recovery-focused content which helped to motivate her, but she was still struggling with her ED:

*"In the beginning it did help but like I followed people who were doing better so it was really motivational. So that was before I, it when I was quite ill."*

Others reported using social media in unhelpful ways when they were immersed in their ED and less motivated to recover:

*"When I was ill like in the beginning, I was posting pictures of myself at sort of thinner angles and that kind of thing." (Holly)*

For many participants, as they journeyed towards recovery the less helpful aspects of using social media became more apparent. This led participants to moderate their use; many reported taking a step back from social media, particularly the 'recovery community', as they moved further towards recovery:

*"Then eventually said look I'm, I'm not going to keep up this recovery Instagram anymore, I don't feel a need to, I think it's a bit disordered to keep posting so I'm going to bid this community farewell but I'm going to leave my posts up there."*  
(Hattie)

Kara, on the other hand, spoke of being able to use social media more now that she was

further through her recovery; she was at a place where she could follow content related to EDs and mental health now, without getting triggered:

*“I'm at a place where I can actually follow stuff now... For years I did not follow anything... I think you need to be at a place where you know you won't get triggered.”*

## **DISCUSSION**

This study explored experiences of using social media in people recovering from an ED, focusing on the helpful and unhelpful experiences of using social media during recovery from an ED. The results will be discussed in line with the research questions, previous research and applicable psychological theory.

Social media was experienced as a motivating resource that offered participants the opportunity to manage their own recovery, promoting empowerment and enhancing personal responsibility for recovery. Motivation to change is an important aspect in the treatment and recovery process (Casasnovas et al., 2007; Knowles, Anokhina, & Serpell, 2013; Matusitz & Martin, 2013). The results from this study suggest that social media, if used helpfully, can capitalise on motivation to change and can be used to help work towards recovery.

Participants used social media to learn about the recovery process, document and reflect on their progress through recovery, and to find inspiration and support from others. This fits with content analyses of social media platforms (e.g. Branley & Covey, 2017; LaMarre & Rice, 2016) which suggest that, through observing the content of information on social media, social media can be used to motivate recovery in users. Findings are also consistent with research on the use of moderated online ED support groups, which suggest that engaging with such resources is associated with becoming an active partner in the management of one's ED, facilitating agency and engagement in personal recovery (Aardoom, Dingemans, Boogaard, & Van Furth, 2014; Kendal, Kirk, Elvey, Catchpole, & Prymachuk, 2015).

Social support was a key benefit to using social media when recovering from an ED.

Relatedness to others is often compromised in EDs, with loneliness (Levine, 2012) and poor social relationships serving as causal and maintaining factors (Treasure, Corfield, & Cardi, 2012). Social media allowed participants to feel connected, understood, and supported by

others. The supportive nature of social media meant that participants felt able to open up about their experiences of recovery, and to challenge stigma and negative misconceptions of EDs in the wider population.

Findings offer support for the social identity model of recovery (Best et al., 2016); users were able to build up a social identity centred on recovery and support. Connecting with others who were also making progress in their recovery enhanced motivation to recover, and participants were able to create a supportive space centred around sharing, hope and self-acceptance. Using social media to build up their life outside the ED may have enabled some participants to move away from the ED being their sole source of interest, allowing them to develop a sense of purpose and meaning in life.

Whilst there were key benefits to using social media, there were also clear dangers. Social media could be used to maintain ED difficulties by promoting comparisons and competition, and through encouraging ED-related thoughts and behaviours. There is growing evidence of the dangers of social media use on ED symptoms. A systematic review by Holland and Tiggeman (2016) concluded that social media use is associated with body image dissatisfaction and disordered eating outcomes, and appearance-based social comparison was suggested to mediate this relationship. There is also evidence of the dangers of ‘pro-ED’ online content - websites that promote a positive view of EDs, promoting weight loss and ED symptoms (Borzekowski, Schenk, Wilson, & Peebles, 2010; Juarascio, Shoaib, & Timko, 2010). Pro-ED content was readily available on social media, which participants found triggering. The open nature of social media meant that pro-ED and recovery-focused content sat side by side, the dangers of which have been highlighted by previous research (Branley & Cooper, 2017; De Choudhury, 2015; Wang, Ianni, & Mentzakis, 2018; Yom-Tov, Fernandez-Luque, Weber, & Crain, 2012).

The ways in which participants navigated social media through their recovery was an interesting finding. The tension between the helpful and less helpful aspects of social media perhaps reflects the ambivalence that many people with EDs experience in relation to recovery (Schmidt & Treasure, 2006; Serpell & Treasure, 2002). The daily conflict between the desire to engage in ED behaviour and the desire to recover seemed to be reflected by similarly being pulled between using social media helpfully or unhelpfully. Participants had developed, or were developing, insight into the less helpful aspects of social media, and ways to manage this. Their use of social media appeared to change dependent on their stage of motivation and recovery. This fits with Keski-Rahkonen and Tozzi (2005)'s suggestion that online support groups may be helpful at a particular time in one's recovery, providing peer support and disseminating awareness about EDs during the early stages of treatment. In the later stages of recovery, however, interacting online with others with EDs could maintain difficulties and delay recovery, and should therefore be discouraged. Additional research, however, is needed in order to further understand this association.

### **Clinical implications**

The findings of this study have important clinical implications, offering insight into how social media may promote engagement in recovery outside of traditional healthcare services, and to how clinicians may work with and alongside a patient's social media use. This is important given the ubiquitous nature of social media use.

Discussions of social media should be incorporated into conversations with patients, aiming to understand how they use social media and incorporating this into a psychological formulation that sensitively considers how social media links to ED difficulties. Encouraging reflection on the helpful and less helpful aspects of social media for recovery could be important. Notably, clinicians need to consider the dangers of social media but also how it



may be used in a helpful way to promote recovery. This is incorporated in the FREED model (Brown et al., 2018) but also represents good practice for the treatment of EDs.

Exploring ways to modify social media use to promote recovery may be helpful. This may involve ‘unfollowing’ unhelpful accounts to create a less image-focused feed, engaging with recovery style content, reducing unstructured browsing, and/or limiting overall use. Research indicates that targeting appearance-based comparisons is particularly important (Holland & Tiggeman, 2016). Encouraging time away from social media and supporting the development of offline relationships and interests could also be beneficial. Moreover, resources could be developed, for example psychoeducational material promoting healthy social media use. Services could consider running groups that focus on the benefits and risks of social media, which may allow patients to share ways in which they have been able to manage their social media use with others.

### **Research strengths and limitations**

This study adds to the limited literature on the role of social media in ED recovery. The qualitative method allowed for detailed exploration into participants’ experiences of using social media, and the flexible interview schedule allowed the voice of each participant to be heard, which is helpful for a subject area where research is limited. Viewing the participant’s social media profiles during the interviews and including social media posts in the analysis enhanced the richness of the data and provided validity and depth. This also had the potential to reduce any social desirability effects by not solely relying on the subjective perceptions of participants.

The researcher was mindful of subjectivity and remained reflexive, utilised supervision and kept a research diary throughout. However, researcher bias may have influenced the study findings, such as the researcher being a social media user. Interpretation of images is also

more open to bias and subjectivity, which may have influenced the findings.

Participants were a self-selecting group who had volunteered to take part in the study. The selected sample were actively engaged with using social media and were keen to participate in the study. However, there may be other individuals who use social media in different ways (e.g. in more passive, or unhelpful ways), who may have been less likely to take part in a study focused on recovery. Furthermore, whilst it was intended to recruit a diverse sample, the recruited participants were all female, predominantly white British, and the majority had a diagnosis of AN. This limits the generalisability of the results, particularly to populations of different diagnoses and demographics. However, whilst the recruited sample were not representative of the overall ratio of different ED diagnoses and demographics, this may reflect the types of individuals that are most active and visible on social media. LaMarre and Rice (2017) note how social media reinforces stereotypical representations of EDs and what recovery looks like. Those who do not fit such stereotypes (e.g. males, or those with other diagnoses) may be less likely to engage with ED content on social media, and equally less likely to respond to take part in a study of this nature.

It was possible to characterise the current ED symptoms of participants by obtaining EDE-Q data. This allowed for reflection on variability within the sample in terms of current ED symptomatology. Participants all identified as ‘working towards recovery’, however some participants still endorsed a high degree of current ED symptoms. The interview findings also need to be interpreted in this context, and perceptions of social media use are likely to differ according to different stages of recovery.

### **Future research**

Being open and curious about the experience of recovering from an ED is key to research in this area. Future research could use quantitative measures to assess the impact of social media

use on ED symptoms and recovery outcomes, complementing qualitative work. Further investigation into the stage of recovery, motivation to change, and associated social media use is also needed. Grounded theory (Strauss & Corbin, 1997), for example, could be used to develop a model of the process of recovery from an ED and how social media use varies across this process. Future research should also aim to include more diverse samples, including males with EDs, and those with other diagnoses (especially BED, which was absent within this sample).

## **Conclusion**

The findings from this study suggest that people with EDs use and interact with social media platforms in different ways during their recovery. There were perceived benefits to engaging with social media during the recovery process, promoting motivation and providing a platform for social support and self-disclosure. Results also suggest, however, that social media can be used to maintain or exacerbate ED symptoms and may pose a risk to recovery at times. Balancing the helpful and less helpful aspects of social media was a challenge for many - something which participants were learning to manage based on their level of motivation and stage in their recovery journey. Findings have important implications for clinical practice, working alongside, not against, social media use in those with EDs.

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Section C:  
Appendix of supporting material

A thesis submitted in partial fulfilment of the requirements of  
Canterbury Christ Church University for the degree of  
Doctor of Clinical Psychology  
SEPTEMBER 2019

SALOMONS  
CANTERBURY CHRIST CHURCH UNIVERSITY

## Section C: Appendices of supporting material

### Appendix A: Critical appraisal tables (Section A)

Table 1. *Critical Appraisal of Quantitative Studies (and those with a Quantitative Component) using the National Institute of Health (NIH, 2014) Quality Assessment Tool for Observational Cohort and Cross-sectional Studies.*

	Was the research question or objective in this paper clearly stated?	Was the study population clearly specified and defined?	Was the participation rate of eligible persons at least 50%?	Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?	Was a sample size justification, power description, or variance and effect estimates provided?	For the analyses in this paper, were the exposure(s) of interest measured prior to the outcome(s) being measured?	For exposures that can vary in amount or level, did the study examine different levels of the exposure as related to the outcome (e.g., categories of exposure, or exposure measured as continuous variable)?	Were the exposure measures (independent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Was the exposure(s) assessed more than once over time?	Were the outcome measures (dependent variables) clearly defined, valid, reliable, and implemented consistently across all study participants?	Were the outcome assessors blinded to the exposure status of participants?	Was loss to follow-up after baseline 20% or less?	Were key potential confounding variables measured and adjusted statistically for their impact on the relationship between exposure(s) and outcome(s)?	Additional limitations
<b>Aardoom et al. (2014)</b>	Yes	Yes	Yes	Yes (although risk of selection bias)	No	No (cross-sectional)	N/A	Yes (although bias towards females)	No (cross-sectional)	Yes (although based on self-report)	No	N/A	No	Retrospective design risks recall bias
<b>De Choudhury (2015)</b>	Yes	Yes (although data doesn't contain any clinical information)	N/A	Yes (although some users may be mis-identified or missing)	No	No (observational)	N/A	Yes	No	Yes	No	N/A	No	



		or demographi c details)												
Saffran et al. (2016)	Yes	Yes	Yes	Yes (although risk of selection bias)	No	No (cross-sectional)	N/A	Yes (although bias towards females)	No (cross-sectional)	Yes (although one questionnaire was created for the study, and based on self-report)	No	N/A	No	
Tan et al. (2016)	Yes	Yes	Yes	Yes (although risk of selection bias)	No (small sample size)	No (cross-sectional)	N/A	Yes (although bias towards females)	No (cross-sectional)	Yes (although one questionnaire was created for the study, and based on self-report)	No	N/A	No	Mostly descriptive; statistical tests used are not clear
Teufel et al. (2013)	Yes	Yes	N/A	Yes (although a number of groups couldn't be included due to restriction access)	No	No (observational)	N/A	N/A	No	Yes	No	N/A	No	Facebook is constantly changing so reproducibility is limited
Wang et al. (2018)	Yes	Yes (although data doesn't contain any clinical information or demographic details)	N/A	Yes (although some users may be mis-identified or missing)	No	No (observational)	N/A	Yes	No	Yes	No	N/A	No	

<b>Weseman n and Grunwalk (2008)</b>	Yes	Yes (although data doesn't contain any clinical information or demographi c details)	Yes	Yes (although some users may be mis-identified or missing)	No	No (observati onal)	N/A	Yes	No	Not sure (qualitative inaccuracies may have occurred during classificatio n, which subsequentl y may have effected the quantitative parameters)	No	N/A	No	
<b>Yom-Tov et al. (2012)</b>	Yes	Yes (although data doesn't contain any clinical information or demographi c details)	N/A	Yes (although some users may be mis-identified or missing)	No	No (observati onal)	N/A	Yes	No	Yes	No	N/A	No	Limited to communitie s on Flickr; little interaction data such as viewing behaviour

Table 2. *Critical Appraisal of Qualitative Studies (and those with a Qualitative Component) using the Critical Appraisal Skills Programme (CASP; Public Health Research Unit, 2006)*

	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?	Additional limitations
<b>Branley and Covey (2017)</b>	Yes	Yes	Yes	Yes (posts sampled to reach data saturation)	Yes	No (theoretical stance and personal assumptions not stated)	Yes	Yes	Yes	Discusses contribution to knowledge/ understanding and future research needed	Demographic details and clinical characteristics not known (although predicted female bias); not possible to capture/analyse full social media data
<b>Eichorn (2008)</b>	Yes	Yes	Yes	Yes	Yes	Partly (theoretical stance stated but not personal assumptions)	No (no statement of ethical considerations or privacy issues)	Yes	Yes	Compliments the literature on types of social support solicited and provided in online support groups.	Findings are only directly comparable to Yahoo! groups and may not represent the content of ED support groups on other websites; Demographic details/ clinical characteristics not available
<b>Eikey and Booth (2017)</b>	Yes	Yes	Yes	Yes (self-selective, some participants had been formally diagnosed and some not; all female)	Yes	No (personal assumptions / theoretical stance not stated)	No (no statement of ethical approval or how informed consent was obtained)	Yes	Yes	The only study exploring experiences of using social media from the perspective of people who use it. Important	

<b>Flynn and Stana (2012)</b>	Yes	Yes	Yes	Yes (saturation reached)	Yes	Partly (theoretical stance stated but not personal assumptions)	No (no statement of ethical considerations or privacy issues)	Yes (two coders)	Yes	clinical implications. Important contribution to female-biased literature	Demographic details and clinical characteristics unknown; limited to one forum
<b>Hastings et al. (2016)</b>	Yes	Yes	Yes	Yes (online recruitment, although no justification for sample size; all female)	Yes (data collected online using familiar interactions)	Partly (theoretical stance stated but not personal assumptions)	Yes	Yes	Yes	Important contribution to understanding of the role of social identity in promoting recovery within online communities. Important clinical implications.	Retrospective accounts of group experiences
<b>Holmes (2017)</b>	Yes	Yes	Yes	No (subjective justification for sample size)	Yes	Yes (theoretical stance and researcher's own experience with ED is stated)	No (no statement of ethical approval or acknowledgment of privacy issues)	No (single researcher, no mention of research supervision to validate themes and discourses)	No (lengthy summary of findings, results and discussion section are combined)	Subjective (appears to relate to the researcher's personal experiences and opinions)	
<b>Kendal et al. (2015)</b>	Yes	Yes	Yes	Yes	Yes (although data collected over 4 months, seasonal trends not identified)	No (personal assumptions and theoretical stance not stated)	Yes	Yes	Yes	Important contribution to the literature	Did not evaluate the impact of moderation
<b>Keski-Rahkonen and Tozzi (2005)</b>	Yes	Yes	Yes	Yes	Yes	Partly (theoretical stance stated but not personal assumptions)	Yes	No (analytic process not clearly outlined; no cross-validation)	Yes (examples given)	Interesting study related to the stages of change model of recovery, valuable findings	Accuracy of available information (demographics, clinical information) was assumed based on self-report

<b>LaMarre and Rice (2017)</b>	Yes	Yes	Yes	Yes (although no justification for number of images)	Yes	Partly (theoretical stance stated but not personal assumptions)	No (no statement of ethical approval or acknowledgment of privacy issues)	Can't tell (text examples are used to illustrate the themes but no images)	Yes	Good contribution to literature, challenging stereotypical representation of EDs	Little known about the people posting e.g. demographics, clinical characteristics; Did not analyse viewer comments
<b>McCormack and Coulson (2009)</b>	Yes	Yes	Yes	Yes	Yes (although observation specific to one time period, majority female users)	Partly (theoretical stance stated but not personal assumptions)	Yes	Yes (although only two coders)	Yes	Discusses contribution to existing knowledge, clinical implications, and future research needed	Observation specific to one time period; limited to one forum; some demographics and clinical characteristics not collected
<b>McNamara and Parsons (2016)</b>	Yes	Yes	Yes	Yes (although no justification for sample size)	Yes	Partly (theoretical stance stated but not personal assumptions)	Yes	Yes	Yes	Provides new insights into the role of social identity within online community and how this can promote (rather than hinder recovery)	Participant demographics/ clinical characteristics not reported
<b>Periera et al. (2016)</b>	Yes	Yes	Yes	Yes (although small sample)	Yes (first 50 videos chosen)	No (personal assumptions / theoretical stance not stated)	Partly (ethical issues are considered in limitations)	Yes (although hypotheses were developed after the data had been collected – results may be biased in favour of these hypotheses)	Yes	Valuable contribution to video testimonials on YouTube	Demographic details/ clinical characteristics not confirmed
<b>Riley et al. (2009)</b>	Yes	Yes	Yes	No	No (data collected over a 3-days over	Partly (theoretical stance stated	Yes	Not clear (analytic process,	Yes	Discusses contribution to existing	Demographic data not available, absence of gender in analysis

					Christmas - not representative)	but not personal assumptions)		bracketing and validation not clear)		knowledge, clinical implications, and future research needed	
<b>Walstrom (2000)</b>	Yes	Yes	Yes	No (very small sample size – 3 exchanges of communication – no justification for this)	Yes (although only 3 exchanges of communication)	Partly (theoretical stance stated but not personal assumptions)	Partly (subjective acknowledgement of ethical issue)	Partly (lengthy description of analytic process, although only one researcher and no mention of research supervision to validate themes and discourses)	No (lengthy summary of findings, difficult to follow)	Small contribution to literature and understanding	Written in first person
<b>Weseman and Grunwald (2008)</b>	Yes	Yes (mixed- methods)	Yes	Yes	Yes	No (personal assumptions and theoretical stance not stated)	No (no statement of ethical approval or acknowledgement of privacy issues)	No (states that grounded theory was used, although the analytic procedure is not clear; categorisation by only two raters)	No (grounded theory model is not clear)	Valuable contribution to literature on BN (opposed to AN)	Qualitative inaccuracies may have occurred during classification, which subsequently may have effected the quantitative parameters
<b>Winzelberg (1997)</b>	Yes	Yes	Yes	Yes	Yes (although data collected over a brief time period)	No (personal assumptions and theoretical stance not stated)	Partly (stated that consent wasn't obtained due to public nature)	No (analytic process not clear, examples of themes not given)	Partly (research findings are outlined but these are not always backed up with examples)	One of the first studies on online support groups for people with EDs	Limited to one forum, demographic details not collected

## Appendix B: Interview question guide

What are the main social media accounts that you use?

- *Facebook? Instagram? Tumblr? Pinterest? Any others?*

How do you use social media?

- *How often? How long for?*

How interactive are you on social media?

- *Do you upload pictures/posts? What sort of things do you post?*
- *Do you post about your eating disorder? What sort of things?*
- *Do you post about your recovery? What sort of things do you post about your recovery?*
- *Do you comment on others' posts? Do you like others' posts?*
- *Do you look at pictures/read content? What sort of things?*
- *Do you follow other people who post about their eating disorder and recovery? Do you interact with them too?*

Thinking more broadly about recovery from an eating disorder, what would you say recovery means to you?

How do you feel using social media affects your recovery from an eating disorder?

- *When you upload pictures/posts, how does this affect you?*
- *How does it affect you when you post about your recovery?*
- *How does it affect you when others like your posts? What if you don't get many likes?*
- *How does it affect you when others comment on your posts?*
- *How does it affect you when you look at pictures or read content?*
- *How does it affect you when you see others post about their recovery?*
- *How does it affect you when you see posts/pictures of people that are not at the same stage of recovery as you?*
- *What do you find most helpful about using social media in your recovery?*
- *What do you find least helpful about using social media in recovery?*
- *Is there anything about it that makes recovery or weight gain more difficult?*

Do you remember when you started using social media in relation to your recovery?

- *What made you start?*
- *What was helpful at the time?*
- *How does that compare to now?*

Would you mind showing me an example of something that you post?

- *Can you remember what your intention was behind this post? What were you thinking? How did you feel? What were you doing?*
- *Can you remember how you felt when other people commented on it?*
- *You got 'x' likes, how did that make you feel?*
- *How did posting that influence your thoughts and feelings about yourself and your eating disorder?*
- *Did it influence your behaviour? Your eating?*

- *Is this typical of the sort of things that you post? Would you mind showing me another example of something you've posted recently?*

Would you mind showing me an example of someone that you follow?

- *How do you feel when you see a post like that? How does it affect you?*
- *Is this typical of the people that you follow?*

It would be really helpful if I could include an example of a post in my analysis. Would you mind sharing an example of a post that you feel is particularly helpful for your recovery? (either your own post, or one that is publicly accessible)

- *How do you feel this is helpful? What's helpful about it?*
- *Would it be ok if I took a copy of this to include in the analysis?*

Could you now share an example of a post that you feel is less helpful for your recovery? (either your own post, or one that is publicly accessible)

- *How do you feel this is unhelpful? What's unhelpful about it?*
- *Would it be ok if I took a copy of this to include in the analysis?*

Are there any types of posts that you would try to actively avoid looking at on social media?

When would you be most likely to use social media?

- *When would you be most likely to post?*
- *What thoughts, feelings, situations make you more likely to use it?*

How does using social media compare to any other self-help / eating disorder websites that you know of?

- *Have you ever been part of any online recovery forums or support groups? What was this like? How does using social media compare to this?*
- *Have you ever used any other types of websites relating to eating disorders? What was this like? How does using social media compare to this?*

Is there anything else that you find helpful about using social media, in general?

- *Does it affect your friendships? Relationships? Hobbies/interests?*

Is there anything else that you find unhelpful about using social media, in general?

- *Is there anything that is difficult about it?*
- *Do you find yourself comparing yourself to others?*

Do you interact with people without eating disorders on social media too?

- *How does this compare to speaking to people with eating disorders?*
- *What are the main differences?*
- *Does this affect your recovery at all?*



## Appendix C: Demographic questionnaire

### 'About me' Questionnaire

The information reported on these pages will be confidential and will be kept separate from your interview. These details will not be made available to anyone other than the lead researcher Jenny Beardwood. Any data reported will be anonymised.

<b>Full name</b>			
<b>Date of birth</b>			
<b>Gender</b>	<input type="checkbox"/> Female <input type="checkbox"/> Male <input type="checkbox"/> Transgender <input type="checkbox"/> Prefer not to say <input type="checkbox"/> Other (please specify) .....		
<b>Ethnicity</b>	<b>White</b> <input type="checkbox"/> British <input type="checkbox"/> Irish <input type="checkbox"/> European (please specify) ..... <input type="checkbox"/> Any other white background (please specify) .....	<b>Black</b> <input type="checkbox"/> British <input type="checkbox"/> African <input type="checkbox"/> Caribbean <input type="checkbox"/> Any other black background (please specify) .....  <b>Asian</b> <input type="checkbox"/> British <input type="checkbox"/> Indian <input type="checkbox"/> Chinese <input type="checkbox"/> Japanese <input type="checkbox"/> Any other Asian Background (please specify) .....	<b>Mixed</b> <input type="checkbox"/> White and Black African <input type="checkbox"/> White and Black Caribbean <input type="checkbox"/> White and Asian <input type="checkbox"/> Asian and Black Caribbean <input type="checkbox"/> Asian and African <input type="checkbox"/> Any other mixed background (please specify)  <input type="checkbox"/> Any other ethnic group (please specify) ..... ..... ..... ..... <input type="checkbox"/> Prefer not to say

<b>Education</b>  (please tick your highest education level)	<input type="checkbox"/> School (up to age 16) <input type="checkbox"/> School/college (up to age 18) <input type="checkbox"/> Apprenticeship <input type="checkbox"/> Degree (undergraduate) <input type="checkbox"/> Masters (postgraduate) <input type="checkbox"/> PHD/Doctorate <input type="checkbox"/> Other (please state) .....	
<b>Current employment status</b>	<input type="checkbox"/> Employed full time <input type="checkbox"/> Employed part time <input type="checkbox"/> Self-employed <input type="checkbox"/> Unemployed <input type="checkbox"/> Student <input type="checkbox"/> Other (please state) .....	
<b>Relationship status</b>	<input type="checkbox"/> Single <input type="checkbox"/> Married <input type="checkbox"/> In a relationship <input type="checkbox"/> Divorced/Separated <input type="checkbox"/> Widowed <input type="checkbox"/> Other (please state) .....	
<b>Eating disorder diagnosis</b>	Please state (if known):	
<b>When did your eating disorder first emerge?</b>	Year:	
<b>When was your first contact with eating disorder services?</b>	Year:	
<b>Are you currently receiving treatment for your eating disorder?</b>	<input type="checkbox"/> Yes <input type="checkbox"/> No If yes, please state the service you are currently under ..... ..... If no, please state your GP practice ..... .....	

**Appendix D: EDE-Q**

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## Appendix E: Theme development flow chart

**Data were systematically read and worked through using NVIVO software; interesting aspects of the data were noted**

(15 individual interview transcripts, 97 social media posts)



**Initial codes ('nodes') were identified using NVIVO**

Codes were reviewed and refined; some were combined, discarded or replaced



**Searching for themes**

Codes were reviewed and categorised into broad themes. Themes were clear patterns and important ideas that linked to the research questions.

19 broad themes were identified across the entire data set:

1. Managing and learning about recovery
2. Documenting and reflecting on progress and achievements
3. Social support
4. Motivation
5. Life outside the eating disorder
6. Self-acceptance
7. Self-disclosure
8. Safe space
9. Showing the reality of recovery

10. Raising awareness and reducing stigma
11. Anonymity, confidentiality and privacy
12. Comparisons and competition
13. Maintains eating disorder behaviour
14. Distressing and triggering content
15. Impact on thoughts and feelings
16. Conflict between the helpful and less helpful aspects of using social media
17. Managing the less helpful aspects
18. Changing use of social media at different stages of recovery
19. Exclusivity and unwritten rules



### **Reviewing themes**

The themes were reviewed to see if there were sufficient data to support them and whether they were present and/or meaningful across participants. Themes that were not sufficiently supported were discarded; for example, ‘exclusivity and unwritten rules’ was only talked about by 3 participants.

Broad themes were compared with one another to see if they could be combined. For example, ‘managing and learning about recovery’ and ‘documenting and reflecting on progress and achievements’ were combined under the theme ‘managing my own recovery’

Data within each theme were reviewed to ensure that they clearly related to each other. Data across themes were reviewed to ensure they were meaningfully related whilst being distinctly different from each other.

**Appendix F: Full interview transcript**

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**Appendix G: Table of codes with data examples**

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**Appendix H: Confirmation of ethical approval from REC**

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**Appendix I: Confirmation of ethical approval from HRA**

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## **Appendix J: Participant information sheet**

### **Participant Information Sheet**

#### ***Social Media, Eating Disorders and Recovery***

*Experiences of using social media in people with eating disorders who are working towards recovery*

#### **Introduction**

You have been invited to take part in a research project that aims to explore experiences of using social media in people with eating disorders who are working towards recovery. Please take the time to read this information sheet before you decide whether you would like to give consent to take part in the study. The following information outlines why the research is being carried out and what it will involve.

#### **What is the purpose of the research?**

The study aims to gain an understanding of people with eating disorders' experience of using social media, and how this may affect their recovery. Research has shown that using social media may influence recovery, in both positive (e.g., by increasing opportunities for social support) and negative (e.g., through negative comparisons to others) ways. However, there has been little research that has involved actually speaking to people with eating disorders who use social media to explore what they find helpful and unhelpful about it, and how they feel this may affect their recovery journey. This study aims to provide a greater understanding of the experience of using social media for people working towards recovery from an eating disorder. This may help to tailor treatments for eating disorders to accommodate social media use and to promote positive social media use for those with an eating disorder.

#### **The researchers**

This research is being carried out by Jenny Beardwood, a Trainee Clinical Psychologist at the Salomons Centre for Applied Psychology, Canterbury Christ Church University. The study is part of Jenny's Clinical Psychology Doctorate training, and is being supervised by Dr Karina Allen (Clinical Psychologist, Maudsley Eating Disorder Service) and Dr Daniel Salter (Clinical Psychologist, Salmons Centre for Applied Psychology).

#### **Why have I been invited to take part in the study?**

You have been invited to take part in this research as you have either responded to an advert to say that you are interested in taking part, or you have consented be contacted about potential research projects.

### **Do I have to take part?**

You are under no obligation to take part in the research. Even if you do agree to take part you may change your mind at any time, without having to give a reason. Participation is entirely voluntary. Your decision will not affect the care that you receive in any way. You may wish to take this information sheet away with you and speak with someone independent, such as a friend, family member, or trusted professional when deciding whether to take part in the research.

### **What will happen to me if I take part?**

If you would like to take part in the research, please contact us on the contact details provided. You can ask any questions that you may have and if you would still like to take part we can arrange to meet at a time that is convenient to you.

Interviews will be conducted at the **Eating Disorders Service at the Maudsley Hospital, Denmark Hill, London, SE5 8AZ**. We can offer assistance with travel costs.

When we first meet, you will be asked whether you have any further questions, and we will check whether you still want to go ahead with the interview. If you still want to take part, you will be asked to read and sign a consent form to show that you agree to take part in the research.

You will then be asked to complete an 'about you' questionnaire, which includes questions about your age, occupation, and how long you have experienced an eating disorder for. You will also be asked to complete a questionnaire which is a measure of eating disorder symptoms. This is so that we have some basic information about the people who take part in the research.

After this you will be interviewed for around 45 minutes to one hour. You will be asked questions such as how often you use social media, what sort of things you post, how this affects you, and your opinions about whether this has impacted on your recovery from eating difficulties. You will also be asked whether you would mind sharing some examples of the things that you post on social media, and the people that you follow. If you are happy to do this, please could you bring along your device that you use for social media (e.g. your phone or tablet). This is entirely up to you, however, and if you would prefer to describe or talk about a post, rather than sharing it, this would be fine too. You do not have to answer any questions that you do not want to.

The interview will be audio-recorded so that we can type up what was said during the interview. After the interview, you will be asked again whether you are happy for the interview to be included in the study. If you are happy with this, you will be asked to sign the consent form again. If, following the interview, you would prefer for your comments to not be included in the study, this is also fine. In this case, the audio recording will be deleted and will not be typed up or included in the study.

After the interview, you will have the opportunity to ask any questions or discuss any concerns that you may have about taking part in the research. Following the interview, you will also be asked if you are happy to be contacted again, during the analysis stage, to bear your thoughts on the themes of the analysis. If you are happy to do this, you will be contacted via telephone.

### **What will happen to this information?**

After the interview, the audio-recording will be typed out so that we can review the interview in detail. We aim to look at themes that may come from the interviews to see whether people share any similar experiences and opinions. All typed transcripts will remain anonymous; your name or details will not be linked to your interview and we will not include your name in the transcript (instead assigning an ID number). Once the interview has been transcribed and made anonymous, the audio-recording will be deleted. All transcripts will be accessed from a secure NHS or University computer, and password protected.

Once the study has finished, the anonymous written transcript and any other data relating to the study will be kept in a secure, lockable filing cabinet at the Salomons centre for Applied Psychology. The data will be kept for 10 years after completion of the study, after which it will be permanently deleted and destroyed.

The research team will look at anonymised sections of the transcripts to support thinking and ideas about the interviews and any themes that emerge. The findings will be written up in a research report as part of the Doctorate training programme. Anonymised extracts from interviews will be used within the report, and a full anonymised transcript of each interview will be included in an Appendix. Your demographic information will not be linked to the transcript in any way, so that participants cannot be identified in any way.

In the future, we hope to publish the research in an academic journal and present the findings at relevant conferences. At the end of the research interview you will be asked if you would like a summary of the findings once the research has been written up. Alternatively, you are welcome to read the full research report.

### **Payment and expenses**

As a thank you, you will be given £10 for your participation in the interview. We will also reimburse up to £10 for travel expenses. Please keep a receipt and we will reimburse you on the day.

### **What are the possible disadvantages and risks of taking part?**

During the interview you will be asked to think about the impact that using social media has had on your recovery through eating difficulties. This is personal information and has the potential to be distressing for you. Every effort will be made to minimise any distress, for example stopping the interview if you wish, or taking breaks.

After the interview you will have the opportunity to ask any questions or raise any concerns about the research interview. You will be given an information sheet about who to contact for further support if you wish to access this after we meet.

If during the interview we become concerned about your welfare or safety, or the safety of anyone else, we will have to share this information so that appropriate support can be provided. If you are part of the Maudsley Eating Disorder Service, we will contact your named clinician to pass this information on to the clinical team. If you are not part of the service, we will contact your GP to let them know. However, this would only occur if we were seriously worried about your or others' welfare or safety and we would discuss this with you before sharing information.

### **What are the potential benefits of taking part?**

The findings from this research will help us understand the impact that social media has on individuals with eating disorders, and how people who use social media can be supported during treatment for eating disorders. We expect this to have benefits for the treatment and support offered to individuals with eating disorders. You may also find that talking about your experiences is helpful to you at a personal level.

### **What will happen if I don't want to carry on with the study?**

If you decide you wish to withdraw from the study please let us know by contacting us on the email address or telephone number given at the end of this information sheet. If you have already completed the interview you will be asked what you would like to happen to the data. It can either be included in the study, or destroyed. Either option is perfectly acceptable. The standard of care you receive will not be affected in any way by your decision to take part or withdraw from the research.

### **What if there is a problem?**

If you have any concerns about any aspect of this research, you can contact Jenny Beardwood and she will do her best to answer your questions and to address your concerns. Alternatively, you can contact the research supervisors, Dr Karina Allen or Dr Daniel Salter, whose contact details are below. If you remain unhappy and wish to make a complaint formally, you can do this by contacting Professor Paul Camic, Research Director, Salomons Centre for applied psychology – [paul.camic@canterbury.ac.uk](mailto:paul.camic@canterbury.ac.uk)

### **Will my taking part in this study be kept confidential?**

All information gathered during the research will be kept strictly confidential. All identifiable information such as names and addresses will be stored securely on an NHS or University computer. This personal information will only be kept for the duration of the study, after which it will be deleted.

All data relating to the research, such as the written transcript, social media posts, and any other questionnaires that you complete, will be made anonymous and stored on a secure

NHS or university computer system. Your identifiable information will be kept separately from your anonymised interview transcript and any other data relating to the study.

Once the study has finished, the anonymous written transcript and any other anonymous data relating to the study will be kept in a secure, lockable filing cabinet at the Salomons centre for Applied Psychology. The data will be kept for 10 years after completion of the study, after which it will be permanently deleted and destroyed.

As with any meeting with a health professional there are some limits to confidentiality. We are obliged to breach confidentiality and inform another professional, if you disclose any information that suggests that either you or anybody else is at risk of harm. If this is the case, we will discuss this with you first.

### **Who is organising and funding the research?**

The research study is organised and funded by Canterbury Christ Church University, in collaboration with South London and Maudsley NHS Foundation Trust.

### **Who has reviewed the study?**

All research in the NHS is looked at by independent group of people who sit on a Research Ethics Committee. This process is to protect your rights, safety and dignity. This study has been reviewed and approved by the London and Chelsea Research Ethics Committee.

**Contact Details**

**Jenny Beardwood** (Trainee Clinical Psychologist)

Email address: [j.c.beardwood1216@canterbury.ac.uk](mailto:j.c.beardwood1216@canterbury.ac.uk)

Telephone number: **07840 582 997**

**Dr Karina Allen** (Senior Clinical Psychologist)

Eating Disorder Service, Maudsley Hospital, South London and Maudsley NHS Foundation Trust

Email address [karina.allen@slam.nhs.uk](mailto:karina.allen@slam.nhs.uk)

Telephone number: 020 3228 3180

**Dr Daniel Salter** (Clinical Psychologist)

Salomons Centre for Applied Psychology

Email address: [daniel.salter@canterbury.ac.uk](mailto:daniel.salter@canterbury.ac.uk)

Telephone number: 01227 927 070

**Further support**

If you would like further support with your eating disorder, please visit the Beat eating disorders website: [www.beateatingdisorders.org.uk](http://www.beateatingdisorders.org.uk)

Beat also provides helplines for adults and young people offering support and information about eating disorders. You can call 0808 801 0677 to speak to a helpline support worker.

## Appendix K: Participant consent form

### CONSENT FORM

**Title of Project:** *Social media, eating disorders and recovery*

**Name of Researcher:** *Jenny Beardwood*

Please tick

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that participation will involve my interview being audio-taped, with use of anonymised verbatim quotation. ☐
4. I agree that anonymous quotes from my interview may be used in published reports of the study findings. ☐
5. I agree to share example social media posts, and for these to be included in the study. ☐
6. I understand that my information will be stored securely, and the information I provide will be anonymised for use in the study; I will not be identified in any way. ☐
7. I agree to take part in the above study. ☐

Name of Participant \_\_\_\_\_ Date \_\_\_\_\_

Signature \_\_\_\_\_

Name of Person taking consent \_\_\_\_\_ Date \_\_\_\_\_

Signature \_\_\_\_\_



**RE- CONSENT**

8. Following completion of the interview, I agree for my information to be used in the study.

☐

Name of Participant \_\_\_\_\_ Date \_\_\_\_\_

Signature \_\_\_\_\_

Name of Person taking consent \_\_\_\_\_ Date \_\_\_\_\_

Signature \_\_\_\_\_

**Appendix L: Feedback to HRA/REC**

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**Appendix M: Feedback to participants**

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**Appendix N: Research diary**

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