

Young people and online eating disorder content: a qualitative evidence synthesis

Meena Khatwa, Rebecca Rees
Kelly Dickson, Claire Stansfield
and James Thomas

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Young people and online eating disorder content: a qualitative evidence synthesis

Meena Khatwa, Rebecca Rees, Kelly Dickson, Claire Stansfield, James Thomas

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For further details, please contact:

Dr Meena Khatwa

Evidence for Policy and Practice Information Centre (EPPI Centre)

UCL Social Research Institute

18 Woburn Square

London WC1H 0NR

United Kingdom

Email: m.khatwa@ucl.ac.uk

Twitter: [@EPPICentre](https://twitter.com/EPPICentre)

Website: <http://eppi.ioe.ac.uk/>



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Advisory panel and young stakeholder input

The review was guided by an advisory panel, consisting of professionals and academics working in the field of eating disorders and consultations were held with young people with lived experience of online eating disorder content. At the time of writing some of the young people are working with the authors on communicating the review's findings.

Acknowledgements and conflict of interest

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Guarantor of the review

James Thomas, Professor of Social Research and Policy, EPPI Centre, University College London, UCL Institute of Education.

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How to read this report

Because this is the technical report of a systematic review that uses transparent methods, some sections of the report are necessarily detailed. Without compromising on the transparency that is expected of a systematic review, we have structured this report to help those who are more concerned with the findings than the methods. Part I contains the findings and implications, preceded by the background and a brief section on methods. The findings are split between two chapters. Chapter 3 presents a descriptive overview of all the studies included in the review. Chapter 4 presents the findings of a synthesis of young people's views and experiences of online eating disorder content and the influence it has on their body image and eating disorder symptoms. Part I concludes with a discussion of the findings and gaps in the evidence and implications for future research. Part II contains additional detail about the review's methods, processes and explains the review's relationship to an earlier systematic mapping of the broader evidence-base about online eating disorder content, which is reported separately. A set of appendices contains a PRISMA checklist, details of the search strategy and critical appraisal of the studies, as well as detailed tables of the included studies.

Executive Summary

Background

It is estimated that over three million people in the UK are living with an eating disorder (ED), such as anorexia nervosa (AN), bulimia nervosa (BN), and binge eating disorder (BED). These disorders present in different ways but are all characterised by distress or concern about body image and eating. While eating disorders are most commonly seen in girls and young women, there have been calls to direct research attention to the needs of various under-served populations.

The causes of an eating disorder involves a complex interaction of factors. Historically, traditional media have been seen as a social arena that generates and reproduces discourses about ideal bodies. Consideration has more recently extended to the impact on young people of digital media, such as Instagram, blogging, forums and vlogs, and there have been growing concerns about the accessibility and wider scope of this online ED content. For the purposes of this review, online eating disorder content (OEDC) is defined as material or exchanges identified by young people as holding potential to influence their own, or others', distress or concern about body image or about behaviours related to body size, shape or weight.

UK policymakers and practitioners have been working together to explore how individuals navigate digital media landscapes, as well as the potential benefits and risks they pose, to help inform online harm prevention policies.

There is a large body of evidence on appearance-related content and body image disturbance and ED symptomology. However, to date there has not been a systematic review that synthesises the findings of qualitative studies on digital media and eating disorders. A systematic map of research (described in Part II of this report) indicated that there was a sufficient body of qualitative primary research to answer the following review question:

What are young people's views and experiences of online eating disorder content and what influence does it have on their relationships with their bodies, weight control behaviours, and/or any other eating disorder symptoms?

Methods

Stakeholder engagement: This project has been informed by consultations with a group of young people with lived experience of OEDCs and a stakeholder advisory group.

Study identification: Studies included in this review were identified from a systematic map of empirical literature investigating the relationship between online eating disorder content and young people's body image concerns, weight control behaviours, or eating disorder symptoms. Searches for the map were undertaken in 17 health, psychology and education databases. We also searched online resources and conducted focused searches of eating disorder topic journals. The searches were undertaken between February and early March 2021. Additional searching on Microsoft Academic was also completed on 10th May 2021.

Studies were included in this review if they used qualitative methods to explore young people's experiences of online eating disorder content. Studies needed to be published from 2007 and focus on populations sampled from member countries of the Organisation for Economic Co-operation and Development (OECD), with a mean age of participants falling between 11 and 25 years.

Critical appraisal and synthesis of findings: Judgements about study quality were based on the reliability and usefulness of the findings contained in each study. Using the line-by-line coding function in EPPI-Reviewer software, the coding of data from studies was then organised under themes and higher-order themes and written up as a narrative thematic synthesis of the findings.

Key findings

Eighteen studies were included in the synthesis. Studies were grouped and organised into two syntheses. **Part one** contains findings from studies of young people with lived experience of an eating disorder. This includes the initial discovery of content through to young people's experience of OEDC while in recovery from an ED. **Part two** contains findings from studies of young people who are not identified as living with an eating disorder. It considers their exposure to and consumption of online content and broader ideas of body image and weight control behaviours. The synthesis of both sets of studies led to three main themes: (1) Comparing (2) Curating and (3) Community. The *Comparing* theme illustrates how young people use online content to evaluate their own and others' bodies and behaviours. The *Curating* theme explores the ways in which young people manage and create this content. The *Community* theme explores the reasons why young people are drawn to social spaces where content is shared, and what purposes these spaces serve.

Part 1: Views of young people with lived experiences of eating disorders (n=7 studies)

Comparing: A range of content posted online was used by young people to evaluate others and themselves, such as food portions, weight loss accounts and stories of ED-related achievement, as well as images of bodies. Such online ED content was easily accessible and could lead to feelings of both affirmation and failure, as well as the triggering of negative thoughts or actions. Accounts of online comparisons in recovery were sometimes positive, but not always. Comparisons were linked to both feelings of superiority and power as well as to competitive dieting behaviours, some of which were aimed at extremely low weight goals.

Curating: Young people described many reasons for curating content for themselves and others and mentioned stigma, disclosure, and encouraging others to recover and raising awareness about EDs in particular. Activities, which covered most recognised types of online engagement, included the seeking out of certain content producers or types of content, liking and providing feedback to others' individual posts or otherwise interacting with existing content, as well as deliberately creating new material. These young people with experience of EDs emphasised the importance of authenticity and stories that could be identified with. Those in recovery talked of the value of being critical and selective with content.

Community: Young people were attracted to online, virtual spaces where these offer a sense of community, identifying with others with shared experiences and aspirations. These spaces were experienced as both helpful and harmful. Engagement with different communities was influenced by where a young person was in their ED journey and included both pro-ED (also sometimes known as 'pro-ana', or pro-anorexic) and pro-recovery spaces (as described in included studies). In the early stages of experiencing pro-ED sites, an individual might be curious or seeking similar others. Here young people talked of finding understanding and acceptance that were sorely missing in the offline world. More broadly speaking they also talked of mutual support and learning – for both maintaining disordered behaviours and for the recovery process. Previous users of pro-ED sites who are in

recovery, however, indicated that online community connections could also lead to reduced physical and emotional wellbeing. The complexity of joining and leaving communities was also emphasised.

Part 2: Views of other young people (n=11 studies)

This set of studies involved individuals who did not identify as having an eating disorder

Comparing: Young people in studies where there was no identification of eating disorder experience also referred to their own evaluations of bodies seen in online content. The included studies often explored online content labelled as ‘#fitspiration’, however the focus was more often on body ideals and transformations brought about through exercising than on the more restrictive weight control behaviours common to eating disorder presentations. While some young people were seen as viewing online content through a critical lens, there were also concerns voiced by young people about the potential for negative influence on mood and behaviour, and some references to the potential for disorder. The sense of endless opportunities for body-related comparisons and negative consequences in these accounts mirrors that among young people with lived ED experience and suggests considerable commonality for young people as a whole.

Curating: Young people in the 11 studies that did not require participants to have lived experience of an ED, also described steps that they took to manage online content. While there were no references to the writing of blogs around food or exercise in relation to their bodies, young people reported the need for care when using hashtags and likes. They also reported considerable effort in managing the choice of images they posted of themselves, and awareness of some techniques for reducing the negative impact for themselves of others’ material. These young peoples’ accounts mirror those from young people with lived experience of EDs in their emphasis on the value of authenticity and the need to be restrictive about access to others’ content. However, there is notably less reference in these 11 studies to the value of supporting others through online responses compared to the studies of people with eating disorders, possibly because the interactions under discussion are more fragmented, with less of a feeling of shared identity.

Community: The theme of community was found in only one of these 11 studies. In this study young men were interviewed if they had a public Instagram account and were using the hashtag ‘#fitfam’ – described by the study authors as ‘a popular hashtag that has been created to provide its viewers with information and tips on exercising, training and being in shape’. The authors report that these young mens’ initial motivation related to encouragement for body transformation which was only accessible to them in online rather than offline spaces. There was an indication that, unlike for young people with lived ED experience, there was a lack of unconditional support in these online community groupings.

Discussion and conclusions

This report presents the first systematic review to collect, analyse and discuss qualitative research exploring young people’s experiences and views of eating disorder-related material on digital online platforms. The review applies novel methods to combine insights from young people both with and without lived experience of eating disorders. Limitations in the extent of the existing research base, and rapid changes in the field of digital content were both identified as challenging.

Cross-cutting themes

The evidence synthesis of seven studies where participants had direct experience of an eating disorder suggests that online communities can offer refuge from the stigma and judgement of the offline world and meet a need to belong and be understood. These young people described embracing spaces where they could learn, comfortably self-evaluate, and share insights with others as to their shifting ED identities. However, this is also juxtaposed with young people's awareness of associated dangers especially for those individuals who described themselves as in recovery. These findings illustrate the contradictory and complex nature of these online platforms, which could be summed up as offering a *double-edged sword*.

Findings from the additional 11 studies of young people who were interviewed regardless of their experience of an eating disorder, show some similarities. These young people identified a range of ways in which online content might be considered to present distortions of reality. They also reported that it could adversely influence weight control behaviours and goals. This broader group of young people also emphasised the considerable individual effort put into managing their own representations online to avoid social sanctions. Participation through following a #fitspiration hashtag was discussed in mixed terms, again with some indication of hope that this could meet a social need not met in the offline world.

Implications for policy and practice

Since the findings of this systematic review are drawn from qualitative studies about young people's experiences of online eating disorder content, they do not provide any evidence regarding the likely effectiveness of policies or practices, however they offer important insights into how policy and practice could respond to these issues. New and existing policy interventions focused on supporting young people in this area could consider whether professionals routinely explore the role of digital online platforms as a tool that can support or hinder recovery from eating disorders. A key recommendation in NICE guidelines for the treatment of eating disorders is assessment of the wider social community, including the internet and social media, alongside the impact of the home, education and work, throughout treatment (NICE 2017). This understanding could be extended to explore complexities of online communities which to some extent contribute to ED identity formation, especially since some aspects of engagement in online communities seem to serve as barriers to recovery, because they continue to be a source of unhelpful beliefs and interactions. It would also be important not to overlook the value of provision of an online space for young people when they feel stigmatised in the offline world. Similarly digital literacy interventions, particularly when related to online harms, could potentially support young people to understand not only that engagement with certain types of content can be detrimental to their mental health including body image and self-esteem, but also that identifying the line between helpful and unhelpful is subjective and therefore can be difficult to determine and could require outside help to decipher (for example, by consulting with family, friends, peers or teachers). Given that young people often go online to seek information and support, there is not only scope for digital online platforms, such as social media and social networking sites, to direct young people towards professional help, but for platforms, including mobile applications to become tools for increasing the accessibility of help for young people. The design of digital interventions could also be informed by how young people use

online spaces so as to address eating disorders and body image concerns in ways that build upon young people's resilience and resourcefulness online.

Gaps in the evidence and future research

The synthesis highlighted the gender imbalance in the studies, with only two studies out of 18 sampling male participants and a resulting evidence gap with respect to male experiences of EDs and body norms. There was also no demographic data reported on LGBTQIA+ experiences, despite body image being a significant issue for this community. Although there were 11 studies with samples from different ethnic groups, the number of participants taking part was small (see Appendix 3 for further information). It would be useful for future research to collect data from ethnic minority participants and to detail whether their cultural/religious upbringings play any role in what type of ED content they engage with. Similar views on the absences of these demographics were also shared by the young people stakeholder groups.

There is an ever-increasing number of younger children using digital devices and gaining access to online platforms. However, the syntheses largely analysed data from older participants (18+), although some participants had received EDs diagnoses at a noticeably young age.

The studies of social media platforms found for this review focused almost exclusively upon Instagram. As this report is being written, Tik Tok use is still growing but ED content on this platform seems yet to have been explored qualitatively by researchers.

Part I: Background, brief methods, findings and implications

1 Background

1.1 Young people and eating disorders

It is estimated that between 1.25 to 3.4 million people in the UK are living with an eating disorder (ED). Eating disorders, such as anorexia nervosa (AN), bulimia nervosa (BN), and binge eating disorder (BED), present in different ways but are all characterised by distress or concern about body image and eating (American Psychological Association, 2013). Eating disorder symptoms can be detected from as young as six into late adulthood; with peak onset in adolescence (Kessler et al., 2013, Sadler et al., 2018, Wood et al., 2019). Higher incidence of eating disorders is reported in girls and young women, however, emerging research with boys and young men has begun to identify specific disordered eating and weight gain behaviours related to body ideals that emphasise muscularity and leanness, and which can lead to elevated ED symptoms (Nagata et al., 2019, Gorrell et al., 2021). Globally, eating disorders increases both the risk of suicide and premature death, with the highest mortality rates occurring in young people with anorexia (Arcelus et al., 2011, Chesney et al., 2014). Living with an eating disorder can be highly disruptive, exerting a negative impact on a young person's sense of self, relationship with others and overall quality of life (Joyce et al., 2019, Sibeoni et al., 2017).

1.2 Factors contributing to an eating disorder in young people

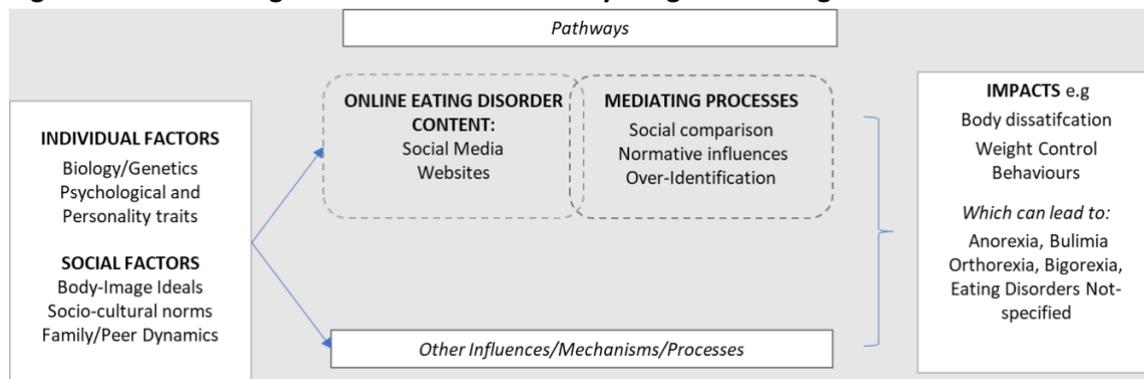
Eating disorders are caused by a complex interaction of bio-psychosocial and environmental factors (Culbert et al., 2015, Trace et al., 2013). As greater understanding of this complex interplay has evolved, a key area of investigation has been how sociocultural views about 'ideal' bodies interact with genetic and other factors (for example, personality traits, family environment, genetics) to increase the risk of an eating disorder (Becker et al., 2004, Bulik, 2005). Historically, traditional media (for example, television, films, magazines) have been theorised as a social arena that generate and reproduce discourses about ideal bodies (Levine and Murnen, 2009). This has resulted in a large volume of empirical research attempting to demonstrate the effects of mass media on eating disorders in children and young people. (Holmstrom, 2004, Spettigue and Henderson, 2004). This literature has now extended to consider the impact of digital media on young people's body dissatisfaction and disordered eating (Tiggemann and Slater, 2013, Tiggemann and Slater, 2017). A distinguishing feature of online digital media platforms, such as websites, online forums and social networking sites, is their interactivity. They enable young people to be sources and receivers of personally generated and targeted content, often simultaneously (Livingstone and Brake, 2010). A recent trend in this direction has been the development of both pro-eating disorder and eating disorder recovery content online. While pro-ED content actively encourages disordered eating behaviours, pro-recovery content aims to support and promote getting better (Branley and Covey, 2017, Peebles et al., 2012). With the advent of digital media, there have been growing concerns about the accessibility and expanding scope of ED content, which, no longer confined to websites and online forums, is being produced and reproduced in more sophisticated ways via digital media platforms (for example, Instagram, Tumblr, YouTube, Pinterest, Facebook) (Custers, 2015, Peebles et al., 2012). Given all of this complexity, this review has aimed for a broad scope and has been driven by young people's own definitions. For the purposes of this review, online eating disorder content (OEDC) is defined as material or exchanges identified by young people as holding potential to

influence their own, or others', distress or concern about body image or about behaviours related to body size, shape or weight.

1.3 Conceptual pathways between online content and eating disorders

A causal pathway, adapted from Perloff's (2014) 'transactional model of social media and body image concerns', reflects current thinking in this area (see figure 1). This pathway provides a simplified illustration of how the interaction of multiple causal factors can lead to the development of eating disorders and body image concerns; and how online eating disorder content can influence and interact with pre-existing individual and social factors to impact young people's body image and disordered eating. The pathway also identifies psychological processes (for example, social comparison, over-identification, and/or internalisation of body size ideals) potentially mediating this impact. The temporal nature of those impacts, particularly during adolescence, may not necessarily reach a clinical threshold for eating disorders but can nonetheless be problematic for young people and act as an early warning signal prompting the need for intervention.

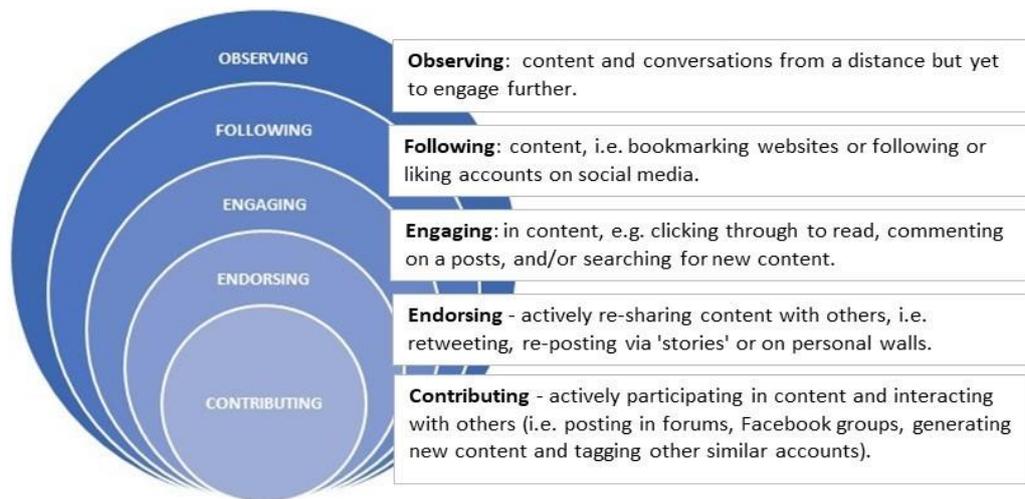
Figure 1: online eating disorder content and body image and eating disorder outcomes*



**Adapted from Perloff et al. 2014*

Given the complexity of digital media influences and the multi-dimensional nature of eating disorders and body image disturbances, it is important to go beyond a simple hypothesis of 'direct exposure' to online content to consider what young people, as active social agents with a range of individual and contextual strengths and vulnerabilities, bring to that content (Perloff, 2014, Rodgers, 2016). One way to approach this is to conceptualise young people's engagement with digital media as being on a continuum from observing to contributing (see figure 2); whereby young people are understood to move between different forms of engagement, at any one time, subjectively filtering and negotiating a variety of online digital experiences (Rodgers and Melioli, 2016, Wang et al., 2019). This approach broadens the focus to how young people 'interact with, mobilise and generate' that ED content within any given context, not only what content is available to them. This can then aid a more nuanced understanding of young people's relationship with digital media, their body image and the potential for developing eating disorders (Goodyear, 2020).

Figure 2: Levels of engagement with online digital media



1.4 Policy context

Digital media has marked an unparalleled shift in young people's patterns of social interaction and the social arenas in which they live (Livingstone et al., 2019). The 2018 Ofcom survey estimates that 99% of 12- to 15-year-olds in the UK spend over 20 hours per week online, 83% have their own smartphone and that a further 69% have a social media account (Ofcom., 2018). As the popularity and widespread use of digital media has grown among young people, so have concerns about its impact on their mental health and psychosocial wellbeing (Boyd 2011). The psychological impact of COVID-19 has brought this into even sharper focus amid rising anxieties about the consequences of quarantine, extended time online and young people's mental health; especially for those with preexisting mental health difficulties such as eating disorders (Fernández-Aranda et al., 2020, Touyz et al., 2020). In response to these concerns, UK policymakers and practitioners continue to work together to explore the potential benefits and risks posed by digital media and how individuals can navigate advancing technological landscapes to maximise their potential (Department of Health and Social Care, 2019, RoyalCollege of Paediatrics and Child Health, 2019). The UK government have shown a further commitment to these issues with the Department for Digital, Culture, Media & Sport and the Home Office's joint Draft Online Safety Bill, sent out for public consultation in 2019. The white paper sets out the government's plans for a package of legislative and non-legislative measures to ensure companies take greater responsibility for online safety (Department for Digital, Culture, Media & Sport, 2019). The introduction of online harm prevention policies, underpinned by legislation targeting whole populations, can contribute to a systemic approach that addresses the wider mental health needs of all children and young people in the UK, including those most vulnerable (Levine, 2020).

1.5 Review question

To date, systematic reviews on digital media and eating disorders have largely focused on quantifying the mental health impact of exposure to internet and social media use, rather than exploring a specific type of content-based engagement, such as viewing images and content related to the maintenance of eating disorders (Holland and Tiggemann, 2016, Rodgers et al., 2016). Since those reviews were published, primary research on the mental health implications of eating disorder

content has started to grow, suggesting that a systematic review in this area would be timely (Wang et al., 2019). To identify possible areas for evidence synthesis, a systematic map of research was conducted to identify and describe the full range of empirical evidence on the effects of online eating disorder content on body image and eating disorders in young people (Dickson et al., 2022). The findings from the map indicated that there was a sufficient body of qualitative primary research to answer the following review question:

What are young people's views and experiences of online eating disorder content and what influence does it have on their relationships with their bodies, weight control behaviours, and/or any other eating disorder symptoms?

2 Brief methods

This chapter provides a brief overview of the methods used to conduct this Qualitative Evidence Synthesis (QES). A more detailed description of the methods is provided in Part II, Chapter 7 of this report. The development of the methods for this review were in consultation with members of the policy team at the Department of Health and Social Care. This report adheres to the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) guidance reported in Appendix 1. Where necessary, the PRISMA guidance has been adapted to accommodate the systematic map approach taken. The metadata for each of the studies is also available in an online searchable database.

The review comprises two strands of work, both of which were informed by consultative work with stakeholders:

1. A systematic map (presented in a separate report, Dickson et al., 2022).
2. A qualitative synthesis of studies of young people's views of OEDC (presented in this report).

2.1 Stakeholder involvement

The review work was informed by a consultation with an advisory panel and with two consultative workshops with a group of young people.

2.2 Eligibility criteria

To be included in the qualitative evidence synthesis, studies needed to meet the following criteria:

- **Language and date:** studies needed to be published from 2007.
- **Geographical location:** conducted in an OECD country.
- **Population:** sample is of young people where the mean age is between 11 to 25 years old.
- **Topic and study design:** qualitative studies exploring young people's experience of online eating disorder content

2.3 Study identification

Searches were undertaken in 15 health, psychology, social science and education databases. We also searched other online resources, browsed websites and conducted focused searches of eating disorder topic journals. The searches were undertaken in early 2021, based on search concepts of (1) disordered eating, body dissatisfaction or over-exercising symptoms and behaviours, (2) online content, social media, blogs, instant chat (3) adolescents and young adults. Selective reference and citation searching on Microsoft Academic was undertaken.

2.4 Data extraction

A coding tool was used to extract descriptive data in two stages from full text reports of each study. In stage one, using existing EPPI Centre tools, key coding dimensions were identified (for example, date, geographical location, study design, population details, outcomes and factors). This data became part of the systematic map (Dickson et al., 2022). In stage two, further codes were developed to extract more specific descriptive data to inform the critical appraisal process and findings were extracted that addressed the review's question. Data is stored on EPPI-Reviewer 4.

2.5 Critical appraisal

Each study was critically appraised against eight questions, these included: what steps were taken to strengthen rigour in sampling, data collection and analysis; and were findings supported by the breadth and depth of data and participants' views? Judgements about study quality were based on the reliability and usefulness of the findings contained in each study.

2.6 Synthesis

Data was synthesised thematically. Qualitative data (both direct participant quotes and primary study authors' interpretations) were coded line-by-line in EPPI-Reviewer. The coding of that data was then organised into themes and higher-order themes. During this process studies were organised by whether the participants had lived experience of eating disorders or not, to inform two separate but complementary syntheses.

3 Overview of identified studies

A total of 13,224 citations were identified from the systematic search. After duplicate removal, 6,173 citations were screened on title and abstract. Of these, 442 were retrievable and screened on full text. From this process 93 studies reported in 103 papers were included in the map. The flow of literature is shown in Figure 8.1.

The majority of studies investigating young people’s experience of online eating disorder content have been published since 2019 (n=13; 72%) suggesting that this a relatively new field of qualitative enquiry. Studies have been conducted across a range of OECD countries including a third from the UK (N=6; 33%), followed by the USA (N=5; 27%). Other OECD countries included: the Czech Republic (N=2), Canada (N=1), Australia (N=1), New Zealand (N=1), Spain (N=1), and a study conducted in multiple countries (N=1). Over half of the studies sampled girls and young women only (n=11; 61%) with only one study focusing solely on young men. The remaining studies included mixed sex samples (n=6; 33%). The majority of studies focused on young people 11-25 (N=14; 77%) with only four studies sampling younger cohorts (n=4; 22%).

Seven studies specifically focused on young people with lived experience of an eating disorder, while the remaining 11 studies sampled populations of young people more broadly. Although studies collected information about class and ethnicity, exploration of disadvantage such as how ethnicity or socioeconomic status might intersect with subjective experiences of engaging with online content which was not a focus in any of the studies. All seven studies on young people with lived experiences of eating disorders explored their active participation with pro-eating disorder content (n=4) or content promoting body-image ideals (n=3) on websites or social media. While the 11 studies of general young people focused more on body image (n=8) or content relating to health and nutrition (n=3).

Two key qualitative methods to collect data were utilised across the 18 studies: interviews (N=11,61%) or focus groups (N=5, 27%). One study used both interviews and focus groups, while the remaining study used open-ended questions as part of a survey. Choice of data analysis methods varied, however over half of the studies used thematic analysis (n=12, 66%).

Full study characteristics of the included studies are presented in: Details of Studies – Appendix 3.

Table 3.1 Overview of studies included in the review

Author	Population details	Type of content, platform, level of engagement	Methods
Studies of young people with lived experience of eating disorders (N=7)			
Eikey & Booth, 2017	Location: USA Sample size: n=16 Mean age: 18-25 Sex: Women	Online Content: Body Image Ideals, Fit, Thin Online platform: Websites, Instagram Engagement: Contributing	Sample setting: University and the Community Data collection: Interviews Data analysis: Thematic analysis
Firkins, 2017	Location: UK Sample Size: n=3 Sex: Women Mean age: 18-25	Online Content: Pro-eating disorder Online platform: Websites, social media Engagement: Contributing	Sample setting: Community Data collection: Interviews Data analysis: Narrative analysis

Author	Population details	Type of content, platform, level of engagement	Methods
Hockin-Boyers et al., 2021	Location: UK Sample size: n=19 Mean age: 18-25 Sex: Women	Online Content: Body Image Ideals, Fit Online platform: Instagram Engagement: Contributing	Sample setting: Community Data collection: Interviews Data analysis: Interpretive Phenomenological Analysis
Mincey, 2019	Location: USA Sample size: N=10 Sex: Mixed Mean age: 18-25	Online Content: Pro-eating disorder Online platform: Websites Engagement: Contributing	Sample setting: Community Data collection: Interviews Data analysis: Hermeneutic phenomenological approach
Saunders et al., 2020	Location: USA Sample size: n=15 Mean age: 18-25 Sex: Women	Online Content: Body Image Ideals: Beauty/Attractiveness Online platform: social media Engagement: Contributing	Sample setting: Community Data collection: Interviews Data analysis: Thematic analysis
Smahelova et al., 2020	Location: Czech Republic Sample Size: n=30 Sex: Women Mean age: 18-25	Online Content: Pro-eating disorder Online platform: social media, Websites Engagement: Contributing	Sample setting: Community Data collection: Interviews Data analysis: Thematic analysis
Yeshua-Katz and Martins, 2013	Location: Multi-country Sample size: Sex: Women only Mean age: 18-25	Online Content: Pro-anorexia Online platform: Websites Engagement: Contributing	Sample setting: Community Data collection: Interviews Data analysis: Grounded theory
Studies of general populations of young people (n=11)			
Baker et al., 2019	Location: Czech Republic Sample size: n=27 Sex: Women Mean age: 18-25	Online Content: Body Image Ideals: Fit, Thin Online platform: Instagram Engagement: Contributing	Sample setting: University Data collection: Focus groups Data analysis: Inductive thematic analysis
Bell et al., 2019	Location: UK Sample size: n=77 Mean age: 11-17 years Sex: Mixed	Online Content: Body Image Ideals: Fit, Thin Online platform: social media Engagement: Engaging	Sample Setting: School Data collection: Focus groups Data analysis: Reflexive thematic analysis
Booth and Trauth, 2019	Location: USA Sample Size: n=30 Mean age: 11-17 Sex: Mixed	Online Content: Health and nutrition Online platform: social media Engagement: Engaging	Sample setting: Schools Data collection: Interviews Data analysis: Thematic analysis
Camacho-Minano et al., 2019	Location: Spain Sample Size: n=37 Mean age: 11-17 Sex: Girls	Online Content: Body Image Ideals: Fit Online platform: Instagram Engagement: Contributing	Sample setting: Schools Data collection: Focus groups Data analysis: Poststructuralist discourse analysis
Chatzopoulou et al., 2020	Location: UK Sample Size: n=25 Mean age: 18-25 Sex: Men	Online Content: Body Image Ideals: Fit Online platform: Instagram Engagement: Contributing	Sample setting: Community Data collection: Interviews Data analysis: Thematic analysis
Easton et al., 2018	Location: UK Sample size: n=20 Mean age: 18-25 Sex: Mixed	Online Content: Body Image Ideals: Fit Online platform: Facebook, Pinterest, Snapchat, Twitter, Youtube Engagement: following	Sample setting: Community Data collection: Focus groups Interviews Data analysis: Inductive thematic analysis

Author	Population details	Type of content, platform, level of engagement	Methods
Ferguson et al., 2020	Location: New Zealand Sample Size: n=14 Mean age: 18-25 Sex: Women	Online Content: Body Image Ideals: Fit Online platform: Instagram Engagement: Observing	Sample setting: Community Data collection: Interviews Data analysis: Thematic analysis
Papathomas et al., 2019	Location: UK Sample Size: n=84 Sex: Mixed Mean age: 11-17	Online Content: Health and nutrition Online platform: Social Media Engagement: Engaging	Sample setting: Schools Data collection: Focus groups Data analysis: Thematic analysis
Raggatt et al., 2018	Location: Australia Sample Size: n=155 Mean age: 18-25 Sex: Mixed	Online Content: Body Image Ideals: Fit, Thin Online platform: social media Engagement: Contributing	Sample setting: Online Data collection: Open-ended survey questions Data analysis: Thematic analysis
Toll and Norman, 2021	Location: Canada Sample Size: n=9 Sex: Women Mean age: 18-25	Online Content: Health and Nutrition Online platform: Instagram Engagement: Contributing	Sample setting: Online Data collection: Interviews Data analysis: Thematic analysis
Welker, 2019	Location: USA Sample size: N=6 Mean age: 18-25 years Sex: Women	Online Content: Body Image Ideals: Fit Online platform: Instagram Facebook Engagement: following	Sample setting: University Data collection: Focus groups Data analysis: Thematic analysis

4. Young peoples' views and experiences of online eating disorder content

The synthesis is presented in two parts. The first contains findings about discussions with young people identified by researchers as having lived experiences of an eating disorder. The second contains findings from young people who are not identified as living with an eating disorder. The coding and synthesis of both sets of studies led to the emergence of three main themes: (1) Comparing (2) Curating and (3) Community. The *Comparing* theme illustrates how young people use content to evaluate their own and others' bodies and behaviours. The *Curating* theme explores how young people manage and create content. The *Community* theme explores the reasons why young people are drawn to social spaces where content is shared, and what purposes these serve.

Table 4.1: Included studies in the synthesis: (N=18)

	Main Study report	Linked reports
1	Baker et al., 2019	
2	Bell et al., 2019	
3	Booth & Trauth , 2019	
4	Camacho-Minano et al., 2019	
5	Chatzopolou et al., 2020	
6	Easton et al., 2018	
7	Eikey & Booth, 2017	Eikey & Reddy, 2017
8	Ferguson et al., 2020	
9	Firkins, 2017	Firkins et al., 2019
10	Hockin-Boyers et al., 2021	Hockin-Boyers et al., 2020
11	Mincey, 2019	
12	Papathomas et al.,	Goodyear et al., 2019, Goodyear & Quennerstedt, 2020, Goodyear et al., 2021
13	Raggat et al., 2018	
14	Saunders et al., 2020	Saunders et al., 2018
15	Smahelova et al., 2020	Drtilová et al., 2021
16	Toll & Norman, 2021	
17	Welker, 2019	
18	Yeshua-Katz & Martin, 2013	

Part 1: Views of young people with lived experiences of eating disorders

There were seven studies identified which explore the lived experiences of young people with eating disorders. Notably, nearly all the participants providing their experiences were aged below 27 but some were in their 30s and had been diagnosed or had an ED since their childhood. The key themes are presented below.

Theme 1.1: Comparing

This first theme describes and groups the reports of young people with lived ED experiences, and about using ED content to evaluate others and themselves. A variety of content posted online was used in comparisons, such as food portions, weight loss accounts and stories of achievement, as well as images of bodies. This content was found through diverse platforms. Online content was described as very easily accessible for such comparisons and reference was made to the triggering of negative thoughts or actions, and to related feelings of affirmation but also failure. How the content made young people feel appeared to be influenced by where they were in their eating disorder

journey. Accounts of online comparisons in recovery were sometimes positive, but not always. Comparisons were linked to both *feelings*, of superiority and power, as well as to competitive dieting *behaviours*, some of which were aimed at extremely low weight goals.

Comparisons are constant – “seeing thin people on my feed helps” (Eikey and Booth 2017)

A range of content posted online was used in comparisons, including the sizes of food portions, accounts of exercise taken (Eikey and Booth 2017) and popularity in the form of views or likes (Saunders et al., 2020), as well as images of bodies (Eikey and Booth 2017, Firkins 2017, Saunders et al., 2020, Smalehova et al., 2020). This content used in comparisons was found on diverse platforms, including anorexia-focused and pro-recovery forums (Eikey and Booth 2017, Firkins 2017, Mincey 2019, Smalehova et al., 2020) but also Instagram and other social networking sites (Eikey and Booth 2017, Hockin-Boyers et al., 2021, Saunders et al., 2020, Smalehova et al., 2020).

Undesirable online content was described as very easily accessible for such comparisons, with young people using terms like “constantly” (Eikey and Booth 2017, p235; Hockin-Boyers et al. 2020, p14), and “bombarding” and “attacking” (Drtilová et al., 2021, p5). As one young person, commenting on how ‘thinspiration’ accounts (alluding to a lifestyle choice) reaffirmed her decision to restrict food intake, put it, “... constantly seeing thin people on my feed helps. I was like, “Okay, I kind of look like that so I’m okay” ... So, make me not eat more” (Eikey and Booth 2017, p235).

The ubiquity of comparative online words and images meant they were also implicated as potential triggers of negative emotions (Hockin-Boyers et al., 2021, Smalehova et al., 2020, Mincey 2019, Yeshua-Katz and Martins 2013). Triggering material was reported as particularly troubling for some who were at the recovery or treatment phase in the ED journey, where comparing to others led to weight loss behaviours and “pulled them back to the illness” (Smalehova et al., 2020, p6). In one study of bloggers, participants reported feeling responsible for the way their writing held potential for triggering (Yeshua-Katz and Martins 2013). However, active seeking of such triggering material online to “fulfill participants’ behaviours” was also described (Mincey, 2019, p134).

Comparison can affirm but also undermine sense of self –

“this person is skinnier than me so she’s sicker than me” (Mincey 2019)

Comparison was linked with feelings of personal affirmation, but also failure (see Competitive comparisons below for discussion of the influence of such feelings on disordered behaviours). There was reference to how seeing others’ content could strengthen existing feelings of not being sick enough to deserve support. Here online comparisons could influence the development of feelings of low self-esteem whereby, when faced with others’ accounts of their behaviours or bodies, participants felt like “losers” (Mincey 2019, p109 and p118):

“Anytime I see someone ‘sicker’ than me ...it makes me think, in a disordered way that I know is not reality, I should eat less or lose weight, or exercise more. That I should be doing what these people are doing because they are doing a better ‘job’ of having an eating disorder” (Mincey, 2019, p108-9).

The emotional impacts of looking at online content and comparisons in the recovery process were sometimes recounted in more positive terms. Here the visual changes that were exhibited of online body transformations, from underweight to deliberately gaining muscular weight, or ‘becoming body builders’ resonated (Eikey and Booth 2017, p232), as did young people’s reflections upon documenting their own self-transformation:

“I have seen [Instagram accounts] where people are trying to gain back weight, and they really celebrate that. And it’s encouraging to see ...” (Eikey and Booth 2017, p232).

“... Oh gosh, has my body changed or has this changed or a visual thing, it’s just I feel good in myself, I want to share that, thank you – post!” (Hockin-Byers et al., 2021, p106).

How online content made young people feel appeared to be dependent upon where they were in their eating disorder journey, but young people gave varied accounts of experiences during recovery in particular (Hockin-Byers et al., 2021, Mincey 2019, Drtilová et al., 2021, Saunders et al., 2020). As one participant noted, of their initial use of pro-ED sites, “I think, certainly in the beginning, it was very easy to ... look at other people and compare yourself to them. So, it does distort your view of yourself” (Mincey 2019, p122). Negative comparisons with others’ bodies through selfies was described by young people in recovery as “a tendency ... in the depths of their disorder” (Saunders et al. 2020 p4). In terms of selfie use when recovering, young people who were weightlifting as part of their recovery reported comparisons between their own before and after photos to be helpful, for example: “I just like to see ... when I look back at what I used to look like and what I look like now it helps me be, like, ok. I am going in the right direction and other people can see it.” (Hockin-Byers et al., 2021 p106). However, fears of negative effects from using selfies were described as common among those in recovery in another study. Here, one young person described how this was like, “dangling ... teetering on a line of like slipping right back into everything, because you’re comparing what you used to look like, and what you look like.” (Saunders et al., 2020 p4).

Competitive comparisons of behaviours and outcomes –

“That girl weighs only 39 kilos; I should do something about it” (Drtilová et al., 2021)

The quote used in this sub-theme is an example of a young person suggesting disordered behaviour might follow on from an affective response to online content. Here the representation of an extremely low weight online was thought likely to prompt others to chase that as a goal (Drtilová et al., 2021 p7). Some young people in these studies reported experiencing pressures also to show they were aiming for extreme low weights. As this same young person noted, “These girls are super competitive at that moment, like, who would be thinner or who would throw up more often... and more raised bones.” (Drtilová et al., 2021 p7). Also reported were competitive exchanges between individuals in the depth of disorder, which were described as joking of a kind that manifested in “odd ways such as setting up crash diets and seeing who could go the longest” or “a fair share of insulting each other about weight gain.” (Mincey 2019, p107). One participant noted that competitive behaviour was also present in the offline world when young people engaged with others about EDs, but that this offline pro-ana behaviour was harder to find.

Young people also described feeling superior and powerful when in a disordered state as a result of posting images of themselves and then receiving comments:

“When I posted a picture of me in a bathing suit, people would comment, ‘Oh my God, you look so good. Teach me your ways.’... It fueled it [my eating disorder] more obviously. I was like, ‘Oh my gosh, I’m great.’ [laughs] ... I just felt like I could just eat less than a normal person, so I was just better ... I could tell other people were jealous of me kind of, that I was good at something.” (Eikey and Booth, 2017, p235).

“[reflecting back on competitive behaviour]... what was I thinking? Like, who was I trying to impress, like, what does it even matter is what I think? And then, like, here (healthy selfie) I think look happier

and like I'm over it and... I don't think anyone should think they need to look like that (sick selfie) ... to, I don't know, to feel powerful?" (Saunders et al., 2020, p5).

Theme 1.2: Curating

This overarching theme groups lived experiences of the act of managing and creating online content about eating disorders that is shared on digital platforms. This activity includes all levels of engagement as illustrated in Figure 2 in Chapter 1, but particularly focuses on activities beyond observing content to consider the activities of following, engaging, endorsing and contributing content. In summary, curation captures activities where young people modifying the material they or others see online. Whilst there was no explicit mention of endorsing, for example through the re-sharing of content, the activities reported ranged widely. They included: the use of hashtags or other means for seeking out certain content producers or types of content; liking and providing feedback to others' individual posts or otherwise interacting with existing content. They also deliberately created new material, such as uploading images on Instagram (annotated or otherwise), posting questions and responses in specialised forums and writing blog articles. This theme was illustrated by all but one study (Firkins, 2017). The following sub-themes present the ideas of young people with experience of EDs that link curation to ideas about authenticity and identity, and being critical and selective. Also captured are the rationales that young people gave for spending time and effort in curating content for themselves and others, which were manifold, but included reference to stigma, disclosure, encouraging others to recover and raising awareness about EDs.

Seeking out and creating content that is authentic –

"I think it gives us more access to real people" (Hockin-Boyers et al. 2020)

One element of curation that young people described was seeking out online ED content that resonated because they could relate to it alongside their own journeys. Young people searching for pro-ED material expressed a desire for following "concrete – real people with ED and their stories" (Smalehova et al., 2020, p630). Other participants reported gaining motivation for recovery from finding "realistic examples of the recovery process in other users who shared their difficulties, thoughts, and information about what helped them" (Smalehova et al., 2020, p631). One participant who was in recovery recalled, "I think in the past it was just magazines and celebrities, whereas with Instagram ... it's so much more real" (Hockin-Boyers et al., 2020 p7). She then explained that she used to stick photos of, "just skinny people in fashion magazines" on her wall, but now had access to others "who are having the same thoughts", which she explained related for her to being well and happy through using exercise (Hockin-Boyers et al., 2020 p11).

The value of authenticity was also noted by blog creators as well as followers, who in one study were keen to "share and declassify", which meant opening up about themselves (Drtilová et al., 2021, p7). Some of the young people in this same study also described changing their content so as to report about their "whole life, not just about their pro-ED behavior" and, more generally, those writing pro-recovery blogs emphasised complexity by, for example, positioning their posts "within their everyday life and family context" (Smalehova et al., 2020 p631). One young woman at the beginning of her recovery described how:

"I often refer to how my blog is my true self and how in real life I have to act and hide my true feelings. I often call myself an actress on a stage playing out a part in my real life. My blog is who I am backstage when I'm stripped of the make-up and costume" (Yeshua-Katz and Martins, 2013 p6).

In contrast to the positives of identifying with and aiming to produce and share authentic photos and stories, participants in one study also described negative impacts associated with inauthentic content such as image manipulation, as well as the unhelpful selective sharing of content (Drtilová et al., 2021). One participant in this study, when commenting about using social network sites complained how, “virtual reality is one big fraud” (Drtilová et al., 2021, p5-6). Another described the impact, despite their awareness of manipulation:

“A person has a feeling that they have a boring life or that everyone is beautiful and amazing because they see many profiles where the most beautiful things are presented, an abstract image of a person ... So, I think that influenced me even when I realized it ... even when it was not a real image of life.” (Smalehova et al., 2020, p6).

One group of authors labels this inauthentic content as “negative inspiration” (Drtilová et al., 2021 p6) and reported that young people specifically mentioned that it can come from “pro-ana blogs that represented EDs as a desirable lifestyle”. They quote one young participant who said, “Probably it is about the fact that youngsters are somehow depressed. They want to be thin and popular, and these anorectics are presented as beautiful, fragile and wonderful creatures... an ED could give them a life purpose.” (Drtilová et al., 2021 p6). Similar ideas about identification with others who post ED content online can be found below under the theme of Community.

Managing and interacting with others’ content –

“it’s not a good or a bad thing, it’s a tool” (Hockin-Byers et al., 2020)

Young people described a wide range of purposes for responding to others’ content. The intensity of interactions was also commented upon, with some noting just how many different people could potentially join in with reactions (Smahelova et al., 2020).

Young people reported replying to others’ posts so as to provide individual support, whether this was in pro-ED discussion sites (Mincey 2019, Smalehova et al., 2020) or in recovery-focused discussions (Eikey and Booth, 2017, Hockin-Byers et al., 2021, Saunders et al., 2020):

“If I have a friend who lost a lot of weight. I’ll always comment ... “you’re on a good path, you’ve done this in a healthy way [...] I try to encourage them in a healthy way” (Eikey and Booth, 2017, p234).

Some responses also seemed to be aimed more critically and have a more general audience in mind. For example, in response to transformation photos on Instagram, one participant in recovery recalled posting, “just a friendly reminder that weighing less does not make you happier (stop girl emoji)” (Hockin-Byers et al., 2021, p105).

Some also described the value of being selective as to who they followed online, so they could manage what content they would then see. This was labelled *digital pruning* by this study’s authors (Hockin Byers et al., 2020):

“I have to go through and unfollow people sometimes. People that are just unhelpful.” (Hockin Byers et al., 2020 p12).

But this unfollowing could also serve other purposes:

“I normally unfollow as an act of defiance, if I think someone is selling something like skinny teas or like, skinny coffee or like, you know, those slightly awful ... I instantly unfollow.” (Hockin Byers et al., 2020 p13).

This study was one of only two reporting reasoned appraisals by young people with experience of EDs. Here one young person noted, of the internet as a whole, “It’s not a good or a bad thing, it’s a tool and like anything else, it depends on the way that you use it and the way that you engage with it” (p12).

However, the authors of the study, of young people in recovery, argue that, while some reported feeling liberated, this had resulted from earlier, less positive experiences:

“While all participants who used social media expressed pride in having developed healthy, connected and socially conscious digital spaces, it became clear during interviews that this process had been one of trial and error. Like a vaccine, women seemingly had to experience at least a small dose of negative affect in order to make the decision to protect against it.” (p14).

Varied motivations for generating new content – “it’s like to say it out loud” (Eikey and Booth 2017)

The young people referred to many factors as motivating them to generate new content (content other than annotations or direct responses to others’ material), with variation seen across the different platforms and formats of communication, as well as ED stages.

For bloggers, who mainly described themselves as still living with ED in the included studies, there was an emphasis on producing content as a means of self-expression (see above Seeking out and creating content that is authentic), gaining support, and coping with stigma (Smalehova et al., 2020, Yeshua-Katz and Martins 2013). In one study, which was focused on motivation for pro-ED blogging, most participants stated that they started “because they did not want to feel alone or were interested in finding similar others” (Yeshua-Katz and Martins. 2013 p503). This aspect is explored further under the theme of Community below. These young people also described a freedom in sharing their writing about ED online, with this enabling them to “express themselves without judgement.” (Yehsua Katz et al., 2013 p503). Half of the participants in this study reported starting their blog as a means for coping with social disapproval. As one young woman put it, “having an ED was so socially unacceptable that it pushed me to seek others that I could tell my story to” (Yeshua-Katz and Martins 2013, p503).

This idea of sharing and disclosing through writing is also seen in another study, where a young woman is quoted as formulating her motivation for creating her pro-ED blog as “the need to find relief from struggles with ED, to disclose to someone, and to receive support of other visitors” (Smalehova et al., 2020, p631). Some pro-ED bloggers also reported writing to counteract inaccurate portrayals of EDs, to “make them realize that it’s not what everybody makes it out to be” (Yeshua-Katz and Martins 2013, p504).

In contrast, in one study young people commenting on blogs aimed at encouraging recovery said they felt writing them helped their own recovery, as well as helping others. Describing these therapeutic properties of disclosure, one young woman noted, “there really happened an extreme disclosure and I think it was one of the most important steps (for recovery) ... by putting it down in

written form, and actually identifying with it ... It's like to say it out loud ... I get rid of this stigma in myself" (Smalehova et al., 2020, p631).

Rationales for creating and sharing content on social networking platforms in seven studies of people with lived experience of EDs were nearly all from young people who identified themselves as in recovery. These young people also reported intentions of raising awareness and helping others with the recovery process, for example, "[reflecting upon posting during their own recovery journey and since] I just felt like all these people were very supportive and that helped... I'm like, 'If anyone needs help please speak up. You shouldn't have to go through this alone', because really, I just want people that are struggling to talk to me ... I'm in a sorority, and I feel like just if I post on Instagram, they'll all see it." (Eikey and Booth, 2017, p234).

Instead of a focus on writing for self-expression, such as with blogs, reference was also made to sharing photos of visually appealing healthy meals or body transformations. This sharing of visual matter related to recovery was described by those sharing as ways to "celebrate progress and motivate others" (Hockin-Byers et al., 2021). Young people also referred to posting such online material for themselves, with this serving as an "archive for memories" (Smalehova et al., 2020 p7).

Theme 1.3: Community

The findings in this theme provide an insight into why young people are drawn to online virtual spaces, which can evoke a sense of community when people identify with each other as having shared experiences and aspirations. However, these ED communities appear to be complex spaces, which can be both helpful and harmful. As Mincey (2019) states, "researchers have indicated the sense of community that occurs in these online groups, forums, and webpages can lead to adaption of behaviours and symptoms of eating disorders" (p2).

It was evident from the studies that the reasons for engaging with online communities was influenced by where the young person was in their ED journey. In the early stages an individual might be curious or seeking connections. Later in the ED journey there could be impacts on physical and emotional wellbeing, and disengaging could be complicated. There was very little mention, or evidence of the salience of collective action, for example, the influence of group-based decision-making. Views and experiences generating this theme were found in all but one of the studies (Saunders et al., 2020). The following sub-themes describe the nature of the double-edged sword of these online communities and, in turn, address finding acceptance not found in the offline world, education and mutual support and the complexity of joining and leaving.

Combatting loneliness and being misunderstood – "nobody normal understands why you want to starve yourself" (Yeshua-Katz and Martins 2013)

The attraction of online communities was referred to in five of the seven studies, where young people with experience of EDs revealed feelings of isolation, loneliness and being misunderstood by the offline world (Firkins, 2017, Hockin-Byers et al., 2021, Mincey 2019, Smalehova et al., 2020, Yeshua-Katz and Martins 2013). In contrast, these young people described how the online world offered spaces that were less judgmental with the potential for both instructive and emotional support, and meaningful and interactive connection:

[From a blogger, described as living with the disorder] "I don't receive much support from friends and family, who have no idea what I am really going through. My mother calls me 'greedy' when I binge, and my boyfriend praises me, as he doesn't realize they are a part of the disorder no matter

how many times I tell him. However, online, other bloggers tell me that it's not the end of the world, they say encouraging things which stop me from wanting to purge or self-harm, and I know they all understand and have been there. That gives me hope that I can get through the binge." (Yeshua-Katz and Martins 2013, p7).

"They [pro-ana forums] are all inclusive. You don't have to hide where you want to go with your eating disorder, so to say... if you want to stop it, if you want to engage in it, you can just be there" (Mincey 2019 p67).

In four studies young people conveyed there was no alternative for them when in a disordered state, and that the offline world did not offer what they needed (Firkins 2017, Mincey 2019, Smalehova et al. 2020, Yeshua-Katz and Martins 2013). As one young person put it, "I almost felt that I was an alien that I just didn't fit in anywhere... I think it's where I belonged and that's where I felt comfortable... I didn't feel like I was in turmoil there" (Firkins, 2017 p84).

Alongside acceptance, and sense of belonging, anonymity was described as a key driver of engagement with online communities:

"Online, there is no visual attachments to people with whom you speak, so it is easier to converse without feeling threatened and to find people who understand" (Yeshua-Katz and Martins 2013, p505).

"For some, the anonymity was a benefit for building self-confidence and for depersonalization while talking about problems" (Smalehova et al., 2020 p6).

However, two studies also highlighted awareness of the negative impacts of acceptance within ED-related communities. As one young woman, reflecting on being in a disordered state, put it: "that was not a healthy acceptance" (Firkins, 2017, p85). Another who was part of a fitness recovery community reported feeling, "like I go on about it a bit and I don't want to be, you know, the 'eating disorder girl' " (Hockin-Byers et al. 2021 p107). Elsewhere, young people who were in recovery, reported that prior to this, when in a disordered phase, the pro-ED platforms 'could keep them in isolation'. In this study, all but one of the participants who had used pro-ED sites reported no longer using them (Smalehova et al., 2020, p631). The dangers of anonymity helping "to radicalize some people's opinions" were also raised (Drtilová et al., 2021, p5).

Sourcing support strategies –

"I was only interested in how to endure so I did not have to eat" (Smalehova et al., 2020)

This quote and others across the studies illustrate how young people turned to online communities for information. Pro-eating disorder sites were viewed as useful resources where practical tips and tricks and knowledge were shared by more experienced users, such as how to hide ED symptoms, and suppress appetites, and otherwise bring about weight loss (Firkins, 2017, Mincey 2019, Smalehova et al., 2020, Yeshua-Katz and Martins 2013).

There was also reference to advice about avoiding "suffering from the condition" (Mincey 2019 p.64-5]. In one study, participants characterised this form of advice as harm reduction, and provided illustrations, for example:

“Things like, after purging not brushing your teeth because you would brush the stomach acid around your mouth, and you’d rot your teeth faster. Things like that have been really helpful and probably why I still have all of my teeth.” (Mincey 2019, p.88).

Young people described learning from ED content online about both the development of eating disorders (Mincey, 2019) and about the recovery process (Eikey and Booth, 2017). Access to support for recovery was also reported whereby “similar-minded women, started to feel better, and received help” (Smahelova et al., 2020, p631).

Despite use of the term community, discussions of support and learning in all but two cases made no reference to anything other than individual actions. One participant referred to mentoring others and having been awarded by her peers the status of “advanced warrior... in recognition of her Pro-Ana successes.” (Firkins 2017, p72). In another study there was reference to the role of a moderator who maintains pro ED webpages, and how so-called Ana Coaches “would be called out in the thread”, presumably as a means of alerting others to danger (Mincey 2019 p119).

Online communities are a double-edged sword – “the eating disorder slowly crept up” (Firkins, 2017)

This final sub-theme describes different initiations, and degrees of interaction within the online communities and how these intersect with the young person’s ED journey (emotions and behaviour). Young people themselves identify how online groupings can have negative as well as positive impacts and how, at times, their online and offline journeys are nonlinear.

Young people described different experiences of seeking out pro-ED content or wanting to connect with others with EDs online. It could begin with “lurking” or being “curious” (Mincey 2019, p60). Others described primarily “looking for healthier recipes” (Firkins 2017, p74), or how pro-ED content “popped up when ... looking for other weight-loss things” (Mincey, 2019, p61). One young woman identified that they were already feeling suicidal when they found, “[a] YouTube video on anorexia, where the main character had become progressively sicker” and reported that she then realised “she wanted that for herself” (Firkins 2017, p.73).

Young people also talked about the initial influence of ED content on the pathway towards a greater eating disorder. The pro-ana content found following the YouTube video described above was described by this young person as enabling her eating disorder to “bloom” (Firkins 2017 p71). Others talked about going “deeper into illness ... thanks to the anonymity, the presentation of extreme cases, and the safe environment where visitors are supportive and nice to each other” (Smahelova et al., 2020, p630).

The complexity of these communities was emphasised. One young woman shared, “Looking back at my own personal experiences, as much as pro-ED sites have helped me, they have also made me sicker ... They taught me lots more ways to hide my eating disorder and they gave me lots more ways to lose weight quickly ... I can definitely say, they have made me feel more in control of my eating disorder. But they have also made me sicker.” (Mincey 2019, p.98).

Experiences also were not linear. One young woman described how her use would shift back and forward in a cycle between intense and frequent visits for ideas and support and stepping away to avoid “listen[ing] to everyone else’s problems” (Firkins 2017 p74).

And young people in recovery still reported using pro-ana sites in various ways. One young person described revisiting so as to look for friendship despite a fear of relapse (Firkins 2017 p103). Another described being in recovery but panicking over weight gain and so feeling the need to log in again (Firkins, 2017, p104). Another young woman reported using pro-ana sites alongside other pro-recovery content:

“Now, in recovery, it is harder to find recovery blogs, but the ones that I read are often more professional. But I still follow some non-recovery blogs because I feel it’s hard to totally abandon them.” (Yeshua-Katz and Martins 2013 p7).

Part 2: Views of other young people

As stated, the same three main themes: comparing, curating and community, were evident in the additional set of 11 studies that recruited young people more generally (i.e., without them having to be identified as having lived with an eating disorder). Some commonalities and differences between the young people in the two sets of studies are picked up within each theme below. It is important to note that the topics explored in the two sets are distinct in some ways. Unlike the studies of young people with lived ED experience, many of the studies in the set of 11 explored online content labelled as ‘#fitspiration’, and the focus was often on body ideals and transformations brought about through exercising (rather than more restrictive weight control behaviours common to eating disorder presentations). The following themes described below are not described in-depth as the seven studies in part 1. Here the main purpose is to provide a broad spectrum and additional context to lived experiences of EDs.

Theme 2.1: Comparing

Like studies of young people with lived experience of eating disorders, the 11 studies of broader groups of young people contained references to their own evaluations of bodies seen in social media content. As the following discusses, while some young people were seen as viewing online content through a critical lens, there were also concerns voiced by young people about the potential for negative influence on mood and behaviour, and some references to the potential for disorder.

The studies show participants’ familiarity with the operation of norms among young people’s interactions with online content related to bodies, food and exercise. For example, young people in two studies noted the negative online comments that could be directed at young women as a result of their online posts, “she was a healthy weight and then she took it a bit too far and so people started skinny shaming her” (Goodyear et al., 2021, p8-9), “...she’s thin and they call her anorexic or things like that because she does sports, that she has a problem or an obsession when she’s just doing sports” (Camacho-Minano et al., 2019, p660). Only one study contained a reference, by a single young person, to the value of representing diverse body types online (Welker, 2019).

As in the studies with young people with lived experience of EDs, these young people emphasised the extent of the influence of online content and made reference to receiving automated content, for example:

“...we are influenced so much. You see it every day, what the ideal body is and what you should look like.” (Ferguson et al., 2020, p14).

“There are so many suggested images, like transformations. Like you see a girl that is really big and then six weeks later she’s really slim now.” (Goodyear et al., 2019, p681).

Online influencers and their impacts were a particular focus of discussions within this group of 11 studies; something which was not seen in the other study set. The young people expressed an awareness of the impact of these influencers on their own body ideals, for example, "...maybe because I started doing that sort of thing (workouts designed to build muscle) and saw my body changing, and I liked the way that it was starting to look. Then I saw people who had way more amped up versions (Instagram influencers) and I thought they looked pretty good too." (Ferguson et al., 2020, p13).

Some young people were concerned at the potential negative impacts of these influencers, for example:

"I feel like, just the way that I've heard people talk about her, and types of people like her, think that [body transformation] can happen quickly or that that is achievable or a very normal standard to have a body that looks like that. Like, I mean she's a model in the fitness industry ... I have also heard more unrealistic expectations from friends who are all very aesthetic based over performance based, like 'Oh, I want to have abs,' and with the prevalence of these models showing up it makes it seem like everyone looks like that, but in reality, no one does." (Toll and Norman, 2021, p72-3).

In one study of young women who use protein supplements to support their aim for a slim yet toned body, all but one had started after an Instagram influencer had recommended these powders for alleviating hunger. The authors also claimed this eased a fear of out-of-control eating (Ferguson et al., 2020).

In other studies, references were made more directly to the dangers of disordered behaviour (Bell et al. 2019, Easton et al. 2018, Raggatt et al. 2018), for example:

"If I followed their food account where they tell me to eat healthily and I couldn't, I'd probably end up with an eating disorder." (Easton et al. 2018 p7).

"...they [#fitspiration messages] can promote, like, addictive lifestyles, where you push yourself too much" (Bell et al. 2019, p9).

However, young people were sometimes very dismissive of #fitspiration posts, especially when these were seen as unrepresentative or unreal:

"[Participants] ...evaluated the character of #fitspiration models [as] ...obsessive. It's only a small percentage [who] workout that much ...and it's not, probably, that good for you, to work out that much" (Male #7).' (Bell et al. 2019, p6-7).

"[The young women] pointed out how some of the images were 'fake', having been edited or taken from a specific photo angle or posture. Similarly, they were aware of unhealthy practices that these models could engage in (such as cosmetic surgery or extreme diets)." (Camacho-Minano et al. 2019, p657).

The authors of one study involving young men claimed that this critical stance was more common among those who had a positive body image (Chatzpoulou et al., 2020). In another study, some participants felt not all were equally immune, for example, "I study marketing ... I'm a lot more knowledgeable and less naïve to the content being advertised to me" [Female] '(Easton et al. 2018, p8).

While the negative effect and behaviours linked to online body-related comparisons that are reported by the young people in this set of 11 studies are far less extreme than some of those described in the studies with young people with lived ED experience, the sense of endless opportunities for these comparisons and negative consequences, is notable among accounts across the young people as a whole.

Theme 2.2: Curating

The young people in the subset of 11 studies, like those with experience of an eating disorder in the set of seven studies, described steps that they took to manage their own online content and their exposure to others'. While there were no references to the writing of blogs around food or exercise in relation to their bodies, young people reported the need for care when using hashtags and likes. The young people also reported considerable effort in managing the choice of images they posted of themselves, and awareness of some techniques for reducing the impact for themselves of others' material.

The complexity of communication online was made particularly clear in one study. Here the predicted responses of others were described as important just for the act of liking someone else's post. The authors note: "If the person who liked the post didn't get a like back on their other posts – from the person who made the original post – this acted as a form of judgement on their behaviour or body type". Female 1: "The really muscly people, if you were to ever like them or something, they wouldn't like you back because you might be not as skinny as they want you to be" (Goodyear et al., 2019, p683). Elsewhere in this same study, young men described the need for care when using a certain hashtag so to avoid the censure of their peers, "About two years ago everyone was using the #bitofagym lad ['bit of a gym lad']. It was like an ironic thing. It was anytime anybody did anything remotely athletic, they posted #bitofagym lad ... You can either use it ironically or unironically, I guess. It's mainly ironic ... Yes, you'd get roasted if you put unironically #Imagym lad" (Goodyear and Quennerstedt, 2020, p26).

In several studies young people were described in the main as avoiding posting pictures of their own bodies for fear of criticism (Chatzpoulou et al., 2020, Goodyear and Quennerstedt 2020, Camacho-Minano et al. 2019). Young men in one study described restricting themselves to browsing, "I was secretly wishing to have the confidence to post my body without being laughed at when I was fat" (Chatzpoulou et al., 2020, p1279) and young women in one study referred to the need before posting for "the required perfect body" (Camacho-Minano et al., 2019, p660). Continued posting was accompanied by competitive pressures for some young men in one of these studies. As one put it, "[as] long as the picture is better than the one I posted last week, it will go up... I feel ...anxious... there's always someone better and you've got to try and beat that person". In the same study, steroid consumption was reported as a means to "maintain a good body shape so as to be able to continue posting pictures of their body on Instagram" (Chatzpoulou et al., 2020, p1285).

Others used photo techniques to manage the presentation of their bodies, for example "I'd say I try to work the angles. Sometimes ...I try and look kind of skinnier. I'd say I do this because of celebrities trying to work the angles, so that's probably what I do." (Baker et al., 2019, p279). The actual editing of pictures was considered to be a form of cheating in another study, where it was also thought to contribute to the poor body image of other users, as well as being a consequence of "negative thoughts and feelings about one's own body" (Toll and Norman, 2021, p70).

In terms of managing the impacts of others' content, there was one explicit mention of avoiding being "completely immersed" and using content "for inspiration now and then" to reduce the risk of psychological harm (Easton et al. 2018, p8). There was also reference to the selective following of others to keep realistic about body goals:

"I always like to follow normal people as well ... these things are actually achievable" (Easton et al. 2018, p8).

"I have to make sure that the pages I follow are realistic. I don't follow any fashion models or people that will make me feel shit about myself. I like to follow people who are honest about how hard it can be to lose weight and to stay healthy." (Raggatt et al., 2018, p1002).

The accounts above mirror those from young people with lived experience of EDs in their emphasis on the value of authenticity and the need to be restrictive about access to others' content. There is notably, however, far less reference to the value of supporting others through online responses, possibly because the interactions under discussion are more fragmented, with less of a feeling of shared identity around EDs (see Community immediately below).

Theme 2.3: Community

This theme – about the draw of virtual groupings of people – was far less prevalent than in the studies of young people with lived experience. It was found in only one of the 11 studies of broader groups of young people (Chatzpoulou et al., 2020). In this study young men were interviewed if they had a public Instagram account and were using the hashtag #fitfam. Described by the study authors as 'a popular hashtag that has been created to provide its viewers with information and tips on exercising, training and being in shape,' the 'fam' component loosely references the idea of family or friendship. The hashtag's use for searches and/or as a label for posts could enable the finding of others with similar interests and enable connections between them. The authors report that these young men's initial motivation related to encouragement for body transformation which wasn't accessible to them offline:

Use of the hashtag was not without risks, however. The authors note, '...negative reinforcement is used by fitness hashtag members to discourage people from posting pictures of bodies that do not conform to the instabod ideal. Some ...felt they could not post on the platform when their body was fat or skinny for fear of being ridiculed by other community members. "I have gone on that, seen what other people are posting so that I knew what was and wasn't acceptable to post."' (Chatzpoulou et al., 2020, p1281). Furthermore, some hashtag users criticised others for using them 'to increase the number of followers, gain likes and comments from random users... "Using tags that mean "look at me I'm part of the fit family" or "I'm inspirational". It's like they're doing it just to feel secure about themselves."' (Chatzpoulou et al., 2020, p1279-80).

The references here to unhelpful offline experiences and the consequent seeking of support in an online community mirror to some extent those made in the studies of young people with lived experience of EDs (albeit in the one study only). However, there is a suggestion that this is not followed by the receipt of unconditional support, as reported by those describing membership of pro-ana or pro recovery groupings online.

5. Discussion and conclusions

5.1 Summary of findings and cross-cutting themes

Our main objectives were to collect, analyse and present evidence on young people's experiences and views of engagement with eating disorder-related material on online platforms. As the research question proposed, the aim was to explore what kind of influences online eating disorder content has on young people's relationships with their body, weight control behaviours, and/or any other eating disorder symptoms.

The synthesis of seven studies of participants with direct experience of an eating disorder identifies diverse practices of comparing and curating online, and an emphasis on the value and challenges of being part of online ED-related communities. It starts to unpack the potential impacts online ED content can have on these young people. Recent quantitative primary studies have shown that social media platforms can be spaces of self-compassion and empowerment (Seekis et al.; 2020) but have also seen participants reporting the disadvantages and advantages of social networking (Cavazos-Regh et al.; 2020).

Reduced levels of interaction with the offline world and a lack of external support/provision seemed to be a central experience of these young people. Online communities hold potential to offer refuge from the stigma and judgement of the offline world and to fulfil a need to belong and be understood. A 2015 study using a netnographic approach to explore posts within youth moderated online ED forums also echoed this notion in its identification of a "trusted environment for individuals to talk about isolation, fear... mutual support and acceptance" (Kendal 2015 p103).

The use of pro-ana blogs was seen to provide emotional support, as other studies of online posts have shown (Tong et al., 2013, Dias et al., 2003). Young people described embracing spaces where they could learn, comfortably self-evaluate, and share insights with others as to their shifting ED identities and therefore strengthen bonds (Custers 2015). However, this is also juxtaposed with young people's awareness of associated dangers. Pro-ED communities had been experienced as helpful but also damaging by young people.

The potential for online content to trigger unwanted behaviours seemed particularly pertinent in this group. Other studies have also found similar findings on triggering content (for example, Basterfield., et al 2018). A level of awareness of potential triggers when producing and uploading content is also referred to by bloggers in one of the reviewed studies. This suggests a degree of responsibility and a perspective among online content producers that would benefit from further investigation. This review's findings, however, should already illustrate for practitioners and policymakers how young people are active agents and producers of such content and not just passive consumers.

The current review's findings also illustrate the contradictory and very complex nature of online experiences, thus evoking the idea of these environments comprising a 'double-edged sword' (Durvasula & Lysonski., 2008, Bunworth, 2020). This phrase is also used by author Justine Reel who discusses it in relation to "helping or harming one's mental health and tendency towards eating disorders" (2018, p298). An understanding of this complexity could also inform the work of social media providers in developing more effective detection and reporting tools for OEDC on their platforms, as well as educational materials for users.

Findings from the additional 11 studies of young people who were interviewed regardless of their experience of an eating disorder, show some similarities. While not discussing the potential for material to trigger, these young people reported considering that it could adversely influence weight control behaviours and goals.

Both groups of young people emphasised the importance of authenticity and how material might present distortions of reality. The sense of endless opportunities for body-related comparisons and negative consequences in both sets of studies suggests considerable commonality of experience for young people as a whole.

The broader group of young people emphasised the considerable individual effort put into managing their own representations online so as to avoid social sanctions. This was more of a focus than in the studies of young people with lived ED experience, who instead referred to the value of supporting through responses to others' posts, and the stigma and need for support that could be addressed through creating their own content. Unlike participants in the studies of those with experience of an eating disorder, there was very little reference in the broader group to the potential benefits of finding groupings of like-minded and supportive people in online spaces, possibly because the interactions under discussion were more fragmented, with less of a feeling of shared identity.

The identification of community as an important theme across both set of studies of young people's engagement with online content could be used to build an extra dimension into the conceptual framework outlined in this report's background (Rodgers and Melioli, 2016, Wang et al., 2019). The observation of content, and the curating acts of following, commenting and contributing content, are all likely to have different meanings for young people when done in the context of entering, engaging within, and leaving virtual social spaces where shared identity seems to be so key.

5.2 Strengths and limitations

This is the first systematic qualitative evidence synthesis to examine online eating disorder content. The research was conducted according to systematic review principles, with highly sensitive search strategies, inclusion criteria, robust data extraction and quality assessment methods, and consultations with diverse stakeholder groups. By broadening the scope of how EDs and body image are explored, the evidence generated combined heterogeneity of different population groups. Insights derived from the seven studies which provide data from people with lived ED experience are made richer by the additional contributions of the 11 studies and broaden the scope of the review's findings and implications. The approach led to development of themes such as 'community' which had not yet been explored to any depth within the context of online eating disorder content. At the time of finalising this report, the authors are still working with some of the young people who participated in consultations about the review. They plan, together, to write up reflections about the impact of this work on the review in a separate publication.

There are multiple terms used in the literature to describe the many complexities of eating disorders and body image. In this review we have tried to represent views and experiences by adhering to the ways that these have been expressed and reported in the 18 included studies. As the review examined ED content in the broadest context, as indicated in the research question (see Methods chapter 7), it also took into consideration terms such as 'recovery'. Recovery was identified as a recurring theme in the seven studies on lived experiences. It was either part of the main study focus and was expanded further in a study's findings (four studies), or in data generated in the remaining three studies, revealing recovery in relation to online content. Furthermore, five of the authors

explicitly use terms such as ‘formally diagnosed’ or ‘in recovery’ in their methods (see Appendix). However, there was very little discussion by the young people studied of the use of recovery sites, or in-depth discussion of how different content and sites could impact on recovery. This could be considered limitations to the review, but all reviews are necessarily limited by the studies that are available. It is worth noting that study authors in this field face ethical challenges when seeking to carry out research with young people who are in the midst of an eating disorder.

One additional limitation relates to time; more recent primary studies may now have been published, and this does appear to be a rapidly growing area of research (Dickson et al., 2022). Digital platforms, distinct from those discussed in the research identified to date, may now be more preferred by users.

5.3 Implications for policy and practice

The synthesis provides an important account of how young people experience online eating disorder and idealised body image content. The findings highlight synergies in engagement around the key themes of comparing, curating and community. They also identify key differences in perspectives within those themes, depending on whether young people have lived experience of an eating disorder and where they are in their ED recovery process. This analysis provides a complex and nuanced picture of how young people navigate content online, which can both positively and negatively influence their relationship with eating, exercising, body size, shape and weight. The review also draws attention to the need for further engagement with this complexity, given the ongoing relationship young people have with digital online platforms and the subjectivity of their experiences in those spaces. Furthermore, the approach to content generation described by young people within existing research, which includes awareness of potential impact, suggests a level of criticality and responsibility which could be harnessed to inform the development of policy and practice.

The findings also provide insight into how policy and practice could respond to these issues more generally, but of course do not provide any evidence regarding the likely effectiveness of any particular policy. New and existing policy interventions focused on supporting young people in this area could consider whether professionals routinely explore the role of online platforms as a tool that can support or hinder recovery from eating disorders. A key recommendation in NICE guidelines for the treatment of eating disorders is assessment of the wider social community, including the internet and social media, alongside the impact of the home, education, and work, throughout treatment (National Institute for Health Care Research 2017). This assessment could be extended to explore the impact of online communities. It could examine possible contributions to ED identity formation of engaging in online communities, and the extent to which this is serving as a barrier to recovery, because they continue to be a source of unhelpful beliefs and interactions. It could also examine whether such communities are providing important online social supports. A focus on specific interventions to address concerns about online material is outside the scope of this review. Nonetheless, there is much potential for initiatives where those with lived experience of eating disorders and the use of online content work with health professionals and researchers to co-design online spaces and campaigns (Wade et al, 2021).

Similarly, digital literacy interventions, particularly when related to online harms, could support young people to understand not only that engagement with certain types of content can be detrimental to their mental health, including body image and self-esteem, but also that identifying

the line between helpful and unhelpful is subjective. Therefore, it can be difficult to determine and could require outside help to decipher (for example, by consulting with family, friends or teachers). Given that young people often go online to seek information and support, there is not only scope for online platforms, such as social media and networking sites, to direct young people towards professional help, but also for platforms, including mobile applications, to become tools for increasing the accessibility of help for young people. The design of digital interventions could also be informed by how young people use online spaces, to develop a person-centred and strength-based approach to addressing eating disorders and body image concern. Furthermore, the awareness demonstrated by young people about online content and inauthenticity, competitiveness and self-critiquing requires further scope for alternative-evidence based prevention/intervention approaches (for example, self compassion, Goss & Allan 2014).

5.4 Gaps in the evidence and future research

The synthesis highlighted the gender imbalance in the studies, with only two studies out of 18 involving male participants. This suggests that there are evidential gaps here and that further investigation into male experiences of EDs and body norms is needed. There was also no demographic data reported on sexuality or exploration of the experiences of the LGBTQIA+ community, despite body image being a significant issue for this community. Although there were 11 studies with participants from different ethnic groups, the number of participants taking part was small. It was also difficult to discern from the data the ethnicity of individuals and whether that this had any bearing on their lived experience. This lack of disclosure could be to protect the individual. However, it would be useful for future research to collect data from ethnic minority participants and members of the LGBTQIA+ community purposively, to explore whether their cultural/religious upbringings or identities play any role in the types of ED content they engage with and the nature of this engagement. Similar views on the absences of discernable views from participants with these demographics were also shared by the young people consulted for the review. As we see an ever-increasing number of younger children using digital devices and gaining access to online platforms, it may be useful to investigate this within the ED context. Many of the included studies primarily focused on older participants (18+), although it was evident that some had EDs from a young age. This is an extremely sensitive topic and ethical care would have to be taken when considering how to explore eating disorders with younger children. The 'Community' theme could also be examined further within the context of preventative intervention research, which some participants alluded to. Finally, in terms of media platforms, the studies in the review primarily analysed data about Instagram. However new platforms are emerging all the time, with Tik Tok recently a growing trend, and there is a need for both researchers and reviewers to somehow keep abreast of the platforms young people are actually using.

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Part II: Technical description of the review

7 Detailed Methods

This chapter describes in more detail the methods used for the qualitative evidence synthesis (QES) described in this report; the approach used to search for, identify, analyse and synthesise the studies relevant to this review's research question. The protocol for this review and the systematic map that preceded it was published on PROSPERO:

https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=249969

This report adheres to the Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA) guidance which can be found in Appendix 1. Where necessary, the PRISMA guidance has been adapted to fit with a systematic review of qualitative rather than quantitative data. The review comprises two strands of work, both of which were informed by consultative work with stakeholders:

1. A systematic map (presented in a separate report, Dickson et al. 2022);
2. A qualitative synthesis of studies of young people's views of OEDC (presented in this report).

The primary aim of this research, commissioned by the Department of Health and Social Care (DHSC) in England. The review question for the QES was:

What are young people's views and experiences of online eating disorder content and what influence does it have on their relationship with their bodies, weight control behaviours, and/or any other eating disorder symptoms?

7.1 Stakeholder involvement

Consultations with stakeholders consisted of working closely with an advisory panel and with a group of young people. All consultations were convened for the purposes of the review.

7.2.1 Review commissioners

Review facility team members (KD, RR, MK and JT) met with the DHSC mental health policy team throughout the research process to ensure the review remained closely aligned with their needs and emerging policy requirements. We discussed with this team the scope of the protocol, the findings from the map and the interim findings of the qualitative evidence synthesis.

7.2.2 Policy and practice consultation

A multidisciplinary advisory panel was set up to inform and guide the review. It consisted of professionals specialising in child and adult eating disorders. The group met once, at the stage of emerging findings about the nature and quantity of research evidence identified by the map to support the scope and shape of review.

7.2.3 Consultations with young people

We held two online workshops to consult with a group of eight young people with lived experience of online eating disorder content to help ensure the review explored areas of relevance to young people. This work was supported by a specialist in the active involvement of young people in research. Workshop 1 was held when coding work had started to identify the extent and nature of existing research studies. Workshop 2 was held when findings were starting to emerge from the

qualitative synthesis. Workshop discussions were informal and open-ended but were structured around the following questions:

- Workshop 1: What are the different types of online eating disorder content (OEDC) that you think young people might engage with? What matters most to young people about OEDC? What terms/language might young people use when discussing this topic online?
- Workshop 2: Looking at the draft list of themes that we have found, is there anything which you think is really important, or less important, is there anything you were surprised by, or is there anything missing?

An interactive white board was used to encourage the anonymous posting and analysis of ideas. Participants were also encouraged to use the meeting software's chat function and their microphones.

7.2 Search strategy

Studies included in this review were identified from a systematic map of empirical literature investigating the relationship between eating disorder content online and young people's body image concerns, weight control behaviours, or eating disorder symptoms (Dickson et al. unpublished).

To produce this systematic map, searches were undertaken in 15 health, psychology and education databases: ASSIA (Proquest); British Education Index (EBSCO); CINAHL PLUS (EBSCO); Child Development and Adolescent Studies (EBSCO); ERIC (EBSCO); EMBASE (OVID); IBSS (Proquest); MEDLINE (OVID); PsycINFO (OVID); Scopus, Social Policy and Practice (OVID); Sociological Abstracts (Proquest); and Web of Science databases: Book Citation Index – Social Science; Emerging Sources Citation Index; and Social Science Citation Index.

We also searched the following online resources: Mental Elf, NICE Evidence Search, Schools Health Education Unit website, UK Safer Internet Centre website, focused searches of: Bielefeld Academic Search Engine (BASE), Google, Google Scholar, Microsoft Academic. Focused searches were also undertaken within the journal pages of *Appetite*, *Eating Disorder Journal*, the *Journal of Eating Disorders* and the *International Journal of Eating Disorders* and citation searching, reference checking and related item searching of included qualitative studies and relevant systematic reviews, using Microsoft Academic. We also invited the stakeholder advisory group to provide any references they knew of.

The searches were undertaken between February and early March 2021, based on search concepts of 1) disordered eating, body dissatisfaction or over-exercising symptoms and behaviours, 2) online content, social media, blogs, instant chat, 3) adolescents and young adults. Searching on Microsoft Academic was undertaken on 28 April 2021 and repeated from newly identified relevant studies on 10 May 2021. The search terms were developed by an information specialist in consultation with the lead author and included pilot screening of a sample of 350 references identified from broad and focused scoping searches of which 59 were potentially relevant. We also consulted previous systematic reviews, for example, Ali et al. 2015, Dickson et al. 2018, Grist et al. 2017, and Rousenfell et al. 2019. A further detailed search strategy for MEDLINE is set out in Appendix 2; this was translated for searches of other sources.

7.3 Study identification

Studies were selected according to the criteria outlined in table 7.1

Table 7.1: Criteria for inclusion and exclusion of studies

A. Criteria for inclusion in the systematic map.

	Include studies:	Exclude studies:
Participants	Young people between 11 and 25 years old.	Not reporting data where the mean population is aged between 0-25
Exposure	Online eating disorder content	Not focused on online ED content
Comparison	No restrictions	No restrictions
Outcomes	Quantitative measures of: eating disorder symptoms, weight control behaviours, body image	Not reporting quantitative data on eating disorder symptoms, weight control behaviours or body image
Study Design (for map)	i) Observational studies including prospective cohort and case – control studies and randomised controlled trials (if available). ii) Qualitative studies of young people’s views and experiences	Not i) measuring the association between engagement with online eating disorder content and differences in eating disorder symptoms, weight control behaviours or body image;
		Not i) reporting qualitative data collection methods, analysis or empirical data (for example quotes/author description) on online eating disorder content and its relationship to young people’s body image concerns, or any aspect of eating disorders
Geographical Location	Conducted in OECD Countries	Not conducted in OECD countries
Date	Post-2007	Pre-2007
Language	Published in English	Not published in English
Availability	Electronically available in full text	Paper-based / hard copies of studies

B. Additional criteria for inclusion in the Qualitative Evidence Synthesis

Study Design (for QES)	Qualitative studies of young people’s views and experiences	Not reporting qualitative data collection methods, analysis or empirical data (for example quotes/author description) on online eating disorder content and its relationship to young people’s body image concerns, or any aspect of eating disorders
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Participants: To ensure we focused on children and young people we included studies where the mean age of participants is 25 years or lower.

Exposure: Included studies needed to investigate and report results on the relationship between eating disorder content online (exposure) and body image concerns or eating disorder symptoms (outcome). For the purpose of this review, eating disorder content is defined as any content online which encourages or discourages disordered eating and thinking about body size, shape or weight. By focusing on the full range of eating disorder content it was possible to ascertain a more comprehensive account of the possible impact of that content in young people's lives. Engagement in eating disorder content may be measured in terms of both how often (frequency) and how long (duration) young people spend viewing eating disorder-content, in addition to types of engagement. We adopted a broad definition of digital media to include any online space providing a platform to share written, visual or audio content (for example, websites, forums, blogs, social networking sites, instant chat).

Geographical location: To ensure we included empirical literature relevant to the UK context, we only included studies conducted in OECD countries.

Study designs: In the map we included: i) experimental studies that compares exposure to a pro-eating disorder website to a comparison condition or ii) correlational or longitudinal studies measuring the association between engagement with eating disorder content and body image concerns and eating disorder symptoms. We also included iii) qualitative studies that capture children and young people's experiences and perspectives of online eating disorder content and its relationship to their body issues and concerns, or any aspect of eating disorder symptomology, using open-ended data collection methods, such as interviews and focus groups. The QES contains a subset of studies included in the map. To be included in the QES, studies needed to meet the criteria for qualitative studies.

Language, date and availability: We included English language studies published from 2007 onwards, as this is when 'image-based' digital media became more prevalent, and there was a marked shift in the use and ownership of mobile-web-based technologies (for example, 'web 2.0'). We restricted studies to those available electronically given the current difficulty (COVID-19 quarantines) with obtaining hard copies from libraries.

7.4 Study selection

Search results were de-duplicated and imported into the systematic review software, EPPI-Reviewer 4 (Thomas et al. 2010), which was also used to manage all subsequent stages of the review described below. We piloted the exclusion criteria by comparing decisions in groups of two or more reviewers using worksheets with guidance notes on a small sample of records (for example, 10-20). Disagreements were resolved through consensus and any required refinements to the criteria will be made and recorded in a working protocol document. A further sample of records were screened by reviewers independently and differences resolved by discussion or consulting with a third reviewer. When agreement was adequate (90-95%) for this second sample, the remaining citations were screened by a single reviewer. References were screened initially on titles and abstracts and full reports were obtained for those references judged as meeting the inclusion criteria or where there was insufficient information from the title and abstract to assess relevance. A second opinion was made available for any study where a reviewer was unsure of its eligibility. A record of the screening process is reported in this report using the PRISMA flow diagram.

7.5 Data Extraction

The data extraction was carried out in two stages, for the map and for the QES. Coding tools were devised from ones used in previous reviews (Brunton et al., 2016, Dickson et al., 2018, Lester et al., 2019). For the first stage the tool included codes such as geographical location, population, study design. The second stage included coding for study aims, and sampling and data collection methods, types of online content, platform and ED, as well as an extraction of the authors' summary description of their findings. Two reviewers (MK, RR) independently piloted the second tool. Each study was then coded independently by two reviewers who then reached consensus to produce a final agreed coding. Detailed descriptions of each of the studies in turn can be found in Appendix 3.

7.6 Critical appraisal

The reviewers critically appraised the allocated studies against eight questions used in previous QES reviews (for example Rees et al., 2014). These addressed: steps taken to strengthen rigour in sampling, data collection and data analysis; the extent to which findings were supported by data, the breadth and depth of findings, and the privileging of participants' views. Judgements about study quality were based on the reliability and usefulness of the findings contained in each study (see Chapter 9 for further information). Appraisal was done independently by two reviewers who then reached consensus, as described above for the data extraction stage.

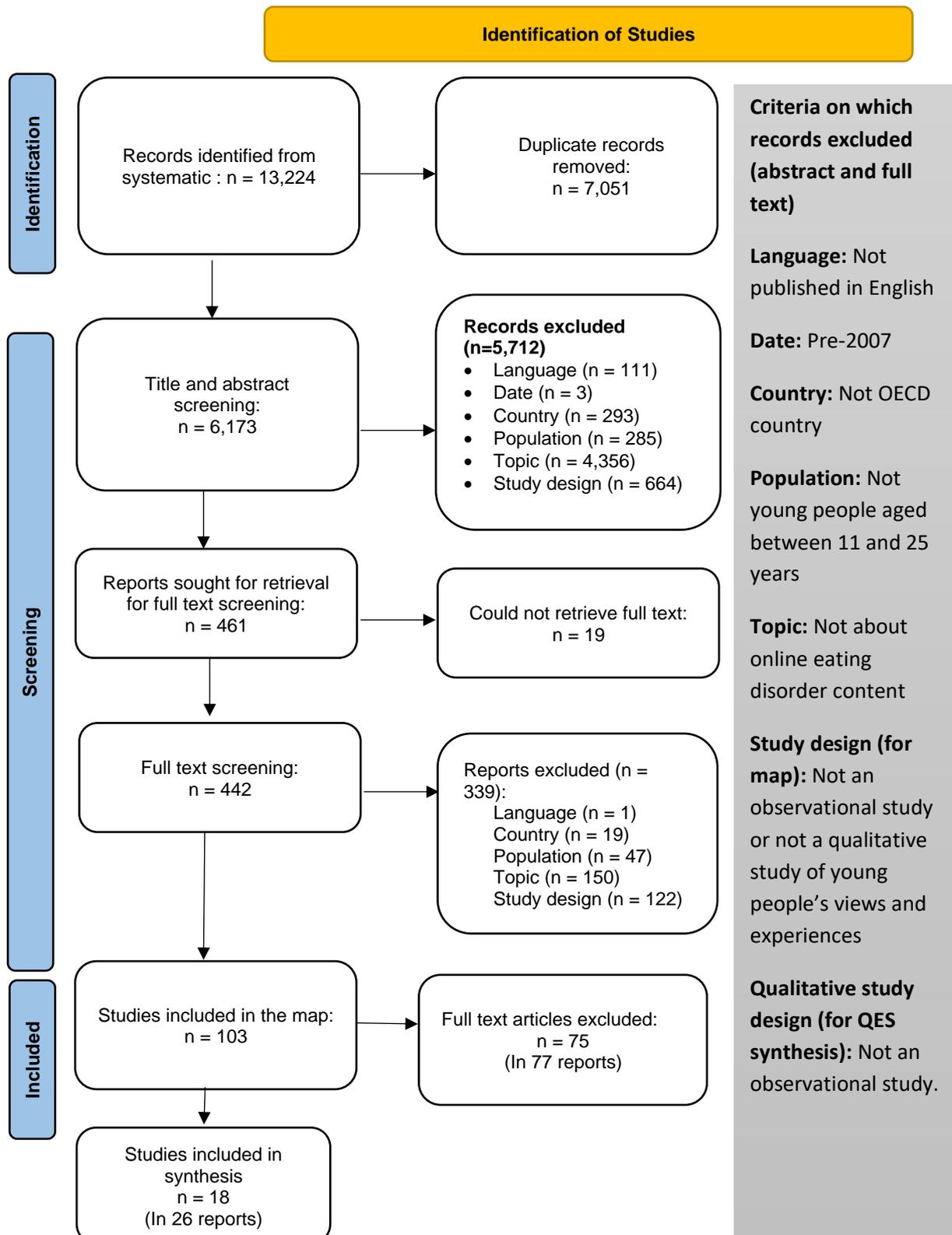
7.7 Synthesis

Data were synthesised thematically (Thomas and Harden, 2008). Qualitative data (both direct participant quotes and primary study authors' interpretations) were coded line-by-line by two reviewers (MK and RR) independently using the coding function in EPPI-Reviewer. The coding of that data was then organised into themes and higher-order themes through repeated individual coding and follow-up discussions between these two reviewers. At the start of this process studies were separated by whether participants had lived experience of eating disorders so as to inform two separate but complementary syntheses. Coding and a draft narrative synthesis was prepared first for the studies of views from young people with lived experience of EDs. The remaining studies were then coded with this initial framework in mind, which led to further iterations of the coding frame and themes, until a final set of two distinct but complementary narratives was agreed. The second synthesis explored the same overarching themes, but in less depth. The main purpose of the second synthesis was to put the first into a broader context by identifying possible commonalities in perspective, regardless of ED experience. It also aimed to identify some possible differences in perspective.

8 Flow of literature through the review

A total of 13,224 citations were identified from the systematic search. After duplicate removal, 6,173 citations were screened on title and abstract. Of these, 442 were retrievable and screened on full text. From this process 93 studies reported in 103 papers were included in the map and 18 studies, reported in 26 papers were included in the qualitative evidence synthesis. The flow of literature is shown below:

Figure 8.1 Flow of studies through the review



9 Results of study quality assessment, and stakeholder consultations

9.1 Quality assessment

Quality assessments of studies using qualitative methods addressed their rigour according to the following methodological criterion: 1) sampling; 2) data collection; 3) data analysis; and 4) the extent to which the study findings are grounded in the data and their usefulness according to 5) whether the study privileges the perspectives of young people; and 6) the breadth and depth of findings. The rigour in relation to reliability considers the judgments made for criteria 1-4. The rigour in relation to usefulness is measured by the judgements made to questions 5 and 6.

Overall, study quality was judged to be a combination of high or medium reliability and usefulness (n=13) with the remaining studies judged to be of low reliability (n=4) or usefulness (n=5). All three studies judged to be of high reliability were also judged to be highly useful. The majority of the eleven studies judged to be of medium reliability were judged to be of medium usefulness (n=8), while the remaining three studies were judged to be of high (n=2) or low usefulness (n=1). Four studies judged to be of low reliability were also judged to be of low usefulness.

Table 9.1 Critical appraisal of studies: Reliability and usefulness

Author	Reliability			Usefulness		
	High	Medium	Low	High	Medium	Low
Baker et al., 2019		✓			✓	
Bell et al., 2019	✓			✓		
Booth & Trauth, 2019			✓			✓
Camacho-Minano et al., 2019		✓				✓
Chatzopoulou et al., 2020		✓			✓	
Easton et al., 2018		✓			✓	
Eikey & Booth 2017			✓			✓
Ferguson et al., 2020		✓			✓	
Firkins et al., 2017		✓		✓		
Hockin-Boyers et al., 2021	✓			✓		
Mincey, 2019		✓			✓	
Papathomas et al., 2019		✓			✓	
Raggatt et al., 2018			✓			✓
Saunders et al., 2020		✓			✓	
Smahelova et., Al 2020	✓			✓		
Toll & Norman, 2021		✓			✓	
Welker, 2019			✓			✓
Yeshua-Katz & Martins 2013		✓		✓		

9.2. Stakeholder consultations

Advisory panel

Overall, the advisory group confirmed the salience of the review topic, the value in exploring both quantitative and qualitative data, and to remain sensitive to issues of diversity and heterogeneity. The discussion covered the following topics/issues:

Prevalence and risk factors

- Current observation is that nationally, since the second lockdown in September 2020, there has been a 60% increase of urgent referrals of under-18s to Children and Young People's Mental Health Services.
- There has also been a noticeable increase in referrals to Anorexia and Bulimia Care and the National Centre for Eating Disorders, since lockdown, particularly by parents concerned about their children.
- This has potentially been exacerbated by children being at home with social media and an increased fear of obesity which could drive ED psychopathology.
- Different population groups present different risks: for example, the risk of young people developing ED, young people with ED and the young people trying to recover; it is therefore important to disentangle in the literature those who have an ED from those who do not, so as more to understand engagement with content online.
- Figure 1 is useful as there is not a single pathway and there are many factors at play.
- Furthermore, the pathway from body dissatisfaction to body dysmorphic disorder into ED is not very well characterised in the literature but is evolving and young people's views might shed further light.
- Gender still remains one of the biggest risk factors for developing an ED; but further work on boys' experience is also needed.
- Excessive social comparison with body image ideals online is an important risk factor/mechanism.
- When young people search for help and support with ED (for example, on Google) it also brings up anti-ED content and affects further algorithms – this can hinder young peoples' recovery goals.

Young people's experiences, types of OEDC content and intervention strategies

- Young peoples' engagement with online eating disorder content is often a hidden activity for example, from parents and other professionals such as psychiatrists/therapists.
- Young people often do not share how/where they are interacting online as they are afraid their access may be removed or limited, but they also fear not being part of these groups despite potential harms.
- In line with what is reported from the young people's consultation, online communities can be a lifeline for some, thus useful to consider benefits as well as harms.
- Online gaming may also be an influence – for example, online gaming communities which talk to each other and discuss avatars and the clothes they wear – often choosing slim, attractive avatars. However, avatars may not be new (for example, Barbie has BMI of 12) – thus it is important to pick apart the new aspects of online world. These may include the rise of celebrities discussing their struggles with weight, content shared by popstars and influencers generally, the move to 'firm' not necessarily 'thin' body ideals and the increase and possible harmful effects of exercise and body building content.

Also raised were early intervention/prevention in schools (for example, around EDs, social media and online harms generally), the use of red flag systems/alerts online, linking findings with obesity strategy, and giving further consideration to ED at a public health as well as clinical level.

First workshop consultation with young people

Responses are presented below in line with each of the main questions posed in the workshop.

1. What are different types of OEDC that you think young people might engage with?

Young people identified a vast range of online content, confirming the breadth of the topic. This spanned visual and interactive content for example: images (desirable/undesirable, before/after, what I've eaten today/my fitness regime), videos/vlogs/photos, fitness accounts, 'influencers', people selling diet and wellbeing products, pro-ana (anorexia) sites, recovery stories/journeys and communities, online support groups and chats (some with strict rules/body checks). They emphasised how the range of available platforms continues to change rapidly.

2. What matters most to young people about OEDC?

Young people reflected that online content and platforms can:

- provide access to people who understand you, can share resources, support and insights, can validate your experiences, can hold you accountable and can link you to activist groups;
- provide support and a sense of community that is always accessible – especially when young people have been told they are not ill enough for overwhelmed services. Eating disorders are a lonely illness;
- challenge stereotypes or represent different body types, but not always. They can help identify how eating disorders are more than just wanting to be thin. But non-white, non cis-gendered, disabled and larger bodies are often not visible;
- sometimes be experienced as competitive, toxic and triggering, and certain forms contribute to maintaining illness – disordered behaviours can be encouraged and normalised, and young people can find they are pushed to achieve unhealthy goals and can have difficulties moving on to recover;
- are in need of young people's involvement in OEDC regulation and education initiatives.

3. What terms/language might young people use when discussing this topic?

A range of terms were identified for example: body image, body checks, thinspo, ana, specific diets (for example, keto, intermittent fasting) acronyms like HW/LW/GW/UGW to indicate weight (for example, goal weight/under goal weight). In breakout sessions young people had the opportunity to reflect and share further (continued overleaf).

Key issues included:

- The 'community keeps you ill' – how online communities' support or praise of weight loss/food portions/exercise routines posted and linked online can be a hindrance;
- However, online communities can be motivating and supportive too – for example, through the sharing of invalidating experiences with families and health professionals and other struggles – "helping feed you, even if you are not eating";
- Yet it can be difficult to move away from online spaces, to support recovery, as the eating disorder becomes a 'part of your identity', 'part of you can want to be triggered';

- Stalking of recovery accounts can intensify a competitive culture, as well as individuals' symptoms;
- Online closed support groups that aim to provide safe spaces can be helpful, as can influencers who emphasise that recovery is an ongoing process;
- Young people also reflected on different stages of a young person's experience of having an eating disorder and how this influences how they engage with content online, and how this is not static. For example, some content might be more or less triggering depending on different stages of the illness;
- The need for research on/specific support for diverse groups (for example People of Colour, LGBTQ+ etc).

Second workshop consultation with young people

Responses to the question, what issues are raised by the team's presentation of emerging findings? The young people identified several issues as important ones that the research team should explore further by examining the studies under review, including:

- Demographic research gaps – what kinds of young people have been included in studies of OEDC and whose views might be missing (for example, ethnicity, gender, age)?
- ED research gaps – what kinds of eating disorder and related content are most addressed by the studies and which less so (for example, EDs other than anorexia such as 'other specified feeding or eating disorders')?
- What do the studies report about:
 - the more recent social media developments (for example, TikTok)?
 - young people who are not posting, but who are a kind of 'silent consumer' of OEDC?
 - young people's frustration with OEDC and their views on the potential for it to be damaging?
 - young people's use of OEDC for self-validation?
 - promotional forms of OEDC (material that is ultimately aimed at selling something)?
 - sites that present themselves as focused upon ED recovery?
 - experiences that lead to the seeking of OEDC (for example, of a lack of knowledge/support elsewhere)?

10 Appendices

Appendix 1: PRISMA Checklist

Section/topic	#	Checklist item	Reported in Chapter #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	Executive Summary
BACKGROUND			
Rationale	3	Describe the rationale for the review in the context of what is already known.	1
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	1
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (for example, web address), and, if available, provide registration information including registration number.	CRD249969
Eligibility criteria	6	Specify study characteristics (for example, PICOS, length of follow-up) and report characteristics (for example, years considered, language, publication status) used as criteria for eligibility, giving rationale.	2, 7
Information sources	7	Describe all information sources (for example, databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	7, Appendix 2
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	7, Appendix 2
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	2, 7
Data collection process	10	Describe method of data extraction from reports (for example, piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	2, 7
Data items	11	List and define all variables for which data were sought (for example, PICOS, funding sources) and any assumptions and simplifications made.	7, Appendix 2
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	
Summary measures	13	State the principal summary measures (for example, risk ratio, difference in means).	n/a
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (for example, I^2) for each meta-analysis.	n/a

Section/topic	#	Checklist item	Reported in Chapter #
Section/topic	#	Checklist item	Reported in Chapter
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (for example, publication bias, selective reporting within studies).	
Additional analyses	16	Describe methods of additional analyses (for example, sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	3, 8
Study characteristics	18	For each study, present characteristics for which data were extracted (for example, study size, PICOS, follow-up period) and provide the citations.	3 and Appendix 3
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	See 9 for critical appraisal
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Appendix 3
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	4
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	n/a
Additional analysis	23	Give results of additional analyses, if done (for example, sensitivity or subgroup analyses, meta-regression [see Item 16]).	n/a
DISCUSSION			
Summary of evidence	24	Summarise the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (for example, healthcare providers, users, and policy makers).	5
Limitations	25	Discuss limitations at study and outcome level (for example, risk of bias), and at review-level (for example, incomplete retrieval of identified research, reporting bias).	5
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	5
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (for example, supply of data); role of funders for the systematic review.	Pg2

Appendix 2: Searching methods in detail

Appendix 2.1 Search sources

Searches for reviews were undertaken in ASSIA (Proquest); British Education Index (EBSCO); CINAHL PLUS (EBSCO); Child Development and Adolescent Studies (EBSCO); ERIC (EBSCO); EMBASE (OVID); IBSS (Proquest); MEDLINE (OVID); PsycINFO (OVID); Scopus, Social Policy and Practice (OVID); Sociological Abstracts (Proquest); and Web of Science databases: Book Citation Index – Social Science; Emerging Sources Citation Index; and Social Science Citation Index. We also searched the following online resources: Mental Elf, NICE Evidence Search, Schools Health Education Unit website, UK Safer Internet Centre website, focused searches of: Bielefeld Academic Search Engine (BASE), Google, Google Scholar, Microsoft Academic. Focused searches within the journal pages of Appetite, Eating Disorder Journal, the Journal of Eating Disorders and the International Journal of Eating Disorders and citation searching, reference checking and related item searching of included studies, using Microsoft Academic.

Appendix 2.2 Medline Search Strategy

Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process, In-Data-Review & Other Non-Indexed Citations and Daily <1946 to February 19, 2021>

Search Strategy:

1 blogging/ or social media/ or internet/ or online social networking/ (83311)

2 social networking/ and (online or web or internet or website* or computer? or electronic or computing or mobile or digital).ti,ab,kw,oa. (1466)

3 (instagram* or facebook* or Twitter or reddit or pinterest or YouTube* or MySpace or Tiktok or Tumblr or 4chan or imgur or "telegram messenger" or snapchat or whatsapp or imessage or wechat or viber or skype or flickr or linkedin or badoo or bebo or Cyworld or Orkut or Renren or Vkontakte or Friendster or "see you too" or "CU2" or "friends reunited" or "telegram messenger").ti,ab,kw,oa. (23291)

4 (blogs or blogger or blogging or bloggers or microblog* or "micro blog*" or "web log*" or weblog* or "web-based log" or vlog* or "videoblog*").ti,ab,kw,oa. (1806)

5 ("online chat" or chatroom* or chatbot* or "chat bot" or "chat bots" or "chat room" or "chat rooms" or "chat applications" or "chat app" or "chat apps" or "social media" or "digital media" or cyberspace or cyberculture or "web 2.0" or "social networking site" or "social networking sites" or "social web*" or retweet or tweet or tweeting).ti,ab,kw,oa. (17737)

6 ("computer mediated communication" or (((instant or mobile or online or "on line" or digital or apps or app or applications or software) adj2 (messaging or messenger)) or "social network site" or "social network sites" or ((instant or mobile or online or "on line" or digital or apps or app) adj2 communication) or "social computing")).ti,ab,kw,oa. (2971)

7 ((online or "on line" or web or internet or digital or website* or "new technolog*" or "new media" or virtual or cyber?) adj3 (forum or forums or network* or community or communities or social or

socially or interact* or platform or platforms or chat or participat* or world or membership or communication)).ti,ab,kw,oa. (32182)

8 ((online or "on line" or web or internet or digital or website* or "new technolog*" or "new media" or virtual or cyber?) adj3 (users or engage or interact* or selfies or post or posts or posting or clicking or commenting or following or follower* or engaging or engagement or engag* or sharing or share or endorsing or endorse or tagging or tag or repost or reposts or reposting or tweet or retweet or contributing or contribute* or (content adj1 generat*) or (group adj1 membership*) or (passive* adj1 scrolling) or friending)).ti,ab,kw,oa. (14766)

9 ((online adj2 content) or (online adj2 harms) or (online adj2 exposure*) or ("on line" adj2 content) or ("on line" adj2 harms) or ("on line" adj2 exposure*) or ((online or "on line") adj3 (sites or sites))).ti,ab,kw,oa. (1109)

10 (((website* or web or internet) adj10 (harms or exposure*)) or ("web sites" or websites or "web page*" or "internet site" or "internet sites" or "internet pages") or ((website* or web or internet) adj10 (content not "content analysis"))).ti,ab,kw,oa. (20046)

11 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 (147012)

12 ("anti ED" or "anti eating*" or "antieating*" or "anti mia" or "anti ana" or "Anti Pro Anore*" or "pro eating" or Proeating or "e ana" or "pro ana" or "pro mia" or "pro ED" or "e mia" or "pro anorex*" or "pro anorec*" or proanorec* or "anti bulim*" or "pro bulim" or probulim* or antibulim* or "e bulim*").ti,ab,kw,oa. (212)

13 (thinspiration or fitspiration* or bonespiration* or ?thinspiration* or ?fitspiration* or ?bonespiration* or ?cheatmeal* or malefitspo* or ?malefitspo* or "thin inspiration*" or "body inspiration*" or "fitness inspiration" or "bone inspiration*" or "cheat meal*" or Bopo or fitspo or ?fitspo or ?bopo or fitstagram*).ti,ab,kw,oa. (87)

14 ("body positive" adj10 (content or online or "on line" or web or website* or internet or media)).ti,ab,kw,oa. (10)

15 ((Body* or eating or "food intake" or appetite or muscle) adj3 (Dysfunc* or Dymorph* or disorder* or disfunction*) adj10 (content or online or "on line" or web or website* or internet or media)).ti,ab,kw,oa. (668)

16 ((anorexi* or bulimic or bulimia or boulimia or bulimarexia or diabulimia or bigorexia or orthorexia or pica or "Adonis complex" or manorexia or drunkorexia or "muscle dysmorphia" or EDNOS or EDNS or ARFID or "food neophobia" or "food addiction" or "addictive eating" or "night eating syndrome*" or "compulsive eating" or "body shame" or "athlete triad syndrome" or "rumination syndrome" or "rumination syndromes" or "rumination disorder*" or merycism) adj10 (content or online or "on line" or web or website* or internet or media)).ti,ab,kw,oa. (371)

17 12 or 13 or 14 or 15 or 16 (1177)

18 (anorexi* or bulimic or bulimia or boulimia or bulimarexia or diabulimia or bigorexia or orthorexia or pica or "Adonis complex" or manorexia or drunkorexia or "muscle dysmorphia" or EDNOS or EDNS or ARFID or "food neophobia" or "food addiction" or "addictive eating" or "night eating syndrome*" or "compulsive eating" or "body shame" or "athlete triad syndrome" or "rumination syndrome" or "rumination syndromes" or "rumination disorder*" or merycism or ((Body or eating or "food intake"

or appetite or muscle) adj3 (Dysfunc* or Dymorph* or disorder* or disfunction*))).ti,ab,kw,oa. (67926)

19 (ED adj1 (symptom* or diagnos* or development or behav*)).ti,ab,kw,oa. (1665)

20 Dymorphophobia.ti,ab,kw,oa. (180)

21 ("body image" adj3 (problem* or disorder* or disturb* or distort* or disfunction* or dysfunction* or perception*)).ti,ab,kw,oa. (2680)

22 Body Dissatisfaction/ or Body Dymorphic Disorders/ or Body Image/ or Body Image Disorders/ or Compulsive Behavior/ or "Feeding and Eating Disorders"/ or Bulimia Nervosa/ or

Somatoform Disorders/ or Anorexia Nervosa/ or "Avoidant Restrictive Food Intake Disorder"/ or "Binge-Eating Disorder"/ or Bulimia Nervosa/ or Diabulimia/ or "Food Addiction"/ or Night Eating Syndrome/ or Pica/ or "Relative Energy Deficiency in Sport"/ or Rumination Syndrome/ or Female Athlete Triad Syndrome/ or Body Composition/ or Thinness/ or Weight Lifting/px (105484)

23 18 or 19 or 20 or 21 or 22 (148397)

24 ("body positive" or "positive body" or "fitness movement" or "fitness culture" or "body talk" or "thin ideal" or "thinness ideal" or "body satisfaction" or "body attribute*").ti,ab,kw,oa. (2117)

25 (drive adj3 (thin or thinness or fitness or muscular*)).ti,ab,kw,oa. (1570)

26 (((body adj2 ideal*) or "body image" or "body weight" or muscular* or fitness) adj3 (content or exposure or images or imagery)).ti,ab,kw,oa. (1560)

27 ((negative or maladaptive) adj2 (body or eating or exercise or exercising or "weight control")).ti,ab,kw,oa. (3546)

28 ((excess* or problem* or atypical or harmful* or harms or disorder*) adj3 (exercise or exercising or dieting or diet or diets or eat or eating or purge or purging or vomit* or fasting or ruminating or fitness or "weight control")).ti,ab,kw,oa. (28241)

29 ((dissatisfis* or anxiety or distress or concerns or fear) adj5 (body or appearance or fat or thin or thinness or muscular* or eating)).ti,ab,kw,oa. (7450)

30 (esteem adj5 (body or appearance or acceptance)).ti,ab,kw,oa. (1834)

31 (appreciation adj5 (body or appearance)).ti,ab,kw,oa. (333)

32 ((perception* or understanding or comprehension) adj5 (body or appearance or acceptance or fat or overweight or underweight or fitness or thin or thinness or muscular*)).ti,ab,kw,oa. (9430)

33 ((restrictive or disturbed or disordered or controlled or controlling or addiction or addictive or constrained or restrained or restraining or concerns or harms or compulsive or compulsion or compulsive or unconstrained or uncontrolled or binge or bingeing or addiction or addictive or intention or unrestrained or obsessive or preoccupied or preoccupied) adj3 (food or exercise or eating or exercising or diet or dieting or diets or fasting or purging or vomit* or "weight control")).ti,ab,kw,oa. (21369)

34 ((internalis* or "pre occupation" or "pre occupied" or "over concern" or rumination or ruminating) adj3 (body or muscular* or fat or thin or thinness or weight or eating or exercise or exercising)).ti,ab,kw,oa. (317)

35 ("over eat*" or "under eat*" or overeat* or undereat*).ti,ab,kw,oa. (3394)

36 ((unhealthy or choice* or behav* or beliefs or attitud* or motivation or motivations or patterns or psycholog* or psychopathology or symptom* or pathology*) adj3 (dieting or eating or purging or vomit* or ruminating or fasting or purge or fitness or "body fat" or exercise or exercising or "weight control")).ti,ab,kw,oa. (38600)

37 ("Exercise dependence" or "Food avoidance" or "dietary restraint").ti,ab,kw,oa. (1794)

38 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 (90213)

39 child/ or adolescent/ or young adult/ or students/ or Adolescent Behavior/ or Adolescent Health/ (3294540)

40 ("young people*" or schoolchild* or adolescen* or youth* or "young person*" or teen* or ((emerging or emergent or young or transition*) adj2 adult*) or (Young adj2 (men or "men's" or women* or female or females or male or males or user or users)) or (Millennial* or "college students" or undergraduate* or freshmen* or freshman* or Sophomore* or "generation Y")).ti,ab,kw,oa. (609291)

41 (children or boys or girls or students).ti,ab,kw,oa. (1355137)

42 adolescen*.jw. (47556)

43 39 or 40 or 41 or 42 (3974246)

44 23 or 38 (206458)

45 11 and 44 (1933)

46 43 and 45 (1037)

47 17 or 46 (1975)

48 limit 47 to yr="2007 -Current" (1711)

49 limit 48 to english language (1636)

50 limit 49 to (comment or letter or news) (8)

51 49 not 50 (1628)

52 animals/ not (animals/ and humans/) (4757437)

53 51 not 52 (1599)

Appendix 3: Details of studies

N	Author(s) (Year) Title Study Focus	Aims	Characteristics	Authors top level findings	Study quality	
					Relevance	Reliability
1	<p>Baker et al., 2019 A Qualitative Study Exploring Female College Students' Instagram Use and Body Image.</p> <p>Study focus: Priori focus on ED type: No Priori focus on ED related content: No Priori focus on Digital platforms: Yes Instagram</p>	<p>The current aim was to gain understanding of young women's experiences using Instagram. The exploratory study was guided by the following, research questions: (1) How do female college students use Instagram, and what features and/or functions (for example, posting, liking, and commenting) are most important when using Instagram? (Question 2) Does Instagram use impact female college students' body image and in what ways?</p>	<p>No of participants: (27) Age: 18-22 Gender: f (27) Ethnicity: White (17) African-America/black (4) Hispanic (3) Asian (3) SES: upper-middle class/family income between \$76,900 -\$105,999 Lived Experience of diagnosed with ED: not stated Other relevant details: participants had Instagram accounts for an average of 6 yrs, spent 1-2 hours daily/checked every half hour – few hours.</p>	<p>Three themes pertaining to body Image:</p> <ul style="list-style-type: none"> • Responding to beauty ideals, • Comparing self with others • Display of self <p>Participants recognized and strove to adhere to a variety of beauty standards, appearance dissatisfaction when trying to measure up to ideals. Frequent comparisons were made with their looks or number of likes/comments with others.</p>	Medium	Medium
2	<p>Bell et al., 2019 "When you think of exercising, you don't really want to think of puking, tears, and pain": Young adolescents' understanding of fitness and #fitspiration".</p> <p>Study focus: Priori focus on ED type: No Priori focus on ED related content: Yes, specific information about fitness,</p>	<p>This study used a bottom-up qualitative approach to understand (1) young adolescents' perspectives on fitspiration content on social media and (2) how young adolescents, growing up in an appearance-focused culture that has created #fitspiration, relate to this content and conceptualise fitness more broadly. More specifically, the</p>	<p>No of participants: (77) Age: mean age (12.49) Gender: f (27) m – not stated Ethnicity: Not stated SES: All participants attended the same fee-paying, co-educational school in Northern England, where some also resided. The cost of tuition fees (£15,000 per annum non-residential, £26,500 per annum residential) would indicate that the majority of</p>	<p>Four themes developed:</p> <ul style="list-style-type: none"> • Fitness enhances physical function and appearance (not always linked) • Fitness is transformative but requires hardwork • Fitness should be an intrinsically motivated choice • Pain in the pursuit of fitness 	High	High

N	Author(s) (Year) Title Study Focus	Aims	Characteristics	Authors top level findings	Study quality	
					Relevance	Reliability
	including content labelled as #fitspiration, through social media Priori focus on Digital platforms: Yes, specific includes Digital Platform types: More specifically, the study focuses on affluent youth, who are more likely to use Instagram (Lenhart, 2015), where #fitspiration content is most prevalent	study focuses on affluent youth, who are more likely to use Instagram (Lenhart, 2015), where #fitspiration content is most prevalent (Tiggemann et al., 2018).	participants were from affluent backgrounds. Lived Experience of diagnosed with ED: not stated Other relevant details: Took part in the study as part of 'Body Image and Eating Disorders Awareness Day' at a local university campus. Participants self-identified as regular Instagram users, though no detailed social media usage data were collected.	<ul style="list-style-type: none"> The majority of adolescents described engaging in some form of sport or exercise, both in and out of school. Many were familiar with #fitspiration content, having seen images in places such as the gym and in sports stores ('So saying strong is the new sexy, buy our stuff' (M5: male, focus group 5). They also reported seeing them in traditional media such as TV and digital media (including Instagram, for example, in sponsored ads or the search page – 'Every single day they're on my Explore page [Instagram]' (F3: female, focus group 		
3	Booth et al., 2019 "Moving Beyond Text: How Teens Evaluate Video-Based High Stakes Health Information via Social Media"	The study reported here explored how US teenagers evaluate high-stakes information in the form of videos on social media by	No of participants: (30) Age: 13-18 Gender: f (23) m (7) Ethnicity: Black (5) Hispanic (5) White (17) Asian (1)	Result's organized by Gasser et al., sub constructs: <ul style="list-style-type: none"> Cues: Advertisements 	Low	Low

N	Author(s) (Year) Title Study Focus	Aims	Characteristics	Authors top level findings	Study quality	
					Relevance	Reliability
	<p>Study focus: Priori focus on ED type: No Priori focus on ED related content: Yes, but not more specific – video-based nutrition and exercise content Priori focus on Digital platforms: Not specific but – high-stakes content online.</p>	<p>examining the strategies young people employ to assess fitness information across social media platforms. It explores young people’s decision making, what they value, and what they perceive to be important when making decisions about high-stakes content that is presented in the form of videos and images.</p>	<p>SES: participants were recruited from two low-SES school districts and two high-SES school districts. Participants were equally distributed across high and low- SES districts. Lived Experience of diagnosed with ED: not stated Other relevant details: Participants were not required to have an interest in fitness; beyond the 13–18 years age range, the only participation requirement was having at least one active social media account participants had at least one active social media account. US region (Midwest 8, Northeast 22)</p>	<ul style="list-style-type: none"> • Cues: Negative, unrealistic or dangerous language • Visual and Interactive elements: engagement, graphic quality vs content quality & video-specific criteria • Participants indicated that they are wary of advertisements and language that encourages extreme weight loss yet prefer video content that is “fun” and engaging. • Additionally, participants reported having explicit and implicit criteria • For evaluating videos with health content that includes both graphic and content quality 		
4	<p>Camacho-Minano et al., 2019 "Postfeminist biopedagogies of Instagram: Young women learning about bodies, health and fitness" Study focus: Priori focus on ED type: No</p>	<p>To examine how girls and young women negotiate contemporary discourses around body, health and fitness circulating through Instagram and the subjectivities such technology enables [from abstract] How do young women</p>	<p>No of participants: (37) Age: 15-17 Gender: f (37) Ethnicity: Not stated SES: Not stated Lived Experience of diagnosed with ED: not stated</p>	<ul style="list-style-type: none"> • Fitness content on Instagram reached them in different ways and had a significant influence on their health practices and subjectivities [from intro to results]. 	Medium	Low

N	Author(s) (Year) Title Study Focus	Aims	Characteristics	Authors top level findings	Study quality	
					Relevance	Reliability
	<p>Priori focus on ED related content: Yes specific – "Photo and video sharing social networks are emerging as sites of media practices through which images of the perfect fit body circulate, popularly known as 'fitspiration' media."</p> <p>Priori focus on Digital platforms: Yes specific – Instagram</p>	<p>participate in Instagram fitness cultures? [RQs] What meanings do young women construct about being a fit female on Instagram? How does this postfeminist digital space shape young women' physical activity experiences and subjectivities?"</p>	<p>Other relevant details: participants had "self-defined physically-active young women who possessed a personal Instagram account and defined themselves as viewers and/or followers of fitness content on Instagram... [all were from] Secondary Education schools (two public and one semi-private) located in a medium-sized town (50,000 inhabitants) in the centre of Spain"</p>	<ul style="list-style-type: none"> • Themes were: "fitness cultures on Instagram and the 'perfect' feminine body. • Learning about fitness as an 'aesthetic labour' to achieve the perfect body. • Transformation, the body and gender within Instagram; the gaze and the power of surveillance both online and offline 		
5	<p>Chatzoulou et al., 2020 "Instagram and body image: Motivation to conform to the "instabod" and consequences on young male wellbeing". Study focus: Priori focus on ED type: No Priori focus on ED related content: No Priori focus on Digital platforms: Yes specific – Instagram</p>	<p>The current study explores why male Instagram users (MIU) engage with fitness hashtags (i.e., #fitfam), engage in body image transformation and explores the consequences on their wellbeing. Therefore, the current study aims to develop a theoretical framework which can potentially explain the various effects on consumer wellbeing of engaging with fitness hashtags on Instagram.</p>	<p>No of participants: (27) Age: 18-22 Gender: f (27) Ethnicity: African-America/black (4) Hispanic (3) Asian (3) SES: upper-middle class/family income between \$76,900 - \$105,999 Lived Experience of diagnosed with ED: not stated Other relevant details: participants had Instagram accounts for an average of 6 yrs, spent 1-2 hours daily/checked every half hour – few hours.</p>	<p>Author describe phases:</p> <ul style="list-style-type: none"> • From low to high engagement • Joining #fitfam community • Following Instagram trends • Gain popularity and appear successful • Author's study proposes that popular Instagram hashtags (for example, #fitfam, #fitspiration) are able to affect the perceptions, lifestyle and 	Medium	Medium

N	Author(s) (Year) Title Study Focus	Aims	Characteristics	Authors top level findings	Study quality	
					Relevance	Reliability
				behavior of young millennials. <ul style="list-style-type: none"> The Instagram community, united by popular fitness hashtags, develops the ideal body image (instabod) and fosters adherence as a result of various social and psychological factors pressuring hashtag followers. 		
6	Easton et al., 2018 “Young People’s Experiences of Viewing the Fitspiration Social Media Trend: Qualitative Study” Study focus: Priori focus on ED type: No Priori focus on ED related content: Yes specific – ‘Fitspirational’ Priori focus on Digital platforms: No	Authors’ aimed to address a gap in the literature for exploratory research on this topic from the perspective of users. Authors used a qualitative approach to explore how people experience viewing Fitspiration on social media including why and how they engage with this material and how they perceive that it affects their thoughts, emotions, behaviour and health.	No of participants: (20) Age: 18-25 Gender: f (14) m (6) Ethnicity: White-British (14) SES: students, including 14 undergraduates and 2 postgraduates. Lived Experience of diagnosed with ED: not stated Other relevant details: who self-declared themselves to be Fitspiration followers to participate in either focus groups or individual interviews.	Four main themes <ul style="list-style-type: none"> A tool with potential to support healthy living Unrealistic, untrustworthy content Negative effects on emotional wellbeing Vulnerability and protective factors This study suggests that Fitspiration on social media can be attractive and compelling for young people but appears to bring about negative as well as positive effects. 	Medium	Medium

N	Author(s) (Year) Title Study Focus	Aims	Characteristics	Authors top level findings	Study quality	
					Relevance	Reliability
				<ul style="list-style-type: none"> Future research should aim to confirm the scale and intensity of positive and negative effects and investigate ways of harnessing desirable outcomes and minimising undesirable outcomes. 		
7	<p>Eikey & Booth, 2017 "Recovery and maintenance: How women with eating disorders use Instagram"</p> <p>Study focus: Priori focus on ED type: Yes specific – anorexia nervosa and bulimia nervosa and disordered eating behaviours related to these disorders because behaviours associated with these two types of eating disorders are similar Priori focus on ED related content: No Priori focus on Digital platforms: Yes specific -this study sheds light on how Instagram can exacerbate and</p>	<p>The authors' study differs in that they examine how women with eating disorders who interact with social media platforms, specifically, Instagram can use these interactions to aid recovery as well as exacerbate symptoms.</p>	<p>No of participants: (16) Age: 18-25 Gender: f (16) Ethnicity: White (12) Asian American or pacific islander (2) multi-racial (1) Native America (1) SES: Not stated Lived Experience of diagnosed with ED: most reported being in recovery. ED from 2 months – 7 years. 4 out of 16 were diagnosed Other relevant details: not stated</p>	<p>Four main themes on Instagram and aiding recovery:</p> <ul style="list-style-type: none"> Learn about recovery process Track own recovery Learn about healthy food and exercise Reduce stigma, increase awareness, create a community for social support. SM /ICTs not inherently good or bad ICTs Instagram can help with aid ED recovery as well as exacerbate. Depends on motivation needs, stages of recovery – consider different types of users 	Low	Medium

N	Author(s) (Year) Title Study Focus	Aims	Characteristics	Authors top level findings	Study quality	
					Relevance	Reliability
	improve eating disorder symptoms					
8	<p>Ferguson et al., 2020 "Complex contradictions in a contemporary idealised feminine body project".</p> <p>Study focus: Priori focus on ED type: No Priori focus on ED related content: Yes specific - Fitespiration</p> <p>Priori focus on Digital platforms: Yes specific – Instagram influencers. The visual facilities of Instagram, Tumblr, Facebook and Twitter are referred to in background.</p>	To critically investigate how the ambiguities of a specific body project (“a contemporary version of the idealised female body, the ‘athletic ideal’, characterised by toned abdominal muscles, thin waistlines, well-rounded buttocks and low body fat”) are experienced “[...]given] an evolving social media landscape where messages about women’s bodies as simultaneously slim, strong and empowered proliferate”, and investigate where young women find support.	<p>No of participants: (14) Age: 18-22 Gender: f (14) Ethnicity: New Zealand /European (2 being also Māori, 1 Fijian, 1 European other) (10) African Hispanic, Chinese, Indonesian, Singaporean (4) SES: not stated Lived Experience of diagnosed with ED: not stated Other relevant details: To be included, all needed to be a woman who had been actively using a protein supplement for the last six months or longer. Also presented are details of 1) BMI. 2) Brand of Protein Powder used, and frequency and period of use (at time of interview) [authors describe how participants "reported diverse protein powder usage "]. 3) Name of their main Instagram influencer.</p>	<p>Four themes:</p> <ul style="list-style-type: none"> • constant striving. • misplaced empowerment. • knowing gnawing hunger • and conflating language to manage tensions and contradictions. <p>The results examine the sense-making strategies used by women to navigate this idealised feminine body and consider the impact of marketplace resources.</p>	Medium	Medium
9	<p>Firkins et al., 2017 "Disordered Eating in a Digital Age: Narratives of Withdrawal from pro-ana/Mia Forums by Regular Site Users" Study focus:</p>	To address gaps in the pro-ana literature by conducting qualitative interviews with those who have regularly used pro-ana forums; with a focus on better understanding not only	<p>No of participants: (3 – age incl for review) 6 in total study Age: 24 or under Gender: f (3) Ethnicity: White British (3) African-America/black (4) Hispanic (3) Asian (3)</p>	The strongest storyline of coming to pro-ana was aspirations for further weight loss and a search for a connection. The strongest storyline of withdrawal	Medium	High

N	Author(s) (Year) Title Study Focus	Aims	Characteristics	Authors top level findings	Study quality	
					Relevance	Reliability
	<p>Priori focus on ED type: Yes specific- Anorexia stated as disorder of main interest in study's s aims (although bulimia is also referred to in the title, and pro-mia sites are referred to in the interview participant info sheets)</p> <p>Priori focus on ED related content: Yes specific – Both Pro-ana and Pro-mia sites are referred to in the interview participant info sheets, but the focus appears mainly to be on the former</p> <p>Priori focus on Digital platforms: Yes specific - Reference made in the title and participant info sheets only to 'websites' but the main focus, from methods section, seems to be on forums. The background sections expand on this, mentioning: Blogs, LiveJournals or Vlogs on YouTube. Myspace, Facebook, Twitter, Flickr, Instagram, Pinterest and Tumblr</p>	<p>what led individuals to join this community but also how they storied the disengagement process and any impact it had on their lives"</p> <p>From abstract: To "investigate[d] accounts of Pro-Ana withdrawal and its associated impact"</p>	<p>SES: educational level, at time of the study participants all in higher education All described (themselves? p45) as middle class.</p> <p>Lived Experience of diagnosed with ED: onset reported from childhood (11-15) Official diagnosis was yes type not specified by doctor, but participant described as Anorexia, EDNOS</p> <p>Other relevant details: participants needed to have regularly visited pro-ana sites in the past and have either reduced their use of them or stopped altogether. Pro-ana sites were first visited at age 14-15, all three participants aged 24 and under reported having been visiting daily at multiple times at the peak of their use, for between three and 25 hours/week. Out of the three, one had not posted/chatted to others on the site, two had (Table 1a).</p>	<p>involved a quest for recovery, though accounts varied widely in agency surrounding this act and for a small proportion disengagement was actually a sign of things getting worse. Notably, storylines of strengthening different identity aspects and connecting with different social support systems featured heavily in most recovery accounts. From the six [NB] accounts, two overarching storylines emerged: 1. Disengagement as recovery: Here, in the initial act of withdrawal participants varied in the degree of agency they storied themselves having, but all positioned it as a necessary first step in the recovery trajectory. Inevitably, the construction of recovery was storied differently across individuals and the trajectory was highly variable across accounts. 2. Disengagement in the absence of recovery: This storyline portrayed individuals</p>		

N	Author(s) (Year) Title Study Focus	Aims	Characteristics	Authors top level findings	Study quality	
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				questioning the legitimacy of their ED resulting in introversion, isolation, and greater ED severity. a. "Feeling like a failure in developing an eating disorder": A need to isolate."		
10	<p>Hockin-Boyers et al., 2021 "#gainingweightiscool: the use of transformation photos on Instagram among female weightlifters in recovery from eating disorders".</p> <p>Study focus: Priori focus on ED type: yes, but not specific transformation photos of women in recovery</p> <p>Priori focus on ED related content: Yes, not specific we explore transformation photos on Instagram as 'digital artefacts'</p> <p>Priori focus on Digital platforms: Yes specific – Instagram</p>	By triangulating interview, photo elicitation and netnography data from research on female weightlifting as a tool for recovery from eating disorders, authors explore transformation photos in relation to three intersecting themes: 1) new modes of 'becoming', 2) representation and 'mediated memories', and finally, 3) survivorship and identity	<p>No of participants: (19) Age: 17-36 Gender: f (19) Ethnicity: Not stated SES: Not stated Lived Experience of diagnosed with ED: Female participants, aged 17 and over, living in the UK, who have a history of eating disorders and are weightlifting during their recovery. Other relevant details: Not stated</p>	<p>Themes:</p> <ul style="list-style-type: none"> • New modes of becoming • Representation and 'mediated memories' • Survivorship and identity <p>Authors' findings demonstrate that transformation photos are integral to the process and practice of recovery for women who use weightlifting as a tool for recovery from eating disorders. Moreover, they suggest that by engaging with a popular mimetic device (transformation photos), they were able to 'meet participants where they are' and offer a novel qualitative approach to understanding how digitally mediated lives are lived.</p>	High	High

N	Author(s) (Year) Title Study Focus	Aims	Characteristics	Authors top level findings	Study quality	
					Relevance	Reliability
11	<p>Mincey, 2019 "An exploratory qualitative inquiry on the lived experiences of people who engage with pro-eating disorder online media</p> <p>Study focus: Priori focus on ED type: yes, not specific</p> <p>Priori focus on ED related content: Yes, specific Pro eating disorder</p> <p>Priori focus on Digital platforms: Yes, specific Focus on online media webpages and applications/forums. Broader range mentioned in background "Webpages such as Tumblr, Instagram, Private or public online forums, ...Facebook, Reddit..."</p>	<p>To investigate the meaning pro-eating disorder online media may have on individuals who use this form of social media. Ultimately, the objective of this study was to discover the voiced perceptions of those who engaged in pro-eating disorder online media, and their voiced purpose(s) of engaging in pro-eating disorder online media</p>	<p>No of participants: (10) but for this review (5) Age: 18-31 (5) = 24 or under Gender: f (10) but for this review (5) Ethnicity: Caucasian (3) African American (1) Biracial (1) SES some high school (3), college (2) Lived Experience of diagnosed with ED: Participants are not categorised using diagnosis, to be included, participants needed to be accessing and using pro-eating disorder online media at the time of the study Other relevant details: height and weight (current, highest, lowest and ideal), BMI and Scores of EAT – 26 and BAS-2, Scores of BDS. Location at time of study: US (n=6 – 4 of which aged 24 or under), Australia (n=1, aged 10), Canada, Ireland and Germany each with n=1 (all aged >24). Inclusion criteria were "...participants must be 18 years of age or older, and participants must be accessing and using pro-eating disorder online media at the time of the study ... Participants scores on the BDS ranged from 1 to 6 (M = 3.2, SD = 1.75). Four participants had scores of four or higher. According to Mutale et al. (2016), higher scores indicate a higher</p>	<p>Analysis revealed a large number of themes and subthemes, including Curiosity, spiraling down, increased knowledge, unfulfilled needs (subthemes (a) acceptance, (b) belonging, (c) connection, (d) control, and (e) understanding) Support, safety (subtheme – (a) harm reduction), community (subthemes – (a) genuine relationships, (b) loneliness, and (c) relatability), Duality, lack of understanding from professionals (subtheme – (a) misconceptions and perceived judgment), Harmful Aspects (subthemes (a) risk of predators, and (b) triggering content), Motivation for eating disorders (subthemes – (a) competitive aspects, (b) never sick enough, (c) intentional harmful behaviour, and (d) tips and tricks), Recovery (subthemes – (a) hope related to recovery, and (b) struggles with recovery).</p>	Medium	Medium

N	Author(s) (Year) Title Study Focus	Aims	Characteristics	Authors top level findings	Study quality	
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			level of body dissatisfaction. Participants scores on the EAT-26 ranged from 7 to 50 with only two participants had an EAT-26 lower than 20. A score higher than 20 indicates a high level of concern about body weight and eating behaviours (Garner et al., 1982). Six participants had a 58 score over 40 on the EAT – 26 with three participants scoring a 50 (M = 36.6, SD			
12	<p>Papathomas et al., 2018 10 Young people, social media, and disordered eating. In <i>Young people, social media and health</i></p> <p>Study focus: Priori focus on ED type: yes, not specific chapter presents an analysis focused upon eating disorders specifically, but other papers by Goodyear and colleagues make clear that "data collection was framed by an initial focus on health-related social media in the areas of physical activity, diet/nutrition, body image and sleep"</p>	The research question guiding this study was: What social media activities do adolescent girls engage with that informs their health-related attitudes, knowledge and behaviours? [From the Goodyear, Armour and Wood (2019) paper] "Understanding the health-related opportunities and issues generated by social media from the perspective of young people... with the dynamic interaction with and generation of content as a key analytical lens... [so as to produce a] robust empirical account[s] of the content and form of the health-related material young	<p>No of participants: (236) (some = n=84 – of these young people participated in both the class activities and the focus groups). Authors presumed that the young people from the same schools who were involved in the stakeholder workshop reported in Papathomas were from this same group, although this isn't stated.</p> <p>Age: 13-15 Gender: f (135) m (101) Ethnicity: range of backgrounds, with just under a third of students across these schools speaking English as a second language" SES: "[Participating] schools were located in diverse socio-demographic areas"</p>	Analysis proposes three principal themes for consideration: <ul style="list-style-type: none"> • Social media-induced body dissatisfaction. • Self(ie)-objectification practices. • Health and nutrition Insta-norms. 	Medium	Medium

N	Author(s) (Year) Title Study Focus	Aims	Characteristics	Authors top level findings	Study quality	
					Relevance	Reliability
	<p>Priori focus on ED related content: Not specific just social media</p> <p>Priori focus on Digital platforms: Not specific just social media</p>	<p>people access and attend to, or the health-related content they create and share... Research questions: (i) What health-related information is/isn't accessed by young people through social media; (ii) What health-related information do young people attend to and use to inform their health-related behaviours."</p>	<p>Lived Experience of diagnosed with ED: not stated</p> <p>Other relevant details: (some = n=84 – of these young people participated in both the class activities and the focus groups). We presume that the young people from the same schools who were involved in the stakeholder workshop reported in Papathomas were from this same group, although this isn't stated.</p>			
13	<p>Raggatt et al., 2018</p> <p>"I aspire to look and feel healthy like the posts convey": engagement with fitness inspiration on social media and perceptions of its influence on health and wellbeing"</p> <p>Study focus:</p> <p>Priori focus on ED type: No</p> <p>Priori focus on ED related content: Yes, specific</p> <p>Fitspiration we offer a broadened definition of fitspiration as a category of social media content including images posted to social media with the hashtags (#) '#fitspiration' or '#fitspo'; as</p>	<p>To 1) describe the types of fitspiration content that user's access and how they engage with content, 2) investigate the disordered eating and exercise behaviours and psychological distress of individuals who access fitspiration, and 3) understand the perceived influence of fitspiration on health and wellbeing.</p>	<p>No of participants: (155)</p> <p>Age: 18-22</p> <p>Gender: f (151)</p> <p>Ethnicity: Not stated</p> <p>SES: 76% of respondents stated their education level to be "post high school" 40% reported having > \$80 recreational spending money, per week.</p> <p>Lived Experience of diagnosed with ED: A proportion of participants are judged to have been at high or very high risk of an eating disorder or of addictive exercise behaviour.</p> <p>"According to the EAT-26 scale, 17.7% (n = 21) of participants were classified as at high risk of an eating disorder. K10 scores indicative of psychological distress were highly prevalent with 25.4% (n = 35) of participants having</p>	<p>Participants described both positive and negative influences of engaging with fitspiration content. The influence on their health beliefs and behaviours was explained through four key themes</p> <ul style="list-style-type: none"> • Setting the 'healthy ideal', • Failure to achieve the 'ideal', • Being part of a community, and • Access to reliable health information. 	Low	Low

N	Author(s) (Year) Title Study Focus	Aims	Characteristics	Authors top level findings	Study quality	
					Relevance	Reliability
	<p>well as profile pages or blogs by personal trainers, fitness models or body builders; and content related to fitness challenges, diets, and health cleanses."</p> <p>Priori focus on Digital platforms: Not specific While participants have not been instructed to reflect only on specific platforms, recruitment advertisements were placed on Facebook and Instagram also reference to Tumblr</p>		<p>'high' and 17.4% (n = 24) having 'very high' psychological distress. From the EAI scale, 10.3% (n = 15) of participants were at risk of addictive exercise behaviours." [data is also presented showing the median and mean of respondents' scores on the Eating Attitudes Test-26 (EAT-26) and the Exercise Addiction Inventory (EAI) respectively.]</p> <p>Other relevant details: 53.1% live with parents, 16.8% have a child/children</p>			
14	<p>Saunders et al., 2020 "From self(ie)-objectification to self-empowerment: The meaning of selfies on social media in eating disorder recovery".</p> <p>Study focus: Priori focus on ED type: yes, but not specific "women self-identifying as in ED recovery" Priori focus on ED related content: yes, specific Selfies – Analysis was of discussion of"</p>	<p>Guided by objectification theory, to qualitatively examine the subjective role of selfies in young women's ED recovery process [and]... to identify differences between subjectively helpful and subjectively harmful selfies in composition and content. The primary goal of the overarching study [involving 30 participants] was to examine the types, targets, and effects of social</p>	<p>No of participants: (27) Age: 18-22 Gender: f (27) Ethnicity: African-America/black (4) Hispanic (3) Asian (3) SES: upper-middle class/family income between \$76,900 -\$105,999 Lived Experience of diagnosed with ED: not stated Other relevant details: participants had Instagram accounts for an average of 6 yrs, spent 1-2 hours daily/checked every half hour – few hours.</p>	<p>"The narratives surrounding selfies fell into four distinct, complimentary categories:</p> <ul style="list-style-type: none"> • the harmful or hindering role of selfies on ED recovery • the health promoting role of selfies • willingness to be seen during ED recovery • the role of self-confidence and self-esteem in both 	Medium	Medium

N	Author(s) (Year) Title Study Focus	Aims	Characteristics	Authors top level findings	Study quality	
					Relevance	Reliability
	selfies previously shared on social media and accompanying narrative" Priori focus on Digital platforms: Yes, specific Instagram	comparison for this population (Saunders and Eaton, 2018).		sharing selfies and maintaining recovery. The latter three themes highlight the ways in which selfies can serve to bolster women's recovery experiences."		
15	Smahelova et al., 2020 Internet Usage by Women with Eating Disorders during Illness and Recovery. Study focus: Priori focus on ED type: Yes, specific type@ frames interest as being in spectrum Anorexia, Bulimia, binge eating. Priori focus on ED related content: Not specific – all types of internet. Priori focus on Digital platforms: Not specific all types were of interest websites SNS blogs applications (including apps for smart phones) and online communities.	Authors' aim are to present a complex view from the perspective of people with ED, and we propose the following research questions: Q1: Which online platforms and activities do women with eating disorders report? Q2: How do the identified platforms and activities fit into the three levels of the interactions model proposed by Rodgers (2016)? Q3: Which motivations to use specific online platforms do women with eating disorders report?	No of participants: (30) Age: 16-28 Gender: f (30) Ethnicity: Not stated SES: Not stated Lived Experience of diagnosed with ED: Participants needed to have experience (now or in the past) of a form of an eating disorder. Participants' stated experiences were with: Anorexia Nervosa – AN N = 13, Bulimia Nervosa – BN N = 3, Binge Eating Disorder BED N = 1, or multiple ED diagnoses EDM N = 13. ... either currently suffered with the ED and were in the recovery process (N = 22) or they had recovered (N = 8). [discussion notes all] had already received some kind of formal treatment for ED Other relevant details: all were Czech	The results provided insight into the participants' experience with the following online environments: <ul style="list-style-type: none"> • nonprofessional pro-eating disorder platforms. • nonprofessional pro-recovery platforms. • social networking sites (SNS). • platforms for counting calories and setting weight goals. • platforms about food, exercise, and lifestyle. • platforms providing professional help. The participants noted many benefits these platforms could provide; however, their ability to achieve 	High	High

N	Author(s) (Year) Title Study Focus	Aims	Characteristics	Authors top level findings	Study quality	
					Relevance	Reliability
				<p>the benefits was affected by their motivation for treatment.</p> <p>As a result, even platforms designed to support recovery could be used for illness maintenance. The results are discussed in the context of research on the changing motivations for recovery in people with eating disorders and the theory of different processes connected to the course of the eating disorders according to the differential interactivity of digital platforms.</p>		
16	<p>Toll et al., 2021 "More than meets the eye: a relational analysis of young women's body capital and embodied understandings of health and fitness on Instagram"</p> <p>Study focus: Priori focus on ED type: No</p> <p>Priori focus on ED related content: No</p>	Examines how young women garner digital body capital on Instagram, with a particular focus on their embodied understandings of health and fitness.	<p>No of participants: (9) Age: 20-24 Gender: f (9) Ethnicity: Arab Muslim (1) Chinese (1) while the remaining seven did not self-identify. Although using visual markers of racial identity is itself a problematic practice, Authors nonetheless cautiously observed that the seven participants who did not self-identify visually presented as white</p>	<p>Authors identified four informal 'rules':</p> <ul style="list-style-type: none"> • Showing the body • Being vainglorious without being vainglorious • Enhancing but not editing your pictures • Showcasing a healthy and active lifestyle <p>Authors' conclude the paper by arguing for a methodological approach to</p>	Medium	Medium

N	Author(s) (Year) Title Study Focus	Aims	Characteristics	Authors top level findings	Study quality	
					Relevance	Reliability
	Priori focus on Digital platforms: Yes, specific Instagram as a popular social media platform		<p>SES: graduate students (4) undergraduates (5). Although socioeconomic background was not asked, based on their enrolment in university programmes, along with some insight into physical activity and leisure practices, authors speculate that the participants shared a similar, mostly middle class, background</p> <p>Lived Experience of diagnosed with ED: not stated</p> <p>Other relevant details: Authors recruited students currently enrolled in Kinesiology degree programmes because authors made the assumption that they would have a specialised interest in health and fitness and an increased likelihood that their future careers will position them as influential leaders in health and fitness. active Instagram users</p>	digital media, more specifically social media, that accounts for the myriad of factors that shape Instagram experiences, practices and meanings as a way of accessing the space between the digital, human and discursive.		
17	<p>Welker, 2019 “Exploration of use and perceptions of exercise-related fitness pages on social networking sites: Impact on appearance motivation”</p> <p>Study focus: Priori focus on ED type: No</p>	This exploratory study sought to learn more about the ways in which college women used fitspiration pages on social networking sites, and their perceptions of these pages.	<p>No of participants: (6) Age: 18-30 [19 (3) 20 (2)] Gender: f (27) Ethnicity: white (3) African American (1) Asian (2) SES: Three of the women were completing their second year of school, while one woman each was in her third, fourth, and sixth year</p>	<p>Author identified four main themes:</p> <ul style="list-style-type: none"> • Fitspiration pages not always believable • Fitspiration pages can promote body acceptance • Fitspiration pages can be motivating and de-motivating 	Low	Low

N	Author(s) (Year) Title Study Focus	Aims	Characteristics	Authors top level findings	Study quality	
					Relevance	Reliability
	<p>Priori focus on ED related content: Yes, specific Fitspiration</p> <p>Priori focus on Digital platforms: Not specific just social networking sites</p>		<p>Lived Experience of diagnosed with ED: not stated</p> <p>Other relevant details: exercised at least one day per week, and used at least one social networking site regularly. Results from analysis of data from the Background Information Form was as follows. One woman saw herself as being underweight, four reported they were a normal weight, while one did not report her perceived weight status. The women participated in an average of 3.66 days of exercise per week (SD = 1.03, range 2-5 days). Participants could report multiple reasons for engaging in exercise. Three women indicated exercising to lose weight, one to gain weight, two to maintain weight, three to build muscle, three to reduce stress, two to improve heart health, four to feel better, two to improve their athletic ability, and two for enjoyment. able to speak English and use social media regularly.</p>	<ul style="list-style-type: none"> • The are many reasons for using Fitspiration pages. Participants reported that pages could be useful. They placed trust in pages that depicted models who looked “real”, presenting women of many body types. Results provided insight into the ways fitspiration is used by college women. Future studies should explore ways in which viewing fitspiration pages influence health behaviours. 		
18	<p>Yeshua-Katz & Martins, 2013 "Communicating stigma: the pro-ana paradox"</p> <p>Study focus:</p>	<p>The purpose of the study is to explore the motivations, benefits, and drawbacks of blogging about a stigmatised mental illness, as taken from the bloggers’ own perspective.</p>	<p>No of participants: (33) Age: 15-33 Gender: f (27) Ethnicity: Caucasian (22) Mediterranean (2) African American (1) other (8)</p>	<p>Authors identified these findings:</p> <ul style="list-style-type: none"> • Motives to publish a blog • Perceived benefits of communicating about eating disorders 	Medium	High

N	Author(s) (Year) Title Study Focus	Aims	Characteristics	Authors top level findings	Study quality	
					Relevance	Reliability
	<p>Priori focus on ED type: yes, specific pro-ana if it included instruction for initiating and maintaining anorexia nervosa</p> <p>Priori focus on ED related content: Yes specific Authors interested in studying people who identified themselves as pro-anas. In order to meet this goal, sought out blogs that were clearly pro-ana sites. Priori focus on Digital platforms: Yes, specific authors searched for pro-ana blogs via blog-hosting platforms such as blogger.com, Tumblr.com, and Livejournal.com. Pro-ana blogs were also found through blogrolls – that is, a list of links to other blogs that the author of one blog likes to read. To be included in the sampling frame, the blogs had to be updated at least once in the past six months (for example, Hu, 2009). Blogs presided over by mental health</p>		<p>SES Most of the participants were in high school (n=16) or attending college (n = 17).</p> <p>Lived Experience of diagnosed with ED: The length of time most of the participants reported living with an ED was 6.8 years in spite of our efforts to include only bloggers who identified themselves as pro-ana (for example, defining anorexia as a lifestyle) as described in the published literature, participants expressed different approaches to their health condition. Indeed, most of the bloggers (n = 27) reported living with the disorder but six were in recovery. Twentyfour bloggers defined their eating disorder as a mental illness, six bloggers defined their illness as a coping mechanism, and only three bloggers defined it as a lifestyle.</p> <p>Other relevant details: Not stated</p>	<ul style="list-style-type: none"> • Drawbacks of pro-ana blogging <p>The fear that the eating disorder will be revealed if the blog is exposed and the concern that the blog encourages disordered eating were the perceived negative consequences of maintaining such a blog. Thus, blogging about anorexia serves to both alleviate and trigger anxiety about living with this stigmatised illness.</p> <p>Recommendations for future research are made.</p>		

N	Author(s) (Year) Title Study Focus	Aims	Characteristics	Authors top level findings	Study quality	
					Relevance	Reliability
	professionals, caregivers, or advocates were excluded.					

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Social Science Research Unit, UCL Social Research Institute
UCL Institute of Education, University College London
18 Woburn Square
London WC1H 0NR

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Email: ioe.ssru@ucl.ac.uk
Telephone: +44 (0)20 7331 5263