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Research Article

A Mixed Studies Systematic Review on the Health and Wellbeing Effects, and Underlying Mechanisms, of Online Support Groups for Chronic Conditions

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Objective: This systematic review examines whether online support groups affect the health and wellbeing of individuals with a chronic condition, and what mechanisms may influence such effects.
Method: In February 2023, literature searches were conducted across electronic databases (Medline, Embase, PsycInfo, Web of Science and Google Scholar), pre-publication websites (MedRxiv and PsyArXiv) and grey literature websites. Qualitative and quantitative studies were included if they explored the impact of online support groups on the health and wellbeing outcomes of individuals with a chronic condition.
Results: In total 83 papers, with 91 studies, met the inclusion criteria. Health and wellbeing outcomes were categorised as: physical health, mental health, quality of life, social wellbeing, health-related behaviour and decision-making, and adjustment. Mechanisms reported in these studies related to exchanging support, sharing experiences, content expression, and social comparison. User and group characteristics were also explored.
Conclusion: The included studies suggest that online support groups can have a positive impact on social wellbeing, behaviour, and adjustment, with inconclusive findings for physical health and quality of life. However, there is also the possibility for a negative effect on anxiety and distress, particularly when hearing other group members' difficult experiences. Research comparing different types of support groups is needed.

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Introduction

Chronic conditions have been defined as health problems that require ongoing management over a period of years and that cannot currently be cured, but can be controlled, such as diabetes or Long Covid [1]. Almost half of the UK population reported having a long-standing health problem in 2020 [2], and globally it is estimated that chronic diseases kill almost 41 million a year [3]. Although more recent data on the prevalence of chronic conditions is unavailable, it is likely to have increased since the COVID-19 pandemic, with nearly 2 million people reporting symptoms of Long Covid in March 2023 [4]. Living with a chronic condition is associated with reduced health-related quality of life [5][6] and leaves many individuals unable to carry out day-to-day activities, socialise or work, which can result in them being dependent on other people [7][8]. Indeed, it was estimated that 2.5 million people in the UK were unable to work in 2022 due to long-term sickness, an increase of half a million from 2019 [9].

Alongside experiencing symptoms of a chronic condition, individuals may also face challenges such as prejudice [10], stigma [11] and feeling alone as others do not understand what they are going through [8]. One way in which individuals can connect with others, and find support, is through online support groups. Such groups can be synchronous via audio or video calls, or they can be asynchronous via social media platforms, such as Facebook groups and discussion boards, or via direct messages, such as in WhatsApp groups. An advantage of these online support groups, as opposed to in-person groups, is that they can transcend geographical boundaries and are less restricted by time or location, which is particularly beneficial to those with limited mobility and those living in rural communities [12].

Previous systematic and scoping reviews have been conducted to explore whether online support groups are beneficial amongst individuals with a particular chronic condition, such as HIV [13] and cancer [14]. These reviews report that online support groups are a place where group members can receive social support and experience a sense of community, which can result in increased adaptive coping and reduced loneliness. However, the reviews also report that group content can be negative (e.g., reading distressing personal information or complaints), and that lack of replies and absence of nonverbal communication can lead to misunderstandings and distress.

Previous reviews have also explored the impact of online support groups on multiple chronic conditions, including how online groups influence daily life [15] and illness self-management [16]. However, these reviews excluded quantitative studies, which resulted in the exclusion of many studies, particularly intervention studies, that could provide further evidence regarding the impact of online support groups on group member experiences. A meta-analysis exploring health outcomes in relation to online support groups for health conditions did include intervention studies, but only those with a fixed start and end point and which included an educational component, which is not representative of existing online support groups [17]. The outcomes included were also limited to social support, depression, quality of life and self-efficacy. Thus, there is a gap in the literature regarding a systematic review on the effects on health and wellbeing of using an online support group which includes both qualitative and quantitative studies and covers a greater number of health and wellbeing outcomes.

In addition to understanding the health impacts of online support groups, it is also important to consider how these effects occur. A literature review of mechanisms in online support groups, more broadly, considers the role of writing, expressing emotions, gathering information and developing relationships on patient empowerment [18]. Furthermore, Ziebland and Wyke [16] conducted a review and identified five ways in which online patients' experiences (e.g., blogs, forums, social networking sites, consumer reviews) could affect their health (e.g., feeling supported). In the context of chronic conditions, studies with adults diagnosed with either breast cancer, fibromyalgia or arthritis have identified five empowering processes (e.g., exchanging information) and three disempowering processes (e.g., reading posts with complaints), which subsequently influence empowering outcomes (e.g., enhanced social wellbeing) [19][20]. There are similarities between these classifications as they highlight the importance of finding and exchanging information, receiving emotional support, and sharing experiences [18][19][20]. Previous research has also considered factors relating to the ways in which participants use online support groups, such as being a passive or active member of the group [21], as well as the role of group features [17]. More social support was reported when online support groups were of a longer duration and included both synchronous and asynchronous channels. Meanwhile, larger groups are reported to be positively associated with quality of life scores but negatively associated with social support [17]. However, there is not a review looking at the potential mechanisms underlying each type of health outcome and synthesising group and usage characteristics as well as support group content (e.g., support) in the context of online support groups for chronic conditions.

Current study

As the number of individuals experiencing, and having their lives disrupted by, chronic conditions increase, it is important to explore potential ways to improve health outcomes. One such way is online support groups. Therefore, it is important to understand the impact of these groups on the health and wellbeing of group members. It is also important to identify the factors underlying any impact of online support groups on health and wellbeing outcomes, to optimise the experience of using an online support group and enhance health and wellbeing of group members. To the authors' knowledge, there has not yet been a systematic review synthesising the evidence from qualitative and quantitative studies regarding both the impact of online support groups on health and wellbeing and the factors influencing any such impact. This systematic review aims to address these lacunae with the following research questions:

1. What are the effects of online support groups on the observed and self-reported health and wellbeing of individuals with a chronic condition?
2. What are the mechanisms by which online support groups affect the health and wellbeing of individuals with a chronic condition?

Method

Protocol and registration

This systematic review was conducted in concordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [22]. The systematic review was pre-registered prior to the search with Prospero, registration number: CRD42023399258.

Search criteria

In line with recommendations [23], the following databases were searched for peer-reviewed publications on February 14th, 2023:

- Embase 1974 to February 13, 2023
- Ovid MEDLINE® ALL 1946 to February 13, 2023

- APA PsycInfo 1806 to February Week 1 2023
- Web of Science Core Collection
- Google Scholar (first 200 items)

Grey literature searches were also conducted, to ensure comprehensiveness, on February 14th, 2023, using Google Advanced Search and British Library directory of online doctoral theses (EThOS) without any date restrictions. MedRxiv and PsyArXiv were searched to identify any pre-publication articles uploaded between January 1st and February 14th, 2023.

Search terms were based on the target population (i.e., those with a chronic condition) and intervention (i.e., online support groups). To avoid unintentionally excluding articles, the study outcomes were not included in the search terms as they relate more broadly to health and wellbeing as opposed to specific outcomes (e.g., depression). Search terms were developed by the research team based on previous reviews on similar topics [13][24], the types of chronic conditions listed by the National Health Service (NHS) [1] and preliminary literature searches. See Tables 1-5 in Supplementary File 1 for the full search strategy. MeSH headings were also included for searches conducted on Embase, Medline, and PsycInfo.

Eligibility Criteria

The full inclusion and exclusion criteria are detailed in Table 1. To answer research question 1, studies had to explore the effects of online support groups on the health and/or wellbeing of individuals with a chronic condition. To answer research question 2, which explored underlying mechanisms, the review included any mechanisms that authors have tested or participants have proposed. The review included studies from any country if they were published in English. The review used the following definition of chronic conditions when deciding eligibility of studies: a health problem that requires ongoing management over a period of years or decades and is one that cannot currently be cured, but can be controlled with the use of medication and/or other therapies [1]. Both qualitative and quantitative studies were included to ensure the comprehensiveness of the review.

Area of study	Inclusion criteria	Exclusion criteria
Population	Individuals experiencing symptoms of, or diagnosed with, a chronic condition	Individuals not experiencing symptoms of / not diagnosed with a chronic condition.
Intervention	All types of online peer support groups, involving more than two participants, will be included. The support groups can be asynchronous (e.g., social media group, forum, email) or synchronous (e.g., video call) and can be text- and/or video-based. The review will also include support groups with or without a moderator (led by either a support group member or professional).	In-person support groups, unless they are a comparator for online support groups, will be excluded. The study will also exclude complex interventions (i.e., when a support group is one component of a broader intervention), unless the study specifically reports the independent effects of support groups.
Comparator	The review will include studies with or without a control group. Control groups may include, but are not limited to, in-person support groups, waitlist or standard care.	N/A
Outcome	Changes in physical health may include but are not limited to: symptom presence; symptom duration; symptom severity; and changes in limitations in activities due to such physical symptoms (e.g., activities associated with individuals' usual role, physical activities, social activities) [25][26]. These can be clinical or self-report measures. Changes in wellbeing may include, but are not limited to: psychological functioning, cognitive-evaluation dimensions, social relationships, meaning making and changes in limitations in activities due to such symptoms [25][26]. These can be clinical or self-report measures.	Outcomes that are not related to the health and wellbeing of support group members. For example, studies assessing the acceptability of support groups.
Type of study	Both qualitative, quantitative and mixed studies will be included. All types of quantitative studies	Reviews, position papers, conference abstracts and protocol papers will be

Area of study	Inclusion criteria	Exclusion criteria
	will be included (e.g., randomised controlled trials; non-randomised controlled trials; before and after studies; cohort studies; cross-sectional studies; and surveys). All types of qualitative studies (e.g., interviews and focus groups) will be included.	excluded. Studies involving an analysis of support group content (e.g., studies reporting the types of content posted on online support groups) will also be excluded, unless they contain analysis of the specific effects of support groups on outcomes.

Table 1. Inclusion and exclusion criteria

Study selection

Results of the literature searches were exported into the review screening website Rayyan [27]. Initial screening was carried out for all titles by the first author, with each title being categorised as either ‘maybe’ or ‘excluded’. Then, the first author screened the abstracts of articles categorised as ‘maybe’, categorising these articles as “include”, “maybe” or “exclude”. To improve robustness of the review process, 10% of articles underwent title and abstract screening by the third author. The authors agreed on 94.93% of the articles.

Both the ‘include’ and ‘maybe’ articles then underwent full text screening by the first author whereby all articles were categorised into either ‘include’ or ‘exclude’. During full text screening, two studies were excluded because although they reported effects of online support groups on health and wellbeing outcomes, the measures did not specifically explore online support groups, as one measured online interest groups, [28] and another reported the effects of patient empowerment gained through online health communities, but the measures assessed empowerment through physicians [29]. Thus, the inclusion criteria were tightened to ensure the studies specifically measure online support group use (e.g., membership or participation). The inclusion criteria were also tightened to focus on individuals currently experiencing the chronic condition, and therefore excluded studies which focused on cancer survivors, and to exclude studies that focused exclusively on chronic mental, as opposed to chronic physical health conditions (unless they were one of many included conditions in a study). The inclusion criteria regarding the underlying mechanisms was also strengthened so that it related specifically to the online groups themselves, and other sources of support (e.g., offline support from family) were not included (e.g., [30]). To further improve robustness of the review, the third author conducted full text screening of 5% of the studies, where there was 70% agreement between authors. As the reasons for disagreement mostly applied to studies with complex interventions (i.e., where online support groups were one component of an intervention), the first author repeated the full text screening of the complex intervention studies and subsequently included a further four studies. The screening process can be seen in the PRISMA flowchart in Figure 1.

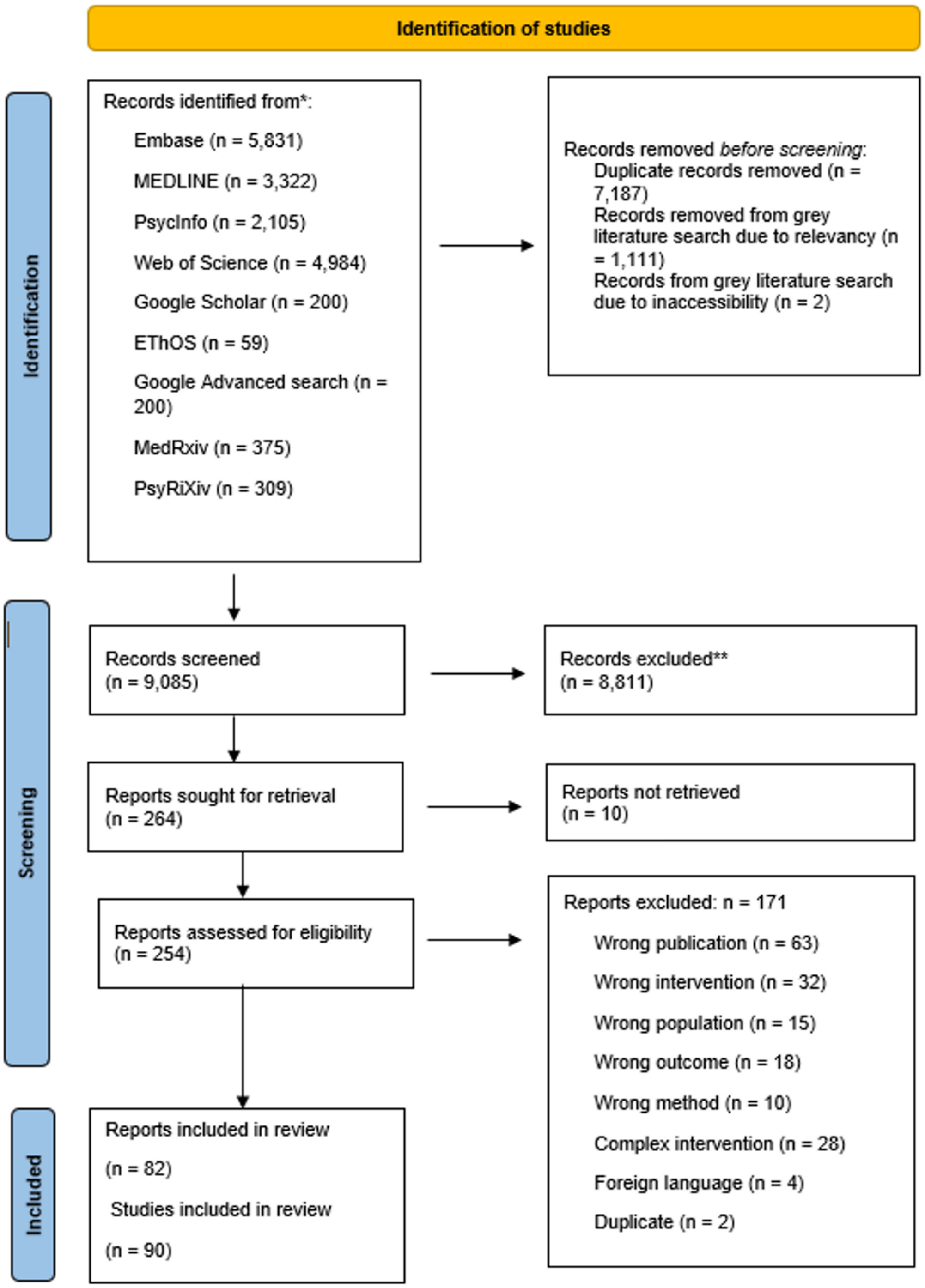

Figure 1.PRISMA flow diagram of the identification of studies

Data extraction and synthesis

Data were extracted in a tabular form on Microsoft Excel by the first author. After piloting with the first study, the following information was extracted: authors, title, year of publication, type of document (e.g., journal article or thesis), publication place of origin, study design, sample size and details, chronic condition, recruitment location, description and duration of the online support group and any comparator, health and wellbeing outcome measure, results and mechanisms relating to health and wellbeing outcomes, and reported study limitations. To check accurate extraction, the third author conducted data extraction on nine articles (10%) which were compared to the first author's extractions. Results were synthesised using a data-based convergent approach (also called an integrated approach), whereby quantitative and qualitative studies are analysed using the same synthesis method and results are presented together [31][32]. Quantitative data underwent data transformation, which involved creating textual descriptions of quantitative findings. Findings of health and wellbeing were coded in themes using thematic synthesis. Each finding was first coded as 'outcome' or 'mechanism'. To organise the data, each outcome was coded into themes relating to the type of health outcome (e.g., physical or mental health). Findings within each theme were then coded into sub-themes based on the specific finding (e.g., pain or depression), with similar codes being grouped together. This was an iterative process with the grouping of codes and themes changing following discussions amongst the research team. For mechanisms, each finding was reported in relation to their respective health outcome and were thematically grouped for the discussion (e.g., support or content exchange).

Quality assessment

The Mixed Methods Appraisal tool (version 2018) was used to evaluate the quality of included studies [33]. This was a suitable appraisal tool as it was designed for systematic reviews that include qualitative, quantitative, and mixed methods studies. The tool comprises of two questions that apply to all studies, followed by five questions relevant to each methodology. The first author carried out the quality appraisal.

Results

Study selection

In total, 17,385 search results were extracted from electronic databases and grey literature searches. Duplication screening was conducted on Rayyan, resulting in 9,085 articles for title and abstract screening. Full text screening was conducted on 264 articles, with 82 papers, totalling 90 studies. Another paper, that was not identified in the initial search, was included as it met the inclusion criteria [34], resulting in 83 papers totalling 91 studies included in the final review. A study has been defined as a separate empirical study within a paper that uses a separate research method to evaluate an online support group. For example, mixed methods designs (e.g., conducting post-intervention quantitative survey and qualitative interviews) [35], or two sequential studies [36]. It is important to note that some papers analysed the same participants but reported different outcome measures (e.g., [37][38] and [39][40][41][42]), and these are also classified as separate studies. The final review also deviated from the pre-registration protocol reported, as the authors did not repeat the search for conditions that were not in the initial search strategy (e.g., endometriosis). When studies report analyses before and after the inclusion of covariates, only the findings of analyses with the inclusion of covariates have been reported (e.g., [43]), and when studies report regression analyses after a correlation only the regression findings are reported.

Study characteristics

A summary of the characteristics of each study can be found in Supplementary File 2. Numbers of articles excluded for each reason during the full text screening can be found in Supplementary File 3. Across the 83 included papers, 21 chronic conditions were included, with breast cancer (n = 20), other types of cancer (n = 12), HIV/AIDS (n = 9) and diabetes (n = 7) being the most frequently studied. A full list of included chronic conditions can be found in Table 2.

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Chronic Condition	Number of papers	References
Breast cancer	20	[34][39][40][41][42][43][44][45][46][47][48][49][50][51][52][53][54][55][56][57]
Other/multiple types of cancer	12	[58][59][60][61][62][63][64][65][66][67][68][69]
HIV/AIDS	9	[21][36][70][71][72][73][74][75][76]
Multiple conditions	8	[19][20][77][78][79][80][81][82]
Diabetes	7	[83][84][85][86][87][88][89]
Arthritis	4	[90][91][92][93]
Multiple Sclerosis	4	[94][95][96][97]
Asthma	3	[35][98][99]
Chronic pain	2	[37][38]
Hepatitis B	2	[100][101]
Inflammatory bowel conditions (Chron's disease and ulcerative colitis)	2	[102][103]
Long Covid	2	[104][105]
Cystic fibrosis	1	[30]
Ehlers-Danlos Syndrome	1	[106]
Endometriosis	1	[107]
Hearing impairment	1	[108]
Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)	1	[109]
Parkinson's Disease	1	[110]
Polycystic ovaries	1	[111]
Vestibular disorders	1	[112]
Alopecia	1	[113]

Table 2. Chronic Conditions identified in the review

Most studies were conducted in the USA (n = 22), followed by the UK (n = 7), Netherlands (n = 7) and Canada (n = 6). Many studies did not report the country of origin, which may be due to analysing online groups for which the location of group members is unknown. Most studies recruited participants from either online support groups or through hospitals. The effects of online support groups were tested with a variety of methods with the most frequent being cross-sectional surveys (n = 35), cross-sectional interviews (n = 15), quasi-experimental studies (e.g., non-randomised controlled trials, pre-post intervention studies, longitudinal interventions; n = 21) and randomised controlled trials (RCTs; n = 7). One study used electronic health records for outcome measures [89]. Experimental studies introduced participants to a new online support group, often created for the experiment, whereas cross-sectional, and longitudinal surveys, were naturalistic as they typically assessed the impact of groups in which participants were already a member. Interventions lasted between 1 and 6 months, whilst the duration of support group membership in cross-sectional studies ranged between less than 1 week to 15 years with reported mean duration being between 1 and 4.6 years.

Quality Appraisal

The MMAT checklist can be found in Supplementary File 4. The authors of the MMAT recommend against calculating an overall score for each study, as it is not informative, and instead suggest describing the overall quality of the studies included within the review [33]. Overall, the quality of the studies was good. Most studies set clear objectives and used suitable methodologies to answer these questions. Most quantitative descriptive and qualitative papers used opportunistic sampling as participants were recruited via adverts posts in online support groups, so it was often not possible to identify non-response bias. Many authors acknowledged that this sampling strategy results in a self-selected sample, with participants potentially differing to the online support group members that did not take part. Similarly, most studies also did not discuss characteristics of the target population, so it is not possible to identify whether the samples are representative of other individuals with the chronic condition or representative of online support group members. Furthermore, whilst many studies used standardised scales and statistical analyses, some papers only reported percentage agreements to health and wellbeing-related statements. Randomised and non-randomised (including longitudinal intervention and naturalistic studies) typically used standardised measures and accounted for confounders in their analysis (e.g., demographics or baseline scores). Many studies also reported that the intervention was administered as intended but often did not report blinding procedures. When participants did leave the study, some studies reported their reasons and statistical differences in baseline scores, but not all.

Synthesis

The sections below present findings in relation to seven health and wellbeing outcomes: physical health, mental health, quality of life, social wellbeing, health-related behaviour and decision-making, and adjustment. Each category presents a related outcome and mechanisms which may influence them. Evidence for possible underlying mechanisms comes from content analysis of messages posted on online groups, self-reported survey items and explanations given in interviews. Mechanisms included group features (e.g., moderated vs unmoderated), giving and receiving support; expressed content (e.g., religious expression, insightful disclosure, emotional disclosure); sharing experiences; and social comparison, amongst others. It is also important to note that the categorisation of outcomes in this review may differ to the labelling given by study authors. This is so that similar outcomes can be grouped together here. The findings of each outcome are grouped by research method, with RCTs being presented first followed by non-randomised controlled trials, longitudinal studies, cross-sectional quantitative studies, and cross-sectional qualitative studies.

Tables 3 and 4 present findings on how usage characteristics (e.g., level of engagement and intensity of use) and group type may influence each health outcome. Furthermore, a cross-sectional survey also reported that participants liked having the option to ‘lurk’ [68]. As most of these studies are cross-sectional and naturalistic, it is important to interpret findings with caution as they cannot establish cause and effect. Indeed, when a study identifies an association between engagement and poorer health outcomes it is not possible to identify whether poor health outcomes are a result, or cause, of increased engagement.

Health outcome	Level of engagement (e.g., poster vs lurker[1])	Intensity of usage (e.g., daily vs non-daily user)	Membership length
Physical health			
Symptoms and functioning	Higher engagement and better symptoms and functioning [79][85] Higher engagement and reduced symptoms and functioning [21][53] No relationship between engagement level and symptoms and functioning [21][46][53][79][85].	Less intensity of use and better symptoms and functioning [72] No relationship between intensity of use and symptoms and functioning [72][85]	
Pain	No relationship between engagement and pain [21][37].	No relationship between intensity of use and pain [72].	
Mental Health			
Broad mental health	No relationship between engagement level and broad mental health outcomes [21][43][47][48][85].	No relationship between intensity of use and broad mental health outcomes: [47][48][72][85].	
Depression	Higher engagement and increased depression scores [46] No relationship between engagement and depression [21][37][43][47][48][53]	Higher intensity and better depression scores [73] No relationship between intensity of use and depression [47][48][112]	Longer duration and better depression scores [63][73] No relationship between duration and depression [112]
Anxiety	No relationship between engagement and anxiety [37]	No relationship between intensity of use and anxiety [112]	Longer duration and better anxiety scores [63].

Health outcome	Level of engagement (e.g., poster vs lurker[1])	Intensity of usage (e.g., daily vs non-daily user)	Membership length
			No relationship between duration of use and anxiety [112]
Distress	No relationship between engagement and distress [21]		
Quality of life			
Quality of life	No relationship between engagement and quality of life [21]		Longer duration of use and better quality of life [63]
Social Wellbeing			
Social wellbeing	Higher engagement and better social wellbeing [19][21] No relationship between engagement and social wellbeing [46]	Higher intensity of use and poorer social wellbeing [72]	Longer duration of use and better social wellbeing [82]
Loneliness and isolation	No relationship between engagement and loneliness [21]	Higher intensity of use and reduced loneliness [69][73]	
Connections and friendships	Higher engagement and better connection outcomes [85] No relationship between engagement and connection [53]	Higher intensity of use and better outcome [85]	
Health-related behaviour			
Behaviour change	Higher engagement and better behavioural outcomes [85]	Higher intensity of use and better behavioural outcomes [85]	

Health outcome	Level of engagement (e.g., poster vs lurker[1])	Intensity of usage (e.g., daily vs non-daily user)	Membership length
Motivation	Higher engagement and better motivation scores [79].		
Treatment decision-making	Higher engagement and better treatment-decision making outcomes [59][85],	Higher intensity of use and better treatment decision-making outcomes [59][85][112]. No relationship between intensity and treatment decision-making [112].	Longer membership duration and better treatment confidence [82] No relationship between membership duration and treatment decision-making [112].
Self-efficacy	Higher engagement and higher self-efficacy [87] No relationship between engagement and self-efficacy [21][53]	Higher intensity of use and higher self-efficacy [87]	Longer duration of use and better self-efficacy outcomes [63]
Empowerment	Higher engagement and better empowerment outcomes [85]	Higher intensity of use and better empowerment outcomes [85].	
Adjustment			
Illness acceptance	No relationship between engagement and illness acceptance [19][21]		No relationship between membership duration and illness acceptance [82]
Feeling less alone	Higher engagement and feeling less alone [85]	Higher intensity of use and feeling less alone [85]	
Feeling understood	Higher engagement and feeling more understood [85].	Higher intensity of use and feeling more understood [85].	
Stigma	No relationship between engagement and stigma [74]		

Health outcome	Level of engagement (e.g., poster vs lurker[1])	Intensity of usage (e.g., daily vs non-daily user)	Membership length
Self-esteem	No relationship between engagement and self-esteem [19]		No relationship between duration of use and self-esteem [82]
Optimism and hope	No relationship between engagement and optimism and hope [19][21]	No relationship between intensity of use and optimism and hope [61][112]	Longer duration of use and better optimism scores [73] No relationship between duration of use and optimism and hope [61][112]
Coping	Higher engagement and better coping outcomes [21].	Higher intensity of use and better coping outcomes [72]. No relationship between intensity of use and coping [72][112]	Longer membership duration and better coping outcomes [112]

Table 3. The role of usage characteristics on health outcomes

[1] *The term 'lurker' refers to a passive user of online support groups, choosing to read posts rather than start a discussion*

Group type	Finding
Professionally moderated vs unmoderated groups	In a longitudinal RCT, pain, depression, anxiety, and self-efficacy scores increased in both a researcher-moderated and unmoderated Facebook group [37][38]. A longitudinal RCT found no effect of group type (professional vs peer-led) on depression scores [34]. In a cross-sectional survey, more than 85% of participants reported being happy that the online support group was peer-to-peer (i.e., run by regular people 'like me' who have also experienced the condition) rather than trained professionals (e.g., therapists, doctors or nurses) [68].
Online vs face-to-face groups	In one cross-sectional survey, there was no difference in depression or anxiety outcomes between those attending an online or face-to-face group, but those attending a face-to-face group reported more positive wellbeing and less distress [58]. Participants in another cross-sectional survey reported that they felt more comfortable in an online group, compared to face-to-face, as they knew no-one was looking at them when they shared their stories / feeling / problems or asking questions [68].
Closed groups	The closed nature of the groups were reported to be advantageous as it allows users to openly discuss their condition without concerns of being stigmatised [102],
Local groups	Local groups provided opportunities for patients to connect and maintain a sense of belonging offline, as well as in the online groups [101].

Table 4. The relationship between group type and health outcome*Physical health*

Physical health

Physical health outcomes included symptoms and functioning, and pain.

Symptoms and functioning: Fourteen studies explored symptoms and functioning outcomes (e.g., fatigue, physical functioning, functional wellbeing, role limitation). This included two RCTs, four quasi-experiments, five cross-sectional quantitative studies, one cross-sectional qualitative study and two longitudinal surveys. Seven of the 14 studies did not report on effects of online support groups more broadly but reported on underlying mechanisms (e.g., the role of religious expression).

Outcome: The two RCTs found no effect of online support groups on symptoms and functioning over time [52] or compared to website controls [52][91]. However, in post-intervention interviews following a non-randomised control trial, 53% of participants reported that participating in an online support group contributed to a reduction in their symptoms [96]. A longitudinal intervention study found no differences between users and non-users in functional wellbeing at six weeks or three months of using the online support group [53]. Furthermore, one cross-sectional survey found lower self-reported symptom scores and higher function scores in online support group members compared to members of a face-to-face support group [58]. A cross-sectional analysis of health records found that patients with diabetes from a closed Facebook group had lower blood sugar levels compared to those not in the Facebook group, but there were no differences in other health outcomes [89]. Additionally, one cross-sectional qualitative study, reported enhanced functional wellbeing and expedited recovery [36].

Mechanisms: One cross-sectional survey found that online emotional and informational support was positively related to physical quality of life [101]. Similarly, an interview study suggested that sharing experiences and information on the group was attributed to improved symptoms and functioning [36]. Additionally, participants who reported that the online community helped them to learn strategies to improve insurance coverage were more likely to have increased blood sugar levels [85]. However, there were conflicting findings regarding the role of religious expression and insightful disclosure. Of five pre-post content analyses, within intervention and naturalistic settings, three found that greater religious expression and insightful disclosure by participants were associated with improved self-reported functional wellbeing [39][40][45], but two did not [46][55]. One also reported no association between disclosure of negative or positive emotions and functional wellbeing [40]. Another cross-sectional survey found no relationship between perceived competence of online discussions and diabetes related complications or blood sugar levels and that participants who reported that the online community helped them to learn strategies to improve insurance coverage were more likely to have increased blood sugar levels [85].

Pain: Five studies explored pain outcomes, including two RCTs, one quasi-experiment, and two cross-sectional qualitative studies.

Outcome: One of the two RCTs reported a reduction in pain severity and interference amongst members of moderated and unmoderated Facebook support groups [38]. However, the other found no significant change in pain scores in a virtual community group compared to usual care [75]. A pre-post intervention study reported positive outcomes on reactions to pain [44] and two cross-sectional qualitative studies reported that online support groups helped with reduction [106][107]. In particular, a participant reported that suggestions made on online support groups helped them to stay ahead of their pain, when previously they would have gone to hospital [107]

Mental health

This section includes broad mental health, depression, anxiety, and distress.

Broad mental health: Here we consider measures of emotional benefits, emotional health, (psychological or emotional) wellbeing, negative feelings, difficult emotions, mental health and mood. Mental health was measured across 30 papers, including two RCTs, five quasi-experiments, nine cross-sectional quantitative studies, 12 cross-sectional qualitative studies and two longitudinal surveys. Eight reported only on underlying mechanisms.

Outcome: The two RCTs reported mixed findings. One found that there were improvements in mood scores across all participants after the intervention and at follow-up, but there were no differences between the intervention group (moderated weekly calls plus education) and the control (education only) [49]. Another found that women in an unmoderated email group had poorer wellbeing at both 4 and 12 months than women using an educational website [52]. Moreover, a longitudinal survey reported no change in emotional wellbeing over time [47]. Three cross-sectional quantitative studies also found no association between online support group participation and mental health [48][84][97], whereas a further three reported a positive effect on mental health [68][108][109]. For example, in one cross-sectional survey, 100% of participants agreed that the online support group made a positive difference in their emotional health [68] and another reported that between 75%% indicated that being involved with online support groups increased their satisfaction with daily life, 57.9% reported reduced sadness and 27.6% expressed that involvement in the online support group had decreased thoughts of suicide [109]. However, one cross-sectional quantitative survey compared online to face-to-face support groups and found that more people attending a face-to-face group (two-thirds of participants) reported positive wellbeing than those attending an online support group (one-third of participants) [58]. Six cross-sectional qualitative studies reported a positive effect on mental health [36][101][103][105][106][107], but eight reported reduced wellbeing, including feelings of frustration, upset, sadness, overwhelm, guilt and disappointment [20][71][81][94][103][105][109][111].

Mechanisms: Six studies explored the role of expressed content. Content analyses in a pre-post intervention and longitudinal survey reported that the use of a higher percentage of religious words predicted lower levels of self-reported negative emotions, but not emotional wellbeing [39][46]. Similarly, insightful disclosure in two intervention studies was predictive of lower levels of self-reported negative emotions and improved emotional wellbeing [40][55]. Furthermore, although a survey found that 85.8% participants said that writing down thoughts and feelings made them feel better [68], a content analysis in an intervention study found no association between disclosure of negative or positive emotions and emotional wellbeing [40]. Additionally, communicating about oneself within an online support group in an intervention study (measured through first person pronoun use, e.g., 'I') was associated with higher levels of negative emotions, but communicating about others (measured through use of relational pronouns, e.g., 'we' or 'you') was not [41].

Four cross-sectional quantitative studies reported on the role of support, and found that receiving online emotional support was positively associated with emotional wellbeing [66], but giving and receiving social support, and receiving informational support, was not associated with mental health [42][66]. Online support network size also had an indirect positive effect on emotional wellbeing in a cross-sectional survey, through online received emotional support [66]. Furthermore, a cross-sectional survey found that social comparison negatively affected emotional wellbeing when it is as pessimistic comparison, such as downward identification (fearing that future will be similar) and upward contrast (feeling frustrated at own situation), whereas optimistic strategies, such as upward identification (realising it is possible to improve) and downward contrast (realising how well you are doing), did not negatively affect emotional wellbeing [43].

Of 12 qualitative studies, four suggested that online support groups improved mental health as they provided a space to share experiences, receive social support, have an outlet for feelings and to help others [36][101][105][107]. Three also suggested that mental health improved due to improvements in social wellbeing and companionship [36][101][106]. On the other hand, four suggested that poorer wellbeing was influenced by exposure to negative aspects of conditions (such as hospitalisation, relapses, suicidal thoughts, and death of other members), as well as complaints by other members [20][81][94][105]. However, for some people, positive stories were also damaging, for example reading about people with better medical care or quality of life [109]. Two studies also found that online support groups can focus too much on the condition [111], and can be overwhelming in terms of the information [71][94]. One also found that some participants experienced personal attacks or ridicule for their views and opinions, which led to feelings of mistrust and fear [71]. Feelings of frustration and disappointment were also reported in two qualitative studies, if participants were unable find online groups suited to their unique needs (e.g., due to having multiple conditions or greater severity) [81] and when having to wait for reply [103].

Depression: Sixteen studies measured depression, including five RCTs, five quasi-experiments, and four cross-sectional quantitative studies and two longitudinal surveys. Five reported only on underlying mechanisms.

Outcome: Of four RCTs, one reported a reduction in depression over time in both an unmoderated and moderated Facebook group, with effects being sustained after one month [37]. However, three RCTs reported no differences in depression scores between online support groups (weekly moderated groups or a peer-led Facebook group – sometimes plus education), and control groups (education or usual care) [49][67][91]. Another longitudinal RCT reported no effect of time on depression in both a professionally moderated group and unmoderated group [34]. Furthermore, a pre-post intervention reported a reduction in depression following a 16-week intervention of weekly meetings combined with a private asynchronous newsgroup [44] but another found no change following a 12-week weekly video-based online support group [95]. Additionally, a longitudinal intervention reported no differences in depression scores between users and non-users at six weeks or 3 months [53]. Two non-randomised control trials compared depression between participants in moderated weekly video groups and control groups (journalling or no treatment) and found no differences between conditions [95][96]. Additionally, one longitudinal survey also found no change in depression over time [47]. Another cross-sectional survey reported no difference in depression scores between an online and face-to-face group [58].

Mechanisms: One study reported that posters' negative feelings towards the online support group was positively correlated with depression in a cross-sectional survey, whilst for lurkers, emotional expression (on the support group) was negatively correlated [51]. In terms of content expressed, two analyses of posts made on online support groups within experimental and naturalistic settings reported no association between each of empathy expression [54] and religious expression [46] with depression. With regards to support and comparison, two cross-sectional surveys reported that depression was negatively predicted by social support [60] and upward contrast (but not downward identification, upward identification or downward contrast) [43].

Anxiety: Fourteen studies, including three RCTs, three quasi-experiments, two cross-sectional quantitative studies and six cross-sectional qualitative studies, explored the impact of online support groups on anxiety. Of these, one reported only on mechanisms.

Outcome: Of three RCTs, one reported reductions in anxiety scores in both a moderated and unmoderated Facebook group, but these effects were only sustained 1-month post-intervention in the unmoderated group and not the moderated group [37]. However, two RCTs found no difference in anxiety scores over time between the online support groups (moderated synchronous text-based sessions or moderated Facebook group) plus education and an educational control [49][91]. Furthermore, two of three, quasi-experiments reported a reduction in anxiety. Indeed, quantitative findings of one quasi-experiment reported reduced anxiety in a moderated synchronous online support group compared to a no-treatment control group [96], with these findings being echoed in post-intervention interviews of an unmoderated email-based support group [50]. However, another reported no differences between a moderated synchronous weekly chat group and treatment as usual [65]. A cross-sectional survey also found no difference in anxiety scores between participants in an online or face-to-face support group [58]. Furthermore, half (three) of the cross-sectional qualitative studies reported a reduction in anxiety [71][101][104] but the other half reported the potential for online support groups to increase anxiety [81][103][111]. Indeed, some participants in one study reported that the awareness of the potential to heighten worry led to the decision to limit usage of the group [111]

Mechanisms: Qualitative findings suggested that online support groups quelled anxiety as they helped to manage unfamiliar symptoms and provided emotional and informational support [50][71][101][104]. However, they also suggested that online support groups may increase anxiety after reading ‘horror stories’ and messages that can bring attention to specific issues that could be faced in the future [81][103][111].

A cross-sectional survey found that for those who were active posters, exchanging emotional support and receiving advice was negatively correlated with anxiety, whereas for lurkers emotional expression, receiving advice and insight/universality (learning more about oneself after realising experiences were shared) were negatively correlated [51].

Distress: Distress refers to distress from traumatic events and emotional distress more generally. It was measured in five studies including one RCT, one quasi-experiment, two cross-sectional quantitative surveys and one cross-sectional qualitative survey.

Outcome: An RCT compared an unmoderated email group with an educational website and found no difference in distress scores over time or between groups [52]. However, a quasi-experiment found that distress significantly decreased over time amongst participants in a moderated synchronous online support group and in the no treatment control [96]. Furthermore, a cross-sectional survey found that 100% of participants reported that private email groups helped them deal with their emotional distress [68]. Another survey reported that distress was less frequent in a face-to-face group than an online support group [58]. Qualitative findings also suggested that seeing others' stories can lead to increased distress [107].

Mechanisms: Participants in a cross-sectional qualitative survey reported that distress increased when the posts are skewed to sad or negative [107]. This study also found that positive stories can be distressing, for example reading members' pregnancy stories can be difficult for those with fertility issues [107].

Quality of life

The following studies refer to a broadly measured quality of life; where sub-scales of quality of life are reported (e.g., role functioning) these are reported in their respective section (e.g., [21]). Quality of life was measured in nine studies including two RCTs, two quasi-experiments and five cross-sectional quantitative studies. Three studies measured only mechanisms.

Outcomes: Both RCTs and the quasi-experiment found no differences between an online support group (private Facebook group or moderated synchronous groups) and control (education or usual care) [65][67][91]. However, in two, of four, cross-sectional quantitative studies between 94.7% and 100% of participants in a private email group said that the group made a positive difference to their quality of life [68][76]. Furthermore, another cross-sectional survey reported lower quality of life scores in a face-to-face group than an online support group [58].

Mechanisms: Giving and receiving informational support was not associated with quality of life in a cross-sectional survey and a content analysis within an intervention study [57][110], whereas perceived emotional support was, with this outcome being mediated by contentment [110]. A cross-sectional quantitative study found no association between perceived competence of discussions within an online support group and quality of life [85].

Social wellbeing

Social wellbeing outcomes include broad social wellbeing, feelings of belonging, connections and friendship, and loneliness and isolation.

Broad social wellbeing: Social wellbeing was measured, broadly, in a quasi-experiment and two cross-sectional studies. Most (two) studies looked at mechanisms only.

Outcome: One cross-sectional study found that 52% of participants reported enhanced social wellbeing from being part of an online support group [82].

Mechanisms: Results from two cross-sectional surveys suggested that exchanging social support [78][82] and encountering emotional support [78] were positively associated with social wellbeing. However, there were conflicting findings regarding the role of sharing experiences as whilst one cross-sectional study found that it was positively associated with social wellbeing [78], another reported that it was not [82]. A cross-sectional survey and a quasi-experiment reported that enhanced social wellbeing was not predicted by use of religious expression [46], information exchange [82], helping others [82] or comparison with others [82].

Feelings of belonging: Twelve studies, including one quasi-experiment, one cross-sectional survey and ten cross-sectional qualitative studies, reported outcome measures relating to feelings of belonging.

Outcome: A pre-post intervention survey had mixed results as although women in an unmoderated email group agreed that they felt a sense of belonging, some also reported leaving groups as they felt different from other members, which affected their ability to feel close to the group [50]. Furthermore, 90% of participants in a cross-sectional survey also reported a sense of belonging as a result of comments or posts from other members [109]. Feelings of belonging were also reported in ten cross-sectional qualitative studies [20][36][81][85][94][99][101][102][111][113].

Mechanisms: Qualitative responses across four cross-sectional interviews suggested that these feelings of belonging arose from interactions with others and were attributed to the common ground amongst group members and to being part of a group of people living with the same condition, which helped group members to fit in, have discussions and develop a shared identity [36][81][94][102]. However, another interview study found that some participants felt like outsiders due to difficulties in joining conversations and receiving no, or unhelpful, responses [111].

Connections and friendship: Eleven studies reported outcomes relating to the formation of social connections and friendships, including two quasi-experiments, five cross-sectional quantitative studies and four cross-sectional qualitative studies.

Outcome: The quantitative findings of an intervention study did not find an increase in the number of friendships following a combined synchronous and asynchronous online support, but the qualitative responses suggested that participants were more confident in their ability to make and socialise with friends following the 12-week synchronous chat sessions [35]. Furthermore, a longitudinal intervention reported no differences in bonding scores between users and non-users at six weeks or 3 months [53]. Three, of four, cross-sectional surveys reported that between 44 and 66% of participants formed new friendships in asynchronous groups [64][78][85] and another found that 94.7% bonded with the other women in an email group [68]. This is echoed in all four cross-sectional qualitative studies, as participants reported developing true friendships and bonds and feeling connected to others [20][71][87][94]. Two qualitative studies also looked at the interaction of new online friendships and existing offline relationships and found mixed findings; sometimes new social contacts replaced friendships lost because of their condition [20], sometimes they supplemented existing offline friendships [20], and other times they led to a decline in real-life relationships due to being over-reliant on online relationships and decreased attention to offline relationships [71]. Furthermore, participants in one interview study reported difficulties forming new relationships [71].

Mechanisms: One interview study reported that participants felt connected to other members through the conveyed emotion, although some participants found this difficult due to the lack of body language and not being an active member [94]. Another found a positive correlation between the perceived credibility and competence of discussion on online communities and social capital within online groups [85].

Loneliness and isolation: Loneliness and isolation refers to the formation of friendship and groups connections and is distinguished from feeling less alone (included in the adjustment sections) following seeing others with similar experiences. Loneliness and isolation outcomes have been grouped together, despite the differences in definitions [114], as the terms are used interchangeably within the included studies to refer to an absence or presence of social connections. These outcomes were reported in 14 studies. Of these 14 studies, one was an RCT, three were quasi-experimental, three were cross-sectional quantitative studies and seven were cross-sectional qualitative studies.

Outcome: An RCT compared a moderated synchronous group plus educational website to the website alone and found better loneliness scores in the online support group condition [49]. Three quasi-experimental studies reported conflicting results. Indeed, quantitative and qualitative findings from a post-intervention study found reductions in loneliness scores after a 12-week synchronous chat session intervention [35]. However, two quasi-experiments reported no effects online support groups (combined synchronous and synchronous groups or moderated synchronous group alone) on loneliness over time [99] or compared to a no treatment control [96]. On the other hand, in three cross-sectional surveys, between 47 and 75% of participants reported that they felt less lonely [64][78][109]. This was echoed in five cross-sectional qualitative studies [20][36][81][107][113]. However, two cross-sectional qualitative studies suggested that participants sometimes felt isolation within an online support group [94] and after logging off [103].

Mechanisms: Qualitative studies suggest that such reductions occurred by being an active member and by connecting with others, making new friends, and becoming more outgoing [20][35][36][81][107][113]. However, a qualitative study reported that participants can feel isolated in online support groups as they lack human touch and connection [94].

Health-related behaviour and decision-making

Health-related behaviours includes behaviour change, motivation treatment adherence, treatment decision-making, self-efficacy and empowerment.

Behaviour change: 13 studies reported behavioural changes, such as disease management or adopting a healthy lifestyle. These studies included two RCTs, one quasi-experiment, three cross-sectional quantitative studies and seven cross-sectional qualitative studies. One cross-sectional survey reported on only an underlying mechanism.

Outcomes: The quantitative findings of an RCT, comparing an online support group plus an educational website to an educational website alone, found no difference in behaviours relating to disease management or health promotion between the groups after the intervention [91]. However, the qualitative findings of another RCT suggested that participants tried new things and were more active after using the online support group [92]. Similarly, post-intervention interviews of a quasi-experiment suggested that participants learned tips to help with their day-to-day life (e.g., where to place an inhaler) [99]. Furthermore, whilst one (of three) cross-sectional survey found higher scores for self-management of diabetes amongst participants not belonging to an online support group compared to online support group members [83], another reported increased odds for lifestyle changes for those who had participated in online support groups in the previous year [86]. Furthermore, seven cross-sectional qualitative results suggested that upon joining an online support group, participants gained the skills for self-management of their condition [87] and started taking better care of themselves (e.g., engaged in preventative activities, changed risky behaviours, purchased assistive devices, and tried other people's dietary habits) [20][36][88][90][103][106].

Mechanisms: Five qualitative studies suggested that behaviour change was possible after reading about the experiences of others and through sharing advice in online support groups [36][88][90][103][106], and a quantitative survey found that credibility of discussion on online communities positively correlated with self-care [85].

Motivation: Five papers explored motivation to enact positive behaviour change, including one quasi-experiment, one cross-sectional survey, and three cross-sectional qualitative studies.

Outcome: Interviews following a quasi-experiment, including a moderated discussion forum plus education (compared to education alone), suggested that participants were motivated to keep up with self-management [92]. A cross-sectional survey reported mixed findings on motivation outcomes, as it found an increase in motivation scores amongst participants with Type 2 diabetes but a decrease amongst those with Type 1 [84]. Moreover, three cross-sectional qualitative studies reported an increase in motivation to change behaviour [36][88][102].

Mechanisms: Post-intervention interviews suggested that participants were motivated to keep up with self-management after reading posts of other people who were still active despite their pain [92]. This was echoed in cross-sectional qualitative studies which reported that motivation was influenced by seeing other people make healthy lifestyle choices, sharing success stories and receiving non-judgmental personalised advice [36][88][102].

Treatment adherence: Five papers assessed treatment adherence, including one RCT, two cross-sectional quantitative studies and two cross-sectional qualitative studies. One interview study only discussed influencing factors of adherence.

Outcome: One RCT reported no effects of support group membership on medication and infection control adherence, within and between conditions [98]. This is supported by a cross-sectional survey which found that social networking support group membership was not related to self-reported infection control adherence [30]. However, improvements in medication adherence were reported by online support group users in an interview and Delphi study, in the same paper [36].

Mechanisms: Two qualitative studies suggested that treatment and medication adherence was facilitated by observing similar patients' health status, sharing (positive and negative) experiences and being able to discuss with others (e.g., tracking and side-effects) [36][93]. However, a cross-sectional survey found no relationship between perceived social support from online peers and reported medical adherence [30].

Treatment decision-making: Treatment decision-making refers to group members' ability to make decisions relating to their treatment, revising their initial treatment plan and feeling confident in their treatment. It was measured in 14 studies, including seven cross-sectional quantitative and seven cross-sectional qualitative studies.

Outcome: Four cross-sectional quantitative studies (including one Delphi study) reported changes in treatment decision-making, with the percentages of participants choosing to change their initial treatment after participating in an online group ranging from 25% to 80.5% [36][58][59][112]. When comparing to face-to-face support groups, one cross-sectional survey found no differences between the groups in proportion of participants who had revised their initial treatment decision after consulting their respective support group (25%) [58]. Another cross-sectional survey reported that 51.6% of participants reported improved confidence in their treatment [82]. Furthermore, seven cross-sectional qualitative studies reported feeling empowered in relation to treatment decision-making and feeling more confident in their treatment [20][36][88][106][107][111][113].

Mechanisms: Three of five qualitative studies reported that support with treatment decision-making occurred through connecting with other group members and sharing experiences and information as it allowed members to assess the benefits and side-effects of treatment and identify best practice [20][36][50][107]. With regards to treatment confidence, two cross-sectional quantitative surveys reported that social comparison [82] and finding recognition [78] predicted treatment confidence. However, there was conflicting evidence regarding the role of receiving emotional support, as although one cross-sectional survey found that it predicted treatment confidence [78], another did not [82]. These two surveys also reported that treatment confidence was not predicted by information exchange, helping others or sharing experiences [78][82].

Self-efficacy: Eighteen papers reported self-efficacy outcomes, including 3 RCTs, four quasi-experiments, four cross-sectional quantitative studies and seven cross-sectional qualitative studies.

Outcome: Two RCTs reported improvements over time in moderated and unmoderated Facebook groups (sometimes plus education) [38][91], although one reported no difference between the online support group and educational control [91]. However, another RCT found that emotional self-efficacy declined amongst participants in an unmoderated email group [52]. Furthermore, post-intervention surveys found no difference over time following a 12-week synchronous online support group [35], but other post-intervention interviews reported improvements after an 8-week synchronous online support group supplemented with gamification communication [99]. Two cross-sectional surveys and a Delphi study reported improvements in self-efficacy amongst participants, but there was variation in the proportions of people reporting such an effect (19.1-88.5%) [36][62][82]. Seven cross-sectional qualitative studies also reported improvements in self-efficacy [20][36][85][87][88][107][111].

Mechanisms: With regards to content expressed on online support groups, two content analyses within intervention studies and a cross-sectional survey found that writing a higher number of religious expressions [39], using more positive emotion words [40], receiving social support [70] and helping others [70] was associated with improved self-efficacy, but disclosing negative emotions was not [40]. Similarly, qualitative studies found that the information and support on online support groups enabled people to take an active role in managing their condition and feel like they can regain control over their personal lives [20][88][111].

Empowerment: Nine studies reported changes in empowerment, with one reporting only on mechanisms. Of these nine studies, one was an RCT, one a quasi-experiment, two cross-sectional quantitative studies and five cross-sectional qualitative studies.

Outcome: An RCT comparing a peer-led Facebook group plus online education to education alone found no differences in empowerment at 3 or 6 months [91]. However, post-intervention interviews following an unmoderated email-based support group found that participants felt empowered following the intervention [50]. Furthermore, across two quantitative studies between 73-80.7% of participants reported that online support groups improved empowerment [36][85]. Cross-sectional qualitative studies also suggested that participants feel more empowered by being part of an online support group [85][88][102][104][107]

Mechanisms: Qualitative studies suggested that feeling empowered was mostly in relation to the information shared, which enabled group members to feel in control [50][102][107]. Participants also reported feeling empowered by helping others [85][88] and being part of a collective voice [104]. A quantitative study reported that empowerment was positively associated with perceived credibility of discussions on online communities and behaviours such as requesting or sharing informational and emotional support [85].

Adjustment

This section includes illness acceptance, feeling less alone, feeling understood, feeling reassured, self-esteem, optimism and hope, uncertainty, post-traumatic growth, identity, stigma, and coping.

Illness acceptance: Illness acceptance was measured in 15 studies, including a quasi-experiment, seven cross-sectional quantitative studies, and seven qualitative studies. Five studies only reported on underlying mechanisms.

Outcome: One cross-sectional survey reported that 34% of participants said that the online support group helped them find meaning in their experience [62], whilst another reported that 27.2% of participants reported improved acceptance of their condition [82]. However, another cross-sectional survey reported that face-to-face support group members accepted their illness better than those in online support groups [58]. Seven qualitative studies also found that online support groups helped group members to accept their illness [20][90][103][107][113], view it more positively [103], reappraise it as something that can be successfully managed [103], overcome its uncertainty [104], conceptualise the illness as chronic rather than terminal [50], and allowed members to understand their condition as defined by the community [90].

Mechanisms: Four qualitative studies suggested that illness acceptance was facilitated by emotional expression [113], comparison with other group members (particularly those with more severe symptoms) [90][103] and finding others in a similar situation [107]. Two cross-sectional surveys and a content analysis within a longitudinal intervention found that illness acceptance and positive reframing were not associated with empathy reception [42], receiving emotional/social support [42][78][82], information exchange [78][82], helping others [78][82], finding recognition [78], sharing experiences [78][82] or religious expression [39]. On the other hand, across three cross-sectional quantitative studies positive reframing and illness acceptance was positively associated with numbers of days and hours a week on online support groups, exchanging social support [42][82], empathy expression [42] and comparison with others [73][82]. Additionally, a cross-sectional survey found that those who were inhibited from making contributions to online support groups because they either felt a poor sense of community or had concerns about privacy and disclosure were less likely to feel they had found positive meaning from the online support groups [77].

Feeling less alone: Feeling less alone was measured in 11 studies, including one quasi-experiment, four cross-sectional quantitative studies and seven cross-sectional qualitative studies.

Outcome: Post-intervention interviews in one quasi-experiment reported that participants felt less alone following the intervention [99]. Three cross-sectional quantitative [58][68][85] and seven cross-sectional qualitative studies [20][71][75][81][88][103][106][113] also reported that participants felt less alone. In the surveys, this occurred in 76-100% of participants.

Mechanisms: Participants in cross-sectional qualitative studies reported feeling less alone as they can connect with others [113], compare to other group members knowing that others have similar feelings, emotions and experiences [71][88] and have shared understanding and empathy amongst group members [81]. As online support groups are closed to those not experiencing similar conditions, participants in cross-sectional qualitative studies reported feeling part of a majority [106] and safe within the community [103]. A cross-sectional survey also found that feeling less alone was also positively associated with perceived credibility of discussions on online communities and behaviours such as requesting or sharing informational and emotional support [85].

Feeling understood: Five studies reported feeling understood, including one cross-sectional quantitative survey and four cross-sectional qualitative studies. The cross-sectional survey only reported on an underlying mechanism.

Outcome: All (four) cross-sectional qualitative studies reported that online support groups enabled participants to feel understood [20][85][103][109].

Mechanisms: A cross-sectional qualitative study reported that participants felt understood because of the shared experience [20]. A cross-sectional survey found that feeling understood was positively associated with perceived credibility of discussions on online communities and behaviours such as requesting or sharing informational and emotional support [85].

Feeling reassured: Seven studies reported on feeling reassured, including one cross-sectional quantitative survey and six cross-sectional qualitative studies.

Outcome: One cross-sectional survey reported that 15% of participants reported that they felt reassured in a moderated asynchronous online support group [64]. All (four) cross-sectional qualitative studies reported that online support groups reassured group members [20][71][92][103][105][107]. Half (two) of the qualitative studies reported that online support groups reassured group members that they were not 'crazy' and that their symptoms were not 'psychosomatic' [20][105].

Mechanisms: Five qualitative studies reported that feeling reassured was influenced by reading other members' experiences, as they could see others in the same position and see others manage their condition successfully [71][92][103][105][107].

Optimism and hope: Sixteen studies measured optimism and hope, including one RCT, one quasi-experiment, five cross-sectional quantitative studies and nine cross-sectional qualitative studies. Two cross-sectional surveys reported on mechanisms only.

Outcome: One RCT found a deterioration in hope scores after 4 months in an unmoderated email group, but no differences found between the online support group and an educational website [52]. On the contrary, post-intervention interviews following a quasi-experiment suggested that an unmoderated email-based support group increased hope [50]. Furthermore, three cross-sectional surveys reported increases in optimism and hope, and suggest that between 68% and 75% of participants experienced improvements [62][109][112]. All (nine) cross-sectional qualitative studies reported increases in optimism and hope [20][36][71][101][102][103][105][109][111] but two also suggested decreases in these outcomes [109][111].

Mechanisms: Eight qualitative studies highlighted the importance of reading success stories of other group members (including how others successfully cope with the condition), and comparing to other group members [36][50][71][101][102][103][105][111], with one qualitative study suggesting that other members serve as positive role models [20]. Two cross-sectional surveys suggest that receiving emotional support, finding recognition and positive meaning predicts optimism and hope [73][78]. However, there was conflicting evidence between two cross-sectional surveys regarding receiving information and helping others, as one found that these factors did predict optimism [73] but another found that they did not [78].

Self-esteem: Nine studies measured self-esteem, including six cross-sectional quantitative surveys and three cross-sectional qualitative studies.

Outcome: Five cross-sectional studies (including a Delphi study) reported enhanced self-esteem, suggesting that between 26% and 88.4% of participants experienced improvements in self-esteem and self-confidence [36][58][64][78][82]. However, one cross-sectional survey found no difference between those who use Facebook forums and those who do not [84]. Three qualitative cross-sectional studies also report enhanced self-esteem and self-confidence [20][36][103].

Mechanisms: A cross-sectional qualitative study suggested that enhanced self-esteem was facilitated by receiving appreciation from other group members and through the gratification they felt from being active online [20]. Two, of six, cross-sectional quantitative surveys also suggest that self-esteem was not associated with information exchange [78][82], finding recognition [78], comparison with other members [82], helping others [78][82] or sharing experiences [78][82], but may be predicted by encountering emotional support [78] and exchanging social support [82].

Uncertainty: Three studies reported uncertainty outcomes, including one cross-sectional survey, which only included mechanisms, and two interview studies.

Outcome: One of the two interview studies reported that online support groups reduced uncertainty, as participants saw others experiencing similar symptoms [104], whereas another found that exposure to negative aspects of the condition led to increased uncertainty [94].

Mechanisms: One study reported that perceived online informational support was not related to uncertainty [110].

Post-traumatic growth: Post-traumatic growth was explored in two studies: an RCT and quasi-experiment.

Outcome: An RCT found no change pre-post in post-traumatic growth amongst participants in a weekly synchronous online support group compared to usual care [67]. Similarly, a quasi-experiment found no significant differences over time in any post-traumatic growth subscale (i.e., relating, new possibilities, strength, spirituality or appreciation) [44].

Identity: Seven studies reported identity outcomes, including one cross-sectional quantitative study and six cross-sectional qualitative studies.

Outcome: One cross-sectional survey reported that 93.1% of participants said that group participation had helped them recover their sense of self [68]. Similar findings are reported in two cross-sectional qualitative studies as participants reportedly formed new identities through accepting the changes that come with their condition and by returning to a lost version of themselves [101][113]. Four qualitative studies also reported that participants felt "normal" again after participating in the online support group [81][88][93][106].

Mechanisms: Across six qualitative studies, three reported that they felt normal again included as their experiences were normalised [81], they were part of a majority (vs being an outlier) [106], and they shared gallows humour [88]. Two cross-sectional qualitative studies also reported that participants formed new identities through accepting the changes that come with the condition [113] and feeling connected to a group [101].

Stigma: Three studies, including one quasi-experiment and two cross-sectional qualitative studies explored the role of online support groups on stigma.

Outcome: A pre-post intervention study found no difference in stigma scores between baseline and 12 months [74]. However, participants in two interview studies reported a reduction in shame and embarrassment attached to their condition [113] and that being part of a Facebook group protected them against social stigma [102].

Mechanisms: An interview study found that as Facebook groups could only be accessed by those with the condition, group members could safely share their experiences without concern of stigma [102] and have a sense of understanding within online support groups [113].

Coping: Amongst 14 studies, four only reported findings on underlying mechanisms. There was one RCT, four quasi-experiments, five cross-sectional quantitative studies and four cross-sectional qualitative studies.

Outcome: One RCT found better coping outcomes in an educational control compared to a 12-weekly moderated online support group during the intervention [49]. However, after the intervention, coping outcomes on one sub-scale (self-blame) were more favourable in the online support group condition. Three quasi-experimental studies measured coping outcomes with mixed findings. One pre-post intervention study found an increase in support-seeking coping following weekly synchronous groups supplemented with a gamification social setting, with these quantitative findings echoed in the qualitative evaluation [99]. However, in a similar study by the same research team, quantitative findings from a pre-post intervention study found no differences in coping scores following a 12-week moderated synchronous online support group, but post-intervention interviews suggested that participants sought more support-seeking coping strategies after the intervention [35]. Furthermore another pre-post study reported reduced coping following a combined synchronous and asynchronous online support group [44] and another study found no difference between participants attending five weekly moderated sessions and those in treatment as usual [65]. Three cross-sectional quantitative surveys reported that between 60% and 88.1% of participants found that the online support group helped them to cope with their condition [62][109][112]. Four cross-sectional qualitative studies reported coping outcomes with all suggesting that online support groups help people cope with their condition [20][36][107][113]. One interview study reported that 82.7% of participants found that online interactions helped them learn how to cope with the social, physical and health consequences of the diseases [36].

Mechanisms: Qualitative studies suggested that coping was facilitated by connecting with other people who understand [107], having individual differences accepted [113], and receiving social support [36]. Across two cross-sectional quantitative studies and two content analyses within intervention studies, giving and receiving informational support, empathy reception, social support, and finding positive meaning were positively associated with adaptive coping [54][57][60][70], whereas helping others and empathy expression were not [54][57].

Discussion

This systematic review identified and summarised the findings of 91 studies in 83 papers to investigate whether online support groups affect health and wellbeing of people with chronic conditions and to identify factors influencing such effects. Health outcomes were categorised as physical health, mental health, social wellbeing, health-related behaviour and decision-making, and adjustment, which broadly aligns with outcomes from a recent umbrella review exploring the role of peer support for people with chronic conditions [115]. In response to research question one, analysis suggested that effects varied by the health outcome being measured, and the research method employed to investigate such effects. In response to research question two, there were often only limited studies measuring each underlying mechanism, making it difficult to draw conclusions. The sections below, organised by health outcome, mechanisms, and user and group characteristics, summarise, and discuss the findings. Table 5 summarises the findings for each health outcome and the identified mechanisms.

Physical health

Compared to other health outcomes, the impact of online support groups on physical health has been explored less often. Nevertheless, the existing evidence suggests that online support groups are unlikely to worsen group members' symptoms and functioning. However, whilst the findings suggest that online support groups may improve pain outcomes, the results on symptoms and functioning differed between research methods. Indeed, RCTs reported no effects, whilst qualitative methods reported improvements. This echoes a similar review, which found mixed effects of peer support in care settings on physical health outcomes [116]. Although online support groups are unlikely to worsen physical health of group members, the review suggests that alternative interventions should be sought to alleviate these symptoms.

Mental health

The impact of online support groups on mental health varies depending on the type of mental health outcome. Most studies showed either an improvement or no change in depression, which suggests that although online support groups do not always improve these outcomes, they are unlikely to worsen outcomes. This is partially in line with a previous meta-analysis, which reported that participation in computer-mediated support was associated with less depression [17]. However, as people with chronic conditions are more likely to develop depression [117], if individuals experience these symptoms they should seek alternative support from a healthcare professional.

Furthermore, many studies also reported improvements or no changes in broader mental health, anxiety and distress. However, some also reported increased anxiety and a negative effect on experiencing frustration, sadness, and guilt. One explanation for the variation in these findings may be the way in which they were operationalised across studies, as outcome measures varied. However, it is also likely that online support groups can simultaneously help and hinder mental health and may be dependent on various factors, such as users' mood when engaging with the groups, group content and external pressures. As a result, participants should be aware of this potentially harmful effect and should be attentive to how they feel when using online support groups and take a break if they notice a deterioration, as recommended by participants in previous studies [118].

Quality of life

Most studies showed either an improvement or no change in quality of life, which suggests that although online support groups do not always improve these outcomes, they are unlikely to worsen outcomes. This is partially in line with a previous meta-analysis, which reported that participation in computer-mediated support was associated with less depression and greater quality of life [17].

Social wellbeing

The included studies suggest that online support groups may enhance group members' social wellbeing, as many group members reported a sense of belonging and felt less isolated, with approximately half of online support group members developing friendships within the groups. This is in line with previous reviews which identified similar benefits to social relationships [15][16]. Enhanced social wellbeing may also be a pre-cursor for other positive health outcomes, as a meta-analysis (conducted with mostly community settings) found that social relationships and integration are predictive of increased survival [119]. This review may also provide evidence in support of the Social Identity Model of Identity Change as for some support group members new contacts replaced lost offline contacts (supporting the identity gain pathway), while for others new contacts supplemented existing relationships (supporting the identity continuity pathway) [120]. However, for some, new relationships were developed at the expense of existing friendships, which may cause future difficulties.

Outcomes were explored predominantly in asynchronous naturalistic groups, which reflects the online support groups often used on social media platforms. However, quasi-experimental studies reported that there were no increases in friendships, nor any changes in loneliness. One explanation for this could be that participants felt less connected to other group members as they knew it was a short-term study, whereas naturalistic studies measure existing permanent groups. One quasi-experiment also reported that some people left a group as they felt different from others. This highlights the importance of those with a chronic condition exploring available groups to find like-minded people, as has been highlighted in a recent study [118].

Health-related behaviour and decision-making

Online support groups may change behaviour, motivation, treatment decision-making and empowerment, but the findings for treatment adherence and self-efficacy are less clear. Most studies reporting a positive impact on general behaviour change and motivation were qualitative and suggest that after reading others' experiences or advice, participants were motivated to keep up with self-management, change behaviour and adopt new behaviours (e.g., changing diet or purchasing assistive devices). This is in line with a systematic review and meta-analysis reporting that social networking sites may be effective for changing health behaviours [121]. For treatment decision-making and empowerment, most studies were positive and suggested that by sharing personal experiences and information group members can assess the benefits and side-effects of treatment, which in turn, may increase empowerment. However, it is not possible to know whether these decisions have a positive or negative effect on group members' physical health. The benefits of the decisions may be context dependent and vary according to the revised treatment option and group preferences [122]. It is also important to be cautious of misinformation and anecdotal evidence. As these studies were mostly naturalistic, they provide insight into the effects of online support groups used by participants in their day-to-day lives, but they cannot establish cause and effect, nor did they analyse behaviour over time.

Most studies showed either an improvement or no change in self-efficacy, which is in line with a previous meta-analysis which also found that participation in online support groups was associated with improved self-efficacy [17]. For treatment adherence, half of the studies reported improvements in medication adherence, and the other half reported no effect. However, as most of these were cross-sectional it is not possible to know if new behaviours were sustained in the long-term or if they resulted in subsequent changes to other health outcomes. Furthermore, although the qualitative studies were mostly positive, quantitative studies suggested no differences in behaviour or better outcomes for those not in an online support group. One explanation for this difference between quantitative and qualitative studies may be the outcome measures, as the types of behaviour measured in standardised scales (e.g., Health-Promoting Lifestyle Profile II) may not reflect behaviours relevant to improving particular chronic conditions (e.g., eat 2-3 servings of milk, yoghurt or cheese each day) [123], whereas qualitative studies allow participants to discuss any behaviour relevant to improving their condition (e.g., purchasing an assistive device).

Adjustment

The effect of online support groups on adjustment was mostly positive. Indeed, positive findings were reported for illness acceptance (e.g., positive re-framing and meaning making), feeling less alone, feeling understood, feeling reassured, identity (e.g., developing a new identity and rediscovering sense of self), stigma, and self-esteem. These studies were mostly naturalistic, which provides an insight into the effects of online support groups used by participants in their day-to-day lives, but they cannot establish cause and effect, nor did they analyse behaviour over time. However, experiences of the different types of cognitive changes varied, which suggests that the extent to which online support groups help group members to adjust to their condition may depend on a myriad of factors that are beyond the scope of this review, such as baseline scores and offline support. Furthermore, most studies showed either an improvement or no change in coping and optimism. However, one RCT found that positive coping results varied depending on time-point of measurement (i.e., during vs post-intervention) and on the scale used [49].

Mechanisms

The underlying mechanisms most explored within the studies in this review can be broadly grouped as giving and receiving support, expressed content, exchanging experiences, and comparison.

Support:

The findings suggest that whilst informational support may aid cognitive and behavioural changes, which in turn, may influence physical health, emotional support may improve illness acceptance and mental health. Indeed, informational support was positively associated with cognitive and behavioural outcomes, particularly related to adaptive coping, receiving treatment, including decision-making, confidence, self-efficacy, empowerment, motivation and general behaviour change (e.g., changes routine or requesting different medication). In turn, these positive changes made participants feel healthier and worry less. On the other hand, qualitative studies suggested that receiving emotional support can improve wellbeing, reduce anxiety, and make individuals feel less alone, particularly in the absence of other care. This may particularly be the case for chronic conditions with increased ambiguity, such as chronic fatigue syndrome, whereby accessing formal support is more difficult, for example due to difficulties in diagnoses [124]. As previous research suggests that the focus on informational or emotional support in online support groups may differ across health conditions [125], and across different online support groups within the same health conditions [118], it may be important for individuals to be aware of all available groups, and acknowledge the health outcome they need assistance with, to identify the most suitable type of support.

There may also be differential health benefits to giving and receiving emotional support. For example, giving emotional support was positively associated with positive reframing, but receiving such support was not, whereas depression was not associated with giving emotional support but receiving empathy was associated with less depression. Although it is not possible to determine cause and effect from cross-sectional studies, these findings may suggest that group members offer emotional support after accepting the illness and that receiving emotional support may be important in navigating depression. A previous review of mechanisms of peer support reported that helping others enabled peers to find meaning in their own chronic conditioning, thus highlighting the relationship between helping others and coming to terms with a chronic condition [115]. However, when measuring helping others more broadly two studies in the present review did not find associations between helping others and illness acceptance or self-esteem, which suggests that it may be important to differentiate between providing informational and providing emotional support.

Expressed content:

Expressed content, including religious expression, insightful and emotional disclosure, and pronoun use (relational vs first-person), was mostly measured through content analysis of posts made on online support groups and survey measures for outcome measures. Due to the limited number of studies for each type of expression it is difficult to draw conclusions, but the studies do suggest that these factors may influence broad mental health and self-efficacy. The findings for religious expression suggest that it predicted reduced negative emotions and self-efficacy, but did not influence emotional wellbeing, positive re-framing, social wellbeing, or depression. The relationship between religious expression and physical health is unclear, as one study found that it predicted functional wellbeing, but another found no relationship. One explanation may be due to the type of online support group as one study was part of a broader RCT [39] whereas the other was a cross-sectional study using existing peer-led groups [46]. Moreover, insightful disclosure (i.e., words representing learning or understanding) was associated with some improved functional and emotional wellbeing and improved self-efficacy, whilst emotional disclosure aided illness acceptance as it helped people come to terms with their conditions. This echoes the support mechanisms whereby emotional support may facilitate illness acceptance whilst informational support facilitates self-efficacy and physical functioning. Furthermore, a higher percentage of first pronoun words predicted higher levels of negative emotions, but there was no impact of relational pronouns (e.g., we, us, our) [41]. However, it is important to note that use of relational pronouns did not predict reduced negative emotions. This study is also cross-sectional, so it may be the case that people struggling with their mental health may need to speak of their personal experiences more to receive support from other members.

Exchanging experiences:

The findings suggest that sharing experiences can have a positive effect on general behaviour change and treatment-decision making but may negatively influence some mental health outcomes. By learning of others' experiences, group members can learn from them and feel more confident to change their behaviour. It also allows group members to assess the benefits and side-effects of treatments, alleviate fear around certain treatments and feel more in control. This is in line with a previous review which found improvements in self-management from reading about others' experiences [16]. Exchanging experiences may also increase optimism and hope as participants see how others manage the condition, particularly when reading recovery stories. However, these findings are mostly from qualitative studies, with quantitative studies reporting no effects on optimism and hope or treatment confidence. Furthermore, reading of others' shared experience may also negatively influence broad mental health, anxiety and distress. This is particularly the case if posts are negatively oriented or include worse symptoms or experiences, as readers feel upset or guilty. Therefore, it is important for group members to be aware of these potential negative outcomes when choosing which posts to engage with.

Social Comparison:

Comparing to other group members can promote illness acceptance, optimism and make group members feel less alone. Indeed, comparison to other group members facilitated illness acceptance, including normalising the condition, viewing the condition more positively, and meaning making, and increased optimism and hope as their experience was put into 'proportion'. [82][102]. Studies also suggested that comparison made people feel less alone as they realised that their problems were not unique and they were not alone in dealing with the illness [20][71], nor were they 'crazy' [20]. This provides evidence for social comparison theory, which suggests that in order to evaluate oneself, people often compare to others [126]. This is typically done under uncertainty [126], which is often the case for people experiencing a chronic condition, particularly novel or under-researched conditions such as Long Covid. However, it is important to note that if group members undertake pessimistic comparison strategies (e.g., feeling frustrated at others doing better or anxious of people being worse) then they may have a negative effect on mental health, so it is important that individuals draw inspiration from other group members rather than dwelling on negative aspects of comparison.

Usage and group characteristics

In addition to the underlying mechanisms, health outcomes may also differ depending on usage (e.g., level of engagement, intensity of use and membership duration) and group characteristics (e.g., moderated vs unmoderated and synchronous vs asynchronous). For many health outcomes, the included studies suggest that they are not impacted by the extent, or intensity, to which group members engage. For some outcomes (e.g., feeling less alone and more understood, enhanced social wellbeing and general behaviour change) the findings suggest that it may be beneficial to engage more actively and frequently. However as most of the studies were cross-sectional, it may be that individuals who already have these positive outcomes engage more with the groups. Also, a limited number of studies explored each outcome and characteristic, often with conflicting findings or different definitions and measurements, which makes it difficult to identify the optimal level of interaction with online support groups.

The role of group type was assessed in a small number of studies, so it is not possible to identify the optimal group structure. Synchronous groups were explored in ten experimental studies, which mostly reported no effects on health outcomes. However, it is not possible to establish whether this was due to the design of the support group or the experimental nature of the study. The remaining studies either explored asynchronous groups or did not report details on the groups. Only two papers (with the same participants) compared unmoderated and moderated groups and found health improvements in both groups. This is in line with a study which found no differences in depressive symptoms between participants allocated to a moderated or peer-led online support group [34]. However, it is not possible to generalise to other moderated groups, as groups can be moderated by researchers, peers or psychologists and can vary in activity from approving posts to actively guiding the conversation.

Limitations

Some limitations of the studies included and of the review itself should be acknowledged when considering the findings. First, most studies were cross-sectional, therefore it is not possible to identify a causal relationship between use of the online support groups and health and wellbeing. Also, whilst many naturalistic studies described the activity level and size of the groups used for recruitment, it is possible that members used multiple online support groups and that group values or content varied, with each group potentially influencing health and wellbeing differently [115]. Many of the studies also included mostly White and married participants, so these findings may not extrapolate to other demographics. This is important as chronic conditions may be more prevalent in deprived groups [127] and there may be different support needs between married and single participants [128].

When considering the review itself, although the authors sought to be as rigorous as possible in designing the search strategy, it is possible that some studies were not identified within the search. Second, although the first author worked thoroughly to apply to the inclusion and exclusion criteria systematically and objectively, it is likely that some level of subjectivity may have affected the screening process. Additionally, there are many offline factors, such as offline support and symptom severity, that may also underly any effects of online support groups on health and wellbeing [108], which were beyond the scope of this review. Finally, most studies were conducted in populations with cancer, which may skew the findings as there are considerable differences between the available formal support (e.g., diagnostic difficulties, lack of effective treatment, and dismissals from healthcare professionals [129]) for cancer patients compared to contested conditions with increased uncertainty such as chronic fatigue syndrome or Long Covid.

Implications and future research

Living with a chronic condition can have various consequences on health and wellbeing, with many turning to online support groups to support these health outcomes. This review can be used by clinicians, online support group administrators and those with a chronic condition to optimise their experience of using online support groups. The following recommendations can be made based on this review: i) As many health outcomes were not affected by level and intensity of engagement, group members can engage with the groups at their own pace without harming their health; ii) Online support groups may be able to bridge the decline in offline relationships that can occur with the diagnosis of a chronic condition, but it is important to not do this at the expense of offline relationships; iii) If group members are looking to make a behavioural change or find support with treatment decision-making, they may benefit from informational support, but should also conduct their own research or speak to a healthcare professional; iv) If individuals do not know anyone else with their condition, seeking emotional support from an online support group may help them feel less alone and more understood; v) Learning of others' experiences, particularly those who are successfully managing the condition, can support illness acceptance and feeling 'normal', particularly for conditions with increased uncertainty; vi) Individuals should be aware that online support groups have the potential to increase distress, anxiety and negative emotions, so it is important that they avoid negatively oriented posts and negative comparison strategies and take a break from groups if their mental health begins to decline.

There is scope for further research to be conducted, particularly regarding the effects of different group types. Moderation took various forms in the included studies so future research should compare these approaches to identify the optimal level of moderation, as well as the most suitable type of moderator (e.g., peer or healthcare professional). Studies conducted after this review also highlight how existing online support groups can take many forms, including local and international [118]. This is briefly touched on in one study, where participants discuss the advantages of a local group, so this is also an area to be explored in the future. Similarly, there were limited, and sometimes conflicting, findings for usage characteristics so it is important for studies to formally define active and passive users and further explore how this influences health outcomes. Furthermore, many of the mechanisms were explored in a small number of studies so future research should continue to explore these to draw more formal conclusions, particularly regarding the differential impact of offering and seeking support. As most studies included in this review were cross-sectional, future research should also consider a longitudinal design to see if such effects were sustained over time and to identify possible spill-over effects, such as the effect of behavioural changes on physical health. More research is also needed on chronic conditions such as cystic fibrosis, endometriosis and ME/CFS as they were underrepresented in the current review.

Conclusions

This review synthesised findings on 28 health outcomes for people with chronic conditions and suggests that online support groups broadly have a positive effect on social wellbeing (e.g., feeling connected to others and less isolated), health-related behaviours (e.g., adopting positive behaviours)), and adjustment (e.g., illness acceptance, identity, and feeling understood). For physical health, the findings suggest a positive influence on pain but a mixed result for symptoms and functioning. In terms of mental health, online support groups may have a positive or negative impact on outcomes, such as anxiety and emotional or psychological wellbeing, and this will depend on group content and comparison strategies.

Category	Health and Wellbeing Outcome	Summary of findings
Physical health	Symptoms and functioning	**Summary**: there is mixed evidence for the impact of online support groups on symptoms and functioning. While some studies report improvements, others found no change. **Mechanisms**: informational support and sharing experiences may positively influence symptoms and functioning.
	Pain	**Summary**: the evidence from cross-sectional and experimental studies suggests that online support groups may be able to help with group members' pain.
Mental health	Broad mental health	**Summary:** the effects of online support groups on mental health is mixed. While many studies report improvements in mental health, more report either no or negative effects. **Mechanisms:** influencing factors for positive wellbeing include receiving emotional support, having an outlet for feelings, sharing experiences, helping others and through improved social wellbeing. Influencing factors for negative wellbeing include negative social comparison, information overload, reading emotional information, unsuitable groups and lack of replies.
	Depression	**Summary:** no study reported a negative effect of online support groups on depression, but it is unclear whether online support groups have a positive or neutral effect on depression. **Mechanisms:** receiving emotional support may positively influence depression scores, whilst negative social comparison can negatively influence it. Some studies also highlight the complexity of factors such as emotional expression.
	Anxiety	**Summary:** there was mixed evidence regarding the impact of online support groups on anxiety with studies reporting, positive, negative and no effects.

Category	Health and Wellbeing Outcome	Summary of findings
		Mechanisms: anxiety can be mitigated through emotional and informational support which helps manage unfamiliar symptoms but can be heightened through reading horror stories.
	Distress	**Summary:** findings are mixed with studies reporting positive, negative and no effects on distress. **Mechanisms:** distress may increase when posts are skewed to be sad or negative.
Quality of life	Quality of life	**Summary:** no studies reported a negative effect of online support groups but the evidence is mixed relating to a positive or neutral effect on quality of life. **Mechanisms:** emotional support may enhance quality of life.
Social wellbeing	Broad social wellbeing	**Summary:** one study looked at social wellbeing more broadly and found that 52% of participants reported improvements. **Mechanisms:** factors associated with enhanced social wellbeing include emotional support.
	Feelings of belonging	**Summary:** evidence, from mostly qualitative data, suggests that group members feel a sense of belonging to the online support group. However, when it is hard to join in conversations or there is no response to message one study found that it can lead to people feeling like an outsider and sometimes leaving the group. **Mechanisms:** being part of a group with people living with the same condition, which helps people feel part of a group, have discussions and develop a shared identity.
	Connections and friendship	**Summary:** many members of online support groups form new friendships and social connections, but this is not the case for everyone and can be difficult to do. **Mechanisms:** positive association between perceived credibility and competence of discussion on online communities and social capital

Category	Health and Wellbeing Outcome	Summary of findings
		within online groups.
	Loneliness and isolation	**Summary:** the evidence on isolation and loneliness outcomes is mostly positive but there is also the potential for feelings of isolation to resurface when logging off from the groups. **Mechanisms:** being an active member and making new friends positively influences loneliness and isolation.
Health-related behaviour and decision-making	Behaviour change	**Summary:** the evidence suggests that online support groups can encourage positive behaviour change such as engaging in preventative behaviours, changing risky behaviours, purchasing assistive devices and trying other people's dietary habits. **Mechanisms:** behaviour change may be facilitated by reading others' experiences and through the shared advice and the perceived credibility of such discussions.
	Motivation	**Summary:** studies suggest that participation in online support groups may increase motivation to make a positive lifestyle change or keep up with self-management. **Mechanisms:** motivation may be influenced by sharing experiences, seeing success stories, receiving non-judgmental advice.
	Treatment adherence	**Summary:** there is mixed evidence regarding the role of online support groups in facilitating treatment adherence with half of the studies reporting an improvement and half reporting no effects. **Mechanisms:** treatment adherence may be influenced by sharing experiences and discussing treatments and medication with others.
	Treatment decision-making	**Summary:** findings suggests that online support groups may influence treatment decision making (e.g., changing initial treatment and assessing benefits and side-effects), although there is large variability in the proportion of participants reporting this.

Category	Health and Wellbeing Outcome	Summary of findings
		Mechanisms: sharing experiences and information and receiving emotional support may influence treatment-decision making. Intensity of usage may also influence treatment decision making (i.e., being a daily user) but this depends on the measurement.
	Self-efficacy	**Summary**: most studies reported positive effects of online support groups on self-efficacy, although there is large variation in the proportion of participants reporting improvements. No studies reported a decrease in self-efficacy, although some studies reported nor changes over time, nor any added benefits compared to educational controls. **Mechanisms**: receiving informational and emotional support, helping others, religious expression and using positive emotion words has been found to be associated with self-efficacy.
	Empowerment	**Summary:** most studies report improvements in empowerment. **Mechanisms:** feeling empowered may be related to the information shared and being part of a collective voice as it enables group members to feel in control.
Adjustment	Illness acceptance	**Summary:** findings suggest that online support groups may help group members accept their illness and have a positive appraisal of their condition. **Mechanisms:** illness acceptance may be influenced by social support, comparison with others and findings others in a similar situation.
	Feeling less alone	**Summary:** the evidence suggests that group members may feel less alone by being part of an online support group. **Mechanisms:** participants reported feeling less alone after seeing others having similar feelings, emotions and experiences and receiving emotional support.
	Feeling understood	**Summary:** the evidence suggests that online support groups may help group members feel understood.

Category	Health and Wellbeing Outcome	Summary of findings
		Mechanisms: participants felt understood because of the shared experience and such feelings were associated with perceived credibility of discussions.
	Feeling reassured	**Summary:** evidence suggests that online support groups may reassure group members. **Mechanisms:** reassurance has been reported to be influenced by seeing other people in the same position and seeing others manage their condition successfully.
	Optimism and hope	**Summary:** the evidence, from mostly qualitative studies, suggests that members of an online support group feel optimistic and hopeful towards the future after using a group. **Mechanisms:** optimism and hope is influenced by reading success stories, positive comparison, receiving emotional support and finding positive meaning.
	Self-esteem	**Summary:** most studies suggest that online support groups may enhance self-esteem **Mechanisms:** studies suggest that self-esteem is associated with emotional and social support.
	Uncertainty	**Summary:** only two studies reported changes in uncertainty with both reporting conflicting findings. As a result, it is difficult to suggest whether online support groups can reduce uncertainty of group members. **Mechanisms:** only one study explored potential mechanisms and found that informational support was not related to uncertainty.
	Post-traumatic growth	**Summary:** the evidence suggests no change in post-traumatic growth.
	Identity	**Summary:** evidence from eight cross-sectional studies suggests that participating in online support groups may help group members

Category	Health and Wellbeing Outcome	Summary of findings
		personal and group identities as they rediscover their sense of self, return to a lost version of themselves, feel normal again and connect with others. **Mechanisms:** sharing humour, being part of a majority and illness acceptance may facilitate changes in identity.
	Stigma	**Summary:** stigma was only measured in two studies with conflicting findings. **Mechanisms:** a sense of understanding and being able to share experiences reduces the concern of stigma
	Coping	**Summary:** the findings are mixed regarding the effect of online support groups on coping. While many studies report a positive influence, some report either a negative or no effect on coping. **Mechanisms:** Connecting with others who understanding, being accepted and receiving social support may influence coping.

Table 5. Summary of findings

Statements and Declarations

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