Psychological Aspects of Holistic Approaches to Healthcare: The Roles of Co-Production and ACT for Self-Management in the care of Long-Term Conditions

Rachel L. Russell

Doctorate in Clinical Psychology
University of East Anglia
Faculty of Medicine and Health Sciences

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Abstract

Introduction

It has been argued that care for people with long-term conditions (PLTC) needs to move towards holistic models. Co-production involves service users, professionals, relatives, and communities in the design and delivery of services and has been associated with increased service effectiveness, and improved psychological outcomes. Self-management interventions for PLTC have moved from patient education to psychological interventions. Acceptance and Commitment Therapy (ACT) is a transdiagnostic approach that may have utility for PLTC.

Method

A systematic review was conducted investigating the utilisation and evaluation of co-production in health and social care services. A systematic review and meta-analysis was conducted investigating the efficacy of ACT for holistic self-management of LTCs, in terms of physical, psychological, and social outcomes in line with a holistic definition of self-management. The reviews were both conducted in line with PRISMA reporting standards and the review protocols were registered with PROSPERO.

Results

The systematic review found 23 reports relating to 11 studies, that were almost exclusively within a mental health context. A range of facilitators and barriers to co-production were identified. Outcome measurement, including psychological outcomes, focused on the output of co-production rather than the process. The systematic review and meta-analysis found 27 reports relating to 21 RCTs of ACT for LTCs (n = 1173). Preliminary evidence was found for the efficacy of ACT for a range of psychological outcomes, with small to moderate effect sizes. Preliminary evidence was found for the efficacy of ACT for holistic self-management for rheumatological conditions, with moderate to large effect sizes. However, issues related to risk of bias and study quality across both reviews, limit possible conclusions.

Conclusions

Both reviews helped to establish the current evidence base in their respective areas. However, there is insufficient evidence to draw firm conclusions and higher quality research is needed.

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CHAPTER ONE

Introduction to the Thesis Portfolio

Introduction

Importance of Improving Care for People with Long-Term Conditions

Improving care for people with long-term conditions (PLTC) has been identified as one of the most prominent challenges facing the NHS (Coulter et al., 2013). Long-term conditions can be defined as "…a condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies" (DoH, 2012, pp.3). It has been argued that care needs to move away from reactive models, to holistic and person-centred models of care for PLTC (Coulter et al., 2013). A substantial number of people with LTCs have two or more conditions, known as co- or multi-morbidity respectively (Goodwin et al., 2010). In 2012, the Department of Health (DoH) predicted that whilst the number of people living with one LTC would remain relatively stable over the following 10 years; the level of multi-morbidity would rise (DoH, 2012). More recent statistics examining trends in acute emergency admissions found that over 60% of people admitted had at least one LTC, and one in three admissions had five or more health conditions (Deeny et al., 2018; Steventon et al., 2018).

In addition to being a prominent challenge for the NHS, LTCs also have a significant human impact due to their impact on quality of life (QoL; Coulter et al., 2013; Lempp et al., 2009; Mujica-Mota et al., 2015; Peters et al., 2019). Evidence suggests this may be particularly so where multimorbidity is present (Mujica-Mota et al., 2015; Peters et al., 2019). Lower health-related quality of life (HRQoL) has been associated with outcomes including decreased self-efficacy (belief in one's ability to exercise control over behaviour and to self-regulate; Bandura, 1997) and higher disease burden for PLTC (Peters et al., 2019). Greater disparity has been found between physical health aspects of HRQoL as compared to mental health aspects in a comparison of individuals with rheumatoid arthritis and schizophrenia, highlighting the reciprocal relationship between health domains (Lempp et al., 2009). There is heterogeneity in QoL for PLTC, which suggests that QoL is not wholly influenced by factors such as disease severity but that much of the variance may instead be explained by psychological factors (Graham et al., 2011, 2013, 2014). The findings of research into QoL for PLTC highlight the importance of taking a holistic approach to health that acknowledges the reciprocal relationship between health domains (physical, psychological, and social domains). In addition, its contribution to the significance of the human impact of LTCs serves to reinforce the importance of improving care for PLTC.

A Dynamic Biopsychosocial Model of Health

The biopsychosocial model (Engel, 1980), developed as an alternative to the medical model of care, concerns the biological, psychological, and social factors that impact health. Lehman et al. (2017) expanded this by integrating it with other systems models, including Bronfenbrenner's (1977) ecological model, to form a dynamic biopsychosocial model of health. The concept of centrality is key to Lehman's (2017) model, which acknowledges that these factors are not static but dynamic in their interplay over time. This interplay between physical, psychological, and social aspects of health for PLTC is well documented in research (DiMatteo et al., 2000; NHS England, 2016; Stanton et al., 2007). Whilst the relationship is likely to be complex, people with chronic physical health problems appear more likely to experience mental health difficulties, which in turn are associated with poorer physical health outcomes (Cooke et al., 2007; DiMatteo et al., 2000; Stanton et al., 2007).

Regarding psychological factors, important interactions have been found with physical aspects of health for PLTC (DiMatteo et al., 2000; Naylor et al., 2012; NHS England, 2016; Stanton et al., 2007). Cooke et al., (2007) found that people with chronic physical health problems may be more likely to experience mental health difficulties and there may be a cumulative effect, with co- and multi-morbidity associated with increasing likelihood of mental health difficulties. Having co-morbid mental health difficulties can lead to poorer physical health outcomes for PLTC; for example, it has been associated with reduced quality of life (QoL), non-adherence to medical treatment, the experience of greater complications, and having a negative impact of self-management capability, as well as increasing healthcare costs due to greater healthcare utilisation (DiMatteo et al., 2000; Naylor et al., 2012; Stanton et al., 2007). PLTC may be as much as two to three times more likely to experience mental health difficulties, with this association being evidenced in a wide range of LTCs, but particularly evident for diabetes, cardiovascular diseases, musculoskeletal conditions, and chronic obstructive pulmonary disease (COPD; Naylor et al., 2012). As indicated by Lehman et al., (2017) relationships between health domains are likely to be complex, which is supported by Cooke et al., (2007), who found that mental health difficulties both precede and follow the onset of physical health problems because of their impact. This highlights the importance of considering the interplay between physical and mental health for PLTC.

The psychological process of adjustment to living with a LTC is also an important consideration. Significant heterogeneity has been found in adjustment not only between people but also over time (Hoyt & Stanton, 2012; Stanton et al., 2007). Danoff-Burg & Revenson, (2005) found that over 70 percent of respondents with rheumatoid arthritis (RA) reported experiencing interpersonal benefits, which were predictive of lower levels of disability at 12-month follow-up. Hoyt & Stanton, (2012) argued there are both positive and negative aspects of adjustment to LTCs, such as being able to experience positive emotions in the face of difficulties, highlighting the importance of outcomes measuring both aspects. Several factors, such as interpersonal relationships, cognitive appraisals, and culture, have been found to influence adjustment to LTCs across multiple health domains, and have been conceptualised as operating at individual, community, and societal levels (Putnam et al., 2003; Stanton et al., 2007).

The consideration of social factors at multiple systemic levels was also key to Lehman's (2017) dynamic biopsychosocial model of health. At a more individual systemic level, social networks have been found to be an integral part of the management of LTCs, both in respect of supporting self-management and reducing costs associated with healthcare utilisation (Reeves et al., 2014; Vassilev et al., 2011). Supportive relationships have been found to be associated with positive psychological adjustment to LTCs and conversely, social isolation has been found to be a risk factor in this area (Stanton et al., 2007). Living with a LTC can be associated with disability, and it has been found that people with disabilities are at increased likelihood of experiencing social isolation and loneliness (Macdonald et al., 2018), which is significant given that this is a risk factor for adjustment for PLTC (Stanton et al., 2007). In addition to the psychological process of adjustment, peer support has also been identified as an important part of supported self-management interventions for PLTC (Deeny et al., 2018) and research has highlighted the importance of situating self-management within a relational and social context (Morris et al., 2015).

The relationship between wider social factors and health is also an important consideration (Marmot et al., 2010). For example, socio-economic status (SES) influences health through both direct and indirect means (Stanton et al., 2007). Stanton et al., (2007) conceptualised SES as a predictor of psychological adjustment, but also acknowledged its complex relationship with other health domains, for example, the impact that ability to work could have on SES. Socio-economic deprivation may also play a role in the relationship between multi-morbidity and psychological distress (Naylor et al., 2012). This may be due to multi-morbidity being more prevalent within deprived areas, but also due to multi-morbidity having a greater impact on psychological distress in the context of deprivation (Naylor et al., 2012). The inverse care law states that there tends to be an inverse relationship between the availability of and need for healthcare (Mercer & Watt, 2007). A study by Mercer & Watt,

(2007) found that deprivation was associated with increased LTCs, multi-morbidity, and psychological difficulties. Whilst deprivation was associated with greater complexity and increased difficulties, they found that accessing care took longer and the length of clinical contacts was shorter (Mercer & Watt, 2007).

Holistic Approaches to Care for PLTC

Research and healthcare policy has called for a person-centred and integrated, holistic approach to care for PLTC, which is person-centred and integrated (Coulter et al., 2013; DoH, 2005b, 2005c; Entwistle & Cribb, 2013; Goodwin et al., 2010; NHS England, 2016). The Chronic Care Model (CCM) developed by Wagner (1998), advocated the need for proactive, integrated care for PLTC, highlighting that health systems need to change to improve health outcomes for PLTC and that the needs of PLTC could not be met by a reactive health system organised around the provision of acute care (Bodenheimer et al., 2002; Coulter et al., 2013; Wagner, 1998). The House of Care model (Coulter et al., 2013), argues for a holistic, integrated, whole-systems approach to care for PLTC and was developed to aid those in primary care utilise the CCM. The House of Care model highlights the interdependence of the different aspects of the system including the role of organisational processes and responsive commissioning, engaged service users and healthcare professionals committed to working in partnership, and person-centred care in collaboration between service users and professionals (Coulter et al., 2013). In addition, the House of Care model and the CCM highlight the importance of supporting PLTC to have the knowledge, confidence, and skills to self-manage their condition(s) (Coulter et al., 2013; Wagner, 1998).

The importance of taking a holistic approach to health is also reflected in the biopsychosocial model and is an important research as well as clinical consideration (Lehman et al., 2017; Suls & Rothman, 2004). One of the criticisms of health psychology research is the failure to explicitly account for the complexity of biopsychosocial factors that affect health, particularly in relation to social factors (Suls & Rothman, 2004). Research examining the number of papers published in the 'Health Psychology' journal over a year from November 2001 found that only 26% papers included measures from all domains of the biopsychosocial model, including wider societal factors (Suls & Rothman, 2004). Suls and Rothman (2004) argued that to understand the complex relationships between these factors it is important to include a diverse range of biopsychosocial outcomes.

The Co-Production of Care for PLTC

Co-production has long been championed by movements advocating for greater citizen participation. Arnstein (1969) argued a central tenet of citizen participation entails redistribution of power and highlighted the role of structural barriers such as racism, paternalism and poverty in impeding this process (Arnstein, 1969). Citizen participation was seen as a driver for social reform and Arnstein (1969) outlined the 'ladder' of participation, with eight typologies from manipulation to citizen control, each involving differing degrees of participation with the critical difference being the power to effect change.

Early writings on the concept of co-production describe the active role those typically viewed as passive recipients of services can have in their production (Ostrom, 1996). Co-production has been argued to have utility in developing countries and in addressing power imbalances for marginalised groups of people. Conversely, it has been argued that whilst it may lead to service improvements, it may not lead to change of wider structural issues such as those associated with austerity (Farr, 2018; Fisher et. al, 2018; Ostrom, 1996). The importance of imbalances in power and barriers to participation, being identified and addressed at both individual and wider systemic levels, has been highlighted within co-production literature as well as literature related to community change more broadly (Evans & Loomis, 2009; Roper et al., 2018).

Whilst there is no single agreed definition, Boyle and Harris (2009) outlined true co-production occurs when the knowledge of professionals and service users, as well as other stakeholders, is utilised in the design and delivery of services. As such, true co-production requires a relational shift to balance the distribution of power between stakeholders, recognising and valuing the expertise of those who use services, their families and communities, rather than viewing them as passive recipients of care (Bovaird, 2007; Boyle and Harris, 2009; Needham & Carr, 2009).

There have been shifts in both health and social care sectors towards the utilisation of co-production in the commissioning, design and delivery of services, and of co-producing individual health outcomes for those who use services (Coulter et al., 2013; National Collaborating Centre for Mental Health, 2019; Needham & Carr, 2009; NHS England, 2016, 2019; Slay & Penny, 2014). Examples of this are found in the key recommendations of the NHS Five Year Forward View for Mental Health (NHS England, 2016) regarding the co-produced commissioning of services, and NHS England commissioned the National Collaborating Centre for Mental Health (NCCMH) to develop evidence-based approaches to co-production in the commissioning of mental health services (NCCMH, 2019). Co-production has also been promoted at the level of individualised care, being central in the Kings Fund’s ‘House of Care’ (Coulter et al., 2013), a whole-systems model of care for people with long-term conditions. Slay & Penny, (2014) suggested that co-production can play a role in ensuring services meet the needs of the populations they work with, hence increasing the effectiveness and reach of services. The active participation of communities has also been associated with the development of more holistic approaches, due to their understanding and insight into the complexities and intersections of the issues they face (World Health Organization; WHO, 2002).

The benefits of co-production have been suggested to span physical and mental health, including wellbeing, prevention, social connectedness, and the encouragement of self-help (Boyle & Harris, 2009; NCCMH, 2019). The NCCMH (2019) also found evidence that there were benefits for those involved in the process co-production itself. Slay & Penny (2014), indicated that the co-production of public services has the potential to meet the innate psychological needs of competence, autonomy, and relatedness as postulated by Self-Determination Theory (SDT), which has in turn been linked with wellbeing (Patrick & Williams, 2012; Ryan & Deci, 2000; Slay & Penny, 2014).

Whilst there is a growing body of literature for co-production, one of the main criticisms of the evidence is that much of the research focuses on defining typologies of co-production rather than evaluating outcomes (Clarke et al., 2017; NCCMH, 2019; Voorberg et al., 2015). However, it appears that co-production has the potential to lead to improved outcomes and that it may also have utility for PLTC given its links with SDT, and the encouragement of self-help (Boyle & Harris, 2009; NCCMH, 2019; Patrick & Williams, 2012; Ryan & Deci, 2000; Slay & Penny, 2014). The potential utility of co-production for PLTC is also supported by the relationship between wider social factors and health and its potential to address power imbalances for marginalised communities, and the association of participation with the development of more holistic approaches to care (Farr, 2018; Marmot et al., 2010; Ostrom, 1996; WHO, 2002).

Self-Management of LTCs

Given the known interplay between physical, psychological, and social aspects of health for PLTC, and the emphasis within guidance and policy on providing holistic, integrated care for PLTC, it follows for the definition of self-management to encompass more than solely the management of disease. Whilst there are differing definitions of self-management, this paper adopts the following definition of self-management: "The tasks that individuals must undertake to live well with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management, and emotional management of their conditions." (Adams et al., 2004, pp.57).

The role of self-management in the care of PLTC is well-documented both in research and guidance (Deeny et al., 2018; DoH, 2005b; NHS England & NHS Improvement, 2020). PLTC are reported to spend less than one percent of their time in contact with healthcare professionals and are therefore mostly managing their health outside of the context of interactions with healthcare professionals (Deeny et al., 2018). Corbin & Strauss, (1985), identified three tasks associated with self-management of LTCs, which were: illness work, everyday life work, and biography. Illness work related to tasks associated with medical management, everyday life work related to tasks associated with everyday living and role management, and biography related to psychological factors including the emotional sequelae of living with a LTC (Corbin & Strauss, 1985; Lorig & Holman, 2003). These tasks were not seen as being independent processes, but instead that they are inter-related processes that are negotiated in the process of self-management (Corbin & Strauss, 1985). The DoH (2005a) definition of self-care, also accounts for physical, psychological, and social needs.

Research by the Health Foundation (Deeny et al., 2018) investigating levels of patient activation (having the confidence, knowledge, and skills to self-manage their condition) in over 9,000 adults, found that those with higher levels of activation had fewer acute emergency admissions, fewer visits to accident and emergency departments (A&E), shorter length of stay during elective admissions and were less likely to miss scheduled healthcare appointments. Hibbard and Greene, (2013) also found evidence of patient activation being associated with improved health outcomes and experiences of care, and that patient activation is amenable to intervention. In a longitudinal study of PLTC, patient activation at baseline was associated with subsequent medication adherence, self-management knowledge and health behaviours at four year later follow up (Hibbard et al., 2015). McBain et al., (2015) indicated that aspects of self-management may lead to reduced costs within secondary care but increased pressures elsewhere however, the findings of Deeny et al., (2018) are supported by other research which has found increased self-management capability to be associated with reduced healthcare utilisation across primary and secondary care (Barker et al., 2018; Hibbard et al., 2015).

A systematic review of chronic disease management interventions in primary care based on the CCM, found evidence that self-management support was associated with positive outcomes for PLTC, particularly for hypertension and diabetes (Reynolds et al., 2018). Research looking into the moderating effects of depression and multi-morbidity on the efficacy of the Chronic Disease Self-Management Programme (CDSMP), indicated that whilst co-existing physical and mental health difficulties were associated with increased illness burden, people with physical multi-morbidity and depression appeared to benefit most from the CDSMP (Harrison et al., 2012). Evidence has also suggested that self-management support led by Experts by Experience can be efficacious in improving self-efficacy among PLTC and cost-effective (Kennedy et al., 2007). Reviews of self-management interventions for PLTC have found evidence indicating their utility; however, there are challenges in evaluating efficacy across interventions due to the theoretical underpinnings and components of self-management interventions not always being made explicit (Barlow et al., 2002; Newman et al., 2004).

Theoretical Approaches

There have been varying theoretical approaches to interventions for self-management for PLTC with regards to their developmental influences (Newman et al., 2004). More traditional approaches relied upon patient education and the provision of information; however, it has been found that interventions relying upon this approach are less effective at improving health outcomes for PLTC than more modern self-management approaches (Bodenheimer et al., 2002; Coates & Boore, 1996; Gibson et al., 2002; Newman et al., 2004; Wagner et al., 1999). Whilst education is an important part of self-management, a criticism of purely educational interventions is that they do not address the barriers that individuals may face in the application of the information they have been given (Mulligan et al., 2009). It follows, particularly when considering the role of psychological factors in adjustment and QoL for PLTC (Graham et al., 2011, 2013, 2014; Stanton et al., 2007), that psychological models have also influenced the development of self-management interventions (Newman et al., 2004). Such models have included social cognitive theory (SCT; Bandura, 1986), which highlights the role of self-efficacy, expectations, and goals in self-management behaviour (Serlachius & Sutton, 2009). Other psychological models include the transtheoretical model (TTM; Prochaska et al., 2008; Prochaska & Velicer, 1997), which posits discrete stages of change from pre-action through to maintenance and long-term change, and the stress coping model (Lazarus & Folkman, 1984), which highlights the role of cognitive appraisals and coping in stress.

Psychological models of self-management postulate the mechanisms through which interventions should aim to promote change. For example, the TTM aims to align interventions to an individual's stage of change and includes ten processes of change, such as self-efficacy and decisional balance. Interventions derived from SCT aim to increase self-efficacy to improve self-management. Another theory that has lent itself to understanding self-management is self-determination theory (SDT), which posits that people have psychological needs for autonomy, competence, and relatedness (Ryan et al., 2008). In the context of health behaviour, it has been suggested that supporting these core psychological needs is associated with increased engagement in treatment and maintenance of outcomes (Ryan et al., 2008). Trappes-Lomax, (2016), argued that SDT may have utility in primary care settings due to the complexities associated with co-morbidity potentially impacting on the sustainability of self-efficacy, and the desire of service users for control, knowledge, skills, and respect in managing their condition(s).

Cognitive-Behavioural Approaches

Cognitive-behavioural models such as the common sense, or self-regulation, model (CSM) have also influenced the development of self-management interventions for PLTC (Leventhal et al., 2012), which describes the process via which PLTC come to make sense of and cope with their condition(s) (Serlachius & Sutton, 2009). The use of psychological interventions, such as cognitive-behavioural therapy (CBT) have been shown to be effective in managing aspects of self-management across a variety of LTCs including chronic pain, multiple sclerosis and diabetes (Bernard et al., 2018; Broderick et al., 2016; Hind et al., 2014; Hofmann et al., 2012; Ismail et al., 2004; Mehta et al., 2019; Morley et al., 1999; Winkley et al., 2020) and CBT for depression for adults with LTCs is included in National Institute of Health and Care Excellence (NICE) guidance (NICE, 2009). In addition to improved health outcomes, Moore et al., (2007) found a cognitive behavioural chronic disease management programme (CB-CDMP) for people with refractory angina led to sustained reductions in the costs related to hospital admission. CBT has been suggested to be indicated in the case of LTCs due to the influence of cognitive factors on psychological responses and due to the importance of understanding meanings related to aspects of LTCs (White, 2001). In addition, there is the potential for overlap in the promotion of collaboration in CBT and self-management (White, 2001).

Acceptance and Commitment Therapy

Another development with influences from clinical psychology, is Acceptance and Commitment Therapy (ACT) for PLTC (Graham et al., 2016). One of the core premises of ACT is that pain and suffering are an inevitable part of being human, and that attempts to avoid, control or eliminate painful private experiences (for example, difficult thoughts, feelings or sensations) lead to increased suffering (Harris, 2009; Hayes et al., 2012). Therefore, ACT aims to enable people to live a meaningful life in the presence of pain and suffering and posits that this is achieved by increasing psychological flexibility (Harris, 2009). This is defined as 'the ability to contact the present moment more fully as a conscious human being, and to change or persist in behavior when doing so serves valued ends' (Hayes et al., 2006, pp.7). As such, reduction in distress following ACT is conceptualised as a by-product rather than an aim of therapy (A-Tjak et al., 2015).

There is a growing evidence base for the use of ACT in managing psychological distress, promoting adjustment and self-management behaviours for PLTC (A-Tjak et al., 2015; Dahl, 2009; Dindo et al., 2017; Feliu-Soler et al., 2018; Graham et al., 2015, 2016; Gregg et al., 2007; Thompson & McCracken, 2011). While second wave CBT aims to address or modify maladaptive illness-related beliefs, ACT focuses on developing acceptance and living in accordance with personal values more broadly (Graham et al., 2016). This may have utility for PLTC, as shown by research highlighting the role of acceptance and psychological flexibility in LTCs such as diabetes, muscle disorders, and chronic pain (Feliu-Soler et al., 2018; Graham et al., 2015; Graham et al., 2016; Gregg et al., 2007; Thompson & McCracken, 2011). The LTC chronic pain has sufficient evidence for the National Institute for Health and Care Excellence (NICE) to give guidance to consider ACT for those with chronic primary pain who are aged 16 years and over (NICE, 2021). ACT may also have utility for PLTC as it can be delivered flexibly and as a brief intervention; although it has been noted that further research is needed evaluating cost-effectiveness (Dindo et al., 2017).

ACT may also have utility for LTCs is its transdiagnostic nature, meaning it has the potential to address co-morbid physical and/or mental health difficulties (Brassington et al., 2016; Dindo et al., 2017). This is particularly salient given the evidence showing the rise in levels of co- and multi-morbidity (Deeny et al., 2018; Dindo et al., 2017; Steventon et al., 2018). Brassington et al., (2016) highlighted that there is limited evidence of interventions for PLTC within the context of co-morbidity and that this was also true of the evidence base for ACT for PLTC, which they noted tended to take a transdiagnostic approach to psychological difficulties but not to LTCs. Brassington et al., (2016) evaluated the efficacy of a transdiagnostic ACT group intervention for PLTC and found that it led to improvements in psychological distress, limitations of the LTC and in valued living. The authors noted that further research is needed to explore the potential indications and contra-indications for delivering transdiagnostic approaches within this context (Brassington et al., 2016).

In summary, current evidence suggests that ACT may have utility for PLTCs, as supported by a systematic review by Graham et al., (2016). However, whilst Graham et al., (2016) found that the evidence base indicated that ACT has utility in some areas, that there were few randomised controlled trials (RCTs) and the majority of studies were of low quality, highlighting the need for further research. Öst, (2008; 2014), in a meta-analysis of the efficacy of third wave approaches to psychological therapies in 2008, and later updated for ACT in 2014, also highlighted the need for study quality to improve and identified recommendations for future research to improve this.

Summary

There has been a shift towards the re-organisation of healthcare systems to provide holistic, integrated care for PLTCs in research and guidance, which is line with a dynamic biopsychosocial model of health (Coulter et al., 2013; DoH, 2005b, 2005c; Entwistle & Cribb, 2013; Goodwin et al., 2010; Lehman et al., 2017; NHS England, 2016; Wagner, 1998). Within this the role of self-management, development of self-management interventions, and the potential utility of ACT for PLTC has been discussed (Dahl, 2009; Dindo et al., 2017; Feliu-Soler et al., 2018; Graham et al., 2015, 2016; Gregg et al., 2007; Newman et al., 2004;

Thompson & McCracken, 2011). This shift has been suggested to occur alongside a parallel move away from models of paternalistic care, towards a model of care where the expertise of service users is acknowledged and utilised (Coulter & Ellins, 2009). This can be seen more widely in the co-production of health and social care services with those who access services, their families, and communities (Coulter et al., 2013; Coulter & Ellins, 2009; NCCMH, 2019; Needham & Carr, 2009; NHS England, 2016, 2019; Slay & Penny, 2014).

Aims of Thesis Portfolio

This thesis portfolio aims to conduct a systematic review of the utilisation and evaluation of co-production with health and social care settings. This includes exploring the process of co-production and any identified facilitators and barriers to co-production, as well as establishing how co-production has been evaluated. In addition, given the evidence of a link between co-production and the development of holistic approaches and outcomes including improved wellbeing and mental health (NCCMH, 2019; Ryan & Deci, 2000; WHO, 2002), this review will also establish whether studies of co-production have measured psychological outcomes. Establishing the current landscape of the utilisation and evaluation of co-production across health and social care, may aid clinical psychologists and other health and social care professionals in implementing and evaluating co-production in the future. This will be followed by a systematic review and meta-analysis of the efficacy of ACT for self-management in LTCs in terms of physical, psychological, and social outcomes, consistent with a holistic definition of self-management that aligns itself with recommendations for health psychology research and wider shifts towards the provision of holistic, integrated care for PLTC (Coulter et al., 2013; DoH, 2005b, 2005c; Entwistle & Cribb, 2013; Goodwin et al., 2010; NHS England, 2016; Suls & Rothman, 2004).

CHAPTER TWO

Systematic Review

Prepared for submission to Health and Social Care in the Community

Author guidelines can be found in appendix A

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The Utilisation and Evaluation of Co-Production in Health and Social Care: A Systematic Review of the Literature

Rachel L. Russell[a*], Karolina Kaminska[a], Dr Catherine Ford[a], & Dr Katherine Deane[b]

[a] Department of Clinical Psychology and Psychological Therapies, Faculty of Medicine and Health Sciences, University of East Anglia, Norwich, Norfolk, NR4 7TJ

[b] School of Health Sciences, Faculty of Medicine and Health Sciences, University of East Anglia, Norwich, Norfolk, NR4 7TJ

* Corresponding author: Rachel Russell r.russell@uea.ac.uk

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Declaration of interest: None.

Abstract

Co-production has been associated with improvement of the effectiveness and efficiency of services, and psychological outcomes including wellbeing and self-determination. Aims of the current systematic review were to establish how co-production has been utilised and evaluated within health and social care services, including whether psychological outcomes were measured. Medline, CINAHL, PsycINFO and AMED databases were systemically searched in January 2021, for studies of co-production in health and/or social care services that met the definition of co-production outlined in the review. Study quality was assessed using a risk of bias (RoB) assessment created for the purposes of the review. A narrative synthesis of the findings was conducted to answer the review questions. The protocol for the systematic review was registered with PROSPERO (CRD42021227921). The systematic search found 23 reports relating to 11 studies that were almost exclusively within a mental health context. RoB assessments indicated concerns across studies. Narrative synthesis highlighted several themes related to the process and procedures of co-production, although this was not always described in detail. The results highlighted facilitators and barriers to co-production, which operated at individual, service, and organisational levels. Outcome measurement, including psychological outcomes, focused on the output of co-production not the process, and focused on experiences of EBE or service users. The identification of facilitators and barriers to co-production may aid future implementation of co-production, particularly within a mental health context. Issues related to study quality limit the conclusiveness of findings and recommendations for future research are discussed in line with the complexity of evaluating co-production.

What is Known About this Topic?

- Co-production requires the redistribution of power between stakeholders, and valuing the expertise of those who use services, their families, and communities
- It has been indicated to improve the effectiveness and efficiency of services
- Co-production has been associated with improved outcomes, including psychological outcomes such as wellbeing

What this Paper Adds

- Exploration of the processes and procedures of co-production in healthcare
- Exploration of the facilitators and barriers to co-production, at the individual, service, and organisational level
- Exploration of how co-production has been evaluated in healthcare, and whether and how psychological outcomes have been measured

Keywords

Co-production, Service design, Service delivery, Healthcare, Social care, Delivery of healthcare

Introduction

Co-production has long been championed by movements advocating for greater citizen participation and redistribution of power (Arnstein, 1969), going beyond models of service user consultation (Boyle & Harris, 2009). Boyle and Harris (2009) outlined true co-production occurs when the knowledge of professionals and service users, as well as other stakeholders, is utilised in the design and delivery of services. This has the potential to address power imbalances by requiring the redistribution of power between stakeholders, and valuing the expertise of those who use services, their families, and communities, rather than viewing them as passive recipients of care (Bovaird, 2007; Boyle and Harris, 2009; Needham & Carr, 2009; Ostrom, 1996).

Co-Production in Health and Social Care

Co-production challenges traditional paternalistic and biomedical approaches to healthcare (Dunston, Lee, Boud, Brodie, & Chiarella, 2009; Freeman et al., 2016; Owens & Cribb, 2012). Health and social care sectors have moved towards co-production in commissioning, designing, and delivering services, as well as individual healthcare (Coulter, Roberts & Dixon, 2013; National Collaborating Centre for Mental Health, 2019; Needham & Carr, 2009; NHS, 2019; NHS England, 2016; Slay & Penny, 2014). Examples are found in key recommendations of the NHS Five Year Forward View for Mental Health (NHS England, 2016) regarding co-produced commissioning, and in NHS England commissioning the National Collaborating Centre for Mental Health (NCCMH) to develop evidence-based approaches to co-produced mental health service commissioning (NCCMH, 2019). Co-production has also been promoted for individualised care (Coulter et al., 2013; NCCMH, 2019). The Kings Fund's 'House of Care' (Coulter et al., 2013), a whole-systems model of care for long-term conditions, has the notion of collaboration and person-centred care planning to co-produce health outcomes at its centre.

Current Evidence for Co-Production

Co-production brings opportunities to utilise the expertise of service users and is an inherently more democratic method of service delivery, which ensures that services meet the needs of the populations they serve (Boyle & Harris, 2009; Newman & Carr, 2009; Ryan, 2012; Slay & Penny, 2014). Active participation of communities is associated with the development of holistic approaches to care, due to communities' insight into the complexities and intersections of issues they face (World Health Organization; WHO, 2002).

The potential utility of co-production to address power imbalances has salience when considering the relationship between wider social issues and health (Chamberlain & Murray, 2009; Fisher, Balfour, & Moss, 2018; Marmot et al., 2010; McCubbin, 2009). However, traditional power dynamics can be difficult to influence and whilst co-production may lead to service improvements, it may not influence wider social issues (Farr, 2018; Fisher et al., 2018; Fotaki, 2011; Hyde & Davies, 2014; Kaehne, Beacham & Feather, 2018; Munoz, 2013; Ostrom, 1996; Owens & Cribb, 2012). Therefore, power imbalances need to be addressed at both individual and systemic levels (Evans & Loomis, 2009; Roper, Grey, & Cadogan, 2018).

The NCCMH's review of co-production (2019) found wellbeing was the strongest theme. Slay and Penny (2014) indicated that co-production of public services has the potential to meet innate psychological needs of competence, autonomy and relatedness postulated by Self-Determination Theory, the fulfilment of which has been linked with wellbeing and health behaviour (Patrick & Williams, 2012; Ryan & Deci, 2000; Slay & Penny, 2014). Other suggested benefits include empowerment, prevention, social connectedness and promoting self-help (Boyle & Harris, 2009; Munoz, 2013; NCCMH, 2019). The NCCMH (2019) found benefits for those involved in co-production itself. Identified challenges to co-production exist regarding accountability, individual and organisational health literacy, and availability of resources at individual and organisational levels, highlighting that co-production is not a panacea (Bovaird, 2019; Fotaki, 2011; Flemig & Osborne, 2019; Joshi & Moore, 2004; Palumbo & Manna, 2018).

Much of the research has defined typologies of co-production, rather than evaluating its outcomes (Voorberg, Bekkers, & Tummers, 2015; NCCMH (2019). Despite rigorous evaluation being needed, few evaluations of co-production have used high-quality forms of evidence such as controlled trials and systematic reviews (Clarke, Jones, Harris & Robert 2017; Durose, Needham, Mangan & Rees 2017). Co-production may be seen as inherently virtuous, and the positioning of co-production within public services may be disproportionate to the size of the formal evidence base (Durose, Needham, Mangan, & Rees, 2017; Voorberg et al., 2015). Whilst not a panacea, the available evidence suggests co-production may have utility in fostering empowerment and improving services through the redistribution of power between stakeholders (Bovaird, 2019; Boyle & Harris, 2009; Munoz, 2013; NCCMH, 2019; Slay & Penny, 2014).

Aims

The aims of the systematic review were to establish how co-production has been utilised and evaluated within health and social care services. This included exploring the process of co-production and its facilitators and barriers, as well as establishing how co-production has been evaluated. Given the links between co-production and the development of holistic approaches, with outcomes including improved wellbeing (NCCMH, 2019; Ryan & Deci, 2000; WHO, 2002), this review also aimed to establish whether studies of co-production measured psychological outcomes. The review aimed to meet these objectives by answering the following question:

1. In what ways has co-production been utilised and evaluated within health and social care?
    a. What are the processes and/or procedures of co-production?

b. What are the identified facilitators and barriers to co-production?

c. How has co-production been evaluated?

d. Have psychological outcomes of co-production been measured? If so, in what way?

Method

The protocol for the systemic review was registered with PROSPERO (CRD42021227921; appendix B). The review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009). See appendix C for the PRISMA checklist.

Eligibility Criteria

Research examining the utilisation of co-production within health and social care services was eligible for inclusion in the review. Research within health and/or social care where the primary focus was not on the utilisation of co-production, or where the focus was on co-production in a setting with no formal health or social care service involvement, was not eligible. Studies on the Recovery College, co-produced courses within mental health settings, were also excluded as these have been recently reviewed (Theriault, Lord, Briand, Piat & Meddings, 2020).

No restrictions were placed on study design or method and both quantitative and qualitative studies were eligible for inclusion. It was anticipated given the review topic, that studies would be observational and not include comparators. However, where present, the comparator was pre-determined to be treatment or organisation of care as usual. Only published primary research studies, accessible in the English language with full-text availability, were eligible for inclusion; conference abstracts or unpublished theses were excluded. This was to ensure sufficient detail was available to appraise methodology, its risk of bias and the results.

Definition of Co-Production

The definition of co-production for the review, consistent with Boyle & Harris (2009), was the involvement of professionals and service users, as well as other stakeholders such as families or communities, in aspects of both the design and delivery of services. Studies were eligible for inclusion if co-production involved both professionals and service users in aspects of both the design and delivery of services; involvement of other non-professional stakeholders was not required. The co-production could relate to design and delivery of a service, or an intervention delivered by a service. Studies focussing on other elements of services, for example staff training or resource development, were not eligible.

Studies were required to meet the definition of co-production and other eligibility criteria, rather than simply use the term ‘co-production’. Studies using key terms that may have been used synonymously with co-production, such as ‘co-creation’, ‘value co-creation’ or ‘co-design’, were therefore eligible for inclusion if they met the criteria.

Outcomes

In line with the review’s aims, the outcomes of interest were the processes or procedures of co-production, identified facilitators and barriers of co-production, methods used to evaluate co-production and whether psychological outcomes were measured, and how.

Search Method

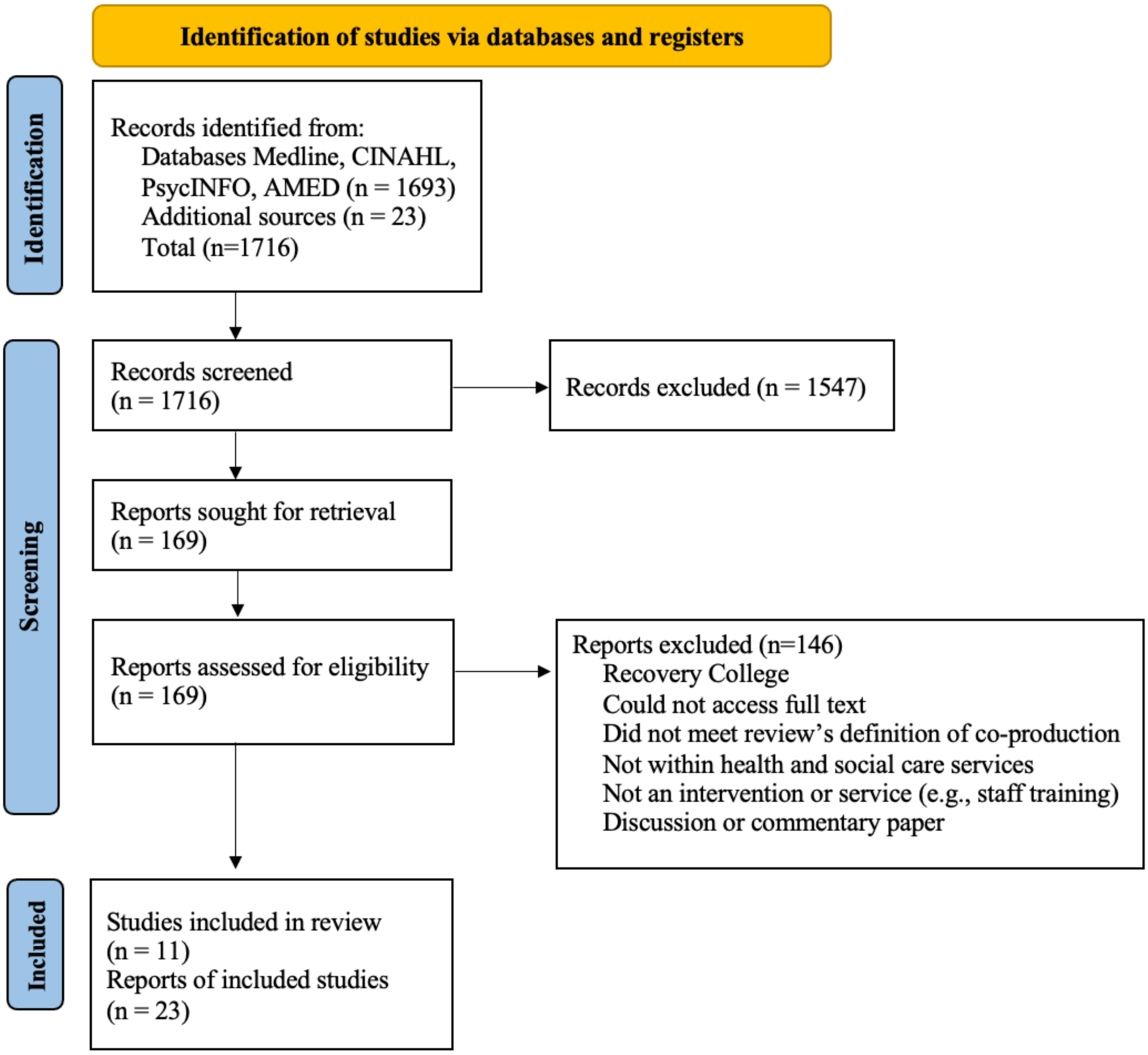
The sources searched for the systematic review included electronic databases, reference lists of eligible studies and review articles, and grey literature. The electronic databases Medline, PsycINFO, CINAHL, and AMED were searched in January 2021. Search strings were a mix of free text and controlled vocabulary, an example of the Medline search string being: 1. co-produc*.ti,ab; 2. co-design*.ti,ab; 3. co-creat*.ti,ab.; 4. 1 or 2 or 3; 5. exp Community Health Services/; 6. exp Social Work/; 7. health*care; 8. exp Health Services/; 9. social*care; 10. 5 or 6 or 7 or 8 or 9; 11. 4 and 10. Reference lists of included studies and review articles were scanned for any relevant studies not identified. A grey literature search was conducted with the eligibility criteria of full reports being available, from sources such as governmental, health and third sector organisation reports. Please see appendix D for the search strings used for each database.

Review and Synthesis Method

Following searches and the exportation of results, titles and abstracts were screened against eligibility criteria by the primary reviewer (RR), with 20% co-screened independently by another member of the review team (KK). The agreement rate was high at 84%. Following this, a full-text review of remaining studies was conducted by the review team. The primary reviewer had oversight of all full-text screening to aid consistency of decision-making. Following a pilot of the screening process, 20% of studies were co-screened by the primary reviewer and a member of the review team (CF). The agreement rate was high at 79%. The procedure at initial and full-text review stages was for any uncertainty or disagreement regarding eligibility to be discussed and taken to another review team member (KD) if agreement could not be sought. Reasons for disagreement largely related to whether the definition of co-production was met, reflecting the complexity of co-production but also lack of clarity in the reporting of studies. The review team met regularly to discuss individual studies where uncertainty arose. Please see Figure 1 for the PRISMA flowchart depicting the process of study selection.

Figure 1.

PRISMA Flowchart (adapted from Page et al., 2021)



Data extraction and risk of bias (RoB) assessments were conducted for all included studies by RR. The risk of bias checklist was created to meet the needs of the mixed methods review, including original and adapted items (Appendix E; Lockwood, Munn, & Porritt, 2015; National Heart, Lung, and Blood Institute and Research Triangle Institute International, n.d.; Tong, Sainsbury, & Craig, 2007). A member of the review team co-rated 20% of RoB assessments and any uncertainty or disagreement regarding ratings was discussed and agreement sought. Agreement between reviewers, for checklist items per study, was 60% on average.

A narrative synthesis was conducted following guidance by Popay et al., (2006). One study, Taylor (2018), only reported an evaluation of the output of the co-production so is not included in synthesis around the process, facilitators, barriers and evaluation of the co-production process.

Studies are referred to by their study identifier (ID; first author surname and year of publication of the main paper), which relates to findings from the main paper and associated reports (see table in supplementary material). Expert by experience (EBE) and expert by profession (EBP) are used to describe stakeholders of co-production that may traditionally be referred to as service users or professionals. The authors acknowledge these terms are not mutually exclusive and are used to describe the role of the stakeholder in the co-production described.

Results

Study Characteristics

The systematic search identified 11 studies and 23 associated reports (see Table 2). Studies were mostly observational or descriptive in design, with many of mixed quantitative and qualitative methods. All included studies concerned healthcare (k=11) with no studies meeting criteria from social care services. Within this, most were in a mental health context (k=9), with one in a physical health context (De Rosis, 2020) and one in a physical and mental health context (Turner, 2015a). The physical health study concerned public health promotion (De Rosis, 2020). Studies were almost evenly split between describing co-production of a service (k=6) and of a specific intervention (k=5). Co-produced services were exclusively in mental health settings, with one in a residential community setting (Casadio, 2018) and the remaining five in community services (Kirkegaard, 2018; Lwembe, 2017; Mayer, 2017; Pocobello, 2020; Tober, 2013). The interventions were mostly group psychoeducation programmes on topics such as recovery and self-management (k=3, Higgins, 2017a; Taylor, 2018; Turner, 2015a).

Demographic variables, relevant to this review, concerned those involved in the co-production process. Few studies (k=4) reported detailed demographic information for those involved in the co-production process and of these, two reported on demographics of EBE only and two reported only on demographics of EBE involved in the described study, not necessarily the whole co-production process. Co-production processes appeared to involve a range of stakeholders such as EBE, EBP, relatives and volunteers, across age ranges from adolescence into adulthood.

Table 1.

Table of Study Characteristics

Study ID	Study Design of main paper	Study Participants	Context	Participants of CP	Objectives of CP	Output of CP	Evaluation Method	Evaluation of Psychological Outcomes
Taylor (2018)	Observational - Service evaluation	Total n=23 SUs of the output of CP, Male (n=13), Age (Mean)=48, White British (91%), with a range of co-morbid mental health difficulties.	Healthcare – Mental health. Secondary mental health services in an NHS Trust in Southeast England, across five localities.	Peer Support Specialists (PSS; people with lived experience of mental health difficulties) and NHS professionals.	A PSS pilot project to coproduce an 'Enabling Recovery' group as a step towards 'Recovery College' courses.	The 'Enabling Recovery' groups ran weekly over five weeks. Co-facilitated by PSS and NHS professionals. Session lasted at least two hours, covering topics related to recovery.	Mixed methods evaluation of output rather than CP process: evaluation forms, focus group, and referral, discharge, and service contact data.	No
Tober (2013)	Descriptive	Total n=29 SHs of the CP process and SUs. Phase 1: Prospective Mentors (n=15/18), Clinical staff (n=3/3), University staff (n=3/4).	Healthcare – Mental health. NHS addictions agency.	Clinicians and SUs. SUs approached to be involved had achieved abstinence for the addiction for which they had been treated.	To co-produce an addictions aftercare service, the 'Learning to Live Again' project. Aimed to build 'recovery capital'.	The 'Learning to Live Again' (LTLA) project: an aftercare addictions service offering a range of activities led by peer mentors with support from clinicians, to support SUs	Interviews – separated by phase of the project. Led to 37 interviews for 29 participants.	N/a

		Phase 2: Mentors (n=5), Clinical staff (n=3), SUs (n=8). All mentors and clinical staff also interviewed in phase 1.				to maintain abstinence in establishing a lifestyle without substances.		
Kirkegaard (2018)	Ethnographic case study	Two community mental health services. Interview participants: Professionals from CMHT (n=12), VCO volunteers (n=7), VCO staff (n=4), SUs (n=23, aged 18-30).	Healthcare – Mental health. Two Danish community mental health services.	Partnerships between community mental health services, voluntary and community organisations. Involvement of SUs, peer workers, and volunteers.	To support the recovery of young people through social networking and integration within the community.	Co-production model adopted by Danish community mental health services. Interventions included group sessions, courses, social activities, meetings, shared meals, recreational activities, creative workshops, and individual counselling.	Approximately 15-25 hours participation per week over 8 months. Field notes from observations. Interviews (n=49)	N/a
De Rosis (2020)	Observational study	Total n=49 Adolescents aged 16-17 Age: 17 (73.5%); Female (67%);	Healthcare: Physical health. Healthy promotion in	10 high school institutes (one for each province).	To co-produce a healthy lifestyle promotion (beFood) with	beFood – a healthy lifestyle promotion intervention for adolescents.	Mixed methods: field observations, 2 self-report questionnaires,	No

		Family composition: parents (87.7%), siblings (71.5%), other relatives (18.4%); Working people in family: parents (98%), siblings (47%), other relatives (85.7%); Higher education level in family: low (40.8%), medium (32.7%), high (26.5%)	schools supported by the Department of Health Promotion (DHP) in Tuscany.	49 adolescents aged 16-17 recruited on a voluntary basis, a multi-disciplinary committee of experts (professionals; DHP and its local bodies).	adolescents for the early prevention of overweight and obesity.	Intervention included the dissemination of healthy messages and a web app that incorporated a survey of lifestyle related behaviours and gave personalised feedback to users.	opportunity cost-analysis. Evaluation of process and output.	
Lwembe (2017)	Observational study	Interviews: SUs (n=6), Community group (n=1), Public health (n=1), Mental health provider (n=1), Mental health champion (n=3) Focus group: SUs (n=6)	Healthcare – Mental health. IAPT services in West London, England delivered in partnership between secondary care, primary care and a VCO.	Multi-stakeholder initiative including public health, a community organisation, mental health practitioners and SUs.	To co-design and co-deliver IAPT services to black and minority ethnic (BME) communities.	Recruitment of residents as Mental Health Champions and targeted outreach work in the local area. Delivery of two-hour psychological interventions linked with mild-moderate physical activities over a six-week period	PAR, qualitative methods – emergent thematic analysis of field notes and observations, individual interviews (SU interviews on entry and exit of the service), and focus group with SUs at end of treatment.	N/a

						that were co-facilitated by EBP and EBE. Ongoing monitoring and evaluation of the project.		
Mayer (2017)	Observational design	Total n=5 EBE, Male, Age (mean) = 25, black British (n=4), full-time in the service (n=1), had spent time in prison (n=4), previously used service (n=2).	Healthcare – Mental health. Youth mental health charity that worked with young people in a large, ethnically diverse, and urban part of the UK.	Young people from the local area, many of whom have been SUs and mental health professionals.	Co-production of the design and implementation of its core services was described as central.	Service model of community psychology, with co-production central to this – young people are paid alongside professionals in the delivery of support to young people; as well as providing education to statutory services about their experiences.	IPA	Yes – exploration of psychological outcomes via IPA
Pocobello (2020)	Observational, cross-sectional design	CP centre (n=37), SUs, Male (70%), Age (Mean) 42.7, Education level: high school (48.6%),	Healthcare – Mental health.	Public mental health services and a citizens association (many members	Not explicitly stated – the centre became recognised officially as an 'experimental	Co-production of a mental health centre. Activities include maintenance	Comparison of a co-produced mental health centre in the South of Italy, and traditional day centres.	No

		Single/widowed (75.7%), Income status: pension (61.1%) Comparison (n=40), SUs, Male (48%), Age (Mean) 45.95, Education level: none/obligatory (75%), Single/widowed (71.8%), Income status: pension (71.1%) Focus group of CP centre: n=26, SUs (n=18), relatives (n=4), young professionals (n=4).		were EBE and their relatives). Initiated by 3 mental health professionals and a group of volunteers.	centre of co-production' in 2012 (pp.3.).	activities e.g., shopping or cooking, and other activities e.g., peer support groups, cultural activities inside and outside of the centre itself.	Mixed methods: survey, hospitalisation rates, psychiatric medication use. User-led focus group of experience of the co-produced centre.	
Casadio (2018)	Descriptive design Additional report: Evaluation of group process	Total n=26, Male (85%), Age (mean) ranged from 21 to 30 across the 4 groups who completed a stay at the Recovery House, Employment on	Healthcare: Mental health. The Recovery House, in Trieste, Italy.	Trieste Mental Health Department, International Mental Health Collaborating Network, SUs (aged 18-35 years, psychosis, and other	A Recovery Community was developed centred around the Recovery House- a pilot project to support people with psychosis and other	The Recovery House – intention to create a democratic way of operating, seeing mental health difficulties as "human	Additional report undertakes group process evaluation of CP in the pilot group (SUs n=6, practitioners, volunteers, mental health operators) via observatory methods	No

		arrival: unemployed (n=15).		complex mental health needs, in contact with mental health services), relatives, workers from co-operatives and mental health centres, students and representatives from NGO's, other groups. Two co-ordinators from a prior Recovery House.	complex mental health needs in their recovery.	experiences to be learnt from" rather than being conceptualised as disease (pp.2).		
Simmons (2018)	Descriptive study Additional report: Observational design, non-randomised comparison study	Output evaluation: Total SUs n=229: Intervention n=149, Female (63%) Historical comparison n=80, Female (56%)	Healthcare: Mental health. CHOICE pilot project in an enhanced primary care early intervention service in Australia, that provides services for young people between the	Clinical staff at the clinic and a group of young people aged 16-25 years who were employed to provide a "youth informed perspective" to their services.	Developing a combined peer work and shared decision-making intervention for young people accessing the service.	The CHOICE pilot project was a service for young people aged 16+ and accessing the service for the first time. Peer workers (n=8, aged 16-25, EBE), employed part time. Peer workers helped SUs pre-	Output evaluation: outcome measures related to decisional conflict (pre- and post-), shared decision making (post-), and service satisfaction (post-) were completed pre- and/or post-assessment. Comparison of intervention and historical	Output evaluation: decisional conflict

			ages of 12 and 25, with mild to moderate mental health difficulties.			and post-assessment and supported to complete an online shared decision tool that was then used by professionals to facilitate shared decision making in assessment.	comparison group data.	
Higgins (2017a)	Descriptive study Additional reports: Observational design (x3)	Output evaluation: SU programme: n=12 matched data sets, Male (50%), Age 30-63 years old. Family programme: n=18 matched data sets, Male (24%), Age range 31-68 years old. Influence on professional recovery beliefs/practices (EBP): facilitators (n=12, Female	Healthcare: Mental Health. A community mental health team in Ireland.	MDT community mental health team, SUs, families, voluntary agencies, and academics.	To develop a peer and clinician led information programme on recovery from mental health difficulties, for people with a diagnosis of schizophrenia or bipolar disorders and their families or significant others.	A peer and clinician led information programme on recovery from mental health difficulties. Two programmes were developed (SU and family member) via the development process. Each programme was designed to be delivered over eight weeks, with seven to	Output evaluation: Mixed methods – pre and post quantitative outcome measures: knowledge scale (designed for the project), RAQ-7, Herth Hope Index, 10 item scale from Patient Self-Advocacy Scale, 5 items from DAI-10. Family member outcome measures were the same with additions of the GHQ-12 and the Social Network of Support Scale	Output evaluation: self-advocacy, recovery attitudes, hope Output evaluation of co-facilitation training: confidence

		n=10), co-ordinators (n=16, Female n=11). Outcomes of co-facilitation training (EBE and EBP: facilitators total (n=128), SUs (n=40), relatives (n=24), clinician (n=63).				eight sessions lasting 90 minutes each.	(created by the study team). Post-programme also had satisfaction questionnaire. Interviews conducted post-programme about their experience. Influence on professional recovery beliefs/practices: qualitative interviews and focus group. Outcomes of co-facilitation training: mixed methods pre/post survey and qualitative interviews.	
Turner (2015a)	Observational design.	Output evaluation: Total n=1170, Age (mean) 56.3, Female (64%), White (81%), Accommodation owner occupier	Healthcare: Physical health and mental health – long-term conditions. Part of a national	The Expert Patient Programme Community Interest Group, with condition specific content developed by	Aimed to improve self-management in the four populations it was developed for. Part of 'co-creating	A self-management programme (SMP) for people with long-term conditions (LTC). (COPD,	Output evaluation: Quantitative: pre- and post- outcome measures: PAM, EuroQol index, HADS, heiQ, plus condition specific measures for COPD,	Output evaluation: activation, anxiety and depression. Process Evaluation:

	(61%), Living alone (32%), Age left education 16-18 years (41%). Longitudinal follow-up depression: total n=302, Age (Mean) 49.4, Female (70%), White (87%), Accommodation owner occupier (58%), Living alone (17%), Left education 16-18 years (47%). Process evaluation: Observations: SMP clinical tutors (n=37), SMP lay tutors (n=37) Interviews: SMP clinical tutors (n=9), SMP lay tutors (n=11), patient attendees (n=unclear for SMP)	quality improvement demonstration program called co-creating health developed by The Health Foundation.	steering groups at demonstration sites, with clinicians and SUs.	health' initiative by the Health Foundation.	depression, diabetes, musculoskeletal pain). Co-delivered by EBE and EBP tutors. Seven-week programme.	depression, diabetes and pain. Longitudinal follow up for depression (same outcome measures + PHQ-9) Process evaluation: observation, self-determination scales, qualitative interviews.	self-determination

Notes: ID = identifier; CP = co-production; Participants of CP = participants of the co-production process rather than the study; SU = service user; CMHT = community mental health team; VCO = voluntary and community organisation; IAPT = Improving Access to Psychological Therapies; PAR = participatory action research; Psychological outcomes = where these have been explicitly measured or explored; EBE = expert by experience; EBP = expert by profession; IPA = interpretative phenomenological analysis; RAQ-7 = Recovery Attitudes Questionnaire 7; DAI-10 = Drug Attitude Inventory; GHQ-12 = General Heath Questionnaire; SMP = self-management programme; COPD = chronic obstructive pulmonary disease; PAM = Patient Activation Measure; HADS = Hospital Anxiety and Depression Scale, heiQ = Health Education Impact Questionnaire; PHQ-9 = Patient Health Questionnaire.

Study Quality

RoB assessment (Table 2) indicated some concerns across studies. It was complicated, however, by methodological variation between studies and quality of reporting. RoB due to lack of patient and public involvement (PPI) was high across studies, with only one (Pocobello, 2020) clearly describing PPI.

The Processes and Procedures of Co-Production

The processes and procedures of co-production were not always described in detail. Some co-production processes were initiated by feedback from service users (Taylor, 2018; Tober, 2018). The principles of participatory action research (PAR) were utilised by Higgins (2017a) with focus groups conducted to explore and identify priorities of different stakeholders for a co-produced programme on recovery. Establishing partnerships was central across studies, in relation to partnerships between stakeholders within services and organisations but also with other statutory, voluntary and community organisations (Casadio, 2018; Higgins, 2017a; Kirkegaard, 2018; Lwembe, 2017).

Some co-production involved distinct stages of development, for example research, training, project development, implementation, and evaluation (De Rosis, 2020; Higgins, 2017a; Turner et al., 2015a), and some had an identified framework, or key principles and values, underpinning co-production of the intervention or service (Casadio, 2018; Higgins, 2017a; Lwembe, 2017). Some of these concerned ideas central to the service, for example principles of recovery in Casadio (2018). Others related to the process of co-production, for example agreed values of the steering group in Higgins (2017a). In some studies, co-production was led by a specific steering group, for example Higgins (2017a). In others, particularly where the focus was a service rather than intervention, co-production was seen as a collective process involving all stakeholders (Casadio, 2018).

Facilitators of Co-Production

Shared Aims and Values. Having a shared aim, goal or set of underpinning values facilitated the process of co-production for stakeholders (k=3; Casadio, 2018; Higgins, 2017a; Tober, 2013). This included processes such as agreeing on a shared language for designations and stakeholder experiences, that was not technical or centred on EBP's experience (Casadio, 2018). Higgins (2017a) described a set of values agreed by stakeholders, which provided a consistent ethos throughout represented by the acronym SUPPORT (support, understanding, partnership, participation, openness, respect and trust). Having a shared aim appeared to facilitate co-production (Casadio, 2018; Tober, 2013) and mitigate between different expectations or agendas between stakeholders. An EBE in one study suggested co-production was the first time they had felt part of a group that had "…come together with one common goal" (Tober, 2013, pp. 228).

Valuing Expertise and Difference. This was an almost universal theme among included studies, particularly in relation to expertise that lay in lived experience (k=8; Kirkegaard, 2018; Lwembe, 2017; Mayer, 2017; Pocobello, 2020; Simmons, 2018; Tober, 2013; Turner et al., 2015a). Tober (2013) noted the expertise of EBE lay in their lived experience, which was fundamental for the service's success, whereas that of EBP lay in managing wider organisational processes such as the agency's commitment to the project. As such, valuing expertise appeared to extend to mutual esteem for the expertise of different stakeholders (Mayer, 2017; Pocobello, 2020; Tober, 2013; Turner et al., 2015a).

Table 2.

Risk of Bias Assessment

Study ID	Question aligns with method	Representative study population	Demographics evidence representativeness	>50% participation	Met sample size	Loss to follow up <20%	PPI involvement in design, analysis and reporting of research	Qual: Congruity between philosophy and method	Qual: Accounted for researcher characteristics	Qual: Rigorous data collection	Qual: Data saturation	Qual: participant correction of transcripts	Qual: recording of the uptake of participant correction	Qual: participant/PPI feedback on findings	Qual: Reliability & validity addressed	Qual: Sufficient evidence
Taylor (2018)	Y	N	?	N	N	Y	?	?	Y	?	?	N	N/a	N	Y	Y
Tober (2013)	Y	Y	?	?	N/a	N/a	N	?	?	Y	?	N	N/a	N	?	Y
Kirkegaard (2018)	Y	Y	?	?	N/a	N/a	N	?	N	Y	?	N	N/a	N	N	Y
De Rosis (2020)	Y	N	?	Y	N	Y	?	?	?	?	?	N/a	N/a	N	N	N/a
Lwembe. (2017)	Y	Y	?	?	N/a	?	N	?	N	Y	?	Y	N	N	Y	Y
Mayer (2017)	Y	N	?	?	N/a	N/a	N	Y	Y	Y	?	N	N/a	Y	Y	Y
Pocobello (2020)	Y	Y	?	?	N	N/a	Y	Y	N	Y	?	Y	N	Y	Y	Y
Casadio (2018)	Y	Y	N/a	N/a	N/a	N/a	N	N/a	N/a	N/a	N/a	N/a	N/a	N/a	N/a	N/a
Simmons (2018)	Y	N/a	N/a	N/a	N/a	N/a	N	N/a	N/a	N/a	N/a	N/a	N/a	N/a	N/a	N/a
Higgins (2017a)	Y	Y	?	?	N/a	N/a	?	?	N	Y	?	N	N/a	N	N	Y
Turner (2015a)	Y	N	?	Y	N	N	N	N/a	N/a	N/a	N/a	N/a	N/a	N/a	N/a	N/a

Note: ID = Identifier; Y = Yes; N = No; N/a = Not applicable; ? = Unclear; Qual = Qualitative

Identifying Stakeholder Needs. Another important facilitator was recognising stakeholders' differing needs during co-production and responding flexibly, such as identified training needs and the need for cultural competence (Higgins, 2017a; Lwembe, 2017; Simmons, 2018). Recognising barriers to participation for EBE was another factor. Simmons (2018) developed an accessible recruitment process tailored to the EBE they hoped to recruit. Two studies (Lwembe, 2017; Pocobello, 2020) acknowledged the role of holistic approaches to problems and recovery in the process of developing co-produced services, which included recognising the conflicting needs those accessing services may have and viewing recovery as a collective process.

Role Clarity. Role clarity was another facilitator identified by several studies and was present at organisational and local levels (k=5; De Rosis, 2020; Kirkegaard, 2018; Lwembe, 2017; Simmons, 2018; Tober, 2013). At service and organisational levels, Lwembe (2017) described a process of prior agreement regarding the distinct roles of partners in delivering the service. Role clarity at an individual level was described by Tober (2013) as a mitigating factor for EBE of the challenges of navigating the boundaries of their role as peer mentors, which was echoed by Simmons (2018). In contrast, Kirkegaard (2018) viewed the purposeful blurring of roles between stakeholders as important for co-production, providing an example where a conscious decision was made not to have a noticeboard about who worked in the service. The specific role of a project co-ordinator in supporting the co-production process was also highlighted (Higgins, 2017a; Tober, 2013).

Developing Relationships. Relationship development was an almost universal theme across studies and was present at individual, service, and organisational levels, within and between statutory, voluntary and community organisations (Casadio, 2018; Higgins, 2017a; Kirkegaard, 2018; Lwembe, 2017). At an individual level, developing trust between EBE and EBP was a key facilitator, with one EBP in Casadio (2018) highlighting the dichotomy between trusting and power relationships. Trust was found to mitigate potential barriers related to power imbalances between stakeholders (Casadio, 2018; De Rosis, 2020; Higgins, 2017a). Transparency in the process of co-production, and feeling connected, valued, cared for and respected in relationships in the co-production process were seen as further facilitators (Lwembe, 2017, Mayer, 2017; Pocobello, 2020; Tober, 2013). De Rosis (2020) highlighted the enabling role of EBP in their relationship with EBE was more salient than operational support.

Agency. Having agency in the co-production process provided EBE with a sense of ownership in using their lived experience to inform the design and delivery of projects. This led to EBE having ownership over activities and to the addiction aftercare service moving away from a drop-in model, which was positively viewed by multiple stakeholders (Tober, 2013). Lwembe (2017) found that service users valued having a sense of ownership of the service and being able to express their needs.

Shared Decision Making. Shared decision-making was a common theme across studies. Some studies explicitly considered how they could facilitate this process, through assembly, away days and open meetings (Casadio, 2018; Kirkegaard, 2018; Tober, 2013). EBE in Mayer (2017) described how shared decision-making avoided them feeling like they had passive roles and instead made them feel accountable and responsible. Shared decision-making was evident from individual interactions to wider service decisions, such as determining activity provision and recruitment processes (Lwembe, 2017; Pocobello, 2020; Simmons, 2018; Tober, 2013). Being reflexive and open to challenge were reported as mitigating barriers to shared decision-making (Casadio, 2018).

Barriers to Co-Production

Organisational Commitment. Organisational commitment was highlighted as a facilitator to co-production (Tober, 2013; Turner, 2015a) and changes at an organisational level inconsistent with the ethos of co-production risked undermining it. A participant in Mayer (2017) described feeling like a "lab rat" (Mayer, 2017, pp.4) when they felt they were not part of wider decisions. Organisational commitment was also important for mitigating barriers related to wider policies, for example Simmons (2018) described needing approval to make age and lived experience a necessary requirement for an employed peer worker role.

Resources. Resource limitations were identified as potential barriers to co-production (k= 4; Mayer, 2017; Simmons, 2018; Tober, 2013; Turner, 2015a). This theme was present at both individual, service, and organisational levels, such as issues related to capacity and funding (Turner, 2015a). Capacity and resources of individual stakeholders to take part in co-production was important at the individual level, for example the long-term conditions of EBE were cited as one of the potential barriers to participation in a co-produced self-management programme (Turner, 2015a).

Understanding of Co-Production. Whilst this theme was most salient in Turner (2015a) it is salient due to its potential impact on co-production. Turner et al (2015a) found the understanding managers had of co-production ultimately shaped the way it was implemented but also whether there was wider organisational reach of co-production outside the programme.

Past Experiences. Past experiences were identified as a barrier to co-production for EBE (k=3; Higgins, 2017a; Lwembe, 2017; Mayer, 2017). Negative previous experiences of services resulted in challenges in forming relationships for EBE, due to suspicion, distrust and reluctance to engage in co-facilitation with EBP (Higgins, 2017a; Lwembe, 2017; Mayer, 2017).

Relational Tensions. Tensions between stakeholders could function as potential barriers to co-production (k=3; Casadio, 2018; Simmons, 2018; Tober, 2013). Tensions between university staff and clinicians in early stages of co-production in Tober (2013) resulted in withdrawing university staff from the project. Changes in relationships between EBE and EBP were also a potential source of tension, as highlighted in a staff survey that found EBP had concerns about how to navigate this relational shift (Simmons, 2018). In a study of a co-produced Recovery House (Casadio, 2018), negotiating a balance between individuality and collectivism was also identified as a potential source of tension when issues of engagement arose.

Role Ambiguity and Conflict. Role ambiguities and conflicts were also identified as potential barriers (k=6; Casadio, 2018; Higgins, 2017a; Kirkegaard, 2018; Mayer, 2017; Simmons, 2018; Tober, 2013). Role ambiguity was associated with EBE taking a step back in co-facilitation of an information programme (Higgins, 2017a). For EBE, role ambiguity and conflict largely related to navigating the boundaries of a new role and experiencing role conflict between lived experience and a more 'professional' role (Mayer, 2017; Tober, 2013). Role conflict was associated with the credibility of blurred boundaries, where these inadvertently reinforced the dichotomy between service provider and user (Kirkegaard, 2018). An example of this was observation of an interaction in which an EBP took on a more traditional role of authority in trying to encourage engagement in response to disengagement of a service user from an activity (Kirkegaard, 2018).

Power Imbalance. Power imbalance as a potential barrier to co-production was an almost universal theme. The challenge of moving away from traditional power dynamics was noted to require ongoing negotiation and reflection (Casadio, 2018). Moving away from the privileging of professional expertise was also a barrier across studies, with EBP, EBE and volunteers all sometimes observed to privilege professional over lived expertise (Higgins, 2017a; Kirkegaard, 2018; Turner, 2015a). An EBP facilitator remaining the keyholder for the venue of a co-delivered programme, served as a metaphor of enduring power imbalance for an EBE in Higgins (2017a).

The Evaluation of Co-Production

Seven studies evaluated the output of co-production (De Rosis, 2020; Higgins, 2017a; Lwembe, 2017; Pocobello, 2020; Simmons, 2018; Taylor, 2018; Turner, 2015a) mostly using quantitative pre/post outcome measures related to the aims of the co-produced intervention and focused on end user outcomes. Two studies evaluated co-produced services rather than interventions, using quantitative outcomes such as medication use, hospitalisation, and treatment completion rates (Lwembe, 2017; Pocobello, 2020). De Rosis (2020) also undertook an opportunity cost-analysis.

Three studies evaluated outcomes for stakeholders in the co-production process (De Rosis, 2020; Higgins, 2017a; Mayer, 2017). These used either mixed (Higgins, 20017a; De Rosis, 2020) or qualitative methods (Mayer, 2017) and mostly focused on exploring the impact of stakeholders' experiences of co-production. Except for Higgins (2017a) these focused on EBE experiences. Seven studies (Casadio, 2018; De Rosis, 2020; Higgins, 2017a; Kirkegaard, 2018; Lwembe, 2017; Pocobello, 2020; Tober, 2013) evaluated the process of co-production, mostly through interviews and field observations, and less often with questionnaires. De Rosis (2020) outlined a framework for evaluating co-production in terms of its inputs, goals, and anticipated outputs, measuring and evaluating outcomes.

Psychological Outcomes of Co-Production

There was a distinction between studies reporting psychological outcomes as part of the output or process of co-production. Three studies reporting psychological outcomes of the output of co-production, concerned co-produced interventions, rather than services (k=3, Higgins, 2017a; Simmons, 2018; Turner, 2015a). Two studies (Mayer, 2017; Higgins, 2017a) evaluated psychological outcomes of the co-production process and were evenly split between co-produced services (Mayer, 2017) and interventions (Higgins, 2017a).

Psychological outcomes of the output of co-production were typically assessed via self-report measures pre/post co-produced interventions. A range of psychological outcomes were measured, relevant to the intervention aims, for example a self-management programme for long-term conditions measured anxiety, depression, and patient activation (Turner, 2015a). Regarding psychological outcomes of the process of co-production, Mayer (2017) evaluated a co-produced service whereas Higgins (2017a) evaluated a co-produced intervention, making direct comparison difficult although both utilised qualitative means to explore stakeholders' experiences. While few studies formally evaluated psychological outcomes of the process of co-production, themes of empowerment, confidence and recovery were reported across a larger group of studies (k=6; Casadio, 2018; De Rosis, 2020; Lwembe, 2017; Pocobello, 2020; Tober, 2013; Turner, 2015a).

Discussion

This is the first review to synthesize research on the processes and procedures, facilitators and barriers and evaluation of co-production in health and social care, including the extent to which psychological outcomes have been examined.

The drivers for co-production included addressing specific issues, such as health inequalities, or responding to service user feedback (Lwembe, 2017; Taylor, 2018; Tober, 2013). Some studies had distinct developmental stages (e.g., De Rosis, 2020; Higgins, 2017a), and two studies used participatory action research (PAR) methods as part of the co-production process (Lwembe, 2017; Higgins, 2017a). Other key processes and procedures identified were formalising partnerships within and between organisations and agreeing a framework or underlying values for services or the co-production process (De Rosis, 2020; Kirkegaard, 2018; Lwembe, 2017; Higgins, 2017a; Casadio, 2018).

Facilitators and barriers to co-production were apparent at organisational, service, and individual levels (see Figure 2). Whilst the concept of power was not always explicitly discussed in relation to the facilitators and barriers of co-production, many of the themes such as agency, shared decision-making and valuing expertise and difference, arguably have the concept of power at their core and it is a central concept among the literature base (Arnstein, 1969; Bovaird, 2007; Boyle & Harris, 2009; Needham & Carr, 2009; Ostrom, 1996). The importance of identifying and addressing power at both individual and wider systemic levels in co-production has been highlighted (Roper et al., 2018) and therefore, the findings of the synthesis are described at individual, service, and organisational levels, with an acknowledgement of the overarching role of power (Figure 2).

At an organisational level, key facilitators were identified as relationship development, organisational commitment, and resources. These facilitators included developing partnerships with other statutory, voluntary and community organisations, and the availability of resources, such as funding (Lwembe, 2017; Turner, 2015a). Organisational commitment was identified as a potential barrier if absent, for example when wider organisation decisions were made in a way that was inconsistent with co-production (Mayer, 2017).

At a service level, key facilitators included shared aims and values, valuing expertise and difference, developing relationships, role clarity, shared decision-making, understanding co-production and resources. Themes within this included having an agreed framework for co-production with other stakeholder groups, agreeing a common language and valuing the lived experience of EBE and recognising the needs of stakeholders in line with their expertise, and having a project co-ordinator to help sustain the project (Higgins, 2017a; Lwembe, 2017; Tober, 2013). A notable barrier was potential for managerial misunderstanding of co-production to limit its wider organisational impact (Turner, 2015a).

Service level facilitators identified also operated at the individual level, except for misunderstanding of co-production. Having a sense of agency was also indicated to facilitate co-production at the individual level, particularly for EBE (Tober, 2013). Role clarity and developing trusting relationships between EBE and EBP were also important (Casadio, 2018;

Tober et al., 2013). Role ambiguity and negative past experiences of accessing services were potential barriers (Casadio, 2018; Simmons, 2018); although case studies by Kirkegaard (2018) advocated for the purposeful blurring of boundaries between stakeholders. Valuing the lived experience of EBE, or over-valuing that of EBP, were identified as a potential facilitators and barriers respectively (Casadio, 2018; Higgins, 2017a; Kirkegaard, 2018; Tober, 2013; Turner, 2015a). The personal and professional resources of both EBE and EBP were identified as potential barriers to co-production (Turner, 2015a).

Commonalities exist between the current findings and previous literature, in relation to the centrality of power in co-production (Arnstein, 1969; Bovaird, 2007; Boyle & Harris, 2009; Needham & Carr, 2009; Ostrom, 1996). Almost all studies were set within a mental health context, which may be salient in considering the recovery movement in mental health and the potential role of co-production in addressing power imbalances (Farr, 2018; Fisher et al., 2018; McCubbin, 2009; Ostrom, 1996). This was explored within the context of health inequalities in mental health services for people from Black Minority Ethnic (BME) communities in Lwembe (2017), who found preliminary evidence co-production can overcome some barriers experienced by BME communities in accessing mental health services. However, true co-production may be difficult to achieve where it occurs due to public services failing to meet the needs of those they serve (Joshi & Moore, 2004), which might be relevant for co-production processes aiming to address health inequalities.

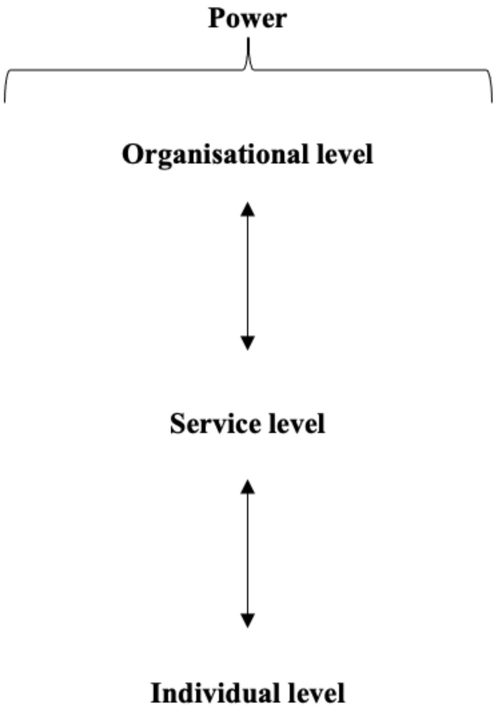
The relational context of co-production was a recurring theme in this and previous reviews (Durose et al., 2017), with the potential for relationships to act as facilitators or barriers to co-production (Owens & Cribb, 2012). Owens & Cribb (2012) highlighted the potential for tensions to arise due to differing perspectives of stakeholders, which was reflected in the tensions apparent in some studies in the current review around negotiating shifts in power and moving away from paternalistic relationships (Higgins, 2017a; Kirkegaard, 2018; Turner, 2015a). Owens and Cribb (2012) posited that the complexity of health, and its relationships to both biomedical and psychosocial factors, which may be better recognised by EBP and EBE respectively may be a contributing factor. They suggested adopting a critical realist view of health, aligned with more holistic approaches such as the biopsychosocial model (Engel, 1980), as a way to resolve these tensions (Owens & Cribb, 2012).

Valuing the expertise of people with lived experience and challenging traditional paternalistic models privileging professional expertise has been described as a central tenet of co-production and this was an almost universal theme of the current review (Bovaird, 2007; Boyle & Harris, 2009; Dunston et al., 2009; Freeman et al., 2016; Needham & Carr, 2009; Owens & Cribb, 2012). Conversely, over-valuing professional expertise was highlighted as a barrier by some studies and challenging this was an ongoing process, reflecting the difficulty of challenging traditional power imbalances (Farr, 2018; Fotaki, 2011; Higgins, 2017a; Hyde & Davies, 2004; Kaehneet al., 2018; Kirkegaard, 2018; Munoz, 2013; Owens & Cribb, 2012; Turner, 2015a). It has been argued true co-production is difficult to achieve given the systems in which it operates, and that service level changes may not permeate through wider organisations (Farr, 2018; Owens & Cribb, 2012). This was reflected in one of the studies of the current review, which found managerial misunderstanding of co-production affected not only the implementation of a co-produced intervention but also limited the impact of co-production at wider organisational levels (Turner, 2015a).

Freeman et al., (2016) described a framework for working towards co-production through three levels that are partly reflective of the individual, service, and wider organisational factors. The first layer of the framework focuses on creating a foundation for co-production by developing trust and co-producing care at the individual level with service users (Freeman et al., 2016). This foundational level was reflected in the facilitators of shared aims and values, and developing relationships found in the current review. The next level focuses on developing skills needed for all stakeholders to engage in co-production, which is reflective of the facilitators and barriers of valuing expertise and difference and resources in the current review (Freeman et al., 2016). The final layer involves building on the partnerships developed during initial stages, so all stakeholders have the “knowledge, skills, experience, confidence, and appropriate support” (Freeman et al., 2016, pp. 203) to engage in co-production of designing and delivering services. Factors that may support and sustain the process of co-production are also important considerations, such as having a guiding ethos for the service, considering appropriate reimbursement and individual needs with regards to involvement in co-production (Freeman et al., 2016). However, other suggestions for implementing co-production within services include adopting a pragmatic model of co-production that seeks to achieve a more holistic approach to care and provides clarity of the role of EBE in service changes whilst considering issues of capacity and system complexity (Kaehne et al., 2018).

Figure 2.

Presence of Facilitators and Barriers of Co-Production at Different Operational Levels



Another key question of the review was how studies were evaluated, and whether psychological outcomes were measured. Few studies reported demographic information of those involved in co-production, other than those involved in the study. Given the potential utility of co-production in addressing imbalances of power for people from marginalised communities and the known links between wider social issues and health (Chamberlain & Murray, 2009; Fisher et al., 2018; Marmot et al., 2010), reporting demographic information to indicate the representativeness of those involved in co-production may be particularly salient. However, the emphasis on representativeness has been rejected by Kaehne et al., (2018), as people can only represent themselves.

Previous literature indicated improved wellbeing, physical and mental health, empowerment, encouragement of self-help and self-determinism as potential outcomes of co-production (Boyle & Harris, 2009; Munoz, 2013; NCCMH, 2019; Patrick & Williams, 2012; Ryan & Deci, 2000; Slay & Penny, 2014). However, the current review found outcome measurement focused on the output of co-production, not the process, and focused on experiences of EBE or service users, rather than stakeholders more generally. This poses challenges for developing an evidence base for co-production in differentiating the effects and mechanisms of action. Process evaluations found in the current review tended to be qualitative and exploratory or descriptive in nature. The relational context of co-production makes traditional methods of evaluation more difficult, with it often taking place at a local level within services rather than a formal context (Durose et al., 2017). These issues are reflected in findings on the evaluation of co-production found in this review and the assessment of study quality.

Concerns identified in the review relating to study quality, are consistent with those expressed by previous reviews. Lack of clear reporting regarding implementation of service improvements and lack of evaluation of co-production have been raised previously as well as in the current review (Clarke et al., 2017; NCCMH, 2019; Voorberg et al., 2015). Clarke et al., (2017) found that not all authors commented directly on the process of co-production, or factors related to the progress of co-production or its sustainability; concluding there was a lack of rigorous evaluation for co-production, which was supported by the findings of the current review. Issues relating to study quality may be understood in the relational and often locally specific context in which co-production occurs (Clarke et al., 2017; Durose et al., 2017). De Rosis (2020) proposed a framework for evaluating co-production which highlights the importance of reporting: the characteristics and determinants (inputs of co-production such as the goals, design and development, collaboration between stakeholders), immediate results (outputs such as participation, the experience of those involved) and final impact of co-production at multiple levels (outcomes at service/organisational levels, for EBE, and at wider community and societal levels). Durose et al., (2017) posed the question of how to generate 'good enough' evidence for co-production. Durose et al., (2017) suggested due to the complexity of evaluating co-production it should involve theory-driven methodologies and highlight the value, in this context, of knowledge-based practice, suggesting methodologies including appreciative inquiry, peer learning and data sharing as ways to evaluate co-production.

The limitations of this review include issues of study quality such as RoB, reporting quality and the methodologies used, which limits the generalisability of findings. Studies were also almost exclusively within a mental health context and no studies were found within the social care sector. Whilst similar themes were found among studies in physical health and mixed healthcare fields, the number of studies (k=2) is too small for meaningful comparison. Whilst study quality was generally low, the review has utility in being the first to investigate the implementation and evaluation of co-production and has highlighted important recommendations for future research. Another limitation is the review's focus on implementation and evaluation of co-production rather than outcome; however, no other systematic review of co-production across health and social care has been conducted to the authors' knowledge. Therefore, establishing the landscape is important in moving towards a comprehensive evaluation of the evidence base for co-production.

Conclusions and Implications for Clinical Practice and Research

Implications for clinical practice are the facilitators and barriers to co-production, which have been identified in the current review and were found to be reflected in the wider literature. Identification of the facilitators and barriers and an understanding of how they operate over individual, service, and organisational levels, may aid future implementation of co-production, particularly within a mental health context. Principles identified for operationalising co-production are highlighted below; however, these should be considered in the context of the project or service being developed:

- Working to gain commitment of stakeholders at all levels, including organisational levels

- Identifying what needs stakeholders, both professional and non-professional, might have to be able to fully engage with the co-production process, and how these can be met
- Consider what resources might be required from different stakeholders at all levels, including at individual and service levels, and whether these are available
- Clarity of roles in the co-production process. Whilst role clarity in terms of the distinction between EBE and EBP was questioned in Kirkegaard et al. (2018), clarity of role in the co-production process was a common facilitator
- Agreeing to the aims, goals, and values underpinning co-production for the project or service
- Consider having a project co-ordinator to proactively support the process of co-production
- Shared decision making that values the expertise of all stakeholders, should underpin decision making
- Developing trusting relationships with all stakeholders was highlighted as an almost universal factor in co-production, and therefore should be central to the process.

Future research should evaluate outcomes of the process and output of co-production, which should be considered at multiple levels, from the perspective of multiple stakeholders (De Rosis, 2020). Higher quality studies of co-production within health and social care are required, particularly within social care given the lack of findings within this sector. Given the complexities of evaluating co-production consideration should be given to generating good enough evidence for co-production via methods including appreciative inquiry, peer learning and data sharing (Durose et al., (2017). The adoption the evaluative framework posited by De Rosis (2020), would aid the clarity of reporting and evaluation of co-production. Where De Rosis (2020) evaluated final impacts for EBE, based on the findings of the current review the authors would recommend evaluating outcomes for all involved stakeholders. The final recommendation relates to public and patient involvement (PPI). PPI can help ensure research is accessible and meaningful for those it intends to benefit (Health

Research Authority/INVOLVE, 2016), and the context of co-production of healthcare lends itself to the co-production of its evidence base.

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Supplementary Material

Summary Table of Included Studies and Additional Reports

Study ID	Associated reports
Taylor (2018)	Taylor, Dorer, and Gleeson (2018) (Main study)
Tober (2013)	Tober et al., (2013) (Main study)
Kirkegaard (2018)	Kirkegaard and Andersen (2018) (Main study)
De Rosis (2020)	De Rosis, Penucci, Noto, and Nuti (2020) (Main study) De Rosis, Corazza, Penucci, and Nuti (2018)
Lwembe. (2017)	Lewmbe, Green, Chigwende, Ojwang, and Dennis (2017) (Main study)
Mayer (2017)	Mayer and McKenzie (2017) (Main study)
Pocobello (2020)	Pocobello et al., (2020) (Main study)
Casadio (2018)	Casadio et al., (2018) (Main study) Thomé et al., (2018)
Simmons (2018)	Simmons, Batchelor, Dimopoulos-Bick, and Howe (2018)
Higgins (2017a)	Higgins et al., (2017a, plus corrigendum) (Main study) Higgins et al., (2017b, plus corrigendum) Higgins et al., (2018) Higgins et al., (2020)
Turner (2015a)	Turner, Anderson, Wallace, and Bourne (2015a) (Main study) Turner, Realpe, Wallace, and Kosmala-Anderson (2015b) Newbronner, Chamberlain, Borthwick, Baxter, and Sanderson (2013) Sharma, Wallace, Kosmala-Anderson, and Turner (2013) Wallace et al., (2012)

Note: ID = Identifier

CHAPTER THREE

Systematic Review and Meta-Analysis

Prepared for submission to the Journal of Contextual Behavioral Science

Author guidelines can be found in appendix F

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Acceptance and Commitment Therapy for Holistic Self-Management of Long-Term Conditions: A Systematic Review and Meta-Analysis

Rachel L. Russell[a*], Dr Catherine Ford[a], & Dr Katherine Deane[b]

[a] Department of Clinical Psychology and Psychological Therapies, Faculty of Medicine and Health Sciences, University of East Anglia, Norwich, Norfolk, NR4 7TJ

[b] School of Health Sciences, Faculty of Medicine and Health Sciences, University of East Anglia, Norwich, Norfolk, NR4 7TJ

* Corresponding author: Rachel Russell r.russell@uea.ac.uk

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Abstract

Background

Acceptance and Commitment Therapy (ACT) is a transdiagnostic psychotherapy with potential to support holistic self-management of long-term conditions (LTCs). This systematic review and meta-analysis, aimed to investigate the efficacy of ACT for holistic self-management of LTCs in terms of physical, psychological, and social outcomes, consistent with a holistic definition of self-management.

Methods

Medline, PsycINFO, CINAHL, and AMED were systematically searched in April 2021 for randomised controlled trials (RCTs) of ACT for adults with LTCs, which reported validated physical and psychological, social, or multi-domain outcomes. Study quality was assessed using the Cochrane Risk of Bias Tool (RoB2). Meta-analysis was conducted to estimate effect sizes of ACT at post-intervention for physical, psychological, and multi-domain outcomes using a random-effects model, where sufficient data were available. Standardised mean difference was calculated to account for variance in measurement scales for reported outcomes. The protocol for the systematic review and meta-analysis was pre-registered with PROSPERO (registration number: CRD42021251920).

Results

Twenty-seven manuscripts reporting outcomes from 21 RCTs (n = 1173) met inclusion criteria and were categorised into studies of ACT within oncology (k=7, n=405), endocrinology (k=4, n=337), neurology (k=6, n=169), and rheumatology (k=4, n=242). The results provide preliminary evidence of the efficacy of ACT for psychological outcomes including acceptance, anxiety, depression and general mental health/QoL, with small to moderate effect sizes reported. Preliminary evidence of the efficacy of ACT for holistic self-management for rheumatological conditions was also found, with moderate to large effect sizes for pain, fibromyalgia impact, and depression. Substantial heterogeneity across studies, concerns regarding study quality, the limited number of studies, and small sample sizes, limited the ability to draw conclusive findings.

Conclusion

Given the findings of the current review, to date there is not sufficient evidence to be able to advocate for the widespread implementation of ACT for PLTC. Further large-scale, high-quality research measuring holistic biopsychosocial outcomes with patient and public involvement is needed.

Highlights

- A systematic review and meta-analysis of ACT for holistic self-management of long-term conditions was conducted
- Preliminary evidence indicates that ACT is associated with improvements in psychological and physical outcomes, particularly for people with rheumatological conditions
- Concerns about study quality and heterogeneity across studies limit the conclusiveness of the findings. There was insufficient evidence to determine the efficacy of ACT for holistic self-management for long-term conditions
- Further high-quality research is needed to measure the impact of ACT on holistic biopsychosocial outcomes and needs to include patient and public involvement in its design.

Keywords

Acceptance and Commitment Therapy; Long-term conditions; Self-management; Holistic

Introduction

Improving care for people with long-term conditions (PLTC) has been identified as one of the most prominent challenges facing the NHS (Coulter et al., 2013). In 2012, the UK Department of Health (DoH) predicted the number of people with multi-morbidity would rise over the following 10 years (DoH, 2012); a rise which has been reflected in acute emergency admissions (Deeny et al., 2018; Steventon et al., 2018). Given this rise, it has been argued that healthcare should move away from reactive approaches to holistic and person-centred models (Coulter et al., 2013), with a focus on supporting self-management in the care of PLTC (DoH, 2005a; Deeny et al., 2018; NHS England & NHS Improvement, 2020).

The biopsychosocial model (Engel, 1980), developed as an alternative to the medical model of care, concerns the biological, psychological and social factors that impact health. Lehman et al. (2017) expanded this by integrating it with other systems models, including Bronfenbrenner's (1977) ecological model, to form a dynamic biopsychosocial model of health, which acknowledges that these factors are not static but dynamic in their interplay over time. This interplay between physical, psychological and social aspects of health for PLTC is well documented in research (DiMatteo et al., 2000; NHS England, 2016; Stanton et al., 2007). Whilst the relationship is likely to be complex, people with chronic physical health problems appear more likely to experience mental health difficulties, which in turn are associated with poorer physical health outcomes (Cooke et al., 2007; DiMatteo et al., 2000; Stanton et al., 2007). Living with a LTC has also been shown to impact on quality of life (QoL; Lempp et al., 2009; Mujica-Mota et al., 2015; Peters et al., 2019) particularly where multimorbidity is present (Mujica-Mota et al., 2015; Peters et al., 2019). It has been suggested that much of the variance in the heterogeneity of QoL for PLTC may be explained by psychological factors rather than disease severity (Graham et al., 2011; Graham et al., 2013; Graham, et al., 2014).

The psychological process of adjustment to living with a LTC is also important, with a number of factors affecting adjustment and significant heterogeneity not only between individuals but also over time (Stanton et al., 2007). This supports Lehman's dynamic biopsychosocial model, which posits that the central importance of different domains of health vary over time (Lehman et al., 2017; Stanton et al., 2007). These factors have been conceptualised as operating at individual, community and societal levels (Putnam et al., 2003; Stanton et al, 2007). For example, societal factors such as isolation, influence adjustment to LTCs (Stanton et al., 2007). Living with a LTC may be associated with disability, and people with disabilities have increased likelihood of experiencing social isolation and loneliness (Macdonald et al., 2018). Wider social factors also affect adjustment to LTCs, such as socio-economic status, which influences health outcomes through both direct and indirect means (Stanton et al., 2007). This supports situating self-management within a relational and social context (Morris et al., 2015).

Given the known interplay between physical, psychological and social aspects of health for PLTC (DiMatteo et al., 2000; NHS England, 2016; Stanton et al., 2007), and the emphasis within guidance and policy on providing holistic, integrated care for PLTC (Coulter et al., 2013; DoH, 2005a; DoH, 2005b; Entwhistle & Cribb, 2013; Goodwin et al., 2010; NHS England, 2016), the definition of self-management needs to encompass more than disease management alone. Whilst there is no standard definition of self-management (Barlow et al., 2002), this review adopted the following definition: "The tasks that individuals must undertake to live well with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management, and emotional management of their conditions." (Adams et al., 2004, pp.57).

Self-management interventions for PLTC range from educational approaches to approaches from health and clinical psychology (Bodenheimer et al., 2002; Newman et al., 2004; Wagner et al., 1999). These have been influenced by psychological theories such as the Common Sense, or Self-Regulation Model (CSM, Leventhal et al., 2012), which postulates a process by which PLTC make sense of and cope with their condition(s) and their emotional impact (Serlachius & Sutton, 2009). There is also a positive evidence base for the application of psychological interventions to self-management. For example, Cognitive-Behavioural Therapy (CBT) is reported to provide effective support for the self-management of a number of health conditions (Broderick et al., 2016; Hind et al., 2014; Hofman et al., 2012; Ismail et al., 2004; Morley et al., 1999; Winkley et al., 2020).

Acceptance and Commitment Therapy (ACT), a third wave CBT approach, has been modified for PLTC (Graham et al., 2016). One of the core premises of ACT is that pain and suffering are an inevitable part of being human, and attempts to avoid, control or eliminate painful private experiences (for example, difficult thoughts, feelings or sensations) lead to increased suffering (Harris, 2009). ACT aims to enable people to live a meaningful life in the presence of pain and suffering through increasing psychological flexibility (Harris, 2009), defined as “the ability to contact the present moment more fully as a conscious human being, and to change or persist in behavior when doing so serves valued ends” (Hayes et al., 2006, pp.7).

ACT has a growing evidence base in managing psychological distress and promoting adjustment and self-management behaviours in PLTC (Dahl, 2009; Feliu-Soler et al., 2018; Graham et al., 2016; Graham et al., 2015; Gregg et al., 2007; Thompson & McCracken, 2011). While second wave CBT aims to address or modify maladaptive illness-related beliefs, ACT focuses on developing acceptance and living in accordance with personal values more broadly (Graham et al., 2016). This may have utility for PLTC, as shown by research highlighting the role of acceptance and psychological flexibility in LTCs such as diabetes, muscle disorders, and chronic pain (Feliu-Soler et al., 2018; Graham et al., 2015; Graham et al., 2016; Gregg et al., 2007; Thompson & McCracken, 2011). The LTC, chronic pain, has sufficient evidence for the National Institute for Health and Care Excellence (NICE) to recommend considering ACT for those with chronic primary pain aged 16 years and over (NICE, 2021). ACT may also have utility for PLTC more generally, due to its transdiagnostic nature (Brassington et al., 2016), especially given the prevalence of co- and multi-morbidity (Deeny et al., 2018; Steventon et al., 2018). Whilst Brassington et al., (2016) found evidence to support transdiagnostic ACT interventions for PLTC, it was noted that there was debate regarding their utility and that further research was needed to explore the delivery of transdiagnostic, as opposed to condition-specific, interventions within this context. A systematic review by Graham and colleagues (2016) also found preliminary evidence in support of ACT for PLTCs. However, there has also been criticism of the ACT evidence base given issues related to the quality and size of previous studies (Graham et al., 2016; Öst, 2008; Öst, 2014). This has been specific to research investigating the efficacy of ACT for PLTC, but also more broadly, and led to a call for larger, higher quality studies of ACT to be conducted to assess the conclusiveness of preliminary findings (Graham et al., 2016; Öst, 2008; Öst, 2014).

One criticism of health psychology research is the failure to explicitly take into account the complexity of the factors that affect health (Suls & Rothman, 2004). Research examining the number of papers published in the ‘Health Psychology’ journal over a year from November 2001 found that only 26% papers included measures from all domains of the biopsychosocial model, including wider societal factors, and argued that to understand the complex relationships between these factors it is important to include a diverse range of biopsychosocial outcomes (Suls & Rothman, 2004).

Given the need for holistic, integrated care for PLTCs highlighted in research and guidance (Coulter et al., 2013; DoH, 2005a; DoH, 2005b; Entwhistle & Cribb, 2013;

Goodwin et al., 2010; NHS England, 2016) and evidence supporting the potential utility of ACT for PLTC (Graham et al., 2016), this review aimed to investigate the efficacy of ACT for holistic self-management of LTCs in terms of physical, psychological and social outcomes, consistent with a holistic definition of self-management and recommendations to measure a diverse range of variables within health psychology research (Suls & Rothman, 2004). In addition to updating the systematic review by Graham et al., (2016) whose searches were completed in 2015, this review extends the findings of previous reviews of ACT for LTCs by taking adopting a holistic approach to the definition of self-management by evaluating a diverse range of physical, psychological and social outcomes, and conducting a meta-analysis on studies within this context to evaluate its efficacy.

Method

The protocol for the systematic review and meta-analysis was pre-registered with PROSPERO (registration number: CRD42021251920, appendix G) and conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009; appendix H).

Eligibility Criteria

This review focussed on randomised controlled trials (RCTs) of ACT for physical LTCs. The definition of long-term conditions adopted for the review was "…a condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies" (DoH, 2012, pp.3). Mental health conditions were only included if co-morbid with a long-term physical health condition and weight management interventions were not independently eligible for review outside of the context of LTCs. Diagnostic criteria for LTCs were not prescriptive to allow clinical judgement to be sufficient. Only studies involving adults and older adults (18 years and above) were eligible for inclusion. Studies that could not be meaningfully grouped by medical specialism were not included in the review in either meta-analysis or narrative synthesis due to the low number of studies, as indicated in Figure 1. During the review process, NICE guidance was published on ACT for chronic pain (NICE, 2021) so studies of ACT for chronic pain related conditions were excluded from the current review, since the strength of the evidence suggested a separate review of its efficacy as a holistic self-management intervention would be more appropriate.

Regarding the ACT interventions, studies were excluded if the intervention included other active interventions outside of ACT. Psychoeducation or educational elements were not considered a reason for exclusion. ACT is not a linear model of therapy but is instead based around the core principles of psychological flexibility (Harris, 2009). In addition, it has been applied with a diverse range of populations, in a diverse range of settings and delivery formats including group and brief interventions (Hayes et al., 2012; Graham et al., 2016). As such, the ACT interventions described had to align with the ACT model and its core processes (acceptance, contact with the present moment, defusion, self-as-context, values, committed action; Harris, 2009), but there were no restrictions regarding the format or method of delivery of the ACT intervention. Published, peer-reviewed, primary research studies available in English with full-text availability, reporting validated outcome measures were eligible for inclusion in the review. Conference abstracts and unpublished theses were excluded.

Using the holistic definition of self-management adopted for the review (Adams et al., 2004), as the person's ability to manage physical, emotional, and social facets of their LTC, self-management can be measured through a range of outcome measures including measures of physical outcomes such as pain, emotional outcomes such as anxiety, and social outcomes such as social isolation. It can also be measured through outcomes evaluating more specific elements of self-management such as the Patient Activation Measure (PAM) which assesses the "knowledge, skills, beliefs and behaviors that a patient needs to manage a chronic illness"

(Hibbard et al., 2004 pp.1006). To focus on the efficacy of ACT for holistic care of LTCs, studies were only included if they reported a physical outcome and a psychological, social, or quality of life outcome using validated measures. Pain was excluded as a condition in its own right, but not as an outcome of other conditions that met eligibility criteria. When studies reported quality of life subscales, these were considered physical, social, psychological outcomes as appropriate.

Search Strategy

Four electronic databases (Medline, PsycINFO, CINAHL, and AMED) were searched from inception to April 2021. An example search string for Medline was: 1. exp. "Acceptance and Commitment Therapy", 2. Accept* and Commit* Therapy.ti,ab, 3. Accept* and Commit* Training.ti,ab, 4. Psychological Flexibility, 5. 1 OR 2 OR 3 OR 4. Due to the broad definition of LTC in the eligibility criteria, a broad search strategy was utilised, as in Graham et al., (2016). Reference lists of eligible studies and review articles were also searched for additional studies. Please see appendix I for the search strings for the relevant databases.

Study Selection and Data Extraction

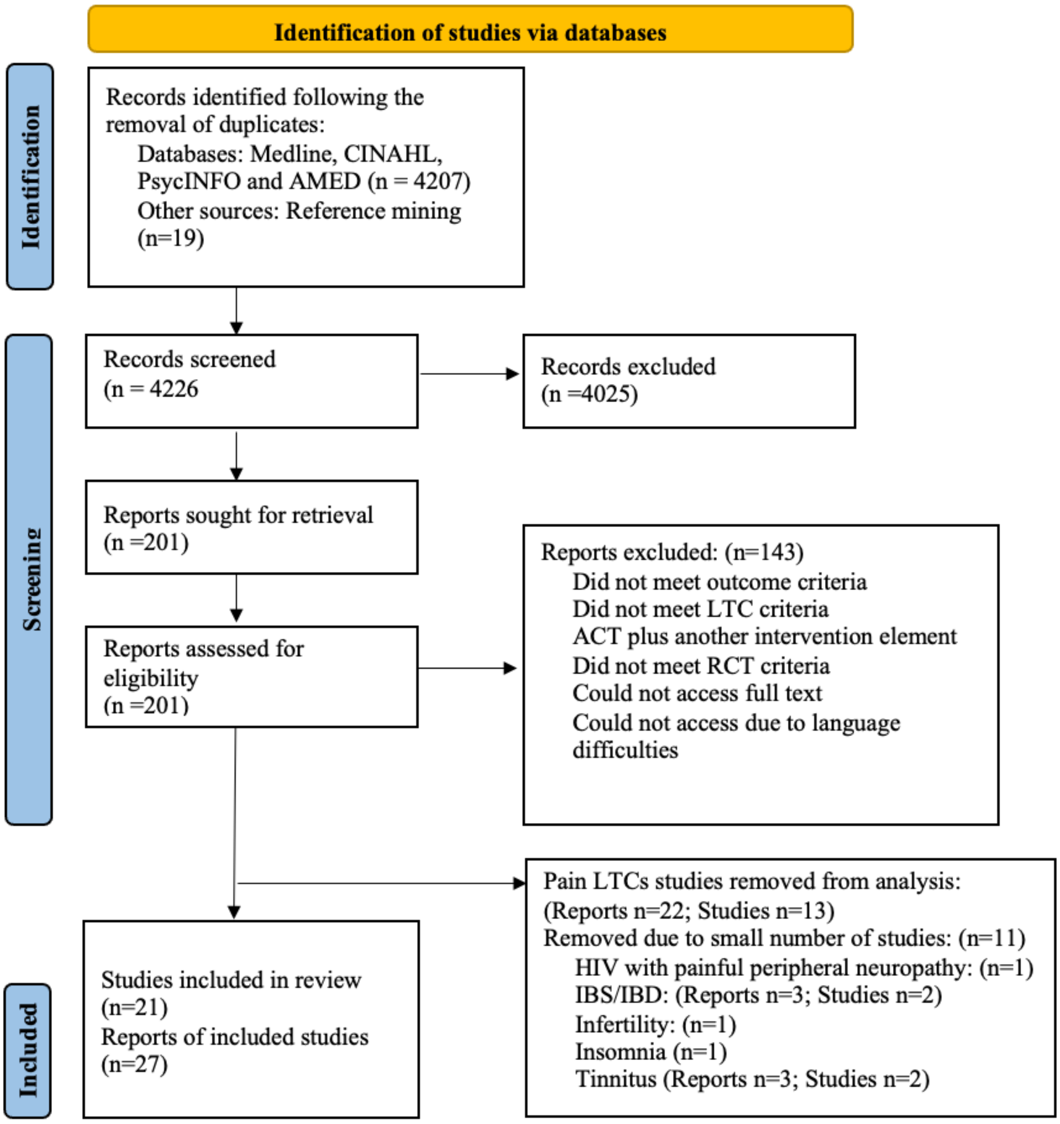
Study titles and abstracts were screened against the eligibility criteria, with a member of the review team independently screening 20% of studies. The agreement rate was high at 97% and the remaining 3% were resolved upon discussion. Full texts were then assessed for inclusion by the review team. The primary reviewer had oversight over the process to aid consistency of decision making and 20% of studies were co-screened. The agreement rate was high at 86% and the remaining 14% were resolved on discussion. Uncertainty or disagreement about study inclusion was discussed to consensus (see Figure 1). Data extraction was conducted by two members of the review team (RR and KD) in accordance with the study protocol (appendix G).

Risk of Bias Assessment

Risk of bias (RoB) assessments were conducted using the Cochrane risk of bias tool, RoB2, (Sterne et al., 2019; Higgins et al., 2021a), with the addition of items regarding Patient and Public Involvement (PPI) and treatment fidelity. A member of the review team co-rated 20% of RoB assessments. Agreement rate for risk of bias assessments ranged from 57% to 86% with the main reason for difference relating to the interpretation of items, which was resolved on discussion.

Figure 1.

PRISMA Flow-Chart (adapted from Page et al., 2020)



Meta-Analysis

Meta-analysis was conducted to estimate effect sizes of ACT at post-intervention for physical, psychological, and multi-domain outcomes using a random-effects model, where sufficient data were available.

Analyses were conducted using Cochrane Review Manager software (RevMan 5; The Cochrane Collaboration, 2020) and following Cochrane guidance (Higgins et al., 2021b). Included studies reported continuous outcomes. The standardised mean difference (SMD) with a 95% Confidence Interval (CI) was calculated, to account for studies that used different measurement scales to measure the same outcome (Higgins et al., 2021c), with 0.2 indicating a small effect, 0.5 indicating a moderate effect and 0.8 indicating a large effect. As SMD does not account for differences in the direction of change between outcomes, the means of studies where higher scores were desirable were multiplied by minus one (Higgins et al., 2021c). Heterogeneity was assessed using I^2, with I^2 <40% taken to indicate no important heterogeneity between studies, 30 to 60% indicating moderate heterogeneity, 50 to 90% indicating substantial heterogeneity and 75 to 100% indicating considerable heterogeneity (Deeks et al., 2021). Post-intervention values were used and studies reporting change scores omitted from analysis as Cochrane guidance suggests they should not be used in a meta-analysis where SMD is calculated (Deeks et al., 2021). Standard errors (SE) were transformed into standard deviations (SD) consistent with Cochrane guidance (Higgins et al., 2021c). Where studies had multiple comparators, the comparator closest to waitlist or treatment as usual was chosen for analysis. Missing data were not imputed, and sensitivity analyses were not conducted in relation to missing data, since small sample sizes meant these were unlikely to aid understanding of results.

The primary analysis assessed the efficacy of ACT for physical, psychological, and social outcomes across LTCs. Due to the wide range of LTCs identified, sub-group analyses were categorised by medical specialism (see Table 1 for sub-group analyses by medical specialism and Table 2 for study characteristics and sub-groups).

A wide variety of outcomes and outcome measures were used across included studies. Meta-analysis was not conducted where there were fewer than three studies available for a given outcome. A lack of reported social outcomes meant that a meta-analysis could not be conducted within this domain. Table 1 shows a breakdown of the meta-analyses and sub-group analyses conducted. One study, Esmali (2015) was omitted from all analyses and narrative synthesis as it was unclear in which direction the QoL measure improved, and a reference for the measure could not be found. Within the physical domain, HbA1C data could not be included in the meta-analysis due to the method of reporting by Whitehead (2017) differing from the remaining studies, meaning there were not enough studies with consistent reporting of the measure for statistical analysis to take place. Within the psychological domain, Clarke (2017) was not included in statistical analysis for acceptance, due to differences in reporting method from other studies. In addition, the data available for the Acceptance and Action Diabetes Questionnaire (AADQ) in the endocrinology sub-group indicated it had been scored differently across studies, altering the direction of change for Whitehead (2017), and this was corrected for in the analysis.

Outcomes of interest that could not be included in the meta-analysis were incorporated into a narrative synthesis, conducted in accordance with guidance by Popay et al., (2006). Additional sub-group analyses of interactions between intervention format or delivery and intervention effect were planned but were not appropriate, due to the small number and sample size of included studies.

Table 1.

Outcomes for meta-analysis, organised by domain, medical specialism, and sub-group analysis.

Domain	Outcome	Medical Specialism of Included Studies	Number of studies (k)	Inclusion in Sub-group Analyses
Physical	Physical health QoL	Oncology	k=1	N/a*
		Neurology	k=2	
		Rheumatology	k=1	
	Fatigue	Oncology	k=3	Oncology
	Pain	Oncology	k=1	
		Neurology	k=1	
		Rheumatology	k=3	Rheumatology
	Fibromyalgia Impact	Rheumatology	k=3	Rheumatology
	Self-care	Endocrinology	k=3	Endocrinology
Psychological	Acceptance	Oncology	k=3	Oncology
		Endocrinology	k=3	Endocrinology
		Neurology	k=3	Neurology
		Rheumatology	k=2	
	Values	Oncology	k=1	N/a*
		Neurology	k=1	
		Rheumatology	k=1	
	Anxiety	Oncology	k=3	Oncology
		Endocrinology	k=1	
		Neurology	k=3	Neurology
		Rheumatology	k=2	
	Depression	Oncology	k=3	Oncology

		Endocrinology	k=2	
		Neurology	k=3	Neurology
		Rheumatology	k=3	Rheumatology
	Psychological/Mental health QoL	Oncology	k=1	N/a*
		Neurology	k=2	
		Rheumatology	k=2	
Quality of Life	QoL	Oncology	k=1	
		Neurology	k=3	Neurology
		Rheumatology	k=1	

Note: Quality of life (QoL). *Sub-group analyses were not conducted where there were fewer than three studies.

Results

Characteristics of Included Studies

In total there were 27 reports for 21 included studies (Table 2). Studies and their additional reports are referenced to throughout utilising the first author's surname and date of publication of the main study (see supplementary material for a table of included studies and associated additional reports). Most studies compared ACT to passive control conditions for example, waitlist control or treatment as usual, or non-psychological support for example, education or yoga. Most ACT interventions included an element of education or psychoeducation, which was considered an intrinsic part of the therapeutic intervention rather than a reason for exclusion. Most studies were parallel RCTs with two arms; however, there were three studies with three arms (Luciano, 2014; Johns, 2020; Whitehead, 2017). In this instance, the most passive control condition was chosen for analysis, for example a waitlist control condition would be chosen over an active control. In total, 12 studies undertook an intention to treat (ITT) analysis and 10 studies undertook a sample size and power calculation. Most studies which undertook a power calculation based these on related research rather than on a previous trial of the same protocol, which could be anticipated given many were pilot RCTs.

Across the 21 studies, there were a total of 1173 randomised participants with a mean of 56 per study and range from 18 (Lungren, 2008a) to 135 (Arch, 2021), equating to a mean of 28 participants per condition, with a range of 8 (Lundgren, 2008a) to 68 (Arch, 2021). Of the 21 studies, three had data that could not be utilised in meta-analysis as previously stated (Esmali, 2015; Johns, 2020; Mosher, 2018). Based on the LTCs in included studies, they were divided into sub-groups based on medical specialism: oncology (k=7, n=405), endocrinology (k=4, n=337), neurology (k=6, n=169) and rheumatology (k=4, n=242). The categorising of studies in this way allowed meaningful sub-group analysis to take place for LTCs with shared commonalities.

The presentation of demographic data varied widely across studies, with some studies providing no demographic information and others presenting detailed demographics; however, from the data presented, it could be seen that most participants across studies were female and there was a mean age range of 24 to 67 years old. In studies reporting ethnicity, participants were mostly white, although 10 studies did not report ethnicity.

Demographic information for individual subgroups indicated that in the oncology sub-group, most participants had a diagnosis of breast cancer. Most participants were white and female. In the endocrinology sub-group, all participants had a diagnosis of Type II diabetes with one study focusing on neuropathic pain. Participants were approximately split between male and female. The neurology sub-group contained a wider range of diagnoses, which were evenly split across the six studies: multiple sclerosis (MS), epilepsy and traumatic brain injury (TBI). One study (Dindo, 2020) focused on TBI with associated co-morbidities of pain and stress psychopathology. Most participants in the neurology sub-group were female. In the rheumatology sub-group, participants mostly had a diagnosis of fibromyalgia with one study focusing on osteoarthritis. Most participants were female.

The ACT interventions were mostly in group format (k=12) and there were two interventions that were self-led. Delivery was mostly face-to-face, although telephone (k=3) and online (k=1) interventions were also reported. A range of professionals delivered the ACT interventions including psychologists, post-graduate or doctoral level clinical psychology students/trainees, clinical or Masters level social workers, therapists, and mental health nurses. Not all studies gave the exact profession of the professional leading or supporting the intervention; however, of those that did, most were delivered by a psychologist or clinical psychologist. In addition, four studies had the same professional delivering both the ACT and comparator intervention. In terms of number of sessions, this ranged from one to 12, with a mean of six sessions.

There was a wide range of outcome measures across studies in the different domains (physical, psychological, and social). Out of the 21 studies, 14 measured ACT process outcomes such as acceptance within the psychological domain and three studies (Dindo, 2020; Sefarty, 2019; Whiting, 2020) measured outcomes across all three domains. See Table 2 for outcome measures included in the meta-analysis and see appendix J for a more detailed summary of reported outcomes among studies and across outcome domains.

Table 2.

Table of Study Characteristics

Study ID (first author and year)	Study Design and Location	Long-Term Condition	Intervention Format and Delivery	Comparison	Participants (n)	Outcome measures Included in Meta-Analysis	ITT Analysis (Yes/No)
			Oncology				
Arch 2021	RCT – parallel USA	Breast cancer 59% Blood cancer 13% Gastrointestinal 10% Other 18% Stage I 40% Stage II 26% Stage III 26% Other 8%	Group. 7 weekly sessions (2 hours). In-person in clinics. Professional led (clinical social workers)	EUC. Usual care plus additional support information and encouragement to contact clinical social worker as needed	Total n=135 ACT n=68 EUC n=67	Vitality RAND SF-36, HADS-A, CESD	Yes
Mosher 2018	Pilot RCT – parallel USA	Stage IV breast cancer	Individual. 6 weekly sessions (50-60 minutes). Telephone delivered. Professional led (Masters level social worker)	Education/ Support. 6 weekly sessions (50-60 minutes). Telephone delivered. Professional led (PhD student in clinical psychology)	Total n=47 ACT n=23 Education/ Support n=24	N/a	Yes
Shari 2020	RCT – parallel Malaysia	Breast cancer	Individual. 4 weekly sessions (1 hour), every 3 consecutive weeks. In	Waitlist (received brief ACT post-intervention)	Total n=42 ACT n=32 Waitlist n=30	FACT-F, HADS-A, HADS-D, AAQ-II	No

			person. In clinic prior to chemotherapy sessions. Professional led				
Serfaty 2019	RCT – parallel UK	Advanced cancer (diagnosed as not amenable to cure)	Individual. 8 sessions (period of therapy not specified). In person in outpatient clinic. Professional led	Talking control. Professional led (same therapist as ACT)	Total n=42 ACT n=20 Talking control n=22	FACT-G physical and emotional wellbeing subscales, AAQ-II, VLQ, EQ-5D-5L	No
Esmali 2015	RCT – parallel Iran	Breast cancer	Group. 8 sessions (90 minutes) over 4 successive weeks. In person, in a hospital setting. Professional led	Control – no treatment	Total n=30 ACT n=15 Control n=15	N/a	Yes
Mosher 2019	Pilot RCT – parallel USA	Advanced lung cancer (Stage III or IV non-small cell or extensive stage small cell lung cancer)	Mix of individual and with caregiver sessions. 6 sessions (50 minutes), weekly. Telephone sessions. Professional led (Masters level social worker)	Education/ support. 6 sessions (50 minutes) weekly. Telephone sessions. Professional led (PhD student in clinical psychology)	Total n=50 dyads ACT n=25 dyads Education/ support n=25 dyads	PROMIS pain intensity, PROMIS fatigue, PROMIS SF anxiety, PROMIS SF depression, PEACE acceptance subscale	Yes
Johns 2020	Pilot RCT – parallel USA	Breast cancer: stage I to III, completed curative treatment (ongoing	Group. 6 sessions (2 hours) weekly. In person. Professional led (doctoral level)	SE. Group. 6 sessions (2 hours weekly). In person. Professional led (Masters level	Total n=91 *ACT n=33 Survivorship education (SE) n=32 *EUC n=26	N/a	Yes

		endocrine therapy permitted)		oncology social workers) EUC. Group. 1 coaching session (30 minutes) plus given resources. Professional led (doctoral level oncology nurse)			
				Endocrinology			
Gregg 2007	RCT – parallel USA	Type II diabetes	Workshop (approximately 4 hours education, plus ACT components). Professional led (author of the manual)	Education. Workshop (7 hours). Professional led (senior author of manual or one of four masters level graduate students)	Total n=81 ACT and education n=43 Education n=38	SDSCA, AADQ	No
Davoudi 2020	RCT – parallel Iran	Type II diabetes with neuropathic pain	8 sessions (90 minutes) weekly. In person. Professional led (clinical psychologist). In a medical centre.	Psychoeducation protocol established by Ministry of Health of Iran. 8 sessions (90 minutes) weekly. In a medical centre. In person.	Total n=50 ACT n=25 Psychoeducation n=25	BDI	No

				Professional led (clinical psychologist).			
Whitehead 2017	RCT – parallel New Zealand	Type II diabetes (uncontrolled)	Workshop. 1 day (10:00-17:00). Central city location. Professional led (mental health nurse).	Education. Workshop. 1 day (10:00-17:00). Professional led (nurse). Central city location Control. Usual diabetes care	Total n=157 *ACT and education n=54 Education n=51 *Control n=52	SDSCA, HADS-A, HADS-D	Yes
Shayeghian 2016	RCT – Parallel Iran	Type II diabetes	Group. 10 sessions (2 hours) weekly	Education. Workshop - 1 day	Total n=100 ACT and education n=50 Education and routine treatment n=50	SDSCA, AADQ	No
				Neurology			
Proctor 2018	Pilot RCT – Parallel UK	MS	Supported self-help (book plus 8 weekly support calls from a trainee clinical psychologist)	TAU. Typically involved referral for psychological intervention or medication for mood. None in TAU condition accessed psychological therapy	Total n= 27 ACT and TAU n=14 TAU n=13	GAD-7, PHQ-9, AAQ-II, EQ-5D-5L	Yes

Whiting 2020	Pilot RCT – Parallel Australia	Severe TBI (post-traumatic amnesia ≥7 days)	Group. 6 sessions (1.5 hours) weekly + 1 FU session after 1 month. Professional led (clinical psychologist)	Befriending therapy. Group. 6 sessions (1.5 hours) weekly + 1 FU session after 1 month. Professional led (clinical psychologist, psychologist, clinical psychology post-graduate student)	Total n=19 ACT n=10 Befriending therapy n=9	SF-12 physical and mental health subscales, HADS-A, HADS-D, AAQ-II	Yes
Lundgren 2008a	RCT - Parallel India	Epilepsy	Mix of individual and group. 2 sessions in total (1 individual and 1 group). Professional led (two clinical psychologists)	Yoga. Professional led (yoga teacher)	Total n=18 ACT n=10 Yoga n=8	WHOQoL-BREF	No
Dindo 2020	RCT – Parallel USA	Mild TBI (co-morbid chronic pain, stress-based psychopathology e.g., MDD, GAD, PTSD)	Group. Workshop (5 hours). Professional led (2 clinical psychologists)	TAU. Followed standard care, including psychiatric and medical services	Total n=39 ACT n=27 TAU n=12	BPI pain severity, AAQ-II	No
Giovannetti 2020	Pilot RCT – Parallel Italy	MS	Group. 7 sessions (2.5 hours) weekly + 2.5 hour booster session. Professional led (study co-ordinator)	Relaxation training. Group. 7 sessions (1 hour) weekly + booster session after 5 weeks.	Total n=39 ACT (READY) n=20 Relaxation n=19	MSQoL physical and mental health subscales, HADS-A, HADS-D, VLQ, AAQ-II	Yes

				Professional led (study co-ordinator)			
Lundgren 2006	RCT – Parallel South Africa	Epilepsy	Individual and group. 1 individual session (1.5 hours), 2 group sessions (3 hours), 1 individual session (1.5 hours) + individual booster sessions at 6 and 12 months (booster sessions conducted post-data collection for that time-point). Professional led	Supportive therapy. Equal amount of professional support offered. Professional led	Total n=27 ACT n=14 Supportive therapy n=13	WHOQoL	No
				Rheumatology			
Luciano 2014	RCT – Parallel Spain	Fibromyalgia	Group. 8 sessions (2.5 hours). Professional led	RPT - Recommended pharmacological treatment (GPs given 2-hour information session) Waitlist. No active treatment during study period	Total n=156 *ACT n=51 RPT n=52 *Waitlist n=53	Pain VAS, FIQ, HADS-A, HADS-D, CPAQ, EQ-5D-5L VAS	Yes
Simister 2018	RCT - Parallel	Fibromyalgia	Individual. 7 modules over 8 weeks. Online.	TAU. Continued with regular treatment. Prescribed	Total n=67 ACT n=33 TAU n=34	FIQ-R, CESD, CPAQ-R, VLQ	No

			One to one professional support, self-led online intervention	and over the counter analgesics were most commonly reported			
Wicksell 2013	RCT – Parallel Sweden	Fibromyalgia	Group. 12 sessions (90 minutes) weekly. In person. Professional led (psychologist led 10 sessions, physician 2)	Wait list	Total n=40 ACT n=23 Waitlist n=17	FIQ, SF-36 physical and mental health subscales, Pain intensity NRS, BDI, STAI (state anxiety)	Yes
Clarke 2017	Pilot RCT - Parallel UK	Knee/hip osteoarthritis	Group. 6 sessions (1.5 hours) weekly. University or hospital premises. In person. Professional led (clinical psychologist)	Usual Care	Total n=31 ACT n=16 Usual Care n=15	Pain NRS, GHQ-12	Yes

Note: Esmali (2015), Mosher (2018) and Johns (2020) were excluded from statistical meta-analysis as previously indicated. * = the arms included in analysis for 3-arm RCTs; RCT = randomised control trial; USA = United States of America; ACT = Acceptance and Commitment Therapy; EUC = Enhanced Usual Care; UK = United Kingdom; MS = Multiple Sclerosis; TBI = Traumatic brain injury; MDD = Major Depressive Disorder; GAD = Generalised Anxiety Disorder; PTSD = Post-Traumatic Stress Disorder; HADS (A/D) = Hospital Anxiety and Depression Scale (Anxiety/Depression); CESD = Center for Epidemiological Studies - Depression; IES-R = Impact of Events Scale-Revised; PROMIS = Patient-Reported Outcomes Measurement Information System; FSI = Fatigue Symptom Inventory; FACT = Functional Assessment of Cancer Therapy (F = fatigue; G = general); AAQ-II = Acceptance and Action Questionnaire; VLQ = Valued Living Questionnaire; PEACE = Peace, Equanimity and Acceptance in the Cancer Experience questionnaire; GAD-7 = Generalised Anxiety Disorder – 7; PHQ 8/9 = Patient Health Questionnaire – 8/9; CAAQ = Cancer Acceptance and Action Questionnaire; SDSCA = The Summary of Diabetes Self-Care Activities; AADQ = Acceptance and Action Diabetes Questionnaire; BDI = Beck Depression Inventory; GHQ-12 = General Health Questionnaire – 12; BPI = Brief Pain Inventory; PTSD = Post-Traumatic Stress Disorder; PCL-C = PTSD checklist – Civilian; Pain VAS = visual analogue scale; FIQ = Fibromyalgia Impact Questionnaire, NRS = numeric rating scale; CPAQ = Chronic Pain Acceptance Questionnaire; STAI = State-Trait Anxiety Inventory; ITT = Intention to Treat analysis.

Risk of Bias

Table 3 provides a summary of risk of bias (RoB) assessment domains, conducted using the Cochrane Risk of Bias Tool, RoB2 (Sterne et al., 2019; Higgins et al., 2021a), with the addition of items on treatment fidelity and Patient and Public Involvement (PPI). Low RoB for treatment fidelity was considered if fidelity assessment had been conducted and the results reported. Low RoB was considered for PPI if there was clear evidence and detail of PPI throughout the research process.

There were elements of high RoB almost exclusively across studies and sub-groups. Randomisation had mostly low risk of bias (k=10) and concerns in this area typically related to quality of reporting of the randomisation process. The deviation from intended interventions raised some concerns about RoB due to lack of reporting on any deviations from intended interventions.

The proportion of missing data and concerns regarding the handling of this, with only 12 studies using intention to treat analyses, were the most common reason for concerns in the missing outcome data domain, along with not providing an explicit explanation for missing data. Due to the relatively small sample sizes of the studies, missing data greater than 10% was considered cause for concern. Outcome measurement was often unblinded due to the high use of self-report measures, which was anticipated due to the nature of the review, and this was the most common reason for a high RoB rating in this domain of the RoB tool. Reasons for there being less concern in the outcome measurement domain, were where studies had reported on participant preference regarding treatment condition (k=1), where comparator participants were informed they would be offered the active intervention following the study (k=4), were blinded to the study hypothesis (k=1), or where HbA1C was the outcome of focus of the RoB assessment and was assumed not to be subject to bias in this domain as it was not based on self-report data. Concerns within the selection of reported results were often due to a paucity of available published protocols (k=5), with two being included in the supplementary material for the main study, three being pre-published (although full-text availability was not available for one study protocol and therefore was not consulted). The protocols for two further studies were available in an unpublished thesis; however, as it was an unpublished thesis it was not a pre-published analysis plan.

High RoB in the fidelity domain often reflected absence of fidelity assessment reporting and/or reporting of the results, with nine studies reporting on fidelity assessment. Two studies reported PPI, and neither of these reported detailed PPI throughout the research process and as such were rated as there being some concerns relating to RoB. It is important to note that the RoB assessment was based on one outcome, in this case, the most salient physical outcome for each study, and therefore may differ were other outcomes assessed.

The potential for publication bias is another consideration in quality assessment of included studies. Overall, given the findings of RoB assessments and the relatively small number of studies within each outcome domain, further investigation for publication bias using funnel plot graphs to test for asymmetry was not conducted.

Table 3.

Summary of risk of bias assessments for included studies

Study ID (First author and year)	**Domain 1: Randomisation**	**Domain 2: Deviations from intended interventions**	**Domain 3: Missing outcome data**	**Domain 4: Measurement of outcome**	**Domain 5: Selection of the reported result**	**Fidelity/ Adherence:**	**PPI:**
			Oncology				
Arch (2021)	Low	Some concerns	High	Some concerns	Some concerns	Low	High
Mosher (2018)	Low	Some concerns	High	High	Some concerns	Low	High
Shari (2020)	Some concerns	Some concerns	Low	High	Some concerns	Some concerns	High
Serfaty (2019)	Low	High	High	Some concerns	Some concerns	High	High
Esmali (2015)	High	High	High	High	Some concerns	High	High
Mosher (2019)	Low	Some concerns	Low	High	Some concerns	Low	High
Johns (2020)	Low	Some concerns	Some concerns	Some concerns	Some concerns	Low	High
			Endocrinology				
Gregg (2007)	Some concerns	Some concerns	Low	Low	Some concerns	High	High
Davoudi (2020)	Some concerns	Some concerns	Low	High	Some concerns	Low	High
Whitehead (2017)	Low	Some concerns	Low	High	Some concerns	Low	Some concerns
Shayeghian (2016)	Some concerns	Some concerns	Low	Low	Low	High	High
			Neurology				
Proctor (2018)	Some concerns	Low	Some concerns	High	Some concerns	Some concerns	High
Whiting (2020)	Low	Some concerns	High	High	Some concerns	Low	High
Lundgren (2008a)	Some concerns	High	Low	High	Some concerns	High	High
Dindo (2020)	Some concerns	Some concerns	High	High	Some concerns	High	Some concerns
Giovannetti (2020)	Some concerns	Some concerns	Low	High	Low	Some concerns	High
Lundgren (2006)	High	Some concerns	Low	High	Some concerns	High	High

Rheumatology							
Luciano (2014)	Low	Low	Low	Some concerns	Some concerns	Low	High
Simister (2018)	Some concerns	Some concerns	Low	Some concerns	Some concerns	High	High
Wicksell (2013)	Low	Some concerns	Low	Some concerns	Some concerns	Low	High
Clarke (2017)	Low	Low	High	High	Some concerns	Some concerns	High

Note: PPI = patient and public involvement.

Meta-Analysis Findings

Table 4 summarises meta-analysis findings for physical, psychological, and multi-domain outcomes.

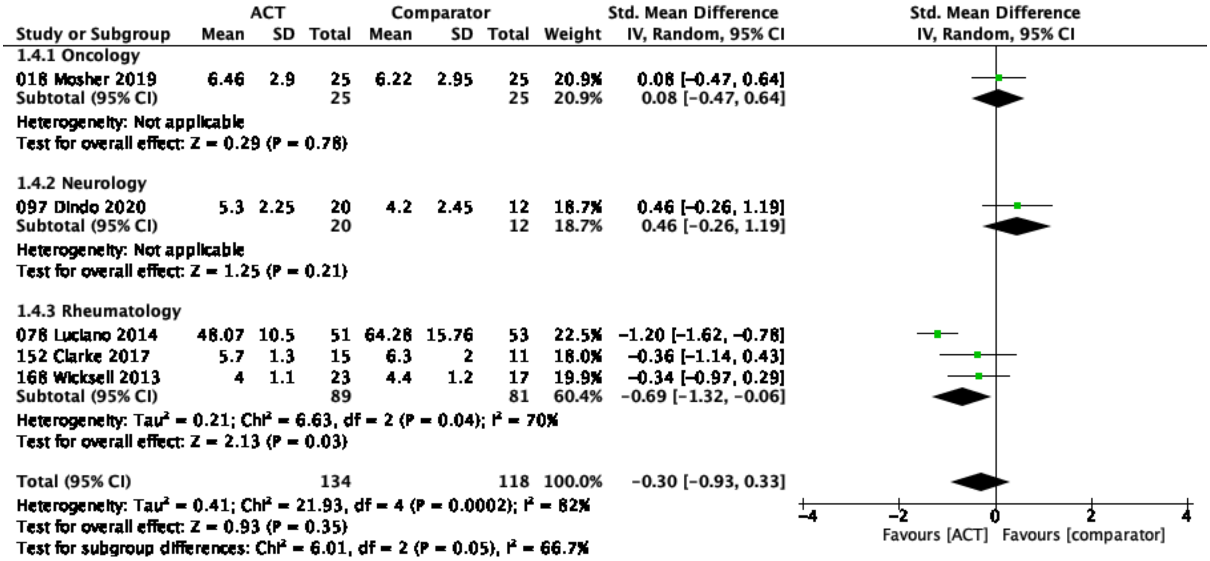
Physical Outcomes

Physical outcomes included physical health QoL (representing physical wellbeing and physical health QoL measures and subscales), fatigue, pain, fibromyalgia impact, and self-care. Overall, these did not show a significant summary effect of ACT compared to comparator (Table 4). One study included in the review reported a significant benefit of ACT for physical health QoL but could not be included in the meta-analysis due to reporting change scores (Johns, 2020).

The key findings within the physical domain were significant effects found at sub-group level for rheumatology in relation to pain and fibromyalgia impact. The rheumatology subgroup showed significant improvements in pain with a moderate effect size (p=0.03, I^2= 70%, SMD -0.69, 95% CI -1.32, -0.06), although substantial heterogeneity was found and sample sizes of individual studies was relatively small (total mean n=57, equating to a mean n=29 per condition). The minimum clinically important change (MCIC) has been suggested to be 20mm for the pain visual analogue scale (VAS) and 2.5 for the numeric rating scale (NRS) (Ostelo & de Vet, 2005) for people with chronic low back pain, which were not met by any of the included studies in the rheumatology sub-group. Whilst the MCIC indicators presented are based on a chronic low back pain population, comparison of the findings indicates that it is likely that the results are statistically but not clinically significant.

Figure 2

Forest Plot for the Physical Domain: Pain

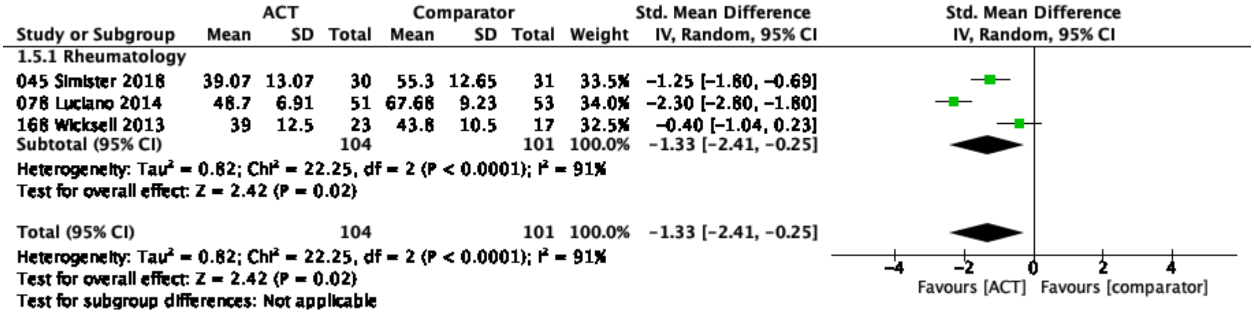


Study or Subgroup	ACT Mean	ACT SD	ACT Total	Comparator Mean	Comparator SD	Comparator Total	Weight	Std. Mean Difference IV, Random, 95% CI
1.4.1 Oncology								
018 Mosher 2019	6.46	2.9	25	6.22	2.95	25	20.9%	0.08 [−0.47, 0.64]
Subtotal (95% CI)			25			25	20.9%	0.08 [−0.47, 0.64]
Heterogeneity: Not applicable								
Test for overall effect: Z = 0.29 (P = 0.78)								
1.4.2 Neurology								
097 Dindo 2020	5.3	2.25	20	4.2	2.45	12	18.7%	0.46 [−0.26, 1.19]
Subtotal (95% CI)			20			12	18.7%	0.46 [−0.26, 1.19]
Heterogeneity: Not applicable								
Test for overall effect: Z = 1.25 (P = 0.21)								
1.4.3 Rheumatology								
078 Luciano 2014	48.07	10.5	51	64.28	15.76	53	22.5%	−1.20 [−1.62, −0.78]
152 Clarke 2017	5.7	1.3	15	6.3	2	11	18.0%	−0.36 [−1.14, 0.43]
168 Wicksell 2013	4	1.1	23	4.4	1.2	17	19.9%	−0.34 [−0.97, 0.29]
Subtotal (95% CI)			89			81	60.4%	−0.69 [−1.32, −0.06]
Heterogeneity: Tau² = 0.21; Chi² = 6.63, df = 2 (P = 0.04); I² = 70%								
Test for overall effect: Z = 2.13 (P = 0.03)								
Total (95% CI)			134			118	100.0%	−0.30 [−0.93, 0.33]
Heterogeneity: Tau² = 0.41; Chi² = 21.93, df = 4 (P = 0.0002); I² = 82%								
Test for overall effect: Z = 0.93 (P = 0.35)								
Test for subgroup differences: Chi² = 6.01, df = 2 (P = 0.05), I² = 66.7%								

Fibromyalgia impact was statistically significant (Figure 3) with a large effect size (p=0.02, I²= 91%, SMD -1.33, 95% CI -2.41, -0.25). The MCIC for the fibromyalgia impact questionnaire (FIQ) is 14% change (Bennett et al., 2009), so the observed changes of between 11 to 29.3% are likely to be clinically as well as statistically significant, although it should be noted that considerable heterogeneity was also found and sample sizes of individually studies was overall relatively small (total mean n=68, equating to a mean n=34 per condition).

Figure 3

Forest Plot for the Physical Domain: Fibromyalgia Impact



Study or Subgroup	ACT Mean	ACT SD	ACT Total	Comparator Mean	Comparator SD	Comparator Total	Weight	Std. Mean Difference IV, Random, 95% CI
1.5.1 Rheumatology								
045 Simister 2018	39.07	13.07	30	55.3	12.65	31	33.5%	−1.25 [−1.80, −0.69]
078 Luciano 2014	48.7	6.91	51	67.68	9.23	53	34.0%	−2.30 [−2.80, −1.80]
168 Wicksell 2013	39	12.5	23	43.8	10.5	17	32.5%	−0.40 [−1.04, 0.23]
Subtotal (95% CI)			104			101	100.0%	−1.33 [−2.41, −0.25]
Heterogeneity: Tau² = 0.82; Chi² = 22.25, df = 2 (P < 0.0001); I² = 91%								
Test for overall effect: Z = 2.42 (P = 0.02)								
Total (95% CI)			104			101	100.0%	−1.33 [−2.41, −0.25]
Heterogeneity: Tau² = 0.82; Chi² = 22.25, df = 2 (P < 0.0001); I² = 91%								
Test for overall effect: Z = 2.42 (P = 0.02)								
Test for subgroup differences: Not applicable								

No overall significant summary effect for pain was found. Mosher (2018) was not included in statistical analyses due to reporting change scores and found no significant difference on measures of pain. Three studies reported no evidence in support of ACT for pain interference (Mosher, 2018, 2019; Dindo, 2020).

Fatigue was reported only in oncology studies (n=4). Mosher (2018) was not included in the meta-analyses due to the presentation of change scores. The meta-analysis and Mosher (2018) found no significant effect. Mosher (2018; 2019) additionally reported on fatigue interference and neither found a significant effect, in line with the findings for fatigue.

Sleep was not subject to meta-analysis, due to the differing aspects of the construct measured. Four studies reported sleep outcomes. Two oncology studies reported sleep disturbance (Mosher, 2019) and sleep impairment (Mosher, 2018), whilst two endocrinology studies measured sleep quality (Davoudi, 2020; Simister, 2018). Only Davoudi (2020) found a significant improvement in sleep quality.

Self-care was only reported by studies in the endocrinology subgroup, specifically in relation to diabetes management, and did not yield a significant summary effect estimate (Table 4). Two further endocrinology outcomes were not included in the meta-analysis: blood glucose levels (HbA1C) and understanding of diabetes. HbA1C reports were not included in statistical analyses due to inconsistent reporting of results. All studies reported reductions in HbA1C, two of which were statistically significant (Gregg, 2007; Shayeghian, 2016). Understanding of diabetes did not change significantly in two studies (Gregg, 2007; Whitehead, 2017).

Two epilepsy studies reported a seizure index (Lundgren, 2006, 2008a). Whilst this was too few studies for meta-analysis both studies reported significant findings in favour of ACT.

Table 4.

Summary of findings from meta-analyses

Domain	Outcome	Overall Summary Effect p-value, I², SMD (CI 95%)	Sub-group Analysis	Sub-group Summary Effect p-value, I², SMD (CI 95%)
Physical	Physical health QoL	p=0.90, I²= 0%, 0.02 (-0.35, 0.4)	N/a	N/a
	Fatigue	N/a	Oncology	p=0.78, I²=67%, 0.07 (-0.4, 0.54)
	Pain	p=0.35, I²= 82%, -0.30 (-0.93, 0.33)	**Rheumatology**	**p=0.03, I²= 70%, -0.69 (-1.32, -0.06)**
	Fibromyalgia Impact	N/a	**Rheumatology**	**p=0.02, I²= 91%, -1.33 (-2.41, -0.25)**
	Self-care	N/a	Endocrinology	p=0.16, I²= 41%, -0.24 (-0.57, 0.09)
Psychological	Acceptance	**p=0.001, I²= 78%, -0.59 (-0.95, -0.23)**	Oncology	p=0.24, I²= 91%, -0.78 (-2.09, 0.53)
			Endocrinology	**p=0.02, I²= 17%, -0.32 (-0.6, -0.04)**
			Neurology	p=0.10, I²= 0%, -0.31 (-0.69, 0.06)
	Values	p=0.11, I²=0%, -0.30 (-0.67, 0.07)	N/a	N/a
	Anxiety	**p=0.006, I²= 73%, -0.49 (-0.84, -0.14)**	Oncology	p=0.21, I²= 88%, -0.50 (-1.29, 0.29)
			Neurology	p=0.07, I²= 16%, -0.45 (-0.94, 0.04)
	Depression	**p=0.005, I²= 82%, -0.56 (-0.96, -0.17)**	Oncology	p=0.22, I²= 83%, -0.42 (-1.08, 0.24)
			Neurology	p=0.19, I²= 18%, -0.33 (-0.83, 0.16)
			Rheumatology	**p=0.01, I²= 86%, -1.08 (-1.91, -0.24)**
	General Mental health / QoL	**p=0.0007, I²= 0%, -0.60 (-0.95, -0.26)**	N/a	N/a
Quality of Life	QoL	p=0.55, I²= 86%, -0.27 (-1.16, 0.62)	Neurology	p=0.80, I²= 0%, -0.06 (-0.54, 0.42)

Note: Physical health QoL and General Mental health / QoL outcomes included outcome measures related to physical and mental wellbeing, and/or physical and mental health QoL (a full break down of outcome measures by study and domain can be found in appendix J). p-value = statistical significance with significance level set at $p<0.05$; I^2 = measure of heterogeneity (%); SMD = standardised mean difference; CI 95% = Confidence Interval at 95%.

Psychological Outcomes

All psychological outcomes (acceptance, values, anxiety, depression and general mental health/QoL) had significant overall summary effect estimates, except for the outcome of values (Table 4).

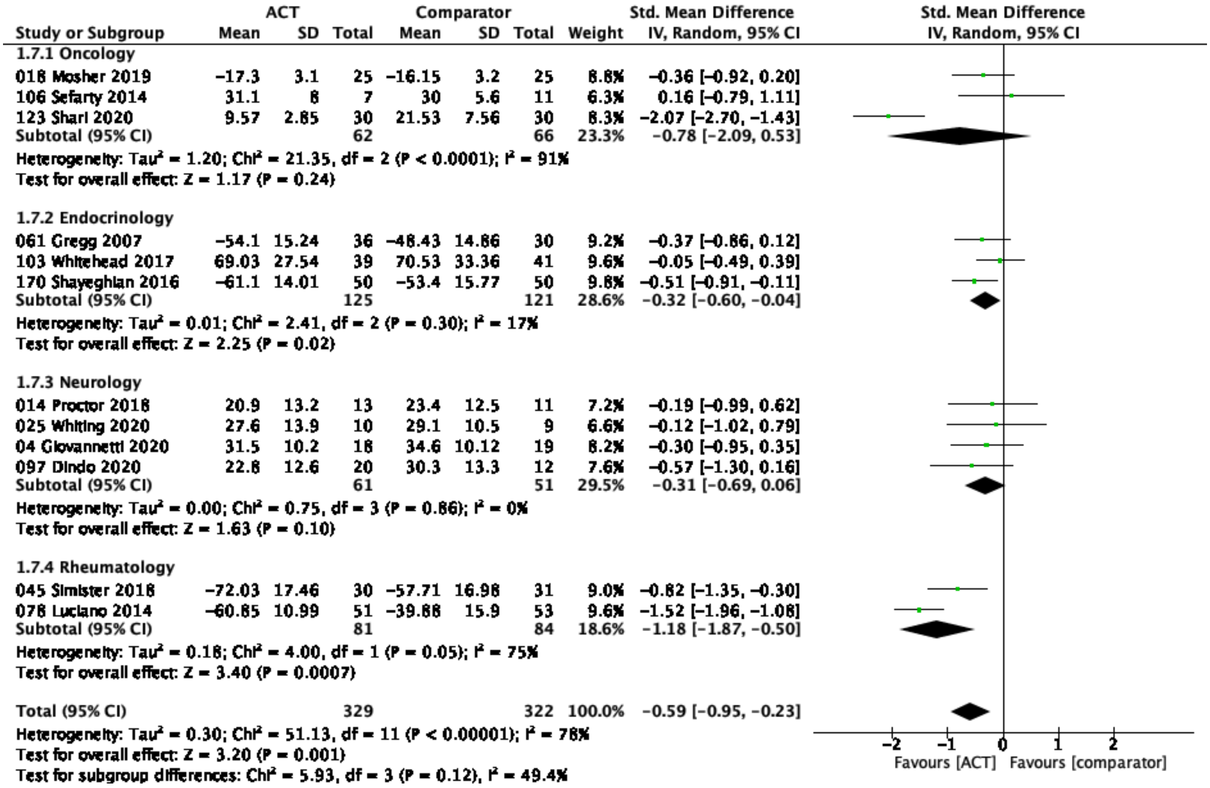
The overall summary effect estimate for acceptance was significant (Figure 4) with a medium effect size ($p=0.001$, $I^2= 78\%$, SMD -0.59, 95% CI -0.95, -0.23). One study (Johns, 2020) could not be included in the meta-analysis but also reported a significant between group effect ($p<0.05$). Of the subgroup analyses conducted (oncology, endocrinology, and neurology) only the endocrinology subgroup analysis demonstrated a significant effect with a small effect size ($p=0.02$, $I^2= 17\%$, SMD -0.32 95% CI -0.6, -0.04). However, there was significant heterogeneity and sample sizes were relatively small (total mean n=54, equating to a mean n=27 per condition).

Measures relating to personal values, showed a nonsignificant difference between ACT and controls (see supplementary material for corresponding forest plot graph). Whiting (2020) reported on values using the Survey of Life Principles; however, the method of reporting made it difficult to ascertain the direction of change and therefore the results were not used in the analysis.

Two studies (Giovannetti, 2020; Simister, 2018) reported on mindfulness outcomes; however no statistically significant effects were found. The same two studies also reported on cognitive fusion with Giovennetti (2020) finding a nonsignificant between groups effect and Simister (2018) reporting a small improvement ($d=0.25$) relative to TAU post-treatment. Due to the small number of studies these outcomes were not included in the meta-analysis.

Figure 4.

Forest Plot for the Psychological Domain: Acceptance

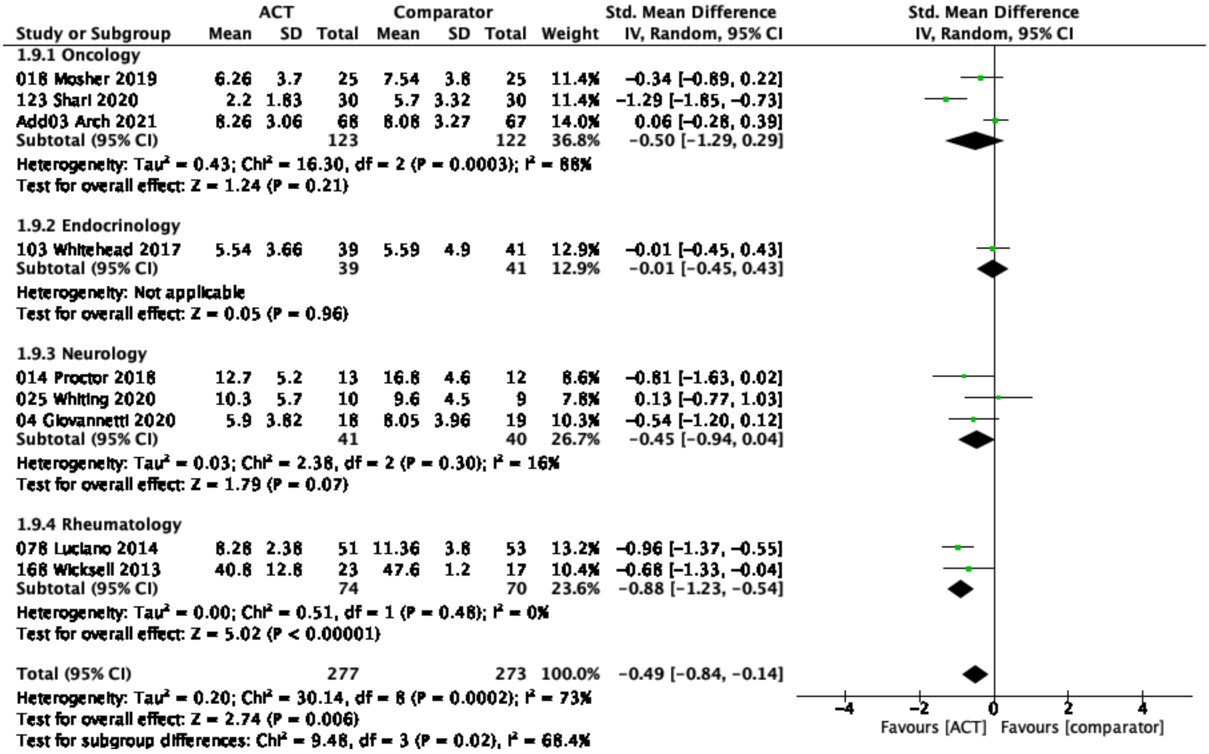


	ACT			Comparator				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
1.7.1 Oncology								
018 Mosher 2019	−17.3	3.1	25	−16.15	3.2	25	8.8%	−0.36 [−0.92, 0.20]
106 Sefarty 2014	31.1	8	7	30	5.6	11	6.3%	0.16 [−0.79, 1.11]
123 Shari 2020	9.57	2.85	30	21.53	7.56	30	8.3%	−2.07 [−2.70, −1.43]
Subtotal (95% CI)			62			66	23.3%	−0.78 [−2.09, 0.53]
Heterogeneity: Tau² = 1.20; Chi² = 21.35, df = 2 (P < 0.0001); I² = 91%								
Test for overall effect: Z = 1.17 (P = 0.24)								
1.7.2 Endocrinology								
061 Gregg 2007	−54.1	15.24	36	−48.43	14.86	30	9.2%	−0.37 [−0.86, 0.12]
103 Whitehead 2017	69.03	27.54	39	70.53	33.36	41	9.6%	−0.05 [−0.49, 0.39]
170 Shayeghian 2016	−61.1	14.01	50	−53.4	15.77	50	9.8%	−0.51 [−0.91, −0.11]
Subtotal (95% CI)			125			121	28.6%	−0.32 [−0.60, −0.04]
Heterogeneity: Tau² = 0.01; Chi² = 2.41, df = 2 (P = 0.30); I² = 17%								
Test for overall effect: Z = 2.25 (P = 0.02)								
1.7.3 Neurology								
014 Proctor 2018	20.9	13.2	13	23.4	12.5	11	7.2%	−0.19 [−0.99, 0.62]
025 Whiting 2020	27.6	13.9	10	29.1	10.5	9	6.6%	−0.12 [−1.02, 0.79]
04 Giovannetti 2020	31.5	10.2	18	34.6	10.12	19	8.2%	−0.30 [−0.95, 0.35]
097 Dindo 2020	22.8	12.6	20	30.3	13.3	12	7.6%	−0.57 [−1.30, 0.16]
Subtotal (95% CI)			61			51	29.5%	−0.31 [−0.69, 0.06]
Heterogeneity: Tau² = 0.00; Chi² = 0.75, df = 3 (P = 0.86); I² = 0%								
Test for overall effect: Z = 1.63 (P = 0.10)								
1.7.4 Rheumatology								
045 Simister 2018	−72.03	17.46	30	−57.71	16.98	31	9.0%	−0.82 [−1.35, −0.30]
078 Luciano 2014	−60.85	10.99	51	−39.88	15.9	53	9.6%	−1.52 [−1.96, −1.08]
Subtotal (95% CI)			81			84	18.6%	−1.18 [−1.87, −0.50]
Heterogeneity: Tau² = 0.18; Chi² = 4.00, df = 1 (P = 0.05); I² = 75%								
Test for overall effect: Z = 3.40 (P = 0.0007)								
Total (95% CI)			329			322	100.0%	−0.59 [−0.95, −0.23]
Heterogeneity: Tau² = 0.30; Chi² = 51.13, df = 11 (P < 0.00001); I² = 78%								
Test for overall effect: Z = 3.20 (P = 0.001)								
Test for subgroup differences: Chi² = 5.93, df = 3 (P = 0.12), I² = 49.4%								

The overall summary effect estimate for anxiety was significant (Figure 5) with a small effect size estimate (p=0.006, I²= 73%, SMD -0.49, 95% CI -0.84, -0.14), although there was substantial heterogeneity across studies and the mean sample size of individual studies was relatively small (total mean n=55, equating to a mean n=28 per condition). No subgroup analyses yielded a significant effect (please see Table 4). Mosher (2018) and Johns (2020) were not included in the meta-analysis due to reporting change scores; both studies found no significant between group effects.

Figure 5.

Forest Plot for the Psychological Domain: Anxiety

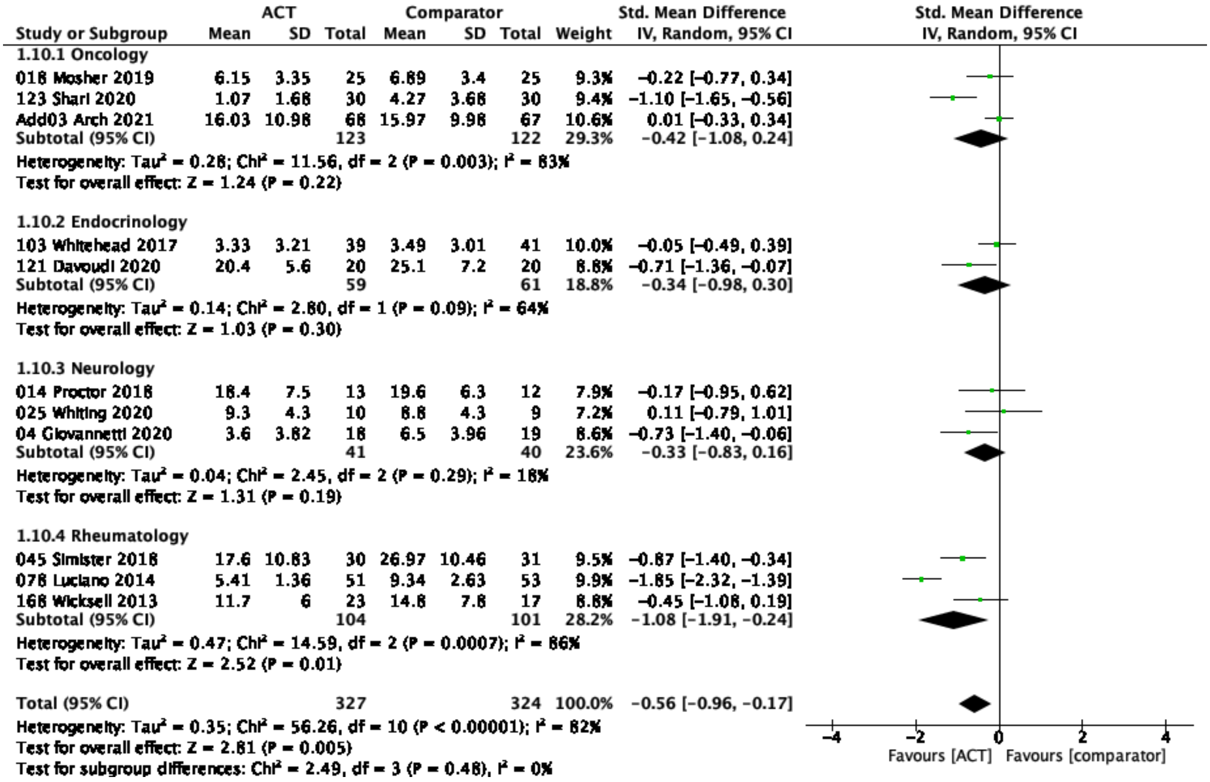


	ACT			Comparator				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
1.9.1 Oncology								
018 Mosher 2019	6.26	3.7	25	7.54	3.8	25	11.4%	−0.34 [−0.89, 0.22]
123 Shari 2020	2.2	1.83	30	5.7	3.32	30	11.4%	−1.29 [−1.85, −0.73]
Add03 Arch 2021	8.26	3.06	68	8.08	3.27	67	14.0%	0.06 [−0.28, 0.39]
Subtotal (95% CI)			123			122	36.8%	−0.50 [−1.29, 0.29]
Heterogeneity: $Tau^2 = 0.43; Chi^2 = 16.30, df = 2 (P = 0.0003); I^2 = 88\%$								
Test for overall effect: $Z = 1.24 (P = 0.21)$								
1.9.2 Endocrinology								
103 Whitehead 2017	5.54	3.66	39	5.59	4.9	41	12.9%	−0.01 [−0.45, 0.43]
Subtotal (95% CI)			39			41	12.9%	−0.01 [−0.45, 0.43]
Heterogeneity: Not applicable								
Test for overall effect: $Z = 0.05 (P = 0.96)$								
1.9.3 Neurology								
014 Proctor 2018	12.7	5.2	13	16.8	4.6	12	8.6%	−0.81 [−1.63, 0.02]
025 Whiting 2020	10.3	5.7	10	9.6	4.5	9	7.8%	0.13 [−0.77, 1.03]
04 Giovannetti 2020	5.9	3.82	18	8.05	3.96	19	10.3%	−0.54 [−1.20, 0.12]
Subtotal (95% CI)			41			40	26.7%	−0.45 [−0.94, 0.04]
Heterogeneity: $Tau^2 = 0.03; Chi^2 = 2.38, df = 2 (P = 0.30); I^2 = 16\%$								
Test for overall effect: $Z = 1.79 (P = 0.07)$								
1.9.4 Rheumatology								
078 Luciano 2014	8.28	2.38	51	11.36	3.8	53	13.2%	−0.96 [−1.37, −0.55]
168 Wicksell 2013	40.8	12.8	23	47.6	1.2	17	10.4%	−0.68 [−1.33, −0.04]
Subtotal (95% CI)			74			70	23.6%	−0.88 [−1.23, −0.54]
Heterogeneity: $Tau^2 = 0.00; Chi^2 = 0.51, df = 1 (P = 0.48); I^2 = 0\%$								
Test for overall effect: $Z = 5.02 (P < 0.00001)$								
Total (95% CI)			277			273	100.0%	−0.49 [−0.84, −0.14]
Heterogeneity: $Tau^2 = 0.20; Chi^2 = 30.14, df = 8 (P = 0.0002); I^2 = 73\%$								
Test for overall effect: $Z = 2.74 (P = 0.006)$								
Test for subgroup differences: $Chi^2 = 9.48, df = 3 (P = 0.02), I^2 = 68.4\%$								

Within the anxiety outcome, two oncology studies reported on fear of cancer recurrence, with Johns (2020) finding no significant between groups effect and Arch (2021) finding a significant condition and time interaction effect for ACT (p=0.003). Two rheumatology studies reported on pain catastrophising (Luciano, 2014; Simister 2018) with Luciano (2014) reporting a significant group and time interaction effect in favour of ACT and Simister (2018) reporting no statistically significant difference. Three studies reported on symptoms of post-traumatic stress (Oncology: Arch, 2021; Johns, 2020; Neurology: Dindo, 2020); however, these could not be included in the meta-analysis due to reporting change scores in Johns (2020). Arch (2021) found a significant condition and time interaction in favour of ACT; however no statistically significant effects were reported in the remaining studies.

Figure 6.

Forest Plot for the Psychological Domain: Depression



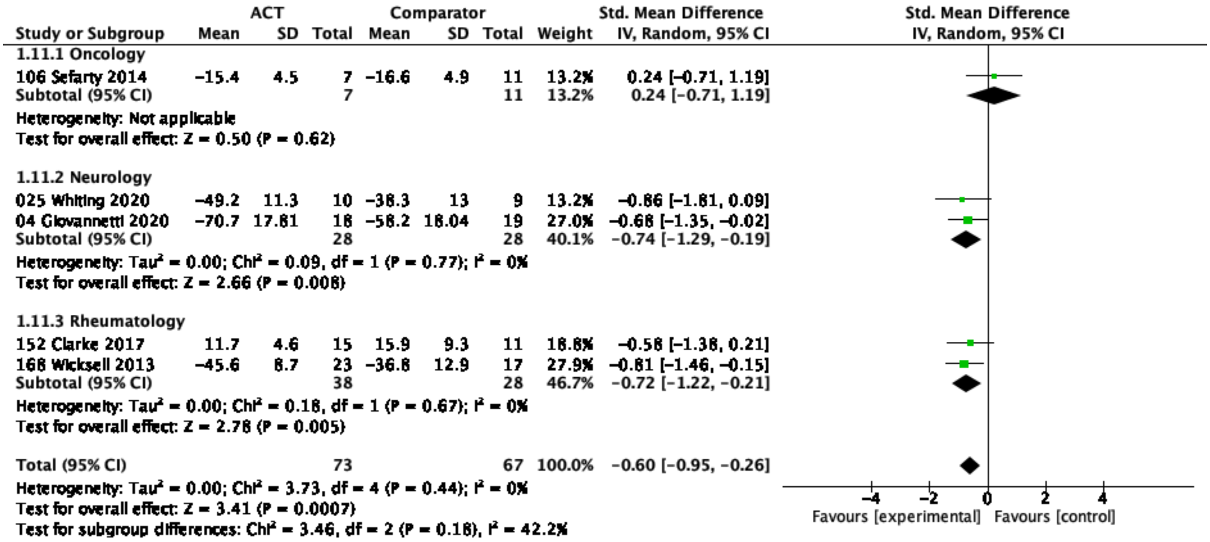
	ACT			Comparator				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
1.10.1 Oncology								
018 Mosher 2019	6.15	3.35	25	6.89	3.4	25	9.3%	−0.22 [−0.77, 0.34]
123 Shari 2020	1.07	1.68	30	4.27	3.68	30	9.4%	−1.10 [−1.65, −0.56]
Add03 Arch 2021	16.03	10.98	68	15.97	9.98	67	10.6%	0.01 [−0.33, 0.34]
Subtotal (95% CI)			123			122	29.3%	−0.42 [−1.08, 0.24]
Heterogeneity: Tau² = 0.28; Chi² = 11.56, df = 2 (P = 0.003); I² = 83%								
Test for overall effect: Z = 1.24 (P = 0.22)								
1.10.2 Endocrinology								
103 Whitehead 2017	3.33	3.21	39	3.49	3.01	41	10.0%	−0.05 [−0.49, 0.39]
121 Davoudi 2020	20.4	5.6	20	25.1	7.2	20	8.8%	−0.71 [−1.36, −0.07]
Subtotal (95% CI)			59			61	18.8%	−0.34 [−0.98, 0.30]
Heterogeneity: Tau² = 0.14; Chi² = 2.80, df = 1 (P = 0.09); I² = 64%								
Test for overall effect: Z = 1.03 (P = 0.30)								
1.10.3 Neurology								
014 Proctor 2018	18.4	7.5	13	19.6	6.3	12	7.9%	−0.17 [−0.95, 0.62]
025 Whiting 2020	9.3	4.3	10	8.8	4.3	9	7.2%	0.11 [−0.79, 1.01]
04 Giovannetti 2020	3.6	3.82	18	6.5	3.96	19	8.6%	−0.73 [−1.40, −0.06]
Subtotal (95% CI)			41			40	23.6%	−0.33 [−0.83, 0.16]
Heterogeneity: Tau² = 0.04; Chi² = 2.45, df = 2 (P = 0.29); I² = 18%								
Test for overall effect: Z = 1.31 (P = 0.19)								
1.10.4 Rheumatology								
045 Simister 2018	17.6	10.83	30	26.97	10.46	31	9.5%	−0.87 [−1.40, −0.34]
078 Luciano 2014	5.41	1.36	51	9.34	2.63	53	9.9%	−1.85 [−2.32, −1.39]
168 Wicksell 2013	11.7	6	23	14.8	7.8	17	8.8%	−0.45 [−1.08, 0.19]
Subtotal (95% CI)			104			101	28.2%	−1.08 [−1.91, −0.24]
Heterogeneity: Tau² = 0.47; Chi² = 14.59, df = 2 (P = 0.0007); I² = 86%								
Test for overall effect: Z = 2.52 (P = 0.01)								
Total (95% CI)			327			324	100.0%	−0.56 [−0.96, −0.17]
Heterogeneity: Tau² = 0.35; Chi² = 56.26, df = 10 (P < 0.00001); I² = 82%								
Test for overall effect: Z = 2.81 (P = 0.005)								
Test for subgroup differences: Chi² = 2.49, df = 3 (P = 0.48), I² = 0%								

The overall effect estimate for depression was significant (Figure 6) with a medium effect size estimate (p=0.005, I²= 82%, SMD -0.56 95% CI -0.96, -0.17), although substantial heterogeneity was found and mean sample size of individual studies was relatively small (total mean n=59, equating to a mean n=30 per condition). Sub-group analyses did not yield significant summary effect estimates, aside from the rheumatology sub-group which yielded a significant effect (p=0.01, I²= 86%, SMD -1.08 95% CI -1.91, -0.24). However, substantial heterogeneity across studies for the rheumatology sub-group analysis was found. Two studies in the oncology sub-group that were not able to be included in the meta-analysis (Mosher, 2018; Johns, 2020) reported no significant between group effects.

The general mental health/QoL outcome was based on measures of general psychological or mental health, and psychological or mental health QoL. Analysis yielded a significant overall summary effect estimate (Figure 7) with a medium effect size estimate ($p=0.0007$, $I^2= 0\%$, SMD -0.60, 95% CI -0.95, -0.26). This was supported by an additional study that could be not included in the meta-analysis (Johns, 2020) which also found a significant effect of ACT ($p<0.01$). No subgroup analyses were conducted due to insufficient studies. Whilst no heterogeneity was found across studies included in the analysis, the number of studies was small (k=5) and study sample size was also small (total mean n=28, equating to a mean n=14 per condition).

Figure 7.

Forest Plot for the Psychological Domain: General Mental health/QoL



	ACT			Comparator				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
1.11.1 Oncology								
106 Sefarty 2014	−15.4	4.5	7	−16.6	4.9	11	13.2%	0.24 [−0.71, 1.19]
Subtotal (95% CI)			7			11	13.2%	0.24 [−0.71, 1.19]
Heterogeneity: Not applicable								
Test for overall effect: Z = 0.50 (P = 0.62)								
1.11.2 Neurology								
025 Whiting 2020	−49.2	11.3	10	−38.3	13	9	13.2%	−0.86 [−1.81, 0.09]
04 Giovannetti 2020	−70.7	17.81	18	−58.2	18.04	19	27.0%	−0.68 [−1.35, −0.02]
Subtotal (95% CI)			28			28	40.1%	−0.74 [−1.29, −0.19]
Heterogeneity: Tau^2 = 0.00; Chi^2 = 0.09, df = 1 (P = 0.77); I^2 = 0%								
Test for overall effect: Z = 2.66 (P = 0.008)								
1.11.3 Rheumatology								
152 Clarke 2017	11.7	4.6	15	15.9	9.3	11	18.8%	−0.58 [−1.38, 0.21]
168 Wicksell 2013	−45.6	8.7	23	−36.8	12.9	17	27.9%	−0.81 [−1.46, −0.15]
Subtotal (95% CI)			38			28	46.7%	−0.72 [−1.22, −0.21]
Heterogeneity: Tau^2 = 0.00; Chi^2 = 0.18, df = 1 (P = 0.67); I^2 = 0%								
Test for overall effect: Z = 2.78 (P = 0.005)								
Total (95% CI)			73			67	100.0%	−0.60 [−0.95, −0.26]
Heterogeneity: Tau^2 = 0.00; Chi^2 = 3.73, df = 4 (P = 0.44); I^2 = 0%								
Test for overall effect: Z = 3.41 (P = 0.0007)								
Test for subgroup differences: Chi^2 = 3.46, df = 2 (P = 0.18), I^2 = 42.2%								

Multi-domain outcomes: QoL

A meta-analysis of multi-domain QoL outcomes was undertaken, which did not include individual subscales already included in analysis in either the physical or psychological outcome domains. No significant effect was found. See the supplementary material for remaining forest plot graphs not presented here, including for QoL.

Discussion

This systematic review and meta-analysis for the efficacy of ACT for holistic for self-management for LTCs is the first review to the authors' knowledge to take this stance in reviewing the efficacy of ACT for PLTC. In doing so it builds on the findings of previous reviews such as that by Graham et al., (2016), in addition to capturing the increase in RCTs of ACT for LTCs and analysing the results of these statistically. This is salient as it has been argued that it is important to assess a diverse range of variables from across the biopsychosocial domains within health psychology research, to aid our understanding of the complexity of health rather than viewing it through a reductionist lens (Suls & Rothman, 2004).

The results of the meta-analysis and narrative synthesis provide promising preliminary evidence of the efficacy of ACT for psychological outcomes including acceptance, anxiety, depression and general mental health/QoL, with small to moderate effect sizes reported. There was also preliminary evidence of the efficacy of ACT for holistic elf-management for people with rheumatological conditions in terms of pain, fibromyalgia impact and depression, with moderate to large effect sizes reported. However, the MCIC for the measures utilised in the pain analysis indicated that the results for this outcome may be statistically but not clinically significant. However, there were generally substantial levels of heterogeneity across studies and this, in addition to concerns related to RoB and the small number of studies and sample sizes of them, limits the ability to draw conclusive findings from the review.

Another important finding was that social outcomes could not be analysed, due to a lack of reporting of these across studies that rendered meaningful analysis or synthesis of the results impossible. It is notable that only three studies reported on outcomes in each of the physical, psychological, and social domains. Similarly to Suls and Rothman (2004), macro level factors such as employment tended to be used to aid description of the sample rather than being considered in the analysis and there was a high degree of variation in what demographic variables were reported across studies. This is despite the importance of taking into account social factors for PLTCs (Lehman et al., 2017; Macdonald et al., 2018; Putnam et al., 2013; Stanton et al., 2007).

One of the aspects of ACT that could have utility for LTCs is their transdiagnostic nature. This is salient for PLTC given the rise in multi-morbidity for (DoH, 2012) and evidence has been found in support of transdiagnostic ACT interventions (Brassington et al., 2016). However, in the current review, only one study (Dindo, 2020) actively recruited participants with co-morbidities and many studies did not report on any co-morbidities of participants. Whilst it has been suggested it is important to account for the specific aims of self-management interventions with specific populations and how these may differ (Newman et al., 2004), the rise in multi-morbidity (DoH, 2012) indicates a potential need for transdiagnostic self-management interventions.

Another important consideration when interpreting the findings of the review is to consider the theoretical underpinnings of ACT. ACT does not aim to reduce pain, but to enable people to live a meaningful life in the presence of pain and suffering and posits that this is achieved by increasing psychological flexibility (Harris, 2009). Any change in subjective experiences of pain or distress are considered a by-product rather than an aim of ACT and as such attempts to evaluate it solely via measures of pain or distress leave scope for misrepresentation both of ACT and its evidence base.

The current review did not find conclusive evidence of the efficacy of ACT in process outcomes such as acceptance and values, although there was an overall significant effect of acceptance and an effect for the endocrinology sub-group. However, these findings could have been confounded by a number of factors. Firstly, acceptance and values are two of six aspects of psychological flexibility, and therefore it may be that these are not wholly sufficient to assess psychological flexibility. Secondly, it was surprising that given the proposed mechanisms of ACT that not all studies reported ACT process outcomes (k=14) meaning that only measures of acceptance and values could be analysed, despite some studies reporting on other aspects of psychological flexibility, such as cognitive defusion. Thirdly, the relatively small number of studies, sample sizes and concerns regarding the level of heterogeneity and potential for bias in the results limit the conclusiveness of the findings.

In addition to potential concerns about the way ACT is measured in relation to outcome, it may also be that improvements in self-management can occur independently of observed improvements in physical, psychological, and social outcomes. No studies reported specific self-management outcome measures outside of within the endocrinology sub-group, although the measure used, the Summary of Diabetes Self Care Activities, (SDSCA; Toobert et al., 2000) focuses on physical and practical aspects of self-management rather than taking a holistic stance.

A final consideration in relation to possible explanations for the findings may relate to the format and delivery of ACT interventions included in the review. Many studies reported brief, group-based interventions with limited PPI. It may be that there is a dose effect of ACT for people with LTCs (Graham et al., 2016); however, due to the small number of studies in the review, it was not possible to analyse the potential effects of these variables. Given the chronicity of LTCs, this may be an important consideration.

The findings of the current review were consistent with those of previous systematic and meta-analytic reviews (Graham et al., 2016; Öst, 2008; 2014), which have highlighted methodological and quality concerns across studies, and a wide variation in the intensity of reported ACT interventions (Graham et al., 2016; Öst, 2008; 2014). Graham et al., (2016) reported that the rate of intervention studies for ACT appeared to be increasing and given their finding of eight RCTs, it appears that this has continued to increase. In a broader review of ACT not specific to LTCs, Öst (2008) concluded that ACT did not meet the criteria for empirically supported treatments. In an updated review Öst, (2014) concluded that there had been no significant methodological improvements since their 2008 review, and that they could not yet make conclusions on the efficacy ACT outside of its probably efficacy for certain conditions such as chronic pain, which has been highlighted in NICE guidance (NICE, 2021). Graham et al., (2016) noted that due to the relative infancy of the evidence base, the increasing utilisation of ACT could reflect both its efficacy for LTCs but also potentially a “therapeutic fad” (pp.56).

On comparison of the current review with recommendations made by Öst (2008), many of the same themes emerge and those recommendations salient to the review are discussed. One of the recommendations related to using an active control with known efficacy for the condition to be used as the comparator for ACT in RCTs, rather than waitlist controls or TAU, and noted that TAU was often poorly defined. Due to the variation in passive and more active controls, the most passive comparator was chosen for the current review to allow for more consistency in the comparator; however, it was notable that the description of passive control conditions varied across studies.

Another recommendation by Öst (2008) highlighted the importance of robust power analyses being undertaken prior to studies and it was notable that only ten studies reported any power calculation or sample size justification in the current review. Other recommendations related to the robustness of objective randomisation procedures, and one of the main causes of concern for RoB within this domain in the current review was lack of detail in the reporting of this part of the procedure.

Using valid and reliable outcome measures that are both specific to the condition studied and more general was also highlighted by Öst (2008). This has salience for the current review given not only given the relatively low number of studies reporting on ACT process outcomes, but also the wide variety of outcome measures used within and across sub-groups. A particular example of this was the difference noted in the scoring and direction of change of the AADQ found between studies.

Further recommendation was for multiple therapists, randomised to participants, to be used so that therapist effects can be accounted for (Öst, 2008). Many studies in the current review reported on group ACT interventions; however, this recommendation is applicable to both group and individual interventions, and it was noted that four studies had the same professional delivering both ACT and comparator interventions. Nine studies out of the 21 included in the current review conducted and reported the results of fidelity assessments to ensure adherence in the delivery of the intervention, and this was another key recommendation of Öst (2008).

With regards to analysis, Öst (2008) also made recommendations relating to the importance of accounting for and describing attrition, concomitant treatments and conducting an ITT analysis. Issues related to the description and extent of missing data as well as its handling were common concerns in RoB assessments in the current review, and not all studies reported ITT analysis (k=12). Assessing clinical, as well as statistical significance was also recommended, as well as ensuring the representativeness of the participant sample.

Limitations

The limitations of the current systematic review and meta-analysis are influenced by the issues related to study quality, number, representativeness of participant sample and outcomes across domains, as previously described. Another potential limitation is the diversity of intervention characteristics such as format and delivery, which may have influenced the results; however, due to the small number of studies this was not able to be meaningfully analysed statistically. Taking a holistic approach may have also narrowed the scope of the findings due to strict eligibility criteria around the reporting of at least one physical and psychological or social outcome; however, it has been argued that it is pertinent to take account of the complexity of health in health psychology research and to evaluate a diverse range of biopsychosocial outcomes (Suls & Rothman, 2004). In addition, LTCs were divided into sub-groups related to medical specialisms, which meant some sub-groups contained participants with different diagnoses. Whilst this may limit conclusions drawn from sub-group analyses for individual diagnoses, the subgroups reflected commonalities across conditions and part of ACT's potential utility is its transdiagnostic nature, therefore it was felt this provided a way to conduct a meaningful more detailed analysis across outcome domains.

Conclusions and Implications for Clinical Practice and Research

Given the findings of the current review, to date there is not sufficient evidence to be able to advocate for the widespread implementation of ACT for PLTC. As such, the findings of the current review have limited implications for clinical practice as there remains insufficient evidence of the efficacy of ACT for holistic self-management for PLTCs. This reflects methodological issues such as study quality, sample size and representativeness, and a lack of the reporting across holistic outcome domains.

Recommendations for future research remain similar to those highlighted by Öst (2008; 2014). Larger, higher quality studies of ACT for LTCs are required for more definitive evidence of efficacy for PLTCs. Maintaining the consistency of valid, reliable outcome measures and the direction of change used would aid future meta-analytic reviews and interpretation of the evidence base. A range of ACT process outcomes should be measured as standard to allow meaningful analysis of the mechanisms of the ACT, and in the context of the focus of this review more specific measures of self-management could be utilised in future research to investigate the relationship between ACT and self-management. An example of one such measure would be the Patient Activation Measure (PAM) which assesses the “knowledge, skills, beliefs and behaviors that a patient needs to manage a chronic illness” (Hibbard et al., 2004 pp.1006). Further recommendations relate to the importance of accounting for the complexity of human health and the interplay between biological, psychological and social factors by measuring a diverse range of outcomes across these domains in line with a holistic approach to health for PLTC (Lehman et al., 2017; Suls & Rothman, 2004). Within this, future research should account for the representativeness of participant samples and report on a diverse and consistent range of participant demographics, as also highlighted by Öst (2008). A final recommendation for future research is the involvement of PPI throughout the research process, to ensure that research is accessible and meaningful for those it intends to benefit (Health Research Authority/INVOLVE, 2016).

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Supplementary Material

- Table of study identifier (ID) and corresponding studies and reports
- Forest plot graphs for remaining outcomes across outcome domains

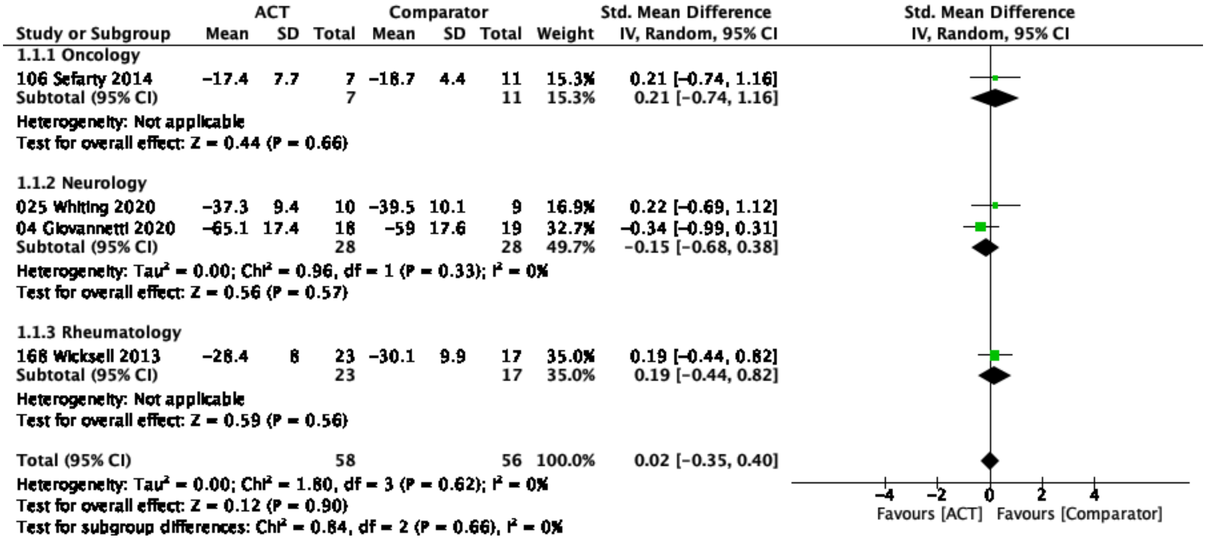
Supplementary material: Table of study identifier (ID) and corresponding studies and reports

Study ID (first author and year)	Main Study and Additional Papers
Arch 2021	Arch et al., (2021) (Main study) Arch et al., (2019) (Protocol) Arch and Mitchell (2016) (Development study)
Mosher 2018	Mosher et al., (2018) (Main study)
Shari 2020	Shari et al., (2020) (Main study)
Serfaty 2019	Serfaty et al., (2019) (Main study) Low et al., (2016) (Protocol)
Esmali 2015	Esmali and Alizadeh (2015) (Main study)
Mosher 2019	Mosher et al., (2019) (Main study)
Johns 2020	Johns et al., (2020) (Main study)
Gregg 2007	Gregg et al., (2007) (Main study) (Could not access cited manual)
Davoudi 2020	Davoudi et al., (2020) (Main study)
Whitehead 2017	Whitehead et al., (2017a) (Main study) Whitehead et al., (2017b) (Process evaluation)
Shayeghian 2016	Shayeghian et al., (2016) (Main study) (Protocol in supplementary material of main study)
Proctor 2018	Proctor et al., (2018) (Main Study)
Whiting 2020	Whiting et al., (2020) (Could not access published protocol)
Lundgren 2008a	Lundgren et al., (2008a) (Main study) (Unpublished thesis for this study and Lundgren, 2006)
Dindo 2020	Dindo et al., (2020)
Giovannetti 2020	Giovannetti et al., (2020) (Main study) (Protocol in supplementary material of main study)
Lundgren 2006	Lundgren et al., (2006) (Main study) Lundgren et al., (2008b) (Mediation analysis)
Luciano 2014	Luciano et al., (2014) (Main study) Luciano et al., (2017) (Economic analysis)

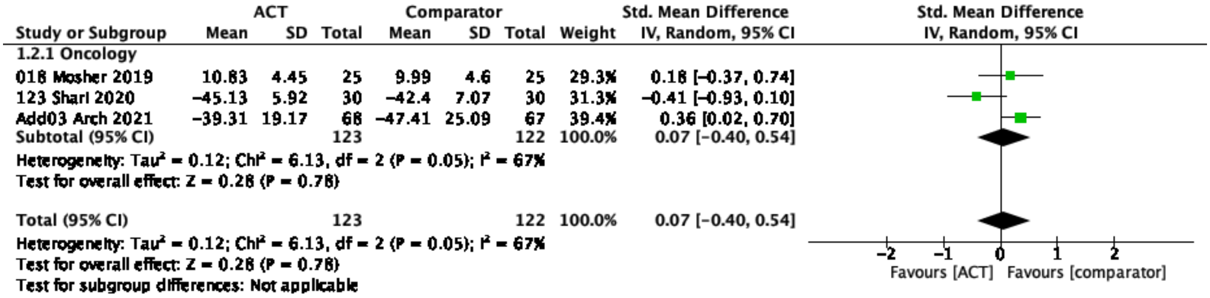
Simister 2018	Simister et al., (2018) (Main study)
Wicksell 2013	Wicksell et al., (2013) (Main study)
Clarke 2017	Clarke et al., (2017) (Main study)

Supplementary material: Forest plot graphs for remaining outcomes across outcome domains

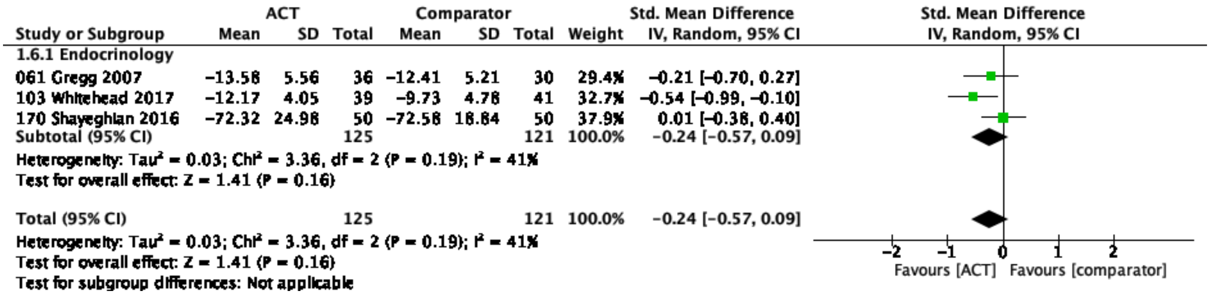
Forest Plot for the Physical Domain: Physical health/QoL



Forest Plot for the Physical Domain: Fatigue

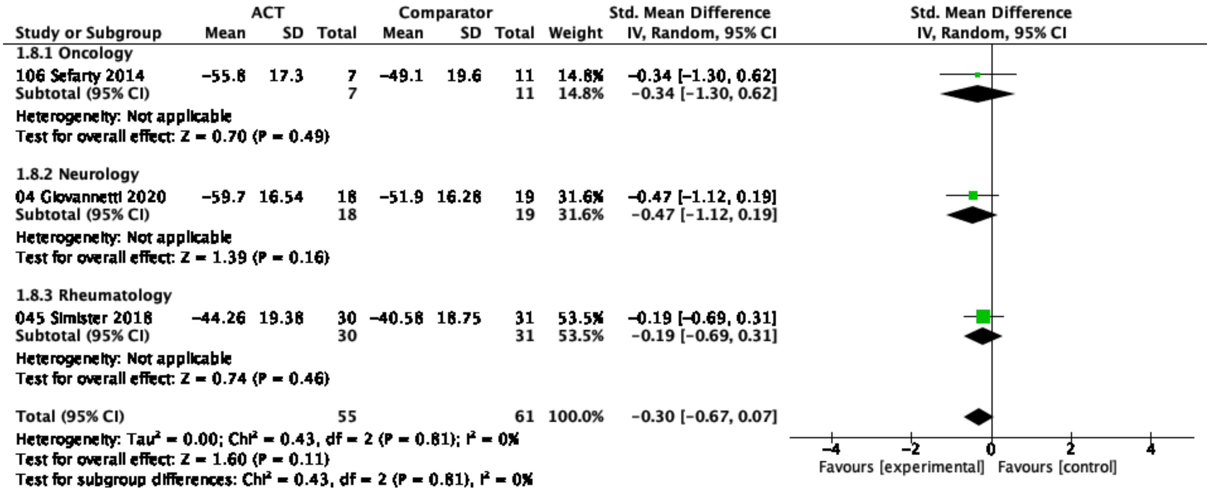


Forest Plot for the Physical Domain: Self care



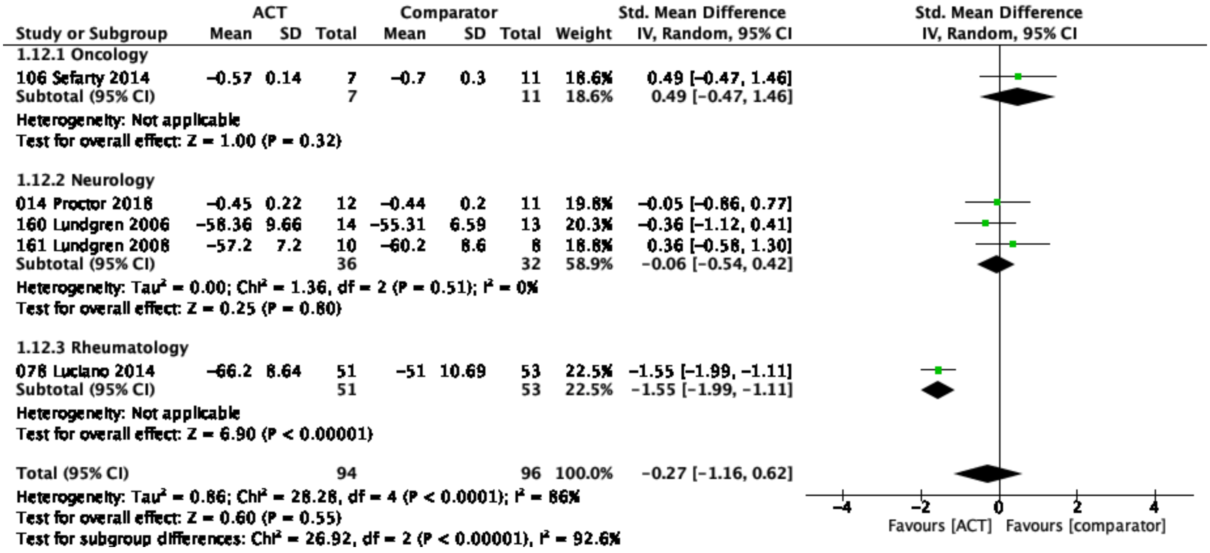
	ACT			Comparator				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
1.6.1 Endocrinology								
061 Gregg 2007	−13.58	5.56	36	−12.41	5.21	30	29.4%	−0.21 [−0.70, 0.27]
103 Whitehead 2017	−12.17	4.05	39	−9.73	4.78	41	32.7%	−0.54 [−0.99, −0.10]
170 Shayeghian 2016	−72.32	24.98	50	−72.58	18.84	50	37.9%	0.01 [−0.38, 0.40]
Subtotal (95% CI)			125			121	100.0%	−0.24 [−0.57, 0.09]
Heterogeneity: Tau^2 = 0.03; Chi^2 = 3.36, df = 2 (P = 0.19); I^2 = 41%								
Test for overall effect: Z = 1.41 (P = 0.16)								
Total (95% CI)			125			121	100.0%	−0.24 [−0.57, 0.09]
Heterogeneity: Tau^2 = 0.03; Chi^2 = 3.36, df = 2 (P = 0.19); I^2 = 41%								
Test for overall effect: Z = 1.41 (P = 0.16)								
Test for subgroup differences: Not applicable								

Forest Plot for the Psychological Domain: Values



	ACT			Comparator				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
1.8.1 Oncology								
106 Sefarty 2014	−55.8	17.3	7	−49.1	19.6	11	14.8%	−0.34 [−1.30, 0.62]
Subtotal (95% CI)			7			11	14.8%	−0.34 [−1.30, 0.62]
Heterogeneity: Not applicable								
Test for overall effect: Z = 0.70 (P = 0.49)								
1.8.2 Neurology								
04 Giovannetti 2020	−59.7	16.54	18	−51.9	16.28	19	31.6%	−0.47 [−1.12, 0.19]
Subtotal (95% CI)			18			19	31.6%	−0.47 [−1.12, 0.19]
Heterogeneity: Not applicable								
Test for overall effect: Z = 1.39 (P = 0.16)								
1.8.3 Rheumatology								
045 Simister 2018	−44.26	19.38	30	−40.58	18.75	31	53.5%	−0.19 [−0.69, 0.31]
Subtotal (95% CI)			30			31	53.5%	−0.19 [−0.69, 0.31]
Heterogeneity: Not applicable								
Test for overall effect: Z = 0.74 (P = 0.46)								
Total (95% CI)			55			61	100.0%	−0.30 [−0.67, 0.07]
Heterogeneity: Tau^2 = 0.00; Chi^2 = 0.43, df = 2 (P = 0.81); I^2 = 0%								
Test for overall effect: Z = 1.60 (P = 0.11)								
Test for subgroup differences: Chi^2 = 0.43, df = 2 (P = 0.81), I^2 = 0%								

Forest Plot for the Multi-Outcome Domain: QoL



	ACT			Comparator				Std. Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
1.12.1 Oncology								
106 Sefarty 2014	−0.57	0.14	7	−0.7	0.3	11	18.6%	0.49 [−0.47, 1.46]
Subtotal (95% CI)			7			11	18.6%	0.49 [−0.47, 1.46]
Heterogeneity: Not applicable								
Test for overall effect: Z = 1.00 (P = 0.32)								
1.12.2 Neurology								
014 Proctor 2018	−0.45	0.22	12	−0.44	0.2	11	19.8%	−0.05 [−0.86, 0.77]
160 Lundgren 2006	−58.36	9.66	14	−55.31	6.59	13	20.3%	−0.36 [−1.12, 0.41]
161 Lundgren 2008	−57.2	7.2	10	−60.2	8.6	8	18.8%	0.36 [−0.58, 1.30]
Subtotal (95% CI)			36			32	58.9%	−0.06 [−0.54, 0.42]
Heterogeneity: Tau^2 = 0.00; Chi^2 = 1.36, df = 2 (P = 0.51); I^2 = 0%								
Test for overall effect: Z = 0.25 (P = 0.80)								
1.12.3 Rheumatology								
078 Luciano 2014	−66.2	8.64	51	−51	10.69	53	22.5%	−1.55 [−1.99, −1.11]
Subtotal (95% CI)			51			53	22.5%	−1.55 [−1.99, −1.11]
Heterogeneity: Not applicable								
Test for overall effect: Z = 6.90 (P < 0.00001)								
Total (95% CI)			94			96	100.0%	−0.27 [−1.16, 0.62]
Heterogeneity: Tau^2 = 0.86; Chi^2 = 28.28, df = 4 (P < 0.0001); I^2 = 86%								
Test for overall effect: Z = 0.60 (P = 0.55)								
Test for subgroup differences: Chi^2 = 26.92, df = 2 (P < 0.00001), I^2 = 92.6%								

CHAPTER FOUR

Discussion and Critical Evaluation

Discussion and Critical Evaluation

This thesis portfolio aimed to investigate psychological aspects of holistic approaches to healthcare for people with LTC. The aim was to explore this by conducting a systematic review of the utilisation and evaluation of co-production within health and social care settings, including whether and how psychological outcomes were measured. This was to establish the current landscape of co-production across health and social care, to aid clinical psychologists and other health and social care professionals in implementing and evaluating co-production in the future. In addition, a systematic review and meta-analysis was conducted, which aimed to evaluate the efficacy of ACT for self-management in LTCs in terms of physical, psychological, and social outcomes, consistent with a holistic definition of self-management.

Overview of Key Findings

The key findings of the co-production systematic review were consistent with the wider evidence base regarding the centrality of the concept of power in co-production (Arnstein, 1969; Bovaird, 2007; Boyle & Harris, 2009; Needham & Carr, 2009; Ostrom, 1996). Facilitators and barriers to co-production were identified at organisational, service, and individual levels. At the organisational level, relationship development, organisational commitment to co-production and resources served as key facilitators. These factors were inter-related with facilitators at the service level, which also included facilitators of shared aims and values, valuing expertise and difference, shared decision-making, role clarity, and understanding of co-production. Many service-level facilitators also operated at an individual level between stakeholders, with an additional key facilitator being a sense of agency. The relational context of co-production and importance of valuing the expertise of stakeholders, particularly that of EBE, were almost universal themes across included studies in the review. Previous research has indicated a range of psychological benefits of co-production (Boyle &

Harris, 2009; Munoz, 2013; NCCMH, 2019; Patrick & Williams, 2012; Ryan & Deci, 2000; Slay & Penny, 2014). It was notable that the findings of the review indicated that outcome measurement tended to focus on the level of output of co-production rather than the process and generally focused on the experience of EBE, which poses challenges for the development of the evidence base for co-production. In addition, there was a paucity of psychological outcome measurement. The review found concerns related to RoB and reporting quality across studies, that few studies reported PPI and studies were almost exclusively within a mental health context, which limits the generalisability of findings. One study reported on a co-produced self-management programme for PLTC (Turner, 2015a); although, as it was one study, conclusions regarding the implementation and evaluation of co-production for people with physical LTCs cannot be made. Whilst there were concerns regarding RoB and quality of the reporting of studies, as was noted by Durose et al., (2017) the evaluation of co-production is complicated by its relational context, and therefore the current review was still able to contribute to the evidence base of the utilisation and evaluation of co-production in healthcare, particularly within a mental health context.

The results of the systematic review and meta-analysis evaluating the efficacy of ACT for self-management for LTCs, found preliminary evidence for the efficacy of ACT for psychological outcomes including acceptance, anxiety, depression and general mental health/QoL, with small to moderate effect sizes reported. Preliminary evidence was found for a holistic impact of ACT for people with rheumatological conditions, in terms of moderate to large effects for not only depression, but also pain and fibromyalgia impact. However, the minimal clinically important differences for measures utilised in the pain analysis indicate that this particular finding may be statistically, but not clinically, significant. Moreover, there were generally substantial levels of heterogeneity between studies and this, in addition with concerns related to RoB and the small number and sample sizes of included studies, limit the conclusiveness of findings relating to the efficacy of ACT for self-management in LTCs. A key finding of the meta-analysis was also that it did not find conclusive evidence of an effect of ACT on process outcomes such as acceptance and values; however, these findings could have been confounded, as not all studies reported on ACT process outcomes and the construct of psychological flexibility comprises six core aspects which were not fully represented in outcome measurement of studies. Another notable finding was the lack of social outcomes reported, resulting in no social outcomes being included in either the meta-analysis or narrative synthesis. It was also notable that only three studies reported outcomes across all the biopsychosocial domains. In addition to issues related to how ACT was measured in included studies, it is also a possibility that improvements in self-management can occur independently of observable improvements in biopsychosocial outcomes and therefore future research should measure specific self-management outcomes. The findings of the review were consistent with those of previous systematic and meta-analytic reviews (Graham et al., 2016; Öst, 2008; 2014) and concluded that larger, high-quality studies are needed to determine the efficacy of ACT for holistic self-management for PLTC. As such, to date there is not sufficient evidence for the widespread implementation of ACT for PLTC.

Critical Appraisal of the Research

A key strength of the co-production systematic review was that to the authors' knowledge it is the first systematic review investigating the utilisation and evaluation of co-production across health and social care, and to specifically consider psychological outcomes. This is a particular strength given the finding by Durose et al., (2017) of there being few sources of evidence for co-production, such as systematic reviews, that count as higher quality evidence. The systematic review was registered with PROSPERO and conducted thoroughly, in line with PRISMA guidelines (Moher et al., 2009).

Limitations of the review mostly centre on the generally low quality of included studies and that they were almost exclusively within a mental health context. Whilst this may limit the conclusiveness or generalisability of the findings there are challenges to the evaluation of co-production, particularly in relation to its relational context (Durose et al., 2017). This led to an exploration of potential frameworks and solutions to the evaluation of co-production as identified within the literature (such as De Rosis, 2020; Durose et al., 2017), where the salience of generating good enough evidence for co-production was highlighted (Durose et al., 2017). Therefore, whilst these limitations remain, the systematic review was able to contribute to the evidence base in terms of implications for clinical practice and future research, particularly related to the utilisation and evaluation of co-production in a mental health context, in a meaningful way.

A key strength of the systematic review and meta-analysis is that to the authors' knowledge this is the first systematic review and meta-analysis to evaluate the efficacy of ACT for holistic self-management for PLTC. This a particular strength given the recommendations within clinical health psychology research regarding the importance of acknowledging the complexity of human health and measuring a diverse range of biopsychosocial outcomes (Suls & Rothman, 2004). In addition, the review was conducted in accordance with PRISMA guidelines (Moher et al., 2009) and a formal RoB assessment tool was used to appraise to RoB.

Key limitations of the systematic review and meta-analysis largely related to issues of RoB and study quality, such as the substantial heterogeneity across studies and the small numbers and sample sizes of included studies that impacted on the conclusiveness and generalisability of the findings. However, the methodological issues identified during the review were important findings in and of themselves, as it was significant that seven years on from Öst's (2014) updated meta-analysis on the efficacy of ACT many of the same recommendations remain. Another potential limitation is that the narrow eligibility criteria of the review in specifically looking for a diverse range of outcomes, may have impacted on the number of studies included in the review and therefore the power of the meta-analysis to find an effect. However, as previously stated, the importance of not viewing health through a reductionist lens has been highlighted in recommendations for clinical health psychology research, and therefore the findings are meaningful in allowing an evaluation of the current evidence base for the efficacy of ACT in relation to holistic outcomes and recommendations for future research being made.

A limitation that was notable in the findings of both reviews, was the lack of patient and public involvement (PPI) across the studies found. Whilst PPI may not commonly be considered when undertaking systematic reviews or meta-analysis, it is deemed a limitation of the current review particularly in light of the ethos of holism and co-production underpinning the thesis portfolio. The initial stages of the thesis benefited enormously from dedicated steering group involvement for an empirical study into co-production that unfortunately had to be stopped just prior to the point of recruitment due to the COVID-19 pandemic. Efforts were made to facilitate sustainability of the steering group to enable involvement in the systematic review and meta-analysis on the efficacy of ACT for holistic self-management for PLTC; however, a second lockdown unfortunately made this untenable. However, the research team was able to meet with the Director of the local Sustainability and Transformation Project (STP) in relation to the systematic review and meta-analysis, which supported the development of a review that had relevance for clinical practice at a local level.

Clinical, Theoretical and Research Implications

Clinical implications from the co-production systematic review, centre on the importance of identifying and addressing power imbalances in the process of co-production (Arnstein, 1969; Bovaird, 2007; Boyle & Harris, 2009; Needham & Carr, 2009; Ostrom, 1996). The importance of valuing expertise and acknowledging difference to facilitate co-production, and developing trusting relationships between stakeholders, particularly for EBE are key implications for clinical practice. Another clinical implication is the importance of being aware of how the facilitators and barriers to co-production operate across individual, service and organisational levels and the potential interplay between them; as well as how barriers to co-production can lead to the perpetuation of traditional paternalism (Bovaird, 2007). Regarding evaluation of co-production and its potential psychological outcomes, awareness of the challenges of evaluating the process of co-production due to its relational context is in itself a clinical implication, as is consideration of what good enough evidence for co-production looks like in terms of selecting a methodology that is most suited to the relational and often local context of co-production.

Clinical implications of the systematic review and meta-analysis evaluating the efficacy of ACT for holistic self-management for PLTC, are that whilst there is preliminary evidence of its efficacy for psychological outcomes in the context of LTCs, such as acceptance, anxiety, depression and general mental health/QoL and preliminary evidence of a holistic impact of ACT for those with rheumatological conditions, to date there is not sufficient evidence to support the widespread implementation of ACT for PLTC.

It is important to note that for both reviews, there were widespread issues with RoB and study quality. Whilst both reviews have highlighted implications for clinical practice, these issues limit the conclusiveness of the findings and generalisability of the findings.

Regarding theoretical implications of the research, there was insufficient evidence to draw definitive conclusions related to the psychological aspects of holistic approaches to care for PLTC in line with Lehman's (2017) dynamic biopsychosocial model. However, both reviews still made meaningful contributions to their respective evidence bases and highlighted the continued relevance of recommendations made for future research seven and

14 years ago for Öst (2014) and Suls and Rothman (2004) respectively. This suggests that wider movements towards taking a holistic, biopsychosocial approach to health for PLTC may currently not be as represented in research as it is in wider guidance and theory (Coulter et al., 2013; DoH, 2005b, 2005c; Entwistle & Cribb, 2013; Goodwin et al., 2010; Lehman et al., 2017; NHS England, 2016; Wagner, 1998).

Recommendations for future research are therefore, for larger, higher quality RCTs of ACT for holistic self-management of LTCs, that measure a diverse range of biopsychosocial outcomes, including those specific to self-management, as well as the still salient methodological recommendations of prior reviews Öst (2008; 2014). For co-production in health and social care, recommendations for future research are that more research is needed in a range of contexts as well as in mental health services. Additionally, further exploration is needed of the methods for evaluating co-production, and its outcomes, that are both pragmatic and meaningful given the identified challenges and complexity of this area. This should take into account the potential operation of outcomes over multiple levels and take into account the multiple perspectives of stakeholders. A final recommendation across both reviews, is the for future involvement of PPI.

Reflections on the Thesis Portfolio

The motivation for undertaking the thesis portfolio, was that the ethos of holistic approaches to health and co-production were aligned with my own values as a clinical psychologist and therefore it felt important that these extended to my involvement in research. On reflection there were many challenges, having gone on our own exploration of how to evaluate co-production in the design stages of the original empirical research project. Keeping a bullet journal throughout the research process was helpful in overcoming some of these challenges, by allowing a space to reflect on issues related to power at different operational levels and how these may be perpetuated through the research process, as well as clinical practice. The recruiting of a steering group was a way of mitigating some of these issues, which whilst it was not full co-production, aimed to ensure that the voices of those the research aimed to benefit were present throughout. The process of setting up the steering group was a valuable experience. Maintaining a steering group during COVID-19 and national lockdowns, proved untenable due to the need to recognise the conflicting demands that may be experienced by all members including the research team. This resonates with some of the themes of the co-production systematic review around the importance of being able to recognise the needs of stakeholders in the process of co-production.

Conclusions

The importance of taking a holistic approach to health has been highlighted in research and theory (Lehman et al., 2017; Suls & Rothman, 2004). The thesis portfolio aimed to explore psychological aspects of holistic approaches to the care of PLTC, with a focus on the potential roles of co-production and ACT for holistic self-management of LTCs. To meet these aims, a systematic review was conducted of co-production across health and social care to explore how it had been utilised, evaluated and what psychological outcomes had been measured. To meet the second aspect of these aims, a systematic review and meta-analysis was conducted evaluating the efficacy of ACT for holistic self-management of LTCs in physical, psychological, and social outcomes. The findings of both reviews led to implications for clinical practice about key facilitators and barriers to co-production, particularly within a mental health context, and that despite preliminary evidence for the efficacy of ACT across a range of psychological outcomes in the context of LTCs, and of holistic benefits of ACT for people with rheumatological conditions, to date there is not sufficient evidence to advocate for the widespread implementation of ACT for PLTC. Widespread issues related to study quality limited the conclusiveness of these findings and raised important considerations for future research.

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Appendix A

Health and Social Care in the Community Author Guidelines

Health and Social Care in the community Author Guidelines

1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

Health and social care in the community is a fast-moving field in the context of empirical papers we normally would expect the last data point to be no more than 5 years old at the point of submission.

Once the submission materials have been prepared in accordance with the Author Guidelines, manuscripts should be submitted online at https://mc.manuscriptcentral.com/HSCC

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2. AIMS AND SCOPE

Health and Social Care in the Community is an international peer-reviewed journal with a multidisciplinary audience including social workers, health care professionals with a community or public health focus e.g. public health practitioners, GP's, Community Nurses and Social Care researchers and educators.

The Journal promotes critical thinking and informed debate about all aspects of health and social care. Original papers are sought that reflect the broad range of policy, practice and theoretical issues underpinning the provision of care in the community.

Health and Social Care in the Community publishes systematic and other types of reviews, policy analysis and empirical qualitative or quantitative papers including papers that focus on professional or patient education.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

Quantitative Articles

WORD LIMIT: *5000* (excluding abstract, figures, tables and the reference list) double-spaced with a wide margin on either side.
RESEARCH REPORTING CHECKLIST: May be required – see section 5 EDITORIAL POLICIES AND ETHICAL CONSIDERATIONS

Qualitative Articles

WORD LIMIT: 5000 (excluding figures, tables and the reference list) double-spaced with a wide margin on either side.
MAIN TEXT: Should be structured under the following headings: Introduction; Methods; Findings; Discussion. See **here** for details on what *HSCC* requires in a qualitative article.
RESEARCH REPORTING CHECKLIST: May be required – see section 5 EDITORIAL POLICIES AND ETHICAL CONSIDERATIONS

Review Papers

WORD LIMIT: 7000 (excluding figures, tables and the reference list) double-spaced with a wide margin on either side.
MAIN TEXT: See **here** for details on what *HSCC* requires in a review article.
RESEARCH REPORTING CHECKLIST: May be required – see section 5 EDITORIAL POLICIES AND ETHICAL CONSIDERATIONS

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Authors should be mindful that *HSCC* is an international journal and where possible the discussion should draw from international sources.

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iii. Main text;
iv. References;
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Book

Bradley-Johnson, S. (1994). *Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school* (2nd ed.). Austin, TX: Pro-ed.

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Appendix B

PROSPERO Protocol for the Systematic Review

Systematic Review Protocol

The Utilisation and Evaluation of Co-Production in Health and Social Care: A Systematic Review of the Literature

Author and Primary Reviewer

Rachel Russell

University of East Anglia

Review Team

Karolina Kaminska, Co-screener, Trainee Clinical Psychologist

Dr Katherine Deane, Primary Supervisor, University of East Anglia

Dr Catherine Ford, Secondary Supervisor, University of East Anglia

Background and Aims

The term co-production is one for which there is no single agreed definition, and other terms, such as co-creation, are often used synonymously with it (Boyle & Harris, 2009; Voorberg, Bekkers, & Tummers, 2015). Co-production goes beyond models of service user consultation (Boyle & Harris, 2009), and whilst there is no single agreed definition, Boyle & Harris (2009) outlined that true co-production occurs when the knowledge of professionals and service users, as well as other stakeholders, is utilised in the design and delivery of services. As such, true co-production requires a shift to balance the distribution of power between stakeholders, recognising and valuing the expertise of those who use services, their families and communities, rather than viewing them as passive recipients of care (Boyle and Harris, 2009; Needham & Carr, 2009).

There have been shifts in both health and social care sectors towards the utilisation of co-production in the commissioning, design and delivery of services, and of co-producing individual health outcomes for those who use services (Coulter, Roberts & Dixon, 2013; National Collaborating Centre for Mental Health, 2019; Needham & Carr, 2009; NHS, 2019; NHS England, 2016; Slay & Penny, 2014;). Examples of this are found in the key recommendations of the NHS Five Year Forward View for Mental Health (NHS England, 2016) regarding the co-produced commissioning of services, and NHS England commissioned the National Collaborating Centre for Mental Health (NCCMH) to develop evidence-based approaches to co-production in the commissioning of mental health services (NCCMH, 2019). In addition to co-production being promoted at the level of commissioning, it has also been promoted at the level of individualised care (Coulter et al., 2013; NCCMH, 2019). For example, at the centre of the Kings Fund's 'House of Care' (Coulter et al., 2013), a whole-systems model of care for people with long-term conditions, is the notion of person-centred care planning and collaboration between clinicians and those who use services, to co-produce health outcomes.

Co-producing services brings opportunities to utilise the expertise, resources and skills of those who use services (Boyle & Harris, 2009; Newman & Carr, 2009; Slay & Penny, 2014). Slay & Penny (2014) suggested that co-production is an inherently more democratic method of public service delivery and that co-production can play a role in ensuring services meet the needs of the populations they work with, hence increasing not only the effectiveness of services, but also their reach. The active participation of communities has also been associated with the development of more holistic approaches, due to their understanding and insight into the complexities and intersections of the issues they face (World Health Organization; WHO, 2002).

A review of the evidence of co-production in statutory and voluntary, community and social enterprise organisations by the NCCMH (2019) found that wellbeing, including physical and mental health, was the strongest theme among the evidence they reviewed. Other benefits of co-production have been suggested to be prevention, social connectedness, and the encouragement of self-help (Boyle & Harris, 2009; NCCM, 2019). The NCCMH (2019) also found evidence that there were benefits for those involved in the process co-production itself. The theme of wellbeing also arose in Slay & Penny (2014), who indicated that the co-production of public services has the potential to meet the innate psychological needs of competence, autonomy, and relatedness as postulated by self-determination theory, which has in turn been linked with wellbeing (Ryan & Deci, 2000; Slay & Penny, 2014).

Whilst there is a growing body of literature for co-production, one of the criticisms as highlighted by Voorberg et al., (2015), in a systematic review of co-production not specific to health and social care, was that much of the research focuses on defining typologies of co-production, rather than evaluating outcomes of co-production. This was also highlighted more recently by the NCCMH (2019), which recommended that there was a need for future research to focus on the outcomes of co-production and co-produced commissioning. As such, the aims of the current systematic review are to establish how co-production has been utilised and evaluated within health and social care settings. This includes exploring the process of co-production and any identified facilitators and barriers to co-production, as well as establishing how co-production has been evaluated. In addition, given the evidence of a link between co-production and the development of holistic approaches, and outcomes including improved wellbeing and mental health (NCCMH, 2019; Ryan & Deci, 2000; WHO, 2002), this review will also establish whether studies of co-production have measured psychological outcomes. Establishing the current landscape of the utilisation and evaluation of co-production within health and social care, may aid health and social care providers in implementing and evaluating co-production in the future.

Review Question

In what ways has co-production been utilised and evaluated within health and social care?

e. What are the processes/procedures of co-production?
f. What are the identified facilitators and barriers to co-production?
g. How is co-production evaluated?
h. Are psychological outcomes measured, and how?

Review Procedure

Eligibility Criteria

Inclusion criteria for the review will be research examining the utilisation of co-production within health and social care services. Research within health and/or social care where the primary focus is not on the utilisation of co-production, or where the focus is on co-production in a sector outside of health and social care, will not be eligible for inclusion in the review. For example, projects or provisions with no formal health or social care service involvement will not be eligible for inclusion in the review. For the purposes of the review co-production will be defined, in line with that described by Boyle & Harris (2009), as the involvement of professionals and service users, as well as other stakeholders such as families or communities, in aspects of both the design and delivery of services. The co-production described in the studies must involve both professionals and service users in aspects of both the design and delivery of services; however, the review will include studies with or without the involvement of other non-professional stakeholders such as families or communities. With regards to the design or delivery of services, this could be in relation to co-production of the service as a whole, or of an intervention delivered within a service for service users; as such, co-production of other elements of services for example, staff training or resources for service users, will not be independently eligible for inclusion in the review. This definition must be met for inclusion in the review, and therefore studies that use other key terms that may have been used synonymously with co-production, such as ‘co-creation’, ‘value co-creation’ or ‘co-design’ will be eligible for inclusion, if they meet the definition above and other eligibility criteria. The review will exclude studies that do not meet this definition of co-production, and the number excluded for this reason will be reported in the review.

The review will be of mixed methods, including both quantitative and qualitative studies. It is anticipated that due to the nature of the focus of the review, studies will be observational and therefore not include comparators or controls; however if studies with comparators or controls are found, the comparator will be treatment or organisation of care as usual. There are no restrictions on study design to be included in the review; however only published primary research studies that are accessible in the English language and have full-text availability will be included in the review; conference abstracts or unpublished theses will be excluded. This is to ensure that sufficient detail will be available to appraise the methodology, its risk of bias and the results.

In summary, the inclusion and exclusion criteria for the review are as follows:

- Studies examining co-production within health and/or social care services
- The co-production described in the studies must meet the pre-defined definition for the review
- Studies that may use different terminology but that meet the definition of co-production as defined for the review will also be included
- Studies can be of any design methodology
- Comparators/controls will be treatment or organisation of care as usual, if applicable
- Full-text availability of the study
- Access to the study in the English language

Outcomes

Regarding outcomes, in line with the aims of the review they will be establishing the process or procedure of co-production, the identified facilitators and barriers of co-production, the methods used to evaluate co-production, and whether psychological outcomes are measured and how.

Search Method

The sources that will be searched for the systematic review include electronic databases, reference lists of eligible studies and review articles, and grey literature. The electronic databases that will be searched for the review are Medline, PsycINFO, CINAHL, and AMED. The reference lists of included studies and review articles will be scanned for any studies relevant to the review. In addition, a grey literature search will be conducted and accepted within the remit of full reports being available, from sources such as governmental, health, and third sector organisation or body reports. Please see appendix A for an example search string.

Review and Synthesis Method

Regarding study selection, searches will be conducted followed by a review of titles and abstracts against the eligibility criteria. The primary reviewer will be responsible for conducting the searches and the initial title and abstract reviews, with a member of the review team co-screening 20% of studies at this stage. Any studies where the reviewer is unclear as to whether they meet the inclusion criteria will be discussed between the primary reviewer and co-screener and if no agreement can be reached this will be discussed with the primary supervisor. The same process will be followed for any studies where there is disagreement between the primary reviewer and co-screener. Following this, a full-text review of studies included at this stage will be conducted by the review team and 20% of studies will be co-screened. Studies where there is agreement between the reviewers will be included in the review, and studies where there is any uncertainty or disagreement will be discussed and agreement sought. If agreement cannot be reached, then this will be discussed with the primary supervisor to reach a decision. A PRISMA flowchart will be compiled to show the process of study selection.

Following this, data extraction will occur. Data extraction will be conducted by the primary reviewer and a referencing manager such as Endnote will be used to store and organise the studies extracted. With regards to data extraction, this will be done using Microsoft Excel and broken down as below:

- Study title and full APA reference
- Year of publication
- Sector and context: for example, physical health / mental health / social care / physical health and social care / mental health and social care / health and social care (all) and any other contextual information
- Participants: age-range, gender, other reported demographic information

- Study method and design: quantitative or qualitative, case study etc.
- Definition of co-production utilised
- Intervention: how co-production was utilised (for example, aims/objectives, process/procedure)
- Facilitators/barriers to co-production identified
- Outcome method: method of evaluation
- Psychological outcomes: whether psychological outcomes were measured and how
- Interpretation: interpretation, conclusions
- Other: anything else of note for the study not included above

Risk of bias assessments will then be conducted for all included studies. As this is a mixed methods review, a risk of bias checklist has been created to meet the needs of the review. The checklist includes original items and items adapted from existing sources (Lockwood, Munn, & Porritt, 2015; National Heart, Lung, and Blood Institute and Research Triangle Institute International, n.d.; Tong, Sainsbury, & Craig, 2007). Risk of bias assessments will be conducted by the primary reviewer and at least 20% will be co-rated by a member of the review team. Should there be any disagreement or uncertainty regarding ratings, this will be discussed by the primary review and co-rater. If no agreement can be sought, then this will also be discussed with the primary supervisor. Please see appendix B for a copy of the risk of bias checklist.

Following this, data synthesis will be conducted by the primary reviewer. In order to answer the questions outlined in this systematic review, a narrative synthesis of included studies will be undertaken. Guidance for conducting the narrative synthesis will be in accordance with that published by Popay et al., (2006). This review does not aim to conduct a statistical analysis of the data. However, if enough data are identified then this may be sub-divided according to setting (for example, health or social care), or by health condition.

Dissemination Plans

This systematic review is being conducted as part of a thesis portfolio for the Doctoral Programme in Clinical Psychology at the University of East Anglia. In addition, it will also be submitted for publication in a relevant academic journal.

Key words

Co-production, service design, service delivery, health care, social care, delivery of health care

Timeline

It is anticipated that this review will be complete by 24th September 2021.

References

Boyle, D., and Harris, M (2009). *The challenge of co-production: How equal partnerships between professionals and the public are crucial to improving public services.* London: NESTA

Coulter, A., Roberts, S., and Dixon, A. (2013). *Delivering better services for people with long-term conditions: Building the house of care.* London: The Kings Fund

Lockwood C, Munn Z, Porritt K. (2015). Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. *Int J Evid Based Healthc.*,13(3):179–187

Needham, C., & Carr, S., (2009). *Co-production: An emerging evidence base for adult social care transformation.* London: Social Care Institute for Excellence

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Appendices

Appendix A: Example search string

Appendix B: Risk of Bias checklist

Appendix A: Example Search String

Review Title:

The utilisation and evaluation of co-production in health and social care: a systematic review of the literature

Example search string (Medline Ovid):

1. co-produc*.ti,ab
2. co-design*.ti,ab
3. co-creat*.ti,ab.
4. 1 or 2 or 3
5. exp Community Health Services/
6. exp Social Work/
7. health*care
8. exp Health Services/
9. social*care
10. 5 or 6 or 7 or 8 or 9
11. 4 and 10

Appendix B: Risk of Bias Checklist v1.2 23.12.2020

Risk of Bias Checklist v1.2 23.12.2020

Item	**Yes**	**No**	**Unclear**	**Not Applicable**
For quantitative and qualitative papers:				
Did the research question(s) or objective(s) align with the methodology used?				
Was the study population representative of the whole population of interest to the current review?				
Did the reported demographic information evidence recruitment of a representative sample?				
Was the participation rate of eligible persons at least 50%?				
Was recruitment achieved to a sample size that was justified with a power calculation including variance or effect size estimates?				
Was loss to follow-up after baseline 20% or less over a year? If qualitative, was how many people declined to participate or dropped out reported?				
Did they have Patient and Public Involvement (PPI) in the design, analysis and reporting of the research?				
For qualitative papers only:				
Is there congruity between the stated philosophical stance and the research methodology?				
Have they accounted for researcher characteristics, experiences and bias?				
Was data collected rigorously? (e.g. audio-recording of interviews)				
Was data saturation considered to have been achieved?				

Were participants offered the opportunity to comment or correct transcripts following data collection?				
Was uptake of participant comment or correction of transcripts recorded?				
Did participants (and/or a PPI steering group) give feedback on the findings?				
Were issues of reliability and validity of the findings explicitly addressed?				
Was sufficient evidence provided (e.g. quotes) to support the development of themes reported?				

References

The above checklist includes original items and items adapted from the following existing sources.

Lockwood C, Munn Z, Porritt K. (2015). Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. *Int J Evid Based Healthc.*,13(3):179–187

National Heart, Lung, and Blood Institute and Research Triangle Institute International (n.d.). *Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies.* Retrieved from https://www.nhlbi.nih.gov/health-topics/study-quality-assessment-tools

Tong, A., Sainsbury, P., and Craig, J. (2007). Consolidation criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care,* 19 (6), pp. 349-357. Doi: 10.1093/intqhc/mzm042

Appendix C

PRISMA Checklist for the Systematic Review

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	X - Title
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Abstract completed but full PRISMA abstract checklist not used
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	X - Introduction
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	X – Aims section of Introduction
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	X - Method
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	X - Method
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	X – Method and appendix
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	X – Method
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	X - Method
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	X - Method
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	X – Method and Results
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	X – Method, Results and

Section and Topic	Item #	Checklist item	Location where item is reported
			Appendix
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	X - (as applicable to a mixed methods review)
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	N/a all studies were eligible for inclusion in synthesis
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	X - Method
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	X – Tables of study characteristics
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	X - Method
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/a
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/a
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/a
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	X – Method, Results, Appendix
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	X - Results
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	X – Method/Results
Study characteristics	17	Cite each included study and present its characteristics.	X - Results
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	X - Results
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	N/a
Results of	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	X - Results

Section and Topic	Item #	Checklist item	Location where item is reported
syntheses	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/a
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/a
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/a
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/a
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	X – Results/Discussion
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	X - Discussion
	23b	Discuss any limitations of the evidence included in the review.	X - Discussion
	23c	Discuss any limitations of the review processes used.	X - Discussion
	23d	Discuss implications of the results for practice, policy, and future research.	X - Discussion
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	X - Method
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	X - Method
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/a
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	X
Competing interests	26	Declare any competing interests of review authors.	X
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	X detail given regarding study table in supplementary material. N/a to other material publicly available

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

Appendix D

Search Strings for the Systematic Review

Medline:

12. co-produc*.ti,ab
13. co-design*.ti,ab
14. co-creat*.ti,ab.
15. 1 or 2 or 3
16. exp Community Health Services/
17. exp Social Work/
18. health*care
19. exp Health Services/
20. social*care
21. 5 or 6 or 7 or 8 or 9
22. 4 and 10

CINAHL:

1. TI co-produc*
2. AB co-produc*
3. S1 or S2
4. TI co-design*
5. AB co-design*
6. S4 or S5
7. TI co-creat*
8. AB co-creat*

9. S7 or S8
10. S3 or S6 or S9
11. (MM “Community Health Services+”)
12. (MM “Social Work+”)
13. health*care
14. (MM “Health Services”)
15. social*care
16. S11 or s12 or S13 or S14 or S15
17. S10 and S16

PsycINFO:

1. TI co-produc*
2. AB co-produc*
3. S1 or S2
4. TI co-design*
5. AB co-design*
6. S4 or S5
7. TI co-creat*
8. AB co-creat*
9. S7 or S8
10. S3 or S6 or S9
11. MM "Community Services" OR MM "Community Mental Health Services" OR MM "Community Welfare Services" OR MM "Emergency Services" OR MM "Home Care" OR MM "Home Visiting Programs" OR MM "Public Health Services"
12. MM "Social Casework" OR MM "Social Group Work"

13. health*care
14. MM "Health Care Services" OR MM "Behavioral Health Services" OR MM "Continuum of Care" OR MM "Electronic Health Services" OR MM "Health Care Delivery" OR MM "Hospital Programs" OR MM "Long Term Care" OR MM "Mental Health Services" OR MM "Palliative Care" OR MM "Patient Centered Care" OR MM "Prenatal Care" OR MM "Primary Health Care"
15. social*care
16. S11 or S12 or S13 or S14 or S15
17. S10 and S16

AMED:

1. TI co-produc*
2. AB co-produc*
3. S1 or S2
4. TI co-design*
5. AB co-design*
6. S4 or S5
7. TI co-creat*
8. AB co-creat*
9. S7 or S8
10. S3 or S6 or S9
11. (ZU “community health services”)
12. (ZU “social work”)
13. health*care
14. (ZU “health services”)

15. social*care

16. S11 or S12 or S13 or S14 or S15

17. S10 and S16

Appendix E

Risk of Bias Checklist for the Systematic Review

Risk of Bias Checklist v1.2 23.12.2020

Item	**Yes**	**No**	**Unclear**	**Not Applicable**
For quantitative and qualitative papers:				
Did the research question(s) or objective(s) align with the methodology used?				
Was the study population representative of the whole population of interest to the current review?				
Did the reported demographic information evidence recruitment of a representative sample?				
Was the participation rate of eligible persons at least 50%?				
Was recruitment achieved to a sample size that was justified with a power calculation including variance or effect size estimates?				
Was loss to follow-up after baseline 20% or less over a year? If qualitative, was how many people declined to participate or dropped out reported?				
Did they have Patient and Public Involvement (PPI) in the design, analysis and reporting of the research?				
For qualitative papers only:				
Is there congruity between the stated philosophical stance and the research methodology?				
Have they accounted for researcher characteristics, experiences and bias?				
Was data collected rigorously? (e.g. audio-recording of interviews)				

Was data saturation considered to have been achieved?				
Were participants offered the opportunity to comment or correct transcripts following data collection?				
Was uptake of participant comment or correction of transcripts recorded?				
Did participants (and/or a PPI steering group) give feedback on the findings?				
Were issues of reliability and validity of the findings explicitly addressed?				
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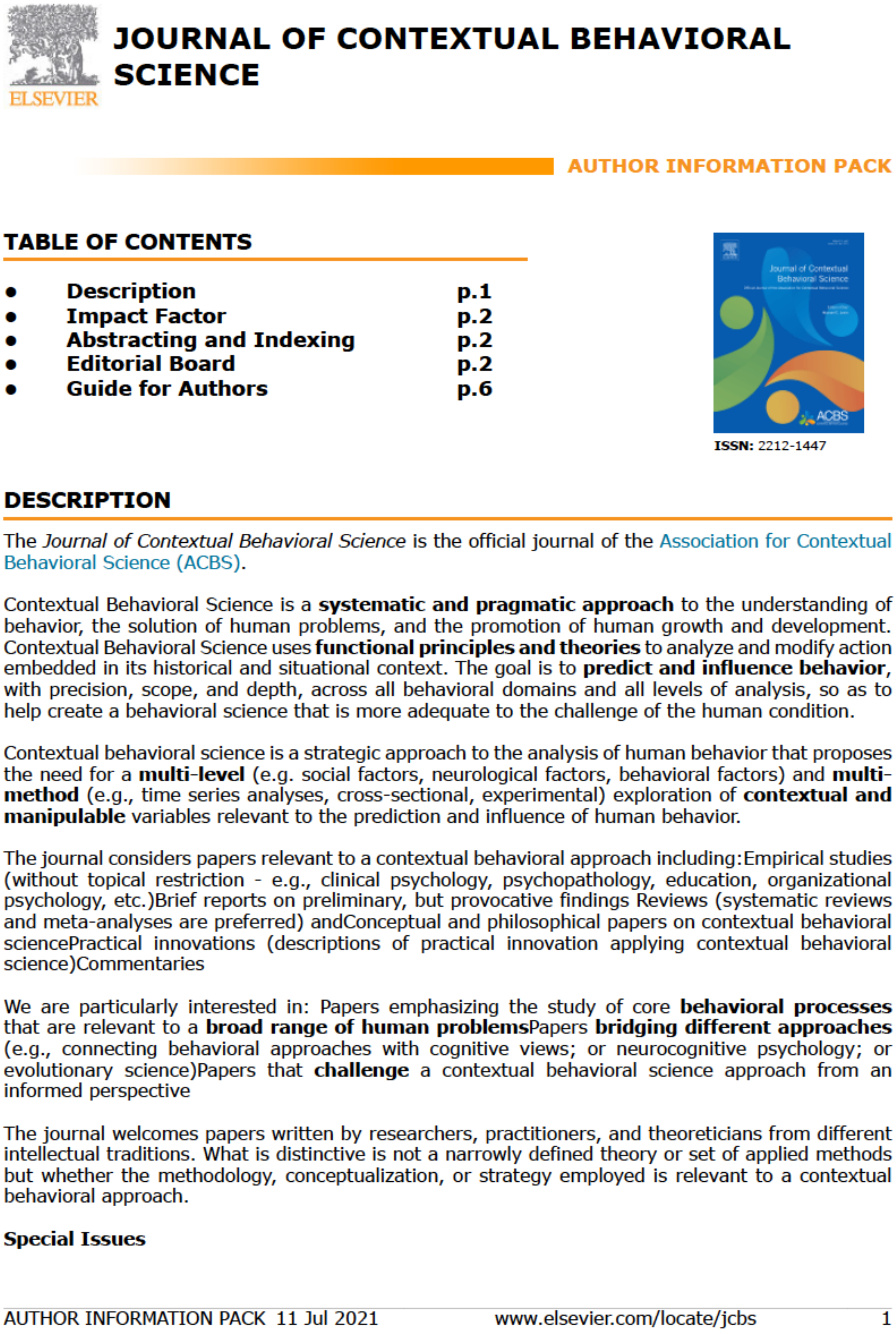
Tong, A., Sainsbury, P., and Craig, J. (2007). Consolidation criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care,* 19 (6), pp. 349-357. Doi: 10.1093/intqhc/mzm042

Appendix F

Journal of Contextual Behavioral Science Author Guidelines



JOURNAL OF CONTEXTUAL BEHAVIORAL SCIENCE

AUTHOR INFORMATION PACK

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ISSN: 2212-1447

DESCRIPTION

The *Journal of Contextual Behavioral Science* is the official journal of the Association for Contextual Behavioral Science (ACBS).

Contextual Behavioral Science is a **systematic and pragmatic approach** to the understanding of behavior, the solution of human problems, and the promotion of human growth and development. Contextual Behavioral Science uses **functional principles and theories** to analyze and modify action embedded in its historical and situational context. The goal is to **predict and influence behavior**, with precision, scope, and depth, across all behavioral domains and all levels of analysis, so as to help create a behavioral science that is more adequate to the challenge of the human condition.

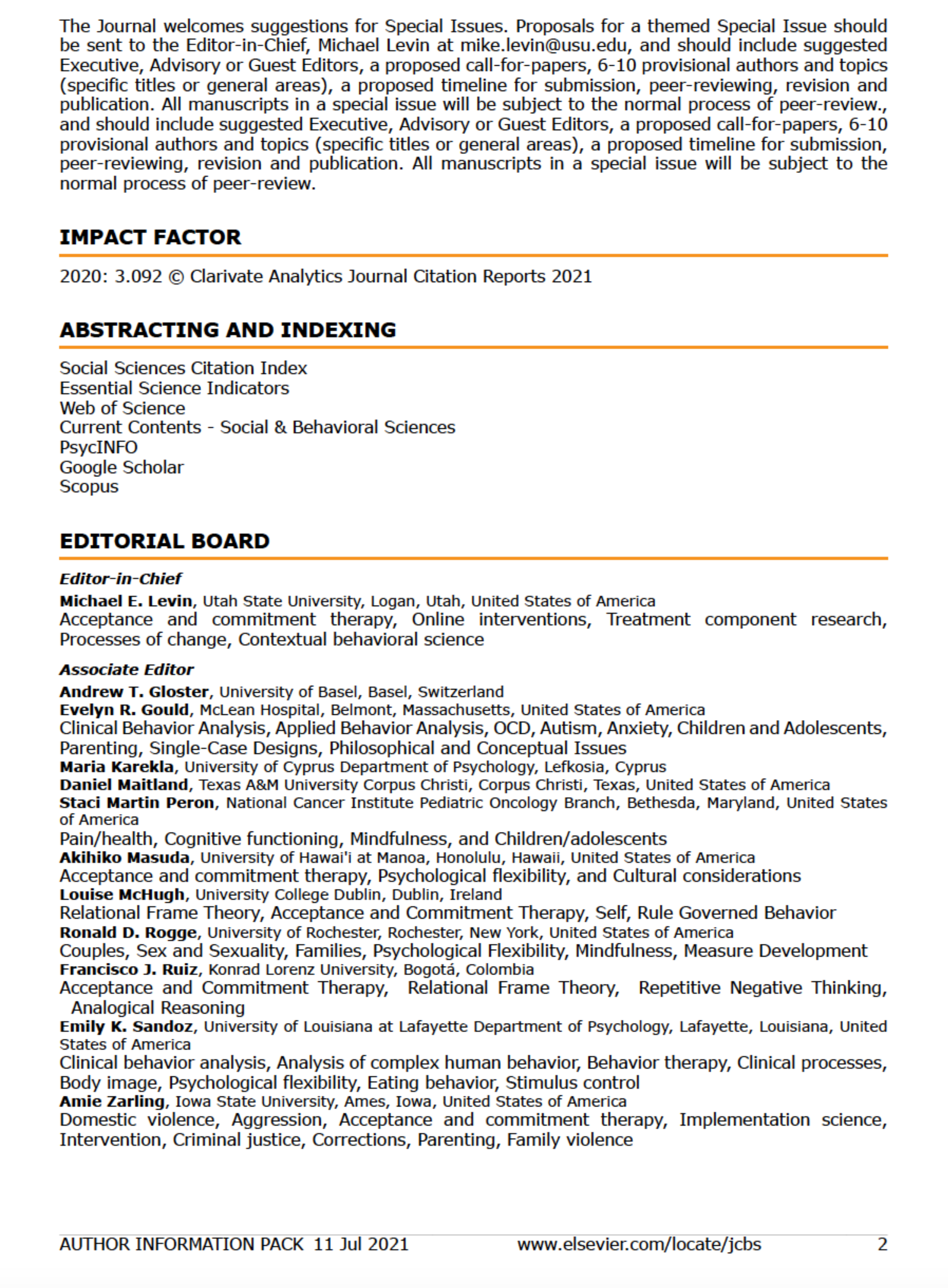
Contextual behavioral science is a strategic approach to the analysis of human behavior that proposes the need for a **multi-level** (e.g. social factors, neurological factors, behavioral factors) and **multi-method** (e.g., time series analyses, cross-sectional, experimental) exploration of **contextual and manipulable** variables relevant to the prediction and influence of human behavior.

The journal considers papers relevant to a contextual behavioral approach including:Empirical studies (without topical restriction - e.g., clinical psychology, psychopathology, education, organizational psychology, etc.)Brief reports on preliminary, but provocative findings Reviews (systematic reviews and meta-analyses are preferred) andConceptual and philosophical papers on contextual behavioral sciencePractical innovations (descriptions of practical innovation applying contextual behavioral science)Commentaries

We are particularly interested in: Papers emphasizing the study of core **behavioral processes** that are relevant to a **broad range of human problems**Papers **bridging different approaches** (e.g., connecting behavioral approaches with cognitive views; or neurocognitive psychology; or evolutionary science)Papers that **challenge** a contextual behavioral science approach from an informed perspective

The journal welcomes papers written by researchers, practitioners, and theoreticians from different intellectual traditions. What is distinctive is not a narrowly defined theory or set of applied methods but whether the methodology, conceptualization, or strategy employed is relevant to a contextual behavioral approach.

Special Issues



The Journal welcomes suggestions for Special Issues. Proposals for a themed Special Issue should be sent to the Editor-in-Chief, Michael Levin at mike.levin@usu.edu, and should include suggested Executive, Advisory or Guest Editors, a proposed call-for-papers, 6-10 provisional authors and topics (specific titles or general areas), a proposed timeline for submission, peer-reviewing, revision and publication. All manuscripts in a special issue will be subject to the normal process of peer-review., and should include suggested Executive, Advisory or Guest Editors, a proposed call-for-papers, 6-10 provisional authors and topics (specific titles or general areas), a proposed timeline for submission, peer-reviewing, revision and publication. All manuscripts in a special issue will be subject to the normal process of peer-review.

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Clinical psychology, Eating disorders
Ben Pierce, University of Minnesota Twin Cities, Minneapolis, Minnesota, United States of America
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Acceptance and commitment therapy, Mindfulness, Anxiety disorders, Exposure therapy, Contextual behavioral science
Matthew Smout, University of South Australia, Adelaide, South Australia, Australia
Improving delivery of psychological therapies in routine practice, Therapist behaviour, Acceptance and Commitment Therapy and Schema Therapy
Miles Thompson, University of the West of England, Bristol, United Kingdom
ACT, Chronic Pain, Social, global and environmental justice
Kathryn Tomasino, Northwestern University Feinberg School of Medicine, Chicago, Illinois, United States of America
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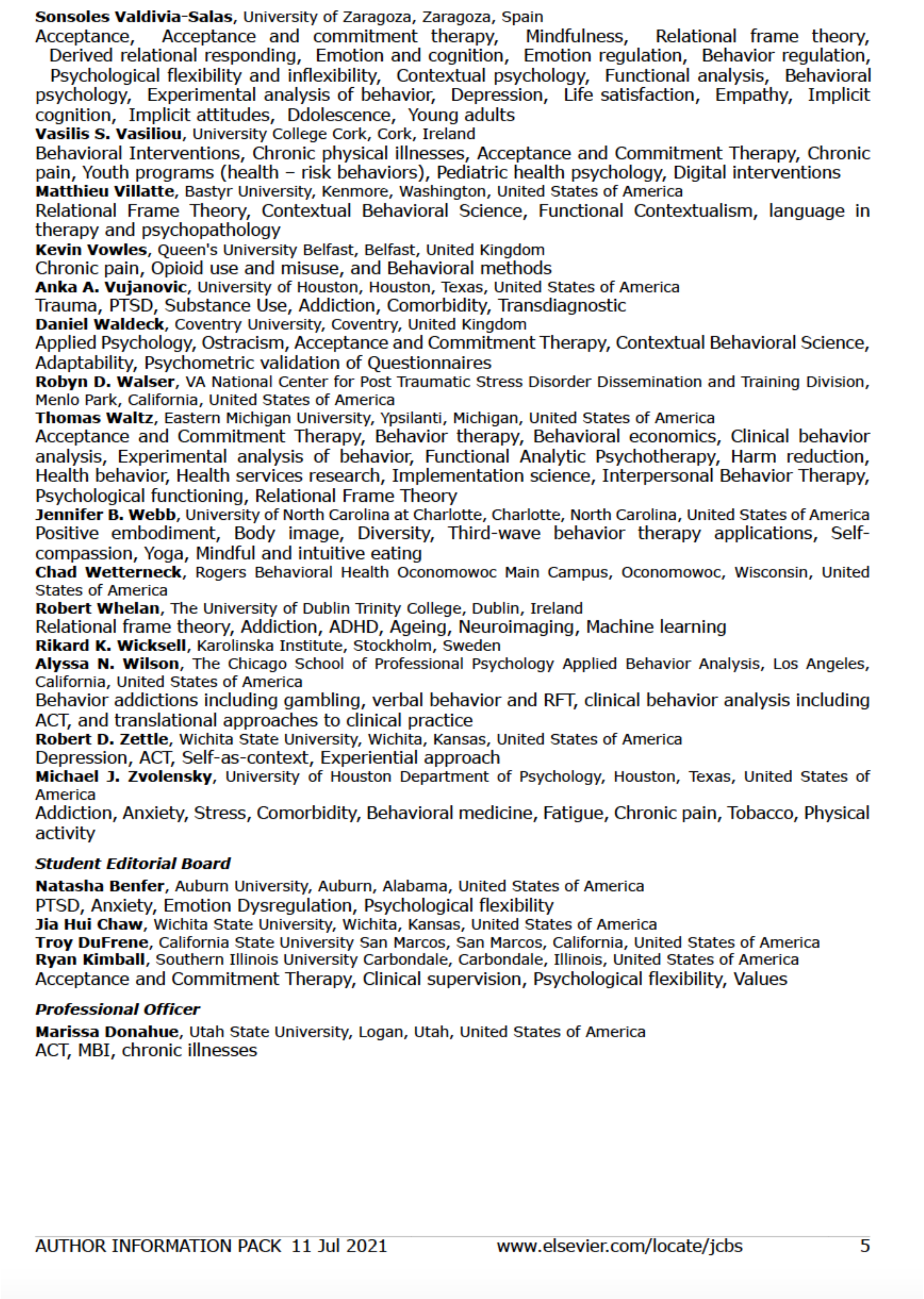
ACT, obsessive compulsive and related disorders, anxiety disorders, single subject design
Ian Tyndall, University of Chichester, Chichester, United Kingdom
Psychological Flexibility, Experiential Avoidance, Cognitive Defusion, Relational Frame Theory, Behavior Analysis
Nigel Vahey, Technological University Dublin, Dublin, Ireland
Addiction, Implicit Cognition, Impulsivity, Neuroscience, RFT, ACT, Motivational Interviewing, Philosophy of science, Personalized Diagnosis, Procrastination, Stress Management, Undergraduate Student Welfare



Sonsoles Valdivia-Salas, University of Zaragoza, Zaragoza, Spain
Acceptance, Acceptance and commitment therapy, Mindfulness, Relational frame theory, Derived relational responding, Emotion and cognition, Emotion regulation, Behavior regulation, Psychological flexibility and inflexibility, Contextual psychology, Functional analysis, Behavioral psychology, Experimental analysis of behavior, Depression, Life satisfaction, Empathy, Implicit cognition, Implicit attitudes, Ddolescence, Young adults
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Thomas Waltz, Eastern Michigan University, Ypsilanti, Michigan, United States of America
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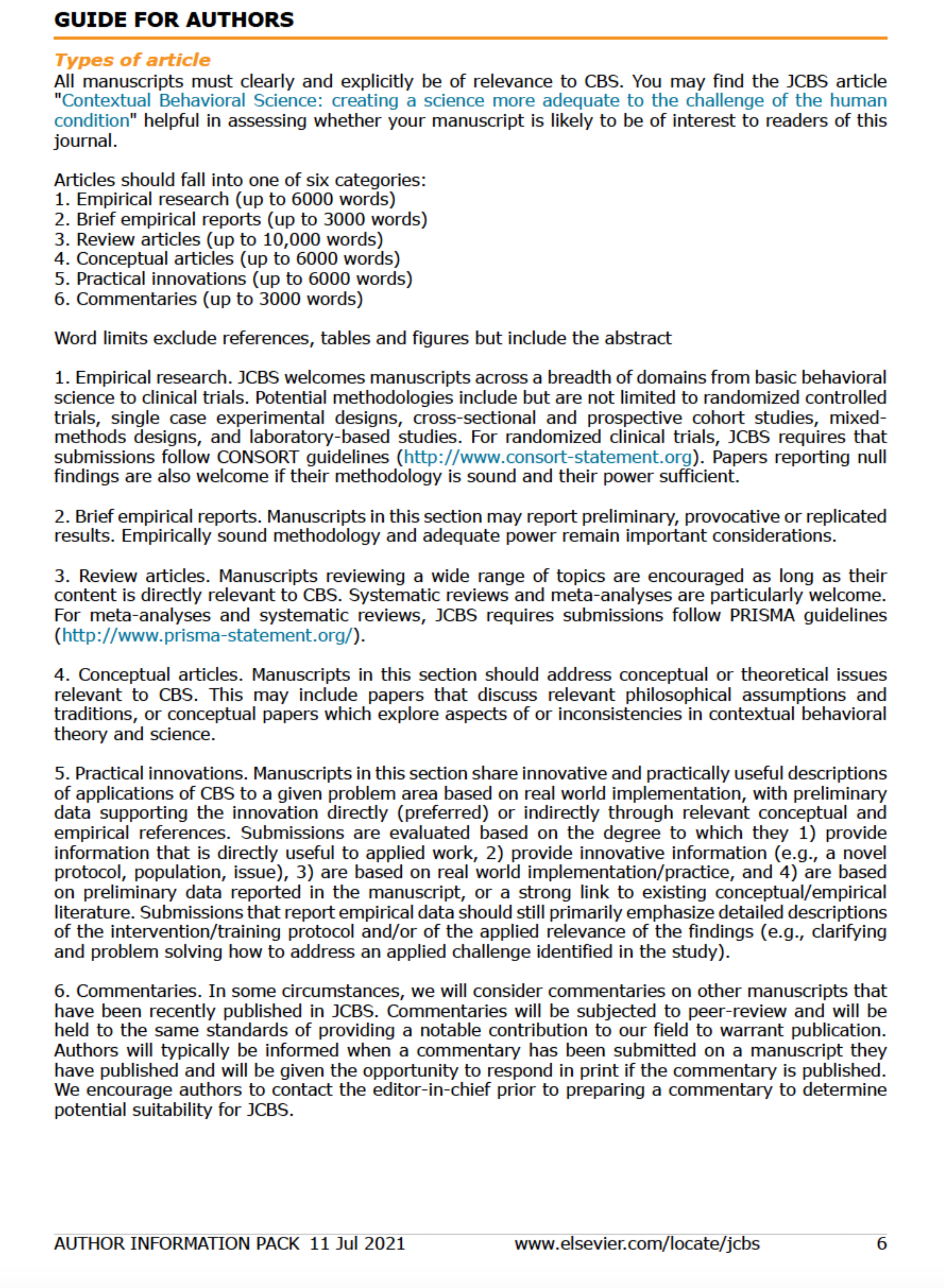

GUIDE FOR AUTHORS

Types of article

All manuscripts must clearly and explicitly be of relevance to CBS. You may find the JCBS article "Contextual Behavioral Science: creating a science more adequate to the challenge of the human condition" helpful in assessing whether your manuscript is likely to be of interest to readers of this journal.

Articles should fall into one of six categories:
1. Empirical research (up to 6000 words)
2. Brief empirical reports (up to 3000 words)
3. Review articles (up to 10,000 words)
4. Conceptual articles (up to 6000 words)
5. Practical innovations (up to 6000 words)
6. Commentaries (up to 3000 words)

Word limits exclude references, tables and figures but include the abstract

1. Empirical research. JCBS welcomes manuscripts across a breadth of domains from basic behavioral science to clinical trials. Potential methodologies include but are not limited to randomized controlled trials, single case experimental designs, cross-sectional and prospective cohort studies, mixed-methods designs, and laboratory-based studies. For randomized clinical trials, JCBS requires that submissions follow CONSORT guidelines (http://www.consort-statement.org). Papers reporting null findings are also welcome if their methodology is sound and their power sufficient.

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3. Review articles. Manuscripts reviewing a wide range of topics are encouraged as long as their content is directly relevant to CBS. Systematic reviews and meta-analyses are particularly welcome. For meta-analyses and systematic reviews, JCBS requires submissions follow PRISMA guidelines (http://www.prisma-statement.org/).

4. Conceptual articles. Manuscripts in this section should address conceptual or theoretical issues relevant to CBS. This may include papers that discuss relevant philosophical assumptions and traditions, or conceptual papers which explore aspects of or inconsistencies in contextual behavioral theory and science.

5. Practical innovations. Manuscripts in this section share innovative and practically useful descriptions of applications of CBS to a given problem area based on real world implementation, with preliminary data supporting the innovation directly (preferred) or indirectly through relevant conceptual and empirical references. Submissions are evaluated based on the degree to which they 1) provide information that is directly useful to applied work, 2) provide innovative information (e.g., a novel protocol, population, issue), 3) are based on real world implementation/practice, and 4) are based on preliminary data reported in the manuscript, or a strong link to existing conceptual/empirical literature. Submissions that report empirical data should still primarily emphasize detailed descriptions of the intervention/training protocol and/or of the applied relevance of the findings (e.g., clarifying and problem solving how to address an applied challenge identified in the study).

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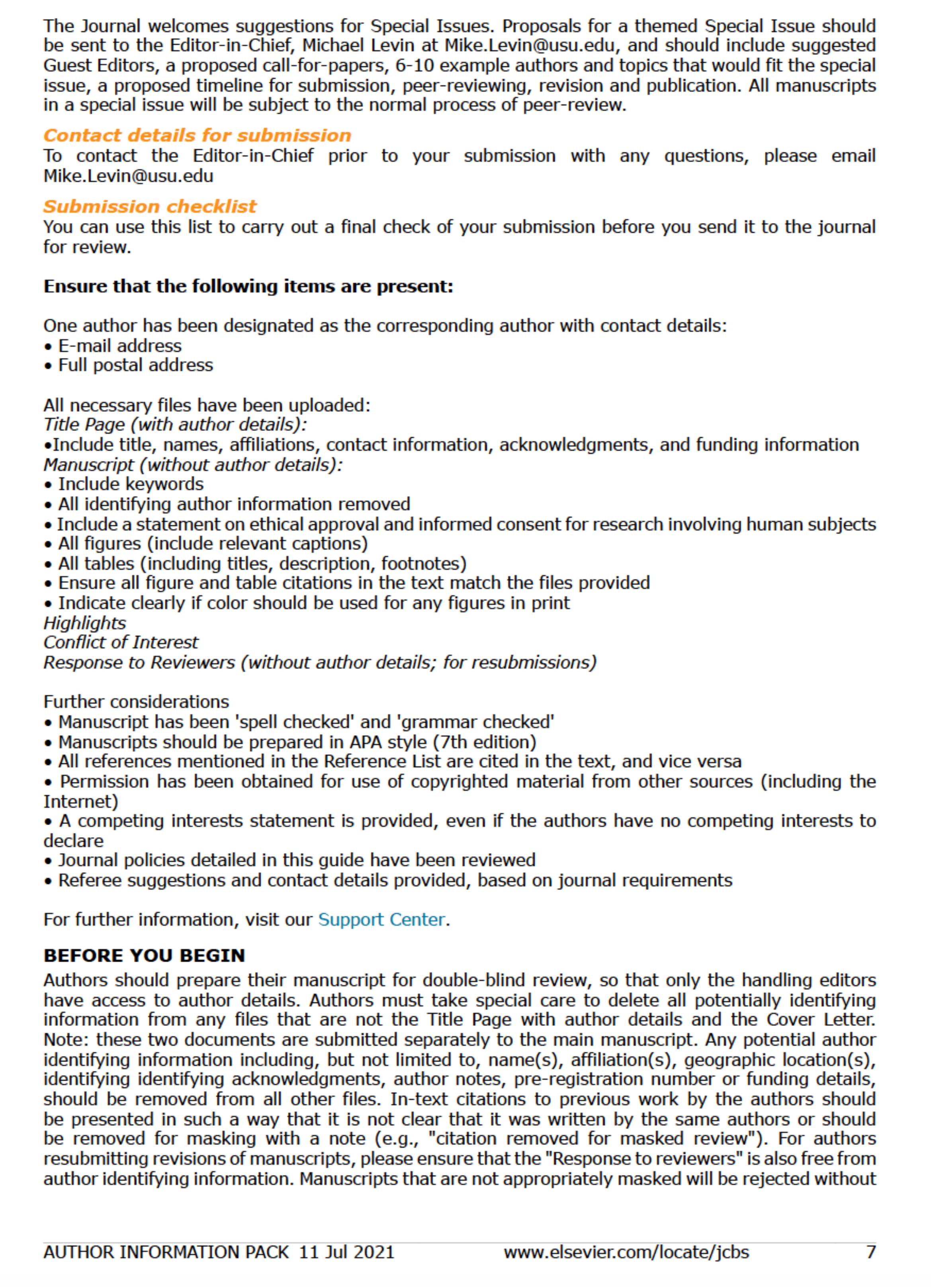

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Contact details for submission

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Submission checklist

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Ensure that the following items are present:

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- Full postal address

All necessary files have been uploaded:
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- Include title, names, affiliations, contact information, acknowledgments, and funding information

Manuscript (without author details):
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- All identifying author information removed
- Include a statement on ethical approval and informed consent for research involving human subjects
- All figures (include relevant captions)
- All tables (including titles, description, footnotes)
- Ensure all figure and table citations in the text match the files provided
- Indicate clearly if color should be used for any figures in print

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Conflict of Interest
Response to Reviewers (without author details; for resubmissions)

Further considerations
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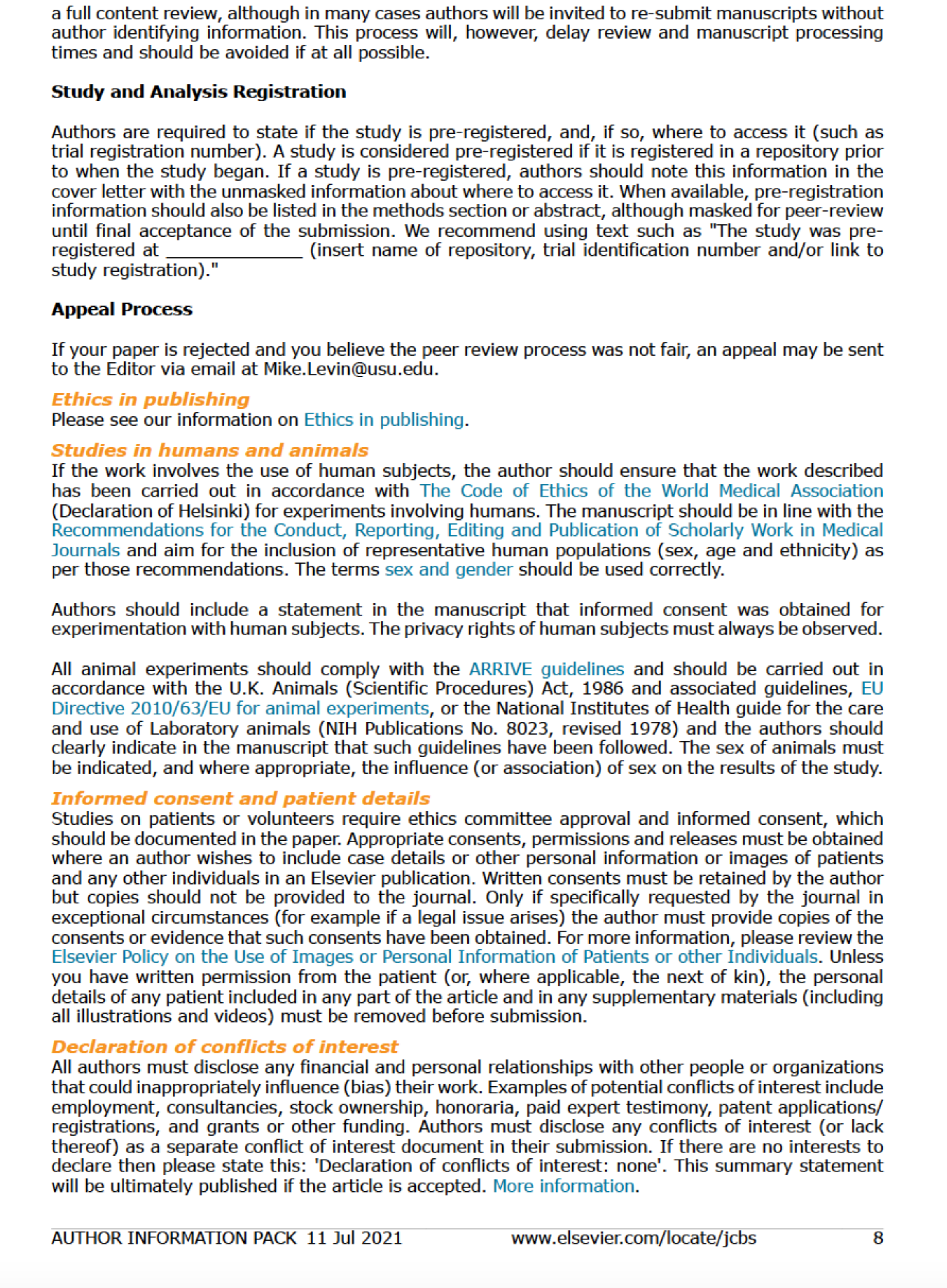

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All authors should have made substantial contributions to all of the following: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content, (3) final approval of the version to be submitted.

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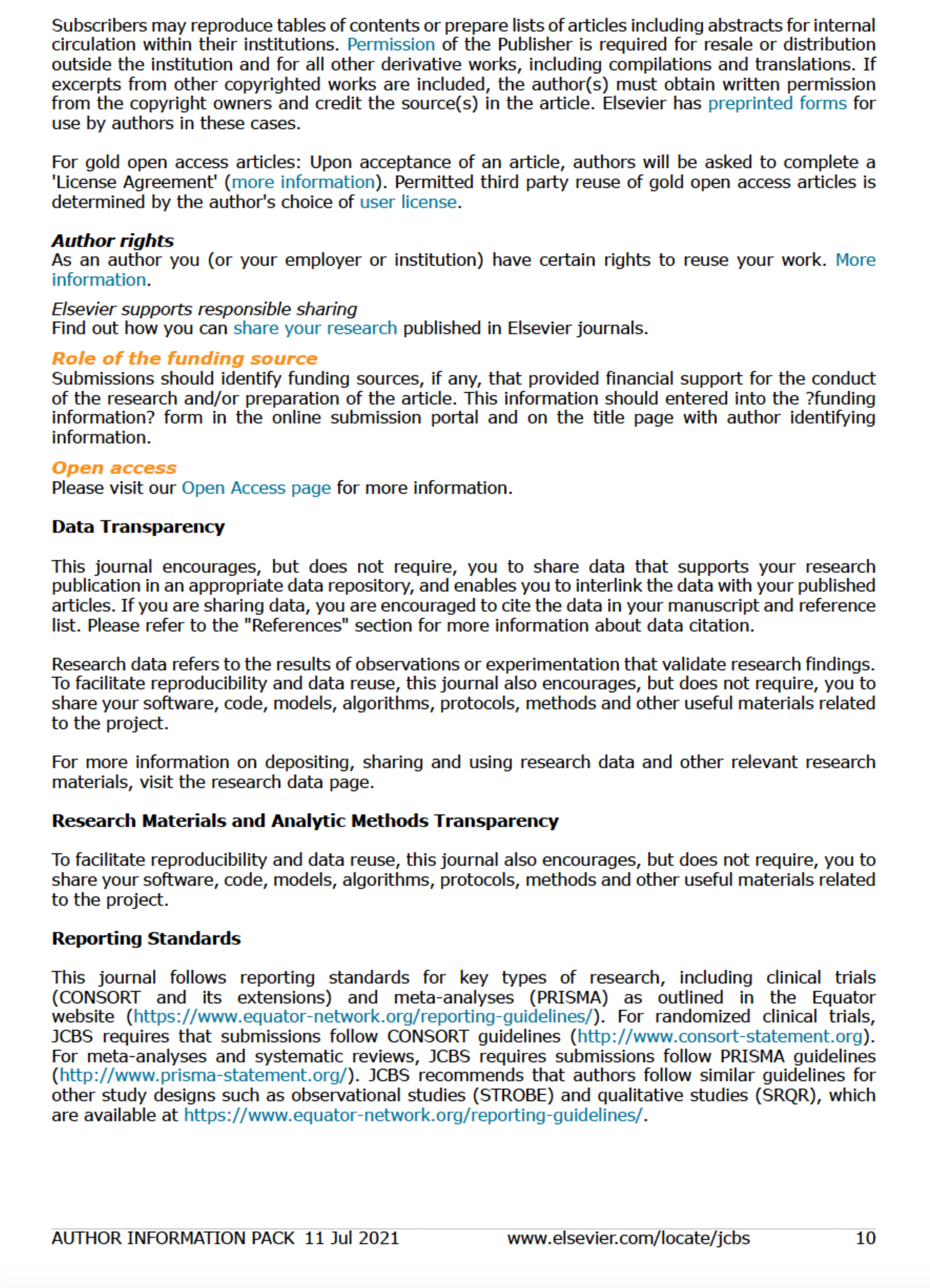

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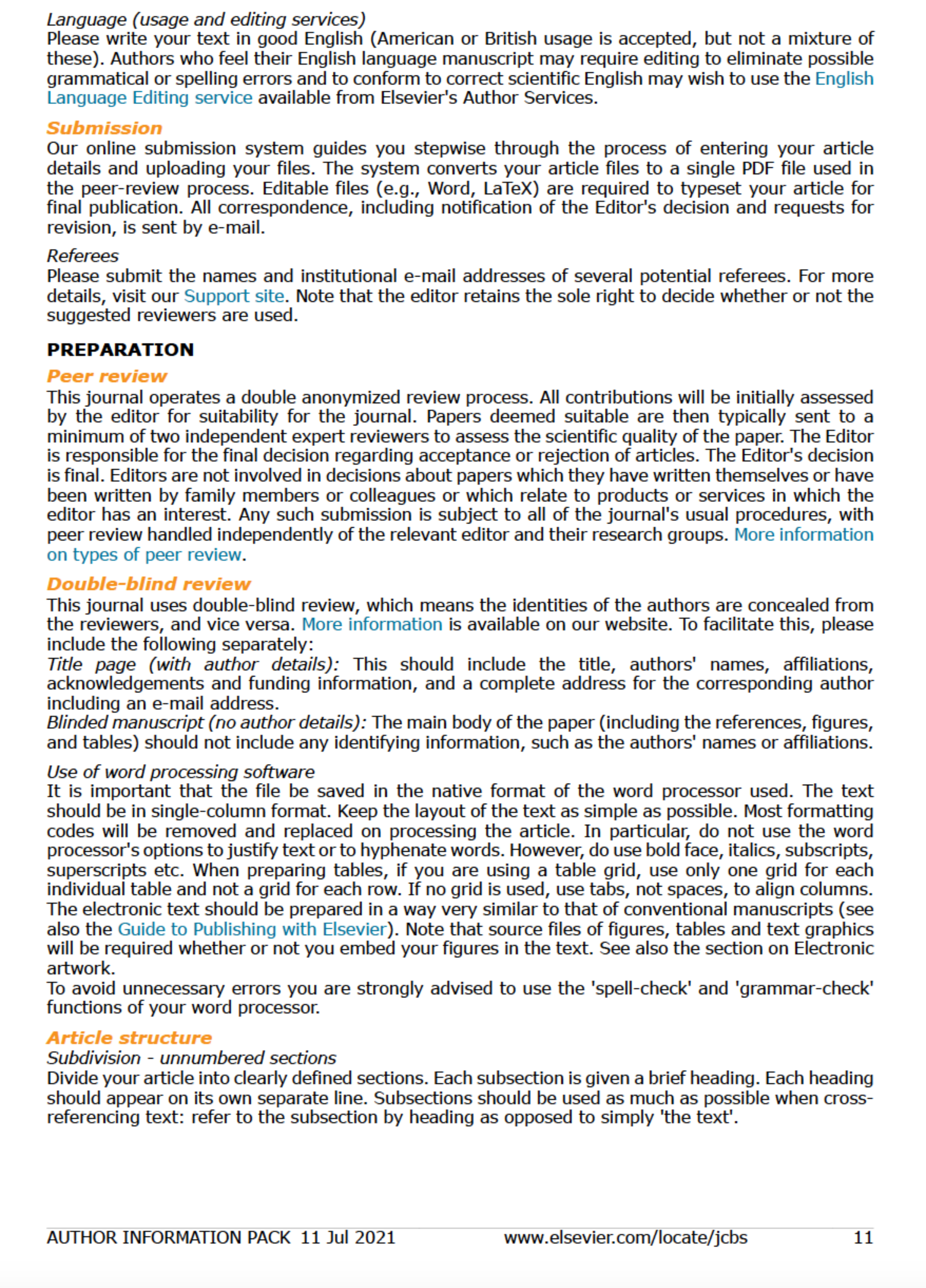

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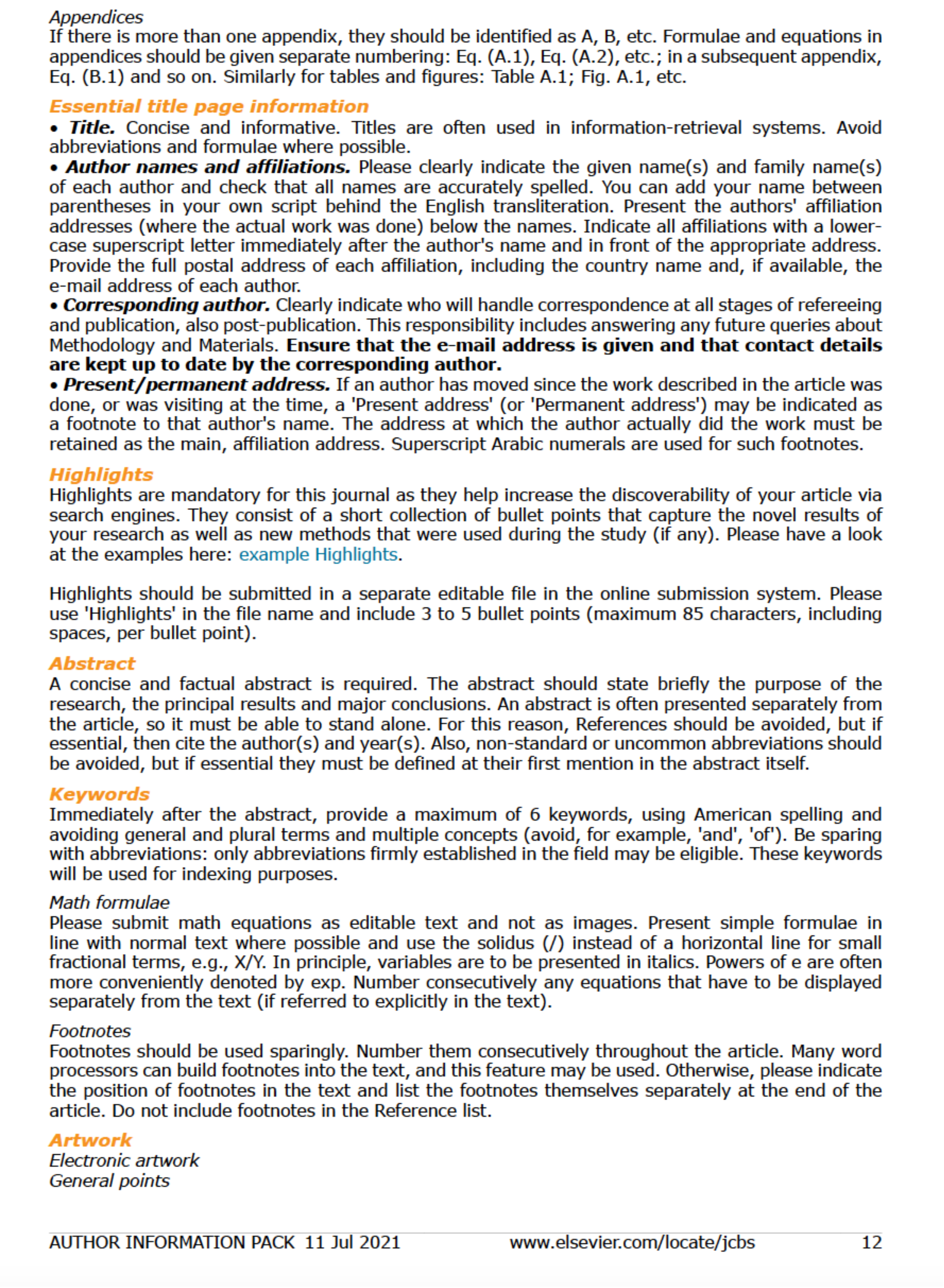

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Please submit math equations as editable text and not as images. Present simple formulae in line with normal text where possible and use the solidus (/) instead of a horizontal line for small fractional terms, e.g., X/Y. In principle, variables are to be presented in italics. Powers of e are often more conveniently denoted by exp. Number consecutively any equations that have to be displayed separately from the text (if referred to explicitly in the text).

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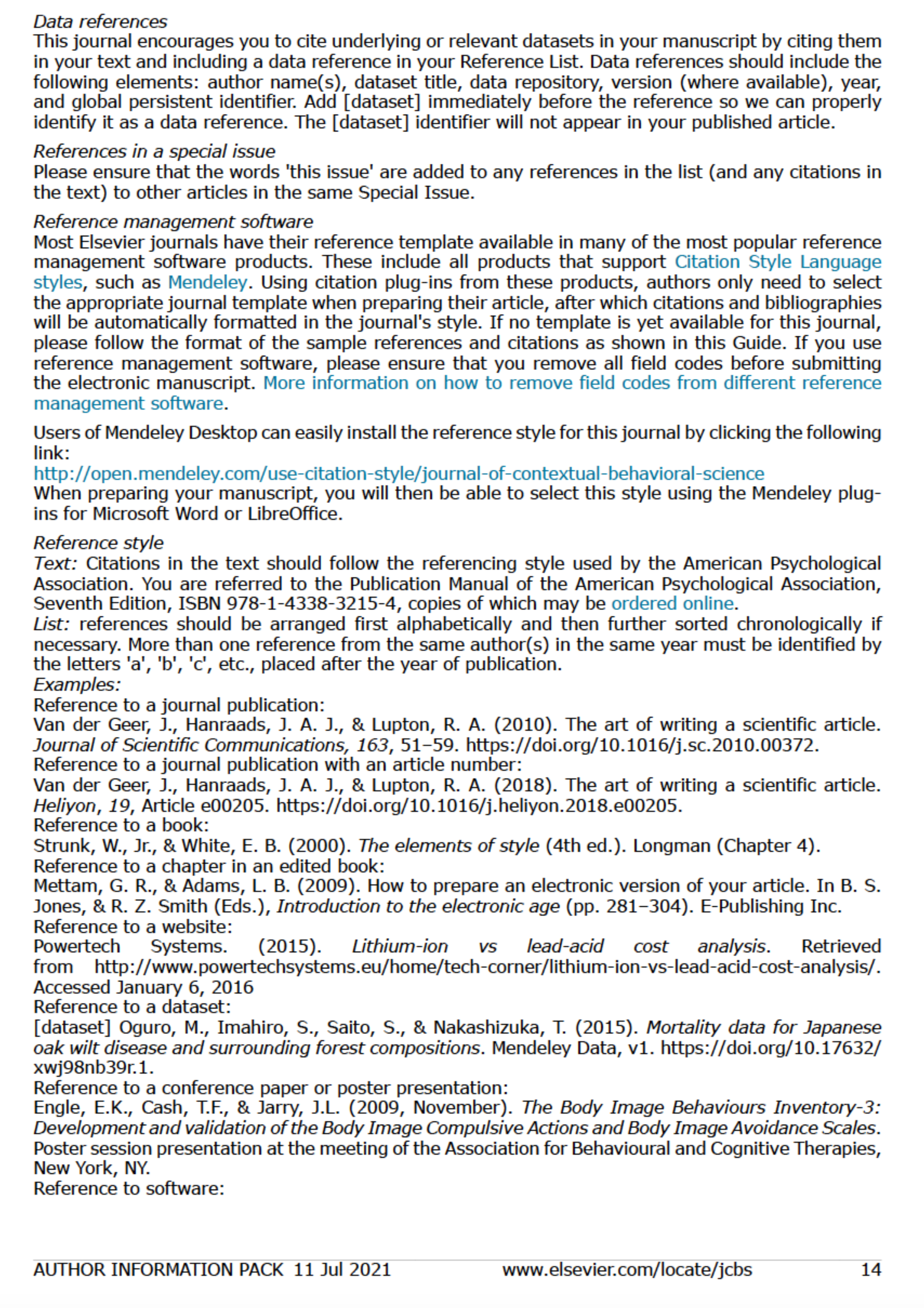

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[dataset] Oguro, M., Imahiro, S., Saito, S., & Nakashizuka, T. (2015). *Mortality data for Japanese oak wilt disease and surrounding forest compositions*. Mendeley Data, v1. https://doi.org/10.17632/xwj98nb39r.1.
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Engle, E.K., Cash, T.F., & Jarry, J.L. (2009, November). *The Body Image Behaviours Inventory-3: Development and validation of the Body Image Compulsive Actions and Body Image Avoidance Scales*. Poster session presentation at the meeting of the Association for Behavioural and Cognitive Therapies, New York, NY.
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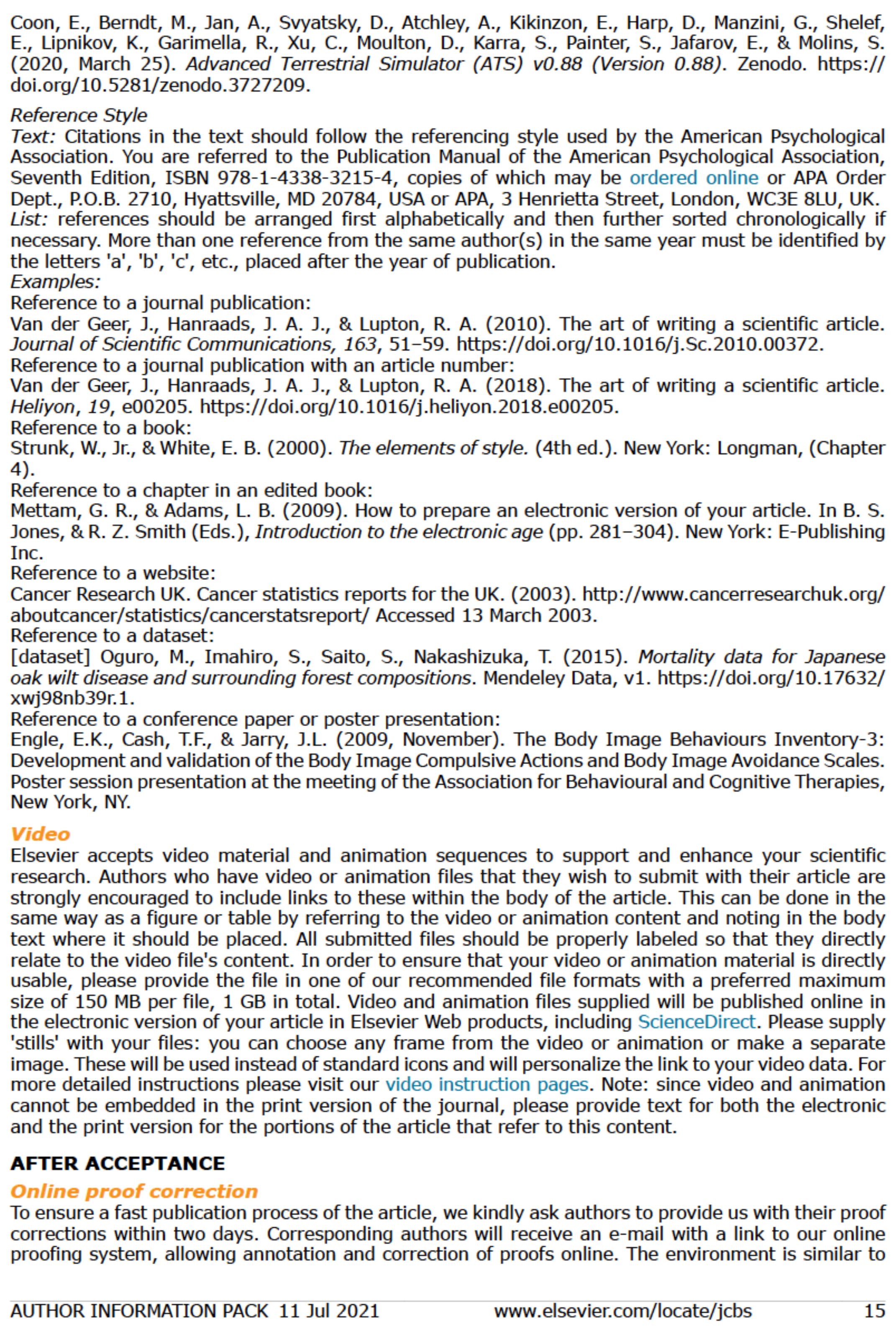

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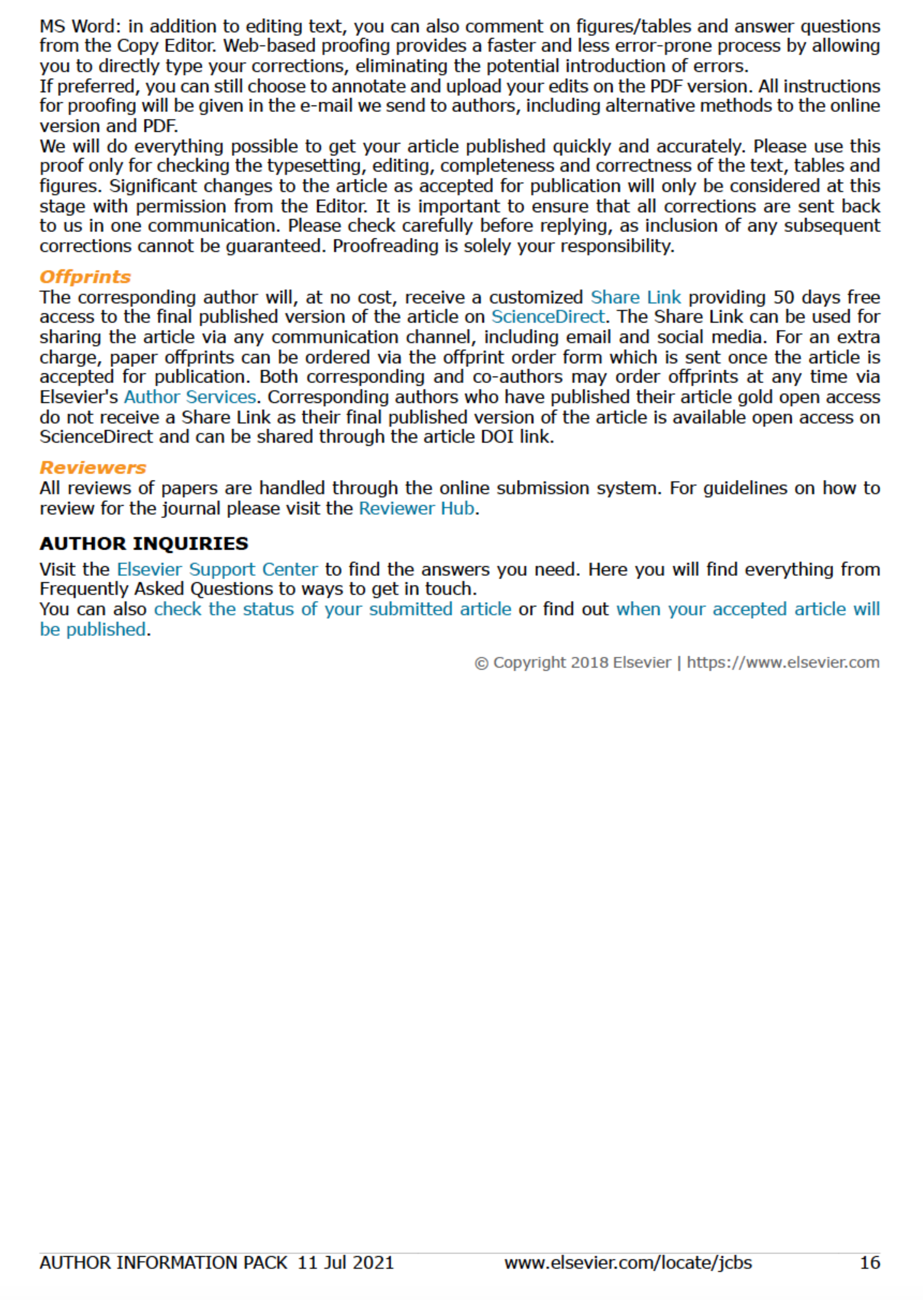

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Appendix G

PROSPERO Protoctol for the Systematic Review and Meta-Analysis

Systematic Review with Meta-Analysis Protocol

Acceptance and Commitment Therapy for Self-Management in the care of Long-Term Conditions: A Systematic Review and Meta-Analysis

Author and Primary Reviewer

Rachel Russell

University of East Anglia

Review Team

Dr Catherine Ford, Secondary Supervisor, University of East Anglia

Dr Katherine Deane, Primary Supervisor, University of East Anglia

Background and Aims

Improving care for people with long-term conditions (PLTC) has been identified as one of the most prominent challenges facing the NHS (Coulter, Roberts, & Dixon, 2013). It has been argued that care needs to move away from reactive models, to holistic and person-centred models of care (Coulter et al., 2013) and the role of self-management in the care of PLTC has also been highlighted (Department of Health, 2005b; Deeny, Thorlby, & Steventon, 2018; NHS England & NHS Improvement, 2020). In 2012, the Department of Health (DoH) predicted that the number of people with multi-morbidity would rise over the following 10 years (DoH, 2012) and this has been reflected in more recent research investigating acute emergency admissions (Deeny et al., 2018; Steventon, Deeny, Friebel, Gardner, & Thorlby, 2018).

There are important interactions between physical, psychological and social aspects of health for PLTC (DiMatteo, Lepper, & Croghan, 2000; NHS England, 2016; Stanton, Revenson, & Tennen, 2007). Whilst the relationship is likely to be complex, research has indicated that people with chronic physical health problems may be more likely to experience mental health difficulties and that this may also be associated with poorer physical health outcomes (Cooke et al., 2007; DiMatteo et al., 2000; Stanton et al., 2007). Living with a LTC has also been shown to impact on quality of life (QoL; Lempp et al., 2009; Mujica-Mota et al., 2015; Peters, Potter, Kelly, & Fitzpatrick, 2019) and evidence suggests this may particularly so where multimorbidity is present (Mujica-Mota et al., 2015; Peters et al., 2019). It has been suggested that much of the variance in the heterogeneity of QoL for PLTC may be explained by psychological factors rather than wholly by disease severity (Graham, Rose, Grunfeld, Kyle, & Weinman, 2011; Graham, Rose, Hankins, Chalder, & Weinman, 2013; Graham, et al., 2014).

The psychological process of adjustment to living with a LTC is also an important consideration within this domain. A number of factors have been found to affect adjustment and significant heterogeneity has been reported not only between individuals but also over time (Stanton et al., 2007). These factors have been conceptualised as operating at individual, community and societal levels (Putnam, Geenen, & Powers, 2003; Stanton et al, 2007). Social factors such as isolation, have been found to influence adjustment to LTCs (Stanton et al., 2007). Social isolation is particularly important given that living with a LTC may be associated with disability, and people with disabilities have increased likelihood of experiencing social isolation and loneliness (Macdonald et al., 2018). Other social factors such as socio-economic variables may also play a role in adjustment to LTCs, as socio-economic status influences health outcomes through both direct and indirect means (Stanton et al., 2007). As such, it is important to consider the physical, psychological and social care needs of PLTC and to acknowledge the reciprocal relationship between them.

The need for a holistic approach to care for PLTC, that is person-centred and integrated, is well documented in research (Coulter et al., 2013; DoH, 2005a; DoH, 2005b; Entwhistle & Cribb, 2013; Goodwin, Curry, Naylor, Ross, & Duldig, 2010; NHS England, 2016), as is the role of self-management in the care of PLTC (DoH, 2005b; Deeny et al., 2018; NHS England & NHS Improvement, 2020). Whilst there has been some research indicating that aspects of self-management lead to reduced costs within secondary care but may increase pressures elsewhere (McBain, Shipley, & Newman, 2015), there has also been research suggesting that increased self-management capability is associated with reduced healthcare utilisation across primary and secondary care (Barker, Steventon, Williamson, & Deeny, 2018) and that higher levels of patient activation may be associated with outcomes such as reduced emergency healthcare utilisation and fewer missed scheduled healthcare appointments (Deeny et al., 2018). However, the importance of situating self-management within a relational and social context has been highlighted (Morris, Kennedy, & Sanders, 2015).

Given the known interplay between physical, psychological and social aspects of health for PLTC (DiMatteo et al., 2000; NHS England, 2016; Stanton et al., 2007), and the emphasis within guidance and policy on providing holistic, integrated care for PLTC (Coulter et al., 2013; DoH, 2005a; DoH, 2005b; Entwhistle & Cribb, 2013; Goodwin et al., 2010; NHS England, 2016), the definition of self-management needs to encompass more than solely disease the management of disease. Whilst there is no set standard definition of self-management (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002), the current systematic review and meta-analysis will adopt the following definition:

> The tasks that individuals must undertake to live well with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management, and emotional management of their conditions. (Adams, Greiner, & Corrigan, 2004, pp.57)

There have been a range of approaches to providing self-management for PLTC, from interventions based on educational approaches to those based on approaches from health and clinical psychology (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Newman, Steed, & Mulligan, 2004; Wagner, Davis, Schaefer, Von Korff, & Austin, 1999). Psychological theories such as the Common Sense, or Self-Regulation Model (CSM, Leventhal et al., 2012) have influenced the development of self-management interventions for PLTC. This model postulates the process by which PLTC make sense of and cope with their condition(s) and the emotional impact of these conditions (Serlachius & Sutton, 2009). There is a positive evidence base for the application of psychological interventions to self-management. For example, Cognitive-Behavioural Therapy (CBT) has been reported to provide effective support for the self-management of health conditions (Broderick et al., 2016; Hind et al., 2014; Hofman, Asnaani, Vonk, Sawyer, & Fang, 2012; Ismail, Winkley, & Rabe-Hesketh, 2004; Morley, Eccleston, & Williams, 1999; Winkley et al., 2020).

Acceptance and Commitment Therapy (ACT), a third wave CBT approach, has been modified for PLTC (Graham, Gouick, Krahé & Gillanders, 2016). One of the core premises of ACT is that pain and suffering are an inevitable part of being human, and attempts to avoid, control or eliminate painful private experiences (for example, difficult thoughts, feelings or sensations) lead to increased suffering (Harris, 2009). ACT aims to enable people to live a meaningful life in the presence of pain and suffering and posits that this is achieved by increasing psychological flexibility (Harris, 2009), defined as ‘the ability to contact the present moment more fully as a conscious human being, and to change or persist in behavior when doing so serves valued ends’ (Hayes, Luoma, Bond, Masuda, & Lillis, 2006, pp.7). ACT has been shown to have utility for PLTC and there is a growing evidence base its use in managing psychological distress, promoting adjustment and self-management behaviours in this context (Dahl, 2009; Feliu-Soler et al., 2018; Graham et al., 2016; Graham, Simmons, Stuart & Rose, 2015; Gregg, Callaghan, Hayes & Glenn-Lawson, 2007; Thompson & McCracken, 2011). While second wave CBT approaches aim to address or modify maladaptive illness-related beliefs, ACT focuses on developing acceptance and living in accordance with personal values more broadly, which may be particularly useful for PLTC (Graham et al., 2016). This is supported by research highlighting the role of acceptance and psychological flexibility for LTCs such as diabetes, muscle disorders, and chronic pain (Feliu-Soler et al., 2018; Graham et al., 2015; Graham et al., 2016; Gregg et al., 2007; Thompson & McCracken, 2011). An example of a long-term condition for which there is particular evidence for the utility of ACT is chronic pain, for which the National Institute for Health and Care Excellence (NICE) guidance states to consider ACT for those with chronic primary pain who are aged 16 years and over (NICE, 2021). ACT may also have utility for

PLTC, due to its transdiagnostic nature (Brassington et al., 2016), especially given the prevalence of co- and multi-morbidity (Deeny et al., 2018; Steventon et al., 2018). Whilst Brassington et al., (2016) found evidence to support transdiagnostic ACT interventions for PLTC, it was noted that there was debate regarding their utility and that further research was needed to explore the delivery of transdiagnostic, as opposed to condition-specific, interventions within this context. A systematic review by Graham and colleagues (2016) also supported the utility of ACT for PLTCs.

Given the highlighted need for holistic, integrated care for PLTCs with research and guidance (Coulter et al., 2013; DoH, 2005a; DoH, 2005b; Entwhistle & Cribb, 2013; Goodwin et al., 2010; NHS England, 2016) and the evidence supporting the potential utility of ACT for PLTC (Graham et al., 2016), this review aims to conduct a systematic review and meta-analysis of the efficacy of ACT for self-management in LTCs in terms of physical, psychological and social outcomes, consistent with a holistic definition of self-management. This review will further contribute to the evidence base on previous reviews such as that by Graham et al., (2016), by taking a holistic approach to the definition of self-management and by aiming to conduct a meta-analysis on included studies within this context.

Review Question

Is Acceptance and Commitment Therapy (ACT) an effective intervention for self-management in relation to physical, psychological and social outcomes for people with long-term conditions (PLTCs)?

Review Procedure

Eligibility Criteria

In order to be eligible for inclusion in the review, studies must be randomised controlled trials (RCTs) of Acceptance and Commitment Therapy (ACT) for people with long-term conditions. Long-term conditions will be defined as '…a condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies' (DoH, 2012, pp.3). For the purposes of this review, mental health conditions will only be included if co-morbid with a long-term physical health condition. Examples of long-term conditions eligible for inclusion include diabetes, rheumatoid arthritis, chronic obstructive pulmonary disease, and hypertension. Diagnostic criteria for these LTCs will not be prescriptive and will allow clinical judgement to be sufficient. Weight management interventions will only be included within the context of LTCs. Only studies involving adults and older adults (18 years and above) will be included. There will be no restriction with regards to the format or method of delivery of the ACT intervention. Only published, primary research studies reporting validated outcome measures will be eligible for inclusion in the review. In addition, studies must have been peer-reviewed, have full-text availability and be available in English; conference abstracts and unpublished theses will be excluded.

In sum, the following criteria must be met for inclusion in the review:

- Acceptance and commitment therapy
- Adults or older adults with at least one long-term physical health condition
- Randomised controlled trials
- All formats and delivery methods will be accepted
- Validated outcome measures in the physical domain and in at least one of the psychological or social domains, in line with the holistic definition of self-management previously outlined (physical, psychological and social outcomes)

Outcomes

In order to be eligible for inclusion in the review, the outcomes reported in the studies must be validated measures within their respective area (physical, psychological, social). In line with the holistic definition of self-management adopted for this review, in order to be eligible for inclusion, studies must report on validated measures in the physical domain and in at least one of the psychological or social domains.

Search Method

The sources that will be searched for the systematic review include electronic databases, reference lists of eligible studies and review articles. The electronic databases that will be searched for the review are Medline, PsycINFO, CINAHL, and AMED. The reference lists of included studies and relevant review articles will be scanned for any studies relevant to the review. Please see appendix A for an example search string.

Review and Synthesis Method

Regarding study selection, searches will be conducted followed by a review of titles and abstracts against the eligibility criteria. The primary reviewer will be responsible for conducting the searches and the initial title and abstract reviews, with a member of the review team independently screening 20% of studies at this stage. Any disputes will be resolved through discussion between reviewers and if necessary, with the primary supervisor. Following this, a full-text review of studies included at this stage will be conducted by the review team and 20% of studies will be co-screened. Studies where there is agreement between the reviewers will be included in the review, and studies where there is any uncertainty or disagreement will be discussed, and agreement sought. If agreement cannot be reached, then this will be discussed with the primary supervisor to reach a decision. A PRISMA flowchart will be compiled to show the process of study selection.

Following this, data extraction will occur. Data extraction will be conducted by the primary reviewer and the primary supervisor, and a referencing manager such as Endnote will be used to store and organise the studies extracted. With regards to data extraction, this will be done using Microsoft Excel and broken down as below:

- Authors

- Year of publication
- Aims
- Design
- PPI: was there PPI in the study?
- Participants: number of participants, age, gender, ethnicity, other demographic information (per group)
- LTC
- Co- or multi-morbidity?
- Intervention format: individual, group, length of intervention (number of sessions and duration)
- Intervention content: any expert by experience involvement in content creation, any information on content of sessions for example, skills taught, or topics covered
- Intervention delivery: professional or peer led, in person or remote, delivery setting
- Comparison: treatment as usual, wait list, other psychological intervention or active control
- Measures: the validated physical, psychological and social outcome measures used
- Results: study outcomes (mean, standard deviation for each group, effect size), effect sizes, power
- Other: anything else of note for the study not included above

Risk of bias assessments will then be conducted for all included studies. The Cochrane risk of bias tool, RoB2, (Sterne et al., 2019; Higgins, Savović, Page, Elbers & Sterne, 2021) will be followed to assess risk of bias, with additional items: whether there has been Patient and Public Involvement (PPI) in the studies and fidelity of the intervention to the model of ACT. Risk of bias assessments will be conducted by the primary reviewer and at least 20%

will be co-rated by a member of the review team. Should there be any disagreement or uncertainty regarding ratings, this will be discussed by the primary review and co-rater. If no agreement can be sought, then this will also be discussed with the primary supervisor.

Following this, data synthesis and analysis will be conducted by the primary reviewer. In order to answer the questions outlined in this systematic review, a meta-analysis and narrative synthesis of included studies will be undertaken. Guidance for conducting the narrative synthesis will be in accordance with that published by Popay et al., (2006).

Outcomes

It is anticipated that the studies included in the review will likely use a range of outcomes and utilise a range of validated measures. For the current review, continuous outcomes will, in general, be preferred over dichotomous outcomes. For example, if a study were to present both a change score for anxiety (continuous outcome) and whether participants scored below the clinical threshold for anxiety (dichotomous outcome), then the continuous data will be included in the meta-analysis.

There is no primary outcome measure for this review as it aims to assess the impact of ACT on physical, psychological and social outcomes. It is anticipated that data will be able to be extracted for the following outcomes:

- Physical outcomes, which may include:
    - Clinical outcomes such as activities of daily living, weight, levels of physical activity, pain, fatigue, medication adherence
    - Surrogate outcomes such as blood pressure, HbA1c (average blood glucose)
- Psychological outcomes, such as measures of psychological flexibility, acceptance, anxiety, depression
- Social outcomes, such as measures of participation, return to work

- Multi-domain outcomes, such as quality of life outcomes that may cut across outcome domains. Such outcomes will be considered separately, and therefore if for example a study reported on a physical outcome and quality of life it would meet the eligibility criteria for inclusion. If studies utilising quality of life outcomes report independent subscales, for example a physical health subscale, then these may be considered as outcomes within their respective area.

Analysis

A meta-analysis of the data will be conducted if sufficient data is available and of adequate quality. A meta-analysis will not be conducted where there are three or more studies available. Data analysis will be conducted using the Cochrane Review Manager software (RevMan 5; The Cochrane Collaboration, 2020) and will be conducted in accordance with Cochrane guidance (Higgins et al., 2021) using a random-effects model. For studies reporting dichotomous outcomes, such as whether participants scored below a clinical threshold for anxiety or depression, the Risk Ratio (RR) with a 95% confidence interval (CI) will be calculated (Higgins, Li, & Deeks, 2021). For studies reporting continuous outcomes, such as change scores for anxiety or depression, the standardised mean difference (SMD) with a 95% CI will be calculated, as it is anticipated that analysis will need to account for studies that use different measurement scales to measure the same outcome (Higgins, Li, & Deeks, 2021). Missing data will be handled in accordance with Cochrane guidance (Deeks, Higgins, & Altman, 2021). Where possible replacement values (the mean) will be imputed, and a sensitivity analysis conducted (Deeks et al., 2021).

The primary analysis will assess the impact of ACT on key physical, psychological and social outcomes across long-term conditions. If data for long term conditions have not been separated into individual diagnoses, a group labelled “LTCs” will be included in the meta-analysis.

Additional sub-group analyses will be conducted to see if there is an interaction between intervention format or delivery (i.e., individual versus group delivery, and in person versus remote delivery) and intervention effect, if the data allow. A narrative synthesis will be undertaken of any salient data that cannot be analysed statistically. Guidance for conducting the narrative synthesis will be in accordance with that published by Popay et al., (2006).

Dissemination Plans

This systematic review is being conducted as part of a thesis portfolio for the Doctoral Programme in Clinical Psychology at the University of East Anglia. In addition, it will also be submitted for publication in a relevant academic journal.

Key words

Acceptance and Commitment Therapy; Long-term conditions; Self-management; Holistic

Timeline

It is anticipated that this review will be complete by 24th September 2021.

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Appendices

Appendix A: Example search string

Appendix A: Example Search String

Review Title:

Acceptance and Commitment Therapy for Self-Management in the care of Long-Term Conditions: A Systematic Review and Meta-Analysis

Example search string (Medline Ovid):

1. exp. “Acceptance and Commitment Therapy”
2. Accept* and Commit* Therapy.ti,ab
3. Accept* and Commit* Training.ti,ab
4. Psychological Flexibility
5. 1 OR 2 OR 3 OR 4

Appendix H

PRISMA Checklist for the Systematic Review and Meta-Analysis

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	X - Title
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Abstract completed but full PRISMA abstract checklist not used
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	X - Introduction
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	X – Introduction and method
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	X – Method and analysis
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	X - Method
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	X – Method and appendices
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	X - Method
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	X - Method
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	X – Method and appendices
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	X - Method
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	X - Method

Section and Topic	Item #	Checklist item	Location where item is reported
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	X - Method
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	X- Method
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	X - Method
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	X – Method/ Results
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	X- Method
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/a (explained why further subgroup/sensitivity analysis not appropriate in method)
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/a
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	X Method
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	X Method/Results
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	X – Method/Results
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	X – Analysis and Results
Study characteristics	17	Cite each included study and present its characteristics.	X - Results
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	X - Results
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	X - Results
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	X - Results
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision	X - Results

Section and Topic	Item #	Checklist item	Location where item is reported
		(e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/a
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/a
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	X - Results
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	X results
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	X
	23b	Discuss any limitations of the evidence included in the review.	X
	23c	Discuss any limitations of the review processes used.	X
	23d	Discuss implications of the results for practice, policy, and future research.	X
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	X - Method
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	X - Method
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/a Any amendments made through PROSPERO so protocol is up to date
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	X
Competing interests	26	Declare any competing interests of review authors.	X
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	X information in supplementary materials and appendices related to remaining forest plot graphs for all analyses, and study outcomes table

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

Appendix I

Search strings for the Systematic Review and Meta-Analysis

Medline

6. exp. “Acceptance and Commitment Therapy”
7. Accept* and Commit* Therapy.ti,ab
8. Accept* and Commit* Training.ti,ab
9. Psychological Flexibility
10. 1 OR 2 OR 3 OR 4

CINAHL

1. (MH ”Acceptance and Commitment Therapy”)
2. TI Accept* and Commit* Therapy
3. AB Accept* and Commit* Therapy
4. TI Accept* and Commit* Training
5. AB Accept* and Commit* Training
6. Psychological Flexibility
7. S1 OR S2 OR S3 OR S3 OR S5 OR S6

PsycINFO

1. DE “Acceptance and Commitment Therapy”
2. TI Accept* and Commit* Therapy
3. AB Accept* and Commit* Therapy
4. TI Accept* and Commit* Training
5. AB Accept* and Commit* Training

6. Psychological Flexibility
7. S1 OR S2 OR S3 OR S4 OR S5 OR S6

AMED

1. (ZU “acceptance and commitment therapy”)
2. TI Accept* and Commit* Therapy
3. AB Accept* and Commit* Therapy
4. TI Accept* and Commit* Training
5. AB Accept* and Commit* Training
6. Psychological Flexibility
7. S1 OR S2 OR S3 OR S4 OR S5 OR S6

Appendix J

Table of Study Outcomes for the Systematic Review and Meta-Analysis

Study ID (First author and year)	Long-Term Condition	Physical Outcomes (Measure)	Psychological Outcomes (Measure)	Social Outcomes (Measure)	Multi-Domain Outcomes (Measure)
			Oncology		
Arch 2021	Breast cancer Blood cancer Gastrointestinal Other	*Energy/fatigue (Vitality RAND SF-36)	*Anxiety (HADS-A) *Depression (CESD) **Fear of cancer recurrence (CARS) **Post-Traumatic Stress (IES-R) Sense of meaning (FACIT) Mood/anxiety disorder (Clinical severity rating)	N/a	N/a
Mosher 2018	Stage IV breast cancer	Symptom interference (MDASI) **Pain interference (PROMIS) **Fatigue interference (7 items from FSI) **Sleep impairment (PROMIS) **Pain intensity (PROMIS) **Fatigue (PROMIS SF) Sleep disturbance (PROMIS SF)	**Anxiety (PROMIS SF) **Depression (PROMIS SF)	N/a	N/a

Shari 2020	Breast cancer	*Fatigue (FACT-F) Subjective cognitive impairment (FACT-COG)	*Anxiety (HADS-A) *Depression (HADS-D) *Acceptance (AAQ-II)	N/a	N/a
Serfaty 2019	Advanced cancer	Physical ability (2-minute walk, 1-minute sit to stand) *Physical wellbeing (FACT-G Physical Wellbeing subscale)	*Acceptance (AAQ-II) *Values (VLQ) *Emotional wellbeing (FACT-G Emotional Wellbeing subscale) Psychological distress (K10)	Social/family wellbeing (FACT-G Social/Family Wellbeing subscale) Functional wellbeing (FACT-G Functional Wellbeing subscale)	*QoL (EQ-5D-5L) QoL (FACT-G)
Mosher 2019	Advanced lung cancer	**Fatigue interference (7 items from FSI) *Pain intensity (PROMIS) *Fatigue (PROMIS) **Sleep disturbance (PROMIS SF) Breathlessness (4 items from MSAS; PROMIS 1 item related to task avoidance due to dyspnea)	*Anxiety (PROMIS SF) *Depression (PROMIS SF) Distress (distress thermometer) *Acceptance (PEACE subscale) Struggle with illness (PEACE subscale)	N/a	N/a

		Symptom interference (MDASI Global symptoms interference subscale) **Pain interference (PROMIS)			
Johns 2020	Breast cancer: stage I to III	**Global physical health (PROMIS Global Health)	**Anxiety (GAD-7) **Depression (PHQ-8) **Fear of cancer recurrence (FCRI) **Post-traumatic stress symptoms (IES-R) **Global mental health (PROMIS Global Health) **Acceptance (CAAQ)	N/a	QoL (PROMIS Global Health)
			Endocrinology		
Gregg 2007	Type II diabetes	**Blood glucose (HbA1C) *Self-management (SDSCA) **Understanding of diabetes (DCP – Understanding of diabetes subscale)	*Acceptance (AADQ)	N/a	N/a
Davoudi 2020	Type II diabetes with neuropathic pain	**Sleep (PSQI)	*Depression (BDI)	N/a	N/a

Whitehead 2017	Type II diabetes (uncontrolled)	**Blood glucose (HbA1C) *Self-management (SDSCA) **Understanding of diabetes (DCP)	*Anxiety (HADS-A) *Depression (HADS-D) Satisfaction with treatment (DTSQ)	N/a	N/a
Shayeghian 2016	Type II diabetes	**Blood glucose (HbA1C) *Self-management (SDSCA)	*Acceptance (AADQ) Coping (Brief COPE questionnaire)	N/a	N/a
Neurology					
Proctor 2018	MS	MS Impact – Physical (MSIS) Disability (EDSS)	*Anxiety (GAD-7) *Depression (PHQ-9) MS Impact – Psychological (MSIS) *Acceptance (AAQ-II)	N/a	*QoL (EQ-5D-5L)
Whiting 2020	Severe TBI	*Physical health QoL (SF-12)	*Anxiety (HADS-A) *Depression (HADS-D) Affect (PANAS) Distress (DASS) *Mental health QoL (SF-12) Mental health (GHQ-12) *Acceptance (*AAQ-II; AAQ-ABI) Motivation (MOT-Q) Values (SLP)	Psychosocial reintegration (SPRS)	QoL (SF-12)

Lundgren 2008b	Epilepsy	**Seizures (Seizure index)	Satisfaction with life (SWLS)	N/a	*QoL (WHOQoL-BREF)
Dindo 2020	Mild TBI	*Pain severity (BPI) **Pain Interference (BPI)	Distress (DASS) **PTSD (PCL-C) *Acceptance (AAQ-II)	Community reintegration (MCQ) Disability (WHO Disability Assessment Schedule)	N/a
Giovannetti 2020	MS	*Physical health QoL (MSQoL)	*Anxiety (HADS-A) *Depression (HADS-D) *Mental health QoL (MSQoL) Resilience (CD-RISC 25) Stress (PSS) ACT processes (CompACT) **Mindful Attention (MAAS) *Values (VLQ) **Defusion (DDS) *Acceptance (AAQ-II)	N/a	QoL (MSQoL-54)
Lundgren 2006	Epilepsy	**Seizures (Seizure index; seizure frequency)	Satisfaction with life (SWLS)	N/a	*QoL (WHOQoL)
			Rheumatology		

Luciano 2014	Fibromyalgia	*Pain (PAIN VAS) *Physical impact of fibromyalgia (FIQ)	*Anxiety (HADS-A) *Depression (HADS-D) **Pain catastrophising (PCS) *Acceptance (CPAQ)	N/a	*QoL (EQ-5D-5L VAS)
Simister 2018	Fibromyalgia	*Physical impact of fibromyalgia (FIQ Revised) **Sleep (PSQI) Physical activity (6-minute walk; sit to stand) Pain (MPQ – sensory and affective domains)	*Depression (CESD) **Pain catastrophising (PCS) Kinesiophobia (TKS) *Acceptance (CPAQ-R) **Mindfulness (FFMQ) **Cognitive fusion (CFQ) *Values (VLQ)	N/a	N/a
Wicksell 2013	Fibromyalgia	*Physical impact of fibromyalgia (FIQ) *Physical health QoL (SF-36) Pain disability (PDI) *Pain intensity (Numeric scale)	*Depression (BDI) *State anxiety (STAI) Trait anxiety (STAI) Self-efficacy (Self-efficacy scale) Inflexibility to pain (PIPS) *Mental health QoL (SF-36)	N/a	QoL (SF-36)
Clarke 2017	Knee/hip osteoarthritis	Intermittent and constant pain (ICOAP) *Pain (numerical rating scale)	Pain anxiety (PASS-20) *Mental health (GHQ-12) Acceptance (CPAQ)	N/a	N/a

* Included in statistical meta-analysis. ** Included in narrative synthesis. Esmali (2015) was excluded from this summary table, as the authors could not find the outcome measures as reported in the study and the data was excluded from analysis due to the method of reporting. Abbreviation: HADS (A/D) = Hospital Anxiety and Depression Scale (Anxiety/Depression); CESD = Center for Epidemiological Studies - Depression; CARS = Concerns about Recurrence Scale; IES-R (cancer specific version) = Impact of Events Scale-Revised; FACIT = Functional Assessment of Chronic Illness Therapy; MDASI = MD Anderson Symptom Inventory; PROMIS = Patient-Reported Outcomes Measurement Information System; FSI = Fatigue Symptom Inventory; FACT = Functional Assessment of Cancer Therapy (F = fatigue; G = general, COG = cognitive function); AAQ-II = Acceptance and Action Questionnaire; UK = United Kingdom; VLQ = Valued Living Questionnaire; K10 = Kessler Psychological Distress scale; MSAS = Memorial Symptom Assessment Scale; PEACE = Peace, Equanimity and Acceptance in the Cancer Experience questionnaire; GAD-7 = Generalised Anxiety Disorder – 7; PHQ 8/9 = Patient Health Questionnaire – 8/9; FCRI = Fear of Cancer Recurrence Inventory; IES-R = Impact of Events Scale – Revised; CAAQ = Cancer Acceptance and Action Questionnaire; SDSCA = The Summary of Diabetes Self-Care Activities; DCP = Diabetes Care Profile; AADQ = Acceptance and Action Diabetes Questionnaire; PSQI = Pittsburgh Sleep Quality Index; BDI = Beck Depression Inventory; DTSQ = Diabetes Treatment Satisfaction Questionnaire; MSIS = Multiple Sclerosis Impact Scale; EDSS = Expanded Disability Status Scale; PANAS = Positive and Negative Affect Schedule; DASS = Depression, Anxiety and Stress Scale; GHQ-12 = General Health Questionnaire – 12; MOT-Q = Motivation for TBI rehabilitation questionnaire; SLP = Survey of Life Principles; SPRS = Sydney Psychosocial Reintegration Scale; SWLS = Satisfaction with Life Scale; BPI = Brief Pain Inventory; PTSD = Post-Traumatic Stress Disorder; PCL-C = PTSD checklist – Civilian; MCQ = Military to Civilian Questionnaire; MSQoL-54 = Multiple

Sclerosis Quality of life – 54; CD-RISC 25 = Connor-Davidson Resilience Scale; PSS = Perceived Stress Scale; MAAS = Mindful Attention Awareness Scale; DDS = Drexel Defusion Scale; CompACT = Comprehensive Assessment of ACT processes; Pain VAS = visual analogue scale; FIQ = Fibromyalgia Impact Questionnaire, PCS = Pain Catastrophizing Scale; CPAQ = Chronic Pain Acceptance Questionnaire; MPQ = McGill Pain Questionnaire; TKS = Tampa Scale of Kinesiophobia; FFMQ = Five Facet Mindfulness Questionnaire; CFQ = Cognitive Fusion Questionnaire; PDI = Pain Disability Index; STAI = State-Trait Anxiety Inventory; PIPS = Psychological Inflexibility in Pain Scale; ICOAP = Intermittent and Constant Osteoarthritis Pain; PASS-20 = Pain Anxiety Symptoms Scale – 20.