



Review Article

What outcomes matter to service users who experience persistent depression: A mixed-method narrative review and synthesis

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ABSTRACT

Background: It is unclear whether current outcome measures capture what is important to service users experiencing treatment-resistant depression (TRD). This review aims to understand what outcomes are important to people receiving treatment for TRD, and to ascertain how this is being measured or could be measured to aid values-based commissioning in the implementation of specialist services.

Methods: A systematic search was conducted across nine databases: EMBASE, PSYCHINFO, AMED, EMCARE, PubMed, BNI, HMIC, CINHAL, and Medline. Quantitative and qualitative studies, and non-empirical work were included. No publication date restrictions were set. Included studies were appraised for quality.

Results: Twenty-two studies met inclusion for the review, including two opinion pieces. Thematic analysis was used to extract five themes: important outcomes beyond recovery from symptoms; differentiations in perspectives; patient preferences; essential sets of outcome measures; and underdeveloped outcome measures from the patient's perspective.

Limitations: The search strategy was partially systematic due to the exploratory nature of the subject and the lack of available research in the field. Studies included collect data on patient perspectives but did not demonstrate co-production throughout the whole research process.

Conclusions: Outcomes in persistent depression have been neglected, especially from the patient perspective. The findings from this review make an important contribution to agreeing desirable outcomes for people with TRD by drawing together the literature and highlighting how and why it is necessary to apply certain methods to persistent depression. The report identifies areas where further understanding and research is needed and how to inform current service commissioning practices.

1. Introduction

UK National Institute for Health and Care Excellence (NICE) guidelines recommend that all service users with a diagnosis of major depressive disorder (MDD) who have not responded to two or more antidepressants at an adequate dose and duration should be referred to a specialist service, delivered by a specialist multi-professional team, for "treatment-resistant depression" (TRD) or "persistent depression"

(NICE, 2009). Persistent depression includes TRD, however it is important to note that persistent depression encompasses a wider range of depressive presentations that do not improve over time. NICE's recommended collaborative care approach incorporates a model of working in which joint assessments by psychologists and psychiatrists are performed and a range of psychological and pharmacotherapy treatments are available (Gunn et al., 2006), and in which structured management plans are developed in accordance with protocols both for

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psychotherapy and pharmacology and are based on NICE guidelines for depression (Gunn et al., 2006).

Despite NICE recommendations, only a small number of randomized control trials (RCTs) have examined the effectiveness of collaborative treatment services. Research has largely been limited to single interventions, such as pharmacotherapy or psychotherapy for the treatment for chronic depression. Even intensive use of these individual approaches leaves many cases unremitted (Morriss et al., 2016). For example, the STAR*D RCT showed that only 67% of outpatients with MDD who received 12 months of systematic and tailored pharmacological or psychological treatment achieved remission after 1 year (Rush et al., 2006). In comparison, a pilot trial investigating the effects of combining psychotherapy and optimized pharmacotherapy in an integrated specialist depression service (SDS) for people with persistent moderate-to-severe clinical depression, showed increased remission rates at the end of 4 months of treatment, compared with community treatment as usual (Murray et al., 2010). Moreover, one large scale RCT investigated the clinical efficacy and cost-effectiveness of an SDS on depression symptoms and function, compared with usual mental health treatment as directed by a consultant psychiatrist (Morriss et al., 2016). Providing pharmacotherapy and psychological treatments from a collaborative specialist team significantly reduced depressive symptoms after 18 months.

Whilst emerging evidence suggests integrated, collaborative specialist care provides a better approach for the treatment of persistent depression, current commissioning practice in the UK increasingly requires information beyond evidence on effectiveness and cost-effectiveness generated from RCTs (RSPH, 2013). It emphasizes the need for co-production and identification of outcomes that are important for service users (Stickley, 2006). Over recent years, there has been a period of considerable change in health and social care commissioning in the UK (Perry et al., 2013). Traditionally, commissioning approaches have been guided by 'evidence-based practice' (EbP), a model based on the idea that forms of scientific and objective research evidence provide the most effective way to inform policy making and clinical decision making. The model however has been criticised due to its overlook of the thoughts, feelings and opinions of service users and carers (Hewitt, 2009). To address this gap, the concept of 'values-based practice' (VbP) has been developed as a framework complementary to EbP (Fulford, 2004). VbP is a clinical skills-based approach to working with complex and conflicting values in healthcare and to support clinical decision making based on values, rather than factually derived scientific knowledge (Fulford, 2008). This approach aims to empower service users and carers by focusing on individual values and allowing more direct control over decisions relating to treatment, access to services and choices about care (Perry et al., 2013). VbP purpose is to link science with the unique values of the service users and make explicit the diverse values of all those involved in the process of clinical decision making (Perry et al., 2013).

VbP is being gradually applied to commissioning of mental health services through values-based commissioning (VbC), which is central to the NHS 10 Year Plan (England, 2019), and rests equally on three pillars: 1) knowledge derived from scientific or other systematic approaches; 2) clinical expertise; 3) patient and carer perspective (RSPH, 2013). In VbC, service users and carers can work jointly with commissioners to influence decisions relating to the commissioning of mental health services (RSPH, 2013; Heginbotham, 2012). As with VbP, there is a much stronger focus on co-production and considering the outcomes that are important for service users (Perry, 2013).

Despite service user involvement and participation being considered highly desirable to the development of high-quality mental health services, it is only in the past decade that it has received close attention (McIntosh et al., 2010). The concept of VbC is also closely aligned to value-based health care (VBHC) (Porter and Teisberg, 2006). VBHC aims to refocus health systems from activity to value. Value (not to be confused with moral or ethical 'values') is defined as the outcomes that

matter to patients, divided by the cost of achieving those outcomes (Baggaley, 2020). VBHC has four key requirements: 1) measuring outcomes that matter for patients; 2) measuring the costs of achieving these outcomes; 3) focusing on a particular medical condition; and 4) focusing on the whole cycle of care. In this framework, value is achieved by improving outcomes, reducing cost, or both, via quality improvement (QI) initiatives (Baggaley, 2020).

Accordingly, defining, measuring, and agreeing on desirable outcomes is central to current commissioning practice, but has been particularly challenging in mental health. Establishing specific outcomes in both physical and mental health can be a complex task, especially when taking into consideration both the patient and clinician perspective. Various approaches have been adopted in the design and pursuit of high-level outcomes of care for mental health services over recent decades, such as questionnaires designed to assess the severity of a particular mental health condition and frameworks to assess broader aspects of people's lives (Collins, 2019). Current outcome measures in mental health, used in both clinical and research settings, were mainly developed in the 1990s, and are used to tentatively diagnose, assess severity, and aid clinical decisions rather than to address underlying factors that might contribute to people experiencing a mental health condition (Collins, 2019). Growing evidence suggests these measures do not capture what is important to service users. It has been argued that these measures ignore the nature of people's lives and do not consider the broader social issues that contribute to mental ill health (Walker, 2018; Beresford, 2002).

Understanding the outcomes that are important for people with persistent depression, their relative value, and how to maximize those outcomes, is important if we are to evaluate mental health service provision. In the present work, we aim to review what outcomes that are important to people receiving treatment for persistent depression, and to ascertain how this is being measured or could be measured to aid VbC for the implementation of specialist services for persistent depression in the UK.

2. Method

2.1. Study design

A mixed methods design, integrating quantitative, qualitative, and mixed method evidence, was used to address these aims. The use of a review of qualitative and quantitative evidence was justified for this research question due its broad and exploratory aims. Although several methods can be used to integrate different types of evidence, a narrative synthesis of evidence extracted from multiple studies, has been chosen. This approach is recommended when other approaches are not feasible for bringing together broad knowledge from a variety of methodologies and approaches (Popay et al., 2006). Furthermore, a narrative approach to synthesis is recommended where the review question includes a range of different research designs, both qualitative and quantitative findings, and/or non-research evidence is the most appropriate method (Mays et al., 2005).

2.2. Search strategy

A systematic search was conducted on 13 May 2021 across nine databases: EMBASE, PSYCHINFO, AMED, EMCARE, PubMed, BNI, HMIC, CINHAL, and Medline. The search used text words and medical subject headings related to patient views on outcomes and outcome measures in depression ('outcomes', 'outcome measures', 'patient values', 'patient perspective', 'depression', 'depressive disorder', 'persistent depression', 'treatment resistant depression', 'depressive episode').

Finding qualitative research can be challenging, therefore additional search strategies were used to identify them, including hand searching of relevant publications and screening of references. The search strategy included a forward and backward citation search of relevant papers and

policy guidelines, as well as searching grey literature. Relevant papers known to the authors were also included. Original study authors were not contacted for information or references. No publication date restrictions were set, but limits were applied to papers published in English, due to lack of resources for translation.

The inclusion of papers that addressed depression rather than persistent depression or TRD was because some studies may not have specifically targeted TRD itself, however many patients with depression, will have some degree of treatment resistance and persistence of symptoms, as evidence by the large proportion not responding to first line treatment. Furthermore, due to the lack of inconsistency in defining TRD and persistent depression, accompanied by the limited literature, the overlap of results was valuable to explore.

2.3. Selection of studies

Following an initial scoping search, inclusion and exclusion criteria were clarified, and search strategies developed. Very little work could be found relating to persistent depression or TRD and outcomes from the patient perspective. Therefore, this review uses clinical suggestions from the knowledge derived surrounding research literature and published work on depression more broadly to move forward. Studies and articles were considered for inclusion through titles and abstracts screening, followed by full-text screening. The inclusion criteria employed were as follows: 1) The population of interest was adults 18 years of age or older with depression, and 2) the study reported outcomes from the patient perspective. Given our research question and the limited availability of empirical work specifically on persistent depression, quantitative and qualitative studies, and non-empirical work such as narrative reviews and opinion pieces were considered for inclusion, as were case reports, provided they met the inclusion criteria. Studies that met any of the following criteria were excluded: (1) not published in or translated to English; (2) reported carer outcomes only (i.e., did not look at patient outcomes). Recognising the limitations of opinion pieces, we do not include these in thematic analysis but address some in the discussion.

2.4. Quality assessment

Due to the variety of studies included in the review quality assessment was carried out using three critical appraisal checklists. 16 studies were evaluated using the Mixed Methods Appraisal Tool (MMAT), four with the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Text and Opinion Papers, and two using the Critical Appraisal Skills Programme (CASP).

The Mixed Methods Appraisal Tool (MMAT) is critical appraisal tool designed for the appraisal stage of systematic mixed studies review. The MMAT includes 25 items for appraising methodological quality. Each item is rated on a categorical scale ('yes', 'no', 'cannot tell') and the number of items rated 'yes' counted to provide an overall score out of 5 (Hong et al., 2018). As this is a narrative review combining quantitative, qualitative, and mixed method studies, we selected the MMAT as the most appropriate quality appraisal tool to use. Furthermore, there were not enough RCTs within the papers found to perform a pooling of data to measure effect size. We recognise that in comparison to systematic reviews, a narrative review lacks rigour and is at risk of bias; however, use of the MMAT brings approaches used in more traditional systematic reviews to assess overall quality.

The MMAT can be used to appraise the quality of empirical studies (i.e., primary research based on experiment, observation, or simulation). However, it cannot be used for non-empirical papers such as review and theoretical papers (Abbott, 1998). Some specific designs such as economic and diagnostic accuracy studies cannot be assessed with the MMAT, and other critical appraisal tools are relevant for these designs (Hong et al., 2018). Therefore, the methodological quality of the systematic reviews was assessed using Critical Appraisal Skills Programme (CASP) Checklist for systematic reviews. The checklist comprised ten

questions in which validity, relevance and results were covered. Conclusions were made as to whether articles were "Low", "Moderate" or "High" in quality, based on frequency of "Yes", "No" and "Can't Tell" answers and answers provided within the broader questions of the checklist. The four papers that were either expert opinion pieces or brought together groups of experts to draw conclusions, were assessed for quality using the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Text and Opinion Papers.

One reviewer performed the quality assessment, and no studies were excluded based on their quality assessment.

2.5. Analysis

This narrative review synthesis followed the guidance and steps developed by Popay et al. (2006), namely 1) preliminary analysis, 2) exploration of relationships, and 3) assessment of the robustness of the synthesis. We extracted descriptive characteristics of the studies in tabular form and produced contextual summary of results for the preliminary synthesis. Thematic analysis was used to extract the main themes from the literature; the themes generated represent the main areas of knowledge available about outcomes that are important to service users experiencing persistent depression.

2.6. Results

2.6.1. Study selection

We identified 116 records from database searches and removed 22 duplicates prior to screening. We screened 94 articles and excluded 77 based on title and abstract. We sought 17 reports for retrieval and full-text versions of studies were screened for eligibility. We also identified 26 records through websites and citation searching with a total of 10 articles being excluded because they did not include data or information on outcomes or outcome measures in depression. A total of 20 studies and 1 opinion paper was included in the review (See Fig. 1 for a flow diagram of the study selection process) Table 1 displays the summary details of the studies included.

2.6.2. Characteristics of included studies

The Table of Characteristics (Supplementary Material Appendix 1) presents the main aspects of the 21 articles included in the review. Of these, 11 studies were undertaken in the USA (outpatient private practices), two in England (general practices in Southampton, Liverpool, Norfolk, Bristol, Liverpool and York), 1 in Australia (Primary Care), 1 in Belgium, 1 in Finland, and 1 was an international survey study. 1 study was carried out in 4 different countries including: Belgium, Germany, Poland, and USA. Nine studies employed quantitative descriptive methods, including data collected via questionnaires, measures, and surveys. Five studies used qualitative methods, including focus groups, semi-structured interviews, structured interviews, and structured computer assisted telephone interviews. One study used a mixed method approach, with pre and post outcome measures and semi-structured interviews. Two systemic reviews were identified, two papers brought together a group of multi-stakeholders to discuss an essential set of outcome measures for depression, of these one used a Delphi technique to manage the group's decision and the other a harmonized methodology. Finally, one paper reported on a prospective cohort study and one opinion paper.

With regard to the number of participants and diagnoses reported in each study: 18 studies included a total of 7204 participants from which the majority were classified as having a major mood disorder ($n = 4625$) or represented a broad range of depression severity ($n = 1062$). TRD made up the smallest proportion of the overall sample of participants involved in the studies ($n = 392$) and the remaining proportion was made up of patients related to general practitioners (GPs) ($n = 34$), health care professionals ($n = 627$) and informal carers ($n = 464$).

The study that used a Delphi technique (Obbarius et al., 2017)

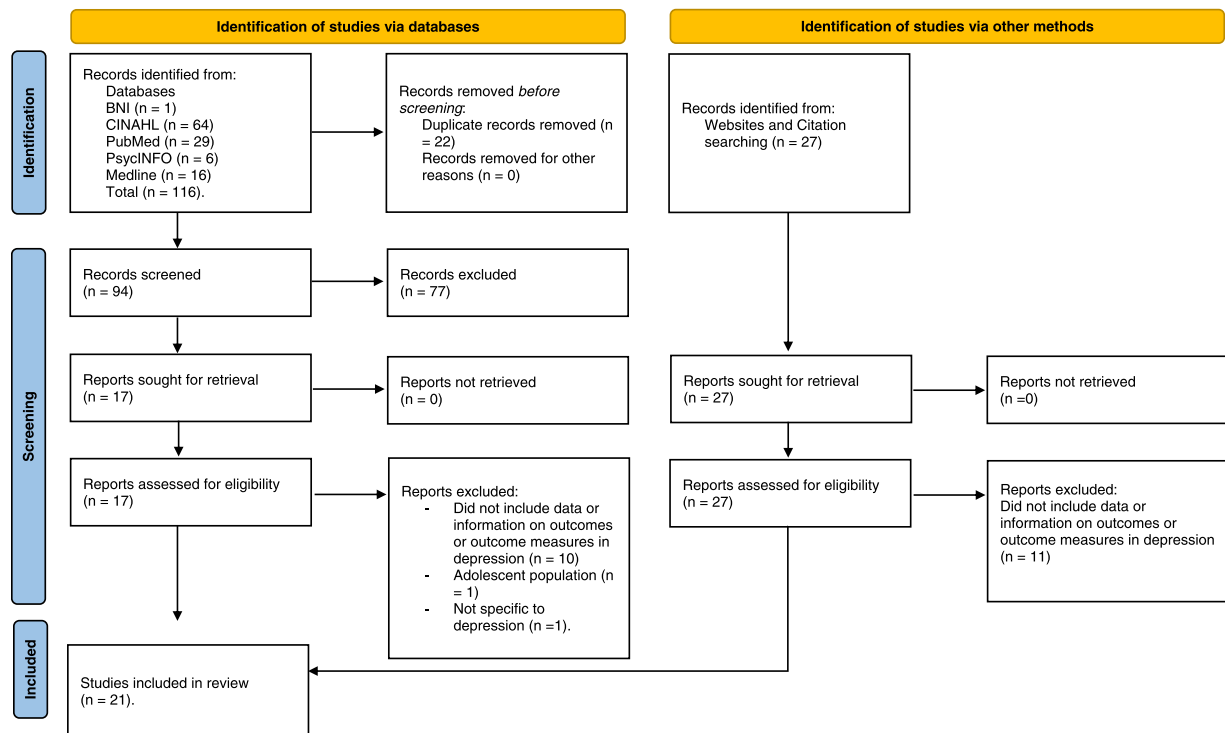


Fig. 1. Flow diagram of study selection process.

included 24 experts, including 10 health outcomes researchers, ten clinical experts from all continents, two patient advocates, and two International Consortium for Health Outcomes Measurement (ICHOM) coordinators. The group worked to develop recommendations based on existing evidence using a structured consensus-driven modified Delphi technique. The harmonized methodology paper (Gliksch et al., 2020) employed a panel that included clinicians; payers; government agencies; industry; and medical speciality, health care quality, and patient advocacy organizations.

2.7. Result of appraisal

Quality assessment using the MMAT tool was predominantly high across 16 of the studies. The range of fulfilled criteria fell between 60% and 100%, with an average of 80%. All five of the qualitative studies fulfilled 100% of the criteria, enabling us to compare and draw strong conclusions. The lowest scoring items from the checklist included employing a sample representative of the target population (45%) and risk of nonresponse bias (50%). The two systematic review studies assessed using the CASP checklist also showed good quality, fulfilling on average 83% of the criteria. The four papers that used the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for Text and Opinion Papers demonstrated overall good quality, scoring an average of 95%. Results of the quality assessment are presented in Appendix 2.

2.8. Results of synthesis

Five themes were extracted from the literature: important outcomes beyond symptom recovery, differentiations in perspectives, patient preferences, essential set of outcome measures, and underdeveloped outcomes measures from the patient perspective (Supplementary material Appendix 3).

Theme 1: Important outcomes beyond symptom recovery

Two studies carried out by Zimmerman et al. (2006, 2008) used questionnaires to ask outpatients being treated for MDD what they considered important in defining remission. The three items most

frequently judged to be “very important” included: the presence of positive mental health features (such as optimism and self-confidence), a return to one’s “normal self”, and a return to a usual level of functioning. In addition, the authors examined the independent and additive association between the level of severity of depressive symptoms and functional impairment when predicting depressed patients’ subjective evaluation of their remission status. The findings indicated symptom severity, functional impairment from depression, and quality of life were all significantly and highly intercorrelated, and each was significantly associated with subjective remission status. The results of a logistic regression analysis indicated that each of the three variables were a significant, independent, predictor of remission status.

De Smet et al. (2020) examined the experiences of patients classified as “recovered” or “improved” following cognitive behavioural therapy and psychodynamic therapy for major depression. An explanatory sequential mixed methods design was employed. Quantitative data was collected on outcome scores before/after treatment using the Beck Depression Inventory II (BDI-II). Semi-structured interviews were used to ask patients about their experiences of therapy, changes that occurred during that time, and what they believed influenced these changes. Both recovered and improved patients believed a positive outcome could be understood as feeling empowered and finding personal balance, with changes in self-confidence, coping skills, sense of calmness, interpersonal harmony, and self-understanding (De Smet et al., 2020).

Frank et al. (2007) aimed to obtain views on depression and early symptom resolution. Focus groups were carried out with 31 individuals between the ages of 18 and 64 years who had experienced a major depressive episode within the past 6 months and had treatment success with at least one antidepressant. Irritability was a key symptom and remitted earlier than others. Important to participants were low mood, low energy, suicidality, lack of motivation, lack of focus/concentration, feelings of guilt, self-critical thoughts, feeling overwhelmed, lack of enjoyment, hypersomnia, restlessness, anger, and irritability.

Johnson et al. (2009) conducted a qualitative study using structured, computer-assisted telephone interviews of 484 patients, one year after treatment, who were asked how they would know someone’s symptoms

Table 1
Summary table of included studies.

Author, year, country	Setting	Population(Sample, n)	Research question or aim	Study design	Key findings and conclusions
Chevance et al., 2020	Survey in 52 countries	Patients (1912) Informal carers (464) HCPs (627)	To generate a comprehensive list of outcome domains for depressive disorders and bipolar depression that matter to patients, informal caregivers, and HCPs.	Survey	Eighty domains to assess the benefits of depression treatment were identified. Mental pain and functioning were widely reported by participants but are typically not represented in depression-rating scales.
De Smet et al., 2019 Belgium	Outpatients in a single city	'Recovered' MDD patients (28) 'Improved' MDD patients (19)	To examine the experiences of patients marked as "recovered" and "improved" following cognitive-behavioural therapy and psychodynamic therapy for major depression: what does a 'good' outcome mean to patients?	Sequential mixed methods (survey & semi structured interviews)	Recovered and improved patients believe a positive outcome can be understood as feeling empowered and finding personal balance, with changes in self-confidence, coping skills, sense of calmness, interpersonal harmony, and self-understanding. There was variation in experience, in both groups – with some patients describing an ongoing struggle.
Dowrick et al., 2009 UK	Primary care, multiple sites	Current MDD patients (34) Primary care physicians (24)	To understand doctors' and patients' views of the introduction of severity questionnaires for depression and their interpretation in practice	Semi structured interviews	Discrepancy was found in the value of measures between practitioners and patients: <ul style="list-style-type: none"> • Patients favoured the measures • PCPs were cautious about the validity and utility, preferring to use clinical judgement • Both groups felt the assessments should be seen as one aspect of holistic care.
Frank et al., 2007 US	Outpatient, multiple locations	Current MDD patients (31)	To obtain patient views on depression and early symptom resolution.	Focus groups	Participants cited mostly negative symptoms as important: <ul style="list-style-type: none"> • irritability, anger, and ability to cope with life stressors. • gender differences were observed in first symptoms reported to remit.
Gliklich et al., 2020 US		N/A	To develop a minimum set of standardized outcome measures relevant to both patients and clinicians that can be collected in depression registries and clinical practice.	Multistakeholder panel	The panel recommended use of the PHQ-9, supplemented with measures of QOL, suicidal ideation, all-cause mortality, adverse events, resource use and work productivity.
Hershenberg et al., 2020 US	Outpatient, single site	TRD patients (302) Treatment-naïve MDD patients (344)	How closely do PROs approximate clinician rating scales measures in TRD?	Survey	Findings generally supported acceptably high levels of agreement between patient (BDI-II; QIDS) and clinician (MADRS; HAM-D) ratings of baseline depression severity. The authors conclude however that more work is needed before PROs can be used in isolation, and since clinical studies require a comprehensive understanding of treatment effects, both clinician rating scales and PROs should continue to be used in this setting.
Hobbs et al., 2020 UK	Primary care, multiple sites	Patients with low mood, depressive episodes or symptoms, or recent MDD episode (554)	To examine the extent to which changes in depression scale scores disagreed with primary care patients' perceptions of changes in their mood.	Survey	Marked disagreement between clinically important changes in PHQ-9 and BDI-II scores and patient-rated change. Severe anxiety and QOL were associated with disagreements between instrument-rated improvement and patient-rated change. Authors suggest that PRO scales ignore the perspective and propose using more holistic measures of patient-rated recovery alongside these instruments.
Hudgens et al., 2020 US	Outpatient, multiple trial sites	TRD patients participating in clinical trials of esketamine	Assess meaningful change, and determine the meaningful change threshold for the PHQ-9 and the MADRS	PRO questionnaire within trials	Meaningful change thresholds determined for PHQ-9 (-6); and MADRS (-10). Authors suggest both instruments are suitable for use as key endpoints in clinical trials in MDD and TRD, to characterise both clinician and patient perspective.
IsHak et al., 2011 US	N/A	N/A	To review the empirical literature and provide information regarding QoL measurement, impairment, impact of comorbidity, and treatment effects in MDD.	Systematic review	QOL is greatly affected by depression, and remains low compared to healthy controls even when symptoms are in remission. QOL should be considered as a primary outcome measure in MDD

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Table 1 (continued)

Author, year, country	Setting	Population(Sample, n)	Research question or aim	Study design	Key findings and conclusions
Johnson et al., 2009 Australia	Primary care	Current MDD patients (484)	To contribute to the discussion about the concept of recovery from depression from the patient perspective.	Structured, computer-assisted telephone interviews	Three broad indicators of recovery were identified: <ul style="list-style-type: none"> • a person's actions • their appearance • their thoughts and feelings A greater focus on patient-centred 'goal' setting is warranted
Lewis et al., 2019 Belgium, Germany, Poland, and USA.	Outpatient, multiple trial sites	TRD patients involved in a clinical trial of esketamine (90)	To evaluate the patient treatment experience in a clinical trial of treatment-resistant depression utilizing exit interview methodology.	Semi-structured interviews	Participants receiving placebo tended to report negative health changes, those receiving the intervention tended to note positive changes in mood, potential cognitive benefits such as mental alertness, improved sleep, and better concentration. <p>Most participants rated these changes to be at least moderately important, with most being rated "very important" to "extremely important."</p> <p>Perspectives on remission may be differentially perceived across patient groups</p> <ul style="list-style-type: none"> • females more likely to rate emotional stabilization as very important, older patients more likely to consider a broad range of factors, placed greater importance on positive features
McGlinchey et al., 2006 US	Outpatient, single centre	Current MDD patients (566)	What is the influence of age, gender, and current depressed state on the factors patients consider important in defining remission?	Survey	The group proposed an assessment of potential outcome predictors at: <ul style="list-style-type: none"> • baseline (47 items: demographics, functional, clinical status, etc.) • during the treatment process (19 items: symptoms, side effects, etc.) • annual assessment of broader treatment outcomes (45 items: remission, absenteeism, etc.) Further suggested reporting disease-specific symptoms for depression (PHQ-9); anxiety (GAD-7); physical, occupational, and social functioning (WHODAS 2.0)
Obbarius et al., 2017	N/A	N/A	To propose an essential set of outcome domains relevant across countries and cultures; a set of easily accessible patient reported instruments; and a psychometric approach to make scores from different instruments comparable.	Delphi study (experts in health outcomes research, psychiatry, and patient advocates)	Further suggested reporting disease-specific symptoms for depression (PHQ-9); anxiety (GAD-7); physical, occupational, and social functioning (WHODAS 2.0)
Pushparajah, 2018	N/A	N/A	How to engage patients in a consistent manner.	Opinion paper	The author (a UCB employee), presents a model for patient engagement, describing four overarching principles: shared ambition; transparency; accountability; and respect. <p>Low-quality evidence that assessing severity in a structured way at diagnosis using a validated tool leads to interventions that were appropriate to the severity of depression.</p> <p>Patients and GPs had different perceptions of the assessment of depression at diagnosis; patients being more positive.</p>
Shaw et al., 2013	Primary care studies	NA	To systematically review the effectiveness of routine assessment of depression severity using structured tools in primary care, and to determine the views of PCPs and patients regarding their use.	Systematic Review	Psychotherapy service users described their experiences along three constructs: historical, situational, and moral. <p>Authors concluded that the values of service users should be taken into account to ensure positive outcomes.</p> <p>Patients placed importance on presence of features of positive mental health: <ul style="list-style-type: none"> • a return to one's usual, normal self • return to usual level of functioning </p>
Valkonen et al., 2011 Finland	Not specified	Current MDD patients (14)	To examine and interpret the experiences of users of psychotherapy regarding the outcomes of their therapy.	Semi structured interviews	Symptom severity, functional impairment from depression, and quality of life were significant, independent, predictors of remission status. <p>Results suggest the concept of remission should be encompass assessments of functioning and quality of life.</p>
Zimmerman et al., 2006 US	Outpatient, single centre	Current MDD patients (487)	What do depressed patients consider important in defining remission?	Survey	Patients indicated RDQ was a better indicator of overall mental health state, treatment goals, and remission.
Zimmerman et al., 2008 US	Outpatient, single centre	Current MDD patients (514)	What are the independent and additive associations between severity of depressive symptoms and functional impairment in predicting depressed patients' subjective evaluation of their remission status?	Survey	
Zimmerman et al., 2011 US	Outpatient, single centre	Current MDD patients (102)	To examine patient acceptability of a new measure, the RDQ, compared with QIDS	Survey	

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Table 1 (continued)

Author, year, country	Setting	Population(Sample, n)	Research question or aim	Study design	Key findings and conclusions
Zimmerman et al., 2012 US	Outpatient, single centre	Current MDD patients (274)	Why do some depressed outpatients not in remission according to the HAMD consider themselves to be in remission?	Survey	Compared to patients who did not consider themselves to be in remission, remitters reported better QOL, less functional impairment, higher positive mental health scores, and better coping ability. Caution should be exercised in relying exclusively on symptom-based definitions of remission to guide treatment decisions
Zimmerman et al., 2013 US	Outpatient, single centre	Current MDD patients (Test-retest: 60; convergent and discriminant validity: 274)	To test the reliability and validity of the RDQ	Survey	The RDQ demonstrated excellent internal consistency and reliability. The RDQ was significantly associated with patients' self-reported remission status.

Notes: BDI-II: Beck Depression Inventory-II; GAD-7: Global Anxiety Disorder Assessment

HAMD: Hamilton Depression Rating Scale; HCPs: Health care professionals; MADRS: Montgomery-Asberg Depression Rating Scale; MCT: meaningful change threshold; PCPs: Primary care physicians; PHQ-9: Patient Health Questionnaire; PRO: Patient Reported Outcome measure; QIDS: Quick Inventory of Depressive Symptomatology; QOL: Quality of life; RDQ: Remission from Depression Questionnaire; SDS: Sheehan Disability Scale; WHODAS 2.0: WHO Disability Assessment Schedule.

of depression had improved. A rich range of responses were categorised into either a person's behaviour (such as being more active and social); appearance (the way a person presents themselves); and their thoughts and feelings (such as a change in outlook, a feeling of change, and understanding of oneself). Many participants explained how complex and subjective the notion of recovery from depression is and therefore how challenging they found the question. The authors propose a language of recovery that is not represented in current diagnosis and outcome measures.

Theme 2: Differentiations in perspectives

A qualitative international online study explored the views of patients with a history of depression, informal carers, and healthcare professionals. The survey employed a range of online platforms and techniques to capture participants views and asked four open-ended questions concerning their perspective on the expected benefits of treatment for depression. From the patient perspective it was reported that important outcomes of treatment include functioning and interpersonal relationships, prevention of future recurrences, managing depression, and achieving personal goals. Clinicians focused on symptom reduction and clinical improvement, as well as social functioning and interpersonal relationships, patient satisfaction, and achievement of predetermined goals (Chevance et al., 2020). The results also revealed, that after experiencing several depressive episodes patients adapt their treatment goals, strengthening the argument for more work in this area.

Some studies have reported gender differences in what symptoms are significant to patients with depression. Men report irritability to be one of the first symptoms to remit, whereas women noticed changes in motivation and energy levels (Frank et al., 2007). Furthermore, relative to men, women have voiced features of emotional regulation, such as managing and coping with everyday stress, to be an important factor of recovery (McGlinchey et al., 2006). Variances in preferences by age were noted by McGlinchey et al. (2006), whereby older individuals with depression emphasized factors associated with positive mental health states to be most important to their recovery. These findings highlight how different populations may perceive outcomes in depression.

Other papers have explored how the current outcome measures demonstrate meaningful change. For example, Hobbs et al. (2020) discovered that the changes in scores on the BDI-II and Patient Health Questionnaire (PHQ-9) were not aligned with patient-rated change. The discrepancy between patient scores and patient-rated change was even greater for patients who did not report feeling better over time, stressing the importance for a more suitable outcome measure for persistent depression.

Differentiation between the clinician and patient perspective in using

outcome measures to assess (or diagnose) depression was a theme raised across the literature. One study found that patients reported positive experiences, describing the use of outcome measures as a supplement to medical judgement and evidence that the practitioner was taking their problem seriously (Shaw et al., 2013; Dowick et al., 2009). In comparison, some practitioners have taken a more cautious position, particularly around the validity and application of measures, reporting to consider their clinical judgement as more important than the outputs of measures (Dowick et al., 2009). Both groups felt assessments of severity should be seen as one aspect of holistic care.

Further work by Hershenberg et al. (2020) examined the differences between patient-reported outcome measures (PROMS) and clinician-reported outcome measures (CROMS) for depression severity in a 'treatment resistant' sample and a 'treatment naïve' sample. Patient reported outcome measures included the Beck Depression Inventory (BDI) and the Quick Inventory of Depressive Symptomatology Self-report (QIDS-SR); clinician-reported measures were the Hamilton Depression Rating Scale (HDRS) and the Montgomery-Åsberg Depression Rating Scale (MADRS). The study showed a significantly moderate-to-strong relationship/agreement between patient- and clinician-rated severity scores was established for the treatment-resistant group. Considering these results, it that although there are some differences between the patient and client perspective there is also considerable overlap.

Theme 3: Patient preferences and heterogeneity of MDD

Qualitative work has investigated the influence of patient expectations on treatment outcomes in psychotherapy for depression. This study demonstrated that people with a "life historical orientation" envisage therapy to support them to repair a broken self-narrative, whereas people with a "situational story" hope to receive support with their present problems. Individuals with the "inner moral narrative" believed therapy would enable them to organise their perspectives (Valkonen et al., 2011).

De Smet et al. (2020) highlighted that recovery is an ongoing journey for some, with variation between experiences. Many individuals face recurring difficulties, emphasising the need for more insight into persistent depression. Qualitative research also highlights the fluctuating nature of a person's outlook, which can vary with symptom severity. However, McGlinchey et al. (2006) did not find different perspectives between recovered and depressed patients with respect to the importance of outcomes. They recommend clinicians reflect on their patient's pre-therapy orientations, preferences, and values, and should view the patient as an active agent seeking to better understand themselves and the world around them through therapy. Despite McGlinchey

et al.'s findings it is important to consider that their conclusions were drawn from a single outpatient clinical practice, therefore results may not be generalisable. None the less the findings both support the notion that clinicians need to use a person-centred and collaborative care approach when discussions take place between clinician and patient about their individual treatment goals.

Theme 4: Preferred outcome measures

Zimmerman et al. (2011) examined patient acceptability of a new measure, the Remission from Depression Questionnaire (RDQ) scale, designed to capture a broader array of domains patients consider relevant to construct of remission. Outpatients being treated for a major depressive episode ($n = 102$) completed the RDQ and the Quick Inventory of Depressive Symptomatology (QIDS). Patients indicated the RDQ was a better indicator of their overall state and treatment goals. Patients judged the RDQ to be a more accurate and preferred measure to determine treatment outcome, and a more accurate indicator of remission. Zimmerman et al. (2013) tested the reliability and validity of the RDQ. The RDQ demonstrated internal consistency and reliability and was significantly associated with patients' self-reported remission status.

Gliklich et al. (2020) examined what outcome measures were considered essential from the perspective of multiple stakeholders and aimed to generate a minimum set of measures for depression with harmonized definitions. Outcome measures included: mortality, death from suicide, remission, response, recurrence, adverse events, suicidal ideation and behaviour, quality of life, resource use and work productivity. The workgroup did not reach consensus on any patient-reported outcome domains other than quality of life (QOL). They recommended that the PHQ-9 should be supplemented with a measure of functioning. There were two TRD organisations involved in this project; however, collectively the organisations concluded that further work was needed to explore outcome measures and the relevance towards other types of depression.

Quality of life measures are strongly emphasised in the literature to be included as an outcome measure for interventions in major depressive disorder, alongside suicidal ideation, and mortality reports. Ishak et al. (2001) conducted a systematic review of the empirical literature to explore information regarding QOL measurement, impairment, impact of comorbidity, and treatment effects in MDD. They found QOL to be affected greatly by depression; the severity of depression was also a major contributor to further reduction in QOL when depression was comorbid with other psychiatric and medical disorders. Treatment for MDD has been shown to improve QOL in the acute treatment phase, but QOL remains low compared to healthy controls even when symptoms are in remission following treatment (Ishak et al. 2001). The authors concluded that clinicians should include a QOL assessment when treating depression and recommend further research to examine the factors contributing to poor QOL in MDD and to develop interventions to ameliorate it.

Theme 5: Underdeveloped outcomes measures

Obbarius et al. (2017) set out to propose an essential set of outcome domains relevant across countries and cultures, a set of easily accessible patient reported instruments, and a psychometric approach to make scores from different instruments comparable. Twenty-four experts, including 10 health outcomes researchers, 10 clinical experts from all continents, two patient advocates, and two ICHOM coordinators worked to develop recommendations based on existing evidence using a structured consensus-driven modified Delphi technique. The group proposes to combine an assessment of potential outcome predictors at baseline (47 items: demographics, functional, clinical status, etc.), with repeated assessments of disease-specific symptoms during the treatment process (19 items: symptoms, side effects, etc.), and a comprehensive annual assessment of broader treatment outcomes (45 items: remission, absenteeism, etc.). An international standard of health outcomes assessment has the potential to improve clinical decision making, enhance health care for the benefit of patients, and facilitate scientific

knowledge. However, the working group was dominated by clinicians and researchers, with only two patient advocates.

Only two studies were identified specifically looking at persistent depression or TRD. Hudgens et al. (2021) assessed meaningful change for the PHQ-9 and the Sheehan Disability Scale (SDS). Hershenberg et al. (2020) included a TRD sample and a treatment-naïve sample with major depression. Both studies found acceptably high levels of agreement between patient and clinician ratings of baseline depression severity. They concluded that more work is needed to determine the extent to which PROs can improve outcomes for depression and, more specifically, TRD. Given the lack of data about outcome measures and persistent depression, more work is needed to determine the extent to which outcome measures can improve treatment for this group.

3. Discussion

Across the literature it is evident that current outcome measures for depression are not orientated primarily towards the views of patients. When examining the included studies, considerable overlap was found between the patient and clinician objectives, supporting the notion that the patient perspective supplements and complements clinician views and current measures. The patient experience is important to examine in conjunction with outcome measures, they should be explored together between the patient and clinician, ensuring that the language used is understood by all.

By synthesising the available data, five themes were extracted, giving an indication of what is currently understood about the outcomes that are important to people receiving treatment for depression, how these are currently being measured, and where these measures are not in line with patient preferences. The first theme, patients emphasizing outcomes beyond recovery from symptoms, highlights how existing measures are not representative of a proposed language of recovery from the patient perspective. The "differentiations in perspective" theme identified variations across treatment timepoints, depression severity, gender, depression severity, and clinician compared to patient views when considering outcomes for depression. From Theme 3, it is also important the patient's preferences are listened to and heterogeneity of MDD is fully considered. A collaborative care approach between the clinician and patient to establish treatment goals is evidently essential. Patients should be viewed as active agents with unique care objectives, expectations, and values. Studies looking at essential outcome measures from the perspective of multiple stakeholders (Theme 4), suggest that symptom scales such as the PHQ-9 may be useful but should be better combined with measures of functioning and quality of life to fulfil patients' perspectives. The final theme establishes the lack of research and consensus on suitable outcome measures for persistent depression, including how interpretation of current outcome measures should be taken with caution, incorporating context and personal narrative.

Clinicians, commissioners, and the pharmaceutical industry should consider these themes to ensure that the future development of outcome measures embed patient insights into outcomes for depression to enhance the value of treatment. Internationally, it is recognised that patient and public involvement (PPI) is essential for high quality research, improving the relevance and outcomes of the research itself. Work into how best to engage patients in creating suitable outcome measures comes from Pushparajah (2018), who suggested four key principles as being essential for effective collaboration: ambition, transparency, accountability, and respect. In addition, research needs to be clear about how PPI was incorporated, for example, who was involved, what their role was and how this influenced the overall work.

Integrating qualitative, quantitative, and mixed method evidence provides insight in relation to the heterogeneity of depression and treatment resistant depression. The studies in this review demonstrate how the measurement and development of outcomes in TRD have been neglected, especially those capturing the priorities of the patient. Throughout the literature, authors have recognised the recurring nature

of depression and identified the limitations in applying current measures and results to all types of depression, calling for more research into what outcomes are important and how best to incorporate outcome measures into treatment. For example, the work by [Hershenberg et al. \(2020\)](#) supports the notion that patients with TRD have a greater understanding of their depressive symptoms, and perhaps a different perspective and outlook, compared to treatment-naïve patients. This data, however, was captured at one time point; it would be advantageous to look at the patterns and alignments between PROMs and CROMs throughout treatment and follow-up, in a more longitudinal sense. Given the lack of data regarding outcome measures and TRD, it is agreed across the literature that more work is needed to determine which outcome measures are most suitable for guiding treatment decisions

4. Limitations

It is important to note the limitations of this review. The search strategy used was only partly systematic due to the explanatory nature of the subject being reviewed and the lack of available research in the field. While the aim of the present study was to review the outcomes for persistent depression, we expanded the scope to cover all types of depression, owing to a lack of studies in the initial target population. A large proportion of the work found through the search strategy was qualitative. We were concerned we might have missed studies in the search and therefore to supplement our findings citation tracking was also used. We were unable to perform a traditional systematic review and the narrative review does not include the same methodological rigour. The topic has not been researched extensively within the literature, so only preliminary conclusions have been established within both this review and the literature.

While the quality of the studies reviewed was generally high, they were not without their limitations. A few studies had major issues with generalisability. For example, the body of work by [Zimmerman et al. \(2006; 2008; 2011; 2012; 2013\)](#), and the development of the RDQ, which was conducted within one American private outpatient health care setting and most of the patients were white females. More work is needed to understand how well this measure works with different settings, treatments, ages, genders, and types of depression (bipolar/unipolar/psychotic/TRD). In addition, one of the studies which brought together a multi-disciplinary working group to develop an essential set of outcome domains was dominated by clinicians, raising the question of whether the sample was able to sufficiently represent patient views ([Obbarius et al., 2017](#)). Finally, it is important to note that although the studies collected patient perspectives, they did not demonstrate co-production throughout the whole research process (a practice, as previously highlighted, central to future work within healthcare).

5. Conclusion

We review current scientific knowledge on outcomes that matter to patients with depression and highlight how and why it is necessary to apply this to persistent depression. Approaches such as the use of focus groups, quantitative work examining meaningful change, and learning from previous studies' limitations, should be applied to populations with persistent depression, accompanied by service user involvement at every level of the commissioning process, to produce an effective treatment pathway. More work is needed to understand how perspectives from different cultures impact outcomes for depression and persistent depression. In addition, when looking at the overall population health and general outcomes, it is essential commissioners do not lose sight of the individual and humanitarian care ([Collins, 2019](#)). Our findings may contribute to the process of agreeing desirable outcomes for people with persistent depression, identify areas where further understanding and research is needed, and help to inform current commissioning practices in the UK.

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Authors contributions

L.J. and C.W. designed the research programme this review belongs to, K.C. and L.H. carried out the review and, along with J.P., drafted the manuscript. J.P. supervised K.C.'s and L.H.'s work. All the authors reviewed and contributed to the final draft of this manuscript.

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