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A scoping review to identify process and outcome measures used in acceptance and commitment therapy research, with adults with acquired neurological conditions

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Abstract

Background: Acceptance and Commitment Therapy interventions are increasing in use in neurological populations. There is a lack of information on the measures available.

Purpose: To identify and classify the measures used in Acceptance and Commitment Therapy research studies with adults with acquired neurological conditions.

Methods: PRISMA-ScR guided scoping review. MEDLINE, PsycInfo and CINAHL databases searched (up to date 29/06/2022) with forward and backward searching. All study types included. Extraction of Acceptance and Commitment Therapy process-of-change and health-related outcome measures. Outcomes coded using the Core Outcome Measures in Effectiveness Trials (COMET) taxonomy.

Results: Three hundred and thirty three papers found on searching. Fifty four studies included and 136 measurement tools extracted. Conditions included multiple sclerosis, traumatic brain injury and stroke. Thirty-eight studies measured processes of change, with 32 measures extracted. The process measure most often used was the Acceptance and Action Questionnaire ($n = 21$ studies). One hundred and four health-related outcome measures extracted. Measures exploring quality of life, health status, anxiety

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and depression occurred most frequently, and were used in all included neurological conditions. COMET domains most frequently coded were emotional functioning/well-being ($n = 50$), physical functioning ($n = 32$), role functioning ($n = 22$) and psychiatric ($n = 22$).

Conclusions: This study provides a resource to support future identification of candidate measures. This could aid development of a Core Outcome Set to support both research and clinical practice. Further research to identify the most appropriate and relevant targets and tools for use in these populations should include expert consensus, patient, carer and public involvement and psychometric examination of measures.

Keywords

Neurological conditions, scoping review, processes of change, outcomes, Acceptance and Commitment Therapy (ACT)

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Introduction

Mental health needs are commonly unmet in people with neurological conditions,^{1,3} and developing interventions to support wellbeing is a global research priority.^{4,8} Acceptance and Commitment Therapy is a trans-diagnostic approach⁴ that shows promise.^{5,7} There is evidence, for example, trials in multiple sclerosis (MS)^{8,11} and traumatic brain injury (TBI),^{12,13} of decreased anxiety¹¹ and psychological distress,^{12,13} and increased acceptance.^{9,10} However, it is unclear which measures are available for process of change and outcomes.

The process of change in Acceptance and Commitment Therapy is increased psychological flexibility^{4,14,15}; ‘...to respond to situations in ways that facilitate valued goal pursuit’.¹⁶ Psychological flexibility is conceptualised with six facets that support or undermine its expression; the ‘Acceptance and Commitment Therapy hexaflex’¹⁷ and ‘in-hexaflex’¹⁵, respectively (see Figure 1). A growing number of tools purport to measure this mechanism of change.

Increasing psychological flexibility is posited to benefit outcomes such as depression and anxiety.^{14,15} Clinical trials seek standardised outcome measures to enable data pooling to guide clinical practice.¹⁸ The Core Outcome Measures in Effectiveness Trials (COMET) initiative supports standardisation, providing a taxonomy¹⁹ to classify outcomes used in trials. This may be useful in categorising measurement tools across different study types.

This review identified and summarised process and health-related outcome measures used in Acceptance and Commitment Therapy intervention studies with adult neurological populations, to inform the choice of measures for future studies to meet mental health needs and support well-being.²⁰

Objectives

1. Identify acquired neurological populations in which Acceptance and Commitment Therapy has been evaluated
2. Identify time-points at which the measurement tools were used
3. Identify and categorise tools used to explore Acceptance and Commitment Therapy process of change
4. Identify and categorise tools used to investigate health-related outcomes
5. Code outcome measurement tools according to COMET taxonomy¹⁹

Methods

This review was informed by Arksey & O’Malley’s five-stage scoping review methodology²⁰ and enhanced using strategies recommended by Levac et al.²¹ Reporting was guided by the Preferred Reporting Items for Systematic reviews and

Meta-Analyses extension for Scoping Reviews.²² A protocol for this review was written in advance of data collection and retrospectively published as a pre-print at: <https://osf.io/cm4kt/>.

Eligibility criteria: Studies were included in the review according to the following criteria:

Adult population (≥ 18 years old) with an acquired neurological condition. Our working definition of this term was:

- Acquired: not inherited, present at birth or neurodevelopmental.
- Neurological conditions: disorders of the brain, spinal column or peripheral nerves with a range of causes,²³ including progressive conditions, such as MS and dementia, and acquired brain injuries, such as stroke and TBI.

Interventions of interest were those identified by the original authors as: Acceptance and Commitment Therapy, based on Acceptance and Commitment Therapy or where Acceptance and Commitment Therapy is a component (i.e. interventions were included if they used other strategies as well as Acceptance and Commitment Therapy), where intervention was provided due to the presence of the acquired neurological condition. We included studies with or without a comparator.

Included studies had at least one health-related outcome or Acceptance and Commitment Therapy-related process measure. The latter are those relevant to the mechanism of change in Acceptance and Commitment Therapy – psychological flexibility, or its facets (see Figure 1). Health-related outcome measures are those targeting any aspect of health (physical or mental). Measures that exclusively explored satisfaction, adherence, usability and cost were excluded.

We included all study designs that use pre- and post-measurement of outcomes and/or processes of change, for example, clinical reports, service evaluations, case studies, quasi-experimental studies and randomised controlled trials (RCTs) and excluded reviews. We included studies with full texts available in English. Some studies used translated versions of measures published in English.

The translations are reported together with the English versions and not classified separately.

Study identification and selection: We searched the following bibliographic databases in 2020 and most recently on 29 June 2022: MEDLINE, PsycInfo and the Cumulative Index to Nursing and Allied Health Literature (CINAHL). As scoping reviews aim to be comprehensive, further information sources were consulted. The Association for Contextual Behavioural Science hosts a list; ‘Acceptance and Commitment Therapy Randomized Controlled Trials Since 1986’ (https://contextualscience.org/ACT_Randomized_Controlled_Trials) which we screened on 6 July 2022. *The Neuropsychologist* (a professional publication by the British Psychological Society, BPS) is not included in database searches, but as we were aware of a relevant article we screened all twelve published volumes for relevant studies.

Forward and backward searching was carried out with all included papers. Study authors were contacted in instances where the full paper was not available online, where additional information was required to make decisions about inclusion, or to answer methodological questions.

The umbrella term ‘acquired neurological conditions’ is not consistently used in the literature. Therefore, conditions were entered individually as keyword search terms and related MeSH terms, using the same terms as a Cochrane review with a similar population.²⁴ The following search terms were used to capture the intervention [“Acceptance and Commitment Therapy”/] and “Acceptance and Commitment Therapy”.mp. The search strategies were drafted in consultation with a university librarian (See Supplemental materials for MEDLINE search strategy. This was adjusted for PsycInfo and CINAHL, using differing MeSH terms.).

Identified papers were imported into Endnote and duplicates removed. Screening comprised of two stages: title and abstract, full text.

Stage one – Title and abstract phase

- (a) Initial learning phase – two members of the research team screened a small batch of papers ($n = 5$) and then discussed any discrepancies in screening decisions. This

learning process was repeated a number of times until consistency was reached.

- (b) Fifty percent of the papers were independently screened by two researchers. A moderate level of agreement (i.e. the value of kappa is ≥ 0.41 (Altman, 1991 cited in²⁵) was required to proceed to the next stage. We erred on the side of inclusion if there was any disagreement between the researchers.
- (c) The other 50% of total papers were screened by one researcher.

Stage two – Full text screening phase:

- As above, however disagreements were resolved by:
 - Discussion between the researchers aiming for consensus
 - Contacting the study authors to request additional information
 - Consensus discussion with all authors of this review (AB, SC, EP).

Data extraction: This was completed for papers that met the inclusion criteria. This included descriptive data such as: author, title, overall aim of the study, date, country, type of study, sample size, participants' diagnoses. A bespoke data extraction tool was developed iteratively and piloted on a small number of studies (see Supplemental materials for a copy of this tool). All tools measuring processes or health-related outcomes were also extracted. For each tool, we extracted the name, the authors' description of what the tool was measuring and the time points at which it was administered. Time points were converted into months post-intervention, subtracting the length of the treatment phase from the length of time post-baseline. A second researcher carried out data extraction for a randomly allocated third of the papers. The data extraction of the two researchers was compared and any inconsistencies discussed in order to reach consensus.

Data synthesis: Study type was categorised based on author description and consensus between review authors. Measures were identified as *process*

measures if they measured a mechanism of change, relevant to Acceptance and Commitment Therapy, as determined by the review authors. Acceptance and Commitment Therapy-specific measures were identified from the ACBS website and relevant Acceptance and Commitment Therapy literature.^{14,26,27}

When measures were relevant to Acceptance and Commitment Therapy mechanisms but were not directly developed in the context of Acceptance and Commitment Therapy, information about each measure was reviewed (e.g. tool development papers), alongside data extracted from the studies. Consensus on whether to include the measure as a process measure was reached through discussion between review authors.

The process measurement tools identified were grouped according to what aspect of the Acceptance and Commitment Therapy hexaflex they measured (see Figure 1). The authors organised measures according to the hexaflex in a best-fit manner, with reference to rationale for the use of the measure provided in the included studies, papers describing the development of the measures, consulting a previous review,²⁸ and discussion between authors of this review.

In addition, *health-related outcome measures* used in any of the studies were identified and:

1. Categorised broadly according to what they were measuring, based on data extracted from the papers, available development papers, assessment manuals and publisher descriptions, followed by consultation between the review authors. Then;
2. Coded according to the COMET taxonomy, which is organised into five core areas: death, physiological/clinical, life impact, resource use and adverse events. Each core area consists of a number of outcome domains. There are 38 outcome domains in total. As per guidance,¹⁹ each measure was coded according to all relevant outcome domains addressed in the measure; achieved through reviewing every item on each measure. If measures were not freely available to

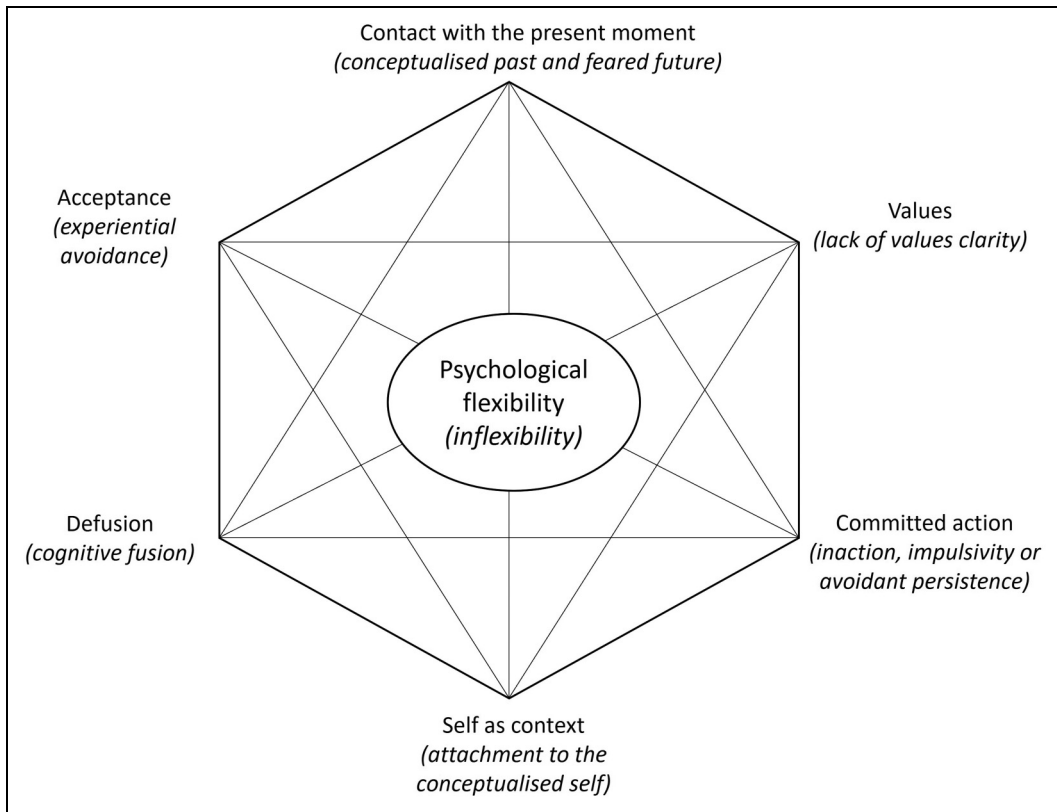


Figure 1. The acceptance and commitment therapy hexaflex (and in-hexaflex)¹⁵ (adapted from copyright Steven C. Hayes. Used by permission).

review individual items, coding was done based on overall aims and any other information freely available.

In order to ensure robustness of COMET coding, Susanna Dodd (author of the taxonomy) was consulted with questions on the coding process and regarding uncertainties in classification of specific tools. Furthermore, MP independently carried out COMET coding for 10% of the measures found. MP and HF first discussed any discrepancies and then Dodd was consulted regarding any outstanding uncertainties.

Step (2) was only carried out for measures extracted from studies identified in the original 2020 search. For reasons detailed in the discussion,

this step was not completed for measures identified during the 2022 updated search.

Results

Searching yielded 333 papers (see Figure 2). After duplicate removal and screening there were 54 included studies (from 65 reports). Reviewers had at least a substantial level of agreement ($\kappa = 0.67$) at first stage screening.

Most of the studies were RCTs ($n = 22$) or other non-randomised research studies (i.e. those with non-randomised group allocation) ($n = 16$), with fewer clinical reports ($n = 8$) and $n = 8$ unclear for categorisation. The overall mean sample size was 44.1 (range 1–240). Most studies are from the

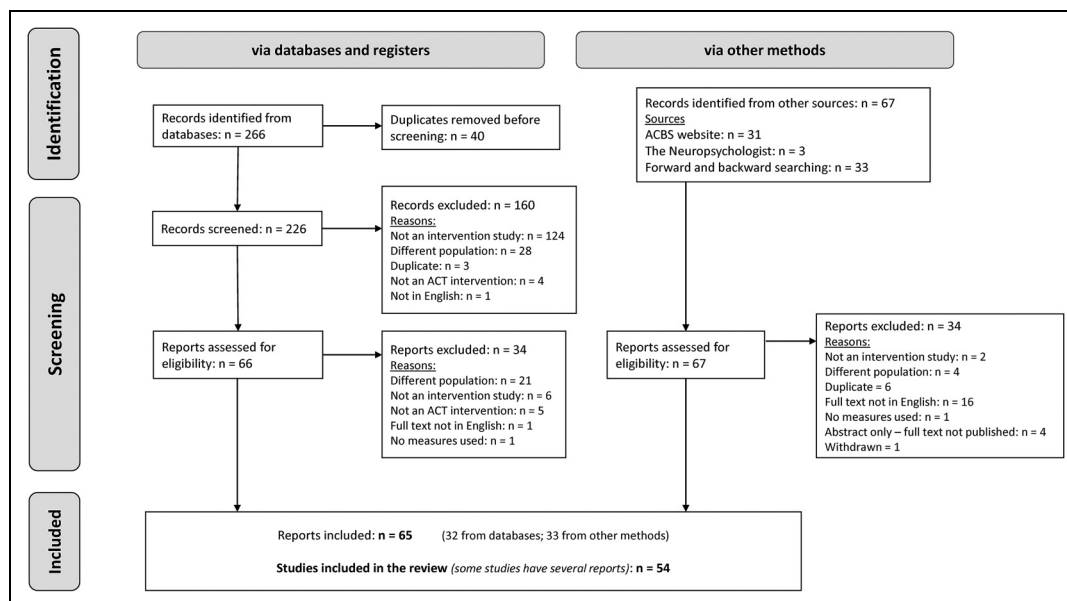


Figure 2. PRISMA flowchart – selection of sources of evidence.

UK ($n = 13$), Iran ($n = 12$), US ($n = 9$) and Australia ($n = 7$). In total, 136 measurement tools were extracted. Many studies did not specify whether tools used were selected on the basis of measuring processes of change or outcomes.

Objective 1. Neurological populations

The participants had a range of acquired neurological conditions: of the 22 RCTs identified, eight were in MS, six in TBI, three in stroke, two in epilepsy, one in Parkinson's disease, one in spinal cord injury and one for both TBI and stroke. Some studies included participants with a range of different neurological conditions. Throughout the results, these studies are referred to as including 'multiple conditions'.

The most commonly stated aim of studies was to reduce psychological distress (including anxiety, depression, post-traumatic stress disorder, stress, and emotional and psychological difficulties) ($n = 30$ studies). This aim was stated across studies in all neurological populations included in this review (apart from studies with multiple

conditions). Physical symptoms were targeted in studies in certain conditions, for example, seizures in epilepsy ($n = 2$) and pain in MS ($n = 3$). Other studies had nuanced intended aims or outcomes for their interventions, for example, increasing psychological adjustment across multiple conditions, including TBI and MS ($n = 5$) and increasing resilience in MS ($n = 5$).

Objective 2. Time points

All studies used pre- and post-intervention measures. Thirty-three of 54 studies (61%) carried out assessments at other follow-up time points, ranging from 1 month post-intervention to 12 months post-intervention.

Objective 3. Process measurement tools

There were 32 different Acceptance and Commitment Therapy-related process measurement tools identified, across 38 of the 54 included studies (70%) (see Table 1). Eleven of the 24 tools (34%) were used in more than one study. Twenty-seven

Table 1. Summary of measures relevant to acceptance and commitment therapy processes.

Name of measurement tool	Target neurological population	n = studies that have used this tool	Conditions represented in the studies using this tool (study reference/s)
Psychological flexibility (n = 29 studies)			
Acceptance and Action Questionnaire: AAQ-II ^{29 a} or AAQ-9 ^{30 a}	General	21	Multiple sclerosis ^{8,10,11,31,35} Stroke ^{36,37} Stroke and TBI ^{38,39} TBI ^{12,13,40,41} Multiple conditions ^{42,43} Brain tumour, ⁴⁴ Spinal cord injury ⁴⁵
Acceptance and Action Questionnaire-Acquired Brain Injury (AAQ-ABI) ^{46 a}	Acquired brain injury	7	Stroke and TBI ^{38,39} TBI ^{12,41,47} Multiple conditions ^{48,49}
Chronic pain acceptance questionnaire (CPAQ) ^{50 a}	General (chronic pain)	2	Multiple sclerosis ^{31,51}
The comprehensive assessment of Acceptance and Commitment Therapy processes (CompACT) ^{52 a}	General	3	Multiple sclerosis ^{8,33,53}
Acceptance and Action Epilepsy Questionnaire (AAEpQ) ^{54 a}	Epilepsy	1	Epilepsy ⁵⁴
Avoidance and Fusion Questionnaire-Youth (AFQ-Y) ^{55 a}	General	1	Multiple conditions ⁴⁸
Adult Hope Scale ^{56 b}	General	1	Stroke ⁵⁷
Adult State Hope Scale ^{58 b}	General	1	Stroke ³⁷
Multidimensional Psychological Flexibility Inventory (MPFI) ⁵⁹	General	1	Multiple sclerosis ⁶⁰
Values (12 studies)			
Engaged Living Scale (ELS) ⁶¹ (also targeting committed action)	General	1	TBI ⁴⁷
Valued Living Questionnaire (VLQ) ^{62 a}	General	7	Multiple conditions ⁴⁹ Stroke and TBI ^{38,39} TBI ⁶³ Multiple Sclerosis ^{8,33,64}
Survey of Life Principles Version 2.2 – Card sorting task ^{65 a}	General	2	TBI ^{12,47}
Values Bull's eye ^{66 a}	General	2	Epilepsy ⁵⁴ TBI ⁶⁷
Valuing Questionnaire (VQ) ^{68 a}	General	1	Multiple conditions = 42
Defusion/fusion (10 studies)			
Cognitive Fusion Questionnaire (CFQ) ^{69 a}	General	6	Stroke and TBI ^{38,39} TBI ⁶³ Multiple sclerosis ^{34,35} Spinal cord injury ⁴⁵
Drexel Defusion Scale (DDS) ^{70 a}	General	3	Multiple sclerosis ^{8,33,64}
Pain catastrophizing scale (PCS) ^{71 b}	General (pain)	1	Multiple sclerosis ⁵¹
Acceptance/experiential avoidance (6 studies)			
Acceptance of Chronic Health Conditions MS version (ACHC-MS) ^{72 b}	Multiple sclerosis	1	Multiple sclerosis ⁹

(Continued)

Table 1. (Continued)

Name of measurement tool	Target neurological population	n = studies that have used this tool	Conditions represented in the studies using this tool (study reference/s)
Multiple Sclerosis Acceptance Questionnaire (MSAQ) ^{73 a}	Multiple sclerosis	1	Multiple sclerosis ⁶⁴
Intolerance of Uncertainty Scale (IUS) ^{74 b}	General	1	Multiple sclerosis ⁹
White Bear Suppression Inventory (WBSI) ^{75 b}	General	1	Multiple sclerosis ⁷⁶
Appraisal of Threat and Avoidance Questionnaire (ATAQ) ^{77 b}	General	1	Multiple conditions ⁴⁸
Avoidance-Endurance Questionnaire Pain-Related Behavioral Responses Scale (AEQ) ^{78b}	General	1	Multiple sclerosis ⁵¹
Emotional Avoidance Strategy Inventory (EAS) ⁷⁹	General	1	Multiple sclerosis ⁸⁰
Contact with the present moment (6 studies)			
Mindful Attention Awareness Scale (MAAS) ^{81 b}	General	5	Multiple sclerosis ^{8,33,64,76} Spinal cord injury ⁴⁵
Five Facet Mindfulness Questionnaire (FFMQ) ^{82 b}	General	1	Multiple conditions ⁴²
Committed action (2 studies)			
Motivation for Traumatic Brain Injury Rehabilitation Questionnaire (MOT-Q) ^{83 b}	Traumatic brain injury	2	TBI ^{12,41}
Other (3 studies)			
Cognitive Emotion Regulation Questionnaire (CERQ) ^{b 84}	General	1	Epilepsy ⁸⁵
Cognitive Flexibility Inventory (CFI) ^{b 86}	General	1	Spinal cord injury ⁸⁷
Emotion Regulation Questionnaire (ERQ) ^{b 88}	General	1	Spinal cord injury ⁸⁷
Locus of Control Scale (LoC) ^{b 89}	General	1	Multiple sclerosis ⁹⁰
Sense of Coherence Scale (SOC) ^{b 91}	General	1	Multiple sclerosis ⁹⁰

^aDeveloped with Acceptance and Commitment Therapy in mind.

^bNot developed specifically for Acceptance and Commitment Therapy.

tools were generic and five were condition-specific. Two pain specific measures were identified and were used with MS populations.

Acceptance and Commitment Therapy-related processes were measured in studies of MS, acquired brain injury (including stroke and TBI), spinal cord injury, epilepsy, brain tumour and multiple conditions.

Composite measures of psychological flexibility were most commonly used, that is, in 29/38 (76%) of the studies that included a process measure. The Acceptance and Action Questionnaire^{29,30} was the tool most often used (21 studies, 55% of the studies including a process measure). A number of condition-specific variations of this measure were

also identified in this review (Acceptance and Action Questionnaire-Acquired Brain Injury,⁴⁶ Acceptance and Action Epilepsy Questionnaire,⁵⁴ Chronic Pain Acceptance Questionnaire⁵⁰ bringing the total number of studies using the Acceptance and Action Questionnaire and/or variants to 26.

Other tools measured a specific facet of the hexaflex (Figure 1). Values were measured most commonly (and most often using the Valued Living Questionnaire,⁶² $n = 7$ studies), followed by defusion (or conversely, cognitive fusion), acceptance (or conversely experiential avoidance), contact with the present moment and committed action. No tools specifically targeted self-as-context. In contrast, five other process measures were

identified that were not specifically linked to any of the hexaflex facets.

Objective 4. Outcome measurement tools

There were 104 distinct outcome measurement tools extracted from the 54 included studies. Seventy-three (70%) of these tools were used once. Table 2 lists all the extracted tools organised by category, with COMET coding presented for tools extracted from studies identified in the 2020 search (see objective 5 for a summary of this COMET coding).

The first category is **Health status, Quality of life and Well-being**. There were 23 tools identified, across 27 studies. Many tools measured a combination of health status, quality of life and well-being and are reported together in Table 2. All neurological conditions represented in this review included a measure in this category. Seven measures in this category were condition specific, to MS ($n = 3$), cancer – brain ($n = 1$), Parkinson’s disease ($n = 1$), TBI ($n = 1$) and spinal cord injury ($n = 1$).

The most commonly used measurement tools were the 12-Item Short Form Survey⁹² ($n = 6$ studies) and the EQ-5D⁹⁴ ($n = 6$ studies), followed by the Multiple Sclerosis Quality of Life Instrument,⁹⁵ Satisfaction with Life Scale⁹⁶ and the World Health Organization Quality Of Life measure⁹⁹ (each used in $n = 4$ studies).

The second category is **anxiety and depression and other psychological disorders**. Overall, there were 22 tools identified that measured a psychological disorder, across 38 studies. Most commonly, these tools measured anxiety and/or depression and were used across each of the neurological conditions represented in this review. All measures in this category were general, apart from one epilepsy specific measure. Measurement tools assessing both anxiety and depression were used in 22 studies, for example, the Hospital Anxiety and Depression Scale¹¹⁷ ($n = 14$ studies), and the Depression, Anxiety, and Stress Scale¹¹⁹ ($n = 9$ studies). Tools measuring depression alone were used in 13 studies. The most commonly used tools were the Beck Depression Inventory¹²³ ($n = 6$ studies) and Patient Health Questionnaire¹²⁶ ($n = 4$ studies). Anxiety alone was measured in 10 studies, for example, the Generalised Anxiety

Disorder Assessment¹³¹ in five studies and the Beck Anxiety Inventory¹³² in two. The other tools identified were general measures of psychological disorders ($n = 6$ studies) and measures of post-traumatic stress disorder ($n = 3$ studies). Post-traumatic stress disorder was only measured in studies in traumatic brain and spinal cord injury. Twenty-two of the studies included both a measure of health status, quality of life, well-being and a measure of a psychological disorder/s.

Further outcome categories identified were participation (i.e. involvement in life situations) ($n = 13$ studies), stress ($n = 6$ studies), resilience ($n = 5$ studies), pain ($n = 4$ studies), fatigue ($n = 3$ studies), seizures ($n = 3$ studies), self-efficacy ($n = 3$), sleep ($n = 3$ studies) and memory ($n = 2$ studies). Each tool in these categories was used in a maximum of four studies. Pain, fatigue and resilience were only measured in MS and seizures were specific to studies in epilepsy.

Objective 5. COMET taxonomy

Fifty-three of 76 tools (those identified in the 2020 search) were freely available and reviewed item-by-item. COMET coding of all extracted measures showed that three of the five COMET core areas (physiological/clinical, life impact and adverse events) and 13 of the 38 outcome domains were represented in the data set (see Table 3). As discussed in methods, COMET outcome domains are not mutually exclusive (see Table 2).

The physiological/clinical core areas present in the data are in line with the eligibility criteria for this review. Within the life impact and adverse event core areas, all outcome domains were present in the data. The core areas not represented are death and resource use, ineligible for this review. The most frequently occurring core areas and domains are summarised below.

The most commonly occurring physiological domain was ‘psychiatric’. There were also ‘general’ outcomes, including pain, fatigue and life expectancy. According to the COMET guidance, the physiological/clinical domains should be classified according to underlying cause/body system. Therefore, certain measures relating to neurological

Table 2. Outcome measurement tools.

Name of measurement tool	Target neurological population	<i>n</i> = studies that have used this tool	Conditions represented in studies using this tool [study reference]	COMET outcome domains
Health status, quality of life and well-being (n = 27 studies)				
12-Item Short Form Survey (SF-12) ⁹²	General a	6	Stroke and TBI ^{38,39} TBI ^{12,40,41} Epilepsy ⁹³	Emotional, general, perceived health status, physical, role, social
EQ-5D (5L specified in 3) ⁹⁴	General a	6	Stroke ^{37,57} Stroke and TBI ³⁸ Multiple sclerosis ^{11,53,60} Multiple sclerosis ^{8,33,60,64}	Emotional, general, perceived health status, physical, psychiatric, role Cognitive, emotional, global quality of life, nervous system, perceived health status, physical, role, social
Multiple Sclerosis Quality of Life Instrument (MSQoL-54) ⁹⁵	Multiple sclerosis	4		
Satisfaction with Life Scale (SWLS) ⁹⁶	General a	4	Epilepsy ^{97,98} TBI ⁴⁷ Multiple conditions ⁴⁹	Global quality of life
World Health Organization Quality Of Life (WHOQOL-BREF) ⁹⁹	General a	4	TBI ⁴⁰ Epilepsy ^{97,98} Spinal cord injury ⁴⁵	Cognitive, emotional, global quality of life, perceived health status, personal circumstances, physical, role, social
Multiple Sclerosis Impact Scale (MSIS-29) ¹⁰⁰	Multiple sclerosis	3	Multiple sclerosis ^{11,53,101} Stroke ⁵⁷	Cognitive, emotional, physical, role, social
Warwick and Edinburgh Mental Well-being Scale ¹⁰²	General a	2	Multiple conditions ⁴⁹	Cognitive, emotional, social
EuroQol Visual Analogue Scale (EQ-VAS) ⁹⁴	General a	1	Multiple conditions ⁴²	Perceived health status
Functional Assessment of Cancer Therapy scale – Brain ¹⁰³	Cancer – brain	1	Brain tumour ⁴⁴	Adverse events/effects, cognitive, emotional, general, global quality

(Continued)

Table 2. (Continued)

Name of measurement tool	Target neurological population	n = studies that have used this tool	Conditions represented in studies using this tool [study reference]	COMET outcome domains
Mental Health Continuum Short Form (MHC-SF) ¹⁰⁴	General a	1	Multiple sclerosis ⁶⁰	of life, nervous system physical, role, social
Multiple Sclerosis Quality of life index (QLI) ¹⁰⁵	Multiple sclerosis	1	Multiple sclerosis ³¹	Cognitive, delivery of care, emotional, global quality of life, perceived health status, personal circumstances, physical, role social
Numerical rating scale 'Which numeric rating score from 1 (very bad) to 10 (very well) do you give your life in general?' (study specific)	General	1	Multiple sclerosis ³⁴	
Parkinson's Disease Questionnaire-39 (PDQ-39) ¹⁰⁶	Parkinson's disease	1	Parkinson's disease ¹⁰⁷	Cognitive, emotional, nervous system, physical, social
Personal Well-being Index (PWI) ¹⁰⁸	General a	1	Epilepsy ⁵⁴	Emotional, global quality of life, perceived health status, social
Quality of life after brain injury (QOLIBRI) ¹⁰⁹	TBI	1	TBI ⁴⁷	
Quality of Life Inventory (QOLI) ¹¹⁰	General a	1	Multiple sclerosis ⁷⁶	Emotional, global quality of life, social, role
Quality of life rating on a scale of 1-10 (study specific)	General a	1	TBI ⁶³	Global quality of life
Sheehan Disability Scale ¹¹¹	General a	1	TBI ⁴⁰	Role, social
Schedule for the Evaluation of Individual Quality of Life-Direct Weighting SEIQoL-DW ¹¹²	General a	1	Multiple sclerosis ⁸	Outcome domains depend on individual choices

(Continued)

Table 2. (Continued)

Name of measurement tool	Target neurological population	n = studies that have used this tool	Conditions represented in studies using this tool [study reference]	COMET outcome domains
Short Form 36 Health Survey (SF-36) ¹¹³	General a	1	Multiple sclerosis ⁷⁶	Emotional, general, perceived health status, physical, role, social
Spinal Cord Injury – Quality of Life (SCI-QOL) ¹¹⁴	Spinal cord injury	1	Spinal cord injury ⁴⁵	
Visual analogue scale – ‘How content are you with your daily life?’ (study specific)	General	1	Multiple sclerosis ³⁴	
Wellbeing Evaluation Scale (WES) ¹¹⁵	General a	1	Multiple conditions ¹¹⁶	Emotional, physical, social
Hospital Anxiety and Depression Scale (HADS) ¹¹⁷	General a	14	Multiple sclerosis ^{8,10,32,33,53,60} Multiple conditions ^{49,118} Stroke and TBI ^{38,39} Stroke ³⁷ TBI ^{12,41,63} Stroke ¹²⁰ Stroke and TBI ^{38,39} TBI ^{12,41,47,67} Multiple sclerosis ¹²¹ ; Spinal cord injury ⁴⁵ TBI ^{13,40} Stroke and TBI ³⁹	Emotional, physical, psychiatric
Depression, Anxiety, and Stress Scale (DASS-21) ¹¹⁹	General a	9		Emotional, psychiatric
Brief Symptom Inventory – 18 (BSI-18) ¹²²	General a	3		Cognitive, emotional, psychiatric, social
Seven-point Likert scale – ‘I feel depressed’ and ‘I feel anxious’ (study specific)	General	1		
Beck Depression Inventory (BDI I or II) ¹²³	General a	6	Brain tumour ⁴⁴ Multiple	Emotional, physical, psychiatric, role, social

(Continued)

Table 2. (Continued)

Name of measurement tool	Target neurological population	<i>n</i> = studies that have used this tool	Conditions represented in studies using this tool [study reference]	COMET outcome domains
Patient Health Questionnaire (PHQ-9) ¹²⁶	General a	4	sclerosis ^{10,76,124,125} Parkinson's disease ¹⁰⁷ Multiple conditions ⁴³ Multiple sclerosis ¹¹ Stroke ⁵⁷ TBI ⁴⁰ Epilepsy ⁹³	Cognitive, emotional, physical, psychiatric
Neurological Disorders Depression Inventory for Epilepsy (NDDI-E) ¹²⁷	Epilepsy	1		Emotional, psychiatric
Hamilton Depression Scale (HAM-D-24) ¹²⁸	General a	1	Stroke ¹²⁹	
Self-rating Depression Scale (SDS) ¹³⁰	General a	1	Multiple Sclerosis ³⁵	
Generalised Anxiety Disorder Assessment (GAD-7) ¹³¹	General	Anxiety (n = 10 studies) 5	Multiple conditions ⁴³ Multiple sclerosis ^{9,11} Stroke ⁵⁷ Epilepsy ⁹³	Emotional, psychiatric
Beck Anxiety Inventory (BAI) ¹³²	General a	2	Parkinson's disease ¹⁰⁷ Multiple sclerosis ¹²⁴ Stroke ¹³⁴	Emotional, psychiatric
Hamilton Anxiety Rating Scale ¹³³	General a	1	Brain tumour ⁴⁴	Cognitive, emotional, psychiatric
State-Trait Anxiety Inventory (STAI) ¹³⁵	General a	1	Multiple sclerosis ³⁵	Emotional, psychiatric
Self-rating Anxiety Scale (SAS) ¹³⁶	General a	1		
Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P) ¹³⁷	General a, various b	Participation (n = 13 studies) 3	Stroke and TBI ^{38,39} Multiple sclerosis ³⁴	Physical, role, social
Barthel Index (BI) ¹³⁸	Various b	2	Multiple sclerosis ¹³⁹ Stroke ¹²⁹	Physical, role, social
Participation Assessment with Recombined Tools-Objective (PART-O) ¹⁴⁰	TBI	2	TBI ¹³	Physical, role, social

(Continued)

Table 2. (Continued)

Name of measurement tool	Target neurological population	n = studies that have used this tool	Conditions represented in studies using this tool [study reference]	COMET outcome domains
Sydney Psychosocial Reintegration Scale-2 (SPRS-2) ¹⁴¹	ABI	2	TBI ^{12,41}	Physical, role, social
Community Integration Questionnaire (CIQ) ¹⁴²	TBI	1	Multiple conditions ⁴⁹	
Nottingham Extended Activities of Stroke Daily Living index (NEADL) ¹⁴³	Stroke	1	Parkinson's disease ¹⁰⁷	Physical, social
Participation Objective, Participation Subjective (POPS) ¹⁴⁴	Brain injury	1	Multiple conditions ⁴⁸	Physical, role, social
Work and Social Adjustment Scale (WSAS) ¹⁴⁵	General a	1	Epilepsy ⁹³	Physical, role, social
Psychological disorders – general (n = 6 studies)				
General Health Questionnaire-12 (GHQ-12) ¹⁴⁶	General a	2	TBI ^{12,41}	Cognitive, emotional, psychiatric
Symptom Checklist-90-Revised (SCL-90-R) ¹⁴⁷	General a	2	Multiple conditions ⁴⁸ TBI ¹⁴⁸	Emotional, psychiatric
Clinical Outcome in Routine Evaluation-10 (CORE-10) ¹⁴⁹	General a	1	Multiple conditions ⁴²	Emotional, psychiatric, social
Structured Clinical Interview for DSM-5 (SCID-5) ¹⁵⁰	General a	1	Brain tumour ⁴⁴	Emotional, psychiatric
Stress (n = 6 studies)				
Perceived Stress Scale (PSS) ¹⁵¹	General a	4	Multiple sclerosis ^{8,33,152} , multiple conditions ¹¹⁸ Epilepsy ¹⁵⁴	Emotional
Perceived Stress Questionnaire (PSQ) ¹⁵³	General a	1		
Additional stress since last assessment – dichotomous question (study specific)	General a	1	Brain tumour ⁴⁴	Emotional
Resilience (n = 5 studies)				
Connor-Davidson Resilience Scale (CD-RISC 25) ¹⁵⁵	General a	4	Multiple sclerosis ^{8,33,60,101} Multiple sclerosis ⁶⁴	Cognitive, emotional, social
	General a	1		Cognitive, emotional

(Continued)

Table 2. (Continued)

Name of measurement tool	Target neurological population	<i>n</i> = studies that have used this tool	Conditions represented in studies using this tool [study reference]	COMET outcome domains
15-item Resilience Scale (RS-15) ¹⁵⁶				
Brief Pain Inventory (BPI) ¹⁵⁷	General a	Pain (n = 4 studies) 2	Multiple sclerosis ^{31,51}	General
MOS Pain Effects Scale (PES) ¹⁵⁸	Multiple sclerosis	2	Multiple sclerosis ^{31,76}	Emotional, physical, role, General
McGill Pain Questionnaire (MG PQ) ¹⁵⁹	General a	1	Multiple sclerosis ¹⁶⁰	General
Modified Fatigue Impact Scale (MFIS) ¹⁵⁸	Modified Fatigue Impact Scale (MFIS) ¹⁵⁸	Fatigue (n = 3 studies) Modified Fatigue Impact Scale (MFIS) ¹⁵⁸	Modified Fatigue Impact Scale (MFIS) ¹⁵⁸	Modified Fatigue Impact Scale (MFIS) ¹⁵⁸
Fatigue Severity Scale (FSS) ¹⁶¹	Fatigue Severity Scale (FSS) ¹⁶¹	1	Fatigue Severity Scale (FSS) ¹⁶¹	Fatigue Severity Scale (FSS) ¹⁶¹
Multidimensional Fatigue Inventory (MFI) ¹⁶²	Multidimensional Fatigue Inventory (MFI) ¹⁶²	1	Multidimensional Fatigue Inventory (MFI) ¹⁶²	Multidimensional Fatigue Inventory (MFI) ¹⁶²
Post-traumatic stress disorder (n = 3 studies)				
PTSD Checklist, Military Version ¹⁶³	General a	1	TBI ⁴⁰	Cognitive, emotional, physical psychiatric, social
Impact of events scale revised (IES-R) ¹⁶⁴	General a	1	TBI ⁶³	Cognitive, emotional, psychiatric
Clinician Administered Post-Traumatic Stress Disorder Scale (CAPS) ¹⁶⁵	General a	1	Spinal cord injury ¹⁶⁶	
PTSD symptom scale – interview for diagnostic statistical manual DSM-5 ¹⁶⁷	General a	1	TBI ⁶³	Cognitive, emotional, psychiatric
Seizures (n = 3 studies)				
Seizure frequency (study specific)	Epilepsy	3	Epilepsy ^{93,97,98}	Nervous system
	Epilepsy	2	Epilepsy ^{97,98}	Nervous system

(Continued)

Table 2. (Continued)

Name of measurement tool	Target neurological population	<i>n</i> = studies that have used this tool	Conditions represented in studies using this tool [study reference]	COMET outcome domains
Seizure index (frequency X duration) (study specific)				
General Self-Efficacy Scale (GSES) ¹⁶⁸	General a	Self-efficacy (n = 3 studies) 	Parkinson's disease ¹⁰⁷	Cognitive, emotional
Multiple sclerosis Self Efficacy Scale (MSSE) ¹⁶⁹	Multiple sclerosis		Multiple sclerosis ⁵³	
TBI Self-Efficacy Scale (TBI-SES) ¹⁷⁰	TBI	Sleep (n = 3 studies) 	Multiple sclerosis ⁴⁹	
Athens Insomnia Scale (AIS) ¹⁷¹	General a		Multiple sclerosis ³⁵	Cognitive, emotional, physical, psychiatric, role
Insomnia Severity Index ¹⁷²	General a		TBI ⁴⁰	
Pittsburgh Sleep Quality Index (PSQI) ¹⁷³	General a		Multiple sclerosis ³⁵	
Rating of sleep quality – poor to excellent (study specific)	General a		Brain tumour ⁴⁴	Psychiatric
Everyday Memory Questionnaire-Revised (EMQ-R) ¹⁷⁴	Various b	Memory (n = 2 studies) 	Multiple sclerosis ⁴⁹	
Wechsler Memory Scale – Third Edition (WMS-III) ¹⁷⁵			Multiple sclerosis ¹⁷⁶	
Positive and Negative Affect Schedule (PANAS) ¹⁷⁷	General a	Other outcomes (n = 20 studies) 3	TBI ^{12,41}	Emotional
Post-Traumatic Growth Inventory ¹⁷⁸	General a	2	Multiple sclerosis ⁶⁰ Stroke ³⁷	Emotional, social
Self-Compassion Scale (SCS) ¹⁷⁹	General a	2	Multiple sclerosis ⁹⁰ Multiple sclerosis ⁴⁸	Emotional
10 Meter Walk Test (10MWT) ¹⁸⁰	Various b		Spinal cord injury ⁴⁵	Physical
Alcohol Use Disorders Identification Test (AUDIT) ¹⁸¹	General a		Parkinson's disease ¹⁰⁷ TBI ⁴⁰	Emotional, physical, psychiatric, role

(Continued)

Table 2. (Continued)

Name of measurement tool	Target neurological population	<i>n</i> = studies that have used this tool	Conditions represented in studies using this tool [study reference]	COMET outcome domains
Cognitive Failure Questionnaire (CFQ) ¹⁸²	General a	1	Multiple Sclerosis ⁸⁰	
Columbia Suicide Severity Rating Scale ¹⁸³	General a	1	TBI ⁴⁰	Emotional, physical, psychiatric
Computerized Stroop Test (CST) ¹⁸⁴		1	Multiple sclerosis ¹⁷⁶	
Death Attitude Profile-Revised (DAP-R) ¹⁸⁵	General a	1	Multiple sclerosis ¹³⁹	
Dimensions of Anger Reactions II ¹⁸⁶	General a	1	TBI ⁴⁰	Cognitive, emotional, social,
Engagement in Meaningful Activities Survey (EMAS) ¹⁸⁷	General a	1	Spinal cord injury ⁴⁵	
Freezing of Gait (FOG) Questionnaire ¹⁸⁸	Parkinson's disease	1	Parkinson's disease ¹⁰⁷	Nervous system, physical
Functional Independence Measure (FIM) Scale ¹⁸⁹	General a	1	Spinal cord injury ¹⁶⁶	
Key Behaviors Change Inventory (KBCI) ¹⁹⁰	Traumatic brain injury	1	TBI ⁴⁸	Cognitive, emotional, social
Mayo Portland Adaptability Inventory (MPAI-4) ¹⁹¹	Acquired brain injury	1	Multiple conditions ⁴⁸	Cognitive, emotional, nervous system, physical, role, social
National Institutes of Health Stroke Scale (NIHSS) ¹⁹²	Stroke	1	Stroke ¹²⁹	
Orbach & Mikulincer Mental Pain Scale (OMMP) ¹⁹³	General a	1	Multiple sclerosis ¹⁹⁴	
Orientation Toward Productive Activities Scale ¹⁹⁵	General a	1	Multiple conditions ⁴⁸	Cognitive, emotional, physical, role, social
Paced Auditory Serial Addition Test (PASAT) ¹⁹⁶	Various b	1	TBI ⁴⁸	Cognitive
Psychological Adaptation Scale (PAS) ¹⁹⁷	General a	1	Multiple sclerosis ¹⁹⁸	Cognitive, emotional, social
Rivermead Postconcussion	Brain injury	1	TBI ²⁰⁰	Cognitive, emotional, nervous system

(Continued)

Table 2. (Continued)

Name of measurement tool	Target neurological population	<i>n</i> = studies that have used this tool	Conditions represented in studies using this tool [study reference]	COMET outcome domains
Symptoms Questionnaire (RPQ) ¹⁹⁹				
Rosenberg Self-Esteem Scale (RSES) ²⁰¹	General a	1	Epilepsy ⁹³	Emotional
Schneider's life expectancy questionnaire	General a	1	Multiple sclerosis ²⁰²	General
Social Phobia Inventory (SPIN) ²⁰³	General a	1	Epilepsy ¹⁵⁴	
Templer Death Anxiety ²⁰⁴	General a	1	Multiple sclerosis ²⁰⁵	Emotional
Things I'd like to change (TILTC) ²⁰⁶	General a	1	Multiple conditions ⁴³	Outcome domains depend on individual choices
Timed One Leg Stance Test (OLST) ²⁰⁷	Various b	1	Parkinson's disease ¹⁰⁷	Physical
Wearing-off Questionnaire (WOQ-19) ²⁰⁸	Parkinson's disease	1	Parkinson's disease ¹⁰⁷	Nervous system

^aTools which are not related to a neurological condition.

^bTools designed for use in neurological conditions of various causes.

Table 3. COMET core areas and outcome domains represented in the data set.

Core area	Outcome domain	Frequency
Physiological/ clinical	Psychiatric	22
	General	10
	Nervous system	9
Life impact	Emotional functioning/ wellbeing ^a	50
	Physical functioning ^a	32
	Role functioning ^a	22
	Social functioning ^a	13
	Cognitive functioning ^a	9
	Global quality of life	8
	Perceived health status	8
	Personal circumstances	2
	Delivery of care	1
Adverse events	Adverse events/effects	1

^aThe names of these domains are shortened to physical, social, role, emotional and cognitive in Table 2.

conditions specifically were coded under the ‘nervous system’ domain (e.g. Parkinson’s Disease Questionnaire-39¹⁰⁶ and Functional Assessment of Cancer Therapy scale – Brain.¹⁰³).

The most commonly classified domain was the life impact domain ‘emotional functioning/well-being’. Measures of mental health signs and symptoms (e.g. anxiety and depression) were classified in this domain, as well as under ‘psychiatric’ (above).

The health status, quality of life and well-being measures identified were coded against all the COMET core areas and outcome domains above (see Table 2 for measure specific results). As per taxonomy guidance, only composite items on quality of life or health status were classified under the ‘global quality of life’ and ‘perceived health status’ domains. For example, the World Health Organization Quality Of Life measure⁹⁹ was classified as such, as it contains the composite questions ‘How would you rate your quality of life?’ and ‘How satisfied are you with your health?’. Most health status, quality of life and/or well-being measures included items targeting multiple individual domains. These frequently included the functioning domains (physical, social, role, emotional/well-being and cognitive) as well as often including an item/s about physiological signs and symptoms.

Discussion

This review found that a large number of studies utilised Acceptance and Commitment Therapy for people with a range of acquired neurological conditions (with MS being the most common), using many different measurement tools. Measures targeting psychological flexibility as a composite were commonly used and, in accordance with previous research,²⁰⁹ this was most often measured by the Acceptance and Action Questionnaire-II.²⁹ The majority of studies aimed to reduce psychological distress and thus selected a wide variety of non-condition specific health-related outcome measures exploring distress, anxiety and/or depression.

This proliferation of measures warns us of challenges pooling and comparing data unless we reach consensus on process and outcome measures for future studies. We found that the most commonly measured COMET taxonomy domains were in the life impact core area. This is encouraging as the theoretical model of Acceptance and Commitment Therapy aims to improve functioning and well-being, rather than just focusing on the reduction of psychological distress.^{7,18} The majority of studies reported measurement time points relative to the end of the intervention in contrast to recommendations to report relative to baseline.²¹⁰ In categorising the measures it became clear that there is inconsistency in the definitions and use of terms such as health status, quality of life and well-being, as previously reported.²¹¹

A strength of this review is the meticulous process of categorising and coding all measures with reference to literature, including the novel application of the COMET taxonomy to Acceptance and Commitment Therapy research.¹⁹ Coding consensus was achieved through substantial consultation both internally (paper authors) and externally (with Susanna Dodd, author of the COMET taxonomy). Item-by-item coding of each health-related outcome measure (when freely available) enabled comprehensive mapping according to all outcome domains measured. However, a risk of item-by-item classification is that it does not take into account how the measurement tools have been constructed, and therefore may overestimate the domains that have been measured. Furthermore, as the domains in the COMET

taxonomy are not mutually exclusive, the coding process did not aid the categorisation of the many tools into distinct groups. Due to these limitations, COMET categorisation was not completed for additional measures extracted when the review was updated in 2022.

A ‘broader’ level categorisation of the measures (as described in methods) was also provided to make overall sense of the tools. This broad categorisation of the outcome measures, and the categorisation of process measures according to the Acceptance and Commitment Therapy hexaflex, were done in a best-fit manner by the authors. Data extracted from the studies themselves were used to inform these decisions, but inconsistencies in this information, and lack of reporting, meant that author consultation was often used, which remains subjective and open to further debate.

This review is limited in only including studies reported in English. However, the inclusion of multiple study types, and of studies that included Acceptance and Commitment Therapy plus other interventions, enabled comprehensive identification of measures used in Acceptance and Commitment Therapy in acquired, neurological populations.

A strength of this review is the enhancement of the scoping review methodology²¹ through use of double reviewing during study selection, data extraction and data synthesis.

This review contributes recommendations and future research directions. Our findings highlight reporting inconsistencies in the field that could be improved. The use of suitable reporting guidance (<https://www.equator-network.org/>) would facilitate data synthesis from Acceptance and Commitment Therapy research trials in systematic reviews. Authors should clarify whether measures were selected to explore processes of change or health outcomes. Authors should explicitly state the process and outcome domains that they are aiming to measure, as well as the measurement tools themselves. There is on-going development of core outcome sets relevant to a number of the populations included in this review. Where available, it is recommended that clinical trials of Acceptance and Commitment Therapy use relevant core outcome sets to inform their choice of measures.

The findings of this review of what has been measured are a useful resource to support identification of candidate measurement tools. However, this cannot be extrapolated to inform what should be measured, or which tools should be used.

In order for specific recommendations to be made for use of Acceptance and Commitment Therapy in acquired, neurological populations, future research is required and should include consensus by experts, use of patient, carer and public involvement,^{212,213} and examination of the psychometric properties of the measures.

Conclusion

This review summarises a detailed categorisation of the process and outcome measures previously used in Acceptance and Commitment Therapy studies in acquired neurological populations. Acceptance and Commitment Therapy has primarily been used to target psychological distress, but other outcomes including physical health outcomes have also been targeted. We highlight that a wide range of both process and outcome measurements are in use, with little guidance available on selection. This review provides a resource for other researchers and could support development of core outcome sets.

Clinical messages

- Mental health needs of adults with neurological conditions are poorly addressed and there is an imperative to deliver evidence-based interventions to promote well-being.
- Clinical guidance on whether Acceptance and Commitment Therapy is useful for this clinical population is being hampered by the lack of agreement on which of the many measures available should be used to evaluate the process of change and outcomes following intervention.
- Key stakeholders should be involved in consensus-based decision-making, which draws on resources such as this review of candidate measures.

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Author contributions

HF, AB, SC and EP designed the study. HF and MP charted and collated the data. All authors contributed to discussions about the methodology and analysis of data. HF took the lead on summarising the results and drafted the article. All authors critically reviewed and revised the article and approved the final version for submission.

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Supplemental material

Supplemental material for this article is available online.

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