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Reporting dose in complex self-management support interventions for long-term conditions: is it defined by researchers and received by participants? - a systematic review

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3 **Reporting dose in complex self-management support**
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6 **interventions for long-term conditions: is it defined by**
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9 **researchers and received by participants? - a systematic**
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11 **review**
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15 Tasmin A Rookes, Neurology Department (U3), Royal Free Hospital, Rowland Hill
16 Street, London, NW3 2PF, t.rookes@ucl.ac.uk, 07823686064, University College
17
18 London, Institute of Neurology, London, UK. (Corresponding Author).
19
20
21
22

23
24 Atena Barat, Yvonne Carter Building, 58 Turner Street, London, E1 2AB,
25
26 a.barat@qmul.ac.uk, Queen Mary University of London, Institute of Population
27
28 Health Sciences, London, UK
29
30
31

32
33
34 Rebecca M Turner, 90 High Holborn, London, WC1V 6LJ, becky.turner@ucl.ac.uk,
35
36 University College London, Institute of Clinical Trials and Methodology, London, UK
37
38
39

40
41 Steph JC Taylor, Yvonne Carter Building, 58 Turner Street, London, E1 2AB,
42
43 s.j.c.taylor@qmul.ac.uk, Queen Mary University of London, Institute of Population
44
45 Health Sciences, London, UK
46
47
48

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51
52 and Guidelines.
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59
60

Abstract:

Background: The minimum clinically effective dose and whether this is received in randomised controlled trials (RCTs) of complex self-management interventions in Long-Term Conditions (LTCs) can be unclear. The Template for Intervention Description and Replication (TIDieR) checklist states that dose should be clearly reported to ensure validity and reliable implementation.

Objectives:

To identify whether the expected minimum clinically effective dose is stated and the dose participants received reported within articles.

To determine whether reporting has improved since the TIDieR checklist was published.

Methods: Four databases were systematically searched (MEDLINE, PsycINFO, AMED and CINAHL) to identify published reports between 2008 and 2020 for RCTs investing complex self-management interventions in LTCs. Data on reporting of dose was extracted and synthesised from the eligible articles.

Results: 82 articles covering various LTCs including diabetes, stroke and arthritis were included. Most complex interventions involved behaviour change combined with education and/or exercise. The maximum dose was usually reported (97.6%), but the expected minimum clinically effective dose and the dose received were reported in only 23.2% and 62.2% of articles, respectively. Reporting of the expected minimum clinically effective dose and the dose participants received did not improve following the publication of the TIDieR checklist in 2014.

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5 **Conclusions:** Poor reporting of dose within complex self-management interventions
6
7 for LTCs makes the results difficult to interpret and implement. If trial findings
8
9 indicate benefit from the intervention, clear reporting of dose ensures reliable
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11 implementation to standard care. If the results are non-significant, detailed reporting
12
13 enables better interpretation of results i.e. differentiating between poor
14
15 implementation and lack of effectiveness. This ensures quality of interventions and
16
17 validity and generalisability of trial findings. Therefore, wider adoption of reporting the
18
19 TIDieR checklist dose aspects is strongly recommended. Alternatively, customised
20
21 guidelines for reporting dose in complex self-management interventions could be
22
23 developed.
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30 **Registration:** Prospero ID CRD42020180988

31
32 **Keywords:** dose; reporting; complex self-management intervention; long-term
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34 condition; systematic review; TIDieR checklist; fidelity
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40 **Strengths and limitations of this study:**

- 41
42 • This is the first systematic review of its kind to look at whether dose is being
43
44 reported as the guidelines recommend in self-management interventions.
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46
- 47 • Double screening and data extraction were completed, ensuring all eligible
48
49 papers were included and accurate data extracted. This process was also
50
51 piloted and any issues resolved before being applied to all eligible papers.
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- 54 • Determining eligibility based on the definition of complex self-management
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56 was challenging, but we developed a systematic approach to limit any
57
58 potential bias.
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- Quality assessment of eligible papers was not conducted, but it could have been interesting to see if quality of study correlated with quality of reporting.

Background:

It is estimated that 30% of the UK population live with a Long-Term Condition (LTC) and that LTCs account for 70% of health and social care spending within the NHS (1). This prevalence extends globally, with a growing awareness of the importance of monitoring prevalence and developing interventions to overcome LTCs, due to the aging population, predicted increase in LTCs and the associated costs (2, 3).

Therefore, the management of LTCs is a priority for the NHS. LTCs are defined as “diseases of long duration and are the result of a combination of genetic, physiological, environmental and behavioural factors” (4). The current evidence base suggests LTC treatment should focus on supporting effective self-management to result in better health outcomes (5). Self-management here is defined in conjunction with the US Institute of Medicine definition, echoed by the Department of Health; “Self-management is defined as the tasks that individuals must undertake to live with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management and emotional management of their conditions.” (6, 7).

Complex self-management interventions are known to improve a variety of health outcomes in LTCs, including self-efficacy (confidence in ability to execute specific behaviours), patient activation (confidence, skills and knowledge to manage their own health care), self-rated health, clinical outcomes and social outcomes (8).

Complex self-management interventions contain several interacting components that

1
2
3 aim to change patients' behaviour. However, determining which parts of the complex
4 intervention are necessary to result in a potential benefit can be difficult. Therefore,
5 complex self-management interventions should go through stages of development
6 before being evaluated, typically in randomised control trials (RCTs), to identify how
7 much of which components result in the best outcomes (9). Once decided upon, at
8 least the expected minimum clinically effective dose of the complex self-
9 management intervention should be compared to standard care for the LTC to see if
10 health outcomes improve. However, in published reports of RCTs it is often unclear
11 how the minimum clinically effective dose of the intervention was determined or,
12 indeed, what the researchers believe the expected minimally clinically effective dose
13 to be.
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31 The concept of dose refers to the number of intended units of each intervention
32 (dose delivered) and the extent of engagement of participants with the intervention
33 (dose received) (10). Treatment fidelity refers to the extent to which the intervention
34 is delivered as expected, how much of the intervention is received and the amount of
35 treatment enactment of the intervention by participants. Focussing on fidelity of
36 treatment receipt, if the number and length of sessions received is in line with that
37 stated in the protocol, it is essential researchers determine what they think the
38 minimum clinically effective dose is and measure if it is received by participants
39 within the trial, so fidelity of treatment receipt can be assessed (11, 12). Collecting
40 and reporting this information ensures the quality and integrity of the intervention and
41 enables assessment of how valid and generalisable the findings are (10).
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55 Additionally, not stating the expected minimum clinically effective dose and if it has
56 been delivered and received makes it difficult to interpret RCT results. If trial results
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3 are non-significant and fidelity of treatment receipt is not reported, it is unclear if this
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5 result is due to a lack of effectiveness or failed implementation of the intervention.
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7 Ensuring non-significant effects are due to lack of intervention effectiveness helps to
8
9 avoid a type ii error, whereby the treatment is deemed not effective when the
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11 findings are due to confounding variables, such as poor implementation (13).
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17 To improve the reporting of all types of interventions the Template for Intervention
18
19 Description and Replication (TIDieR) checklist (14) was developed in 2014. The 12
20
21 items explain how interventions should be described in published articles, so that
22
23 trials with effective interventions can be replicated validly and implemented into
24
25 standard practice reliably. The intervention details required for non-pharmacological
26
27 interventions, such as the behavioural and educational components used in complex
28
29 self-management interventions, are explained. Focusing on dose, Item 8 of the
30
31 checklist highlights 'when and how much', whereby RCT articles should clearly state
32
33 the number of sessions in the intervention, their duration and over what time period
34
35 they are delivered. Also, Items 11 and 12 of the checklist state that the planned,
36
37 delivered and received doses should be included to ensure both adherence and
38
39 fidelity can be assessed (outlined in Table 1). No previous, published reviews within
40
41 the LTC complex self-management literature have reviewed whether dose and
42
43 fidelity are being reported in this way.
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49 Table 1. Extract from the TIDieR checklist of the relevant item descriptions for this
50
51 review.
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TIDieR Checklist Item	Description
Item 8	When and how much: Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose
Item 11	How well (planned): If intervention adherence or fidelity was assessed, describe how and by whom, and if any

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2	
3	strategies were used to maintain or improve fidelity,
4	describe them
5	Item 12
6	How well (actual): If intervention adherence or fidelity was
7	assessed, describe the extent to which the intervention
8	was delivered as planned
9	

10
11 This systematic review aimed to identify how complex self-management intervention
12 doses for patients with LTCs are reported in RCTs. We assessed this by evaluating
13 whether what the researchers believe to be the minimum clinically effective dose
14 was stated, how this dose was determined, if the dose received by study participants
15 was stated and how it compared to the expected minimum clinically effective dose
16 (fidelity of treatment receipt). We also aimed to determine if reporting of expected
17 minimum clinically effective dose and treatment dose received improved following
18 the publication of the TIDieR checklist in 2014. Finally, we aimed to identify whether
19 reporting of expected minimum clinically effective dose and treatment dose received
20 differed depending on whether the primary outcome results were statistically
21 significant or not. We hypothesised that reporting of dose would have improved since
22 the publication of the TIDieR checklist and that studies with non-significant primary
23 outcomes may report dose more clearly than studies with a significant outcome in an
24 attempt to explain their results.

25 **Methodology:**

26 **Search strategy for systematic review and inclusion and exclusion criteria**

27 The systematic review was conducted in accordance with PRISMA (Supplementary
28 Table 1). MEDLINE, CINAHL, AMED and PsychInfo were systematically searched.
29 The full search strategies can be found in Supplementary Figure 1. Publications
30 were included if published between January 2008 and June 2020, to identify if there

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2
3 was a trend towards improved reporting of treatment dose from 6 years before to 6
4 years after the TIDieR checklist was published (2014).
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10 ***Inclusion criteria (PICOS)***

- 12 • Population: populations with long-term conditions (4)
- 13 • Intervention: complex self-management support with structured sessions
14 (containing several interacting components that aim to change patients'
15 behaviour), delivered to patients (6, 7)
16
17 • Comparator: any
18
19 • Outcome: any
20
21 • Study Design: randomised controlled trials
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28 ***Exclusion criteria***

- 29 • Does not include human participants
- 30 • Not a complex self-management support intervention with structured sessions
31 e.g. exercise or psychotherapy only interventions
32
33 • Interventions delivered to carers, health care professionals etc.
34
35 • Only published as an abstract
36
37 • Ongoing studies
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48 The articles from the database searches were exported into EndNote, duplicates
49 removed and brief screening completed (e.g. removing systematic reviews). Those
50 remaining were uploaded into Abstrackr (<http://abstrackr.cebm.brown.edu/>) and the
51 two reviewers (TR and AB) independently screened titles and abstracts against the
52 inclusion criteria, classifying articles as included, excluded and maybe eligible.
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3 Identified discrepancies were discussed with ST to reach a final decision for full text
4 data extraction.
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10 **Data extraction and analysis**

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12 Data was independently extracted by TR and AB onto a Word based proforma
13 designed for the study and any disagreements discussed until consensus was
14 reached.
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21 For all studies we extracted trial authors, country, year of publication, intervention
22 name, intervention description and components, LTC disease area, maximum
23 intervention dose that could be delivered in the context of their study, expected
24 minimum clinically effective dose, any rationale given for this, actual dose received,
25 fidelity of treatment receipt and intervention delivery, and statistical significance of
26 the primary outcome.
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37 Within the articles, reporting of dose was determined by the number and length of
38 sessions available to participants and how many they attended. Minimum expected
39 clinically effective dose was either explicitly stated or stated as the number of
40 sessions needed to be attended to be considered a 'completer' or to be included in
41 the per protocol analysis. If no detail was provided, then this was recorded as 'not
42 reported'. An example of the data extraction process can be seen in Supplementary
43 Table 2. Due to the subjective interpretation of some data points, we piloted this
44 process to ensure accurate and consistent interpretation. The Items included from
45 the TIDieR checklist are outlined in Table 1.
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As this was a review of trial reporting, rather than of trial findings, a formal quality assessment was not undertaken. Simple summary statistics were used to report the percentage of trials reporting the various aspects of dose.

Patient and public involvement

No patients involved in research project.

Results

After database searching and deduplication, 14661 titles and abstracts were screened for data extraction and 124 full-text articles screened for eligibility, of which 82 were included in the synthesis, see Figure 1 PRISMA flow diagram.

Characteristics of included RCTs

The population and intervention characteristics varied among the RCTs included.

With 25 different LTCs investigated across the 82 articles, including diabetes, cancer survivors, COPD, dementia, arthritis, stroke, serious mental illness and HIV. The complex self-management interventions investigated included Chronic Disease Self-Management Program (CDSMP (15)), Arthritis Self-Management Program (ASMP (16)), health education programs (17-19), health education combined with exercise programs (20-22), Cognitive Behavioural Approaches (23, 24), and problem-solving and goal setting (25-27). The number of sessions for the intervention ranged from 2 to over 30. A summary of the LTCs, self-management interventions and number of sessions are presented in Tables 2, 3 and 4, respectively. Further details of all included articles are supplied in Supplementary Table 3, with the full reference list of included trials in Supplementary Figure 2.

Table 2. LTCs investigated in the 82 articles included in the systematic review.

Long Term Conditions Investigated	Number of Trials (%)
Type 1 and/or 2 Diabetes	24 (29%)

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3	Fibromyalgia	2 (2%)
4	Epilepsy	2 (2%)
5	Chronic Hepatitis C	1 (1%)
6	Cancer Survivorship	3 (4%)
7	Dementia/Neurocognitive disorder	2 (2%)
8	Hypertension	2 (2%)
9	Arthritis	9 (11%)
10	HIV	2 (2%)
11	Spinal Cord Injury	3 (4%)
12	COPD	3 (4%)
13	Amputation	2 (2%)
14	Stroke	6 (7%)
15	Multiple Sclerosis	1 (1%)
16	Psychosis	3 (4%)
17	Serious Mental Illness	3 (4%)
18	Heart Failure	3 (4%)
19	Asthma	2 (2%)
20	Myocardial Infarction	2 (2%)
21	Generic Chronic Somatic Disease	1 (1%)
22	Depression	1 (1%)
23	Chronic Kidney Disease	2 (2%)
24	Chronic Fatigue Syndrome	1 (1%)
25	Coronary Heart Disease	1 (1%)
26	Skin Picking	1 (1%)
27		
28	Total	82 (100%)
29		
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31		
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33		

Table 3. Complex self-management interventions in the 82 trials included in the systematic review.

Complex Self-Management Intervention	Number of Trials (%)
Chronic Disease Self-Management Program	8 (10%)
Health Education	28 (34%)
Health Education Combined with Exercise	10 (12%)
Cognitive and Behaviour Change Approach	9 (11%)
Problem Solving and Goal Setting	14 (17%)
Arthritis Self-Management Program	3 (4%)
Other	10 (12%)
Total	82 (100%)

Table 4. Number of sessions delivered in the 82 trials included in the systematic review.

Number of Sessions	Number of Trials (%)
1	0
2-6	42 (51%)
7-12	26 (32%)
>12	13 (16%)
Unclear	1 (1%)

Total	82 (100%)
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Reporting of Dose

Of the 82 trials included, 80 (97.6%) reported the maximum number of sessions that could be delivered, 63 (76.8%) reported the length of these sessions and 19 (23.2%) reported the expected minimum clinically effective dose. Of the 19 reporting the expected minimum clinically effective dose, 8 (42.1%) justified how this had been determined. In addition, 51 (62.2%) reported what dose participants actually received and 40 (48.8%) discussed if this was equal to, or greater than, that scheduled to be delivered in the protocol (fidelity of treatment receipt). It was unclear in 41 articles (50%) whether the expected minimum clinically effective dose had been received by participants, as no detail was provided. Of the 41 studies where this information was present, in 29 (70.7%) participants received the expected minimum clinically effective dose, which for 11 of these (26.8%) was also the maximum dose available.

No improvement in reporting of dose since the publication of the TIDieR checklist was observed. Of the 31 articles published between 2008 and 2014 and the 51 published between 2015 and 2020, 6 (19.4%) and 13 (25.5%), respectively, reported the expected minimum clinically effective dose. Of the 31 articles published between 2008 and 2014 and the 51 published between 2015 and 2020, 22 (71.0%) and 29 (56.9%), respectively, reported the number of sessions received and 15 (48.4%) and 20 (39.2%), respectively, reported the length of sessions received. The percentage of trials reporting the expected minimum clinically effective dose, as number of sessions, and the treatment dose participants received per year are represented in Figure 2.

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3 There was no substantial difference in reporting of expected minimum clinically
4 effective dose or the dose received based on the statistical significance of the trial's
5 primary outcome. Of the 52 articles with a significant primary outcome result and the
6 30 with a non-significant primary outcome result, 10 (19.2%) and 9 (30%),
7 respectively, reported the expected minimum clinically effective dose. Of the 52
8 articles with a significant primary outcome result and the 30 with a non-significant
9 primary outcome result, 29 (55.8%) and 22 (73.3%), respectively, reported the dose
10 received.
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24 **Discussion**

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26 The included trials covered a variety of LTCs and self-management interventions. As
27 expected, almost all of the trials included in this systematic review reported the
28 maximum number of sessions and just over three quarters reported the length of
29 sessions of the complex self-management intervention. Less than a quarter reported
30 the expected minimum clinically effective dose and, when this was reported, less
31 than half explained how this had been determined. Under two thirds reported the
32 number of sessions dose and under half reported length of sessions dose
33 participants received and within these even fewer discussed whether there was
34 fidelity of treatment receipt, i.e. if the dose received was equal to or greater than that
35 specified in the protocol. Improvements in the reporting of the expected minimum
36 clinically effective dose or the dose received were not seen after the TIDieR checklist
37 was published in 2014. There was also no difference in the reporting of these doses
38 depending on whether the primary outcome was statistically significant or not.
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59 **Results in Context**

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3 In RCTs of complex self-management interventions in patients with LTCs it is often
4 difficult for the maximum dose to be received by all participants, due to the
5
6 complexity of both the participants' disease and the intervention itself. However, the
7
8 number of sessions attended and amount of contact with the intervention leader(s) is
9
10 often associated with improved patient outcomes (18, 28). It is well documented that
11
12 receiving 4 of the 6 sessions available in CDSMP results in a beneficial clinical effect
13
14 (29). Of the 8 papers investigating CDSMP in this review, 4 papers discussed this
15
16 minimum clinically effective dose and only 2 stated it (30, 31). If no minimum
17
18 clinically effective dose is stated, interpreting whether the dose participants received
19
20 was greater than, or equal to, the minimum dose needed to see an improvement
21
22 (fidelity of treatment receipt) is almost impossible, unless all participants receive the
23
24 maximum dose available, which is uncommon (13). If the minimum clinically effective
25
26 dose is stated and received by participants, then a negative result might be
27
28 interpreted as an ineffective intervention. If the dose is not received then a negative
29
30 result could be due to poor implementation of the intervention, rather than a lack of
31
32 effectiveness. Therefore, by not reporting the dose received, potentially effective
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34 interventions could be abandoned, due to the results not being able to be interpreted
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36 in relation to the dose received, resulting in a type ii error (13, 32).
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47 If the dose received is stated and is low, further investigation can be done by trial
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49 authors or other researchers to determine why and how it relates to patient
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51 outcomes i.e. due to poor trial and/or intervention design. Collecting this information
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53 and reporting on it enables those implementing the intervention to know what and
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55 how much needs to be received to ensure the best outcomes. In the Ackerman et al.
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57 trial (33), 27% of those approached to participate declined, as they could not attend
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3 all 6 sessions, and of those who were recruited many did not attend the ASMP
4
5 sessions. Many adaptations were made to avoid this, such as booking venues close
6
7 to participants' homes and scheduling on varying days and times. As the authors
8
9 provided this detail, future researchers are aware of these potential challenges and,
10
11 in their trials, could adapt the intervention to be delivered another way i.e. home-
12
13 based, via telephone or web-based to make it more accessible and improve
14
15 recruitment and retention. Also, if policy-makers have this information when
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17 designing guidelines and making recommendations for scaling up interventions into
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19 standard care, effects seen in trials are more likely to be translated into routine care
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21 (34-36).
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29 In addition, researchers must take the time within the early developmental phases of
30
31 an intervention to ensure the expected minimum clinically effective dose is estimated
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33 as accurately as possible, through pilot studies, systematic reviews and / or
34
35 longitudinal research (9). Although difficult, this focus on early development would
36
37 prevent fully funded RCTs going ahead when the minimum clinically effective dose
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39 has not been determined or measured, potentially resulting in type ii error.
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45 Even when fidelity is mentioned within trial papers, the focus is often on how it was
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47 assessed rather than the actual findings, limiting the use of fidelity data to interpret
48
49 the trial findings, and making the fidelity assessment almost useless (37-39).
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51 Understanding the reasons why fidelity is poorly reported is complex, but it is thought
52
53 to be attributed to lack of knowledge and the practicalities of comprehensively
54
55 assessing fidelity within an RCT (40). Despite the extra resources needed to conduct
56
57 a full assessment of fidelity, the economic and scientific costs of not completing and
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1
2
3 reporting fidelity outcomes are far greater (13). Variations in intervention delivery
4
5 within trials may influence efficacy and result in biased conclusions.
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10 Although the TIDieR checklist was designed to improve reporting of interventions, no
11
12 improvement in the reporting of the expected minimal clinically effective dose and
13
14 dose received and discussion of the fidelity of the treatment received was found in
15
16 this review. Also, within the articles, there was little to no mention of the TIDieR
17
18 checklist and reporting of interventions in accordance with it. This is in line with other
19
20 systematic reviews investigating the implementation of the TIDieR checklist into trial
21
22 reporting. Investigating implementation in the cardiovascular medicine literature,
23
24 Palmer et al. (2020) (41) found over one fifth failed to report the dose of the
25
26 treatment received (Item 11). Within behaviour change research similar results to
27
28 this review have been found (42), with the maximum dose available always reported,
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30 but other elements of dose poorly described.
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38 Researchers may be less familiar with the TIDieR checklist, due to the dissemination
39
40 being less extensive than other reporting guidelines e.g. CONSORT and PRISMA
41
42 (41). Therefore, broader dissemination of the TIDieR checklist or incorporating the
43
44 checklist within Item 5 of the CONSORT statement, could improve reporting, as the
45
46 information would be required by journals for publication (41). Poor implementation
47
48 of the TIDieR checklist could also be due to the guidelines being too broad and
49
50 generic and difficult for authors to adapt to their own interventions (43). Making the
51
52 TIDieR checklist clearer and developing customised versions for specific intervention
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54 types could increase implementation of the checklist guidelines and ultimately
55
56 improve intervention description and reporting (44) .
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Limitations

The subjective nature of determining the eligibility of trials based on whether the intervention was a complex self-management intervention, could have introduced bias. All those marked potentially eligible were discussed by the study team to limit any potential bias and if there were any doubts the paper was included for data extraction. If consensus on eligibility could not be met, the paper was sent to a third reviewer (ST), with extensive experience in self-management support interventions for a final decision. Through these discussions decisions around eligibility for inclusion were as consistent as possible given the flexible and varied definition of complex self-management interventions within the literature.

Also, a formal quality assessment was not completed, as we were not looking at the outcome measures. It could be of interest to compare the quality of study with the accuracy of dose reporting, but this was not within the scope and capacity of this review.

Future Research

Following this review, reporting standards of complex self-management intervention doses do not appear to have improved since the publication of the TIDieR checklist. Ensuring that guidelines provide recommendations for how to define and assess dose within complex self-management interventions is vital for accurate reporting and so, interpretation and implementation of trial results. Therefore, either the TIDieR checklist should be updated or novel, specialised methodological guidelines developed to ensure that dose in these trials is determined, measured and reported

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3 as accurately as possible. Additionally, looking at whether quality of study correlates
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5 to quality of reporting dose could be completed.
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10 **Conclusion**

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12 Reporting of the minimum clinically effective dose, the dose received in the trial and
13
14 the fidelity of treatment receipt are not consistent in studies of complex self-
15
16 management interventions for LTCs. Although this detail is outlined in the TIDieR
17
18 checklist, published in 2014, there has been no improvement in reporting following
19
20 its publication. Currently we recommend that when publishing RCTs, researchers
21
22 should describe the intervention dose according to the TIDieR checklist. This will
23
24 enable clinicians and policy-makers to reliably replicate the interventions in future
25
26 trials and/or interpret findings to implement them into practice. Going forward, the
27
28 TIDieR checklist could be made clearer with versions for specific intervention types
29
30 and wider dissemination of the checklist to increase implementation of the guidelines
31
32 and improve intervention reporting. To facilitate this, funders, reviewers and journal
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34 editors should encourage dose and fidelity of treatment receipt to be collected and
35
36 discussed, to increase reporting in this way.
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45 **Abbreviations**

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47 RCT: Randomised controlled trial; LTC: Long-term condition; TIDieR: Template for
48
49 intervention description and replication; CDSMP: Chronic disease self-management
50
51 program; ASMP: Arthritis self-management program
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56 **Declarations**

57 **Funding**

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1
2
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6
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28
29

30 **Competing interests**

31
32 The authors declare that they have no competing interests
33
34

35 **Data sharing**

36
37 The datasets used and/or analysed during the current study are available from the
38 corresponding author on reasonable request.
39
40

41 **Author contributions**

42
43 TR, supervised by ST and RT, designed the review and conducted the searches,
44 data extraction, and analysis. TR and AB undertook double screening and data
45 extraction. The authors read and approved the final manuscript.
46
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48
49

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Figure legends

Figure 1. PRISMA Systematic Review Flow Diagram

Figure 2. Bar graph illustrating the percentage of trials reporting the expected minimum clinically effective dose and the treatment dose received by year.

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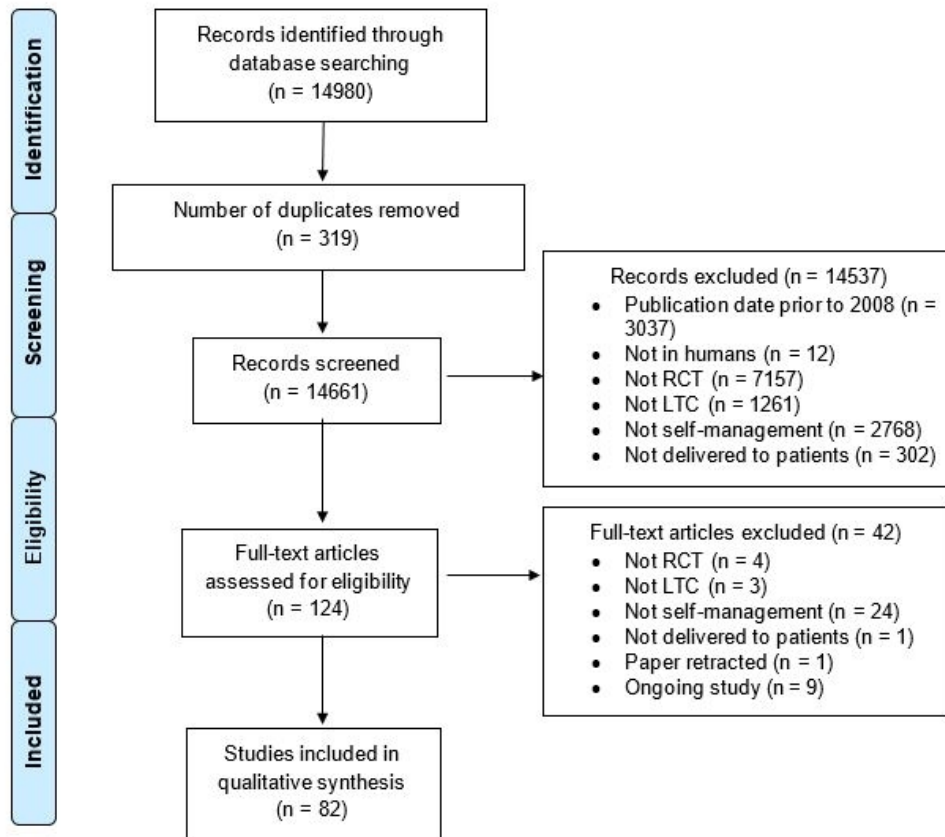


Figure 1. PRISMA Systematic Review Flow Diagram

Figure 1. PRISMA Systematic Review Flow Diagram

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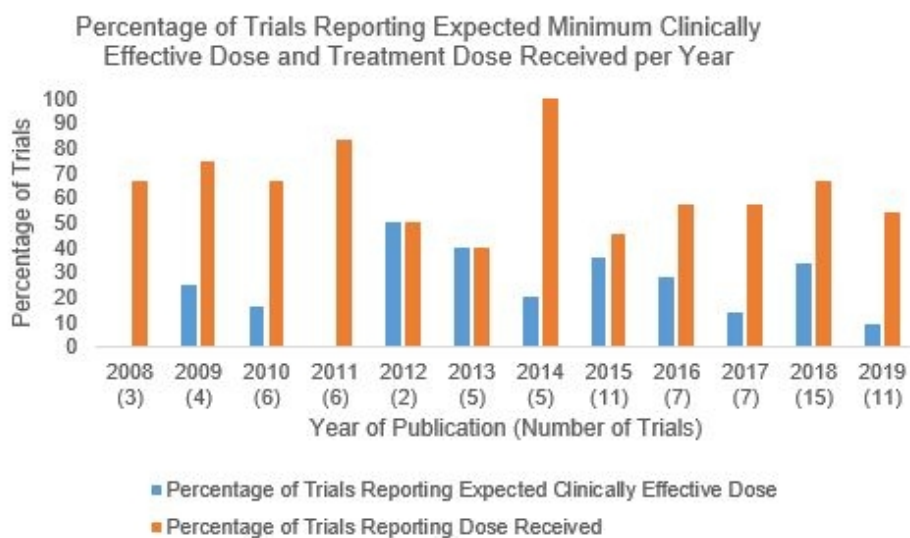


Figure 2. Bar graph illustrating the percentage of trials reporting the expected minimum clinically effective dose and the treatment dose received by year.

134x77mm (96 x 96 DPI)



PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	2-3
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	4-7
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	7
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	8
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	7
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Supplementary figure 1
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	8-9
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	9 and supplementary table 2
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	9
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	9
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	10
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	8-9
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics or data conversions.	N/A
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	N/A
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	9
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analyses, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting bias).	N/A
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A



PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	10 and figure 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	N/A
Study characteristics	17	Cite each included study and present its characteristics.	10-11 and supplementary figure 2
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	N/A
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	N/A
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	N/A
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	14-16
	23b	Discuss any limitations of the evidence included in the review.	17
	23c	Discuss any limitations of the review processes used.	17
	23d	Discuss implications of the results for practice, policy, and future research.	17-18
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	3
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	19
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	19
Competing interests	26	Declare any competing interests of review authors.	19
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	19 and supplementary table 3

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

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1 36/bmjopen-2021-056532 on August 17, 2022. Downloaded from <http://bmjopen.bmj.com/> on April 8, 2023 by guest. Protected by copyright.

Supplementary Table 1: Example of data extraction (including study details, intervention details and dose / fidelity reporting)

Study Title	
Year, Author, Country, Link	Year after 2008?: Yes <input type="checkbox"/> No <input type="checkbox"/> If No stop and log as reason for exclusion TIDieR checklist (2014): Before <input type="checkbox"/> After <input type="checkbox"/>
Pre-extraction Screening	Needs translating: Yes <input type="checkbox"/> No <input type="checkbox"/> If Yes stop and log RCT: Yes <input type="checkbox"/> No <input type="checkbox"/> In No stop and log as reason for exclusion Self-management intervention: Yes <input type="checkbox"/> No <input type="checkbox"/> If No stop and log as reason for exclusion Participants with LTCs: Yes <input type="checkbox"/> No <input type="checkbox"/> If No stop and log as reason for exclusion Ongoing study: Yes <input type="checkbox"/> No <input type="checkbox"/> If Yes stop, log and consider contacting author
Research Question / Aim	

Methods:

Intervention Summary Features	CDSMP <input type="checkbox"/> ASMP <input type="checkbox"/> EPP <input type="checkbox"/> Other <input type="checkbox"/> Specify if known Disease specific <input type="checkbox"/> or Generic <input type="checkbox"/> LTCs included: Delivered by: Health care professional <input type="checkbox"/> Lay person <input type="checkbox"/> Other <input type="checkbox"/> Specify if known Individual one-to-one sessions: Yes <input type="checkbox"/> No <input type="checkbox"/> Group sessions: Yes <input type="checkbox"/> No <input type="checkbox"/> Number in group: Face-to-Face sessions <input type="checkbox"/> / Remote sessions <input type="checkbox"/> Location where is the intervention delivered: Inpatient <input type="checkbox"/> Outpatient <input type="checkbox"/> Community Based <input type="checkbox"/> Home <input type="checkbox"/> Unclear <input type="checkbox"/> Other <input type="checkbox"/> Specify if known Description: Any necessary components for adherence:
Dose of Intervention	Maximum dose: Number of sessions: Session Duration (hours): Total hours: Duration intervention delivered over:
Adherence and compliance	Anticipated clinically effective dose: Number of sessions: Session Duration (hours): Total hours:

<p>1 2 3 4 5 6 7 8 9 10 11</p> <p>may be used synonymously, but the distinction and data needs to be teased out</p>	<p>How clinically effective dose decided by authors:</p> <p>Author comments on Adherence (the number of sessions participants attended):</p> <p>Author comments on Compliance (the number of sessions participants need to attend to be including in the analysis):</p>
<p>12 13 14 15 16 17 18 19 20 21 22</p> <p>Fidelity of Intervention</p>	<p>Did the study describe attempts to ensure fidelity of the interventions i.e. what was delivered was what was intended to be delivered: Yes <input type="checkbox"/> No <input type="checkbox"/> Not stated/unclear <input type="checkbox"/></p> <p>If Yes, specify:</p> <p>Comments / Additional details:</p>

Results:

<p>26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42</p> <p>Dose of Intervention</p>	<p>Dose actually delivered: Number of sessions: Session Duration (hours): Total hours: Duration Intervention Delivered Over:</p> <p>Dose actually received (specifically for groups): Number of sessions: Session Duration (hours): Total hours: Duration Intervention Delivered Over:</p> <p>Was the dose delivered \geq anticipated clinically effective dose: Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/></p> <p>Details:</p> <p>Further author comments on dose:</p>
<p>43 44 45 46 47 48 49 50 51 52</p> <p>Fidelity of Intervention</p>	<p>Was there fidelity around the dose in the trial?: Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/></p> <p>Was fidelity reported on in?: Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/></p> <p>Do the authors discuss the impact of fidelity?: Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/></p> <p>Further author comments on fidelity:</p>
<p>53 54 55 56 57 58 59 60</p> <p>Primary Outcome Result</p>	<p>Was the Primary Outcome Statistically Significant: Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Details:</p> <p>Was the Primary Outcome Clinically Significant: Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/></p> <p>Details:</p>

Supplementary Table 2. Full details of all 82 articles included in the systematic review

1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45	46
First Author	Year	Country	Intervention	Disease	Delivered by	Location	Maximum dose stated (number of sessions)	Maximum dose stated (length of sessions)	Anticipated Clinically Effective dose stated	Dose actually delivered stated (Number of sessions)	Dose actually delivered stated (length of sessions)	Was dose delivered ≥ anticipated clinically effective dose	Was fidelity reported and discussed?	Was the primary outcome statistically significant?																															
Ackerman	2012	Australia	ASMP	Hip or Knee Osteoarthritis	HCPs and Lay leaders	Outpatient clinic and Community	Yes	Yes	Yes	Yes	Yes	No	Yes	No																															
Ambrosino	2008	USA	Coping skills training - learning to deal better with day-to-day problems that arise,	Type 1 Diabetes	HCPs	Unclear	Yes	Yes	No	Yes	Yes	Unclear	No	No																															
Anvar	2018	Iran	ASMP	Rheumatoid Arthritis	HCPs	Outpatient clinic	Yes	Yes	No	Yes	Yes	Unclear	No	Yes																															
Bantum	2014	USA	Surviving and Thriving with Cancer website adapted from CDSMP	Cancer survivors	Lay leaders	Web-based	Yes	No	No	Yes	No	Yes	Yes	Yes																															
Berry	2015	USA	Diabetes group visits - an individualized session to review medications and a medical examination and a group session for diabetes self-management education	Diabetes	HCPs	Community based	Yes	No	No	Yes	No	Unclear	No	Yes																															
Bersani	2017	Italy	group psychoeducation focused on healthy lifestyle - including sleep, physical activity, diet, voluptuary habits	Mood and Psychotic disorders	HCPs	Outpatient clinic	Yes	Yes	No	Yes	Yes	Unclear	No	Yes																															
Bosworth	2008	USA	Tailored behavioural intervention with 9 educational modules	Hypertension	HCPs	Telephone	Yes	No	No	Yes	Yes	Yes	Yes	No																															
Breedland	2011	The Netherlands	FIT program - physical activity combined with an education program	Rheumatoid Arthritis	HCPs	Outpatient clinic	Yes	Yes	No	Yes	No	Unclear	No	Yes																															
Brorsson	2019	Sweden	Guided Self-Determination-Young (GSD-Y) a person-centered communication and reflection education model	Type 1 Diabetes	HCPs	Outpatient clinic	Yes	Yes	No	Yes	Yes	Yes	No	Yes																															

1				that can be used in educational program											
2	Chamany	2015	USA	Telephone support through problem solving and goal setting	Diabetes	HCPs	Telephone	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes
3															
4															
5	Chen	2018	China	Patient-centered self-management empowerment intervention (PCSMEI)	Stroke	HCPs	Inpatient, Outpatient and Telephone	Yes	Yes	No	No	Unclear	No	Yes	
6															
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9	Chew	2018	Malaysia	Value-based emotion-focused educational programme (VEMOFIT)	Type 2 Diabetes	HCPs	Other: Health Clinic	Yes	Yes	Yes	Yes	Yes	No	No	
10															
11															
12	Christiansen	2018	USA	A behaviour change intervention based on social cognitive and control theories of behavior change targeting physical exercise, walking activity, and disease self-management	Dysvascular Amputation (Unilateral TTA)	HCPs	Telephone	Yes	Yes	No	Yes	Yes	No	No	
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19	Cook	2013	USA	Wellness Recovery Action Planning including lectures, individual and group exercises, personal sharing and role modeling, and voluntary homework	Serious Mental Illness	Lay leaders	Community based	Yes	Yes	No	No	Unclear	No	Yes	
20															
21															
22															
23															
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25															
26	Corado	2018	USA	Active, Linkage, Engagement, Retention and Treatment (ALERT) opics included HIV health literacy, Navigating the Health Care System, Disclosure, Adherence, and Self-Efficacy	HIV	HCPs	Outpatient clinic and Community	Yes	No	No	No	Unclear	Yes	No	
27															
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32	Dash	2015	India	Epilepsy health education program designed for those from a low education background.	Epilepsy	HCPs	Outpatient clinic	Yes	Yes	No	Yes	Yes	No	Yes	
33															
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36															
37	Detaille	2013	The Netherlands	CDSMP adapted for workers with chronic disease	A diagnosed chronic somatic disease	Lay leaders	Community based	Yes	Yes	Yes	No	Unclear	No	Yes	
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1	Dinh	2019	Vietnam	Teach-back heart failure self-management intervention individual teach-back before discharge, plus a booklet, a weighing scale, a diary, and a telephone call follow-up at 2 weeks following discharge	Heart failure	HCPs	Outpatient clinic and Telephone	Yes	Yes	No	No	Unclear	No	Yes
2														
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6	Dziedzic	2013	UK	Looking after your joints programme - Self Management in OA of the Hand (1) joint protection; (2) hand exercises; (3) joint protection and hand exercises combined	Hand Osteoarthritis	HCPs	Outpatient clinic	Yes	Yes	Yes	Yes	Yes	Yes	Yes
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13	Ehde	2015	USA	Telephone delivered self-management intervention - cognitive-behavioral and positive psychology strategies for helping participants self-manage pain, depression, and fatigue	Multiple Sclerosis	HCPs	Telephone	Yes	Yes	Yes	Yes	Yes	Yes	No
14														
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20	Fernandez Guijarro	2019	Spain	Health-promotion programme covering healthy eating, lifestyle changes, physical activity, hydration, tobacco and alcohol consumption, stress reduction, and sleep quality and nurse led physical activity.	Serious Mental Illness	HCPs	Community based	Yes	Yes	No	Yes	Unclear	No	Yes
21														
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29	Ferrone	2019	Canada	Integrated disease management - case management, education, and skills training	COPD	HCPs	GP practice and telephone	Yes	No	No	No	No	No	Yes
30														
31														
32														
33	Forjuoh	2014	USA	CDSMP and PDA	Type 2 Diabetes	Lay leaders	Clinic and community	Yes	Yes	Yes	Yes	Yes	No	No
34														
35	Fukuoka	2019	Japan	Disease management program - nurses worked with the subjects and their to achieve individualized clinical target values and goals through education booklets and journal.	Stroke	HCPs	Unclear	Yes	No	No	No	Unclear	No	No
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1	Gallinat	2019	Germany	CBT techniques covering psychoeducation, self-management, supportive monitoring and counselling	Skin Picking	HCPs	Web-based	Yes	No	No	Yes	No	No	No	Yes
2															
3															
4	Geremia	2019	Brazil	Compact, cost-effective, education program (CEPT)	Type 1 Diabetes	HCPs	Community based	Yes	Yes	No	Yes	Yes	Yes	No	Yes
5															
6	Goldberg	2013	USA	CDSMP adapted for psychiatric settings 'Living Well'	Serious Mental Illness with comorbid chronic medical condition	HCPs and Lay leaders	Outpatient clinic and Community	Yes	Yes	No	Yes	No	No	No	Yes
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12	Golshahi	2015	Iran	Hypertension self-management - Group A educated about self-care behaviors through eight sessions, group B and group C educated through four pamphlets or eight SMS.	Hypertension	HCPs	Outpatient clinic and Telephone	Yes	Yes	Yes	Yes	No	Unclear	No	Yes
13															
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19	Grammatopoulou	2016	Greece	Holistic Intervention - recognise facilitators and barriers faced to develop the necessary behaviors and skills to control their disease	Asthma	HCPs	Outpatient clinic and home	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
20															
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24	Groessl	2010	USA	CDSMP adapted for veterans	Chronic Hepatitis C	HCPs and Lay leaders	Outpatient clinic	Yes	Yes	No	Yes	Yes	Yes	No	Yes
25															
26															
27	Grønning	2012	Norway	Arthritis out Patient Educational Program	Polyarthritis	HCPs	Outpatient clinic	Yes	Yes	No	Yes	No	Unclear	No	Yes
28															
29															
30	Harington	2010	UK	Exercise and education scheme through exercise, guest speakers, goal-setting and social session	Stroke	HCPs	Community based	Yes	Yes	Yes	Yes	No	No	Yes	Yes
31															
32															
33															
34	Heutink	2011	The Netherlands	CONECSI (COPing with NEuropathic Spinal cord Injury pain) comprises educational, cognitive, and behavioural elements targeted at coping with CNSCIP	Spinal cord injury	HCPs	Rehabilitation Centre	Yes	Yes	No	Yes	Yes	Yes	No	No
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1	Hewlett	2011	UK	CBT, problem solving and goal setting for fatigue and well-being self-management	Rheumatoid Arthritis	HCPs	Unclear (Face-to-face)	Yes	Yes	No	Yes	Yes	No	Yes
2														
3	Holt	2019	UK	STEPWISE - Each session covered lifestyle changes to help the participants take control of their weight through problem solving	schizophrenia, schizoaffective disorder or first-episode psychosis	HCPs	Community based and telephone	Yes	Yes	Yes	Yes	No	Yes	No
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8	Houlihan	2017	USA	My Care My Call - promote skill development and facilitate motivation using consumer-centered goal-setting and coaching, education, resource referral, and support-network building	Spinal cord injury	Lay leaders	Telephone	Yes	No	No	Yes	Unclear	No	Yes
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15	House	2018	UK	Standardized supported self-management - goal setting, resources and barriers influencing success in reaching goals, and self-monitoring of goal attainment	Type 2 Diabetes with intellectual disability	HCPs	Home	Yes	Yes	Yes	Yes	Yes	Yes	Yes
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21	Jaipakdee	2015	Thailand	Diabetes self-management support (DSMS) with a computer-assisted instruction	Diabetes	HCPs	Community based	No	Yes	No	No	Yes	No	Yes
22														
23														
24	James	2015	Australia	ENRICH: Exercise and Nutrition Routine Improving Cancer Health	Cancer survivors	HCPs	Community based	Yes	Yes	No	Yes	Yes	No	Yes
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28	Jiang	2019	China	Self-efficacy-focused structured education programme provided diabetes-related knowledge and DSM skills based on self-efficacy theory	Type 2 Diabetes	HCPs	Outpatient clinic	Yes	Yes	No	No	Unclear	No	Yes
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33	John	2013	UK	Cognitive Behavioural Education Programme - challenge their way of thinking, changing maladaptive coping skills, cognitions or emotions to lead to more adaptive changes in behaviour	Rheumatoid Arthritis	HCPs	Outpatient clinic	Yes	Yes	No	No	Unclear	No	Yes
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41	Ju	2018	China	Peer support provided with usual education	Diabetes	Lay leaders	Community based	No	No	No	No	Unclear	No	Yes
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1	Kasteleyn	2015	The Netherlands	Three home visits by a diabetes nurse to increase self-efficacy and illness perceptions	Type 2 Diabetes and first acute coronary event	HCPs	Home	Yes	Yes	Yes	Yes	Yes	Yes	No	No
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5	Kessler	2018	France, Germany, Italy, Spain	Adapted Living well with COPD Programme - home monitoring and e-health through telephone/web platform	COPD	HCPs	Home and Telephone and web-based platform	Yes	No	Yes	No	Yes	Yes	Yes	No
6															
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10	Kooijmans	2017	The Netherlands	HABITS intervention - optimizing intentions toward a healthier lifestyle and improving perceived behavioral control	Spinal cord injury	HCPs	Community based and home	Yes	No	No	No	Yes	Yes	Yes	No
11															
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15	Laakkonen	2016	Finland	Self-management group rehabilitation to enhance participants' mastery, self-efficacy, and problem-solving skills and to empower them	Dementia	HCPs	Community based	Yes	Yes	No	No	Unclear	No	No	Yes
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19															
20	Luciano	2011	Spain	Psychoeducation Program included information about symptoms, comorbid conditions, potential causes, psychosocial factors, current treatments, exercise, and barriers to behavior change and training for relaxation, pain relief, and stress reduction	Fibromyalgia	HCPs	GP practice	Yes	Yes	No	Yes	No	No	No	Yes
21															
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29	Ludman	2016	USA	self-management support service – depression self-management training, recovery coaching, and care coordination	Depression	HCPs and Lay leaders	Community based and telephone	Yes	No	Yes	No	No	No	Yes	Yes
30															
31															
32															
33															
34	Manning	2014	UK	Education, Self-Management, and Upper Extremity Exercise Training in People with Rheumatoid Arthritis [EXTRA] program	Rheumatoid Arthritis	HCPs	Outpatient clinic	Yes	Yes	No	No	Yes	No	No	Yes
35															
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39	Mansouri	2019	Iran	Oral and Written Education Program	Heart failure	HCPs	Outpatient clinic	Yes	Yes	No	No	Unclear	No	No	Yes
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1	Markle-Reid	2018	Canada	The program offered up to 3 in-home visits; monthly group wellness sessions; monthly case conferences; and ongoing nurse-led care coordination.	Type 2 Diabetes with 3+ comorbidites	HCPs and Lay leaders	Community based and home	Yes	No	No	No	Unclear	Yes	No
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5	Marsden	2009	Australia	Community Living After Stroke for Survivors and Carers' (CLASSIC) - each session included a 1-hour physical activity followed by a 1-hour education delivered via presentations, group discussions and group activities	Stroke	HCPs	Outpatient clinic	Yes	Yes	No	Yes	Yes	No	No
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14	Mohammadpour	2015	Iran	A supportive educational intervention plus follow up telephone calls with information on functions of cardiovascular system, aetiology, management of MI risk factors, adherence to treatment and dietary regimens	Myocardial Infarction	HCPs	Outpatient clinic and Telephone	Yes	Yes	No	No	Unclear	No	Yes
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23	Muchiri	2016	South Africa	Nutrition Education Programme	Diabetes	HCPs	Community based	Yes	Yes	No	Yes	Yes	No	No
24														
25	Nguyen	2018	Vietnam	CKD booklet and a handout, one face-to-face session and two brief follow-up sessions.	Chronic Kidney Disease	HCPs	Outpatient clinic and Telephone	Yes	Yes	No	No	Unclear	No	Yes
26														
27														
28	Pérez-Escamilla	2015	USA	Culturally tailored diabetes education and counselling treatment group including education, skills, and support in the areas of nutrition, physical activity, blood glucose monitoring, medication adherence, and medical appointments.	Type 2 Diabetes	HCPs	Home	Yes	No	No	No	Unclear	Yes	Yes
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37	Pinxsterhuis	2017	Norway	self-management program for coping with their illness and dealing with healthcare professionals and family, developed through educational presentations, the exchange of experiences,	Chronic fatigue syndrome	HCPs and Lay leaders	Outpatient clinic	Yes	Yes	No	Yes	Yes	No	No
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modelling of self-management skills, guided mastery practice, and informative feedback.

Ridsdale	2018	UK	Self-management education for people with poorly controlled epilepsy (SMILE [UK]), based on MOSES	Epilepsy	HCPs	Community based	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
Rothschild	2014	USA	Mexican American Trial of Community Health Worker (MATCH) knowledge and skills in diabetes self-management, with opportunities to practice goal setting and self-management.	Type 2 Diabetes	HCPs	Home	Yes	Yes	No	No	No	No	No	Yes	Yes
Sajatovic	2018	USA	TargetEd MAnageMent Intervention [TEAM]	Stroke and TIA	HCPs and Lay leaders	Outpatient clinic and Telephone	Yes	Yes	No	No	No	No	Unclear	No	Yes
Salyers	2014	USA	Illness management and recovery - Incorporating psychoeducation, cognitive-behavioral approaches, relapse prevention, social skills training, and coping skills training.	Schizophrenia or schizoaffective disorder	HCPs	Community based	Yes	No	No	No	No	No	No	Yes	No
Smeulders	2010	The Netherlands	CDSMP	Congestive Heart Failure	HCPs and Lay leaders	Outpatient clinic	Yes	Yes	No	No	No	No	Unclear	No	No
Spencer	2011	USA	Racial and Ethnic Approaches to Community Health (REACH) Initiative - setting patient specific goals and supporting their progres	Diabetes	HCPs	Outpatient clinic and Home and Telephone	Yes	Yes	No	No	No	Yes	No	No	Yes
Stuifbergen	2010	USA	The Lifestyle Counts intervention developed from the Wellness for Women with MS curriculum	Fibromyalgia	HCPs	Outpatient clinic and Telephone	Yes	Yes	No	No	No	No	Yes	No	No
Swoboda	2016	USA	Multiple-Goal Intervention - combination of goal setting and decision support coaching	Diabetes	HCPs	Outpatient clinic and Telephone	Yes	No	Yes	No	No	No	No	No	Yes

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1	Taggart	2017	UK	DESMOND-ID (Diabetes and Self-Management for Ongoing and Newly Diagnosed for patients with Type 2 diabetes)	Type 2 Diabetes with intellectual disability	HCPs	Community based	Yes	Yes	No	No	No	Yes	Yes	Yes
2															
3															
4															
5	Thoolen	2009	The Netherlands	Beyond Good Intentions – a 12 week self-management course	Type 2 Diabetes	HCPs	Community based	Yes	Yes	No	No	Unclear	No	Yes	
6															
7															
8	Van der Meer	2009	The Netherlands	Internet based self-management program sthma control monitoring and treatment advice, online and group education, and remote Web communications with a specialized asthma nurse.	Asthma	HCPs	Web-based and Unclear	Yes	Yes	No	No	Unclear	No	Yes	
9															
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14															
15	Van Rooijen	2010	South Africa	Dietary and physical activity education for ongoing nutrition self-management and physical activity	Type 2 Diabetes	HCPs	Outpatient clinic	Yes	No	No	No	Unclear	No	Yes	
16															
17															
18															
19	Vos	2019	The Netherlands	Beyond Good Intentions	Type 2 Diabetes	HCPs	Community based	Yes	Yes	No	No	Unclear	No	No	
20															
21	Walker	2011	USA	Telephonic behavioural intervention focused on medication adherence and lifestyle changes through healthy eating and physical activity	Diabetes	HCPs	Telephone	Yes	No	No	Yes	Unclear	No	Yes	
22															
23															
24															
25															
26															
27	Wang	2016	Singapore	The Myocardial Infarction Home-based Self-management Programme (MIHSMP) with Heart Recovery Education Booklet (HREB)	Myocardial Infarction	HCPs	Outpatient clinic and Telephone	Yes	Yes	No	No	Unclear	No	No	
28															
29															
30															
31															
32															
33	Wang	2018	Singapore	Coronary Heart Disease Self-management Programme (CHDSMP)	Coronary Heart Disease	HCPs	Home and Telephone	Yes	Yes	No	No	Unclear	No	No	
34															
35															
36	Webel	2010	USA	Positive Self-Management Program (PSMP)	HIV	Lay leaders	Community based	Yes	Yes	No	No	Unclear	No	No	
37															
38															
39	Wegener	2009	USA	Promoting Amputee Life Skills Self-management program	Limb loss	HCPs and Lay leaders	Community based	Yes	Yes	Yes	Yes	Yes	No	Yes	
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1	Wolf	2017	USA	CDSMP	Stroke	HCPs	Outpatient clinic	Yes	Yes	Yes	No	Unclear	No	No
2	Wu	2017	Australia and Taiwan	T-CDSMP adapted for Taiwanese speaking	Cardiovascular disease and Diabetes	HCPs	Outpatient clinic and Telephone	Yes	Yes	No	No	Unclear	No	No
3														
4														
5	Wu	2018	Taiwan	Innovative self-management intervention a video, trainee manual, participation in the self-efficacy- enhancing program, and telephone interviews	End Stage Renal Disease	HCPs	Outpatient clinic and Telephone	Yes	Yes	Yes	No	Unclear	No	Yes
6														
7														
8														
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10														
11	Yip	2008	Hong Kong	ASMP with added goal-directed exercise component	Osteoarthritis	HCPs	Outpatient clinic	Yes	Yes	No	No	Unclear	No	Yes
12														
13														
14	Young	2016	China	Psycho-education group understanding dementia, coping skills, exercise, diet, mood, own strengths, accepting change, communication, relationships, the future	Major neurocognitive disorder	HCPs	Community based	Yes	Yes	No	No	Unclear	No	No
15														
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20														
21	Zakrisson	2018	Sweden	Self-management intervention based on Bandura's theory of self-efficacy using techniques such as performance mastery, modelling, interpretation of symptoms, and social persuasion	COPD and Coronary Heart Failure	HCPs	Community based	Yes	Yes	No	Yes	Unclear	Yes	No
22														
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27														
28	Zhang	2015	USA	Stay Dry program biofeedback pelvic floor muscle exercise plus a support group or telephone contact	Prostate cancer with urinary incontinence	HCPs	Telephone and unclear	Yes	Yes	No	No	Unclear	No	Yes
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Supplementary Figure 1. Medline, AMED, PsychINFO and CINAHL Full Search Strategies.

Medline Search Strategy

1. (Long term adj3 condition*).mp.
2. chronic*.mp.
3. ((persistent or long* term or ongoing or degenerative) adj3 (disease* or ill* or condition* or insufficienc* or disorder*)).tw.
4. long term care/
5. long* term care.tw.
6. exp cardiovascular diseases/
7. (heart disease* or heart failure or myocardial ischemia or coronary disease* or coronary artery disease* or myocardial infarction or hypertension or high blood pressure).tw.
8. sickle cell.mp.
9. exp lung diseases obstructive/
10. (obstructive lung disease* or obstructive pulmonary disease* or copd or asthma or bronchitis).tw.
11. exp emphysema/
12. exp pulmonary emphysema/
13. emphysema.tw.
14. (cystic fibrosis or respiratory distress).mp.
15. exp nervous system diseases/
16. (brain adj (disease* or damage* or injur*)).tw.
17. (cerebrovascular or brain ischemia or cerebral infarction or carotid artery disease* or stroke or epilep* or seizure*).tw.
18. (neurodegenerative or Huntingdon* or Parkinson* or amyotrophic lateral sclerosis or multiple sclerosis or motor neuron disease).tw.
19. (paralys* or quadriplegi* or tetraplegi* or paraplegi* or locked in syndrome).tw.
20. ((communication or learning or consciousness or perpetual or speech or voice or vision or hearing or psychomotor) adj disorder*).tw.
21. (hearing loss or hearing aid* or deaf* or blind* or stutter*).tw.
22. down* syndrome.tw.
23. cerebral palsy.tw.
24. exp gastrointestinal diseases/
25. (gatroenter* or intestinal or bowel or colonic).tw.
26. renal insufficiency/
27. ((renal or kidney) adj (failure* or insufficienc*)).tw.
28. diabetes mellitus/
29. (diabetes or diabetic*).tw.
30. exp nutrition disorders/
31. (underweight or malnutrition or malnourished or overweight or obes*).tw.
32. exp arthritis/
33. exp rheumatic diseases/
34. (arthritis or osteoarthritis or rheumati* or fibromyalgia).tw.
35. ((back or neck) adj pain).tw.
36. exp thyroid diseases/
37. thyroid.tw.
38. exp hypersensitivity/
39. (hypersensitivit* or allerg* or intolerance or anaphyla*).mp.
40. exp neoplasms/
41. (cancer* or oncolog* or neoplasm* or carcinom* or tumo?r* or malignan* or leuk?emia).tw.
42. exp hiv infections/

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- 3 43. (hiv infect* or hiv disease*).tw.
- 4 44. exp mental disorders/
- 5 45. exp behavio?ral symptoms/
- 6 46. ((mental* or psychiatr* or psychological*) adj (ill* or disorder* or disease* or distress* or disab* or
- 7 problem* or health* or patient* or treatment)).tw.
- 8 47. ((personality or mood or dysthymic or cognit* or anxiety or stress or eating or adjustment or
- 9 reactive or somatoform or conversion or behavio?r or perception or psycho* or impulse control or
- 10 development* or attention deficit or hyperactivity or conduct or motor skills or movement or tic or
- 11 substance related) adj disorder*).tw.
- 12 48. (psychos#s or psychotic* or paranoi* or schizo* or neuros#s or neurotic* or delusion* or
- 13 depression or depressive or bipolar or mania or manic or obsessi* or compulsi* or panic or phobic or
- 14 phobia or anorexia or bulimia or neurastheni* or dissociative or autis* or Asperger* or Tourette or
- 15 dyslex* or affective or borderline or narcissis* or suicid* or self injur* or self harm or adhd).tw.
- 16 49. (((substance or drug or alcohol) adj abuse) or "substance use" or "illegal drug use" or addict* or
- 17 alcoholism or (problem* adj1 drinking)).tw.
- 18 50. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or
- 19 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37
- 20 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49
- 21 51. self efficacy/ or self care/
- 22 52. self administration/ or self assessment/ or self concept/
- 23 53. patient compliance/ or patient education as topic/ or patient participation/ or patient satisfaction/
- 24 54. consumer health information/ or consumer participation/
- 25 55. attitude to health/ or health behavio?r/ or health education/ or health knowledge, attitudes,
- 26 practice/ or health promotion/
- 27 56. life style/ or disease management/ or risk reduction behavio?r/
- 28 57. adaptation, psychological/ or motivation/ or goals/ or problem solving/ or exp decision making/
- 29 58. health plan implementation/
- 30 59. (self care or selfcare or self management or selfmanagement or self efficacy or selfefficacy or self
- 31 monitor\$ or selfmonitor\$).tw.
- 32 60. ((self or oneself) adj3 care).tw.
- 33 61. ((patient\$ or consumer\$ or client\$) adj5 (educat\$ or participat\$ or behavio?r\$ or behavio?r\$ or
- 34 compliance or centered)).tw.
- 35 62. (health adj5 (promot\$ or educat\$ or behav\$)).tw.
- 36 63. (risk adj3 reduc\$ adj3 behav\$).tw.
- 37 64. ((patient\$ or consumer\$ or client\$) adj5 manag\$ adj5 disease\$).tw.
- 38 65. (((behav\$ adj3 chang\$) or (problem\$ adj3 solv\$) or (goal\$ adj3 setting) or (decision\$ adj3 mak\$)
- 39 or coping) adj5 (patient\$ or consumer\$ or client\$)).tw.
- 40 66. 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65
- 41 67. randomized controlled trial/ or pragmatic clinical trial/
- 42 68. randomi?ed controlled trial.mp.
- 43 69. controlled clinical trial/
- 44 70. randomized controlled trial/
- 45 71. double-blind method/ or random allocation/ or single-blind method/
- 46 72. Clinical Trials as Topic/
- 47 73. placebo.mp.
- 48 74. randomi?ed.mp.
- 49 75. Drug Therapy/
- 50 76. drug therapy.mp.
- 51 77. randomly.mp.
- 52 78. clinical trial/
- 53 79. trial.mp.
- 54 80. groups.mp.
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- 3 81. 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80
- 4 82. exp animals/ not humans.sh.
- 5 83. (#81 not #82).mp.
- 6 84. 50 and 66 and 83
- 7

AMED Search Strategy

- 10 1. (Long term adj3 condition*).mp. [mp=abstract, heading words, title]
- 11 2. chronic*.mp.
- 12 3. ((persistent or long* term or ongoing or degenerative) adj3 (disease* or ill* or condition* or
- 13 insufficienc* or disorder*)).mp. [mp=abstract, heading words, title]
- 14 4. long term care/
- 15 5. long* term care.tw.
- 16 6. Cardiovascular disease/
- 17 7. (heart disease* or heart failure or myocardial ischemia or coronary disease* or coronary artery
- 18 disease* or myocardial infarction or hypertension or high blood pressure).tw.
- 19 8. sickle cell.mp.
- 20 9. lung disease/
- 21 10. (obstructive lung disease* or obstructive pulmonary disease* or copd or asthma or bronchitis).tw.
- 22 11. emphysema/
- 23 12. pulmonary emphysema/
- 24 13. emphysema.tw.
- 25 14. (cystic fibrosis or respiratory distress).mp.
- 26 15. (brain adj (disease* or damage* or injur*)).tw.
- 27 16. (cerebrovascular or brain ischemia or cerebral infarction or carotid artery disease* or stroke or
- 28 epilep* or seizure*).tw.
- 29 17. (neurodegenerative or Huntingdon* or Parkinson* or amyotrophic lateral sclerosis or multiple
- 30 sclerosis or motor neuron disease).tw.
- 31 18. (paralys* or quadriplegi* or tetraplegi* or paraplegi* or locked in syndrome).tw.
- 32 19. ((communication or learning or consciousness or perpetual or speech or voice or vision or hearing
- 33 or psychomotor) adj disorder*).tw.
- 34 20. (hearing loss or deaf* or blind*).tw.
- 35 21. down* syndrome.tw.
- 36 22. cerebral palsy.tw.
- 37 23. exp gastrointestinal disease/
- 38 24. exp nervous system disease/
- 39 25. (gatroenter* or intestinal or bowel or colonic).tw.
- 40 26. ((renal or kidney) adj (failure* or insufficienc*)).tw.
- 41 27. diabetes mellitus/
- 42 28. (diabetes or diabetic*).tw.
- 43 29. exp nutrition disorders/
- 44 30. (underweight or malnutrition or malnourished).tw.
- 45 31. exp arthritis/
- 46 32. exp rheumatic disease/
- 47 33. fibromyalgia.tw.
- 48 34. ((back or neck) adj pain).tw.
- 49 35. exp thyroid disease/
- 50 36. thyroid.tw.
- 51 37. exp hypersensitivity/
- 52 38. (hypersensitivit* or allerg* or intolerance or anaphyla*).mp.
- 53 39. exp neoplasms/
- 54 40. (cancer* or oncolog* or neoplasm* or carcinom* or tumo?r* or malignan* or leuk?emia).tw.
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- 3 41. exp hiv infections/
- 4 42. (hiv infect* or hiv disease*).tw.
- 5 43. exp mental disorders/
- 6 44. ((mental* or psychiatr* or psychological*) adj (ill* or disorder* or disease* or distress* or disab* or
- 7 problem* or health* or patient* or treatment)).tw.
- 8 45. ((personality or mood or dysthymic or cognit* or anxiety or stress or eating or adjustment or
- 9 reactive or somatoform or conversion or behavio?r or perception or psycho* or impulse control or
- 10 development* or attention deficit or hyperactivity or conduct or motor skills or movement or tic or
- 11 substance related) adj disorder*).tw.
- 12 46. (psychos?s or psychotic* or paranoi* or schizo* or neuros?s or neurotic* or delusion* or
- 13 depression or depressive or bipolar or mania or manic or obsessi* or compulsi* or panic or phobic or
- 14 phobia or anorexia or bulimia or neurastheni* or dissociative or autis* or Asperger* or Tourette or
- 15 dyslex* or affective or borderline or narcissis* or suicid* or self injur* or self harm or adhd).tw.
- 16 47. (((substance or drug or alcohol) adj abuse) or "substance use" or "illegal drug use" or addict* or
- 17 alcoholism or (problem* adj1 drinking)).tw.
- 18 48. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or
- 19 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37
- 20 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47
- 21 49. self efficacy/ or self care/
- 22 50. self administration/ or self assessment/ or self concept/
- 23 51. patient compliance/ or patient education/ or patient participation/
- 24 52. attitude to health/ or health behavio?r/ or health education/ or health knowledge, attitudes,
- 25 practice/ or health promotion/
- 26 53. life style/ or disease management/ or risk reduction behavio?r/
- 27 54. adaptation, psychological/ or motivation/ or goals/ or problem solving/ or exp decision making/
- 28 55. (consumer health information or consumer participation).mp. [mp=abstract, heading words, title]
- 29 56. health plan implementation.mp.
- 30 57. (self care or self management or self efficacy or self monitor\$).tw.
- 31 58. ((self or oneself) adj3 care).tw.
- 32 59. ((patient\$ or consumer\$ or client\$) adj5 (educat\$ or participat\$ or behavio?r\$ or behavio?r\$ or
- 33 compliance or centered)).tw.
- 34 60. (health adj5 (promot\$ or educat\$ or behav\$)).tw.
- 35 61. (risk adj3 reduc\$ adj3 behav\$).tw.
- 36 62. ((patient\$ or consumer\$ or client\$) adj5 manag\$ adj5 disease\$).tw.
- 37 63. (((behav\$ adj3 chang\$) or (problem\$ adj3 solv\$) or (goal\$ adj3 setting) or (decision\$ adj3 mak\$)
- 38 or coping) adj5 (patient\$ or consumer\$ or client\$)).tw.
- 39 64. 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63
- 40 65. randomized controlled trial.pt.
- 41 66. controlled clinical trial.pt.
- 42 67. randomized.ab.
- 43 68. placebo.ab.
- 44 69. randomly.ab.
- 45 70. clinical trials.sh.
- 46 71. trial.ti.
- 47 72. 65 or 66 or 67 or 68 or 69 or 70 or 71
- 48 73. exp animals/ not humans.sh.
- 49 74. 72 not 73
- 50 75. 48 and 64 and 74
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- 57 PsychINFO Search Strategy
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1. (Long term adj3 condition*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]
2. chronic*.mp.
3. ((persistent or long* term or ongoing or degenerative) adj3 (disease* or ill* or condition* or insufficienc* or disorder*)).tw.
4. long term care/
5. long* term care.tw.
6. (heart disease* or heart failure or myocardial ischemia or coronary disease* or coronary artery disease* or myocardial infarction or hypertension or high blood pressure).tw.
7. sickle cell.mp.
8. (obstructive lung disease* or obstructive pulmonary disease* or copd or asthma or bronchitis).tw.
9. exp emphysema/
10. exp pulmonary emphysema/
11. emphysema.tw.
12. (cystic fibrosis or respiratory distress).mp.
13. exp nervous system disorders/
14. exp cardiovascular disorders/
15. exp lung disorders/
16. (brain adj (disease* or damage* or injur*)).tw.
17. (cerebrovascular or brain ischemia or cerebral infarction or carotid artery disease* or stroke or epilep* or seizure*).tw.
18. (neurodegenerative or Huntingdon* or Parkinson* or amyotrophic lateral sclerosis or multiple sclerosis or motor neuron disease).tw.
19. (paralys* or quadriplegi* or tetraplegi* or paraplegi* or locked in syndrome).tw.
20. ((communication or learning or consciousness or perpetual or speech or voice or vision or hearing or psychomotor) adj disorder*).tw.
21. (hearing loss or hearing aid* or deaf* or blind* or stutter*).tw.
22. down* syndrome.tw.
23. cerebral palsy.tw.
24. exp gastrointestinal disorders/
25. (gastroenter* or intestinal or bowel or colonic).tw.
26. renal insufficiency/
27. ((renal or kidney) adj (failure* or insufficienc*)).tw.
28. diabetes mellitus/
29. (diabetes or diabetic*).tw.
30. eating disorders/
31. (underweight or malnutrition or malnourished or overweight or obes*).tw.
32. exp arthritis/
33. rheumatoid arthritis/
34. (arthritis or osteoarthritis or rheumati* or fibromyalgia).tw.
35. ((back or neck) adj pain).tw.
36. thyroid disorders/
37. thyroid.tw.
38. exp hypersensitivity/
39. (hypersensitivit* or allerg* or intolerance or anaphyla*).mp.
40. exp neoplasms/
41. (cancer* or oncolog* or neoplasm* or carcinom* or tumo?* or malignan* or leuk?emia).tw.
42. exp AIDS/ or exp HIV/
43. (hiv infect* or hiv disease*).tw.
44. exp mental disorders/
45. exp Behavior Problems/ or behavio?ral symptoms.mp.

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3 46. ((mental* or psychiatr* or psychological*) adj (ill* or disorder* or disease* or distress* or disab* or
4 problem* or health* or patient* or treatment)).tw.
5 47. ((personality or mood or dysthymic or cognit* or anxiety or stress or eating or adjustment or
6 reactive or somatoform or conversion or behavior?r or perception or psycho* or impulse control or
7 development* or attention deficit or hyperactivity or conduct or motor skills or movement or tic or
8 substance related) adj disorder*).tw.
9 48. (psychos#s or psychotic* or paranoi* or schizo* or neuros#s or neurotic* or delusion* or
10 depression or depressive or bipolar or mania or manic or obsessi* or compulsi* or panic or phobic or
11 phobia or anorexia or bulimia or neurastheni* or dissociative or autis* or Asperger* or Tourette or
12 dyslex* or affective or borderline or narcissis* or suicid* or self injur* or self harm or adhd).tw.
13 49. (((substance or drug or alcohol) adj abuse) or "substance use" or "illegal drug use" or addict* or
14 alcoholism or (problem* adj1 drinking)).tw.
15 50. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or
16 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37
17 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49
18 51. self efficacy/ or self care/
19 52. self administration/ or self assessment/ or self concept/
20 53. patient compliance/ or patient education as topic/ or patient participation/ or patient satisfaction.
21 54. consumer health information/ or consumer participation/
22 55. attitude to health/ or health behavior?r/ or health education/ or health knowledge, attitudes,
23 practice/ or health promotion/
24 56. life style/ or disease management/ or risk reduction behavior?r/
25 57. adaptation, psychological/ or motivation/ or goals/ or problem solving/ or exp decision making/
26 58. health plan implementation/
27 59. (self care or selfcare or self management or selfmanagement or self efficacy or selfefficacy or self
28 monitor\$ or selfmonitor\$).tw.
29 60. ((self or oneself) adj3 care).tw.
30 61. ((patient\$ or consumer\$ or client\$) adj5 (educat\$ or participat\$ or behavior?r\$ or behavior?r\$ or
31 compliance or centered)).tw.
32 62. (health adj5 (promot\$ or educat\$ or behav\$)).tw.
33 63. (risk adj3 reduc\$ adj3 behav\$).tw.
34 64. ((patient\$ or consumer\$ or client\$) adj5 manag\$ adj5 disease\$).tw.
35 65. (((behav\$ adj3 chang\$) or (problem\$ adj3 solv\$) or (goal\$ adj3 setting) or (decision\$ adj3 mak\$)
36 or coping) adj5 (patient\$ or consumer\$ or client\$)).tw.
37 66. 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65
38 67. exp Randomized Controlled Trials/
39 68. exp Clinical Trials/
40 69. exp Randomized Controlled Trials/ or exp Randomized Clinical Trials/
41 70. exp Placebo/
42 71. exp Drug Therapy/
43 72. randomly.mp.
44 73. trial.mp.
45 74. groups.mp.
46 75. 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74
47 76. exp animals/ not humans.sh.
48 77. (#75 not #76).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title,
49 tests & measures, mesh]
50 78. 50 and 66 and 77
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CINAHL Search Strategy

S1. long term condition

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- 2
- 3 S2. chronic
- 4 S3. ((persistent or long term or ongoing or degenerative) (disease or ill* or condition or insufficienc* or
- 5 disorder))
- 6 S4. long term care
- 7 S5. cardiovascular diseases
- 8 S6. (heart disease or heart failure or myocardial ischemia or coronary disease or coronary artery
- 9 disease or myocardial infarction or hypertension or high blood pressure)
- 10 S7. sickle cell
- 11 S8. lung diseases, obstructive
- 12 S9. (obstructive lung disease or obstructive pulmonary disease or copd or asthma or bronchitis)
- 13 S10. down* syndrome
- 14 S11. cerebral palsy
- 15 S12. emphysema
- 16 S13. gastrointestinal disorders
- 17 S14. renal insufficiency
- 18 S15. ((renal or kidney) failure)
- 19 S16. diabetes mellitus
- 20 S17. nutrition disorders
- 21 S18. arthritis
- 22 S19. rheumatic diseases
- 23 S20. fibromyalgia
- 24 S21. (cystic fibrosis or respiratory distress)
- 25 S22. thyroid disease
- 26 S23. (hypersensitivity or allergy or anaphylaxis)
- 27 S24. (cancer* or oncolog* or neoplasm* or tumo?r*)
- 28 S25. (hiv infection or hiv disease or hiv)
- 29 S26. mental disorders
- 30 S27. ((mental or psychiatric or psychological) (ill* or disorder or disease or distress or disability))
- 31 S28. ((personality or dysthymic or anxiety or stress or eating or reactive or behavio?r or perception or
- 32 impulse control or developmental or attention deficit or hyperactivity or conduct or motor skills or
- 33 movement or tic) disorder
- 34 S29. (psychosis or schizophrenia or neurosis or depression or bipolar or mania or obsessive or
- 35 compulsive or panic or phobia or anorexia or bulimia or dissociative or autism or Asperger's or
- 36 Tourette or affective or borderline or suicide or self injury or self harm or adhd)
- 37 S30. ((substance or drug or alcohol) abuse or addiction) or alcoholism
- 38 S31. self efficacy or self care
- 39 S32. nervous system diseases
- 40 S33. self administration or self assessment or self concept
- 41 S34. patient compliance or patient education or patient participation
- 42 S35. consumer health information or consumer participation
- 43 S36. attitude to health or health behavio?r or health education or health promotion
- 44 S37. disease management or risk reduction behavio?r
- 45 S38. health plan implementation
- 46 S39. self care or self management or self efficacy
- 47 S40. ((patient or consumer or health) (education or participation or behavio?r or compliance or
- 48 disease management))
- 49 S41. (((behavio?r change) or (problem solving) or (goal setting) or (decision making) or coping or
- 50 motivation) (patient or consumer))
- 51 S42. (brain (disease or damage or injury))
- 52 S43. MH randomized controlled trials
- 53 S44. MH double-blind studies
- 54 S45. MH single-blind studies
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3 S46. MH random assignment
4 S47. MH pretest-posttest design
5 S48. MH cluster sample
6 S49. TI (randomised OR randomized)
7 S50. AB (random*)
8 S51. TI (trial)
9
10 S52. MH (sample size) AND AB (assigned OR allocated OR control)
11 S53. (cerebrovascular or brain ischemia or cerebral infarction or carotid artery disease or stroke or
12 epilepsy or seizure)
13 S54. MH (placebos)
14 S55. PT (randomized controlled trial)
15 S56. AB (CONTROL W5 GROUP)
16 S57. MH (CROSSOVER DESIGN) OR MH (COMPARATIVE STUDIES)
17 S58. AB (CLUSTER W3 RCT)
18 S59. S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S54 OR
19 S55 OR S56 OR S57 OR S58
20 S60. MH ANIMALS+
21 S61. MH (ANIMAL STUDIES)
22 S62. TI (ANIMAL MODEL*)
23 S63. S60 OR S61 OR S62
24 S64. (neurodegenerative or Huntingdon's or Parkinson's or amyotrophic lateral sclerosis or multiple
25 sclerosis or motor neuron disease)
26 S65. MH (HUMAN)
27 S66. S63 NOT S65
28 S67. S59 NOT S66
29 S68. ((communication or learning or speech or vision or hearing or psychomotor) disorder)
30 S69. (deaf or blind)
31 S70. S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13
32 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR
33 S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S32 OR S42 OR S53 OR S64 OR S68 OR S69
34 S71. S31 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41
35 S72. S67 AND S70 AND S71
36 S73. S67 AND S70 AND S71
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Supplementary Figure 2. Reference list for the 82 eligible articles included in this systematic review.

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BMJ Open

Reporting dose in complex self-management support interventions for long-term conditions: is it defined by researchers and received by participants? - a systematic review

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3 **Reporting dose in complex self-management support**
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6 **interventions for long-term conditions: is it defined by**
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9 **researchers and received by participants? - a systematic**
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11 **review**
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15 Tasmin A Rookes, Neurology Department (U3), Royal Free Hospital, Rowland Hill
16 Street, London, NW3 2PF, t.rookes@ucl.ac.uk, 07896878267, University College
17
18 London, Institute of Neurology, London, UK. (Corresponding Author).
19
20
21
22

23
24 Atena Barat, Yvonne Carter Building, 58 Turner Street, London, E1 2AB,
25
26 a.barat@qmul.ac.uk, Queen Mary University of London, Wolfson Institute of
27
28 Population Health, London, UK
29
30
31

32
33
34 Rebecca M Turner, 90 High Holborn, London, WC1V 6LJ, becky.turner@ucl.ac.uk,
35
36 University College London, Institute of Clinical Trials and Methodology, London, UK
37
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39

40
41 Steph JC Taylor, Yvonne Carter Building, 58 Turner Street, London, E1 2AB,
42
43 s.j.c.taylor@qmul.ac.uk, Queen Mary University of London, Wolfson Institute of
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45 Population Health, London, UK
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Abstract:

Background: The minimum clinically effective dose, and whether this is received in randomised controlled trials (RCTs) of complex self-management interventions in Long-Term Conditions (LTCs), can be unclear. The Template for Intervention Description and Replication (TIDieR) checklist states that dose should be clearly reported to ensure validity and reliable implementation.

Objectives: To identify whether the expected minimum clinically effective dose, and the dose participants received is reported within research articles and if reporting has improved since the TIDieR checklist was published.

Methods: Four databases were systematically searched (MEDLINE, PsycINFO, AMED and CINAHL) to identify published reports between 2008 and 2020 for RCTs investigating complex self-management interventions in LTCs. Data on reporting of dose was extracted and synthesised from the eligible articles.

Results: 82 articles covering various LTCs including diabetes, stroke and arthritis were included. Most complex interventions involved behaviour change combined with education and/or exercise. The maximum dose was usually reported (n=80; 97.6%), but the expected minimum clinically effective dose and the dose received were reported in only 19 (23.2%) and 52 (62.2%) of articles, respectively. Reporting of the expected minimum clinically effective dose and the dose participants received did not improve following the publication of the TIDieR checklist in 2014.

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3 **Conclusions:** Interpreting results and implementing effective complex self-
4 management interventions is difficult when researchers' reporting of dose is not in
5 line with guidelines. If trial findings indicate benefit from the intervention, clear
6 reporting of dose ensures reliable implementation to standard care. If the results are
7 non-significant, detailed reporting enables better interpretation of results i.e.,
8 differentiating between poor implementation and lack of effectiveness. This ensures
9 quality of interventions and validity and generalisability of trial findings. Therefore,
10 wider adoption of reporting the TIDieR checklist dose aspects is strongly
11 recommended. Alternatively, customised guidelines for reporting dose in complex
12 self-management interventions could be developed.
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28 **Registration:** Prospero ID CRD42020180988

29 **Keywords:** dose; reporting; complex self-management intervention; long-term
30 condition; systematic review; TIDieR checklist; fidelity
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38 **Strengths and limitations of this study:**

- 39 • This is the first systematic review to explore whether dose is being reported
40 as the guidelines recommend in randomised trials of self-management
41 interventions.
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- 43 • Double screening and data extraction was completed, following piloting,
44 ensuring all eligible papers were included and accurate data extracted.
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- 46 • Determining complex self-management study eligibility was challenging, but
47 we developed a systematic approach to limit potential bias.
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- 49 • Quality assessment of eligible papers was not conducted, but it could have
50 been interesting to see if quality of study correlated with quality of reporting.
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Background:

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6 It is estimated that 30% of the UK population live with a Long-Term Condition (LTC)
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8 and that LTCs account for 70% of health and social care spending within the NHS
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10 (1). This prevalence extends globally, where LTCs are the leading cause of ill health
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12 and result in 70 percent of all deaths (2), with a growing awareness of the
13
14 importance of monitoring prevalence and developing interventions to overcome
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16 LTCs, due to the aging population, predicted increase in LTCs and the associated
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18 costs (3, 4). Therefore, the management of LTCs is a priority for the NHS. LTCs are
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20 defined as “diseases of long duration and are the result of a combination of genetic,
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22 physiological, environmental and behavioural factors” (5). The current evidence base
23
24 suggests LTC treatment should focus on supporting effective self-management to
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26 result in better health outcomes (6). Self-management here is defined in conjunction
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28 with the US Institute of Medicine definition, echoed by the Department of Health;
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30 “Self-management is defined as the tasks that individuals must undertake to live with
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32 one or more chronic conditions. These tasks include having the confidence to deal
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34 with medical management, role management and emotional management of their
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36 conditions.” (7, 8).
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45 Complex self-management interventions are known to improve a variety of health
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47 outcomes in LTCs, including self-efficacy (confidence in ability to execute specific
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49 behaviours), patient activation (confidence, skills and knowledge to manage their
50
51 own health care), self-rated health, clinical outcomes and social outcomes (9).
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54 Complex self-management interventions contain several interacting components that
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56 aim to change patients' behaviour. However, determining which parts of the complex
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58 intervention are necessary to result in a potential benefit can be difficult. Therefore,
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3 complex self-management interventions should go through stages of development
4 before being evaluated, typically in randomised control trials (RCTs), to identify how
5 much of which components result in the best outcomes (10). Once decided upon, at
6 least the expected minimum clinically effective dose of the complex self-
7 management intervention should be compared to standard care for the LTC to see if
8 health outcomes improve. However, in published reports of RCTs it is often unclear
9 how the minimum clinically effective dose of the intervention was determined or,
10 indeed, what the researchers believe the expected minimally clinically effective dose
11 to be.
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26 The concept of dose refers to the number of intended units of each intervention
27 (dose delivered) and the extent of engagement of participants with the intervention
28 (dose received) (11). Treatment fidelity refers to the extent to which the intervention
29 is delivered as expected, how much of the intervention is received and the amount of
30 treatment enactment of the intervention by participants. Focussing on fidelity of
31 treatment receipt, if the number and length of sessions received is in line with that
32 stated in the protocol, it is essential researchers determine what they think the
33 minimum clinically effective dose is and measure if it is received by participants
34 within the trial, so fidelity of treatment receipt can be assessed (12, 13). This is
35 determined through discussions between those involved in the development of the
36 intervention, to decide what they expect the minimum number of sessions attended
37 are needed to result in a meaningful change. There are two possible explanations for
38 why this information is not reported, either researchers are not having these
39 conversations during intervention development, or they are not reporting what this
40 should be in their methods and papers. Collecting and reporting this information
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3 ensures the quality and integrity of the intervention and enables assessment of how
4 valid and generalisable the findings are (11). Additionally, not stating the expected
5 minimum clinically effective dose and if it has been delivered and received makes it
6 difficult to interpret RCT results. If trial results are non-significant and fidelity of
7 treatment receipt is not reported, it is unclear if this result is due to a lack of
8 effectiveness or failed implementation of the intervention. Ensuring non-significant
9 effects are due to lack of intervention effectiveness helps to avoid a type ii error,
10 whereby the treatment is deemed not effective when the findings are due to
11 confounding variables, such as poor implementation (14).
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26 To improve the reporting of all types of interventions the Template for Intervention
27 Description and Replication (TIDieR) checklist (15) was developed in 2014. The 12
28 items explain how interventions should be described in published articles, so that
29 trials with effective interventions can be replicated validly and implemented into
30 standard practice reliably. The intervention details required for non-pharmacological
31 interventions, such as the behavioural and educational components used in complex
32 self-management interventions, are explained. Focusing on dose, Item 8 of the
33 checklist highlights 'when and how much', whereby RCT articles should clearly state
34 the number of sessions in the intervention, their duration and over what time period
35 they are delivered. Also, Items 11 and 12 of the checklist state that the planned,
36 delivered and received doses should be included to ensure both adherence and
37 fidelity can be assessed (outlined in Table 1). No previous, published reviews within
38 the LTC complex self-management literature have reviewed whether dose and
39 fidelity are being reported in this way.
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58 Table 1. Extract from the TIDieR checklist of the relevant item descriptions for this
59 review.
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TIDieR Checklist Item	Description
Item 8	When and how much: Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose
Item 11	How well (planned): If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them
Item 12	How well (actual): If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned

This systematic review aimed to identify how complex self-management intervention doses for patients with LTCs are reported in RCTs. We assessed this by evaluating whether what the researchers believe to be the minimum clinically effective dose was stated, how this dose was determined, if the dose received by study participants was stated and how it compared to the expected minimum clinically effective dose (fidelity of treatment receipt). We also aimed to determine if reporting of expected minimum clinically effective dose and treatment dose received improved following the publication of the TIDieR checklist in 2014. Finally, we aimed to identify whether reporting of expected minimum clinically effective dose and treatment dose received differed depending on whether the primary outcome results were statistically significant or not. We hypothesised that reporting of dose would have improved since the publication of the TIDieR checklist and that studies with non-significant primary outcomes may report dose more clearly than studies with a significant outcome in an attempt to explain their results.

Methodology:

Search strategy for systematic review and inclusion and exclusion criteria

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3 The systematic review was conducted in accordance with PRISMA (16)
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5 (Supplementary Table 1). MEDLINE, CINAHL, AMED and PsychInfo were
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7 systematically searched. The full search strategies were developed in consultation
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9 with the UCL Library team and can be found in Supplementary Figure 1. Publications
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11 were included if published between January 2008 and June 2020, to identify if there
12
13 was a trend towards improved reporting of treatment dose from 6 years before to 6
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15 years after the TIDieR checklist was published (2014). An update of the review was
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17 conducted, searching the literature between June 2020 and January 2022. The
18
19 same methodological process was followed.
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26 ***Inclusion criteria (PICOS)***

- 27 • Population: populations with long-term conditions (5)
- 28 • Intervention: complex self-management support with structured session(s)
29 (containing several interacting components that aim to change patients'
30 behaviour), delivered to patients (7, 8)
- 31 • Comparator: any
- 32 • Outcome: any
- 33 • Study Design: randomised controlled trials

34 ***Exclusion criteria***

- 35 • Does not include human participants
- 36 • Not a complex self-management support intervention with structured sessions
37 e.g., exercise or psychotherapy only interventions
- 38 • Interventions delivered to carers, health care professionals etc.
- 39 • Only published as an abstract
- 40 • Ongoing studies

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5 The articles from the database searches were exported into EndNote, duplicates
6 removed, and brief screening completed (e.g., removing systematic reviews). Those
7 remaining were uploaded into Abstrackr (<http://abstrackr.cebm.brown.edu/>) and the
8 two reviewers (TR and AB) independently screened titles and abstracts against the
9 inclusion criteria, classifying articles as included, excluded and maybe eligible. For
10 the update, Rayyan was used instead of Abstrackr, as the software was more user
11 friendly. Forward and backward citation screening was performed on eligible papers.
12 Identified discrepancies were discussed with ST to reach a final decision for full text
13 data extraction.
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28 **Data extraction and analysis**

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30 Data was independently extracted by TR and AB onto a Word based proforma
31 designed for the study and any disagreements discussed until consensus was
32 reached.
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40 For all studies we extracted trial authors, country, year of publication, intervention
41 name, intervention description and components, LTC disease area, maximum
42 intervention dose that could be delivered in the context of their study, expected
43 minimum clinically effective dose, any rationale given for this, actual dose received,
44 fidelity of treatment receipt and intervention delivery, and statistical significance of
45 the primary outcome.
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56 Within the articles, reporting of dose was determined by the number and length of
57 sessions available to participants and how many they attended. Minimum expected
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3 clinically effective dose was either explicitly stated or stated as the number of
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5 sessions needed to be attended to be considered a 'completer' or to be included in
6
7 the per protocol analysis. If no detail was provided, then this was recorded as 'not
8
9 reported'. An example of the data extraction process can be seen in Supplementary
10
11 Table 2. Due to the subjective interpretation of some data points, we piloted this
12
13 process to ensure accurate and consistent interpretation. The Items included from
14
15 the TIDieR checklist are outlined in Table 1.
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21 As this was a review of trial reporting, rather than of trial findings, a formal quality
22
23 assessment was not undertaken. Simple summary statistics were used to report the
24
25 percentage of trials reporting the various aspects of dose.
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28 No patients were involved in research project.
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33 **Results**

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35 In the original search, after database searching and deduplication, 14661 titles and
36
37 abstracts were screened for data extraction and 124 full-text articles screened for
38
39 eligibility, of which 82 were included in the synthesis. For the update 2311 titles and
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41 abstracts were screened, 35 were full-text screened, with 12 papers included. See
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43 Figure 1 PRISMA flow diagram.
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49 **Characteristics of included RCTs**

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51 The population and intervention characteristics varied among the RCTs included.
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53 With 27 different LTCs investigated across the 94 articles, including diabetes, cancer
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55 survivors, COPD, dementia, arthritis, stroke, serious mental illness and HIV. The
56
57 complex self-management interventions investigated included Chronic Disease Self-
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3 Management Program (CDSMP (17)), Arthritis Self-Management Program (ASMP
4 (18)), health education programs (19-21), health education combined with exercise
5 programs (22-24), Cognitive Behavioural Approaches (25, 26), and problem-solving
6 and goal setting (27-29). The number of sessions for the intervention ranged from 2
7 to over 30. A summary of the LTCs, self-management interventions and number of
8 sessions are presented in Tables 2, 3 and 4, respectively. Further details of all
9 included articles are supplied in Supplementary Table 3, with the full reference list of
10 included trials in Supplementary Figure 2.
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22 Table 2. LTCs investigated in the 94 articles included in the systematic review.
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24 Long Term Conditions Investigated	25 Number of Trials (%)
26 Type 1 and/or 2 Diabetes	25 (27%)
27 Fibromyalgia	2 (2%)
28 Epilepsy	2 (2%)
29 Chronic Hepatitis C	1 (1%)
30 Cancer Survivorship	4 (4%)
31 Dementia/Neurocognitive disorder	2 (2%)
32 Hypertension	3 (3%)
33 Arthritis	11 (11%)
34 HIV	2 (2%)
35 Spinal Cord Injury	3 (3%)
36 COPD	4 (4%)
37 Amputation	2 (2%)
38 Stroke	8 (9%)
39 Multiple Sclerosis	1 (1%)
40 Psychosis	3 (3%)
41 Serious Mental Illness	3 (3%)
42 Heart Failure	3 (3%)
43 Asthma	2 (2%)
44 Myocardial Infarction	2 (2%)
45 Generic Chronic Somatic Disease	1 (1%)
46 Depression	1 (1%)
47 Chronic Kidney Disease	2 (2%)
48 Chronic Fatigue Syndrome	1 (1%)
49 Coronary Heart Disease	1 (1%)
50 Skin Picking	1 (1%)
51 Chronic Pain	2 (2%)
52 Multimorbidity	2 (2%)
53 Total	54 94 (100%)

Table 3. Complex self-management interventions in the 94 trials included in the systematic review.

Complex Self-Management Intervention	Number of Trials (%)
Chronic Disease Self-Management Program	9 (10%)
Health Education	32 (35%)
Health Education Combined with Exercise	14 (15%)
Cognitive and Behaviour Change Approach	10 (11%)
Problem Solving and Goal Setting	16 (17%)
Arthritis Self-Management Program	3 (3%)
Other	10 (11%)
Total	94 (100%)

Table 4. Number of sessions delivered in the 94 trials included in the systematic review.

Number of Sessions	Number of Trials (%)
1	0
2-6	44 (48%)
7-12	34 (37%)
>12	15 (16%)
Unclear	1 (1%)
Total	94 (100%)

Reporting of Dose

Of the 94 trials included, 90 (97.8%) reported the maximum number of sessions that could be delivered, 72 (78.3%) reported the length of these sessions and 28 (30.4%) reported the expected minimum clinically effective dose. Of the 28 reporting the expected minimum clinically effective dose, 12 (42.9%) justified how this had been determined. In addition, 62 (67.4%) reported what dose participants received and 48 (52.2%) discussed if this was equal to, or greater than, that scheduled to be delivered in the protocol (fidelity of treatment receipt). It was unclear in 44 articles (47.8%) whether the expected minimum clinically effective dose had been received by participants, as no detail was provided. Of the 48 studies where this information was present, in 36 (75.0%) participants received the expected minimum clinically effective dose, which for 11 of these (22.9%) was also the maximum dose available.

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No improvement in reporting of dose since the publication of the TIDieR checklist was observed. Of the 31 articles published between 2008 and 2014 and the 63 published between 2015 and 2022, 6 (19.4%) and 22 (34.9%), respectively, reported the expected minimum clinically effective dose. Of the 31 articles published between 2008 and 2014 and the 63 published between 2015 and 2022, 22 (71.0%) and 40 (63.5%), respectively, reported the number of sessions received and 15 (48.4%) and 28 (44.4%), respectively, reported the length of sessions received. The percentage of trials reporting the expected minimum clinically effective dose, as number of sessions, and the treatment dose participants received per year are represented in Figure 2.

Reporting of the expected minimum clinically effective dose, or the dose received did improve based on the statistical significance of the trial's primary outcome. Of the 55 articles with a significant primary outcome result and the 39 with a non-significant primary outcome result, 12 (21.8%) and 16 (41.0%), respectively, reported the expected minimum clinically effective dose. Of the 55 articles with a significant primary outcome result and the 39 with a non-significant primary outcome result, 31 (56.4%) and 31 (79.5%), respectively, reported the dose received.

Discussion

The included trials covered a variety of LTCs and self-management interventions. As expected, almost all the trials included in this systematic review reported the maximum number of sessions and just over three quarters reported the length of sessions of the complex self-management intervention. Less than a third reported

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3 the expected minimum clinically effective dose and, when this was reported, less
4 than half explained how this had been determined. Just over two thirds reported the
5 number of sessions dose and under half reported length of sessions dose
6 participants received and within these even fewer discussed whether there was
7 fidelity of treatment receipt, i.e., if the dose received was equal to or greater than that
8 specified in the protocol. Improvements in the reporting of the expected minimum
9 clinically effective dose or the dose received were not seen after the TIDieR checklist
10 was published in 2014. However, there was an improvement in the reporting of these
11 doses depending on whether the primary outcome was statistically significant or not,
12 with those with non-significant results reporting the expected minimum clinically
13 effective dose and dose received more often than those with statistically significant
14 differences.

33 **Results in Context**

35 In RCTs of complex self-management interventions in patients with LTCs it is often
36 difficult for the maximum dose to be received by all participants, due to the
37 complexity of both the participants' disease and the intervention itself. However, the
38 number of sessions attended and amount of contact with the intervention leader(s) is
39 often associated with improved patient outcomes (20, 30). It is well documented that
40 receiving 4 of the 6 sessions available in CDSMP results in a beneficial clinical effect
41 (31). Of the 8 papers investigating CDSMP in this review, 4 papers discussed this
42 minimum clinically effective dose and only 2 stated it (32, 33). If no minimum
43 clinically effective dose is stated, interpreting whether the dose participants received
44 was greater than, or equal to, the minimum dose needed to see an improvement
45 (fidelity of treatment receipt) is almost impossible, unless all participants receive the

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3 maximum dose available, which is uncommon (14). If the minimum clinically effective
4 dose is stated and received by participants, then a negative result might be
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6 interpreted as an ineffective intervention. If the dose is not received then a negative
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8 result could be due to poor implementation of the intervention, rather than a lack of
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10 effectiveness. Therefore, by not reporting the dose received, potentially effective
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12 interventions could be abandoned, due to the results not being able to be interpreted
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14 in relation to the dose received, resulting in a type ii error (14, 34).
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22 If the dose received is stated and is low, further investigation can be done by trial
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24 authors or other researchers to determine how it relates to patient outcomes i.e., due
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26 to poor trial and/or intervention design. Collecting this information and reporting it
27
28 enables those implementing the intervention to know what and how much needs to
29
30 be received to ensure the best outcomes. In the Ackerman et al. trial (35), 27% of
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32 those approached to participate declined, as they could not attend all 6 ASMP
33
34 sessions, and of those who were recruited many did not attend. Adaptations were
35
36 made to avoid this, such as booking venues close to participants' homes and
37
38 scheduling on varying days and times. As the authors provided this detail, future
39
40 researchers are aware of these potential challenges and, in their trials, could adapt
41
42 the intervention to be delivered another way i.e., home-based, via telephone or web-
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44 based to make it more accessible and improve recruitment and retention. Also, if
45
46 policymakers have this information when designing guidelines and making
47
48 recommendations for scaling up interventions into standard care, effects seen in
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50 trials are more likely to be translated into routine care (36-38).
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3 In addition, researchers must take the time within the early developmental phases of
4 an intervention to ensure the expected minimum clinically effective dose is estimated
5 as accurately as possible, through pilot studies, systematic reviews and/or
6 longitudinal research (10). Although difficult, this focus on early development would
7 prevent fully funded RCTs going ahead when the minimum clinically effective dose
8 has not been determined or measured.
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19 Even when fidelity is mentioned within trial papers, the focus is often on how it was
20 assessed rather than the actual findings, limiting the use of fidelity data to interpret
21 the trial findings, and making the fidelity assessment almost useless (39-41).
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26 Understanding the reasons why fidelity is poorly reported is complex, but it is thought
27 to be attributed to lack of knowledge and the practicalities of comprehensively
28 assessing fidelity within an RCT (42). Despite the extra resources needed to conduct
29 a full assessment of fidelity, the economic and scientific costs of not completing and
30 reporting fidelity outcomes are far greater (14). Variations in intervention delivery
31 within trials may influence efficacy and result in biased conclusions.
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42 Although the TIDieR checklist was designed to improve reporting of interventions, no
43 improvement in the reporting of the expected minimal clinically effective dose and
44 dose received was found in this review. Also, within the articles, there was little to no
45 mention of the TIDieR checklist and reporting of interventions in accordance with it,
46 in line with other systematic reviews. Investigating implementation in the
47 cardiovascular medicine literature, Palmer et al. (2020) (43) found over one fifth
48 failed to report the dose of the treatment received (Item 11). Within behaviour
49 change research similar results to this review have been found (44), with the
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3 maximum dose available always reported, but other elements of dose poorly
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5 described.
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10 An improvement in reporting of dose was seen in studies reporting non-significant
11 results. It is possible that, due to publication bias, reporting standards of studies that
12 are published with non-significant results are of higher quality than studies with
13 significant results.
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21 An alternate explanation is that researchers may be less familiar with the TIDieR
22 checklist, due to the dissemination being less extensive than other reporting
23 guidelines e.g., CONSORT and PRISMA (43). Therefore, broader dissemination of
24 the TIDieR checklist or incorporating the checklist within Item 5 of the CONSORT
25 statement, could improve reporting, as the information would be required by journals
26 for publication (43). Poor implementation of the TIDieR checklist could also be due to
27 the guidelines being too broad and generic and difficult for authors to adapt to their
28 own interventions (45). Making the TIDieR checklist clearer and developing
29 customised versions for specific intervention types could increase implementation of
30 the checklist guidelines and ultimately improve intervention description and reporting
31 (46).
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49 **Limitations**

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51 The subjective nature of determining the eligibility of trials based on whether the
52 intervention was a complex self-management intervention, could have introduced
53 bias. All those marked potentially eligible were discussed by the study team to limit
54 any potential bias and if there were any doubts the paper was included for data
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3 extraction. If consensus on eligibility could not be met, the paper was sent to a third
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5 reviewer (ST), with extensive experience in self-management support interventions
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7 for a final decision. Through these discussions decisions around eligibility for
8
9 inclusion were as consistent as possible given the flexible and varied definition of
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11 complex self-management interventions within the literature.
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17 Also, a formal quality assessment was not completed, as we were not looking at the
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19 outcome measures. It could be of interest to compare the quality of study with the
20
21 accuracy of dose reporting, but this was not within the scope and capacity of this
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23 review.
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28 **Future Research**

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30 Following this review, reporting standards of complex self-management intervention
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32 doses do not appear to have improved since the publication of the TIDieR checklist.
33
34 Ensuring that guidelines provide recommendations for how to define and assess
35
36 dose within complex self-management interventions is vital for accurate reporting
37
38 and so, interpretation and implementation of trial results. Therefore, either the
39
40 TIDieR checklist should be updated or novel, specialised methodological guidelines
41
42 developed to ensure that dose in these trials is determined, measured and reported
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44 as accurately as possible. Additionally, looking at whether quality of study correlates
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46 to quality of reporting dose could be completed.
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54 **Conclusion**

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56 Reporting of the minimum clinically effective dose, the dose received in the trial and
57
58 the fidelity of treatment receipt are not consistent in studies of complex self-
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3 management interventions for LTCs. Although this detail is outlined in the TIDieR
4 checklist, published in 2014, there has been no improvement in reporting following
5 its publication. Currently we recommend that when publishing RCTs, researchers
6 should describe the intervention dose according to the TIDieR checklist. This will
7 enable clinicians and policymakers to reliably replicate the interventions in future
8 trials and/or interpret findings to implement them into practice. Going forward, the
9 TIDieR checklist could be made clearer with versions for specific intervention types
10 and wider dissemination of the checklist to increase implementation of the guidelines
11 and improve intervention reporting. To facilitate this, funders, reviewers and journal
12 editors should encourage dose and fidelity of treatment receipt to be collected and
13 discussed, to increase reporting in this way.
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31 **Abbreviations**

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33 RCT: Randomised controlled trial; LTC: Long-term condition; TIDieR: Template for
34 intervention description and replication; CDSMP: Chronic disease self-management
35 program; ASMP: Arthritis self-management program
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3 necessarily those of the NIHR, NHS or the UK Department of Health and Social
4
5 Care.

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16
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18
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20 21 **Ethical Approval Statement**

22
23 Not applicable

24 25 **Competing interests**

26
27 The authors declare that they have no competing interests

28 29 **Data sharing**

30
31 The datasets used and/or analysed during the current study are available from the
32
33 corresponding author on reasonable request.

34 35 **Author contributions**

36
37 TR, supervised by ST and RT, designed the review and conducted the searches,
38
39 data extraction, and analysis. TR and AB undertook double screening and data
40
41 extraction. The authors read and approved the final manuscript.

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46
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48
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50 51 **Figure legends**

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53 Figure 1. PRISMA Systematic Review Flow Diagram

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3 Figure 2. Bar graph illustrating the percentage of trials reporting the expected
4 minimum clinically effective dose and the treatment dose received by year.
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34 Lorencatto F. Focusing on fidelity: narrative review and recommendations for improving
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17 interventions. American Journal of Physical Medicine & Rehabilitation. 2021;100(1):5-16.
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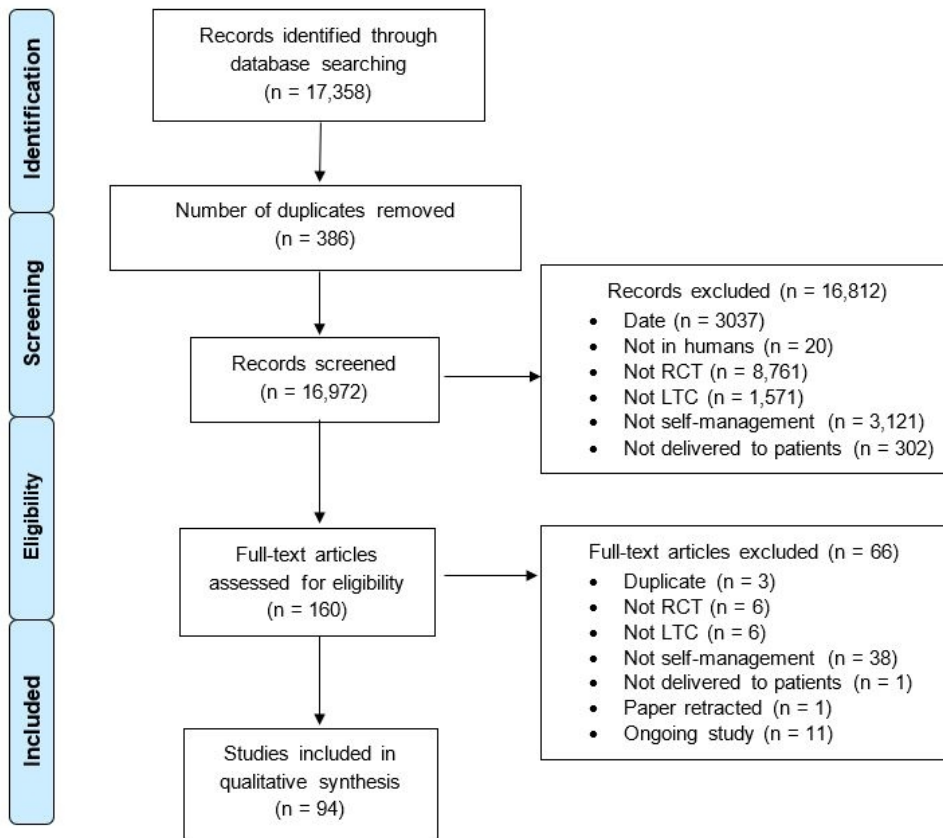


Figure 1. PRISMA Systematic Review Flow Diagram

Figure 1. PRISMA Systematic Review Flow Diagram

131x121mm (144 x 144 DPI)

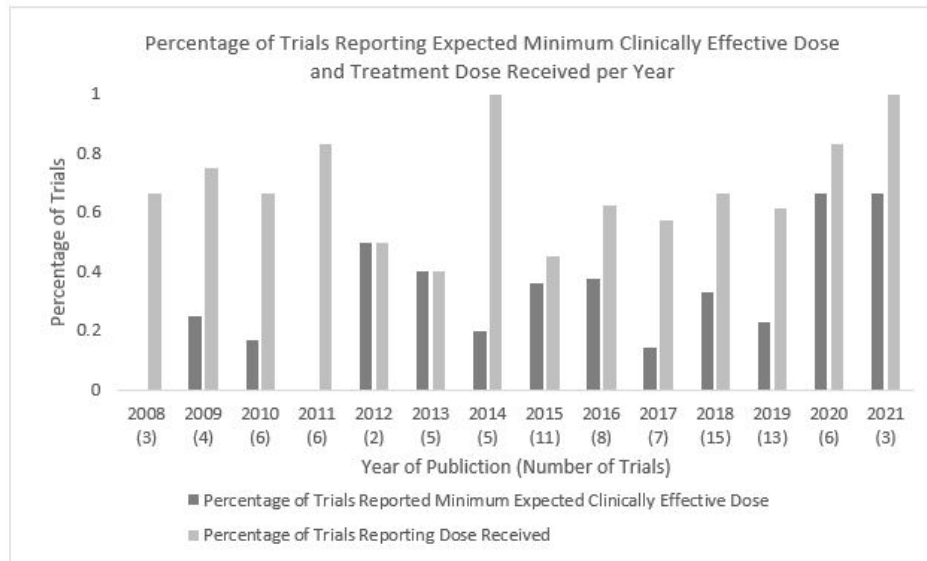


Figure 2. Bar graph illustrating the percentage of trials reporting the expected minimum clinically effective dose and the treatment dose received by year.

Figure 2. Bar graph illustrating the percentage of trials reporting the expected minimum clinically effective dose and the treatment dose received by year.

118x80mm (144 x 144 DPI)

Supplementary Figure 1. Medline, AMED, PsychINFO and CINAHL Full Search Strategies.

Medline Search Strategy

1. (Long term adj3 condition*).mp.
2. chronic*.mp.
3. ((persistent or long* term or ongoing or degenerative) adj3 (disease* or ill* or condition* or insufficienc* or disorder*)).tw.
4. long term care/
5. long* term care.tw.
6. exp cardiovascular diseases/
7. (heart disease* or heart failure or myocardial ischemia or coronary disease* or coronary artery disease* or myocardial infarction or hypertension or high blood pressure).tw.
8. sickle cell.mp.
9. exp lung diseases obstructive/
10. (obstructive lung disease* or obstructive pulmonary disease* or copd or asthma or bronchitis).tw.
11. exp emphysema/
12. exp pulmonary emphysema/
13. emphysema.tw.
14. (cystic fibrosis or respiratory distress).mp.
15. exp nervous system diseases/
16. (brain adj (disease* or damage* or injur*)).tw.
17. (cerebrovascular or brain ischemia or cerebral infarction or carotid artery disease* or stroke or epilep* or seizure*).tw.
18. (neurodegenerative or Huntingdon* or Parkinson* or amyotrophic lateral sclerosis or multiple sclerosis or motor neuron disease).tw.
19. (paralys* or quadriplegi* or tetraplegi* or paraplegi* or locked in syndrome).tw.
20. ((communication or learning or consciousness or perpetual or speech or voice or vision or hearing or psychomotor) adj disorder*).tw.
21. (hearing loss or hearing aid* or deaf* or blind* or stutter*).tw.
22. down* syndrome.tw.
23. cerebral palsy.tw.
24. exp gastrointestinal diseases/
25. (gatroenter* or intestinal or bowel or colonic).tw.
26. renal insufficiency/
27. ((renal or kidney) adj (failure* or insufficienc*)).tw.
28. diabetes mellitus/
29. (diabetes or diabetic*).tw.
30. exp nutrition disorders/
31. (underweight or malnutrition or malnourished or overweight or obes*).tw.
32. exp arthritis/
33. exp rheumatic diseases/
34. (arthritis or osteoarthritis or rheumati* or fibromyalgia).tw.
35. ((back or neck) adj pain).tw.
36. exp thyroid diseases/
37. thyroid.tw.
38. exp hypersensitivity/
39. (hypersensitivit* or allerg* or intolerance or anaphyla*).mp.
40. exp neoplasms/
41. (cancer* or oncolog* or neoplasm* or carcinom* or tumo?r* or malignan* or leuk?emia).tw.
42. exp hiv infections/

- 1
- 2
- 3 43. (hiv infect* or hiv disease*).tw.
- 4 44. exp mental disorders/
- 5 45. exp behavio?ral symptoms/
- 6 46. ((mental* or psychiatr* or psychological*) adj (ill* or disorder* or disease* or distress* or disab* or
- 7 problem* or health* or patient* or treatment)).tw.
- 8 47. ((personality or mood or dysthymic or cognit* or anxiety or stress or eating or adjustment or
- 9 reactive or somatoform or conversion or behavio?r or perception or psycho* or impulse control or
- 10 development* or attention deficit or hyperactivity or conduct or motor skills or movement or tic or
- 11 substance related) adj disorder*).tw.
- 12 48. (psychos#s or psychotic* or paranoi* or schizo* or neuros#s or neurotic* or delusion* or
- 13 depression or depressive or bipolar or mania or manic or obsessi* or compulsi* or panic or phobic or
- 14 phobia or anorexia or bulimia or neurastheni* or dissociative or autis* or Asperger* or Tourette or
- 15 dyslex* or affective or borderline or narcissis* or suicid* or self injur* or self harm or adhd).tw.
- 16 49. (((substance or drug or alcohol) adj abuse) or "substance use" or "illegal drug use" or addict* or
- 17 alcoholism or (problem* adj1 drinking)).tw.
- 18 50. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or
- 19 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37
- 20 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49
- 21 51. self efficacy/ or self care/
- 22 52. self administration/ or self assessment/ or self concept/
- 23 53. patient compliance/ or patient education as topic/ or patient participation/ or patient satisfaction/
- 24 54. consumer health information/ or consumer participation/
- 25 55. attitude to health/ or health behavio?r/ or health education/ or health knowledge, attitudes,
- 26 practice/ or health promotion/
- 27 56. life style/ or disease management/ or risk reduction behavio?r/
- 28 57. adaptation, psychological/ or motivation/ or goals/ or problem solving/ or exp decision making/
- 29 58. health plan implementation/
- 30 59. (self care or selfcare or self management or selfmanagement or self efficacy or selfefficacy or self
- 31 monitor\$ or selfmonitor\$).tw.
- 32 60. ((self or oneself) adj3 care).tw.
- 33 61. ((patient\$ or consumer\$ or client\$) adj5 (educat\$ or participat\$ or behavio?r\$ or behavio?r\$ or
- 34 compliance or centered)).tw.
- 35 62. (health adj5 (promot\$ or educat\$ or behav\$)).tw.
- 36 63. (risk adj3 reduc\$ adj3 behav\$).tw.
- 37 64. ((patient\$ or consumer\$ or client\$) adj5 manag\$ adj5 disease\$).tw.
- 38 65. (((behav\$ adj3 chang\$) or (problem\$ adj3 solv\$) or (goal\$ adj3 setting) or (decision\$ adj3 mak\$)
- 39 or coping) adj5 (patient\$ or consumer\$ or client\$)).tw.
- 40 66. 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65
- 41 67. randomized controlled trial/ or pragmatic clinical trial/
- 42 68. randomi?ed controlled trial.mp.
- 43 69. controlled clinical trial/
- 44 70. randomized controlled trial/
- 45 71. double-blind method/ or random allocation/ or single-blind method/
- 46 72. Clinical Trials as Topic/
- 47 73. placebo.mp.
- 48 74. randomi?ed.mp.
- 49 75. Drug Therapy/
- 50 76. drug therapy.mp.
- 51 77. randomly.mp.
- 52 78. clinical trial/
- 53 79. trial.mp.
- 54 80. groups.mp.
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81. 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80
82. exp animals/ not humans.sh.
83. (#81 not #82).mp.
84. 50 and 66 and 83

AMED Search Strategy

1. (Long term adj3 condition*).mp. [mp=abstract, heading words, title]
2. chronic*.mp.
3. ((persistent or long* term or ongoing or degenerative) adj3 (disease* or ill* or condition* or insufficienc* or disorder*)).mp. [mp=abstract, heading words, title]
4. long term care/
5. long* term care.tw.
6. Cardiovascular disease/
7. (heart disease* or heart failure or myocardial ischemia or coronary disease* or coronary artery disease* or myocardial infarction or hypertension or high blood pressure).tw.
8. sickle cell.mp.
9. lung disease/
10. (obstructive lung disease* or obstructive pulmonary disease* or copd or asthma or bronchitis).tw.
11. emphysema/
12. pulmonary emphysema/
13. emphysema.tw.
14. (cystic fibrosis or respiratory distress).mp.
15. (brain adj (disease* or damage* or injur*)).tw.
16. (cerebrovascular or brain ischemia or cerebral infarction or carotid artery disease* or stroke or epilep* or seizure*).tw.
17. (neurodegenerative or Huntingdon* or Parkinson* or amyotrophic lateral sclerosis or multiple sclerosis or motor neuron disease).tw.
18. (paralys* or quadriplegi* or tetraplegi* or paraplegi* or locked in syndrome).tw.
19. ((communication or learning or consciousness or perpetual or speech or voice or vision or hearing or psychomotor) adj disorder*).tw.
20. (hearing loss or deaf* or blind*).tw.
21. down* syndrome.tw.
22. cerebral palsy.tw.
23. exp gastrointestinal disease/
24. exp nervous system disease/
25. (gatroenter* or intestinal or bowel or colonic).tw.
26. ((renal or kidney) adj (failure* or insufficienc*)).tw.
27. diabetes mellitus/
28. (diabetes or diabetic*).tw.
29. exp nutrition disorders/
30. (underweight or malnutrition or malnourished).tw.
31. exp arthritis/
32. exp rheumatic disease/
33. fibromyalgia.tw.
34. ((back or neck) adj pain).tw.
35. exp thyroid disease/
36. thyroid.tw.
37. exp hypersensitivity/
38. (hypersensitivit* or allerg* or intolerance or anaphyla*).mp.
39. exp neoplasms/
40. (cancer* or oncolog* or neoplasm* or carcinom* or tumo?r* or malignan* or leuk?emia).tw.

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- 3 41. exp hiv infections/
- 4 42. (hiv infect* or hiv disease*).tw.
- 5 43. exp mental disorders/
- 6 44. ((mental* or psychiatr* or psychological*) adj (ill* or disorder* or disease* or distress* or disab* or
- 7 problem* or health* or patient* or treatment)).tw.
- 8 45. ((personality or mood or dysthymic or cognit* or anxiety or stress or eating or adjustment or
- 9 reactive or somatoform or conversion or behavio?r or perception or psycho* or impulse control or
- 10 development* or attention deficit or hyperactivity or conduct or motor skills or movement or tic or
- 11 substance related) adj disorder*).tw.
- 12 46. (psychos?s or psychotic* or paranoi* or schizo* or neuros?s or neurotic* or delusion* or
- 13 depression or depressive or bipolar or mania or manic or obsessi* or compulsi* or panic or phobic or
- 14 phobia or anorexia or bulimia or neurastheni* or dissociative or autis* or Asperger* or Tourette or
- 15 dyslex* or affective or borderline or narcissis* or suicid* or self injur* or self harm or adhd).tw.
- 16 47. (((substance or drug or alcohol) adj abuse) or "substance use" or "illegal drug use" or addict* or
- 17 alcoholism or (problem* adj1 drinking)).tw.
- 18 48. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or
- 19 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37
- 20 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47
- 21 49. self efficacy/ or self care/
- 22 50. self administration/ or self assessment/ or self concept/
- 23 51. patient compliance/ or patient education/ or patient participation/
- 24 52. attitude to health/ or health behavio?r/ or health education/ or health knowledge, attitudes,
- 25 practice/ or health promotion/
- 26 53. life style/ or disease management/ or risk reduction behavio?r/
- 27 54. adaptation, psychological/ or motivation/ or goals/ or problem solving/ or exp decision making/
- 28 55. (consumer health information or consumer participation).mp. [mp=abstract, heading words, title]
- 29 56. health plan implementation.mp.
- 30 57. (self care or self management or self efficacy or self monitor\$).tw.
- 31 58. ((self or oneself) adj3 care).tw.
- 32 59. ((patient\$ or consumer\$ or client\$) adj5 (educat\$ or participat\$ or behavio?r\$ or behavio?r\$ or
- 33 compliance or centered)).tw.
- 34 60. (health adj5 (promot\$ or educat\$ or behav\$)).tw.
- 35 61. (risk adj3 reduc\$ adj3 behav\$).tw.
- 36 62. ((patient\$ or consumer\$ or client\$) adj5 manag\$ adj5 disease\$).tw.
- 37 63. (((behav\$ adj3 chang\$) or (problem\$ adj3 solv\$) or (goal\$ adj3 setting) or (decision\$ adj3 mak\$)
- 38 or coping) adj5 (patient\$ or consumer\$ or client\$)).tw.
- 39 64. 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63
- 40 65. randomized controlled trial.pt.
- 41 66. controlled clinical trial.pt.
- 42 67. randomized.ab.
- 43 68. placebo.ab.
- 44 69. randomly.ab.
- 45 70. clinical trials.sh.
- 46 71. trial.ti.
- 47 72. 65 or 66 or 67 or 68 or 69 or 70 or 71
- 48 73. exp animals/ not humans.sh.
- 49 74. 72 not 73
- 50 75. 48 and 64 and 74
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- 57 PsychINFO Search Strategy
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1. (Long term adj3 condition*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]
2. chronic*.mp.
3. ((persistent or long* term or ongoing or degenerative) adj3 (disease* or ill* or condition* or insufficienc* or disorder*)).tw.
4. long term care/
5. long* term care.tw.
6. (heart disease* or heart failure or myocardial ischemia or coronary disease* or coronary artery disease* or myocardial infarction or hypertension or high blood pressure).tw.
7. sickle cell.mp.
8. (obstructive lung disease* or obstructive pulmonary disease* or copd or asthma or bronchitis).tw.
9. exp emphysema/
10. exp pulmonary emphysema/
11. emphysema.tw.
12. (cystic fibrosis or respiratory distress).mp.
13. exp nervous system disorders/
14. exp cardiovascular disorders/
15. exp lung disorders/
16. (brain adj (disease* or damage* or injur*)).tw.
17. (cerebrovascular or brain ischemia or cerebral infarction or carotid artery disease* or stroke or epilep* or seizure*).tw.
18. (neurodegenerative or Huntingdon* or Parkinson* or amyotrophic lateral sclerosis or multiple sclerosis or motor neuron disease).tw.
19. (paralys* or quadriplegi* or tetraplegi* or paraplegi* or locked in syndrome).tw.
20. ((communication or learning or consciousness or perpetual or speech or voice or vision or hearing or psychomotor) adj disorder*).tw.
21. (hearing loss or hearing aid* or deaf* or blind* or stutter*).tw.
22. down* syndrome.tw.
23. cerebral palsy.tw.
24. exp gastrointestinal disorders/
25. (gastroenter* or intestinal or bowel or colonic).tw.
26. renal insufficiency/
27. ((renal or kidney) adj (failure* or insufficienc*)).tw.
28. diabetes mellitus/
29. (diabetes or diabetic*).tw.
30. eating disorders/
31. (underweight or malnutrition or malnourished or overweight or obes*).tw.
32. exp arthritis/
33. rheumatoid arthritis/
34. (arthritis or osteoarthritis or rheumati* or fibromyalgia).tw.
35. ((back or neck) adj pain).tw.
36. thyroid disorders/
37. thyroid.tw.
38. exp hypersensitivity/
39. (hypersensitivit* or allerg* or intolerance or anaphyla*).mp.
40. exp neoplasms/
41. (cancer* or oncolog* or neoplasm* or carcinom* or tumo?* or malignan* or leuk?emia).tw.
42. exp AIDS/ or exp HIV/
43. (hiv infect* or hiv disease*).tw.
44. exp mental disorders/
45. exp Behavior Problems/ or behavio?ral symptoms.mp.

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2
3 46. ((mental* or psychiatr* or psychological*) adj (ill* or disorder* or disease* or distress* or disab* or
4 problem* or health* or patient* or treatment)).tw.
5 47. ((personality or mood or dysthymic or cognit* or anxiety or stress or eating or adjustment or
6 reactive or somatoform or conversion or behavior?r or perception or psycho* or impulse control or
7 development* or attention deficit or hyperactivity or conduct or motor skills or movement or tic or
8 substance related) adj disorder*).tw.
9 48. (psychos#s or psychotic* or paranoi* or schizo* or neuros#s or neurotic* or delusion* or
10 depression or depressive or bipolar or mania or manic or obsessi* or compulsi* or panic or phobic or
11 phobia or anorexia or bulimia or neurastheni* or dissociative or autis* or Asperger* or Tourette or
12 dyslex* or affective or borderline or narcissis* or suicid* or self injur* or self harm or adhd).tw.
13 49. (((substance or drug or alcohol) adj abuse) or "substance use" or "illegal drug use" or addict* or
14 alcoholism or (problem* adj1 drinking)).tw.
15 50. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or
16 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37
17 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49
18 51. self efficacy/ or self care/
19 52. self administration/ or self assessment/ or self concept/
20 53. patient compliance/ or patient education as topic/ or patient participation/ or patient satisfaction.
21 54. consumer health information/ or consumer participation/
22 55. attitude to health/ or health behavior?r/ or health education/ or health knowledge, attitudes,
23 practice/ or health promotion/
24 56. life style/ or disease management/ or risk reduction behavior?r/
25 57. adaptation, psychological/ or motivation/ or goals/ or problem solving/ or exp decision making/
26 58. health plan implementation/
27 59. (self care or selfcare or self management or selfmanagement or self efficacy or selfefficacy or self
28 monitor\$ or selfmonitor\$).tw.
29 60. ((self or oneself) adj3 care).tw.
30 61. ((patient\$ or consumer\$ or client\$) adj5 (educat\$ or participat\$ or behavior?r\$ or behavior?r\$ or
31 compliance or centered)).tw.
32 62. (health adj5 (promot\$ or educat\$ or behav\$)).tw.
33 63. (risk adj3 reduc\$ adj3 behav\$).tw.
34 64. ((patient\$ or consumer\$ or client\$) adj5 manag\$ adj5 disease\$).tw.
35 65. (((behav\$ adj3 chang\$) or (problem\$ adj3 solv\$) or (goal\$ adj3 setting) or (decision\$ adj3 mak\$)
36 or coping) adj5 (patient\$ or consumer\$ or client\$)).tw.
37 66. 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65
38 67. exp Randomized Controlled Trials/
39 68. exp Clinical Trials/
40 69. exp Randomized Controlled Trials/ or exp Randomized Clinical Trials/
41 70. exp Placebo/
42 71. exp Drug Therapy/
43 72. randomly.mp.
44 73. trial.mp.
45 74. groups.mp.
46 75. 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74
47 76. exp animals/ not humans.sh.
48 77. (#75 not #76).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title,
49 tests & measures, mesh]
50 78. 50 and 66 and 77
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CINAHL Search Strategy

S1. long term condition

- 1
- 2
- 3 S2. chronic
- 4 S3. ((persistent or long term or ongoing or degenerative) (disease or ill* or condition or insufficiency* or
- 5 disorder))
- 6 S4. long term care
- 7 S5. cardiovascular diseases
- 8 S6. (heart disease or heart failure or myocardial ischemia or coronary disease or coronary artery
- 9 disease or myocardial infarction or hypertension or high blood pressure)
- 10 S7. sickle cell
- 11 S8. lung diseases, obstructive
- 12 S9. (obstructive lung disease or obstructive pulmonary disease or copd or asthma or bronchitis)
- 13 S10. down* syndrome
- 14 S11. cerebral palsy
- 15 S12. emphysema
- 16 S13. gastrointestinal disorders
- 17 S14. renal insufficiency
- 18 S15. ((renal or kidney) failure)
- 19 S16. diabetes mellitus
- 20 S17. nutrition disorders
- 21 S18. arthritis
- 22 S19. rheumatic diseases
- 23 S20. fibromyalgia
- 24 S21. (cystic fibrosis or respiratory distress)
- 25 S22. thyroid disease
- 26 S23. (hypersensitivity or allergy or anaphylaxis)
- 27 S24. (cancer* or oncology* or neoplasm* or tumor*?)
- 28 S25. (hiv infection or hiv disease or hiv)
- 29 S26. mental disorders
- 30 S27. ((mental or psychiatric or psychological) (ill* or disorder or disease or distress or disability))
- 31 S28. ((personality or dysthymic or anxiety or stress or eating or reactive or behavior* or perception or
- 32 impulse control or developmental or attention deficit or hyperactivity or conduct or motor skills or
- 33 movement or tic) disorder
- 34 S29. (psychosis or schizophrenia or neurosis or depression or bipolar or mania or obsessive or
- 35 compulsive or panic or phobia or anorexia or bulimia or dissociative or autism or Asperger's or
- 36 Tourette or affective or borderline or suicide or self injury or self harm or adhd)
- 37 S30. ((substance or drug or alcohol) abuse or addiction) or alcoholism
- 38 S31. self efficacy or self care
- 39 S32. nervous system diseases
- 40 S33. self administration or self assessment or self concept
- 41 S34. patient compliance or patient education or patient participation
- 42 S35. consumer health information or consumer participation
- 43 S36. attitude to health or health behavior* or health education or health promotion
- 44 S37. disease management or risk reduction behavior*
- 45 S38. health plan implementation
- 46 S39. self care or self management or self efficacy
- 47 S40. ((patient or consumer or health) (education or participation or behavior* or compliance or
- 48 disease management))
- 49 S41. (((behavior* change) or (problem solving) or (goal setting) or (decision making) or coping or
- 50 motivation) (patient or consumer))
- 51 S42. (brain (disease or damage or injury))
- 52 S43. MH randomized controlled trials
- 53 S44. MH double-blind studies
- 54 S45. MH single-blind studies
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- 3 S46. MH random assignment
- 4 S47. MH pretest-posttest design
- 5 S48. MH cluster sample
- 6 S49. TI (randomised OR randomized)
- 7 S50. AB (random*)
- 8 S51. TI (trial)
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- 10 S52. MH (sample size) AND AB (assigned OR allocated OR control)
- 11 S53. (cerebrovascular or brain ischemia or cerebral infarction or carotid artery disease or stroke or
- 12 epilepsy or seizure)
- 13 S54. MH (placebos)
- 14 S55. PT (randomized controlled trial)
- 15 S56. AB (CONTROL W5 GROUP)
- 16 S57. MH (CROSSOVER DESIGN) OR MH (COMPARATIVE STUDIES)
- 17 S58. AB (CLUSTER W3 RCT)
- 18 S59. S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S54 OR
- 19 S55 OR S56 OR S57 OR S58
- 20 S60. MH ANIMALS+
- 21 S61. MH (ANIMAL STUDIES)
- 22 S62. TI (ANIMAL MODEL*)
- 23 S63. S60 OR S61 OR S62
- 24 S64. (neurodegenerative or Huntingdon's or Parkinson's or amyotrophic lateral sclerosis or multiple
- 25 sclerosis or motor neuron disease)
- 26 S65. MH (HUMAN)
- 27 S66. S63 NOT S65
- 28 S67. S59 NOT S66
- 29 S68. ((communication or learning or speech or vision or hearing or psychomotor) disorder)
- 30 S69. (deaf or blind)
- 31 S70. S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13
- 32 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR
- 33 S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S32 OR S42 OR S53 OR S64 OR S68 OR S69
- 34 S71. S31 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41
- 35 S72. S67 AND S70 AND S71
- 36 S73. S67 AND S70 AND S71
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Supplementary Figure 2. Reference list for the 82 eligible articles included in this systematic review.

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44 with pre-end-stage renal disease in Taiwan: A randomized, controlled trial. *Japan Journal of
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47 experimental study of a self-management arthritis programme with an added exercise
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55 improved performance and satisfaction with regard to own selected activities; A longitudinal
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3 94. Zhang AY, Fu AZ. Cost-effectiveness of a behavioral intervention for persistent
4 urinary incontinence in prostate cancer patients. *Psycho-Oncology*. 2016 Apr;25(4):421-7.
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For peer review only

Reporting checklist for systematic review (with or without a meta-analysis).

Based on the PRISMA guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the PRISMA reporting guidelines, and cite them as:

Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, Shamseer L, Tetzlaff JM, Akl EA, Brennan SE, Chou R, Glanville J, Grimshaw JM, Hróbjartsson A, Lalu MM, Li T, Loder EW, Mayo-Wilson E, McDonald S, McGuinness LA, Stewart LA, Thomas J, Tricco AC, Welch VA, Whiting P, Moher D. The PRISMA 2020 statement: An updated guideline for reporting systematic reviews

	Reporting Item	Page Number
Title		
Title	#1 Identify the report as a systematic review	1
Abstract		
Abstract	#2 Report an abstract addressing each item in the PRISMA 2020 for Abstracts checklist	2-3
Introduction		
Background/rationale	#3 Describe the rationale for the review in the context of existing knowledge	4-7
Objectives	#4 Provide an explicit statement of the objective(s) or question(s) the review addresses	7

Methods

1	Eligibility criteria	#5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses	8-9
2				
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6	Information sources	#6	Specify all databases, registers, websites, organisations, reference lists, and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted	8
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14	Search strategy	#7	Present the full search strategies for all databases, registers, and websites, including any filters and limits used	Supplementary figure 1
15				
16				
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20	Selection process	#8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and, if applicable, details of automation tools used in the process	9
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30	Data collection process	#9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and, if applicable, details of automation tools used in the process	9 and supplementary table 2
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41	Data items	#10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (for example, for all measures, time points, analyses), and, if not, the methods used to decide which results to collect	10
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51	Study risk of bias assessment	#11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and, if applicable, details of automation tools used in the process	10
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1	Effect measures	#12	Specify for each outcome the effect measure(s) (such as risk ratio, mean difference) used in the synthesis or presentation of results	N/A
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6	Synthesis methods	#13a	Describe the processes used to decide which studies were eligible for each synthesis (such as tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5))	8-9
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14	Synthesis methods	#13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics or data conversions	N/A
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20	Synthesis methods	#13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses	N/A
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24	Synthesis methods	#13d	Describe any methods used to synthesise results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used	9-10
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34	Synthesis methods	#13e	Describe any methods used to explore possible causes of heterogeneity among study results (such as subgroup analysis, meta-regression)	N/A
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39	Synthesis methods	#13f	Describe any sensitivity analyses conducted to assess robustness of the synthesised results	N/A
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43	Reporting bias assessment	#14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases)	N/A
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48	Certainty assessment	#15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome	N/A
49				
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52	Data items	#10b	List and define all other variables for which data were sought (such as participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information	N/A
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Results

Study selection	#16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram (http://www.prisma-statement.org/PRISMAStatement/FlowDiagram)	10 and figure 1
Study selection	#16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded	N/A
Study characteristics	#17	Cite each included study and present its characteristics	10-12 and Supplementary figure 2 and Supplementary Table 3
Risk of bias in studies	#18	Present assessments of risk of bias for each included study	N/A
Results of individual studies	#19	For all outcomes, present for each study (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (such as confidence/credible interval), ideally using structured tables or plots	N/A
Results of syntheses	#20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies	N/A
Results of syntheses	#20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (such as confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect	N/A
Results of syntheses	#20c	Present results of all investigations of possible causes of heterogeneity among study results	N/A
Results of syntheses	#20d	Present results of all sensitivity analyses conducted	N/A

		to assess the robustness of the synthesised results	
1			
2	Risk of reporting	#21 Present assessments of risk of bias due to missing	N/A
3	biases in syntheses	results (arising from reporting biases) for each	
4		synthesis assessed	
5			
6			
7	Certainty of evidence	#22 Present assessments of certainty (or confidence) in	N/A
8		the body of evidence for each outcome assessed	
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10			
11	Discussion		
12			
13	Results in context	#23a Provide a general interpretation of the results in the	14-17
14		context of other evidence	
15			
16	Limitations of	#23b Discuss any limitations of the evidence included in	17-18
17	included studies	the review	
18			
19	Limitations of the	#23c Discuss any limitations of the review processes	17-18
20	review methods	used	
21			
22	Implications	#23d Discuss implications of the results for practice,	18
23		policy, and future research	
24			
25	Other information		
26			
27	Registration and	#24a Provide registration information for the review,	3
28	protocol	including register name and registration number, or	
29		state that the review was not registered	
30			
31	Registration and	#24b Indicate where the review protocol can be accessed,	20
32	protocol	or state that a protocol was not prepared	
33			
34	Registration and	#24c Describe and explain any amendments to	N/A
35	protocol	information provided at registration or in the protocol	
36			
37	Support	#25 Describe sources of financial or non-financial	19-20
38		support for the review, and the role of the funders or	
39		sponsors in the review	
40			
41	Competing interests	#26 Declare any competing interests of review authors	20
42			
43	Availability of data,	#27 Report which of the following are publicly available	20 and
44	code, and other	and where they can be found: template data	supplementary
45	materials	collection forms; data extracted from included	table 3
46		studies; data used for all analyses; analytic code;	
47		any other materials used in the review	
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Notes:

- 7: supplementary figure 1
- 9: 9 and supplementary table 2
- 16a: 10 and figure 1
- 17: 10-12 and Supplementary figure 2 and Supplementary Table 3
- 27: 20 and supplementary table 3

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Study Details:

Study Title	
Reference No.	
Data Extractor	
Year, Author, Country, Link	Year after 2008?: Yes <input type="checkbox"/> No <input type="checkbox"/> TIDieR checklist (2014): Before <input type="checkbox"/> After <input type="checkbox"/>
Pre-extraction Screening	Needs translating: Yes <input type="checkbox"/> No <input type="checkbox"/> RCT: Yes <input type="checkbox"/> No <input type="checkbox"/> Self-management intervention: Yes <input type="checkbox"/> No <input type="checkbox"/> Participants with LTCs: Yes <input type="checkbox"/> No <input type="checkbox"/> Ongoing study: Yes <input type="checkbox"/> No <input type="checkbox"/>
Research Question / Aim	

Methods:

Study Design	Participant Characteristics:
	RCT details e.g. clusters, unclear:
	How is the control arm described:
	Number of centres: Single centre <input type="checkbox"/> Multi-centre <input type="checkbox"/> Unclear <input type="checkbox"/>
Intervention Summary Features	CDSMP <input type="checkbox"/> ASMP <input type="checkbox"/> EPP <input type="checkbox"/> Other <input type="checkbox"/> Specify if known Disease specific <input type="checkbox"/> or Generic <input type="checkbox"/> LTCs included: Delivered by: Health care professional <input type="checkbox"/> Lay person <input type="checkbox"/> Other <input type="checkbox"/> Specify if known Individual one-to-one sessions: Yes <input type="checkbox"/> No <input type="checkbox"/> Group sessions: Yes <input type="checkbox"/> No <input type="checkbox"/> Number in group: Face-to-Face sessions <input type="checkbox"/> / Remote sessions <input type="checkbox"/>

	<p>Location where is the intervention delivered: Inpatient <input type="checkbox"/> Outpatient <input type="checkbox"/> Community Based <input type="checkbox"/> Home <input type="checkbox"/> Telephone <input type="checkbox"/> Web-based <input type="checkbox"/> Unclear <input type="checkbox"/> Other <input type="checkbox"/> Specify if known</p> <p>Description:</p> <p>Any necessary components for adherence:</p>
<p>Dose of Intervention</p> <p>Adherence and compliance may be used synonymously, but the distinction and data needs to be teased out</p>	<p>Maximum dose: Number of sessions: Session Duration (hours): Total hours: Duration intervention delivered over:</p> <p>Anticipated clinically effective dose: Number of sessions: Session Duration (hours): Total hours: How clinically effective dose decided by authors:</p> <p>Author comments on Adherence (the number of sessions participants attended):</p> <p>Author comments on Compliance (the number of sessions participants need to attend to be including in the analysis):</p>
<p>Fidelity of Intervention</p>	<p>Did the study describe attempts to ensure fidelity of the interventions i.e. what was delivered was what was intended to be delivered: Yes <input type="checkbox"/> No <input type="checkbox"/> Not stated/unclear <input type="checkbox"/> If Yes, specify:</p> <p>Comments / Additional details:</p>

Results:

Participants		Number	Age (mean, SD)	SES (add measure used)	Ethnicity (% white)	Gender (% female)
	Intervention:					
	Control:					
	All:					
LTCs details:						
Dose of Intervention	<p>Dose actually delivered: Number of sessions: Session Duration (hours): Total hours: Duration Intervention Delivered Over:</p> <p>Dose actually received (specifically for groups): Number of sessions: Session Duration (hours): Total hours: Duration Intervention Delivered Over:</p>					

1 2 3 4 5 6	Was the dose delivered \geq anticipated clinically effective dose: Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/> Details: Further author comments on dose:
7 8 9 10 11 12 13 14 15 16 17	Fidelity of Intervention Was there fidelity around the dose in the trial?: Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/> Was fidelity reported on in?: Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/> Do the authors discuss the impact of fidelity?: Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/> Further author comments on fidelity:
18 19 20 21 22 23 24 25	Primary Outcome Result Was the Primary Outcome Statistically Significant: Yes <input type="checkbox"/> No <input type="checkbox"/> Details: Was the Primary Outcome Clinically Significant: Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/> Details:

Cochrane Risk of Bias Assessment:

26 27 28 29 30 31 32	1. Selection Bias Randomisation and Allocation Concealment Your assessment of this bias: 'Low risk' <input type="checkbox"/> 'High risk' <input type="checkbox"/> 'Unclear risk' <input type="checkbox"/>
33 34 35 36	2. Performance Bias Blinding of Participants and Clinical staff Your assessment of this bias: 'Low risk' <input type="checkbox"/> 'High risk' <input type="checkbox"/> 'Unclear risk' <input type="checkbox"/>
37 38 39 40	3. Detection Bias Blinding of Outcome Assessors Your assessment of this bias: 'Low risk' <input type="checkbox"/> 'High risk' <input type="checkbox"/> 'Unclear risk' <input type="checkbox"/>
41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56	4. Attrition Bias Incomplete Outcome data – for each outcome Outcome: Attrition reported: Yes <input type="checkbox"/> No <input type="checkbox"/> Exclusions reported: Yes <input type="checkbox"/> No <input type="checkbox"/> % dropped out: Intervention Group: Control Group: Reasons for LTFU: Intervention Group: Control Group: Your assessment of this bias: 'Low risk' <input type="checkbox"/> 'High risk' <input type="checkbox"/> 'Unclear risk' <input type="checkbox"/>
57 58 59 60	5. Reporting Bias Selective Outcome Reporting Your assessment of this bias: 'Low risk' <input type="checkbox"/> 'High risk' <input type="checkbox"/> 'Unclear risk' <input type="checkbox"/>

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60 6. Other Sources of Bias	Bias due to other problems Your assessment of this bias: 'Low risk' <input type="checkbox"/> 'High risk' <input type="checkbox"/> 'Unclear risk' <input type="checkbox"/>
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Supplementary Table 2. Full details of all 94 articles included in the systematic review

	First Author	Year	Country	Intervention	Disease	Delivered by	Location	Maximum dose stated (number of sessions)	Maximum dose stated (length of sessions)	Minimum clinically Effective dose stated	Dose received stated (number of sessions)	Dose stated (length of sessions)	Was dose delivered \geq minimum clinically effective dose	Was fidelity reported and discussed	Was the primary outcome statistically significant
8	Ackerman	2012	Australia	ASMP	Hip or Knee Osteoarthritis	HCPs and Lay leaders	Outpatient clinic and Community	Yes	Yes	Yes	Yes	Yes	No	Yes	No
10	Ambrosino	2008	USA	Coping skills training - learning to deal better with day-to-day problems that arise	Type 1 Diabetes	HCPs	Unclear	Yes	Yes	No	Yes	Yes	Unclear	No	No
15	Anvar	2018	Iran	ASMP	Rheumatoid Arthritis	HCPs	Outpatient clinic	Yes	Yes	No	Yes	Yes	Unclear	No	Yes
17	Bantum	2014	USA	Surviving and Thriving with Cancer website adapted from CDSMP	Cancer survivors	Lay leaders	Web-based	Yes	No	No	Yes	No	Yes	Yes	Yes
20	Berg	2019	USA	AWAKE - app based weekly modules with aligned homework, combined with weekly phone calls from a coach to discuss content and homework	Cancer survivorship	Healthcare professional	Web-based and telephone	Yes	No	Yes	Yes	No	Yes	No	No
28	Berry	2015	USA	Diabetes group visits - an individualized session to review medications and a medical examination and a group session for diabetes self-management education	Diabetes	HCPs	Community based	Yes	No	No	No	No	Unclear	No	Yes
37	Bersani	2017	Italy	group psychoeducation focused on healthy lifestyle - including sleep, physical activity, diet, voluptuary habits	Mood and Psychotic disorders	HCPs	Outpatient clinic	Yes	Yes	No	No	Yes	Unclear	No	Yes

1	Bosworth	2008	USA	Tailored behavioural intervention with 9 educational modules	Hypertension	HCPs	Telephone	Yes	No	No	Yes	Yes	Yes	No
2														
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4	Breedland	2011	The Netherlands	FIT program - physical activity combined with an education program	Rheumatoid Arthritis	HCPs	Outpatient clinic	Yes	Yes	No	No	No	Unclear	No
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8	Brorsson	2019	Sweden	Guided Self-Determination-Young (GSD-Y) a person-centered communication and reflection education model that can be used in educational program	Type 1 Diabetes	HCPs	Outpatient clinic	Yes	Yes	No	Yes	Yes	Yes	No
9														
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16	Chamany	2015	USA	Telephone support through problem solving and goal setting	Diabetes	HCPs	Telephone	Yes	No	Yes	Yes	Yes	Yes	Yes
17														
18														
19	Chen	2018	China	Patient-centred self-management empowerment intervention (PCSMEl)	Stroke	HCPs	Inpatient, Outpatient and Telephone	Yes	Yes	No	No	No	Unclear	No
20														
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23	Chew	2018	Malaysia	Value-based emotion-focused educational programme (VEMOFIT)	Type 2 Diabetes	HCPs	Other: Health Clinic	Yes	Yes	Yes	Yes	Yes	Yes	No
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27	Christiansen	2018	USA	A behaviour change intervention based on social cognitive and control theories of behavior change targeting physical exercise, walking activity, and disease self-management	Dysvascular Amputation (Unilateral TTA)	HCPs	Telephone	Yes	Yes	No	Yes	Yes	Yes	No
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35	Cook	2013	USA	Wellness Recovery Action Planning including lectures, individual and group exercises, personal sharing and role modeling, and voluntary homework	Serious Mental Illness	Lay leaders	Community based	Yes	Yes	No	No	No	Unclear	No
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1	Corado	2018	USA	Active, Linkage, Engagement, Retention and Treatment (ALERT) topics included HIV health literacy, Navigating the Health Care System, Disclosure, Adherence, and Self-Efficacy	HIV	HCPs	Outpatient clinic and Community	Yes	No	No	Yes	No	Unclear	Yes	No
2															
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9	Daryabeygi-Khotbehsara	2021	Iran	Education promoting low-fat food consumption, carb counting and physical activity	Type 2 Diabetes	Healthcare professional	Community Based	Yes	Yes	No	Yes	No	Unclear	No	No
10															
11															
12															
13	Dash	2015	India	Epilepsy health education program designed for those from a low education background.	Epilepsy	HCPs	Outpatient clinic	Yes	Yes	No	Yes	Yes	Yes	No	Yes
14															
15															
16															
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18															
19	Detaille	2013	The Netherlands	CDSMP adapted for workers with chronic disease	A diagnosed chronic somatic disease	Lay leaders	Community based	Yes	Yes	Yes	No	No	Unclear	No	Yes
20															
21															
22	Dinh	2019	Vietnam	Teach-back heart failure self-management intervention individual teach-back before discharge, plus a booklet, a weighing scale, a diary, and a telephone call follow-up at 2 weeks following discharge	Heart failure	HCPs	Outpatient clinic and Telephone	Yes	Yes	No	No	No	Unclear	No	Yes
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33	Dziedzic	2013	UK	Looking after your joints programme - Self Management in OA of the Hand (1) joint protection; (2) joint protection and hand exercises; (3) joint protection and hand exercises combined	Hand Osteoarthritis	HCPs	Outpatient clinic	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
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1	Ehde	2015	USA	Telephone delivered self-management intervention - cognitive-behavioural and positive psychology strategies for helping participants self-manage pain, depression, and fatigue	Multiple Sclerosis	HCPs	Telephone	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
2															
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9	Fernandez Guijarro	2019	Spain	Health-promotion programme covering healthy eating, lifestyle changes, physical activity, hydration, tobacco and alcohol consumption, stress reduction, and sleep quality and nurse led physical activity. Integrated disease management - case management, education, and skills training	Serious Mental Illness	HCPs	Community based	Yes	Yes	No	Yes	Yes	Unclear	No	Yes
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18	Ferrone	2019	Canada	Integrated disease management - case management, education, and skills training	COPD	HCPs	GP practice and telephone	Yes	No	No	Yes	No	No	Yes	Yes
19															
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22															
23	Forjuoh	2014	USA	CDSMP and PDA	Type 2 Diabetes	Lay leaders	Clinic and community	Yes	Yes	Yes	Yes	Yes	Yes	No	No
24															
25	Fukuoka	2019	Japan	Disease management program - nurses worked with the subjects and their to achieve individualized clinical target values and goals through education booklets and journal.	Stroke	HCPs	Unclear	Yes	No	No	No	No	Unclear	No	No
26															
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29															
30															
31															
32															
33	Gallinat	2019	Germany	CBT techniques covering psychoeducation, self-management, supportive monitoring and counselling	Skin Picking	HCPs	Web-based	Yes	No	No	Yes	No	No	No	Yes
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1	Geremia	2019	Brazil	Compact, cost-effective, education program (CEPT1)	Type 1 Diabetes	HCPs	Community based	Yes	Yes	No	Yes	Yes	Yes	No	Yes
2															
3	Goldberg	2013	USA	CDSMP adapted for psychiatric settings 'Living Well'	Serious Mental Illness with comorbid chronic medical condition	HCPs and Lay leaders	Outpatient clinic and Community	Yes	Yes	No	Yes	Yes	No	No	Yes
4															
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7	Golshahi	2015	Iran	Hypertension self-management - Group A educated about self-care behaviors through eight sessions, group B and group C educated through four pamphlets or eight SMS.	Hypertension	HCPs	Outpatient clinic and Telephone	Yes	Yes	Yes	No	No	Unclear	No	Yes
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16	Grammatopoulou	2016	Greece	Holistic Intervention - recognise facilitators and barriers faced to develop the necessary behaviors and skills to control their disease	Asthma	HCPs	Outpatient clinic and home	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
17															
18															
19															
20															
21															
22	Groessl	2010	USA	CDSMP adapted for veterans	Chronic Hepatitis C	HCPs and Lay leaders	Outpatient clinic	Yes	Yes	No	Yes	Yes	Yes	No	Yes
23															
24															
25	Grønning	2012	Norway	Arthritis outpatient Educational Program	Polyarthritis	HCPs	Outpatient clinic	Yes	Yes	No	No	No	Unclear	No	Yes
26															
27	Harel-Katz	2020	Israel	Improving participation after stroke self-management developed from CDSMP focused on managing home, community, work and social	Stroke	Healthcare professional	Community Based	Yes	Yes	Yes	Yes	Yes	Yes	No	No
28															
29															
30															
31															
32															
33															
34															
35	Harrington	2010	UK	Exercise and education scheme through exercise, guest speakers, goal-setting and social session	Stroke	HCPs	Community based	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
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1	Härter	2016	Germany	Telephone based health coaching intervention, to enhance health behaviour change through MI, goal setting, shared decision making	diabetes type 2, coronary artery disease, hypertension, heart failure, asthma, chronic obstructive pulmonary disease, chronic depression or schizophrenia	Healthcare professional	Telephone	Yes	No	Yes	Yes	Yes	Yes	Yes	No
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10	Heutink	2011	The Netherlands	CONESCI (COPing with NEuropathic Spinal cord Injury pain) comprises educational, cognitive, and behavioural elements targeted at coping with CNSCIP	Spinal cord injury	HCPs	Rehabilitation Centre	Yes	Yes	No	Yes	Yes	Yes	No	No
11															
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17															
18	Hewlett	2011	UK	CBT, problem solving and goal setting for fatigue and well-being self-management	Rheumatoid Arthritis	HCPs	Unclear (Face-to-face)	Yes	Yes	No	Yes	Yes	Yes	No	Yes
19															
20															
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22															
23	Holm	2020	Denmark	GLA:D exercise and education program	Knee Osteoarthritis	Healthcare professional	Community Based	Yes	Yes	Yes	Yes	Yes	No	Yes	No
24															
25	Holt	2019	UK	STEPWISE - Each session covered lifestyle changes to help the participants take control of their weight through problem solving	schizophrenia, schizoaffective disorder or first-episode psychosis	HCPs	Community based and telephone	Yes	Yes	Yes	Yes	Yes	No	Yes	No
26															
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32	Houlihan	2017	USA	My Care My Call - promote skill development and facilitate motivation using consumer-centered goal-setting and coaching, education, resource referral, and support-network building	Spinal cord injury	Lay leaders	Telephone	Yes	No	No	Yes	Yes	Unclear	No	Yes
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1	House	2018	UK	Standardized supported self-management - goal setting, resources and barriers influencing success in reaching goals, and self-monitoring of goal attainment	Type 2 Diabetes with intellectual disability	HCPs	Home	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
2															
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7	Jaipakdee	2015	Thailand	Diabetes self-management support (DSMS) with a computer-assisted instruction	Diabetes	HCPs	Community based	No	Yes	No	No	No	Yes	No	Yes
8															
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11	James	2015	Australia	ENRICH: Exercise and Nutrition Routine Improving Cancer Health	Cancer survivors	HCPs	Community based	Yes	Yes	No	Yes	Yes	Yes	No	Yes
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15	Jiang	2019	China	Self-efficacy-focused structured education programme provided diabetes-related knowledge and DSM skills based on self-efficacy theory	Type 2 Diabetes	HCPs	Outpatient clinic	Yes	Yes	No	No	No	Unclear	No	Yes
16															
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22	John	2013	UK	Cognitive Behavioural Education Programme - challenge their way of thinking, changing maladaptive coping skills, cognitions or emotions to lead to more adaptive changes in behaviour	Rheumatoid Arthritis	HCPs	Outpatient clinic	Yes	Yes	No	No	No	Unclear	No	Yes
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32															
33	Ju	2018	China	Peer support provided with usual education	Diabetes	Lay leaders	Community based	No	No	No	No	No	Unclear	No	Yes
34															
35	Kasteleyn	2015	The Netherlands	Three home visits by a diabetes nurse to increase self-efficacy and illness perceptions	Type 2 Diabetes and first acute coronary event	HCPs	Home	Yes	Yes	Yes	Yes	Yes	Yes	No	No
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1	Kessler	2018	France, Germany, Italy, Spain	Adapted Living well with COPD Programme - home monitoring and e-health through telephone/web platform	COPD	HCPs	Home and Telephone and web-based platform	Yes	No	Yes	Yes	No	Yes	Yes	No
2															
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4															
5	Kooijmans	2017	The Netherlands	HABITS intervention - optimizing intentions toward a healthier lifestyle and improving perceived behavioural control	Spinal cord injury	HCPs	Community based and home	Yes	No	No	Yes	No	Yes	Yes	No
6															
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11	Laakkonen	2016	Finland	Self-management group rehabilitation to enhance participants' mastery, self-efficacy, and problem-solving skills and to empower them	Dementia	HCPs	Community based	Yes	Yes	No	No	No	Unclear	No	Yes
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19	Lopez-Lopez	2020	Spain	Physical therapy exercise plus self-management program with education and a problem-based session	COPD	Healthcare professional	Inpatient	Yes	No	No	No	No	Unclear	No	Yes
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25	Luciano	2011	Spain	Psychoeducation Program included information about symptoms, comorbid conditions, potential causes, psychosocial factors, current treatments, exercise, and barriers to behavior change and training for relaxation, pain relief, and stress reduction	Fibromyalgia	HCPs	GP practice	Yes	Yes	No	Yes	Yes	No	No	Yes
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38	Ludman	2016	USA	self-management support service – depression self-management training, recovery coaching, and care coordination	Depression	HCPs and Lay leaders	Community based and telephone	Yes	No	Yes	Yes	No	No	Yes	Yes
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1	Manning	2014	UK	Education, Self-Management, and Upper Extremity Exercise Training in People with Rheumatoid Arthritis [EXTRA] program	Rheumatoid Arthritis	HCPs	Outpatient clinic	Yes	Yes	No	Yes	No	Yes	No	Yes
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6	Mansouri	2019	Iran	Oral and Written Education Program	Heart failure	HCPs	Outpatient clinic	Yes	Yes	No	No	No	Unclear	No	Yes
7															
8	Markle-Reid	2018	Canada	The program offered up to 3 in-home visits; monthly group wellness sessions; monthly case conferences; and ongoing nurse-led care coordination.	Type 2 Diabetes with 3+ comorbidites	HCPs and Lay leaders	Community based and home	Yes	No	No	Yes	No	Unclear	Yes	No
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15	Marsden	2009	Australia	Community Living After Stroke for Survivors and Carers' (CLASSiC) - each session included a 1-hour physical activity followed by a 1-hour education delivered via presentations, group discussions and group activities	Stroke	HCPs	Outpatient clinic	Yes	Yes	No	Yes	Yes	Yes	No	No
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27	Miller	2020	Canada	COMMENCE - chronic pain self-management support with pain science education and exercise	Chronic pain	Healthcare professional	Community Based	Yes	Yes	Yes	Yes	No	No	No	Yes
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32	Minshall	2020	Australia	Stroke Care Optimal Health Program (SCOHOP) Workbook based psychsocial intervention with education, self-management and reflective exercises	Stroke	Healthcare professional	Outpatient or Home or Telephone	Yes	Yes	No	Yes	Yes	Unclear	No	No
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1	Mohammadpour	2015	Iran	A supportive educational intervention plus follow up telephone calls with information on functions of cardiovascular system, aetiology, management of MI risk factors, adherence to treatment and dietary regimens	Myocardial Infarction	HCPs	Outpatient clinic and Telephone	Yes	Yes	No	No	No	Unclear	No	Yes
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11	Muchiri	2016	South Africa	Nutrition Education Programme	Diabetes	HCPs	Community based	Yes	Yes	No	Yes	Yes	Yes	No	No
12															
13	Nguyen	2018	Vietnam	CKD booklet and a handout, one face-to-face session and two brief follow-up sessions.	Chronic Kidney Disease	HCPs	Outpatient clinic and Telephone	Yes	Yes	No	No	No	Unclear	No	Yes
14															
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16															
17	O'Toole	2021	Ireland	OPTIMAL intervention promoting accomplishments, vicarious learning, persuasion, interpretation of emotional states	Multimorbidity	Healthcare professional	Community Based	Yes	Yes	Yes	Yes	Yes	Yes	No	No
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24	P'erez-Escamilla	2015	USA	Culturally tailored diabetes education and counselling treatment group including education, skills, and support in the areas of nutrition, physical activity, blood glucose monitoring, medication adherence, and medical appointments.	Type 2 Diabetes	HCPs	Home	Yes	No	No	No	No	Unclear	Yes	Yes
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1	Pinxsterhuis	2017	Norway	self-management program for coping with their illness and dealing with healthcare professionals and family, developed through educational presentations, the exchange of experiences, modelling of self-management skills, guided mastery practice, and informative feedback.	Chronic fatigue syndrome	HCPs and Lay leaders	Outpatient clinic	Yes	Yes	No	Yes	Yes	Yes	No	No
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14	Ridsdale	2018	UK	Self-management education for people with poorly controlled epilepsy (SMILE [UK]), based on MOSES	Epilepsy	HCPs	Community based	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
15															
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18															
19	Rothschild	2014	USA	Mexican American Trial of Community Health Worker (MATCH) knowledge and skills in diabetes self-management, with opportunities to practice goal setting and self-management.	Type 2 Diabetes	HCPs	Home	Yes	Yes	No	Yes	No	No	Yes	Yes
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28	Sajatovic	2018	USA	TargetEd MAnageMent Intervention [TEAM]	Stroke and TIA	HCPs and Lay leaders	Outpatient clinic and Telephone Community based	Yes	Yes	No	Yes	No	Unclear	No	Yes
29															
30	Salyers	2014	USA	Illness management and recovery - Incorporating psychoeducation, cognitive-behavioral approaches, relapse prevention, social skills training, and coping skills training.	Schizophrenia or schizoaffective disorder	HCPs	Community based	Yes	No	No	Yes	No	No	Yes	No
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39	Smeulders	2010	The Netherlands	CDSMP	Congestive Heart Failure	HCPs and Lay leaders	Outpatient clinic	Yes	Yes	No	Yes	No	Unclear	No	No
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1	Spencer	2011	USA	Racial and Ethnic Approaches to Community Health (REACH) Initiative - setting patient specific goals and supporting their progress	Diabetes	HCPs	Outpatient clinic and Home and Telephone	Yes	Yes	No	Yes	Yes	No	No	Yes
2															
3															
4															
5															
6	Still	2021	USA	TechSupport, integrating technology based components and emotional/empathic components known as positive psychological training	Hypertension	Healthcare professional	Web-based	Yes	Yes	Yes	Yes	Yes	Yes	No	No
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14	Stuifbergen	2010	USA	The Lifestyle Counts intervention developed from the Wellness for Women with MS curriculum	Fibromyalgia	HCPs	Outpatient clinic and Telephone	Yes	Yes	No	Yes	No	Yes	No	No
15															
16															
17															
18															
19	Swoboda	2016	USA	Multiple-Goal Intervention - combination of goal setting and decision support coaching	Diabetes	HCPs	Outpatient clinic and Telephone	Yes	No	Yes	Yes	No	No	No	Yes
20															
21															
22															
23	Taggart	2017	UK	DESMOND-ID (Diabetes and Self-Management for Ongoing and Newly Diagnosed for patients with Type 2 diabetes)	Type 2 Diabetes with intellectual disability	HCPs	Community based	Yes	Yes	No	Yes	No	Yes	Yes	Yes
24															
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29	Thoolen	2009	The Netherlands	Beyond Good Intentions – a 12-week self-management course	Type 2 Diabetes	HCPs	Community based	Yes	Yes	No	No	No	Unclear	No	Yes
30															
31															
32	Van der Meer	2009	The Netherlands	Internet based self-management program asthma control monitoring and treatment advice, online and group education, and remote Web communications with a specialized asthma nurse.	Asthma	HCPs	Web-based and Unclear	Yes	Yes	No	Yes	No	Unclear	No	Yes
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1	van Erp	2019	Netherlands	Back on Track education, self-management and goal setting intervention, including cognitive behavioural approaches	Chronic lower back pain	Healthcare professional	Community Based	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
2																
3																
4																
5																
6	Van Rooijen	2010	South Africa	Dietary and physical activity education for ongoing nutrition self-management and physical activity	Type 2 Diabetes	HCPs	Outpatient clinic	Yes	No	No	No	No	Unclear	No	No	Yes
7																
8																
9																
10																
11	Vos	2019	The Netherlands	Beyond Good Intentions	Type 2 Diabetes	HCPs	Community based	Yes	Yes	No	No	No	Unclear	No	No	No
12																
13	Walker	2011	USA	Telephonic behavioural intervention focused on medication adherence and lifestyle changes through healthy eating and physical activity	Type 2 Diabetes	HCPs	Telephone	Yes	No	No	Yes	Yes	Unclear	No	No	Yes
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20																
21	Walsh	2020	UK	FASA facilitating activity and self-management through problem solving and exercise derived from ESCAPE intervention	Lower limb osteoarthritis and chronic lower back pain	Healthcare professional	Community Based	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes
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26																
27	Wang	2016	Singapore	The Myocardial Infarction Home-based Self-management Programme (MIHSMP) with Heart Recovery Education Booklet (HREB)	Myocardial Infarction	HCPs	Outpatient clinic and Telephone	Yes	Yes	No	No	No	Unclear	No	No	No
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33																
34	Wang	2018	Singapore	Coronary Heart Disease Self-management Programme (CHDSMP)	Coronary Heart Disease	HCPs	Home and Telephone	Yes	Yes	No	No	No	Unclear	No	No	No
35																
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38																
39	Webel	2010	USA	Positive Self-Management Program (PSMP)	HIV	Lay leaders	Community based	Yes	Yes	No	No	No	Unclear	No	No	No
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42																
43																
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1	Wegener	2009	USA	Promoting Amputee Life Skills Self-management program	Limb loss	HCPs and Lay leaders	Community based	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
2															
3	Wolf	2017	USA	CDSMP	Stroke	HCPs	Outpatient clinic	Yes	Yes	Yes	No	No	Unclear	No	No
4															
5	Wu	2017	Australia and Taiwan	T-CDSMP adapted for Taiwanese speaking	Cardiovascular disease and Diabetes	HCPs	Outpatient clinic and Telephone	Yes	Yes	No	No	No	Unclear	No	No
6															
7	Wu	2018	Taiwan	Innovative self-management intervention a video, trainee manual, participation in the self-efficacy-enhancing program, and telephone interviews	End Stage Renal Disease	HCPs	Outpatient clinic and Telephone	Yes	Yes	Yes	No	No	Unclear	No	Yes
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15															
16	Yip	2008	Hong Kong	ASMP with added goal-directed exercise component	Osteoarthritis	HCPs	Outpatient clinic	Yes	Yes	No	No	No	Unclear	No	Yes
17															
18	Young	2016	China	Psycho-education group understanding dementia, coping skills, exercise, diet, mood, own strengths, accepting change, communication, relationships, the future	Major neurocognitive disorder	HCPs	Community based	Yes	Yes	No	No	No	Unclear	No	No
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27	Zakrisson	2018	Sweden	Self-management intervention based on Bandura's theory of self-efficacy using techniques such as performance mastery, modelling, interpretation of symptoms, and social persuasion	COPD and Coronary Heart Failure	HCPS	Community based	Yes	Yes	No	Yes	Yes	Unclear	Yes	No
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35	Zhang	2015	USA	Stay Dry program biofeedback pelvic floor muscle exercise plus a support group or telephone contact	Prostate cancer with urinary incontinence	HCPs	Telephone and unclear	Yes	Yes	No	No	No	Unclear	No	Yes
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BMJ Open

Reporting dose in complex self-management support interventions for long-term conditions: is it defined by researchers and received by participants? - a systematic review

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3 **Reporting dose in complex self-management support**
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6 **interventions for long-term conditions: is it defined by**
7
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9 **researchers and received by participants? - a systematic**
10
11 **review**
12
13

14
15 Tasmin A Rookes, Neurology Department (U3), Royal Free Hospital, Rowland Hill
16 Street, London, NW3 2PF, t.rookes@ucl.ac.uk, 07896878267, University College
17
18 London, Institute of Neurology, London, UK. (Corresponding Author).
19
20
21
22

23
24 Atena Barat, Yvonne Carter Building, 58 Turner Street, London, E1 2AB,
25
26 a.barat@qmul.ac.uk, Queen Mary University of London, Wolfson Institute of
27
28 Population Health, London, UK
29
30
31

32
33
34 Rebecca M Turner, 90 High Holborn, London, WC1V 6LJ, becky.turner@ucl.ac.uk,
35
36 University College London, Institute of Clinical Trials and Methodology, London, UK
37
38
39

40
41 Steph JC Taylor, Yvonne Carter Building, 58 Turner Street, London, E1 2AB,
42
43 s.j.c.taylor@qmul.ac.uk, Queen Mary University of London, Wolfson Institute of
44
45 Population Health, London, UK
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50 Key words: Public Health, Primary Care, Statistics and Research Methods, Protocols
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52 and Guidelines.
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57 Word Count:

58
59 Abstract: 299 and Main text: 3536
60

Abstract:

Background: The minimum clinically effective dose, and whether this is received in randomised controlled trials (RCTs) of complex self-management interventions in Long-Term Conditions (LTCs), can be unclear. The Template for Intervention Description and Replication (TIDieR) checklist states that dose should be clearly reported to ensure validity and reliable implementation.

Objectives: To identify whether the expected minimum clinically effective dose, and the dose participants received is reported within research articles and if reporting has improved since the TIDieR checklist was published.

Methods: Four databases were systematically searched (MEDLINE, PsycINFO, AMED and CINAHL) to identify published reports between 2008 and 2022 for RCTs investigating complex self-management interventions in LTCs. Data on reporting of dose was extracted and synthesised from the eligible articles.

Results: 94 articles covering various LTCs including diabetes, stroke and arthritis were included. Most complex interventions involved behaviour change combined with education and/or exercise. The maximum dose was usually reported (n=90; 97.8%), but the expected minimum clinically effective dose and the dose received were reported in only 28 (30.4%) and 62 (67.4%) of articles, respectively. Reporting of the expected minimum clinically effective dose and the dose participants received did not improve following the publication of the TIDieR checklist in 2014.

1
2
3 **Conclusions:** Interpreting results and implementing effective complex self-
4 management interventions is difficult when researchers' reporting of dose is not in
5 line with guidelines. If trial findings indicate benefit from the intervention, clear
6 reporting of dose ensures reliable implementation to standard care. If the results are
7 non-significant, detailed reporting enables better interpretation of results i.e.,
8 differentiating between poor implementation and lack of effectiveness. This ensures
9 quality of interventions and validity and generalisability of trial findings. Therefore,
10 wider adoption of reporting the TIDieR checklist dose aspects is strongly
11 recommended. Alternatively, customised guidelines for reporting dose in complex
12 self-management interventions could be developed.
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28 **Registration:** Prospero ID CRD42020180988

29 **Keywords:** dose; reporting; complex self-management intervention; long-term
30 condition; systematic review; TIDieR checklist; fidelity
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38 **Strengths and limitations of this study:**

- 39 • This is the first systematic review to explore whether dose is being reported
40 as the guidelines recommend in randomised trials of self-management
41 interventions.
42
- 43 • Double screening and data extraction was completed, following piloting,
44 ensuring all eligible papers were included and accurate data extracted.
45
- 46 • Determining complex self-management study eligibility was challenging, but
47 we developed a systematic approach to limit potential bias.
48
- 49 • Quality assessment of eligible papers was not conducted, but it could have
50 been interesting to see if quality of study correlated with quality of reporting.
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Background:

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6 It is estimated that 30% of the UK population live with a Long-Term Condition (LTC)
7
8 and that LTCs account for 70% of health and social care spending within the NHS
9
10 (1). This prevalence extends globally, where LTCs are the leading cause of ill health
11
12 and result in 70 percent of all deaths (2), with a growing awareness of the
13
14 importance of monitoring prevalence and developing interventions to overcome
15
16 LTCs, due to the aging population, predicted increase in LTCs and the associated
17
18 costs (3, 4). Therefore, the management of LTCs is a priority for the NHS. LTCs are
19
20 defined as “diseases of long duration and are the result of a combination of genetic,
21
22 physiological, environmental and behavioural factors” (5). The current evidence base
23
24 suggests LTC treatment should focus on supporting effective self-management to
25
26 result in better health outcomes (6). Self-management here is defined in conjunction
27
28 with the US Institute of Medicine definition, echoed by the Department of Health;
29
30 “Self-management is defined as the tasks that individuals must undertake to live with
31
32 one or more chronic conditions. These tasks include having the confidence to deal
33
34 with medical management, role management and emotional management of their
35
36 conditions.” (7, 8).
37
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45 Complex self-management interventions are known to improve a variety of health
46
47 outcomes in LTCs, including self-efficacy (confidence in ability to execute specific
48
49 behaviours), patient activation (confidence, skills and knowledge to manage their
50
51 own health care), self-rated health, clinical outcomes and social outcomes (9).
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54 Complex self-management interventions contain several interacting components that
55
56 aim to change patients’ behaviour. However, determining which parts of the complex
57
58 intervention are necessary to result in a potential benefit can be difficult. Therefore,
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3 complex self-management interventions should go through stages of development
4 before being evaluated, typically in randomised control trials (RCTs), to identify how
5 much of which components result in the best outcomes (10). Once decided upon, at
6 least the expected minimum clinically effective dose of the complex self-
7 management intervention should be compared to standard care for the LTC to see if
8 health outcomes improve. However, in published reports of RCTs it is often unclear
9 how the minimum clinically effective dose of the intervention was determined or,
10 indeed, what the researchers believe the expected minimally clinically effective dose
11 to be.
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26 The concept of dose refers to the number of intended units of each intervention
27 (dose delivered) and the extent of engagement of participants with the intervention
28 (dose received) (11). Treatment fidelity refers to the extent to which the intervention
29 is delivered as expected, how much of the intervention is received and the amount of
30 treatment enactment of the intervention by participants. Focussing on fidelity of
31 treatment receipt, if the number and length of sessions received is in line with that
32 stated in the protocol, it is essential researchers determine what they think the
33 minimum clinically effective dose is and measure if it is received by participants
34 within the trial, so fidelity of treatment receipt can be assessed (12, 13). This is
35 determined through discussions between those involved in the development of the
36 intervention, to decide what they expect the minimum number of sessions attended
37 are needed to result in a meaningful change. There are two possible explanations for
38 why this information is not reported, either researchers are not having these
39 conversations during intervention development, or they are not reporting what this
40 should be in their methods and papers. Collecting and reporting this information
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3 ensures the quality and integrity of the intervention and enables assessment of how
4 valid and generalisable the findings are (11). Additionally, not stating the expected
5 minimum clinically effective dose and if it has been delivered and received makes it
6 difficult to interpret RCT results. If trial results are non-significant and fidelity of
7 treatment receipt is not reported, it is unclear if this result is due to a lack of
8 effectiveness or failed implementation of the intervention. Ensuring non-significant
9 effects are due to lack of intervention effectiveness helps to avoid a type ii error,
10 whereby the treatment is deemed not effective when the findings are due to
11 confounding variables, such as poor implementation (14).
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26 To improve the reporting of all types of interventions the Template for Intervention
27 Description and Replication (TIDieR) checklist (15) was developed in 2014. The 12
28 items explain how interventions should be described in published articles, so that
29 trials with effective interventions can be replicated validly and implemented into
30 standard practice reliably. The intervention details required for non-pharmacological
31 interventions, such as the behavioural and educational components used in complex
32 self-management interventions, are explained. Focusing on dose, Item 8 of the
33 checklist highlights 'when and how much', whereby RCT articles should clearly state
34 the number of sessions in the intervention, their duration and over what time period
35 they are delivered. Also, Items 11 and 12 of the checklist state that the planned,
36 delivered and received doses should be included to ensure both adherence and
37 fidelity can be assessed (outlined in Table 1). No previous, published reviews within
38 the LTC complex self-management literature have reviewed whether dose and
39 fidelity are being reported in this way.
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58 Table 1. Extract from the TIDieR checklist of the relevant item descriptions for this
59 review.
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TIDieR Checklist Item	Description
Item 8	When and how much: Describe the number of times the intervention was delivered and over what period of time including the number of sessions, their schedule, and their duration, intensity or dose
Item 11	How well (planned): If intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them
Item 12	How well (actual): If intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned

This systematic review aimed to identify how complex self-management intervention doses for patients with LTCs are reported in RCTs. We assessed this by evaluating whether what the researchers believe to be the minimum clinically effective dose was stated, how this dose was determined, if the dose received by study participants was stated and how it compared to the expected minimum clinically effective dose (fidelity of treatment receipt). We also aimed to determine if reporting of expected minimum clinically effective dose and treatment dose received improved following the publication of the TIDieR checklist in 2014. Finally, we aimed to identify whether reporting of expected minimum clinically effective dose and treatment dose received differed depending on whether the primary outcome results were statistically significant or not. We hypothesised that reporting of dose would have improved since the publication of the TIDieR checklist and that studies with non-significant primary outcomes may report dose more clearly than studies with a significant outcome in an attempt to explain their results.

Methods:

Search strategy for systematic review and inclusion and exclusion criteria

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3 The systematic review was conducted in accordance with PRISMA (16)
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5 (Supplementary Table 1). MEDLINE, CINAHL, AMED and PsychInfo were
6
7 systematically searched. The full search strategies were developed in consultation
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9 with the UCL Library team and can be found in Supplementary Figure 1. Publications
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11 were included if published between January 2008 and June 2020, to identify if there
12
13 was a trend towards improved reporting of treatment dose from 6 years before to 6
14
15 years after the TIDieR checklist was published (2014). An update of the review was
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17 conducted, searching the literature between June 2020 and January 2022. The
18
19 same methodological process was followed.
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26 ***Inclusion criteria (PICOS)***

- 27 • Population: populations with long-term conditions (5)
- 28 • Intervention: complex self-management support with structured session(s)
29 (containing several interacting components that aim to change patients'
30 behaviour), delivered to patients (7, 8)
- 31 • Comparator: any
- 32 • Outcome: any
- 33 • Study Design: randomised controlled trials

34 ***Exclusion criteria***

- 35 • Does not include human participants
- 36 • Not a complex self-management support intervention with structured sessions
37 e.g., exercise or psychotherapy only interventions
- 38 • Interventions delivered to carers, health care professionals etc.
- 39 • Only published as an abstract
- 40 • Ongoing studies

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5 The articles from the database searches were exported into EndNote, duplicates
6 removed, and brief screening completed (e.g., removing systematic reviews). Those
7 remaining were uploaded into Abstrackr (<http://abstrackr.cebm.brown.edu/>) and the
8 two reviewers (TR and AB) independently screened titles and abstracts against the
9 inclusion criteria, classifying articles as included, excluded and maybe eligible. For
10 the update, Rayyan was used instead of Abstrackr, as the software was more user
11 friendly. Forward and backward citation screening was performed on eligible papers.
12 Identified discrepancies were discussed with ST to reach a final decision for full text
13 data extraction.
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28 **Data extraction and analysis**

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30 Data was independently extracted by TR and AB onto a Word based proforma
31 designed for the study and any disagreements discussed until consensus was
32 reached.
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40 For all studies we extracted trial authors, country, year of publication, intervention
41 name, intervention description and components, LTC disease area, maximum
42 intervention dose that could be delivered in the context of their study, expected
43 minimum clinically effective dose, any rationale given for this, actual dose received,
44 fidelity of treatment receipt and intervention delivery, and statistical significance of
45 the primary outcome.
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56 Within the articles, reporting of dose was determined by the number and length of
57 sessions available to participants and how many they attended. Minimum expected
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3 clinically effective dose was either explicitly stated or stated as the number of
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5 sessions needed to be attended to be considered a 'completer' or to be included in
6
7 the per protocol analysis. If no detail was provided, then this was recorded as 'not
8
9 reported'. An example of the data extraction process can be seen in Supplementary
10
11 Table 2. Due to the subjective interpretation of some data points, we piloted this
12
13 process to ensure accurate and consistent interpretation. The Items included from
14
15 the TIDieR checklist are outlined in Table 1.
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21 As this was a review of trial reporting, rather than of trial findings, a formal quality
22
23 assessment was not undertaken. Simple summary statistics were used to report the
24
25 percentage of trials reporting the various aspects of dose.
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28 No patients were involved in research project.
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33 **Results**

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35 In the original search, after database searching and deduplication, 14661 titles and
36
37 abstracts were screened for data extraction and 124 full-text articles screened for
38
39 eligibility, of which 82 were included in the synthesis. For the update 2311 titles and
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41 abstracts were screened, 35 were full-text screened, with 12 papers included. See
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43 Figure 1 PRISMA flow diagram.
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49 **Characteristics of included RCTs**

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51 The population and intervention characteristics varied among the RCTs included.
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53 With 27 different LTCs investigated across the 94 articles, including diabetes, cancer
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55 survivors, COPD, dementia, arthritis, stroke, serious mental illness and HIV. The
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57 complex self-management interventions investigated included Chronic Disease Self-
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3 Management Program (CDSMP (17)), Arthritis Self-Management Program (ASMP
4 (18)), health education programs (19-21), health education combined with exercise
5 programs (22-24), Cognitive Behavioural Approaches (25, 26), and problem-solving
6 and goal setting (27-29). The number of sessions for the intervention ranged from 2
7 to over 30. A summary of the LTCs, self-management interventions and number of
8 sessions are presented in Tables 2, 3 and 4, respectively. Further details of all
9 included articles are supplied in Supplementary Table 3, with the full reference list of
10 included trials in Supplementary Figure 2.
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22 Table 2. LTCs investigated in the 94 articles included in the systematic review.
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24 Long Term Conditions Investigated	25 Number of Trials (%)
26 Type 1 and/or 2 Diabetes	25 (27%)
27 Fibromyalgia	2 (2%)
28 Epilepsy	2 (2%)
29 Chronic Hepatitis C	1 (1%)
30 Cancer Survivorship	4 (4%)
31 Dementia/Neurocognitive disorder	2 (2%)
32 Hypertension	3 (3%)
33 Arthritis	11 (11%)
34 HIV	2 (2%)
35 Spinal Cord Injury	3 (3%)
36 COPD	4 (4%)
37 Amputation	2 (2%)
38 Stroke	8 (9%)
39 Multiple Sclerosis	1 (1%)
40 Psychosis	3 (3%)
41 Serious Mental Illness	3 (3%)
42 Heart Failure	3 (3%)
43 Asthma	2 (2%)
44 Myocardial Infarction	2 (2%)
45 Generic Chronic Somatic Disease	1 (1%)
46 Depression	1 (1%)
47 Chronic Kidney Disease	2 (2%)
48 Chronic Fatigue Syndrome	1 (1%)
49 Coronary Heart Disease	1 (1%)
50 Skin Picking	1 (1%)
51 Chronic Pain	2 (2%)
52 Multimorbidity	2 (2%)
53 Total	54 94 (100%)

Table 3. Complex self-management interventions in the 94 trials included in the systematic review.

Complex Self-Management Intervention	Number of Trials (%)
Chronic Disease Self-Management Program	9 (10%)
Health Education	32 (35%)
Health Education Combined with Exercise	14 (15%)
Cognitive and Behaviour Change Approach	10 (11%)
Problem Solving and Goal Setting	16 (17%)
Arthritis Self-Management Program	3 (3%)
Other	10 (11%)
Total	94 (100%)

Table 4. Number of sessions delivered in the 94 trials included in the systematic review.

Number of Sessions	Number of Trials (%)
1	0
2-6	44 (48%)
7-12	34 (37%)
>12	15 (16%)
Unclear	1 (1%)
Total	94 (100%)

Reporting of Dose

Of the 94 trials included, 90 (97.8%) reported the maximum number of sessions that could be delivered, 72 (78.3%) reported the length of these sessions and 28 (30.4%) reported the expected minimum clinically effective dose. Of the 28 reporting the expected minimum clinically effective dose, 12 (42.9%) justified how this had been determined. In addition, 62 (67.4%) reported what dose participants received and 48 (52.2%) discussed if this was equal to, or greater than, that scheduled to be delivered in the protocol (fidelity of treatment receipt). It was unclear in 44 articles (47.8%) whether the expected minimum clinically effective dose had been received by participants, as no detail was provided. Of the 48 studies where this information was present, in 36 (75.0%) participants received the expected minimum clinically effective dose, which for 11 of these (22.9%) was also the maximum dose available.

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No improvement in reporting of dose since the publication of the TIDieR checklist was observed. Of the 31 articles published between 2008 and 2014 and the 63 published between 2015 and 2022, 6 (19.4%) and 22 (34.9%), respectively, reported the expected minimum clinically effective dose. Of the 31 articles published between 2008 and 2014 and the 63 published between 2015 and 2022, 22 (71.0%) and 40 (63.5%), respectively, reported the number of sessions received and 15 (48.4%) and 28 (44.4%), respectively, reported the length of sessions received. The percentage of trials reporting the expected minimum clinically effective dose, as number of sessions, and the treatment dose participants received per year are represented in Figure 2.

Reporting of the expected minimum clinically effective dose, or the dose received did improve based on the statistical significance of the trial's primary outcome. Of the 55 articles with a significant primary outcome result and the 39 with a non-significant primary outcome result, 12 (21.8%) and 16 (41.0%), respectively, reported the expected minimum clinically effective dose. Of the 55 articles with a significant primary outcome result and the 39 with a non-significant primary outcome result, 31 (56.4%) and 31 (79.5%), respectively, reported the dose received.

Discussion

The included trials covered a variety of LTCs and self-management interventions. As expected, almost all the trials included in this systematic review reported the maximum number of sessions and just over three quarters reported the length of sessions of the complex self-management intervention. Less than a third reported

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3 the expected minimum clinically effective dose and, when this was reported, less
4 than half explained how this had been determined. Just over two thirds reported the
5 number of sessions dose and under half reported length of sessions dose
6 participants received and within these even fewer discussed whether there was
7 fidelity of treatment receipt, i.e., if the dose received was equal to or greater than that
8 specified in the protocol. Improvements in the reporting of the expected minimum
9 clinically effective dose or the dose received were not seen after the TIDieR checklist
10 was published in 2014. However, there was an improvement in the reporting of these
11 doses depending on whether the primary outcome was statistically significant or not,
12 with those with non-significant results reporting the expected minimum clinically
13 effective dose and dose received more often than those with statistically significant
14 differences.

33 **Results in Context**

35 In RCTs of complex self-management interventions in patients with LTCs it is often
36 difficult for the maximum dose to be received by all participants, due to the
37 complexity of both the participants' disease and the intervention itself. However, the
38 number of sessions attended and amount of contact with the intervention leader(s) is
39 often associated with improved patient outcomes (20, 30). It is well documented that
40 receiving 4 of the 6 sessions available in CDSMP results in a beneficial clinical effect
41 (31). Of the 9 papers investigating CDSMP in this review, 4 papers discussed this
42 minimum clinically effective dose. If no minimum clinically effective dose is stated,
43 interpreting whether the dose participants received was greater than, or equal to, the
44 minimum dose needed to see an improvement (fidelity of treatment receipt) is almost
45 impossible, unless all participants receive the maximum dose available, which is
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3 uncommon (14). If the minimum clinically effective dose is stated and received by
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5 participants, then a negative result might be interpreted as an ineffective
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7 intervention. If the dose is not received then a negative result could be due to poor
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9 implementation of the intervention, rather than a lack of effectiveness. Therefore, by
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11 not reporting the dose received, potentially effective interventions could be
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13 abandoned, due to the results not being able to be interpreted in relation to the dose
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15 received, resulting in a type ii error (14, 32).
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22 If the dose received is stated and is low, further investigation can be done by trial
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24 authors or other researchers to determine how it relates to patient outcomes i.e., due
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26 to poor trial and/or intervention design. Collecting this information and reporting it
27
28 enables those implementing the intervention to know what and how much needs to
29
30 be received to ensure the best outcomes. In the Ackerman et al. trial (33), 27% of
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32 those approached to participate declined, as they could not attend all 6 ASMP
33
34 sessions, and of those who were recruited many did not attend. Adaptations were
35
36 made to avoid this, such as booking venues close to participants' homes and
37
38 scheduling on varying days and times. As the authors provided this detail, future
39
40 researchers are aware of these potential challenges and, in their trials, could adapt
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42 the intervention to be delivered another way i.e., home-based, via telephone or web-
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44 based to make it more accessible and improve recruitment and retention. Also, if
45
46 policymakers have this information when designing guidelines and making
47
48 recommendations for scaling up interventions into standard care, effects seen in
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50 trials are more likely to be translated into routine care (34-36).
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3 In addition, researchers must take the time within the early developmental phases of
4 an intervention to ensure the expected minimum clinically effective dose is estimated
5 as accurately as possible, through pilot studies, systematic reviews and/or
6 longitudinal research (10). Although difficult, this focus on early development would
7 prevent fully funded RCTs going ahead when the minimum clinically effective dose
8 has not been determined or measured.
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19 Even when fidelity is mentioned within trial papers, the focus is often on how it was
20 assessed rather than the actual findings, limiting the use of fidelity data to interpret
21 the trial findings, and making the fidelity assessment almost useless (37-39).
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26 Understanding the reasons why fidelity is poorly reported is complex, but it is thought
27 to be attributed to lack of knowledge and the practicalities of comprehensively
28 assessing fidelity within an RCT (40). Despite the extra resources needed to conduct
29 a full assessment of fidelity, the economic and scientific costs of not completing and
30 reporting fidelity outcomes are far greater (14). Variations in intervention delivery
31 within trials may influence efficacy and result in biased conclusions.
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42 Although the TIDieR checklist was designed to improve reporting of interventions, no
43 improvement in the reporting of the expected minimal clinically effective dose and
44 dose received was found in this review. Also, within the articles, there was little to no
45 mention of the TIDieR checklist and reporting of interventions in accordance with it,
46 in line with other systematic reviews. Investigating implementation in the
47 cardiovascular medicine literature, Palmer et al. (2020) (41) found over one fifth
48 failed to report the dose of the treatment received (Item 11). Within behaviour
49 change research similar results to this review have been found (42), with the
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3 maximum dose available always reported, but other elements of dose poorly
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5 described.
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10 An improvement in reporting of dose was seen in studies reporting non-significant
11 results. It is possible that, due to publication bias, reporting standards of studies that
12 are published with non-significant results are of higher quality than studies with
13 significant results.
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21 An alternate explanation is that researchers may be less familiar with the TIDieR
22 checklist, due to the dissemination being less extensive than other reporting
23 guidelines e.g., CONSORT and PRISMA (41). Therefore, broader dissemination of
24 the TIDieR checklist or incorporating the checklist within Item 5 of the CONSORT
25 statement, could improve reporting, as the information would be required by journals
26 for publication (41). Poor implementation of the TIDieR checklist could also be due to
27 the guidelines being too broad and generic and difficult for authors to adapt to their
28 own interventions (43). Making the TIDieR checklist clearer and developing
29 customised versions for specific intervention types could increase implementation of
30 the checklist guidelines and ultimately improve intervention description and reporting
31 (44).
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49 **Limitations**

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51 The subjective nature of determining the eligibility of trials based on whether the
52 intervention was a complex self-management intervention, could have introduced
53 bias. All those marked potentially eligible were discussed by the study team to limit
54 any potential bias and if there were any doubts the paper was included for data
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3 extraction. If consensus on eligibility could not be met, the paper was sent to a third
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5 reviewer (ST), with extensive experience in self-management support interventions
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7 for a final decision. Through these discussions decisions around eligibility for
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9 inclusion were as consistent as possible given the flexible and varied definition of
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11 complex self-management interventions within the literature.
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17 Also, a formal quality assessment was not completed, as we were not looking at the
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19 outcome measures. It could be of interest to compare the quality of study with the
20
21 accuracy of dose reporting, but this was not within the scope and capacity of this
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23 review.
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28 **Future Research**

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30 Following this review, reporting standards of complex self-management intervention
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32 doses do not appear to have improved since the publication of the TIDieR checklist.
33
34 Ensuring that guidelines provide recommendations for how to define and assess
35
36 dose within complex self-management interventions is vital for accurate reporting
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38 and so, interpretation and implementation of trial results. Therefore, either the
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40 TIDieR checklist should be updated or novel, specialised methodological guidelines
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42 developed to ensure that dose in these trials is determined, measured, and reported
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44 as accurately as possible. Additionally, looking at whether quality of study correlates
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46 to quality of reporting dose could be completed.
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54 **Conclusion**

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56 Reporting of the minimum clinically effective dose, the dose received in the trial and
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58 the fidelity of treatment receipt are not consistent in studies of complex self-
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3 management interventions for LTCs. Although this detail is outlined in the TIDieR
4 checklist, published in 2014, there has been no improvement in reporting following
5 its publication. Currently we recommend that when publishing RCTs, researchers
6 should describe the intervention dose according to the TIDieR checklist. This will
7 enable clinicians and policymakers to reliably replicate the interventions in future
8 trials and/or interpret findings to implement them into practice. Going forward, the
9 TIDieR checklist could be made clearer with versions for specific intervention types
10 and wider dissemination of the checklist to increase implementation of the guidelines
11 and improve intervention reporting. To facilitate this, funders, reviewers, and journal
12 editors should encourage dose and fidelity of treatment receipt to be collected and
13 discussed, to increase reporting in this way.
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30 **Abbreviations**

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33 RCT: Randomised controlled trial; LTC: Long-term condition; TIDieR: Template for
34 intervention description and replication; CDSMP: Chronic disease self-management
35 program; ASMP: Arthritis self-management program
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45 **Declarations**

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3 necessarily those of the NIHR, NHS or the UK Department of Health and Social
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5 Care.

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10 The views expressed in this publication are those of the author(s) and not
11
12 necessarily those of the National Institute for Health and Care Research or the
13
14 Department of Health and Social Care.

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16
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18
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20 21 **Ethical Approval Statement**

22
23 Not applicable

24 25 **Competing interests**

26
27 The authors declare that they have no competing interests

28 29 **Data sharing**

30
31 The datasets used and/or analysed during the current study are available from the
32
33 corresponding author on reasonable request.

34 35 **Author contributions**

36
37 TR, supervised by ST and RT, designed the review and conducted the searches,
38
39 data extraction, and analysis. TR and AB undertook double screening and data
40
41 extraction. The authors read and approved the final manuscript.

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46
47 Institute of Clinical Trials and Methodology, UCL and the UCL library for their
48
49 support.

50 51 **Figure legends**

52
53 Figure 1. PRISMA Systematic Review Flow Diagram

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3 Figure 2. Bar graph illustrating the percentage of trials reporting the expected
4 minimum clinically effective dose and the treatment dose received by year.
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33 [and-communities](https://www.health.org.uk/publications/at-the-heart-of-health-realising-the-value-of-people-and-communities)]
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22 physical activity behaviors improves cardiovascular disease risk factors in adults with type 2
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28 interventions vs combined behavioral weight management programs: a systematic review
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48 Management Program for people with hip and knee osteoarthritis in real-world clinical
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4 implementation of health promotion interventions: insights and recommendations from a
5 scoping review. *Implementation Science*. 2019 Dec;14(1):1-2.
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21 interventions. *Trials*. 2018 Dec;19(1):1-4.
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26 intervention fidelity within trials of health behaviour change interventions. *Health psychology*
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For peer review only

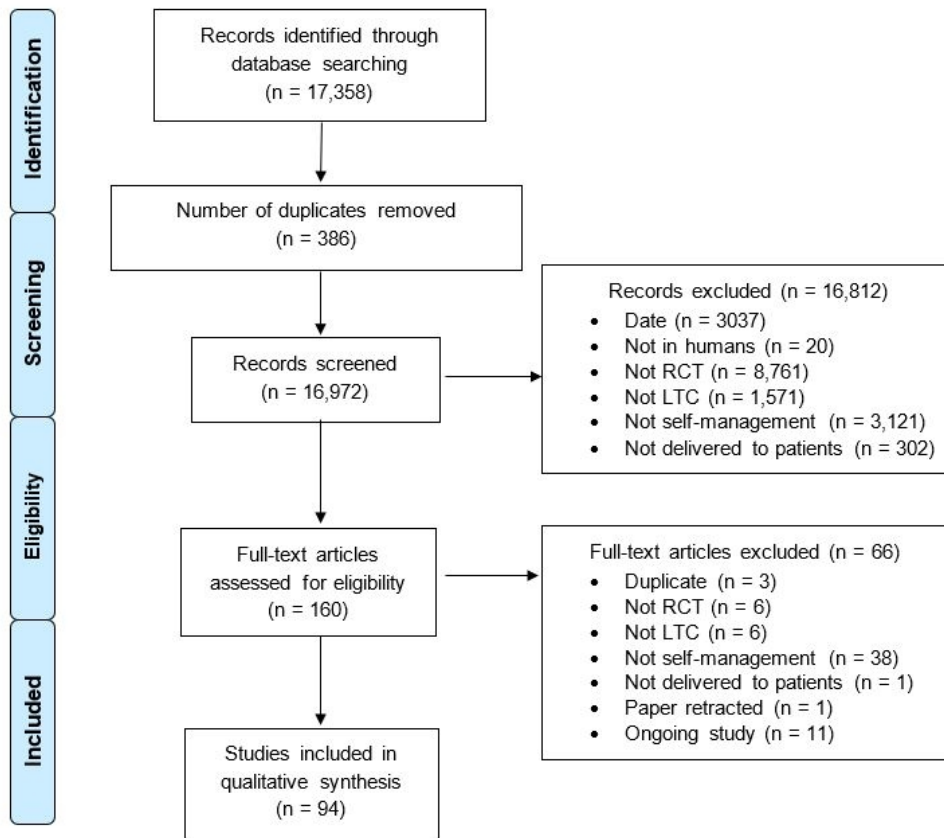


Figure 1. PRISMA Systematic Review Flow Diagram

Figure 1. PRISMA Systematic Review Flow Diagram

131x121mm (144 x 144 DPI)

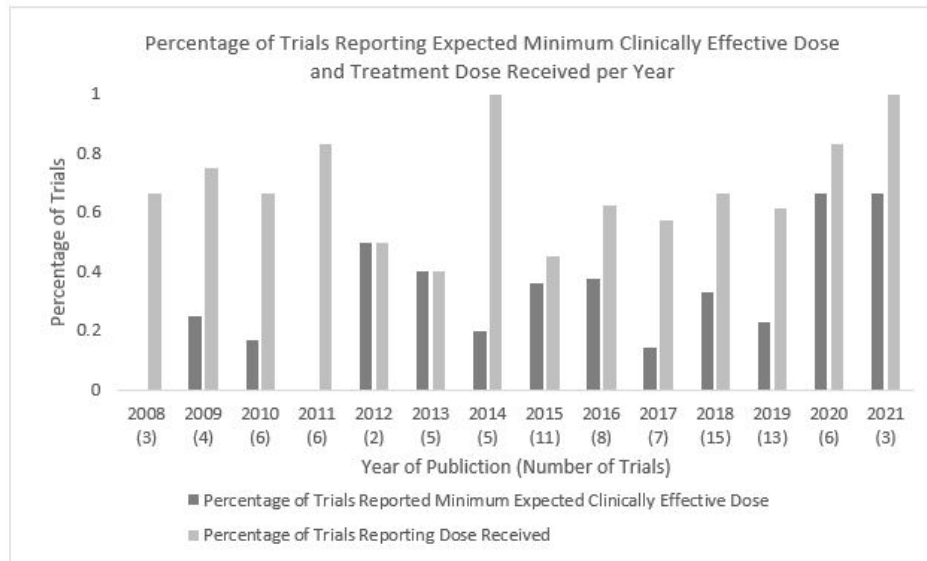


Figure 2. Bar graph illustrating the percentage of trials reporting the expected minimum clinically effective dose and the treatment dose received by year.

Figure 2. Bar graph illustrating the percentage of trials reporting the expected minimum clinically effective dose and the treatment dose received by year.

118x80mm (144 x 144 DPI)

Supplementary Figure 1. Medline, AMED, PsychINFO and CINAHL Full Search Strategies.

Medline Search Strategy

1. (Long term adj3 condition*).mp.
2. chronic*.mp.
3. ((persistent or long* term or ongoing or degenerative) adj3 (disease* or ill* or condition* or insufficienc* or disorder*)).tw.
4. long term care/
5. long* term care.tw.
6. exp cardiovascular diseases/
7. (heart disease* or heart failure or myocardial ischemia or coronary disease* or coronary artery disease* or myocardial infarction or hypertension or high blood pressure).tw.
8. sickle cell.mp.
9. exp lung diseases obstructive/
10. (obstructive lung disease* or obstructive pulmonary disease* or copd or asthma or bronchitis).tw.
11. exp emphysema/
12. exp pulmonary emphysema/
13. emphysema.tw.
14. (cystic fibrosis or respiratory distress).mp.
15. exp nervous system diseases/
16. (brain adj (disease* or damage* or injur*)).tw.
17. (cerebrovascular or brain ischemia or cerebral infarction or carotid artery disease* or stroke or epilep* or seizure*).tw.
18. (neurodegenerative or Huntingdon* or Parkinson* or amyotrophic lateral sclerosis or multiple sclerosis or motor neuron disease).tw.
19. (paralys* or quadriplegi* or tetraplegi* or paraplegi* or locked in syndrome).tw.
20. ((communication or learning or consciousness or perpetual or speech or voice or vision or hearing or psychomotor) adj disorder*).tw.
21. (hearing loss or hearing aid* or deaf* or blind* or stutter*).tw.
22. down* syndrome.tw.
23. cerebral palsy.tw.
24. exp gastrointestinal diseases/
25. (gatroenter* or intestinal or bowel or colonic).tw.
26. renal insufficiency/
27. ((renal or kidney) adj (failure* or insufficienc*)).tw.
28. diabetes mellitus/
29. (diabetes or diabetic*).tw.
30. exp nutrition disorders/
31. (underweight or malnutrition or malnourished or overweight or obes*).tw.
32. exp arthritis/
33. exp rheumatic diseases/
34. (arthritis or osteoarthritis or rheumati* or fibromyalgia).tw.
35. ((back or neck) adj pain).tw.
36. exp thyroid diseases/
37. thyroid.tw.
38. exp hypersensitivity/
39. (hypersensitivit* or allerg* or intolerance or anaphyla*).mp.
40. exp neoplasms/
41. (cancer* or oncolog* or neoplasm* or carcinom* or tumo?r* or malignan* or leuk?emia).tw.
42. exp hiv infections/

- 1
- 2
- 3 43. (hiv infect* or hiv disease*).tw.
- 4 44. exp mental disorders/
- 5 45. exp behavio?ral symptoms/
- 6 46. ((mental* or psychiatr* or psychological*) adj (ill* or disorder* or disease* or distress* or disab* or
- 7 problem* or health* or patient* or treatment)).tw.
- 8 47. ((personality or mood or dysthymic or cognit* or anxiety or stress or eating or adjustment or
- 9 reactive or somatoform or conversion or behavio?r or perception or psycho* or impulse control or
- 10 development* or attention deficit or hyperactivity or conduct or motor skills or movement or tic or
- 11 substance related) adj disorder*).tw.
- 12 48. (psychos#s or psychotic* or paranoi* or schizo* or neuros#s or neurotic* or delusion* or
- 13 depression or depressive or bipolar or mania or manic or obsessi* or compulsi* or panic or phobic or
- 14 phobia or anorexia or bulimia or neurastheni* or dissociative or autis* or Asperger* or Tourette or
- 15 dyslex* or affective or borderline or narcissis* or suicid* or self injur* or self harm or adhd).tw.
- 16 49. (((substance or drug or alcohol) adj abuse) or "substance use" or "illegal drug use" or addict* or
- 17 alcoholism or (problem* adj1 drinking)).tw.
- 18 50. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or
- 19 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37
- 20 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49
- 21 51. self efficacy/ or self care/
- 22 52. self administration/ or self assessment/ or self concept/
- 23 53. patient compliance/ or patient education as topic/ or patient participation/ or patient satisfaction/
- 24 54. consumer health information/ or consumer participation/
- 25 55. attitude to health/ or health behavio?r/ or health education/ or health knowledge, attitudes,
- 26 practice/ or health promotion/
- 27 56. life style/ or disease management/ or risk reduction behavio?r/
- 28 57. adaptation, psychological/ or motivation/ or goals/ or problem solving/ or exp decision making/
- 29 58. health plan implementation/
- 30 59. (self care or selfcare or self management or selfmanagement or self efficacy or selfefficacy or self
- 31 monitor\$ or selfmonitor\$).tw.
- 32 60. ((self or oneself) adj3 care).tw.
- 33 61. ((patient\$ or consumer\$ or client\$) adj5 (educat\$ or participat\$ or behavio?r\$ or behavio?r\$ or
- 34 compliance or centered)).tw.
- 35 62. (health adj5 (promot\$ or educat\$ or behav\$)).tw.
- 36 63. (risk adj3 reduc\$ adj3 behav\$).tw.
- 37 64. ((patient\$ or consumer\$ or client\$) adj5 manag\$ adj5 disease\$).tw.
- 38 65. (((behav\$ adj3 chang\$) or (problem\$ adj3 solv\$) or (goal\$ adj3 setting) or (decision\$ adj3 mak\$)
- 39 or coping) adj5 (patient\$ or consumer\$ or client\$)).tw.
- 40 66. 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65
- 41 67. randomized controlled trial/ or pragmatic clinical trial/
- 42 68. randomi?ed controlled trial.mp.
- 43 69. controlled clinical trial/
- 44 70. randomized controlled trial/
- 45 71. double-blind method/ or random allocation/ or single-blind method/
- 46 72. Clinical Trials as Topic/
- 47 73. placebo.mp.
- 48 74. randomi?ed.mp.
- 49 75. Drug Therapy/
- 50 76. drug therapy.mp.
- 51 77. randomly.mp.
- 52 78. clinical trial/
- 53 79. trial.mp.
- 54 80. groups.mp.
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81. 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74 or 75 or 76 or 77 or 78 or 79 or 80
82. exp animals/ not humans.sh.
83. (#81 not #82).mp.
84. 50 and 66 and 83

AMED Search Strategy

1. (Long term adj3 condition*).mp. [mp=abstract, heading words, title]
2. chronic*.mp.
3. ((persistent or long* term or ongoing or degenerative) adj3 (disease* or ill* or condition* or insufficienc* or disorder*)).mp. [mp=abstract, heading words, title]
4. long term care/
5. long* term care.tw.
6. Cardiovascular disease/
7. (heart disease* or heart failure or myocardial ischemia or coronary disease* or coronary artery disease* or myocardial infarction or hypertension or high blood pressure).tw.
8. sickle cell.mp.
9. lung disease/
10. (obstructive lung disease* or obstructive pulmonary disease* or copd or asthma or bronchitis).tw.
11. emphysema/
12. pulmonary emphysema/
13. emphysema.tw.
14. (cystic fibrosis or respiratory distress).mp.
15. (brain adj (disease* or damage* or injur*)).tw.
16. (cerebrovascular or brain ischemia or cerebral infarction or carotid artery disease* or stroke or epilep* or seizure*).tw.
17. (neurodegenerative or Huntingdon* or Parkinson* or amyotrophic lateral sclerosis or multiple sclerosis or motor neuron disease).tw.
18. (paralys* or quadriplegi* or tetraplegi* or paraplegi* or locked in syndrome).tw.
19. ((communication or learning or consciousness or perpetual or speech or voice or vision or hearing or psychomotor) adj disorder*).tw.
20. (hearing loss or deaf* or blind*).tw.
21. down* syndrome.tw.
22. cerebral palsy.tw.
23. exp gastrointestinal disease/
24. exp nervous system disease/
25. (gatroenter* or intestinal or bowel or colonic).tw.
26. ((renal or kidney) adj (failure* or insufficienc*)).tw.
27. diabetes mellitus/
28. (diabetes or diabetic*).tw.
29. exp nutrition disorders/
30. (underweight or malnutrition or malnourished).tw.
31. exp arthritis/
32. exp rheumatic disease/
33. fibromyalgia.tw.
34. ((back or neck) adj pain).tw.
35. exp thyroid disease/
36. thyroid.tw.
37. exp hypersensitivity/
38. (hypersensitivit* or allerg* or intolerance or anaphyla*).mp.
39. exp neoplasms/
40. (cancer* or oncolog* or neoplasm* or carcinom* or tumo?r* or malignan* or leuk?emia).tw.

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- 2
- 3 41. exp hiv infections/
- 4 42. (hiv infect* or hiv disease*).tw.
- 5 43. exp mental disorders/
- 6 44. ((mental* or psychiatr* or psychological*) adj (ill* or disorder* or disease* or distress* or disab* or
- 7 problem* or health* or patient* or treatment)).tw.
- 8 45. ((personality or mood or dysthymic or cognit* or anxiety or stress or eating or adjustment or
- 9 reactive or somatoform or conversion or behavio?r or perception or psycho* or impulse control or
- 10 development* or attention deficit or hyperactivity or conduct or motor skills or movement or tic or
- 11 substance related) adj disorder*).tw.
- 12 46. (psychos?s or psychotic* or paranoi* or schizo* or neuros?s or neurotic* or delusion* or
- 13 depression or depressive or bipolar or mania or manic or obsessi* or compulsi* or panic or phobic or
- 14 phobia or anorexia or bulimia or neurastheni* or dissociative or autis* or Asperger* or Tourette or
- 15 dyslex* or affective or borderline or narcissis* or suicid* or self injur* or self harm or adhd).tw.
- 16 47. (((substance or drug or alcohol) adj abuse) or "substance use" or "illegal drug use" or addict* or
- 17 alcoholism or (problem* adj1 drinking)).tw.
- 18 48. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or
- 19 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37
- 20 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47
- 21 49. self efficacy/ or self care/
- 22 50. self administration/ or self assessment/ or self concept/
- 23 51. patient compliance/ or patient education/ or patient participation/
- 24 52. attitude to health/ or health behavio?r/ or health education/ or health knowledge, attitudes,
- 25 practice/ or health promotion/
- 26 53. life style/ or disease management/ or risk reduction behavio?r/
- 27 54. adaptation, psychological/ or motivation/ or goals/ or problem solving/ or exp decision making/
- 28 55. (consumer health information or consumer participation).mp. [mp=abstract, heading words, title]
- 29 56. health plan implementation.mp.
- 30 57. (self care or self management or self efficacy or self monitor\$).tw.
- 31 58. ((self or oneself) adj3 care).tw.
- 32 59. ((patient\$ or consumer\$ or client\$) adj5 (educat\$ or participat\$ or behavio?r\$ or behavio?r\$ or
- 33 compliance or centered)).tw.
- 34 60. (health adj5 (promot\$ or educat\$ or behav\$)).tw.
- 35 61. (risk adj3 reduc\$ adj3 behav\$).tw.
- 36 62. ((patient\$ or consumer\$ or client\$) adj5 manag\$ adj5 disease\$).tw.
- 37 63. (((behav\$ adj3 chang\$) or (problem\$ adj3 solv\$) or (goal\$ adj3 setting) or (decision\$ adj3 mak\$)
- 38 or coping) adj5 (patient\$ or consumer\$ or client\$)).tw.
- 39 64. 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63
- 40 65. randomized controlled trial.pt.
- 41 66. controlled clinical trial.pt.
- 42 67. randomized.ab.
- 43 68. placebo.ab.
- 44 69. randomly.ab.
- 45 70. clinical trials.sh.
- 46 71. trial.ti.
- 47 72. 65 or 66 or 67 or 68 or 69 or 70 or 71
- 48 73. exp animals/ not humans.sh.
- 49 74. 72 not 73
- 50 75. 48 and 64 and 74
- 51
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- 57 PsychINFO Search Strategy
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1. (Long term adj3 condition*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh]
2. chronic*.mp.
3. ((persistent or long* term or ongoing or degenerative) adj3 (disease* or ill* or condition* or insufficienc* or disorder*)).tw.
4. long term care/
5. long* term care.tw.
6. (heart disease* or heart failure or myocardial ischemia or coronary disease* or coronary artery disease* or myocardial infarction or hypertension or high blood pressure).tw.
7. sickle cell.mp.
8. (obstructive lung disease* or obstructive pulmonary disease* or copd or asthma or bronchitis).tw.
9. exp emphysema/
10. exp pulmonary emphysema/
11. emphysema.tw.
12. (cystic fibrosis or respiratory distress).mp.
13. exp nervous system disorders/
14. exp cardiovascular disorders/
15. exp lung disorders/
16. (brain adj (disease* or damage* or injur*)).tw.
17. (cerebrovascular or brain ischemia or cerebral infarction or carotid artery disease* or stroke or epilep* or seizure*).tw.
18. (neurodegenerative or Huntingdon* or Parkinson* or amyotrophic lateral sclerosis or multiple sclerosis or motor neuron disease).tw.
19. (paralys* or quadriplegi* or tetraplegi* or paraplegi* or locked in syndrome).tw.
20. ((communication or learning or consciousness or perpetual or speech or voice or vision or hearing or psychomotor) adj disorder*).tw.
21. (hearing loss or hearing aid* or deaf* or blind* or stutter*).tw.
22. down* syndrome.tw.
23. cerebral palsy.tw.
24. exp gastrointestinal disorders/
25. (gastroenter* or intestinal or bowel or colonic).tw.
26. renal insufficiency/
27. ((renal or kidney) adj (failure* or insufficienc*)).tw.
28. diabetes mellitus/
29. (diabetes or diabetic*).tw.
30. eating disorders/
31. (underweight or malnutrition or malnourished or overweight or obes*).tw.
32. exp arthritis/
33. rheumatoid arthritis/
34. (arthritis or osteoarthritis or rheumati* or fibromyalgia).tw.
35. ((back or neck) adj pain).tw.
36. thyroid disorders/
37. thyroid.tw.
38. exp hypersensitivity/
39. (hypersensitivit* or allerg* or intolerance or anaphyla*).mp.
40. exp neoplasms/
41. (cancer* or oncolog* or neoplasm* or carcinom* or tumo?* or malignan* or leuk?emia).tw.
42. exp AIDS/ or exp HIV/
43. (hiv infect* or hiv disease*).tw.
44. exp mental disorders/
45. exp Behavior Problems/ or behavio?ral symptoms.mp.

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2
3 46. ((mental* or psychiatr* or psychological*) adj (ill* or disorder* or disease* or distress* or disab* or
4 problem* or health* or patient* or treatment)).tw.
5 47. ((personality or mood or dysthymic or cognit* or anxiety or stress or eating or adjustment or
6 reactive or somatoform or conversion or behavior?r or perception or psycho* or impulse control or
7 development* or attention deficit or hyperactivity or conduct or motor skills or movement or tic or
8 substance related) adj disorder*).tw.
9 48. (psychos#s or psychotic* or paranoi* or schizo* or neuros#s or neurotic* or delusion* or
10 depression or depressive or bipolar or mania or manic or obsessi* or compulsi* or panic or phobic or
11 phobia or anorexia or bulimia or neurastheni* or dissociative or autis* or Asperger* or Tourette or
12 dyslex* or affective or borderline or narcissis* or suicid* or self injur* or self harm or adhd).tw.
13 49. (((substance or drug or alcohol) adj abuse) or "substance use" or "illegal drug use" or addict* or
14 alcoholism or (problem* adj1 drinking)).tw.
15 50. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or
16 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37
17 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49
18 51. self efficacy/ or self care/
19 52. self administration/ or self assessment/ or self concept/
20 53. patient compliance/ or patient education as topic/ or patient participation/ or patient satisfaction.
21 54. consumer health information/ or consumer participation/
22 55. attitude to health/ or health behavior?r/ or health education/ or health knowledge, attitudes,
23 practice/ or health promotion/
24 56. life style/ or disease management/ or risk reduction behavior?r/
25 57. adaptation, psychological/ or motivation/ or goals/ or problem solving/ or exp decision making/
26 58. health plan implementation/
27 59. (self care or selfcare or self management or selfmanagement or self efficacy or selfefficacy or self
28 monitor\$ or selfmonitor\$).tw.
29 60. ((self or oneself) adj3 care).tw.
30 61. ((patient\$ or consumer\$ or client\$) adj5 (educat\$ or participat\$ or behavior?r\$ or behavior?r\$ or
31 compliance or centered)).tw.
32 62. (health adj5 (promot\$ or educat\$ or behav\$)).tw.
33 63. (risk adj3 reduc\$ adj3 behav\$).tw.
34 64. ((patient\$ or consumer\$ or client\$) adj5 manag\$ adj5 disease\$).tw.
35 65. (((behav\$ adj3 chang\$) or (problem\$ adj3 solv\$) or (goal\$ adj3 setting) or (decision\$ adj3 mak\$)
36 or coping) adj5 (patient\$ or consumer\$ or client\$)).tw.
37 66. 51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65
38 67. exp Randomized Controlled Trials/
39 68. exp Clinical Trials/
40 69. exp Randomized Controlled Trials/ or exp Randomized Clinical Trials/
41 70. exp Placebo/
42 71. exp Drug Therapy/
43 72. randomly.mp.
44 73. trial.mp.
45 74. groups.mp.
46 75. 67 or 68 or 69 or 70 or 71 or 72 or 73 or 74
47 76. exp animals/ not humans.sh.
48 77. (#75 not #76).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title,
49 tests & measures, mesh]
50 78. 50 and 66 and 77
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CINAHL Search Strategy

S1. long term condition

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- 3 S2. chronic
- 4 S3. ((persistent or long term or ongoing or degenerative) (disease or ill* or condition or insufficienc* or
- 5 disorder))
- 6 S4. long term care
- 7 S5. cardiovascular diseases
- 8 S6. (heart disease or heart failure or myocardial ischemia or coronary disease or coronary artery
- 9 disease or myocardial infarction or hypertension or high blood pressure)
- 10 S7. sickle cell
- 11 S8. lung diseases, obstructive
- 12 S9. (obstructive lung disease or obstructive pulmonary disease or copd or asthma or bronchitis)
- 13 S10. down* syndrome
- 14 S11. cerebral palsy
- 15 S12. emphysema
- 16 S13. gastrointestinal disorders
- 17 S14. renal insufficiency
- 18 S15. ((renal or kidney) failure)
- 19 S16. diabetes mellitus
- 20 S17. nutrition disorders
- 21 S18. arthritis
- 22 S19. rheumatic diseases
- 23 S20. fibromyalgia
- 24 S21. (cystic fibrosis or respiratory distress)
- 25 S22. thyroid disease
- 26 S23. (hypersensitivity or allergy or anaphylaxis)
- 27 S24. (cancer* or oncolog* or neoplasm* or tumo?r*)
- 28 S25. (hiv infection or hiv disease or hiv)
- 29 S26. mental disorders
- 30 S27. ((mental or psychiatric or psychological) (ill* or disorder or disease or distress or disability))
- 31 S28. ((personality or dysthymic or anxiety or stress or eating or reactive or behavio?r or perception or
- 32 impulse control or developmental or attention deficit or hyperactivity or conduct or motor skills or
- 33 movement or tic) disorder
- 34 S29. (psychosis or schizophrenia or neurosis or depression or bipolar or mania or obsessive or
- 35 compulsive or panic or phobia or anorexia or bulimia or dissociative or autism or Asperger's or
- 36 Tourette or affective or borderline or suicide or self injury or self harm or adhd)
- 37 S30. ((substance or drug or alcohol) abuse or addiction) or alcoholism
- 38 S31. self efficacy or self care
- 39 S32. nervous system diseases
- 40 S33. self administration or self assessment or self concept
- 41 S34. patient compliance or patient education or patient participation
- 42 S35. consumer health information or consumer participation
- 43 S36. attitude to health or health behavio?r or health education or health promotion
- 44 S37. disease management or risk reduction behavio?r
- 45 S38. health plan implementation
- 46 S39. self care or self management or self efficacy
- 47 S40. ((patient or consumer or health) (education or participation or behavio?r or compliance or
- 48 disease management))
- 49 S41. (((behavio?r change) or (problem solving) or (goal setting) or (decision making) or coping or
- 50 motivation) (patient or consumer))
- 51 S42. (brain (disease or damage or injury))
- 52 S43. MH randomized controlled trials
- 53 S44. MH double-blind studies
- 54 S45. MH single-blind studies
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- 3 S46. MH random assignment
- 4 S47. MH pretest-posttest design
- 5 S48. MH cluster sample
- 6 S49. TI (randomised OR randomized)
- 7 S50. AB (random*)
- 8 S51. TI (trial)
- 9
- 10 S52. MH (sample size) AND AB (assigned OR allocated OR control)
- 11 S53. (cerebrovascular or brain ischemia or cerebral infarction or carotid artery disease or stroke or
- 12 epilepsy or seizure)
- 13 S54. MH (placebos)
- 14 S55. PT (randomized controlled trial)
- 15 S56. AB (CONTROL W5 GROUP)
- 16 S57. MH (CROSSOVER DESIGN) OR MH (COMPARATIVE STUDIES)
- 17 S58. AB (CLUSTER W3 RCT)
- 18 S59. S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S54 OR
- 19 S55 OR S56 OR S57 OR S58
- 20 S60. MH ANIMALS+
- 21 S61. MH (ANIMAL STUDIES)
- 22 S62. TI (ANIMAL MODEL*)
- 23 S63. S60 OR S61 OR S62
- 24 S64. (neurodegenerative or Huntingdon's or Parkinson's or amyotrophic lateral sclerosis or multiple
- 25 sclerosis or motor neuron disease)
- 26 S65. MH (HUMAN)
- 27 S66. S63 NOT S65
- 28 S67. S59 NOT S66
- 29 S68. ((communication or learning or speech or vision or hearing or psychomotor) disorder)
- 30 S69. (deaf or blind)
- 31 S70. S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13
- 32 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR
- 33 S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S32 OR S42 OR S53 OR S64 OR S68 OR S69
- 34 S71. S31 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41
- 35 S72. S67 AND S70 AND S71
- 36 S73. S67 AND S70 AND S71
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Supplementary Figure 2. Reference list for the 82 eligible articles included in this systematic review.

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4 urinary incontinence in prostate cancer patients. *Psycho-Oncology*. 2016 Apr;25(4):421-7.
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For peer review only

Reporting checklist for systematic review (with or without a meta-analysis).

Based on the PRISMA guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the PRISMA reporting guidelines, and cite them as:

Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, Shamseer L, Tetzlaff JM, Akl EA, Brennan SE, Chou R, Glanville J, Grimshaw JM, Hróbjartsson A, Lalu MM, Li T, Loder EW, Mayo-Wilson E, McDonald S, McGuinness LA, Stewart LA, Thomas J, Tricco AC, Welch VA, Whiting P, Moher D. The PRISMA 2020 statement: An updated guideline for reporting systematic reviews

	Reporting Item	Page Number
Title		
Title	#1 Identify the report as a systematic review	1
Abstract		
Abstract	#2 Report an abstract addressing each item in the PRISMA 2020 for Abstracts checklist	2-3
Introduction		
Background/rationale	#3 Describe the rationale for the review in the context of existing knowledge	4-7
Objectives	#4 Provide an explicit statement of the objective(s) or question(s) the review addresses	7

Methods

1	Eligibility criteria	#5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses	8-9
2				
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6	Information sources	#6	Specify all databases, registers, websites, organisations, reference lists, and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted	8
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14	Search strategy	#7	Present the full search strategies for all databases, registers, and websites, including any filters and limits used	Supplementary figure 1
15				
16				
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20	Selection process	#8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and, if applicable, details of automation tools used in the process	9
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30	Data collection process	#9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and, if applicable, details of automation tools used in the process	9 and supplementary table 2
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41	Data items	#10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (for example, for all measures, time points, analyses), and, if not, the methods used to decide which results to collect	10
42				
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51	Study risk of bias assessment	#11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and, if applicable, details of automation tools used in the process	10
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1	Effect measures	#12	Specify for each outcome the effect measure(s) (such as risk ratio, mean difference) used in the synthesis or presentation of results	N/A
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6	Synthesis methods	#13a	Describe the processes used to decide which studies were eligible for each synthesis (such as tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5))	8-9
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14	Synthesis methods	#13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics or data conversions	N/A
15				
16				
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20	Synthesis methods	#13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses	N/A
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24	Synthesis methods	#13d	Describe any methods used to synthesise results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used	9-10
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34	Synthesis methods	#13e	Describe any methods used to explore possible causes of heterogeneity among study results (such as subgroup analysis, meta-regression)	N/A
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39	Synthesis methods	#13f	Describe any sensitivity analyses conducted to assess robustness of the synthesised results	N/A
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43	Reporting bias assessment	#14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases)	N/A
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48	Certainty assessment	#15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome	N/A
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52	Data items	#10b	List and define all other variables for which data were sought (such as participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information	N/A
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Results

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4	Study selection	#16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram (http://www.prisma-statement.org/PRISMAStatement/FlowDiagram)
5			10 and figure 1
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13	Study selection	#16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded
14			N/A
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18	Study characteristics	#17	Cite each included study and present its characteristics
19			10-12 and
20			Supplementary
21			figure 2 and
22			Supplementary
23			Table 3
24			
25			
26			
27	Risk of bias in studies	#18	Present assessments of risk of bias for each included study
28			N/A
29			
30	Results of individual studies	#19	For all outcomes, present for each study (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (such as confidence/credible interval), ideally using structured tables or plots
31			N/A
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39	Results of syntheses	#20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies
40			N/A
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44	Results of syntheses	#20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (such as confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect
45			N/A
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54	Results of syntheses	#20c	Present results of all investigations of possible causes of heterogeneity among study results
55			N/A
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58	Results of syntheses	#20d	Present results of all sensitivity analyses conducted
59			N/A
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		to assess the robustness of the synthesised results	
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2	Risk of reporting	#21 Present assessments of risk of bias due to missing	N/A
3	biases in syntheses	results (arising from reporting biases) for each	
4		synthesis assessed	
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7	Certainty of evidence	#22 Present assessments of certainty (or confidence) in	N/A
8		the body of evidence for each outcome assessed	
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11	Discussion		
12			
13	Results in context	#23a Provide a general interpretation of the results in the	14-17
14		context of other evidence	
15			
16	Limitations of	#23b Discuss any limitations of the evidence included in	17-18
17	included studies	the review	
18			
19	Limitations of the	#23c Discuss any limitations of the review processes	17-18
20	review methods	used	
21			
22	Implications	#23d Discuss implications of the results for practice,	18
23		policy, and future research	
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26	Other information		
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28	Registration and	#24a Provide registration information for the review,	3
29	protocol	including register name and registration number, or	
30		state that the review was not registered	
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32	Registration and	#24b Indicate where the review protocol can be accessed,	20
33	protocol	or state that a protocol was not prepared	
34			
35	Registration and	#24c Describe and explain any amendments to	N/A
36	protocol	information provided at registration or in the protocol	
37			
38	Support	#25 Describe sources of financial or non-financial	19-20
39		support for the review, and the role of the funders or	
40		sponsors in the review	
41			
42	Competing interests	#26 Declare any competing interests of review authors	20
43			
44	Availability of data,	#27 Report which of the following are publicly available	20 and
45	code, and other	and where they can be found: template data	supplementary
46	materials	collection forms; data extracted from included	table 3
47		studies; data used for all analyses; analytic code;	
48		any other materials used in the review	
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Notes:

- 7: supplementary figure 1
- 9: 9 and supplementary table 2
- 16a: 10 and figure 1
- 17: 10-12 and Supplementary figure 2 and Supplementary Table 3
- 27: 20 and supplementary table 3

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Study Details:

Study Title	
Reference No.	
Data Extractor	
Year, Author, Country, Link	Year after 2008?: Yes <input type="checkbox"/> No <input type="checkbox"/> TIDieR checklist (2014): Before <input type="checkbox"/> After <input type="checkbox"/>
Pre-extraction Screening	Needs translating: Yes <input type="checkbox"/> No <input type="checkbox"/> RCT: Yes <input type="checkbox"/> No <input type="checkbox"/> Self-management intervention: Yes <input type="checkbox"/> No <input type="checkbox"/> Participants with LTCs: Yes <input type="checkbox"/> No <input type="checkbox"/> Ongoing study: Yes <input type="checkbox"/> No <input type="checkbox"/>
Research Question / Aim	

Methods:

Study Design	Participant Characteristics:
	RCT details e.g. clusters, unclear:
	How is the control arm described:
	Number of centres: Single centre <input type="checkbox"/> Multi-centre <input type="checkbox"/> Unclear <input type="checkbox"/>
Intervention Summary Features	CDSMP <input type="checkbox"/> ASMP <input type="checkbox"/> EPP <input type="checkbox"/> Other <input type="checkbox"/> Specify if known Disease specific <input type="checkbox"/> or Generic <input type="checkbox"/> LTCs included: Delivered by: Health care professional <input type="checkbox"/> Lay person <input type="checkbox"/> Other <input type="checkbox"/> Specify if known Individual one-to-one sessions: Yes <input type="checkbox"/> No <input type="checkbox"/> Group sessions: Yes <input type="checkbox"/> No <input type="checkbox"/> Number in group: Face-to-Face sessions <input type="checkbox"/> / Remote sessions <input type="checkbox"/>

	<p>Location where is the intervention delivered: Inpatient <input type="checkbox"/> Outpatient <input type="checkbox"/> Community Based <input type="checkbox"/> Home <input type="checkbox"/> Telephone <input type="checkbox"/> Web-based <input type="checkbox"/> Unclear <input type="checkbox"/> Other <input type="checkbox"/> Specify if known</p> <p>Description:</p> <p>Any necessary components for adherence:</p>
<p>Dose of Intervention</p> <p>Adherence and compliance may be used synonymously, but the distinction and data needs to be teased out</p>	<p>Maximum dose: Number of sessions: Session Duration (hours): Total hours: Duration intervention delivered over:</p> <p>Anticipated clinically effective dose: Number of sessions: Session Duration (hours): Total hours: How clinically effective dose decided by authors:</p> <p>Author comments on Adherence (the number of sessions participants attended):</p> <p>Author comments on Compliance (the number of sessions participants need to attend to be including in the analysis):</p>
<p>Fidelity of Intervention</p>	<p>Did the study describe attempts to ensure fidelity of the interventions i.e. what was delivered was what was intended to be delivered: Yes <input type="checkbox"/> No <input type="checkbox"/> Not stated/unclear <input type="checkbox"/> If Yes, specify:</p> <p>Comments / Additional details:</p>

Results:

Participants		Number	Age (mean, SD)	SES (add measure used)	Ethnicity (% white)	Gender (% female)
	Intervention:					
	Control:					
	All:					
LTCs details:						
Dose of Intervention	<p>Dose actually delivered: Number of sessions: Session Duration (hours): Total hours: Duration Intervention Delivered Over:</p> <p>Dose actually received (specifically for groups): Number of sessions: Session Duration (hours): Total hours: Duration Intervention Delivered Over:</p>					

1 2 3 4 5 6	Was the dose delivered \geq anticipated clinically effective dose: Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/> Details: Further author comments on dose:
7 8 9 10 11 12 13 14 15 16 17	Fidelity of Intervention Was there fidelity around the dose in the trial?: Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/> Was fidelity reported on in?: Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/> Do the authors discuss the impact of fidelity?: Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/> Further author comments on fidelity:
18 19 20 21 22 23 24 25	Primary Outcome Result Was the Primary Outcome Statistically Significant: Yes <input type="checkbox"/> No <input type="checkbox"/> Details: Was the Primary Outcome Clinically Significant: Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/> Details:

Cochrane Risk of Bias Assessment:

26 27 28 29 30 31 32	1. Selection Bias Randomisation and Allocation Concealment Your assessment of this bias: 'Low risk' <input type="checkbox"/> 'High risk' <input type="checkbox"/> 'Unclear risk' <input type="checkbox"/>
33 34 35 36	2. Performance Bias Blinding of Participants and Clinical staff Your assessment of this bias: 'Low risk' <input type="checkbox"/> 'High risk' <input type="checkbox"/> 'Unclear risk' <input type="checkbox"/>
37 38 39 40	3. Detection Bias Blinding of Outcome Assessors Your assessment of this bias: 'Low risk' <input type="checkbox"/> 'High risk' <input type="checkbox"/> 'Unclear risk' <input type="checkbox"/>
41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56	4. Attrition Bias Incomplete Outcome data – for each outcome Outcome: Attrition reported: Yes <input type="checkbox"/> No <input type="checkbox"/> Exclusions reported: Yes <input type="checkbox"/> No <input type="checkbox"/> % dropped out: Intervention Group: Control Group: Reasons for LTFU: Intervention Group: Control Group: Your assessment of this bias: 'Low risk' <input type="checkbox"/> 'High risk' <input type="checkbox"/> 'Unclear risk' <input type="checkbox"/>
57 58 59 60	5. Reporting Bias Selective Outcome Reporting Your assessment of this bias: 'Low risk' <input type="checkbox"/> 'High risk' <input type="checkbox"/> 'Unclear risk' <input type="checkbox"/>

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60 6. Other Sources of Bias	Bias due to other problems Your assessment of this bias: 'Low risk' <input type="checkbox"/> 'High risk' <input type="checkbox"/> 'Unclear risk' <input type="checkbox"/>
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For peer review only

Supplementary Table 2. Full details of all 94 articles included in the systematic review

	First Author	Year	Country	Intervention	Disease	Delivered by	Location	Maximum dose stated (number of sessions)	Maximum dose stated (length of sessions)	Minimum clinically Effective dose stated	Dose received stated (number of sessions)	Dose stated (length of sessions)	Was dose delivered \geq minimum clinically effective dose	Was fidelity reported and discussed	Was the primary outcome statistically significant
8	Ackerman	2012	Australia	ASMP	Hip or Knee Osteoarthritis	HCPs and Lay leaders	Outpatient clinic and Community	Yes	Yes	Yes	Yes	Yes	No	Yes	No
10	Ambrosino	2008	USA	Coping skills training - learning to deal better with day-to-day problems that arise	Type 1 Diabetes	HCPs	Unclear	Yes	Yes	No	Yes	Yes	Unclear	No	No
15	Anvar	2018	Iran	ASMP	Rheumatoid Arthritis	HCPs	Outpatient clinic	Yes	Yes	No	Yes	Yes	Unclear	No	Yes
17	Bantum	2014	USA	Surviving and Thriving with Cancer website adapted from CDSMP	Cancer survivors	Lay leaders	Web-based	Yes	No	No	Yes	No	Yes	Yes	Yes
20	Berg	2019	USA	AWAKE - app based weekly modules with aligned homework, combined with weekly phone calls from a coach to discuss content and homework	Cancer survivorship	Healthcare professional	Web-based and telephone	Yes	No	Yes	Yes	No	Yes	No	No
28	Berry	2015	USA	Diabetes group visits - an individualized session to review medications and a medical examination and a group session for diabetes self-management education	Diabetes	HCPs	Community based	Yes	No	No	No	No	Unclear	No	Yes
37	Bersani	2017	Italy	group psychoeducation focused on healthy lifestyle - including sleep, physical activity, diet, voluptuary habits	Mood and Psychotic disorders	HCPs	Outpatient clinic	Yes	Yes	No	No	Yes	Unclear	No	Yes

1	Bosworth	2008	USA	Tailored behavioural intervention with 9 educational modules	Hypertension	HCPs	Telephone	Yes	No	No	Yes	Yes	Yes	No
2														
3														
4	Breedland	2011	The Netherlands	FIT program - physical activity combined with an education program	Rheumatoid Arthritis	HCPs	Outpatient clinic	Yes	Yes	No	No	No	Unclear	No
5														
6														
7														
8	Brorsson	2019	Sweden	Guided Self-Determination-Young (GSD-Y) a person-centered communication and reflection education model that can be used in educational program	Type 1 Diabetes	HCPs	Outpatient clinic	Yes	Yes	No	Yes	Yes	Yes	No
9														
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15														
16	Chamany	2015	USA	Telephone support through problem solving and goal setting	Diabetes	HCPs	Telephone	Yes	No	Yes	Yes	Yes	Yes	Yes
17														
18														
19	Chen	2018	China	Patient-centred self-management empowerment intervention (PCSMEl)	Stroke	HCPs	Inpatient, Outpatient and Telephone	Yes	Yes	No	No	No	Unclear	No
20														
21														
22														
23	Chew	2018	Malaysia	Value-based emotion-focused educational programme (VEMOFIT)	Type 2 Diabetes	HCPs	Other: Health Clinic	Yes	Yes	Yes	Yes	Yes	Yes	No
24														
25														
26														
27	Christiansen	2018	USA	A behaviour change intervention based on social cognitive and control theories of behavior change targeting physical exercise, walking activity, and disease self-management	Dysvascular Amputation (Unilateral TTA)	HCPs	Telephone	Yes	Yes	No	Yes	Yes	Yes	No
28														
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35	Cook	2013	USA	Wellness Recovery Action Planning including lectures, individual and group exercises, personal sharing and role modeling, and voluntary homework	Serious Mental Illness	Lay leaders	Community based	Yes	Yes	No	No	No	Unclear	No
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1	Corado	2018	USA	Active, Linkage, Engagement, Retention and Treatment (ALERT) topics included HIV health literacy, Navigating the Health Care System, Disclosure, Adherence, and Self-Efficacy	HIV	HCPs	Outpatient clinic and Community	Yes	No	No	Yes	No	Unclear	Yes	No
2															
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9	Daryabeygi-Khotbehsara	2021	Iran	Education promoting low-fat food consumption, carb counting and physical activity	Type 2 Diabetes	Healthcare professional	Community Based	Yes	Yes	No	Yes	No	Unclear	No	No
10															
11															
12															
13	Dash	2015	India	Epilepsy health education program designed for those from a low education background.	Epilepsy	HCPs	Outpatient clinic	Yes	Yes	No	Yes	Yes	Yes	No	Yes
14															
15															
16															
17															
18															
19	Detaille	2013	The Netherlands	CDSMP adapted for workers with chronic disease	A diagnosed chronic somatic disease	Lay leaders	Community based	Yes	Yes	Yes	No	No	Unclear	No	Yes
20															
21															
22	Dinh	2019	Vietnam	Teach-back heart failure self-management intervention individual teach-back before discharge, plus a booklet, a weighing scale, a diary, and a telephone call follow-up at 2 weeks following discharge	Heart failure	HCPs	Outpatient clinic and Telephone	Yes	Yes	No	No	No	Unclear	No	Yes
23															
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33	Dziedzic	2013	UK	Looking after your joints programme - Self Management in OA of the Hand (1) joint protection; (2) joint protection and hand exercises combined	Hand Osteoarthritis	HCPs	Outpatient clinic	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
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1	Ehde	2015	USA	Telephone delivered self-management intervention - cognitive-behavioural and positive psychology strategies for helping participants self-manage pain, depression, and fatigue	Multiple Sclerosis	HCPs	Telephone	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
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9	Fernandez Guijarro	2019	Spain	Health-promotion programme covering healthy eating, lifestyle changes, physical activity, hydration, tobacco and alcohol consumption, stress reduction, and sleep quality and nurse led physical activity. Integrated disease management - case management, education, and skills training	Serious Mental Illness	HCPs	Community based	Yes	Yes	No	Yes	Yes	Unclear	No	Yes
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18	Ferrone	2019	Canada	Integrated disease management - case management, education, and skills training	COPD	HCPs	GP practice and telephone	Yes	No	No	Yes	No	No	Yes	Yes
19															
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22															
23	Forjuoh	2014	USA	CDSMP and PDA	Type 2 Diabetes	Lay leaders	Clinic and community	Yes	Yes	Yes	Yes	Yes	Yes	No	No
24															
25	Fukuoka	2019	Japan	Disease management program - nurses worked with the subjects and their to achieve individualized clinical target values and goals through education booklets and journal.	Stroke	HCPs	Unclear	Yes	No	No	No	No	Unclear	No	No
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33	Gallinat	2019	Germany	CBT techniques covering psychoeducation, self-management, supportive monitoring and counselling	Skin Picking	HCPs	Web-based	Yes	No	No	Yes	No	No	No	Yes
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1	Geremia	2019	Brazil	Compact, cost-effective, education program (CEPT1)	Type 1 Diabetes	HCPs	Community based	Yes	Yes	No	Yes	Yes	Yes	No	Yes
2															
3	Goldberg	2013	USA	CDSMP adapted for psychiatric settings 'Living Well'	Serious Mental Illness with comorbid chronic medical condition	HCPs and Lay leaders	Outpatient clinic and Community	Yes	Yes	No	Yes	Yes	No	No	Yes
4															
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6															
7	Golshahi	2015	Iran	Hypertension self-management - Group A educated about self-care behaviors through eight sessions, group B and group C educated through four pamphlets or eight SMS.	Hypertension	HCPs	Outpatient clinic and Telephone	Yes	Yes	Yes	No	No	Unclear	No	Yes
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16	Grammatopoulou	2016	Greece	Holistic Intervention - recognise facilitators and barriers faced to develop the necessary behaviors and skills to control their disease	Asthma	HCPs	Outpatient clinic and home	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
17															
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19															
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21															
22	Groessl	2010	USA	CDSMP adapted for veterans	Chronic Hepatitis C	HCPs and Lay leaders	Outpatient clinic	Yes	Yes	No	Yes	Yes	Yes	No	Yes
23															
24															
25	Grønning	2012	Norway	Arthritis outpatient Educational Program	Polyarthritis	HCPs	Outpatient clinic	Yes	Yes	No	No	No	Unclear	No	Yes
26															
27	Harel-Katz	2020	Israel	Improving participation after stroke self-management developed from CDSMP focused on managing home, community, work and social	Stroke	Healthcare professional	Community Based	Yes	Yes	Yes	Yes	Yes	Yes	No	No
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35	Harrington	2010	UK	Exercise and education scheme through exercise, guest speakers, goal-setting and social session	Stroke	HCPs	Community based	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
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1	Härter	2016	Germany	Telephone based health coaching intervention, to enhance health behaviour change through MI, goal setting, shared decision making	diabetes type 2, coronary artery disease, hypertension, heart failure, asthma, chronic obstructive pulmonary disease, chronic depression or schizophrenia	Healthcare professional	Telephone	Yes	No	Yes	Yes	Yes	Yes	Yes	No
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10	Heutink	2011	The Netherlands	CONECIS (COPing with NEuropathic Spinal cord Injury pain) comprises educational, cognitive, and behavioural elements targeted at coping with CNSCIP	Spinal cord injury	HCPs	Rehabilitation Centre	Yes	Yes	No	Yes	Yes	Yes	No	No
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17															
18	Hewlett	2011	UK	CBT, problem solving and goal setting for fatigue and well-being self-management	Rheumatoid Arthritis	HCPs	Unclear (Face-to-face)	Yes	Yes	No	Yes	Yes	Yes	No	Yes
19															
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22															
23	Holm	2020	Denmark	GLA:D exercise and education program	Knee Osteoarthritis	Healthcare professional	Community Based	Yes	Yes	Yes	Yes	Yes	No	Yes	No
24															
25	Holt	2019	UK	STEPWISE - Each session covered lifestyle changes to help the participants take control of their weight through problem solving	schizophrenia, schizoaffective disorder or first-episode psychosis	HCPs	Community based and telephone	Yes	Yes	Yes	Yes	Yes	No	Yes	No
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32	Houlihan	2017	USA	My Care My Call - promote skill development and facilitate motivation using consumer-centered goal-setting and coaching, education, resource referral, and support-network building	Spinal cord injury	Lay leaders	Telephone	Yes	No	No	Yes	Yes	Unclear	No	Yes
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1	House	2018	UK	Standardized supported self-management - goal setting, resources and barriers influencing success in reaching goals, and self-monitoring of goal attainment	Type 2 Diabetes with intellectual disability	HCPs	Home	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
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7	Jaipakdee	2015	Thailand	Diabetes self-management support (DSMS) with a computer-assisted instruction	Diabetes	HCPs	Community based	No	Yes	No	No	No	Yes	No	Yes
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11	James	2015	Australia	ENRICH: Exercise and Nutrition Routine Improving Cancer Health	Cancer survivors	HCPs	Community based	Yes	Yes	No	Yes	Yes	Yes	No	Yes
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14															
15	Jiang	2019	China	Self-efficacy-focused structured education programme provided diabetes-related knowledge and DSM skills based on self-efficacy theory	Type 2 Diabetes	HCPs	Outpatient clinic	Yes	Yes	No	No	No	Unclear	No	Yes
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21															
22	John	2013	UK	Cognitive Behavioural Education Programme - challenge their way of thinking, changing maladaptive coping skills, cognitions or emotions to lead to more adaptive changes in behaviour	Rheumatoid Arthritis	HCPs	Outpatient clinic	Yes	Yes	No	No	No	Unclear	No	Yes
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33	Ju	2018	China	Peer support provided with usual education	Diabetes	Lay leaders	Community based	No	No	No	No	No	Unclear	No	Yes
34															
35	Kasteleyn	2015	The Netherlands	Three home visits by a diabetes nurse to increase self-efficacy and illness perceptions	Type 2 Diabetes and first acute coronary event	HCPs	Home	Yes	Yes	Yes	Yes	Yes	Yes	No	No
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1	Kessler	2018	France, Germany, Italy, Spain	Adapted Living well with COPD Programme - home monitoring and e-health through telephone/web platform	COPD	HCPs	Home and Telephone and web-based platform	Yes	No	Yes	Yes	No	Yes	Yes	No
2															
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5	Kooijmans	2017	The Netherlands	HABITS intervention - optimizing intentions toward a healthier lifestyle and improving perceived behavioural control	Spinal cord injury	HCPs	Community based and home	Yes	No	No	Yes	No	Yes	Yes	No
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11	Laakkonen	2016	Finland	Self-management group rehabilitation to enhance participants' mastery, self-efficacy, and problem-solving skills and to empower them	Dementia	HCPs	Community based	Yes	Yes	No	No	No	Unclear	No	Yes
12															
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19	Lopez-Lopez	2020	Spain	Physical therapy exercise plus self-management program with education and a problem-based session	COPD	Healthcare professional	Inpatient	Yes	No	No	No	No	Unclear	No	Yes
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24															
25	Luciano	2011	Spain	Psychoeducation Program included information about symptoms, comorbid conditions, potential causes, psychosocial factors, current treatments, exercise, and barriers to behavior change and training for relaxation, pain relief, and stress reduction	Fibromyalgia	HCPs	GP practice	Yes	Yes	No	Yes	Yes	No	No	Yes
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38	Ludman	2016	USA	self-management support service – depression self-management training, recovery coaching, and care coordination	Depression	HCPs and Lay leaders	Community based and telephone	Yes	No	Yes	Yes	No	No	Yes	Yes
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1	Manning	2014	UK	Education, Self-Management, and Upper Extremity Exercise Training in People with Rheumatoid Arthritis [EXTRA] program	Rheumatoid Arthritis	HCPs	Outpatient clinic	Yes	Yes	No	Yes	No	Yes	No	Yes
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6	Mansouri	2019	Iran	Oral and Written Education Program	Heart failure	HCPs	Outpatient clinic	Yes	Yes	No	No	No	Unclear	No	Yes
7															
8	Markle-Reid	2018	Canada	The program offered up to 3 in-home visits; monthly group wellness sessions; monthly case conferences; and ongoing nurse-led care coordination.	Type 2 Diabetes with 3+ comorbidites	HCPs and Lay leaders	Community based and home	Yes	No	No	Yes	No	Unclear	Yes	No
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15	Marsden	2009	Australia	Community Living After Stroke for Survivors and Carers' (CLASSiC) - each session included a 1-hour physical activity followed by a 1-hour education delivered via presentations, group discussions and group activities	Stroke	HCPs	Outpatient clinic	Yes	Yes	No	Yes	Yes	Yes	No	No
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27	Miller	2020	Canada	COMMENCE - chronic pain self-management support with pain science education and exercise	Chronic pain	Healthcare professional	Community Based	Yes	Yes	Yes	Yes	No	No	No	Yes
28															
29															
30															
31															
32	Minshall	2020	Australia	Stroke Care Optimal Health Program (SCOHOP) Workbook based psychsocial intervention with education, self-management and reflective exercises	Stroke	Healthcare professional	Outpatient or Home or Telephone	Yes	Yes	No	Yes	Yes	Unclear	No	No
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1	Mohammadpour	2015	Iran	A supportive educational intervention plus follow up telephone calls with information on functions of cardiovascular system, aetiology, management of MI risk factors, adherence to treatment and dietary regimens	Myocardial Infarction	HCPs	Outpatient clinic and Telephone	Yes	Yes	No	No	No	Unclear	No	Yes
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11	Muchiri	2016	South Africa	Nutrition Education Programme	Diabetes	HCPs	Community based	Yes	Yes	No	Yes	Yes	Yes	No	No
12															
13	Nguyen	2018	Vietnam	CKD booklet and a handout, one face-to-face session and two brief follow-up sessions.	Chronic Kidney Disease	HCPs	Outpatient clinic and Telephone	Yes	Yes	No	No	No	Unclear	No	Yes
14															
15															
16															
17	O'Toole	2021	Ireland	OPTIMAL intervention promoting accomplishments, vicarious learning, persuasion, interpretation of emotional states	Multimorbidity	Healthcare professional	Community Based	Yes	Yes	Yes	Yes	Yes	Yes	No	No
18															
19															
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24	P'erez-Escamilla	2015	USA	Culturally tailored diabetes education and counselling treatment group including education, skills, and support in the areas of nutrition, physical activity, blood glucose monitoring, medication adherence, and medical appointments.	Type 2 Diabetes	HCPs	Home	Yes	No	No	No	No	Unclear	Yes	Yes
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1	Pinxsterhuis	2017	Norway	self-management program for coping with their illness and dealing with healthcare professionals and family, developed through educational presentations, the exchange of experiences, modelling of self-management skills, guided mastery practice, and informative feedback.	Chronic fatigue syndrome	HCPs and Lay leaders	Outpatient clinic	Yes	Yes	No	Yes	Yes	Yes	No	No
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14	Ridsdale	2018	UK	Self-management education for people with poorly controlled epilepsy (SMILE [UK]), based on MOSES	Epilepsy	HCPs	Community based	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
15															
16															
17															
18															
19	Rothschild	2014	USA	Mexican American Trial of Community Health Worker (MATCH) knowledge and skills in diabetes self-management, with opportunities to practice goal setting and self-management.	Type 2 Diabetes	HCPs	Home	Yes	Yes	No	Yes	No	No	Yes	Yes
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27															
28	Sajatovic	2018	USA	TargetEd MAnageMent Intervention [TEAM]	Stroke and TIA	HCPs and Lay leaders	Outpatient clinic and Telephone Community based	Yes	Yes	No	Yes	No	Unclear	No	Yes
29															
30	Salyers	2014	USA	Illness management and recovery - Incorporating psychoeducation, cognitive-behavioral approaches, relapse prevention, social skills training, and coping skills training.	Schizophrenia or schizoaffective disorder	HCPs	Community based	Yes	No	No	Yes	No	No	Yes	No
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39	Smeulders	2010	The Netherlands	CDSMP	Congestive Heart Failure	HCPs and Lay leaders	Outpatient clinic	Yes	Yes	No	Yes	No	Unclear	No	No
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1	Spencer	2011	USA	Racial and Ethnic Approaches to Community Health (REACH) Initiative - setting patient specific goals and supporting their progress	Diabetes	HCPs	Outpatient clinic and Home and Telephone	Yes	Yes	No	Yes	Yes	No	No	Yes
2															
3															
4															
5															
6	Still	2021	USA	TechSupport, integrating technology based components and emotional/empathic components known as positive psychological training	Hypertension	Healthcare professional	Web-based	Yes	Yes	Yes	Yes	Yes	Yes	No	No
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14	Stuifbergen	2010	USA	The Lifestyle Counts intervention developed from the Wellness for Women with MS curriculum	Fibromyalgia	HCPs	Outpatient clinic and Telephone	Yes	Yes	No	Yes	No	Yes	No	No
15															
16															
17															
18															
19	Swoboda	2016	USA	Multiple-Goal Intervention - combination of goal setting and decision support coaching	Diabetes	HCPs	Outpatient clinic and Telephone	Yes	No	Yes	Yes	No	No	No	Yes
20															
21															
22															
23	Taggart	2017	UK	DESMOND-ID (Diabetes and Self-Management for Ongoing and Newly Diagnosed for patients with Type 2 diabetes)	Type 2 Diabetes with intellectual disability	HCPs	Community based	Yes	Yes	No	Yes	No	Yes	Yes	Yes
24															
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29	Thoolen	2009	The Netherlands	Beyond Good Intentions – a 12-week self-management course	Type 2 Diabetes	HCPs	Community based	Yes	Yes	No	No	No	Unclear	No	Yes
30															
31															
32	Van der Meer	2009	The Netherlands	Internet based self-management program asthma control monitoring and treatment advice, online and group education, and remote Web communications with a specialized asthma nurse.	Asthma	HCPs	Web-based and Unclear	Yes	Yes	No	Yes	No	Unclear	No	Yes
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1	van Erp	2019	Netherlands	Back on Track education, self-management and goal setting intervention, including cognitive behavioural approaches	Chronic lower back pain	Healthcare professional	Community Based	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
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3															
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5															
6	Van Rooijen	2010	South Africa	Dietary and physical activity education for ongoing nutrition self-management and physical activity	Type 2 Diabetes	HCPs	Outpatient clinic	Yes	No	No	No	No	Unclear	No	Yes
7															
8															
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11	Vos	2019	The Netherlands	Beyond Good Intentions	Type 2 Diabetes	HCPs	Community based	Yes	Yes	No	No	No	Unclear	No	No
12															
13	Walker	2011	USA	Telephonic behavioural intervention focused on medication adherence and lifestyle changes through healthy eating and physical activity	Type 2 Diabetes	HCPs	Telephone	Yes	No	No	Yes	Yes	Unclear	No	Yes
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21	Walsh	2020	UK	FASA facilitating activity and self-management through problem solving and exercise derived from ESCAPE intervention	Lower limb osteoarthritis and chronic lower back pain	Healthcare professional	Community Based	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
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27	Wang	2016	Singapore	The Myocardial Infarction Home-based Self-management Programme (MIHSMP) with Heart Recovery Education Booklet (HREB)	Myocardial Infarction	HCPs	Outpatient clinic and Telephone	Yes	Yes	No	No	No	Unclear	No	No
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34	Wang	2018	Singapore	Coronary Heart Disease Self-management Programme (CHDSMP)	Coronary Heart Disease	HCPs	Home and Telephone	Yes	Yes	No	No	No	Unclear	No	No
35															
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39	Webel	2010	USA	Positive Self-Management Program (PSMP)	HIV	Lay leaders	Community based	Yes	Yes	No	No	No	Unclear	No	No
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1	Wegener	2009	USA	Promoting Amputee Life Skills Self-management program	Limb loss	HCPs and Lay leaders	Community based	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes
2															
3	Wolf	2017	USA	CDSMP	Stroke	HCPs	Outpatient clinic	Yes	Yes	Yes	No	No	Unclear	No	No
4															
5	Wu	2017	Australia and Taiwan	T-CDSMP adapted for Taiwanese speaking	Cardiovascular disease and Diabetes	HCPs	Outpatient clinic and Telephone	Yes	Yes	No	No	No	Unclear	No	No
6															
7	Wu	2018	Taiwan	Innovative self-management intervention a video, trainee manual, participation in the self-efficacy-enhancing program, and telephone interviews	End Stage Renal Disease	HCPs	Outpatient clinic and Telephone	Yes	Yes	Yes	No	No	Unclear	No	Yes
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16	Yip	2008	Hong Kong	ASMP with added goal-directed exercise component	Osteoarthritis	HCPs	Outpatient clinic	Yes	Yes	No	No	No	Unclear	No	Yes
17															
18	Young	2016	China	Psycho-education group understanding dementia, coping skills, exercise, diet, mood, own strengths, accepting change, communication, relationships, the future	Major neurocognitive disorder	HCPs	Community based	Yes	Yes	No	No	No	Unclear	No	No
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27	Zakrisson	2018	Sweden	Self-management intervention based on Bandura's theory of self-efficacy using techniques such as performance mastery, modelling, interpretation of symptoms, and social persuasion	COPD and Coronary Heart Failure	HCPS	Community based	Yes	Yes	No	Yes	Yes	Unclear	Yes	No
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35	Zhang	2015	USA	Stay Dry program biofeedback pelvic floor muscle exercise plus a support group or telephone contact	Prostate cancer with urinary incontinence	HCPs	Telephone and unclear	Yes	Yes	No	No	No	Unclear	No	Yes
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