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# The PRISMS taxonomy of self-management support: derivation of a novel taxonomy and initial testing of its utility

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# **The PRISMS taxonomy of self-management support: derivation of a novel taxonomy and initial testing of its utility**

## *Abstract*

**Background:** Supporting self-management is a core response of health care systems globally to the increasing prevalence of long-term conditions. Lack of a comprehensive taxonomy (or classification) of self-management support components hinders characterisation and, ultimately, understanding of these frequently complex, multi-component interventions.

**Objective:** To develop a comprehensive, descriptive taxonomy of self-management support components.

**Methods:** Components were derived from the 969 unique RCTs described in the 102 systematic reviews, and 61 implementation trials, examining 14 diverse long-term conditions included in the PRISMS (Practical Reviews In Self-Management Support) project followed by discussion at an expert stakeholder workshop. The utility of the taxonomy was then tested using a self-management support intervention for cancer survivors.

**Results:** The PRISMS taxonomy comprises 14 components that might be used to support self-management (e.g., information about condition/management, provision of equipment, social support), when delivered to someone with a long-term condition or their carer.

Overarching dimensions are delivery mode; personnel delivering the support; intervention targeting; and intensity, frequency and duration of the intervention. The taxonomy does not consider the effectiveness or otherwise of the different components or the overarching dimensions.

**Conclusions:** The PRISMS taxonomy offers a framework to researchers describing self-management support interventions, to reviewers synthesising evidence and to developers of health services for people with long-term conditions.

As the population ages,(1) the number of people with long-term conditions (LTCs) is increasing,(2,3) placing increasing demands on the provision of health and social care.(4) Approximately half of all adults in the US have at least one of ten common LTCs (including hypertension, coronary heart disease, stroke, diabetes, cancer, arthritis, hepatitis, chronic kidney disease, asthma, and chronic obstructive pulmonary disease) and around 60 million (about a quarter of the adult population) have more than one of these conditions.(5) In the UK, LTCs now account for 50% of all general practitioner appointments, 64% of outpatient visits and 70% of inpatient days.(6) Evidence from a wide range of health care systems suggest that optimising supported self-management(7) could greatly enhance the efficiency of provision.(6,8)

The terms self-management and self-care are often used interchangeably. However, we have adopted the distinction made by Parsons (9) where self-care refers to a wider set of behaviours that every person should take to remain healthy, whilst self-management refers to those behaviours specifically related to an established health condition. For example, tooth brushing is generally self-care, but the use of assistive devices to enable tooth brushing (10) and reduce the risk of tooth decay and periodontal disease amongst people with rheumatoid arthritis constitutes self-management. We have thus adopted the definition of self-management proposed by the US Institute of Medicine (11):

*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.*

Self-management is not the sole responsibility of the individual living with a LTC. It requires a collaborative approach in which the health care system delivers on-going support for people who are living with and managing their own LTC(s).(12) Any activities that support people in their self-management are called self-management support, this support often consists of

complex, multi-faceted interventions, and may include training for professionals, provision of resources, and flexible access to advice and information.(13)

Identifying, and then implementing, effective self-management support can be challenging. One potential barrier to both may be the poor standard of reporting of complex interventions,(14) which hampers providers and commissioners of health care services struggling to implement poorly defined interventions (15), researchers aiming to build on or replicate trials,(14) and reviewers seeking to synthesise evidence (16,17). A taxonomy (or classification) of potential components may thus be a valuable tool to facilitate conceptualisation of self-management support, improve reporting of interventions and promote the use of a common language of self-management support for commissioners, service providers, health care professionals, researchers and people with LTCs.

Although Barlow *et al*(18) Fisher *et al*(19), and the Richmond Group of Charities and the King's Fund (20) have made valuable inroads into characterising self-management support interventions and their components, none provide a universal and comprehensive, practical taxonomy of self-management support. Michie *et al.*'s 93-item taxonomy of behaviour change techniques (BCT) is a detailed method of characterising the active components of behaviour change interventions,(16) but does not include the broader services required to deliver self-management support. Furthermore, in order to code a behaviour change technique within the BCT taxonomy, the coder needs to know which behaviour the intervention is aiming to change. However, self-management support is more often about patient activation – giving people with LTCs general knowledge, skills and confidence to manage all aspects of their condition (21).

Whilst conducting a systematic overview of self-management support across a range of LTCs (Practical Reviews In Self-Management Support (PRISMS)), we recognised the need for a taxonomy of all the potential components of self-management support (22). In the

absence of a suitable tool, we developed one which we have subsequently refined and tested for utility against an existing self-management support manual for cancer survivors (HOPE-Help to Overcome Problems Effectively (23)). We present its development and preliminary testing as a basis for discussion and further refinement.

## **Methods**

The PRISMS project involved synthesising the quantitative and qualitative systematic review level evidence on self-management support for 14 LTCs in a number of quantitative and qualitative ‘meta-reviews’ (systematic reviews of systematic reviews). It also included an original systematic review of studies reporting the implementation of self-management support interventions in the LTCs.(24, 25) Full details are provided in the PRISMS report.(22)

The taxonomy was developed in several stages (see Figure 1). The first stage was a multidisciplinary expert workshop involving patients and carers, commissioners, academics and the voluntary sector. In preparation, we asked participants both to list and characterise LTCs, and to list potential components of self-management support interventions. This then led to consensus exercises during which delegates identified 14 diverse LTCs (see Table 1) that exemplified a wide range of key LTC characteristics considered to be potentially relevant to self-management support (see (22) for further details). We then systematically searched nine databases (including MEDLINE, CINAHL, EMBASE, PsychINFO, AMED, BNI, and ISI Proceedings) 1993-2012 for published systematic reviews of self-management support and for original studies of the implementation of self-management support for each of these 14 conditions. Full details of our search strategies are published elsewhere (22). We also conducted manual searches of key journals, and forward citation searches of included reviews.

## *Development of version 1 of the PRISMS Taxonomy of Self-Management Support*

### **Step I – extraction of components from asthma and type 2 diabetes mellitus PRISMS reviews.**

Asthma and Type 2 diabetes were two of the 14 conditions identified by the expert workshop. We choose these two conditions because self-management support is well established in both with a substantial evidence base providing a large volume of data from which to derive our initial list of components. Informed by existing, related taxonomies or similar classifications (16,18-20) and by the list of components suggested by workshop participants, we systematically extracted potential components included in self-management support interventions from the descriptions in the systematic reviews and the primary implementation studies for each condition.

An iterative process was used to categorise this extracted information into core components. This process was conducted initially by two authors (ST and HLP), and was a fluid process involving the creation, removal, and merging of categories with the ultimate aim of creating a list of comprehensive, and mutually exclusive taxonomy components. This process resulted in the creation of the first version of the taxonomy.

### **Step II – refining the taxonomy of self-management support**

The taxonomy derived in step 1 was then tested against components described in the systematic reviews and implementation studies evaluating self-management support in people living with any of the remaining 12 LTCs (see Table 1). Additional identified components were tested against, and incorporated into, the components of the taxonomy, which was modified as necessary. This step was conducted primarily by three researchers (ST, HLP, EE).

Throughout this iterative process, the PRISMS team identified and discussed components described in the included studies that did not fit comfortably into the components

of the taxonomy. This way the taxonomy was challenged and, where necessary, adapted to accommodate new components, eliminate overlap between components and clarify definitions. The definitions were modified to accommodate examples of activities in different LTCs to ensure they were widely applicable.

### **Step III – expert feedback on the taxonomy of self-management support**

At an end-of-project multidisciplinary expert workshop we presented our refined taxonomy to the participants for comment and revision. The PRISMS research team (ST, HP, EE, GP, HLP) then collated any feedback and finalised the first version of the taxonomy.

### *Development of version 2 of the PRISMS Taxonomy of Self-Management Support*

#### **Step IV –utility testing of the taxonomy of self-management support and further refinement**

We then tested the utility of the taxonomy against the description of a novel self-management support programme in a LTC not included in our original list of 14 (in Table 1), the HOPE self-management support programme for cancer survivors (23) (licensed by Macmillan Cancer Support) described in Supplementary File 1. A researcher not involved in the initial development of the taxonomy (CB), systematically coded activities within the HOPE facilitator manual with reference to the taxonomy. In an addition to the first version of the taxonomy, the coder also noted the ‘dose’ of any particular activity within a component (i.e. frequency with which it occurred) as it was recognised that outcomes could be influenced by a dose-response effect.

Codes were then checked and disputes discussed with members of the PRISMS team (GP, ST and HP). Where components of the taxonomy needed further clarification, this was noted and refinements agreed within the team. This led to the development of the second version (version 2) of the Taxonomy of Self-Management Support, which was then ‘reality checked’ in discussion with expert advisors (academics, commissioners, service providers

and health care professionals). This involved consultation to gain feedback on whether the taxonomy resonated with the expert advisors' real-world experience.

## **Results**

### *Multidisciplinary expert workshop and consensus exercise*

The pre-workshop open round was completed by 19 out of the 83 invited (23%) people, 14 of whom attended the workshop. A total of 27 delegates (33% of those invited) attended the conference, encompassing health-care managers, commissioners, policy-makers, patients and HCPs. Potential components of self-management support suggested by the respondents as important in the open round were collated and analysed thematically into 10 categories (training and education, access to information, monitoring, environmental adaptations, care planning, access to a specialist team, emotional/social/psychological support, users having financial control, financial incentives, and 'large scale' public health initiatives). Key features of interventions were discussed including patient centeredness, complexity, multidisciplinary, disruption to the individual, involvement of carers/families, generic/disease-specific, duration, accessibility and integration into mainstream health care (see (22) for further detail).

### *PRISMS dataset*

The PRISMS dataset comprised 102 quantitative systematic reviews reporting 969 unique RCTs of self-management support interventions (22). Of these, 18 were reviews of self-management support in asthma (157 unique RCTs) and 17 were reviews in Type 2 diabetes (179 unique RCTs). The 61 implementation studies included 19 in asthma and eight in Type 2 diabetes and from these we identified 14 different self-management support components. At this early stage, we focussed the taxonomy on components delivered directly to people with LTCs and their carers, though highlighted that some were delivered indirectly through interventions delivered to professionals and/or organisations.

This initial list of components was then tested against the PRISMS dataset for the remaining 12 LTCs, which included a total of 67 systematic reviews encompassing 633 unique RCTs, and 34 implementation studies. Through discussion, we recognised that as well as defining what was delivered in each component, there were overlapping dimensions which described how, by whom or to whom the intervention was delivered. These distinctions were of practical importance but represented dimensions that differed from the initial classification of components. For example, training was a component but the medium could be paper, interactive computer games, individually in clinical consultations, or in group sessions (how). Similarly, training could be provided by health care professionals, peers, or professional educators (by whom), and it could be targeted at individuals or communities, generic or tailored and/ or culturally specific (to whom). We therefore defined dimensions of: 1) mode of delivery; 2) personnel delivering; and 3) to whom the intervention was targeted.

Feedback from the multidisciplinary workshop broadly confirmed the taxonomy, but there was a strong suggestion that interventions to support self-management included ‘indirect interventions’ (those interventions delivered to professionals and/or organisations which indirectly support a person’s self-management by enabling professionals and/or organisations to deliver the direct components to the person) and that these should be recognised in the taxonomy. We added these into the first version of the taxonomy,(22) which now included 14 direct components and five indirect components.

### *Utility testing of the taxonomy of self-management support and further refinement*

The taxonomy successfully enabled coding of all the components of the HOPE manual.(23) Of the 14 direct components categorised by version 1 of the taxonomy, six were coded as being present in the HOPE programme (see Supplementary File 2 for the included components and coding examples).

Utility testing resulted in three modifications to the taxonomy:

1. Detailed description of the components. Although we had elaborated on some (but not all) of the components, it became clear that that we needed to provide more detailed descriptions of each component (as well as some examples of specific activities) to enable those unfamiliar with the taxonomy to code accurately and consistently.
2. Modifications to specific components. The coding process identified that a clearer distinction should be made between two components: 'Training/rehearsal for psychological strategies' and 'Lifestyle advice and support', as the latter may also require psychological strategies. For example, managing stress by using relaxation techniques could be coded under both components. In the revised version of the taxonomy, 'Lifestyle advice and support' explicitly focusses on practical advice (for example, on how to increase levels of physical activity, or dietary advice) as opposed to psychological strategies.
3. Modification of the taxonomy dimensions. Within the HOPE programme,(23) we successfully coded the mode of delivery (group-based, face-to-face), personnel delivering the intervention (expert patient, lay (cancer survivor) facilitators) and to whom the intervention was targeted (HOPE was delivered in NHS and community settings targeting patients, specifically cancer survivors). We added the dimension of 'intensity, frequency and duration' (e.g. 2.5 hours weekly for 6 weeks). It was also noted that the description of the components needed to specify the 'dose' (e.g. goal setting as part of training/rehearsal in psychological strategies occurs weekly).

Final discussions took place with all authors to further develop the detail of the descriptions for the second version of the taxonomy. Academics, commissioners, service providers and health care professionals were also consulted as expert advisors during this process. All 14 components delivered directly to people with LTCs or their carers stayed the

same in essence from version 1 to version 2 (see supplementary file 3). Subsequently, we recognised that the taxonomy is of potential components of self-management support – rather than a taxonomy of ways of influencing or inducing professionals and organisations to provide the direct components of self-management support. We, therefore, decided to remove the enumeration of the ways to enable professionals or organisations to provide self-management support, though the taxonomy explicitly reminds readers of the possibility of indirect support for the components.

The full version of the PRISMS Taxonomy of Self-Management Support is shown in Table 2 with a list of the dimensions, plus descriptions of the components and examples taken from the PRISMS dataset. It includes 14 distinct components which may be delivered directly to people with LTCs and/or their caregivers. Self-management support is typically multi-faceted so the expectation is that several (though not necessarily all) of these components may be present in interventions. A note at the beginning of the version 2 taxonomy reminds readers of the possibility of indirect self-management support.

The four overlapping dimensions are 1) mode of delivery (e.g., face-to-face, remote, telehealthcare, web-based); 2) personnel delivering the support (e.g., health care professionals, lay educators, both); 3) targeting (e.g., individually tailored, group-based, cultural group specific, generic or condition-specific); and 4) intensity, frequency and duration of the intervention (as opposed to dose of the individual components) (e.g., how much of the intervention, how often, for how long). Within these dimensions, interventions are not mutually exclusive, for example, an intervention may be both culturally specific and individually tailored.

## **Discussion**

We believe the proposed taxonomy of the components of self-management support will be of use to those providing, commissioning, designing and researching self-

management support interventions. Following a clearly described process of development and testing, and derived from over 100 systematic reviews of self-management support, the PRISMS taxonomy of self-management support proposes a 14-item classification system of the components of self-management support interventions. It includes four over-arching dimensions: mode of delivery; the personnel delivering or facilitating the support; the targeting of the intervention; and the intensity, frequency and duration of the intervention. In addition, a detailed description including the 'dose' of the components within the intervention needs to be explicitly reported. We also recommend that the 'intensity' of the individual components within the intervention is discussed, as this may have implications for effectiveness (e.g., provision of a leaflet with information about the condition is lower in intensity and therefore may be less effective than a one hour workshop about the condition with opportunity to discuss and ask a professional questions).

### *How the results relate to published literature*

The defining feature of the PRISMS taxonomy is that it describes components of interventions designed to support self-management. In contrast, the widely cited behaviour change techniques taxonomy of Michie *et al.*(16) focuses exclusively, and in considerable detail, on characterising the active ingredients of behaviour change interventions. Behaviour change contributes to some of the components of the PRISMS taxonomy (e.g. improving adherence, social support or lifestyle activities) and the behaviour change techniques taxonomy will therefore be an important tool for those responsible for delivering those aspects of self-management support. However, the PRISMS taxonomy serves a different purpose and is broader - including service components, such as 'regular clinical review', 'provision of easy access to advice or support when needed' and 'clinical action plans'. By including aspects, such as 'provision of information on resources', the PRISMS taxonomy might also be applied to preventive health activities, for example, the brief opportunistic

advice and signposting of ‘making every contact count.’(26) Barlow *et al.*(18) consider the content, format and mode of delivery of effective self-management interventions, which may contribute to some of the components of the more comprehensive PRISMS taxonomy. The PRISMS taxonomy of self-management support may be a valuable tool to facilitate conceptualisation of self-management support, improve reporting of interventions and promote the use of a common language of self-management support for commissioners, service providers, health care professionals, researchers and people with LTCs (14-17). Furthermore, the taxonomy is applicable to self-management support regardless of the underlying philosophy behind the support (27).

### ***Strengths and limitations***

The process for developing the taxonomy has a number of strengths. We derived our initial list of self-management support activities from systematic reviews of interventions in 14 exemplar conditions selected by a multidisciplinary expert advisory group to represent a broad range of characteristics of LTCs.(22) We then tested the utility of the taxonomy on an additional LTC not included in that list. The 102 systematic reviews and 61 implementation studies provided a large evidence base from which to work, and our multidisciplinary research team enabled balanced interpretation. For example, the breadth of evidence and experience enabled us to appreciate discrepancies in terminology when it became apparent that the term ‘action plan’ was understood differently by clinicians (e.g., asthma action plans) and those with a background in psychology (e.g., action planning as a behaviour change technique(16)).

The PRISMS overview was an efficient method of reviewing a large amount of literature on a broad subject in order to inform the commissioning of self-management support services. However, meta-reviews report systematic reviews, which, in turn, report RCTs, so they are one level removed from the source data. Therefore, nuances of the

interventions may not have been reported in the evidence the PRISMS team used to develop the initial taxonomy. Meta-reviewing also imposes a time delay as, for example, if the most recent systematic review included was from 2012, then their most recent primary study may be from 2008. New interventions may have been introduced since the last included RCT, so we may not have identified all possible components relevant to self-management support. The PRISMS project aimed to cover a broad range of LTCs with very different characteristics, including conditions with different severity, disease progression, variability, symptoms and responsiveness to treatment or self-management. Also, it was not only meta-review evidence that informed the initial stages of this taxonomy development, but the PRISMS systematic review of implementation of interventions (22, 24, 25). In addition, the utility testing was carried out using a self-management support intervention designed for people with a heterogeneous LTC not included in the original PRISMS project (survivors of all types of cancer). Despite this, we acknowledge our taxonomy may not cover all LTCs and self-management support interventions. However, the taxonomy is designed to evolve (as indeed it did during utility testing) and the concept of dimensions means that as innovative modes of delivery develop (such as elaborations on telehealthcare), they can be readily accommodated.

We acknowledge the possibility of the indirect delivery of self-management support (i.e. delivered at the professional and organisational level) but there were fewer of these interventions included for review within the PRISMS report compared to direct interventions (i.e. support delivered directly to the person with a LTC or their carer). We therefore recommend that those wishing to deliver a self-management support intervention at an indirect level or within a whole systems approach use our taxonomy in combination with the approach suggested by the Cochrane Effective Practice and Organisation of Care Group (EPOC).(28) The EPOC taxonomy considers professional, financial (provider, patient), organisational (provider orientated, patient orientated), structural and regulatory

interventions. It should be noted that the taxonomy does not include statements relating to the absolute or relative effectiveness of the different potential components. We also know little about the mechanisms of action and the outcomes of self-management that are important to people. These should be considered in self-management support interventions and may impact on the choice of components included within interventions. The taxonomy may be a useful tool for researchers examining barriers and facilitators to self-management support.

### *Implications for future research, practice and policy*

Whilst it was possible to code all elements of the HOPE programme, many were grouped under the ‘training/rehearsal for psychological strategies’ component. This is a reflection of the theoretical underpinning of the HOPE programme in positive and health psychology.(29-32) Self-management support services tailored to other conditions would be expected to prioritise other components. The taxonomy is thus not intended as a checklist of components that should be included in an intervention, but rather a list of what should be considered. There is a need for further utility testing of this taxonomy with self-management support in diverse clinical and health care contexts, which may indicate the need for further clarification and/or development of additional components.

Self-management support is a core component of the chronic care model(33) and other models of care for people with LTCs.(34-36) The PRISMS taxonomy thus has potential as a tool for commissioners and providers of health care seeking to develop self-management support as well as patient charities promoting services that meet the needs of people with LTCs. A useful next step in policy would be for guideline organisations, such as the National Institute for Health and Clinical Excellence in the UK, to recommend the use of the taxonomy as a common language for describing and comparing self-management support interventions. The taxonomy will also be useful to help researchers describe self-management support interventions and as a framework for evidence syntheses. However, there remains a

need for authors to be explicit when describing the activities coded under each component, so that others can understand exactly what has been delivered as part of the intervention.

## **Conclusion**

The PRISMS taxonomy is a classification of the components of self-management support developed to provide a framework for researchers designing and describing interventions, reviewers synthesising evidence and developers of health care for people with LTCs. We hope it will stimulate discussion amongst commissioners, providers, LTC charities and researchers in this field.

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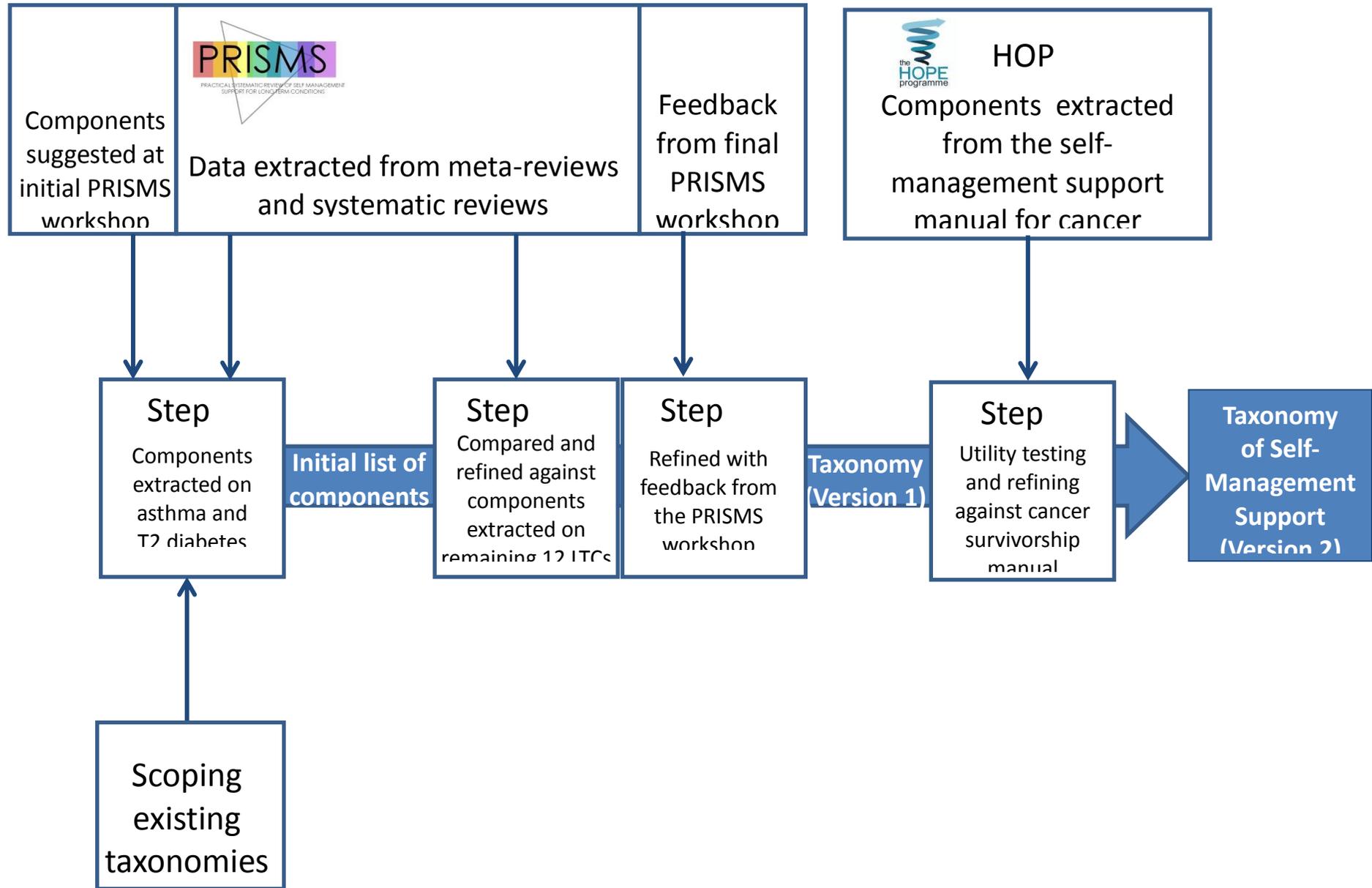
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Figure 1. Diagram of the process we carried out to create the PRISMS taxonomy of self-management support



*Table 1. The 14 long-term conditions in the PRISMS project*

**The 14 LTCs selected by multidisciplinary expert participants using consensus methodology at a project workshop for the PRISMS meta-reviews and implementation review.**

*Used in step I of taxonomy development:* Asthma and Type 2 Diabetes Mellitus (T2DM)

*Used in step II of taxonomy development:* Chronic Kidney Disease (CKD); Chronic Obstructive Pulmonary disease (COPD); dementia; depression; epilepsy; hypertension; inflammatory arthropathies (consisting of rheumatoid arthritis, psoriatic arthritis and lupus erythematosus); Irritable Bowel Syndrome (IBS); low back pain; progressive neurological disorders (consisting of motor neurone disease, multiple sclerosis and Parkinson's disease); Type 1 Diabetes Mellitus (T1DM); and Stroke.

Table 2. The PRISMS taxonomy

| <p><b>Over-arching dimensions:</b></p> <ul style="list-style-type: none"> <li>• <b>Modes of delivery</b> (e.g. face-to-face, remote, telehealthcare, web-based)</li> <li>• <b>Personnel delivering the support</b> (e.g. healthcare professionals, lay educators)</li> <li>• <b>Targeting</b> (e.g. individual or groups, generic or condition-specific, cultural groups)</li> <li>• <b>Intensity, frequency and duration of the intervention</b> (not the individual components)</li> </ul> |  |   |
|--|--|---|
| <p><b>Taxonomy of direct components</b>, i.e. those components delivered directly to people with LTCs and/or carers. Please note for brevity where person with a LTC is used in this table it indicates the person with an LTC and /or their carer.<br/>It should be noted that self-management may also be supported by enabling health care professionals or organisations to deliver these components (“indirect self-management support”).</p>   |  |   |
| Component  | Description  | Examples of activities from PRISMS dataset ( <i>LTC in brackets</i> )   |
| A1. Information about condition and /or its management   | Providing people with LTCs with information and instruction about their LTC or about general aspects and principles of managing their LTC (physiology, medication, prognosis, emotional, psychosocial etc.)  | <ul style="list-style-type: none"> <li>- Explanation of anatomy, pulmonary physiology, pathophysiology of lung and factors that can provoke asthma (<i>Asthma</i>)</li> <li>- Two day patient education programme, covering living with epilepsy, epidemiology, basic knowledge, diagnostics, therapy, self-control, prognosis, psychosocial aspects and network (<i>Epilepsy</i>)</li> </ul> |
| A2. Information about available resources  | Providing people with LTCs with information (e.g. written, verbal, visual) on issues such as financial benefits, sources of social or peer support, charitable organisations.  | <ul style="list-style-type: none"> <li>- Advice on obtaining financial assistance and transport (<i>Stroke</i>)</li> <li>- Referral to benefits advisor to ensure individual is in receipt of benefits to which they are entitled (<i>COPD</i>)</li> </ul>  |
| A3. Provision of/agreement on specific clinical action plans and/or rescue medication  | Written instructions prepared with or by a healthcare professional to enable the person to stay in control of their condition, tailored to the person, LTC, and severity. Includes how to take medication, recognise symptoms of deterioration and what actions to take. | <ul style="list-style-type: none"> <li>- Written action plan to enable self-adjustment of medications in response to worsening asthma based on symptoms and/or peak flow (<i>Asthma</i>)</li> <li>- Specific advice on adjusting insulin dosage, or managing hypoglycaemia. (<i>Diabetes</i>)</li> </ul>  |
| A4. Regular clinical review  | A regular, scheduled review of the person, their condition and self-management, conducted by a health care professional.   | <ul style="list-style-type: none"> <li>- Regular clinical visits reviewing the person’s condition and self-management(<i>Stroke, Asthma and other LTCs</i>)</li> </ul>  |
| A5. Monitoring of condition with   | Monitoring symptoms, behaviours or objective measures related to LTC. Can be done by the person  | <ul style="list-style-type: none"> <li>- Daily log completion including peak flow, triggers, and ratings of benefits (<i>Asthma</i>)</li> </ul>   |

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| feedback   | with a LTC or by others but the results must be fed back to the patient. Interpretation, decision and/or action is undertaken by the patient, but may be supported by a professional. Professionals may support self-management by reviewing monitored data and providing feedback to the patient. | <ul style="list-style-type: none"> <li>- Patients could send information about self-monitoring drug regimen and physiologic variables to physicians, who reviewed the data and sent personalised recommendations back to the patients (<i>T2 diabetes</i>)</li> </ul>  |
| A6. Practical support with adherence (medication or behavioural)     | Provision of practical help to improve a person's adherence to medication or behaviour change activities.  | <ul style="list-style-type: none"> <li>- Diary of medication use and seizures, Dosette medication containers, and prescription refill and appointment-keeping reminders (<i>Epilepsy</i>)</li> <li>- Adherence improvement strategies such as taking medication with regularly scheduled activities (<i>Asthma</i>)</li> <li>- Weekly reminder telephone calls to perform foot care (<i>T2 diabetes</i>)</li> </ul>                      |
| A7. Provision of equipment   | Provision of equipment to enable, assist or promote self-monitoring and/or self-management of the LTC.   | <ul style="list-style-type: none"> <li>- Bag of supplies to enable foot care (containing soap, towel, socks, mirror, toenail clippers, lotion samples) (<i>T2 diabetes</i>)</li> <li>- Provision of a peak flow meter free of charge (<i>Asthma</i>)</li> <li>- Home coagulation testing equipment (<i>Stroke</i>)</li> </ul>  |
| A8. Provision of easy access to advice or support when needed        | People with LTCs are provided with flexible access to and timely advice from health services in the event of an urgent or non-urgent question or concern arising.  | <ul style="list-style-type: none"> <li>- Contact details of specialist nurse helpline for information or support or to advise in the event of clinical deterioration (<i>Stroke</i>)</li> <li>- Provision of an out of hours service for advice and support (<i>various LTCs</i>)</li> </ul>   |
| A9. Training/rehearsal to communicate with health care professionals | Teaching people with LTCs to develop communication skills/techniques to improve relationships, better communicate needs, and enhance shared decision making with healthcare professionals. Also supporting/mentoring people with LTCs to practise the skills they have been taught.                | <ul style="list-style-type: none"> <li>- Strategies for communicating with health care providers, such as taking a tape recorder to doctors' visits and recording consultation (<i>Asthma</i>)</li> <li>- Community Support Workers from minority ethnic/deprived groups who provide advocacy and support communication with healthcare professionals, attending an appointment with the person with LTC (<i>T2 diabetes</i>)</li> </ul> |
| A10. Training/rehearsal for everyday activities                      | Teaching people with LTCs to develop skills that support everyday activities and/or supporting people with LTCs to practise the skills they have been taught.  | <ul style="list-style-type: none"> <li>- Occupational therapy activities such as transfers, washing and dressing practice (<i>Stroke</i>)</li> <li>- Cognitive rehabilitation (<i>Dementia</i>)</li> </ul>   |
| A11. Training/rehearsal for practical self-management                | Teaching people with LTCs to develop specific practical skills that will enable them to manage their LTC, and/or supporting people with LTCs to practise   | <ul style="list-style-type: none"> <li>- Inhaler technique instruction (<i>Asthma</i>)</li> <li>- Practising foot care procedures (<i>T2 diabetes</i>)</li> <li>- Teaching patients to use a home dialysis machine (<i>CKD</i>).</li> </ul>  |

|  |   |  |
|--|---|--|
| activities   | the skills they have been taught.   | - Teaching patients to take their own blood pressure ( <i>Hypertension</i> )   |
| A12. Training/<br>rehearsal for<br>psychological<br>strategies | Teaching people with LTCs skills in using psychological strategies to help them better manage the consequences of a LTC and/or supporting them to practice the skills they have been taught.<br>May include: problem-solving strategies, relaxation techniques, re-framing, distraction, cognitive restructuring, goal setting and action planning (prompts detailed planning of performance of the behaviour/outcome of the behaviour, NB this does not have to be health behaviour focussed). | - Personal goals aimed at reducing risk of further stroke ( <i>Stroke</i> )<br>- Computerised game which challenges the player to ‘think’ about asthma control. If a problem is noted, the player can create a solution and ‘act’ ( <i>Asthma</i> )                    |
| A13. Social support  | Facilitation of social support, where a person feels cared for and supported by others in a social network.<br>May include befriending, peer support, peer mentoring and group socialising.   | - Encouraging participants to interact and assess their own and their peers’ progress toward managing their diabetes by sharing ideas, advice, and support ( <i>T2diabetes</i> )<br>- School asthma education to enhance peer understanding/support ( <i>Asthma</i> ). |
| A14. Lifestyle advice<br>and support                           | Provision of advice and support around health and lifestyle.<br>Relates to <i>practical</i> advice and support in relation to handling life stressors, NOT psychological elements that relate to handling life stressors (see A12 for <i>training/rehearsal in psychological strategies</i> ).<br>May include general lifestyle advice and support concerning diet, physical activity, smoking cessation, and alcohol intake.   | - Assist the parent in smoking cessation ( <i>Paediatric asthma</i> )<br>- Monthly clinic visits with nutritionist providing advice to enhance physical activity and dietary intake ( <i>T2DM</i> ).<br>- Salt restriction advice ( <i>Hypertension</i> )              |

*Supplementary file 1: Outline of the HOPE programme of self-management support for cancer survivors (23).*

| <b>Week 1 Content</b> |                                |
|-----------------------|--------------------------------|
| 1                     | Welcome/Introductions          |
| 2                     | Responsibilities/Ground Rules  |
| 3                     | Instilling HOPE                |
| 4                     | Diaphragmatic Breathing        |
| 5                     | Gratitude Diary                |
| 6                     | Goal Setting                   |
| <b>Week 2 Content</b> |                                |
| 1                     | Solution Focused Goal Feedback |
| 2                     | Gratitude Diary                |
| 3                     | Managing Stress                |
| 4                     | Mindfulness                    |
| 5                     | Goal Setting                   |
| <b>Week 3 Content</b> |                                |
| 1                     | Solution Focused Goal Feedback |
| 2                     | Gratitude Diary                |
| 3                     | Managing Fatigue               |
| 4                     | Sleeping Better                |
| 5                     | Guided Imagery                 |
| 6                     | Goal Setting                   |
|                       |                                |

| <b>Week 4 Content</b> |                                    |
|-----------------------|------------------------------------|
| 1                     | Solution Focused Goal Feedback     |
| 2                     | Gratitude Diary                    |
| 3                     | Body Changes, Sexuality & Intimacy |
| 4                     | Communication                      |
| 5                     | Goal Setting                       |
|                       |                                    |
| <b>Week 5 Content</b> |                                    |
| 1                     | Solution Focused Goal Feedback     |
| 2                     | Gratitude Diary                    |
| 3                     | Fear of Recurrence                 |
| 4                     | Get Active, Feel Good              |
| 5                     | Goal Setting                       |
| <b>Week 6 Content</b> |                                    |
| 1                     | Solution Focused Goal Feedback     |
| 2                     | Gratitude Diary                    |
| 3                     | Character Strengths                |
| 4                     | Priorities (Rock in a Jar)         |
| 5                     | Motivational Imagery               |
| 6                     | Open Space Forum                   |
| 7                     | Sharing our Successes/Word Cloud   |

Supplementary file 2: Taxonomy components present in the HOPE manual, elaboration of the techniques under each component, direct examples from the HOPE manual (23) and the dose of the component (coded using version 1 of the taxonomy)

| Taxonomy component  | Elaboration  | Examples from HOPE cancer facilitator manual ( <i>dose</i> )   |
|---|--|--|
| <b>A2. Information about available resources</b>                            |  | Participants are provided with information throughout the programme and a resource table is provided ( <i>every week</i> ).  |
| <b>A8. Safety netting</b>   | Participants are able to call programme facilitators between sessions if needed  | Participants are provided with contact details for programme facilitators who they can call if needed ( <i>this is a constant throughout the programme</i> ).  |
| <b>A9. Training/rehearsal to communicate with health care professionals</b> |  | <i>Session 4:</i> communication with friends/work colleagues/health professionals. Includes role play activity and problem solving ( <i>session 4 only</i> ).  |
| <b>A12. Training/rehearsal in psychological strategies</b>                  | Including: <ul style="list-style-type: none"> <li>• relaxation</li> <li>• goal setting (including action planning)</li> <li>• solution focussed goal feedback</li> <li>• problem solving</li> <li>• gratitude activity</li> <li>• self-reward and social reward</li> <li>• managing stress</li> <li>• sexuality and intimacy</li> <li>• managing fear of recurrence</li> </ul> | Relaxation (including guided imagery, diaphragmatic breathing, mindfulness), gratitude activity, goal setting activity (including action planning), solution focussed goal feedback and rewards ( <i>once every week</i> )<br><br>Problem solving ( <i>this is a constant throughout the programme</i> ).<br><br><i>Session 2:</i> managing stress ( <i>session 2 only</i> ).<br><i>Session 4:</i> sexuality and intimacy ( <i>session 4 only</i> ).<br><i>Session 5:</i> Managing fear of recurrence ( <i>session 5 only</i> ). |
| <b>A13. Social support</b>  | Including: <ul style="list-style-type: none"> <li>• practical support</li> <li>• emotional support</li> </ul>  | Participants are encouraged to share experiences, advice, ideas and support each other ( <i>this is a constant throughout the programme</i> ).   |
| <b>A14. Lifestyle advice and support</b>                                    | Including: <ul style="list-style-type: none"> <li>• sleeping better</li> <li>• body changes, sexuality and intimacy</li> <li>• physical activity</li> <li>• priorities</li> </ul>  | <i>Session 3:</i> sleeping better ( <i>session 2 only</i> ).<br><i>Session 4:</i> body changes, sexuality and intimacy ( <i>session 2 only</i> ).<br><i>Session 5:</i> get active, feel good ( <i>session 2 only</i> ).<br><i>Session 6:</i> priorities (rocks in a jar) – this activity is about managing your priorities effectively ( <i>session 2 only</i> ).  |

Supplementary file 3. Components of the PRISMS taxonomy - version 1 to version 2 (changes in bold)

| Version 1   | Version 2   |
|---|---|
| <b>Direct components - delivered to A: people with LTCs and/or caregivers</b>   |   |
| <p>A1 <b>Education</b> about condition and /or its management</p> <p>A2 Information about available resources</p> <p>A3 Provision of/agreement on specific action plans and/or rescue medication</p> <p>A4 Regular clinical review</p> <p>A5 Monitoring of condition with feedback to the patient</p> <p>A6 Practical support with adherence (medication or behavioural)</p> <p>A7 Provision of equipment</p> <p>A8 <b>Safety netting</b></p> <p>A9 Training/rehearsal to communicate with healthcare professionals</p> <p>A10 Training/rehearsal for <b>activities of daily living</b></p> <p>A11 Training/rehearsal for practical self-management activities</p> <p>A12 Training/rehearsal for psychological strategies</p> <p>A13 Social support</p> <p>A14 Lifestyle advice and support</p> | <p><b>Information</b> about condition and /or its management</p> <p>Information about available resources</p> <p>Provision of/agreement on specific action plans and/or rescue medication</p> <p>Regular clinical review</p> <p>Monitoring of condition with feedback</p> <p>Practical support with adherence (medication or behavioural)</p> <p>Provision of equipment</p> <p><b>Access to support when needed</b></p> <p>Training/rehearsal to communicate with healthcare professionals</p> <p>Training/rehearsal for <b>everyday activities</b></p> <p>Training/rehearsal for practical self-management activities</p> <p>Training/rehearsal for psychological strategies</p> <p>Social support</p> <p>Lifestyle advice and support</p> |
| <b>Indirect components – either delivered to B: individual health or social care professionals, or C: whole organisations</b>   |   |
| <p>B/C1 Education and Training</p> <p>B/C2 Provision of equipment</p> <p>B/C3 Prompts</p> <p>B/C4 Feedback and review</p> <p>C5 Financial Incentives</p>  | <p><b>Indirect components removed, mention of possibility of indirect self-management support retained.</b></p>   |