What are the outcomes of self-management that matter to stakeholders? Study protocol for the Self-Management VOICED project

Sara Demain, Emma Boger, Sue Latter, Matthew Hankins, Anne Kennedy, Claire Foster, Fiona Jones, Ian Kellar

Abstract

Background: The number of people living with a long-term health condition is increasing. Self-management has been identified as a significant way of managing the burden of long-term health conditions for patients and for health services. It has been highlighted that increased support for self-management is needed and that services should be commissioned to underpin this. However, little is known about which outcomes of such support are meaningful to differing stakeholder groups. The protocol described in this paper describes a programme of research which aims to explore the outcomes of self-management support which are valued by patients, family or friends with caring responsibilities, health professionals and commissioners of self-management support services. This will ensure the relevance of future self-management support services to all stakeholder groups.

Methods: This research consists of three distinct but related phases. Phase one will systematically review the literature to identify which outcomes of self-management have been considered important. Phase two seeks to explore differing stakeholder perceptions of the preferred outcomes of self-management support. Phase three uses the findings from the previous phases to explore and map consensus and disparity regarding the outcomes of importance in a nationally derived Delphi process study.

Discussion: The findings will provide information regarding the outcomes of self-management support considered important by differing stakeholder groups and identify areas for development within self-management support interventions.

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Background

The rapid increase in people living with a long-term health condition (LTHC) has resulted in self-management (SM) becoming an important contemporary issue. SM represents an ideological shift towards increased partnership where patients and their families are given the support needed to be confident and capable at managing their health (Wilkinson and Whitehead, 2009). The direction of United Kingdom health policy endorses both increased support for SM (DoH, 2005, DoH, 2008, DoH, 2011) and the commissioning of services to support self-management (Imison et al., 2011, Richards, 2012). There is less clarity around how SM is viewed, the indicators of successful SM required to target services, and which SM outcomes are prioritised and valued by different stakeholder groups, such as patients, their families, health professionals and commissioners (Chodosh et al., 2005, Coster and Norman, 2009, The Health Foundation, 2011). The Self-management VOICED project (**V**alued **O**utcome of

Importance: **C**ons**E**nsus and **D**ifference) is a two-year programme of research funded by The Health Foundation, which seeks to explore the outcomes of self-management that matter most to differing stakeholder groups.

A recent review of SM interventions for LTHCs identified that over 70 different assessed outcomes were used as indicators of self-management (Nolte and Osborne, 2013). Few of these measures have been developed from patients' or families' perspectives (Boger et al., 2013). The diversity of indicators of successful SM is arguably indicative of the conceptual complexity of SM. However, given that clear outcome expectations aid the design and evaluation of complex interventions (Campbell et al., 2007), the absence of certainty regarding the preferred outcomes of SM represents a critical limitation. Without knowledge of the preferred outcomes, there is potential for irrelevant outcomes to be targeted and evaluated. Additionally, if interventions target concepts and outcomes deemed irrelevant to patients or their families, there is a risk of SM support to narrowly reflect the views of healthcare professionals or commissioners and for unacceptably high attrition rates (Bury and Pink, 2005, Paterson and Hopwood, 2010).

Which potential outcomes of SM are valued by stakeholders and the degree of alignment between them has not been sufficiently explored. Evidence suggests disagreement may exist between health professionals and patients regarding the preferred outcomes of SM (Bury et al., 2005, Townsend et al., 2006). A strong direction in policy exists for supported SM, however this is often unsupported in practice due to differing priorities (The Kings Fund, 2011) and lack of health professional expertise in promoting SM (Kosmala-Anderson et al., 2010, Légaré et al., 2012, Wilson et al., 2006). Very little is known about the outcomes of SM valued by commissioners of services (Richards, 2012) despite the new era of commissioning of services in the National Health Service. Research to identify which outcomes differing stakeholder groups think are important is warranted.

We have identified three conditions (diabetes, stroke, colorectal cancer) that vary on important dimensions relevant to SM (for example, disease trajectory, current legitimacy of and provision for SM support, presence of physical or cognitive disability, condition associated stigma) as exemplar conditions for investigating which outcomes of SM are valued by different stakeholders.

The benefits of SM support in these exemplar conditions may include improvements to self-efficacy (Gao and Yuan, 2011, Jones et al., 2009, van der Wulp et al., 2012), mood (Cadilhac et al., 2011, McCorkle et al., 2011, Steed et al., 2003), physical symptoms and function (Johnston et al., 2007, Porter et al., 2008, Thoolen et al., 2007) and reduced health service utilisation (Health Foundation, 2011). However, the extent to which these outcomes are meaningful or important to all stakeholders is not known. Work to conceptualise SM following stroke demonstrated that patients viewed SM as '*doing my bit*' to stay well, in the context of health professionals who also 'do their bit' (Boger et al., 2014). However, SM appeared hindered by a lack of resources and access to appropriate professional support. Similar findings have been reported in relation to other LTHCs (Kielmann et al., 2010, Wilkinson and Whitehead, 2009). Currently there is uncertainty regarding what represents successful SM for the different stakeholders involved. This is key to understanding what outcomes of SM matter most to different groups and thus to informing the design and commissioning of future SM support that meets the needs of the population.

For SM services to be effectively commissioned, and supported by health professionals, enacted by people with LTHCs and assisted by their families, there needs to be consensus amongst relevant stakeholders about which outcomes of SM matter most. Currently, there is a discrepancy between policies which promote self-management and their implementation at the grassroots level. It is assumed that improvements in clinical indicators or health behaviours are the outcomes of most value (Lorig et al., 2001, Nolte and Osborne, 2013) but there is little empirical evidence about which outcomes are of most value to each stakeholder group.

Aims and objectives

Aim: This research seeks to explore current stakeholder consensus and disparity regarding the outcomes of SM which matter to all stakeholder groups.

Objectives: The overall research objectives, which will be achieved in three distinct study phases, are to:
1) Systematically review the literature to identify which outcomes of SM have been considered important
2) Explore differing stakeholder perceptions of the preferred outcomes of SM support
3) Explore and map consensus and disparity regarding the SM outcomes of importance in a nationally derived sample.

Table 1: Key search terms combinations for systematic review

Self-management AND AND outcomes AND	
Patients AND	Stroke OR Diabetes OR Colorectal cancer
Family/ Carer AND	Stroke OR Diabetes OR Colorectal cancer
Health professionals AND	Stroke OR Diabetes OR Colorectal cancer
Commissioner AND	Stroke OR Diabetes OR Colorectal cancer

Design and Methods

Systematic review

Aims: 1) To systematically review published empirical evidence and relevant grey literature to identify which self-management outcomes are important to the following stakeholder groups; patients, family members, healthcare professionals and commissioners

Objectives: 1) Identify which outcomes are of importance from patient, family, HCPs and commissioner perspectives
2) Identify which outcomes are commonly targeted in self-management interventions and policy guidance.
3) Identify areas of generic thematic similarity and disparity in the self-management outcomes considered important across the conditions and stakeholder groups.

Method: Empirical evidence derived by any research design, will be included. Published literature will be systematically searched using the following electronic databases; CINAHL, Psychinfo, Medline, Cochrane, Web of science, EMbase, Evidence search, HMIC, in addition to hand searches of reference lists of review articles, DoH policy documents, and documents from relevant third sector organisations.
Boolean operators or Mesh terms, along with truncated terms (e.g. self-manag*) will be used for search combinations of key terms (Table 1).
Inclusion criteria: Published in English, published 1990- present date.

Exclusion criteria: Study populations under 18years of age. Gestational diabetes.

Papers will not be excluded on the basis of quality judgements. Reference will be made to quality according to an appropriate guideline or quality indicator (e.g. CONSORT, COREQ) and included in summary tables. Articles will be reviewed for the explicit stating of any outcome(s) (actual or anticipated) in relation to self-management. A hierarchy of evidence in relation to the research question was determined as follows:
1) Research which specifically focusses on the views of stakeholders with regard to SM outcomes
2) Research which makes reference to SM outcomes as a finding of other investigations with stakeholders about experiences of SM
3) SM interventions which imply that the aims of the intervention, or outcome measures selected, were directed by stakeholder input.

Table 2. Range of stakeholder interviews and focus groups

<table>
<tr><th></th><th>Stroke</th><th>Diabetes</th><th>Colorectal cancer</th></tr>
<tr><td rowspan="2">Patients</td><td>3* Focus Groups
(1 in each locality)</td><td>3* Focus Groups
(1 in each locality)</td><td>3* Focus Groups
(1 in each locality)</td></tr>
<tr><td colspan="3">1 cross-condition FG</td></tr>
<tr><td rowspan="2">Family members or significant person</td><td>3* Focus Groups
(1 in each locality)</td><td>3* Focus Groups
(1 in each locality)</td><td>3* Focus Groups
(1 in each locality)</td></tr>
<tr><td colspan="3">1 cross-condition FG</td></tr>
<tr><td rowspan="2">Health professionals</td><td>5 interviews
Consultant
Nurse Specialist
Speech and language therapist
Occupational Therapist
Physiotherapist</td><td>5 interviews
Consultant
Nurse Specialist
Dietician
Specialist GP
Podiatrist</td><td>5 interviews
Surgeon
Oncologist
Nurse Specialist
Dietician
Stoma nurse</td></tr>
<tr><td colspan="3">1 cross-condition FG</td></tr>
<tr><td rowspan="2">Commissioners</td><td colspan="3">< 30 interviews
Commissioners whose remit includes each condition
(n = 15)
Commissioners whose remit includes long term conditions and/or self-management (n=15)</td></tr>
<tr><td colspan="3">1 cross-condition FG</td></tr>
</table>

4) SM interventions which state the reasons for the selection of any outcome measures or aims of the intervention
5) SM interventions which identify the expected outcomes of the intervention.

Articles will be analysed for evidence of how and why outcomes were selected for measurement. Findings will aid development of a coding framework for the focus group and interview study.

Focus groups and interviews

Aims: 1) To identify the outcomes of self-management support important to people with a diagnosis of colorectal cancer, type I or II diabetes or stroke and their family members or friends, commissioners of self-management services and health professionals.
2) To identify areas of generic thematic similarity and disparity in the self-management outcomes of importance across the above conditions and stakeholder groups.

Method: Three focus groups per condition with patients and three focus groups per condition with family caregivers will be conducted in three distinct UK locations (Southampton, London and Leeds) selected to cover a range of urban/rural settings with ethnically and socially diverse populations. Interviews with health professionals (n<30) and commissioners (n<30) from each locality will be conducted. One health professional and one commissioner focus group will be conducted (Table 2).

Framework analysis will identify the key elements and themes from participants' accounts (Ritchie and Lewis, 2003). Framework analysis is useful where multiple researchers are working on a project to enable a systematic approach to the data, and for managing large data sets where obtaining a holistic, descriptive overview of the entire data set is desirable (Gale et al., 2013). Analysis will be: i) within each condition and stakeholder group to identify separate perspectives of each; and then ii) across conditions to identify higher-order generic self-management outcomes of importance.

The findings from this qualitative phase will generate a list of important self-management outcomes, from the perspectives of all stakeholder groups, to inform the final Delphi study phase of this research.

Delphi study - Identifying consensus and disparity across stakeholder groups

Aim: To map areas of consensus and disagreement between stakeholder groups in terms of the outcomes of self-management considered important.

Method: Four concurrent Delphi processes (one with each stakeholder group) (Keeney et al., 2001, Powell, 2003) will be conducted to determine within-stakeholder consensus and identify areas of disparity regarding the outcomes of self-management considered important. Each Delphi process will consist of three rounds. Each nationally derived Delphi panel will consist of approximately 30 members, as follows:

1. Patients – all exemplar conditions will be purposively sampled for age, time since diagnosis, gender, socio-economic status and ethnicity.

2. Family/friends

3. Health professionals – condition-specific and self-management experts from a range of relevant professions

4. Commissioner panel - people commissioning services for exemplar conditions and self-management.

Round 1: A list of statements in relation to the outcomes of self-management will be generated from the collective views of all stakeholders in the preceding qualitative phase. The list will be piloted with a lay panel to ensure clarity and legibility before being emailed or posted to members of each Delphi panel. Panel members will be asked to indicate agreement or disagreement with each outcomes' importance, on a five point Likert-style scale. Analysis will be conducted within-stakeholder-groups: 75% agreement within a panel (strongly agree/agree) will be indicative of intra-stakeholder consensus; 75% disagreement (strongly agree/agree) will lead to item removal for the subsequent round for that panel (Keeney et al. 2001).

Round 2: A revised statement list including how all items in the previous round were rated by their relevant panel and each participant's own rating will be sent to panel members. People will be asked to re-evaluate the items not reaching 75% consensus/disagreement and revise their judgements or specify the reasons for remaining outside the consensus.

Round 3: Following round two, the process outlined above will be repeated to provide a final opportunity for participants to either revise their judgements or state reasons for non-consensus.

Discussion

For self-management support to be commissioned, supported and enacted effectively there is a need to understand what consensus (and disparity) exists regarding the outcomes considered important. This will enable the development of relevant self-management interventions and consensus-building interventions around items of disparity. This research seeks to identify a conceptual 'map' of the outcomes of self-management important to relevant stakeholder groups, with defined areas of consensus and disagreement (Figure 1), and will benefit healthcare in several ways. Identifying areas of consensus and divergence about what outcomes matter most is key to developing interventions and support systems which are meaningful to all stakeholders. This is vital if all stakeholders are to engage in the process of commissioning, delivery, support and enactment of self-management. This research will then contribute to developing the partnerships necessary for success. Identifying areas of difference, in addition to consensus, between stakeholder groups will be an important finding and will assist the development of interventions to foster equal partnerships in LTHC management.

No research to date, has investigated the perspectives of commissioners, despite their key role in commis-

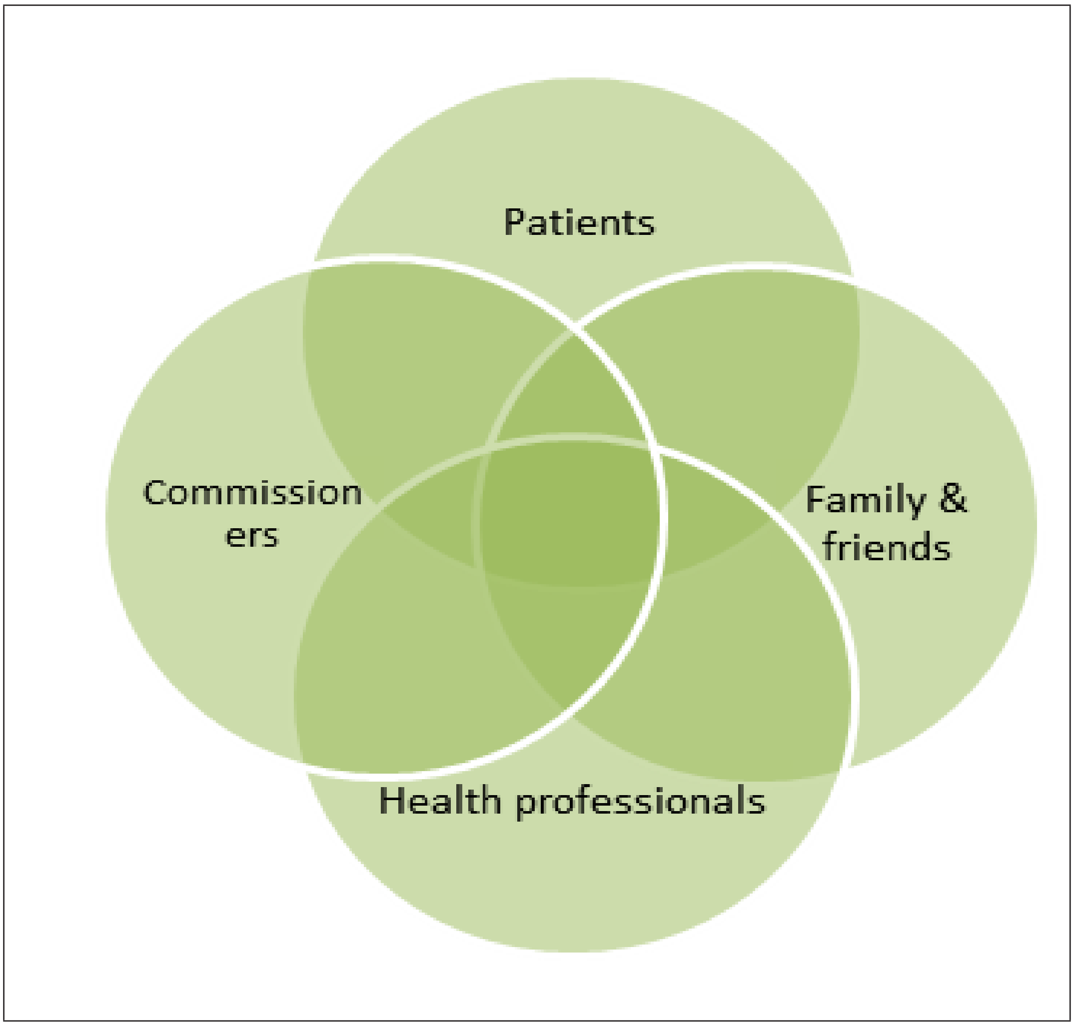

Figure 1. Potential map of stakeholder consensus and disparity regarding self-management outcome of importance.

sioning patient-focussed self-management services. Without in-depth knowledge on the existing preferred outcomes of all stakeholders, there is a risk that support services for self-management will be commissioned that have, and, potentially, limited impact on their target population. This research then has the potential to provide future savings by assisting the development of appropriate and effective self-management support services, and by providing clarity regarding the preferred goals and outcomes of such support.

Identifying outcomes with multi-stakeholder agreement will enable the design and evaluation of future self-management interventions, and potentially improve the uptake and enactment of self-management and reduce the impact of LTHCs. Understanding what outcomes matter most will aid the selection or construction of appropriate outcome measures which capture the concepts relevant to all stakeholders. It is conceivable that current outcome measures do not match these priorities; the findings from this programme of research may guide the development of outcome measures which are valid to evaluate interventions from the perspectives of all stakeholders. Exploration of the outcomes of self-management desired by all key-stakeholders is relevant and opportune and represents a necessary contribution to the current policy and practice debate.

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