

PRISMS: Practical systematic Reviews in Self-Management Support

Invited talk at the NIHR showcase hosted at Glasgow Caledonian University, 13th April 2015

Presented by:



Professor Steph Taylor

Steph is Professor in Public Health and Primary Care in the Centre for Primary Care and Public Health at Barts and The London Medical School, Hon. Consultant in Public Health at Bart's NHS Trust and a sessional GP. Her research is focussed on self-management support for long term conditions - particularly respiratory conditions and chronic pain. She is a member of the Asthma UK Centre for Applied Research and a North Thames Collaboration for Leadership in Applied Health Research and Care (CLAHRC) deputy theme lead.



Dr Gemma Pearce

Gemma is a researcher in the Centre for Technology Enabled Health Research at Coventry University and Public Health at Coventry City Council. Her current role aims to facilitate gaps between research and practice. Prior to her post at Coventry University, she worked at Queen Mary University of London as a researcher on PRISMS project. Her research is focussed on self-management support for people with long-term conditions, physical activity promotion and women's health.

The presentation started by Dr Gemma Pearce:

PRISMS
PRACTICAL SYSTEMATIC REVIEW OF SELF-MANAGEMENT SUPPORT FOR LONG-TERM CONDITIONS

A rapid systematic overview of the evidence on interventions supporting self-management for people with long-term conditions.

Professor Stephanie Taylor & Dr Gemma Pearce

@PRISMS_project
@GemmaSPearce

HS&DR funding acknowledgment: This project was funded by the National Institute for Health Services and Delivery Research programme (project number 11/101404). Department of Health Disclaimer: The views and opinions expressed herein are those of the authors and do not necessarily reflect those of the HS&DR programme, NIHR, NHS or the Department of Health.

NHS
National Institute for Health Research

This is the first presentation in the NIHR showcase presenting funded work from NIHR HS&DR to Queen Mary University of London and University of Edinburgh. It is called the PRISMS project, which stands for Practical systematic Reviews in Self-Management Support for people with long-term conditions. The PRISMS project is very large and we will only be able to give you a whistle stop tour of it today, providing you with snippets to guide you to areas for further reading in the report. Please feel free to tweet.

Aim

To undertake a rapid, systematic overview of the evidence for self-management support interventions in people with long-term conditions to inform commissioners and healthcare providers on the evidence about what works, for whom, in what contexts and why

PRISMS

This was our aim from the funders and I just want to highlight some aspects: that it was a rapid and systematic overview of the topic; that it was to look at interventions that support people with long-term conditions in their self-management; that it was specifically aimed at informing commissioning and service provision; and that it was not only about looking at the effectiveness of interventions (what works?), but also looking at asking questions about how, for whom, and why those interventions are effective.

Defining self-management

“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.”

US Institute of Medicine

PRISMS

Self-management is a term that can be used interchangeably with other terms, and can be defined differently to different people. This makes it a complex topic. For the purpose of this project we defined self-management as different to self-careⁱ. Self-care being the tasks individuals undertake to take care of themselves in everyday life for general health (like cleaning their teeth and eating healthily).

Self-management are the tasks individuals undertake to specifically help them to live with one or more long-term conditionsⁱⁱ (like eating healthily, being more physically active and controlling their blood glucose to manage their diabetes). These tasks include medical, role and emotional management of their conditions.

Also to emphasise that because self-management is about empowerment and autonomy (and moving away from the patient having a passive role), we are not looking at the best ways that patients can self-manage, but at the most effective ways that their self-management can be supported by interventions or services, and how we can work with them to improve their care. Therefore by definition the action that the patient is doing is self-management, and the intervention or service itself is self-management support (rather than ‘a self-management intervention’).

PRISMS project overview

Preliminary scoping

Advisory Group workshop

Agree :
• LTC characteristics
• SM support components
Select LTCs for the review

Rapid literature reviews

Qualitative meta-review

Quantitative meta-review

Implementation syst review

Over-arching narrative synthesis and conclusions

To identify:

- Common themes within and across the LTC characteristics
- Components of clinically effective self-management interventions
- Generic corefactors and disease-specific components

End-of-project stakeholder conference

PRISMS

This is a flow diagram of our project that started with scoping and consulting our expert advisory group at the beginning. The expert advisory group consisted of commissioners, service providers, policy makers, people with long-term conditions and academics to gain a variety of views to inform our project aim.

This then informed the three types of review carried out in the project. These were matched to the MRC frameworkⁱⁱⁱ. The first two were meta-reviews, which are systematic reviews of systematic reviews. The qualitative meta-review included systematic reviews of primary qualitative studies, and the quantitative meta-review included systematic reviews of RCTs. These were systematic meta-reviews in order to fulfil the aim and summarise the large body of evidence on this topic rapidly. However, we proposed an original systematic review of implementation trials because there is less systematic review evidence for this, and we aimed to fulfil this gap in the research.

We combined all three of these review areas together in one large overarching synthesis drawing on long-term condition (LTC) characteristics and self-management support (SMS) intervention components. This project then was then feed back to our expert advisory group and discussed, which was then fed into our final report. In order to synthesis the results based on LTC characteristics and SMS components, we aimed to develop what these were right from the start with the first stages of the project (where the purple box is) and then reflect on these throughout the project.

Presentation outline

- ▷ Chosen long-term conditions and characteristics
- ▷ Taxonomy of self-management support
- ▷ Qualitative meta-review
- ▷ Quantitative meta-review
- ▷ Implementation systematic review

PRISMS

So to outline this presentation, I [Gemma] will take you through what we came up with in our expert advisory group regarding LTCs and their characteristics, how we developed ideas of SMS components and how this led to the taxonomy of self-management support and the qualitative meta-reviews, and then I will pass you over to Steph, who will talk to you about the quantitative meta-reviews and the implementation systematic reviews, and then sum everything up.

Long-term conditions

Characteristics of LTC perceived as potentially most important in designing services to support SM

- Potential of treatment/ SM to improve symptoms
- Impact of symptoms on lifestyle

Exemplar conditions

- * T2 diabetes mellitus
- * Stroke
- * Asthma
- * Depression

Chronic obstructive pulmonary disease
T1 diabetes mellitus
chronic kidney disease
dementia
epilepsy
hypertension
inflammatory arthropathies
irritable bowel syndrome
low back pain
progressive neurological disorders (MND, MS, PD)

PRISMS

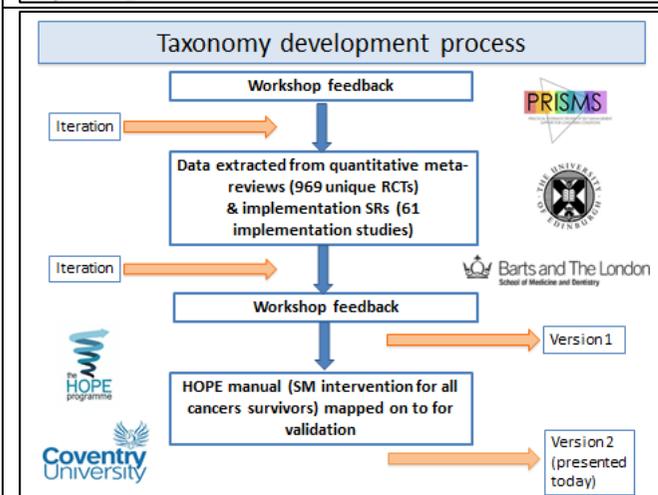
We asked our expert advisory group to come up with all the different characteristics of LTCs and think of them on continua. This was carried out as a Delphi consensus exercise. So for example variability is a characteristic of LTCs. At one end of the continuum a LTC can be very variable and therefore the self-management support would need to be about that variability. On the other end of the continuum, an LTC could be stable and the self-management support would be about that constant element of their condition. So depending on where the LTC sits on the characteristics continua would depend on what self-management support we would recommend.

As part of the Delphi exercise, we asked the experts to prioritise the characteristics they had come up with and rate them in terms of how important they felt they were to designing self-management support services. The two top ones that came out of this was the potential of treatment or self-management to improve symptoms, and the impact of symptoms on a person's lifestyle.

We also asked our expert advisory group to list as many LTCs as possible, and together came up with over a hundred. We discussed where a range of these conditions would sit on the LTC characteristics and their continua. The reason for this was because we proposed to review exemplar conditions, and we wanted to ensure that the LTCs that we choose for this review were representative across LTC characteristics (both high and low across their continua). You can see on the right of the slide the 14 chosen LTCs in our PRISMS review, with the top 4 being the ones that we covered in more depth.



We originally proposed as part of this project that we would come up with a taxonomy of self-management support components with our expert advisory group. However, when we attempted to do this this it was far more complex than we had hoped, and we also could not apply any previously existing taxonomies from the literature for a variety of reasons.



So we decided to use the following stages of the PRISMS project of collecting evidence to inform the development of the taxonomy of self-management support based on the work with the expert advisory group as a starting point. Therefore the taxonomy of self-management support was developed from an evidence base of quantitative meta-reviews with 969 RCTs and an implementation systematic review with 61 implementation trials in it. This was then fed back into the expert advisory group and discussed, and a final first version of the taxonomy of self-management support was produced for the NIHR report that is now published.

Since then we have tested the utility of this taxonomy by coding a self-management support manual for cancer survivors called HOPE (helping overcome problems effectively). This was useful because cancer was a different LTC to any of the ones included in the original PRISMS project. We were able to code this manual successfully using the taxonomy and the 14 items published in the original report remain. The key developments resulting in this work have been about describing the components more clearly and providing further elaboration. This has been a very important piece of refinement and the publication of the second version of this taxonomy is currently under review (and that is the version that is being presented in this presentation).

Taxonomy of self-management support (slides removed as material is unpublished)

Here is [version 1 of the taxonomy](#) in the published NIHR report^{iv}

The key thing to note about the taxonomy is that it is a list of components of self-management support. It does not reflect evidence of effectiveness or cost-effectiveness, and it does not suggest how these components should be used together to create self-management support interventions or services. The aim of the taxonomy is to provide this list as a solution to the problem of the complexity of language and mixture of the ways in which self-management support was being used in terms of interventions and services. Up until now there has not been a consistent language being

used and this has created a difficulty and complexity in assessing the existing evidence and understanding effectiveness and cost-effectiveness. This taxonomy aims to take the first step in collating the existing evidence in order to provide a common language across people working in self-management support, and provide a list (taxonomy) of the self-management support components. There are 14-items describing the components we identified of self-management support in our taxonomy.

Below are a few key aspects that we wanted to point out about the taxonomy (some details are currently unpublished and so these have not been noted below – please contact us if you are interested to know more and watch out for the publication of version 2).

It is important to note the importance of the strength from having an multidisciplinary team in PRISMS and also searching across a range of disciplines for the systematic reviews. A great example of this was highlighted when we found the need to distinguish between clinical action plans (number 3 in the taxonomy) and action planning from the behaviour change literature (which comes under number 12 as psychological strategies in the taxonomy). Clinical action plans are often used for people with asthma for example, and are a written set of instructions often put together with the patient and healthcare professional aiming to help the person stay in control of their condition. It can include how to take medication, recognising symptoms of deterioration and what actions to take if that happens. The action plans should be tailored to the person, condition and severity of the condition. Action planning is a more detailed version of goal setting related to behaviour change.

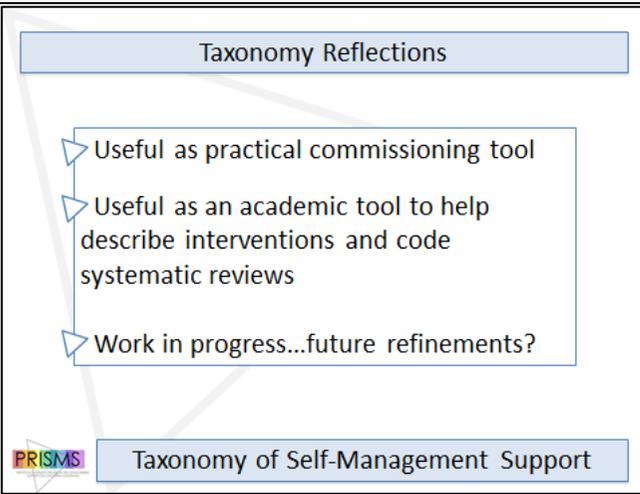
Number 4 of the taxonomy is regular clinical review and we just want to point out that often these regular reviews are very medically focused, but in order to qualify as self-management support, it needs to discuss the person's overall self-management and review their support needs within this.

It is also important to point out with number 5 of the taxonomy that it is about monitoring WITH feedback. Self-monitoring and telehealth came up quite a lot in the review, and one of the key considerations to ensure that it is supporting a person's self-management is if it is empowering the patient and supporting their autonomy. If it is telemedicine or monitoring where the patient is playing a passive role, then this is not self-management support. So for example, monitoring of blood glucose for diabetes or blood pressure for hypertension where the results are fed back to the healthcare professional and the patient does not receive feedback, does not understand how to interpret their results or how to translate these results into lifestyle changes is not useful for their self-management. Therefore only monitoring with feedback should be counted as self-management support.

Number 8 was an important one as this is about offering flexible and timely advice to either urgent or non-urgent questions, such as helplines or out of hours. People with long-term conditions were often worried that self-management actually meant that they were being left to go and look after themselves, without realising that people with LTCs self-manage anyway. Actually the key difference is the support that they can be offered, and although this is often advertised to patients like it will be a one of intervention, it should actually be a healthcare philosophy across the whole system offered at a range of levels. This component is key as it offers people with LTCs to understand when and how they can access different types of support relevant to them for a range of reasons, and reduces their feeling of being left to fend for themselves. Self-management support is about supporting autonomy, not creating isolation.

Also the mismatch of communication between patients and healthcare professionals was also an overarching theme in the qualitative literature, which I will talk more about in the qualitative meta-review section. This is definitely an area in need of development across LTCs and where shared decision making can be enhanced.

On top of the 14 identified components in the taxonomy, we also acknowledge that there are some intervention dimensions that need to be taken into consideration to address the 'how' and 'who', as well as the 'what' elements of self-management support. So when thinking about designing, developing and assessing an intervention or service for self-management support, the mode of delivery, person delivering the intervention, and who is being targeted need to be considered for example.



So because the aim of this taxonomy is to provide a common language for people to use across self-management support, we hope that this will be a useful practical tool across commissioning and service provision, and as an academic tool to describe and develop interventions, and to code systematic reviews. We successfully coded the HOPE manual using the taxonomy, but it was also useful to think about if there were other areas this programme could be developed and how this might differ for different conditions using the taxonomy as a guide for this.

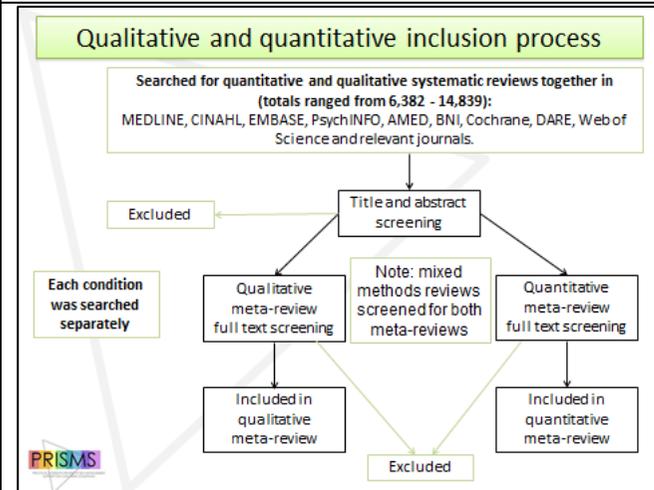
This taxonomy is very much a work in progress and we are keen for people to try using the taxonomy to test its utility and provide us with further feedback, so please do get in contact with us if you wish to do this.




PRISMS: Qualitative meta-reviews to inform interventions supporting self-management.



So now I'm going to talk you through the qualitative meta reviews...



I'm going to start by talking you through the method of how we searched for papers and screened them. The qualitative and quantitative meta-reviews for each LTC were searched together for efficiency. Each LTC was searched separately, hence the range of search hits provided at the top of the flow diagram.

At title and abstract screening level, we excluded articles that were not relevant to the reviews, and also separated the qualitative and quantitative reviews out from each other.

Then from this point onwards those reviews were each taken forward for full text screening, extraction, quality assessment and analysis separately.

Extracted papers

515 unique qual studies in meta-reviews

LTC	Qual MR	Quant MR	Impl SR
	systematic reviews		Primary studies
Stroke	7	13	1
Asthma	1	18	19
Depression	3	-	5
T2 diabetes	1 (plus 4 mixed)	17	8 (plus 16 mixed)
T1 diabetes	3	4	5
CKD	3	3	2
COPD	3	5	2
Dementia	7	3	0
Epilepsy	1	4	0
IBS	0	3	0
LBP	1	12	1
PND	3	4	0
Hypertension	3	21	2
IA	2	11	0
Total	43	118	60

PRISMS

This gives you an indication of how many papers were included for each of these reviews.

Out of the 43 qualitative systematic reviews included in the meta-reviews, there were 515 unique primary qualitative studies included after removing any overlap of included studies across the reviews.

It is important to note that our extraction was at the systematic review level and we did not go back to the primary study level or contact authors for further detail due to the rapid over-viewing nature of this review.

UNIVERSITY OF BRIGHTON

Barts and The London School of Medicine and Dentistry

Stroke
Reviews: N=7 (2003-2012)
Primary studies: N=130 (1974-2008)

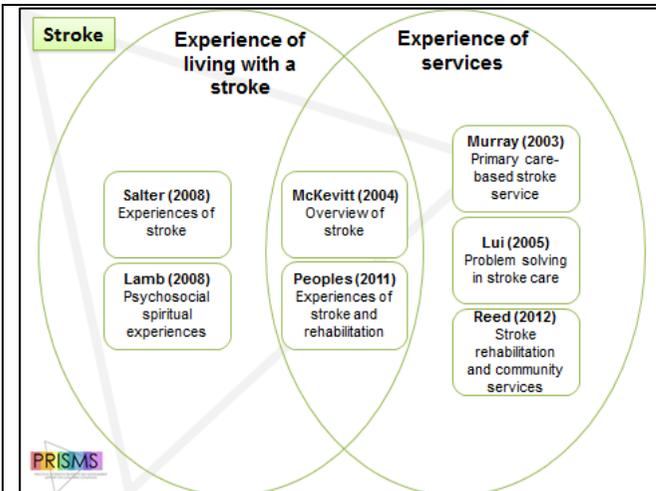


PRISMS

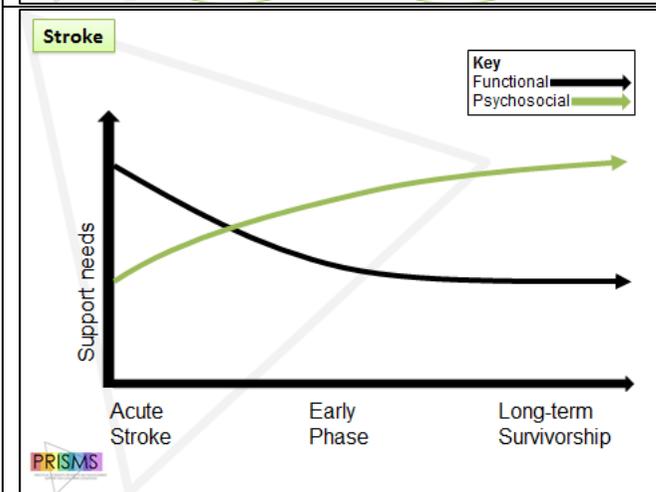
For this presentation, I'm going to provide you with details of stroke and type 2 diabetes as in-depth examples from the qualitative meta-reviews to give you an idea of what we did and found.

The qualitative meta-review examining self-management support for people who have had a stroke included 7 systematic reviews with 130 unique qualitative primary studies.

It is also worth clarifying that we kept our inclusion criteria for the qualitative meta-reviews broad with regards to how these review may inform self-management support. So we did not only include reviews that explicitly aimed to inform self-management support or were explicitly about a person's self-management, but we also included reviews about a person's experience of living with that condition or dealing with related services in order to extrapolate findings to inform self-management support.



This diagram shows you a breakdown of the included 7 reviews and their foci, with 2 being about the experiences of living with having a stroke, 3 about the experience of stroke services and 2 about a mixture of both.



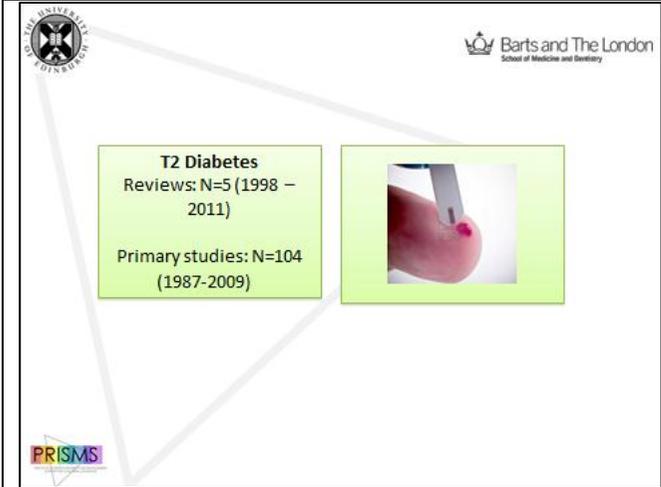
One of the key things that came out of the papers was that it is important to acknowledge that self-management is not stable, and therefore how we support it should not be stable either. The reviews reflected the stroke survivor's journey, and we need to consider where the stroke survivor is in their survivorship journey following their stroke to assess with them what their needs are.

Stroke survivors felt that there was a large focus with recovery on the functional and biomedical from healthcare professionals. This is understandable in acute care when this needs to be a priority. However, we need to be careful and aware that people reach what was referred to a lot in the literature as a 'recovery plateau' with their physical rehabilitation. People tend to feel frustrated that they have not been able to return to their pre-stroke selves.

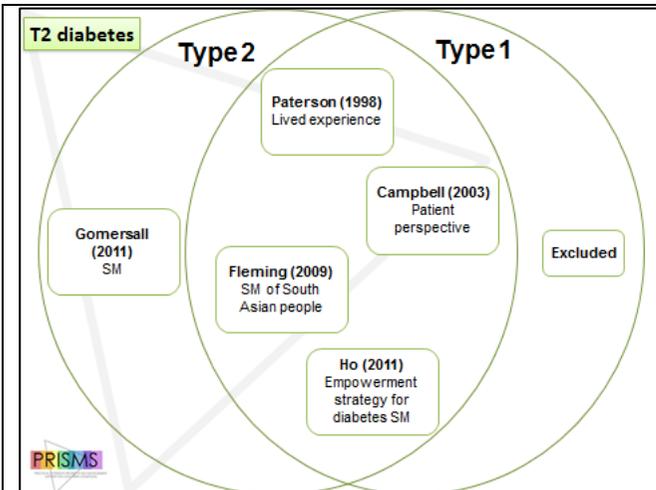
There was a need to support patients in their psychosocial needs as they return home and continue living after stroke.



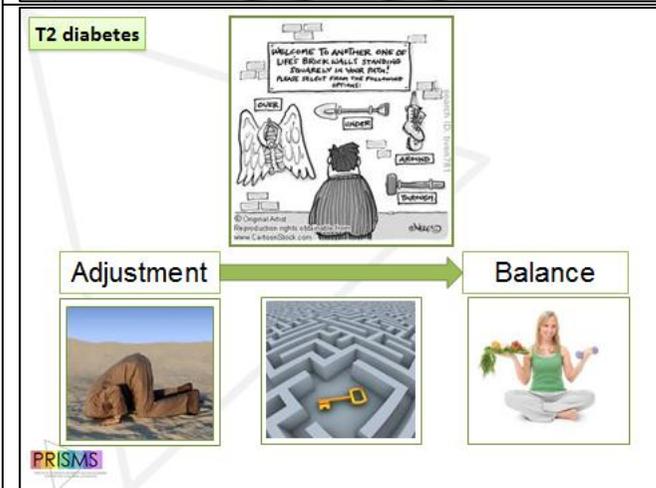
This in turned helped people to feel more positive...



The qualitative meta-review for people with type 2 diabetes included 5 systematic reviews with 104 unique qualitative primary studies.



Reviews on type 1 diabetes were excluded for this meta-review but included for screening in the separate type 1 diabetes meta-review. There was one study explicitly on self-management for people with type 2 diabetes, with the remaining four reviews on both type 1 and 2 diabetes, and we just extracted the relevant findings on type 2 diabetes for this meta-review.



Again type 2 diabetes was discussed as a journey, but this one was more centred on diagnosis. As I previously mentioned, an overarching theme across LTCs was a mismatch of communication between the patient and healthcare professional. With type 2 diabetes, when the patient was diagnosed, they often felt they were given information to manage their condition and then expected to do it while under regular clinical review. However, the big floor in the system here is that most patients said they struggled to come to terms with this life changing diagnosis and what it means. Many felt that to accept this diagnosis also meant they needed to accept they had been living their lifestyles wrong and needed to change. Therefore their support needs following their diagnosis was psychological to support their adjustment, and also social to as the people around them were very important motivators or barriers to incorporating this changing lifestyle and accepting what this diagnoses meant to their lives.

Following this, another communication mismatch that was discussed was about the need for patients to reach balance in their lives between a healthy control of their diabetes and quality of life. The patients said they learnt about their condition and this balance through trial and error, but it was difficult to talk to healthcare professionals about the need for this balance. They felt they were expected to stick to their strict programme but that this was not realistic to achieving quality of life. This could lead to lying to the healthcare professional or the healthcare professional making them feel guilty. This emphasises why shared decision making about a person's care is so important.

T2 diabetes



PRISMS

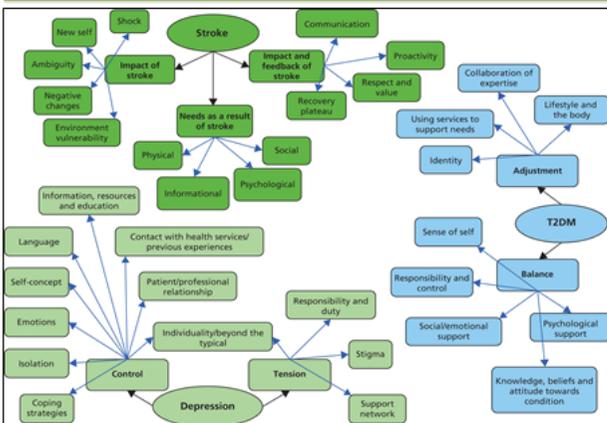
- ▶ Psychological and social support important for adjustment to diagnosis.
- ▶ Professional needs to encourage collaborative communication and facilitate active management (not enhance blame and guilt).
- ▶ Education: layman's terms, individual/cultural, naturalistic setting. Delivered to person with diabetes and those involved in their life and care.

These were the three concluding points from the diabetes meta-review...

You can start to see some of the similarities coming across the meta-reviews like the importance for psychosocial support, reducing the mismatch of collaboration between patients and professionals and thinking about the person's stage of their self-management journey to match their support needs to it.

And at the same time you can see that because those two conditions have quite different long-term condition characteristics, there are some key aspects of self-management support that would need to be tailored differently, ultimately because this means that they will have different self-management journeys.

Main themes from long-term conditions



The next two slides have two purposes.

The first is to draw your attention to our [overarching synthesis section](#) in our NIHR report where these figures are from.

The second is to demonstrate how the analysis was carried out for the qualitative meta-reviews. A meta-ethnographic approach^v was taken with the first step called reciprocal translation. This was to identify patterns arising across the included review's findings and group them together. This figure shows the themes in diagrammatic form for stroke, type 2 diabetes and depression.

Relating themes to self-management support

Themes arising	COPD	CKD	Dementia	Hypertension	RA	LBP	T1DM
Need for collaborative relationships with HCPs	X	X		X	X	X	X
Need for social and emotional support/helpful peer support		X	X				X
Individuality of the experience of illness	X	X					
Importance of striking a balance with carers between support and autonomy		X					X
Need for information and education or explanation about condition from HCP		X	X	X	X	X	X
Psychological support may be important to help adjustment	X		X				
There may be issues around adherence to medication or treatment regimes	X	X		X			

From this stage a lines-of-argument synthesis was carried out. This means that we looked at what these findings told us in relation to our aim of supporting self-management. This table shows some of the support aspects that I have already mentioned and you can see that these also came up for some of the remaining LTCs. You will also notice that they relate to the taxonomy of self-management support.

Qualitative conclusions



- ▶ Qualitative research useful to inform self-management support.
- ▶ Tailored not just to individual but also to condition.
- ▶ Need to consider psychosocial needs and not just medical.
- ▶ Education, communication and collaborative relationships important.

PRISMS

So in conclusion we have learnt a lot from qualitative research and found it really useful to explain why self-management support interventions or services may or may not be effective and how they can improve.

Some key summary points from the overall literature was to ensure it is tailored to the condition, its characteristic and the person's journey through it, as well as the individual. Consider the person's psychosocial needs as well as their medical needs; and education, communication and collaborative relationships were three key aspects of self-management support.

And now I will hand over to Steph...

The presentation continued by Professor Stephanie Taylor:




Self-management support interventions for people with long term conditions: a rapid synthesis of quantitative reviews





LTC	Qual MR	Quant MR	Impl SR
	systematic reviews		Primary studies
Stroke	7	13	1
Asthma	1	18	19
Depression	3	-	5
T2 diabetes	1 (plus 4 mixed)	17	8 (plus 16 mixed)
T1 diabetes	3	4	5
CKD	3	3	2
COPD	3	5	2
Dementia	7	3	0
Epilepsy	1	4	0
IBS	0	3	0
LBP	1	12	1
PND	3	4	0
Hypertension	3	21	2
IA	2	11	0
Total	43	118	60

969 unique quant RCTs in meta-reviews



In the quantitative meta-reviews we included 118 systematic reviews involving nearly 1000 (969) unique randomised controlled trials. The sheer volume of material published is one justification for our meta-review approach.

Stroke: 13 systematic reviews included

- **Explicit self-management support** - 0 RCTs
- Stroke liaison workers
- Active and passive information provision
- Self-efficacy enhancement
- Caregiver problem solving
- Patient held records
- **Therapy rehabilitation**

PRISMS

Here are a couple of examples from the 14 long term conditions we looked at. For full details please do see our full repost which has a separate, detailed chapter on each of the 14 long term conditions. : <http://www.journalslibrary.nihr.ac.uk/hsdr/volume-2/issue-53#hometab0>

For stroke we identified 13 relevant SRs but none were explicitly about self-management. The bulleted list shows the areas they covered – all clearly relevant to our definition of self-management support.

Seven of the SRs were about therapy rehabilitation (they work of occupational therapists).

We concluded that although there was much related to self-management support in stroke the actual term “self-management support” was less commonly used in this condition.

Therapy rehabilitation supports self-management

“aims at **facilitating task performance** by **improving skills** or **developing** and **teaching compensatory strategies**”

“The occupational therapist **educates** and **shares information** with the **family** and **primary caregiver**”



PRISMS

On this slide we explain why we believe that therapy rehabilitation supports self-management. The definition of therapy rehabilitation and the role of the occupational therapist are taken from included systematic reviews.

Stroke: components

- Strong evidence: **therapy rehab** ⇒ **positive impact ADL and extended ADL**
- **Strong evidence:** delivery **early** in recovery
- **Evidence lacking:** delivery **later** in recovery
- Some evidence: **active information provision** ⇒ **beneficial effect on mood**
- Some evidence: **stroke liaison emphasising education and information** ⇒ **positive impact QOL**
- Some evidence: general stroke liaison = no measurable benefits

PRISMS

Our brief was to look at what works (components) for whom (people with our 14 LTCs) in what contexts (settings etc), how (whom delivering, how delivered) and why (from the qualitative meta-reviews?), if possible.

The slide summarises the evidence for stroke in the SRs included in our quantitative meta-review. (ADL = activities of daily living, QOL = quality of life).

Stroke: Who & How?

- Mainly occupational therapists (OTs)
- More integrated, whole systems approach is needed for optimal self-management support.
- A focus on longer term support is also required.

PRISMS

On this slide we attempt to summarise the evidence for who should be delivering the self-management support and how from the meta-review. Obviously one disadvantage of meta-reviews is the very high level nature of the findings and conclusions with loss of granularity as we are far removed from the original studies.

Low back pain: what was included?

- Explicit self-management focus
- Psychological therapies
- Educational interventions
- Other multi-component interventions including “Back schools” and biopsychosocial approaches

PRISMS

Looking at low back pain we included systematic reviews looking at these areas and here some reviews did have an explicit self-management focus.

Low back pain: components

- Overall effect sizes for pain and disability ⇨ modest
- Moderate evidence: **explicit SM interventions** ⇨ modest benefit pain & disability short and longer term
- **Psychological therapies** ⇨ improve pain short term, no evidence long term
- Little evidence: **educational interventions**
- Strong evidence: **intensive multidisciplinary biopsychosocial** interventions reduce pain and improve function
- Little / no evidence: back schools, graded activity, less intensive biopsychosocial interventions /multidisciplinary rehab

PRISMS

Again here we attempt to summarise the findings on components (SM = self-management). Some of the “how” aspects are covered here too.

Overarching conclusions from qualitative and quantitative: core components

- Education important but (generally) not on its own
- Psychological support
- Interventions to promote adherence

PRISMS

Again full details are offered in our full report : <http://www.journalslibrary.nihr.ac.uk/hsdr/volume-2/issue-53#hometab0>

In summary from the quantitative and qualitative meta-reviews combined we concluded that “core” components of self-management support (by which we mean the most frequently used components) and those with the best evidence for effectiveness overall) are:

- Education (with the proviso that although this is virtually always part of a self-management support programme there is good evidence from several, but not all, conditions that education on its own it is not effective. However we believe that it is hard to offer a credible multi-component self-management support intervention without including some education about the condition and its management.)
- Psychological support
- Interventions to promote adherence (in conditions where adherence to treatment or lifestyle modification is important)

More details in the full report from which I quote here:

“Core components

| Education was invariably included in the effective multicomponent self-management support interventions for most LTCs, but there was evidence that it was not effective as an isolated intervention (see Information and education for further details). The only conditions about which there was no evidence, or equivocal findings of benefit from education were LBP and IBS, both of which responded well to psychosocial management interventions.quantMRs: IBS, LBP

| Psychological support was mentioned as potentially helpful in the qualitative meta-reviews (where available) for virtually all the conditions, and the majority of self-management interventions included an element of psychological support. Overall, there was variable evidence for the effectiveness of these components across the different conditions, with strong evidence in some conditions_{quantMRs: LBP, IAs, T1DM} and there is an established role for CBT in depression.¹³⁸ In some conditions, benefit was not sustained long term.quantMRs: LBP, IAs

| Interventions to support adherence with medication or treatment had a positive effect in some conditions_{quantMRs: CKD, HT, T1DM} but overall there was little evidence to support these sort of interventions in epilepsy.”

Overarching conclusions from qualitative and quantitative: disease specific components

- Action plans
- Therapy rehabilitation
- Monitoring and feedback
- Intensive education



In addition to the above, these components are important and well-evidenced in specific conditions.

Action plans – where symptoms of the long term condition fluctuates greatly and patients experience “flare ups”, eg asthma

Therapy rehabilitation was useful in several of the disabling conditions

Monitoring and feedback -the only LTC which was reported as benefiting from monitoring and feedback was hypertension, an asymptomatic condition in which progress could only be measured by BP readings

Intensive education – where treatment regimens are complicated eg diabetes and for those with end stage renal failure on dialysis



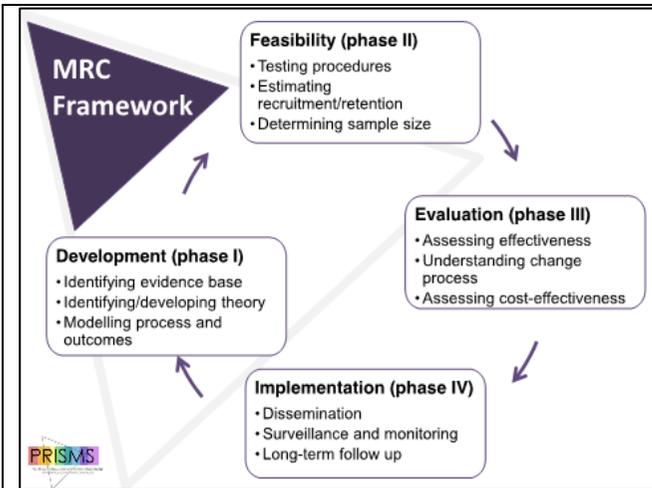
PRISMS: systematic review of Phase IV implementation interventions supporting self-management



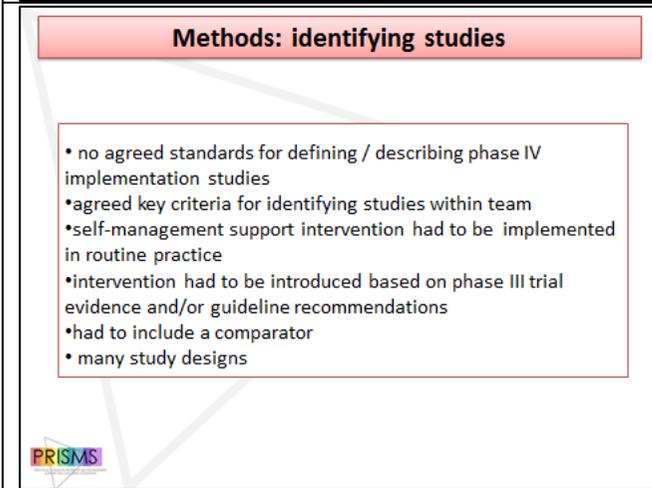
The systematic review of implementation studies was the only original systematic review (as opposed to the reviews of reviews in the PRISMS study).

The terminology Phase IV implementation study comes from the MRC Complex interventions guidance from 2000 (BMJ. 2000 Sep 16; 321(7262): 694–696.). When the guidance was updated in 2008 they had dropped this term (<http://www.mrc.ac.uk/documents/pdf/complex-interventions-guidance/>).

We retained the term Phase IV implementation study, to indicate a true implementation study following proven effectiveness studies or based on a belief or effectiveness, in the PRISMS report.



This is the MRC complex intervention development, evaluation, implementation and refinement cycle (references above).



We conducted a systematic review of original implementation studies looking at the implementation of self-management support interventions across all 14 long term conditions included in the meta-reviews.

It was very difficult to actually identify true implementation studies! There are no universally agreed definitions and no standards for reporting implementation studies. We found these studies were often “shoe-horned” into journals under the guise of an effectiveness study.

To identify the sort of studies we were interested in we had to agree identifying criteria within the group. We included many study designs as long as they had a comparison group (including before and after studies where the intervention was delivered to the whole group).

Methods: analysis

- Primarily professional training +/- organisational change
- Primarily patient education +/- organisational change
- Primarily organisational change
- Whole systems approach with components operating explicitly at patient, professional and organisational level

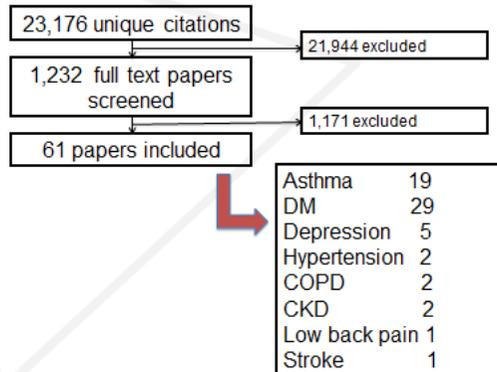
PRISMS

We analysed the studies using Kennedy's whole-systems approach as a framework for a narrative analysis (Kennedy A, et al. Support for self care for patients with chronic disease. BMJ 2007;337:968-70. <http://dx.doi.org/10.1136/bmj.39372.540903.94>). This considers interventions from a multilevel perspective engaging patients, professionals and the organisation in a collaborative way.

We classified the studies according to whether or not the intervention was:

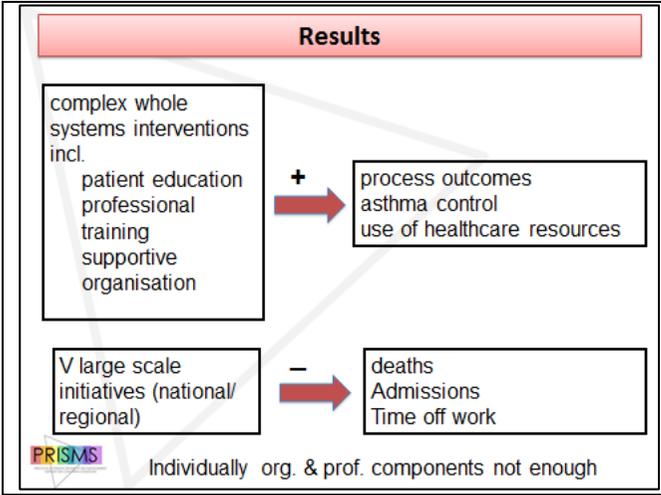
- primarily professional training, with or without organisational change
- primarily patient education, with or without organisational changes
- primarily organisational change
- a whole-systems approach with components operating at patient, professional and organisational level.

Screening flow chart



PRISMS

This is the review flow chart – most self-management support implementation studies concerned asthma or DM.



The key message from these studies is that implementation in the real world is complex, fraught with barriers which impact on patients' uptake of education, professionals' engagement with discussing and creating personalised action plans, and health-care organisations' prioritisation of self-management as a core component of care. Most randomised trials have focused on one or two aspects of a whole-systems approach – most clearly demonstrated in the asthma studies, but echoed by the evidence in other conditions. The evidence suggested that implementation focusing on the patient, professional and organisation levels together was most likely to succeed.

- Large-scale initiatives suggest that programmes which are most likely to succeed are:
- promoted by policy ensuring meaningful adoption (and ideally provision of resources, reimbursement of costs) by health services
 - provide training programmes for professionals, and
 - focus on structured self-management education for patients in the context of overall disease management and are sufficiently flexible to address local, cultural and personal variation.

...Harvest plots...
 (slide removed as material is unpublished)

Pinnock H, Epiphaniou E, Pearce G, Parke H, Greenhalgh T, Sheikh A, Griffiths C, Taylor SJC. Implementing supported self-management for asthma: a systematic review and suggested hierarchy of evidence of implementation studies. BMC Medicine [Under review]

This paper (under review) provides more data and the evidence to support this in asthma self-management support.

What authors say about implementation

- commitment of the healthcare system/ local practice
- professional training in self-management with on-going evaluation
- collaborative multidisciplinary working with good communication and referral systems between professionals
- effective patient education supported by regular reviews
- partnership with patients

- Achieving change is a challenge, even in well-motivated teams
- Need to build relationships with existing services
- Need for regular oversight and frequent review to ensure intervention fidelity.

PRISMS

We also extracted all the primary study author's comments about implementation.

Current state of implementation studies

- Hard to identify
- Relatively rare
- Often of poor quality
 - Attrition
 - Lack of info on those lost to follow up
 - Lack of info on generalisability of study populations
- RCTS v rare

- Hard to synthesise
- May be differences between long term conditions?

PRISMS

This slide summarises our findings about implementation studies. This has led to another project StaRI: STAndards for Reporting Implementations studies:
<http://www.equator-network.org/wp-content/uploads/2013/09/Proposal-for-reporting-guidelines-of-Implementation-Research-StaRI.pdf>

Some overarching conclusions of PRISMS

- ▶ Context delivery important, as well as how and by whom it can be delivered.
- ▶ Tailor programmes to the condition, the patient and the context.
- ▶ Training professionals is not enough, consider the organisational facilitators and barriers.
- ▶ Education for patients is essential but not sufficient, 'optimise' self-management with the other generic/disease specific components.
- ▶ Self-management (and its support) needs change over time.

PRISMS

Here is a flavour of some of our overarching conclusions based on the three stands of PRISMS. Please see the main report for more details!

PRISMS

PRACTICAL SYSTEMATIC REVIEW OF SELF-MANAGEMENT SUPPORT FOR LONG-TERM CONDITIONS

Thank you!

PRISMS:

@PRISMS_project

Professor Stephanie Taylor:
s.i.c.taylor@gmul.ac.uk

Dr Gemma Pearce:
gemma.pearce@coventry.ac.uk

@GemmaSPearce

Barts and The London
School of Medicine and Dentistry

Coventry
University

NHS
National Institute for
Health Research

PRISMS team acknowledgements

Grant-holders:

Stephanie Taylor
Hilary Pinnock
Chris Griffiths
Aziz Sheikh
Trish Greenhalgh
John Ribchester

Research team:

Eleni Epiphaniou
Gemma Pearce
Hannah Parke
Anna Schwappach
Neetha Purushotham
Sadhana Jacobs
Andrea Takeda
David Salisbury
Jenny Basford



Taylor SJC, Pinnock H, Epiphaniou E, Pearce G, Parke HL et al.
A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS – Practical systematic Review of Self-Management Support for long-term conditions. *Health Serv Deliv Res* 2014;2 (53).

References

- ⁱ Parsons S, Bury M, Carter S, Hurst P, Magee H, Taylor D. *Self Management Support Amongst Older Adults: The Availability, Impact and Potential of Locally Based Services and Resources*. Report for the National Institute for Health Research Service Delivery and Organisation Programme. London: HMSO; 2010. URL: www.nets.nihr.ac.uk/projects/hsdr/081715161 (accessed April 2014)
- ⁱⁱ Adams K, Greiner AC, Corrigan JM, editors. *The 1st Annual Crossing the Quality Chasm Summit: A Focus on Communities*. Washington, DC: The National Academic Press; 2004.
- ⁱⁱⁱ Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. *Developing and Evaluating Complex Interventions: New Guidance*. London: Medical Research Council; 2008. URL: www.mrc.ac.uk/complexinterventionsguidance (accessed April 2014).+
- ^{iv} Taylor SJC, Pinnock H, Epiphaniou E, Pearce G, Parke HL et al. A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS – Practical systematic Review of Self-Management Support for long-term conditions. *Health Serv Deliv Res* 2014;2 (53).
- ^v Noblit GW, Hare RD. *Meta-Ethnography: Synthesizing Qualitative (Qualitative Research Methods Volume 11)*. Newbury Park, CA: Sage Publications; 1988.