



Name

Address

Date

Dear xxxxx

**A rapid synthesis of the evidence on interventions supporting self  
management**

**for people with long-term conditions**

Thank you for agreeing to be a member of a multidisciplinary Expert Advisory Board for our National Institute for Health Research (NIHR) Service, Development and Organisation (SDO) funded systematic review which aims to undertake a rapid, systematic overview of the evidence for self management support interventions in people with long-term conditions (LTCs) in order to inform commissioners and healthcare providers on the evidence about what works, for whom, in what contexts and why.

Commissioners and providers of services for people with LTCs cannot provide different models of service for all the different LTCs. On a practical level it will be useful to be able to group LTCs according to characteristics which influence the type of self-management support they might need, and to identify features of self-management support interventions which might reflect these needs. This exercise is also necessary for us to make sense of the extensive evidence on self-management for our rapid synthesis. We are therefore starting the project by developing groupings of long-term conditions and identifying components of self-management support.

This letter introduces you to the first phase of the process. There are three tasks, which we anticipate should take you about 30 minutes overall:

1. Please turn to the next sheet and list any characteristics of LTCs which you think we should take into account when developing a taxonomy of LTCs
2. List on the following sheet any components of SM support which you think should be taken into account when developing services for people with LTCs
3. Finally, please add to our list of LTCs on the final sheet

**Please return the lists to [p.s.broome@qmul.ac.uk](mailto:p.s.broome@qmul.ac.uk) by 23<sup>rd</sup> April 2012**

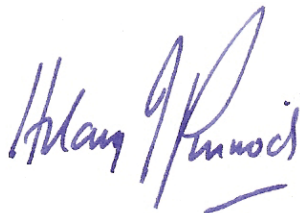
We will compile your suggestions and feedback the results at the workshop on Friday 4<sup>th</sup> May. We will then provide some background information, and ask you to discuss possible groupings of LTCs and components of self-management support. In the afternoon we will move to considering which of the broad range of long-term conditions would be good exemplar conditions for our systematic review.

Thank you for your help with this process which will underpin our project, and we hope will provide a foundation for commissioning and implementing self-management for long-term conditions within healthcare services.

Dr Hilary Pinnock ([hilary.pinnock@ed.ac.uk](mailto:hilary.pinnock@ed.ac.uk)) or Professor Steph Taylor ([s.j.c.taylor@qmul.ac.uk](mailto:s.j.c.taylor@qmul.ac.uk)) would be pleased to answer any questions.

Thank you for your help with this project.

Yours sincerely



Dr Hilary Pinnock

Professor Steph Taylor

# 1 Open round (LTCs)

## A rapid synthesis of the evidence on interventions supporting self management

### for people with long-term conditions

*Background: The diversity of long-term conditions*

The Department of Health estimates that around 15 million people in England (including half of all those aged over 60 years) are living with at least one LTC. There is, however, no definitive list of LTCs and the potential range of diseases is both extensive and diverse. This represents a challenge both for commissioners/providers seeking a practical approach to developing services and for this project as it is not possible within the suggested timeframe of 12 months to consider all possible individual LTCs in depth. We therefore intend to group LTCs into 'clusters' based on core characteristics which might be predicted to impact on the design of a clinically-effective and cost-effective service to support self management. This approach will allow us to select 'exemplar conditions' within each 'LTC cluster' for detailed analysis of the evidence, which might then be extrapolated to pre-defined conditions which share similar characteristics. Similarly, there are some conditions for which the evidence about self-management support is currently very limited, but it may be possible for commissioners or providers of services to generalise from our conclusions to LTCs within the same cluster.

*Examples of characteristics of LTCs which we think might be important.*

- Degree of variability in symptoms: for example a variable condition such as asthma might need a different model of care to an on-going condition like osteoarthritis with less variability
- Presence or absence of symptoms: for example an asymptomatic condition such as hypertension may benefit from a different approach to a condition with persistent symptoms such as multiple sclerosis
- Potential implication of flare-ups: for example a severe exacerbation of COPD might be fatal, an exacerbation of inflammatory bowel disease might result in time off work, a flare up of eczema might just be a nuisance.
- Potential for serious long term complications: for example diabetes, if poorly managed, may be associated with long term complications whereas osteoarthritis may deteriorate over time but is not associated with life threatening long term complications

These are just ideas to help explain what we are looking for – they may not be correct, or there may be more important characteristics.

**Overleaf, please list any characteristics of LTCs which you think we should take into account when grouping LTCs.**

**It is important to remember that we are considering the issue from the perspective of healthcare services, not just at the level of providing care for an individual with a long-term condition.**

**List any characteristics of characteristics of LTCs which you think we should take into account when grouping LTCs into clusters**

**Please add more lines if required**


**Now please turn to the next page and list any components of SM support which you think should be taken into account when developing services for people with LTCs**

## 2 Open round (SMs)

### A rapid synthesis of the evidence on interventions supporting self management for people with long-term conditions

#### Background

##### *Definition of self-management*

We have adopted the definition of self management proposed by the US Institute of Medicine: “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.”

##### *The range of self management support interventions*

Self management support may range from the provision of disease-specific information via a website or leaflet, to extensive generic programmes such as the Expert Patient Programme which aim to promote behavioural change by building the confidence of individuals to manage their condition and the bio-psycho- social effects of LTCs. ‘Personalised Care Planning’ is an ambitious programme involving improved access to and provision of information for the 15 million people living with LTCs, which emphasises personal involvement and choice in health care (“no decisions about me without me”). A key component of personalised care planning is support for self management.

Other initiatives include interactive educational projects, complex interventions involving repeated contact with health care professionals from a variety of disciplines in a range of settings (home, clinic, physician’s office). Tele-monitoring is seen as a means of promoting self management for a broad range of LTCs.

##### *Examples of characteristics of self management support which we think might be important.*

- Systematic education programmes: for example in rehabilitation programmes, or one-to-one teaching with LTC nurses
- ‘Written’ actions plans: for example widely promoted in asthma. Maybe this should be broadened to include electronic support
- Flexible access to expert support: for example telephone helplines, telemonitoring.
- Peer (or lay) support
- Provision of rapid feedback: for example pedometers, near patient INR results

These are just ideas to help explain what we are looking for – they may not be correct, or there may be more important characteristics.

**Overleaf, please list any characteristics of self-management support interventions which you think should be taken into account when developing SM support services for people with LTCs**

**It is important to remember that we are considering the issue from the perspective of healthcare services, not just at the level of providing an individual with self-management education or an action plan.**

**Now please list any components of self-management support which you think should be taken into account when developing services for people with LTCs.**

**Please add more lines if required**


**Now please add to our list of common or important LTCs on the next page.**



### 3 List of LTCs

Finally please add to our list of common or important LTCs.

Allergy/anaphylaxis Asthma Atrial fibrillation Childhood constipation Chronic fatigue syndrome/ME Chronic kidney disease Chronic obstructive pulmonary disease Chronic pain Congestive heart failure Dementia Depression Diabetes: Type I Diabetes: Type II Endometriosis Epilepsy Hypertension Hepatitis B Hepatitis C HIV Inflammatory bowel disease Irritable Bowel Disease Low Back Pain Migraine Multiple sclerosis Osteoarthritis Parkinson's disease Rheumatoid arthritis Schizophrenia	
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**Thank you!**

**Please return these lists to [REDACTED] by 23<sup>rd</sup> April 2012**