

# READING WELL

## Reading Well Books on Prescription for long-term conditions: consultation paper August 2016

### 1. Introduction

As part of its successful Reading Well Books on Prescription (RWBOP) programme, The Reading Agency and the Society of Chief Librarians are planning to develop a new scheme for public libraries focusing on the needs of people with long-term conditions (LTCs). This work will be developed and delivered with relevant health agencies and organisations. It supports the Society of Chief Librarians' Public Library Health Offer, a national strategy that articulates the role that libraries can play in promoting the health and wellbeing of local communities.

#### 1.1 Reading Well Books on Prescription

[Reading Well Books on Prescription](#) is delivered by The Reading Agency in partnership with the Society of Chief Librarians with funding from Arts Council England and the Wellcome Trust. The scheme is endorsed by leading [national health organisations](#), works within national clinical guidelines and provides book-based support available from public libraries for a variety of health conditions. It is the first national Books on Prescription programme in England and builds on a model that was first developed in Wales in 2005 by Professor Neil Frude.

Health professionals can refer people to recommended reading from quality assured lists of around 25/30 books, but people can also use the scheme independently as the first step to understanding and managing symptoms and seeking help. The programme has been used extensively by GPs and psychological wellbeing practitioners delivering supported self-help for anxiety and depression within Improving Access to Psychological Therapy services (IAPT).

Launched in 2013 with a list providing adults with self-help reading for [common mental health conditions](#) such as depression and anxiety, RWBOP is delivered by 97% of English public libraries. A second list supporting people with [dementia and their carers](#) was launched in 2015, while a third list supporting [young people's mental health](#) was launched in April this year.

In its first two years, the programme reached almost 445,000 people, with loans of the adult mental health list increasing by 97% and of the dementia list by 346% compared to borrowings in the previous year.<sup>1</sup> The programme is used regularly by around 6,500 health professionals. In addition, the majority of users of the adult mental health and dementia schemes are self-referring, rather than being signposted by a health professional.

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<sup>1</sup> [Reading Well Books on Prescription Evaluation Report - BOP consulting \(2015\)](#)

A survey of people using RWBOP conducted as part of the 2014/15 evaluation found that 90% of those who had read a title from the adult mental health list had found it helpful and 85% said that it had made them feel more confident about managing their symptoms. [Read the second year evaluation in full](#). In addition to boosting access to relevant books, the scheme also promotes the role of public libraries in enhancing health literacy generally and signposting the public to local services and charities.

## 1.2 Partners

Current programme partners include:

Alzheimer's Society, British Association for Counselling and Psychotherapy, British Association for Behavioural and Cognitive Psychotherapies, The British Psychological Society, Carers UK, Dementia UK, NHS England (IAPT and Children and Young People's Mental Health), Innovations in Dementia, Mental Health Foundation, Mind, National Association of Primary Care, Public Health England, Royal College of GPs, Royal College of Nursing, Royal College of Psychiatrists, YoungMinds.

New partners representing long-term conditions will be invited to support work on the new scheme and people with experience of long-term conditions will also be closely involved in its development following a co-production model. All partners will be credited on relevant leaflets and materials. A list of potential partner organisations is presented in the [Appendix](#).

### **Consultation question 1**

**Are there any additional organisations with whom we should consult in developing RWBOP for LTCs that are not identified in the Appendix?**

*Please submit your response at the following link: [www.surveymonkey.co.uk/r/consultationLTC](http://www.surveymonkey.co.uk/r/consultationLTC)*

## 2. The consultation

The purpose of this consultation is to map out an appropriate framework for constructing a RWBOP booklist and delivery framework to help people understand and manage both the physical and mental health symptoms associated with LTCs. This will draw on our experience of developing the three previous lists but will also be informed by the views of experts and the target audience to make it relevant to the needs of people with LTCs and their families. It will focus on the underlying policy framework, the evidence base, and the needs of the potential community of users for the scheme. This consultation is aimed primarily at professionals, professional bodies and charities. A parallel consultation process involving people with LTCs, and their families or carers will also be undertaken. Responses to the consultation questions can be made online at: [www.surveymonkey.co.uk/r/consultationLTC](http://www.surveymonkey.co.uk/r/consultationLTC)

### 3. Classification of long-term conditions

Physical illnesses such as asthma or diabetes, which following diagnosis usually continue to present throughout a person's lifetime, were once referred to as *chronic* physical diseases or illnesses. Unlike *acute* physical health problems for which successful medical treatment can often provide a cure and lead to full patient recovery, LTCs are best characterised as those for which a cure leading to full recovery does not exist and medical treatment comprises the management of symptoms for the remainder of the person's life. As such, LTCs have a lasting and persistent impact on people's functioning that may affect quality of life, as well as placing great demands on health services through GP consultations, out-patient clinics, hospital admissions and the costs of prescribed medications and interventions.

#### 3.1 Long-term conditions

Although LTCs are wide-ranging, from idiopathic neurological diseases such as multiple sclerosis or Parkinson's through to cancer, cardiovascular disease and renal failure, and have their own individual pathologies and treatments, they also share common aspects of treatment and management that has led to them being frequently referred to in the last couple of decades as 'long-term conditions' by health professionals. Moreover, these illnesses are becoming more prevalent due to the combined effects of an ageing population and the impact of lifestyles and behaviours (for example diet and obesity, smoking, alcohol abuse) on their occurrence. Encouragingly, however, the increase in prevalence of LTCs is also partly due to people with many more conditions that once resulted in considerably reduced life expectancy now living much longer and fuller lives as a result of advances in medical science.

Although health care organisations have devised a variety of definitions for LTCs, they have extensive overlap:

- **The Department of Health:** 'A long term condition is a condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies.'<sup>2</sup>
- **NICE Guidelines (NG22):** 'One that generally lasts a year or longer and impacts on a person's life... may also be known as a chronic condition.'<sup>3</sup>
- **The King's Fund:** 'Long-term conditions or chronic diseases are conditions for which there is currently no cure, and which are managed with drugs and other treatment.'<sup>4</sup>
- **The Royal College of GPs (RCGP):** 'A long term condition is any medical condition that cannot currently be cured but can be managed with the use of medication and/or other therapies. This is in contrast to acute conditions which typically have a finite duration such as a respiratory infection, an inguinal hernia or a mild episode of depression.'<sup>5</sup>

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<sup>2</sup> [Long Term Conditions Compendium of Information: Third Edition - Department of Health \(2012\)](#)

<sup>3</sup> [Older people with social care needs and multiple long-term conditions \[NG22\] - NICE \(2015\)](#)

<sup>4</sup> [Long Term Conditions & Multi-morbidity - The King's Fund](#)

<sup>5</sup> [Written Evidence Long Term Conditions - Royal College of GPs \(2012\)](#)

However, the RCGP then goes on to say that the best way to gauge whether a patient has a LTC is on an individual basis with discussion between a patient and their health practitioner. As we will review within Section 4, contemporary approaches to the management of LTCs stress the need to treat the whole patient rather than just the disease, to emphasise the importance of proactive ‘living well and wellbeing’ approaches, as well as medical interventions that can include a consideration of patient goals and the need to individually plan care taking into account multiple co-morbidities and the impact of these conditions on social care needs and support.

Health conditions that are often identified as coming under the LTCs banner include, but are not restricted to: asthma, cancer, cardiovascular disease, chronic fatigue syndrome, chronic kidney disease, chronic obstructive pulmonary disease, chronic pain, diabetes, irritable bowel syndrome, multiple sclerosis, obesity/weight loss intervention, osteoarthritis, rheumatoid arthritis, Parkinson’s disease, stroke. This is the list used in NHS Scotland’s Matrix Guide<sup>6</sup> to delivering psychological therapies for LTCs.

Long-term mental health problems, especially depression but also schizophrenia and bipolar disorder, together with some dementias, are also regarded as LTCs. The RWBOP list for LTCs will not deal *specifically* with serious mental illnesses such as recurrent depression, psychoses and dementia since some of these conditions have already been referred to within the adult mental health and dementia lists. However, when depression or anxiety are associated with a LTC, their management will be considered. Other persistent conditions such as HIV and AIDS and sickle cell disease are also sometimes included. Indeed, the term LTCs is designed to be inclusive and not strictly defined by a rigid diagnostic scheme.

### 3.2 Long-term conditions and mental health

LTCs have also been of interest to mental health practitioners since, unsurprisingly, rates of common mental health conditions such as anxiety and depression are frequently elevated within these patient groups.<sup>7</sup> The emphasis on more holistic treatment of the individual has meant that it has become more common to offer both physical and psychological treatments to people with LTCs. The overlap between the conditions is illustrated strikingly in Figure 1 below, taken from a King’s Fund report. Providing effective treatment for co-morbid conditions such as depression often results in improved quality of life and more effective physical management of the condition, leading to savings in health care provision. In 2011 the Department of Health’s Improving Access to Psychological Therapies (IAPT) programme undertook to establish a series of pathfinder projects to examine the viability of extending IAPT services to encompass LTCs. This was an extension of the most prevalent collaborative care model, as reflected in the recently published NICE guidance on depression and LTCs,<sup>8</sup> of building partnerships between specialist mental health services and primary care in tackling LTCs.

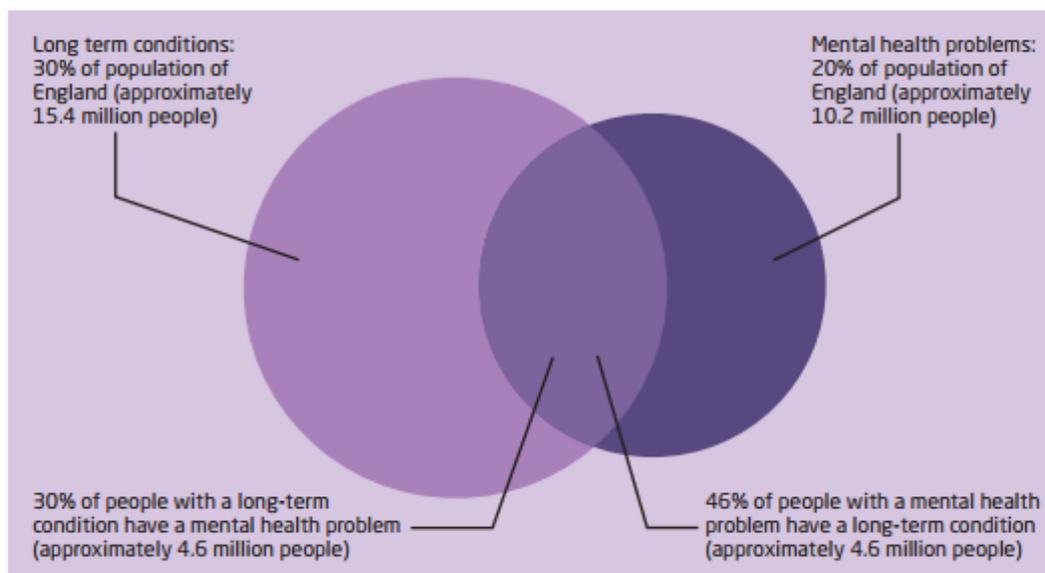
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<sup>6</sup> [Matrix Guide to delivery psychological therapies for LTCs - NHS Scotland](#)

<sup>7</sup> [Long-term conditions positive practice guide - IAPT \(2008\)](#), [Long-term conditions and mental health: the cost of co-morbidities - The King's Fund \(2012\)](#), [Emotional and psychological wellbeing for patients with long-term conditions - NHS confederation \(2012\)](#)

<sup>8</sup> [Depression in adults with a chronic physical health problem: recognition and management \[CG91\] – NICE \(2009\)](#)

**Figure 1** The overlap between long-term conditions and mental health problems



### 3.3 Medically unexplained symptoms or functional symptoms

The distinction, however, between physical and mental health conditions is not straightforward. There are many conditions which impact on patients' lives, through either loss of function or debilitating pain, for which clinical and diagnostic assessments provide no identifiable physical diagnosis or pathology. These conditions are often referred to as 'medically unexplained symptoms' (MUS) but previously have been described as 'functional or psychosomatic complaints'. It should be noted that this diagnostic term relies not on the positive identification of a disease by the presentation of specific symptoms but the absence of pathology. These terms are often disliked by patients since they imply that their physical symptoms and suffering are 'all in the mind' and hence not amenable to medical treatment. The term is also unpopular with many health professionals since it encourages false dualistic thinking that illnesses are either physically or psychologically caused.<sup>9</sup> Indeed, Roth and Pilling<sup>10</sup> when scoping competences for the IAPT workforce in delivering psychological interventions for people with LTCs and MUS, suggested using the more comprehensive and descriptive term of 'persistent physical health conditions' when referring to both LTCs and MUS.

Conditions frequently identified as MUS include fibromyalgia, irritable bowel syndrome and chronic fatigue syndrome. A recent good practice guide published by IAPT<sup>11</sup> lists in addition to these three common conditions: temporomandibular joint dysfunction, atypical facial pain, non-cardiac chest pain, hyperventilation, chronic cough, loin pain haematuria syndrome, functional weakness/movement disorders, dissociative (non-epileptic) attacks and chronic pelvic pain/dysmenorrhea.

Furthermore, in as many as 30% of patients referred for diagnostic tests for common complaints such as chest or back pain, no physical pathology or medical diagnosis will be revealed, suggesting that these complaints might be functionally associated with anxiety or depression. It is argued that MUS cost the NHS significant resources in terms of repeated and unrevealing outpatient appointments and diagnostic testing.

<sup>9</sup> [The cognitive behavioural model of medically unexplained symptoms: A theoretical and empirical review - Deary, Chalder & Sharpe \(2007\)](#)

<sup>10</sup> [Psychological Interventions with People and Persistent Physical Health Problems - Kings College London \(2011\)](#)

<sup>11</sup> [Medically unexplained symptoms good practice guide - IAPT \(2015\)](#)

Recently it has been suggested that services might consider identifying MUS or offering these patients the opportunity for psychological interventions in order to reduce the financial impact of MUS on acute hospital services.

### 3.4 Summary

Persistent physical health conditions have major impacts on individuals and their families/carers, together with growing demands on both health and social care. Rather than dealing with each chronic physical condition separately, health professionals have striven to adopt a common approach to assessing and managing people with these physical illnesses. As we will see in the next sections, this has emphasised personalised care, which is proactive and planned to encompass all LTCs, and integrates *both* physical and psychological needs, *together* with health and social care provision. It is also argued that people with MUS where clinical assessments have failed to identify an underlying pathology or physical diagnosis would also benefit from systems of care developed for people with LTCs, together with interventions targeting positive adaptation and living well, and wellbeing.

#### Consultation question 2

- a. 'Long-term condition' is an inclusive term and many conditions can be defined as such. However, we need to produce a booklist of approx. 25–35 titles for this scheme and so will not be able to provide targeted books for all long-term conditions. Taking into account prevalence, need and relevance of book-based information provided by RWBOP please select the 10 LTCs that you believe the RWBOP LTC scheme should target from the list below:

- *Angina*
- *Arthritis – includes osteoarthritis and rheumatoid arthritis*
- *Asthma*
- *Cancer*
- *Cardiovascular disease (CVD) – includes coronary heart disease, stroke, peripheral arterial disease and aortic disease*
- *Chronic fatigue syndrome (CFS), or ME*
- *Chronic kidney disease (CKD)*
- *Chronic obstructive pulmonary disease (COPD) – includes chronic bronchitis, emphysema, chronic obstructive airways disease*
- *Chronic pain*
- *Chronic skin conditions – includes eczema and psoriasis*
- *Diabetes*
- *Endometriosis*
- *Epilepsy*
- *Fibromyalgia*
- *High blood pressure, or hypertension*
- *HIV and AIDS*
- *Inflammatory bowel disease (IBD) – includes Crohn's Disease and Ulcerative Colitis*
- *Irritable bowel syndrome (IBS)*
- *Motor Neuron Disease (MND)*
- *Multiple sclerosis (MS)*
- *Parkinson's Disease*
- *Sickle cell disease*

- b. Please indicate any additional LTCs not identified above that you think should be prioritised by the list and tell us why.**
- c. Is there any terminology relating to long-term conditions that you would advise we avoid using?**

Please submit your response at the following link: [www.surveymonkey.co.uk/r/consultationLTC](http://www.surveymonkey.co.uk/r/consultationLTC)

## 4. Policy framework

Delivering health services for people with chronic disease or LTCs has been a major focus for policy makers, health professionals and charities for the last two decades. A summary of international approaches and a strategic framework identifying key policy issues surrounding long-term care was published in 2003 by the World Health Organisation.<sup>12</sup> It was becoming clear that the demands on health service provision arising from a growing and ageing population requiring medical and social care for a variety of different LTCs was a major challenge for health care planners and policy makers, not to mention health economists and politicians.

Below we summarise our understanding of the scale of the challenge in meeting the needs of people with LTCs and the associated costs of providing services and impact on health care in general. We also review the most recent UK developments in policy within this area originating from governments, professional bodies, and patient groups and charities. Based on this evidence we argue the case that the current policy framework supports the development by The Reading Agency and Society of Chief Librarians of a Books on Prescription scheme for people with LTCs and their relatives/carers.

### 4.1 The extent of the problem: statistics and costs

#### Statistical and economic profiles

Numerous reports detail the prevalence of common LTCs, the changing demographic profile, the impact on the uptake of GP and hospital outpatient and inpatient services, and the overall economic burden of providing care and meeting the needs of these patients. For example, the Department of Health's own LTC Compendium of Information<sup>13</sup> lists the following statistics:

- **Fifteen million people** in England have one or more LTCs, and the number of people with multiple conditions (multi-morbidity) is rising.
- Around **70%** of the total healthcare spend in England is attributed to caring for people with long-term conditions.
- People with long-term conditions account for **50%** of all GP appointments.
- The majority of people aged over 65 have two or more LTCs; the majority of over 75s have three or more; and, overall, the number of people with multiple conditions is rising.

<sup>12</sup> [International policy issues in long-term conditions - World Health Organisation \(2003\)](#)

<sup>13</sup> [Long Term Conditions Compendium of Information: Third Edition - Department of Health \(2012\)](#)

A more recent set of revised statistics produced by NHS England reports the following:<sup>14</sup>

- About **26 million** people in England have at least one LTC.
- About **10 million** people have two or more LTCs, 1 million with frailty, 0.5 million at end of life.
- There's a three-fold increase in cost of health care for those with frailty.
- Some people living in deprived areas will have health problems 10–15 years earlier than people in affluent areas.
- **15%** of young adults aged 11–15 have a LTC.
- Only **59%** of people living with LTCs are in work, compared with **72%** of the general population.
- LTCs account for:
  - **50%** of all GP appointments
  - **64%** of all hospital outpatients appointments
  - **70%** of all hospital bed days
  - **70%** of health and care spend
  - **33%** of GP appointments for patients with multiple LTCs
  - **50%** of emergency bed days for over 75s
  - **25%** of bed days occupied by someone dying
- **64%** of people living with LTCs at present say they feel supported, so there is room for improvement.
- People living with LTCs are being supported to develop their own care plans. However, at present, only **3.2%** have written their own plan.
- On average people living with LTCs spend just four hours a year with a health professional and **8,756 hours** self-managing.
- **80%** of carers report that caring for someone living with a LTC has had a negative impact on their health. In addition, **£1 billion** in carer's allowance is unclaimed each year.

### **Multi-morbidity and mental health problems**

A major contributor to the costs of LTCs care is the frequent co-morbidity with mental health problems, particularly depression. A recent King's Fund report<sup>15</sup> indicates that people with a LTC are two to three times more likely to also experience depression. Similarly, around 30% of people with a LTC will experience some form of mental health problem. Furthermore, having depression alongside a LTC can exacerbate the physical condition(s) and raises health care costs by 45% for each person affected. Furthermore, experiencing depression alongside at least one LTC significantly worsens quality of life compared to the experience of the LTC alone<sup>16</sup> with the impact of depression becoming greater the more LTCs the patient experiences.

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<sup>14</sup> [Long-term conditions metrics infographic - NHS England \(2016\)](#)

<sup>15</sup> [Long-term conditions and the cost of co-morbidity - The Kings Fund \(2012\)](#)

<sup>16</sup> [Depression, chronic diseases, and decrements in health: results from the World Health Surveys - Moussavi et al \(2007\)](#)

Similar conclusions were reached by the British Heart Foundation in their publication *Twice as likely: Putting long term conditions and depression on the agenda*.<sup>17</sup> Indeed, the NHS Confederation also published a report reviewing the impact of LTCs on people's mental health and wellbeing and recommending how services should respond to this challenge.<sup>18</sup>

### Impact on unemployment, benefits and work

An important area that has received considerable attention is the impact of LTCs on work and employment. A recent report by the Work Foundation has calculated the impact of LTCs on working lives. People with LTCs frequently struggle to maintain employment due to significant disabilities. This impacts on business and employers in terms of skill shortages and unemployment, sickness absence and presentism. They illustrate the scale of the problem by presenting relevant statistics for six common LTCs:<sup>19</sup>

- The average age of retirement for someone with multiple sclerosis is **42 years old**
- Over **45%** of people with asthma report going to work when ill, increasing the risk of prolonged sickness and affecting their ability to perform effectively
- Just **8%** of people with schizophrenia are in employment, despite evidence that up to 70% of people with severe mental illness express a desire to work
- People with heart failure lose an average of **17.2 days** of work per year because of absenteeism caused by their condition
- Over **52%** of people with diabetic macular oedema are of working age
- A **10%** reduction in sickness absence for people with psoriasis would provide a **£50 million** boost to the UK

[Public Health England](#) and [NHS Employers](#) have both published advice to employers about positive approaches to supporting people with LTCs within employment.

### Impact of long-term conditions and services on people's lives

Finally, a recent report published by the Richmond Group of Charities documents the impact of LTCs on people's lives, together with the quality of services provided to people with LTCs. Some relevant findings are summarised below.<sup>20</sup>

- **44%** of adult inpatients say they are not sufficiently informed about clinical decisions.
- Only **40%** of people could understand the stroke information packs given to them.
- Only **1.6%** of people with diabetes attended structured courses in education that met NICE standards.
- More than **two thirds** of people with neurological conditions report not having been offered a care plan.

We should also stress the burden of care and associated costs of employment and benefit support for the families and carers of people with LTCs. For example, in a recent survey circulated by Carers UK the costs of

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<sup>17</sup> [Twice as likely: putting long-term conditions and depression on the agenda - The British Heart Foundation \(2012\)](#)

<sup>18</sup> [Investing in emotional and psychological wellbeing for patients with long-term conditions - NHS confederation \(2012\)](#)

<sup>19</sup> [The impact of long-term conditions on the economy - The Work Foundation, The University of Lancaster \(2016\)](#)

<sup>20</sup> [Vital Signs report - The Richmond Group of Charities \(2015\)](#)

informal caring are estimated as being equivalent to the NHS budget.<sup>21</sup> Previous reports by Carers UK have also emphasised the increase in stress, depression and social isolation felt by carers of people with LTCs. Indeed, a recent [King's Fund report](#) on integration between physical and mental health care emphasises the importance of providing support to carers of people with LTCs.<sup>22</sup>

### **Consultation question 3**

**Are there important socio-economic impacts relating to long-term conditions that we have missed?**

Please submit your response at the following link: [www.surveymonkey.co.uk/r/consultationLTC](http://www.surveymonkey.co.uk/r/consultationLTC)

## **4.2 Policy development: reviews and guidance**

It is clear that LTCs have had a major impact on the delivery of health care and the costs of NHS provision. It is not surprising, therefore, that LTCs have been the subject of numerous policy reviews and reports coming from both health professionals and the Government. Moreover, in recent years it has been acknowledged that patients with LTCs need to be consulted more extensively and encouraged to actively engage in their treatment. This has come from patients themselves and also the various charities and voluntary organisations representing them.

We will not attempt an exhaustive review of policy development in the last decade or so, but instead will attempt to identify the key issues that have emerged. There are several key reports that mark significant milestones in the development of health care provision for LTCs. Perhaps the publication of the first National Service Framework (NSF) for Long-term Conditions in 2005 is a convenient starting point, which illustrates some of the key policy areas and their development in the coming years. The NSF specifically targeted people with long-term neurological conditions such as multiple sclerosis, Parkinson's disease, and cerebral palsy in adults. Nevertheless, a key purpose was to describe how health and social services should provide an integrated service to support and rehabilitate people with neurological conditions and other LTCs. It listed a number of quality requirements including:<sup>23</sup>

- A person-centred service
- Early recognition, prompt diagnosis and treatment
- Emergency and acute management
- Early and specialist rehabilitation
- Community and vocational services
- Providing practical support including equipment and accommodation
- Personal care and support
- Palliative care
- Supporting families and carers

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<sup>21</sup> [State of Caring 2016 - Carers UK \(2016\)](#)

<sup>22</sup> [Bringing together physical and mental health: a new frontier for integrated care - The Kings Fund \(2016\)](#)

<sup>23</sup> [National Service Framework for Long Term Conditions - Department of Health \(2005\)](#)

Many of the principles identified above have become incorporated into service planning for a whole range of LTCs. Perhaps the most important is the recognition of **personalised care** and the importance of treating the person/patient and not the condition.<sup>24</sup> Other important principles have included encouraging **self-management**, and the development of the expert patients programme and patient held records. These innovations have arisen particularly for people with diabetes where the focus has been to encourage patients to be actively involved in managing their own condition. Asthma is another area where there has been a focus on self-management and patient recorded outcomes.

These approaches very much rely on the provision of accessible and high quality information.<sup>25</sup> Indeed, there have been several recent initiatives to provide greater access to learning about **self-care** for both patients and professionals through e-learning resources. For many conditions, there has been a shift towards pro-active and innovative programmes aimed at facilitating **positive adaptation** to living with a LTC, as well as general improvements in **healthy lifestyles and wellbeing**. Good examples being for people with cardiovascular disease, arthritis, Parkinson's disease, some types of cancer and HIV. For people with more disabling conditions, or older people with LTCs who may also have mobility or social care needs, the focus has been on **integrated care planning** involving health and social services assessments, co-ordinated **written care plans** and **individualised budgets and payments**.<sup>26</sup> More recently, the focus has been on multi-morbidities which are usually the norm within older populations.<sup>27</sup>

Many of the above initiatives have been combined in a single initiative promoted by the [King's Fund](#) and [NHS England](#), termed the *House of Care*.<sup>28</sup> The 'House' is a metaphor, whereby the central aspect of delivering care for LTCs is personalised care planning. However, for this to be effective, patients have to be informed and motivated, and staff committed to partnership working. The foundations for this are responsive commissioning, whereas the entire process requires oversight and appropriate organisational processes.

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<sup>24</sup> [Improving the wellbeing of people with LTCs - Department of Health \(2010\)](#), [Improving health and wellbeing of people with long term conditions in Scotland - NHS Scotland \(2009\)](#), [Our vision for the future: action on long-term conditions - Coalition of collaborative care \(2011\)](#)

<sup>25</sup> [Our health, our care, our say: A new direction for community services - Department of Health \(2006\)](#), [Patients in control: why people with long-term conditions must be empowered - Institute for Public Policy Research \(2014\)](#)

<sup>26</sup> [Multimorbidity: clinical assessment and guidelines - NICE \(2016\)](#), [Improving the lives of people with long term conditions - Royal College of GPs \(2012\)](#), [Executive summary: Personalised care and support planning handbook The journey to person-centred care - NHS England \(2016\)](#)

<sup>27</sup> [Older people with social care needs and multiple long-term conditions \[NG22\] - NICE \(2015\)](#)

<sup>28</sup> [Delivering person centred care in long term conditions - BMJ Eaton Simon, Roberts Sue, Turner Bridget \(2015\)](#)



### 4.3 Policy implications for a Reading Well Books on Prescription for long-term conditions scheme

Due to the widespread and major impacts that LTCs have on people's lives, the delivery of health services and the socioeconomic costs, it is not surprising that these conditions have been a prime focus for government thinking and policy formulation. The priority that has been given to tackling LTCs and introducing new models of care, therefore, would support The Reading Agency and Society of Chief Librarians' decision to target LTCs for its next Reading Well Books on Prescription scheme. As can be seen from the policy review, there are certain key principles such as providing high quality information to patients and their relatives, self-care and management, personalised care planning, providing group education and support, emphasising healthy lifestyles and wellbeing, and tackling anxiety and depression, which are all consistent with the aims of RWBOP. The focus of RWBOP is the provision of evidence-based, quality-endorsed books designed to inform, educate and help people manage their health conditions. This is made possible by widely disseminated reading lists of relevant books either from health professionals or made available through public libraries and other community resources.

The recent emphasis on treating mental health conditions alongside LTCs<sup>29</sup> is also consistent with the RWBOP approach and would allow for titles relating to the mental health implications of living with a LTC to be featured on the list, as well as signposting to the existing adult common mental health conditions and dementia lists. The common mental health conditions booklist was shaped by the views of IAPT therapists (both low and high intensity psychological therapists) and we would envisage that this would also be appropriate for a LTCs list.

<sup>29</sup> [Long-term conditions positive practice guide - IAPT \(2008\)](#), [MUS positive practice guide - IAPT \(2014\)](#), [Long-term conditions and mental health: the cost of co-morbidities - The Kings Fund \(2012\)](#), [Investing in emotional and psychological wellbeing for patients with long-term conditions - NHS confederation \(2016\)](#), [Investing in emotional and psychological wellbeing for patients with long-term conditions - NHS confederation \(2016\)](#), [Bringing together report - The Kings Fund \(2016\)](#).

#### **Consultation question 4**

- a. How far do you agree or disagree with our analysis of the policy framework for a RWBOP scheme for LTCs? Please let us know the reasons for your answer.**
- b. If you are aware of any relevant policy initiatives that we have not included please tell us about them here.**

Please submit your response at the following link: [www.surveymonkey.co.uk/r/consultationLTC](http://www.surveymonkey.co.uk/r/consultationLTC)

## **5. Clinical guidelines, quality standards and the evidence base**

### **5.1 Overview**

A major effort was made when establishing the English RWBOP for common mental health conditions scheme to ensure that it was informed by the relevant NICE guidance surrounding particular conditions. There was also a strong focus on corroborating research evidence supporting the use of particular books or manuals. A summary of the evidence base is provided on [The Reading Agency website](#).<sup>30</sup> Where there was evidence of ineffective or potentially harmful self-help interventions, these conditions (for example, post-traumatic stress disorder) were not included on the book list.

With the original [RWBOP list for common mental health conditions](#) the strategy for gathering evidence to support particular self-help books for conditions where they might be beneficial relied heavily on recommendations about the use of guided CBT self-help books or self-help groups contained within the relevant NICE clinical guidelines. Given that the majority of books offering CBT self-help were for identified conditions where NICE guidance was available, this ensured that an identifiable and transparent evidence base was deployed. Additional guidance was provided by an expert panel of relevant health professionals. Some books on the list referred to problems where no *specific* NICE guidance was available (these included anger, relationship problems, self-esteem, sleep, stress and worry). It was, however, acknowledged that there was a need for quality endorsed guidance relating to these everyday problems associated with psychological distress. The books selected were endorsed by professionals and had been subject to evaluation research and scientific scrutiny.

When attempting a similar exercise in scoping the evidence for the RWBOP dementia list, we became aware that the evidence base for individual self-help books was less developed. We therefore adopted a more general approach that critically examined the role of books and psycho-educational materials in enhancing care standards as identified by NICE and key charities in promoting the quality of dementia services. Rather than just focusing on self-help strategies to ameliorate symptoms, titles from the dementia list were about providing information for people worried about symptoms at the time of diagnosis, about how to 'live well with dementia,' and providing support for relatives and carers. Several biographical and

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<sup>30</sup> [Evidence base for Reading Well Books on Prescription - The Reading Agency website](#)

fictional accounts of dementia were also recommended by both individuals and charities as being extremely useful in helping people to understand the experience and inner worlds of people with dementia. For the young people's list, we adopted aspects of both approaches identified above. We were also strongly guided by the views of young people themselves since for this particular project we adopted a strong co-production model for consultation and book selection.

The situation regarding LTCs is less than clear. Although many self-help books are available that cover LTCs in general, very few appear to be evidence-based or derived from clinical evaluations or trials. A few titles have been based on educational programmes<sup>31</sup> that have tended to be delivered in a group format (see next section). Some are extensions of well researched interventions such as CBT<sup>32</sup> or mindfulness<sup>33</sup> that have been applied to specific LTCs. However, very few, if any, of these books are specifically recommended in NICE clinical guidelines. This is in contrast to the RWBOP common mental health conditions list, where direct links with NICE could be made.

In order to summarise the potential links between NICE and a list for RWBOP for LTC, we have scanned and summarised the relevant NICE guidance and identified either specific psychological approaches or self-help materials that might form the basis for recommendations for a list. A useful reading list and summary of the LTC literature was published by the King's Fund<sup>34</sup> in 2014. We have also scoped various systematic reviews of LTCs and searched the literature for relevant psychological interventions, self-help strategies and self-management and support programmes. We will also aim to foster an active dialogue with people with LTCs, relatives, carers, professionals and charities concerning additional titles not necessarily associated with NICE guidance that should also be considered. Given the absence of clinical trials or evaluations of specific titles, we believe that professional endorsement, together with the views of people with lived experience of LTCs, will be major components of the book selection process. A library survey of existing titles regarding LTCs and the extent to which they have been borrowed will also inform the later book selection process.

## 5.2 NICE<sup>35</sup> and long-term conditions

There are three sources of NICE guidance that are relevant to the development of the book list. First, there have been several general guidelines about LTCs, together with care planning for older people. There are also condition-specific NICE guidelines (for example, diabetes, epilepsy), which cover the majority of conditions relevant to our list. Finally, there are NICE guidelines for mental health conditions such as depression, which is often seen as a LTC in itself, plus specific NICE guidance for depression experienced by people with LTCs.

### General guidance

NICE guidelines ([NG22](#)) provide the framework for integrated care planning, self-management and support for carers of older people with multiple LTCs. It stresses the importance of accessible and good quality information at every stage of the development of the patient's care plan. It also stresses providing relevant information and support to carers. Guidance that is about to be published (expected September 2016) on

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<sup>31</sup> [Living a Healthy Life with Chronic Conditions: For Ongoing Physical and Mental Health Conditions - Kate Lorig, Halsted Holman, David Sobel \(2013\)](#)

<sup>32</sup> [Overcoming chronic pain - Cole et al \(2010\)](#)

<sup>33</sup> [Mindfulness for Health: A practical guide to relieving pain, reducing stress and restoring wellbeing - Burch et al \(2013\)](#)

<sup>34</sup> [Library reading list: long-term conditions - The Kings Fund \(2014\)](#)

<sup>35</sup> [National Institute for Health and Care Excellence \[NICE\]](#)

multi-morbidity in LTCs will also help select those at risk and who would particularly benefit from more intensive and individualised care. Although it is doubtful that older people with multi-morbidity may benefit directly from RWBOP, relevant information from a LTC list, together with the RWBOP for dementia list, might benefit relatives and carers.

### Specific NICE guidance

Most individual conditions such as asthma ([QS25](#)), arthritis ([CG79](#)), diabetes ([CG87](#)) and epilepsy ([CG137](#)) have individual NICE clinical guidelines about treatment and management. Generally, they all emphasise the importance of providing good quality information to patients and their relatives from the time of diagnosis onwards. Good quality, according to NICE, means individually tailored to the patient's level of understanding and designed to be accessible. Providing information is said to improve a patient's understanding of their condition, which can then help motivate them to control their symptoms through self-management. Indeed, it is argued that good information provision leads to an increase in perceived control over the condition (i.e. self-efficacy) and also better understanding (for example, health literacy). The latter is seen as a good predictor for positive outcomes in treatment trials of people with LTCs.<sup>36</sup> Individual guidance for asthma and diabetes particularly recommend setting up psycho-educational groups to encourage self-management of the condition. It also suggests that information sessions and support should be offered on an individual basis to both patients and carers.

For some LTCs, specific psychological interventions are also mentioned:

- For rheumatoid arthritis ([CG79](#)), psychological interventions such as stress management and relaxation, together with cognitive coping skills, are recommended.
- For asthma ([QS25](#)) and chronic obstructive pulmonary disease ([CG101](#)), psychological approaches to breathing control are suggested as components of an education programme.
- For stroke, the teaching of psychological principles within rehabilitation programmes is stressed.
- For epilepsy ([CG137](#)), psychological interventions such as CBT, relaxation training and biofeedback are recommended.
- NICE guidelines for some specific conditions such as coronary heart disease ([CG108](#)), stroke ([CG162](#)), multiple sclerosis ([CG186](#)) and chronic kidney disease ([QS25](#)) all emphasise the importance of detecting depression and making adequate provision for treatment.

We have dealt with some of the most common NICE clinical guidelines referring to LTCs; others also exist (for example, chronic fatigue syndrome, chronic pain and irritable bowel syndrome) but space prevents comprehensive coverage.

### NICE guidance for depression and long-term conditions

It has already been stressed that individual NICE guidance marks out the importance of diagnosing and treating depression in people with LTCs. Indeed, a specific guideline was produced that was intended to supplement the recently published NICE guideline on depression ([CG90](#)) and to focus specifically on managing depression associated with LTCs, particularly within the context of primary care. As well as recommending the provision of good quality information, the guideline also

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<sup>36</sup> [Health Literacy website](#)

recommends that for cases of mild to moderate depression, guided self-help CBT should be provided either individually or within a group, and possibly supplemented with computerised or online resources. It is suggested that a collaborative care model might be adopted whereby people with depression are seen within primary care but with inputs and supervision from secondary care mental health specialists. For more severe depression, intensive psychological therapy and/or medication are recommended.

### 5.3 Meta-analyses and systemic reviews

There have been several important meta-analyses and systematic reviews of LTCs published, many written as the basis for reports published by the King's Fund and other organisations. Perhaps the most current has been published by National Voices, outlining the evidence supporting person centred care.<sup>37</sup> They conclude that the provision of personalised information specific to an individual's condition, preferably online and with some source of support (online/telephone), should improve patients' knowledge of their condition, enhance their experience of services, and have positive impacts on service use and cost and ultimately patients' health. Similar conclusions have also been published by various other health organisations including NHS England and the Coalition for Collaborative Care, the National Institute of Health<sup>38</sup> and National Voices. These reviews have attempted to identify the most effective components of what are usually quite complex group psycho-education interventions. For example, National Voices concluded that elements such as specific education delivered in health care settings, supplemented by lay-lead generic self-management courses, with telephone support and self-monitoring were optimum. The National Institute of Health review is significant since it identifies psycho-education delivered across various formats as being important, especially when an interactive format supported by health professionals was employed. However, the passive use of education materials was concluded not to be effective. This would seem to echo the debate around supported/guided self-help<sup>39</sup> within the mental health field. A recent Cochrane review<sup>40</sup> looking specifically at the efficacy of personalised care planning revealed small improvements in a range of LTCs health outcomes, reduced depression and improved personal confidence and skills to manage health. Another positive meta-analysis also demonstrated psychological benefits from 'chronic disease self-management programmes', although direct impacts on health care utilisation were limited.<sup>41</sup> A summary of these reviews, which focused on implementing best practice, was published by the Centre for Reviews and Dissemination at the University of York.<sup>42</sup> The review identified key features for successful implementation, as well as identifying barriers such as other family commitments, transport and costs. Overall, they stressed the importance of clinical leadership, staff training and ongoing evaluation in the successful delivery of these programmes.

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<sup>37</sup> [Improving information and understanding - National Voices \(2016\)](#)

<sup>38</sup> [A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions - National Institute of Health \(2014\)](#)

<sup>39</sup> [Good practice guidance on the use of self-help materials within IAPT services - NHS England](#)

<sup>40</sup> [Personalised care planning for adults with chronic or long-term health conditions - Coulter - 2015 - The Cochrane Library - Wiley Online Library](#)

<sup>41</sup> [A meta-analysis of health status, health behaviours, and healthcare utilization outcomes of the Chronic Disease Self-Management Program - Brady et al \(2013\)](#)

<sup>42</sup> [Supporting self-management: helping people manage long-term conditions - The University of York \(2015\)](#)

The application of self-help psychological interventions to people with LTCs has also been reviewed. Matcham et al.<sup>43</sup> in a meta-analysis of self-help interventions for people with physical illnesses provide some support for the efficacy of CBT for depression. Similarly, a systematic review by Farrand and Woodford identified 11 studies that yielded small effect sizes for treating depression or anxiety using CBT.<sup>44</sup> They comment on the poor quality of studies conducted in this area. A recent unpublished review by Hadert makes some useful practical suggestions as to how CBT for LTCs might be modified to make it more acceptable to these patients.<sup>45</sup>

In summary, there is considerable evidence to support the effectiveness of personalised, self-management programmes for LTCs. While the cost-effectiveness of these programmes has yet to be convincingly demonstrated since impacts on physical symptom outcomes and health care utilisation are difficult outcomes to achieve, there is substantial evidence for the positive impacts of these programmes on patient quality of life, wellbeing and sense of control. The provision of both condition-specific information and more generic information are important components of these self-management programmes. However, the literature supports the provision of psycho-education in group formats provided by health care professionals over a period of time, rather than the passive provision of bibliotherapy or unsupported self-help. In addition, there is some support for the use of psychological interventions such as CBT in the treatment of depression and anxiety in people with LTCs.

### **Consultation question 5**

- a. How far do you agree or disagree with our summary of NICE guidelines relevant to a RWBOP scheme for LTC? Please let us know the reasons for your answer.**
- b. How far do you agree or disagree with our summary of meta-analyses and systematic reviews relevant to a RWBOP scheme for LTCs? Please let us know the reasons for your answer.**
- c. If you are aware of any key reviews relevant to a RWBOP scheme for LTCs that we have not included please tell us about them here.**

*Please submit your response at the following link: [www.surveymonkey.co.uk/r/consultationLTC](http://www.surveymonkey.co.uk/r/consultationLTC)*

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<sup>43</sup> [Self-help interventions for symptoms of depression, anxiety and psychological distress in patients with physical illnesses - Matcham et al \(2014\)](#)

<sup>44</sup> [Effectiveness of Cognitive Behavioural Self-Help for the Treatment of Depression - Farrand & Woodford \(2015\)](#)

<sup>45</sup> [Adapting Cognitive Behavioural Therapy Interventions for Anxiety or Depression to Meet the Needs of People with Long-term Physical Health Conditions - Hadert \(2013\)](#)

## **6. Developing a Reading Well Books on Prescription for long-term conditions scheme**

### **6.1 Function of scheme**

In order to outline the potential of the RWBOP scheme to help and support people with LTCs it is helpful to consider how the current schemes, for people with mental health conditions and dementia, and young people with mental health issues, are used. These existing RWBOP schemes serve a number of useful purposes which include the following:

- a.** Provision of general information concerning health conditions for the general public and raising levels of health literacy.
- b.** Enhancing awareness and promoting help-seeking for unrecognised/undiagnosed conditions.
- c.** Providing self-help books for specific conditions or problems, which can be used by the individual in confidence and without stigma, either unguided or guided by a health professional.
- d.** Provision of self-help resources, which may be adopted either within face-to-face or group-facilitated therapy and/or education.
- e.** Provision of information for relatives and carers.
- f.** Support for living well with a diagnosed condition.
- g.** Support for understanding the experience from an informed personal/fictional perspective.
- h.** Provision of information for non-health care professionals (for example teachers, care workers, etc.).
- i.** Provision of a non-stigmatised, community-based resource for associated meetings/group activities (for example, memory cafes for dementia).
- j.** Provision of signposting to relevant local services and charities through the provision of the RWBOP leaflet and [website](#), or through library staff and enquiries. It should be noted that over two million RWBOP leaflets have been distributed across public libraries in England.

### **Consultation question 6**

- a. Which three functions from this list would you consider to be the most important for the new LTC list and why?**
- b. Are there any functions listed above that you consider inappropriate for the new list?**
- c. If you answered 'Yes', please tell us why:**
- d. Are there any additional functions that the LTC list could serve that are not identified above?**

Please submit your response at the following link: [www.surveymonkey.co.uk/r/consultationLTC](http://www.surveymonkey.co.uk/r/consultationLTC)

## **6.2 Format of books**

To achieve the goals identified above, a variety of different types/styles of books were recommended by professionals and service users for the existing RWBOP schemes and these include:

- a.** Books that provide general information about a specific condition, ranging from medical and psychological explanations of the condition, prognosis and outcomes, common treatments, ways of managing the condition, and more.
- b.** Specific self-help books based on a clinical trial or published therapy manual. These may take the form of a traditional book or a workbook for completion by the reader.
- c.** Books written for relatives and carers about supporting and caring for an individual with a specific condition.
- d.** Books written for common problems and difficult experiences (for example sleep, anger, relationships, stress).
- e.** Biographical and fictional accounts of a particular condition which may be written from the perspective of the person with the condition, or from that of a relatives or carers.

### **Consultation question 7**

- a. Which of the five types of book listed above would you recommend including within the LTC booklist? Please say why.**
- b. Would you recommend including any other types of books not mentioned above?**

Please submit your response at the following link: [www.surveymonkey.co.uk/r/consultationLTC](http://www.surveymonkey.co.uk/r/consultationLTC)

### 6.3 Access to the book list

As with previous RWBOP schemes, people will access the LTCs list through their public library service – books will be displayed on the open shelves of library branches for anyone to borrow and library staff can also recommend titles to visitors. We would envisage people will also be recommended specific titles from the list by their GP or by staff at specialist clinics for LTCs, or mental health services (for example IAPT services).

#### **Consultation question 8**

**Do you consider the following to be appropriate ways for people to access the RWBOP LTC scheme?**

- **Through recommendation by GPs**
- **Through recommendation by specialists in outpatient clinics**
- **Through recommendation by specialist nurses**
- **Through recommendation by IAPT / mental health services**
- **Through Patient Advice and Liaison Services**
- **Accessing the books independently from public libraries**
- **Other (please specify)**

Please submit your response at the following link: [www.surveymonkey.co.uk/r/consultationLTC](http://www.surveymonkey.co.uk/r/consultationLTC)

### 6.4 What would a Reading Well Books on Prescription for long-term conditions scheme look like?

We would argue that many of the benefits of existing RWBOP schemes will be relevant for people with LTCs and their relatives and carers. The review of current policy and clinical guidance emphasises the importance of providing quality information about medical conditions. This is usually considered to be part of a patient's treatment: the information is provided through booklets and leaflets during the consultation and possibly followed up with individual counselling or group educational programmes. RWBOP could supplement this strategy by providing supporting information through the public library system to patients and their carers and family awaiting referral, during or following treatment, or when the provision of routine information leaflets may not be available. As such, it could be seen as a safety net to ensure adequate provision of quality information. For some patients, relatives and carers, books might provide a more comprehensive guide to a particular condition than leaflets and booklets available from clinics. The RWBOP for LTCs titles could also supplement online information available from charities (for example [Asthma UK](http://www.asthma.org.uk), [Diabetes UK](http://www.diabetes.org.uk)).

As well as providing specific information about individual LTCs, RWBOP could also usefully offer more generic information about positively managing LTCs and ways of facilitating healthy living. It may be that there are some common areas such as exercise, nutrition and diet, sleep, meditation, stress reduction and relaxation that could be addressed. This could also be extended to common mental health conditions, especially depression, which frequently exist as co-morbid conditions. Titles that specifically deal with depression in the context of specific medical conditions would be most appropriate. However, it might also be appropriate to signpost patients to the RWBOP for common mental health conditions list. The approach to mental health problems such as depression needs sensitive treatment. People with LTCs might be reluctant to accept that they are also experiencing psychological problems. Indeed, some might argue that depression is a realistic response to disabling and frequently life-threatening conditions. Although, this doesn't mean that it shouldn't be amenable to some sorts of treatment.

A decision will need to be made concerning whether biographical or fictional accounts of people with LTCs should be included on the list. This category of book was not considered for the first RWBOP scheme for common mental health conditions. However, biographical titles were included in the dementia list and feedback indicated that they were highly valued. Similarly, the inclusion of fiction within the young people's list was a key requirement emerging from the consultation and co-production process and has received very positive feedback from young people and health professionals. The general view is that the young people's list is accessible and appealing.

In summary, our recommendation is that the titles chosen for the list should address a number of specific LTCs, generic approaches to managing LTCs and promoting healthy living, and approaches to managing associated mental health problems. The target readers would be people with LTCs and their relatives and carers.

## **6.5 Book selection**

A book selection group will be created to choose the titles for the RWBOP LTC list. This group will be made up of invited representatives from professional bodies and charities, and people with LTCs. This consultation paper, and responses to the linked survey, will contribute to the framework for book selection. These will also be discussed, together with a survey of titles already in use with public libraries in England, at a roundtable discussion held in September 2016 at the Free Word Centre, London, which will then shape a [book selection protocol](#).

When deciding which titles and LTCs the book list should prioritise, we envisage that the book selection panel will need to take into account, among other things: which are the most prevalent LTCs within society as a whole, where additional support for LTCs is most needed, evidence of the efficacy of self-help for particular LTCs, availability of suitable titles, and the absence of any reports of negative effects of bibliotherapy for a LTC. The choice of titles is also likely to be determined by design features, length, accessibility and suitability for library use (such as the nature of binding).

To ensure wide accessibility of the list, materials for people with learning disabilities and people with lower reading levels will be considered. Titles available in a wide range of different formats (including e-books, audio and large print) will also be sought. We are proposing the final list be targeted at adults.

### **Consultation question 9**

- a. How far do you agree or disagree with our approach to book selection for the RWBOP scheme for LTCs in terms of prevalence and efficacy? Please let us know the reasons for your answer.
- b. How far do you agree or disagree with our proposed focus on an adult audience? Please let us know the reasons for your answer.
- c. Please tell us about any other factors that the book selection panel should take into consideration when choosing titles for the list.
- d. Are there any specific books relating to LTC that you or your organisation would recommend for inclusion on the list? Please say why.
- e. Are there any titles relating to LTC that you would not recommend? Please say why.
- f. Please provide details of any relevant booklists that provide support for people with LTC. Where possible, please provide a URL or send a PDF/Word doc of the booklist to [readingwell@readingagency.org.uk](mailto:readingwell@readingagency.org.uk).

Please submit your response at the following link: [www.surveymonkey.co.uk/r/consultationLTC](http://www.surveymonkey.co.uk/r/consultationLTC)

## **7. Professional bodies and patient organisations that should be consulted**

To date, the RWBOP programme has been developed with and supported by a group of health organisations and charities, which have included the following:

Alzheimer's Society, British Association for Counselling and Psychotherapy, British Association for Behavioural and Cognitive Psychotherapies, The British Psychological Society, Carers UK, Dementia UK, NHS England (IAPT and Children and Young People's Mental Health), Innovations in Dementia, Mental Health Foundation, Mind, National Association of Primary Care, Public Health England, Royal College of GPs, Royal College of Nursing, Royal College of Psychiatrists, YoungMinds.

We hope to work with these supporting organisations to develop the new RWBOP scheme for LTC and have also sent a briefing paper about the initiative to the organisations listed in Appendix 1. We would be keen to receive suggestions of any other organisations, especially those representing patients or carers that we may have omitted from this list. We are particularly keen to involve people with the lived experience of LTCs directly with the consultation, although are also aware of the practical challenges of working with a broad range of partners and targeted communities of people with specific long-term conditions. We are keen to receive suggestions as to possible co-production models and approaches.

**Consultation question 10**

- a. Are there any professional or patient groups that we should add to our list of potential partners?
- b. Do you have any suggestions as to how we might engage people with long-term conditions or patient groups in the development of the scheme?

Please submit your response at the following link: [www.surveymonkey.co.uk/r/consultationLTC](http://www.surveymonkey.co.uk/r/consultationLTC)

## Appendix

Action for ME  
 Action on Hearing Loss  
 Association of Directors of Adult Social Services  
 Age UK  
 Anglia Ruskin University  
 Arthritis Care Pain UK  
 Arthritis Research UK  
 Arthritis UK Pain Centre  
 Association of British Clinical Diabetologists  
 Association of British Neurologists  
 Association of Chartered Physiotherapists in Respiratory Care  
 Asthma UK  
 British Association for Behavioural and Cognitive Psychotherapies  
 British Psychological Society  
 Breast Cancer Now  
 British Association for Counselling and Psychotherapy  
 British Association for Sexual Health and HIV  
 British Association of Social Workers  
 College of Occupational Therapists  
 British Heart Foundation  
 British Kidney Patient Association  
 British Lung Foundation  
 British Thoracic Society  
 Cancer Research UK  
 Centre for Mental Health  
 Cystic Fibrosis Trust  
 Cystitis and Overactive Bladder Foundation  
 Devon Partnership NHS Trust  
 Diabetes and Research Wellness Foundation  
 Diabetes UK  
 Endometriosis UK  
 Epilepsy Action  
 Epilepsy Research  
 Fibromyalgia Action UK  
 Herpes Virus Association  
 Hypermobility Syndromes Association  
 Kidney Research UK  
 Macmillan Cancer Support  
 Mental Health Foundation  
 Mind  
 MND Association  
 MS Trust  
 Multiple Sclerosis Society  
 Muscular Dystrophy UK  
 National Association of Primary Care  
 National AIDS Trust  
 National Centre for Children and Families  
 National Collaborating Centre for Mental Health  
 National Council for Palliative Care  
 National Institute for Health Research  
 National Osteoporosis Society  
 National Voices  
 NHS Choices  
 NHS England (IAPT)  
 Nottingham University  
 Pain Concern National  
 Parkinson's UK  
 Primary Care Respiratory Society  
 Public Health England  
 Rethink Mental Illness  
 Rheumatoid Arthritis Society  
 Royal College of GPs  
 Royal College of Nursing  
 Royal College of Physicians  
 Royal College of Psychiatrists  
 Royal Society of Public Health  
 Self Management UK  
 Sickle Cell Society  
 Social Care Institute for Excellence  
 Society for Academic Primary Care  
 Stroke Association  
 Tavistock and Portman NHS Foundation Trust  
 The British Society of Rheumatology  
 The IBS Network  
 The King's Fund  
 The Nuffield Trust  
 The Open University: Faculty of Health and Social Care  
 The Richmond Group of Charities  
 The Work Foundation  
 Trigeminal Neuralgia Association UK  
 UK Kidney Research UK  
 University of Exeter  
 University of Hull  
 University of Manchester School of Nursing, Midwifery and Social Work  
 University of the West of England  
 Vulval Pain Society