

## Annex 1

# Scoping review of the evidence base: overview and methods

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This report was produced by the Institute of Health & Society, Newcastle University on behalf of the Realising the Value consortium. It forms one of the annexes to the report *At the heart of health. Realising the value of people and communities.*

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### **About this report**

This report was produced by J Hislop, J Gray and L Vale of the Institute of Health & Society, Newcastle University on behalf of the Realising the Value consortium. It forms one of the annexes to the report 'At the heart of health - Realising the value of people and communities' which can be found on the programme website [www.realisingthevalue.org.uk](http://www.realisingthevalue.org.uk).

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## Executive Summary

### *Introduction*

The Realising the Value programme seeks to identify a set of evidence based approaches to help the NHS to do more to support people with long-term conditions in managing their own health and care. The programme involves a consortium of collaborators including Nesta, The Health Foundation, The Behavioural Insights Team, Newcastle University and Voluntary Voices (including the organisations National Voices, Regional Voices, the National Association for Voluntary and Community Action and Volunteering Matters). To inform the decisions determining which approaches would be most appropriate to focus on in more detail for the Realising the Value programme, a scoping review (a review of the entire scope of the relevant literature but without the in depth review required of a formal systematic review) of the evidence base on person- and community-centred approaches for health and wellbeing and a shortlisting process were conducted. This report summarises the scoping review and shortlisting process and results.

### *Methods*

Source documents of potentially relevant evidence were gathered from members of the Realising the Value consortium. The reference lists of all these sources were extracted and duplicates removed. Additional searches were conducted in tandem, using search terms that had previously been used to inform several of the original source documents. We included systematic reviews of person- and community-centred approaches for health and wellbeing and reports of comparative (randomised and non-randomised) person- and community-centred approaches for health and wellbeing that took place in the UK. We excluded papers that reported only qualitative data, protocol information or where no person- or community-centred approach to health and wellbeing was administered. We also excluded studies that solely considered a specific subgroup of the population with the exception of age (in order to allow both paediatric and adult studies). All included review and UK-study abstracts had to also indicate statistically significant change in at least one outcome of interest. Outcomes of interest were finalised during the multi-criteria decision analysis (MCDA) process. Studies that did not report significant change in any outcome were excluded, as were those that did not report significant change across the pre-specified range of outcomes finalised during the MCDA process.

The MCDA process involved a range of stakeholders who discussed their preferred criteria for prioritising person- and community-centred approaches for health and wellbeing during a meeting held in London on 15<sup>th</sup> July 2015. These

criteria included balancing condition-specific and non-condition specific approaches; the quality of the evidence base; applicability to an English health and social sector context; scalability; transferability; cross-agency input (including the community/third sector); magnitude of impact and potential to reduce inequalities. These criteria were refined at a meeting of the Realising the Value consortium and Advisory Group held in London on 22<sup>nd</sup> July 2015, and on the basis of these criteria, specific outcomes of interest for the scoping review were finalised and categorised as (i) financial/resource (ii) health-related (including bio-medical, behaviour change or individual well-being/empowerment) or (iii) social. Abstracts reporting significant change in any social outcome or most (i.e. with the exception of 'satisfaction') individual well-being empowerment outcomes were included; otherwise significant change in at least two categories of outcome was required.

For all included studies, pre-existing cut-offs were used and additional arbitrary cut-offs were derived in order to categorise results by 'effect size' i.e. "small", "medium" or "large". Studies showing "medium" and or "large" effects were summarised in tables, which were presented at a final shortlisting meeting held in London on 14<sup>th</sup> August 2015 and used, in conjunction with information on the "grey" literature and expert opinion to inform the choice of five person- and community-centred approaches for health and wellbeing.

## **Results**

In total 913 systematic reviews were initially identified from our sources, as well as 308 UK-based studies, of which 58 were included as comparative studies of effectiveness of person- and community-centred approaches for health and wellbeing. For the systematic reviews, 521 were taken forward to the shortlisting stage after excluding protocols, reviews that related to a specific population subgroup, and/or did not relate to a specific approach, reviews with no quantitative data or significant change. At the shortlisting stage, more specific outcome criteria were then applied and 154 reviews met our inclusion criteria, of which 84 studies showed "large" or "medium" outcome effects. Most included reviews related to self-management and/or education (19.5% and 15.6% respectively). In terms of specialty, most reviews related to approaches used in diabetes, followed by mental health specialties (12.3% and 11.0% respectively). Among studies that had shown "medium" and/or "large" effects, health and wellbeing outcomes were most commonly reported (44.4% of all outcomes reported), followed by outcomes relating to behaviour change (26.5%). It should be noted that the number and type of outcomes found, is itself a function of the nature and purpose of the original reviews and so results must be treated with caution. However, these data were deemed sufficient to be summarised to help inform the selection of five of the most "promising" approaches. The final five

approaches chosen were (1) self-management education, (2) peer support, (3) health coaching, (4) group activities to promote health and well-being and (5) asset-based approaches in a health and well-being context.

### **Discussion**

Summarising evidence to such a high-level means that our conclusions are indicative of the key lessons learned from the existing research. The purpose of this process was to identify “promising” approaches, the methods described in this work provide a picture of the evidence available but might be subject to change in a full and comprehensive systematic review (which would have been both more time consuming to complete and much more costly). This work has shown that there are a variety of person- and community-centred approaches for health and wellbeing that show promise across a range of outcomes. The evidence is less clear for resource use changes and wider social impacts on account of these outcomes being less frequently reported than health and well-being, behavioural and biomedical outcomes.

The vast majority of the evidence regarding person- and community-centred approaches for health and wellbeing is currently disease-centred and lies within health care specialties and this may be due to the need to conduct RCTs where feasible to push the evidence base forward. Such studies may be methodologically or logistically difficult to conduct in community-settings. This shows that it was appropriate for the decision-making process to also consult expert opinion and the existing ‘grey’ literature as well as the results of this scoping review.

In addition, person- and community-centred approaches are themselves difficult to define and measure. It is a potentially vast area of research and so within the timeframe, scope and resource limits of the programme it was not possible to conduct a comprehensive systematic review at individual study-level. In keeping our inclusion criteria broad we have ensured we would not miss a potentially ‘promising’ approach, but this came at the cost of including and compiling information about a lot of studies that were ultimately not relevant for our purposes. Other methodological difficulties were faced in terms of compiling information where the consistency of reporting varied across studies, and categorising data into “small”, “medium” or “large” effects. Nevertheless, in terms of shining a light on what is known about the relative effectiveness of person- and community-centred approaches for health and wellbeing, this overview has achieved that purpose and contributed to the decision-making process.

## Introduction

The Five Year Forward View [1] makes a specific commitment for the NHS in England to do more to support people with long term conditions to manage their own health and care. With help of voluntary sector partners, it signals the need for significant investment in evidence-based approaches. To support delivery of this commitment, NHS England developed Realising the Value, a new programme of work to develop the field of person and community-centred approaches for health and wellbeing, by building the evidence base and developing tools, resources and networks to support the spread and increase the impact of key approaches. This programme of work is being undertaken by the *Realising the Value* consortium, involving The Health Foundation, Nesta, the Behavioural Insights Team, the Institute of Health & Society at Newcastle University and Voluntary Voices, which itself comprises the organisations National Voices, Regional Voices, the National Association for Voluntary and Community Action (NAVCA) and Volunteering Matters (formerly known as “Community Service Volunteers”).

Since a key part of the work requires informed decisions to be made about the efficiency and value for money of introducing and strengthening person- and community-centred approaches, the health economics component of the *Realising the Value* programme aims to develop:

- an economic evaluation in the form of a cost consequence analysis, to assess the impact of key evidence-based approaches to person- and community-centred health and wellbeing
- tools to support implementation via the commissioning process.

A cost-consequence analysis, like all forms of economic evaluations involves the comparative analysis of alternative courses of action (in evaluation terms normally defined as the ‘interventions’) in term of both their use of resources (i.e. costs) and the benefits they provide. Costs and benefits (consequences) are, in the case of a cost-consequence analysis presented in a disaggregated manner. Critical to the process of an economic evaluation or indeed any comparative evaluation, is the choice of the interventions to be compared. The definition of person- and community-centred approaches and the range of interventions that could be potentially captured and evaluated under this umbrella term is vast. Therefore, in order to allow a useful contribution to the wider programme, a pragmatic approach to shortlisting a small number of appropriate interventions for potential evaluation, was first necessary. It should be noted that all forms of economic evaluation involve the comparative analysis of comparative courses of action (in evaluation terms normally defined as the ‘interventions’). The terminology used in this report therefore in places differs from the main programme report, which describes a number of person and community-centred ‘approaches’ and the five programme ‘focus areas’.

To facilitate this shortlisting, a scoping review was required to ascertain, from the existing literature from across the theme of person- and community-centred

approaches for health and wellbeing, particular approaches that had good quality effectiveness data. In doing so, this scoping review would also help inform the choice of local partner sites where empirical aspects (including the cost-consequence analysis and toolkit development) of the *Realising the Value* programme would be conducted. Please see [www.realisingthevalue.org.uk](http://www.realisingthevalue.org.uk) for more detail about the scope of the wider programme.

The aim of this paper is to provide an overview of this scoping review, its methods, and results, which were used to inform those making decisions about the most promising person- and community-centred approaches for health and wellbeing to consider for further work within the *Realising the Value* programme. The economic analyses which these data will inform are not presented here.

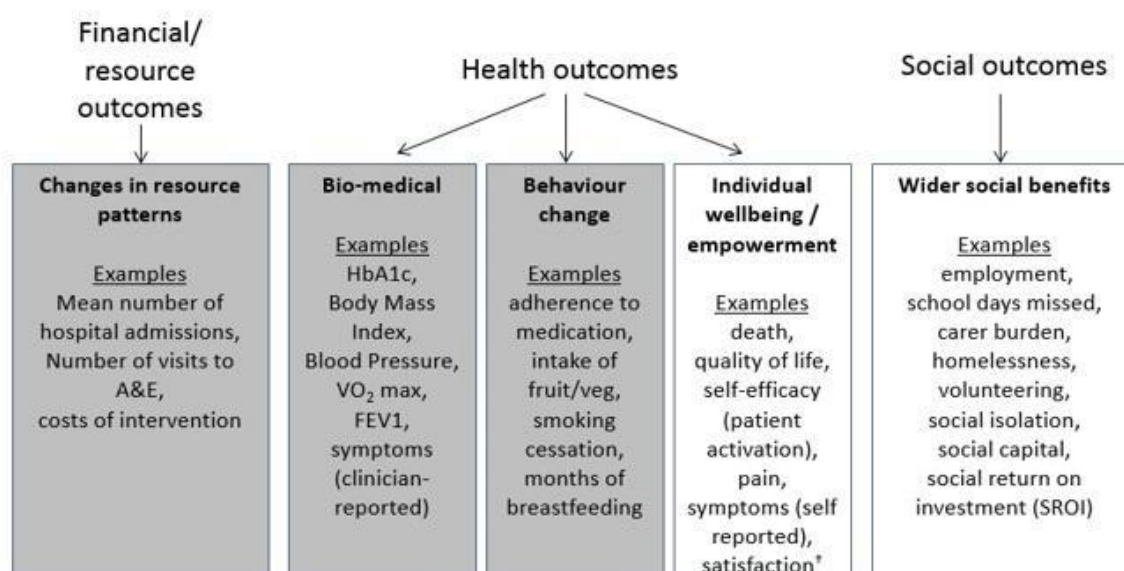
## Methods

A scoping review approach was taken to identifying and summarising the existing evidence. We have defined this approach as a mean to consider the breadth of relevant evidence but focused on existing evidence summaries. Such an approach serves to illuminate the existing evidence within a timely and low research cost manner.

A summary of the methods used can be found in Figure 1. The text describes the process in more detail.

## Figure 1: Summary of Methods

- Sources identified from Realising the Value consortium members, supplementary searches. Reference lists documented and duplicates removed.
- Initial exclusion criteria applied. Study protocols, studies with no quantitative data (e.g. qualitative reviews), studies where the population was a specific population subgroup (except in terms of age), studies that did not contain an intervention (e.g. review of outcome measures) and studies where no evidence of effectiveness was found for any outcome are removed.
- Shortlisting meeting presents information on intervention areas, specialty and range of outcomes. Criteria for decision-making is discussed.
- Further meeting where criteria for decision-making are refined as are the inclusion criteria, based on outcome as follows:



- Studies reporting significant change in one outcome that falls within either of the white boxes meet inclusion criteria, except in the case of satisfaction (see below).
- Studies reporting significant change in an outcome that falls within any of the grey boxes, and satisfaction (a person-centred outcome but one that does not necessarily imply effectiveness) outcomes, must also show significant change in another outcome from any of the other boxes, to meet the inclusion criteria.
- Data are extracted, “small”, “medium” and “large” effect sizes calculated, presented in Tables and used to aid the decision.

### Capturing the initial evidence base

There were three stages to the scoping review of the evidence base:

- an initial look at the breadth of the evidence across the broad area of “person- and community-centred approaches for health and wellbeing”;
- a ‘shortlisting’ consensus process in order to prioritise areas for further work (e.g. determining the criteria that constitute a “promising”



- person- and community-centred approach to health and wellbeing and hence what data should be sought from the relevant literature); and
- (iii) a more detailed review of the evidence within these prioritised areas, to select “promising” interventions for further research. It is these results that are summarized in the next section.

For stage (i) members of each organisation in the *Realising the Value* consortium were asked to provide relevant possible sources of information to help identify “promising” person- and community-centred approaches for health and wellbeing. No specific limits were initially placed on the kinds of information sources that might be useful. So a range of different types of information sources were provided in response to this request including reviews, reviews of reviews, and policy documents. A list of the sources was then compiled, the reference list for each source was documented and then (comparing across all sources) duplicate publications in the reference lists were removed. The list of original sources that were provided is given in Appendix 1 to this report.

A mixture of reviews, comparative studies and non-comparative studies were expected to be identified from the reference list of all the provided sources of information. Furthermore, as person-and community-centred approaches for health and wellbeing is a broad concept, we also expected the number of relevant studies to be very large. Since our aim was to facilitate the choice of a selection of interventions underpinned by a solid evidence base, systematic reviews, the highest level of evidence available, were prioritised. A systematic review “attempts to identify, appraise and synthesize all the empirical evidence that meets pre-specified eligibility criteria to answer a given research question”.[2] They are widely accepted as providing the most robust evidence on a given topic because they compile information from across individual comparative studies on the same subject[3] and researchers “conducting systematic reviews use explicit methods aimed at minimizing bias, in order to produce more reliable findings that can be used to inform decision making”.[2] However, due to our UK focus and potential issues with generalisability, we also sought to identify comparative (randomised and non-randomised) evaluations of UK-based person- and community-centred approaches for health and wellbeing; accepting that these may provide more directly applicable data to inform decision-making in England. Thus, the method adopted sought to be both comprehensive of the relevant evidence base worldwide whilst at the same time drawing out directly applicable UK data.

At the initial stage, we extracted information on the intervention being considered and the specialty/clinical area within which the intervention took place, from the abstracts available for each paper. For this we used PubMed or another similar source .g. Research Gate if a PubMed link was not found. Additional searches were conducted in tandem with this process, using search terms that had been used to inform several of the previous reference source documents (as listed in Appendix 1) conducted by National Voices and the Health Foundation (Debra de Silva, personal communication, 4<sup>th</sup> June 2015) and by request from the consortium (Johanna Ejbye, personal communication,

12<sup>th</sup> June 2015) to identify more recent studies on the subject. The search terms used in these supplementary searches are provided in Appendix 2.

We excluded papers that reported only qualitative data, protocol information or where no intervention was being administered, as well as those where the abstract stated that no conclusive evidence was found to indicate effectiveness for any outcome. We also excluded studies that solely considered a specific subgroup of the population (except for age to accommodate both paediatric and adult studies). This meant, for example, a study with a population of older adults was permitted, but a study including just older women was not. While this is an atypical exclusion criterion for a systematic review, where the focus is on precision of effect and minimising bias, it allowed this work to focus on studies that could be shown to contain “promising” interventions, as required by the programme remit.

### **Criteria for shortlisting**

The selection of studies relevant to this review was focussed using a multi-criteria decision analysis process.[4, 5] This process involved a workshop held in London on the 15<sup>th</sup> of July 2015, as part of a wider meeting whereby stakeholders with an interest in person- and community-centred approaches for health and wellbeing were invited to attend and hear more about the *Realising the Value* programme. The results of the initial stage of the review (as described above with the exclusion of protocols, studies on specific population subgroups, studies with either no intervention, comparative data or effectiveness shown in any outcome) were presented to give participants an idea of the breadth of the subject matter. Participants were then asked to discuss their preferred criteria for prioritising the approaches that the rest of the programme would focus on. The feedback from these discussions was compiled and a range of criteria were identified, from which to build the discussion about how to select the most ‘promising’ interventions. These were:

- Striking a balance between condition specific vs non-condition specific interventions
- Quality of evidence base
- Applicability (to an English health and social sector context)
- Scalability
- Transferability
- Presence of cross-agency input, including the community/third sector
- Magnitude of impact
- Potential to reduce inequalities

These criteria were then circulated at a further meeting of the Realising the Value Consortium, Advisory Group and additional practitioner and subject matter experts, which was held in London on the 22<sup>nd</sup> of July 2015. This latter meeting sought to finalise the specific criteria by which the interventions identified from the review would be judged for final inclusion in the shortlist.

Following the presentation of the results of discussions, the criteria for inclusion of studies were further discussed and decisions about whether particular criteria

should be “weighted” in terms of relative importance or not, took place. While the previous range of criteria were appropriate for making decisions about specific interventions, there was also a need to refine the evidence base to ensure that the shortlist of interventions to which these criteria would be applied, was manageable in terms of size. To do this, additional specific criteria relating to the outcomes reported in the reviews were finalised in email discussions following the meeting and were then used to finalise the shortlist of potentially relevant interventions. The outcome criteria used are shown in Figure 1 above.

### *Finalising the interventions*

Data were extracted from all studies meeting the criteria for all outcomes of statistical significance with regard to either improvement or deterioration (i.e. having a p-value of  $<0.05$  or explicitly stated as being statistically significance where no p-value was reported). For clarity, a p-value of  $<0.05$  indicates strong evidence against the null hypothesis i.e. the hypothesis that there will be no difference found between the intervention and comparator groups in terms of the outcome being observed. Where meta-analyses had been performed, standardised effect sizes/weighted mean differences were reported and categorised into a small, medium or large effect size based on the method of Cohen’s  $d$ , where  $d$  is the standardised difference between means.[6] For reported odds ratios, the formula by Chinn was used, whereby the log odds ratio is divided by 1.81.[7] For relative risk (RR) estimates, we referred to the rule of thumb noted by Ferguson, whereby small, medium and large effects were RR values of greater than 2, 3 and 4 respectively. [8] For dichotomous data, we used a modified interpretation of that devised by Grimshaw et al, whereby ‘small’ was used to describe effect sizes of  $\leq 5\%$ , ‘modest’ referred to effect sizes of  $>5\%$  but  $\leq 10\%$ , ‘moderate’ referred to describe effect sizes of  $>10\%$  but  $\leq 20\%$  and ‘large’ referred to effect sizes of  $>20\%$ .[9] As we required three categories, in our modified version small referred to effect sizes of  $\leq 7.5$ , medium referred to effect sizes of  $>7.5\%$  but  $\leq 20\%$  and ‘large’ referred to effect sizes of  $>20\%$ . Alternative cut-offs could be used, for example expanding the “small” category to define all effect sizes of  $\leq 10\%$ . While this would have given more equally spaced categories ( $\leq 10\%$ ,  $>10\%$  but  $\leq 20\%$ ,  $>20\%$ ) it might be argued that by expanding the “small” effect size category to  $\leq 10\%$  it may have been more difficult for an intervention to achieve a the “medium” or “large” effect size required to be defined as “promising” and taken forward to the shortlisting meeting.

In addition, we anticipated that because many reviews were summarising data across complex interventions, pooled analysis would be unlikely and many narrative syntheses of results were expected. This poses problems as the evidence base is likely to show mixed results for these studies overall, but for particular outcomes of interest, the evidence may have indicated positive results. We included reviews if, for any outcome of relevance, two-thirds of studies included in the review reporting it showed significant change for this outcome, as opposed to no significant change.

Following this, we also needed to determine a proxy measure of 'effect size' from these data. An arbitrary method used the number of studies reporting a significant change, divided by the total number of studies included in the review (i.e. not just the total number of studies reporting that outcome). While this is by no means perfect, it was hoped that this would provide a conservative estimate of the effect of the intervention for that outcome, rather than over-estimating its effect. For example, consider that there are 7 studies in a review that showed significant change in an outcome, of 10 included studies that reported that outcome. This means that more than two thirds of studies reporting that outcome showed significant change. However, let's say there were a total of 40 studies in that review, we would then use 7/40 to calculate the effect size of 17.5% which is 'medium' (according to our modified interpretation of the criteria by Grimshaw et al) rather than using 7/10 – an effect size of 70% which would be considered 'large'.

Interventions for which there was a large effect, and interventions for which a moderate effect was shown in at least one outcome, were sent to the Consortium, the programme Advisory Group which includes relevant academics, representatives from the wider research community, leading practitioners and decision-makers in the field of person- and community-centred health and wellbeing and subject matter experts, for discussion and finalisation of the chosen intervention areas at a third meeting held on 14<sup>th</sup> August 2015 in London. The selection of the final five focus areas was taken within the wider philosophy surrounding the programme; 'co-production' and using 'asset-based' approaches. To this end, the evidence base was discussed alongside the additional 'grey' literature (submitted via an open consultation earlier in the year which received just under 100 responses – available on request from Nesta) and with input from experts working within the field of person- and community-centred health and wellbeing. Consensus was reached and the selected five focus areas were chosen to be (1) self-management interventions with an education component, (2) peer support, (3) health coaching, (4) group activities to promote health and well-being (5) asset-based approaches in a health and well-being context.

Overall, these five focus areas cover a range of practices which all demonstrate a commitment to the principles of person- and community-centred health and wellbeing. The evidence of impact is more well-developed for some of the five focus areas than others. With regard specifically to both group activity and asset-based approaches, there is a lack of relevant systematic review level evidence in these two emerging areas of practice. These two approaches were therefore chosen based on the criteria and other evidence (e.g. grey literature) and the expertise of the consortium/advisory group and other stakeholders involved in the process. None of the included systematic reviews identified from this scoping review of person- and community-centred approaches for health and wellbeing were deemed to be relevant examples of either group activity or asset-based approaches.

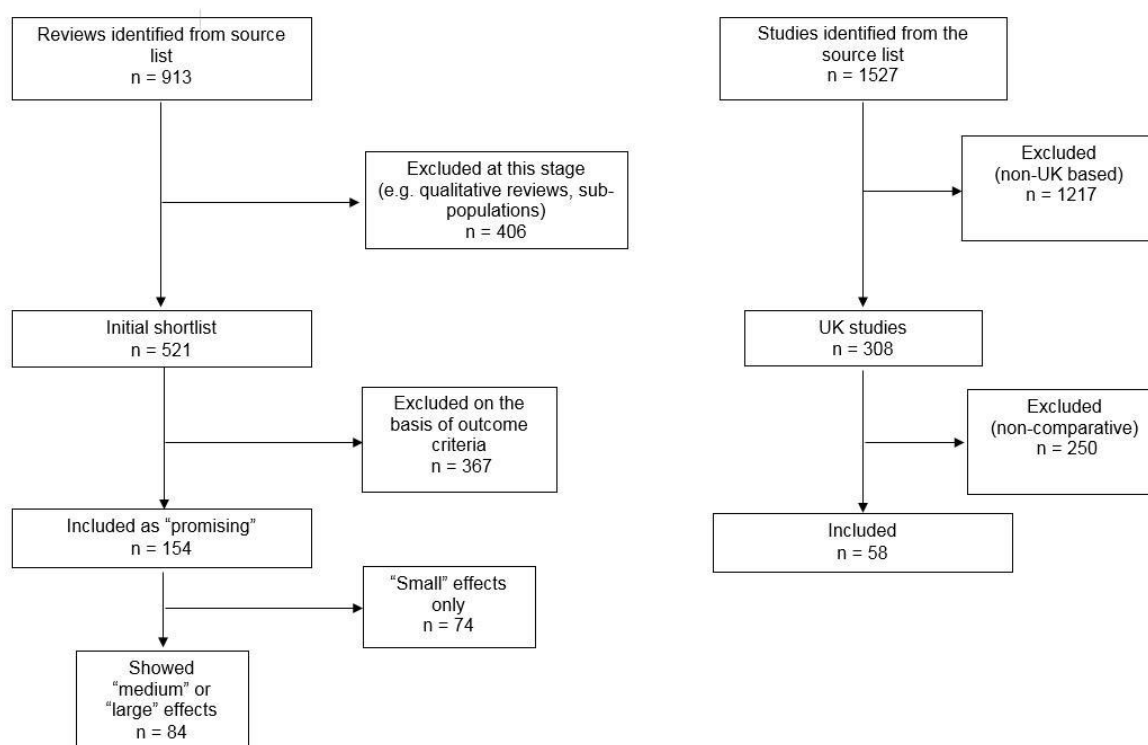
## Results

### Results from the initial work

A list of sources initially provided by the consortium can be found in Appendix 1 to this report. The reference lists of these sources were compiled and following the removal of duplicates a total of 913 systematic reviews had been identified, of which 868 came from our original source list and 45 came from supplementary searches. The 45 results from the supplementary searches represent 20.8% (n=216) of the reviews originally deemed 'potentially relevant' from a total of 2294 search hits. Applying our exclusion criteria led to 521 systematic reviews being taken forward to the shortlisting process stage.

In addition, a total of 308 studies from the UK were identified, of which 58 were included as comparative (either randomised controlled trials or non-randomised comparative) studies of effectiveness. The remainder were excluded for being either news articles/editorials, qualitative or grey literature, assessing ineffective interventions or not being an intervention study at all. A figure summarising this review process can be found below in Figure 2.

**Figure 2: The Review process**



To enable us to present an overview of the intervention types included in the evidence base, for the meeting on the 15<sup>th</sup> July, a method of categorisation was required and so we chose to modify the framework adopted by Foot et al [10] that set out key forms of individual involvement including:

- engaging people in keeping healthy
- shared decision-making
- supported self-management
- having a personal health or social care budget
- involving families and carers

Based on the information available in the abstracts of the systematic reviews, it was not always possible to determine whether interventions involved families and carers or extended to having a personal health or social care budget. However we were able to characterise the interventions using the first three categories in this framework, by intervention type and area of application as set out in Table 1 below and presented these to stakeholders along with a summary of the types of outcomes measures that had been found, namely:

- Disease specific scales
- Self-reported generic physical health, mental health, well-being, quality of life, activation scales
- Health indicators /health events
- Behaviour change measures- e.g. time in physical activity, smoking rates, attendance, adherence
- Use of formal care resources
- Patient satisfaction
- Self-efficacy scales
- Cost effectiveness

**Table 1**

<b><i>Engaging people in keeping healthy/supported self-management</i></b>	
<b>Intervention</b>	<b>Area ( number of studies)</b>
Community led interventions	CVD (1), Housing (1), Maternal/Neonatal care (1), Physical Activity (1), Public Health (1), Smoking Cessation (2)
Community health workers	TB (1)
Education	Arthritis (8), Cancer (1), CHD (1), Chronic Conditions (1), Diabetes (12), Kidney Disease (2), Low Back Pain (4), Mental Health (2), Orthopaedics (2), Screening (2),

	Smoking Cessation (2), NHS staff (1), Stroke (1)
Education and IT based peer support	Chronic conditions (1)
Education, self-management, behavioural interventions	Public Health (2), Sexual Health (2), Smoking Cessation (3)
School/work based interventions	Alcohol Misuse (1), chronic conditions (1), CVD (1), Mental Health (1), obesity/weight management (9), Physical Activity (2), Public Health (9), Smoking Cessation (1)
Behavioural interventions/behaviour change (including IT-based interventions)	CVD (3), General (1), Housing (1), Pain/Disability (1), Physical Activity (9), Public Health (6), Sexual Health (3)
Community engagement in schools	Obesity/Weight Management (2)
Educational & Behavioural Interventions	Asthma (4), Diabetes (5), Epilepsy/Neurological Disorders (1),
Environmental interventions/policies	Public Health (2), Smoking Cessation (2)
Mass media interventions	Cancer (1), General (2), Housing (1), Physical Activity (1), Screening (1), Smoking Cessation (1)
Self-management behavioural interventions	Housing (6), Hypertension (1), Kidney Disease (1), Learning Disabilities (2), Low Back Pain (3), Maternal/Neonatal Care (1), Mental Health (1), obesity/weight management (9), Physical Activity (8), Public Health (3), Smoking Cessation (1)
Smoking Cessation Interventions	Mental Health (1), Smoking Cessation (4)
Suicide Prevention Programmes	Mental Health (1)
Volunteering	Diabetes (1), General (1)
<b><i>Shared decision-making and involving families &amp; carers</i></b>	
<b>Intervention</b>	<b>Area ( number of studies)</b>

Care Management	Smoking Cessation (3)
Communication	Advanced/Serious Illness (1), Cancer (5), Childhood Vaccinations (1), General (4), Geriatrics/Paediatrics (1), Screening (1), Stroke (7)
Decision aids/support tools	Cancer (1), General (3), Genetics (2), Maternal/Neonatal Care (1), Musculoskeletal Health (1), Surgery (1), Screening (3)
Shared Decision Making (General)	Advanced/Serious Illness (1), Breastfeeding (1), Emergency Medicine (1), Gynaecology (1), HIV (1), NHS Staff (1)
Involving Families and Carers	Advanced/Serious Illness (1), Alcohol Misuse (1), Dementia (1), Diabetes (1), Geriatrics/Paediatrics (2), Obesity/Weight Management (3), Physical Activity (1),
<b>Supporting Self-Management</b>	
<b>Intervention</b>	<b>Area ( number of studies)</b>
Rehabilitation/Early Discharge support interventions	CHD (1), Low back pain (1), Pain/Disability (1), Stroke (1)
Care management	Advanced/Serious Illness (1), Breastfeeding (2), Cardiac Rehabilitation (1), CVD (1), Dementia (1), Diabetes (3), Epilepsy/Neuro (1), General (4), Geriatrics/Paediatrics (1), Hypertension (1), Mental Health (1), Palliative Care (1), Physical Activity (1), Public Health (2), Screening (2), Sexual Health (4)
Community-based interventions	COPD (1), General (2), Geriatrics/Paediatrics (2)
Education/Coaching interventions	Asthma (8), CHD (1), COPD (4), Epilepsy/Neuro (4), General (2), MSK (2), Obesity/Weight Management (4),
Fall Prevention Programmes	Geriatrics/Paediatrics (3)
Group Therapy	Dementia (1)
Health Literacy	COPD (4), General (4), Geriatrics/Paediatrics (3), MSK (1)



Information	Arthritis (1), Asthma (3), Cancer (4), General (2), Maternal/Neonatal Care (1), Mental Health (1), Rehabilitation (1), Physical Activity (2), Smoking Cessation (1), NHS Staff (1), Stroke (1)
IT-based interventions	Asthma (1), Anxiety/Depression (2), Cancer (1), Chronic Conditions (5), COPD (1), Diabetes (7), General (13), Geriatrics/Paediatrics (2), Mental Health (1), Obesity/Weight Management (4), Public Health (3), Sexual Health (1), Smoking Cessation (1), NHS Staff (1)
Lay workers	Maternal/Neonatal Care (2)
Mobile phone interventions	General (1), Chronic Conditions (2), Diabetes (1)
Occupational Therapy	Dementia (1), Occupational Therapy (1), Stroke (2)
Patient adherence/prompts	Blood Donation (1), Childhood vaccinations (1), Chronic Conditions (2), COPD (1), CVD (1), Diabetes (2), Kidney Disease (1), Mental Health (5), Public Health (1) Screening (7), Sexual Health (1)
Patient-centred approaches	Chronic Conditions (1)
Self-management/monitoring/efficacy	Anticoagulation (6), Anxiety/Depression (5), ENT (1), Cancer (3), Cardiac Rehab (1), Chronic Conditions (4), COPD (1), CVD (4), Diabetes (15), General (3), Heart Failure (2), Hypertension (2), IBS (1), Mental Health (6), obesity/weight management (3), Pain/Disability (1), Physical disability (1), Smoking Cessation (3), Stroke (2)
Peer support	Breastfeeding (2), Cancer (2), Cardiac Rehab (1), CHD (1), COPD (2), Maternal/Neonatal Care (1), Mental Health (8), Pain/Disability (1), Public Health (2)
Psychological interventions	Asthma (3), Cancer (3), Diabetes (2), Epilepsy/Neuro (2), Gynaecology (1), IBS (1), Low Back Pain (1), MSK (3), Obesity/Weight Management (2), Oral Health (1), Smoking Cessation (3)
Telemedicine	Asthma (2), CHD (1), Chronic Conditions (3), COPD (1), CVD (1), Diabetes (2), General (3), Geriatrics/Paediatrics (1), Heart Failure (2),
Telephone based interventions	Maternal/Neonatal Care (1), Obesity/Weight Management (1), Public Health (1), Smoking Cessation (2)

By then applying the rules for review outcomes criteria (see Figure 1), this led to 154 reviews meeting our inclusion criteria. A list of the included studies is found below in Appendix 3.

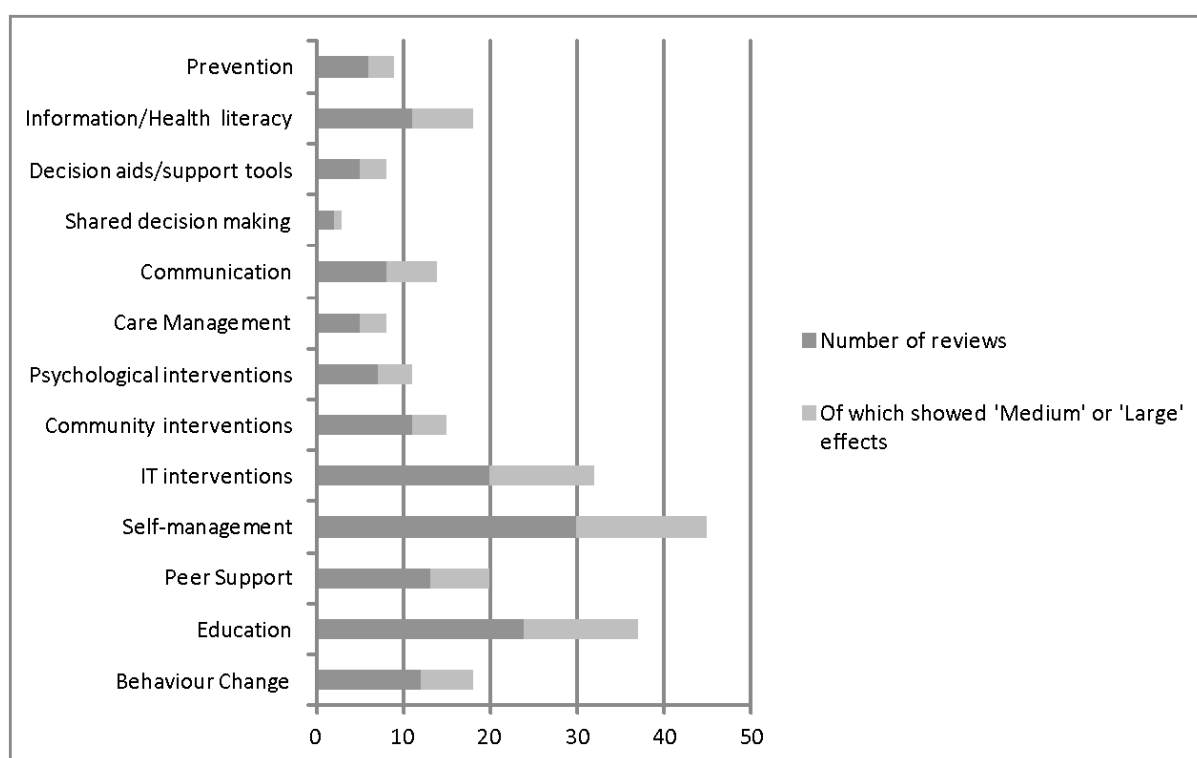
From within this list, a total of 84 studies (as shown in Table 2 below) contained at least one outcome of either "moderate/medium" or "large" effect size, as defined by our methods.

Figure 3 shows the results of the review for different kinds of person- and community-centred approaches for health and wellbeing. Almost one-third of the included reviews related to either self-management (30 reviews; 19.5%) or education (24 reviews; 15.6%). A further 19 reviews (12.3%) were psychological or behaviour change interventions. Thirteen reviews (8.4%) described peer support interventions and 11 (7.1%) were community based studies, usually involving nutrition and/or physical activity promotions in schools and/or workplaces. Twenty reviews (13.0%) described these interventions with one or more elements either enhanced or replaced by technology (e.g. internet self-management or telephone-based support).

Aside from these health improvement interventions, five reviews (3.2%) described care management (i.e. organisational interventions) approaches to improve person- and community-centred health and wellbeing. The remaining 32 reviews contained interventions to improve information to and from the patient, including communication interventions for patient consultations (8 reviews; 5.2%), shared decision-making, decision aids and support (7 reviews; 4.5%), improving information for patients and health literacy (11 reviews; 7.1%) and prevention campaigns to share health messages with target audiences (6 reviews; 3.9%).

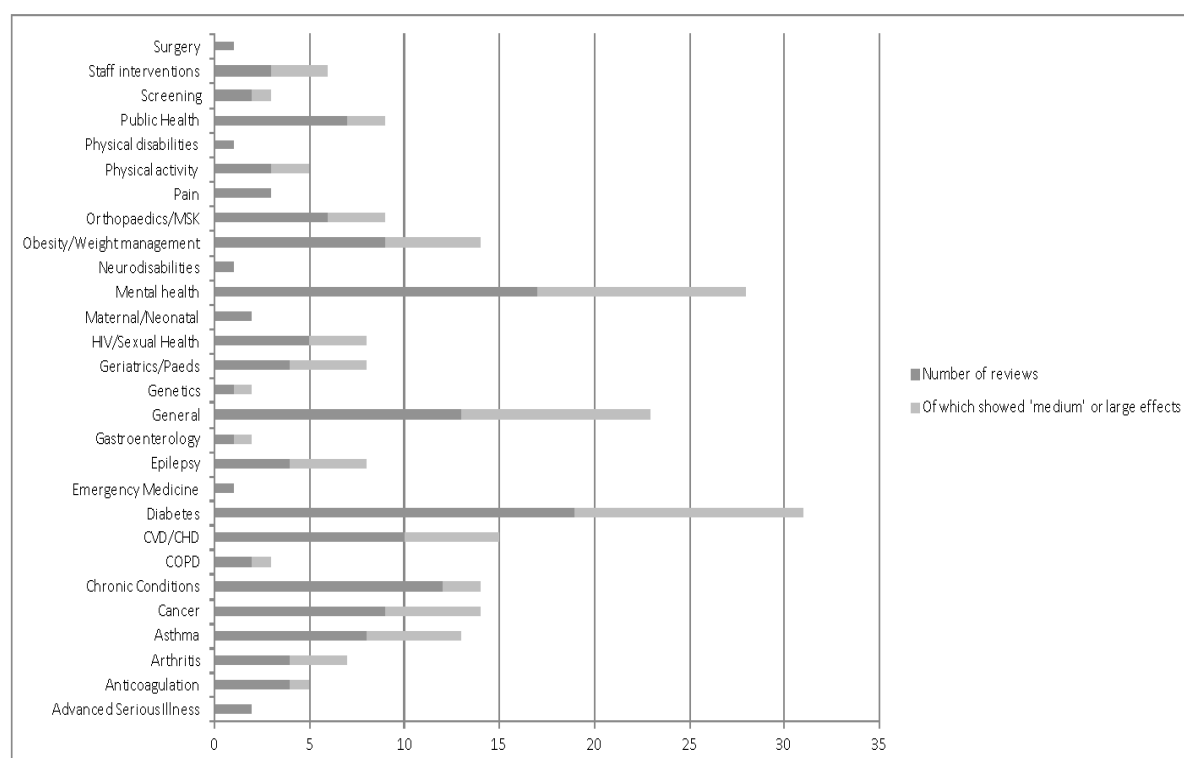
For the reviews, the proportion of the evidence showing 'medium' or 'large' effects ranged from 36.4% for community interventions, to 75% for communication interventions. On average, around 55% of reviews indicated 'medium' or 'large' effects of relevance for included interventions.

**Figure 3: Included reviews by intervention area**



Considering speciality-specific areas of research, as Figure 4 shows, diabetes interventions were most commonly found (19 reviews; 12.3% of all included reviews), followed by mental health (17 reviews; 11.0%), general/cross-specialty interventions (13 reviews; 8.4%), mixed chronic diseases (12 reviews; 7.8%) and cardiovascular/coronary heart disease (10 reviews, 6.5%). These five areas comprised almost half (71 of the 154 included reviews; 46.1%). Other specialities with evidence from more than ten reviews were asthma (8 reviews; 5.2%), cancer (9 reviews; 5.8%), obesity/weight management (9 reviews; 5.8%), orthopaedics/musculoskeletal illnesses (6 reviews; 3.9%) and public health (7 reviews; 4.5%). All other specialties contributed  $\leq 5$  reviews, including advanced/serious illness (2 reviews), anticoagulation (4), arthritis (4), COPD (2), emergency medicine (1), epilepsy (4), gastroenterology (1), genetics (1), geriatrics/paediatrics (4), HIV/sexual health (5), maternal/neonatal health (2), neurodisabilities (1), pain (3), physical activity (3), physical disabilities (1), screening (2), staff interventions (3) and surgery (1).

**Figure 4: Included reviews by specialty**



In terms of outcomes, 'medium' and 'large' effects were reported for 306 individual outcomes across the 84 included reviews that had identified 'medium' and 'large' effects of person- and community-centred approaches for health and wellbeing, as defined by our methods. Of these 306 outcomes, 136 (44.4%) were health and well-being outcomes, 81 outcomes (26.5%) were reported for measures of behaviour change, 36 (11.8%) were for biomedical outcomes, 27 (8.8%) were for wider social outcomes and 26 (8.5%) related to resource use. It should be noted that the most frequently reported outcomes will be strongly influenced by the specialties most commonly identified in the inclusion process. So, a large number of diabetes related outcomes reflects the fact that diabetes was the specialty with the largest number of included reviews.

Among the health and well-being outcomes reported, the most common were self-efficacy (20 times), mental well-being outcomes, for example depression/anxiety (18 times), global measures of health/quality of life (10 times), disease specific measures, for example pain, functioning or symptom changes (31 times), knowledge outcomes (30 times) and satisfaction (8 times).

Common reported behavioural outcomes related to the focus of the intervention. For example, abstinence behaviours or safe sex precautions were reported in sexual health reviews (7 times), dietary behaviours (6 times) in nutrition/weight loss reviews including those for people with diabetes. Physical activity outcomes

were reported 7 times, medication adherence/compliance with treatment 10 times. Occasionally, 'health behaviours' were grouped together and no further details were given (6 times). Various coping, self-care and symptom control outcomes were reported (15 times). In addition, some studies focusing on communication interventions for improving person- and community-centred health and wellbeing reported changes in clinicians' behaviours during the consultation process (12 times).

As with behavioural outcomes, biomedical outcomes were related to the focus of the intervention and the most commonly reported ones included HbA1c (6 times), and blood glucose (3 times). More generally, frequently reported biomedical outcomes were change in bodyweight/BMI (6 times), blood pressure (4 times) and cholesterol (3 outcomes).

Commonly reported resource use outcomes were admissions/hospitalisations (4 times), length of stay (2 times), visits to emergency departments (4 times), provider time spent (4 times), GP/clinic referrals (4 times) and uptake of tests (2 times).

For wider social impacts, work/school absences were commonly reported (4 times), as were family impacts (10 times), teacher-related outcomes (7 times) and social support outcomes (2 times).

**Table 2: Included studies with "medium" and "large" outcome effects.**

<b>Study</b>	<b>Intervention</b>	<b>Area</b>	<b>Outcomes (Effect Size)</b>
Ahmad 2011	Education	Asthma	hospital admissions (L), school days missed (L)
Ammerwerth 2012	Patient portals	General	Medication adjustments (L), messaging to/from patient (L), self-efficacy (L), telephone contacts to Primary care (L)
Blank 2012	Outreach	Sexual Health	use of emergency contraception (M), time to use of emergency contraception (M)
Boren 2009	Self-management education	Diabetes	HbA1c (M)
Bower 2001	Self-management	Anxiety /Depression	Anxiety (M), general health (L), symptoms (L)

Chinman 2014	Peer interventions	Mental health	Attendance/Participation (M), Recovery (M), Self-efficacy (M), therapeutic relationship with providers (M)
Christensen 2007	Self-management	Haematology	Increased time within INR range (L)
Cooper 2012	Care management	Geriatrics/paediatrics	quality of life (L)
Dale 2012	Peer support interventions for diabetes	Diabetes	Exercise (M), Self-efficacy (M)
de Freitas 2013	Counselling and other self-management based therapies	Musculoskeletal	Functional impairment (M), Pain (L), perceived symptom improvement (M)
de Jongh 2012	Mobile phone self-management	Chronic conditions	Peak flow (L), self-efficacy (L), social support (L)
Deakin 2005	Group based training	Diabetes	bodyweight (M), knowledge (L), fasting blood glucose (L), glycated haemoglobin (L), systolic BP (L)
Dissanayake 2010	Patient information	Arthritis	attention control (M), coping (M), depression (M), disability (M), pain (M), self-efficacy (M)
Dolder 2003	Psychological Interventions	Mental health	fear (M), hospitalisations (M), insight/attitude (L), knowledge (M), adherence (M), psychopathology (L), relapse (M), social functioning (M)
Dorn 2010	Self-management	Irritable Bowel Syndrome	cognitive scale (M), consultations (M), disease specific quality of life (M), global improvement (L), knowledge, symptoms (L)

Dwamena 2012	Care management	General	consultation process (M)
Edwards 2008	Decision aids	Genetics	knowledge (L),
Edwards 2013	Decision aids	Screening	odds of making an informed choice (M)
El-Gayar 2013	IT	Diabetes	behaviour (M), HbA1c (L)
Enwald 2010	Behaviour change	Obesity /weight management	diet (L), physical activity (M), stage of behaviour change (M), weight loss (M)
Facchiano 2011	Self- management education	COPD/R espiratory	admissions (M), disability (M), emergency department visits (M), fatigue (M), pain (M), self-efficacy (M), symptom measures (M)
Fan 2009	Self- management education	Diabetes	knowledge (L), metabolic control (M)
Fernandez 2006	Education	Mental Health	knowledge (L)
Fitzpatrick 2013	Self- management education	Diabetes	patient activation (M), symptoms of hypoglycaemia (M), use of resources (M)
Forster 2012	Patient information	Stroke	carer knowledge (M)
Fox 2009	Education	General	symptoms (M), use of preventative behaviours (M)

Gibson 2004	Patient Information	Asthma	knowledge (M)
Glynn 2010	Care management	Hypertension	blood pressure (L)
Goedendorp 2009	Psychosocial interventions	Cancer	fatigue (L)
Goode 2012	Telephone interventions	Obesity /weight management	initiating behaviour change (L), physical activity (L)
Gremeaux 2010	Education/IT	General	depression/distress (M), HbA1c (M), knowledge (M), symptoms (M)
Griffiths 2006	IT/Psychological interventions	Anxiety /Depression	anxiety (M), depression (M),
Guevara 2003	Self-management education	Asthma	lung function (M)
Guse 2012	IT	Sexual health	abstinence (L), changes to social media security (M), condom use (L), knowledge/attitudes (L), perceived susceptibility (M), self-efficacy (L), social media references to sex (M)
Gysels 2004	Communication	Cancer	appropriate responses (M), asking open questions (L), control (M), expressions of empathy (L), history taking (M), perceived importance of listening/trust (M), perceived importance of communicating with patient (L), psychological assessment (M), psychological probing (L), self-efficacy/confidence (L), self-rated clinician improvement (M)



Hamel 2013	IT	Obesity /weight management	energy intake (M), knowledge (L)
Harrington 2004.	Patient information	General	Attendance (M), expressed affect (M), patient participation (M), patients asking for clarification (L)
Harris 2005	Education	Chronic conditions	adherence (L), BMI (M), HbA1c (M)
Heinrich 2010	Self-management	Diabetes	knowledge (L), quality of life (L)
Hieftje 2013	Behaviour change	Public Health	diet (M), physical activity (M), self-care behaviour (L)
Hirai 2006	Self-management	Anxiety /Depression	symptom management (M)
Hutchinson 2012	Self-management	Obesity /weight management	cholesterol (L), fitness (L), physical activity (L)
Johnson 2003	Patient information	General	knowledge (L), visits to the ER (L)
Johnson 2011	Behaviour change	Sexual Health	sexual health behaviours (L)
Joosten 2008	Shared decision making	Staff	adherence (M), knowledge (M), mental health (M), satisfaction (M)
Kastner 2008	Decision aids	Musculo skeletal	investigations for disease (L)
Li 2010	Prevention	Diabetes	blood glucose monitoring (L), diet (L), knowledge (L), using lotion (L), wearing appropriate shoes/socks (L)

Lindsay 2010	Self-management education	Epilepsy	emergency department visits (L), knowledge (L), parents' behaviour during seizure (L), parents knowledge (L), participation (L), satisfaction (L), self-care (L), social skills (L), teacher's behaviour (L)
Loveman 2003	Education	Diabetes	HbA1c (L), knowledge (L)
McWhirter 2013	Prevention	Cancer	intentions (L), knowledge/understanding (L), self-efficacy (M), skin melanin content (M), sun tanning behaviours (L)
Montgomery 2006	Behaviour change	Geriatrics/paediatrics	behaviour intensity scores (L), behaviour problem scores (L), behaviour as rated by fathers (L), behaviour as rated by mothers (L), sleep scores (L), teacher's behavioural rating score (L)
Nguyen 2004	IT	General	anxiety/stress (M), health distress (M)
Niedermann 2004	Education	Arthritis	compliance (L), knowledge (L), self-efficacy (M),
Osilla 2012	Self-management	Public Health	absenteeism (M), mental health (M), smoking cessation (M)
Parry 2010	Peer support	Coronary Heart Disease (CHD)	anxiety (M), ER visits (M), health behaviours (M), self-care (M), self-efficacy (M)
Pincus 2013	Communication	Staff	anxiety (M), enablement (M), intention to adhere (M), satisfaction (L), symptom burden (M)
Postma 2009	Environmental interventions	Asthma	activity limitation (L), number of nights carer awoken (M)
Primac	IT	General	knowledge (M), pain (M)

k 2012			
Ramades	IT/self-management	Diabetes	blood glucose (L), cholesterol (L), clinical composite score (M), depression (M), HbA1c (L), medication use (m), quality of life (M), self-efficacy (M), social support (M), weight (M)
Ramaratnam 2008	Psychological Interventions	Epilepsy/neurological disorders	adjustment (M), coping (M), depression (L), satisfaction (L), seizure frequency (M)
Ranma I 2008	Communication	Cancer	use of tools (M), duration of use of tools (M), general competence (M), social competence (M), social support (parents values) (M), teacher ratings of: behaviour (M), cognition (M), physical competence (M), social competence (M)
Repper 2011	Peer support	Mental Health	empowerment (M), length of stay (M)
Reupert 2013	Peer support	Mental Health	anxiety (L), cognitive function (M), depression (L), emotional disruption (L), functioning (M), homelessness risk (M), physical activity (M), satisfaction with life (M), self-esteem (L), social behaviour (M), stressful family situations (M), understanding (L), wellbeing (M)
Riemsma 2003	Education	Arthritis	patient global assessment (M)
Ring 2007	Self-management education	Asthma	having a treatment action plan (L)
Rowe 2002	Communication	Staff	control (M), uptake of HIV test (M), uptake of screening (M), clinicians: information giving (M), advice given (M), asking more questions (M),

			communication skills (M), knowledge (M), method of history taking (M), time spent (M),
Samoocha 2010	IT	General /patient empowerment	diabetes empowerment scale (M), mastery (L)
Savelkoul 2003	Self-management education	Musculoskeletal	self-confidence (M)
Schroeder 2004	Behaviour change	Cerebrovascular Disease (CVD)	adherence (L)
Scott 2001	Information	Cancer	amount of clarification requested (M), empowerment (M), satisfaction (L), visits to GP (M)
Shaw 2007	Self-management education	Epilepsy/neurological disorders	compliance (L), hazardous coping (L), knowledge (L), misconceptions (L)
Sheehan 2012	Decision aids	General	feeling informed (M), knowledge (L), values clarity (M)
Sheridan 2011	Self-management	General	comfort care preferences (M)
Simpson 2002	Peer support	Mental Health	adherence (M), attitude (M), face to face contacts (M), family burden (M), flexible scheduling (M), inpatient days (M), longer time in supervision (M), need for emergency responses (M), quality of life (M), social functioning (M)

Siskind 2012	Self-management	Mental Health	hospitalisations (L), quality of life (M), remission/disease symptoms (M), satisfaction (M), social functioning (M)
Sorensen 2006	Behaviour change	Physical activity	physical activity (L)
Stinson 2009	IT-based self-management	Geriatrics/paediatrics	adherence (L), biomedical indicators of disease control (L), days of school missed (L), days restricted activity (M), medication use (M), pain (M)
Thomas 2006	Psychological Interventions	Epilepsy/neurological disorders	coping (M)
van Boeijen 2005	Self-management	Anxiety/Depression	anxiety (M), symptom severity (M), symptoms (M)
van Dam 2003	Self-management	Diabetes	blood glucose (L), BMI (M), number of clinic referrals (M), provider efficiency (M), provider guideline compliance (M), satisfaction (L), self-efficacy (M), sick days (L),
Van Dam 2005	Peer support	Diabetes	disease control (M), family involvement (M), knowledge (L), partner weight loss (M), perceived social support (M), provider time (M), quality of life (L), stress (M)
Van Lippevelde 2012	Behaviour change	Obesity/weight management	BMI (M), dietary knowledge (L), health behaviours (M)
Veronovici 2013	Self-management	Cerebrovascular Disease	sleep (M), self-care (M), instruction time required (M), healthcare utilisation (L), cholesterol (M), blood pressure (M),

		(CVD)	anxiety depression (L)
Vuille min 2011	Behaviour change	Physical activity	physical fitness (L)

## Discussion

### *Findings*

Our results indicate there are a range of person- and community-centred approaches for health and wellbeing that show promise across a range of outcomes. However, using evidence as summarised to this level, conclusions can only be considered indicative and it is not advisable to make specific claims about the relative effects of specific interventions. What we have done is to highlight interventions that show promising biomedical, behavioural changes and health and well-being impacts. So it is important that findings are not interpreted as evidence that there is no evidence to support any other interventions. Rather that there were interventions where there was clearer evidence to conclude that they looked more promising. Given the complex nature of implementing person- and community-centred approaches for health and wellbeing in practice, this is sufficient as it helps guide the focus of further empirical work onto approaches that might work best in England. The evidence is unclear in terms of the extent to which resource use changes and wider social impacts are demonstrated from implementing these types of interventions, because these outcomes were less frequently reported. However, sufficient data were gathered to inform the decision on shortlisted interventions, thereby the initial purpose of the task was fulfilled.

It is of note that studies relating to community interventions or public health had lower proportions of studies showing “medium” and “large” effects. This may be a function of both the difficulties of conducting studies in these areas, as well as our methods, in that there may be a lack of systematic reviews in these areas, as we found for two of the selected focus areas, group activities and community-assets based approaches for health and wellbeing. Newer or ‘one-off’, locally-based interventions may be disproportionately disadvantaged. Given the main focus and purpose of the scoping review we believe that this is acceptable.

### *Limitations of the review*

This review encountered some practical limitations, particularly because person- and community-centred approaches for health and wellbeing is a vast area of research. Within the timeframe, scope and resource limits of this programme it was not possible to conduct a comprehensive and detailed systematic review of individual studies. Nor given the purpose of the review is it clear that this would have been appropriate. The desire and need to keep the intervention criteria as broad as possible so as not to miss potentially 'promising' interventions was traded off against a more focused systematic review which might have allowed the estimation of unbiased effectiveness estimates. Our approach has ensured that the whole research programme did not focus too early on the more well-known, established person- and community-centred approaches for health and wellbeing. This came at the cost of including and compiling information about a lot of studies that were not ultimately relevant to the overall aims of the work.

In addition, a high level scoping review, including mainly systematic reviews as reported here is subject to the limitations of the evidence base. This of course relates to the limitations of the primary studies. Key limitations of primary studies are limited methodology, incomplete reporting and lack of coverage over relevant interventions and the limitations of the existing review literature. Existing reviews may be limited in terms of scope (i.e. what they deemed relevant to included), methodology and reporting. This is a recognised limitation of such overviews. Nevertheless, we believe that the overview still achieves its purpose of shining a light on what is known about the relative effectiveness of person- and community-centred approaches for health and wellbeing in terms of the domains of value we have focused upon.

Finally, our method for defining "small", "medium" or "large" effects for narratively summarised reviews may not fully capture the magnitude of effect of person-centred care. However, it was recognised that it was important to include reviews that had not been able to meta-analyse data, because complex interventions are less likely to be sufficiently homogenous for meta-analysis by their very nature, so a method was required to provide an indicator of relative effect for the available outcome data that whilst not perfect would still be informative.

### ***Measuring person- and community-centred approaches for health and wellbeing***

Embracing the benefits of taking a more person- and community-centred approach is now the goal for many health care systems but this is difficult to define and measure, and it is perhaps this uncertainty about how to measure the value of person- and community-centred approaches for health and wellbeing that may explain some of the trends in the existing evidence base.

Within the Realising the Value programme, we have sought to describe a wide range of person- and community-centred approaches for health and wellbeing with a common ambition of giving people more choice and control over their own health and wellbeing, i.e. forefronting the 'active patient'. Within healthcare, such approaches have often commonly been termed person-(or patient) centred care (see *At the heart of Health: Realising the value of people and communities* for a full description of the three 'tributaries' to person- and community-centred approaches for health and wellbeing). However, we note that within the empirical literature there is no universally accepted definition of person-centred care. It is a multi-faceted concept and so the Picker Institute separate it into eight dimensions: respect for patient preferences, information, medication communication, coordination of care, emotional support, physical comfort, involvement of the family, continuity and transition and access to care. [11, 12] suggest that approaches to measuring person-centred care attempt to measure either the holistic concept or specific sub-components such as communication or shared decision-making . Furthermore, they highlight that studies of person-centred care tend to focus on one of four main issues:

1. examining how patients or professionals define the components of person-centred care (definitions),
2. examining the type of care that patients want or professionals' attitudes and values (preferences),
3. examining the extent to which care feels person-centred (experiences), and  
examining what happens as a result of person-centred care (outcomes).

Heidenreich and colleagues[13] suggest that the dominant metric to consider and measure these issues is satisfaction. However, De Silva and colleagues suggest other outcomes to measure in addition to satisfaction, including quality of life, functional status or health service use.[12] Specific tools for its measurement are validated and include the Individualised Care Scale,[14] the Measure of Processes of Care[15] and the Person-Centred Care Assessment Tool[16] but there is no evidence that indicates these tools are superior to other existing instruments currently being utilised in the studies that make up the evidence base for person-centred care.

Person- and community-centred health and wellbeing must not be mistaken as 'quality of care'. NHS England defines quality of care as encompassing three equally important parts:

- Care that is **clinically effective**– not just in the eyes of clinicians but in the eyes of patients themselves;
- Care that is **safe**; and,



- Care that provides as positive an **experience** for patients as possible

High quality care is only being achieved when all three dimensions are present. Hence, patient satisfaction and experience should not be prioritized over clinical effectiveness and safety and vice versa. Thus, it can be argued that high quality of care should involve an evaluation of clinical effectiveness, safety and user experience. However, in terms of evaluation ideology, similarities between these perspectives must be understood, in order that researchers can better methodologically evaluate interventions and services in terms of quality.

Clinical effectiveness and safety are central to the concept of evidence based medicine and practice which is cited by Sackett (1996) as "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients".[17] Evidence based medicine relies on randomized controlled trials (RCTs) and systematic reviews of RCTs as the 'gold standard' for assessing the relative performance of treatments in healthcare that is disease centred. Traditionally, RCTs do not incorporate the preferences of users of care, and indeed have often used very narrowly defined definitions of clinical effectiveness and safety that might not be of most relevance to patients. Bensing and colleagues (2000) highlights that there are very few studies incorporating both the terms 'evidence-based medicine' and 'patient-centred medicine'.[18] They also note that these terms focus on different aspects of medical care and have, in fact, little in common. Evidence-based medicine is positivistic and biomedical, whereas patient-centred medicine is basically a humanistic, biopsychosocial perspective, combining ethical values with psychotherapeutic theories on facilitating patients' disclosure of real worries, and negotiation theories on decision-making. It is argued however, in this approach, that the ideological base is better developed than its evidence base with the empirical literature dominated by scientific research based on populations that are groups of patients with a specific condition.

RCT, where feasible, are the strongest research design for generating unbiased measures of relative effect.[19] It is therefore unsurprising that the majority of the evidence regarding the effectiveness of person- and community-centred approaches for health and wellbeing lies in health care and is disease-centred where RCTs and subsequent systematic review and meta-analysis are the dominant evaluative methodologies. There has been considerable reluctance to apply RCTs to complex social interventions that may incorporate person- and community-centred approaches for health and wellbeing in the UK, partly because of a perception that they are 'unfair' and partly because of a belief that contexts in social initiatives are simply too heterogeneous and dynamic to allow inference from an RCT. [20, 21, 22] The challenges of conducting RCTs of

complex social programmes are not insignificant [23], but there are a number of successfully implemented examples.[24, 25]

If person- and community-centred health and wellbeing and evidence based practice do indeed belong to very different worlds in terms of an evaluative perspective,[18] the academic community and research funders of health and social care need to develop and or specify evaluative methodologies that incorporate users' preferences into high quality effectiveness studies.

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## Appendix 1: Sources initially included in review of the evidence base

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## Appendix 2: Search Terms

### Health literacy

1. Health literacy
2. Information literacy
3. Low literacy
4. Information
5. Education
6. Informatics
7. Leaflet
8. Patient OR consumer
9. 8 AND (4 OR 5 OR 6 OR 7)
10. Multimedia OR interactive OR audio OR video
11. 10 AND (4 OR 5)
12. Readability
13. Comprehension
14. Simplified
15. Plain language
16. (12 OR 13 OR 14 OR 15) AND (4 OR 5 OR 7)
17. Internet
18. World wide web
19. Online
20. (17 OR 18 OR 19) AND (4 OR 5)
21. Mass media
22. Media campaign
23. Health
24. Screening
25. (21 OR 22) AND (23 OR 24)
26. Digital TV
27. New media
28. (26 OR 27) AND 8 AND 23
29. Underserved
30. Disadvantaged
31. Deprived
32. (29 OR 30 OR 31) AND (4 OR 5)

### Clinical decision-making

1. Shared decision making
2. Informed decision making
3. Decision aid
4. Decision support



5. Risk communication
6. Communication skills
7. Training
8. Education
9. 6 AND (7 OR 8)
10. Improv\*
11. Communication
12. Interaction
13. 10 AND (11 OR 12)
14. Informed choice
15. Recording OR summary
16. Consultation
17. 15 AND 16
18. Patient participation
19. Patient involvement
20. Sharing
21. Partnership
22. Decision making
23. Treatment decision
24. Management decision
25. (18 OR 19 OR 20 OR 121) AND (22 OR 23 OR 24)
26. Patient centred
27. Consultation
28. Care
29. 26 AND (27 OR 28)
30. Question prompt
31. Question sheet

### **Self-care**

1. Self care
2. Self manage\*
3. Self efficacy
4. Patient education
5. Self help
6. Self monitor\*
7. Home monitor\*
8. Telemonitor\*
9. Self diagnos\*
10. Self treat\*
11. Self medicat\*
12. Social support
13. Peer support

14. Mutual support
15. Coping skills
16. Coping behaviour
17. Virtual communit\*
18. Telephone support
19. Telecare
20. Telemedicine
21. Home
22. 20 AND 21
23. Patient held record
24. Nursing record system
25. Recording OR summary
26. Consultation
27. 25 AND 26
28. Copying letter
29. Copy\*
30. Referral letter
31. 29 AND 30

### **Care experience**

1. Patient choice
2. Consumer choice
3. Provider
4. Doctor
5. Physician
6. Plan
7. Choos\*
8. Choice
9. (7 OR 8) AND (3 OR 4 OR 5 OR 6)
10. Choice behaviour
11. Report card
12. Performance report
13. Performance data
14. Performance measure\*
15. Performance indicator
16. Performance information
17. Public NEAR disclos\*
18. Quality NEAR improve\*
19. (7 OR 8 OR 17 OR 18) AND (11 OR 12 OR 13 OR 14 OR 15 OR 16)
20. Patient satisfaction
21. User satisfaction

22. Consumer satisfaction
23. Patient NEAR survey
24. User NEAR survey
25. Consumer NEAR survey
26. Patient feedback
27. Patient evaluation
28. Patient report
29. Patient assessment
30. Patient complaint
31. Complaints system
32. Patient advocacy
33. Health advocacy
34. PALS#

**Community-Based Search Terms (developed from the literature).[26]**

1. community action/development/engagement/building/transformation
2. active communities
3. social capital/value
4. co-production
5. needs-based approach/asset-based approach/needs-and-asset based approach
6. cross-sector working
7. resident-led/neighbourhood partnerships

### Appendix 3: List of all 154 included reviews (regardless of effect size)

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