Self-Management of Long-Term Conditions

Joint Strategic Needs Assessment Report

09/08/2018

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Executive Summary

The aim of this JSNA report is to assess the health needs of people with long term conditions (LTCs), specifically to inform the planning of better self-management support in Cornwall.

Chapter 1 sets out the Aim and Scope of the report, including definitions of self-management and long-term conditions covered.

Chapter 2 describes the Methodology; the report brings together data, evidence, policy, service models and local community views.

Chapter 3 sets the National Context including prevalence of long-term conditions and multimorbidity.

Chapter 4 describes the Policy Context and why the self-management of long-term conditions is a national and local priority, for example in the Five Year Forward View.

Chapter 5 summarises qualitative and quantitative data gathered from Community Voice co-production and engagement activities, including local surveys and focus groups. It gives insight into what local people think is important to encourage self-management, and gaps and opportunities in local services.

Chapter 6 describes What’s Happening in Cornwall. This covers need, based on the prevalence and distribution of long-term conditions in Cornwall, and also supply and demand, based on the services available to meet those health needs.

Chapter 7 gives the findings of a rapid evidence review on Effective Interventions to support self-management.

Chapter 8 sets out the next steps for the report.
## Recommendations

This needs assessment has identified a number of recommendations that should be incorporated into future strategies and service developments.

1. Stakeholders to take into account the findings of this needs assessment in commissioning and service improvement work.

2. Self-management of LTCs should be used as a key performance indicator using relevant measures, for example PAMs.

3. Project management support should continue to be provided to implement and improve self-management support across long term conditions.

4. There are gaps in research around self-management support. Interventions with stronger evidence base should be prioritised, and all interventions should be evaluated for acceptability, accessibility, relevance, equity, effectiveness and efficiency (cost/benefits).

5. Effort should be made to ensure self-management support reduces health inequalities, e.g. targeting those from deprived areas.

6. Evidence is lacking on how best to support people with multi-morbidity. Stakeholders should continue to monitor policy and research around what works as the evidence base develops.

7. Strong links should be created between Healthy Cornwall (healthy lifestyle services) and services provided for people with Long Term Conditions, to ensure that as many people as possible are supported in stop smoking, alcohol reduction, physical activity, weight management and healthy eating.

8. Mental health and wellbeing support should be developed for people with physical LTCs.

9. The Voluntary and Community Sector should be enabled to increase their capacity to support people with LTCs through peer, social and practical support.

10. Ensure people with long term conditions are provided with wider social and practical support, such as advice on employment, housing and welfare.

11. Ensure digital support is carefully curated and coordinated across the system to avoid fragmentation of effort. Ensure resources are available to support initial and ongoing implementation and evaluation.

12. Commission appropriate condition specific information and programmes that support self-management, e.g. structured education and pulmonary rehab.

13. Partners should continue to develop ways to implement personalised care and action planning, particularly for conditions where there is risk of deterioration e.g. COPD.

14. Training and workforce development should be in place to support the principles and practice of self-management.
1. **Aim and Scope**

A Health Needs Assessment is a “systematic method for reviewing the health issues facing a population, leading to agreed priorities and resource allocation that will improve health and reduce inequalities” (Cavanagh and Chadwick, 2005). The aim of this JSNA report is to assess the health needs of people with long term conditions (LTCs), specifically to inform the planning of better self-management support in Cornwall. It brings together data, evidence, policy, service models and local community views.

Improvements in medical treatment and public health interventions mean people are living longer, but often with a long-term illness or disability. The Department of Health defines LTCs as “those conditions that cannot, at present, be cured, but which can be controlled by medication, and other therapies” (Department of Health, 2012). LTCs include (but are not limited to) asthma, coronary heart disease (CHD), most cancers, chronic obstructive pulmonary disease (COPD), chronic kidney disease (CKD), dementia, diabetes, epilepsy, and stroke. Severe Mental Illnesses (SMI), including psychoses such as schizophrenia and severe depression, are also considered to be LTCs.

People have a key role in protecting their own health, choosing appropriate treatments and managing long-term conditions. The following definition of self-management is used in this report:

“**Self-management includes all the actions taken by people to recognise, treat and manage health and wellbeing independently of or in partnership with the health and social care system.**” (National Voices)

This is a broad definition covering primary, secondary and tertiary prevention of illness. However, this report focuses on self-management after the point of diagnosis, to prevent people experiencing unnecessary exacerbations or complications from their illness (a type of secondary/tertiary prevention). Self-management support for people with Long Term Conditions (LTCs) is a priority for people in Cornwall and for the health and social care system.

Figure 1 shows the spectrum of health and care needs of the population, from those who are living well to those at end of life. This report and accompanying strategy is most relevant to those in the ‘Supported to self-manage’ segment. The right support can prevent or delay more intensive support needs.
This report only highlights cancer, diabetes, respiratory conditions and heart conditions as examples of LTCs where self-management can play a role. These conditions were agreed as a starting point by stakeholders as they represent a significant burden on individuals and the healthcare system (see, for example, the 5-5-75 model shown in figure 1). Other conditions, such as stroke and musculoskeletal conditions, also represent a significant burden, but work is already ongoing to improve pathways and support, so it was felt more value could be added elsewhere. Mental health was held to be very important by stakeholders; however, since the physical health needs of people with Severe Mental Illness were being reviewed in separate work (Sharpe, 2019), it was agreed this report would include the mental health and wellbeing of people with physical LTCs, but the self-management of mental health conditions independently of other conditions is outside of scope.

Other LTCs should not be overlooked in self-management support; these conditions are given as examples only. Additionally, a number of types of self-management support, for example healthy lifestyle support, are transferable across a number of conditions. The scope covers adults (age 18+) only.
2. Methodology

Shaping Our Future (SoF) is the name for a partnership of organisations and people across the health and social care system in Cornwall. Under this programme, a Self-Management Leadership Group was convened in September 2017 to guide the development of self-management support in Cornwall and ensure strong engagement and co-production throughout. The group is called a ‘Leadership’ group not because its members are in powerful leadership positions in the health and care system, but as an acknowledgement that leadership, energy and ideas can come from anywhere – whether from people with experience of a condition, voluntary sector, carer, clinician or commissioner. The group works as an equal partnership.

The Self-Management Leadership Group considers self-management principles across conditions but has also held subgroups to better understand the experiences of people with specific conditions. The group informed the direction of this JSNA report.

To identify the health needs of this population group, a variety of information sources were reviewed, including;

- National and local policy
- Local and national outcome data
- Discussion with key local stakeholders, including commissioners, service providers, and third sector organisations
- Local surveys
- Information on current service provision
- Published research
3. National Context

Key messages

• Nationally, the number of people living with one or more LTC is increasing.
• Caring for people with LTCs uses 70% of hospital and primary care resources.
• LTCs are more common in older people, and people living in deprived areas.
• Many people with long-term physical health conditions also have mental health problems, which can affect people’s ability to self-manage. It is estimated that 12 - 18% of all NHS expenditure on long-term conditions is linked to poor mental health and wellbeing.
• Healthcare delivery needs to shift from a single-disease model to a more integrated approach, which looks at the needs of the person as a whole, but this can be challenging in practice.

In England, the Department of Health estimates 15 million people (over a quarter of the population) have at least one LTC. The number of people with three or more conditions in England is expected to increase from 1.9 million in 2008 to 2.9 million in 2018 (Department of Health, 2012).

Caring for people with LTCs uses 70% of hospital and primary care budgets in England, including 50% of GP appointments and 70% of inpatient days. Care takes place across primary care, emergency care, hospital inpatient and outpatient care, rehabilitation, social care and community health care.

LTCs are more prevalent in older people (58% of people over 60 compared to 14% under 40) and in more deprived groups (people in the poorest social class have a 60% higher prevalence than those in the richest social class and 30% more disease severity). Some people living in a deprived area will have multiple health problems 10-15 years earlier than people in affluent areas.

People who manage their own health, wellbeing and care both have a better experience of care and a reduced demand for high-intensity acute services. However, 40% of people have low levels of knowledge, skills and confidence to manage their health and wellbeing (Eliilins and Coulter, 2005) and 44% say they would like to be more involved in making decisions about their care (CQC Inpatient Survey, 2014).

People with multiple LTCs (multi-morbidity) are more likely to find it difficult to manage their conditions, and there is evidence that the number of conditions can be a greater determinant of a patient’s use of health service resources than specific diseases (Barnett et al., 2012). There is currently no consensus on a definition of multi-morbidity. Researchers differ in the number, type and selection criteria for the LTCs included in a multi-morbidity definition. For example, some researchers define multi-morbidity as the presence of two or more coexisting conditions,
others define it as three or more. Some include both physical and mental health conditions, others do not. This makes it challenging to estimate multi-morbidity prevalence.

Many people with long-term physical health conditions also have mental health problems. These can lead to significantly poorer health outcomes and reduced quality of life. Costs to the health care system are also significant – by interacting with and exacerbating physical illness, co-morbid mental health problems raise total health care costs by at least 45% for each person with a physical long-term condition and co-morbid mental health problem. It is estimated that 12 - 18% of all NHS expenditure on long-term conditions is linked to poor mental health and wellbeing – between £8 billion and £13 billion in England each year (Naylor et al., 2012). The more conservative of these figures equates to around £1 in every £8 spent on long-term conditions.

Multi-morbidity is more common among deprived populations, especially multi-morbidity including a mental health problem (Barnett et al., 2012). People with long-term conditions and co-morbid mental health problems disproportionately live in deprived areas and have access to fewer resources of all kinds. The interaction between co-morbidities and deprivation makes a significant contribution to generating and maintaining inequalities. Figure 2 shows the patterns of co-morbidities between the most affluent and most deprived deciles, showing higher levels of all the diseases shown in deprived groups.

**Figure 2: Patterns of selected co-morbidities between most affluent and most deprived deciles**

Source: (Barnett et al., 2012)
Overall, the evidence suggests that at least 30% of all people with a long-term condition also have a mental health problem (Cimpean and Drake 2011). This is likely to be a conservative estimate. Figure 3 shows the relationship between mental health and long-term conditions.

Figure 3: The relationship between mental health and long-term conditions

![Diagram showing the relationship between mental health and long-term conditions.](image)

Source: Naylor et al., 2012

Depression is two to three times more common in a range of cardiovascular diseases including cardiac disease, coronary artery disease, stroke, angina, congestive heart failure, or following a heart attack (Fenton and Stover 2006; Benton et al 2007; Gunn et al 2010; Welch et al 2009). Prevalence estimates vary between 20 - 50% depending on the conditions studied and the assessment approach used, but the two- to threefold increase compared with controls is consistent across studies. Anxiety problems are also common in cardiovascular disease (Goodwin et al 2009). People living with diabetes are two to three times more likely to have depression than the general population (Fenton and Stover 2006; Simon et al 2007; Vamos et al 2009). Prevalence estimates vary but the proportionate increase is consistent. There is also an independent association with anxiety. Mental health problems are around three times more prevalent among people with chronic obstructive pulmonary disease than in the general population (NICE 2009). Anxiety disorders are particularly common; for example, panic disorder is up to 10 times more prevalent than in the general population (Livermore et al 2010).

A significant part of the explanation for poorer clinical outcomes is that co-morbid mental health problems can reduce a person’s ability to actively manage their own physical condition and are associated with unhealthy behaviours such as smoking. Self-management is impeded significantly by poor mental health, which can reduce the motivation and energy needed for self-management, and lead to poorer adherence to treatment plans (DeMatteo et al 2000). For similar reasons mental health problems are also associated with low attendance rates for medical appointments.

It is now widely accepted that healthcare delivery for people with multi-morbidity needs to shift from the current single-disease model, which tends to focus on the management of individual conditions, to a more integrated approach, which looks at the needs of the person as
a whole. However, in practice there are still challenges to implementing this approach in the current system.

4. Policy Context

Key messages

- Self-management of LTCs is supported by a range of national organisations and policy. The NHS Five Year Forward View set out a clear ambition for the NHS to become better at helping people to manage their own health. To meet this commitment, NHS England is making supported self-care a key part of personalising care.
- Locally, self-management is supported by Shaping Our Future, the Cornwall Council Strategy and Adult and Social Care commissioning plans.

The challenges relating to long term conditions and a move to self-management and co-production are global. Examples can be seen in the New Zealand self-management model (New Zealand Ministry of Health, 2016), the Welsh Prudent Healthcare Movement, and the Choosing Wisely Canada movement.

4.1 National Policy

The NHS Five Year Forward View set out a clear ambition for the NHS to become better at helping people to manage their own health. To meet this commitment, NHS England is making supported self-care a key part of personalising care. This involves scaling up support for people living with LTCs to manage and make decisions about their own health and wellbeing.

To support the Five Year Forward View, NHS England set up the Realising the Value Programme to strengthen the case for change; identify evidence-based approaches that engage people in their own health and care; and develop practical tools to support implementation across the NHS and local communities. These approaches include self-management education courses for people with specific conditions, peer-to-peer support and community-based activities. Resources and tools were developed in partnership with a range of stakeholders, led by Nesta and the Health Foundation (Nesta, 2015a).

The NHS Constitution for England says that people have the right to be involved in discussions and decisions about their healthcare and to be given information to enable them to do this.

The Health and Social Care Act requires all health and social care providers to, where appropriate, provide opportunities for service users to manage their own care or treatment; and provide appropriate opportunities, encouragement and support to service users in relation to promoting their autonomy, independence and community involvement.
The Care Quality Commission, which regulates the quality of health and social care on behalf of patients, service users, their carers and families, has issued guidance to providers on meeting the statutory requirements to enable people to have choice and control and to manage their own care.

The General Medical Council says doctors should support people in caring for themselves to improve and maintain their health. Good Medical Practice suggests: "This may include advising patients on the effects of their life choices on their health and well-being and the possible outcomes of their treatments."

The Nursing and Midwifery Council says nurses and midwives "must support people in caring for themselves to improve and maintain their health."

Other useful publications include:

- Patients in Control (IPPR, 2014)
- Future Hospital, Person Centered Care Approaches (Royal College of Physicians)
- From Vision to Action: making patient-centered care a reality. (Richmond Group, 2012).

4.2 Local policy

Shaping Our Future

The vision of Shaping Our Future is:

“Working together to ensure the people of Cornwall and the Isles of Scilly stay as healthy as possible for as long as possible; supporting people to help themselves and each other for longer-lasting independence; and providing services that everyone can be proud of and that reduces overall cost to the system”.

Self-management is a key part of the Kernow STP Outline Business Case, alongside wider determinants and healthy lifestyles, and sits under the New Models of Care workstream (Shaping Our Future, 2016). This includes a commitment to “create a self-care service to inform, enable and support people to manage their own care. There will be structured education programmes for Long Term Conditions (LTC) and Patient Activation Measures (PAM) will be used to identify those able to manage their LTC and patients where more support is needed.”

Cornwall Council Strategy

Self-management of LTCs supports the Cornwall Council Strategy which has five priority areas including better health for everyone (figure 4).
This report sets out a framework to reshape Adult Social Care services, ensuring community based preventative services support people to stay in their own homes for as long as possible. The Framework sets high expectations around maximising independence; supporting adults of all ages to take part in purposeful activity and live in their own home; and working age adults to be in paid employment. It also addresses the challenge of managing demand for those with eligible unmet care needs through preventative support for people with low levels of need – including self-management support.
5. Community Voice

Key Messages

- There is no ‘one size fits all’ approach to self-management support – it is important to offer a range of options and formats.
- Mental wellbeing is fundamental to the self-management of physical conditions. Social and emotional support can make all the difference.
- Digital support is likely to suit some people more than others, and some will need support to feel confident in using new technologies. Not everyone has access to smart phones/computers or knows how to use them.
- Healthy lifestyles, such as being smoke free, healthy eating, healthy weight, physical activity, and reducing alcohol, are all key to good self-management, and people would welcome more support to keep up lifestyle changes.
- Peer and social support is really important, but not everyone is comfortable in group settings.
- For people on a low income, homeless or socially marginalised, it can be hard to make health and wellbeing a priority – meeting basic needs comes first.

This section summarises themes and findings from a range of engagement activities. Collectively, the findings do not give quantitative answers about what, when and how self-management support should be provided, and they are not representative of the views of every person in Cornwall, but they offer vital insight into people’s experience that help with planning and improving services.

5.1 What is Co-production?

A key principle of self-management of LTCs is empowering people to be engaged in health and wellbeing. Co-production is a way of working that involves people who use health and care services, carers and communities in equal partnership, engaging groups of people at early stages of service design, development and evaluation.

Co-production recognises that people with ‘lived experience’ of a particular condition are often best placed to advise on what support and services will make a positive difference. Done well, co-production helps to ground discussions, and keep a person-centred perspective. Co-production is part of a range of approaches that includes citizen involvement, participation, engagement and consultation. It is a cornerstone of self-care and person-centred care.
Co-production is also endorsed as a way to develop and deliver health and wellbeing initiatives in NICE Guidelines on *Community engagement: improving health and wellbeing and reducing health inequalities* (NICE, 2016).

The Coalition for Collaborative Care have developed a model for co-production showing how to create a culture of co-production, and this model is becoming widely used among the NHS and partners (Coalition for Collaborative Care). It promotes a culture where certain values and behaviours are the norm (Figure 5).

**Figure 5: Co-production Values**

In keeping with these values, the Cornwall Self-Management Leadership Group have used various methods to gather views and engage people in a conversation about self-management support in Cornwall. Importantly, co-production and engagement are an ongoing process, not one-off activities:

- Cornwall Residents Survey
- Shaping Our Future engagement events
- Self-management of LTCs Public and Professional Surveys
- Condition-focused subgroups
- Outreach engagement

### 5.2 Cornwall Residents Survey

The 2017 Cornwall Residents Survey had responses from 11,247 residents (38% response rate) and gives us some insight into how people feel about the state of their health and their confidence to manage their own health.

*‘How is your health in general?’* (n=11,043)

70% said their health was very good or good, 8% said it was bad or very bad. The proportion of residents aged 16-34yrs (74%) and 35-64yrs (75%) saying their health was either very good or good was significantly higher than those 65+yrs (58%).

*‘How confident are you that you can manage your own health?’* (n=11,047)
52% said they were very confident in managing their health, 40% said they were somewhat confident. 6% said they were not too confident and 1% said they were not at all confident in managing their own health. The proportion of residents saying they were very confident in managing their own health was significantly higher in those aged 16-34yrs (57%) and 35-64yrs (56%) compared with those 65+yrs (43%), (dropping to 26% for those who were 85+yrs).

This shows there is room to increase people’s confidence in managing their own health, particularly in older age groups. However, it is likely that people’s confidence is correlated to the state of their health, i.e. older age groups lose confidence as they begin to experience more health problems.

The survey found that people reporting fair health were five times more likely to have a low mental wellbeing score\(^1\) compared to those in good or very good health, and those with bad or very bad health were 29 times more likely (figure 6). Those with day to day activities limited a little due to a health problem or disability were three times more likely to have a low mental wellbeing score compared to those who activities were not limited, and those who were limited a lot were 14 times more likely. The effect is stronger for those with activities limited due to a mental health condition, who were 25 times more likely to have a low mental wellbeing score, compared to those with a physical long-term condition or illness, who were four times more likely. This shows the importance of recognising the impact poor physical health can have on mental wellbeing.

### Figure 6: Health condition and risk of low mental wellbeing

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<td>General health status; Good or very good health</td>
<td>1</td>
<td>5.43 (4.66-6.32)***</td>
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<tr>
<td>Fair</td>
<td>28.98 (20.92-40.16)***</td>
<td></td>
</tr>
<tr>
<td>Bad or very bad health</td>
<td>1</td>
<td>2.86 (2.46-3.32)***</td>
</tr>
<tr>
<td>Day to day activities limited due to a health problem or disability in last 12 months; No</td>
<td>1</td>
<td>13.57 (10.93-16.84)***</td>
</tr>
<tr>
<td>Yes, limited a little</td>
<td>13.57 (10.93-16.84)***</td>
<td></td>
</tr>
<tr>
<td>Yes, limited a lot</td>
<td>24.73 (10.06-60.79)***</td>
<td></td>
</tr>
<tr>
<td>Due to a mental health condition</td>
<td>4.27 (3.57-5.10)***</td>
<td></td>
</tr>
<tr>
<td>Due to a long-term illness or condition</td>
<td>4.27 (3.57-5.10)***</td>
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* P<0.05, **P<0.00, *** P<0.000

* Adjusting for participant age, sex and IMD score

Source: Sharpe, 2017

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\(^1\) Self-reported using WEMWBS – Warwick and Edinburgh Mental Wellbeing Scale.
5.3 Shaping Our Future engagement

In 2017, the Shaping Our Future engagement events found people support the following approaches and priorities:

- Promote **health knowledge** and emotional resilience in children and young people
- More focus on lifestyles and wider determinants of health e.g. housing, employment
- **Social prescribing programmes** using community assets to tackle social causes of ill health
- **Recognise value of third sector** for tackling social isolation, but don’t just leave it to them
- **Carers** need to be given proactive support for their wellbeing and to prevent crisis
- Mental health prevention services need to be focused and given **greater priority**
- Increase **physical activity** and tackle childhood obesity
- Targeted prevention approaches using demographic information, **lifestyle advice** and Making Every Contact Count
- **Develop a comprehensive self-care and self-management approach**, including technology
- **Proactive management of conditions in primary care** to avoid escalation
- **Encourage independence** and focus on re-ablement and rehabilitation especially following a stay in a care setting
- Address ‘frequent flyers / revolving door’ patients (e.g. falls, alcohol)
- Learn from existing initiatives & use **existing resources**
- Identify patients with **physical health difficulties that would benefit from MH support** to prevent depression & anxiety.
- Consider integrating prevention with community teams
- Increase **patient and carer support** groups
- Increase access to existing activities that promote healthier lifestyles
- Include **health promotion and self-care as part of individual care planning**
- Consider impact of **transport** issues
- Refuse support that **undermines** self-care & independence
- Provide **self-care training & lifestyle education** to staff as well as public
- **Promote self-care** alongside public health messaging
- Develop **digital solutions** to promote independence
- **Intervene sooner** & include mental health

“We need a whole system approach. People do not want a lecture on their poor diet when they cannot even afford their rent.”

“Patients by experience are good advocates of prevention – use them more to provide peer support.”

“Provide online advice/strategies that people can use and suggest activities people can do on their own for people who are currently sitting on long waiting lists.”

“We need a whole system approach. People do not want a lecture on their poor diet when they cannot even afford their rent.”
5.4 Public and professional surveys

From December 2017 to February 2018 the Self-management Leadership Group designed and ran surveys for the people with experience of LTCs (n=118) and professionals and the voluntary sector (n=97), to understand how confident people felt in managing their health, and what kind of self-management support they thought was important.

The online survey was promoted through stakeholder networks and media channels. Postal copies were available by request, but few copies were requested, so the majority of respondents were people with internet access. It is also likely that the people who responded to the survey already had an interest in the self-management of LTCs and may be already well engaged in health and wellbeing matters. Due to methodological and resource limitations, the survey is a not a representative sample of the population of Cornwall, so findings should be interpreted with caution. However, it provides local insight that can be combined with more robust sources of research to strengthen the overall evidence base. Qualitative insights are included as quotes but were not a main focus of the survey.

Survey Findings

**Respondent characteristics**

- 74% had a long-term condition, and 37% were carers or family members of someone with a long-term condition.
- 68% were female, 32% were male.
- Respondent ages ranged from 30 – 84, with most responses in the 50-54 age range.

Figure 7 shows the types of LTCs people had, with most responses from people with diabetes (41%). Many respondents had more than one condition. Due to the limitations of the survey design software and team capacity to analyse the results, it was not possible to ask condition-specific questions on every long-term condition, so the condition-specific sections were limited to diabetes, cancer, heart conditions, respiratory conditions, and ‘other’.

“We need to individualise care. I had a cardiac patient who said you’re the first person to explain how exercise will improve my health.”

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2 This likely skewed responses to a younger demographic (selection bias).
Confidence in managing health

27% were very confident in managing their health, 52% were somewhat confident, 16% were not too confident and 4% were not at all confident (Figure 8). The proportion who were not confident was higher than the Cornwall Residents Survey respondents, which may reflect the higher number of people already diagnosed with health conditions in this survey.

Figure 8: Confidence in managing health

<table>
<thead>
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<th>Condition</th>
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<tr>
<td>Heart disease</td>
<td>22 (20%)</td>
</tr>
<tr>
<td>Diabetes</td>
<td></td>
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<tr>
<td>- Type 1</td>
<td>14 (13%)</td>
</tr>
<tr>
<td>- Type 2</td>
<td>23 (21%)</td>
</tr>
<tr>
<td>Respiratory</td>
<td>38 (34%)</td>
</tr>
<tr>
<td>COPD</td>
<td>17 (15%)</td>
</tr>
<tr>
<td>Emphysema</td>
<td>4 (4%)</td>
</tr>
<tr>
<td>Asthma</td>
<td>15 (16%)</td>
</tr>
<tr>
<td>Other</td>
<td>9 (8%)</td>
</tr>
<tr>
<td>Cancer</td>
<td>18 (16%)</td>
</tr>
<tr>
<td>Other – arthritis, depression, anxiety, fibromyalgia, dementia, Parkinson’s, Huntingdon’s, eczema, lupus</td>
<td>38 (34%)</td>
</tr>
</tbody>
</table>
**Patient Activation Measure**

The Patient Activation Measure (PAM) is a validated set of questions that helps measure people’s skills, knowledge and confidence in taking care of their condition. People are given a set of statements and asked whether they strongly agree (4), agree (3), disagree (2) or strongly disagree (1). Figure 9 gives an indication of the average response level for each statement – the higher the number, the more strongly people agreed, on average, with that statement.

The statements people agreed most strongly with were:

- “I am the person who is responsible for my own health”;
- “Taking an active role in my own health care is the most important thing that affects my health”;
- “I know what each of my prescribed medications do.”

The statements people most strongly disagreed with were:

- “I am confident that I can maintain lifestyle changes, like healthy eating and exercising, even during times of stress”;
- “I am confident I can work out solutions when new problems arise with my health”
- “I have been able to maintain lifestyle changes, like healthy eating or exercising.”
Figure 9: Patient Activation Measure

Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally by ticking your answer.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Mean Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am the person who is responsible for taking care of my health. (n=77)</td>
<td>3.56</td>
</tr>
<tr>
<td>Taking an active role in my own health care is the most important thing that affects my health. (n=76)</td>
<td>3.43</td>
</tr>
<tr>
<td>I know what each of my prescribed medications do. (n=76)</td>
<td>3.25</td>
</tr>
<tr>
<td>I am confident I can help prevent or reduce problems associated with my health. (n=78)</td>
<td>3.03</td>
</tr>
<tr>
<td>I am confident I can tell whether I need to go to the doctor or nurse or whether I can take care of a health problem myself. (n=77)</td>
<td>3.06</td>
</tr>
<tr>
<td>I am confident that I can tell a doctor or nurse concerns I have even when he or she does not ask. (n=78)</td>
<td>3.21</td>
</tr>
<tr>
<td>I am confident I can carry out medical treatments I may need to do at home. (n=77)</td>
<td>3.09</td>
</tr>
<tr>
<td>I understand my health problems and what causes them. (n=77)</td>
<td>2.80</td>
</tr>
<tr>
<td>I know what treatments are available for my health problems. (n=76)</td>
<td>2.61</td>
</tr>
<tr>
<td>I have been able to maintain lifestyle changes, like healthy eating or exercising. (n=78)</td>
<td>2.83</td>
</tr>
<tr>
<td>I know how to prevent problems with my health. (n=77)</td>
<td>2.49</td>
</tr>
<tr>
<td>I am confident I can work out solutions when new problems arise with my health. (n=78)</td>
<td>2.37</td>
</tr>
<tr>
<td>I am confident that I can maintain lifestyle changes, like healthy eating and exercising, even during times of stress. (n=77)</td>
<td>2.37</td>
</tr>
</tbody>
</table>

**Barriers to managing an LTC**

People were asked “Is there anything that makes it more difficult for you or the person you care for to manage your long-term condition(s)? Please tick all that apply.” (Table 10) Every category had at least 40% of people responding ‘yes’, showing these are all barriers to some extent, but the highest responses were for ‘access to health or social care professionals’ (70%)\(^3\), ‘not enough information’ (67%) and ‘few support groups near me’ (63%).

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\(^3\) This is difficult to interpret further as ‘access’ can be interpreted in a number of ways, e.g. geographical access, or access to certain types of health professional may be perceived as more difficult than others.
Figure 10: Factors that make it more difficult to manage a long-term condition

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to health or social care professionals</td>
<td>49 (70%)</td>
<td>21 (30%)</td>
<td>70</td>
</tr>
<tr>
<td>Not enough information</td>
<td>48 (66.67%)</td>
<td>24 (33.33%)</td>
<td>72</td>
</tr>
<tr>
<td>Few support groups near me</td>
<td>45 (63.38%)</td>
<td>26 (36.62%)</td>
<td>71</td>
</tr>
<tr>
<td>Low mood, anxiety or depression</td>
<td>45 (61.64%)</td>
<td>28 (38.36%)</td>
<td>73</td>
</tr>
<tr>
<td>Poor quality information</td>
<td>43 (61.43%)</td>
<td>27 (38.57%)</td>
<td>70</td>
</tr>
<tr>
<td>Not enough time</td>
<td>35 (51.47%)</td>
<td>33 (48.53%)</td>
<td>68</td>
</tr>
<tr>
<td>Low income</td>
<td>33 (50%)</td>
<td>33 (50%)</td>
<td>66</td>
</tr>
<tr>
<td>Low confidence</td>
<td>31 (46.27%)</td>
<td>36 (53.73%)</td>
<td>67</td>
</tr>
<tr>
<td>Access to transport</td>
<td>28 (40.58%)</td>
<td>41 (59.42%)</td>
<td>69</td>
</tr>
<tr>
<td>Few family/friends nearby</td>
<td>27 (40.3%)</td>
<td>21 (30%)</td>
<td>70</td>
</tr>
</tbody>
</table>

“*It can be hard to manage a long-term condition without getting weighed down by it all, so emotional support is really important.*”

**Mental wellbeing**

80% of respondents said they had experienced low mood, anxiety or depression related to their condition, but only 40% had received support for it. Of those who had received support, it came from their GP (31%), Outlook South West (24%), the hospital health psychology service (17%), or other (28%).

**Preferred type of delivery**

People were asked: “Self-management support can be delivered in a number of different ways. How comfortable would you, or the person you care for, be managing your condition(s) in the following ways: in a group session, face to face, over the phone, by text, using smart phone e.g. apps, or online e.g. by laptop (table 11). The answers show that the majority of respondents are most comfortable with face to face support (90% were somewhat or very comfortable). The other responses show that there is not ‘one size fits all’ for type of delivery – in every category there are people who are very comfortable and not at all comfortable with that format.

For example, 48% were somewhat or very comfortable using smart phones including apps to manage their condition, but 37% were not at all comfortable with this format. 59% were
somewhat or very comfortable using online support through laptop or computer, but 22% were not at all comfortable with this format.

Digital support is likely to suit some people more than others, and some people will need support to feel confident in using new technologies. Digital formats are best used as a supplement to, not replacement of, face to face contact.

57% were somewhat or very comfortable over the phone, and 44% were somewhat or very comfortable in group sessions. It is also worth noting that a relatively high proportion (31%) said they were ‘not at all comfortable’ in a group. Again, this shows different types of support suit different people.

**Figure 11: Preferred type of delivery for self-management support**

<table>
<thead>
<tr>
<th>Type of delivery (responses)</th>
<th>Not at all comfortable</th>
<th>Not too comfortable</th>
<th>Somewhat comfortable</th>
<th>Very comfortable</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>In a group session (83)</td>
<td>26 (31%)</td>
<td>18 (22%)</td>
<td>21 (25%)</td>
<td>16 (19%)</td>
<td>2 (2%)</td>
</tr>
<tr>
<td>Face to face (82)</td>
<td>2 (4%)</td>
<td>4 (5%)</td>
<td>16 (20%)</td>
<td>57 (70%)</td>
<td>2 (2%)</td>
</tr>
<tr>
<td>Over the phone (82)</td>
<td>19 (23%)</td>
<td>15 (18%)</td>
<td>19 (23%)</td>
<td>28 (34%)</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>By text (82)</td>
<td>36 (44%)</td>
<td>12 (15%)</td>
<td>16 (20%)</td>
<td>15 (18%)</td>
<td>3 (4%)</td>
</tr>
<tr>
<td>Using smartphone e.g. apps (82)</td>
<td>30 (37%)</td>
<td>9 (11%)</td>
<td>17 (21%)</td>
<td>22 (27%)</td>
<td>4 (5%)</td>
</tr>
<tr>
<td>Online e.g. by laptop or computer (83)</td>
<td>18 (22%)</td>
<td>11 (13%)</td>
<td>22 (27%)</td>
<td>27 (32%)</td>
<td>5 (6%)</td>
</tr>
</tbody>
</table>
**Figure 12: What people would find most useful to help them manage their condition**

<table>
<thead>
<tr>
<th>Service Description</th>
<th>Heart</th>
<th>Diabetes</th>
<th>Cancer</th>
<th>Respiratory</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual care plan including what to do if the condition gets worse</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Devices to help monitor the condition at home</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Access to patient health record</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group education on how to manage the health condition</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Healthy lifestyles coaching/support</td>
<td></td>
<td></td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical activity/exercise on referral</td>
<td>1</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referral to community activity e.g. gardening/social group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary care review</td>
<td></td>
<td></td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support from specialist nurse</td>
<td>2</td>
<td>2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support from pharmacist</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information when diagnosed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Online information and support, e.g. websites or chat rooms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support from professionals to help manage low mood, anxiety or depression related to the health condition/s</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support from others who have experience of the same condition</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Online information and support, e.g. websites or chat rooms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support from professionals to help manage low mood, anxiety or depression related to the health condition/s</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support from others who have experience of the same condition</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (please comment)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Preferred types of support**

People were asked: “Thinking about the things you have NOT been offered, how useful would the following be to help you (or the person you care for) manage your condition well?” The full responses to these are in Appendix 1. Table 11 and 12 shows the top three responses for each condition. An Individual care plan including what to do if the condition gets worse featured strongly for all conditions, as did Support from professionals to help manage low mood, anxiety or depression related to the health condition/s. Healthy lifestyles coaching/support and physical activity/exercise on referral scored highly for people with diabetes or cancer.

Professional and voluntary sector responses also thought an individual care plan would be useful, and healthy lifestyle support or physical activity. They also placed strong emphasis on information when diagnosed.

**5.5 Outreach engagement**

The Patients Association is a member of the Cornwall Self-Management Leadership Group. They are an independent support organisation for all users of UK health and social care services with a mission is to harness the patient voice, to improve services and support people to engage fully in their own care. The Patients Association is also a partner with a project led by Plymouth University called E-health Productivity and Innovation in Cornwall and the Isles of Scilly (EPIC) aiming to improve the use of e-health in Cornwall.

As the EPIC programme was exploring similar health and wellbeing themes, it was recognised that the Patients Association could carry out engagement activity that would add insight to both programmes. The Self-Management Leadership Group were keen to hear from people who might not normally take part in consultation and engagement opportunities, sometimes known as ‘seldom-heard’ groups. Based on previous experience it was important to go to people rather than inviting people to focus group meetings.

Informal interviews were carried out during May 2018 in four different locations in Cornwall:

- Coastline Housing homeless day centre in Camborne
- Camborne Food bank
- Hearing Voices support group in Bodmin
- Breathers group in Liskeard

People were invited to speak one to one or in a group. A total of 30 people were spoken to in the various locations using a topic guide with questions designed to gauge people’s views about self-care of long-term conditions and current and potential use of digital technology. People
had a range of health conditions including cancer, gall bladder, mental health (depression, anxiety, paranoia), digestive problems, alcohol/substance misuse, COPD, diabetes, DVT/bad legs/lymphedema, atrial fibrillation.

**Findings**

Each setting produced slightly different feedback which had some common themes and individual characteristics for that specific user group as outlined below.

**Common themes**

- Not knowing what medication side effects might occur;
- Social isolation and wanting to be connected up to other people with similar conditions;
- Access to “fit bits”, exercise classes and advice on diet and weight loss but don’t know how to get it and can’t afford it;
- Don’t know how to load apps or what is free – would like prompts for activity, mindfulness and diet;
- Clinicians have no time or are not listening and often focus on wrong things;
- Support groups are helpful for people with same condition and when set up by people themselves seem more effective and sustainable;
- Keep it simple and don’t make assumptions about people’s ability to use technology or awareness of it;
- Technology can complement but not replace human contact;
- Greater awareness needed of what is available and alternative options to medication;

**Key messages from specific groups**

**Homeless Day Centre**

Six people were spoken to individually, one couple and a health professional

- Don’t make assumptions about people’s ability to use smart phones even if they have one and phones get frequently lost or stolen
- Poor self-esteem and chaotic lifestyles detract from ability to keep healthy and look after own wellbeing
- Anxiety/ fear of using Facebook but want to connect with local people
- Maslow’s Hierarchy of Needs applies – food/shelter tend to be high on priority list and technology low
- Need a communication access point – community pharmacies are very good for this and could be used more
- Facilities for couples to move onto or to be supported are more difficult to find yet still needed

**Foodbank**

Six people were spoken to including a brother and sister and two volunteers. They described a range of conditions including physical health conditions, mental health issues and learning disability. All had seen their GP within the last three weeks and had one or more long term condition.
Key points:

- People attend foodbanks for more than just food- informal support and drop in is very important
- Chaotic lifestyles prevent healthy lives and taking ownership of this
- Groups have been tried such as cooking etc but not easy to get people to attend
- Benefits help is needed and is often a cause of problems
- Lot of people attending have mental and physical health conditions
- Need access to support that hands back control to the person
- Little access to computers or knowledge about how to use smart phones, apps etc
- More use of text may be useful
- More opportunity for referral to activities that people enjoy such as gardening, football, activities but don’t cost money
- Healthy diet is perceived as expensive and time consuming
- People want to be treated as human beings not a number.

**Hearing Voices (mental health support group)**

Four people were spoken to with mental health conditions who also had physical health conditions such as cancer, diabetes etc.

Key points:

- Community Psychiatric Nurses (CPNs) do not always offer right type of help
- Would like techniques on how to manage own condition
- Help with benefit advice and access to therapies is needed
- Fit bits and other apps to help monitor activity levels, weight and diet are seen as useful but people need to know how to use them- fear that these are difficult to use and expensive
- Exercise classes are wanted but perceived as too expensive
- Gardening is popular and more opportunities to do this would be welcomed
- Need side effects of medication explaining in advance so can weigh up the pros and cons of taking this
- Group/peer support is helpful but not everyone likes this, and some people feel uncomfortable in group situations.

**Breathers group – support group for people with COPD**

Attended two meetings – 12 –15 people in attendance at each.

Key points:

- Many people have complex health problems and need to support the health issue which seems most worrying or felt to have the most impact on the person’s health needs at that time
- People with COPD and diabetes need support with diet. Concern by wheelchair users about putting on weight due to lack of exercise but not knowing where to get help about this. This should include how to have more energy to do exercises etc to help with her breathing – could an app do this?
- Make use of TV for information about diet and exercise as this would be much easier and more familiar for people than computers
- Could a flash stick be used to avoid need for computer or WIFI?
• Potential use of virtual reality to show what the impact on the body is of certain behaviours
• Helping others to see what can happen if you smoke - this seems to have big impact - give in depth and shorter talks to third year nurses and talks to school children about the dangers of smoking.

Outreach engagement conclusion

Although this was a small consultation exercise there were some in-depth interviews carried out with a range of people who are not often heard from and who had useful points to make about their experience of health and care services in Cornwall.

Generally, people were struggling with day to living with more than one long term condition and often associated mental health issues. The need to take account of people’s day to pressures, busy and/or chaotic lifestyles, poor self-esteem, social isolation and lack of access to or knowledge about technology is important. The health and social care system is confusing for most people and access to housing and benefits also needs to be considered as a whole system approach. Several of these organisations can only be accessed online, by computer yet so often people are not equipped to do this. Many people still do not have access to computers in Cornwall (one example was a cleaner in her 30s who couldn’t afford a computer) and even if someone has a smart phone it does not mean they know how to use it.

Peer support is increasingly important both in terms of support groups and drop in facilities though not everyone likes groups. Many people said they are frightened of Facebook yet would like to connect up with other people with similar conditions locally and the potential for a safe, online, virtual café facility was raised in several different types of settings.

More use of text, email and phone calls to save people travelling to unnecessary hospital appointments that take time and money both for organisations and patients was frequently mentioned. One person recently had to pay £60 for a taxi to get to an outpatient appointment.

What came out clearly was the increasing gap between the formal, professional NHS services and the more informal, voluntary and peer support which appear to offer a more sustainable and appropriate type of service. The need to start where people are, not make assumptions and communicate in a way that people can relate to is so important as well as giving people the tools to lead a more fulfilling and healthier lifestyle without preaching or telling people what to do. By working alongside people as equals and listening to what people saying it is more likely that services in the future will better meet people’s needs.

Section Author: Heather Eardley, Head of Projects and Partnerships, The Patients Association
6. What’s happening in Cornwall – Need, Supply and Demand

Key messages

This section summarises data on health and wellbeing for people with long term conditions in Cornwall, and factors that may impact ability to self-manage. It is not an exhaustive picture of LTCs need in Cornwall. Further detail can be found in other JSNA reports and data sources. It also describes some of the services available to support people to manage their conditions in Cornwall, and measures of their uptake and effectiveness where available. In healthcare, supply and demand do not always align with need.

6.1 Population

Cornwall and the Isles of Scilly is the second largest local authority area in the South West region, covering an area of 3,559 sq. km. It has varied landscapes including remote rural and coastal communities, interspersed with villages and market towns; where affluence sits alongside disadvantage. In line with national trends, Cornwall has a growing and ageing population (Figure 13), although this is not consistent across all areas of Cornwall. Typical challenges include areas of deprivation and associated health inequalities, high demand for affordable housing, transport infrastructure and the economy. However, Cornwall is a relatively safe place, and its environmental assets are extremely valuable to the economy and quality of life.

Figure 13: Population of Cornwall in 2015 and 2030 estimated projections
Figure 14 shows deprivation across Cornwall, across the six Integrated Care Communities and 20 STP working areas. Areas of deprivation are spread across the county rather than concentrated in one part. There are no areas in the 10th decile – the most affluent decile nationally.

Figure 14: Deprivation in Cornwall by Integrated Team Working Areas

4 Working Areas and Integrated Care Communities are a way of taking a ‘place-based’ approach to organising and planning healthcare. They are usually organised around clusters of GP practices.
Life expectancy and healthy life expectancy (PHE, 2018a)

Life expectancy at birth is similar to the national average:
79.6 for males compared to 79.5 for England
83.4 for females compared to 83.1 for England

Healthy life expectancy at birth is similar to the national average:
64.3 for males compared to 63.3 for England
62.4 for females compared to 63.9 for England

The gap in life expectancy at birth between the most deprived and least deprived is 6.4 years for males and 5.3 years for females.

Burden of LTCs in Cornwall

21.4% of the population report they have a health problem or disability that limits their day-to-day activities and has lasted, or is expected to last, at least 12 months, higher than the England average of 18.4% (PHE, 2018b).

67.5% of people are feeling supported to manage their condition (better than the England average of 64%). Health-related quality of life for people with LTCs is 0.73 (average EQ-5D score), similar to the England average of 0.74 (HSCIC, 2017).

The Global Burden of Disease Study is an international study analyses prevalence, mortality, and morbidity, and combines this data to show the relative burden of different conditions (Institute for Health Metrics and Evaluation, 2018).

Figure 15 shows the disability-adjusted life years (DALYs) lost to different diseases in the South West. The size of the box is proportionate to the burden contributed by that disease. As in other industrialised countries, a significant proportion of these are chronic, non-communicable diseases. Significant DALYs are lost to Ischaemic Heart disease (IHD), cancer, COPD, and diabetes, as well as various mental health and neurological conditions and musculoskeletal problems.

Figure 16 shows Years Lived with a Disability (YLD), defined as years of life lived with any short-term or long-term health loss. Similar to the DALYs, the majority is represented by chronic non-communicable diseases, but a greater proportion is represented by mental health and neurological conditions, sensory and skin conditions, and musculoskeletal conditions compared to cardiovascular and respiratory.

Figure 15: Relative burden of illnesses, shown by disability-adjusted life years (DALYs), South West, 2016

Figure 16: Relative burden of illnesses, shown by years lived with a disability (YLDs), South West, 2016


Figure 17 shows the prevalence of common long-term conditions in Cornwall, most of which are higher than the England average.

Figure 17: Prevalence of long-term conditions in Cornwall
Figure 18: Main drivers of life expectancy gap in Cornwall

Scarf chart showing the breakdown of the life expectancy gap between the most deprived quintile and least deprived quintile of Cornwall & Isles of Scilly, by broad cause of death, 2015-17

The biggest contributor for both males and females is circulatory disease. The biggest contributor for both males and females is circulatory disease.

Analysis by Public Health England Epidemiology and Surveillance team based on ONS death registration data, and mid-year population estimates, and DCLG Index of Multiple Deprivation, 2015.

Circulatory disease includes coronary heart disease and stroke. Respiratory disease includes flu, pneumonia and chronic obstructive airways disease. Digestive disease includes alcohol-related conditions such as chronic liver disease and cirrhosis. External causes include deaths from injury, poisoning and suicide. Mental and behavioural includes dementia and Alzheimer’s disease.

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6 Analysis by Public Health England Epidemiology and Surveillance team based on ONS death registration data, and mid-year population estimates, and DCLG Index of Multiple Deprivation, 2015.
7 Circulatory disease includes coronary heart disease and stroke. Respiratory disease includes flu, pneumonia and chronic obstructive airways disease. Digestive disease includes alcohol-related conditions such as chronic liver disease and cirrhosis. External causes include deaths from injury, poisoning and suicide. Mental and behavioural includes dementia and Alzheimer’s disease.
6.2 Mental health and wellbeing

As described in section 3, mental health and physical health are inter-linked, and poor mental health may impact on a person’s ability to self-manage a physical condition. For example, anxiety and depression are thought to impair cognitive factors, energy and motivation towards self-management, with depressed patients having a three-fold increased risk of non-compliance with medical treatment recommendations compared to non-depressed patients (DeMatteo et al., 2000). Depression can also lead to low attendance rates for medical appointments and finding it difficult to put in place self-care regimes such as smoking cessation, dietary changes, diabetes self-care and cardiac rehabilitation programmes (Naylor et al., 2012). For further information on the links between physical and mental health, see the forthcoming JSNA Focus Paper on Physical and Mental Health.

In Cornwall:

- 9.3% of people report a low happiness score, similar to the national average of 8.5% (PHE, 2018a).
- 17.55 of people report a high anxiety score, similar to the national average of 19.9% (PHE, 2018a).
- 76.1% report a high happiness score, similar to the England average of 74.7% and 83.4% report a high satisfaction score, similar to the England average of 81.2% (PHE, 2018b).
- There are similar prevalence rates of depression (8.9% vs 9.1%), depression and anxiety (13.5% vs 13.7%), and long-term mental health problems (5.7% vs 5.7%) when compared to England (PHE, 2018b).
- In the South West, 8.5% of people have coexisting long-term physical and mental health conditions, which varies between women (10.4%) and men (6.6%). These prevalence estimates have been used to estimate the number of people with a co-existing physical and mental health conditions in Cornwall and the Isles of Scilly (Table 19).^8

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^8 This does not account for local variations or potential changes in prevalence rates with time. Using local population estimates should be reviewed alongside these population profiles when they become available in 2018. A range in population estimates is necessary to inform future policy and practice because of the uncertainty in the projections and local variance. Also, this estimate is not reflective of those accessing specialist mental health services as previously described.
Support for emotional and mental wellbeing is often provided informally by family, friends, carers or the voluntary sector. Nationally there is increasing recognition of the value of providing IAPT (Increasing Access to Psychological Therapies) for people with physical LTCs, an approach that recognises that mental and physical health are intrinsically linked. In Cornwall, IAPT for LTC is being piloted in group sessions and through SilverCloud, an online platform. Psychological therapy is also available through clinical health psychology services, but this is limited to certain conditions.

### 6.3 Multi-morbidity

Regional multi-morbidity estimates show multi-morbidity must be addressed across the life course and particularly for those in deprived areas.

Of the 1.3 million people with multi-morbidity (2+ conditions) in the South West, 46.6% were under the age of 65. In the most deprived areas in the region, the figure was higher at 56.3%.

In the south west, multi-morbidity as well as physical and mental health comorbidity increases with age (figures 20 and 21). The prevalence of multi-morbidity and physical and mental health comorbidity was higher among females than males, especially in the 85+ age group.
Physical and mental health co-morbidity is disproportionately high among those in their mid-40s to mid-80s in the most deprived areas, in males.

In Cornwall, 81,654 people (almost 30% of the population) have 2 or more chronic conditions (table 21).
### 6.4 Ambulatory care sensitive conditions

Ambulatory care sensitive conditions (ACSCs) are conditions for which effective management and treatment should prevent admission to hospital. They can be classified as: chronic conditions, where effective care can prevent flare-ups; acute conditions, where early intervention can prevent more serious progression; and preventable conditions, where immunisation and other interventions can prevent illness (The King’s Fund, 2012).

In 2017, Cornwall and the Isles of Scilly had an ACSC admission rate of 680 per 100,000 population, which is in the lowest 30% of CCGs in England.\(^9\) This equates to over 4,500 admissions across Cornwall and the Isles of Scilly in 2017. Although admission rates are comparatively low they have increased since 2012/13 where rates were 522 per 100,000 population.

Nationally, the average increase of 2% per year between 2003/04 and 2012/13 for all ACSCs is made up of a decrease in the admission rate for long-term ACSCs, particularly for older people, and an increase in the admissions rate for acute ACSCs.

There is a small number of conditions driving up most of these admissions:

- Five long-term ACSCs – ‘other chronic obstructive pulmonary disease’, atrial fibrillation and flutter, asthma, heart failure and angina pectoris.
- Seven acute ACSCs – urinary tract infection (site not specified), lobar pneumonia (unspecified), diarrhoea and gastroenteritis of presumed infectious origin (increase has been driven by coding changes in these conditions), cellulitis, acute upper respiratory infections (multiple and unspecified sites), convulsions (not elsewhere classified) and viral and other specified intestinal infections.

The increase in the admission rate for acute ACSCs, particularly for older people, seems to indicate that an acute condition may be caused by the frailty of people with multiple LTCs and that looking at acute and chronic indicators together may provide a more complete picture.

---

\(^9\) Unplanned hospitalisation for chronic ambulatory care sensitive conditions Jan 2017- Dec 2017 (NHS outcomes framework 2.6)
6.5 Health service provision

Primary, secondary and tertiary healthcare all have a role to play in supporting people to self-manage their conditions, including from wider community providers such as pharmacies and voluntary sector. Under *Shaping Our Future*, integrated care in Cornwall is being planned by seven Integrated Care Communities (ICC) (including the Isles of Scilly). Spread across the seven ICCs are 20 clusters/working areas of GP practices that are collaborating to provide various services. In total there are 61 GP practices. Figure 23 shows the distribution of these GP practice clusters.

**Figure 23: STP Integrated Care Communities**

Secondary prevention of cardiovascular disease

Figure 24 shows the opportunities for CVD prevention in Cornwall and the Isles of Scilly (PHE and NHS England, 2018). The estimates of impact are indicative, but they show the scale of the opportunity to prevent heart attacks and strokes by improving the detection and management of high-risk conditions like atrial fibrillation, high blood pressure and high cholesterol. Achieving this at scale would deliver substantial benefits to individuals and savings in health and social care spend.
Figure 24: Cardiovascular Disease Prevention: Individual and Population Interventions

PHE working with Imperial College, commissioned a series of modelled prevalence estimates for the conditions shown in figure 25. This shows Cornwall has significantly higher than national average prevalence of hypertension and COPD (4.2%). Hypertension, both diagnosed (23.7%) and undiagnosed (13.4%).

High risk conditions like high blood pressure, atrial fibrillation and high cholesterol are major causes of heart attack and stroke (CVD events). Figure 25 shows the diagnosis and treatment gap for high risk conditions.
Late diagnosis and under-treatment is common, but preventive treatment is very effective, and offers substantial opportunities, for example:

- Reducing blood pressure in all adults with diagnosed and undiagnosed hypertension by 5 mmHg: **reduces risk of CVD events by 10%**
- Statin therapy to reduce cholesterol by 1 mmol in people with a 10-year risk of CVD risk greater than 10%: **reduces risk of CVD events by 20-24%**
- Anti-coagulation of high-risk AF patients: **averts one stroke in every 25 treated**

### The burden: first ever CVD events, 2015/16

<table>
<thead>
<tr>
<th>CVD Event</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coronary Heart Disease</td>
<td>2,050</td>
</tr>
<tr>
<td>Stroke</td>
<td>900</td>
</tr>
<tr>
<td>Heart Failure</td>
<td>650</td>
</tr>
</tbody>
</table>

### The opportunity: potential events averted and savings over 3 years by optimising treatment in AF and hypertension, 2015/16

<table>
<thead>
<tr>
<th>Treatment Description</th>
<th>Outcome</th>
<th>Cost Savings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Optimal anti-hypertensive treatment of diagnosed hypertensives averts within 3 years:</td>
<td></td>
<td>Up to £0.90 million saved</td>
</tr>
<tr>
<td>Optimally treating high risk AF patients averts within 3 years:</td>
<td></td>
<td>Up to £2.50 million saved</td>
</tr>
</tbody>
</table>
It is estimated that there are 62,033 people with undiagnosed hypertension in NHS Kernow CCG. The GP practice range of observed to expected hypertension prevalence ranges from 0.33 in Cardrew Health Centre to 0.69 in Old Bridge Surgery (PHE, 2017).

6.6 NHS Health Checks

The NHS Health Check is a health check-up for adults in England aged 40-74, designed to spot early signs of stroke, kidney disease, heart disease, type 2 diabetes or dementia. Early diagnosis is the first step on a person’s journey of LTC self-management. Cornwall has a lower offer rate of health checks than the national average, representing unrealised opportunity for early diagnosis and awareness.

- 44.5% of the eligible population aged 40-74 were offered an NHS Health Check in the five-year period 2013/14 - 2017/18, worse than the national average of 90.9% (PHE, 2018a).
- 48.4% of eligible population aged 40-74 who were offered an NHS Health Check received an NHS Health Check in the five-year period 2013/14 - 2017/18, similar to the national average of 48.7%
- 21.6% of the eligible population aged 40-74 received an NHS Health Check in the five-year period 2013/14 - 2017/18, worse than the national average of 44.3%

Flu vaccination

Influenza causes exacerbations and complications in people with LTCs, and is a significant cause of hospital admissions.

- In CIOS, 68.4% of over 65s had flu vaccination in 2016/2017, worse than the national average of 70.5% (PHE, 2018a).
- 44.4% of at risk individuals had flu vaccination in 2016/2017, worse than the national average of 48.6%

Uptake of flu vaccination is affected by both system factors, such as effective invitations and accessible appointments, and individual/social factors, such as perception of risk.

Cardiovascular disease

For further data on respiratory disease in Cornwall refer to the forthcoming JSNA Cardiovascular Disease Summary.¹⁰

Approximately 26% of deaths in the UK are due to cardiovascular disease (CVD).¹¹ Figure 26 shows summary statistics for Cornwall.

¹⁰ Available at: https://www.cornwall.gov.uk/health-and-social-care/public-health-cornwall/joint-strategic-needs-assessment-jsna/

¹¹ Cardiovascular disease (CVD) describes a family of diseases with a common set of risk factors that result from atherosclerosis (furring or stiffening of artery walls), particularly coronary heart disease, stroke and peripheral
Figure 26: summary statistics for Cornwall

<table>
<thead>
<tr>
<th>Statistic</th>
<th>Percentage</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arterial disease</td>
<td>16%</td>
<td>(88,577)</td>
</tr>
<tr>
<td>Hypertension (High blood pressure)</td>
<td>4%</td>
<td>(22,861)</td>
</tr>
<tr>
<td>Coronary Heart Disease (CHD)</td>
<td>3%</td>
<td>(14,900)</td>
</tr>
<tr>
<td>Cardiovascular disease</td>
<td>26%</td>
<td>(1,674)</td>
</tr>
</tbody>
</table>

Figure 27: Cardiovascular Disease Risk Factors

Figure 27 shows the main risk factors for cardiovascular disease. Some risk factors, such as family history, cannot be modified, while other risk factors, like high blood pressure, can be modified with treatment or prevented altogether, such as not smoking. Having more than one risk factor means the overall risk of CVD is much higher.

- **Age** - CVD is most common in people over 50 and the risk of developing it increases as people get older.
- **Obesity** - Being overweight or obese increases the risk of developing diabetes and high blood pressure, both of which are risk factors for CVD.
- **Alcohol** - Excessive alcohol consumption can also increase your cholesterol and blood pressure levels, and contribute to weight gain.
- **High cholesterol** - Cholesterol is a fatty substance found in the blood. High cholesterol can cause blood vessels to narrow and increase the risk of developing a blood clot.
- **Physical inactivity** - Low levels of physical activity can increase the risk of high blood pressure, high cholesterol levels and obesity. All of these are risk factors for CVD. Exercising regularly helps keep the heart healthy. When combined with a healthy diet, exercise can also help you maintain a healthy weight.
- **Ethnic background** - In the UK, CVD is more common in people of South Asian and African or Caribbean background. This is because people from these backgrounds are more likely to have other risk factors for CVD, such as high blood pressure or type 2 diabetes.
- **Stress** - Can exacerbate symptoms in people with pre-existing heart disease, and can contribute to high blood pressure.

- **Gender** - Men are more likely to develop CVD at an earlier age than women.
- **High blood pressure** - High blood pressure (hypertension) is one of the most important risk factors for CVD. If blood pressure is too high, it can damage blood vessels.
- **Tobacco** - Smoking and other tobacco use is also a significant risk factor for CVD. The harmful substances in tobacco can damage and narrow your blood vessels.
- **Diabetes** - Diabetes is a lifelong condition that causes blood sugar levels to become too high. High blood sugar levels can damage the blood vessels, making them more likely to become narrowed. Many people with type 2 diabetes are also overweight or obese, which is also a risk factor for CVD.
- **Family history of CVD** - If you have a family history of CVD, your risk of developing it is also increased. You're considered to have a family history of CVD if either:
  - a father or brother were diagnosed with CVD before they were 55
  - a mother or sister were diagnosed with CVD before they were 65
- **Unhealthy Diet** - An unhealthy diet can lead to high cholesterol and high blood pressure.
22,861 people (4%) across Cornwall and the Isles of Scilly were on the CHD disease register in 2016/17. This is higher than the prevalence for England (3.09%). The observed prevalence for CHD across Cornwall and Isles of Scilly is thought to be about 49% of the estimated prevalence, indicating around 51% of the population with CHD are undiagnosed. 6,337 people (1.1%) across Cornwall and Isles of Scilly were on the heart failure disease register in 2016/17. This is higher than the prevalence for England (0.77%). 14,232 (2.5%) across Cornwall and Isles of Scilly were on the Atrial Fibrillation disease register in 2016/17. This is higher than the prevalence for England (1.79%). The numbers of people registered with CHD, heart failure and atrial fibrillation is increasing annually in line with a growing and ageing population.

In 2016/17 the admission rate for CHD in NHS Kernow CCG was 619.9 per 100,000 population (4,026 admissions). This is significantly higher than the England rate (516 per 100,000) (figure 28). In 2016/17 the heart failure admission rate in NHS Kernow CCG was 144.9 per 100,000 population (965 admissions).

**Figure 28: CHD admissions (all ages)**

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The diagnosed prevalence of cardiovascular diseases is calculated from the returns submitted to NHS Digital as part of the Quality and Outcomes Framework (QOF) by each GP practice. Diagnosed prevalence is defined as the proportion of registered patients who are found to have a particular health condition on 31 March in a given financial year. Practice returns are combined to calculate a prevalence rate for the local CCG.
In line with England, cardiovascular disease is the second leading causes of death across Cornwall and the Isles of Scilly. However, mortality rates are falling. In 2016, 1,674 people across the area died from cardiovascular diseases, 26.5% of total deaths. Chronic Ischaemic heart disease, other forms of heart disease and acute myocardial infarction accounted for over 60% of CVD deaths in 2016 (figure 29).

*Other includes: Intracerebral haemorrhage (4.6%), Hypertensive diseases, exc. secondary hypertension (3.5%), Pulmonary heart disease and diseases of pulmonary circulation (3.5%)

Source: JSNA Cardiovascular Disease Topic Summary

Early mortality (under 75 years) rates from coronary heart disease are similar to the England rate (figure 30). Between 2014-2016, the early mortality rate for CHD in NHS Kernow CCG was 36.9 per 100,000 people. CVD under 75 mortality rates mortality rates across Cornwall and the Isles of Scilly have improved over the past 15 years, showing a reduction of 32%. However, this has not been as great as the England-wide reduction of 39%.

Deprivation and social class are key risk factors for CVD mortality. CVD is the most significant contributor to the gap in life expectancy between the most and least deprived groups in Cornwall, accounting for over 25% of the gap.
Across England premature death rates from cardiovascular disease in the most deprived 10% of the population were almost twice as high as the least deprived 10% in 2013-15. Higher smoking prevalence, unemployment, job insecurity and low education levels are all associated with increased risk of cardiovascular disease.

Figures 31 and 32 show a clear social gradient in cardiovascular disease mortality rates and mortality considered preventable by deprivation decile across CIoS.

Figure 31: Under 75 mortality rates from all cardiovascular disease – England, 2014-16 – data partitioned by county & UA deprivation deciles in England (IMD2015)

![Graph showing social gradient in cardiovascular disease mortality rates across deprivation deciles.]

Source: PHE, 2018a

Figure 32: Under 75 mortality rate from all cardiovascular diseases considered preventable – England, 2014-16 – data partitioned by county & UA deprivation deciles in England (IMD2015)

![Graph showing social gradient in preventable cardiovascular disease mortality rates across deprivation deciles.]

Source: PHE, 2018a

Better management of cardiovascular conditions in primary care has a significant influence on the usage of secondary care. Specialist treatment, combined with cardiac rehabilitation, leads to better outcomes and optimal quality of life. Getting treatment quickly is important for serious heart attack, where the coronary artery is blocked. In 2016/17, the South Western Ambulance Service Trust recorded 73.0% of these patients receiving primary percutaneous coronary intervention (primary PCI) treatment within 150 minutes from the time a call for help was made, worse than the England average of 85.8% (PHE, 2018c).
2258 patients were referred to Cornwall Community Cardiac services (Cornwall Partnership Foundation Trust) between April 2017 and March 2018. Cardiac teams are based in North and East, Central, and West Cornwall. Geographical distance and transport can be a barrier to uptake in Cornwall, so to mitigate this the team see patients in their own homes, community hospitals, in clinics, GP surgeries, nursing homes, residential homes as well as on hospital wards. Empowering patients and carers in order to achieve self-management is included in the service specification.

The service provides
- Information and health promotion
- Support to patients and family
- Medication titration
- Patient education including self-care strategies
- Formal education sessions for health care practitioners

They aim to complete a Comprehensive Assessment within 2 weeks for all patients, including risk assessments for:
- CVD risk factor management
- Lifestyle Management
- Psychosocial Wellbeing (e.g. HADS & Dartmouth COOP)
- Exercise/functional risk stratification

All patients and carers, referred to the service, are offered the support of a specialist nurse. Education and advice (verbal and written) is provided for all patients, tailored to their individual needs. All patients are supported and educated to enable them to become active self-managers of their condition.

NICE Guidance recommends cardiac rehabilitation to prevent further cardiovascular disease in people aged 18 and over who have had a myocardial infarction. In Cornwall, 13 cardiac rehab exercise groups run each week, providing specialist exercise information and treatment to 76 patients a week. After rehab, support is provided through Phase 4 exercise classes or local patient support groups, however, these are not available throughout Cornwall.

6.7 Diabetes

There are two main types of diabetes, type 1 and type 2. Both are characterised by having higher than normal blood sugar levels, but the cause and development of the conditions are different. Figure 33 shows some common differences between type 1 and type 2 diabetes, however there are exceptions to this, for example 20% of people with type 2 diabetes are a healthy weight when diagnosed. In the UK, 10% of people with diabetes have type 1, and 90% of people with diabetes have type 2. 56% of people with diabetes are men and 44% are women.
Figure 33: Common differences between type 1 and type 2 diabetes

<table>
<thead>
<tr>
<th>Type 1 Diabetes</th>
<th>Type 2 Diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Often diagnosed in childhood</td>
<td>Usually diagnosed in over 30-year olds</td>
</tr>
<tr>
<td>Not associated with excess body weight</td>
<td>Often associated with excess body weight</td>
</tr>
<tr>
<td>Often associated with higher than normal ketone levels at diagnosis</td>
<td>Often associated with high blood pressure and/or cholesterol levels at diagnosis</td>
</tr>
<tr>
<td>Treated with insulin injections or insulin pump</td>
<td>Is usually treated initially without medication or with tablets</td>
</tr>
<tr>
<td>Cannot be controlled without taking insulin</td>
<td>Approx 70% reversible and can go into remission with intensive lifestyle interventions</td>
</tr>
</tbody>
</table>

In Cornwall, 6.5% of the population (30,471 people) are on the diabetes QOF register, similar to the England average of 6.7%, but the estimated prevalence of diabetes – both diagnosed and undiagnosed, is 9.8% (45,923), higher than the England average of 8.5%. By 2025, there will be 51,713 people living with diabetes in Cornwall (both diagnosed and undiagnosed), or 10.6% of the population (PHE, 2015).

There is also a high estimated prevalence of adults with non-diabetic hyperglycaemia (sometimes known as ‘pre-diabetes’), at 12.6% (58,050 people) compared to 11.4% England average. If pre-diabetes is identified early and treated with lifestyle interventions including weight loss, dietary changes and physical activity, it can be prevented from developing into diabetes.

Cornwall has an estimated diagnosis rate of 65.3%, defined as the observed number of people with a formal diagnosis of diabetes as a proportion of the estimated number with diabetes. A value close to 100% indicates a small gap between the observed prevalence and estimated prevalence and indicates that a system is good at proactively identifying people with hitherto undiagnosed diabetes. This value is worse than the national average and worse compared to Cornwall’s CIPFA nearest neighbours (Figure 34).

Figure 34: Estimated diabetes diagnosis rate, CIPFA nearest neighbours (2017)

<table>
<thead>
<tr>
<th>Area</th>
<th>Recent Trend</th>
<th>Neighbour Rank</th>
<th>Count</th>
<th>Value</th>
<th>95% Lower CI</th>
<th>95% Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>~</td>
<td>~</td>
<td>77.1</td>
<td>~</td>
<td>73.7</td>
<td>80.1</td>
</tr>
<tr>
<td>Cornwall</td>
<td>~</td>
<td>~</td>
<td>65.9</td>
<td>~</td>
<td>62.1</td>
<td>68.3</td>
</tr>
<tr>
<td>Shropshire</td>
<td>~</td>
<td>~</td>
<td>71.3</td>
<td>~</td>
<td>67.7</td>
<td>74.7</td>
</tr>
<tr>
<td>Herefordshire</td>
<td>~</td>
<td>~</td>
<td>70.5</td>
<td>~</td>
<td>66.5</td>
<td>73.5</td>
</tr>
<tr>
<td>Cheshire West and Chester</td>
<td>~</td>
<td>~</td>
<td>79.7</td>
<td>~</td>
<td>75.9</td>
<td>83.4</td>
</tr>
<tr>
<td>Wirral</td>
<td>~</td>
<td>~</td>
<td>74.0</td>
<td>~</td>
<td>70.4</td>
<td>77.4</td>
</tr>
<tr>
<td>Cheshire East</td>
<td>~</td>
<td>~</td>
<td>75.7</td>
<td>~</td>
<td>72.0</td>
<td>79.2</td>
</tr>
<tr>
<td>East Riding of Yorkshire</td>
<td>~</td>
<td>~</td>
<td>61.2</td>
<td>~</td>
<td>57.1</td>
<td>65.0</td>
</tr>
<tr>
<td>North Somerset</td>
<td>~</td>
<td>~</td>
<td>73.6</td>
<td>~</td>
<td>69.7</td>
<td>77.0</td>
</tr>
<tr>
<td>Northumberland</td>
<td>~</td>
<td>~</td>
<td>82.7</td>
<td>~</td>
<td>79.6</td>
<td>86.5</td>
</tr>
<tr>
<td>Isle of Wight</td>
<td>~</td>
<td>~</td>
<td>67.0</td>
<td>~</td>
<td>64.0</td>
<td>70.9</td>
</tr>
<tr>
<td>North Lincolnshire</td>
<td>~</td>
<td>~</td>
<td>81.0</td>
<td>~</td>
<td>78.2</td>
<td>83.9</td>
</tr>
<tr>
<td>Calderdale</td>
<td>~</td>
<td>~</td>
<td>71.9</td>
<td>~</td>
<td>68.4</td>
<td>75.6</td>
</tr>
<tr>
<td>Stockport</td>
<td>~</td>
<td>~</td>
<td>75.1</td>
<td>~</td>
<td>71.4</td>
<td>78.4</td>
</tr>
<tr>
<td>South Gloucestershire</td>
<td>~</td>
<td>~</td>
<td>79.0</td>
<td>~</td>
<td>75.0</td>
<td>82.7</td>
</tr>
<tr>
<td>Knowsley</td>
<td>~</td>
<td>~</td>
<td>76.5</td>
<td>~</td>
<td>73.1</td>
<td>79.5</td>
</tr>
<tr>
<td>Wakefield</td>
<td>~</td>
<td>~</td>
<td>63.0</td>
<td>~</td>
<td>59.0</td>
<td>66.6</td>
</tr>
</tbody>
</table>

Source: PHE, 2018a
People with diabetes have an increased risk of other cardiovascular conditions, both acute and chronic, such as angina, myocardial infarction, heart failure and stroke. Stopping smoking and lowering HbA1c levels, blood fats and blood pressure can prevent or slow down complications.

The majority of diabetic care is delivered in primary care, and supported by specialist nurses, employed by Cornwall Partnership Foundation Trust.

**NHS RightCare** is a programme committed to reducing unwarranted variation to improve people’s health and outcomes and reduce inequalities in health access, experience and outcomes. It makes sure that the right person has the right care, in the right place, at the right time, making the best use of available resources. Figure 35 shows the opportunities identified by NHS Rightcare to improve care for people with diabetes (NHS Rightcare, 2018). It includes structured education programmes to improve self-management.

Figure 35: NHS Rightcare Pathway: Diabetes

![NHS Rightcare Pathway: Diabetes](image)

Source: NHS Rightcare (2018)

It is a local priority to improve the NICE three treatment targets (blood pressure, cholesterol, HbA1c), with an objective to demonstrate overall increase of 6.8% improvement in achievement of 3TT, (equal to 2,040 adults with diabetes) by March 2019.
There is wide variation in the number of people with diabetes who met all three treatment targets by GP practice, from 52.4% in St Mary’s Health Centre, to 21.7% in Chacewater Health Centre (2015/16).\(^\text{13}\) At least 13,868 people did not meet the three treatment targets.

48.4% of people with diabetes have received all nine care processes (2016/17), similar to the England average of 46.6%). There is wide variation in the number of people with diabetes who have received all nine processes by GP practice, from 84.7% in Key Lane Surgery, to 7.5% in Bottreaux Surgery (2015/16).\(^\text{14}\) At least 11,401 people did not receive all nine processes.

Figure 36 shows various diabetic care indicators. The standardised ratio for diabetes complications is 108.9, statistically similar to the England benchmark of 100.

### Figure 36: Diabetic Care Indicators

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Period</th>
<th>Kernow Count</th>
<th>Kernow Value</th>
<th>Sub-region Value</th>
<th>England Value</th>
<th>England Worst/Lowest</th>
<th>Benchmark</th>
<th>Range</th>
<th>Best/Highest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major diabetic lower-limb amputation procedures</td>
<td>2014/15-16/17</td>
<td>119</td>
<td>15.0</td>
<td>-</td>
<td>21.3</td>
<td>Low</td>
<td>2.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Minor diabetic lower-limb amputation procedures</td>
<td>2014/15-16/17</td>
<td>346</td>
<td>33.2</td>
<td>-</td>
<td>43.8</td>
<td>Low</td>
<td>6.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital spells for diabetic foot disease</td>
<td>2014/15-16/17</td>
<td>1,515</td>
<td>171.8</td>
<td>158.1*</td>
<td>145.5</td>
<td>Low</td>
<td>71.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median length of hospital stay for diabetic foot disease</td>
<td>2014/15-16/17</td>
<td>-</td>
<td>0.0</td>
<td>-</td>
<td>8.0</td>
<td>Low</td>
<td>3.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adjusted length of hospital stay for diabetic foot disease</td>
<td>2014/15-16/17</td>
<td>-</td>
<td>9.3</td>
<td>-</td>
<td>11.7</td>
<td>Low</td>
<td>5.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>People with type 1 diabetes who have received an annual foot check</td>
<td>2016/17</td>
<td>1,665</td>
<td>71.2%*</td>
<td>66.4%*</td>
<td>70.1%*</td>
<td>Low</td>
<td>83.0%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>People with type 2 diabetes who have received an annual foot check</td>
<td>2016/17</td>
<td>21,280</td>
<td>79.8%*</td>
<td>74.5%*</td>
<td>79.4%*</td>
<td>Low</td>
<td>95.2%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: PHE, 2018d

The rate at which major amputations occur in a diabetic population can be used as a good overall proxy measure of the effectiveness of healthcare and the diabetic foot care systems. Survival rates and quality of life for patients following a major diabetic lower-limb amputation can often be poor. The rates of major and minor lower-limb amputations and hospital spells for diabetic foot disease are all worse than the national average.

**Structured education** is one of part of the Menu of Preventative Interventions recommended by PHE that could provide benefits to patients and the health and social care system within a five-year timeframe (PHE 2016b). It is also recommended in NHS Rightcare (figure 35 above). The aim is to improve patient outcomes and reduce complications associated with diabetes. Structured education can support patients to stabilise blood glucose levels, reducing the risk of complications and improving quality of life, thus reducing the financial burden on the NHS and

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\(^{13}\) Not all practices participated in the Diabetes Audit. Full data set available from PHE (2017).

\(^{14}\) Not all practices participated in the Diabetes Audit. Full data set available from PHE (2017).

**Self-management of Long-Term Conditions** JSNA Report

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wider social care system (APPG on Diabetes, 2015). NHS England estimates that X-PERT (type 2 diabetes focused) could save between £66 to £76 per person p.a. One organisation delivering the programme to 3,500 patients could save £260k per year. Delivery of DAFNE (type 1 focused) could deliver savings of an estimated £93,000 per 100,000 population.

Currently only 5.7% of newly diagnosed diabetes patients attended a course in 2014/15 nationally. A lack of robust data collection on provision and uptake, services that are insufficiently holistic for patients’ needs and referrals of insufficient quality are some of the principal barriers to achieving good uptake.

In Cornwall, 55.5% of people with diabetes diagnosed less than a year ago were referred to diabetes structured education (2014/15), worse than the England average of 77.3%.

Kernow CIC\textsuperscript{15} will be delivering DESMOND education (type 2 focused), from Sept/Oct 2018. Group sessions called “Living Better with Diabetes” have also been piloted by Outlook South West to support the mental wellbeing of people with diabetes, designed to reduce stress, low mood and anxiety while supporting management of diabetes and a healthy lifestyle.

Cornwall Local Pharmaceutical Committee are piloting a community Pharmacist-led ‘Patient Activation Service’ for people with diabetes, with the aim of improving clinical outcomes and reduce hospital admissions due to diabetic ketoacidosis through increased patient activation, monitoring and self-management. The first phase focused on people with type 2 diabetes, the current phase focuses on recruiting people with type 1. Pharmacists are using a 1-2-1 health coaching approach including techniques such as motivational interviewing, to support people to set achievable goals that will improve their diabetes care, follow them up closely over a three-month period. The baseline and follow-up measurement is the Patient Activation Level (PAM), with the rationale that an increase of only one point has is associated with improvements in long term health outcomes, ultimately aiming to reduce the risk of hospital admissions due to ketoacidosis and also long-term complications associated with poor diabetes control. After the first pilot phase, 85% of participants maintained the goals they had set, and 74% had increased their PAM score, with a greater proportion of those who had started at a low PAM score increasing their score, resulting in a mean increase of 7.4 for all participants.

Support is also available through diabetes support groups, for example the West Cornwall Diabetes Support Group, which provides education and social connection for people with diabetes and aim to help people become confident at managing their condition. The number of groups is currently limited, but work is underway to strengthen links with local GP practices to increase referrals to the group and increase their reach.

\textbf{6.8 Respiratory disease}

For further data on respiratory disease in Cornwall refer to the forthcoming JSNA Respiratory Summary.\textsuperscript{16}

\textsuperscript{15} A Community Interest Company single provider for GP Practices in Cornwall and the Isles of Scilly.

\textsuperscript{16} Available at: \url{https://www.cornwall.gov.uk/health-and-social-care/public-health-cornwall/joint-strategic-needs-assessment-jsna/}
Respiratory diseases include asthma, chronic obstructive pulmonary disease (COPD), pneumonia, emphysema, bronchitis and acute respiratory distress syndrome (ARDS). Chronic obstructive pulmonary disease (COPD), describes a group of irreversible lung conditions, including bronchitis and emphysema.

Kernow CCG has a higher prevalence of respiratory disease than England, similar to the south west.

**Figure 37: Acute Respiratory Disease Prevalence**

Exacerbations and hospitalisations in patients with COPD represent a major health burden for both patients and healthcare systems. Acute exacerbations are the most common reason for hospital admissions and death among patients with COPD. Patients with COPD also have reported lower health-related quality of life (HRQoL), which is further impaired by acute and repeated exacerbations. Acute exacerbations are the main cost drivers for COPD care, accounting for more than 70% of COPD-related costs incurred as the result of emergency visits and hospitalisations (Puhan et al., 2016).

NHS Kernow emergency and total COPD admissions are lower than the England and South West averages. Respiratory deaths in under 75s are lower than the England average.

Deaths from acute respiratory disease (excluding influenza and pneumonia) are highest in the 85+ age group, in females and are increasing annually (figure 37).
Deaths from chronic lower respiratory disease are more common in males, more evenly spread across age groups, and are decreasing annually (figure 38).

A countywide specialist respiratory service provides care to adults with respiratory disease across Cornwall and the Isles of Scilly. Increasing self-management is a key aim for the service. Community respiratory nursing offers community (included home) based support and education to people with chronic respiratory disease, providing long term case management where necessary and working with other professionals and services to provide consistent care. Service users and their carers are offered information and ongoing support groups/services, including pulmonary rehabilitation when appropriate, to be able to manage their respiratory condition more effectively.

The pulmonary rehabilitation programme lasts for 9 weeks, at which stage service users are signposted to local support groups such as Breathe Easy or exercise groups. Reassessment is offered 6-9 months following completion of a programme.

Assessment and treatment by a Specialist Respiratory Nurse aims to be offered within 18 weeks of receipt of referral for at least 95% of patients. When a referral is received the service user
will be contacted by telephone as soon as possible within two weeks. Priority may be given to service users who require urgent assessment. Each patient will have a Personalised Care Plan within 4 weeks of being assessed, developed and managed in accordance with the Department of Health policy for the care and management of people with long term conditions.

Pulmonary rehabilitation is currently limited in geographical reach and capacity. In 2014/15, 11.3% of people with COPD and Medical Research Council (MRC) Dyspnoea Scale >=3, identified on GP systems, were referred to pulmonary rehabilitation, lower than the England average of 18.8%.

Peer support is provided through a number of volunteer-led groups, for example Breather’s groups in Liskeard, Torpoint, Kernow, Looe, Newquay, St Ives and Saltash, set up by patients in Cornwall to support each other after pulmonary rehabilitation ended\(^{17}\) and also through various British Lung Foundation Breathe Easy groups.\(^{18}\)

\[\text{"I am so inspired by the group, every week I look forward to going. I used to think I was the only one with COPD til I joined, even my husband understands more about the condition since I joined, I can’t praise it enough."}\]

Breather’s member

6.9 Cancer

For further data on respiratory disease in Cornwall refer to the forthcoming JSNA Cancer Summary.\(^{19}\)

It is estimated that 1 in 2 people in the UK born after 1960 will get cancer in their lifetime (CRUK, 2018). Cancer accounted for 28.5% of all deaths registered across England in 2016 and remains the most common broad cause of death for both men and women.\(^{20}\) Although cancer takes many forms, four types account for over 50% of all new cancer registrations across England every year: breast, prostate, lung, and colorectal cancer.\(^{21}\)

Cancer survival rates have improved dramatically in England in recent decades, and in Cornwall almost 46% of cancer patients survive 10 years or more from diagnosis. But people who have recovered from cancer are often left with a lasting impact on their mental and physical wellbeing, which means ‘living with and beyond cancer’ now shares many characteristics of living with other long-term conditions, and long-term care planning and facilitating self-management has been recommended nationally (National Cancer Survivorship Initiative, 2013).

Cancer survival varies greatly between cancer types, ranging from 98% for testicular cancer to just 1% for pancreatic cancer.

\[\text{\footnotesize 17} \text{http://breathers.org.uk/about/}\]
\[\text{\footnotesize 18} \text{https://www.blf.org.uk/support-in-your-area?field_lat_long_distance%5Blocation%5D=tr1+3ay}\]
\[\text{\footnotesize 19} \text{Available at: https://www.cornwall.gov.uk/health-and-social-care/public-health-cornwall/joint-strategic-needs-assessment-jsna/}\]
\[\text{\footnotesize 20} \text{Deaths registered in England and Wales: 2016, ONS}\]
\[\text{\footnotesize 21} \text{Cancer registration statistics, England: first release, 2016, ONS}\]
• Cornwall had 674 per 100,000 new cases of cancer in 2014/15, higher than England at 523 new cancer cases per 100,000 population. During 2014/15, a total of 3,726 new cancer cases were diagnosed in Cornwall and the Isles of Scilly residents.
• 2,243 people died from cancer between 2014-16. 54% of cancer deaths could be prevented
• Breast, prostate, lung and bowel cancers together accounted for over a third (36%) of new cancer cases across Cornwall and IoS between 2013 and 2015.
• The incidence of all cancers is rising steadily nationally, regionally and locally. Across Cornwall and the Isles of Scilly the crude incidence rate of cancer has been consistently higher than both the South West and England since 2009. Due to the older age profile of Cornwall, crude incidence of all cancers (ex. non-melanoma skin cancer) is higher than the England average, and increasing, however age standardised rates for the four cancer types (breast, colon, prostate and lung) are all lower than England.
• The Under 75 mortality rate from cancer considered preventable across Cornwall and the Isles of Scilly between 2014 -2016 was 69.0 per 100,000 population. This is significantly better than the rates for the South West (71.8) and England (79.4).
• Cancer incidence is higher in males than females (figure 40).

Figure 40: Cancer Incidence by Gender

Cancer is generally associated with socioeconomic deprivation, especially for tobacco and other lifestyle-related cancers. However, cancers of the breast, prostate and malignant melanoma are more common in those with higher socioeconomic status. In Cornwall, many of the areas with the highest incidence contain areas which are within the most 20% deprived nationally. Falmouth wards showed the highest incidence for breast cancer and the wider Falmouth
Penryn area for lung cancer. **Cancer deaths** are more common in people living in the most deprived areas.

Across Cornwall and the Isles of Scilly, 17% of the difference in life expectancy between the highest and lowest deprivation quintile is due to cancer, with lung cancer being the most common single type of cancer responsible for this difference.

The tables below show that the most deprived people in Cornwall and the Isles of Scilly have the highest cancer early and preventable death rates and that rates get steadily better moving up the deprivation deciles. Those in the least deprived decile have the lowest early and preventable death rates.

**Figure 41: Under 75 mortality rate from cancer – England, 2014-16 – data partitioned by county and UA deprivation deciles in England (IMD 2015)**

![Graph showing mortality rate from cancer by deprivation decile in England](image)

Source: PHE, 2018a
In Cornwall, cancer patients are treated by the Royal Cornwall Hospital Trust. Support is also provided through The Cove, a Macmillan Cancer Support Centre. They offer information and advice, counselling and psychological therapies, finance and benefits advice, health and wellbeing activities and advice, and patient support groups. There are also various site-specific cancer peer support groups across Cornwall. The challenge in Cornwall is around demand and access; there are waiting lists for some of the Cove’s services, especially counselling, and support is more easily accessible for people who live in central Cornwall. Health and wellbeing, including self-management, is being prioritised for people living with and beyond cancer through the Cancer Transformation Fund, including health and wellbeing assessments/plans for individuals and access to health and wellbeing activities. ‘Orientation’/education is available for certain site-specific cancers, for example all men diagnosed with prostate cancer are invited to a half-day workshop to help them understand their condition, practical ways to look after their physical and mental health and wellbeing and are given the option to stay in touch with each other for peer support. This format appears to get high uptake and good feedback from participants. Various site-specific cancer peer support groups are also available across Cornwall.

6.10 Healthy lifestyles

In Cornwall, 75% of deaths and disability are cause by five diseases, which are caused by five main risk factors (Figure 43). Supporting people to live a healthy lifestyle, including building social connections, can bring substantial benefits to individuals and communities and prevent a range of LTCs.
• 64.2% of the population meet the recommended ‘5 a day’ on a usual day (adults), better than the national average of 57.4%.

• 64.3% of adults are classified as overweight or obese, similar to the national average of 61.3%.

• 69.0% of adults meet CMO recommendations for physical activity (150+ moderate intensity minutes per week), similar to the national average of 66.0%.

• 19.7% of adults are physically inactive (>30 minutes moderate intensity minutes per week), similar to the national average of 22.2%.

• 14.8% of adults are current smokers, similar to the national average of 14.9%. There is wide variation in the registered QOF smoking prevalence of GP practices in Cornwall, from 28.2% in Cardrew Health Centre, to 10.1% in Carnon Downs (PHE, 2017).

• Cornwall had 738 per 100,000 population hospital admissions for alcohol-related conditions, (all ages, directly age standardised rate), worse than the national average of 636 per 100,000 population (PHE, 2018a).

Healthy lifestyle support (for stop smoking, physical activity, healthy eating and healthy weight) is an important component of LTC self-management. People have told us that keeping up healthy lifestyle changes is one of the main things they find difficult around managing their condition, and they would welcome more support. People can currently get some education/support through condition-specific programmes, e.g. diabetes structured education, or cardiac rehab, but this is either time-limited or not available everywhere. Some healthy lifestyle support is also provided through local voluntary groups, e.g. Newquay Happy Hearts have British Heart Foundation accredited trainers who lead physical activity sessions.

Support is also available through Healthy Cornwall22, who provide lifestyle reviews, stop smoking clinics and healthy weight group sessions. From April 2017 – March 2018, 352 adults completed a healthy weight course with Healthy Cornwall. Of these, 38% had a heart condition or high blood pressure, 37% had any chronic condition (may overlap with first category), and 15% had type 1 or 2 diabetes. Currently, although Healthy Cornwall support a number of people with

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22 Healthy Cornwall website [https://www.healthycornwall.org.uk/](https://www.healthycornwall.org.uk/)
LTCS, there are some limitations, for example people with heart conditions are not able to take part in the physical activity part of the healthy weight courses. This could be mitigated by training HC staff in Level 4 Cardiac Exercise Training, to ensure they can safely deliver sessions to people with heart conditions. Additionally, staff would welcome further skills and training to be able to support people with LTCS with other aspects of self-management, such as breathlessness and symptom management, where appropriate.

6.11 Social connections

Social connection is a protective factor for health and wellbeing, and there is a clear link between loneliness and poor mental and physical health. 42.4% of adult social care users have as much social contact as they would like (similar to the national average of 45.4%) (PHE, 2018a).

Figure 44 shows Cornwall has a high percentage of people aged 65+ living alone (14.8%), compared to similar CCGs and the national average (12.4%).

**Figure 44: Percentage of people aged 65+ living alone, 2011**

Source: PHE, 2016c

Finding social and community support can be a challenge for both professionals and people living with a condition. For those with digital access, Age UK are trying to meet this need by developing a new website called Cornwall Link. Statutory information is also available through the Cornwall Council Support in Cornwall website. A number of GP practices now have Care
Navigators and Community Builders in place. A new social prescribing service in Cornwall will employ eight link workers, linked to GP practices, who can refer people for social and community support in the local area. Social prescribing provides one route to wider practical and social support.

6.12 Employment

Meaningful work is generally good for both physical and mental health and wellbeing. People with an LTC are less likely to be employed than those without a LTC, and in Cornwall the gap is worse than the national average at 34%, and one of the worst among its CIPFA nearest neighbours (Figure 45).

Figure 45: Gap in the employment rate between those with an LTC and overall employment rate, CIPFA nearest neighbours (2016/17)

<table>
<thead>
<tr>
<th>Area</th>
<th>Recent Trend</th>
<th>Neighbour Rank</th>
<th>Count</th>
<th>Value</th>
<th>95% Lower CI</th>
<th>95% Upper CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>29.4</td>
<td>29.2</td>
<td>30.5</td>
</tr>
<tr>
<td>Cornwall</td>
<td>–</td>
<td>–</td>
<td>–</td>
<td>34.3</td>
<td>30.1</td>
<td>38.7</td>
</tr>
<tr>
<td>Shropshire</td>
<td>–</td>
<td>1</td>
<td>–</td>
<td>27.4</td>
<td>31.3</td>
<td>24.0</td>
</tr>
<tr>
<td>Herefordshire</td>
<td>–</td>
<td>2</td>
<td>–</td>
<td>30.9</td>
<td>34.4</td>
<td>26.6</td>
</tr>
<tr>
<td>Cheshire West and Chester</td>
<td>–</td>
<td>3</td>
<td>–</td>
<td>35.4</td>
<td>37.2</td>
<td>33.9</td>
</tr>
<tr>
<td>Wiltshire</td>
<td>–</td>
<td>4</td>
<td>–</td>
<td>30.7</td>
<td>28.2</td>
<td>33.0</td>
</tr>
<tr>
<td>Cheshire East</td>
<td>–</td>
<td>5</td>
<td>–</td>
<td>34.4</td>
<td>28.6</td>
<td>40.7</td>
</tr>
<tr>
<td>East Riding of Yorkshire</td>
<td>–</td>
<td>6</td>
<td>–</td>
<td>31.7</td>
<td>33.9</td>
<td>29.5</td>
</tr>
<tr>
<td>North Somerset</td>
<td>–</td>
<td>7</td>
<td>–</td>
<td>26.5</td>
<td>23.7</td>
<td>29.2</td>
</tr>
<tr>
<td>Northumberland</td>
<td>–</td>
<td>8</td>
<td>–</td>
<td>26.8</td>
<td>26.0</td>
<td>29.6</td>
</tr>
<tr>
<td>Isle of Wight</td>
<td>–</td>
<td>9</td>
<td>–</td>
<td>27.6</td>
<td>24.9</td>
<td>30.0</td>
</tr>
<tr>
<td>North Lincolnshire</td>
<td>–</td>
<td>10</td>
<td>–</td>
<td>25.5</td>
<td>22.5</td>
<td>29.0</td>
</tr>
<tr>
<td>Cumbria</td>
<td>–</td>
<td>11</td>
<td>–</td>
<td>26.3</td>
<td>25.4</td>
<td>27.2</td>
</tr>
<tr>
<td>Stockport</td>
<td>–</td>
<td>12</td>
<td>–</td>
<td>30.2</td>
<td>27.6</td>
<td>32.8</td>
</tr>
<tr>
<td>South Gloucestershire</td>
<td>–</td>
<td>13</td>
<td>–</td>
<td>27.1</td>
<td>24.5</td>
<td>30.7</td>
</tr>
<tr>
<td>Kirklees</td>
<td>–</td>
<td>14</td>
<td>–</td>
<td>28.4</td>
<td>26.5</td>
<td>32.8</td>
</tr>
</tbody>
</table>

Source: ONS Annual Population Survey
Source: PHE, 2018a

6.13 Carers

Over six million people are involved in informal caring, a quarter of them full time, with the total value estimated at £132bn a year – greater than the NHS budget (Yeandle and Buckner, 2015). They are the biggest ‘workforce’ and deliver the bulk of care. In Cornwall 28.9% of carers say they have as much social contact as they like, lower than than England average of 35.5%.

6.14 Healthy Homes

Living in a cold, damp, hazardous home can exacerbate many long-term conditions. It is estimated that the cost to the NHS of all homes with significant hazards in England is £2.0bn in first year treatment costs alone: excess cold and falls present the greatest hazards (Nichol et al., 2015). There is a clear link between excess winter deaths and cold homes, cardiovascular disease, and respiratory illness, and also increases in falls and injuries.
In Cornwall, 34,176 households (14.2% of households) experience fuel poverty, compared to the England average of 11.0%.\(^{23}\) Figure 46 shows that NHS Kernow has a high level of fuel poverty compared to similar CCGs. *Commissioning for Value* recommends that CCGs and Local Authorities should work together to routinely identify people at risk and offer access to integrated services and interventions which can enable the home environment to be a healthy one, and in doing so, reduce hospital admissions, length of stay, delayed discharge, readmission rates and ultimately improve outcomes, particularly by promoting equality (PHE, 2016c). The Cornwall Winter Wellbeing service provides housing interventions and advice to those with poor housing, and people with long term conditions are one of the service’s target groups. A Cold Homes Toolkit is also available for professionals to help them identify and refer people at risk of poor housing.\(^{24}\)

**Figure 46: Percentage of households that experience fuel poverty**

![Percentage of households that experience fuel poverty](https://www.citizensadvice.org.uk/about-us/how-we-provide-advice/advice-partnerships/cold-homes-toolkit/)

Source: PHE, 2016c

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\(^{23}\) Based on the "Low income, high cost" methodology (PHE, 2018a).

Information and Advice

Information on maintaining a healthy lifestyle is available from major charities, such as Macmillan Cancer Support\(^{25}\), British Heart Foundation\(^{26}\), British Lung Foundation\(^{27}\), and Diabetes UK\(^{28}\). Much of this information is online so is easier to access for people who are comfortable with technology.

In 2017, 89% of adults in the UK had recently used the internet (in the last 3 months), up from 88% in 2016; while 9% had never used the internet, down from 10% in 2016 (ONS, 2017). There were significant differences by age group, with 99% of all adults 16 to 34 years were recent internet users (99%), in contrast with 41% of adults aged 75 years and over (figure 47). However, increasing numbers of older people are going online, with recent internet use among women aged 75 and over almost trebling from 2011, and this trend is set to continue. 22% of disabled adults had never used the internet in 2017, down from 25% in 2016.

**Figure 47: Internet Users in the UK by age group, 2017**

Almost 9 in 10 adults in the UK have recently used the internet (89%)

Almost all adults aged 16 – 54 years have recently used the internet ...

- 16-34: 99%
- 35-54: 97%
- 55-64: 90%
- 65-74: 78%
- 75+: 41%

... but just 4 in 10 adults aged 75+ years have used the internet in the last 3 months

Source: ONS, 2017.

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\(^{25}\) Macmillan Cancer Care. [https://www.macmillan.org.uk/](https://www.macmillan.org.uk/)

\(^{26}\) British Heart Foundation. [https://www.bhf.org.uk/](https://www.bhf.org.uk/)

\(^{27}\) British Lung Foundation. [https://www.blf.org.uk/](https://www.blf.org.uk/)

\(^{28}\) Diabetes UK. [https://www.diabetes.org.uk/](https://www.diabetes.org.uk/)
Information is also provided through local peer support groups, and at various points in condition care pathways, however it is difficult to assess the quantity and quality of information given and to what extent it meets the needs of the individual. The Patient Information Forum has developed a toolkit to help services assess and improve the information they provide to people (Patient Information Forum, 2018).

Health and social care videos, developed by clinicians and specialists at Torbay and South Devon NHS Foundation Trust, are currently being made available through primary care in Cornwall to help people get information on how to manage their condition. Their reach and engagement are under evaluation.  

### 6.15 LTC peer support

Various peer support groups exist across Cornwall which can offer social support, education, physical activity opportunities and information and advice. Appendix 2 maps some groups across Cornwall but is not exhaustive. Some are linked to national charities, such as Diabetes UK, British Heart Foundation, Macmillan and the British Lung Foundation, often run by local volunteers. Others are independently set up and run by local volunteers.

Challenges can include recruiting new members and volunteers, creating links with GP surgeries, and long-term sustainability. It can also be a challenge for groups to raise awareness and get themselves known among professionals and patients. One solution is the Cornwall Link community directory. Social prescribing may also be another potential referral route that would strengthen links between GP practices and groups.

**Expert Patient Programme**

The Expert Patient Programme (EPP) is a six-week course run over weekly 2.5-hour sessions, delivered by trained lay (patient) tutors at local community venues. It provides group-based support for people in the self-management of their LTC. The programme is aimed at a wide range of people with different LTCs and of varying ages and ethnicity.

The EPP is an NHS initiative launched in 2002, based on the Chronic Disease Self-Management Programme (CDSMP) model developed in the United States. It teaches people to manage their conditions using five core skills:

- problem solving
- decision making
- making the best use of resources
- developing effective partnerships with healthcare providers
- taking action (on a personal level)

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29 [https://www.torbayandsouthdevon.nhs.uk/?s=health+and+care+videos+](https://www.torbayandsouthdevon.nhs.uk/?s=health+and+care+videos+)
The course helps patients to develop their communication skills, manage emotions, manage daily activities, interact with the healthcare system, find health resources, plan for the future, understand exercise and healthy eating, and manage fatigue, sleep, pain, anger and depression.

The programme has achieved good outcomes, albeit primarily for an ‘activated’, middle-class, female cohort (Rogers et al., 2008), and has gone on to deliver courses to over 100,000 people with LTCs. However, the programme also has its limitations; it has been criticised for its over-reliance on self-efficacy at the cost of social factors, its inability to work effectively with statutory services (e.g. to encourage effective referral systems from healthcare professionals), and for its relatively low involvement of patients from lower socioeconomic and ethnic minority backgrounds (Kendall and Rogers, 2007; Batehup et al., 2011).

The programme reaches around 100 people in Cornwall each year.

**Digital Support and Technology Enabled Care**

Technology enabled care is an umbrella term that includes assistive, adaptive, and rehabilitative devices and the process used in selecting, locating, and using them. Assistive technology promotes greater independence by enabling people to perform tasks that they had difficulty accomplishing before. Under the Transforming Adult Social Care programme there is a project aimed at considering the future use of assistive technology.

- **Telecare** includes services that incorporate personal and environmental sensors in the home or remotely, that enable people to remain safe and independent for longer.

- **Telehealth** includes electronic sensors or equipment that monitor health markers in the home or remotely. Readings are automatically sent to a trained person and can inform treatment decisions without the patient needing to attend a healthcare venue.

- A **smart home** has advanced automation systems that give people monitoring and control over the building’s functions. For example, a smart home may control lighting, temperature, multi-media, security, window and door operations. Assistive demotics aims to help people with illnesses or disabilities to live independently. For example, automated reminders or audio messages prompted by motion sensors; to remind someone to turn off the oven or lock the front door.

A new Telehealth service specification is being developed in Cornwall that includes self-management support.

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30 [https://www.cornwallft.nhs.uk/about-us](https://www.cornwallft.nhs.uk/about-us)
7. Effective Interventions (evidence)

Key messages

The evidence base on self-management is substantial but cannot answer all questions about how best to prioritise person-centred self-management. Issues to keep in mind include:

- More research has taken place on some interventions, such as structured education for self-management, than others, such as psychological support for people with long term physical health conditions.
- Few studies have followed up longer-term outcomes of interventions.
- Most research is from North America. We need to consider whether each study is generalisable to Cornwall.
- There is good evidence that some interventions make a difference, especially to patient-reported outcome measures (PROMs), but there is less evidence on cost-effectiveness.
- Evidence is lacking on how to ensure self-management of long-term conditions reduces health inequalities and reaches those who find it hard to take part.

Evidence shows key components to enable self-management are:

- **Education for patients and carers**: condition-specific education in a variety of formats have been studied (group, individual, lay-led, online) but it is unclear whether any one format is most effective
- **Practical support**: for example, treatment or medication adherence support and occupational and physiotherapy to help people with long-term conditions cope with activities of daily living
- **Action planning** in conditions such as COPD where risk of deterioration is high
- **Psychological support**: helping people address changes to their ‘normal’ life and identity as a consequence of their long-term condition
- **Social support**: the need for social support is a major issue, particularly in diabetes, stroke and dementia.
Rapid Evidence Review

Self-management of long-term conditions is a clear local and national policy driver. Alongside policy and local engagement, an overview of research is required to make sure local decisions are evidence-based and to inform policy and practice. Therefore, a brief structured literature review was completed to better understand effective interventions.

Methodology

To inform the scope of the review, an initial search found that the University of York Centre for Research Dissemination (CRD) conducted some high-quality briefings and reviews at the beginning of 2015.

• Supporting self-management: helping people manage long term conditions (February 2015)
• Effects of lay-led self-care education programmes (December 2014)

Two further relevant reviews were available - Supporting self-management: summarising evidence from systematic reviews (National Voices, 2015), and Peer Support (Nesta, 2015a). The findings of these reviews are summarised below. Despite methodological limitations, they are considered to be adequate summaries of the evidence base up to 2015. This rapid review therefore focused on searching literature from 2015 onwards.

Literature searches were conducted in Pubmed electronic database using synonyms for self-management interventions (see Appendix 3). Searches were restricted to systematic reviews, published from 2015 onwards, in English language.

Limitations and gaps in the evidence

A total of 1732 potential articles were identified. Following screening of title and abstracts, 271 relevant systematic reviews were identified, which highlighted a range of interventions to improve self-management support for long term conditions. A formal systematic review of self-management interventions was not possible due to resource limitations, so the summary below is indicative but not exhaustive. Due to time constraints, the summary is restricted to Cochrane Reviews, which are considered to be highly methodologically robust. 22 relevant Cochrane Reviews were identified. Summary information only is provided; refer to articles for further details on intervention/ participation characteristics and outcomes.

The evidence base is substantial but cannot answer all questions about how best to prioritise person-centred self-management support. Issues to keep in mind include:

• More research has taken place on some interventions, such as structured education for self-management, than others, such as psychological support for people with long term physical health conditions.
• Few studies have followed up longer-term outcomes of interventions.
• Most research is from North America. We need to consider whether each study is generalisable to Cornwall.
• There is good evidence that some interventions make a difference, especially to patient-reported outcome measures (PROMs), but there is less evidence on cost-effectiveness.
• Evidence is lacking on how to ensure self-management of long-term conditions reduces health inequalities and reaches those who find it hard to engage.

Summary of Findings

This section includes summaries of the most relevant ‘reviews of reviews’ up to 2015.

The University of York Centre for Reviews and Dissemination (CRD, 2015) Supporting self-management: helping people manage long term conditions

This review is largely based on the findings of two well conducted systematic reviews about self-management.\(^{31,32}\) It found successful self-management interventions are multi-component and should be tailored to the individual. Support that fits well with people’s existing circumstances and ways of dealing with their condition is more likely to be successful.

Key components of self-management support are:

- **Education for patients and carers**: condition-specific education in a variety of formats have been studied (group, individual, lay-led, online) but it is unclear whether any one format is most effective
- **Practical support**: for example, treatment or medication adherence support and occupational and physiotherapy to help people with long-term conditions cope with activities of daily living
- **Action planning** in conditions such as COPD where risk of deterioration is high
- **Psychological support**: helping people address changes to their ‘normal’ life and identity as a consequence of their long-term condition
- **Social support**: the need for social support was a major issue, particularly in diabetes, stroke and dementia

Age is not a necessarily a barrier to learning self-management skills. However, recruiting and retaining patients is a major challenge, particularly in deprived communities. Work schedules, family commitments, lack of transport, cost of medication and dietary changes may be barriers to engaging with self-management. Barriers perceived by patients can be overcome with good communication, including clinicians listening to and hearing what is said by patients, and providing broader support to patients so that they feel capable of acquiring and understanding knowledge.

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There is a lack of evidence on self-management for people with multi-morbidity, which is important as people with multi-morbidity potentially face significant barriers to self-management support but may also have the greatest capacity to benefit. The majority of participants in studies of self-management support are highly selected: they are interested, feel capable and are committed to developing self-management skills. There is therefore a risk that self-management interventions may widen health inequalities unless effort is made to reach those who find it harder to engage.

Engagement is more likely when interventions are tailored to the needs of individual patients. For example, men may find self-management support more attractive when it is seen as action-oriented, having a clear purpose, and offering practical strategies that can be integrated into daily life (Galdas et al., 2014). Asking patients, particularly those with multi-morbidity “what would you like to focus on today?” may be useful.

Organisational culture is important for integrating self-management principles into routine care. Key elements for successful implementation include:

- Strong clinical leadership to ensure self-management is prioritised
- Involving stakeholders so that professionals are engaged with the process of change
- Training to ensure all staff have the necessary skills
- Resources to enable ongoing delivery
- Regular evaluation

The evidence is focused on disease-specific self-management support which may present some complexity for service delivery. However, it has been suggested that a more generic approach could potentially be used for a number of conditions and may be useful for patients with multi-morbidity.

The University of York Centre for Reviews and Dissemination (CRD, 2014), Effects of lay-led self-care education programmes

This evidence summary focused on lay-led self-care education programmes. A Cochrane review assessed lay-led self-care education programmes for people with a range of long-term conditions (Galdas et al., 2014). Facilitators were generally lay people (some of whom had a long-term condition), health professionals or students. Most programmes were delivered over six weekly 2.5-hour sessions. The review found small, short-term improvements in self-efficacy, self-rated health, cognitive symptom management and frequency of exercise. There was no evidence that lay-led self-care education improved health-related quality of life or reduced primary care visits and emergency department visits.

A more recent systematic review included a number of RCTs including two trials of the UK Expert Patient Programme, launched in 2001.

The UK Expert Patient Programme
Delivered by one or two lay facilitators with a chronic condition
Six weekly sessions of 2.5 hours
Face-to-face sessions, plus educational manual or video
Sessions addressed:
• Communicating with health professionals
• Lifestyle change e.g. diet, exercise
• Medication management
• Psychological issues
• Symptom management
• Self-management
• Social support

The review found some short-term improvement across a number of health status measures including pain, depression and self-rated health; health behaviour outcomes including exercise and communication with professionals; and self-efficacy. There was no evidence of impact on health care utilisation.

Over 70% of participants in the Cochrane review of lay-led self-care education programmes were women. Participants in the UK trials of the Expert Patient Programme were “self-referred” and were therefore interested and committed to developing self-care skills. Many rated their health as reasonably good at baseline. Evaluation of the Expert Patient Programme suggests a programme that fits well with people’s existing mechanisms for dealing with their condition is more likely to be successful, and self-care may be improved by addressing people’s needs and access to welfare support, as well as focusing on developing self-efficacy.

Recruiting and retaining volunteers is essential to the success of lay-led education. Contact through community projects and newsletters is likely to be more successful than more formal recruitment methods. Managing and training volunteers requires expertise and considerable time commitment. Programmes are more likely to be successful where there are good social networks and links in the community.


The Evidence Centre, an independent organisation, completed this evidence review for National Voices. The review used systematic processes but is not a systematic review. It is a useful summary of research and themes but has some methodological limitations.

Two reviewers independently searched bibliographic databases to identify relevant systematic reviews and other high-level narrative reviews. The databases were Medline / Pubmed, Embase, CINAHL, the Cochrane Library and Google Scholar. Specialist websites and the reference lists of identified articles were also searched. The databases were searched for systematic reviews published in English language journals between January 1998 and December 2013.

Reviews were included if they focused on interventions designed to enhance the active role of patients and lay people. Reviews where patients were solely the ‘objects’ of an intervention that targeted professionals were excluded. Two reviewers independently assessed the relevance and quality of each review. More than 40,000 studies were screened and a total of 779 systematic reviews were identified for inclusion, broken down into the following categories:
• supporting self-management (228 reviews)
• supporting shared decision-making (48 reviews)
• enhancing experience (110 reviews)
• improving information and understanding (85 reviews)
• and promoting prevention (308 reviews)

The authors concluded that the best ways to support people to self-manage are:

• providing self-management education for people with specific conditions which is integrated into routine healthcare
• generic self-management education courses co-led by peers / laypeople*
• interactive online self-management programmes
• telephone support and telehealth initiatives
• self-monitoring of medication and symptoms

*Despite this conclusion, the evidence they include appears to support condition-specific group education focusing on specific disease strategies more strongly than generic group education.

Nesta (2014), Peer Support: What is it and does it work? Summarising evidence from more than 1000 studies

The Evidence Centre, an independent organisation, completed this evidence review for NESTA/National Voices. The review used systematic processes but is not a systematic review. It is a useful summary of research and themes but has some methodological limitations.

Peer support involves people sharing knowledge, experience or practical help with each other. Many voluntary and community groups encourage peer support. Peer support can take many forms, such as informal telephone calls, group meetings, online forums or structured training offered by paid peers in partnership with professionals.

Peer support is of interest to UK policy makers, statutory services and the voluntary and community sector. For example, NHS England’s Five Year Forward View refers to peer support as one of the ‘slow burn, high impact’ interventions that should be seen as ‘essential’ to the future of the NHS. However, in policy and commissioning circles there can be limited understanding of the different forms peer support can take or the infrastructure and training needed. This review aimed to summarise what is known to build on good practice.

Two reviewers searched ten bibliographic databases independently to find studies published between January 2000 and January 2015. Any study design was included, as long as it was published in English and focused on peer support in OECD countries. Research with people with long-term physical or mental health conditions or their carers was prioritised, but other studies were included to illustrate how widely peer support has been used. After screening more than 20,000 studies, the authors included 1,023 studies; 524 studies examined the outcomes of peer support and the others described processes.

33 www.england.nhs.uk/ourwork/futurenhs/
Findings

Peer support can be classified in terms of:

- **who** is involved (such as people with specific health conditions or from certain age or ethnic groups),
- **what** type of support is offered (such as education, coaching or informal discussions),
- **how** it is provided (such as in person, online or by telephone),
- **where** it is provided (such as in hospital, primary care clinics, schools, community venues or people’s homes)
- **and when** peer support is offered (such as one hour every week or month).

The authors state that peer support has been found to:

- Have the potential to improve experience, psycho-social outcomes, behaviour, health outcomes and service use among people with **long-term physical and mental health conditions**;
- Potentially improve experience and emotional aspects for **carers**, people from certain age and ethnic groups and those at risk, though the impact on health outcomes and service use is unclear for these groups;
- Be most effective for improving health outcomes when facilitated by **trained peers**, lay people (not necessarily peers) or professionals;
- Be most effective for improving health outcomes when delivered **one-to-one or in groups** of more than ten people;
- Work well when delivered **face-to-face, by telephone or online**;
- Be most effective for improving health outcomes when it is based around specific activities (such as exercise or choirs) and focus on **education, social support and physical support**;
- Work well in a **range of venues**, including people’s own homes, community venues, hospitals and health services in the community.

Limitations

- The literature consists of quantity over quality. Only 17% of the studies identified were reviews and randomised trials, and these tended to have less favourable findings than other studies.
- Even where good quality evidence was available, it often did not include details about exactly how peer support was offered or what the most useful components were, making it difficult to replicate. Peer support includes many variables such as the type of participants, whether facilitators are trained or paid, location and delivery method. So, even when peer support is associated with benefits, it is difficult to say which component made the difference.
• Much of the research is from North America. This does not necessarily mean the findings cannot be generalised to the UK, but the context may affect the results.

Gaps in Research

The authors recommended that current programmes build the following into their evaluation to fill current research gaps:

Participation
• What type of support do people prefer?
• What influences whether or not people participate in peer support?
• How could more people be encouraged to take part?

Implementation
• Is training needed to provide effective peer support?
• What is the best way to train people to provide peer support?
• Does the duration of peer support make a difference?

Impacts
• What are the longer-term impacts of peer support?
• How cost-effective are different types of peer support?

What influences effectiveness?
• Why are some types of peer support more effective than others?
• Does the effectiveness of specific types of peer support differ depending on the people involved (e.g. children versus adults, physical versus mental health, people at risk versus those diagnosed)?
• What are the fundamental characteristics needed to ensure successful peer support?
• What do peers do more effectively than professionals and what types of support may professionals provide more effectively than peers?

Cochrane Reviews on Self-Management Support

This section includes summaries of relevant Cochrane Reviews since 2015, organised by theme. Some studies may be relevant to more than one theme, e.g. telehealth support for healthy lifestyles.

Multimorbidity

Smith et al. (2016) undertook a systematic review on interventions designed to improve outcomes for people with multi-morbidity including professional, organisational and patient-oriented interventions. They found little or no difference in most clinical outcomes. Mental health outcomes improved, showing modest reductions in mean depression scores for the studies that targeted participants with depression. Effective interventions included collaborative care using stepped care protocols.

They found a small improvement in patient-reported outcomes. The patient-oriented studies were mixed and do not suggest that patient-oriented interventions are generally effective.
However, there was an indication that a focus on functional capacity and activity participation may be effective, with one study reporting a reduction in mortality at four year follow-up. The intervention may make little difference to health service use, may slightly improve medication adherence, probably slightly improves patient health behaviours, and probably improves provider behaviour in terms of prescribing behaviour and care quality.

The evidence supporting specific interventions is limited and there are uncertainties due to the low number of RCTs conducted in this area, but the authors suggest it may support targeting specific problems that people with comorbidities are experiencing and targeting common comorbid conditions such as depression. Interventions need to integrate into existing healthcare systems to be sustainable.

**Healthy lifestyle support**

Barth et al. (2015) reviewed psychosocial interventions for smoking cessation in people with coronary heart conditions e.g. behavioural therapy, phone support, self-help materials. After a cardiac event about 30% to 50% of smokers with CHD quit without professional help. Additional psychosocial interventions show a better quit rate in the short-term. Interventions for smoking cessation in CHD patients should last for more than 1 month. Brief interventions were not effective unless followed up. About fifteen patients had to be treated for one person to be abstinent from tobacco after one year. For intense interventions only 12 people needed to be treated for one to be abstinent.

In women with gestational diabetes, Brown et al. (2017) found lifestyle interventions including healthy eating, physical activity and blood glucose self-monitoring can reduce the risk of the baby being born large-for-gestational age, increased the likelihood that women met their weight goals one year after giving birth, and decreased the risk of depression after birth.

**Psychological support**

Many adults with type 2 diabetes mellitus (T2DM) experience psychosocial burden and mental health problems associated with the disease. Diabetes-related distress (DRD) affects self-care behaviours and disease control. Improving DRD in adults with T2DM could enhance psychological well-being, health-related quality of life, self-care abilities and disease control, also reducing depressive symptoms (Chew et al., 2017). However, overall the authors were not able to draw firm conclusions based on current evidence about whether emotion focused, or cognitive focused psychological interventions work to improve DRD or disease control, though they did find a small and positive effect on confidence for self-care and HbA1c in adults with type 2 diabetes.

People with severe mental illness are at higher risk of diabetes and diabetes-related complications, but current evidence on self-management of type 2 diabetes mellitus; including self-monitoring of blood glucose, diet or exercise behaviour is insufficient to show what works to improve outcomes (McBain et al, 2016).
**Person-centred care**

**Personalised care planning** involves interventions that engage patients in a shared decision-making process involving both goal setting and action planning (Coulter et al., 2015). Personalised care planning leads to improvements in some indicators of physical and psychological health status, and people’s capability to self-manage their condition. The effects are not large, but they appear greater when the intervention is more comprehensive, more intensive, and better integrated into routine care. The effects of personalised care planning were greater when more stages of the care planning cycle were completed, when contacts between patients and health professionals were more frequent, and when the patient’s usual clinician was involved in the process. Evidence on the relative cost effectiveness of this approach is limited.

However, evidence on condition-specific action plans is more mixed: the evidence is not strong enough to recommend personalised asthma action plans (PAAP) (Gatheral et al., 2017) but Howcroft et al. (2016) found people with COPD who are given an action plan have fewer emergency department visits and hospital stays related to breathing problems over a year. For every 19 people given a COPD action plan, one person would avoid a hospital stay for an exacerbation.

Adding strength to this evidence, Lenferink et al. (2017) found for people with COPD there was a beneficial effect of self-management interventions with action plans on HRQoL and lower risk for at least one respiratory-related hospital admission. To prevent one respiratory-related hospital admission over one year, 12 participants with high baseline risk needed to be treated, and 17 participants with low baseline risk. Subgroup analyses showed improvements in HRQoL in self-management interventions with a smoking cessation programme compared to studies without a smoking cessation programme. The authors recommend COPD self-management action plans should take into account comorbidities to ensure safety of the self-management interventions.

**Decision aids** are tools that support patients by making their decisions explicit, providing information about options and associated benefits/harms, and helping clarify congruence between decisions and personal values. There is some evidence that people exposed to decision aids feel more knowledgeable, better informed, and clearer about their values, and they probably have a more active role in decision making and more accurate risk perceptions. Further research is needed on the effects on adherence with the chosen option, cost-effectiveness, and use with lower literacy groups (Stacey et al., 2017).

**Digital/telehealth support**

Podaski et al. (2016) reviewed automated telephone communication systems (ATCS) that send voice messages and collect health information from people using their telephone’s touch-tone keypad or voice recognition software. There are several types of ATCS: one-way voice messages to patients (unidirectional), interactive voice response (IVR) systems, those with added functions like referral to advice (ATCS Plus), or those where ATCS are part of a complex intervention (multimodal).
For long-term management, they found multimodal ATCS had inconsistent effects on medication adherence. ATCS Plus probably improves medication adherence versus usual care. ATCS Plus and IVR probably slightly improve adherence, while unidirectional ATCS may have little, or slightly positive, effects. No intervention consistently improved clinical outcomes. Multimodal ATCS, but not other ATCS types, probably decrease cancer pain and chronic pain. Outcomes may improve to a small degree when ATCS are applied to physical activity, weight management, alcohol use and diabetes. However, there is little or no effect in heart failure, hypertension, mental health or quitting smoking. In several conditions there is not enough evidence to tell what effects ATCS have.

There is moderate to high quality evidence that interactive telemedicine (remote monitoring or video conferencing) can improve outcomes or provide comparable results to usual care (Flodgren et al., 2015). There was no difference in mortality between participants with heart failure receiving care through telemedicine, compared to those receiving health care without telemedicine, and disease-specific quality of life was slightly improved for heart failure participants. Telemedicine may improve glucose control in people with diabetes and may decrease LDL cholesterol and blood pressure. There were no differences in the effect of mental health and substance abuse therapy delivered over video-conferencing, compared to face-to-face delivery. Findings from other studies varied; there was some evidence that monitoring via telemedicine improved blood pressure control in participants with hypertension, and a few studies reported improvement for those with a respiratory condition. However, the cost of implementing TM, compared with usual care, was only reported in 25% of included studies and no studies assessed how TM might alter the structure of health service delivery and payment.

Current evidence does not support the widespread implementation of telemonitoring with healthcare provider feedback for asthma patients (Kew and Cates, 2017).

Inglis et al. (2015) found that supporting people with heart failure at home using structured telephone support or non-invasive telemonitoring can reduce the rates of death and heart failure-related hospitalisation. It can improve people’s quality of life and knowledge about heart failure and self-care. Most patients, even those who are elderly, learn to use the technology easily and are satisfied with the interventions. However, the equipment for these interventions was in most cases provided as part of the study, so purchase, installation and maintenance of such equipment in the real world needs to be considered as these may be barriers to use and cost-effectiveness. The authors also had concerns over publication bias.

Adler et al. (2013) reviewed mobile phone text messaging to improve medication adherence in secondary prevention of cardiovascular disease. Although 6 out of 7 reported a positive effect, the risk of bias was high and the small number of studies means there is not yet enough evidence to change practice.

Devi et al. (2015) reviewed internet-based interventions designed to promote a healthy lifestyle and medicines management and reduce cardiovascular risk in people with CHD, excluding interventions that focused on smoking cessation alone. No effects for all-cause mortality or clinical outcomes. Due to the low-quality evidence in study outcomes and limited findings to date, there are no implications for practice at present. There was some evidence for beneficial effects on HRQOL, dietary outcomes, and physical activity, but firm conclusions cannot yet be made. Completion of ongoing trials will add to the evidence base.
McCabe, McCann and Brady (2017) found some evidence that smart technologies can improve HRQoL and physical activity up to six months, but there is a need to maintain patient engagement longer term. It may be more beneficial for some people than for others, for example, those with an interest in using technology may get greater benefit. The quality of the evidence was not high.

The NHS Digital Apps Library provides a quality assurance process for health apps.34 Apps featured in the library have to meet standards in evidence of outcome, clinical safety, data protection, security, usability and accessibility, interoperability and technical stability. This provides some evidence and assurance over the quality and effectiveness of the featured apps and should therefore be the first starting point when recommending or procuring apps to support people to improve their health and wellbeing.

**Condition-specific programmes**

Cancer patients can be supported to self-manage with home-based multidimensional survivorship (HBMS) programmes, including more than one of the following components: educational (such as information provision and self-management advice), physical (such as exercise training and resistance training) and psychological (such as counselling and cognitive therapies). Kin Fong Cheng et al. (2017) found HBMS programmes may increase quality of life immediately after the intervention. There was some reduction in short-term anxiety, fatigue and insomnia. The effects did not persist long-term.

Lawrenson et al. (2018) reviewed interventions to improve uptake of diabetic retinopathy screening. They included targeted interventions, as well as general strategies to improve diabetes care processes. Strategies were coded using the Cochrane EPOC QI intervention classification and the Behaviour Change Taxonomy (BCT) and included those targeted at individuals with diabetes (e.g. reminders, promotion of self-management), healthcare professionals (e.g. education, audit and feedback) or the healthcare system (e.g. electronic registries, team changes). Overall, DRS attendance increased by 12%, but the evidence was low quality. All BCT combinations were associated with significant improvements, particularly in those with poor attendance. Higher effect estimates were found in subgroup analyses for the BCTs ‘goal setting’ and ‘feedback on outcomes of behaviour’, ‘restructuring the social environment’ and ‘credible source’.

Importantly, there was no statistically-significant difference between interventions specifically aimed at DRS and those which were part of a general QI strategy for improving diabetes care. This is an important finding, because of the additional benefits of general QI interventions in terms of improving glycaemic control, vascular risk management and screening for other microvascular complications.

34 NHS Digital. [https://apps.beta.nhs.uk/how-we-assess-apps/](https://apps.beta.nhs.uk/how-we-assess-apps/)
A range of self-monitoring versus conventional glucose monitoring options have been trialled for pregnant women with pre-existing type 1 or 2 diabetes, but evidence for most outcomes were very low quality due to study design limitations. Additional evidence from large well-designed randomised trials is required to inform choices of glucose monitoring techniques (Moy et al. 2017).

A consensus statement on the definition of COPD self-management has been developed which states (Effing, 2016):

“"A COPD self-management intervention is structured but personalised and often multi-component, with goals of motivating, engaging and supporting the patients to positively adapt their health behaviour(s) and develop skills to better manage their disease. The ultimate goals of self-management are: a) optimising and preserving physical health; b) reducing symptoms and functional impairments in daily life and increasing emotional well-being, social well-being and quality of life; and c) establishing effective alliances with healthcare professionals, family, friends and community. The process requires iterative interactions between patients and healthcare professionals who are competent in delivering self-management interventions. These patient-centred interactions focus on: 1) identifying needs, health beliefs and enhancing intrinsic motivations; 2) eliciting personalised goals; 3) formulating appropriate strategies (e.g. exacerbation management) to achieve these goals; and if required 4) evaluating and readjusting strategies. Behaviour change techniques are used to elicit patient motivation, confidence and competence. Literacy sensitive approaches are used to enhance comprehensibility.”

Puhan et al. (2016) found pulmonary rehabilitation for COPD patients increased HRQoL total score, improved six-minute walk distance, on average, by 62 meters, and reduced hospital readmissions. Future researchers must investigate how the extent of rehabilitation programmes in terms of exercise sessions, self-management education and other components affects outcomes, and how the organisation of such programmes within specific healthcare systems determines their effectiveness.

Home-based cardiac rehab has been found to be as safe as centre-based rehabilitation (Anderson et al., 2017). Despite some caution over the low evidence grading, the authors conclude that this update supports previous research that home- and centre-based forms of cardiac rehabilitation are similarly effective in improving clinical and HRQoL outcomes in patients with heart disease. They point out that offering the choice of participating in a more traditional and supervised centre-based programme or a home-based programme takes into account patient preferences and gives more flexibility in how programmes are delivered locally.

This review found no important difference in the cost of providing home- versus centre-based programmes though costs will depend on the healthcare system. Home-based programmes often require support from healthcare staff which can be the major cost driver.

Clarkesmith et al. (2017) reviewed educational and behavioural interventions to improve oral anticoagulation therapy in patients with atrial fibrillation (AF) but found there is not yet enough evidence to support educational or self-monitoring interventions over usual care. Self-monitoring may not be a feasible option for many patients, particularly as it requires additional training and is costly, and new anticoagulants are now available which do not require
monitoring. There is a need for interventions to provide effective illness-specific educational tools, which incorporate relevant behaviour change techniques.

**Learning from other Evidence/Service Models**

Over the last decade, self-management support in the UK has formed part of a wider shift towards more person-centred and integrated care (see Section 3). Self-management support has tended to be implemented either in the form of standalone programmes, or as part of continuous service improvement and overall shift in culture/approach. This section gives examples of models/initiatives that aim to facilitate self-management.

NHS England’s commitment to increasing support for self-care includes using the **Patient Activation Measure (PAM)**, a validated tool to assess people’s skills, knowledge and confidence and the extent to which people feel engaged and confident in managing their condition. The PAM segments people managing LTCs into four activation levels. The proportion found in each segment has been found to be consistent across conditions and socioeconomic backgrounds. Supporting people to increase their activation level has been found to increase positive health behaviours, improve clinical outcomes and reduce healthcare costs.

Cornwall has 25,000 PAM licences available free to use before 2021. PAM should be considered as an option alongside other available measures such as condition-specific Health Related Quality of Life measures, wellbeing measures such as WEMWBS, and Self-Management Screening (SeMaS) (Eikelenboom, 2015).

Patient activation describes the knowledge, skills and confidence a person has in managing their own health and care. It is a key part of person-centred care, supporting people to recognise and develop their own strengths and abilities.

Patient activation is closely linked to other concepts such as ‘self-efficacy’ and ‘readiness to change’, but is a broader concept, reflecting attitudes and approaches to self-management and engagement with health and healthcare, rather than being tied to specific behaviours.

Patient activation can be used to reduce health inequalities and deliver improved outcomes, better quality care and lower costs. Research shows that appropriately designed interventions can increase patients’ levels of activation, with associated health benefits (The King’s Fund, 2014). Patients who start with the lowest scores tend to increase their scores the most, suggesting that effective interventions can help engage even the most disengaged.

Patient activation is a better predictor of health outcomes than known socio-demographic factors such as ethnicity and age. Patient activation can therefore provide new insights into risk when used in population segmentation and risk stratification.

People who are more activated are significantly more likely to attend screenings, check-ups and immunisations, to adopt positive behaviours (e.g. diet and exercise) and have clinical indicators in the normal range (body mass index, blood sugar levels (HbA1c), blood pressure and cholesterol).
Patients who are less activated are significantly less likely to prepare questions for a medical visit, know about treatment guidelines or be persistent in clarifying advice. Less-activated patients have costs approximately 8 per cent higher than more-activated patients in the baseline year, and 21 per cent higher in the subsequent year.

The Patient Activation Measure (PAM) is a validated, commercially licenced tool and has been extensively tested with reviewed findings from a large number of studies. It helps to measure the spectrum of skills, knowledge and confidence in patients and captures the extent to which people feel engaged and confident in taking care of their condition.

Individuals are asked to complete a short survey and based on their responses, they receive a PAM score (between 0 and 100). The resulting score places the individual at one of four levels of activation, each of which reveals insight into a range of health-related characteristics, including behaviours and outcomes. The four levels of activation are:

- **Level 1**: Individuals tend to be passive and feel overwhelmed by managing their own health. They may not understand their role in the care process.
- **Level 2**: Individuals may lack the knowledge and confidence to manage their health.
- **Level 3**: Individuals appear to be taking action but may still lack the confidence and skill to support their behaviours.
- **Level 4**: Individuals have adopted many of the behaviours needed to support their health but may not be able to maintain them in the face of life stressors.

Four activation levels along a continuum

0-100 point scale.
The PAM can be used as:

1. **Tailoring tool** – Measuring patient activation gives healthcare professionals a starting point to meet the people ‘where they are’, helping them to tailor their approaches to the individuals more appropriately to support them on their ‘journey of activation’. Using the PAM in this way as a tailoring tool encourages the provision of proactive system support for people with long-term conditions to develop the skills, knowledge and confidence to manage health and keep well at home. For example, one GP practice in Sheffield has redesigned their diabetes review process through offering longer appointments using the PAM to tailor discussion according the individual’s level of activation.

2. **Tailoring tool and outcome measure** – As a quantifiable measure, PAM can be used at scale and to assess whether the services/interventions are providing effective and tailored support to people’s needs. Aggregate/cohort PAM scores can be used to evaluate commissioned programmes to understand if they increased people’s activation, or if any changes are required to the types of services required in the local area according to people’s needs. It can be used to compare outcomes from different programmes.

A person’s level of activation is a dynamic concept, not a label. The individual may have high levels of knowledge, skills and confidence, and so be highly activated. However, if they then receive a new diagnosis or experience a new complication, their level of knowledge, skills and confidence may decrease, until they have developed the knowledge, skills and confidence to manage it well. A person may also think they are knowledgeable about their condition but taking part in an intervention makes them realise they knew less than they thought, so their score may decrease temporarily as a result.

The **Co-creating Health programme (CCH)** aimed to embed self-management support within mainstream health services and ran over two phases across eight sites in England and Scotland with each focusing on four clinical services, including pain management, depression, Chronic Obstructive Pulmonary Disease (COPD) and diabetes (The Health Foundation, 2013). It comprised three strands of work delivering self-management support to patients, alongside training for clinicians and a service improvement workstream. CCH piloted self-management support in a group context which was condition-specific, and led by a paired trainer model, with a lay person (living with an LTC) and clinician (specialist in the specific condition) leading the sessions together. Support through this model provided education about LTCs, and support to improve confidence and skills to work with health professionals and better manage health conditions. An evaluation of the programme indicated that the programme led to improved patient activation and improved use of self-management support practices among clinicians. The implementation of specific strands of delivery for both clinicians (i.e. the Advanced Development Programme) and patients (i.e. the Self-Management Support Programme) was found to be a key factor in the success of the programme.

**People Powered Health** ran six pilots between 2011 and 2013 supporting community-based partnerships between patients (and their families/carers), health professionals and the voluntary sector for people with LTCs. The programme delivered a range of initiatives including peer support, social prescribing, time banking and group consultation and personalised care planning. Unlike many other self-management programmes, People Powered Health was
delivered by non-traditional providers who are often perceived as being better able to signpost people onto other sources of community support, compared to more traditional healthcare providers. The programme was well supported by local voluntary and community services which encompassed a broader goal of supporting people to live with LTCs rather than focusing specifically on self-management support (The Health Foundation, 2014).

The Year of Care ran over three years across three pilot sites, testing a micro-to-macro commissioning model, which used individual patient needs and goals to drive commissioning of local services at the population level for people with diabetes. This included supporting patients to self-manage their LTCs and take an active role in their care. The programme has since been developed and adopted by 12 other sites, and expanded to include other LTCs (Nesta, 2012). This wider rollout is being carried out through the House of Care Programme, which looks to support patients to access a wider range of support services than would be available under the NHS or social care services alone. The House of Care model is used as a metaphor to describe the coordinated delivery system of integrated and person-centred care needed to address the challenge of managing patients with LTCs. It encompasses a broad system-wide approach to care planning that includes the patient, carers, healthcare professionals, services and organisations, and commissioners. Within this, self-management support to patients plays a key role in supporting patients and their carers to become more engaged and informed about their health and healthcare (Coulter et al., 2013).

Better Conversations

There is increasing consensus that the quality and content of verbal interactions between health professional and patient can have a big impact on health outcomes, especially if underpinned by behaviour change theory. There are various approaches, including health coaching, Making Every Contact Count (MECC), care navigation and active signposting.

Health coaching is a patient-centred process that entails goal setting determined by the patient, encourages self-discovery in addition to content education, and incorporates mechanisms for developing accountability in health behaviours. The evidence is that there are many benefits associated with health coaching. In order for it to be fully effective health coaching may need to be implemented as part of a wider programme supporting education and behaviour change. A health coaching approach is synonymous with person-centered care and the skills are central to many related approaches including care and support planning and shared decision making. Although health coaching principles can be implemented during brief consultations, often better results can be achieved from more in depth 1-2-1 sessions over a longer period.

A rapid evidence review conducted by Health Education East of England and the NHS Evidence Centre reviewed a total of 275 studies about health coaching plus studies about training professionals to support behaviour change more generally (NHS Evidence Centre, 2014). It remains unclear whether health coaching from a clinician with whom people have an established relationship has greater benefits.

35 Better Conversations. http://www.betterconversation.co.uk/
Themes from this evidence review are:

- **Improved attitudes and self-efficacy.** There is some evidence that health coaching can support people’s motivation to self-manage.
- **Improving behaviour.** There is some evidence that health coaching can support people to adopt healthy behaviours.
- **Improving health outcomes.** There is mixed evidence about the impact of health coaching on physical outcome such as blood sugar levels, weight and cholesterol possibly because these factors can take time to change and the impact of health coaching is realised too quickly.
- **Improving healthcare costs.** There is insufficient evidence to conclude whether health coaching reduces healthcare use or costs. This was primarily because many of the studies were from outside the UK which made generalisation difficult to achieve.

Health coaching appears to be most effective for people who are highly motivated to change from the outset and who have the most severe conditions or unhealthy lifestyles.

**Making Every Contact Count (MECC)** is a less intensive approach to behaviour change that uses the millions of daily interactions that organisations and people have to encourage changes in behaviour that have a positive effect on the health and wellbeing of individuals, communities and populations. It involves training people across the health and social care system to understand behaviour change and motivation and have positive conversations with people that encourage them to take small steps toward a healthier lifestyle.

**My Health My Way – A Comprehensive Self-Management Service in Dorset**

Launched in November 2013, **My Health My Way (MHW)** is a comprehensive non-clinical self-management programme open to anyone with an LTC living in Dorset. MHW aims to target people of a lower health literacy who are less activated, as well as younger people (aged 30-45 years old) in work, people from Dorset’s rural communities and people without access to a computer.

Clients can self-refer or be referred via a clinician or community service. They are directed to a central gateway team who provide basic information about the service and assess whether the client wants to continue. Clients are then directed either to the Know Your Own Health (KYOH) web-portal, containing local information and an online assessment, or directly to health coaches. Health coaches explore the client’s needs and goals, and then together they decide which of the following support methods would best suit them:

- **One-to-one health coaching,** which provides face-to-face, telephone and e-mail support for up to six sessions. Coaching is based on motivational interviewing;
- **Face-to-face group courses,** where clients receive a self-management handbook and take part in courses covering a range of topics (e.g. frustration, fatigue, pain and isolation; appropriate use of medication; communicating effectively with family, friends and health professionals);
- **Peer support groups,** which meet face-to-face and are designed to support clients following the end of one-to-one health coaching or face-to-face group courses.
- **Information and signposting** is supported by an online platform and is designed to be used both alongside other forms of support (e.g. coaching and group courses)
• Online self-management support allows clients to access the KYOH Patients eLearning programme. This is a six-week course covering concepts of self-care and health and wellbeing, that can be facilitated by a health coach or can be carried out by the client on their own;
• Online peer support provides a space in the form of an online forum for people to discuss issues that are relevant to them with people who may be in a similar situation; and,
• Carers of clients are also able to access all of the information available on the KYOH web-portal.
• Although there was limited data to provide information about other aspects of client backgrounds, analysis of available data indicates that MHMW appears to be successful at attracting clients from ‘hard to reach groups’, e.g. clients with lower levels of education, those with low incomes and the unemployed – 80% of those responding to income-related questions reported a household income of under £15,000.
• Clients reported a wide range of health conditions, including some reporting multiple morbidities. Musculoskeletal conditions were the most commonly reported primary condition, affecting a quarter of clients. Fibromyalgia, Diabetes and Heart Disease also affect a high proportion of clients.
• Clients favoured one-to-one support (via face-to-face sessions or telephone). Some clients also accessed multiple forms of support, suggesting that clients were comfortable moving between the different types of support or were actively encouraged to do so.
• Analysis of HEI-Q scores (a self-management measure) indicates that there were statistically significant improvements between baseline and follow up scores reported by clients for all domains.

The average PAM score of the client population at the baseline level was 48.2 and the average score at the follow up level was 53.7, representing an average increase in PAM score of 5.5.

Cost-effectiveness

Overall the evidence on cost-effectiveness of self-management support is limited. Healthcare utilisation may increase if previously unmet need is being addressed; however, if this results in improved management and reduced complications this still has the potential to reduce overall resource use as well as improving patient outcomes (Smith et al. 2016).

Evidence on cost-effectiveness of self-management support is limited but some estimates exists. The Wanless Review suggests that ‘for every £100 spent on encouraging self-care, around £150 worth of benefits can be delivered in return’ (Wanless, 2002).

Nesta estimates that providing four initiatives; peer support to people with mental health issues and coronary heart disease, and self-management education to people cardiovascular disease and asthma, could offer a net savings of £2,100 to the health system per person per year (Nesta, 2015b).

It is worth noting that self-management may increase the use of services in the short-term if people attend regular checks or seek help when they notice exacerbations in health issues, however this should prevent more serious, resource-intense complications later on (NHS Evidence Centre, 2014).
My Health My Way provides illustrative examples of potential cost-saving impacts linked to changes in HEI-Q scores. Our analysis estimates that MHMW led to direct cost-savings to the NHS and indirect costs-saving to the clients accessing the service of between £1,119 and £4,512 (based on two client case studies).
8. Next Steps / Action Plan

This health needs assessment is accompanied by the Cornwall Self-Management of Long-Term Conditions Model, and Action Plan (Bird, 2019), which sets out our next steps.

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Public Health Specialty Registrar
Wellbeing and Public Health
29 January 2020
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Cornwall Rural Community Charity
Falmouth University
Healthwatch Cornwall
Healthy Cornwall
Liskeard and South East Cornwall Breathers
Macmillan Cancer Care
Newquay Happy Hearts
NHS Kernow Clinical Commissioning Group
Outlook South West
Plymouth University
Royal Cornwall Hospitals NHS Trust
The Patient’s Association
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Appendix 1: Patient Survey Responses

Thinking about the things you have NOT been offered, how useful would the following be to help you (or the person you care for) manage CANCER well?

<table>
<thead>
<tr>
<th>Individual care plan including what to do if the condition gets worse</th>
<th>I have already been offered this</th>
<th>Not at all useful (1)</th>
<th>Not very useful (2)</th>
<th>Quite useful (3)</th>
<th>Very useful (4)</th>
<th>Avg</th>
<th>σ</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1 (10 %)</td>
<td>0 (0 %)</td>
<td>1 (10 %)</td>
<td>2 (20 %)</td>
<td>6 (60 %)</td>
<td>3.56</td>
<td>0.68</td>
<td>10</td>
</tr>
<tr>
<td>Devices to help monitor the condition at home</td>
<td>1 (10 %)</td>
<td>1 (10 %)</td>
<td>4 (40 %)</td>
<td>3 (30 %)</td>
<td>1 (10 %)</td>
<td>2.44</td>
<td>0.83</td>
<td>10</td>
</tr>
<tr>
<td>Access to patient health record</td>
<td>1 (8.33 %)</td>
<td>1 (8.33 %)</td>
<td>2 (16.67 %)</td>
<td>7 (58.33 %)</td>
<td>1 (8.33 %)</td>
<td>2.73</td>
<td>0.75</td>
<td>12</td>
</tr>
<tr>
<td>Group education on how to manage the health condition</td>
<td>0 (0 %)</td>
<td>1 (8.33 %)</td>
<td>4 (33.33 %)</td>
<td>4 (33.33 %)</td>
<td>3 (25 %)</td>
<td>2.75</td>
<td>0.92</td>
<td>12</td>
</tr>
<tr>
<td>Healthy lifestyles coaching/support</td>
<td>0 (0 %)</td>
<td>2 (16.67 %)</td>
<td>1 (8.33 %)</td>
<td>4 (33.33 %)</td>
<td>5 (41.67 %)</td>
<td>3</td>
<td>1.08</td>
<td>12</td>
</tr>
<tr>
<td>Physical activity/exercise on referral</td>
<td>1 (8.33 %)</td>
<td>2 (16.67 %)</td>
<td>1 (8.33 %)</td>
<td>3 (25 %)</td>
<td>5 (41.67 %)</td>
<td>3</td>
<td>1.12</td>
<td>12</td>
</tr>
<tr>
<td>Referral to community activity e.g. gardening/social group</td>
<td>0 (0 %)</td>
<td>2 (16.67 %)</td>
<td>3 (27.27 %)</td>
<td>3 (27.27 %)</td>
<td>3 (27.27 %)</td>
<td>2.64</td>
<td>1.07</td>
<td>11</td>
</tr>
<tr>
<td>Primary care review</td>
<td>1 (10 %)</td>
<td>0 (0 %)</td>
<td>1 (10 %)</td>
<td>4 (40 %)</td>
<td>4 (40 %)</td>
<td>3.33</td>
<td>0.67</td>
<td>10</td>
</tr>
<tr>
<td>Support from specialist nurse</td>
<td>1 (10 %)</td>
<td>1 (10 %)</td>
<td>0 (0 %)</td>
<td>5 (50 %)</td>
<td>3 (30 %)</td>
<td>3.11</td>
<td>0.67</td>
<td>10</td>
</tr>
<tr>
<td>Support from pharmacist</td>
<td>0 (0 %)</td>
<td>2 (16.67 %)</td>
<td>2 (16.67 %)</td>
<td>6 (54.55 %)</td>
<td>1 (9.09 %)</td>
<td>2.55</td>
<td>0.89</td>
<td>11</td>
</tr>
<tr>
<td>Online information and support, e.g. websites or chat rooms</td>
<td>2 (25 %)</td>
<td>1 (12.5 %)</td>
<td>1 (12.5 %)</td>
<td>3 (37.5 %)</td>
<td>1 (12.5 %)</td>
<td>2.67</td>
<td>0.94</td>
<td>8</td>
</tr>
<tr>
<td>Support from professionals to help manage low mood, anxiety or depression related to the health condition/s</td>
<td>1 (9.09 %)</td>
<td>0 (0 %)</td>
<td>0 (0 %)</td>
<td>3 (27.27 %)</td>
<td>7 (63.64 %)</td>
<td>3.7</td>
<td>0.46</td>
<td>11</td>
</tr>
<tr>
<td>Support from others who have experience of the same condition</td>
<td>0 (0 %)</td>
<td>0 (0 %)</td>
<td>2 (20 %)</td>
<td>4 (40 %)</td>
<td>4 (40 %)</td>
<td>3.2</td>
<td>0.75</td>
<td>10</td>
</tr>
<tr>
<td>Other (please comment)</td>
<td>0 (0 %)</td>
<td>0 (0 %)</td>
<td>0 (0 %)</td>
<td>1 (100 %)</td>
<td>0 (0 %)</td>
<td>3</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

Avg (Matrix) 2.96
Thinking about the things you have NOT been offered, how useful would the following be to help you (or the person you care for) manage HEART DISEASE well?

<table>
<thead>
<tr>
<th>Service Provided</th>
<th>I have already been offered this</th>
<th>Not at all useful (1)</th>
<th>Not very useful (2)</th>
<th>Quite useful (3)</th>
<th>Very useful (4)</th>
<th>Avg</th>
<th>σ</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual care plan including what to do if the condition gets worse</td>
<td>1 (5.56 %)</td>
<td>0 (0 %)</td>
<td>0 (0 %)</td>
<td>6 (33.33 %)</td>
<td>11 (61.11 %)</td>
<td>2.65</td>
<td>0.48</td>
<td>18</td>
</tr>
<tr>
<td>Devices to help monitor the condition at home</td>
<td>1 (5.56 %)</td>
<td>0 (0 %)</td>
<td>2 (11.76 %)</td>
<td>3 (17.65 %)</td>
<td>11 (64.71 %)</td>
<td>3.06</td>
<td>0.7</td>
<td>17</td>
</tr>
<tr>
<td>Access to patient health record</td>
<td>1 (5.56 %)</td>
<td>1 (5.56 %)</td>
<td>2 (11.11 %)</td>
<td>8 (44.44 %)</td>
<td>6 (33.33 %)</td>
<td>3.12</td>
<td>0.82</td>
<td>18</td>
</tr>
<tr>
<td>Group education on how to manage the health condition</td>
<td>2 (10.53 %)</td>
<td>2 (10.53 %)</td>
<td>2 (10.53 %)</td>
<td>6 (31.58 %)</td>
<td>7 (36.84 %)</td>
<td>3.39</td>
<td>1</td>
<td>19</td>
</tr>
<tr>
<td>Healthy lifestyles coaching/support</td>
<td>2 (10.53 %)</td>
<td>2 (10.53 %)</td>
<td>2 (10.53 %)</td>
<td>5 (26.32 %)</td>
<td>8 (42.11 %)</td>
<td>3.12</td>
<td>1.02</td>
<td>19</td>
</tr>
<tr>
<td>Physical activity/exercise on referral</td>
<td>2 (10.53 %)</td>
<td>2 (10.53 %)</td>
<td>1 (5.26 %)</td>
<td>5 (26.32 %)</td>
<td>9 (47.37 %)</td>
<td>3.24</td>
<td>1</td>
<td>19</td>
</tr>
<tr>
<td>Referral to community activity e.g. gardening/social group</td>
<td>1 (5.26 %)</td>
<td>3 (15.79 %)</td>
<td>2 (10.53 %)</td>
<td>6 (31.58 %)</td>
<td>7 (36.84 %)</td>
<td>2.94</td>
<td>1.08</td>
<td>19</td>
</tr>
<tr>
<td>Primary care review</td>
<td>1 (5.26 %)</td>
<td>0 (0 %)</td>
<td>1 (5.56 %)</td>
<td>6 (33.33 %)</td>
<td>10 (55.56 %)</td>
<td>3.53</td>
<td>0.67</td>
<td>18</td>
</tr>
<tr>
<td>Support from specialist nurse</td>
<td>1 (5.26 %)</td>
<td>1 (5.26 %)</td>
<td>0 (0 %)</td>
<td>5 (26.32 %)</td>
<td>12 (63.16 %)</td>
<td>3.55</td>
<td>0.76</td>
<td>19</td>
</tr>
<tr>
<td>Support from pharmacist</td>
<td>1 (5.56 %)</td>
<td>2 (11.11 %)</td>
<td>2 (11.11 %)</td>
<td>6 (33.33 %)</td>
<td>7 (38.89 %)</td>
<td>3.06</td>
<td>1</td>
<td>18</td>
</tr>
<tr>
<td>Online information and support, e.g. websites or chat rooms</td>
<td>1 (5.56 %)</td>
<td>1 (5.56 %)</td>
<td>4 (22.22 %)</td>
<td>6 (33.33 %)</td>
<td>6 (33.33 %)</td>
<td>3</td>
<td>0.91</td>
<td>18</td>
</tr>
<tr>
<td>Support from professionals to help manage low mood, anxiety or depression related to the health condition/s</td>
<td>1 (5.26 %)</td>
<td>0 (0 %)</td>
<td>3 (15.79 %)</td>
<td>5 (26.32 %)</td>
<td>10 (52.63 %)</td>
<td>3.39</td>
<td>0.76</td>
<td>19</td>
</tr>
<tr>
<td>Support from others who have experience of the same condition</td>
<td>2 (10.53 %)</td>
<td>3 (15.79 %)</td>
<td>1 (5.26 %)</td>
<td>5 (26.32 %)</td>
<td>8 (42.11 %)</td>
<td>3.06</td>
<td>1.17</td>
<td>19</td>
</tr>
<tr>
<td>Other (please comment)</td>
<td>1 (33.33 %)</td>
<td>1 (33.33 %)</td>
<td>0 (0 %)</td>
<td>0 (0 %)</td>
<td>1 (33.33 %)</td>
<td>2.5</td>
<td>1.5</td>
<td>3</td>
</tr>
</tbody>
</table>

*Avg (Metric)* 3.24
Thinking about the things you have NOT been offered, how useful would the following be to help you (or the person you care for) manage DIABETES well?

<table>
<thead>
<tr>
<th>Service Provided</th>
<th>Not at all useful</th>
<th>Not very useful</th>
<th>Quite useful</th>
<th>Very useful</th>
<th>Avg</th>
<th>SD</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Individual care plan including what to do if the condition gets worse</td>
<td>0 (0%)</td>
<td>1 (1.2%)</td>
<td>10 (11.2%)</td>
<td>20 (22.2%)</td>
<td>3.61</td>
<td>0.55</td>
<td>32</td>
</tr>
<tr>
<td>2. Devices to help monitor the condition at home</td>
<td>1 (1.2%)</td>
<td>0 (0%)</td>
<td>2 (2.5%)</td>
<td>10 (11.2%)</td>
<td>3.62</td>
<td>0.58</td>
<td>28</td>
</tr>
<tr>
<td>3. Access to patient health record</td>
<td>4 (4.5%)</td>
<td>2 (2.5%)</td>
<td>0 (0%)</td>
<td>13 (14.0%)</td>
<td>3.11</td>
<td>0.46</td>
<td>32</td>
</tr>
<tr>
<td>4. Group education on how to manage the health condition</td>
<td>2 (2.0%)</td>
<td>5 (5.5%)</td>
<td>11 (12.3%)</td>
<td>12 (13.3%)</td>
<td>3.63</td>
<td>0.97</td>
<td>32</td>
</tr>
<tr>
<td>5. Healthy lifestyles coaching/support</td>
<td>2 (0%)</td>
<td>0 (0%)</td>
<td>7 (7.7%)</td>
<td>15 (16.6%)</td>
<td>3.34</td>
<td>0.77</td>
<td>32</td>
</tr>
<tr>
<td>6. Physical activity/exercise on referral</td>
<td>0 (0%)</td>
<td>2 (2.5%)</td>
<td>10 (11.2%)</td>
<td>13 (14.0%)</td>
<td>3.65</td>
<td>0.56</td>
<td>30</td>
</tr>
<tr>
<td>7. Referral to community activity e.g. gardening/social group</td>
<td>1 (1.1%)</td>
<td>14 (15.3%)</td>
<td>10 (11.2%)</td>
<td>11 (12.2%)</td>
<td>3.65</td>
<td>0.73</td>
<td>34</td>
</tr>
<tr>
<td>8. Primary care review</td>
<td>2 (2.2%)</td>
<td>1 (1.2%)</td>
<td>10 (11.2%)</td>
<td>16 (17.6%)</td>
<td>3.69</td>
<td>0.81</td>
<td>32</td>
</tr>
<tr>
<td>9. Support from specialist nurse</td>
<td>10 (11.1%)</td>
<td>0 (0%)</td>
<td>5 (5.5%)</td>
<td>14 (15.2%)</td>
<td>3.65</td>
<td>0.56</td>
<td>30</td>
</tr>
<tr>
<td>10. Support from pharmacist</td>
<td>8 (8.8%)</td>
<td>2 (2.2%)</td>
<td>13 (14.4%)</td>
<td>3.86%</td>
<td>3.65</td>
<td>0.56</td>
<td>30</td>
</tr>
<tr>
<td>11. Online information and support e.g. websites or chat rooms</td>
<td>0 (0%)</td>
<td>5 (5.5%)</td>
<td>12 (13.3%)</td>
<td>2.93%</td>
<td>2.93</td>
<td>0.44</td>
<td>29</td>
</tr>
<tr>
<td>12. Support from professionals to help manage low mood, anxiety or depression</td>
<td>3 (3.3%)</td>
<td>2 (2.2%)</td>
<td>10 (11.2%)</td>
<td>3.82%</td>
<td>3.45</td>
<td>0.62</td>
<td>34</td>
</tr>
<tr>
<td>13. Support from others who have experience of the same condition</td>
<td>0 (0%)</td>
<td>1 (1.1%)</td>
<td>11 (12.2%)</td>
<td>3.78%</td>
<td>3.08</td>
<td>0.33</td>
<td>9</td>
</tr>
<tr>
<td>14. Other (please comment)</td>
<td>1 (1.1%)</td>
<td>0 (0%)</td>
<td>1 (1.1%)</td>
<td>3.78%</td>
<td>3.08</td>
<td>0.33</td>
<td>9</td>
</tr>
</tbody>
</table>

Avg (Metric) 3.26
Thinking about the things you have NOT been offered, how useful would the following be to help you (or the person you care for) manage the RESPIRATORY CONDITION well?

![Bar chart showing responses to harmful events](chart.png)

1. Individual care plan including what to do if the condition gets worse
2. Devices to help monitor the condition at home
3. Access to patient health record
4. Group education on how to manage the condition
5. Healthy lifestyles coaching/support
6. Physical activity/exercise on referral
7. Referral to community activity e.g. gardening/social group
8. Primary care review
9. Support from specialist nurse
10. Support from pharmacist
11. Online information and support, e.g. websites or chat rooms
12. Support from professionals to help manage low mood, anxiety or depression related to the health condition(s)
13. Support from others who have experience of the same condition
14. Other (please comment)

<table>
<thead>
<tr>
<th></th>
<th>Not at all useful</th>
<th>Not very useful</th>
<th>Quite useful</th>
<th>Very useful</th>
<th>Avg</th>
<th>σ</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual care plan</td>
<td>4 (13.33 %)</td>
<td>1 (3.33 %)</td>
<td>1 (3.33 %)</td>
<td>10 (33.33 %)</td>
<td>20 (66.67 %)</td>
<td>3.73</td>
<td>0.57</td>
</tr>
<tr>
<td>Devices to help monitor the condition</td>
<td>5 (17.24 %)</td>
<td>1 (3.33 %)</td>
<td>0 (0 %)</td>
<td>8 (27.59 %)</td>
<td>15 (51.72 %)</td>
<td>3.56</td>
<td>0.71</td>
</tr>
<tr>
<td>Access to patient health record</td>
<td>2 (7.41 %)</td>
<td>2 (7.41 %)</td>
<td>0 (0 %)</td>
<td>2 (6.89 %)</td>
<td>10 (34.48 %)</td>
<td>3.04</td>
<td>0.96</td>
</tr>
<tr>
<td>Group education on how to manage the condition</td>
<td>0 (0 %)</td>
<td>3 (10.71 %)</td>
<td>1 (3.33 %)</td>
<td>2 (6.89 %)</td>
<td>14 (48.28 %)</td>
<td>3.34</td>
<td>1.1</td>
</tr>
<tr>
<td>Healthy lifestyles coaching/support</td>
<td>2 (6.89 %)</td>
<td>1 (3.33 %)</td>
<td>1 (3.33 %)</td>
<td>2 (6.89 %)</td>
<td>10 (34.48 %)</td>
<td>3.36</td>
<td>0.65</td>
</tr>
<tr>
<td>Physical activity/exercise on referral</td>
<td>2 (6.89 %)</td>
<td>1 (3.33 %)</td>
<td>1 (3.33 %)</td>
<td>2 (6.89 %)</td>
<td>15 (51.72 %)</td>
<td>3.53</td>
<td>0.85</td>
</tr>
<tr>
<td>Referral to community activity e.g. gardening/social group</td>
<td>1 (3.33 %)</td>
<td>4 (13.89 %)</td>
<td>1 (3.33 %)</td>
<td>2 (6.89 %)</td>
<td>9 (30.33 %)</td>
<td>2.73</td>
<td>0.97</td>
</tr>
<tr>
<td>Primary care review</td>
<td>4 (13.89 %)</td>
<td>1 (3.33 %)</td>
<td>1 (3.33 %)</td>
<td>5 (16.67 %)</td>
<td>16 (55.17 %)</td>
<td>3.64</td>
<td>0.85</td>
</tr>
<tr>
<td>Support from specialist nurse</td>
<td>5 (17.24 %)</td>
<td>0 (0 %)</td>
<td>1 (3.33 %)</td>
<td>0 (0 %)</td>
<td>17 (58.62 %)</td>
<td>3.67</td>
<td>0.65</td>
</tr>
<tr>
<td>Support from pharmacist</td>
<td>3 (10.71 %)</td>
<td>2 (7.41 %)</td>
<td>1 (3.33 %)</td>
<td>11 (37.14 %)</td>
<td>11 (37.14 %)</td>
<td>3.04</td>
<td>0.89</td>
</tr>
<tr>
<td>Online information and support, e.g. websites or chat rooms</td>
<td>3 (10.71 %)</td>
<td>1 (3.33 %)</td>
<td>1 (3.33 %)</td>
<td>9 (30.33 %)</td>
<td>9 (30.33 %)</td>
<td>3.13</td>
<td>0.85</td>
</tr>
<tr>
<td>Support from professionals to help manage low mood, anxiety or depression related to the health condition(s)</td>
<td>3 (10.71 %)</td>
<td>1 (3.33 %)</td>
<td>1 (3.33 %)</td>
<td>10 (33.33 %)</td>
<td>13 (44.64 %)</td>
<td>2.4</td>
<td>0.75</td>
</tr>
<tr>
<td>Support from others who have experience of the same condition</td>
<td>2 (6.89 %)</td>
<td>3 (10.71 %)</td>
<td>0 (0 %)</td>
<td>8 (27.59 %)</td>
<td>10 (33.33 %)</td>
<td>3.25</td>
<td>1.2</td>
</tr>
<tr>
<td>Other (please comment)</td>
<td>1 (3.33 %)</td>
<td>1 (3.33 %)</td>
<td>0 (0 %)</td>
<td>3 (10.71 %)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Avg (Metric): 3.26
Thinking about the things you have NOT been offered, how useful would the following be to help you (or the person you care for) manage your condition well?

<table>
<thead>
<tr>
<th>Service Provided</th>
<th>Not at all useful (1)</th>
<th>Not very useful (2)</th>
<th>Quite useful (3)</th>
<th>Very useful (4)</th>
<th>Avg</th>
<th>n</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual care plan including what to do if the condition gets worse</td>
<td>2 (6.67%)</td>
<td>1 (3.33%)</td>
<td>0 (0%)</td>
<td>11 (35.67%)</td>
<td>10 (33.33%)</td>
<td>2.5</td>
<td>0.68</td>
</tr>
<tr>
<td>Devices to help monitor the condition at home</td>
<td>2 (7.14%)</td>
<td>6 (21.43%)</td>
<td>3 (10.71%)</td>
<td>7 (25%)</td>
<td>10 (33.33%)</td>
<td>2.81</td>
<td>1.18</td>
</tr>
<tr>
<td>Access to patient health record</td>
<td>1 (3.57%)</td>
<td>3 (10.71%)</td>
<td>4 (14.29%)</td>
<td>6 (20.67%)</td>
<td>12 (42.86%)</td>
<td>3.07</td>
<td>1.02</td>
</tr>
<tr>
<td>Group education on how to manage the health condition</td>
<td>4 (13.33%)</td>
<td>5 (16.67%)</td>
<td>7 (23.33%)</td>
<td>4 (13.33%)</td>
<td>10 (33.33%)</td>
<td>2.73</td>
<td>1.15</td>
</tr>
<tr>
<td>Healthy lifestyles coaching/support</td>
<td>3 (10%)</td>
<td>2 (6.67%)</td>
<td>4 (13.33%)</td>
<td>6 (20.67%)</td>
<td>12 (40%)</td>
<td>3.16</td>
<td>1.04</td>
</tr>
<tr>
<td>Physical activity/exercise on referral</td>
<td>2 (6.67%)</td>
<td>6 (20%)</td>
<td>3 (10%)</td>
<td>6 (20.67%)</td>
<td>11 (36.67%)</td>
<td>2.66</td>
<td>1.15</td>
</tr>
<tr>
<td>Referral to community activity e.g. gardening/social group</td>
<td>2 (6.67%)</td>
<td>8 (26.67%)</td>
<td>9 (30%)</td>
<td>3 (10%)</td>
<td>0 (6.67%)</td>
<td>2.29</td>
<td>2.18</td>
</tr>
<tr>
<td>Primary care review</td>
<td>4 (13.33%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>10 (33.33%)</td>
<td>12 (40%)</td>
<td>3.20</td>
<td>0.5</td>
</tr>
<tr>
<td>Support from specialist nurse</td>
<td>4 (13.33%)</td>
<td>1 (3.33%)</td>
<td>1 (3.33%)</td>
<td>6 (20.67%)</td>
<td>11 (36.67%)</td>
<td>3.23</td>
<td>0.9</td>
</tr>
<tr>
<td>Support from pharmacist</td>
<td>5 (16.67%)</td>
<td>3 (10.71%)</td>
<td>3 (10.71%)</td>
<td>11 (36.67%)</td>
<td>1 (3.33%)</td>
<td>2.76</td>
<td>0.92</td>
</tr>
<tr>
<td>Online information and support, e.g. websites or chat rooms</td>
<td>2 (6.67%)</td>
<td>1 (3.33%)</td>
<td>2 (6.67%)</td>
<td>11 (36.67%)</td>
<td>10 (33.33%)</td>
<td>3.28</td>
<td>0.78</td>
</tr>
<tr>
<td>Support from professionals to help manage low mood, anxiety or depression related to the health condition/s</td>
<td>2 (6.67%)</td>
<td>2 (6.67%)</td>
<td>1 (3.33%)</td>
<td>6 (20.67%)</td>
<td>10 (33.33%)</td>
<td>3.48</td>
<td>0.88</td>
</tr>
<tr>
<td>Support from others who have experience of the same condition</td>
<td>4 (13.33%)</td>
<td>3 (10.71%)</td>
<td>4 (13.33%)</td>
<td>6 (20.67%)</td>
<td>12 (40%)</td>
<td>3.22</td>
<td>2.02</td>
</tr>
<tr>
<td>Other (please comment)</td>
<td>1 (25%)</td>
<td>1 (25%)</td>
<td>0 (0%)</td>
<td>2 (50%)</td>
<td>3 (75%)</td>
<td>2.83</td>
<td>1.47</td>
</tr>
</tbody>
</table>

Avg (Metric) 3.07
Appendix 2: Mapping of community support

These maps show some of the community support that is available in Cornwall for people with long term conditions. It is not an exhaustive list.

What services do we know are out there?:
Self management community groups for people with LTCs

- Cornwall Rural Community Council
- WWW.NHS.UK
- ME association
- Outlook Southwest
- Parkinson’s Association – Young onset
- Cornwall Memory Café Network Forum
- Get out there Cornwall
- Creative Spaces – Sensory Trust
- Breathe Club
- Social prescribing (partial)
- Expert Patient Programme (4x6 sessions for 100 people)
- Neuro Care Advisory service (CFT)
- Promas Carers training
- Kernow Carers service
- Pulmonary Rehab
- IAPT
- MIND
- Outlook Southwest (Stress Busters, Anger, worry, depression, mindfulness PND)
- One to One CBT/counselling (delivery group face to face – online (CCBT); telephone/skype
- Health Promotion – health trainers
- University of the Third Age
- Connect UK
- Cancer support groups - listed in Cornwall
- Cancer Services Directory
- Support for children & young people with diabetes in Cornwall (SKYD T1)
- Re-think (Mental Health)
- Sea Sanctuary (Mental Health)
- Healthy Weight Matters
- Cornwall Voluntary Sector Forum (Digital skills sessions, EH groups, memory cafes)
- 60+ carer groups
- 36 carer forums
- Aged veteran support
What services do we know are out there?:
Self management community groups for people with LTCs

North
- Bude Walk & Talk
- Launceston Breathe Easy
- Health wise – Crackington Haven
- Wadebridge Breathers
- Health wise fitness group Launceston

East
- Bi-polar UK
- Kernow Positive Support
- Launceston Diabetes Support Club
- My COPD (web support)
- Saltash Walk & Talk
- Looe Breathers
- Tamar Valley Walk & Talk
- Centipede Club Liskeard
- Pensilva Breathers
- Liskeard Breathers
- Oak Tree Valley Group
- Saltash Breathers
- Torpoint Breathers

Truro
- Kernow Positive Support
- Diabetes Support Group
- Carrick Mind
- Leukaemia Care Myeloma Support Group
- Young Women’s Cancer Group
- Upbeat
- The Cove Macmillan cancer support
- RCHT diabetes, dietician type 2 groups (for diet only)
- Diabetes support group for Type 1 diabetes for adults (separate for children)
What services do we know are out there?:
Self management community groups for people with LTCs

Newquay
Age UK leg group
(Part of a proposed Pentreath Mental Health project)
Newquay Breathers
Newquay Happy Hearts

North Kerrier
CRASH Support Group
North Kerrier diabetes group
PENTA mental health & wellbeing, Camborne

Penwith
Breathe Easy Helston

Mid
National Rheumatoid Arthritis Society
Restormel Mind
Merlin MS Centre
EDEN Diabetes Walk
Social prescribing
Exercise prescription by GPs at St Austell HC group
St Austell Heart & Stop Group
St Austell pilot project (COPD, diabetes, IBS, Chronic pain) – Step 3/step 3 CBT groups planned.

Penwith
Bipolar UK
Diabetes Support
Hayle Breathers Club
Diabetes structured education group
Age UK/Macmillan
Living Well
St Ives Breathers
Penwith Integrated Care Forum
Singing for Breathing
Appendix 3: Evidence Review Search Strategy and Table of Findings

Search Strategy

The search strategy was developed using the PICO framework (Table 45). The review answered the following research question:

“What self-management interventions are effective for adult patients with heart conditions, diabetes, cancer or respiratory conditions, compared to usual care, to improve various health, clinical, patient-related and healthcare outcomes?”

**Figure 48:**

<table>
<thead>
<tr>
<th>PICO Category</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Population</strong></td>
<td>Adult patients aged over 18, with heart conditions, diabetes, cancer or respiratory conditions.</td>
</tr>
<tr>
<td><strong>Intervention</strong></td>
<td>Self-management or self-care interventions involving primary or secondary healthcare setting, or in the community</td>
</tr>
<tr>
<td><strong>Comparator/control</strong></td>
<td>Usual care or no-intervention group</td>
</tr>
<tr>
<td><strong>Outcomes</strong></td>
<td>Health/clinical outcomes, hospital admissions, readmissions, length of stay, A&amp;E use or health care costs, quality of life scores, patient-related outcome measures</td>
</tr>
</tbody>
</table>

Modified from – title and abstract searches
<table>
<thead>
<tr>
<th>Key words</th>
<th>Text words with their synonyms</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Setting</td>
<td>Community OR home</td>
</tr>
<tr>
<td>2. Self-management</td>
<td>“Self-care” OR “self-care” OR “self-management” OR “patient compliance” OR “patient compliance” OR “patients compliance” OR “compliance patient*” OR “therapy compliance” OR “therapies compliance” OR “compliance therapy**” OR “non-compliance” OR “medication adherence” OR “patient adherence” OR “patients adherence” OR “adherence patient” OR “adherence patients” OR “therapy adherence” OR “therapies adherence” OR “adherence therapy” OR “adherence therapies” OR “non-adherence” OR “self-monitoring” OR “concordance” OR “self-regulation” OR “self-monitoring” OR “self-control” OR “patient activation” OR “PAM”</td>
</tr>
<tr>
<td>3. Methodology/type of study design</td>
<td>Systematic OR meta-analyst* OR “meta analyst**”</td>
</tr>
</tbody>
</table>

Combine 1 AND 2 AND 3

Key
RR = Relative risk
OR = Odds ratio
CI = Confidence interval
SMD = standardised mean difference
HRQoL = Health Related Quality of Life
PROMs = patient reported outcome measures
Evidence Review Table of Findings

<table>
<thead>
<tr>
<th>Author (year), location of corresponding author. Title.</th>
<th>No. of included studies, No. from the UK</th>
<th>Quality of included studies</th>
<th>Population</th>
<th>No. of RCT Included</th>
<th>Type of interventions included</th>
<th>Outcome/s of interest</th>
<th>Summary of main finding/s</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adler et al. (2013), UK. Mobile phone text messaging to improve medication adherence in secondary prevention of cardiovascular disease.</td>
<td>7, 0</td>
<td>Very low quality. Small, heterogeneity, high risk of bias. GRADE: VERY LOW + + +</td>
<td>Patients with established arterial occlusive events</td>
<td>7</td>
<td>Mobile phone text messaging. Comparator was no intervention or other modes of communication</td>
<td>Adherence to treatment</td>
<td>Six out of seven trials showed a beneficial effect of mobile phone text messaging for medication adherence. One trial showed an improved adherence score for the control group compared to the intervention group (smallest and shortest trial). The low quality of evidence means it is not possible to draw conclusions for practice from this review.</td>
</tr>
</tbody>
</table>
| Anderson et al. (2017), UK. Home-based versus centre-based cardiac rehabilitation. | 23, 4                                  | Evidence quality ranged from very low to moderate the main reason for the low assessment of quality was poor reporting in the included studies. | Adults with myocardial infarction, angina, heart failure or who had undergone revascularisation. | 23                          | Centre-based cardiac rehabilitation (e.g. hospital, gymnasium, sports centre) compared with home-based programmes | Primary outcomes  
  • Total mortality.  
  • Cardiac events:  
  • Exercise capacity assessed by validated outcome measure (e.g. VO₂ peak, 6-minute walk test).  
  • Validated measures of health-related quality of life (HRQoL) (e.g. Short Form Health Survey 36) | Women accounted for only 19% of recruited participants; four trials did not include women.  
  No evidence of a difference was seen between home- and centre-based cardiac rehabilitation in clinical primary outcomes up to 12 months of follow up: total mortality (RR) = 1.19, 95% CI 0.65 to 2.16; participants = 1505; very low-quality evidence, exercise capacity (SMD) = -0.13, 95% CI -0.28 to 0.02; participants = 2255; studies; low quality evidence). HRQoL up to 24 months was not estimable. Trials were generally short, with only three studies reporting outcomes beyond 12 months (exercise capacity: SMD 0.11, 95% CI -0.01 to 0.23; participants = 1074; moderate quality |
Blinding was not possible due to the type of intervention.

- Withdrawal from the exercise programme.

**Secondary outcomes**
- Modifiable coronary risk factors (i.e. blood lipid levels, blood pressure, smoking behaviour).
- Adherence to cardiac rehabilitation.
- Costs and health service use (e.g. use of medication, primary care contacts).

Form Health Survey (SF-36), Sickness Impact Profile, Nottingham Health Profile.

Evidence). However, there was evidence of marginally higher levels of *programme completion* (RR 1.04, 95% CI 1.00 to 1.08; participants = 2615; low quality evidence) by home-based participants.

Despite some caution over the low evidence grading, the authors conclude that this update supports previous research that home- and centre-based forms of cardiac rehabilitation are similarly effective in improving clinical and HRQoL outcomes in patients with heart disease. They point out that offering the choice of participating in a more traditional and supervised centre-based programme or a home-based programme may reflect local availability and consider the preference of the individual patient.

Costs will vary across healthcare systems, but this review found no important difference in the cost of providing home- versus centre-based programmes. Home-based programmes often require support from healthcare staff which can be the major cost driver.
After a cardiac event about 30% to 50% of smokers with CHD quit without professional help. Additional psychosocial interventions show a superior quitting rate compared to usual care in the short-term. Long-term follow-up showed an attenuation in the benefit of psychosocial interventions for smoking cessation, but psychosocial smoking cessation intervention are still a promising strategy. Interventions for smoking cessation in CHD patients should last for more than 1 month. Brief interventions were not effective unless followed up. About fifteen patients had to be treated for one person to be abstinent from tobacco after 1 year (NNT = 14.9, CI 11.1 to 24.3). For intense intervention the NNT is somewhat lower (NNT = 11.9, CI 9.6 to 16.7). No clear evidence that any treatment strategy was more efficacious than others. There was no difference in the chance of quitting for multiple risk factor cardiac rehabilitation programmes, compared with interventions focusing on smoking cessation only.

Lifestyle interventions were associated with a reduction in the risk of baby being born large-for-gestational age. No clear difference in number of new-borns experiencing low blood glucose levels (moderate quality). Birthweight was also lower in the lifestyle intervention group. Lifestyle interventions made no clear difference in the number of women with pregnancy-induced high blood pressure or having a caesarean section (low-quality evidence), or on induction of labour (high-quality evidence). Similar numbers of women experienced perineal trauma or tearing or developed type 2 diabetes at a maximum of 10 years after giving birth (low- to moderate-quality evidence). More women in the lifestyle group had met their weight goals one year after giving birth, and lifestyle interventions were associated with a decrease in the risk of depression after birth (low quality evidence).

- **Cheng et al. (2017), Singapore.** *Home-based multidimensional survivorship programmes for breast cancer survivors.*
- **Ranged from moderate to very low.**
- **Breast cancer survivors:** 22 RCT, 4 quasi-RCT
- **Home-based multidimensional survivorship (HBMS) programmes, including more than one of the following components:** educational (such as information provision and self-management advice), physical (such as exercise training and resistance training) and psychological (such as counselling and cognitive therapies). Comparator was usual care.
- **Quality of life, anxiety, depression, fatigue. No study reported on health service needs and utilisation.**
- **HBMS programmes may increase breast cancer-specific quality of life and global quality of life immediately after the intervention, as measured by Functional Assessment of Cancer Therapy-Breast (FACT B) and European Organisation for Research and Treatment of Cancer Quality of Life C30 (EORTC C30) (moderate quality evidence). Reduction in short-term anxiety, fatigue and insomnia (low quality evidence). These effects did not persist long-term.**


- **Chew et al. (2017), Netherlands.** *Psychological interventions for diabetes-related distress in adults with type 2 diabetes mellitus.*
- **Low.** Overall, the quality of the evidence was low because of small studies, missing data, and limitations in the design and implementation of the included studies. Four studies are awaiting further assessment,
- **Type 2 diabetes participants with diabetes-related distress:** 30
- **Psychological interventions, either emotion-focused, cognitive-focused, or both.**
  - **Emotion-focused:** Positive affects; positive well-being; resilience; managing negative affects; integrating psychosocial adjustment to daily life; healthy coping; motivation.
  - **Cognitive-focused:** Knowledge, comprehension or awareness about
- **Primary outcomes were diabetes-related distress (DRD), health-related quality of life (HRQoL) and adverse events.** Secondary outcomes were self-efficacy, glycosylated haemoglobin A1c (HbA1c), blood pressure, diabetes-related complications, all-cause mortality and socioeconomic effects.
- **Psychological interventions have a small and positive effect on confidence for self-care and glycosylated haemoglobin A1c (HbA1c - a long-term measure of glucose control) in adults with type 2 diabetes. Compared to usual care, psychological interventions showed no firm effect on diabetes-related distress, health-related quality of life, death from any cause, adverse events or blood pressure levels. No study reported on diabetes-related complications (like stroke, heart attacks or kidney impairment) or socioeconomic effects (such as absence from work or costs for medication). Authors were not able to compare the effectiveness of emotion-focused versus cognitive focused programmes.**
  
  Compared to usual care, psychological interventions appear to have small and uncertain beneficial effects on self-efficacy and HbA1c after 6 to 12 months. Not all psychological interventions have a substantial effect on DRD. DRD showed improvement following emotion-cognition interventions that
diabetes, complications and treatment options, taking medication, healthy eating, being active, goal setting to promote health, risk reduction, self-efficacy and confidence in one’s own ability to manage diabetes are brief and simple compared to usual care. There are no substantial adverse events or mortality in participants of psychological interventions. Existing psychological interventions have no different effect on HRQoL and blood pressure levels compared to usual care. Evidence is non-existent on diabetes-related complications and socioeconomic impacts. The small difference of effects is a valid consideration when developing psychological interventions in resource-challenged health facilities. Wise strategies include adoption of theory-based and proven psychological interventions and need to be modified locally and in a culturally appropriate way.

A meta-analysis of all psychological interventions combined versus usual care showed no firm effect on DRD SMD -0.07; 95% CI -0.16 to 0.03; P = 0.17, HRQoL (SMD 0.01; 95% CI -0.09 to 0.11; P = 0.87), all-cause mortality (11 per 1000 versus 11 per 1000; risk ratio (RR) 1.01; 95% CI 0.17 to 6.03; P = 0.99; or adverse events (17 per 1000 versus 41 per 1000; RR 2.40; 95% CI 0.78 to 7.39; P = 0.13. We saw small beneficial effects on self-efficacy and HbA1c at medium-term follow-up (6 to 12 months): on self-efficacy the SMD was 0.15 (95% CI 0.00 to 0.30; P = 0.05) in favour of psychological interventions; on HbA1c there was a mean difference (MD) of -0.14% (95% CI -0.27 to 0.00; P = 0.05; 3165 participants; in favour of psychological interventions. Our included trials did not report diabetes-related complications or socioeconomic effects.

| Clarke et al. (2017), Educational and behavioral interventions for anticoagulant | 11, 2 | Low to very low. Main risk of bias was due to lack of blinding. | Oral anticoagulant therapy in patients with atrial fibrillation | Education, self-monitoring plus education, or decision aid. Comparator was usual care. | Time in therapeutic range (TTR), decision conflict (patient’s uncertainty in making health-related decisions), percentage of international normalised | The effect of self-monitoring plus education on TTR was uncertain compared with usual care (MD 6.31, 95% CI -5.63 to 18.25, I² = 0%, 2 trials, 69 participants, very low-quality evidence). We found small but positive effects of education on anxiety (MD -0.62, 95% CI -1.21 to -0.04, I² = 0%, 2 trials, 587 participants, low-quality evidence) and depression (MD -0.74, 95% CI -1.34 to -0.14; I² = 0%, 2 trials, 587 participants, |
| Therapy in patients with atrial fibrillation. | Ratios (INRs) in the therapeutic range, major bleeding, stroke and thromboembolic events, patient knowledge, patient satisfaction, quality of life (QoL), beliefs about medication, illness perceptions, and anxiety and depression. | Low-quality evidence) compared with usual care. The effect of decision aids on decision conflict favoured usual care (MD = -0.1, 95% CI -0.17 to -0.02, I² = 0%, 2 trials, 721 participants, low-quality evidence).

Patients participating in both educational interventions and self-monitoring interventions (with education) appear to spend more time within the therapeutic INR range, but pooled analyses of the AF data did not significantly favour self-monitoring plus education over usual care. Evidence is limited, as there were few trials with small samples of AF patients. More trials are needed to examine the impact of intensive educational interventions on anticoagulation control in AF patients and the impact on TTR. Self-monitoring may not be a feasible option for many patients, particularly as it requires additional training and is costly, and new anticoagulants are now available which do not require monitoring. There is a need for interventions to provide effective illness-specific educational tools, which incorporate relevant behaviour change techniques. |

**Table:**

| Coulter et al. (2015), UK. Personalised care planning for adults with chronic or long-term health conditions. | Moderate. Main risk of bias was lack of blinding which is not possible for this type of intervention. | Adult patients with long-term health conditions: 12 studies focused on diabetes, three on mental health, one on heart failure, one on end-stage renal disease, one on 16 RCTs, 3 cluster Interventions that explicitly engaged patients in a shared decision-making process involving both goal setting and action planning. | Primary outcomes were effects on physical health, psychological health, subjective health status, and capabilities for self-management. Secondary outcomes included effects on health-related behaviours, resource use and costs, and type of intervention. |

All but three of the personalised care planning interventions took place in primary care or community settings; the remaining three were located in hospital clinics. **Physical health**

Small positive effect favouring personalised care for glycated haemoglobin (HbA1c), mean difference (MD) of -0.24% (95% confidence interval (CI) -0.35 to -0.14).

Positive effect favouring personalised care for systolic blood pressure, mean difference of -2.64 mm/Hg (95% CI -4.47 to -0.82).

No significant effect on diastolic blood pressure, MD -0.71 mm/Hg (95% CI -2.26 to 0.84).
<table>
<thead>
<tr>
<th>Subjective health status</th>
<th>Psychological health</th>
<th>Self-management capabilities</th>
<th>Other outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>No effect found on the physical component summary score of the SF-36 or SF-12: SMD 0.16 (95% CI -0.05 to 0.38) or the mental component summary score SMD 0.07 (95% CI -0.15 to 0.28). Of the three other studies that measured generic health status, two found improvements related to personalised care and one did not.</td>
<td>Small positive effect favouring personalised care for improving depression: SMD of -0.36 (95% CI -0.52 to -0.20). Four other studies used a variety of psychological measures that were conceptually different so could not be pooled. Of these, three found greater improvement for the personalised care group than the usual care group and one was too small to detect differences in outcomes.</td>
<td>Small positive result in favour of personalised care planning for self-management capabilities using self-efficacy measures: SMD 0.25 (95% CI 0.07 to 0.43). Two studies found evidence of an effect on patient activation, one found an effect on empowerment, and one found improvements in perceived interpersonal support.</td>
<td>No effect found on exercise levels due to personalised care planning, but there was a positive effect on people's self-</td>
</tr>
<tr>
<td>Devi et al. (2015), UK. Internet-based interventions for the secondary prevention of coronary heart disease.</td>
<td>11, 2</td>
<td>Low. Lack of blinding, uncertainty around the magnitude of effect, and loss to follow-up. Limited generalisability.</td>
<td>Patients with coronary heart disease</td>
</tr>
</tbody>
</table>
Risk of bias was low in 38% of studies, unclear in 41% and high in 21% of studies. No studies were judged to be at high risk of selection bias. In studies with a high risk of bias the most common source of bias was a lack of blinding in the assessment of non-objective measures of outcome.

Patients with the following clinical conditions:
- Cardiovascular disease (36),
- Diabetes (21),
- Respiratory conditions (9),
- Mental health or substance abuse conditions (7),
- Conditions requiring a specialist consultation (6),
- Comorbidities (3),
- Urogenital conditions (3),
- Neurological injuries and conditions (2),
- Gastrointestinal conditions (2),
- Neonatal conditions requiring specialist care (2),
- Solid organ transplantations (2),

Telemedicine provided remote monitoring (55 studies), or real-time video-conferencing (38 studies), which was used either alone or in combination. The main TM function varied depending on clinical condition, but fell typically into one of the following six categories, with some overlap: i) monitoring of a chronic condition to detect early signs of deterioration and prompt treatment and advice, (41); ii) provision of treatment or rehabilitation (12), for example the delivery of cognitive behavioural therapy, or incontinence training; iii) education and advice for self-management (23), for example nurses delivering education to patients with diabetes or providing support to parents of very low birth weight infants or to patients with home parenteral nutrition; iv) mortality, disease-specific and general measures of health status using validated measures, healthcare resource use, costs.

No difference in mortality between participants with heart failure receiving care through telemedicine, compared to those receiving health care without telemedicine (high quality evidence). Differing results for hospital admissions, from a relative decrease of 64% to an increase of 60% (moderate quality evidence). Disease-specific quality of life was slightly improved for heart failure participants receiving telemedicine as compared to those receiving usual care only (moderate evidence).

Telemedicine may improve glucose control in people with diabetes (mean difference (MD) 0.30 percentage points) (high evidence) but the effect varied: from a MD of -0.72 to 0.20 percentage points. Some evidence for a decrease in LDL cholesterol (MD -12.45 mg/dL), and a greater decrease in blood pressure in those allocated to telemedicine (moderate evidence).

Seven studies that recruited participants with different mental health and substance abuse problems reported no differences in the effect of therapy delivered over video-conferencing, compared to face-to-face delivery. Findings from other studies varied; there was some evidence that monitoring via telemedicine improved blood pressure control in participants with hypertension, and a few studies reported improvement for those with a respiratory condition.

The cost of implementing TM, compared with usual care, was only reported in 25% of included studies and no studies assessed how TM might alter the structure of health service delivery and payment. Summarising the cost of TM, compared with usual care, in any meaningful way was limited by each study attributing costs to different resources.
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Complexity</th>
<th>Group 1</th>
<th>Group 2</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gatheral et al. (2017), UK. <em>Personalised asthma action plans for adults with asthma</em></td>
<td>15, 5</td>
<td>Low or very low</td>
<td>Adults with asthma</td>
<td>PAAP alone compared with no PAAP: People using a PAAP did not show any difference in hospital admissions due to exacerbations. This result was the same for changes in asthma symptom scores and mortality due to asthma. People with a PAAP showed an improvement in quality of life compared with those without a PAAP, but the difference was not large enough to be clinically meaningful. PAAP plus education compared with education alone: No significant difference between people using a PAAP and education and those just receiving education. This finding was the same for all outcomes, hospital admissions for exacerbations, changes in symptom scores and quality of life. Analysis of available studies was limited by variable reporting of primary and secondary outcomes; therefore, it is difficult to draw firm conclusions related to the effectiveness of PAAPs in the management of adult asthma. The authors recommend further research with a particular focus on key patient-relevant outcomes, including exacerbation frequency and quality of life, in a broad spectrum of adults, including those over 60 years of age.</td>
<td>15</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Modality</td>
<td>Population</td>
<td>Results</td>
<td></td>
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<tr>
<td>Howcroft et al. (2016), Australia. <em>Action plans with brief patient education for exacerbations in chronic obstructive pulmonary disease</em></td>
<td>Australia</td>
<td>Action plans</td>
<td>Individuals with exacerbations of chronic obstructive pulmonary disease</td>
<td>Action plans offer a form of self-management that can be delivered in the outpatient setting to help individuals recognise and initiate early treatment for exacerbations. Comparator was usual care. Primary outcomes: Healthcare utilisation, including respiratory-related hospital admission, treatment in an emergency department (ED) and GP visits for COPD. Mortality: respiratory-related and all-cause. Use of medication: time to initiation of therapy after symptom onset; courses/duration of antibiotic or corticosteroid use, or both; participant initiation of antibiotic or steroid use, or both. People with COPD who are given an action plan have fewer emergency department visits and hospital stays related to breathing problems over a year. For every 19 people given an action plan, one person would avoid a hospital stay for an exacerbation. People with an action plan took more corticosteroid and antibiotic medicines for exacerbations — on average just under one more course of corticosteroids and two more courses of antibiotics over a year. Some studies showed that giving people an action plan improved their ability to recognise and self-start treatment for worsening COPD symptoms. Giving people an action plan made no difference in their chance of dying from any cause over a year, but this finding showed some variability. It was not possible to say whether follow-up phone calls added benefit over following an action plan alone.</td>
<td></td>
</tr>
<tr>
<td>Inglis et al. (2015), Australia. <em>Structured telephone support or non-invasive telemonitoring.</em></td>
<td>Australia</td>
<td>Structured telephone support or telemonitoring</td>
<td>People with heart failure</td>
<td>Structured telephone support reduced all-cause mortality (RR 0.80, 95% CI 0.68 to 0.94) and heart failure-related hospitalisations (RR 0.71, 95% CI 0.60 to 0.83). Structured telephone support reduced all-cause mortality (RR 0.87, 95% CI 0.77 to 0.98)) and heart failure-related hospitalisations (RR 0.85, 95% CI 0.77 to 0.93).</td>
<td></td>
</tr>
</tbody>
</table>
telemonitoring for patients with heart failure.

Neither structured telephone support nor telemonitoring demonstrated effectiveness in reducing the risk of all-cause hospitalisations.

This review demonstrates that supporting people with heart failure at home using information technology can reduce the rates of death and heart failure-related hospitalisation. It can improve people’s quality of life and knowledge about heart failure and self-care. Most patients, even those who are elderly, learn to use the technology easily and are satisfied with these interventions.

Compared to usual conventional care, implementation of structured telephone support and non-invasive home telemonitoring reduces mortality and heart failure-related hospitalisations, improves quality of life, heart failure knowledge and self-care behaviours and therefore should be considered evidence-based strategies to improve the quality of care and outcomes for people with heart failure.

As the equipment for these interventions was in most cases provided as part of the study, the implications for purchase, installation and maintenance of such equipment for use of telemonitoring in particular in the real world needs to be considered as these may be barriers to the use of telemonitoring.

Kew and Cates (2016), UK. Home telemonitoring and remote feedback between clinic visits for asthma.

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Setting</th>
<th>Population</th>
<th>Outcome measures</th>
<th>Results</th>
</tr>
</thead>
</table>
|       | randomised controlled trial | telephone | people with asthma | exacerbations requiring oral corticosteroids | No clear evidence whether asthma telemonitoring with feedback from a healthcare professional increases or decreases the odds of exacerbations that require a course of oral steroids (OR 0.93, 95% confidence interval (CI) 0.60 to 1.44), a visit to the emergency department (OR 0.75, 95% CI 0.36 to 1.58) or a stay in hospital (OR 0.56, 95% CI 0.21 to 1.49) compared with usual care. Confidence was limited by imprecision in all three primary outcomes. None of the
| Lawrenson et al. (2018), UK. | Low or unclear risk of bias | Patients with type 1 or 2 diabetes eligible for diabetic retinopathy screening | 66 | Any quality improvement intervention - any planned strategy or combination of strategies to improve attendance for diabetic DRS targeted at individuals with diabetes (e.g. reminders, promotion of self-management), healthcare professionals (e.g. education, audit and feedback) or the healthcare system (e.g. electronic registries, team changes). Comparator was usual care. Interventions included those specifically targeting DRS, as well as those studies recorded serious or non-serious adverse events separately from asthma exacerbations. Evidence for measures of asthma control was imprecise and inconsistent, revealing possible benefit over usual care for quality of life (MD 0.23, 95% CI 0.01 to 0.45), but the effect was small and study results varied. Telemonitoring interventions may provide additional benefit for two measures of lung function. Current evidence does not support the widespread implementation of telemonitoring with healthcare provider feedback between asthma clinic visits.

The primary outcome was the difference in DRS attendance (one or more visits) within a two-year period following implementation. This could be based on self-reports, medical insurance claims databases or health-record audits (hospital, primary care physician or screening administration system record).

Fifty-six studies (329,164 participants) compared intervention versus usual care. Overall, DRS attendance increased by 12% (risk difference (RD) 0.12, 95% confidence interval (CI) 0.10 to 0.14; low-certainty evidence) compared with usual care, with substantial heterogeneity in effect size. Both DRS-targeted (RD 0.17, 95% CI 0.11 to 0.22) and general QI interventions (RD 0.12, 95% CI 0.09 to 0.15) were effective, particularly where baseline DRS attendance was low. All BCT combinations were associated with significant improvements, particularly in those with poor attendance. Higher effect estimates found in subgroup analyses for the BCTs ‘goal setting (outcome)’ (RD 0.26, 95% CI 0.16 to 0.36) and ‘feedback on outcomes of behaviour’ (RD 0.22, 95% CI 0.15 to 0.29) in interventions targeting patients, and ‘restructuring the social environment’ (RD 0.19, 95% CI 0.12 to 0.26) and ‘credible source’ (RD 0.16, 95% CI 0.08 to 0.24) in interventions targeting healthcare professionals. Ten studies (23,715 participants) compared a more intensive (stepped) intervention versus a less intensive intervention. In these studies DRS attendance increased by 5% (RD 0.05, 95% CI 0.02 to 0.09; moderate-certainty evidence).
that were part of a general strategy to improve processes of diabetes care. Interventions were coded using the Cochrane EPOC QI intervention classification, and the Behaviour Change Taxonomy.

Overall, there was insufficient evidence to draw robust conclusions about the relative cost effectiveness of the interventions compared to each other or against usual care. With the exception of gender and ethnicity, the characteristics of participants were poorly described. Seventeen studies (25.8%) were conducted in disadvantaged populations.

There was no statistically-significant difference between interventions specifically aimed at DRS and those which were part of a general QI strategy for improving diabetes care. This is an important finding, because of the additional benefits of general QI interventions in terms of improving glycaemic control, vascular risk management and screening for other microvascular complications.

| Lenferink et al. (2017), Netherlands. **Self-management interventions including action plans for exacerbations versus usual care in patients with chronic obstructive pulmonary disease.** | Patients with chronic obstructive pulmonary disease (COPD) | 22 | Self-management interventions including action plans for COPD exacerbations. For this review, an action plan refers to specific behaviour to be initiated when respiratory symptoms deteriorate; the plan needed to describe when, where and how one should act. An action plan is an agreed strategy by which people act appropriately when symptoms deteriorate (indicating the start of a COPD exacerbation), for | **Primary outcomes** | Health-related quality of life (HRQoL). Respiratory-related hospital admissions. **Secondary outcomes** Number of all-cause hospital admissions. Use of (other) healthcare facilities (e.g., number of emergency department (ED) visits, number of all-cause and respiratory-related hospitalisation days in total and per patient, general practitioner (GP), number of nurse and specialist visits). | Over 12 months, there was a statistically significant beneficial effect of self-management interventions with action plans
• on HRQoL, as measured by the St. George’s Respiratory Questionnaire (SGRQ) total score, where a lower score represents better HRQoL - mean difference of -2.69 points (95% CI -4.49 to -0.90; 1,582 participants; 10 studies; high-quality evidence).
• lower risk for at least one respiratory-related hospital admission (OR 0.69, 95% CI 0.51 to 0.94; 3,157 participants; 14 studies; moderate-quality evidence). NNT to prevent one respiratory-related hospital admission over one year was 12 (95%CI 7 to 69) for participants with high baseline risk and 17 (95% CI 11 to 93) for participants with low baseline risk.
• Subgroup analyses showed significant improvements in HRQoL in self-management interventions with a |
example, by contacting a healthcare provider for support or initiating self-treatment. It may also include maintenance treatment and advice to avoid situations in which viral infection might be prevalent. The self-management intervention needed to include formal training on how and when to use an action plan for AECOPD. Comparator was usual care.

Rescue medication use. Health status. Number of COPD exacerbations. All-cause mortality. Self-efficacy. Days lost from work.

**smoking cessation** programme compared to studies without a smoking cessation programme.

No statistically significant difference:
- in probability of at least one all-cause hospital admission (OR 0.74, 95% CI 0.54 to 1.03; 2467 participants; 14 studies; moderate quality evidence).
- in no. of all-cause hospitalisation days, emergency department visits, GP visits, and dyspnoea scores.
- in effect on the no. of COPD exacerbations
- in all-cause mortality observed (RD 0.0019, 95% CI 0.0225 to 0.0263; 3296 participants; 16 studies; moderate-quality evidence).
- No. of behavioural change techniques included, duration of intervention and adaptation of maintenance medication as part of the action plan did not affect HRQoL.

Exploratory analysis showed a very small, but **significantly higher respiratory-related mortality rate** in the self-management intervention group compared to usual care (RD 0.028, 95% CI 0.0049 to 0.0511; 1219 participants; 7 studies; very low-quality evidence). However, the authors note none of the seven included studies where respiratory-related mortality was an a priori defined outcome, there may be a risk that the cause of mortality was defined differently in the study groups (misclassification). Preliminary findings from a recent large home-based multi-component COPD self-management intervention with 319 participants showed unambiguously higher mortality rates in the usual care group (N = 23 (14.2%)) compared to self-management (N = 3 (1.9%)) that were mainly respiratory-related (Bourbeau 2016). The authors recommend
**COPD self-management action plans should take into account comorbidities** to improve safety of COPD self-management interventions.

<table>
<thead>
<tr>
<th>Study</th>
<th>Risk of bias</th>
<th>Outcome in intervention</th>
<th>Comparator</th>
<th>Primary outcomes</th>
<th>Secondary outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>McBain et al. (2016), UK. <strong>Self-management interventions for type 2 diabetes in adult people with severe mental illness.</strong></td>
<td>1, 0</td>
<td>Risk of bias was mostly unclear but was high for selective reporting.</td>
<td>Adults with type 2 diabetes and severe mental illness</td>
<td>Interventions to improve self-management of type 2 diabetes mellitus; including interventions that targeted, for example, self-monitoring of blood glucose, diet or exercise behaviour. Interventions may or may not have included self-management of severe mental illness but were excluded if they that focused solely on management of mental health. Comparator provided another active intervention or usual/standard care.</td>
<td>Primary outcomes: Self-care behaviours, diabetes-related complications, adverse events. A range of secondary outcomes including mortality, lifestyle-related behaviours and clinical markers.</td>
</tr>
<tr>
<td>McCabe, McCann and Brady (2017), Ireland. <strong>Computer and mobile technology interventions for self-management</strong></td>
<td>3, 0</td>
<td>High risk of bias, poor quality evidence.</td>
<td>Adults with a clinical diagnosis of COPD</td>
<td>Remote and Web 2.0-based interventions defined as technologies including personal computers (PCs) and applications (apps) for mobile technology, such as iPad, Android tablets, smart phones, and Skype, on behavioural change towards self-</td>
<td>Primary outcomes: health-related quality of life (HRQoL) as measured by the Clinical COPD Questionnaire (CCQ) or St George’s Respiratory Questionnaire (SGRQ). Hospital admissions Acute exacerbations</td>
</tr>
</tbody>
</table>
Secondary outcome: physical activity as measured by daily step counts

Group and eight events in the control group (P = 0.001). Mostly musculoskeletal, due to increased physical activity.

Short term outcomes at week four, month four, and month six, showed the effect of smart technology on self-management and subsequent HRQoL in terms of symptoms and health status was significantly better than when participants received face-to-face/digital and/or written support for self-management of COPD (SMD -0.22, 95% CI -0.40 to -0.03; P = 0.02).

Only one study reported hospital admissions and acute exacerbations but did not detect a difference.

The single study that reported HRQoL at 12 months found no significant differences between groups (MD 1.1, 95% CI -2.2 to 4.5; P = 0.50). Also, hospitalisations (OR 1.6, 95% CI 0.8 to 3.2; P = 0.19) and exacerbations (OR 1.4, 95% CI 0.7 to 2.8; P = 0.33) did not differ between groups in the single study that reported these outcomes at 12 months.

The activity level of people with COPD at week four, month four, and month six was significantly higher when smart technology was used (MD 864.06 daily steps between groups, 95% CI 369.66 to 1358.46; P = 0.0006). The only study that measured activity levels at 12 months reported no significant differences between groups (mean -108, 95% CI -720 to 505; P = 0.73).

Participant engagement in this study was not sustained between four and 12 months. The only study that included smoking cessation found no significant treatment effect (OR 1.06, 95% CI 0.43 to 2.66; P = 0.895).
<table>
<thead>
<tr>
<th>Reference</th>
<th>Page, Column</th>
<th>Study Details</th>
<th>Participants</th>
<th>Monitored Parameters</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moy et al. (2017), Malaysia. <em>Techniques of monitoring blood glucose during pregnancy for women with pre-existing diabetes.</em></td>
<td>10, 3</td>
<td>Very low due to design limitations in the studies, wide confidence intervals, small sample sizes, and few events.</td>
<td>Women with pre-existing diabetes</td>
<td>Self-monitoring versus standard care, self-monitoring versus hospitalisation, monitoring before meals versus monitoring after meals, glucose monitoring, automated monitoring versus conventional system, continuous glucose monitoring (CGM) versus intermittent monitoring and constant CGM versus intermittent CGM</td>
<td>Macrosomia, preterm birth, miscarriage or death of baby</td>
</tr>
<tr>
<td>Posadski et al. (2016), Singapore. <em>Automated telephone communication systems for preventive healthcare and management of long-term conditions.</em></td>
<td>132, 2</td>
<td>Risk of bias for many outcomes – leading to downgrading of quality of evidence. Risk of bias arising from processes was low for just over half the studies and unclear for the remainder. Most studies at unclear risk of</td>
<td>Participants at risk of developing long-term conditions, patients/healthcare consumers, patients with various conditions or at risk of low adherence to medication or laboratory tests, patients with cancer, diabetes mellitus, heart</td>
<td>Automated telephone communication systems (ATCS) send voice messages and collect health information from people using their telephone's touch-tone keypad or voice recognition software. There are several types of ATCS: one-way voice messages to patients (unidirectional), interactive voice response (IVR) systems, those with added functions like referral to advice (ATCS Plus), or those where ATCS are</td>
<td>For long-term management, multimodal ATCS had inconsistent effects on medication adherence. ATCS Plus probably improves medication adherence versus usual care. Compared with control, ATCS Plus and IVR probably slightly improve adherence, while unidirectional ATCS may have little, or slightly positive, effects. No intervention consistently improved clinical outcomes. IVR probably improves test adherence, but ATCS Plus may have little effect.</td>
</tr>
</tbody>
</table>

Evidence for almost all reported outcomes were very low quality due to design limitations in the studies, wide confidence intervals, small sample sizes, and few events. No evidence that any glucose monitoring technique is superior to any other technique among pregnant women with pre-existing type 1 or type 2 diabetes. The evidence base for the effectiveness of monitoring techniques is weak and additional evidence from large well-designed randomised trials is required to inform choices of glucose monitoring techniques.
Performance or detection bias, and of bias from missing data and selective outcome reporting. | Failure, hypertension. Other participants were included but only results relevant to long term condition self-management are presented in this summary | Part of a complex intervention (multimodal). | Obstructive pulmonary disease, HIV/AIDS, high cholesterol, obstructive sleep apnoea, spinal cord dysfunction, carers’ psychological stress, there is not enough evidence to tell what effects ATCS have.

| Puhan et al. (2016), Switzerland. Pulmonary rehabilitation following exacerbations of chronic obstructive pulmonary disease. | Low risk of allocation bias (when reported). Blinding not possible; this may have introduced bias for HRQoL but less likely for mortality or admissions. Minor attrition bias. No evidence of reporting bias. | Participants with COPD after inpatient or outpatient care for acute exacerbation. This review required that more than 90% of study participants were patients with COPD. | Randomised controlled trials (RCTs) comparing pulmonary rehabilitation of any duration after exacerbation of COPD versus conventional care. Pulmonary rehabilitation programmes had to include at least physical exercise (endurance or strength exercise, or both). Rehabilitation programmes could include additional components such as self-management education, psychological support, dietary advice and breathing exercises. We | Primary outcome: hospital admissions Secondary outcomes: mortality, HRQL and exercise capacity. | 20 studies involving 1477 participants with COPD. Rehabilitation programmes started in hospital in some trials and after discharge in others. Variation in exercise training (e.g. number of completed exercise sessions, type and intensity of exercise), patient education (none to extensive self-management programmes) and how programmes were organised (within one setting, e.g. pulmonary rehabilitation, to across several settings, e.g. hospital, outpatient center and home).

Statistically significant effect on HRQoL SGRQ total score (high quality evidence), which was above the minimal important difference (MID) of four points (mean difference (MD) - 7.80, 95% CI -12.12 to -3.47; I² = 64%). Important effects found for the impact and activities domains but not for the SGRQ symptoms domain.

Six-minute walk distance (6MWD) improved, on average, by 62 meters (95% CI 38 to 86) (high quality evidence).
did not apply a criterion for the minimum number of exercise sessions a rehabilitation programme had to offer to be included in the review. Control groups received conventional community care without rehabilitation.

Reduced hospital readmissions (OR) 0.44, 95% CI 0.21 to 0.91, but results were heterogenous ($I^2 = 77\%$) (moderate quality evidence). Extensiveness of rehabilitation programmes and risk of bias may explain the heterogeneity.

Future researchers must investigate how the extent of rehabilitation programmes in terms of exercise sessions, self-management education and other components affects the outcomes, and how the organisation of such programmes within specific healthcare systems determines their effects after COPD exacerbations on hospital readmissions and mortality.

<table>
<thead>
<tr>
<th>Smith et al. (2016), Ireland.</th>
<th>Minimal risk of bias, but blinding of participant and clinicians often impossible</th>
<th>Adults with multimorbidity (two or more long term conditions). This included both comorbidity, defined as particularly common combinations of conditions such as diabetes and heart disease, and also multimorbidity, defined as having any</th>
<th>Any intervention designed to improve outcomes for people with multi-morbidity including professional-, organisational- and patient-oriented interventions. Comparator was usual care.</th>
<th>Full meta-analysis not possible due to heterogeneity of participants and interventions.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interventions for improving outcomes in patients with Multi-morbidity in primary care and community settings.</td>
<td>18, 1</td>
<td>18</td>
<td>Patient clinical or mental health outcomes • PROMs (e.g. quality of life, well-being, measures of disability or functional status). • Utilisation of health services Patient behaviour (e.g. measures of medication use and adherence, and other objective measures such as goal attainment • Provider behaviour (e.g. chronic disease management scores).</td>
<td></td>
</tr>
<tr>
<td>18 RCTs - range of complex interventions for people with multimorbidity. Nine studies on defined comorbid conditions especially depression, diabetes and cardiovascular disease. The rest focused on multimorbidity, generally in older people. In 12 studies, the main intervention element was a change to the organisation of care delivery, e.g. through case management or enhanced multidisciplinary team work. In six studies, the interventions were mainly patient-oriented, e.g. education or self-management support.</td>
<td></td>
<td></td>
<td></td>
<td>Little or no difference in clinical outcomes (moderate quality evidence). Mental health outcomes improved (high quality evidence). Modest reductions in mean depression scores for the studies that targeted participants with depression (SMD) −2.23, 95% CI −2.52 to −1.95) – effective interventions included collaborative care using stepped care protocols.</td>
</tr>
</tbody>
</table>
### Possible combination of more than one chronic health condition.

- Acceptability of the service to recipients and providers that reported objective outcome measures behaviour.
- Economic outcomes

<table>
<thead>
<tr>
<th>Study</th>
<th>Methods</th>
<th>Participants</th>
<th>Interventions</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stacey et al. (2017), Canada.</td>
<td>Selective reporting and blinding of participants/staff were mostly rated</td>
<td>Adults considering treatment or screening decisions</td>
<td>Decision aids are interventions that support patients by making their decisions explicit, providing information about</td>
<td>Small improvement in patient-reported outcomes (moderate certainty evidence). The results from the six patient-oriented studies were mixed and do not suggest that patient-oriented interventions are generally effective. However, there was an indication that a focus on functional capacity and activity participation may be effective, with one study reporting a reduction in mortality at four-year follow-up. The intervention may make little or no difference to health service use, may slightly improve medication adherence (both low quality evidence), probably slightly improves patient health behaviours (moderate quality evidence), and probably improves provider behaviour in terms of prescribing behaviour and quality of care (moderate quality evidence). Cost data were limited. Evidence supporting specific interventions is limited and there are remaining uncertainties due to the relatively low number of RCTs conducted in this area, but authors suggest it may support targeting specific problems that people with comorbidities are experiencing and targeting common comorbid conditions such as depression. Interventions need to integrate into existing healthcare systems to be sustainable.</td>
</tr>
</tbody>
</table>

**Decision aids** for people facing health treatment or screening decisions. Based on the International Patient Decision Aid Standards (IPDAS), were attributes related to the choice compared to usual care across a wide variety of decision contexts, people exposed to decision aids feel more knowledgeable, better informed, and clearer about their values, and they probably have a more active role in decision making and more accurate risk perceptions. There is growing evidence that decision aids may improve values-congruent
| screening decisions. | unclear risk of bias due to inadequate reporting. Twelve of 105 studies were at high risk of bias. | options and associated benefits/harms, and helping clarify congruence between decisions and personal values. Comparator was usual care or an alternative intervention. | made and the decision-making process. Secondary outcomes were behavioural, health, and health system effects. | choices. There are no adverse effects on health outcomes or satisfaction. New for this updated is evidence indicating improved knowledge and accurate risk perceptions when decision aids are used either within or in preparation for the consultation. Further research is needed on the effects on adherence with the chosen option, cost-effectiveness, and use with lower literacy populations. |

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