

The  
Richmond  
Group  
of Charities

# Multimorbidity

## Understanding the challenge

A report for the Richmond Group of Charities  
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*January 2018*



# Preface from the Richmond Group of Charities

The Richmond Group of Charities brings together 14 of the leading health and social care organisations in the voluntary sector, with the aim of improving care and support for the 15 million people living with long-term conditions that we represent.



**We come together not only to collectivise our influence and amplify our voices on the issues that affect the individuals we work with every day, but also to recognise and respond to the common issues and challenges that we encounter across all of the communities with which we work.**

We know that many of the people who contact our organisations seeking support with one condition are also living with one or more other long-term conditions. And we know that too often these individuals find themselves faced with a health and care system that refuses to recognise the reality of how these conditions affect them in the round, but instead expects them to adjust their needs to the way the system works.

This challenge – which the health system calls ‘multimorbidity’ – far from being a rarity, is rapidly becoming routine.

As leading charities, we wanted to better understand the nature and scale of the challenge of multimorbidity, how it affects people’s lives, and why the system struggles to respond. We also wanted to understand how our own service and support offers might be adjusted to better respond to the needs of people with more than one long-term condition.

This report summarises the insights drawn from a brief scoping study that we commissioned to start to think through some of these issues.

We do not claim to hold all of the answers at this stage, but by identifying gaps in the evidence and key questions for further consideration, this study represents an essential starting point in our efforts to understand and respond to one of the largest and most complex challenges facing modern health and care systems. Our plans for addressing the issue of multimorbidity, outlined at the end of this report, have been shaped by the overarching principle that people should be enabled to live as well as possible for as long as possible because:

- the development of multiple conditions is delayed or prevented and;
- where people live with multiple conditions, health and care services and the voluntary sector’s offer are well-aligned to support them.

**We are publishing this report as a call for others to join us as we use these insights to shape our input on the future of health and care services.**

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# Executive summary

## About multimorbidity

Multimorbidity is usually defined as the presence of two or more long-term conditions in the same individual. Estimates for the percentage of people living with multimorbidity in England vary from 15 per cent to 30 per cent according to different national and local sources. People who have long-term conditions – which cannot be cured but are managed with drugs or other treatments – account for 50 per cent of GP appointments, 64 per cent of outpatient appointments, 70 per cent of inpatient bed days and 70 per cent of the total health and care spend in England.<sup>1</sup>

But the problem with our current understanding of multimorbidity is that it puts too much emphasis on the conditions a person has, and not enough emphasis on how these conditions affect that person. There is an urgent need to address the gap in evidence about the lived experience of people with multimorbidity.

Developing holistic understandings of multimorbidity would help focus on how conditions affect people's day-to-day lives, and the lives of those around them. It would also bring into sharper focus the importance of action on the wider determinants of health. There is a strong link between socioeconomic deprivation and multimorbidity: multimorbidity occurs 10–15 years earlier in people living in the most deprived areas than it does in those living in the most affluent areas. It is vital that this link is understood as we consider policy and practice responses to multimorbidity.

## Key issues in responding to multimorbidity

Despite gaps in the evidence, we know that people living with multimorbidity are at greater risk of negative outcomes such as increased mortality, lower quality of life, and greater use of healthcare services, including unplanned admissions. They also face challenges in navigating the health and care system and managing their health, and are generally less satisfied with the care they receive.

**A fragmented system:** Health and social care systems in England are not designed to support people with multiple conditions. As a result of having to engage with a fragmented and siloed system, people living with multiple conditions are often in contact with multiple health professionals, and are more likely to report care coordination problems. In particular, people with multiple conditions are likely to be vulnerable to the adverse consequences of transitions in care, which are further complicated by poor communication and inadequate data flow across the health and care system.

**Attitudinal and cultural barriers:** Despite their medical knowledge about long-term conditions and the essential biomedical aspects of long-term condition management,<sup>2</sup> not all clinicians have the key skills needed to deliver that care for people with multiple conditions, for example in terms of care and support planning. In addition, for many healthcare professionals, the clinical ethos or 'traditional way of doing things' within their workplace acts as a barrier to engaging in shared decision-making.

**The single disease focus:** There is growing consensus that existing payment structures, measurement systems and incentive mechanisms are not operating effectively for people living with multimorbidity. Specifically, there are concerns that by rewarding GPs for carrying out specific activities in relation to individual conditions, the system makes GPs less likely to consider how patients are doing in the round, and how non-medical interventions – such as social prescribing – might improve outcomes in the long-term.<sup>3</sup>

Until there are fundamental changes to the way in which care is designed and delivered, people with multiple health conditions will continue to be let down by the health and care systems in England.

## Key questions identified by this review

### Coordinating care, including better data use

- What practical steps should be taken to improve the coordination of care across primary, community, secondary and social care settings for people with multiple conditions? What can we learn from past and current initiatives to mainstream coordinated care and support?
- How might a greater understanding of the needs and experiences of people with multiple health problems help inform initiatives to mainstream care coordination, and encourage wider uptake of these models across the health and care system?
- How can we find the right balance between protecting patients' interests and making meaningful patient information and data available (with consent) to health and social care professionals across the system?

### Shifting attitudes and shaping behaviours

- What practical steps can be taken to enable clinicians to support people with multiple conditions more effectively?
- How do we develop incentive structures that are effective in driving improvement for individual conditions while enabling people living with multimorbidity to receive personalised and appropriate care?
- What would an outcomes-based incentive structure look like and how could we make it work?
- What changes are needed to enable the development of clinical guidelines that reflect and address the experiences of people living with multimorbidity?

### Raising awareness

- How can we draw on people's lived experience of having more than one health problem to find better ways of describing and understanding the issues?
- What can be done to increase patients' and public awareness of the issue and impact of multimorbidity?
- How can we engage people with multimorbidity to speak out, and become champions for improvement?

### Person-centred approaches: a way forward?

- Is a general person-centred approach sufficient, or are there other more specific factors that need to be taken into account to ensure that care and support meets the needs of people living with multiple conditions?
- What action can be taken to ensure more people have access to person-centred care and support planning?

### Accounting for context: socioeconomic deprivation

- What needs to happen to ensure responses to multimorbidity take into account the strong links to socioeconomic deprivation? What lessons can be drawn from current practice for health in deprived communities?

## Richmond Group response: time for action

The Richmond Group of Charities believes now is the time to respond to these challenges head-on. But we cannot do this alone so we now plan to convene a cross-sector taskforce. We would like to work collaboratively with others across the health and care sector to develop new responses to this new reality – to enable people living with multiple long-term conditions to live as well as possible for as long as possible.

Over the coming months, the Richmond Group of Charities will invite a wide range of individuals and organisations – including people with experience of living with multiple conditions and those from the policy making, commissioner, provider, and academic communities – to join us as we further shape our plans and take forward this vital work.

# Introduction

**Supporting people living with long-term conditions to maintain a good quality of life is one of the key challenges facing our public health, healthcare and social care systems today.**

One in three British adults (36 per cent) say they have a long-standing illness or disability and one in five (20 per cent) say they have a long-standing condition which limits their day-to-day activity.<sup>4</sup> The impact of long-term conditions on healthcare use is known to be considerable. In fact it is estimated that people who have long-term conditions, which cannot be cured but are managed with drugs or other treatments, account for 50 per cent of GP appointments, 64 per cent of outpatient appointments, 70 per cent of inpatient bed days and 70 per cent of the total health and care spend in England.<sup>1</sup>

While we lack precise figures, it is clear that a rising number of people now have at least two long-term conditions – a situation defined as multimorbidity. While multimorbidity is not a new phenomenon, demographic changes, such as population ageing and advances in medical research and healthcare, mean that an increasing number of people are able to live for longer with multiple health conditions.

Care for people living with multimorbidity is complicated by the fact that different conditions and treatments may interact in complex ways, resulting in unique impacts. Moreover, delivery of care tends to be based on the different conditions a person happens to have, rather than the needs and circumstances of the person as a whole. This can lead to fragmented provision of care that does not take account of the impact of multimorbidity on a person's quality of life. Without profound changes to the way that people living with multimorbidity are viewed by the health and care systems, patients will continue to be let down.

As set out in the NHS Five Year Forward View,<sup>5</sup> health and care systems are continuing to evolve in response to the growing challenges of long-term care, widening inequality, and financial constraints. Yet it is important for key stakeholders within the health and social care sector, and more widely, to take stock of these issues and ask what further action is needed and how they can effectively meet the challenges presented by multimorbidity.

**Drawing on current evidence and conversations with a range of experts from the public health, healthcare and social care sectors (see Appendix A), this report highlights:**

- What we know about multimorbidity and why we need to tackle it
- Key challenges and questions for consideration

It is estimated that people who have long-term conditions, which cannot be cured but are managed with drugs or other treatments, account for:



**50% of GP appointments**



**64% of outpatient appointments**



**70% of inpatient bed days**



**70% of the total health and care spend in England<sup>1</sup>**

# Part I

## Understanding multimorbidity

### KEY POINTS

- The simplest definition of multimorbidity is ‘the presence of two or more long-term conditions’, but this tells us nothing about the nature or the impact of those conditions on the patient.
- Research on multimorbidity and its impacts has grown over the last three decades, but it is still very limited in comparison to the research on single conditions.
- More holistic understandings of multimorbidity, which look at multimorbidity not just from an individual perspective but also from household and community perspectives, and at a population level, may help improve understandings of multimorbidity and its wider social determinants.

### What is multimorbidity?

**Multimorbidity is a fairly broad concept, commonly defined as the co-occurrence of at least two long-term (chronic) conditions in the same individual.<sup>6</sup> Despite its simplicity, however, there are issues with this definition of multimorbidity, including disputes about what constitutes a ‘long-term condition’.**

### What do we mean by ‘long-term condition’?

Aside from being mindful that some conditions are difficult to diagnose,<sup>7</sup> we also need to be clear about what, in the context of discussions about multimorbidity, is meant by a ‘long-term condition’. In its definition of multimorbidity, the National Institute for Health and Care Excellence (NICE) describes the kind of long-term health conditions that multimorbidity can include:

- Defined physical and mental health conditions such as diabetes or schizophrenia
- Ongoing conditions such as a learning disability
- Symptom complexes such as frailty or chronic pain
- Sensory impairment such as sight or hearing loss
- Alcohol and/or substance dependency<sup>8</sup>

The Department of Health defines a long-term condition as one that ‘cannot, at present, be cured but is controlled by medication and/or other treatment/therapies’.<sup>1</sup> Yet this definition doesn’t cover all ongoing experiences of compromised health and/or wellbeing.\* The definition has also been criticised for appearing to ‘emphasise a single-disease approach to treatment’ rather than ‘treating the person with multiple conditions as a whole.’<sup>10</sup>

\*For example, ‘cancer survivorship’ does not appear to fall under this definition but is increasingly being recognised as a chronic condition in its own right,<sup>9</sup> with 20–25 per cent of those treated for cancer estimated to be living with the adverse consequences of cancer or cancer treatment.<sup>10</sup>

One way of unpacking the concept of multimorbidity is to look at common combinations of conditions.<sup>11</sup> We already know that certain conditions are more likely to coexist alongside others (see Appendix B). For example, almost half of people with a heart, lung or mental health condition also have a musculoskeletal condition by the age of 65.<sup>12</sup> Researchers are now increasingly interested in whether clusters of co-occurring conditions can be identified (see Appendix C). By identifying the key underlying risk factors, research on these clusters could improve our wider understanding of how multimorbidity develops and thus help identify where preventative approaches should be focused.<sup>2,13</sup>

**However, the biggest issue with these simple definitions of multimorbidity is that they take little or no account of how people themselves define their problems. Too little attention is paid to what matters to people living with multiple health problems.**

For example, most definitions of multimorbidity focus on chronic conditions despite the fact that many people may also experience disability, acute conditions, or more severe conditions that are more sudden in onset than long-term conditions.<sup>14</sup> Definitions of multimorbidity reflect the priorities of policy makers and healthcare leaders, who are concerned with the impact of long-term conditions on the demand for primary care services,<sup>15</sup> but seem to ignore which condition or conditions have the most impact on a person's life.



**Almost  $1/2$   
of people with  
a heart, lung or  
mental health  
condition also have  
a musculoskeletal  
condition by the  
age of 65**

## Multimorbidity, comorbidity and frailty

**Two terms commonly used in connection with multimorbidity are comorbidity and frailty.**

**Comorbidities** are often defined in terms of a reference condition (or index condition), which is clinically dominant, and other conditions which are then described as comorbidities. And, as with multimorbidity, comorbidity lacks a single definition and this lack of clarity can be a source of confusion. As with multimorbidity, the definition of comorbidity places more emphasis on the conditions that people have, than on the impact on their lives.

**Frailty** is a distinctive state of health, characterised by increasing vulnerability or decreasing resilience to seemingly minor health events, such as an infection or changes in medication.<sup>16,\*</sup> While previous definitions of frailty have often been closely linked with the ageing process (a connection which has faced criticism for suggesting a negative and stereotypical view of ageing) frailty is increasingly viewed as a multidimensional concept.<sup>19</sup> Unlike multimorbidity or comorbidity, where the focus is only on health conditions, multidimensional views of frailty take account of social and environmental factors, as well as physical and psychological factors.<sup>19</sup>

Both comorbidity and frailty are useful for thinking about and responding to multimorbidity. For example, a better understanding of the relationships between comorbid conditions could lead to improvements in the care and support that patients receive. Identifying frailty at an early stage, for example in primary care, could be important for people who are managing multiple health conditions.<sup>16</sup>

We believe there is a clear need to develop consistent ways of thinking about multimorbidity, comorbidity and frailty, which more effectively take account of the thoughts, feelings and circumstances of the individuals living with multimorbidity.

## Towards more holistic understandings of multimorbidity

Although the definition of multimorbidity tends to draw focus on to the conditions that a person has, many of the risks associated with multimorbidity relate to wider factors that influence a person's health. The Academy of Medical Sciences suggests that a three-tier model, which looks at multimorbidity at a household and neighbourhood level, as well as at an individual level, may help improve our understanding of multimorbidity.<sup>2</sup>

Exploring multimorbidity from a household or community perspective could help capture the risk factors in those settings that lead to individuals developing long-term conditions at different stages of their lives, as well as the factors that could help prevent multimorbidity. As discussed later on, our understanding of the risk factors that contribute to multimorbidity is still limited, but the evidence to date suggests that the focus should be on socioeconomic factors, deprivation and inequality. Considering multimorbidity in this way is a useful reminder that many health issues are also social issues.<sup>20</sup> This is particularly pertinent to the wide range of voluntary sector organisations involved in highlighting and helping to address the social determinants of health, via, for example, advocacy services or by improving people's housing or raising educational attainment.

\* While NICE's definition of multimorbidity includes frailty as a symptom complex (i.e. a group of symptoms which characterise frailty), some believe that multimorbidity and frailty should be treated as separate but overlapping terms.<sup>17</sup> Some have even suggested that frailty should be treated as a long-term condition in its own right, as frailty shares many of the features of a long-term condition – such as being treatable but not curable, and having an adverse impact on life experience. The argument is that treating frailty as a long-term condition could help improve the recognition and management of frailty.<sup>18</sup>

# The impact of multimorbidity – the case for action

## KEY POINTS

- People living with multimorbidity are generally less satisfied with the care they receive, possibly due to fragmented services resulting from the single disease focus that drives current health care.
- Multimorbidity is associated with increased mortality, lower quality of life, and greater use of healthcare services including unplanned admissions.
- Multimorbidity is also associated with higher costs, e.g. hospital admission costs, and may have an impact on people's ability to work.
- There are substantial gaps in our knowledge about people's lived experiences of multimorbidity.
- The impact of multimorbidity on individuals' carers and families receives very little attention.

## The personal impact on individuals and carers/families

**While the health-related and financial consequences of multimorbidity are more consistently highlighted, evidence on the lived experiences of people with multiple health conditions is limited.**

We know that people living with multimorbidity are generally less satisfied with the care they receive, perhaps due to the fragmentation and poor coordination of care resulting from the need to see multiple health professionals in primary and secondary care.<sup>21</sup> Although many people living with multimorbidity are able to endure attending multiple appointments, for some it is too difficult.<sup>22</sup> Research suggests that people living with multimorbidity can be confused about who is caring for them. They may also face problems communicating with their clinicians concerning their care, suggesting that services need to place a greater focus on the experiences of patients living with multimorbidity.<sup>23</sup>

Very little is known about the impact of multimorbidity on the carers or families of those affected. Carers – usually family members – may end up taking significant responsibility for supporting people with increasingly complex needs, doing everything from providing meals to administering medicine, to coordinating care. And the task of carers can be made more difficult by a lack of access to information on patients' health conditions, and how those conditions interact or interrelate with one another. Carers and other family members may not feel fully informed on how to manage multiple conditions holistically or where to turn themselves for care and support.<sup>24</sup>

Carers often have health conditions too, and it is likely that many carers are living with multimorbidity themselves. However, very little is known about how multimorbidity affects different households or how it is managed within families. While significant work has been done to highlight the health needs of carers, it is possible that carers and families of people living with multimorbidity have particular needs, which may not yet be fully understood and are therefore unlikely to be met.



**Very little is known about the impact of multimorbidity on the carers or families of those affected**

## The health and care impact

There is growing evidence of the impact of multimorbidity on health and of its financial implications. Multimorbidity is known to be associated with:

- increased or premature mortality
- lower quality of life
- greater use of health services, including GP visits and unplanned admissions
- a higher number of prescriptions (with higher healthcare costs as a result)
- a higher risk of disability<sup>11,13,15,25</sup>

One of the most common consequences of being affected by multiple health conditions is receiving multiple medications for long periods of time – a phenomenon known as polypharmacy. Polypharmacy increases with age and while some polypharmacy can be appropriate, it can be harmful if poorly managed, especially among people living with frailty.<sup>26</sup>

**Studies have also found that people living with multimorbidity are more likely to need long-term care and support, especially those living with Parkinson’s Disease or dementia.<sup>27</sup>**

Mental health problems are also more common among people living with multimorbidity.<sup>21</sup> Anxiety and depression are particularly common and can have an impact on people’s ability to manage other long-term conditions. Patients living in deprived areas are particularly vulnerable to multimorbidity that includes mental health conditions. We also know that people living with mental health conditions and other long-term conditions are at an increased risk of emergency admission to hospital.<sup>28</sup>

## The financial impact

International research suggests that comorbid mental health problems, in particular, are typically associated with a 45–75 per cent increase in service costs for people with long-term physical health conditions.<sup>28</sup>

Within the UK, data from the South Somerset Symphony Project found that average health and social care costs increase with the number of conditions that a person has, rather than other factors such as age.<sup>29</sup> Interestingly, the increase in average costs was found to be almost exponential for people with up to five long-term conditions (see Figure 1).

Similar findings were reported in another British study, focusing on Stoke-on-Trent, which found that people with ‘pairs’ of conditions were more likely to experience higher hospital admission costs than those with one condition.<sup>30</sup> For example, annual hospital admission costs were £651 higher for patients with chronic heart failure and chronic obstructive pulmonary disease (COPD) than for patients with COPD alone. Similarly, the annual hospital admission costs for patients with coronary heart disease and diabetes are £423 higher than for patients with diabetes alone.

In addition, the physical symptoms and frequent medical appointments associated with multiple chronic conditions might reduce employees’ productive time, possibly leading to periods of unemployment.<sup>31</sup> More research is needed to understand what proportion of the costs associated with multimorbidity may be avoidable and, accordingly, where any savings could be made.

There is also some evidence that multimorbidity can have an impact on people’s individual financial wellbeing. For instance, a report by the Work Foundation found that current services are not doing enough to support people with long-term conditions to stay in employment.<sup>32</sup> In addition, people with multimorbidity may face increased costs due to the necessity of attending multiple medical appointments – with associated costs of travel, and lost work time.

+

# 45–75%

**increase in service costs for people with long-term physical health conditions with comorbid mental health problems**

**+** Figure 1: Average healthcare cost per patient by number of chronic conditions (Episode Treatment Groups) in South Somerset



Source: Centre for Health Economics, University of York<sup>29</sup>

It is clear that working with multimorbidity will be increasingly important, as rising state pension ages will mean that people will need to continue to work for longer in the future. A recent study funded by Arthritis Research UK has demonstrated that significant numbers of current workers aged 50–64 are already living with two or more markers of frailty. It will therefore be important to have interventions to support and enable people's health and wellbeing in the workplace.<sup>12</sup>

# Measuring multimorbidity: prevalence and distribution

## KEY POINTS

- Estimates for the percentage of people living with multimorbidity in England vary from 15 per cent to 30 per cent according to different national and local sources.
- Multimorbidity becomes more prevalent with age and affects more than half of people aged 65 or over. However, in absolute numbers, the majority of people living with multimorbidity are under the age of 65.
- Multimorbidity is more prevalent among women, those who are obese and people from lower socioeconomic backgrounds.
- There seems to be very little research on potential risk factors other than lifestyle factors (i.e. smoking and obesity) and socioeconomic factors, which are known to be strongly correlated with multimorbidity.
- Multimorbidity appears 10–15 years earlier in people living in the most deprived areas than for those living in the most affluent areas.

## How prevalent is multimorbidity?

Evidence from various countries suggests that multimorbidity is becoming more common. Studies indicate that multimorbidity is not only becoming the norm, but is emerging earlier in the life course, particularly for low-income and obese individuals.<sup>33</sup>

Given the issues related to defining multimorbidity and the kinds of conditions that are counted as long-term conditions, it is difficult to find consistent statistics on the prevalence of multimorbidity across the UK. One of the most frequently used statistics comes from the Department of Health, which predicted that the number of people with three or more long-term conditions in England would increase from 1.9 million in 2008 to 2.9 million by 2018.<sup>1,\*</sup> It found that there were about 14.4 million people living with long-term conditions in England in 2008 – approximately 28 per cent of the population. About 5 million people were found to have two or more conditions, which would suggest a prevalence of almost 10 per cent.

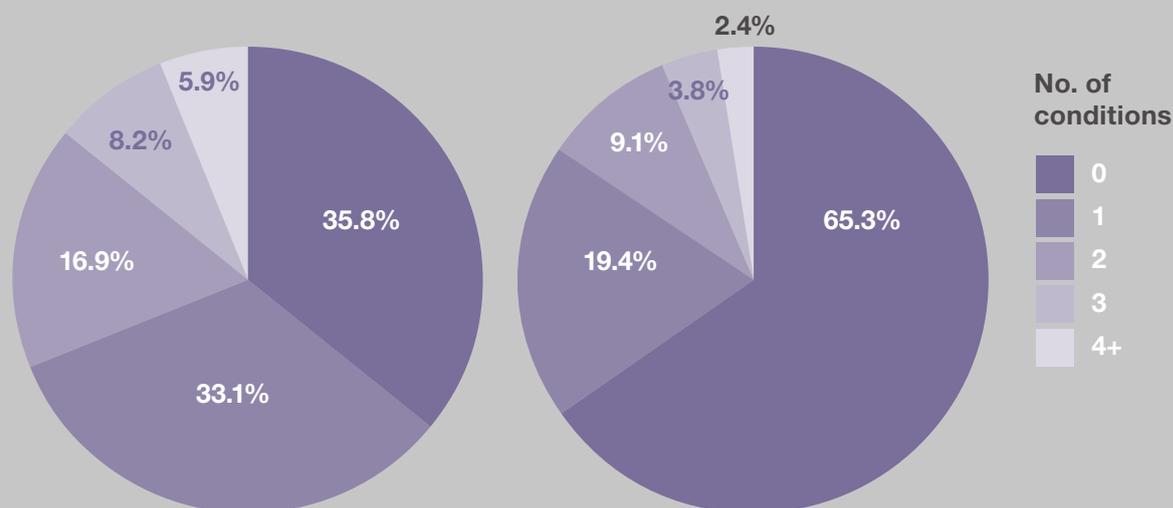
We can look to other sources for more recent estimates, but these offer very different pictures of the prevalence of multimorbidity in England. For example, data from the GP Patient Survey suggest that 31 per cent of people have two or more long-term conditions, while the Health Survey of England found 15 per cent of people have two or more long-lasting illnesses (see Figure 3). Clearly, this makes it difficult to pick a single estimate for the number of people living with multimorbidity across the country, but either of these surveys could be used to track changes over time.

We can also look to a small number of regional and community-based studies, often based on GP records, which offer local estimates of the prevalence of multimorbidity.<sup>11,29,34</sup> However, while these studies provide valuable information on the prevalence and nature of multimorbidity in particular regions or communities, we cannot draw comparisons between them because they all rely on different measurement techniques.

**In fact, one of the major challenges in measuring multimorbidity has been the failure to develop a standardised way of measuring the prevalence and distribution of multimorbidity. The numerous approaches employed vary in terms of the conditions included and the way in which they are measured (see Appendix D for a sample of these measures).<sup>35</sup>**

\*The data for this projection were extracted from the Quality and Outcomes Framework (2010/11) and the now defunct General Lifestyle Survey (2009).

**+** Figure 2: Percentage breakdown of respondents in the General Practice Patient Survey 2012 (left) and the Health Survey for England 2014 (right) by number of long-term conditions (both weighted)



Sources: Paddison et al.<sup>36</sup> and Health Survey for England (2014)

Arguably, the variation in prevalence figures is not as important as knowing how people are affected by their health conditions. While some may have the resources and support they need to cope with their conditions, others may experience substantial reductions in their quality of life as a consequence of multimorbidity. Some may have positive experiences of the health and care systems, while others may not. Ultimately, these issues are of greater significance than the raw numbers of people affected by multimorbidity.



**2.9 million**

**people predicted to be living with three or more long-term conditions in England by 2018**

## Sociodemographic distribution of multimorbidity

Numerous studies have shown that multimorbidity increases with age.<sup>11,34,37</sup> According to a study carried out in Scotland, less than 2 per cent of people under the age of 25 have multiple conditions, but this increases to 11 per cent for people aged 25–44, 30 per cent for people aged 45–64, 65 per cent for people aged 65–84, and almost 82 per cent for people aged 85 or over.<sup>34</sup> However, there are more people under the age of 65 living with multimorbidity in absolute numbers, than there are over the age of 65.

The age profile of multimorbidity is at least partly due to advances in the treatment of certain life-limiting childhood and adult conditions, which have led to the emergence of ‘new ageing populations’ (NAPs).<sup>10</sup> Examples include people with congenital heart disease and people living with HIV. What is not yet certain is how these new ageing populations will fare as they continue to age.

Research also suggests that women are more likely to have multiple long-term conditions than men.<sup>11,34,37</sup> The number and percentage of women with multimorbidity is higher in every age group, but the differences are small for people over the age of 65. The biggest male/female difference is found in the 45–54 age group: one in four women (26 per cent) has multiple long-term conditions compared with one in five men (20 per cent) in this age group.

For women below the age of 55 living with multimorbidity, depression appears to be the most prevalent condition, whereas hypertension is the commonest condition for those over the age of 55.<sup>11</sup> Among men living with multimorbidity, substance dependency has the highest prevalence for men aged 25–34, depression for men aged 35–44, and hypertension for men aged 45 and over. Women have a consistently higher prevalence of depression, pain, irritable bowel syndrome (IBS) and thyroid disorders across all age groups.<sup>11</sup> Substance (alcohol and drugs) dependency is the only condition where prevalence is notably higher for men than women below the age of 45, and the same is true of coronary heart disease (CHD) and diabetes for men compared with women over the age of 45.

Multimorbidity is strongly associated with socioeconomic deprivation, especially where the multimorbidity includes mental health conditions.<sup>34,37</sup> One of the starkest indicators of this association is that multimorbidity appears 10–15 years earlier in people living in the most deprived areas, than for those living in the most affluent areas. The most socioeconomically deprived young and middle-aged people have substantially higher rates of multimorbidity than their peers from more affluent backgrounds – as much as double in some areas.<sup>34</sup>

**In addition, the number of mental health conditions experienced by people increases with the number of physical conditions that they have, and this link also shows a strong socioeconomic connection.**

In the General Practitioners at the Deep End project, which drew on the experiences of doctors working with some of the most deprived communities, a common theme was the difficulty in adequately addressing a host of interrelated medical, psychiatric and social problems in the context of limited resources and low availability of high-quality services such as clinical psychology.<sup>38</sup> This underlines the complex interaction between multimorbidity and deprivation.<sup>28</sup>

There is also evidence to suggest that obesity is strongly associated with multimorbidity, especially among women, and that lifestyle factors such as smoking are heavily linked with multimorbidity among men.<sup>39</sup>

## Other risk factors – more to learn?

Despite the exponential growth in the number of research articles on multimorbidity since the 1990s,<sup>40</sup> the literature remains dwarfed by that on single conditions and there are significant gaps in our understanding of the causes and consequences of multimorbidity.

Beyond that on sociodemographic factors, there seems to be very little research on the risk factors for multimorbidity. There are few, if any, studies evaluating the links between genetic background, biological factors (e.g. cholesterol, blood pressure), or environmental factors (e.g. air pollution, social environment) and the development of multimorbidity.<sup>25</sup> While these factors are known to increase the risk of developing certain conditions, it is not clear how they affect the risk of developing multiple health conditions.

**According to the Department of Health,<sup>41</sup> there are at least two key groups of people living with multimorbidity, which require different emphases of action:**

- People living with multimorbidity mostly due to increased life expectancy and prolonged exposure to risk factors over time, who may need more support to maintain everyday functioning and quality of life through coordinated health and social services.
- People living with multimorbidity arising from more intense exposure to risk factors (e.g. obesity and physical inactivity), often due to personal and societal factors throughout the life course including persistent and growing socioeconomic deprivation – where action on these wider determinants of health will be the priority.

However, it is clear that we do not yet have enough evidence to develop a comprehensive response either to preventing or addressing multimorbidity across the population, and filling this research gap must be a priority.



**Multimorbidity appears 10–15 years earlier in people living in the most deprived areas**

# Part 2

## Key issues in responding to multimorbidity

### KEY POINTS

- Health and social care systems in England are not designed to treat people with multiple conditions, who are, as a result of system fragmentation, often in contact with multiple health professionals, and so more likely to report care coordination problems.
- People with multiple conditions are likely to be particularly vulnerable to experiencing adverse consequences of poorly managed transitions in care.
- Improving the collection and use of patient data could help to improve the care and support offered to people living with multimorbidity, both at an individual and system-wide level.
- There is a need for a cultural and attitudinal shift in the health and care sector, with a stronger focus on enabling staff to respond to the combined impact of conditions on a person's quality of life and on how treatment can best enhance overall outcomes for the patient.
- There is a growing consensus that we should be considering how outcome measures and quality standards could be made more relevant to the needs of people with multimorbidity, and focus more directly on patients' quality of life.
- Existing clinical guidelines and quality standards are not based on, and do not reflect, the lived experiences of people with multiple health conditions.
- We lack shared, accessible language and strong patient voice to inform patients about the specific consequences of multimorbidity on their lives and to inform the public about the impact that multimorbidity is having on national and local systems as a whole.

**Improving our response to multimorbidity has the potential to improve the quality of life for people with multiple health conditions and to make better use of health and social care resources.<sup>42</sup> As multimorbidity becomes more common, key to this response will be identifying and addressing the structural and attitudinal changes that are needed to improve health and care systems for people affected by multimorbidity.**

### Coordination of care

Patients living with multimorbidity experience a number of specific challenges related to care coordination. Many of these issues are widely understood already, and include:

- Standardised care plans that do not match patients' needs.
- Different care plans that are in conflict with each other or are too complex.
- Healthcare professionals who focus on their own clinical speciality rather than on the patient's overall situation.
- Healthcare professionals who do not communicate with each other.
- Inconsistent information from different healthcare providers (which may in part be due to data sharing issues or miscommunication between providers).<sup>43</sup>

While there are likely to be examples of good practice across the country, many people with long-term conditions experience poorly coordinated care.<sup>43</sup> In fact, patients with three or more long-term conditions are 25–40 per cent more likely to report care coordination problems than those with a single condition.<sup>44</sup> Patients with multiple health conditions are typically in contact with multiple health and/or social care professionals, due to a fragmented system,<sup>10</sup> and often report that their interactions with the health and social care system feel confusing.<sup>45</sup>

Coordinating care can be challenging for patients with one condition, but the issues are compounded for those living with multimorbidity due to disconnects between different parts of the health and care systems. The disjointed nature of the health and care system can affect patients with multiple conditions in multiple ways. For example:

- According to the Association of British Clinical Diabetologists, the NHS is not ‘optimally structured’ to treat patients living with multimorbidity in the community.<sup>10</sup>
- Separate locations and other forms of fragmentation could be leading to adverse outcomes such as slow referrals, which may mean that GPs have to act as touchpoints for patients and other clinicians. However, increasing complexities in treatment and pressures on primary care mean that GPs are finding it more and more difficult to respond to the needs of patients living with multimorbidity.<sup>46</sup>
- People who have a combination of mental and physical health conditions may face particular challenges due to the fact that Mental Health Trusts are not always coterminous with other health providers (e.g. Foundation Trusts), leading to even greater challenge in joining up care across providers.

Again, these problems are not unique to patients living with multimorbidity, but the risk and impact of these problems is potentially greater for people with multiple health conditions.<sup>22</sup> As long as patients are expected to fit into organisational structures – as opposed to systems being designed around patients – this fragmented system will continue to undermine efforts to improve health and social care outcomes among people living with multimorbidity.<sup>10</sup>

## KEY QUESTIONS

- What practical steps should be taken to improve the coordination of care across primary, community, secondary and social care settings for people with multiple conditions? What can we learn from past and current initiatives to mainstream coordinated care and support?
- How might a greater understanding of the needs and experiences of people with multiple health problems help inform initiatives to mainstream care coordination, and encourage wider uptake of these models across the health and care system?

**Patients with multiple health conditions often report that their interactions with the health and social care system feel confusing**

## Care interfaces and data governance

Patients living with multimorbidity may be particularly at risk of experiencing the adverse consequences of poorly-managed transitions in care.

Ideally, health and care systems would allow for seamless communication across sites of care to avoid duplicate testing, allow for medication reconciliation, and enable transfer of essential information about allergies, medication, recent and past history, and decision-making capabilities.<sup>13</sup> However, this is not currently the case.

Because England's health system and care system have evolved in different ways over many years, they are particularly prone to fragmented care provision caused by poor communication and inadequate data flow. This is only exacerbated by the complexity of the information that needs to flow in the cases of those living with multimorbidity. While much work on transitional care has focused on the transitions between the hospital and post-hospital settings for people with single conditions, transitions between outpatient providers may be equally important for the long-term management of multiple health conditions.

According to the Royal College of General Practitioners (RCGP), there is a need for improved communication at the interface of primary and secondary care – e.g. through use of in-reach teams and advice lines for GPs and other primary care staff – to ensure patients do not receive fragmented care.<sup>47</sup> While commissioners and providers may be able to implement some changes relatively easily, other changes may require efforts to redesign the interface between multiple providers.<sup>48</sup>

Improving the coordination of support for people living with multiple conditions is also an area for development within the voluntary and community sector, as the case study below illustrates.

### CASE STUDY

## Stroke Association & Alzheimer's Society – joined-up services in Fylde Coast

In North West England, the Stroke Association have partnered with the Alzheimer's Society to deliver joined-up community and support services. Both charities' regional teams were keen to explore the potential of collaboration to support stroke survivors and people living with dementia and to improve the teams' connections into other services.

The teams set up a pilot in 2016. They started by learning about each other's services and referral pathways, with a view to delivering joint training across the two organisations. As part of this process, the teams have visited each other's support groups and learnt about the work carried out by each organisation, first hand.

The result has been an increase in referrals across the two teams, with several joint visits to families where stroke and dementia are being managed. This includes people with both conditions, as well as families where one person has stroke and another has dementia. The teams are now collaborating on the delivery of activities which would previously have been carried out by one or other of the organisations alone. For example, memory checks and blood pressure tests at community events are now delivered jointly.

The North West teams hope that this will lead to improvements in service connectivity and, ultimately, better care and support for service users. The collaboration is welcomed and supported by local commissioners.

## Improving the use of patient data could help to improve the care and support offered to people living with multimorbidity both at an individual and system-wide level.

Although there are significant challenges associated with linking data across silos, getting this right could be very helpful for people living with multimorbidity. To some extent, enriched Summary Care Records (SCRs) may help improve information flow across the health and care systems, but there is also a need to ensure that these capture what matters to patients. Allowing patients to access their data could help them monitor and influence their own health more effectively, and could eliminate the frustration associated with having repeatedly to describe one's health to multiple practitioners.<sup>49</sup>

There may be opportunities to use existing condition-specific surveys to capture additional data on the impact of living with multiple conditions. For example the UK MS Register collects data on co-morbidities and could be a model for similar approaches in relation to other conditions.

Capturing data at a system-wide level could also help to address knowledge gaps, with the potential to generate better information on the risk factors associated with multimorbidity and more consistent data on its prevalence. In turn, this could help improve the overall commissioning and provision of care and support for people with multimorbidity.

### KEY QUESTIONS

- How can we find the right balance between protecting patients' interests as they navigate health and care systems and making information and data about patients available (with their consent) in ways that are meaningful to health and social care professionals across the system?

## Cultural and attitudinal barriers

While structural changes are important, we know that they are unlikely to result in the desired outcomes unless attitudinal and behavioural changes occur at the same time.

Although GPs and other clinicians have considerable medical knowledge about long-term conditions and the essential biomedical aspects of long-term condition management,<sup>2</sup> not all have the key skills for the delivery of that care, for example in terms of care and support planning. Many clinicians believe they practise shared decision-making. However, evidence suggests a gap between perception and reality, due to misconceptions about the nature of shared decision making – what it takes in terms of skills and time, and the degree to which patients, families, and carers wish to share in decision making.<sup>50</sup>

In fact, many healthcare professionals may work in settings where the clinical ethos or 'traditional way of doing things' acts as a barrier to addressing the knowledge and power imbalance between clinicians and patients in consultations. Established ways of working do not encourage clinicians to enable patients to express their wishes and engage in shared decision-making. This lack of active communication may be compounded by the complexity of multimorbidity, making it even more difficult for healthcare professionals to draw out patients' preferences.

It is also worth bearing in mind that although much of the research on multimorbidity has focused on clinicians' opinions and attitudes, very little research has been undertaken to explore patients' perspectives. Consequently, we do not know to what extent people with multiple health conditions feel their experiences of the health and social care systems are influenced by the fact of their multimorbidity or other factors. Understanding the barriers and opportunities that people living with multimorbidity encounter in the health and care systems could enable system improvements. This is a significant knowledge gap that needs to be filled.

### KEY QUESTIONS

- What practical steps can be taken to enable clinicians to support people with multiple conditions more effectively?



## Current change within the NHS is creating a fresh opportunity to review incentive frameworks across the health system

### Incentive structures

Over the years, complex payment structures, measurement systems and incentive mechanisms have been introduced into England's health and care systems. The aim of these is to drive improvements in the performance of the system overall and to improve outcomes for individuals. However, when it comes to multimorbidity, there is growing consensus that these mechanisms are not operating effectively.

The Quality and Outcomes Framework (QOF) is a pay-for-performance initiative introduced in 2004 as part of a new General Medical Services contract. It provides primary care practices with financial incentives for undertaking specified activities related to the management of long-term conditions, including secondary prevention. The QOF has been effective in driving improvements in the treatment and support of people living with a wide range of different conditions. Additionally since its introduction, there have been measureable improvements in outcomes for people living with multimorbidity, including older adults and people from socioeconomically deprived areas.<sup>51</sup> However, there are concerns that the operation of the QOF is not as effective as it could be in ensuring that patients with multiple conditions receive optimal treatment. Specifically, there are concerns that by only rewarding GPs for carrying out specific activities in relation to individual conditions, the system makes GPs less likely to consider how patients are doing in the round and how non-medical interventions – such as social prescribing – might improve outcomes in the long-term.<sup>3</sup>

Scotland has already dismantled QOF, while NHS England is looking to pilot alternative contract arrangements as part of the new voluntary GP contract under the Five Year Forward View.<sup>5</sup> However, beyond the QOF, there is little evidence of other formalised approaches to incentivising chronic condition management or the organisation of care around the needs of patients living with multimorbidity.<sup>52</sup>

Current change within the NHS is creating a fresh opportunity to review incentive frameworks across the health system. As part of this there may be opportunities to build in mechanisms which more effectively align incentives with the needs and wishes of people living with multimorbidity. Ideally these would support a focus on outcomes rather than process, and more explicitly recognise the importance of personalised approaches for those living with multimorbidity.

However, the gaps in our current system of measures do not end there. For example, in their 2017 report on person-centred care, National Voices found that, currently, 'we cannot adequately measure or assess person-centred care across the boundaries of settings and services, and there is no direct read across between healthcare and social care'.<sup>53</sup> Getting this right will be essential to mainstreaming person-centred approaches as our needs become increasingly complex.

### KEY QUESTIONS

- How do we develop incentive structures that are effective in driving improvement for individual conditions while enabling people with multimorbidity to receive personalised and appropriate care?
- What would an outcomes-based incentives structure look like, and how could we make it work?

## Clinical guidelines and quality standards

Clinical guidelines have the potential to improve the care of people with long-term conditions but seldom account for people with multiple conditions explicitly.<sup>26</sup> This reflects the way in which clinical evidence is created: the emphasis is on specific diseases and conditions (using studies focusing on people with single conditions). Few, if any, guidelines have been developed using evidence involving people with multiple conditions.

The use of guidelines in healthcare services has helped reduce practice variation and has helped increase quality standards.<sup>54</sup> But clinical decision making is more difficult with respect to people with multiple conditions because clinicians and patients often struggle to balance the benefits and risks of multiple recommended treatments. Combining clinical and economic evidence produces rational guidance for individual conditions, but combining recommendations for patients living with multimorbidity can result in harmful or burdensome overall treatment regimens.<sup>26,54</sup>

Efforts are currently underway to increase the applicability of NICE clinical guidelines and quality standards to people living with multimorbidity. These efforts include a new quality standard for managing multimorbidity across the healthcare system that emphasises the importance of person-centred care and care coordination.<sup>55</sup> While this is welcome, we must acknowledge that the uptake of guidelines and quality standards is uncertain.

### KEY QUESTIONS

- What changes are needed to enable the development of clinical guidelines that reflect and address the experiences of people living with multimorbidity?

## Communicating about multimorbidity

As mentioned above, effective conversations between clinicians and patients could help ensure that patients are more involved in the coordination of their care. For some clinicians this is the norm, but for many it will require enhanced communication skills training. The system needs to encourage clinicians to become more responsive to patients' priorities and preferences and to talk to patients as equals.

In addition, because the language used in relation to health conditions is often inaccessible, it may be difficult to effectively engage people affected by multimorbidity on the particular challenges that their conditions present. It is not clear to what extent people are familiar with the term 'multimorbidity' or, more importantly, the idea of multimorbidity. 'Multimorbidity' is not a commonly used or understood term and the issue does not receive much public attention. Conversations about multimorbidity are currently limited to policy makers, medical professionals, academics and other interested stakeholders, but if we are to achieve meaningful systemic change it will be vital that the voices of people living with multimorbidity are heard.

There is no strong patient voice around multimorbidity at present, as most patient organisations have a condition-specific focus, mirroring the current set-up of the health system. There is a clear need for specific advocacy on this issue and people living with multimorbidity will need clear ways to engage in this process.

### KEY QUESTIONS

- How can we draw on people's lived experience of having more than one health problem to find better ways of describing and understanding the issues?
- What can be done to increase patients' and public awareness of the issue and impact of multimorbidity?
- How can we engage people with multimorbidity to speak out and become champions for improvement?

# Part 3

## Delivering person-centred care for people living with multimorbidity

### KEY POINTS

- The evidence base on interventions designed to support people living with multimorbidity is still underdeveloped. However, there is growing evidence that person-centred approaches to care could lead to better health outcomes, especially for people with multiple long-term conditions.
- Collaborative care and support planning, shared decision-making and self-management support may provide a solid basis for a person-centred approach to support people living with multimorbidity.
- There is much that can be learnt from preventative and curative interventions that have been evaluated for people with specific conditions and these could add value for people living with multimorbidity.
- Interventions that provide emotional and practical support are also vital, not only for people living with multimorbidity but also for the carers and families of those affected.

Although more research should be carried out to look at the specific effects of particular interventions on multimorbidity, there seems to be a broad consensus that the current focus should be on changing the way that existing activities are designed and delivered. Realignment of current provision should enable people with multiple long-term conditions to benefit from a 'universal offer' of support, such as that set out in the People and Communities Board's proposal for 'A new relationship with people and communities'.<sup>56</sup>

This is understandably more difficult where responsibility for, and control over, a person's care sits with multiple different specialists. However, in some community and intermediate care settings, providers are increasingly offering more generalist services, where many of the services people need are provided under one roof. It is possible that looking towards these examples and re-thinking where the locus of control should sit for people with multiple conditions, may support delivery of more person-centred approaches to care.

Person-centred approaches provide one perspective on realigning existing provision in ways that could benefit patients with multiple health conditions. In their report on delivering cost-effective, quality care The King's Fund and the Richmond Group of Charities identified five interconnected themes (Table 1).<sup>57</sup>



**Person-centred approaches to care could lead to better health outcomes**

## + Table 1: Key elements of cost-effective, quality care\*

Person-centred activities	Self-management support
	Shared decision-making
	Collaborative care and support planning
Prevention and support	Prevention, early diagnosis and response
	Emotional, psychological and practical support

Together they provide a useful framework with which to consider the kinds of activities that health and social care organisations must undertake in order to deliver comprehensive support for people living with multimorbidity.\*\*

Health and social care professionals and their teams and organisations can play a key role in encouraging change to take place, both by improving their own practices and by working with other partners to demonstrate how the wider health and care systems could be improved, as recognised in the Integrated Personal Commissioning (IPC) approach.

## Person-centred activities

Complementing the findings of the King's Fund report, the Health Foundation<sup>58</sup> identifies the four principles that form the basis of the person-centred care framework:

- Affording people dignity, compassion and respect
- Offering coordinated care, support or treatment
- Offering personalised care, support or treatment
- Supporting people to recognise and develop their own strengths and abilities to enable them to live an independent and fulfilling life.\*\*\*

Adopting these principles should encourage health and social care professionals and other stakeholders to focus more on people and their needs, rather than the separate conditions that they have, and the treatment and interventions that may help manage those conditions. The person-centred activities described below can bring these principles into action.

\*The term 'person-centred activities' is taken from a report by The Health Foundation, which stated that these kinds of activities can help organisations ensure that they deliver services based on person-centred care and support principles.<sup>50</sup>

\*\*The outcomes associated with these themes are included in Appendix E.

\*\*\*The person-centred approach described in this piece is illustrated through 'Dorothy' – a fictitious 72-year old woman living with knee problems, diabetes and COPD.

## Self-management support

Self-management support is designed to help people look after their own health. It involves a range of activities, including peer-to-peer support, group education programmes, reablement and rehabilitation strategies, health coaching and behaviour change or lifestyle counselling, all developed to promote and facilitate self-management of health or recovery.<sup>58</sup>

Many patients already self-manage, but for others 'self-management is a distant aspiration rather than a starting point'.<sup>59</sup> The barriers to self-management that people living with multimorbidity experience are not necessarily caused by their health conditions, but by a wide range of factors including personal, social and economic factors.<sup>60</sup> Conversely, despite the compounding effect of having multiple conditions, some studies have found that people

living with multimorbidity may in fact have improved self-management skills.<sup>31</sup> This may be because people with multiple health conditions develop coping mechanisms as a result of their experience, by learning to prioritise their conditions, reconcile their clinicians' advice, and so on.

Rather than making assumptions about a person's ability to self-manage, tools such as the Patient Activation Measure (PAM) can help determine which particular forms of support people may most benefit from by building on existing capabilities. The Triangle of Care approach and self-assessment tool, originally developed by Carers Trust in collaboration with mental health providers, could also be very relevant to multimorbidity.

### CASE STUDY

## Using the Patient Activation Measure (PAM) in Tower Hamlets

Tower Hamlets is an area with high levels of deprivation, where many of the local population have multiple health conditions. In fact, over a third of patients that attend a particular GP practice in Tower Hamlets are living with multimorbidity.

This GP practice is now planning to use PAM to segment patients with long-term conditions to understand how best to support them to manage their health. Patient activation describes the knowledge, skills and confidence a person has in managing their own health and care. The idea is to stratify patients according to how activated they are in relation to their health in order to identify which patients would benefit from different kinds of tailored support.

People with lower activation scores (level 1) need more support – in the form of, for example, social prescribing and reconnection services, debt and housing support and advice, language skills – to become more activated. People with level 2 or 3 activation scores are more likely to benefit from support and education about their condition such as diabetes courses.

Those with higher activation scores (level 4) are likely to be more engaged in self-management practices, but may benefit from digital help, e.g. access to online resources or pointers on how to order prescriptions online. Digital healthcare communication of this type could mean patients need to make fewer trips to the GP surgery for routine check-ups.

This is a slow process, but the GP practice is currently trying to understand the process and how it can be used in Tower Hamlets, looking at issues such as how many people are registered for online access to services and using those services. The clinic then hopes to record PAM scores for its patients with long-term conditions over the next few years, and use that data to help deliver more effective stratified interventions.

## Shared decision-making

In conjunction with self-management, shared decision-making activities are designed to support patients to confidently make informed decisions about their health or healthcare, such as whether or not to follow a particular treatment regimen.<sup>58</sup> Aside from the ethical rationale for person-centred care, there is growing evidence that shared decision-making and self-management support can lead to improvements in patient experience, care quality and health outcomes.<sup>61</sup>

Many organisations already provide tools and decision aids to support patients and their clinicians to make shared decisions.\* Many of these decision support tools are condition-specific, but tools are now being created which support people living with multimorbidity and frailty (e.g. by Year of Care). These tools are increasingly taking the form of smartphone apps.<sup>50</sup> The RCGP recommends that these tools are used by both patients and clinicians to make shared decisions on issues such as optimising medicines use (e.g. 'deprescribing').<sup>47</sup> New principles and guidelines, such as the Ariadne principles,<sup>62</sup> are also being developed to inform shared decision-making processes involving people living with multimorbidity. These principles could also be used to reconfigure existing decision support tools and aids (see Appendix F).

One way of managing complex conditions is to bring together a team of healthcare professionals within one organisation, connecting and coordinating all current functions being provided in primary, secondary and community care. However, this kind of approach is not easy to implement. Critical to the success of such an approach would be agreement on which healthcare professionals should hold responsibility for care coordination and how, and opportunities for people with multiple conditions to form ongoing relationships with those providing their care.<sup>47</sup>

## CASE STUDY

### Age UK – Integrated Care Services Programme

Age UK's Integrated Care Programme operates across England. It brings together voluntary sector organisations and health and care services in local areas to provide a combination of medical and non-medical support for older people who are living with multiple long-term conditions and at risk of recurring hospital admissions.

Risk stratification tools are used to identify those older people most likely to be admitted to hospital and to focus resources most appropriately. Using a 'guided conversation' an Age UK Personal Independence Coordinator then works with and alongside the older person to draw out the goals that are most important for them. While the volunteers provide support, the older person is encouraged to take the lead in managing their own care and wellbeing.

Through the programme, Age UK staff and volunteers become members of primary-care-led multidisciplinary teams based within a primary care setting. Integrated working is coordinated and supported through a shared care plan, developed with the older person and reviewed regularly by the multidisciplinary team, and underpinned by shared information flows.

Piloting of the programme has been underway in Cornwall since 2012, and is now integral to Living Well – a wider local partnership that is one of the Government's 14 Integrated Care Pioneers. The early results from the Cornwall pathfinder project are promising in terms of improved wellbeing and preventing unplanned admissions to hospital. Using the Warwick-Edinburgh Mental Well-being Scale, a 23 per cent average in well-being was observed among older people in the cohort and there were 30 per cent fewer non-elective hospital admissions.<sup>63</sup>

\*For example, tools such as 'This Is Me', offered by the Alzheimer's Society, can help ensure that patients' preferences, needs and interests are taken into account when they are deemed clinically fit to leave hospital. See [www.alzheimers.org.uk/info/20033/publications\\_and\\_factsheets/680/this\\_is\\_me](http://www.alzheimers.org.uk/info/20033/publications_and_factsheets/680/this_is_me)

## Collaborative care and support planning

In addition to the systemic changes to care coordination mentioned in the previous chapter, collaborative care and support planning – through which patients are enabled to make more informed decisions about their care and support packages, and to improve their ability to self-manage<sup>58</sup> – is another way in which patients' experience of care can be improved. Effective collaborative planning consultations should also help patients identify both the clinical and non-clinical sources of care and support that will help them to achieve their goals.<sup>56</sup> The process can involve setting proactive goals, the use of multidisciplinary teams, longer consultations or continuity of care across transitions.<sup>47</sup>

One way in which collaborative care and support planning can be put in place is through the robustly-evaluated House of Care approach. The House of Care was initially piloted by primary care teams as part of the Year of Care programme, working with people affected by diabetes, with the support of Diabetes UK. Experience increasingly suggests that the House of Care approach can improve the care of people with multiple conditions.\* Advocates of this approach acknowledge the administrative complexity of incorporating issues related to multiple conditions into one holistic care and support plan. Yet the programme found that the skills needed to deliver care and support planning and to implement shared decision-making to improve the care of people with (multiple) long-term conditions, can be acquired and that attitudes towards patient empowerment can be modified. The potential benefits of the approach are considered to be worth the additional effort.<sup>64</sup>

### CASE STUDY

## Diabetes UK & Year of Care – care and support planning in Tower Hamlets, London

The Year of Care Partnership set out to demonstrate how routine care can be redesigned and commissioned to provide a personalised approach for people with long-term conditions, using diabetes as an exemplar in three pilot sites including Tower Hamlets Primary Care Trust (PCT).

The pilot aimed to transform the diabetes annual review into a constructive and meaningful dialogue between the healthcare professional and the person with diabetes.

Tower Hamlets PCT's 2005 type 2 diabetes care indices were among the worst 10 per cent in England. By March 2012 Tower Hamlets PCT was able to report the best in England. Care and support planning is now the norm: 95 per cent of people with type 2 diabetes have had at least one annual care planning consultation and 40 per cent have had more than one.

Data capture and use has improved dramatically. Measures at the heart of good secondary prevention are routinely collected and shared with each individual as part of the care and support planning process. Consequently, patient-reported involvement in care decisions rose from 56 per cent in 2006 to 82 per cent by 2010 in Tower Hamlets.

All the pilots showed that if care planning and support for self-management are implemented systematically across a healthcare community, there can be improvements in patient and professional experience, care processes and clinical outcomes. Where people with care and support plans develop other long-term conditions, the response to these can be incorporated into their existing care and support planning process.

\*See [www.yearofcare.co.uk](http://www.yearofcare.co.uk)

## Prevention and support

### Prevention, early diagnosis and response

In comparison to that for specific long-term conditions, there is currently little evidence-based guidance on how to prevent multimorbidity. However, given that healthy behaviours such as regular physical activity and the modification of harmful habits, such as smoking, are known to prevent a number of individual conditions, it is likely that adopting new lifestyle behaviours or modifying existing ones could help prevent multimorbidity.

**Key stakeholders in the health and care sectors would therefore be justified in promoting the benefits of such interventions as part of healthier lifestyles. For example, by:**

- Delivering multimorbidity-specific messages that raise awareness of the benefits of adopting or modifying relevant health-related behaviours.
- Thinking about how prevention messages could be conveyed by different organisations across sectors, e.g. by developing messages which work for people with varying conditions.
- Developing generic and specialist training and interventions.
- Signposting people with multiple conditions to the relevant activities of other organisations.

In addition, more focus could be placed on preventative public health measures as part of a wider response to multimorbidity. Health checks and screening programmes are already being used to identify people at high risk or in the early stages of developing specific conditions. These checks could also help identify those at risk of multimorbidity and thereby help to target preventative action. For example, a person's lung function, measured by a spirometer, is as good an indicator of non-respiratory mortality as is blood pressure and body mass index (BMI) even among lifelong non-smokers.<sup>65</sup>

In terms of future focus, understanding the development of multimorbidity, by for example, understanding how multimorbidity clusters develop, may be particularly useful for secondary prevention. Knowing how certain conditions interact, recognising the linkages between mental and physical health conditions, and understanding the pathways that lead to certain combinations of conditions arising, could lead to more targeted secondary interventions.

### Emotional, psychological and practical support

One of the consequences of multimorbidity is that people are more likely to experience physical, psychological and emotional symptoms. Undesirable symptoms and losses in physical functioning can make it more difficult for people to carry out day-to-day activities, including those tasks required to successfully self-manage. For example, many patients report that their pain is one of the biggest factors limiting their ability to self-manage effectively.<sup>31</sup>

Practical support for individuals and their carers/families is provided by many organisations within the health and care sectors, and more widely. Demand for such support is likely to grow as multimorbidity becomes more prevalent. Ensuring that our response to multimorbidity takes account of the close links between multimorbidity and socioeconomic deprivation will clearly be vital.

**With an increasing number of people developing multimorbidity earlier in life, the impact of multimorbidity on employment could increase in the future. As a result, financial and employment support is also likely to be vital.**

Individual and social resources will be critically important if we are to support people's capacity, responsibility, and motivation for improving their health. There is therefore a need to balance the role of health services and wider enabling networks. Practical and psychosocial interventions, such as those mentioned above, could support people living with multimorbidity to overcome certain social, financial and psychological barriers to improved health and wellbeing. However, action will also be needed at a community and societal level to address these wider social determinants of health.

## Macmillan Cancer Support – Improving the Cancer Journey in Glasgow

Improving the Cancer Journey (ICJ) is an integrated multi-agency approach which includes Macmillan, Glasgow City Council and NHS Greater Glasgow and Clyde working in partnership.

ICJ works by contacting every newly diagnosed cancer patient in Glasgow, offering them time with a link worker to discuss their support needs and to coproduce an individual care plan. This Holistic Needs Assessment (HNA) covers six areas of concern: physical, practical, family/relationship, emotional, spiritual/religious and lifestyle or information needs. Patients' three main areas of concern were money and housing, fatigue and tiredness, and mobility.

An evaluation of the first two years of ICJ found that service users reported positive changes in their quality of life and a reduction in their concerns and feelings of isolation. The report also found that:

- 61 per cent of those supported by ICJ came from the most deprived category of people living in Glasgow, with another 16 per cent from the second most deprived category. This is of key importance, given that deprivation is a fundamental indicator of multimorbidity.
- ICJ has helped people claim almost £1.7 million in financial support such as welfare payments, and write off more than £100,000 of debt.

Altogether, almost 2,000 assessments were carried out between February 2014 and August 2016, with over 10,000 concerns raised from those assessments. Onward referrals totalling 6,700 have been made to more than 230 organisations in Glasgow which provide further support. The Scottish Government has pledged support to roll out similar services across the nation.

Key to the success of ICJ has been a joined-up approach between relevant organisations, the offer of support at the earliest opportunity, and the provision of a link worker giving help with all kinds of concerns as a single point of contact.

### KEY QUESTIONS

- Is a general person-centred approach sufficient, or are there other more specific factors that need to be taken into account to ensure that care and support meets the needs of people living with multiple conditions?
- What action can be taken to ensure more people have access to person-centred care and support planning?
- What needs to happen to ensure responses to multimorbidity take into account the strong links to socioeconomic deprivation? What lessons can be drawn from current practice for health in deprived communities?

# Conclusion

**The multimorbidity challenge is not one of developing a care pathway for a specific group of patients, but about ensuring that the health and care systems can adapt to the new reality faced by its users. To date, the increasing prevalence of multimorbidity and the growing demand that it will place on health and care services have not been matched by any urgency of response from key stakeholders.**

Stakeholders across the health and care sectors must show greater urgency and leadership in considering and tackling the challenges presented by the increasing prevalence of multimorbidity.

Although there seems to be recognition of the importance of the challenges posed by multimorbidity, there now needs to be a coming together of all stakeholders across the health and care sectors to develop a collective response. In light of the evidence presented in this report, it is clear that collaboration, leadership and commitment will be essential to driving through national and local programmes of change which deliver for people living with multimorbidity.

But we do not have to wait for structural change. Despite gaps in our knowledge, this report has highlighted some of the issues people with multiple conditions face on a daily basis, as well as some promising existing approaches that may improve their health outcomes and experiences of care. Health and social care professionals, and their teams and organisations, can play a role in making change happen, both by improving their own practices and by working with other partners to demonstrate how the wider health and care systems could be improved.\* The voluntary and community sector also has work to do to ensure that the needs of people with multiple conditions are considered and accounted for in their own activities and service offers.

As work on this issue continues, it must be based on a recognition that multimorbidity is a social issue, not just a health issue. While the evidence base is limited, what there is points to socioeconomic deprivation as one of the key determinants of multimorbidity. We all need to ensure that the link between multimorbidity and the wider social determinants of health is not lost in policy and practice discussions on how to respond to multimorbidity.

But the key voice missing in the discussions around multimorbidity is the voice of those living with multimorbidity. A better understanding of the experiences, wishes and goals of people with multiple conditions will help inform the design and delivery of health and social care services. It would also help to inform targeted work to address the wider structural factors that are blocking an effective response to the multimorbidity challenge.

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\* See [www.england.nhs.uk/ipc/](http://www.england.nhs.uk/ipc/)

# The challenge: in summary

## What we know, what we don't know and what we need to consider

### Understanding multimorbidity

Greater effort is needed to develop a research agenda on multimorbidity. Research on multimorbidity has grown over the last three decades, but it is still limited in comparison to the research on single conditions. In particular, not enough is known about the impact of multimorbidity on people, their carers and families. More information on this, as well as on the numbers of people affected by multimorbidity, would inform more coherent responses from providers, commissioners and policy makers.

### Coordinating care, including better data use

Commissioning and care pathways do not currently align with the priorities and preferences of people with multiple health conditions and significant change is needed to ensure treatment is properly coordinated across primary, community, secondary and social care settings. Existing approaches like collaborative care and support planning, supporting self-management of long-term conditions and facilitating professional involvement in coordinated person-centred care, may hold some of the answers here.

In many cases, fragmented care provision is caused by poor communication and inadequate data flow, which is only exacerbated by the complexity of information needs in care for those with multimorbidity. Enabling with-consent data flow across different health and care settings could reduce the burden on people with multiple health conditions, allowing them more time to concentrate on their health and wellbeing priorities, rather than having to deal with administrative issues.

### KEY QUESTIONS

- What practical steps should be taken to improve the coordination of care across primary, community, secondary and social care settings for people with multiple conditions? What can we learn from past and current initiatives that have so far failed to truly mainstream coordinated care and support?
- How might a greater understanding of the needs and experiences of people with multiple health problems help inform initiatives to mainstream care coordination, and encourage wider uptake of these models across the health and care system?
- How can we find the right balance between protecting patients' interests as they navigate health and care systems and making information and data about patients available (with their consent) in ways that are meaningful to health and social care professionals across the system?

## Shifting attitudes and shaping behaviours

Shifting health and care sector culture will be critical. We need to enable staff to respond to the combined impact of conditions on a person's quality of life and to focus on how treatment can best enhance overall outcomes for patients.

Incentives structures, outcomes measures and clinical guidelines and quality standards could all be used to support this shift. However, they are not currently based on, nor do they reflect, the lived experiences of people with multiple health conditions or the outcomes that matter to them. We need to consider how outcomes measures and quality standards could be made more relevant to the needs of people with multiple conditions, and focus more directly on patients' quality of life.

### KEY QUESTIONS

- What practical steps can be taken to enable clinicians to more effectively support people with multiple conditions?
- How do we develop incentive structures that are effective in driving improvement for individual conditions, while enabling people with multimorbidity to receive personalised and appropriate care?
- What would an outcomes-based incentive structure look like and how could we make it work?
- What changes are needed to enable the development of clinical guidelines that reflect and address the experiences of people living with multimorbidity?

## Raising awareness

We lack a shared, accessible language with which to inform patients, practitioners and the wider public about the impact of multimorbidity both on individuals, and on systems and the local and national level. And the voice of patients with multimorbidity is missing from the debate. Greater patient involvement in discussions and decisions about the treatment of their long-term conditions may increase the demand for, and incentivise provision of, information which is attuned to their individual needs and circumstances. Meanwhile, opening up the conversation about the impact of multimorbidity both locally and nationally would increase awareness and help to drive action.

### KEY QUESTIONS

- How can we draw on people's lived experience of having more than one health problem to find better ways of describing and understanding the issues?
- What can be done to increase patients' and public awareness of the issue and impact of multimorbidity?
- How can we engage people with multimorbidity to speak out and become champions for improvement?

## Person-centred approaches: a way forward?

There is growing evidence that person-centred approaches to care could lead to better health outcomes, especially for people with multiple long-term conditions. However, we need more research to fully understand how existing interventions and support for people with long term conditions works for people living with multimorbidity, and how they could be adjusted to better meet these needs.

Meanwhile, current access to person-centred services is patchy. Making person-centred support more widely available is likely to be part of the solution to ensuring that services provided across the voluntary, community and statutory sectors are responsive to the needs and wishes of people living with multiple conditions.

### KEY QUESTIONS

- Is a general person-centred approach sufficient, or are there other more specific factors that need to be taken into account to ensure that care and support meets the needs of people living with multiple conditions?
- What action can be taken to ensure more people have access to person-centred care and support planning?

## Accounting for context: socioeconomic deprivation

The evidence reveals close links between multimorbidity and socioeconomic deprivation. This strong correlation suggests that any effective response to multimorbidity must take account of the wider determinants of health both at an individual and societal level.

### KEY QUESTIONS

- What needs to happen to ensure responses to multimorbidity take into account the strong links to socioeconomic deprivation? What lessons can be drawn from current practice for health in deprived communities?

The key voice  
missing in the  
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multimorbidity is the  
voice of those living  
with multimorbidity

# Our response: next steps proposed by the Richmond Group of Charities

This study has condensed the evidence on the most pressing challenges presented by the issue of multimorbidity. In articulating the scale and complexity of this issue, this study has reinforced our belief that the time for action on multimorbidity is now and that the voluntary and community sector is well-placed to respond to the challenge. We are therefore committed to increasing our activity in this area in the months and years ahead. This will include:

## A taskforce on multimorbidity

The phenomenon of multimorbidity requires concerted action from organisations across the health and social care sector and beyond. Therefore, we want to work in partnership as we tackle this issue.

We will convene a broad, cross-sector group of partners working in and beyond the health and care sector to form a taskforce, to think through and tackle the challenge of multimorbidity together.

Over the coming months we will set out a detailed plan of action for the taskforce, informed by this research. We will be inviting others to join us, working together to build our knowledge and develop effective responses.

## Listening to people with multimorbidity

As this research has laid bare, the voices of people living with multimorbidity are seldom heard. If our response to the increasing prevalence of multimorbidity is to truly reflect patient need, we need to hear their voice. As a first step, we intend to commission further work to understand the lived experiences, needs and wishes of people living with multimorbidity, and to further shape the taskforce agenda.

And we hope that our taskforce will play a role in stimulating further research into the impact of multimorbidity, with a particular emphasis on exploring and gaining a greater understanding of people's lived experiences, including those of their families and carers.



Over the coming months we will set out a **detailed plan of action for the taskforce, informed by this research**



**We want to work with system leaders and policy makers to consider how we can support the health and care systems to change and meet the challenges of multimorbidity**

### **Broadening the conversation**

It is clear that the debate around multimorbidity has been confined largely to academic and health and care specialist circles. If our health and care system is to respond to the challenge of increasing multimorbidity, this must change.

We want to play a role in drawing more individuals, communities and organisations, including those working on deprivation, into the debate about multimorbidity. We will draw on our insight work with people living with multimorbidity to consider how best to articulate this issue in public, in order to draw out more voices of experience, and to engage the wider population in this debate.

### **Addressing gaps in provision**

We want to work with system leaders and policy makers to consider how we can support the health and care systems to change and meet the challenges of multimorbidity. In particular, we want to enable people with multimorbidity to feel supported and empowered as they move around the health and care systems.

Through our work in partnership with the Somerset Sustainability and Transformation Plan partnership, we are already working with local statutory and voluntary sector organisations to develop more collaborative ways of working and join up our services and support offers.

However, we recognise there is more we can do. So we intend to work together to think about how best we can bring together the information, advice and support we, as individual charities, offer to the many people who have more than one health condition.

### **Creating consistent messaging**

If messages about non condition-specific issues are to have an impact, they must be consistent and consistently delivered by all providers of relevant help and support.

Through our work with Sport England we have already begun to think about how we might develop general messages about the benefits of physical activity, and we will continue to look at opportunities to develop clear messages that can be shared across different audiences and conditions in other areas.

### **Addressing the wider determinants of health**

This research has revealed the very close connection between multimorbidity and socioeconomic deprivation, demonstrating clearly the potential value of voluntary-sector-led approaches which address practical, social and emotional needs in supporting people with multimorbidity. We will continue to work with others to build our understanding of this relationship and to ensure that the wider determinants of health are addressed as part of our response to multimorbidity at both an individual and a societal level.

**We hope that actors from across the medical, research, provider, commissioner and policy making community will join with us as we help our health and care system respond to the new reality it faces.**

# Glossary

**Comorbidity**

Comorbidities are often defined in terms of an index condition, which is clinically dominant, and other conditions which are then described as comorbidities.

**Frailty**

Frailty is recognised as a state of high vulnerability to adverse health outcomes, including disability, dependency, falls, need for long-term care, and mortality.

**House of Care**

A person-centred approach to collaborative care and support planning.

**Long-term condition**

A chronic health condition that cannot be cured but can be managed through medication and/or therapy.

**Multimorbidity**

The co-occurrence of two or more conditions within one individual, which are usually taken to mean long-term conditions.

**Patient activation**

An individual's knowledge, skill, and confidence for managing their health and health care. As a behavioural concept, it captures a number of core components of patient involvement, each of which is important for active engagement and participation.

**Person-centred care**

A holistic approach to care which treats a person with dignity, compassion and respect and in order to realise care that is personalised, coordinated and enabling.

**Polypharmacy**

The concurrent use of medication items by an individual, which may be appropriate for an individual but harmful if managed poorly.

**Quality and Outcomes Framework (QOF)**

A national incentive scheme for all GP practices in the UK, which rewards them financially for how well they care for patients. Under the scheme, GP practices score points according to their level of achievement against a series of indicators, e.g. the percentage of patients with a new diagnosis of a certain condition.

# Appendices

## Appendix A: Research methods

The evidence for this report was drawn from two key sources:

- A review of the literature on multimorbidity and related terms.
- Interviews with experts in the field of health and social care.

### Literature review

The literature review involved a rapid assessment of recent literature on multimorbidity according to four key themes:

- **Prevalence:** the overall prevalence of multimorbidity within the UK population and the most common patterns of comorbid conditions, and shared risk factors (e.g. deprivation, obesity or age).
- **Good practice/services:** evidence from existing services/interventions, including how services deal with the effects of interactions between conditions, as well as the impact of comorbid conditions on service delivery e.g. dementia.
- **Attitudes:** people's attitudes toward multimorbidity.
- **Outcomes:** identifying what matters to people living with multimorbidity and to clinicians dealing with multimorbidity.

The review included academic papers, health and social care guidance and quality standards (especially those published by NICE) and grey literature (e.g. government and voluntary sector reports) published since 2000, with an emphasis on literature produced in the UK within the last five years.

### Expert interviews

The literature review was complemented by 18 semi-structured interviews with experts – some within the Richmond Group of Charities and some with experts from the academic, public and voluntary sectors. A list interview participants follows.

**Table A.1:** List of people who were interviewed as part of this project

Interviewee	Organisation
Charles Alessi	Public Health England
Nuzhat Ali	Public Health England
Chris Annus	British Heart Foundation
Bridget Birgin	Stroke Association
Andrew Boaden	Alzheimer's Society
Matthew Booker	University of Bristol
Ellie Bullard	Royal College of General Practitioners
Daisy Ellis	Asthma UK
Charli Hadden	Rethink
Robin Hewings	Diabetes UK
Andrew Jazaerli	Macmillan Cancer Support
Chris Larkin	Stroke Association
Tracey Loftis	Arthritis Research UK
Sarah MacFadyen	British Lung Foundation
Tom Margham	Tower Hamlets PCT
Lea Renoux	Age UK
Fay Scullion	Macmillan Cancer Support
Fiona Smith	Macmillan Cancer Support
Bill Tiplady	CNWL NHS Foundation Trust

## Appendix B: Common pairs of conditions

**Figure B.1:** Percentage of people with condition X who also have condition Y, in Scotland

	Asthma	CHD	COPD	Diabetes	Hyper-tension	Hypo-thyroidism	Osteo-arthritis	Stroke	Back pain	Depression	Other joint disorders	Skin disorders	Other
Asthma		4	9	4	12	2	3	1	11	7	6	7	31
CHD	7		8	11	32	4	6	5	14	6	8	6	80
COPD	31	15		9	24	3	6	4	14	7	8	7	49
Diabetes	7	10	4		28	3	5	3	12	6	7	6	41
Hyper-tension	7	10	4	10		4	6	4	11	5	7	5	39
Hypo-thyroidism	8	8	4	6	24		5	3	13	9	8	5	45
Osteo-arthritis	9	11	5	10	30	4		3	18	8	22	7	47
Stroke	6	14	7	11	39	4	5		11	5	7	6	60
Back pain	8	6	3	6	14	3	4	2		10	9	5	37
Depression	8	3	2	4	9	3	3	1	15		7	5	46
Other joint disorders	8	7	3	7	18	3	11	2	19	9		6	41
Skin disorders	8	4	2	5	11	2	3	1	9	6	5		32

**Source:** NHS National Services Scotland<sup>66</sup>

## Appendix C: Multimorbidity clusters

Although there are limitations in the data that are currently collected,<sup>67</sup> researchers are beginning to identify clinically relevant clusters. An early study carried out in the US,<sup>68</sup> identified six multimorbidity clusters:

- A metabolic cluster including diabetes, hypertension, hyperlipidemia and coronary heart disease.
- An obesity cluster including osteoarthritis, low back pain, enlarged prostate, gastroesophageal reflux disease and obesity.
- A mixed anxiety-depression cluster with depression, PTSD and other anxiety disorders.
- A neurovascular cluster including peripheral vascular disease, stroke, transient ischaemic attack, Alzheimer's disease and seizures.
- A liver cluster including Hepatitis B, Hepatitis C, chronic liver disease and HIV.
- A dual diagnosis cluster including substance abuse, alcohol dependence, schizophrenia and bipolar disease.

### **A more recent German study<sup>69</sup> identified three overlapping multimorbidity patterns among older patients (aged 65 and over):**

- 1 Cardiovascular/metabolic disorders including hypertension and diabetes mellitus (30 per cent of women; 39 per cent of men).
- 2 Anxiety/depression/somatoform disorders and pain including depression and osteoporosis (34 per cent of women; 22 per cent of men).
- 3 Neuropsychiatric disorders including chronic stroke and dementias (6 per cent of women; 0.8 per cent of men).

Almost half of the men (48 per cent) and women (50 per cent) in the German sample could be assigned to at least one of the three clusters, but there were also considerable differences between the male and female sample in terms of the conditions involved.

There are risks with this approach, such as over-focusing on conditions within a cluster to the point of ignoring conditions that are more likely to belong to other clusters. However, as the quality of research in this area improves, it could provide opportunities to design and implement better condition management programmes, improved clinical guidelines and other benefits for people living with multimorbidity.<sup>68</sup>

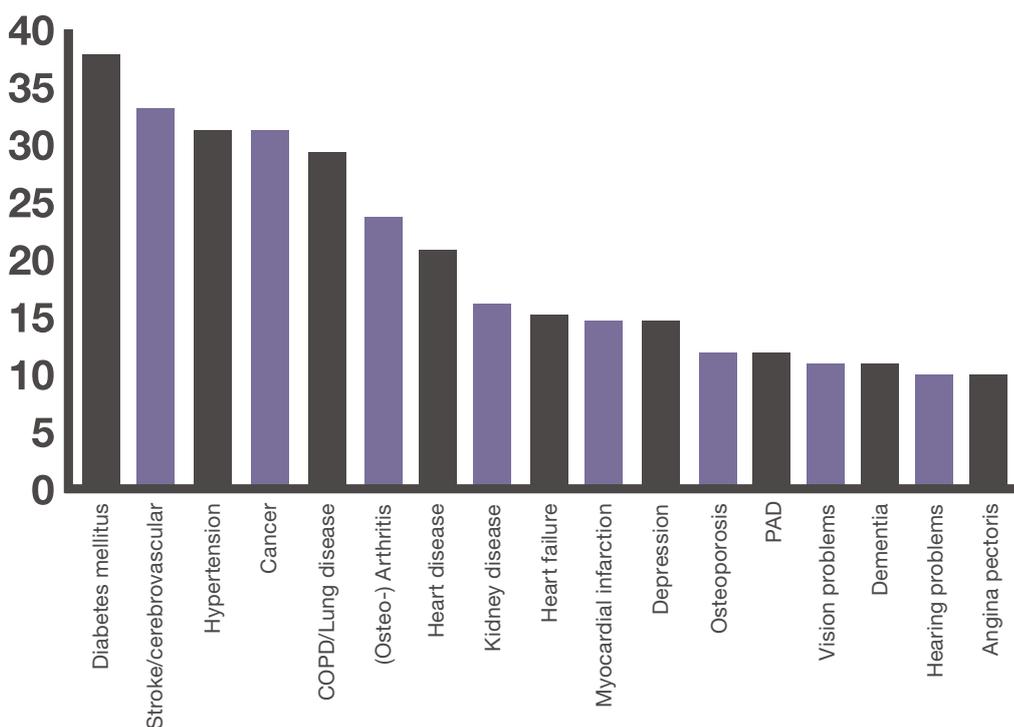
## Appendix D: Multimorbidity indices

Studies have shown that different measures are better at predicting different things such as health care costs, health care utilisation, mortality and quality of life.<sup>70,71</sup> Some of the most commonly used measures include:

- The Charlson Index: a diagnosis-based multimorbidity measure that weights diseases on the basis of the strength of their association with mortality.
- Expanded Diagnosis Clusters (EDC): groupings of diagnostic codes which are clinically similar.
- Adjusted Clinical Groups (ACGs): groupings of patients with similar health needs into mutually-exclusive categories.
- Simple counts of the number of conditions an individual has, e.g. based on the number of QOF morbidity categories\* into which a patient falls.

One study looked at 39 different indices of multimorbidity and found widespread variation in the types of condition included (see Figure D.1). Almost all of the indices included diabetes as one of the conditions, and stroke/cerebrovascular disease, hypertension, cancer and COPD/lung disease were also common. At the other end of the scale, less than a third of the indices included vision problems, hearing problems or dementia.

**Figure D.1:** List of diseases which are considered in 39 different multimorbidity indices<sup>35</sup>



\*The QOF includes indicators related to almost 20 specific long-term conditions: asthma, atrial fibrillation, cancer, cardiovascular disease, chronic kidney disease, chronic obstructive pulmonary disease (COPD), coronary heart disease, dementia, depression, diabetes mellitus, epilepsy, heart failure, hypertension, hypothyroidism, osteoporosis, peripheral arterial disease (PAD), rheumatoid arthritis, and stroke and transient ischaemic attack (TIA). It also includes indicators related to learning disabilities and mental health. See [www.nice.org.uk/standards-and-indicators/qofindicators?categories=3903&page=1](http://www.nice.org.uk/standards-and-indicators/qofindicators?categories=3903&page=1)

## Appendix E: Delivering person-centred care through the voluntary sector

**Table E.1:** Key themes in voluntary sector activity and corresponding outcome

Theme	Outcomes
<b>Self-management support</b>	<ul style="list-style-type: none"> <li>• People with long-term conditions can manage their condition appropriately because they have the right opportunities, resources and support.</li> </ul>
<b>Shared decision-making</b>	<ul style="list-style-type: none"> <li>• All patients and carers can take an active role in decisions about their care and treatment because they are given the right opportunities, information and support.</li> <li>• Services reflect the needs of patients because patients and carers are meaningfully involved in service commissioning, planning, design and improvement.</li> </ul>
<b>Collaborative care and support planning</b>	<ul style="list-style-type: none"> <li>• People feel that the care they receive is seamless because it is organised around them and their needs.</li> </ul>
<b>Prevention, early diagnosis and intervention</b>	<ul style="list-style-type: none"> <li>• Everyone can access services that support them to improve their health.</li> <li>• People are supported to access services early to reduce or prevent episodes of crisis.</li> </ul>
<b>Emotional, psychological and practical support</b>	<ul style="list-style-type: none"> <li>• Everyone with long-term care needs, whether mental or physical, can access appropriate emotional, psychological and practical support to improve their health and wellbeing.</li> </ul>

**Source:** The Richmond Group of Charities and The King's Fund<sup>45</sup>

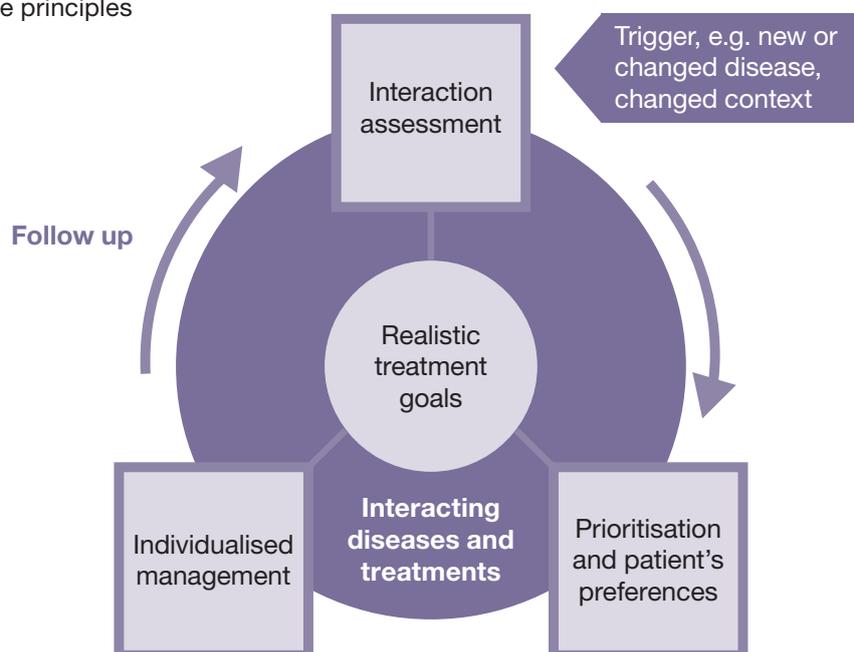
**Table E.2:** Overview of roles which voluntary, community and social enterprise (VCSE) organisations can play to support people at different stages of the care and support planning process

Stage	Potential roles of VCSE organisations
<b>1. Prepare</b>	<ul style="list-style-type: none"> <li>• Providing information around the person’s condition and the choices which may be open to them.</li> <li>• Support to understand and engage with the process.</li> <li>• Enabling confidence in order that the person is able to set their own agenda.</li> <li>• Supporting people to access peer support as an important first step to the person deciding what matters to them and as an opportunity to ‘normalise’ their experience.</li> <li>• VCSE organisations can also be a useful link between the person and their clinicians, helping them to ask for, and understand, test results and health assessments before they have their care and support planning conversation.</li> </ul>
<b>2. Discuss</b>	<ul style="list-style-type: none"> <li>• The person may identify someone working within a voluntary or community organisation to support them in their care and support planning discussion. For instance, this could be a health coach or a peer supporter.</li> <li>• VCSE organisations may also provide advocacy support to ensure that people are genuinely involved in discussions and know their entitlements; and to maintain a focus on strengths and aspirations.</li> </ul>
<b>3. Record</b>	<ul style="list-style-type: none"> <li>• Offering practical and motivational support around using apps to record and maintain their plan.</li> <li>• Supporting the person to use a paper-based record which provides space for the person to keep clinical records, record questions to raise with their clinicians and to share their priorities with their health and care professionals.</li> <li>• Enabling the person to record their plan in a creative format which makes sense for them; for instance by using their usual communication tools as a basis for recording their plan in a way they can understand.</li> </ul>
<b>4. Review</b>	<ul style="list-style-type: none"> <li>• VCSE organisations can play a key role in ensuring that reviews focus on what matters to the person, and happen in ways which enable the person to express their views about what’s going well, as well as what needs to change. The person-centred review process is an effective model for ensuring that reviews are person-led, rather than service-driven. Reviews should enable the person and their professional team to consider their full range of social and clinical strengths, needs and support.</li> </ul>

**Source:** National Voices<sup>72</sup>

## Appendix F: The Ariadne principles

**Figure F.1:** The Ariadne principles



**Source:** Muth et al.,<sup>62</sup> originally published by Springer

### Assess potential interactions – the patient's conditions and treatments, constitution and context

- Keep a list of all current conditions, assess their severity and impact, and review the medication currently taken.
- Actively monitor for signs of anxiety, distress and depression, or cognitive dysfunction, including problems of addiction and non-specific signs or symptoms such as sleeping problems, loss of appetite, or hydration problems.
- Elicit and consider social circumstances, financial constraints, living conditions and social support, health literacy, functional autonomy, and coping strategies.
- List other physicians and therapists involved in the patient's care and assess overall treatment burden.

### Elicit preferences and priorities – the patient's most and least desired outcomes

- Elicit preferences for generic health outcomes, such as survival, independence, pain, and symptom relief including palliative care needs, and be aware of your own (implicit) preferences, as they may not be the same as the patient's.

- If applicable, consider preferences of informal caregivers or family.
- Agree on a realistic treatment goal with the patient (and patient's caregiver if appropriate).

### Individualise management to reach the negotiated treatment goals

- Weigh up whether the expected benefits of treatment (and prevention) outweigh the likely downsides and harms, given the individual patient's risk level and preferences.
- Assess the incremental and combined treatment burden of the patient (and caregiver, if applicable).
- Consider self-management according to the patient's needs and capabilities.
- Provide instructions for safety-netting such as symptoms of side effects and recommendations about the appropriate management.
- Agree with the patient on the schedule for follow-up visits to evaluate goal attainment and re-assess interactions.
- Consult other health care providers and informal caregivers who are involved with the patient. Ideally, all health care providers involved are informed about treatment decisions or have access to information.

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## Multimorbidity

Understanding the challenge

A report for The Richmond Group of Charities  
**Hardeep Aiden**

*January 2018*

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