

## **Report: What matters to people with multiple conditions (multimorbidities) and their carers?**

**27 September 2019**

### **Introduction**

Multimorbidity has been described as the greatest clinical challenge facing the NHS and social care system. NIHR has led recent initiatives to increase research activity in this area. However, the NIHR Strategy Board identified a gap in the NIHR portfolio, around the lived experience of older people living with multiple conditions and their carers. Future funding calls will aim to raise awareness of the lived experience of multimorbidity, stimulate research activity that values the perspectives of patients and carers, and foster collaboration between organisations and individuals engaged in multimorbidity research development. To support these priorities within future NIHR commissions, the Older People and Frailty PRU was asked to conduct a time-limited exercise on issues that are important to older people with multiple conditions,<sup>1</sup> and their carers.

This briefing document focuses on issues that are specific or unique to the lived experience of older people living with multiple conditions. It draws on work conducted in 2017, to support the James Lind Alliance (JLA) Priority Setting Partnership (PSP) exercise on Multiple Conditions in Later Life.<sup>2</sup> The JLA worked with older people, carers, and a range of health and social care professionals<sup>3</sup> to identify both professional and public research priorities. This briefing highlights the concerns of care recipients and the public. The aim is to identify, highlight and synthesise the issues that are important to older people living with multiple conditions and their carers.

### **Methods**

This report synthesises data from four sources :

- Priorities identified by the JLA PSP on Multiple Conditions in Later Life, 2017.

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<sup>1</sup> 'Multiple conditions' is the preferred nomenclature for many people with multimorbidities, and their families.

<sup>2</sup> The James Lind Alliance is a non-profit making initiative that brings together patients, carers and clinicians in Priority Setting Partnerships to identify and prioritise unanswered questions or evidence uncertainties. Their aim is to ensure research funders are aware of the issues that matter most to the people who need to use the research in their everyday lives.

<sup>3</sup> Including, geriatricians, general practitioners, nurses, pharmacists, dentists, physiotherapists, occupational therapists, audiologists, speech and language therapists, dieticians, social workers, care home staff, housing and charity workers.

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- Qualitative data collected from 354 older people, carers and other stakeholders for the JLA PSP on Multiple Conditions in Later Life.
- Workshops with older people and carers, on living with multiple conditions, July 2019
- A review of all JLA PSPs to identify priorities of relevance to people with multiple conditions.

We have re-examined the qualitative data collected during the JLA PSP on Multiple Conditions, and gathered views about the challenges for people living with long-term conditions from participants in workshops. These sources of information combine the rigorous and exhaustive process of consultation within JLA PSP, with additional qualitative work to include people who might otherwise be overlooked, precisely because of the challenges presented by their multiple conditions.

### **Workstream 1: JLA PSP Multiple Conditions in Later Life priorities**

The top ten priorities identified in the JLA PSP on multiple conditions in later life were extracted into this report. Findings from the qualitative data review and workshops were mapped to these priorities (Table 1).

### **Workstream 2: Qualitative data review**

A range of qualitative data was collected in workshops and interviews for the 2017 JLA PSP, but not subject to formal analysis or included in the final outputs. For this report, we conducted a thematic analysis, focussing on concerns raised by older people, carers or family members, rather than health and social care professionals.

### **Workstream 3: Workshops on living with multiple conditions**

Two workshops with older people and carers were held in July 2019, one in London and one in Newcastle. The workshops were facilitated by VOICE<sup>4</sup> to explore experiences of living with multiple conditions and the challenges posed by the care and treatment of those conditions. Fifteen people participated, ranging in age from 45-89 years. Eleven participants were living with multiple conditions, four were carers.

### **Workstream 4: Review of JLA Priorities relevant to multiple conditions**

The shortlisted published priorities of new PSPs (since 2017) were reviewed, to identify any questions and priorities related to multimorbidity / multiple conditions. This updates a similar exercise undertaken for the JLA PSP on Multiple Conditions in Later Life in 2017.

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<sup>4</sup> VOICE is a network of citizens and community of patients, carers and members of the public, who contribute their lived experiences to focus health and care research on unmet needs and priorities. They are supported by Newcastle University and the National Innovation Centre for Ageing.

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## Summary of findings

The areas of interest identified from the three data sources (JLA PSP, review of qualitative data and workshops) are summarised in Table 1, below. The priorities from the JLA PSP on Multiple Conditions in Later Life are listed in the first column, and other findings mapped to these priorities. It is important to note that these JLA priorities have been assessed against existing evidence. Any potential priorities that were found to be already supported by evidence were excluded from the prioritisation list. This filter has **not** been applied to the qualitative data review or to the data drawn from the workshops.

Three topics - primary care, financial concerns and management of conditions at home -were identified by older people and carers, but not included in the JLA Multiple Conditions in Later Life list of top ten priorities. Conversely, the JLA priorities relating to comprehensive geriatric assessment and falls risk were not mentioned by older people or carers. No data from older people contained any reference to frailty.

**Table 1 Priorities and concerns for care professionals and people living with multiple conditions:  
Summary of findings by source, mapped to priorities identified by JLA PSP Multiple Conditions in Later Life**

<b>JLA PSP on Multiple Conditions in Later Life, top ten priorities</b>	<b>Review of Qualitative Data collected for JLA PSP on Multiple Conditions in Later Life 2017</b>	<b>Workshops</b>
<b>Professional, public, care recipient and carer views</b>	<b>Care recipient and carer views</b>	<b>Care recipient and carer views</b>
<b>Optimising health, social care and voluntary sectors to meet needs.</b>	<i>Service co-ordination</i>	<i>Holistic or personalised care Communication in the NHS A personalised care record</i>
<b>Effective and cost effective ways to reduce social isolation</b>	<i>Impact of social isolation</i>	<i>Impact of social isolation</i>
<b>Supporting carers to maintain physical and psychological wellbeing.</b>	<i>Burden and challenges of caring for family members</i>	<i>Support for carers</i>
<b>Effective, cost effective and acceptable to improve psychological wellbeing.</b>	<i>Impact of multiple conditions on mental health.</i>	<i>Impact of multiple conditions on mental health.</i>
<b>Enabling independent living effectively and acceptably</b>	<i>Support to live independently.</i>	
<b>Effective, cost effective and acceptable strategies for preventing multiple conditions.</b>		<i>Prioritising the prevention of multiple conditions</i>
<b>Effective, cost effective and acceptable form of exercise therapy. How does this affect outcomes?</b>	<i>Knowledge and understanding of appropriate exercise regimes.</i>	
<b>Recognising and managing frailty. Would this lead to improved quality of life?</b>	<i>Older person and carer management of multiple conditions</i>	
<b>Optimising delivery of Comprehensive Geriatric Assessment</b>		
<b>Perception and management of falls risk. Addressing fear of falling effectively.</b>		
	<i>Difficulties and challenges with GP-care.</i>	<i>Limitations of primary care services.</i>
	<i>Financial impacts on older people and carers</i>	<i>Financial impacts and service funding</i>

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## Workstreams 2 and 3: Synthesised Findings

The following section presents views and experiences of older people and carers who are living with multiple conditions. These findings are derived from analysis of data collected within workshops (2019) and interviews (2017). No attempt has been made to assess the volume or quality of existing research evidence on each of these topics, and therefore, they are presented as topics of importance to people with multiple conditions rather than research priorities.

The findings are organised into themes common to the different sources. The key issues under each theme are highlighted at the start of each section.

### A. The organisation of health and social care services, including the voluntary sector

#### Key issues:

- **Disjointed services**
- **Absence of care coordination**
- **Poor communication between settings and sectors**

Older people and carers in the original JLA PSP exercise and the recent workshops voiced their frustrations at the lack of joined-up care and support, with many calling for a 'centralised' service.

*It would be good if instead of multiple visits to multiple health specialists there could be regular visits to one place where finger nail cutting, doctors etc. could be. [Friend/family member of someone living with multiple conditions (JLA data)]*

Participants spoke of poor communication between primary and secondary health services; between health and social care; and between health/care services and local organisations (non-statutory) providing services (housing, home care, care homes). Participants reported that they had to tell their story multiple times, starting from the beginning at each appointment. This was attributed by some, to the absence of shared records.

*It's always, tell me your medical history or what conditions do you have at the start of an appointment. When you have to tell them about all 6, there is no time to speak to them about what you came in for, as you've only got 10 minutes! [Patient insight (Workshop)]*

There was a recognition that care and support needs are broader than health alone, and that housing and other carer support also need to be addressed. Sometimes, older people suggested it could be helpful to have a discussion about housing or finances, for example. Participants also proposed that a keyworker, or care co-ordinator could help them to navigate the system and ensure that their care is joined-up.

*Need joined-up health and social care as they are so linked. In my stepmother's case, she needs one person to take responsibility for her care and coordinate with the rest of the*

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*system and community.* [Friend/family member of person living with multiple conditions (JLA data)]

## **B. Challenges in Primary Care**

### **Key issues**

- **Short consultation length**
- **Resources constrain the delivery of holistic or person-centred care**
- **GP understanding, knowledge and expertise on multiple conditions**
- **A care system designed for multiple conditions**

The concerns of older people and their carers around primary care centred on the limited time available within standard consultations. Participants felt that it was impossible for GPs to provide (what participants described as) holistic, person-centred care for someone with multiple conditions, within a 10-minute appointment slot.

*I feel that there is nobody who sees them as a whole person, rather than someone with a single condition. Their care is all about their individual ailments, not their overall health e.g. several health appointments in a single week to get warfarin level checked, blood pressure checked, arthritis clinic, hearing clinic, rheumatology clinic, flu jab. Each individual health professional is good, but they don't provide holistic care. How can I help my parents to manage this better?* [Friend/family member of person living with multiple health conditions in later life (JLA data)]

Participants also reported a lack of understanding within primary care, of patient and carer needs and abilities; a perceived failure to respect patient choices and limited appreciation of their lived experience of multiple conditions.

## **C. Managing conditions, pain and medication**

### **Key issues**

- **Desire for a greater understanding of conditions and interactions**
- **Difficulties managing pain, medications and side effects**
- **Understanding of the purpose of medications**

Older people living with multiple conditions expressed a wish to have a better understanding of their symptoms and prescribed medications, and of the interactions between their different health conditions. They also reported a need for more information to support treatment decisions and in particular, on alternatives to pharmaceutical treatments.

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*I would like to know a bit more about how things go together or if they don't. I mean when I had my heart attack, I must have been likely to have problems long term and because I smoked and that. I think it would be helpful for people like me to know ... but I get its difficult and everyone is doing the best they can. [Patient insight (Workshop)]*

People with multiple conditions are often prescribed medications by a range of different specialists, and the potential for these to interact was a worry for some participants. It is noteworthy that a number of older people perceived the side-effects of medication to be worse than the condition being treated.

*The side-effects of the drugs I take are really quite frightening. It seems that some of these are even worse than the effect they are intended for. [Older adult living with multiple conditions (JLA data)]*

Some participants spoke about their lack of understanding of what each of their medications was for, as the names were complex and the packaging not informative. Pharmacists were proposed as one part of a potential solution, to provide medication reviews.

*The medication I am given is ok, but it is impossible for me to understand or pronounce the even common tablets. e.g. Paracetamol is pronounced at 'Tomasemol' it is easier to say. Most of the tablets I know only by the day I take them or their colour! Ointments by the colour of the tube! I would like an easier way to refer to these items? Older adult living with multiple conditions (JLA data)*

## **D. Carers' needs**

### **Key issues**

- **Burden of care**
- **Difficulties navigating the system**
- **Accessing information about conditions and treatments**
- **Impact of caring on physical and psychological health**

The burden placed on people supporting and caring for older people with multiple conditions was a major concern. Navigating the health and social care system to coordinate complex care services was perceived to be difficult and time-consuming. Carers wanted information about care and support services that was easy to access. In particular they expressed a need for information on where to get help, and on their eligibility for time off work for caring.

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*To what extent are people aware of the range of support available to them, how easy is it to access and understand? Even if people know where to start, it can still be incredibly difficult and frustrating navigating your way around the social care maze. It can feel like information is given in a drip feed and has to be collected from a range of different sources within the local authority - with no one source of information giving the full picture. [Friend/family member of person living with multiple conditions (JLA data)]*

Carers felt that it was important for them to be able to access information about the health conditions of the cared-for person, and the relationships between conditions, medications, interactions and side-effects. Distinguishing between symptoms of multiple conditions and side-effects of medication, was a challenge for carers with no health care experience. Participants commented that simple guidelines about how to care for a person with multiple conditions would be valuable to carers.

*To what extent some symptoms may be a result of taking a number of different medications - either reaction to one or a combination of meds - rather than symptoms of health conditions themselves. Fatigue as a particular example. [Carer of person living with multiple conditions (JLA data)]*

Caring was described as more than a full-time 'job', taking its toll on carers' physical and mental health and financial status. Isolation from friends, family members and work colleagues was common, as caring becomes all encompassing. Concerns about taking time off work to care were raised, along with worries about being able to afford paid care.

*I think it is very easy to forget about the effect that looking after an older person with health problems can have on carers. This in return can eventually impact on the effectiveness of the care being given. [Former carer of person living with multiple conditions (JLA data)]*

*My mam is the most complex and difficult person, she has delirium, and it got to the stage where she was calling me through the night. She wouldn't let them [respite care] in. Multiple strokes, blindness and deafness, it was intense. I've lost everything. I feel invisible. I've done nothing but care. [Carer Insight (Workshop)]*

## **E. Social isolation and mental health**

### **Key issues**

- **Social isolation impacts on physical and mental health**
- **Need for information on how to maintain mental health**

Older people with multiple conditions talked about their experiences of becoming socially isolated because of their increased needs and difficulties in getting out of the house. Participants talked

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about their experience of isolation, or their fear of it, together with its relationship with depression and overall adverse impact on mental and physical health. Concern was also expressed about loneliness. (Note that it is unclear whether or not participants were making a distinction between social isolation, as an objective paucity of social contacts, or the more subjective concept of loneliness.)

*I wonder if this decline in physical health would have happened anyway - or could it have been avoided by tackling the issues early on that stopped mum taking part in the activities she had always been involved in (or at least an alternative) the year before the decline she was bowling 5 days a week and going out with friends twice a week. The lack of physical activity and social interaction has had a noticeable impact on her physical and mental health.*

[Friend/family member of person living with multiple health conditions in later life (JLA data)]

Some carers talked about the need for information and guidance on how to 'keep their spirits up' and how to support older people who were grieving, as well as expressing their own loss and isolation, as highlighted in the quote at the end of section D.

## **F. Financial impact and funding for care**

### **Key issues**

- **Financial costs of care**
- **Lack of understanding of how care is funded**

Many participants were concerned about the costs of care that they face, worrying about having to sell their home, or find ways of financing the care needed.

*Yes, the financial costs of care is a constant worry.* [Person aged  $\geq 80$  years living with multiple conditions (JLA data)]

*I think it's a problem that things like your teeth, feet, hearing and eyes and that have all gone private and none us can afford it so we don't go. And yet there was something on the other day about bad teeth causing cancer or something and I thought yes you've let that go and yet it's those things that actually cause loads of people loads of problems.* [Patient insight (Workshop)]

Participants who were still in work were concerned about taking time out of work to attend medical appointments and the possibility that they might lose their job and financial security.

*I am permanently worried. All the time. I wake up in the morning and for 5 seconds I feel ok then this fog comes down. And it's because ....of all my money worries. It's all the time. I*

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*actually had to say that I'd hurt my leg playing football, cos if they knew I had a problem with me lungs, as well as me back I might get passed over for someone younger. It's on my mind all the time.* [Patient insight (Workshop)]

## **G. Exercise and physical activity for multiple conditions**

### **Key issues**

- **Understanding the appropriate types and amount of exercise/physical activity**
- **Importance of diet and activity**
- **Fatigue**

Many older people and carers expressed uncertainty about the type and amount of physical activity to undertake. Some thought that healthcare professionals did little to promote the importance of diet, exercise and staying active. Tailored advice from health professionals seemed to be lacking, particularly for the oldest old.

*It is fashionable to tell everyone to exercise- to walk and cycle but what about disabled people who are disadvantaged and need to be considered?* [Person aged  $\geq 80$  years living with multiple conditions (JLA data)]

*Yes, I find it frustrating that health professionals seem to completely ignore this, the benefits of good diet, exercise and other therapies just because they are dealing with an elderly person whose motivation to change is poor. Why is there not more emphasis put on the whole picture, encouraging elderly people to eat well, socialise etc.* [Friend/family member of person living with multiple health conditions in later life (JLA data)]

For some, the problem of fatigue and lethargy, whether caused by the conditions or the medication taken, made it difficult for people to engage in physical activity and exercise. Those who were 'bed-bound' had found their symptoms and conditions worsen through inactivity.

## **H. Support for independent living**

### **Key issues**

- **Desire to be independent, despite multiple conditions**
- **Services presenting barriers to independent living**
- **Timely access to equipment**

A strong desire to maintain independence was evident, but it was acknowledged that this was challenging in the presence of multiple conditions.

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*I want to be independent. Will do my best to be so. I try to live my own life in spite of my problems people who really need care ask for the least.* [Person aged ≥80 years living with multiple conditions (JLA data)]

Some carers spoke of the barriers that services can present to independent living. A paucity of (well-trained) staff to support independence, and the lack of timely access to equipment such as wheelchairs were highlighted.

## **I. Preventing multiple conditions**

### **Key issues**

- **Prioritise research to prevent multiple conditions**

Prevention was identified as a priority in the JLA PSP exercise on multiple conditions in later life. At the workshops held in July 2019, older people and carers felt that this should be the number one priority.

*In some ways, we need to concentrate on the future. So if we concentrate on preventing multiple conditions that may help services for future generations.* [Patient insight (Workshop)]

### **Workstream 4: Findings - Review of JLA PSPs to identify priorities of relevance to multiple conditions**

Our updated review of JLA PSPs identified 63 new PSPs since 2017. One PSP from Canada was conducted on frailty but no other new priorities or questions were identified that are relevant to older people living with multiple conditions. The top ten questions from the Canadian PSP are listed in the appendix to this report, along with those from the original 2017 review of PSPs. There are a number of topics that are common to the PSP on Multiple Conditions in Later Life and the data presented in this report. They include coordination of care, isolation, exercise and support for carers.

### **Conclusion**

Many of the current concerns of older people and their carers align with the research priorities identified previously by the James Lind Alliance Priority Setting Partnership on Multiple Conditions in Later Life in 2017. Our exploration of the views and experiences of older people who are living with multiple conditions highlights the importance of care coordination, and a need for services that are designed around a person rather than a disease. Older people and carers talked spontaneously about issues that are encompassed by the following JLA priority areas:

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- Care services tailored to the needs of older people living with multiple conditions
- Social isolation in older people with multiple conditions
- Support for carers of older people with multiple conditions
- Physical activity for older people with multiple conditions
- Prevention of multiple conditions in later life
- Mental well-being of older people with multiple conditions
- Independent living with multiple conditions

In addition, older people and carers identified three areas of importance to them, that had not featured in the JLA top ten priorities: *limitations of primary care; the personal costs of services; and understanding and management of their conditions at home, particularly dealing with multiple medications.*

This work was conducted with potential beneficiaries of research on multiple conditions, and it provides a critical perspective that should be helpful to inform future research commissioning. It also affirms the relevance of previous JLA work that identified research priorities relevant to older people living with multiple conditions.

### **Acknowledgement**

In the preparation of this report, we were fortunate to be able to draw on the generous participation of the large number of participants in two James Lind Alliance Priority Setting Partnerships of specific relevance to older people living with multiple conditions and/ or frailty, and workshop attendees.

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## Appendix A

The **original JLA PSP Exercise** produced the following top 10 research priorities (the research priorities highlighted in *italics* only appeared in the data from health and social care professionals):

1. How can current health, social care and voluntary sectors in the UK be optimised to more effectively meet the needs of older people living with multiple conditions?
2. What are the most effective, cost effective and acceptable ways to reduce social isolation in older people with multiple conditions?
3. *What are the most effective, cost effective and acceptable strategies for the prevention of multiple conditions in later life?*
4. In what ways can carers of older people with multiple conditions be supported to maintain their own physical and psychological well-being?
5. What is the most effective, cost effective and acceptable form of exercise therapy in different health and social care settings with older people with multiple conditions? How does exercise therapy affect outcomes in this population?
6. *How can the recognition and management of frailty be improved in older people with multiple conditions? Would this lead to an increase in perceived quality of life?*
7. *How can Comprehensive Geriatric Assessment be optimally delivered in different patient populations experiencing multiple conditions in older age?*
8. What are the most effective, cost effective and acceptable interventions to improve the psychological well-being of older people with multiple conditions?
9. How can independent living be most effectively and acceptably enabled in older people with multiple conditions in the UK?
10. *How do older people with multiple conditions perceive and manage their risk of falls? How can fear of falling be effectively addressed?*

One PSP identified in the review, which did not set an age criterion, but was likely to be relevant to those aged 80+ with multiple conditions, was *Frailty (Canada)*. The top ten questions from this PSP were:

1. How can health systems be organized to provide integrated/coordinated care that would better meet the health and social care needs of older adults living with frailty, and their family/caregivers?
2. How can care, services and treatments be tailored to meet the needs of older adults living with frailty who are isolated and/or without family/caregiver support or advocates?

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3. What is the impact of community- and home-based services, programs and resources in preventing and managing frailty (including slowing progression and/or minimizing the impact of frailty)?
4. What are the costs and benefits of alternative models of housing, including multigenerational or shared living, for older adults living with frailty?
5. What would help avoid unnecessary hospitalizations and emergency department visits for older adults living with frailty?
6. What frailty-related attitudes, skills and knowledge should health and social care providers have? What are effective ways of improving attitudes and providing skills and knowledge about frailty for health and social care providers?
7. What would help older adults living with frailty and their family/caregivers recognize when living at home is no longer viable?
8. What are effective ways of supporting family/caregivers of older adults living with frailty to maintain their own health and wellbeing and/or that of older adults living with frailty?
9. How can frailty measures be used by health care practitioners, older adults and family/caregivers to inform treatment and care decisions?
10. What is the impact of exercise and physical activity (including type, duration and intensity) in preventing and managing frailty (including slowing progression and/or minimizing the impact of frailty)?

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