

'Addressing the global challenge of multimorbidity': Call for written evidence questions

* *Mandatory fields*

* Name: Professor Chris Salisbury

* Job title: Professor of Primary Health Care

* Organisation/institution: University of Bristol

* Email address: c.salisbury@bristol.ac.uk

Telephone number: (0117) 3314530

* Is this input submitted as an organisational or individual response? Individual

* Are you happy for your response to be published by the Academy? Yes

Definitions

1. There is no standard definition of 'multimorbidity' – various different definitions are used. Which definitions (or aspects of definitions) do you think are most helpful to efforts to describe and understand multimorbidity?

Please provide references for any published research, and highlight any other initiatives related to multimorbidity that the Academy may be interested in.

The most commonly used definition is two or more chronic conditions. However, given the high prevalence of multimorbidity using this definition in the elderly, the use of three or more conditions may well be more discriminatory. The prevalence of multimorbidity will therefore obviously depend on the conditions searched for and included in any list. Although there has been much discussion about standardising such a list of conditions I think any attempt to define this will be arbitrary. In itself this may not matter too much but it could be problematic for studies across countries and settings given that the common diseases will vary. For example, tuberculosis would be an important condition to include in some countries but not others. I think it would prove impossible to come up with one consensus definition of multimorbidity which is equally applicable and relevant in all settings.

This problem comes about because of the tendency to treat multimorbidity as like another single disease label. Multimorbidity is a *concept*, a way of thinking which challenges a single disease approach, rather than being a diagnostic label or an object. In that sense it is rather like the concept of 'frailty' or 'poor quality of life' rather than like a diagnosis such as diabetes which has a relatively clear underlying biological mechanism.

Another analogy might be the concept of 'raised cardiovascular risk'. Operationalising the concept of raised cardiovascular risk can be done in various ways of increasing sophistication, depending on how many risk factors are included, but however it is operationalised the concept is still useful because it predicts an important outcome (ie the risk of a cardiovascular event). The same is true of multimorbidity. There are different ways in which this could be operationalised, with increasing sophistication, number of diseases included, weighting of those diseases, etc, and some of these may be more or less useful for predicting outcomes. All disease labels are arbitrary to a greater or lesser extent but are useful for characterising a group of patients who have a predictable prognosis and response to treatment. Some (but not all) diagnostic labels are useful for understanding causation. But the causes of multimorbidity, like other complex concepts such as frailty or poor quality of life, are multi-factorial.

The concept of multimorbidity is mainly useful because it draws attention to the fact that people with multiple chronic diseases have high rates of healthcare utilisation, high treatment burden, and poor outcomes (particularly poor quality of life). The main reason the concept has come to prominence is because health care has become increasingly standardised along single disease lines and this may not be appropriate for the increasingly large number of people with multimorbidity due to increased life expectancy. Following the logic that disease labels are useful to the extent to which they inform treatment decisions, I think most attention should be given to defining multimorbidity in ways which best predict patient outcomes and ways which differentiate those patients which need different forms of treatment from those with single diseases. I think this would be more fruitful than using it to characterise underlying causes or biological mechanisms. The concept and definition of multimorbidity has been thoughtfully considered in a useful and highly cited paper by Valderas et al.¹

There are several different measuring tools which have been developed to capture the concept of multimorbidity and which have been used to study associations for various determinants and outcomes. We have described these different measures and their associations with determinants and outcomes in a systematic review.²

In summary, I would define multimorbidity as having any combination of multiple chronic diseases which have an enduring impact on health status, health care (including patients' experience of health care), or prognosis.

Current knowledge base

When answering these questions, please consider both national and international populations of high, middle, and low income countries. Please provide examples and case studies to illustrate your arguments where appropriate. Please provide references for any published research.

2. What are the key data, and what data sources exist, on the prevalence, burden (including costs and impact on health systems) and determinants of multimorbidity? Are there significant gaps in such data and, if so, what are they?

A very useful source of information is the International Research Community on Multimorbidity website (<http://crmcspl-blog.recherche.usherbrooke.ca/>). They produce a bibliography of publications on multimorbidity. (https://www.usherbrooke.ca/crmcspl/fileadmin/sites/crmcspl/documents/Publications_on_multimorbidity_01.pdf)

This is updated every few months (last updated 8 November 2016) and includes papers under headings such as definitions/conceptualisation, epidemiology, interventions, etc.

In the UK there have been two key studies of the epidemiology of multimorbidity. The first, conducted by my team, was based on the primary care records of 100,000 people in England.³ It described the prevalence of multimorbidity operationalised in two ways, one using the major diseases included in the GP Quality Outcome Framework and the other based on the Johns Hopkins ACG (Adjusted Clinical Groups) system. It showed prevalence in different age and sex groups, associations with deprivation, and the impact on health care utilisation in terms of consultation rates in primary care and continuity of care. This was followed by a similar paper based on the primary care records of patients in Scotland which operationalised multimorbidity in terms of forty major chronic conditions.⁴ This reached similar conclusions to the earlier English paper but placed more emphasis on the importance of deprivation and on co-morbid combinations of conditions.

There have been a number of other studies of the epidemiology of multimorbidity using medical records data from Europe and from North America. These studies of the prevalence of multimorbidity have been usefully summarised in a systematic review.⁵ The patterns of association with age, sex and deprivation and the impacts in terms of high usage of both primary and secondary care and impacts on patients in terms of poor physical and mental health, reduced life expectancy, reduced quality of life and high treatment burden are consistent in many quantitative and qualitative studies. See the previously mentioned bibliography for details. The exact prevalence of multimorbidity varies according to which diseases are included in the definition but this is less important than the clear patterns of associations.

Data from low and middle income countries have been reported, and some have tried to use similar methods described above, but this is much more difficult because of the lack of comprehensive medical records in many countries. Therefore studies have generally been based on self-report (e.g. work I have been involved in in India).⁶⁻⁸

There is less research on the cost of multimorbidity, particularly in primary care. Our group in Bristol has attempted to address this gap by studying which approaches to measurement of multimorbidity best predict the cost of primary care and which combinations of diseases increase or decrease the cost of primary care.^{9 10} More attention has been given to the cost of secondary care given the high overall contribution of this to health service costs. Most of this research has been done in the context of predicting costs in insurance based healthcare systems such as the USA, for instance using the Johns Hopkins ACG case mix system.

In terms of gaps in the data, one notable gap is quantitative data about the impact of different forms of multimorbidity on patients' quality of life ('illness burden') and in particular on their 'treatment burden', i.e. the work generated for patients by taking large numbers of drugs, undertaking self-management measures and attending numerous healthcare appointments. This is partly because of difficulties in measuring the impact of multimorbidity on quality of life in ways which are meaningful for patients with multimorbidity that are sensitive to change and also to a lack of methods for measuring treatment burden. These gaps are important because I think the most important reason for studying multimorbidity is because of the recognition that a single disease approach is not useful in terms of improving patients' quality of life and reducing treatment burden.

3. What are the key data, and what data sources exist, on the prevention of multimorbidity? Are there significant gaps in such data and, if so, what are they?

The question about prevention of multimorbidity tends to assume that multimorbidity is one entity, even though it may have multiple causes. For the reasons discussed above I do not think it is helpful to think about multimorbidity in this way. Paying attention to preventing the individual diseases which contribute to multimorbidity will in itself prevent multimorbidity, e.g. the obvious factors such as losing weight, stopping smoking, etc, will reduce all the obesity and smoking related diseases which in turn will reduce multimorbidity. I doubt there are any mechanisms to prevent multimorbidity which do not work through reducing individual diseases. There will, however, be 'gearing' effects by focussing on common risk factors which increase prevalence of several diseases for which smoking is again a good example.

4. What are the key data, and what data sources exist, on the management of multimorbidity? Are there significant gaps in such data; if so, what are they?

The term 'management' here could refer to clinical interventions designed to specifically treat patients with multimorbidity as well as strategies for the delivery of healthcare services patients with multimorbidity. The term also refers to a wide range of management approaches that may differ by the specific diseases that co-exist.

Smith et al have published a systematic review of the effectiveness of interventions to improve the management of multimorbidity in primary care.¹¹ This topic has also been reviewed as part of the recently published NICE guidelines on multimorbidity. Both these reviews have highlighted the lack of evidence for effectiveness of different interventions. However there seems to be a general consensus around the ingredients of better care such as improved continuity of care, improved care co-ordination between agencies, shared decision making with patients, encouraging patient self-management, individualisation of care in response to patients' particular priorities, attention to mental health and social care as well as physical health, attention to polypharmacy and medication adherence, care planning, etc. However, evidence for the effectiveness of many of these strategies individually is sparse, either in patients with single diseases or multimorbidity. For example, sharing care plans with patients sounds an eminently sensible idea and is commonly advocated but at present there is relatively little evidence that it leads to benefits.

With respect to multimorbidity many new models of care combine some of these strategies but there is often a lack of attention to a theoretical basis for how these strategies will be used in combination and the mechanism of change by which they will lead to improved patient outcomes. There is also a lack of evidence about cost effectiveness of new models of care. Better care is likely to require better integration of primary and secondary care and health care and social care but most research has been within these sectors rather than involving models that integrate them. Most of the research has been based on re-organising primary care and there has been little attention to evaluation of new models of care within hospitals. Many patients in hospital have multimorbidity but they are treated within specialist teams. My suspicion is that in-patient management of multimorbidity will vary considerably according to the specialist team under which a patient is admitted, with most attention given to the disease area that specialist team is expert in and other conditions given less attention.

5. What are the key sources of funding for research into multimorbidity? Are there gaps in funding and, if so, where?

In the UK most of the funding on multimorbidity has come from NIHR. It is notable that NIHR had few applications in a recent call for research. This probably reflects that there are relatively few research teams with expertise in this area. Within the UK the main research teams are in Bristol (led by Salisbury), Manchester (led by Bower), Glasgow (led by Mercer) and Dundee (led by Guthrie). This phenomenon of few applications for research grants reflects limited capacity in teams with relevant interest and expertise. The fact that few teams have addressed this area reflects the fact that most research funders have tended to focus on biological mechanisms and laboratory based science (e.g. the MRC) and the major medical charities funding research are almost entirely organised around single diseases. Furthermore the most prestigious medical journals are either entirely focussed on specific diseases or have a strong preference for papers relating to single diseases as these tend to be highly cited because there is a much larger mass of other researchers to refer to this work. Understandably research teams have responded to the opportunities. The fact that a wider range of funding bodies are now recognising the importance of multimorbidity will almost certainly lead to expansion in research capacity, but this will take time.

Looking forward

6. What should the definition of 'multimorbidity' be? How would this definition improve research and/or treatment?

My comments in response to question 1 apply here. I would define multimorbidity as people with multiple diseases which have an enduring impact on their health status, health care or prognosis. Although it may be necessary to define this more closely it will be important to bear in mind that any such operationalisation will be arbitrary and the concept is more important than how exactly it is defined. There are many ways in which indices of multimorbidity could be constructed but these are likely to be different in order to predict different outcomes, e.g. hospital utilisation, quality of life and mortality. Some would argue for the inclusion of patients with multiple acute as well as chronic diseases but I think this will prove to be less fruitful because it is the enduring impact of chronic diseases and their implications for long-term health care and patient self-management that make multimorbidity a priority. I think it would be helpful to build a consensus about which are the most important diseases to be measured when collecting data about multimorbidity in order to ensure comparability between different studies within a particular country, as long as we recognise that any such list will need to be adapted for research in different settings.

7. What are the priorities for research about the prevalence, burden and determinants of multimorbidity?

We need more research about the impact of multimorbidity on patients. There is considerable qualitative research about this topic but much less quantitative research to define and measure this. In particular, current approaches to measuring health related quality of life are not sufficient or responsive to change due to better medical treatment. There are no good measures of treatment burden which are not disease specific, although we are currently developing such a measure.

I know that some people think that a better understanding of clusters of conditions will unlock the problem of multimorbidity. I think this approach may make some contribution but that it probably will not be major. Again, referring to the paper by Valderas et al may be helpful in thinking about the likely ways in which comorbid conditions may be associated.¹ Several people have already tried to study the ways in which diseases cluster within patients' within multimorbidity – one such study is currently underway at UCL.

Clustering can happen for several reasons. Previous studies have often identified clusters which have obvious and well known common risk factors, e.g. the diseases related to smoking or diseases related to obesity. In other cases, diseases cluster because of well recognised sequences of events, e.g. hypertension leading to strokes leading to hip fractures. Other apparent clusters simply reflect the arbitrary nature of our disease labelling systems or imprecisions in diagnostic coding behaviour, e.g. many patients with COPD are also labelled as having asthma and patients with depression are often labelled as having anxiety and it is debatable whether these are different manifestations of the same condition or different conditions.

It is possible that further work on clusters within multimorbidity will identify new common risk factors or causal pathways which are not already well known. I think it is worth investing some money in this search but I personally doubt it will be fruitful and I would put more priority on understanding the impact on patients and how health services need to be re-organised to better meet patients' needs. Identifying new clusters would be helpful if it identifies new causes which are amenable to change. It is likely that overwhelmingly the most important determinant will be non-modifiable, i.e. age. Many cases of multimorbidity will just be chance association of two or more common conditions in the same individual, but that does not make the phenomenon of multimorbidity any less important. Even if there is no common factor and these are just chance associations, for that individual patient having multiple conditions still has major impacts on their quality of life, illness burden and treatment burden and it would still likely predict their health care utilisation. Having multiple morbidity, even for unrelated diseases, may still mean that patients are not well served by an approach to health care dominated by a single disease model. For these reasons I think attention to improving management of patients with multimorbidity is more likely to be fruitful than looking for new biological causes.

8. What are the priorities for research about the prevention of multimorbidity?

No comment.

9. What are the priorities for research about the management (as defined above) of patients with multimorbidity?

We need more research about:

- the management of multimorbidity within primary care
- management of multimorbidity at a whole system level with new models of integration of primary care, secondary care and social care
- better management of patients with multimorbidity within hospitals.
- We need to understand better the problems patients experience with current models of care.

- We need stronger conceptual frameworks and logic models to identify the key problems, strategies to address those problems and under what circumstances they will lead to desired improvements, and greater clarity about the outcomes that are most important to patients and the health service.
- In particular, there are strategies which might in theory be effective, but previous research has shown that it has been very difficult to achieve organisational or attitudinal change so that these strategies actually get implemented in a meaningful way within health care. The WISE trial of care planning is a good example where despite considerable efforts to train health care staff, few patients actually received care plans.¹² Therefore we need better implementation research about how to achieve change in health care organisation given all of the powerful structural reasons within medicine that reinforces a single disease approach, e.g. the way doctors are trained, the way hospital departments are organised and the way care is commissioned.

10. What should be the strategic response of both national and international research funders and agencies be to multimorbidity?

The current situation reminds me of the state of primary care research until the 1990s. The MRC commissioned Professor David Mant from Oxford University to review the priorities for primary care research¹³ and the DH asked him to advise about the state of primary care research.¹⁴ He presented a framework of priorities for research and also made recommendations for a gradual but consistent expansion in research capacity. He felt it was important to avoid a sudden influx of too much funding in advance of there being enough researchers with relevant interests and expertise, but a gradual expansion in funding which included growing research capacity through investment in training and infrastructure. This has resulted in a much stronger primary care research infrastructure in the UK which now has critical mass and is probably the international leader in the field. I hope this initiative from the Academy of Medical Sciences will follow a similar path.

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