Cross-funder multimorbidity research framework

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Medical Researc Council **NIHR** | National Institute for Health Research



About the framework

Background

Following the publication of the Academy of Medical Sciences report, '*Multimorbidity: a priority for global health research*', the Medical Research Council (MRC), the Department of Health and Social Care (DHSC) through the National Institute for Health Research (NIHR) (DHSC/NIHR), Wellcome and the Academy agreed to develop a multimorbidity research interest group. As partners, these organisations have developed a cross-funder framework that provides a vision for how we, as a funding community, will drive forward the multimorbidity¹ research agenda in the UK and globally.

A meeting held in November 2018 brought together a broader range of funding organisations to further develop the concept and detail of the framework. The framework aims to help co-ordinate the efforts and initiatives in which the various funders are engaged, and to highlight opportunities for funders to work together on areas of common interest and/or where joint working would be beneficial. It embraces the multidisciplinary nature of the problem and recognises that working in partnership will help to overcome common barriers.

The framework is intent on delivering a step-change for the understanding of the mechanisms and causes, the prevention of and the management and treatment of multimorbidity through research. Much important work in this area is already underway in the UK and globally, summarised here in '<u>The framework in context</u>'.

This document is a working framework and is therefore subject to changes and further developments. Specifics of ongoing and planned future activities, relevant initiatives and more general information are being collated though a designated web resource hosted by the Academy of Medical Sciences, <u>Multimorbidity: helpful resources</u>.

Introduction

The draft framework has two pillars underpinned by a programme of complementary aims, associated activities and ways of working. The aims under each pillar are not listed in any particular order.

Pillar 1 aims to 'drive advances in our understanding of multimorbidity', **Pillar 2** aims to 'foster a change in research culture to tackle multiple chronic conditions'.

¹ We recognise that the term multimorbidity is not well understood, or used consistently across different communities. To discuss multimorbidity in a meaningful way in different settings or with different groups, it can be important to use varying terminology. This framework will work to develop a shared language and terminology, which in particular takes into account the views and preferences of those people with multiple long-term conditions.

The funding framework

Abbreviations used in this framework are set out at **Appendix 1**. For ease of reference, **overarching aims** are abbreviated to '**OA**'.

To understand how the framework relates to the current landscape of multimorbidity research, read '<u>The framework in context</u>'.

Quick navigation

Click on the overarching aims below to jump to associated activities and ways of working.

Pillar 1: Driving advances in our understanding of multimorbidity

OA1.1. Facilitate the holistic development and evaluation of simple, scalable diagnostics, interventions and care provision to prevent and treat multimorbidity

OA1.2. Facilitate relevant clinical and longitudinal population-based studies (LPS), data collection and sharing in multiple, diverse and representative populations and patient groups

OA1.3. Facilitate multimorbidity-inclusive clinical trials and research

OA1.4. Understand patients' and the public's views and lived experience

OA1.5. Understand biological mechanisms and epidemiology of multimorbidity, with specific focus on common 'clusters' of conditions

Pillar 2: Changing research culture to tackle multiple chronic conditions

OA2.1. Assess multimorbidity-related research proposals in an objective, effective and consistent manner

OA2.2. Increase awareness of multimorbidity among the scientific community, policymakers, healthcare systems, publishers and the public

OA2.3. Support interdisciplinary and 'team science' approaches to multimorbidity research, healthcare and policy globally

OA2.4. Promote a common terminology around multimorbidity

Pillar 1: Driving advances in our understanding of multimorbidity

OA1.1. Facilitate the holistic development and evaluation of simple, scalable diagnostics, interventions and care provision to prevent and treat multimorbidity

Associated activities that will support the achievement of this aim include:

- a. Research into 'technology-enabled' solutions, such as Artificial Intelligence (AI) to support early detection, prevention, care and treatment for multimorbidity.
- Research into health and social care service configuration in the UK and Low and Middle Income Countries (LMICs) including health economics and service delivery research.
- c. Research to understand how some diseases are related to or interact with other conditions. For example, how musculoskeletal conditions are linked to heart disease, or how mental and physical health conditions are related.
- d. Encouraging 'holistic' approaches to patient care, by showcasing examples of best practice from the UK and LMIC settings.

Ways of working that will support the achievement of this aim include:

- e. Individual and/or partnership funding.
- f. Alignment of research support mechanisms, including funding, with the aims and directions of the NHS Long Term Plan, the Life Sciences Industrial Strategy and the Industrial Strategy Challenge Fund.

OA1.2. Facilitate relevant clinical and longitudinal population-based studies (LPS), data collection and sharing in multiple, diverse and representative populations and patient groups

Associated activities that will support the achievement of this aim include:

- a. Encouraging the inclusion of a more diverse populations in research.
- b. Standardising definitions and outcome measures for multimorbidity.
- c. Developing measures to collect, link, store and share appropriate data and outcomes for multimorbidity, particularly focusing on longitudinal aspects including continuous disease monitoring.
- d. Improving the quality and cost-effectiveness of data, to reduce research participant burden.

- e. Mapping existing sources of samples and data, to obtain a clear picture of resources available to support multimorbidity research and to improve understanding and awareness of these. For example, UK Biobank, British birth cohorts, ELSA UKHLS and Labour Force Survey.
- f. Encouraging the use and enhancement of existing relevant data sources, such as pharmacovigilance data, electronic health records, biobanks and patient cohorts by overcoming barriers of access, connectivity, data linkage and data quality.
- g. Bringing together long-term remote monitoring, digital epidemiology and continuous disease monitoring.
- h. Futureproofing data collections towards research in 2050 and beyond.

Ways of working that will support the achievement of this aim include:

- i. Fostering multidisciplinarity by encouraging networking single-disease focussed research communities
- j. Sharing expertise in data analysis, including methods such as machine learning.
- k. Re-purposing existing data where possible, to maximise the value of available resources to address important questions such as identification of multimorbidity 'clusters' and their trajectories.
- I. Encouraging access to and sharing of samples and data in a secure and ethical way to maximise the value of available resources, e.g. through facilitating data linkage.

OA1.3. Facilitate multimorbidity-inclusive clinical trials and research

Associated activities that will support the achievement of this aim include:

- a. Addressing the problem of exclusion and inclusion criteria through engagement with regulators such as Medicines and Healthcare Products Regulatory Agency and Health Research Agency.
- b. Reviewing of funding policies and guidance by individual funders to ensure inclusivity.
- c. Developing more innovative, effective, and efficient trial designs through engagement with trial units.
- d. Developing and testing the collection of real-world evidence, and real-world trials.
- e. Collecting more comprehensive data, to minimise patient burden and maximising outcomes from trials.

- f. Improving determinants of health outcomes and multimorbidities, for example early surrogate or technical markers.
- g. Aligning patient reported outcomes measures (PROMs) across the sector, where appropriate.

Ways of working that will support the achievement of this aim include:

- h. Increasing the involvement of industry partners, health economists, social scientists and other partners in clinical trials and research.
- i. Encouraging applied research and natural experiments where possible.
- j. Moving away from primary endpoints to capture wider endpoints.

OA1.4. Understand patients' and the public's views and lived experience

Associated activities that will support the achievement of this aim include:

- a. Facilitating the patient voice through lived experience research, such as around pain, reduced mobility and sensory experience.
- b. Understanding clusters of conditions in terms of patient experience, such as symptoms, functionality and/or treatments.
- c. Understanding opportunities for early detection and prevention of multimorbidity.
- d. Understanding the impact and burden of single-disease focused approaches on health and social care systems, such as unsynchronised appointments, constant retelling of story, conflicting advice and the effects of polypharmacy.
- e. Reviewing existing research beyond the biomedical literature.
- f. Health and social care delivery research to understand how best to configure and deliver patient-centred care for people with multiple long-term conditions.

Ways of working that will support the achievement of this aim include:

- g. Working with the social science sector to help understand patient and carer experiences and priorities.
- h. Focussing on improving quality of life and service delivery for people with multimorbidity.
- i. Developing and using appropriate and accessible language for different communities.

OA1.5. Understand biological mechanisms and epidemiology of multimorbidity, with specific focus on common 'clusters' of conditions

Associated activities that will support the achievement of this aim include:

- a. Assessing trends, patterns and clustering of co-existing conditions, the concomitant burden and what the trajectory of condition development might be over the lifetime, both in the UK and globally.
- Identifying common biological processes and signalling pathways that underlie different conditions within disease clusters through mechanistic research, clinical and population studies, deep patient phenotyping (including multi-omic approaches) and preclinical models.
- c. Understanding the effects of treatment burden and polypharmacy to identify ways of managing and reducing it.

Pillar 2: Changing research culture to tackle multiple chronic conditions

OA2.1. Assess multimorbidity-related research proposals in an objective, effective and consistent manner

Associated activities that will support the achievement of this aim include:

- a. Ensuring that review processes do not penalise multimorbidity-related research proposals, for example because of their complexity.
- b. Developing tailored mechanisms and processes for the review of multimorbidityrelated research proposals.

OA2.2. Increase awareness of multimorbidity among the scientific community, policymakers, healthcare systems, publishers and the public

Associated activities that will support the achievement of this aim include:

- a. Working with publishers to promote the exploration of multimorbidity and related issues in scientific journals and forums, as well as in the mainstream media.
- b. Promotion of relevant funding calls, important scientific updates and collaborative efforts around multimorbidity at meetings, events and conferences.
- c. Fostering the generation and use of collaborative digital platforms to share, promote and coordinate multimorbidity-related work across sites, disciplines and sectors.
- d. Encouraging academics, many of whom are already working in this area, to identify as multimorbidity researchers.

Ways of working that will support the achievement of this aim include:

- e. Cooperation and engagement between the scientific community, funders, third sector and policymakers to develop the conversation around multimorbidity research, prevention and management.
- f. Supporting a dialogue with people who have multiple long-term conditions about health and care research, how it affects them and how they can become involved in research.
- g. Ensuring the voice of patients with multimorbidity, their family and carers are heard by researchers and policymakers, including through accounts of lived experiences.
- h. Involving policymakers, healthcare systems and industry partners from the early stages of multimorbidity research to support implementation of outcomes.

OA2.3. Support interdisciplinary and 'team science' approaches to multimorbidity research, healthcare and policy globally

Associated activities that will support the achievement of this aim include:

- a. Providing support for building teams, collaborations and networks.
- b. Involving social sciences, engineering, informatics, economics and environmental sciences in multimorbidity research and priority setting.
- c. Providing training and support for researchers from a wide range of disciplines and backgrounds focusing on skills and networking for multimorbidity research.
- d. Creating and enabling career pathways that would complement and support multimorbidity research.
- e. Promotion of equitable partnerships between UK and LMIC researchers to ground research in the local context and build capacity.

Ways of working that will support the achievement of this aim include:

- f. Encouraging and promoting 'team science' by involving social sciences, engineering, informatics, economics and environmental sciences in multimorbidity research and priority setting.
- g. Ensuring relevant cross-disciplinary involvement in the review and assessment of research proposals.

OA2.4. Promote a common terminology around multimorbidity

Ways of working that will support the achievement of this aim include:

- a. Adopting a common definition of multimorbidity for research and science communication as recommended in the Academy of Medical Sciences (AMS) report, '<u>Multimorbidity: a priority for global health research'</u>.
- b. Consistent use of the terminology 'multimorbid', 'multimorbidity' and 'multimorbidities' in scientific and policymaking settings or publications.
- c. Use of 'multiple long-term conditions' as optional alternative terminology in public engagement, mainstream media and patient care settings.

Updates to the framework

This framework was last updated and published in November 2019.

If you would like anything amended or added in this framework, please contact Dr Sarah Ritchie at <u>sarah.ritchie@acmedsci.ac.uk</u>.

Likewise, please communicate updates about ongoing and planned future activities to Dr Sarah Ritchie for inclusion on the website, <u>Multimorbidity:</u> <u>helpful resources</u>.

The framework in context

Multimorbidity, the co-existence of two or more chronic conditions, is a significant and rapidly increasing health, economic and societal problem in low-, middle- and highincome settings. In 2018, the Academy of Medical Sciences published '<u>Multimorbidity: a</u> <u>priority for global health research</u>'. This international policy report asserted that barriers to commissioning and executing high quality research on multimorbidity are not insurmountable, if we come together to address them.

Following this report, the Academy, Medical Research Council (MRC), Department of Health and Social Care through the National Institute for Health Research (DHSC/NIHR), and Wellcome organised a joint implementation workshop in June 2018 which led to an exciting, ongoing partnership between our organisations. We believe a collective, coordinated effort can deliver a step-change in the prevention, measurement, management and treatment of multimorbidity through research. Our funders group aims to overcome the structural and cultural barriers facing multimorbidity research, and support research to better understand the trends, mechanisms and burden of multimorbidity research framework, which was developed in consultation with a number of medical research and disease charities, and aim to take a leading role in adopting its approach.

We are encouraged that much has happened in the last three to four years to deepen understanding and awareness of multimorbidity. The <u>Global Alliance for Chronic Disease</u> <u>issued a researchers' statement</u>, contending that 'a greater focus on multimorbidity is overdue and necessary to successfully improve global health outcomes'. The Economic and Social Research Council (ESRC) published '<u>Multiple chronic conditions: an emerging</u> <u>healthcare challenge</u>'. Meanwhile, the Richmond Group of Charities, The Royal College of General Practitioners and Guy's and St Thomas' Charity have formed a Taskforce on Multiple Conditions and published the key report, '<u>Multimorbidity: Understanding the</u> <u>challenge</u>'.

Multimorbidity has been made a research theme at institutes including the NIHR Oxford Biomedical Research Centre (2015) and the East Midlands Applied Research Collaboration (2019). An NIHR-run <u>James Lind Alliance Priority Setting Partnership set</u> <u>priorities for research into safe care for adults with complex needs</u>, such as those who have more than one health condition, in 2019. Findings of key studies have been published, such as the <u>University of Bristol 3D study</u>, and funding has been made available for further new and important initiatives.

A recent £3m joint-funding call from MRC and NIHR, '<u>Multimorbidity in the UK</u> <u>population: understanding disease clustering</u>', has supported projects that will provide new and important insight into our understanding of multimorbidity mechanisms, clustering and trajectories in the UK. A <u>Global Challenges Research Fund (GCRF)</u> <u>multimorbidity seed-funding</u> call, funded by MRC, will make £2.5 million available for research to understand and tackle multimorbidity in low- and middle- income countries (LMICs). Wider funders also have dedicated multimorbidity programmes, including the £1 million <u>Multiple Long Term Conditions 'Challenge Fund'</u> administered by King's College London on behalf of Guy's and St Thomas' Charity.

Efforts to improve data linkage that will support multimorbidity research are underway. Health Data Research UK's (HDR UK) <u>National Multimorbidity Resource project</u> will bring together six datasets of anonymised information on over 10 million people to explore multimorbidity in the UK at a scale never done before. The <u>METADAC</u>, established in 2015, is a multi-agency multi-study data access structure that services several major UK cohort studies. Globally, <u>The Low and Middle Income Longitudinal Population Study</u> <u>Directory</u> (LMIC LPS Directory) enhances opportunities for international and interdisciplinary research collaboration.

Multimorbidity has been the subject of a host of international meetings. The Journal of Internal Medicine Symposium, '<u>Multimorbidity research at the crossroads: developing the</u> <u>evidence for clinical practice and health policy</u>', informed a <u>special issue on</u> <u>multimorbidity</u>. In 2019, the UK Academy of Medical Sciences and Academy of Sciences South Africa (ASSAF) ran a <u>workshop in on improving the prevention and management</u> <u>of multimorbidity in sub-Saharan Africa</u> while the funders group organised a session at the 11th European Congress on Tropical Medicine and International Health on multimorbidity in LMICs. Looking forward, an International Multimorbidity Symposium will be held in Canada in November 2019.

Research has begun to generate recommendations for front-line care. A <u>Royal College of</u> <u>General Practitioners (RCGP) spotlight project</u> explored effective multimorbidity management in 2018-19, while since 2011, the <u>Integrating Mental & Physical healthcare:</u> <u>Research, Training & Services (IMPARTS)</u> project has been working to integrate mental and physical across King's Health Partners.

Multimorbidity is gaining interest, recognition, and a community interested in supporting or conducting multimorbidity research. Such communities are greatly supported by online resources, such as The <u>International Research Community on Multimorbidity</u> and the funders group's webpage, <u>Multimorbidity: helpful resources</u>.

Finally, the Taskforce on Multiple Conditions have shone invaluable light on the patient experience of multimorbidity in the report '*Just one thing after another: Living with multiple conditions*'. This has since been further brought to life through <u>short films</u> and <u>blogs</u> featuring experts by experience.

Many of these excellent and varied activities complement and build upon this framework. We are delighted that multimorbidity is beginning to get the interest and investment it deserves, including as part of government <u>investment into tackling debilitating illnesses</u>. This new initiative will be supported through the <u>UK Research and Innovation (UKRI)-led</u> <u>Strategic Priorities Fund</u> and the NIHR, and will support further research which is urgently required to better understand the growing challenge of multimorbidity. We hope that this framework offers a valuable tool to guide such much-needed further work, support cutting edge-science, and promote a positive research culture to tackle multimorbidity and improve lives worldwide.

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