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Citation for published version:

Stokes, J, Bower, P, Smith, SM, Guthrie, B, Blakeman, T, Valderas, JM & Salisbury, C 2023, 'A primary care research agenda for multiple long-term conditions: A Delphi study', *British Journal of General Practice*.
<https://doi.org/10.3399/BJGP.2023.0163>

Digital Object Identifier (DOI):

[10.3399/BJGP.2023.0163](https://doi.org/10.3399/BJGP.2023.0163)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Publisher's PDF, also known as Version of record

Published In:

British Journal of General Practice

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Accepted Manuscript

British Journal of General Practice

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DOI: <https://doi.org/10.3399/BJGP.2023.0163>

To access the most recent version of this article, please click the DOI URL in the line above.

Received 31 March 2023

Revised 28 October 2023

Accepted 02 November 2023

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When citing this article please include the DOI provided above.

Author Accepted Manuscript

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A primary care research agenda for multiple long-term conditions: a Delphi study

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Abstract (245/250)

Background

Multiple long-term conditions (MLTC, multimorbidity) has been identified as a priority research topic, globally. Research priorities from the perspectives of patients and research funders have been described. Although most care for MLTC is delivered in primary care, the priorities of academic primary care have not been identified.

Aim

To identify and prioritise the academic primary care research agenda for MLTC.

Design and Setting

Three-phase study with primary care MLTC researchers from the UK and other high-income countries.

Method

(i) Open-ended survey question; (ii) face-to-face workshop to elaborate questions with researchers from the UK and Ireland; (iii) and a two-round Delphi consensus survey with international multimorbidity researchers.

Results

Twenty-five primary care researchers responded to the initial open-ended survey and generated 84 potential research questions. In the subsequent workshop discussion (18 participants), this list was reduced to 31 questions. The long list of 31 research questions was included in round one of the Delphi; 27 of the 50 (54%) round one and 24 of the 27 to round two (89%) invitees took part in the Delphi. Ten questions reached final consensus. These focused broadly on addressing complexity of the patient group with (a) development of new models of care for multimorbidity, (b) methods and data development.

Conclusion

These high priority research questions offer funders and researchers a basis upon which to build future grant calls and research plans. Addressing complexity in our research is needed to inform improvements in our systems of care and for prevention.

Keywords

Multimorbidity, chronic conditions, primary health care, models of care

How this fits in

- Research on Multiple Long-Term Conditions (MLTC) has been identified as a priority, globally.
- To date, research and funding has focused on outlining and breaking down the problem of MLTC for the current system, with calls now for applied solutions based predominantly in primary care.
- Primary medical care is responsible for most MLTC care, and this study draws on the expertise of academic primary care researchers to prioritise the applied research agenda for the next decade.
- These priorities offer funders and researchers a basis upon which to build future grant calls and research plans.

(2,500/2,500)

Introduction

Treating patients with multimorbidity (Multiple Long-Term Conditions, MLTC) has been identified as a global research priority.¹ Recent years have seen significant investment by public research funders to examine topics clustering of multiple conditions,^{2,3} a priority setting exercise on MLTC in later life from the patient's perspective,⁴ and support from the third sector.⁵

Much of the current research on MLTC is at the 'basic science' stage, largely dealing with definitional issues, including which conditions should be counted,^{6,7} outlining the problems of having MLTC,⁸⁻¹⁰ and examining how conditions co-occur.^{11,12} Research in high-income countries is also at a different stage to that in low- and middle-income,¹³ since the challenges faced are currently different. The

hope is that better understanding of the current situation might point to (preventable) mechanisms and prioritised treatment groups.

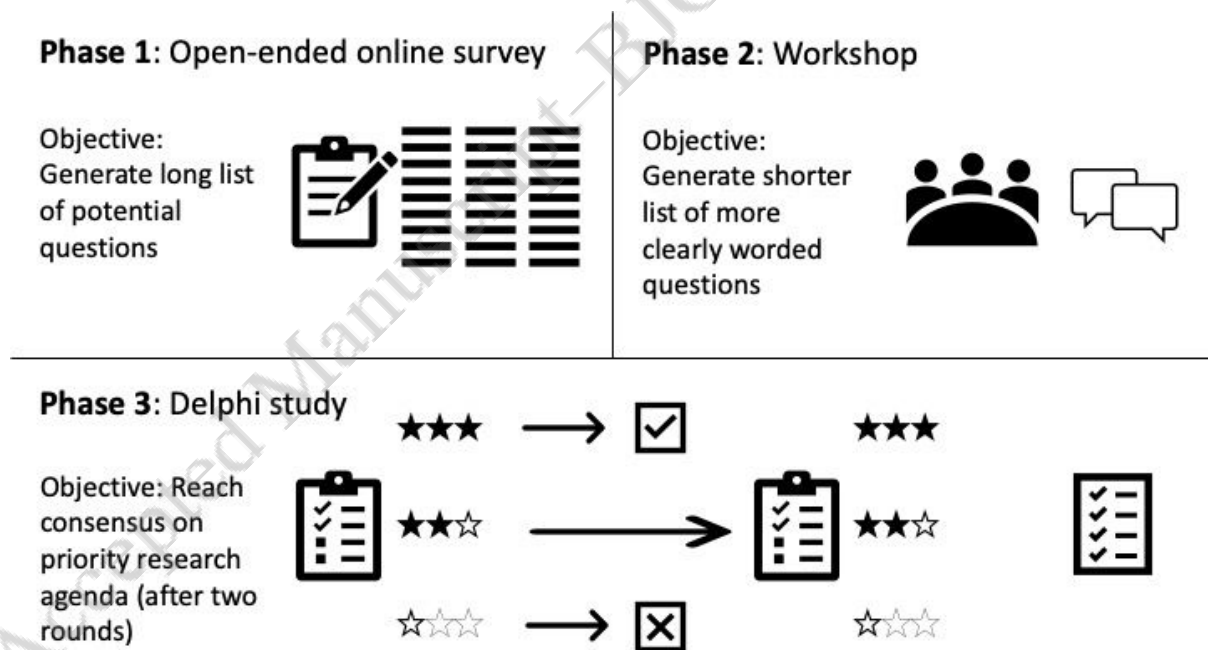
There has been less focus on applied MLTC research, developing and testing new ways of working. The majority of primary care contacts are for patients with MLTC,¹⁴ and this research is of direct relevance to GPs and the wider workforce.^{15,16} As the only generalist discipline in many health systems, it is arguably the most important clinical discipline for this highly heterogenous patient population. The academic primary care perspective, including academic clinicians and primary care researchers,¹⁷ is therefore vital for informing research strategy. This setting is also considered the bedrock of any integrated care across the wider system.¹⁸

Results of interventions trialled in this setting have achieved mixed results to date,¹⁹ and many uncertainties remain. We therefore asked the academic primary care community to provide their priorities for the future MLTC research agenda.

Method

We used a three-phase study (open-ended survey question; face-to-face workshop; and a two-round Delphi study) with academic primary care MLTC researchers from the UK and other high-income countries, as outlined in Figure 1.

Figure 1: Outline of three-phase study design



Open-ended online survey

In early February 2022, we invited each of the nine academic centres that make up England's National Institute for Health and Care Research (NIHR) School for Primary Care Research (SPCR) to

nominate up to three representatives to take part. Those invited already had experience of researching MLTC which improved the efficiency of the input.

Participants were asked to answer the question, “What are the big unanswered questions about MLTC (multimorbidity) in primary care that need to be addressed by the academic research community?”. Responses were not limited in number per participant, but were anonymous except for a final self-report question on institutional affiliation. Participants were also given the option to forward the survey to colleagues who might be interested and in this way experts from other parts of the UK and Ireland joined the process. The initial questions were then grouped into three overarching topic areas by the authors to structure workshop discussions.

Workshop

The workshop was held face-to-face on the 25th April 2022 in Manchester, UK. We invited 31 researchers, 20 (65%) of whom represented NIHR SPCR centres. It was held for 5.5 hours and was structured based on the topic areas identified from the open-ended survey. We began each topic with a short presentation from one of the project team and then aimed to distil or expand the initial list of submitted questions through discussion, ordering and re-wording of printed copies. This shorter list of more clearly worded questions was the basis for the Delphi consensus study. We captured the content of group discussions with notetaking and the resulting prioritisation of the printed questions with any amendments made. JS summarised the discussion notes, checked for accuracy and representation of the discussions by co-authors (PB, TB, and CS).

Delphi study

We followed guidance on conducting and reporting Delphi studies.²⁰ The Delphi panel consisted of the original workshop invitees plus a purposively selected group of other ‘academic primary care researchers conducting MLTC research in high-income country settings’, which were the broad inclusion criteria we applied. We approached researchers known to the authors, searched and screened PubMed for relevant abstracts and their first authors using keywords for MLTC, primary care, and high-income countries, and screened reference lists from selected international systematic reviews (see Appendix).^{21,22} Finally, we posted a call for volunteers through the International Research Community on Multimorbidity blog.²³ In total, we invited 50 participants to the first round of the Delphi survey (n=34, the 31 original workshop invitees plus three additional researchers known to authors; n=5 responses to the blog; n=11 from the literature).

Participants were asked to rate the questions in terms of their priority for the academic research community over the next 5-10 years. Rating was carried out using a Likert scale of 1–9, where 1= a research priority and 9= highest priority for research. Participants were briefed that research areas to be prioritised might involve either qualitative or quantitative methods (or both) in practice. The research areas might also vary from more fundamental to more applied, and more specific research questions to more broadly defined areas of research interest. Regardless, we asked them to rank in terms of their overall priority. Round one also had an option to add any comments on the questions, and a final section to add additional question suggestions.

After round one, participants were sent a summary report showing the status of each question (see Appendix). We calculated consensus given pre-specified criteria. A score of 7-9 indicated endorsement, while a score of 1-3 indicated rejection. Questions which over 70% of participants

endorsed (and less than 20% rejected) were deemed to have reached consensus. Questions less than 40% endorsed, or over 20% rejected, were removed from round two.²⁴ All other questions, plus new suggestions or re-wording after discussion amongst the co-authors, were re-evaluated in a second round. All surveys were conducted using the Qualtrics platform.

We received a letter of ethical exemption from the University of Manchester, since the study focused on asking professionals questions strictly within their professional competence and not of a personal, sensitive, or confidential nature.

Results

Open-ended online survey

From the initial online survey, we received 84 questions from 25 respondents at eight of the NIHR SPCR centres (84% of respondents), plus four other UK and Irish institutions. We initially grouped these into three topics for workshop discussions: 1. Models of care (the largest area, sub-divided into a) 'Service delivery', and b) 'Organisation, back-office, and role of primary care'); 2. Research methods/data; and 3. Outcomes (see Appendix for full list).

Workshop

Eighteen participants attended the workshop (n=14, 78%, from NIHR SPCR centres). Discussion topics included the main differences between research on MLTC rather than single conditions, which participants felt was the complexity and variety of the patients encountered. This means there is less potential for standardisation of care, maybe requiring more flexibility and ownership for GPs and other clinicians to offer 'holistic' care. However, participants also recognised the likely trade-offs and paradigm shift of this type of care, for example perhaps away from more guideline-based care, and potential knock-on effects for other system concerns such as waiting times (see Box 1 for further details of workshop discussions).

Following discussion of the printed research questions, including rankings by small groups within the workshop, an executive group of the authors finalised the wording for 31 research questions for further consideration.

Box 1: Workshop discussions summary

MLTC clusters

In recognition of the tensions between system and patient demands, some kind of stratification, or 'clustering', of patients was generally preferred by participants as a way of prioritising or differentiating care requirements. However, concerns about 'actionable clusters' were paramount, likely taking more of a bio-psycho-social approach than currently prevalent in the MLTC clustering literature, where clusters were felt to be largely observational and with findings dependent on the specific statistical method employed. It was not always obvious how these current clusters could then be employed to inform clinical practice and outcomes. For example, participants discussed potential for including social circumstances and needs rather than conditions alone. Even separating 'risk factors', from 'symptoms', from 'complications', from 'individual conditions' was not considered a straightforward task, either conceptually or using existing data (for example for targeting specific clusters of patients or intervening at an appropriate point in a predicted trajectory). Improving understanding of clinically-relevant clustering might require recording of socio-economic and lifestyle factors which are currently

lacking in many healthcare records, and there was concern about the time and resource available for collecting this data.

Financial and non-financial incentives for managing MLTC

Financial incentives were outlined as key for driving provider behaviour, including data collection, and system changes supporting clinical practice, e.g., extended consultations. Additionally, indicators and standards (e.g., treatment targets and clinical guidelines) recorded at system level were perceived as potentially helping drive system change previously, particularly if led from a national regulatory body. There was therefore speculation whether it was possible to think about which set of indicators might be most useful to monitor and incentivise for MLTC patients.

Primary care as part of management of MLTC across a wider system

The theme of 'complexity' also carried through to discussions of interactions with the wider care system. Researching the role and amount of responsibility primary care should have in ensuring prevention, and how the primary care agenda should fit with other parts of the system, such as community assets, social prescribing, and the interface with secondary care, were also debated, together with the need to ensure continuity across different formal and informal sectors.

Measuring appropriate outcomes for MLTC patients

Similar complexity was also identified in terms of patient outcomes, for example the potential that needs and goals might vary substantially between individual patients. The ability of conventional measures of benefit, such as health-related quality of life, to capture MLTC-relevant outcomes was questioned.

Capturing complexity with appropriate study designs

Optimal study designs were also considered, noting the need for a wider range of comparative study designs than randomised controlled trials (RCTs) that can adequately capture the complexity and variation. Multi-component, 'system of care', interventions with interacting elements, increasing use of observational quasi-experimental studies, 'adaptive platform trials', systems science approaches, and realist methods, were all put forward as potential alternatives to deal with complexity.

Delphi study

Twenty-seven of the 50 invitees responded to the first Delphi survey (54% response rate). Participants included 10 (37%) men and 17 (63%) women from institutions based in the UK (n=20), Ireland (2), Canada (1), Denmark (1), France (1), Singapore (1), and the USA (1), similar characteristics to those invited (see Appendix). Sixteen (59%) represented NIHR SPCR centres. Seven of the 31 survey questions met the criteria for consensus after round one. Four were removed from round two. Twenty questions remained uncertain and re-evaluated (five of these were reworded in response to written feedback). Three additional research questions were suggested by participants and introduced. Twenty-three research questions were therefore evaluated in the second round.

Round two of the survey received responses from 24 of the 27 invitees (89% follow-up rate). Three further questions met the criteria for consensus, making a total of ten (see Table 1). An additional one met the criteria for rejection. Nineteen questions remained uncertain (see Appendix).

The final list of prioritised questions can broadly be grouped into two, questions relating to researching new and adapted (i) models of care, and (ii) methods and data. Those dealing with models of care tended to have a higher proportion of respondents endorsing prioritisation.

Accepted Manuscript—BJGP—BJGP.2023.0163

Table 1: Research questions that reached consensus at the end of the Delphi process

Prioritised unanswered questions about MLTC (multimorbidity) in primary care for the academic research community over the next 5-10 years	Delphi consensus round	% endorsing (% rejecting)	Type of question
1. What skill-mix and training are needed for the primary care workforce to manage MLTC?	2	71% (8%)	Models of care
2. Which aspects of the current primary care model need to be adapted to improve management of MLTC?	1	74% (7%)	Models of care
3. How can we best develop care pathways for people with MLTC that are patient-centred and reduce burden of treatment?	1	81% (0%)	Models of care
4. How can primary care interventions contribute to prevention of disease onset or decline in function or quality of life?	2	79% (8%)	Models of care
5. How can primary care better interact with the wider health and social care system to improve MLTC care?	1	78% (4%)	Models of care
6. What are the barriers to implementation of potentially effective interventions?	1	89% (4%)	Models of care
7. How should MLTC be incorporated into primary care resource allocation models to better reflect the complexity of care and provide adequate resources?	1	78% (4%)	Methods and data
8. How can we improve the quality of data we gather from primary care for a better understanding of MLTC (e.g., disease severity, social factors, biological measures)?	1	74% (19%)	Methods and data
9. How can we make better use of administrative data and quasi-experimental observational studies to improve evaluation of MLTC interventions?	2	71% (8%)	Methods and data
10. What are the best ways of measuring well-being and quality of life for trials of MLTC interventions in primary care?	1	70% (7%)	Methods and data

Discussion

Summary

We conducted a three-phase consensus study with academic primary care experts to identify priorities for MLTC research. Consensus was reached on 10 priority questions relating to development of (a) new models of care for MLTC, (b) methods and data. These largely reflected the core theme of discussion in the workshop - the need to deal with the complexity of this patient group.

For models of care, priorities included both development and evaluation (of new models) and examination of implementation challenges. Priorities also included outcome measurement, such as a focus on experiential outcomes (patient-centred care, and reducing treatment burden), and capturing upstream efforts for reducing negative outcomes (prevention of disease and functional decline or worsening quality of life). They reflected the complex challenge of re-orienting the wider health and care system. They also included, perhaps more immediate, challenges of adapting current models of care and skill-mix and identifying and addressing training needs of the primary care workforce.²⁵

For methods and data, priorities reflected the need for these models to adequately resource (through funding formulas) the complexity of management. There was an identified need for new (or linked) data beyond what is commonly collected within primary care to better capture determinants of outcomes and prevention opportunities. Finally, opportunities to expand use of quasi-experiments and other evaluation methods to explore what is ultimately effective, perhaps requiring new measures of relevant outcomes.

Strengths and limitations

The study used a three-stage approach to identify consensus research priorities of academic primary care. Limitations of the approach, however, include the relatively small sample size and the modest response rate to the Delphi study. Nevertheless, the sample size is generally considered adequate for Delphi studies, where above 12 participants is likely to be subject to diminishing returns in terms of reliability.²⁶ We expected from the outset that the potential pool of researchers with expertise in the area would anyways be small overall. The follow-up rate in round two of the Delphi was high, so the sample was largely consistent between rounds. A limitation is that respondents were UK-centric, because of the funding and geographical location of the face-to-face workshop. Many of the UK participants were also affiliated with the NIHR SPCR, although this influence reduced over the phases (84% of open-ended survey responses, versus 59% and 54% of round one/two Delphi responses). For all participants, researcher funding needs might have influenced responses. Nevertheless, we expanded our sample for the Delphi phase, and the final set of questions generated are likely to be relevant in many or most high-income countries. The final question set, however, does not necessarily represent all important issues in the topic area. There is an argument that creativity is what is needed, and new ideas will not necessarily reach consensus.

Comparison with existing literature

Our findings complement previous MLTC priority setting work, such as the James Lind Alliance (JLA) from the perspective of older patients,⁴ recommendations and research priorities from the Academy

of Medical Sciences (AMS),¹ and the UK's NIHR strategic framework for MLTC.²⁷ We have mapped areas of overlap and difference in the Appendix. Five of ten of our priority questions did not clearly overlap with any of the previous suggestions. Similarities shared across our findings and all these other exercises include a focus on prevention of disease onset (or further decline, our priority number four), and the need for a co-ordinated response to (integrated) care across the whole health and care system (our priority number five). The AMS priorities further overlapped recognising a need for strategies to improve MLTC management (although, not specifically in primary care, our priority number two). The NIHR priorities also overlapped with the need for patient-centred care pathways (our priority number three) and to augment our outcome measures to those most relevant to patients (similar to our priority number ten).

In contrast to our priority findings, the JLA priorities tended to emphasise specific outcome priorities for older patients (such as social isolation, psychological wellbeing, independent living, and risk of falls), and specific intervention areas (such as supporting carers, exercise therapy, and Comprehensive Geriatric Assessment). Arguably, several of these also emphasised a change to organisation of care to deliver the specific outcome/intervention.⁴ The AMS, on the other hand, had three priorities related specifically to clusters of conditions which did not come up in our exercise - trends and patterns (also reflected in the NIHR priorities)²⁷, identifying clusters causing the greatest burden, and their determinants.¹ Academic primary care researchers, particularly in our workshop, raised potential limitations with the clinical relevance and application of cluster studies. For example, it is questionable how clusters might inform any attempt to reduce secondary care costs, where a large number of co-occurring conditions each contribute to a very small fraction for MLTC patients.²⁸

Unlike these previous exercises, academic primary care researchers, understandably, also prioritised several methods and data questions. These addressed complexity and problems in adequately developing, evaluating, and implementing improved models of care, and being able to judge whether 'effectiveness' has been achieved (our priorities six, eight and nine, which did not feature in previous exercises). Additionally, and perhaps reflecting the current pressures on healthcare systems, the specific emphasis on workforce skill-mix and training (our priority one), and resource allocation decisions (our priority seven) to support MLTC care have not featured previously.²⁵ Ensuring these practical aspects receive attention is likely to be important for impact of research funding, policymakers, practitioners, and, ultimately, patient outcomes.

As outlined above, the priorities generated also differ quite substantially from the bulk of funded and published MLTC research to date. This perhaps also reflects the stage of the current MLTC evidence-base, where the main gap is now application to build on the basic research already conducted.

Implications for research and/or practice

These priorities can offer funders and researchers a basis upon which to build future grant calls and research plans. However, as raised in the workshop, the nature of the competitive scientific funding process might create challenges in obtaining support for novel, potentially ground-breaking, research in this area as there might be a real or perceived higher level of risk.²⁹ For example, tensions between allowing clinicians to recruit potentially eligible patients for interventions using the clinical expertise and judgement they apply in routine care, and concerns about selection bias, or risks of using novel methods and data collection. Aligning research funding to the exploration of complexity

might be the next frontier and is likely to require context-specific solutions. Seeking to ignore complexity with traditional research methods which minimise variation in participants, intervention, implementation and outcomes, is no longer an option for improving our systems of care or for disease prevention.³⁰

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Funding

This study is funded by the National Institute for Health and Care Research (NIHR) School for Primary Care Research for a workshop held in Manchester, UK, on 25th April 2022, “Developing an updated agenda for Primary Care research on Multiple Long-Term Conditions (Multimorbidity)”.

The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Susan Smith is supported through HRB Collaborative Doctoral Award in Multimorbidity, grant reference CDA-2013-003.

Jonathan Stokes was additionally supported by an MRC Fellowship, grant reference MR/T027517/1.

Peter Bower and Chris Salisbury are NIHR Senior Investigators.

Ethical approval

The authors received a letter of ethical exemption from the University of Manchester, since the study focused on asking professionals questions strictly within their professional competence and not of a personal, sensitive, or confidential nature.

Data availability

Data is available in the Appendix, with any additional, shareable, data available upon request from the authors.

Competing interests

The authors have all received funding to conduct research on MLTC and are likely to seek further funding on this topic in future. They declare no other competing interests.

Acknowledgements

The authors would like to thank all the participants who contributed to each stage of the research.