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# Service innovations for people with multiple long-term conditions: reflections of a rapid evaluation team

*Jon Sussex, Judith Smith and Frances M Wu*





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# Abstract

## Service innovations for people with multiple long-term conditions: reflections of a rapid evaluation team

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**Background:** People living with multiple long-term conditions represent a significant concern for National Health Service policy and practice, and their care is a major theme in the 2019 National Health Service Long Term Plan. The Birmingham RAND and Cambridge Rapid Evaluation Centre team has undertaken a thematic synthesis of the 10 evaluations it has conducted from 2018 to 2023, exploring the needs, priorities and implications for people with multiple long-term conditions.

**Objectives:** The aims for this overarching study were to: (1) build a body of learning about service innovations in primary and community settings for people of all ages with multiple long-term conditions, focused on questions that matter most to people with multimorbidity; and (2) develop methodological insights about how rapid evaluation can be used to inform the scoping, testing and implementation of service innovations for people with multiple long-term conditions.

**Design:** The focus on multiple long-term conditions came from a Birmingham RAND and Cambridge Rapid Evaluation Centre prioritisation process undertaken in 2018 using James Lind Alliance methods. Cross-analysis of the findings from the 10 individual rapid evaluations was supplemented by (1) building aspects of multimorbidity into the design of later evaluations; (2) interviewing national and regional stakeholders ( $n = 19$ ) working in or alongside integrated care systems; (3) undertaking a rapid review of evidence on remote monitoring for people with multiple long-term conditions (19 papers included); and (4) testing overall insights with organisations representing patients and carers through a patient, public and professional engagement workshop with 10 participants plus members of the research team.

**Results:** While living with multiple long-term conditions is common and is the norm for people over the age of 50 using health and care services, it is not often a focus of health service provision or innovation, nor of research and evaluation activity. We discuss six themes emerging from the totality of the study: (1) our health system is mainly organised around single conditions and not multiple long-term conditions; (2) research calls and studies usually focus on single conditions and associated services; (3) building opportunities for engaged, informed individuals and carers and improved self-management; (4) the importance of measures that matter for patients and carers; (5) barriers to developing and implementing service innovations for people with multiple long-term conditions; and (6) what is needed to make patients with multiple long-term conditions a priority in healthcare planning and delivery.

**Limitations:** Care of people with multiple long-term conditions was not the principal focus of several of the rapid evaluations. While this was a finding in itself, it limited our learning about designing and implementing, as well as methodological approaches to evaluating, service innovations for people with multiple long-term conditions.

**Conclusions:** Through a thematic analysis of the portfolio of evaluations, we have deduced a set of suggested implications for how the needs of people with multiple long-term conditions can be better embedded in policy, research and practice.

## ABSTRACT

**Future work:** Areas of uncertainty related to the care of people with multiple long-term conditions should be further explored, including developing and testing measures of patient experience of (un)co-ordinated care across settings, and interrogating the experience of health and care staff when working with people with multiple long-term conditions, to understand what works.

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# List of supplementary material

**Report Supplementary Material 1** Review of published frameworks and theories for conceptualising services for people with multiple long-term conditions

**Report Supplementary Material 2** Cross-analysis matrix of BRACE evaluations

**Report Supplementary Material 3** Review of published evidence on remote monitoring for people with multiple long-term conditions

**Report Supplementary Material 4** Findings from interviews with stakeholders

Supplementary material can be found on the NIHR Journals Library report page (<https://doi.org/10.3310/PTRU7108>).

Supplementary material has been provided by the authors to support the report and any files provided at submission will have been seen by peer reviewers, but not extensively reviewed. Any supplementary material provided at a later stage in the process may not have been peer reviewed.



## List of abbreviations

A&E	accident and emergency	ORQ	overarching research question
AI	artificial intelligence	PEoLC	palliative and end-of-life care
BRACE	Birmingham RAND and Cambridge Rapid Evaluation Centre	PPI	patient and public involvement
COPD	chronic obstructive pulmonary disease	PROM	patient-reported outcome measure
CQC	Care Quality Commission	QOF	quality and outcomes framework
DHSC	Department of Health and Social Care	SELFIE	Sustainable intEgrated chronic care modeLs for multi-morbidity: delivery, Flnancing and performancE
HSDR	Health and Social Care Delivery Research	WHH	Women's Health Hub
NICE	National Institute for Health and Care Excellence	WHO	World Health Organization
NIHR	National Institute for Health and Care Research		



## Plain language summary

Many people in England live with two or more physical and/or mental health conditions that are expected to last for years. Estimates vary, but it is likely that a majority of National Health Service services are serving people living with two or more long-term conditions. We wanted to find out how well the needs of this group are taken into account when new types of health care are introduced, or existing services are reorganised.

To do this, we went back to all 10 of the health service innovations that had been studied by our Birmingham RAND and Cambridge Evaluation Centre from 2018 to 2023. We did some extra research, including discussions with patient representatives and interviews with National Health Service policy-makers and managers at national and regional levels. We also looked at what new research had been published about one example of a new healthcare technology that is intended to help people who have several long-term health conditions: monitors that can be used by health service staff to measure patients' symptoms when they are in their own home.

Our main finding was that most National Health Service attention is given to organising care for single conditions, often treating them in isolation. Patients' many treatments and needs are not routinely considered all at the same time by healthcare staff, nor by researchers. Care for one condition is too often not co-ordinated with care for other health problems that a patient may have. Although the situation of people living with several long-term health conditions is in principle understood by healthcare staff, managers and researchers, relatively little is done in practice to meet their needs. We conclude by suggesting ways that policy-makers, healthcare staff and researchers could improve how they help people living with multiple long-term conditions.





# Chapter 1 Introduction

This is the report of an overarching study of the National Institute for Health and Care Research (NIHR)-funded Birmingham RAND and Cambridge Rapid Evaluation Centre's (BRACE) portfolio of studies, undertaken to explore the ways in which evaluations of service innovations take account of and impact on people living with multiple long-term conditions. The report is a thematic synopsis of 10 evaluations that have each been published as a standalone research report by the NIHR Journals Library. The 10 evaluations are set out in [Table 1](#) along with the corresponding references where their findings can be read in full.

This report sets out a reflective account of 5 years' learning from scoping, undertaking and disseminating a portfolio of rapid evaluations. The cross-project analysis and reflection were supplemented by a programme of patient, public and professional engagement workshops; a set of interviews with national

**TABLE 1** Source documents for the BRACE evaluations

Evaluations	Source documents
Primary Care Networks – evaluation of early development and implementation <sup>1</sup>	Smith J, Parkinson S, Harshfield A, Sidhu M. Early evidence of the development of primary care networks in England: a rapid evaluation study. <i>Health Soc Care Deliv Res</i> 2022; <b>10</b> (27).
Acute hospitals managing general practice services – Phase 1 <sup>2</sup>	Sidhu M, Pollard J, Sussex J. Vertical integration of GP practices with acute hospitals in England and Wales: rapid evaluation. <i>Health Soc Care Deliv Res</i> 2022; <b>10</b> (17).
Children and Young People's Mental Health Trailblazers <sup>3</sup>	Ellins J, Hocking L, Al-Haboubi M, Newbould J, Fenton S-J, Daniel K, <i>et al.</i> Early evaluation of the Children and Young People's Mental Health Trailblazer programme: a rapid mixed-methods study. <i>Health Soc Care Deliv Res</i> 2023; <b>11</b> (8). <a href="https://doi.org/10.3310/hsdr-tr-130818">https://doi.org/10.3310/hsdr-tr-130818</a>
Telephone-first primary care for people with multiple conditions <sup>4</sup>	Saunders CL, Gkousis E. Impact of telephone triage on access to primary care for people living with multiple long term health conditions: rapid evaluation. <i>Health Soc Care Deliv Res</i> 2022; <b>10</b> (18).
COVID Oximetry at Home main evaluation <sup>5</sup>	Fulop N, Walton H, Crellin N, Georghiou T, Herlitz L, Litchfield I, <i>et al.</i> A rapid mixed methods evaluation of remote home monitoring models during the COVID-19 pandemic in England. <i>Health Soc Care Deliv Res</i> 2023; <b>11</b> (13).
COVID Oximetry at Home in care homes <sup>6</sup>	Sidhu M, Litchfield I, Miller R, Fulop NJ, Janta B, Tanner J-R, <i>et al.</i> Using pulse oximeters in care homes for residents with COVID-19 and other conditions: a rapid mixed-methods evaluation. <i>Health Soc Care Deliv Res</i> 2022; <b>10</b> (35).
Artificial intelligence and social care <sup>7</sup>	Glasby J, Litchfield I, Parkinson S, Hocking L, Tanner D, Roe B, Bousfield J. New and emerging technology for adult social care – the example of home sensors with artificial intelligence (AI) technology. <i>Health Soc Care Deliv Res</i> 2023; <b>11</b> (9):1–64. <a href="https://doi.org/10.3310/HRYW428">https://doi.org/10.3310/HRYW428</a>
Digital-first primary care as experienced by people with multiple conditions and their carers <sup>8</sup>	Newbould J, Hocking L, Sidhu M, Daniel K. Digital first primary care for those with multiple long-term conditions: the views of stakeholders. <i>Health Soc Care Deliv Res</i> 2023 (under review).
Acute hospitals managing general practice services – Phase 2 <sup>9</sup>	Sidhu M, Saunders CL, Davies C, McKenna G, Wu F, Litchfield I, <i>et al.</i> Vertical integration of GP practices with acute hospitals in England: rapid impact evaluation. <i>Health Soc Care Deliv Res</i> 2023; <b>11</b> (17).
Women's reproductive health hubs <sup>10</sup>	Daniel K, Bousfield J, Hocking L, Jackson L, Taylor B. Evaluation of Women's Health Hubs. <i>Health Soc Care Deliv Res</i> 2023 (under review).

## INTRODUCTION

and regional stakeholders working in or alongside integrated care systems; and a rapid evidence review of remote monitoring within the care of people living with multiple long-term conditions. Lessons are drawn from this overarching study about how the needs of people with multiple long-term conditions can be better embedded within practice, policy and research.

The protocol for this study, along with an update to the approach agreed in October 2022 to take account of the English NHS context of new Integrated Care Systems, is available in [www.fundingawards.nihr.ac.uk/award/NIHR134284](http://www.fundingawards.nihr.ac.uk/award/NIHR134284).

## Chapter 2 Background

### The BRACE overarching study

When commissioning two rapid evaluation teams in 2018, the NIHR asked each team to propose a longer-term study to run alongside the programme of rapid evaluation projects. The BRACE team agreed with the NIHR that rather than undertake an additional primary empirical study, we would conduct an overarching synthesis study of our portfolio of evaluations, doing this through the specific lens of people living with multiple long-term conditions. In particular, we explored whether those service innovations in health and social care evaluated by the BRACE team took account of, or were designed with due consideration of the needs of, people with multiple long-term conditions.

The intention was to use an overarching thematic framework deduced from a review of evidence about multiple long-term conditions to undertake detailed and focused synthesis and learning from the BRACE evaluations. We sought to understand what our rapid evaluations of service innovations meant for the specific issues and questions identified by people of all ages living with multiple long-term conditions and needing care and support from health services. This included both prospective exploration in some evaluations of the needs and experiences of people living with multiple long-term conditions, and retrospective study of our full portfolio of rapid evaluations to understand how our work had (or had not) accounted for, or revealed insights into, the implications of service innovations for this population group.

The decision to focus the overarching study on people living with multiple long-term conditions was informed by work undertaken by the BRACE team in discussion with patient and public involvement (PPI) and other stakeholders to identify a set of thematic priorities to underpin the team's work. Service innovations for people of all ages with multiple long-term conditions was the highest-rated topic (of 20 on the longlist) in our initial BRACE prioritisation process undertaken in summer 2018 using James Lind Alliance principles and expert facilitation. More information about this process is set out in [Chapter 3](#).

### Defining and mapping 'multiple long-term conditions'

The terms 'multiple morbidity' and 'multimorbidity' are widely used in academic literature but are sometimes criticised from a PPI perspective as being too much akin to technical jargon. In this report, we generally refer instead to 'living with multiple long-term conditions', although occasionally 'multimorbidity' will occur where that is the term used in the source material being referred to. In this report, we use the terms 'living with multiple long-term conditions' and 'multimorbidity' interchangeably.

The definition of living with multiple long-term conditions is in essence straightforward, but numerous variants exist. Skou *et al.* summarise the range and present several of these.<sup>11</sup> Our focus is on people who live with at least two long-term conditions. This is the group of the population with an enduring need for at least one other condition to be taken into account whenever they are in contact with healthcare services. For the purposes of our overarching study, we start from the National Institute for Health and Care Excellence (NICE) definition of multiple long-term conditions, or multimorbidity, as 'the presence of two or more long-term health conditions', which NICE states as including:

- *defined physical and mental health conditions such as diabetes or schizophrenia*
- *ongoing conditions such as learning disability*
- *symptom complexes such as frailty or chronic pain*
- *sensory impairment such as sight or hearing loss*
- *alcohol and substance misuse.*<sup>12</sup>

The proportion of the population in the UK that is living with multiple long-term conditions is uncertain but large. The Richmond Group of Charities has reported estimates ranging from 15% to 30% of the total population<sup>13</sup> and a more recent study suggests that it could be as much as 53% of adults in the UK.<sup>14</sup> People living with multiple long-term conditions are likely to have a disproportionately high demand for health care; hence at least a large minority, and possibly the majority, of NHS activity is for people living with multiple long-term conditions. Prevalence increases with age, to the extent that there are few over-80s who do not have multiple long-term conditions,<sup>14</sup> but there are large numbers of people in all age groups living with two or more long-term conditions. Progression from single to multiple long-term conditions is much more likely, and happens at a younger age, for individuals from socioeconomically deprived backgrounds than for others, meaning that there are significant inequalities in when people acquire, and how long they have to live with, multiple long-term health conditions.<sup>14,15</sup> People from several ethnic minority groups in the UK are at increased risk of having to live with multiple long-term conditions (after adjusting for age and sex) and adults from sexual and gender minority populations have a greater risk of living with multiple long-term conditions even after adjusting for socioeconomic status and ethnic group.<sup>16,17</sup>

The possible number of combinations of long-term conditions is vast and it is essential not to think of people in this situation as having uniform requirements. However, people with whatever combination of multiple long-term conditions are known to be more intensive users of NHS services and likely to have poorer life expectancy and lower quality of life than other members of the population.<sup>13,18</sup> A systematic review of the lived experience of mental and physical multimorbidity found that 'the phenomenology of multimorbidity is experienced as a complex state that goes beyond counts of conditions and symptom burden and incorporates psycho-social problems played out against a backdrop of uncertainty and constant flux'.<sup>19</sup> The World Health Organization (WHO) describes people with multiple long-term conditions, compared to other members of the population, as facing:

*more frequent and complex interactions with health care services leading to greater susceptibility to failures of care delivery and coordination; the need for clear communication and patient-centred care due to complex patient needs; demanding self-management regimens and competing priorities; more vulnerability to safety issues ...*<sup>20</sup>

### Multiple long-term conditions in NHS policy and research

Caring for people living with multiple long-term conditions is a high-profile issue in NHS policy and practice. It was a major theme in the NHS Long Term Plan<sup>21</sup> and the Academic Health Science Network, NIHR and NHS England report on priorities for innovation and research.<sup>22</sup> In July 2019, the Academy of Medical Sciences, NIHR, Department of Health and Social Care (DHSC), Medical Research Council and Wellcome Trust jointly declared '[m]ultimorbidity is recognised as an important priority across all our organisations and we all take a special interest in it'.<sup>23</sup> In a similar vein, research by healthcare charities has highlighted the complex issues faced by patients in a health system that is largely organised around single diseases rather than the needs of people living with multiple long-term conditions.<sup>24</sup>

The NIHR, in 'Best Research for Best Health: The Next Chapter', identified 'improving the lives of people with multiple long-term conditions through research' as one of its seven areas of strategic focus.<sup>25</sup> This has been further underlined within the DHSC's updated 'Areas of Research Interest' where the management of multiple long-term conditions forms part of Priority One (early action to prevent poor health outcomes).<sup>26</sup>

Research programmes and funding typically do not yet reflect this desire to embrace the needs of people with multiple long-term conditions, as noted by Lamont *et al.*: 'Research systems have reinforced these distortions, with a focus often on single condition research, typically excluding people with comorbidities as trial participants'.<sup>27</sup>

Much of the interventional research has been explanatory randomised trials, requiring ideal conditions under which to demonstrate a beneficial effect and thereby excluding patients with multiple long-term conditions to control confounding. But there is growing recognition of the need for pragmatic designs in 'real-world' settings to inform organisational decision-making.<sup>28</sup>

## Aims, objectives and research questions of the BRACE overarching study

Following a structured and collaborative process of prioritising topics for evaluation (see [Methods](#)), the BRACE team concluded that living with multiple long-term conditions would be a very relevant and appropriate way of framing, interrogating and synthesising the series of evaluations undertaken over the 5 years of funding for the Centre.

The aims for this overarching study were:

1. to build a coherent body of learning about service innovations in primary and community settings for people of all ages with multiple long-term conditions, focused on those questions that matter most to those living with multiple long-term conditions
2. to develop methodological insights about how rapid evaluation approaches can be used to inform the scoping, testing and implementation of service innovations for people living with multiple long-term conditions.

We sought to do this by connecting the BRACE series of evaluations within the single overarching theme of living with multiple long-term conditions, to distil insights for policy and practice beyond what is possible with discrete rapid evaluation studies.

Specifically, we had these three objectives:

- to build cumulatively into later evaluations what we had learnt from earlier projects about avenues related to multiple long-term conditions identified as requiring further research
- to focus on what is consequential for health and social care services from the existence of multiple long-term conditions within one person, as distinct from caring for an array of patients each living with only one condition
- to propose methodological developments in the practice of rapid evaluation of service innovations for people living with multiple long-term conditions, by comparing and reflecting on our experience across individual studies in the BRACE portfolio.

To fulfil these study aims and achieve the project objectives, we determined a set of six overarching research questions (ORQs) for this study:

ORQ1: Do people living with multiple long-term conditions and their carers have specific health and care requirements, including for service co-ordination, that people with single conditions, and their carers, either have to a lesser degree or not at all?

ORQ2: To what extent and how are these requirements met by commissioning and provision of health and care services? Who takes overall responsibility for the totality of care and support?

ORQ3: How effectively and cost-effectively are these requirements being met?

ORQ4: To what extent are people with multiple long-term conditions being supported to design, co-ordinate and manage their own care?

ORQ5: How do services aimed at people with multiple long-term conditions affect inequalities in access to care and inequalities in health, and how are these services' impacts affected by inequalities (of all kinds)?

ORQ6: What can we learn from synthesis of a set of rapid evaluation studies about the health service delivery and organisational outcome measures that are important to people living with multiple long-term conditions and their carers?

The BRACE portfolio of evaluations is set out in [Table 1](#).

We developed a typology of these evaluation projects to inform how to use them for analyses of multiple long-term conditions, along with a thematic approach that drew on two major studies of multiple long-term conditions in health services (see [Table 2](#)).

The methods we used in the overarching study are set out in the next section of this report, followed by descriptions of the thematic framework adopted, the typology of evaluations, and how these were used to undertake the cross-project analysis and develop insights and implications related to service innovations for people living with multiple long-term conditions.

## Chapter 3 Methods for the overarching study

This overarching study was necessarily dynamic in nature as our BRACE team portfolio of evaluations took shape over 5 years. This is reflected in our account here of the research methods used by the team to interrogate, inform and synthesise the portfolio of studies. The methods are set out in five phases that reflect the evolution of the study over time:

Phase 1: development and scoping of overarching study

Phase 2: initial work on cross-cutting themes

Phase 3: cross-analysis of data from individual evaluations and identifying knowledge gaps

Phase 4: targeted research to fill knowledge gaps

Phase 5: overall analysis and synthesis.

Discussions among the research team, reflecting on findings to date and planning subsequent steps in the light of them, were an important element of all five phases.

### Phase 1: development and scoping of overarching study

The initial driver for this study to focus on multiple long-term conditions was a prioritisation process undertaken by the BRACE team in 2018 using James Lind Alliance priority setting principles and methods to determine a longlist and then a shortlist of five candidate topics for evaluation. This process was guided and facilitated by our James Lind Alliance co-applicant in the BRACE team (Katherine Cowan) and commenced with an e-mail – sent to all BRACE Steering Group and Health and Care Panel members – asking for topic suggestions. The BRACE Health and Care Panel has over 40 members including patients and the public, system leaders, managers, clinicians and other practitioners, voluntary sector organisations, and health service researchers. Over 100 suggestions were received and reviewed using a Delphi process.<sup>29</sup> A final shortlist of 20 topics was brought to a one-day Prioritisation Workshop in July 2018, chaired by Katherine Cowan and attended by 25 members of the Health and Care Panel including PPI representatives, health and social care professionals and managers, health services researchers, and people working for national healthcare representative organisations. Working first in small groups and then in plenary, attendees participated in three rounds of facilitated discussion and prioritisation. The workshop culminated in a prioritised list of topics, as shown in [Box 1](#), with BRACE committing to taking the top five topics forwards into discussions with the NIHR Health and Social Care Delivery Research (HSDR) Programme.

#### BOX 1 BRACE Panel's top 20 priority topics for rapid evaluation

##### The 20 topics in order of priority

1. Redesigning services around people with multiple morbidities
2. Use of technology to support health, well-being and chronic disease management
3. Supporting people to self-manage and live well
4. Supporting fair access to health care for underserved groups
5. Innovative services for children and young people with mental health problems
6. Tackling loneliness and isolation among older people
7. Patient involvement in service design, improvement and evaluation
8. Transfers of care
9. Personalised care
10. Workforce redesign
11. Managing demand in acute hospitals, particularly for accident and emergency (A&E) services
12. Redesigning care for people in older age with frailty and/or complex health needs
13. Community-based prevention activities
14. Improving access to psychological therapies for people with long-term conditions



15. Innovations in palliative and end-of-life care (PEoLC)
16. Multidisciplinary teams/multiagency working for groups with complex health needs
17. Electronic health records
18. Delivering care closer to home
19. Outcomes-based commissioning
20. Getting it Right the First Time Programme

It is of note that in addition to the number one priority topic, several others reflect dimensions of the health and care needs of people with multiple long-term conditions, including the use of technology to support chronic disease management, supporting people to self-manage and live well, and patient involvement in service design and innovation. This confirms one of the overriding insights from this overarching study, namely that living with long-term conditions is what very many people do, including more than three-quarters of adults in England aged over 60,<sup>14</sup> and hence this emerges swiftly as a key priority for both user and professional stakeholders.

Following discussion with the HSDR Programme Director and secretariat, it was agreed that the needs of people with multiple long-term conditions should form the focus of the BRACE overarching study.

The BRACE team next undertook a literature review to identify and explore existing frameworks and theories for conceptualising services for people of all ages who are living with multiple long-term conditions. The review of frameworks and theories searched the Health Management Information Consortium via Ovid up to July 2019 (<https://ospguides.ovid.com/OSPguides/hmicdb.htm>). The search on frameworks yielded 78 results. The review was written up in an internal BRACE working paper (see [Report Supplementary Material 1](#)) and was used as the basis for the BRACE team to hold a project workshop in October 2019 to determine which frameworks and theories would be most appropriate to inform the overarching analysis of our portfolio of evaluations. The selected frameworks – House of Care<sup>30</sup> and SELFIE (Sustainable intEgrated chronic care modeLS for multimorbidity: delivery, Financing and performance)<sup>31</sup> – are described in [Chapter 4](#).

A full protocol was developed for the overarching study in November 2019–January 2020, working in close partnership with our PPI Panel, Steering Group and the full BRACE research team. The protocol was revised in Autumn 2020 in response to NIHR HSDR feedback. The scoping of the overarching study, development of research questions and writing of the protocol was led by three members of the BRACE team, including the Centre director and RAND/Cambridge BRACE lead.

## Phase 2: initial work on cross-cutting themes

Building on the initial prioritisation work and literature review of frameworks and theories for studying multiple long-term conditions, we undertook the following activities:

- *Initial thematic analysis of BRACE evaluations in 2021.* Informed by team workshops and our PPI activity, we examined project data from the BRACE evaluations that were completed or in progress at that point, and identified four initial themes of potential interest, which we followed up on in interviews with key informants (e.g. academics outside BRACE who work on rurality and health care). The themes we decided to explore at this initial stage were:
  - rurality and its impact on experiences of people living with multiple long-term conditions;
  - workforce models and the ways in which these are adapted (or not) to meet the needs of people with multiple long-term conditions;
  - the role of new care models and
  - approaches to information-sharing within and between organisations providing services to people with multiple long-term conditions.



The picture that began to emerge at this stage was of apparently widespread awareness in the NHS and research communities of multiple long-term conditions as an important issue for health care, but few examples of this being reflected in services currently provided, or in service innovations being researched.

- *Work with our PPI co-applicant National Voices.* We interviewed the Chief Executive of National Voices and met with approximately 20 members of the Heads of Policy group of National Voices' member organisations at a workshop in April 2021. Those organisations represent health service users and carers. We tested our emerging insights from initial work for the overarching study and explored these questions:
  - What do people with multiple long-term conditions most need as we recover from the COVID-19 pandemic?
  - Are any of the cross-cutting themes in this study (e.g. rurality, workforce models, care models, information sharing) especially important for understanding the experience or delivery of care for people with multiple long-term conditions?
  - Are there particular service issues faced by people with multiple long-term conditions from rural areas?
  - From the perspective of people with multiple long-term conditions, are there any concerns about how changes in the healthcare workforce might affect their experience of care?

The National Voices Heads of Policy workshop revealed an overriding concern for better co-ordination between different parts of health services when presented with patients with multiple long-term conditions. This was a general concern and not specific to rurality, or workforce changes, or particular care models or approaches to information sharing. The lack of co-ordination was described as particularly stark for people with both mental and physical health conditions – they reported little co-ordination between mental health services and other health services.

- *Building aspects of multiple long-term conditions into the design of individual evaluations.* Members of the research team for the overarching study on multiple long-term conditions worked closely with the principal investigator and team of each BRACE evaluation. For example, this resulted in Phase 2 of the hospitals managing general practices evaluation<sup>9</sup> focusing on the impact of this service model on people living with multiple long-term conditions. In a similar vein, the evaluation of the impact of telephone-first general practice<sup>4</sup> assessed the extent of any inequalities in access for people living with multiple long-term conditions, and this study of digital-first primary care<sup>8</sup> examined the experience of health professionals in providing care for people with multiple long-term conditions. The BRACE overarching study team provided input to the design of research tools for these studies, as they did to others where the focus on multiple long-term conditions was less explicit.

### Phase 3: cross-analysis of data from individual evaluations and identifying knowledge gaps

In team discussions, the researchers reflected on what had been learnt in Phase 2 and agreed that it indicated a need to focus the remainder of the overarching study on understanding the apparent divergence between seemingly widespread awareness of, but rather less attention to addressing, the particular needs of patients living with multiple long-term conditions. The next phase of activity entailed cross-analysis of the data amassed through individual BRACE evaluations, using this to develop a set of three further questions to inform the final analysis and synthesis of the evaluation portfolio. Thus, Phase 3 was:

- *Synthesis of findings from the final reports of 10 BRACE rapid evaluations,* to determine what they revealed collectively about how service innovations work (or not) for people with multiple long-term conditions. We used the House of Care model<sup>30</sup> and the SELFIE framework<sup>31</sup> to underpin and

structure the synthesis of findings. Our approach took a cross-case analysis approach, starting from the research questions in the protocol. The findings from the first seven completed evaluations were analysed in July–August 2022 and from the remaining three evaluations in January 2023.

Synthesis was undertaken through desk research, with two researchers reviewing all outputs from evaluations and bringing them together in a first draft of a matrix (which ultimately developed into the version provided in [Report Supplementary Material 2](#)), summarising what evidence can be drawn from each evaluation in relation to the overarching study research question. The research team discussed and agreed the draft matrix. A synthesis workshop was then held in August 2022 with eight members of the wider BRACE research team, including at least one researcher from the research team of each of the seven evaluations that were then complete, to discuss and revise the matrix and identify themes emerging from the cross-case analysis. One of the two researchers who had conducted the initial review of evaluation outputs then, in January 2023, reviewed the outputs from the final three BRACE evaluations, added them to the cross-analysis matrix, and discussed them with researchers from those three evaluation teams. The resulting complete matrix was then reviewed by the other members of the research team for the overarching study.

We concluded following the synthesis workshop in August 2022 that, referring to the SELFIE framework (Leijten *et al.*),<sup>31</sup> our evidence was most plentiful with respect to the dimension ‘service delivery’ (most notably in the studies of hospitals managing general practice,<sup>9</sup> Primary Care Networks,<sup>1</sup> digital-first primary care<sup>8</sup> and telephone-first general practice<sup>4</sup>) and to the dimension ‘technologies and medical products’ [which was prominent in the BRACE evaluations of pulse oximetry<sup>6</sup> and artificial intelligence (AI) technology in social care<sup>7</sup>]. With reference to the House of Care framework,<sup>30</sup> BRACE evaluations had predominantly concerned the ‘organisational and supporting processes’ aspect.

#### Phase 4: targeted research to fill knowledge gaps

In view of this emerging overall picture, and following discussion with the HSDR secretariat in October 2022, we developed in a research team meeting the following questions and methods to fill knowledge gaps identified by the overarching study team and to guide the remaining phase of this study:

- *What might good remote monitoring for people with multiple long-term conditions look like?* The BRACE evaluations of oximetry at home<sup>6</sup> and AI in social care<sup>7</sup> had both touched on the role of remote monitoring outside healthcare settings but found little specifically about people with multiple long-term conditions. Telecare technologies such as those are, however, potentially highly relevant to people living with multiple long-term conditions. By focusing on one specific type of service (remote monitoring), we sought to explore what evidence already exists of whether and how people with multiple long-term conditions have needs or wishes (for remote monitoring) that differ from those of other people; the outcomes; and how far such different needs are being met.

*Method: A focused, rapid review of published evidence on remote monitoring for people with multiple long-term conditions (October–November 2022), followed by a research team workshop with PPI input to reflect on that evidence (December 2022).*

- *To what extent does it appear that the needs of people with multiple long-term conditions are driving the approach to integration being taken by Integrated Care Systems and the organisations within them?* We had found from BRACE evaluations of Primary Care Networks<sup>1</sup> and vertical integration of hospitals and general practices<sup>9</sup> that the needs of people with multiple long-term conditions had not had much of a driving role in the places we studied. With Integrated Care Boards taking over local commissioning responsibilities in the NHS in England after 1 July 2022 alongside Integrated Care Systems, we decided to return to some previous interviewees to seek their views on whether this recent organisational change might be expected to affect how they could meet the needs of serving people with multiple long-term conditions in driving efforts towards integration.

*Method: Interviews with stakeholders at local and regional level in Integrated Care Systems covering those local areas where BRACE evaluations have been undertaken (late October to mid-December 2022).*

- *What might a system of service innovation that prioritised people with multiple long-term conditions look like, and how could this be achieved?* Cross-analysis of BRACE evaluations in 2022 revealed little evidence of the service innovations concerned having prioritised people with multiple long-term conditions. Interviews with a sample of national and regional stakeholders were planned to seek insights into how a system of service innovation that does prioritise people with multiple long-term conditions would differ from the current approach.

*Method: Interviews with stakeholders at national level with policy-makers, innovation/research funders and organisations representing service providers (December 2022–January 2023).*

For the rapid review, a search strategy was developed by the study team and searches were conducted in Scope and PubMed. Both searches targeted English-language papers published from 1 January 2017 onwards and were conducted on 4 and 5 October 2022, respectively. The search was limited to the UK, European Economic Area (EEA) countries, Switzerland, Australia, Canada, New Zealand and the USA. The search process found 1411 papers in total. A pilot screening was conducted where 30 articles were dual-screened for eligibility based on title and abstract, after which the inclusion and exclusion criteria were further refined (see [Report Supplementary Material 3, Table 3.3](#)). A total of 17 papers met the inclusion criteria at screening, with a further two identified via snowballing in the citations of included papers during the extraction stage, resulting in a total of 19 papers – 2 reviews and 17 primary studies – included in the review. The 19 papers were extracted by a single reviewer using a template, which was analysed by the research team to identify main themes using narrative analysis.

For the interviews, a semistructured interview guide was developed and covered the topic of service innovations for people with multiple long-term conditions, with specific questions related to local Integrated Care System work, along with questions about identification of good practice, integration with mental health, and barriers to better meeting the needs of people with multiple long-term conditions.

The sampling approach consisted of both convenience and snowball sampling. An initial list of potential participants was general by the research team ( $n = 21$ ). Participants were also asked during recruitment and interviews to identify additional individuals that the research team should approach. A total of 18 interviews (with 19 individuals) were carried out over the period November 2022–January 2023 by three researchers. Participants held senior positions within Integrated Care Systems or Integrated Care Boards, acute trusts, Primary Care Networks and other provider organisations. We also interviewed academics and individuals with a policy-oriented background working for or representing coalitions of health and care charities (see [Report Supplementary Material 4, Table 4.1](#) for the roles of the interviewees).

The interview approach received ethical approval from the University of Birmingham Arts and Humanities Research Ethics Committee. Interviews were held online via videoconferencing software (Microsoft Teams®, Microsoft Corporation, Redmond, WA, USA) and were recorded using the built-in recording and transcription software. All individuals who agreed to participate were given a participant information sheet, had an opportunity to ask questions, and were asked to review and sign the consent form. All but two interviews were recorded using the recording and transcription software within Microsoft Teams, and these were used to summarise responses to questions in the interview topic guide for each participant. For the two interviews that were not recorded (due to failure of the technology), the interviewer took extensive notes during the interview and used those to summarise in line with the other interviews. The summaries of responses under each question were collated and analysed across both national and subnational levels and key themes were distilled into a working paper.

## **Phase 5: overall analysis and synthesis**

The research team held two internal synthesis workshops (in January and February 2023) to consider together the findings of the evidence review on remote monitoring, the thematic analysis of national and regional stakeholder interviews, and the cross-project analysis. This led to the collective drafting of a framework for this report.

On 6 March 2023, a 90-minute, online workshop was held to sense-check the implications for policy, research and practice developed by the study team and explored in this report. The 10 workshop participants included representation from academia, an NHS Academic Health Science Network, a general practice super-partnership, NICE, NHS England, health/social care charities and two individuals with lived experience. During the workshop we shared the emerging themes from the synthesis of our work to date and sought discussion and input about the implications for our work for practice, policy and research.

In the next section of this synopsis report, we explain how we framed the overarching study of service innovations for people with multiple long-term conditions and how the portfolio of BRACE evaluations was interrogated for this purpose. Later sections set out our findings, organised according to the six themes identified, followed by implications for practice, policy and research.

# Chapter 4 Our framing of multiple long-term conditions and analysis of the portfolio of evaluations

## Frameworks for evaluating service innovations for people with multiple long-term conditions

Given the high proportion of people in the population who live with multiple long-term conditions, it is likely that any healthcare service innovation will have some effect on that group. The essence of this overarching study can be thought of as always asking the question whether and how providing effective and efficient care for a person with two or more long-term conditions might differ from providing care for people each living with just one of those conditions. This difference is where the significance of multimorbidity lies for patients, healthcare professionals, NHS providers and commissioners, and policy-makers.

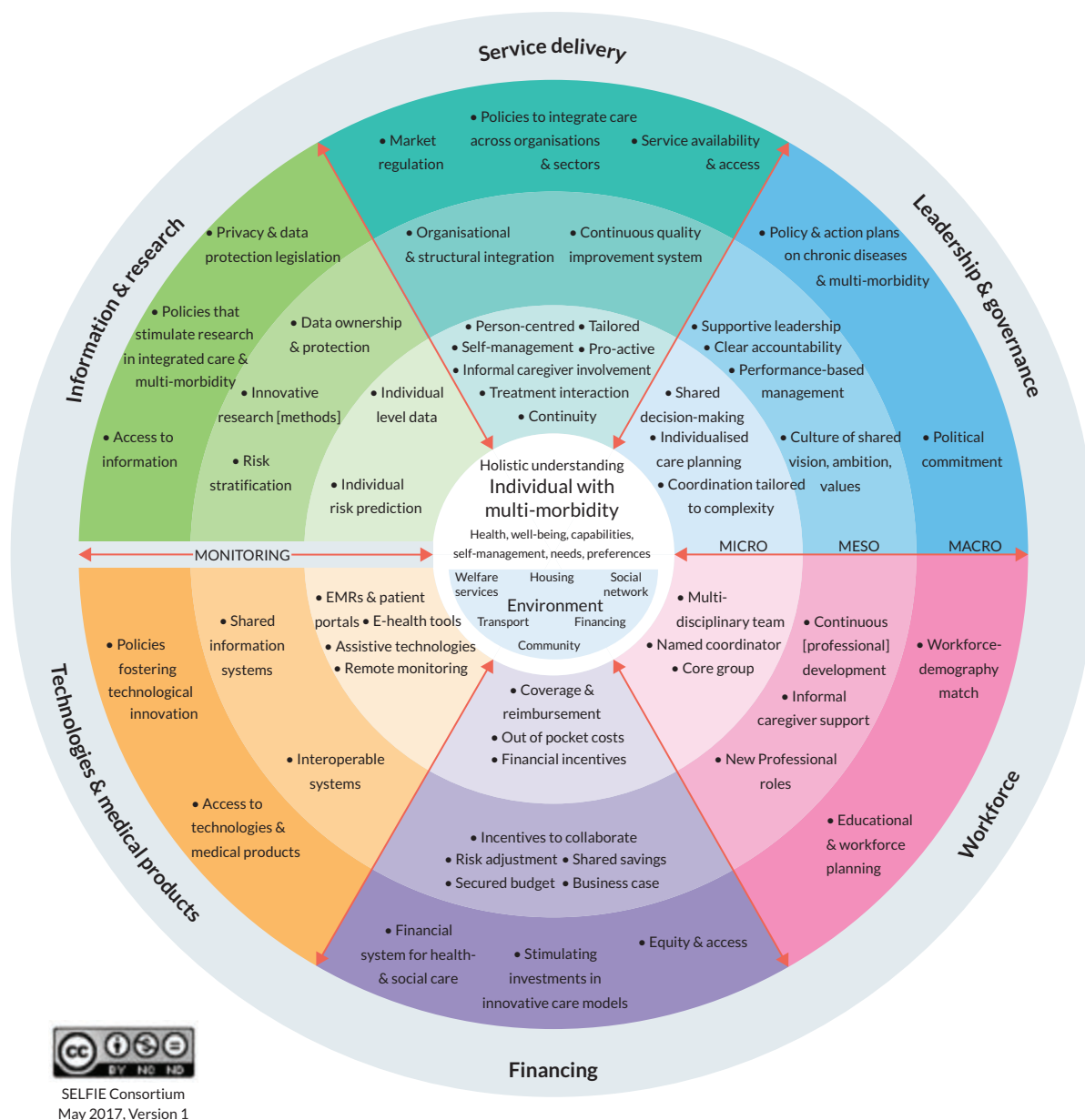
The high degree of specialisation in health care exists for good reasons, including the ways in which medical practice has evolved over time to consist of many specialties that are reflected in training, professional practice and identity, and the broader organisation of health services.<sup>32</sup> Patients want to be treated by healthcare professionals who are experts in the specific relevant fields of medicine or surgery. But focusing on single diseases risks missing the combined impact they have on an individual living with multiple conditions and often overlooks the need for co-ordination of a patient's care. A patient quoted from a consultation with the Patient and Carer Network of the Royal College of Physicians<sup>33</sup> captured the point succinctly:

*Patients want to see a specialist in the bit of you that is going wrong but what would be welcomed would be seeing a doctor who sees a patient as a whole person.*<sup>33</sup>

As noted earlier a member of our research team (AN) undertook a review of the literature to identify frameworks to help to structure thinking about evaluating health and care services for people with multiple long-term conditions. We found two frameworks to be particularly helpful: the SELFIE framework<sup>31</sup> and the House of Care Model.<sup>30</sup> There are numerous other frameworks and models that offer additional insights (see [Report Supplementary Material 1](#)).

### The SELFIE framework

The SELFIE framework was originally created to support the development, description, implementation and evaluation of integrated care for people with multiple long-term conditions. The patient and their environment are at the core of the framework and concepts of integrated care for people with multimorbidity are described at the micro, meso and macro levels respectively on the basis of six WHO components: service delivery, leadership and governance, workforce, financing, technologies and medical products, and information and research ([Figure 1](#)).<sup>31</sup> The SELFIE framework is comprehensive, and we note that the 50 individual elements identified within it could just as well be used to characterise integrated care for single morbidities.



**FIGURE 1** The SELFIE framework for integrated care of people with multiple long-term conditions. Reproduced from Leijten *et al.*, 2018.<sup>31</sup> This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution Non-Commercial No Derivatives (CC BY-NC-ND 4.0) license, which permits others to distribute this work provided the original work is properly cited, the use is non-commercial, and it is not remixed, transformed or built upon. See <https://creativecommons.org/licenses/by-nd-nc/1.0/>.

### The House of Care Model

The House of Care Model<sup>30</sup> provides a simplified framework, which helpfully complements SELFIE, having been developed to structure thinking about services for people with long-term conditions, explicitly including those with multiple long-term conditions. The House of Care Model focuses on achieving personalised, holistic care for each patient and comprises four main elements that form the ‘walls, floor and roof’ of the House of Care within which personalised care planning can be achieved: healthcare professionals committed to partnership working; engaged, informed patients, to which we would add their informal or formal carers; organisational processes; and responsive commissioning of health services.<sup>30</sup> The House of Care metaphor is used to emphasise that a whole-system approach is required, recognising the interdependency of each part and the various components that need to be in place to hold it together.



We refer to both the SELFIE and House of Care Model frameworks when discussing our research and its findings in the rest of this report.

## The BRACE portfolio of evaluations

Our core research material for addressing the ORQs for this study is the findings of the 10 individual rapid evaluations undertaken by the BRACE during the 5 years from April 2018 to March 2023. The 10 evaluations undertaken by the BRACE team are set out in [Table 1](#) in the Introduction, along with the corresponding references where their findings can be read in full.

In the event, none of the BRACE evaluations was suitable to address the sixth research question ORQ6 (see [Chapter 2, Aims, objectives and research questions of the BRACE overarching study](#)), that is about outcome measures specifically. This reflects the fact that none of the service innovations we evaluated had been designed with people with multiple long-term conditions as a particular target group in the population for whom the innovation was intended. All the innovations evaluated would affect people with multiple long-term conditions as well as other service users. Nevertheless, considering the first research question ORQ1 (see [Chapter 2, Aims, objectives and research questions of the BRACE overarching study](#)) about the health and care requirements of people with multiple long-term conditions also has implications for the types of outcome measures that might be most important to people living with multiple long-term conditions.

## Developing a typology of BRACE evaluations

Some BRACE evaluations were not directly concerned with the impact of service innovations on people with multiple long-term conditions, but others were. We therefore conceptualised our BRACE studies as being of two main types, as illustrated in [Table 2](#):

- *Type 1* evaluations are those in which people with multiple long-term conditions are not the main focus of the service innovation being evaluated, but their perspective is one lens through which to view and assess the innovation. For example, BRACE undertook an initial rapid evaluation of acute hospitals managing general practice services, which is a form of vertical integration.<sup>2,34</sup> The initial evaluation<sup>2</sup> focused on why and how such vertical integration was being implemented across three

**TABLE 2** BRACE evaluations and typology from the perspective of care for people with multiple long-term conditions

<b>Type 1 Care of people with multiple long-term conditions is one factor in the evaluation project but not the principal focus of the initial evaluation</b>		
<b>1A. Multiple long-term conditions may be one aspect among several but not the focus</b>	<b>1B. Prompted by findings from the initial study, a follow-up includes a focus on multiple long-term conditions</b>	<b>Type 2 Care of people with multiple long-term conditions is the principal focus of the evaluation from the outset</b>
Primary Care Networks – evaluation of early development Vertical integration of acute hospitals with GP practices – Phase 1 Children and Young People’s Mental Health Trailblazers COVID Oximetry at Home main evaluation COVID Oximetry at Home in care homes AI and social care Women’s reproductive health hubs	Vertical integration of acute hospitals with GP practices – Phase 2	Telephone-first primary care for people with multiple conditions Digital-first primary care as experienced by people with multiple conditions and their carers

case study sites; how services were affected; and the impact on primary and secondary healthcare workforces. Better care co-ordination, pathway redesign and sharing of patient data were all opportunities that have been linked with vertical integration and are highly relevant to care for people with multiple long-term conditions, but they were not the principal focus of the evaluation. BRACE also undertook a second phase of evaluation<sup>9</sup> of where acute hospitals are managing general practice services, looking at the impact on patients' experience of care and their use of hospital services, which includes a particular focus on whether these are different for patients with multiple long-term conditions compared to others. We characterise this type of follow-up evaluation as a Type 1B rapid evaluation, to distinguish it from the more broadly aimed, initial, rapid evaluation, which we label Type 1A.

- *Type 2* evaluations are individual BRACE studies focused from the outset on care for people with multiple long-term conditions. Examples of such projects were the quantitative evaluation of 'telephone-first' primary care and the experience of this service innovation by people with multiple long-term conditions,<sup>4</sup> and the qualitative evaluation of digital-first primary care for those with multiple long-term conditions.<sup>8</sup>

In the Type 1B evaluation and two Type 2 evaluations we undertook, we included in the respective protocols questions that specifically sought to address whether people with multiple long-term conditions were being affected by the service innovation differently from other service users. Thus, in the Phase 2 evaluation of vertical integration of acute hospitals with GP practices<sup>9</sup> (Type 1B study), our research questions – and hence the evaluation findings – included:

- What impact is vertical integration having on secondary care utilisation (outpatient attendances, A&E attendances, all inpatient admissions, emergency inpatient admissions, inpatient admissions for ambulatory care sensitive conditions, bed days, readmission within 30 days of discharge)? Does this impact differ for people with multiple long-term conditions compared to other patients without long-term conditions, or living with a single condition?
- What impact is vertical integration having on the patient journey regarding access to and overall experience of care? How does the experience differ for people with multiple long-term conditions compared to those living with no or one long-term condition?

In the evaluation of telephone-first primary care,<sup>4</sup> we investigated the following:

- Considering people living with multiple long-term health conditions only, does a telephone triage approach affect how quickly people can see or speak to an appropriate primary care professional?
- What is the size of that effect relative to the effect on people contacting a general practice who do not have multiple long-term health conditions?
- Are there any subgroups of the population with multiple long-term health conditions who are particularly affected (either positively or negatively) in terms of how quickly they see or speak to an appropriate primary care professional, both generally and when a telephone triage approach is used?

In respect of digital-first primary care,<sup>8</sup> we evaluated the following:

- What is the experience of digital-first primary care for health professionals and stakeholders (including academics, policy-makers and primary care providers), both before and during the COVID-19 pandemic?
- What is the impact of digital-first primary care on the nature of consultations for unpaid carers/ patients with multiple long-term conditions, from the perspectives of health professionals and stakeholders, which includes aspects such as the health professional(s) spoken to, timeliness of care and continuity of care?
- What are the advantages or disadvantages of digital-first primary care for patients with multiple long-term conditions, and their unpaid carers, as reported by health professionals and stakeholders?



- What lessons can be learnt from staff and stakeholders, for future service delivery for patients with multiple long-term conditions in primary care? Are there individual groups within the community where there is particular learning for future service provision?

In addition to these focused research questions in three BRACE evaluations, the other seven evaluations provided the opportunity for interviewees consulted in those studies, and documentation reviewed in those studies, to yield information pertinent to the care of people with multiple long-term conditions. Sometimes that happened and sometimes not, but even the latter cases can be revealing of the attention given (or not) within service innovation to the concerns of this (substantial) group of the population. Consequently, in our analysis of the BRACE portfolio of evaluations, we actively noted when mention of people with multiple long-term conditions was absent, as well as when it had occurred.

## Cross-project analysis of the portfolio of BRACE evaluations

As explained in the *Methods* chapter, members of the BRACE research team undertook a cross-analysis in August 2022 of the reports of the seven BRACE evaluations that had then been completed. The cross-analysis was based on the mixed-methods matrix approach described in O’Cathain *et al.*<sup>35</sup> To complete the cross-analysis, the remaining three BRACE evaluations were added in January 2023 by the researcher who had led the first stage (JSu) in discussion with researchers from each of those three studies. To facilitate the cross-project analysis, we used a data extraction table (see [Report Supplementary Material 2](#)) to capture relevant information from each BRACE evaluation. [Table 3](#) maps the data extraction headings to the research questions.

When members of the research team (JSu, BL) extracted evidence under these headings from the final reports of the first seven BRACE evaluations completed and discussed it with members of those evaluations’ respective research teams (at an internal BRACE team analysis workshop in August 2022), it became clear that issues related to people with multiple long-term conditions were seldom raised by stakeholders unless they had been specifically prompted to do so.

The findings of the first six Type 1A evaluations listed in [Table 1](#) [the evaluation of Women’s Health Hubs (WHHs) had not been completed at that time] offered some insights, particularly into how the service innovations in question were or were not meeting the specific health and care requirements of people with multiple long-term conditions, and what some of those requirements might be. Additionally, the telephone-first primary care evaluation<sup>4</sup> (a Type 2 evaluation) had found that all patients had benefited by speedier access to a healthcare professional, and that this improvement was similar regardless of the number of long-term conditions with which a patient was living. The research team was also expecting the ongoing evaluations of digital-first primary care<sup>8</sup> (Type 2) and the Phase 2 study of hospitals managing general practice<sup>9</sup> (Type 1B) to yield findings directly pertinent to care of people with multiple long-term conditions. But it was clear that some additional research focused on aspects of innovation in care for this section of the population would be valuable.

At the August 2022 overarching study workshop, the research team discussed and prioritised options for further research that could complement the work already done and add most value within the remaining time and resources available to the BRACE. Evidence from the BRACE portfolio largely fell within three of the six segments of the SELFIE framework, namely:

- service delivery
- technologies and medical products
- workforce.

**TABLE 3** Data extraction headings for the cross-analysis of the BRACE evaluation portfolio, mapped to the overarching study research questions

Research question	Data extraction heading
<p>ORQ1: Do people living with multimorbidity, and their carers, have specific health and care requirements, including for service co-ordination, that people with single morbidities, and their carers, either have to a lesser degree or not at all?</p> <p>ORQ6: What can we learn from rapid evaluation studies about the health service delivery and organisational outcome measures that are important to people living with multiple long-term conditions and their carers?</p>	<p>Did the research ask about specific health and care requirements for people with multiple long-term conditions? If so, what?</p> <p>Did the research identify specific health and care requirements for people with multiple long-term conditions (or their carers) even if not prompted specifically to do so? If so, what?</p>
<p>ORQ2: To what extent and how are these requirements met by commissioning and provision of health and care services? Who takes overall responsibility for the totality of care and support?</p>	<p>Did the research ask how the innovation could meet, or fail to meet, the specific health and care needs of people with multiple long-term conditions?</p> <p>Whether or not specifically asked for, did the research find evidence about meeting the specific health and care needs of people with multiple long-term conditions? If so, what?</p> <p>Whether or not specifically asked for, did the research find evidence that a method/innovation (dis)advantages people with multiple long-term conditions relative to people with single conditions? If so, how?</p> <p>Did the research ask who takes overall responsibility for the totality of care, or for co-ordination of care?</p> <p>Whether or not specifically asked for, did the research find evidence about who takes overall responsibility for the totality of care, or for co-ordination of care? If so, who?</p>
<p>ORQ3: How effectively and cost-effectively are these requirements being met?</p>	<p>Did the research ask about effectiveness and/or cost-effectiveness related to meeting health and care needs for people with multiple long-term conditions?</p> <p>Whether or not specifically asked for, did the research find evidence about the cost-effectiveness related to meeting health and care needs for people with multiple long-term conditions? If so, what?</p>
<p>ORQ4: To what extent are people with multiple long-term conditions being supported to design, co-ordinate and manage their own care?</p>	<p>Did the research ask about whether and how people with multiple long-term conditions are being supported to design, co-ordinate and manage their own care?</p> <p>Whether or not specifically asked for, did the research find evidence about whether and how people with multiple long-term conditions are being supported to design, co-ordinate and manage their own care? If so, what?</p>
<p>ORQ5: How do services aimed at people with multiple long-term conditions affect inequalities in access to care and inequalities in health, and how are these services' impacts affected by inequalities (of all kinds)?</p>	<p>Did the research ask about inequalities related to services aimed at people with multiple long-term conditions? If so, what?</p> <p>Whether or not specifically asked for, did the research find any evidence related to inequalities in access or outcomes for services aimed at people with multiple long-term conditions? If so, what?</p> <p>Did the research find evidence that services for people with multiple long-term conditions are affected by inequalities? If so, what?</p>

We considered where within those segments a rapid literature review might yield most value and identified remote monitoring of people with multiple long-term conditions as promising: what might good remote monitoring for people with multiple long-term conditions look like? This decision was also informed by the strong policy push from NHS England to adopt remote monitoring more extensively in the NHS post-pandemic, including as part of 'virtual wards'.<sup>36</sup>

The BRACE evaluations of COVID oximetry at home<sup>6</sup> and AI in social care<sup>7</sup> both examined aspects of the role of remote monitoring outside healthcare settings but found little specifically about people with multiple long-term conditions. Telecare technologies such as those are, however, potentially highly relevant to people with multiple long-term conditions. We therefore focused part of our further research on reviewing the published evidence on one specific type of service, namely remote monitoring. This would enable us to see, within the bounds of a limited and rapid additional study:

- what evidence already exists of whether and how people with multiple long-term conditions have needs or wishes (for remote monitoring) that differ from those of other people (ORQ1)
- the outcomes (relevant to remote monitoring) that evidence refers to (ORQ6)
- how far such different needs are being met (ORQ2)
- how effectively (ORQ3), and whether people were being better supported to manage their own care (ORQ4) as a result.

Given the low profile of people with multiple long-term conditions in most of the service innovations BRACE has evaluated, we sought to understand more about how far the needs of those people are driving the approach to integration being taken by NHS Integrated Care Systems and the organisations within them. We re-contacted some interviewees from previous BRACE evaluations to seek their views on this and approached a sample of national-level stakeholders (as explained in the *Methods* chapter) to interview them about what a system of service innovation that does prioritise people with multiple long-term conditions might look like, and how this might be achieved.

The value of the BRACE seeking to have an overarching focus on people with multiple long-term conditions was evidenced in how this increasingly served as a prompt to the individual evaluation teams when scoping a study, being questioned about the focus of the evaluation approach, and which data sources to use to try and gain insights into the experiences of this patient population. We noted that, in most cases, the needs of people with multiple long-term conditions were not presented to the evaluation team by commissioners (local or national) of the studies as being a core concern, despite the active attention accorded to this group in policy circles, as discussed earlier.<sup>8-14</sup>



## Chapter 5 The findings of our overarching study

We commenced the overarching study with no preconceptions as to priority issues concerning services and research in the field of care for people living with multiple long-term conditions. As reflected in the study protocol, we attempt to bring an independent perspective to analyse the data collected during the BRACE portfolio of evaluations over the period 2018–23 and the additional research described in [Chapter 3](#). In the synthesis meetings in January and February 2023, when all parts of the analysis were brought together and discussed, the research team for the overarching study identified the following six main themes as emerging:

1. A healthcare system mainly organised around single conditions
2. Research calls and studies are usually focused on single conditions and associated services
3. Building opportunities for 'engaged, informed individuals and carers' and improved self-management
4. The importance of measures that matter for patients and carers
5. Barriers to developing and implementing service innovations for people with multiple long-term conditions
6. What is needed to make meeting the needs of people with multiple long-term conditions a priority in healthcare planning and delivery.

In this chapter we discuss our findings, and the evidence leading to them, according to each of these themes in turn.

### Theme 1: a healthcare system mainly organised around single conditions

This theme relates to the likelihood – apparent from all parts of the overarching study – that sufficient elements of the SELFIE framework to produce integrated care for people living with multiple long-term conditions will not be present. In the BRACE evaluations and the interviews we conducted for this overarching study, we have not found evidence of whole-system approaches as described in the House of Care model.

#### Health service context

As noted in the [Background](#), it is the norm and not an exception to have more than one long term health condition.<sup>23</sup> This begs an important question as to why living with multiple long-term conditions is so often framed as something special or exceptional that requires particular attention in policy, research and practice. As a respondent to our interviews noted:

*So we need to think of this in terms of mainstream services. I guess most people over 40 will have one condition, so most over 50 or 55 will fall into your categories [the NICE definition of multimorbidity]. So we're not looking about sort of niche or special services. This needs to be how business as usual can adopt and help this patient cohort I think.*

([Report Supplementary Material 4](#) presents the overall findings from the stakeholder interviews.)

The development of the healthcare system in England has followed various critical paths, including from pre-NHS times, when as early as 1920 the Dawson Report<sup>37</sup> set out a blueprint for integrated preventative, primary and secondary health care, recognising the already siloed nature of service provision. Our findings suggest that the ambition in the Dawson Report is arguably still to be achieved, as the historical development of NHS (and many other countries') health services has adapted to reflect the constant expansion in what is technologically possible in terms of treatment and has led to

greater specialisation within the hospital sector; kept primary, mental health and secondary care largely separate; and tended to deal with patients according to a single presenting health condition.<sup>38</sup>

### **Clinical specialism and generalism**

Clinical specialisation is an important and much-needed aspect of our health system. Patients rightly expect to be cared for by specialists when this is necessary, and the help required is deemed to be beyond the scope of primary or secondary generalist care. However, there is increasing evidence that current models of hospital care organised on a disease-specific basis do not serve well the large and rising number of patients with multiple long-term conditions. Hence there are associated calls for a revival of medical generalism.<sup>39</sup> This builds on analysis by the Royal College of Physicians' Future Hospital Commission of 2013,<sup>40</sup> which set out a vision of hospitals where care would be organised to meet the needs of the largest cohort of patients: people with multiple long-term conditions.

The original Royal College of Physicians' proposal<sup>40</sup> was for a medical division led by a chief of medicine who would be responsible for all medical services in a hospital, with care organised so that specialist input and services would come to patients in an acute care hub where they would be stabilised before a co-ordinated acute and community plan of care was put in place. Following a 3-year programme of piloting ideas in the Future Hospital Programme, the Royal College of Physicians set out an updated vision for medical care based on principles for improving future health and care, noting, '[t]he ... vision of improving patient care through enhanced access to specialist medical care closer to home and earlier in hospital pathways was realised in part' (page 9).<sup>41</sup> This would seem to suggest that achieving major change to how the care of people with multiple long-term conditions would be organised within hospitals proved too hard to effect, yet also points to other ways in which the needs of such a patient population might be met, such as via specialist outreach into community locations.

NIHR-funded research by Vaughan *et al.*<sup>39</sup> examined models of medical generalism used in small hospitals from patient, professional and service perspectives. They concluded that while the case-mix of smaller hospitals was dominated by patients whose conditions were amenable to generalist care, there was no evidence to change models of care per se (echoing the conclusions of the Royal College of Physicians' Future Hospital Commission), but rather to better match hospital staff to meet local needs and seek to ensure more collaborative environments.

The siloed and single disease focus of the healthcare system was highlighted by almost all interviewees in this study. This is reflected in, or reflects, the highly specialised organisation of clinician training and careers whereby doctors, nurses and other healthcare professionals are expected to opt for a particular specialism or training pathway at a relatively early stage. This then translates to the ways in which services are organised and patients are treated. Even within the patient group charity sector, organisations are often single-condition specific, although there are some umbrella groups such as National Voices and The Richmond Group that attempt to find commonalities across charities and represent broader patient and carer needs and expectations.

### **When multimorbidity matters**

A recurring theme in interviews for this study, and in our analysis of the BRACE portfolio of evaluations was that long-term conditions are not of themselves a problem until they cause a particular concern for a patient, including when patients seek help to manage and live with the conditions. One interviewee commented: '[F]or most people multimorbidity it's fine as it is. You don't need to do anything different [...] You could have loads of conditions, but actually be managing just fine and you don't need a different approach to care'.

The heterogeneity of people living with multiple long-term conditions, and the combinations and severities of those conditions, was emphasised by interviewees. To make this more tractable when thinking about organising health care, one respondent referred to a pyramid, which recalled the Kaiser

Permanente Triangle of Care<sup>42</sup> whereby the top represents the most severe needs (with or without end-of-life care), the middle tier represents those needing secondary care and/or enhanced primary care support, and the bottom tier represents those managing well with self-care and routine family medicine input. The Triangle of Care drew on Wagner's Chronic Care Model<sup>43</sup> in its use of strong patient self-management as the foundation of effective care, supported by community and acute care diagnostic and clinical support where necessary.

### **What an examination of the BRACE portfolio revealed**

Our cross-analysis of the 10 evaluations within the BRACE portfolio bears witness to how the needs of people with multiple long-term conditions are not typically foregrounded when service innovations are designed and planned for implementation. The topics identified for evaluation by BRACE that could have broken the single-condition-focus mould included the early implementation of Primary Care Networks;<sup>1</sup> hospitals managing general practice;<sup>2,9</sup> the impact of telephone-first (Telefirst) access to general practice;<sup>4</sup> and the use of AI with sensors in home-based social care.<sup>7</sup>

In practice, BRACE rapid evaluation did not find that these service innovations were taking direct account of the needs and priorities of people with multiple long-term conditions. For example, serving patients with multiple long-term conditions did not emerge as a theme in the Primary Care Networks evaluation,<sup>1</sup> albeit these new networks have proactive and better co-ordinated care as a key policy objective. The Primary Care Network structure and resources arguably offer a receptive context for designing services to meet at least some of the specific needs raised by living with multimorbidity, whether at the self-management or the enhanced primary care level. Indeed, some of the interventions planned for and by Primary Care Networks have the potential to improve the care of people with multiple long-term conditions.

In the BRACE second phase evaluation of hospitals managing general practice,<sup>2</sup> the research team for that project specifically looked for differential impacts of this new organisational model on people living with multiple long-term conditions. They found evidence that it might slightly reduce use of emergency hospital care, but this is as much in patients with single or no long-term conditions as in patients living with multiple long-term conditions.<sup>9</sup>

Similarly, in the BRACE study of telephone-first access to general practice,<sup>4</sup> the researchers built in an explicit focus on seeking evidence of inequalities in access related to multiple long-term conditions yet did not find any.<sup>4</sup> They did however identify that differences between general practices in how they organise care appear to affect people's access to appointments, suggesting that in the case of telephone-first innovations it is important for attention to be given first to improving care arrangements in the less well performing practices and then to monitoring carefully for differential impacts on different patient groups.<sup>4</sup>

The BRACE study of AI and sensors for home care<sup>7</sup> found that problems with planning and implementing the technology at a local level meant that it was not yet impacting on anyone's (social) care.<sup>7</sup> This echoed the BRACE studies of hospitals managing general practice, which found that there is a need to keep considering the needs and experiences of people with multiple long-term conditions over the longer term, for early evaluation is likely to be less granular and more likely to reveal more general barriers to progress that affect all users, not specifically those with more complex needs.

### **Bridging the gaps**

In addition to there being a single-disease focus in the healthcare system, service provision is often siloed at the individual patient level. Mutual recognition and communication between specialty teams is too often poor and it is then left with the patient's GP, if not the patient and their family, to fill and bridge the gaps. It was also noted that clinicians need to have knowledge of different referral pathways and services to meet patients' wider needs, together with confidence to talk about areas beyond their own specialism.



An example of how the needs of people with multiple long-term conditions could be better assured within health service provision was highlighted by a PPI participant in the stakeholder workshop we undertook for this study. They proposed that GPs and other healthcare professionals should be willing to discuss more than one condition per appointment, rather than keep to the 'one thing at a time' approach that patients had encountered in primary care, where a holistic and comprehensive approach to care is arguably most expected and needed.<sup>44</sup> Siloed teams often have distinct ways of working (sometimes even within a single organisation), making integration of care at the patient level challenging. In addition, IT infrastructure is often not connected across systems or teams, and especially when crossing healthcare organisations, making sharing patient data and care co-ordination challenging.<sup>45</sup>

### ***The role of funding and incentives***

A further factor that can entrench (or reduce, if used appropriately) siloed working within the health system is funding mechanisms and incentives. Interviewees pointed out that care for people living with multiple long-term conditions is typically not recognised in the way that services are commissioned and incentivised, as funding streams in both secondary and primary care sectors reflect unifocal services and specialties. For instance, in general practice there is a desire to offer a multifocal and holistic approach to care, but funding is made to practices partly on a single condition basis, as in payments for care for specific conditions such as diabetes or hypertension, and with no funding directly to pay for care co-ordination. In addition, general practices are not measured on their ability to offer continuity of care, which research consistently shows to be associated with improved patient outcomes,<sup>46</sup> but instead on the number of patients seen. One interview respondent noted: 'it's [multimorbidity is] not a focus, ... if it was something that we were specifically measured against and harassed against, we'd measure it and we'd do something about it.'

We return to the issue of how best to measure what matters for people living with multiple long-term conditions in Theme 4 later in this report.

A further issue raised in study interviews was a lack of funding to develop and deliver innovations for people with multiple long-term conditions and particularly for sustained resources beyond the pilot stage of a new service development. In most BRACE evaluations, meeting the needs of people living with multiple long-term conditions did not emerge as a theme unless we explicitly sought to raise it. This is very evident from the summary of our cross-project analysis set out in [Report Supplementary Material 2](#).

### ***The nature of service innovations for people with multiple long-term conditions***

In a similar vein, interviewees were for the most part unable to recall any service innovations that were specifically for people with multiple long-term conditions:

*I could honestly say I know of virtually no service innovations for people with multimorbidity, but I do know of lots of service innovations for older people or people in later life which are effectively multimorbidity interventions in groups of people who are expected to benefit more or have more problems.*

Other interviewees described innovations for people with multiple long-term conditions as 'patchy', 'variable and bitty' and 'evolving', with good practice located in pockets but not consistent or widespread. When asked about service innovations for people with multiple long-term conditions, respondents cited a wide variety of examples. But these were often not specific to people with multiple long-term conditions and were rarely connected by respondents to the specific care needs of people with multiple long-term conditions, unless prompted by the interviewer. Innovations mentioned that could be linked to people with multiple long-term conditions are listed in [Table 5](#) in Theme 5 below, alongside the care need(s) they seek to address.



Interestingly, interviewees generally considered relatively simple (but not costless) things like longer appointment times, asking patients if they wanted to see the same clinician as previously, and specific clinics for people experiencing frailty as a result of multiple long-term conditions, as being 'innovative'. One interviewee commented that basic administrative support for care needs to be subject to sustained modernisation and attention, for example, ensuring that records are up to date, avoiding duplication of services and improving data sharing for care co-ordination. This echoes work by the King's Fund that explored the impact of NHS administration on patient care.<sup>47</sup> While not 'exciting' as a service innovation, giving careful attention to improving NHS patient administration holds significant potential to address some of the needs of people with multiple long-term conditions by helping them feel safe, with well-co-ordinated and organised care and clarity about what is to happen next and why.<sup>48</sup> As the King's Fund report notes in its 'key messages':

*For people who live with long-term conditions, use multiple health and care services or who have additional needs, for example, people with a disability, their experience of admin can play a critical role in their overall experience of care.<sup>47</sup>*

## Theme 2: research calls and studies are usually focused on single conditions and associated services

### Context

Health research in many ways mirrors the single-specialty and siloed nature of the healthcare system and how care is organised at the individual level, as explored in the previous section of this report. This is unsurprising as most UK empirical health research is conducted within the NHS, often led by clinician-academics who are trained and work within single specialties or sectors. Even in the more generic area of health services research, academics often have some form of sector or specialty focus to their research interests, following the way in which calls for research are scoped, programmes of study crafted and career reputations built. Where researchers do undertake work that is more generic in nature, it is often on organisational issues such as integrated care, care co-ordination or partnership working, rather than the needs of people living with multiple long-term conditions per se.

The Chief Medical Officer for England, Professor Sir Chris Whitty, along with other senior national medical leaders, wrote in 2020 of the need to shift the paradigm of medical training, practice and research to reflect that, '[t]reating each disease in a patient as if it exists in isolation will lead to less good outcomes and complicate and duplicate interactions with the healthcare system.'<sup>18</sup> He went on to note that:

*Medical science is also disease based. Clinical trials still often exclude people who have more than one condition. Good vertical integration exists from bench to bedside for a single condition or disease, but there is little or no horizontal integration between diseases that often coexist. This will require an intellectual shift and rethinking some elements of our research, training, and practice in virtually every discipline.<sup>18</sup>*

*Reproduced from Whitty et al.<sup>18</sup> This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY-NC 4.0) licence, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial.  
See: <http://creativecommons.org/licenses/by-nc/4.0/>*

The authors of an editorial examining how research funders might respond to the challenges of multimorbidity<sup>27</sup> drew together the overarching health system focus on single specialties with the

need for holistic research that attends to the majority needs of people living with multiple long-term conditions:

*More people now live with several health problems at an earlier age and health inequalities have increased, but most clinical services remain geared towards management of single diseases. Research systems have reinforced these distortions, with a focus often on single condition research, typically excluding people with comorbidities as trial participants.<sup>27</sup>*

It seems from our work for the overarching study reported here that the health research community, much as with the broader healthcare system and its organisation of services, has not yet made significant progress towards achieving the changes recommended in health research policy. Just as the need for better integrated care is frequently highlighted as a central policy priority, so is the need for researchers to attune their intellectual time and energy to the complex overlapping needs of people of all ages living with many different combinations of long-term conditions, rather than exclusively studying treatment or service innovations designed with a single condition or speciality in mind. In both cases – health services delivery and research – it seems the challenges presented by multimorbidity are profound in respect of behavioural and cultural change, meaning that it is easier to keep commissioning and doing research that reflects the status quo of professional specialities and often siloed healthcare organisation and provision.

### **Research policy ambitions**

The overarching strategy of the NIHR ‘Best Research for Best Health: The Next Chapter’<sup>25</sup> has ‘improving the lives of people with long-term conditions’ (page 30) as an area of strategic focus and acknowledges the requirement for action:

*The needs of people living with MLTC are not well served either by clinical services or by science, both of which are organised vertically around single conditions. NIHR is taking steps to address these needs through research, working in partnership with the Academy of Medical Sciences, the MRC, Wellcome and a number of medical research charities, but we know that more needs to be done.<sup>25</sup>*

*Reproduced from NIHR 2021.<sup>25</sup> p. 30 The text above includes minor formatting changes to the original text.*

The NIHR is investing in studies to map and understand trajectories and clusters of long-term conditions using data science and AI and acknowledges the need for more research to understand better the specific needs of people with long-term conditions and their carers, and how to get evidence-based interventions into practice. Other initiatives have included offering additional funding for research teams to extend current studies to accommodate the needs of people with multiple long-term conditions; research calls (including ones that embrace the full suite of NIHR programmes) with an explicit focus on services to meet such needs; resource for innovative methodological approaches that can help examine how care interventions work (or not) for people with multimorbidity; and global health research programmes to learn about the topic from an international perspective.

The NIHR published a strategic framework for multiple long-term conditions research in 2020<sup>49</sup> setting out priorities and ‘a pathway to foster the cultural changes’<sup>25</sup> required. This included commitments to (1) review all funding processes to ensure they actively support multimorbidity-focused applications; (2) ensure that studies do not unjustifiably exclude people with multiple long-term conditions; (3) encourage team science across health, social care and public health research and (4) deliver research that helps the health system to implement changes that are required to meet the needs of people with long-term conditions. That a bespoke strategy for multiple long-term conditions research has been established in the UK is clearly important. How far it is feeding through into research calls, study applications and the work of local health research teams remains to be seen.

### **What an examination of the BRACE portfolio revealed**

Our cross-analysis of 10 BRACE evaluations revealed that the needs of people with multiple long-term conditions were seldom a specific focus of the service innovations we were asked to evaluate (see

[Table 1](#) and [Report Supplementary Material 2](#)). Some innovations evaluated by BRACE may in practice be more advantageous for people with multiple long-term conditions than for other patients. For example, vertical integration of hospital and primary care in one case study was set up following a national Vanguard project aimed at redesigning services for people with multiple long-term conditions, but we found no specific impacts related to the needs of this population within the scope of our two BRACE vertical integration studies.<sup>2,9,34</sup> In the digital-first primary care evaluation, we found the innovation to be disadvantageous for people with multiple long-term conditions because algorithms for accessing care implicitly assumed single condition issues.<sup>8</sup> BRACE's evaluation of Telefirst general practice showed that people with multiple long-term conditions enjoyed speedier access to healthcare professionals as a result of the innovation but so did other patients and to a very similar extent.<sup>4</sup>

The BRACE evaluation of WHHs was not concerned with multiple long-term conditions, but the study revealed parallels between integrating these acute care services designed to meet women's diverse health needs across the life course and integrating care for people with multiple long-term conditions<sup>10</sup> ([Box 2](#)). A survey responded to by 12 WHHs revealed that reproductive health care for women is not well integrated currently, and that a one-stop shop for the patient or a co-ordinated hub-and-spoke arrangement would be valuable to enable multiple issues to be addressed in the same appointment. Eleven of the 12 responding hubs had providing 'holistic' care as an objective (to women, within the scope of women's reproductive health services, in this case).

#### BOX 2 Findings from the BRACE early evaluation of WHHs

##### What is the innovation?

WHHs function to meet women's sexual and reproductive health needs by integrating care (including the provision of both gynaecological services and contraception), enabling women to be seen in the community by practitioners with appropriate skills, usually within primary care (though not necessarily within their own practice).

##### Who were the targeted users?

Any woman in the local area with sexual and reproductive health needs.

##### What did we do?

Online survey of WHH leaders, interviews with regional and national stakeholders, and in-depth evaluation of four WHH sites.

##### What did the evaluation find?

WHHs evaluation findings	Insights for innovations for people with multiple long-term conditions
<p>About half of WHHs (7 of 16) are co-commissioned between local authority and CCG (or equivalent). Creative co-commissioning approaches have begun to address longstanding barriers to providing both contraceptive and gynaecological services, though concerns were raised around the impact of workarounds on the standardisation, scale-up and spread of WHHs.</p> <p>Measurement of hub processes and outcomes varies considerably, presenting challenges in evidencing activity and impact. Accurate and consistent reporting will be important to enable in-depth evaluation and understanding of relative performance and costs of models.</p>	<p>Non-traditional commissioning approaches may benefit people with multiple long-term conditions who require services provided across NHS, community, and voluntary organisations.</p> <p>Considering what are the outcomes that matter for people with multiple long-term conditions and how to measure those outcomes in a way that allows for understanding activity and impact.</p>

WHHs evaluation findings	Insights for innovations for people with multiple long-term conditions
<p>CCG involvement had facilitated hub implementation in some sites. The move to Integrated Care Boards/Integrated Care Systems led to uncertainties related to competing priorities across health and social care and varying population needs. There was a desire for more Integrated Care Board input to navigate commissioning barriers and provide a population health perspective.</p>	<p>Integrated Care Boards have a clear role to play in setting the priorities and groundwork for care across organisations.</p>
<p>Information-sharing issues were a common barrier to both initiation and ongoing operation of WHHs. This was particularly related to lack of interoperability between different IT systems, for example, between GPs within a Primary Care Network and between Networks, and across primary, community and secondary care.</p>	<p>Such information-sharing challenges are similar for people with multiple long-term conditions, whose care spans various healthcare settings, and relate to activities such as prescribing, appointment booking, ordering and processing tests.</p>
<p>Strong and committed leadership were critical to the implementation and success of WHHs. Collaborative clinical and non-clinical leaders working across boundaries, with sufficient workforce capacity and enthusiasm are also important. Some WHH leaders performed their roles with limited or no financial reimbursement; there were other ways in which pilots relied on the goodwill of others, highlighting challenges for sustainability and scale-up.</p>	<p>Additional support beyond passionate and motivated leadership and workforce is needed for feasible and sustained work to improve care for people with multiple long-term conditions.</p>
<p>CCG, Clinical Commissioning Group. Source: Daniel <i>et al.</i>, under review.<sup>10</sup></p>	

These examples from BRACE's portfolio of evaluations point to the significant potential of finding ways in which evaluations of innovations for single service areas or conditions can offer important insights for people with multiple long-term conditions if there is sufficiently consistent and focused attention to this priority issue. Later in this report, we explore how such attention might be better assured within broader health research practice.

### ***Bridging the gaps***

The example of the BRACE WHHs evaluation<sup>10</sup> illustrates how, with focused attention to the needs of people living with multiple long-term conditions, a study of a single service or innovation designed for a specific population group can be mined for insights for the overarching priority of meeting the needs of people living with multiple long-term conditions. In the view of the research team for the overarching study, this seems to require the development of a set of criteria (perhaps in the form of a checklist) to apply to a study to explore implications for people with multiple long-term conditions. We suggest that there might in future be a requirement that all research proposals should explicitly consider the implications for people living with multiple long-term conditions, much as research proposals to NIHR are already required to consider PPI and engagement, and equality, diversity and inclusion. These latter two examples bear witness to the need to make an issue critically important for it to start to form a core part of research priorities, planning and practice.

A further area that appears to us to need attention within research funding would be to find ways in which multiple long-term conditions can be understood, profiled and applied as being about the needs of people across their life course. Hence any application of multiple long-term conditions criteria to research commissioning needs to include projects about children and young people's conditions and services, those of women in pregnancy, people living with disabilities, and those people of working age with perhaps one condition but likely to acquire others within a few years. Explicit attention to younger age groups would generate data and insights that could help services to address age-related issues and inequalities.

On average, people experiencing socioeconomic deprivation are more likely than others to be living with multiple long-term conditions and they start doing so at younger age.<sup>50</sup> This also points to the need for more longitudinal studies of how people can be supported to manage their long-term conditions at

whatever age these emerge, and what innovations might be needed to enable them to expand such self-management into having several conditions. We suggest that more use of large-scale and longitudinal studies – such as Biobank and the ZOE cohort studies – could prove fruitful here, pointing to the need for more use of data sources across different research traditions.

In the interviews, it was pointed out that there is potential for much more secondary analysis of health research trials data, examining aspects of implementation of innovations that may not have been central to the core study. An example was given of an Extended Stroke Rehabilitation Service (EXTRAS) trial led by Helen Rodgers of Oxford,<sup>51</sup> where health economics analysis showed that having sufficient levels of allied health professional-delivered reviews – which included identification of rehabilitation needs, joint goal setting, and action planning – made a significant difference to the health-related quality of life of stroke survivors<sup>52</sup> and led to less use of social care resource longer term. One interviewee commented that these were ‘gold-dust findings but largely ignored as they were secondary analysis’, yet were about what really matters to patients and carers. In our view, this points to the need for more emphasis within research commissioning on implementation studies to understand core features and contextual factors for adoption, and for this to occur across different types/disciplines of research funding programmes.

The issue of having core data to understand the profile and needs of the population living with multiple long-term conditions was cited by several respondents to the study interviews. Some interviewees were unaware of any data collected specifically or routinely about or for people with multiple long-term conditions and others were unsure about what data could be used to show whether a service innovation or more integrated approach to care was benefiting people with multimorbidity.

Across the portfolio of evaluations undertaken by the BRACE, our experience was that routinely collected data, such as the national General Practice Patient Survey and Hospital Episode Statistics, can be used to investigate some differential impacts for people with multiple long-term conditions compared with other patients (e.g. on the use of and satisfaction with some NHS services). The BRACE evaluation of telephone triage<sup>4</sup> is an example ([Box 3](#)).

**BOX 3** Findings from the BRACE evaluation of the impact of telephone triage on access to primary care for people living with multiple long-term health conditions evaluation

#### **What was the innovation?**

Every patient asking to see a general practitioner or other primary care professional calls the general practice and usually speaks to a receptionist first, who records a few details. The patient is then telephoned back by the general practitioner or other primary care professional.

#### **Who were the targeted users?**

Anyone seeking care from their general practitioner.

#### **What did we do?**

Quantitative evaluation using data from the GPPS and the Understanding Society survey. Multimorbidity was measured using counts of self-reported long-term health conditions. For each survey, respondents are asked to identify their long-term conditions. Respondents reporting more than one health condition were considered to be living with multimorbidity. Our analyses considered people with zero, one, two, three or four or more conditions separately to explore differences associated with the increasing burden of long-term health conditions.

**What did we find?****Evaluation findings**

Although there are differences in the time taken to see or speak to an appropriate primary care professional for people with multimorbidity and people without, both before and after the introduction of telephone triage, these differences are small compared with the overall improvement for all patients when a general practice switches to a telephone triage approach.

**Insights for innovations for people with multiple long-term conditions**

Practice-level changes such as telephone triage impact all patients within the practice. Findings support the suggestion that inequalities are more likely to arise because of variability in implementation between practices, rather than for groups of patients within the same practice.

GPPS, General Practice Patient Survey.  
Source: Saunders and Gkousis, 2022.<sup>4</sup>

We conclude that ways in which the gap between the NIHR research priority for people with multiple long-term conditions and actual research practice might be bridged include:

- having clarity of definition of who constitutes a person with multiple long-term conditions
- how they can be identified within NHS patient registers and data sets
- what data sources are available to researchers to understand the needs of this population
- which clusters of conditions are most common.

National Institute for Health and Care Excellence has undertaken important work in this area, developing guidelines for optimising the care of people with multimorbidity<sup>12</sup> and this should arguably be made available to researchers when planning studies, through links in research commissioning briefs. Furthermore, the NIHR strategy about research for people with multiple long-term conditions could be more strongly profiled and encouraged as a core consideration in health services and other research calls.<sup>25</sup>

***Speaking evidence to policy and power***

The relative lack of evaluation evidence about whether and how service innovations address the needs of people with single or multiple conditions was suggested by Marmor<sup>53</sup> to present a particular risk of 'policy fads and fashions' being adopted. Some of the stakeholders we interviewed asserted that too many innovations advocated by policy-makers for people with multiple long-term conditions are not sufficiently evidence based, giving the example of virtual wards where evidence of effectiveness remains uncertain.<sup>54,55</sup> This highlights a profound risk related to the relative absence of research that is properly and consistently focused on the needs of the many NHS users who are living with multiple long-term conditions. Namely, where a service innovation is identified, such as pulse oximetry at home (which was rapidly evaluated jointly by BRACE and other teams during the COVID-19 pandemic) or virtual wards, they may be deemed too quickly to 'work', without sufficient attention being paid to understanding the results of early evaluation and using these to build more extensive trials or implementation studies.

A point made strongly to us in the interviews was that it can appear to be more attractive to policy-makers and NHS leaders to adopt a 'shiny new' innovation that lacks a deep and extensive evidence base, rather than exploring how to implement in a sustained manner less glamorous interventions already known to be effective and important for patients and carers, such as improving patient communication and administration;<sup>47,48</sup> implementing multidisciplinary teams at scale so that all people living with complex multiple conditions can have such support when they need it;<sup>56</sup> or ensuring meaningful regular medicines reviews with people and integrated communication with their team of health and social care professionals.<sup>57</sup>



### Theme 3: building opportunities for ‘engaged, informed individuals and carers’ and improved self-management

#### Context

All BRACE evaluations had at least one research question relating to patient or service user experience or impact in relation to the particular service innovation. It was therefore unsurprising that the analysis undertaken in our overarching study underlines the importance of this feature. This echoes the ‘engaged, informed individuals and carers’ dimension (or wall as it was termed) of the House of Care model, which is one of the two conceptual approaches underpinning this study. In exploring the theme of user engagement and self-management, we have focused particularly on two components of the SELFIE framework, highlighting what we have learnt from our overarching study of the BRACE portfolio of evaluations in the areas of technology and service delivery especially as they relate to integrated care.

A foundation of the House of Care is people with long-term conditions who are ‘fully engaged in articulating their needs and capacities, deciding on priorities, agreeing goals, and jointly developing a plan for achieving these’.<sup>30</sup> Such involvement is asserted by the developers of that model to lead to people having more confidence and engagement in their own care. Activities such as structured individual or peer support and education related to health conditions, social prescribing and health coaching may help patients to better manage their own conditions. Such enabling care is described by the Health Foundation<sup>58</sup> as including ‘supporting people to recognise and develop their own strengths and abilities to enable them to live an independent and fulfilling life’ (p. 6). Yet Ham *et al.*<sup>59</sup> describe how far we are from the ideal scenario presented in the Wanless report,<sup>60</sup> which outlined factors needed for a high-quality health service, where the public were fully engaged in taking responsibility for their health. The NHS Long Term Plan<sup>21</sup> renews calls for increased support for shared responsibility for care management between providers and patients.

Our analysis of the BRACE portfolio of evaluations sheds light on the complexities of supporting self-management of care. [Table 4](#) summarises points from the BRACE evaluations that, based on our cross-analysis, appear relevant to the issue of supporting people with multiple long-term conditions to self-manage their care. Thus, the evaluations of COVID oximetry at home<sup>5</sup> and in care homes,<sup>6</sup> which was intended to support people to self-manage in one specific regard (presenting at hospital with severe respiratory problems due to COVID), found that pulse oximeters were generally considered to be easy

**TABLE 4** BRACE studies relevant to self-management of care for people with multiple long-term conditions

BRACE evaluation	Relevance to self-management of care
COVID oximetry at home, main evaluation – Fulop <i>et al.</i> 2023 <sup>5</sup>	Innovation not aimed at multiple long-term conditions. But COVID oximetry at home was about supporting patients to stay in their own homes, which implies they or their carers being supported to manage their care. Patients and carers reported positive experiences (93% rated the service as good or excellent) and felt that services and human contact received as part of these services reassured them and were easy to engage with. Findings indicated that patients with COVID-19 can engage with remote monitoring services but may require support from staff and family/friends to do so. Findings indicate that burden of treatment may be experienced by patients and families with acute conditions.
COVID Oximetry at Home in care homes – Sidhu <i>et al.</i> 2022 <sup>6</sup>	Innovation not aimed at multiple long-term conditions. But COVID oximetry in care homes was about supporting patients to stay in their care homes, which implies they or their carers being supported to manage their care. Care home managers and staff reported that pulse oximeters are easy for residents to use, supported by care home staff as necessary.
AI and home sensors in social care – Glasby <i>et al.</i> 2023 <sup>7</sup>	Evaluation found that in general that people who draw on care and support and their carers expressed interest in how the technology might impact on their care and the shared decision-making associated with it. This included concerns that pilots might reduce social care provided by care staff, and might erode choice and control (e.g. a feeling that analysis by the technology might drive what care is provided, rather than the person being able to exercise a degree of choice and control). Thus, by supporting self-management, the innovation might reduce the care received.

to use by people outside healthcare settings – many of whom would have been living with multiple long-term conditions. But the evaluation of AI plus home sensors in social care<sup>7</sup> revealed service user concerns that the support for self-management that the technology might provide would be at the cost of less in-person social care, and they did not want that.

Building on these insights from the BRACE portfolio, one of our interviewees articulated the potential role of technology to support shared responsibility:

*I would like to think that we'll be able to use technology so that patients will be ... able to monitor their own disease progression and maintenance much better. And actually hand back some of the responsibility for management to the patient. I think one of the challenges over the last few years is that we've tried to professionalise care, which has meant that we've actually disempowered people from looking after themselves.*

### **Remote monitoring to enable care for people with multiple long-term conditions**

This connection between the theme of enabling or self-managed care and the role of technology emerged from our cross-project analysis of the BRACE portfolio of evaluations (in particular pulse oximetry at home,<sup>5</sup> social care sensors and AI<sup>7</sup> and digital-first primary care<sup>8</sup>) and led us to undertake an additional rapid evidence review of remote monitoring to support care for people living with multiple long-term conditions. [Box 4](#) summarises the findings from that review. We highlight in the following paragraphs what this literature reveals about how innovations such as remote monitoring can support the care for people with more than one long-term condition.

We found few studies that related specifically to remote monitoring for people with more than one long-term condition: only four studies in the UK met our eligibility criteria (see [Report Supplementary Material 3](#) presenting the evidence review). There was some evidence in the literature assessed in our rapid review of remote monitoring innovations being a means to support self-management of care, improve mental health and well-being, and enhance quality of life for people with multiple long-term conditions. For example, in one study, participants with heart failure, uncontrolled hypertension and diabetes reported that a remote monitoring intervention that collected data via a phone-based app and Bluetooth-enabled weighing scales, blood pressure and blood glucose monitors made it easier to take readings and provided users with more oversight of their condition.<sup>61</sup>

There was little evidence in respect of whether remote monitoring can improve clinical outcomes related to specific conditions or hospital utilisation outcomes. The Ware *et al.* study, for example, despite positive findings regarding patient empowerment, did not find evidence that the interventions had an impact on quality of life, mental health or physical health.<sup>61</sup> Such results call for more research specific to innovations for people with multiple long-term conditions, and research designed with the involvement of service users and carers. But such results also raise questions about how decisions are made to pilot or adopt technologies related to self-management. Are user benefits sufficient to justify adoption, or must such technologies show improvements in clinical outcomes or hospital utilisation measures?

**BOX 4** Summary of findings from the literature review on remote monitoring for people living with multiple long-term conditions

- People with multiple long-term conditions can face burdens related to managing their health, including issues related to a lack of co-ordination of care, difficulty prioritising between multiple health needs, and symptoms from one condition making it challenging to manage others. The complex health needs of people with multiple long-term conditions can be a challenge to the healthcare system, and helping people with multiple long-term conditions to self-manage their health has been a focus within the NHS.
- Evidence from the published literature indicates that remote monitoring can be helpful for people with multiple long-term conditions in feeling empowered and confident in managing their conditions, and can help ease some of the burden of reporting symptoms or measurements to healthcare providers.



- There is some evidence to suggest that remote monitoring can improve quality of life, mental health and well-being in people with multiple long-term conditions. However, evidence is mixed. The majority of studies looking at the impact of remote monitoring on physical health, healthcare utilisation and health outcomes in people with multiple long-term conditions have not found evidence of such impact.
- There is some evidence to suggest that remote monitoring technologies can be helpful in saving resources within the healthcare system. However, more evidence is needed to understand the cost-effectiveness of different remote monitoring interventions.
- Some groups of people with multiple long-term conditions may need additional support in using remote monitoring, such as older people and people with cognitive impairment. Remote monitoring technologies often require computer, smart phone and/or internet access, which can contribute to health inequalities among people who are digitally excluded.
- There are several ways in which the remote monitoring interventions for people with multiple long-term conditions might be improved. There should be careful consideration of how much clinical input is required for remote monitoring, along with consultation processes whereby the needs and views of patients and their carers are carefully considered in the design of interventions. Improvements to the co-ordination of care would also improve how remote monitoring can be used for people with multiple long-term conditions.

Several studies in the literature we reviewed for this overarching study mentioned issues about health inequalities. They focused on inequalities in access to digital technologies and digital capabilities by age, geography, education or socioeconomic status.<sup>62,63,69,70</sup> People with particular vulnerabilities or health conditions may also face additional challenges in accessing and using technology. For example, a qualitative study of older adults with mild cognitive impairment found that although individuals report benefits from remote monitoring technology, such as increased feelings of security and independence, they reported wanting more educational material (including about technical issues and connectivity of devices) and more consideration of their specific needs (e.g. about forgetfulness).<sup>62</sup>

Several of the studies we reviewed excluded people without smartphones, computers or internet access,<sup>63-65</sup> which indicates the potential for remote monitoring to exclude certain populations that may already face issues with health inequalities. This represents a wider issue related to telemonitoring and limits the degree to which telemonitoring might close health equality gaps where vulnerable populations lack key facilitators of remote monitoring such as internet access. There are also selection biases in some studies, in that the people who participated in prospective studies had already agreed to use technology<sup>66</sup> and so may be expected to have more favourable than average views of technology.

### ***Applying lessons from the review of evidence on remote monitoring***

Our rapid review of evidence on remote monitoring highlighted factors related to the design and use of technological innovations to support the care needs of people with multiple long-term conditions which were also present in our BRACE portfolio of evaluations. Several studies emphasised the need for greater patient and carer engagement in the design and development of software applications and digital healthcare interventions,<sup>63,67-69</sup> which can help ensure that technologies meet user needs, are easy to use, and can be integrated into existing routines and healthcare pathways. These findings mirror what we learnt in the BRACE evaluation of digital-first primary care<sup>8</sup> highlighted in [Box 5](#).

#### **BOX 5** Lessons on technology use from the BRACE evaluation of digital-first primary care

##### **What was the innovation?**

People were asked to submit requests for help and advice to their GP practices via an online system or mobile application.

##### **Who were the targeted users?**

Anyone who wanted help or advice from their GP.

**What did we do?**

A review of the literature, co-designing the evaluation approach with service users, and interviews with patients/ carers.

**What did the evaluation find?**

Evaluation findings	Insights for innovations for people with multiple long-term conditions
<p>Digital-first primary care approaches can enable patients to speak with a health professional more quickly than traditional approaches. Some participants expressed preferences to see patients face-to-face, particularly those with multiple long-term conditions, to identify non-verbal cues about a patient's health. Some healthcare professionals reported preferring to see patients with multiple long-term conditions in person, in order to have the opportunity to more holistically assess the patient. Digital-first primary care approaches provided an opportunity for carers of patients living with multiple long-term conditions to become more involved in their care, though there were concerns around consent and confidentiality.</p>	<p>Those with multiple long-term conditions can submit healthcare readings from home, though they may struggle navigating systems not designed to capture the nuances associated with living with multiple conditions.</p>
<p>Patients wishing to access primary care through online mechanisms were taken through questions that did not allow for answers that indicated that multiple conditions need to be discussed simultaneously. The software algorithms suited people with a straightforward single condition issue but did not allow for wider contextualisation by the patient. Thus when faced with a patient with multiple conditions, the software may too-readily divert the patient away from the GP and to A&amp;E.</p>	<p>Some technologies may not be well-suited for patients living with multiple long-term conditions in general. Involvement of such patients and their carers is essential to design appropriate interventions that meet the needs of this growing segment of the population.</p>
<p>Source: Newbould <i>et al.</i>, under review.<sup>8</sup></p>	

People living with multiple long-term conditions may need additional support in using technology such as remote monitoring. We have already mentioned the presence of inequalities in access to digital technologies and digital capabilities by age, geography, education or socioeconomic status.<sup>63,66-68</sup> It is critical to account for how technological innovations such as remote monitoring have the potential for widening disparities in healthcare provision. Yet, in our rapid evidence review, several studies excluded people without smartphones, computers or internet access.<sup>63-65</sup>

In one study within the BRACE portfolio, we evaluated the use of pulse oximetry within care homes<sup>6</sup> (Box 6) and found that people with dementia or learning disabilities may require a different approach to using oximetry. Staff reported that occasionally people with dementia would be confused and not understand what was happening or become agitated in the process of taking an oximetry reading. While the evaluation focused on the usefulness of using pulse oximetry within care homes and did not explore the specific effects of the diagnostic on people with multiple long-term conditions, our findings may have some relevance for people with more than one condition and including cognitive impairments.

**BOX 6** Lessons on technology use from the BRACE evaluation of pulse oximetry in care homes

**What was the innovation?**

Pulse oximeters were used to monitor COVID-19 and other health conditions in care home settings.

**Who were the targeted users?**

Care home residents at risk of COVID-19. The most common characteristics of residents living at care homes whose manager responded to our survey included older residents and residents with dementia, physical disabilities, complex needs and/or learning and sensory impairments.

**What did we do?**

Scoping interviews with NHS leaders, care association directors and care home managers; online survey of care home managers; interviews with care home managers and staff at six case study sites.

**What did the evaluation find?****Evaluation findings**

Nearly half of responding care home managers agreed that residents felt reassured by the use of oximetry, but a few reported that residents both felt reassured and anxious by oximetry use. This may indicate that residents had variable views of using pulse oximetry. Nearly all respondents felt that oximetry provided timely identification of deterioration of a resident's health. In both nursing and residential homes, staff reported that residents readily accepted staff taking routine oximetry measurements (with the resident's consent). There were some compliance issues among residents with dementia or learning disabilities. They would sometimes fail to understand what was happening and remove the device before a reading could be made, or they became agitated during the process.

Source: Sidhu *et al.*, 2022.<sup>6</sup>

**Insights for innovations for people with multiple long-term conditions**

Some technologies may not be well-suited for patients living with multiple long-term conditions given specific conditions or combinations of conditions that they may have. Development and evaluation of innovations need to include the perspective of diverse users, especially people who are at risk of experiencing inequalities in health and health care.

Finally, the use of remote monitoring technologies needs to be built proactively into care pathways from the outset. Many interventions included regular engagement between patients and healthcare providers, which provided both clinical oversight and person-to-person contact.<sup>61,69-71</sup> More input from healthcare providers in remote monitoring appears to be beneficial to user experience and increases the effectiveness of interventions bringing into question the potential for remote monitoring as a direct substitute for any in-person aspects of care. Kroenke *et al.*<sup>71</sup> suggest a stepwise approach to interventions, in which a more resource-intensive intervention can be deployed if self-management is not producing the desired outcomes, which can increase the cost-effectiveness of the intervention for the overall population.

This again mirrors findings from a study in the BRACE portfolio of work: the rapid evaluation of AI for digital social care work<sup>7</sup> (Box 7). We concluded in that study that service users and frontline social care staff both needed to be involved in decision-making and implementation related to new technology. New roles and staff training to accompany technological implementation are needed if technological innovations are to help people living with multiple long-term conditions to co-ordinate and manage their own care.

**BOX 7** Lessons on technology use from the BRACE evaluation of AI plus home sensors in social care**What was the innovation?**

Multiple sensors to monitor adults in the home setting and AI based on sensor data to help social care workers identify situations where individuals may need support.

**Who were the targeted users?**

Adults receiving social care. Service users included adults with learning disabilities, adults with physical disabilities, and those with multiple long-term conditions including physical and mental health conditions.

**What did we do?**

A rapid review of literature, key informant interviews, and interviews with operational leads, care staff and technology providers at three case study sites.

**What did the evaluation find?****Evaluation findings**

Findings highlighted the lack of a systematic approach to decision-making related to the adoption of technology (e.g. a lack of shared understanding of the problem to be solved, a lack of established decision criteria on adoption), limited staff engagement and insufficient training activities to support implementation. Staff perceived the voluminous data collected by the technology operating company as being an analytical burden, and they did not want access to such data because they were not trained to identify and appropriately respond to any warning signs. Practical difficulties with installation and monitoring and the lack of clearly perceived benefits in the context of high short-term pressures on staff also negatively impacted staff experience.

**Insights for innovations for people with multiple long-term conditions**

Innovations should be developed with a clear need in mind, including the needs of people living with multiple long-term conditions. Implementation of innovations should consider the perspective of both the service user and the care staff who are intended to use the innovation, as well as the systems within which the innovations are to be implemented.

Source: Glasby *et al.*, 2023.<sup>7</sup>

Taken together, our findings from a rapid evidence review and cross-project analysis of the BRACE portfolio indicate that relatively little work has been done in respect of innovations specific to people living with more than one long-term condition. Though not specific to this population, the BRACE evaluations highlight the complexity of interventions to improve self-management and in particular the multiple considerations needed to be taken into account, perhaps even more so for people with multiple conditions, when embedding technology to support self-management activities. These include involvement of patients and their carers to develop innovations; considerations related to access for disadvantaged populations including populations with specific needs (e.g. learning disabilities or cognitive impairments); and the intricacies of implementation within complex organisations. While we see widespread recognition of the potential to better leverage technology to improve patient care, including that for people with multiple long-term conditions, we find that implementation of such technological innovations needs to account better for the breadth of sociotechnical issues that arise, including those related to broader systems, care pathways, and staff roles that interact with the technology.

**Theme 4: the importance of measures that matter for patients and carers****Context**

This theme directly relates to the 'information and research' segment of the SELFIE framework and is an important support to the 'responsive commissioning of health services' 'wall' of the House of Care model. If what gets measured is what matters,<sup>72</sup> then the experience of people living with multiple long-term conditions and their carers clearly does not yet matter sufficiently within the NHS. Reflecting the single-specialty or -condition focus of how health services are organised, routine measurement of inpatient and outpatient activity, patient experience and outcomes usually happens within these condition-specific boundaries. Quality and finance reports from NHS trusts are typically organised around clinical services or directorates, with data set out for each department or specialty and not in respect of how patients – particularly those with complex or multiple long-term conditions – experience their care within and across different departments and specialties, and across into primary care, mental health, social care and other services. As Crump *et al.*<sup>73</sup> noted in their research designing and testing a survey to capture users' experience of care co-ordination:

*Understanding user experience is an important way for providers to assess how well the full package of care is meeting users' needs. But measuring user experience of receiving integrated care from multiple sources can be hampered because of the limited availability of tools for capturing user and carer experience of care co-ordination across organisational boundaries.*

*Reproduced from Crump et al.<sup>73</sup> This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) license, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: <https://creativecommons.org/licenses/by/4.0/>. The text above includes minor additions and formatting changes to the original text.*

The context of siloed specialties and services has of itself led to this lack of available assessment tools that start from and focus on the actual experience of patients and carers making their way through the health system. The NHS Patient Survey Programme collects data on patient experience by organisation for five separate services (maternity care, adult inpatient, community mental health, children and young people's services, and urgent and emergency care) and questions are focused on a single episode of care (e.g. on the adult inpatient experience that includes at least one overnight stay, and for adults using A&E department or urgent care centre services). Similarly, individual trusts usually administer their Friends and Family Test and other patient experience surveys by ward, department or clinical specialty. While this approach makes sense in respect of performance management of specific areas of a healthcare organisation, it is fundamentally based on a professional or institutional perspective of what needs to be understood, rather than being curious about the lived experience of patients and their carers across health and social care services and organisations and what works or not.

Measures of professional performance in primary care (and associated incentives or penalties) are similarly focused largely on single diseases and their treatment, as evidenced by the quality and outcomes framework (QOF) for GPs, where measures largely ignore combinations of diseases, care integration or factors that matter to patients living with multiple long-term conditions, as discussed further in Theme 5. It is likewise difficult to use routine NHS data to monitor the extent to which patients are able to have continuity of care from their GP, despite research evidence and guidance favouring continuity.<sup>46,74</sup>

The importance of continuity of care as a measure that particularly matters to people with multiple long-term conditions was underlined by the interviews we undertook, where the metrics most frequently cited as being highly relevant were:

- *continuity of care* (especially in complex or poorly controlled conditions, not as important for people with fewer well-controlled conditions)
- *experiences of care co-ordination, fragmentation and communication* (e.g. 'Do you think your clinician knew what was happening in other areas of your care?', whether GP and specialist can both access a patient's care records, having a comprehensive care and support plan across all services being used, and whether the patient's preferences have been taken into account)
- *impact of services received on carers.*

One interviewee commented that a particular challenge of trying to collect information from carers about their experiences of service co-ordination or fragmentation is that the system is not always aware of their existence and even where their name and role are logged in patient records, little appears to be done with this information. The importance of the carer's (and in this study, social carer's) role in interpreting and profiling the importance of the patient's lived experience (including care co-ordination and integration) was underlined by Reinhoudt-den Boer et al.<sup>75</sup> when reporting on a longitudinal study in the Netherlands of the care trajectories of people with multiple problems:

*Formal caretakers seem to have a key role in initiating integrated care for this client group [people with multiple health problems]. This approach requires formal caretakers who can build strong trust relationships*

*with CWMPs [clients with multiple problems], can organize shared reflexivity to unravel the complexity of CWMPs' situations, and can take on supportive, compassionate and confrontational roles (coaching).*

*Reproduced from Reinhoudt-den Boer et al.<sup>75</sup> This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) license, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited.*

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Other researchers have argued for a shift from examining care co-ordination or integration towards exploring care fragmentation, applying the logic that there is a need to start from understanding what is not working for patients and why not, before setting out to determine local or policy solutions. This turns much of the 'integrated care' literature on its head, challenging researchers to reorientate their attention, methods and analysis to the experience of care fragmentation (Nolte et al.).<sup>76</sup> Crump et al.<sup>73</sup> developed this approach in the UK context, designing and testing a user-reported measure of care co-ordination and noting its uniqueness:

*[this tool] will be able to offer some insights to purchasers and providers about how patients experience their efforts to coordinate services across boundaries of provision [...] and also provide some information about how well services are supporting patients and service users in achieving their own life goals. In this respect, the survey tool has the potential to occupy a role not currently filled within an English context.<sup>73</sup>*

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That such a tool needed to be developed and tested reveals the systematic lack of attention to the experience within and across health services of users who live with multiple long-term conditions. As revealed in our work for this report, so many measures in the health system are focused on single conditions, or sometimes clusters of conditions, such as the QOF in general practice, Primary Care Network Directed Enhanced Services specifications and measures, or the Getting it Right First Time programme focused on evidence-based improvements to NHS care.

### **BRACE evaluations cross-analysis findings**

That there are few measures of care co-ordination and integration that are holistic or truly take the patient or service user perspective and are applied within policy and practice was echoed by our analysis of the 10 BRACE evaluations. It was only in our Type 2 evaluations (see [Table 1](#)) where an explicit focus was placed on the experience of people living with multiple long-term conditions that methods were designed to explore this. Examples here were the evaluation of the extent of any inequalities in access to Telefirst general practice by people with multiple long-term conditions,<sup>4</sup> and the impact of hospitals managing general practice on the use of hospital and other health services by people living with multiple long-term conditions.<sup>9</sup>

For the other BRACE studies, the perspectives and measures that were of interest to evaluation commissioners were almost always at the specific service innovation or organisational level, as with the early implementation of Primary Care Networks<sup>1</sup> (e.g. their stage of development, impact on professionals, ability to establish new services required by the Primary Care Network contract), pulse oximetry at home<sup>5</sup> (e.g. implementation of this addition to COVID-19 services, impact on hospitalisation, experience of staff supervising care) or Mental Health Trailblazers<sup>3</sup> (e.g. impact on pupils' mental health, parents/families and schools, mental health service provision as a result of the programme).

It is of note that in the BRACE team's experience of rapid evaluation practice, it proved easier to do this using quantitative methods, and in particular analysis of routine healthcare utilisation data,



than to adopt a more qualitative approach. This was evidenced in the evaluation of Telefirst general practice, where the national General Practice Patient Survey was analysed along with data from the national Understanding Society survey to triangulate dimensions of socioeconomic and other potential disadvantage with patterns of general practice access<sup>4</sup> (see [Box 3](#)). However, in the BRACE evaluation of the impact of digital-first primary care on people with multiple long-term conditions and their carers,<sup>8</sup> it proved so hard to secure ethical approvals and access to patients for the qualitative research within the timeframe of the rapid evaluation that professionals' views of impact on users had to be adopted as a pragmatic and imperfect proxy approach to gaining these insights.

In the second phase of the hospitals managing general practices evaluation,<sup>9</sup> the research team was able to interview patients as well as professionals, and then compare these insights with analysis of routine primary care experience data and secondary care utilisation data, reaching conclusions about how people with multiple long-term conditions experienced this form of general practice compared to other patients ([Box 8](#)). The results indicate that changes in patients' use of acute hospital services when hospitals started to run the general practice where they are registered were similar regardless of how many long-term conditions the patient was living with; for example, there was a slight reduction in non-elective hospital activity for all patients.<sup>9</sup>

#### **BOX 8** Findings from the BRACE Phase 2 evaluation of hospitals managing general practices

##### **What is the innovation?**

Acute hospitals taking responsibility for GP contracts, which may lead to greater (vertical) integration between organisations operating at different stages along the patient pathway.

##### **Who were the targeted users?**

People who seek care from acute hospitals or GP practices that implemented the vertical integration model.

##### **What did we do?**

An analysis of NHS provider annual reports and accounts and other NHS data sources. Interviews with patients with multiple long-term conditions and interviews/focus groups with NHS staff, including clinical and non-clinical directors, GPs, Primary Care Network leads and other primary care staff. A quantitative analysis of General Practice Patient Survey and Hospital Episode Statistics data.

In the quantitative analysis, multimorbidity was measured using counts of self-reported long-term health conditions from the General Practice Patient Survey. When using Hospital Episode Statistics data, we identified multimorbidity using ICD-10 codes to identify the 17 long-term health conditions that are widely used in the Charlson Multimorbidity Score.

##### **What did the evaluation find?**

###### **Evaluation findings**

Vertical integration provides opportunities to embed specialist clinicians from secondary care into primary care settings and target patients at greatest need including those living with multiple long-term conditions.

###### **Insights for innovations for people with multiple long-term conditions**

Initiatives coming out of the vertically integrated model, such as multidisciplinary teams, were not specifically designed for people with multiple long-term conditions but benefited this patient population. Also, while the vertically integrated model has potential to improve care for people with multiple long-term conditions, much of that potential remains to be realised.

Evaluation findings	Insights for innovations for people with multiple long-term conditions
<p>Quantitative analyses revealed no statistically significant change in patient experience for five out of six of the patient experience outcomes before and after practices switch to a vertically integrated model compared with control practices. Continuity of care (ability to make an appointment with a preferred GP) for patients within vertically integrated practices was statistically significantly lower, though by only a small amount, relative to practices that did not merge.</p>	<p>Our quantitative analysis found no difference in patient experience for people with multiple long-term conditions compared to those with no long-term conditions. Our quantitative analysis found no difference in continuity of care for people with multiple long-term conditions compared to those with no long-term conditions.</p>
<p>Vertical integration is associated with statistically significant, modest reductions in rates of A&amp;E attendances, outpatient attendances, emergency admissions and readmissions at hospitals.</p>	<p>We found no evidence that the impact of vertical integration on hospital use differs for people with multiple long-term conditions.</p>
<p>ICD-10, <i>International Classification of Diseases</i>, Tenth Revision. Source: Sidhu <i>et al.</i>, 2023.<sup>9</sup></p>	

### Challenges of adopting measures that matter to patients and carers

The challenges faced by the BRACE team were mirrored by comments made in our interviews with national and regional stakeholders. For example, some interviewees were unaware of any data collected specifically for people with multiple long-term conditions, and certainly not any collected in a systematic or routine manner. Others were unsure what data could be collected to show if an innovation intended to benefit people with multiple long-term conditions was actually doing so. For example, one interviewee explained:

*I am very sceptical about how we measure integration and how we monitor integration [...] In response to a single condition, you can probably track the impact of that through RCTs [randomised controlled trials] or other uh, you know, experimental designs to see how effective that innovation is. [...] If you are looking at a pathway innovation as opposed to a tech innovation, as soon as you start to drop in multiple factors into an individual, it becomes incredibly difficult to find out what has been the single thing that has changed the outcomes for that individual or that system. And that's part of the reason it's so hard to measure it at an integrated level.*

Other interviewees mentioned data that are collected that are not specific to people with multiple long-term conditions but which include and are relevant to much of this population, including access-related outcomes (e.g. attendances to services, number of contacts, duplications of contacts, referrals); health outcome data; patient experience feedback; and patient activation measures. Some interviewees commented that there were a lot of data already available, but these needed to be better linked to be able to track at a patient level and hence allow population health analyses.

An interviewee noted that one of the main challenges with existing NHS data is that there is no system identifier for multiple long-term conditions to make this patient group more tangible. Furthermore, it was asserted that while routine utilisation data within secondary care tend to be more readily accessible to researchers, many people with multiple long-term conditions receive much of their care from primary, community health and social care services, so broader improvements in data collection outside hospitals and linkage across sectors would be important for this population.

### Suggested measures and approach

In the interviews we explored stakeholders' thoughts about measures that matter to patients and carers. Patient-reported outcome measures (PROMs) were thought to be potentially important in monitoring the experiences of people with multiple long-term conditions. Examples given included quality of life, well-being measures, the degree of understanding of their conditions, and describing and assessing outcomes that matter to the individual patient (e.g. living and dying where you want, meeting goals that were set by the patient in collaboration with their informal and professional carers).



Clinical outcome measures (e.g. physical function, illness-specific dimensions of health) were also considered useful to collect as they can act as proxy measures to assess overall care. Other information suggested as worth considering included data examining health inequalities, staff measures related to a service innovation (e.g. staff satisfaction) and economic analyses. Two national-level interviewees commented that there is much quantitative data available already, but the use and triangulation of more qualitative data could improve understanding of impacts on patients and carers. This clearly echoes the finding from our cross-project analysis of the BRACE portfolio that it can prove more difficult to use qualitative (as opposed to quantitative) methods to explore the outcomes and experiences of people living with multiple long-term conditions.

The issue of measures is fundamental to understanding and researching integrated and co-ordinated care as well as the needs of people with multiple long-term conditions. The cross-analysis of BRACE evaluations highlighted the importance of measures that matter most to patients and service users, the themes of these being their experience of care; continuity of care; and the impact on carers. National Voices has developed and updated 'I Statements' from its work with patients, concisely capturing what it is patients want from integrated care.<sup>77</sup> Based on our cross-project analysis and stakeholder engagement work in interviews and workshops, we suggest in [Box 9](#) the questions to consider in the development and use of measures that matter to patients living with multiple long-term conditions.

**BOX 9** Questions to inform the development and use of measures that matter to people living with multiple long-term conditions

How have patients and carers been involved in the development of the measure and how far does it reflect their concerns?

Does this measure track and reflect the actual journey of the patient across services, organisations and sectors?

Is the measure concerned with the whole of the care experience?

Is the measure informed by UK and international research evidence on patient measures of care co-ordination and fragmentation?

How might the 'I Statements' developed by National Voices<sup>77</sup> inform the development and use of measures of care experience for people living with multiple long-term conditions?

Is there a way of exploring care fragmentation as the basis for considering how well (or not) services are co-ordinated?

How could the CQC's initial provider collaboration reviews and analysis of the challenges presented by Integrated Care Systems be translated into a new set of measures that matter to people with multiple long-term conditions?

What insights do the OECD's PaRIS Surveys of people with multiple long-term conditions offer, in particular its focus on PROMs and PREMs?

How could measures be used for medium- and longer-term monitoring of the experience of people with multiple long-term conditions?

CQC, Care Quality Commission; OECD, Organisation for Economic Co-operation and Development; PaRIS, Patient-Reported Indicator Surveys; PREM, patient-reported experience measure.

## Theme 5: barriers to developing and implementing service innovations for people with multiple long-term conditions

The process of designing, implementing, evaluating and sustaining service innovation in health care is complex. In our overarching study we have observed – in the rapid evaluations undertaken by BRACE, in the interviews with national and regional stakeholders, and in the review of literature evaluating remote

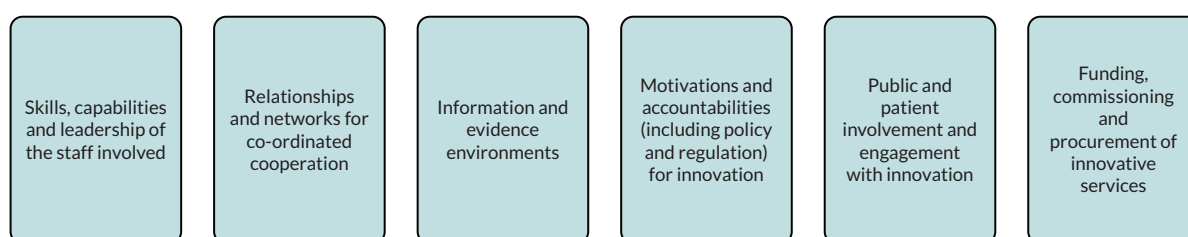
monitoring for people living with multiple long-term conditions – that, despite the high prevalence of people living with long-term conditions, their particular needs are only occasionally a specific focus of an innovation, and that the implications for people living with multiple long-term conditions are seldom reported for other innovations. We found in our interviews that there was recognition of the importance of considering the needs of this group, but few examples of where this was in fact a focus of innovation. While this theme relates to all constituents of the House of Care Model and all segments of the SELFIE framework, it most directly concerns ‘service delivery’, ‘workforce’ and ‘information and research’ in the latter. In the following paragraphs, we set out what the work of the BRACE has revealed about the barriers to developing and implementing service innovations for people with multiple long-term conditions.

### Stony ground

Service innovation in health and care refers to new ways of delivering services. This may be an entirely new approach or technology, or the application of an existing approach or technology in a setting, or for a patient group, where it has not previously been used. The focus of service innovation is on improving any or all of the following: health and care service quality, users’ experience of care, efficiency, and cost-effectiveness. Innovation is a process of establishing, implementing, sustaining, scaling and spreading the new approach or technology before any outcomes are achieved. The success or otherwise of an innovation is inevitably affected by the context(s) into which it is introduced. An innovation landing on stony ground, that is in a difficult context, will not be taken up by service providers and users.<sup>78</sup> Marjanovic *et al.*<sup>79</sup> identify six groups of key contextual factors influencing innovation in health care, as listed in [Figure 2](#).

Weak or absent drivers of innovation under these headings represent barriers to innovation of all kinds in the NHS including, but not limited to, that which might benefit people living with multiple long-term conditions. The lack of sufficient or appropriately skilled staff with time to familiarise themselves with and adopt innovations, let alone help to create them, is a major constraint, we have found.<sup>80</sup> This may be manifested in too few healthcare staff relative to patient demand for their services, or the available skill mix not matching service needs. In our interviews, the point was made that heavily loaded healthcare professionals are likely to lack the ‘head space’ to think about innovating and changing how they work in order to better support patients with multiple long-term conditions. Multidisciplinary teams are desirable to support many patients, but especially those with multiple conditions. Our stakeholder engagement work highlighted that the staffing level and mix needed to build multidisciplinary teams, and even the physical space in clinics, etc., to house such teams, may be insufficient.

Overall, the overarching study has revealed several barriers to innovation or to the implementation of innovation for people living with multiple long-term conditions. Some of the barriers cut across more than one of the innovation factors identified by Marjanovic *et al.*,<sup>79</sup> but others relate to single factors, for example, a lack of opportunities for active PPI and engagement with innovation. The degree to which barriers are specific to service innovation for people with multiple long-term conditions or obstruct



**FIGURE 2** Key contextual factors influencing innovation in health care. Reproduced from Marjanovic *et al.*<sup>79</sup> This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) license, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: <https://creativecommons.org/licenses/by/4.0/>. The figure above includes formatting changes to adapt the original text into a figure.

health service innovation more generally also varies. A lack of drivers of the kind listed above is a barrier for any innovation. In the following paragraphs, we concentrate on those barriers that seem specific to, or at least particularly obstructive to, innovation for people with multiple long-term conditions.

### **Focus on single conditions**

As discussed earlier in this report, the healthcare system and training of healthcare professionals to work in that system are designed around treatment pathways for single diseases or conditions. However, it may be that clinicians are less likely to refer to other services needed by a patient with multiple conditions if there is no clear pathway to do so. Furthermore, patients' own expectations may reflect an understanding of the care on offer that is focused on single conditions. It was suggested by a PPI participant that patients may lack the confidence to press for multiple conditions to be considered at the same time when consulting a healthcare professional who evidently wishes to focus on one condition at a time.

Faced with clinical and patient expectations like these, there may seem to potential innovators to be little reason to seek an approach that is more accommodating of multiple long-term conditions. Indeed, such an approach may not be considered at all. An example of how a lack of attention to multiple long-term conditions appears to have been a barrier to service innovation for this population was revealed in the BRACE evaluation of digital-first primary care<sup>8</sup> (see [Box 3](#)) where we found that digital-first primary care algorithms suited people with a straightforward single condition issue but did not allow for wider contextualisation by the patient.

The review of evidence on evaluations of remote monitoring technologies for people with multiple long-term conditions demonstrated that there are nevertheless a few innovations that are aimed at this group (see the discussion in Theme 3). The barrier of single-disease focus can evidently be overcome. In the next thematic section of this report below, we consider how the priority accorded to research for the large part of the population living with multiple long-term conditions can be augmented.

### **Lack of a clear understanding of what matters to people living with multiple long-term conditions**

It is widely accepted that patients' needs should be the focus of innovation in health care, and that it is essential to involve patients and the public in developing innovations, but it is also recognised that this does not always happen.<sup>81</sup> A national-level stakeholder we interviewed reinforced this in respect of health technology innovation. They expressed the view that it can be difficult to identify innovators willing to work with the healthcare system to create and design technologies in response to system and patient needs, rather than developing a product and then finding a healthcare need that product might address.

None of the innovations that BRACE was commissioned to evaluate were specifically aimed at people living with multiple long-term conditions. However, our rapid evidence review found several studies that described steps that were taken to meet the needs of people with multiple long-term conditions by including them and their carers in the design process. For example, Doyle *et al.*<sup>82</sup> describe a process of consulting with patients, as well as clinicians and other stakeholders, to design bespoke features for a remote monitoring intervention that would cater specifically to people with multiple long-term conditions. Through this process, Doyle *et al.* found that patients may be prone to focusing on one condition at the expense of others, which led them to implement a 'flower' user interface, presenting multiple facets at once to provide unobtrusive prompts for conditions that were not being monitored. Two studies also discussed the need to include a patient's entire care network when designing remote monitoring interventions, with some providing an option to share data with carers and family members.<sup>62,82</sup> Other studies emphasised the need for greater patient and carer engagement in the design and development of apps and digital healthcare interventions to help to ensure that technologies meet user requirements.<sup>63,67-69</sup>

In the interviews we conducted, participants mentioned innovations they felt to be relevant, but rather than being specifically aimed at people with multiple long-term conditions the innovations merely happened to be used predominantly by those people. The innovations mentioned were rarely discussed in relation to the specific care needs of people with multiple long-term conditions, unless prompted by the interviewer.

### **Failure to sustain implementation of innovations beyond pilots**

Challenges relating to the adoption of innovations have been long known and much researched.<sup>83,84</sup> Such research includes highly diverse literature on implementing and sustaining innovations, and points to the 'iterative, complex and multidirectional' process of implementation whereby both formal and informal decisions by individual users comprise the ongoing process of assimilating innovations within organisations.<sup>85</sup> Understanding the innovations themselves, as well as under what conditions a service innovation may or may not be successful, may be critical to its scale-up and spread within and across organisations.

After prompting, interviewees mentioned a number of innovations that were considered to have been targeted at, or had proved useful to, people with multiple long-term conditions. These innovations are listed in [Table 5](#) alongside the care need(s) they address. This is not intended to represent a comprehensive list of recent innovations beneficial for people with multiple long-term conditions but is

**TABLE 5** Innovations for people with multiple long-term conditions and their carers

<b>Innovation</b>	<b>Care need(s) addressed</b>
Offering one clinic, one appointment to address multiple concerns (e.g. vaccination clinics doing screening/health checks at the same time)	Holistic care, person-centred care, access
Longer appointment times (e.g. with nurses) to permit discussion of multiple conditions	Holistic care, integrated care
3D model – one long annual review of a patient with multiple conditions rather than multiple separate single-condition reviews (as in the House of Care Model <sup>30</sup> )	Integrated care, care co-ordination, continuity of care
Virtual wards (often single-condition focused, but also for frailty) and remote monitoring technology (which may include external devices such as blood pressure monitors, pulse oximeters, blood glucose machines)	Access to care, self-management/care
Self-monitoring apps or websites (often condition specific and used by proactive patients). No automatic feedback loop to clinician	Self-management/self-care
Complex care models/neighbourhood initiatives	Holistic care, integrated care, person-centred care, care co-ordination, polypharmacy
Multidisciplinary team meetings and 'huddles' to discuss patients with complex and multiple long-term conditions	Holistic care, integrated care, person-centred care, care co-ordination, polypharmacy
Continuity team for people with long-term conditions – practice nurses working alongside physician associates, pharmacists, a community psychiatric nurse (employed directly by the practice) and GPs, care co-ordinators, social prescribers, health and well-being coaches	Continuity of care, person-centred care
Single-record web interfaces that all healthcare professionals can use and share (USA)	Person-centred care, care co-ordination
Frailty consultant (once a month) or medicines management programme to help medicine optimisation for people with multiple long-term conditions	Polypharmacy
Behaviour change programme aimed at increasing physical activity in people with multiple long-term conditions	Holistic care

indicative of what these expert informants to our overarching study actively had in mind. This suggests that well-evidenced service innovations suitable to meet the needs of people with multiple long-term conditions exist. But they are not yet implemented at sufficient scale or with sustainable funding across the NHS. Shaw *et al.*<sup>86</sup> echo this when noting that, while health and care technologies may often succeed on a small scale, they often do not achieve widespread use or become routine practice in other locations or settings. Thus, a major challenge is to progress beyond pilots (which may themselves have multiple purposes), to find ways to roll out and sustain across the NHS long term service change to benefit people with multiple long-term conditions.<sup>87</sup>

Reviews of healthcare innovations from the implementation science literature highlight the multilevel factors that impact their implementation.<sup>83,88,89</sup> In their review of evidence-based health innovations, Chaudoir *et al.*<sup>89</sup> classify implementation factors at the innovation, patient, provider, organisational, and structural/environmental levels. Robert *et al.*,<sup>83</sup> in their review of implementations of technological innovations in the UK context, note the importance of various contextual factors in implementation, such as the role of power and politics, that is the dominant role of clinicians in advocating for adoption/implementation and the quality of interprofessional relationships in implementations of technological innovations in the UK context.<sup>83,88,89</sup>

### **Financial incentives focus on single conditions**

Financial incentives for providers of secondary care in the NHS are focused on a combination of overall budget constraint, via block payments, and incentivising increased activity in the form of individual episodes of specialty-based care, via case mix-adjusted activity-based payments.<sup>90</sup> There are no specific incentives for meeting the needs of patients with multiple conditions. In the absence of such incentives, the drive to innovate services to help those patients is weaker than it need be.

In NHS primary care, the financial arrangements for GP practices reward larger patient list sizes, the quantity of some condition-specific services (such as vaccinations) and, by means of the QOF, the achievement of a long list of pre-specified service quality targets. All the indicators that are used in the QOF to determine payments to GP practices concern the provision of individual services and none is related to addressing needs resulting from multiple long-term conditions (with the possible exception of the palliative care indicator: 'the contractor establishes and maintains a register of all patients in need of palliative care/support irrespective of age'). There are no indicators of care co-ordination or continuity of care across conditions, for example. [Box 10](#) lists the categories of indicators under the QOF used to incentivise GPs: all focus on single conditions.<sup>91</sup>

#### **BOX 10** Categories of indicators in the QOF

##### **Clinical domain**

- Atrial fibrillation
- Secondary prevention of coronary heart disease
- Heart failure
- Hypertension
- Peripheral arterial disease
- Stroke and transient ischaemic attack
- Diabetes mellitus
- Asthma
- COPD
- Dementia
- Depression
- Mental health
- Cancer
- Chronic kidney disease
- Epilepsy
- Learning disabilities
- Osteoporosis: secondary prevention of fragility fractures
- Rheumatoid arthritis

Palliative care  
Non-diabetic hyperglycaemia

**Public health domain**

- Blood pressure
- Obesity
- Smoking
- Vaccination and immunisations
- Cervical screening

**Quality improvement domain**

- Prescription drug dependency
- Optimising access to general practice

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COPD, chronic obstructive pulmonary disease.

### **Barriers in summary**

The range of barriers to innovation aimed at helping people living with multiple long-term conditions is broad. Nevertheless, there are such innovations – for example, as revealed in our focused review of evidence on remote monitoring for patients with multiple long-term conditions – but they are relatively rare given the large number of people living with multiple long-term conditions. Barriers to innovation arise from contextual factors in the healthcare system. As discussed earlier in Themes 1 and 2, there is a general tendency in healthcare systems to focus on single conditions, and hence the problems of living with multiple simultaneous conditions are relatively overlooked. An insufficient focus on gaining a clear understanding of what matters to people contributes to that relative neglect. We find, unsurprisingly, that finance and resources also have an influence: successful innovation requires sustained devotion of resources into the future, not just during initial piloting; and financial incentives do not yet stimulate innovation for people living with multiple long-term conditions.

In the next and final theme, we reflect on how such barriers might be overcome, by making the needs of people living with multiple long-term conditions a priority in planning and delivering health care.

## **Theme 6: what is needed to make meeting the needs of people with multiple long-term conditions a priority in healthcare planning and delivery**

People with multiple long-term conditions can be expected to benefit from healthcare planning and delivery for the single conditions they have. There is no suggestion that specialisation is undesirable. But we have found from this overarching study that much more attention needs to be given to healthcare planning and delivery that recognises that people being treated for one condition are often going to be living with multiple long-term conditions. This maps to the ‘service delivery’, ‘leadership and governance’ and ‘financing’ segments of the SELFIE framework, and to the ‘organisational processes’ and ‘responsive commissioning’ dimensions of the House of Care framework. Living with multiple conditions is not exceptional and recognising this fact would mean explicitly prioritising the needs consequent on having multiple conditions, especially to enable personalised and holistic care and for co-ordination of treatments across conditions.

### **Explicit focus at all levels in the NHS on people living with multiple long-term conditions**

In the last 10 years, NHS policy in England has been significantly influenced by two national policy documents: NHS England’s ‘Five Year Forward View’<sup>192</sup> and the ‘NHS Long Term Plan’.<sup>21</sup> The ‘Five Year Forward View’ led to the piloting of five types of ‘Vanguard’ models of care (primary and acute care systems, multispecialty community providers, urgent and emergency care, acute care collaboratives



and enhanced health in care homes) across a total of 50 locations in England. Local evaluations were funded for each Vanguard scheme and the NIHR Policy Research Programme commissioned a national evaluation. MacInnes *et al.*<sup>93</sup> concluded from the national evaluation that only the Enhanced Health in Care Homes model had been scaled and spread across health services in England, despite extensive spending on the setting-up and piloting of the Vanguards, and their overall assessment underlined the challenges of sustaining innovative care models beyond a pilot phase:<sup>93</sup>

*Our study suggests that the general scaling up of the Vanguard programme was difficult to achieve. We found little evidence that the service changes introduced locally had any significant influence on subsequent service developments. Lack of leadership or direction near the end of the Vanguard programme, lack of ongoing resources, and limited success in providing real-time monitoring and evaluation may all have contributed to the failure to straightforwardly scale and spread most of the Vanguard models.*

*Reproduced from MacInnes *et al.*<sup>93</sup> in accordance with the terms of the CC BY 4.0 license (<https://creativecommons.org/licenses/by/4.0/>), which permits any use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access page (<https://us.sagepub.com/en-us/nam/open-access-at-sage>). The text above includes minor formatting changes to the original text.*

Some of the Vanguard models focused on care integration, and there were examples within these of people with multiple long-term conditions being a particular focus because of the complexity of their needs and because, in the most severe cases, of their exceptionally high use of healthcare services. One of these examples is the 'Greenvale' case study site in the BRACE phase one evaluation of hospitals running GP practices,<sup>2</sup> which had, prior to the start of that 'vertical integration', been a pilot site for a 'Five Year Forward View' 'Vanguard' new model of care. In that example, care was reorganised for patients with complex and multiple conditions who were the heaviest users of healthcare resources.

In the words of the 'The Government's 2022–23 mandate to NHS England', which at the time of writing is the most recently published annual set of objectives from the UK Government for the NHS in England: 'The NHS Long Term Plan continues to be the guiding strategy for the NHS' (paragraph 2.8).<sup>94</sup> The NHS Long Term Plan<sup>21</sup> recognises at one point (on page 100) the contribution to rising NHS costs of people with multiple conditions, but otherwise all discussion of care provision is in terms of single disease areas – cancer, cardiac, etc. – with no proposals or strategies set out to better tackle the care issues raised by living with multiple long-term conditions. The Government's mandate to NHS England makes no mention of serving people who are living with multiple long-term conditions, and none of the metrics it is using to measure NHS progress refers to them.<sup>94</sup>

Thus, the policy context within which the NHS in England operates does not currently give prominence to promoting or supporting the care of people with multiple long-term conditions, and it is within this context that BRACE evaluations have been undertaken. At an operational level, the NICE has published a clinical guideline (NG56) for the NHS on 'Multimorbidity: Clinical Assessment and Management'.<sup>12</sup> This guides healthcare professionals to:

*Consider an approach to care that takes account of multimorbidity if the person requests it or if any of the following apply:*

- *they find it difficult to manage their treatments or day-to-day activities*
- *they receive care and support from multiple services and need additional services*
- *they have both long term physical and mental health conditions*
- *they have frailty or falls*
- *they frequently seek unplanned or emergency care*
- *they are prescribed multiple regular medicines.*<sup>12</sup>

NICE [2016, paragraph 1.2.1; © NICE (2016) 'Multimorbidity: Clinical Assessment and Management'. Available from [www.nice.org.uk/guidance/ng56](http://www.nice.org.uk/guidance/ng56). All rights reserved. Subject to Notice of Rights. Reproduced in line with the licence ([www.nice.org.uk/re-using-our-content/uk-open-content-licence](http://www.nice.org.uk/re-using-our-content/uk-open-content-licence)). The text above includes minor formatting changes to the original text.

NG56 makes it clear that multimorbidity should not be overlooked. But, to put this in context, there are hundreds of NICE guidelines focused on clinical assessment and management of single conditions. Given the thousands of combinations of long-term conditions that are possible, it is not reasonable to expect guidelines to focus on specific combinations of conditions beyond those that occur frequently. Stokes *et al.*<sup>95</sup> found no clear high cost (in terms of hospital use) combinations of long-term conditions as possible targets for intervention. Using NHS data from England, they found 63,124 unique combinations of conditions for hospital patients with multiple long-term conditions in 2017–8; only seven of these unique combinations contributed any more than 1% of total cost of secondary care for patients with multiple morbidities, and the highest share of hospital costs for a single combination of conditions was 3.2% (diabetes plus hypertension). So, rather than guidelines for particular combinations of conditions, we propose that what might be more feasible would be for guidelines focused on single conditions to also prompt healthcare professionals always, by default, to consider whether the patient has other conditions and how care might best be delivered in the light of that. The need for this can be seen from the work of Guthrie *et al.*,<sup>96</sup> who investigated how multimorbidity was accounted for in three exemplar NICE guidelines for common long-term conditions (type 2 diabetes, depression and heart failure). They found that: '[c]omorbidity was rarely accounted for in the clinical research questions that framed the development of the exemplar guidelines and was rarely accounted for in treatment recommendations.'<sup>96</sup>

In the interviews we undertook, several stakeholders, both at national and at regional (Integrated Care System) level, commented that people with multiple long-term conditions represent a large proportion of patients and acknowledged that they have particular care needs, for example, for personalised and holistic care, and for care to be communicated and co-ordinated across conditions, services and sectors. But, in the words of one interviewee: 'some of the national frameworks just don't align to help the incentives that need to happen to make multimorbidity more joined up at the local level'.

National interviewees were asked specifically about their thoughts on the role of the (regional) Integrated Care Systems and Integrated Care Boards in driving service improvement for people with multiple long-term conditions. Answers predominantly concerned setting a strategic vision for integrated working and linking services together with joint funding that was collaborative rather than competitive, and sharing learning across the locality. Respondents underlined the importance of robust needs assessments for people with multiple long-term conditions with services commissioned and provided based on these assessed needs. The provision of funding and support to foster innovation for people with multiple long-term conditions was thought to be part of the role of new Integrated Care Systems. Indeed, interviewees at Integrated Care System level referred to examples of a regional initiative to fund a 'complex care service' and another to develop 'personalisation' of care. The value of national support and impetus for innovation was evident from the findings of the BRACE evaluation of WHHs,<sup>10</sup> for example. In that study, interviewees highlighted that support at a national policy level had helped to drive change and develop and embed WHHs but that there was, unhelpfully, a lack of associated national funding or guidance for the policy (at the time of fieldwork).

### **Service design with patients and carers**

Our interviews elicited that Integrated Care Systems and the service providers within them need to be clear about what it is they aim to achieve for people with multiple long-term conditions. When asked about what a system for service development that prioritises people with multiple long-term conditions would look like, a national interviewee proposed that there would be frameworks for decision-making developed with NICE, NIHR and the Royal Colleges, and with a lot of patient and carer involvement. This interviewee drew a parallel with work led by NHS England to produce consensus guidelines for PEOC.<sup>97</sup>



Palliative care focuses on the patient, not the individual conditions they may be living with, and as such can be seen as an example to learn from. Integrated Care Boards have a statutory duty to commission palliative care services; guidance on how they are to do this, including links to resources and good practices, has been developed by NHS England to support that statutory duty. Indeed, Integrated Care Boards are required by statute to take the NHS England guidance into account and that guidance in turn requires that:

*Every ICB [Integrated Care Board] should commission PEOLC [Palliative and End of Life Care] services that meet people's needs, aligning to the commitments within the Ambitions for Palliative and End of Life Care: A national framework for local action 2021–2026.<sup>97</sup>*

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The framework referred to in the statutory guidance was developed and published jointly by 34 organisations, including a large number of patient and carer charities along with Royal Colleges, health and social care professional and provider associations, and NHS England, Health Education England and Public Health England.<sup>98</sup> It is notable that the first of the six 'ambitions' that make up the framework is that 'each person is seen as an individual' and that another 'ambition' is that 'care is co-ordinated'. [Box 11](#) summarises what we see as the key elements of successful co-design and promotion of such guidance. Providing guidance co-designed with patient and carer groups, even when backed by a statutory requirement to follow it, does not guarantee that the desired care will be available. But it is clear about what is wanted. Similarly, clear and forceful guidance developed with strong patient and carer input might well help to give priority to serving people with multiple long-term conditions.

#### BOX 11 Co-designing and promoting guidelines: the example of PEOLC

Based on the example of 'Palliative and End of Life Care. Statutory Guidance for Integrated Care Boards (ICBs)'. 29 September 2022. NHS England. [www.england.nhs.uk/wp-content/uploads/2022/07/Palliative-and-End-of-Life-Care-Statutory-Guidance-for-Integrated-Care-Boards-ICBs-September-2022.pdf](http://www.england.nhs.uk/wp-content/uploads/2022/07/Palliative-and-End-of-Life-Care-Statutory-Guidance-for-Integrated-Care-Boards-ICBs-September-2022.pdf)<sup>97</sup>

- Integrated Care Boards have a *statutory duty* to commission palliative care services.
- *NHS England* provides *guidance* to Integrated Care Boards on how to comply with this duty.
- Guidance is based on a *national framework for local action*.
- Framework is jointly designed and promoted by organisations representing:
  - patient and carer charities
  - clinical Royal Colleges
  - health and social care professional associations
  - health and social care provider associations
  - NHS England.

At the level of an individual service, as distinct from an overall approach to be taken to providing health care in an area, some of the studies we found in our evidence review of remote monitoring describe steps being taken to meet the needs of people living with multiple long-term conditions. For example, Doyle *et al.*<sup>82</sup> describe a process of consulting with patients, clinicians and other stakeholders such as experts and academics, to design a remote monitoring intervention that would cater specifically to people living with multiple long-term conditions. This contrasts with what BRACE researchers found in the evaluation of AI with home sensors in social care,<sup>7</sup> where it was evident that different stakeholders were seeking to resolve a number of potentially different problems and seeking a number of different outcomes, with an apparent lack of a shared understanding of what success would look like.

Another study in our evidence review highlighted a way to gather feedback from people living with multiple long-term conditions, their carers and healthcare providers. Craven *et al.*,<sup>68</sup> in their qualitative study to inform the development of a remote measurement technology, used a method they called 'universal points of care (UPOC)' as a way to elicit and analyse care pathways using scenarios. This

method includes asking patients and clinicians how they would go about sharing data, communicating and selecting treatments across different conditions. We consider that similarly inclusive approaches to planning provision of other healthcare services would help lead to care that better supports people with multiple long-term conditions.

### ***Financial incentives***

The subthemes of explicit focus and the co-designing of services with patients and carers, presented in the preceding paragraphs, respond to some of the barriers to developing and implementing appropriate services that were set out in Theme 5. These barriers concerned the single-condition focus evident in NHS organisation; the training and ways of working of healthcare professionals, and even the expectations of patients; and the lack of a clear understanding of what matters to people living with multiple long-term conditions. We also noted within Theme 5 that interviewees had pointed out that financial incentives to primary care and secondary care providers in the NHS are aligned with care for single conditions, and that none reward co-ordination of care across conditions for someone living with more than one of them.

We propose that incentives that signal the importance of measures to support specifically patients with multiple long-term conditions would help direct more of the scarce management time in secondary care (where funding goes to the provider organisation, i.e. the NHS trust or NHS foundation trust) and GP/practice management time (where funding goes to the practice) towards that end. For example, specific QOF indicators for care co-ordination for patients with multiple conditions, and hence associated payments to GP practices, might help to overcome the very practical difficulties of giving more staff time to achieve that. The existence of such incentives would also signal the seriousness with which co-ordinating care for patients with multiple long-term conditions is taken.

We note that while financial incentives might prove helpful, they do not appear to be a necessary condition for better serving patients with multiple long-term conditions. The BRACE evaluation of WHHs<sup>10</sup> – see [Box 2](#) in the discussion of Theme 2 – found that where these hubs had been established, this was due to local initiative rather than a specifically funded or financially incentivised development. WHHs exist to co-ordinate care for women for their reproductive health, which although different from the issue of multiple long-term conditions has parallels with that, particularly concerning the desirability of better co-ordination of care and taking account of wider health needs and inequalities. The experience with WHHs implies that improved care co-ordination is prioritised in some places (and for this patient group), without there being targeted funding or incentives.

### ***Challenging the narrative that multimorbidity is inevitable***

Reflecting the nature of the portfolio of service innovations that BRACE has evaluated, our attention in this report is mainly on how healthcare services are, or could be, provided. But achieving priority for patients who are already living with multiple long-term conditions may need to be associated with making 'multiple long-term conditions' explicitly part of the public health agenda by including strategies and activities aimed at risk identification – underpinned by data analytics – and prevention, or at least delayed onset, of people acquiring multiple long-term conditions. More prioritisation of, and hence investment in, primary prevention and secondary prevention would, in the words of one of the national-level stakeholders we interviewed, 'challenge the narrative that multimorbidity is inevitable when actually so much of it isn't'. Such prioritisation and investment would at the same time be fully aligned with the desire to reduce health inequalities, as people in more deprived groups of the population acquire multiple long-term conditions years younger than do others.<sup>14,50,99</sup>

## Chapter 6 Implications for policy and practice

Our synthesis of the cross-analysis of the BRACE portfolio of evaluations, interviews with national and regional stakeholders, and a rapid review of evidence on remote monitoring for people with multiple long-term conditions implies a range of actions for policy and practice. These actions are focused on how to improve consideration of the needs and care of the large part (for many age groups the majority) of the patient population who live with multiple long-term conditions. Our main suggestions arising from the synthesis are described in the following paragraphs and summarised in [Table 6](#), where we identify the groups of stakeholders most directly implicated. Implications for research funding and research practice are presented in the subsequent section.

### Recognising multiple long-term conditions as the norm

An overriding implication of this study is the need for policy and practice to make consideration of living with multiple long-term conditions the norm, not the exception, at a patient level. This represents a policy ambition whereby the whole picture of care for an individual is central to any interaction they have with the health system, and it would be considered unacceptable for those who plan and deliver care to fail to take account of the whole set of health conditions. There is much discussion of the need for 'holistic care' and consequent 'personalised care' in numerous contexts, but they are most important for people living with multiple long-term conditions. As noted in this report, there is too often a recourse to new initiatives or pilot projects to try to enable 'integrated care' or 'care co-ordination' without attending to the patients' own experiences of multiple conditions, and without addressing fundamental problems with the administration and communication of different appointments, treatments, medications and services.

One potential approach to rectifying this inattention to the needs of patients with multiple long-term conditions, highlighted by one of our interviewees, is to emulate the work led by NHS England to produce consensus guidelines for PEOLC and do something similar for care for people with multiple

**TABLE 6** Summary of policy and practice implications and for whom

	Department of Health and Social Care	NHS England	NHS regulators: NICE; CQC	Integrated care boards/ systems	Primary and secondary care provider managers	Healthcare professionals	Professional associations and Royal Colleges
Make considering MLTCs the norm	✓	✓	✓	✓	✓	✓	✓
Develop and implement consensus guidelines		✓	✓				✓
Including MLTCs in commissioner and provider strategies			✓	✓	✓		
Consult patients with MLTCs and their carers	✓	✓	✓	✓	✓	✓	✓
Identifying evidence-based innovation to spread/scale-up		✓	NICE	✓			✓
Metrics that matter to people with MLTCs	✓	✓	✓	✓	✓	✓	✓

MLTCs, multiple long-term conditions.

long-term conditions. Palliative care focuses on the patient and their priorities for symptom control, quality of remaining life and wishes in respect of dying, not the individual condition(s) they are living with. Integrated Care Boards are required by statute to commission palliative care services and are guided in how to do this by NHS England, who in turn consulted widely in creating that guidance. Patient and carer charities, Medical Royal Colleges, health and social care professional and provider associations, NHS England, Health Education England and Public Health England all collaborated to produce the framework on which the guidance is built, and which sets out six 'ambitions' and describes the 'building blocks' that need to be put in place to achieve them.<sup>98</sup>

Whether or not it would be appropriate for it to be a statutory requirement, we consider it would be a significant step towards better range and co-ordination of holistic services if consideration of this population group were to be a core part of Integrated Care Board, Integrated Care System and provider organisation strategies, with associated requirements to take account of the complete patient history and their experience of care across departments, services and organisations, etc., and to measure experience and outcomes from the user and carer perspective. Regulation by the CQC could then include monitoring of whether these strategies exist and how far they are being acted upon, using experience and outcomes data to inform this process.

There is a current NICE guideline specifically focused on care for people living with multiple long-term conditions<sup>12</sup> and information about particular comorbidities is included in many of NICE's condition-specific guidelines. But consideration of multiple long-term conditions within care guidance could go further, for example, including prompts to clinicians to ask patients (or their carers) about (other) long-term conditions they may be living with, how the treatment pathway that is the current focus intersects with other treatment pathways and medications, and whether any active co-ordination and information sharing with other clinicians is needed.

We conclude that it is necessary to find more systematic and sustained ways to involve patients with multiple long-term conditions and their carers in determining needs and designing ways to improve care. Our work has revealed how a clear understanding of what matters most to people living with multiple long-term conditions is sometimes lacking. What matters to patients with multiple long-term conditions (where one or more conditions are becoming problematic in everyday living) may not be a new technology or service; it may be as basic as wanting different parts of their care to be properly co-ordinated. For example, they may want the healthcare professionals they come into contact with to each know what each of the others is contributing to that person's care. National Voices summarised this as: 'I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me.'<sup>100</sup> Achieving that would help to reduce the treatment burden on the patient and the 'navigation work' that the patient has to undertake.

National Voices' 'Ask How I Am' report and recommendations additionally highlight the importance of always asking about emotional and mental well-being, even if that is not the primary purpose of a contact with the NHS, offering a further possibility for how the needs of people with multiple conditions might become part of routine concern and care when people interact with the healthcare system.<sup>101</sup>

Based on our review of literature on remote monitoring, there is an existing evidence base, albeit a patchy one, for some innovations that do effectively (and possibly cost-effectively, although evidence about cost-effectiveness is as yet scarce) serve the needs of people with multiple long-term conditions. Examples of possibly cost-effective innovations from our evidence review include home monitoring for patients with advanced heart and lung failure<sup>66</sup> and remote monitoring of COPD among patients with multiple long-term conditions.<sup>102</sup> The innovations of interest, beyond examples such as those, do not have to be particularly new, but their implementation would not yet be widespread or at scale. There is a role for identifying evidence-based service improvements and how to implement them generally and/or scale them up.

Within Theme 4 we discussed the importance of collecting and monitoring data to measure the care being provided to patients living with multiple long-term conditions and of doing this from the perspective of the user rather than according to an institution or service. Using such metrics would reinforce the importance of caring for this significant element of the patient population and could be used to inform assessments of care quality by the CQC. They might even be included within revisions to the QOF for GPs, and hence be linked to financial incentives, in contrast to the largely single-condition focus of current primary care targets and incentives. Such metrics might focus on measures of care that assess the degree of co-ordination, rather than fragmentation, that indicate whether holistic and personalised care are actually being provided. Examples of such metrics exist (e.g. Crump *et al.*<sup>73</sup>), but they need to be implemented, tested and refined at scale.

On 24 January 2023, the Secretary of State for Health and Social Care announced to Parliament that 'in consultation with NHS England and colleagues across government, my Department will develop and publish a Major Conditions Strategy'. The announcement was quite brief but nevertheless took the space to emphasise the importance of caring for people with multiple long-term conditions:

*Our approach will harness the potential of whole person care, addressing the fact that our health and care system has been built in silos, often focused around specific diseases or organs in the body. Our workforce model needs to adapt, reflecting that the NHS is caring for patients with increasingly complex needs and with multiple long-term conditions. We need greater emphasis on generalist medical skills to complement existing deep specialist expertise in the NHS, supporting clinical professionals to heal with whole person care.*<sup>103</sup>

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This is an encouraging announcement. We hope that the implications of this study, as set out above, can be reflected in that strategy and its subsequent implementation.



## Chapter 7 Implications for research

The findings of this overarching study of 10 BRACE evaluations in respect of research are presented with two distinct but sometimes overlapping audiences in mind:

- health services researchers
- health research funders

### Implications for health services researchers

A strong theme throughout this study is the need to routinely take into account when designing, undertaking, and reporting on health services research and evaluation that many people are living with multiple long-term conditions. There is therefore a need for the proposed policy guidance referred to in Theme 6 to be translated into criteria that can be used by researchers to ensure that their studies are properly taking account of the needs of people living with multiple long-term conditions in much the same way that PPI, or research inclusion, are expected to be woven into health services evaluation proposals and protocols.<sup>104,105</sup> The development of explicitly pragmatic research designs that reflect the likely user group(s) of an intervention have supported inclusion of otherwise excluded populations.<sup>28</sup> Utilising the typology of evaluations (see [Table 2](#)) to situate studies or organise reviews can also help researchers account for if and how their work are taking into account people living with multiple long-term conditions; other suggestions for criteria are set out in [Box 12](#).

**BOX 12** Suggested multimorbidity criteria to be applied to health services evaluation proposals

- How might the proposed intervention in your evaluation affect people living with multiple (two or more) long-term conditions?
- Where is your study located within the typology (shown in [Table 2](#)) of evaluations of innovations for people living with multiple long-term conditions?
- Is this population group a central focus of the study and, if so, how will they be involved in its design, operation and reporting?
- If people living with multiple long-term conditions are not the central focus of the study, how will you explore the impact of the intervention on this group?
- Could you include specific research questions, broader samples, secondary data analysis or other approaches that would enable exploration of the implications for people living with multiple long-term conditions?
- Are people living with multiple long-term conditions and their carers involved in your patient and public involvement and engagement arrangements for the evaluation, including in scoping research questions, methods, outcome measures and dissemination?
- If you are measuring patient and/or carer experience, does this include the individual user's perspective on how well their care is co-ordinated across sectors, organisations and services in respect of all the long-term conditions they may be living with?

These criteria could provide a specific multiple long-term conditions focus to prior advice and checklists proposed for the evaluation of innovations intended to improve health care, as in Bardsley *et al.*'s review<sup>106</sup> of the experience of undertaking over 30 studies of community-based interventions intended to deliver more integrated care. That synthesis of evaluation practice warned in particular of the perils of assuming that a measure such as 'avoided emergency admissions to hospital' would demonstrate 'success' and the importance of tracking care across services and sectors, using linked data where possible.

A further implication for researchers of our overarching analysis of how the needs of people with multiple long-term conditions are attended to within evaluations is the importance of exploring diverse ways of undertaking patient and carer research within rapid evaluations. This includes how



to identify the group of patients living with multiple long-term conditions, for example, through GP practice registers, routine hospital episode statistics data, national patient surveys, or NHS trust patient administration systems. Organisations, practices and professionals do not commonly tag or identify this group. It would seem to be a priority to address this, so that people with multiple long-term conditions (often a majority group within a patient population) can be assured that sufficient research, policy and practice attention will be paid to them and their needs.

### Implications for health services research funders

Research funding needs to attend systematically to the needs of people living with multiple long-term conditions. It is therefore desirable that research funders explore how the needs of this population can best be threaded through research studies in a systematic manner that profiles their importance and 'being the standard'. One example of how this might be addressed is the approach used previously by the NIHR HSDR Programme (and other NIHR programmes) to offer funding to commissioned research teams for enhancements known as 'studies within a project'<sup>107</sup> that address the needs of people with multiple long-term conditions. Another approach that could be taken would be to require that criteria like those set out in [Box 12](#) be used when scoping and designing an evaluation of a service innovation, along with subsequent reporting of the impact on and experience of people with multiple long-term conditions.

This overarching study in itself points to the potential for substantial, multiyear analysis to be carried out on the basis of a series of shorter-term, focused evaluations, provided that there is resource and commitment on behalf of research commissioners to doing the synoptic thematic work. This enables another axis of learning over and above that which emerges from individual projects, and is arguably another application of the NIHR 'studies within a project' approach, being perhaps a 'study across linked projects' analysis.

Above all, we conclude that there needs to be a constant challenge to the single-specialty or -condition focus of studies. While such a focus will sometimes be justified, on other occasions there will be significant potential to explore the implications of a service innovation for a broader population including those with multiple long-term conditions, and to be alive to the consequences for this group.

We have identified a need for the health services research community to profile more assertively the evidence of what service innovations work, even if long known. While policy-makers may prefer to highlight the 'shiny new' service innovation, too often these are not sustained beyond a pilot phase, nor in a widespread manner. Innovations for people living with multiple long-term conditions could include 'less exciting' improvements that help to resolve the long-standing struggle in the NHS for better patient administration and communication. Too often, rather than explore why it has been so hard to make arguably unexciting but important changes, researchers are drawn by policy priorities to the as yet unproven 'fad or fashion'.<sup>53</sup> Skills in evidence synthesis and information science need to be more widely available to research teams, as evidence needed to scope a new study may be located within research from a different service or sector, international experience or evaluation material published in non-traditional formats.

A third implication for research funders, and indeed the broader health services research community, is to commission more implementation research to explore and (as appropriate to the innovation) support sustained spread of promising innovations beyond pilots and trials. There is a need to build ever stronger connections across funding programmes so that innovations can routinely draw on expertise in cultural and behavioural change, service development and improvement, adapting professional roles, and other organisational matters, to ensure the best possible chances of exploring sustainability and spread of innovation.



Finally, we list in [Box 13](#) some areas of uncertainty related to the care of people with multiple long-term conditions that arose from our overarching study and that we share as possible topics for the commissioning of future research.

**BOX 13** Areas of thematic uncertainty needing research

***What is important to people with multiple long-term conditions and how to measure it?***

Explore which administrative and patient services issues matter most to patients with multiple long-term conditions and undertake research in sites where work has been done to address these, developing proposals about what it would take to have fully integrated and electronic patient administration and communication that is organised completely from the patient and carer perspective.

Examine how much specialism matters to people, especially when they live with multiple long-term conditions, and what trade-offs they might make in respect of complex care arrangements, many appointments and medicines, and the dimensions of quality of life that work best for them.

Interrogate the experience of health and care staff when working with people living with multiple long-term conditions to understand what works, or not, from their perspective.

Explore different ways to assess outcomes that matter most to patients with multiple long-term conditions and their carers.

Develop and test measures of patient experience of (un)co-ordinated care across diverse settings and sectors.

***How to improve care for people living with multiple long-term conditions?***

Explore what has happened in previously vaunted innovative or outstanding service developments such as integrated care schemes or hospital at home, returning to find out 'what happened next' and what worked longer term, and what context, interventions, support, roles, funding, etc. can enable sustainable change at scale.

Explore what learning might be gained for service organisation and provision for people with multiple long-term conditions from the ways in which PEOLC has evolved to have core principles and practice beyond individual conditions.

Consider using long COVID as a particular test case for how the needs of people with a complex mix of long-term conditions stretching beyond usual specialties and services can be accommodated in ways that enable co-ordinated and person-centred care and avoid duplication and fragmentation of services.

Examine the different workforce requirements needed to deliver care that is attuned to the needs of people living with multiple long-term conditions, exploring these in different sectors and types of healthcare organisation.

Understand user experience of remote monitoring interventions across different care settings for people living with multiple long-term conditions and examine the level of clinical support that is acceptable for those requiring varying levels of clinical input.



## Chapter 8 Limitations

This overarching study is based on our analysis of the BRACE portfolio of studies; thus it is based on the 10 evaluations that have been published by the NIHR Journals Library and is not meant to be exhaustive. The work has been supplemented by research activities with a limited scope, including a rapid but replicable review of the literature related to remote monitoring technology for people living with multiple long-term conditions and a set of interviews with national and regional stakeholders based on a convenience sample. Given the pragmatic approach, detailed demographic data on stakeholder participants were not collected, nor are we able to synthesise participant information across the 10 evaluations to understand possible areas of under-representation in this overarching study.



## Chapter 9 Conclusion

In this synopsis report, we have explored the 10 studies undertaken by the BRACE over the period 2018–23, focusing on the ways in which these evaluations of service innovations took account of and impacted on people living with multiple long-term conditions. Through a thematic analysis of the portfolio of evaluations, we have deduced a set of suggested implications for policy, research and practice in respect of attending to the needs of people with multiple long-term conditions when designing and undertaking evaluations of service innovations, and for health and care policy and research more generally. What is clear is that while multimorbidity is a common occurrence, and usually the norm for people over the age of 50 using health and care services, it is not yet at the heart of health service provision, nor of research and evaluation activity. We hope that this overarching study offers useful pointers to how progress might be made in paying greater attention to the health and care needs and priorities of people living with multiple long-term conditions.



# Equality, diversity and inclusion

## Participant representation

The study reported here draws mainly on the BRACE portfolio of evaluations, supplemented by a focused review of literature and interviews with NHS policy- and decision-makers at national and sub-national levels in England.

The ways in which BRACE researchers sought to ensure appropriate representation and reflection of diverse population groups in individual evaluations is described in the corresponding report of each of the individual evaluations, and they are published in the NIHR Journals Library. Overall, BRACE researchers in each evaluation have used a range of strategies to promote inclusivity. For example, the team offered interviewees different modes of interview [in person, telephone or online via Microsoft Teams or Zoom (Zoom Video Communications, San Jose, CA, USA)] and different times depending on participants' preferences to ensure accessibility for as many people as possible given workforce and work-life balance constraints.

## Participant characteristics

For the supplementary interviews conducted for this overarching report, participants were invited based solely on their (managerial and clinical) roles and necessarily were all adults of working age. De facto we interviewed female and male participants from a range of ethnic backgrounds. The study team did not collect data relating to interviewees' personal demographics such as gender, age and ethnicity as we focused on professional characteristics.

## Research topics relating to equality, diversity and inclusion

In all parts of the overarching study, we have paid active attention to any mention of inequalities for any population subgroups. We had a clear focus on inclusivity in relation to capturing the experience of those serving and living with multiple long-term conditions, a group which in the past has been identified as a priority when designing and co-ordinating care across the NHS in a range of settings. Indeed, the focus of this study has been on the need to bring an often-ignored yet large patient population – those living with multiple long-term conditions – to the forefront of research, policy and practice, drawing and reflecting on our BRACE portfolio of evaluations.

## Reflections on the research team and wider involvement

### Research team

The research team for the overarching study was a small, mixed-methods, multidisciplinary group (applied health services research, health services management, health economics, statistics). Team members included two senior researchers, two mid-career researchers and a number of early career researchers. The research team had a majority of female members. All team members' contributions have been recognised, and all were given opportunities to attend analysis workshops. Throughout the overarching study and as an integral part of our research method, the research team held frequent meetings to discuss project management, data collection, analysis and write-up, with additional workshops to shape the interpretation of findings.

***Wider involvement***

Throughout the evaluation, the team sought the advice of external academic experts experienced in aspects of the study ('critical friend' colleagues at the University of Birmingham and RAND Europe who were not otherwise involved in this study), the BRACE Steering Group and members of the BRACE PPI Panel.



## Patient and public involvement

**B**RACE PPI Panel members were involved at key stages throughout this overarching study, as well as in all 10 BRACE evaluations on which this study draws. Six members participated in the prioritisation process that identified multiple long-term conditions as the focus for the overarching study. In the workshop with National Voices in April 2022, organisational representatives of health service users and carers were involved in distilling focus areas relating to health services for people living with multiple long-term conditions. For these two activities, we asked participants to provide their own input into the process and to sense check and challenge as necessary the questions we were asking to help ensure we were asking the right questions.

Additionally, the protocol for this study was developed with inputs from two members from the BRACE PPI Panel, and two Panel members participated in the online workshop to synthesise overall findings and develop implications of the work in March 2023. The plain English summary of the report has been reviewed by the same two members of the BRACE PPI Panel. Participation of PPI Panel members in these activities helped to ensure the study approach was sound, focused on the needs and priorities of people with multiple long-term conditions, and that the conclusions we were drawing from the work were appropriate.



# Additional information

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## Contributions of authors

**Jon Sussex** (<https://orcid.org/0000-0001-8970-4546>) (Chief Economist at RAND Europe and Co-Director of the Cambridge Centre for Health Services Research, a collaboration between RAND Europe and University of Cambridge) co-led the study. He contributed to the conception and design of the study, the theoretical framework, and overall data analysis and interpretation, and writing of the final report. He is corresponding author of the final report.

**Judith Smith** (<https://orcid.org/0000-0003-4036-4063>) (Professor of Health Policy and Management, and Director of the BRACE) was the principal investigator and co-led the study. She contributed to the conception and design of the study, overall data analysis and interpretation, and writing of the final report.

**Frances M Wu** (<https://orcid.org/0000-0002-9951-6626>) (Senior Analyst, RAND Europe) was a researcher for the study. She contributed to data collection, overall data analysis and interpretation, and writing of the final report.

All authors contributed to integrating the findings of the study. Judith Smith and Jon Sussex made critical revisions to the report for important intellectual content and approved the final manuscript. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the article are appropriately investigated and resolved.

## Disclosure of interests

**Full disclosure of interests:** Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at <https://doi.org/10.3310/PTRU7108>.

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### **Data-sharing statement**

Each BRACE evaluation report referred to in this report includes its respective data-sharing statement. Data from the supplementary interviews will be accessible to participants who took part in this rapid evaluation following GDPR, RAND Europe and University of Birmingham data protection guidelines upon request. To protect the anonymity of interviewees, the data are not publicly available. Further information can be obtained from the corresponding author.

### **Ethics statement**

Ethical approval was obtained from the University of Birmingham Arts and Humanities Research Ethics Committee (ERN\_13-1085AP49) on 3 November 2022.

### **Information governance statement**

University of Birmingham and RAND Europe Community Interest Company are committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679.

### **Department of Health and Social Care disclaimer**

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This monograph was published based on current knowledge at the time and date of publication. NIHR is committed to being inclusive and will continually monitor best practice and guidance in relation to terminology and language to ensure that we remain relevant to our stakeholders.

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