LOGO

FUNDED BY

FULL/LONG TITLE OF THE STUDY

The Care-Full Study: A systems approach to older adults with multiple long term conditions' home-based care: mapping, scoping, feasibility, and modelling of factors affecting outcomes for unpaid caregiving.

SHORT STUDY TITLE / ACRONYM

The Care-Full Study: A systems approach to older adults with multiple long term conditions' home-based care / Care-Full

PROTOCOL VERSION NUMBER AND DATE

Version control: V1.0 08/11/23

Versi

STUDY SUMMARY

Study Title	The Care-Full Study: A systems approach to older adults with multiple long term conditions' home-based care: mapping, scoping, feasibility, and modelling of factors affecting outcomes for unpaid caregiving
Internal ref. no. (or short title)	The Care-Full Study: A systems approach to older adults with multiple long term conditions' home-based care
Planned Size of Sample (if applicable)	Up to 45 participants (WP1, WS1 – Up to 30 participants, 10 per workshop (x3); WP1, WS2 – Up to 15 unpaid carer participants)
Planned Study Period	18 months

FUNDING AND SUPPORT IN KIND

FUNDER(S) (Names and contact details of ALL organisations providing funding and/or support in kind for this study)	**FINANCIAL AND NON-FINANCIAL SUPPORT GIVEN**
Jointly funded between the National Institute for Health and Care Research (NIHR) and the UK Research and Innovation Engineering and Physical Sciences Research Council (EPSRC). Call specification here: https://www.nihr.ac.uk/documents/systems-engineering-innovation-hubs-for-multiple-long-term-conditions-seismic/31133	£204,825.89 to cover the full cost of the study.

INVESTIGATORS

NAME	**Position**
Professor Caroline Nicholson	Professor of Palliative Care and Ageing – Joint Principal Investigator (PI)
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Professor Tao Chen	Professor in Chemical Engineering; Associate Dean (International) – Co-Investigator (Co-I)
Rebecca Sharp	External Co-Investigator (Social Care)
Marie Cooper	External Co-Investigator (PPIE)
Professor Heather Gage	Professor of Health Economics – Co-Investigator
Professor Gustavo Carneiro	Professor of AI and Machine Learning – Co-Investigator (Co-I)

STUDY PROTOCOL

1. Abstract

Background: 1.5 million older people are estimated to have an unmet need from state care provision, and this is expected to more than double by 2051. Unpaid carers often meet this gap and 1 in 5 adults in the UK are carers. Caring can be rewarding but also brings health and financial challenges. Unpaid carers of older people with multiple conditions carry out complex care work, are the first point of call in an emergency, but are less likely to receive support than other types of carers. This partnership brings system engineers, unpaid carers, older people, and care providers together, to develop understanding, and translate real-world information into unpaid caring system model(s). Possible model applications include proactive identification of unpaid carers at risk of adverse outcomes and predictive modelling of scenarios to support the decisions that carers make in the daily trade-offs of caring, e.g., how to balance caring and other work priorities.

Aims: This project has the following aims: 1) To understand the key events, trajectories and outcomes for unpaid carers and community-dwelling older people with multiple conditions within a care system. 2) To identify what evidence and data sources can be collected for modelling this care system. 3) To explore how modelling methods drive interventions to support better outcomes for unpaid carers and older people with multiple conditions.

Method: Over 18-months we will carry out 3 work packages (WPs). WP1, comprised of two Work Streams (WS), uses participatory workshops, a literature review, and repeat interviews with a longitudinal cohort involving unpaid carers and those they care for across three research sites in England. WP2 will use mathematical systems modelling to identify links between the experiences and outcomes of unpaid carers and older people, to inform optimal service delivery. Possible model applications include proactive identification of unpaid carers at risk of adverse outcomes and predictive modelling of scenarios to support the decisions that carers make in the daily trade-offs of caring, e.g., how to balance caring and other work priorities. WP3 involves building the research capacity, infrastructure, and knowledge base for unpaid caregiving research and innovation, contributing directly to the development for a second stage bid for the Systems Engineering Innovation hubs for Multiple long-term Conditions (SEISMIC) funding call that will fund a national caregiving research centre, referred to by the funder as “Hub”.

Outputs: (1) Innovative systems models of home-based care provision for older people with multiple conditions. The novelty of our proposed approach is that it enables informed suggestions for action even amidst significant uncertainty, risk, and complexity. The ability to make targeted interventions lays the groundwork for the Hub stage where we look at doing this at scale, whilst incorporating constraints and variables. Thus, we can tailor the tool to specific scenarios and predict major carer events impacting themselves and the older people for whom they care. (2) Contribution to platform study design- In contrast to a ‘common-sense’ approach that might improve one aspect of care provision through an intervention between a small number of causes and their immediate effects, the systems model(s) we propose will enable decision-making under uncertainty, considering the multitude of causal factors, actors, events, and possible outcomes. (3) Understanding of the types and feasibility of data that can be collected to scale in the Hub. A strong partnership team working on the future Hub call. (4) Dissemination through publications and outputs on aspects of the partnership methods, including Care-

Full Companion involvement - co-produced with patient and public involvement and engagement (PPIE) representatives and strategic partners.

2. Background or rationale of the project

Multimorbidity has been described as the greatest clinical challenge facing the NHS and social care system[1] and is associated with increased mortality, lower quality of life, and greater use of healthcare services, including unplanned hospital admissions.[2] Older people requiring care are set to increase by 113% by 2051.[3] The level of demand for care outweighs current state provision and 1.5 million older people are estimated to have an unmet need for care.[4] The gap between care need and care provision is likely to be met by family and friends; currently 1 in 5 adults in the UK are providing unpaid care.[5] While caregiving can be enriching it can also bring challenges. Carers UK's 2022 survey[6] found a fifth of carers surveyed said their physical health was bad or very bad (21%) and 30% said their mental health was bad or very bad. 29% of carers reported always/often feeling lonely, 41% have not taken a break from their caring role in the last year, and 75% continue to juggle work and care. Caring for an older person with multiple conditions presents unique challenges; experiencing less support from healthcare services compared to caring for those with single illnesses[7] and additional care work associated with complexity, e.g., managing polypharmacy and coordinating with multiple services across care sectors.[8] Carer burden increases with more responsibilities, e.g., young children, and rises with combined cognitive and physical vulnerability.[9,10] Evidence is weak around the effectiveness of targeted interventions to support unpaid carers,[11] and support from the care system is ad hoc, inequitable, and reactive.[12] Unpaid carers are infrequently built into the care system as equal partners,[13] and often experience a "double bind of being responsible for care delivery without information, skills, or support to deliver that care.[14]

Built upon the application team's expertise on ageing population and systems engineering research, this proposal seeks to establish a new CARE-Full partnership and Hub. To systematically interrogate the complex real world of unpaid caregiving and the interlinking of health and wellbeing between unpaid carer and the person for whom they care. This new partnership will involve three key building blocks (described as work packages in Section 6 below). Firstly, knowledge and views from key stakeholders of unpaid caring, including unpaid carers, older persons with multiple conditions, and health and social care providers, will be systematically extracted and documented using a Participatory Systems Mapping approach.[15,16] This will enable an overall picture of the complex factors in unpaid caring to be used in the modelling phase. Secondly, the partnership will seek to scope available and informative primary and secondary data sources related to unpaid caring and assess the feasibility of primary data collection with participants; ensuring that the real-world complexities of unpaid caring can be reliably measured and modelled. Thirdly, we will seek to build system models of unpaid caring, utilising advanced simulation and reinforcement learning techniques to identify factors that impact carer outcomes. Future Hub phase work will use these models to predict events that may happen in unpaid caregiving, to inform a series of interventions for optimising complex decisions and daily trade-offs faced by unpaid carers, e.g., how to balance the caring and other work, family needs and individual needs, and who to involve in decisions about care. Jointly, the three building blocks, alongside the building of partnerships with key stakeholders across the care system, will lay the groundworks for a CARE-Full Hub that will further enrich and interrogate system models with large-scale data across diverse contexts and cultures to test and implement actionable sequential interventions to better outcomes for unpaid carers and older people.

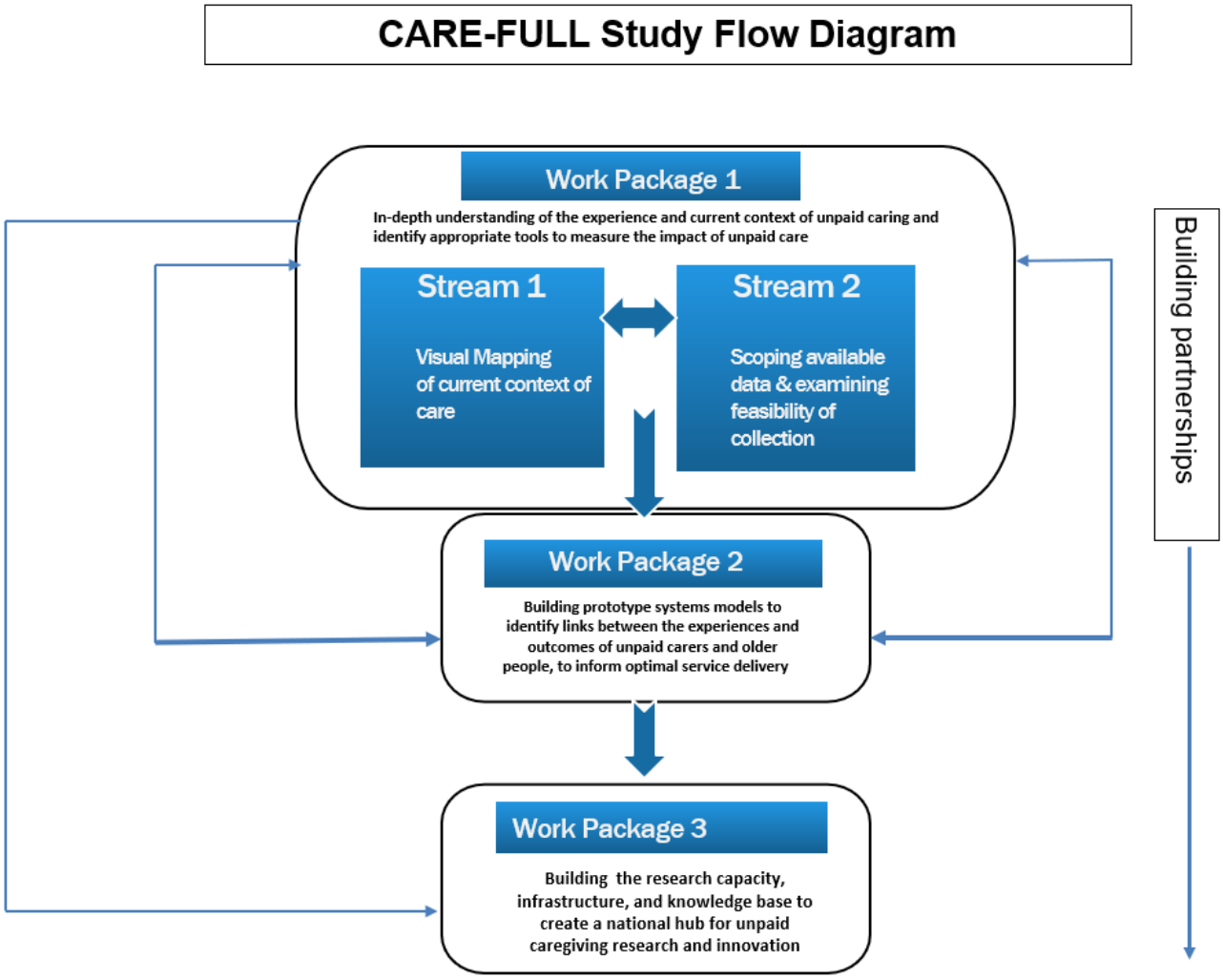
3. Patient/Participant involvement and study governance

This research design is directly informed by Patient and Public Involvement and Engagement (PPIE) representatives and research participants from the National Institute for Health and Care Research

(NIHR) funded Palliative Upstreaming ('PALLUP') study (reference code: ICA-SCL-2018-04-ST2-001) and contributes to the broader research programme of the study.

The funders for this research require that data management and project advisory representatives have oversight of this study and a joint project data management and ethics group (DMEG) and project advisory group (PAG) has been formed for this study, known hereafter as the Project Steering Group (PSG). This group is comprised of two PPIE representatives, four data management representatives, and six project advisory representatives and will meet three times over this 12-month study. A separate PPIE group will also be formed from representatives drawn from the study site localities who will continue to support this study throughout, taking on advisory roles in study governance and providing peer support to support the delivery of research activity. This will be done using a 'portfolio' approach to working with PPIE representatives, which recognises their needs as busy people with existing workload burdens, which require us – in seeking to be sensitive to their needs – to arrange our work with PPIE in a flexible way that will mutually support their needs and the needs of the research. This requires more planning and a flexible approach but will have greater long-term benefit for the study, allowing for building sustainable working relationships that emphasise mutual respect and reciprocity.

Further, a team of three current or recently former unpaid carers for an older person with multiple long-term conditions, identified through existing PPIE networks and Care-Full study sites, will be invited to serve as peer researchers, known as 'Care-Full Companions', for this study across the three study site areas for Work Package 1, Workstream 2. They will receive training and support from a trained coach. The Care-Full companions will support WP1 Stream 2 data collection through undertaking remote monthly check-ins via Microsoft Teams with study participants, to support both the data collection process and the involvement of those who are participating in the study.



4. Study Aims

This project has the following aims:

1) To understand the key events, trajectories and outcomes for unpaid carers and community-dwelling older people with multiple conditions within a care system (Work Package 1).

2) To identify what evidence and data sources can be collected for modelling this care system (Work Package 1 Stream 2).

3) To explore how modelling methods drive interventions to support better outcomes for unpaid carers and older people with multiple conditions (Work Package 2).

4) To develop the capacity, skills, and infrastructure for the creation of a national hub for unpaid carers research. (Work Package 3).

5. Recruitment Methods

5.1 Sample Criteria

Study participants include ***unpaid carers, care advocates,*** and ***key stakeholders***, defined for the purpose of this study as follows:

An **unpaid carer** is defined as someone who:

- identifies as a carer and cares for someone who:
    - is aged 65 years or over
    - lives in the community (rented/owned domestic dwelling, sheltered accommodation, or independent living)
    - has multiple conditions, defined as living with frailty and ≥3 long-term conditions including at least one of the following: hypertension, diabetes, coronary heart disease, and/or chronic obstructive pulmonary disease (COPD), as the most common long-term conditions in older adults
- lives with or has face to face contact with the older person at least once a week
- is able to engage with an online survey using a personal computer and/or smartphone (with technical assistance from the team as required)
- lives in one of three named geographic regions: Bradford, West Sussex or South London (sites selected due to past research participant connections and regional and geographical diversity)

A **care advocate** is defined as someone who plays a role in supporting or advocating for unpaid carers and the older people living with multiple long-term conditions that unpaid carers support, through their role in a voluntary, charity, and/or community organisation.

A **key stakeholder** is defined as someone who has an interest in the area of provision of care to older people living with multiple long-term conditions across the care pathway from an academic, policy, and/or health and social care perspective.

5.2 **Recruitment**

A multi-pronged recruitment strategy will be adopted to maximise the recruitment pool for this study, recognising the challenges that carers face to find time to participate in research. Recruitment will be via open methods (advertisement through regional and national bodies, with their agreement, across community and voluntary sectors, as described under the Work Package 1, Stream 2 heading below), snowballing methods (recruiting new participants identified by existing participants) and targeted methods (recruiting from a cohort of participants identified from past or existing studies who have given consent to be contacted regarding future studies). These recruitment methods are as follows:

Work Package 1

Stream 1: Up to 10 participants comprising of unpaid carers and carer advocates will be recruited to the first participatory mapping workshop (PMW1), then up to 10 key stakeholders from academic, policy, and health and social care sectors will be recruited for the second participatory mapping workshop (PMW2). For the final participatory mapping workshop (PMW3), up to 10 unpaid carers and key stakeholders who have taken part in previous rounds of participatory mapping workshops will be recruited to further refine a draft participatory systems map, or if necessary new participants will be recruited to fill recruitment gaps via the recruitment methods described in the paragraph above.

Stream 2: Up to 5 unpaid carers of older person living with multiple long-term conditions (referred to here and onwards as 'unpaid carers') from three areas in England: West Sussex, South London, and Bradford. Each of these unpaid carers will be recruited in one of the following ways:

- Recruitment from a pre-identified set of study participants through data collection in the ongoing PALLUP study and have given consent to be approached for further research.
- Recruitment from a pre-identified set of study participants through data collection from Work Package 1, Workstream 1 of the ongoing Care-Full study.
- Recruitment through voluntary and key stakeholder groups in three regions in England: Surrey and West Sussex, South London, and Bradford. Gatekeeper approval has been granted from the following sites: Carers Support (West Sussex), St Christopher's Hospice (South London), and Health Action Local Engagement (Bradford). Further sites will be recruited following ethical approval and will only become recruitment sites when gatekeeper approval evidence has been submitted to and then confirmed by University of Surrey Ethics.

6. Benefits of the study

Direct benefits for participating in the study include the following:

- An offer of a £50 gift voucher to participants of the participatory mapping workshops component of the research, as an expression of gratitude for the participants' time (Work Package 1, Stream 1).
- Participants of the longitudinal cohort component of the research will be offered gift vouchers at twelve intervals over the 12 months of an initial voucher of £30, followed by a £20 voucher per month for the remaining 11 months to a total of £270 per participant, recognising their ongoing support, time, and energy given to this undertaking. This has been calculated as the equivalent of roughly double the average wage of someone working in England for the approximately eight and a half hours of time that will be asked from participants to take part in this study over an extended period.

- Participants of the longitudinal cohort component of the research will also be offered the possibility of using a smartphone and a sleep monitoring device to be able to, respectively, answer survey questions from the research team and record and monitor their own sleep, and which they will be able to retain ownership of following completion of the study if they wish (Work Package 1, Stream 2).
- An offer to receive coaching from a trained external supplier to support and enhance the work and skills of the participants as unpaid carers will be given to participants of the longitudinal cohort component of the research. This will be optional and data will only be used for developing general reflections on the coaching process and common themes identified by the carer coach, as outlined in the Participant Information Sheet (Appendix A) (Work Package 1, Stream 2).

Indirect benefits for participating may include self-reflection and a better understanding of participants' own caring practices. The discussion of issues with a group of people in similar position in the Participatory Systems Mapping (PSM) workshops can provide helpful insights and reflections as well as a sense of social support or relief. Participants can also request a summary describing the main findings.

Benefits of the study more widely include the collected data providing an in-depth understanding of the experiences, needs, and outcomes for unpaid carers for older people living with multiple long-term conditions. This data will be used to build systems models to better understand key moments in the carer journey when support would have the greatest benefit. This work will inform an existing programme of work and will contribute to a larger Carers Innovation Hub funding application.

7. Adverse Publicity

The needs, experiences, and outcomes of unpaid carers are understudied but widely recognised as an area of importance in society. We expect the study to highlight important areas for possible support for carers and do not anticipate adverse publicity from this study in relation to the subject area. Advertising of the study recruitment will be primarily through past research participants and gatekeeper carer organisations, with little opportunity for wider media attention. Advertising of study findings will be through existing research group communication channels and large-scale advertising of study findings will be undertaken with the University of Surrey's media team.

8. Informed Consent and Withdrawal of Consent

Consent process

The consent processes will be described across the three work packages in turn:
Work Package 1, Stream 1 (three participatory mapping workshops over 8 months);
Work Package 1, Stream 2 (evidence scoping exercise and repeat interviews with a longitudinal cohort over 12 months);
Work Package 2 (systems modelling as a process of data analysis over 10 months); and
Work Package 3 (national hub development – no consent required)

(1) Work Package 1, Stream 1 (WP1, WS1) – Participatory Mapping Workshops

Pre-research activity:

Once identified through one of the three recruitment approaches described in Section 5.2 above, possible participants will be emailed a participant information sheet for WP1, WS1 of the study (see Appendix A). The participant information sheet, constructed with PPIE input, contains an explanation of the study and the requirements for taking part, so that possible participants can make an informed decision regarding taking part. Possible participants will be given the contact details for the research team who they can contact at any point if they have any questions.

The research team will contact the possible participant after 48 hours have elapsed since having sent them the participant information sheet, to ask if they are willing to take part in the study. If the participant disagrees, the participant will be thanked, and no further contact will be made. If the participant agrees, the participant will be provided with details for attending the research activity and provided with preliminary information to review ahead of the research activity taking place.

The participant will be informed that they can give written consent in person at the first participatory workshop or online using an online form on Qualtrics that will be sent to the participant by email. Possible participants will be informed they have the right to change their mind and withdraw from the study at any stage but will be informed that any data collected up to the point of withdrawal will be retained as part of wider conversation with other participants. A copy of the paper consent form and a Microsoft Word version of the digital consent survey are provided (see Appendix B and Appendix C respectively). Following provision of this information, if the participant agrees to take part, the participant will be provided with details for attending the research activity and provided with preliminary information to review ahead of the research activity taking place.

The consent form will include the following optional components:

- Consent to be contacted after the workshop to give feedback on a visual representation of the map created and a summary of the discussion.
- Consent to be invited back to a secondary workshop as part of the research activity for WP1, WS1 of the study.
- Consent to be invited to participate in WP1, WS2 of this research activity (separate consent to participate in WP1, WS2 will be required).
- Consent to retain contact information for invitation to future research studies.

First stage of research activity:

Informed consent will be collected prior to any data collection taking place. On the first day of research activity the interviewer will confirm that the possible participants understand the study processes and requirements and ensure consent has been obtained from everyone participating in the workshop. The research team will check any consent records submitted in advance to ensure these have been satisfactorily completed. Participants will also be reminded that while they may withdraw from the study at any time without giving a reason, they will not be able to withdraw any data they contribute to the workshop before leaving, due to the nature of discussions and the inability of the researcher to ignore what has been said by different workshop participants. As consent will be collected more than

24 hours after the participant agreed to take part in the study, the risk of rushing participants into taking part is felt to be minimal.

On the day of the workshop, participants will be reminded at the start of the workshop they have the right to change their mind and withdraw from the study at any stage. Participants will also be reminded that their anonymity cannot be guaranteed in the workshop, but participants will be asked to keep the discussions confidential, and the research team will keep any information collected confidential, as is described in the participant information sheet.

Second stage of research activity

For the final participatory mapping workshop (PMW3), up to 10 participants will take part. These participants will be selected from within the sample of participants who opt to take part in PMW1 and PMW2. An equal division will be sought from unpaid carers/carer advocates (N=5) and key stakeholders (N=5) to further refine a draft participatory systems map. As the research activity is substantively the same as was completed by these participants in the first stage of the research activity, additional consent will not be sought and consent for this second stage of the research activity will be included in the written consent form for the first stage. However, processual consent[40] will be followed by reminding everyone of what this research is about and their rights regarding this research and then by asking prior to commencement of this research activity if each participant is happy to continue with this activity.

If there are challenges with recruiting sufficient people for PMW3 from the participants of PMW2 and PMW3, then other possible participants identified as part of the recruitment strategy described in Section 8.2 of the protocol above will be invited to participate and recruited for this research activity via the method that has been outlined in the paragraphs above in this section of the protocol.

(2) *Work Package 1, Stream 2 (WP1, WS2)* – Evidence Scoping and Repeat Interviews with a Longitudinal Cohort over 12 months

Consent will not be required for the evidence scoping review, as this is a synthesis of evidence available in publicly available publications, repositories, and grey literature and does not involve working with record level data.

Longitudinal cohort study pre-research activity:

Once identified, possible participants will be given a participant information sheet for WP1, WS2 of the study (see Appendix D). The participant information sheet contains an explanation of the study and the requirements for taking part, so that possible participants can make an informed decision regarding taking part. Possible participants will be given the contact details for the research team who they can contact at any point if they have any questions.

The research team will contact the possible participants within one week of their having provided the participants with the participant information sheet to ask if they would be willing to have a short phone or MS Teams call with a member of the study team, to ensure they understand the study and that they fit the criteria for participating in the study. If fitting inclusion criteria, these possible participants will

then be asked at the end of the call if they are willing to take part in the study, followed up in writing by email.

Longitudinal cohort study recruitment:

If the participant does not fit the inclusion criteria or does not wish to participate, then they will be thanked, and no further contact will be made.

The participants will be informed that they can give written consent via post or online using an online form on Qualtrics that will be sent to the participant by email. Possible participants will be informed they have the right to change their mind and withdraw from the study at any stage but informed that only data collected within the first month of the study can be withdrawn if the participant chooses to withdraw from the study in the first month. Otherwise, after this date, all data collected cannot be withdrawn, due to the limited number of participants and the high level of importance placed on the collection of longitudinal data for this study to produce meaningful results. A copy of the physical paper consent form and the digital consent survey (exported to Microsoft Word) are provided (see Appendix E and Appendix F respectively). Following provision of this information, if the participant agrees to take part, the participants will be provided with details regarding the research activities they will be taking part in ahead of the start of the research activity taking place.

During research activity:

Informed written consent will be collected prior to any data collection taking place. As consent will be collected more than 24 hours after the participant agreed to take part in the study, the risk of rushing participants into taking part is felt to be minimal. Informed processual consent will continue to be re-sought at regular intervals throughout the study through the 'monthly check in' component of the research, described in Section 8 of this protocol. On the first day of research activity the interviewer will confirm that the possible participants understand the study processes and requirements and ensure consent has been obtained from each of the participants in the participant unpaid carers. The research team will check any consent records submitted in advance to ensure these have been satisfactorily completed. Participants will also be reminded that they have the right to change their mind and withdraw from the study at any stage but informed that only data collected within the first month of the study can be withdrawn if the participant chooses to withdraw from the study in the first month. Otherwise, after this date, all data collected cannot be withdrawn, due to the limited number of participants and the high level of importance placed on the collection of longitudinal data for this study to produce meaningful results. Participants will be reminded that all data will be anonymised prior to use for de-identified computational analysis of data in systems modelling in Work Package 2.

Table 1. Schedule of Events

See Appendix L

9. Experimental design, data collection and methods (including data analysis)

Study activities will be described in this protocol across three work packages:
Work Package 1, Stream 1 (three participatory mapping workshops over 8 months);
Work Package 1, Stream 2 (evidence scoping exercise and repeat interviews with a longitudinal cohort over 12 months);
Work Package 2 (systems modelling as a process of data analysis over 10 months); and
Work Package 3 (national hub development)

The interrelationships between these work packages are illustrated in the study flow diagram below.

Work Package 1 - Understanding and representing the experience and current context of unpaid care giving - Consists of two streams:

Stream 1: Visual representation of the connections, people, and multiple relationships important in integrating unpaid carers into home-based care provision.

Stream 2: Scoping evidence, data sources and testing feasibility of primary data collection with a longitudinal cohort.

Stream 1 - Mapping of issues facing unpaid carers for older adults with multiple conditions receiving home-based care

Aim (1): To conduct detailed participatory system mapping to extract and document knowledge and views from key stakeholders involved in unpaid caring and visualise the home-based care system for older adults with multiple conditions.

Study design: Participatory System Mapping (PSM)[15] methodology collaboratively works with groups of stakeholders to construct an illustrative model or 'map' of a specific system, its components, drivers, and interconnections within a workshop setting. The map is based on stakeholder's knowledge of, and personal experience within the system, including important social, environmental, and behavioural factors and their interconnections, thereby producing an integrated picture of possible indirect effects and unanticipated consequences of interventions, change or events. It is particularly useful in situations, like unpaid caregiving where empirical data is lacking or partial and where personal experience on the ground and in context is important to understand system dynamics. It also allows understanding and visualisation of and visual what factors matter in a system, how they interact and hence define a system boundary in complex open systems.

Participants: Up to 15 unpaid carers and/or unpaid carer advocates from community, voluntary, and/or charity sectors, and up to 15 care providers from health and/or social care sectors.

Methods: Three mapping workshops underpinned by the PSM toolkit[18] will capture anything that impacts decision making and outcomes as experienced by unpaid carers and care providers on the ground. Workshops will be over half days structured to take into consideration constraints on carers' and care providers' time. While we aim to work in person as much as possible for a high-quality participatory process, a collaborative online system mapping platform[18] will be used as needed. The study team, with training, will support the process.

Workshop 1: Using existing evidence on key needs and outcomes of unpaid caregiving and care providers as a starting point (Stream 2, WP1) unpaid carers and carer advocates will agree essential functions/outcomes for themselves and patients, then together generate factors that influence these on the ground, and collaboratively map the interconnections of these factors within care systems. Results will inform data scoping and outcome collection (Stream 2, WP1).

Workshop 2: A key stakeholder care providers workshop, recruited through existing networks and targeted recruitment (described in the previous section) will add their perspective to the collaborative map building and verification, collect additional factors and link information to allow connection to system modelling (WP2).

Between Workshops: Follow up verification and map building activities with workshop participants to finalise structure and verify the map. Cross check the factors in the system map with scoped data sources and feasibility data from WP1 Stream 2, to ensure the map is valid and informed by real-life data.

Workshop 3: A joint unpaid care givers and/or advocates with care providers' workshop. Presentation of preliminary analysis and suggested system design interventions. Feedback and discussion. Posing the following questions: How does this match your experience? How could this help you improve your situation? How could healthcare providers or other external organisations best use these findings?

Post Workshops: Following Workshop 3 there will be some final follow up and verification of the map with workshop attendees. The map will then be used as a component for systems modelling as part of the work described in Work Package 2 and will be further developed with input from carer organisations and policy bodies as part of WP3 of building a national carers hub, which will also feed into the modelling process described in Work Package 2.

Data Generation and Management: The data collected at the systems mapping workshop will be in two forms, a co-constructed hand-written map and typed notes concerning the content of discussions. The map constructed by the participants themselves, in the form of a causal map drawn on flipchart paper consisting of "factors" written on post it notes with arrows, will represent perceived causal connections, drawn between factors on the paper. The factors consist of a) desirable or undesirable outcomes of the care process, both for carers themselves and/or for those they care for and b) issues or factors of any kind which participants believe influence or are influenced by these outcomes. All outcomes and factors will be generated by individual or group and then group discussion. The causal connections drawn between factors will be generated by group discussion and will represent what participants believe are the causal mechanisms that they experience or that exist.

Both factors and arrows are generated by group discussion and have no individually identifiable data associated with them. In some circumstances, if significant disagreement exists on what the nature of a causal connection is, then alternative links may be drawn, or the link will be recorded as contentious by a member of the research team serving as a dedicated notetaker during the workshops. In such circumstances, disagreements will be ascribed within notes using a generalised format (e.g. a 'Unpaid Carer' disagreed with a 'Health Care Sector' representative). These broad descriptors will ensure that such attribution could refer to at least three or more workshop participants, to protect anonymity of participants' contributions. These notes will be type-transcribed on a University of Surrey laptop and saved directly to the Care-Full Study SharePoint held on University of Surrey secure servers.

Figure 1: An example of a participatory systems map collectively produced by workshop participants

The paper map produced will photographed after the end of each workshop and will then be digitized for visualisation and further analysis. The image of the map and a database of factor names, links, and link information (description of mechanism, strength as discussed by participants) will be stored in the Care-Full Study's designated SharePoint held on secure University of Surrey servers. Once the image of the map and database of factor names have been created and stored digitally, the original paper version of the map will be destroyed.

Analysis: The map will be analysed using firstly standard drawing software, and then excel spreadsheet and Gephi network analysis software to undertake a combination of network centrality and causal flow analysis combined with subjective information from stakeholders to determine possible risks or opportunities for intervention in the system, to provide actionable insights for more effective system design or possible interventions. This will involve identifying both structurally influential factors, which influence important outcomes or control multiple paths, which might be vulnerable to external influence, change or unexpected events. No personally identifiable data will be contained in the map.

Outputs: *A collaboratively generated systems map providing visual representation of the underlying structural systems of care giving to highlight evidence gaps and inform data collection for Stream 2 (WP1). *Provide basic structure for systems model with additional information on factors and links collected to allow connection to Reinforcement Learning[19] approaches (WP2).

Stream 2 - Understanding current evidence, data sources and feasibility of primary data collection to capture the experiences and outcomes of a longitudinal cohort of unpaid carers

Aim (2): Scope available and informative data types and sources and assess feasibility of use of these data sources to support system mapping and modelling of unpaid carer involvement in the care of older adults with multiple conditions.

Objective 1: Scope existing evidence, data types and sources detailing carer involvement and associated outcomes, to capture the experience and what matters most in unpaid caring for older people with multiple conditions.

Study Design: A scoping and mapping exercise informed by Arksey and O'Malley.[20]

Methods: Mapping of available data sources will include both routinely collected population data (e.g., Census) and individual level (e.g., health and social care records). Individual unpaid carer records will be accessed, following informed consent, from up to 15 unpaid carers/older person unpaid carers taking part in the feasibility study. A study proforma will support documentary review, recording any type of carer assessment, unpaid carer outcomes, and/or experiences. Scoping will inform the study team's development of instruments and technologies for data collection and the broader feasibility work taking place as part of Objective 2.

Objective 2: Test primary data collection technologies via feasibility exercises with cohorts of unpaid carer/older person unpaid carers to assess for data acceptability, relevance, and quality.

Study Design: A feasibility exercise testing data collection instruments informed by case study methodology[21] will collect prospective data over 12 months.

Participants: up to 15 unpaid carers purposively selected from 3 study sites: (West Sussex, South London, and Bradford).

An unpaid carer is defined for this study as the primary carer to an older adult with multiple conditions. Within this study multiple conditions are defined as living with frailty and ≥2 other long-term conditions including at least one of the following: hypertension, diabetes, coronary heart disease, and/or chronic obstructive pulmonary disease (COPD) (the most common long-term conditions in older adults). A small number of participants collecting data in real time will provide a rich understanding of types of data as well as feasibility of data collection, important in trajectories of illness in older people with multiple conditions- which are unpredictable and prone to sudden fluctuation.[23]

Methods: Testing data tools- Fortnightly self-assessment by unpaid carers, including unpaid carer quality of life, care giving activities, interactions with touchpoints within the care system, and assessing the well-being of each unpaid carer. Most data collection will be through a study-specific digital survey run on Qualtrics, delivered via smartphone app or webpage, serving to minimise the burden of assessment. survey content, and the data consultation group and PPIE will test and feedback on survey content and design prior to data collection. In the event of a "point of change" occurring for the unpaid carer (e.g., the person they care for has symptoms that need medical attention, or experiences a fall, etc.), identified through the regular fortnightly survey or by participant self-report to the study team, then more regular but much shorter surveys covering the same topics will occur daily over the following week to support the identification of important unpaid carer factors and outcomes. The surveys will be tested

through at least two iterations with unpaid carers as part of survey development to ensure items are understandable, capture the data needed and is of least burden on the participants as much as possible.

Baseline assessment- Information about the unpaid carers wider circumstances will be collected at the beginning of the data collection period with an online meeting or in-person visit from a member of the research team (by participant preference) to support uptake and continuity within the study. This will include qualitative measures, see Appendix H, and will involve a process of 'Eco Mapping', where participants will draw and write a map of key relationships with people and organisations important to them. Such data will support the context of individual unpaid carers, support an understanding of data collected throughout the remainder of the study in context, and individual case studies of participants over time.

Monthly Care-Full Companions check ins- Past unpaid carers who will serve as peer researchers for this study, and henceforth called 'Care-Full Companions', will receive active listening training to support data collection with up to 5 participants each monthly via telephone or MS Teams calls within an agreed upon standardised framework that will produce easy to input data for modelling purposes.

Optional coaching sessions- Marie Cooper, study co-applicant and Care-Full Companion will deliver up to two coaching sessions with participating unpaid carers (via MS Teams or phone delivery, determined by participant preference), one at baseline, one at six months, to support participants and produce a more equitable research relationship, while also supporting carers to be able to better express themselves and their needs, thereby improving data collection and quality. Importantly, this is an optional component for participants, in the spirit of the *reciprocity* of the study and no direct research data will be collected as part of these coaching sessions.

Post data collection check in- Participants will be asked as an optional consent component to consent to a follow up check in up to one month after this series of data collection has been completed. This is to check in with participants as to how they are doing and also gather broader qualitative feedback on their experiences of participation in this research and their views about the feasibility of data collection using this method.

Additionally, a reflective account of the experience of delivering of the optional coaching component for unpaid carers will be undertaken by the coach (MC) Marie Cooper, drawing on personal reflections and including generalised themes without specific reference to any individual study participants, to input into our learnings from the study and for future work.

Analysis: We will examine the acceptability, validity, and quality of the survey data (e.g., missingness, low-quality responses), and use these to optimise data collection methods for national roll out. Quantitative and qualitative data collected will be de-identified, assigning each participant with a unique identifier, prior to analysis in Work Package 2. Analytical outputs will be in the format of abstracted systems models, as visual representations of generalised relationship between unpaid carer unpaid carers and other stakeholders. We will also examine the feasibility of collecting data in this manner with unpaid carers and analyse quantitative and qualitative data from unpaid carers as part of a case study approach to better understand changes that occur for participants over time. The coding framework for these different forms of data will be developed iteratively and using learnings from the Participatory Systems Mapping workstream.

Outputs: *Understanding of available primary and secondary data sources and appropriate and feasible data collection for larger-scale study at the hub stage. *Increased connections with strategic partners to

build into Care-Full hub. *Methodological and partnership learnings for feasibility of work with unpaid carers for capturing breadth and depth of data over extended periods and how we can scale up this activity at hub stage.

Work Package 2 - Iterative development of systems models of home-based care for older adults with multiple conditions focusing on unpaid caregiving

Note this work package describes the process of data analysis that will use a combination of published, publicly available data at an aggregate level and quantitative and qualitative participant data where a unique identifier is generated for each participant for the analysis, but the data is otherwise deidentified prior to analysis.

Aim (3): Use data and the systems map generated from Aims 1 & 2 to build and analyse preliminary system models to begin to identify key factors and outcomes of interest for novel interventional focus for unpaid carer unpaid carers in larger scale work.

Objective 1: Use advanced mathematical, computational, simulation, and/or artificial intelligence-powered tools to model and predict the dynamics and outcome trajectories for older adults with multiple conditions and their unpaid carers receiving home-based care, thereby laying the groundwork for implementation, and testing novel interventions at scale.

Objective 2: Conduct two dissemination events involving key stakeholders and the Care-Full research team to gather initial feedback, strengthen partnerships and shape writing for larger funding call (WP2). These are impact activities involving the dissemination of research findings and are not components of the research activity.

Study Design: Systems modelling is likely to include discrete event simulation, reinforcement learning, network control, and machine learning methods, outlined in more detail below.

Methods: System modelling through two steps:

Step 1: Creation of a logical network model informed by WP1 and powered by discrete event simulation to understand the care pathways involved in home-based care.

The PSM map will be subjected to automated augmentation with detailed information on critical factors central to actionable daily decision-making and trade-offs faced by unpaid carers, such as controllability, or how easy it is for unpaid carer to intervene on a factor (easy, medium, hard, uncontrollable), influence, or how many other factors a factor influences downstream, and uncertainties, or how much level of sureness desired effects will be achieved.[16,24]

Analysis: Preliminary complex network analysis can then highlight factors of paramount interest, e.g., factors with high out-degree (influence on other factors downstream) and high importance (for at least one set of stakeholders) on the system map. These then serve as starting points for the ensuing analysis (see Step 2 that can determine “touchpoints” along trajectories to steer towards desired outcomes (e.g., ensuring sufficient caring is given to the older person with multiple conditions meanwhile minimising the stress of unpaid carer). Further, discrete Event Simulation (DES)[25] will be applied to enable the transformation of the system map (conceptual) to a system model (logical) that is amenable to analysis (learning, prediction, control). DES simulates discrete sequences of events[26] (WP1) and hence is best placed to produce the simulated trajectories of desired outcomes and behaviours of both unpaid carers and older adults with multiple conditions.

Step 2: Analyse pathways and identify interventions for optimal outcomes while satisfying constraints

Exploration of various systems and machine learning techniques to suit the topology, size, and number of different actions/options available at various stages along pathways in the systems model. Network control theory, which has a prominent role in control systems engineering, will be applied to the logical network model. This provides the ability to direct a network from any initial state (node or factor) to any other given state (target node). The target nodes will represent the desired outcomes. The choice of starting node will be informed by the network analysis, e.g., influence. Reinforcement Learning (RL) will then be applied to derive the series of interventions necessary to go from the start node to the target node. RL is a particular breed of machine learning focused on sequential decision-making in an uncertain environment, or situations where the exact function is not well understood, or understanding is based on incomplete or noisy data. RL learns directly from outcomes and thus is well suited for the analysis of the complex system considered here. This builds on recent work in a similar vein by Dr Moschoyiannis' group that has successfully established modelling-based interventions for transport networks,[27,28] gene regulatory mechanisms,[29,30,31,32] and other complex systems.[33,34,35] For example, recent work[36] has shown how a series of optimal, in the sense of least number of, interventions (activating / repressing a gene) can be learned in a logical network that captures the behaviour of a gene regulatory network with 200 nodes (or factors). The combination with deep learning over graphs means enables stochastic modelling with thousands of possible pathways (different network realisations) emerging at each step.

In addition, we will innovatively combine DES with RL to minimise the amount of training and data needed (sample efficiency). This WP will also explore the use of latent variables to account for missing data or, more importantly, any inaccuracies introduced when moving from the conceptual system map to the logical network systems model. The use of DES to simulate transitions as well as the use of a causal model for learning a control policy in RL have not been attempted before but look promising in the setup of this study and can set the standard for subsequent work in this direction, including at the hub stage.

Dissemination workshops: Dissemination events will present "typical scenarios", simulated, and optimised in the DES/RL tool as a digital twin model,[37,38] to relevant stakeholders (CARE-Full participants, identified key partnerships e.g., Carer Associations supporting unpaid carers, pharmacists, paramedics, and social care) to raise profile of this work and support network growth for next funding stage.

Outputs: Preliminary systems models of home-based care that enables navigation amongst the numerous causal factors, actors, events and produces the best series of decisions to achieve a desired outcome, with an evidence-based degree of confidence, ready for testing in the Care-Full hub.

Work Package 3: Development of National Hub for Research on Unpaid Caregiving

***Note* this work package is concerned with research capacity, infrastructure, and knowledge base for creating a national hub for unpaid caregiving research and innovation, contributing directly to the development for a second stage bid for the SEISMIC funding call and as such is a project aim that does not involve data collection. It is included in the protocol to support communication of the aims of this research and the proposed direction for generating maximum impact from this work.**

Outputs: (1) Innovative systems models of home-based care provision for older people with multiple conditions. The novelty of our proposed approach is that it enables informed suggestions for action even

amidst significant uncertainty, risk, and complexity. The ability to make targeted interventions lays the groundwork for the Hub stage where we look at doing this at scale, whilst incorporating constraints and variables. Thus, we can tailor the tool to specific scenarios and predict major carer events impacting themselves and the older people for whom they care. (2) Contribution to platform study design- In contrast to a 'common-sense' approach that might improve one aspect of care provision through an intervention between a small number of causes and their immediate effects, the systems model(s) we propose will enable decision-making under uncertainty, considering the multitude of causal factors, actors, events, and possible outcomes. (3) Understanding of the types and feasibility of data that can be collected to scale in the Hub. A strong partnership team working on the future Hub call. (4) Dissemination through publications and outputs on aspects of the partnership methods, including Care-Full Companion involvement - co-produced with PPIE and strategic partners- to inform future work and Hub development.

10. **Risk Assessment**

1. **Identified Risks**	2. **Likelihood**	3. **Possible Impact/ Outcome**	4. **Possible Severity of Outcome**	5. **Risk Management/Mitigating Factors**	
Identify risks/hazards present	*Identify how likely the event is i.e.* *Very likely/ Likely/ Possible/ Unlikely*	*Who might be harmed and how?* *Ensure you have considered the research team, participants and anyone not directly involved in the research.*	*Classify the severity of outcomes identified in 3.* *i.e. High/ Medium/ Low*	*Evaluate the risks and decide on the precautions.*	*Standard Operating Procedures*/ risk assessments* *Enter Ref no/ title/ expiry date*
Risk of verbal attack when interviewing participants alone (WP1 Stream 2)	Unlikely	Researcher: Psychological Harm	Low	Participants identified in ways that indicate they have an interest in talking about their experiences Researcher to follow local lone working policy when conducting face-to-face fieldwork	N/A
Discussion of a sensitive topic in an interview or group setting has possible to cause participant	Possible	Participant: Psychological stress Researcher:	Low	Offer to cease interview if participant becomes distressed Signpost options to all participants to end interview or leave a	NA

1. Identified Risks	2. Likelihood	3. Possible Impact/ Outcome	4. Possible Severity of Outcome	5. Risk Management/Mitigating Factors	
distress WP 1, Streams 1 and 2)		Anxiety about dealing with complex situation		group mapping session at any time without providing a reason or to pause an interview or temporarily step out of a group mapping session. Signpost participant to external support services in Participant Information Sheet as well as linking to local organisations that are supporting recruitment Conduct debrief at the end of the interview / group mapping session Regular repeat interviews for WP1, WS1 support a process of checking participants' welfare. Follow up check in process offered to participants to check their welfare described in the	

1. Identified Risks	2. Likelihood	3. Possible Impact/ Outcome	4. Possible Severity of Outcome	5. Risk Management/Mitigating Factors	
				Participant Information Sheet	
Risk of data loss	Unlikely	Participant: Contribution wasted Researcher: Stress due to imperilment of research	Low	Quantitative data collected through secure Qualtrics survey system, backed up and security protected. Recordings capturing qualitative interview and workshops data will be securely stored until transcription and then destroyed in accordance with Data Management (Section 10). Anonymised transcripts will be stored in a secure location on University servers	NA
Risk of identifying participants	Unlikely	Participant/ researcher: Anxiety due to role in the research being in the public domain	Low	Consent documentation will be securely stored on university secure servers Interview and workshop transcripts will be	NA

1. Identified Risks	2. Likelihood	3. Possible Impact/ Outcome	4. Possible Severity of Outcome	5. Risk Management/Mitigating Factors	
		Reputational risk		anonymised and stored securely Data will be de-identified by members of the core team for the analysis and results will be reported without direct (e.g. names) identifiers Group mapping workshop participants will participate with an understanding of expected shared discretion about what is said within a workshop	

11. Data Management

The study will comply with the requirements of the General Data Protection Regulations with regards to the collection, storage, processing, and disclosure of personal information and will uphold the regulation's core principles. The study will further be guided by four specifically designated data management steering group representatives to give feedback and advice on the data collection process for this study.

Anonymity and confidentiality

The research team are responsible for ensuring that participant anonymity and confidentiality is protected, maintained and managed in accordance with the General Data Protection Regulations and University policy. This includes ensuring participant identities are protected from any unauthorised parties. The University of Surrey research team will have access to all participant data. No identifiable information will be used in reporting in this study. Direct quotations taken from the research activities will be presented in an anonymised format.

Transcription

University of Surrey approved external companies will written transcribe recorded qualitative data. The transcription service will have contracts with University of Surrey, which document the requirement for maintaining confidentiality and anonymity. All data will be sent using a secure electronic file transfer service. The transcription service will ensure all typed transcripts are fully anonymised, not transcribing names and places which could be identified. The transcription service will delete all files once the transcription has been completed. All transcribed data and all electronic files will be coded alpha-numerically for identification purposes. The key for this will be held separately to the transcripts themselves in a password protected file, stored encrypted on the University of Surrey's secure server, which is backed up every 23 hours. The research team are responsible for ensuring all transcription data is depersonalised and replaced with non-identifying information. Each transcript has a unique identifier, a consistent layout throughout, numbered pages and pseudonyms to anonymise personal identifying information.

Data handling

The research team have responsibility for safe custody of all confidential data. No participant information will be transferred or revealed to any party outside the research team, and all data will be anonymised prior to publication/dissemination of findings. Regarding the specific handling procedures:

Name and contact details of possible participants will be held on a password protected laptop and secure server at University of Surrey which only the research team can access. Participants' personal information and data from interviews and workshops will be stored encrypted on a password protected laptop and secure server at University of Surrey, which only the research team can access. Microsoft Teams interviews will be conducted with unique meeting numbers, using passwords, and meetings will be locked after they begin. Interviews will be recorded using the Microsoft Teams record feature, but this will be downloaded directly to the secure server at University of Surrey and transcribed from the MP4 video file. The use of participant information in this way is referred to in the participant information sheet (see Appendix A).

Record storage, retention and archiving

Following receipt of informed consent from participants, any identifiable information required for administrative purposes, such as name and contact details will be stored in an excel spreadsheet as documented in Data Handling above. All paper consent forms and other paper-based research data, e.g. from the PSM workshops and Longitudinal Study Monthly Check-ins will be stored in a locked filing cabinet in a University of Surrey building with restricted access. Electronic copies of the qualitative data

files will be stored password protected, on a password protected laptop and secure server at University of Surrey which only the research team can access. There may be times when data needs to be transported where it is not possible to carry the secured laptop. In these cases, it will be saved to an iron key which is encrypted and password protected. All data will be deleted from the iron key as soon as the research activity has been completed.

Paper copies of the study data will be archived for ten years in University of Surrey's secure facility on completion of the study. All personal data will be destroyed within 12 months of the completion of the study (expected to finish January 2026). Scanned copies of consent forms will be retained for 6 years, the original paper documents being securely destroyed. For participants who give consent to be contacted at a later date concerning participation in further relevant research, their names and contact details will be compiled on a specific, new excel spreadsheet and saved on the secure server at University of Surrey registry.

Audio recordings and original interviews will be deleted once study analysis is complete and systems models have been developed. The research outputs will be retained to support study dissemination and for training both within and beyond the study.

Access to the final study dataset

The final dataset will be accessed by the research team only.

12. Ethical considerations

Important ethical considerations and strategies to address them:

- **Recruitment:** Possible participants will receive clear, accessible study information. This will highlight the opportunity to discuss questions or concerns with the Research team
- **Withdrawal:** It will be made clear in Participant Information Sheets and Consent Forms that participation is voluntary and that participants have the option to withdraw at any time without giving a reason. For participants of the participatory systems mapping, participants will be informed that while they can withdraw at any point, data already collected will remain as part of the study due to the nature of the data being embedded within the wider data collected as part of this process.
- **Anonymity and confidentiality:** Information about anonymity and confidentiality for the study is made clear on the Participant Information Sheets. Study outputs will be in the form of computational models derived from deidentified study data, posing minimal risk to confidentiality. The collection, storage, and use of data is described in the Data Management Plan in Section 10 above.
- **Consent and capacity:** Informed consent will be obtained prior to data collection. Preliminary conversation with possible participants for Work Package 1 Work Stream 1 research activity will take place to check possible participants meet the inclusion criteria and are able to commit to a 12 months study.
- **Possible for distress:** The research team are aware that the topic of caring as a family carer for an older person living with multiple long-term conditions may lead to conversation that is distressing. Steps are outlined in the participant information sheets regarding pausing or terminating research activity if a participant becomes distressed, including signposting for participants to seek support and follow up procedures to check participant welfare after fieldwork has taken place for the different research activities occurring in Work Package 1.

- **Incentives:** Patient and Public Involvement and Engagement advice has suggested that offering an optional gift voucher of £50.00 is a suitable gesture to thank participants for their time and effort in participating in the research in Work Package 1, Work Stream 1. For Work Package 1, Work Stream 2, Participants of the longitudinal cohort component will be offered gift vouchers at twelve intervals over the 12 months of an initial voucher of £30, followed by a £20 voucher per month for the remaining 11 months to a total of £270 per participant, recognising their ongoing support, time, and energy given to this undertaking. This has been calculated as the equivalent of roughly double the average wage of someone working in England for the approximately eight and a half hours of time that will be asked from participants to take part in this study over an extended period. This approach has been informed by past research and by best practice guidance from NIHR INVOLVE for appropriate rates and approaches for recompensing those who support research to take place.

  Also for Work Package 1, Work Stream 2, optional coaching and retaining an optional study smartphone on study completion will be offered as gestures of thanks for participants' involvement over an extended period. This information is made clear in the participant information sheet.
- **Research Safety:** Researchers will follow local lone working policy when undertaking lone working. Researchers will be supported by the PI and Co-Is with regular check-ins and reviews following interviews, to discuss the topics raised during fieldwork and check researchers' welfare.

Prior to study initiation, approval will be sought from the University of Surrey Ethics Committee.

13. Dissemination

Dissemination policy

- The University of Surrey will own all data arising from the study.
- On completion of the study the data will be analysed and can be accessed through articles for publication in relevant peer reviewed journals.
- Only the PIs and members of the research team will have rights to publish any of the study data.
- The NIHR and ESPRC will be acknowledged within research outputs as joint funders of the study in accordance with funders' policies.
- Findings will be disseminated to research participants, if they have indicated on their consent form that they would wish for this, through a final summary report.

Authorship eligibility guidelines

The Research team will be responsible for drafting all articles and reports and will be authors of the published papers

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Amendment History *(to be completed for subsequent versions after initial authorisation)*

Amendment No.	Protocol version no.	Date issued	Author(s) of changes	Details of changes made

List details of all protocol amendments here whenever a new version of the protocol is produced.