Detailed Research Plan

1. Full title of project

Improving end of life care: supporting the workforce and reducing hospitalisations through an implementation study in care homes

2. Summary of Research (abstract)

Background and rationale: End of life care in care homes is inadequate, despite high levels of morbidity and mortality.[1,2] Residents can experience uncontrolled symptoms, poor quality deaths and futile/burdensome hospitalisations. Care home staff can feel unprepared and unsupported to look after residents at end of life. Although models exist for improving end of life care in care homes, these are primarily education-focused and do not adequate triage residents to focus on those most at risk of dying without a plan in place,[3,4] and rarely integrate clinical care. Recent work conducted in Australia by the project team tested a novel way of providing specialist palliative care to care home residents. The new approach is 'Palliative Care Needs Rounds' (or 'Needs Rounds') combine triaging, with anticipatory person-centred planning, case-based education and case-conferencing. The approach has been synthesised into a check-list to provide guidance to clinicians running Needs Rounds.[5] Our Australian study showed reduced length of stay in hospital, dying in preferred place, improved symptoms at end of life,[6,7] and normalised death/dying to care home staff.[8] Care home staff felt more confident looking after the residents. Preventing hospital admissions saved $1.7m over a year (nearly £1m).

Aim: To co-design and implement an appropriate scalable UK model of Needs Rounds, which takes account of the different policy/practice context in the UK.

Design and methods: This is a pragmatic implementation study using the PARIHS (Promoting Action on Research Implementation) framework. We will determine what works, for whom, and in what circumstances for the UK Needs Rounds model. The approach uses six case studies, where a case is defined as a specialist palliative care service connecting with 4-6 care homes each.

Phase 1 stakeholder interviews (n=40) across the 6 cases, will be used to develop a programme theory. Subsequently we will run a workshop to co-design UK Needs Rounds.

Phase 2 involves implementing, adapting and evaluating UK Needs Rounds in the six cases. Prospective data collection in phase 2 will focus on stakeholder interviews, and quantitative data to allow for comparison with the Australian study on hospitalisations, residents' quality of death,[9] and care home capability of adopting a palliative approach.[10]

Phase 2 will enable description and refinements of case studies' contexts, mechanisms and outcomes to generate a mid-range theory of implementation.

Patient and public involvement (PPI): Three lay people are co-investigators and have contributed to the proposal development and will continue to contribute throughout the whole study, including data analysis, contributing to the co-design workshops, dissemination and blogs.

Timeframe: The project starts 1-Oct-2020, with Phase 1. Phase 2 commences 1-Jun-2021 (month 9). The study runs for 28 months, concluding 31-Jan-2023.

Dissemination, outputs and impact: We will disseminate to policy-makers, care home/palliative care practitioners, care home residents/relatives, and academic audiences. Infographics, blogs, policy briefings, talks at carer groups/conferences will all be used. An implementation package will be developed for practitioners that provides all the tools and resources required to adopt UK Needs Rounds.

3. Background and rationale

3.1 Scale of the problem: Between 26% and 50% of people admitted to UK nursing homes die within 6 months.[1] Care homes (including nursing homes that provide 24/7 nursing cover and residential care homes which do not have nursing staff) increasingly look after older people with complex multiple morbidities.[11] Care homes will be the most common place of death by 2040.[2] There is therefore an urgent need for evidence-based approaches to support older people at the end of their life, and reduce avoidable and often detrimental admissions to acute care.

3.2 The risks of not improving care: Some care home residents (hereafter 'residents') experience multiple admissions to hospital prior to their death,[12] despite some admissions being preventable.[13] Hospital admissions are costly and may prompt futile or burdensome interventions that can cause distress to residents and family members[14] Many residents will require specialist palliative care to enable care home staff to manage complex symptoms[11] to avoid hospitalisation at end of life. Well managed death and dying is contingent on high quality interdisciplinary care,[15] anticipatory care[16,17] and resident-centred planning.[18]

3.3 Current, but suboptimal approaches currently used: Care homes can be homely, warm and supportive environments. Supporting these establishments to improve the care they give at end of life can make them even better places for people to spend their final months and weeks of life, especially when compared with clinical settings like hospitals. Care homes are an important location in the nexus of service provision for older people.

Care home education interventions have improved outcomes for staff and residents requiring a palliative approach.[19] Education in advance/anticipatory care planning, as part of palliative care provision has led to increasing rates of completed plans and advance directive, improving consistency of clinical decision with resident preferences.[16,20] Advance care planning interventions led by nurses are also shown to mitigate distress and improve communication with relatives.[21] However, interventions are often inadequate to result in changing clinical behaviour, approaches are inconsistent, and the necessary steps for sustainable change are lacking.[19,22] Realistic Medicine is gaining traction, yet personalising care, tackling unwanted variation and reducing harm/waste remain urgent priorities.[23]

Providing end of life support to care homes is an increasingly busy area of service development. UK service delivery innovations such as ECHO,[4] Gold Standard Framework, Macmillan's education for carers 'Foundations in Palliative Care', Six Steps to Sucess[24], the EU funded PACE work[3] and person-centred dementia care with the Namaste programme[25] offer staff training, but rarely provide facilitation of evidence-based clinical input for people diagnosed as dying. Currently, only the PACE study been tested in an RCT. Hence our Needs Rounds model offers an approach over and above that which already exists. Needs Rounds complement the care home Vanguards, and can learn from their reported barriers to effective implementation[26] while boosting the effectiveness of vanguard care homes by providing an evidence-based structure for, and direct care from, specialist services.

It could be argued that creating a basic organisational structure that promotes palliative care collaboration through monthly multi-disciplinary meetings (both internal and external health and social care professionals) is an important first step on which to build a solid foundation to provide palliative care. Such a foundation helps to break the isolation of care homes and can promote greater sustainability of further initiatives.

No current NIHR studies focus on care home residents and end of life care; only one past NIHR funded project relates to this, which described the uptake of the Liverpool Care Pathway in nursing homes, prior to the pathway's demise.[27] A new NIHR/ESRC study led by Prof Sampson will pilot an approach to delivering person-centred end of life care, but is focused solely on people living with dementia. A recent systematic review identifies a paucity of robust work in this field.[28]

3.4 NHS policy and practice: There's commitment but as yet no robust approach to delivering optimal care to care home residents. NHS England wants to improve care in all settings, and has committed to 'explore improvements' (p13)[29] for residents in care homes, but recognises that there are substantial difficulties in providing adequate care in these settings. The Care Quality Commission (CQC) articulate a requirement for "a clear focus on end of life care and applies in all services where end of life care is delivered. The approach includes […] care homes." (p21).[29] The CQC further state that there is more outstanding care by hospices than any other service, yet their data separate hospice care from nursing/care home care. This underlines a fundamental problem that care homes are not yet considered to be providing effective palliative care, despite the evident morbidity and mortality of residents.

Facilitating improved end of life care in care homes is an explicit driver for NHS England.[30] The 'Ambitions framework' for palliative and end of life care has yet to be fully realised, but includes important elements such as fair access to care and staff/communities able to provide care and talk about death/dying. Clinical commissioning of palliative care clinical and education services across England is variable.[31]

The Scottish Government's Strategic Framework for Action on Palliative and End of Life Care sets out a vision of universal access to palliative care by 2021. This includes individuals, families and carers having timely and focussed conversations with appropriately skilled professionals to plan end of life care, in accordance with their needs and preferences. The vision will be achieved by widening the range of health and care staff providing palliative care, delivering appropriate training, and supporting clinical and health economic evaluations of palliative and end of life care models. Further, Healthcare Improvement Scotland commits to testing and implementing improvements to identify those who can benefit from palliative and end of life care, yet at present there is no delivery model for this in care homes.

Wales has set out a priority action in Health Boards providing access, support and education from specialist palliative care to care homes,[32] but with no dominant model being offered beyond each community clinical nurse specialist linking with one or more care home. Northern Ireland guidelines recommend a designated nurse within the specialist palliative care team for care homes,[33] and although ECHO is a strong model this does not provide the triage and anticipatory planning function of Needs Rounds.

Care home culture: Care home culture inevitably impacts working practices and resident care/experiences.[34] Our study will also be informed by studies which have reported interventions in care homes, and applying their learning. This includes from co-applicants McCormack, and Hockley regarding the need for high quality leadership and facilitation alongside innovation,[35] and consideration of the nursing workforce and culture of education.[36]

Our study is predicated on the need to understand context and adjust implementation in response to care home culture, including local priorities, readiness for change and facilitation champions.[37] Care home culture, and the culture change movement, has become a research focus to identify characteristics which lead to care improvements.[38-41] Care homes which embrace culture change are more likely to provide better resident care.[42]

Measuring care home culture change is challenging,[43] yet the ORCA measure offers useful structure for data capture.[44]

3.5 Intervention description: One promising new approach called Palliative Care Needs Rounds (hereafter 'Needs Rounds') has been developed and tested (stepped wedge trial with 1700 care home residents) in Australia by the Chief Investigator.[7] This model offers structured outreach from specialist palliative care services to care homes. Needs Rounds are monthly hour-long triage meetings where specialist palliative care staff and care home staff discuss 6-8 residents who are at greatest risk of dying in the next six months without a plan in place. Needs Rounds use a checklist[5] to trigger identifying suitable residents (including educating staff on identifying dying), discussion of the biopsychosocial concerns (leading to case-based education on symptoms and anticipated symptoms when dying), and necessary actions (e.g. direct clinical work from specialist palliative care, anticipatory care planning, anticipatory or de-prescribing). Needs Rounds therefore also trigger some face-to-face work with residents e.g. clinical assessments and chairing case conferences. Needs Rounds therefore are a model of care which provides a structure for specialist palliative care and care homes to discuss residents' needs, and inform personalised and tailored interventions suitable to each individual.

3.6 How our approach addresses the practice deficit and meets policy commitments: This intervention addresses NIHR/Marie Curie/James Lind Alliance priorities of: workforce and skills, managing symptoms and reducing hospitalisations. The approach draws together a number of recognised requirements for looking after older people in care, including case management and specialist outreach services,[45] increasing advance care planning,[46] and staff education [47,48]. Our approach strengthens current models by widening the beneficiary beyond those with advanced dementia.[49] Our project will meet recognised needs of decreasing hospitalisations, improving symptom management,[50] and increasing preferred place of death.[51] Our approach offers a framework to provide person-centred care to residents and tailored education to staff.[23]

First, care home staff wish to reduce preventable hospitalisations, yet often lack clear methods of doing so.[52] Second, increasing anticipatory planning (including Advance Care Plans – and anticipatory prescribing) improves the confidence of care staff to discuss goals of care and leads to a reduction in hospitalisations.[53] Further, nurses employed in care home who are supported to administer anticipatory medications reduce hospital admissions and facilitate faster symptom management.[54] Provision of support to nursing home staff has been shown to improve end of life care for residents.[55] Needs Rounds have clear benefits to health outcomes: reducing admissions to acute care and improving quality of dying. Needs Rounds also increase workforce knowledge and confidence.[5,6,8]

Our outcomes (as a result of implementing the Needs Rounds intervention in Australia) all reflect NIHR priorities: we decreased the length of hospitalisations ($p<0.01$; CI −5.05 to −1.41 days), increased residents dying in their preferred place[6] and enabled staff to normalise death and dying[8] by adopting an out-reach model of specialist palliative care. In our definitive study, a stepped wedge trial of 1700 care home residents, we achieved similar levels of reduced acute length of stay ($p=0.048$), and evidenced improvements in residents dying with dignity, compassion and comfort ($p=0.019$) and workforce confidence ($p=0.09$).[7]

3.7 Why is this research needed now: Care homes now operate as sub-acute units with high levels of morbidity and mortality. New data care homes will be the leading place of death by 2040.2 Mortality can be as high as 56% within a year of admission.[47] Consequently we urgently need to find methods to provide optimal end of life care to this growing group.

Although some specialist palliative care teams report offering services to care home residents, recent surveys in England, Wales and Scotland demonstrate that referrals are usually reactive rather than anticipatory, but there is considerable goodwill from specialist palliative care to support residents in care homes.[56-58] The National Audit of Care at the End of Life has prioritised systems and processes that support care home residents to receive personalised end of life care.[59]

The definitive stepped wedge trial of Needs Rounds has only recently concluded.[7] Until this year, there was no conclusive evidence to support the model. However, as of 2019, we have robust evidence from 1700 residents that the new approach to care can substantially improve outcomes for residents, staff and the acute sector. Supporting the need for this approach now, the Needs Rounds approach won the ‘Innovation’ award from Palliative Care Australia in September 2019, won the 2018 Quality and Safety Improvement Award in the Australian Capital Territory, and was cited in evidence to the 2019 Australian Royal Commission into care quality in residential care homes. The study findings also led to investment in the Australian Capital Territory Health Department and Federal Budget measures to adopt the approach to care. The study is thus needed now as there is formal recognition of the potential to substantially improve end of life care by using Needs Rounds.

In order to deliver the Needs Rounds model in the UK, adaptation is required due to the different service organisation and delivery models here, and the need to engage with key stakeholders such as residents, carers, palliative care services, care homes and the acute care sector [60].

Australian care homes vary, as do UK care homes. Many of the practicalities are similar, and both countries face similar tensions in service deliveries, for example high turn-over of staff and residents with complex multiple morbidities. The five core elements by which the two countries’ care home contexts differ are:

1. The sites involved in the Australian study all employed a registered nurse, which is an important difference to be addressed in adapting and implementing Needs Rounds in the UK. This may mean that Needs Rounds in the UK require greater links with primary care to facilitate the prescribing and administering of medication. It may also mean that the Needs Round ‘case based education’ component of the model will include greater emphasis on core information and skills.
2. Our Australian sites tended to be larger than the average size in the UK. This means that the delivery of Needs Rounds is likely to need to be different. Our co-design process will help refine what this would look like, for example more in-depth discussion of each resident, or less frequent Needs Rounds meetings.
3. Usual care in the area of Australia where we conducted the stepped-wedge trial was reactive provision of direct clinical care from the local specialist palliative care team. This is very similar to most UK provision [56,57], though we note the introduction of various local initiatives to connect care homes with specialist palliative care teams, this is not proactive

care and does not involve actively triaging residents for intervention. We will map local service provision/delivery as part of Phase 1 to understand local care and adapt the model accordingly.

4. Both countries operate care homes without mandatory training for their staff on palliative or end of life care. In Australia, care home staff are able to access a national education programme (PEPA – programme of experience in the palliative approach) which enabled care home staff to attend a workshop on palliative care, and some days shadowing staff from specialist palliative care (e.g. in the inpatient unit). In the UK, education is provided via initiatives such as ECHO, and 6-Steps. Further, the Gold Standard Framework for education and accreditation is used in the UK, but not in the region of Australia where we tested Needs Rounds. These differences in education/training provision do not necessarily complicate implementation. Baseline staff scores in their capability of adopting a palliative approach will be taken, along with follow-up, so we can compare these data with the changes in staff scores in Australia.
5. General practice provides first line medical care for care homes, but ways of working, quality and impact are highly variable. From 2020 in England, Primary Care Networks are contracted to deliver an enhanced health in care homes service. This national service specification has emerged from the work of the NHS England care home vanguard programme. The seven core elements include enhanced and consistent primary care, multidisciplinary team input and high quality end of life care. Our proposed programme of work is timely, as it has the potential to shape the development and implementation of this new model of care.

The proposed study will adapt the Needs Rounds model using a co-production approach so that it can be used in UK care homes, to replicate the positive outcomes evidenced in Australia.[5,6,8] The UK has a more collaborative health/social care environment and thus the study will need to explore how we can ensure a good fit with the person-centred and shared decision-making approach in the UK.

4. Aims and objectives

New knowledge will be generated regarding how the UK can adopt and adapt the Australian evidence-based model to maximise positive health outcomes. We will generate implementation methods for use across the UK. We will also facilitate new inter-organisational working and relationships.

Simply replicating the Australian stepped wedge study would not add sufficiently to our knowledge base regarding what works and for whom. A further randomised trial would not be appropriate stewardship of finances, when the most important questions to address are around how to adapt the intervention to the UK setting and determine the enablers and blocks for use in the UK.

The study will produce an approach to care which can be used across the UK care home sector, thus having wider reach and significance beyond the study sites, by offering specialist palliative care input, using pragmatic and effective inter-organisational working.

The aim is to co-design and implement an appropriate scalable UK model of Needs Rounds, which offers specialist palliative care outreach to care homes, in order to improve the lives and deaths of care homes residents.

The implementation objectives are:

1. Co-design a UK version of Needs Rounds, which is responsive to the different (macro, meso and micro) contextual characteristics of the UK care home sector. (Phase 1)
2. Implement the adapted model of care, assess feasibility, acceptability and effectiveness, and ultimately propose how the model of care can be further refined and adopted in the UK context, to reap the benefits demonstrated in the Australian work. (Phase 2)

The intervention objectives are to:

3. Determine the transferability of the core elements of the Needs Rounds intervention in a UK context
4. Delineate the mechanisms of action (individual and group) that enable more effective palliative and end of life care practices to be realised in UK care homes
5. Identify the relationships between (a) the mechanisms of action embedded in Needs Rounds, (b) how these mechanisms function in different care home contexts and (c) the outcomes arising for different stakeholders and parts of the care system.

The process evaluation objectives are to:

6. Document the outcomes of UK Needs Rounds on hospitalisations (including costs), quality of death/dying, and staff capability.
7. Assess and report the perspectives of care home residents/relatives/staff and palliative care staff on using UK Needs Rounds.

5. Research Plan

5.1 Research design

This is a pragmatic critical-realist implementation study[61] using the PARIHS (Promoting Action on Research Implementation in Health Services) framework[62,63] in six case studies. We will use the Kitson and Harvey (2016) iPARIHS Framework to theoretically frame the study. iPARIHS builds on the original PARIHS Framework [64] and addresses many of the criticisms of PARIHS concerning issues such as, missing elements from context, the place of innovation, the work of facilitators and its general utility in practice. iPARIHS represents an integrated approach to implementation practices, recognising that most implementation (such as the one proposed in this study) is a complex social intervention requiring attention to multiple factors simultaneously in order for an innovation to be successful. Innovation in this context is in line with Rogers' [65] idea of 'Diffusion of Innovations' which needs to pay attention to different and multiple voices, different motivations for change as well as the role of leadership and facilitation. iPARIHS pays attention to all these factors through clarity of the role of the facilitator who utilises a variety of skills to work at the level of individual participant as well as internal and external systems. This fluidity between individuals and systems is important in our study given the nature of the intervention and its successful implementation being in part dependent on engagement by individuals in the care home itself and external actors (such as the primary care teams). The facilitator role uses systematic approaches to pay attention to these factors and alter the implementation process accordingly.

The PARIHS Framework: Central to the PARiHS framework, is the development of theory which enables effective implementation of research evidence in everyday practice.[66] Consequently, theory development runs alongside the co-design and implementation components of this study.

Theory can be grand, mid-range, or small. The development of grand theories (such as social determinants of health) is not within the remit of implementation science. However, developing small and mid-range practical theories are key to implementation, and hence forms a core part of this study's design. Small theories, referred to as programme theories within implementation science, explain micro changes and transactions, such as working hypotheses or local theories of change. These programme theories need to be explored and mined to elucidate core concepts, in order to then develop mid-range theories, which have greater explanatory potential to predict and plan for change across different settings.[66]

Theories need to be generated regarding (i) influential components of the UK context, and (ii) the mechanisms of how to implement Needs Rounds in order to deliver desired outcomes. In shorthand, these are referred to as the **c**ontext, **m**echanisms and **o**utcome **c**onfigurations (or, CMOc).

Consequently, in this study we will initially develop small/mid-range theories, and use these to generate a fully specified mid-range theory which accounts for the contextual features, structures, behaviours, and processes necessary to implement UK Needs Rounds.[66]

Study phases

The project will achieve its aim of co-designing and implementing an appropriate scalable UK model of Needs Rounds over two phases:

Phase 1: With key stakeholders, we will conduct concept mining and theoretical modelling to generate programme theories and hypotheses about how Needs Rounds could be used. This theory development will proceed by examining ‘what elements of Needs Rounds would work, for whom, in what circumstances and why, in the UK context’. This will take account of core differences between Australia and the UK, such as (i) UK sites having potentially fewer registered nurses and therefore needing greater links with primary care to facilitate the prescribing and administering of medication; (ii) smaller care homes in the UK meaning less frequent Needs Rounds or more in-depth discussion of each resident; (iii) the need to understand current service delivery between care homes and specialist palliative care for our sites (iv) care home engagement in palliative care training opportunities, (v) how UK Needs Rounds fit with improvements in primary care provision in enhanced care in care homes.

Phase 2: The programme theories generated in Phase 1 will be tested and refined by implementing, adapting and evaluating UK Needs Rounds in six case studies. The evaluation of Phase 2 will examine the outcomes predicted from the theories, developing insights into the context, and reasoning/resource mechanisms that lead to the achievement of these outcomes.[67] We will assess acceptability, appropriateness, feasibility, implementation cost, coverage, and sustainability. These assessments will report contexts, mechanisms and outcomes to generate a mid-range theory of implementation which conceptualises the core learning from across all sites.

Definitions:

- A case study is: a specialist palliative care team’s input with their local care homes, and their associated health services.
- Key stakeholders are: health care practitioners working within specialist palliative care who deliver the intervention, care home registered nurses/assistants in nursing/managers, care home residents/relatives, and acute care staff involved in emergency presentations (emergency department staff and ambulance staff).

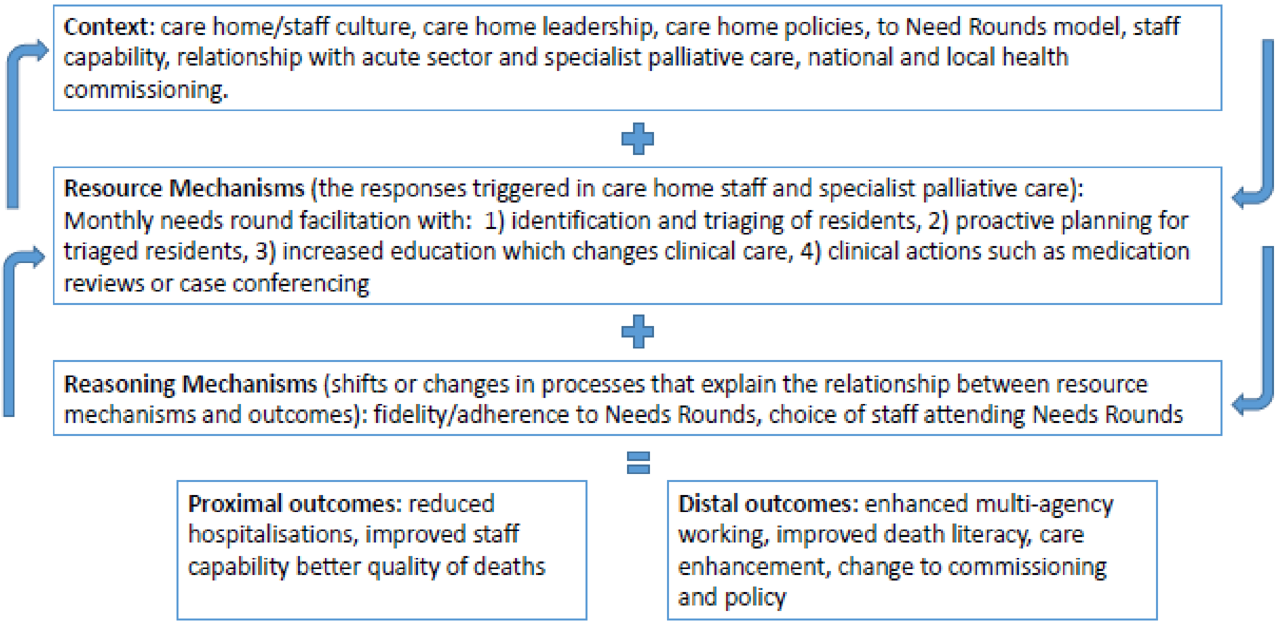
5.2 Methods

The study Flow Chart illustrates the components and connections of research methods across phases.

Phase 1: We will conduct interviews with key stakeholders to generate initial programme theories to explain how Needs Rounds could be used in the UK. We will then train key personnel (senior specialist palliative care nurses) in running Needs Rounds.

Figure 1 (below) illustrates hypothesised Context Mechanisms and Outcomes (CMOc) generated from the Australian work. Context (e.g. care home policy, or leadership) refers to the conditions within a care setting that shape and feed into mechanisms. Mechanisms trigger action (mechanisms could be both resource-related such as provision of case-based education) or reasoning (e.g. choosing which staff to attend Needs Rounds). This Figure also illustrates the initial focus for data collection in Phase 1 (described in more detail below).

FIGURE 1: indicative programme theories derived from the Australian trial of Needs Rounds



Context: care home/staff culture, care home leadership, care home policies, to Need Rounds model, staff capability, relationship with acute sector and specialist palliative care, national and local health commissioning.

Resource Mechanisms (the responses triggered in care home staff and specialist palliative care): Monthly needs round facilitation with: 1) identification and triaging of residents, 2) proactive planning for triaged residents, 3) increased education which changes clinical care, 4) clinical actions such as medication reviews or case conferencing

Reasoning Mechanisms (shifts or changes in processes that explain the relationship between resource mechanisms and outcomes): fidelity/adherence to Needs Rounds, choice of staff attending Needs Rounds

Proximal outcomes: reduced hospitalisations, improved staff capability better quality of deaths

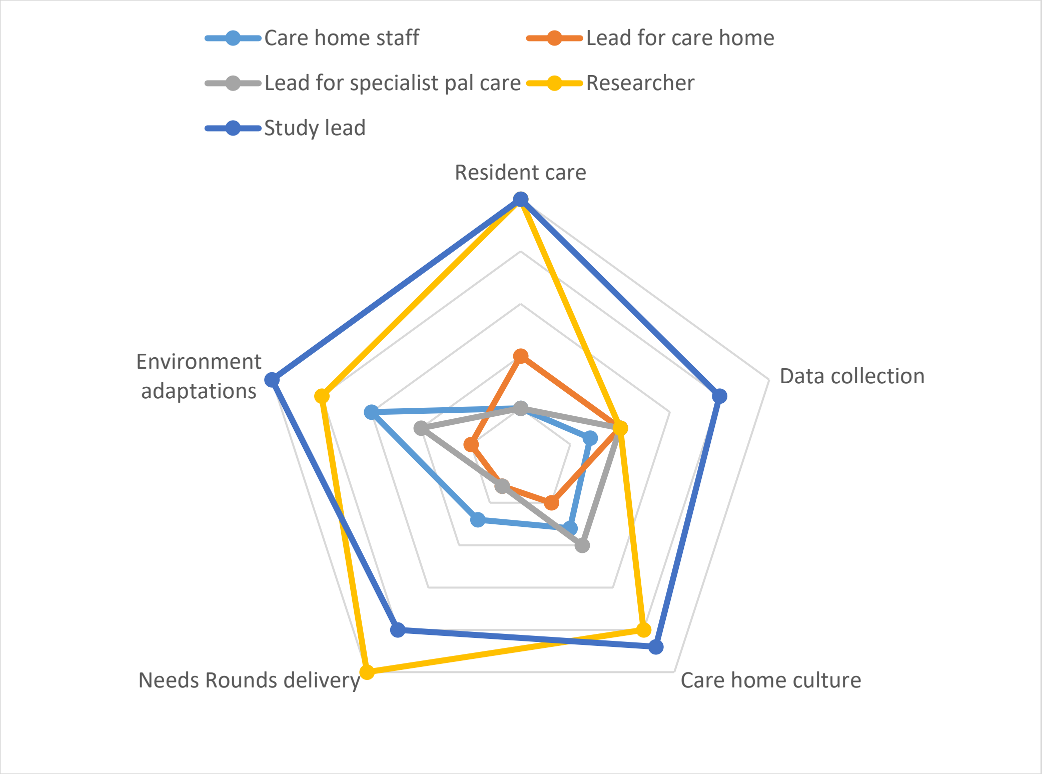
Distal outcomes: enhanced multi-agency working, improved death literacy, care enhancement, change to commissioning and policy

The theories and themes derived from interviews will be presented at a workshop in Phase 1. Workshop participants - key stakeholders in the case - will then co-design case study implementation plans, ensuring that the local plans align with local values, goals and service culture. This co-design phase will attend to core differences between the Austrlian and UK context, as noted in section 5.1. Workshop data will be captured on flipchart and converted into flow-charts/ infographics and project plans for sites.

The PARIHS framework asserts that implementing a new approach will require facilitation,[68,69] Facilitation can be a role, a process or a structure. Several people have facilitation roles, including care home staff (facilitating daily changes in practice), care home leads for the project (facilitating organising Needs Rounds meetings and ensuring follow-up activities occur), specialist palliative care leads (chairing Needs Rounds and promoting best practice in end of life care), the research team (facilitating data collection) and the project lead (facilitating commitment and enthusiasm for the study). Each facilitator plays a role in improving the care provided to residents, but in different ways and with varying intensity across tasks. Figure 2 below shows the facilitation partners, tasks, influence, and responsibility, with care home residents located at the centre. The facilitators vary in their proximity to certain tasks. For example, the lead for the care home strongly facilitates daily care of the residents and environmental/cultural changes needed, but is less involved in data collection. The lead for specialist palliative care has a strong facilitation role in resident care, but facilitates less in changing care home culture. The facilitation ecology is also influenced by structures such as the culture of the care home, local and national policy context of care provision.

Facilitation requires people to be leaders or champions. During Phase 1 data collection we will determine the best facilitators for each site. As described in Figure 2, facilitation linked with Needs Rounds delivery is likely to be clinicians from the specialist palliative care services (who then chairs Needs Rounds meetings) and staff members from each care home (most likely the service manager/team leader).[70] Facilitators will be identified in each specialist palliative care setting and care home, based on criteria for most effective characteristics for successful implementation.[70] Recognizing the likelihood of high turn-over of staff in care homes, at least two facilitators will be identified in each site.

FIGURE 2: Facilitation ecology



Care home and specialist palliative care facilitators will be prepared for their role through training in Phase 1. This training will be delivered via zoom web-conferencing by the project lead and Nikki Johnston (lead specialist palliative care clinician in the Australian work). Training will involve discussion of the practicalities of running Needs Rounds, subsequent clinical work, case conferences and referrals. Resources created for the Australian work will be re-purposed to assist in this training, including presentations on Needs Rounds, copies of the Checklist and data from Australian participants on implementation.[71]

Phase 2: Implementation of UK Needs Rounds will commence in the six Phase 1 case study sites. Phase 2 will test/evaluate the CMOc and theories to generate a coherent assessment of implementation and adaptations made in Phase 1. Further refinements to implementation will be made as based on the feedback received during Phase 2, and reflected in Figure 1, via recursive feedback loops between different elements of the CMO model. This feedback loop is exemplified in instances whereby change in one part of the system generates changes elsewhere, e.g. as resource mechanisms of case-based education are absorbed, this can shift the culture of the care home about staff learning.

A Phase 2 workshop with representatives from all 6 sites will have three functions. First, there will be a ‘sharing learning’ forum to discuss implementation successes and strategies. Second, we will share emergent findings from the qualitative interviews to prompt further discussion to continue co-designing UK Needs Rounds that will generate a single mid-range theory which fits all contexts, in order to harmonise implementation. Third, this workshop will be used to create dissemination materials such as brief ‘talking head’ videos.

For implementation, the case study configurations will expand to include up to 18 more care homes. Consequently, during Phase 2, there will be a ratio of specialist palliative care service to care homes, between 1:4 and 1:6. The number of care homes each specialist palliative care service works with will vary depending on local context (for example size of care homes). Recruitment is described in further detail below.

5.3 Setting and sample

- Inclusion criteria: Specialist palliative care services (hospice or community based) in the UK; care home for over 65s, situated within the service boundaries of a participating specialist palliative care team.
- Purposive maximum variability sampling of specialist palliative care services will focus on recruiting a heterogeneous and information-rich sample to reflect, for example: urban/rural, service size, deprivation, cultural demographics, use of ECHO or other specialist palliative care input models, national charity/independent management, funding models, hospital transfer policies. Participants will be recruited via purposive and criterion sampling and include: care home managers, residents, relatives, nursing and allied health, ambulance, pharmacy, and specialist palliative care managers/clinicians.
- Six specialist palliative care sites have confirmed involvement: Strathcarron Hospice, Forth Valley; Highland Hospice, Inverness; St Helena, Colchester; St Giles' Hospice, Walsall; Arthur Rank Hospice, Cambridge; Princess Alice Hospice, Surrey. We will work with ENRICH care home research network throughout (see Letter of Support).
- The Australian study informed the sample sizes and data collection time points, which will give adequate opportunity to qualitatively and rigorously examine the relevance of the programme theories and mid-range theory when implementing across heterogeneous contexts. Further, the sample sizes are congruent with accepted standards for qualitative data (interviews, Phase 1 and 2).[72]
- For the quantitative sample, we anticipate an average size of the care homes to be 52 beds, and the rate of emergency admission to hospital to be 0.173 per bed within the four month period, for an average of 9 admissions per care home.[73] A sample of 30 care homes would allow us to detect a change in the hospitalisation rate of 0.02 per bed ($\alpha=0.05$, $\beta=0.2$, $\Delta s.d.=0.040$). This is sufficient to detect a clinically meaningful change in the primary outcome (reduction of one hospitalisation per four month period in a typical care home) for the quantifiable data in phase 2.

Target population: Care home residents with less than 6 months life expectancy, in case study sites across the UK (to ensure the resulting model can be implemented across policy/commissioning jurisdictions).

Inclusion criteria

Stakeholders (for interviews in Phase 1 and 2)

1. Work for specialist palliative care or a care home in one of the six cases; or are a resident in one of the care homes; or are a relative of a care home resident in one of the six cases; or work in acute care impacted by hospitalised care home residents
2. Willing to provide informed consent
3. Have capacity to provide their own consent to participate
4. Not engaged in any current safeguarding investigations.

Care homes (Phases 1&2)

1. Located near to the specialist palliative care team
2. Provide care to residents who have high clinical nursing/medical needs
3. Willing to sign a memorandum of understanding with the research team, outlining provision of hospitalisation data, facilitate access to staff for interviews, and engagement in Needs Rounds
4. A range of sizes (focusing primarily on larger care homes, following CQC data indicating lower quality in larger facilities)[74], sole traders and large corporate provider, and with a range of funding models (NHS/social care and self-funded residents).

Residents (who are discussed at Needs Rounds in Phase 2)

1. Resident in a collaborating care home in one of the six case study locations
2. An anticipated life-expectancy of less than 6 months

3. At risk of dying without appropriate planning in place
4. Experiencing inadequately managed bio-psycho-social symptoms
5. Not engaged in any current safeguarding investigations.
6. Able to provide their own informed consent

Residents/relatives completing family views questionnaires

1. Resident who was discussed in Needs Rounds, or a relative
2. Able to provide their own informed consent

5.4 Recruitment

Six specialist palliative care teams have been recruited to the study. Due to considerable enthusiasm with the study's approach and goals, other services have confirmed interest in joining if any site should become unavailable between date of submission of proposal and study commencement. Key contacts from these palliative care teams are named as collaborators in this application. These sites were selected for their heterogeneity, including rural/urban and independent/national status, as well as an explicit strong commitment to the study.

Recruitment of care homes will be conducted by the specialist palliative care team, with support when required from the research team. Specialist palliative care teams will invite their local care homes to take part and/or draw on the NIHR ENRICH network of care homes with an interest in engaging in research. ENRICH England and Scotland have confirmed their willingness to assist in the study recruitment. We will apply to be an NIHR portfolio study to provide additional support in recruitment. All specialist palliative care teams currently have relationships with some local care homes, and these would be examined initially against inclusion criteria for commencing the study.

Recruitment of interviewees in Phase 1 and 2 will be informed by theoretical sampling – seeking to focus on stakeholders most likely to provide insight into the generation of programme theories and the ultimate mid-range theory. Recruitment of care home staff, residents and relatives will all proceed via the care home manager, asking them to identify and then pass invitation letters to relevant stakeholders. Recruitment of acute care staff will proceed via recommendation by specialist palliative care or care home staff, whereby invitations letters will be emailed to relevant personnel.

5.5 Data collection

Phase 1: Programme theories will be generated from 40 interviewees (individual or small-groups) from six case study sites. Sample size justification is in a section 5.3. Interviewees will be key stakeholders: residents/relatives/clinicians/managers in care homes, clinicians in specialist palliative care and related acute/primary care, and allied health practitioners. Formal respondent checking of transcripts will not be used, since the workshop will provide opportunity to clarify, check accuracy and validate ideas/opinions with participants. Data will be collected initially during face-to-face site set-up visits, and subsequently via telephone.

We will ask interviewees about their local context, such as services' geography, policy, structure, funding and practice elements, generated from the working programme theories from the Australian trial (Figure 1). We will also collect relevant documentation (e.g. service policies). These data will enable us to develop realist theories regarding how implementation would work in practice, what might influence implementation in each case study site, to identify Contextual factors, Mechanisms (including both reasoning and resources) and Outcomes (CMO).

Phase 2: Phone or video-call qualitative interviews with key stakeholders in each case study will be conducted to ask about the process and mechanisms of change and examine the CMOs/theories that were generated in Phase 1. Interviews will collect prospective data on acceptability, appropriateness, feasibility, implementation cost, coverage, and sustainability. The context will be examined alongside how the intervention is delivered in each site (mechanisms including resources and reasoning such as preparedness of sites, agency to affect practice), and how that maps onto adherence to the delivery of the intervention as planned. In the final interviews, stakeholders will be asked to reflect on mechanism to disseminate the findings (see section 6 below). Formal respondent checking of transcripts in Phase 2 will not be used but interviews at month 4, 8 and 12 will provide an opportunity for respondents to reflect on views expressed earlier in the study.

Interviews will be audio-recorded and conducted at 4 months (capturing early adoption), 8 months (mid-range) and 12 months (longer term implementation). Our Australian work showed that six-months allows time for clinicians and services to become sufficiently familiar with the Needs Rounds model. The Australian study indicated month-on-month improvements in staff capability over time, and hence this 12 month timeframe allows us to plot the dose effect over time. Interviews in Phase 1 and 2 are likely to last similar lengths of time to our Australian process evaluation interviews, of circa 45-60 minutes,

The main outcome will be determining the characteristics of effectiveness regarding *what works in what circumstances with* Needs Rounds within the UK, derived from through qualitative interviews with key stakeholders (residents, relatives, care home staff, specialist palliative care staff, and acute care staff). Secondarily, we will determine *for whom* Needs Rounds work, focusing on core stakeholder groups: the NHS, residents, care home staff. These include health outcomes which mirror those of the Australian work, to facilitate comparison:

- **Economic evaluation** will be a cost-benefit analysis[75] drawing on the following data (Table 1 and Table 2)

Cost type	**Cost detail**	**Measurement of costs**
Direct costs	Intervention costs on-site • Staff time • Travel • Consumables and Equipment • Workshop costs	Included within the project budget and therefore directly recorded. Where appropriate additional detail will be collected directly from the care homes.
	Additional NHS staff time attending care home Additional prescriptions	Estimated in the SoECAT, with additional costs recorded by intervention staff as required.
Indirect costs	Wider additional costs incurred by the care home, including: • Changes in their staffing • Changes to facilities (i.e. use of rooms), or overheads as a result of hosting the intervention.	These changes, and their associated costs, will be collected from care homes in a proforma through the interviews
Intangible costs	Inconvenience to staff, residents, family and carers as a result of the intervention.	These will not be measured directly, but will be explored in the qualitative interviews in the main study.

Table 1: *Intervention cost elements*

The **total benefit** from an NHS and Personal Social Services perspective is the change in health and social care service costs that result from the intervention. The costs of hospitalisation will be constructed from resident-level data on length of stay collected by the care homes, and costed using the National Tariffs and hospital -specific PLICS data for both England and Scotland. Total costs for the each of the pre and post periods will be calculated by summing these costs across all residents admitted to hospital from a given site, and the benefit is the difference between pre and post health service-use costs.

Cost type	Cost detail	Measurement of costs
Direct costs	Costs of ambulance journeys	Estimated from the 2019/20 National Tariff Payment System.[1]
	Hospital stay cost	Hospital-specific PLICs data for England[2] and Scotland[3] on stay costs by age and gender to estimate a day rate to use in the hospital costing.
	Primary care usage	Collected from care home sites in a proforma through interviews
Indirect costs	Wider additional costs incurred by the care home, in connection with resident hospital admissions, including staffing, travel, equipment or facilities.	These costs will be collected from care homes in a proforma through the interviews
Intangible costs	Inconvenience to residents and their family/carers arising from hospitalisation	These will not be measured directly, but will be explored in the qualitative interviews in the main study.

Table 2: Health service cost elements

We will not seek linked hospital data as this would require considerable additional resource (time and personnel) and result in reduced data of less robust quality for drawing generalisable conclusions. The reduced volume and robustness of data would occur as a result of requiring individual-level consent to acquire such information, effectively reducing the pool of data to those without cognitive impairment. Since care average prevalence of dementia in care home residents is 69%[76] this presents an unacceptable reduction in sample size.

- **Staff capability** of adopting a palliative approach (CAPA), assessed on a 9-item validated self-report questionnaire.[10] CAPA has a uni-dimensional scale; higher scores indicate greater capacity. Internal consistency reliability is very high with a Cronbach's alpha of 0.95, and split-half reliability coefficient of 0.93.[10] Measures will be taken at baseline from all nursing assistants and registered nurses, and then prospectively each month from those attending Needs Rounds. Final assessment will be taken from all staff following the 12 month trial period. Questionnaires will be filled in by care home staff, either hard copy or online depending on site preferences.
- The **Quality of Death and Dying** Index,[9] (QODDI) completed by care home staff for each decedent resident prospectively throughout the study. This 17 item questionnaire examines four correlated but distinct domains: symptom control, preparation, connectedness and transcendence. The decedent's experience is rated on a 0 to 10 scale, where higher scores indicate a better experience. The Cronbach's alpha for the QODDI total score is 0.89. Following correspondence with the scale's originator confirming psychometric robustness of excluding items, one item on access to euthanasia will be removed, as this is not legal in the UK.

  The QODDI was designed for completion by relatives, however, staff are more consistently likely to have seen the resident in the weeks prior to death, hence staff completion will result in

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[1] https://improvement.nhs.uk/resources/national-tariff/

[2] https://digital.nhs.uk/data-and-information/publications/statistical/mi-acute-patient-level-activity-and-costing/2018-19

[3] https://www.isdscotland.org/Tariff/

more reliable and valid data. No suitable staff measure exists. Questionnaires will be filled in either hard copy or online depending on site preferences.

- **Family perceptions of care** from relatives of residents who are discussed at Needs Rounds, using the CANHELP lite.[77] We will use the second part of the questionniare which focuses on satisfaction with care. 22-items collect self-report data on family views of care home staff, illness management, communication, relationships with clinicians and relative involvement. The Cronbach's alpha for the total score is 0.88-0.94. Questionnaires will be filled in either hard copy or online depending on family/site preferences.
- **Environmental/contextual data** will draw from conceptual work by Estabrook[44] and be qualitative in nature to dynamically explore each care home's culture. Interview topics will cover, for example, leadership, culture, time/space, staff/resident turnover or introduction of new policies/procedures, and prioritisation of the intervention in workload. Data will be collected for each case, from interviews and site documentation. Activity logs will also be generated, to capture time spent by all parties, and additional work generated beyond the Needs Rounds meeting.
- A bespoke tool will capture **resident level data**. This will include basic demographic information (unique study identifier, date of birth, ethnicity, category of primary diagnosis – such as heart disease, dementia, organ failure). We will also document their preferred place of death (and actual place of death if they die during the study). We will also collect individual-level information regarding the assessments and interventions which are triggered by Needs Rounds. This might include, for example, physical assessments, blood/urine tests or other clinical investigations. We will record any referrals to other NHS services, changes in pharmacotherapy, commencement of syringe drivers and so forth which are triggered by the resident having been discussed at Needs Rounds. Data will be collected from the care homes by one of 6 research assistants, who will be employed on sessional contracts, and located close to each of the case study sites. Following learning from the Australian studies, we recognise the importance of developing and maintaining strong relationships with the local sites. The case-study local researchers will collect: resident-level data (i.e. hospitalisation, place of death, demographics) data from care home records, and collect/scan/return all data to return to the research team.
- We will collect data on the **experiences and process of PPI** throughout the study. We will conduct interviews with PPI members and the research team, including all co-investigators and representatives from the case study sites (both specialist palliative care and care homes). One-to-one phone/video-conference interviews will be conducted to examine the successes and opportunities of patient/public involvement in this study, to enhance future PPI work. This is likely to be conducted by the study RF, presenting some limitations with objectivity and an independent RF will be used if possible.

5.6 Data analysis

Qualitative data: Transcripts of audio data and documentary evidence will be stored and organised using Nvivo. Within and between case analysis will be conducted inductively, drawing on process tracing and constant comparative methods respectively. Differences between the Australian context (see 5.1) and the UK will be surfaced to facilitate detailed reporting on the specificity of the UK model to the local context. Deductive analysis will also be used to refine the CMO theories. Thematic analysis will underpin the analytic approach, and follow the five-step process outlined by Braun and Clarke.[78]

Estimating the treatment effect of the intervention on health service outcomes

Baseline data will be collected on the number and duration of hospitalisations over the preceding 4 months. This will be compared to the number and duration of hospitalisations recorded in months 9 to 12 of the intervention. This allows time for the intervention to be established, and ensures that equivalent 4 month periods are being compared to control for seasonality.

The treatment effect will be estimated as paired t-tests of the rate of hospitalisation, and number of hospital days, respectively. We will also conduct multilevel regression modelling of the two outcome measures, controlling for local area deprivation, sector of the care home, and other characteristics to describe the wider factors associated with the changes in the outcomes observed. We will estimate a weighted least squares model of the outcomes, with cases weighted by the number of beds in the care homes, as a further robustness check. The estimates of the treatment effect will be used in the cost effectiveness analysis, incorporating the uncertainty of the estimates in the analysis.

Estimating the cost effectiveness of the intervention on health service outcomes

A cost-benefit analysis of the intervention will be undertaken from a health and social services perspective. The intervention cost will be calculated to include both direct and indirect costs to both NHS and care homes of delivering the intervention. Benefits are calculated as the change in NHS costs incurred following the intervention, including both primary and secondary care. We will estimate these by valuing the reduction in hospital stays and hospital days as a result of the intervention. These will be measured using hospital day rates and ambulance costs. Where possible, we will also collect data on additional health costs such as GP callouts and visits by specialists.

The CBA will be conducted from the perspective of the NHS and Personal Social Services. We will compare the costs of the intervention to the changes in health service costs from reduced hospitalization. When calculating costs and benefits, we take account of i) uncertainty in the estimate of the treatment effect; ii) projected costs over a five-year period; and iii) spatial variation in cost across jurisdictions. Wherever possible the analytical specification will follow that of the NICE Reference Case.[79] While there are also likely to be individual and broader societal benefits arising from the intervention these are challenging to value in financial terms and beyond the scope of this economic evaluation. They will be explored instead in the qualitative portion of the study.

We will model the net benefits of the intervention over a five year period separately for care homes in i) England and ii) Scotland, given the estimate of cost savings per care home bed and the total number of care home beds in each jurisdiction, and applying an annual discount rate. We will model these predictions at the point estimate for the treatment effect, and also for the upper and lower bounds of the 95% confidence interval around the treatment effect, to provide a range of plausible costs savings over five years incorporating the uncertainty in the main study.

We estimate the treatment effect using a pre and post design. One of the limitations of this design is that aggregate time trends can be a confounder. We have attempted to mitigate this by using multiple sites across the country, and by measuring the baseline and post-treatment outcomes at the same time of year. However, in interpreting the results we still need to be mindful that national-level time trends could explain part of the differences observed.

We want to represent the uncertainty of the estimated treatment effect in our cost effectiveness analysis. We will use the 95% confidence intervals from the estimated treatment effect to calculate estimated cost effectiveness ranges i.e. we will report the cost effectiveness at i) the lower bound of the 95% confidence interval; ii) the point estimate of the treatment effect; and iii) the upper bound of the 95% confidence interval. Reporting a cost effectiveness range will allow us to capture the uncertainty in the treatment estimate in our cost effectiveness figures.

Some sub-group analysis is likely to be conducted, for example to examine cases focused on independent specialist palliative care teams, and public versus private care homes.

5.7 Timescale and milestones (month in brackets)

Section 11 outlines the timeline. In brief, the project will proceed as follows:

Phase 1 (month 1 – month 8): Ethics permission secured (end of month 3), interviews with stakeholders (months 4-5), analysis (months 5-6), co-design groups formed (months 6-7), analysis, reporting, facilitator training (month 8).

Phase 2 (months 9-28): Implementation starts (month 9), Prospective interviews complete (months 12,16,20), Cost analysis complete (month 25) UK Needs Rounds model finalised (month 27), Dissemination (month 28).

6. Dissemination, Outputs and Anticipated Impact

Dissemination (public engagement) will occur throughout the project, not just at the end, using a range of mechanisms, and involve all members of the project team including PPI members. Our dissemination plan was developed with PPI input.

We intend to focus our engagement activities on promoting:

1. Capacity and capability of care homes to care for people at end of life (to those in the study and those not in the sample)
2. Informal carers (relatives) to be aware of the approach to care, in order to lobby local services for this improvement
3. Policy and commissioning groups to adopt UK Needs Rounds.

Informal carers are a key group to disseminate to. We will link with Carers Scotland and Carers UK to send written updates throughout the study, and liaise with them to identify opportunities to disseminate to informal carers face-to-face. We will also develop a project Twitter tag, and build a following of informal carers on social media. We will use Carers Week (in June) and World Hospice and Palliative Care day (October) each year to promote the study using print press, broadcast media and social media.

Quarterly newsletters will be sent to case study sites to update them on the study's progress. The study is reliant on these sites for the success of the study, so maintaining good relationships and open communication is critical throughout, not just at the end. Hence we will disseminate updates to them on progress including staffing on the project (e.g. study post-doctoral fellow), recruitment, retention, steering group meetings, PPI engagement and influence on the study, links to blogs about the study and other spaces/places in which the research is discussed.

Community engagement will occur by pitching the study to the following outlets, which target engaged/educated members of the public: Festival of Science, Dine and Debate, Sceptics Societies. We will offer talks at outlets which target older people such as U3A and carer groups.

At the commencement of the study we will take photos of the study team, which will be used in the range of dissemination activities we have planned. We note that having all team members in one place is unlikely so several photos of sub-groups will be necessary. We will also consent clinicians involved in the case studies to take photographs to be used to target social media outlets.

Key stakeholders for impact and knowledge transfer include:
Policy makers: Objective: To promote adoption of UK Needs Rounds in policy and practice. Method: a briefing document will summarise the key findings and recommendations. We will advocate for national adoption of the model at key policy groups, e.g. the cross party/all-party groups on palliative care/care homes/older people's health. We will work with palliative care organisations (such as Hospice UK and the Scottish Partnership for Palliative Care) to lobby ministers and civil servants. The applicant team has strong networks in these third sector organisations. Further, the PI regularly attends the Scottish Cross-Party Group on Palliative Care. Measure of success: Discussion of the study and findings with government Ministers and senior civil servants.

Practitioners: Objective: To facilitate uptake of the model to benefit care home residents across the UK. Methods: an implementation guide will be disseminated via care home networks. Infographics will disseminate interim and full results through clinical networks. For case study site staff (hospices and care homes) participating in the study, we will offer education sessions about the study, at a time/date convenient to them. This will be conducted via zoom hence accruing no additional non-staff costs.
Measures of success: Downloads of the implementation package from a dedicated study website; brief survey to generate feedback on use of the materials. Oral paper at palliative care conference to present the findings.

Public: to enable lay advocacy for Needs Rounds, an infographic summary of the project will be distributed through local and national care home organisations, palliative care support organisations, print press and broadcast media; regular social media updates on emergent findings. Hands-on events will also be sought, e.g. during carers' week and science festivals. University of Stirling media team will support ongoing communications with media about this project. Measures of success: >100 re-tweets of study findings on social media to reach wide population base; participation in carer/science forums in year 2/3 of the project.

Academic: Objective: share data, advance the field of end of life care in care homes.
Methods: Quarterly infographic newsletters to international networks in palliative care and carers; regular social media updates. A study hashtag will be used for twitter alongside other relevant tags (e.g. #palliative #carehomes) to increase re-sharing of updates. Present at international palliative care (EAPC) and carer conferences to target academics and clinicians. Peer review journal articles in key palliative care publications. Gold open access journal articles (Palliative Medicine) and an article in The Conversation will drive further use and implementation of the model and its evidence base. Data sharing will be facilitated through appropriate ethics and consent approvals. We will publish a minimum of four outputs. These will be produced in the following sequence:

1. The protocol: we will publish the methodology, analysis plan and outcome measures shortly after funding has been secured. (BMJ Open)
2. The primary goal, addressing the main study question: how can Needs Rounds be implemented in the UK context?
3. The subsidiary goals, addressing the questions: how do Needs Rounds in the UK impact staff capability, resident deaths, resident hospitalisations and family perceptions of care?
4. A report for INVOLVE summarising the PPI evaluation.

The main findings paper and protocol will be Gold open access (costed into the budget). In line with NIHR Open Access Policy, all other journal articles are planned as green open access and will be deposited in institutional repositories, as well as Europe PMC. However, the Chief Investigator will also make individual institutional requests to support Gold open access for peer review journal articles reporting secondary and qualitative outcomes.

The results of the study will first be shared with study collaborators who will be given the opportunity to comment on the report. The final version of the primary and secondary outcomes papers will be agreed by the Steering Committee before submission for publication.

To maximise the impact of the study findings, in addition to high-impact peer review articles (e.g. Palliative Medicine; Age and Ageing), we will also write for practice-based/practitioner journals (e.g. Nursing Standard).

We will synchronise the publication of the main results with an article in The Conversation (where the team have experience of publishing on palliative care and carers).

6.1 What do you intend to produce from your research?

A primary product will be an innovative translation package which enables staff across the UK to readily understand how to implement Needs Rounds. The package will clearly articulate the mid-range theory which is produced through the work.

The translation package will be co-produced with key stakeholders who are experts-by-experience including care home residents, relatives and staff, and specialist palliative care staff, as part of Phase 2. The package will comprise instructional videos of Needs Rounds, talking heads of stakeholders expressing what was most powerful/helpful to them, and the outcomes.

The package will be underpinned by a pedagogical framework, rather than delivered as 'flat information' recognising that learning occurs through the interaction of four forms of presence: social (feeling connected to other learners), cognitive (confirming meaning through sustained reflection/discourse), teaching (design/facilitation and instruction) and emotional presence (the relationship between affect and learning) [80]. We will leverage the inter-relationship of these four presences to achieve deep learning experiences [81]. The package will assume that learning is dynamic, building experience of palliative care practices rather than merely assimilating information. Thus the instructional video will adopt an approach of 'walking alongside' the viewer, asking them to engage in reflecting on their own practice and how Needs Rounds can be used in their setting. For example, the videos will include a mock-up of a Needs Round, where a voice-over invites the viewer to reflect on the kind of meeting spaces and technologies available to them in their locale. Clinicians accessing the package will be invited to join a community of practice, to offer the potential of a critical mass of people using the approach. Strategies for building the community of practice will include a common twitter hashtag and blog where users can reflect with each other.

The resources (instructional videos, documents outlining the ‘how to’ guide derived from the mid-range theory, evidence from this study and the Australian research, alongside the Australian ‘checklist to guide practice’) will be made freely available via the University Of Stirling website.

6.2 How will your outputs enter our health and care system or society as a whole?

We recognise the number of innovations in this setting which have overlap (e.g. anticipatory/ advance care planning initiatives) or not been fully adopted (6-steps). We believe our Needs Rounds model is different and therefore more likely to gain traction for wider implementation because it has the robust evidence base generated from the stepped wedge trial demonstrating that *it has effective and desirable outcomes*, combined with this implementation study on *how* Needs Rounds can be used in the UK. Most other studies lack one or both of these components.

We will liaise with Government palliative care leads and cross party/all party groups on palliative care and older people. Our policy briefings, using infographics to summarise the study progress/results, will make the study readily accessible to these audiences. We will request time at the cross party/all party groups to present the study and thus actively lobby for changes to systems.

Our dissemination strategy is multi-pronged and consequently will enable us to reach a range of audiences to facilitate the transfer of findings to the health and care system as well as wider society. As summarised in a subsequent sub-section (6.5 ‘what do you think the impact will be and for whom’), the study will impact residents, relatives, care home staff, palliative care staff, and the wider community. Our dissemination approach will enable each of these stakeholder groups to be informed of, and ultimately lobby for, uptake of the model.

We will liaise with organisations such as Hospice UK and the Scottish Partnership for Palliative Care to promote dissemination and uptake across the health and care sector. The Scottish lead for palliative care has been invited to join the project steering group.

6.3 What further funding or support will be required if this research is successful (e.g. From NIHR, other Government departments, charity or industry)?

No additional funding will be required to run the research, though care homes will be providing in-kind contributions regarding staff time to attend Needs Rounds and implement recommendations from the Needs Rounds.

To continue implementing Needs Rounds, experienced nurses from the specialist palliative care teams would need funding to liaise with care homes. Since specialist palliative care teams within hospices are funded partly by NHS and partly through charitable donations, there is an assumption that support would be required by both parties if rolling out beyond the study.

In Australia, health service funding was allocated to continue and expand provision of the Needs Rounds approach, recognising the considerable cost savings delivered to acute care in the Australian Capital Territory. Needs Rounds therefore represents a ‘spend to save’ investment in reducing hospital costs, while driving up the standards of care in care homes, improving resident care and enhancing staff capability in end of life care. As described above, unlike other initiatives in this space, no other intervention has both a robust evidence base and implementation data to support it as the preferred model of delivering anticipatory person-centered end of life care to care home residents.

6.4 What are the possible barriers for further research, development, adoption and implementation?

1. Turnover of care home staff is a barrier to adoption and implementation. Care homes are notorious for rapid turnover of staff. Changes in key staffing reduces the potential for adoption and implementation, and commitment to the approach will be hard to sustain over rapidly changing staff team. While we have no control over this systemic and endemic issue, we are confident from our work in Australia that senior staff staying in the sector are likely to want to

use Needs Rounds with their new employer. For more junior staff, and employees leaving the care home sector, exposure to Needs Rounds will have contributed to increasing community understandings of palliative care, death and dying.

2. Allocation of specialist palliative care staff to provide anticipatory support to care homes is a potential barrier to adoption. Continuation may require either additional staffing, or redeployment from traditional community services (provided in people's own homes) to care homes. Thus communication with local commissioners (using policy briefings) will be key to continued funding of Needs Rounds.
3. Funding and commissioning present potential barriers to adoption. Providing specialist palliative care for care home residents is part of the ongoing cultural change from historical views of palliative care being provided only to people with cancer. Funding/commissioning will need to adapt to the increasing need to provide specialist palliative care to people with non-malignant diseases residing in care homes. Funding may need to be routed from acute care to specialist palliative care to achieve this. Since the Needs Rounds approach has cost outcome data[6,71] to support this 'invest to save' approach, we are confident that there are considerable cost savings in the acute sector from adopting Needs Rounds.
4. Other approaches to service delivery in care homes being prioritised, e.g. Gold Standards Framework or 6 Steps may curtail adoption. Needs Rounds complement these approaches and also offer considerable advantages due to their provision of direct clinical work as well as case-based (and therefore tailored) education.
5. Because the team has conducted considerable work in this territory, we do not foresee any future research barriers, rather there are many opportunities for extending this work into other areas including telemedicine for remote/rural sites and use internationally.

6.5 What do you think the impact of your research will be and for whom?

- Care home residents: it will improve their quality of dying and death. It will enable them to live well until they die, by improving the confidence and competence of the staff supporting them on a daily basis. Developing a model which works across the UK means that we can effectively use UK Needs Rounds to benefit all care home residents who are in their last few months of life.
- Care home staff: it will foster greater capability and knowledge in end of life care. Qualitative findings from the pilot work indicate that staff feel greater job satisfaction, and feel more confident in discussing residents' care needs with GPs and with relatives.[8] The approach also helps normalise death/dying which facilitates a change in care home culture, which benefits future residents and relatives.
- Families of residents: it will drive up their confidence in care home staff looking after relatives in their last year of life. Families are anticipated to report greater satisfaction with illness management, communication, relationship with clinical staff and feeling more involved.
- Wider community: the research will drive up confidence in care homes to provide skilled care at end of life. Normalising death/dying and providing reassurance that care homes can access anticipatory care which is as good as hospice care, reduces current inequalities in access to specialist palliative care.
- Palliative care: the work will contribute to the further widening of specialist palliative care to people with non-malignant diagnoses and promote recognised good practice of early referral. The project will increase the evidence base, and provide data and insight into how to adapt a successful Australian model for different countries. Consequently, while the study will directly impact the UK, it will offer other countries opportunities to identify how they too can improve services in residential care homes.

7. Project management

The study will be sponsored by the University of Stirling. LF, the chief investigator (CI), will maintain oversight of the whole study. LF will lead the project team (including all study co-applicants and the research fellow) which will oversee the study and hold monthly meetings, via zoom video-conferencing. Additional ad hoc discussions may be convened on a needs-led basis throughout, for example during crucial phases of the study. LF will have a formal weekly meeting with the research fellow, who will be based at the University of Stirling.

The CI will be the project manager, working closely with the appointed research fellow and being the named contact for PPI members. The research fellow will be the main point of contact for each of the case study sites and also liaise closely with the PPI members.

Six-monthly reports to NIHR will be produced. In the interim the research team will monitor budgets and progress at each collaborating institution. The proposed monitoring will ensure that a high quality study is delivered on time and within budget.

A project steering group (PSG) will be convened and meet a minimum of annually throughout. The PSG will include Emma Hodges (Chief Executive at St Giles Hospice, Honorary Lecturer in the School of Law at Keele University, and currently completing her doctorate on organisational factors influencing hospices provision of services for people with dementia). Other members include Sandra Prew (ENRICH lead for the West Midlands and care home nurse), Carol Andrew, who is the senior commissioning manager at NHS Birmingham and Solihull Clinical Commissioning Group. She is currently leading new commissioning work focused on care home provision. Members of other NIHR funded teams focused on care homes (Dr Neil Chadborn), as well as palliative and end of life care specialist palliative care in the North East of England, and a further PPI representative. The NIHR terms of reference will be used to guide the structure, content and reporting mechanisms of the PSG.

8. Ethics

- University of Stirling will act as the Sponsor. University and NHS ethical permissions will be gained. REC reviews will be flagged for an England-based panel to ensure care home coverage and panel A in Scotland to provide oversight and compliance with the Adults with Incapacity Act.
- Management approval from care homes will be sought in writing as part of the approvals process. Care homes will act as the data custodians for resident data, including hospitalisations. Consequently, there will be no requirement to access to individual-level linked administrative NHS data on hospital episodes. Following the Australian study, and UK studies collecting similar data,[46] individual permissions to be discussed at Needs Rounds will not be sought. Individual care homes will provide consent to introduce the approach to care in their site, given the impracticalities of gaining informed consent from a large population many of whom are likely to have substantial cognitive impairment (with few appointed medical lasting power of attorneys at commencement), with low risk to participants, and sufficient protection of participant privacy.
- Researchers will have a current PVG certificate/DBS check.
- We have estimated four months to gain approvals, based on feedback from HRA that approvals take around 20 calendar days, and RECs work within 60 calendar days.

9. Patient and Public Involvement

Our PPI approach is informed by the National Standards and INVOLVE guidelines. The aim of our PPI engagement and involvement is to ensure the study is focused on improving services for residents and families. Both consultation and collaboration will be used as appropriate throughout the study. The study has PPI representatives as full members to ensure that study leadership is informed by people with lived experience of relatives/friends receiving end of life care in care homes. An audit of PPI resources/finance will be conducted to appraise and report costs at the end of the project.

The three PPI representatives, Ms Ogden, Ms McKenzie and Ms Soulsby, bring expertise through experience of relatives and close friends residing in care homes. Our PPI network crosses the UK, to ensure that we gain insight from people with a range of backgrounds and experiences. Ms Ogden and Ms Soulsby are based in the North East of England, and Ms McKenzie in London.

We will also secure further PPI engagement through a third sector organisation.

Co-investigators will be remunerated for their time attending and preparing for meetings in addition to having travel costs paid. Payments will be made through the University of Stirling accounts team, who typically pay claims within 10 days. Travel advances can also be arranged, and the University team can book travel to ensure PPI members are not out of pocket for study travel.

Plain language is always used for communication with PPI members.

We will evaluate our PPI work throughout, and produce a summative document at the end of the study.

10. Project / research expertise

This is a senior and multi-disciplinary team with expertise from psychology (LF), nursing (BMcC, JH, KS, NJ), statistics and economics (AR), and personal experience of care homes (MO, MM, IS). We have methodological expertise in implementation (BMcC, JH), qualitative methods (LF, BMcC, JH), and case study methodology (LF). Together, we provide all the expertise required to deliver this project.

Individual contributions:

- **Dr Forbat** (20% throughout), is the CI. She is a research psychologist and family systems psychotherapist. She led the Australian Needs Rounds trial and has expertise in specialist palliative care, ageing, interventions, qualitative research and case study methodology. She won an award for her user involvement work from the National Cancer Research Institute (2011). She will lead this study, drawing on her track record of delivering high quality studies on time and on budget.
- **Prof McCormack** (10% throughout) is an internationally recognised leader in implementation science, ageing, nursing and care homes. He is one of the founders of the PARHiS implementation science framework and has applied the methodology to dozens of implementation studies. His writing and research focuses on person-centred practice, gerontological nursing, and practice development. He is Editor Emeritus of the “International Journal of Older People Nursing”, holds an honorary appointment as consultant nurse in NHS Forth Valley (one of our case study locations), and is on the Board of Age Scotland.
- **Prof Spilsbury** (5% throughout) has developed a programme of clinically and policy relevant research in the areas of the workforce, care for older people and care homes. She leads a portfolio of research with care homes: including the RCN Foundation funded project addressing support for nurses in care homes; the first UK study of the relationship between staffing and quality in care homes; and is Academic Director of NICHE-Leeds (https://niche.leeds.ac.uk/) a partnership between the care sector and academia to enhance quality of care, quality of life and quality of work in care homes. She has widely disseminated her work to promote impact and benefits for health and care. She was Associate Editor for the International Journal of Nursing Studies and a former NIHR HSDR Commissioning Board member.
- **Dr Hockley** (5%) is an expert in palliative care, nursing and care homes. She has considerable expertise in facilitation’s role in implementation, and has been involved in both the PACE European study on improving care in nursing homes and the Namaste person-centred approach to care in nursing homes.
- **Prof Rutherford** (25days total)is a health economist and social statistician specialising in working with administrative data on hospitalisation, care and the third sector. He led the Scottish Civil Society Data Partnership, and has been a co-investigator in the Scottish Administrative Data Research Centre; the Centre for Population Change; and the Scottish Longitudinal Study of Ageing (HAGIS). He is a member of the Scottish Informatics and Linkage Collaboration Strategic Management Board; and is a board member of Age Scotland.
- Prof Hanratty (5%) is GP with expertise in primary care, palliative care and care homes. She holds and NIHR grant using a critical realist methodology, and will ensure Needs Rounds evolve to suit the primary care clinical context of the UK.
- **Ms Ogden** won the 2019 award for her PPI role ‘Putting Patients and Carers First (palliative care) from South London Clinical Research Network. She has relatives who have lived in care homes, and experience of acute hospital provision of specialist palliative care. She will link with Age UK and Carers UK to garner further PPI input into the study. She attended International

Research Summer School in 2011 (palliative care) at Lancaster University. She was also a member of NCRI Clinical Studies Group on palliative care and sub-group on pain management. She has completed projects on sedation, breathlessness, social determinants at end of life (place of death), childhood bereavement and transitions into palliative care. She has also conducted a piece of work on evaluating PPI for the Cicely Saunders Institute of Palliative care.

- **Ms McKenzie** worked in the NHS and has expertise in psychological first aid. She cared for her father-in-law and is passionate about bringing her personal and professional experience to improving nursing home care.
- **Ms Soulsby** has links with the Newcastle carers network, and is a PPI representative for projects in Scotland and England. She has taken part in a James Lind Alliance Priority Setting Partnership (PRIORITY II) as a Steering Group member and has also been a member of the Steering Group for RAINDROP (**R**esource **A**llocation **i**n **N**HS **D**entistry: **R**ecognition **o**f societal **P**reference). She is a PPI representative on Trial Steering Groups and Trial Management Groups, and a Patient Research Ambassador for the North East and North Cumbria. She is an expert by experience with several neighbours experiencing care and an elderly friend receiving dementia care. Her father and aunt both received palliative care. Ms Soulsby will use her enthusiasm for the work to ensure everyone gets the best possible care, being treated with dignity, compassion and respect.
- **Specialist palliative care teams:** We have named a co-applicant from each of the specialist palliative care teams implementing UK Needs Rounds, who have acted as our strategic leads for each site providing authorisation for the study to proceed. After securing funding, each specialist palliative care team will then identify suitable practitioners who will deliver Needs Rounds in those sites. Some sites will redeploy current staff, other sites may recruit new staff to deliver Needs Rounds; these practical decisions have not yet been taken and hence the members are staff are not named in the application.
- **Partner:** Nikki Johnston is a nurse practitioner and was the lead clinician in the Australian study. She has extensive experience in providing specialist palliative care in nursing/care homes in Australia, and won the Australian ‘HESTA’ 2019 nursing ‘team excellence’ award for the Needs Rounds project, and also won the inaugural Australian Health Minister’s Award for ‘Nursing Trailblazers’ in 2019.
- Co-investigators will contribute intensively at key times pertinent to their expertise. So time % reflect denser periods of full engagement and fallow periods where other team members’ expertise will be used.

11. Project / research timetable (key milestones are in red)

	Oct 20	Nov 20	Dec 20	Jan 21	Feb 21	Mar 21	Apr 21	May 21	Jun 21	July 21	Aug 21	Sep 21	**Oct 21**	Nov 21	Dec 21	Jan 22	Feb 22	Mar 22	Apr 22	May 22	Jun 22	Jul 22	Aug 22	Sep 22	**Oct 22**	Nov 22	Dec 22	Jan 23
Month	**1**	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28
Governance/staffing																												
Appoint research fellow	🟦																											
Ethics approvals	🟦	🟦	🟦	🟦																								
PPI key tasks	🟥	🟥	🟥	🟥	🟦	🟥	🟥	🟥	🟦	🟥	🟦	🟦	🟥	🟦	🟦	🟦	🟥	🟦	🟦	🟦	🟥	🟥	🟦	🟦	🟥	🟥	🟥	🟥
Steering group meetings		🟦						🟦						🟦						🟦						🟦		
Empirical data tasks																												
Stakeholder interviews					🟦	🟦																						
Analysis						🟦	🟦		🟦					🟦				🟦				🟦	🟦	🟦	🟦	🟦	🟦	
Co-design workshop							🟥		🟥											🟥								
Identify and train facilitators								🟥																				
Implementation										🟥	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦							
Prospective interviews													🟦				🟦				🟦				🟦			
Prospective data collection on residents										🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦							
Cost analysis completed																								🟥				
UK Needs Rounds model finalised																											🟦	🟦
PPI evaluation data collection																							🟦	🟦	🟦			
Analysis													🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟦	🟥	🟥
Dissemination																												
Social media and 3rd sector updates		🟦					🟦			🟦			🟦			🟦			🟦			🟦			🟦		🟦	🟦
Site newsletters/updates		🟦			🟦			🟦			🟦			🟦			🟦			🟦			🟦			🟦	🟦	🟦
Conference: EAPC																											🟦	🟦
Develop and submit journal articles																											🟦	🟦
Policy-maker dissemination		🟦								🟦																	🟥	🟥
Translation tools																											🟥	🟥

12. Success criteria and barriers to proposed work

The key milestones are:

- Co-designing UK Needs Rounds by month 7
- Identifying and training facilitators by month 7
- implementation commencing at all case studies by month 9
- Disseminating the findings to policy-makers in month 28

These milestones are underpinned by a further success criteria of active PPI engagement throughout.

Potential barriers and mitigating strategies:

1. Substantial turnover in care homes of key staff. Loss of key staff may jeopardise implementation. This risk will be managed by recruiting a minimum of 2 care home staff per facility and engaging in frequent contact to be alerted early if staff move jobs. This will provide time to offer support to the care home to identify and train another member of staff. We will monitor care home staff ratios and collect qualitative data on staffing ratios and their impact on use of Needs Rounds.
2. Lack of engagement in the idea of Needs Rounds. This is a low risk, since discussions with care homes and specialist palliative care teams across the UK have indicated a high level of interest in the idea. Nevertheless, care homes may experience Needs Rounds as additional drain on limited staff resources. We will draw from learning in the Australian studies in supporting recruitment and retention. The Chief Investigator has data and vignettes which clearly outline the benefits of participating for sites.
3. Specialist palliative care teams being overwhelmed at the number of referrals. From the Australian work[6-8] we recognise the enormity of care home residents' unmet needs. The training offered to specialist palliative care clinicians will reinforce the need to triage residents and pace themselves.
4. Research team illness or absence. Our professional networks are very well developed and will be drawn on to engage new team members, if required.
5. Oversight of research assistants collecting monthly care home data. Recruitment will be conducted through PhD gerontology networks to secure sufficiently skilled individuals. Monthly call-in meetings will be held by the study Chief Investigator, to rapidly identify and manage any difficulties in data collection. This monthly meeting will also ensure RAs are working to the same criteria and standards of data collection.
6. Ethical review processes and governance approvals. Multi-site studies spanning countries and care sectors pose considerable challenges to timelines. The study lead and project postdoc will be in frequent contact with all relevant ethics/governance personnel to address any queries and encourage timely passage through approval processes. The team has considerable experience in conducting complex studies, and this has been used to inform the approvals timeline, and will be drawn on to develop high quality paperwork requiring minimal revisions for approval.

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