STUDY PROTOCOL

Full study title: SUPPORTED: Supporting, enabling and sustaining homecare workers to deliver end-of-life care: a multiple-methods community-based case study

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1.0 SUMMARY

This is a 30-month multi-methods study in three work-packages (Work Packages) to address our objectives:

1. Understand the experiences and needs of homecare workers (HCWs) and the views of care users and carers (families and friends), and other health and social care staff about the HCW role, including identification of good practice (Work Package 1)
2. Determine health and social care organisational views and priorities and identify gaps in current policy and guidance about the contribution of HCWs to End of Life care (EoLC). (Work Package 1)
3. Identify EoLC training/skills development needs of HCWs, make recommendations and develop a HCW training resource in a form that can be tested and evaluated (Work Package 2&3).
4. Identify ways to include and support HCWs in the wider care team around the service user/carer to transform support, reduce isolation and burnout (Work Package 2&3).

Bronfenbrenner's Ecological Systems Theory, with five inter-related systems which capture the multiple, complex interactions between individuals' characteristics and care workers within the dynamic contexts of family, community and societal life over time enabling a whole system approach, adapted for palliative care[1], is the strategic theoretical framework informing our design and analysis throughout. All stakeholder groups will meet regularly during the project ensuring meaningful input and co-design where required throughout.

Work Package 1. Multiple in-depth case studies[2] (Hull, Bradford Metropolitan, Bromley [South London]) with qualitative interviews/focus groups. We will use the 3-stage Design of Care Study Research in Health Care Case Study model.[3] We have chosen three case studies to add breadth and wider applicability, comparability and generalisation.[4, 5]

- Work Package 1a: Qualitative study. Through ~three care agencies per site, we will recruit a total of: 45 service users and carers, 45 HCWs. We will also recruit 30 community nurses/GPs; 30 agency managers and commissioners (total participants n = 150). All interviewees will have the option to use Pictor, a 'relational' visual technique to aid explanation, recall and novel thinking,[6-8] exploring social interactions and relationship dynamics including over time, or a conventional interview.
- Work Package 1b: Quantitative content analysis[9] of local/national policy documents relevant to EoLC and identified during Work Package 1a.

Work Package 2. Development and usability testing of a training resource. We will synthesise Work Package 1 data alongside stakeholder engagement to inform a co-designed training resource for HCWs. We will conduct initial user (HCW) training resource testing for acceptability and relevance,

Work Package 3. We will develop policy and practice recommendations with our Partner, service user/carer, and HCW groups including in relation to training and support networks for HCWs.

Our deliverables will be i) an HCW training resource ready for formal evaluation, and ii) recommendations for policy and practice.

2.0 STUDY PARTNER GROUPS; SERVICE USER/CARER (SUC) AND HOMECARE WORKER (HCW) ADVISORY GROUPS

Throughout the project, we will conduct regular virtual meetings with our Study Partners (Bradford Metropolitan District Council, Hull City Council, Care Point Services Bromley, London Association of Directors of Adult Social Services, Skills for Care) and our SUC and HCW advisory groups. We will present ongoing progress and emerging findings and receive feedback. These meetings are to ensure that sense-checking, problem-solving, sense-making of emerging findings, building collaborations, identifying routes to impact are threaded throughout the whole study.

Service User and Carer advisory group

During project set-up, the group advised on participant information materials for service users and carers, consent and issues which needed consideration to inform the ethics application. To inform Work Package 1, the group reviewed the inclusion/exclusion criteria and recruitment methods for fairness and practicality. They considered the proposed research methods and potential burden placed on participants, and advised on modifications or support needed to reduce this. They also commented on draft interview guides, and all participant facing information. As this work progresses, they will help to resolve potential recruitment problems. We will share emerging findings from Work Package 1 & 2 with the group for discussion, and they will advise on ways of sharing these with study participants and the wider public. During Work Package 2 we will involve the group in helping to develop the training resource and finalising our recommendations for policy and practice, in collaboration with other stakeholders. Members of the group will help to plan and run dissemination workshops in Hull, Bradford and Bromley (South London) towards the end of the project. They will participate in other activities as required throughout the project.

HCW advisory group

During project set-up this group advised on participant information materials for HCWs. To inform Work Package 1, the group advised on approaches to recruitment and will help resolve any challenges. We will share emerging findings from Work Package 1 with the group for discussion, and they will then advise on ways of sharing these with HCWs. During Work Package 2 we will involve the group in helping to develop the training resource and finalising our recommendations, in collaboration with other stakeholders. Members of the group will help to plan and run the dissemination workshops in Hull, Bradford and Bromley towards the end of the project.

Further details are given in section 8.0.

3.0 BACKGROUND AND RATIONALE

Our focus is on the crucial, but under-researched, role of homecare workers (HCWs) caring for people at the end-of-life (EoLC). Homecare helps people stay at home and live well during illness or other needs, and when dying, helps prevent avoidable residential care or hospital admissions[10-12] We know little about how to provide the skills and support for HCWs to provide EoLC at home. HCWs support the person and family, and often work alongside other health and social care providers, but are often poorly trained and supported themselves.[11,13,14]Employed by commercial companies in the main, HCWs work outside the NHS and local authorities. Workforce challenges include low status, poor pay, a flat career structure and employment and contract insecurity (42% zero hours contracts).[15,16]
The precariousness of homecare was highlighted by the COVID-19 pandemic, where excess home deaths have persisted.[17,18] From March 2020 to 28 May 2021 over 59,000 (39%) more deaths occurred at home in England and Wales than on average from 2015-19 not simply because people did not choose to go to hospital or care homes.[18] The Health Foundation[19] observed, "social care issues are under-the-radar and under-appreciated. The longstanding political neglect of social care in England has been laid bare for all to see."
By 2040, numbers needing EoLC are expected to increase by 42%, annual deaths of those aged 85 and over increasing from 39% to 54% of all deaths, and community deaths increasing by 108% (in care homes) and 89% (at home).[20] Robust infrastructure for community EoLC is needed to prevent a marked rise in avoidable and unwanted hospital deaths. HCWs are often key in this complex care network, but a review of service delivery models for older people at EoL, found little reference to social care.[21] Recent reports on English homecare make no reference to palliative or EoLC.[15,16]
HCWs generally work in isolation, with little peer-learning and support, exacerbating a lack of formal EoLC training. This may contribute to high staff turnover (30.4% 2019/20[15]) straining continuity of care. A Skills for Care (SfC) report[15] did not mention EoLC or EoL training despite emerging concerns[11,13,14,21,22] about HCWs providing EoLC such as: i) unacknowledged emotional attachment to dying clients and a lack of bereavement support; ii) unmet training needs; and iii) role ambiguity, keeping professional boundaries. Challenges facing HCWs caring for people with advanced disease other than dementia[4,13,14,]are largely unexplored. HCWs provide emotional support to families and individuals, work which requires high levels of emotional intelligence and social skills,[13] they undertake domestic and personal care work in changing, unmonitored, difficult circumstances. Improvements in the quality, continuity, value and safety of HCW-provided care are key to achieving many people's wish to die in their place of choice.[12]

Personal care or delegated health care, distinct from nursing care, is provided by 1.52 million HCWs[15] in over 0.5 million people's homes (mostly 65 years+).[23] The Homecare Association (formerly UKHCA) estimates 249 million hours of care are delivered annually in England.[16] Our proposal aims to develop quality EoL training tailored to HCWs' needs, inter-disciplinary working and support networks. This builds on government commitment to 'professionalise' the social care sector. HCW staff require skills and confidence which builds on their values, addressing often unacknowledged emotional attachment to dying clients and their carers, addressing their lack of bereavement support when faced with loss of clients. Development of a wide community of learning, which promotes greater involvement and engagement with the local multidisciplinary teams, should help to reduce isolation and improve wellbeing and resilience. This alone will not resolve poor pay or unsustainable contracts, but is associated with improved job satisfaction and workforce retention,[15] and should attract commissioners' interest, and promote care quality. Supporting HCWs' voices to be heard by policy makers and agency managers may help improve professionalism, pay and rewards, terms and conditions.[24]

The James Lind Alliance Priority Setting Partnership (Palliative and EoLC) identified as the most important research priority, "… the best ways of providing palliative care outside of working hours to avoid crises and help patients to stay in their place of choice." HCWs play a vital part in this but are poorly understood "cogs in the wheel". Other EoL priorities are relevant: i) adequate training of all staff (JLA 5); ii) how to provide and maintain homecare (JLA 8). Our study site partners have prioritised provision of sustainable, equitable, quality EoL homecare. Their enthusiastic engagement with this proposal to date (see letters of support) demonstrates this priority, as the Director of Adult Social Services Bromley states, 'We would be very interested in being involved in this, as a One Bromley System we prioritise end of life care so this would be very helpful.'

More people are living longer with multiple health conditions and will die from progressive long-term conditions. Described as a UK Industrial Strategy's Grand Challenge, the impacts on homecare are reflected in the Government's "Future of an Ageing Population": services must meet the needs of older people across the health and social care sector.[25] While many younger disabled adults use homecare services, the social care needs of older people are expected to double in England by 2040 and those needing 24-hour care to rise by over a third by 2035.[16] Homecare agencies, mainly in the private sector, are increasing in number in the UK but need to be sustainable and able to support the professionalisation of their staff. District or community nurses and HCWs provide the backbone of formal support at home in addition to family and friends. HCWs are the 'front line' social care system. Poor integration,[12] and strain on services leaves EoLC at risk given the estimated 42% increase in demand by 2040.[20]

After years of inaction, social care reform is a priority, with COVID-19 and the large excess of at home deaths[14] pushing it "up the political agenda and on to the front pages".[26] The Government's Plan for Health and Social Care, "Building back better", pledges to "make care work a more rewarding vocation, offering a career where people can develop new skills and take on new challenges as they become more experienced. This will include developing a plan to support professional development and the long-term wellbeing of the workforce" (Section 48)[27]

Understandings of HCWs' abilities, values, training and support needs as part of the professionalism of social care and how they integrate with the wider healthcare workforce are vital for Integrated Care Systems and their partners,[28] and to put the Government's plan into action. However, a systematic review (1990 - 2011) of the role of non-qualified nursing or social support workers in EoLC at home or care homes found only 9 papers (UK, USA).[29] Challenges of emotional attachment, role ambiguity, and lack of training/support were found. We conducted a rapid review of the role of non-professionally qualified social support workers in EoLC at home or care homes from 2011 to date (Embase, Medline) using the search terms from Herber *et al*[29] (excluding nursing terms) and broadening the scope to include interventions. We found 6 further papers (UK, USA, Japan) confirming the emotional and role challenges previously outlined.[29] A major evidence gap about HCWs' EoL training was highlighted.[29-33] Further, observational and qualitative work showed HCWs were key to enabling death at home[8] including during COVID-19.[17,34,35] There is a serious evidence gap about the best way to support HCWs to provide sustainable, quality, integrated care for those wanting EoLC at home.

4.0. AIMS AND OBJECTIVES

AIM: To improve the quality and sustainability of person-centred end of life care by HCWs through skill development and empowerment, and to inform employment practices, commissioning and policy.

OBJECTIVES: To:
1. Understand the experiences and needs of HCWs (including training and skills development) and the views of care users and family/friend carers, and other health and social care staff about the HCW role, including identification of good practice (Work Package 1 [Work Package 1a])
2. Determine health and social care organisational views and priorities and identify gaps in current policy and guidance about the contribution of HCWs to EoLC. (Work Package 1b)
3. Identify EoLC training/skills development needs of HCWs, make recommendations and develop HCW training resources in a form that can be tested and evaluated (Work Package 2&3).
4. Identify ways to include and support HCWs in the wider care team around the service user/carer to transform support, reduce isolation and burnout (Work Package 2&3).

5.0. RESEARCH PLAN / METHODS

Theoretical underpinnings

Bronfenbrenner's Ecological Systems Theory, enabling a whole system approach, adapted[1] for complexity in palliative care, is the strategic, theoretical framework informing our design and analysis across all Work Packages. This recognises five inter-related systems (micro-, meso-, macro-, exo-, chrono-), which capture the multiple, complex individual and service-level interactions which evolve over time within the dynamics of families, communities and society, informing a whole systems approach to end-of-life care and palliative care.

5.1. WORK PACKAGE 1. MULTIPLE CASE STUDIES

5.2. SUMMARY DESIGN AND METHODS

Multi-methods study using multiple in-depth case studies[2,4,5] (Hull, Bradford Metropolitan, Bromley [South London]) with:
1) qualitative interviews/focus groups (Work Package 1a);
2) quantitative content analysis of local/national policy documents relevant to EoLC (Work Package 1b),
3) user/client and Study Partner (Bradford Metropolitan District Council [BMDC], Hull City Council [HCC], Care Point Services [Bromley], London Association of Directors of Adult Social Services (London ADASS), Skills for Care [SfC]) engagement throughout Work Package 1.
Work Package 1 data synthesis will be conducted post data collection.

Given the lack of consensus,[4] we will use a pragmatic paradigm: the 3-stage DESCARTE (Design of Care Study Research in Health care) model (research and researcher situation, determination of design components, three stances of analysis).[3] Case studies facilitate data collection and analysis within and across settings to produce transferable findings.[2] They offer a flexible approach enabling holistic enquiry from multiple perspectives.[3]

Although single case studies may offer insights beyond their specific settings,[2,4] we have three, for breadth and wider applicability, and generalisation.[2,5] The core issues we are exploring reflect a national crisis in a national context. There is a balance between discovering a range of concerns and allowing that much will be recognisable and generalisable across many other settings, or at least relevant and applicable.[36] We argue that studying three sites represents value of information and money, and that adding further sites will result in diminishing returns for increasing study costs. Use of qualitative methods and quantitative document content analysis will help our understanding, and also strengthen impact and generalisability, maximising influence on policy and practice.

Work Package 1 findings and an exercise to map existing training resources, will inform co-creation of an EoLC training resource for HCWs using the principles of Experience-Based Co-Design (Work Package 2). Recommendations for practice (Work Package 3) will be developed using expert stakeholder consensus informed by emerging Work Package 1&2 findings and agreed at completion of data synthesis.

5.3 SETTING: Three settings are selected for demographic differences: i) Hull: urban; majority white British (94%) ii) Bradford Metropolitan: mixed urban-rural; ethnic and culturally diverse (Asian/British Asian 27%), iii) London Borough of Bromley (South London): population of 333k, a diverse generally owner-occupying affluent Borough; substantial rural area; largest older population of all London Boroughs; 16.3% from ethnic groups (Black African the largest). Hull is the most, and Bradford the second most economically deprived in Yorkshire & Humber although both have affluent areas. There is a wide range of homecare agencies, community health and social care providers in all three sites. Two of our three research sites are in Northern England and in areas of multiple deprivation. Hull is also an area under-represented in research reflecting NIHR commitment to reaching areas that are under-served by research.

Bromley: The London Borough of Bromley (South London): Bromley is a relatively prosperous Borough, although there are substantial differences within the Borough. Life expectancy at birth (81.3 years for men, 84.8 for women) and health related factors such as smoking prevalence, obesity and levels of physical activity, all fall within the highest (75th – best) percentiles. Under 75 mortality (all cause, cardiovascular and cancer) also all fall into 75th - best percentiles. Population demographics indicate a projected growth in the percentage of the population aged 65 years or over, with an attendant need identified for health and social care services to reflect this changing age profile. There is very high employment in the Borough with substantial numbers commuting to other parts of London. The population is served by many homecare agencies based in or around the Borough.

Bradford: Bradford is the fifth largest metropolitan district in England. Population health data indicate that life expectancy at birth is lower than the figures for England for men and women (77.3 and 81.5 years respectively). Under 75 years mortality (all causes and cardio-vascular) are within the worst – 25th percentiles for England. The percentage of physically active adults is low in comparison to the figure for England. Population demographics highlight the ethnic diversity within the authority in which approximately 64% identify as White British and approximately 25% as Asian or Asian British, although diversity varies substantially across the district. Population projections indicate that the number of older people in the area is expected to increase. Home ownership is at 65%, with 18.1% of households privately renting. Employment levels are lower than the national average. There are 70 homecare agencies operating in the area.

Hull: Hull is an urban, unitary authority with a population of 259,126 (2020). It is an area of higher-than-average poverty, with 45.2% of neighbourhoods in Decile 1 (most deprived). Over half the population (56.2%) live in social rented property (significantly higher than English average ~20%). Unemployment is high at 6.3%. The population also experiences significant levels of ill-health, with 39.2% of neighbourhoods in the most deprived decile for health, and life expectancy at birth (77.3 years for men, 81.5 years for women) is lower than the overall figures for England. Similarly, mortality at under 75 years (all causes) is considerably higher than the UK as a whole. Prevalence of smoking (22%) is higher than the English benchmark of 13.9%; figures for obesity, admissions for alcohol related conditions, physical (in)activity, and diet (consumption of 'five a-day') are all poorer than the national benchmark and are in the 'worst – 25th percentile. These data on lifestyle factors are reflected in high under 75 mortality figures for preventable cancers, cardio-vascular, liver and respiratory disease (all of which are in the worst – 25th percentile). Only [15.2%]) of the population is aged 65+ but a higher than national average lives in care homes. There are 32 homecare agencies in the city. There are small non-White populations, mainly Chinese and Black African but most non-UK nationals are from the European Union.

Whilst our sites above are chosen for ethnic and socio-economic diversity, we will use the NIHR CRN INCLUDE Guidance[37] to underpin diversity and accessibility in our participant information, consent and data collection processes.

5.4. WORK PACKAGE 1a: QUALITATIVE STUDY

5.4.1 AIMS AND OBJECTIVES

AIMS: to improve the quality and sustainability of person-centred EoLC by HCWs through training, skill development and empowerment, and to inform employment practices, commissioning and policy.

OBJECTIVES: to

1. Understand the experiences and needs of HCWs and the views of homecare clients and carers (families and friends who provide care and support), and other health and social care staff about the HCW role, including identification of good practice.
2. Identify EoLC training, skills and development needs of HCWs, make recommendations and develop a HCW training resource in a form that can be tested and evaluated.
3. Identify ways to include and support HCWs in the wider care team around the client/carer to transform support, and reduce isolation and burnout.

5.4.2 PARTICIPANTS

Eligible participants will be people involved in providing/receiving EoL homecare: i) HCWs providing EoLC and cared for ≥1 EoL client within the last 12 months; ii) people at EOL (expected to be in the last 6 months of life) receiving homecare from HCWs; iii) carers co-resident or other but substantially involved in providing support; iv) community health, specifically district nurses and local authority professionals; v) homecare managers/employers and commissioners. All must have capacity to give written/verbal informed consent to participate in an interview or focus group (~30 to 60 minutes), and sufficient English (or with support of a communication assistant or interpreter). People expected to die <7 days as reported by the social care provider or other will be ineligible. See Table 1 for inclusion and exclusion criteria for all categories of participants.

Table 1. Participant groups, target recruitment, and eligibility criteria

Participants	Number to be recruited	Inclusion criteria	Exclusion criteria
Homecare Workers	45 in total	Providing EoLC as part of their role Have provided care for one or more clients at EoL in the previous 12 months	HCW has not had recent (i.e., in the previous 12 months) experience of delivering EoLC.
Clients (service users) and Carers	45 in total	Individuals at EoL, and who are anticipated to be in the last 6 months of life	Anticipated to die within the next 7 days, as reported by the homecare provider or other (such as health practitioner)

		Who are also receiving homecare from HCWs Who have the capacity to consent to participating in the research (verbally or in writing) Are able to participate in a single interview for approximately 30 – 60 minutes Have sufficient spoken English to participate in data collection, or are able to participate with the assistance of a communication assistant or interpreter.	Lack capacity to consent (after adjustments have been made to facilitate decision making).
Carers	As above	Carers (family/friend) of a client at EoL who is currently or previously receiving homecare May be co-resident or live elsewhere Former (bereaved) carers at least 3 months after bereavement and no more than 12 months after bereavement. Have sufficient English to be able to participate, or are able to participate with the assistance of a communication assistant or interpreter.	Carers of relative or friend who is anticipated to die within the next 7 days, as reported by the home care provider or other (such as health practitioner)
Community practitioners	30 in total,	Health and social care practitioners – for example practitioners working as district/community nurses, GPs, palliative care practitioners, and as social workers	Practitioners who do not have a current or recent (within the last 12 months) role in supporting people at EoL.

Homecare agency managers; local authority commissioners; continuing healthcare commissioners (NHS)	30 in total	Working to support and/or commission the delivery of homecare, including EoLC. Or to have held this role within the previous 12 months.	Managers and commissioners who do not have a current or recent role (within the past 12 months) in supporting and/or commissioning services for people at EoL.

* EOLC = end of life care; EOL = End of life; HCW = homecare worker

Overall targets for recruitment are as follows:

- Homecare workers – total 45 (which may also include managers if appropriate). At least 10 per geographic locality, with the remainder recruited flexibly across the three areas
- Clients and carers - 45 in total. In each geographic area we will recruit a minimum of 5 clients and 5 carers. The remainder will be recruited flexibly across the three areas.
- Community practitioners - 30 in total. A minimum of 7 per geographic area, with the remainder recruited flexibly.
- Homecare managers and commissioners – 30 in total, of which at least 7 will be drawn from each geographic area, with the remainder recruited flexibly. No minimum number of managers and commissioners is required.

5.4.3. RECRUITMENT

5.4.3.1. Sampling strategy

Clients, carers, HCWs and community practitioners will be purposively sampled, and we will endeavour to achieve a sample which is diverse in respect of:

- Ethnicity
- Gender
- Age
- Socio-economic status
- Urban/suburban/rural location
- For clients - source of care funding: whether clients' homecare is funded by the local authority or is self-funded or a mix with NHS funding
- For carers – whether they are co-resident or live elsewhere, including carers who live in the locality as well as 'distance carers'.
- For HCWs – whether they are in full or part time HCW employment; duration of employment, to reflect a range of experience.

Homecare agency managers and local authority commissioners will be sampled using convenience sampling.

5.4.3.2. Recruitment of homecare provider agencies and workers

Homecare provider agencies

In each three case study areas, the researchers will develop a list of homecare providers delivering care within the locality, drawing upon data within the public domain, as well as existing contacts. Convenience sampling will then be undertaken in each area, drawing initially on existing contacts of the research team, and striving to include both local authority providers (if and where available), private, commercial 'for profit' providers, and charitable or not-for-profit agencies.

The researchers will contact the managers of each agency sampled, by email or phone, and will inform the manager about the study. Initial phone contact will be followed by the provision of written information about what participation in the study will involve for the agency, and for HCWs, clients and carers. The researchers will re-contact the manager twice over the next four weeks, if they have not received any response.

Homecare Workers

We will employ multiple approaches to ensure recruitment of HCWs. HCWs will be recruited from homecare agencies across the three study sites, including a mix of local authority and private providers. Homecare managers in each agency will be asked to identify HCWs who meet the study criteria and to provide information to them about the study. This will be in the form of a short information sheet/flyer which will outline key information about the study and provide the researcher's contact details, as well as the more detailed PIS, which will provide fuller information. HCWs can contact the researchers directly to find out more information and/or express interest in taking part, or, if HCWs prefer, they can ask the managers to forward their contacts to the researchers, who will then get in touch with the HCWs. The PIS will make it clear that participation is entirely the HCW's decision, that participation/non-participation and interview data will not be reported back to the manager, and that all data will be anonymised. Where possible, the researchers may attend team meetings to meet with staff and outline the study – this will be done virtually or in person depending on local requirements and agency preferences.

Following the initial contact, the researchers will arrange to discuss the study with potential participants. This discussion may be conducted online, by phone or in-person according to individual preference and at the convenience of the individual. The PIS will be discussed and the researcher will address any questions potential participants may have; if the potential participant wishes to take part, a time and place for the interview will be arranged at their convenience.

In addition, the following approaches will be employed:

- We will use our contacts in Hull, Bradford and Bromley (and the surrounding areas) to identify potential participants. Where any HCW in these areas expresses interest in the research we will ask if we can keep their details on a project database, enabling us to contact them during the data collection period.

- We will share information about the research on our research units' social media (Twitter, LinkedIn and Facebook), and invite HCWs to contact the researchers direct.
- Snowballing – on completion of interviews the researchers will ask participants if they know other HCWs in the local area who may be interested and eligible to participate, and ask the participant to pass on information about the study, including the researchers' contact details. Potential participants receiving information through snowballing will be asked to contact the researchers directly.
- *We will establish links with hospices providing end-of-life care in the three regions, and use as possible sites to recruit homecare workers who are known to the hospice in providing care for hospice patients.*

All HCWs identified through the additional methods outlined above will be provided with a brief information sheet providing a summary of the research, as well as a more detailed PIS. The researchers will make a time to discuss the research with each HCW, and, once they have had an opportunity to ask any questions, they will be invited to participate in an interview, at a time and place which is convenient to them.

All recruitment materials are in Plain English and have been developed in partnership with the HCW advisory group.

While not our primary approach to data collection, in the event that a care provider indicates that the most effective way to meet with HCWs would be *via* a focus group, this will be undertaken with the HCWs in that agency. Managers will share information about the study with eligible potential participants (summary flyer and PIS) and will inform them of the arrangements (date, time, place) for the focus group. Participants can contact the researchers direct or can ask their manager to provide contact details on their behalf. The recruitment materials explain that participants don't have to tell their manager that they are taking part. Any HCW who wishes to participate but is unable to attend the focus group discussion will be invited to undertake an interview instead. At the beginning of the focus group, participants will be given information about the study, and reminded of the need for confidentiality in respect of the information discussed by colleagues. They will then be asked to complete and sign a consent form, and to complete an anonymised demographics form based on the questions which are asked in the interviews for HCWs. Any HCWs who would prefer an individual interview will be able to arrange this with the researchers.

Clients

Participating homecare agencies will conduct searches of their databases to identify potential participants, having regard to the eligibility criteria. They will review the current record of care of those who appear eligible to participate, and check with relevant HCWs regarding their most recent status and their perceived capacity to consent to taking part in the study.

The homecare manager (or other senior member of staff) will contact potential participants initially by letter (including a brief information sheet and copy of the PIS) followed by phone call.

Where individuals indicate that they are willing to consider taking part in the study the homecare manager will forward their contact details to the researchers (with their agreement), and details of how they prefer to be contacted in the first instance; contact details will be shared using a secure method of data transfer. The manager will also provide the researchers' contact details, which are also included on the information provided, so that the client can contact them directly if they wish. The researcher will contact the client, using their preferred method of contact. They will discuss the study, address any questions and, if the client wishes to participate, they will arrange the interview at a time which is convenient to the participant.

If the potential participant agrees, we will arrange an interview with consent taken immediately prior to undertaking the data collection. The researchers will be trained to assess capacity to provide consent for study participation. If any individuals' demeanour raises concerns about their capacity to consent to their participation the researcher will assess their capacity to make a decision about participating the interview (with reference to the Mental Capacity Act Code of Practice). This may lead to a decision to exclude the participant, or to postpone the interview, in the event that they appear to have fluctuating capacity; these matters will be sensitively handled.

At the end of the interview, the client will be asked if they have any family member or friend who provides care and support who may be interested in participating in the study. In this event, they will be contacted as in the section below.

Clients may also be identified through establishing links with hospices and hospitals providing care within the three geographical regions. The hospice or hospital will contact patients known to be in receipt of homecare using an appropriate method for the individual person. Contact details of the research team will then be shared with potential participants so they can liaise directly to request further information and arrange interviews.

We will also employ snowballing techniques to reach potential client participants. Where carers (family and friends) take part in the study, we will ask them (if judged to be appropriate, and the person meets the study criteria) whether the person they support might be willing and able to participate in the research, and in some cases, carers might volunteer this information during their contact with the research team. In this instance, a brief information sheet and a Participant Information Sheet (PIS) will be provided for the carer to share with the potential participant. If the client is available, sufficiently well and is keen to participate immediately they will be able to proceed to consent and interview, having first had time to consider and discuss the information provided. However, they will not be under any pressure to do so and will be made aware they can take as much time as they wish to reflect on the study and to decide whether they want to take part. They will receive the researchers' contact details and so can contact the researchers to find out more about the study and arrange to take part at their convenience, or can ask their carer to initiate contact if they prefer.

Further snowballing will take place following participation in the study by HCWs who will be asked whether they know clients (and also carers – see below) who may be able and willing to participate in the study, and who meet the study inclusion criteria. In this case, and if they are comfortable to do so, they will be asked to share the brief information sheet and PIS with any potential participants. Before doing so, they will be fully briefed about the research, including the eligibility criteria and the way this study is being articulated to potential participants (see section on ethics). Clients who receive this information will be able to contact the researchers direct or they can ask the HCW to forward their contact details using a secure method. Community practitioners will also be asked if they can share information with individuals in their personal networks.

Carers

Carers will be identified through multiple routes.

1. Through contact with clients. Where carers have been identified by a participating client, a brief information sheet and a Participant Information Sheet (PIS) will be provided for the client to give to the carer. In the event that the carer is keen to participate and wishes to proceed immediately to consent and interview, given the low-risk nature of the study, and need to minimise imposition on participants at this stage of life, then this may be facilitated. However, carers may take as much time as they need to decide whether to participate. These carers will be asked to contact the researchers to find out more information and arrange to take part if they wish.
2. Through homecare agencies. Where carers have not been identified by participating clients, participating homecare agencies will conduct database searches to identify clients who have a carer (family member or friend) who is known to provide support, having regard to the eligibility criteria. They will review the care records of the person receiving care for potentially eligible carers (see Table 1). The homecare manager (or other senior member of staff) will contact potential carer participants initially by letter (including a brief information sheet and copy of the PIS) followed by phone call. Where individuals indicate that they are willing to consider taking part in the study the homecare manager will forward their contact details to the researchers (with their agreement), and details of how they prefer to be contacted in the first instance; contact details will be shared using a secure method of data transfer. If the carer prefers, the manager will provide the researchers' contact details, so that the carer can initiate contact. The researcher will contact the carer, using their preferred method. They will discuss the study and address any questions. If the potential participant agrees, we will arrange an interview at a time and place convenient to the carer, with consent taken immediately prior to undertaking the data collection.

3. Through contact with carers' centres and carer support groups. We will also seek carer participants through contacting local carers' centres and groups and ask them to share information about the study – for example via newsletters, websites or displaying information at their premises. Where possible we will attend meetings at carers' centres on invitation to publicise the study. Carers who find out about the research in this way will be asked to make contact with the researchers.
4. Through local hospices and hospitals. Hospices and hospitals will be supported to promote the study to carers of patients known to be receiving homecare. Contact details of the research team will then be shared with potential participants can they liaise directly to request further information and arrange interviews.

We will also employ snowballing methods to support carer recruitment, and will ask HCWs whether they know any carers who may be willing, able and eligible to participate in the research. In these instances, they will be asked to forward information (brief and full PIS) about the study to carers (following the process in the section above on client recruitment) having first been made aware of the criteria for the study and considerations in respect of language.

Carers are eligible to participate in their own right as a carer, with the participation of the person receiving end-of-life care not required as a prerequisite.

Our exclusion criteria states that carers who have been bereaved in the previous 3 months will not participate. In the event that a carer who has expressed interest in participating in the study experiences a bereavement prior to the interview, the researchers will contact them, acknowledge their bereavement, and ask them if they are willing to be contacted after 3 months. They will be asked to indicate if they do not wish to be contacted again; in such instances no further contact will be made.

Community practitioners

Individual community practitioners (including GPs, palliative care practitioners, district/community nurses, social workers) will be identified using multiple approaches which include the following:

- The researchers will develop a database of current community practitioner contacts, including those developed through their existing research and/or clinical practice, with their agreement or using contacts which are in the public domain. Such practitioners will also be asked to forward information about the study to individuals in their own networks.
- Homecare managers will be asked to forward information (a brief information sheet accompanied by more detailed PIS) about the research to community-based practitioners known to them. They will seek their permission to pass their contact details to the research team, as well as providing the researchers' contact details.

- We will use social media to advertise the research and invite potential participants practising in the relevant regions to contact the research team for further information.
- Request necessary approvals from the HRA and relevant community Research and Development team to recruit through GP practices and community health teams in the case study areas. Following these approvals recruitment may also take place in GP practices and community teams - an information flyer prepared by the researchers will be shared with practice leads and managers inviting practitioners to make contact with the researchers for further information.
- We will use local hospices and hospitals in the three geographic areas to help identify community practitioners including hospice staff. Contact details of the research team will be shared so potential participants can liaise directly to request further information and arrange interviews.

Potential participants will be provided with a PIS and will have an opportunity to discuss the study and ask any questions. If they wish to participate an interview will be arranged at their convenience.

Homecare agency managers

We will select managers, using the publicly available lists of homecare agencies in each area, based on factors such as location (rural/urban); sociodemographic profile of the population served; agency size. Managers will be contacted by the researchers and will be sent a brief information sheet and a PIS.

Commissioners

Commissioners will be identified, using information in the public domain. Adult services' personnel whose roles include commissioning EoLC through contracts or as part of individual care plans will be invited. We will also ask the local authorities to pass on information about the research to their commissioners.

5.4.3.2.1. Recruitment materials

Recruitment materials for all participant groups will clearly emphasise the optional and voluntary nature of participation, and that individuals can withdraw from the study at any time without detriment. All materials will be produced in alternative formats as required (for example, using large font size) and will be written with principles of 'readability' and Plain English taken into consideration. Where required, interpreters will be used to support recruitment as well as during interviews.

All HCWs, clients, carers will be offered a voucher as a token of thanks for their participation. Information to this effect will be included in recruitment materials. These will only be offered to local authority or community health practitioners who are unable to participate during their work hours, as payments for their time during those hours will be reimbursed to their organisations. All those participating in a professional capacity, i.e. commissioners, community health practitioners and homecare agency managers will be offered a 'Certificate of Participation' after interview for their own CPD records.

5.4.4. CONSENT

All participants will be required to provide their consent to take part in the study.

Participants will be asked to sign a written consent form prior to interview. If any participant is unable to sign the consent form for any reasons, verbal consent will instead be taken. For face-to-face interviews, written or witnessed verbal consent will be signed immediately prior to interview. Where data collection is undertaken online, participants will be provided with a copy of the consent form ahead of the interview, and recorded consent will be taken before starting the interview, following each item on the consent form.

Participants will be made aware that consent is voluntary and that they may withdraw at any point. Additional reassurances will be given to HCWs who will be informed that their decision to participate will not be shared with their employer, will not affect their employment and that any information which could identify them, their organisation or specific clients, will not be included in any reports. Similar reassurances will be given to clients and carers, who will be informed that the homecare provider will not be informed of their participation (unless to raise specific concerns identified - see below) and that their decision about whether to participate will not impact on their care.

Participants will be asked to consent that in the event that they withdraw from the study, all data collected up until the point of withdrawal may be retained and that anonymous quotes may be used in study outputs. To support discussions about the research, the homecare agency will be asked for any information which can facilitate communication, ensuring that unmet communication needs are not a barrier to consent and that language which is meaningful to the individual is used. Interpreters will also be used if required. The researcher will ensure that all participants have the opportunity to ask questions, and that these are addressed to their satisfaction.

We are mindful that some service users may lack capacity to consent or that they may have fluctuating capacity. Although the initial assessment of mental capacity will be made by the homecare agency staff in order to make the initial invitation, all researchers will be trained in the principles of the Mental Capacity Act (MCA) and the MCA Code of Practice, and will have undertaken the relevant Good Clinical Practice (GCP) modules in taking consent. In the event of any indicators that capacity to consent may be lacking, then capacity will be assessed by the researchers undertaking data collection prior to proceeding further.

Assessments will have reference to the following questions:

- Can the person understand the information provided (and has information been given in a way which is meaningful and accessible to them)?

- Can they retain that information?
- Can they weigh up and communicate their decision?

In the interval between initial discussions and the research interview, capacity may have diminished for some participants. If any individual appears to lack capacity the researcher will seek to ascertain (for example, through discussion with a carer or HCW) whether this appears to be an ongoing lack of capacity or a fluctuation; in the latter case, a further appointment at a more suitable time may be offered.

During data collection an ongoing approach to consent will be taken, and researchers will be vigilant to any signs which suggest that the interview should be paused and consent checked. Although, from the research team's experience, fluctuating capacity during a single interview of the planned duration is very unlikely, if any participant shows signs of fluctuating capacity, the researcher will stop the interview, check their capacity, and if this has been lost, refer the participant for review by their usual care team. The researcher may rearrange a time to complete the data collection if the situation resolves favourably. If the lack of capacity persists further attempts at interview will not be possible. If the person withdraws from the research or is withdrawn due to loss of capacity, the data already collected will be retained; this is explained in the PIS and included on the consent form.

The researchers will also be alert to expressions of pain and fatigue which, while not necessarily impacting on capacity, may make continued participation in the interview inappropriate. If such are observed, the researcher will pause the interview and check the individual's willingness to continue. In such cases the interview will either restart if the person wishes (having had as much time as they need before re-starting), be rescheduled, or a decision taken that no further data will be collected with that individual.

If the researcher observes signs of persistent pain or discomfort, they may contact the relevant health care professional (with the participant's permission).

For any participant and researcher, interviews about end-of-life may elicit painful feelings. Our approach to participant distress and to supporting the researchers is detailed in section 5.4.8 which outlines ethical considerations.

5.4.5. DATA COLLECTION

Two types of semi-structured interviews will be offered: i) Pictor-guided interviews and; ii) Semi-structured interviews or focus groups. All participants will have the opportunity to undertake a Pictor focussed interview or a more conventional semi-structured interview.

For all participant groups interviews (covering Pictor activities and semi-structured interviews) will be conducted face to face where possible. In the event of COVID-19 or other such restrictions or concerns, interviews will instead be conducted online or by phone. When conducting data collection remotely, participants will be asked to create and photograph their Pictor chart, with support from the researcher provided remotely, and materials delivered to participants.

During (and prior to) all data collection activities, attention will be paid to individual communication needs. Interpreters will be provided as required, as well as other forms of support, such as deaf-assist workers, to ensure that no participants are excluded due to communication barriers.

Where home visits are undertaken, the University of Hull and King's College London's lone worker policies will be followed. Both require research staff to leave information with another member of their research team about where the interview will be conducted and the time this is expected to end. They will be required to contact their colleague on completion of the interview; should they not make contact at the agreed time, the colleague will in the first instance try to call them. If they do not receive a reply, or the reply causes them concern, they will then escalate this to ensure that a protective response is made. All researchers will carry mobile phones when undertaking home visits.

5.4.5.1. Interviews with HCWs, service users, carers, professionals

Interviews with HCWs, service users, carers, and community health staff will explore networks and social processes and skills/training needs around HCW involvement EoLC as it happens in practice.

Our preferred method of interviewing these participants, is Pictor,[6] a 'relational' visual technique to aid explanation, recall and novel thinking, exploring social interactions and relationship dynamics e.g., conflict, provision or lack of support, continuity of care.[7,38-39] Should any participant not wish to create a Pictor chart, they will instead be able to participate in a conventional semi-structured interview.

Pictor has a proven track record of use with patients and senior clinicians in EoL research,[38-39] which helps participants to represent the dynamics of social interaction and collaboration in an accessible way. It has also been suggested as a way to overcome noted barriers in research participation by those with advanced disease.[8,38] The technique is focused and quick and enables the participant to conceptualise multidisciplinary care based on their own experiences without being led by researcher assumptions.
Pictor uses techniques from personal construct psychology[39] focused on the use of role descriptors to recreate 'real' events in an abstract way. HCWs and health and care professionals will be invited to focus on their experience of an episode of care at the end of a person's life; service users and carers will be asked to focus on a recent episode of care. The participant writes lay and professional roles involved in the episode of care on to semi-adhesive arrows and arranges these on flip-chart paper to 'tell the story' of care around a patient. The self (the care user, carer or professional participant) is always represented by an arrow. The participant is then invited to tell the story represented by the chart, and the interviewer asks about the direction of and distance between arrows to explore implicit social dynamics – for example, arrows are often placed close together to represent allegiance, point-to-point to represent conflict, or distant from the care user to represent absence or lack of involvement.

Pictor focuses on micro- and mesosystems, but participants can also use arrows to represent organisations (macro- and exosystem) where appropriate. The visual diagram is abstract enough to represent a single critical event or multiple episodes over time (chronosystem). It can be used flexibly – the semi-adhesive arrows can be folded or arranged to represent concepts such as 'nodes' of collaboration, timelines of care, or legislative boundaries where this makes more sense to the participant and is often used in this way by clinicians. Professionals' Pictor interviews will explore role ambiguity, support (including training access and quality) and isolation, while non-HCW participants' views on HCWs' support needs and networks can also be explored, to identify key areas for better health and social care integration as well as care team member communication.
Pictor charts are photographed, and interview dialogue recorded and transcribed; charts can be used to evidence the professional roles involved in specific types of care and ensure that interview recruitment is evolving in a way which includes appropriate networks. Pictor is flexible; semi-structured interviews can be used if unable to create a chart. If COVID-19 restrictions are increased, participants will be asked to create (supported virtually) and photograph a Pictor chart where possible, and semi-structured interviews based on the photographed chart will be conducted by telephone or online.

All interviews will be conducted at a time and place convenient to participants. Construction of the chart takes between 5 to 10 minutes, and the interviews are expected to take 30 – 60 minutes. Participants will be informed that they can take a break at any time. Where HCW focus groups are used, we will offer participants the opportunity to create a Pictor diagram using a modified technique to create a group chart based around clients they have supported, the others involved in that person's care, the kinds of care and support provided. Questions have been developed to facilitate this group discussion.

5.4.5.2. Data collection with homecare agency managers and local authority commissioners

Interviews with agency managers and commissioners will be informed by emerging findings from stream 1 interviews and explore their views of HCWs' needs, matters relating to workforce quality and retention, and the influences of competing service priorities.

Homecare agency managers and local authority commissioners in each site will have the option of attending an individual interview or focus discussion group (separate groups will be held for managers and commissioners). If taking part in an interview, they will be able to choose whether to undertake a Pictor interview, or a conventional semi-structured interview. Data collection will be conducted online or in person according to participants' choice.

A semi-structured interview schedule will be developed for each participant group and used where this format is selected. These will be informed by emerging findings from the data collected through the Pictor interviews and through the HCW advisory group, and will explore participant perspectives on the following subjects:

- HCWs' support needs
- HCWs' training needs and the provision available
- Personal and professional networks for HCWs
- Workforce retention
- Coordination and continuity of care for clients, and any difficulties and challenges in assuring this.

5.4.5.3 Data recording

In-person data collection (Pictor interviews, individual interviews and focus groups), as well as any interviews conducted by phone will be audio recorded (with explicit consent). They will be transcribed using a University-authorised external transcriber and/or transcription company (with a confidentiality agreement in place).

Online interviews will be recorded using the recorder function in Teams or the preferred online system (and audio recorded as a back-up). Recordings will either be transcribed (see above) or the transcription function used, checked by the researcher conducting the interview for accuracy.

Detailed notes will be taken if any participant does not consent to the recording of their interview.

5.4.6. DATA ANALYSIS

Analysis will adopt a case-based approach, as described above.[3,4] We will initially conduct within-case analysis for each of the three geographic sites, and subsequently make comparisons across sites as described in 5.4.6.4 below. Analytic approaches will be driven by the nature of the data.

5.4.6.1. Interview and focus group analysis

Reflexive thematic analysis will be conducted with interview and focus group data.[39,40,41] This begins with reading and re-reading transcripts to become familiar with the data, and moves on to coding concepts in the data in a systematic fashion, comparing coded data and collating it into themed categories. Codes and themes will be reviewed iteratively by the research team through discussion as analysis progresses. Themes will then be refined, clearly defined and organised into a coding framework which describes and interprets the data set. Reflexive thematic analysis also takes account of researcher subjectivity, articulating the fundamental assumptions that shape their analytic approach.

5.4.6.2 Pictor chart analysis

Multiple Pictor charts will be analysed within and across sites using methods outlined by King et al, 2013.[39] Exploration of chart patterns and arrow positioning will be used to examine the dynamics of care interactions. For example, the frequency of collaboration between multidisciplinary roles/services or across care settings will be explored by conducting frequency counts of roles and services appearing on the charts. Patterns of dominance of specific multidisciplinary roles across client, carer and HCW Pictor charts will be compared by examining arrow positioning.

5.4.6.3 Member checking

Member-checking[42] is a way of assessing the resonance and trustworthiness of qualitative analysis by presenting study findings to stakeholder groups and inviting discussion. Study findings will be discussed with SUC and HCW advisory groups, and with a broader range of stakeholders such as local authority representatives and social care interest groups.

5.4.6.4 Synthesis of Work Package 1

Matrix analysis[43] will provide a cohesive approach to combining all data sets, using key categories from the theory to re-interpret and categorise recommendations arising from the interviews, discussion groups and document analysis. This will synthesise the outputs above with an *a priori* focus on the five domains in the adapted Bronfenbrenner theory[1]:

- The microsystem – needs and characteristics of clients, carers and HCWs
- The chronosystem – changing needs and complexity over time
- The mesosystem – the interactions between clients, carers and practitioners (HCWs and other health and social care professionals)
- The exosystem – service and system level factors
- The macrosystem – societal factors

Findings from this stage of the study will inform Work Package 2 and Work Package 3.

5.4.7. DATA MANAGEMENT

All participant data will be processed in accordance with the General Data Protection Regulation (GDPR) and the Data Protection Act 2018, and all members of the research team will be trained in GDPR and data management.

All identifiable participant data (including contact details, recorded verbal consent, signed consent forms) will be held securely, either in a locked filing cabinet in locked offices at the University of Hull and King’s College London (where the researchers will be based) or saved digitally using secure networks, available only to members of the research team.

All identifying information will be kept separate from anonymised research data. Recordings of participant interviews will be downloaded from audio recording devices and/or Teams (or other online call systems) to secure networks at the earliest opportunity, and then deleted from the audio device/online system; these recordings will be deleted as soon as transcripts have been prepared and checked for accuracy. Participants will be asked to write roles rather than names onto arrows in Pictor charts, but each chart will be checked and anonymised at the close of the interview; any arrow marked with an identifying name will be replaced with an arrow with the appropriate role descriptor (e.g., son, GP, carer by the researcher, and the original arrow destroyed.

When any participant contacts the researchers by email, this will be deleted at the earliest opportunity. Should it be necessary to keep the email, this will be stored either as hard copy in a locked filing cabinet or digitally and deleted when no longer required along with other identifiable data.

The audio files will be shared with authorised transcribers using a secure method of transfer, and a confidentiality agreement will be in place.

Similarly, where interpreters or communication assistants are required, a confidentiality agreement will be in place.

Identifiable data (such as signed consent forms) will be kept for a maximum of one year after the end of the study before being securely destroyed. Non-identifiable research data will be kept for 10 years after the end the study.

5.4.8. ETHICAL CONSIDERATIONS

5.4.8.1 Process for seeking ethical approval

NOTES

- **I) This section refers to the requirements for WORK PACKAGE 1a.**
- **II) Whole study governance and oversight is detailed in Section 7.0**
- **III) Ethical permissions required for WORK PACKAGES 2 are shown in Section 5.10.**

Before recruiting any participants, the PIs will ensure that all appropriate and necessary approvals are in place, which will be dependent on the route of identification and invitation. The process for seeking approvals is as follows:

- Application to the Hull York Medical School, University of Hull, Research Ethics Committee (HYMS REC)
    - **Approval granted 12.12.2022 Reference 22-23 23**
- Application to the Health Research Authority (HRA) Social Care Research Ethics Committee (SCREC) or another committee flagged to approve social care research.
    - **IRAS project IS: 321292. NHS Research Ethics approval granted 31.03.2023.: West Midland – Coventry and Warwickshire; REC reference 32/WM/0030**
- Research Governance approvals if required from Hull City Council; City of Bradford Metropolitan District Council; London Borough of Bromley.
    - **No further approvals required**
- NHS Research and Development Capacity and Capability approvals from relevant primary care health bodies for healthcare practitioners recruited through NHS services.

5.4.8.2. Amendments process

Any amendments to the research will be initially submitted to the HYMS REC and then to the Sponsor for approval, prior to submission to the HRA Social Care Research Ethics Committee.

5.4.8.3 Ethical issues in relation to care of participants and researchers

Given the nature of the research, some of the research participants (particularly clients at end-of-life and their carers) require sensitive and flexible approaches. Homecare workers are often operating under stressful circumstances which will also require recognition and sensitivity in the research. Therefore, the following areas will be addressed throughout the study:

This research, which involves the discussion of end-of-life experiences and care may be distressing for individuals from any of the participant groups, whether through reflecting on the experiences discussed in the research, or on past/anticipated experiences associated with death, dying and bereavement (personal or professional). We will take the following actions to reduce the risks for all participants, while recognising that these cannot be fully mitigated:

1. Client participants. We wish to interview people receiving homecare in the last months of life about their experience of and views about HCW-provided care.
    a. <u>Ensuring opportunity for an often-unrepresented group to participate balanced against the risk of coercion.</u> The initial invitation will be through the homecare agency manager rather than by the researcher to facilitate the ability to decline. We know from published research that people at the end-of-life wish to make the decision to accept or decline such an invitation themselves, but that gatekeeping by staff can be an issue particularly if they are not familiar with research. We will reassure care managers that the method of approach, and the invitation materials have been prepared in conjunction with our service user PPI advisory group. We will not disclose to the care manager which clients have agreed to participate or not. Clients can choose to permit managers to pass their details to the research team, or to contact them directly. The information given will emphasise that consent is voluntary and declining will have no detrimental impact on their care. There are no direct benefits anticipated for participants, although it is hoped that they will value the opportunity to share their experiences, be heard and contribute to the knowledge base.
    b. <u>Capacity.</u> Because of the nature of the study, we need participants able to take part in an interview and with sufficient mental capacity to i) provide informed consent to participate and ii) participate in an interview with a researcher. Care agency managers and care staff have mental capacity as core training and will make the initial assessment; managers will screen the records of those who appear eligible to participate, and check with relevant HCWs regarding their most recent status and their perceived capacity to consent to taking part in the study. If likely to be eligible, the manager will contact the potential participant by post, followed by a phone call (which allows another opportunity for the manager to be alert to any capacity concerns). If the client is willing to speak to the researcher, the researcher (trained to assess capacity to provide consent for study participation) will contact the client.

If any individuals' demeanour raises concerns about their capacity to consent to their participation the researcher will assess their capacity to make a decision about participating the interview.

c. Sensitivity to clients' understanding of their illness. We have reflected carefully on the use of language in participant facing documents, recognising that not all clients and carers will recognise that they are at 'end-of-life'. The short study title used in all participant facing documents refers to 'advanced illness', and we use this term and also 'approaching the last months of life' within documents. For clients and carers use of the terms 'end of life' or 'palliative care' have been avoided, although are retained in the practitioner documents alongside the above terms for additional clarity. The approach to language has been undertaken in consultation with the Service User and Carer group to check acceptability of language used.

d. Burden. As clients will be estimated to be in the last months of life, we expect that fatigue will be a common issue, or less commonly, discomfort. We will therefore be sensitive to this during the consent process (using simple, clear documentation, and allowing clients' own pace to discuss whether or not they wish to participate) and by limiting the participation to a single interview of about an hour. We have deliberately chosen the "Pictor" chart methods to facilitate the interviews as previous work has shown that people with advanced disease find it useful to help them participate. However, if the client prefers to have an "ordinary" interview, this will be respected. Similarly, although our preference is to conduct face-to-face interviews, if a client does not wish this, a remote interview will be conducted in accordance with their preference.

Although the focus of the interview is the experience of homecare rather than their illness, it is likely that the questions will cause the participant to reflect on their illness and its impact on them. Our team is skilled in interview research at the end of life. If any participant shows signs of distress during interview, the researcher will offer them the opportunity to stop the interview or take a break (although participants will not be pressurised to do so, as some may wish to 'tell their story', despite experiencing distress). The researchers will draw on their skills and experience to offer immediate empathy and support for any individual who becomes distressed, and will offer – in the case of clients and carers – to contact someone on their behalf, should they so wish. Clients, as well as carers and HCWs will be offered an information and support sheet which will provide information on local and national sources of support (for example helplines or support groups).

If poor practice is disclosed, we make it clear in the information sheet that this will need to be reported through the appropriate safe-guarding channels.

e. Safeguarding participants. Researchers will be aware of and mindful of the potential sensitivity surrounding end-of-life care, and therefore the that they may witness or receive a disclosure of possible neglect, abuse, ill-treatment or poor professional practice during data collection with members of any participant group. Researchers will be aware of their responsibilities to report concerns, ideally with the consent of the person, to be aware of safeguarding policies and procedures, and will have identified links within the research team and in each participating local authority area should they need to discuss or report concerns.

    f. Anonymity. This is crucial and we will emphasise that interview data will be anonymised, in what we analyse, store and publish/present. (See data management)
    g. Intrusion (both clients and carers). Inclusion criteria have been adopted so that clients who are close to end of life (anticipated to be in the final days of life), and carers who are anticipated to be approaching a bereavement (in the next 7 days) or who have been bereaved in the previous 3 months, are ineligible to participate in the study.

2. Homecare worker participants.

   Coercion. We are aware that this may be a risk with invitations to participate coming from their manager. HCWs can therefore to agree or decline via their manager, or, contact the team directly (or not, if declining). Also, even if the HCW agrees for their details to be passed onto the research team, the researcher is trained in consent, and will make it clear that this is entirely voluntary, and we will not report which invited HCWs have or have not participated. We will also have other routes of recruitment (social media, snowballing) which will give HCWs opportunity to participate without their manager being involved in the process. Again, if poor practice is disclosed, we make it clear in the information sheet that this will need to be reported through the appropriate safeguarding channels.

3. Other professional participants.
    a. Disclosure of poor practice. If poor practice is disclosed, we make it clear in the information sheet that this will need to be reported through the appropriate safe-guarding channels.
    b. Time pressures. In recognition of time pressures, we will restrict participation to a single interview or participation in a single focus group. We will work flexibility around participant preference in terms of interview or focus group, use of Pictor or standard interview, timing and place of interview.

4. Care of the researchers.

   The emotional demands of the research for the researchers are also noted and approaches to support researcher wellbeing have also been identified. These include ensuring they have the necessary training (e.g., in Pictor, mental capacity) and have information about the following: the support available to them; guidance on how to work with people who become distressed; an opportunity to 'debrief' with another member of the team following interviews, with signposting to sources of support if needed; regular individual and team supervision.

5.4.8.4 Ethical issues in relation to legal and management

Confidentiality
All participant (and agency) information will remain confidential. Homecare managers will only share information from potential participants with the researchers when they have agreed to that (and all will have the option of instead themselves contacting the researchers). All identifying information will be removed from any reports and papers, and any direct quotes will be anonymised. Information will only be shared about individual participants if any safeguarding issues are shared or observed - all PIS documents contain information to this effect.

1. Data management: At all times our data handling will comply with GDPR regulations. All our research team are up-to-date with their mandatory training on data management. Details of data management can be found in the relevant section.
2. Data sharing: The consent form seeks explicit permission for anonymised data to be used in future research by authorised researchers. If this is not given, the participant may be enrolled, but we will not include their data in any shared dataset.

All participant data will be anonymised and the confidentiality of all participants assured.

Participant and agency identities (and those of any other individuals mentioned during interview) will be removed at or following transcription and replaced with a simple participant code, and names on all Pictor charts will be anonymised by the researcher collecting the data. No identifying information will be provided in publications, presentations or reports. All quotes used will have identifying information removed, and generic markers used to identify the participant group represented (for example, HCW; client). Care will be taken when reporting demographic data and participants' professional roles to ensure that these data are reported in such a way that participants cannot be identified (for example, if a professional has an unusual or very specialised job title this will be amended, using a broader category to preserve anonymity).

Participants' identities will only be shared with relevant others such as the clinical or care team, the adult safeguarding service in the participant's local authority should any safeguarding concerns or suggestions of poor practice be identified, ideally with the consent of the individual concerned. In such instances, as outlined above, concerns will be reported (on a need-to-know basis and in line with safeguarding policies); this will be detailed in the PIS and participants will also be informed of this verbally. Similarly, if there are concerns about a possible deterioration, these will be shared with members of the clinical team.

To further protect individual and agency confidentiality, the locations and names of the participating local authorities will not be detailed in any project reports and publications.

5.4.8.5 Responding to COVID-19 infection risk

Throughout the study the research team will be vigilant to fluctuating levels of COVID-19 and other relevant infections in the community and any changes in local or national guidance. The study will be guided by a risk assessment, which will be regularly reviewed and will highlight mitigation strategies to be adopted if necessary. The criteria for selection includes:

5.5. WORK PACKAGE 1b. QUANTITATIVE CONTENT ANALYSIS OF LOCAL/NATIONAL POLICY DOCUMENTS RELEVANT TO END-OF-LIFE CARE

5.5.1 AIMS and OBJECTIVES

Aims: To improve the quality and sustainability of person-centred end of life care by HCWs through skill development and empowerment, and to inform employment practices, commissioning and policy.

Objectives: To:

1. Determine health and social care organisational views and priorities and identify gaps in current policy and guidance about the contribution of HCWs to EOLC by:
    a. Quantifying the macro- (societal) and exosystem (services/systems) context for EoL homecare; if, and how, it is present in English health and social care policy.
    b. Identifying gaps in policy guidance

Hypotheses: i) There are few direct references to EoLC in policy documents and the context within which HCWs deliver care at the EoL is not specific to this phase of life. ii) There are more direct references in local documents compared with national.

5.5.2. SUMMARY DESIGN AND METHODS

Document review of current local/national policy and strategy documents will be undertaken using quantitative content analysis to make replicable and valid inferences from the document texts with the contexts of their use.[9] This will give a broad overall picture[40] of current EoLC priorities (or not) in homecare including support and training for the workforce. Both direct (EoL stated) and indirect (EoL unspecified, but text transferable to EoL) references will be noted.

We will follow a stepped approach[44]: i) sample relevant texts; ii) organise and; iii) prepare documents for annotation; iv) assess authenticity of documents; v) explore document's agenda, biases; vi) note the author, audience, tone and style; vii) ask questions about the document e.g., Produced by who? For who? Purpose?; viii) explore content.

5.5.2.1. Document selection, organisation, prepare for annotation, authenticity (steps i to iv)

National documents: We will identify documents for review through research team, collaborator and stakeholder knowledge and selected following the “Who? What? Why? What type?” approach[45]:

The criteria for selection includes: Currently in use; relevant to the health/social care interface; status; direct impact on practice and service delivery *or* as briefings for policy and practice development; authorship; statutory and non-government organisations. Our Partners (BMDC, HCC, Skills for Care, Care Point, London ADASS) will review our selection, identify gaps and rate those they consider to be most important.

Local documents: We will request our interview participants, focus groups and stakeholders to nominate any key local or regional documents for review such as Joint Strategic Needs Assessments or early documents from local Integrated Care Systems.

Documents will be saved in pdf or text format and imported into NVivo data management software to allow word frequency searching, memo writing and thematic coding within the *a priori* framework described below. Authenticity will be reviewed as part of the selection process.

5.5.2.2. Data analysis: tone/style, document questioning, content exploration (steps vi to viii)

Documents (both the data collection units and units for analysis) will be initially "skim-read" to enable data extraction regarding steps vi and vii. We will predetermine the codes of interest: words, phrases, and concepts in relation to i) end of life/palliative/care of the dying/bereavement and ii) workforce support and training relevant to our hypotheses.

We will then quantify their use (existence, frequency) in each document. If there is no specific use of end-of-life terms, we will still search for support and training that could indicate the commitment, or lack of, to increase skills and job satisfaction of HCWs.

We will organise the information using the modified Bronfenbrenner theory[1] to describe an overall picture of the material being reviewed to address our Work Package 2 and Work Package 3 objectives. Given the high-level question being asked, statistical comparisons will not be conducted although we will present descriptive frequencies in national and local documents.

5.5.3. WORK PACKAGE 1 SYNTHESIS: We will synthesise the outputs from Work Package 1a and b, using Bronfenbrenner's theory[1] representing a cohesive analytic approach. A simplified framework analysis approach will be taken, in which the key categories of the theory will be used to categorise and interpret recommendations arising from the interviews, focus group and document analysis. Findings will inform subsequent work packages (Work Package 2 and Work Package 3) in the multi-methods study.

5.6. WORK PACKAGE 2. DEVELOPMENT AND EARLY USER TESTING OF A TRAINING RESOURCE FOR HOME CARE WORKERS

5.6.1. AIMS AND OBJECTIVES

Aims: We aim to develop a training package that is suitable to be tested in the professional population.

Objectives:

1. To map existing training, teaching and support networks for HCWs involved in EoLC.
2. To develop the content and delivery mode for a HCW training resource that is usable and relevant to the workforce
3. To understand and describe the characteristics of a Community of EoL Learning for HCWs including options for delivery.

5.6.2. SUMMARY DESIGN

We will draw on the evidence from the previous work packages, interpret this alongside examples of existing training, and then work with key stakeholders. We will achieve Work Package 2 aims by:

1. Conducting a mapping exercise to identify training resources aimed at supporting HCWs in delivering End-of-Life care. (Work package 2a)

2. Inviting HCWs and stakeholders to participate in co-design workshops to develop a training package that meets the identified needs of HCWs in delivering End-of-Life Care. (Work Package 2b)

5.6.3. WORK PACKAGE 2a. MAPPING EXERCISE FOR EXISTING END-OF-LIFE CARE TRAINING RESOURCES FOR HCWS

In delivering this work package, we will work with our partner organisations and their networks to identify current training resources being delivered across the sector. Skills for Care (SfC) is the national lead for HCW workforce training. The SfC Head of Workforce Capacity and Transformation, Jim Thomas, will support the team to undertake the mapping exercise for existing EoL training and teaching for HCWs. The following approaches will be utilised to identify existing training resource.

5.6.3.1. Identification of training resources

Contact database: As part of the overall SUPPORTED study, we will use the links developed through the project development process to establish a database of contacts and will continue to build this throughout to establish national, regional and local contacts supporting the HCW workforce/EoL. For the purposes of Work Package 2, these contacts will be asked to (1) share any direct teaching and resources that they are using, (2) disseminate requests to share training and (3) help identify candidates for the co-creation workshops in Work Package 2b.

Output from Work Package 1b: Where Work Package 1b identifies relevant local and national policy documents, these will be searched for reference to the provision of training in the relevant areas. Where this is identified, organisations will be approached directly for further information, examples of training resources, and any evaluations that have been undertaken.

Grey literature search: A grey literature search / website search of key national/regional organisations will be conducted to identify existing resources already being delivered across the sector (although we know this is limited), and any available evaluations. This will be led the post-doctoral researcher attached to the project.

Contact through Specialist Palliative Care services: Through the study management group, and through local contacts in the study areas, we will identify hospice and palliative care unit education teams. We will work with these teams to identify any that are providing formal or informal EoL training to their local HCWs. Where this is taking place, we will ask if they are able to share their content, uptake, facilitators/barriers to engagement, and any available evaluations.

Call through Social Media accounts: The above processes will be supplemented by a ‘call for evidence’ via social media accounts. Accounts for staff members of the project working group and accounts linked to the organisations involved in project delivery will be used to disseminate a request to share examples of teaching and training programmes related to EoLC delivery for HCWs, together with information on uptake, facilitators/barriers to engagement, and any available evaluations.

5.6.3.2. Synthesis

Review of the training resources, information on barriers/facilitators and any evaluations completed will be undertaken by the research team. This will identify best practice examples, commonalities in training content and delivery, and will be informed by the knowledge and skills gaps identified from Work Package 1a and b analysis. A summary document will be produced by the team and used as one of the ‘touch points’ for discussion in co-creation workshops.

5.7.4. WORK PACKAGE 2b. CO-CREATION AND EARLY TESTING OF A TRAINING RESOURCE

5.7.4.1. Methods

5.7.4.1.1. Co-design workshops

Home Care Workers (HCWs) and managers with recent experience of providing and/or managing End of Life (EoL) care will meet for a series of four two-hour experience-based co-design (EBCD)[46-48] workshops at months 16, 19, 22 and 25. The purpose of the workshops will be to develop the content and delivery mode for a HCW training resource that is usable and relevant to the workforce.

Before starting the series of workshops, a resource pack for staff and managers will be sent to introduce the goals, ways of working (the EBCD process), and ground rules for participation in the workshops, as well as copies of the resources for the first workshop. Where feasible, we shall enable participation of participants using video-conferencing. Workshop draft agendas are given in Box 1.

BOX 1 Workshop agendas

Workshop 1 - in-person and/or online (month 16):

- Introductions
- Reminder of goals, ways of working, and ground rules
- Introduction to potential learning and delivery methods
- Exploration of key areas and challenges to address in the co-design process
- Presentation and discussion around models of training delivery.
- Presentation and discussion around findings from WP2a and early data from WP1a
- Initiail specification of delivery method
- Agreement on feedback processes outside of the workshops and focus of agenda for Workshop 2, including touchpoint areas

Workshop 2 – in-person and/or online (month 19):

- Feedback from individual working groups, including touchpoints where appropriate
- Discussion of emerging findings from Work Package 1a, including touchpoints where appropriate
- Initial specification of educational materials
- Agreement on focus of agenda for Workshop 3

Workshop 3 - online (month 22):

- Feedback from individual working groups, including touchpoints where appropriate
- Discussion of emerging findings from Work Package 1b and 1a, including touchpoints where appropriate
- Further specification of educational materials and delivery method
- Agreement on focus of agenda for Workshop 4

Workshop 4 - online (month 25):

- Feedback from individual working groups, including touchpoints where appropriate
- Discussion of final synthesised findings from Work Packages 1a and 1b, including touchpoints where appropriate
- Final specification of educational materials and delivery method
- Celebration of co-design outputs

We recognise that trusting relationships between HCWs and managers who may have very different lived experiences of practice in the co-design workshops will be highly important. This will enable people to honestly share their experiences and develop an appreciation of others' experiences, thereby enabling new ways of thinking about and addressing the challenges that will need to be addressed in the co-design process.[49] The first and second workshop will be held online and/or F2F to enable different discussions for managers and homecare workers, in line with advice from PPI groups, Head of Care Services Joan Bothma, and WP1a interviews. Workshops three and four will be held online to allow all participants to help shape the content of the training, but separate "breakout" rooms will be used to keep managers and HCW's separate in line with recommendations from PPI groups and Head of Care Services, Joan Bothma.

In the workshops we shall use 'touch points' as a way of succinctly and vividly communicating people's experiences of caring for a loved one at the end of life, of working in the community to provide EoL care, or of managing services that provide EoL care. These touch points will then provide a focus for discussing and exploring challenges from the different perspectives of workshop participants. The sources for the touch points in the workshops will be:

1. Experiences of HCWs providing EoL care, people at EoL, carers, community health and local authority professionals, homecare managers/employers and commissioners (qualitative findings, WP1a)
2. Local/national policy and strategy (findings from quantitative content analysis document review, Work Package 1b)
3. Existing training for HCWs in palliative and EoL care (findings of mapping exercise, Work Package 2a)

Consistent with the INVOLVE principles for co-producing research,[50] workshops will be co-developed with a Head of Care Services (Joan Bothma).

5.7.4.1.2. Development of delivery methods.

The preferred delivery method has the potential to be guided by preferences expressed in Work Package 1. Many potential methods exist, including e-learning, App-based learning, face-to-face learning and remote video conference-based learning (such as Project Echo). Whilst we aim to allow flexibility in the final delivery method, we propose that one or both of two broad approaches to developing the prototype education package will be identified as most suitable. The first approach is the creation of presentation "slide decks" and notes based on priority topics which can be used for face-to-face teaching/video conference teaching. The second approach is the creation of an e-learning module which can be accessed and used via a computer or smartphone. If additional delivery methods are highlighted by participants, these will be considered.

5.7.4.1.3. Early user testing: We will subject the first prototype to user testing. Through the Skills for Care homecare agency manager network – thereby including perspectives beyond our Work Package 1 sites, we will seek up to 20 HCWs and educators who are willing to test this first version for usability, relevance and for feedback regarding any necessary modification. We will then refine the training resource accordingly. By completion of Work Package 2b, we therefore aim to have a training resource which is ready for further testing and evaluation.

5.8.5. WORK PACKAGE 2c: UNDERSTANDING AND DESCRIBING AN INTEGRATED NETWORK OF SUPPORT

5.8.5.1. AIMS AND OBJECTIVES

AIMS: To explore and characterise options for support networks for HCWs.

OBJECTIVE: To understand and describe the characteristics of a Community of EoL Learning for HCWs including options for delivery.

5.8.5.2. Methods

We will draw on information from Work Package 1 and the expertise of contacts in Skills for Care and stakeholder agencies.

Interview data findings pertinent to HCW support (what – if anything – they have, and what they would find helpful) from Work Package 1a will be identified. We will also explore intelligence in this area via our Skills for Care partners including using their Care Agency Manager network surveying what, if anything, is available for their employees.

We will undertake the following in our Partner, SUC and HCW groups:

1. Consider the purpose and remit of Communities of Learning/Practice for HCWs as a forum for shared experiences and a network of support to complement the training resource.
2. Consider whether membership should be extended to all HCWs, or only those who have completed the training, whether these should be a local or national community with options/needs for funding, curation etc.

We will summarise our findings to characterise options for a HCW support network at local and/or national levels. This will inform our recommendations regarding HCW support in Work Package 3.

5.9 WORK PACKAGE 3: DEVELOPMENT OF POLICY AND PRACTICE RECOMMENDATIONS

AIM: We will develop policy and practice recommendations with our Partner, service user/carer, and HCW groups including in relation to training and support networks for HCWs using the feedback and consultation mechanisms described earlier.

OBJECTIVE

1. Develop and agree recommendations for policy and practice

RECOMMENDATION GENERATION BY STUDY PARTNER AND ADVISORY GROUPS
Draft recommendations for training and support will be drawn iteratively as findings emerge from Work Packages 1&2.

Preliminary findings on HCW training priorities and implications for home care agencies will be presented to the advisory and study partner group for feedback and revision at month 16 following Work Package 1 data analysis. Recommendation development will thereafter be a standing agenda item for the group meetings enabling sustained contribution to building and consolidating recommendations at the final study group meeting (month 28).

At this final meeting, we will present our findings so far, including the initial findings of the training resource protype testing and most recent recommendation drafts to reach consensus regarding, i) the content and level of HCW training and ii) HCW support to inform policy and practice.

Policy summary documents for the recommendations will be prepared to be used as part of our dissemination strategy

5.10. ETHICS AND GOVERNANCE

Studies in Work Packages 2 and 3 are not classified as research requiring NHS ethics approvals (document analysis, mapping, and co-design including user testing involving researchers and stakeholders rather than research participants). However, HYMS Ethics Committee approval will be in place prior to the study starts.

- **HYMS ethics approval granted 17.02.2023 Reference 22-23 38**

6.0. WHOLE STUDY OVERSIGHT

6.1. Protocol compliance

Compliance with the research protocol will be monitored through regular meetings of the research team, individual/group supervision with the researchers and the Study Steering Committee (see below).

6.2. Committees

The study will be overseen, managed and advised by the following groups:

6.3 Study management group

This group consists of the full research team, and two service users and carers (SUC). They are responsible for the day-to-day management and oversight of the study. It will meet monthly for the duration of the study, and will oversee the conduct and management of all Work Packages.

6.4 Study Steering Committee

An independent Study Steering Committee will provide overall supervision of all Work Packages on behalf of the Study's Sponsor and ensure that it is conducted to the standards set out in the Department of Health's Research Governance Framework for Health and Social Care and the Guidelines for Good Clinical Practice. The Committee will be convened in accordance to NIHR guidance and members (including SUC/HCWs) subject to their approval.

The Steering Committee will provide the following:

- Advice, through its Chair, to the Funder, Sponsor, Chief Investigator, host institution, and contractor.
- Monitor the project's progress, adherence to the protocol, and patient safety (as appropriate), and to consider new information of relevance to the research question.
- Consider the rights, safety and well-being of the participants as the most important considerations which should prevail over the interests of science and society.
- Ensure appropriate ethical and other approvals are obtained in line with the project plan.
- Agree proposals for substantial protocol amendments and provide advice to the Sponsor and Funder regarding approvals of such amendments.
- Provide advice to the investigators on all aspects of the project.

6.5. Service user and carer advisory group

- This group will consist of 4 members from each study site. It will meet every 4 – 6 months. Its role is described in detail in section 8.0 on public involvement.

6.6. Homecare worker advisory group

- This group will consist of 2 representatives from each study site. It will meet 4 times throughout the study. Its role is described in detail in section 8.0 on public involvement.

7.0. DISSEMINATION

The findings of the study will be widely disseminated, using a range of strategies to engage with social care practitioners, managers, commissioners, policy makers and the public, as well as to share study findings with participants.[51,52] The dissemination plan for this study recognises the importance of an ongoing approach to dissemination throughout the life of a project, and incorporates the following activities:

- Ongoing social media activity through the research units'/departments' project Twitter pages and/or Facebook and LinkedIn which will provide information and updates about the research.
- Public, professional and/or policy making workshops.
- Presentations at conferences, nationally and internationally.

- Publications – these will include commentaries in practice and academic journals, and open access papers in peer reviewed journals.
- Plain English summaries. These will be available on the project website and be used in social media activity. Participant summaries will also be prepared in Plain English which will present the findings to participants if they wish to receive them; these will be made available to HCWs, health and social care practitioners, and any carers/clients who so wish.
- Cartoons, infographics, videos and blogs will all be used to present the study activities and findings in engaging, accessible and culturally appropriate ways.
- Evidence Briefings and making findings available via the NIHR Centre for Engagement & Dissemination.
- End of project dissemination workshops and events.
- Study final report for publication in NIHR Journal.

8.0 PUBLIC INVOLVEMENT

8.1 Service users and carers

The funding proposal for this study was developed in consultation with people with experience of providing or receiving end-of-life care at home organised through the group Involve Hull (at the University of Hull) and the Social Work Lived Experience Group.

The study includes a Service User and Carer (SUC) Advisory Group. This will involve representation from all three study sites with 4 members from each site. Recruitment will pay careful attention to diversity, ensuring inclusivity and representation of diverse community groups and experiences. The group will meet 4-6 monthly with a total of approximately 7 meetings anticipated in total. Meetings will be conducted online (using Zoom video conferencing), this will help to reduce travel requirements and demands for participants, and fit around their other commitments; however, in person meetings will be arranged if the group so wishes. Participants will also have the option of sharing their views via email, phone or 1:1 meetings with Helen Roberts, supported by Liz Walker, who leads the work with this group. This will allow the participation of those who would otherwise be excluded due to lack of digital access or concerns about the impact of emotional triggers in a group context.

Group members will be recruited through existing networks such as Involve Hull; Bradford Institute for Health Research; PPI Advisory Group of the NIHR Policy Research Unit in Health and Social Care Workforce, King's College London; local groups (e.g., Age UK and Carers' Centres; Councils for Voluntary Services), and informal support groups online, to ensure diversity of perspectives. Recruitment to the SUC advisory group will take the diversity and inclusiveness of the group into consideration. Interpreters will be provided if needed to facilitate participation and written materials will be translated as required.

To ensure that service users and carers have a voice in the management and direction of the project, two to three volunteers will sit on each study governance group (management, steering).

A budget is in place to remunerate participants for activities undertaken and to meet any expenses associated with their involvement, such as travel and providing replacement care; refreshments/lunch will be provided at any in-person meetings. Participants will also be offered a remote working payment to cover Wi-Fi/Broadband costs.

The SUC advisory group will be involved in the following activities within this Work Package:

- Providing advice on the ethical issues involved in conducting research with people approaching end-of-life and their families.
- Helping design the study documents for participants, ensuring clarity and accessibility for families and people receiving homecare.
- Reviewing the recruitment strategy, including inclusion and exclusion criteria, and ensuring that these are fair and robust.
- Advising on the methodology for Work Package 1a and how to minimise the burden on participants.
- Providing guidance on interview topics and questions.
- Sense checking emerging research findings.
- Advising on dissemination strategies to ensure that the findings from this stage of the study are accessible to members of the public.
- Assisting the researchers with addressing any problems which arise during this Work Package, including recruitment difficulties and drop out.

The needs of SUC group members will be taken into consideration, given the nature of the study and the sensitivity of the issues to be discussed. All members will receive a leaflet which will signpost to national and local forms of support. If any group members appear distressed during meetings one of the facilitators will offer support during the meeting or contact them after the meeting.

8.2 Home care workers

Home care workers are our main stakeholders and the study therefore also includes a Homecare Worker (HCW) Advisory Group. Two representatives from each study site will sit on the group, which will meet a planned 4 times during the study. We will use the same approach outlined above to support and engage with HCW group members. We will recruit volunteers through partner home care agencies and social media.

To ensure that home care workers have a voice in the direction of the project, we will also seek one to two volunteers to sit on the study steering committee.

The HCW advisory group will be involved in the following activities:

- Helping design the study documents for participants, ensuring clarity and accessibility for home care workers.

- Provide advice on interview questions and topics.
- Advising on the recruitment strategy and helping to resolve any challenges, and on how to minimise the burdens for HCWs, clients and carers, based on their experience and expertise.
- Sense checking the emerging research findings.

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