Care of people at the end of their lives in the rural and coastal communities of the Southwest Peninsula of England: A participatory realist evaluation NIHR 167160

Research Protocol

Short study title/acronym: EoL Study SW: A Participatory Realist Evaluation

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Plain English Summary of Research

Background: We will all die at some point; however, the way people and families are supported at the end of life varies significantly. Evidence suggests that people living in rural and coastal areas may find it harder to access the care they want at the end of their lives. End of Life (EoL) care is defined as the care of people in their last twelve months of life, with a focus on supporting physical, emotional, and spiritual needs. In Devon, Cornwall and Somerset, 78% of people live in rural or coastal locations. These places also have a higher number of older people and people facing social and economic challenges. Whilst we know there are problems in accessing EoL care, there hasn't been much research into understanding why these problems exist and how we can improve EoL care in these areas.

Study aims: This study will look at how people in Devon, Cornwall and Somerset are cared for and supported at the end of their lives, particularly in rural and coastal areas. We will use a method called realist evaluation to understand what works well and what doesn't in providing support for people and their families. There are four work packages (WP) which will run in parallel over 28 months.

WP1 involves case studies in the six geographical areas in Devon Cornwall and Somerset to understand EoL care. We will also undertake case studies on six different populations such as rural farmers, older people and people who are homeless. The case studies will involve observations, focus groups, and interviews with people at the end of life, their families, professionals who care for them, the voluntary sector, and those organising services.

WP 2. We will survey people responsible for EoL care across the UK and interview local, regional, and national EoL leaders to understand the challenges rural and coastal areas face in delivering accessible EoL care for everyone. We will host regular online discussions with stakeholders from local, regional, and national groups.

WP3. We will use existing NHS data, collected both nationally and locally, to explore and better understand reasons for difference in care during the last 12 months of life.

WP4 brings together findings from WP1-3. Our research team, alongside a patient and family stakeholder group and a professional stakeholder group, will meet to help confirm and develop our understanding.

Involving people as partners in the study: The importance of this study became clear during the extensive engagement work we did in 2023, where we spoke with 45 health and care professionals and 18 individuals who were nearing the end of life, their carers or bereaved family members. A PPIE (Patient and Public Involvement and Engagement) group has met to support the preparation of this study, and a patient and family stakeholder group will actively support how this study runs, how we understand the results of the research, and how we tell others about the work. Additionally, there are two co-applicants, a family member whose father died, and a care manager representing the voice of care home residents. Both have contributed to the development of this proposal.

We will share our findings regularly during the study, directly linking into healthcare practice to reach those responsible for organising, planning, and providing care. We will publish our findings in peer-reviewed journals and take part in policy events. Additionally, we will present our research at relevant conferences both nationally and internationally.

Scientific Abstract

Background

Death and dying are a natural and unavoidable part of our lives; the significance of high-quality care in the last year of life cannot be underestimated (3). There are significant inequalities in access to end of life (EoL) care including geographical inequality. The Southwest (SW) Peninsula region of England, encompassing Devon, Cornwall and the Isles of Scilly, and Somerset, is a largely rural area with an extensive coastline, 78.2% of the population live in rural inland, coastal rural, or coastal town locations (15) and the area has some of the oldest populations and projected need for EoL Care in the UK.

Aims

To identify inequalities in access to, and experiences of, EoL care in the SW Peninsula, to inform decision-making about EoL care services in coastal and rural communities across the UK.

Objectives

- Map and understand inequalities in EoL care in coastal and rural communities
- To understand the conditions that generate good care at the EoL and factors driving inequalities.
- Explore access and outcomes associated with different pathways of service provision for people at the EoL.
- Build (with stakeholders) contextualised explanations of how inequalities in service provision/delivery can be addressed locally through actionable insights, and commissioning
- Use programme theories and strategic intelligence to inform and influence strategy and system (ICB) impact and contribute to wider policy and evidence development to address geographical inequalities in EoL care
- Develop a platform of work to contribute to the local, national, and international evidence base on EoL, including how strategic intelligence can be better deployed to support future commissioning.

Methods

The study will use a participatory realist approach with four work packages (WP) which will run concurrently across 28 months.

WP1. 12 Case studies across the 6 geographical networks for EoL care and 6 population groups including interviews with patients, family, health care and voluntary sector professionals; focused ethnographies; and focus groups.

WP 2. Survey with EoL leads across the UK, and 30 – 35 interviews with local and national stakeholders, EoL care policy analysis, systematic review of global innovations to address challenges to providing EoL care in rural and coastal areas.

WP3. Analysis of routine data collected using local and national data sets.

WP4. Synthesis of WP 1-3. Six workshops will take place with stakeholder groups to support development and refinement of programme theory, stakeholder involvement, knowledge exchange, and policy impact.

Analysis

Data analysis will initially be inductive (working 'outwards' from particular instances) then deductive (testing propositions). Analysis will be iterative, using the different data sources within and across all the WPs to develop our understanding of the relationships between context, mechanisms, and outcomes of care for people at the EoL in the SW Peninsula.

Dissemination

This proposal has been co-produced with public partners and key stakeholders including all the hospices across the SW Peninsula. Their engagement and involvement is central to the design and delivery and dissemination of the study. The study will support the development of policy on EoL inequalities, readdress EoL research inequalities in areas of high need. We will develop policy briefings, publish findings in peer-reviewed journals, present at national and international conferences.

The Study Team

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Main Protocol

1. Background and rationale

Death and dying are normal and unavoidable parts of life, yet they remain poorly understood and insufficiently supported within health services. While the importance of high-quality care in the last year of life is widely acknowledged (Care Quality Commission, 2023), there are persistent inequalities in access to such care (Baylis et al., 2023; Chief Medical Officer, 2021; 2023; Hospice UK, 2021). These inequalities arise from a range of factors, including disease type, a lack of resources, poor coordination and integration, and the wider disadvantages experienced by populations affected by poverty, ethnicity, age, gender, rurality, and coastal living as set out by the Chief Medical Officer (2021; 2023). Evidence consistently shows that it is those already disadvantaged who suffer most (Sallnow et al., 2022). Availability of palliative and end of life care (PEoLC) is highly variable across England, with structural inequalities shaping both resources and access (Baylis et al., 2023; Pask et al., 2022; Sleeman et al., 2018; 2021). Specialist services, as well as generalist primary and community services, remain under severe pressure (Johansson et al., 2024).

In England, end-of-life (EoL) care refers to treatment and support provided when underlying conditions are expected to lead to death within the coming year. It emphasises holistic, person-centred care that addresses physical, psychological, social, and spiritual needs, while also supporting family members and carers (National Palliative and End of Life Care Partnership, 2021). Palliative care extends from the point of diagnosis of a life-threatening illness, continuing through to the end of life. The scale of need for these forms of care is significant. In 2022, 540,000 people died in England, including 27,940 in the Southwest (SW) Peninsula (Office for National Statistics, 2021). It is estimated that around 90% of people would benefit from palliative care as they approach the end of life (Marie Curie and the Association for Palliative Medicine, 2022; Marie Curie, 2021), and demand is projected to increase by 25% nationally by 2040 (Etkind et al., 2017). In the Southwest, the projections are even higher: Cornwall, for example, is expected to see a 32% increase by 2043 (Cornwall Council, 2024). The greatest growth is expected among older people with dementia (Etkind et al., 2017; Yorganci et al., 2024), and by 2040 an estimated three-quarters of all deaths will occur at home or in care homes (Bone et al., 2018).

The SW Peninsula of England, comprising Devon, Cornwall, the Isles of Scilly, and Somerset, is predominantly rural and coastal, with a population of 2.3 million people, over three-quarters of whom live in rural inland, coastal rural, or coastal town locations (Gibson & Asthana, 2021). The geography of the region, characterised by poor transport links and coastal boundaries, creates challenges both for people accessing services and for services themselves in achieving economies of scale (National Palliative and End of Life Care Partnership, 2021). Coastal areas in particular are associated with some of the worst health outcomes in England (Chief medical Officer, 2021), combined with some of the oldest populations in the UK (Chief Medical Officer, 2023). Socio-economic disadvantage and older age both contribute to inequalities in access to healthcare. The Southwest has the highest proportion of people aged 65 and over in England, at 24.6% compared to

the national average of 18.4%, and one of the highest rates of people dying in care homes (Public Health England, 2019). It also faces acute pressures from a lack of support for older people at home, leading to frailty-related hospital admissions and prolonged stays (Transforming NHS, online resource). Despite these challenges, and despite PEoLC being a statutory responsibility of Integrated Care Boards (Oliver, 2022), such care is rarely prioritised by commissioners (All-Party Parliament Group, 2024; Baylis et al., 2023; Sleeman et al., 2021).

There is compelling evidence of unmet need at the end of life. A recent national survey of over 1,000 bereaved people in England and Wales found the health and care system to be overstretched, with one in five dying people having no contact with their GP in the last three months of life and half of respondents dissatisfied with at least one aspect of care (Johansson et al., 2024). Fewer than half reported having a key contact to coordinate services. These findings echo research carried out in the SW Peninsula (Hodge et al., 2025; Kallis et al., 2025), where people reported lack of choice, poor coordination of care, and feelings of isolation and abandonment. Although national data on deaths and hospital admissions are available, they provide only a limited understanding of the quality of care, and there remains no consensus on what measures constitute a "good death" (Hoare et al., 2024). Nor is there evidence that one service model is consistently more cost-effective or produces higher quality outcomes than others (Durand et al., 2017). District nurses, community services, and families are widely recognised as central to delivering good EoL care (Baylis et al., 2023; Coldrick & Crimmons, 2019; Pask et al., 2022), yet resources for these services remain scarce. Families who are not involved in care are also more likely to experience severe levels of vulnerability in grief (Harrop et al., 2020).

The Southwest's demographic profile makes the region a particularly important context in which to study EoL care. With an ageing population that is further ahead on the demographic curve than other parts of England, the region offers valuable insight into the challenges and service needs that will become increasingly pressing nationally. At the same time, the Southwest remains under-represented in palliative and end-of-life research, ranking among the lowest regions in participant recruitment (Hansford et al., 2024). Addressing these gaps is essential to inform future policy and commissioning, to ensure that people in rural and coastal communities are not left behind, and to improve care for people at the end of their lives (Chief Medical Officer, 2021; 2023; Sallnow et al., 2022; UK Government, 2022).

2. Research and linked studies

The evidence base for understanding palliative and EoL care in rural and coastal communities is limited. To explore what is already known, a preliminary international literature review was undertaken. Searches were carried out in Embase, Medline, Emcare, CINAHL, and PsychInfo using terms related to palliative care, dying, terminal illness, and EoL care, alongside terms for settings such as home, hospital, hospice, rural, coastal, and low-income. The search yielded 5,767 papers, which reduced to 2,909 after removal of duplicates. Screening identified 202 studies on palliative or

EoL care in rural and coastal contexts, including 22 literature reviews published in the last decade, predominantly from the United States, Australia, and Canada.

Only seven UK studies were identified, of which four were conducted in England. Hansford and colleagues (2023; 2024) reported on a community engagement programme in Southwest England, delivered as part of the NIHR End of Life Research Partnership (NIHR 135312). This work, involving members of the current study team, highlighted that rural and coastal communities have long been overlooked in health research, including in the field of palliative care. It underscored the need for investment in sustainable partnerships, training, and community engagement to strengthen EoL care provision. Mogan and colleagues (Mogan et al., 2024) interviewed 20 family carers in remote areas of the UK, finding that geographical isolation, transport difficulties, and workforce recruitment and retention posed major barriers to accessing specialist palliative care. More recently, members of the present team conducted focus groups with patients, carers, and professionals in the SW Peninsula (Hodge et al., 2025; Kallis et al., 2025). Participants reported a lack of choice and agency, inadequate coordination of care, insufficient resources, and widespread experiences of isolation.

Recent work by Hospice UK has highlighted the specific challenges of delivering palliative and Eol care in rural, remote, and island settings. The *Bringing Care Closer to Home* report (Hospice UK, 2025) draws on the experiences of patients, carers, and professionals across the UK, emphasising persistent inequalities linked to geography, including limited access to services, workforce shortages, and the difficult trade-offs faced by those who wish to remain in their communities while receiving appropriate support. This report provides the first UK-wide policy analysis focused on the needs of rural and coastal populations and underscores the urgency of developing sustainable, community-based models of care tailored to these contexts.

Across the wider literature, research specific to coastal communities remains particularly scarce, with only three relevant studies identified (Hansford et al., 2023; 2024; Phillips et al., 2006). Two were from the UK, and one from Australia, which found that low wages, poor housing, weak transport infrastructures, and limited access to healthcare services negatively impacted EoL care (Phillips et al., 2006). These findings are consistent with wider UK evidence on socioeconomic and health disadvantages in coastal areas (Gibson & Asthana, 2021; Pask et al.,2022). Ageing populations, higher burdens of chronic disease, and above-average mortality rates are particularly pronounced in coastal contexts (Gibson & Asthana, 2021; Phillips et al., 2006).

In rural contexts, a larger but still limited body of research highlights persistent inequalities in care provision and access compared to urban areas (Tobin et al., 2022). Geographical variations affect patient access to services (Suntai et al., 2020), their choice of place of death (Rainsford et al., 2017; Spelten et al., 2019), and the ability of clinicians to deliver care in people's homes (Caxaj et al., 2018). Healthcare professionals working in rural communities often lack access to specialist training and education in palliative care (Cai & Lalani, 2021; Cerni et al., 2023; Lalani & Cai, 2022), leading to delays in referral (Lalani & Cai, 2022; Tedder et al., 2017) and poorer quality care (Cerni et al., 2023). Limited resources and staffing shortages compound difficulties in communication and coordination across health and social care providers (Caxaj et al., 2018; Curd & Hong, 2024; Marshall et al., 2023;

Reed et al., 2014), undermining both patient and carer experiences (Mogan et al, 2024; Nelson et al., 2016; Racine et al., 2022; Rainsford et al, 2017). While some studies have captured the perspectives of family carers (Jansson et al., 2017; Kirby et al., 2016; Patano et al., 2024; Rainsford et al., 2018), relatively few have documented the voices of patients themselves. The majority of patient-focused studies rely on secondary or survey data, or very small disease-specific samples. Innovations trialled in rural contexts have tended to focus on technology-driven approaches, such as telehealth (Fasolino et al., 2023; Gordon et al., 2021) or virtual hospice models (Taylor et al., 2018) and remain small-scale or service-specific.

Taken together, the evidence points to a lack of robust research into the challenges and opportunities for EoL care in rural and coastal areas. Coastal communities are particularly under-researched, and patient perspectives are insufficiently represented. There is little evidence to guide commissioners and providers on what works in addressing these inequalities, or on how to design and deliver integrated care across different service settings. Work Package 2 of this study will address this gap through a systematic review and narrative synthesis of international literature on service innovations.

There are also important links with ongoing research. Several NIHR Health and Social Care Delivery Research (HSDR) studies are currently examining inequalities in rural and coastal communities, including work on mental health (Co-CIs Hardwick and Byng) and social care (CI Clarke), with data collection in the Southwest. Another NIHR HSDR study is exploring palliative and EoL care in community and primary care settings in Yorkshire (CI Mitchell). In addition, a team at King's College London has recently completed an NIHR Programme Development Grant examining the potential for routine data to monitor and reduce inequalities in EoL care (NIHR 204588; Sleeman et al.). The present study team has already established connections with these groups, ensuring that this work will contribute to, and build upon, a wider national programme of research.

The critical state of EoL care provision (Hospice UK, 2021; Sleeman et al., 2021), the scarcity of UK-based research in rural and coastal settings, and the demographic pressures faced by the SW Peninsula (Cornwall Council, 2024; Hansford et al., 2024; Public Health England, 2019) demonstrate the urgent need for this study. By addressing these evidence gaps and generating actionable insights, the study will strengthen the evidence base for planning, commissioning, and delivering care, and will help to ensure that the needs of people at the end of life in rural and coastal communities are not overlooked.

3. The study

3.1 Research question for the study:

How does the intersection between rural and coastal geographies and populations generate inequalities in EoL care, and how can health and care services, the voluntary sector and communities better support access to high quality care at the end of life?

3.2 The aims of the study:

To understand the nature of the inequalities in access to, and experiences of, end of life (EoL) care in the SW Peninsula, identify ways of addressing these challenges to inform decision-making about these services in coastal and rural communities across the UK.

a) To understand the contexts and mechanisms driving inequalities in end-of-life care in rural and coastal communities
b) To identify actionable insights that will support the commissioning and the provision of evidence-based care at the EoL for people in rural and coastal communities nationally.

3.3. Objectives of the study:

1. Map and understand inequalities in EoL care in coastal and rural communities (WP1-3)
2. To understand the conditions that generate good care at the EoL and factors driving inequalities. Explore access and outcomes associated with different pathways of service provision for people at the EoL (WP1-3)
3. Build (with stakeholders) contextualised explanations of how inequalities in service provision/delivery can be addressed locally through actionable insights, and commissioning (WP2, 4)
4. Use programme theories and strategic intelligence to inform and influence strategy and system (ICB) impact and contribute to wider policy and evidence development to address geographical inequalities in EoL care (WP2-4).
5. Develop a platform of work to contribute to the local, national, and international evidence base on EoL, including how strategic intelligence can be better deployed to support sustainability (future commissioning) (WP1-4).

3.4 Design and theoretical conceptual framework

3.4.1 A Participatory Realist Study

We shall use a participatory realist approach to identify what is working (or not) in the receiving and the delivery of care, for whom, in what circumstances, and within different contexts (Pawson & Tilley, 1997). Co-production, shared experiences, and stakeholder involvement will be central throughout the study (Downey et al., 2023; Heron & Reason, 2006). This builds on previous stakeholder research across the Southwest (Hansford et al., 2023; 2024; Hodge et al., 2025; Kallis et al., 2025) and six months of extensive knowledge exchange and stakeholder engagement. The study has the strong support of key stakeholders. We have presented and engaged at a number of individual meetings with EoL Leads and other professional leads in all ICBs; meetings with Data Managers across all the ICBs; Voluntary, Community or Social Enterprise services (VCSE) across Devon Cornwall and Somerset; meetings with EoL leads at NHSE and NHSESW; we have also led knowledge exchange events and meetings with all the hospices individually and together. This in-depth engagement has reinforced the challenges being faced in rural and coastal communities in the access to and delivery

of care together with the need and extensive support for this study and its position as a research priority. The involvement of patients, families, professionals, and the leaders of care has supported the development (focus and design) of this application. The participatory focus of this Realist approach will enable patients, families, and professionals to have a strong voice in the case studies, shaping of the programme theories, and recommendations for policy and practice.

Realist methods aid theory building and provide a framework to draw together evidence (Pawson & Tilley, 1997), helping to explain which contextual characteristics and mechanisms are key for high-quality EoL care within rural and coastal communities in Devon, Cornwall and the Isles of Scilly, and Somerset.

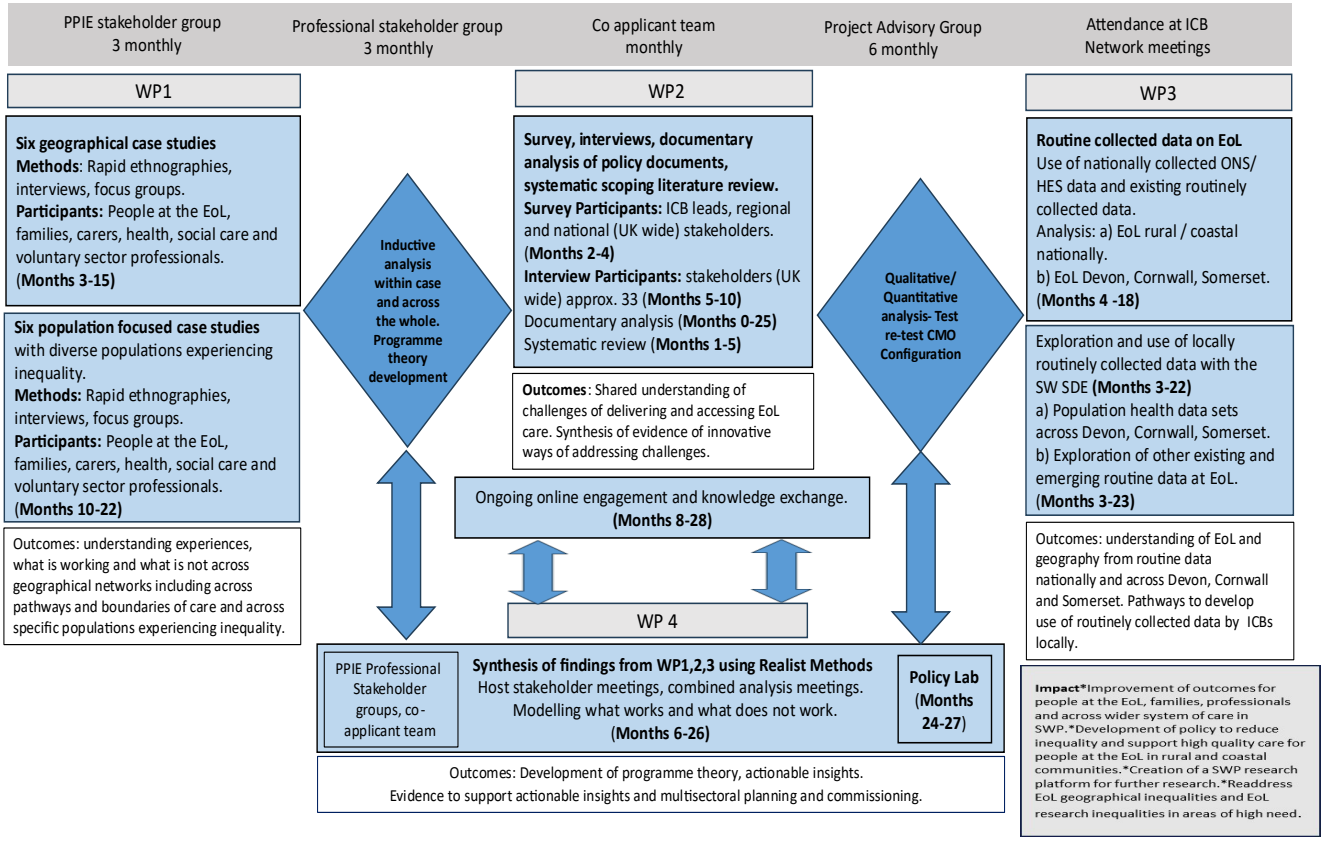
EoL care is a complex intervention existing within the broader health and social care system. Our methods will explicitly recognise the complex nature of the system and draw on the Medical Research Council's complex intervention framework to explore this from a real-world, whole-system perspective, fostering an inductive understanding of experiences, process pathways, and local context (Fletcher et al., 2016; Skivington et al., 2021). We will strive to understand the whole system across each locality/ network. We will include all the key actors and organisations and communities in this (specialist PEoLC providers, community and primary care, social care providers, established VCSE organisations and local community and faith groups).

3.4.2 Work Packages

This project has four interconnecting work packages (WPs) which will run concurrently over 28 months, working together to refine and develop context mechanisms and outcome configurations as programme theory evolves. Data from interviews with patients, families, carers, professionals, and regional/national stakeholders will inductively support understanding of experience, processes, pathways, and context of what is working and what is not working in the delivery of care at the end of people's lives.

We will use realist approaches to set out the theories that explain how EoL care is organised and works within rural and coastal communities. Case studies with interviews, observations and focus groups (Crowe et al., 2011; Stake, 1995; Yin & Robert, 2017;) will capture the depth and complexity of experiences among specific populations and networks of care across of Devon, Cornwall, and Somerset (WP1). This will be linked with wider perspectives across the UK in WP2, through documentary analysis, surveys, and interviews with wider stakeholders and linked internationally with the systematic narrative review. Theories developed from WP1 and WP2 will be further tested against WP3's analysis of routinely collected data, supporting and informing exploration between causal mechanisms and how context impacts outcomes. The Realist Framework for this study and the intersection between workstreams is supported by WP4. WP4 will support the further development and refinement of programme theory, supporting stakeholder involvement, knowledge exchange, and policy impact. We will report according to RAMESES reporting standards for Realist Evaluation (Wong et al., 2016). Figure 1 below illustrate the whole study design.

Figure 1. Whole Study design



3.4.3 Setting and the context of the study

This study will take place across the Integrated Care systems (ICS) of Devon, Cornwall and the Isles of Scilly, and Somerset (Figure 1). Together, this area is known as the Southwest (SW) Peninsula and areas covered by NIHR PenARC, NIHR SW Research Delivery Network (RDN). There are six geographical networks for palliative and EoL care across the SW Peninsula. Devon ICS is split into localities with four localities identified for palliative and EoL care. These are listed below; the maps illustrate the localities of Devon and the SW Peninsula as a whole.

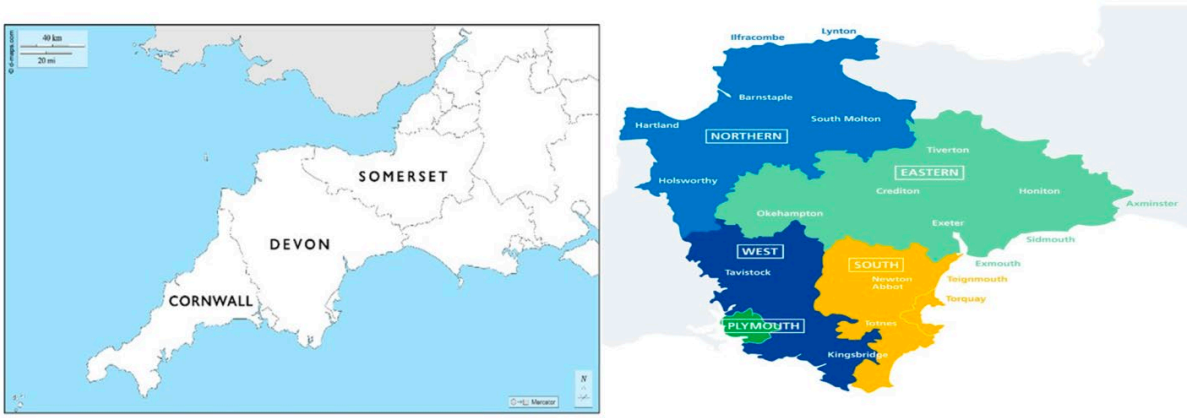


Figure 2: Maps to show case study areas. Source: https://onedevon.org.uk/about-us/areas-covered-lcps/

The six geographical networks of the study are: Cornwall (Cornwall and Isles of Scilly Integrated Care Board, Cornwall Council, Cornwall Hospice Care); Somerset (St Margarets Hospice, Somerset Council, Somerset ICB); Devon-Eastern, (Hospiscare, Royal Devon University Hospital, Devon County Council); Devon- North (North Devon Hospice, Royal Devon University Hospital, Devon County Council); Devon-Plymouth (and some west) (St Luke's Hospice, University Hospital Plymouth NHS Trust, Livewell, Plymouth County Council); Devon- South (and some West) (Rowcroft Hospice, Torbay and South Devon NHS Foundation Trust, Integrated care organisation including Torbay Council). Adult and children's services are organised and commissioned separately and are guided by different National strategies and guidance (National Institute for Health and Care Excellence, 2019a; 2019b). This study will be for adults.

4. Work Packages (WPs)

4.1 Work Package 1 The case studies

4.1.1 Overview and setting

Case studies will take place across the SW Peninsula, specifically targeting rural and coastal communities served by Integrated Care Systems (ICSs) and ICBs. The selected settings reflect diverse geographical and socioeconomic contexts, including areas with known disparities in access to healthcare services and support at the end of life. Each case study will represent a distinct geographical area or population where EoL care is delivered across multiple boundaries – including primary care, community services, specialist palliative care, social care, and the voluntary, community and social enterprise (VCSE) sector.

1. Geographical case studies will be across the six networks of care in the SW Peninsula which support how health and care is organised for people living at the end of life across the Devon, Cornwall, and Somerset ICBs (see Figure 1). This includes Cornwall and Somerset and the four network areas in Devon. Key stakeholders and EoL leads within each network have been identified and are already engaged in the study. Geographical case studies will begin before the population-focused case studies (see below). Hospices and their networks and EoL lead in each area will be key to helping identify participants through their wider links and networks of care.
2. Six population-focused case studies – each will focus on a particular population that has highlighted inequalities in rural and coastal areas at the end of life. A population case study will be 'nested' or located within each geographical area. Extensive work with stakeholders has suggested these will include a population who are living in a rural isolated community on Dartmoor or inland Somerset, a care home or care home group in Cornwall or Somerset, a homeless hostel and the associated multiprofessional team and VSCE organisations and community/ faith groups in Torquay or Newquay, a coastal town with high degree of poverty in North Devon or East Devon. A further two will be identified and accessed through key stakeholder engagement and through analysis of initial data from the geographical case studies and routine data.

Within each case study site, data collection will take place in settings where care is delivered, co-ordinated or experienced. This includes participants' homes, GP practices, community sites, hospices, care homes, local authority hubs, voluntary sector organisations, and spaces used by community and support groups. Observation in the rapid ethnographies will occur in multi-disciplinary and multi-agency meetings and settings related to EoL care planning and delivery. Focus groups and workshops may be held in accessible community venues, university premises, or conducted virtually depending on participant preference and practical feasibility. Across all settings, attention will be paid to creating inclusive, safe, and respectful environments for participants.

4.1.2 Methods of data collection

Interviews

Semi-structured qualitative interviews will take place with patients, family/bereaved, and health and care professionals (including VSCE and other service providers). Patients and families will need to be 18 or over, live in a rural or coastal location, and have experience of living with or caring for people in the last 12 months of life. Professionals will be drawn from a range of settings, including community, palliative, social care, and voluntary sector services and community groups. Interviews will last approximately 45 to 60 minutes and will be conversational in tone, guided by a flexible topic guide that includes open-ended questions and tailored prompts. This approach enables the elicitation of participants' personal narratives while ensuring consistency across interviews (DiCicco-Bloom & Crabtree, 2006; Fontana & Frey, 2000;). Interviews will take place at a time and location convenient to the participant- either online or in-person. For in-person interviews, a private but informal

environment will be arranged to ensure participant comfort. All interviews will be audio-recorded with consent and transcribed verbatim. Interviewers will be skilled qualitative researchers with experience of conducting sensitive interviews on end of life and health-related topics. Interview Guides and researchers will employ reflexive and empathetic listening techniques, including the use of participants' own language, the ability to gently redirect conversation, and allowing time for considered responses (Seidman, 2006). Where appropriate, joint interviews involving patients and carers/family members will be offered. Interview guides for professionals will explore their experiences of delivering EoL care, including barriers, enablers, and opportunities for improving sustainable and equitable care delivery. Interviews with patients and carers will focus on experiences of care, what was helpful or unhelpful, and suggestions for service improvement.

Focus groups

In total, 12 focus groups will be conducted (one for each case study) at the end of the case study data collection period and will include 8-10 participants. These focus groups will bring together a range of stakeholders, including health and social care professionals working within the case studies, leaders from statutory and voluntary sector organisations, and representatives of relevant community groups. The purpose of the focus groups is to understand the system dynamics that enable or inhibit effective care across organisational boundaries and care pathways, particularly within rural and coastal contexts. Each focus group will be facilitated by two experienced researchers to ensure a safe, inclusive and well-managed discussion environment. Focus groups will adopt a semi-structured format using a flexible topic guide to prompt discussion while allowing participants to raise their own experiences and reflections in a conversational and open-ended manner. This approach is well-suited to generating rich, contextualised accounts of complex systems and relationships in health and social care (Kitzinger, 1995; Tong et al., 2007). Focus groups will complement interview and observational data by generating collective insights into patterns of care, collaboration, and challenges across the system.

Rapid ethnographies

Ethnographic, non-participant observation will be conducted across all 12 case study areas, comprising approximately 30 hours of non-participant observation across geographical case studies and 15 hours across population case studies. This will include observations of key settings and practices where EoL care is co-ordinated or delivered- such as multi-disciplinary team (MDT) meetings, interagency case discussions, routine care co-ordination forums, and in some cases, the shadowing of professionals during community-based visits.

Direct patient care will not be observed. All observation periods will involve verbal consent and agreement of the team, professionals, and if relevant, family and patient for the researcher to be present. Informal communication and clarification during the period's observation, they will be recorded as nonverbatim field notes.

Non-participant observation will focus on the everyday practices, decision-making processes, interprofessional dynamics, and interactions across care boundaries. Researchers will take detailed

non-verbatim fieldnotes to document the observed context, culture, routines, and behaviours. This will involve documenting: the physical and organisational setting; practices, interactions, and communications; professional roles and team dynamics. Fieldnotes will also include researchers' own reflexive impressions and interpretations, in line with established ethnographic practice (Emerson, Fretz, & Shaw, 2011). Field notes will be taken during and after each observation session. This approach is particularly useful for understanding the "real-world" context of service delivery and how care is organised and experienced (Reeves et al., 2008).

4.1.3 Sampling approach

Sampling of the interviews for the population case studies will be theoretically and purposively informed to ensure representation geographically, reflecting populations in rural and coastal geographies, particularly those who experience inequalities at the end of their lives. Sampling of health and care professionals will ensure diversity in role, setting, and organisation type.

Geographical case studies will have a total of about 20 interviews: Patients (n=5), family/bereaved (n=5), health and care professionals (n=10); Population case studies a total of about 14: Patients (n=4), family/bereaved (n=4), health and care professionals (n=6). Focus groups will involve 8-10 participants each.

Patient interviews: Inclusion criteria

- Male or female. Aged 18 or over.
- Living in a rural or coastal location within the SW Peninsula (Devon, Cornwall, Somerset).
- Towards the end of life (within the last 12 months) (Harding and Higginson 2010).
- Able and willing to provide informed consent.
- Able to communicate in English (or with support if translation is needed).

Family members/bereaved carer interviews: Inclusion criteria

- Aged 18 or over.
- Living in a rural or coastal location within the Southwest Peninsula.
- Have experience of caring for someone towards the end of life.
- A bereaved family member or someone currently caring for someone approaching the end of life- definition is here: [2]
- Able and willing to provide informed consent.
- Able to communicate in English (or with support, where necessary).
- At least six weeks since bereaved.

Health and care professional interviews: Inclusion criteria

- Working within primary, community, acute, social care or voluntary sector services supporting people at the end of life.
- Based within one of the identified geographical or population case study areas.
- Able and willing to provide informed consent.

- Able to participate in a 45–60-minute interview in-person or online.

Focus groups: Inclusion criteria

- Professionals involved in the delivery, co-ordination, or leadership of EoL care.
- Leaders or senior staff from VCSE organisations, care providers, and community groups working in EoL care.
- Based within the geographical or population case study areas.
- Have experience or insight into how EoL care is delivered across boundaries and sectors (e.g. health, social care, VCSE).
- Aged 18 or over.
- Able and willing to provide informed consent.
- Able to participate in a 60–90-minute group discussion (online or in-person).

4.1.4 Recruitment

Patients and family/bereaved: Recruitment will occur via hospices, care homes, community services and VCSE partners. A known professional or research nurse will introduce the study and provide an Invitation Letter; If they are interested in hearing more about the study, they can either contact the researcher/let the professionals know and they will be given a Participant Information Sheet. They will have an opportunity for the researcher to go through it with them at their convenience and answer questions. Patients and family members/bereaved will be given as much time as they need to think about participation (minimum 48 hours). If they would like to participate, the researcher will arrange a time for the interview in the place they would prefer. Before the interview, the researcher will check that the participant is still informed/happy to participate. After this and just before the interview, written consent will be obtained using a consent form in person or via JISC.

Professionals: Recruitment for interviews and focus groups will be via professional networks, NHS/social care contacts and VCSE partners. Invitation letters and PIS will be emailed; inviting people who are interested in participating to contact the researcher by email or telephone. The researcher will then provide further information/answer any questions. If the professionals would still like to participate, a time and convenient place for the interview will be arranged or the focus group date given. Before the interview, the researcher will check that the participant is still informed/happy to participate. After this and just before the interview/ focus group, written consent will be obtained using a consent form

4.1.5 Ethical issues

This part of study will obtain approval from the University of Plymouth (UoP) Faculty Research Ethics and Integrity Committee and will undergo NHS REC and HRA review alongside Work package 4 (IRAS 355730). All procedures will comply with the UK Policy Framework for Health and Social Care Research, the Data Protection Act 2018 and UK GDPR.

Principal ethical risks to this part of the study relate to informed consent, anonymity and confidentiality, emotional sensitivity (including bereavement and end-of-life contexts), and researcher safety.

Informed consent

Consent will be obtained prior to participation and re-affirmed immediately before data collection. For interviews and focus groups, written consent will cover participation, audio-recording and use of anonymised quotations in outputs. Participants will be told they may pause/stop at any time without giving a reason and that participation/non-participation will not affect care or services. The nature of informed consent will be ongoing, and participants will be able to withdraw at any time without giving a reason.

In the rapid ethnographies researchers will present the study to relevant teams, provide a study summary sheet and posters and get verbal agreement from teams. At the start of each observation, the researcher will ensure verbal consent from all who are present. For any observation which may include patient or family member such as shadowing a home visit, verbal consent will be sought from the patient and family by the professional beforehand. Researchers will not observe any direct patient care and will be very sensitive of the need to leave at any time. Observations will be non-participant in nature, with researchers maintaining a discrete presence. Informal conversational exchanges (e.g. clarification questions) will be recorded as non-verbatim field notes and not treated as interview data.

There will be one researcher leading each case study and all the data collection (under the guidance of the Chief Investigator), they will hold meetings with key stakeholders and health and care leads within the case study and be available to answer any questions about the planned research. In all settings, the researchers will make their role and purpose transparent and will leave any environment if it is not appropriate to be there.

Conduct of data collection and managing sensitivity

Interviews: Interviews will be held at a time/place convenient to participants (online or in-person, in a private setting). Interviews will be undertaken by experienced qualitative researchers trained in sensitive EoL research and reflexive, empathetic listening. Topic guides are flexible and conversational to allow participants to control depth and pace. Joint interviews (e.g. patient with family member) may be offered with both parties' consent. If distress occurs, the interview will be paused; continuation will only occur with the participant's agreement. Participants will be reminded they can stop at any time. A distress protocol will be followed, including provision of relevant support information and a researcher follow-up check-in after the interview. If a participant becomes distressed, the interview will be paused and will only continue with the participant's agreement. Participants will be reminded that they can stop the interview at any time without giving a reason. This process will be outlined in the distress protocol. Researchers will check in with the participant following the interview.

Focus groups: focus groups will be facilitated by two researchers, in-person or online (MS Teams/Zoom). A semi-structured guide will prompt discussion while allowing participants to raise relevant experiences. The limits of confidentiality in group settings will be explained at the outset, and participants asked to respect each other's confidentiality.
Rapid ethnographies: non-participant observation will focus on real-world practices of EoL coordination and delivery (e.g. MDTs, interagency case discussions, routine coordination forums). Researchers will not observe any direct patient care and will be very sensitive of the need to leave at any time. Observations will be non-participant in nature, with researchers maintaining a discrete presence. All researchers will be briefed on maintaining discretion and sensitivity, especially during shadowing of care professionals or potential observation of patient interactions. All researchers will maintain reflexive fieldnotes and receive clinical supervision and debriefing.

Accessibility, capacity and language

Materials will be available in accessible formats where required. Where language or communication support is needed, translation/interpretation (e.g. BSL, easy read) will be provided. Only adults with capacity to consent will be enrolled; capacity will be assessed by trained researchers at the point of consent and reconfirmed before data collection.

Safeguarding, disclosures and researcher safety

If participants disclose information that indicates risk of harm to self or others, or safeguarding concerns, researchers will follow relevant organisational policies, informing participants of any required breach of confidentiality. Lone-working and researcher safety procedures will be followed for all fieldwork, including risk assessment of sites, check-in/check-out processes, and supervisor debriefs.

4.1.6 Data analysis

Each element of qualitative data in the case studies will be analysed using Reflexive Thematic Analysis (Braun & Clarke, 2021) using NVivo V14 pro. The analysis will be iterative and inductive, to support the development of theory. Data will be analysed as a case, firstly within individual data type and then triangulated across data types. Data then will be analysed across the six geographical case studies and the six population case studies. Higher order themes will be identified across all WP1 data, providing a framework for theory building and refinement. A realist logic of analysis (exploratory and open to novel insights into how contexts interact with mechanisms and lead to certain outcomes) will be applied to interpret and judge the contribution to building theories and refinement from each data source both within and case studies. Data analysis will initially be inductive (working 'outwards' from particular instances) then deductive (testing propositions) cross-case comparison. Analysis will be iterative, using the different data sources in WP1 and then across all the WPs to develop our understanding of the relationships between context, mechanisms and outcomes of care of people at the end of life in the Devon, Cornwall and the Isles of Scilly and Somerset.

4.1.7 Outputs

This WP will map and support our understanding of care at the end of life in coastal and rural communities. It will provide evidence of the depth and complexity of care for specific populations and geographical areas. We will understand the conditions which generate good care at the EoL, what is working or not. The WP will give voice to the experience of patients and family on EoL care contribution to regional and national policy. WP1 will be key to developing Context-Mechanism-Outcome (CMO) configurations and programme theory for this study in constant dialogue with WPs 2, 3, and 4.

4.2 Work Package 2, Understanding wider contexts

4.2.1 Overview

WP2 comprises four interlinked strands:

- A systematic review and narrative synthesis of the global literature detailing innovations to address the challenges to providing and accessing EoL care in rural and coastal areas will be conducted.
- A UK-wide survey of EoL care ICB leads, regional and national leaders in EoL, workforce, and inequality leads to understand the nature of challenges of providing and accessing EoL care in these areas.
- Scrutiny of UK policy documents related to the provision of EoL in rural and coastal communities
- And an in-depth qualitative study will be carried out with purposively sampled leads and commissioners across the UK to explore the specific nature of the inequalities, the conditions which generate them, the populations most affected and ways they are seeking to address these challenges

The survey, interviews and documentary analysis will be UK wide across England, Scotland, Northern Island and Wales

4.2.3 Methods of data collection

Systematic review and narrative synthesis

Systematic review and narrative synthesis of innovative practices/ approaches/ technologies to overcome the challenges of accessing and delivering EoL care in rural and coastal communities

A systematic search across leading databases (Cochrane Library, Trip PRO, OVID MedLine, APA PsycInfo, ASSIA, and Public Health Database ProQuest) will be conducted to identify studies describing innovative practices to address rural and coastal challenges to providing or accessing EoI care. The search will be restricted to English language studies conducted in the last 25 years. We will include articles from any country that focus on one or more of the identified challenges regarding rural and coastal EoI care. Articles providing empirical data, policy analysis, or comprehensive

reviews will be included. We will exclude articles focusing on urban settings without relevance to rural or coastal EoL care. Editorials without substantial data or analysis will also be excluded. We will conduct a narrative synthesis of the findings to provide a comprehensive overview of the global evidence.

Interviews

We will purposively sample national leads for the care of people at the end of their lives and regional and local leads in areas with rural and or coastal populations for semi-structured interviews. These interviews will explore disparities in EoL care, focusing on the geographical challenges in rural and coastal areas, what is needed to reduce geographical inequalities, and wider contextual issues and challenges that impact this. We aim to conduct ten interviews with EoL and ICB leads across the SW peninsula, 5-8 interviews with EoL leads from other rural/ coastal ICBs and the national lead in England, and up to 5 interviews with EoL leads in Scotland, Wales, and Northern Ireland.

Interviews will be conversational in style, semi-structured style interviews will be conducted online, digitally recorded, and transcribed. The interviews will include questions to explore: their population and geography; how PEoLC is organized for rural and coastal populations (workforce models); challenges to care delivery to people towards the end of their lives in rural and coastal areas; local innovations, policies, commissioning models; what an ideal vision of care for people at the end of their lives would look like. Interview participants will be asked if they would like information about webinars, general information sharing and possible stakeholder engagement opportunities. They will also be asked to share policy documents related to EoI care provision.

Invitations and participant Information sheets will be sent by email via national and regional networks and through snowballing techniques; participant information sheets will be attached to the email and people will be invited to get in contact with the research team if they would like more information/ interested in participation. Contact has been made in all four nations and key people; mechanisms and networks have been identified.

Inclusion criteria:

- Over 18 years of age
- Leadership role in EoL care, commissioning, workforce or related area.
- Has been working in that area or aligned area for over 4 months.
- Able to participate in an interview conducted in English

Survey of leads for the care of people towards the end of life care across England, Scotland, Northern Ireland and Wales

A national scoping survey will aim to explore geographical (rural/coastal) challenges of providing care to people at the end of their lives, understand national policies for palliative care and care at the end of life and explore any inequalities in access and provision of care and local solutions to these barriers. This will provide wider context to the overall study in an area where in the UK there has

been little research. It will also help illustrate the extent of rural and coastal inequality in the provision of EoL care across the UK.

The survey will be distributed electronically via JISC. A participant information sheet will be attached to the survey emails and participants will be asked to complete a consent form before accessing the survey in JISC. The survey will take place after the interviews and systematic review and will be refined in light of their emerging findings. The study has been discussed with National regional EoL leads and it will be sent out through networks in NHS Scotland, Wales, Northern Ireland and England and across other networks; the timing of the survey (after the interviews) was suggested by stakeholders in England in order for changes to ICBs and loss of structures such as NHS England to have taken place. The survey will be distributed electronically via JISC (UK digital, data and technology agency). A participant information sheet will be attached to the survey emails. The consent form will be before the survey in JISC. It is envisaged that the survey sample will be about 50-70 across the UK

Inclusion criteria:

- Over 18 years of age
- Leadership in care for people at the end of their lives, commissioning, workforce or related area.
- Has been working in that area or aligned area for over 4 months
- Able to complete the survey in Welsh or English

Survey participants will also be asked on JISC if they would like to have information about webinars and other parts of the study.

Documentary analysis

The aim of documentary analysis will be to scrutinise regional/national policy documents related to EoI care provision to provide a rich picture of the pathways for EoL care, and the metrics used to monitor care across the UK. EoL policy documents will be collected through professional interviews/ survey professional stakeholder engagement activities. Findings from the (policy) documentary analysis will be triangulated with survey and interview data and findings.

4.2.3 Ethical issues

The interviews and survey in this Work Package study will obtain approval from the University of Plymouth (UoP) Faculty Research Ethics and Integrity Committee it does not require HRA review. All procedures will comply with the UK Policy Framework for Health and Social Care Research, the Data Protection Act 2018 and UK GDPR.

4.2.4 Data analysis

Interview transcripts will be analysed thematically using an iterative, reflexive approach (NVivo 14 Pro will be used to organise data). They will be analysed across groups of interviews initially (e.g. SW

Peninsula Stakeholders, rural and coastal experience, national perspectives) and then across the whole. Interviews will be analysed for patterns according to role/regional or national and rural/coastal geography.

Survey data will be exported into excel and descriptive statistics used to analyse the quantitative data. Thematic analysis will be used for qualitative data. Data will be analysed thematically according to country, region and characteristics of the health system and the populations to highlight similarities and differences in the organisation and delivery of EoL care for rural and coastal areas across the UK.

Analysis obtained from the survey, interviews and policy documents will be triangulated and used to inform the wider context of the overall study. This data will support the development of context, mechanism and outcome configurations and programme theory of what is working and not working in the care of people at the end of life; particularly those living in rural and coastal communities.

4.2.5 Outputs

The engagement of key stakeholders, knowledge mobilisation, and shared understanding across the region and the UK are key. There will be a systematic identification and synthesis of global evidence on innovation and technologies to address challenges in the access and delivery of EoL care in rural and coastal communities. We will understand the UK-wide and SW Peninsula-specific inequalities, challenges and identify innovative solutions to these challenges. WP2 will closely link to WP1 and WP4 in the development of developing programme theory.

4.3. Work Package 3 Use of Routinely collected data for EoL care.

4.3.1 Overview

This WP will support the understanding in variations in EoL care, particularly geographical, using routinely collected data; to explore what is available and how it can be better used through two separate but linked components.

1. This will use data from England as a whole, using modelling that predicts small area variations in place-of-death. The aim is to understand the specific contribution of individual, organisational and geographical factors on place-of-death outcomes. The national data will be used to place patterns in SW England in context, allowing for an exploration of similarities and differences relative to the rest of the country.

2. This focuses on routinely collected data available within the SW Peninsula. It will focus on how Population Health Data is collated by ICBs from data provided by a wide range of primary, secondary and social care organisations; and include exploration of the use of data on EoL across ICBs with ongoing communication and knowledge exchange.

4.3.2 A multilevel analysis of national data

Data and Sources The ONS-HES linked dataset for 2022 and 2023 (2 years) will be linked to HES APC, OP & A&E data for same year plus previous year. All data will be accessed via NHS England's Data Access Request Service (DARS). Substantive analysis of national HES data will therefore start by July 2026, with findings available to the wider research team by October 2026. Analysis thereafter will address specific issues arising from WP1 and 2 and the WP3 sub-regional analysis.

The combined dataset will include ~98% of the 1,084,387 deaths registered in 2022/23 and will allow place-of-death to be modelled with reference to age, sex, and each individual's underlying cause of death, alongside HES-derived metrics summarising their previous use of Inpatient, Outpatient or A&E services and place(s) of residence (at Lower Super Output Area (LSOA) level) in the year prior to death. [There are 33,755 LSOAs in England each comprising 400-1200 households and 1000-3000 people; https://tinyurl.com/2wucnpen]. SNOMED codes are available for the Emergency Care Data Set (ECDS), some ECDS SNOMED codes such as accommodation status will be used. SNOMED codes are not yet available for other HES datasets, however when available more detailed SNOMED codes will be utilised.

Access to LSOA of residence will allow us to (a) establish whether individuals lived in coastal and/or rural localities, (b) determine the socio-economic characteristics of the specific neighbourhoods in which they lived, (c) calculate distances from where they lived to, for instance, the nearest hospital, hospice, and GP, and (d) incorporate data on local staffing levels (e.g. via Skills for Care workforce estimates (https://tinyurl.com/57vdyv94) or the ADR Nursing and Midwifery Council Register linked to Census 2021 dataset (https://tinyurl.com/yeyvhy3e).

Methods: Multilevel (ML) modelling will be used to determine the relative contribution of individual (e.g. age, sex, ethnicity, cause of death and co-morbidities resulting in hospital visits) and locality factors (as listed above) once the organisational context (e.g. ICB) has been 'controlled for' as a 'random effect' in the model.

Using a ML approach with respect to the 1.1 million deaths registered during 2022-23 provides a rich basis upon which to quantify and explain variation. Our granular focus is essential for understanding how place-of-death outcomes vary according to who you are and where you live.

We will be given access to pseudo anonymised ONS data on all adult deaths during 2022 and 2023 (2 years) – including details on cause and place of death – linked to NHS Hospital Episode Statistics (HES) Admitted Patient Care (APC), Outpatient (OP) & Emergency Care (EC) data. NHS England's Data Access Request Service (DARS) will be used to negotiate access to this data for the purposes of this specific project.

Data access and management Following a well-established and rigorous DARS application process we will negotiate access to selected ONS/HES variables within the NHS Secure Data Environment (SDE). We will work with the DARS team to ensure our request has a sound legal basis (GDPR Article 6(1)(e) - Public task) and that all NHS data governance requirements are fully met. The ONS-HES data linkage and data extract will be undertaken on our behalf and made available to us in a project-specific virtual space in the NHS Secure Data Environment (SDE).

Individual-level data cannot be extracted from the NHS Secure Data Environment, and any summary tables or other outputs are assessed to ensure they are non-disclosive before they can be exported from the SDE. In practice, as the research objective is to use multilevel modelling to quantify the relative impact of diverse factors on place-of-death outcomes, most findings will be expressed, for the research team as well as in any subsequent publications, in terms of model parameters. The only exception to this will be as we seek to describe variations in place-of-death at small-area level (e.g. LSOAs). Here, if necessary, we will use deciles (of n=33,755 LSOAs) or similar statistics to summarise LSOA-level rates in a non-disclosive manner.

Alex GIbson (ONS Accredited Researcher 37799) University of Plymouth Senior Research Fellow is the only person who will have access to the individual-level data within the NHS SDE and individual level data will not be shared, including with others in the wider research team. Access will be via a dedicated University of Plymouth managed PC located in a secure, sole-use office (Rm 2, 6 Kirkby Place). Paper-based notes of data on the NHS SDE will not be taken, and mobile devices, including phones, will not be used to copy or view either the original ONS/HES data or summary extracts extracted from the NHS SDE.

No personal or sensitive data will (or can) be extracted from the NHS SDE. Non-disclosive LSOA level summary data and model outputs derived from the ONS/HES data will be extracted and may be made publicly available (e.g. in publications, on a project website, dedicated GitHub site and/or the NIHR's own Open Data site – see below). Metadata will be included to detail the analytical steps taken to derive the data (including R scripts etc) although, given the secure nature of underlying data source, we will not be able to provide a full RAP (Reproducible Analytical Pipeline). Links to NHS HES/ONS metadata on the variables used will be provided.

Ethics Data collected by NHS England is done so under a rigorous ethical and legal framework (https://www.gov.uk/government/publications/nhs-englands-protection-of-patient-data/nhs-englands-protection-of-patient-data) and the DARS application process is designed to ensure that any secondary use of NHS data for research purposes fulfils the conditions under which the data have been collected. We will apply to University of Plymouth Ethics committee demonstrating adherence to the University of Plymouth's Research Ethics & Integrity Policy (https://www.plymouth.ac.uk/research/governance/research-ethics-policy)

4.3.3 Routinely collected data in Devon, Cornwall and Somerset

Data and Sources will include data held in primary care, secondary care, social care and public health settings. As this work is exploratory and noting the variations in data collection between areas, this will first establish available data sources and what can be compared across the Southwest Peninsula. We will work with SWP Consultants in Public Health, End of Life Care Leads, Business Intelligence partners and provider organisations including care homes and hospices concerned with managing or using EoL data to establish precisely which metrics drawn from which routinely collected data would be valuable for monitoring and improving the provision of EoL care. The framework of the SW SDE and the Hub work will support the development of a Peninsula-wide 'EoL Care Dataset' which captures key characteristics of individuals on EoL pathways. We have developed positive, collaborative relationships across the SW Peninsula with key decision makers and data managers across the systems. We expect these collaborative relationships and ongoing knowledge exchange to deepen across the study, which will be very valuable. We will also explore the value of other routine data such as the Vital Signs project, new medical examiner information that is intended to provide independent scrutiny of deaths as they emerge https://www.england.nhs.uk/patient-safety/patient-safety-insight/national-medical-examiner-system/

Population health management principles will be used to explore variation and inequalities in EoL pathways and outcomes based on geography, protected and personal characteristics (such as ethnicity, age sex and disability), socio-economic characteristics and clinical factors, using segmentation, age standardisation and regression techniques to determine patterns of variation. Specific data items will be defined through the project but will reference the Personalised End of Life Care (PEoLC) Information Standard (https://theprsb.org/palliativeandendoflifecare/), and are likely to include preferred place of death, actual place of death, presence of advance care plan, completion of terminal illness medical report, gold standards framework prognostic indicators, and palliative care support. Over the course of the study, we will explore access to routine data transferred from Hospices to Hospice UK and the implementation of the routine data set for care homes DACHA https://dachastudy.com/

Methods: The Southwest Secure Data Environment (SWSDE) will provide the environment for secure access and analysis of data across the three ICBs. No individual data, nor potentially disclosive findings, will leave this secure environment. This is one of the Sub National SDEs in England https://arc-w.nihr.ac.uk/research/projects/developing-the-south-west-secure-data-environment-sde/. SWSDE has CAG approval for a dynamic research dataset, and a documented process for adhering to commitments under this CAG and REC, though a local access approach. The SWSDE has HRA and CAG approval

This project will link together multiple datasets at scale and create collaborative working across multiple care disciplines. The SWSDE will provide data access and sharing agreements, data analysts for extraction, information governance, storage and compute for data within the platform. University of Plymouth Researchers in WP3 will be given access to de-identified data within a virtual desktop environment.

Data management

SWSDE is hosted within an Azure Cloud tenant, protected by multiple layers of security (including in the architecture design, access process, employment checks and ongoing threat monitoring). The security and output controls are consistent with mandatory standards under the SATRE framework, applying five safes principles. The SWSDE will provide the storage and back up for the linked data set. No individual data, nor potentially disclosive findings, will leave this secure environment. SWSDE will store data within a secure cloud environment, hosted by BNSSG ICB. Access and security will be managed by the SW SDE

Ethics The SWSDE has their own well-managed plan to secure data and protect patient data from any activity breaching the GDPR and Data Protection Act 2018. The SWSDE has HRA and CAG approvals in place. We will apply to University of Plymouth Ethics committee demonstrating adherence to the University of Plymouth's Research Ethics & Integrity Policy (https://www.plymouth.ac.uk/research/governance/research-ethics-policy)

4.3.4 Outputs

Analysis of national data, will alongside WP2, support the generalisability and transferability of the study. SW Peninsula routinely collected data will be used alongside WP1 and WP4 to support the development of context mechanism and outcome configurations and programme theory of what is working and not working in the care of people at the end of life. Exploratory work on how data is collected and how to better use routine data will also contribute to local impact and decision making and to a wider evidence base. This WP with the SWSDE will support the development of a routine data set for EoL across the SW Peninsula

4.4. Work Package 4 Stakeholder workshops

4.4.1 Overview

Using the development and refinement of programme theory this WP will work collaboratively with stakeholders to bring together and weigh-up the complexity of findings from WPs 1-3; to understand

the implications of findings for the care of people at the end of their lives in rural and coastal communities and to develop actionable insights to support the delivery of care and policy.

In a series of workshops, we shall use the principles of experience-based co-design (Locock et al., 2014) defined in the International Association for Public Participation's spectrum (International Association for Public Participation Australasia, 2015) as a collaborative approach that goes beyond involvement and as far as empowerment (where final decision-making is made by the public), to synthesise the findings from WP1-3. A realist approach will structure the development and refinement of programme theory so that actionable insights can be identified. Geographical and population inequality case study findings, and stakeholder interviews will be linked to quantitative data to test the initial programme theories of what good care or poor care looks like, which then, with wider stakeholder groups will be refined and further developed. Monthly data meetings with the researchers and leads of WP1-3 will commence three months into data collection, to iteratively identify patterns, test and retest CMO configurations and develop programme theories. From months 6-23, PPIE and professional stakeholder groups will meet online quarterly (a total of six times). Separate groups will be initially convened for PPIE and professional stakeholders to encourage group cohesion and enable participants to develop an understanding of the process and their confidence in contributing to it. The research team have built strong local relationships with patients, families professionals and key organisations developing collaboration and engagement.

4.4.2 Methods of data collection

Workshops

A series of six participatory realist workshops will be undertaken to support the refinement of programme theory across WPs 1–4. These workshops will enable stakeholders to confirm, refute, or expand emerging explanatory statements by exploring how different contexts and mechanisms produce outcomes in the delivery of EoL care in rural and coastal communities. This iterative process will be grounded in a realist logic of analysis (Pawson & Tilley, 1997), using 'if… then… because…' formulations to articulate how and why care outcomes are produced (Manzano, 2016; Pearson et al., 2015). Workshops will draw on experience-based co-design (EBCD) principles to frame conversations around 'catalyst materials' (e.g., anonymised excerpts from interviews, case scenarios, or video/audio clips), as well as formalised findings from WPs 1–3. These materials will be used to stimulate collective sense-making about the pathways, experiences, and inequalities within EoLC provision.

Workshops will be co-designed and co-facilitated by two experienced researchers (including at least one with prior expertise in participatory and realist methodologies), with support from a wider project team and PPIE contributors. The format will be semi-structured, conversational, and reflexive, enabling open dialogue and the surfacing of tacit knowledge and diverse perspectives (Donetto et al., 2015; Jagosh et al., 2012). The workshops will consist of small groups of 10-12 participants from different experiential backgrounds i.e. patient/family member or health and care professional (care home manager, VCSE worker, volunteer, community group lead; professionals across primary,

community, acute, social care and specialist PEoLC (including nurse, GP, Medical Consultant, allied health professional, social care worker, manager, commissioner). Co-applicants will also be invited to participate in the workshops with professionals and the mixed workshops with professionals and patients and family.

Participants will be prepared for the workshops using written materials and 1:1 or small group briefings (via phone, video call, or email) to build understanding of the project goals, the rationale for co-production, and the realist approach. This preparatory work will help ensure that all participants are empowered to contribute fully, regardless of background or professional expertise (Locock et al., 2014). Patient and Family will also have the opportunity to meet with the researcher after the workshop to debrief.

Inclusion criteria:

- Individuals aged 18 or over with lived experience of EoL in a rural or coastal community in the SW Peninsula (as a patient, carer, family member, or bereaved person). Family members who are recently bereaved to be at least 10 weeks since bereavement.
- Professionals working in EoL care across health, social care, voluntary, community, or policy sectors in rural and coastal areas.
- Stakeholders involved in the planning, commissioning, delivery, or support of EoL care (e.g. managers, commissioners, community leads, researchers, policymakers).
- Inclusion criteria for all:
- Willingness and ability to contribute to collaborative workshops aimed at improving EoL care through participatory and co-design approaches.
- Able to give informed consent and communicate in English (translation support will be offered where appropriate).

4.4.3 Recruitment to workshops

Purposive sampling will be used to recruit a diverse group of stakeholders with varying perspectives and experiences. Participants will primarily be recruited through:

- Networks already engaged in the study through WPs 1–3.
- Collaborating organisations including hospices, community groups, VCSE organisations, local health and social care providers, and ICBs.
- Participants will be invited via direct contact (email or phone), newsletter distribution through partner organisations, and targeted outreach using existing stakeholder networks.

- Participant Information Sheets will be provided in advance outlining the purpose and process of the workshops.
- Follow-up conversations via phone, video, or email will be offered to answer questions and support the informed consent process.
- Participation is voluntary. If participants withdraw from the workshops, others will be recruited.
- Reasonable adjustments will be offered to maximise accessibility (e.g. travel cost reimbursement, virtual attendance options, translation or facilitation support, alternative formats).

Workshop Series Structure

Workshop 1 (Month 6, in-person, 2 hrs, separate PPIE and professional groups)

- Introductions, aims, ways of working, and ground rules
- Overview of the project, realist methodology, and EBCD approach
- Mapping initial themes and challenges emerging from WPs 1–3
- Formation of small working groups and discussion of ongoing involvement
- Agreement on communications and feedback channels

Workshop 2 (Month 9, online, 2 hrs, separate PPIE and professional groups)

- Feedback from working groups
- Introduction to draft 'if… then… because…' analytic statements
- Small-group discussions to refine theory using participants lived/professional insight
- Agreement on shared priorities and agenda-setting for Workshop 3

Workshops 3–5 (Months 12, 15, and 18: mixed groups)

- Workshop 3 (online, 2 hrs) and Workshop 5 (online, 2 hrs): focus on refinement of theory
- Workshop 4 (in-person, 5 hrs, including all co-investigators): focused collaborative co-production of actionable insights and policy/practice implications
- Continued use of small-group dialogues followed by plenary synthesis
- Iterative refinement of realist statements based on participant feedback and study data

Workshop 6 (Month 21, online, 2 hrs)

- Final workshop to agree upon and finalise a set of actionable insight statements, which will inform guidance, resources, and dissemination strategies

The workshops will be recorded (with consent), and detailed notes will be taken to support analysis and transparency. Accessibility needs (e.g., alternative formats, interpretation) will be accommodated to ensure full participation.

4.4.3 Ethics

This part of study will obtain approval from the University of Plymouth (UoP) Faculty Research Ethics and Integrity Committee and will undergo NHS REC and HRA review alongside Work package 4 (IRAS 355730). All procedures will comply with the UK Policy Framework for Health and Social Care Research, the Data Protection Act 2018 and UK GDPR. Ethical issues are outlined in more detail in the ethics section below.

4.4.4 Data analysis

Data from the stakeholder workshops will be analysed using a realist-informed framework approach (Pawson & Tilley, 1997), integrating both inductive and deductive elements. The core aim will be to refine and test emerging programme theories about what supports or hinders effective EoL care in rural and coastal communities. Analysis will focus on identifying and developing explanatory CMO configurations. These configurations will be derived from participant discussions and group feedback across workshops, especially as they relate to the 'if…then…because' statements developed collaboratively.

The workshop data will consist of anonymised notes, audio transcripts, and any written contributions shared by participants. Transcripts and notes will be coded using a structured framework based on realist principles (Wong et al., 2016), allowing for comparison across different groups (e.g. PPIE vs professionals) and settings. Emerging patterns will be discussed in iterative data meetings involving WP leads and PPIE partners. Where appropriate, we will triangulate findings with data from WPs 1–3 to confirm, refute, or refine programme theories.

The analysis will remain sensitive to power dynamics, differing stakeholder perspectives, and experiential knowledge. Insights will be returned to participants between workshops to check interpretation and allow for further refinement, supporting the co-design of the final actionable insights.

4.4.5 Outputs

The output from this WP will be a programme theory of care at the EoL across the rural and coastal communities in the SW Peninsula- modelling what works and what does not work. We will develop evidence-based, action-oriented statements that can inform the equitable design and delivery of the

care of people at the end of life in rural and coastal communities in both the SW Peninsula and nationally. The findings of WP4 will be taken to the Policy Lab

4.4.6 Policy Lab

The aim of the policy lab component of WP4 is to translate the actionable insights and programme theory from the study into actionable policy to support change at both ICB level and nationally. The Policy Institute KCL will lead a policy lab towards the end of the study and will build on the engagement and participation of stakeholders throughout. The Policy Institute has a track record of supporting this process and will bring the skills, methods, and an outside perspective to support the translation of the study's findings to inform policy options that can help improve outcomes for people at the EoL.

Methods: The policy lab will take place in month 27 following engagement between the KCL team and WP4 leads and key stakeholders. The KCL team will identify further partnerships required to move the programme theory into policy and practice change. A policy lab event will include SW ICBS leads, PPIE, national and policy leads, key charities Marie Curie/ Hospice UK, Kings Fund, DHSC. It will take place over one day. The lab will include an Expert NHS change facilitator and together with the KCL Lab facilitators will engage with the findings and co-develop new ideas and approaches to inform policy. With the research team and stakeholders, the Policy Lab will then create communication mechanisms and policy briefings in a way that policymakers can engage.

Outputs: *W*ill be for both ICB level and National policy change- rural and coastal communities and PEoLC. Policy briefings and policy pamphlet documents will be produced (pamphlets are short documents designed to stimulate focusing on the most salient issues and those more relevant to policymakers). Working with the policy context at the time a pathway for policy implementation will be developed.

5. Patient and Public Involvement and Engagement (PPIE)

Patients, service users, and carers will be involved in the study as research participants in WP1 and 4, as co applicants and members of Project Advisory Group. There are two PPIE co-applicants in this study, both have helped shaped the design of the study, particularly PPIE involvement. A PPIE group have met to review this proposal, the language used in our Plain English summary (PES) and to review all participant facing materials.

The study takes a participatory approach that is centred around the active and meaningful involvement of patients, families, and the public throughout its various phases including the shaping of research findings and informing policy and practice recommendations. Central to this approach is the Patient and Public Involvement and Engagement (PPIE) stakeholder group, which will include twelve patients and families and meet six times over the course of the study. The two PPIE co-applicants will attend the stake holder group, they will also attend the monthly co applicant meeting which will be online. There is an awareness that people living at the end of life may not be able or want to attend/ commit to a long-term study as PPIE stakeholder members. We have therefore

costed in 10 individual PPIE sessions in the patient's home or online to offer flexible ways for people to be involved and take account of individual needs and preferences.

The Project Advisory Group (which will meet five times) will include at least two PPIE members. All of the PPIE members involved in the project advisory group, the stakeholder group and co applicants' group will be offered training on methods and ethics. PPIE members will be offered support through briefings, tailored information materials, as well as support during meetings or workshops where needed. We will use INVOLVE rates to recognise people's time, including preparation time for each meeting and be mindful of individual circumstances, paying people with vouchers if more appropriate. Debriefing processes will be in place for PPIE members throughout the study, after each workshop, interview or PPIE event ensuring that all parties have access to appropriate support mechanisms. We will also provide access to someone independent from the project that people can discuss any aspect of their involvement they are uncomfortable or unhappy with.

PPIE members have been costed to be involved in a local dissemination event and four PPIE stakeholders are costed to be part of the Policy Lab in London including travel and overnight stay. All PPIE activity will be supported by the PPIE Lead GK. SP and KW will support GK in this. KW has considerable experience in partnering with under-served populations (such as people living in poverty) and in sensitive issues such as mental distress, end of life care. GK supported patient and stakeholder engagement for this proposal and previous EoL care research; SP is a highly experienced EoI researcher particularly involving patients (and a nurse) will lead individual PPIE sessions with patients.

Patients and carers are an important part of the wider PPIE stakeholder groups (see WP4). However, it is important to emphasise here the centrality of the PPIE stakeholder group being inclusive and diverse and it will support the development of appropriate recruitment strategies and information

6. Ethical considerations

6.1 Informed consent

Informed consent will be obtained from all participants prior to their involvement in the study. The process will follow the principles of Good Clinical Practice (GCP), the UK Policy Framework for Health and Social Care Research (HRA, 2017), and the General Data Protection Regulation (GDPR, 2018).

Consent procedures will be tailored to the type of study activity:

- **Interviews, focus groups and workshops:** The study should be discussed by one of the research team with the participant in detail and the participant provided with a copy of the Participant Information Sheet (PIS) to take away with them to consider further. The PIS outlines the purpose of the study, what participation involves, how their data will be used, and their right to withdraw at any time without consequence. Participants will be given sufficient time to consider the study, allowing time for discussion with other family/friends,

and for the participant to ask questions of the research team prior to written consent being given. Interviews/focus groups/workshops will only commence once consent has been confirmed.

- **Observations:** A member of the research team will present the study to relevant teams, provide a study summary sheet and informational posters to be displayed, then get verbal agreement from teams. At the start of each observation, the researcher will ensure verbal consent from all who are present. In all settings, the researchers will make their role and purpose transparent and will leave any environment when it is not appropriate to be there.
- **Surveys:** Before beginning the survey, participants will be presented with a consent form embedded within JISC. They will be required to confirm their agreement to proceed before accessing the survey questions.
- **Workshops:** For participatory workshops, participants will be provided with an information sheet in advance and asked to complete an electronic consent form. All consent materials have been designed to be clear, accessible, and proportionate to the level of involvement. Participants will be informed about the measures taken to protect confidentiality and data security, including anonymisation of transcripts and secure storage of research data. They will also be reminded that their participation is voluntary, that they may withdraw from the study at any time up until data analysis has commenced, and that withdrawal will not affect them in any way. Consent to continue participation will be checked before each workshop.

6.2 Anonymity

Anonymity will be maintained throughout the study and across all data collection methods, including interviews, focus groups, observations, and workshops. All participants will be assigned pseudonyms or ID numbers, and no personal identifiable data will be included in transcripts, fieldnotes, or reports. The following procedures will be in place to ensure participant confidentiality:

Interviews

- Interviews will be conducted in private rooms or online and digitally recorded with consent.
- Interview transcripts will be anonymised, with participants referred to using pseudonyms or ID numbers (e.g. “P07_Family” or “HCP03_Nurse”).
- A participant identification key linking names to ID numbers will be securely stored in a password-protected file, accessible only to the research team. This will be destroyed at the end of the data retention period.
- Audio recordings will be securely deleted once transcripts are verified and anonymised.
- Any quotes used in outputs will be anonymised and checked to prevent indirect identification.

Focus groups

- Focus groups will be facilitated by two researchers and either recorded online or in private spaces.
- All participants will be asked to respect each other's confidentiality, but due to the group setting, absolute anonymity cannot be guaranteed.
- Transcripts will be anonymised, with participants referred to using codes (e.g. "FG3_Participant1").
- Identifiable details shared during discussions will be removed or anonymised during transcription.
- Any quotes used in outputs will be anonymised and checked to prevent indirect identification.

Observation

- Observations will be non-participant and take place in health and social care meetings, interactions, and visits.
- No identifiable information will be recorded about patients, professionals, or settings during observations.
- Fieldnotes will consist of anonymised descriptions of interactions, behaviours, and contextual details relevant to the research.
- Informal conversations or clarifications that occur during observations will be recorded as non-verbatim anonymised fieldnotes.

Workshops

- Workshops will include participants with lived experience and professionals, recorded with consent, and used to develop programme theory.
- Transcripts and written contributions will be anonymised, using participant IDs where needed.
- Any shared materials or feedback will be anonymised prior to inclusion in analysis or reporting.
- Participants will be reminded at the start of each workshop about confidentiality, and identifiable contributions will not be shared externally without explicit consent.

6.3 Confidentiality

Confidentiality will be upheld in all aspects of the research, in line with UK GDPR and the Data Protection Act 2018, and in accordance with institutional and HRA guidelines. All participants will be

informed about the measures taken to protect their confidentiality during the consent process and in the PIS.

All identifiable information collected as part of this research will be treated as confidential and stored securely. This includes names, contact details, and any other information that could directly or indirectly identify an individual. Identifiable data will be held separately from research data (e.g. transcripts) and will only be accessible to authorised members of the research team. Any physical data will be kept in a locked cabinet at the researcher's workplace only accessible by the researcher in the very short-term until they can be scanned and uploaded onto the researcher's UoP password protected OneDrive account. At this point, any physical data will be destroyed.

Personal identifiers will be removed from transcripts and fieldnotes, and unique participant IDs will be used. Care will be taken during analysis and reporting to ensure individuals are not identifiable, particularly when quoting participants or describing specific professional roles or locations. In group settings such as focus groups and workshops, participants will be reminded of the importance of respecting each other's confidentiality. While the research team will anonymise all data collected, it will be explained that confidentiality cannot be absolutely guaranteed in group settings due to the presence of others.

Data will be stored on encrypted, password-protected university OneDrive and SharePoint accounts, in line with the study's Data Management Plan. Identifiable data (such as consent forms or contact details) will be retained securely for the duration of the study and then securely destroyed.

6.4 Sensitivity

This study involves engaging with people who may be experiencing emotionally challenging circumstances, including individuals living near the end of life, those who are caring for them, and people who have been recently bereaved. We recognise the potential emotional sensitivity of the subject matter and have designed the study with great care to minimise distress and ensure that participants feel respected, supported, and in control at all times.

All members of the research team conducting interviews, focus groups, observations, and workshops will have prior experience of sensitive qualitative research and will receive additional training in conducting research related to palliative and EoL care. This will include guidance on active listening, recognising distress, and responding with empathy and professionalism.

Participation will always be voluntary, and individuals will be clearly informed that they can pause or stop their participation at any time without needing to give a reason and without any impact on the care or services they receive. At the beginning of interviews or group discussions, researchers will check in with participants about their comfort and readiness to proceed. During the course of interviews or workshops, researchers will remain attentive to signs of emotional discomfort. If a participant becomes distressed, researchers will offer to take a break or end the session and provide information about relevant support services, such as bereavement charities or hospice support. Researchers will follow-up participants the next day with a phone call or email to check-in on them. Researchers will follow a distress protocol.

The interview topic guides have been designed to be flexible, conversational, and participant-led, allowing individuals to reflect on what they feel comfortable sharing. Researchers will avoid intrusive questioning and allow participants space and time to respond, with sensitivity to each person's context and communication needs. When engaging with bereaved participants, we will ensure that sufficient time has passed since the death of their loved one (typically a minimum of 6 weeks for interviews and 10 weeks for workshops) and that the invitation to participate is extended through appropriate channels (e.g. trusted hospice or community care contacts). For those at the end of life or caring for someone who is, contact will be made sensitively and through clinicians or organisations already supporting them. `

Our aim is to ensure that participation in the research feels meaningful and supportive, and not burdensome. Researchers will also have access to debriefing and supervision throughout the project to reflect on their own emotional wellbeing when conducting this sensitive work.

6.5 Risks to the researcher

This study involves engagement with participants in emotionally sensitive contexts, including individuals at the end of life and bereaved family members, as well as observations of EoL care settings. As such, the emotional and psychological wellbeing of the research team is a key consideration.

Researchers may encounter distressing accounts or witness emotional situations during interviews, focus groups, observations, and workshops. To mitigate risks:

- **Training and preparation**: All researchers will be trained in conducting research in sensitive settings and will receive guidance on emotional boundaries, managing distressing conversations, and responding appropriately to participants' emotions.
- **Pairing and support**: For focus groups and workshops, two researchers will be present to share facilitation responsibilities and provide mutual support. This approach also helps manage unexpected situations more effectively.
- **Debriefing and supervision**: Researchers will have access to clinical supervision, regular debriefing sessions with the study lead or a designated senior team member to reflect on their experiences. Additional ad-hoc support will be made available following particularly challenging encounters. There is also a distress protocol for researchers.
- **Clear exit protocols**: If a situation becomes emotionally overwhelming for a researcher, they will be encouraged to step away and seek support without any stigma. Similarly, researchers observing in care settings will be briefed on how to manage their own emotional responses and will not be required to continue if they feel unable to do so.
- **Lone working protocols**: For home visits or any fieldwork conducted alone, researchers will follow the UoP Lone Working Policy.

- **Health and safety**: All fieldwork will be covered by a risk assessment which will be reviewed regularly. Researchers will have access to university or host organisation support services if needed.

By embedding these safeguards into the study design, we aim to protect the wellbeing of the research team throughout the project.

7. Research management

7.1 Organisation

The study will be managed by a core research team based at the University of Plymouth, together with the study's co applicant team. The teams will work in collaboration with national and regional partners across health, social care, and voluntary sectors. The University of Plymouth is the research sponsor and will oversee all governance and compliance arrangements in line with HRA and University requirements.

The Chief Investigator (CI) will have overall responsibility for the day-to-day delivery of the study, ensuring adherence to the research protocol, timelines, and ethical standards. The CI will be supported by co-investigators, research associates, and administrative staff, with defined responsibilities for specific work packages and deliverables. The research team will hold regular meetings to co-ordinate progress, manage risks, and review emerging findings.

A Project Advisory Group, including PPIE representatives, clinical stakeholders, and academic advisors, will meet every six months to provide oversight, guidance, and critical reflection on the research process. The PAG will have 75 % independence. This group will ensure that the project remains grounded in the needs and priorities of service users and system leaders, that it meets it aims and objectives, reporting timelines and that findings are interpreted in a way that supports relevance and impact.

A formal risk register and data management plan will be maintained throughout the study. Ethical, contractual, and data protection requirements will be managed in line with GDPR and institutional policies. All researchers will complete necessary training in information governance, consent, safeguarding, and good research practice. Study progress will be reported through regular updates to funders and ethics committees as required, including submission of amendments, annual progress reports, and a final report.

The CI has responsibility for the study. Day-to-day running of the study will be overseen by the Project Manager; the CI is responsible for ensuring that data acquisition is completed. The CI holds responsibility for ensuring study processes are adhered to. Work package leads ensure eligibility at the outset of the work package, however data collection and written consent (where relevant) will be undertaken by Research fellows employed by the University of Plymouth

The audio recordings will be transcribed by an external transcription service approved by the University and working within confidentiality and Governance agreements. All data will be stored on university secure shared servers and anonymised. All data will be coded and no identifiable reference to the participants will be held with the data. Coded data held electronically will be stored on password protected UoP computers. Data will be stored for 10 years, in accordance with the Data Protection Policy and GDPR. Oversight of the intellectual property issues are the responsibility of the CI.

7.2 Timelines

Start date anticipated as October 1st, 2025 (see GANTT) Participant completion is defined as end of survey/observation/interviews/focus groups/workshops. Study completion is defined as the recruitment of sufficient numbers for survey/interviews/focus groups/workshops (and completion of these) and completion of the realist evaluation.

7.3 Protocol compliance

All researchers taking part in the study will be required to attend a start-up meeting to ensure compliance with the proposal and to provide training on study procedures and data collection methods. The CI will monitor the compliance of researchers in the team on an ongoing basis. Where non-compliance with the protocol is suspected, the CI will liaise with the research team and resolve the matter according to Good Clinical Practice (GCP) principles and the 2017 Policy Framework for Health and Social Care Research (particularly relevant for health service research such as this). This protocol is a combination of individual protocols for the work packages and any amendments will be submitted to the properly constituted independent Research Ethics Committees (REC), in agreement with local legal and sponsor requirements, for formal approval of the study conduct. The REC approval decision will be provided to the sponsor before commencement of this study.

7.4 Data protection and patient confidentiality

All procedures will be conducted in accordance with the General Data Protection Regulation (GDPR) and the Data Protection Act (2018). The Chief Investigator is the Data Custodian and is responsible for the safe and secure storage of all data.

Participants will provide their consent for the use of their personal data to be used in this study by completing the consent forms provided. Each participant will be given a Unique Participation Number (UPN) once they have consented to participate in the study. Identifiable information (e.g. consent forms, contact details, ID keys) will be stored separately from research data in encrypted, password-protected university OneDrive/SharePoint locations with access restricted to authorised team members. Audio files will be deleted once transcripts are checked and anonymised. Transcripts, fieldnotes and focus group data will be anonymised; potentially identifying details (e.g. unique roles, specific locations) will be generalised to reduce risk of indirect identification, which is a particular consideration in small rural/coastal communities. Any physical data will be destroyed once it has been uploaded to the electronic databases. No personal data will be used in the final report,

conference presentations or publications arising from the study. Data will be retained for 10 years in line with institutional policy and then securely deleted.

7.5 Project finance, indemnity and insurance and reporting

Funding costs for this study have been provided by the NIHR and it will be submitted for adoption onto the NIHR portfolio. The University of Plymouth has indemnity insurance in place for research activities through Zurich Municipal. This insurance covers harm to participants arising from the design or conduct of the research, including activities carried out by university-employed researchers and collaborators acting under university oversight. This cover applies to both negligent and non-negligent harm where the University is the sponsor or where the research is conducted under the University's auspices. It includes protection for participants involved in interviews, workshops, and all other elements of the study. The indemnity arrangements comply with standard requirements for research involving NHS and non-NHS participants. A final report will be submitted to the NIHR, HRA (REC) and sponsor.

7.6 Regulatory principles

The team will conduct the study according to GCP guidelines and UoP research policy. Participants have the right to withdraw from the study at any time for any reason. This study will be carried out in accordance with the World Medical Association Declaration of Helsinki (1964) and all subsequent amendments. Study data will belong to the University of Plymouth (as per collaboration/NIHR agreements) and the CI is the custodian of the data.

7.7 Project timetable

A detailed monthly GANTT chart is provided in Appendix 1 providing clear timelines for each WP across the 28-month project.

8. Outputs and publication policy

This study will develop an overarching programme theory of EoL in rural and coastal communities and across we will provide actionable insights for ICBs locally and nationally developing impact at a system level. The study will develop methods and understanding of the use of routine level collected data. The study will direct routes into practice, the planning of resources across systems, and routes into national and UK wide policy.

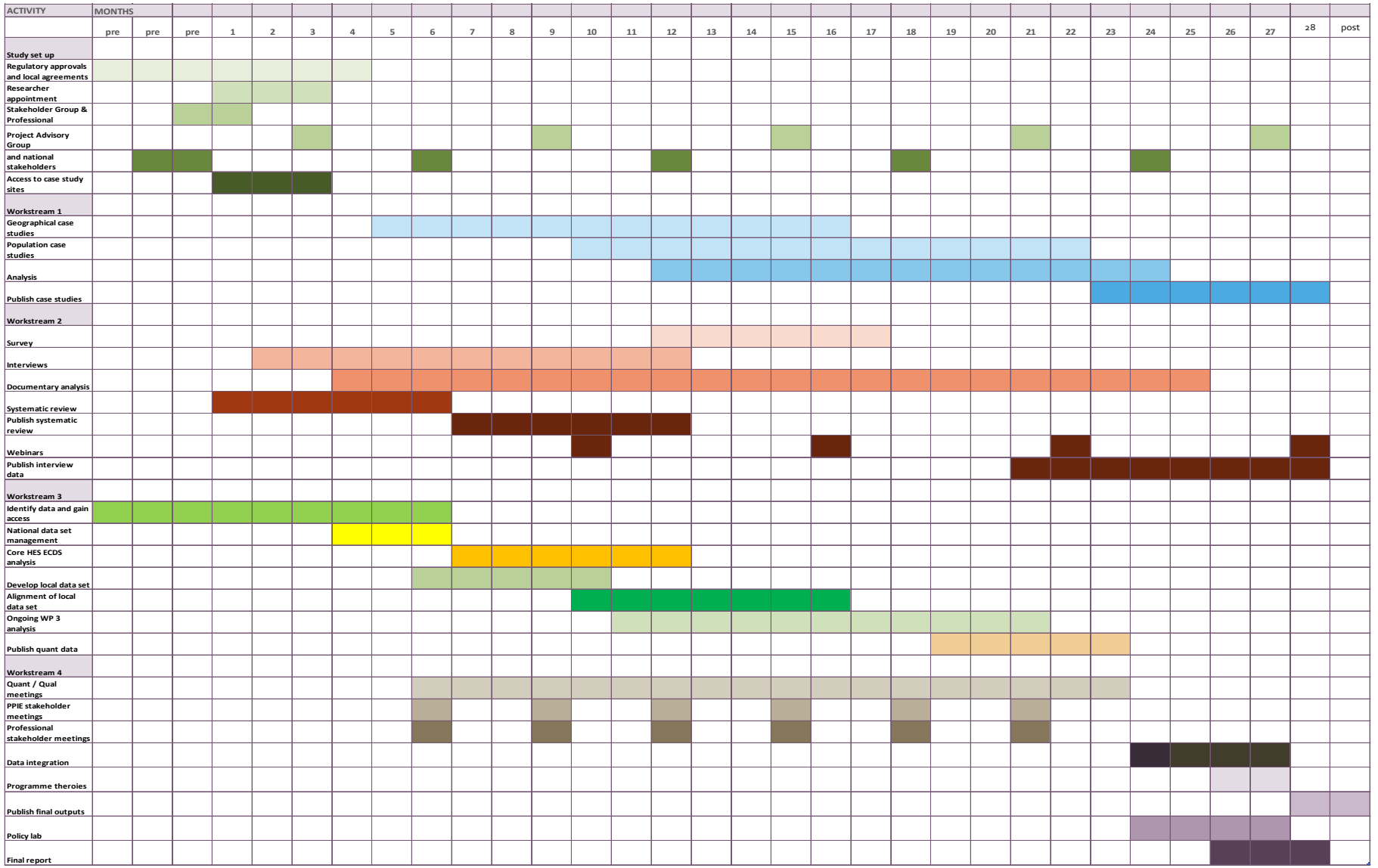
Routes for dissemination (outputs) will include:

- Online dissemination at meetings at ICB, SW Peninsula, NHSE SW and national level EoL Networks in Wales, Scotland and Northern Ireland and through the NIHR Health Determinants Research Collaboratives. We will engage locally and nationally by regularly attending key meetings and events. We will also offer to go to regional meetings and specific ICBs to share the findings and help them think through service changes based on the results. We will develop dashboards of ongoing insights from the study for use by the

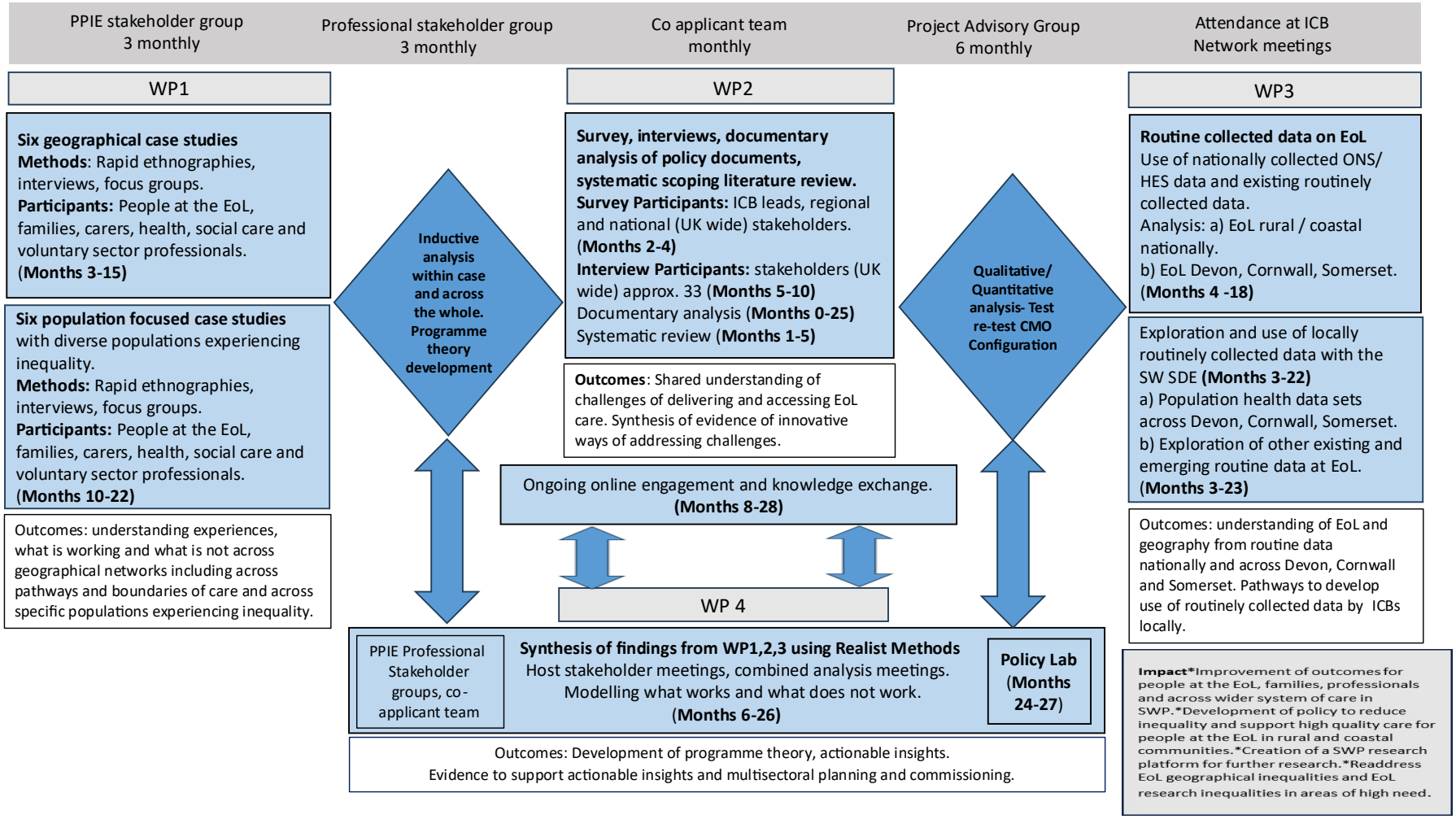
ICBs. Ongoing dissemination will enable National policy leads and practitioners to input to the research, gain timely feedback and support further dissemination.

- WP1 and WP3 will have direct impact and resonance to local decision-making and support the use of the patient's voice, carer and professional experience, understanding of the context and mechanisms in EoL care and the use of routinely collected data for planning care for improving outcomes in care.
- We have a Policy Lab supported by the Policy Institute at King's College London to support wider impact into policy. This will include charities, national leads, DHSC and provide a report and policy briefings.
- We plan to have three national webinars during the course of the study, the third at the end of the study will support National policy drivers. There will be other webinars and online dissemination for local stakeholders and audiences. Participants from the four nations will be invited to the national webinars and to the online stakeholder events. We have costed for a small number to attend the final face to face stakeholder event in Plymouth and the Policy Lab in London.
- Accessible public information and ongoing lay summaries about the progress and findings of the research will be disseminated via networks and the project website. We will provide summaries of results to individual participants asking for this at consent.
- Peer-reviewed open access journal articles will be submitted to world-leading journals (e.g. Palliative Medicine, BMJ Supportive and Palliative Care, HSJ), Papers will be submitted on the systematic and narrative review, survey and stakeholder interviews (WP2), geographical case studies (WP1), population case studies (WP2)— use of routinely collected data for PEoLC (WP3) whole study Realist paper (WP4) Methods papers will also be written.
- Presentations will take place at international conferences— including EAPC x 2 and - Marie Curie Palliative Care Conference (UK) Hospice UK
- A final report will be submitted to NIHR HSDR
- The research team will use an impact tool PURE – Research Information Management system to track conversations, meetings, presentations to support the articulation of impact. https://www.elsevier.com/en-gb/products/pure

Appendix 1: GANTT Chart



Appendix 2: Study Figure



Appendix 3: Protocol Amendments

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