

## DAPPLE RESEARCH PROTOCOL

### Full title of project

Developing effective service models for Adult Palliative and end of life care for People with a Learning disability (DAPPLE)

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### Ethical Approval

Ethical approval for WP3a has been obtained from Open University Human Ethics Committee (HREC) (30/08/2024, Reference 2024-0560-2).

Ethical approval for WP3b has been obtained from the Research Health Authority (HRA) via the Integrated Research Application System (IRAS; 15.05.2025, IRAS 328278).

### Version control

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V1	Irene Tuffrey-Wijne	Acronyms (incl "LD") replaced with full words WP1: Detail added (rationale and feasibility count) WP3B: Proviso added if case notes are not accessible to researchers. Outputs: co-produced patient exemplars changed from "12" to "9-12" GANTT chart removed	31/07/2024
V2	Rebecca Anderson-Kittow, Christina Roberts	Update to co-investigators list. Update with ethical approval information for WP3b. WP3b: Timeframe added for approaching families for retrospective case studies. Details of consent procedures added as recommended by HRA.	7/05/2025
V3	Christina Roberts	Consent procedures clarified to explain the role of advisors and how they are identified.	04/09/2025

## Glossary of abbreviations

CPRD	Clinical Practice Research Datalink
CQC	Care Quality Commission
DAPPLE	Developing effective service models for adult palliative and end of life care for people with a learning disability
GP	General Practitioner
HES	Hospital episode statistics
HRA	Health Research Authority
IRAS	Integrated Research Application System
LeDeR	Learning from Lives and Deaths of People with a Learning Disability and Autistic People
MLTC	Multiple long-term conditions
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health and Care Research
NHS	National Health Service
ONS	Office for National Statistics
PEOLC	Paliative and end of life care
PPIE	Patient and Public Involvement and Engagement
PRISMA-ScR	Preferred Reporting Items for Systematic Reviews and Meta-Analysis – Scoping Reviews
SWAP	Study within a project
WP	Work Package

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## Summary of research (abstract)

### Aims

To improve quality and accessibility of Palliative and End Of Life Care (PEOLC) for people with a learning disability by producing robust guidance for health and social care services, with recommendations and accessible resources.

### Objectives

- (1) Map PEOLC trajectories of people with a learning disability, using national electronic health record data bases
- (2) Develop an understanding of existing evidence
- (3) Explore, compare, and contrast PEOLC services for people with a learning disability, with regards to (a) current models of care, commissioning practices and service coordination; (b) timely identification of PEOLC need; and (c) individualised PEOLC provision/interventions for people with a learning disability
- (4) Co-produce actionable recommendations and resources for service providers and commissioners, including interventions for timely identification of PEOLC need
- (5) Build capacity and produce guidance for future inclusive research with people with a learning disability

### Research questions

- What are the service delivery models and interventions within health and social care services that (a) enable timely identification of the palliative and end of life care (PEOLC) needs of people with a learning disability, and (b) are effective in meeting those needs?
- Within a range of service exemplars, what are the barriers and enablers to providing accessible, high quality PEOLC to people with a learning disability; and what are the replicable elements of good practice?

### Methods

This is a co-produced study, involving a diverse team (including co-researchers with a learning disability) in academic and service provision settings. There are 4 Work Packages (WP):

**WP1:** Retrospective cohort analysis of the Clinical Practice Research Datalink (includes 87,790 people with a learning disability), comparing people with and without a learning disability in order to detect inequalities: registration of PEOLC need and subsequent survival time; primary care and hospital care utilisation; palliative care referrals.

**WP2:** A rapid scoping review to inventorise what is known with regards to (a) identifying need, (b) assessing and meeting need, (c) coordination and delivery of local services and interventions (e.g. staff training).

**WP3:** Within 4 localities (Study Sites) in England: **(A)** Interviews with commissioners and senior managers in services (n=16), stakeholder conversations and local stakeholder engagement events (n=12); **(B)** Case studies of people with a learning disability currently approaching end of life (n=up to 20), using ethnographic methods; and retrospective case reviews of people with a learning disability who have died (n= up to 40), using family/carer/staff interviews and case file analysis; **(C)** Development and testing of methods for enabling systematic identification of PEOLC need, using Experience-Based Co-Design.

**WP4:** PPI activities, engagement and outputs for a wide range of audiences; work with self-advocates with a learning disability to co-produce outputs.

**Data analysis and data synthesis** will involve researchers across Study Sites and include co-researchers, using adapted Framework Analysis methodology.

### Anticipated impact and dissemination

Outputs include written actionable recommendations and policy guidance; a series of 12 practice exemplars; a logic model; materials for varied audiences (including easy-read); social media activities, website, blogs and webinars; conference presentations; OpenLearn resources for health/social care professionals and carers.

## Background and rationale

### Inequalities in access to palliative and end of life care (PEOLC)

There are around one million people with a learning disability in England (2% of the population),<sup>1</sup> many of whom have complex health and social care needs. People with a learning disability die on average 22 years earlier than the general population and are much more likely to die in hospital (62% vs 42%).<sup>2</sup> They face stark health and mortality inequalities,<sup>3,4</sup> highlighted during the Covid pandemic, with people with a learning disability dying at six times the rate of the general population.<sup>5</sup> When people with a learning disability do reach the end of life, they need to be well supported in a way that meets their needs and is in line with their wishes.

The rationale for this study builds on our systematic review of the literature on PEOLC needs of people with a learning disability (2020)<sup>6</sup> updated with recent research and developments (in particular NIHR129491<sup>7</sup> and NIHR202963<sup>8</sup>) and a consideration of current national policies regarding both PEOLC services and learning disability services. Our proposed study fits a known research need, as a range of national policy makers have recognised unacceptable inequities in PEOLC provision for people with a learning disability (e.g. National Institute for Health and Care Excellence (NICE),<sup>9</sup> Care Quality Commission (CQC),<sup>10</sup> the Ambitions Framework,<sup>11</sup> Hospice UK<sup>12</sup>).

### Identification of PEOLC need

Lack of timely identification of people who may benefit is seen as one of the greatest barriers to early palliative care.<sup>9,13</sup> However, identifying when someone with a learning disability approaches the last year of life is particularly difficult, especially given the challenges in communicating and noting signs of ill-health and frailty, and multiple co-morbidities that may go unnoticed.<sup>14,15</sup> An investigation of 222 deaths of people with a learning disability supported by UK learning disability service providers found that less than a third of these deaths were anticipated by staff.<sup>16</sup> This has a significant impact on the ability to plan for PEOLC and connect with PEOLC services in a timely manner.<sup>12,14,16</sup>

This difficulty has been further highlighted in our current study (NIHR202963) on involving people with a learning disability in PEOLC planning.<sup>8,17</sup> Our findings indicate that planning for end of life support is hindered by the lack of insight into appropriate triggers for end of life care planning among health and social care professionals and informal carers. NICE recommends using identification tools such as the Gold Standards Framework<sup>18</sup> or the Supportive and Palliative Care Indicators Tool<sup>19</sup>, but these have not been validated for people with a learning disability and may not be suitable for this population.<sup>20</sup> There have been some early attempts at developing learning disability -specific tools, but this needs further investigation.<sup>14,21</sup>

### High quality PEOLC delivery

Challenges in PEOLC for people with a learning disability include: difficulties with communication which affect all aspects of palliative care provision, including pain and symptom assessment; difficulties with patient insight into the condition, its treatment and possible outcomes; lack of involvement in end-of-life decision-making; multi-morbidity and polypharmacy; complex social circumstances involving families as well as care staff; lack of reasonable adjustments to care; transitions in care settings; lack of experience among healthcare staff of people with a learning disability; and lack of experience among learning disability staff of illness, death and dying, leading to fear and avoidance.<sup>4,15,22–25</sup> Staff providing PEOLC to people with a learning disability have significant training needs.<sup>26–28</sup>

NICE,<sup>9</sup> Care Quality Commission (CQC),<sup>10</sup> the Ambitions Framework<sup>11</sup> and Hospice UK<sup>12</sup> all note a lack of understanding among healthcare professionals about the care needs of people with a learning disability and failure to access PEOLC services, contributing to poorer and often avoidable outcomes.

In recent years, NHS England has set out its vision to improve end of life care throughout England, in the 2019 NICE guideline<sup>9</sup> and the 2021 Ambitions Framework.<sup>11</sup> These place a strong emphasis on the importance of integrating palliative care within new models of integrated health and social care, with collaboration between the NHS, voluntary sector and the social care system. NICE says that joined-up care means responding effectively to the widest range of difficulties people experience, with an awareness of the need for pro-active care. They stress that local care systems must encompass the needs of people with a learning disability, whose needs are too often considered peripheral to the response required for people living with more predictable care needs.<sup>9</sup>

## Ambitions Framework

The Ambitions Framework<sup>11</sup> is the starting point for this study.

It sets out **six areas of importance** in achieving excellence:

(A) individualised care, (B) fair access to care, (C) maximising comfort and wellbeing, (D) coordinated care, (E) preparedness of staff, and (F) preparedness of communities.

It further identifies **eight foundations** that need to be in place to achieve these ambitions:

(1) Personalised care planning, (2) Shared records, (3) Evidence and information, (4) Involving, supporting and caring for those important to the dying person, (5) Education and training, (6) 24/7 access, (7) Co-design, and (8) Leadership.

How these **six ambitions** can be achieved and how the **eight foundations** can be put in place consistently for people with a learning disability, across the wide range of living situations and settings, is not clearly understood, as our systematic review of the literature on PEOLC needs of people with a learning disability<sup>6</sup> demonstrates. Guidance and policy in this field is mostly built upon theoretical and anecdotal evidence with a very limited empirical knowledge base. In particular, the perspectives and experiences of people with a learning disability themselves are very poorly represented.<sup>29</sup>

This project, therefore, is focused on **investigating how the national guidance for PEOLC, with its emphasis on identification of need, individualised care and cross-organisational working, can be applied to people with a learning disability**. In particular, we focus on how the Ambition Framework's eight foundations can be operationalised for this population, in order to achieve the six ambitions.

We will produce rigorous and relevant evidence about how health and social care services can work together to assess and meet the needs of people with a learning disability at the end of life, in the setting most suited to meeting those needs; and to provide adequate support for them and for their families and professional caregivers. We will pay particular attention to intersectionality with other factors known to be disadvantaging in relation to accessing PEOLC, notably ethnicity,<sup>30</sup> rurality<sup>31</sup> and different levels of learning disabilities. Co-production (in particular, including of people with a learning disability themselves) is a fundamental part of this project.

## Evidence explaining why this research is needed now

### Healthcare need

The need to address healthcare inequalities is urgent. The benefits of timely and appropriate PEOLC are well known in terms of patient and carer well-being, and public service costs. 'Getting it wrong' is expensive. In 2021, 49% of deaths of people with a learning disability in England were rated as 'avoidable', compared with 22% for the general population.<sup>2</sup> Inequalities and avoidable mortality stem from factors associated with the social determinants of health for people with a learning disability (e.g. dependence on others for noticing and dealing with health problems; poor health literacy); multiple co-morbidities (people with a learning disability have an average of eight long-term health conditions at their time of death)<sup>32</sup>; and failings in healthcare delivery.<sup>3</sup>

### Expressed need

NICE noted that people with a learning disability are at particular risk of missing out on access to end of life care.<sup>9</sup> The Ambitions Framework 2021-2026 similarly notes specifically that there remain unacceptable inequities and inequalities in access to PEOLC particularly for those with a learning disability. They assert that it is a collective responsibility on all of those involved in the commissioning and provision of EOLC to put this right.<sup>11</sup> The CQC expressed concern about a lack of understanding among healthcare professionals about the care needs of people with a learning disability, including assumptions about quality of life, demonstrated by inappropriate use of Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) forms and the Clinical Frailty Scale.<sup>10</sup>

### Sustained interest and intent

Growing numbers of people with a learning disability now live into adulthood, including those with profound and multiple disabilities, with highly individual palliative care needs that may not have previously been the concern of adult services. Increased life expectancy for this population has also been associated with the onset of complex long term conditions such as dementia, diabetes and frailty

that require specialist support. Furthermore, investing in getting it right for people with a learning disability will have high relevance for other vulnerable groups such as people with dementia, autism or mental health conditions, with obvious interest for commissioners and providers.

### **Capacity to generate new knowledge**

The persistence of inequalities despite national recommendations and policies implies current interventions are not effective, resources are not targeted and isolated good practice has not become mainstream. This national study, with data collection from a wide range of sources, localities and level of disability, ensures the widest possible capture of good practice and potential for generalisability for all people with a learning disability and all service settings. The considerable scale and scope of this programme provide the capacity to generate the substantial new knowledge required to develop service models and interventions that truly address the inequalities in PEOLC for people with a learning disability, and meets their needs.

### **Generalisable findings and prospects for change**

This is a multi-site study. Quantitative and qualitative data are collected from across England, and from a wide range of sources, localities and level of need amongst learning disabled people, ensuring the widest possible generalisability for all people with a learning disability. The NHS Long Term Plan pledges that “the NHS will personalise care, to improve end of life care” (p25).<sup>33</sup> The policies and skills needed to provide good PEOLC for people with a learning disability, requiring the highest possible level of personalisation, are transferable. The findings and outputs of this project are also likely to be transferable. Investing in getting it right for people with a learning disability will therefore benefit all patients, in particular other vulnerable patient groups.

### **Building on existing work**

This project builds on over two decades of the Principal Investigator (PI)’s inclusive research around PEOLC for people with a learning disability, demonstrating that doing research with people with a learning disability around death and dying is not only feasible, but welcomed. It has grown out of extensive discussions with those affected, including learning disability service providers, family carer groups, self-advocacy groups of people with a learning disability, national policy makers, and others. In particular, the research questions have been articulated following two NIHR projects: NIHR202963 (2022-2024) on end of life care planning with people with a learning disability;<sup>8,34</sup> and NIHR129491 (2020-2023) on the support needed for older people with a learning disability and family carers.<sup>7</sup> Co-applicant research in barriers to PEOLC focussing on ethnicity is also relevant (NIHR17/05/30).<sup>35</sup> We benefit from strong and effective collaborative links built between universities and with service providers within those projects.

### **How the proposal addresses current gaps in the literature**

Empirical evidence on end-of-life care provision for people with a learning disability is extremely limited.<sup>36,37</sup> A NICE systematic review of the literature on PEOLC for people with a learning disability found limited evidence on the views and experiences of people with a learning disability and their families; no evidence on effectiveness or cost-effectiveness; and studies about practitioner views had low to moderate internal validity.<sup>38</sup> Evidence suggests that better collaboration between professionals would improve PEOLC for people with a learning disability, but NICE rated the quality of this evidence as low to moderate. Largely anecdotal evidence from practice initiatives in the UK to improve PEOLC provision to people with a learning disability shows (and our stakeholder/PPI consultation corroborates) that good practice is over-dependent on committed individuals and not embedded within policies and organisational cultures.<sup>38</sup> There have been no studies into the availability, nature and effectiveness of service models or interventions. There has been a lack of involvement of people with a learning disability in PEOLC research. The current evidence base is insufficient for the development of interventions and does not yet meet the requirement of the developmental first stage of the Complex Interventions Framework.<sup>39</sup>

The reference point for this study is the NHS England 2021 Ambitions Framework<sup>11</sup> building on the 2019 NICE guideline<sup>9</sup> which set out a vision to improve end of life care throughout England. Our research addresses how these national ambitions for high quality PEOLC can be achieved consistently for people with a learning disability, across the wide range of living situations and settings. We will co-produce rigorous and relevant evidence about how health and social care services can work together to assess and meet the needs of people with a learning disability at the end of life, in the setting most suited to meeting those needs; and to provide adequate support for them and for their families and professional caregivers. We will pay particular attention to intersectionality with other factors known to be disadvantaging in relation to accessing PEOLC, notably ethnicity,<sup>30</sup> rurality<sup>30</sup> and different levels of learning disabilities. Co-production (in particular with people with a learning disability themselves) is a fundamental part of this project.

## Aims and objectives

### Aim

To improve quality and accessibility of palliative and end of life care (PEOLC) for people with a learning disability by producing robust guidance for health and social care service providers, with workable recommendations and resources.

### Research questions

- What are the service delivery models and interventions within health and social care services that enable timely identification of the PEOLC needs of people with a learning disability and are effective in meeting their PEOLC needs?
- Within a range of service exemplars, what are the barriers and enablers to providing accessible, high quality PEOLC to people with a learning disability; and what are the replicable elements of good practice?

### Objectives

- 1. To map PEOLC trajectories of people with a learning disability nationwide**, using electronic health record data from the Clinical Practice Research Datalink (CPRD), and compare this with people with a learning disability, to gain insight into differences and inequities with regards to registration of PEOLC need, patterns of hospital admission and referrals to PEOLC services (Ambition B, Foundation 3)
- 2. To develop an understanding of existing evidence** about service models and interventions for PEOLC for people with a learning disability, with regards to **(i)** identifying need, **(ii)** assessing and meeting need, and **(iii)** coordination and delivery of local services, including professional development (all Ambitions / Foundations)
- 3. Within 4 localities (Study Sites) across England, to explore, compare, and contrast PEOLC services for people with a learning disability** by identifying barriers, enablers and exemplars of replicable good practice with regards to: **(a)** currently used models of care, commissioning practice and services coordination (Ambitions D and E; Foundations 2, 3, 5, 6 and 8); **(b)** timely identification of PEOLC need within learning disability service providers, primary care services and specialist palliative care services (Ambition B; Foundations 3 and 6); and **(c)** appropriate, specific, individualised PEOLC provision for people with a learning disability (Ambitions A and C; Foundations 1, 4 and 7);
- 4. To co-produce actionable recommendations and resources** for providers and commissioners, primary care services, palliative care services, and social care service providers, including: **(i)** workable method(s) for identification of PEOLC need; **(ii)** a set of good practice exemplars; **(iii)** a logic model; **(iv)** online training materials (All Ambitions / Foundations; especially Foundations 5 and 7)
- 5. To build capacity and produce guidance for future inclusive health and social care research** with people with a learning disability, within academic communities and self-advocacy groups

## Research plan / methods

This is a **co-produced research project**, using mixed methods and involving co-applicants and collaborators in academic and service provision settings, including co-researchers with a learning disability. This diverse team will work together, sharing power and responsibility throughout the project, including the generation of knowledge. Previous research relationships between co-applicants provide strong foundations for the effective collaboration needed for co-production, which is necessary for ensuring meaningful outputs.

### Design and theoretical/conceptual framework

This project is underpinned by the co-produced Ambitions Framework<sup>40</sup> and assumes that this framework provides the gold standard of PEOLC. Our research questions and methodological approaches are guided by this framework, providing a focus for the study. We investigate how and to what extent the Ambition Framework's **8 foundations** (see page 3) are present with regards to people with a learning disability, and/or how they might be better achieved: **(1)** Personalised care planning, **(2)** Shared records, **(3)** Evidence and information, **(4)** Involving, supporting and caring for those important to the dying person, **(5)** Education and training, **(6)** 24/7 access, **(7)** Co-design, and **(8)** Leadership.

We assume the Social Model of Disability<sup>41</sup>, which seeks to change society and systems to accommodate people with disability, rather than place problems of unequal access within the individual. Our theoretical construct is that care is a situated practice, located in a nexus of healthcare infrastructure, interpersonal relationships, personal lived experiences, and wider societal contexts. As such, to understand it we cannot rely on only verbal accounts or single perspectives; nor do we assume definitive triangulation is possible. Instead, the aim is to understand as best as possible how things occur and with what consequences, being open to unanticipated and unexpected interpretations.

The research questions are addressed in four Work Packages (WPs), enabling comprehensive insights through a combination of data sources. **WP1** (analysing large national electronic patient data sets) and **WP2** (scoping reviews) will map the current state of affairs and provide insights and context for WP3. **WP3** is the central Work Package, with data collection in 4 geographical areas in England ('Study Sites'), where we aim to understand and make sense of how the delivery of the Ambitions Framework is achieved/constrained in practice, and how it might be optimised. In WP3, we will use a qualitative approach drawing on interviews, ethnographic methods<sup>42</sup> and Experience-Based Co-Design<sup>43</sup> methodologies. This enables a systematic study of social interactions, behaviours and perceptions, typically gained through the involvement with and perspective of 'insiders', that results an in-depth description and explanation of groups, organisations and communities. **WP4** is focused on engagement and stakeholder involvement, culminating in the co-production of outputs, including free online training resources, and actionable recommendations. Here, the findings from all parts of the study are integrated.

Our approach is focused on collecting data to describe the 'what' in a connected way that highlights issues and multiple understandings of power, structure, and care - rather than a purely realist approach that has a stronger emphasis on identifying causal mechanisms for 'what works'. We will use inclusive data analysis and output development approaches with a focus on framework analysis and mind-mapping techniques.<sup>44,45</sup> We have found that these work well with, and can be understood by, a diverse group of researchers, including co-researchers with a learning disability.<sup>46,47</sup>

### WP1: A retrospective cohort study using electronic health records of PEOLC in people with and without a learning disability: registration, survival time, referrals and healthcare utilisation

**WP1 Lead:** Dr Freya Tyrer (University of Leicester)

**Aim:** To compare people with and without a learning disability in order to detect inequalities: registration of PEOLC need and subsequent survival time; primary care and hospital care utilisation; palliative care referrals. WP1 is hypothesis-generating.

**Objectives:** **(1)** Investigate differences/inequalities (between people with and without a learning disability) in the GP recording of generic end-of-life care and end-of-life care registration [*outcomes* =

*end-of-life care; end-of-life care register flag*] (2) Investigate differences (between people with and without a learning disability) in survival time after GP recording and registration of end-of-life care [*outcome = death*] (3) Compare the characteristics of people with and without learning disabilities who die while registered at the GP surgery, but are not recorded as being at the end of their lives [*outcome = differences in proportions*] (4) Investigate the pattern of healthcare utilisation after GP recording of end-of-life care, as measured by the number of primary care consultations and secondary care episodes – and if this differs for people with and without learning disabilities and people who have end-of-life care records [*outcomes = consultations; hospital visits*] (5) Compare differences in referrals to palliative care specialists by learning disability and end-of-life care status [*outcomes = referrals*]

**Methods:** A retrospective electronic health record cohort study of people on the Clinical Practice Research datalink (CPRD) in England aged 18+ years between 1 Jan 2010 to the last available update (includes 87,790 people with a learning disability). Data will be linked to hospital episode statistics (HES), Office for National Statistics (ONS) mortality data and deprivation data (approximately 75% of GP surgeries in England agree to the linkage scheme).

**Rationale for use of linked data:** We will use CPRD data linked with hospital data, ONS mortality data and deprivation data. As hospital data linkage is available for England only, WP1 will be restricted to England. The rationale for data linkage of mortality data is that we need complete information on mortality for accurate trajectories to end-of-life. Hospital data are needed to identify comorbidities and to assess whether there are differences in hospitalisations between people with and without learning disabilities – and between people who have an end-of-life care record and those that are not (i.e. we anticipate that people who are at the end of their lives have more hospitalisations if specialist healthcare provision is not in place). Deprivation data is needed to assess any differential healthcare by socioeconomic status.

**Feasibility counts:** A feasibility count conducted in April 2024 on people with and without learning disabilities and end-of-life care records given a sample population size of 1.7 million adults ( $\geq 18$  years) who meet the eligibility criteria (see below – 2010 to latest date available). Of these, 15,247 have a learning disability and 623,020 individuals do not have a learning disability. In the learning disability population, 3,126 (21%) individuals have an end-of-life care record. In the comparison group, 396,302 (24%) individuals have an end-of-life care record.

**Definition of the study population:** Index date will be the date of PEOLC need registration or one year prior to death (depending on the research objective). Included: Learning disability recorded prior to index date (identified through Read codes as having a learning disability, determined from previous research conducted by the team<sup>48</sup>); AND Registration at an up-to-standard (CPRD quality indicator) GP surgery from 2010 (to latest date available); AND Aged 18+ years; AND Recorded on the end-of-life care register OR Death recorded while at the GP surgery. Adults will be followed up until they leave the surgery, die or at the last surgery update (whichever is first).

**Statistical analysis:** We will describe the characteristics of the population for all covariates under investigation by learning disability status, using means (standard deviation; continuous covariates) and numbers (percentages; binary/categorical covariates). **Objective 1:** Differences in the recording of individuals for end-of-life care between people with and without learning disabilities will be explored using multiple logistic regression, controlling for the effects of age, gender, ethnicity, deprivation, and common comorbidities (see exposure, outcomes and covariates section). **Objective 2:** Differential survival comparisons from end-of-life care reporting will be made using Cox proportional hazards or flexible parametric models (depending on hazard proportionality), also adjusting for age, gender, ethnicity, deprivation and common comorbidities (as above). **Objectives 3,5:** The characteristics of people who die while registered at the GP surgery but are not recorded as being at the end of their lives will be compared to those who have an end-of-life care record, also stratifying by learning disability status, using age-standardised differences between independent proportions, with 95% confidence intervals. Differential referral patterns (objective 4) will also be compared using age-standardised differences between proportions. **Plan for addressing confounding:** We will adjust for covariates conceptually associated with both mortality and learning disabilities, including age, gender, ethnicity, deprivation status and comorbidities. **Plan for addressing missing data:** Missing data will be treated as a separate category given that multiple imputation scenarios are not always suitable (e.g. body mass

index). We will repeat the analysis using complete case methodology as a sensitivity analysis. We will consider multiple imputation using delta-adjustment, if appropriate.

**Outputs:** The findings from this data base analysis will be used to inform WP3 and contribute to WP4 outputs. Plus: Peer-reviewed publication; webinar.

## **WP2: Scoping the evidence: a rapid review of identifying, assessing and meeting PEOLC need for people with a learning disability, and coordination and delivery of local services and interventions**

**WP2 Lead:** Dr Joanne Jordan & Prof Elizabeth Tilley (The Open University)

**Aim:** The aim of WP2 is to develop an understanding of existing evidence about service models and interventions for PEOLC for adults with a learning disability, with regards to (a) identifying need, (b) assessing and meeting need, (c) coordination and delivery of local services including professional development.

**Research questions:** What is known about: **(1)** Methods for identifying PEOLC need in people with a learning disability, **(2)** Interventions for meeting individualised PEOLC needs for people with a learning disability, and **(3)** Service models for coordination of care, service delivery and staff training in PEOLC for people with a learning disability?

**Rationale:** We have completed two rapid scoping reviews as part of two recent studies, around support needs and resources available for older people with a learning disability (NIHR129491)<sup>49</sup> and end of life care planning for people with a learning disability (NIHR202963).<sup>50</sup> Those reviews identified a lack of evidence around end of life care planning for people with a learning disability, particularly those with severe or profound disabilities and/or behaviours that challenge others. They also indicated a wider body of research detailing issues relevant to the delivery of PEOLC for people with a learning disability which has not yet been systematically reviewed across the three areas of identifying need, meeting individualised need and coordination of care.

**Methods:** To address this gap in knowledge we will undertake a rapid scoping review using a systematic framework incorporating existing reviews, empirical research and grey literature.<sup>29</sup> We anticipate the inclusion of international material, published in English from 2007. This is the year of publication of Mencap's Death by Indifference report<sup>51</sup> which triggered a growing interest in the experiences of people with LD at the end of life. Scoping the literature will enable the inclusion of a broad range of evidence drawn from diverse sources.<sup>52</sup> Constituting an early stage of the project, the reviews require timely completion, ideally suited to a rapid review.<sup>53</sup> For the scoping aspect, we will adhere to the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) extension for Scoping Reviews (PRISMA-ScR).<sup>54</sup> In the absence of reporting guidelines, for the rapid aspect, we will adhere to expert guidance,<sup>55</sup> including the 'additional steps' recommended by Plüddemann et al.<sup>56</sup> (p.202) to promote rigour. An information specialist will provide expert support to: help refine review questions; advise on the selection of databases and other methods of searching for evidence; design and execute database searches; manage the process of initial screening of evidence; and carry out full text retrieval. A protocol will be developed for the review.

**Information sources and search strategy (for each review):** We will undertake preliminary searching to (a) identify the most relevant databases in terms of question focus and types of evidence required and (b) refine database search strategies to achieve an appropriate balance between specificity and sensitivity. Preliminary searching will be of Medline and Social Policy and Practice (SPP) databases, selected for their varied content. Text words and index terms will be used in the design of a primary search strategy, with appropriate limits and restrictions (e.g. by language, date of publication). The strategy will be tested against known relevant records identified by preliminary searching and, if necessary, revised. The confirmed primary search strategy will be translated into the other database search strategies, taking account of database and interface-specific functionalities. All search strategies will be peer reviewed using Peer Review of Electronic Search Strategies.<sup>52</sup> We will search for grey literature using database and supplementary methods; the latter will also be used to augment searching for published literature.

**Selection of sources of evidence (for each review):** After de-duplication, records returned from database searching will be imported into Rayyan.<sup>57</sup> Two reviewers will independently screen using titles and abstracts (where available) against explicit inclusion criteria. Full-text copies of evidence not excluded at this stage will be obtained. Two reviewers will independently review all full texts. To promote transparency and consistency, a tailored inclusion form will be used for full text review. At both initial screening and full text review any discrepancies will be discussed by the two reviewers and, if necessary, with the wider review team. All sources of evidence excluded on the basis of full text review will be recorded, alongside the reasons for exclusion. Using a PRISMA flowchart<sup>58</sup> we will record the process of screening to full text inclusion.

**Data extraction (for each review):** A tailored Excel extraction form developed collaboratively by the review team will be piloted by one reviewer on three included sources of evidence, selected to reflect its likely heterogeneity. Using the final form, one reviewer will extract data from included sources. All completed data extraction forms will be independently reviewed against relevant texts by review team members to check for gaps and errors.

**Critical appraisal of individual sources of evidence:** The conduct of critical appraisal in both scoping and rapid reviews is considered optional. For scoping reviews, the central issue concerns the inclusion of many types of evidence. For rapid reviews, it concerns the nature of the evidence and the time available. Final decisions concerning if and how the appraisal is undertaken and how the findings of appraisal inform the interpretation of evidence will be made once we know the volume and nature of included evidence.

**Synthesis of findings:** The likely diversity of included evidence necessitates a flexible, but robust, approach to synthesis. We will summarise key characteristics of included evidence in a Table of Characteristics and identify patterns and trends in its volume, focus and content. We will synthesise findings using a narrative approach,<sup>59</sup> appropriate when findings are derived from varying sources (research and non-research). We will aim to interpret these findings to generate new conceptual understanding, captured in analytical themes and constituent sub-themes. Synthesis will be led by two researchers; all drafts will be shared with the research team and selected drafts with the Project Advisory Group to promote full analytical insight, strategic relevance, and clarity.

**Outputs and integration:** Findings from these reviews will be used to inform WP3 (including WP3B: development of methods for identification of PEOLC need) and contribute to WP4 outputs. Plus: Peer-reviewed publication; webinar.

## WP3: Explore, compare and contrast PEOLC services for people with a learning disability at four Study Sites, and develop methods for timely identification of PEOLC need

**Overall WP3 lead:** Prof Irene Tuffrey-Wijne (Kingston University)

**Aims:** To identify barriers, enablers, and good practice exemplars for the systematic delivery of timely, appropriate, individualised and co-ordinated PEOLC.

**Objectives:** Explore, compare and contrast PEOLC services for people with a learning disability at four Study Sites, including models of care, identification of need and individualised PEOLC provision; and develop methods for timely identification of PEOLC need.

**Research questions:** Within WP3, there are three main sets of interlinked research questions, each with a distinct methodology (see further details in “Methods” below):

- (A) **Models of care:** What models of care can be implemented by health and social care services to ensure that the eight Foundations are in place locally? What are the **local system approaches** and strategic/commissioning priorities and practice in relation to PEOLC for people with a learning disability? What are the barriers and enablers of **professional development** and **cross-organisational collaboration** that promotes effective and timely delivery of PEOLC to people with a learning disability? *Methodology: Interviews*
- (B) **Delivery of PEOLC:** What do people with a learning disability, families and carers perceive as their care and support need? What is the nature of PEOLC service delivery to adults with a learning

disability? How is this experienced by people with a learning disability, families, carers and professionals? What do they see as **barriers and enablers to good PEOLC**? *Methodology: Case studies, using ethnography*

- (C) **Developing methods for identification of need:** How do GPs, learning disability services and specialist palliative care services currently identify PEOLC need? What are the processes, decision points, barriers and enablers of timely service delivery of PEOLC to local adults with a learning disability who have PEOLC need? What are workable methods for identifying PEOLC need in local populations? *Methodology: Experience-Based Co-Design*

Study Site	Site Partners	Site Lead
1 Croydon (South London)	St Christopher's Hospice	Prof Irene Tuffrey-Wijne (Kingston University)
2 Kirklees (West Yorkshire)	St Anne's Community Services	Prof Irene Tuffrey-Wijne (Kingston University)
3 Bedfordshire, Luton and Milton Keynes	MacIntyre & Willen Hospice	Prof Elizabeth Tilley and Prof Erica Borgstrom (The Open University)
4 Leicester	LOROS Hospice	Dr Zoebia Islam and Dr Chris Williams (LOROS Hospice)

**Study Sites:** Four *geographical* areas across England will serve as study sites (see table above). These sites have been purposively selected to include a range of urban/rural settings and levels of deprivation; various mixes of ethnicity within the local population; and different organisational approaches to PEOLC provision for people with a *learning disability*. Efforts will be made to engage participants from diverse communities and across the *learning disability* spectrum, including those with severe/ profound *learning disabilities* (under-represented the research literature).

It is important to note that data collection is not restricted to participants (patients/caregivers/ managers/staff) within the named service providers at these sites. We aim to explore, compare and contrast PEOLC need and service delivery across *all* health and social care services within the geographical area. However, to ensure maximum participant engagement and rich, relevant and useful data, we have prioritised localities and where we have collaborative links with a significant palliative care and/or learning disability service provider who has/have: a known interest in developing PEOLC provision for people with a learning disability; a track record in developing/piloting relevant service delivery models (and variation in which organisation/service took the initiative or lead); and/or good working relationships with the research team.

**Site Partners:** Within each site, we have identified Site Partners, who meet the above criteria. Site Partners provide important local knowledge and participant access as required within sampling strategies.

**WP3B Site Researchers:** Each study site will have a dedicated Site Researcher, responsible for promoting local stakeholder engagement, participant recruitment, Local WP3B data collection and data analysis. Site Researchers will work closely with their local Site Partners.

**Overall WP3 Lead:** Prof Tuffrey-Wijne. Ensuring that methodologies (including data analysis) are aligned and integrated across case study sites and researchers are adequately trained and supported in research with people with a learning disability.

**WP3A Lead (all Study Sites):** Prof Louise Wallace (The Open University). Responsible for WP3A data collection and analysis.

**WP3B Site Leads:** Each Study Site has its own Site Lead (see table above), responsible for supervising their Study Site Researcher and overseeing delivery of the study objectives at their site.

WP3 methodological (ethnographic) advice and support: Prof Erica Borgstrom (The Open University).

**WP3C Lead (all Study Sites):** Dr Rebecca Anderson-Kittow (Kingston University).

**Methods:** Within each site, we will undertake the following areas of work, linked by key dependencies: (note: n=total across all 4 sites)

- A. Models of care and local scoping/stakeholder events (month 1-9):** General scene setting investigation through discussion and interviews with commissioners and senior managers in learning disability and palliative care services (n=16), scoping visits and informal stakeholder conversations (n=up to 12), local stakeholder engagement events (n=up to 12).
- B. Case studies (month 10-32):** *Case studies of people with a learning disability currently receiving PEOLC or expected to be at end of life* (n=up to 20), using ethnographic methods: Participant observation (up to 420 hrs); conversations with people with learning disability/family/carers/peers/managers/professionals, recorded as detailed field notes (n=up to 200); case file analysis where possible (n=up to 20).  
*Retrospective case studies will be conducted of people with a learning disability who had non-sudden deaths in past 12 months* (n=up to 40). Interviews with family/carers/managers/professionals (n=up to 120), recorded & transcribed; case file analysis where possible (n=up to 20).
- C. Developing interventions for identification of PEOLC need (month 12-33)** using adapted Experience-Based Co-Design: Focused exploration, development and testing of interventions for enabling a systematic way of identifying people with a learning disability who are approaching the end of life.

**Table 2: Overview and more detailed breakdown of WP3 data collection and participants**

What/with who?	How many (n=?)
<b>A. Models of care: Scene setting, preparation and recruitment (month 1-9 plus follow-up)</b>	
<b>Interviews</b> with senior staff within learning disability and PC services, and commissioners	<b>Per site:</b> n=2, plus n=2 repeat senior interviews at the end of site data collection <b>Total:</b> n=8 (month 1-6), plus n=8 (month 26-29) (n=16)
<b>Informal conversations</b> with stakeholders including senior service managers, to understand local landscape and population of people with a learning disability	<b>Per site:</b> n=1 to 3 managers of the main palliative care and learning disability providers. Informal field visits to local champions/interested organisations: n= 1 to 3 <b>Total:</b> n=4 to 12 manager conversations; n= 4 to 12 field visits
<b>Stakeholder events</b> with local services, including learning disability service providers, palliative care services, GP practices, family carer & self advocacy groups – to build engagement and promote participant recruitment	<b>Per site:</b> 3 events (to fit in with local need and practice). This may include online events <b>Total:</b> 12
<b>B. Case studies (month 10-32)</b>	
<b>Current:</b> People with a learning disability with recognised PEOLC need or who may be in the last year of life	
<b>Participant inclusion criteria:</b> <ul style="list-style-type: none"> <li>• Adult (over 18)</li> <li>• Learning disability (mild to severe/profound)</li> </ul> Plus any one of the following: <ul style="list-style-type: none"> <li>• Recognised PEOLC need (e.g. EOLC register, or receiving PEOLC service)</li> <li>• Advanced life limiting illness e.g. cancer, dementia</li> <li>• Negative answer from formal carers to Surprise Question (“Would you be surprised if they died within 12 months?”)</li> </ul>	<b>Per site:</b> n=2 to 5 <b>Total:</b> n=8 to 20 The size of the potential sampling frame is unknown, but likely to be small, partly due to “invisibility” of the target population and the difficulties in identifying PEOLC need (which underlies this study). <b>We will invite all potential participants who meet the inclusion criteria</b> , up to max n=5 per site. <i>If 0 or only 1 suitable participants can be recruited at a site by month 28, the number or retrospective case reviews (see below) will be increased by n=2</i>
<b>Participant observation:</b> “Hanging out” with the person with a learning disability. Exact timings and	<b>Estimates: Per case:</b> 21 hours <b>Per site:</b> 42-105 hours <b>Total:</b> 168-420 hours

duration of data collection sessions will be agreed locally and with the participants and will depend partly on the participants' health situation. Aim to spend time with participant in variety of contexts, incl at home, hospital/Dr appointment, in-patient setting.	We estimate an average of 7 sessions per participant (average session: 2-4 hours), but this is likely to be highly variable, with time frames from 1 day to 24 months
<b>Unstructured ethnographic conversations</b> People with a learning disability/ families/ friends/ direct care givers/ managers/ professionals involved. To explore perception of need, experience of service provision, challenges, what works well and what is difficult.	<b>Estimates: Per case: n= 10 Per site: n=20 to 50</b> <b>Total: n=80 to 200</b> 10-30 mins per conversation. The same participant may be spoken with at different time points. Conversations may be held with more than 1 participant at a time (e.g. with staff team or with group of housemates)
<b>Document analysis</b> (social care notes and/or clinical notes, where feasible**)	<b>Per case: n=1 to 2 Per site: n=2 to 10 Total: n=8 to 40</b> Each file takes approximately 1 hour to study
<b>Retrospective: People with LD who have died in the past 12 months</b>	
<b>Inclusion criteria:</b> •Adult (18+ at time of death) •Learning disability •Died during 12 months before recruitment •Non-sudden death* <b>Excluded:</b> Sudden (unexpected) death without recognized EOLC need	<b>Per site: n=8-10</b> <b>Total: n=32-40</b>
<b>Semi-structured interviews</b> with staff/carers/ families/peers. To explore perception of need, how need was identified (or missed), experience of service provision, challenges, what worked well and what was difficult. Family/peer participants will only be approached for participation at least 6 weeks following the death of the person. There will be no such limit for staff/carers but advice will be sought from gatekeepers about when it is appropriate to approach these participants.	<b>Per case: n=2 to 3 Per site: n=16 to 30 Total: n=96-120. Duration: 30-60 mins</b> Interviews may be held with more than 1 participant at a time, e.g. with staff team or with group of housemates
<b>Document analysis</b> (social care notes and/or clinical notes, where feasible**)	<b>Per case: n=1 to 2 Per site: n=8 to 20 Total: n=32 to 80.</b> Each file takes approximately 1 hour to study
<b>C. Developing methods for identification of PEOLC need (month 12-33)</b>	
<b>Preparation</b> (month 12-16): Produce a video of WP2 and early WP3 findings; Recruit co-production group	
<b>Development/co-design</b> (month 17-25): 8 sessions of 2 hours (online) <b>Session 1:</b> present the video of early WP3 findings/views and present relevant WP2 findings (scoping review on identification of PEOLC need in people with a learning disability); use this as a starting point to identify priorities. <b>Session 2-5:</b> work together to co-design workable methods to be used locally. This may involve adapting existing assessment methods for identifying PEOLC need in the general population, and/or adapting non-UK tools for identifying PEOLC need of people with a learning disability for use within UK health/social care services. <b>Session 6:</b> Local online or in-person meeting, run by the Site Lead: Assess co-designed methods for suitability for local implementation. <b>Session 7:</b> Finalise methods of assessment. <b>Session 8:</b> Share final results; identify national/local differences. Which aspects are nationally generalizable, and which depend on local ways of working?	
<b>Testing</b> (month 26-33): Data collection for the testing stage builds on stage 2 outcomes. It may include observation, interviews with stakeholders and/or a questionnaire.	

\*Non-sudden death is defined as: Recognised PEOLC need (was on EOLC register or received PEOLC services), OR period of at least 7 days of ill-health/ decline before death, OR hospital admission in the 3 months prior to death

\*\*Where case documents are not accessible to Site Researchers, key informants with access to such taking part in interviews will be encouraged to consult case documents prior to interview, and will be asked to reflect on these documents

**WP3b consent procedures:** Accessible study information (in the form of Easy Read and/or a video) will be given to all participants. Consent will not be obtained until at least one week after the potential

participant has been given the information. The research team will follow up with the participant/gatekeeper if the potential participant has not responded two weeks after being given the information. Capacity to consent will be assessed by the site researchers/leads based on detailed conversations with the individual and those that know them well. Capacity to consent will be assumed (as per the Mental Capacity Act) unless there is reason to suggest the person does not have capacity. We will work with family members and/or staff who are close to the person to maximise their capacity to make and/or participate in the decision. We will consult with an advisor who knows the person well to understand the ways to communicate (this includes being sensitive about the person's current level of knowledge around their condition and prognosis), times of day and settings which will be most likely to support the person be able to understand the information. Capacity decisions will be regularly reviewed as capacity may fluctuate (in either direction) over time.

If the site researcher/lead assess that the person does not have capacity to make the decision, then we will seek advice from an appropriate consultee who can assess the participant's interests in accordance with current legislation and guidance. If the consultee advises that the person would like to participate, we will also discuss the proposed study with the participant themselves where possible, in a way appropriate to their understanding. Consultees and advisors will be identified through the gatekeeper.

Willingness to be involved in ethnographic observations may change over time or on a day-to-day basis. Researchers will work with participants and consultees to understand how the person with a learning disability expresses discomfort or distress. Where possible they will also agree with participant and/or consultee about an easy way to show they would like the researcher to leave (e.g. holding a sign, turning away). If the person shows any signs of not wanting to be observed, researchers will reassure the participant that this is ok, leave the premises, and arrange a time to discuss their ongoing involvement. There will be regular check-ins between observations sessions and participants will be able to phone, post a reply slip or email researchers between sessions if they no longer wish to take part, giving the choice of whether or not to speak the researcher directly. Providing ample opportunities for people with learning disabilities and their families to withdraw will be particularly important as the person gets more unwell towards the end of their life. Researchers will discuss with participants and their families whether/when it is appropriate for them to be present.

**Data analysis:** We will use content analysis using the framework method, and include mind-mapping techniques.<sup>44,45</sup> Framework analysis has the advantage of being adaptable and allowing engagement of people with less qualitative research experience;<sup>61</sup> in our experience, it also works well with researchers with a learning disability.<sup>46,62</sup> After each data collection session (including all data types, e.g. documents reviewed) key issues will be noted in a structured summary template with no formal coding. Sections include participant and data collection details, plus deductive headings (developed from the research questions) and inductive headings (to allow new issues to emerge). Further template sections will include key documents, observations, quotations (verbatim quotations will be added when transcripts are ready) and reflections. To bring teams together and ensure integration of data and learning across sites, there will be monthly online data analysis sessions with WP3 researchers across the four sites (including two researchers with a learning disability), to share development of themes, reflections and puzzles. We will also link the data analysis with WP4 (Co-production, engagement and PPI) through discussing emerging findings at a monthly advisory group of people with a learning disability.

**Outputs: (a) 9 to 12 co-produced patient exemplars**, highlighting positive practice, pathways and experiences. These will represent a range of different settings, contexts, profiles of people with a learning disability, and illness/dying trajectories. Each exemplar will demonstrate how the Ambitions Framework's Foundations 1, 2, 4, 6 and 7 were achieved, along with recommendations about how this might adapted to different settings/localities. It will be developed and finalised by the full research team with the support of the Study Advisory Group in a series of online meetings to extract examples of excellence and discuss potential for replicability. This process will start during across-site data analysis sessions, and will be supported by the WP4 co-production group (see below). **(b) Final methods and guidance for identification of PEOLC need** (produced by the WP3 co-production group) made freely available (for use within health and social care services, including learning disability services, specialist palliative care and primary care services) **(c) At least 5 peer-reviewed publications**, including the findings of the different parts of WP3, as well as a methodological paper **(d) 3 webinars (e) Information**

on potential resource implications for commissioners to inform commissioning decisions, and researchers to inform future trials of complex interventions.

## WP4: Co-production, Patient and Public Involvement and Engagement (PPIE), and Outputs

**WP4 Leads:** PPIE: Richard Keagan-Bull & Jo Giles (Kingston University)

Outputs: Prof Erica Borgstrom (The Open University)

**Aims:** (1) To ensure that **PPIE and active involvement of people with a learning disability is embedded** across all WPs. (2) To **co-produce actionable recommendations, tools and resources** for providers and commissioners, primary care services, palliative care services, and social care service providers.

**Rationale:** Engagement with a wide range of stakeholders throughout the project is a crucial part of our pathway to impact and therefore warrants a dedicated WP. To ensure that the outputs from the research can begin to be implemented immediately following the end of the research, we will engage with stakeholders throughout the project, with special attention throughout to the experiences, applicability and generalisability across localities and including minority ethnic populations (focus on Equality, Diversity and Inclusion).

**Methods:** The PPIE Leads will work with groups of self-advocates to help interpret and disseminate findings, feeding into those outputs. They will convene a national group of up to 10 people with a learning disability, who will meet monthly online, advising on all WPs and giving feedback on emerging findings. The approach for WP4 builds on positive experiences with and learning from ongoing national stakeholder engagement in our current project NIHR202963<sup>34</sup> as well as the *Staying Alive and Well Group*. This is a successful online co-production group of 10 people with a learning disability for the national NHSE 'Learning from Lives and Deaths of People with a Learning Disability' (LeDeR) programme, co-led by Keagan-Bull and Tuffrey-Wijne.<sup>63</sup> The PPIE Leads will work closely with all research team members with a learning disability and the co-applicant stakeholders, as well as with the site leads and other WP leads, who will use the PPI input as they work on outputs specific to each part of the study.

**Activities:** A dedicated website (building on expertise gained from our current successful NIHR202963 website<sup>34</sup>), regular blogs, mailing lists, specialist networks, and webinars. Development of some specific outputs will be led by other co-applicants, in particular OpenLearn training resources developed at The Open University (led by Borgstrom). We will explore the possibility and desirability of local meetings with specific stakeholder groups. In particular, we will meet with self-advocacy groups in all the 4 study site localities. These engagement activities will allow an exchange of information and ideas by showcasing our research outputs and seeking feedback from stakeholders about how to best implement them in practice. We will also explore with the CQC, national commissioning leads for a learning disability (via the Association of Directors of Adult Social Services) and strategic leads at NHS England and NHS Improvement, to see how our findings and recommendations fit with policy, inspection criteria and commissioning priorities. Invitees from the devolved nations will be considered.

**Outputs:** A **logic model** that is accessible and understandable by people with a learning disability (and therefore by everyone), based on an inclusive 'Theory of Change' model. We will develop this together with our co-researchers and self-advocates as study findings begin to emerge. Questions we will ask during this process are: "What change do we want to see? Who needs to change? How do people and organisations change? What are the small steps to get to the change we want? What does success look like?" We will disseminate both our innovative approach and results via: **(a) Two academic articles** focused on the methodologies of inclusive co-production. **(b) Producing high-quality engaging resources and outputs** that synthesise and promote the study findings. Outputs will be in suitable formats aimed at different academic and lay audiences, including easy-read. It will include guidance for commissioners, service providers, health/social care professionals, and families/informal carers. **(c) A series of online-hosted resources and outputs including OpenLearn educational/training resources** (an award-winning free educational platform with 16 million+ annual visits).

## Summary of patients/service users/carers/public as research participants

**WP3:** Each Study Site is a geographical area, not restricted to any particular service provider – all services potentially providing care to people with a learning disability at the end of life, and all people with a learning disability living and dying within the area (including those living at home with families, or those not engaged with any learning disability or palliative care service providers) are included in the sampling frame. It is estimated that only 20% of people with a learning disability in England are known to social care services,<sup>64</sup> so people with a learning disability are a ‘hidden population’, making this a hard-to-reach group. The success of this project is dependent on recruiting a diverse range of research participants in WP3. Starting with excellent working relationships with key services within each Study Site locality is crucial to building stakeholder engagement and subsequently recruiting participants. Site Researchers will spend significant amounts of time (especially during the first nine months) getting to know local organisations and holding stakeholder events, working closely with our Site Partners.

Recruiting senior service managers and commissioners for the first round of interviews (aimed at understanding mapping existing local services and models of care) will be led by co-investigator Prof Louise Wallace, who has long experience of conducting executive-level interviews. Engagement with local primary care services, community learning disability teams, family groups, self-advocacy groups and learning disability service providers will be helped by the high profile of the co-applicants and our collaborators. The Open University team have excellent relationships via Willen Hospice into local services, as do the LOROS team with regards to the South Asian community across Leicestershire, and the Kingston University team in South London and Kirklees. We are confident, therefore, that we will be able to engage with stakeholder and recruit a sufficient number of participants.

**Case studies:** We aim to recruit up to 5 people with a learning disability within each Study Site, who have current PEOLC need or are thought to be approaching the last year of life. As the sampling frame is potentially small, we will use convenience sampling, with all those fitting the inclusion criteria being approached (if deemed suitable by the gatekeeper). We base our recruitment approach on our significant experience in conducting ethnographic research within PEOLC settings, including with people with a learning disability. We have learnt that successful recruitment of this kind is usually a result of the researcher being ‘known’ to gate keepers; hence the importance of a sufficiently lengthy engagement phase. We will identify potential participants through contact with a ‘gatekeeper’ – any of the stakeholders we have engaged with. This could be one of their learning disability, palliative care or primary care service providers. Introducing a researcher as participant observer (ethnography) at such a sensitive time needs careful consideration. The gatekeeper will pass on study information materials to the potential participant and their family, caregiver(s) and staff in suitable formats, including easy-read and video. For those lacking capacity to consent, we will seek advice from a consultee, in accordance with the Mental Capacity Act. The Site Leads and Site Researchers will be available to answer questions. Data collection procedures (such as time, place and duration of visits) will be mutually agreed and guided by the participant. We will use ‘process consent’, clarifying with each visit whether the participant is still happy to be involved. We will produce appropriate and targeted study information materials for the participant’s family, caregivers, peers, and health and social care staff, who may consent to being included as informal informants (recorded as field notes).

For **retrospective case studies** (n=8 to10 per Study Site) we will produce a sampling framework to ensure diversity with regards to severity of learning disability, communication ability, mental capacity, age, gender, ethnicity, diagnosis/cause of death, and social/family situation. Recruitment and consent procedures are similar to the ethnographic case studies above.

**Co-production (Experience Based Co-Design):** A group of 8-10 stakeholder participants will be purposively selected from across all four Study Sites, including family carers, health and social care staff. They do not need to be involved in any of the case studies, but need to be able to contribute to the development of a workable assessment tool. They will be approached by the WP4 Leads and given information in a suitable format.

**WP4:** An advisory group of up to10 people with a learning disability will be purposively selected to be part of a monthly 2-hour online meeting. Recruitment will be through outreach activities within local self-advocacy groups and our extensive networks.

## Dissemination, outputs and anticipated impact

### What do you intend to produce from your research?

Outputs	People with a learning disability	Families / caregivers	Palliative care services	Social care services incl learning disability	Healthcare services incl primary & secondary	Policy makers	Commissioners	Academics
Implementable recommendations to improve access to and delivery of PEOLC to people with a learning disability – format and content specific to each stakeholder / target audience			X	X	X	X	X	
Method/tool and guidance for identifying PEOLC need		X	X	X	X			
12 exemplars of good practice	X	X	X	X	X	X	X	
Logic model, based on an accessible Theory of Change	X	X	X	X	X	X	X	
Project website with blogs, vlogs, progress update etc	X	X	X	X	X	X	X	X
Production of OpenLearn resources/course(s) (exact resources type and content to be determined in WP4; costed to include bespoke AV)	X	X	X	X	X	X	X	X
Free online staff training/learning materials			X	X	X			
6 webinars & final (hybrid) conference	X	X	X	X	X	X	X	X
Minimum 8 academic peer-reviewed publications in open-access social/health/science journals			X	X	X	X	X	X
Minimum 4 national & 2 international conference presentations			X	X	X	X	X	X
Reports for variety of audiences (including video/easy-read format), made publicly available via platforms agreed with Project Advisory Group	X	X	X	X	X	X	X	X
Guidance for conducting inclusive research with people with a learning disability	X							X

### How will you inform and engage patients/service users, carers, NHS, social care organisations and the wider population about your work?

Our audience for engagement and dissemination is: People with a learning disability, families, learning disability services, specialist palliative care services, primary care, secondary healthcare, NHS England, CQC, commissioners, local authorities and academics. All these are represented on our Project Advisory Group. We aim to engage with government agencies from health and social care agencies in all devolved nations in the UK. We will engage with stakeholders through sharing progress and findings on social media, using a dedicated hashtag and website link. The co-applicant and collaborator teams have extensive combined X (previously Twitter) and other social media audiences and reach into carer networks, self-advocacy groups, health and social care organisations and policy makers. We will continue or current activities of producing a regular blog, with occasional vlogs and podcasts, including sharing ongoing learning as it emerges. We anticipate continuing to build a ‘following’ this way, which will promote awareness, engagement and uptake of final outputs. The outputs will be further distributed and promoted by our collaborators and Project Advisory Group members, ensuring a wide reach into social care. We will explore with policy makers (in particular, the CQC) how our findings and recommendations fit with their benchmarks and inspection methodology.

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

Further research and development is crucial for reaching medium- and long-term outcomes as described in the table below. Identifying the key barriers and enablers to adoption and implementation is part of our project plan. We will describe a relevant Theory of Change and develop a Logic Model.

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

We are confident that this research will have significant impact in the short- and medium-term; see table 3 below for a non-exhaustive overview. Achieving the longer-term outcomes and the production of recommendations will be aided by a logic model. They are unlikely to be achieved by this study alone and will require further research, development and engagement activities, including the development of complex interventions. This study is a crucial step to those long-term outcomes.

<b>Short-term outcomes</b> End of research	<b>Medium-term outcomes</b> 1-5 years post-research	<b>Long-term outcomes</b> 5+ years post-research
<b>People with a learning disability, families and carers</b>		
Co-designed outputs better reflect needs/preferences	Families/carers included as partners in care; people with a learning disability are involved in decisions	Consistently improved outcomes; all care is personalised
Increased understanding of PEOLC & available services	Increased access to and use of PEOLC	Consistently improved awareness and access to services
<b>Workforce: Health Care (primary care, secondary care, specialist palliative care) &amp; Social Care (adult LD service providers)</b>		
Barriers and enablers to good PEOLC are known	Staff address barriers e.g. by identifying and implementing "reasonable adjustments"	Consistently inclusive services are able to demonstrate personalised PEOLC for a learning disability
Increased staff awareness of issues, available resources, and own role	Research outcomes shared widely. Resources widely available and easily accessible	Workforce is confident and competent in providing PEOLC for people with a learning disability
Interventions/tools/resources identified and developed	Testing complex interventions	Complex interventions are implemented on a large scale
Improved communication and understanding of roles between services	Service managers understand their role in PEOLC for people with a learning disability, and support this	Health and social care services consistently provide coordinated care
<b>Commissioners, policy makers and national &amp; local authorities</b>		
Opportunities for different policy-making bodies and commissioners to share knowledge/insights in PEOLC processes for people with a learning disability	Access to evidence base needed to make decisions around excellence and sustainability of PEOLC for people with a learning disability	Local/national policy makers and funders understand the evidence around PEOLC for people with a learning disability, and base informed decisions on this
<b>Social care academics and research communities</b>		
Developing new research leaders in this field	More researchers are independently able to develop funding proposals	Researchers involved in the project have become independent research leaders
Widening the pool of trained and competent co-researchers and advisors with a learning disability	People with a learning disability are involved in teaching and developing more research funding proposals	Significant employment opportunities for co-researchers with a learning disability

Learning from inclusive research is publicly available	Academic communities nationwide have access to learning about inclusive research	Co-production embedded in all PEOLC research including people with a learning disability
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## How will you share with study participants your progress and findings?

Continuing engagement with research participants is important, as is giving feedback on the study outcomes. We will inform all participants our engagement activities that are specific to their stakeholder group/needs, with the possibility of signing up to receive our weekly updates/blog. We will also offer participants the possibility of being sent the results in a suitable format at the end of the study. This is particularly important for bereaved families, caregivers and staff who were part of the WP3 case studies.

## Project management

The co-applicant team bring a strong and complementary mix of skills, knowledge and expertise, including project management, managing tight budgets and timetables, translating research into policy, practice guidance and training resources, involving people with a learning disability and families in research, working with a wide range of national and local stakeholders, and innovative dissemination strategies. The co-applicant team benefits from having worked together on previous projects, including research and practice development.

The full research team, including all co-applicants, will meet online every three months. The WP3B researchers will meet online every month. More meetings will be organised either within or across university teams, as appropriate for specific agenda items. These will be organised and co-ordinated by the Project Manager, who will be responsible for organising: the Project Advisory Group, Study Steering Committee, co-production events and meetings, ethics and research governance, staff appointments, internal and external communication, monitoring the project and deliverables, and reporting to the NIHR.

The **DAPPLE Advisory Group** will meet twice a year. Membership will comprise of a wide range of stakeholders, including national palliative care and learning disability organisations, policy makers, service providers, family carers and people with a learning disability. Confirmed members include representatives from NHS England, Learning Disability England, Voluntary Organisations Disability Group, Making Families Count, Marie Curie and Hospice UK. The DAPPLE Advisory Group will advise on all aspects of the project, including sampling, data collection methodologies and outputs. They will also be involved in analysis workshops and co-production events. The work of the WP4 group of advisors with a learning disability will feed into the DAPPLE Advisory Group.

The **Study Steering Committee** with an external chair will be appointed by the NIHR. Professor Jill Manthorpe CBE (Policy Institute at King's College London) has confirmed she is willing to fulfil this role. The Committee will meet to approve the protocol and then at three key points. We will not require a separate Data Monitoring and Ethics Committee (DMEC).

## Ethics

A favourable ethical opinion for WP3 will be sought from a relevant Ethics Committee. Approvals for WP3A (interviews with commissioners and service managers) will be sought from The Open University Human Research Ethics Committee before the start of the project. Approval for parts B and C (case studies and co-production) will be sought from a Social Care Research Ethics Committee during the first 9 months of the study. We have comprehensive experience of obtaining ethical approvals for studies of this kind, including those involving people who lack capacity and ethnographies with people with a learning disability who are dying. There are important ethical considerations with regards to informed consent, power imbalance, confidentiality, and the management of distress around a sensitive research topic. Interview topic guides and observation guides will be included in the application with associated covering letters, information sheets (including in easy-read and video format), consent forms and de-brief (including complaint procedures). In the ethnographic field work (case studies) care will be taken to ensure that people are happy to be observed and have the researcher (and in some cases, co-

researcher) 'hanging out' with them using 'process consent'. For those with communication difficulties, familiar accessible communication methods will be used. We will ensure that all WP3 participants (including families, caregivers and staff) are provided with signposts where they might get help if questions or concern arise. Furthermore, the research team will pay close attention to issues of mental capacity, in accordance with the Mental Capacity Act 2005. This includes the decision whether to take part in research. If the person lacks capacity to make this decision at this time (which may be due to their learning disability or to the fact that they are ill), the advice of a consultee (someone who knows them well) will be sought. However, we will make every effort to maximise their capacity by using accessible information materials and consent forms, explained face to face with each participant by the researcher and, where appropriate, with someone who knows the participant well.

General Data Protection Regulation (GDPR) legislation will be followed for data security and best practice in managing and anonymising data storage, analysis and outputs. Transcribed data will be anonymised and all identifiable features removed. All data will be stored on University secure systems, password protected and accessible only to the research team. For shared data and project materials/protocols/outputs/anonymised data SharePoint will be used hosted by Kingston University.

## Multiple long-term conditions (MLTC) - study within a project (SWAP)

**SWAP Lead:** Prof Irene Tuffrey-Wijne (Kingston University)  
in collaboration with Prof Andre Strydom (Kings College London)

**Background and rationale:** There is a very high prevalence of multiple long term conditions (MLTC) among people with a learning disability, e.g. asthma, diabetes, heart conditions, dementia, epilepsy, obesity. In this SWAP, we will use data from NHS England's LeDeR programme (Learning from Lives and Deaths of People with a Learning Disability and Autistic People). LeDeR data from 6,775 adults with a learning disability who died between 2018-2020 show that they had on average 8 long term conditions when they died; only a small proportion (3%) had three or fewer conditions.<sup>65</sup> We will do a focused analysis of a sub-sample of LeDeR data, in order to explore the care received at the end of life by people with a learning disability who had 5 or more long term conditions when they died. Over 3000 deaths of people with a learning disability in England are reported to LeDeR annually and subject to an Initial Review. A proportion of these (around 500) are forwarded for a more in-depth review ("Focused Review"). Focused Reviews are carried out by a trained reviewer, who explores in more detail the life and death of the person and any examples of good practice and areas where care could be improved. Initial Reviews are forwarded for a Focused Review if the initial reviewer feels there is significant learning to be gained from the death, or if the family requested it. All deaths of people from ethnic minorities are also subject to a Focused Review. The review data are analysed at Kings College London who produce an annual report. However, this analysis is broad and mostly quantitative.

**SWAP aim:** To investigate concerns and potential issues with care, and positive practice, during the last year of life of people with a learning disability who had MLTC; and to identify learning.

**Methods:** Detailed qualitative analysis of focused reviews (including any uploaded medical notes) of the deaths of 100 people with a learning disability who had MLTC, to gain understanding of the story and the issues. The sample consists of the latest available dataset reviews (n=100, to ensure feasibility, likelihood of saturation, and a sufficiently diverse sample) that meet the following criteria: (1) The person who died had 5 or more long term conditions at time of death; (2) the LeDeR reviewer was able to speak to the GP; (3) the LeDeR reviewer held conversation(s) with someone involved in the care of the person who died; (4) the review includes a pen portrait of the person who died; (5) the review contains free text in response to the following two standard Focused Review questions: (1) identify any issues, concerns of potential issues with care, any learning or action (2) identify any positive practice that could benefit other people if the same was available to them. NOTE: Sampling will continue in reverse date order until n=100 is reached; this may include Focused Reviews of deaths occurring from January 2021 onwards (the start date of data reporting by King's College London). **Duration:** 15 months (from start of project)

**Outputs:** A stand-alone report and paper submitted to peer-reviewed journal, detailing the issues identified with regards to positive practice and concerns around end of life care, lessons learnt, and recommendations for practitioners, policy makers and commissioners. The report will be shared with NHS England, who may include the findings in the LeDeR annual report. It will also feed into WP3.

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## FLOW DIAGRAM

