Palliative and end of life care research 2011-2018/19

Marie Curie and National Institute for Health and Care Research (NIHR) portfolio snapshot

January 2024

NIHR | National Institute for Health and Care Research

Marie Curie

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Glossary

ARCs = Applied Research Collaborations
CBI = NIHR Central Business Intelligence Team
CLAHRCs = Collaborations for Leadership in Applied Health Research and Care
CSO = Chief Scientist Office, Scotland
DHSC = Department of Health and Social Care
EME = Efficacy and Mechanism Evaluation Programme
ESP = Evidence Synthesis Programme
HEE = Health Education England
HRCS = Health Research Classification System
HSDR = Health and Social Care Delivery Programme
HTA = Health Technology Assessment Programme
i4i = Invention for Innovation Programme
JLA = James Lind Alliance
KCL = King's College London
PEoLC = Palliative and end of life care
PeolcPSP = Palliative and end of life care Priority Setting Partnership
PHR = Public Health Research Programme
MCPCRC = Marie Curie Palliative Care Research Centre, Cardiff University
MCPCRD = Marie Curie Palliative Care Research Department, UCL
MND Association = Motor Neurone Disease Association
MSA = Multiple system atrophy
PSP = Progressive supranuclear palsy
MS = Multiple sclerosis
NCRI = National Cancer Research Institute
NIHR = National Institute for Health and Care Research
PGfAR = Programme Grants for Applied Research
RCGP = Royal College of General Practitioners
RfPB = Research for Patient Benefit Programme
UCL = University College London
UKCRC = UK Clinical Research Collaboration

Executive summary

Everyone will be affected by dying, death and bereavement, in different ways and potentially at multiple times in their life.

Although up to 82% of people who die could benefit from PEoLC (Murtagh, 2014) funding to produce the evidence needed to ensure high quality care for all at the end of life is extremely low, at 0.21% of all health-related research in the UK in 2018. Of approximately £2.5 billion of health-related research project and programme investment in the UK in 2018, only £5,489,591 was spent on PEoLC research (UKCRC, 2020).

In 2018 NIHR was identified as the largest funder of PEoLC research in the UK (46%), followed by Marie Curie as the second-largest funder overall (34%) and the largest charitable funder. All governmental research funders in the devolved nations have funded PEoLC research, and they, and a small number of other charitable funders and research councils, make up the remaining 20% of funding in the area *(ibid)*.

The analysis presented in this report is the culmination of exploratory collaborative work to understand Marie Curie and NIHR's combined investment in PEoLC research. To our knowledge, this is the first attempt of its kind to take a comprehensive and detailed deep dive into research funding in this challenging and important area of research. Our aim was to identify and better understand our joint portfolio to help us to identify gaps in funding provision and funding mechanisms that a future research agenda should address and to raise awareness of the low research investment in this area. We draw attention to the caveats and limitations to our approach and the analysis and these are set out in section 3.5.

Summary of the analysis

- Our analysis indicates that between 2011 and 2018/19 the combined NIHR and Marie Curie portfolio of PEoLC projects and programmes included 189 awards (109 NIHR and 80 Marie Curie awards) totalling a £77.3 million combined investment (NIHR £51.4 million, Marie Curie £25.9 million)[1].
- NIHR's investment in PEoLC research represents roughly 1.4 - 2% of the total NIHR research portfolio every year. For NIHR, this percentage has remained consistent over time, with the increased funding in the area between 2011 and 2018 happening in tandem with an overall increase in NIHR funding. Marie Curie's investment in PEoLC has remained relatively constant at about £3 million per year after an initial increase in 2011/12.
- The most common award types for both funders were research project and programme awards (149), with only a few personal (27) and smaller infrastructure (13) awards. Not all NIHR funding programmes were represented; there was good representation by RfPB, HSDR and HTA programmes but no awards were identified for EME, PHR and i4i NIHR research programmes[2].
- Investments in research were distributed across England, with pockets of funding within the devolved nations, but there was variation in spend across the UK. Host organisations located in Northern Ireland and the South West region of England received least funding, followed by the West and East Midlands. In contrast, host organisations in London and Yorkshire/Humber received most funding.
- When analysed according to the Health Research Classification System (HRCS) health categories, most awards were associated with 'generic health relevance' rather than a particular disease or condition. Where specific conditions were addressed, most awards concentrated on care for people with cancer, followed by neurological and respiratory conditions. Within neurological conditions, most studies addressed dementia. There was also some funding for motor neurone disease (MND), but next to nothing addressing the potential end of life care needs of people with with multiple sclerosis (MS), Parkinson's disease, progressive supranuclear palsy (PSA) and multiple system atrophy (MSA). Only a small number of awards addressed frailty and multi-morbidities.

[1 and 2] Note that this excludes NIHR infrastructure awards.

- Other health categories not frequently addressed were Stroke; Oral, Gastrointestinal, Renal, Urogenital and Cardiovascular conditions; and Mental Health.
- The majority of the funded research portfolio focused on treatment evaluation, disease management and health services research, which suggests that much of this investment related to the health and care needs of those receiving palliative and end of life care, their carers and families rather than early phase clinical research.
- Most research studies focused on care provided within hospital settings, with other studies focusing on home, hospice, primary care, care home and community settings. This list includes research where research was carried out in more than one setting.
- With the exception of age and a small number of studies addressing experiences of LGBT communities, there was a dearth of research addressing PEoLC with respect to protected characteristics and the needs of different groups of people.
- Study populations tended to include a mix of research participants, for example, patients, carers and health and social care professionals. There was a lack of research studies into volunteering (only a small number of awards funded by Marie Curie in collaboration with Dimbleby Cancer Care) or specifically addressing the needs of families, carers, friends and or communities. A lack of methodological studies in the area was also observed.

Considerations for the future

Based on the analysis and the challenges, we conclude with the following points that research funders, researchers and policy makers may consider in relation to future work.

For research funders:

- Future work related to further analyses of this portfolio might include:
    - o expanding to include relevant NIHR infrastructure investments
    - o geographic spread of NIHR CRN recruitment sites for PEoLC projects
    - o different models of NIHR CRN support for hospice and community PEoLC research
    - o assessment of outcomes and impacts emerging from the joint research portfolio, including those related to influencing policy and practice in PEoLC in the UK, and development of case studies to illustrate how impact is achieved and where charitable and government funders can complement each other's funding mechanisms
    - o maintaining, developing and adapting the coding framework to enable tracking of the PEoLC portfolio in the long term, enabling strategic oversight and planning of future research investment.
- Our analysis shows opportunities for expanding research which investigates conditions not commonly studied, where relevant and appropriate. This might include the categories of Stroke, Oral and Gastrointestinal, Renal and Urogenital, Cardiovascular, and Mental Health; as well as end of life care needs for people with multiple system atrophy (MSA), Parkinson's, progressive supranuclear palsy (PSP) and multiple sclerosis (MS).
- Further research could also address gaps in investigation into the needs of end of life carers and volunteers.

- Identify ways in which to diversify the geographic spread of research investment across the UK, for instance, enabling increased investment in Northern Ireland, South West of England and the West and East Midlands, in addition to supporting existing centres of excellence in London and Yorkshire.
- Support research into PEoLC provided in the community, care homes, primary care and home, where more and more care will be provided in the future.
- When undertaking portfolio reviews, adopt a collaborative approach that meets the needs of the partners involved. This includes developing a collaborative review methodology from the outset to build consensus around common issues that may arise, e.g. terminology, definitions, inclusion/exclusion criteria, coding, ways of working, resource and feasibility. Ensure portfolio review activities are adequately resourced from the outset.

For researchers

- Given the gaps identified through this analysis, consider investigating conditions not commonly identified in the analysis, such as Stroke, Oral and Gastrointestinal, Renal and Urogenital, Cardiovascular conditions and Mental Health as well as end of life care needs for people with multiple system atrophy (MSA), Parkinson's, progressive supranuclear palsy (PSP) and multiple sclerosis (MS).
- Based on the analysis, develop more research into PEoLC provided in the community, care homes, primary care and home, where more and more care will be provided in the future.
- Design research to address issues of inequity in access to and experience of PEoLC related to protected characteristics, in particular sex/gender, ethnicity, religion/belief and disability.
- Develop research into the specific needs and experiences of carers / families and volunteers.
- Provide meaningful information on the research question when putting together funding applications and include adequate information in the title, abstract and summary to convey the focus and scope of the work and who it is intended to benefit.

For policy makers

- There is a signficant body of PEOLC research that decisionmakers can draw on to inform their work.
- Identify the most important evidence gaps and needs in PEoLC and work with researchers and funders to address them.
- Be aware of the lack of evidence addressing inequities in access to and experience of palliative and end of life care.

What we have learned through this portfolio review process

- Resourcing a significant portfolio analysis project that spans the resourcing capabilities of two very different organisations is challenging and requires flexibility, active relationship management and ongoing reflection to work effectively.
- Engaging a varied group of passionate subject matter experts, policy colleagues and those with lived experience to advise, support and steer is invaluable.
- Effective portfolio analysis relies on high quality information in the title, abstract and summary to convey the scope of the research and its relevance to a particular field of research interest. High quality information in titles and abstracts ensures awards and research are picked up in systematic review and portfolio insight work undertaken by researchers and research funders alike and enables the reduction of bureaucracy in research by facilitating secondary analysis.
- Working with PEoLC data can have an emotional impact for some and this should be highlighted at the outset, with signposting to appropriate support where needed.

1. Background: Palliative and end of life care research in the UK

Palliative care is an approach that improves the quality of life of people with life-limiting illness (adults and children) and their families, carers and friends. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual (WHO, 2020).

The need for palliative care (generalist and specialist) has been conservatively estimated to be between 69 and 82% of all deaths in high-income countries (Murtagh, 2014), based on deaths in England between 2006 and 2008. A publication currently under review with more recent figures has found an even higher percentage of 90% (Fantoni et al, 2023). Population analyses predict that as a result of our ageing population, there will be more than 100,000 more people dying in England and Wales by 2040, an increase of 25%, up from 501,424 in 2014 to more than 628,000 deaths per year (Etkind et al, 2017). Additionally, increased need for palliative care will be driven by more complex needs due to chronic progressive illnesses with long disease courses (such as dementia) and diseases with complex symptoms, such as cancer (Etkind et al., 2017).

However, the evidence base for PEoLC is underdeveloped (Parry et al., 2013) and research in this area is underfunded compared with studies into curative treatments of life-limiting conditions (Higginson, 2016; Hasson et al., 2020). A previous analysis of cancer-related research funding carried out by the National Cancer Research Institute (NCRI) on behalf of Marie Curie showed that in 2013, of a total of £503 million spent on cancer research by NCRI partners in the UK, only £3.08 million or 0.61% was spent on PEoLC research (NCRI and Marie Curie, 2015). However it is important to look at research spend beyond that related to cancer, as palliative care can also benefit people with non-cancer conditions through timely identification of deteriorating health, holistic assessment of needs, management of pain and other problems, and person-centred planning of care (Murray and Sheikh, 2008 and Murray et al, 2017).

The UK Clinical Research Collaborative (UK CRC) undertakes regular data collection exercises, approximately every 5 years, to identify and analyse health-related research investment in the UK. This includes research grants and awards dealing with any specific health condition as well as research of generic health relevance (UKCRC Health Research Classification System). The most recent data collection was published in 2020, reviewing research grants and awards active in 2018. It included government funders as well as charitable organisations via the Association of Medical Research Charities (AMRC).

According to the most recent UKCRC analysis of £2.5 billion of UK health-related research projects and programmes active in the UK in 2018, only 0.21% was spent on PEoLC research (UKCRC, 2020). This was a slight increase from 0.16% in 2014 (UKCRC, 2015). However, as illustrated in Figure 1, there is a clear mismatch between the growing need for PEoLC and investment into creating a strong evidence base.

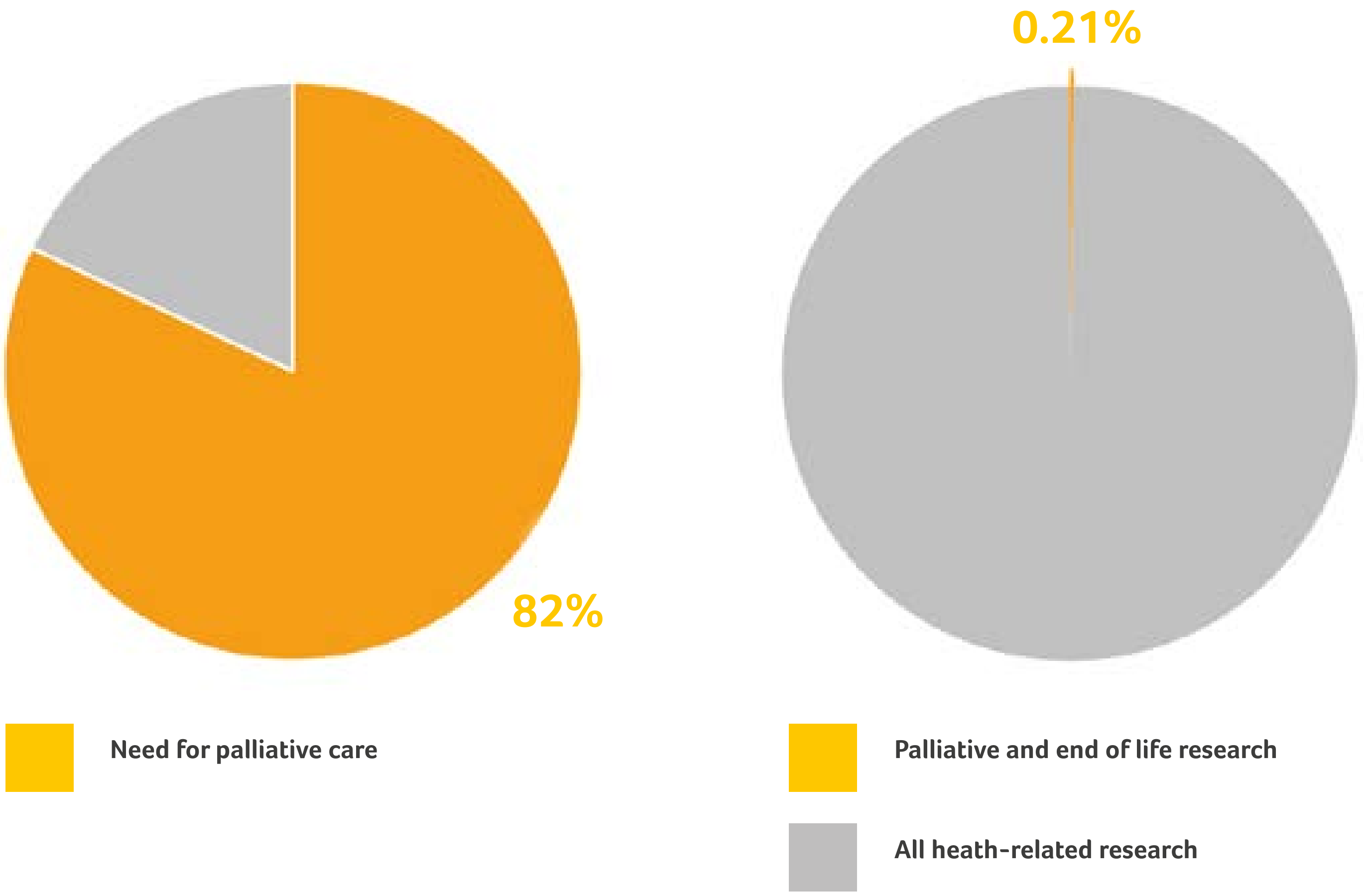

Figure 1: Comparison of the need for palliative care in high income countries (‘up to 82% of those who die need palliative care’; Murtagh, 2014) with investment in PEoLC research in the UK in 2018 (UKCRC, 2020).

2. Introduction: aims and objectives

Within the research funding landscape, both NIHR and Marie Curie play differing but potentially complementary roles to support PEoLC research. Both organisations enable and support research throughout the research lifecycle and translational pathway, e.g. from investigating initial concepts through to front-line care and support, identifying joint priorities for research, or working collaboratively. In 2015, Marie Curie and NIHR both took part in the Palliative and end of life care Priority Setting Partnership (PeolcPSP) with the James Lind Alliance (JLA) that asked carers, health and social care professionals, and patients about their questions and evidence needs in PEoLC (PeolcPSP, 2015). The PSP identified 83 questions and prioritised 10 broad research priorities. A subsequent grant mapping exercise that mapped the questions identified to research active in the UK in 2014 (UKCRC 2015), showed that for some questions, there was no or very little active research as well as no relevant systematic review (Todd Fordham et al, 2017).

Marie Curie has funded research since its inception and has focused solely on PEoLC research since 2010, increasing its research investment in this space substantially in 2010 to between £2.5 to 3 million per year. The charity currently funds two research centres, at University College London (UCL) and Cardiff University. It also invests in an annual, open and competitive Research Grants Scheme that provides a consistent and reliable funding source for the PEoLC research sector and has included partnerships with organisations such as Dimbleby Cancer Care, Chief Scientist Office, Scotland, Motor Neurone Disease Association (MNDA), the Brain Tumour Charity and Pancreatic Cancer UK.

Marie Curie also invests in capacity building by funding Academic Research Fellows in a model of joint working between university hosts and Marie Curie hospices, and by supporting four Research Professorships at its centres. The charity supports PEoLC research nurses in its own services and supports its staff to be evidence-led by making available small research grants to address evidence gaps in any area of the charity, including policy and clinical practice. In addition, a new Research Impact Fund has recently been established, to support the next steps for research to impact on policy and/or practice.

NIHR's mission is to improve the health and wealth of the nation through research (NIHR, 2021). Funded by the Department of Health and Social Care (DHSC), NIHR focuses on the elements of the 'innovation pathway' from early translational research through clinical research and on to applied health and social care research. With a budget of over £1.2 billion[3] NIHR delivers its mission through six core workstreams: funding high quality research; investing in world-class expertise, facilities and a skilled workforce; partnering with patients, service users, carers and communities; attracting, training and supporting the best researchers; collaborating with other public funders, charities and industry; and funding applied global health research and training. In June 2021, NIHR published Best Research for Best Health: The Next Chapter which sets out NIHR's priorities now and into the future.

As mentioned earlier in this report, in 2018 only 0.21% of all health-related research project and programme funding in the UK (excluding privately funded research and infrastructure support) addressed PEoLC (UKCRC, 2020). Considering these limited funds for PEoLC research, at the outset of this project, we wanted to explore Marie Curie and NIHR's contribution to PEoLC research, and to understand what difference our combined investments in PEoLC research were making. Fundamentally, we wanted to shed light on how and if these investments were making a difference. What became clear very early in the work was that to be able to achieve this aim, we first needed to

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[3] Total NIHR spending 2021/22 including Official Development Assistance (£m) is 1,324.4. NIHR Annual Report 2021/2022: https://www.nihr.ac.uk/documents/annual-report-20212022/32238

clarify what should – and should not – be included from the NIHR portfolio. So we focused our attention in the first instance on understanding how PEoLC research funding had been allocated and whether there were synergies and/or gaps in the portfolios of the two largest funders of PEoLC research. Both funders recognise that our aim should be to ensure funding efforts complement each other, add value, and that synergies are optimised to help maximise the chances of impact and efficiency of public and charitable funding. To do this, we need to better understand where and how our collective investment in PEoLC research is being allocated.

This report is the culmination of collaborative work by both Marie Curie and NIHR to better understand our research portfolios. To our knowledge, this is the first attempt of its kind to take a collaborative deep dive into this challenging and important area of research. By doing so, we demonstrate where investments are being made, and identify gaps in PEoLC care research that future research should address.

This report has three main objectives:

1. clearly identify and better understand the investment in PEoLC research across combined portfolios of Marie Curie and NIHR between 2011 and 2018/19
2. provide a comprehensive description of our combined investment in PEoLC using available health research funding management data, in terms of funding mechanisms, type of research, topics addressed, by whom and in which locations
3. share insights, identify gaps, raise awareness and generate learning about the portfolio to help funders, researchers and policy makers to better support PEoLC research.

The report has been prepared by the project working group – a unique opportunity to bring together research managers, researchers, data analysts, impact leads and palliative care experts from across both funders. The working group was supported by an independent project advisory group in its early stages, composed of patient and public involvement representatives, DHSC policy lead and senior clinical academics in PEoLC. Details of the membership of the project advisory group are provided in “Appendix 1: Project Advisory Group Members”.

This report provides NIHR, Marie Curie and the Department of Health and Social Care (DHSC) with a robust picture of PEoLC activities funded by NIHR and Marie Curie between 2011– 2018 (2019 for Marie Curie). The data offer insights into potential gaps, needs and challenges and has the potential to inform and complement future research funding efforts. It is anticipated that these insights will be used in a formative way to inform and strengthen impact and evaluation, business intelligence, organisational learning and other portfolio-related activities within both organisations. It is hoped that this report will also be of interest to other research funders, researchers, evaluation practitioners and members of the public.

By exchanging, reflecting and sharing our experiences, lessons learned and our approach, we aim to stimulate evaluative thinking, promote and encourage shared learning and transparency around funders’ monitoring, evaluation and learning activities and help foster future collaborative projects between funders and/or with other stakeholders.

3. Overview of Methods

This section details a brief overview of our approach to identify and better understand our combined investment in PEoLC research. Full details of the methodology and approach can be found in “Appendix 7. Detail of methods and approach”. This portfolio review consisted of multiple activities, as follows:

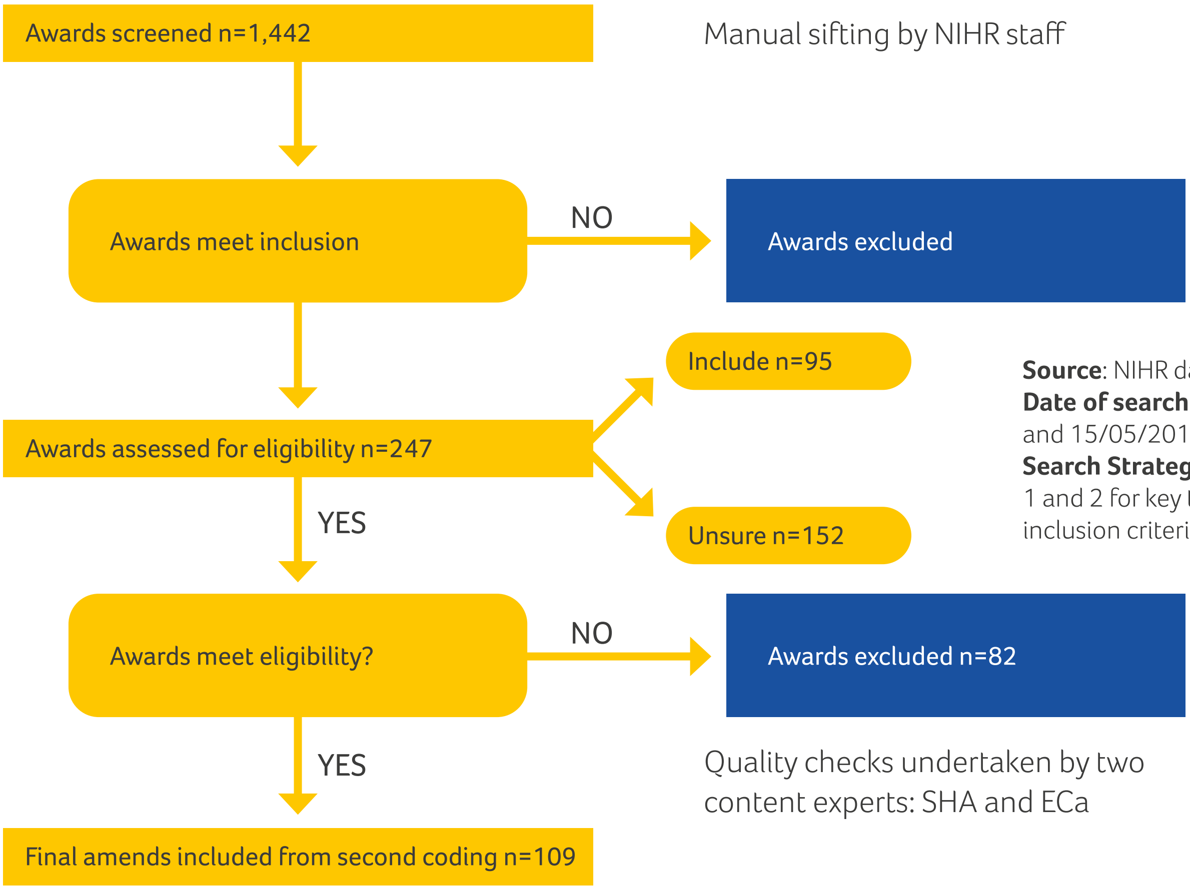
3.1 Analysis of publicly available funding data

UK research funding data included in the 2018 UK Health Research Analysis (UKCRC, 2020) was downloaded in MS Excel. Only the proportion of an award in 2018 allocated to Research Activity Code 7.2 (palliative and end of life care), and not the total award sum or total 2018 award sum, was included in our calculations.

3.2 Identification of NIHR PEoLC research

As all Marie Curie funded research is focused on PEoLC, there was no need to develop a search process for identifying relevant awards. Therefore, the first task for the portfolio review was to identify a comparable NIHR PEoLC research dataset.

We took a pragmatic decision to include NIHR awards that were available on InfoNIHR (a database containing awards funded by the NIHR that were active at any time on or after 1st April 2011 to present) plus research funded and supported through the NIHR Evidence Synthesis Programme and NIHR Research Schools. NIHR CCF managed Infrastructure awards and CRN Infrastructure data were excluded from this portfolio analysis. To extract awards not included



Manual sifting by NIHR staff

Source: NIHR data warehouses
Date of searches: 13/07/2017 and 15/05/2018
Search Strategy: See Appendix 1 and 2 for key terms and inclusion criteria

Quality checks undertaken by two content experts: SHA and ECa

Figure 2: Flow diagram illustrating the process of screening and selecting studies for inclusion in the NIHR dataset

on InfoNIHR Data, other NIHR dataset warehouse systems were searched on the same criteria. Two keyword searches were conducted on award titles and abstracts within the InfoNIHR and other warehouses (full search strategy depicted in “Appendix 3: Key words”). This identified a long list (n = 1442) of NIHR PEoLC awards that were active (at some point) between 2011 – 2018. Awards were screened against eligibility criteria (“Appendix 2: Inclusion and exclusion criteria to identify palliative care and end of life research funded by NIHR”), resulting in 109 eligible awards. Figure 2 details this approach.

3.2.1 Combining the NIHR and Marie Curie research datasets

The NIHR PEoLC dataset (awards active between 1 April 2011–15 May 2018) was combined with Marie Curie’s PEoLC dataset (awards active between 1 April 2011–30 September 2019) to produce a single ‘combined’ dataset. This combined funder dataset included funder, award title and reference, application abstract, lay summary, funding, award host institution, Principal Investigator, start and end date, and HRCS classification data.

3.3 Development and application of coding frameworks to the combined funder dataset

We developed a series of coding frameworks (i.e. setting, specific terminal condition, population, population age; protected characteristics and research focus) using a predominantly grounded approach, drawing on the UK Equality Act 2010 and previous work (Nelson 2020; Mularski et al 2007). The final coding frameworks can be found in “Appendix 4: New NIHR and Marie Curie Coding Frameworks”.

3.4 Analysis of the combined funder dataset and UKCRC dataset

3.4.1 UKCRC HRCS dataset

In this analysis, health-related research funding data are categorised using the UKCRC HRCS. The HRCS Health Categories dimension captures the health or disease area while the Research Activity Codes (RAC) classify the types of research activities. In the UKCRC analysis, the application of the HRCS framework allows up to five codes per health category and research activity per research award. This means that the value of an award can be equally split across two or more research activities and only the amount coded to the relevant code is counted. NIHR and Marie Curie code their respective funded research portfolios as a business as usual process. Each award is attributed to at least one Health and one Research Activity code.

3.4.2 Analysis of sum of research funding

Research funding has been calculated as a flat profile per year rather than actual spend. This means that the total award value has been equally split across all of the months it is active within a given financial year across all the financial years it is active. Within our comparative funding analysis, we included data from financial years 2011/12 – 2017/18 to ensure having full years’ worth of data. Figures were not corrected for inflation.

3.4.3 Analysis of coding frameworks

As all coding frameworks allowed for double coding (i.e. an award can be allocated to more than one code per coding framework), awards were analysed in two ways:

Every code contributed wholly to an award and was therefore counted as a whole number.

According to equal proportions (weighting). This means that where awards received multiple codes from the same coding framework, each code contributed an equal proportion towards each award. For an award with three codes attributed, each code would contribute one-third equally.

3.4.4 Geo Mapping

The mapping analysis of the NIHR and Marie Curie PEoLC combined dataset was completed using the awards’ postcode centroids to generate X and Y coordinates for each host organisation. The host organisations awards were aggregated, dictating the size of the spheres seen, for the individual NIHR and Marie Curie distribution maps with the Devolved Administrations boundaries, from the Office for National Statistics Open Geography Portal (Figure 6).

3.5 Limitations of and Caveats to our approach

1. NIHR CCF managed infrastructure (Centres, Units and Collaborations, etc.) and support (CRN) was excluded from this analysis. As a result, the NIHR dataset is most likely an underestimate of NIHR's funding and support in research that is directly or indirectly applicable to PEoLC.
2. Coding of the combined dataset using the six frameworks was reliant on the information available in the source funding administrative data (i.e. titles, abstract and summaries of award data where contracts have been awarded). Some awards did not provide adequate detail in their abstracts or plain summaries to allow for coding; thus in some cases the nature of research may be under-represented where that information was not explicitly mentioned. An outline of some of the challenges encountered when coding the NIHR and Marie Curie awards can be found in "Appendix 6: Notes on coding and classification of research portfolios ".
3. Coder bias is inevitable. Coders were coding based on their own knowledge and experience which was wide ranging across the team so there is a possibility that a potential bias was introduced when interpreting the codes in the coding framework. However, this was mitigated, as much as possible, by going through the additional effort of blind double coding the research awards, guided by an agreed set of inclusion and exclusion criteria and the six coding frameworks. In addition, discrepancies identified were resolved through group discussion between the coding groups which provided further reassurance. Such an approach minimised the likelihood that the coders influenced award inclusion or analysis.
4. Geographical spread of research awards was only undertaken at the host institution level. This only tells us which institutions successfully obtained funding and not necessarily where (i.e. the actual location) the research was taking place.
5. Funding figures were not corrected for inflation.

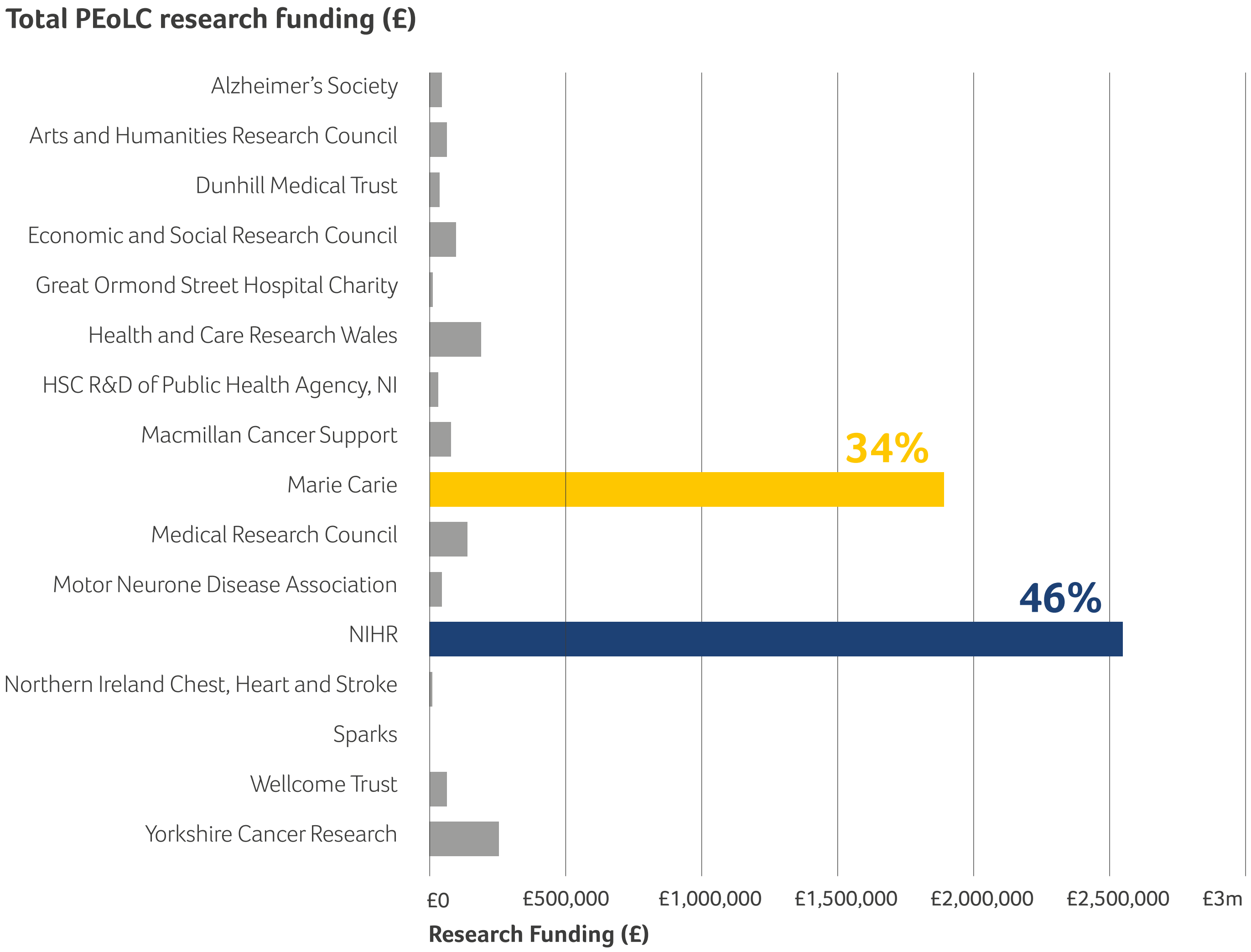
4. Findings

4.1 Analysis of publicly available funding data for 2018

Our analysis of the UKCRC 2018 dataset of health-related research project and programme funding in the UK in 2018 identified NIHR and Marie Curie as the two largest funders in PEoLC research (the dataset excludes commercial and large infrastructure funding though the former is of very limited importance in PEoLC research). NIHR provided 46% and Marie Curie 34% of the £5,489,591 of research funding identified as relevant to the area in 2018.

We also found that of the 123 UK research funding organisations with research funding data included in the UKCRC dataset, only 16 funded PEoLC research in 2018, all to a limited degree. Figure 3 shows the amounts of funding specifically for PEoLC research provided by UK research funding organisations according to the UKCRC dataset (UKCRC, 2020).

These 16 funding organisations include government health research agencies in England, Wales and Northern Ireland. The PEoLC research investment of the Chief Scientist Office in Scotland was not separately reported in the HRCS database. CSO co-funded three awards with Marie Curie at a value of £87,863 for the year 2018 (annual value only). Of the Research Councils, MRC, ESRC and AHRC feature in the list. A number of research



Total PEoLC research funding (£)

Figure 3: Allocated research funding for PEoLC by research funder using HRCS data submitted as part of the 2018 UKCRC analysis (UKCRC, 2020). Only the proportion of funds coded to Research Activity code 7.2 is included where awards were double or triple-coded.

charities concentrating on specific conditions such as dementia, cancer, motor neurone disease or heart disease (MND Association, Alzheimer's Society, Macmillan Cancer Support, NI Chest Heart and Stroke), groups of people such as younger or older people (Dunhill Medical Trust, GOSH, Sparks), geographical areas (Yorkshire Cancer Research) and generic health (Wellcome) fund PEoLC research at a low level.

There are 90 awards included in the HRCS dataset that were active in 2018 and were coded at least in some proportion to Research Activity Code 7.2. The total funds coded as PEoLC research are £5,489,591.

The proportional and total funding values are extremely low, compared to other research areas. An analysis of another highly important but under-funded area of research, pregnancy, found that £40.9 million was spent in 2017 on pregnancy research (RAND, 2020), more than 5 times what we have found to have been spent on PEoLC research in 2018. The database of the National Cancer Research Institute (NCRI) lists a total of £673 million spend on cancer research in the UK in 2017/18 (NCRI, 2021). The median cost of a drug clinical trial between 2010-2015 was found to be $3.4 million for phase I trials involving patients, $8.6 million for phase II and $21.4 million for phase III trials (Martin et al 2017).

Many disease-specific charities and other organisations tend to focus their research activities on finding a cure. This is an important contribution to the health of the nation and is valuable for people faced with the diagnosis of a life-limiting illness. However, as Dame Cicely Saunders put it so well when developing her vision for the hospice movement, 'How people die remains in the memory of those who live on' (Saunders, 1989). Everyone will be affected by dying, death and bereavement, in different ways and potentially at multiple times in their life, and therefore PEoLC deserves to receive more attention from a research perspective than it currently does. It also highlights the discrepancy between the volume of investment in research that aims to increase quantity vs quality of life.

4.2 Descriptive analysis of the combined NIHR and Marie Curie research portfolio between 2011 and 2018/19

4.2.1 Overall allocated funding and funding schemes

The combined NIHR and Marie Curie dataset that was identified for this analysis includes 189 awards totalling £77.3 million combined investment in allocated funding in the timeframe. The data present a snapshot of the research funded by the two funders that was active between 2011 and 2018 (NIHR) or 2011 and 2019 (Marie Curie).

The combined portfolio is made up of:

- Marie Curie: 80 awards active between April 2011 and September 2019 (with allocated funding between 2010 and 2024) equating to **£25,982,203**. These awards include research centres, research projects and programmes, fellowships and studentships.
- NIHR: 109 awards active between April 2011 and May 2018 (with allocated funding between 2007 and 2024) equating to **£51,357,611**. These include NIHR Research Programmes, schools, fellowships and evidence synthesis research support awards. NIHR CRN and infrastructure (centres, units, collaborations, etc) data are not included in this portfolio review analysis.

Table 1 shows the breakdown of research by type of funding scheme, number of awards, and funder.

Table 1: breakdown of the combined dataset by funding scheme type. Funding figures are the sum of full award spend on all awards active between April 2011 and May 2018 (NIHR) or July 2019 (Marie Curie) including award years before and after those dates if awards were active beforeor after.

Funding Scheme Type	Marie Curie (#awards)	NIHR (#awards)	Grand Total (#awards)	Funding
Capital/Infrastructure/Support[a]	10	3	**13**	**£10,377,398**
Personal Award[b]	9	18	**27**	**£10,469,003**
Research Award[c]	61	88	**149**	**£56,493,413**
Grand Total	**80**	**109**	**189**	**£77,339,814**

[a] includes research support awards made by NIHR funded through the NIHR's Evidence Synthesis Programme

[b] includes professorships, fellowships and studentships

[c] includes research projects and programmes.

Marie Curie's infrastructure support in the past 10 years consists wholly of core grant support for its three Research Centres at University College London and Liverpool and Cardiff Universities. Core awards since 2010 were allocated for between one and five years, depending on the developmental stage of the Centres. For NIHR, this analysis excluded NIHR infrastructure, as it was not feasible within the resources available for this project to determine what percentage of infrastructure at the project level (e.g. NIHR CRN and CCF managed centres, units, collaborations, etc) was relevant to PEoLC. However, we recognise that NIHR's long term investment in infrastructure and research support plays a critical role in PEoLC research within the UK (e.g. NIHR ARCs South London and East of England[4], CLAHRC Greater Manchester and CRN). As one of the funding schemes for the NIHR Evidence Synthesis Programme (ESP) includes research support for Cochrane Reviews, it has been included in this analysis and three systematic reviews received funding for research support.

It is worth noting that, due to the difference in size of the two funders, awards that count as infrastructure for Marie Curie (core centre grants) are of a similar size (in the £500k/year area) as awards funded through, for example, NIHR's PGfAR (programme awards), which is why Marie Curie's centre funding was included in the analysis.

NIHR's 18 personal research awards with relevance to PEoLC between 2011 and 2018 are made up of 10 NIHR Fellowships, 1 Professorship, 5 NIHR/ HEE (Health Education England) Integrated Clinical Academic Programme awards and 2 related fellowships / Doctoral Training studentships.

Marie Curie's personal award funding (9 awards) consisted of three Professorship awards to two Professors, one fellowship (jointly funded with the Royal College of General Practitioners) and five PhD studentships held at the Marie Curie Palliative Care Research Department at UCL. Marie Curie has since introduced a new Senior Research Fellowship scheme in which universities act as hosts for fellows who work jointly across the university (3 days) and the local Marie Curie hospice (2 days), supporting capacity building at different levels.

[4] https://www.nihr.ac.uk/documents/applied-research-collaborations-research-themes-and-national-leadership-areas/28825

The most common award type for both Marie Curie and NIHR was research awards; 149 awards for research projects and programmes across both funders.

In the relevant funding period, Marie Curie supported 61 research awards. Table 2 shows the number of awards/grants made by different funding mechanisms.

Table 2: number of research awards supported by Marie Curie by scheme or department, noting those that have been co-funded by other funders/organisations.

Marie Curie scheme/department		Number of grants/awards
Marie Curie Research Grants Scheme (some co-funded with Chief Scientist Office, Scotland, the MND Association and Pancreatic Cancer UK)		50 project grants
Marie Curie Palliative Care Research Department (MCPCRD)		3 programme grants
Marie Curie co-funded with Dimbleby Cancer Care		8 project grants
	Total	**61 grants/awards**

Table 3: number of NIHR research awards funded by programme

NIHR programme/School		Number of research awards
Research for Patient Benefit		28
Health and Social Care Delivery Research (formerly Health Service Delivery Research)		21
Health Technology Assessment		20
Programme Grants for Applied Research		5
School for Primary Care Research		5
School for Social Care Research		3
Programme Development Grants		3
Evidence Synthesis (formerly Systematic Review programme)		2
Policy Research		1
	Total	**88**

During this period NIHR issued 88 research awards. **Table 3** shows the number of awards by NIHR research programme/School.

Our analysis did not identify any PEoLC research awards funded through the Efficacy and Mechanism Evaluation (EME), the Public Health Research (PHR), and the Invention for Innovation Programme (i4i) NIHR Research Programmes.

Figure 4 shows that NIHR's investment in PEoLC research has represented between approximately 1.4 and 2% of the total NIHR research funding (programme and personal awards), depending on the year[5]. The increase of actual allocated funding to PEoLC research by NIHR between 2011/12 and 2017/18 is mainly a reflection of an overall increasing amount of funding allocated for all awards by NIHR (see Figure 5), with the percentage of all funding allocated to PEoLC research more or less stable.

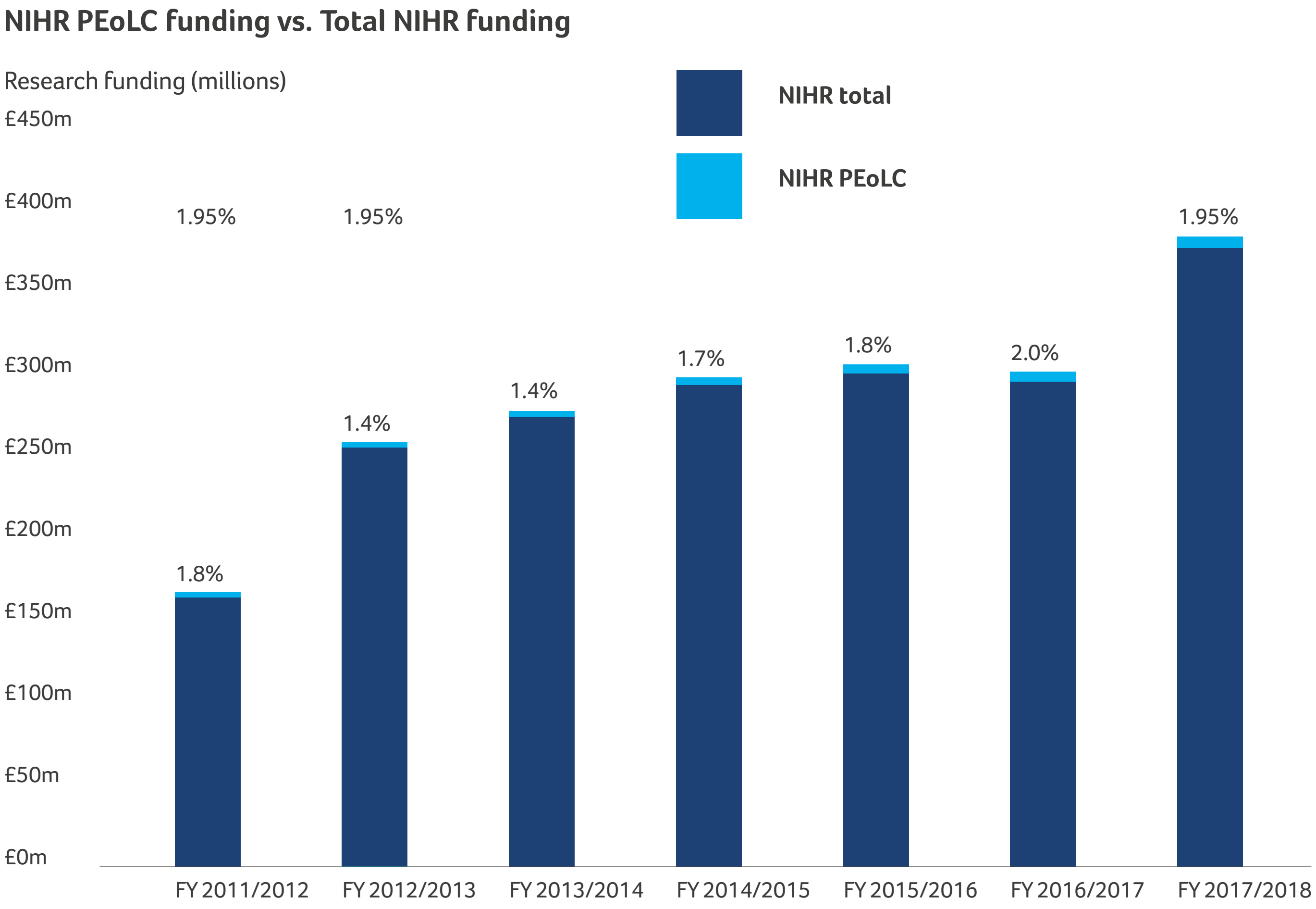


Figure 4: Column chart showing the proportion of NIHR's annual allocated funding in PEoLC as a proportion of total NIHR research funding (programme and personal awards) actual spend. Total NIHR research funding (data provided by NIHR CBI) excludes NIHR infrastructure and Schools' research funding.

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[5] Figures were provided by NIHR CBI and exclude NIHR infrastructure and Schools' funding.

Figure 5 depicts annual award value in PEoLC between financial years 2011/2012 and 2017/2018, which represents around £53 million out of the £77.3 million of combined investment and shows that Marie Curie's investment increased initially since 2011/12, as a result of a strategic decision in 2009 to concentrate its research funding on PEoLC research only, both in terms of overall investment as well as number of grants, with both figures then remaining relatively level over the timeframe reviewed.

NIHR and Marie Curie awards and funding

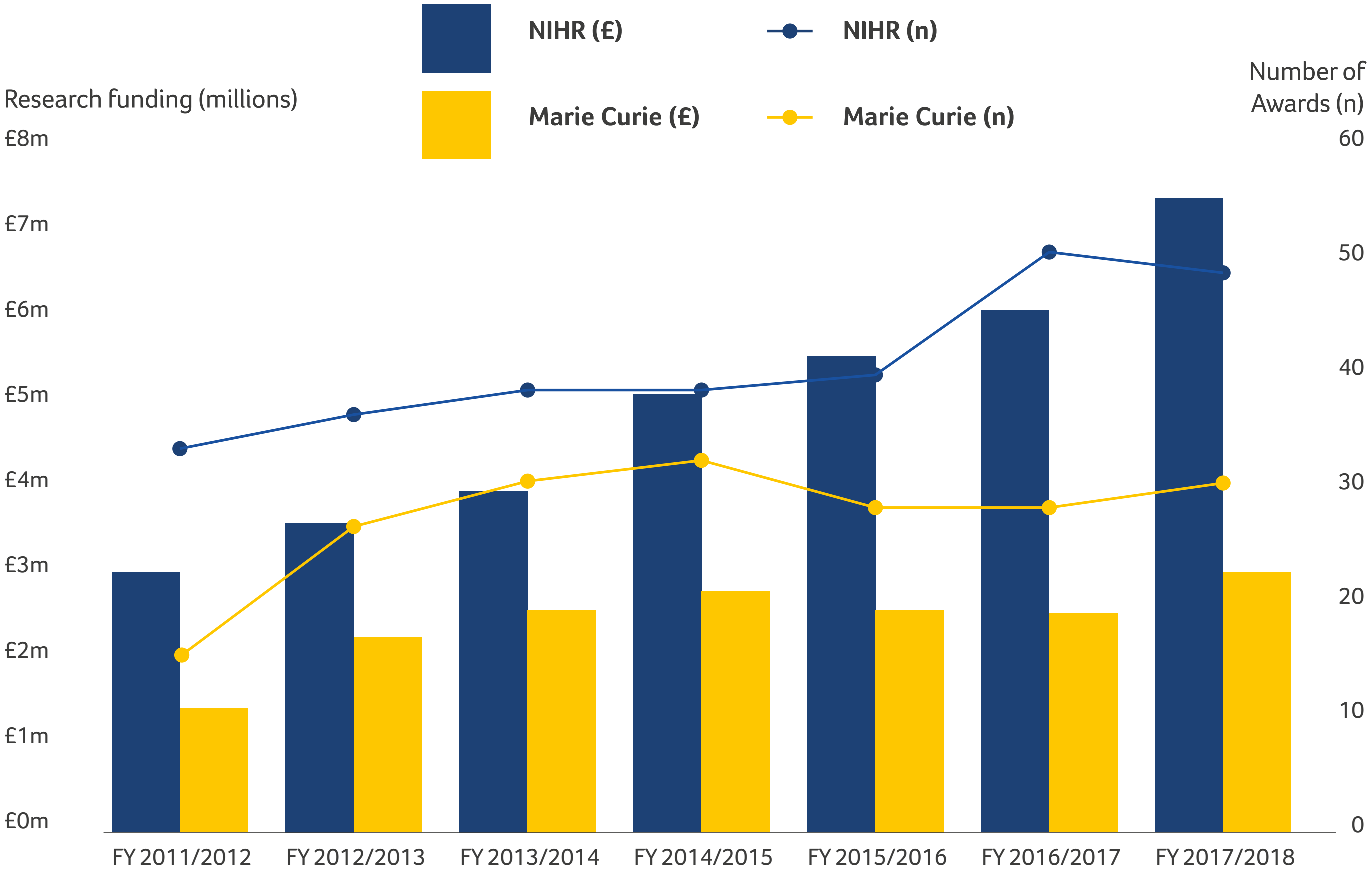


Figure 5: Column chart showing number of awards (n) and annual allocated funding in PEoLC research per funder per financial year for the window 2011/12 to 2017/18.

4.2.2 Geographical spread of allocated PEoLC funding

Table 4 shows numbers of awards and total amount of funding per region and devolved nation in the period 2011 to 2018/19, ordered by funding level.

Table 4: number of awards and award totals by region/devolved nation

Region of UK	Number of awards	Total
London	57	£28,956,849
Yorkshire and The Humber	23	£10,289,882
Wales	11	£7,250,293
North West	21	£7,190,759
South East	27	£6,885,055
Scotland	13	£4,639,007
North East	4	£3,469,453
East of England	10	£2,725,098
East Midlands	8	£1,956,671
West Midlands	6	£1,829,217
South West	3	£1,348,006
Northern Ireland	5	£794,525
Not included in Geospatial Analysis	1	£5,000
Total	**189**	**£77,339,815**

Figure 6 shows the geographical spread of Marie Curie and NIHR funded awards by number of awards per host organisation. Both NIHR and Marie Curie have strong representation in London which is not surprising considering London is the site of two established palliative care research centres, the Marie Curie Palliative Care Research Department (MCPCRD) at University College London (UCL) and the Cicely Saunders Institute at King's College London (KCL) which is closely associated with the King's College Hospital NHS Foundation Trust (KCL NHS FT).

The maps show that there is a wide breadth of coverage across England beyond London and pockets of funding within the devolved nations. There are only relatively small amounts of funding at Cambridge and Oxford Universities, showing a distribution of funding not typical of the

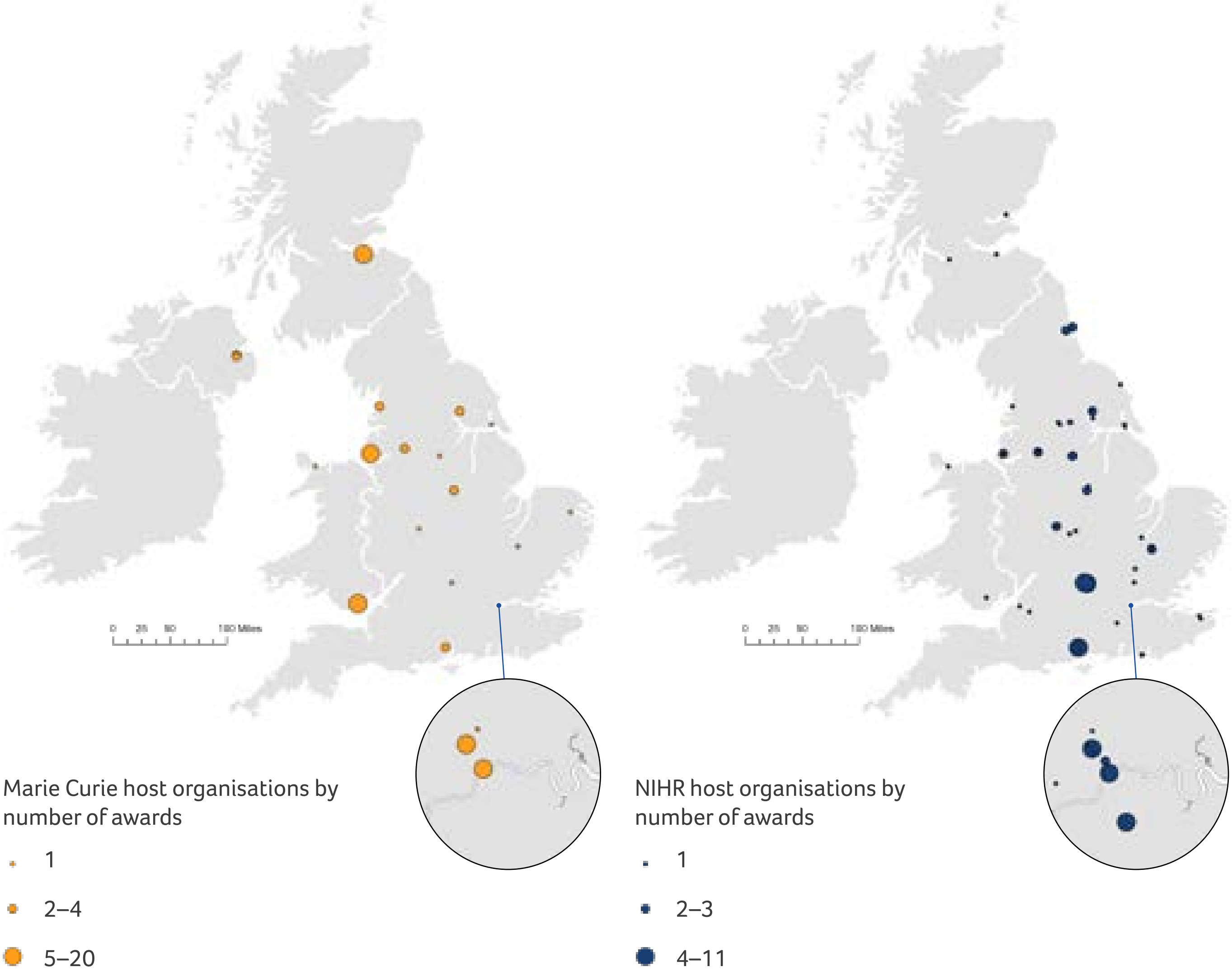


Figure 6: Geographic distribution of Marie Curie (left) and NIHR (right) awards by host organisation. The larger the sphere, the greater the number of research awards.

Source: Office for National Statistics licensed under the Open Government Licence v.3.0 **Source**: Contains OS data ©Crown copyright and database right (2022) **Source**: Marie Curie Palliative and End of Life Care (Grants included are grants active between 1 January 2011 and 30 September 2019) Prepared by the NIHR Centre for Business Intelligence

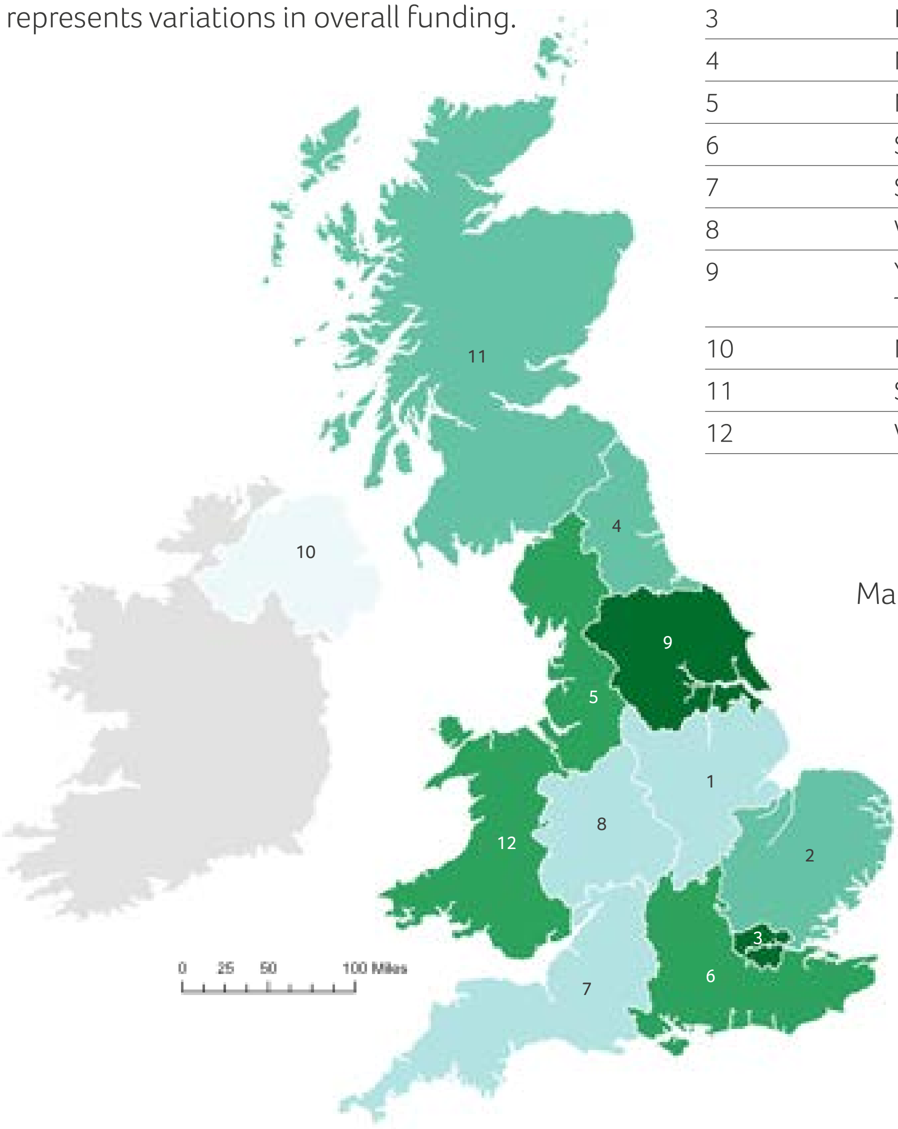
Source: Office for National Statistics licensed under the Open Government Licence v.3.0 **Source**: Contains OS data ©Crown copyright and database right (2022) **Source**: NIHR Palliative and End of Life Care (Awards active between April 2011 and August 2018) Prepared by the NIHR Centre for Business Intelligence commonly seen ‘golden triangle’.

Figure 7 shows that despite the wide breadth of coverage, there are variations in allocated funding across the UK. Host organisations located in Northern Ireland and the South West of England have received least funding from NIHR and Marie Curie, followed by West and East Midlands. In contrast, host organisations in London and Yorkshire/Humber have received most funding. However, funding in PEoLC research is so low across the country, that individual Programme Grants (of which there were five in the portfolio) and Marie Curie Centres (three in the dataset) have the ability to completely change the funding landscape for a particular region.

It needs to be noted that the geographical spread highlights allocated funding for host organisations only and does not necessarily depict the physical location/s of the research undertaken as some of the funding might have been awarded for multi-site studies with wider geographical spread of collaborative sites.

Figure 7: Distribution of combined NIHR and Marie Curie awards. The numbered geographic region is shown in the table along with the combined number of awards (per host organisation) within each region. The variation in shades of green represents variations in overall funding.

Geographical region	English region/ devolved administration	Number of awards by host organisation
1	East Midlands	8
2	East of England	10
3	London	57
4	North East	4
5	North West	21
6	South East	27
7	South West	3
8	West Midlands	6
9	Yorkshire and The Humber	23
10	Northern Ireland	5
11	Scotland	13
12	Wales	11



Marie Curie/NIHR awards sites by spend

⬜	£795k (Northern Ireland)
🟩	£1.8m – 2m
🟩	£2.7m – £4.6m
🟩	£6.9m – £7.3m
🟩	£10.3m (Yorkshire and The Humber) and £29m (London)

Source: Office for National Statistics licensed under the Open Government Licence v.3.0 **Source**: Contains OS data ©Crown copyright and database right (2022) **Source**: NIHR Palliative and End of Life Care (Awards active between April 2011 and August 2018) **Source**: Marie Curie Palliative and End of Life Care (Grants included are grants active between 1 January 2011 and 30 September 2019) Prepared by the NIHR Centre for Business Intelligence

4.2.2.1 Individual English regions

Table 5 below shows how the PEoLC funding delivered by NIHR and Marie Curie is spread across the English regions.

Table 5: NIHR and Marie Curie's PEoLC funding, by English region

Region	Funder	Number of awards	Total allocated funding	Organisations funded (number of awards)
London	NIHR	29	£16,034,127	1) King's College London (11) 2) King's College London NHS Foundation Trust (6) 3) University College London (4) 4) London School of Economics and Political Science (3) 5) Camden and Islington NHS Foundation Trust (1) 6) University College London Hospitals NHS Foundation Trust (1) 7) Central and North West London NHS Foundation Trust (1) 8) London School of Hygiene and Tropical Medicine (1) 9) Imperial College London (1)
	Marie Curie	28	£12.922,723	1) MCPCRD, University College London (15) 2) University College London (5) 3) King's College London (7) 4) Institute for Volunteering Research (1)
South West	NIHR	3	£1,348,006	1) University Hospitals Bristol NHS Foundation Trust (1) 2) Bristol NHS CCG (1) 3) Royal United Hospital Bath NHS Trust (1)
	Marie Curie	0	0	
South East	NIHR	23	£5,951,896	1) Cochrane Pain, Palliative and Supportive Care Group (based in Oxford) (6) 2) University of Southampton including University Hospital Southampton NHS Trust (6) 3) University of Oxford (6) 4) Brighton and Sussex University Hospitals NHS Trust (1) 5) Royal Surrey County Hospital NHS Foundation Trust (1) 6) Sussex Community NHS Trust (1) 7) East Kent Hospitals University NHS Foundation Trust (1) 8) University of Kent (1)
	Marie Curie	4	£933,159	1) University of Southampton (3) 2) University of Oxford (1)
East	NIHR	8	£2,274,817	1) Cambridge University Hospitals NHS Foundation Trust (2) 2) East and North Hertfordshire NHS Trust (1) 3) Cambridgeshire Community Services NHS Trust (1) 4) NHS Cambridgeshire and Peterborough CCG (1) 5) Royal Papworth Hospital NHS Foundation Trust (1) 6) University of Hertfordshire (1) 7) University of Cambridge (1)
	Marie Curie	2	£450,281	1) University of Cambridge (1) 2) University of East Anglia (1)

Region	Funder	Number of awards	Total allocated funding	Organisations funded (number of awards)
East Midlands	NIHR	4	£1,501,453	1) University of Nottingham (3) 2) Nottingham University Hospitals NHS Trust (1)
	Marie Curie	4	£455,218	1) University of Nottingham (4)
West Midlands	NIHR	5	£1,687,453	1) Heart of England NHS Foundation Trust (2) 2) University of Warwick (1) 3) Birmingham Women's and Children's Hospital NHS Foundation Trust (1) 4) University Hospitals Coventry and Warwickshire NHS Trust (1)
	Marie Curie	1	£141,764	1) University of Birmingham (1
North West	NIHR	11	£3,088,239	1) University of Liverpool (3) 2) The Christie NHS Foundation Trust (3) 3) Lancaster University (1) 4) NHS Central Manchester CCG (1) 5) NHS Liverpool CCG (1) 6) Central Manchester University Hospitals NHS Foundation Trust (1)
	Marie Curie	17	£9,473,296	1) Marie Curie Palliative Care Institute Liverpool (3) 2) University of Liverpool (2) 3) University of Lancaster (2) 4) University of Manchester (4)
Yorkshire and the Humber	NIHR	17	£9,473,296	1) University of York (3) 2) University of Sheffield (3) 3) Sheffield Teaching Hospitals NHS Foundation Trust (2) 4) University of Leeds (1) 5) University of Hull (1) 6) York Teaching Hospital NHS Foundation Trust (1) 7) NHS Bradford Districts CCG (1) 8) Hull and East Yorkshire Hospitals NHS Trust (1) 9) Scarborough and North East Yorkshire Health Care NHS Trust (1) 10) Bradford Teaching Hospitals NHS Foundation Trust (1) 11) Leeds Teaching Hospitals NHS Trust (1) 12) Kleijnen Systematic Reviews Ltd, a systematic review company (1)
	Marie Curie	6	£816,586	1) University of York (4) 2) University of Hull (1) 3) University of Sheffield (1)
North East	NIHR	4	£3,469,453	1) University of Newcastle upon Tyne 2) Northumbria Healthcare NHS Foundation Trust
	Marie Curie	0	0	

4.2.2.2 Devolved nations

Table 6 summarises how NIHR and Marie Curie's PEoLC funding has been distributed across the devolved nations.

Table 6: NIHR and Marie Curie's PEoLC funding by devolved nation

Devolved nation	Funder	Number of awards	Total allocated funding	Organisations funded (number of awards)
Scotland	NIHR	3	£3,038,439	1) University of Dundee (1) 2) Glasgow Caledonian University (1) 3) University of Edinburgh (1)
	Marie Curie	10	£1,600,568 (includes £215,678 of co-funding by the Chief Scientist Office)	1) University of Edinburgh (10)
Wales	NIHR	2	£2,471,151	1) Bangor University (1) 2) Velindre NHS Trust (1)
	Marie Curie	9	£4,779,142	1) Marie Curie Palliative Care Research Centre (MCPCRC), Cardiff University (4) 2) Cardiff University (4) 3) Bangor University (1)
Northern Ireland	NIHR	0	0	
	Marie Curie	5	£794,525	1) Ulster University (3) 2) Queen's University Belfast (2)

4.2.2.3 Summary

Host organisations located in Northern Ireland and the South West of England have received least funding from NIHR and Marie Curie, followed by West and East Midlands. In contrast, host organisations in London and Yorkshire/Humber have received most funding. However, it is important to note that funding in PEoLC research is so low across the country, that individual Programme Grants (of which there were five in the portfolio) and Marie Curie Centres (three in the dataset) have the ability to completely change the funding landscape for a particular region.

In the period of the analysis, NIHR funded research awards to host organisations in all English regions, Wales and Scotland, but not Northern Ireland. NIHR funding is centred on England but collaborates closely with the devolved administrations in Scotland, Wales and Northern Ireland. Marie Curie funded research awards to host organisations in all devolved nations and in all English regions except the South West and the North East.

For NIHR, our analysis identified that NIHR funded research in all English regions as well as Wales and Scotland. Most host organisations were within England. We identified one award contracted to a Cochrane Review team situated in Europe (not shown on Figures 5 or 6). Few host organisations are in receipt of NIHR funding for PEoLC research in the South West of England or in Scotland or Wales. Our analysis did not identify any NIHR PEoLC awards allocated to host organisations in Northern Ireland in the period under review.

4.3 Health Research Classification of the combined NIHR and Marie Curie dataset between 2011 and 2018/19

4.3.1 HRCS Health Categories

Figure 8 shows that the largest number of awards within the combined dataset (n=84) have been coded to Generic Health Relevance. Within the coding structure, Generic Health Relevance applies to research that is “applicable to all diseases and conditions and/or to general health and wellbeing of individuals” (HRCS, 2020). This is consistent with the fact that many aspects of PEoLC, including many specialist and generalist end of life care services, are not disease-specific. This is followed by awards relevant to Cancer (n=60). Palliative medicine has largely emerged from the care of people with cancer and often difficult and distressing symptoms at the end of life which explains the prevalence of awards relating to cancer care in the portfolio. Neurological (n=26) and Respiratory (n=16) are next in line in terms of frequency in the combined dataset. However, there are very few awards in the combined dataset for PEoLC addressing Stroke (n=2), Reproductive Health and Childbirth (n=2), Blood (n=3), Oral and Gastrointestinal (n=5), Cardiovascular (n=7), Mental Health (n=6), and Renal and Urogenital (n=5) health categories.

HRCS coding only allows for an overall description of the research portfolio and is not very granular, which is why we sought advice from the Advisory Group, to develop a further breakdown in some categories to understand the funding data better (see section 4.4).

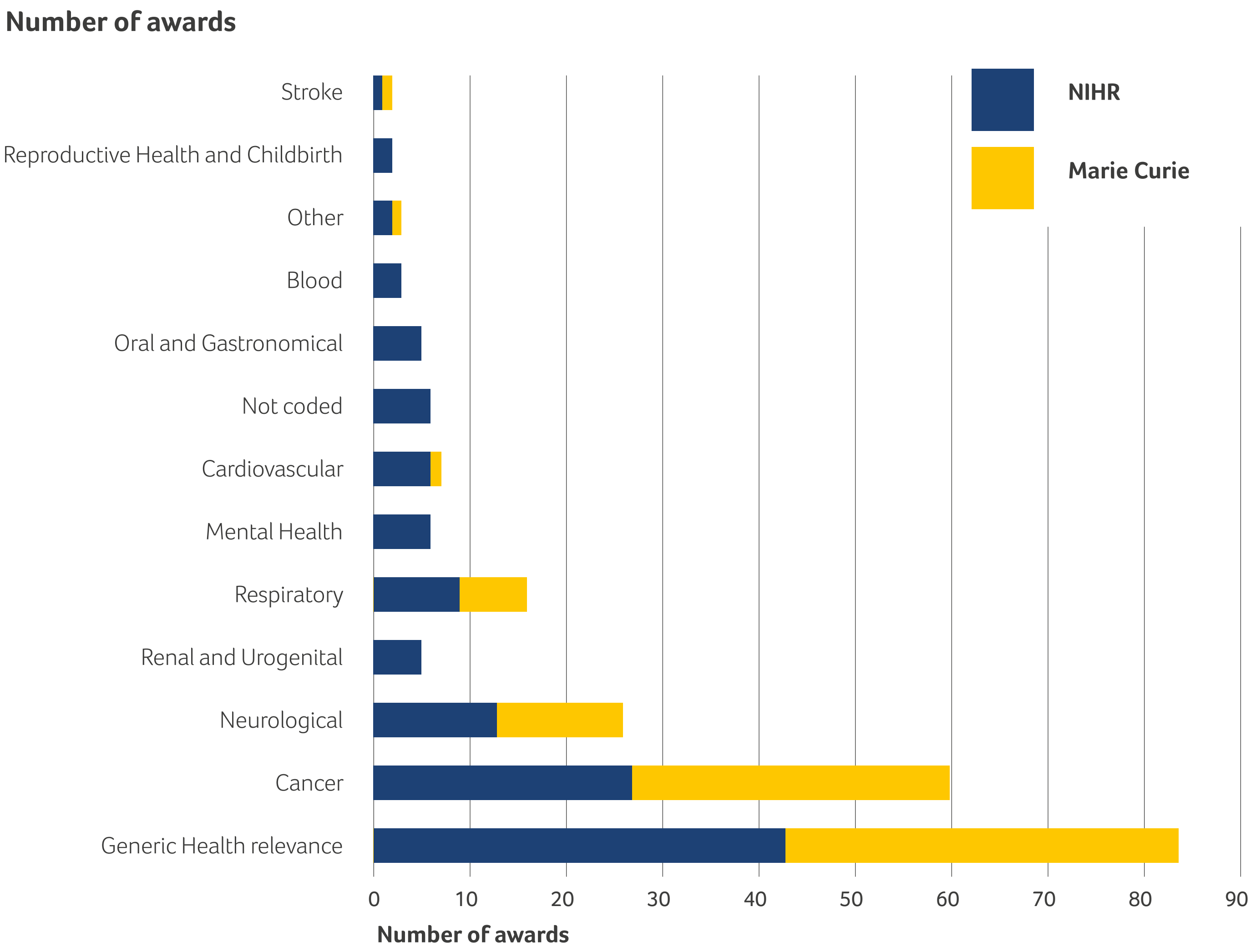


Figure 8: Bar chart showing HRCS Health coding for NIHR and Marie Curie. Bar chart shows the number of awards categorised to each HRCS health category. Awards can be double coded. A small proportion (n=6) of NIHR awards are uncoded (NIHR Schools).

4.3.2 HRCS Research Activity Codes

A breakdown of HRCS Research Activity Codes (RAC) in **Figure 9** shows that the majority of funded research has been coded as Disease Management, followed by Treatment Evaluation, and Health Services research which are in the translational and very applied end of the research spectrum. There is a negligible amount of research coded as underpinning research or aetiology, i.e. more basic research. There is also very little to no research coded to Prevention, Detection and Diagnosis, and Treatment Development.

Percentage of allocated spend by HRCS RAC group

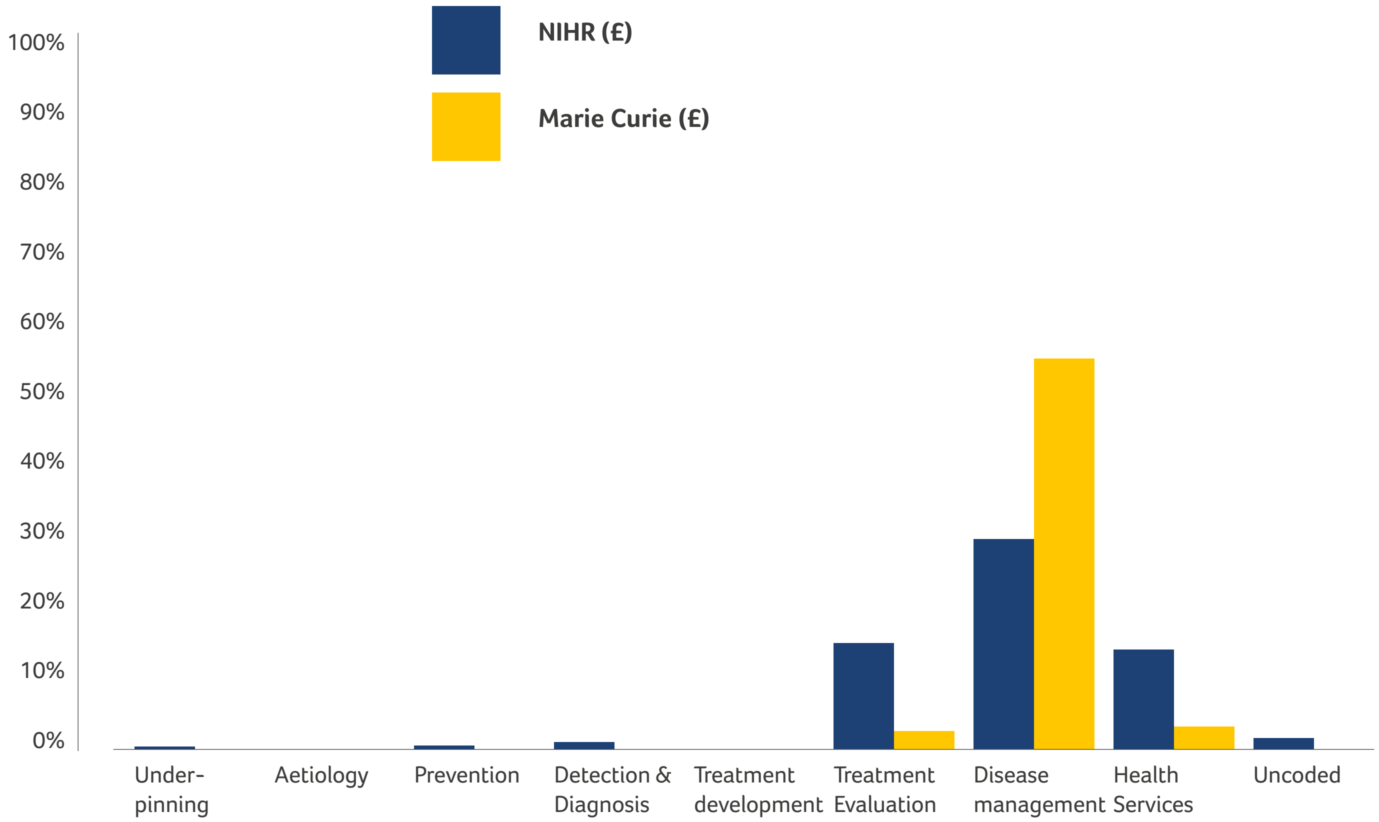


Figure 9: Column chart showing the percentage of allocated funding per HRCS Research Activity Groups for NIHR and Marie Curie datasets separately. Chart shows from basic research (underpinning and aetiology) through to translational and very applied research. The code names are the official short names given for each RAC. A small proportion of NIHR awards are uncoded (NIHR Schools). Multiple coding is possible and allocated funding has been apportioned accordingly.

Drilling down into those overarching RAC groups, **Figure 10** shows that the majority of research awards in the combined dataset were coded as Palliative (RAC 7.2 End of Life care) (NIHR 55/109 awards, representing 50% of NIHRs PEoLC care dataset and Marie Curie 79/80 awards, representing 99% of Marie Curie's dataset). This was followed by RAC 8.1: Organisation and Delivery of Services.

RAC 7.4 (Resources and Infrastructure) is mostly attributed to Marie Curie's portfolio and refers to Marie Curie's investment for its Research Centres. NIHR large infrastructure investments (e.g. Centres and CRN support) were excluded from this analysis.

Research Activity Codes 6.5 (Radiotherapy) and 6.1 (Pharmaceutical) cover palliative cancer treatment (RAC 6.1 covers chemotherapy). There is only one award coded to complementary approaches to treatment, funded by Marie Curie.

Number of awards coded to HRCS Research Authority

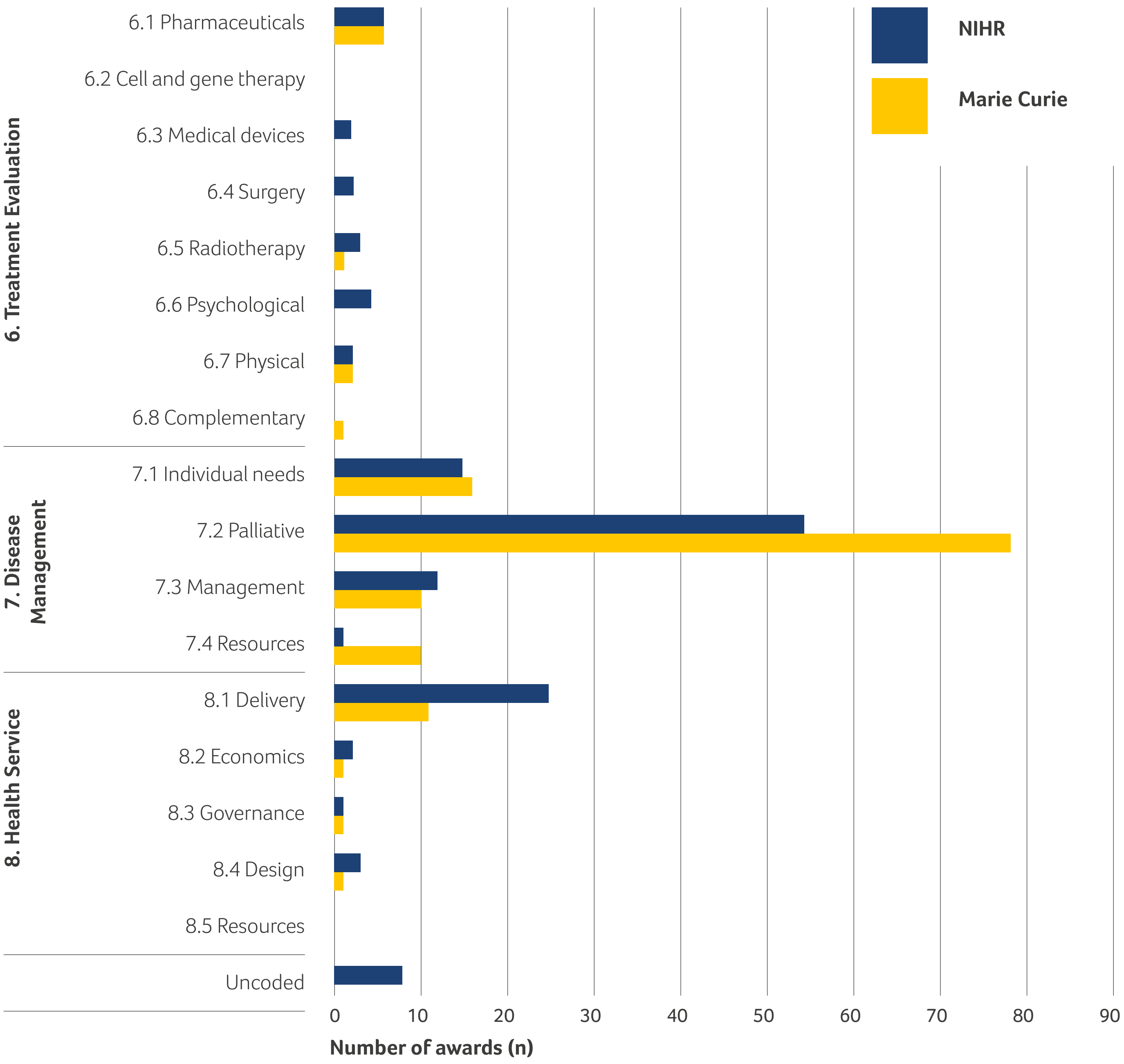


Figure 10: Bar charts showing HRCS Research Activity coding for NIHR and Marie Curie awards in the joint funder dataset, specifically the number of awards categorised to HRCS Research Activity codes 6, 7 and 8. The names for codes follow the official short naming convention.

4.4 Further understanding the combined NIHR and Marie Curie dataset between 2011 and 2018/19 using new coding frameworks

In this section we report analyses using new coding frameworks ("Appendix 4: New NIHR and Marie Curie Coding Frameworks") developed by the project team to further understand the combined portfolio dataset. This was deemed necessary as HRCS codes are mainly overarching codes, many without reference to more specific underlying conditions. It was undertaken on the advice of the Advisory Group who particularly highlighted the lack of granularity in the Neurological HRCS code. This further analysis also allowed us to drill down further into other relevant aspects of the data. All data are reported as the number of awards per code. Marie Curie professorship awards were excluded from the coding as the sources used to code the research did not provide sufficient detail to enable the awards to be coded.

4.4.1 Specific Terminal Condition

The new specific terminal condition coding framework adds granularity to the data described in section 4.3.1. As this coding was carried out independently of the HRCS coding, numbers can slightly differ between the two sets of coding. Figure 11 shows that the analysis of our specific terminal condition framework mirrors the HRCS Health coding analysis as presented in section 4.3.1 in that Generic Health (52%; 97 of 186 awards) and Cancer (33%; 61 of 186 awards) are the two codes that have been applied the most to the combined funder dataset.

Within the **Generic Health category**, 8 awards were specifically addressing frailty, and of these, 3 awards were also coded to multi-morbidities.

Three quarters (45 of 61) of all awards relevant to **Cancer** were not site-specific. The highest number of awards relevant to a site-specific cancer were coded to lung cancer (9 awards). Awards addressing other site-specific cancers were fewer in number; for example, 3 awards were coded to gynaecological cancers (vaginal, ovarian, endometrial, cervical, and vulva), of which two awards were coded to ovarian cancer and the third was inclusive of all. Two awards addressed end of life care for people with haematological malignancies, and one each oesophageal, pancreatic and colon/rectal cancers.

Our new terminal condition coding framework also provides further insights for particular conditions addressed by PEoLC research in the **Neurological** category. Within this category, most research has been coded to dementia (n=18) followed by motor neurone disease (MND, n=9). The latter category included 3 awards jointly funded by Marie Curie and the MND Association. There was only one award that addressed PEoLC for any of the other four neurological conditions identified in the new coding framework which has been equally coded to multiple system atrophy (MSA), Parkinson's, progressive supranuclear palsy (PSP) and multiple sclerosis (MS) – this award also addressed MND (n=1).

In the **Respiratory** category, our new coding framework revealed that most research in this category has been coded to COPD (n=7) and Interstitial lung disease (n=4), including one award addressing both. One award included a reference to not further specified respiratory conditions.

For the **Cardiovascular category**, eight awards were coded to heart failure and one to cardiovascular not further specified (n=1).

For the **Oral and Gastrointestinal category**, all six awards were coded to liver disease/cirrhosis (n=6). The Marie Curie contribution here is based on an individual workstream within the Marie Curie Palliative Care Research Department at UCL as part of its core grant.

Within the **Renal and Urogenital** category, three awards were coded to chronic kidney disease, all funded by NIHR, and two awards to other renal/urogenital conditions.

Gaps for future consideration, according to our dataset are around Cardiovascular Disease, Renal and Urogenital, Oral and Gastrointestinal conditions and Stroke, as well as Mental Health.

Number of awards by Specific Terminal Condition

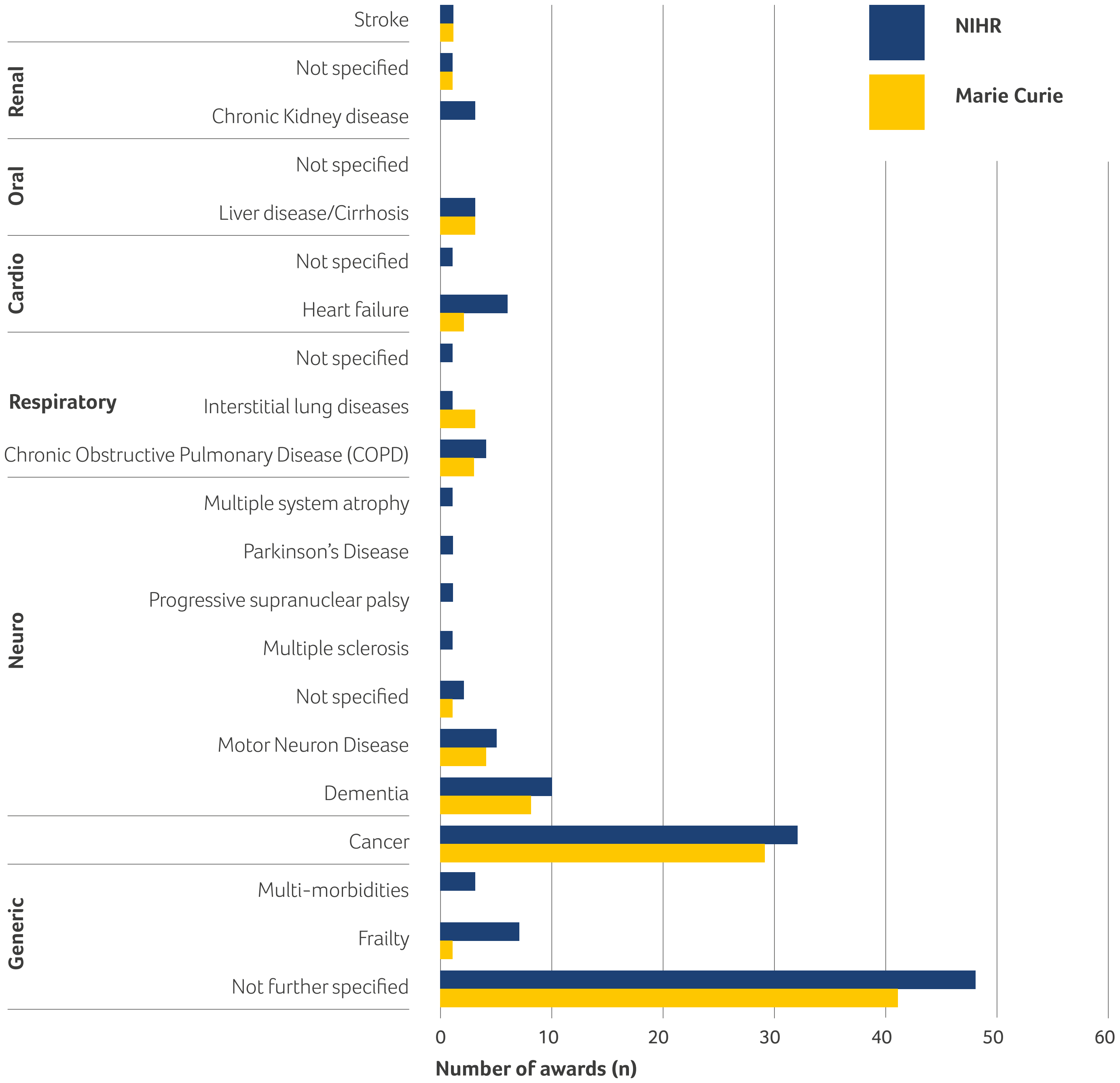


Figure 11: Bar chart for the specific terminal condition coding framework showing number of awards for each funder per specific terminal condition. Double-coding was possible, i.e. one award might have been coded to one or more subcodes. Names for the overarching codes use the official HRCS short name convention to aid graph viability.

4.4.2 Care Setting

Figure 12 shows that of the (combined) awards that mentioned a setting, hospital was the most common setting (n=64) followed by home (n=43), hospice (n=21), primary care (n=20), care home (n=18) and awards that specifically mentioned community care (coded as such if community, but no other setting was mentioned, n=17). A number of awards (n=49) mentioned more than one setting.

Most research addressed care provided in hospitals, and more research is required in the community, care homes, primary care and home, where more and more care will be provided in the future.

The “Not mentioned” category was used when the research study did not state the care setting(s) and or where the care setting was not applicable to the research (e.g. a review). Care looking at transitions between settings was also picked up through this framework (n=6). Research funded through Marie Curie included other settings not picked up in the framework, including prisons (n=1, a single award), and schools and ambulances (n=1, a single award). Other studies included research into internet/online platforms (n=1, a single award) and homelessness (n=3).

Number of awards by setting

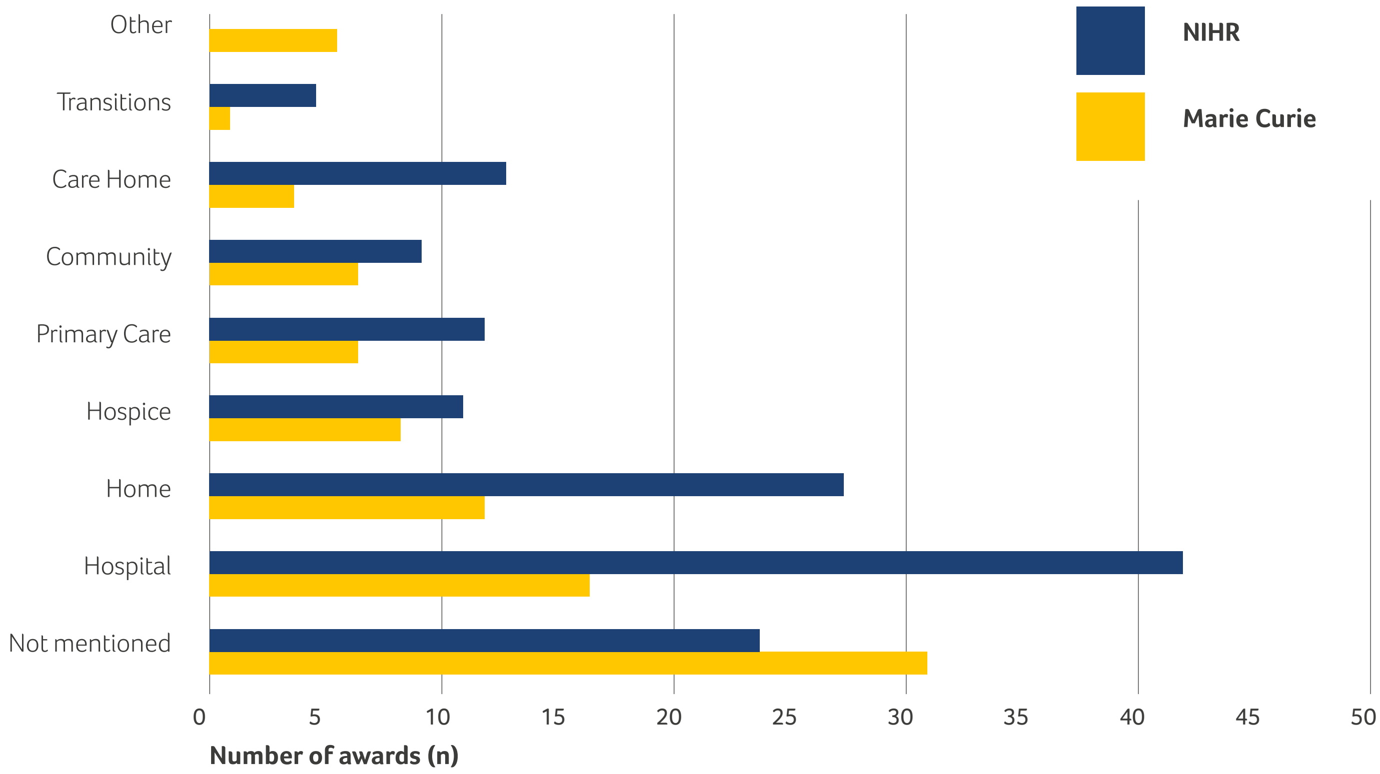


Figure 12: Number of awards by setting. The graph shows the number of awards within the combined funder dataset for each funder per care setting.

4.4.3 Protected Characteristics

Figure 13 shows the combined NIHR and Marie Curie dataset coded against the nine protected characteristics of the Equality Act 2010[6]. Out of the combined dataset of 187 awards coded, only 59 awards mentioned any of the protected characteristics. For these awards, the protected characteristic mostly did not constitute the main focus of the research. In many cases, where awards mentioned that a protected characteristic was being taken into consideration, it was included in the code, and research was coded to as many relevant protected characteristics as mentioned in the award abstract. Most of the research was coded as not having a focus or mention of a protected characteristic (n=128 combined).

The most common protected characteristic addressed by research in the dataset was age (n=45 combined). This included both research studies looking at care for older people (n=32) as well as care for children and young people (n=15). A couple of awards included work programmes for both children and young people and older people (n=2).

Some research took into consideration **sex and gender** (n=8 combined), three of these were interventions specifically for women with ovarian or gynaecological cancers, and five analysed datasets with gender being one of the parameters.

Three awards mentioned **sexual orientation**, two of which were also relevant to **gender reassignment** – these were three awards funded by Marie Curie addressing the needs of

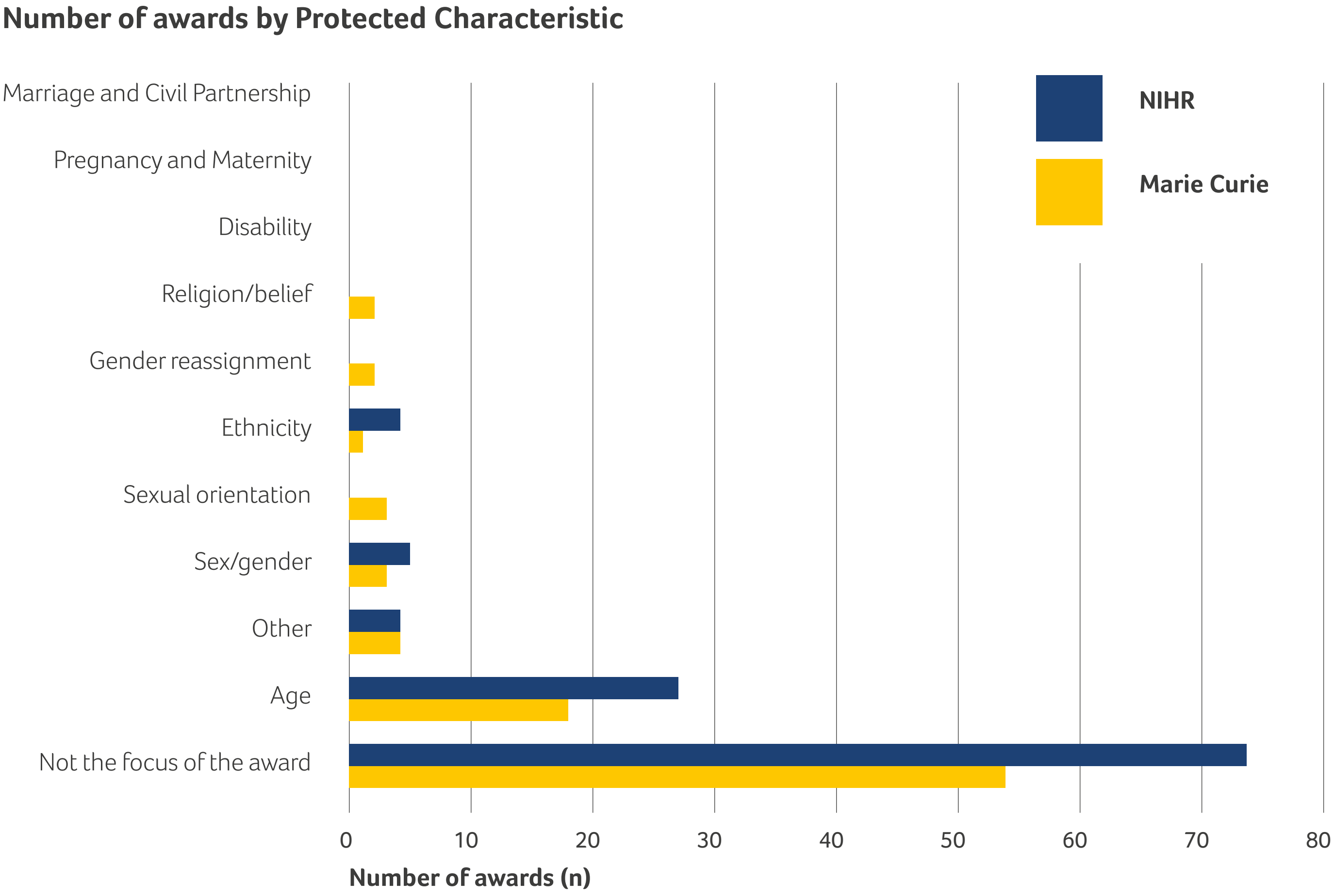


Figure 13: Bar chart for the protected characteristic coding framework depicts the whole number of awards that have been coded to each diversity category in the framework.

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[6] Age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation (Equality Act 2010).

LGB and LGBT people respectively. Since 2018, NIHR has funded a follow-on study that has developed evidence-based guidance to support LGBT+ inclusivity in health and social care ('ACCESSCare-C').

Ethnicity (n=5 combined) was also coded within both funder research portfolios; all such awards included ethnicity as one demographic variable in a larger analysis.

Two awards mentioned religion and belief – these were both part of core grants to the Marie Curie Palliative Care Research Department at UCL where one of a number of workstreams was spirituality and end of life.

More research funded by Marie Curie was coded across a broader range of categories than NIHR funded research (i.e. sexual orientation and religion and belief). Neither funder had research coded which had a focus on disability, marriage or civil partnerships, or pregnancy and maternity.

In some instances, we came across important characteristics that were not captured across the nine protected characteristics and were coded as 'other'. These were awards which focused on or mentioned homelessness (n=3), socio-economic factors (n= 4) and cultural factors (n=1).

4.4.4 Population

Figure 14 shows the results of the coding against the research population framework. This framework represents the participants of the research studies. The key most common study participants were patients (n = 145), followed by families, carers, friends/communities (n= 103) and staff and healthcare professionals (n = 101). The population with the least awards coded was volunteers for both research funders (n = 9). Examples of 'other' study participants picked up during coding included policy makers, commissioners and researchers/academics.

Number of awards by research population

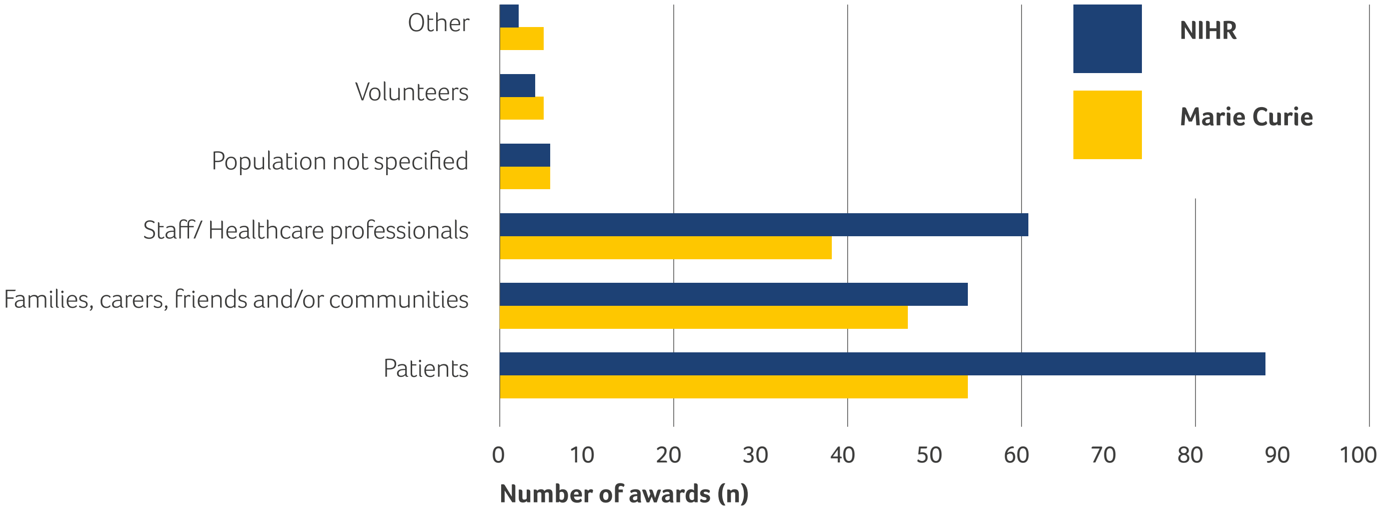

Figure 14: Bar chart for the research population coding framework. The graph depicts the whole number of awards that have been coded to each population group category in the framework.

However, looking into the dataset in more detail shows that most of the awards address multiple populations. Only two awards look solely at volunteers (two Marie Curie awards) and only seven awards concentrate solely on families, carers, friends and/or communities (i.e. not patients or staff and healthcare professionals).

4.4.5 Research Focus

The data shows that a large number of awards mentioned a research focus (n = 181). Figure 15 shows that the area of focus with the greatest number of awards is organisation and delivery of care (n=106), followed by managing symptoms and/or medications (n=84), support (n=56) and understanding dying (n=56). Fewer awards have a focus on communication (n=32) and methodology (n=12).

The area of PEoLC research could benefit from more methodological studies. An example of such research is recently completed work by (Hussain et al, 2022) that highlighted ways to reduce, handle and report missing data in PEoLC trials. Both funders were involved with NIHR funding the fellowship and Marie Curie supporting a final workshop to refine the recommendations and funding the publication of detailed guidelines for general use (Hussain et al, 2022; Marie Curie, 2022).

Number of awards by focus of the research

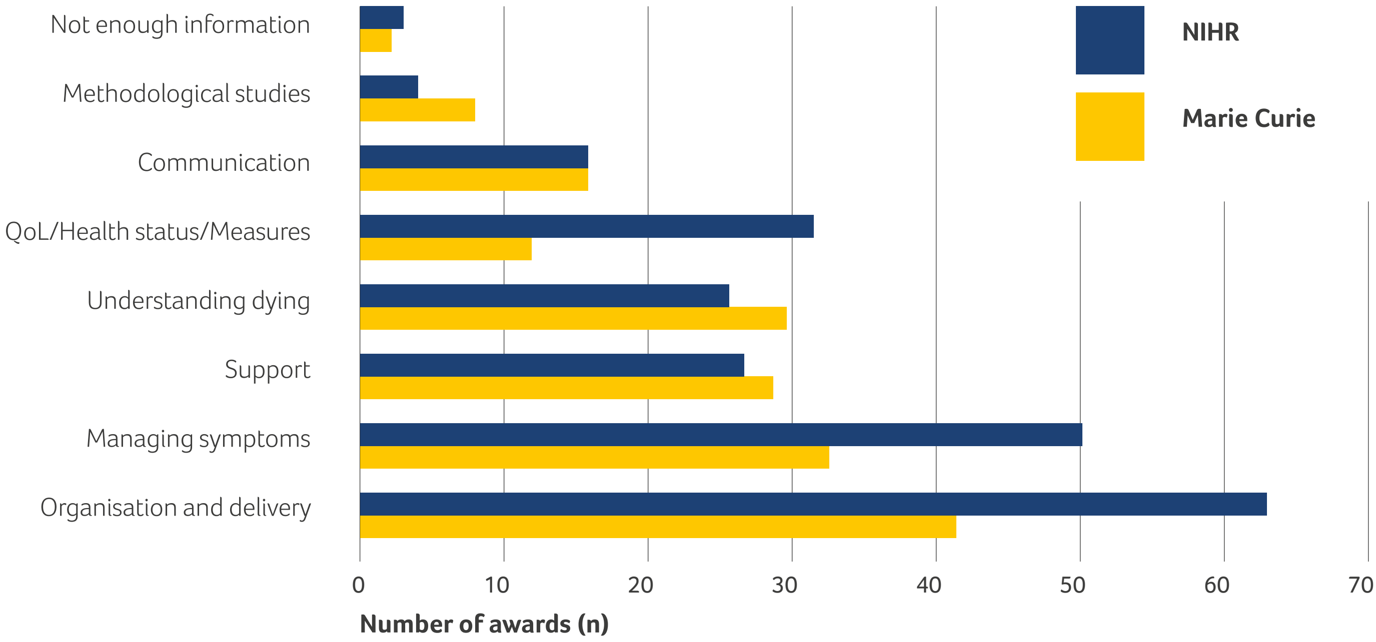

Figure 15: Bar chart for the research focus coding framework. The graph depicts the whole number of awards that have been coded to each research focus group category in the framework.

5. Actionable insights, reflections and key learning

Undertaking this collaborative work, investigating the combined portfolio of the two largest UK funders of PEoLC research is, to our knowledge, the first time such an exercise has been undertaken. We have learned as much about the process of undertaking this type of activity as we have about our shared research portfolio.

5.1 Cross-funder working: Remit and perspectives

The two organisations came together to explore investments made into PEoLC research, as the two largest funders of such research in the United Kingdom. Whilst we share a common interest in this area of research, each organisation has a very distinct purpose. PEoLC is the sole focus of Marie Curie's policy and research strategy. The NIHR has a significantly wider breadth of research priorities within its strategy. As a result, the perspectives we brought, although complementary, were different.

The governance and positioning of each organisation differs. Marie Curie is a charitable organisation whose funding originates from donations and public appeals. Working in partnership with the NHS, universities, local government, other research funders, patients and the public, the NIHR funds, enables and delivers world-leading health and social care research that improves people's health and wellbeing and promotes economic growth. The NIHR is funded by the UK Department of Health and Social Care, and focuses on early translational research, clinical research and applied health and social care research.

As a result, each organisation brought to the project different perspectives and experiences, both in terms of the subject matter to be assessed, as well as the options available to us in designing and delivering our joint analysis. To support us in navigating these complexities, we engaged a project advisory group consisting of academic and public and policy members (see Appendix 1). They added rigour to the project, ensuring that each element was carefully considered across a breadth of perspectives from the wider research community.

To enable us to reach consensus, guide and prioritise our approach, the project team developed a logic model (Appendix 5) to underpin the work. As a project team we had the skills needed to undertake the portfolio analysis and evaluation, but we initially lacked the more detailed subject matter expertise in the diverse field of PEoLC. The project advisory group provided invaluable expert advice during the first phase of this project and supported us with the challenging task of identifying the portfolio and guiding our interpretation of the initial data we generated. We expanded our project team to include external subject matter expertise.

5.2 Resourcing

A key learning from the project is the necessity to build in appropriate resourcing and risk management at the planning stage, particularly pertinent when undertaking a research analysis project that spans the resourcing capabilities of two or more organisations working in partnership.

5.3 Challenges in identification of relevant research

Marie Curie fund and manage PEoLC research only and therefore identifying the relevant portfolio was a relatively straightforward task, applying the appropriate date parameters. This was not the case for NIHR given its broad remit. To make this even more challenging, for many diagnoses and conditions which could involve a PEoLC population, it was not always clear if the study was about this aspect or actually about a new technology or even life-prolonging intervention. In the context of this project, this adds complexity when projects are exploring interventions or experiences for patients, families and staff around illnesses that may or may not fall under the remit of PEoLC. Thus, identifying which projects focus on PEoLC can be challenging, unless this is an explicitly stated aim of the research.

Thus, by necessity, we undertook an iterative approach to exploring, understanding and then classifying the NIHR portfolio in the first instance; and then developed this further with the Marie Curie portfolio. We applied an extensive set of keyword searches to the total NIHR portfolio, before undertaking a significant amount of coding to determine whether each award returned in our data search was or was not to be considered within the portfolio for analysis.

Awards were assessed based on the title, abstract and summaries provided. The project team invested a significant amount of time into this phase of the project as a large volume of awards did not provide sufficient information in these fields to definitively indicate that they were or were not relevant to PEoLC. This is a common challenge for research funders across many portfolio identification activities. This experience highlights the importance (for research funders) of requesting and guiding researchers to provide sufficient and detailed information to enable accurate coding to be applied to all awards within their titles and abstracts. For researchers, it highlights the importance of crafting the title, abstract and summary to convey the focus of the award and its relevance to PEoLC and/or other fields of research interest. High quality information will ensure awards and research are picked up in any systematic review or portfolio insight work undertaken by researchers and research funders alike and enable the reduction of bureaucracy in research by enabling reuse of existing information.

5.4 Publication of research results

Funders are aware of individual studies that were funded but did not publish the research results. In a research area with such scarce resource, and where one third of funding is provided by a fundraising charity, there is an even stronger need to reduce research waste and a further ethical obligation to publish all results.

In many cases people willingly give up precious time at the end of their lives to take part in studies to improve end of life experience for people who will be in a similar situation after them. They deserve that their contribution be used as best as possible to change end of life care for the better.

NIHR has been co-leading, and Marie Curie has contributed to, a cross-funder initiative, Ensuring Value in Research (EViR, https://evir.org/), that aims to increase the value of health-related research (Chinnery et al, 2018) and address issues of potential research waste first raised in 2009 (Chalmers and Glasziou, 2009). The failure to report and publish the results of research is an issue that researchers and research funders need to address together.

6. Untapped potential: next steps

This snapshot report is the culmination of exploratory collaborative activity between Marie Curie and the NIHR to document and build understanding of our shared investments in PEoLC research. As a result of this shared endeavour, we have learned as much about the PEoLC portfolio (2011-18/19) as we have about how to best identify and classify this important, complex and challenging area of research. This work is intended to demonstrate where and how these investments are being made, and also help us to identify gaps in PEoLC research that the future research agenda can address.

It is important to note that subsequent NIHR and Marie Curie research funding activity has taken place since this analysis.

The NIHR recognises the need to continue to develop partnerships, networks and collaborations in PEoLC. In 2021 the NIHR launched a two-part call:

21/54 NIHR Palliative and End of Life Care Research Partnerships

Part One was a Commissioned call for applications between £50,000 - £100,000 to undertake partnership and capacity building over a period of 12 - 18 months. Thirty applications were submitted to Part One of the call, and 16 have been recommended for funding. The partnerships are spread across the four devolved nations. Full details of the funding committee minutes can be viewed here. Part Two of the funding call is an NIHR commissioned call that was launched through four of the NIHR research programmes (EME/HTA/HSDR/PHR) in December 2022, and which is seeking high-quality, evaluative, applied healthcare research proposals to address important and enduring evidence gaps in delivering personalised palliative and end of life care.

In 2022 NIHR commissioned a Palliative and End of Life Care Policy Research Unit, providing investment in research across a breadth of policy issues worth up to £3 million. Research will adopt a health inequalities lens to the various work streams, which include: access to and quality of care; integration of services to provide personalised care; recruitment and retention of workforce; and practitioner training; public understanding of PEoLC.

NIHR also enables PEoLC research through its investment in Applied Research Collaborations, and provides support to the national ARC theme lead in PEOLC research – a national NIHR forum for improving palliative and end of life care services in England.

NIHR now has a strategic framework and definition for multimorbidities[7] (now known as multiple long-term conditions) which if applied to our dataset, might provide different insights.

Marie Curie has been extending its Senior Research Fellowship scheme, a unique scheme that aims to support early career researchers in PEoLC to develop a research focus and develop their careers as well as attract early career researchers into the field. It is unique in that fellows spend part of their time in close collaboration with Marie Curie hospices and other services, as well as with policy colleagues, to support research access for hospices, capacity-building for clinicians and evidence-based policy.

The aims of the Marie Curie Senior Research Fellowship scheme are:

- to support capacity-building in PEoLC research and support the future leaders of research
- to support and enable research to take place at Marie Curie hospices and place-based community services, making services more research-active and evidence-aware locally. This includes taking part in external research studies as well as developing research studies based on local evidence needs and priorities

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[7] https://www.nihr.ac.uk/documents/nihr-strategic-framework-for-multiple-long-term-conditions-multimorbidity-mltc-m-research/24639

- to work with Marie Curie research and policy teams locally and nationally and lead on impact-focused research studies, for instance through the Marie Curie small internal research grants scheme.
- The scheme is accompanied by a network of in-house Research Nurses that support recruitment and governance to enable PEoLC services and its users to take part in research and constitutes an important development opportunity for nursing staff.
- In addition, a new Research Impact Fund has recently been established by Marie Curie, to support the next steps to impact on policy and/or practice. Marie Curie has also highlighted inequities in access to and experience of PEoLC in its new Research, Policy and Public Affairs Strategy (https://www.mariecurie.org.uk/research/strategy).

Looking forward, future work could focus on:

- understanding the barriers and enablers that support researchers in this field to improve health and care practice at the end of life
- identifying the outcomes the joint research portfolio has had on policy and practice in PEoLC in the UK, potentially through a joint Researchfish data analysis[8] as well as using data intelligence tools such as Overton and Dimensions, and other data sources
- systematically assessing the outcomes and/or impacts achieved from the PEoLC portfolio using a mixture of qualitative and quantitative approaches that reflect evaluation questions and needs identified by key stakeholders
- developing case studies to illustrate the various pathways to impact, provide evidence of the difference PEoLC funded research makes, and to encourage more research in the field
- maintaining, developing and adopting the coding framework to enable tracking of the PEoLC portfolio in the long-term, enabling strategic oversight and planning of future research investment. Dimensions could be considered as a tool to assist with (auto) coding in future years
- utilising the portfolio to reduce and/or limit duplication of effort either at a funder-level in terms of commissioning activities or at an applicant-level to ensure future research is building on existing work, but delivering unique insights
- using the established portfolio to inform future NIHR, Marie Curie and other funders' end of life research portfolio gaps and priorities
- analysing the NIHR CRN portfolio to understand geographic spread of recruitment sites for PEoLC projects. This would need to be resourced appropriately, and potentially commissioned externally. All NIHR and Marie Curie funded studies can apply for portfolio status and an analysis of available support could encourage more researchers to use this support
- future analyses could be expanded to include the NIHR Infrastructure (Centre, Units, Collaborations).

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[8] An analysis of NIHR awards ResearchFish data has been completed for internal purposes and can be accessed by DHSC/NIHR upon request.

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Appendices

Appendix 1: Project Advisory Group Members

Professor Christopher Ecclestone,
University of Bath (Chair)

Angela McCullagh (PPI),
Marie Curie Research Voices Group

Kathy Seddon (PPI),
Marie Curie Research Voices Group

Professor Michael Bennett,
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Professor Gunn Grande,
University of Manchester

Professor Irene Higginson,
King's College London

Dr Becky Black,
Senior Research Officer, DHSC

Appendix 2: Inclusion & exclusion criteria to identify palliative care and end of life research funded by NIHR

A2.1 Introduction

These inclusion/exclusion criteria have been developed by NIHR and Marie Curie with advice from researchers, clinicians and public contributors. In developing these criteria, we acknowledge that the terminology around what is deemed palliative and end of life care is a contested space (Todd Fordham & Noble, 2016; Maciasz et al., 2013; Bennett et al., 2010). However, we have taken a pragmatic approach concentrating on research that is directly applicable to palliative and end of life care. This does not include research that is not specifically focused on palliative and end of life care as the primary intention of the grant/award.

A2.2 Include research:

If it relates to advanced/terminal/progressive/life-limiting conditions with reference to palliative and end of life care (e.g. cancer, dementia, heart failure, COPD etc.) AND outcomes relate to palliative and end of life care, including but not limited to:

- decision making in relation to palliative and end of life care (e.g. discontinuing treatment, patient preferences, care pathways etc.);
- physical, emotional, psychological, social and spiritual support for patients, families and carers in relation to palliative and end of life care;
- quality of life in relation to palliative and end of life care;
- bereavement in relation to advanced/terminal/progressive/life-limiting conditions.

A2.3 Exclude research if outcomes are not specifically related to and/or focussed on palliative and end of life care. Examples include:

- curing/treating illnesses/acute events (including prolonging life/halting progression /assessing treatments and their delivery etc.);
- management of non-terminal chronic illnesses (e.g. diabetes, asthma etc.);
- suicide and self-harm;
- treatment of conditions/infections that are not linked to terminal disease (e.g. seasonal flu, HIV etc.);
- pregnancy/gestational issues etc.;
- prevention of illness/acute events etc.;
- public health interventions like smoking cessation;
- development of methods/tools for screening/diagnosis;
- care when applied to general workforce reviews.

A2.4 Definitions

Our definitions of palliative and end of life care are based on those outlined by The National Palliative and End of Life Care Partnership:

A2.4.1 End of life

Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with: a) advanced, progressive, incurable conditions; b) general frailty and co-existing conditions that mean they are expected to die within 12 months; c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition; d) life-threatening acute conditions caused by sudden catastrophic events. In General Medical Council guidance the term 'approaching the end of life' also applies to those extremely premature neonates whose prospects for survival are known to be very poor, and to patients who are diagnosed as being in a persistent vegetative state (PVS) for whom a decision to withdraw treatment may lead to their death.

A2.4.2 Palliative care

The World Health Organisation has defined palliative care as follows: Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families; enhances quality of life and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications. Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions.

Appendix 3: Key words

Appendix 3 provides a list of the 73 keywords used to search the NIHR research portfolio. This list was informed by the 139 keyword terms used on a grant mapping activity (Todd Fordham et al 2017). The '% symbol here is a wildcard symbol to include leading or trailing characters in the search.

'% ALS %'
'%advance care plan%'
'%ACP%'
'%advanced%cancer%'
'%advanced%disease%'
'%advanced%illness%'
'%advance%directive%'
'%anticipatory prescri%'
'%anticipatory pain%'
'%Bereav%'
'%breaking bad news%'
'%chaplain%'
'%die %'
'%dead%'
'%death%'
'%dying%'
'%end of life%'
'%EOL%'
'%End Stage%'
'%Gold Standards Framework%'
'%GSF%'
'%Grief%'
'%Holistic%'
'%Hospice%'
'%Life limiting%'
'%Life threatening%'
'%Liverpool Care Pathway%'
'%LCP%'
'%Living Will%'
'%Non cur%'
'%PGD%'
'%Prolonged Grief Disorder%'
'%Palliat%'
'%Palliati%'
'%Prognos%'
'%Progressive disease%'
'%Progressive illness%'
'%Relig%'
'%respite%'
'%spiritual%'
'%symptom relief%'
'%sympton relief%'
'%symptom management%'
'%sympton management%'
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'%cachexi%'
'%dysphagia%'
'%artifical hydration%'
'%artificial hydration%'
'%artifical nutrition%'
'%artificial nutrition%'
'%feeding tube%'
'%morphine%'
'%opioid%'
'%parenteral nutrition%'
'%syringe driver%'
'%Amyotrophic Lateral Sclerosis%'
'%Advanced Alzheimer%'
'%Advanced Brain Tumour%'
'%Advanced COPD%'
'%Advanced Chronic Obstructive Pulmonary Disease%'
'%Advanced dementia%'
'%Glioblastoma%'
'%heart failure%'
'%liver failure%'
'%MND%'
'%Motor Neuron%'
%Advanced Multiple Sclerosis%'
'%organ failure%'
'%Advanced Parkinson%'

Appendix 4: New NIHR and Marie Curie Coding Frameworks

Setting

This code refers to where a person's care is taking place and the services involved in providing the care within the research project. This framework was developed by the NIHR and Marie Curie Project Team taking into account those already in use. ***Only code with the main "Settings code"*** but can use more than one code if required.

Settings code	Comments to help define the "Settings code"
HOSPITAL	Use this code when care is being provided in the following settings, including but not limited to: • Inpatient • Outpatient • Emergency care (including Accident and Emergency) • Secondary care • Specialist care unit / tertiary care • Acute medical / surgical unit • Intensive Care Unit • Perinatal care / neonatal care • Radiology unit • Stroke rehab • Thoracic surgical centre • Renal unit • Acute oncology unit • Hepatobiliary unit • Spinal injury unit • Acute hospital • Community hospital
HOSPICE	Use this code when care is being provided from a hospice site, including but not limited to: • Out / day patient services in a hospice • Respite care in a hospice
HOME	Use this code when care is being provided at home, including but not limited to: • Hospice care provided at home • Informal settings • Home respite care
CARE HOME	Use this code when care is being provided in a care home, including but not limited to: • Nursing home • Residential home
PRIMARY CARE	Use this code when care is being provided in primary care settings, including but not limited to: • General Practice • Pharmacy • Dentistry
TRANSITIONS	Use this when the research covers transitions between any or all of the above setting codes.
OTHER	Use this code when the research setting has been stated but does not fit the above setting codes. For example, including but not limited to: • Prisons • Hostels • Traveller communities
COMMUNITY	Use this code when the award specifically mentions the term "community" but does not provide any further information on the specific community setting. Do not use this code when a specific community setting is mentioned (e.g. hospice); use that specific setting code instead.
NOT MENTIONED	Use this code when the setting has not been made clear enough to code to one or all of the above codes.

Specific terminal condition

This code provides further granularity to the Health Research Classification System (HRCS) health category and the "Specific terminal condition code" was developed by the NIHR and Marie Curie Project Team taking into account those already in use. ***Code using both columns, that is the "HRCS health category code" and the "Specific terminal condition code"***, but can use more than one code for each column if required. .

HRCS health category code	Specific terminal condition code
Code using the HRCS framework https://hrcsonline.net/health-categories/	This will be the specific terminal condition that is mentioned in the abstract, if not listed below. Label as "Not further specified" if there is not enough information to code.
BLOOD	
CANCER AND NEOPLASM	Use the list from https://www.icrpartnership.org/cancer-type-list to code the specific type of cancer
CARDIOVASCULAR	• Heart failure • Not further specified
CONGENITAL	
EAR	
EYE	
INFECTION	
INFLAMMATORY/IMMUNE	
INJURIES AND ACCIDENTS	
MENTAL HEALTH	
METABOLIC AND ENDOCRINE	
MUSCULOSKELETAL	
NEUROLOGICAL	• Dementia • Motor neurone disease • Multiple sclerosis • Progressive supranuclear palsy • Parkinson's disease • Multiple system atrophy • Not further specified
ORAL/GASTROINTESTINAL	• Liver disease/cirrhosis • Not further specified
RENAL/UROGENITAL	• Chronic kidney disease • Not further specified
REPRODUCTIVE HEALTH & CHILD BIRTH	
RESPIRATORY	• Interstitial lung disease • Chronic obstructive pulmonary disease (COPD) • Not further specified
SKIN	
STROKE	
GENERIC HEALTH RELEVANCE	• Multi-morbidities • Frailty • Not further specified

Population

This code was developed by the Marie Curie and NIHR Project Team to give an insight into the population that is the subject of the research being conducted. ***Only code with the main "Population category code"*** but can use more than one code if required.

Population category code	Comments to help define the "Population category code"
PATIENTS	Use this code where the research population is patients living with a terminal illness, approaching the end of life and / or receiving end of life or palliative care.
FAMILIES, CARERS, FRIENDS AND / OR COMMUNITIES	Use this code where the research population is families, carers, friends and or wider communities of patients living with a terminal illness, approaching the end of life and / or receiving end of life or palliative care.
VOLUNTEERS	Use this code where the research population is volunteers in palliative and end of life care.
STAFF / HEALTHCARE PROFESSIONALS	Use this code when the research population is staff and / or healthcare professionals in palliative and end of life care.
OTHER	Please specify if another population is mentioned as the subject of the research e.g., general public.
POPULATION NOT SPECIFIED	Use this code when the population of the research is not specified.

Population age

This code gives an insight into the specific age of the population in the study. These codes are based on the legal definition of 'children'. If the award makes reference to 'young people' this was included in the children and young people category. ***Only code with the main "Age category code"*** but can use more than one code if required.

Age category code	Comments to help define the "Age category code"
CHILDREN AND YOUNG PEOPLE	Use this code where the research specifies that it targets children and young people OR that it specifies that the target group is <18 years OR if the average age of the sample/population is under 18 years. This age code includes neonatal research.
	Also code to this category when the researchers describe the target population as young people even if the age category for the research cover 18+ years. Use this code also for research describing the transition to adult services.
ADULT	Use this code when the research specifies that it is targeting an adult population.
OLDER ADULT	Use this code when the research specifies that it targets older adults. Where the terms 'older' or 'elderly' are not specifically mentioned, code as older adult if the average age is 65+.
AGE NOT SPECIFIED	Use this code when the research makes no mention of the age it is targeting.

Protected Characteristics

This coding framework was created using the Equality Act 2010. ***Only code with the main "Protected characteristics code", except for the "OTHER" category (where there is an opportunity for further coding if mentioned in the abstract)*** but can use more than one code if required.

Protected characteristics code	**Comments to help define the "Protected characteristics code"**
AGE	Use this code when the research targets one of the two specific age codes: • Older adults • Children and young people
DISABILITY	Use this code when the research targets a specific disability (physical and learning).
GENDER REASSIGNMENT	
MARRIAGE AND CIVIL PARTNERSHIP	
PREGNANCY AND MATERNITY	
ETHNICITY	Use this code when the research specifically mentions that it will target or includes specific or a range of minority ethnic groups.
RELIGION / BELIEF	Use this code when the research specifically mentions that it will target or explore specific religious groups or beliefs.
SEX / GENDER	Use this code when the research specifically mentioned that it will target or explore gender-related issues.
SEXUAL ORIENTATION	
OTHER POTENTIAL CIRCUMSTANCES	Add the following detail if mentioned. For example, including but not limited to: • Socio-economic status (e.g. deprivation) • Culture and lifestyle (e.g. travelling communities) • Mental capacity • Inequalities • Location (e.g. rurality) • Homelessness
PROTECTED CHARACTERISTIC OR OTHER POTENTIAL CIRCUMSTANCES NOT THE FOCUS OF THE AWARD	Use this code when the research makes no mention of any protected characteristic.

Research focus

This coding framework was based upon research themes arising from the James Lind Alliance Palliative and end of life care Priority Setting Partnership (PeolcPSP), Beyond the Questions – Shared experiences of palliative and end of life care, James Lind Alliance Living With and Beyond Cancer Priority Setting Partnership (LWBC PSP) and a Systematic Review of Measures of End-of-Life Care and Its Outcomes. ***Code using both columns, that is the "Research focus code" and the "Additional sub-level code"*** but can use more than one code for each column if required.

Additional information regarding the population that is the subject of the research focus is captured in the "Population code"

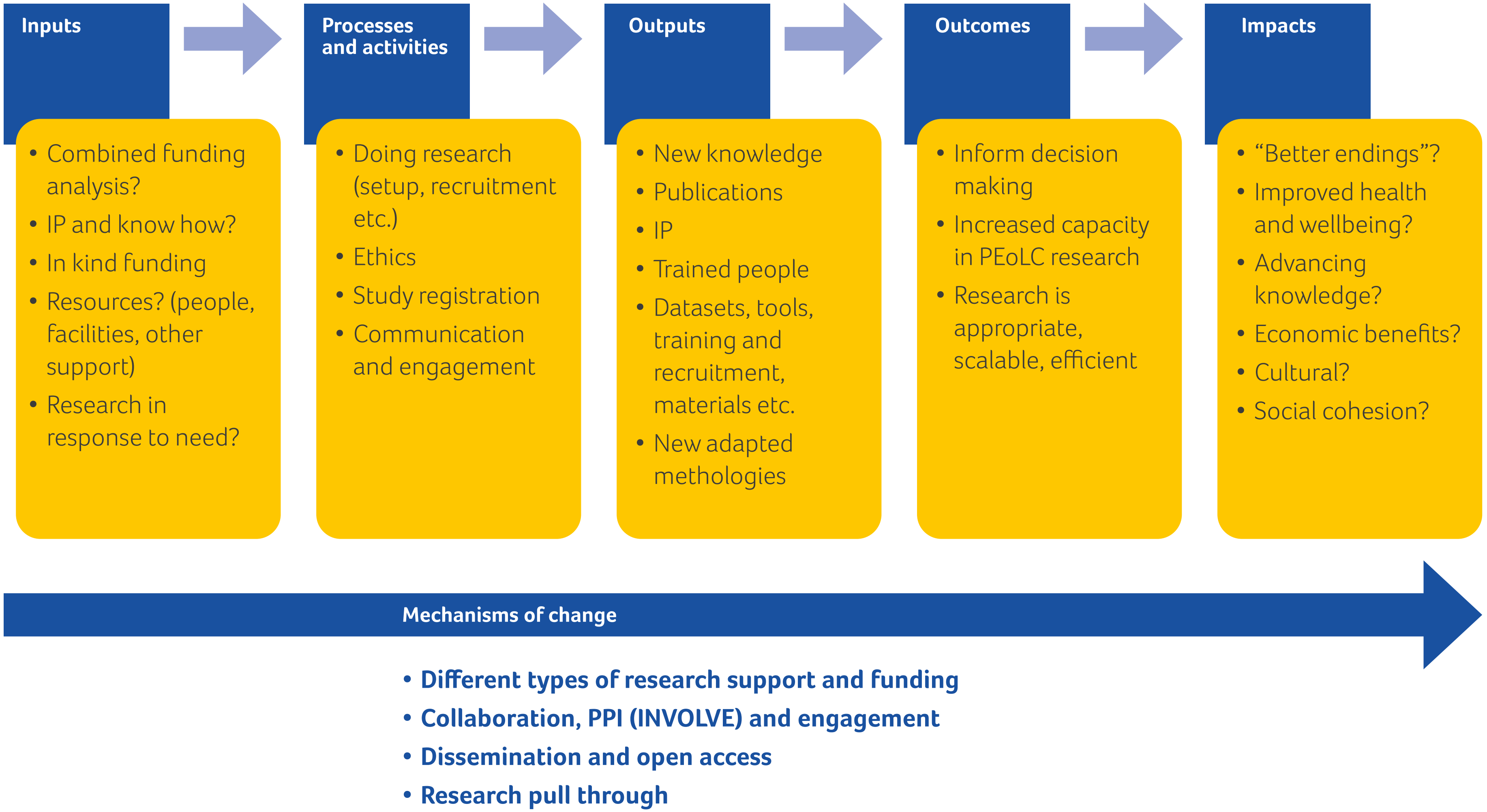
Research focus: high level code	Additional sub-level codes
COMMUNICATION	• Prognosis • Advance care planning (including preferences for care) • Do not attempt cardiopulmonary resuscitation (DNACPR) • Other (please specify) • Not specified
MANAGING SYMPTOMS, ISSUES AND / OR MEDICATIONS	• Specific symptoms / issues: o Agitation / distress o Bleeding o Blood clots / deep vein thrombosis / pulmonary embolism o Breathlessness (chronic and acute) o Cachexia / sarcopenia (muscle wasting) o Continence o Constipation o Cough o Death rattle / terminal secretions o Delirium o Diarrhoea o Dry mouth o Fatigue o Hydration (including withdrawal) o Itching o Nausea / vomiting o Nutrition (including withdrawal) o Oedema (fluid retention) o Pain o Psychiatric / psychological symptoms (including depression, anxiety, low mood etc.) o Restlessness o Side effects of treatment (please specify) o Swallowing o Sweating o Other (please specify) o Not specified
SUPPORT	• Type of support: o Grief and bereavement o Training and / or education o Financial, housing and transport o Spiritual / religious o Language o Other (please specify) o Not specified

Research focus: high level code	Additional sub-level codes
ORGANISATION AND DELIVERY OF CARE (INCLUDING SERVICE USE)	• Identification of palliative and end of life care populations • Respite • Care coordination • Continuity of care • Accessing services • Place and type of care and death • Out of hours and emergency support • Service evaluation and quality improvement • Workforce planning • Quality of and / or satisfaction with care • Other (please specify) • Not specified
UNDERSTANDING DYING	• Perceptions / experiences of palliative care • Attitudes to dying / death • Grief and bereavement • Prognostication • Trajectory • Care after death • Palliative and end of life care needs • Assisted dying/euthanasia • Other (please specify) • Not specified
QUALITY OF LIFE / HEALTH STATUS / UTILITY MEASURES	• Please specify if specific aspects of quality of life are being considered and the tool used, including (but not limited to): • Symptoms o Edmonton Symptom Assessment Scale (ESAS) o Memorial Symptom Assessment Scale (MSAS) o Symptom Assessment Scale o Symptom Distress Scale o MD Anderson Symptom Inventory o Brief Pain Inventory (BPI) o Multidimensional Fatigue Assessment Scale o Brief Fatigue Inventory • Functioning o Barthel Index o Dependency Scales • Psychological o HADS o Patient Health Questionnaire 9 (PHQ9) o PROMIS Anxiety and Depression Scales • Holistic needs and Distress o Distress Thermometer o Sheffield Profile for Assessment and Referral for Care (SPARC) o Macmillan e-HNA • Quality of life o EORTC QLQ (whole family of generic and specific scales) o FACT (as for EORTC) o McGill Qol (MQOL) o WHOQOL

Research focus: high level code	Additional sub-level codes
	• Health Utility/Status o Euroqol/EQ5D-5L o Short form 36 (SF-36) o Nottingham Health Profile (NHP) • Palliative care specific outcomes o POS o STAS • Composite measures o Comprehensive Geriatric Assessment
METHODOLOGICAL STUDIES	• Please specify, can include development of new outcome measures, evaluation of research tools and methods, research ethics, patient, carer & public involvement (PPI), other (please specify) • Not specified
NOT ENOUGH INFORMATION TO CLASSIFY RESEARCH FOCUS	

Appendix 5: Logic Model

Developed a logic model to plan our approach



Inputs

- Combined funding analysis?
- IP and know how?
- In kind funding
- Resources? (people, facilities, other support)
- Research in response to need?

Processes and activities

- Doing research (setup, recruitment etc.)
- Ethics
- Study registration
- Communication and engagement

Outputs

- New knowledge
- Publications
- IP
- Trained people
- Datasets, tools, training and recruitment, materials etc.
- New adapted methologies

Outcomes

- Inform decision making
- Increased capacity in PEoLC research
- Research is appropriate, scalable, efficient

Impacts

- "Better endings"?
- Improved health and wellbeing?
- Advancing knowledge?
- Economic benefits?
- Cultural?
- Social cohesion?

Mechanisms of change

- **Different types of research support and funding**
- **Collaboration, PPI (INVOLVE) and engagement**
- **Dissemination and open access**
- **Research pull through**

Appendix 6: Notes on coding and classification of research portfolios

Research focus: Understanding the focus of the research has been challenging and required some level of interpretation from the reader. We came to realise that the codes were not mutually exclusive, with grey areas specifically around quality and satisfaction of care (under ORGANISATION AND DELIVERY OF CARE) and perception and experience with care (under UNDERSTANDING DYING). We also noted that SUPPORT, concentrates around practicalities of care, and training and education for staff/carers/patients but there is a grey area around research which is looking at holistic levels of support (i.e. care) for patients. In addition, awards looking at improving design and delivery of care may also involve understanding of dying, communication and perception of care as part of the recommendations for improvement. This was the same for service evaluations, which may include perception of care, assessing existing service etc. We have needed to take a pragmatic approach and to code at face value. We have needed to code based on what is in the research summary/abstract, taking note of what is stated but how this was stated. We reflected that sometimes it was difficult to distinguish between the overarching problem (wider context) and the aspect the research is seeking to address.

When we developed our coding frameworks, we created a framework for Research Focus which incorporated two levels. This was fairly unique across our frameworks and provided an opportunity to go into some depth around the areas of focus, which might hopefully provide future insight for areas of research. However, after the second round of coding, the coders raised the issue that coding to such depth proved difficult and required an element of content knowledge and expertise. This was backed up by the fact that none of the two rounds of coding (1st and 2nd) provided an agreement for any award. In order to ensure that the project kept moving forward, there was an agreement to park the second level coding. However, the frameworks will be made available as part of the open publication process and recommendations could be made for further analysis in this space, if this was seen to be a strategic priority.

Limitation of HRCS coding: When HRCS coding is undertaken at the NIHR, it is not undertaken with a P&EoL care lens (only). This means that the NIHR may not have coded to the terminal condition of the population in the research, but rather we have coded to what we have termed in this project ‘Research Focus’. For example, research looking at constipation in frail end of life communities, will have been coded (HRCS Health) according to the constipation element whereas we have coded such awards to both (constipation in research focus and frail end of life in specific terminal condition) within the coding framework applied to this project. We knew that the existing HRCS coding held by NIHR was not giving us everything that we needed, which is why we have undertaken this further coding. This misalignment adds weight for undertaking this work. It shows that had we only used the HRCS coding (as it originally stood), it would not have given a good idea of the specific conditions that each of the research awards is seeking to address.

Appendix 7. Detail of methods and approach

This portfolio review consisted of four activities:

1. Analysis of publicly available funding data (HRCS)
2. Identification of the NIHR PEoLC portfolio
3. Developing and applying the coding frameworks to the combined PEoLC portfolio
4. Analysis of PEoLC portfolio

1: Analysis of publicly available funding data

UK research funding data coded according to the HRCS framework and submitted as part of the 2018 UK Health Research Analysis (UKCRC, 2020) were downloaded from the HRCS website as an MS Excel file. The data in the dataset had been annualised (by UKCRC) to include only the proportion of an award that was awarded for the duration of 2018. The data were filtered to only include research that had a HRCS Research Activity Code of 7.2 (for PEoLC). Only the proportion of an award in 2018 allocated to Activity Code 7.2, and not the total award sum or the total 2018 award sum, was included in our calculations, as done in the UKCRC analysis (UKCRC, 2020). The total amount of funding for palliative and end of life care research in 2018, as coded to Research Activity Code 7.2, was £5,489,591 or 0.21% of the whole dataset. Research funding was grouped by funder and the relevant percentage of the above total in activity code 7.2 calculated. NIHR funding included funds made available via the Department of Health and Social Care and Health Education England. Marie Curie funding included in the HRCS database represents Marie Curie funding only and does not include any contributions by funding partners.

In total, 146 organisations took part in the UKCRC analysis for 2018. Of these, 23 provided qualitative submissions only and 123 provided both narrative and data for the analysis. A total of 16 funders (counting NIHR as one funder covering DHSC and HEE funding) were found to have awards that were at least partially coded to Activity Code 7.2. The co-funding provided by the Chief Scientist Office (CSO) to Marie Curie in 2018 was not included in the dataset, but was £87,863 in 2018 to 3 awards at the University of Edinburgh.

2: Identification of NIHR PEoLC research

As all Marie Curie funded research is focused on PEoLC, there was no need to develop a search process for identifying relevant awards. The project team worked on the assumption that all activity funded by Marie Curie would be included in the analysis as PEoLC is the primary research focus of the organisation. For awards where a funding partner contributed to Marie Curie funding (CSO, Dimbleby Cancer Care, RCGP), the full value of those awards was included in the Marie Curie dataset.

Therefore, the first task for the portfolio review was to identify a comparable NIHR PEoLC research dataset within a similar timeframe.

We took a pragmatic decision to include NIHR awards that were available on InfoNIHR data, plus research funded and supported through the NIHR Evidence Synthesis Programme and NIHR Research Schools. Therefore, this portfolio review does not include NIHR Infrastructure awards (i.e. Centres, Units, Groups, Collaborations), Senior Investigators or data from the Clinical Research Network (CRN). InfoNIHR data contains research that was active on 1st April 2011 and therefore a comparable date to Marie Curie's dataset. Other NIHR dataset warehouse systems were searched on the same criteria to extract awards not included on InfoNIHR Data.

Two keyword searches were conducted on NIHR award titles and application summaries and abstracts contained in the InfoNIHR and other NIHR data warehouses using search terms previously identified by Marie Curie in its grant mapping exercise (Todd Fordham et al 2017), shown in "Appendix 3: Key words". This process identified a long list (n=1,442) of NIHR PEoLC awards that were active between 2011 - 2018, which were extracted in Microsoft Excel and de-duplicated.

Drawing on the award data, inclusion and exclusion criteria were developed by the project team with input from the external project advisory group ("Appendix 1: Project Advisory Group Members"). The unique list of awards was independently reviewed by three members of the project team (KL, CV, HS with input from other team members and colleagues across NIHR), for inclusion and exclusion against the criteria, resulting in 247 eligible awards. NIHR project team members were not subject matter experts in PEoLC, so on the first sifting of the awards careful consideration was undertaken before excluding awards. The approach was that if in doubt they were included as 'unsure' for further assessment at stage 2 by subject matter experts from NIHR (SAH) and Marie Curie (EC) with some early input from the project advisory group. The eligible awards were classified as either awards being directly applicable to PEoLC (n=95), or 'unsure' (n=152) and requiring further deliberation. To ensure quality control across the single-coded eligible awards, a second round of coding was conducted by two subject matter experts (EC, SAH), independently of each other. In this second coding step, 82 awards were excluded, resulting in a final eligible NIHR dataset of 109 awards. The inclusion and exclusion criteria helped to facilitate the consistent identification of PEoLC studies from within the NIHR funding portfolio, and any disagreements or discrepancies were resolved through group discussion and consensus.

3: Development and application of coding frameworks to the combined funder dataset

To help further classify and provide more granularity to the combined funder dataset, as recommended by the Project Advisory Group, the project team developed a series of coding frameworks (i.e. setting, specific terminal condition, population, population age, protected characteristics, methods and designs, and research focus) using a predominantly grounded approach, drawing on the UK Equality Act 2010 and previous work (Nelson 2020, Mularski et al 2007). The coding frameworks were assessed for relevance and accuracy by the project advisory group and then applied to the combined funder dataset. The final coding frameworks can be found in "Appendix 4: New NIHR and Marie Curie Coding Frameworks".

Awards were independently double coded by two coding groups from the project team and a consensus was reached by two members of the project team where there was a disagreement in coding. To reduce the risk of bias we employed a minimum two-stage process both in the identification of the NIHR dataset and when coding the combined funder dataset.

4: Analysis of the combined funder dataset and UKCRC dataset

The combined funder dataset was stored on a shared NIHR Google platform accessible to both funders and coding was undertaken using Google sheets to ensure ease of access to coders from both funders. All subsequent descriptive analysis was undertaken using Microsoft Excel.

4.1 Analysis of Health Research Classification System (HRCS) UK CRC dataset

In this analysis, health-related research funding data are categorised using the Health Research Classification System (HRCS), which is a bespoke system used to classify the full spectrum of biomedical and health research. The HRCS health categories dimension captures the health or disease area while the research activity codes (RAC) classify the types of research activities. One research activity code, 7.2, covers palliative and end of life care research. In the UK CRC dataset, codes are equally apportioned where awards receive multiple codes from the Health and RAC, each code contributed an equal proportion towards each award.

The Health Research Classification System (HRCS) is a way to classify biomedical and other health-related research in order to glean insight into research funding across different disciplines. The HRCS is split into two areas: Health codes and Research Activity Codes. NIHR and Marie Curie code their respective funded research portfolios as a business as usual process. Each award is attributed to at least one Health and one Research Activity code. Up to five codes per area can be applied and the results are reported based on equal proportions between the respective codes.

4.2 Analysis of research funding

Research funding has been calculated as a flat profile per year rather than actual spend. This means that the total award value has been equally split across all of the months it is active within a given financial year across all the financial years it is active. Within our analysis, we were only interested in the financial years 2011-2017 to ensure having full years' worth of data. This is because the dataset included research awards that started before 2011 or will be active post 2018. Also, as the NIHR dataset was made in May 2018, awards made after this month are not included. This means that the analysed funding during the 2011-2017 window does not represent the total research funding for this dataset

4.3 Analysis of coding frameworks (HRCS and project coding frameworks)

As all coding frameworks allowed for double coding (i.e an award can be allocated to more than one code per coding framework), awards were analysed in two ways:

- Every code contributed wholly to an award and was therefore counted as a whole number.
- According to equal proportions (weighting). This means that where awards received multiple codes from the same coding framework, each code contributed an equal proportion towards each award. For an award with three codes attributed, each code would contribute one-third equally.

4.4 Geo Mapping

The mapping analysis of the NIHR and Marie Curie PEoLC combined dataset was completed using the awards postcode centroids to generate X and Y coordinates for each host organisation. The host organisations awards were aggregated, dictating the size of the spheres seen, for the individual NIHR and Marie Curie distribution maps (Fig. 6) with the Devolved Administrations boundaries, from the Office for National Statistics Open Geography Portal.

For the funding distribution map (Fig. 7) which combines NIHR and Marie Curie award funding, the host organisations X and Y coordinates were plotted, and a spatial lookup was performed to generate the English Regions and Devolved Administrations in which these host organisations are located. The funding totals and number of awards by English Region/Devolved Administration were again aggregated and projected against English Regions and, for awards outside the English Regions, Devolved Administration boundaries. Thus, creating a choropleth map for funding where the greater the green shading the higher the funding values. To avoid overcrowding, the award count by geographic region is totalled in the table to the right-hand side of the map.