

WOLFSON PALLIATIVE CARE RESEARCH CENTRE

ANNUAL REPORT for the year 2024



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A welcome from the Director

Welcome to our annual report for 2024. For the first time, this report relates to a whole calendar year (Jan – Dec 2024). There is much good news to share. **Cindy Forbes**, who gained her permanent appointment with us as Lecturer in 2023, was successful in internal promotion to Senior Lecturer in 2024. And **Mark Pearson**, who was Reader with us, was successful in 2024 with internal promotion to Professor of Implementation Science. In 2024, **Jason Boland** – now primarily based in Education but remaining closely affiliated with us in WPCRC - was promoted to Professor of Palliative Medicine and Education; he is Director of Medicine with a Gateway Year and Academic Lead Phase III (final year) for the medical school. Miriam, Jonathan, Liz and I are delighted to welcome Mark into the WPCRC senior



leadership group, and to see Cindy and Jason taking the next steps in their careers. We welcomed two new PhD students to start their PhDs with us in 2024; Steph Meddick-Dyson (Sept 2024 start) and Donna



Wakefield (Jan 2024 start); both successfully gained NIHR PhD Fellowships with our support (Steph was previously working with us as an NIHR Academic Clinical Fellow). Four of our PhD students successfully gained their PhDs in the last twelve months (see photo from left to right: Mike Patterson, Gochi Nwulu, Steph Meddick-Dyson (awarded MSc), Alex Wray (at back), and Sophie Pask, with Fliss Murtagh, Alex Bullock and Cindy Forbes, at the University of Hull graduation ceremony in July 2024).

We have continued to grow our grant income and were successfully awarded 19 grants in 2024, to a total of £13.4m (with over £5.2m income to the University of Hull). It has been especially good to see funding for the North Yorkshire Health Determinants Research Collaboration North Yorkshire (co-led with North Yorkshire Council) and the NIHR Policy Research Unit in Palliative and End of Life Care (co-led with King's College London), as well as ESRC funding on Dying at Home, gained with Prof Liz Walker. We maintained our publication record (with focus on improved quality in higher impact journals) and achieved considerable impact with policy-makers and practitioners at key international and national conferences.



We were awarded a number of prizes in 2024. Jordan Curry (right) was awarded the prestigious **2024 Marie Curie Tammy Prescott Patient and Public Involvement Award** for his doctoral work developing an online supportive care platform for people with lung cancer. His inclusive approach highlighted the pivotal role of patient partners in contributing to a PhD.



We were very pleased to see Helene Elliott-Button (left), one of our early career researchers, awarded the **inaugural Booth Breathlessness memorial award** for her PhD work on older adults with frailty and breathlessness, presented at The

Dyspnea Society's international meeting in Montreal, Canada, June 2024. Mark Pearson was awarded the Inspired Hull, Best Module for his Introduction to Implementation Science for Palliative Care and Long-term Conditions module. Sarah George (essay - first prize), Kate Binnie, Mary Kimani and Steph Meddick-Dyson (paper/abstract - joint first prize) and Megan Coverdale (published paper – first prize) were all successful in the Dorothy Robson prize awards. We continue to consolidate our work, plan new studies, and build capacity in palliative care research, and very much look forward to the next twelve months. I hope you enjoy reading the report, which highlights different research projects and aspects of our work, rather than including all our work. Much more detail of each project is available on our webpages.

Our year at a glance 2024

Our team:



4 Professors
1 Senior Lecturer and 1 Lecturer
17 Research Fellows and Associates
4 professional services staff

Capacity building:

Our outputs: 66 peer-reviewed papers



11 PhD Fellows of whom 2 have NIHR PhD Fellowships; 8 Clinical Academic training posts; 3 other Fellows.

61 international keynote
or invited oral
conference
presentations



7 students have commenced our new MSc in Palliative Care: Implementing Best Practice

Research grants:

Leading & collaborating on grants > £13.3m WPCRC grant income > £5.2m

The team



The WPCRC team at our away day in January 2025

Back: Dawn Wood, Miriam Johnson, Fliss Murtagh, Justine Krygier, Jonathan Koffman, Jordan Curry, Christina Ramsenthaler (honorary), Alex Bullock, Caroline White, Mark Pearson

Middle: Rebecca Corridan, Lauren Beadle (primary affiliation is with the Cancer, Awareness, Screening, Pathways group; however, part of the 2023 PhD cluster), Jane Deville, Flavia Swan, Helene Elliott-Button, Gillian Jackson, Ali Waring

Front: Sophie Pask, Sophie Law-Clucas, Steph Meddick-Dyson, Cindy Forbes, Elisha De Alker, Assem Khamis.

The team: In the WPCRC team, we now have four Professors – Fliss Murtagh, Miriam Johnson, Jonathan Koffman, and Mark Pearson. Prof Liz Walker is part of our senior team, helping lead WPCRC (contributing alongside her other responsibilities). At the mid-career level in the team are Cindy Forbes (newly promoted in 2024 to Senior Lecturer) and Joseph Clark, Lecturer in Global Palliative Care. We also have 17 Research Fellows/Associates, four professional services staff (part-time) and 11 PhD students. In total, including our staff, students, and doctors in training, the WPCRC team comprises 51 people.

Capacity building:

- In September 2024, seven students commenced the new multi-professional, online MSc in Palliative Care: Implementing Best Practice.
- Six Academic Foundation doctors, two medical Academic Clinical Fellows, one NIHR HEE/NIHR ICA Pre-doctoral Clinical and Practitioner Academic Fellow, one Year 4 medical student and one elective medical student undertook research with the WPCRC team in 2024.
- Of our 2024 graduating PhD students, Mike Patterson and Sophie Pask now work with us as Research Associates; Alex Wray works part time at University of York St John's and part time in the NHS, and Gochi Nwulu works for the NIHR.
- Internal promotions achieved by Cindy Forbes, Mark Pearson, and Jason Boland are reported elsewhere in this report.
- Three mid-career researchers are currently working on Fellowship applications.

Team changes: In 2024, Ali Waring was appointed as project facilitator for our awarded North Yorkshire Health Determinants Research Collaboration and the NIHR Policy Research Unit in Palliative and End of Life Care. As already noted, in 2024 we have been delighted to see successful internal promotions for Dr Cindy Forbes to Senior Lecturer and Dr Mark Pearson to Professor of Implementation Science and Dr Jason Boland to Professor of Palliative Medicine and Education. It has been excellent to work more closely with Dr Christina Ramsenthaler (who has an honorary appointment with us) in 2024, with her outstanding statistical, epidemiological and psychometric support; we congratulate her too on promotion to Professor at the ZHAW School of Health Sciences Institute of Nursing, Switzerland. We also welcome Dr Jane Deville who started working in August 2024 as an *'embedded researcher in health inequalities'* working within the NIHR Health Determinants Research Collaboration North Yorkshire and Dr Caroline White who is working on the Carer Support Needs project. We say goodbye to Dr Alison Bravington who left us in November 2024 to commence work as a Senior Research Fellow at Bradford Teaching Hospitals NHS Foundation Trust.

Visitors: We had many visitors throughout 2024, from India, Australia, Japan, Switzerland, other European countries and the UK, and we particularly value our UKRI-funded I3 exchange programme visits with the University of Technology, Sydney. Several of the UTS team have visited us in Hull and several of the WPCRC team have visited the University of Technology, Sydney; always valuable and productive visits.

Our purpose

"Our purpose is to deliver world-class research which supports equitable access to high-quality palliative care for everyone affected by advanced illness."

We are committed to involving people affected by advanced illness, their families and local communities as active partners in shaping our research. We want to make sure that people with different experiences of advanced illness and end of life have the chance to influence what we do and how we do it. This helps us to focus our research on what really matters to people and their families.

In addition, we want to build palliative care research capacity, to help sustain and underpin high-quality palliative care for the future. Palliative and end-of-life research is poorly resourced, with very limited capacity; it is important to us to expand future capacity for research as the need for palliative care increases over the coming years.

Research inclusion and diversity has become an increasing priority, to improve our research and especially to consider in more detail in our research applications and our research delivery. We are a very diverse and inclusive research team in many senses — with wide diversity of disciplines, research methods expertise, and cultural backgrounds. Over the coming twelve months, we will work to increase inclusion and diversity, among our patient and public partners and in recruitment — and we also aim to capture the metrics to demonstrate this more fully, including any gaps or lack of diversity or inclusion.

Our strategic objectives

We believe that all those with advanced illness have the right to high-quality palliative and end-of-life care, wherever and whoever they are. We also believe that research is the lifeblood of high-quality care, and so we strive to deliver world-class research which supports equitable access and high-quality palliative and end-of-life care for all people with advanced illness and their families.

Our strategic objectives are:

- 1. To study under-researched symptoms and problems of those with advanced illness and their families
- 2. To **reduce inequalities in palliative care outcomes**, through research on improving access to and optimising delivery of palliative care services, both in the UK and globally
- 3. To **research health and social care systems** to inform and improve palliative care services and outcomes in low- and middle-income countries
- 4. To develop, research and report measurement of individual-level palliative care outcomes and implementation of these measures into practice to improve care
- 5. To research the social and psychological aspects of palliative care
- 6. To develop better methods and test novel approaches for palliative care research
- 7. To advance education and research on the implementation of palliative care evidence into policy and practice

The perspectives of those with lived experience

The voices of individuals with lived experience of advanced illness are crucial for conducting high-quality, impactful research that not only enhances care but also aligns with the needs and priorities of those most affected. This inclusion is especially important for people with advanced illnesses, who may face significant challenges in finding the time and energy to make their voices heard.

We are committed to actively involving patients, families, and public partners throughout all stages of our work. Each project is enriched by the invaluable contributions of our patient and public involvement and engagement (PPIE) partners, whose insights are instrumental in shaping and guiding our research. We also extend our sincere gratitude to Helen Roberts, the Patient and Public Involvement Co-ordinator at the University of Hull, whose exceptional support has been pivotal in transforming and enhancing our collaborative efforts with PPIE partners. Below, we highlight examples of how the perspectives of those with lived experience inform and drive our work, along with an overview of some of our ongoing projects.

Box 1: Spotlight on Patient and Public Involvement: Marie Curie 'Better End of Life Care 2024'

Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales

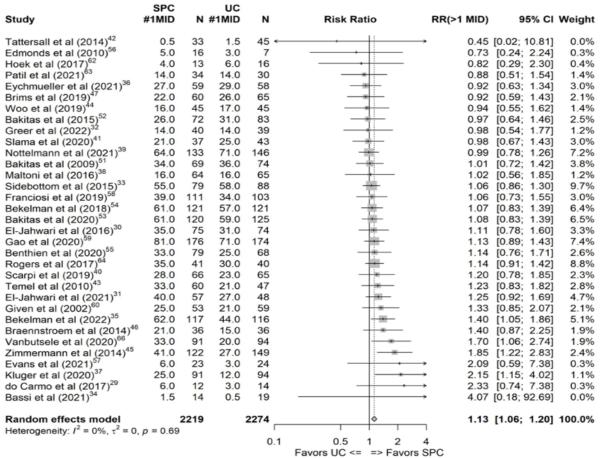
The 'Better End of Life' research report 2024 (https://www.mariecurie.org.uk/document/experiences-at-the-end-of-life-in-england-and-wales) was written with our Patient and Public Involvement (PPI) group, who are people with lived experience of advanced illness and may be caring for family members towards the end of life. These individuals were involved throughout the research process, including shaping the post-bereavement survey through discussions about the choice of questions and guiding the development of accompanying study information. The PPI group also contributed to the analysis of data and identification of the key themes presented in this report. Throughout the research (from inception to completion), our PPI group emphasised the value of conducting the survey, to learn more about people's experiences at the end of life and understand systematically where improvements must be made.



"Many respondents told us that they completed the survey in order to make a difference for future care, even though it sometimes brought back distressing memories. Their accounts provide crucial evidence about what dying, death and bereavement is like today. We must ensure that the lessons learned from the many people who took the time to share their experiences with us are used, by policy makers, to ensure better care and better support for people approaching the end of their life, their families and carers". (PPI group members)

Box 2: Spotlight on benefits of specialist palliative care

We conducted a systematic review published in <u>PLOS Medicine</u> with meta-analysis and meta-regression to estimate the summary effect of specialist palliative care (SPC) across settings on quality of life and emotional wellbeing and identify the optimum service delivery model. The review comprised 42,787 records from 39 international RCTs (*n*= 38 from high- and middle-income countries)



Forest plot of the relative risk effect size for the quality of life outcome at 12 weeks

SPC works and works well:

- Here is hard evidence that SPC does what it purports to do, providing better quality of life and better emotional well-being for people with advanced disease, with moderate/good effect sizes.
- We demonstrate an NNT similar (or better) than many other well-accepted interventions, such as cardiac rehabilitation.

Too little, too late:

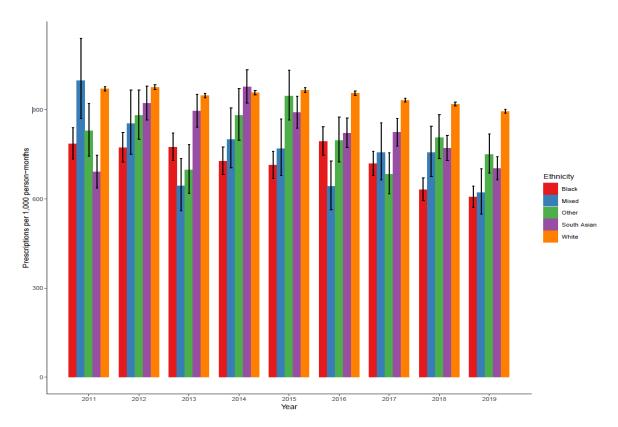
- However, the current common practice across the UK is for referrals to SPC to be too late for real benefit; currently, most SPC referrals occur within weeks of death; our data seriously challenge this practice (too little, too late) because the evidence shows that SPC needs three months to maximal benefit (although there is certainly some benefit before then).
- See https://journals.sagepub.com/doi/full/10.1177/0269216318781417 a national study with 42,758 people who died, which showed the median time from referral to death across specialist palliative care services nationally was 48 days; cancer (53 days) and non-cancer (27 days). Note this study was prepandemic; the duration of SPC may well be shorter still now.
- SPC picks up the most complex cases, and often relieves the NHS including reducing unplanned
 admissions and bed days; but its ability to do this is reducing markedly, as third-sector providers
 experience major financial and workforce squeezes and reduce the numbers and duration of those seen.

Box 3: Spotlight on addressing inequalities at the end of life - minority ethnic communities

We have made significant contributions to undertaking research among previously under-researched population groups. Specifically, we have led the field in progressing palliative care-related research among patients and their families from minority ethnic backgrounds and in developing methods, culminating in the completion of two key studies (submitted but not yet published).

Patient ethnicity and evidence of inequity in prescribing opioids

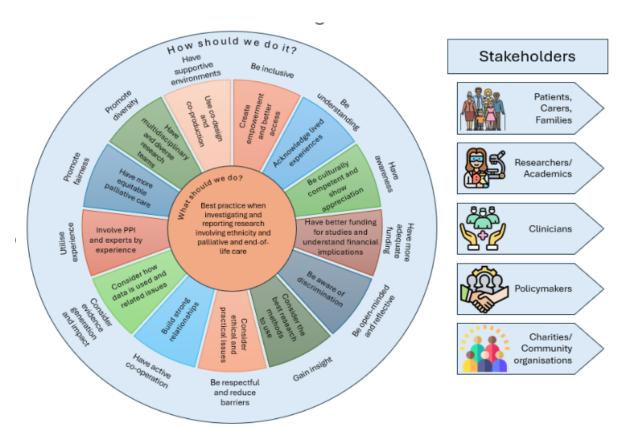
- Funded by NIHR and led by Professor Jonathan Koffman in collaboration with researchers from King's College London and Cambridge University, we examined the prescribing of opioids to cancer patients for pain across different ethnic groups at the end of life. Using national data from the Clinical Practice Research Datalink (CPRD), Hospital Episode Statistics (HES), and the Office for National Statistics (ONS), we analysed the prescribing patterns of Step 2 opioids and Step 3 opioids at the end of life. The study included data from 2011-2019 and comprised 232,329 patients, encompassing 4 million prescriptions of which 620,000 were issued in the final three months of life.
- After adjusting for patients' sociodemographic and clinical characteristics, our findings revealed opioid
 prescribing rates were consistently lower for all patients from minority ethnic backgrounds compared to
 the White British reference population.
- We also demonstrate the total quantities of opioids prescribed, measured in morphine milligram equivalents, were also lower for these patients.
- Reasons for these disparities remain opaque and multifaceted and underscore the urgent need for further
 research to explore the root causes of these inequities. We can then develop and evaluate interventions
 that ensure equitable access to high-quality pain management for all patients.



Rates of prescriptions of opioids in the final three months of life across different ethnic groups from 2011-2019

Better science to investigate experience and outcomes of care of patients and their families from minority ethnic backgrounds

- The second study builds on a <u>pivotal editorial</u> and <u>systematic review</u> published in *Palliative Medicine* which highlighted the presence of inadvertent racism in both palliative care and palliative care research emphasizing the urgent need to collect data that enables the equitable assessment and monitoring of racial and ethnic disparities, as well as their intersections with other protected and social characteristics.
- This call to action paved the way for a Medical Research Council's 'Better Guidance, Better Methods'
 funded study led by Professor Jonathan Koffman and Helene Elliot Button at WPCRC, to establish
 methodological best practice principles for qualitative and quantitative research related to ethnicity in
 palliative and end-of-life care.
- Research employed a national, modified Delphi approach across three rounds, engaging 45 participants in each round. This process resulted in the development of 13 guidance principles designed to ensure greater scientific rigor when conducting research involving minority ethnic communities.
- These principles will be disseminated nationally and internationally to researchers, funding bodies, and
 other key stakeholders. The aim is to promote more equitable research practices and pave a clearer path
 toward improving health outcomes and experiences for patients and families from minority ethnic
 backgrounds.



Representation of principles to guide palliative care research focused on minority ethnic communities

Box 5: Spotlight on costs of providing informal care in the last year of life:

Little is known about replacement costs of care provided by informal carers during the last year of life for people dying of cancer and non-cancer diseases. In our paper in <u>Palliative Medicine</u>, we provide population-level evidence replacing their care with social and healthcare services would incur an estimated national replacement cost (England only) of at least £28.7 billion per year. Increased costs were associated with longer care duration and intensity, older age, death at home (when living together), non-cancer causes of death, and greater socioeconomic deprivation.

Calculations for population scaled costs

Type of care	Study participants providing care for one decedent over the last 5 years n (%)	Those providing care scaled to the total adult population* 2017 n (6.5% of 44,981,459)	Application of minimum and maximum average cost per carer to the total adult population providing care	Cost per year per carer for care provided in the last year of life** (divide by 5) (in billions, to 1 dp)
Personal care				
minimum	521/7997 (6.5)	2,923,794.835	£18,557 x 2,923,794.835 = £54,256,860,753.095	£10.8 billion
maximum			£22,072 x 2,923,794.835 = £64,533,999,598.12	£12.9 billion
Other help	•	•		
minimum	1010/7997 (12.6)	5,667,663.834	£11,656 x 5,667,663.834 <u>=</u> £66,062,289,649.104	£13.2 billion
maximum			£13,697 x 5,667,663.834 = £77,629,991,534.298	£15.5 billion

^{*}Assuming study sample is representative of the whole population

A wake-up call:

- These findings highlight a significant challenge for future of universal care coverage in the UK and globally, as the ageing population reduces the pool of unpaid carers able to support dependents.
- Alarmingly, nearly 1 in 10 unpaid carers in our study reported that they would not be willing to provide
 care again under similar circumstances. Improving their experience is critical to maintaining future
 willingness to care.
- The homecare workforce crisis remains unaddressed. A rapid review of 19 papers on the needs and experiences of homecare workers revealed severe challenges, including:
 - A lack of emotional support and professional end-of-life care training.
 - Poor terms and conditions.
 - Isolated working practices and poorly defined professional boundaries.
 - These factors contribute to critically low recruitment and retention rates, which are unsurprising given the current situation.

So, what are the solutions?

1. Support current informal carers:

 Relationships between longer care duration and intensity, older age, death at home (when living together), non-cancer causes of death, and increased costs underscore need for better recognition and provision of statutory support for informal carers.

2. Invest effectively in formal social and healthcare services:

• Ensure homecare services are adequately resourced, well-supported, and professionally trained, enabling timely and effective support for family and friends providing care now.

3. Prepare for the future:

 Scale up formal social and healthcare services to address the projected 25% increase in deaths by 2040, effectively bridging the widening "care gap."

^{**} Assuming the episodes of caregiving are evenly distributed over 5 years

Global and international research

Box 6: Spotlight on Global Breathlessness Research and the 'Breathe-India' Project

Advancing Global Breathlessness Research

In May 2024, the University of Hull hosted a global breathlessness workshop, convened by Dr. Joseph Clark, which brought together international experts, including Dr. Seema Rao (Karunashraya Hospice, India) and Professor Monsur Habib (Bangladesh Primary Care Respiratory Society). The workshop addressed key challenges in global breathlessness research, particularly in low- and middle-income countries (LMICs), where differing approaches may be required compared to high-income settings. The team published a paper, *Breathlessness Without Borders:* An Agenda for Global Research (https://doi.org/10.1038/s41533-024-00384-9), highlighting the unique challenges of managing breathlessness in LMICs. These include its high prevalence, environmental risk factors, and multifactorial causes that are often untreated. The paper also underscored the urgent need for implementation research to address these challenges.



Building on the workshop's recommendations, Dr collaborated with colleagues Bangladesh, India, and Nepal to submit a grant application to the National Institute of Health Research for а three-country Hybrid Implementation Study. Under the Breathe-India initiative, Dr Clark and his team co-developed culturally relevant breathlessness management resources for community use in India. The proposed study will assess the feasibility of implementing breathlessness education across hospital, primary care, and community settings.

Dr Clark with 'Breathe-India' team members and collaborators at Karunashraya Hospice, Bangalore, November 2024

Exploring Low-Risk Interventions

Professor Miriam Johnson, Dr Joseph Clark, and collaborator Dr Tim Luckett (University of Technology Sydney) coauthored a letter responding to calls for further clinical studies on the effectiveness of handheld fans for managing breathlessness. The letter, accepted for publication in the *European Respiratory Society Journal*, critiques the use of evaluation frameworks designed for pharmacological interventions when applied to low-risk, potentially beneficial tools like handheld fans. It advocates a pragmatic "nothing to lose, much to gain" approach to assessing such interventions.

Pioneering Research in LMICs

Dr Clark was also part of the first prevalence study of breathlessness in an LMIC, conducted in India. The study revealed that 44% of the general population experience breathlessness limiting exertion, with an estimated 626 million people in India affected, including 52 million suffering from severe breathlessness (https://doi.org/10.1371/journal.pgph.0002655).

Since the study's publication in May 2024, Dr. Clark has led dissemination efforts, delivering an invited lecture at a hospice in Bangalore and presenting findings at the *National Conference on Pulmonary Diseases (NAPCON) 2024* in Coimbatore, India. His growing international influence in the field has also been recognized through his appointment as an Adjunct Faculty Member at Manipal Academy of Higher Education and his invitation to join the Global Breathlessness Research Network, led by the International Primary Care Respiratory Group.

Education and capacity building

Box 7: Spotlight on Education

Undergraduate Teaching

Over the past year, researchers and academics at the WPCRC have delivered eight Scholarship and Special Interest Programme (SSIP) modules to Hull York Medical School undergraduate medical students. These modules, typically involving groups of 8–10 students, cover diverse topics related to palliative and end-of-life care and research. By introducing medical students to the significance of palliative care research early in their education, the SSIP modules provide a vital foundation for future medical practice.

Our efforts continue to inspire many former SSIP students to return for electives, summer projects, or Foundation research attachments with the Centre. Beyond SSIP teaching, WPCRC academics have contributed to the Hull York Medical School MB BS programme, delivering critical appraisal and ethics workshops and lectures as part of the Health & Society module.

Postgraduate Taught Programmes



The Centre's new online MSc **Palliative Implementing Best Practice** (also offered as a PG Certificate and PG Diploma) welcomed its first cohort of seven students in September 2024, exceeding recruitment goals despite widespread enrolment financial and challenges in UK Higher Education. This innovative programme is designed to empower healthcare and social care professionals, policymakers, and researchers to enhance palliative care and manage long-term conditions.

Students engage in core and optional modules, such as *Palliative Care Research and Practice, Introduction to Implementation Science, Global Palliative Care, Qualitative Research Skills for Palliative Care,* and *Design & Evaluation of Complex Interventions*. The programme culminates in supervised research projects, where students undertake secondary data analysis or systematic reviews guided by Wolfson Centre academics.

Building on the success of the *Introduction to Implementation Science* module—which attracted 8 CPD students in 2024/25—the MSc modules will be offered as standalone CPD options in the upcoming academic year, aligning with Hull York Medical School's strategic focus on Continuing Professional Development (CPD).



International Postgraduate Education

In November 2024, Professors Jonathan Koffman and Mark Pearson delivered an intensive week-long programme of workshops on Palliative Care and Implementation Science at the School of Nursing, Faculty of Health & Social Sciences, Hong Kong Polytechnic University. The sessions were tailored to postgraduate students, researchers, and academic staff, covering lectures on *Implementation* Science, Frameworks and Theories, Clinical Trials, and Evidencing Pathways to Impact.



Professors Jonathan Koffman and Mark Pearson running the Advanced Implementation Science workshop

The week-long programme included interactive workshops on topics such as writing for publication and grant applications, one-to-one surgeries with PhD students, and a faculty-wide seminar titled *Implementation Science Comes of Age: Why the Science of Evidence into Practice is Vital for the Care of People with Long-Term Conditions and Palliative Care* (attended by 52 participants) further enriched the programme.

It was very well received. Feedback included, for example: "wonderful talks from Prof Koffman and Prof Pearson on complex interventions and implementation science"; "truly inspiring"; "you can only listen to these talks in one of the best nursing schools".

This collaboration has strengthened ties with the School of Nursing, led by Professor Janelle Yorke, Hong Kong SAR Global STEM Professor, and will underpin the WPCRC's ongoing efforts to advance international research capacity, education, and impact in palliative care.

Where are they now?

We turn the spotlight on past medical clinical doctoral students/fellows (supervisor: Johnson).



Paul Taylor completed his HYMS-funded PhD 'Clinical Decision Making at the End of Life' in 2012. In 2017, he took up a substantive position as Senior Clinical Lecturer in Palliative Medicine at SCHARR, University of Sheffield, and is now Head of Research at St Luke's Hospice Sheffield Clinical Senior Lecturer in Palliative Medicine at SCHAAR. He continues as a valued WPCRC collaborator, especially as a co-investigator on the RESOLVE and SUPPORTED studies.

<u>Dr Amy Gadoud</u>, now based at Lancaster University completed her HYMS-funded PhD 'A palliative care approach for people with advanced heart failure,' and won our first NIHR Integrated Academic Training (IAT) Programme Clinical Lectureship. From this post, she was appointed as substantive Clinical Senior Lecturer in Palliative Care at the University of Lancaster. She has recently been appointed as the national speciality lead for Palliative Care in the NIHR-funded Research Delivery Network.





Dr Jamilla Hussain was our first NIHR IAT Academic Clinical Fellow. She completed her Masters in decision-making in end-stage kidney disease and won an NIHR Doctoral Training Fellowship ('Missing data in palliative care trials'). She was then awarded our second NIHR IAT Clinical Lectureship. On completion of clinical training, she was appointed Consultant Palliative Physician and Senior Research Fellow at <u>Bradford Teaching Hospitals NHS Foundation Trust</u>. She is a WPCRC Honorary Senior Lecturer and has started her NIHR Advanced Fellowship exploring inequalities at the end of life. She is the Principal Investigator and is a co-investigator on several WPCRC-led, funded studies. Jamilla said "I would never have imagined I would be doing".

what I'm doing now when I first met Prof Miriam Johnson in a hospice café as a junior doctor about to start specialist training. I have and continue to benefit immensely from the support and mentorship from the WPCRC team."

Ed Richfield completed his Dunhill Medical Trust Doctoral Clinical Fellowship, on Palliative care in Parkinson's disease: developing a needs assessment tool. He completed his geriatric medicine training and is now a Consultant Geriatrician in North Bristol NHS Trust and is active in research. He is a Founder Board Member of the International NeuroPalliative Care Society (INPCS), the current chair of their Clinical Committee, the Chair of the British Geriatric Society movement disorders special interest group and the Academic Director of the Palliative Care Masterclass and the Advanced Parkinson's Masterclass at the Palliative Care Academy, Neurology Academy.





Dr Sunitha Daniel completed her self-funded PhD 'Psychological symptoms in breast cancer patients of Indian heritage', working in part from India. On completion, she took up the post of Lead Consultant in Palliative Medicine at York and Scarborough Teaching Hospitals NHS Foundation Trust, with an Honorary Senior Lectureship with Hull York Medical School and some protected research time. She is a valued WPCRC-affiliate, particularly with our global palliative care stream. She has just submitted her first PI grant application to the NIHR RfPB.

Box 9: Spotlight on the RESOLVE Outcomes Registry project







As part of the Resolve project, and together with Hospice UK, we set up and sustained a national **Outcomes Community of Practice** about the use of outcome measures in palliative care practice.

This consisted of a community of UK-wide clinicians and researchers interested in outcome measures in palliative care, with discussion forums and a monthly Project ECHO* meeting – these online meetings followed Project ECHO methods, and consisted of i) expert input on an outcomes-related topic chosen by attendees, ii) case examples from the attendees about what works and what doesn't in practice, and then iii) dialogue and discussion to share learning and practical experience.

During 2024, the community developed into two networks; one on **Outcome Measures in Practice** (for clinicians in practice) and the second on **Outcomes, Data and Dashboards** (for the data analysts).(*Project ECHO™ (ECHO = Extension of Community Health Outcomes) is an evaluated knowledge sharing methodology developed by the University of New Mexico in 2002 and currently used in 34 countries worldwide. Hospice UK was the first to introduce this to the UK.)

We contributed as follows:

Hospice UK	Hospice UK and WPCRC: Outcome Measures in Practice National Project ECHO meetings			
17 Jan 2024	Update and 'walk through' the RESOLVE training resources.			
	Fliss Murtagh			
17 Apr 2024	How to deal with different types of missing data in a longitudinal dataset in the			
	context of palliative care			
	Assem Khamis and Fliss Murtagh			
18 Sep 2024	How to derive levels or classes of complexity for specialist palliative care			
	Fliss Murtagh			
16 Oct 2024	Changing practice using individual-level outcomes data			
	Fliss Murtagh			

Some of the key findings from the end of year evaluation were:

- 100% of respondents agreed that their participation in the ECHO Network has made them feel more supported in their roles
- 100% agreed participation supported the quality of practice and the care to patients and/or service users.
- The overwhelming majority of participants acknowledged that the ECHO sessions played a pivotal role in achieving the network's outcomes.

These results underscore the significance of collaboration and knowledge sharing and the positive impact it has had within the palliative care sector (source: email received from echo@hospiceuk.org on 25/03/24)

The RESOLVE Outcomes Registry project is funded by



Box 10: Spotlight on the Creating Connections Palliative Care Conference



In July 2024, the Wolfson Palliative Care Research Centre and the University of Technology Sydney convened an in-person and online one-day 'Creating Connections Palliative Care Conference'. This collaboration funded by the Research England's International Investment Initiative (I3) builds on the established partnership between our both our Research Centres. In person conference delegates were represented health and social care professionals from local NHS and voluntary sector organisations, and academics from multiple UK universities.

The conference featured two keynote lectures including policy change in palliative care given by Professor Ilora Finlay, The Baroness Finlay of Llandaff, member of the House of Lords and (ii) Achieving Evidence-based Change in Palliative Care by Professor Irene Higginson OBE, Professor of Palliative Care and Policy, Executive Dean of Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care, King's College London and Scientific Director of Cicely Saunders



Keynote lecture by Professor Irene Higginson 'Achieving evidence-based change in palliative care'

Other lectures focused on changing practice and policy in Australia specifically neglected populations by Professor Meera Agar, changing UK policy and practice including a presentation by Prof Mark Pearson on why implementation science is vital for palliative care and changing UK and global practice and policy chaired by Associate Professor Libby Sallnow from University College London including a highly evocative presentation on the bereavement experiences of parents and children by Dr Alex Wray.



Presentation by Dr Alex Wray on bereavement experiences of parents and children involving intersection of music and images and findings her PhD study resulted in silence and introspection by conference delegates

Posters were presented by PhD students and researchers where delegates discussed in detail exciting developments in national and international research and methods relevant to palliative and end-of-life care. The day culminated in prize-giving for the best poster and oral presentations by Prof Irene Higginson and closing remarks by Professor Miriam Johnson from the WPCRC.

Box 11: Spotlight on University of Hull Research Celebration Week

In October 2024, as part of our contribution to the University of Hull 'Research Celebration Week', we convened a Palliative Care Research Spotlight for academics across the University to understand why palliative care research matters and to showcase our ground-breaking research and impact, specifically our contribution to the Marie Curie 'Better End of Life Care' Reports, the ways in which we have invested in palliative care research capacity, our growing focus of research on inequalities, and to spotlight our capacity building from the perspectives of three PhD and early career researchers: Dr Stephanie Meddick-Dyson, Dr Gillian Jackson and Dr Joseph Clark.



Presentation by Professor Jonathan Koffman on our programme of work focused on inequalities

Box 12: Spotlight on national conference success for St Luke's Hospice including representation from the Wolfson Palliative Care Centre

On the 30 October 2024, almost 100 delegates from 38 hospices across the country, four universities and three NHS Trusts were present for the first St Luke's Hospice national conference on the development of palliative care research. Professor Fliss Murtagh presented to the audience critical steps in designing the research strategy where she explained the purpose of strategy, the imperative for research in palliative care and hospice, our research is guided by national priorities and also the involvement of experts by experience, and sobering statistics current spend on palliative and end-of-life care related research. Professor Miriam Johnson led a presentation on challenges and solutions to engaging in palliative care research. Both Miriam and Fliss led roundtable discussions on "I'm a doctor, how do I develop my clinical academic career"?



(From L-R) St Luke's Consultant and Head of Research Dr Paul Taylor, Professor Fliss Murtagh, Professor of Miriam Johnson, Palliative Care Consultant Dr Felicity Dewhurst St Luke's, Research & Innovation Manager/Research Nurse Clare Pye & St Luke's Medical Director Dr Sam Kyeremateng

Research grant income

We have continued to build on our grant success of previous years, with nineteen successful research grant awards in 2024 to undertake a range of diverse research projects (see Table 1 for details). Over the last six or seven years, we have steadily increased the number and the size of applications, and our success rate has also improved (Figure 1).

From 2021 and 2022, we began to focus our grant applications, so that they were either a) more often on programmes of research rather than individual projects (aiming for fewer awards of larger size), and b) on capacity building awards. We have had success on both counts. For example, in 2024 Mark Pearson has been successful, in partnership with North Yorkshire Council colleagues and colleagues at University of Hull and York, in gaining a £5m NIHR North Yorkshire Health Determinants Research Collaboration award – to increase capacity, awareness and use of research within North Yorkshire Council. Fliss Murtagh was successful, in partnership with Prof Katherine Sleeman at King's College London, in gaining £3m funding to co-lead the NIHR Policy Research Unit in Palliative and End of Life Care. With respect to capacity building, Fliss was also successful gaining funding from The Healthcare Improvement Studies (THIS) Institute to appoint a clinical PhD Fellow (with funding for a senior clinical nurse to undertake a doctorate part time), and supporting Steph Meddick-Dyson to success in an NIHR PhD training Fellowship.

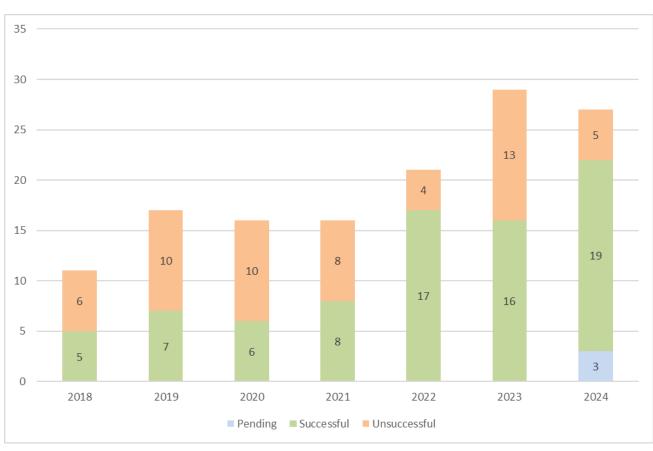


Figure 1: Number of grant applications 2018 - 2024, by year and outcome

In 2024, members of the WPCRC team have led or been co-applicants on bids to a total of more than £13 million; and have brought grant income to University of Hull of £5.28 million. Detail of the successful awards in 2024 having a WPCRC team member as lead or co-lead can be seen in Table 1. Where bids are co-led in partnership with colleagues from other Universities or where we are co-applicants with them, then 'co-lead' or 'co-applicant' is noted the Table.

Table 1: Details of successful research grant awards in 2024

Funder, project title and lead investigator	Grant income to University of Hull	Total grant income awarded
Yorkshire Cancer Research: BE SPeCiaL: Brain tumours — enhancing palliative care for patients and family — Mark Pearson	£0	£961,538
NIHR RfPB: BREEZE 2: A randomised controlled trial of a complex intervention to manage breathlessness in pulmonary fibrosis – Ann Hutchinson	£397,552	£397,552
Yorkshire Cancer Research: CanBenefit3: Implementation of tailored wellbeing advice among people diagnosed with lung cancer – Cindy Forbes	£346,148	£349,964
NIHR PhD Fellowship Co-developing an Implementation Toolkit for Palliative Care in the Intensive Care Unit - Fliss Murtagh and Steph Meddick-Dyson	£475,336	£475,336
NIHR PGfAR: Complexity and outcomes among children and young people with life-limiting/life threatening conditions – Fliss Murtagh (co-applicant)	£11,408	£261,562
NIHR HSDR: DAMPen-D II: Improving Delirium - a cluster RCT - Mark Pearson and Fliss Murtagh	£2,142,656	£2,504,125
Marie Curie: DueCARE - Defining and estimating current and future Unmet palliativE CARE needs in the UK – Fliss Murtagh	£0	£99,934
ESRC: Dying at Home - Liz Walker and Fliss Murtagh	£269,175	£799,665
UKRI: EMPOWER: Empowering a Meaningful Life for All, Dementia Network Plus - Emma Wolverson, Liz Walker and Fliss Murtagh	£361,176	£1,748,414
NIHR: Enabling equity for minority ethnic unpaid and family carers: Cultural acceptability of CSNAT-I – Jonathan Koffman	£283,360	£283,360
NIHR: EPIC-PC: Equitable Palliative care In the Community through Primary Care (EPIC-PC) - Fliss Murtagh (co-applicant)	£30,896	£951,142
NIHR Policy Research Unit (PRU) for Palliative and End of Life Care - Fliss Murtagh (co lead with Kings College London)	£770,950	£2,939,000
NIHR Senior Investigator award – Fliss Murtagh	£80,000	£80,000
Optimising delivery of integrated palliative care and heart failure services: A realist evaluation - Miriam Johnson (co-applicant)	£9,240	£708,318
The Royal Marsden Cancer Charity: The Association of Social Determinants of Health in Decision Making at the End of Life – Jonathan Koffman	£57,496	£57,496
Nuffield Trust: The Wellbeing in Later Life in Bradford Study (WeLL-Bradford) - Fliss Murtagh (co-applicant)	£13,728	£749,559
The International Society of Behavioural Nutrition and Physical Activity (ISBNPA): Understanding physical activity interventions for patients receiving immune checkpoint inhibitor therapy – Jordan Curry	£1,015	£1,015
NIHR ARC: Yorkshire & Humber ARC – 18-month extension (palliative) – Fliss Murtagh (co-applicant)	£30,311	£30,311
NIHR HDRC: Health Determinants Research Collaborative North Yorkshire – Mark Pearson	£989,764	£5,050,482
TOTAL	£5,280,447	£13,398,291

Over the last five years, we have seen a steady increase in our research grant income, allowing us to undertake and deliver research to meet to our strategic objectives, build much-needed capacity for palliative care research, and work towards impact to improve care.

A major boost to income has been the successful start of the Hull Health Trials Unit (launched in mid-2019), which allowed us to bring clinical trials unit funds to the University of Hull, instead of outsourcing to other trials units. Without the Hull Health Trials Unit, several projects (DAMPen-D II, MABEL, BREEZE 1 and 2, BREATHE, FANFIRST and RemoteGO) would have been much harder to achieve, and resulted in less research income to the University of Hull.

APPENDICES

Wolfson Palliative Care Research Centre - Staff

Researchers and Pro	ofessional Ser	vices
Name		Role
Bayley	Zana	Research Associate Band 6 on SUPPORTED – in School of Psychology and Social Work and affiliated to WPCRC
Bravington	Alison	Research Fellow – (Left November 2024)
Bullock	Alex	Clinical Research Fellow
Clark	Joseph	Lecturer in Global Palliative Care
Corridan	Rebecca	Research Administrator
Curry	Jordan	Research Associate
Dawkins	Marsha	THIS PhD Fellowship
Deville	Jane	Embedded Researcher
Elliott-Button	Helene	Research Associate
Forbes	Cindy	Senior Lecturer, in Physical Activity
Harvey	Kathryn	Admin support (social work)
Hernandez	Sebastian	Research Associate
Hutchinson	Ann	Research Fellow in Chronic Breathlessness
Jackson	Gillian	Research Fellow
Johnson	Miriam	Professor of Palliative Medicine
Khamis	Assem	Research Associate (Data)
Koffman	Jonathan	Professor of Palliative Care
Krygier	Justine	Research Associate
Law-Clucas	Sophie	Research Associate
Meddick-Dyson	Stephanie	NIHR PhD Fellowship
Murtagh	Fliss	Professor of Palliative Care
McNaughton	Ciaran	Research Associate
Okwuosa	Ebuka	Research Administrator
Pask	Sophie	Research Associate 100% WTE
Patterson	Michael	Research Associate
Pearson	Mark	Professor in Implementation Science
Swan	Flavia	Research Fellow in Cancer Rehabilitation
Walker	Liz	Professor of Health and Social Work (University of Hull), Associate Director WPCRC
Waring	Ali	PRU Administrator & HDRC Administrator
Wood	Dawn	Research Administrator Lead/PA to Profs Johnson, Koffman & Murtagh

Wolfson Palliative Care Research Centre - PhD Fellows

PhD students				
Name		Primary supervisor	Year	
Binnie	Kate	Miriam Johnson	Year 3	
Kimani	Mary	Fliss Murtagh	3 rd year	
De Wolf Linder	Su	Fliss Murtagh	4 th year (part time)	
Phyo	Yinyin	Meera Agar	UTS 2 nd year	

Wakefield	Donna	Jonathan Koffman	Year 1
Jenkinson	Laura	Mark Pearson	Year 1
Dawkins	Marsha	Fliss Murtagh	Year 1
Bond	Maddie	Joseph Clark	Year 1
Dehpour	Tara	Jonathan Koffman	Year 1
Kearsley	Sarah	Liz Walker (1 st supervisor) Miriam Johnson (2nd supervisor)	Year 2 (University of Hull – School of Psychology and Social Work, rather than HYMS)
Gulliksen	Beth	Fliss Murtagh	Year 1

External PhD Fellows co-supervised by WPCRC Staff

PhD students			
Name		Supervised by	University
Fujimoto	Miki	Jonathan Koffman (2 nd supervisor)	King's College London
Firth	Alice	Fliss Murtagh (2 nd supervisor)	King's College London
Crowther	Lucia	Miriam Johnson (2 nd supervisor)	University of Hull – Dept of Human Geography
Featherstone	Imogen	Miriam Johnson (2nd supervisor)	University of York – Department of Health Sciences/ Hull York Medical School
Kitching	Mark	Miriam Johnson (2nd supervisor)	University of Hull 2 nd year

Wolfson Palliative Care Research Centre – Other Fellows and attached students

Academic Clinical Fellow			
Name Supervised			Year
Young	Jenny	Fliss Murtagh	Maternity Leave

Specialised Foundation Programme				
Name		Supervised by	Year	
Silva	Vishmi	Fliss Murtagh	Dec 23 – Apr 24	
Bushell	Sonya	Fliss Murtagh	Apr 23 – Apr 24	
Dennis	Lizzie	Cindy Forbes	Apr 24 – Aug 24	
Luke	Ishbel	Fliss Murtagh	Apr 24 – Aug 24	
De Alker	Elisha	Fliss Murtagh	Dec 24 – Mar 25	
Hatton	Rebecca	Miriam Johnson	Aug 23 – Aug 25	

Other Fellows			
Name Supervised by		Supervised by	Year
Skipsey	Emma	Fliss Murtagh	NIHR HEE/NIHR ICA Pre-doctoral Clinical and
			Practitioner Academic Fellowship

Yr4 Long SSIP			
Name Supervised by Year			Year
Coverdale	Megan	Fliss Murtagh	Dec 23 – May 24

Elective Medical Students			
Parsons	Zoe		Jul 24 – Aug 24

Wolfson Palliative Care Research Centre - our projects

Full details of our projects are available on our webpages at

 $\underline{\text{https://www.hyms.ac.uk/research/research-centres-and-groups/wolfson/projects}}$

Wolfson Palliative Care Research Centre – our conference presentations in 2024

In 2024, we presented at a wide range of national and international conferences. For reasons of space, we have not presented all our conference presentations here, but some examples include:

Keynote and invited presentations

- 1. Keynote presentation, **6**th **Maruzza International Congress on Paediatric Palliative Care, October 2024**. Jonathan Koffman. What is the evidence we are equal at the end of life and how can we meet our core mandate?'
- Keynote presentation, The Royal Marsden Adult Palliative Care Update Study Day, November 2024, London, UK. Jonathan Koffman. Pain in the margins
- 3. Keynote Oral presentation, Yorkshire & Humber Palliative Care Research Network: **Knowledge Exchange Showcase**, **February 2024**, York UK. Fliss Murtagh. What has the Yorkshire & Humber Palliative Care Research Network achieved?
- 4. Keynote Oral presentation, **Current Issues in Palliative Care 2024**, **April 2024**, London, UK. Fliss Murtagh. Findings from the Better End of Life Project
- 5. Keynote Oral presentation, **UK Kidney Association Kidney Week UK**, June 2024, Edinburgh, UK. Fliss Murtagh. An update on the evidence: what do we know about what works in Kidney Supportive Care?
- 6. Keynote Oral presentation, **Specialised Foundation Programme Training Day, October 2024**. York UK. Stephanie Meddick-Dyson. The Hat Trick: Palliative Reg, Med Reg, and Academic
- 7. Keynote Oral presentation, **Bath, Swindon and Wiltshire Palliative and End of Life Care Alliance**, **October 2024**, online. Fliss Murtagh. Individual-level Outcome Measures: demonstrating the impact of palliative care
- 8. Keynote Oral presentation, **St Barnabas Hospice: national Palliative and End of Life Care conference, November 2024**, Stamford, UK. Fliss Murtagh. Research in Palliative and End of Life Care
- Keynote Oral presentation, Keech Hospice: National masterclass Thinking about complexity in the older populations we serve, September 2024, online. Fliss Murtagh. 1. Complexity and frailty in palliative care populations. 2. Impact of and experiences from a novel Integrated Service for Older Adults at Risk of Frailty
- 10. Keynote Oral presentation, **Hospice UK national conference**, **November 2024**, Glasgow, UK. Fliss Murtagh. Understanding casemix: who are the patients?
- 11. Invited Plenary Speaker, **RCPE symposium Heart Failure October 2024**, online. Miriam Johnson. Delivering equitable palliative care *integrating palliative care and heart failure services
- 12. Invited Plenary Speaker, Indian Association for Palliative Care Conference Ahmedabad, India, February 2024. Miriam Johnson. Palliative care for people with non-malignant lung disease
- 13. Invited Oral presentation at the PCRS (Primary Care Respiratory Society) September 2024, Telford, UK. Ann Hutchinson. Living with Breathlessness: Understanding the impact of breathlessness on the lives of your patients and what you can do to support them.
- 14. Invited Oral presentation, **Karunashraya Hospice, November 2024**, Bengaluru, India. Joseph Clark. Breathlessness management in low resource countries: insights from a realist evaluation conducted in India.
- 15. Invited Oral presentation, **Wolfson Palliative Care Research Centre Conference, July 2024**, University of Hull, UK. Joseph Clark. Global breathlessness research: an agenda for change
- 16. Invited Oral presentation, Hospice UK: **Outcome Measures in Practice national ECHO webinar, January 2024,** online. Fliss Murtagh. Update and 'walk through' the RESOLVE training resources
- 17. Invited Oral presentation, Association for Palliative Medicine Webinar on Palliative Care Research: Why it matters, and why you should do it, February 2024, online. Fliss Murtagh. Hot topics in palliative care research
- 18. Invited Oral presentations, POS and IPOS essentials (day 1), Use and Implementation (day 2): **two day workshop delivering training on use of outcome measures, May 2024,** London UK and online. Fliss Murtagh. 1. Evidence to Underpin POS and IPOS in Practice and Research. 2. The value of the POS family of measures in clinical practice. 3. Where/how are the POS family of measures being used
- 19. Invited Oral presentation, Hospice UK: **Outcome Measures in Practice national ECHO webinar**, **April 2024**, online. Fliss Murtagh. How to deal with different types of missing data of outcome measure (IPOS) in a longitudinal dataset in the context of palliative care
- 20. Invited Oral presentation, Wolfson Palliative Care Research Centre: **National Annual Conference, July 2024,** Hull, UK. Fliss Murtagh. Demonstrating the complexity, value and impact of palliative care through measuring individual person-level outcomes
- 21. Invited Oral presentation, **NHS Wales Palliative and End of Life Care Programme Board briefing, September 2024**, online. Fliss Murtagh. Briefing on the Better End of Life report 2024

- 22. Invited Oral presentation, **Dept of Health and Social Care policy roundtable**, **September 2024**, online. Fliss Murtagh. Briefing on the Better End of Life report 2024
- 23. Invited Oral presentation, ICB Seminar Series Getting end of life care in the community right, September 2024, online. Fliss Murtagh. Briefing on the Better End of Life report 2024, for the England network of Integrated Care Boards
- 24. Invited Oral presentation, Hospice UK: **Outcome Measures in Practice national ECHO webinar**, **September 2024**, online. Fliss Murtagh. How to derive levels or classes of complexity for specialist palliative care
- 25. Invited Oral presentation, **Hull and East Riding Palliative and End of Life Care Network**, **September 2024**, online. Fliss Murtagh. Introduction to individual-level Outcome Measures in Palliative and End of Life Care: learning from the RESOLVE project
- 26. Invited Oral presentation, **Humber and North Yorkshire ICB Frailty Summit**, **October 2024**, Hull, UK. Fliss Murtagh. Frailty-related research: what evidence, priorities, resources, and measures
- 27. Invited Oral presentation, **Research Spotlight** for University of Hull Research Culture week, **October 2024**, Hull, UK. Fliss Murtagh. The Wolfson Palliative Care Research Centre
- 28. Invited Oral presentation, **National Conference: Establishing Research in your Hospice**, **October 2024**, Sheffield, UK. Fliss Murtagh. Designing a Research Strategy
- 29. Invited Oral presentation, **20**th **National Renal Supportive Care Conference**, **November 2024**, Manchester, UK. Fliss Murtagh. The evidence for interventions towards the end of life
- 30. Invited Oral presentation, **POS and IPOS Use and Implementation, May 2024**, London, UK. Mark Pearson. Understanding processes underpinning the successful implementation of outcome measures
- 31. Invited Oral presentation, **University of Hull Research Culture week, June 2024**, Hull, UK. Mark Pearson. Solving wicked problems through collaborative research: NIHR Health Determinants Research Collaboration North Yorkshire
- 32. Invited Oral presentation, **Creating Connections Palliative Care Conference**, **Hull/Sydney (Australia)**, **July 2024**, Hull, UK (online with Australia). Mark Pearson. It's not what you do but the way that you do it... Why Implementation Science is vital for Palliative Care
- 33. Invited Oral presentation, **Hong Kong Polytechnic University**, **Hong Kong**, **November 2024**. Mark Pearson. Implementation Science comes of age: Why the science of 'evidence into practice' is vital for the care of people with long-term conditions and palliative care.
- 34. Invited Oral presentation, **End of life & Palliative Care in the ICU research Network Webinar, June 2024**, online. Stephanie Meddick-Dyson. Implementation of Palliative Care in the Intensive Care Unit
- 35. Invited Oral presentation at the **IPCRG (International Primary Care Respiratory Group) May 2024,** Athens, Greece. Ann Hutchinson. Distressing, disabling, daily breathlessness: State of the art review
- 36. Invited Oral presentation, **Leeds Teaching Hospitals Trust Adult Critical Care Forum, September 2024**, online. Stephanie Meddick-Dyson. Palliative care in the intensive care unit
- 37. Invited Oral presentation, **Hull University Research Spotlight October 2024**, Hull, UK. Stephanie Meddick-Dyson. My journey with Wolfson Palliative Care Research Centre
- 38. Invited Oral presentation, **Association for Palliative Medicine Juniors Conference, November 2024**, online. Stephanie Meddick-Dyson. The Hat Trick: Palliative Reg, Med Reg, and Academic
- 39. Invited Oral presenter, 8th week of MSc palliative care at Wolfson, online. Christina Ramsenthaler. Three sessions and a Q&A session about statistics in palliative care
- 40. Invited Oral presentation, **Marie Curie Research Conference, February 2024**, online. Donna Wakefield. Applying for research funding: practical tips and the reality
- 41. Invited Oral presentation, **APM Juniors conference, February 2024**, online. Donna Wakefield. Getting involved in clinical research
- 42. Invited Oral presentation, Research in Palliative & End-of-life care (RiPEN) North East, regional event, April 2024, Newcastle, UK. Donna Wakefield. Applying for an NIHR Doctoral Fellowship
- 43. Invited Oral presentation, **Palliative Care EDI network, November 2024**, online. Donna Wakefield. Inequities in palliative care related to social class and when there is perceived blame
- 44. Invited Oral presentation, **National Mesothelioma Essential update, Mesothelioma UK/BTOG, December 2024**, London, UK. Donna Wakefield.
- 45. Invited Oral presentation, Annual Scientific Conference of the British Society of Physical & Rehabilitation Medicine, November 2024, Coventry, UK. Cindy Forbes. Cancer Rehabilitation and Patient Reported Clinical Outcomes.
- 46. Invited Oral presentation, **Oxford Advance Symptom Control Course June & July 2024**, online. Miriam Johnson.

- Opioids for breathlessness: a summary of the evidence
- 47. Invited Oral presentation, **Danish Association of Palliative Physicians national meeting, March 2024**, online. Miriam Johnson. Opioids for breathlessness; state of the evidence
- 48. Invited Oral presentation, **National Conference: Establishing Research in your Hospice, October 2024**, Sheffield, UK. Miriam Johnson. Engaging in Research
- 49. Invited Oral presentation, London BTS (British Thoracic Society) November 2024, London, UK. Miriam Johnson. Effectiveness and cost effectiveness of low dose oral modified release morphine versus placebo on patient reported worst breathlessness in people with chronic breathlessness: a multi-site, parallel group, double-blind, randomised, placebo-controlled trial (MABEL)
- 50. Invited Oral presentation, **SAP North (Society of Academic Primary Care), November 2024**, Liverpool, UK. Miriam Johnson. CAncer Patients' Needs ASSESSment in Primary Care: A cluster randomised controlled trial
- 51. Invited Oral presentation at workshop, **University of Sheffield Palliative Medicine Trainees, February 2024**, online. Kate Binnie. Breathlessness & Anxiety in palliative care (a non-pharmacological approach)
- 52. Invited Oral presentation at workshop, **University of Sheffield Palliative Medicine Trainees, February 2024**, online. Kate Binnie. Breathlessness & Anxiety in palliative care (a non-pharmacological approach)
- 53. Invited Oral presentation, **South West Journal Club Palliative care, February 2024**, online workshop. Kate Binnie. Fear and Safety exploring relational mechanisms in the context of non-pharmacological breathlessness management in advanced lung disease.
- 54. Invited Oral presentation, **Royal College of Occupational Therapists Workshop**, **May 2024**. Kate Binnie. An embodied relational approach to managing breathlessness/distress in advanced disease
- 55. Invited Oral presentation, **Trauma informed palliative care platform workshop**, **May 2024**. Kate Binnie. Fostering relational safety and stability in palliative care
- 56. Invited Video & Blogg, Part of the **Medical Care Driving Change** series, produced by the Royal College of Physicians, June 2024 upload available throughout 2024. Fliss Murtagh. Digital Care Management Solution: Hospital Specialist Palliative Care available at https://medicalcare.rcp.ac.uk/content-items/video/digital-care-management-solution-hospital-specialist-palliative-care/
- 57. Invited seminar, **University College London, November 2024**, London, UK. Donna Wakefield. "Inequalities in lung disease"
- 58. Invitation from Prof Naveen Salins, for workshop, Manipal Academy of Higher Education, Manipal, India, February 2024. Miriam Johnson and Joseph Clark. A Presentations, B Introduction to realist reviews, C Introduction to Normalisation Process Theory, DGetting evidence into practice: advance care planning for people with heart disease
- 59. Workshop, Global Breathlessness Research, University of Hull, UK, May 2024. 2-day workshop. Joseph Clark
- 60. Workshop, CANASSESS Results Reveal, **Leeds, UK**. Normalisation Process Theory findings surveys & interviews. Workshop leads Joseph Clark, Miriam Johnson, Flavia Swan
- 61. Workshop, Implementation Science Manipal Academy of Higher Education, Manipal, India, February 2024. 1-day workshop. Workshop co-leads Joseph Clark, Miriam Johnson

Oral presentations

- 1. Oral presentation at the **IPCRG (International Primary Care Respiratory Group) May 2024,** Athens, Greece. Ann Hutchinson. Regional perceptions of exacerbations by people living with COPD: a mixed methods survey conducted in Brazil, China, Europe and the USA
- Oral presentation at the IPCRG (International Primary Care Respiratory Group) May 2024, Athens, Greece. Ann Hutchinson. The differing experiences of people living with COPD during the Covid-19 pandemic: an interview study
- 3. Oral presentation at the **IPCRG (International Primary Care Respiratory Group) May 2024,** Athens, Greece. Ann Hutchinson. Breathlessness self-management: using realist review to develop theory and work with stakeholders to co-design an implementation strategy
- 4. Oral presentation at the ERS (European Respiratory Society) Conference September 2024, Vienna, Austria. Ann Hutchinson. Breathlessness self-management in people with long-term conditions: using a realist review to develop theory and work with stakeholders to codesign an implementation strategy
- 5. Oral presentation at the PCRS (Primary Care Respiratory Society) September 2024, Telford, UK. Ann Hutchinson. Breathlessness self-management: using realist review to develop theory and work with stakeholders to codesign an implementation strategy

- 6. Oral presentation 8th Public Health Palliative Care International Conference: Building Bridges between Science and People October 2024, Bern, Switzerland. Jonathan Koffman. Ethnic disparities in rates of opioid prescribing for cancer pain and impact on health service use in the UK: Findings from an observational cohort study
- 7. Oral presentation, **National Conference on Pulmonary Diseases (NAPCON) 2024, November 2024**, Coimbatore, India. Joseph Clark. Co-design of intervention and implementation programme theory for breathlessness self-management in India: A Realist Review
- Oral Presentation, HYMS Post Graduate Research Conference, July 2024, York, UK. Jordan Curry. Digital Personalised Physical Activity and Education Programme for Lung Cancer Patients: Feasibility and Usability. Awarded Best Oral
- Oral Presentation, HYMS Post Graduate Research Conference, July 2024, York, UK. Susanne de Wolf-Linder.
 Person-centred care for people with dementia: Improving recognition of symptoms and needs in the community care setting
- 10. Chairing Session, HYMS Post Graduate Research Conference, July 2024, York, UK. Susanne de Wolf-Linder.
- 11. Oral presentation, Yorkshire & Humber Palliative Care Research Network: **Knowledge Exchange Showcase**, **February 2024**, York UK. Fliss Murtagh. Grant Success the NIHR Palliative Care Policy Research Unit
- 12. Oral presentation, **Yorkshire & Humber Palliative Care Research Network, February 2024**, York, UK. Mark Pearson. NIHR Health Determinants Research Collaboration North Yorkshire
- 13. Oral presentation, IRIS/NIHR ARC Research Knowledge Mobilisation Networking Event, November 2024, Hull, UK. Mark Pearson. NIHR Health Determinants Research Collaboration North Yorkshire
- 14. Oral presentation, **SAPC North conference (Society for Academic Primary Care) November 2024**, Liverpool, UK. Presenting author. Miriam Johnson. CAncer Patients' Needs ASSESSment in Primary Care: A cluster randomised controlled trial
- 15. Oral presentation, 8th Public Health palliative care international conference, October 2024, Bern, Switzerland. Presenting Author Marcel Ailed. Complete reference: Alied M, Law-Clucas S, Droney J, Costelloe C, Ramsenthaler C, Allsop M, May P, Sleeman K, Verne J, James D, Scerri L, Laverty D, Rosling J, Powell M, Bearne A, Kumar R, Koffman J. (2024). PREPARE: Evaluation of Electronic Palliative Care Coordination Systems to support advance care planning for people living with life-threatening conditions: A retrospective observational cohort study. Poster ID 304, 8th Public Health Palliative Care International Conference, Bern, Switzerland 2024.
- 16. Oral presentation, **POS + IPOS Training Days Workshop**, **May 2024**, London UK. Assem Khamis. Challenges in building a Registry for routinely-collected individual-level palliative care outcomes data
- 17. Oral presentation, **PROMs UK 2024, June 2024**, Exeter, UK. Assem Khamis. Types of missing outcome data in routinely-collected data in different care settings: RESOLVE case study
- 18. Oral presentation, Annual meeting of the European Health Psychology Society. Cascais, September 2024, Portugal. Inequalities in exclusively mobile interventions targeting weight-related behaviours: Systematic review of observational studies. Presenting author, Laura König (Cindy Forbes).
- 19. Oral presentation, **7**th **International Meeting of The Dyspnea Society, June 2024**, Montreal, Quebec, Canada. Miriam Johnson. Breathlessness self-management: using realist review to develop theory and work with stakeholders to co-design an implementation strategy
- 20. Oral presentation, **7**th **International Meeting of The Dyspnea Society, June 2024**, Montreal, Quebec, Canada. Helene Elliott-Button. The Prevalence and Impact of Chronic Breathlessness in an Older, Frail Population in Primary Care: A Mixed-Methods Study. **Award Booth Breathlessness Research Prize** In recognition of having undertaken applied research that will directly benefit people living with chronic breathlessness (for the above abstract, presented at the above conference). This was the inaugural presentation of this award
- 21. Oral presentation, Marie Curie Conference, February 2024, online. Kate Binnie. Body-Mind interventions (BMi) for breathlessness-related distress in advanced disease: A realist review
- 22. Invited Oral presentation, Oxford Department of Psychiatry (Oxford Mindfulness Centre), workshop, May 2024. Kate Binnie
- 23. Oral presentation, Yoga Research Conference, University of Westminster, November 2024, London, UK. Kate Binnie. Safety first: Developing a programme theory to explain how body-mind interventions "work" for people living with breathlessness-related distress (BrD)
- 24. Oral presentation, **Hospice UK National Conference**, **November 2024**, Glasgow, UK. Lucia Crowther. Whose homes are reflected in homelike hospice architecture and design in England?
- 25. Poster presentation, **Hospice UK National Conference, November 2024**, Glasgow, UK. Lucia Crowther. This isn't anybody's home": the views of hospice users on the suitability of homelike hospice design
- 26. Oral presentation, Royal Geographical Society Annual International Conference, August 2024, London, UK.

- Lucia Crowther. Experiences and perceptions of homeliness and home-like design in hospice spaces
- 27. Oral presentation, **British Society of Gerontology Annual Conference**, **July 2024**, Newcastle, UK. Lucia Crowther. Feeling 'at home' in the hospice: considering disparate experiences of homeliness in end-of-life spaces
- 28. Oral presentation, 8th Public Health Palliative Care International Conference, October 2024, Bern, Switzerland. Mary Kimani, "Sorry to make you think my life is a misery, but I am content": Experiences and Perceptions of Social Wellbeing among Older Persons Living with Advanced Illness/es
- 29. Oral presentation, **TRANSFORM Showcase**, **March 2024**, Hull, UK. Alex Bullock. Malnutrition, Sarcopenia, and Cachexia: one and the same? **Prize 3**rd **place presentation**.
- 30. Oral presentation, Hospice UK Conference, November 2024, Glasgow, UK. Alison Bravington. Challenges of the transition to end of life care in patients with malignant bowel obstruction

Poster presentations

- 1. Poster presentations at the ERS (European Respiratory Society) Conference September 2024, Vienna, Austria. Ann Hutchinson. The experiences of people living with COPD during the Covid-19 pandemic: an interview study and How patients act in response to COPD exacerbations: results from a multi-country survey
- Poster presentation 8th Public Health Palliative Care International Conference: Building Bridges between Science and People October 2024, Bern, Switzerland. Jonathan Koffman. PREPARE: Evaluation of Electronic Palliative Care Coordination Systems to support advance care planning for people living with life-threatening conditions: A retrospective observational cohort study
- Poster presentation, HYMS Post Graduate Research Conference, July 2024, York, UK. Marsha Dawkins. Personal
 values and value-based healthcare for an ageing multimorbid population: protocol for a systematic mixedmethods review
- 4. Poster presentation, **HYMS Post Graduate Research Conference, July 2024**, York, UK. Jordan Curry. The development and testing of a website (ExerciseGuide UK) for people with lung cancer: reflections on the added value of patient and public involvement within a doctoral degree.
- 5. Poster presentations, MASCC (Multinational Association of Supportive Care in Cancer), June 2024, Lille, France. Jordan Curry. Poster One: A Novel Website Providing Personalised Physical Activity for Lung Cancer Patients: A Feasibility Study. Poster Two: Developing and testing ExerciseGuide UK for lung cancer patients: examining the value of Patient And Public Involvement in a doctoral study. Awarded a MASCC Exercise Oncology Fellowship (see link: https://mascc.org/2024-fellowship-recipients/)
- 6. Poster presentations, Wolfson Palliative Care Research Centre: **national Annual Conference, July 2024,** Hull, UK. Stephanie Meddick-Dyson. Creation and development of an international research network: the End of Life and Palliative Care in the ICU Research Network (EPCIN). Exploring processes for implementing palliative care in intensive care using normalisation process theory.
- 7. Poster presentations, Alzheimer Europe Conference, October 2024, Geneva, Switzerland. Susanne de Wolf-Linder. Inter-rater reliability in Swiss community dementia nursing assessments: The example of the Integrated Palliative Care Outcome Scale for people with dementia (IPOS-Dem). Meaningful patient and public engagement in dissemination – embedding co-production in dementia research
- 8. Poster presentation, Annual meeting of the Multinational Association of Supportive Care in Cancer, June 2024, Lille, France. Cindy Forbes. Facilitators, barriers, and acceptability of digitally-delivered lifestyle advice among cancer clinicians: a systematic review
- Poster presentation, Annual meeting of the Multinational Association of Supportive Care in Cancer, June 2024, Lille, France. Cindy Forbes. Feasibility and acceptability of the CANcer BEhavioural Nutrition and Exercise Feasibility Trial.
- 10. Poster presentations, International Clinical Trial Methodology Conference, September 2024, Edinburgh, UK. 1. Williams, B., Matamba, A., Northgraves, M., Johnson, M., Fallon, M. ActiGraph Management: The advantages and disadvantages of using a centrally managed ActiGraph distribution system for collecting physical activity data in a multicentre randomised controlled trial. 2.Thompson, C., Williams, B., Matamba, A, Northgraves, M., Johnson, M, Fallon, M. Strategies to encourage site engagement in the Morphine And BrEathLessness Trial (MABEL). 3.Northgraves, M., Thompson, C., Ayuba, O., Matamba, A, Williams, B., Huang, C., Johnson, M., Fallon, M., Cohen, J. Impact on participant recruitment of adding an Infographic to a Patient Information Leaflet in the MABEL trial, a study within a trial (SWAT116).
- **11.** Poster presentations, **Marie Curie Research Conference 2024**, **February**, online. Sophie Pask. Exploring out-of-hours advice lines for adults with advanced illness: a qualitative study and practical framework. **S Pask**, A

Mohamed, R L Chambers, P McFarlane, T Johansson, R Kumar, A Woodhead, I Okamoto, S Barclay, I J Higginson, K E Sleeman. Improving out-of-hours access to end-of-life care medications at home in the United Kingdom: a qualitative study. I Okamoto, S Pask, T Johansson, R L Chamber, A Mohamed, P G McFarlane, I J Higginson, K E Sleeman, F E M Murtagh & Stephen Barclay. The effectiveness of out-of-hours palliative care telephone advice lines for people living at home and their carers — A rapid systematic review. T Johansson, R L Chambers, T Curtis, S Pask, S Greenley, M Brittain, A E Bone, L Laidlaw, I Okamoto, S Barclay, I J Higginson, F E M Murtagh, K E Sleeman

- 12. Poster presentation, , TRANSFORM Showcase, March 2024, Hull, UK. Alex Bullock. "it's not going to happen to me": A qualitative study of older adults' views and experiences of malnutrition, sarcopenia and cachexia. Prize 2nd place poster.
- 13. Finalist in, **Bright in Health awards, in the "Research for local health needs award" category,** November 2024, Donna Wakefield. Palliative & end-of-life care for patients with pleural mesothelioma

Wolfson Palliative Care Research Centre – our peer reviewed publications and reports in 2024

- 1. Adenwalla, S. F., P. O'Halloran, C. Faull, F. E. M. Murtagh, and M. P. M. Graham-Brown. 2024. 'Advance care planning for patients with end-stage kidney disease on dialysis: narrative review of the current evidence, and future considerations', *J Nephrol*, 37: 547-60.
- 2. Aunger, J. A., R. Abrams, R. Mannion, J. I. Westbrook, A. Jones, J. M. Wright, M. Pearson, and J. Maben. 2024. 'How can interventions more directly address drivers of unprofessional behaviour between healthcare staff?', BMJ Open Qual, 13.
- 3. Aunger, J. A., R. Abrams, J. I. Westbrook, J. M. Wright, M. Pearson, A. Jones, R. Mannion, and J. Maben. 2024. 'Why do acute healthcare staff behave unprofessionally towards each other and how can these behaviours be reduced? A realist review', *Health Soc Care Deliv Res*, 12: 1-195.
- 4. Barnes-Harris, M. M. M., S. Datla, A. Abel, A. L. Clark, and M. J. Johnson. 2024. 'Barriers and facilitators for cardiopulmonary resuscitation discussions with people with heart failure', *PLoS One*, 19: e0314631.
- 5. Bedendo, A., A. Papworth, B. Beresford, B. Phillips, C. Vasudevan, G. Lake Walker, H. Weatherly, R. Feltbower, S. Hinde, C. E. Hewitt, F. Murtagh, J. Noyes, J. Hackett, R. Hain, S. Oddie, G. Subramanian, A. Haynes, and L. Fraser. 2024. 'End of life care in paediatric settings: UK national survey', *BMJ Support Palliat Care*.
- 6. Boland, E. G., K. T. Tay, A. Khamis, and F. E. M. Murtagh. 2024. 'Patterns of acute hospital and specialist palliative care use among people with non-curative upper gastrointestinal cancer', *Support Care Cancer*, 32: 432.
- 7. Bravington, A., J. W. Boland, S. Greenley, M. Lind, F. E. M. Murtagh, M. Patterson, M. Pearson, and M. J. Johnson. 2024. 'Exploring pathways to optimise care in malignant bowel obstruction (EPOC): Protocol for a three-phase critical realist approach to theory-led intervention development for shared decision-making', *PLoS One*, 19: e0294218.
- 8. Bravington, A., M. Johnson, and U. Macleod. 2024. 'Turning a Curve: How People Use Everyday Resources to Negotiate Recovery From Cancer Treatment With Curative Intent', *Qual Health Res*, 34: 635-48.
- Braybrook, D., L. Coombes, D. Harethardottir, H. M. Scott, K. Bristowe, C. Ellis-Smith, A. Roach, C. Ramsenthaler, M. Bluebond-Langner, J. Downing, F. E. M. Murtagh, L. K. Fraser, and R. Harding. 2024. 'Development of a child and family centred outcome measure for children and young people with life-limiting and life-threatening conditions: progress to date on the Children's Palliative Care Outcome Scale (C-POS:UK)', *Palliat Care Soc Pract*, 18: 26323524241303537.
- 10. Bristowe, K., D. Braybrook, H. M. Scott, L. Coombes, D. Harethardottir, A. Roach, C. Ellis-Smith, M. Bluebond-Langner, L. Fraser, J. Downing, F. Murtagh, and R. Harding. 2024. "My life is a mess but I cope": An analysis of the language children and young people use to describe their own life-limiting or life-threatening condition", *Palliat Med*, 38: 379-88.
- 11. Bullock, A. F., M. J. Patterson, L. W. Paton, D. C. Currow, and M. J. Johnson. 2024. 'Malnutrition, sarcopenia and cachexia: exploring prevalence, overlap, and perceptions in older adults with cancer', *Eur J Clin Nutr*, 78: 486-93.
- 12. Bushell, S., and F. Murtagh. 2024. "There's never really been an opportunity": perspectives of those with long-term conditions on advance care planning, a qualitative interview study in primary care', *Br J Gen Pract*, 74.

- 13. Chatwin, J., K. Ludwin, D. Jones, and A. Bravington. 2024. 'Understanding interaction in problematic dementia and social care encounters: Protocol for a micro-level study combining video-ethnography and Conversation Analysis (CA)', *PLoS One*, 19: e0305069.
- 14. Clark, J. D., K. Binnie, M. Bond, M. Crooks, D. C. Currow, J. Curry, H. Elsey, M. Habib, A. Hutchinson, I. Soyiri, M. J. Johnson, S. Nair, S. Rao, N. Siqueira-Filha, A. Spathis, and S. Williams. 2024. 'Breathlessness without borders: a call to action for global breathlessness research', *NPJ Prim Care Respir Med*, 34: 26.
- 15. Clark, K., J. W. Boland, and D. C. Currow. 2024. 'Letter to the Editor. A Response to: Palliative Management of Inoperable Malignant Bowel Obstruction: Prospective, Open Label, Phase 2 Study at an NCI Comprehensive Cancer Center', *J Pain Symptom Manage*, 67: e919-e20.
- 16. Coombes, L., D. Braybrook, D. Harethardottir, H. M. Scott, K. Bristowe, C. Ellis-Smith, L. K. Fraser, J. Downing, M. Bluebond-Langner, F. E. Murtagh, and R. Harding. 2024. 'Cognitive testing of the Children's Palliative Outcome Scale (C-POS) with children, young people and their parents/carers', *Palliat Med*, 38: 644-59.
- 17. Coverdale, M. R., and F. Murtagh. 2024. 'Destitute and dying: interventions and models of palliative and end of life care for homeless adults a systematic review', *BMJ Support Palliat Care*, 14.
- 18. Currow, D. C., L. Serresse, D. J. A. Janssen, C. Jenkins, M. J. Johnson, S. Rajan, and T. Similowski. 2024. 'Specialists in Chronic Respiratory Failure Should Serve More than Just Ventilator-Dependent Patients', *Ann Am Thorac Soc*, 21: 1342-43.
- 19. Davies, Joanna M., Javiera Leniz, Kia-Chong Chua, Lesley E. Williamson, Sabrina Bajwah, Thomas Bolton, Anna E. Bone, Mevhibe Hocaoglu, Julia Verne, Lorna K. Fraser, Stephen Barclay, Fliss E. M. Murtagh, Irene J. Higginson, and Katherine E. Sleeman. 2024. 'Association between ethnicity and emergency department visits in the last three months of life in England: a retrospective population-based study using electronic health records', *BMJ Public Health*, 2.
- 20. de Wolf-Linder, S., I. Kramer, M. Reisinger, F. E. M. Murtagh, M. Schubert, and C. Ramsenthaler. 2024. 'Empowering informal caregivers and nurses to take a person-centred view: adaptation and clinical utility of the Integrated Palliative Outcome Scale (IPOS-Dem) for use in acute and community care settings', *BMC Geriatr*, 24: 1030.
- 21. Demoule, A., M. Decavele, M. Antonelli, L. Camporota, F. Abroug, D. Adler, E. Azoulay, M. Basoglu, M. Campbell, G. Grasselli, M. Herridge, M. J. Johnson, L. Naccache, P. Navalesi, P. Pelosi, R. Schwartzstein, C. Williams, W. Windisch, L. Heunks, and T. Similowski. 2024. 'Dyspnoea in acutely ill mechanically ventilated adult patients: an ERS/ESICM statement', *Eur Respir J*, 63.
- 22. Etkind, S. N., S. Barclay, A. Spathis, S. A. Hopkins, B. Bowers, and J. Koffman. 2024. 'Uncertainty in serious illness: A national interdisciplinary consensus exercise to identify clinical research priorities', *PLoS One*, 19: e0289522.
- 23. Ferreira, D., M. Ekstrom, S. Louw, P. McCloud, M. Johnson, K. Clark, and D. Currow. 2024. 'Differences in unidimensional breathlessness measures and thresholds for clinical response in a randomised controlled trial in people with chronic breathlessness: an exploratory study', *BMJ Open Respir Res*, 11.
- 24. Firth, A. M., J. Goodrich, I. Gaczkowska, R. Harding, F. E. Murtagh, and C. J. Evans. 2024. 'Community out-of-hours palliative care 'It's a patchwork of services': A qualitative study exploring care provision', *Palliat Med*: 2692163241302671.
- 25. Forward, C., Z. Bayley, L. Walker, J. Krygier, C. White, K. Mwaba, H. Elliott-Button, P. Taylor, and M. J. Johnson. 2024. 'Homecare workers needs and experiences in end of life care: rapid review', *BMJ Support Palliat Care*, 14.
- 26. Goodrich, J., C. Watson, I. Gaczkowska, R. Harding, C. Evans, A. Firth, and F. E. M. Murtagh. 2024. 'Understanding patient and family utilisation of community-based palliative care services out-of-hours: Additional analysis of systematic review evidence using narrative synthesis', *PLoS One*, 19: e0296405.
- 27. Gross, J., and J. Koffman. 2024. 'Examining how goals of care communication are conducted between doctors and patients with severe acute illness in hospital settings: A realist systematic review', *PLoS One*, 19: e0299933.
- 28. Haber, R., M. Ghezzawi, H. Puzantian, M. Haber, S. Saad, Y. Ghandour, J. El Bachour, A. Yazbeck, G. Hassanieh, C. Mehdi, D. Ismail, E. Abi-Kharma, O. El-Zein, A. Khamis, M. Chakhtoura, and C. Mantzoros. 2024. 'Mortality risk in patients with obesity and COVID-19 infection: a systematic review and meta-analysis', *Metabolism*, 155: 155812.

- 29. Hanchanale, S., A. C. Nwosu, and J. W. Boland. 2024. 'New UK palliative medicine consultants: clinical and non-clinical preparedness after higher specialty training', *BMJ Support Palliat Care*.
- 30. Higginson, I. J., S. T. Brown, A. O. Oluyase, P. May, M. Maddocks, M. Costantini, S. Bajwah, C. Normand, C. Bausewein, S. T. Simon, K. Ryan, D. C. Currow, M. J. Johnson, S. P. Hart, H. Mather, M. Krajnik, S. Tanzi, L. Ghirotto, C. E. Bolton, P. Janowiak, E. Turola, C. J. Jolley, G. Murden, A. Wilcock, B. Farsides, J. M. Brown, and Better- B. consortium. 2024. 'Mirtazapine to alleviate severe breathlessness in patients with COPD or interstitial lung diseases (BETTER-B): an international, multicentre, double-blind, randomised, placebo-controlled, phase 3 mixed-method trial', *Lancet Respir Med*, 12: 763-74.
- 31. Hutchinson, A., R. Russell, H. Cummings, O. Usmani, S. MacFadyen, J. Cohen, T. Morris, H. Muellerova, Y. Xu, G. Hellens, K. Roy, and M. G. Crooks. 2024. 'Exploring the experiences, understandings, and expectations of exacerbations of patients with COPD and their carers: an interview study', *BJGP Open*.
- 32. Jackson, C., C. Malia, H. Zacharias, J. Dyson, and M. J. Johnson. 2024. 'Improving hospice delirium guideline adoption through an understanding of barriers and facilitators: A mixed-methods study', *PLoS One*, 19: e0310704.
- 33. Jackson, G. P., C. E. Jackson, J. W. Boland, I. Featherstone, C. Huang, M. Ogden, K. Sartain, N. Siddiqi, M. Twiddy, M. Pearson, and M. J. Johnson. 2024. 'Improving the Detection, Assessment, Management and Prevention of Delirium in Hospices (the DAMPen-D study): Feasibility study of a flexible and scalable implementation strategy to deliver guideline-adherent delirium care', *Palliat Med*, 38: 447-56.
- 34. Johansson, T., S. Pask, J. Goodrich, L. Budd, I. Okamoto, R. Kumar, L. Laidlaw, C. Ghiglieri, A. Woodhead, R. L. Chambers, J. M. Davies, A. E. Bone, I. J. Higginson, S. Barclay, F. E. M. Murtagh, and K. E. Sleeman. 2024. "Time to care: Findings from a nationally representative survey of experiences at the end of life in England and Wales. ." In. London, UK.: Marie Curie. (September 2024). .
- 35. Johansson, T., R. L. Chambers, T. Curtis, S. Pask, S. Greenley, M. Brittain, A. E. Bone, L. Laidlaw, I. Okamoto, S. Barclay, I. J. Higginson, F. E. M. Murtagh, and K. E. Sleeman. 2024. 'The effectiveness of out-of-hours palliative care telephone advice lines: A rapid systematic review', *Palliat Med*, 38: 625-43.
- 36. Johnson, M. J., D. C. Currow, J. Chynoweth, H. Weatherly, G. Keser, A. Hutchinson, A. Jones, L. Dunn, and V. Allgar. 2024. 'The cost of providing care by family and friends (informal care) in the last year of life: A population observational study', *Palliat Med*, 38: 725-36.
- 37. Johnson, M. J., M. Ekstrom, D. J. Janssen, and D. C. Currow. 2024. 'Re: Liu et al., Effectiveness and safety of opioids on breathlessness and exercise endurance in patients with chronic obstructive pulmonary disease: A systematic review and meta-analysis of randomised controlled trials', *Palliat Med*, 38: 400-01.
- 38. Johnson, M. J., L. Rutterford, A. Sunny, S. Pask, S. de Wolf-Linder, F. E. M. Murtagh, and C. Ramsenthaler. 2024. 'Benefits of specialist palliative care by identifying active ingredients of service composition, structure, and delivery model: A systematic review with meta-analysis and meta-regression', *PLoS Med*, 21: e1004436.
- 39. Karkou, V., J. Omylinska-Thurston, S. Thurston, R. Clark, E. Perris, A. Kaehne, and M. Pearson. 2024. 'Developing a strategy to scale up place-based arts initiatives that support mental health and wellbeing: A realist evaluation of 'Arts for the Blues', *PLoS One*, 19: e0296178.
- 40. Kearsley, S. L., L. Walker, M. J. Johnson, and A. Bravington. 2024. 'Ancillary hospital workers experience during COVID-19: systematic review and narrative synthesis', *BMJ Support Palliat Care*.
- 41. Kilday, C., W. Laughey, and J. W. Boland. 2024. 'Educational impact of COVID-19 on foundation doctors and the decision to take a break from structured approved training programmes in the United Kingdom', *Clin Teach*, 21: e13667.
- 42. Kochovska, S., D. Ferreira, S. Chang, V. Brunelli, D. Morgan, T. Similowski, M. Johnson, M. Ekstrom, and D. Currow. 2024. 'Disability and long-term breathlessness: a cross-sectional, population study', *BMJ Open Respir Res*, 11.
- 43. Kochovska, S., R. Iyer, S. Chang, D. Ferreira, V. N. Brunelli, I. Kinchin, D. J. Eckert, J. Clark, J. Sandberg, M. Ekstrom, D. Currow, and S. Rajan. 2024. 'Prevalence, severity and impacts of breathlessness in Indian adults: An exploratory, nationally representative, cross-sectional online survey', *PLOS Glob Public Health*, 4: e0002655.

- 44. Kochovska, S., F. E. Murtagh, M. Agar, J. L. Phillips, D. Dudgeon, S. Lujic, M. J. Johnson, and D. C. Currow. 2024. 'Creating more comparable cohorts in observational palliative care studies: A proposed framework to improve applicability and replicability of research', *Palliat Med*, 38: 617-24.
- 45. Krukowski, R. A., K. M. Ross, M. J. Western, R. Cooper, H. Busse, C. Forbes, E. Kuntsche, A. Allmeta, A. M. Silva, Y. O. John-Akinola, and L. M. Konig. 2024. 'Digital health interventions for all? Examining inclusivity across all stages of the digital health intervention research process', *Trials*, 25: 98.
- 46. MacArthur, C., D. Bick, V. Salmon, E. Jones, J. Hay-Smith, J. Bishop, E. Gkini, K. Hemming, S. Webb, M. Pearson, T. Coleman, R. Terry, L. Edwards, H. Frawley, E. Oborn, and S. Dean. 2024. *Midwifery-led antenatal pelvic floor muscle exercise intervention to reduce postnatal urinary incontinence: APPEAL research programme including a feasibility and pilot cluster RCT* (Southampton (UK)).
- 47. Martens, E. S. L., D. Becker, C. Abele, D. Abbel, W. P. Achterberg, J. J. Bax, L. Bertoletti, M. E. Edwards, C. Font, A. Gava, J. Goedegebuur, A. A. Hojen, M. V. Huisman, Mjha Kruip, I. Mahe, S. P. Mooijaart, M. Pearson, K. Seddon, S. Szmit, S. I. R. Noble, F. A. Klok, and S. V. Konstantinides. 2025. 'Understanding European patterns of deprescribing antithrombotic medication during end-of-life care in patients with cancer', *Thromb Res*, 245: 109205.
- 48. McFarlane, P. G., C. Bunce, K. E. Sleeman, M. Orlovic, J. Koffman, J. Rosling, A. Bearne, M. Powell, J. Riley, and J. Droney. 2024. 'Advance care planning before and during the COVID-19 pandemic: an observational cohort study of 73 675 patients' records', *BJGP Open*, 8.
- 49. McNeill, R., J. W. Boland, A. Wilcock, A. Sinnarajah, and D. C. Currow. 2024. 'Non-steroidal anti-inflammatory drugs for pain in hospice/palliative care: an international pharmacovigilance study', *BMJ Support Palliat Care*, 13: e1249-e57.
- 50. Meddick-Dyson, S. A., J. W. Boland, M. Pearson, S. Greenley, R. Gambe, J. R. Budding, and F. E. M. Murtagh. 2024. 'Implementing palliative care in the intensive care unit: a systematic review and mapping of knowledge to the implementation research logic model', *Intensive Care Med*, 50: 1778-90.
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- 52. Morsi, R. Z., Y. Zhang, M. Zhu, S. Xie, J. Carrion-Penagos, H. Desai, E. Tannous, S. A. Kothari, A. Khamis, A. J. Darzi, A. Tarabichi, R. Bastin, L. Hneiny, S. Thind, J. E. Siegler, E. R. Coleman, S. J. Mendelson, A. Mansour, S. Prabhakaran, and T. Kass-Hout. 2024. 'Endovascular Thrombectomy with or without Bridging Thrombolysis in Acute Ischemic Stroke: A Cost-Effectiveness Analysis', *Neuroepidemiology*, 58: 47-56.
- 53. Murphy, E., and F. E. M. Murtagh. 2024a. 'Palliative Care in Kidney Disease.' in R.D. MacLeod and L. Van den Block (eds.), *Textbook of Palliative Care* (Springer: Cham.).
- 54. ———. 2024b. 'Understanding and addressing symptoms for those with kidney failure managed conservatively, without dialysis: considerations and models of care', *Ann Palliat Med*, 13: 991-1001.
- 55. Pask, S., A. Omoruyi, A. Mohamed, R. L. Chambers, P. G. McFarlane, T. Johansson, R. Kumar, A. Woodhead, I. Okamoto, S. Barclay, I. J. Higginson, K. E. Sleeman, and F. E. Murtagh. 2024. 'Telephone advice lines for adults with advanced illness and their family carers: a qualitative analysis and novel practical framework', *Palliat Med*, 38: 555-71.
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- 59. Scott, H. M., L. Coombes, D. Braybrook, D. Harethardottir, A. Roach, K. Bristowe, M. Bluebond-Langner, L. K. Fraser, J. Downing, B. Farsides, F. E. Murtagh, C. Ellis-Smith, and R. Harding. 2024. 'What are the anticipated benefits, risks, barriers and facilitators to implementing person-centred outcome measures into routine care for children and young people with life-limiting and life-threatening conditions? A qualitative interview study with key stakeholders', *Palliat Med*, 38: 471-84.
- 60. Selman, L. E., C. B. Shaw, R. Sowden, F. E. M. Murtagh, J. A. Tulsky, R. Parry, F. J. Caskey, and R. K. Barnes. 2024. 'Communicating treatment options to older patients with advanced kidney disease: a conversation analysis study', *BMC Nephrol*, 25: 417.
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