



WOLFSON PALLIATIVE CARE RESEARCH CENTRE

ANNUAL REPORT 2023



WOLFSON PALLIATIVE
CARE RESEARCH CENTRE

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A welcome from the Director

Welcome to our annual report for 2023. We are moving to reporting for a whole calendar year; this report relates to 2023, but with some 2024 updates added. The next report will be devoted to the whole of 2024 (Jan – Dec), and then we will be established in the new cycle by calendar year.

There is much good news to share. Joseph Clark took up his appointment with us as Lecturer in Global Palliative Care in June 2023 and is building global connections and projects. Cindy Forbes, who gained her permanent appointment with us as Lecturer in 2023, has now been successful in internal promotion to Senior Lecturer in 2024. And Mark Pearson, who was Reader with us, has also been successful in 2024 with internal promotion to Professor of Implementation Science. Miriam, Jonathan, Liz and I are delighted to welcome Mark into the WPCRC senior leadership group, and to see Joseph and Cindy progressing well in their careers.



We were successful in gaining a 'PhD scholarships cluster' from the University of Hull and welcomed three new PhD students to start their PhDs in September 2023. We supported two further PhD Fellows to gain external PhD funding for 2023/2024. Four of our PhD students successfully gained their PhDs in the last twelve months. We have continued to grow our grant income and were awarded 14 grants in 2023, to a total of £8.7m (with £2.3m income to the University of Hull). It has been especially good to see funding for the **North Yorkshire Health Determinants Research Collaboration** (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). We maintained our publication record (with focus on improved quality) and achieved considerable impact with policy-makers and practitioners at key international and national conferences. In 2023, we made a big 'splash' at the 18th World Congress of the European Association for Palliative Care, with 24 presentations, plus other inputs. We also had a stand to better promote our work and the new MSc (see Education section).



We were awarded a number of prizes in 2023 and early 2024. Jonathan Koffman (with collaborator, Associate Professor Matthew Allsop from University of Leeds) was awarded the **Helen H Lawson Award for research into end-of-life care decision-making**, at the BMA Foundation awards in November 2023.

Jordan Curry 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 lung cancer patients. His inclusive approach highlighted the pivotal role of patient partners in contributing to a PhD.



We were very pleased to see Helene Elliott-Button, 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. 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 very much hope

you enjoy reading the report, which highlights different research projects rather than providing an exhaustive list. Much more detail is available on our webpages.

Best wishes, **Fliss Murtagh** (Director, Wolfson Palliative Care Research Centre)

Our year at a glance 2023

Our team:

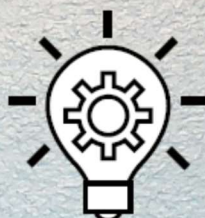


4 Professors
1 Senior Lecturer and 1 Lecturer
15 Research Fellows and Associates
4 Administrative staff

Capacity building:

12 postgraduate students and Fellows (PhD)

7 Clinical Academic training posts, 9 medical students, and interns for electives or research projects, 20 students on the Implementation module



Our outputs:

70 peer-reviewed papers

21 international conference presentations (oral)



Research grants:

Leading & collaborating on grants > £8.7m
WPCRC grant income > £2.3m

The team



The WPCRC team at our away day in December 2023

The team: In the WPCRC team, we now have four Professors – Fliss Murtagh, Miriam Johnson, Jonathan Koffman, and Mark Pearson (newly promoted in 2024 for his major contributions to research and to the MBBS undergraduate programme). Prof Liz Walker is part of our senior team, helping in leading WPCRC (contributing alongside her other responsibilities). At 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 15 Research Fellows/Associates, and four administrative staff (part time). In training posts, we have twelve PhD students, with a further four PhD students co-supervised (either within or beyond the University). In total, including our staff and students, the WPCRC team consists of 37 people.

Capacity building: In addition to our own 12 PhD students, 20 students are undertaking our **Implementation Science for Advanced and Chronic Care** module in 2024. Five Academic Foundation doctors, and two medical Academic Clinical Fellows have also undertaken research with WPCRC in 2023 and 2024 to date. Three of our PhD students have successfully defended their theses in 2023 (Gochi Nwulu, Sophie Pask, and Alex Wray), with a further successful PhD completed in 2024 (Mike Patterson), Of these, two now work with us as Research Associates, one works within NIHR infrastructure, and one in the local NHS Trust and at York St John's University.

Team changes: During 2023, Ali Waring has been appointed as administrator for our awarded North Yorkshire Health Determinants Research Collaboration and our 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 Cindy Forbes and Mark Pearson, as well as Jason Boland's promotion to Professor of Palliative Medicine and Education. It has been excellent to work more closely with Professor Christina Ramsenthaler (who has an honorary appointment with us) in 2023 and 2024, with her outstanding statistical, epidemiological and psychometric support; we congratulate her too on promotion to Professor.

Visitors: We had many visitors through 2023 and 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 coming years.

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 implementation** of palliative care evidence into policy and practice

The perspectives of those with lived experience



Without the voices of those with lived experience of advanced illness, we cannot achieve the highest quality research which is meaningful and relevant to improve care, and which meets the priorities of those most affected. Including the voices of those with lived experience is especially important for those with advanced illness, who may have less time and energy for their voices to be heard.

We involve and engage patient, family and public partners throughout our work. Every project is influenced and shaped by some of our excellent patient and public involvement and engagement (PPIE) partners, and we cannot thank them enough. We also have wonderful help from Helen Roberts, Patient and Public Involvement Co-ordinator at the University of Hull, who

has helped us transform and extend the way we work with PPIE partners.

Here we provide just a few examples of how the perspectives of those with lived experiences shape and inform our work and this section also illustrates some of the projects we are undertaking:

Box 1: Spotlight on Patient and Public Involvement: the SUPPORTED study



Our SUPPORTED study (an NIHR HSDR funded study of homecare workers providing care for people at the end of life) has a very active Service User and Carer group, and Home Care Worker advisory group, in addition to dedicated PPIE representation on both the Study Management and Steering Groups. The PPIE groups have met regularly, have helped to shape the work, and have contributed excellent solutions to some of the project challenges (for instance, transforming our approach to recruiting homecare workers for qualitative interviews, and transforming homecare worker involvement in our co-production workshops). They have also been actively involved in 'sense-checking' emerging findings. We included PPIE members in the researcher training for the PICTOR method of data generation, and – for the first time - involved PPIE members in the qualitative data analysis process itself. This has helped increase the relevance of the project to support home care workers and improve care and will increase our impact in the longer term. We were able to ensure several PPIE members attended the University of Hull's learning event in June for public contributors in grant-funded studies.

Box 2: Spotlight on Patient and Public Involvement: Family bereavement study

What does it feel like for the surviving parent when their partner has died, and they consider their bereaved children?



Exploring the experiences of support with parentally bereaved children and their surviving parents

Alex Wray – who led this project - attributes its success to extensive and ongoing family and public involvement throughout. This work began during the pandemic, meaning all interactions at the start had to be conducted virtually. Public involvement began by working with an established NIHR children research advisory group that gave insight into undertaking research online and specifically undertaking research with children. Alex then developed a dedicated PPIE group for the project, consisting of bereaved children and parents from six families. There were extensive interactions via e-mail and through more than 35 virtual meetings, where families contributed and offered their feedback about the project and wider reflections to inform the research.

These families greatly helped Alex plan the study to ensure participants' needs and well-being remained at the forefront of all research decisions. Families confirmed the need for the study and provided an understanding of the acceptability of the research. They aided the study's design and gave valuable insights into how to undertake research with bereaved families, ensuring they were well supported throughout. They gave ideas about how to recruit families, providing assurance they believed it acceptable if not essential that bereaved families be offered an opportunity to participate.

These families also gave insight into how Alex could build rapport with participants and best collect interview data. This led to the development of a 'get to know me' session which was undertaken with all participant families (children and parents), prior to participating in an interview. The PPIE group also reviewed and gave feedback on all study documentation, took part in pilot interviews, and gave feedback on the 'get to know me session'. As the study progressed, they reflected on study findings and helped to think about key messages and best ways to disseminate the findings.

Later in the project, PPIE partners joined creative workshops alongside study participants to work with an artist to co-create a short animation of findings that is being used to disseminate findings and make a difference for other bereaved families. Some of the stills from the animation you can see in this box.

The animation is hosted on our webpages, the local hospital's bereavement website, and has been disseminated at multiple conferences and webinars, including:

- WPCRC research conference, July 2024, at the University of Hull.
- York St John University.
- Hull University Teaching Hospitals NHS Trust.
- Hull and East Riding Palliative and End of Life Care Group, hosted by the NHS Humber and North Yorkshire Integrated Care Board.
- 'At a Loss For Words', a local bereavement event.
- Hull Child Bereavement Advisory Group.
- Childhood Bereavement Network.
- Hospice UK as part of Dying Matters Week.
- The Compassionate Communities Conference.
- It will also be presented at: the Hospice UK Conference in November 2024, and the Rainbows Bereavement Support Great Britain annual conference November 2024.



Box 3: Spotlight on Patient and Public Involvement: the DAMPen-Delirium study

Our DAMPen-Delirium study is funded by Yorkshire Cancer Research to improve the Detection, Assessment, Management, and Prevention of Delirium in Specialist Palliative Care Units.



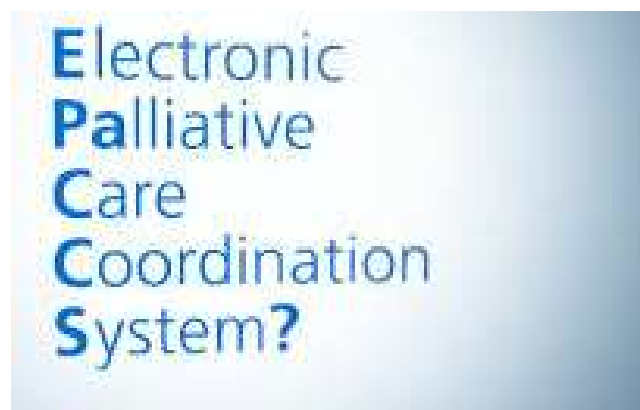
We have involved patients, family carers and the public throughout, in accordance with the framework for good public involvement as detailed by the UK standards for public involvement. We worked with a named PPIE co-applicant, who helped lead PPIE and joined the monthly Study Management Group meetings. PPIE partners were valuable contributors to all aspects of the study. In work package 1 (co-design workshops), our PPIE lead partner co-developed the content of each of the workshops with us and co-facilitated either as co-Chair (Workshop 1) or contributor (Workshops 2 and 3). She found this a challenging and rewarding role: “DAMPen-D has been so valuable to me; the experience of facilitating at the online workshop - a challenge I won't forget.” For the feasibility (work package 2), PPIE partners contributed to discussions and played a pivotal role in bridging the divide between researchers and patients, nurturing collaboration, and increasing mutual comprehension.

A further PPIE partner chaired the Study Steering Committee meetings. Having a PPI member chair the steering committee meetings lent their invaluable lived experiences and insights to guide the committee to consider the lived experience more fully, so better informing decision making, and shaping the research to be more person-centred and focused on improving care.

The study's wider PPIE group met regularly over the duration of the study to discuss challenges in the research, the implications of emerging study findings, and the next steps. All PPIE partners gave valuable feedback on study documentation; their input served to elevate the calibre and relevance of the research materials. Engagement at this level ensured that the study remained anchored in the needs and viewpoints of those directly impacted by the research.

Box 4: Spotlight on Patient and Public Involvement: Electronic Palliative Care Coordination Systems

Our Electronic Palliative Care Coordination Systems study is funded by the BMA Foundation and the Royal Marsden Trust



Electronic Palliative Care Coordination Systems (EPaCCS) are electronic registers designed to facilitate the documentation and sharing of up-to-date information regarding patients' end-of-life preferences and care plans across various health services. These systems aim to enhance patient experiences, improve outcomes, and reduce costs associated with unwanted aggressive care at the end of life. However, there is limited evidence on the equitable implementation of EPaCCS and how effectively advance care planning improves care.

This study therefore sought to evaluate the impact of EPaCCS on healthcare outcomes, service utilisation, and associated costs. Additionally, it explored the relationship between social determinants of health and the content and usage of EPaCCS. Guided by the principle of "nothing about us without us," the study needs to be relevant and useful to individuals living with life-limiting conditions and their families.

Our PPIE collaborators were actively engaged in the design of a national survey to gather insights from key stakeholders, informing the development of our research questions. They also participated in a PPIE Consultative Exercise, where we presented our study plans to the Royal Marsden Patient and Carer Research Review Forum—a diverse PPIE group of 18 regular participants, including current and former patients as well as relatives. The group strongly supported the need for this research. For instance, a bereaved participant shared: "When my father was nearing the end of his life, decisions about his care were rushed. His last days were unnecessarily distressing, which caused pain for our family. If there had been an accessible record of his wishes for his GP, it would have made a huge difference to his final days." Similarly, a current cancer patient stated: "We should strive to ensure that everyone's wishes are respected and heard, particularly at the end of life."

As the study is continuing, our PPIE partners will continue to contribute by promoting accountability (ensuring the work serves the public interest and makes effective use of resources), appropriateness (focusing on patient and population benefit), advocacy (integrating research into routine healthcare planning and delivery), and dissemination (raising awareness of findings through relevant networks).

Education and capacity building

Box 5: Spotlight on Education

Undergraduate teaching:

Over the past year, and in addition to contributing to a range of undergraduate lectures and workshops, we delivered nine **Scholarship and Special Interest Programme modules** to Hull York Medical School undergraduate medical students, with each group typically consisting of 8-10 students. These modules covered a broad range of topics related to palliative and end-of-life care and research. Notably, several former SSIP participants have returned to undertake electives or summer projects with us or join us for their Foundation research attachments.

Post graduate taught courses:

During 2023, we developed a business case and gained Senate approval for a new **MSc in Palliative Care: Implementing Best Practice**, which also includes the possibility of studying for a Postgraduate Certificate or a Postgraduate Diploma. This new MSc is now launched, with September 2024 being the first intake.

- This MSc programme builds upon the highly regarded standalone module, '**Introduction to Implementation Science for Palliative Care and Long-term Conditions**' led by Professor Mark Pearson.
- The MSc is designed to empower healthcare and social care professionals, policymakers, and researchers to develop, implement, and evaluate best practices in palliative care and long-term conditions.
- The programme offers a variety of specialised modules, such as Palliative Care Research and Practice, Introduction to Global Palliative Care, Qualitative Research Skills for Palliative Care, and the Design & Evaluation of Palliative Care Interventions, among others.
- During their research projects, students will be supervised by academics from the Centre, either conducting secondary data analysis or systematic reviews.
- We believe the unique implementation perspectives will be attractive to students, and we hope to grow the MSc year by year.
- We are delighted that – for the first year - we already have nine students committed to undertaking the MSc, including doctors, nurses, and practitioners working in hospice, community, primary care, and ambulance service settings. They will begin in September 2024.

We continue to offer the standalone **Introduction to Implementation Science for Palliative Care and Long-term Conditions module**, which is growing in popularity, with 20 students registered for Sept 2024. Four students from Hong Kong will be studying the module for the coming 2024/5 year.

Box 6: Spotlight on capacity building and researcher development

New PhD students and Fellowships:

We were pleased to welcome three PhD cluster students in September 2023, plus three additional new PhD students. The University of Hull PhD Cluster awards are highly internally competitive. Jonathan Koffman and Fliss Murtagh led this successful application, and we now have three cluster PhD students (commenced Sept 2023) working on i) ethnicity and pain in advanced illness, ii) developing a serious game to facilitate conversations about death and dying, and iii) the experiences of informal caregivers in providing support to adults living with HIV/AIDS in Sub-Saharan Africa.

Fliss Murtagh was successful in obtaining a Health Improvement (THIS) Institute PhD Fellowship for a clinical PhD Fellowship; Marsha Dawkins is now appointed (Oct 2023) to undertake a PhD on the relationship between value-based health care and the personal values of people with advanced illness. Fliss also supported Steph Meddick-Dyson in a successful application for an NIHR PhD Fellowship on Co-developing an Implementation Toolkit for Palliative Care in the Intensive Care Unit (starting Sept 2024).

Successful PhD completions:



We were delighted that four of our team were successfully awarded their PhDs (Mike Patterson, Gochi Nwulu, Alex Wray, and Sophie Pask), and one of our team was awarded her MSc (Steph Meddick-Dyson). Seen here at the University of Hull graduation ceremony in 2024, with staff members Fliss Murtagh, Cindy Forbes and Alex Bullock. Congratulations to all our successful graduates.

Supporting early research interest and the clinical academic pathway:

In addition to a range of elective students, interns and INSPIRE students, we have supported:

- Emma Skipsey – one of the Intensive Care nurses from our local NHS Trust - to gain a 12-month **NIHR Pre-doctorial Clinical Academic Fellowship** (Sept 23 – Sept 24). Emma will work towards a PhD Fellowship application.
- In 2023, we supported five **Academic Foundation** (now Specialised Programme) doctors: Vishmi Silva, Elizabeth Dennis, Ishbel Luke, Rutendo Gambe, and Sonya Bushell, studying a range of topics and developing their interest in a future clinical academic career in palliative care.

- **Two NIHR Academic Clinical Fellows** – Jenny Young and Steph Meddick-Dyson - have started (Jenny) or completed (Steph) their three-year programmes with us (75% clinical time and 25% research time). It is excellent news that Steph has gone on to be successful in gaining an NIHR PhD Fellowship, starting in 2024.

Early and Mid-Career Researcher development:

We continually support our early and mid-career researchers to take relevant external and internal training and development opportunities. We were delighted that both Cindy Forbes and Sophie Pask each gained one of the few University of Hull places on the Aurora leadership development initiative. [Aurora is Advance HE's leadership development initiative for women; It is run as a unique partnership bringing together leadership experts, higher education providers and research institutes to take positive action to address the under-representation of women in leadership positions in the sector.] Several of our team have also joined the excellent internal University of Hull early career development programme (THRIVE). We have supported Cindy Forbes, Joseph Clark and Alison Bravington to get their AdvanceHE Fellowships; these Fellowship recognise individuals whose higher education teaching enables them to evidence additional skills and experience in education. Cindy Forbes, Jordan Curry, Ciaran McNaughton, and Sebastian Hernandez all completed Level 4 Cancer Rehabilitation Specialist Instructor training with CanRehab (see <https://www.canrehab.com/course/canrehab-specialist-instructor-course/>).

As a team, we contribute extensively to Faculty and University of Hull roles; these roles too offer development opportunities and experience of various teaching, organisational and leadership roles within the University.

Implementation and knowledge mobilisation

Box 7: Spotlight on Implementation

The DAMPen-D study: Improving the Detection, Assessment, Management, and Prevention of Delirium in Hospices: Feasibility study of a flexible and scalable implementation strategy to deliver guideline-adherent delirium care, funded by Yorkshire Cancer Research



*The Dampen-D researchers (from left to right):
Professor Miriam Johnson, Professor Mark Pearson, Dr Gillian Jackson, and Dr Jason Boland*

It is common for people to suffer from acute confusion (delirium) towards the end of their life. One-third of people have delirium when they are admitted to a palliative care unit or hospice and a further one-third develop delirium during their stay. People with delirium may see or hear things that aren't there, say or do things that are out of character, and can't 'think straight'. This is distressing for the person, their family, and staff. Delirium also causes unnecessary 'downward spirals' in a person's day-to-day abilities. This results in them having increased care needs in the community and unplanned and expensive hospital admissions. There is clear national guidance on the actions needed to prevent, detect, assess, and manage delirium. However, it is difficult for hospices to put this guidance into practice because delirium care is complex and involves lots of different people, including family, friends and health professionals.

The DAMPen-D feasibility study explored the impact of a theoretically-informed and co-designed implementation strategy (a set of actions to get guidelines into practice) in three hospices on delirium guideline adherence, the proportion of delirium days during an admission, and costs (staff time spent engaging with the implementation strategy). Although the study was exploratory rather than definitive, we found that, following the use of the implementation strategy, there was:

- A 6% absolute reduction in proportion of delirium days in those with a delirium episode
- Improvements in guideline-adherent metrics:
 - clinical delirium diagnosis 15% to 28%;
 - delirium risk assessment 0% to 16%;
 - screening on admission 7% to 35%.

More details about the feasibility work can be found here:

Jackson, G., Jackson, C., Boland, J.W, Featherstone, I., Huang, C., Ogden, M., Sartain, K., Siddiqi, N., Twiddy, M., Pearson, M. & Johnson, M.J (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. *Palliative Medicine* 38 (4) 447-456 <https://journals.sagepub.com/doi/10.1177/02692163241236325>

And the published protocol is here: <https://pubmed.ncbi.nlm.nih.gov/35831039/>

This feasibility study was supported by Yorkshire Cancer Research (Award reference number HEND405DEL). It provided the foundations for developing the DAMPen-D II grant proposal for a Cluster Randomised-Controlled Trial, Economic Analysis and Process Evaluation to evaluate the effectiveness and cost-effectiveness of the implementation strategy in 20 palliative care units across the UK (recently funded through NIHR HSDR).

Box 8: Spotlight on Knowledge Mobilisation

Examples of mobilising knowledge and evidence about breathlessness



Exhibit at the Freedom Festival, showing new artwork to communicate breathlessness

Public and community engagement about breathlessness continued strongly in 2023 through our involvement with the NHSE Breathlessness working group.

Flavia Swan and Miriam Johnson presented at a one-day online breathlessness short course for the British Thoracic Society attended by over 130 clinicians. This course received excellent feedback, including for example:

“Really informative speakers from a range of professions which was great. Great to have some patients and carers to bring it all back to the patient and why we are all doing this. Well timed and paced. Really good comprehensive overview of breathlessness and solidified some of my practice and gave me good ideas and reflections to improve my practice when working with these patients.”

Flavia Swan and Ann Hutchinson contributed to the development of a course on the NHS e Learning Hub entitled “Managing chronic breathlessness” <https://learninghub.nhs.uk/catalogue/chronic-breathlessness> which approximately 400 NHS staff have already completed in the first four months from launching.

Ann took the Bringing Breathlessness into View exhibition <https://www.hyms.ac.uk/research/research-centres-and-groups/wolfson/breathlessness/bringing-breathlessness-into-view-exhibition> to the Freedom Festival and had 199 visitors, many of whom gave good feedback and were interested in the Guide for living well with breathlessness.

NHS
Managing Chronic Breathlessness
elearning programme

- free online training for healthcare staff
- practical tips and self-management techniques
- links to sources of support for people living with chronic breathlessness

Available on the NHS Learning Hub:
learninghub.nhs.uk/catalogue/chronic-breathlessness

Sixteen people took part in interactive workshops led by artist Anna Bean on the subject of “Loneliness and togetherness”. One visitor remarked:

‘Stunning images giving an awareness of a condition that I was not familiar with. The images speak volumes!’



Participants at one of the interactive workshops

Ann and Anna worked together to create new artwork to express how it feels to have an exacerbation of chronic obstructive pulmonary disease, a key symptom of which is breathlessness. This artwork was exhibited at the Freedom Festival and at AstraZeneca’s medical education booth at the international European Respiratory Congress.

You can read Ann’s blog about the Freedom Festival here <https://breathlessness.hyms.ac.uk/?p=1899>

Global and international research

Box 9: Spotlight on Global Breathlessness Research and the Breathe-India Project

Global Breathlessness Research and the Breathe-India Project

Breathlessness is a common symptom of advanced illness which causes considerable distress. A wide range of breathlessness self-management interventions are available, however most evidence for these interventions comes from high-income countries. We don't know whether or how breathlessness self-management interventions can be adapted for low and middle-income countries. Funded by a Medical Research Council grant (£140,833.31), the Breathe-India project aimed to co-design a breathlessness intervention for use in India. Led by Dr Joseph Clark, Lecturer in Global Palliative Care, our international team conducted a realist review with stakeholder engagement, revealing fascinating insights regarding factors likely to influence breathlessness management in India, e.g. the importance of providing nutritional advice as part of healthcare delivery, to align with local health beliefs informed by Ayurveda. Dr Clark and Professor Miriam Johnson were invited to visit key collaborator Professor Naveen Salins at Manipal Academy of Higher Education to deliver an Implementation Research workshop, with a focus on breathlessness research.



Dr Joseph Clark and Professor Miriam Johnson, with collaborator Professor Naveen Salins and workshop attendees in Manipal, Karnataka, India

Joseph Clark was subsequently successful in obtaining a Hull Impact and Knowledge Exchange (HIKE) grant (£4,920) to hold an international breathlessness workshop at the University of Hull. The team are currently preparing an application for submission to the National Institute of Health Research in 2024. Outputs from Breathe-India include:

- Clark, J., Salins, N., Pearson, M., Spathis, A., Currow, D. C., Williams, S., & Johnson, M. (2023). BREATHLEssness in INDIA (BREATHE-INDIA)–Study protocol for the co-design of a community breathlessness intervention in India using realist methods and intervention mapping. PLoS ONE, 18(11 November), Article e0293918. <https://doi.org/10.1371/journal.pone.0293918>
- Oral presentation at the European Association of Palliative Care Conference, Barcelona, 2024
- Knowledge Exchange workshop at Manipal Academy of Higher Education, Manipal, India, 2024
- *Breathlessness without borders* Commentary accepted for publication in the journal, *njp Primary Care Respiratory Medicine* (2024)

Box 10: International work on breathlessness – the use of the handheld fan.

These three papers illustrate international impact in the field, but also demonstrate our contribution to the undergraduate school in enabling research experience, and capacity building with our early and mid-career researchers. None of the pieces of work received external funding (other than through the INSPIRE programme, a UK-wide initiative coordinated by the Academy of Medical Sciences, supported by the Wellcome Trust, and designed to engage medical undergraduates with research) but illustrate how involvement of undergraduates can result in high quality work, gives early and mid-career researchers important supervisory experience, and lead to further grant income.

Brew A, O'Beirne S, Johnson MJ, Ramsenthaler C, Watson PJ, Rubini PA, Fagan MJ, Swan F, Simpson A. Airflow rates and breathlessness recovery from submaximal exercise in healthy adults: prospective, randomised, cross-over study. *BMJ Support Palliat Care*. 2023.

<https://pubmed.ncbi.nlm.nih.gov/37669853/>

Brew and O'Beirne were medical students (on the MBBS programme) who undertook electives with us. They contributed to protocol design, ethics approvals, data collection and co-first authorship writing. Flavia Swan is a WPCRC early-career researcher, who co-led and co-supervised the project with Miriam Johnson, in an interdisciplinary collaboration with Andy Simpson from the University of Hull's School of Sport, Exercise, and Rehabilitation Sciences. Flavia then went on to co-supervise one of Simpsons' Masters students, repeating the study in people with chronic obstructive pulmonary disease.

This paper presents, for the first time, key clinical information that the type of handheld fan does matter in terms of flow rate and appearance. It illustrates effective and novel collaboration with engineers at the University of Hull. The work led to a successful grant award with colleagues (device development engineers and health) at the University Technology Sydney (UTS), and for which we won two impact prizes (UTS Faculty and University level). This also builds on our Research England i3 international collaboration award.

Prihartadi AS, Impelliziere Licastro G, Pearson M, Johnson MJ, Lockett T, Swan F. Non-medical devices for chronic breathlessness: use, barriers and facilitators for patients, carers and clinicians - a scoping review. *BMJ Support Palliat Care*. 2023;13(e2):e244-e53. <https://spcare.bmj.com/content/13/e2/e244>

Prihartadi was an MBBS INSPIRE student, supervised by Flavia Swan and Mark Pearson. The work then contributed to the successful grant award (NIHR RfPB) BREATHE-WELL.

Brown J, Miller I, Barnes-Harris M, Johnson MJ, Pearson M, Lockett T, Swan F. The handheld fan for chronic breathlessness: Clinicians' experiences and views of implementation in clinical practice. *PLoS One*. 2023;18(11):e0294748.

<https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0294748>

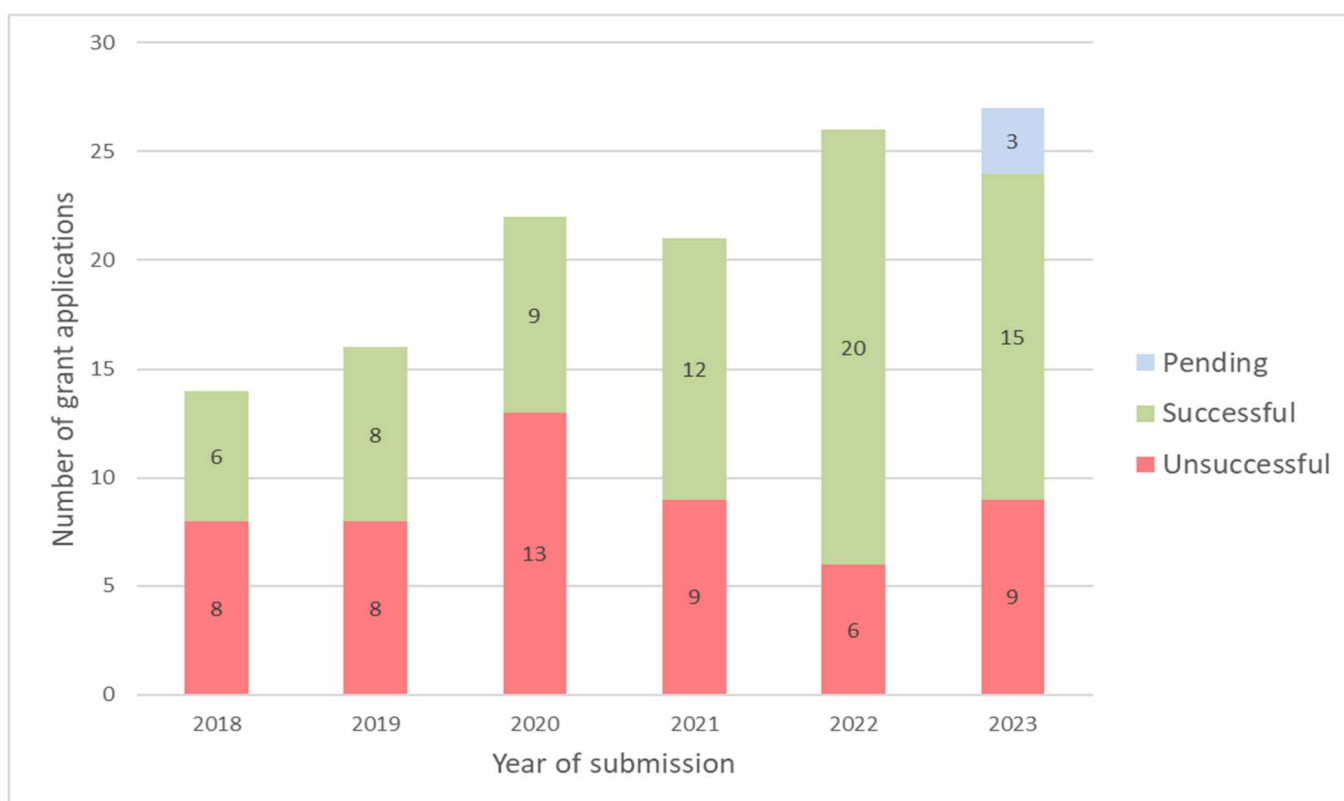
Brown and Miller were MBBS INSPIRE students supervised by Flavia Swan, mentored by Miriam Johnson, and the work in this third paper contributed to the UTS impact prizes. Resulting from her growing experience in the field, Flavia Swan has now submitted her first NIHR RfPB Principal Investigator grant application about chronic breathlessness and has been shortlisted for Stage 2 (2024).

Research grant income

We have continued to build on our grant success of previous years, with fifteen successful research grant awards in 2023 to undertake a range of diverse research projects (see Table 1 for details). Over the last five years, we have steadily increased the number of applications, and our success rate (see Figure 1).

In 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, 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. Fliiss 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, Fliiss 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 support Steph Meddick-Dyson to success in an **NIHR PhD training Fellowship**.

Figure 1: Number of grant applications over the last five years



In 2023, members of the WPCRC team have led or been co-applicants on bids to a total of **over £8.7 million**; and have brought grant income to University of Hull of **over £2.3 million**. Detail of the successful awards in 2023 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. Please note also - we have not included successful grants led by University of Hull collaborators outside of WPCRC; it is important to acknowledge that WPCRC researchers have played important co-applicant roles in gaining successful funding in University of Hull-based collaborations.

Table 1: Details of successful research grant awards in 2023

Project Title	Funder	Project Lead	Total grant awarded (£)	Grant income to University of Hull (£)
Care Under Pressure 3: Optimising the delivery and impacts of interventions to reduce hospital doctors' mental ill-health in the NHS	NIHR National Institute for Health and Care Research: Health Services and Delivery Research	Mark Pearson	22,801	22,801
PROMISE - The Potential for ROutline Data to Monitor and Reduce Inequalities in End-of-life Care	NIHR National Institute for Health and Care Research: Programme Grants for Applied Research	Fliss Murtagh (co-applicant)	8,637	8,637
Principles for research on ethnicity in palliative and end of life care: development of a consensus statement	MRC Medical Research Council	Jonathan Koffman	38,253	38,253
THIS Institute PhD Fellowship application	The Health Improvement (THIS) Institute	Fliss Murtagh	218,116	218,116
Understanding interaction in problematic dementia and social care encounters	NIHR National Institute for Health and Care Research: Research for Social Care	Alison Bravington	6,833	6,833
Living well with chronic breathlessness: Improving the sustainable use of supported self-management strategies	NIHR National Institute for Health and Care Research: Research for Patient Benefit	Mark Pearson	168,478	168,478
Heart failure and palliative care: a national mapping survey	NHS England	Miriam Johnson	15,000	15,000
Disseminating evidence on use of individual-level outcomes	Marie Curie Cancer Care	Fliss Murtagh	9,866	9,866
HEIF: QR Policy Development Fund project	University of Hull internal funding	Mark Pearson	9,262	9,262
The association of social determinants of health in decision-making at end of life	British Medical Association	Jonathan Koffman	60,030	60,030
NIHR Policy Research Unit (PRU) in Palliative and End of Life Care	NIHR National Institute for Health and Care Research: Policy Research Programme	Fliss Murtagh (co-lead with Katherine Sleeman at King's College London)	2,999,938	768,891
North Yorkshire Health Determinants Research Collaboration	NIHR National Institute for Health and Care Research: HDRC	Mark Pearson (co-led with North Yorkshire Council)	4,999,999	989,765
HIKE: SIF BREATHE-ASIA Co-adaptation of a breathlessness intervention developed in India to other low-resource settings	University of Hull internal funding	Joseph Clark	4,920	280
Equitable Bereavement Care for All: qualitative study to improve bereavement services for those from ethnic minority groups	NIHR National Institute for Health and Care Research: Policy Research Programme	Jonathan Koffman (co-applicant)	370,799	14,540
TOTAL			£8,717,733	£2,330,752

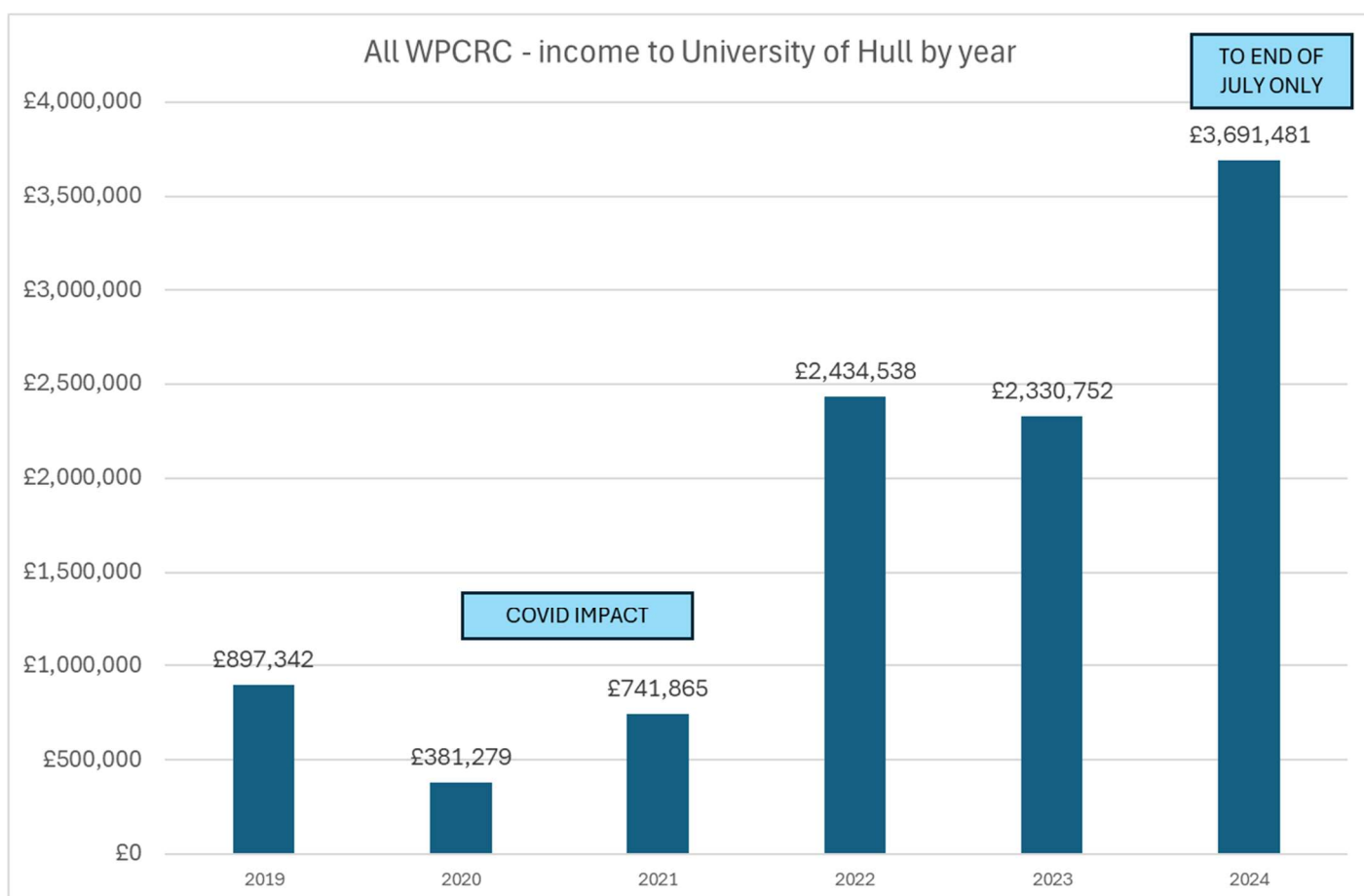
Over the last five years, we have seen a steady increase in our research grant income, allowing us to undertake and deliver research to meet to our strategic objectives, build much-needed capacity for palliative care research, and work towards impact to improve care.

The impact of COVID is clear, substantially affecting research work and bids in 2020 particularly, as several of the team were called back to full time clinical work in 2020; this impacted on our research income in 2021, but we made a good recovery into 2022.

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 harder to achieve.

Details of the growth in our research grant income over this time is shown in Figure 2.

Figure 2: Research grant income to University of Hull, by year



Conference presentations in 2023

We present 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:

- Invited lecture at the **3rd & 4th Joint Sapporo Conference for Palliative and Supportive Care in Cancer**, Sapporo, Japan, 2023. Joseph Clark. Global palliative care development: Promoting access to services and essential medicines, through understanding of international policy and processes.
- Invited lecture at the **Indian Association of Palliative Care conference**, Bangalore, India, 2023. Joseph Clark. BREATHE-INDIA: BREATHIEssness in INDIA - Development of a breathlessness beliefs and behaviour education intervention for use in the community-setting.
- **The International Primary Care Respiratory Group conference in Munich, Germany**. May 2023. Ann Hutchinson. The language COPD patients use to describe exacerbations: findings from an interview study.
- **The International Primary Care Respiratory Group conference in Munich, Germany**. May 2023. Ann Hutchinson. "I want to know what to expect; even though it's not pleasant. I want to know what's going to happen and how to handle it when it does." The views of patients and carers on best care for people with COPD: an interview study.
- **The International Primary Care Respiratory Group conference in Munich, Germany**. May 2023. Oral presentation. Doe G, Taylor SJC, Topalovic M, Russell R, Evans RA, Maes J, Van Orshovon K, Sunjaya A, Scott DA, Prevost T, El-Emir E, Harvey J, Hopkinson NS, Kon S, Patel S, Jarrold I, Spain N, Man WD-C and Hutchinson A. Challenges and opportunities in resuming spirometry services in England post-pandemic with potential to adopt Artificial Intelligence decision support software: a qualitative study.
- **7th National Patient Reported Outcome Measures (PROMs) Research Conference. Sheffield, UK** June 2023. Keynote speaker. Fliss Murtagh. The challenges of measuring outcomes in life limiting conditions.
- **The Annual meeting of the International Society for Behavioural Nutrition and Physical Activity, Uppsala, Sweden**. Short oral presentation. June 2023. König LM (presenting), Forbes CC, Busse H, DeSmet A, Szinay D, Smit E. (2023, June). Inequalities in exclusively mobile interventions targeting weight-related behaviours: A systematic review of observational studies.
- **The Annual meeting of the International Society for Behavioural Nutrition and Physical Activity, Uppsala, Sweden**. Discussant. June 2023. Bultijnck R (presenter), Agasi-Idenburg C (presenter), Saxton J (presenter), Verbestel V (Chair), Forbes CC (Expert Discussant). Implementing exercise and lifestyle support in individuals living with and beyond cancer: a patient-centred approach.
- **Hospice UK conference 2023**. November 2023. Invited speaker. Fliss Murtagh. Data – the pitfalls, the power and the story.
- **University of Bristol**, Department of Primary Care and Department of Philosophy interdisciplinary conference. November 2023 Oral presentation: Kate Binnie. Trauma and epistemic injustice.
- **University of Oxford**, Council for Allied Health Professionals Research conference. December 2023. Oral presentation: Kate Binnie. Safety First: Body-mind approaches for breathlessness in advanced disease. A realist review.



Some of the WPCRC team at the 18th World Congress of the European Association for Palliative Care, 2023

In 2023, 15 of the team attended **the 18th World Congress of the European Association for Palliative Care**, in Rotterdam, The Netherlands, from 15th – 17th June 2023, where we hosted a WPCRC stand for the first time (to help promote our work and the new MSc), and presented on the following topics:

Oral presentations

1. Roles and Experiences of Informal Carers Providing Care for People with Advanced Cancer in Africa: A Systematic Review and Critical Interpretative Analysis. Authors: R Gambe, J Clark, B Ukoha-Kalu, G Nyaaba, F Murtagh (presented by Rutendo Gambe, one of our Academic Foundation doctors, and now published <https://pubmed.ncbi.nlm.nih.gov/37027360/>)
2. Management of out-of-hours crises, medicines, and care in the last days of life for adults living at home with palliative and end-of-life care needs. Authors: S Pask, A Mohamed, R Chambers, P McFarlane, A Bone, S Barclay, I Higginson, K Sleeman, F Murtagh (presented by Sophie Pask, one of our early career researchers, and now published in relation to out of hours telephone support <https://journals.sagepub.com/doi/10.1177/02692163241242329>)
3. How effective is specialist palliative care? A meta-analysis with meta-regression to identify active ingredients of service composition, service structure and delivery model. Authors: Rutterford L, Sunny A, Pask S, Murtagh FEM, Johnson MJ, Ramsenthaler C (presented by Christina Ramsenthaler, Senior Lecturer now Professor, and this is recently published in PLOS Medicine <https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1004436>)

Poster presentations

1. It's Not Going to Happen to Me: A qualitative study of older adults with cancer views and experiences of malnutrition, sarcopenia and cachexia. Authors: AF Bullock, MJ Patterson, D Currow, MJ Johnson
2. Development of a programme theory of shared decision-making in malignant bowel obstruction: A realist review with stakeholder engagement. Authors: A Bravington, J Boland, S Greenley, M Lind, F Murtagh, M Patterson, M Johnson

3. Identifying Different Patterns of Community Episodes of Palliative Care: A Secondary Analysis of Routinely-collected Phase of Illness and IPOS Data. Authors: A Khamis, A Landon, J Boland, M Santerilli, G Nyaaba, K Sartain, J Noble, H Richardson, C Ramsenthaler, F Murtagh.
4. Face Validity of Case-mix Classes in a Community Palliative Care Setting: A Cross-sectional Study. Authors: F Murtagh, A Khamis, A Landon, J Boland, M Santarelli, G Nyaaba, K Sartain, J Noble, H Richardson, C Ramsenthaler.
5. Cool Facial Airflow Speeds Recovery from Exertion Induced Breathlessness in people with chronic breathlessness. Authors: T Burrell, A Simpson M Johnson, F Swan
6. Interviews with Children - The Seldom Heard Voices of Parentally Bereaved Children. Authors: A Wray, C Whitfield, F Murtagh, J Boland
7. Care of Families through Loss: A Grounded Theory Interview Study of Parents' Experiences Supporting their Children Following Parental Death. Authors: A Wray, C Whitfield, F Murtagh, J Boland
8. Safety First: Body-mind approaches for breathlessness-related distress in advanced disease. A realist review. Authors: K Binnie, T Williams, E Harris, M Pearson, J Clark, M Johnson
9. Research Minoritised Communities in Palliative Care: An Agenda for Change. Authors: J Koffman, S Bajwah, J Davies, J Hussain
10. Calculating Worldwide Needs for Morphine for Pain in Advanced Cancer and Proportions Feasibility Met by Country Estimates of Requirements: Retrospective, Time-series Analysis. Authors: J Clark, D Currow, M Johnson, E Muscogliati, R Muscogliati, C Ramsenthaler
11. "Morphine? Respiratory Depression. Morphine? Addiction". It's Like a Brick Wall. Views and Experiences of Opioid Access amongst Clinicians and Public Representatives in Two States in India. Authors: J Clark, N Salins, S Daniel, D Currow, L Jones, M Pearson, R Bunton, J Mankel, C Braithwaite, M Johnson
12. What Impact Does Socioeconomic Status Have on Older Adult Views of Weight Loss? Authors: A Newton-Clark, A Bullock, N Ugochinyere, M Johnson
13. Understanding how people with palliative and end-of-life care needs living at home and informal carers access designated telephone support out-of-hours. Authors: S Park, A Omoruyi, A Mohamed, R Chambers, P McFarlane, A Bone, S Barclay, I Higginson, K Sleeman, F Murtagh
14. Understanding chronic pain, opioid use, and cognitive adverse effects: A qualitative study with older adults at risk of severe frailty and their informal carers. Authors: S Pask, F Murtagh, J Boland
15. Training implications for generalist palliative care settings when using the Integrated Palliative Care Outcomes Scale for People with Dementia (IPOS-Dem) - a secondary qualitative analysis. Authors: S de Wolf-Linder, I Kramer, T Quasdorf, C Ramsenthaler, M Shubert, F Murtagh
16. How prevalent are palliative care related symptoms and needs among people with dementia in the community? - A cross-sectional analysis of the Integrated Palliative Care Outcome Scale Dementia (IPOS-Dem). Authors: S de Wolf-Linder, M Bruschini, I Kramer, F Murtagh, M Schubert, C Ramsenthaler
17. Creation and development of an international research network: the End of Life and Palliative Care in the ICU Research Network (EPCIN). Authors: S Meddick-Dyson, S Humphreys, F Murtagh, J Boland, N Pattison
18. The Psychological Impact of Living with Chronic Breathlessness and Experiences of Identification and Assessment of this Symptom in an Older, Frail Population in Primary Care. Authors: H. L. Elliott-Button, M. J. Johnson, J. Clark

19. How reliable is staff proxy assessment in clinical care? Inter-rater and test-retest reliability of the Integrated Palliative Care Outcome Scale (IPOS). Authors: Christina Ramsenthaler, Assem Khamis, Giovanna Licastro, Zoe Parsons, Fliss E. M. Murtagh
20. Predictors of informal care costs in the last year of life. Authors: Chynoweth J, Keser G, Allgar V, Currow DC, Hutchinson A, Dunn L, Jones A, Weatherly H, Johnson MJ.
21. Delirium Prevention in Hospice In-patient Units: A Focused Ethnography. Authors: Featherstone I, Siddiqi N, Sheldon TS, Bravington A, Dixon R, Kelley R, Hawkins R, Callin S, Johnson MJ

Peer reviewed publications in 2023

During 2023, we have endeavoured to focus on slightly fewer publications, but of higher quality, delivering training on writing for scientific publications, and REF scoring of outputs. We are trying to aim for better quality journals, and to ensure the international and national relevance of our work is made clear. Publications in peer reviewed journals (for 2023 only) are:

1. Abel AAI, Samuel NA, Cuthbert JJ, Brown OI, Pellicori P, Kazmi S, Cleland JGF, Johnson MJ and Clark AL. Hospital admissions in the last year of life of patients with heart failure. *Eur Heart J Qual Care Clin Outcomes* 2024; 10: 168-175. DOI: 10.1093/ehjqcco/qcad047.
2. Antunes B, Barclay S, Kuhn I, Eagar K, Bausewein C, Murtagh F, Etkind S, Bowers B, Dixon S, Lovick R, Harding R, Higginson I and Shokraneh F. Implementing patient-centred outcome measures in palliative care clinical practice for adults (IMPCOM): Protocol for an update systematic review of facilitators and barriers. *F1000Res* 2023; 12: 224. 20231030. DOI: 10.12688/f1000research.131479.2.
3. Aunger JA, Maben J, Abrams R, Wright JM, Mannion R, Pearson M, Jones A and Westbrook JI. Drivers of unprofessional behaviour between staff in acute care hospitals: a realist review. *BMC Health Serv Res* 2023; 23: 1326. 20231130. DOI: 10.1186/s12913-023-10291-3.
4. Bayley Z, Bothma J, Bravington A, Forward C, Hussain J, Manthorpe J, Pearson M, Roberts H, Taylor P, Walker L, White C, Wray J and Johnson MJ. Supported: Supporting, enabling, and sustaining homecare workers to deliver end-of-life care: A qualitative study protocol. *PLoS One* 2023; 18: e0291525. 20231213. DOI: 10.1371/journal.pone.0291525.
5. Bedendo A, Hinde S, Beresford B, Papworth A, Phillips B, Vasudevan C, McLorie E, Walker G, Peat G, Weatherly H, Feltbower R, Hewitt C, Haynes A, Murtagh F, Noyes J, Hackett J, Hain R, Oddie S, Subramanian G and Fraser L. Consultant-led UK paediatric palliative care services: professional configuration, services, funding. *BMJ Support Palliat Care* 2023 20230809. DOI: 10.1136/spcare-2023-004172.
6. Birch F, Boam E, Parsons S, Ghosh J and Johnson MJ. Subcutaneous furosemide in advanced heart failure: service improvement project. *BMJ Support Palliat Care* 2023; 13: 112-116. 20210115. DOI: 10.1136/bmjspcare-2020-002803.
7. Boland JW. Tapentadol for the management of cancer pain in adults: an update. *Curr Opin Support Palliat Care* 2023; 17: 90-97. 20230315. DOI: 10.1097/SPC.0000000000000641.
8. Boland JW and Boland EG. Ensuring patients with malignant bowel obstruction are central in research and clinical decisions. *Lancet Gastroenterol Hepatol* 2023; 8: 863-864. 20230801. DOI: 10.1016/S2468-1253(23)00203-0.
9. Boland JW, Boland EG and Currow DC. High-quality phase 3 studies do not support the use of somatostatin analogues to reduce vomiting in malignant bowel obstruction. *Support Care Cancer* 2023; 31: 211. 20230314. DOI: 10.1007/s00520-023-07669-8.
10. Boland JW, Kabir M, Spilg EG, Webber C, Bush SH, Murtagh F and Lawlor PG. Over a third of palliative medicine physicians meet burnout criteria: Results from a survey study during the COVID-19 pandemic. *Palliat Med* 2023; 37: 343-354. 20230215. DOI: 10.1177/02692163231153067.
11. Bradley A and Boland JW. Effects of Opioids on Immune and Endocrine Function in Patients with Cancer Pain. *Curr Treat Options Oncol* 2023; 24: 867-879. 20230505. DOI: 10.1007/s11864-023-01091-2.
12. Bramwell C, Carrieri D, Melvin A, Pearson A, Scott J, Hancock J, Pearson M, Papoutsi C, Wong G and Mattick K. How can NHS trusts in England optimise strategies to improve the mental health and well-being

of hospital doctors? The Care Under Pressure 3 (CUP3) realist evaluation study protocol. *BMJ Open* 2023; 13: e073615. 20231109. DOI: 10.1136/bmjopen-2023-073615.

13. Bravington A, Johnson M and Macleod U. Turning a Curve: How People Use Everyday Resources to Negotiate Recovery From Cancer Treatment With Curative Intent. *Qual Health Res* 2024; 34: 635-648. 20240117. DOI: 10.1177/10497323231219389.

14. Bravington A, Obita G, Baddeley E, Johnson MJ, Murtagh FEM, Currow DC, Boland EG, Nelson A, Seddon K, Oliver A, Noble SIR and Boland JW. Development of a Core Outcome Set for the research and assessment of inoperable malignant bowel obstruction. *PLoS One* 2023; 18: e0289501. 20230822. DOI: 10.1371/journal.pone.0289501.

15. Brew A, O'Beirne S, Johnson MJ, Ramsenthaler C, Watson PJ, Rubini PA, Fagan MJ, Swan F and Simpson A. Airflow rates and breathlessness recovery from submaximal exercise in healthy adults: prospective, randomised, cross-over study. *BMJ Support Palliat Care* 2023 20230905. DOI: 10.1136/spcare-2023-004309.

16. Brown J, Miller I, Barnes-Harris M, Johnson MJ, Pearson M, Lockett T and Swan F. The handheld fan for chronic breathlessness: Clinicians' experiences and views of implementation in clinical practice. *PLoS One* 2023; 18: e0294748. 20231128. DOI: 10.1371/journal.pone.0294748.

17. Bryans A, Siddiqi N, Burry L, Clarke M, Koffman J, Agar MR and Rose L. A Core Outcome Set for Interventions to Prevent and/or Treat Delirium in Palliative Care. *J Pain Symptom Manage* 2023; 66: 293-300 e298. 20230612. DOI: 10.1016/j.jpainsymman.2023.05.013.

18. Byng R, Kirkpatrick T, Lennox C, Warren FC, Anderson R, Brand SL, Callaghan L, Carroll L, Durcan G, Gill L, Goodier S, Graham J, Greer R, Haddad M, Harris T, Henley W, Hunter R, Leonard S, Maguire M, Michie S, Owens C, Pearson M, Quinn C, Rybczynska-Bunt S, Stevenson C, Stewart A, Stirzaker A, Todd R, Walter F, Weston L, Wright N, Taylor RS and Shaw J. Evaluation of a complex intervention for prisoners with common mental health problems, near to and after release: the Engager randomised controlled trial. *Br J Psychiatry* 2023; 222: 18-26. DOI: 10.1192/bjp.2022.93.

19. Chambers RL, Pask S, Higginson IJ, Barclay S, Murtagh FEM and Sleeman KE. Inclusion of palliative and end of life care in health strategies aimed at integrated care: a documentary analysis [version 2; peer review: 2 approved]. *AMRC Open Res* 2023; 4: 19. DOI: 10.12688/amrcopenres.13079.2.

20. Clark J, Salins N, Daniel S, Currow DC, Jones L, Pearson M, Bunton R, Mankel J, Braithwaite C, Gilchrist MM and Johnson MJ. Views and experiences of opioid access amongst palliative care providers and public representatives in a low-resource setting: A qualitative interview study. *PLOS Glob Public Health* 2023; 3: e0002401. 20230921. DOI: 10.1371/journal.pgph.0002401.

21. Clark J, Salins N, Pearson M, Spathis A, Currow DC, Williams S and Johnson M. BREATHLEssness in INDIA (BREATHE-INDIA)-Study protocol for the co-design of a community breathlessness intervention in India using realist methods and intervention mapping. *PLoS One* 2023; 18: e0293918. 20231102. DOI: 10.1371/journal.pone.0293918.

22. Clarke J, Kinchin I, Kochovska S, Johnson MJ and Currow DC. What If... Caregivers' Subsequent Workforce Participation Was a Measure of Palliative Care Services' Impact? An Hypothesis-Generating Study. *J Palliat Med* 2023; 26: 1042-1047. 20230131. DOI: 10.1089/jpm.2022.0498.

23. Collins A, Hui D, Davison SN, Ducharlet K, Murtagh F, Chang YK and Philip J. Referral Criteria to Specialist Palliative Care for People with Advanced Chronic Kidney Disease: A Systematic Review. *J Pain Symptom Manage* 2023; 66: 541-550 e541. 20230726. DOI: 10.1016/j.jpainsymman.2023.07.013.

24. Coombes L, Harethardottir D, Braybrook D, Roach A, Scott H, Bristowe K, Ellis-Smith C, Downing J, Bluebond-Langner M, Fraser LK, Murtagh FEM and Harding R. Design and Administration of Patient-Centred

Outcome Measures: The Perspectives of Children and Young People with Life-Limiting or Life-Threatening Conditions and Their Family Members. *Patient* 2023; 16: 473-483. 20230523. DOI: 10.1007/s40271-023-00627-w.

25. Coombes L, Harethardottir D, Braybrook D, Scott HM, Bristowe K, Ellis-Smith C, Fraser LK, Downing J, Bluebond-Langner M, Murtagh FE and Harding R. Achieving consensus on priority items for paediatric palliative care outcome measurement: Results from a modified Delphi survey, engagement with a children's research involvement group and expert item generation. *Palliat Med* 2023; 37: 1509-1519. 20231018. DOI: 10.1177/02692163231205126.

26. Crooks MG, Crowther L, Cummings H, Cohen J, Huang C, Pitel L, Pearson M, Morice A, Turgoose J, Faruqi S, Watt M, Morris T and Xu Y. Improving asthma care through implementation of the SENTINEL programme: findings from the pilot site. *ERJ Open Res* 2023; 9 20230509. DOI: 10.1183/23120541.00685-2022.

27. Currow DC, Iyer R, Clark J and Rajan SK. Recognizing and Managing the Burdens of Chronic Breathlessness Alongside the Burdens of Chronic Obstructive Pulmonary Disease. *Am J Respir Crit Care Med* 2023; 208: 1138-1139. DOI: 10.1164/rccm.202307-1303LE.

28. Currow DCSAE and Clark J. Pharmacological Imperialism. *J Palliat Med* 2023; 26: 158-159. DOI: 10.1089/jpm.2022.0573.

29. Date K, Williams B, Cohen J, Chaudhuri N, Bajwah S, Pearson M, Higginson I, Norrie J, Keerie C, Tuck S, Hall P, Currow D, Fallon M and Johnson M. Modified-release morphine or placebo for chronic breathlessness: the MABEL trial protocol. *ERJ Open Res* 2023; 9 20230814. DOI: 10.1183/23120541.00167-2023.

30. Davies JM, Sleeman KE, Ramsenthaler C, Prentice W, Maddocks M and Murtagh FE. The association between socioeconomic position and the symptoms and concerns of hospital inpatients seen by specialist palliative care: Analysis of routinely collected patient data. *Palliat Med* 2023; 37: 575-585. 20220810. DOI: 10.1177/0269216322115331.

31. Dehpour T and Koffman J. Assessment of anticipatory grief in informal caregivers of dependants with dementia: a systematic review. *Aging Ment Health* 2023; 27: 110-123. 20220215. DOI: 10.1080/13607863.2022.2032599.

32. Doe G, Taylor SJ, Topalovic M, Russell R, Evans RA, Maes J, Van Orshovon K, Sunjaya A, Scott D, Prevost AT, El-Emir E, Harvey J, Hopkinson NS, Kon SS, Patel S, Jarrold I, Spain N, Man WD and Hutchinson A. Spirometry services in England post-pandemic and the potential role of AI support software: a qualitative study of challenges and opportunities. *Br J Gen Pract* 2023; 73: e915-e923. 20231130. DOI: 10.3399/BJGP.2022.0608.

33. Doe GE, Williams MT, Chantrell S, Steiner MC, Armstrong N, Hutchinson A and Evans RA. Diagnostic delays for breathlessness in primary care: a qualitative study to investigate current care and inform future pathways. *Br J Gen Pract* 2023; 73: e468-e477. 20230525. DOI: 10.3399/BJGP.2022.0475.

34. Featherstone I, Siddiqi N, Jones L, Coppo E, Sheldon T, Hosie A, Wolkowski A, Bush SH, Taylor J, Teodorczuk A and Johnson MJ. 'It's tough. It is hard': A qualitative interview study of staff and volunteers caring for hospice in-patients with delirium. *Palliat Med* 2023; 37: 993-1005. 20230502. DOI: 10.1177/02692163231170655.

35. Fei F, R JS, Zhang X, Gao W and Koffman J. Symptom clusters, associated factors and health-related quality of life in patients with chronic obstructive pulmonary disease: A structural equation modelling analysis. *J Clin Nurs* 2023; 32: 298-310. 20220130. DOI: 10.1111/jocn.16234.

36. Firth AM, Lin CP, Yi DH, Goodrich J, Gaczkowska I, Waite F, Harding R, Murtagh FE and Evans CJ. How is community based 'out-of-hours' care provided to patients with advanced illness near the end of life: A systematic review of care provision. *Palliat Med* 2023; 37: 310-328. DOI: 10.1177/02692163231154760.
37. Gambe RG, Clark J, Meddick-Dyson SA, Ukoha-Kalu BO, Nyaaba GN and Murtagh FEM. The roles and experiences of informal carers providing care to people with advanced cancer in Africa-A systematic review and critical interpretive analysis. *PLOS Glob Public Health* 2023; 3: e0001785. 20230407. DOI: 10.1371/journal.pgph.0001785.
38. Goedegebuur J, Abbel D, Accassat S, Achterberg WP, Akbari A, Arfuch VM, Baddeley E, Bax JJ, Becker D, Bergmeijer B, Bertolotti L, Blom JW, Calvetti A, Cannegieter SC, Castro L, Chavannes NH, Coma-Auli N, Couffignal C, Edwards A, Edwards M, Enggaard H, Font C, Gava A, Geersing GJ, Geijteman ECT, Greenley S, Gregory C, Gussekloo J, Hoffmann I, Hojen AA, van den Hout WB, Huisman MV, Jacobsen S, Jagosh J, Johnson MJ, Jorgensen L, Juffermans CCM, Kempers EK, Konstantinides S, Kroder AF, Kruij M, Lafaie L, Langendoen JW, Larsen TB, Lifford K, van der Linden YM, Mahe I, Maiorana L, Maraveyas A, Martens ESL, Mayeur D, van Mens TE, Mohr K, Mooijaart SP, Murtagh FEM, Nelson A, Nielsen PB, Ording AG, Orskov M, Pearson M, Poenou G, Portielje JEA, Raczkiwicz D, Rasmussen K, Trinks-Roerdink E, Schippers I, Seddon K, Sexton K, Sivell S, Skjoth F, Sogaard M, Szmít S, Trompet S, Vassal P, Visser C, van Vliet LM, Wilson E, Klok FA and Noble SIR. Towards optimal use of antithrombotic therapy of people with cancer at the end of life: A research protocol for the development and implementation of the SERENITY shared decision support tool. *Thromb Res* 2023; 228: 54-60. 20230513. DOI: 10.1016/j.thromres.2023.05.008.
39. Harvey G, Rycroft-Malone J, Seers K, Wilson P, Cassidy C, Embrett M, Hu J, Pearson M, Semenic S, Zhao J and Graham ID. Connecting the science and practice of implementation - applying the lens of context to inform study design in implementation research. *Front Health Serv* 2023; 3: 1162762. 20230707. DOI: 10.3389/frhs.2023.1162762.
40. Hay-Smith EJC, Pearson M and Dean S. 'Making sense' of urinary incontinence: A qualitative study investigating women's pelvic floor muscle training adherence. *New Zealand Journal of Physiotherapy* 2023; 51. DOI: 10.15619/nzjp/51.1.02.
41. Hocaoglu MB, Murtagh FEM, Walshe C, Chambers RL, Maddocks M, Sleeman KE, Oluyase AO, Dunleavy L, Bradshaw A, Bajwah S, Fraser LK, Preston N, Higginson IJ and CovPall study t. Adaptation and multicentre validation of a patient-centred outcome scale for people severely ill with COVID (IPOS-COV). *Health Qual Life Outcomes* 2023; 21: 29. 20230324. DOI: 10.1186/s12955-023-02102-4.
42. Hoijer CJ and Johnson MJ. Deactivation of implantable defibrillators at the end of life - A register-based study of ICD-deactivation at home and the impact of palliative care. *Int J Cardiol* 2023; 386: 91-94. 20230530. DOI: 10.1016/j.ijcard.2023.05.046.
43. Hutchinson A, Pickering A, Williams P and Johnson M. Predictors of hospital admission when presenting with acute-on-chronic breathlessness: Binary logistic regression. *PLoS One* 2023; 18: e0289263. 20230815. DOI: 10.1371/journal.pone.0289263.
44. Janssen DJA, Bajwah S, Boon MH, Coleman C, Currow DC, Devillers A, Vandendungen C, Ekstrom M, Flewett R, Greenley S, Guldin MB, Jacome C, Johnson MJ, Kurita GP, Maddocks M, Marques A, Pinnock H, Simon ST, Tonia T and Marsaa K. European Respiratory Society clinical practice guideline: palliative care for people with COPD or interstitial lung disease. *Eur Respir J* 2023; 62 20230817. DOI: 10.1183/13993003.02014-2022.
45. Johnson MJ, Pitel L, Currow DC, Forbes C, Soyiri I and Robinson L. Breathlessness limiting exertion in very old adults: findings from the Newcastle 85+ study. *Age Ageing* 2023; 52. DOI: 10.1093/ageing/afad155.
46. Keats MR, Yu X, Sweeney Magee M, Forbes CC, Grandy SA, Sweeney E and Dummer TJB. Use of Wearable Activity-Monitoring Technologies to Promote Physical Activity in Cancer Survivors: Challenges and

Opportunities for Improved Cancer Care. *Int J Environ Res Public Health* 2023; 20 20230308. DOI: 10.3390/ijerph20064784.

47. Kishino M, Koffman J, Nagatomi H, Yuasa M and Ellis-Smith C. Complexity and function of family involvement in advance care planning: A qualitative study of perspectives from people living with advanced cancer, family members and healthcare professionals. *Palliat Med* 2023; 37: 1434-1446. 20230918. DOI: 10.1177/02692163231194202.

48. Kochovska S, Ekstrom M, Hansen-Flaschen J, Ferreira D, Similowski T, Johnson MJ and Currow DC. Hiding in plain sight: the evolving definition of chronic breathlessness and new ICD-11 wording. *Eur Respir J* 2023; 61 20230330. DOI: 10.1183/13993003.00252-2023.

49. Koffman J, Bajwah S, Davies JM and Hussain JA. Researching minoritised communities in palliative care: An agenda for change. *Palliat Med* 2023; 37: 530-542. 20221021. DOI: 10.1177/02692163221132091.

50. Koffman J, Shapiro GK and Schulz-Quach C. Enhancing equity and diversity in palliative care clinical practice, research and education. *BMC Palliat Care* 2023; 22: 64. 20230605. DOI: 10.1186/s12904-023-01185-6.

51. Konig LM, Krukowski RA, Kuntsche E, Busse H, Gumbert L, Gemesi K, Neter E, Mohamed NF, Ross KM, John-Akinola YO, Cooper R, Allmeta A, Silva AM, Forbes CC and Western MJ. Reducing intervention- and research-induced inequalities to tackle the digital divide in health promotion. *Int J Equity Health* 2023; 22: 249. 20231204. DOI: 10.1186/s12939-023-02055-6.

52. Leniz J, Davies JM, Bone AE, Hocaoglu M, Verne J, Barclay S, Murtagh FEM, Fraser LK, Higginson IJ and Sleeman KE. Deaths at home, area-based deprivation and the effect of the Covid-19 pandemic: An analysis of mortality data across four nations. *Palliat Med* 2023; 37: 1034-1039. 20230423. DOI: 10.1177/02692163231167212.

53. Maben J, Aunger JA, Abrams R, Wright JM, Pearson M, Westbrook JI, Jones A and Mannion R. Interventions to address unprofessional behaviours between staff in acute care: what works for whom and why? A realist review. *BMC Med* 2023; 21: 403. 20231031. DOI: 10.1186/s12916-023-03102-3.

54. McFarlane P, Sleeman KE, Bunce C, Koffman J, Orlovic M, Rosling J, Bearne A, Powell M, Riley J and Drone J. Advance Care Planning and Place of Death During the COVID-19 Pandemic: A Retrospective Analysis of Routinely Collected Data. *J Patient Exp* 2023; 10: 23743735231188826. 20230730. DOI: 10.1177/23743735231188826.

55. McKenzie GAG, Johnson MJ, Lind MJ, Kelly C and Parrott S. Geriatric assessment prior to cancer treatment: A health economic evaluation. *J Geriatr Oncol* 2023; 14: 101504. 20230613. DOI: 10.1016/j.jgo.2023.101504.

56. Murphy EM and Murtagh FEM. Palliative Care in Kidney Disease In: MacLeod D and Van den Block L (eds) *Textbook of Palliative Care*. Switzerland: Springer Nature, 2023.

57. Murtagh FEM, Guo P, Firth A, Yip KM, Ramsenthaler C, Douiri A, Pinto C, Pask S, Dzingina M, Davies JM, O'Brien S, Edwards B, Groeneveld EI, Hocaoglu M, Bausewein C and Higginson IJ. A casemix classification for those receiving specialist palliative care during their last year of life across England: the C-CHANGE research programme. 2023. Southampton (UK): National Institute of Health and Care Research, UK.

58. Murtagh FEM, Okoeki M, Ukoha-Kalu BO, Khamis A, Clark J, Boland JW, Pask S, Nwulu U, Elliott-Button H, Folwell A, Harman D and Johnson MJ. A non-randomised controlled study to assess the effectiveness of a new proactive multidisciplinary care intervention for older people living with frailty. *BMC Geriatr* 2023; 23: 6. 20230105. DOI: 10.1186/s12877-023-03727-2.

59. Orlovic M, Droney J, Vickerstaff V, Rosling J, Bearne A, Powell M, Riley J, McFarlane P, Koffman J and Stone P. Accuracy of clinical predictions of prognosis at the end-of-life: evidence from routinely collected data in urgent care records. *BMC Palliat Care* 2023; 22: 51. 20230426. DOI: 10.1186/s12904-023-01155-y.
60. Paley CA, Boland JW, Santarelli M, Murtagh FEM, Ziegler L and Chapman EJ. Non-pharmacological interventions to manage psychological distress in patients living with cancer: a systematic review. *BMC Palliat Care* 2023; 22: 88. 20230706. DOI: 10.1186/s12904-023-01202-8.
61. Papworth A, Hackett J, Beresford B, Murtagh F, Weatherly H, Hinde S, Bedendo A, Walker G, Noyes J, Oddie S, Vasudevan C, Feltbower RG, Phillips B, Hain R, Subramanian G, Haynes A and Fraser LK. Regional perspectives on the coordination and delivery of paediatric end-of-life care in the UK: a qualitative study. *BMC Palliat Care* 2023; 22: 117. 20230816. DOI: 10.1186/s12904-023-01238-w.
62. Prihartadi AS, Impelliziere Licastro G, Pearson M, Johnson MJ, Lockett T and Swan F. Non-medical devices for chronic breathlessness: use, barriers and facilitators for patients, carers and clinicians - a scoping review. *BMJ Support Palliat Care* 2023; 13: e244-e253. 20231207. DOI: 10.1136/bmjspcare-2021-002962.
63. Scott HM, Braybrook D, Harethardottir D, Ellis-Smith C, Harding R and C POS. Implementation of child-centred outcome measures in routine paediatric healthcare practice: a systematic review. *Health Qual Life Outcomes* 2023; 21: 63. 20230703. DOI: 10.1186/s12955-023-02143-9.
64. Scott HM, Coombes L, Braybrook D, Roach A, Harethardottir D, Bristowe K, Ellis-Smith C, Downing J, Murtagh FE, Farsides B, Fraser LK, Bluebond-Langner M and Harding R. Spiritual, religious, and existential concerns of children and young people with life-limiting and life-threatening conditions: A qualitative interview study. *Palliat Med* 2023; 37: 856-865. 20230328. DOI: 10.1177/02692163231165101.
65. Sousa MS, Martin P, Johnson MJ, Lind M, Maddocks M, Bullock A, Agar M, Chang S, Kochovska S, Kinchin I, Morgan D, Fazekas B, Razmovski-Naumovski V, Lee JT, Itchins M, Bray V and Currow DC. Phase II, double blind, placebo controlled, multi-site study to evaluate the safety, feasibility and desirability of conducting a phase III study of anamorelin for anorexia in people with small cell lung cancer: A study protocol (LUANA trial). *PLoS One* 2023; 18: e0285850. 20230517. DOI: 10.1371/journal.pone.0285850.
66. Szinay D, Forbes CC, Busse H, DeSmet A, Smit ES and Konig LM. Is the uptake, engagement, and effectiveness of exclusively mobile interventions for the promotion of weight-related behaviors equal for all? A systematic review. *Obes Rev* 2023; 24: e13542. 20230109. DOI: 10.1111/obr.13542.
67. van der Smissen D, van Leeuwen M, Sudore RL, Koffman J, Heyland DK, van der Heide A, Rietjens JAC and Korfage IJ. Newspaper coverage of advance care planning during the COVID-19 pandemic: Content analysis. *Death Stud* 2024; 48: 33-42. 20230309. DOI: 10.1080/07481187.2023.2180693.
68. Volpato E, Farver-Vestergaard I, Brighton LJ, Peters J, Verkleij M, Hutchinson A, Heijmans M and von Leupoldt A. Nonpharmacological management of psychological distress in people with COPD. *Eur Respir Rev* 2023; 32 20230322. DOI: 10.1183/16000617.0170-2022.
69. Wang Y, Chukwusa E, Koffman J and Curcin V. Public Opinions About Palliative and End-of-Life Care During the COVID-19 Pandemic: Twitter-Based Content Analysis. *JMIR Form Res* 2023; 7: e44774. 20230807. DOI: 10.2196/44774.
70. Wilson I, Ukoha-Kalu BO, Okoeki M, Clark J, Boland JW, Pask S, Nwulu U, Elliott-Button H, Folwell A, Johnson MJ, Harman D and Murtagh FE. Experiences of a Novel Integrated Service for Older Adults at Risk of Frailty: A Qualitative Study. *J Patient Exp* 2023; 10: 23743735231199827. 20230905. DOI: 10.1177/23743735231199827.

