



WOLFSON PALLIATIVE CARE RESEARCH CENTRE

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WOLFSON PALLIATIVE
CARE RESEARCH CENTRE

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A Message from the Director

This year has seen our return to the office – albeit still in a hybrid working pattern. It has been really good to see one another again and to welcome those who have joined us during the pandemic in person, such as our new Professor, Jonathan Koffman, who has joined us from Kings College London. It is a testament to all that we have been able to maintain a sense of cohesion and group identity during this time, despite the challenges of being a sizeable group of 39 staff and post-graduates.



We were proud that our work made a significant contribution to the University's good performance in the Research Excellence Framework (REF 2021) – the UK's system for assessing the excellence of research in Higher Education. The University is one of the highest climbers – increasing its overall ranking by 17 places from 72 (REF 2014) to 55 (joint) out of 157 institutions. For research impact, the University has climbed 23 places to 42 (from joint 65th in 2014). Our work on access to palliative care for people with non-malignant disease was included as one of five impact case studies submitted to our Unit of Assessment, and has been chosen by the Medical Schools Council to be included in a document showcasing some of the highest impact case studies submitted for REF 2021.

We are weathering the research funding changes since COVID-19 well. Our income from Sept 21 to Aug 22 totalled over £10.4m, with grant income to the University of Hull totalling over £2.8m, compared with £3 million and over £750,000 respectively for the previous year Sept 20-Aug 21. We have also been able to secure extension funding for the clinical trials delayed by COVID (CANASsessment and MABEL) in a climate where many non-COVID trials have been closed prematurely. We have maintained our high publication record and been very visible at key international and national conferences by presenting our work.



Our global work is expanding, with increasing recognition and connections. We obtained our first external global funding (MRC PHIND) to work with our collaborators in India. We also look forward to progressing connections with Japan; Professor Yoshiyuki Kizawa visited us in Sept 2022. He is Director of the Department of Palliative and Supportive Care at the University of Tsukuba Hospital and Professor of Palliative Medicine at the University of Tsukuba, Faculty of Medicine. He has recently been re-elected as President of the Japanese Society for palliative medicine in Japan (>12,000 members) and has made substantial contributions to palliative care education across Japan, as well as research into advance care planning and decision-making.

We continue with our aim to support our team, helping them grow; we are particularly pleased this year that Dr Cindy Forbes, in recognition of her contribution to the University, is now on a core-funded ongoing contract. This means she can now fully develop her research group in physical activity. We are also delighted that three members (Cindy Forbes, Joseph Clark and Blessing Ukoha-Kalu) were awarded Fellowship of the Higher Education Academy in recognition of their contribution to teaching.

We look forward to seeing what another year will bring us.

Best wishes,

Miriam Johnson, Director of the Wolfson Palliative Care Research Centre

Our Purpose and Objectives

Our purpose is to deliver world-leading research to improve care and outcomes for those affected by advanced illness.

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 may be.

Research is the lifeblood of high-quality care, and we strive to deliver world-leading research which supports equitable access to, and high-quality palliative care for, all people with advanced illness and their families.

To this end, the strategic objectives of the Wolfson Palliative Care Research Centre 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 measurement of individual and service-level palliative care outcomes** and implementation of these measures into practice, including use for quality improvement and benchmarking
5. To **research the social and psychological aspects** of palliative care
6. To **advance education and research on implementation** of palliative care evidence into policy and practice

Patient, family and public involvement

We are committed to involving people affected by advanced illness, their carers, families and local communities, as active partners in informing our research questions and shaping our research. We want to make sure that people with different perspectives on and experiences of advanced illness and end of life positively influence both **what** research we undertake and **how** we undertake it.

In September 2021, the UK's National Institute for Health and Care Research published 'Next steps for partnership working with patients and the public: Engagement report' www.nihr.ac.uk/documents/next-steps-for-partnership-working-with-patients-and-the-public-engagement-report/28566 Informed by this, we are working to progress learning and sharing: cultivating spaces or networks for continued sharing and learning about partnership working and spreading ownership of the actions: enabling the wider public partnerships community to take action.

Building and sustaining research capacity

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

Our year at a glance 2021-22

Our team:



5 Senior Academics
17 Research Fellows, Associates and Assistants
4 Administrative staff

Capacity building:

13 postgraduate students (PhD and MSc)



6 Clinical Academic training posts
17 medical students, and interns for electives or research projects

Our outputs:
87 peer-reviewed outputs

28 international conference presentations (oral)



15 students completed the Implementation module

Research grants:

Leading & collaborating on grants > £10.4m
WPCRC grant income > £2.8m

Our year at a glance 2020-21

Our team:



4 Senior Academics
17 Research Fellows, Associates and Assistants
2 Administrative staff

Capacity building:

15 postgraduate students (PhD and MSc)



Our outputs:
91 peer-reviewed papers

16 international conference presentations (oral)



5 Clinical Academic training posts, 23 medical students, and interns for electives or research projects, 19 students on the Implementation module

Research grants:

Leading & collaborating on grants > £3m
WPCRC grant income > £750k

Patient and Public Involvement

Figure 1: Spotlight on Patient and Public Involvement 1



Alex Wray, one of our PhD Students, has been working with children with experience of the bereavement of one parent, and their bereaved surviving parent, to understand and recommend how both groups can be better supported. She has worked with bereaved children and parents to plan this study and has been guided by them in analysing and interpreting her in-depth interviews, about their needs, support received, and what is most helpful. Using the rich data from her interviews, she has co-constructed – with PPI partners - the themes and findings.

Families involved in the study were very keen to contribute. They wanted to help make a difference and have their stories heard. The findings have helped them find meaning in their own experiences and others to gain insight into their experiences. As one parent said: *"Probably the only good thing that can come out of my bereavement is helping others by lessening their isolation through increased understanding of such experiences"* (Parent). Children also valued the chance to help other children and being able to talk about grief simply and openly without it being perceived to be a 'difficult' subject. Some of the co-constructed findings are:

When a parent dies, their world comes crashing down around them. Parents go on autopilot, focusing on getting through each day, worrying about the impact of the death and making their children their priority. But they often feel they are 'winging it', supporting their children with no guidance. They expected a professional would automatically support them, but this did not happen. Instead, many faced difficulties accessing professional support. ***"Dealing with your child who's grieving, I had no idea whatsoever, it was really difficult. And then you are feeling bad about that, so it's grieving, grieving for her, and then feeling bad thinking; am I doing a good job here; am I scarring her for life even more; and that was just really difficult."*** (Parent).

Children wanted to talk about their loss but did not know how and were scared of the response they may receive. ***"I used to be sort of scared to tell people what happened because I thought they would treat me differently, and I definitely am still scared to tell people"*** (Child).

Our society now encourages parents to show their emotions - so children know it's ok to be sad - but children struggled to see their surviving parent's grief, so parents have to learn to control their grief. ***"I think it frightened her to see me cry. So, what I realised was, I needed to find a way of managing my grief"*** (Parent). Children are stepping up to support their remaining parent; they have had to grow up perhaps too fast, filling roles within the family and developing their emotional maturity rapidly.

Both children and parents found bereavement alienating; it made people uncomfortable and affected their relationships with others. As a result, they would mask their grief and pretend they were ok, through fear of the reactions they would receive, not wanting to make others uncomfortable, and a feeling that their grief was a burden to others. ***"...there's putting the mask on, 100% everyone, I think everyone who grieves does it. Mum does it."*** (Child).

Unless they have experienced it themselves, the people around did not understand the impact, unpredictability, or longevity of grief which meant support quickly dwindled, and there was an expectation for participants to 'move on'. These findings have great potential to change practice, to shape good bereavement support to become the standard, and to open avenues for further research.

Figure 2: Spotlight on Patient and Public Involvement 2



The Better End of Life programme

We look at the current state of dying, death and bereavement in the UK, and at how to ensure that everyone has the best possible end of life experience.

The Better End of Life programme, funded by Marie Curie, and conducted jointly with King’s College London and the University of Cambridge, publishes our next report in October 2022, titled:

“Mind the gaps: understanding and improving out-of-hours care for people with advanced illness and their informal carers”.

We have worked collaboratively with a group of PPI partners throughout the Better End of Life Programme, to shape and inform the research. However, for this forthcoming report, we – together with PPI partners – decided to do some additional work.

Therefore, in May 2022, a PPI workshop was held with an independent facilitator, to consider all of the research findings which inform the report, to share how these did (or did not) reflect the experiences of PPI participants in the workshop, to consider what insights their experiences added to our understanding of out-of-hours care, how this related to the research findings, and how to incorporate these perspectives into the report.

As a result of this work, the report contains a section called **‘The people’s perspectives’**, written by PPI partners themselves, and based on the workshop outputs. This section describes some of their lived experiences of out-of-hours care. It resonates strongly with – and reflects on - the collated research findings and provides clear recommendations which add considerably to the report.

It remains to be seen how this approach will be received by the stakeholders for whom the report is intended, but we found this approach really added a new dimension. It helped bring to life the ‘facts and figures’ of the report, delivering better insights, and ‘painting the picture’ of how lives are adversely affected by limitations and constraints in out-of-hours care. As one PPI partner said: ***“It is delays and lack of resources that gives the carer so much anxiety, so much worry and so much stress. When you want care, you want it now; tomorrow or next week is no good.”***

The report recommendations include how out-of-hours care for those in the last months or days of life needs to be better valued, prioritised and strengthened. We underline the need to strategically develop, enable, and support greater integration and coordination of out-of-hours services. However, it is the **‘people’s perspectives’** which bring the report to life and add the extra impact of showing how our research findings affect real people and their families.

Our Team

The WPCRC team: This year, we were delighted to welcome our new Professor of Palliative Care – Professor Jonathan Koffman - to join the WPCRC team. This new professorial post could not have been achieved without outstanding support from the University, especially from Professor Una Macleod (Dean of HYMS) and our Faculty Dean, Professor Paul Hagan.



Jonathan brings a particular interest in researching the interface between ethnicity, culture and palliative care, as well as studying clinical uncertainty and how it manifests in end-of-life care. He has an excellent track record of undertaking high-quality research on the development and evaluation of complex interventions using mixed methods research. He has qualifications in Social Administration and Sociology, and undertook a PhD in Cancer Studies, before going on to develop a programme of work on disadvantaged dying and clinical uncertainty at the Cicely Saunders Institute at King's College London. He also led the governance and development of postgraduate programmes as Postgraduate Dean for Taught Studies at King's.

Since Jonathan's appointment in April 2022, our senior faculty now comprises three Professors (plus excellent ongoing support from Professor Liz Walker), one Reader, and one Senior Lecturer. We also have two Fellows with ongoing contracts, one of whom is now core-funded.

In addition, we have eleven Research Fellows/Associates and two Research Assistants on fixed-term contracts, one Research Facilitator/Research Nurse, four administrative staff, and one clinician providing project support. In training posts, we now have twelve PhD students, and one MSc student, with a further five PhD students co-supervised (either within or beyond the University). **In total, including our staff and students, the WPCRC team now consists of 39 people.**

Capacity building: In addition to our own twelve PhD students, and one MSc student, fifteen students completed our Implementation Science for Advanced and Chronic Care over this last year. Four Academic Foundation doctors, and two medical Academic Clinical Fellows have undertaken research with WPCRC. Seventeen medical students or interns completed electives, internships, INSPIRE or other projects with us. In the past year, two PhDs have been awarded within our group: to Dr Gillian Jackson, on "CAMERA – a feasibility study (complete assessment of elderly cancer patients)", and to Dr Mary Kariuki, on "How does the health status of older migrants compare to the Canadian and Australian-born population?" Both Dr Andy Gill and Dr Kitty Jackson successfully achieved their MScs, on public perceptions of palliative care, and delirium guidelines, respectively. Warm congratulations to them all!

New staff and students: We have had new staff join us: Ciaran McNaughton, as Research Associate on the NHIR RfPB REMOTE-GO study; Ahmed Mohamed, as Research Associate across both the MABEL trial & Better End of Life Programme; Gertrude Nyaaba working as Research Fellow on the RESOLVE programme; Blessing Ukoha-Kalu as Research Associate studying frailty in the PACE study; and Marianne Gilchrist as Research Administrator for the CANAssess trial and REMOTE-GO studies. Two new PhD students have also recently joined us – both funded through the I3 project - Mary Kimani and Mark Kitching.

Leaving: As Jonathan arrived, Professor David Currow stepped down from his 20% substantive commitment to the University of Hull due to his appointment as Deputy Vice-Chancellor (Health and Sustainable Futures)

at Wollongong University, Australia. We are delighted that he retains an honorary appointment with us, and remains on our Board. He continues to be a highly valued mentor to many within the WPCRC.

Dr Andy Bradshaw left to go to a new post at King’s College London. Dr Andy Gill has been appointed Consultant in Community and Hospital Palliative Medicine at York and Scarborough Teaching Hospitals NHS Trust; he commenced his post there in April 2022 but continues with WPCRC as an Honorary Senior Lecturer. In May 2022 Sunitha Daniels commenced her post as Lead Consultant Palliative Medicine at York and Scarborough Hospitals NHS Trust; she too will be working closely with WPCRC as an Honorary Senior Lecturer. Dr Jamilla Hussain left us to start as Consultant Palliative Physician at Bradford NHS Trust in March 2022, with one day per week dedicated research time. Although leaving WPCRC, she too will maintain her links with us as an Honorary Senior Lecturer.

Examples of our Awards, Achievements, and Impact

Over the last year, the team achieved a number of prizes, awards, and contributed to a diverse range of events to maximise our knowledge transfer and impact. We report just some of the highlights of our year here.

Prizes and awards

Three of our staff – Cindy Forbes, Joseph Clark, and Blessing Onyinye Ukoha-Kalu - achieved the status of **Fellow (FHEA)** in recognition of attainment against the UK Professional Standards Framework for teaching and learning support in higher education, Advance HE.

Dr Ann Hutchinson has received the following prizes for her continuing work: best Knowledge Exchange poster, **University of Hull Knowledge Exchange Conference 2022**, and best infographic on Prevalence of breathlessness, **Dyspnea 2022**

Alex Wray was awarded a prize for one of the top 10 video presentations of the final value proposition and findings at the **Innovate UK-funded PreCURE Programme**. PreCURE is a 7-week sprint programme for postgraduate researchers, providing a structured way to consider potential benefits and beneficiaries of their research and the value of the work.

Dr Kitty Jackson - one of our NIHR Academic Clinical Fellows - was awarded First Place Oral Presentation for Academic Clinical Fellow at the **Hull York Medical School Integrated Academic Training Programme Highlights** conference in May 2022. This presentation was on her MSc research - Implementation and Evaluation of Palliative Care Inpatient Unit’s Delirium Guidelines: A Service Improvement Project.



This year, Dr Cindy Forbes has been recognised for her research endeavours and was awarded **Faculty of Health Sciences, Developing Researcher of the Year 2022**. Cindy was successful in April 2022 in winning £1.1 million from Yorkshire Cancer Research to conduct a clinical trial to assess the impact of personalised, home-based exercise programmes for people with lung, bowel or breast cancer. This was one of the successes which contributed to her award.



Sunitha Daniel was awarded first place in the **Best Paper Category for the HYMS Dorothy Robson Prize in Palliative Medicine** for the year 2021, title: “I don’t talk about my distress to others; I feel that I have to suffer my problems ...” Voices of Indian women with breast cancer: a qualitative interview study. Sunitha has submitted her PhD thesis which has been awarded, subject to corrections, title: Evaluation of Suffering and Distress in Breast Cancer Patients of Indian Origin Undergoing Treatment.

New roles

Dr Alison Bravington has commenced the role of Associate on the People and Patient Participation, Involvement and Engagement (PoPPiE) working group for the COMET Initiative (Core Outcome Measures in Effectiveness Trials).

Prof Liz Walker - Associate Director of WPRCRC – has begun a secondment as the University Lead for Research Development.

Alex Wray has become Chair and Facilitator of the Dawn Bereavement Support Group, Hull University Teaching Hospitals NHS Trust and Chair of the Hull Child Bereavement Advisory Group.

Prof Fliss Murtagh will be stepping down as Lead for Integrated Academic Training at Hull York Medical School but will be stepping up to become Research Lead for the Applied Health Research in Cancer, Primary Care, Palliative Care group within the Faculty of Health Sciences.

Invitations



Prof Fliss Murtagh is delighted to be invited as a keynote speaker for the [McGill International Congress on Palliative Care](#), in Montréal, 18 to 21 October 2022. The congress is the longest-running palliative care congress in the field. Founded in 1976 by Dr Balfour Mount and colleagues, it brings together over 1,500 delegates from more than 65 countries to participate. It is very interdisciplinary; every other year physicians, researchers, nurses, psychologists, social workers, pharmacists, music therapists, art therapists, physical therapists and volunteers gather from around the globe to learn together.

Prof Jonathan Koffman has been invited to present a keynote lecture at the Association of Palliative Care Social Workers Conference in Sept 2022, on “Multi-cultural needs at the end of life in the age of George Floyd”.

Conferences



In November 2021 and June 2022, we held two more Creating Connections Palliative Care Conferences, following on from our first of these conferences last year. These are jointly organised conferences between our [Wolfson Palliative Care Research Centre](#) , and the [Centre for Improving Palliative, Aged and Chronic Care through Clinical Research and Translation \(IMPACCT\)](#) at the University Of Technology Sydney. These conferences provide an opportunity to showcase some of the exciting and leading-edge research being undertaken as part of our collaboration funded by Research England's International Investment Initiative (i3). The I3 programme builds on the established partnership between our research centres.

The University of Technology Sydney took the lead in organising the (online) conference on 3 November 2021, and we took the lead in organising the (hybrid) conference on 28 June 2022.

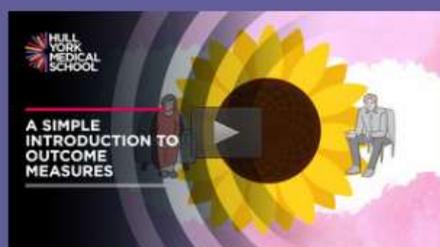
Both were very successful with very good feedback. All the latest presentations are available to view [here](#).

Training resources for clinicians

As part of the RESOLVE project, we have continued to create RESOLVE study training resources - online tools comprising instructional videos and learning materials, which have been designed to support Palliative Care professionals looking for guidance and support in the use and implementation of Outcome Measures, allowing them to assess and monitor changes in the wellbeing of their patients over time.

We have added new videos, and a 'simple introduction' at the request of stakeholders, along with a range of additional supporting resources (see below and www.hyms.ac.uk/resolve).

A simple introduction to Outcome Measures

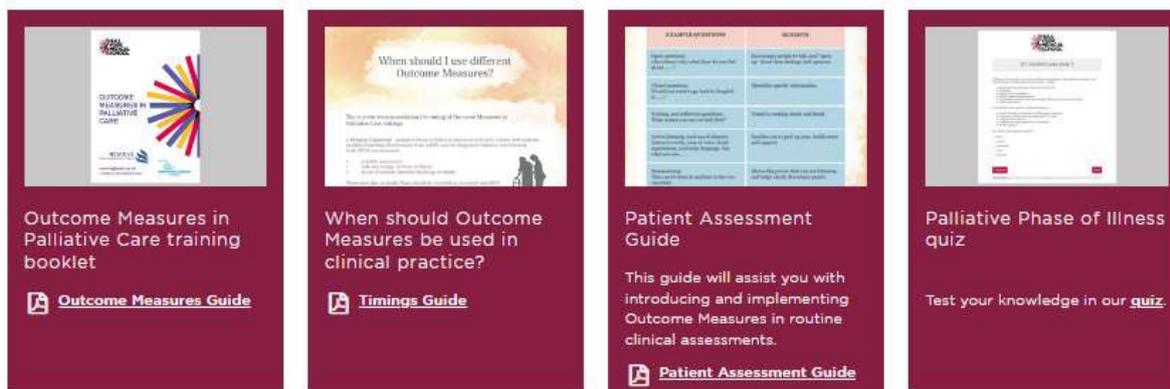


Watch this video to find out:

- What are Outcome Measures?
- Why do we need them?
- How and where are they used?
- How can they help you to support your patients?

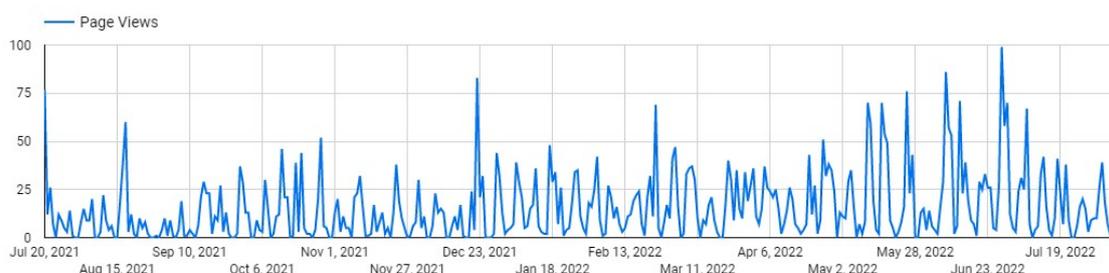
 [Video transcript](#)

Supporting resources



The application of these tools has been part of an ongoing monitoring and evaluation process involving the RESOLVE team, in collaboration with participating site staff, and healthcare professionals in the wider community. Development of the tools has been inspired by learning experience and feedback gathered during the delivery of site teaching sessions, promotional workshops, and via local and external meetings. In addition, assessment of online access and use of the tools are measured on a national and international level via Google Analytics data studio dashboards, which were created for the study by the University of Hull Communications team.

These training videos and other resources are continuing to be very popular; there have been over 10,000 page views (compared with 4,000 last year), and > 2,000 downloads of supporting training materials. Views and downloads increase after workshops, conferences, and other events; we can map activity on the webpage to follow this and assess our impact. During the past year (July 2021-July 2022) we can also see that users from countries other than the United Kingdom included: Australia, Brazil, Canada, Columbia, Finland, France, Germany, Greece, Italy, Japan, New Zealand, Philippines, Portugal, Spain, Sweden, and the United States of America.



The RESOLVE team also gratefully acknowledge feedback on the use of the tools, along with requests for access by palliative care staff from across the UK. Feedback is excellent, for example: *“We have been viewing your resources and training videos which are excellent and we will be using them as part of our staff training [for everyone].”*

Exhibition



Our Breathlessness website (<https://breathlessness.hyms.ac.uk/>) continues to extend the impact of the range of work we undertake on this neglected symptom. Impact includes:

- The 'Bringing Breathlessness Into View' Exhibition continues to be very well received, and now includes a blog site - 5,790 total page views, the blog has had 3,062 views of 12 posts since March 2020.
- A guide to living well with breathlessness – 1,454 total page views and the guide has been downloaded 788 times.

The exhibition has appeared at various conferences over the last year (including EAPC 2022, Dyspnea 2022, Only Connect 2022, European Respiratory Society World Congress 2022, and Humber Business Week 2022) and has formed the basis for a number of clinician workshops including Respiratory Teaching Day for Scottish Palliative Care Physicians and the Mini short course on Breathlessness at the Summer BTS 2022.

These webpages contributed to the [University of Hull's narrative report](#) for the Knowledge Exchange Framework 2021. Ann Hutchinson, our Research Fellow in Palliative Care (breathlessness), has also contributed to the webpages of the [British Lung Foundation](#) and of the [British Heart Foundation](#) on this topic.

Inspired by the exhibition, Hull City Council have just included a page on breathlessness; [how-to-live-well-with-breathlessness](#).

Stemming from her public engagement, knowledge exchange and research impact activities, Ann has recently become the Knowledge Exchange Lead for Wolfson. This year, Ann ran a masterclass on Knowledge exchange, gave updates at team meetings and met with three groups of researchers to support them in their KE activities. She presented her Knowledge Exchange work in both poster and Pecha Kucha format at the University of Hull's Knowledge Exchange conference in 2022.

The work of Ann Hutchinson in public engagement, knowledge exchange and research impact has led to an application by her to the Arts and Humanities Research Council for a Research, Development and Engagement Fellowship. This is entitled "Giving voice to breathlessness: Using arts in scientific approaches to express the experience of breathlessness in educational and clinical settings". Ann has also created the popular blog <https://hospitalsenses.co.uk/bringing-breathlessness-into-view/>.



Grant Income

New grants achieved between Sept 2021 and Aug 2022

Since September 2021, we have had a very successful year. WPCRC team members have led or collaborated on thirteen successful bids which together total over £10.4m, with grant income to the University of Hull totalling over £2.8m. (compared with £3 million and over £750,000 for the previous year, Sept 20-Aug 21). We have secured extension funding for the clinical trials delayed by COVID (CANASsessment and MABEL). In addition, we have three submitted bids awaiting outcome, and five more bids in preparation.

The new grants awarded since Sept 2021 (WPCRC investigators underlined) are:

1. NIHR Health Services and Delivery Research. Identifying interventions which are effective in supporting health care workers better respond to unprofessional behaviours: a realist synthesis. Maben, Mannion, Jones, Westbrook, Wright, Pearson, Abrams. Total award: £274,801 (award to University of Hull £8,479). 1st Oct 2021 – 31st Mar 2023.
2. European Commission. SERENITY: Towards cancer patient empowerment for optimal use of antithrombotic therapy at the end of life. Pearson, Johnson, Murtagh, Greenley, Maraveyas, and European colleagues. Total award €5,999,771 (approx. £4,952,871) (award to University of Hull £182,375). 1 April 2022 – 31 Mar 2027.
3. NIHR. The Yorkshire & Humber Palliative Care Research Network: Addressing Inequalities Across All Ages. Murtagh, Ziegler, Farrin, Fraser, O’Cathain, Johnson, Pearson et al. Total award £99,933 (award to University of Hull £99,933). 1 Mar 2022 – 31 Aug 2023.
4. Subcontracted work for the NIHR project: Real-world Implementation and Evaluation of an AI decision support software (ArtiQSpiro) into primary care respiratory diagnostic pathways. Hutchinson. Total £8,385 (award to University of Hull £8,385). 1 Dec 2021 – 30 Nov 2022.
5. Yorkshire Cancer Research. A phase II, randomised feasibility trial of a tailored, home-based exercise programme on disease-free survival among early-stage high-risk recurring cancers in Yorkshire. Forbes, Cohen, Lind, Saxton, Mitchell, Huang, Young, Twiddy, Pearson, Wilson. Total award: £1,072,014 (award to University of Hull £921,709). 1 May 2022 – 30 Apr 2026.
6. Yorkshire Cancer Research – Endowment Hull. Forbes (PI), Bullock, Curry, Darby, Swan, Lind, Johnson. (2021-2023). CANcer BEhavioural nutrition and exercise feasibility trial (CanBenefit) among older adults with lung cancer. Total award: £120,356 (award to University of Hull £120,356). 1 Sep 2021 - 30 Jun 2023.
7. NIHR RfPB. ENHANCE: Adapting a smartphone-based rehabilitation programme for older adults living with and beyond cancer: a development study using Intervention Mapping. Forbes, Cohen, Huang, Lind, Maddison, Pearson, Rastorn, Swan, Twiddy, Johnson. Total award: £149,317 (award to University of Hull £148,317). 1 Mar 2022 – 31 Aug 2023.

8. NIHR PGfAR. Primary Breathe: programme to develop and test a brief remote primary care intervention for chronic breathlessness. Spathis, Mant, Morris, Sutton, Booth, Lovick, Prevost, Higginson, Maddocks, Reilly, Armstrong, Evans, Farquhar, Johnson, Reeve, Pearson. Total award: £2,416,792 (award to University of Hull £168,530). 1 Apr 2022 – 31 Mar 2027.
9. Social Finance. Research Consultancy. Murtagh, total award: £12,339 (award to University of Hull £12,339). 1st Jan 2022 – 31st Dec 2022.
10. NIHR HSDR. Supporting, enabling, and sustaining home care workers to deliver end-of-life care: a multiple-methods community-based case study. Co-PIs Johnson & Walker, Wray, White, Bravington, Pearson, Taylor, Roberts, Manthorpe, Hussain. Total award: £745,610 (award to University of Hull £584,641) 1 Jun 2022 - 30 Nov 2024.
11. NIHR RfPB. The role of ethnicity in opioid prescribing and health service use in the last three months of life: a population-based comparative cohort study of cancer patients. Koffman, Barclay, Kumar, Bajwah, Chukwusa. Total award: £164,962 (award to University of Hull £164,962) 01 Jun 22 – 31 May 23.
12. Medical Research Council. BREATHE-INDIA: BREATHIEssness in INDIA - Development of a breathlessness beliefs and behaviour education intervention for use in the community-setting [BREATHE-INDIA]. Johnson, Clark, Pearson. Total award: £142,357 (award to University of Hull £109,723) 01 Oct 22 – 31 Mar24.
13. THIS Institute. Values and value-based healthcare: what do these mean in advanced illness? Murtagh, Koffman. Total award: £217,924 (award to University of Hull £217,924) 01 Jan 2023 – 31 Dec 2025.

Some Highlights of our Research Projects

We currently have sixty research projects ongoing or in write up. This research is diverse, across the whole spectrum of applied and clinical health research. It includes experimental designs (randomised controlled trials), quasi-experimental designs, cohort studies, cross-sectional studies, secondary analyses of existing large datasets, qualitative designs, and mixed methods. We spotlight here just two examples of our research in the next pages.

Figure 3: Spotlight on the PACE study – evaluating a novel service for older people living with frailty

In 2018, we were asked to assess the effectiveness of a new, anticipatory, multidisciplinary care service set up in Hull for older people living with severe frailty.



We therefore set up – in partnership with the clinical team and funded by Hull Clinical Commissioning Group - a non-randomised controlled study. We compared those receiving the new integrated care service plus usual care, to a matched sample of people receiving

usual care alone. We collected data from participants on both their well-being and quality of life; at baseline, at 2-4 weeks (primary outcome), and again at 10-14 weeks (to check whether any effect was sustained, and to ensure no worsening of wellbeing or quality of life). We found that well-being notably improved in the intervention group but worsened in the control group, while quality of life improved slightly in the intervention group but was unchanged in the control group. Benefit was sustained at 10-14 weeks. In addition, we surveyed participants receiving the new service about their experience of care. Almost all participants commended the service for its person-centred and integrated approach, as well as the excellent level of communication and care provided by the staff. This novel service was experienced very positively by recipients, but they did also want to see the service integrated even more with other health and social care services, and to extend the follow-up received. Both the trial findings and the results from the experience survey are submitted for publication.

We were able to successfully recruit these older people living with frailty due to their willingness to contribute, and the outstanding support of the Jean Bishop Integrated Care Centre staff. We also learnt a lot about the optimum outcome measures for a trial of this type; quality of life – so commonly used – was less revealing, but wellbeing (i.e. symptoms and other concerns) showed marked improvement following the intervention, which was sustained over three months.

Figure 4: Spotlight on the EPOC Study - Exploring Pathways to Optimise Care in Malignant Bowel Obstruction

This study – funded by Yorkshire Cancer Research – is currently exploring what is known about decision-making and its potential outcomes along current treatment pathways for malignant bowel obstruction. It is also developing theory-driven interventions to support better shared decision-making between patients, caregivers and clinicians.

Fifteen per cent of people with cancer experience malignant bowel obstruction (MBO). This prevents eating and drinking, and causes distressing symptoms, including pain, intense nausea and distressing vomiting, needing urgent management. Various management options are available, from surgery or stenting to less invasive methods such as medication or tube-drainage of intestinal contents, yet little is known about how management decisions are made. Every patient's situation is unique, making clinical decision-making difficult. Where surgery is not an option, a range of other treatments can be used to ameliorate symptoms, but there are currently no nationally agreed guidelines and practice varies widely across the UK. Our research has shown that patients feel burdened with and distressed by uncertainties and conflicting clinical advice about the best treatment.

The study involves three phases.

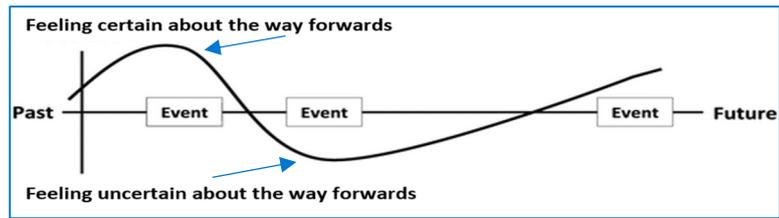
Phase 1: Realist review and stakeholder consultation. This will synthesise what limited evidence there is and explore how decision-making about treatment for MBO is shared between clinicians, patients, and informal caregivers. The aim is to produce a preliminary model of MBO shared decision-making, which can then be refined.

Phase 2: Qualitative in-depth interviews with patients, informal caregivers, and professionals. These interviews will examine how decision-making happens in practice, using novel visual methods to explore care networks and timelines.



We will explore networks of care using Pictor – a graphic elicitation technique in which people are asked to write the roles of everyone involved in an episode of care on to sticky arrows and arrange the arrows in a way which tells the story of their care, using the direction of the arrows to say something about the qualities of social interaction. For patients, this makes it easier to explain what happens to them when seen by multiple professionals. For practitioners, it can focus the interview to relate to a specific patient or critical event.

We will also use ‘timelining’ – mapping the occurrence of symptoms and/or episodes of clinical care along a visual timeline – which can help patients, informal caregivers and practitioners to talk about multiple and complex decision-making events, and provide a ‘bird’s eye’ view to make comparisons over time or, in the case of practitioners, across cases.



Phase 3: Intervention development. The findings of the review and interview study will be synthesised to inform and develop the model of patient-centred decision-making in MBO, using face-to-face workshops with patients, informal caregivers and clinicians. The workshops will use theory-driven co-design techniques to develop interventions to support shared and/or patient-centred decision-making in MBO management and pinpoint modes of delivery.

Our Outputs

In addition to some of the wider impact of the WPCRC work described earlier, we have published 87 outputs over the past year – the majority are papers in peer-reviewed journal. This is a similar number to last year (when we published 91 outputs), although the proportion of peer-reviewed papers is higher. Over the last year, we have also successfully achieved an increased number of accepted oral and posters presentations at various national and international conferences, such as the World Congress of the European Association for Palliative Care, the Palliative Care Congress, the European Respiratory Society Congress, diverse other international/national conferences, and of course our University conferences, such as the Hull York Medical School Postgraduate Conference (see page 8 for details). You can see the full details of all papers and presentations in the Appendix.

We have also held two highly successful I3 Creating Connections Palliative Care Conferences, with our partners at University of Technology in Sydney (see page 8 for details).



In October 2021, Prof Fliss Murtagh was Chair of the Scientific Committee for the 17th World Congress of the European Association for Palliative Care in October 2021. This was an online conference because of the pandemic, but was highly successful, with excellent delegate feedback.



Working with the EAPC Congress team and a diverse international Scientific Committee, Fliss was able to ensure a range of high-quality plenaries, parallel sessions, and open sessions was provided. This gave the opportunities to challenge and advance scientific thinking in the sector, and improve awareness of evidence for clinical practice. As one delegate reported: *“An amazing Congress, plenty of highlights and real food for thought”*. Sincere thanks to the

wonderful Scientific Committee and EAPC team.

Appendix

All peer reviewed publications Sept 2021 – Aug 2022

1. Agar MR, Siddiqi N, Hosie A, Boland JW, Johnson MJ, Featherstone I, et al. Outcomes and measures of delirium interventional studies in palliative care to inform a core outcome set: A systematic review. *Palliat Med* 2021; 35: 1761-1775. 2021/08/28. DOI: 10.1177/02692163211040186.
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All conference abstracts and presentations Sept 2021 – Aug 2022

World Congress of the European Association of Palliative Care, online October 2021

Oral presentations (with presenting author):

- Dr Mabel Okoeki. Title: Experiences of a novel Integrated Care Service for older adults at risk of severe frailty: An analysis of survey and interview data.
- Dr Assem Khamis/Prof Fliss Murtagh. Title: Demonstrating the impact of palliative care: a secondary analysis of routinely-collected person-centred outcomes data among hospice community patients.
- Dr Christina Ramsenthaler. Title: Concurrent validity and prognostic utility of the Needs Assessment Tool: Progressive Disease – Heart Failure
- Dr Jamilla Hussain. Title: Guidelines to Reduce, Handle and Report Missing Data in Palliative Care Trials Co-produced Using a Multi-stakeholder Nominal Group Technique.

Poster presentations (with presenting author):

- Dr Joseph Clark. Title: Worldwide Estimated Morphine Need for Pain in Advanced Cancer: Proportions Feasibly Met by Country Estimated Requirements and Consumption. Retrospective, Longitudinal Cross-sectional Study (1997-2017)”
- Su de Wolf Linder. Title: Cultural adaptation of the Integrated Palliative Care Outcome Scale for Dementia (IPOS-Dem) for the Swiss context: a focus-group interview study with relatives, district nurses, and acute care nurses.
- Dr Assem Khamis. Title: Demonstrating the impact of palliative care: a secondary analysis of routinely-collected person-centred outcomes data among hospice inpatients.
- Dr Jamilla Hussain. Title: Performance Status and Site-level Factors Are Associated with Missing Data in Palliative Care Trials: An Individual Participant-level Data Analysis of 10 Phase 3 Trials.
- Sophie Pask. Title: “Prevalence and patterns of opioids currently prescribed in community-dwelling older adults living with frailty”
- Dr Alison Bravington. Title: Exploring conditions that Render Patients too Unwell to Participate: Challenges from the RAMBO Study
- Dr Alison Bravington. Title: Patient and Clinician experiences of Inoperable Malignant Bowel Obstruction: A Qualitative Study
- Dr Alison Bravington. Title: Development of a core outcome set for the research and assessment of inoperable malignant bowel obstruction
- Dr Andy Gill. Title: The Effect of Culture, Socioeconomic Status and Health Literacy on Public Perceptions of Palliative Care and the Impact on Access: A Systematic Review and Critical Interpretive Synthesis.
- Helene Elliott-Button. Title: The Prevalence of Chronic Breathlessness and Associated Psychological Symptoms in a Frail, Elderly Population within a Community Setting: A Cross-Sectional Survey.

Presentations (Parallel Session)

Improving Care for People Unable to Self-report: The Role of Person-Centred Proxy-Reported Assessment Measures

- Su de Wolf-Linder. Title: Using Structured, Person-Centred Measures for People with Dementia Unable to Self-Report to Identify and Meet Palliative Care Needs: Reflections from Empowering Better End of Life Dementia Care.

Opioids for Chronic Breathlessness – Practical Evidence-Based Prescribing

- Professor Miriam Johnson. Title: What Do We Know, What Don't We Know

Swiss National Palliative Care Congress 2021

Oral (with presenting author)

- Su de Wolf-Linder. Title: Kulturelle Adaption der Integrierten Palliative Care Outcome Skala Demenze an die Primarversorgung

I3 Creating Connections Conference November 2021

Oral Presentation (with presenting author):

- Alex Bullock. Title: Detection and assessment of malnutrition, sarcopenia, and cachexia in older adults with cancer (from chapters four and seven)
- Prof Liz Walker. Key note speaker: Title: Pathways to social impact for palliative care research
- Jordan Curry. Title: Do E-health solutions widen socioeconomic and age inequity in palliative care?

European Delirium Association Conference November 2021

Oral Presentations (with presenting author):

- Dr Kitty Jackson. Title: Implementation and evaluation of a palliative care inpatient unit's delirium guidelines: a service improvement project.

NCRI Festival: Making Cancer Research Better Together 2021

Poster presentation (with presenting author)

- Jordan Curry. Title: Feasibility, acceptability, and efficacy of online supportive care for individuals living with and beyond lung cancer: a systematic review.

World Congress of the European Association of Palliative Care May 2022

Oral presentations (with presenting author):

- Dr Ann Hutchinson. Title: A feasibility cluster randomised controlled trial of a paramedic-administered breathlessness management intervention for acute-on-chronic breathlessness (BREATHE): Study findings.

Poster presentations (with presenting author):

- Dr Kitty Jackson. Title: Implementation and evaluation of a palliative care inpatient unit's delirium guidelines: a service improvement project.

- Helene Elliott-Button. Title: The prevalence of chronic breathlessness and associated psychological symptoms in a frail, elderly population within primary care: a cross-sectional survey within the Proactive Anticipatory Service Evaluation (PACE).
- Su de Wolf-Linder. Title: Separated by a Common Language – Cognitive Interview Study on the Integrated Palliative Care Outcome Scale for People with Dementia (Ipos-Dem) in the Acute And District Nurse/Community Care Setting.

Palliative Care Conference 2022

Poster presentations (with presenting author):

- Dr Kitty Jackson. Title: Implementation and evaluation of a palliative care inpatient unit's delirium guidelines: a service improvement project.

Multinational Association of Supportive Care in Cancer 2022

Oral presentations (with presenting author)

- Alex Bullock. Title: Mixed-methods observational study explaining malnutrition, sarcopenia, and cachexia in older adults with cancer

Joint Webinar: Cancer Prevention and Management SIG of ISBNPA, UK Society of Behavioural Medicine Cancer SIG, Physical Activity SIG of the Society of Behavioural Medicine April 2022

Oral presentation (with presenting author):

- Alex Bullock. Title: Is there a digital divide? A systematic review of mobile interventions for weight-related behaviours.

I3 Creating Connections Conference June 2022

Oral Presentations (with presenting author):

- Dr Flavia Swan. Title: "Prescribing" the hand-held fan and mobility aids in practice; a systematic review
- Dr Gillian Jackson. Title: DAMPEN-D; does a delirium implementation strategy improve delirium care in hospices? – a feasibility study

University of Hull Annual Postgraduate Research Conference 2022

Oral presentations (with presenting author):

- Michael Patterson: Inoperable Malignant Bowel Obstruction – Palliative interventions Outcomes : Mixed-methods systematic review.

Poster presentations (with presenting author):

- Alex Wray: Parental death, support experiences and needs for children and surviving parents: a systematic review
- Su de Wolf Linder: Person-centred outcome guided palliative care for people with Dementia: SENIORS-D Study.

Dyspnea Conference July 2022

Oral Lightening Round Presentation (with presenting author)

- Dr Flavia Swan, Joshua Brown, Isobel Miller, Matilda MM Barnes-Harris, Miriam J Johnson, Mark Pearson, Tim Lockett. Title: The handheld fan in clinical practice: Clinicians' experiences and views of barriers and facilitators to implementation
- Prof Miriam Johnson presented on behalf of Dr Ann Hutchinson. Title: A feasibility cluster randomised controlled trial of a paramedic-administered breathlessness management intervention for acute-on-chronic breathlessness (BREATHE): Study findings.

Poster presentation (with presenting author):

- Kate Binnie. Title: Body-Mind interventions for breathlessness-related distress and emotion regulation in advanced disease: a realist review.
- Dr Flavia Swan, Joshua Brown, Isobel Miller, Matilda MM Barnes-Harris, Miriam J Johnson, Mark Pearson, Tim Lockett. Title: The handheld fan in clinical practice: Clinicians' experiences and views of barriers and facilitators to implementation.
- Gamze Keser, Ann Hutchinson, Daisy Janssen, Miriam J Johnson and Flavia Swan. The implementation of the handheld fan in clinical practice; a survey of clinicians' experience and barriers and facilitators to use

6th International Clinical Trials Methodology Conference 2022

Poster presentation:

- McNaught, E., Clark, J., Johnson, M., Day, F., Wright-Hughes, A., Marsden, L., Shillito, T., Foy, R., McCormack, T., Wilkes, S., Dickson, J., Farrin, A.J. Title: Comparing two different models of Research Nurse deployment to a multi-centre clinical trial in primary care: experiences from the CANAssess2 Trial.

Society on Sarcopenia, Cachexia and Wasting Disorders – Lisbon, Portugal 2022

Poster presentation (with presenting author)

- Alex Bullock. Title: Prevalence and overlap of malnutrition, sarcopenia, and cachexia in hospitalised older adults with cancer: a cross-sectional study.

999 EMS Research Forum 2022 (online)

Oral presentation (with presenting author)

- Dr Ann Hutchinson. Title: A feasibility cluster randomised controlled trial of a paramedic-administered breathlessness management intervention for acute-on-chronic breathlessness (BREATHE): Study findings.

Annual Meeting of the International Society for Behavioural Nutrition and Physical Activity

Oral presentation (with presenting author)

- Dr Cindy Forbes. Title: Mixed-methods exploration of how cancer survivors use smartphone and wearable devices to support physical activity management: A GetAMoveOn Study.

- Dr Cindy Forbes. Title: Examining the usability of a web-based tailored physical activity intervention for those living with and beyond lung cancer (ExerciseGuide UK).

Invited Workshops

- Dr Mark Pearson. Title: Prevention, recognition and management of delirium: What works and how to put it into practice. Hospice UK (online 93 participants) November 2021
- Dr Mark Pearson. Title: The management of breathlessness - putting evidence into practice in palliative care. Hospice UK (online, 142 participants) June 2022

Invited Conference Presentations

- Dr Mark Pearson. Title: How can Implementation Science inform Palliative Care? Improving Palliative, Aged and Chronic Care through Clinical Research and Translation. (IMPACCT) seminar, University of Technology Sydney July 2022.
- Dr Mark Pearson. Title: Emerging findings from the DAMPen-Delirium co-design and feasibility study: Improving the Detection, Assessment, Management, and Prevention of Delirium in Hospices. University of Notre Dame Australia seminar, Sydney, Australia July 2022

VUB UGent End of Life Care Research Group and the Public Health at the End of Life Research Group of the Amsterdam UMC, June 2022

Oral presentation (with presenting author):

- Prof Jonathan Koffman. Title: Known unknowns and Unknowns unknowns Eight lessons from a feasibility cluster RCT of the hospital based intervention to service patients who situations are clinical uncertain.

European Respiratory Society: ERS International Congress 2022. Sept 2022, Barcelona, Spain.

- Thematic Poster. Extended-release morphine for chronic breathlessness in COPD: a randomized controlled trial with blinded uptitration over three weeks Diana Ferreira (Adelaide (SA), Australia), Magnus Ekström, Sungwon Chang, Sandra Louw, Miriam Johnson, Danny Eckert, Belinda Fazekas, Katherine Clark, Meera Agar, David Currow
- Thematic Poster. COPD patients' experiences and understanding of exacerbations: a qualitative study Michael Crooks (East Riding of Yorkshire, United Kingdom), Richard Russell, Helena Cummings, Kay Roy, Omar Usmani, Judith Cohen, Sarah Macfadyan, Tamsin Morris, Hana Mullerova, Yang Xu, Ann Hutchinson
- Thematic Poster. The language COPD patients use to describe exacerbations: a qualitative study Michael Crooks (East Riding of Yorkshire, United Kingdom), Richard Russell, Helena Cummings, Kay Roy, Omar Usmani, Sarah Macfadyan, Judith Cohen, Tamsin Morris, Hana Mullerova, Yang Xu, Ann Hutchinson
- Thematic Poster. The effect of airflow from a hand-held fan on breathlessness recovery from submaximal exercise. S. O'Beirne, A. Brew, M. Johnson, C. Ramsenthaler, P. Watson, U. Adia, P. Rubini, M. Fagan, F. Swan, A. Simpson