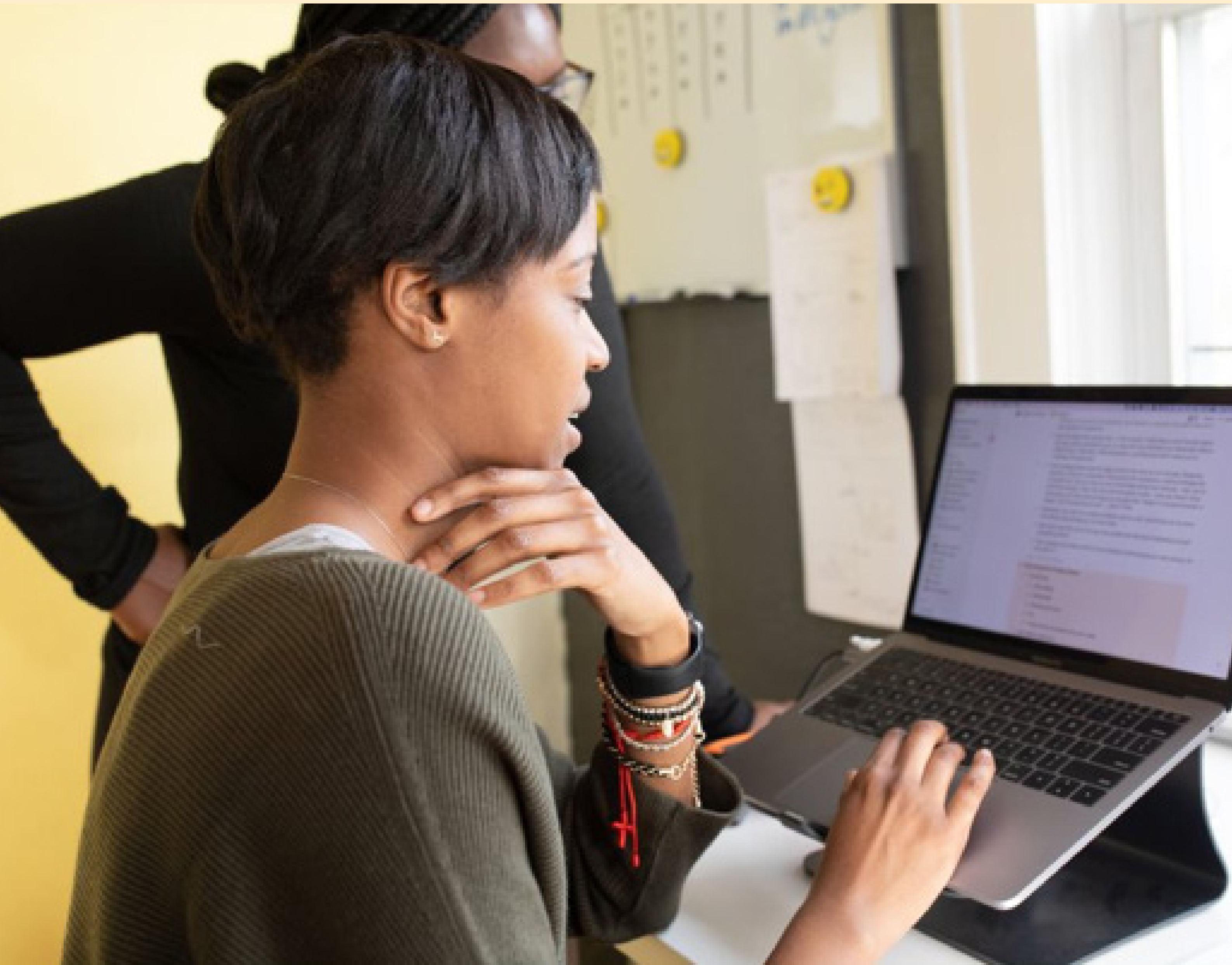
NIHR | Applied Research Collaboration South London

Progress in Palliative and End of Life Care

September
2022



Contents

This ARC South London Palliative and End of Life Care Research Theme aims to improve palliative and end-of-life care for communities in South London and elsewhere, through research and close working with patients and carers.
This report sets out the short-term objectives set by the theme and includes work on the response to the Covid-19 pandemic.

Short-term objective 1: Understaning clusers of multimorbidity

Short-term objective 2: Embedding outcome measures into practice

Short-term objective 3: Developing and evaluating models of care

Short-term objective 4: Work responding to the covid-19 pandemic

Short-term objective 1: Understand clusters of multimorbidity, their geographical variation, relationships to health, social care and costs

In order to understand prevalence of multimorbidity clusters in people with lung cancer, we conducted a population-trend based analysis (Henson LA, Chukwusa E, Ng Yin Ling C, et al.,2021). Using population-level data over a 17-year (2001 – 2017) period for England, we explored trend patterns over time in six most common comorbidities (chronic respiratory disease; diabetes; cardiovascular disease; dementia; cerebrovascular disease and chronic kidney diseases). We found that the proportion of patients with comorbidities increased over time between 2001 and 2017. The numbers of deceased patients with 1 comorbidity increased 54%, while those with two or more comorbidities increased 294%. This work underscores the importance of collaborative working across traditional boundaries of care.

In our ongoing research on geographical variation and health care use, we have examined regional differences in the association between geographic access to inpatient hospice and hospice deaths, using routinely collected records of patients aged ≥ 25 years (n=123,088) who died from non-accidental causes in 2014 (Chukwusa et al., 2020). We found huge geographic variations in access hospices across regions, with a marked north-south differential. Excerpts of this work recently featured in the European Association of Palliative Care (EAPC) blog: “Where You die Where You Live” (Chukwusa and Taylor., 2020) Our findings suggest evidence of geographical inequities of hospice service provision across various regions in the UK. Therefore, understanding the geography of hospice provision could be a key enabler of palliative and end-of-life care service planning, thereby reducing geographic inequities in hospice service provision.

We conducted a systematic review (Wilson R, Hepgul N, Higginson IJ et al., 2019) to understand and assess the empirical evidence describing end-of-life care and place of death for people with serious mental illness. The review found sparse evidence of studies reporting health service use for people with serious mental illness. To fill the knowledge gap, we subsequently conducted a secondary analysis (Wilson R, Gaughran F et al., 2021) using a retrospective cohort of adults with serious mental disorders in South London who died between 2007 and 2015. The study aimed to understand patterns of acute care service use in this patient group. Results of this study showed that patients with comorbidities are more likely to use more burdensome acute health care at the end of life, and are more likely to die in the hospital. Motivated by the findings from our secondary analysis, we expanded our analyses by using nationwide mental health and ONS data linkage to understand factors associated with end-of-life health service use for patients with serious mental illness data. Early findings from this work were presented at the European Psychiatry Congress (Chukwusa, Wilson R et al., 2021). The findings suggest wide regional variations in hospitalisations amongst patients with serious mental illness.

We have begun to make progress in understanding the impact of multimorbidity on service use at the end of life, and the costs associated with this. In one of our adopted projects we explored care costs at the end of life using data from 3 cities in three countries (England (London), Ireland (Dublin) and the United States (New York, San Francisco)). This work focused on older patients with complex needs

(Yi D, Johnston BM et al, 2020). Results indicate that older age (>80 years), facing financial difficulties and poor experiences of home care were the main predictors of high-cost use at the end of life. In addition, we conducted further study to determine and compare informal care costs and their associations with self-reported caregiver burden, rewards, and subsequent caregiver grief. This was part of the International, Access, Rights, and Empowerment (IARE I) study of palliative care in three countries, taking care quality as reported by informal carers into account (Higginson, I.J., Yi, D., Johnston, B.M. et al, 2020). We found that costs to informal carers are larger than those to formal care services for people in the last three months of life.

Publications from core project:

Chukwusa, E., Wilson, R., Gaughran, F., & Wei, G. (2021). Multiple hospitalisations towards the end of life among patients with serious mental illness: A retrospective cohort study in England, UK. European Psychiatry, 64(S1) S399-S399. doi:10.1192/j.eurpsy.2021.1069

Chukwusa, E., Yu, P., Verne, J., Taylor, R., Higginson, I. J., & Wei, G. (2020). Regional variations in geographic access to inpatient hospices and Place of death: A Population-based study in England, UK. PLoS ONE, 15(4), e0231666. [e0231666]. https://doi.org/10.1371/journal.pone.0231666

Henson LA, Chukwusa E, Ng Yin Ling C, et al. Lung cancer deaths (England 2001–2017) comorbidities: a national population-based analysis BMJ Supportive & Palliative Care Published Online First: 06 September 2021. doi: 10.1136/bmjspcare-2021-003107 https://spcare.bmj.com/content/early/2021/09/06/bmjspcare-2021-003107

Higginson IJ, Yi D, Johnston BM, Ryan K, McQuillan R, Selman L, Pantilat SZ, Daveson BA, Morrison RS, Normand C. Associations between informal care costs, care quality, carer rewards, burden and subsequent grief: the international, access, rights and empowerment mortality follow-back study of the last 3 months of life (IARE I study). BMC Med. 2020 Nov 3;18(1):344. PMID: 33138826 Free PMC article. https://doi.org/10.1186/s12916-020-01768-7

Gao W, Gulliford M, Morgan M, Higginson IJ. Primary care service use by end-of-life cancer patients: a nationwide population-based cohort study in the United Kingdom. BMC Fam Pract. 2020;21(1):76. https://doi.org/10.1186/s12875-020-01127-8

Johnson H, Davies JM, Leniz J, Chukwusa E, Markham S, Sleeman KE. Opportunities for public involvement in big data research in palliative and end-of-life care. *Palliative Medicine*. 2021;35(9)1724-1726. doi:10.1177/02692163211002101

Wilson R, Hepgul N, Higginson IJ, Gao W. End-of-life care and place of death in adults with serious mental illness: A systematic review and narrative synthesis. Palliat Med. 2020;34(1):49-68. doi: 10.1177/0269216319867847. Epub 2019 Oct 14.

R. Wilson, F. Gaughran, T. Whitburn, I.J. Higginson, W. Gao, Acute care utilisation towards the end of life and the place of death for patients with serious mental disorders: a register-based cohort study in South London, Public Health, 2021;194:79-85 ISSN 0033-3506, https://doi.org/10.1016/j.puhe.2021.02.032.

Publications from adopted projects:

Fettes L, Neo J, Ashford S, Higginson I J, Maddocks M. Trajectories of disability in activities of daily living in advanced cancer or respiratory disease: a systematic review. Disability and Rehabilitation (2020): 1-12. https://doi.org/10.1080/09638288.2020.1820587

Yi D, Johnston BM, Ryan K, Daveson BA, Meier DE, Smith M, McQuillan R, Selman L, Pantilat SZ, Normand C, Morrison RS, Higginson IJ. Drivers of care costs and quality in the last 3 months of life among older people receiving palliative care: A multinational mortality follow-back survey across England, Ireland and the United States. Palliat Med. 2020 Feb 3:269216319896745. [Epub ahead of print] https://doi.org/10.1177/0269216319896745

Successful grant applications:

- General practice service use towards end-of-life among patients who died before and during the Covid-19 pandemic: a nationwide cohort study using the Clinical Practice Research Data. Higginson. I, Chukwusa. E, Barclay. S, Tausig. J, Verne. J, Martin. G,
  Awarded by the NIHR: £99,744.00: Duration: 01-03-2021 to 31-04-2022

- An NIHR RfPB grant investigating 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. J, Chukwusa. E, Bajwah. S, Barclay. S, Kumar. R, £149,966.00.
  This is a collaboration between South London ARC and ARC East of England & Yorkshire and Humber.

Short-term objective 2: Expand our existing collaborative into a PEoLC Outcomes Action Collaborative (OAC) embedding outcome measurement into practice, including social care settings

We have been supporting implementation of outcome measurement into practice across health and social care settings through launching of an Outcomes Action Collaborative (OAC). Since its launch in February 2020 we have mobilized local, national, and international partnerships. These partnerships support efforts of all clinicians and carers involved in the care of seriously ill persons, to respond to local and national challenges. OAC was launched in the presence of more than 200 delegates and stakeholders from all across the UK, and from international settings such as from Australia, Cyprus, Denmark, Germany, Ireland, Japan, Myanmar, Malaysia, Sweden, Switzerland, Singapore, Taiwan, United Arab Emirates. During this event we addressed outcome measurement in clinical and research settings and scenarios, the POS family of measures, their integration, administration, scoring and interpretation in routine practice, as well as in demonstrating the effects of service.

In March 2021, we have organised the OAC Event 2021 titled ‘Current Concepts and New Directions in Measurement’ as part of Outcomes Action Collaborative (https://pos-pal.org/maix/courses-and-workshops.php). More than 77 delegates attended the half-day RCP accredited virtual event, where we covered the background, challenges and opportunities of patient-centred measurement in clinical practice and research. Locally, we have joined the Patient Outcomes Committee (POC) of the King’s College Hospital NHS Foundation Trust. This allows us to lead on the implementation of King’s Health Partner’s strategic objectives in South London, relating to the development of high-quality services based on excellent clinical outcomes and outcomes that matter most to patients. We are also part of a forum for effective governance of Patient Reported Outcome Measures across KHP. We are participating in the ‘Big Room’ initiative led by KCH Continuous Quality Improvement (CQI) Team. Big Rooms are the foundation of the Flow Coach Academy methodology, and they are set to be a forum where clinical and non- clinical staff work collaboratively and develop a shared purpose to continuously improve patient care, patient-centred outcomes and experience.

In our ongoing efforts of expanding outcome measurement in wider practice and across populations, we have been working with the Respiratory Department on Chronic Obstructive Pulmonary Disease (COPD) Score card development. We have validated Palliative Outcome Scale in Turkish-speaking populations (Hocaoglu, MB et al 2020) and developed a protocol for cross-cultural adaptation of measures (Mis, C et al 2021) and published (Higginson, IJ and Hocaoglu MB, 2021) a chapter on "Clinical audit, quality improvement and safety in Palliative Medicine" in the The Oxford Textbook of Palliative Medicine 6th Edition, outlining the most effective use of patient reported outcomes in audits. With a Fulbright Visiting Scholar Fellowship award based at Harvard Medical School, we will work with US researchers to expand the existing collaborative into an international (UK-Cyprus-USA) Palliative and End of Life care Outcomes Action Collaborative (OAC), embedding outcome measurement into practice, including social care settings to work collectively towards developing and evaluating models of palliative and end of life care spanning health and social care, focused on multimorbidity to improve decision-making, care and outcomes.

We have made substantial progress in embedding measurement-specific populations such as in Dementia, Children and Covid-19. In an MRC funded project (CovPall) on the role and response of palliative care during the pandemic, in a large cohort of severely ill and dying patients, we developed and implemented a proxy-reported patient-centred Covid-19 specific measure (IPOS-COV) to understand the prevalence and trajectory of symptoms, treatments received and their effectiveness. In an EAPC Blog (Higginson IJ and Hocaoglu MB) we presented the preliminary findings from the project. Analysis of patient outcomes based on IPOS-COV showed that the cohort of 572 patients who were severely ill with Covid-19 deteriorated very quickly. Within 48 hours of the first assessment, more than 50% of the patients referred had died. Differences in symptom severity between final and initial assessments, captured with IPOS-COV, shows improvement of symptoms such as breathlessness, pain and anxiety in patients seen by palliative care teams, which provides insights into the role of palliative care that may have been missed otherwise.

EMBED-Care, one of our key adopted projects, has made progress on co-designing patient-centred intervention based on Dementia specific patient outcome measure (IPOS-Dem); we have also completed four co-design workshops for this project. A second key adopted project, CPOS, drafted the CPOS measure, obtained HRA approval and we began data collection for cognitive testing of the tool and published a systematic review on optimal participation methods to support children and young people's self-report of their symptoms.

We have shown the importance of patient outcomes and the necessity of their integration to practice and quality assessment for patients, their families and the public. In a PPIE consultation for CovPall-Connect, six dedicated Cicely Saunders Institute members, as well as 10 further representatives from the HDR UK Voices extended network collaborated and presented findings. The outcome of this consultation emphasized the importance of care as being Person-centred (making adjustments for patient characteristics, understanding patient preferences), and capturing Quality of Care. Quality of Care can be measured by the extent to which it is integrated, and the mechanisms that are in place for shared healthcare records and communication between professionals and the patient. This supports patients' perception and experience of good quality care.

We have made progress towards demonstrating the feasibility of integrating outcome measures into clinical decision-making pathways (Sandham et al 2022). We have used machine learning and network analysis in order to identify changes in key symptoms captured by Palliative Outcome Scale, such as pain or loss of appetite. This helped us identify patients who deteriorated or became unstable.

Publications from Core Project

Antunes B, Rodrigues PP, Higginson IJ, Ferreira PL. Determining the prevalence of palliative needs and exploring screening accuracy of depression and anxiety items of the integrated palliative care outcome scale – a multi- centre study. BMC Palliat Care. 2020 May 14;19(1) https://doi.org/10.1186/s12904-020-00571-8

Bajwah S, Koffman J, Hussain J, Bradshaw A, Hocaoglu MB, Fraser LK, Oluyase A, Allwin C, Dunleavy L, Preston N, Cripps R, Maddocks M, Sleeman KE, Higginson IJ, Walshe C, Murtagh FEM; CovPall study team.Specialist palliative care services response to ethnic minority groups with Covid-19: equal but inequitable-an observational study.BMJ Support Palliat Care. 2021 Sep 12:bmjspcare-2021-003083. doi: 10.1136/bmjspcare-2021-003083

Bradshaw A, Dunleavy L, Walshe C, Preston N, Cripps RL, Hocaoglu M, Bajwah S, Maddocks M, Oluyase AO, Sleeman K, Higginson IJ, Fraser L, Murtagh F; CovPall study team.Understanding and addressing challenges for advance care planning in the Covid-19 pandemic: An analysis of the UK CovPall survey data from specialist palliative care services.Palliat Med. 2021 Jul;35(7):1225-1237 https://doi.org/10.1177/02692163211017387

Dunleavy L, Preston N, Bajwah S, Bradshaw A, Cripps R, Fraser LK, Maddocks M, Hocaoglu M, Murtagh FE, Oluyase AO, Sleeman KE, Higginson IJ, Walshe C. Necessity is the mother of invention': Specialist palliative care service innovation and practice change in response to Covid-19. Results from a multinational survey (CovPall).Palliat Med. 2021 May;35(5):814-829. https://doi.org/10.1177/02692163211000660

Higginson IJ, Brooks D, Barclay S. Dying at home during the pandemic.BMJ. 2021 Jun 8; 373: n1437 https://doi.org/10.1136/bmj.n1437

Higginson, IJ and Hocaoglu, MB. (2021). Clinical audit, quality improvement and safety in Palliative Medicine. Cherny NI, Fallon MT, Kaasa S, Portenoy RK, Currow DC (eds) The Oxford Textbook of Palliative Medicine 6th Edition. Oxford. OUP. Doi: 10.1093/med/9780198821328.003.0127

Hocaoglu, M.B., Hepgul, N., Tunnard, I. et al. Towards patient-centred cancer care: cross-cultural validity and responsiveness of the Turkish Integrated Palliative care Outcome Scale. Health Qual Life Outcomes 2020;18:312 https://doi.org/10.1186/s12955-020-01535-5.

Mis C, Kofali G, Swift B, Yalcin Bahat P, Senocak G, Taneri B, Hummelshoj L, Missmer SA, Becker CM, Zondervan KT, Yuksel Ozgor B, Oral E, Inceboz U, Hocaoglu MB and Rahmioglu N (2021) Protocol for the Cultural Translation and Adaptation of the World Endometriosis Research Foundation Endometriosis Phenome and Biobanking Harmonization Project Endometriosis Participant Questionnaire (EPHect). Front. Glob. Womens Health 2:644609. doi: 10.3389/fgwh.2021.644609

Oluyase AO, Hocaoglu M, Cripps RL, Maddocks M, Walshe C, Fraser LK, Preston N, Dunleavy L, Bradshaw A, Murtagh FEM, Bajwah S, Sleeman KE, Higginson IJ; CovPall study team.The Challenges of Caring for People Dying From Covid-19: A Multinational, Observational Study (CovPall).J Pain Symptom Manage. 2021 Sep;62(3):460-470 https://doi.org/10.1016/j.jpainsymman.2021.01.138

Sandham M, Hedgecock EA, Siegert R, Narayanan A, Hocaoglu MB, Higginson I. Intelligent Palliative Care Based on Patient-Reported Outcome Measures. J Pain Symptom Manage. 2022 Jan 10:S0885-3924(21)00641-2. doi: 10.1016/j.jpainsymman.2021.11.008

Publications from Adopted Projects:

Bone AE., Evans CJ., Henson LA., Etkind SN., Higginson IJ. Influences on emergency department attendance among frail older people with deteriorating health: a multicentre prospective cohort study. Public Health. 2021 May;194:4-10. Epub 2021 Apr 6. PMID: 33836318. https://doi.org/10.1016/j.puhe.2021.02.031

Coombes, L., Bristowe, K., Ellis-Smith, C. et al. Enhancing validity, reliability and participation in self-reported health outcome measurement for children and young people: a systematic review of recall period, response scale format, and administration modality. Qual Life Res 30, 1803–1832 (2021). https://doi.org/10.1007/s11136-021-02814-4

Hodiamont F, Hock H, Ellis-Smith C, Evans C, de Wolf-Linder S, Jünger S, Diehl-Schmid J, Burner-Fritsch I, Bausewein C. Culture in the spotlight-cultural adaptation and content validity of the integrated palliative care outcome scale for dementia: A cognitive interview study. Palliat Med. 2021 Apr 16:2692163211004403. doi: 10.1177/02692163211004403. Epub ahead of print. PMID: 33863246. Link

Leniz J, Higginson IJ, Yi D, Ul-Haq Z, Lucas A, Sleeman KE. Identification of palliative care needs among people with dementia and its association with acute hospital care and community service use at the end-of-life: A retrospective cohort study using linked primary, community and secondary care data. Palliat Med. 2021 Oct;35(9):1691-1700. https://doi.org/10.1177/02692163211019897

O'Donnell SB, Bone AE, Finucane AM, McAleese J, Higginson IJ, Barclay S, Sleeman KE, Murtagh FE. Changes in mortality patterns and place of death during the Covid-19 pandemic: A descriptive analysis of mortality data across four nations. Palliat Med. 2021 Aug 23:2692163211040981
https://doi.org/10.1177/02692163211040981

Oluyase AO, Higginson IJ, Yi D, Gao W, Evans CJ, Grande G, Todd C, Costantini M, Murtagh FEM, Bajwah S. Hospital-based specialist palliative care compared with usual care for adults with advanced illness and their caregivers: a systematic review.Southampton (UK): NIHR Journals Library; 2021 May.
doi: 10.3310/hsdr09120

Sleeman, K.E., Timms, A., Gillam, J. et al. Priorities and opportunities for palliative and end of life care in United Kingdom health policies: a national documentary analysis. BMC Palliat Care 2021(20)108. https://doi.org/10.1186/s12904-021-00802-6

Yorganci, E, Sampson, EL, Gillam, J, et al. Quality indicators for dementia and older people nearing the end of life: A systematic review. J Am Geriatr Soc. 2021;1- 11.
https://doi.org/10.1111/jgs.17387

Successful grant applications:

- CovPall: Rapid evaluation of the Covid-19 pandemic response in palliative and end of life care: national delivery, workforce and symptom management
  MRC Medical Research Council
  Higginson, I., Bajwah, S., Maddocks, M., Sleeman, K., Oluyase, A., Hocaoglu, M.
  £194,134.86
  20/04/2020 to 19/04/2021

- CovPall-Connect Study: Evaluation of how palliative and end of life care teams have responded to Covid-19: Connecting to boost impact and data assets.
  Health Data Research UK (HDR UK)
  Higginson, I., Fraser L, Sleeman, K., Cripps R, Oluyase, A., Hocaoglu, M.
  £49,994.00
  07/01/2021 to 31/11/2022

- Towards a global collaborative to address challenges of health and social care in the age of multiple long-term conditions: Understanding the role of patient reported outcomes in capturing comorbidities, complexity and health and social care costs.
  Hosting Institution:
  Harvard Medical School, Department of Global Health & Social Medicine (PS0032583)
  $17550
  25/03/22 – 25/07/2022

Short-term objective 3: Developing and evaluating models of care

Our **third short-term objective** was to develop and evaluate models of palliative and end of life care spanning health and social care, focussed on multimorbidity to improve decision-making, care, and outcomes.

We have developed and evaluated new models of care to support people with palliative and end-of-life care needs, particularly in populations where multimorbidity is common. Drawing on learning from a substantial synthesis of evidence to identify common elements of service delivery models for people with advanced progressive conditions (Bayly 2021), our research suggests we should look to proactively integrate holistic, multidimensional approaches to care, involving palliative and geriatric experts, earlier in the trajectory of the patients' condition(s).

For example, we have demonstrated the feasibility of a newly developed short-term integrated palliative rehabilitation intervention for people newly diagnosed with thoracic cancer (Bayly et al. 2020). This inclusive intervention has the potential to address a variety of functional needs and overcome known barriers to rehabilitation in this population. A grant has since been awarded by the European Commission Horizon 2021 programme to progress with testing the clinical and cost-effectiveness of this approach across 5 European countries (see below).

Alongside this work, through a qualitative interview study (Brighton et al. 2020a) and a realist review (Brighton et al 2020b), our team developed and are currently feasibility testing a new approach to pulmonary rehabilitation for people with COPD and frailty that incorporates Comprehensive Geriatric Assessment alongside current best practice (Brighton et al 2021). In addition to informing future testing of clinical and cost effectiveness, our work in relation to frailty in respiratory disease has been recognised through funds to lead both an American Thoracic Society workshop report on rehabilitation for people with respiratory disease and frailty, and a European Respiratory Society statement on frailty in respiratory disease.

Evidence syntheses and primary research from our adopted projects continue to expand knowledge of optimal models of palliative and end of life care into a range of populations where multimorbidity is common, including interstitial lung disease (Bajwah et al. 2021), heart failure (Beattie et al. 2020), neurological conditions (Gao et al. 2020, Turner-Stokes et al. 2020, Oliver et al. 2020) and dementia (Evans et al. 2020, Sampson et al. 2019). To support the development and evaluation of these new models of integrated care, our teams have also advanced the science of developing testing complex interventions in palliative and end of life care. Examples include: a new multi-method approach to understanding usual care in trials of complex interventions (Yorganci et al., 2020), illustrating how person-centred research methods like home visits, support with questionnaire completion, and involvement of informal carers support people with advanced disease to fully participate in a drug trial (Lovell et al., 2020), and demonstrating why building and maintaining relationships, working flexibly, and involving those with the most relevant experience are particularly important for meaningful public involvement in palliative care research (Johnson et al., 2020).

Publications from core projects:

Bayly J, Bone A, Ellis-Smith C, Tunnard I, Yaqub S, Yi D, Nkhoma KB, Cook A, Combes S, Bajwah S, Harding R, Nicholson C, Normand C, Ahuja S, Turrillas P, Kizawa Y, Morita T, Nishiyama N, Tsuneto S, Ong P, Higginson IJ, Evans CJ, Maddocks M. Common elements of service delivery models that optimise quality of life and health service use among older people with advanced progressive conditions: a tertiary systematic review BMJ Open 2021;11:e048417. doi: 10.1136/bmjopen-2020-048417

Bayly, J, Fettes, L, Douglas, E, Teixiera, M J, Peat, N, Tunnard, I, … Maddocks, M (2020). Short-term integrated rehabilitation for people with newly diagnosed thoracic cancer: a multi-centre randomized controlled feasibility trial. Clinical Rehabilitation, 34(2), 205–219 https://doi.org/10.1177/0269215519888794

Brighton LJ, Bristowe K, Bayly J, Ogden M, Farquhar M, Evans CJ, Man WD, Maddocks M. Experiences of pulmonary rehabilitation in people living with COPD and frailty: a qualitative interview study. Annals of the American Thoracic Society. 2020a Jul 9. https://doi.org/10.1513/AnnalsATS.201910-800OC

Brighton LJ, Evans CJ, Man WD, Maddocks M. Improving Exercise-Based Interventions for People Living with Both COPD and Frailty: A Realist Review. International Journal of Chronic Obstructive Pulmonary Disease. 2020b;15:841. doi: 10.2147/COPD.S238680

Brighton LJ, Bone AE, Maddocks M. Supportive and palliative care for people with chronic respiratory disease and frailty. Current Opinion in Supportive and Palliative Care. 2020 Sep 1;14(3):206-12. doi: 10.1097/SPC.0000000000000523

Brighton LJ, Evans CJ, Farquhar M, Bristowe K, Kata A, Higman J, Ogden M, Nolan

C, Yi D, Gao W, Koulopoulou M. Integrating Comprehensive Geriatric Assessment for people with COPD and frailty starting pulmonary rehabilitation: the Breathe Plus feasibility trial protocol. ERJ Open Research. 2021 Jan 1;7(1).
doi: 10.1183/23120541.00717-2020

Successful funding applications:

- Rehabilitation for people with respiratory disease and frailty: an ATS Workshop
  Report.
  Awarded by American Thoracic Society.
  Maddocks M, Osadnik CR, Brighton LJ, Man W, Singer J, Burtin C, Lahousse L, Marengoni A, ter Beek L, Cesari M, Harrison S, Lee AM, Franssen F, Evans R, Probst V.
  $1488.
  2021.

- ERS Taskforce: frailty in adults with chronic lung disease.
  Awarded by European Respiratory Society.
  Osadnik CR, Maddocks M, Brighton LJ, Burtin C, Cesari M, Lahousse L, Man WDC, Marengoni A, Singer J, ter Beek L.
  €5,800.
  2020.

Publications from adopted projects:

Models of palliative and end of life care in populations with multiple longterm conditions

Bajwah S, Colquitt J, Loveman E, Bausewein C, Almond H, Oluyase A, Dzingina M, Maddocks M, Higginson IJ, Wells A. Pharmacological and nonpharmacological interventions to improve symptom control, functional exercise capacity and quality of life in interstitial lung disease: an evidence synthesis. ERJ Open Res. 2021 Jan 25;7(1):00107-2020. PMID: 33532482; PMCID: PMC7836673.
doi: 10.1183/23120541.00107-2020.

Beattie JM, Higginson IJ, McDonagh TA. Palliative Care in Acute Heart Failure. Curr Heart Fail Rep. 2020 Dec;17(6):424-437. Epub 2020 Oct 29. PMID: 33123954; PMCID: PMC7683469.
doi: 10.1007/s11897-020-00494-8.

Etkind SN, Lovell N, Bone AE, Guo P, Nicholson C, Murtagh FEM, Higginson IJ. The stability of care preferences following acute illness: a mixed methods prospective cohort study of frail older people. BMC Geriatrics. (2020) 20:370.
https://doi.org/10.1186/s12877-020-01725-2

Evans CJ and Sampson EL ‘Evaluating methods for optimal integration in frailty and dementia: a system-based logic model for Empowering Better End of life Dementia Care (EMBED-Care)’ Palliative Medicine, 2020, 34(1): INV14: pp 8-9
Link

Gao W, Wilson R, Hepgul N, Yi D, Evans C, Bajwah S, Crosby V, Wilcock A, Lindsay F, Byrne A, Young C, Groves K, Smith C, Burman R, Chaudhuri KR, Silber E, Higginson IJ; OPTCARE Neuro Trial Investigators. Effect of Short-term Integrated Palliative Care on Patient-Reported Outcomes Among Patients Severely Affected With Long-term Neurological Conditions: A Randomized Clinical Trial. JAMA Netw Open. 2020 Aug 3;3(8):e2015061. doi: 10.1001/jamanetworkopen.2020.15061

Oliver D, Borasio GD, Veronese S, Voltz R, Lorenzl S, Hepgul N. Current collaboration between palliative care and neurology: a survey of clinicians in Europe. BMJ Support Palliat Care. 2020 Jul 10:bmjspcare-2020-002322.. Epub ahead of print. PMID: 32651190. http://dx.doi.org/10.1136/bmjspcare-2020-002322

Sampson EL, Anderson J, Candy B, Davies N, Ellis-Smith C, Gola A, Harding R, Kenten C, Kupeli N, Mead S, Moore KJ, Omar RZ, Sleeman K, Stewart R, Ward J, Warren J, Evans CJ. EMBED-Care: Empowering Better End-of-life Dementia Care. A mixed methods protocol to achieve integrated person-centred care across settings. International Journal of Geriatric Society 2020 Aug;35(8):820-832. https://doi.org/10.1002/gps.5251

Taylor R, Ellis J, Gao W, Searle L, Heaps K, Davies R, Hawksworth C, Garcia-Perez A, Colclough G, Walker S, Wee B. A scoping review of initiatives to reduce inappropriate or non-beneficial hospital admissions and bed days in people nearing the end of their life: much innovation but limited supporting evidence. BMC palliative care. 2020 Dec;19(1):1-25. https://doi.org/10.1186/s12904-020-0526-2

Taylor R, Ellis J, Gao W, Searle L, Heaps K, Davies R, Hawksworth C, GarciaKOFFMAN J, Yorganci E, Yi D-H, Gao W, Murtagh FE, Pickles A, Barclay S, Johnson H, Wilson R, Sampson L, Droney J, Farquhar M, Prevost T, Evans C., Managing uncertain recovery for patients nearing the end of life in hospital; a mixed-method, feasibility cluster randomised controlled trial of the AMBER care bundle, BMC Trials Aug 2019 20:506 https://doi.org/10.1186/s13063-019-3612-0

Turner-Stokes L, Harding R, Yu P, Dzingina M, Gao W. Cost-efficiency of specialist inpatient rehabilitation for adults with multiple sclerosis: A multicentre prospective cohort analysis of the UK Rehabilitation Outcomes Collaborative national clinical dataset for rehabilitation centres in England. Mult Scler J Exp Transl Clin. 2020 Mar 16;6(1):2055217320912789.. eCollection 2020 Jan-Mar. https://doi.org/10.1177%2F2055217320912789

Research methods for complex trials in multiple longterm conditions’

Johnson H, Ogden M, Brighton LJ, Etkind SN, Oluyase AO, Chukwusa E, Yu P, de Wolf-Linder S, Smith P, Bailey S, Koffman J. Patient and public involvement in palliative care research: What works, and why? A qualitative evaluation. Palliative Medicine. 2020 Sep 11:0269216320956819. https://doi.org/10.1177%2F0269216320956819

Lovell N, Etkind SN, Bajwah S, Maddocks M, Higginson IJ. What influenced people with chronic or refractory breathlessness and advanced disease to take part and remain in a drug trial? A qualitative study. Trials. Feb 2020;21(1):21 https://doi.org/10.1186/s13063-020-4129-2

Yorganci E, Evans C, Johnson H, Barclay S, Murtagh F, Yi D, Gao W, Pickles A, Koffman J. Understanding usual care in randomised controlled trials of complex interventions: A multi-method approach Palliative Medicine. 2020;34(5):667-679. https://doi.org/10.1177%2F0269216320905064

Short-term objective 4: Use the results from objectives 1-3 to launch national PEoLC collaborations and trials, including a national ARC Collaborative. Linking with ARC social care, public health, informatics and implementation themes to increase impact.

Using the findings from our short-term objectives and through our role as joint National Leads for Palliative and End of Life Care, we have been able to launch and facilitate new local, national and international collaborations that work across multiple disciplines and ARC themes. These include:

Successful funding awards:

- A newly funded NIHR Research Partnership on Functional Loss and Rehabilitation towards the end of life, in collaboration with teams across London, Nottingham, Edinburgh, Lancashire, East Anglia, and Leeds
- A successful NIHR programme grant to develop and test a brief remote primary care intervention for chronic breathlessness (‘PrimaryBreathe’) in collaboration with colleagues from ARC East of England
- International multi-centre trial of a short-term palliative rehabilitation intervention to in collaboration with partners across 5 countries (UK, Norway, Denmark, France, Italy).

Collaborative research proposals underway:

- A cross-theme proposal spanning the palliative care and social care themes wto address loneliness in people with chronic breathlessness

Collaborations bridging research and practice:

- Creation of patient-facing information on managing breathlessness at home during the Covid-19 pandemic with colleagues from London, Hull, Cambridge and East Anglia, disseminated in collaboration with King’s Health Partners and the European Lung Foundation
- Joint working with NHS Improvement in delivering our integrated community palliative partnership project
- Join working with NHS England Breathlessness Working Group to produce an implementation framework for breathlessness support services and clinical training via a British Thoracic Society mini-symposium on breathlessness management.

To support these ongoing collaborations, members of our theme have also led collaborative knowledge-exchange activities and successfully applied for capacity-building awards. For example, we have **hosted national meetings for stakeholders in palliative care**, including to facilitate information sharing on providing palliative care during Covid-19 (March 2020), capacity building in translating research for policy (September 2020), and forming new palliative care research partnerships (July 2021). Our teams also led **a knowledge exchange event focused on patient and public involvement** to share learning across ARC partners including King’s College London, King’s College Hospital and the National Institute for Health Research, and a **cross-theme public involvement workshop** held by our palliative care theme, in collaboration with the social care and public health themes, focused on how we can better conduct research with and for people with multiple long-term conditions. The findings of the latter were shared across ARCs nationally during the ARC West Midlands National Seminar on Multimorbidity. Post-doctoral researcher Jo Bayly was also awarded a **NIHR Development Skills and Enhancement award** to increase research skills and capacity in complex clinical trials, in collaboration with national clinical trial experts. This includes mentoring from a Professor of Complex Clinical Trials and Statistics and training in implementation science.

Successful funding applications

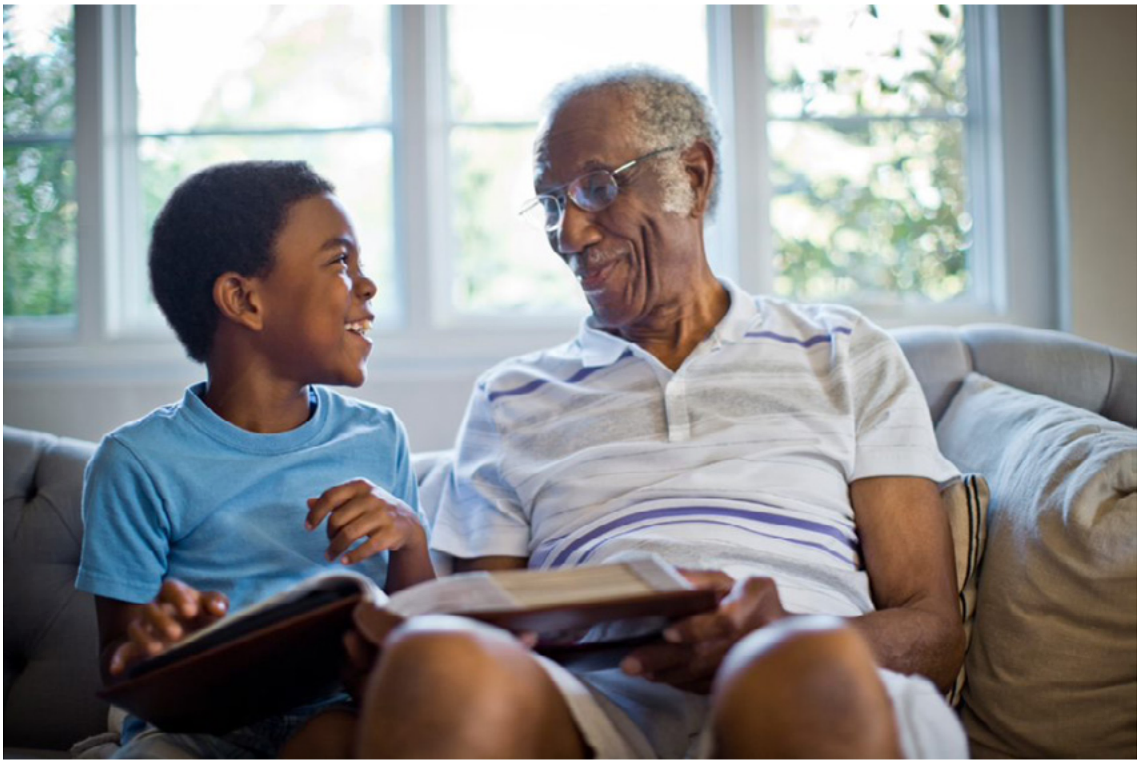
- Bayly J, Development and Skills Enhancement Award (Clinical Trials). 2020. £43,333.00

- Brighton LJ, Coultas C, Manthorpe J. Research with and for people with multiple long-term conditions: a stakeholder workshop. Awarded by King's College London and the Wellcome Trust Strategic Support Fund. £1000. 2020.

- EU Horizon 2020. INtegrated Short-term PallIative REhabilitation to improve quality of life and equitable care access in incurable cancer (INSPIRE). Maddocks M (CI), Normand C, Higginson IJ, Bayly J, ... €4,610,447 (2022-26).

- Maddocks M, Harwood R, Brighton LJ, Cowley A, Peryer G, Connell L, Laird B, Ziegler L. Research partnership on functional loss and rehabilitation towards the end of life. Awarded by the National Institute for Health Research. £99,256.40. 2021.

- NIHR Programme Grant for Applied Research. PrimaryBreathe: programme to develop and test a brief remote primary care intervention for chronic breathlessness. Spathis A (CI), Mant J (co-CI), Morris S, Booth S, Prevost T, Higginson IJ, Maddocks M, Reilly CC, Armstrong N, Evans R, Johnson MJ, Farquhar M, Person M. £2,416,792 (2022-27).



Work responding to the Covid-19 pandemic

Our first study examined the preparedness for, and impact of, the Covid-19 pandemic on hospices in Italy to inform the response in other countries. This survey of 14 hospice services showed hospices were able to respond rapidly and flexibly to Covid-19 but PPE was inadequate, and guidance was not setting specific. This was the first publication on palliative care in Covid-19 worldwide. Similar surveys have now been carried out in India and Africa.

We then conducted a rapid systematic review of the role and response of hospice and palliative care in epidemics and pandemics to inform response to Covid-19. This review helped understand whether and how palliative care had a role, as the speciality was missing from all guidance. This unique paper included recommendations for hospice and palliative care services, including shifting resource to the community, redeploying volunteers, facilitating staff camaraderie, and using technology to communicate with patients/carers. We published a novel case series of the first 101 patients referred to hospital palliative care services (Lovell N et al 2020). We found palliative care input was brief, most common symptoms were breathlessness and agitation, and symptoms usually responded to regular doses of opioid and benzodiazepine.

In May 2020, the CovPall study began a rapid evaluation of the Covid-19 pandemic response in palliative and end of life care with a focus on national delivery, workforce, and symptom management. Findings showed rapid changes , collaboration, inequalities (Bajwah et al 2021) and a 'frugal innovation' model adopted by palliative care and hospice services (Dunleavy L et al 2021). Rehabilitation provision in hospices and palliative care settings were disrupted and were redirected to more remote modes of delivery, affecting the capacity of clinicians and patients to participate in rehabilitation. Covid-19 acted as a springboard for learning and for positive future changes through the adoption of hybrid approaches to rehabilitation that integrate remote and face-to-face provision to expand reach and improve equity (Bayly J and Bradshaw A). Our findings also informed the Marie Curie Better End of Life Report (Sleeman et al 2021).

TheCovPall study comprised a multinational survey (n=458) of services, case studies to uncover impacts of Covid-19 on: service innovation and activity, advance care planning, role of volunteers, care of the dying, rehabilitation services, staff experiences and equity for ethnic minority groups. These components were followed-up by a multicentre cohort study that showed time in palliative care was very short for patients severely ill and dying of Covid-19. Patients with severe breathlessness deteriorated and died much more quickly than those who did not have severe breathlessness at first assessment. Common symptoms of patients receiving palliative care were: Breathlessness, Weakness/lack of energy, Drowsiness, Anxiety, Agitation, Confusion/Delirium, Pain. Symptoms improved during palliative care, especially if teams had more than 2 days to provide care, suggesting earlier referrals are beneficial (Higginson and Hocaoglu, 2021).

Publications

Bajwah S, Koffman J, Hussain J, Bradshaw A, Hocaoglu MB, Fraser LK, Oluyase A, Allwin C, Dunleavy L, Preston N, Cripps R, Maddocks M, Sleeman KE, Higginson IJ, Walshe C, Murtagh FEM; CovPall study team. Specialist palliative care services response to ethnic minority groups with Covid-19: equal but inequitable-an observational study. BMJ Support Palliat Care. 2021 Sep 12:bmjspcare-2021-003083. https://spcare.bmj.com/content/bmjspcare/early/2021/09/10/bmjspcare-2021-003083.full.pdf

Bayly, J., Bradshaw, A., Fettes, L., Omarjee, M., Talbot-Rice, H., Walshe, C., ... & Maddocks, M. (2021). Understanding the impact of the Covid-19 pandemic on delivery of rehabilitation in specialist palliative care services: An analysis of the CovPall-Rehab survey data. Palliative medicine, 02692163211063397. https://doi.org/10.1177/02692163211063397

Boufkhed S, Namisango E, Luyirika E, Sleeman KE, Costantini M, Peruselli C, Normand C, Higginson IJ, Harding R. Preparedness of African palliative care services to respond to the Covid-19 pandemic: A rapid assessment. J Pain Symptom Manage. 2020;60(6):e10-e26. https://doi.org/10.1016/j.jpainsymman.2020.09.018

Costantini M, Sleeman KE, Peruselli C, Higginson IJ. Response and role of palliative care during the Covid-19 pandemic: A national telephone survey of hospices in Italy. Palliat Med. 2020 Apr 9:269216320920780. https://doi.org/10.1177%2F0269216320920780

Dunleavy L, Preston N, Bajwah S, Bradshaw A, Cripps R, Fraser LK, Maddocks M, Hocaoglu M, Murtagh FEM, Oluyase AO, Sleeman K, Higginson IJ, Walshe C (2021). ‘Necessity is the mother of invention’: Specialist palliative care service innovation and practice change in response to Covid-19. Results from a multinational survey (CovPall). Palliative Medicine, 35 (5), 814-829. https://journals.sagepub.com/doi/full/10.1177/02692163211000660)

Etkind SN, Bone AE, Lovell N, Cripps RL, Harding R, Higginson IJ, Sleeman KE. The Role and Response of Palliative Care and Hospice Services in Epidemics and Pandemics: A Rapid Review to Inform Practice During the Covid-19 Pandemic. J Pain Symptom Manage. 2020 Jul;60(1):e31-e40. https://doi.org/10.1016/j.jpainsymman.2020.03.029

Fettes L, Bayly J, de Bruin LM, Patel M, Ashford S, Higginson IJ, Maddocks M. Relationships between prolonged physical and social isolation during the Covid-19 pandemic, reduced physical activity and disability in activities of daily living among people with advanced respiratory disease. Chron Respir Dis. 2021 Jan-Dec;18:14799731211035822PMID: 34382888; PMCID: PMC8370888. https://doi.org/10.1177%2F14799731211035822

Higginson, IJH and Hocaoglu 2021. Role and Response of hospital palliative care during the Covid-19 Pandemic. EAPC Blog. https://eapcnet.wordpress.com/2021/04/21/role-and-response-of-hospital-palliative-care-during-the-covid-19-pandemic/

Janssen DJ, Ekström M, Currow DC, Johnson MJ, Maddocks M, Simonds AK, Tonia T, Marsaa K. Covid-19: guidance on palliative care from a European Respiratory Society international task force. European respiratory journal. 2020 Sep 1;56(3). https://doi.org/10.1183/13993003.02583-2020

Koffman J, Etkind S, Gross J, Selman L. Clinical uncertainty and Covid-19: Embrace the questions and find solutions (Editorial) Palliative Medicine 2020;34(7):829-831. https://doi.org/10.1177%2F0269216320933750

Koffman J, Etkind S, Gross J, Selman L. Uncertainty and Covid-19: How are we to respond?Journal of the Royal Society of Medicine 2020;113(6):211-216 https://doi.org/10.1177%2F0141076820930665

Lin CP*, Boufkhed S*, Pai AA, Namisango E, Luyirika E, Sleeman KE, Costantini M, Peruselli C, Higginson IJ, Ekstrand ML, Harding R, Salins N, Bhatnagar S. Preparedness and capacity of Indian palliative care services to respond to the Covid-19 pandemic: an online rapid assessment survey. 2021 Feb 17; 27(1):152-171. Indian Journal of Palliative Care (*joint first). https://dx.doi.org/10.4103%2Fijpc.ijpc_429_20

Lovell N, Maddocks M, Etkind SN, Taylor K, Carey I, Vora V, Marsh L, Higginson IJ, Prentice W, Edmonds P, Sleeman KE. Characteristics, symptom management and outcomes of 101 patients with Covid-19 referred for hospital palliative care. Journal of Pain and Symptom Management. 2020;60(1):77-81 https://doi.org/10.1016/j.jpainsymman.2020.04.015

Oluyase AO, Hocaoglu M, Cripps RL, Maddocks M, Walshe C, Fraser LK, Preston

N, Dunleavy L, Bradshaw A, Murtagh FEM, Bajwah S, Sleeman KE, Higginson IJ; CovPall study team. The challenges of caring for people dying from Covid-19: a multinational, observational study (CovPall). J Pain Symptom Manage. 2021 Feb 5:S0885-3924(21)00159-7. Epub ahead of print. PMID: 33556496; PMCID: PMC7863772. https://doi.org/10.1016/j.jpainsymman.2021.01.138

Round T, L'Esperance V, Bayly J, Brain K, Dallas L, Edwards JG, Haswell T, Hiley C, Lovell N, McAdam J, McCutchan G, Nair A, Newsom-Davis T, Sage EK, Navani N. Covid-19 and the multidisciplinary care of patients with lung cancer: an evidence-based review and commentary. Br J Cancer. 2021 Aug;125(5):629-640. Epub 2021 May 10. PMID: 33972746; PMCID: PMC8108433. https://doi.org/10.1038/s41416-021-01361-6

Selman L, Chao D, Sowden R, Marshall S, Chamberlain C, Koffman J Bereavement support on the frontline of Covid-19: Recommendations for hospital clinicians Journal of Pain and Symptom Management 2020;60(2):e81-e86 https://doi.org/10.1016/j.jpainsymman.2020.04.024

Sleeman, K.E., Murtagh, F.E.M., Kumar, R., O'Donnell, S., Cripps, R.L., Bone, A., McAleese, J., Lovick, R., Barclay, S. & Higginson, I.J. (King's College London, Cicely Saunders Institute; Hull York Medical School, University of Hull; and University of Cambridge, UK). Better End of Life 2021. Dying, death and bereavement during Covid-19. Research report. London (UK): Marie Curie. 2021 April. https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2021/better-end-of-life-research-report.pdf

Ting R, Edmonds P, Higginson H, Sleeman E K. Palliative care for patients with severe covid-19. BMJ 2020 14 July; 370:m2710. https://doi.org/10.1136/bmj.m2710

Successful funding applications:

- CovPall: Rapid evaluation of the Covid-19 pandemic response in palliative and end of life care: national delivery, workforce and symptom management
  MRC Medical Research Council
  Higginson, I., Bajwah, S., Maddocks, M., Sleeman, K., Oluyase, A., Hocaoglu, M.
  £194,134.86
  20/04/2020 to 19/04/2021

- CovPall-Connect Study: Evaluation of how palliative and end of life care teams have responded to Covid-19: Connecting to boost impact and data assets.
  Health Data Research UK (HDR UK)
  Higginson, I., Fraser L, Sleeman, K., Cripps R, Oluyase, A., Hocaoglu, M.
  £49,994.00
  07/01/2021 to 31/11/2022

- CovPall Care homes, an NIHR grant of £172,336 is a collaboration between South London ARC and ARC East of England

■ General practice service use towards end-of-life among patients who died before and during the Covid-19 pandemic: a nationwide cohort study using the Clinical Practice Research Data.
Higginson. I, Chukwusa. E, Barclay. S, Tausig. J, Verne. J, Martin. G,
Awarded by the NIHR: £99,744.00: Duration: 01-03-2021 to 31-04-2022