

Folder eCC_00010106 is in stage Annual_Report_Due

Name of the University, Hospital, Research Institute, Academy or Ministry

King's College London

Name of the Division, Department, Unit, Section or Area

Department of Palliative Care, Policy and Rehabilitation

City London **Reference Number** UNK-217

Title WHO Collaborating Centre for Palliative care, policy and rehabilitation

Report Year 10-2014 to 10-2015

1. Please briefly describe the progress made in the implementation of your agreed workplan as WHO collaborating centre during the past 12 months (or the reporting period listed above). Please report on how each workplan activity was implemented, if any outputs have been delivered, if any results have been achieved and if any difficulties have been encountered during this time. If an activity has previously been completed, has not started yet, or been placed on hold, please indicate this.

Activity 1

Title: To build knowledge and generate evidence to aid the development of quality, accessible and efficient palliative care and rehabilitation in Europe

Description: Research based development and evaluation of new treatments and services around the following themes:

- Symptom research – To discover new ways of controlling common distressing symptoms, including pain, breathlessness, nausea, fatigue and spasticity
- Evaluating and improving care for people with cancer, respiratory disease, heart failure, liver, kidney and neurological disorders
- Living and dying in society - Investigating care for older people, support for caregivers, cultural issues in palliative care and other issues reflecting how the way we live and die is changing

Symptom research

Focused clinical research in palliative care seeks to discover more effective ways to prevent and treat pain, symptoms and other problems experienced by patients and families towards the end of life.

In the past year, the following pieces of work about (management of) breathlessness have been published: Farquhar MC, Prevost A, McCrone P, Brafman-Price B, Bentley A, Higginson IJ, et al. Is a specialist breathlessness service more effective and cost-effective for patients with advanced cancer and their carers than standard care? Findings of a mixed-method randomised controlled trial. *BMC Med* 2014; 12(1): 194.

In this Phase III RCT, a Breathlessness Intervention Service (BIS) reduced distress due to breathlessness in patients with advanced cancer significantly more than the control group. When costs were linked to the primary outcome, the findings indicate BIS was cost-effective over the follow-up period; the qualitative data showed that BIS made a positive difference to 94% of patients and carers with impacts including reduced fear and worry, and increased confidence about breathlessness. It was concluded that BIS is more effective and cost-effective in advanced cancer than standard care.

Dunger C; Higginson, I. J.; Gysels, M.; Booth, S.; Simon, S. T.; Bausewein, C. Breathlessness and crises in the context of advanced illness: A comparison between COPD and lung cancer patients. *Palliat Support Care*. 2015;13(2):229-37.

This study is one of the few comparative qualitative studies that explored and contrasted the experience of breathlessness of patients with COPD or lung cancer in the context of their illness. Ten COPD and eight lung cancer patients were interviewed. Results showed that both COPD and lung cancer patients experience

physical and psychological crises associated with breathlessness. The main difference was the way in which patients adapted to their particular illness experience and the resulting crises over time. It was concluded that although experiences of patients are similar, reactions and coping mechanisms vary and are more related to the disease and the stage of disease.

Weingartner V; Scheve, C.; Gerdes, V.; Schwarz-Eywill, M.; Prenzel, R.; Otremba, B.; Muhlenbrock, J.; Bausewein, C.; Higginson, I. J.; Voltz, R.; Herich, L.; Simon, S. T. Characteristics of episodic breathlessness as reported by patients with advanced chronic obstructive pulmonary disease and lung cancer: Results of a descriptive cohort study. *Palliat Med.* 2015;29(5):420-8

This is the first study comparing longitudinal data on the self-assessed characteristics of episodic breathlessness in patients with different underlying diseases. Patients with COPD perceived breathlessness episodes as severe, and peak severity was significantly higher than that described by Lung cancer patients. Although breathlessness episodes were predominantly described as lasting only minutes in both groups, the duration of episodes described by COPD patients was slightly longer compared to episodes described by LC patients. These findings emphasize the burden of episodic breathlessness and the challenge regarding its management (short duration). It highlights the need for Disease-specific, needs-based care, and effective management and coping options for COPD and lung cancer patients suffering from episodic breathlessness.

Other studies on breathlessness include the following:

Gysels M, Reilly CC, Jolley CJ, Pannell C, Spoorendonk F, Bellas H, Madan P, Moxham J, Higginson I.J, Bausewein, C. How does a new breathlessness support service affect patients? *Eur Respir J.* 2015 doi: 10.1183/13993003.00751-2015

Reilly CC, Bausewein C, Pannell C, Moxham J, Jolley CJ, Higginson IJ. Patients' experiences of a new integrated breathlessness support service for patients with refractory breathlessness: Results of a postal survey. *Palliat Med.* 2015.

Maddocks M, Reilly CC, Jolley C, Higginson IJ. What next in Refractory Breathlessness? Research questions for the palliative care setting. *J Palliat Care.* 2014;30(4):271-279.

In the past year, the following pieces of work about (management of) other symptoms have been published: Moens K, Siegert RJ, Taylor S, Namisango E, Harding R. Symptom Clusters in People Living with HIV Attending Five Palliative Care Facilities in Two Sub-Saharan African Countries: A Hierarchical Cluster Analysis. *PLoS One.* 2015;10(5):e0126554.

Findings from this cross-sectional study suggest that the greatest burden is associated with the cluster of dermatological symptoms, and should be prioritised in clinical management. Further symptom cluster research in people living with HIV with longitudinally collected symptom data to test cluster stability and identify common symptom trajectories is recommended.

Ashford S, Fheodoroff K, Jacinto J, Turner-Stokes L. Common goal areas in the treatment of upper limb spasticity: A multicentre analysis. *Clin Rehabil.* 2015.

In this study, analysis of a total 1623 goals from five published studies led to the identification of 6 key goal areas in two principal domains, which were mapped on to the WHO International Classification of Functioning (ICF). This analysis confirms that, despite their diversity, goals for management of upper limb spasticity fall broadly into six main goal areas under the two domains; 1: Symptoms/impairment: pain, involuntary movements and range of movement; and 2: Activities/function: passive function (ease of caring), active function (using the affected limb) and mobility.

Other studies on symptom management include the following:

Beynon T; Selman, L.; Radcliffe, E.; Whittaker, S.; Child, F.; Orłowska, D.; Morgans, C.; Morris, S.; Harding, R. 'We had to change to single beds because I itch in the night': A qualitative study of the experiences, attitudes and approaches to coping of patients with Cutaneous T-Cell Lymphoma (CTCL). *The British journal of dermatology.* 2015.

Lokker ME, Gwyther L, Riley JP, van Zuylen L, van der Heide A, Harding R. The Prevalence and Associated Distress of Physical and Psychological Symptoms in Patients With Advanced Heart Failure Attending a South African Medical Center. *The Journal of cardiovascular nursing.* 2015.

Namisango E; Harding, R.; Katabira, E. T.; Siegert, R. J.; Powell, R. A.; Atuhaire, L.; Moens, K.; Taylor, S. A novel symptom cluster analysis among ambulatory HIV/AIDS patients in Uganda. *AIDS care.* 2015:1-10.

Evaluating and improving care for people with cancer, respiratory disease, heart failure, liver, kidney and

neurological disorders

The ultimate goal of our research is to improve patient care. We have conducted several projects directly relating to evaluating and improving care, both in palliative care and in rehabilitation:

Turner-Stokes L; Williams, H.; Bill, A.; Bassett, P.; Sephton, K. Cost-efficiency of specialist inpatient rehabilitation for working-aged adults with complex neurological disabilities: A multi centre cohort analysis of a national clinical dataset. *BMJ Open*. 2015; in press.

This first multi centre analysis of the UK national clinical dataset for specialist rehabilitation demonstrates that patients with complex neurological disability have the potential to gain from specialist rehabilitation across a wide range of conditions. It confirmed across multiple centres and a wider range of neurological conditions that, although the costs of treatment were quite high (£40,000 on average), this investment was offset by savings in the cost of on-going care with approximately 18 months.

Allowing for an estimated 15-year reduction in respect of complex neurological disability, the mean life expectancy of this study group is anticipated to be 25 years or more. Extrapolated over this period, the mean saving of nearly £500 per week (or £26K per year) in on-going costs of care might be expected to lead to overall life-time economic gains in excess of £650,000 or more per patient, or £3.7 billion for the whole study sample.

This analysis also demonstrated that cost efficiency measured in this way was highest in the most dependent group of patients. This not only confirms the results from our previous single centre study in patients with acquired brain injury, but also demonstrates that the reproducibility of this finding across multiple centres and different neurological conditions.

Bajwah S, Ross JR, Wells AU, Mohammed K, Oyeboode C, Birring SS, et al. Palliative care for patients with advanced fibrotic lung disease: a randomised controlled phase II and feasibility trial of a community case conference intervention. *Thorax*. 2015.

This fast-track randomised controlled trial of a case conference intervention in patients with advanced fibrotic ILD and carers identified an improvement in symptom control and quality of life. Notably, there was no worsening of any outcome after receiving the intervention. This suggests that no harm and potentially a prevention of deterioration may have occurred. Mean-change difference scores in Palliative Care Outcome Scale (POS) in the fast-track group were 5.7 points at 4 weeks, sustained at 8 weeks. For POS, a variation of one point in individual items is linked to clinical meaningful change. There was also a promising large effect size. Similar improvements in the waiting list POS once they received the intervention suggest that the intervention may improve the palliative care concerns of these patients. Use of evidence based guidelines and a comprehensive palliative care assessment at the case conference, ongoing palliative care involvement and/or added time with care providers may have contributed to this.

Henson LA; Gao, Wei.; Higginson, I. J.; Smith, M.; Davies, J. M.; Ellis-Smith, C.; Daveson, B. A. Emergency Department Attendance by Patients With Cancer in Their Last Month of Life: A Systematic Review and Meta-Analysis. *J Clin Oncol*. 2015;33(4):370-6.

This systematic review identified demographic (men; black race), clinical (lung cancer), and environmental (low Socio economics status; no palliative care) factors associated with an increased risk of emergency department attendance by patients with cancer in their last month of life. These findings may be used to develop screening interventions and assist policy-makers to direct resources. Future studies should also investigate previously neglected areas of research, including psychosocial factors, and patients' and caregivers' emergency care preferences.

Sleeman KE, Koffman J, Bristowe K, Rumble C, Burman R, Leonard S, et al. 'It doesn't do the care for you': a qualitative study of health care professionals' perceptions of the benefits and harms of integrated care pathways for end of life care. *BMJ open*. 2015;5(9).

The aim of this qualitative study understand healthcare professionals' perceptions of the benefits and potential harms of integrated care pathways for end-of-life care, to inform the development of future interventions that aim to improve care of the dying. 25 healthcare professionals, including doctors, nurses and allied health professionals, interviewed in 2009. This study demonstrates that healthcare professionals were conscious of both benefits and harms of integrated care pathways for end-of-life care. The benefits related to streamlined processes of care, and were experienced by the healthcare professionals themselves. Potential harms related to applying the pathway inflexibly or without thinking, leading to poor clinical decision-making, and were reminiscent of criticisms subsequently published by the media. These findings highlight: (1) the importance of collecting, reporting and using qualitative data when developing and evaluating complex interventions; (2) that

comprehensive education and training in palliative care is critical for the success of any new intervention; (3) the need for future interventions to be grounded in patient-centred outcomes, not just processes of care.

Bristowe K; Carey, I.; Hopper, A.; Shouls, S.; Prentice, W.; Caulkin, R.; Higginson, I. J.; Koffman, J. Patient and carer experiences of clinical uncertainty and deterioration, in the face of limited reversibility: A comparative observational study of the AMBER care bundle. *Palliat Med.* 2015.

This first comparative evaluation of the AMBER care bundle found that it may be associated with increased frequency of discussions about prognosis with patients and families and improved awareness of the clinical situation. However, there were no significant differences in length of hospital stay, satisfaction with communication, or frequency and clarity of information shared.

Other studies relating to evaluating and improving care include the following:

Bristowe K; Horsley, H. L.; Shepherd, K.; Brown, H.; Carey, I.; Matthews, B.; O'Donoghue, D.; Vinen, K.; Murtagh, F. E. Thinking ahead--the need for early Advance Care Planning for people on haemodialysis: A qualitative interview study. *Palliat Med.* 2015;29(5):443-50.

Alexandrescu R, Bottle A, Jen MH, Jarman B, Aylin P. The US hospital standardised mortality ratio: Retrospective database study of Massachusetts hospitals. *Journal of the Royal Society of Medicine.* 2015;6(1):1-8.

Brito M, Gomes B. Non-cancer palliative care in the community needs greater interprofessional collaboration to maintain coordinated care and manage uncertainty. *Evidence-based nursing.* 2015;18(3):79.

Canavan JL, Maddocks M, Nolan CM, Jones SE, Kon SS, Clark AL, et al. Functionally Relevant Cut Point for Isometric Quadriceps Muscle Strength in Chronic Respiratory Disease. *American journal of respiratory and critical care medicine.* 2015;192(3):395-7.

Carey I; Shouls, S.; Bristowe, K.; Morris, M.; Briant, L.; Robinson, C.; Caulkin, R.; Griffiths, M.; Clark, K.; Koffman, J.; Hopper, A. Improving care for patients whose recovery is uncertain. The AMBER care bundle: design and implementation. *BMJ Support Palliat Care.* 2015;5(1):12-8.

Downing J, Powell RA, Marston J, Huwa C, Chandra L, Garchakova A, Harding R. Children's palliative care in low- and middle-income countries. *Arch Dis Child.* 2015.

Etkind SN; Daveson, B. A.; Kwok, W.; Witt, J.; Bausewein, C.; Higginson, I. J.; Murtagh, F. E. Capture, Transfer, and Feedback of Patient-Centered Outcomes Data in Palliative Care Populations: Does It Make a Difference? A Systematic Review. *J Pain Symptom Manage.* 2015;49(3):611-24.

Fheodoroff K; Ashford, S.; Jacinto, J.; Maisonnobe, P.; Balcaitiene, J.; Turner-Stokes, L. Factors Influencing Goal Attainment in Patients with Post-Stroke Upper Limb Spasticity Following Treatment with Botulinum Toxin A in Real-Life Clinical Practice: Sub-Analyses from the Upper Limb International Spasticity (ULIS)-II Study. *Toxins.* 2015;7(4):1192-205.

Grande AJ, Silva V, Maddocks M. Exercise for cancer cachexia in adults: Executive summary of a Cochrane Collaboration systematic review. *Journal of Cachexia, Sarcopenia and Muscle.* 2015.

Harding R, Powell RA, Namisango E, Merriman A, Gikaara N, Ali Z, Higginson IJ. Palliative care-related self-report problems among cancer patients in East Africa: a two-country study. *Support Care Cancer.* 2014;Springer Berlin Heidelberg:1-8.

Harding R, Simms V, Penfold S, Downing J, Namisango E, Powell RA, Mwangi-Powell F, Moreland S, Gikaara N, Atieno M, Higginson IJ. Quality of life and wellbeing among HIV outpatients in East Africa: a multicentre observational study. *BMC Infect Dis* 2014; 14(1): 613.

Harding R; Downing, J.; Ekstrand, M.; Gwyther, L.; Sherr, L. Evidence-based programming of HIV care and support: is the psychosocial "optional"? *Journal of acquired immune deficiency syndromes (1999).* 2015.

Etkind SN, Karno J, Edmonds PM, Carey I, Murtagh FE. Supporting patients with uncertain recovery: the use of the AMBER care bundle in an acute hospital. *BMJ Support Palliat Care* 2014.

Henson LA, Gomes B, Koffman J, Daveson BA, Higginson IJ, Gao W. Factors associated with aggressive end of life cancer care. *Support Care Cancer.* 2015.

Hussain JA; Flemming, K.; Murtagh, F. E.M.; Johnson, M. J. Patient and Health Care Professional Decision-Making to Commence and Withdraw from Renal Dialysis: A Systematic Review of Qualitative Research. *Clin J Am Soc Nephro.* 2015.

Jones SE; Maddocks, M.; Kon, S. S.; Canavan, J. L.; Nolan, C. M.; Clark, A. L.; Polkey, M. I.; Man, W. D. Sarcopenia in COPD: prevalence, clinical correlates and response to pulmonary rehabilitation. *Thorax.* 2015;70(3):213-8.

C, Raleigh C, O'Gara G, Higginson IJ, Daveson B. The gap between policy and practice: a systematic review of patient-centred care interventions in chronic heart failure. *Heart Fail Rev.* 2015. doi:10.1007/s10741-015-9508-5

Koffman J; Goddard, C.; Gao, W.; Jackson, D.; Shaw, P.; Burman, R.; Higginson, I. J.; Silber, E. Exploring meanings of illness causation among those severely affected by multiple sclerosis: a comparative qualitative study of Black Caribbean and White British people. *BMC Palliat Care*. 2015;14(1):13.

Lifford KJ; Witt, J.; Burton, M.; Collins, K.; Caldon, L.; Edwards, A.; Reed, M.; Wyld, L.; Brain, K. Understanding older women's decision making and coping in the context of breast cancer treatment. *BMC medical informatics and decision making*. 2015;15:45.

Lowney AC, Myles HT, Bristowe K, Lowney EL, Shepherd K, Murphy M, et al. Understanding What Influences the Health-Related Quality of Life of Hemodialysis Patients: A Collaborative Study in England and Ireland. *J Pain Symptom Manage*. 2015.

Lowther K; Selman, L.; Simms, V.; Gikaara, N.; Ahmed, A.; Ali, Z.; Kariuki, H.; Sherr, L.; Higginson, I. J.; Harding, R. Nurse-led palliative care for HIV-positive patients taking antiretroviral therapy in Kenya: a randomised controlled trial. *The Lancet HIV*. 2015.

Maddocks M; Kon, S. S.; Jones, S. E.; Canavan, J. L.; Nolan, C. M.; Higginson, I. J.; Gao, W.; Polkey, M. I.; Man, W. D. Bioelectrical impedance phase angle relates to function, disease severity and prognosis in stable chronic obstructive pulmonary disease. *Clinical nutrition (Edinburgh, Scotland)*. 2015.

Maddocks M; Kon, S. S.; Singh, S. J.; Man, W. D. Rehabilitation following hospitalization in patients with COPD: Can it reduce readmissions? *Respirology*. 2015;20(3):395-404.

Martin NH; Lawrence, V.; Murray, J.; Janssen, A.; Higginson, I. J.; Lyall, R.; Burman, R.; Leigh, P. N.; Al-Chalabi, A.; Goldstein, L. H. Decision Making About Gastrostomy and Noninvasive Ventilation in Amyotrophic Lateral Sclerosis. *Qualitative health research*. 2015.

Okamoto I; Tonkin-Crine, S.; Rayner, H.; Murtagh, F. E.; Farrington, K.; Caskey, F.; Tomson, C.; Loud, F.; Greenwood, R.; O'Donoghue, D. J.; Roderick, P. Conservative care for ESRD in the United Kingdom: a national survey. *Clin J Am Soc Nephrol*. 2015;10(1):120-6.

Pivodic L; Harding, R.; Calanzani, N.; McCrone, P.; Hall, S.; Deliens, L.; Higginson, I. J.; Gomes, B. Home care by general practitioners for cancer patients in the last 3 months of life: An epidemiological study of quality and associated factors. *Palliat Med*. 2015.

Selman L; Brighton, L.; Harding, R. Palliative and supportive care needs of heart failure patients in Africa: a review of recent developments. *Curr Opin Support Palliat Care*. 2015.

Selman L; McDermott, K.; Donesky, D.; Citron, T.; Howie-Esquivel, J. Appropriateness and acceptability of a Tele-Yoga intervention for people with heart failure and chronic obstructive pulmonary disease: qualitative findings from a controlled pilot study. *BMC Complement Altern Med*. 2015;15(1):1-13.

Singh T; Harding, R. Palliative care in South Asia: A systematic review of the evidence for care models, interventions, and outcomes. *BMC research notes*. 2015;8:172.

Talbot Rice H, Malcolm L, Norman K, Jones A, Lee K, Preston G, McKenzie D, Maddocks M. An evaluation of the St Christopher's Hospice rehabilitation gym circuits classes: Patient uptake, outcomes, and feedback. *Prog Palliat Care*. 2014;22(6):319-25.

Tonkin-Crine S; Santer, M.; Leydon, G. M.; Murtagh, F. E.; Farrington, K.; Caskey, F.; Rayner, H.; Roderick, P. GPs' views on managing advanced chronic kidney disease in primary care: a qualitative study. *The British journal of general practice : the journal of the Royal College of General Practitioners*. 2015;65(636):e469-77.

Turner-Stokes L, Vanderstay R, Stevermuer T, Simmonds F, Khan F, Eagar K. Comparison of Rehabilitation Outcomes for Long Term Neurological Conditions: A Cohort Analysis of the Australian Rehabilitation Outcomes Centre Dataset for Adults of Working Age. *PLoS One*. 2015;10(7):e0132275.

Turner-Stokes L; R, Harding.; Ashford, S.; Singer, B. A. Patient engagement and satisfaction with goal planning: Impact on outcome from rehabilitation. *International Journal of Therapy and Rehabilitation*. 2015;22(5):210-6.

Living and dying in society - Investigating care for older people, support for caregivers, cultural issues in palliative care and other issues reflecting how the way we live and die is changing

The increasing trend in deaths as a result of cancer and other progressive illness poses a challenge for health professionals, health care spending, and for the wider society. In the future, it is conceivable that debates will focus mainly on ways to meet the growing cultural diversity in our society; euthanasia; advance directives and place of death; and the economic, social, psychological, spiritual and ethical implications of these trends.

Palliative care aims to empower patients at the end-of-life by ensuring appropriate care is delivered where they wish to spend their last days. In order to make this happen, it is necessary to provide the most robust and up-to-date evidence. At the Cicely Saunders Institute, one of our goals is to deliver robust and practically relevant research which will enable the empowerment of people – including the elderly – at the end-of-life.

Some examples are:

Gomes B, Calanzani N, Koffman J, Higginson IJ. Is dying in hospital better than dying at home in incurable cancer and what factors influence this? A population-based study. *BMC Medicine* 2015

To date, this study is the most comprehensive population-based study of factors and outcomes associated with dying at home compared to hospital; it includes over 350 people who died from cancer and their relatives in the largest metropolitan area in the UK. The study fills in a critical gap in providing new evidence suggesting that dying at home is better than hospital for peace and grief, with no difference in the pain level experienced in the last week of life.

Gao W, Ho Y, Verne J, Gordon E, Higginson IJ. Geographical and temporal Understanding In place of Death in England (1984–2010): analysis of trends and associated factors to improve end-of-life Care (GUIDE_Care) – primary research. *Health Serv Deliv Res* 2014; 2(42).

Findings from this study showed that hospital remains the most common place of death, followed by home and care-home. Hospices play an important role for people who died from cancer but little for other diseases. Place of death is strongly associated with the underlying cause of death. The variation in place of death by region, age, marital status and area deprivation suggests that inequities exist, which services and clinical commissioning groups could seek to address.

Harding R; G, Wei.; Jackson, D.; Pearson, C.; Murray, J.; Higginson, I. J. Comparative Analysis of Informal Caregiver Burden in Advanced Cancer, Dementia and Acquired Brain Injury. *J Pain Symptom Manage.* 2015.

Findings from this study show that caregiver-burden differs between cancer, dementia, and acute brain injury caregivers. Overall burden was highest in acute brain injury caregivers and lowest in cancer. This should be considered when designing future intervention strategies to reduce caregiver burden in these groups.

Weisser FB; Bristowe, K.; Jackson, D. Experiences of burden, needs, rewards and resilience in family caregivers of people living with Motor Neurone Disease/Amyotrophic Lateral Sclerosis: A secondary thematic analysis of qualitative interviews. *Palliative Medicine.* 2015.

In this study, experiences of burden, needs, resilience and reward in family caregivers were explored. It highlights that burden, resilience, needs and rewards are interrelated. Caregivers' ability to cope with caring for a person with Motor Neurone Disease/Amyotrophic Lateral Sclerosis oscillates between positive and negative aspects of caring, being at times active, at times passive.

Sleeman KE; Davies, J. M.; Verne, J.; Gao, W.; Higginson, I. J. The changing demographics of inpatient hospice death: Population-based cross-sectional study in England, 1993-2012. *Palliat Med.* 2015.

This population-based study of inpatient hospice deaths showed that both the absolute and relative numbers of people dying in inpatient hospices in England increased between 1993 and 2012, though numbers remain low with just 6.0% of all deaths in 2012 occurring in an inpatient hospice. Although there has been a recent increase in the proportion of non-cancer deaths in inpatient hospices, still the vast majority of inpatient hospice deaths are from cancer. The results also showed that people residing in the least deprived areas are more likely to die in inpatient hospices than people living in most deprived areas, and this gap has grown over time. This deprivation trend is concerning and requires further exploration.

Moens K; Houttekier, D.; Van den Block, L.; Harding, R.; Morin, L.; Marchetti, S.; Csikos, A.; Loucka, M.; Naylor, W. A.; Wilson, D. M.; Teno, J.; Cardenas-Turanzas, M.; Rhee, Y.; Garcia-Leon, F. J.; Deliens, L.; Cohen, J. Place of death of people living with Parkinson's disease: a population-level study in 11 countries. *BMC Palliat Care.* 2015;14:28.

This is the first cross-national study to investigate place of death and associated factors – using death certificate data – in people dying from Parkinson's disease comparing European and non-European countries (Belgium, France, Italy, Hungary, Czech Republic, New Zealand, USA, Canada, Mexico, South Korea and Spain). The findings showed that a substantial proportion of persons living with Parkinson's disease died in hospital in eleven European and non-European countries. However, cross-national variation in place of death is striking. The wide variation between countries in the proportion of deaths from PD occurring in hospital indicates a potential for many countries to reduce these proportions.

Kane PM; Daveson, B. A.; Ryan, K.; McQuillan, R.; Higginson, I. J.; Murtagh, F. E. The need for palliative care

in Ireland: a population-based estimate of palliative care using routine mortality data, inclusive of nonmalignant conditions. *J Pain Symptom Manage.* 2015;49(4):726-33.e1.

In this Population-Based Estimate of Palliative Care Using Routine Mortality Data, the need for palliative care was shown to be considerably high (80% of deaths annually are from conditions considered to have palliative care needs) when compared with estimates from Australia (50%)²³ and the U.K. (63%). The findings suggest that future palliative care policy decisions in Ireland must consider the rapidly aging Irish population with the accompanying increase in deaths from cancer, dementia, and neurodegenerative disease and associated palliative care need. New models of palliative care may be required to address this.

Other studies relating to living and dying in society include the following:

Dzingina MD; Higginson, I. J. Public Health and Palliative Care in 2015. *Clinics in Geriatric Medicine.* 312015. p. 253-63.

Fegg M, Lehner M, Simon ST, Gomes B, Higginson IJ, Bausewein C. What influences end-of-life decisions? : Results of a representative German survey. *Bundesgesundheitsblatt, Gesundheitsforschung, Gesundheitsschutz.* 2015.

Gomes B. Palliative Care: If It Makes a Difference, Why Wait? *Journal of Clinical Oncology.* 2015.

Harding R. Caregivers of people at the end of life: emerging evidence. *Curr Opin Support Palliat Care.* 2014.

Harding R. Response to 'Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries'. *J Epidemiol Community Health.* 2015.

Harding R; Lampe, F.; Molloy, T.; Sherr, L. Do Web-Based and Clinic Samples of Gay Men Living With HIV Differ on Self-Reported Physical and Psychological Symptoms? A Comparative Analysis. *J Med Internet Res.* 2015;17(3):e57.

Jacinto A; Masembe, V.; Tumwesigye, N. M.; Harding, R. The prevalence of life-limiting illness at a Ugandan National Referral Hospital: a 1-day census of all admitted patients. *BMJ Support Palliat Care.* 2015;5(2):196-9.

Kane PM, Murtagh FE, Ryan K, Mahon NG, McAdam B, McQuillan R, Ellis-Smith C, Tracey C, Howley Martin S; Bristowe, K. Last offices: nurses' experiences of the process and their views about involving significant others. *Int J Palliat Nurs.* 2015;21(4):173-8.

Murtagh FEM. What matters time? The importance of time for those with advanced progressive disease and their families. *Palliative Medicine.* 2015;29(1):3-4.

O'Sullivan G, Harding R. Transition: the experiences of support workers caring for people with learning disabilities towards the end of life. *BMJ Support Palliat Care.* 2015.

Powell RA, Ali Z, Luyirika E, Harding R, Radbruch L, Mwangi-Powell FN. Out of the shadows: non-communicable diseases and palliative care in Africa. *BMJ Support Palliat Care.* 2015.

Sarmento VP, Higginson IJ, Ferreira PL, Gomes B. Past trends and projections of hospital deaths to inform the integration of palliative care in one of the most ageing countries in the world. *Palliat Med.* 2015.

Tonkin-Crine S; Okamoto, I.; Leydon, G. M.; Murtagh, F. E.; Farrington, K.; Caskey, F.; Rayner, H.; Roderick, P. Understanding by older patients of dialysis and conservative management for chronic kidney failure. *American journal of kidney diseases: the official journal of the National Kidney Foundation.* 2015;65(3):443-50.

van der Geest IM; van den Heuvel-Eiebrink, M. M.; Falkenburg, N.; Michiels, E. M.; van Vliet, L.; Pieters, R.; Darlington, A. S. Parents' Faith and Hope during the Pediatric Palliative Phase and the Association with Long-Term Parental Adjustment. *J Palliat Med.* 2015.

Activity 2

Title: To develop, refine and disseminate best practice clinical tools, outcome measures, guidance and clinical guidelines.

Description: • To develop, validate, implement and disseminate robust patient-oriented measures of outcomes and casemix in palliative care and rehabilitation for use by multi-disciplinary practitioners, focusing especially on tools used among older people and other vulnerable groups

Title: To develop, refine and disseminate best practice clinical tools, outcome measures, guidance and clinical guidelines.

Description: • To develop, validate, implement and disseminate robust patient-oriented measures of outcomes and case-mix in palliative care and rehabilitation for use by multi-disciplinary practitioners, focusing especially on tools used among older people and other vulnerable group

Palliative care Outcome Scale (POS) and new versions

The Palliative Care Outcome Scale (POS) is an outcome questionnaire specifically developed and validated for use in palliative care settings. The POS has been considerably developed and improved during the period of this annual report.

Integrated Palliative care Outcome Scale (IPOS)

As a result of our improvements and research into the Palliative Care Outcome Scale (POS), we have released a new version of POS – called IPOS – that integrates the best in the POS, the POS symptom module (POS-S), the APCA African POS and other modules. Cognitive testing and further validation is led from the Cicely Saunders Institute with several collaborating centres around the United Kingdom and beyond. Parallel translation and validation studies are taking place in Germany, Greece, Portugal, Romania and Sweden; so that several translated versions can be available on release. Updates are regularly posted on the POS website, www.pos-pal.org.

The development work for POS has been published as follows:

Schildmann EK, Groeneveld EI, Denzel J, Brown A, Bernhardt F, Bailey K, Guo P, Ramsenthaler C, Lovell N, Higginson IJ, Bausewein C, Murtagh FE. Discovering the hidden benefits of cognitive interviewing in two languages: The first phase of a validation study of the Integrated Palliative care Outcome Scale. *Palliat Med.* 2015. doi: 10.1177/0269216315608348

Myeloma- specific quality of life questionnaire (MyPOS)

To help support the care of people with myeloma, earlier in care, we are integrating a new myeloma-specific quality of life questionnaire (MyPOS) – a measure of quality of life of people affected by myeloma – using some of the questions and response scales from the POS, POS-S and IPOS. The MyPOS is intended for use in routine clinical practice as well as for measuring the benefit of treatment in ways that are meaningful to patients. In depth interviews with people with myeloma and a systematic literature review (Osborne et al., 2012) have influenced its development.

The development work for MyPOS has been published as follows:

Osborne TR; Ramsenthaler, C.; Schey, S. A.; Siegert, R. J.; Edmonds, P. M.; Higginson, I. J. Improving the assessment of quality of life in the clinical care of myeloma patients: the development and validation of the Myeloma Patient Outcome Scale (MyPOS). *BMC Cancer.* 2015;15(1):280.

Developing a measure of case-mix in palliative care – the C-CHANGE project

In the C-CHANGE project, we are undertaking a programme of research developing complexity assessment, measuring outcomes and resource utilisation to assess the cost-effectiveness in different models of palliative care. It is a 5 year program which commenced in June 2013. The main objectives of the project are to: define and measure complexity; measure outcomes in relation to complexity to enable bench-marking between services; develop and validate a patient-centred case-mix classification for adult palliative care provisions in England; test the cost-effectiveness of different models of palliative care; and to use findings to inform the development of new palliative-care funding models, and quality indicators.

Implementing outcomes in routine clinical practice – the OACC project

The Outcome Assessment and Complexity Collaborative (OACC) seeks to introduce and embed a suite of outcome measures into routine workflows and is using the data collected to provide individual and aggregated feedback to services to improve care for patients and families. Within the OACC project, we are supporting services throughout the implementation process by providing training, support and feedback through two full time Quality Improvement Facilitators. We are also conducting two research projects alongside the implementation intervention to address the gap in translating research to practice. OACC is very closely allied with work on complexity and case-mix conducted within C-Change

Developing guidance on the routine use of the POS

We are currently undertaking the EU-funded EUROIMPACT project, led by Prof Higginson and Dr Liesbeth Van Vliet, which aims to create more guidance on the routine use of Patient Reported Outcome Measures (PROMs) – particularly the Palliative care Outcome Scale (POS) – in clinical care. This has two arms. In the first, general guidance on the use and implementation of PROMs in clinical care is developed, building on the booklet 'Outcome Measurement in Palliative Care: The Essentials'

(Bausewein, Daveson, Benalia, Simon & Higginson, 2011) and the EAPC White Paper on Outcome

Measures (Bausewein, Daveson, Harding, Higginson among others, 2013). In the second arm, an evidence-based decision support tool is developed on how to respond to different levels of depression, information needs, family anxiety and breathlessness as measured by the Palliative care Outcome Scale. Based on published guidelines and systematic reviews, recommendations on how to respond to identified need are offered. Experts (clinicians, researchers and patient representatives) from all over the world are rating the appropriateness of recommendations in an online Delphi consensus study. The final decision support tool, as well as the general guidance on using and implementing PROMs in clinical care, will be integrated in the C-Change and OACC projects. We continue to publish from “PRISMA”, our pan-European co-ordinating action funded by the European Commission under FP7.

Other patient-oriented outcome measures and best practice clinical tools that have been refined or developed in the past year include:

Gysels M, Evans CJ, Lewis P, Speck P, Benalia H, Preston NJ, et al. MORECare research methods guidance development: recommendations for ethical issues in palliative and end-of-life care research. *Palliat Med.* 2013; 27(10):908-17.

Siegert R, Selman L, Higginson IJ, Ali Z, Powell RA, Namisango E, Mwangi-Powell F, Gwyther L, Gikaara N, Harding R. A Psychometric Evaluation of the Functional Assessment of Chronic Illness Therapy - Palliative Care (FACIT-Pal) Scale With Palliative Care Samples in Three African Countries. *J Pain Symptom Manage.* 2014.

Measures and guidelines for rehabilitation

Outcome measurement is critical to the evaluation of interventions provided in rehabilitation practice. We have developed a set of tools to measure complexity of patient rehabilitation need, service inputs and service outcomes for neurological rehabilitation services. These are undergoing continued testing and refinement, and form part of the national dataset for specialist rehabilitation services, the UK Rehabilitation Outcomes Collaborative (UK-ROC). The UK-ROC is hosted by the Regional Rehabilitation Unit, Northwick Park Hospital, an affiliate of the Cicely Saunders Institute and King's College London. Key measures utilised in UK-ROC are summarised below:

Rehabilitation Complexity Scale

A measure of needs for nursing, medical and therapy interventions, designed to provide a global assessment of complexity, and has been shown to be psychometrically robust.

The Northwick Park nursing and therapy dependency scales

These scales have been developed to provide a more detailed evaluation of needs and service inputs for patients requiring specialised rehabilitation services, and the relative costs of treatment:

- The Northwick Park Dependency Scale (NPDS): a measure of basic care and skilled nursing needs which uses a computerised algorithm to produce an assessment of the care and nursing hours needed for an individual patient.
- The Northwick Park Therapy Dependency Assessment (NPTDA): an equivalent tool for assessing therapy needs which uses a computerised algorithm to produce an assessment of the therapy hours for each therapy discipline (i.e. physiotherapy, occupational, etc.).

UK specialist Rehabilitation Outcomes Collaborative (UK-ROC) dataset

The UK-ROC dataset was set up in 2008 to develop a national database for collating case episodes for inpatient rehabilitation. The first five years have focused on neuro-rehabilitation and include data from all specialist neuro-rehabilitation services (levels 1 and 2) across the UK. The database provides:

- Case-mix and cost data to inform development of complexity-weighted tariffs;
- Benchmarking of service quality and outcomes; and
- Information on rehabilitation requirements, the inputs provided to meet them, outcomes and cost-benefits of rehabilitation for patients with different levels of need.

The dataset represents the inpatient rehabilitation subset of the Long Term Neurological Conditions dataset which is downloadable from the NHS Information centre website.

Goal Attainment Scaling

Measuring effectiveness of brain injury rehabilitation poses major problems due to the heterogeneity of

patients' deficits and desired outcomes. Goal Attainment Scaling (GAS) supports clinical decision making and communication between the patient and the treating team, as well as providing a means to evaluate whether the intended goals for rehabilitation were achieved.

We have been exploring the use of GAS as a person-oriented outcome measure for rehabilitation and also examined and compared different methods of applying GAS. Evidence has been presented which clearly demonstrates that GAS is a valid and sensitive outcome measure for rehabilitation. Following this work, GAS has now been applied as the primary outcome measure in a large international cohort study conducted across 22 countries, led by Professor Lynne Turner-Stokes (see reference below).

Focal spasticity Measures

Upper limb function

Through related work the need for further assessment of upper limb function has been identified.

- **GASeous (GAS – Evaluation of Outcome for Upper-limb Spasticity):** GAS has been further developed and tested in focal spasticity management with botulinum toxin. This has led to a structured method of goal setting and outcome evaluation using GAS for upper limb spasticity and is being used nationally and internationally by clinicians to document outcome.

The development work for LegA has been published as follows:

Ashford S; Siergert, R. J.; Alexandrescu, R. Rasch measurement: the Arm Activity measure (ArmA) passive function sub-scale. *Disabil Rehabil.* 2015;1-7.

- **ArmA – Arm Activity Measure:** a measure of difficulty in passive and active function for application following focal therapy intervention and in particular for spasticity interventions, both physical and with botulinum toxin injection (Ashford et al 2013a). The ArmA has undergone psychometric testing (Ashford et al 2013c) and its utility has been tested in focal spasticity intervention using botulinum toxin (Ashford et al 2014).

- **Upper Limb Spasticity Index (ULSI):** an index developed to record inputs (therapy and medical interventions) and outcomes of focal spasticity intervention using both the GASeous and ArmA alongside other relevant measures. Initial testing of this index has been undertaken and incorporation into a multi centre, international cohort study is under-way.

Upper limb function

This project builds on our previous work in upper limb spasticity, to develop a measure of lower limb function.

- **GASLegs (GAS – Leg Spasticity):** The work undertaken in developing methods for evaluation of upper limb spasticity has resulted in similar work to address outcome in leg spasticity. A structured method of goal setting and outcome evaluation using GAS for lower limb spasticity has also now been developed and is being tested.

- **LegA – Leg Activity measure:** Leading directly from the work on the ArmA, Dr Ashford and Professor Turner-Stokes have developed a programme of work undertaking the development and testing of a measure of passive and active lower limb function. This ongoing project and new tool will address patient and carer reported outcome following spasticity intervention in the leg.

The development work for LegA has been published as follows:

Ashford S; Brown, S.; Turner-Stokes, L. Systematic review of patient-reported outcome measures for functional performance in the lower limb. *Journal of rehabilitation medicine: official journal of the UEMS European Board of Physical and Rehabilitation Medicine.* 2015;47(1):9-17.

- **Lower Limb Spasticity Index (LLSI):** this Index is under development to incorporate the GASLegs and LegA alongside other relevant measures, to record inputs and outcomes of focal spasticity intervention. Initial testing of this index will be undertaken and incorporated into a planned multi centre, cohort study in the UK.

The Needs and Provision Complexity Scale (NPCS) – a measure of met and unmet needs for health and social care services

Our recent research in patients with complex long-term neurological conditions led to the development of a novel outcome measure that draws on information from both sides of the clinician-patient partnership to determine needs and provision of specialist rehabilitation services in the UK.

The Needs and Provision Complexity Scale (NPCS) is a simple, pragmatic tool that directly evaluates the complexity of needs for care and support in two principal domains, Health and Personal Care and Social Care

and Support, and the level of service provision offered to meet these needs. In addition, an algorithm can be applied that expresses met and unmet service needs in terms of costs for the purpose of integrated care planning.

- Part A (NPCS-Needs) is completed by treating clinicians to evaluate each patient's needs for health and social care in any given period.
- Part B (NPCS-Gets) is a mirror image of the same tool, completed by patients/carers at the end of that period, to report the levels of service that have been provided in relation to those needs.
- The difference between NPCS-Needs and NPCS-Gets indicates the extent of met versus unmet needs at individual service level as well as overall.

The NPCS has been appraised in the context of a multi centre prospective cohort study, which followed good overall internal consistency, acceptable repeatability and good concurrent validity

The Northwick Park Therapy Dependency Assessment scale (NPTDA)

The NPTDA is designed as a measure of therapy intervention which reflects both quantitative and qualitative aspects of the inputs provided (including staff time and the different types of intervention) during inpatient rehabilitation. It comprises 30 items grouped into seven domains to reflect the multi-dimensional nature of multidisciplinary therapy inputs.

- Domains A–E comprise 22 items each rated on a scale of 0–4, recording direct hands-on patient care.
- Domain F comprises four items recording indirect patient-related care (multi-disciplinary meetings, report writing, etc.) each on a scale of 0–2.
- Domain G is a checklist only, recording use of facilities and equipment for rehabilitation.
- The total range of the score (domains A–F) is 0–100 (item 2 “Splinting/orthotics” is scored double being divided into 2a “upper limb” and 2b “lower limb”, counting therefore for a maximum score of 8).

Each patient is rated individually on the basis of inputs provided over a one-week period. The UK-ROC software applies a computerised algorithm that translates raw NPTDA item scores into an estimation of therapy hours per week for each discipline involved.

The development work for NPTDA has been published as follows:

Alexandrescu R; Siergert, R. J.; Turner-Stokes, L. The Northwick Park Therapy Dependency Assessment scale: a psychometric analysis from a large multicentre neurorehabilitation dataset. *Disabil Rehabil.* 2015;1-8.

The Workability Scale

This is a new measure that was developed as part of a wider collaboration with colleagues at the Auckland University of Technology, New Zealand. It is designed to:

- Assess the individual's ability to work and support needs in the context of their normal work environment, following the onset of acquired disability,
- Support decision-making with regard to vocational rehabilitation including withdrawal from work where appropriate.

It encompasses the complexity of physical, cognitive and behavioural challenges that are typically associated with neurological disability. However, it also has application in the more general context of work-related disability.

The development work for the Workability Scale has been published as follows:

Fadyl JK; McPherson, K. M.; Schlüter, P. J.; Turner-Stokes, L. Development of a new tool to evaluate work support needs and guide vocational rehabilitation: the Work-ability Support Scale (WSS). *Disability and Rehabilitation.* 2015;37(3):247-58.

Activity 3

Title: To provide education and in-country support, policy guidance and advocacy to aid the international development of palliative care and rehabilitation

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The National Clinical Audit of Specialist Rehabilitation for Patients with Complex Needs Following Major Injury (2015-2018)

The audit will provide a national comparative assessment of the organisation, quality, outcomes and efficiency of specialist rehabilitation services in England and Wales provided for adults with complex needs following major injury. It will drive improved and equitable access to specialist rehabilitation services for these patients. The work will describe how specialist rehabilitation services are currently delivered in the context of trauma network and will support further development and implementation of the relevant national standards and clinical guidelines from Department of Health, British Society of Rehabilitation Medicine and NICE.

Professor Lynne Turner-Stokes' contribution to national guideline development

Professor Lynne Turner-Stokes, Director of the Regional Rehabilitation Unit and a member of staff of the institute, is leading on updating the Royal College of Physicians (RCP) guidelines on the management of spasticity in adults. This work is on-going and outputs are expected within 18 months.

Dr Steven Ashford contribution to national guideline development

Dr Steven Ashford, a member of staff of the institute, has been advising the college of Occupational Therapists and Association of Chartered Physiotherapists in Neurology in London on the guideline on Splinting for the prevention and correction of contractures in adults with neurological dysfunction.

The following publication resulted from this process:

Kilbride C, Ashford S, Baird T, Hoffman K, Tuckey J. Clinical Update: Guideline on splinting. Frontline. Nov 2015; 21(19) Ashford S. Splinting for the prevention and correction of contractures in adults with neurological dysfunction; College of Occupational Therapists and Association of Chartered Physiotherapists in Neurology. London: College of Occupational Therapists; 2015.

Professor Higginson's visit to the House of Commons

In September 2015, Professor Irene Higginson appeared at the House of Commons as a witness, alongside Dr Jane Collins, the Chief Executive of Marie Curie, and Professor Sir Mike Richards, the Chief Inspector of Hospitals for CQC, for The Public Administration and Constitution Affairs Select Committee's (PACAC) 'Dying Without Dignity' evidence session, in response to the findings of the Parliamentary and Health Service Ombudsman's (PSHO) 2 May 2015 report of the same name. The purpose of the session was to raise awareness of the six key shortcomings in the reports casework involving end of life care. These themes were as follows:

- Healthcare practitioners not recognising that people are dying, and not responding to their needs
- Poor symptom control of people who are dying
- Poor communication between patients and healthcare practitioners
- Inadequate out-of-hours service
- Poor care planning
- Delays in diagnosis and referrals for treatment

Since her appearance at the Commons, Professor Higginson has been referenced throughout the media, encouraging the need for greater acknowledgement of the importance of more extensive and improved training of doctors in end of life care. The Daily Mail, The Telegraph, The Times, The Sun, and the Nursing Times quoted Professor Higginson in the plea for more training for doctors in end of life care.

Professor Irene Higginson's visit to Washington DC

In July 2015, Professor Higginson visited Washington DC to attend IPOS and APOS conferences at the World Congress of Psycho-oncology. During her time there, Professor Higginson spoke at the Town Hall Meeting on Goals of Psychosocial Palliative Care for Patients with Advanced Disease Around the World. She was also interviewed on Psycho-oncology TV discussing progress made with IPOS and APOS and also spoke on a series of video interviews contributing to discussions on Palliative and End-of-Life Care: An International Perspective.

Dr Sleeman at the European Students' Conference in Berlin

In September 2015, Dr Katherine Sleeman (Clinical Lecturer at the Cicely Saunders Institute) delivered the closing talk at the European Students' Conference in Berlin. The European Students' Conference (ESC) was established in 1989 to facilitate and promote scientific exchange between young scientists. Held annually in Berlin, the ESC has developed into one of the largest student-organised biomedical conferences worldwide, and is under the patronage of Prof Ernst Rietschel, Chairman of the Berlin Institute of Health. The theme for the 26th ESC was "Science or Fiction? – Imagine the future of medicine", and more than 450 undergraduate medical and biomedical students from 42 countries worldwide (including Albania, Syria, Russia, Indonesia, Uganda) attended. In her talk, Katherine explored the relationship between medicine and mortality, drawing on observations made by Dame Cicely Saunders, latest research in palliative care, and Katherine's own experiences from clinical practice.

CSI Annual Lecture

On Monday 6th July 2015, the Cicely Saunders Institute hosted its Annual Lecture. The lecture was given by Dr Eduardo Bruera, Professor and FT McGraw Chair in the Treatment of Cancer at the University of Texas MD Anderson Cancer Centre. Dr Bruera delivered an inspirational presentation on "Clinical Interventions to enhance the expectation of healing: continuing on the pathway of Dame Cicely". Also present and introducing Dr Bruera was new Principal and President of King's College London, Professor Edward Byrne, who articulated his congratulations on the Institute and its success in the recent Research Excellence Framework (REF). The Institute welcomed over 100 guests for the Lecture. Included amongst them were relatives and former colleagues of Dame Cicely, local and international leaders in the field of palliative care, policy makers and funders. The event was also presented remotely to sites across the United Kingdom, Ireland, Italy, Portugal, the United States and Uganda, reaching approximately 60 more viewers.

In addition to the Annual Lecture, the Cicely Saunders Institute has been hosting an Open Seminar and Lecture series. Since the inception of GlobalCARE, the Institute has hosted 11 open seminars. All seminars have had good attendance and great reception, with the average evaluation score reaching 18/20.

Other Media Appearances

In September, Dr Jonathan Koffman and Dr Katherine Sleeman gave a pivotal talk at the Science Media Centre which was subsequently widely acknowledged and greatly esteemed throughout the media and amongst those in the field. Dr Koffman and Dr Sleeman were consequently referenced in the Belfast Telegraph, Yahoo News, BBC News Online, The Times, The Telegraph, The Daily Mail, the BMJ, Today FM and the Irish Times. In the talk the issues discussed covered:

- What is palliative care and how do we decide who needs it?
- What is the purpose of palliative care?
- What are the differences between the new draft NICE guideline and Liverpool Care Pathway?
- How will we know the new guideline works?
- What research is currently being done into palliative care; is it enough?

The talk underlined a need to encourage more training for doctors in the care of the dying.

In July, Dr Jonathan Koffman appeared on Radio London to discuss the new NICE guidelines on care of the dying.

In May, Dr Katherine Sleeman appeared in the Nursing Times and the New Scientist discussing the inequality gap existent in hospital and hospice care and the need for relatives to play a greater role in helping a loved one die with dignity.

In April, Professor Higginson appeared on BBC Radio 4 to discuss the question 'Is cancer money well spent?' In the interview Professor Irene Higginson outlines how Palliative Care is neglected when it comes to cancer funding and care. She discusses the recent successes in trials analysing effects of early palliative care and encourages a need for a conceptual shift surrounding palliative care in medical and popular discourse.

YouTube presence

We have growing free resources available on YouTube (<https://www.youtube.com/user/CSIKCL>). This includes presentations from seminars, lectures, individual talks, patient involvement, politician and high level visitor engagement. It is viewed by the public, patients and professionals from all parts of the globe.

We offer palliative care courses including a multi-professional MSc, PG Diploma and PG Certificate in Palliative Care, to develop palliative care leadership internationally. We offer palliative care courses including a multi-professional MSc, PG Diploma and PG Certificate in Palliative Care, to develop palliative care leadership internationally.

2. Please briefly describe your collaboration with WHO in regards to the activities of the WHO collaborating centre during the past 12 months (e.g. means of communication, frequency of contact, visits to or from WHO). Please feel free to mention any difficulties encountered (if any) and to provide suggestions for increased or improved communication (if applicable).

Professor Lynne Turner-Stokes is a member of the WHO guideline development group on Rehabilitation which was set up following the publication of WHO report on disability in 2007. This work is in progress and is due to produce publications within the next 12 months.

3. Please briefly describe any interactions or collaborations with other WHO collaborating centres in the context of the implementation of the above activities (if any). If you are part of a network of WHO collaborating centres, please also mention the name of the network, and describe any involvement in the network during the last 12 months.

We take part in regular e-mail exchanges with the other Collaborating Centres relevant to palliative care to share materials (the London, Oxford and Barcelona Collaborating Centres) and have exchanged materials and expertise, and we collaborate with the Copenhagen office on an ad-hoc basis.

We are one of the five collaboration centres that make up the WHO Technology Advisory Group which was formed in response to WHA resolution on Palliative Care. We take part in regular e-mail exchanges with the other Collaborating Centres relevant to palliative care to share materials (the London, Oxford and Barcelona Collaborating Centres) and have exchanged materials and expertise, and we collaborate with the Copenhagen office at an ad-hoc basis.

4. Please briefly describe any type of technical, programmatic, advisory or other support received from WHO during the past 12 months for the implementation of the agreed activities listed above (if any).

Not applicable