The Cicely Saunders Institute is the first purpose built institute for research into palliative care offering palliative care courses and other resources relevant to palliative care. Palliative care is the active total care of patients whose disease is not responsive to curative treatment. The goal is the best possible quality of life for patients and their families, and includes control of pain and other symptoms, as well as attention to psychological, social and spiritual problems.

Researchers from the Cicely Saunders Institute and patient and public representatives have collaborated to publish a paper in the journal: Palliative Medicine, entitled: ‘Results of a transparent expert consultation on patient and public involvement in palliative care research’.

The paper explores priorities between service users and researchers feedback given at a workshop held at the Institute in April 2014. The authors used a previously established method in palliative care – the MORECare Transparent Expert Consultation approach. This MORECare method helped identify individual priorities, generate recommendations and form consensus on priorities for service-user involvement in palliative care.

To access the paper visit [http://ow.ly/OVyMN](http://ow.ly/OVyMN)

We are hosting our next workshop the week beginning 24th August 2015. To get in touch with us about PPI please email csi.ppi@kcl.ac.uk

The OACC Palliative Care Outcome Measures Resource Pack

We are pleased to have launched, in collaboration with Hospice UK, The OACC Palliative Care Outcome Measures Resource Pack (pictured right). These resource packs contain sets of outcome measures (for inpatient and community settings), guidance booklets on how and when to implement outcome measures, and training resources for your team (training videos, animated PowerPoint presentations and prompt cards). They are designed to support hospices and palliative care providers across the UK in implementing outcome measures into clinical practice. As well as hard-copy and electronic resources, other benefits include access to join monthly webinars with presentations given from OACC staff members. Webinar topics are drafted according to service feedback so many will benefit from the topic suggestions. As well as webinars, services are given access to a dedicated telephone support line and email address, for ongoing support and questions. This collaboration between the Institute and Hospice UK has ensured the outcome measures are aligned with the national UK Palliative Care Clinical Dataset and the palliative care Development Currency in England. In the first six weeks of sales, over 80 resource packs have been sold internationally with the majority around the UK, and some in Canada, the USA and New Zealand. The team and Hospice UK are thrilled with the packs popularity so far.

The OACC Palliative Care Outcome Measures Resource Pack, available on the King’s College London estore

Involving service-users in palliative care research

Researchers from the Cicely Saunders Institute and patient and public representatives have collaborated to publish a paper in the journal: Palliative Medicine, entitled: ‘Results of a transparent expert consultation on patient and public involvement in palliative care research’.

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Upcoming Events

For more information please visit [www.csi.kcl.ac.uk](http://www.csi.kcl.ac.uk)

Seminar: A palliative care approach for people with advanced heart failure: recognition of need, transitions in care, and effect on patients, family carers, and clinicians

Wednesday 22nd July 2015

Dr Amy Gadoud, NIHR Clinical Lecturer in Palliative Medicine at Hull York Medical School

Seminar: TBC Advance care planning for people with chronic kidney disease

Wednesday 14th September 2015

Dr Josephine Clayton, Associate Professor of Palliative Care Medicine, University of Sydney/Consultant Physician in Palliative Medicine

Seminar: Non-pharmacological interventions for refractory chronic cough patients

Thursday 24th September 2015

Dr Surinder Birring, Consultant Respiratory Physician, King’s College Hospital NHS Foundation Trust

Seminar: Vocational rehabilitation; supporting a return to work — lessons from stroke

Wednesday 28th October 2015

Dr Kate Radford, Associate Professor in Rehabilitation Research, Faculty of Medicine & Health Sciences, University of Nottingham
Staff Profiles:
Cathryn Pinto, Research Assistant

Cathryn joined the department in February 2015 to work on the C-CHANGE project with Dr Fliss Murtagh, which aims at developing a casemix classification to inform palliative care funding models. Her work focuses on understanding perspectives on complexity, resource use and outcomes through interviews with various stakeholders in specialist palliative care.

Prior to her role at the Institute, Cathryn worked with the Parkinson's disease and Movement Disorder Society in Mumbai, where she worked as a psychologist to support people with Parkinson's and conducted research on Parkinson's disease.

Cathryn completed her MSc in Health Psychology from the University of Bath in 2013. Her dissertation focused on understanding patients' experience of the self-management of cancer treatment-related lymphoedema.

Available Resources
For more information about the Cicely Saunders Institute, please visit our website www.csi.kcl.ac.uk
For more about outcome measurements and specifically the Palliative care Outcome Scale (POS) please visit www.pos-pal.org
A new website is being launched for the whole NIHR CLAHRC South London www.clahrc-southlondon.nihr.ac.uk
To purchase The OACC Palliative Care Outcome Measures Resource Pack for £150.00 plus delivery costs, visit

Contact Us
Via email: Francesca.cooper@kcl.ac.uk
Via telephone: 0207 848 0096
Via social media:
Twitter @CSI_KCL
Facebook https://www.facebook.com/CicelySaundersInstitute
YouTube http://www.youtube.com/user/CSIKCL

Work in the Media
• Read the latest article in the Independent, referencing work from the Institute undertaken by theme lead, Professor Irene Higginson and Project 1 lead Dr Wei Gao http://ow.ly/OP9wE
• Professor Irene Higginson recently gave a radio interview on BBC Radio 4 on a programme entitled ‘Is cancer money well spent?’ http://www.bbc.co.uk/programmes/b05pnsr8
• For more of the Cicely Saunders Institute media coverage please visit our website, Twitter feed and YouTube channel

Project 1: Geographical accessibility to healthcare facilities and place of death in South London
ArcGIS (A Geographic Information System software) has been utilised to calculate distances between each individual death record and its nearest five healthcare facilities (Hospital, Care home, Hospice, Specialist palliative care). Public transport accessibility scores and distances have been merged into the master dataset of nearly 20,000 deaths in South London. We are now developing a detailed analysis plan.

Two abstracts highlighting work to date on the project have been submitted to scientific conferences hosted by Hospice UK and National Cancer Research Institute. A journal article is being prepared comparing different methods of calculating geographical accessibility within the CLAHRC South London area.

The newly committed NIHR project, GUIDE Care Services starting on 1 July 2015, will enable us to expand this stream of work to the national scale and in a more comprehensive view of the role of service factors in place of death. For more details about Guide_Care Services project, see http://www.nets.nihr.ac.uk/projects/hsdr/141922

Project 2: To agree and implement a common set of measures to capture patient needs and outcomes in palliative and end of life care
The team has been running monthly webinars as part of the resource pack, including the quality improvement facilitators presenting on ‘Preparing your service’ and Dr Fliss Murtagh presenting on ‘Capturing outcomes data & integrating this in IT systems’. Both events were highly successful with services from the UK joining.

In South London specifically, the OACC team are continuing to work together with the original OACC services, and have now started to advise additional services (including Trinity Hospice and St Joseph’s Hospice) to support the introduction of the OACC suite of measures. The two research projects running alongside OACC are continuing.

Dr Jonathan Koffman, Sophie Pask, Francesca Cooper, Dr Fliss Murtagh and Katie Witcombe at the Association for Palliative Medicine Conference, April 2014.