



Cicely Saunders
International
Better care at the end of life

WHO Collaborating Centre for
Palliative Care & Older People



KING'S
College
LONDON



Research in Palliative and End of Life Care - Scope for Patient and Public Involvement?

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<http://www.cicelysaundersfoundation.org/research/project-buildcare>

BuildCARE

What I am going to discuss?

- What is palliative and end-of-life care?
- Introducing the Cicely Saunders Institute (CSI)
- Research project BuildCare
 - Dissemination, Engagement & Empowerment (DEE) programme
- CSI Vision and opportunities for PPI
- Example of PPI - OptCare study
- Opportunities for PPI – MORECare Capacity

Palliative care aims to...

Improve the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual
(WHO 2004)

End of life care generally refers...

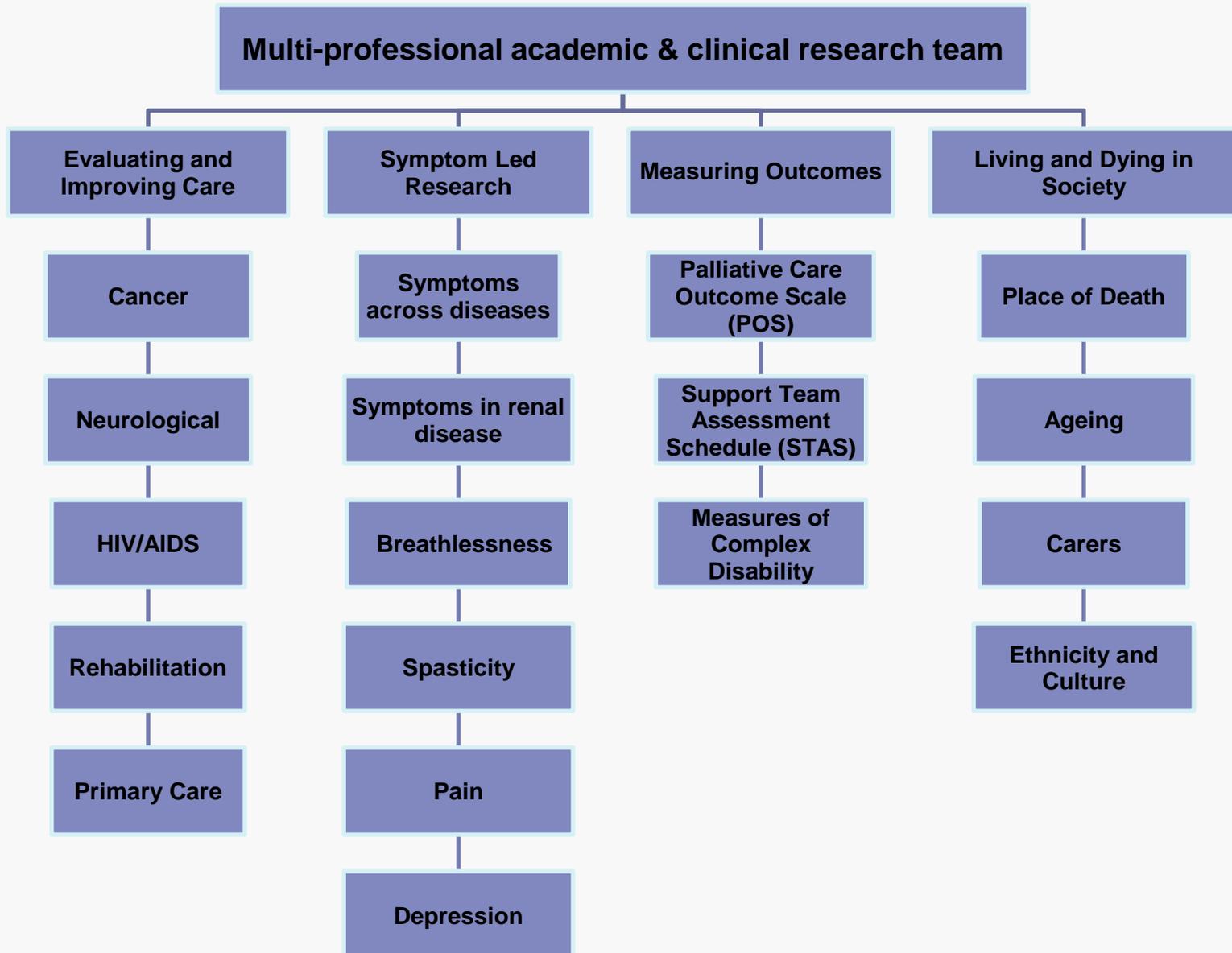
- To people considered to be in the last 12 months of life with:
- Advanced, progressive, incurable condition
- General frailty and co-existing conditions anticipated as in the last 12 months of life
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events

(NCPC 2012)

Cicely Saunders Institute



Cicely Saunders Institute Research Themes



Special Section: The PRISMA Symposium

The PRISMA Symposium 1: Outcome Tool Use. Disharmony in European Outcomes Research for Palliative and Advanced Disease Care: Too Many Tools in Practice

Richard Harding, BSc, MSc, DipSW, PhD, Steffen T. Simon, MSc, MD, Hamid Benalia, BSc, MA, Julia Downing, RN, PhD, Barbara A. Daveson, BMus (Mus Thy), Dip HSM, PhD, Irene J. Higginson, BMedSci, BM BS, FFPHM, FRCP, PhD, and Claudia Bausewein, MSc, MD, PhD, on behalf of PRISMA

Downloaded from pmj.bmj.com on July 9, 2012 - Published by group.bmj.com

Original article

Evaluation of a new model of short-term palliative care for people severely affected with multiple sclerosis: a randomised fast-track trial to test timing of referral and how long the effect is maintained

Irene J Higginson,¹ Massimo Costantini,² Eli Silber,³ Rachel Burman,⁴ Polly Edmonds⁴

<http://pos-pal.org/>

Age and Ageing 2011; 0: 1-5
doi: 10.1093/ageing/afr027

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JOURNAL OF PALLIATIVE MEDICINE
Volume 13, Number 9, 2010
© Mary Ann Liebert, Inc.
DOI: 10.1089/jpm.2010.0068

Assessing quality-of-life in older people in care homes

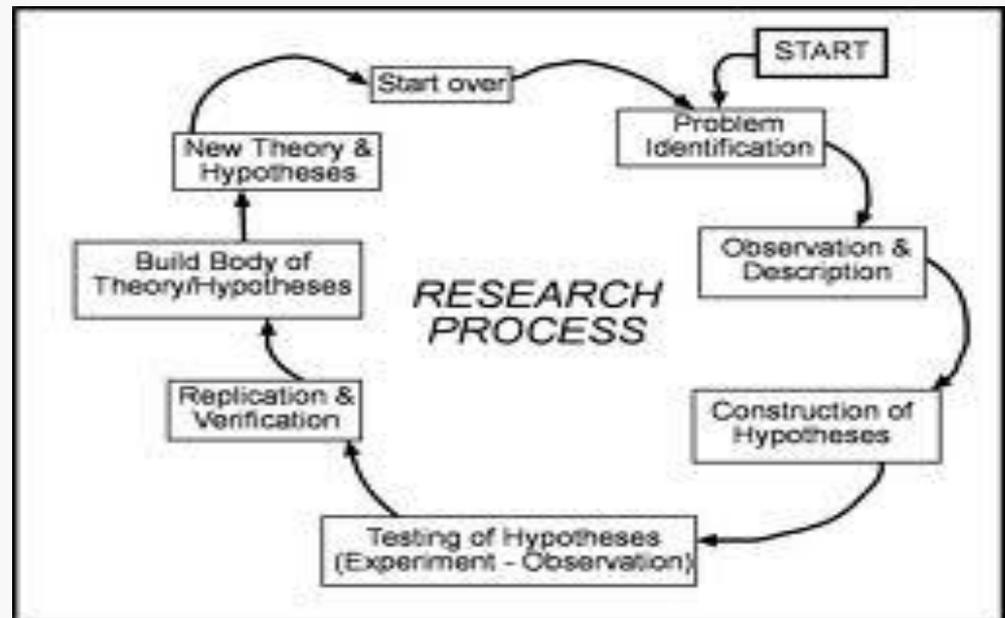
SUE HALL¹, DIANA OPIO², RACHAEL H. DODD¹, IRENE J. HIGGINSON¹

Understanding Breathlessness: Cross-Sectional Comparison of Symptom Burden and Palliative Care Needs in Chronic Obstructive Pulmonary Disease and Cancer

Claudia Bausewein, Ph.D., M.D.,¹ Sara Booth, M.Sc., M.D.,² Marjolein Gysels, Ph.D., M.A., B.A.,³ Robert Kühnbach, M.D.,⁴ Birgit Haberland, M.D.,⁴ and Irene J. Higginson, Ph.D., FRCP, FFPHM, BMedSci, BMBS¹

Conceptualising involvement in research

- Involvement in teaching
- Involvement in research
 - At all stages of the research cycle



Remembering the Research Process

- ▶ Identify the research question(s)
 - ▶ Define the research method(s)
 - ▶ Creating the research tool(s)
 - ▶ Specify the research site
 - ▶ Constructing the sample of research 'subjects'
 - ▶ Negotiate access
 - ▶ Collect the data
 - ▶ Analyze the data
 - ▶ Interpret the findings
 - ▶ Disseminate the findings

Collect Nobel Prize and Become Famous
(Tritter 2012)

Forms of User Involvement

- **Individual and Collective Involvement**
 - Service user agreeing to participate in an RCT
 - Feedback on a Participant Information Sheet from a Pensioner Forum
- **Proactive and Reactive Involvement**
 - Consultation with a cancer support group about possible research questions
 - Seeking feedback from user group on a particular proposal
- **One-off or Continuous Involvement**
 - Focus group to discuss a particular research idea
 - Project User Group or service user membership of steering group (Tritter 2012)

Changes in requirements for research..

From funders

- National Institute for Health Research (NIHR)
 - Research for Patient Benefit identify how patients and users involved in generating the research proposal and part of the research process
- Medical Research Council
- Economic and Social Research Council

Emphasis 'impact' of research

- Relevance of research to the public
- Grant applications, research reports and Research Excellence Framework (quality assessment for HEI)

BuildCARE

Aims to create a 'sea change' in the way palliative and end-of-life care is regarded, implemented and prioritised internationally.

Four-year project, supported by Cicely Saunders International and The Atlantic Philanthropies.

Components

- Dissemination, Engagement & Empowerment (DEE) programme
- International PhD studentships (four studentships)
- International faculty scholarships (two scholarships)
- International Access, Rights & Empowerment (IARE) study

CSI Patient and Public Involvement

- Dissemination, Engagement and Empowerment programme – The DEE Programme
- Embedding change in palliative care through four key aims:
 1. Raise awareness
 2. Inform audiences
 3. Engage audiences
 4. Promote outputs

Achieving DEE programme by

- Disseminating research that demonstrates the value of end-of-life care
- Promote research excellence
- Promote the Cicely Saunders Institute as an international resource for expert advice on palliative and end-of-life care
- Provide information to patients and their families to increase knowledge of the care that is available

Public engagement activity streams

- Online activity programme which includes CSI website, blogging, tweeting and social media e.g. Facebook
- The Cicely Saunders events programme (workshops, lectures and seminars)
- Involvement in creative outreach e.g. artwork projects to reduce stigma attached to death and dying
- Press and public relations work

facebook

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University
The Cicely Saunders Institute (CSI), King's College London, is the first purpose built institute for research into palliative care offering palliative care courses and other resources



Photos

[Like](#) 35

Likes



Study with us



PhD study

Highlights

Cicely Saunders Institute shared a link.
8 August

Mark has been caring for his wife for 5 years, to Carers UK, he describes his experience as "Hard, disturbing, loving."
<http://bit.ly/NRP1ks>



Mark Yates | Carers UK
bit.ly

Mark Yates Mark has been caring for his wife for five years on and off. Mark's advice to carers is:

Also on

- <http://www.csi.kcl.ac.uk>
- https://twitter.com/#!/CSI_KCL
- <http://www.youtube.com/CSIKCL>

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Sousa Guest Shouse
This instbite is one of the best in the uk well done
28 July at 02:58

Katrien Moens



CSI Palliative Care

@CSI_KCL

The Cicely Saunders Institute (CSI), King's College London, is the 1st purpose built palliative care research institute offering courses & other resources

London · <http://www.csi.kcl.ac.uk>

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Tweets

CSI Palliative Care @CSI_KCL 4 Sep
Ideas for our next open seminar series at CSI? We're planning our 2013 programme. #palliative #rehabilitation -Barb Daveson
[Expand](#)

CSI Palliative Care @CSI_KCL 4 Sep
RCN's Peter Carter: 'New initiative will tell the public that nurses are remarkable'- ow.ly/drpUb. #Clinical RT @NursingTimes
[Expand](#)

CSI Palliative Care @CSI_KCL 3 Sep
Was great to meet all who came to last month's CSI Open Seminar. Next one is 26 Sep- ow.ly/dqulw. See you then! #palliative
[Expand](#) [Reply](#) [Retweet](#) [Favorite](#)

CSI Palliative Care @CSI_KCL 3 Sep
Key note presentation from Dr Mary Baines on pioneer days of Homecare@ CSI on 24 Sep - book your place now!
tinyurl.com/cwdhree
[Expand](#)

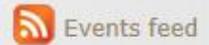
CSI Palliative Care @CSI_KCL 3 Sep
RT @dhgovuk: Join in the conversation on how to strengthen the #NHS Constitution. New blog launched today ow.ly/dqkuj
[Expand](#)

International Seminar Series, workshops 'Making research count for those that count on research: Patient and public involvement in research' Prof Jonathan Tritter, Chair Carolyn Morris, and

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- Patients and families
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Events



Wednesday 28 November 2012

Seminar: 'Palliative care for liver disease and the development of SPICt' by Dr Kirsty Boyd, Honorary Clinical Senior Lecturer, Centre for Population Health Sciences, University of Edinburgh, College of Medicine and Veterinary Medicine

Wednesday 25 October 2012

Seminar: 'Mixed methods in effectiveness research: understanding process to inform implementation', by Professor Alicia O'Cathain, Professor of Health Services Research, University of Sheffield

Wednesday 26 September 2012

Seminar: 'Using Outcome Measures in clinical practice: Theory to Reality' by Professor Sarah Tyson, Professor of Rehabilitation, Manchester Stroke Research Centre and Manchester Academic Health Services Centre, University of Manchester

Monday 24 September 2012

[Homecare: evolution, evidence and experience](#)



CSI Patient and Public Involvement

- CSI Consumer Collaboration and Public Engagement Group (CCPE) will represent and include 6–8 carers, patients and members of public interested in palliative care.
- Aims to provide:
 - Opportunities to work in collaboration with individuals actively involved in palliative care research and service improvements
 - Forum to present new research ideas and receive constructive feedback
 - Opportunity to ensure work reflects the preferences and priorities of the end user, through consultation.

Patient and Public Engagement

- Relevance, acceptability and adequacy of work through:
 - Enhancing our research proposals and resources e.g. public relevance
 - Add value to the research outputs
 - Facilitating research activities e.g. focus groups
 - Interpreting research findings and approaches to analysing data
 - Our champions in raising public awareness
 - Master class in Consumer Involvement (COMPASS, Carolyn Morris facilitated)

Example PPI –OptCare: Optimising palliative care for older people

PPI imperative – model and acceptability of palliative care for frail older people uncertain

- **Consulting** and engaging with local service users in study site to develop protocol, data collection tools (e.g. Older People's Council, Pensioner Action)
- **Collaboration** on-going through Project User Group (12 lay members) and Project Advisory Group
- **Co-investigation** two lay co-investigators work with research team on specific aspects e.g. co-ordination Project User Group, enabling older people's participation

Masterclass ‘ Collaborate and Succeed with Service Users’ (COMPASS)

- Masterclass conceived, developed and delivered by two service users (including Carolyn Morris), supported by researchers funded by COMPASS (NCRI) four workshops during 2009-2010
- An interactive workshop, core message that involvement could help researchers resolve some of the practical problems faced
- *The Masterclass won over people’s hearts and minds – it convinced us to do it. It helped to change our minds from ‘having to do it’ – a tick box mentality – to thinking ‘this is something that could be useful for us’.*
(Kristina Staley Two Can Associates 2011)

Opportunity - MOREcare Capacity: Capacity and Consent in Research on EoLC (Marie Curie Cancer Research UK)

- How best to include individuals with advanced illness in research on EoLC
- Identifying solutions and developing best practice guidance on processes of consent for people with impaired mental capacity
- Using systematic review and stakeholder consultation
- Participate in the consultation:
 - Workshop 3rd Dec 2012 to debate and generate best practice recommendations with lay members, academics, ethicists
 - On-line ranking and commenting on recommendations

<http://www.csi.kcl.ac.uk/mcc.html>

How could we improve our patient and public engagement?



Acknowledgements



BuildCare

Chief Investigator: Irene J Higginson.

Project Co-coordinator: Barbara A Daveson

Research & Dissemination: Danielle Harker

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<http://www.cicelysaundersfoundation.org/research/project-buildcare>

