

Importance of Research in end of life care

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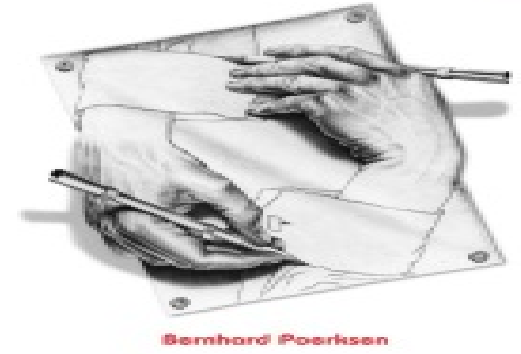


Session Objectives

1. What is research and why is it important
2. EOLC research in the real world
3. Current initiatives in EOLC research
4. Research support



**The Certainty
of Uncertainty**
Dialogues Introducing Constructivism



Research

What comes to mind?





Definition of Research

‘Research is defined as the attempt to derive generalisable or transferable new knowledge to answer or refine relevant questions with scientifically sound methods’

(UK policy framework for health and social care research, v3. 07/11/17)



Evidence Based Practice...

“We need the evidence from research to deliver better care. Much of the care we deliver at the moment is based on uncertainties or experience, but not on evidence? We can only correct that with research”



-Excerpt from the NIHR video 'Enhancing patient care through research'
Professor Dame Sally Davies, CMO for England, Director General of Research & Development and Chief Scientific Adviser for the Department of Health



Research & Audit

“Research is concerned with discovering the right thing to do; audit with ensuring that it is done right”

Smith R. Audit & Research. BMJ 1992;305:905-6

Pressure ulcer example:

“What is the most effective way of preventing Pressure ulcers?” (Research)

“How does our current practice compare to the standards of best practice in the prevention of pressure ulcers.” (Audit)



5. Evaluate
steps 1-4 and
seek ways to
improve next
time

Audit

5 Steps of Evidence-Based Practice

Ask

1. Convert
information
need into an
answerable
clinical
question

Acquire

2. Track down
best evidence
for answering
the question

Appraise

3. Critically appraise the
evidence for validity,
impact & applicability

Apply

4. Integrate
the evidence
into your
clinical
decision
making

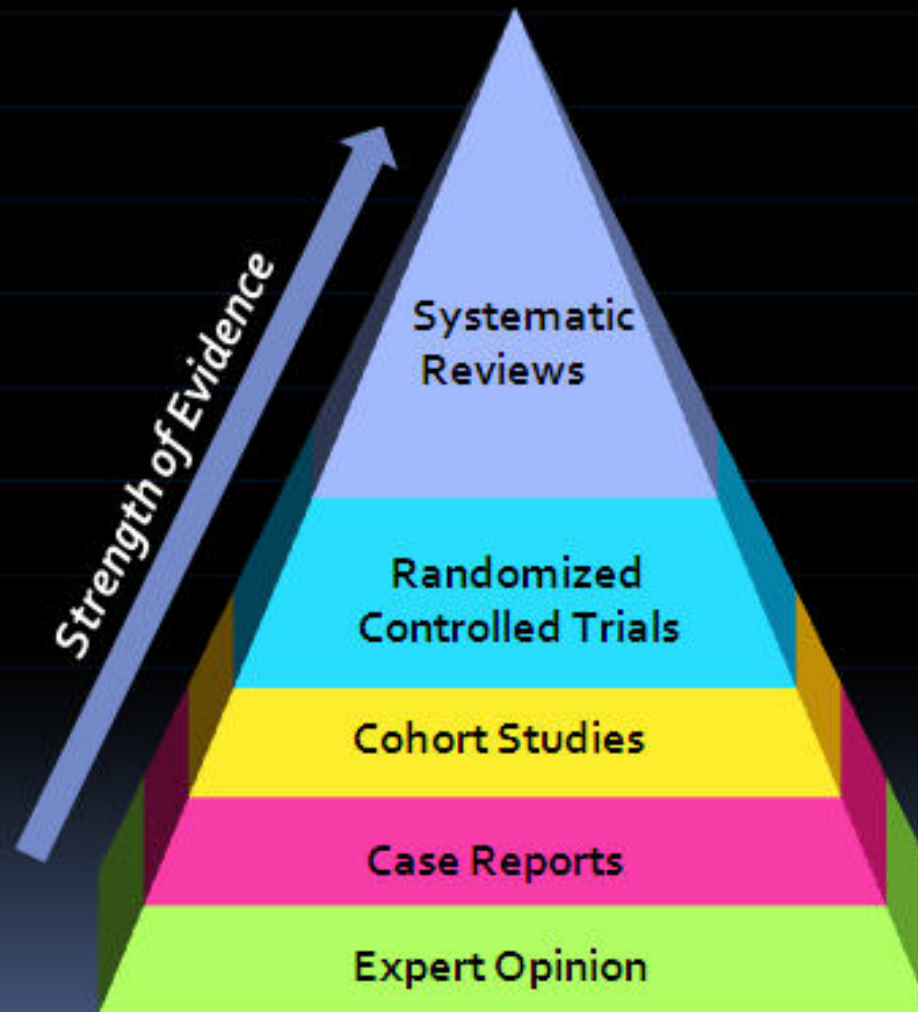


Adapted from Sackett et al 2011, Evidence-based medicine: how to practice and teach EBM

Reference: Turner, M. (2014). "Evidence-Based Practice in Health." Retrieved from University of Canberra website:
<https://canberra.libguides.com/evidence> 04/10/2019



Hierarchy of Evidence



Adopted from: Sackett DL, Straus SE, Richardson WS, et al. *Evidence-based medicine: how to practice and teach EBM*. 2nd ed. Edinburgh: Churchill Livingstone, 2000



Dame Cicely Saunders

St Christopher's Hospice founder 1967

Four components of hospice palliative care:

- Expert pain and symptom control
- Compassionate care
- Teaching
- **Research**

*'Cicely appreciated its importance
and was determined that
St Christopher's should excel in research
and teaching as well as in patient care'*

Biography 2007 p.145





Why carry out research now in end of life care?

An investment for the future

*Without research we cannot
sustain high quality hospice
care*

*To tell us which hospice based
interventions are effective and
how they work*

*Which models of care are best,
and whether they are both
effective and cost-effective.*

Acknowledgements

Dr Fliss Murtagh CSI, London 11th May 2016





Why is research important now in end of life care?

- 1 person dies every minute (NHS England)
- No. of people in Britain aged 85 and over is expected to double in the next 20 years, aged 100+ increase eight-fold (Hospice UK).
- The number of young adults living with life-limiting conditions is also on the increase (Hospice UK).
- Projected that at least 160,000 more people in England & Wales in 2040 will need palliative care - a rise of 25% (Etkind et al 2017).

How does research fit into the real world of eolc?





Pilgrims Recent & Current Research

Current:

- Methylphenidate versus placebo for fatigue in advanced cancer (MePFAC study) – UCL
- Optimum 'Hospice at Home' Services for End of Life Care (Opel H@H Study) – University of Kent

Recent:

- The Prognosis in Palliative care Study II (PiPS2 Study) – led by UCL
- Improving Rehabilitation in Palliative Care using Goal Attainment Scaling (GAS Study) –KCL
- C-Change Workstream 4. Testing a case-mix classification in palliative care Cohort Study –KCL

Soon to start:

- Palliative care and Homelessness training project - UCL
- Understanding and improving community based palliative care out-of-hours –KCL
- Opioids for management of breathlessness (MABEL study) – Hull York Medical School

METHYLPHENIDATE VERSUS PLACEBO FOR FATIGUE IN ADVANCED CANCER (MePFAC)

Cancer-related fatigue is described as an overwhelming sense of tiredness or exhaustion which is unrelieved by rest and is associated with cancer or its treatment. It is a widespread problem in people with cancer at all stages of their illness, whether receiving treatment or not.



This research study is looking to recruit patients who are experiencing fatigue as a result of cancer treatment in order to see whether a drug (Methylphenidate) can reduce the fatigue experienced.



- Study led by CHSS at University of Kent
- + no. of collaborating partners including Pilgrims
- Research Question: What are the features of Hospice at Home models that work, for whom and under what circumstances?
 - Phase 1 national survey of H@H services
 - Phase 2 In-depth data collection to investigate the impact of different models of H@H on patient and carer outcomes and experiences of EOLC.
 - Phase 3 consensus events with stakeholders at the end of data collection to 'sense check' our results



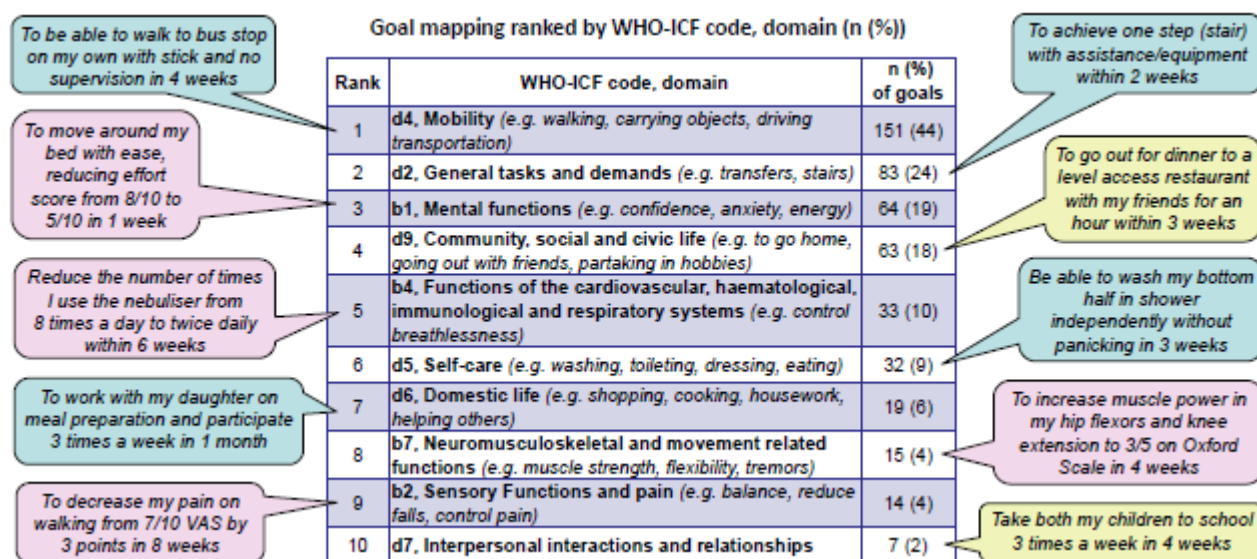
Prognosis in Palliative Care 2

- Adapted from PIPS1
- Testing and validating the PIPs tool
- Evaluate the accuracy of other predictive tools of survival i.e., the Palliative Prognostic (PaP) score, Palliative Prognostic Index (PPI), Palliative Performance Scale (PPS), in a large group of patients across England and Wales.
- Was is a multi-centre study, aiming to recruit 1,780 patients via 28 palliative care services. Patients are eligible to participate in the study if they have advanced, incurable cancer

GAS Study

Improving Rehabilitation in Palliative Care using Goal Attainment Scaling

Goal setting helps to understand what patients want to achieve from rehabilitation services. The Goal Attainment Scale was used to understand the timescale and nature of rehabilitation goals set by palliative care patients.



Preliminary results of first 200 patients presented by KCL research team at EAPC conference March 2017.

- Patients are able to engage in setting functional goals
- Most are short time frames (days or weeks) and focus on retaining independence in life activities and situations
- Patient-set goals can direct appropriate rehabilitation intervention



IMPROVING CARE BY MATCHING
RESOURCES TO NEEDS

Objectives:

- To understand people's palliative care needs
- To develop a standardised way to measure complex needs and match to healthcare resources
- We followed service users through their palliative care journey, collecting data from the patient, their carer and the staff involved in their care when the patient changed care settings and at different phases of their illness.
- Video provides insight into how & why the research study looked at co-ordination of care as an important topic:

<https://www.youtube.com/watch?v=RnOYg0myU0M&feature=youtu.be>



What current & future challenges are there in end of life care research?



Participant
information sheet
for the research
on fatigue



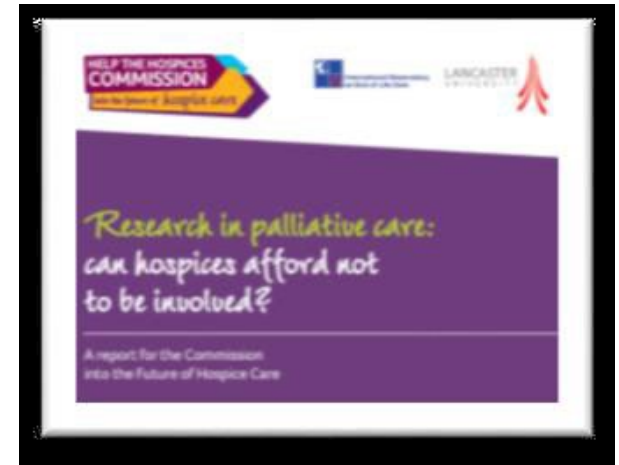
Current initiatives in EOLC research





Commission into the Future of Hospice Care/ Lancaster University (Payne et al, 2013) →

**Recommended a research framework for
Hospices:**



Level 3 – Generating and leading research

level 3: Engagement in research activities
and leadership in developing and
undertaking research

Level 2 – Engagement in research
activities generated by others

level 2: Engagement in research generated
by others

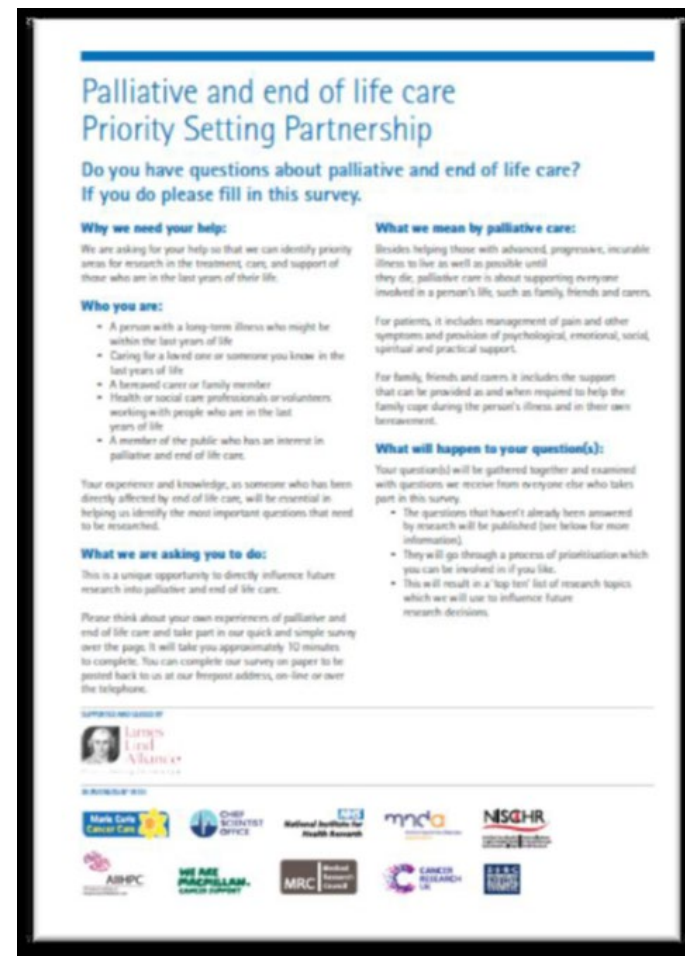
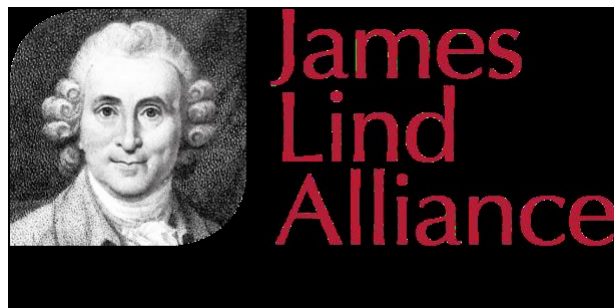
Level 1 – Awareness of research

level 1: Research awareness in all
professional staff

Palliative & EOLC Priority Setting Partnership: 10 top priorities for further research

- Conducted in 2013
- 1403 responses analysed
- 749 initial (interventional) questions
- Checked existing systematic reviews
- Combined to form 83 questions
- Second short-listing survey: 1331 participants
- 28 questions long-listed
- Final priority setting workshop

**Top 10 priorities for research agreed
(Report published 2015)**





Palliative & EOLC Priority Setting Partnership

Top 10 unanswered research questions, in order of priority

1. The best ways of providing care outside of working hours	6. Determine needs for patients with non-cancer diseases
2. Access for everyone regardless of where they are in the UK	7. What core palliative care services should be provided
3. Advance Care Planning –listening to and incorporating patients’ preferences	8. The best ways of providing care in the patient’s home
4. Information and training for carers and families	9. Continuity for patients at the end of life
5. Ensuring staff and health care assists adequately trained, which increases quality of care	10. The best ways to assess and treat pain/discomfort for people at the eol with specific conditions/ difficulties



EOLC is an ‘under-researched’ area:

- funding for cancer related palliative & eolc research below 0.7% of total spend since 2002 (NCRI).
- 0.16% of total health related research activity in the UK in 2014 (UKCRC HRCS grant dataset)

...but new initiatives are helping to increase & support eolc research in the UK:

- Upscaling of promotion & investment from research funders & national charities (e.g. Marie Curie, NIHR, Hospice UK)
- Consortium for Hospice and Community Care Research, set up 2017 between NIHR and Hospice UK.
- Access to palliative care bill 2016-17 – includes advancing research
- NIHR Clinical research network policy extended to support non-NHS organisations such as hospices from January 2018

Support for EOLC research

RESEARCH GOVERNANCE: A GUIDE FOR HOSPICES

This Toolkit has been developed as a guide for researchers working in independent hospices settings to support development of a research governance infrastructure and facilitate the research engagement of independent organisations.



<http://www.nischr-cancerrrg.org/research/>

MORECare statement

36 best practice solutions to develop and evaluate complex interventions in palliative and EoLC



www.pilgrimshospices.org



National Institute for Health Research



ENRICH
Enabling Research In Care Homes

NEWS ALERT: October 2016 is

SPOTLIGHT ON



HOSPICE RESEARCH MONTH

for

#WhyWeDoResearch

@learnhospice



Support for EOLC Research

- Research Facilitator, Pilgrims Hospices
 - Advice/Information source
 - Links to potential collaborators e.g Universities, other clinicians
 - Development of funding applications
 - I need to know what research is happening
 - Database
 - Research Facilitation & Governance Forum
- Research Hub on Intranet
- Kent & Medway Palliative Care Research group
- R&D departments/libraries in NHS Trusts



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Thank you for listening Any Questions...

