End of life care research update report – April 2013

Background

The NCRI has compiled a second research update report (Annex 1) using PubMed search techniques which are outlined in Annex 2.

Actions:

- Members are asked to note the content of Annex 1

- Members are asked to;
  o Comment on the revised search methodology and how it may be further refined.
  o Consider the uses and benefits of the research summaries reports and how the generation of the reports may be sustained.

Research updates: January 2013 – April 2013

1. <u>Learning from the public: citizens describe the need to improve end-of-life-care access, provision and recognition across Europe</u>. Daveson A. *et al*.

   Summary: This international survey (n=9344) identified that within Europe the public recognises the importance of death and dying, quality over quantity of life and wish to see improved end of life care for patients especially for older people and families. Suggested policy responses and education/service delivery and research priorities are outlined.
   <u>European Journal of Public Health</u> 2013 March 13

2. <u>Heterogeneity and changes in preferences for dying at home: a systematic review</u>. Gomes B. *et al*.

   Summary: This literature review suggests that most people prefer to die at home and that most don't change their preference as their illness progresses.
   <u>BMC Palliative Care</u> 2013 February 15

3. <u>Changing patterns in place of cancer death in England: a population-based study</u>. Gao W. *et al.*

   Summary: This UK-based study (n=2,281,223) identified hospital to be the most common place of cancer death (48%) followed by home (24.5%) and hospices at (16.4%) between 1993 and 2010. Inequalities in place of death relating to cancer type, marital and socioeconomic status were identified.
   <u>PLoS Med</u> 2013 March

4. <u>'I am closer to this place'--space, place and notions of home in lived experiences of hospice day care</u>. Moore A. *et al*.

   Summary: This paper explores the view of 11 patients attending hospice day care of hospice as a place. Using concepts from existential and humanistic geography the results indicate that hospices generate a homelike place. Three existential modes that illustrate becoming 'at home' in hospice are proposed by the authors.
   <u>Health and Place</u> 2013 January 19

5. <u>Evaluating palliative care ward staffing using bed occupancy, patient dependency, staff activity, service quality and cost data</u>. Roberts D, Hurst K

   Summary: This study has adapted the acuity-quality workforce planning method for use in hospices by collecting data on bed usage and staff levels from palliative care wards and hospices in England to provide evidence-based recommendations on future nursing workforce size and mix.
   <u>Palliative Medicine</u> 2013 February

6. <u>Methicillin-resistant Staphylococcus aureus (MRSA) management in palliative care units and hospices in Germany: a nationwide survey on patient isolation policies and quality of life</u>. Bukii J. *et al*.

   Summary: This study identified that the rigorous application of MRSA protocols in palliative care units and hospices imposes significant burden at the end of life and particularly in palliative care units often restricted patient's activities and had a negative impact on the patient's quality of life.

[Palliative Medicine](#) 2013 January

7. <u>Uncovering an invisible network of direct caregivers at the end of life: A population study</u>. Burns SM. Et al.

   Summary: This South Australian study (n=23,706) highlighted that a substantial network of caregivers mainly invisible to the health teams provide the majority of end of life care. Extended family members and friends were found to provide 55.9% of hands-on care at the end of life, though the period of care they provided it was often shorter. There is a need to consider how to identify this carer group and how to support them.
   [Palliative Medicine](#) 2013 April

8. <u>What is the extent of potentially avoidable admissions amongst hospital inpatients with palliative care needs</u>? Gott M. *et al*.

   Summary: This study (n=580) highlighted that only 6.7% of patients meeting the diagnostic criteria for palliative care were identified as potentially avoidable hospitalisations suggesting that the extent of avoidable hospitalisations is significantly lower than often suggested.
   [BMC Palliative Care](#) 2013 February 18

9. <u>Providing nutritional support for patients with cancer cachexia</u>. McCreery E, Costello J

   Summary: This paper highlights the cause, treatment and management of cachexia in advanced cancer. The Macmillan approach to weight and eating, which focuses on the social aspects of eating, is particularly supported as it considers the effects of malnutrition on the patient as well as the carer.
   [International Journal of Palliative Nursing](#) 2013 January

10. <u>Issues in caregiving for older people with intellectual disabilities and their ageing family carers: a review and commentary</u>. Ryan A. *et al.*

    Summary: As those with intellectual disabilities are ageing so are their carers. There is a need to recognise their mutually dependent relationships, to develop services and support structures appropriate for the person's age and their intellectual disability, and to support their future planning.
    [International Journal of Older People Nursing](#) 2013 March 15

11. <u>Mortality and medical care after bereavement: a general practise cohort study</u>. King M. *et al.*

    Summary: This cohort study (n=92,129) showed that individuals exposed to a cancer death had a reduced risk of mortality and an increased likelihood of receiving new prescription for an antidepressant or hypnotic.
    [PLoS One](#) 2013 January 25

12. <u>Preferred place of death for children and young people with life-limiting and life-threatening conditions: A systematic review of the literature and recommendations for future inquiry and policy</u>. Bluebond-Langer M. *et al.*

    Summary: Based on a literature review this paper highlights the lack of robust evidence for preferred place of death for children and young people. It recommends rigorous research involving parents, children and siblings to inform future policies on preference for place on death.
    [Palliative Medicine](#) 2013 April 23

13. <u>Survival of people with dementia after unplanned acute hospital admission: a prospective cohort study</u>. Sampson EL. *et al*.

    Summary: This prospective cohort study (n=616) highlighted that people with dementia had half the survival time of those without the disease. The study proposes that clinicians should consider adopting a supportive approach to the care of older people with dementia who have had an emergency hospital admission.
    [International Journal of Geriatric Psychiatry](#) 2012 December

14. <u>Rehabilitation in Advanced, Progressive, Recurrent Cancer: A randomised Controlled Trial</u>. Jones L. *et al.*

    Summary: This randomised controlled trial, which involved 41 participants, showed that rehabilitation interventions were cost-effective and that they reduced the unmet needs of cancer survivors after active treatment.
    [Journal of Pain and Symptom Management](#) 2012 November

15. <u>Preferences for end-of-life care: A nominal group study of people with dementia and their family carers</u>. Dening KH. *et al.*

    Summary: This study highlights that people with dementia are not often involved in decisions regarding their end of life care. The wishes and preferences for people with dementia should be ascertained early in the disease to inform decisions in future care.
    [Palliative Medicine](#) 2013 May 27

Research updates from other sources

[Ehospice website – Journal watch](#)

The journal watch section of the ehospice website is updated regularly and provides details of some of the latest research.

- Journal watch - www.ehospice.com/uk/en-gb/categories/research.aspx.

[End of Life Care Horizon Scanning bulletin](#)

The End of Life Care Horizon Scanning bulletin publishes the most relevant up to date research to support commissioning processes and service design. The bulletin is compiled from a wide array of sources by a group of primary care librarians with the assistance of the content advisory group whom are expert members in their field of specialty.

- Volume 5, Issue 2 ([February](#))
- Volume 5, Issue 3 ([March](#))
- Volume 5, Issue 4 ([April](#))

[BMJ Supportive and Palliative Care Shortcuts](#)

The shortcuts section of the BMJ SuPaC contains summaries of articles of interest from other scholarly journals compiled by researchers active in the field. Access to the full shortcut article requires subscription.

- Volume 3, Issue 1 ([March, 2013](#))

[Barry Ashpole Media Watch](#)

Media Watch is a freely available weekly online resource for people with a special interest in hospice, palliative and end of life care issues. The report contains an annotated listing of articles and reports from the lay press and specialist publications. International in scope, it is intended as an advocacy and research tool.

- Media Watch ([January to April](#))

Databases of research underway

[NCRI Palliative and Supportive Care Clinical Studies Group (PSC CSG)](#)

The PSC CSG is tasked with managing a portfolio of palliative and supportive care studies. Studies currently recruiting and those in set up are included in the CSG's portfolio map which is updated regularly. Each of the studies on the portfolio map links through UKCRN portfolio website where more information on the study, including details such as PI, funder, number of recruiting sites and study type, can be found.

- PSC CSG Portfolio Map ([February 2013 version](#))

[International Cancer Research Partnership (ICRP) database](#)

The ICRP is a partnership of cancer research funders working to enhance global collaboration and strategic coordination of cancer research. The ICRP database includes information on past and current research grants funded by member organisations including NCRI Partners. Each award is categorised by research type using the Common Scientific Outline (CSO). Research with palliative, end of life care, symptom management or quality of life components can be found in CSOs 6.1, 6.6 and 6.9.

- ICRP [database](#)

Methods used to compile the research update report

The NCRI was tasked with identifying research of interest to the NEOLCIN stakeholder group in the area of palliative and end of life care. The previous research update report (January 2013) was compiled following the scanning of research articles from a small number of specialist palliative care journals. Following discussions at the January 2013 meeting it was agreed that the next research update report should incorporate a broader array of palliative and end of life care research and source these from a wider range of academic journals.

To compile this second research update report we used PubMed, the citation database. PubMed includes the citations from an extensive catalogue of journals including a number focussed on ethics, sociology and the social sciences as well as the general medical literature and Cochrane Systematic Reviews.

Given the breadth of research that is published every month we investigated making our own filter and using those developed by others to identify research of interest. The filter developed by Sladek et al (2006) in their article entitled 'Development of a subject search filter to find information relevant to palliative care in the general medical literature', incorporates a number of palliative and end of life care terms to identify articles and was found to be the most effective [J Med Libr Assoc 94(4)].

The filter;
- Includes the terms advance care planning, attitude to death, bereavement, death, hospices, life support care, palliative care, terminal care and terminally ill.
- To narrow the search results only studies published January - April 2013, with an abstract and published in English were included.
- As research applicable to the UK, or carried out in the UK, is more likely to be applicable to the UK population and health service only citations including UK anywhere within in it were taken through to the next stage. Without the UK search term the filter identified in excess of 13,000 articles of interest. With its addition this reduced to 778, a number more feasible to scanning for relevant research.
- An additional search was developed by us using key words of symptoms that are often associated with at the end of life e.g. depression, nausea, cough, pain, cachexia etc. This filter identified more articles (1,123) however the articles identified as of interest and on-topic were already captured in the Sladek filter. Inclusion of terms such as 'older people' and 'elderly' failed to identify research of relevance unless coupled with terms relating more specifically to palliative and end of life care. Such articles are thus picked up by the Sladek filter directly.

Using Sladek filter described above, and as expanded in Appendix 1, research summaries were compiled of articles that were deemed most relevant and included in the final research update report (Annex 1).

Pros and cons of our filter and PubMed.

The use of PubMed to identify research articles of interest enables us to assess a much broader array of journals and articles than our previous search strategy. The research captured does include research from the areas of ageing and sociology.

Potential issues with our search strategy as identified by Sladek et al are that research coming from non-palliative specialists is hard to pick up. They suggested that it may be necessary to analyse the content of language used by such authors to describe palliative care to identify any words or phrases that could be added to the filter in order to improve it. Another limitation of PubMed is that is does not include citations of all relevant journals. Notable exceptions are the BMJ series journals including BMJ Supportive and Palliative Care and Sociology the highest impact sociology journal published by the British Sociological Association.

The Sladek et al (2006) PubMed filter

Key words used for the search query: Exp Advance Care Planning OR Exp Attitude to Death OR Exp Bereavement OR Death OR Hospices OR Life Support Care OR Palliative Care OR exp Terminal Care OR Terminally Ill AND UK

Filters used: Abstract available, Publication date from 2013/01/01 to 2013/04/19, English

Key words	search query Translations
Advance Care Planning	"advance care planning"[MeSH Terms] OR ("advance"[All Fields] AND "care"[All Fields] AND "planning"[All Fields]) OR "advance care planning"[All Fields]
Attitude to Death	"attitude to death"[MeSH Terms] OR ("attitude"[All Fields] AND "death"[All Fields]) OR "attitude to death"[All Fields]
Bereavement	"grief"[MeSH Terms] OR "grief"[All Fields] OR "bereavement"[All Fields] OR "bereavement"[MeSH Terms]
Death	"death"[MeSH Terms] OR "death"[All Fields]
Hospices	"hospices"[MeSH Terms] OR "hospices"[All Fields]
Life Support Care	"life support care"[MeSH Terms] OR ("life"[All Fields] AND "support"[All Fields] AND "care"[All Fields]) OR "life support care"[All Fields]
Palliative Care	"palliative care"[MeSH Terms] OR ("palliative"[All Fields] AND "care"[All Fields]) OR "palliative care"[All Fields]
Terminal Care	"terminal care"[MeSH Terms] OR ("terminal"[All Fields] AND "care"[All Fields]) OR "terminal care"[All Fields]

MeSH* is a comprehensive controlled vocabulary used by PubMed for the purpose of indexing journal articles and books in the life sciences; it can also serve as a thesaurus that facilitates searching.

Boolean operators allow you to combine words and phrases into search statements to retrieve articles from PubMed. Boolean operators AND, OR, NOT can be used to combine search terms in PubMed.

Automatic explosion (Exp, explode): In PubMed MeSH terms are "exploded" automatically to retrieve citations that carry the specified MeSH headings and also retrieve citations that carry any of the more specific MeSH headings indented beneath it.