



Marie Curie's contribution to palliative and end of life care research funding in the UK

An analysis of the NCRI Cancer Research Database, 2002-13

Marie Curie funds palliative and end of life care research for people with all terminal conditions. Most palliative and end of life care research has traditionally focused on people with cancer, who have better recognised palliative and end of life care needs. The National Cancer Research Institute (NCRI) Cancer Research Database has been collecting data on research that is relevant to cancer from NCRI partners from 2002 to the present day. The present analysis was carried out by NCRI on behalf of Marie Curie.

"Since 2002, the NCRI CaRD has been collecting data on direct spend on cancer research from NCRI partners (up to 21 major UK-based funders of cancer research)"

Background

In 2009, Marie Curie made a decision to concentrate its research investment on palliative and end of life care. This lined up with the services that the charity has delivered to patients at the end of their life, and their families, for more than five decades.

Marie Curie funds palliative and end of life care research for people with any terminal illness. Most research in palliative and end of life care has traditionally focused on people with cancer, who have better recognised palliative and end of life care needs. There is a well-developed infrastructure in cancer research in the UK which includes the National Cancer Research Institute and its Cancer Research Database (NCRI CaRD). Since 2002, the NCRI CaRD has been collecting data on direct spend on cancer research from NCRI Partners (up to 21 major UK-based funders of cancer research).

In 2012, Marie Curie approached the NCRI to gain an insight into the portfolio of palliative and end of life care research in the UK. The NCRI developed a search methodology to take account of the intricacies of the Common Scientific Outline (CSO) coding system (see appendices 1 and 2). The analysis was updated in 2014 to include data from 2013. Marie Curie was also interested in what impact its increased research investment since 2010 has had on the UK research landscape.

Introduction

Several reports have highlighted end of life care research as an underdeveloped area [National end of life care strategy, 2008; Rapid Review, NCRI, 2010].

The NCRI holds grant data from 21 member organisations representing the majority of cancer research funded in the UK, with data going back to 2002. In that year, the newly formed NCRI carried out a strategic analysis of cancer research in the UK and identified supportive and palliative care as an area where research investment was low. In 2004, a more detailed analysis was carried out which resulted in a joint initiative by a group of funding bodies (Department of Health, Marie Curie, Macmillan Cancer Support, Cancer Research UK and the Medical Research Council), and an injection of around £5 million over five years in two large Supportive and Palliative Care (SuPaC) Research Collaboratives and eight smaller capacity-building grants in 2006.

A previous analysis looked at one sub-code (6.6 End of life care) in the database for the year 2012 and found that, of the £508 million awarded for research into cancer, just 0.24% (£1.2 million) was spent on palliative and end of life care research. However, this did not include all the infrastructure support provided by the SuPaC initiative and other long-term investments like the Marie Curie Centres (6.9 Resources and infrastructure related to cancer control, survivorship and outcomes research) or research on common symptoms (6.1 Patient care and survivorship issues) and these are included in the current analysis.

Methods

The NCRI's CaRD data are coded using the CSO – an international classification system organised into seven areas of cancer research. Palliative and end of life care appears in code 6 (Cancer control, survivorship, and outcomes research) and, within this, it appears in a number of sub-codes – mainly 6.6 (End of life care). However, other sub-codes are also relevant; for instance, the SuPaC Collaboratives were coded as infrastructure grants in code 6.9.

The NCRI has been collecting research spend data from its (now 21) funding partners since 2002 in the Cancer Research Database. The database contains the data from the main cancer research funders in the UK. If an organisation funds research in other areas, not just cancer, only the cancer research spend is included (so not all of Marie Curie's research spending in palliative and end of life care appears in the database since some of it relates to non-cancer conditions). It also focuses just on the direct cancer research spending (eg it does not include building costs) so organisations may be funding more than shown.

The analysis was carried out by the NCRI data analyst with clinical input from the former Marie Curie Medical Adviser.

Awards with potential relevance were identified by CSO code and keyword searches. Awards which had a CSO 6.1 (Patient care and survivorship issues), 6.6 (End of life care) and 6.9 (Resources and infrastructure related to cancer control, survivorship, and outcomes research) were all considered potentially relevant. In addition, any award from other CSO codes that had a keyword associated with palliative and end of life care was considered potentially relevant. A comprehensive list of terms related to palliative and end of life care is in appendix 2. The keywords were used on all awards (abstracts and titles) in the database from 2002–13.

The results of these searches were combined and duplicates removed. Each award was then assessed manually for relevance and degree of relevance. The degree of relevance was used to determine the relative amount of funds directed to research related to palliative and end of life care. The values reflect the proportion relevant to cancer patients only, ie in research on more generic diseases, only the proportion relevant to cancer research is included in the database.

No evidence was available to indicate whether certain symptoms were more relevant to palliative and end of life care than others, so symptoms research was assigned a 20% relevance to this analysis (adding up to 100% where multiple symptoms were mentioned per patient).

It should be noted that the titles and abstracts included in the database are written by researchers and so the exact focus of the research is subjective and the research methodology relies on an indication of relevance in the award abstract. For example, any infrastructure support for palliative and end of life care studies provided by the National Institute for Health Research (NIHR) Cancer Research Network is not captured in our analysis because specific studies or disciplines are not referred to in the award's abstract.

Several principles were developed in defining the relevance of a particular award:

- No external information should be used to assess an award's relevance or potential relevance.
- No assumptions should be made in determining relevance to palliative and end of life care. For example, research in pancreatic cancer should not, because of the cancer site, be considered more likely to be relevant to palliative and end of life care than a similar project on prostate cancer.
- No assumptions should be made based on the disease stage as described in the award title or abstract. For example, an award focused on patients with advanced or metastatic cancer should not, because of the stage information alone, be considered more relevant to palliative and end of life care than an award where the stage of the disease isn't defined.

Below is a summary of the inclusion/exclusion criteria and the criteria used to define the percentage relevance of a given award to palliative and end of life care. More details can be found in appendix 2.

Inclusion and exclusion criteria

To be included, the research had to be in an end of life setting or focused on the issues of patients in the last year of life, or the family/carers of patients in this situation. Research focused on cure or survivorship,

research involving older people who are not in the last year of life and research on euthanasia was considered out of scope. Research nurses supported by Cancer Research UK were considered out of scope as their focus is on recruitment to diagnostic and treatment trials.

Defining percentage relevance to palliative and end of life care

Most projects, except those focused on symptoms, were included at 100%. Research considered 100% relevant includes projects on the place of death, research to develop methodologies for palliative and end of life care research, research to determine the cost-effectiveness of services for those in their last year of life and infrastructure for research focused on palliative and end of life care.

Research on symptoms was included at 20% per symptom, up to 100%. Symptoms considered relevant to patients in their last year of life included pain, anxiety, depression, coughing, nausea and breathlessness.

Categorisation by research topic

To understand the palliative and end of life care research funded by NCRI partners in greater depth, all relevant awards were categorised on the basis of the primary aim of the research. Each award was assigned to one of 16 research themes. Again, the analyst was reliant on the accuracy of the descriptions of the research to categorise the awards.

The following categories were included:

- health services and care pathways
- infrastructure
- symptoms (seven sub-categories)
- training
- supportive care and rehabilitation
- methodology
- carers, families and bereavement
- palliative chemo and radiotherapy
- complementary therapies
- hope, dignity, religion and spirituality

Results – overall

In 2013, NCRI partners spent £503 million on cancer research per the inclusion criteria for the database. Some £3.08 million or 0.61% of this total was spent on palliative and end of life care research. Figure 1 shows the research spend on palliative and end of life care as a percentage of the total research included in the database, as well as the total amounts spent on palliative and end of life care research in the UK from 2002 to 2013 (adjusted for inflation). The level of funding for palliative and end of life care was consistently below 0.7% of the total cancer research spend.

While there's a slight increase in the actual amount spent on palliative and end of life care research over the last 12 years, the total cancer research spend in the database also increased, from £340 million in 2002 (after adjustment for inflation using the consumer price index) to £503 million in 2013. However, the numbers for overall spending must be considered with caution as the number of NCRI partners contributing data has also changed over time (from 15 in 2002 to 21 in 2013). The percentage values provide a more reliable measure.

While there seems to be a slight trend towards more palliative and end of life care research since 2009, this trend is very slight. Funding is still at such low levels that it is difficult to observe or interpret trends - one or two awards can make a substantial difference to the overall funding for a particular year. The number of awards with some element of cancer-related palliative and end of life care research varies between 30 and 50 awards per year.

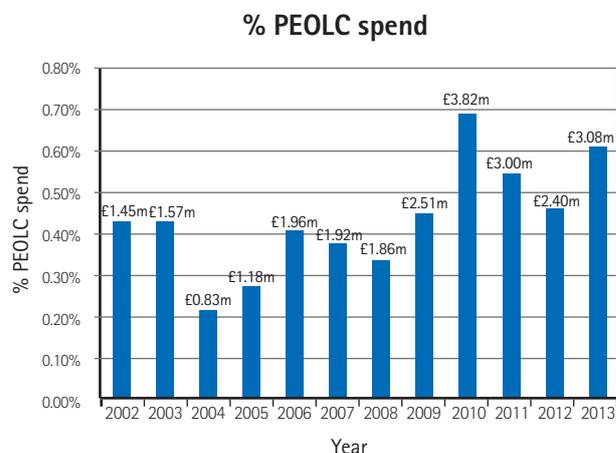


Figure 1: Palliative and end of life care cancer research spend by NCRI partnership (inflation adjusted via consumer price index) in percentage of total NCRI spend or actual figures

"While there seems to be a slight trend towards more palliative and end of life care research since 2009, this trend is very slight"

Most research spending in palliative and end of life care didn't relate to any particular cancer site (86% in 2012) or indeed cancer or non-cancer (though the coding framework is such that in the case of truly generic research into palliative and end of life care, only 25% of the funding would be included in the CaRD database in the first place).

Due to the way data are collected (active grants at 1 April of each year), awards made under the annual £1 million Marie Curie Research Programme, which started in 2010, are included from 2012 onwards only and only include the Marie Curie awards relevant to cancer research.

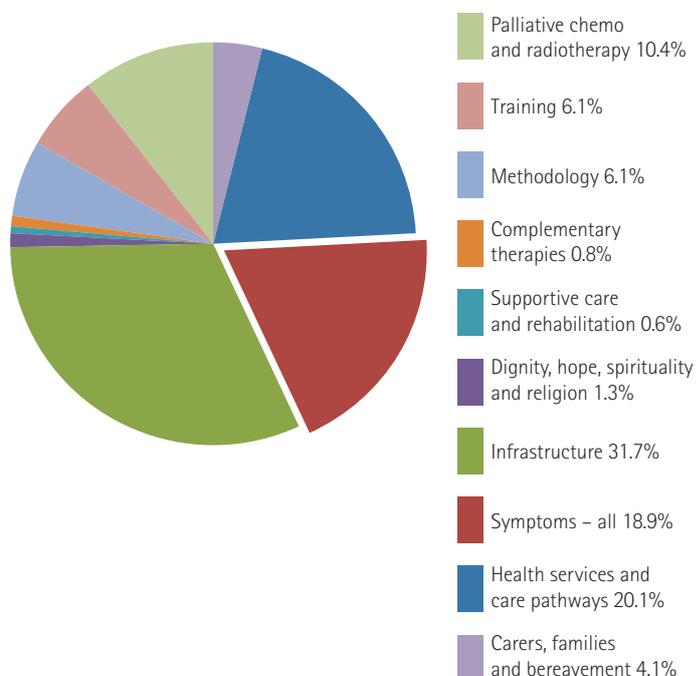
Research categories

A total of 32% of all funds spent on palliative and end of life care research between 2002 and 2013 were used to develop research infrastructure in the field (see figure 2). This percentage is relatively consistent and includes joint funding for the SuPaC Collaboratives and long-term programmes, like the Marie Curie Research Centres.

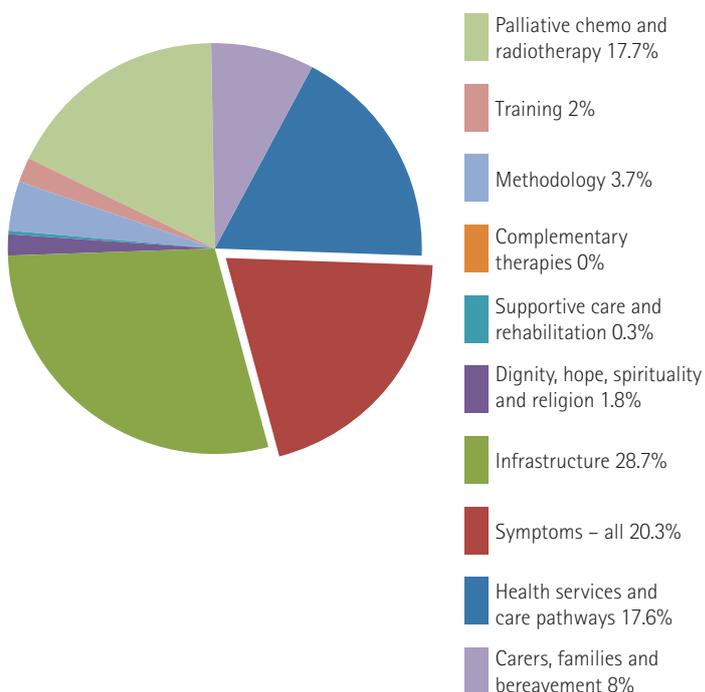
The next biggest research categories, both overall and in 2013, are symptom research (including all symptoms relevant to the end of life), and health services and care pathways. Palliative chemotherapy and radiotherapy also have a substantial share: 10% in all years and just under 18% of the total in 2013. There is some research looking into support for carers and families – this category also includes bereavement research (8% in 2013). There is some research on training and methodology, and a small amount on complementary therapies, rehabilitation or spiritual care.

Figure 2: Total research spend by research category: 2002–2013 total spend (top) and 2013 (bottom)

Total nominal spend by research category (2002 - 2013)



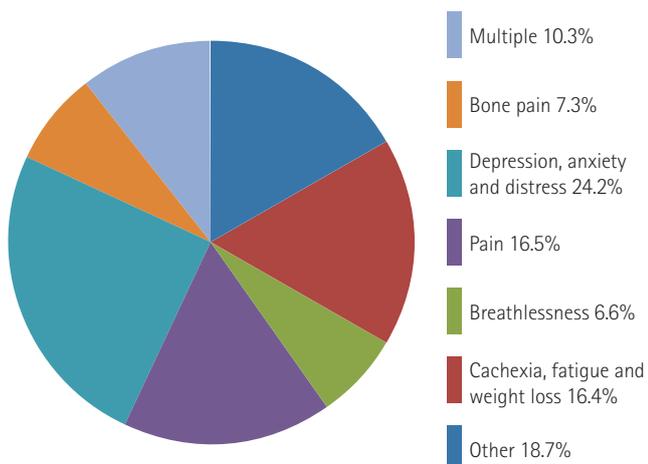
2013 spend by research category



“Funding for Marie Curie’s long-term centres has also increased since 2010”

Figure 3: Research spending on individual symptoms as a percentage of the total spend on symptom research included in the analysis: for 2002–2013 total spend (top) and 2013 (bottom)

Symptoms research – total (2002–2013)



A sub-analysis of the symptom research included in the database (see figure 3) shows that the two most researched symptom areas in palliative and end of life care research are pain, and depression, anxiety and distress. This holds for both the overall spend and expenditure in 2013 specifically. There is consistent, though relatively low, investment in breathlessness research, as well as some investment over the years in cachexia, fatigue and weight loss, though hardly any investment in the latter symptoms currently.

Geographically, there are particular 'hotspots' in palliative and end of life care research (see figure 4). London has two large centres, the Cicely Saunders Institute at King's College London and the Marie Curie Palliative Care Research Department at University College London. Both Liverpool and Cardiff also have Marie Curie Centres. Dundee University is a new player in the list due to a large award in 2013. There is consistent, though lower-level funding in Manchester, Bristol, Leeds, Nottingham, Cambridge and Edinburgh.

Symptom research – 2013

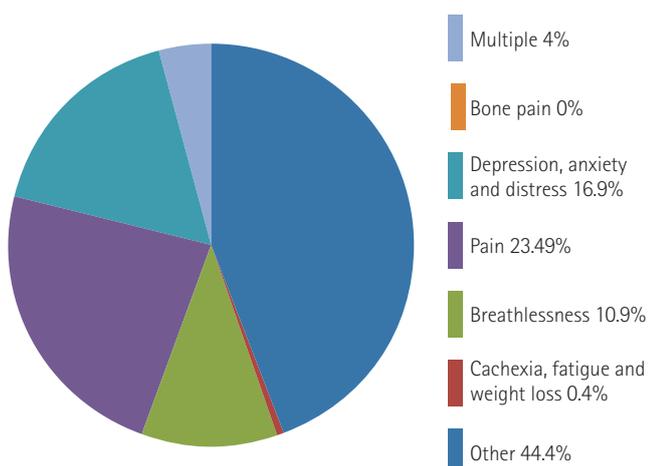


Figure 4: Research spend in palliative and end of life care cancer research by UK location in 2013



Spend by location 2013

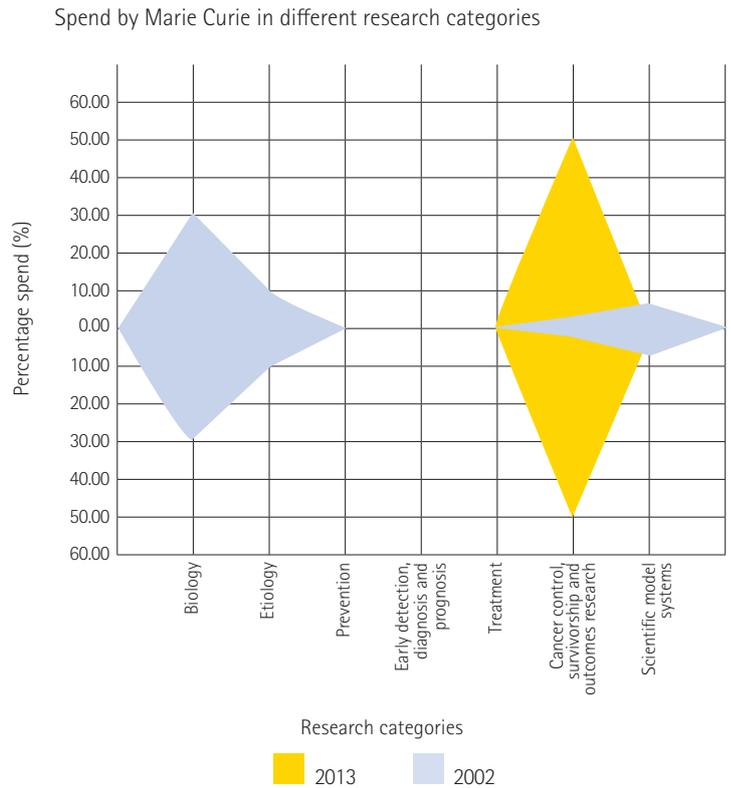
City	PEOLC spend (£)	% of PEOLC spend
London	628,175	20.42
Liverpool	341,919	11.12
Dundee	330,050	10.73
Cardiff	251,197	8.17
Manchester	224,529	7.30
Bristol	216,313	7.03
Leeds	175,831	5.72
Nottingham	147,547	4.80
Cambridge	112,791	3.67
Edinburgh	93,967	3.06

Results – Marie Curie

Marie Curie changed its research strategy in 2009 when it decided to close the Marie Curie Research Institute in Oxted that had been host to nine research groups carrying out basic cancer research. Marie Curie decided to align its research investment with the day to day work of the charity – providing end of life care for people at home and at its nine hospices.

The kite diagram in figure 5 illustrates the change in research strategy. In 2002, Marie Curie's main investment was in basic cancer biology (CSO 1), with additional funding for research into the etiology of cancer (CSO 2), scientific model systems (CSO 7) and a very small amount of funding in palliative and end of life care (CSO 6).

Figure 5: Kite diagram of Marie Curie's research investment in 2002 and 2013



Since 2010, the substantial investment in an open and competitive funding stream for palliative and end of life care research (the Marie Curie Research Programme) and a joint funding stream with Dimbleby Cancer Care (the Dimbleby Marie Curie Research Fund) increased Marie Curie's presence in CSO 6 substantially. Funding for Marie Curie's long-term centres has also increased since 2010, when funding for a third centre, the Marie Curie Palliative Care Research Centre at the University of Cardiff, was first awarded. Palliative and end of life care is now the only area of research that Marie Curie provides funding for.

This analysis is limited to cancer research, so not all of Marie Curie's recent investments are included. In particular a large programme grant to improve end of life care for people with advanced dementia isn't included in the Cancer Research Database.

Figure 6 shows the increasing importance of funding from Marie Curie in palliative and end of life care research. From roughly 5% of the overall spend in palliative and end of life care, the percentage of funding provided by Marie Curie has increased since 2010. In 2012 and 2013, Marie Curie grants made up more than 50% of the research spend in palliative and end of life care in the database.

"In 2012 and 2013, Marie Curie grants made up more than 50% of the research spend in palliative and end of life care in the database"

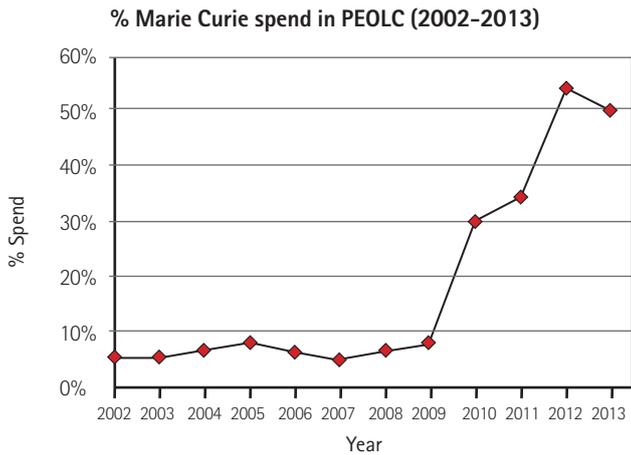


Figure 6: Research spend by Marie Curie as a percentage of the overall expenditure on palliative and end of life care, by year

A more detailed analysis of Marie Curie's investment in the minor codes of CSO code 6 shows that the majority of Marie Curie's research spend up to 2013 has gone to end of life care, with some consistent support for infrastructure.

Limitations of the analysis and future work

The NCRI CaRD database captures only research relevant to cancer and will be missing more general palliative and end of life care research, or research relevant to other diseases. Marie Curie funds palliative and end of life care research related to all terminal illnesses. It has a substantial portfolio of research studies addressing the palliative and end of life care needs of people with dementia, heart disease, stroke or chronic obstructive pulmonary disease for example. By definition, research grants relating to specific conditions other than cancer are not included in the database, but generic palliative and end of life care research is included if it has the potential to be relevant to cancer patients.

The numbers for overall spending in palliative and end of life care need to be considered with caution because the number of NCRI partners has changed over the years (from 15 in 2002 to 21 in 2013). This means the percentages showing investment in palliative and end of life care as a proportion of overall cancer research spend are more reliable measures when looking at trends.

The NCRI CaRD database is a comprehensive database of health-related research investment with year-on-year data in the UK. Other systems, in particular the UK Clinical Research Collaboration's Health Research Classification System (HRCS), exist.

Like all databases, there is a lag between the figures collected and the analysis. The NCRI CaRD database collects data of grants active on 1 April of each year and therefore the 2013 figures are based on grants active on 1 April 2013.

Eventually, the field of palliative and end of life care research, which increasingly departs from its roots in cancer research, might benefit from a wider analysis to capture all the research being funded in the area.

What does this mean for future palliative and end of life care research funding?

On average, 568,000 people die each year in England and Wales, with the number of deaths expected to rise 17% by 2030 to around 590,000 [Gomes and Higginson, 2008]. Figures from the Cicely Saunders Institute at King's College London suggest that between 69% and 82% of people who die (in high-income countries) need palliative care [Murtagh et al, 2014]. This adds up to between 392,000 and 466,000 people each year in the UK.

Research has the potential to improve the quality and experience of care for all people with terminal illnesses. But the evidence base for palliative and end of life care is weak and most treatments are based on expert opinion rather than good quality evidence from research, for instance randomised trials.

The recent National Institute for Health and Care Excellence (NICE) draft guideline for Care of the Dying Adult highlighted a number of gaps in the evidence, as did the report of the Palliative and end of life care Priority Setting Partnership with the James Lind Alliance (www.palliativecarepsp.org.uk).

Large investments into basic, translational and clinical cancer research on diagnosis, treatment and prevention have had a huge impact on survival of cancer patients, with some forms of cancer being transformed into chronic diseases [Duffy 2013; ONS, 2014]. There is the potential for research to have the same impact on the care of people with terminal illnesses and improving their quality of life, by investing in palliative and end of life care research, answering questions relevant to patients, carers and clinicians.

This updated analysis of the NCRI Cancer Research database comes to the same conclusion as previous efforts and shows that palliative and end of life care research is still vastly underfunded. Investment is just about keeping up with the overall increase in cancer research investment, and more funding is greatly needed to increase the evidence base for better care for people with terminal illnesses, their families, carers and friends.

Abbreviations

CaRD – Cancer Research Database
CSO – Common Scientific Outline
HRCS – Health Research Classification System
NCRI – National Cancer Research Institute
NIHR – National Institute for Health Research
SuPaC – Supportive and Palliative Care

Acknowledgements

We are very grateful to Tom White (TW) and Dr Karen Groot (KG) from the National Cancer Research Institute for developing the methodology and carrying out the analysis, and to Dr Teresa Tate, Katie Dougan-Hyde (KDH), Dr Bidisha Chakraborty, Shefali Shah and Rhiannon Smith for their work on the report.

References

The National Cancer Research Institute (NCRI) Strategic Analysis 2002. An overview of Cancer Research in the UK directly funded by the NCRI Partner Organisations (2002) – accessed 4 August 2014
Available from ncri.org.uk/publication/

Supportive and Palliative Care Research in the UK: Report of the NCRI Strategic Planning Group on Supportive & Palliative Care (2004) – accessed 4 August 2014
Available from ncri.org.uk/publication/

End of life care Strategy, Department of Health (2008) – accessed 30 May 2014
Available from gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life

NCRI Rapid review of research in survivorship after cancer and end of life care (2010) – accessed 30 May 2014
Available from ncri.org.uk/publication/

Common Scientific Outline (2006) – accessed 30 May 2014
Available from icrpartnership.org/CSO.cfm

Sleeman KE, Gomes B, Higginson IJ, Research into end of life cancer care – investment is needed, *Lancet* 379: 519 (2012)

Gomes B and Higginson IJ. Where people die (1974–2030): past trends, future projections and implications for care. *Palliat Med.* 2008 22(1):33-41

Murtagh FE, Bausewein C, Verne J, Groeneveld EI, Kaloki YE, Higginson IJ. How many people need palliative care? A study developing and comparing methods for population-based estimates, *Palliat Med.* 2014 28(1):49-58

Duffy, MJ, The war on cancer: are we winning? *Tumour Biol.* 2013 34(3):1275-84

Cancer Survival in England: Adults Diagnosed 2008 to 2012, followed up to 2013, ONS, October 2014

Appendix 1

Common Scientific Outline (CSO) – code 6

6. Cancer control, survivorship and outcomes research

Research in this category includes a broad range of areas: patient care and pain management; tracking cancer cases in the population; beliefs and attitudes that affect behaviour regarding cancer control; ethics, education and communication approaches for patients and healthcare professionals; supportive and end of life care; and healthcare delivery in terms of quality and cost effectiveness

6.1 Patient care and survivorship issues

Examples of science that would fit:

- Quality of life
- Pain management
- Psychological impacts of cancer survivorship
- Rehabilitation
- Reproductive issues
- Long-term morbidity
- Symptom management, including nausea, vomiting, lymphedema, neuropathies, etc.
- Prevention of treatment-related toxicities and sequelae, including symptom management, prevention of mucosities, prevention of cardiotoxicities, etc.

6.2 Surveillance

Examples of science that would fit:

- Epidemiology and end results reporting (e.g. SEER)
- Surveillance of cancer risk factors such as diet, body weight, physical activity, sun exposure, and tobacco use
- Analysis of variations in risk factor exposure by demographic or other factors
- Registries that track incidence, morbidity, and/or mortality related to cancer
- Trends in use of interventional strategies
- Method development for risk factor surveillance

6.3 Behaviour

Examples of science that would fit:

- Behavioural medicine research and interventions
- Influence of social factors such as community, policy, education and legislation, on behaviours related to cancer control
- Attitudes and belief systems and their influence on psychological health and on behaviours related to cancer control. For example, how beliefs can alter attempts to seek screening, detection and treatment
- Interventions to change attitudes and beliefs that affect behaviour related to cancer control and cancer outcomes
- Influences of attitudes and beliefs on compliance with treatment and prevention protocols
- Psychological or educational interventions to promote behaviours that lessen treatment-related morbidity and promote psychological adjustment to the diagnosis of cancer and to treatment effects
- Burdens of cancer on family members/caregivers and psychological/behaviour issues

6.4 Cost analyses and healthcare delivery

Examples of science that would fit:

- Analyses of the cost effectiveness of methods used in cancer prevention, detection, diagnosis, prognosis, treatment and survivor care/support
- Development and testing of health service delivery methods
- Interventions to increase the quality of healthcare delivery
- Impact of organisational, social and cultural factors on access and quality of care
- Studies of providers such as geographical or care-setting variations in outcomes
- Effect of reimbursement and/or insurance on cancer control, outcomes and survivorship support
- Access to care issues

- Health services research, including health policy and practice
- Analysis of health service provision, including the interaction of primary and secondary care; cost effectiveness of treatments

6.5 Education and communication

Examples of science that would fit:

- Development of communication tools and methods
- Education of patients, healthcare providers, at-risk population, and the general population about cancer
- Communication to patients regarding therapeutic options
- Educational interventions to promote self-care and symptom management
- Communicating cancer risk to underserved populations, at-risk populations and the general public
- Alternative teaching methods to communicate therapeutic options and risk-reduction behaviour to patients and the general public
- Communication of lifestyle models that reduce cancer risk, such as communication of nutritional interventions
- Communicating smoking and tobacco cessation interventions
- Special approaches and considerations for underserved and at-risk populations
- Education, information, and prevention/screening/assessment systems for the general public, primary care professionals, or policy makers
- Training, predictive cancer models, pain management, and surveillance systems for primary care professionals, telehealth/telemedicine applications
- Communication regarding cancer genetics, managed oncology care, and communicating with survivors
- Barriers to successful health communication

6.6 End of life care

Examples of science that would fit:

- End of life care issues, including palliative care, psychological interventions with families at end of life, hospice care and pain management for terminally ill patients

6.7 Ethics and confidentiality in cancer research

Examples of science that would fit:

- Informed consent modelling and development
- Quality of Institutional Review Boards (IRBs)
- Protecting patient confidentiality and privacy
- Research ethics

6.8 Complementary and alternative approaches for supportive care of patients and survivors

Examples of science that would fit:

- Hypnotherapy, relaxation, transcendental meditation, imagery, spiritual healing, massage, biofeedback, etc., as used for the supportive care of patients and survivors
- Discovery, development and testing of complementary/alternative approaches such as diet, herbs, supplements or other interventions that are not widely used in conventional medicine or are being applied in different ways as compared to conventional medical uses

6.9 Resources and infrastructure related to cancer control, survivorship and outcomes research

Examples of science that would fit:

- Informatics and informatics networks
- Clinical trial groups related to cancer control, survivorship and outcomes research
- Epidemiological resources pertaining to cancer control, survivorship and outcomes research
- Statistical methodology or biostatistical methods
- Surveillance infrastructures
- Centres, consortia and/or networks
- Psychosocial, economic, political and health services research frameworks and models
- Education and training of investigators at all levels (including clinicians), such as participation in training workshops, advanced research technique courses and Master's course attendance. This does not include longer-term research-based training, such as Ph.D. or post-doctoral fellowships

Appendix 2: Search and inclusion/exclusion criteria

Keywords used in the analysis for palliative and end of life care:

care*, palliat*, end*of*life, supportive, hospice, symptom management, symptom control, death, dying, die, dead, bereav*, prognos*, life*limiting, progressive disease, progressive illness, advanced illness, advanced disease, terminal*, anticipatory prescri*, life*threatening,

dementia, chronic obstructive pulmonary disease, COPD, heart disease, heart failure, mental capacity, nursing home, old peoples' home, sedat*, deliri*, anxi*, community nurse, district nurse, anticipatory plan*, advance* care plan*, advance* directive, living will, distress, pain, fatigue, nause*, vomit*, constipat*, quality*of*life, complementary therap*, breathless*, dyspnea, depress*, cachexia, weight loss, appetite, rehab*, thrombo*, Liverpool Care Pathway, LCP, Gold Standards Framework, GSF, *morphine, syringe driver

Awards to be excluded

- Awards within a curative setting are NOT included.
- Awards within a survivorship setting are NOT included.
- Awards for the elderly are NOT included (unless other criteria warrant inclusion).
- Euthanasia is NOT included.
- Disease trajectory awards with no mention of where in the cancer journey (i.e. diagnosis, EOL) are NOT included (unless palliative care is mentioned).
- Cancer Research UK research nurses are NOT included as they predominantly recruit to diagnostic and (curative) treatment trials.

Awards to be included and their percentage relevance

The principles below were used as a guide to apportion the awards included in the analysis. The relevance was determined by TW, KDH and KG in the first instance. Further work was done by TW to make the methodology consistent and awards that were more difficult to apportion discussed within the NCRI team.

- Health services research relating to palliative and end of life care is included at 100%, for example research to evaluate end of life care service delivery, cost-effectiveness studies and research based within and focused on hospices or hospice-based patients.
- General palliative awards with no mention of disease stage are included at 100%.
- Dignity at the end of life is included at 100%.
- Reducing stress/training/impact on palliative carers is included at 100%.
- Epidemiological research with a link to palliative and end of life care is included, for example research on place of death is included at 100%.
- Views of GPs and nurses on current palliative care provision are included at 100%.
- Marie Curie Centres are included at 100%. The NCRI Supportive and Palliative Care Collaborative contributions are included at 50%. Generic

infrastructure funding does not appear in our analysis as the research abstracts do not include relevant keywords.

- Marie Curie Nurses are included at 100% and Macmillan nurses are included at 50% (includes scoping studies for their recruitment, training etc.).
- Research on the causes (including their biology), treatment or prevention of symptoms related to cancer or its treatment and awards focused on symptoms experienced by patients at the end of life are included at 20%. All symptoms research was included with the exception of research focused on lymphoedema of breast cancer survivors. Awards focused on one symptom alone were given a relevance score of 20%, awards focused on more than one symptom were given scores of 20% up to 100% depending on the degree of focus on end of life care patients in each case. Symptoms research included in our analysis includes studies focused on delirium, nausea (including that experienced by patients during treatment), cachexia and fatigue, depression, and others including dry mouth, metastatic bone pain, insomnia and constipation.

For more information email research.info@mariecurie.org.uk
or visit mariecurie.org.uk/research

