available at www.sciencedirect.com

ScienceDirect

journal homepage: www.ejconline.com

Current perspective

PRISMA: A pan-European co-ordinating action to advance the science in end-of-life cancer care

Richard Harding *, *Irene J. Higginson, On behalf of PRISMA*

King's College London, Department of Palliative Care, Policy and Rehabilitation, School of Medicine at Guy's King's and St. Thomas Hospitals, Cicely Saunders Institute, Bessemer Road, London SE5 9PJ, UK

ARTICLE INFO

Article history:
Received 18 January 2010
Accepted 26 January 2010
Available online 23 February 2010

Keywords:
End-of-life
Europe
Measurement
Outcomes
Cancer
Palliative care
Tools

ABSTRACT

Introduction: The epidemiology of progressive cancer and associated mortality in Europe underlines the essential need for high quality palliative and end-of-life care for its citizens. Currently, care of patients at the end-of-life is under-researched and under-funded. This is due to a lack of prioritisation, challenges in defining end-of-life, lack of a common research strategy for Europe that identifies and implements best practice and highest scientific principles, and the need for common use of appropriate well-validated tools to measure and improve the end-of-life cancer experience in Europe.

Methods: PRISMA is a pan-European co-ordinating action funded under Framework Programme 7 of the European Commission. With 12 partners in 9 countries, it is delivering a series of 8 Work Packages with the common aim of promoting best practice in the measurement of end-of-life care, setting an agenda and guidance that reflects European cultural diversity, and is informed by both public and clinical priorities. Guidance in the selection, adaptation and use of core tools is informed by experts in public health and clinical research.

Discussion: PRISMA is currently producing a series of outputs to be accessible to the wider community of researchers, policy makers, funders and clinicians. We encourage new partnerships to build on the work of PRISMA and to lead high quality work informed by our deliverables. PRISMA, we hope, is redressing the current lack of co-ordination of cancer end-of-life research across Europe, and will catalyse the conduct of evidence-based care that reflects European populations and priorities.

1. Introduction

With an annual 1.7 million deaths from cancer in the whole of Europe,[1,2] there is an urgent need to improve care at the end-of-life for patients and families. Epidemiologically based needs assessment to estimate the number of people with advanced cancer in Europe with symptoms and other problems has shown that there are up to 1.6 million patients with pain each year, and more than one in two will be affected by anxiety/depression, breathlessness, insomnia, nausea, constipation and/or anorexia.[3]

End-of-life care cancer research is under-resourced and under-developed across Europe. The World Health Organisation (Europe) recent guidance *Palliative Care – the Solid Facts*

* *Corresponding author:* Tel.: +44 (0)207 848 5589; fax: +44 (0)207 848 5517.
E-mail address: richard.harding@kcl.ac.uk (R. Harding).
0959-8049/$ - see front matter © 2010 Elsevier Ltd. All rights reserved.
doi:10.1016/j.ejca.2010.01.035

showed that in many countries less than 0.5% of research spending in cancer is allocated to end-of-life and palliative care.[4] Recommendations from the WHO reports are to encourage collaboration in end-of-life research to overcome barriers.

Under the European Commission's Framework Seven Health programme, PRISMA has been funded under the stream of 'end-of-life cancer co-ordinating actions'. In developing the PRISMA co-ordinating action, we appraised and reflected on the current state of science to identify the necessary components of work (termed 'Work Packages' in Framework 7 language).

Firstly, defining end-of-life care is complex. End-of-life care is a diffuse term which tends to be used more in discussion among academic contexts than amongst practitioners or patients and families.[5] In PRISMA we have chosen to take a conservative approach from working definitions by the National Institutes of Health (NIH) State-of-the-Science Conference on Improving End-of-Life Care[6] and the National Institute for Health Research scoping exercise of definitions and priorities in end-of-life care research.[7] Therefore, PRISMA focuses on end-of-life cancer care as the last year of life. This, as a working definition, is a 'flexible understanding' to be debated within our partners. One strand of this proposal will be to explore cultural differences in understanding and prioritising end-of-life care, and how this is being articulated in, and influencing, research. In particular we will discuss the cultural meanings that are placed on end-of-life care. The absence of indicating measures of cultural aspects of palliative care has been identified in a previous systematic review.[8]

Second, despite the great need for further research in end-of-life cancer care, there is no clear agreement on the priorities for action. Any agreement on European priorities must take account of public and patient as well as clinical preferences. Therefore, within this programme we propose including two Europe-wide exercises to determine both public and clinical health professional priorities for end-of-life research.[9]

Third, there are barriers in the conduct of high quality research in end-of-life cancer care.[10] Research is hampered by scientific, practical and ethical differences in conducting research among very ill individuals. This has often led to research that is more descriptive than evaluative. One central issue in the conduct of research in end-of-life cancer care is the measurement of effects and outcomes on patients. This is important for quality improvement, needs assessment, and trials of specific treatments or interventions. The lack of standardised core measurement tools means that there are differences in the interpretation of results of studies, meta analyses are often limited and importantly some studies fail because they have used inappropriate measures without adequate sensitivity.[11–13] There may be differences between patients, carers and health professionals in their views of the priority outcomes at the end-of-life,[14] and even between professionals.[15] There are also challenges in recording measures among patients who are in the last year of life and very ill, who may be confused or cognitively impaired, and in capturing emotional social, spiritual and physical components. However, some measures are in more common use. This use could be enhanced and expanded, providing better guidance on the use of measures through European collaboration. Such collaboration is currently underway to harmonise quality and outcome measurement in cancer end-of-life care in the US, but has not been achieved in Europe to date.[16]

As a model for promoting better collaboration in the use of measures in both quality improvement and research in end-of-life cancer care, PRISMA focuses on the use of two widely adopted measures – the Palliative Outcome Scale (POS) and the Support Team Assessment Schedule (STAS). PRISMA also takes account of activity using alternative measures such as the Memorial Symptom Assessment Scale (MSAS), the Edmonton Symptom Assessment Scale (ESAS) and the EORTC QLQ C15-Pal, a version of the European Organisation for Research into Treatment of Cancer (EORTC) measure designed for palliative care.

The POS was originally developed and validated in eight end-of-life settings in the United Kingdom,[17] based on a systematic literature review of existing potential scales.[18] Uniquely among existing measures it assesses concerns of both the patient and family and it has components that can be patient assessed (when possible) and observer or proxy assessed (using validated staff or family versions) when patients become too ill to complete assessment. The inclusion of patient-identified main problems within the tool ensures 'patient-centredness'. There are now over 450 units who have registered to use POS spanning 20 European countries. A number of independent translations and validations have been published, with versions of the POS available in German, Italian, Dutch, Portuguese, Spanish, Urdu and Punjabi.[19–23] Users and patients views of the POS generally suggest it is valuable and reflects their concerns.[24] Relationships between POS and other scales have been assessed,[25] as well as practical factors involved in using this and similar measures in practice.[26–29]

The STAS was developed specifically for the very last stages in end-of-life care, is multidimensional, was developed for staff completion among those too far advanced or sick to self complete (and indeed has been used in the last few hours), has been used internationally in end-of-life cancer populations and is available in many languages. It was validated to ensure accuracy in completion by patients, families and staff.[30] In advanced cancer it has been shown to have good sensitivity for patients within their last 6 weeks of life in advanced cancer.[31] The expanded or E-STAS has been validated in hospital populations.[32] It has also been used successfully to investigate the final week of life for cancer home deaths in Italy,[33] to measure end-of-life advanced cancer problems in a French version,[34] to measure quality of care and life in a French advanced cancer home and hospital team,[35] and to measure symptoms associated with approaching death in cancer patients.[36] It is well suited to clinical research having been used for opioid evaluation in symptom control studies in terminal cancer.[37] The STAS has been used successfully in quality improvement and clinical audit.[38]

2. Methods

2.1. *Aims and objectives*

The aim of PRISMA is to inform best practice and harmonise research in end-of-life care for cancer patients across Europe

Table 1 – PRISMA Work Packages, lead partners and members.

Work Package	Lead partner	Objectives
WP1: Cultural difference in end-of-life care	Fundacio Clinic per a la Recerca Biomedica (FCRB, University of Barcelona), Spain	1. Explore and map cultural differences in definitions and priorities for EOL care in and across these countries 2. Assess the evidence on culture and end-of-life care 3. Plan coordinated efforts for future directions in achieving culturally appropriate quality standards for end-of-life care
WP2: Public priorities and preferences for end-of-life care	King's College London (KCL), UK	4. Examine existing evidence on public preferences and priorities for end-of-life cancer care 5. Design, commission and disseminate a cross-national opinion poll of public preferences and priorities for end-of-life care in up to eight European countries 6. Identify cross-national and country-specific public preferences and priorities in Europe 7. Promote reflection to shape ways to ensure end-of-life cancer care research and measurement addresses diversities as well as commonalities in public views across Europe
WP3: Clinical research priorities in end-of-life care	Norges Teknisk-Naturvitenskapelige Universitet (NTNU, Norwegian University of Science and Technology), Norway	8. To study and compare how research in end-of-life care in cancer is conducted across Europe 9. To identify the clinical research priorities of clinicians across Europe 10. To develop a research agenda based upon clinical priorities within end-of-life care (EOLC)
WP4: Best practice and resources for the use of end-of-life care quality indicators	Deutsche Gesellschaft fur Palliativmedizin (DGP, German Association Palliative Medicine), Germany	11. To identify and to describe the ways in which measurement tools are used in end-of-life care in European countries 12. To coordinate exchange of experiences in those who use the identified tools in end-of-life care 13. To develop resources and support for those who use the POS and STAS in end-of-life cancer care
WP5: Best practice in symptom measurement	Centro de Estudos e Investigação em Saúde da Universidade de Coimbra (CEISUC, University of Coimbra), Portugal	14. To share aspects of our experience of implementing the POS-S in Portugal 15. To discuss the value of the POS-S as an outcome measure in end-of-life care research 16. To address the usefulness, practicality and impact of the POS-S in a cancer setting, with a view to shape best practice 17. To develop dissemination material for the POS-S (booklet and card for health professionals) 18. To liaise with other researchers using the POS-S and explore ways of working together

(*continued on next page*)

Table 1 – (continued)

Work Package	Lead partner	Objectives
WP6: Best practice in nursing home measurement	Vrije Universiteit Medisch Centrum Amsterdam (VUMCA, Free University Amsterdam), Netherlands	19. To explore what constitutes quality care for those with cancer at the end-of-life in nursing homes. 20. Build capacity by developing a collaborative on end-of-life cancer care in European nursing homes 21. Share the current experiences in measuring quality in end-of-life nursing home care using the POS and other tools, and draw up an inventory of tools currently being used 22. Identify best practice in measuring quality for competent and incompetent nursing home patients 23. Compare the performance of the POS/STAS and other tools in this population (e.g. EORTC, QLQ-C15-PAL, EOLD, RAI PC where they are used). 24. Optimise future research on end-of-life cancer care in nursing homes.
WP7: PRISMA Management	King's College London (KCL), UK	25. Provide scientific leadership to all Work Packages 26. Provide daily coordination and management for the entire project and support to the remaining 7 WPs 27. Take responsibility (including scientific input) for collation and integration of all outputs to unify researchers and ensure commonly agreed best practice and future activity across the consortium 28. Ensure financial regularity and ethics compliance 29. Report to the European Commission 30. Bring together the strategic objectives of each WP to achieve the primary aim 31. Service the Project Management Committee, Project Consortium Scientific Committee and All Assembly Meeting
WP8: Final conference	Universiteit Antwerpen (UA, University of Antwerp), Belgium	32. Co-ordinate a final conference for policy makers, funders, researchers and clinicians 33. Disseminate findings
Additional PRISMA members:	• African Palliative Care Association (APCA), Uganda • Federatie Palliatieve Zorg Vlaanderen (FPZV, Flemish Palliative Care Federation), Belgium • Hospital Santa Maria (HSM), Portugal • Istituto di Ricerca in Medicina Palliativa (ONLUS, Institute for Palliative Medicine Research), Italy	

through comparison and exchange of approaches and experiences in measurement and research priorities.

In order to achieve PRISMA's aim, our appraisal of the state of science revealed that a number of related studies need to be conducted in order to identify a common European agenda and to deliver this using the best scientific approaches. PRISMA, we hope, will facilitate high quality end-of-life cancer care for European citizens through collaborative clinical and public health research methods (see Table 1 for partners and Work Package titles).

The objectives of PRISMA are:

1. To develop collaboration on culture and end-of-life care across different countries in Europe, exploring and mapping differences in priorities and evidence.
2. To study and compare the nature and conduct of research into end-of-life care in cancer across Europe and to compare these with clinical and public priorities.
3. To map and harmonise approaches and experiences in end-of-life cancer care measurement and quality indicators.
4. To develop online resources to support and enhance Pan-European measurement and research in end-of-life care for cancer patients.
5. To foster and facilitate a long-lasting European Collaborative in end-of-life cancer care research.

2.2. Overview of Work Packages

Through a combination of public health and clinical research methods, systematic appraisal of evidence and expert meetings PRISMA will share best research practice. Studies on cancer end-of-life in Europe will be better coordinated, of maximum methodological rigour, feasible and relevant to country data needs and priorities. The integration of Work Packages is shown in Fig. 1.

2.3. WP1: Cultural difference in end-of-life cancer care

There have been few fully realised studies taking a comparative pan-European and co-ordinated approach to reviewing end-of-life care in Europe with respect to culture. End-of-life cancer care should be culturally sensitive and take into account the social and cultural backgrounds of patients and their families at this time. Theoretically, this is already part of holistic palliative care. However, there is evidence that cultural issues are often not addressed adequately in end-of-life care. There is also a paucity of the literature on cultural diversity, and although guidelines on quality end-of-life care do imply sensitivity to cultural issues, there is a lack of expertise on what this encompasses or how to translate it into practice. Ethnic minorities have been identified as an underserved group with regard to access to services.[39]

Most of the evidence in this area comes from the United States. American studies have documented many cultural differences that are relevant at the end-of-life: patient autonomy, advance directives, communication, and the role of the family. As Europe becomes more culturally diverse, the risk to minorities receiving poor end-of-life care due to cultural misunderstandings is likely to grow just as it has in the USA.[40] WP1 will develop collaboration to identify European cultural differences and explain cross-cultural meanings and practices in end-of-life care as well as agree on a common definition of end-of-life.

2.4. WP2: Public priorities and preferences for end-of-life care

Although a small number of studies have conducted cross-sectional survey and small scale qualitative studies on preference for end-of-life care (mainly in the UK), these have been few and have used differing methods, hampering comparison. It is important to ensure that end-of-life care research remains responsive to what people expect, want and need. As cancer is responsible for 1 in 4 deaths, and is increasingly prevalent in the ageing populations of Europe, cancer is seen as central to end-of-life care.

In 2000, the WHO acknowledged the responsiveness of health care to people's preferences and expectations as one of the three intrinsic goals of any health system, alongside health and fairness.[41] People's preferences and priorities have always been central in end-of-life care, under the auspices of a person-centred and individualised approach to care. Existing public polls conducted in the USA and South Australia have shown gaps between some of the things people want and what they get at the end-of-life.[42,43] This is true for example in relation to where terminally ill patients are cared for and die. Numerous studies show that across Europe most people want to die at home, yet the majority die in hospital.[4] Integrated, rigorous and uniform assessment methods are required to identify commonalities and diversities in public views across countries. Although a number of within-country studies have identified specific questions such as priorities for end-of-life, probability samples of comparable pan-European data have not been generated on public preferences.

2.5. WP3: clinical research priorities in end-of-life care

There have been no co-ordinated studies to determine the priorities for clinical research across Europe. Clinical advances often rely on new interventions that are developed over years and tested rigorously in controlled clinical studies. Populations towards the end-of-life are heterogeneous and the clinical interest ranges over a clinical, physiological, psychological, as well as social aspects of the phenomenon in question. The focus is not only the patient, but also the family, the health care system and the entire society. This heterogeneity represents a major challenge for research, and especially when the population approaches the final year of the disease trajectory.[44] While the quantity of end-of-life research seems to be steadily increasing, the quality can be disputed.[45] Few of the studies identified in reviews focus especially on patients with short life expectancy.[46] The recruitment of patients at the end of their lives to prospective studies has been identified as difficult.[47,48] However, some studies in end-of-life care (EOLC) have been conducted

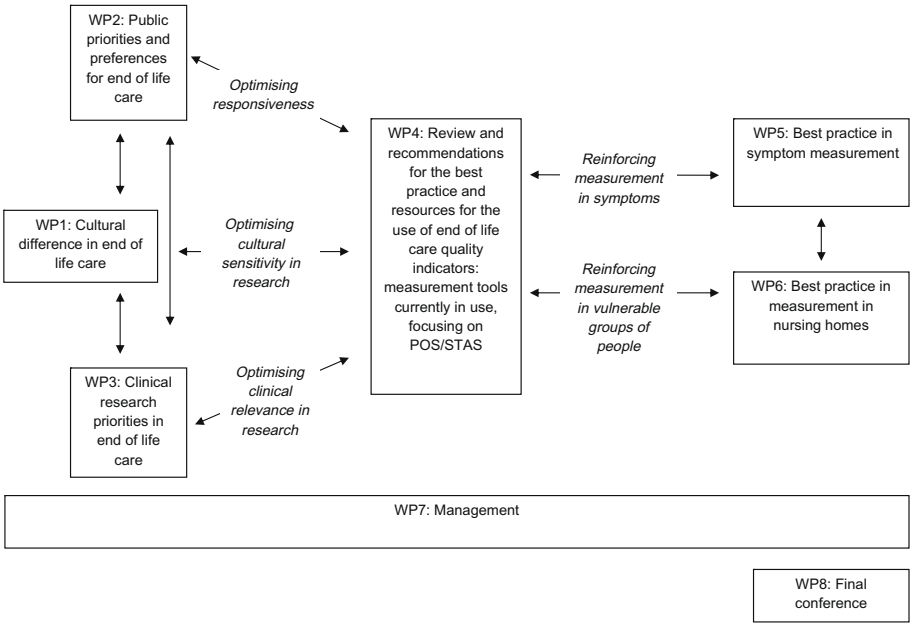

Fig. 1 – Work Package integration.

successfully,[49,50] and a recent review concluded that there are several barriers that might be solved.[51] A series of peer-reviewed articles have elaborated on the challenges and possible solutions to improve EOLC research.[52] Similar barriers have been identified in North American papers and in collaborative networks.[53]

Methodological, organisational, attitudinal, societal, as well as research knowledge/skills in the area of EOLC research have been identified. There is an urgent need to summarise these challenges and identify a common European strategy on how to improve these barriers and build the future research from the existing knowledge and resources. WP3 will conduct pan-European surveys to identify the clinical priorities for research topics and the current methodological practices and challenges in conducting world-class end-of-life cancer research from within Europe.

2.6. WP4: *best practice and resources for the use of end-of-life care outcome measures*

Although there have been a number of studies across Europe using outcome tools in this population, there have been few efforts to co-ordinate activity and identify best practice in their selection, implementation and analysis. There are few robust measures appropriate and validated in the context of end-of-life cancer care among patients and families. Measures specifically developed and validated among this population are rare, and so by reviewing which measures are in use, and appraising these in terms of cultural, clinical and public priorities PRISMA will build support and application of tools that are currently in use. The current problem is that there is a lack of coordination of measurement in Europe and so PRISMA will bring together the use of effective tools through the sharing of best practice and guidance.

A survey of which measures are being used currently among clinicians and researchers across Europe will be conducted. As part of this process we will review the properties and applications of these tools and measure their use. There are particular methodological challenges when researching this patient population at the end-of-life. PRISMA will identify, and share, best methods when collecting data from far advanced patients with limited capacity, utilising the existing datasets, and will ensure coordination and shared approaches across countries. In addition, best practice will be specifically drafted and shared in terms of data collection and best ethical practice. We believe that this approach will significantly advance a field where studies often fail due to the contextual issues of studying patients and families at the end-of-life.

2.7. WP5: *best practice in symptom measurement*

The goal of end-of-life care is to provide comfort and dignity to cancer patients at the end-of-life and their families, offering them the best possible quality of life. Patient symptom control is one of the main targets for end-of-life care and therefore one of its main quality indicators. Well over 50% of patients with end stage cancer experience pain, breathlessness and fatigue, amongst a multitude of other symptoms.[11] To be free of pain and not feel breathlessness has been pointed out as a top priority by the patients, families and care providers.[54].

It is important to ensure that symptom measurement tools are culturally sensitive, responsive to the symptom needs of different patients, and clinically appropriate to different settings. The POS-S, STAS, MSAS and other measures in use offer great potential for discussing and tackling these issues. Although a number of symptom prevalence studies have been published, there has been a lack of guidance on best practice and co-ordination to standardise approaches in the collection and analysis of such data. Within WP5 we

will look particularly at symptom measurement using the POS-S and a number of other tools, including the STAS, Herth Hope Index, EUROQOL, MSAS, MISSOULA, and the EORTC-QLC-C30. Quality symptom measurement tools are needed for evaluating the impact of the existing and new symptom control techniques for cancer patients at the end-of-life. Coordination across researchers and countries on what tools to use and how to improve them will contribute to a better accuracy on measuring symptoms in order to assess different courses of action and interventions in cancer clinical practice. It may also enable the development of cost-effective international studies to pursue and evaluate innovative solutions for symptom control. WP5 will review tools available and validate the POS-S (symptom module). It will develop and publish a brief symptom scoring card for the POS-S to be used in daily clinical practice.

2.8. WP6: best practice in nursing home measurement

More people are now living longer and the proportion of those living beyond 60 years has increased, and will increase further over the next 20 years in most European countries: from around 20–25% in 2000 to an estimated percentage of 25–30% in 2020, and 30–35% in 2050.[55] Along with this ageing there is an increase in the numbers affected by cancer in later life. The provision of end-of-life care to the growing number of older persons is an issue of great clinical and public health importance.[4,56] Because populations in European and other developed countries are ageing rapidly and the proportion of those living beyond 65 years and into very old age is increasing[4,56] they tend to die more often in care homes or nursing homes: in Belgium the death rate in care/nursing homes increased from 20% in 1998 to 25% in 2001. In 2003 in Europe, there was a diverse range of death rates in care/nursing homes: between 14% in Wales and 33% in The Netherlands.[57].

Nursing homes provide a supportive environment for their residents, and many of these patients receive palliative care until they die. Much research has been focused on younger patients with specific diseases (especially cancer), but very little attention has been paid to 'typical' nursing home patients.[4]

The people who are living in nursing homes at the end of their lives are frail or have chronic physical or mental disability, and with multiple morbidities.[58] A nationwide study in The Netherlands showed that the terminal phase of nursing home patients was marked with symptoms of low fluid and food intake, general weakness and respiratory problems/dyspnoea.[22,58] Despite the growing number of persons dying at old age in nursing homes, important gaps remain in our knowledge of how to capture the experiences of persons dying at old age in nursing homes and of their care proxies,[53,59] and to co-ordinate this work. PRISMA WP6 will look specifically at current work on nursing homes and bring together best practice and data to disseminate best practice to better co-ordinate research in this population.

2.9. WP7 PRISMA management

The management function of PRISMA coordinates the integration between Work Packages, the relationship between PRISMA and the European Commission, and facilitates the Management Committee, the Scientific Committee and the annual 'All Assembly' meetings.

2.10. WP8 final conference

At the end of PRISMA funding from the Commission a conference will be held to reflect on, and disseminate, the findings across the Work Packages and to initiate policy, research, funding and clinical responses to the PRISMA outputs and recommendations.

The inclusion of the pan-African partner offers the opportunity to learn from feasible methods in African settings and to appraise research priorities and co-ordination in the light of African needs (e.g. HIV and paediatrics) and models of care (e.g. the focus on home care and integrated antiretroviral therapy for HIV care) which are emphasised in these countries with the associated expertise.

3. Discussion

PRISMA is a 3-year co-ordinating action, funded into 2011. We are now half-way through PRISMA's funded activities and have learned much in terms of developing a co-ordinating action across Europe. Our programme of related studies in public health and clinical research are led by experts across a range of disciplines, and we have successfully integrated Work Packages from a range of disciplines. Outputs are now being disseminated by these experts for the wider community of potential stakeholders (including clinicians, policy makers, patient and family groups) who may wish to utilise the PRISMA co-ordinating action. Our outputs include evidence reviews and statements of best practice, agendas for research priorities, and resources such as symptom score cards, methods and tool selection algorithms, and evidence synthesis. We encourage new collaboration beyond our original members, objectives and funding period. An expected outcome for PRISMA is the development of new partnerships and collaborations to carry forward the pan-European end-of-life cancer research agendas using our scientific recommendations. The outputs will be signposted from our web pages www.prismafp7.eu, and we plan to post a searchable database to identify potential research partners by topic. These outputs will, we hope, lead directly to pan-European research that will inform policy and practice, and redress the current lack of co-ordination in, and attention to, end-of-life cancer care for European citizens.

Conflict of interest statement

None declared.

Acknowledgements

PRISMA is funded by the European Commission's Seventh Framework Programme (contract number: Health-F2-2008-201655) with the overall aim to co-ordinate high-quality international research into end-of-life cancer care. PRISMA aims to provide evidence and guidance on best practice to ensure that

research can measure and improve outcomes for patients and families. PRISMA activities aim to reflect the preferences and cultural diversities of citizens, the clinical priorities of clinicians, and appropriately measure multidimensional outcomes across settings where end-of-life care is delivered. Principal Investigator: Richard Harding. Scientific Director: Irene J. Higginson.

REFERENCES

1. Boyle P, Ferlay J. Cancer incidence, mortality in Europe, 2004. *Ann Oncol* 2005;**16**(3):481–8.
2. International Agency for Research on Cancer. New European cancer figures – World Cancer Agency says major efforts needed toward prevention in Europe. World Health Organisation International Agency for Research on Cancer. http://www.iarc.fr/ENG/Press_Releases/pr174a.html; 2007.
3. Higginson IJ, Costantini M. Dying with cancer, living well with advanced cancer. *Eur J Cancer* 2008;**44**(10):1414–24.
4. WHO. *Palliative care. The solid facts*. Copenhagen, Denmark: World Health Organisation; 2004.
5. Shipman C, Gysels M, White P, et al. Improving generalist end of life care: national consultation with practitioners, commissioners, academics, and service user groups. *BMJ* 2008;**337**:a1720.
6. National Institutes of Health. *National institutes of health state-of-the-science conference statement on improving end-of-life care*. USA: NIH Concensus Development Program; 2004.
7. Higginson IJ, Shipman C, Gysels M, et al. Scoping exercise on gerneralist services for adults at the end of life: research, knowledge, policy and future research needs. National Co-ordinating Centre for NHS Service Delivery and Organisation R&D; 2007.
8. Pasman HR, Brandt HE, Deliens L, Francke AL. Quality indicators for palliative care: a systematic review. *J Pain Symptom Manage* 2009;**38**(1):145–56.
9. Higginson IJ, Davies E, Tsouros AD. The end of life: unknown and unplanned? *Eur J Public Health* 2007;**17**(4):331–2.
10. Higginson IJ. It would be NICE to have more evidence? *Palliat Med* 2004;**18**(2):85–6.
11. Solano JP, Gomes B, Higginson IJ. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. *J Pain Symptom Manage* 2006;**31**(1):58–69.
12. Higginson IJ, Finlay IG, Goodwin DM, et al. Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *J Pain Symptom Manage* 2003;**25**(2):150–68.
13. Harding R, Higginson IJ. What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliat Med* 2002;**17**:63–71.
14. McIlfatrick S. Assessing palliative care needs: views of patients, informal carers and healthcare professionals. *J Adv Nurs* 2007;**57**(1):77–86.
15. Schneider N, Buser K, Amelung VE. Discrepancies in the viewpoints of different German health care providers on palliative care. *Eval Health Prof* 2007;**30**(1):96–109.
16. Seow H, Snyder CF, Shugarman LR, et al. Developing quality indicators for cancer end-of-life care: proceedings from a national symposium. *Cancer* 2009;**115**(17):3820–9.
17. Hearn J, Higginson IJ. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. *Qual Saf Health Care* 1999;**8**(4):219–27.
18. Hearn J, Higginson IJ. Outcome measures in palliative care for advanced cancer patients: a review. *J Public Health Med* 1997;**19**(2):193–9.
19. Stevens AM, Gwilliam B, A'Hern R, Broadley K, Hardy J. Experience in the use of the palliative care outcome scale. *Support Care Cancer* 2005;**13**(12):1027–34.
20. Serra-Prat M, Nabal M, Santacruz V, Picaza JM, Trelis J. Grupo Catalan de Estudio de la Efectividad de los Cuidados Paliativos. Validation of the Spanish version of the Palliative Outcome Scale. *Med Clin (Barc)* 2004;**123**(11):419–20.
21. Horton R. Differences in assessment of symptoms and quality of life between patients with advanced cancer and their specialist palliative care nurses in a home care setting. *Palliat Med* 2002;**16**(6):488–94.
22. Brandt HE, Deliens L, Ooms ME, van der Steen JT, van der WG, Ribbe MW. Symptoms, signs, problems, and diseases of terminally ill nursing home patients: a nationwide observational study in the Netherlands. *Arch Intern Med* 2005;**165**(3):314–20.
23. Bausewein C, Fegg M, Radbruch L, et al. Validation and clinical application of the german version of the palliative care outcome scale. *J Pain Symptom Manage* 2005;**30**(1):51–62.
24. Slater A, Freeman E. Patients' views of using an outcome measure in palliative day care: a focus group study. *Int J Palliat Nurs* 2004;**10**(7):343–51.
25. Higginson IJ, Donaldson N. Relationship between three palliative care outcome scales. *Health Quality Life Outcomes* 2004;**29**(2):68.
26. Dunckley M, Hughes R, ddington-Hall JM, Higginson IJ. Translating clinical tools in nursing practice. *J Adv Nurs* 2003;**44**(4):420–6.
27. Dunckley M, Aspinal F, ddington-Hall JM, Hughes R, Higginson IJ. A research study to identify facilitators and barriers to outcome measure implementation. *Int J Palliat Nurs* 2005;**11**(5):218–25.
28. Hughes R, Aspinal F, ddington-Hall J, et al. Professionals' views and experiences of using outcome measures in palliative care. *Int J Palliat Nurs* 2003;**9**(6):234–8.
29. Hughes RA, Aspinal F, Higginson IJ, et al. Assessing palliative care outcomes for people with motor neurone disease living at home. *Int J Palliat Nurs* 2004;**10**(9):449–53.
30. Higginson IJ, McCarthy M. Validity of the support team assessment schedule: do staffs' ratings reflect those made by patients or their families? *Palliat Med* 1993;**7**(3):219–28.
31. Higginson IJ, McCarthy MA. Comparison of two measures of quality of life: their sensitivity and validity for patients with advanced cancer. *Palliat Med* 1994;**8**(4):282–90.
32. Edmonds PM, Stuttaford JM, Penny J, Lynch AM, Chamberlain J. Do hospital palliative care teams improve symptom control? Use of a modified STAS as an evaluation tool. *Palliat Med* 1998;**12**(5):345–51.
33. Peruselli C, Di GP, Toscani F, et al. Home palliative care for terminal cancer patients: a survey on the final week of life. *Palliat Med* 1999;**13**(3):233–41.
34. Lagabrieelle D, Guyot F, Jasso G, et al. A French tool for evaluation of home palliative care: adaptation of the Support Team Assessment Schedule. *Sante Publique (Bucur)* 2001;**13**(3):263–76.
35. Chvetzoff G, Perol D, Devaux Y, et al. Prospective study on the quality of care and quality of life in advanced cancer patients treated at home or in hospital: intermediate analysis of te Trapado study. *Bull Cancer (Paris)* 2006;**93**(2):213–21.
36. Edmonds P, Higginson I, Altmann D, Sen-Gupta G, McDonnell M. Is the presence of dyspnea a risk factor for morbidity in cancer patients? *J Pain Symptom Manage* 2000;**19**(1):15–22.
37. Morita T, Takigawa C, Onishi H, et al. Opioid rotation from morphine to fentanyl in delirious cancer patients: an open-label trial. *J Pain Symptom Manage* 2005;**30**(1):96–103.

38. Cooper J, Hewison A. Implementing audit in palliative care: an action research approach. *J Adv Nurs* 2002;**39**(4):360–9.
39. Ahmed N, Bestall JC, Ahmedzai SH, Payne SA, Clark D, Noble B. Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. *Palliat Med* 2004;**18**(6):525–42.
40. Krakauer EL, Crenner C, Fox K. Barriers to optimum end-of-life care for minority patients. *J Am Geriatr Soc* 2002;**50**(1):182–90.
41. World Health Organisation. *World Health Report 2000 – Health Systems: improving performance*. Geneva: World Health Organisation; 2000.
42. Foreman LM, Hunt RW, Luke CG, Roder DM. Factors predictive of preferred place of death in the general population of South Australia. *Palliat Med* 2006;**20**(4):447–53.
43. Survey GallupOrganisation. *Knowledge and attitudes related to hospice care*. Arlington, VA: National Hospice Association; 1996.
44. Christakis NA. Advances in palliative care research methodology. *Palliat Med* 2006;**20**(8):725–6.
45. Kaasa S, Hjermstad MJ, Loge JH. Methodological and structural challenges in palliative care research: how have we fared in the last decades? *Palliat Med* 2006;**20**(8): 727–34.
46. Gysels M, Higginson IJ. *Improving supportive and palliative care for adults with cancer: research evidence. Report No: 10 – General palliative care services, incorporating care of dying patients*. London: National Institute for Clinical Excellence; 2004.
47. Grande GE, Todd CJ. Why are trials in palliative care so difficult? *Palliat Med* 2000;**14**(1):69–74.
48. Sinnott C. Problems recruiting cancer patients to a comparative clinical trial of drug treatments for neuropathic pain in palliative care. *J Pain Symptom Manage* 2002;**23**(4):270–2.
49. Currow DC, Abernethy AP, Shelby-James TM, Phillips PA. The impact of conducting a regional palliative care clinical study. *Palliat Med* 2006;**20**(8):735–43.
50. Jordhoy MS, Fayers P, Saltnes T, Hlner-Elmqvist M, Jannert M, Kaasa S. A palliative-care intervention and death at home: a cluster randomised trial. *Lancet* 2000;**356**(9233):888–93.
51. Steinhauser KE, Clipp EC, Hays JC, et al. Identifying, recruiting, and retaining seriously-ill patients and their caregivers in longitudinal research. *Palliat Med* 2006;**20**(8):745–54.
52. Advances in palliative care research methodology (special issue). 20th ed; 2006.
53. National Institutes of Health State-of-the Science Panel. National Institutes of Health State-of-the-Science Conference Statement: Symptom Management in Cancer: Pain, Depression, and Fatigue, July 15–17, 2002. *J Natl Cancer Inst* 2003;**95**(15):1110–7.
54. Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. *J Am Med Assoc* 2000;**284**(19):2476–82.
55. Anderson GF, Hussey PS. Health and population ageing: a multinational comparison. <http:// www.commonwealthfund.org/publications/ publications_show.htm?doc_id=221235>.
56. WHO. *Better palliative care for older people*. Copenhagen, Denmark: World Health Organisation; 2004.
57. Cohen J, Bilsen J, Addington-Hall J, et al. Hospital deaths in six European countries: population-based cross national study of factors associated with dying in hospital; 2008.
58. Brandt HE. *Palliative care in Dutch nursing homes*. Amsterdam: VU University Medical Centre; 2007.
59. National Research Council. *Describing death in America: what we need to know*. Washington, DC: National Academy Press; 2008.