

PRISMA: share best practice in end-of-life cancer care research and measurement

Richard Harding and **Irene J Higginson** explain the rationale, structure and activities of PRISMA, a European programme with the overall aim of co-ordinating high-quality international research into end-of-life cancer care

The provision of appropriate, effective and well-planned end-of-life cancer care is a public health priority for Europe. However, despite demographic projections showing significant increases in the need for palliative care provision, the development and evaluation of quality care at the end of life has, to date, been severely neglected.

Under the European Commission's Seventh Framework Programme, PRISMA has been funded by the European Union to bring together pan-European experts in the field of end-of-life cancer care research. This co-ordinating action project takes a multidisciplinary approach to identifying and promoting best scientific practice in clinical research, to better measure outcomes among patients at the end of life and to enhance translational research (see Box 1).

The project's background

Underinvestment in end-of-life cancer care research

Research in end-of-life cancer care is under-resourced and underdeveloped across Europe. The WHO Europe guidance *The Solid Facts. Palliative Care* shows that, in many countries, less than 0.2% of cancer research funds are allocated to end-of-life and palliative care.¹ The guidance recommends collaboration in end-of-life research to overcome barriers. With an estimated annual 1.7 million deaths from cancer in the whole of Europe in 2004,^{2,3} there is an urgent need to improve care at the end of life for patients and families. Furthermore, epidemiological data have identified a significant symptom burden among European citizens with progressive malignant disease, and these symptoms require excellence in their assessment, measurement and management.⁴

Definition of end-of-life care and research

Defining end-of-life care is complex, and its meaning is likely to be affected by culture. For some, end-of-life care is taken to equate to terminal care in the last few weeks or days of life; for others, it is only the care given just before the very end of life; others again include the whole last year of life.

PRISMA has adopted a conservative interpretation of the working definition in the scoping exercise (overview) of definitions and priorities in end-of-life care by the National Institute for Health Research,⁵ supported by the working definition arising from the *National Institutes of Health State-of-the-Science Conference Statement on Improving End-of-Life Care*.⁶ For our purposes, we therefore focus on end-of-life cancer care as that given in the last year of life.

Key points

- PRISMA is a three-year project funded by the European Commission's Seventh Framework Programme, which began in May 2008 with the overall aim of co-ordinating high-quality international research into end-of-life cancer care.
- PRISMA is investigating how measurement tools such as the Palliative care Outcome Scale (POS) and the Support Team Assessment Schedule (STAS) are being applied, to promote closer collaboration in the use of common tools.
- Other focuses of this European research project include cultural issues, patients' and clinicians' priorities, symptom measurement and nursing home care measurement.
- PRISMA will culminate with the dissemination, at a final meeting and online, of commonly agreed definitions, research goals and agendas, and best practice guidance.

This, as a working definition, is a flexible starting point for our co-ordinating action.

Project PRISMA: what will we be working on?

To facilitate an effective consortium co-ordinating high-quality end-of-life cancer care research, it was clear, from the literature, that a number of related studies needed to be carried out under the auspices of PRISMA. These studies will ensure that methodological best practice is understood in clinical research, and that our activity reflects the definitions and priorities of European patients, academics and clinicians; hence PRISMA's full title, 'Reflecting the positive diversities of European priorities for research and measurement in end-of-life care'.

Determine common research priorities and measurement tools

Despite the great need for further research in end-of-life cancer care, there is currently no clear agreement on the priorities for action. Any consensus on European priorities must take into account the public's, as well as the professionals', viewpoints. Patients' preferences and priorities are key in person-centred end-of-life care. Within this programme, we propose including two Europe-wide exercises to determine both the public's and the healthcare professionals' priorities for end-of-life research.

We will explore the use of the Palliative care Outcome Scale (POS) and the Support Team Assessment Schedule (STAS), and take into account alternative measurement tools used by some, such as the Memorial Symptom Assessment Scale (MSAS) and the European Organisation for Research and Treatment of Cancer (EORTC) questionnaire. This will promote better collaboration in the use of common tools in both quality improvement and research in end-of-life cancer care.

The POS was originally developed and validated in eight different end-of-life and palliative care settings in the UK,⁷ based on a systematic literature review of existing scales.⁸ More than 450 palliative care units, most of them located in 20 European countries, have registered as current users of the POS or expressed an interest in using it; 100 units are either currently using, or have used, the POS for quality improvement or research. Several independent translations and validations have been published, with versions in German,

Box 1. A summary of the aims of PRISMA

PRISMA is funded by the European Commission's Seventh Framework Programme with the overall aim of co-ordinating 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's activities aim to reflect the preferences and cultural diversities of citizens and the clinical priorities of clinicians, and to appropriately measure multidimensional outcomes across settings where end-of-life care is delivered

Italian, Dutch, Portuguese, Spanish, Urdu and Punjabi.⁹⁻¹³ Users' and patients' views of the POS generally suggest it is a valuable tool that reflects their concerns.¹⁴

The STAS was developed specifically for the very last stages of end-of-life care. It is multidimensional, has been widely employed in end-of-life cancer populations, and has also been used in a number of international studies. It has been validated to ensure staff, patient and family completion.¹⁵ The expanded version of the STAS, or E-STAS, has been validated in hospital inpatient populations (that is, in patients with acute and usually terminal illness).¹⁶ It has been used successfully to investigate the final week of life in cancer patients dying at home in Italy;¹⁷ to measure end-of-life advanced cancer problems in a French version;¹⁸ to evaluate quality of care and life within a French advanced cancer home and hospital team;¹⁹ and to determine symptom severity associated with approaching death in cancer patients in Ireland.²⁰ It is well suited to clinical research, having been used for opioid evaluation in symptom control studies on terminal cancer.²¹ The STAS has also been used successfully in quality improvement audits.²²

A further aim of PRISMA is to develop and disseminate a simple method of symptom measurement to be incorporated into daily clinical practice, using an additional brief symptom inventory (Palliative care Outcome Scale-Symptoms [POS-S]).

However, there is a need to harmonise the developments, training and guidance concerning the POS, STAS and other measurement tools such as the MSAS and the EORTC questionnaire. It is also necessary that those who use these tools share best practice and inform their use.

While PRISMA's primary focus is on end-of-life care in cancer, the findings will hopefully be relevant for all diseases with similar

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Table 1. PRISMA's integrated work packages

Number	Title	Details	Led by
Work package 1	Cultural differences	A team of anthropologists is investigating the meaning of end of life across European populations to ensure our measurement tools and research agendas reflect European diversity	University of Barcelona, Spain
Work package 2	Public priorities	To ensure that common research agendas reflect public priorities, large-scale public surveys across European Union member states are being conducted to inform future research	King's College London, UK
Work package 3	Clinical priorities	Clinicians throughout Europe are being surveyed to ensure that our research activity is informed by common clinical challenges, and that we understand the range of methods being applied in clinical research	Norwegian University of Science and Technology (NTNU), Trondheim, Norway
Work package 4	Best practice in Palliative care Outcome Scale (POS) and Support Team Assessment Schedule (STAS) measurement	The current use of a range of tools, and how they are being applied, is being investigated Europe-wide	German Association for Palliative Medicine, Germany
Work package 5	Best practice in symptom measurement	An add-on brief symptom inventory (Palliative care Outcome Scale-Symptoms [POS-S]), is being developed and validated for use in clinical practice	University of Coimbra, Portugal
Work package 6	Best practice in nursing home measurement	An expert group of researchers active in the measurement of populations residing in nursing homes at the end of life is being co-ordinated, and appropriate methods and data analysis approaches are being identified	Vrije Universiteit, Brussels, Belgium
Work package 7* and Work package 8**		Responsible for management and final meeting dissemination	*King's College London, UK and **University of Antwerp, Belgium

trajectories and symptoms that European citizens suffer from at the end of life.

Identification of cultural issues

Although guidelines on quality end-of-life care suggest that sensitivity to cultural issues is needed, there is a lack of expertise on what this encompasses or how it translates into practice. European countries have become multicultural societies. Ethnic minorities have been identified as being less likely than others to have access to palliative care services.²³ PRISMA will develop collaboration with anthropologists to identify cultural differences and explain cross-cultural meanings and practices in end-of-life care.

Pooled data sets and unified analytical approaches

Co-ordinating the methodological experts who are working with PRISMA will enable us to share good practice guidance and harmonise research activities between countries.

For example, we should be able to pool data sets between countries. We should also be able to unify the analytical approaches used to tackle the methodological challenges commonly faced by researchers in end-of-life cancer care, including:

- How to deal with missing data from those unable to complete quality questionnaires
- How to analyse longitudinal data sets
- How to undertake robust and ethical experimental evaluation in a vulnerable population.

Through agreeing on, and disseminating, best practice guidance, we should be able to harmonise activities while adhering to the highest principles of scientific rigour within this complex field of research.

In many European countries, high-care nursing homes play an increasing role in caring for frail older people at the end of life.¹ Despite the high numbers of elderly people dying in nursing homes, healthcare policies in general have little concern with the quality of care

provided for older people. PRISMA will facilitate pooled analysis of data sets to determine how measurement tools perform among nursing home residents.

Workplan and work packages

PRISMA's original workplan is organised around a set of integrated work packages, each making a contribution to the research co-ordination and overall aims (see Table 1). As the lead institution, King's College London is guiding the consortium and integrating activities and outputs (the Department of Palliative Care, Policy and Rehabilitation at King's College London is a WHO Collaborating Centre for Palliative Care and Older People). As well as those member institutions listed in Table 1, additional members from African countries, Italy, the Netherlands and Belgium are also participating in PRISMA's work.

An integrated consortium for future action

PRISMA actions across all work packages will be integrated throughout the duration of the project (which started in May 2008 and will last three years). This will culminate in the dissemination of the results, during a final meeting, to all those engaged in end-of-life cancer care. After that meeting, our commonly agreed definitions, research goals and agendas, best practice and reflection on different populations and care settings will be circulated. A searchable database will be added to the PRISMA website, to enable easy identification of areas of work, best practice, recommended methods, measurement tools and guidance. The website will also give contact details of partners with specific end-of-life cancer care research interests, so that future high-quality research collaborations can be formed.

We encourage policy-makers, healthcare commissioners, researchers and clinicians to visit our pages regularly, to look for potential new partnerships with our members and to use the outputs of PRISMA freely to drive forward better end-of-life cancer care through co-ordinated high-quality clinical research.

Further information on PRISMA, its members, work packages and outputs, as well as contact details, can be found online at www.prismaf7.eu

For more on EU-funded palliative care research, read the Update on the EPCRC project on pain, depression and fatigue by Dagny Faksvåg Haugen and Stein Kaasa published in our previous issue (*European Journal of Palliative Care* 17.3).

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