



# PRISMA: Reflecting the positive diversities of European priorities for research & measurement in end-of-life care

Dr Barbara Daveson

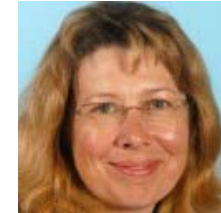
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# Acknowledgements

**Scientific Director** *Prof Irene J Higginson*



**Principal Coordinator** *Dr Richard Harding*



**Work Package 4 Lead** *Dr Claudia Bausewein*



**PRISMA Consortium  
Members**



# Background



- End-of-life research under-resourced & under-developed
- Little international data on public & clinical priorities
- Little cross-national coordination in undertaking research in end-of-life care
- Lack of agreement on what constitutes “end-of-life” cancer care
- Few ways to measure care
- Lack of established best practice
- Poor cultural understanding of end-of-life care in culturally-diverse Europe



# PRISMA's overall aim



To inform best practice & harmonise research in end-of-life care for cancer patients across Europe through comparison & exchange of approaches & experiences in measurement & research priorities



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# PRISMA's objectives



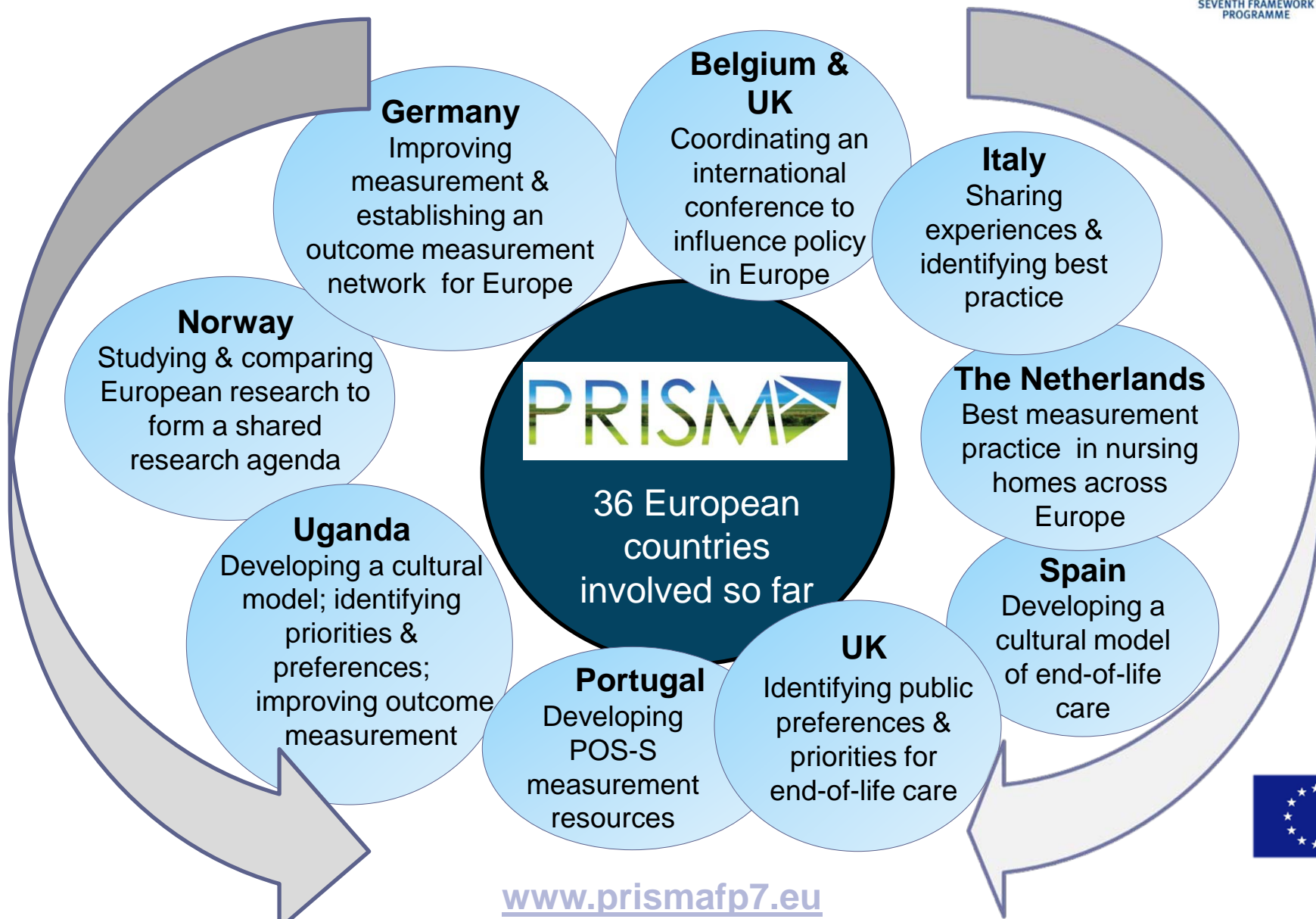
- To develop collaboration on culture & end-of-life care across Europe, exploring & mapping differences in priorities & evidence
- To study & compare the nature & conduct of research into end-of-life care in cancer across Europe & to compare these with clinical & public priorities
- To map & harmonise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



# Streams of work: 8 work packages

WP	WP Title	WP Lead
WP1	Cultural difference in end-of-life care	Dr Marjolein Gysels
WP2	Public priorities & preferences for end-of-life care	Barbara Gomes
WP3	Clinical research priorities in end-of-life care	Prof Stein Kaasa
WP4	Best practice & resources for the use of end-of-life care quality indicators	Dr Claudia Bausewein
WP5	Best practice in symptom measurement	Prof Pedro Lopes Ferreira
WP6	Best practice in nursing home measurement	Prof Luc Deliens
WP7	Management	Dr Richard Harding
WP8	Final conference	Dr Noël Derycke & Dr Barbara Daveson

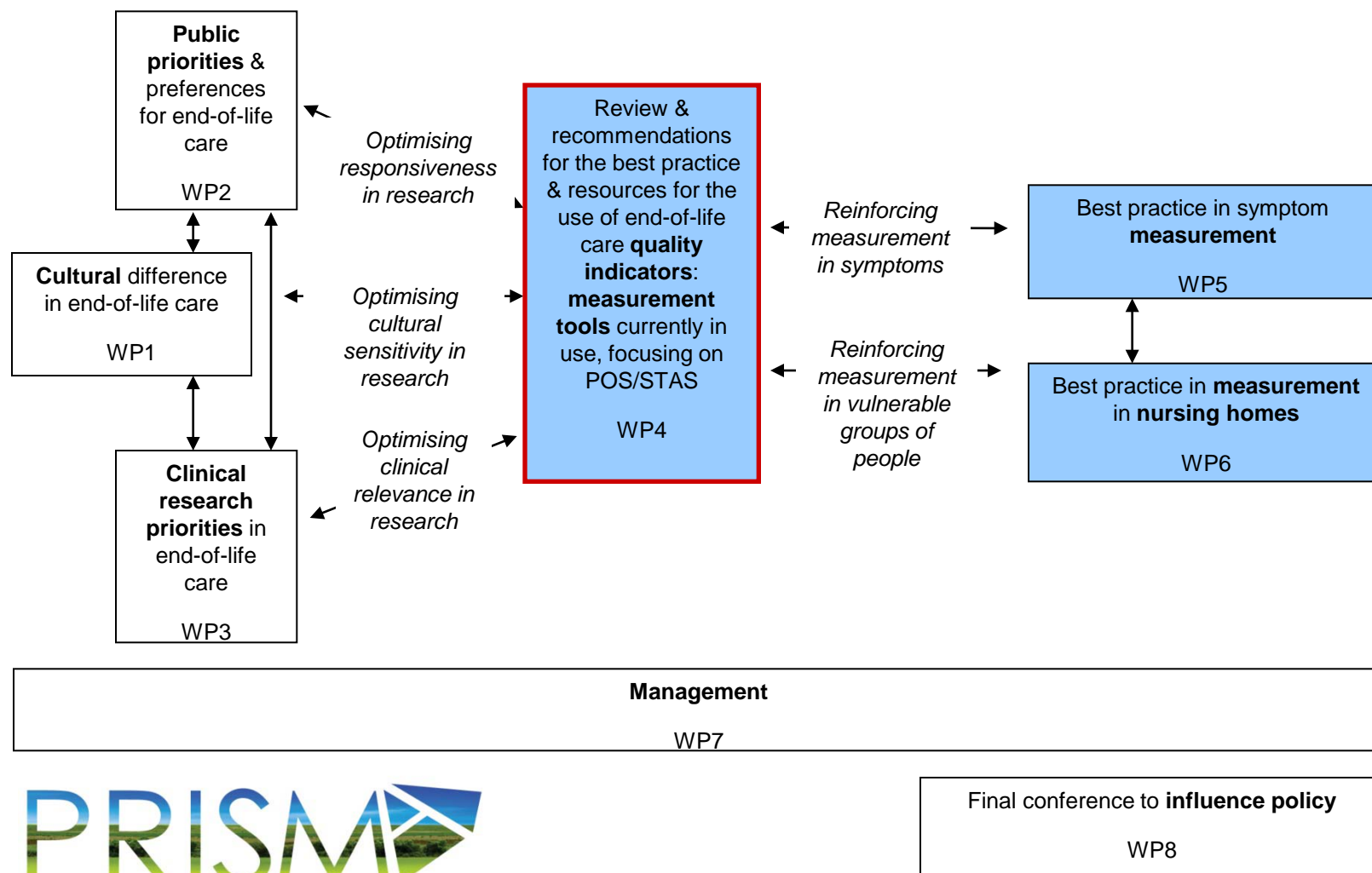
# Pan-European



# Pan-European co-ordinating action examples

- 12,000 participants to be polled across 7 European countries in PRISMA's pan-European opinion poll to determine public priorities & preferences
- Survey responses from 36 European countries regarding how & how well end-of-life cancer care research is performed in Europe
- Participants from 25 European countries participated in research agenda workshop, including 9 Eastern European countries &/ or former Soviet Union member states
- Final conference in 2011

# Outcome measurement



# Work package 4

## Best practice & resources for the use of POS & STAS & other tools in end-of-life cancer care

Led by **Dr Claudia Bausewein**



Core research team: Dr Steffen Simon & Mr Hamid Benalia

Plus additional PRISMA members

Department of Palliative Care, Policy & Rehabilitation, KCL

Deutsche Gesellschaft für Palliativmedizin

# WP4 objectives

- To identify & describe the ways in which measurement tools are used in end-of-life care in European countries
- To coordinate exchange of experiences in those who use the identified tools in end-of-life care
- To develop resources & support for those who use the POS & STAS in end-of-life cancer care



# Survey aims

- To describe the practice of use (purposes, frequencies & so on) of tools & outcome measures in different settings
- To identify which tools are used in clinical care/ audit & research
- To describe the views of users regarding advantages & problems of using outcome measures
- To describe the use & experiences with POS & STAS
- To describe participants' views on further development of outcome measures

# Methods



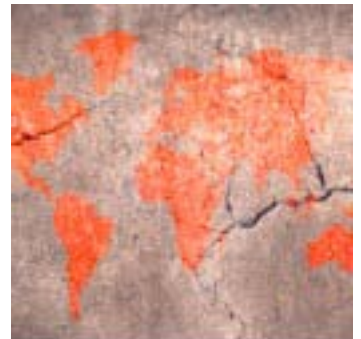
- Web-based online survey
- Questionnaire development
  - Within WP4
  - PRISMA partners at all-assembly meeting 05/09
  - Conducted in English – own language open-ended questions
  - Piloting with 20 people in 7 European countries  
(Austria, Germany, Italy, Netherlands, Norway, Portugal & UK)
  - Revisions regarding wording, layout, invitation letter
- Centre of Evaluation & Methods (ZEM) University of Bonn, Germany

# Questionnaire

- Respondent information
- General questions on use of tools
  - Screening question regarding tool use
- Tools in clinical, audit & research
  - Purpose, frequency, results, advantages & disadvantages, overall experience
- Use of POS & STAS
- Further development of tools

# Sample

- Professionals working in palliative care: physicians, nurses, other professionals
- Sampling
  - National palliative care associations in Europe
  - APCA
  - POS user database
  - POS & STAS authors
  - Palliative care academics in Europe
  - PRISMA members



# Participating national pall care associations

Country	Association	
Africa	APCA	African Palliative Care Association
Belgium	FPCF	Federation Palliative Care
	FWSP	Fédération Wallonne des Soins Palliatifs
Germany	DGP	Deutsche Gesellschaft für Palliativmedizin e.V.
Italy	SICP	Società Italiana di Cure Palliative
NL	NPTN	Palliative Care Network for Terminally Ill Patients
Norway	NFPM	Norwegian Association for Palliative Medicine
Portugal	APCP	Portuguese Association of Palliative Care
Spain	SCBCP	Soc. Catalano-Balear de Cures Palliatives
	SECPAL	Sociedad Española de Cuidados Paliativos
UK	APM	Association for Palliative Medicine of &
	APCSW	Association of Palliative Care Social Workers
	RCN	Royal – Palliative Nursing Group

# Recruitment

## Europe

- 1<sup>st</sup> October 2009 – 22<sup>nd</sup> November 2009
- Two reminders
- 2000 invitations

## Africa

- 12<sup>th</sup> January 2010 – 15<sup>th</sup> February 2010
- One reminder
- 422 invitations



# Actions

- International workshop on outcome measurement in 03/10 in Germany  
32 participants
- Discussions with EAPC
- Collaboration & discussions with PCOC
- Publications & presentations
- Currently forming development strategy
- Resource injection



# Summary & implications

- First survey about professionals views on outcome measures in Europe & Africa
- Variety of tools used in clinical care/ audit & research
- Training & guidance necessary to foster use
- Translation & validation of existing tools
- Optimisation of existing tools
- Pan-European focus

# PRISMA Pan-European Consortium welcomes new collaborators & members



PRISMA meeting in  
The Netherlands



Outcome measurement group in Germany



PRISMA consortium in Spain



VU university medical center





# 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 & improve outcomes for patients and families.

PRISMA activities aim to reflect the preferences & cultural diversities of citizens, the clinical priorities of clinicians, & appropriately measure multidimensional outcomes across settings where end-of-life care is delivered.

Thank you to Dr Claudia Bausewein (WP4 Lead), WP4 researchers, PRISMA members & Lucy Bradley (PRISMA Project Assistant).

Scientific Director: Professor Irene J Higginson

Principal Investigator: Dr Richard Harding

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