

Palliative Care in Scotland: Research Into Practice


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Palliative and end-of-life care research in Scotland 2006-2015: A scoping review


Funded by:
 Scottish Government and Marie Curie

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Overview

1. Review of Scottish palliative care research: 2006 - 15
2. Knowledge exchange



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Research Team

Marie Curie
 Dr Anne Finucane (Edinburgh)
 Dr Emma Carduff (Glasgow)
 Dr Jean Lugton (Edinburgh)
 Dr Juliet Spiller (Edinburgh)

University of Edinburgh
 Prof. Scott Murray
 Prof. Marie Fallon

University of Glasgow
 Prof. Bridget Johnston
 Prof. David Clark

NHS
 Dr Stephen Fenning







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Strategic framework for action in palliative and end of life care

Commitment 5

We will strengthen and co-ordinate research and knowledge exchange across regions, institutions and disciplines by taking further action to support the establishment of a Scottish Research Forum for palliative and end of life care.




December 2015



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Aims

- To provide an insight into the vitality of palliative care research in Scotland.
- To identify and map research relevant to clinicians, policy makers and managers to inform palliative care service delivery.



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Research questions

1. How many Scottish research papers were published over the 10 year period from 2006 – 2015?
2. What areas have been the focus of Scottish research?
3. What types of studies have been undertaken?
4. Where are the strengths?
5. Where are the gaps?

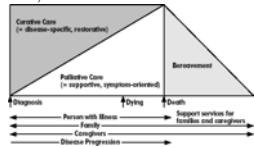
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Methods: search terms

Palliative

- palliative or palliate or palliation or hospice or 'end of life' or 'last year of life'
- 'terminal care'
- dying or bereavement or bereaved or grief
- 'place of death'
- care home or nursing home
- supportive care or supportive oncology
- terminal illness
- (Advanced or late-stage or end-stage) and (disease or illness or cancer or carcinoma or neoplasm) and (symptom control or pain or cachexia or breathlessness or nausea or distress)
- End-stage and (heart or liver or cardiac or kidney or renal)
- Dementia and (advanced or late-stage)




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Methods

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Methods: search terms

Abstract/title contains


- scotland or scottish

Institution contains

- scotland or scottish
- edinburgh
- glasgow
- dundee
- strathclyde
- st Andrews
- west Scotland
- heriot-watt
- edinburgh napier
- Robert Gordon
- abertay
- queen Margaret
- aberdeen
- Stirling
- highlands







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Methods: Databases searched

1. Medline
2. Embase
3. Cinahl
4. PsychInfo
5. Cochrane Palliative Care Database

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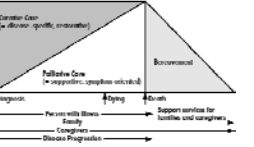
Methods: Inclusion and exclusion

Inclusion


- Focused on palliative and end of life care
- At least one author based at a Scottish institution
- Primary research, secondary research and literature reviews
- Service evaluation or quality improvement underpinned by research methods

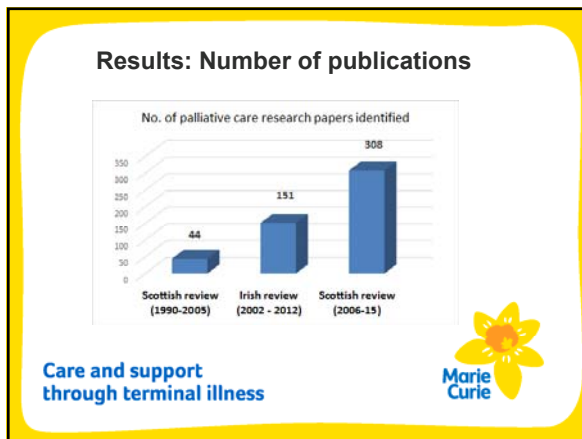
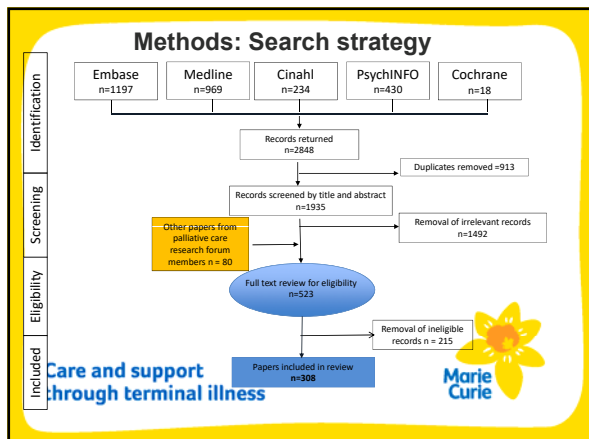
Exclusion

- Research on disease modifying or active treatment
- Studies where data was collected in Scotland but where none of the authors were based in a Scottish institution
- Commentary papers
- Editorials
- Conference abstracts
- Pure service evaluation
- Pure audit
- Case reports
- Non peer reviewed reports
- Theses



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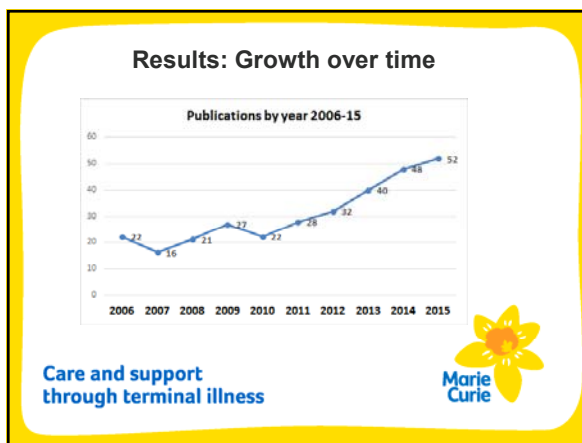




Methods: Data extraction

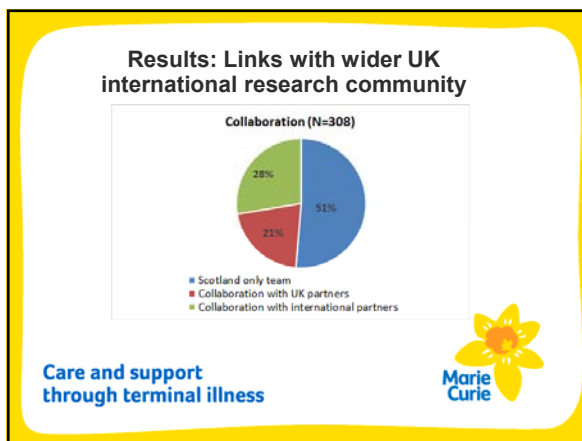
- Author(s)
- Year of publication
- Journal
- Title
- International co-author(s)
- Region(s)
- Aims
- Study population
- Study design
- Evidence type
- Key findings
- Theme 1
- Theme 2
- Theme 3
- Primary audience
- Funder

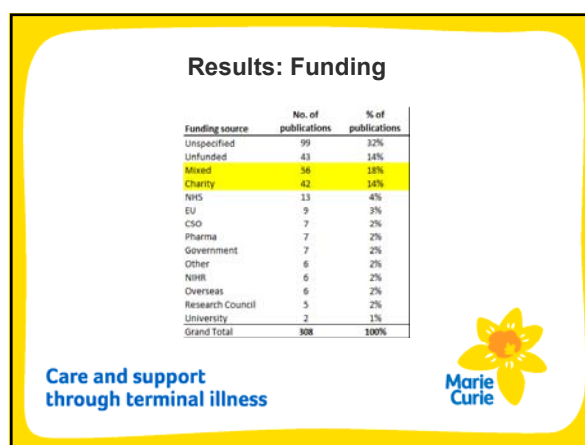
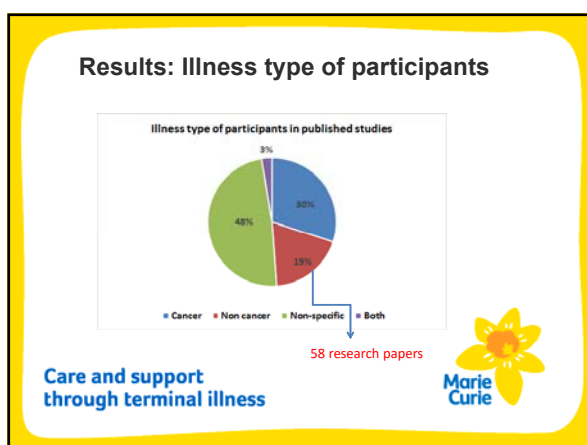
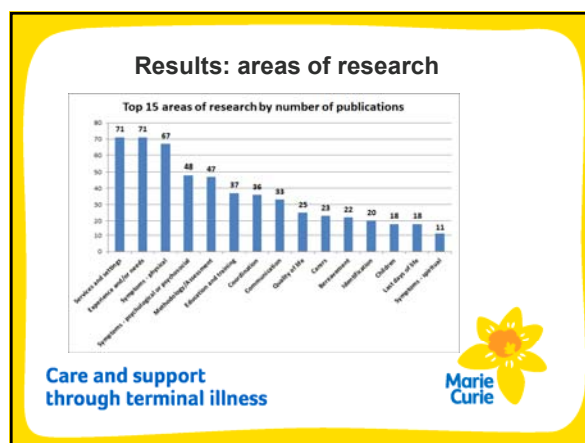
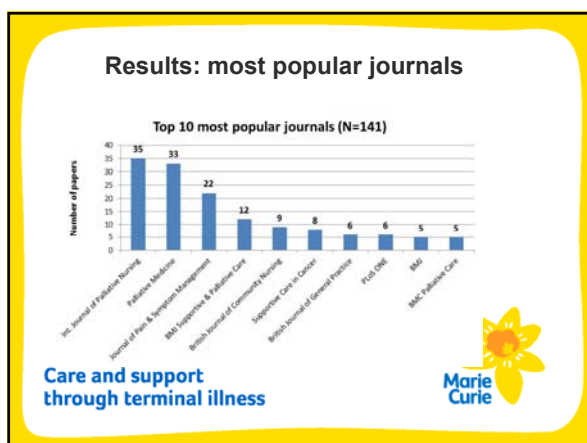
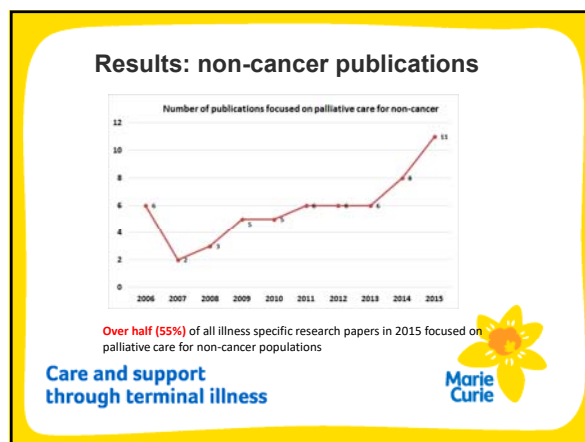
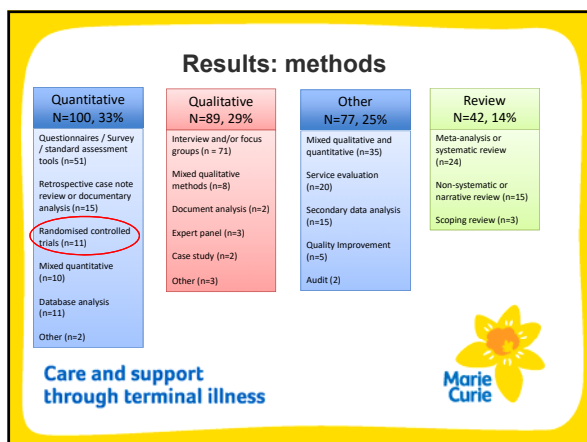
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Results

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Results: Strengths

Strengths

1. Palliative care for people with non-cancer
2. Early and integrated palliative care
3. Rigorous symptom control studies & RCTs
4. Methodological expertise
5. Stable growth in research output
6. High level of collaboration with other UK and international research groups




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Knowledge exchange (KE)

"... a dynamic and iterative process that ... takes place within a complex system of interactions between researchers and knowledge users which may vary in intensity, complexity and engagement"

Canadian Institutes of Health Research



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Ref: Pentland et al. (2011), *Jour. of Advanced Nursing*, p1408-1425.


Results: Gaps

Gaps

1. Intervention studies
2. Cost-effectiveness studies
3. Care homes / frail older people with dementia
4. Non-cancer and multi-morbidity
5. eHealth
6. Public health approaches
7. Out-of-hours
8. Building resilience, promoting autonomy



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KE: Importance of relationships

"Relationships and networks are the most important way in which research is shared, used and reused"

Haas (1992); Best and Holmes (2010); Morton (2015)

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Ref: Pentland et al. (2011), *Jour. of Advanced Nursing*, p1408-1425.

How do we move from research publications to using research findings to inform decision-making?



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Research producers and users

Research users:
Members of the public, policy, or practice communities who use research in conceptual or instrumental ways


Research producers:
Members of the academic community who design and conduct research.

Brokers:
Role in connecting research producers and users

Hybrids:
Mix of roles – producer/users/brokers



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Ref: Morton, S. (2015), *Research Evaluation*, p405-19

Knowledge exchange

Top 15 areas of research by number of publications

Strategic Framework for Action on Palliative and End-of-Life Care (2014-2021)

December 2015

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Evidence review groups

SFA Commitment 1 Identification & coordination

- Dr Stuart Cumming (NHS Forth Valley, HIS)
- Prof. Scott Murray (University of Edinburgh)
- Dr Bruce Mason (University of Edinburgh)
- Dr Sian Tucker (Lothian Unscheduled Care Service)
- Richard Meade (Marie Curie)
- Dr Anne Finucane (Marie Curie)

SFA Commitment 2 Commissioning

- Diana Hekerem (HIS)
- Dr Anne Finucane (Marie Curie)
- Thomas Monaghan (HIS)
- Dr Jo Hockley (University of Edinburgh)
- Dr Bruce Mason (University of Edinburgh)
- Dr Emma Carduff (Marie Curie)
- Dr Juliet Spiller (Marie Curie)
- Susan Lowes (Marie Curie)

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Knowledge exchange

Top 15 areas of research by number of publications

- SFA Commitment 1 Identification & coordination
- SFA Commitment 2 Commissioning
- SFA Commitment 3 Education & training
- SFA Commitment 4 Children and young people
- SFA Commitment 6 Bereavement

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Our approach – evidence review groups

SFA Commitment 3 Education and training

- Sarah Doyle (NES)
- Dr Stephen Fenning (NHS Lothian)
- Tracy Smith (Marie Curie)
- Richard Meade (Marie Curie)
- Erna Haraldsdottir (St Columbas)
- Lyndsay Cassidy (Marie Curie)

SFA Commitment 4 Children and young people

- Dr Fariel Rahman (NHS Greater Glasgow & Clyde)
- Prof. Bridget Johnston (University of Glasgow)
- Dr Anne Finucane (Marie Curie)
- Dr Emma Carduff (Marie Curie)
- Richard Meade (Marie Curie)
- Eilidh MacDonald (Hospice UK)

SFA Commitment 6 Bereavement

- Stuart Wilson (CRUSE Bereavement)
- Dr Emma Carduff (Marie Curie)
- Carole Graham (Prince and Princess of Wales)
- Dr Sally Paul (University of Strathclyde)
- Susan Lowes (Marie Curie)
- Audrey Stephens (Robert Gordon University)

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Evidence review groups

- Established evidence review group around each commitment.
- Consisting of research users and producers.
- Evidence from Scottish review
 - Summaries
 - Key research papers
- Evidence review meeting
 - Key findings of research
 - Implications for practice, service development & policy
 - Evidence gaps
- Speakers drafted presentation (research users)

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Scottish palliative care research forum

- ✓ To facilitate knowledge exchange
- ✓ To Inform evidence based decision making
- ✓ To drive quality improvement


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Thank you

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