

Supportive & Palliative Care Work Package Launch

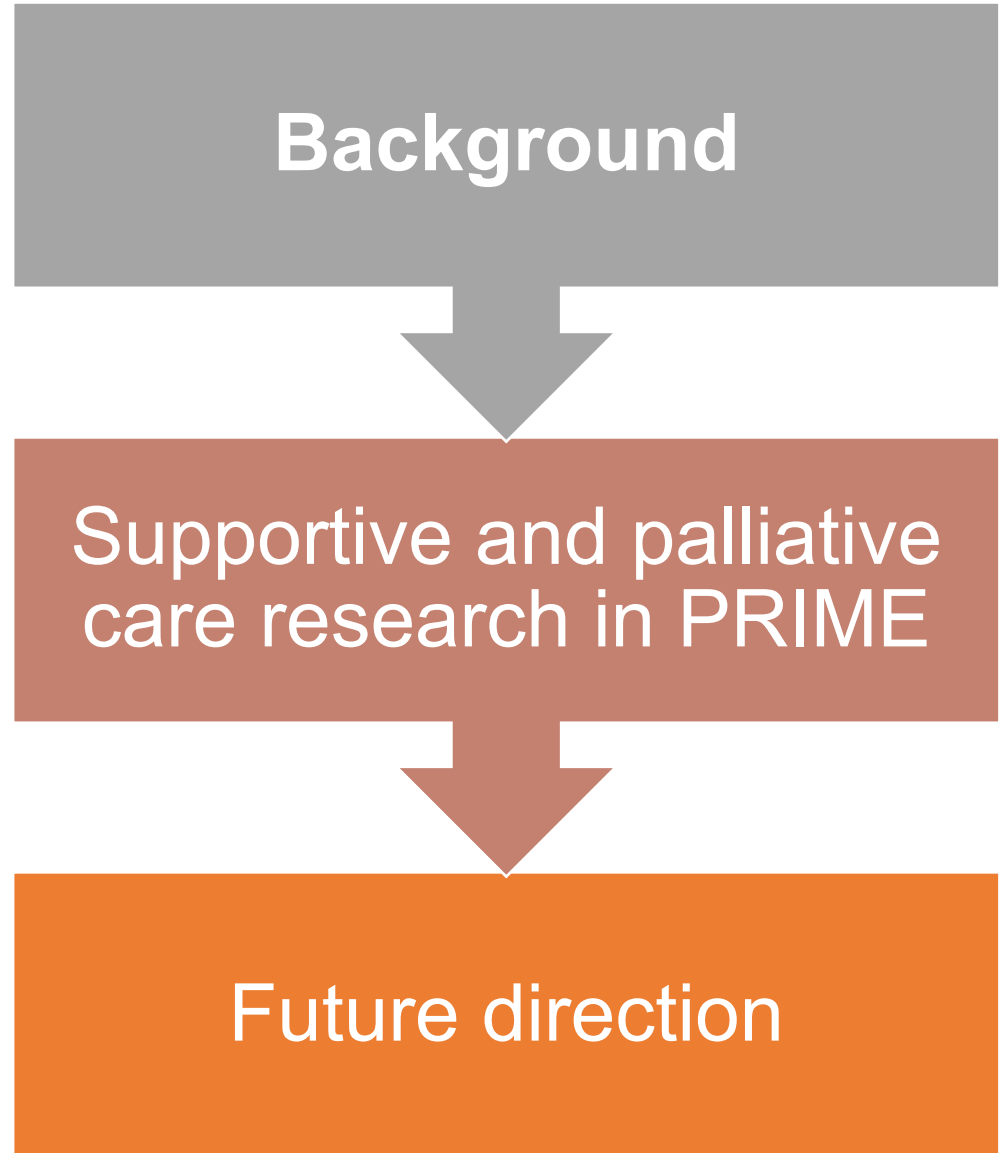
Annmarie Nelson and Marlise Poolman



A celebration!



Overview



Does current palliative and end of life care research match the priorities of patients, carers and clinicians?

A grant mapping analysis of the UK Clinical Research Collaboration's Health Research Classification System dataset 2014



Palliative and end of life care Priority Setting Partnership (PeolcPSP)

Putting patients, carers and clinicians at the heart of palliative and end of life care research

www.palliativecarepsp.org.uk

Supportive and Palliative Care Research is important



Palliative Care Research infrastructure in Wales

Marie Curie Palliative Care Research Centre

- Supportive oncology
 - Difficult decisions, VTE, fitness for treatment
- Transitions of care, bereavement
- Clinical trials
- Cancer: Brain, lung, upper GI, prostate
- IPF, MBO, Late effects/RT
- PPI

Wales Cancer Research Centre

- Evidence synthesis
- Care homes
- Service evaluations/modelling
- Public attitudes





Palliative care in the primary setting

Over 500 000 people die each year in the England and Wales:

- 23.6% at home
- 22.0% in care homes
- 46.6% in hospital
- 5.6% in hospices.
- 45.6% in primary care
- The RCGP & Marie Curie national 2015 survey showed that 97% of GPs felt that general practice plays a key role in the delivery of care to people approaching the end of life, and their families.



Issues in Primary Care

- Out of hours care
- Oncology/specialist interface
- Access to services
- Perceptions of palliative care
- Understanding dying
- Identification of palliative care patients
- Support: Financial, carers, healthcare professionals
- Cancer as chronic illness

Palliative care initiatives



Gold standards framework



Daffodil standards

Community pharmacy daffodil standards



Macmillan categories of care

Overview

- Background
- **Supportive and palliative care research in PRIME**
- Future direction

A celebration!

To improve the
local



Theme 1:

Value-based primary & emerg

- WP1. Infections & antimicrobial resis
- WP2. Emergency, unscheduled & pre
- WP3. Patient safety



Theme 2:

Seamless & social care closer to home

- WP4. Care closer to communities
- WP5. Person-centred care
- WP6. Supportive & palliative care

Workforce development & capacity building

A short history



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Patient safety in palliative care: A mixed-methods study of reports to a national database of serious incidents.

Yardley, I; Yardley, S; Williams, H; Carson-Stevens, A; Donaldson, LJ; (2018) *Patient safety in palliative care: A mixed-methods study of reports to a national database of serious incidents*. Palliative medicine. p. 269216318776846. ISSN 0269-2163 DOI: <https://doi.org/10.1177/0269216318776846>

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A short history (in published papers)...

Patient safety incidents in advance care planning for serious illness: a mixed-methods analysis

Toby Dinnen,¹ Huw Williams,¹ Sarah Yardley,² Simon Noble,³
Adrian Edwards,¹ Peter Hibbert,⁴ Joyce Kenkre,⁵
Andrew Carson-Stevens^{1,4}



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Original Article

Quality improvement priorities for safer out-of-hours palliative care: Lessons from a mixed-methods analysis of a national incident-reporting database

Huw Williams¹, Sir Liam Donaldson², Simon Noble³, Peter Hibbert⁴,
Rhiannon Watson¹, Joyce Kenkre⁵, Adrian Edwards¹
and Andrew Carson-Stevens^{1,4,6}

Palliative Medicine
2019, Vol. 33(3) 346–356
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British Journal of General Practice 2019; 69 (suppl 1): bjpg19X702845 DOI: <https://doi.org/10.3399/bjpg19X702845>

A short history (in published papers)...

Do published patient decision aids for end-of-life care address patients' decision-making needs? A systematic review and critical appraisal

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Georgina Phillips¹ , Kate Lifford¹, Adrian Edwards¹,
Marlise Poolman^{2,3} and Natalie Joseph-Williams¹

A short history (in published papers)...


Review Article



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Georgina Phillips¹ , Kate Lifford¹, Adrian Edwards¹,
Marlise Poolman^{2,3} and Natalie Joseph-Williams¹

Poolman et al. *Trials* (2019) 20:105
<https://doi.org/10.1186/s13063-019-3179-9>


Trials

STUDY PROTOCOL

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CARer-ADministration of as-needed subcutaneous medication for breakthrough symptoms in homebased dying patients (CARIAD): study protocol for a UK-based open randomised pilot trial

Marlise Poolman^{1,2*} , Jessica Roberts¹, Anthony Byrne^{3,4}, Paul Perkins^{5,8}, Zoe Hoare¹, Annmarie Nelson³, Julia Hiscock¹, Dyfrig Hughes⁶, Betty Foster⁷, Julie O'Connor⁵, Liz Raymond⁹, Sue Healy⁹, Rossela Roberts², Bee Wee¹⁰, Penney Lewis¹¹, Rosalynde Johnstone², Sian Roberts², Emily Holmes⁶, Stella Wright¹, Annie Hendry¹ and Clare Wilkinson¹


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Downloaded from <http://spcare.bmj.com/> on January 18, 2017 - Published by group.bmj.com

Research

Dying at home of cancer: whose needs are being met? The experience of family carers and healthcare professionals (a multiperspective qualitative study)

Jackie Pottle,¹ Julia Hiscock,² Richard D Neal,³ Marlise Poolman²

A short history (in published papers)...



Canolfan PRIME **Cymru**
PRIME Centre **Wales**



Overview

- Background
- Supportive and palliative care research in PRIME
- **Future direction**

Future direction

Research activities will focus on:

- **Management of common symptoms** in the last months/weeks/days of life, and service models to support this, e.g. the role of nurse prescribers, medicines management, including de-prescribing
- **Lay caregiver support:** Anticipatory education on preparing for a home death, role-extension (e.g. carer-administration of as-needed injectable medication), and evidence-based bereavement support
- **Improving awareness, societal expectations, knowledge and acceptance of death and dying**



Thank you!