

School for Social Care Research

Webinar 3: Public Involvement in Adult Social Care Research – End of Life Care

1 May 2014



Research Methods and Public Involvement in End of Life Care Research

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Presentation

- End of life care research in social care settings
- Research Methods
- Issues
- Concluding comments

End of Life Care

Claire Goodman, Katherine Froggatt
and Elspeth Mathie

Methods Review 12

Improving the evidence base for
adult social care practice



Research methods review: overview

- Methodological approaches
- Secondary and official data sources
- End of life research in care homes
- Ethical challenges
- User involvement

A shared language?

- ***End-of-life care** for seniors requires an active, compassionate approach that treats, comforts and supports older individuals who are living with, or dying from, progressive or chronic life-threatening conditions. Such care is sensitive to personal, cultural and spiritual values, beliefs and practices and encompasses support for families and friends up to and including the period of bereavement' (Ross et al. 2000:9).*

Living *and* Dying: “Betwixt and Between”

Nicholson et al 2009

- Majority of research in end of life care **health care led** and **defined**
- For older people the trajectory is often unclear may involve multiple transitions in the last years of life
- Disadvantaged groups can become the “disadvantaged dying”
- Majority of dying still within the home, but the majority of deaths take place in hospital
- Noticeably less attention has been given to the experience of dying at home, inter-professional working between health and social care, and the impact of different kinds of social care and support



Issues

- **Defining dying**
- **The focus** (individual, organisational, professional)
- **Talking about dying with different groups**
- **Ethical issues**
- **Patient and public involvement**



Claims for PPI

Methodological : potential to improve quality and impact of research and accountability of researchers = greater transparency

Moral and ethical :involvement as a right for the tax-paying citizen within a democratic society

Political: as a means of enhancing the validity of decision making and policy development

Dramatic increase in PPI Most common format: membership of research committees/teams: often an invisible process

Wilson et al 2014

Public Involvement in end of life care research

- Public Health of dying
- Peer educators
- Co researchers



In conclusion

- **People at the end of life often value the opportunity to participate in and find benefit from their involvement in research.**
- **More research is needed on the costs and resource use associated with end of life care in social care settings.**
- **Need for an evidence base to support the development of good social care practice in end of life care that complements palliative care research and develops resources that are specific to social care.**
- **Narrative and online data sources about the experience of dying and access to support and secondary data sources are underused**
- **Research in end of life of care** would benefit from more social care-appropriate theoretical frameworks.

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*National Institute for
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Heather Maggs
ex-dementia carer

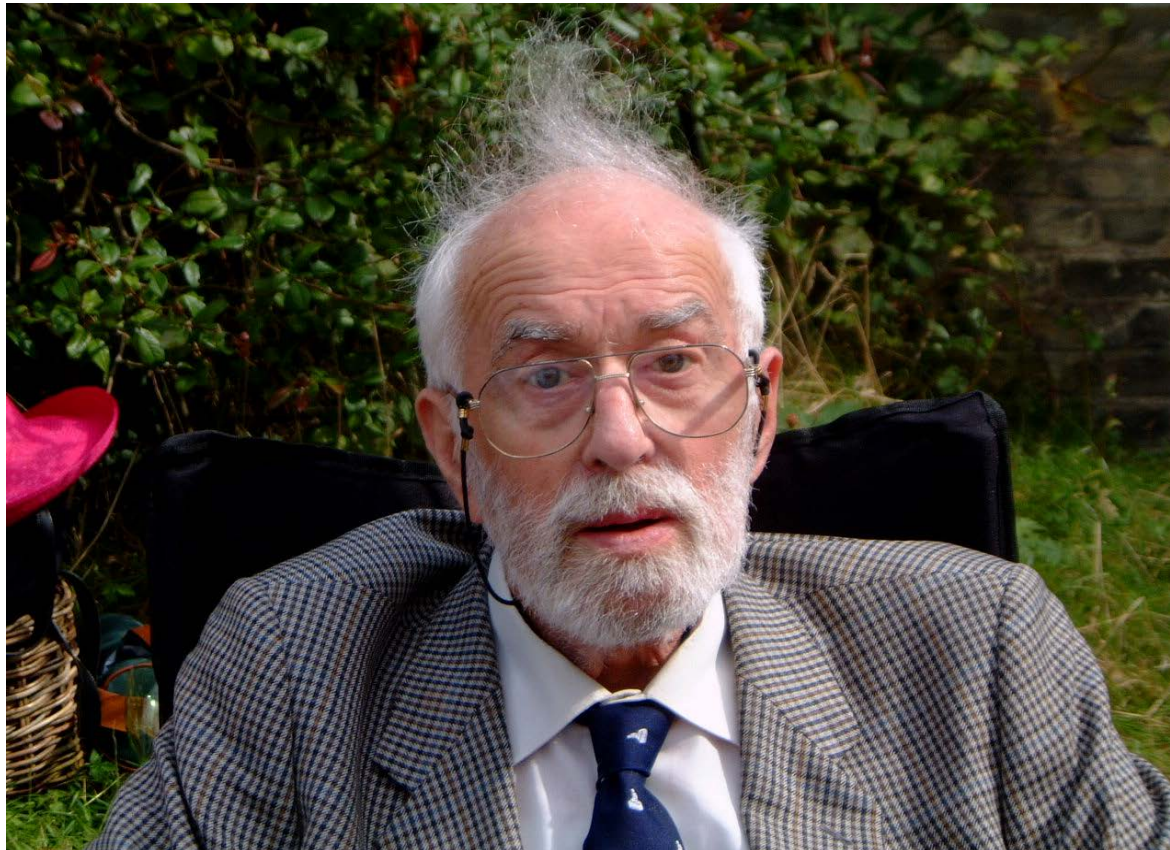
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Introduction: how I came to be involved



How I've been involved in dementia studies

- I seem to have become the person from the PIR group to chair a number of steering groups' dementia studies
 - although not the only member with dementia caring experience
 - possibly as a result of the chairing experience I've had in my “business life

Involvement in end of life care research

- Evidem is the only end-of-life dementia study I've been involved with
- Realised, looking back at my time as a carer, that I didn't know that Dad was at the end of his life
 - or that I and other “statutory” carers were providing end-of-life care
 - (I'm sure they knew!)

Where the involvement work well

- Range of membership: a very engaged committee
- Did feel like a team: worked well together
(had 4 years to develop)
- The Steering Committee had more than one PPI member:
 - so when circumstances resulted in one person having to move on, the committee still had valuable PPI experience to draw on
- Not just an academic link to the research team, but a PPI link as well
 - through Marian Cowie
 - Worked very well

Challenges

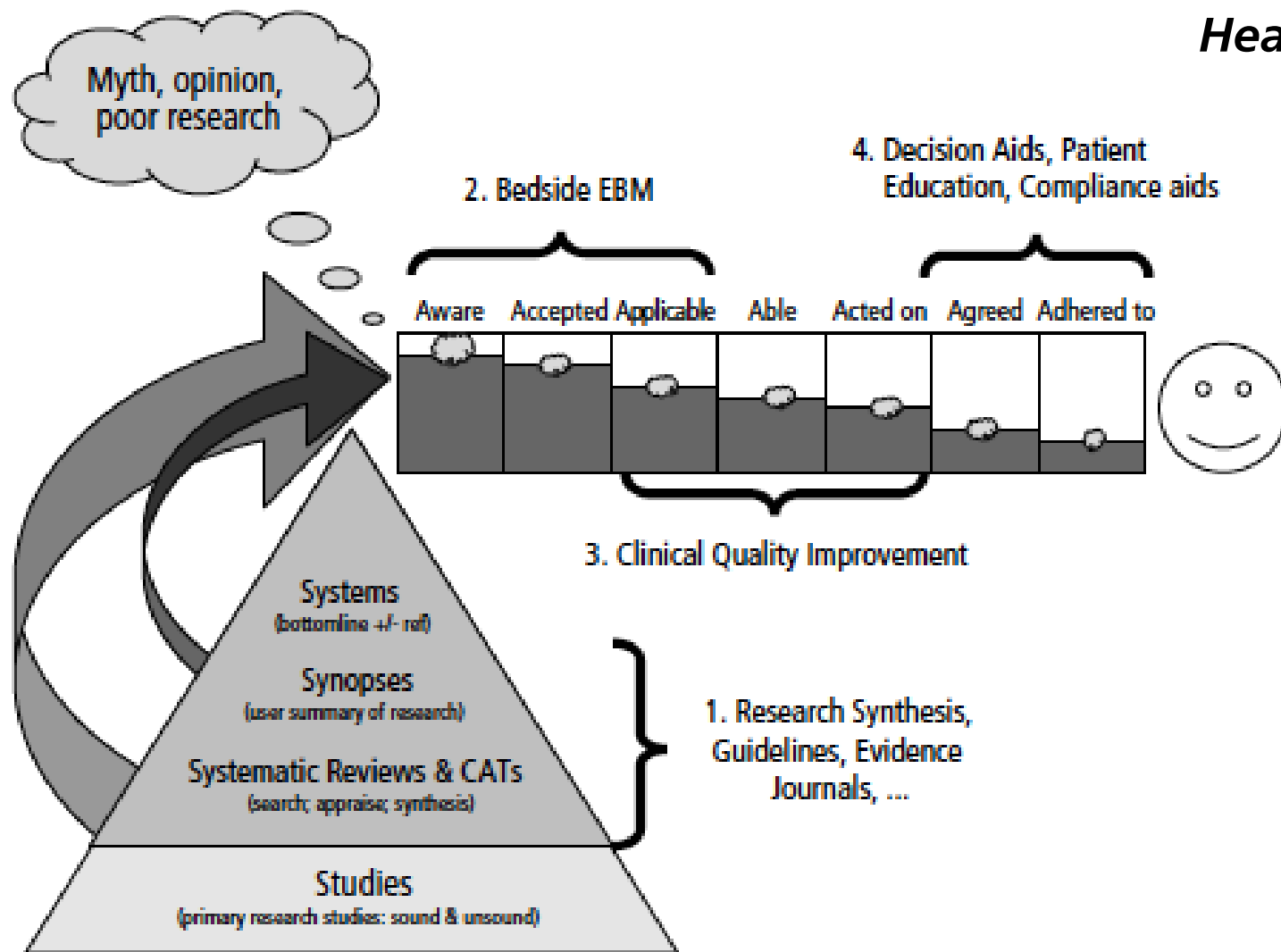
- There is a cost – an emotional one
 - element of both “I wish ..” and anger: why couldn’t Dad have had best practice care?
- Research team found data collection really difficult
 - but the Steering Committee wouldn’t let the team deviate from the original protocol when asked

Challenges

- It was a long study, over 4 years, and both academic and lay members moved on occasionally
 - but there was a positive as the Committee members had time to develop as a team
- Personal one: chairing with other PPI members slightly more difficult

Did Public Involvement make a difference?





Researchers in end of-life care research?

- Don't give up – it's such an important area in which the bar needs to be raised in my opinion
- Expect it to be difficult to recruit patients!
- I also appreciate the ethical difficulties of talking to people for whom it may be difficult to obtain informed consent and those who are protected by well meaning carers

Conclusion

“Life is all memory, except for the present moment that goes by you so quick you hardly catch it going.”

Tennessee Williams

The Palliative and end of life care Priority Setting Partnership with the James Lind Alliance (PeolcPSP)

Determining research priorities from the
perspective of the end user of research

Research methods and public involvement
in End of Life Care Research

1 May 2014

Dr Sabine Best

www.palliativecarepsp.org.uk

What this talk is about

1. Why have we initiated the **Palliative and end of life care Priority Setting Partnership with the James Lind Alliance (PeolcPSP)** ?
2. Who is involved?
3. How does it work?

Background

End of life care research: underfunded research area

(End of life care strategy, 2008; NCRI Rapid Review of research in survivorship after cancer and end of life care, 2010)

Annual Marie Curie Research Programme: £1M/year, since 2010

‘We put patients and families first’

Peer reviewed publications that address research priorities in adult end of life care

- Papers from US, Canada, Europe, UK, Australia
- Research priorities mainly identified by researchers, clinicians, policy makers and health care professionals
- Only 2 papers on patient priorities for palliative care research
- No publications solely asking carers



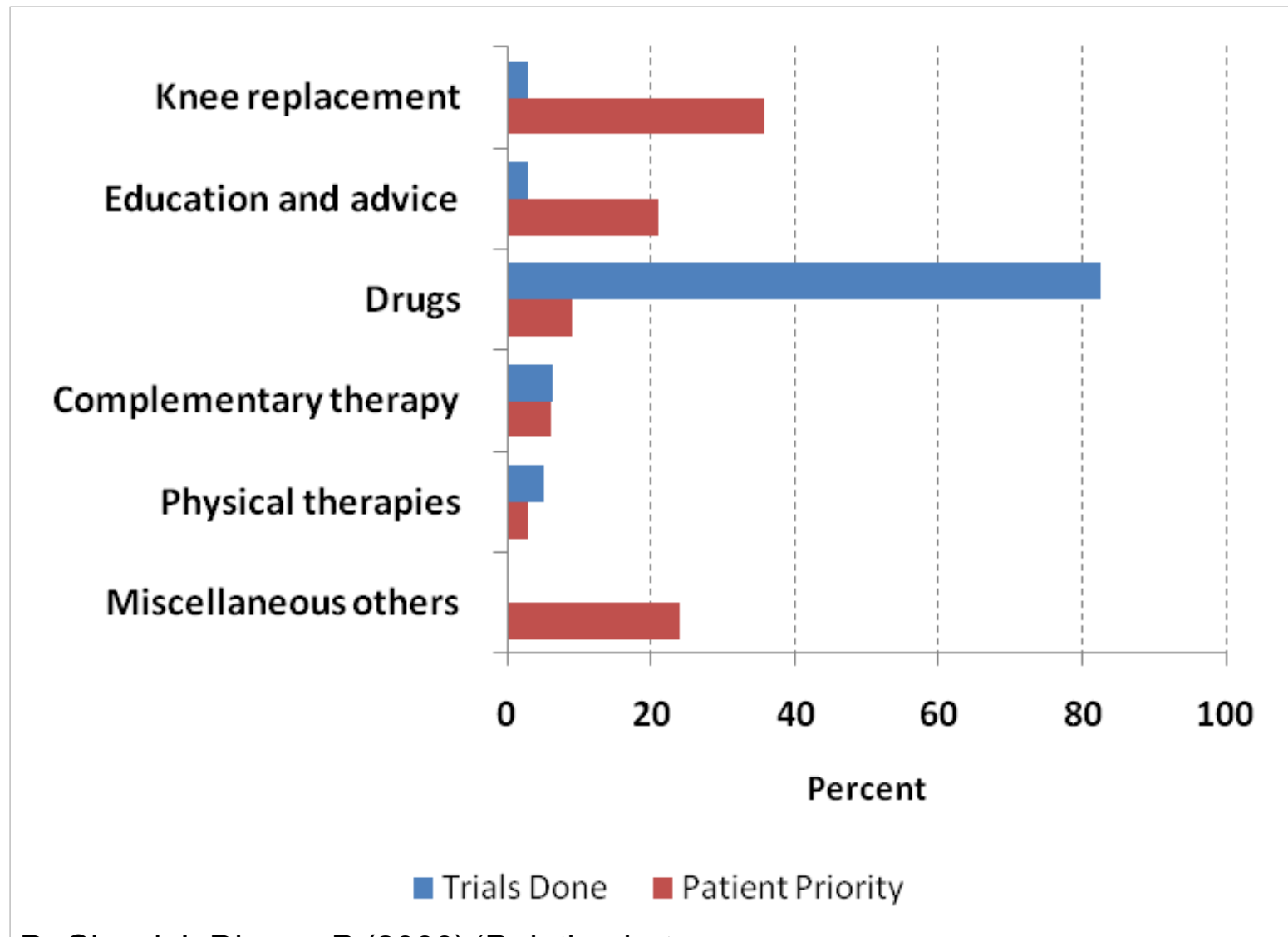
Why public involvement when setting research priorities?

1. To identify patient-centred research priorities that will make a difference to patients, carers and families in the short and medium term
2. Research agendas of researchers and 'research users' might differ substantially
3. Research based on priorities identified by patients, carers and clinicians more likely to be implemented in practice
4. Research funders increasingly look for evidence of PPI when allocating research funds

Who are the *end users of research*:

- Patients
- Carers and families
- Clinicians, health and social care professionals

Why involve consumers?



Tallon D, Chard J, Dieppe P (2000) 'Relation between agendas of the research community and the research consumer', *The Lancet*, Vol. 355. pp. 2037-40



The James Lind Alliance

What is the James Lind Alliance (JLA)?

- Finding out what research is important to:
 - Patients
 - Carers
 - Clinicians / healthcare professionals
- Established in 2004, mainly funded by NIHR
- Since April 2013: part of the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC)
- Established methodology to obtain, clarify and prioritise research questions from patients, carers and clinicians
- Neutral facilitation by a JLA consultant



Completed Partnerships

- Asthma
- Urinary incontinence
- Vitiligo
- Prostate cancer
- Schizophrenia
- Type 1 diabetes
- ENT aspects of balance
- Life after stroke
- Eczema
- Tinnitus
- Cleft lip and palate
- Lyme disease
- Pressure ulcers

Current Partnerships

- Acne
- Childhood disability
- Dementia
- Dialysis
- Head and neck cancer
- Hidradenitis Suppurativa
- Hip and knee replacement for osteoarthritis
- Inflammatory bowel disease
- Intensive care
- Multiple sclerosis
- Parkinson's disease
- Pre-term birth
- Sight loss and vision
- Spinal cord injury

The James Lind Alliance Process

- Invite partners
- Set up steering group
- Gather uncertainties
- Categorise and check uncertainties
- Prioritise uncertainties
- Promote priorities to researchers and funders



Funding Partners and Stakeholders

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Additional Stakeholders:

<http://www.palliativecarepsp.org.uk/partners-and-supporters/>

Age UK, Alzheimer's Society, Association for Palliative Medicine of Great Britain and Ireland, Barts Cancer Institute, The Brain Tumour Charity, Breast Cancer Campaign, British Geriatrics Society, British Lung Foundation, Chest Heart and Stroke Scotland, Cochrane Pain, Palliative and Supportive Care Group, Dimbleby Cancer Care, Help the Hospices, Multiple Sclerosis Society, National Bereavement Alliance, National Cancer Research Institute, National Council for Palliative Care, Parkinson's UK, Roy Castle Lung Cancer Foundation, Royal College of General Practitioners, Royal College of Nursing, Scottish Partnership for Palliative Care, Scottish Stroke AHP Forum, St Christopher's Hospice, St Gemma's Hospice, Stroke Association, Target Ovarian Cancer

Gather uncertainties

Survey

- A person with a long-term illness who might be in the last few years of life
- Caring for a loved one or someone you know in the last few years of life
- A bereaved carer or family member
- A health or social care professional or volunteer working with people who are in the last few years of life
- A member of the public who has an interest in care for people at the end of their lives

Survey to help improve palliative and end of life care

Do you have questions about palliative and end of life care, support and treatment? If you do please fill out this survey.

Why we need your help:

We are asking for your help because we want to improve care, support and treatment for people in the last few years of their lives. We know that many people have important questions about care, support and treatment, and we want to find out what they are. We want to use these questions to set priorities for research that will improve care for people at the end of their lives and their families and carers in the future.

Who you are:

- A person with a long-term illness who might be in the last few years of life
- Caring for a loved one or someone you know in the last few years of life
- A bereaved carer or family member
- A health or social care professional or volunteer working with people who are in the last few years of life
- A member of the public who has an interest in care for people at the end of their lives

Your experience and knowledge, as someone who has been directly affected by end of life care, will help us identify the most important questions that need to be researched.

What we are asking you to do:

Please think about your own experiences of care, support and treatment and fill in our quick and simple survey over the page. It should take you about 10 minutes to complete. You can do the survey on paper and post it back to us free of charge. Or you can complete it online or over the phone.

This is a unique opportunity to directly influence future research into care, support and treatment for people in the last few years of their lives.

What will happen to your question(s):

- All the question(s) we get from everyone who takes part in this survey will be gathered together.
- The questions that we haven't yet got the answers to will be published (see overleaf for more information).
 - We will bring together groups of patients, carers, family members, doctors, nurses and other healthcare professionals to look at these questions and identify the most important ones. You can be involved in this, if you like.
 - This will result in a 'top 10' list of research topics which we will use to influence future decisions about research. For example it could help decide which research projects should get funding.

The online survey is accessible via our website palliativecarepsp.org.uk

What we mean by palliative care:

What we mean by palliative care:
For patients, palliative care includes management of pain and other symptoms and provision of psychological, emotional, social, spiritual and practical support.
For family, friends and carers it includes the support that can be provided to help the family cope during the person's illness and in their own bereavement.
Besides helping those approaching the end of life to live as well as possible until they die, palliative care is about supporting everyone involved in a person's life, such as family, friends and carers.

Palliative and end of life care
Priority Setting Partnership

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Survey respondents (31 March 14)

1.2 Which of the following categories best describes you (more than 1 answer possible)?

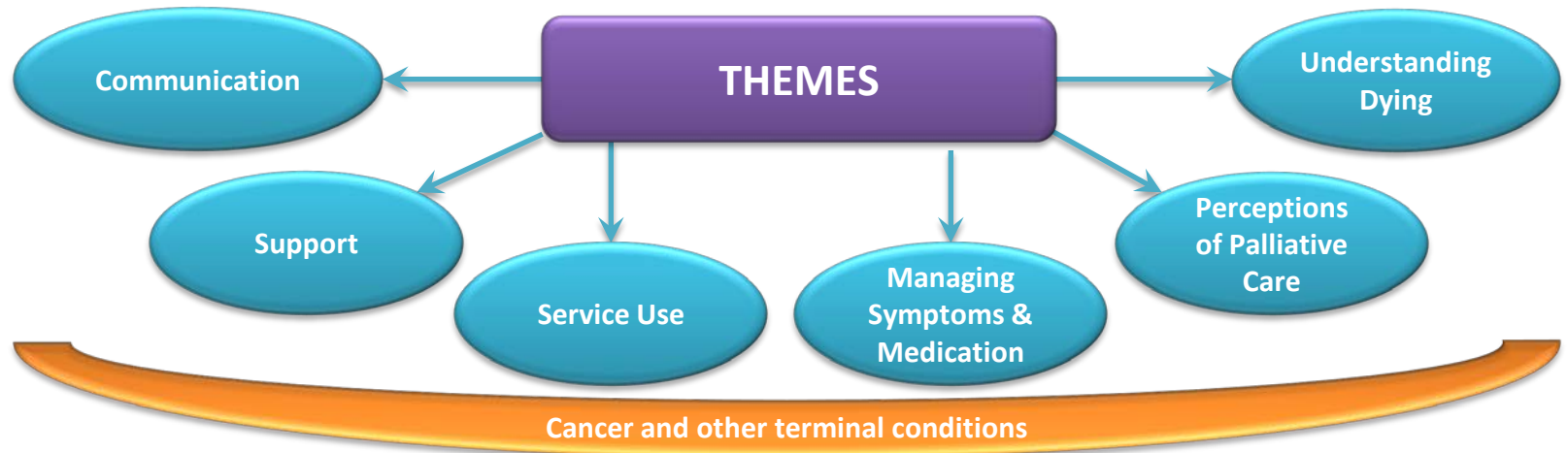
	Total number	Percentage of total completed
I am in the last few years of my life	43	4%
I am a carer or family member or partner or friend of someone in the last few years of their life	132	12%
I am a bereaved carer of family member or friend	419	38%
I am a professional working with people in the last few years of life (please refer to 1.2.1 for breakdown)	492	45%
I am a volunteer working with people in the last few years of life	37	3%
I am a member of the public who has an interest in the subject	148	13%
Other	104	9%

1.2.1 For health and social care professionals – which is your primary profession?

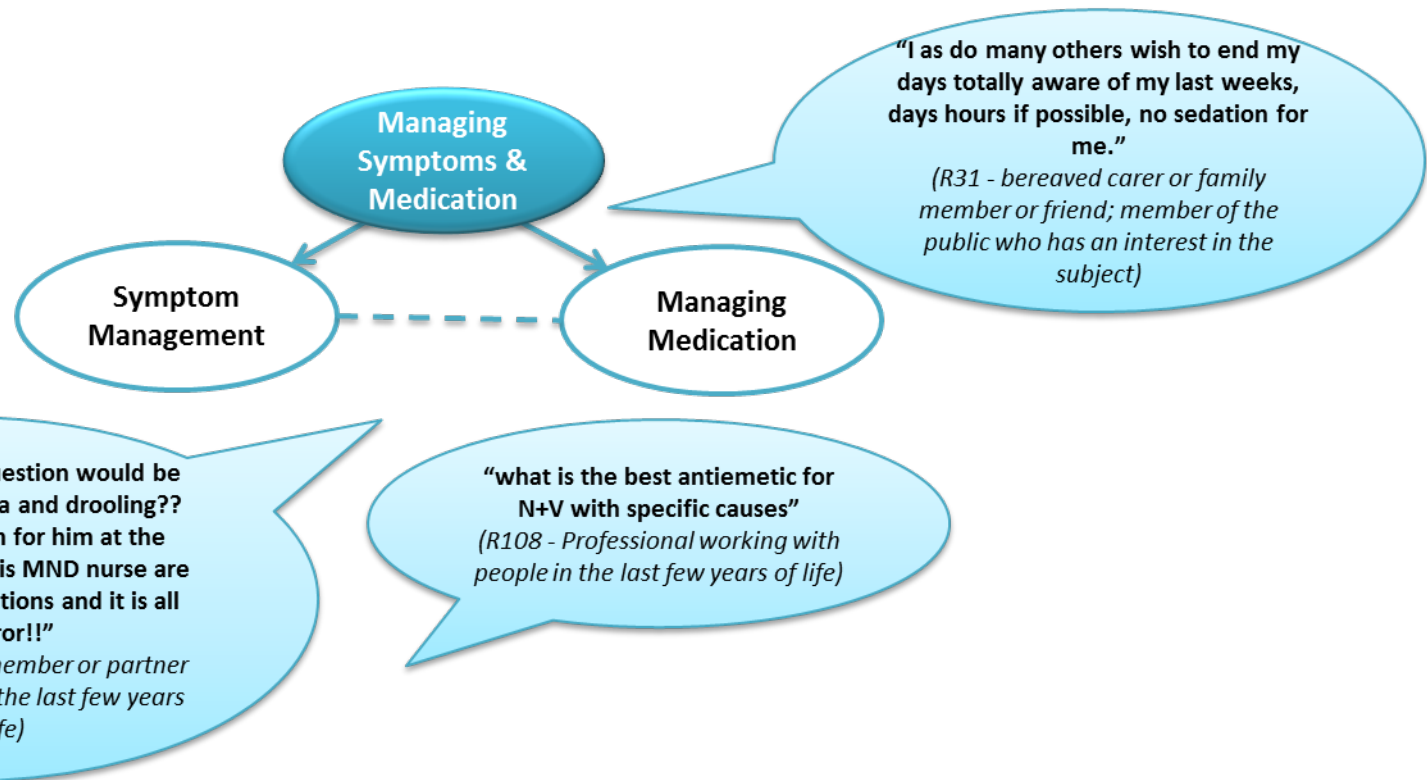
	Total number	Percentage of total [%]
Palliative care doctor	45	14
Other specialist doctor	11	3
General practitioner	32	10
Specialist palliative care nurse	44	14
Other specialist nurse	28	9
Nurse	53	17
Professional allied to medicine	26	8
Social worker	14	4
Care home, or home care, staff	9	3
Chaplain	7	2
Clinical researcher	8	3
Other	38	12



Emerging themes from preliminary analysis



Emerging themes from preliminary analysis



Check the uncertainties

- Prepare the dataset
- Remove out of scope submissions
- Categorise eligible submissions
- Format the submissions
 - PICO questions: Patient/Problem, Intervention, Comparator, Outcome
- Verify the uncertainties
- Prepare the long list



Prioritise uncertainties

- From a long list to a short list
- Priority setting workshop
- Patients, carers and clinicians
- A day of democratic discussion and ranking
 - Nominal Group Technique
- Prioritise the remaining uncertainties
- Agree the top 10



Final priority setting



Final steps

Promote priorities to researchers and funders

- NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC)
- NIHR Health Technology Assessment programme (HTA)
- Dissemination of findings
 - Publications
 - Conferences
 - Report
- DUETs (Database of Uncertainties about the Effects of Treatments)



What difference does it make?

- NIHR Health Technology Assessment Programme recent calls for proposals included:



- UVB light combined with topical corticosteroid for treatment of vitiligo – Vitiligo, priority 8
- Non-pharmacological interventions to reduce weight gain in people with schizophrenia prescribed antipsychotic medication (Feasibility study) – Schizophrenia, priority 10
- Communication therapy post-stroke – Life After Stroke In Scotland, priorities 3 and 8



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All Steering Group members

All funding partners and stakeholders

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Resources

- **How to involve cancer patients as end of life co-researchers.** Wright, D.N.M., Hopkinson, J.B., Corner, J.L. and Foster, C.L.. 2006, Palliative Medicine Vol.20 pp.821-827 <http://www.invo.org.uk/resource-centre/library-resource/?id=212§ion=invonet>
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<http://www.ncpc.org.uk/news/patient-involvement-vital-end-life-care>
- http://www.apcsw.org.uk/uploads/3/0/8/4/3084378/getting_it_right.pdf

INVOLVE Publications

Turning the pyramid upside down : examples of public involvement in social care research

<http://www.invo.org.uk/posttypepublication/turning-the-pyramid-upside-down-examples-of-public-involvement-in-social-care-research/>

Briefing notes for researchers: how to involve members of the public in research <http://www.invo.org.uk/resource-centre/resource-for-researchers/>

Evidence library: references on public involvement in research. <http://www.invo.org.uk/resource-centre/evidence-library/>

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Questions?



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Thank you!

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