

**Dying
Matters**

*Let's talk
about it*

THE
**NATIONAL
COUNCIL FOR
PALLIATIVE
CARE**

Raising Awareness Changing Behaviours and Measuring Success

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How behaviour change happens

- Attitudes are difficult to change and the process is complex
- Attitudinal change does not necessarily lead to change in behaviors
- Need incentives to change supported by legislative and policy frameworks that are implemented
- Monitoring impact not outcomes is crucial
- Long term evaluation is essential to establish awareness raising successful and led to lasting attitudinal and behavioral change
- To evaluate need to establish the baseline

Assess baseline levels of awareness

- Developing initial baseline review of current activity
- Jointly commissioned literature review since 1988 with End of Life Care Programme from Prof Jane Seymour
- Objectives:
 - To examine diversity and similarity in literature in UK and international across population groups including social marketing grey literature - public surveys and polls,
 - To describe the range of initiatives on raising public awareness of death, dying and bereavement issues and effectiveness
 - To consult with national and international colleagues relating emergent thinking about raising public awareness

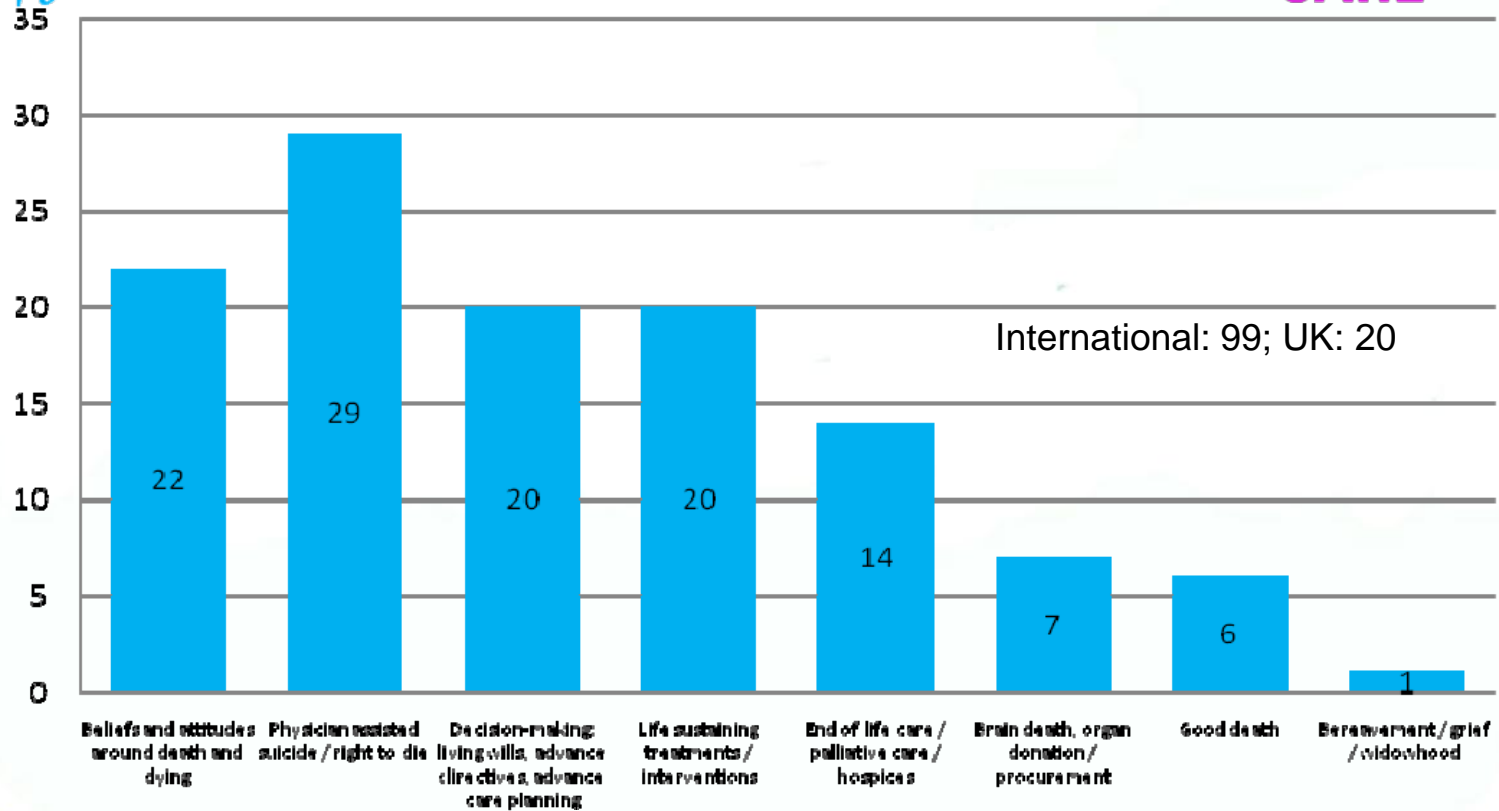
Review Findings

- Lack of public openness about death, which is likely to have a number of negative consequences
- Impression that prevailing social attitudes to death involve regarding it as 'taboo'
- Little empirical examination of perspectives of ordinary members of the general public
- Lack of evaluation of the implications for policy and practice of these perspectives

Results

Themes of empirical research : primary and secondary sources

'Let's talk about it'

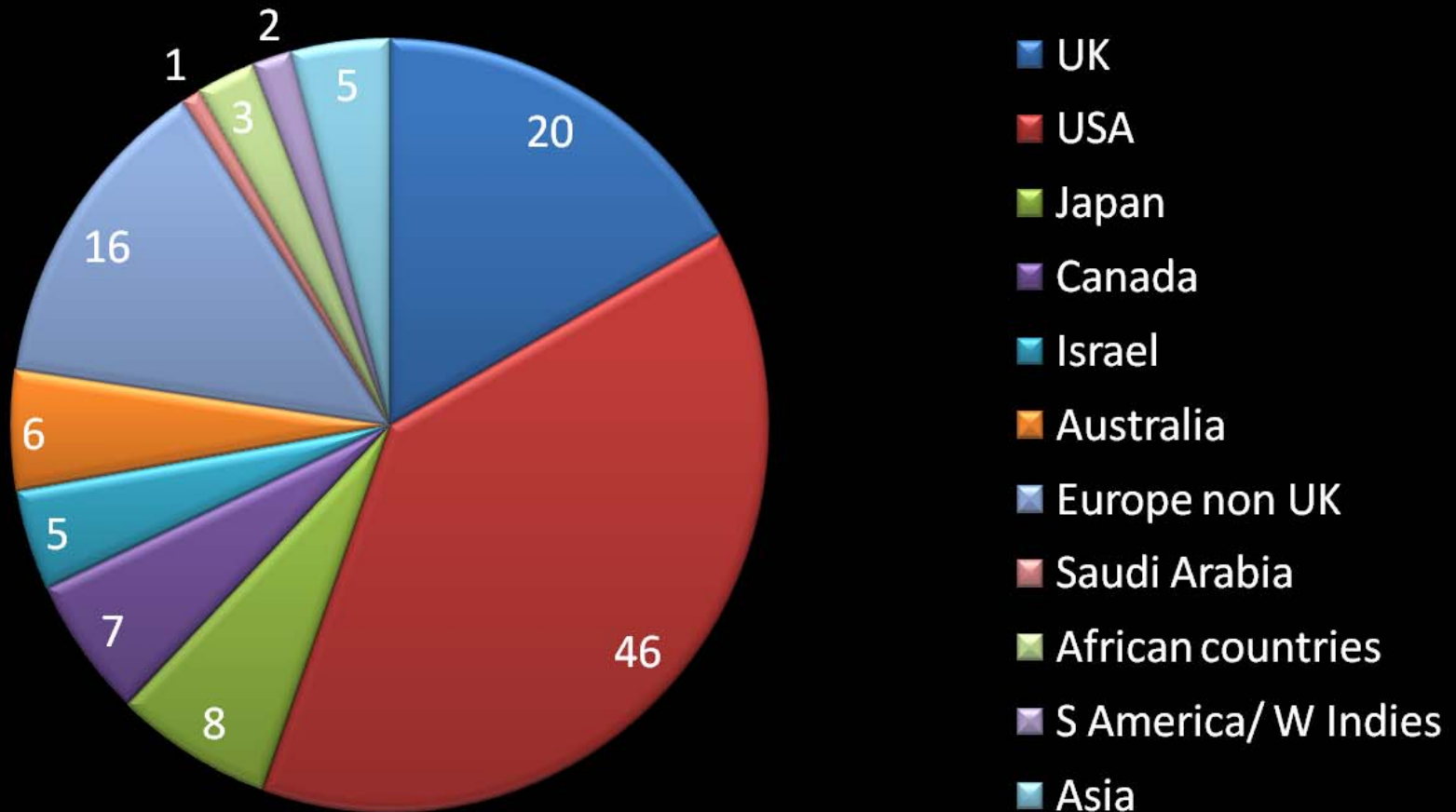


In addition, collected:

- 46 reports (paper/ web based) of campaigns.
- Some included surveys commissioned to underpin a campaign: we found 15 of these in UK between 2002-9
- 22 scholarly commentaries to help us provide a critical analysis.

Location of published empirical studies

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Key findings (1)

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- Most studies are about attitudes to PAS/ euthanasia: overall support between 60-80% since the mid 1970s (US/ UK)
- The strongest studies indicate that people make clear distinctions between acceptability of assisted dying in different circumstances
- The weakest studies offer 'yes' and 'no' alternatives which undermine their results
- Shifting preferences for hospice, home and hospital care tightly related to culture and history
- Theme of 'burden' which appears to be older age and gender related
- 'Hidden concerns': spiritual issues, practical concerns about care of the dying

Key findings(2)

- Welcome clinicians who initiate discussion informing an advance care plan
- Persistent differences across socio demographic groups
- Women prioritise quality over length of life
- Ethnic minorities less keen on withdrawal/ withholding treatment
- Confusion/ contradiction about definitions of death and organ donation
- Wide agreement about characteristics of quality care at end of life

Conclusions

- Assumptions about individualism and control of personal destiny does not fit well with needs and daily experiences of those affected by dying, death and bereavement
- The study of attitudes must be rooted in understanding of the experience of end of life
- Cultural, historical themes are critical too
- Methodological issues:
 - Qualitative research can explain some of the trends seen in the quantitative research: work best in synergy
 - Much of the research 'hypothetical'
 - Clear link between experience and attitudes: some socially structured trends
 - A proper assessment of public attitudes requires a range of methods including focus groups, citizen juries, and in-depth interviews.
 - Assessment of attitudes necessarily bound up with provision of accurate information about end of life care

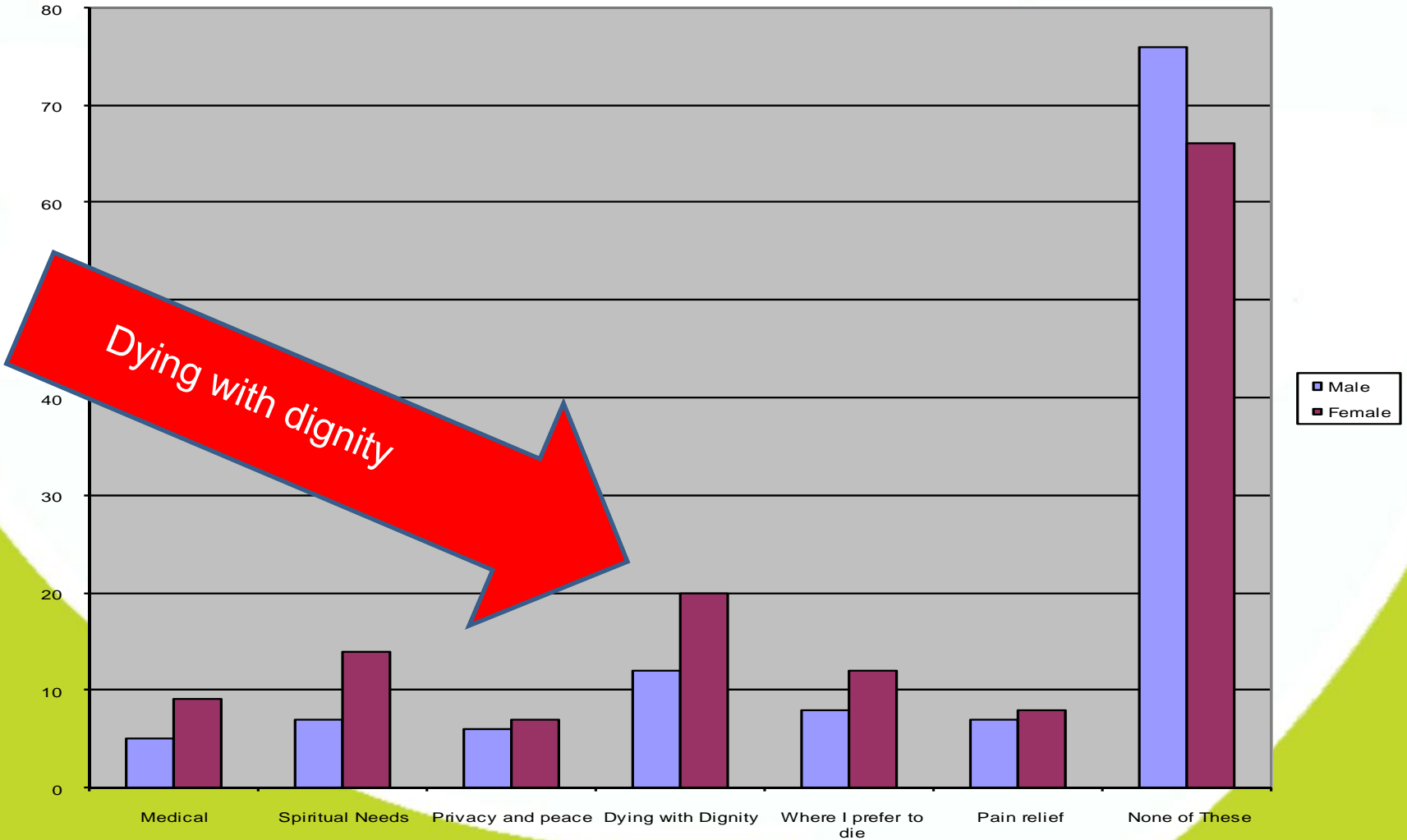
The new Dying Matters Population Survey

This is restricted information as needs
more analysis top line data

- Not yet controlled for age gender social class, when we add controls the data will be adjusted
- Computer assisted in home interviews
NatCen Omnibus survey - around 1500

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Have you discussed your wishes



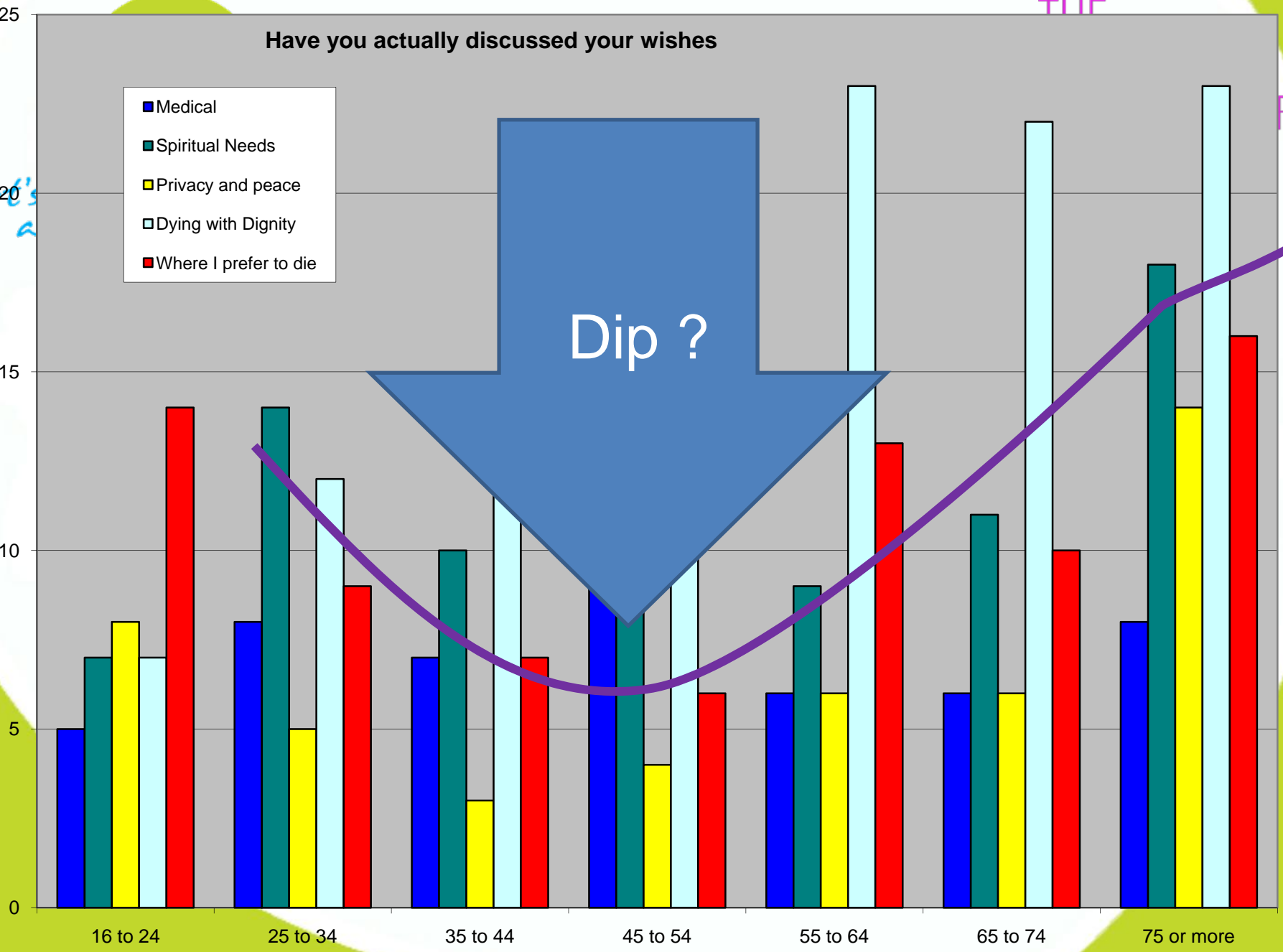
Have you discussed your wishes?

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- Less people (24%) are talking about their wishes than in 2006 (BBC 34%)
- Dying with dignity (i.e. respectful care and support not assisted dying) is what most people have talked about (But only 20% women and less than 12% men) assumes more importance as we grow older
- Women talk more about their wishes than men but few of either gender talk about it
- Talking about many issues appears to dip in the middle years
- 75+ talk most about all aspects of death and dying (but even among this group conversations are not common)

Have you actually discussed your wishes

- Medical
- Spiritual Needs
- Privacy and peace
- Dying with Dignity
- Where I prefer to die



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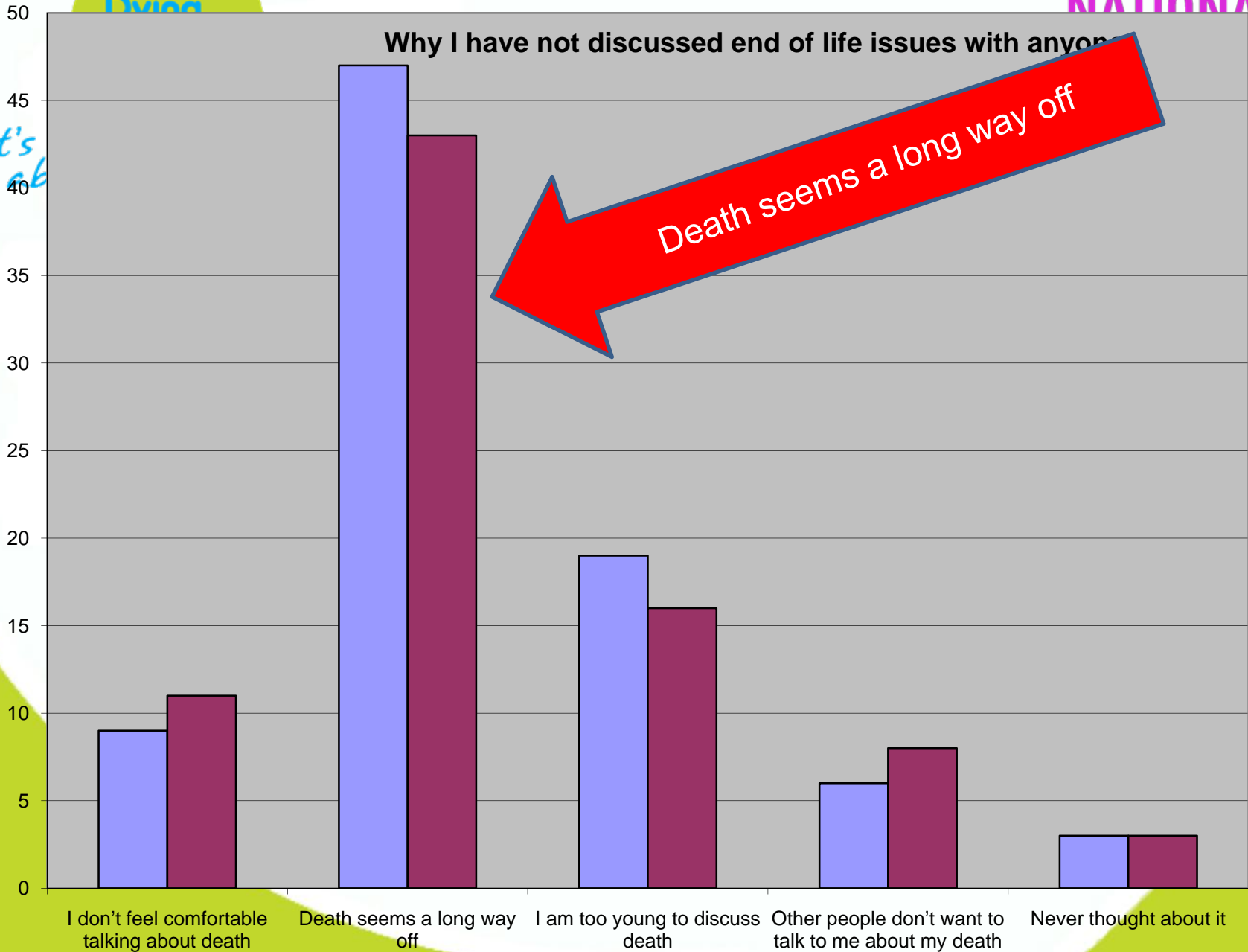
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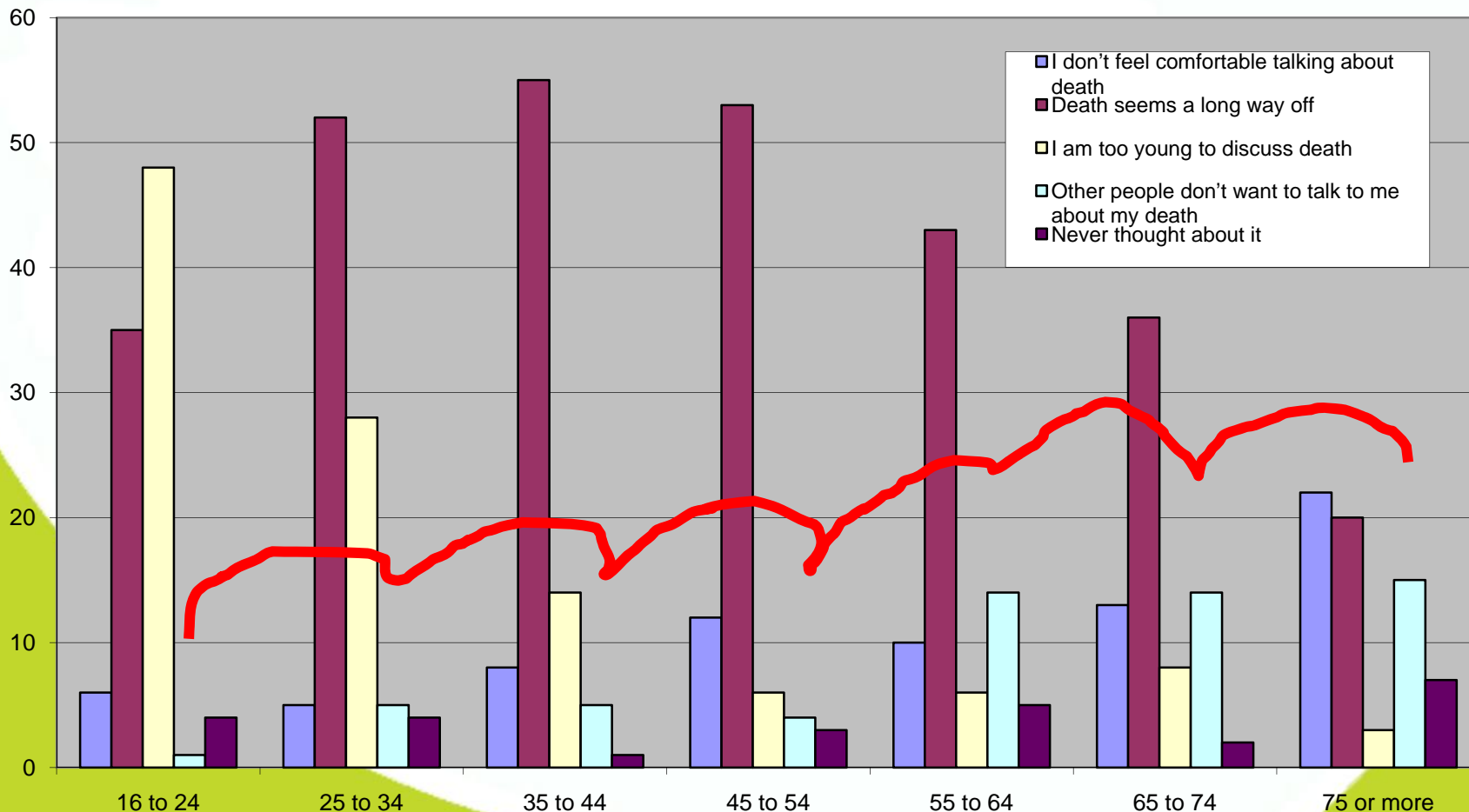


Death seems a long way off

- By far the most important reason (47% men 43% women) people don't talk about end of life issues is that they think death is a long way off
- Even 20% of the 75+ say that death seems a long way off
- 3% of 75+ say that they are too young to think about it !
- Predictably the reasons: *'too young'* and *'death is a long way'* off decline with age
- Feelings of being uncomfortable talking about death and dying increase with age
- As people get older they are more likely to say that *'Other people do not want to talk to me about my death'*

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Why I have not discussed end of life issues with anyone



Implications

- Make it easier for more people to talk about it
- We may need different strategies for men and women
- The middle years are key
- We may need regional strategies
- The “It’s a long way off” perception is key
- Dignity is a key issue

There is much more to analyse and we will use this information to help plan our approach, activities and follow up action

The overall Coalition goals

- To get targeted audiences to talk about death dying and bereavement and take action to plan for their dying and death
- To promote the Coalition, engaging and attracting organisations to join and support activities
- To provide timely, appropriate and interesting materials to support Coalition members awareness raising activities
- To support internal communications keeping Coalition members regularly briefed on activities, relevant issues and best practice

Target Audiences

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Primary target groups:

- Older Adults 40 - 55
- Elders 55+

Secondary audience:

- Young children <10
- Children 10 - 18
- Adults 18 - 40
- Carers
- Families coping with death and bereavement



Developing the Message Strategy:

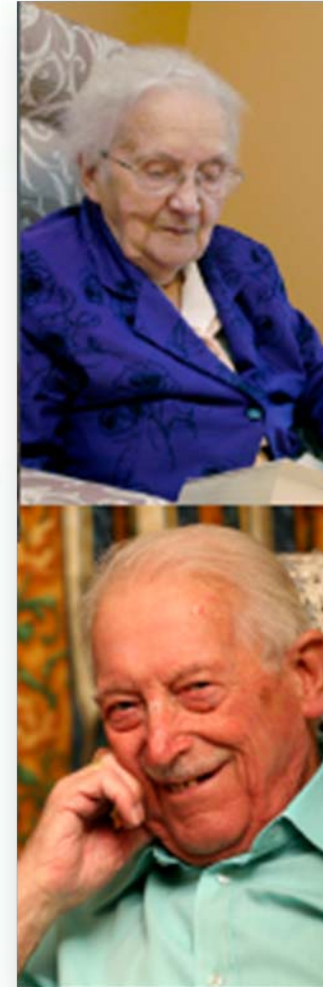


- Completed national public awareness survey June/September 2009
- Publicise findings October 2009
- Focus groups with members of the primary target audience
- Develop possible messages
- Messages piloted in the North East SHA October - December 2009
- National awareness week 15 - 22 March 2010

Key Performance Indicators

Principles

- Keep the KPIs small in number
- If possible based on existing data-measure changes
- They should cover: knowledge, attitudes and behaviour
- Cover key issues



Indicators

Behaviours

- Wishes of the dying regarding their care discussed and recorded
- Wishes to donate organs discussed and recorded
- Funeral wishes discussed and recorded
- More wills written
- More people donating organs-promoting positive 'life-giving'
- More open professional and public discussion about death and dying
- More open discussion by public and professionals about grief and loss

Indicators

Knowledge

- More carers aware of the wishes of the cared for
- More knowledge about possible options that could improve quality of life
- More knowledge of financial implications of death and need for advanced planning
- Better understanding about sources of advice and support

Attitudes

- Less fear of death
- Less fear of the process of dying
- Less avoidance of the ill and dying

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**JOIN the Dying MATTERS
Coalition NOW**

**HELP US, WORK WITH US
and LEARN FROM US**

**DO SOMETHING in
Dying MATTERS WEEK
15-22 MARCH 2010**

www.dyingmatters.org

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*Its later than you think,
talk about it now*