

Working together to raise public awareness to improve palliative and end of life care for all

Eve Richardson, Chief Executive

19th October 2010

“Many consider death to be the last great taboo in our society andmost of us find it hard to engage in advance with the way in which we would like to be cared for at the end of life.”

End of Life Care Strategy, Department of Health, 2008

THE DYING MATTERS COALITION



- Set up by the National Council for Palliative Care, the umbrella Charity for all those involved in palliative care, to support the 2008 End of Life Care Strategy
- It is a broad based, inclusive national Coalition, working in partnership, with over 12,000 members from across the NHS and voluntary and independent health and care sectors, social care and housing, faith and community organisations, schools, the legal profession and the funeral sector.

Our Mission:

- *“Support changing knowledge, attitudes and behaviours towards death, dying and bereavement, and through this to make ‘living and dying well’ the norm.”*

THE CHALLENGES

Dying
Matters

*Let's talk
about it*

Talking

- We don't talk about dying and death - impacting on our end of life choices
- Only 29% of people talked about their wishes in 2009 - less than in 2006 (34%)

Planning

- 500,000 people die each year in England – 58 % in hospitals, yet 70% of people would like to die at home

WORDS USED TO SAY DEATH OR DYING

Dying
Matters

*Let's talk
about it*



INDICATORS OF SUCCESS

Dying
Matters

*Let's talk
about it*

Knowledge:

More carers
aware of the
wishes of the
cared for

More knowledge
about advance
planning and
financial
implications

Better
understanding
about sources of
advice and
support

Attitudes:

Less fear of
death and the
process of dying

Less avoidance
of dying people
and relatives

Less regrets - no
rehearsal

Behaviours:

Wishes of dying
people discussed
and recorded

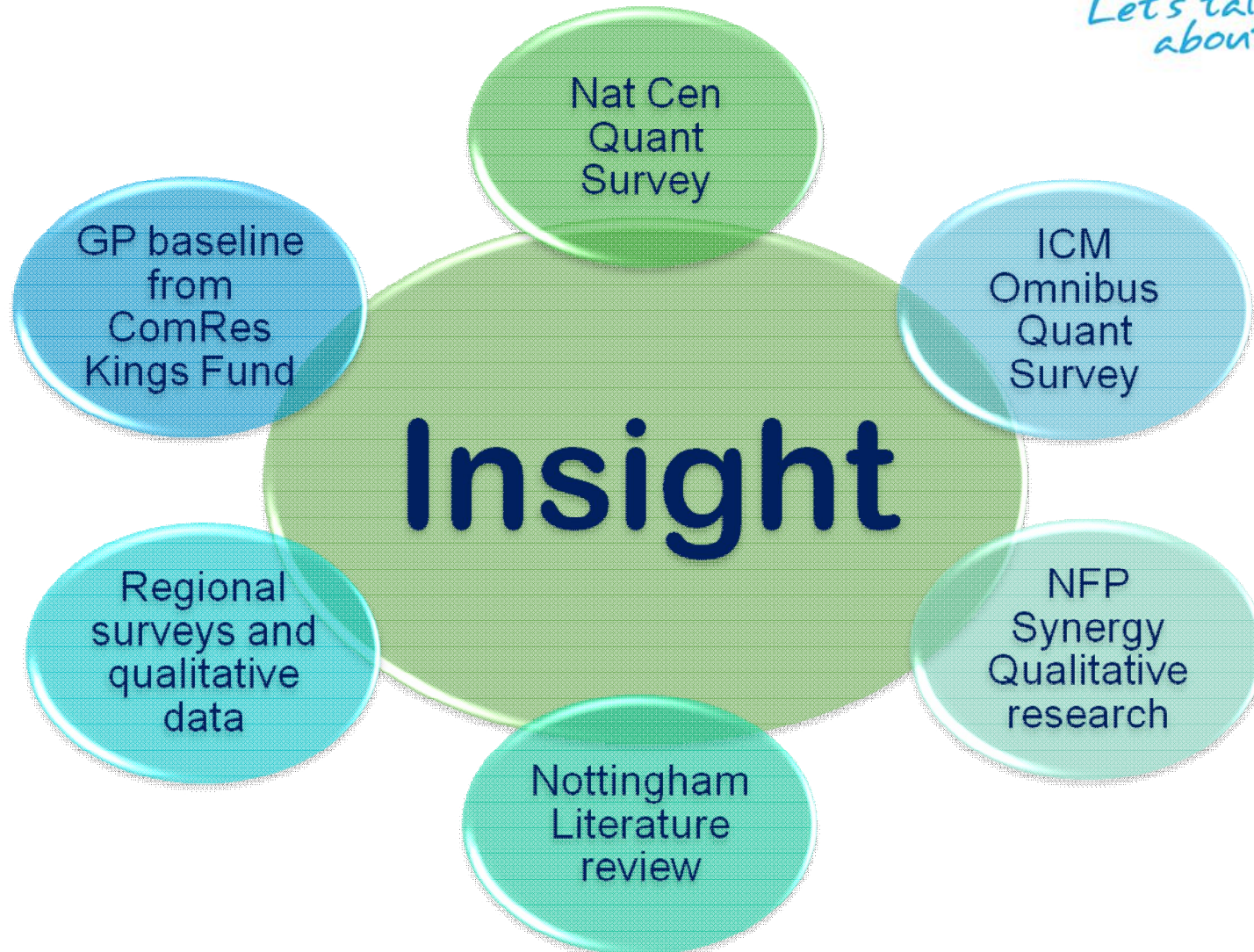
More people
donating organs,
recording funeral
wishes and
writing wills

More open
discussion about
death and dying
and more wishes
met

RESEARCH AND INSIGHT

Dying
Matters

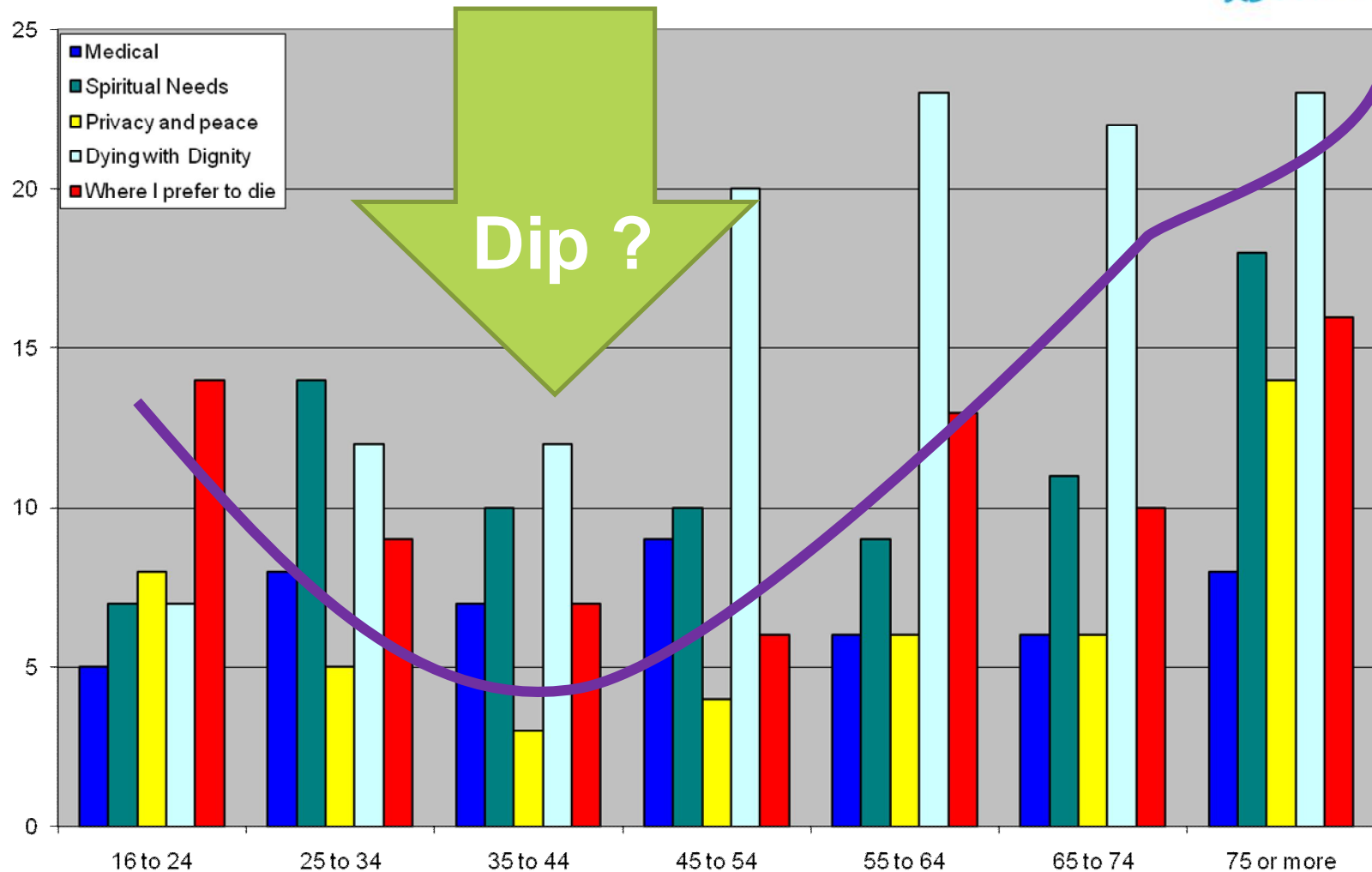
*Let's talk
about it*



DISCUSSED YOUR WISHES?

Dying Matters

Let's talk about it



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WHY WE DON'T TALK ABOUT DYING

Dying Matters

Let's talk about it

Death is a long way off

47% of men

43% of women

20% of 75+



19% of men

3% of 75+

I am too young to think about it



16% of women

www.dyingmatters.org

IMPLICATIONS FOR ACTIONS



Communication

is the key needed to make it easier for more people to talk about it

The “It’s a long way off” perception:
People more likely to talk to trusted family members and GPs

Different Approaches/tools
Needed for target groups/audiences
People 55 – 75 & GPs

TARGET AUDIENCES

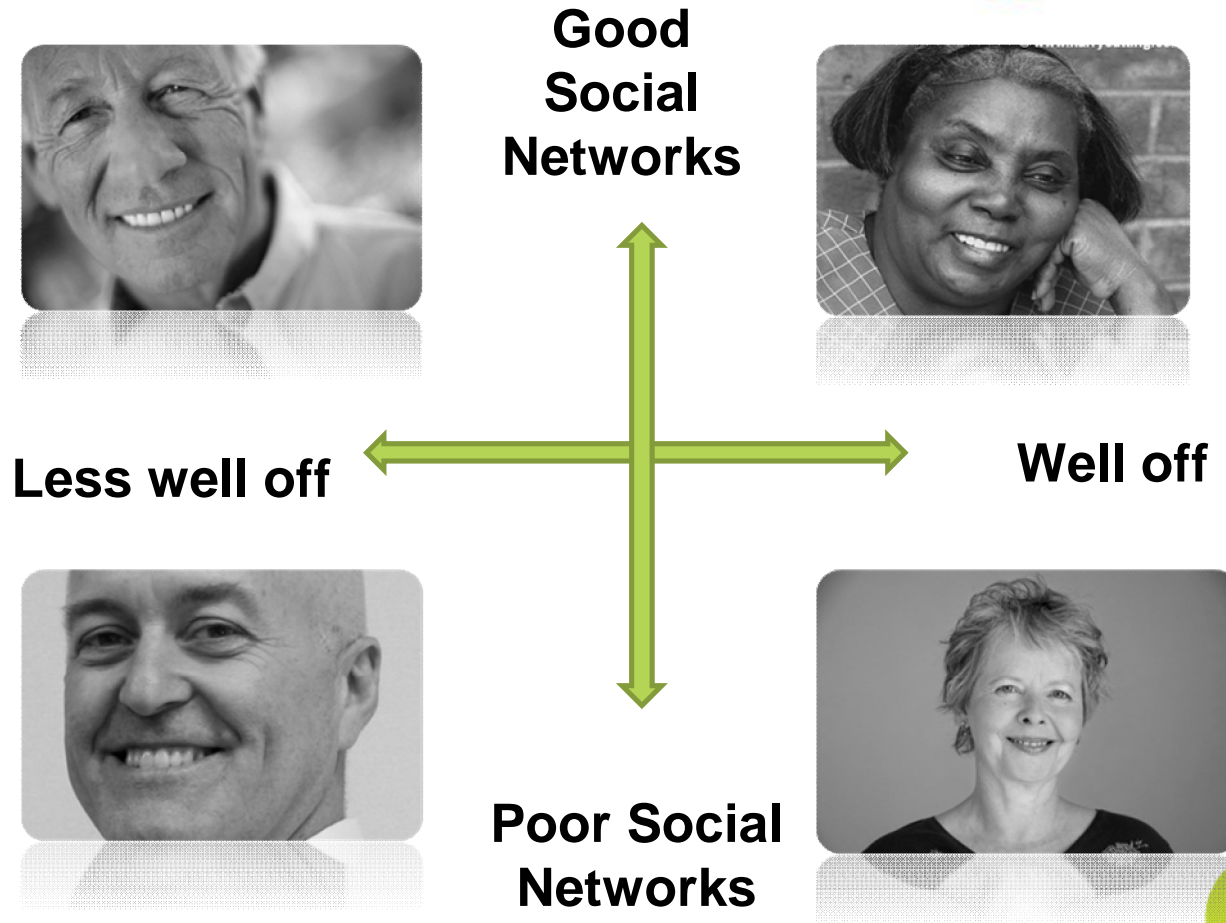
Dying
Matters

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Identified key target groups:

- 55 – 65 years
- 65 – 75 years
- GPs

*"We have
classes if
you're going to
have a baby,
getting
married,
divorced, but
there's nothing
for dying!"*



JAMES: MALE 60 – 65 WEAK NETWORKS - LESS WELL OFF

**Part time manual worker.
Lives in rented
accommodation shift
worker. Has no savings,
worried about future.
Fairly unhealthy
lifestyle. Probably wants
to continue working**

**Media
influences**

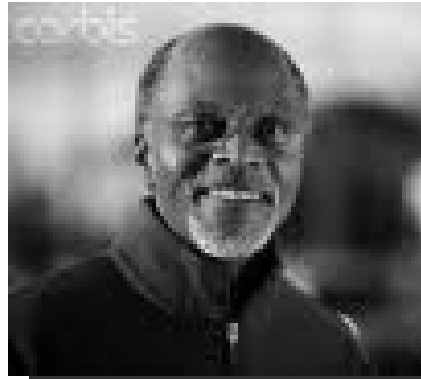
**Few ...tabloid
Talk sport
Local papers**

**Social Networks
/ groups and
clubs**

**Pub
Old work
colleagues
Family**

Key Messages

**You deserve to die well.
Dying well is more likely to be
achieved by talking about it early on.**



Propensity to 'Talk'	1
Has close family members	Partner
Is a carer	Having to care more
Parents alive	No
Has a will	No
No. Visits to a GP per year	2-5

**Partner
organisations
used to target**

**Employers
groups
HR teams
Commercial
providers**

**Proposed
Targeting
Activities**

**Through
media
professional
contact**

Objectives

**Awareness
Will
Talk**

**Activities
2011/12**

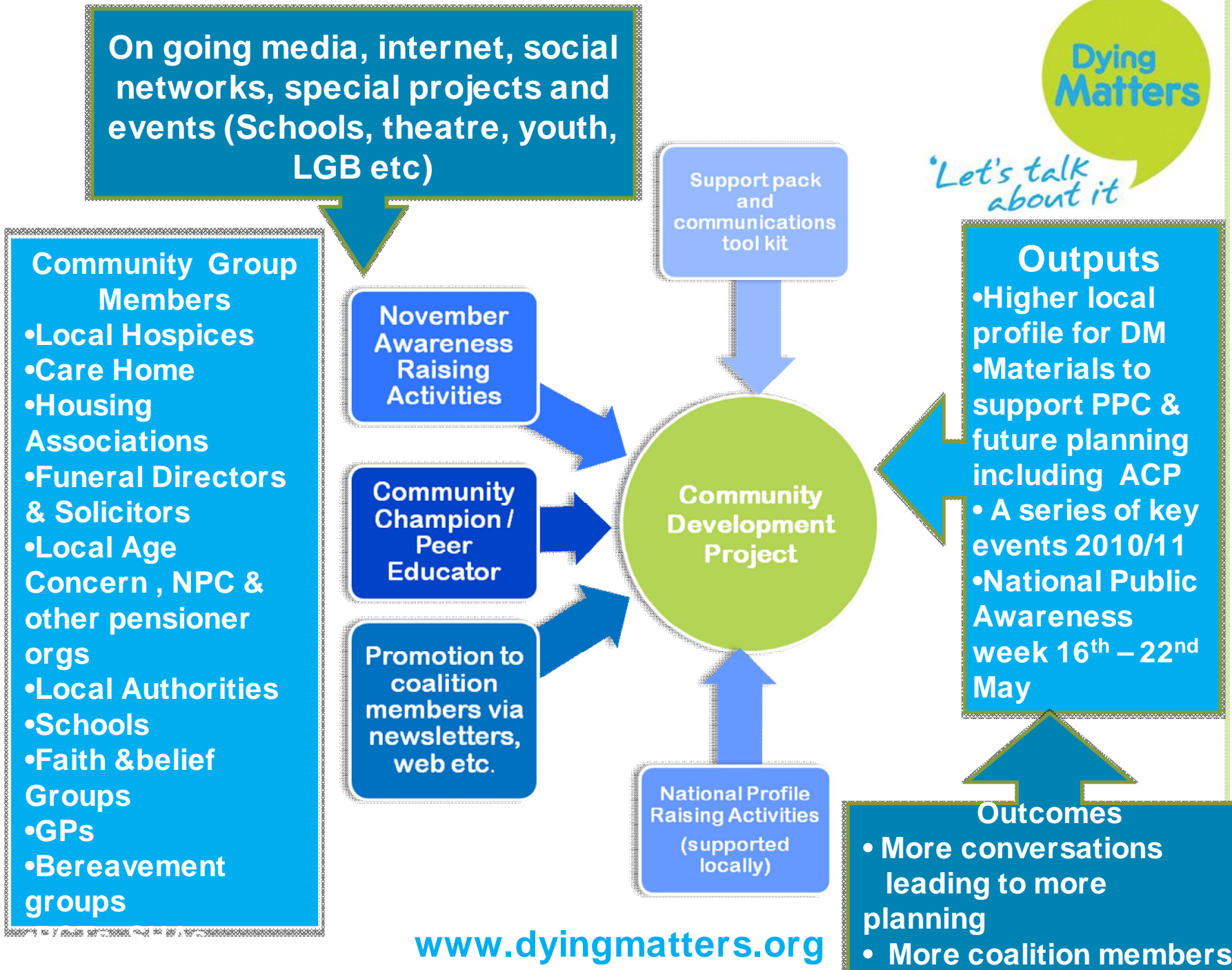
**PR focus
Visits
website**

**Desired
Change by
2012**

**Will
produced
Has spoken
to close
family**



'Let's talk about it'



DYING MATTERS PROJECTS WITH NCPC

Dying
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Let's talk
about it

Working with schools & hospices

"I look forward to the kids coming, I don't often get a chance to speak to people from that generation"

"This is the first time our work has ever meant something to someone else"



"I was really nervous about coming here but it's really nice, you kind of forget that people are ill after a while"

"It's really nice for the patients but it's also great for the staff, there's a different feel on a Wednesday when you guys come in"

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Dying Matters GP Pilot Project

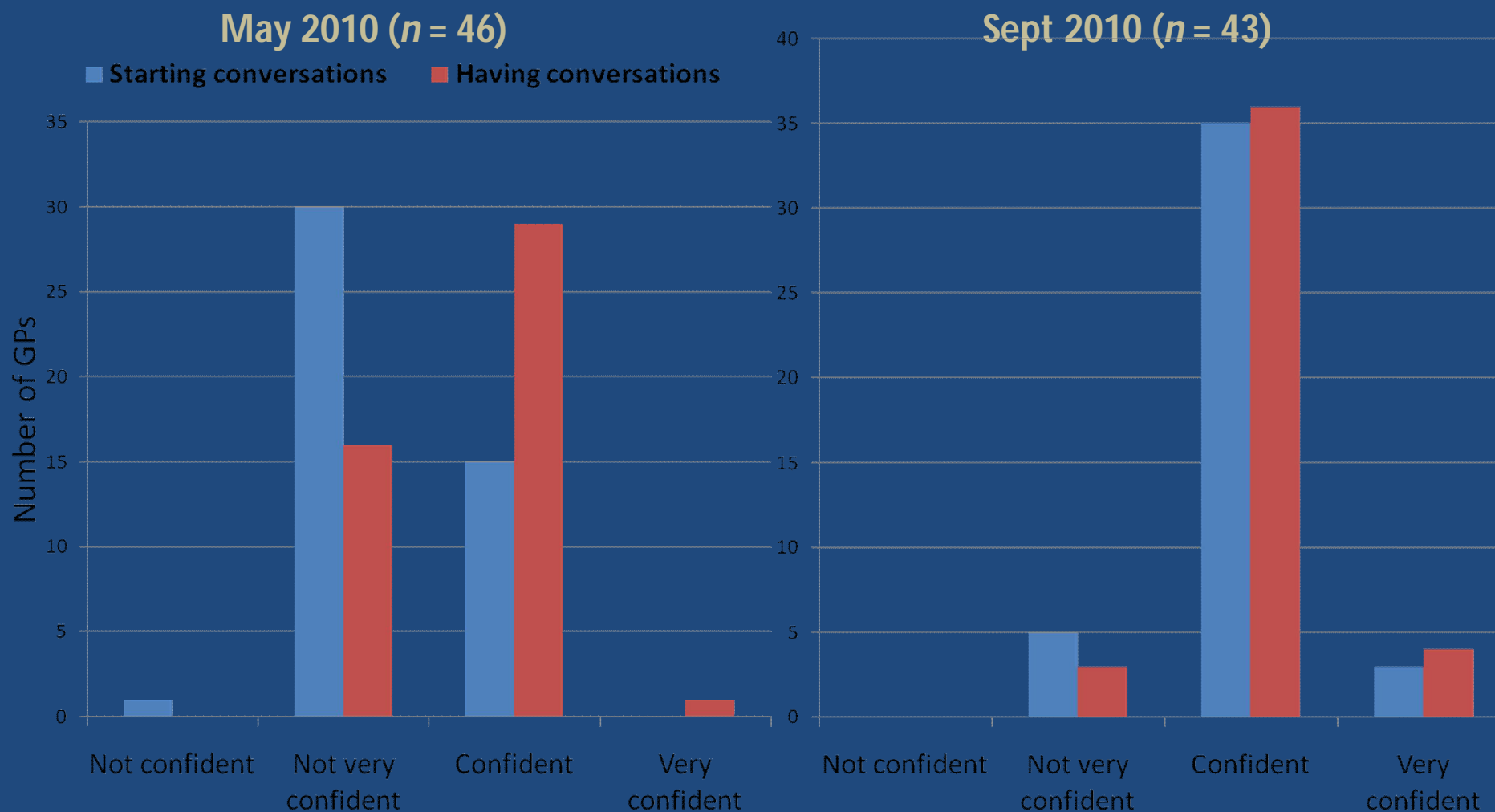
- **Aim: Support GPs in conversations with patients & relatives about dying & death**
- **31% of public would like information about EoLC from their GP**
- **75% of GPs agree they should encourage patients to plan for EoLC.**
- **Yet, only 5% of GPs have written a will, 42% have discussed organ donation and 23% have discussed their funeral plans**

Pilot Participation

Participants and responses	Number
Practices participating	24
GP participating	59
Conversations between GP and patient recorded	139
Median age of patients	75
GPs returning completed both pre- and post-questionnaire	31
Practices undertaking & returning a Death Audit	12
GPs willing to be involved in ongoing work	35
Patient questionnaires returned	21

Change in GP confidence

Change in all GPs self-rated confidence in starting and having conversations pre and post pilot



Evaluation Findings

- It is possible to increase GPs confidence in having end of life conversations
- Conversations between GP and patients, family members and carers result in actions which contribute to a good death
- The Dying Matters communication materials were very useful to GPs and helpful to patients

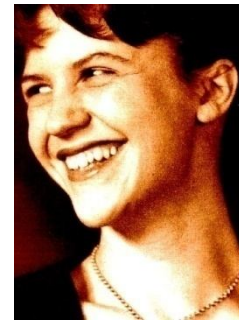
Planning for a 'good death' can include...

- Legal and Financial matters
 - Making a will, insurance, cost of funeral
- Organ Donation – '*save other lives*'
- Preferences
 - Place and type of care and support
 - Share concerns
 - Resuscitation decisions
- Funeral Arrangements
- Leaving a Memorial / Legacy
- Helping people in bereavement
 - What would you like people to know before you die, cherished memories?

DEATH', PLANNING FOR A 'GOOD

Dying is an art,
like everything
else, I do it
exceptionally
well."

Lady Lazarus
by Sylvia Plath



What you can do

- Join the Dying Matters Coalition NOW
- Help us, work with us and learn from us
- Talk about dying now – don't leave it until it's too late
- **www.dyingmatters.org**