

# End of life care for people with dementia

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December 2009



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COUNCIL FOR  
PALLIATIVE  
CARE

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# The National Picture



- *National Service Framework for Older people. 2001*
- *Palliative Care: fourth report of session. 2003-04*
- *Everybody's Business Integrated mental health services for older adults: a service development guide. 2005*
- *Gold Standards Framework: 2005*
- *Who Cares Wins. 2005*
- *Improving services and support for people with dementia. 2007*
- *Dementia Strategy. 2008*
- *End of life care strategy. 2008*

# Aims of the project

- Identify barriers for dementia patients and their carers to access good quality end of life care
- Identify cost effective improvements based on findings

# Stakeholder group

Representation from:

- Health
- Social Services
- Voluntary organisations
- Commissioning
- Care providers
- Expert by experience



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# Project plan

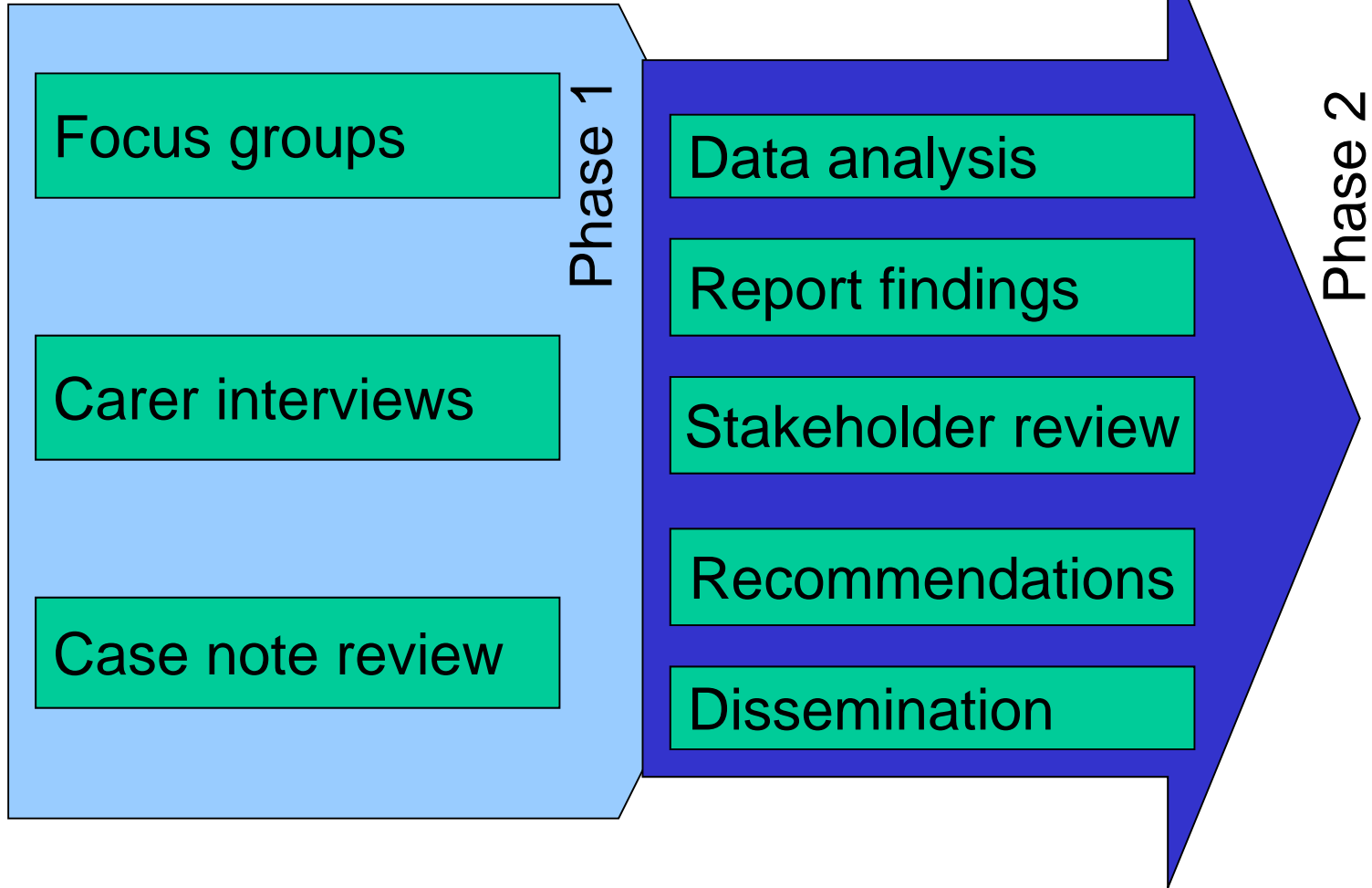
Feb 09

Nov 09



Project protocol

Stakeholder engagement and endorsement



Focus groups

Carer interviews

Case note review

Phase 1

Data analysis

Report findings

Stakeholder review

Recommendations

Dissemination

Phase 2

# Data collection

- What would you wish to learn from interviews with carers?
- What would you wish to find out from social and health professionals – who would you approach?
- What data fields would you want to include within a case note study?

# Phase 1 – data collection



- ✓ 12 carers approached, 7 interviewed:  
2 wives; 3 daughters; 1 son; 1 key care worker
- ✓ 5 focus group and 12 one-to-one meetings:  
PC team, DNs, care home managers, hospice staff, Admiral nurses, GPs, private care agency, OOH team, SS managers, Asian Carers, London Ambulance; acute service providers and community staff
- ✓ 9 case notes reviewed

# Key themes

Based on the knowledge of your own area - what do you think might be the key themes that would arise from the data collection?

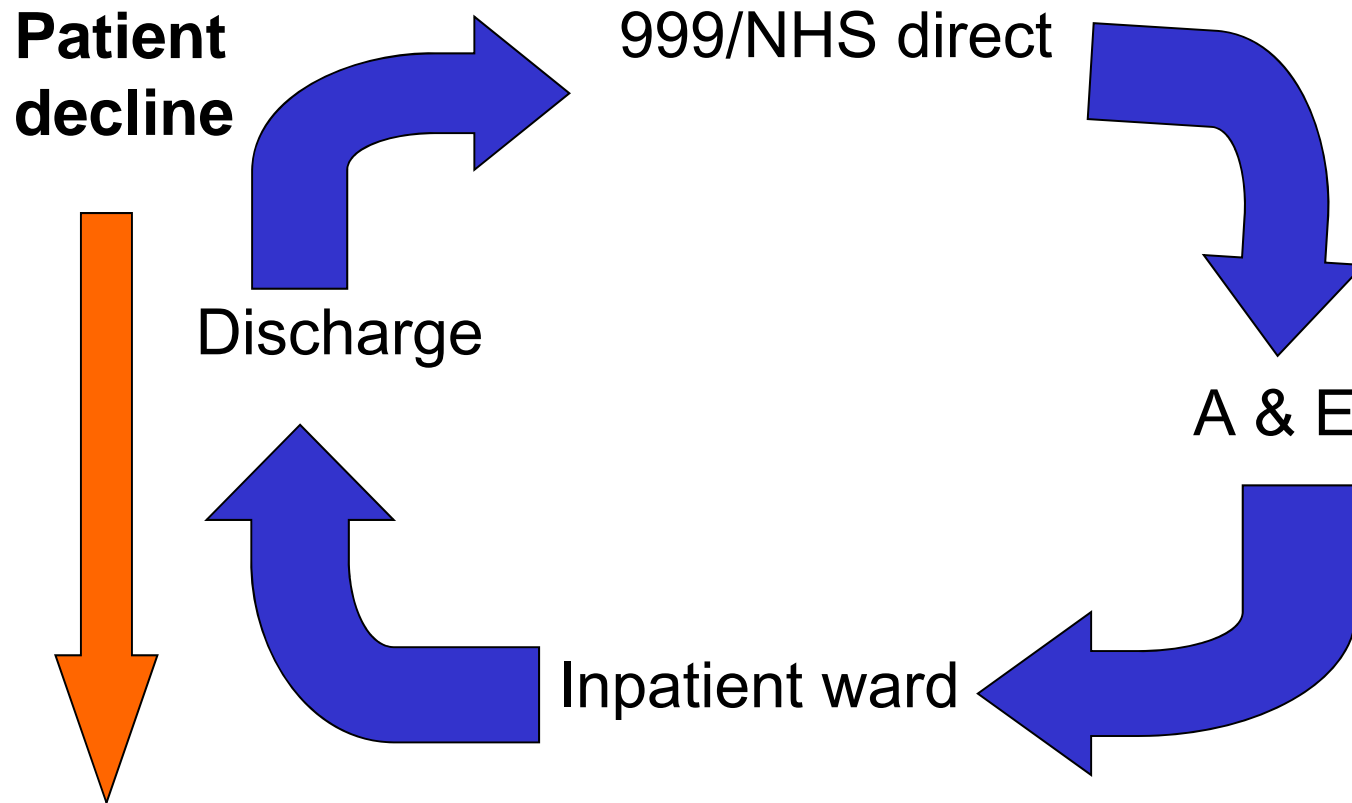
# Key themes

- Patient pathway
- Impact of hospitalisation
- Advance care planning
- Knowledge and skills
- Impact on carers

# Patient pathway

- Reactive service relying on crisis management
- Silo practice
- Lack of knowledge of available services and referral methods and criteria
- Limited knowledge of number of people with dementia and their demand on services

# Impact of hospitalisation



# Resource use

- The average cost of purchasing care over the last six months of life was estimated at £25,000 per person
- Costs were higher for people with dementia in care homes and community hospitals
- Acute hospitalisation represented almost 18% of the total average costs of care
- The majority of admissions to hospital were for ambulatory conditions that could have been treated in the community

# Advance care planning

Little evidence of advance care planning

- Carer exhaustion and denial
- Silo practice
- Difficulty in predicting death

Outcome:

- Stress for carers and patient
- Inappropriate resuscitation attempts

# Impact on carers

- Carers were frequently being asked to supply similar information to support staff and agencies
- Carers had limited awareness of the services to which they are entitled
- Carer crisis may be caused by a breakdown in the care package
- Carers might be asked to make end of life care decisions with limited knowledge, understanding and support
- There was limited bereavement support for carers – both for relatives and care staff

# Skills and training

- A wide range of health and social care staff come into contact with people with advanced dementia; there is a clear need to increase their knowledge and awareness of the likely disease progression
- Many staff groups reported that they did not feel that they have all the necessary knowledge and skills to increase the quality of support for people with dementia

Stigma in community →

← links with PC

No advance care plans →

← Ambulance policy

Lack of confidence →

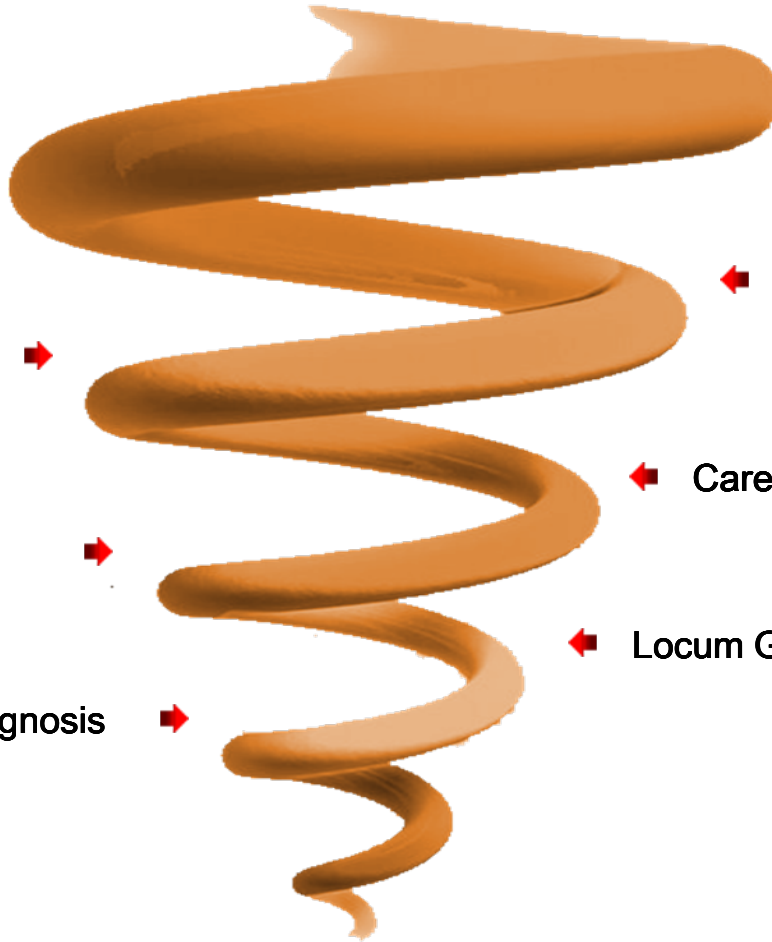
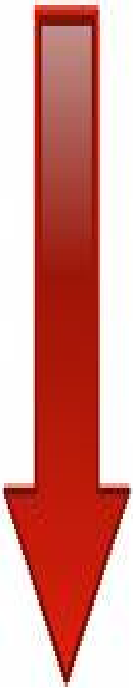
← Carer exhaustion / panic

CQC framework →

← Locum GP / OOH

Lack of diagnosis and prognosis →

Patient decline



# The way forward/challenges

1. Proactive services, decreased hospital admissions and deaths in hospital
2. More integrated working leading to improved efficiency and cost savings
3. Increased education and training about dementia

<http://www.mariecurie.org.uk/dementiaproject2009>

# Project team

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