End of Life Care
for the next 5 years:
What needs to happen next?

NCPC Conference
19th November 2013
Dr Bee Wee
NCD for End of Life Care
Structure of this talk

• Setting the scene: NHS landscape since April 2013

• Looking back: End of Life Care Strategy 2008

• 2013 as a momentous year

• Looking forward: Refresh of End of Life Care Strategy
Landscape prior to April 2013

Department of Health

Policies

Commissioners, service providers, voluntary sector, stakeholders, etc.

National improvement bodies, e.g. NEoLCP
Landscape since April 2013: national

NHS England

NHSIQ

Improving outcomes

Public Health England (PHE)

Health Educ. England (HEE)
Landscape since April 2013: national

Department of Health Mandates and Outcomes Frameworks

NHS England
NHSIQ
Improving outcomes
Public Health England (PHE)
Health Educ. England (HEE)
Landscape since April 2013: national

Department of Health Mandates and Outcomes Frameworks

Oversight of CCGs
Direct commissioning:
- Primary care
- Offender health
- Specialised healthcare
- Military health
- Emergency planning

NHS England
NHSIQ

Public Health England (PHE)

Improving outcomes

Health Educ. England (HEE)
Landscape since April 2013: local

CCGs

Commissioning Support Units
Local Area Teams (27)
Clinical Senates
Strategic Clinical Networks

Health and wellbeing boards

Local authorities

Healthwatch

LETBs

PHE
Our focus – delivering improved outcomes

The NHS Outcomes Framework

Domain 1
Preventing people from dying prematurely

Domain 2
Enhancing quality of life for people with long-term conditions

Domain 3
Helping people to recover from episodes of ill health or following injury

Domain 4
Ensuring people have a positive experience of care

Domain 5
Treating and caring for people in a safe environment and protecting them from avoidable harm

Effectiveness

Experience

Safety
Looking back

- National End of Life Care Strategy: 2008
- National End of Life Care Programme
- Palliative care: generic and specialist
- Modern hospice: Dame Cecily Saunders
- Our Lady’s Hospice (Dublin) and St Joseph’s Hospice (London)
Looking back: much achievement

- Dying Matters
- Electronic palliative care coordinating systems
- Transforming acute care in hospitals
- Core competencies identified
- e-ELCA developed and made available
- National survey of bereaved people
- National End of Life Care Intelligence Network
- Deaths in usual place of residence: 38% -> 43.9%
- and lots more……...
NICE Quality Standard: End of Life Care for Adults

Identification and assessment
- QS1 Identification
- QS2 Communication and information
- QS3 Assessment, care planning and review

Holistic support
- QS4 Physical and psychological
- QS5 Social, practical and emotional
- QS6 Spiritual and religious
- QS7 Families and carers

Access to services
- QS8 Coordinated care
- QS9 Urgent care
- QS10 Specialist palliative care

Care in the last days of life
- QS11 Care in the last days of life

Care after death
- QS12 Care of the body
- QS13 Verification and certification
- QS14 Bereavement support

Workforce
- QS15 Training
- QS16 Planning
Looking back

- Cochrane review (Gomes et al, 2013): expert home palliative care teams:
  - More than doubled the odds of dying at home
  - Reduced symptom burden for patients
  - No impact on caregiver outcomes, e.g. grief
  - Inconclusive evidence of cost-effectiveness
But we know…….

- Although 67% would prefer to die at home: 60% would change mind if doing so without support (DM)

- Overall quality of care: 23% rate as fair/poor
- Urgent care evenings/weekends: 34.8% rate as fair/poor
- Coordination of care:
  - Community services - 13% did not work well together
  - Hospital/community – 31% did not work well together
- Relief pain & suffering at home – 52% partially/not at all

(National Survey of Bereaved People (2012))
Inequity

- Confidential enquiry – premature deaths of people with LD:
  - Most common place of death – hospital
  - 42% of deaths were premature
- Black, Asian and Minority Ethnic groups:
  - lower access to palliative and end of life care services
  - poor communication between professionals and patient/family
- Homeless population:
  - less than 3% of deaths were planned or involved palliative care services
Challenges for palliative and end of life care

• Ageing population – more with LTC and comorbidities
• Complexity difficult to define – when to involve specialists
• Continuing need to build knowledge and evidence
• Difficult to measure effectiveness: changing baseline
• Terminology problematic
• Essentially a ‘people’ business, so human resource intensive
• Our culture and way of doing things
2013 as a momentous year

- Radical change to the NHS landscape
  - new structures
  - new organisations
  - new people
  - new ways of doing things
  - focus shift to outcomes
- Growing financial challenge
- Fundamentally challenging reports: Francis, Berwick
- More Care Less Pathway (Neuberger)
- Blows to public confidence and professional morale
We can be overwhelmed – or……we go forward by:

• Accepting and adapting to new way of doing things
Our focus – delivering improved outcomes

The NHS Outcomes Framework

Domain 1: Preventing people from dying prematurely

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Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm

+ PHE and Adult Social Care Outcomes Framework
Our programme approach

Establishment of a number of cross-cutting programmes to support local delivery of improved outcomes across all five domains of the NHS Outcomes Framework. These programmes will be a key vehicle to support delivery of improved outcomes.
• Accepting and adapting to new way of doing things
• Being prepared to challenge our own assumptions
• Acknowledging that there is no simple solution
“For every complex problem, there is an answer that is clear, simple, and… wrong”

HL Mencken
(1880-1956)
MORE CARE, LESS PATHWAY
A REVIEW OF THE LIVERPOOL CARE PATHWAY
• Accepting and adapting to new way of doing things
• Being prepared to challenge our own assumptions
• Acknowledging that there is no simple solution
• Listening to the voices of people who speak out…….
Person centred coordinated care

“My care is planned with people who work together to understand me and my carer(s), put me in control, co-ordinate and deliver services to achieve my best outcomes”
• Accepting and adapting to new way of doing things
• Being prepared to challenge our own assumptions
• Acknowledging that there is no simple solution
• Listening to the voices of people who speak out – and listening even harder for those who don’t or can’t
• Work towards building mutual respect
Refresh of EoLC Strategy: emerging framework

1. Having a shared understanding and purpose for end of life care
2. Patients and carers feeling supported and able to cope
3. Professionals feeling supported and able to learn and to care
4. Addressing inequity and variations in practice
5. Developing systems that support efficient and effective palliative and end of life care