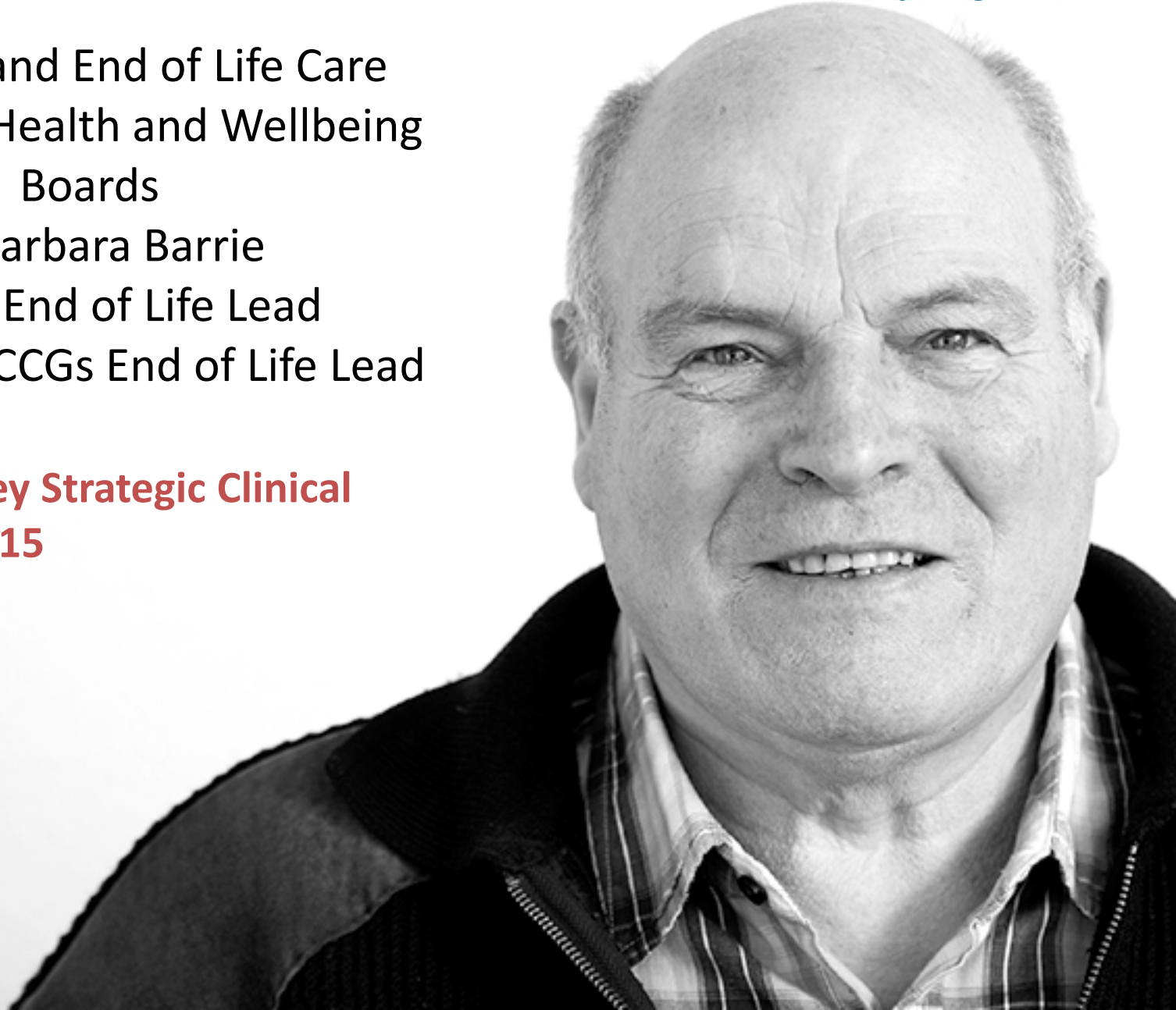


Palliative and End of Life Care
The role of Health and Wellbeing
Boards

Dr Barbara Barrie
TVSCN End of Life Lead
Berks West CCGs End of Life Lead

**Thames Valley Strategic Clinical
Networks 2015**



“Care of the dying is the litmus
test of the NHS....”

**End of Life care is everybody's
business**

Case Study

Organ failure trajectory

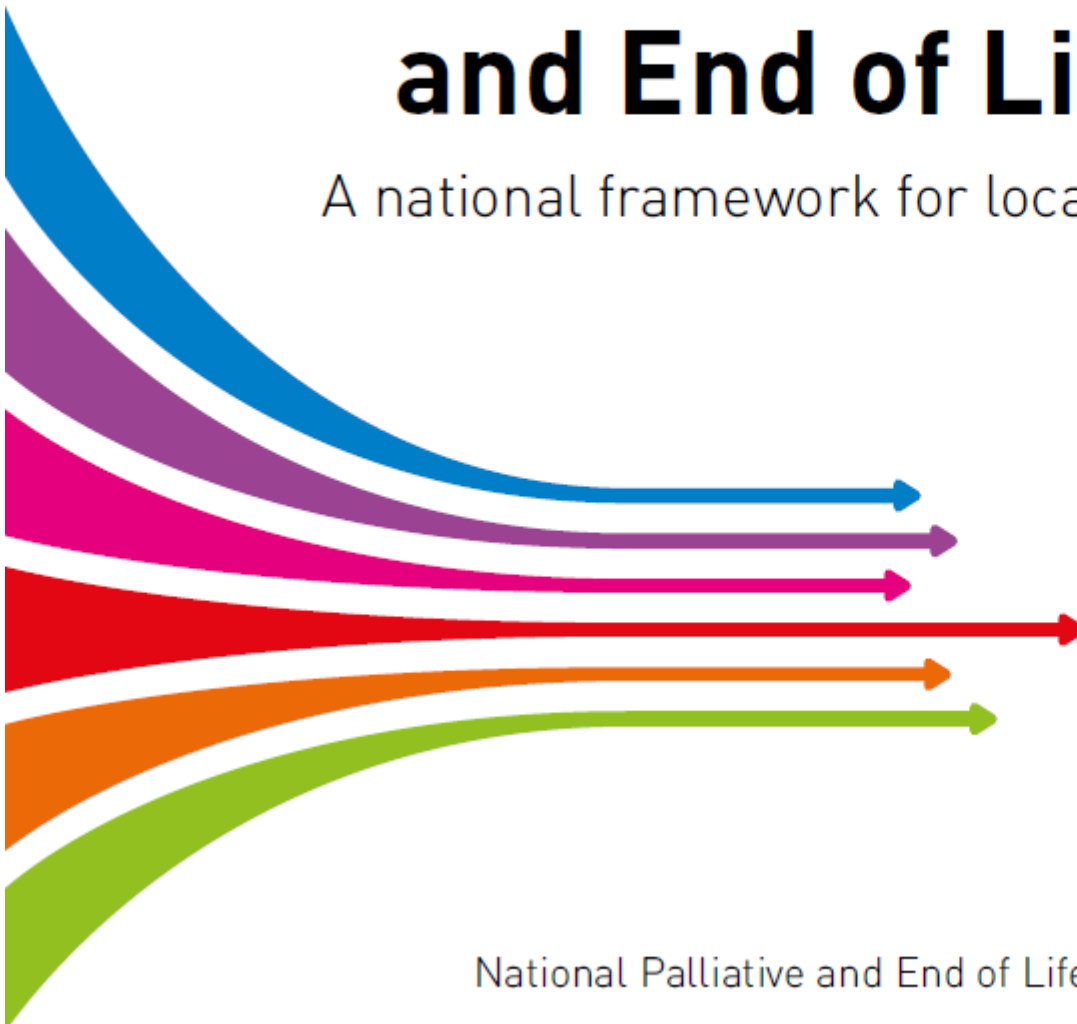


Case study

- Sheila -82yrs old –retired teacher
- Type 2 diabetes, peripheral neuropathy, heart failure
- Housebound, deteriorating vision, care package
- 2 recent hospital admissions-expressed a wish not to go back into hospital
- Advanced care plan completed –DNACPR
- Died at home 4 months later

Ambitions for Palliative and End of Life Care:

A national framework for local action 2015-2020



National Palliative and End of Life Care Partnership

Six ambitions to bring that vision about

01 Each person is seen as an individual

02 Each person gets fair access to care

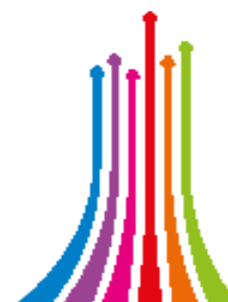
03 Maximising comfort and wellbeing

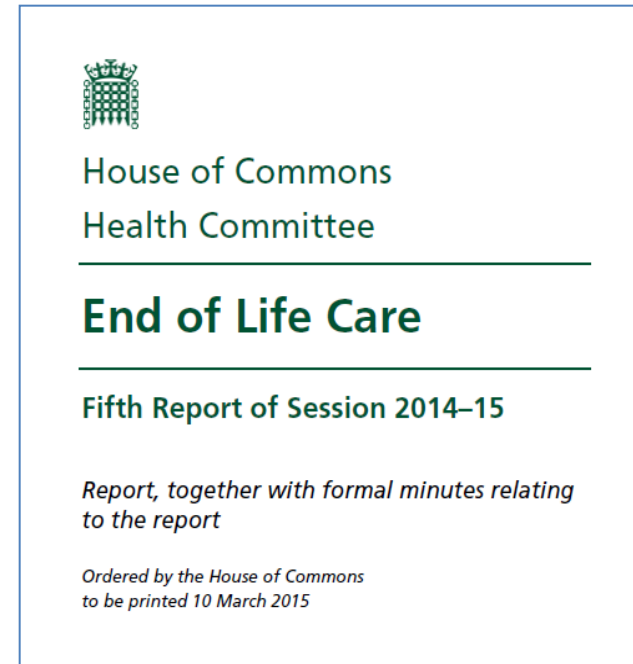
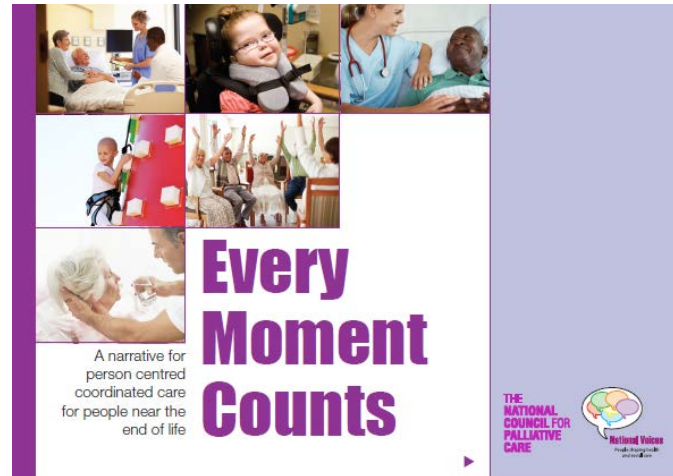
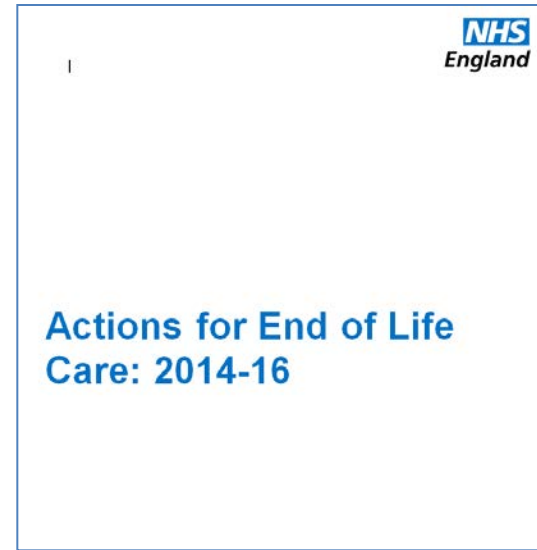
04 Care is coordinated

05 All staff are prepared to care

06 Each community is prepared to help

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."

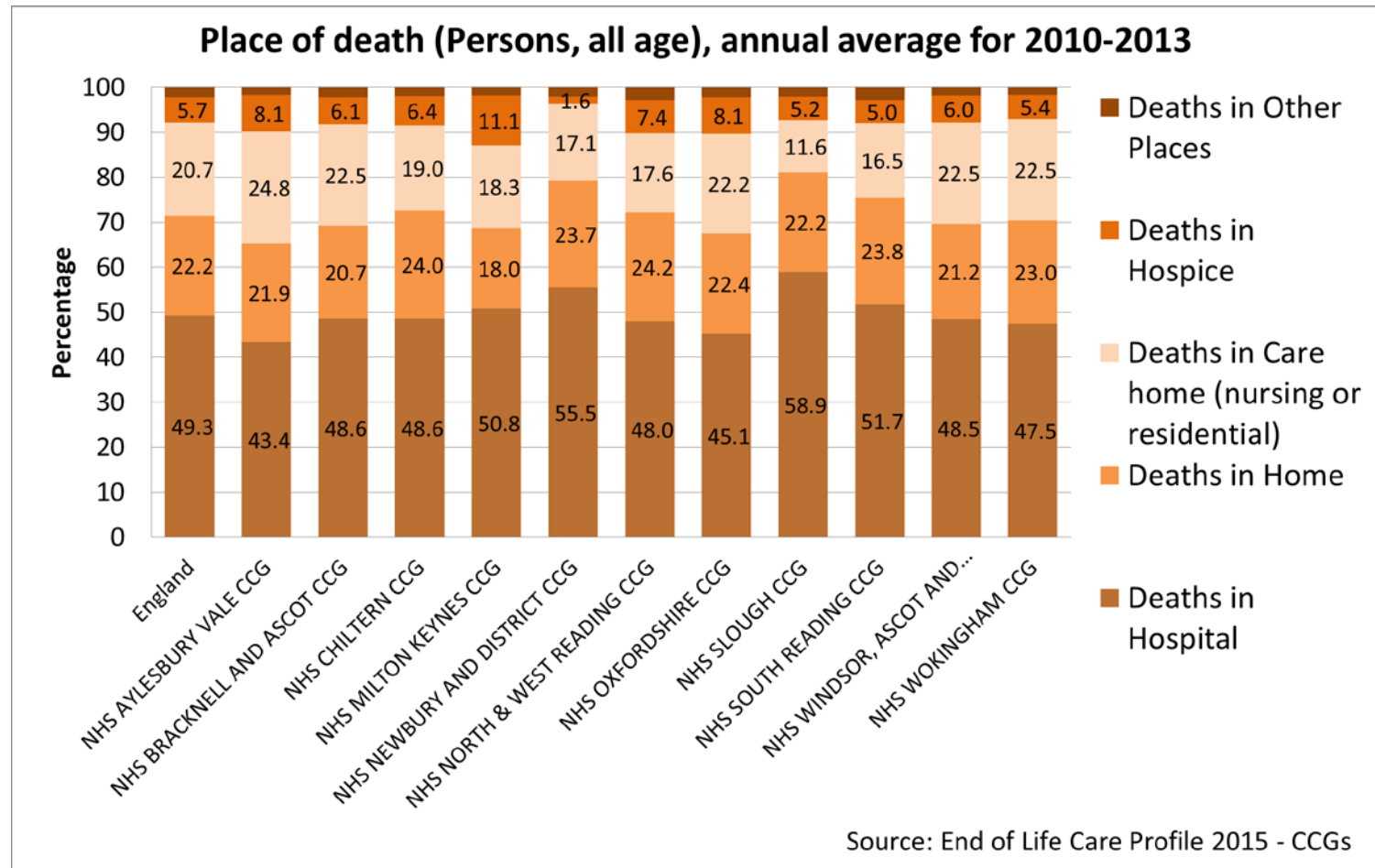




What is a good death?

- 34% of patients ranked “dying in preferred place” as important
- 33% wished to “have as much information as possible”
- 33% wished to be able to “choose who makes decisions about my care”

End of Life Care



A 16% variation in deaths in hospitals exists across Thames Valley

End of Life Care

National Survey of Bereaved People (VOICES) by CCG

Combined data from the 2011 and 2012 VOICES surveys

Session	Overall quality of care	Dignity and Respect		Support for carer and family		
Question	Q51. Overall, and taking all services into account, how would you rate his/her care in the last three months of life?	Q14. Overall, do you feel that the care he/she got from the district and community nurses in the last three months was excellent?	Q19. Overall, do you feel that the care he/she got from the GP in the last three months was excellent?	Q46. Were you or his/her family given enough help and support by the health care team at the actual time of death?1	Q47. After he/she died, did staff deal with you or his/her family in a sensitive manner?	Q49. Looking back over the last three months of his/her life, were you involved in decisions about his/her care as much as you would have wanted?
Answer	Outstanding/Excellent	Excellent	Excellent	Yes, definitely	Yes	I was involved as much as I wanted to be
England	43.21%	78.62% (26,000 respondents)	72.40%	59.76%	93.53%	77.93%
NHS Aylesbury Vale	41.68%	73.33% (n=63)	76.85%	55.32%	94.84%	80.90%
NHS Bracknell and Ascot	46.55%	82.39% (n=21)	73.74%	59.47%	96.14%	74.47%
NHS Chiltern	43.19%	79.08% (n=109)	76.45%	59.78%	94.09%	80.41%
NHS Milton Keynes	38.40%	78.50% (n=73)	69.09%	53.80%	93.12%	76.06%
NHS Newbury and District	44.81%	86.97% (n=37)	79.69%	54.69%	95.75%	81.98%
NHS North & West Reading	48.20%	87.97% (n=47)	68.56%	66.31%	96.34%	89.95%
NHS Oxfordshire	47.09%	80.73% (n=242)	74.99%	59.03%	92.79%	78.88%
NHS Slough	31.93%	55.14% (n=22)	56.52%	52.70%	91.16%	63.95%
NHS South Reading	26.91%	63.01% (n=23)	61.56%	66.92%	91.40%	68.41%
NHS Windsor Ascot and Maidenhead	37.52%	82.66% (n=47)	65.41%	54.44%	92.30%	76.39%
NHS Wokingham	49.08%	80.26% (n=57)	81.93%	59.68%	91.31%	84.67%

Key	Above national average	Below national average
------------	------------------------	------------------------

VOICES - England, 2014 was published on 9th July 2015

<http://www.ons.gov.uk/ons/rel/subnational-health1/national-survey-of-bereaved-people--voices-/2014/stb-voices-2014.html>

**“English Health and Wellbeing
Boards neglect needs of dying
people”**

*National Council for Palliative Care
Sept 2014*

Understanding the case for change

End of life care should be prioritised by Health and Wellbeing Boards because:

- ❖ Every year approximately half a million people die in England. This is expected to rise by 17% by 2030, with a **significant increase in the proportion who are aged over 85 years**.
- ❖ High quality generalist end of life care provided by non specialist health and care staff as core work, is required by all. A proportion of people have complex needs and require specialist palliative care.
- ❖ For at least three quarters of deaths it is not sudden but is expected, **providing opportunity to plan**.
- ❖ In the **last 12 months of life people have on average 3 or more unplanned admissions** to hospital.
- ❖ Nearly 30% of current acute hospital in-patients will die during the next 12 months.
- ❖ It is often inadequately provided for –over 90,000 people a year do not receive the palliative care they need
- ❖ It often lacks proper oversight (various services might be commissioned but no one person looks at coordination, integration and outcomes)
- ❖ There are solutions, and getting it right can save money

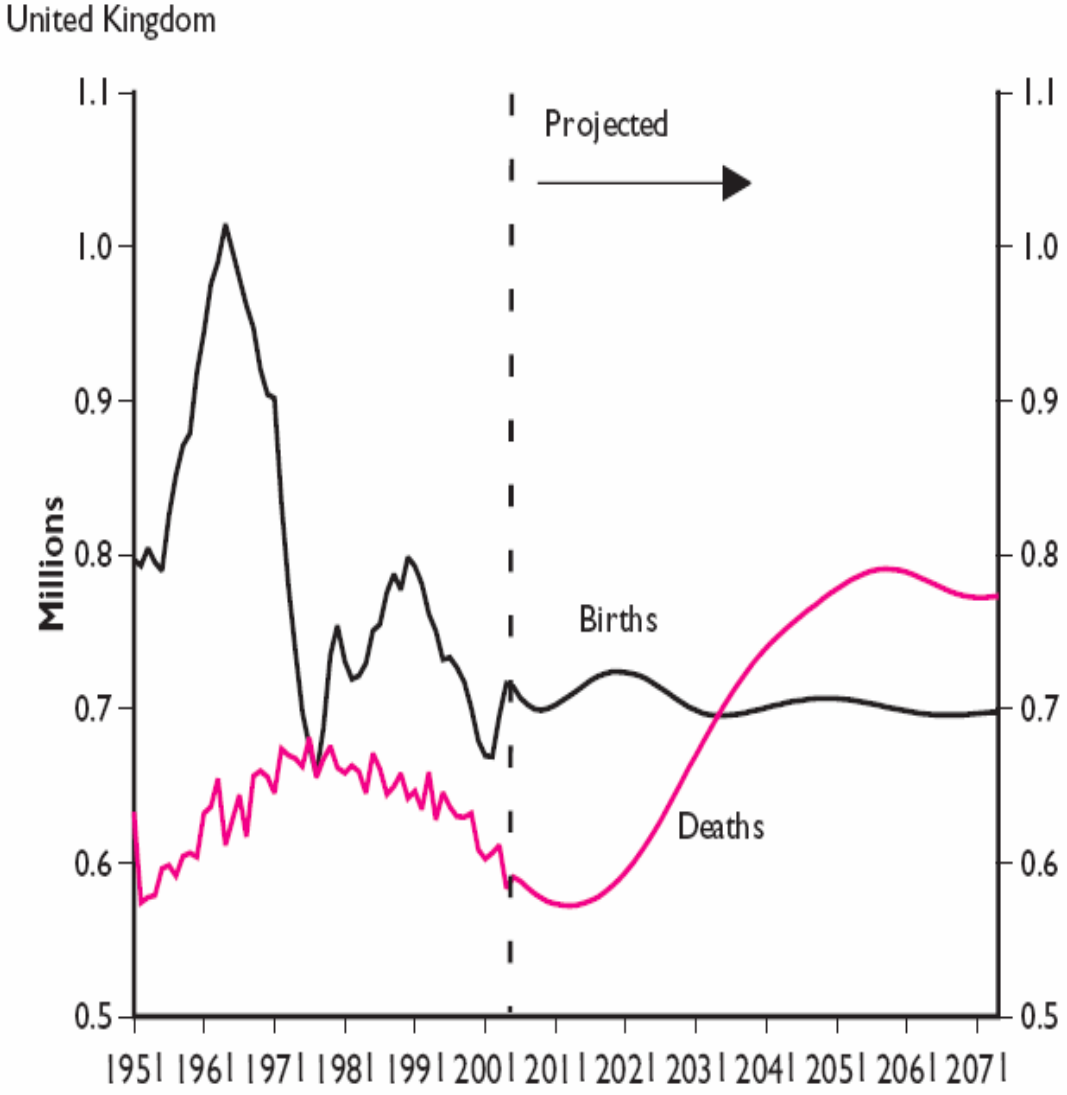
Understanding the case for change

End of Life Care should be prioritised by Health and Wellbeing Boards because:

- ❖ The presence of end of life care in CCG strategies is not consistent across TV.
- ❖ In a review of TV HWB strategies less than half included any reference to end of life care.
- ❖ [End of life care and complaints is a recurring theme in the Ombudsman's Casework. \(“Dying without Dignity”\)](#)
- ❖ Key themes feature again and again in the 12 case studies;
 - poor symptom control
 - poor recognition of dying
 - poor communication
 - inadequate OOH services
 - poor care planning
 - delays in diagnosis and referral
- ❖ ‘With right care and treatment, peoples’ suffering can be avoided or lessened, as can the anguish their relatives and carers experience subsequently.’ (Ombudsman Report)

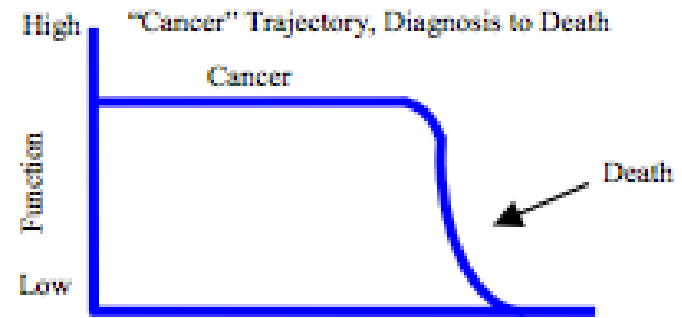
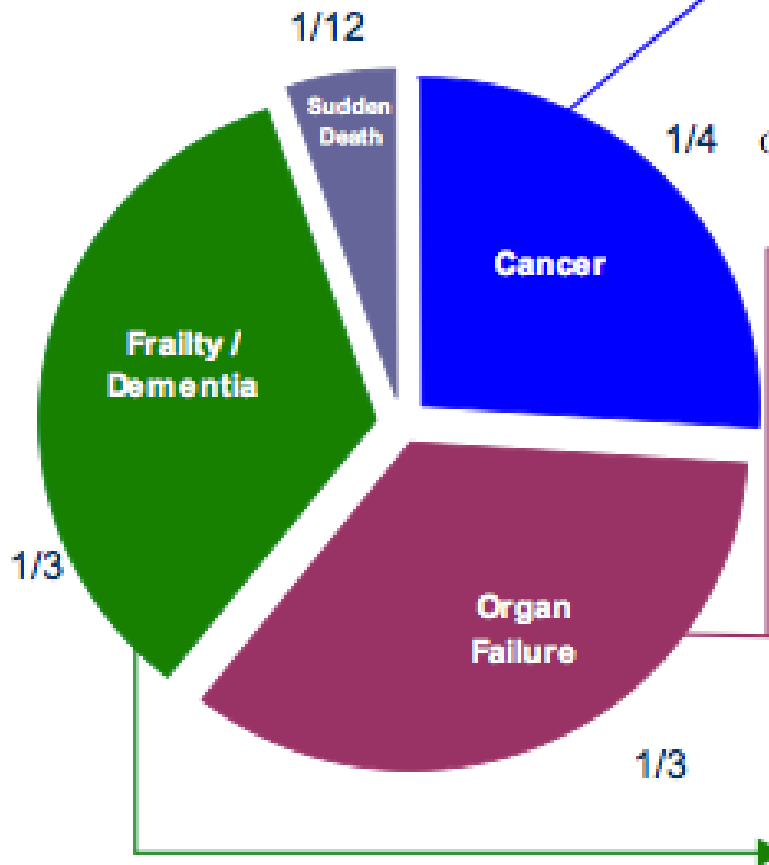
UK projections 1951-2074

Government Actuary Department ,
2004

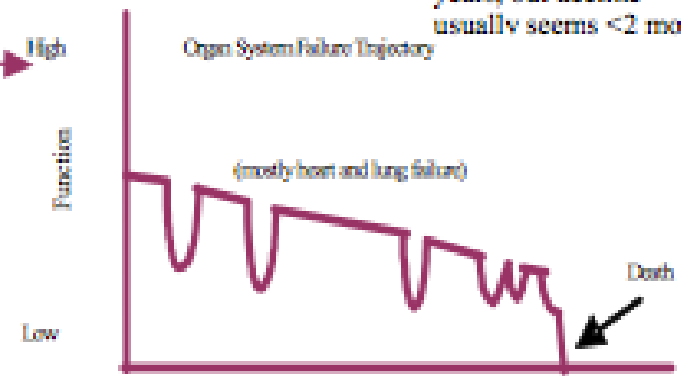


- The population is ageing
- The number who die each year will increase by 17-20% by 2030
- Expensive
 - 15-20% of health care resources are spent on those in the last year of life
 - If current trends continue hospitals will need >20% more beds

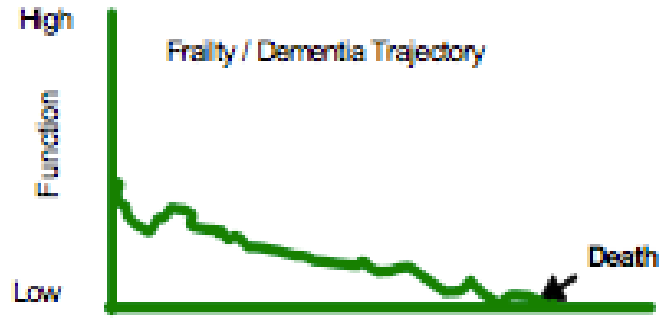
**GP's workload - Average 20 deaths/GP/yr
(approximate proportions)**



Onset of incurable cancer → Time - Often a few years, but decline usually seems <2 months



Begin to use hospital often, self-care → Time ~ 2-5 years, but death usually seems "sudden"

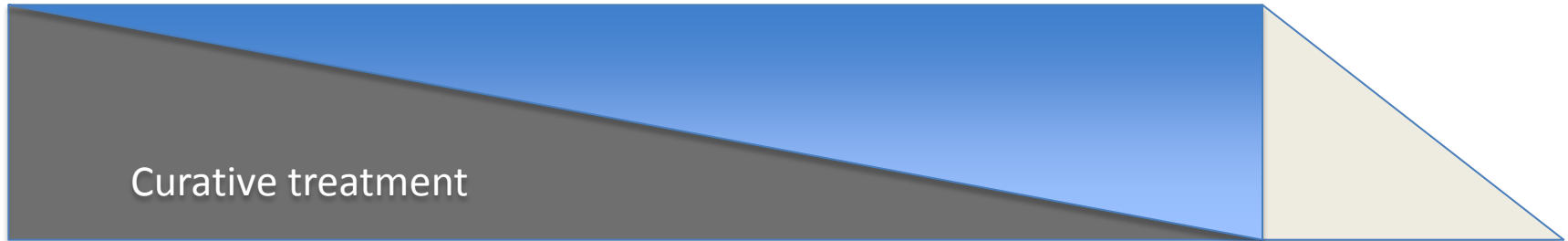


Onset could be deficits in ADL, speech, ambulation → Time ~ quite variable - up to 6-8 years

Early identification 'rectangles to triangles'



Modern concept of palliative care



Bereavement care

Assessing

- **Need** : 0.83% of your population will need end of life care each year. For each person assume one more is caring. Ensure your JSNA includes people approaching end of life and their carers (*NICE modelling tool*, www.endoflifecare-intelligence.org.uk)
- **Commissioning decisions** – has local CCG(s) strategy assessed local end of life care need? Are the right services being commissioned to meet that need ? What is the Local Authority commissioning? (*review the LA performance against 16 indicators at www.endoflifecare-intelligence.org.uk/profiles/la*)

Innovating and Integrating

- **Think broadly**...End of life care is bigger than health. People approaching end of life spend most of their time in the community and have many social care needs. *Does your JHWS include a vision and outcomes for people approaching end of life?*
- **Link** with your End of Life Network –Thames Valley SCN-valuable resource
- **Designate** a member of HWB “End of Life care champion “ to lead on this area
- **Ensure** Board level accountability for End of Life Care –include on Dashboard
- **Check** the CCG(s) strategy for end of life aligns with your strategy

Innovating and integrating

- Are health, social care and housing services integrated?
- Review what local people are saying about integration and coordination of care at end of life
(www.dh.gov.uk/health/2012/07/voices)
- Consider forming a working group/reference group –ask statutory, voluntary, and independent end of life service providers to join. Meaningfully involve people approaching end of life and their carers
- Link this group to CCG EOL Steering group –ensure strong representation
- Consider long-term development of suitable environments for an ageing population to live and die in

**“You matter because you are you,
and you matter to the end of your
life”**

Dame Cicely Saunders (1918 -2005)

Thank you –Questions?

**Thames Valley Strategic Clinical
Networks 2015**

