Public Health England

The ‘Choice Funnel’ Of Life – Starts Wide But Ends Up Narrow: Easy Conclusions From Big Numbers

Professor Julia Verne BSc, MBBS, MSc, PhD, FFPH (julia.verne@phe.gov.uk)

Clinical Lead - National End of Life Care Intelligence Network, Public Health England

INTRODUCTION

In England, concerns about quality, informed consent and choice in end of life care were thrown into the limelight by media coverage of public concerns regarding the Liverpool Care Pathway (LCP). In response, the Government commissioned an enquiry which reported in July 2013 with the title More Care, Less Pathway (1). Patient choice is enshrined in the NHS Constitution (2) and recently the importance of informed choice has been highlighted in the Leadership Alliance for the Care of the Dying Patient report ‘One Chance to Get it Right: Improving people’s experience of care in the last few days and hours of life’ (3) in response to More Care, Less Pathway. The Government then commissioned What's Important to Me: A Review of Choice In End of Life Care (3). While the importance of patient focussed care is not questioned there are increasing concerns that the promotion of choice as an end in itself raises unrealistic expectations especially as the population ages and are increasingly frail for a prolonged period before death. The 'State of Health Care and Adult Social Care in England 2014/15' report by Care Quality Commission (CQC) (4) describes demand for social care increasing with projected further steep increases and that people with multiple long term conditions are becoming the norm.

METHODS

The aim of this study was to consider the way in which ‘choice’ in the end of life care is being presented and undertake a reality check using epidemiological data. This study was based on the current situation in England. There were two phases: 1) A review of recent policy documents published in England, on End of Life Care since 2013, to examine the concept of choice being proposed. 2) A review of epidemiological data on who dies in England, where and from what conditions and what do we know about the prevalence of chronic conditions. In particular, I focus on frail elderly who live or die in care homes as a proxy for an objective limitation of choice. The implications of these findings for patient choice were reflected on from an ethics standpoint.

RESULTS

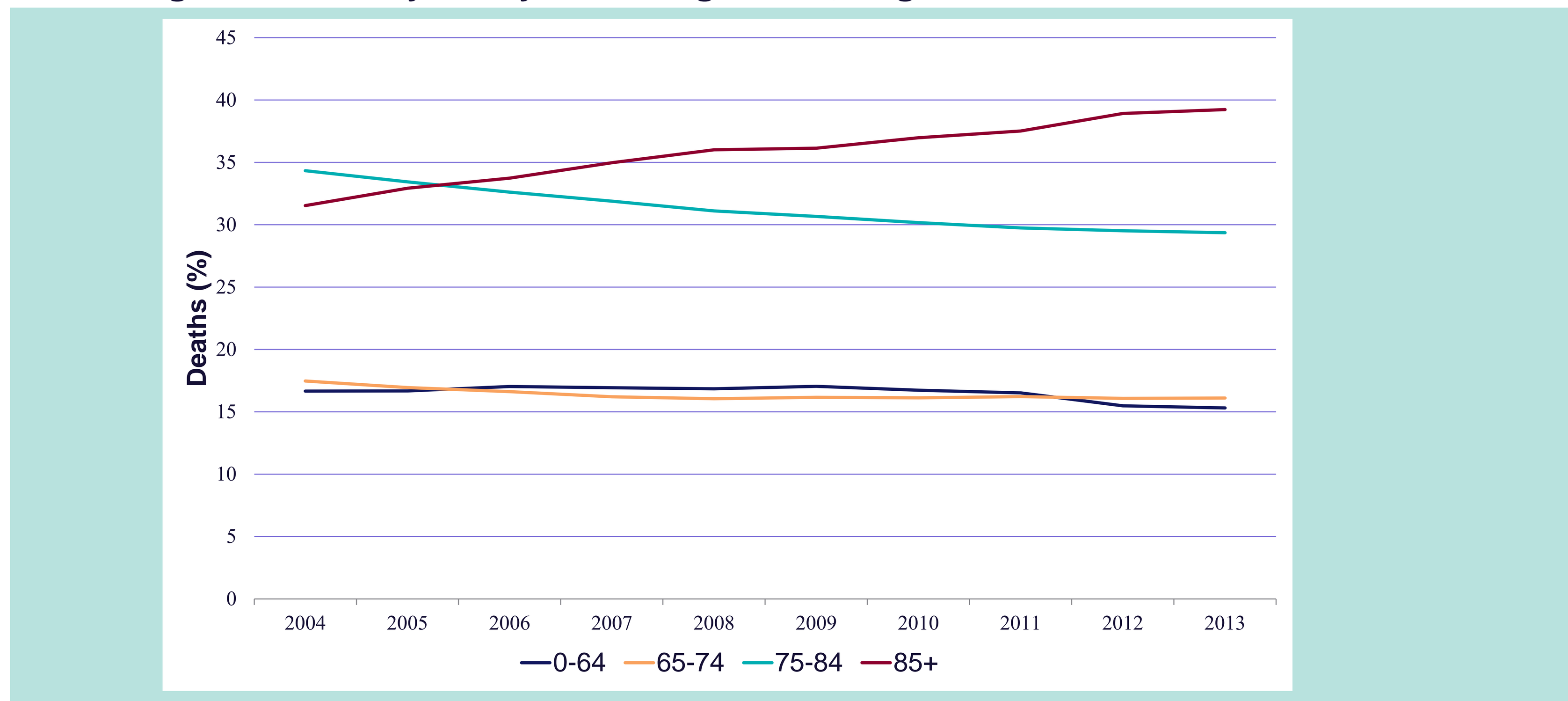
The Choice context and demographic change

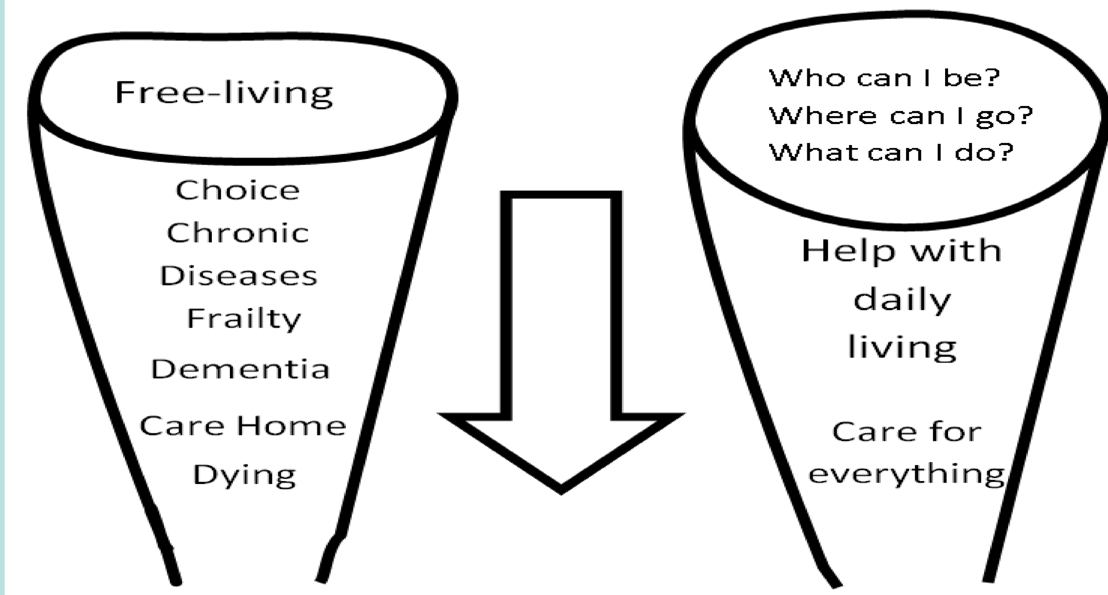
- The rise of individualism and privacy and decline of community and religion have led to a loss of tradition and to insecurity and uncertainty in the face of death. We now turn to ‘experts’ to advise us even on the most natural aspects of our life course including death. The experts may be our own physicians or guidance produced by collectives of ‘experts’ in policy documents and statements. “Constraints are seen as undesirable because they limit choice. A good choice is not judged by external authority but the one I have made, it is authenticated by me the chooser.” (8)
- It has often been said, not least in the End of Life Care Strategy (2008), that the way we care for dying people is a measure of our society.
- In a decade 2004-13 the proportion of people dying at 85+ years increased from 32% to 40%.and 75+ to almost 70%
- In the last 30 years, the number of people aged 90 and over has almost tripled.
- People with multiple long-term conditions are becoming the norm rather than the exception. The number of people in England with two or more conditions at the same time is set to increase from 1.9 million in 2008 to 2.9 million by 2018.(5)

Care homes – place of residence –place of death

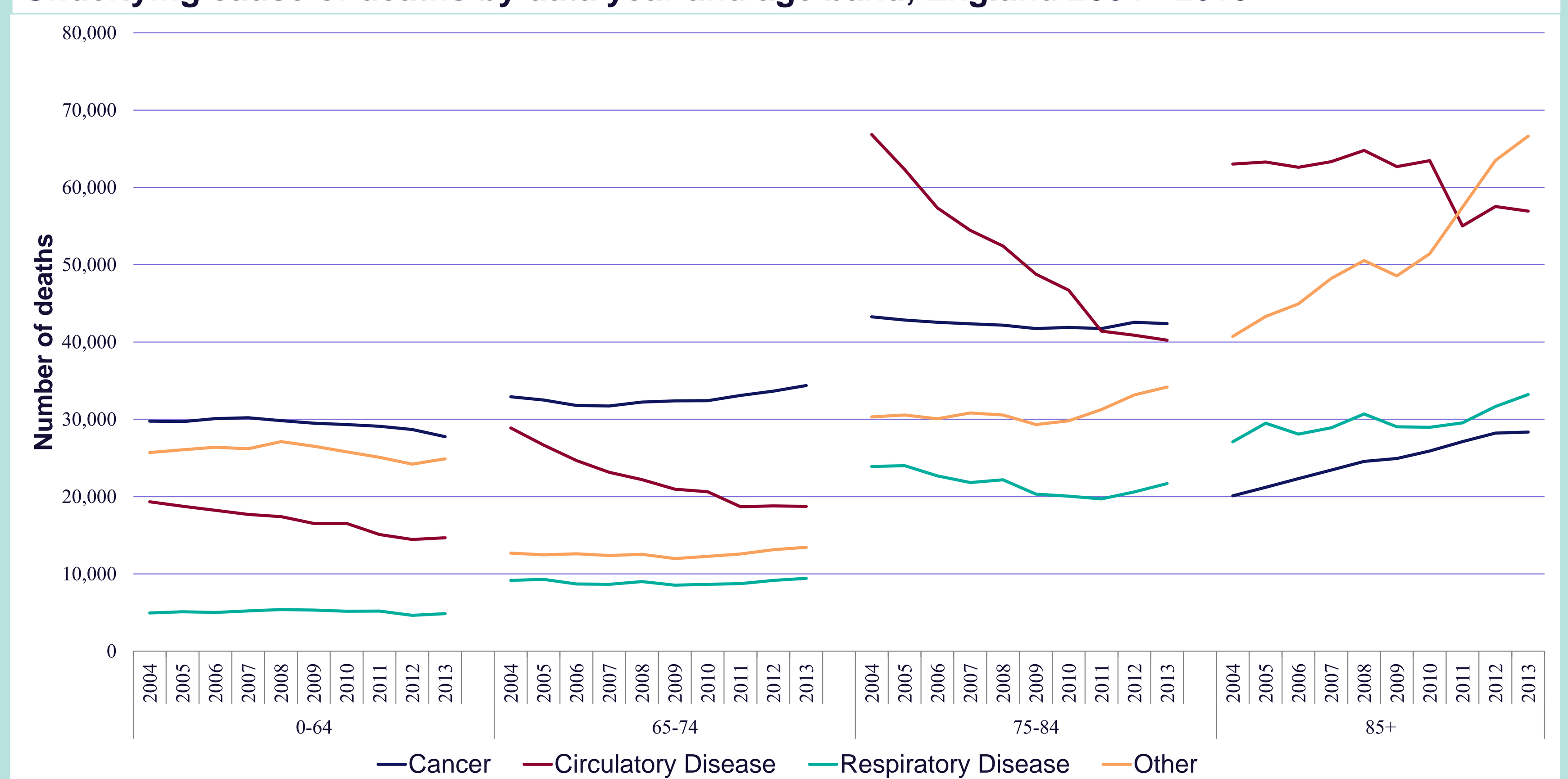
- There are estimated to be 386,000 people living in approximately 17,000 nursing or residential homes.
- ~20% of care home residents are aged 85+, average length of stay 9 and 18 months.
- Care home residents have greater and more complex health needs with multiple co-morbidities.
- Over 100,000 deaths in England now take place in care homes each year. This has increased from just under 80,000 in a decade between 2004-13.
- The proportion of people dying aged 85+ in care homes increased 32% to 38% and in 75-84 year olds from 13% to 15%.
- More people are dying of non-cancer, non-CHD causes with multiple morbidity. At least three-quarters of all those who are dying have reduced agency - physical and/or mental and/or social. Of the ~1/2 million deaths per year ~350,000 people will die with reduced capacity/agency
- Research suggests few elderly people wish to move to care homes or die there but this becomes a necessity because of frailty (6)

Percentage of deaths by data year and age band, England 2004 – 2013

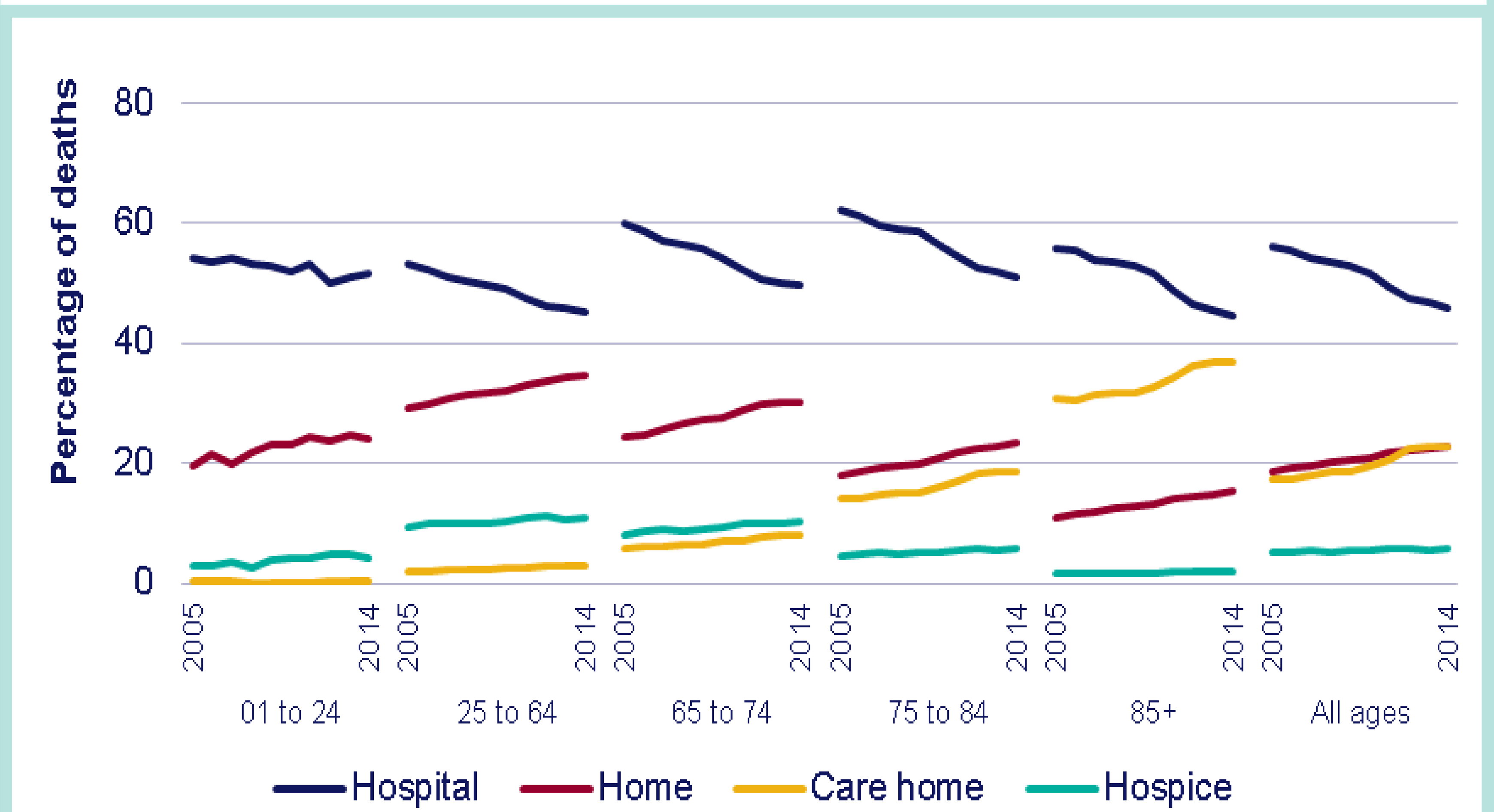




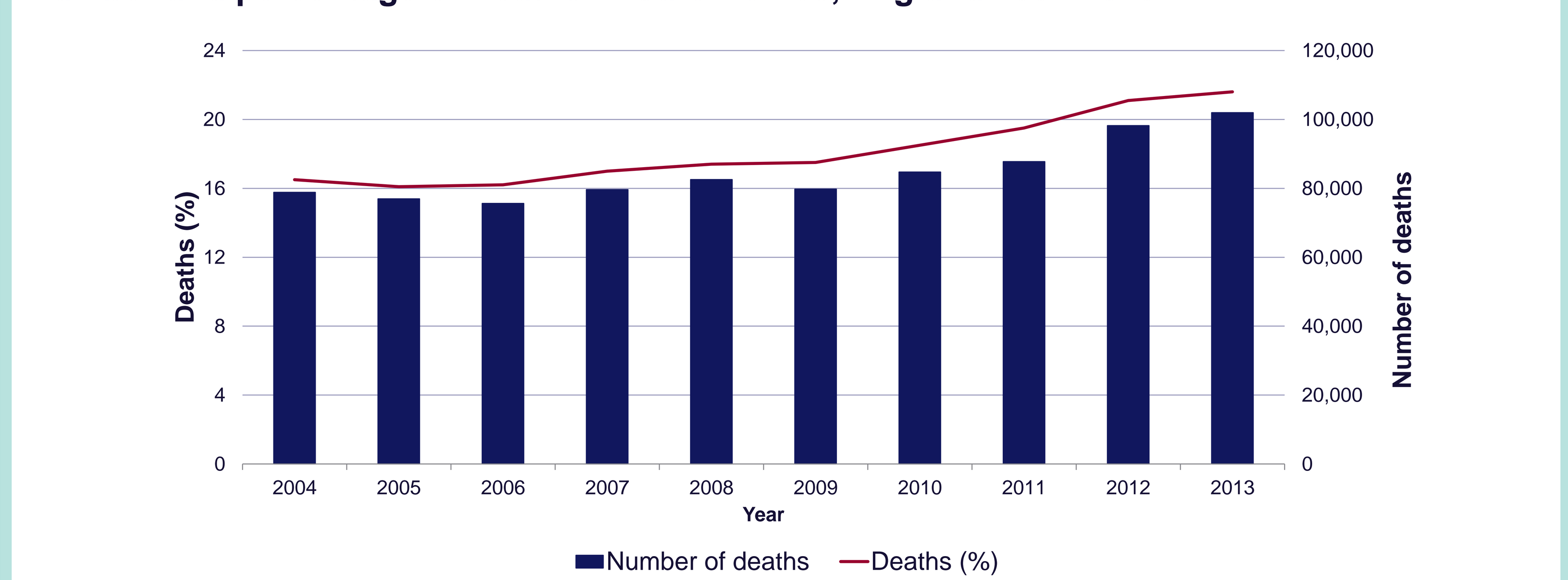
Underlying cause of deaths by data year and age band, England 2004 - 2013



Changing patterns of place of death – proportion of deaths in categories of place of death by age group, England 2005-2014



Number and percentage of Deaths in Care Homes, England 2004-2013



DISCUSSION

Simply analysing national data clearly demonstrates that as the population ages the range of choices related to end of life become reduced. Chronic diseases as cause of death increase, age at death increases and this is likely to be associated with increased frailty. Increasing numbers of people die in care homes – In England now over 100,000 per year. Policy should be circumspect about the reality of choice especially place of death and ensure more emphasis on universality of quality of end of life care whatever the circumstances. Feelings of ‘guilt’ are a recognised feature of bereavement. Health professionals should communicate realistic expectations around caring of the dying with more emphasis on unpredictability of dying.

CONCLUSIONS

The most important issue driving the nature of dying, the support and care needed and choices that are available to patients is demographic change.
It will be important to consider policy especially the issue of Choice at the end of life within this context especially as in England almost 70% of deaths occur in patients over the age of 75 years many of whom will have reduced physical and mental capacity and so the options open to them with respect to choice of where they live, what they can do and how they die is restricted.
Dependency on others for support with daily living becomes a reality for many elderly people and for most people as they approach death.

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