Public Health England

Protecting and improving the nation's health

Using a human rights approach to evaluate Palliative and End of Life Care in England

2nd International Symposium on Palliative Care

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National Lead for Palliative and End of Life Care
National Lead for Liver Disease

UN obligations and political rights

Article 12 International Covenant on Economic, Social and Cultural Rights

Article 7 International Covenant on Civil and Political Rights

‘all member countries of the United Nations are obliged to safeguard patients at the end of life against pain and suffering, allowing them to die with dignity’

The Human Rights Act 1998 (UK) derived from European Convention on Human rights

Rights and Duties

Provides minimum standards enshrined in law about how the state should treat people right up to the end of life.

These are guaranteed in several ways:

The HRA 1998 requires all ‘public authorities’ to act in accordance with the rights and duties set out in the act not only the National Health Service but also part funded services e.g. Hospices

The HRA 1998 places a legal duty on public officials to uphold standards by respecting human rights in everything they do (Section 6 of the HRA). Includes doctors, nurses, social worker but also managers and directors. They must observe the HRA in decisions about individuals AND how services are run.

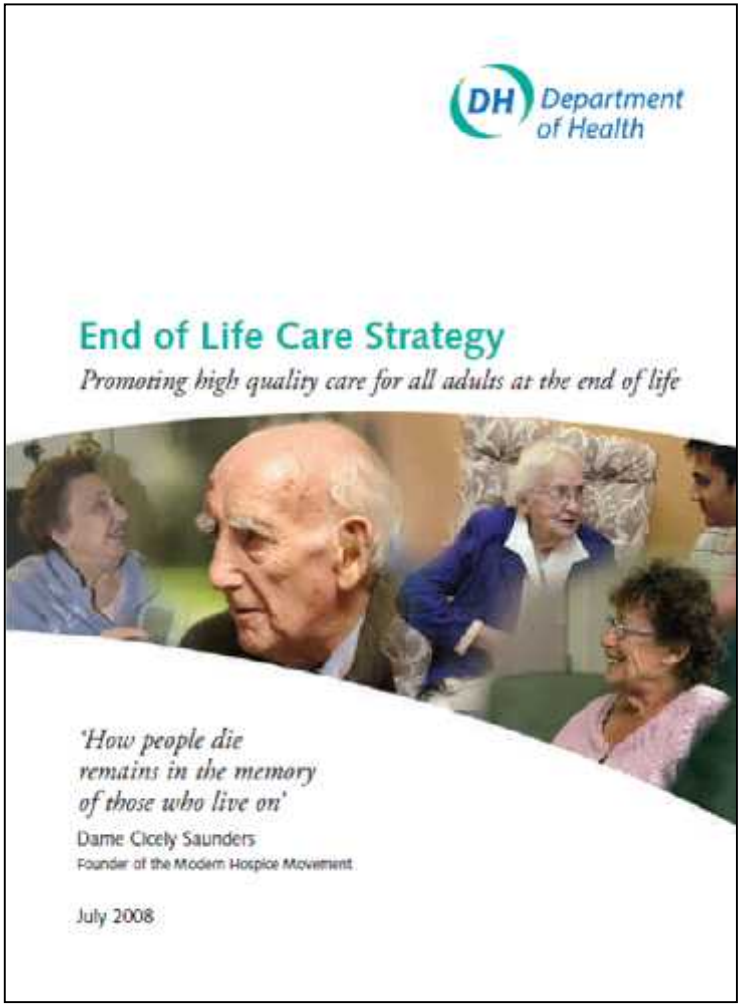
Persons who feel public officials have violated their human rights by acts or omissions or put them at risk can take their case to court/tribunal.

The HRA 1998 is a foundation law

- All legislation including health and social care law has to be compliant (Section 3 HRA):
- Mental Capacity Act 2005 – especially important for elderly patients with dementia
- Equality Act 2010 – important to ensure all societal groups have fair access to P&EOLC
- Care Act 2014 – duties of local authorities (Town Councils) in assessing people's need and eligibility for publicly funded social care (N.B. means tested). Also services directly provided or commissioned must be compliant.

Article of the HRA 1998	Questions
Protection of Life (Article 2 HRA)	How does the right to have life protected interface with the desire of some elderly patients to die?
Alleviation of suffering, protection against inhumane or degrading treatment (Article 3)	What are the types of suffering elderly people experience? What are the risks for elderly patients of inhuman and degrading treatment and how can they and others mitigate against this? How does suffering influence the desire of elderly patients for death?
The right to a private and family life, home and correspondence under which the right to autonomous choices (Article 8 HRA)	What is important to the identity of elderly patients approaching the end of life and how do they want to use their autonomy? SEE PART 1
The Right to Liberty (Article 5) **Prisons, psychiatric hospitals, care homes, hospital, hospices**	Are there threats to the liberty of elderly patients and what protections are in place to protect them?
The Right to freedom of thought, conscience and religion (Article 9)	How important are the freedoms under Article 9 for elderly patients approaching the end of life and how are they protected and promoted? How do they exert freedom of thought and conscience in a liberally driven policy framework about choice? What role does religion play today at the end of life for elderly people and what form if any does it take?
The Right to enjoy all these human rights without discrimination (article 14)	In the context of end of life care do elderly patients have fair and equal access to good quality care or are they discriminated against?

End of Life Care Strategy 2008



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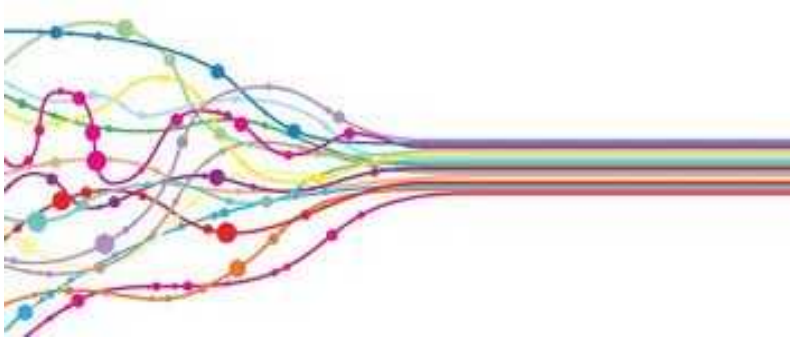
National End of Life Care Intelligence Network



Turning data into information & information into insight

- Established 2010 to improve the collection and analysis of information related to the quality, volume and costs of palliative and end of life care. This intelligence will help drive improvements in the quality and productivity of services.

- National End of Life Care Intelligence Network (NEoLCIN) became part of Public Health England 2013.

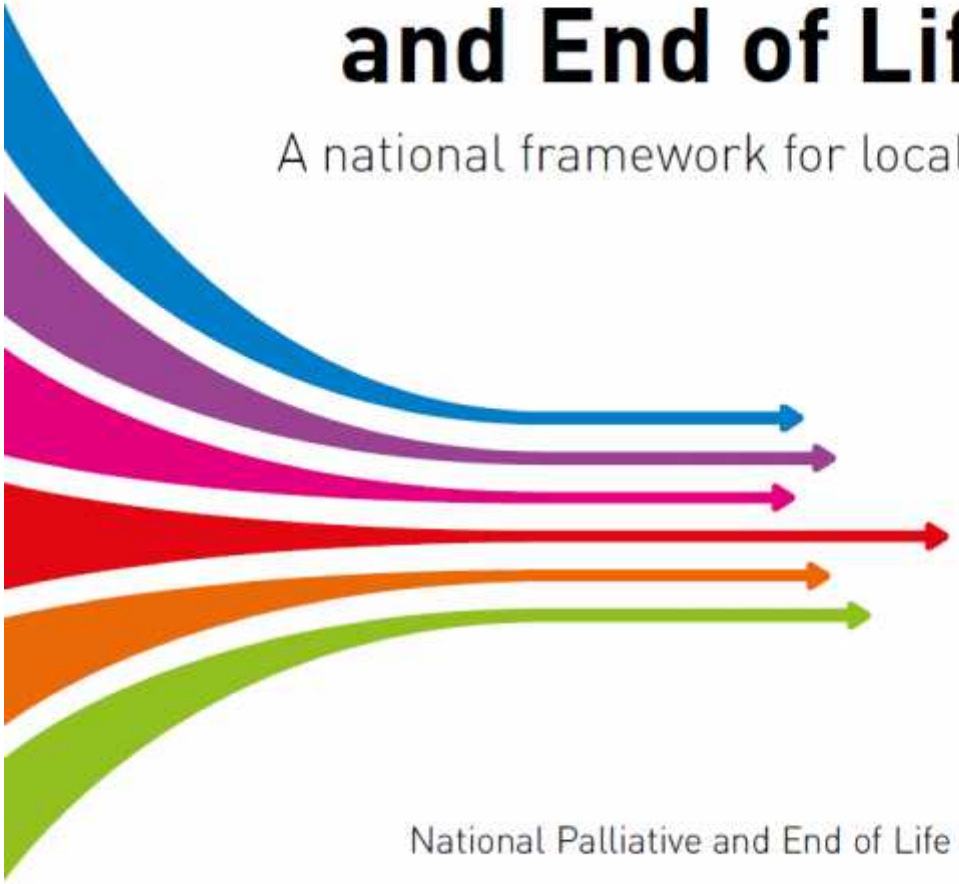

INDEPENDENT REVIEW OF THE LIVERPOOL CARE PATHWAY
MORE CARE, LESS PATHWAY
A REVIEW OF THE LIVERPOOL CARE PATHWAY
ONE CHANCE TO GET IT RIGHT
Improving people's experience of care in the last few days and hours of life.
Published June 2014 by the
Leadership Alliance for the Care of Dying People
Publications Gateway Reference 01509
What's important to me.
A Review of Choice in End of Life Care
EXECUTIVE SUMMARY
Published by
The Choice in End of Life Care
Programme Board
February 2015

National Palliative and End of Life Care Partnership

Association for Palliative Medicine; Association of Ambulance Chief Executives;
Association of Directors of Adult Social Services;
Association of Palliative Care Social Workers; Care Quality Commission;
College of Health Care Chaplains; General Medical Council;
Health Education England; Hospice UK;
Macmillan Cancer Support; Marie Curie;
Motor Neurone Disease Association; National Bereavement Alliance;
National Care Forum; National Council for Palliative Care;
National Palliative Care Nurse Consultants Group; National Voices;
NHS England; NHS Improving Quality;
Patients Association; Public Health England;
Royal College of General Practitioners;
Royal College of Nursing; Royal College of Physicians;
Social Care Institute for Excellence;
Sue Ryder and
Together for Short Live

Ambitions for Palliative and End of Life Care:

A national framework for local action 2015-2020



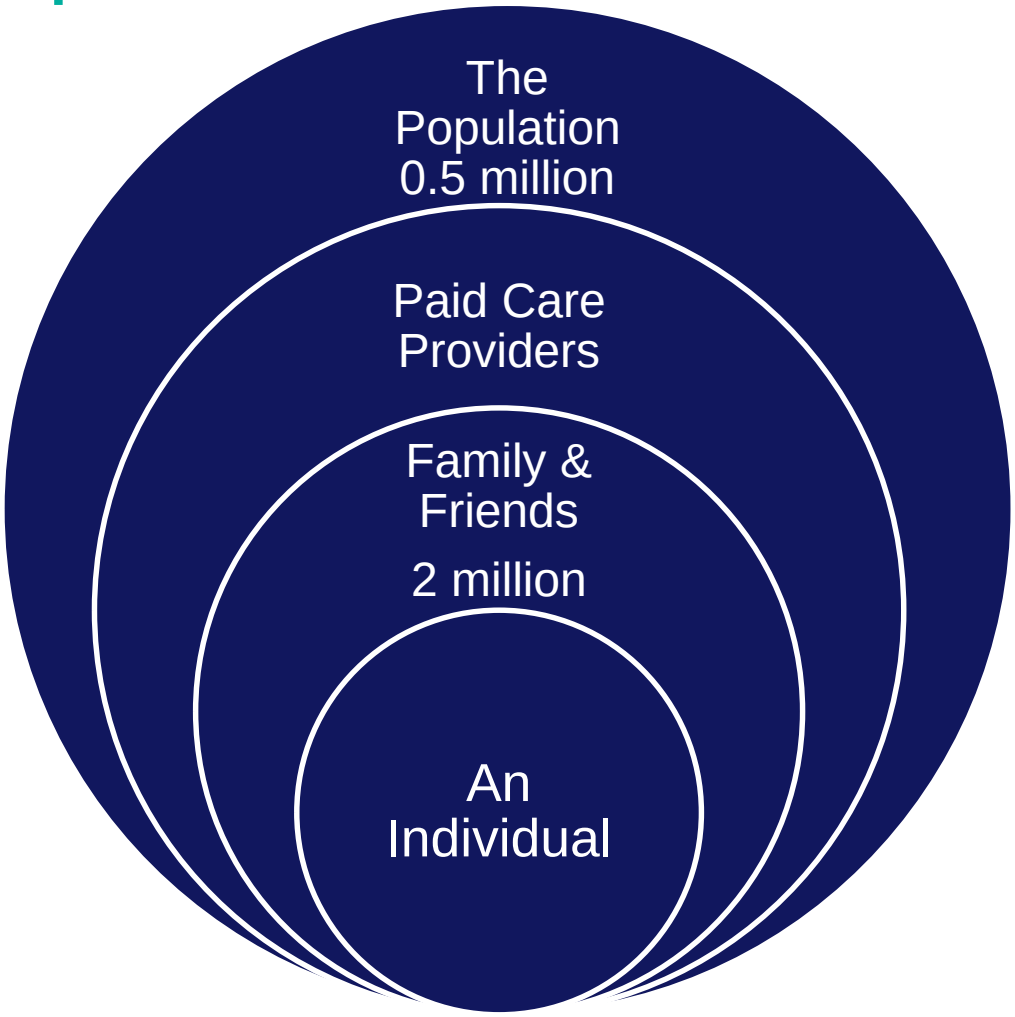
National Palliative and End of Life Care Partnership

"As organisations with experience of, and responsibility for, palliative and end of life care we have made a collective decision to act together to do all we can to achieve for everyone what we would want for our own families."

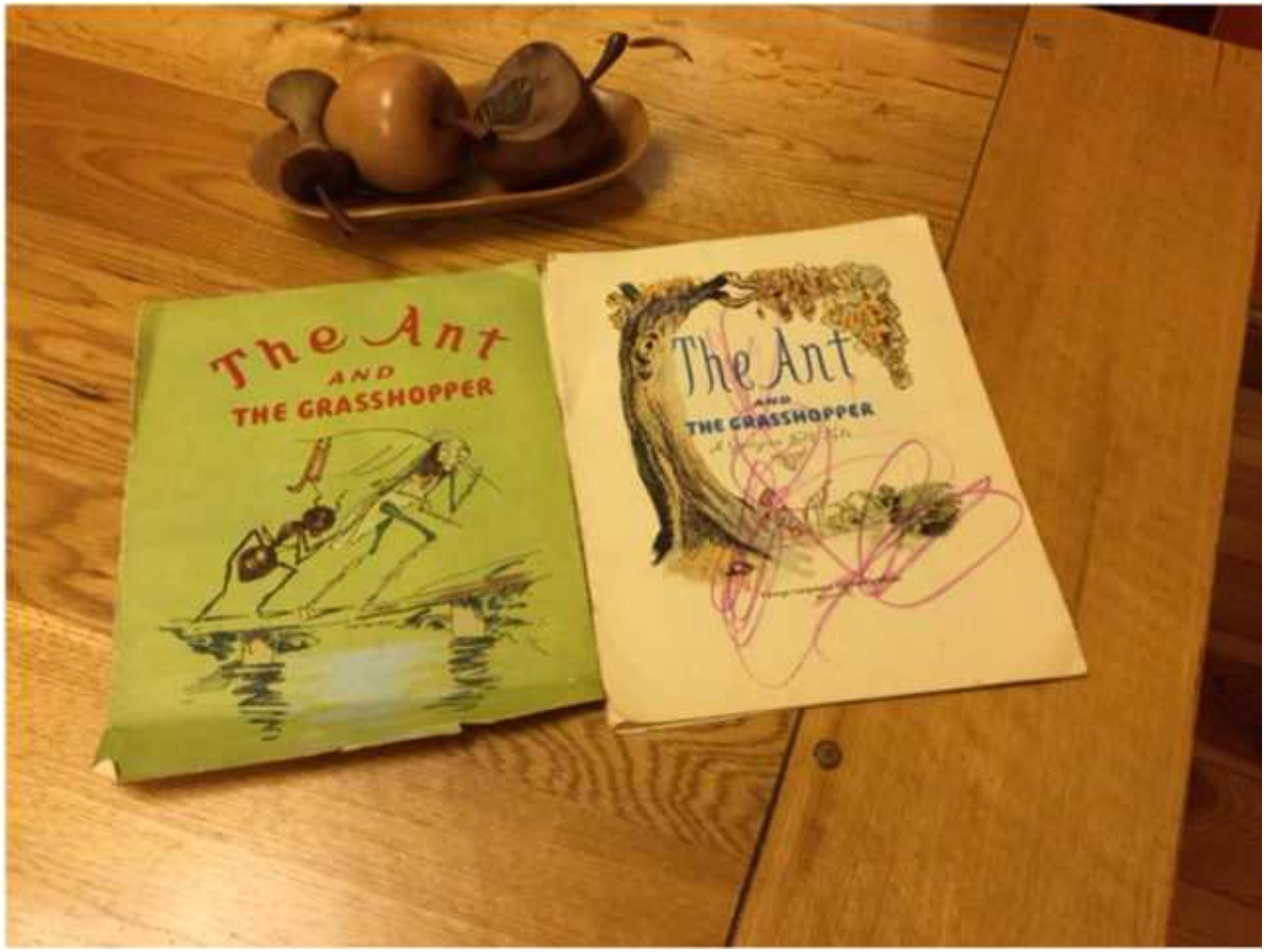
Executive Summary: Ambitions for Palliative and End of Life Care

National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk

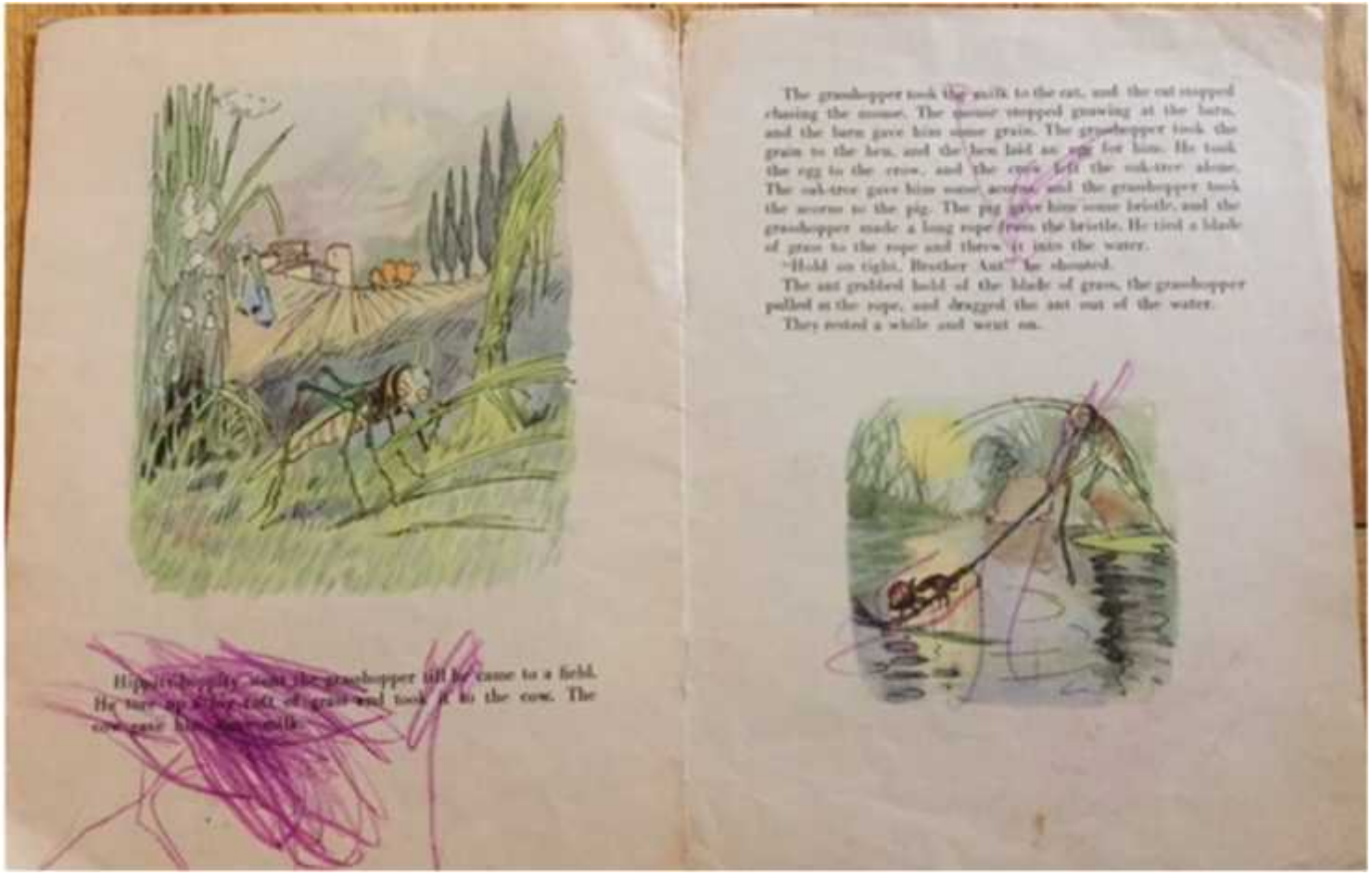
It's not just my job > 2.5m its personal!



Lessons from a Georgian Fairytale



A tale of compassion and collaboration



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From a population – Public Health Perspective in P&EOLC

We are looking beyond cancer (taking the lessons)

Towards the needs of the aging population at the end of life (developing different models)

Number of people estimated to require end of life care

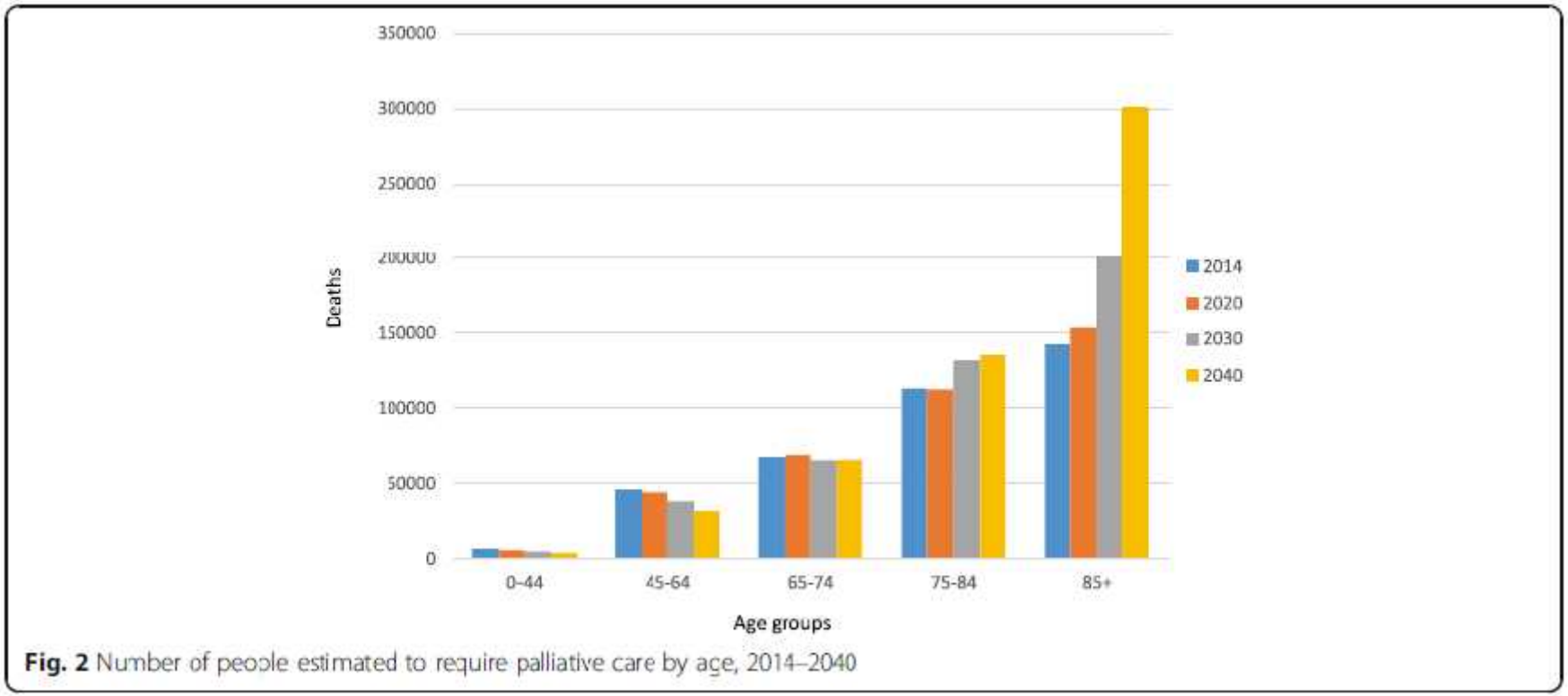


Fig. 2 Number of people estimated to require palliative care by age, 2014–2040

Source: Etkind SN et. al. - How many people will need palliative care in 2040? Past trends, future projections and implications for services - BMC Medicine201715:102

Deaths in older people in 2017 c.f. 2007

- In 2017, there were 498,882 registered deaths in 2017
- 341,620 (68.5%) of these were amongst people aged 75 and older

The total number of deaths is rising, especially amongst the oldest age groups:

Age in years	Age 75-79	Age 80-84	Age 85-89	Age 90+	Total
2017 number of deaths	60,012	80,156	92,178	109,274	341,620
2007 number of deaths	64,953	84,495	83,057	80,837	313,342

Data source: Office for National Statistics

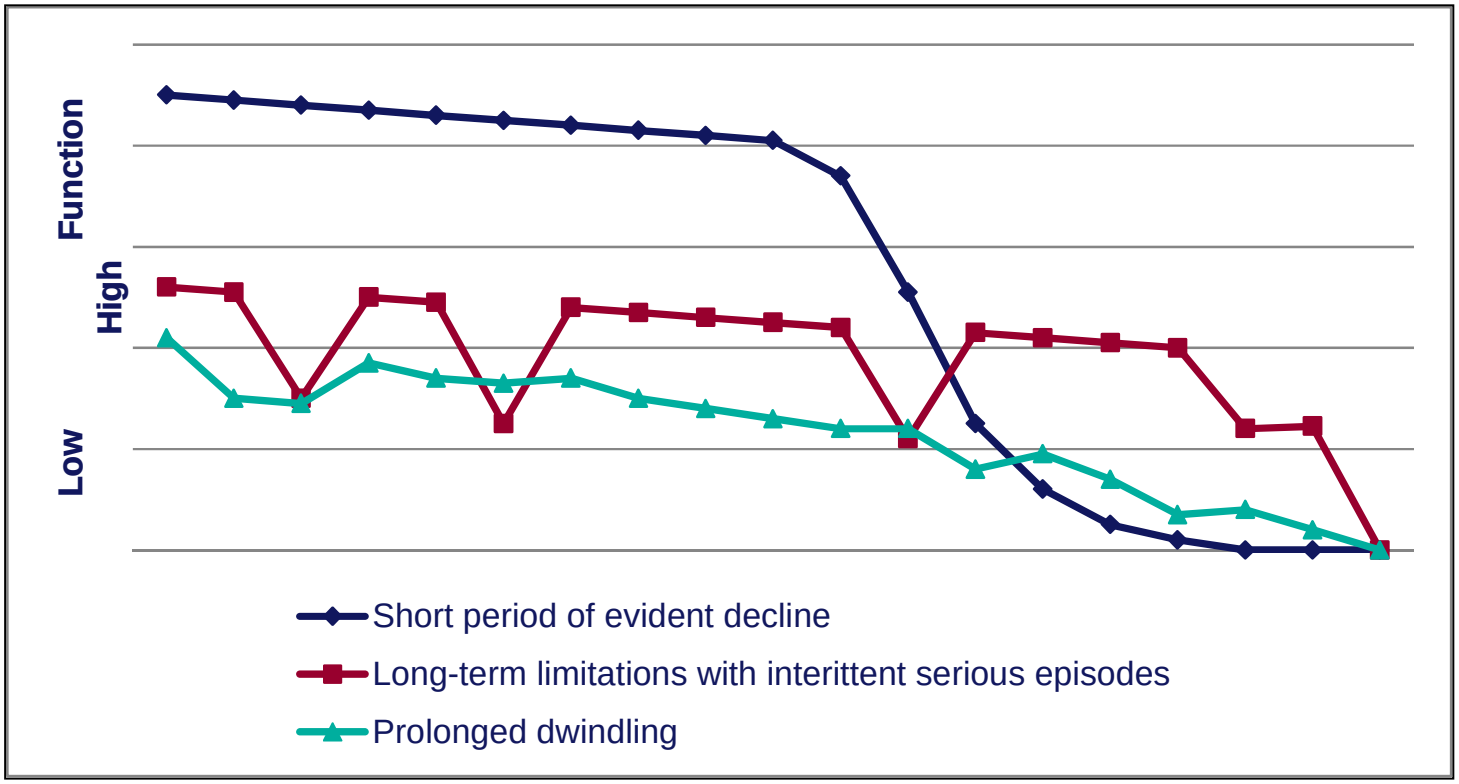
Causes of death amongst people aged 75 and older who died in 2017 c.f. 2007

	2017		2007	
Cause of death	**Number of deaths**	**Proportion of deaths**	**Number of deaths**	**Proportion of deaths**
Cancer	74,112	21.7%	65,798	21.0%
Chronic heart disease	39,307	11.5%	42,329	13.5%
Stroke	23,742	6.9%	32,490	10.4%
Liver disease	3,685	1.1%	2,185	0.7%
Dementia*	87,199	25.5%	40,253	12.8%
COPD*	36,501	10.7%	26,392	8.4%
Other causes	105,758	31.0%	115,769	36.9%

* Dementia and COPD are included as both underlying and contributory causes of death. All other causes of death are underlying causes of death only.

Data source: Office for National Statistics

Chronic illness in the Elderly, three typical trajectories: (schematic) after Lyn et. al. (2003)



Source: NEoLCIN after Lyn et. Al. (Lynn, J. and Adamson, D. M., (2003), Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age, Santa Monica, CA: Rand Health.

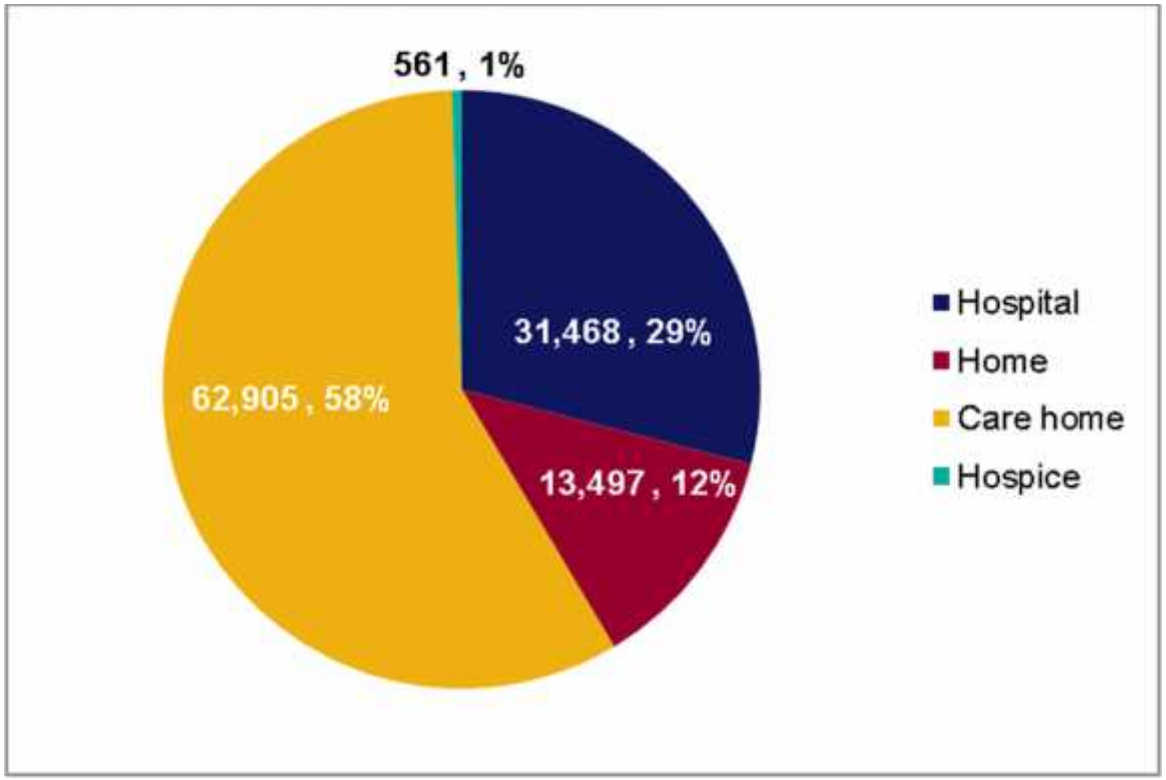
Place of death, death type and end of life care tools, 38 Care homes in Southern England (n=2,444 deaths)

Recorded details of end of life care	n	(Valid %)
Place of death (%)		
Nursing care home	1,768	(72.8)
Other	660	(27.2)
Type of death (%)		
Dwindling	1,192	(50.3)
Terminal condition	621	(26.2)
Acute	454	(19.2)
Sudden	102	(4.3)
Use of end of life care tools (%)		
Evidence of anticipatory prescribing (%)	727	(31)
Use of end of life care plan (%)	341	(14.5)
Advance care planning in place (%)	1,496	(63.6)
Resuscitation decision in place (%)	1,365	(58.2)

Source: Ennis, L., Kinley, J. Hockley, J. and McCrone, P. (2015). P19
http://hsm.sagepub.com/content/28/1-2/16.full.pdf+html

Place of death for those with any mention of dementia or senility as a cause of death aged 75 years and older, England 2013-2015

(108,400 p.a. ~ ¼ of all deaths c.f. cancer)



Figures are average annual deaths, and percentage of deaths by place

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Palliative and End of Life Care is a Human Right

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Article 2 (Human Rights Act UK)

Protection of life (Absolute)

Protection of life in the UK

- Killing a person is illegal under any circumstances including:

  Voluntary Euthanasia

  Physician Assisted Suicide

  Assisting a suicide

- Allowing a natural death is not illegal
- Suicide is not illegal

Public Health England

Protecting and improving the nation's health

Article 3 (Human Rights Act UK)

Alleviation of suffering, protection against inhumane or degrading treatment (Absolute)


nuffieldtrust
The Francis Public Inquiry Report:
a response
Policy response
March 2013
nuffieldtrust
Commissioning high-quality care for people with long-term conditions
Research summary
Judith Smith, Alison Porter, Sara Shaw, Rebecca Rosen, Ian Blunt and Nicholas Mays
Dementia: ethical issues
NUFFIELD COUNCIL ON BIOETHICS

03

Maximising comfort and wellbeing

The building blocks for achieving our ambition

Recognising distress whatever the cause

It is important to recognise all sources of distress quickly, to acknowledge distress and to work with people to assess its extent, its cause and what might be done.

Addressing all forms of distress

The experience of suffering associated with physical symptoms may be exacerbated, or sometimes caused, by emotional, or psychological anguish, or social or spiritual distress. Addressing this requires professionals to recognise, understand and work to alleviate the causes.

Skilled assessment & symptom management

Attending to physical comfort, pain and symptom management is the primary obligation of clinicians at this time of a person's life and their skills and competence to do so must be assured and kept up to date.

Specialist palliative care

People approaching the end of life should have access to Specialist Palliative Care when this is needed. This should include a clear understanding of how to access medicines and equipment as part of the rapid response to changing needs.

Priorities for care of the dying person

People approaching death should expect local systems to accord with the priorities identified by the Leadership Alliance for the Care of Dying People.

Rehabilitative palliative care

Maximising the person's independence and social participation to the extent that they wish requires professionals to work with, and support, the person in helping them to achieve their personal goals.

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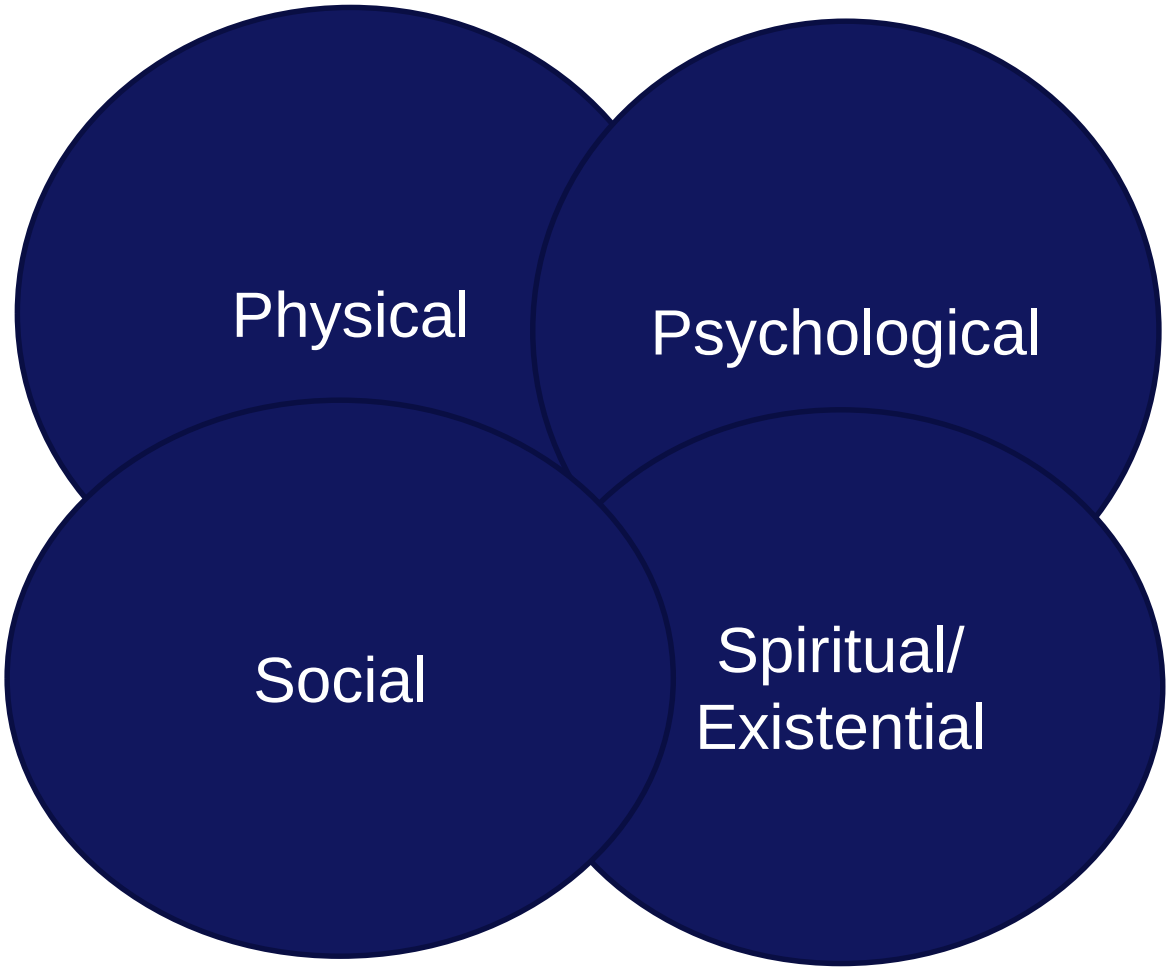
Domains of potential suffering



POOR PHYSICAL HEALTH

- Pain and symptoms
- Co-morbidties
- Frailty
- Dementia –physical aspects, assessment of pain
- Polypharmacy
- Loss of sight/hearing

LOSS

- Physical world is reducing
- Pleasures diminishing
- Sense of loss of purpose
- Dependency on others
- Fear of being a burden
- Loss of dignity

ACTION

- Holistic assessment – geriatricians, palliative care , family doctors
- Physical aids
- Recognition of impact on other spheres of wellbeing

POOR MENTAL HEALTH

- Depression
- Dementia
- Spiritual/existentialist crisis
- Effect of terminal illness, UTI, pneumonia drugs, fear on Mental Capacity

LOSS

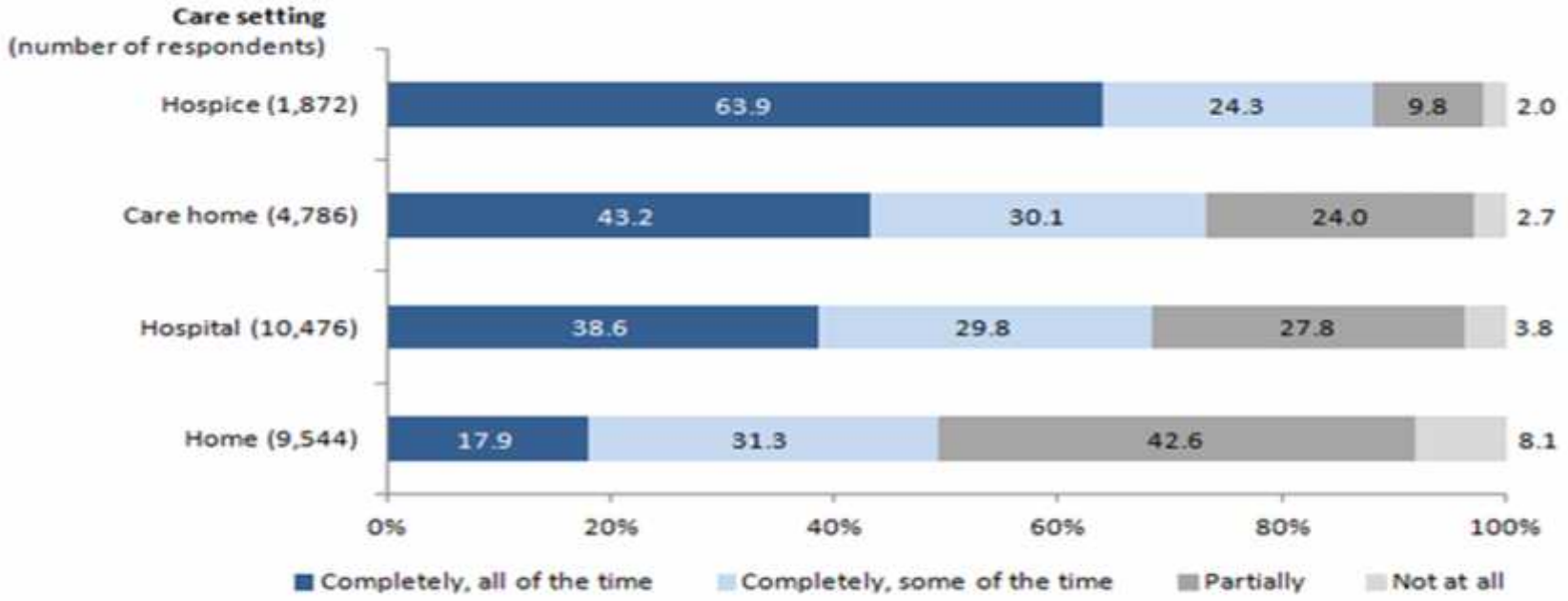
- Loss of identity
- Mental Capacity
- Existentialist Crisis
- Pleasures diminishing
- Sense of loss of purpose
- Dependency on others
- Loss of dignity
- Wish to hasten death (>1/4)

ACTION

- Holistic assessment – geriatricians, palliative care , family doctors
- Increase chances of recognition of issues impacting on mental capacity
- Address & treat what is treatable,
- Refer to others
- Meaning Management therapy

VOICES Survey 2014 – Pain Relief

Pain was reported as being relieved "completely, all of the time" most frequently for patients in hospices (64%) and least frequently for those at home (18%).

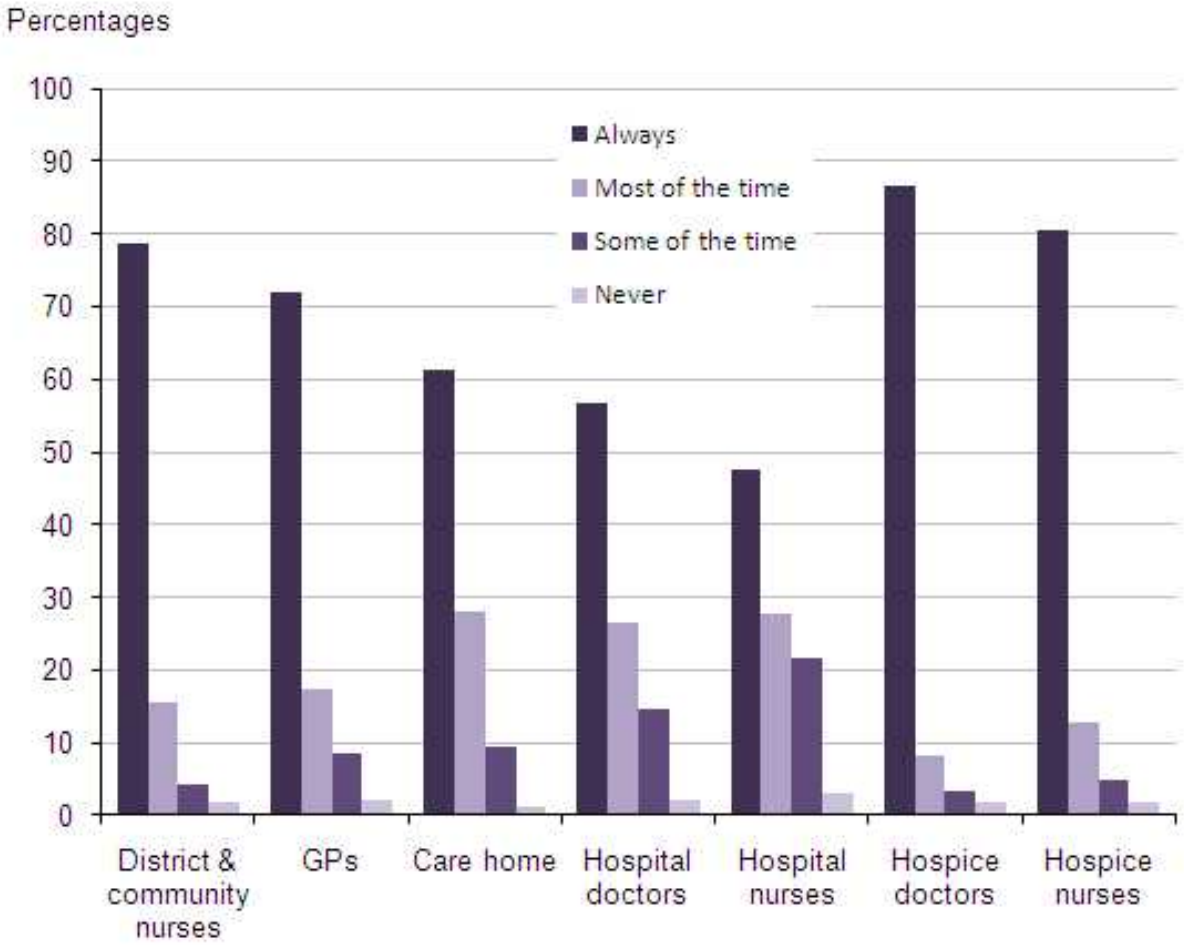


Almost 1 in 13 (8%) of people cared for at home did not have their pain relieved at all.

Percentages may not sum to 100 due to rounding

Source: Office for National Statistics

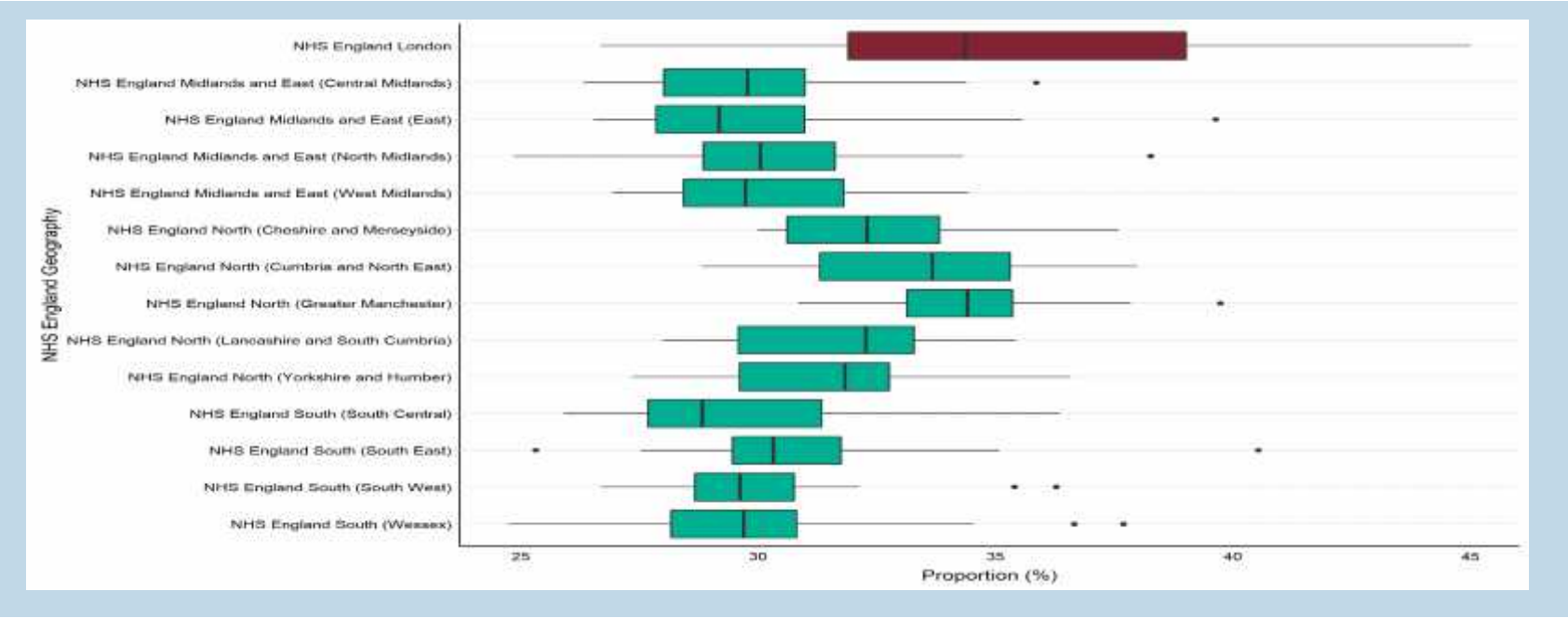
How often the patient was treated with dignity and respect in the last three months: by setting or service provider



Sociological issues

- Living alone
- Loneliness
- Loss of identity
- Loss of dignity
- Not wanting to be a burden
- Need for care which is not medical
- Family resources and willingness to care

Variation of the proportion of people aged 65 and older and living alone (2011) with health regions in England by local authority Interquartile range (box), extent up to 1.5 times the box width (whiskers) and outliers



Who do you have to look after you?

*q23_1. Members of a family and friends often move to different parts of the country. Bearing in mind their health, age and commitments, how many people locally would you say you could count on to give you regular help if you needed it now? (*Respondents had to say how many against each of these three categories below).

…Family members who are local or living with you, including husband, wife, partner

…Neighbours

…Friends who live locally and are not neighbours

Who and how many could be relied on for regular help if needed?

	Relatives/family members	Neighbours	Friends (who are not neighbours)
Could count on for regular help:	3590 %	3590 %	3590 %
None	21	64	53
1 person	33	14	13
2 persons	20	12	16
3 persons	11	3	6
4+ persons	15	7	12

Any one to count on?

- 12% of those aged 45+ had **no** relative, friend or neighbour that they could count on for regular help if the need arose
- 19% claimed there was **one** person
- 37% claimed there were two to four people they thought they could count on.
- 33% thought there were five or more people

Source: Tapp A, Nancarrow C, Morey Y, Warren S, Bowtell N, Verne J. Public responses to volunteer community care: Propositions for old age and end of life PLoS One. 2019; 14(7): e0218597.

The highest incidences of having no-one that could be counted on to provide regular care should the need arise were:

- 42% of those who have no family
- 24% of those who are living alone
- 22% of those who are not parents
- 22% of those who are single / separated / divorced / widowed
- 17% of those in a relationship but not together
- 15% of those who do not actively belong to any local groups (sport / hobby, church etc.)
- **19% of those living in London**

Dame Cicely Saunders

Founded St Christopher's Hospice the world's first purpose-built hospice in 1967.
Died 14 July 2005 (aged 87)

Public Health England

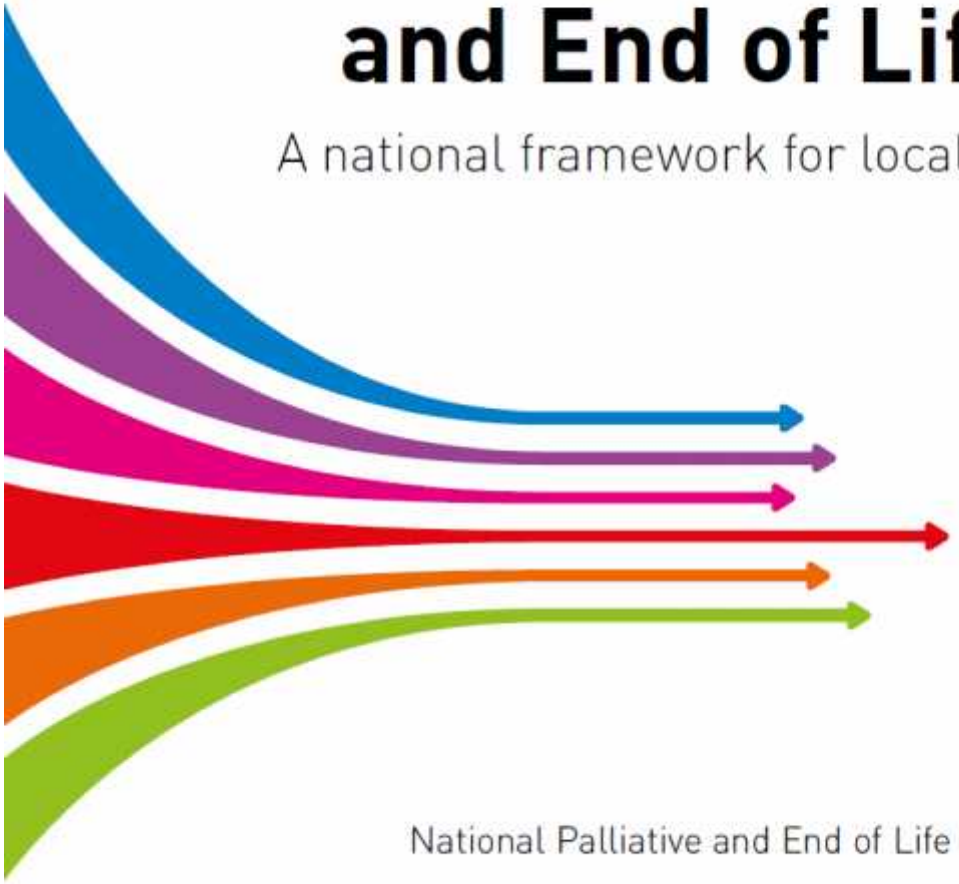
Protecting and improving the nation's health

Article 8 (Human Rights Act UK)

The right to a private and family life, home and correspondence under which the right to autonomous ***choices (Qualified)***

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

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"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)."

Each person is seen as an individual

I, and the people important to me,
have opportunities to have honest,
informed and timely conversations
and to know that I might die soon.
I am asked what matters most to me.
Those who care for me know that
and work with me to do
what's possible.

National Palliative and End of Life Care Partnership
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01

Each person is seen as an individual

The building blocks for achieving our ambition

Honest conversations

Everybody should have the opportunity for honest and well-informed conversations about dying, death and bereavement.

Systems for person centred care

Effective systems need to reach people who are approaching the end of life, and ensure effective assessment, care coordination, care planning and care delivery.

Helping people take control

Personal budgets and integrated personalised commissioning are some of the potentially powerful tools for delivering tailored and personal care for many more people.

Clear expectations

People should know what they are entitled to expect as they reach the end of their lives.

Access to social care

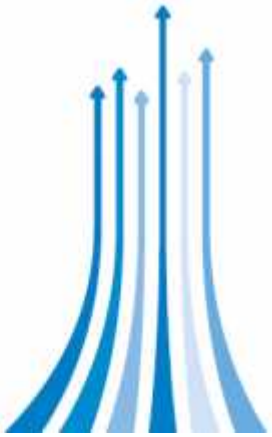
People must be supported with rapid access to needs-based social care.

Integrated care

End of life care is part of new models of integrated health and social care being promoted across the health and social care system.

Good end of life care includes bereavement

Caring for the individual includes understanding the need to support their unique set of relationships with family, friends, carers, other loved ones and their community, including preparing for loss, grief and bereavement.



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What do elderly people want at the end of life?

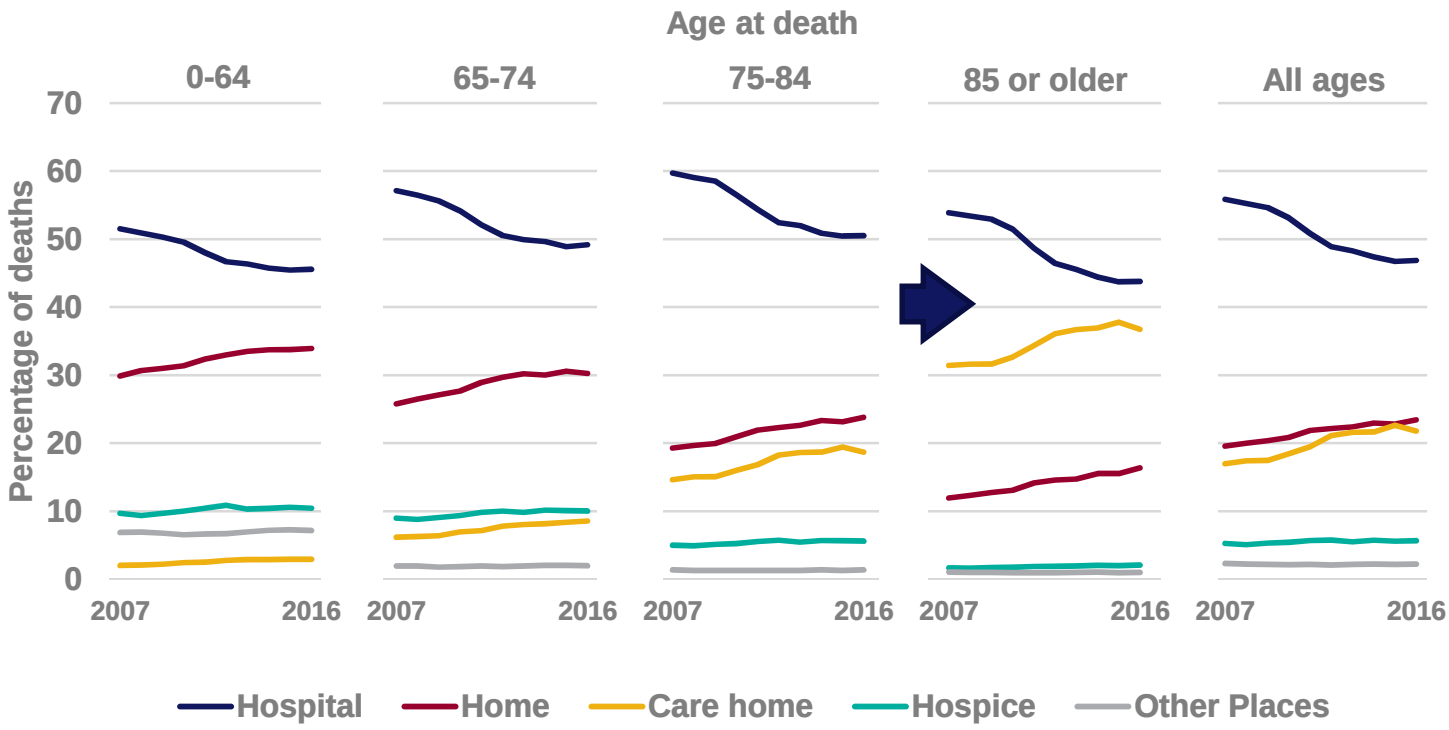
- Pain and symptoms controlled
- Spiritual/existentialist peace/acceptance
- Preservation of identity
- Dignity (wishes, cultural and religious traditions) respected
- Compassionate medical staff
- Die in place of choice – may be influenced by culture
- Not alone (with family present)
- Not to be a burden on family
- Some want to make their own decisions, others to delegate
- *Some want to die – acceptance of life's natural course, loss of identity and independence, 'bored' with life*

A decade of change in place of death: National comparisons 2008 and 2017

	2017		2007	
Place of death	**Number of deaths**	**Proportion of deaths**	**Number of deaths**	**Proportion of deaths**
Hospital	228,486	46.0%	261,435	55.2%
Home	117,522	23.6%	94,684	20.0%
Care home	111,258	22.4%	82,592	17.4%
Hospice	28,965	5.8%	24,284	5.1%
Elsewhere	10,794	2.2%	10,591	2.2%

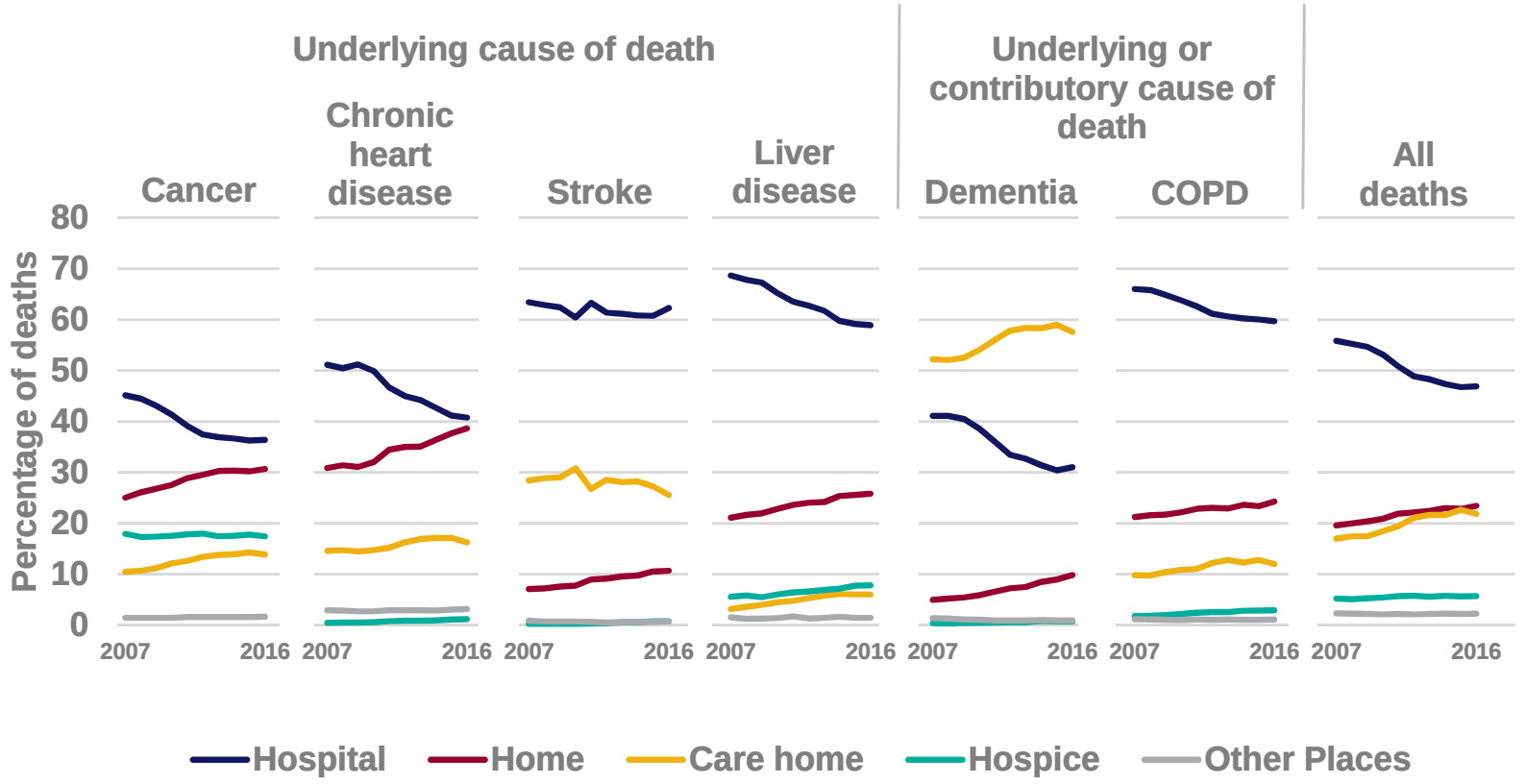
Source : PHE analysis of ONS Annual mortality extract © ONS 2019

Percentage of deaths in each place of death by age, England 2007-2016



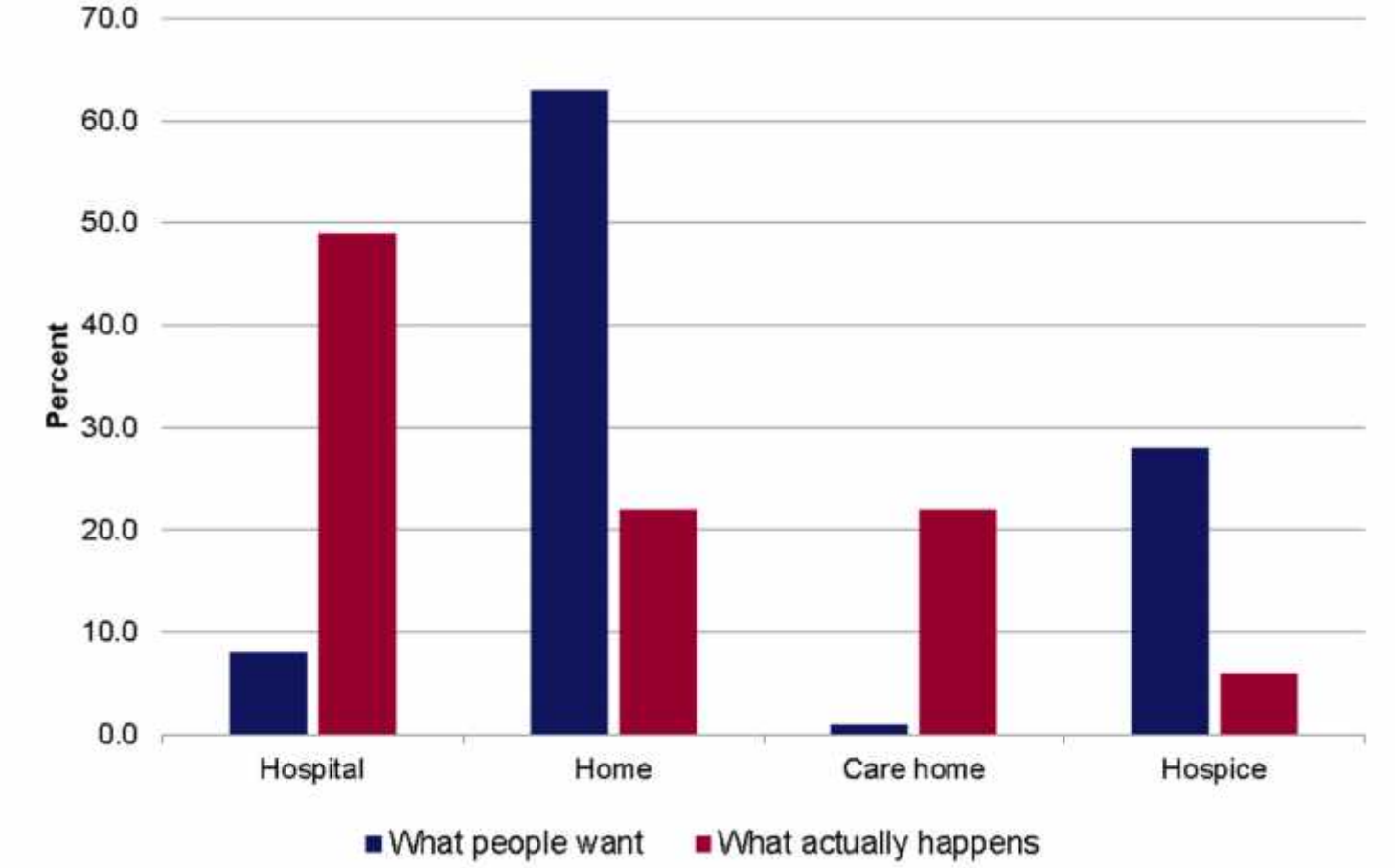
Source: Office for National Statistics: Public Health England Annual Births and Mortality Extract

Percentage of deaths in each place of death by selected cause of death, England 2007-2016



Source: Office for National Statistics: Public Health England Annual Births and Mortality Extract

Preferred and actual place of death – a comparison of quantitative and qualitative data



Public Health England

Protecting and improving the nation's health

Article 14 (Human Rights Act UK)

The Right to enjoy all these human rights without discrimination (Qualified)

Public Health perspective: Inequalities, unwarranted variation, distributive justice

Each person gets fair access to care

I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.

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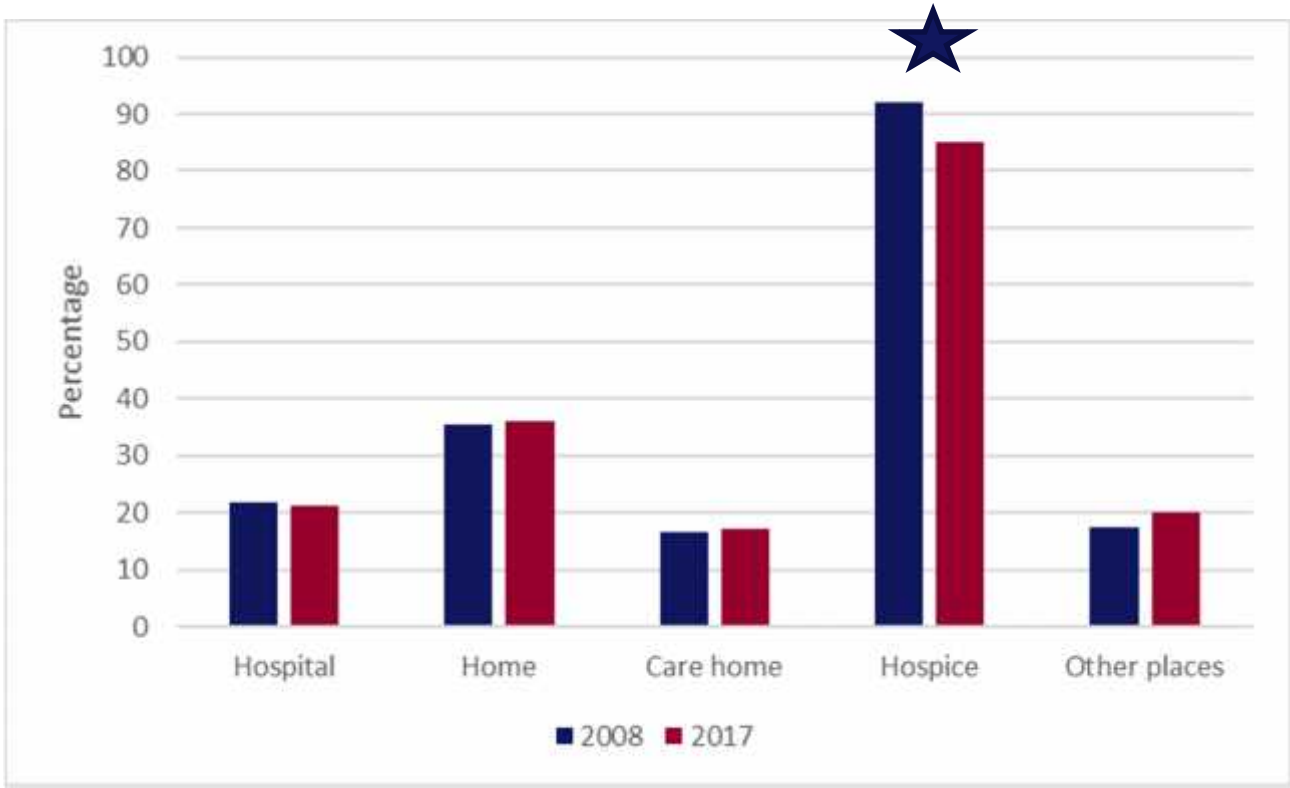
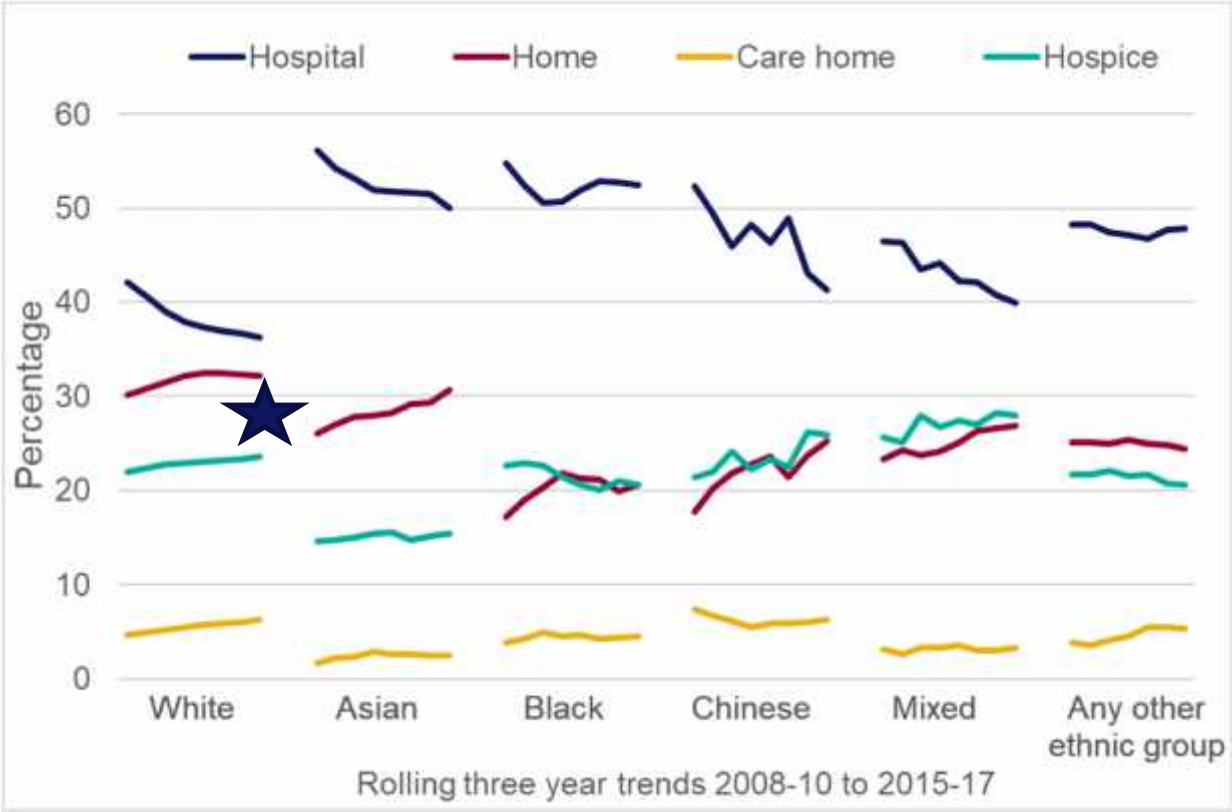
Percentage of deaths from cancer by place of death National Comparisons 2008 and 2017



Source : PHE analysis of ONS Annual mortality extract © ONS 2019

Trends in place of death 2008-2017

Deaths from cancer under 75 years



Source : PHE analysis of ONS Mortality linked to Hospital admissions data © NHS Digital 2019

Palliative care in final admission in which the person died

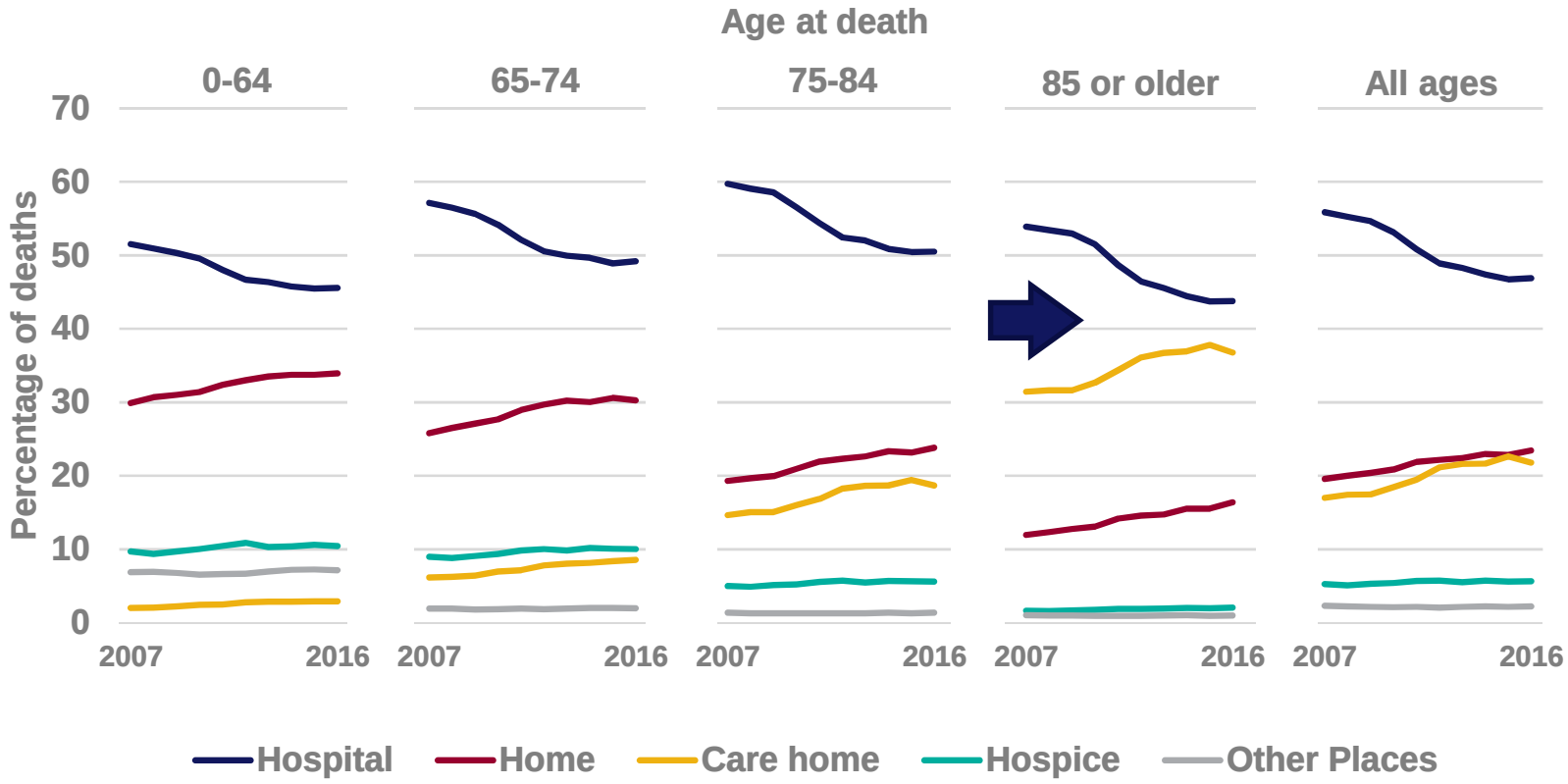
Deaths registered in England, 2017 (Diagnosis code Z515, or treatment speciality code 315)

	Number of people			Percentage
	No	Yes	Total	
Liver -other	2,479	764	3,243	23.6%
Liver - HCC	221	382	603	63.3%
Lung Cancer	4,095	5,944	10,039	59.2%
COPD	11,704	3,129	14,833	21.1%

Analysis only considers admissions during the last year of life

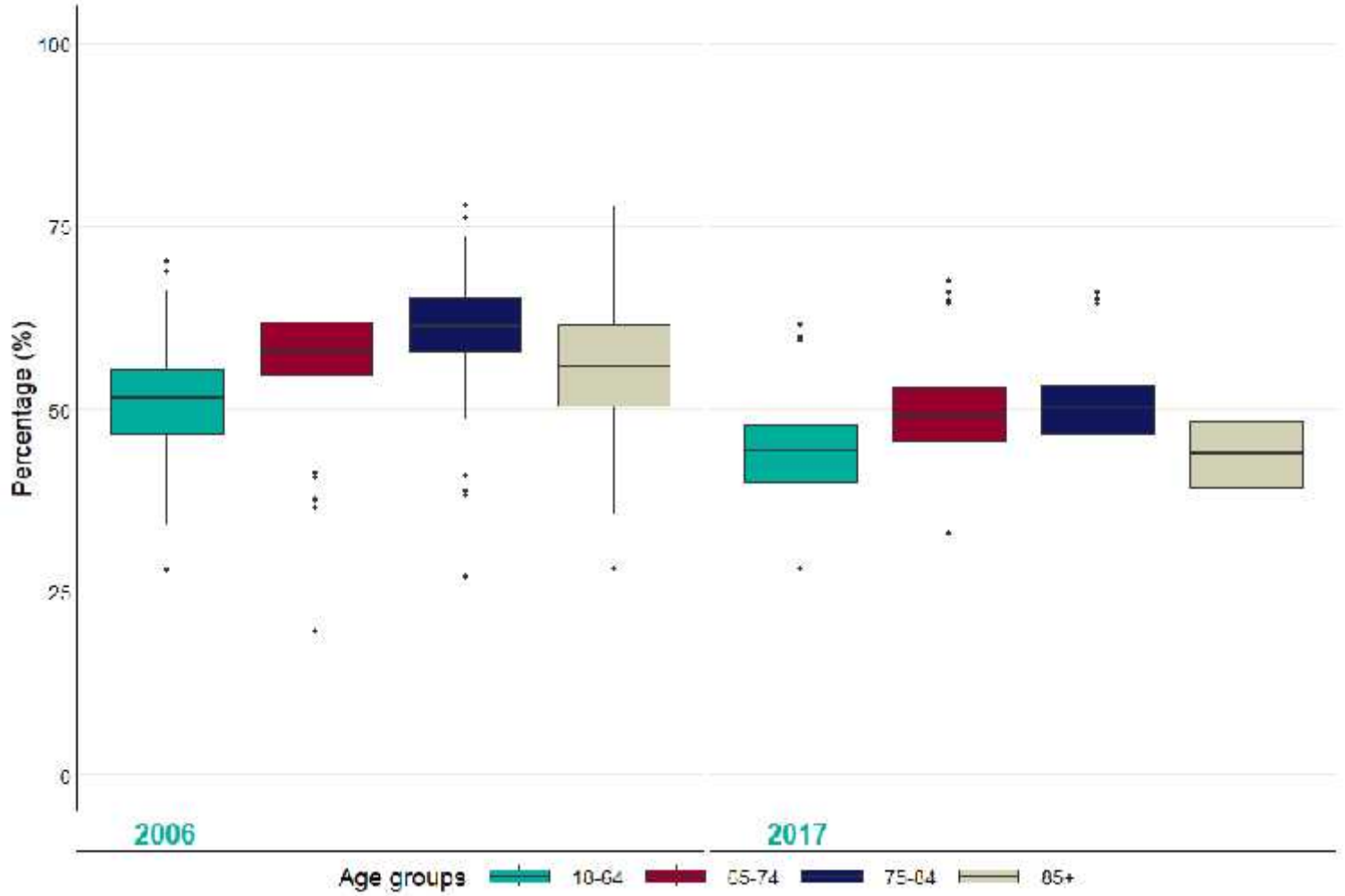
Source: PHE analysis of linked Hospital Episode Statistics with ONS mortality data © NHS Digital 2019

Percentage of deaths in each place of death by age, England 2007-2016



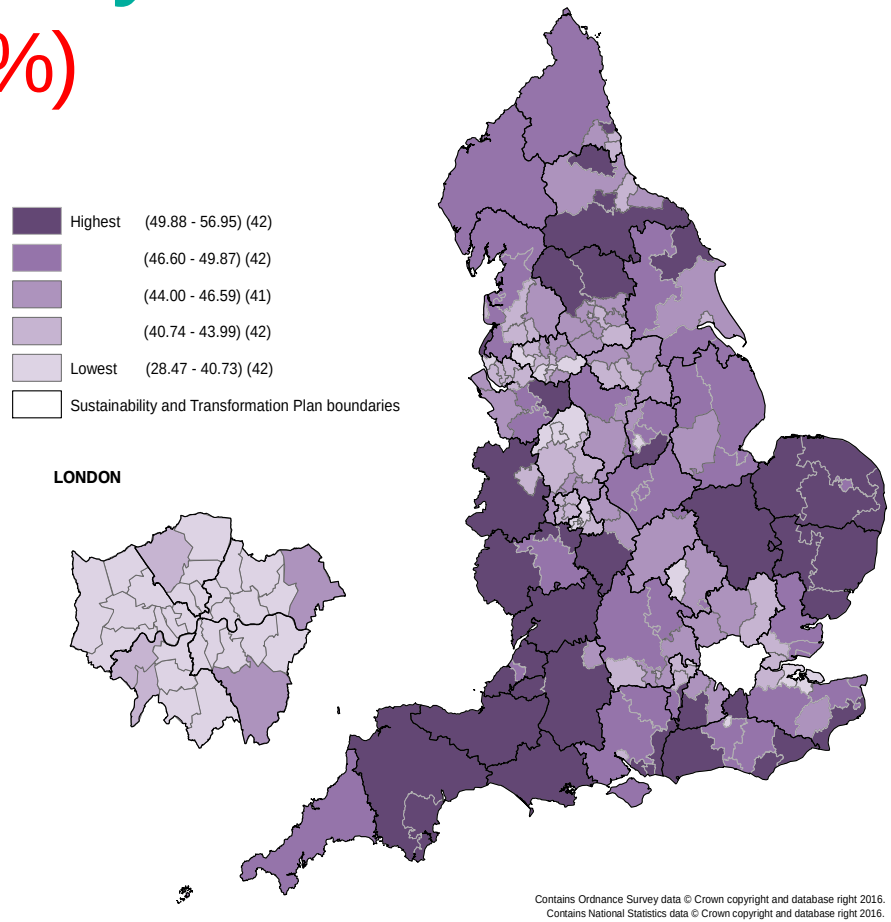
Source: Office for National Statistics: Public Health England Annual Births and Mortality Extract

Variation in proportion of hospital deaths in Clinical Commissioning Groups (CCGs) by age group, 2006 to 2017



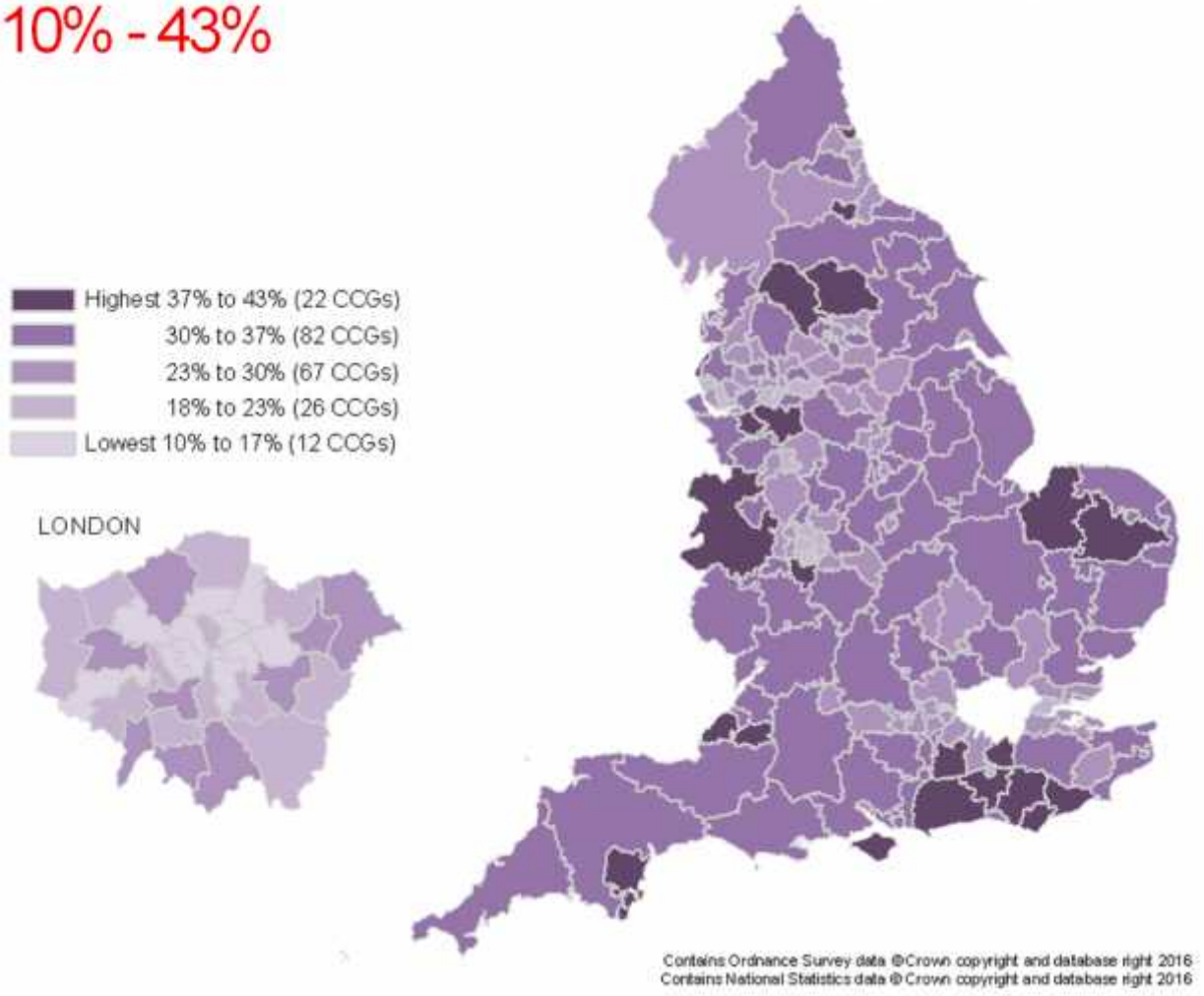
Percentage of deaths in usual place of residence by CCG

(28.5%- 57%)

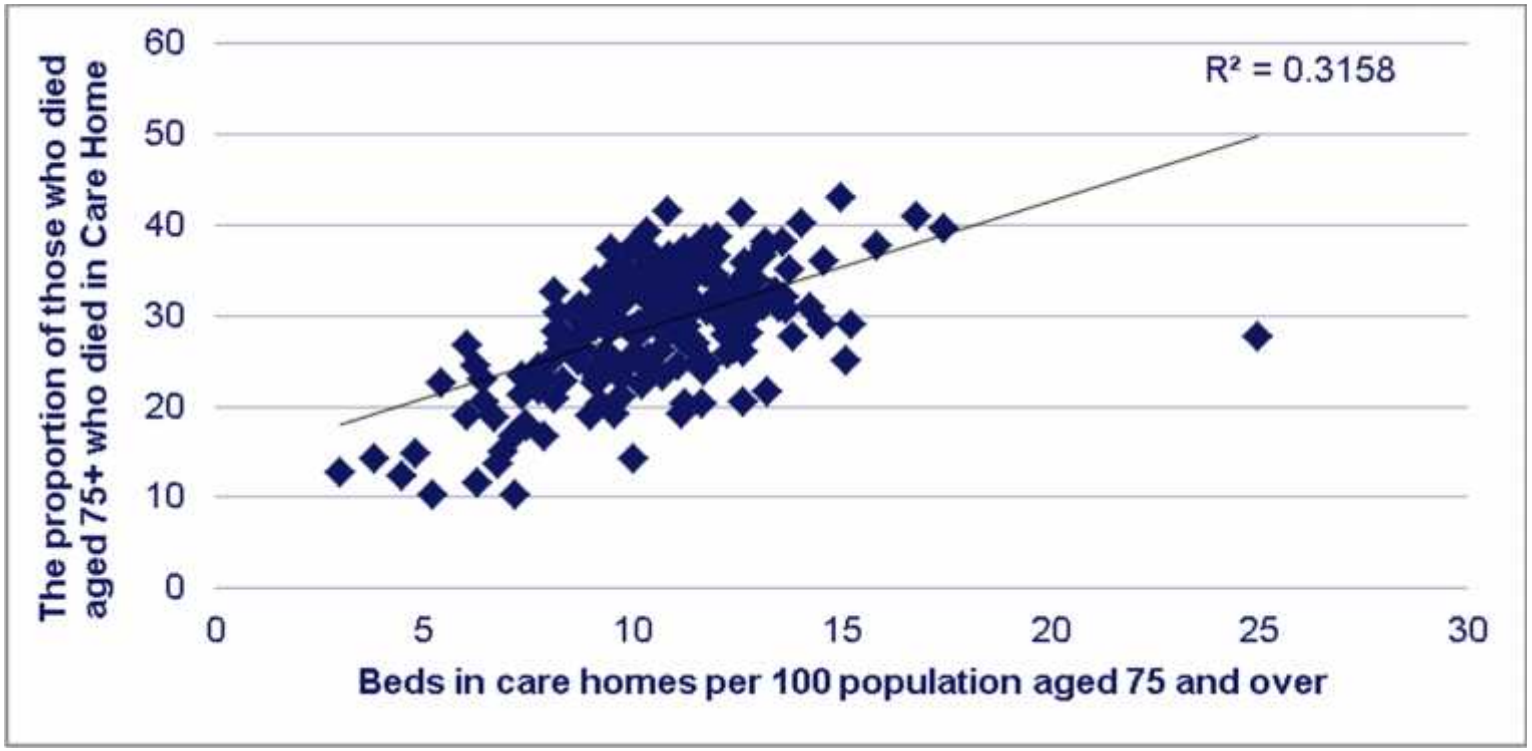


Variation by CCG in proportion of all people who died **aged 75 years and older** in a care home (2015)

Range 10% - 43%



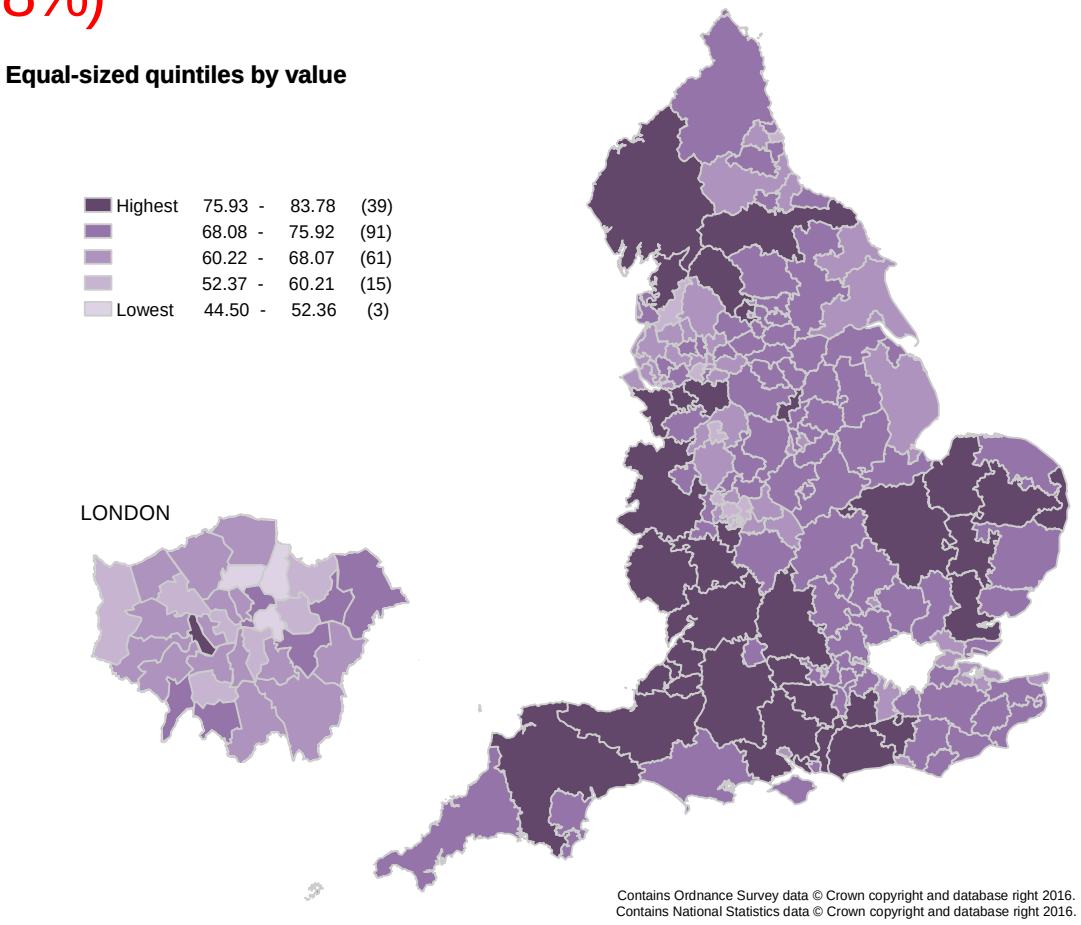
More deaths in care homes in CCGs where there are more beds in care homes



Sources: Population; ONS Mid-Year Population estimates for CCGs; Deaths, ONS Mortality data; Care home beds; Care Quality Commission

Variation in the proportion of care home residents that died in a care home by CCG (2015)

(44.5% - 83.8%)



Public Health England

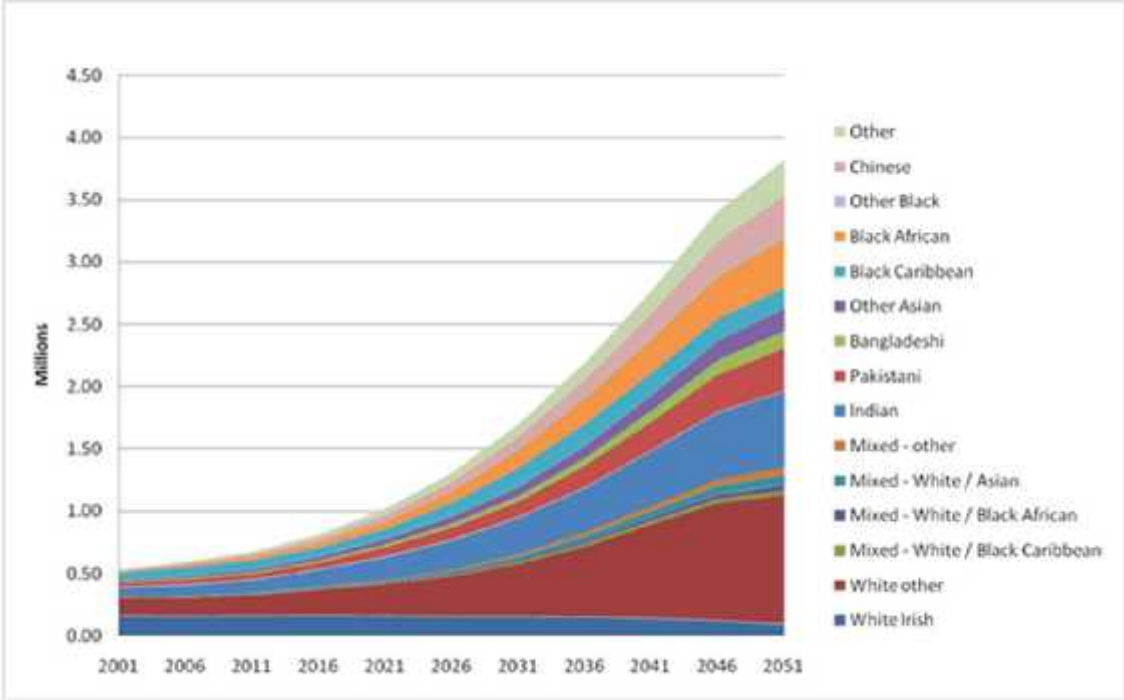
Protecting and improving the nation's health

Article 9 (Human Rights Act UK)

The right to freedom of thought, conscience and religion

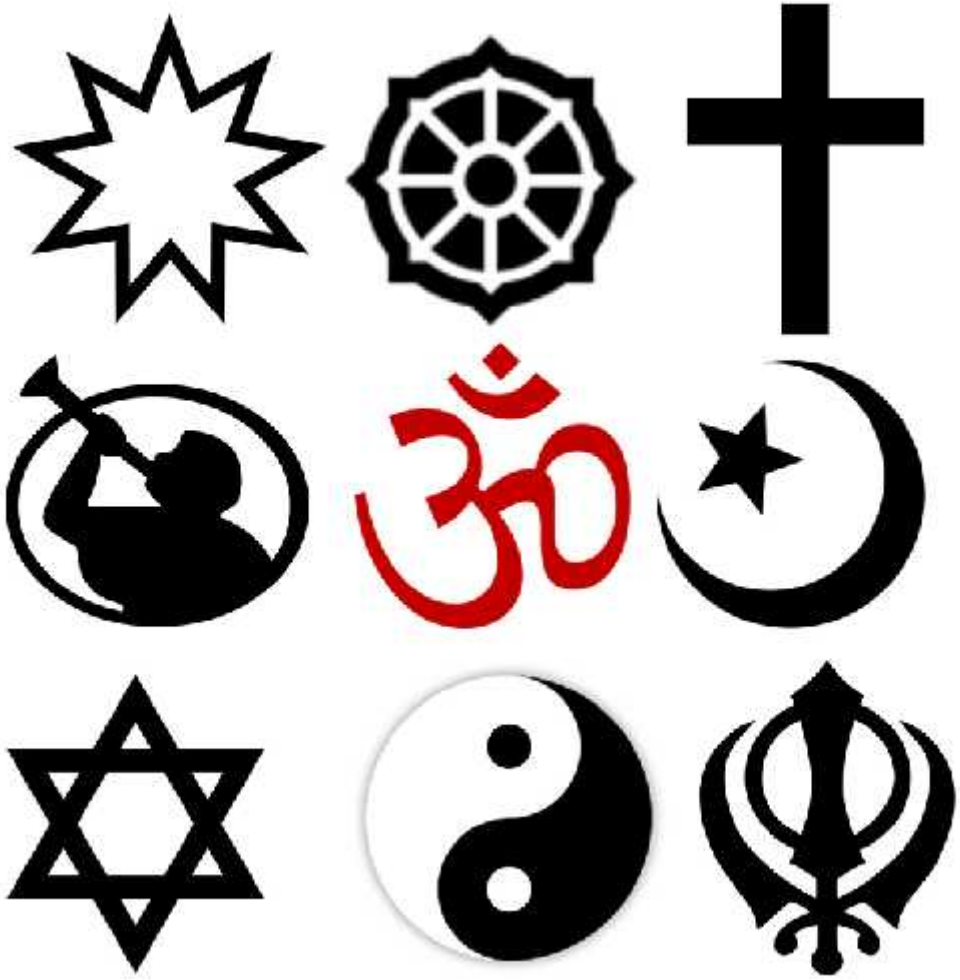
A qualified right

The numbers of older (≥65) people from BAME groups will increase

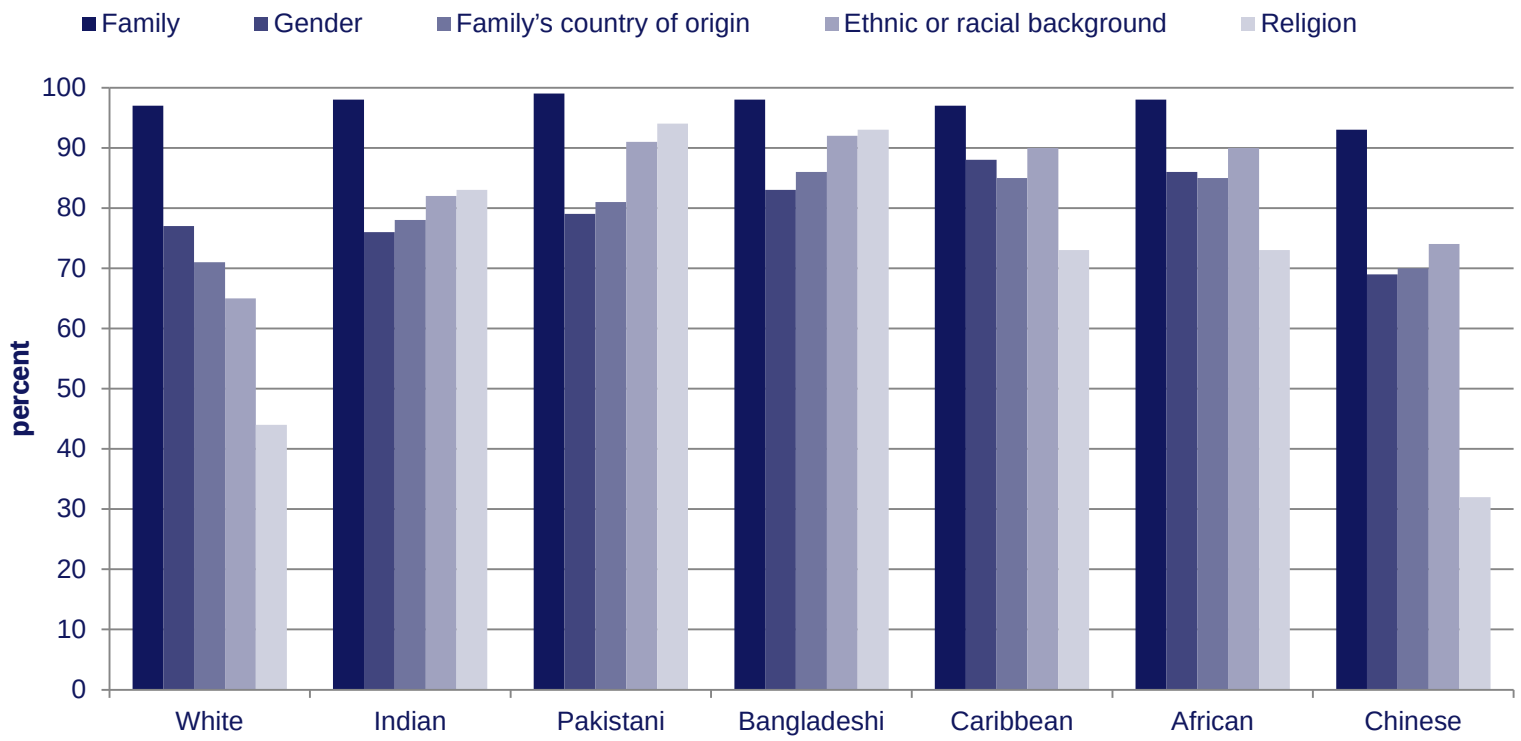


Source : Lievesley –The future ageing of the ethnic minority population of England and Wales, 2010

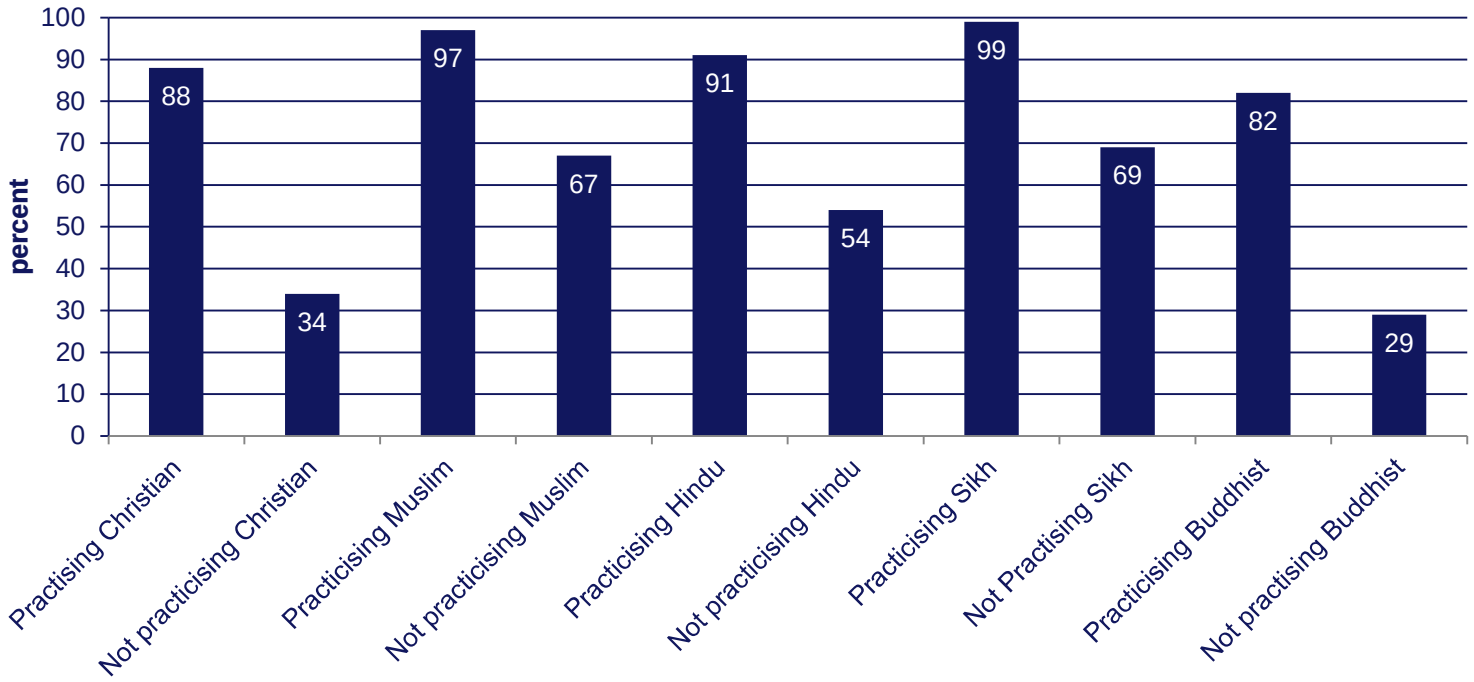
Religion or Spiritual comfort might also be important
N.B. Need for Rituals and Traditions



Factors important to identity, by ethnicity



The importance of religion to identity, by different religions



Source: 2007-08 Citizenship Survey, Communities and Local Government

Faith at end of life

A guide for professionals, providers and commissioners working in communities

Public Health England

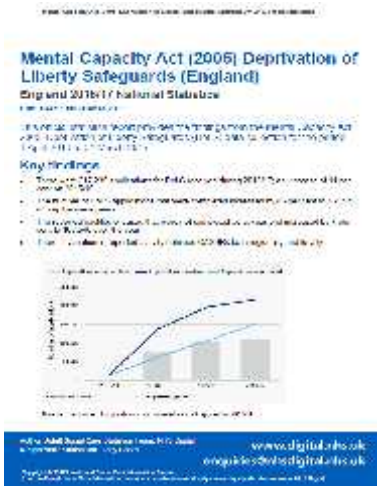
Protecting and improving the nation's health

Article 5 (Human Rights Act UK

The Right to Liberty (Limited)

Prisons, psychiatric hospitals, care homes, hospital, hospices

“A gilded cage is still a cage” – Lady Hale



Deprivation of Liberty Safeguards (DoLS) and potential impact for P&EOLC

Applications: 217,235 (2016/7) vs 195,840 (2015/6)

Completed applications 151,970 (2016/17) 105,055 (2015/6) 13,040 (2013/4).

51% of applications cited dementia.

40% of authorisations took >3 months.

3 in 4 applications granted.

1 in 3 application not granted because patient had already died (8,495).

29% of reviews also found the patient had died while on a DoLS

7.1% (7,073 people) of people ≥85 years had an application made for them

The European Convention on **Human Rights** states that no person shall be denied the right to **education** (Article 2 of Protocol 1). The primary objective of this provision is to guarantee the right of access to existing **educational** facilities.

Public Health England

Protecting and improving the nation's health

The Right to Education

The European Convention on **Human Rights** states that no person shall be denied the right to **education** (Article 2 of Protocol 1). The primary objective of this provision is to guarantee the right of access to existing **educational** facilities.

Education for whom?

Professionals (doctors, nurses, paramedics, psychologists, physiotherapists, occupational therapists, social workers)

Policy makers

Top Managers (Hospitals, Local Authorities, Employers)

The general population

Current state of anomie (Tony Walter)
(Re) educate about dying, death and options

Public, patients, families volunteers

Each community is prepared to help

I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways.

National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk

06

Each community is prepared to help

The building blocks for achieving our ambition

Compassionate and resilient communities

Public health approaches to palliative and end of life care need to be accelerated and support given to people and communities who can provide practical help and compassion.

Public awareness

Those who share our ambition should work to improve public awareness of the difficulties people face and create a better understanding of the help that is available.

Practical support

Local health, care and voluntary organisations should find new ways to give the practical support, information and training that enables families, neighbours and community organisations to help.

Volunteers

To achieve our ambition more should be done locally and nationally to recruit, train, value and connect volunteers into a more integrated effort to help support people, their families and communities.

National Palliative and End of Life Care Partnership
www.endoflifecareambitions.org.uk

Beyond health services and professionals…

Change the way we think about palliative & end of life care

Create a movement for social change

Patienthood → Citizenship

Health services → Social capital

Family → Community

Professional holism → PH holism

Education

Specific examples

- School and workplace plans
- Compassionate City Charter
- Compassionate Watch
- Poster campaigns
- Death cafes
- Art exhibitions
- Public forum on death and loss
- Annual short story competition
- Remembrance day

In Summary

- A human rights framework is useful to judge the progress of implementation of comprehensive palliative and end of life care.
- Human rights legislation can be a useful adjunct to the arguments made for implementing palliative and end of life care to relive suffering and respect the dignity of human beings
- A human rights approach perhaps encourages a more sociological model of P&EOLC

New website: www.gov.uk/government/collections/palliative-and-end-of-life-care