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Ethical challenges in end of life care in a pluralist society

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Acknowledgements

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Is our approach to improving end of life care appropriate for a pluralist society?

- Medical model +++++ medicalisation of social and spiritual/existential
- Individualistic approach to end of life planning
- QIPP KPI Indicator on place of death
- Find your 1% Campaign
- End of Life Care Pathways
- Deep sedation

Autonomy at end of life

- A widely accepted philosophical and bioethical principle enshrined in constitutions and law that individuals should be able to be ‘authors of their own lives’.
- Autonomy is linked with identity.
- Autonomy is a culturally fluid concept.
- People only die once and many would like to die ‘in character with how they have lived’. Its like the final chapter of a life.
- End of life care is not just about medicine
- Beauchamp and Childress propose 4 principles of bioethics: autonomy, non-maleficence, beneficence, and justice.
- Some propose autonomy is ‘primus inter pares’
- US autonomy a basic right, UK consent, European models vary

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Ethical concepts?

- Autonomy
- Paternalism
- Utilitarian approach

Paternalism – beneficent or disregarding

- Medical
- Family
- System (healthcare providers, state/government)

Why worry about pluralism?

Demography

>0.5 million over 65s from ethnic groups in 2011 will rise to over 3.8million by 2051

Very little research on autonomy in this subject

- The majority of published work in ethics focuses on treatment withdrawal, assisted suicide and physician assisted euthanasia in young adults in intensive care or with cancer or neurological diseases

- Very little work on the more complex, far more common dilemmas in a pluralist society

What do 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*

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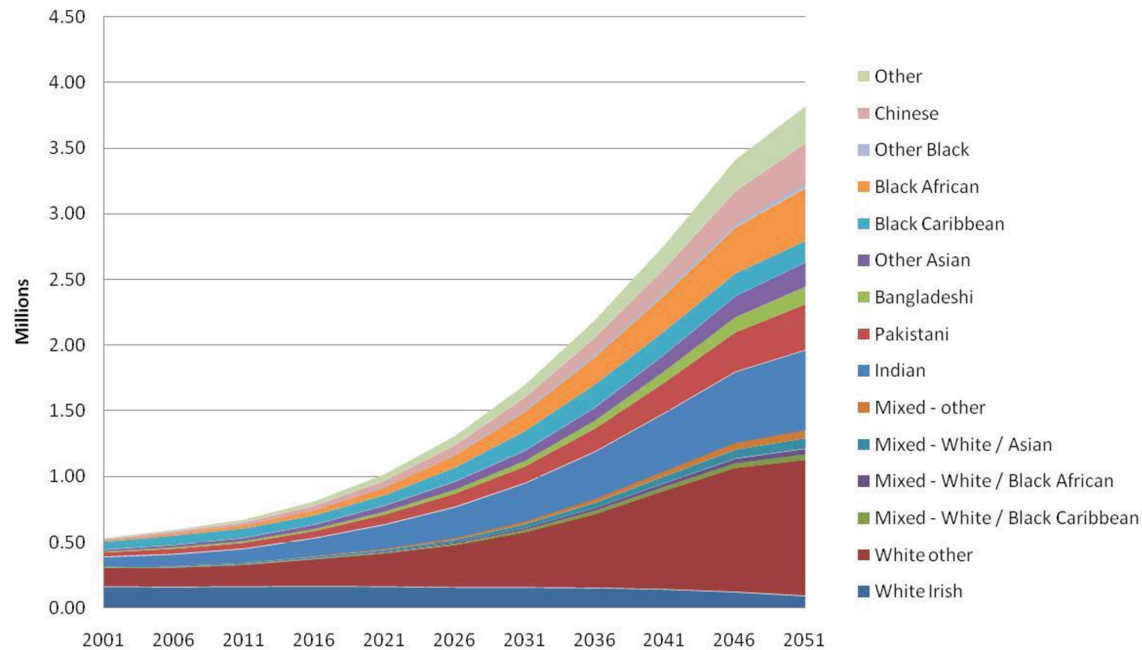
The ethnic minority population of England and Wales aged 65 and over



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

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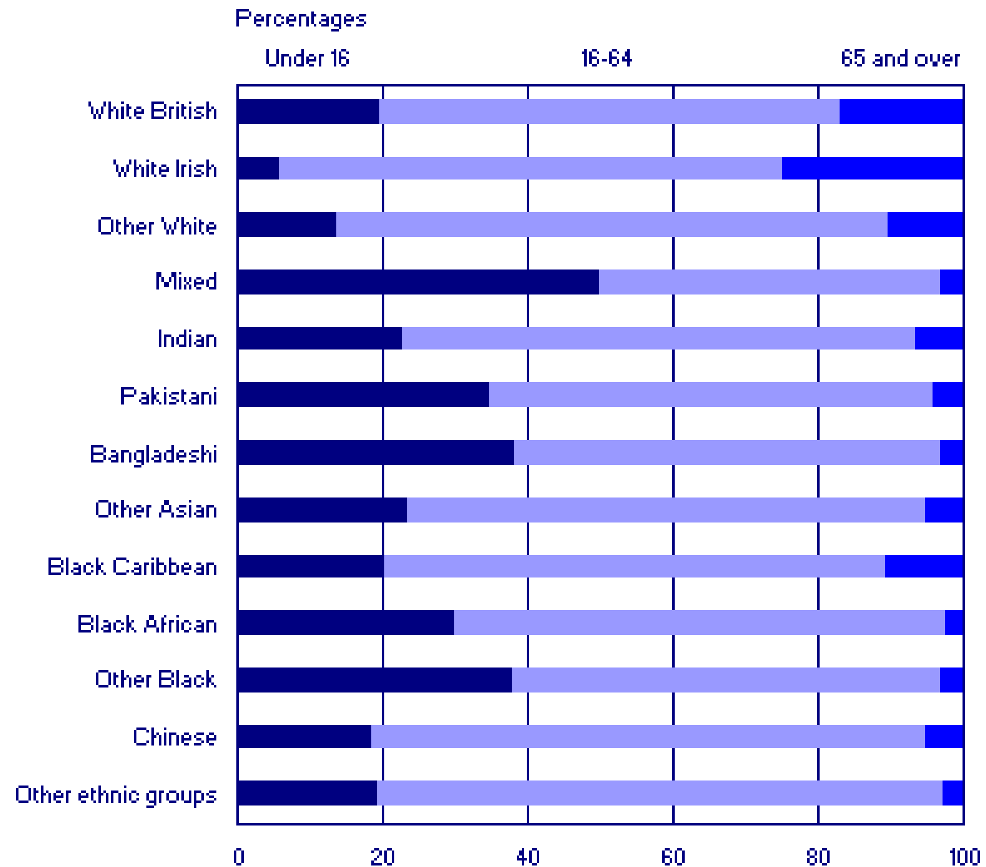
Age distribution: by ethnic group, April 2001



Source: Census 2001, Office for National Statistics

Our identity influences our approach to dying

- Meaning of illness, life and death
- Attitudes to suffering
- Attitudes to responsibility
- Attitudes to truth telling
- Attitudes to locus of decision making
- Attitudes to wakefulness

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Factors important to identity, by country of birth

Born in the UK | Not born in the UK | All

percent

100
90
80
70
60
50
40
30
20
10
0

Family
Interests
National identity
Level of education
Gender
Level of income
Family's country of origin
Age and life stage
Occupation
Where you live
Ethnic or racial background
Social class
Religion

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

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Factors important to identity, by ethnicity

Family | Gender | Family's country of origin | Ethnic or racial background | Religion

percent

100 90 80 70 60 50 40 30 20 10 0

White | Indian | Pakistani | Bangladeshi | Caribbean | African | Chinese

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

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Factors important to identity, by religious affiliation

Religion | Family's country of origin | Ethnic or racial background

100
90
80
70
60
50
40
30
20
10
0

Christian | Muslim | Hindu | Sikh | Buddhist | Other religion | No religion

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

Challenges the paradigm that religiosity is the ‘exception’ to be set against the non-religious ‘norm’.

Religion is claimed by two-thirds of the population.

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The importance of religion to identity, by different religions

	percent
Practising Christian	88
Not practicising Christian	34
Practicising Muslim	97
Not practicising Muslim	67
Practicising Hindu	91
Not practicising Hindu	54
Practicising Sikh	99
Not Practising Sikh	69
Practicising Buddhist	82
Not practising Buddhist	29

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

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Change in religious affiliation, 2001-2011

percent	2001	2011
No religion	14.8	25.1
Christian	71.7	59.3
Muslim	3	4.8
Other	2.8	3.6
Not stated	7.7	7.2

Source: Census 2011, Office for National Statistics

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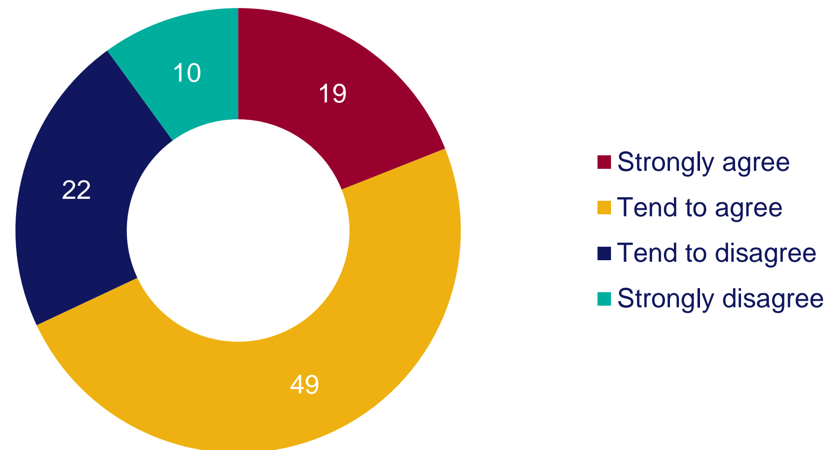
Minority religious groups, 2011 England and Wales

percent

Religion	Percent
Muslim	4.8
Hindu	1.5
Sikh	0.8
Jewish	0.5
Buddhist	0.4
Other religion	0.4

Source: Census 2011, Office for National Statistics

Whether people feel that it is possible to belong to Britain and maintain a separate cultural or religious identity



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

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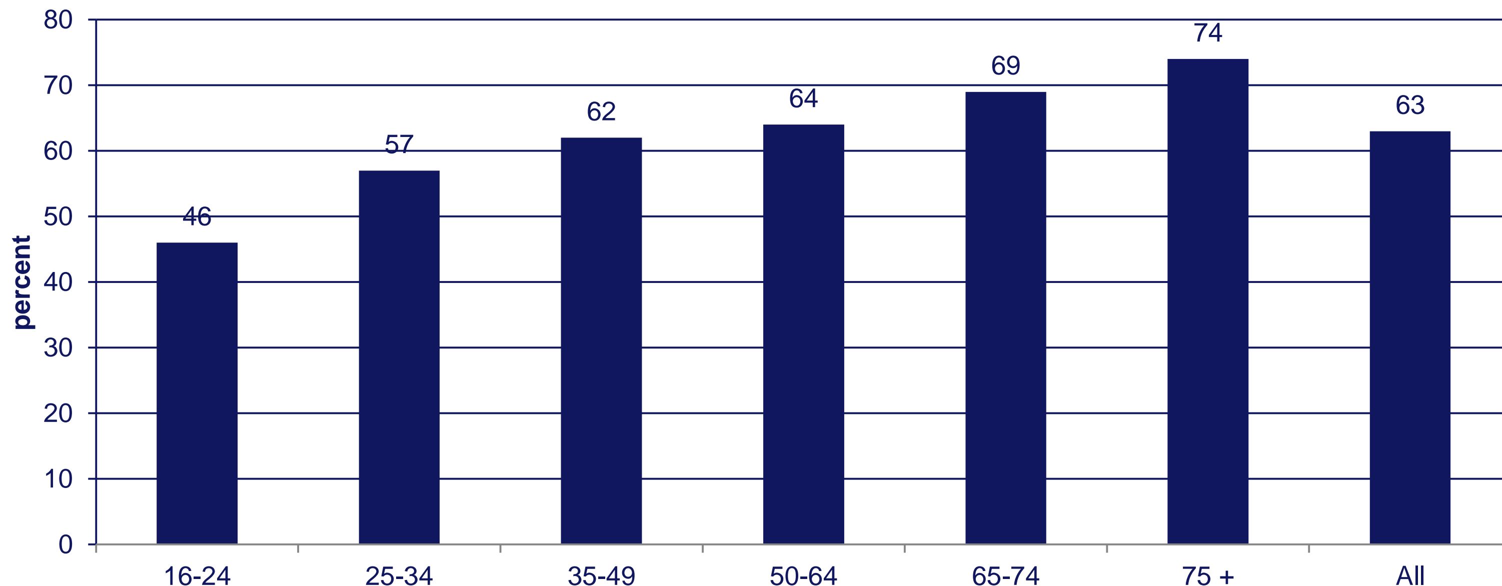
Proportion of people who never feel a conflict between their religious and national identities, by age



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

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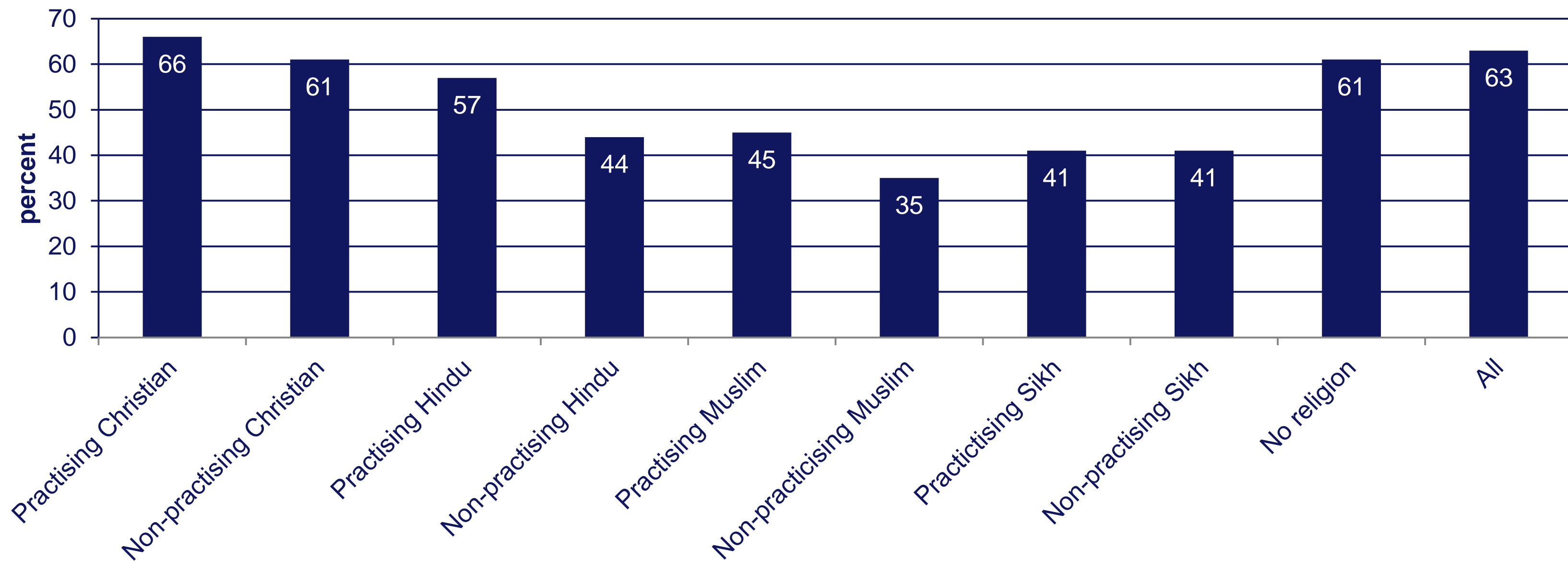
Proportion of people who never feel a conflict between their religious and national identities, by religion



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

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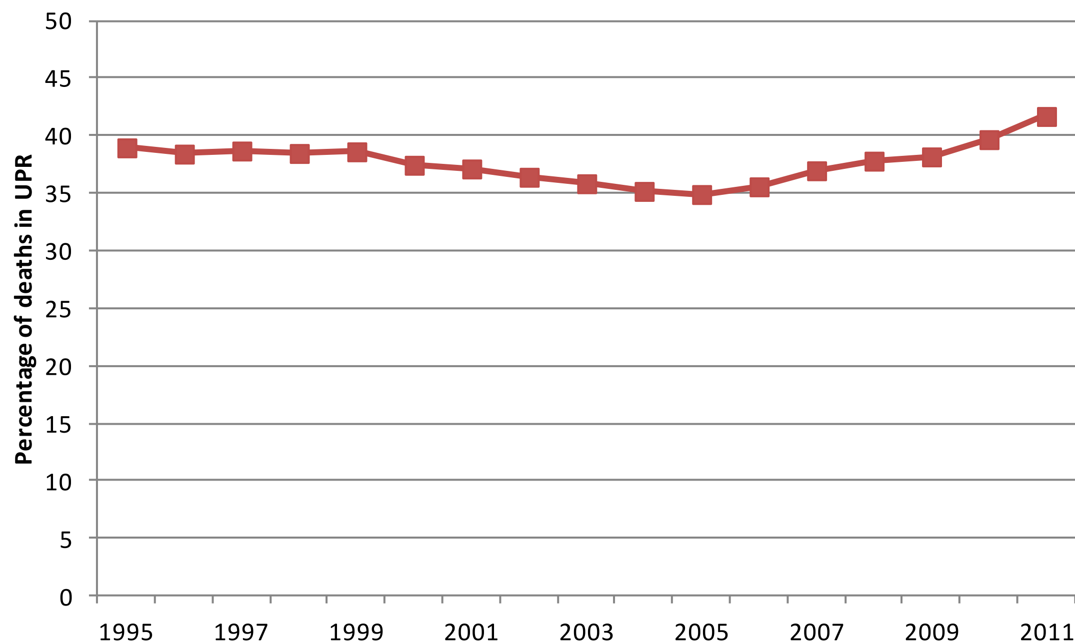
Deaths in usual place of residence



Source: National End of Life Care Intelligence Network (from Office for National Statistics mortality data)

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NB: The following analyses have not been corrected for age, cause of death or socioeconomic group

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Place of death by ethnicity and age – inequality or difference?

	UNDER 65						65 or older					
	Hospital	Home	Care home (nursing or residential)	Hospice	Other	Total	Hospital	Home	Care home	Hospice	Other	Total
British (White)	56.3	25.3	2.5	12.9	3.0	100.0	62.4	14.3	17.2	5.2	1.0	100.0
Irish (White)	56.1	25.6	2.2	12.9	3.3	100.0	62.1	17.1	12.2	7.2	1.3	100.0
Any other White background	60.0	21.7	2.1	12.9	3.4	100.0	63.7	14.3	15.4	5.3	1.3	100.0
White and Black Caribbean (Mixed)	66.2	19.2	1.4	9.6	3.6	100.0	63.3	17.5	10.9	7.4	1.0	100.0
White and Black African (Mixed)	69.6	15.7	1.3	11.0	2.3	100.0	67.3	14.6	7.5	9.7	0.9	100.0
White and Asian (Mixed)	75.9	12.8	0.9	7.9	2.5	100.0	64.8	14.1	14.5	5.3	1.4	100.0
Any other Mixed background	68.5	16.2	1.3	10.3	3.7	100.0	66.3	13.1	13.0	6.4	1.1	100.0
Indian (Asian or Asian British)	75.1	16.3	1.0	5.7	1.9	100.0	76.8	14.9	4.6	2.6	1.0	100.0
Pakistani (Asian or Asian British)	80.8	12.8	0.4	4.2	1.8	100.0	76.4	18.6	1.5	2.0	1.5	100.0
Bangladeshi (Asian or Asian British)	78.8	14.1	0.3	5.0	1.8	100.0	78.2	16.0	1.9	3.1	0.8	100.0
Any other Asian background	74.3	13.1	1.9	8.3	2.4	100.0	74.9	14.8	5.2	4.2	0.9	100.0
Caribbean (Black or Black British)	65.7	17.9	1.6	12.0	2.7	100.0	65.6	16.5	10.2	6.9	0.8	100.0
African (Black or Black British)	76.6	10.9	1.6	8.9	2.1	100.0	67.5	14.0	10.5	7.1	1.0	100.0
Any other Black background	70.4	14.5	2.1	10.0	3.0	100.0	67.0	16.1	10.0	5.7	1.2	100.0
Chinese (other ethnic group)	63.5	16.8	1.7	16.8	1.2	100.0	69.1	12.2	10.4	7.4	0.9	100.0
Any other ethnic group	68.8	16.9	1.8	9.9	2.7	100.0	67.1	14.1	12.9	5.1	0.9	100.0

Source: Linked Hospital Episode Statistics - Office for National Statistics mortality dataset
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Death in usual place of residence: British White 32%, Pakistani 21%, Bangladeshi 18%, Caribbean 27%. **Home death rates**: British white 14%, Pakistani 19%, Bangladeshi 16%, Caribbean 17%

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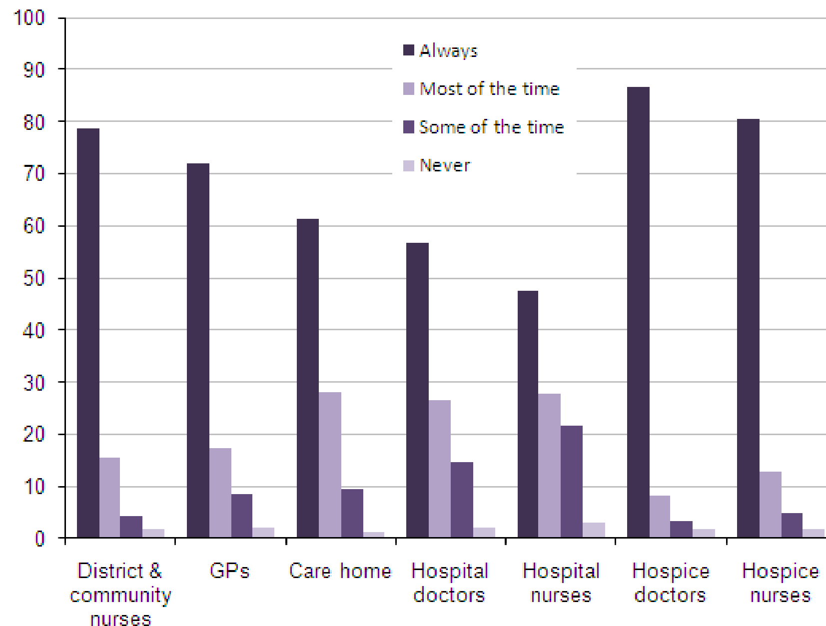
How often the patient was treated with dignity and respect in the last three months: by setting or service provider



Source: Office for National Statistics National Bereavement Services (Voices) 2011

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Differences found for cancer deaths

	Hospital	Home	Care Home	Hospice
White British	44%	26%	11%	18%
Pakistani	57%	30%	1%	11%
African	57%	16%	6%	20%
Chinese	52%	19%	6%	22%

Source : Linked Hospital Episode Statistics – Office for National Statistics mortality dataset
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Differences by gender

	Hospital (F)	Hospital (M)	Home (F)	Home (M)
White British	61%	62%	14%	19%
Pakistani	77%	80%	17%	16%
African	73%	72%	11%	14%
Chinese	65%	70%	14%	13%

Source : Linked Hospital Episode Statistics – Office for National Statistics mortality dataset
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Proportion of people living in social housing in UK, by country of birth, 2005/6

Rank	Country of birth	% in social housing
1=	Australia	5
1=	France	5
1=	USA	5
4=	Poland	8
4=	India	8
4=	South Africa	8
4=	Canada	8
8	China	9
9	Italy	10
10	Kenya	12
11	Sri Lanka	14
12=	Pakistan	15
12=	Philippines	15
14	Cyprus	16
15	UK	17
16	Zimbabwe	20
17	Republic of Ireland	21
17=	Uganda	21
19	Nigeria	29
20	Iran	33
21	Jamaica	35
22	Ghana	39
23	Portugal	40
24	Bangladesh	41
25	Turkey	49
26	Somalia	80

Source: Institute for Public Policy research (IPPR) calculations (IPPR, 2007)

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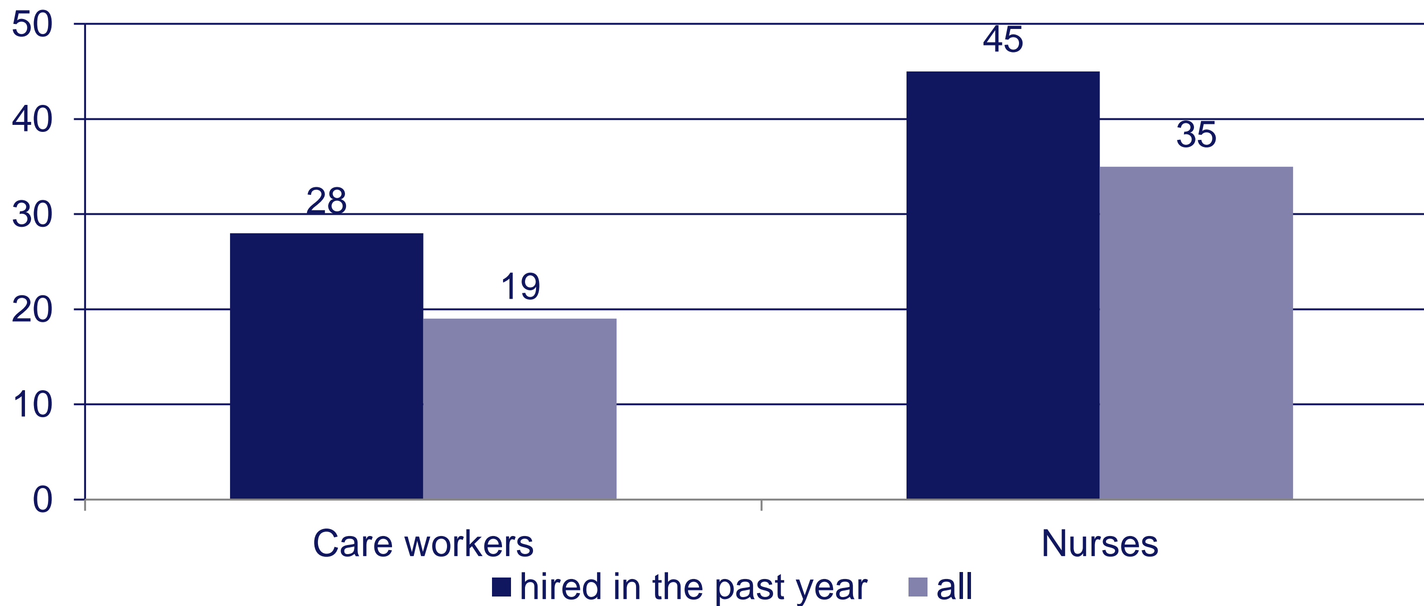
Percentage of ethnic minority care workers and nurses working in care for older people (2008)



Source: Centre on Migration, Policy and Society (COMPAS) (2008). Survey of 557 residential and home care organisations employing 13, 846 care workers and 1,867 nurses.

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Paternalism, specialty, ethnicity and religion – doctors' use of deep sedation and other ethically controversial decisions

- Specialists in care of the elderly more likely to be Hindu or Muslim
- GPs more likely to report a strong religious faith
- Palliative care physicians more likely to be Christian, religious and white
- Non-white doctors more likely to be religious
- Independent of specialty, non-religious (especially very or extremely) were more likely to have given continuous deep sedation until death or decisions that partly or intended to end life

Source: Seale C, The role of doctors' religious faith and ethnicity in taking ethnically controversial decisions during end-of-life-care , J Med Ethics 2010 36: 677-682

Recommendations

- Constant reflection on and questioning of our model of end of life care
- Urgent need for research on patient and carer views and outcomes
- Respect for individual’s identity
- Focus should be on supporting ‘autonomy’ in *culturally sensitive* way
- Religious dimension is under-recognised and ? Under catered for
- Religious/cultural dimensions poorly understood +++
- Support for patient’s own way of doing things – narrative approach
- Clinicians *must* reflect on how own identity may influence practice
- Risks++++ of many of the ‘well intentioned’ approaches
- Cultural sensitivity rather than cultural competence
- Paradigm shift in education – not checks lists but compassion, empathy,
- Some policies may not be culturally sensitive because we do not YET understand

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