

Topline Results
10-002265-01
5th August 2010

- This topline presents the results of a postal survey mailed out to addresses randomly selected from the Small User Postcode Address File (PAF)
- A sample of 2,500 addresses was selected in the East of England SHA area.
- A sample of 1,250 addresses was selected from the rest of England in order to provide a comparison to the East of England results.
- An initial mailing was sent on 26th March to 500 addresses in the East of England SHA area, before the purdah period associated with the May 6th General Election. The remaining 2,000 addresses in the East and 1,250 addresses across the rest of the country were mailed out on 18th May.
- Reminder letters were sent to those addresses from which no response had been received on 8th June and 29th June.
- Weighting has been applied to both sets of data so that it better reflects the known profile of the population. The East of England results are weighted by age, gender, working status and Primary Care Trust. The results from the rest of the country have been weighted separately on age, gender, working status and Government Office Region.
- Unless otherwise specified, all East of England data is based on 693 responses and all data for the rest of England is based on 332 responses.
- Where results do not sum to 100%, this may be due to multiple responses or computer rounding.
- For bases smaller than 30, the number of responses (n.) is given instead of the percentage (%). Where the base is smaller than 30 for only one of the two samples, we have presented both (East of England and Rest of England) as a numerical count in order to make comparison between the two easier.
- In the open ended questions at Q6, Q8 and Q10 the results have been broken down based on the answer given at the previous question. For example, the answers to question 6 are split between those who said the medical and nursing care received was very good/good and those who said it was very poor/poor. Some of the responses appear at odds with the answer to the previous question. However, this largely due to respondents giving multiple or detailed responses. For example, the care overall was very good but the GP was not very good.

SECTION A: GENERAL QUESTIONS

Q1. Which of the following best describes how you feel talking about death generally?

	East of England %	Rest of England %
I feel very comfortable talking about death	32	28
I feel fairly comfortable talking about death	41	39
I have no strong feelings either way	13	15
I feel fairly uncomfortable talking about death	9	13
I feel very uncomfortable talking about death	2	2
Not stated	3	3

Q2. Have you ever attended the funeral of a family member, a friend or work colleague?

	East of England %	Rest of England %
Yes	97	96
No	1	2
Not stated	2	3

Q3. Have you ever seen a dead person? Please do not count instances when you may have seen a dead body on television.

	East of England %	Rest of England %
Yes	71	74
No	27	23
Not stated	2	3

Q4. Has anyone you care for very much (such as a close family member or friend) died within the last 5 years?

	East of England %	Rest of England %
Yes	56	54
No	41	43
Not stated	3	3

Q5. How would you rate the medical and nursing care from the NHS they received in the last days before they died?

Base: All who had someone close die in last 5 years

	East of England (413) %	Rest of England (186) %
Very good	24	20
Good	23	40
Neither good nor poor	13	11
Poor	9	5
Very poor	7	3
Not applicable	23	19
Not stated	1	3

Q6. Why do you say that? [open ended]

Base: All who had someone close die in last 5 years and rate NHS care as good or very good

	East of England (214) %	Rest of England (110) %
The staff/nurses were very good/kind/caring helpful	43	47
Took care/time with relatives/explained things to relatives	11	9
Hospital care was very good/excellent	7	1
Died at home/nursing home/hospice	6	3
Treated with dignity/respect	6	8
Everything possible was done	4	5
District Nursing support excellent	4	1
Care was adequate nothing extraordinary	3	4
GP/Doctor was not very good	3	*
Personal experience/saw it first hand	2	1
Not much information/care given to family	2	1
Excellent McMillan Care	2	0
Staff too busy/inattentive /didn't care	2	1
Poor environmental/lack of facilities/space	2	0
Good pain relief/pain control	1	0
The person was in hospital	1	0
Died suddenly/unexpectedly	1	1
Word of mouth/only what I've heard from family members	1	*
Was not there/didn't see for myself/first hand	1	0
Medical care poor/not always cared for well	1	2
Dependent on nursing staff/some good some bad	1	0

	East of England (214) %	Rest of England (110) %
Wrong/inadequate diagnosis led to death	1	5
Not always clean environment/or personal cleaning	*	0
Hospice excellent	*	3
Lack of/overstretched/unavailable staff	*	0
Died overseas	*	*
Time delays/delay in being seen/left waiting in pain and distress	*	0
Constant changes/agency nurses	*	1
Marie Curie excellent	*	1
Contracted infection/C DIFFICILE/MRSA	0	2
Responded to/treated quickly	0	1
Private care/private hospital care/private sector care was better	0	*
Not applicable/no answer	1	5
Other	3	2
Not stated	24	25

Q6. Why do you say that? [open ended]

Base: All who had someone close die in last 5 years and rate NHS care as poor or very poor

	East of England (57) n.	Rest of England (18) n.
Staff too busy/inattentive/didn't care	24	3
Medical care poor/not always cared for well	14	1
Time delays/delay in being seen/left waiting in pain and distress	10	0
Wrong/inadequate diagnosis led to death	7	3
Not always clean environment/or personal cleaning	5	1
Lack of information about condition/possible outcome to patient/family	5	3
GP/Doctor was not very good	4	1
The staff/nurses were very good/kind/caring/helpful	4	1
Lack of/overstretched/unavailable staff	3	1
Poor environment/lack of facilities/space	2	0
Died at home/nursing home/hospice	2	0
Contracted infection/C Difficile/MRSA	2	2
Constant changes/agency nurses	1	0
Dependent on nursing staff/some good some bad	1	0
Not much information/care given to family	1	2
Lack of joined up care and treatment/communication between departments	1	0
Died overseas	1	0
Excellent MacMillan care	*	0
Poor behaviour of staff/untrained/unknowledgeable	0	2
Better when moved to hospice	0	1
Other	1	1
Not stated	4	2

Q7. And how would you rate the care and support they received from social services in the last days before they died?

Base: All who had someone close die in last 5 years

	East of England (413) %	Rest of England (186) %
Very good	9	8
Good	11	11
Neither good nor poor	13	14
Poor	5	2
Very poor	6	2
Not applicable	53	55
Not stated	3	7

Q8. Why do you say that? [open ended]

Base: All who had someone close die in last 5 years and rate social services care and support as good or very good

	East of England (89) %	Rest of England (40) %
Nurses/Macmillan nurses/staff were good/caring/helpful	21	19
Social services were good/there when needed	12	15
Limited contact/one visit/only came to assess need	10	3
Was in a care home/hospital/hospice not aware of any involvement from social services	6	0
Several aids/equipment was delivered to their home	5	1
Hearsay/other people told me they were good	3	1
Friends/family supported each other	2	0
Good communication/advice received	2	0
I was not there/not there at the time	1	0
They were just doing their job	1	0
Everything took a long time/delays in care/support	1	6
Care was scarce/only came for a limited time/family left to get on with most of the caring	1	0
Sudden death	0	4
Good/attentive GP	0	2
Other	6	4
Not stated	36	58

Q8. Why do you say that? [open ended]

Base: All who had someone close die in last 5 years and rate social services care and support as poor or very poor

	East of England (43) n.	Rest of England (10) n.
No support from/never say anyone from social services	16	1
Pressure from/stress involved in dealing with Social Services	7	
Difficult to obtain/inefficient	6	1
Minimal information/information not given in a timely manner	4	1
Tactless/uncaring	4	0
Care was scarce/only came for a limited time/family left to get on with most of the caring	3	0
Nurses/Macmillan nurses/staff were good/caring/helpful	2	0
Several aids/equipment was delivered to their home	2	0
Everything took a long time/delays in care/support	1	1
Good/attentive GP	1	0
Friends/family supported each other	*	0
Was being looked after/died at home	*	0
Tactless/uncaring	0	*
Limited contact/one visit/only came to assess need	0	*
Other	1	1
Not stated	7	3

Q9. Do you agree or disagree that you and your family received enough support from NHS and social services during and after this difficult time?

Base: All who had someone close die in last 5 years

	East of England (413) %	Rest of England (186) %
Strongly agree	10	13
Tend to agree	21	24
Neither agree nor disagree	23	20
Tend to disagree	6	7
Strongly disagree	8	4
Not applicable	30	26
Not stated	3	6

Q10. Why do you say that? [open ended]

Base: All who had someone close die in last 5 years and agree received enough support from the NHS and social services

	East of England (133) %	Rest of England (67) %
Good support/caring attitude from staff	26	12
It was offered/we were offered support/offered to close family	5	2
No support/no extra support required	5	1
Died at home/nursing home	3	0
Good aftercare/support of family members/following death	3	0
Everything that could be done was done	3	1
Was not there/wasn't involved	2	1
Family/friends supported each other	2	2
Personal experience/what I've witnessed/seen for myself	2	0
Lack of staff/doctors and nurses too busy/not always available	2	0
Support from GP/family doctor	2	1
Lack of care/empathy/understanding from staff	1	0
Word of mouth/hearsay/what I understand from other people	1	1
NHS support was good but not social services	1	2
Case with Ombudsman/complaint made/have taken legal action/representation	1	0
No care support for family members/carers/no recognition of carers	1	0
Care from NHS/Social Services was adequate/did what was necessary/nothing special	1	8
No support from social services	1	0
More information would have been good/information should have been forthcoming	1	1
Follow up support lacking/slow to materialise	*	0
Had to arrange/pay for/sell property to get the help required	*	0
Kept well informed at all times/communication was good	*	9
It was a friend who died so not offered these services	*	0
Died Suddenly	0	2
Hospice was good/helpful/supportive	0	2
More support prior to death/not enough support after death	0	1
Other	5	2
Don't know	1	0
Not stated	44	59

Q10. Why do you say that? [open ended]

Base: All who had someone close die in last 5 years and disagree received enough support from the NHS and social services

	East of England (64) n.	Rest of England (23) n.
Did not receive any support from NHS or Social Services	19	8
More information would have been good/information should have been forthcoming	5	2
Follow up support lacking/slow to materialise	4	1
Lack of staff/doctors and nurses too busy/not always available	3	*
Good support/caring attitude from staff	3	0
NHS support was good but not social services	3	0
Case with Ombudsman/complaint made/have taken legal action/representation	3	*
No nursing/respite care offered or provided	3	1
Lack of care/empathy/understanding from staff	1	0
No care support for family members/carers/no recognition of carers	1	1
Had to arrange/pay for/sell property to get the help required	1	0
Little contact/no dealings with them/wasn't relevant	1	0
No support from social services	1	1
More support prior to death/not enough support after death	1	0
Was not there/wasn't involved	1	0
No counselling/bereavement counselling was offered	1	1
No support/no extra support required	1	1
Caught an infection/MRSA/C Difficile/Food poisoning etc	*	2
Kept well informed at all times/communication was good	*	0
Hospice was good/helpful/supportive	*	*
Personal experience/what I've witnessed/seen for myself	*	0
Support from GP/family doctor	0	1
Care/bereavement counselling took too long/had to go on waiting list	0	1
Other	3	1
Not stated	11	3

Q11. **Would you agree or disagree that it is appropriate for children aged under 12 (primary school age) to attend funerals?**

	East of England	Rest of England
	%	%
Strongly agree	18	16
Tend to agree	30	33
Neither agree nor disagree	28	26
Tend to disagree	17	15
Strongly disagree	5	7
Not stated	2	3

SECTION B: CARE AND SUPPORT NEEDS

Q12. Which of the following best describes how you feel talking about your own death?

	East of England %	Rest of England %
I feel very comfortable talking about my own death	31	24
I feel fairly comfortable talking about my own death	38	33
I have no strong feelings either way	15	22
I feel fairly uncomfortable talking about my own death	11	13
I feel very uncomfortable talking about my own death	4	5
Not stated	2	3

Q13. Have you ever discussed what your wishes would be in relation to each of the following, if you did not have much time left to live?

	Yes, I have discussed this with someone %	No, I have not discussed this with anyone %	Not stated %
Medical and nursing care			
East of England	26	69	6
Rest of England	19	75	6
Any spiritual and religious preferences			
East of England	38	55	7
Rest of England	28	66	6
Privacy and peace			
East of England	26	67	7
Rest of England	20	73	6
Dying with dignity – e.g. respectful care and			
East of England	37	58	6
Rest of England	29	64	7
Where you would prefer to die			
East of England	29	65	6
Rest of England	21	72	7

Q14. Which of these statements best describes why you have not discussed any of these issues with anyone?

Base: All who have not discussed any End of Life matters (280)

	East of England (280)	Rest of England (155)
	%	%
Death feels a long way off	46	46
I'm concerned that it may upset people close to me	21	24
I am too young to discuss death	17	23
I don't feel comfortable talking about death	15	17
Other people do not want to talk to me about my death	12	17
There is no one available for me to talk about death	5	5
Not really thought about it / given it much thought	2	2
Will discuss when I think the time is right / is necessary / know it has to happen	2	
Hasn't come up in conversation / don't feel the need to discuss it	2	1
It's inevitable / everyone's going to die / when you're gone you're gone	1	0
Family/loved ones know what I want/know my wishes	1	*
It's depressing / more interesting / lots of other things to do	1	1
No close family / anyone close to me to discuss it with	1	0
Only spoken about it in general terms / not associated to my own death	1	2
Don't want to think about it / think about it yet	1	1
Am single parent / my children are too young for this discussion	*	1
Other	1	1
Not stated	4	2

Q15. Have you made arrangements for any of the following?

	East of England %	Rest of England %
A will	43	34
An organ donor card (registered as an organ donor)	34	29
My funeral wishes/plan	27	18
Written wishes about organ donation	18	14
My plan for how I would support myself financially when I am dying	10	8
My wishes and preferences about my end of life care if I become unable to decide for myself (sometimes called a 'living will' or 'advance care plan')	8	7
None of these	27	36
Not stated	5	9
MADE ANY ARRANGEMENT	68	55

Q16. If you knew you did not have long to live, which of these would be most likely to make you start planning for your death?

	East of England %	Rest of England %
To make my death/dying easier for my family	79	77
To ensure I had the right care and support when I am dying	44	48
To have the funeral I wanted	24	27
Other	6	6
None of these	2	3
Not stated	4	5

Q17. To what extent do you agree or disagree that each of the following would help you start planning if you did not have much time left to live?

	Strongly agree %	Tend to agree %	Neither agree nor disagree %	Tend to disagree %	Strongly disagree %	Not stated %
Easy access to information about how to plan for my death						
East of England	39	37	14	1	1	8
Rest of England	46	34	12	1	1	7
Support from someone to help me write an end of life care plan (sometimes called a 'living will' or 'advance care plan')						
East of England	34	33	18	3	2	10
Rest of England	35	39	16	2	1	8

Q18. Do you think there is anything else that would help you start planning if you did not have much time left to live? [open ended]

	East of England %	Rest of England %
Advice on financial matters	2	1
Friends/family	2	2
Advice/help/support for family members/ bereavement counselling	2	*
Help/advice on what would happen to my children/guardians for my children	1	1
Enjoy what time was left/wouldn't want to waste time planning/what will be will be	1	*
My will/advice on making a will	1	1
Euthanasia/assisted suicide to be legal	1	*
Religious/spiritual needs	1	1
Concerns for my family/ how to help my family/ loved ones cope	1	*
Internet access/ information/guidance	1	*
A qualified advisor/ personal contact/named individual to help	1	1
Knowing what needed to be sorted/what is available/some sort of check list	1	1
Information on options/what is available	*	1
Definitive time/knowning how long I have left	*	*
Already planned/have plans in place	*	0
Funeral/burial issues	*	1
Other	3	1
Don't know/not thought about it	1	1
No/nothing	7	8
No answer/blank response	77	81

Q19. Who would you like to give you information about planning for your end of life care?

	East of England %	Rest of England %
Friend/family	54	47
Doctor/GP	47	51
Solicitor	20	17
Nurse	17	22
The internet	11	10
Religious or spiritual advisor, such as vicar, priest, imam or rabbi	10	13
Funeral Director	9	11
Independent financial advisor/ bank manager	3	4
Other	4	4
Not stated	6	6

SECTION C: END OF LIFE PREFERENCES

Q20. Thinking about yourself, where do you think would be the best place to die?

	East of England %	Rest of England %
At home	55	54
It depends	17	11
In a hospice	11	10
In a hospital	3	11
In a care home (either residential or nursing)	2	2
Somewhere else	4	3
Don't mind	6	6
Not stated	3	3

Q21. Would you still prefer to die in your own home even if medical or social care was not immediately available if you needed it?

Base: All who would prefer to die at home

	East of England (371) %	Rest of England (176) %
Yes	68	53
No	29	46
Not stated	2	1

Q22. Would you still prefer to die in your own home even if you did not have any support from family or friends?

Base: All who would prefer to die at home

	East of England (371) %	Rest of England (176) %
Yes	32	30
No	64	68
Not stated	4	2

Q23. Thinking about yourself, when the time comes, which of these two options would be more important to you?

	East of England %	Rest of England %
To get the care and support I want	59	69
To die in the place of my choice	37	26
Not stated	5	5

Q24. If you were terminally ill, would you like to be told, or would you prefer not to know?

	East of England %	Rest of England %
Would want to be told	87	85
Would prefer not to know	8	10
Not stated	4	5

Q25. When the time comes for your death, which of the following, if any, do you think would be important for your end of life care?

	East of England %	Rest of England %
To be with family or friends	79	72
To be pain free/without pain	77	73
To keep my dignity	71	65
To be peaceful/calm	71	61
To be sure that I am not a burden on other people	62	59
For people to listen and respect my wishes	61	57
Not stated	2	4

Q26. And which one would be most important?

	East of England %	Rest of England %
To be with family or friends	31	27
To be pain free/without pain	27	26
To keep my dignity	10	14
To be sure that I am not a burden on other people	10	9
To be peaceful/calm	9	11
For people to listen and respect my wishes	9	8
Not stated	3	6

SECTION D: PLANNING FOR DEATH

Q27. Firstly, how confident do you feel that you could plan to get the right sort of care and support if you did not have long to live?

	East of England %	Rest of England %
Very confident	13	11
Fairly confident	49	50
Not very confident	30	29
Not at all confident	5	6
Not stated	3	4

Q28. How confident do you feel that you could plan for your financial support if you did not have long to live?

	East of England %	Rest of England %
Very confident	16	19
Fairly confident	50	49
Not very confident	23	21
Not at all confident	7	7
Not stated	3	5

Q29. How confident do you feel that you could plan your funeral arrangements?

	East of England %	Rest of England %
Very confident	32	22
Fairly confident	49	52
Not very confident	13	17
Not at all confident	3	5
Not stated	3	4

SECTION E: ABOUT YOURSELF

Q30. Is there anyone who you look after or give special help to, for example, someone who is sick, has a long-term physical or mental disability or is elderly?

	East of England %	Rest of England %
Yes	20	19
Yes, but only in a professional capacity as part of my job	3	6
No	72	69
Not stated	5	6

THE FOLLOWING FIGURES ARE ALL UNWEIGHTED

Q31. Are you male or female?

	East of England %	Rest of England %
Male	32	33
Female	65	63
Not stated	3	4

Q32. What was your age on your last birthday?

	East of England %	Rest of England %
16-24	2	3
25-34	8	8
35-44	17	18
45-54	17	17
55-64	22	23
65+	31	27
Not stated	3	4

Q33. In which of these ways does your household occupy your current accommodation?

	East of England %	Rest of England %
Owned outright	44	40
Buying on mortgage	29	32
Rent from council	9	8
Rent from Housing Association/ Trust	5	4
Rent from private landlord	7	8
Other	3	3
Not stated	4	5

Q34. How many adults aged 18 or over are living here?

	East of England %	Rest of England %
One	31	32
Two	50	49
Three	10	7
Four	3	4
Five	0	1
Five and more	0	0
Not stated	6	8

Q35. How many children and young people aged 17 or younger are living here?

	East of England %	Rest of England %
None	70	69
One	9	11
Two	11	12
Three	3	1
Four	1	*
Five or more	0	*
Not stated	6	7

Q36. Which of these activities best describes what you are doing at present?

	East of England %	Rest of England %
Employee in full-time job (30 hours plus per week)	26	33
Employee in part-time job (under 30 hours per week)	13	14
Self employed (full or part-time)	9	6
On a government supported training programme (e.g. Modern Apprenticeship/Training for Work)	0	0
Full-time education at school, college or university	1	*
Unemployed and available for work	2	1
Permanently sick or disabled	5	5
Wholly retired from work	30	27
Looking after the home	8	6
Doing something else	3	3
Not stated	4	4

Q37. Do you have any long-standing illness, disability or infirmity? (Long-standing means anything that has troubled you over a period of time or that is likely to affect you over a period of time)

	East of England %	Rest of England %
Yes	32	29
No	65	66
Not stated	4	5

Q38. Does this illness or disability limit your activities in any way?

All with a long-standing illness, disability or infirmity

	East of England (219) %	Rest of England (97) %
Yes	70	68
No	29	31
Not stated	1	1

Q39. What is your religion or belief system, even if you are not currently practising?

	East of England %	Rest of England %
Christian (including Church of England, Catholic, Protestant and all other Christian denominations)	72	71
Atheist	3	3
Spiritualist/spiritualism	2	2
Agnostic	2	2
Other religion or belief system	2	1
Muslim	1	0
Humanist	1	1
Sikh	0	*
Buddhist	0	1
Hindu	0	0
Jewish	0	1
No religion	13	13
Not stated	3	5