

# End of Life Care

## Introduction

Around half a million people die in England each year, of whom almost two-thirds are aged over 75. The large majority of these deaths follow a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia. Most deaths occur in NHS hospitals.

The pattern of deaths in relation to age profile, cause of death and place of death have changed radically over the course of the past century. One hundred years ago most people died in their own homes and acute infections were a much more common cause of death. A far higher proportion of deaths occurred in childhood or early adult life.

With the changes in the past century, familiarity with death within society as a whole has decreased. Many people nowadays do not experience the death of someone close to them until they are well into midlife. Many have not seen a dead body, except on television. As a society we do not discuss death and dying openly.

Although individuals may have different ideas about what would, for them, constitute a 'good death', for many this would involve:

- being treated as an individual, with dignity and respect;
- being without pain and other symptoms;
- being in familiar surroundings; and
- being in the company of close family and/or friends.

Some people die as they would have wished, but many others do not. Some people experience excellent care in hospitals, hospices, care homes and in their own homes. But the reality is that many do not. Many people experience unnecessary pain and other symptoms. There are distressing reports of people not being treated with dignity and respect and many people do not die where they would choose to.

How we care for the dying is an indicator of how we care for all sick and vulnerable people. It is a measure of society as a whole and it is a litmus test for health and social care services.

The Ambitions for Palliative and End of Life Care (2015)<sup>[i]</sup> calls for everyone approaching the end of life to be offered the chance to create a personalised care plan.

High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere (National End of life Strategy, DH, 2008).

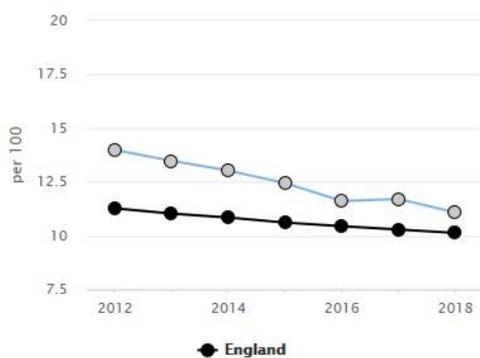
## End of life

As of May 2019 there were 588 patients on the palliative care register in Hartlepool. These individuals account for between 0.2-15% of the caseloads of the GP practices in Hartlepool, with an average of 0.8%.

Within Hartlepool the number of beds in care homes, both nursing and residential, per 100 people 75years or over has been generally declining for six years, although it remains at a level above the national average.

Care home beds per 100 people 75+ Hartlepool

Crude rate - per 100

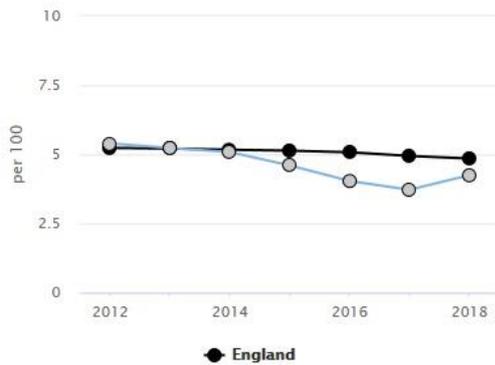


Recent trend: ↓

Period	Count	Hartlepool			North East region	England
		Value	Lower CI	Upper CI		
2012	1,044	14.0	-	-	13.5	11.3
2013	1,038	13.5	-	-	12.9	11.0
2014	1,032	13.0	-	-	12.7	10.8
2015	1,009	12.4	-	-	12.3	10.6
2016	940	11.6	-	-	12.1	10.4
2017	940	11.7	-	-	11.7	10.3
2018	891	11.1	-	-	11.6	10.1

Source: Care Quality Commission (CQC) and Office for National Statistics (ONS)

The number of care home, both residential and nursing, beds per 100 people aged 75 years and over has fallen by 21% in 6 years. However the number of beds in specifically nursing homes, after falling for three years, increased in 2018.



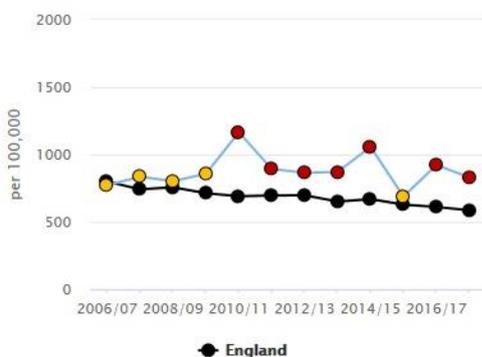
Recent trend: ↓

Period	Hartlepool				North East region	England
	Count	Value	Lower CI	Upper CI		
2012	403	5.4	-	-	7.1	5.2
2013	403	5.2	-	-	7.0	5.2
2014	403	5.1	-	-	6.8	5.2
2015	373	4.6	-	-	6.7	5.1
2016	327	4.0	-	-	6.6	5.1
2017	299	3.7	-	-	6.4	4.9
2018	342	4.3	-	-	6.0	4.9

Source: Care Quality Commission (CQC) and Office for National Statistics (ONS)

Hartlepool’s 2018 rate is within 0.6 of a bed away from the England average, and back at levels not seen since 2015.

This is against a backdrop where the numbers of permanent admissions to care homes, both residential and nursing, have undergone contrasting peaks and troughs, after a period of relative stability.



Recent trend: →

Period	Hartlepool				North East region	England
	Count	Value	Lower CI	Upper CI		
2006/07	115	771	636	925	970	799
2007/08	125	835	695	995	865	741
2008/09	120	801	664	958	885	757
2009/10	130	857	716	1,018	868	712
2010/11	180	1,164	1,000	1,347	902	690
2011/12	140	892	751	1,053	878	696
2012/13	140	864	727	1,019	831	697
2013/14	145	871	735	1,025	804	651
2014/15	181	1,056	908	1,222	836	669
2015/16	119	688	570	823	843	628
2016/17	161	922	785	1,075	838	611
2017/18	147	830	702	976	795	586

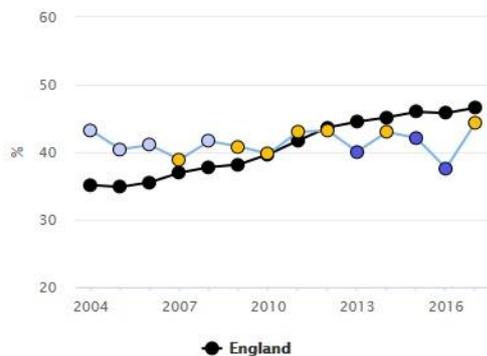
Source: Adult Social Care Outcomes Framework (ASCOF), NHS Digital

After peaking at a rate of 1,164 per 100,000 population in 2010/11, there had been three years where Hartlepool’s rate had stabilised, moving no more than 3.2% in either direction. However since then Hartlepool’s rate has seen a rise up to 1,056 per 100,000 population in 2014/15, followed by a fall to 688 per 100,000 population in 2015/16, the lowest rate in the 12 year reporting period, and a fall of 35%. This was then followed by an increase of 34%, back up to a rate of 922 per 100,000 population in 2016/17. Hartlepool’s rate in 2017/18 of 830 per 100,000 is a fall on the previous year, and in line with the three year period of stability in Hartlepool’s admission numbers from 2010/11 to 2012/13.

The percentage of deaths in usual place of residence, this could be a home, a care home or a religious establishment, for Hartlepool had fallen by 5.6% from 43.2% 2012 to 37.6% in 2016. However in 2017 the Hartlepool rate rose by 6.8% to 44.4%, the highest level in the 14 year reporting period. This places Hartlepool back into a position of statistical similarity with the England average, for the first time in three years.

Percentage of deaths in usual place of residence (DiUPR) (All ages) Hartlepool

Proportion - %



Recent trend: →

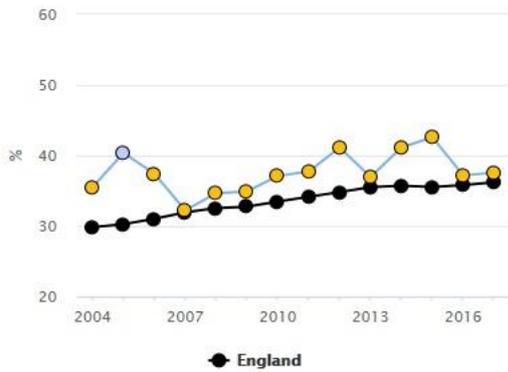
Period		Hartlepool				North East region	England
		Count	Value	Lower CI	Upper CI		
2004	○	435	43.2%	40.2%	46.3%	35.8%	35.1%
2005	○	413	40.4%	37.4%	43.4%	35.5%	34.8%
2006	○	395	41.1%	38.0%	44.2%	36.0%	35.5%
2007	●	380	38.9%	35.9%	42.0%	37.4%	36.9%
2008	○	382	41.6%	38.5%	44.8%	37.5%	37.8%
2009	●	368	40.8%	37.7%	44.1%	37.2%	38.2%
2010	●	355	39.8%	36.6%	43.0%	38.5%	39.7%
2011	●	380	43.0%	39.8%	46.3%	40.3%	41.7%
2012	●	379	43.2%	40.0%	46.5%	43.0%	43.7%
2013	●	357	40.1%	36.9%	43.3%	43.5%	44.5%
2014	●	399	43.0%	39.8%	46.2%	45.0%	45.1%
2015	●	431	42.1%	39.1%	45.1%	46.3%	46.0%
2016	●	360	37.6%	34.6%	40.7%	46.5%	45.8%
2017	●	443	44.4%	41.3%	47.5%	48.3%	46.6%

Source: Office for National Statistics

If this is broken down by age groups, then for those dying aged 0-64 Hartlepool has been at a similar level to both England and the north east since 2006. From a low of 32.2% in 2007 the proportion has generally increased, though with two noticeable declines in 2013 and 2016. The decline from 2015 to 2016 is 5.4% and takes Hartlepool from a 12 year high back to levels similar to that seen in the previous decline in 2013. The 2017 level has maintained the same gap of 1.4% with the England average.

Percentage of deaths in usual place of residence (DiUPR) (<65 yrs) Hartlepool

Proportion - %



Recent trend: ↗

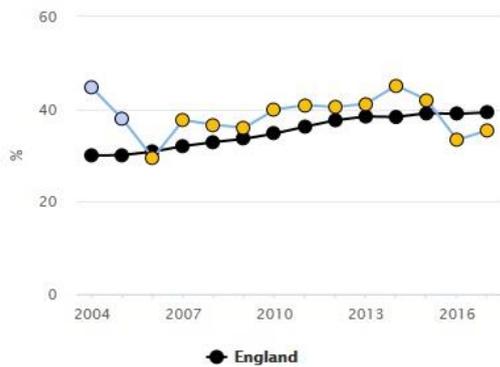
Period		Hartlepool				North East region	England
		Count	Value	Lower CI	Upper CI		
2004	●	71	35.5%	29.2%	42.3%	33.2%	29.8%
2005	●	67	40.4%	33.2%	48.0%	33.7%	30.3%
2006	●	67	37.4%	30.7%	44.7%	34.9%	31.0%
2007	●	58	32.2%	25.8%	39.4%	36.6%	31.9%
2008	●	53	34.6%	27.6%	42.5%	36.0%	32.5%
2009	●	59	34.9%	28.1%	42.4%	36.0%	32.7%
2010	●	56	37.1%	29.8%	45.0%	36.5%	33.5%
2011	●	57	37.7%	30.4%	45.7%	36.5%	34.1%
2012	●	58	41.1%	33.4%	49.4%	39.4%	34.8%
2013	●	51	37.0%	29.4%	45.3%	39.1%	35.5%
2014	●	65	41.1%	33.8%	48.9%	40.3%	35.7%
2015	●	69	42.6%	35.2%	50.3%	40.4%	35.5%
2016	●	58	37.2%	30.0%	45.0%	40.4%	35.8%
2017	●	59	37.6%	30.4%	45.4%	41.5%	36.2%

Source: Office for National Statistics

For those aged 65-74 years at the time of their death, the proportion dying at their usual place of residence in 2016 was below the north east regional level for the first time in the 13 year reporting period. This has improved slightly in 2017, where the Hartlepool level is statistically similar to both the England and the north east averages. This fall in Hartlepool's rate was preceded by 10 years of similarity to both the England and north east averages, which had seen a general increase from 29.5% in 2006 to 42.2% in 2015, peaking at 45.1% in 2014. While Hartlepool's rate increased in 2017, this is still below the 2007 levels.

Percentage of deaths in usual place of residence (DiUPR) (65-74 yrs) Hartlepool

Proportion - %



Recent trend: ↘

Period		Hartlepool				North East region	England
		Count	Value	Lower CI	Upper CI		
2004	●	103	44.6%	38.3%	51.0%	32.5%	30.0%
2005	●	87	37.8%	31.8%	44.2%	31.9%	30.1%
2006	●	61	29.5%	23.7%	36.0%	32.6%	30.8%
2007	●	76	37.6%	31.2%	44.5%	33.5%	32.0%
2008	●	74	36.6%	30.3%	43.5%	35.4%	32.9%
2009	●	55	35.9%	28.8%	43.8%	35.0%	33.6%
2010	●	71	39.9%	33.0%	47.2%	35.4%	34.7%
2011	●	65	40.9%	33.5%	48.6%	37.5%	36.2%
2012	●	72	40.4%	33.5%	47.8%	39.4%	37.6%
2013	●	63	41.2%	33.7%	49.1%	40.4%	38.4%
2014	●	69	45.1%	37.4%	53.0%	41.5%	38.3%
2015	●	79	42.0%	35.2%	49.2%	42.2%	39.1%
2016	●	62	33.3%	27.0%	40.4%	42.6%	39.0%
2017	●	61	35.5%	28.7%	42.9%	43.3%	39.3%

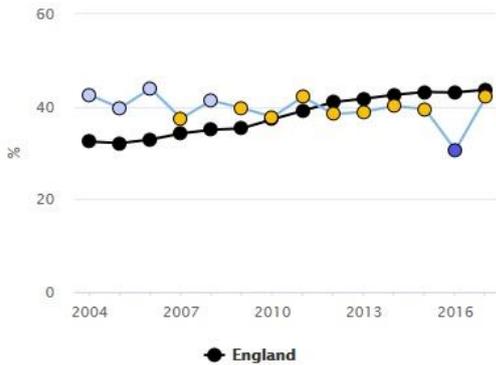
Source: Office for National Statistics

Similarly for 75-84 years, there had also been a decline from 2015 to 2016, falling from 39.4% to 30.6%. This had also taken Hartlepool below the England and north east averages for the first time in the 13 year reporting period. Again the 2017 figure saw a large increase, 11.5%, for this age group taking it up to a six year high of

42.1%. The 2016 decline was preceded by a four year period of general stability, where the year on year change was never more than 0.7%. Similar to the previous age groupings, there had been a long period where Hartlepool was similar or higher in its proportion of those dying at their usual place of residence to England and the north east region.

Percentage of deaths in usual place of residence (DiUPR) (75-84 yrs) Hartlepool

Proportion - %



Recent trend: ➔

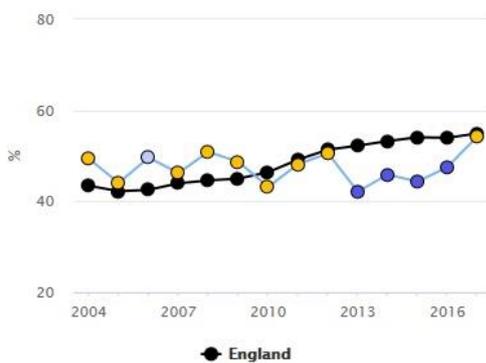
Period		Hartlepool				North East region	England
		Count	Value	Lower CI	Upper CI		
2004	○	142	42.5%	37.3%	47.9%	33.8%	32.4%
2005	○	152	39.7%	34.9%	44.7%	33.6%	32.1%
2006	○	144	43.9%	38.6%	49.3%	34.1%	32.9%
2007	●	124	37.5%	32.4%	42.8%	35.4%	34.2%
2008	○	135	41.3%	36.1%	46.7%	35.0%	35.0%
2009	●	123	39.7%	34.4%	45.2%	34.7%	35.3%
2010	●	108	37.8%	32.3%	43.5%	36.2%	37.3%
2011	●	128	42.1%	36.7%	47.7%	38.7%	39.1%
2012	●	104	38.4%	32.8%	44.3%	41.1%	41.0%
2013	●	115	38.9%	33.5%	44.5%	41.1%	41.7%
2014	●	126	40.1%	34.9%	45.6%	42.6%	42.5%
2015	●	127	39.4%	34.3%	44.9%	44.8%	43.1%
2016	●	95	30.6%	25.8%	36.0%	44.2%	43.0%
2017	●	139	42.1%	36.9%	47.5%	46.2%	43.6%

Source: Office for National Statistics

The final age grouping is those 85 years and over, which, unlike the other age groupings, has had a gradual increase in its level over four years. Also unlike the other age groupings 85 years and above had a prolonged period below the England average.

Percentage of deaths in usual place of residence (DiUPR) (85+ yrs) Hartlepool

Proportion - %



Recent trend: ➔

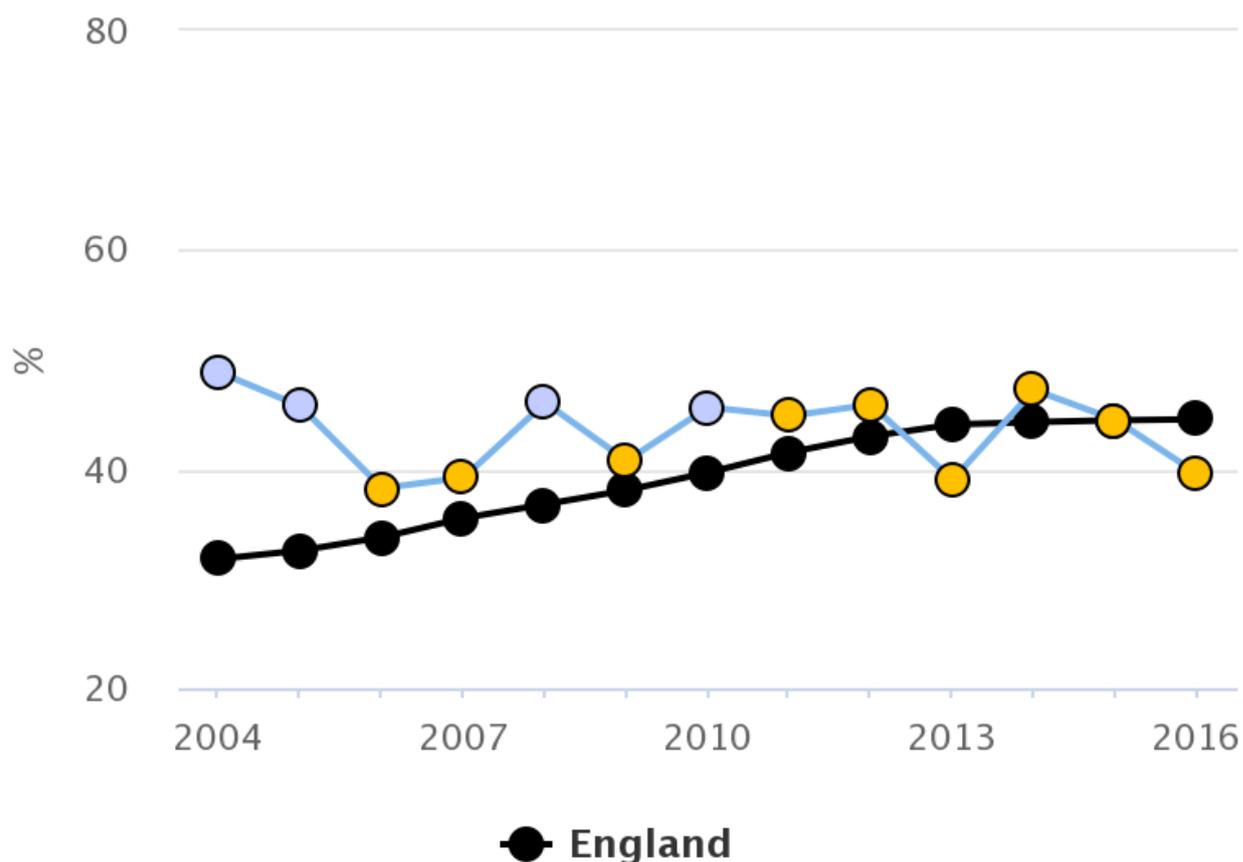
Period		Hartlepool				North East region	England
		Count	Value	Lower CI	Upper CI		
2004	●	119	49.4%	43.1%	55.6%	42.8%	43.4%
2005	●	107	44.0%	37.9%	50.3%	41.4%	42.2%
2006	○	123	49.6%	43.4%	55.8%	41.0%	42.5%
2007	●	122	46.2%	40.3%	52.2%	42.3%	43.9%
2008	●	120	50.8%	44.5%	57.2%	42.2%	44.6%
2009	●	131	48.7%	42.8%	54.6%	41.6%	45.0%
2010	●	120	43.2%	37.5%	49.0%	43.4%	46.4%
2011	●	130	48.1%	42.3%	54.1%	45.2%	49.2%
2012	●	145	50.5%	44.8%	56.3%	48.3%	51.4%
2013	●	128	42.1%	36.7%	47.7%	49.0%	52.2%
2014	●	139	45.9%	40.4%	51.5%	50.9%	53.2%
2015	●	156	44.3%	39.2%	49.5%	51.7%	54.1%
2016	●	145	47.5%	42.0%	53.1%	52.8%	53.9%
2017	●	184	54.3%	49.0%	59.5%	55.1%	54.9%

Source: Office for National Statistics

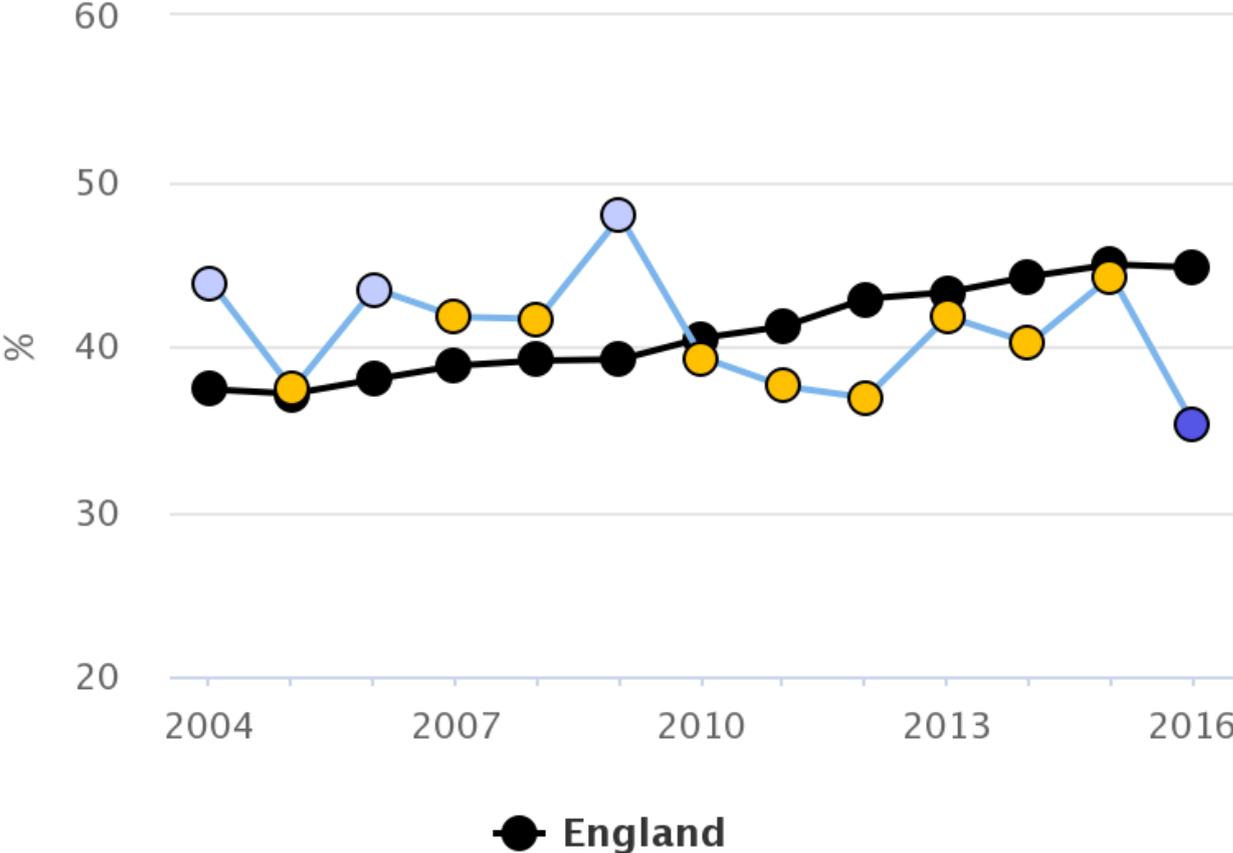
The increase in 2017 took the Hartlepool level for this age group back to a static similarity to England for the first time in five years. Hartlepool's 2017 level of 54.3% is the largest across the 14 year reporting period.

Looking at Hartlepool's proportion of deaths in usual place of residence for cancer, respiratory disease and circulatory disease across all ages, all three have seen a decline in their 2016 levels. Cancer and respiratory disease are on a more gradual two year decline, falling 7.6% and 3.6% respectively over the two year period, whereas circulatory disease has fallen 9% from its 2015 level. Circulatory disease's 35.2% is the lowest level across the 13 year reporting period, and cancer's 39.6% and respiratory disease's 26.8% are both three year lows.

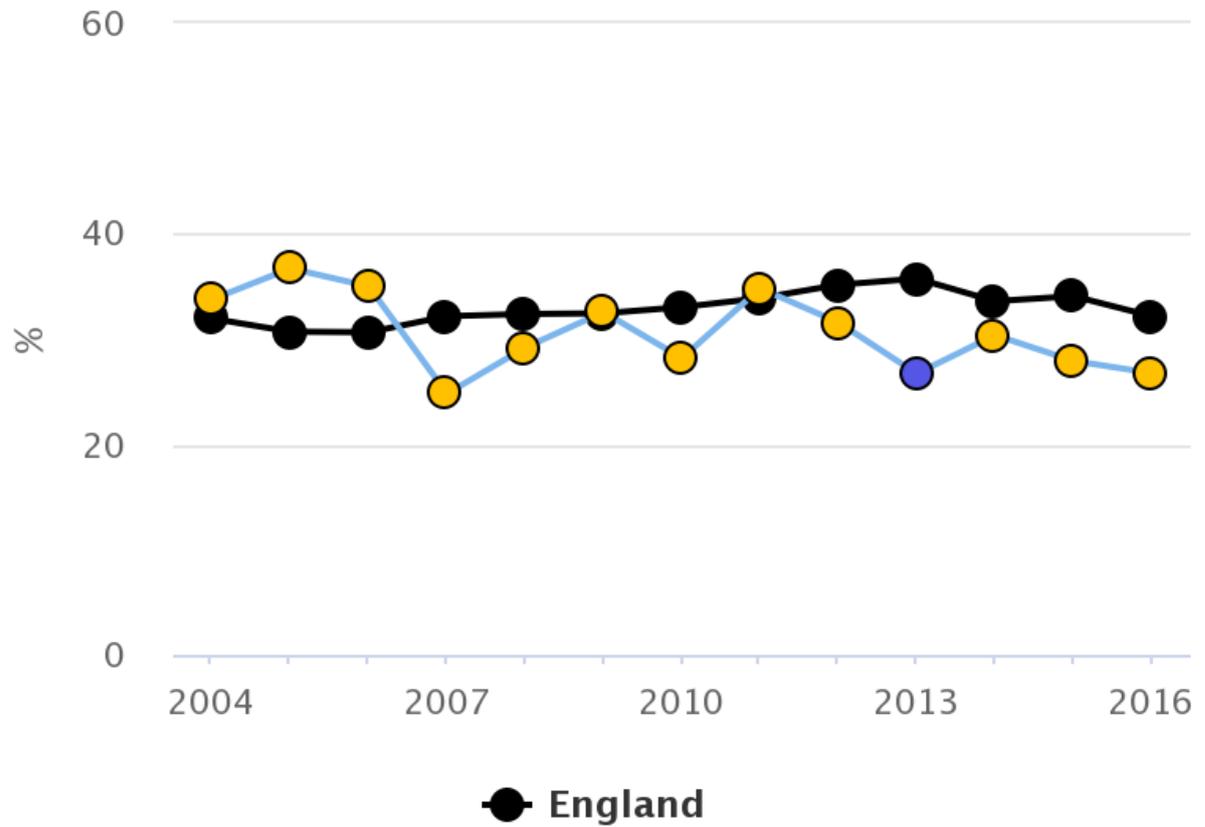
**DiUPR - Cancer (%), Persons, All Ages. - Hartlepool**



**DiUPR – Circulatory disease (%), Persons, All Ages. – Hartlepool**

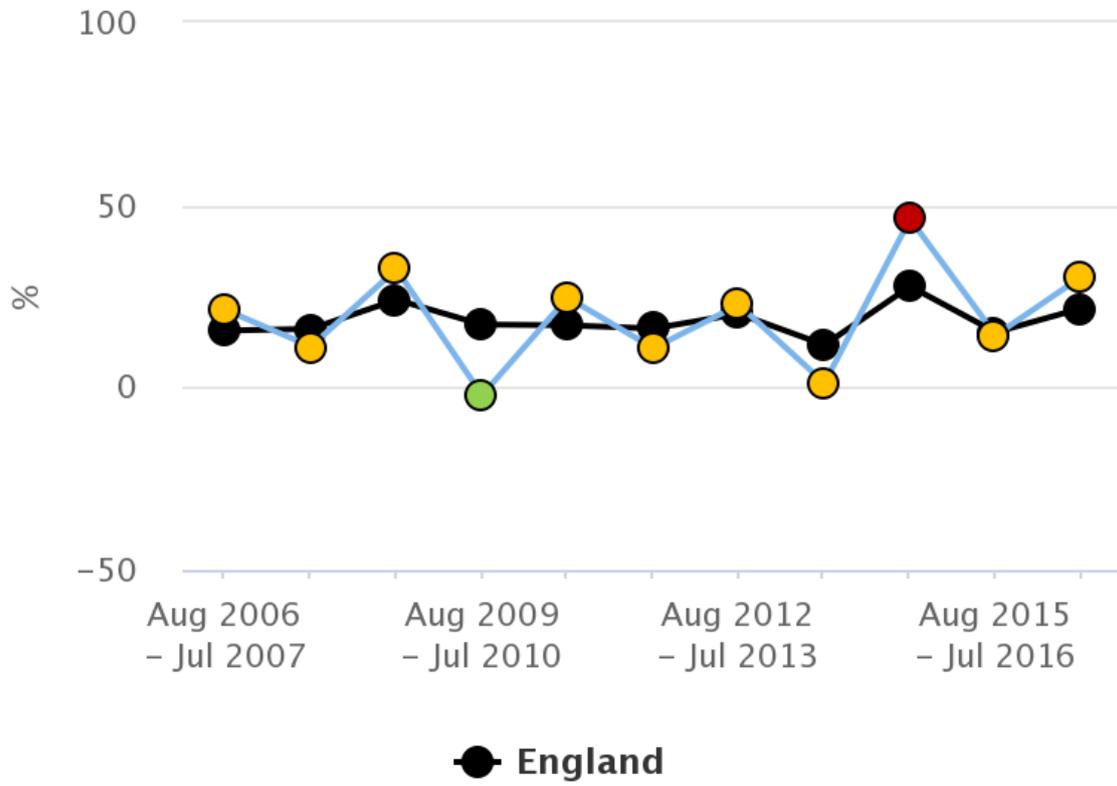


### DiUPR – Respiratory disease (%), Persons, All Ages. – Hartlepool

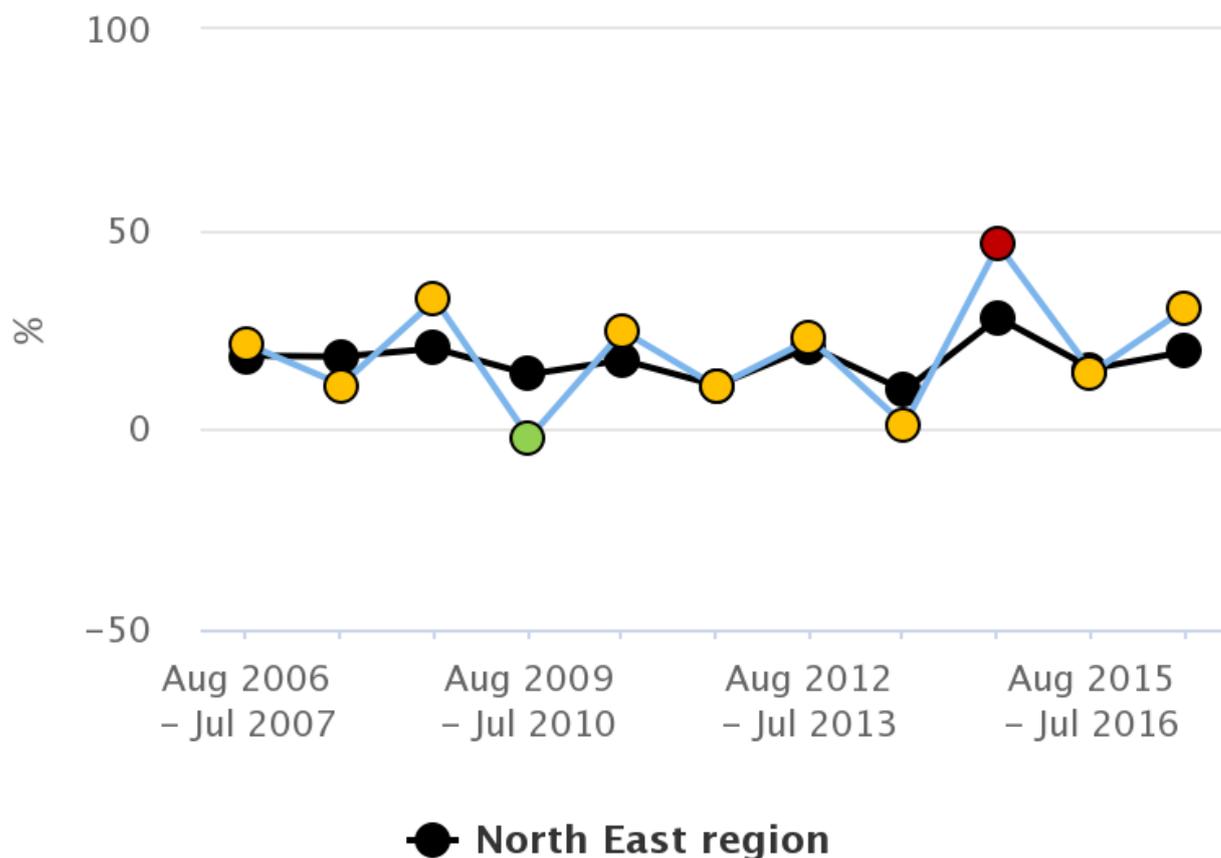


Excess winter deaths for all ages in Hartlepool have shown very little year on year consistency.

4.15i - Excess winter deaths index (single year, all ages) - Hartlepool



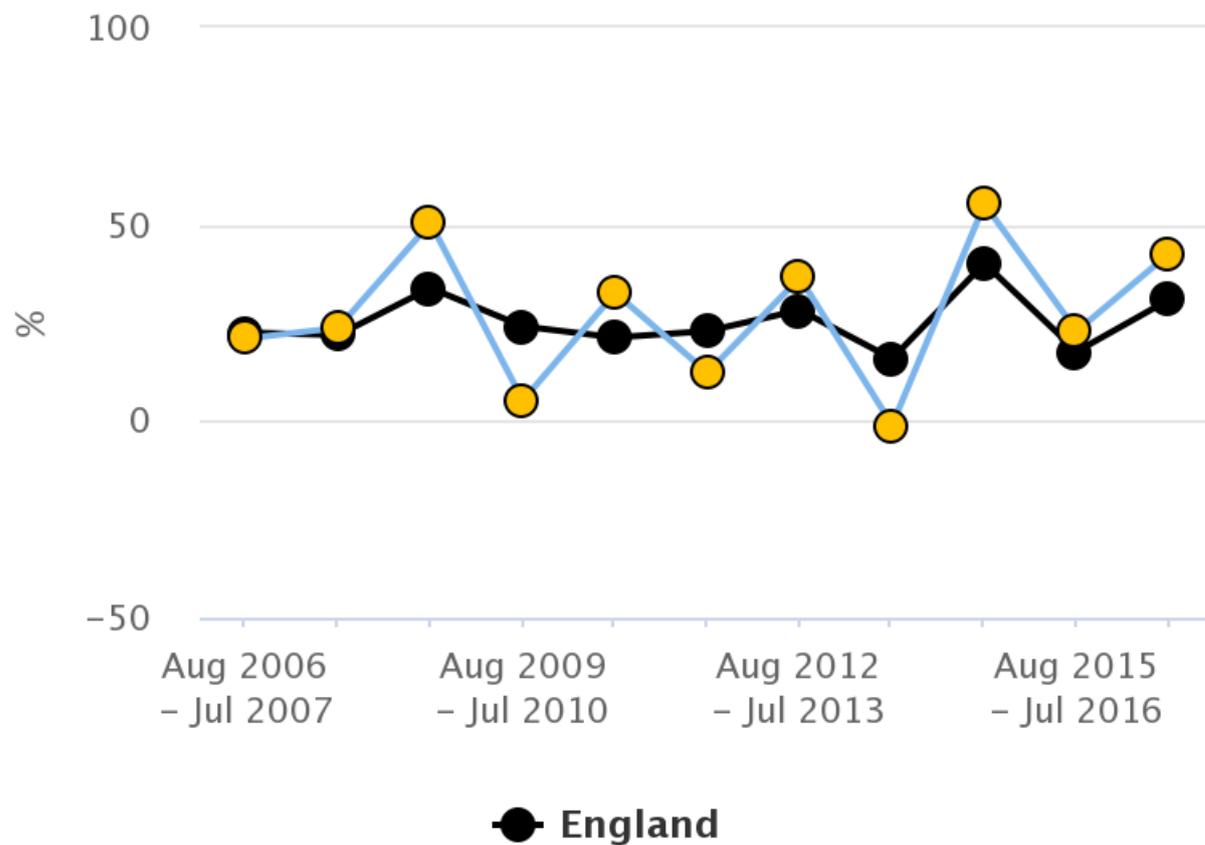
#### 4.15i – Excess winter deaths index (single year, all ages) – Hartlepool



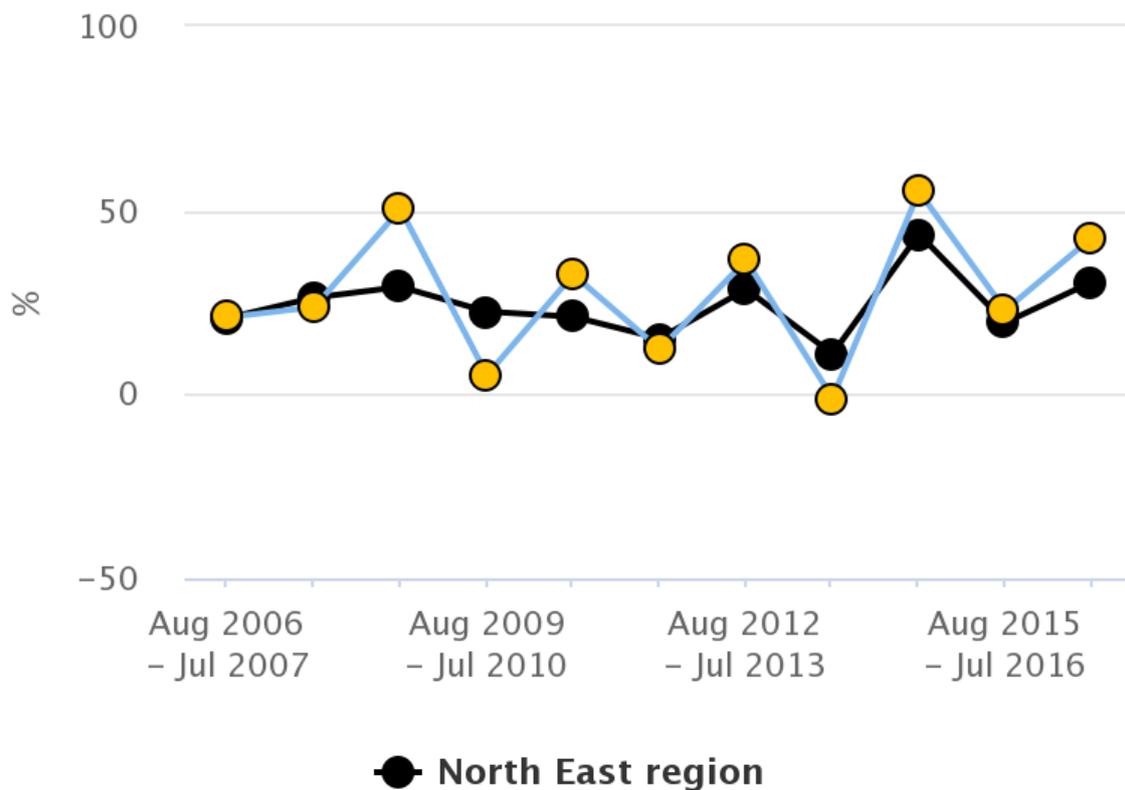
Across the 11 year reporting period the rate has either reduced by at least half or increased to at least double its previous rate every year. The biggest fall across this period was from 32.4% in 2008/09 to -2.1% in 2009/10, and the biggest increase was from 1.2% in 2013/14 to 46.1% in 2014/15. The 2014/15 rate was the largest across the reporting period. Even though Hartlepool's rate at least halved or doubled every year, it stayed statistically similar to both England and the north east in all but two years. In 2009/10 Hartlepool's rate was better than the England and north east averages, and in 2014/15 Hartlepool's rate was worse than the England and north east averages.

Looking at just those aged 85 or over, then the single year excess winter death rate for Hartlepool has remained similar to both the England and north east averages for the last 11 years.

### 4.15ii - Excess winter deaths index (single year, age 85+) (Persons) - Hartlepool



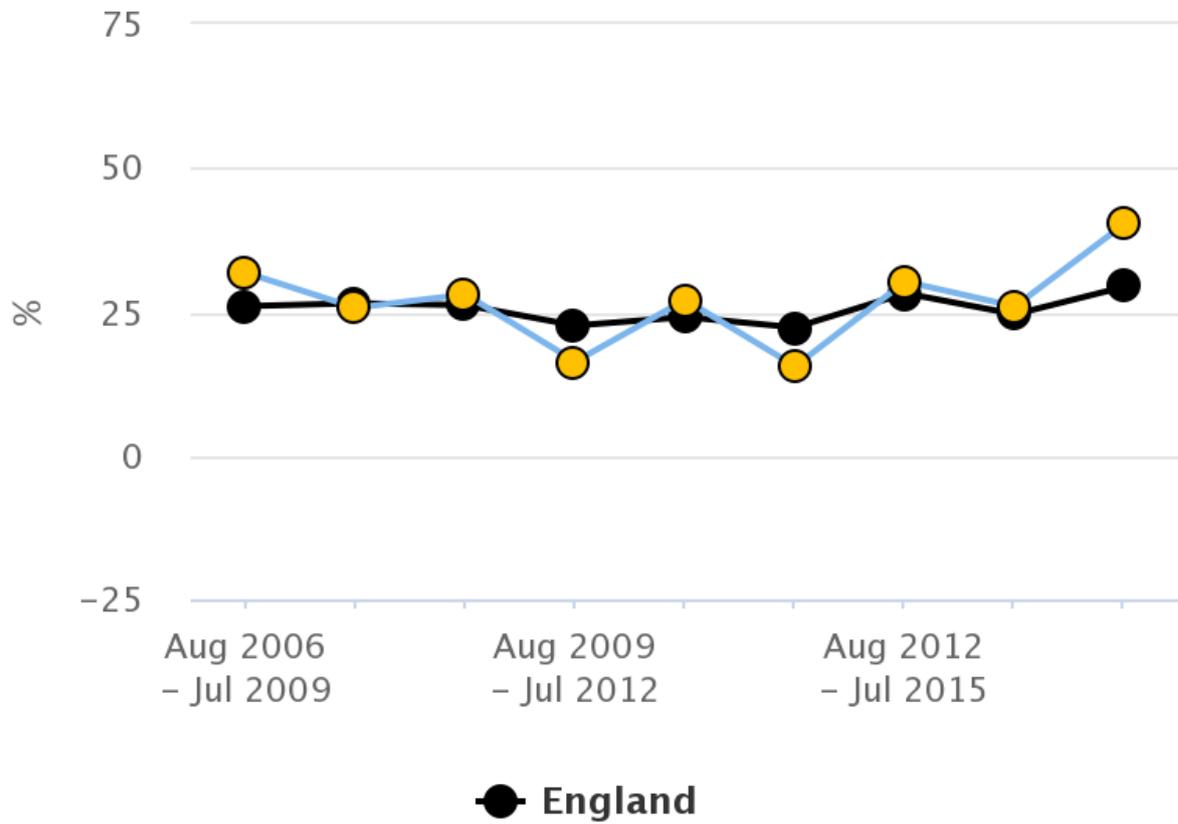
**4.15ii – Excess winter deaths index (single year, age 85+) (Persons) – Hartlepool**



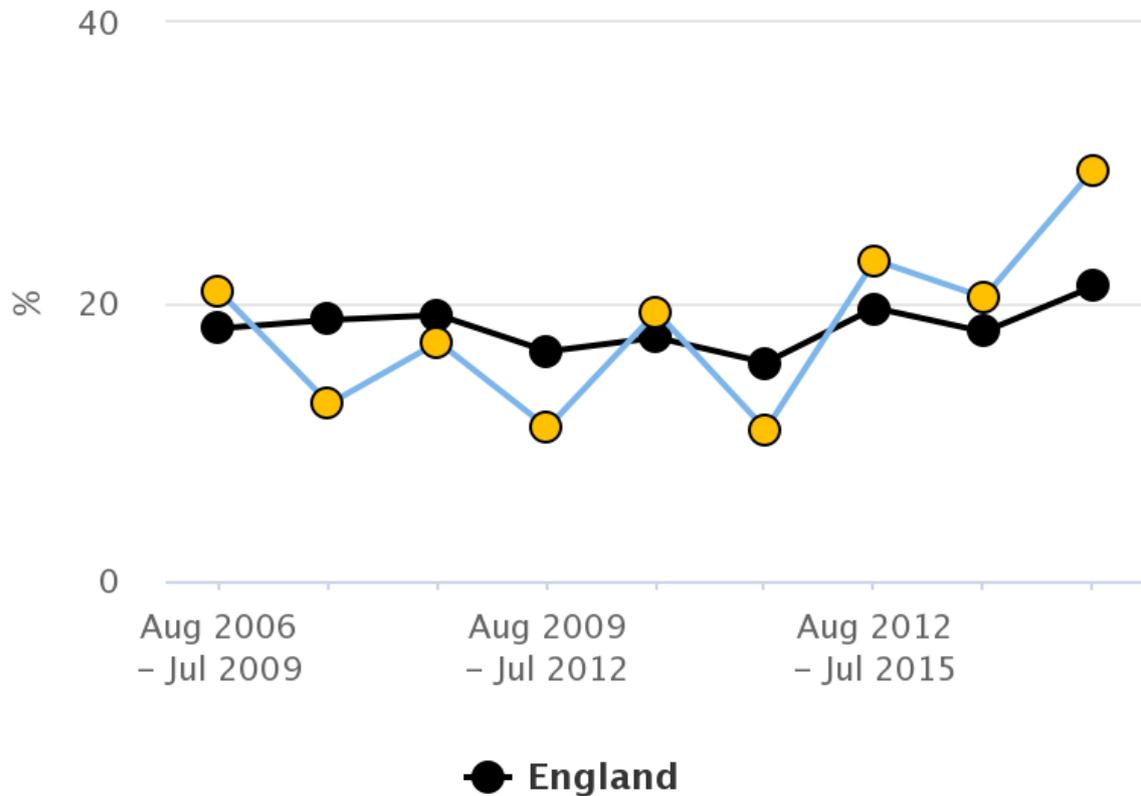
The rate for excess winter deaths 85+ in a single year for Hartlepool, similar for the rate in a single year for all ages, regularly halves or doubles from the rate of the previous year. The average change year on year for Hartlepool is 29.18%, whereas for England and the north east the average change year on year is 10.43% and 12.1% respectively.

If looked at across three year brackets rather than each individual year, then Hartlepool has remained statistically similar to England and the north east across the entire reporting period for both those aged 85+ and for all persons.

4.15iv - Excess winter deaths index (3 years, age 85+) (Persons) - Hartlepool



**4.15iii – Excess winter deaths index (3 years, all ages) (Persons) – Hartlepool**



Hartlepool has the highest rate for both its regional and CIPFA peer comparators for excess winter deaths over 3 years 85+ and all ages, and excess winter deaths in a single year 85+. For excess winter deaths in a single year all ages, Hartlepool has the highest rate in the north east, but only the 3<sup>rd</sup> highest rate against its nearest statistical neighbours. However all four of these figures come with very large confidence intervals, Hartlepool has a confidence interval range of 63.7 for excess winter deaths in a single year for all ages, so they must be approached cautiously.

**Current services**

Hartlepool and Stockton-on-Tees CCG work closely with local partners such as North Tees Hospitals Foundation Trust, hospices, voluntary organisations and GP practices to ensure that end of life care for the population of Hartlepool and Stockton-on-Tees is personalised and well-co-ordinated, enabling real choice for individuals.

The Ambitions for Palliative and End of Life Care (2015)<sup>[i]</sup> calls for everyone approaching the end of life to be offered the chance to create a personalised care plan. The CCG are supporting GP practices, community nursing and specialist palliative care teams to increase the number of patients with a personalised care plan. The care plan should be a holistic assessment developed with the patient and carers allowing the patient to express their preferences for care and set personal goals. It is hoped that with the correct plan in place more patients will be able to die in their preferred place of care reducing the need for emergency admissions at the end of life.

People approaching the last days of life should be identified in a timely way and have their care coordinated and delivered to ensure that individuals die in their preferred place of care. This preferred place of care may be at home, hospice or hospital. Hartlepool and Stockton-on-Tees CCG are committed to working with clinical teams from North Tees and Hartlepool NHS Foundation Trust and GP practices to increase care planning for palliative patients to enable patients to die in their preferred place of care. The CCG have been working in partnership with the specialist palliative care team to review the service and ensure as far as possible, hospital/hospice admission is prevented, early discharge from hospital is facilitated and people with life-limiting illnesses can remain at home if that is their choice.

The CCG have supported the implementation of the regional documentation (Care of the Dying Patient) across primary care, secondary and community services to ensure a standardised approach is adopted across multiple providers to improve the quality of care delivered.

The CCG are supporting GP practices with the End of Life Quality Improvement (QI) offered to GP practices in 19/20 under the Quality Outcomes Framework (QOF) This QI requires GP practices to review their current care for palliative care patients. GP practices are required to identify and keep a register of palliative care patients and review those on the register at regular intervals through a multi-disciplinary meeting. This QI requires GP practices to carry out a retrospective death audit; meaning practices are to audit recent patient deaths to understand how the practice identifies palliative care patients. The results of these audits are to be shared internally within

the GP practice and with neighbouring GP practices, this enables practices to share best practice and formulate an improvement plan focusing on the following key areas:

- Early identification and support for people who might die within 12 months
- Well-planned and coordinated care that is responsive to patient needs
- Identification and support for family/informal care-givers as part of a patient's core support team and as individuals facing bereavement.

The CCG are working with local partners to raise the profile of talking about death and dying. Dying Matters week runs annually in May. The CCG have supported the local campaigns in the hospitals, hospices and voluntary organisations to promote awareness of discussing preferences in care and detailing these in care plans.

### **Future intentions**

The CCG will continue to work closely with GP practices and the newly formed Primary Care Networks (PCNs) in ensuring the best possible provision of palliative and end of life care for the population of Hartlepool and Stockton-on-Tees. This will be achieved through supporting the identification of patients within the last year of life earlier resulting in those difficult conversations occurring at an earlier point in the patient journey allowing for preferences to be considered and documented.

The End of life Care Strategy (2008)<sup>[iii]</sup> identifies the need to improve the co-ordination of care, recognising that people at the end of life frequently received care from a wide variety of teams and organisations. The development of Locality Registers (now Electronic Palliative Care Co-ordination Systems known as EPaCCS) were identified as a mechanism for enabling co-ordination. The CCG will closely monitor the current progress of EPaCCs within pilot CCG sites to understand how this can be utilised to improve care coordination for the population of Hartlepool and Stockton-on-Tees.

The CCG will review the current end of life strategy with a view to create consistency across Hartlepool, Stockton-on-Tees, Middlesbrough, Redcar and Cleveland, Darlington, North Durham and Durham Dales, Easington and Sedgefield.

---

[i] Department of Health. Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020.

[ii] Department of Health. End of Life Care Strategy: promoting high quality care for adults at the end of their life. July 2008.