

# DATA REPORT

A report from Cancer52 on  
National Cancer Intelligence Network data  
on rare and less common cancers



## Foreword

This report pulls together for the first time key data streams supplied on rare and less common cancers and is made available to Cancer52 by Public Health England's National Cancer Intelligence Network (NCIN).

Cancer52 is an alliance of nearly 80 predominantly small charities united in their vision of seeing a better future for everyone affected by the rare and less common cancers, which account for more than half of all cancer deaths in the UK.

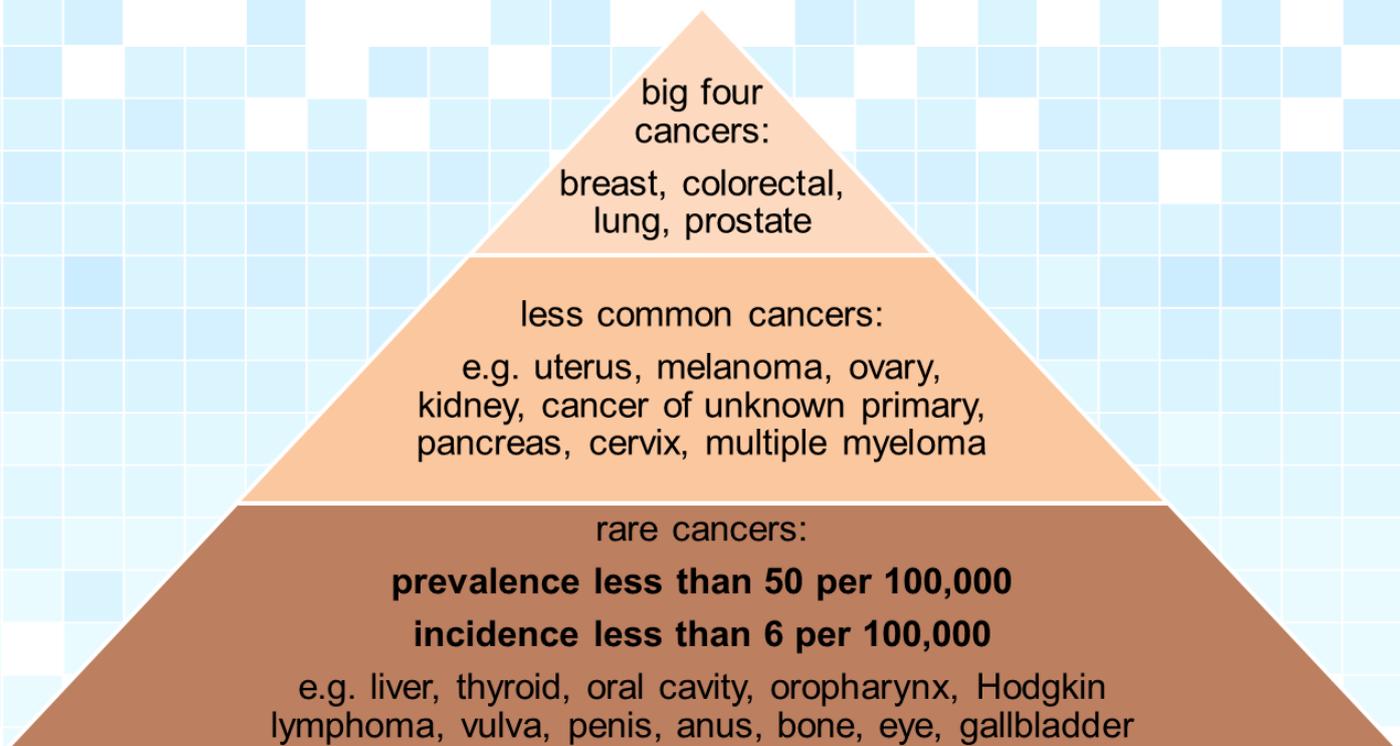
We are extremely grateful to the NCIN team for their work in this area. Improving access to data provides a critical tool for our member charities in understanding how they can best structure their approach to increasing survival in the cancer area in which they work.

**Clara Mackay**  
**Interim Chair**  
**Cancer52**



## Rare and less common cancers

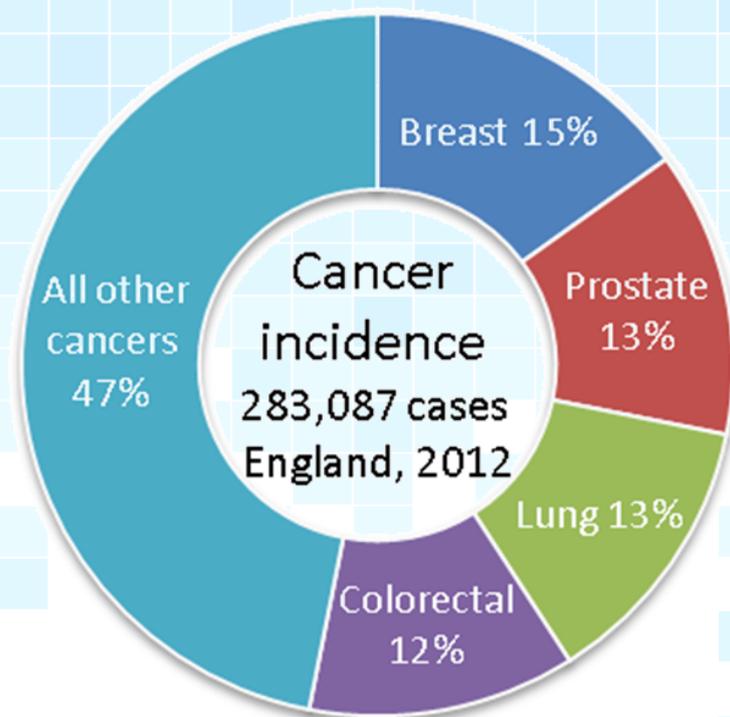
### Where they fit in the Pyramid



## Incidence for rare and less common cancers

**Incidence for rare and less common cancers now at 47%**

- The incidence of those diagnosed with rare and less common cancers is well under half at 47% <sup>1</sup>
- Rare and less common cancers are those cancers outside the 'big four' (of breast, bowel, prostate and lung).



<sup>1</sup> Data taken from Cascade, National Cancer Registration Service, Public Health England accessed 21<sup>st</sup> May 2014

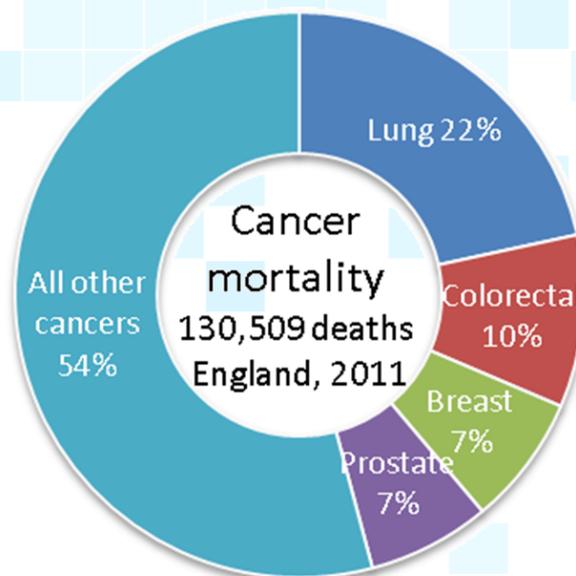
## New cases of cancer\* diagnosed in 2012, England

Cancer type	Cases	% of total
Breast	42,631	15.06%
Prostate	37,117	13.11%
Lung	36,059	12.74%
Colorectal	34,510	12.19%
Melanoma	11,450	4.04%
Non-Hodgkin lymphoma	11,071	3.91%
Bladder	9,157	3.23%
Kidney and unspecified urinary organs	8,760	3.09%
Cancer of Unknown Primary	8,032	2.84%
Pancreas	7,498	2.65%
Leukaemia	7,458	2.63%
Oesophagus	7,295	2.58%
Uterus	7,238	2.56%
Ovary	6,020	2.13%
Stomach	5,689	2.01%
Multiple myeloma	4,404	1.56%
Central Nervous System (incl brain)	4,337	1.53%
Liver	3,916	1.38%
Other malignant neoplasms	2,983	1.05%
Head and neck – Thyroid	2,627	0.93%
Head and neck - Oral cavity	2,566	0.91%
Cervix	2,501	0.88%
Mesothelioma	2,373	0.84%
Head and neck - Oropharynx	2,055	0.73%
Head and neck – Larynx	1,903	0.67%
Testis	1,900	0.67%
Sarcoma: connective and soft tissue	1,609	0.57%
Hodgkin lymphoma	1,577	0.56%
Small Intestine	1,076	0.38%
Vulva	1,059	0.37%
Anus	1,054	0.37%
Gallbladder	686	0.24%
Head and Neck - non specific	614	0.22%
Head and neck - Salivary glands	563	0.20%
Head and neck - Eye	554	0.20%
Sarcoma: Bone	515	0.18%
Penis	509	0.18%
Head and neck - Hypopharynx	463	0.16%
Head and neck - Palate	374	0.13%
Nasal Cavity and Middle Ear	283	0.10%
Vagina	213	0.08%
Head and neck - Nasopharynx	210	0.07%
Heart, Mediastinum and Pleura	178	0.06%
<b>Total*</b>	<b>283,087</b>	<b>100.00%</b>

## Mortality for rare and less common cancers

### Percentage of cancer deaths outside the big four rises to 54% <sup>1</sup>

- Whilst the incidence of rare and less common cancers is 47%, the percentage of cancer deaths from those cancers is rising with a new high of 54% recorded in 2011.
- The patterns vary from cancer to cancer but overall less is invested in research, diagnosis is more complex because the numbers of people with the cancer are smaller and symptoms less well known, once diagnosed the patient experience is worse, and the number of drugs and research programmes developed are fewer with less innovation in the field.
- This disparity perfectly illustrates the challenges faced by those diagnosed with a less common cancer. At every stage of the cancer pathway, from spotting symptoms to diagnosis to access to treatments, everything is more difficult.



<sup>1</sup> Data taken from Cascade, National Cancer Registration Service, Public Health England, accessed 21<sup>st</sup> May 2014

## Deaths due to cancer\* in 2011, England

Cancer type	Deaths	% of total
Lung	28,166	21.58%
Colorectal	12,871	9.86%
Breast	9,702	7.43%
Prostate	9,123	6.99%
Cancer of Unknown Primary	9,109	6.98%
Pancreas	6,954	5.33%
Oesophagus	6,197	4.75%
Other malignant neoplasms	4,392	3.37%
Bladder	4,216	3.23%
Stomach	3,921	3.00%
Non-Hodgkin lymphoma	3,907	2.99%
Leukaemia	3,856	2.95%
Ovary	3,540	2.71%
Kidney and unspecified urinary organs	3,469	2.66%
Liver	3,385	2.59%
Central Nervous System (incl brain)	3,299	2.53%
Multiple myeloma	2,365	1.81%
Mesothelioma	2,009	1.54%
Melanoma	1,871	1.43%
Uterus	1,622	1.24%
Cervix	781	0.60%
Head and neck - Oral cavity	765	0.59%
Sarcoma: connective and soft tissue	666	0.51%
Head and neck - Larynx	640	0.49%
Head and neck - Oropharynx	464	0.36%
Gallbladder	432	0.33%
Small Intestine	354	0.27%
Vulva	338	0.26%
Head and neck - Thyroid	279	0.21%
Hodgkin lymphoma	255	0.20%
Head and Neck - non specific	251	0.19%
Anus	245	0.19%
Sarcoma: Bone	210	0.16%
Head and neck - Salivary glands	159	0.12%
Head and neck - Hypopharynx	157	0.12%
Head and neck - Nasopharynx	102	0.08%
Heart, Mediastinum and Pleura	86	0.07%
Penis	81	0.06%
Vagina	68	0.05%
Head and neck - Palate	61	0.05%
Head and neck - Eye	61	0.05%
Testis	56	0.04%
Nasal Cavity and Middle Ear	24	0.02%
<b>Total*</b>	<b>130,509</b>	<b>100.00%</b>

## Routes to Diagnosis

### Where route to diagnosis impacts on survival rates

- Routes to Diagnosis for rare and less common cancers includes data for over 50 less common and rare cancers, which shows the wide variation in the route by which the cancer was diagnosed and the resulting impact on survival
- This is important because it gives Cancer52 charities the opportunity to look at data specific to the type of cancer they work with, and helps them move people towards the routes to diagnosis that result in better survival rates for their cancer
- Of the less common cancers 12 month survival can be as low as 9% (pancreatic cancer) and 12% (liver cancer) after diagnosis by emergency presentation, which across all cancers gives the lowest survival rate. In contrast 12 month survival for breast cancer diagnosed via the two week wait method is 100%
- Whilst it is not possible with all cancer types to improve survival based purely on Route to Diagnosis, for many people an earlier diagnosis can result in higher survival rates and reduce the stress caused in remaining undiagnosed.

For more information see:

[http://www.ncin.org.uk/publications/routes to diagnosis](http://www.ncin.org.uk/publications/routes%20to%20diagnosis)



# Routes to Diagnosis

## Where route to diagnosis impacts on survival rates

Routes to Diagnosis: Percentage of diagnoses (2006 and 2010), 1-month and 12-month Survival (2006-2010) by Route (for Two Week Wait, GP Referral and Emergency Presentation)

	Two Week Wait		GP referral		Emergency presentation		Survival: Two week Wait		Survival: GP Referral		Survival: Emergency presentation	
	2006	2010	2006	2010	2006	2010	1-Month	12-Month	1-Month	12-Month	1-Month	12-Month
All Malignant Neoplasms (excl. NMSC)	24%	30%	27%	27%	24%	22%						
Confidence Interval	24% 28% 30% 30%	27% 28% 27% 27%	24% 25% 21% 22%									
Female breast (in-situ)	13%	15%	16%	16%	1%	1%		100%		100%		95%
Confidence Interval	12% 14% 14% 16%	15% 17% 15% 17%	1% 1% 1% 1%				98% 100%		90% 100%			80% 98%
Cervix (in-situ)	0%	0%	67%	53%	1%	1%				100%		100%
Confidence Interval	0% 0% 0% 0%	66% 68% 52% 54%	1% 1% 1% 1%						100% 100%			98% 100%
Melanoma	37%	49%	38%	33%	3%	2%	100%	99%	100%	98%	84%	57%
Confidence Interval	30% 30% 46% 50%	37% 30% 33% 34%	3% 3% 2% 3%				90% 90%	100% 100% 97% 98%	82% 80% 54% 60%			
Female breast cancer	41%	45%	16%	16%	5%	4%	100%	98%	99%	96%	73%	50%
Confidence Interval	41% 42% 44% 45%	16% 17% 15% 16%	5% 5% 4% 4%				100% 100% 98% 98%	90% 90% 90% 90%	72% 74% 49% 52%			
Head and neck - Oral cavity	28%	35%	27%	25%	7%	5%	100%	78%	97%	79%	82%	46%
Confidence Interval	26% 30% 33% 37%	25% 29% 24% 27%	0% 8% 5% 6%				90% 100% 77% 80%	90% 98% 78% 81%	70% 85% 42% 50%			
Vulva	32%	39%	41%	37%	8%	6%	100%	84%	100%	92%	81%	41%
Confidence Interval	29% 35% 35% 42%	38% 45% 34% 40%	7% 10% 5% 8%				97% 100% 82% 85%	90% 100% 91% 94%	76% 85% 35% 47%			
Bladder (in situ)	23%	22%	42%	48%	8%	7%		99%	100%	100%	97%	89%
Confidence Interval	21% 24% 20% 23%	40% 44% 40% 50%	7% 9% 0% 8%				95% 100%	90% 100%	95% 98% 85% 91%			
Head and neck – Thyroid	12%	16%	54%	53%	8%	7%	99%	88%	99%	98%	67%	48%
Confidence Interval	10% 13% 14% 17%	52% 57% 50% 55%	7% 10% 0% 8%				98% 90% 85% 80%	90% 100% 97% 98%	63% 70% 44% 52%			
Head and neck - Oropharynx	33%	46%	35%	30%	10%	7%	99%	84%	97%	84%	83%	50%
Confidence Interval	31% 35% 44% 45%	32% 37% 28% 32%	0% 12% 0% 8%				90% 100% 82% 85%	97% 98% 82% 85%	80% 80% 45% 54%			
Prostate	24%	34%	43%	42%	11%	8%	100%	98%	100%	99%	78%	56%
Confidence Interval	23% 24% 34% 35%	42% 43% 41% 42%	10% 11% 8% 8%				98% 98%	90% 100% 90% 90%	78% 70% 56% 57%			
Uterus	35%	44%	39%	35%	9%	8%	100%	94%	99%	93%	81%	56%
Confidence Interval	34% 30% 43% 45%	37% 40% 34% 36%	8% 10% 8% 9%				100% 100% 94% 95%	90% 90% 93% 94%	79% 82% 54% 58%			
Head and neck - (excl. oral cavity, oropharynx, larynx & thyroid)	24%	32%	41%	36%	10%	9%						
Confidence Interval	22% 25% 29% 34%	39% 44% 34% 39%	8% 11% 8% 10%									
Testis	47%	53%	19%	20%	11%	9%		100%	100%	99%	96%	91%
Confidence Interval	45% 49% 51% 50%	18% 21% 19% 22%	0% 12% 8% 11%				90% 100%	90% 100% 98% 90%	95% 98% 88% 92%			
Head and neck – Larynx	28%	37%	43%	37%	12%	10%	100%	88%	98%	87%	76%	44%
Confidence Interval	20% 30% 35% 40%	41% 45% 35% 40%	11% 14% 0% 12%				90% 100%	80% 80%	97% 98% 80% 88%	73% 78% 40% 47%		
Cervix	15%	19%	36%	31%	12%	11%			99%	92%	82%	44%
Confidence Interval	14% 17% 18% 21%	34% 38% 29% 33%	11% 13% 10% 13%				83% 85%	98% 90% 91% 93%	80% 84% 42% 47%			
Head and Neck - non specific	22%	29%	40%	38%	15%	12%		78%	97%	82%	71%	28%
Confidence Interval	19% 25% 25% 32%	30% 44% 34% 42%	12% 18% 10% 16%				74% 81%	90% 98% 70% 84%	65% 75% 23% 33%			
Hodgkin lymphoma	24%	31%	37%	34%	17%	15%		96%	99%	93%	89%	72%
Confidence Interval	22% 25% 29% 34%	35% 40% 32% 37%	15% 19% 14% 17%				95% 97%	98% 90% 92% 94%	87% 91% 69% 74%			
Sarcoma: connective and soft tissue	10%	16%	46%	44%	17%	16%		83%	98%	87%	79%	42%
Confidence Interval	9% 12% 14% 16%	43% 49% 41% 46%	15% 19% 14% 18%				80% 85%	98% 90% 80% 80%	70% 81% 39% 40%			
Bladder	27%	36%	30%	28%	20%	17%	99%	84%	97%	79%	76%	34%
Confidence Interval	20% 28% 35% 37%	29% 31% 27% 29%	10% 21% 17% 18%				90% 100%	83% 85%	97% 97% 78% 80%	75% 77% 33% 35%		
Oesophagus	32%	39%	20%	20%	23%	21%	98%	43%	93%	47%	68%	18%
Confidence Interval	31% 34% 38% 41%	19% 21% 19% 21%	22% 24% 20% 22%				97% 98%	45% 44%	90% 94% 45% 48%	67% 90% 17% 19%		
Leukaemia: chronic lymphocytic	9%	14%	43%	45%	26%	22%		97%	98%	94%	74%	59%
Confidence Interval	8% 10% 13% 15%	41% 45% 43% 47%	25% 28% 21% 24%				95% 98%	90% 98% 94% 95%	72% 76% 57% 61%			
Colorectal	26%	27%	26%	24%	27%	23%	99%	83%	96%	81%	75%	49%
Confidence Interval	20% 27% 27% 28%	25% 26% 24% 25%	27% 28% 23% 24%				98% 90%	83% 83%	95% 90% 81% 81%	75% 76% 48% 49%		
Kidney and unspecified urinary organs	17%	22%	29%	31%	27%	24%	99%	80%	95%	78%	72%	37%
Confidence Interval	16% 18% 21% 23%	28% 31% 30% 32%	26% 28% 23% 25%				98% 90%	70% 81%	94% 95% 77% 79%	71% 73% 36% 38%		
Non-Hodgkin lymphoma	16%	22%	35%	34%	28%	26%	99%	87%	96%	86%	75%	49%
Confidence Interval	15% 17% 21% 23%	34% 36% 33% 35%	27% 29% 25% 27%				98% 90%	80% 88%	90% 90% 80% 87%	74% 75% 48% 50%		
Ovary	21%	27%	25%	25%	32%	30%	98%	85%	94%	80%	73%	43%
Confidence Interval	20% 23% 20% 28%	24% 26% 24% 27%	31% 33% 29% 31%				98% 90%	84% 80%	93% 94% 70% 81%	72% 74% 42% 44%		
Other malignant neoplasms	11%	14%	29%	31%	33%	31%	92%	54%	85%	65%	55%	21%
Confidence Interval	10% 12% 13% 15%	27% 30% 30% 32%	32% 35% 30% 32%				90% 93%	50% 57%	84% 87% 63% 66%	53% 56% 20% 22%		
Stomach	22%	26%	21%	22%	34%	32%	96%	44%	91%	52%	67%	22%
Confidence Interval	21% 23% 25% 27%	20% 22% 21% 24%	33% 35% 31% 33%				90% 90%	43% 45%	90% 92% 50% 53%	65% 68% 21% 23%		
Mesothelioma	16%	22%	27%	24%	36%	34%	97%	44%	90%	43%	72%	24%
Confidence Interval	15% 18% 20% 24%	26% 29% 23% 26%	34% 38% 32% 36%				90% 98%	42% 46%	80% 91% 41% 45%	70% 73% 23% 26%		
Multiple myeloma	11%	14%	32%	36%	37%	34%	99%	85%	96%	82%	79%	51%
Confidence Interval	10% 12% 13% 15%	31% 34% 34% 37%	35% 39% 33% 36%				98% 90%	83% 87%	90% 97% 81% 83%	78% 80% 50% 52%		
Lung	22%	26%	22%	21%	39%	38%	95%	42%	85%	38%	57%	11%
Confidence Interval	22% 23% 26% 27%	22% 23% 21% 22%	39% 40% 37% 38%				95% 95%	41% 42%	84% 85% 38% 39%	57% 58% 11% 12%		
Central Nervous System (incl brain) non-invasive	0%	0%	31%	32%	37%	40%						
Confidence Interval	0% 1% 0% 0%	29% 33% 30% 34%	36% 39% 38% 41%									
Leukaemia (excluding AML and CLL)	5%	7%	27%	29%	45%	44%						
Confidence Interval	4% 0% 0% 8%	25% 29% 27% 31%	43% 47% 42% 46%									
Pancreas	10%	14%	19%	22%	51%	46%	88%	20%	77%	24%	56%	9%
Confidence Interval	9% 11% 13% 15%	19% 20% 21% 23%	49% 52% 44% 47%				87% 89%	19% 21%	76% 78% 23% 25%	56% 57% 0% 10%		
Liver	8%	10%	22%	23%	49%	46%	88%	31%	81%	38%	54%	12%
Confidence Interval	7% 9% 9% 11%	20% 23% 22% 24%	47% 51% 45% 48%				86% 90%	28% 33%	80% 83% 36% 39%	52% 55% 11% 13%		
Leukaemia: acute myeloid	2%	3%	20%	23%	54%	54%	93%	44%	84%	35%	63%	30%
Confidence Interval	2% 3% 3% 4%	19% 22% 21% 25%	52% 56% 52% 56%				90% 95%	38% 40%	82% 85% 33% 37%	62% 64% 28% 31%		
Cancer of Unknown Primary	7%	10%	18%	21%	59%	55%	88%	37%	68%	37%	34%	5%
Confidence Interval	7% 8% 9% 11%	17% 19% 20% 22%	58% 60% 54% 56%				87% 89%	36% 39%	67% 69% 31% 33%	33% 34% 5% 6%		
Central Nervous System (incl brain) malignant	1%	1%	15%	16%	63%	61%						
Confidence Interval	1% 1% 1% 2%	14% 15% 15% 18%	61% 64% 60% 63%									

- All the figures have been rounded to the nearest whole number. This may result in the upper or lower confidence interval being equal to its main figure.  
- There is a known under recording of the proportion of screen detected cervical cancers  
- Survival results are only shown where there are sufficient cases/deaths

## The Deprivation Gap

### Identifying the impact of deprivation <sup>1</sup>: poorer people are more likely to get and die from a particular less common cancer type

- The poorer you are, the more likely you are to get and die from cancer, with more than 19,000 cancer deaths from all cancers every year linked to lower levels of income according to new research <sup>2</sup>
- The gap between rich and poor is particularly marked in lung cancer with by far the largest number of excess cases (11,700 persons per year ) and deaths (9,900 persons per year) in the more deprived
- But the gap was also particularly marked in five less common cancer types - for men this was the kidney, oesophageal and non-Hodgkin lymphoma and for women it was kidney, the throat and the back of the mouth (oropharynx) and vulva.

For more information see the NCIN's Cancer by Deprivation in England report:

[http://www.ncin.org.uk/about\\_ncin/cancer\\_by\\_deprivation\\_in\\_england](http://www.ncin.org.uk/about_ncin/cancer_by_deprivation_in_england)



<sup>1</sup> deprivation based on area of residence

<sup>2</sup> Research compiled by Cancer Research UK and Public Health England's National Cancer Intelligence Network and published on 29th May 2014.

# Cancer by Deprivation in England

## Yearly excess cancer cases 2006-2010 and deaths 2007-2011; England

showing the number of excess cases and deaths for selected cancers and for all cancers combined, where there is a statistically significant trend in the incidence or mortality rate with deprivation

Cancer type	Excess cases	Excess deaths
Lung	11,700	9,900
Cancer of Unknown Primary	1,600	1,700
Stomach	1,400	1,000
Oesophagus	1,200	1,100
Colorectal	770	860
Bladder	730	520
Liver	650	600
Larynx	650	260
Kidney and unspecified urinary organs	640	340
Pancreas	580	430
Cervix*	520	250
Oral Cavity	420	220
Uterus*	<i>(not stat. sign.)</i>	220
Oropharynx	330	190
Vulva*	240	90
Anus	150	70
Acute Myeloid Leukaemia	90	<i>(not stat. sign.)</i>
Non-Hodgkin Lymphoma	70	130
Penis*	70	30
Vagina*	50	20
Chronic Lymphocytic Leukaemia	-70	<i>(not stat. sign.)</i>
Testis*	-80	10
Chronic Myeloid Leukaemia	<i>(not stat. sign.)</i>	10
Salivary Glands	<i>(not stat. sign.)</i>	5
Breast**	-1,900	350
Prostate*	-2,500	<i>(not stat. sign.)</i>
Melanoma	-2,800	-270
<b>All cancers, excl. non-melanoma skin cancer***</b>	<b>15,300</b>	<b>19,200</b>

\* excess for sex-specific sites calculated using male/female figures only

\*\* excess for Breast cancer calculated using female figures only (male figures too small/statistically not significant)

\*\*\* excess for all cancers is calculated separately, not as an aggregate of excess figures for individual cancers

## Credits and thanks

- Cancer52 would like to record particular thanks to Lucy Ellis-Brookes and Jon Shelton, both of the National Cancer Intelligence Network (NCIN) , Public Health England, for all their work on this project
- And to Chris Carrigan, Director of the NCIN for his ongoing support for the organisation



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Cancer52 is a not for profit alliance of charities working in the field of rare  
and less common cancers

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