

**Atlas of cancer incidence and mortality  
of the  
Association of Population-based Cancer Registries in Germany (GEKID)**

**„The interactive cancer atlas of the GEKID“**

**Methodological hints**

**Summary**

The GEKID Atlas presents new cancer cases (incidence) and the mortality of cancer on the federal state level (Bundesländer) for 25 selected cancer sites or cancer groups respectively and for all cancer sites. The incidence rates in the federal states registered by the population-based cancer registries serve as basis for this. The data are published by the several cancer registries since many years in annual reports (partly in the internet, too). They are the basis of the report “Cancer in Germany” published in two-year intervals.

The data in the atlas are presented as age-standardized rates (per 100,000 persons per year, Europe standard population) and also as absolute numbers. An up-to-date projection for Germany serves as comparative reference for these federal state specific numbers and rates.

Not all federal states can be compared unrestrictedly and at each point in time. There are differences in the coverage of the registration (also including the time trend), differences in the number of persons only registered because of a death certificate as well as regional differences in screening programs. That may lead to artificial modifications of numbers and rates. For instance, an increasing coverage of the registration of a certain cancer registry will be reflected as an apparent increasing rate in the charts of the cancer frequencies. In fact, not the cancer frequency is increasing but only the number of cases having been registered.

***Please note the following methodological hints to avoid possible misinterpretations.***

In case of doubts or uncertainties please contact one of the associated cancer registries.

The cancer mortality is presented in analogy to the cancer incidence. Data source is the official mortality statistics of the Federal Statistical Office ([www.gbe-bund.de](http://www.gbe-bund.de)).

**Contact:**

Association of Population-based Cancer Registries in Germany

Internet: [www.gekid.de](http://www.gekid.de)

**Background:**

The association of the population-based cancer registries in Germany (GEKID) is a registered association with the aim to support the population-based cancer registration in Germany and the use of their data. Members are all German population-based cancer registries and also cancer researchers.



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## 1 Data sources

### 1.1 Incidence

The data presented in the atlas are the registered incidence cases of the respective state cancer registry within the registration period.

The data of the several federal states are presented disregarding the estimated coverage of registration. It is known that the coverage of several cancer sites or several states is incomplete over the whole period. Please be aware that the registered incidence has to be interpreted only as an approximation to the “real” incidence of the population.

The registered incidence comprises (according to international guidelines) all invasive neoplasms including those cases only known in the register because of a death certificate (DCO cases). Young registries (5 to 15 years) show higher DCO rates which may lead to artificially increased incidence rates. Please note this for interpretations.

The German cancer registries provide data for the atlas for the follow periods. The current dataset is from December 2011.

Availability of data according to year and federal state										
Federal state	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
Baden-Württemberg	No data available, registry under construction									
Bavaria										
Berlin										
Brandenburg										
Bremen										
Hamburg										
Hesse	No data available, registry under construction									
Mecklenburg-Western Pomerania										
Lower Saxony										
North Rhine-Westphalia*										
Rhineland-Palatinate										
Saxony-Anhalt										
Saxony										
Saarland										
Schleswig-Holstein										
Thuringia										

\* North Rhine-Westphalia is currently represented by the administrative district of Münster

Please find contact addresses and details of the several cancer registries at [www.gekid.de](http://www.gekid.de). There you also find the addresses of the homepages of the registries where the regional data of many registers are partly more differentiated and more often updated than in the atlas.

## 1.2 Mortality

The cancer mortality is presented in analogy to the cancer incidence. Data source is the official mortality statistics by the Federal Statistical Office ([www.gbe-bund.de](http://www.gbe-bund.de)). The mortality data are available for all federal states until 2010.

## 2 Indicators in the atlas

For each federal state and each cancer site the population-based age-standardized rate and the numbers of cases are presented by gender and year of diagnosis. The age-standardization was done according to the Europe standard population (per 100,000).

Bundesland ▲	Rate(ASR)*	Fallzahlen
Baden-Württemberg	Keine Daten	Keine Daten
Bayern	436,6	33.812
Berlin	402,3	8.029
Brandenburg	482,2	8.135
Bremen	461,1	2.028

The age-standardized incidence rate (Europe standard) and the number of registered neoplasms are main indicators of the GEKID atlas.

**Cases:** means the absolute number of cases registered by the respective register for the respective federal state including all cases which are known to the register only by a death certificate. In these cases the year of death is used as the year of diagnosis.

Usually the first invasive tumour counts to the incidence. In case of bladder cancer the first diagnosis

counts to the incidence even if that is non-invasive tumour (ICD-10: D09.0 or D41.4). That is also valid for “all cancer sites”.

**Rate (ASR):** The number of cases is related to the population under risk (cases per 100,000 persons). To eliminate differences in the age and gender structure within the states an age-standardization according to the Europe standard population was done. All rates are directly comparable.

You find the indicator „age-standardized rate“ in the maps and in the charts.

### 3 Selected cancer sites or cancer groups

Cancer is a disease group with more than 100 different diseases. For the atlas 25 cancer sites or cancer groups respectively have been selected used by most of the federal cancer registries in their routine reporting.

The following groups of diagnosis and the related ICD 10-code have been selected:

Cancer site / cancer group	ICD10 code
All cancer sites without non-melanoma skin cancer	C00 to C97 without C44 plus D09.0 and D41.4 (Mortality: C00-C97 without C44)
Oral cavity and pharynx	C00 to C14
Oesophagus	C15
Stomach	C16
Colon and rectum	C18 bis C21
Liver	C22
Pancreas	C25
Larynx	C32
Lung	C33 bis C34
Malignant melanoma of skin	C43
Other malignant neoplasms of skin	C44
Breast	C50
Cervix	C53
Corpus uteri	C54 und C55
Ovaries	C56
Prostate	C61
Testis	C62
Kidney	C64
Bladder	C67, D09.0, D41.4
Brain and nervous system	C70 bis C72
Thyroid gland	C73
Hodgkin's lymphoma	C81
Non-Hodgkin lymphomas	C82 bis C85, 96
Immunoproliferative disease, plasma cell neoplasms	C88, C90
Leukaemias	C91 bis C95
Lymphomas & Leukaemias (together)	C81 bis C96

## 4 Coverage of registration

The coverage of cancer registration is periodically estimated by the German center of cancer registry data. The coverage should exceed 90% according to international request.

For 2008 the following maximum coverage rates are estimated for all cancer sites:

### Coverage of the cancer registration for all cancer sites

Data source: Center for cancer registry data 2011

Baden-Württemberg	no data available
Bavaria	> 90%
Berlin	≈ 80%
Brandenburg	> 90%
Bremen	>90%
Hamburg	>90%
Hesse	no data available
Mecklenburg-Western Pomerania	≈ 90%
Lower Saxony	>90%
North Rhine-Westphalia*	>90%
Rhineland-Palatinate	≈ 90%
Saarland	>90%
Saxony	>90%
Saxony-Anhalt	≈ 80%
Schleswig-Holstein	>90%
Thuringia	≈ 90%

\* North Rhine-Westphalia is currently represented by the administrative district of Münster

Except Berlin and Saxony-Anhalt (about 80%) all participating federal states show coverage sufficient for estimation. Please note: a high rate of coverage for all cancer sites does not ensure a high rate of coverage for each cancer site.

Differences between the federal states of 10 to 20% could be caused by differences in the coverage. This is only a crude estimation. The influence of the coverage on the differences in the incidence between the states depends on the cancer site and the compared states.

## 5 DCO cases

DCO cases are cancer cases which are registered only because of a death certificate. A notification by a hospital or a physician or a pathologist does not exist in the cancer registry. The cancer disease is documented in the death certificate by a physician, but the date of diagnosis is normally unknown. According to international rules the date of diagnosis corresponds to the date of death. Without this procedure a person with cancer would be lost for the statistics. Considering these cases a wrong year of diagnosis is often recorded in the statistics. There is compensation between not covered cases of one year and DCO cases from previous years in stable cancer registries with a long duration of running. In young registries the DCO rates are very often artificially increased because the (unknown) year of diagnosis of DCO case is before the date the registry starts to run. Registries that run 5 to 15 years are young registries.

The DCO rate should be less than 10% (better less than 5%). The appearance of DCO cases is strongly depending on the medical prognosis of the cancer site.

In the table below the DCO rates for all cancer sites for federal state and year are shown.

DCO rates for all cancer sites without non-melanoma skin cancer									
Federal state	2001	2002	2003	2004	2005	2006	2007	2008	2009
Baden-Württemberg	No data available, registry under construction								
Bavaria		26%	22%	18%	17%	15%	13%	13%	11%
Berlin	32%	30%	26%	22%	19%	17%	16%	17%	18%
Brandenburg	15%	14%	13%	12%	11%	11%	11%	10%	10%
Bremen	9%	11%	9%	8%	7%	6%	6%	5%	6%
Hamburg	7%	7%	6%	6%	5%	5%	5%	3%	4%
Hesse	No data available, registry under construction								
Mecklenburg-Western-Pomerania	11%	10%	8%	12%	11%	11%	12%	13%	14%
Lower Saxony			21%	17%	15%	11%	12%	10%	10%
North Rhine-Westphalia*	10%	7%	8%	9%	7%	0%	0%	0%	0%
Rhineland-Palatinate	24%	23%	21%	19%	16%	14%	13%	14%	
Saarland	3%	2%	4%	4%	5%	6%	5%	4%	6%
Saxony	12%	12%	13%	13%	11%	10%	10%	10%	11%
Saxony-Anhalt	22%	20%	22%	21%	20%	21%	19%	17%	17%
Schleswig-Holstein	21%	19%	12%	11%	11%	11%	11%	17%	16%
Thuringia	21%	24%	20%	16%	14%	14%	14%	13%	12%

\* North Rhine-Westphalia is currently represented by the administrative district of Münster

You can get more information on DCO rates and their influence on the incidence rate of the federal states by the respective cancer registry. Contact details you find at ([www.gekid.de](http://www.gekid.de)).

## 6 Projections

A cancer rate for Germany as a whole was projected as a reference in the atlas for comparing the several federal states. The rates were calculated from the year of diagnosis 2003.

### 6.1 Methods of the projection

The data of selected state cancer registries were pooled. From the pooled data respective disease rates were extracted and subsequently transferred and projected to the whole German population. The rate multiplied with the population equals a number of cases. The calculations were done for each of 18 age groups (0-4 years, 5-9, 10-14 ... 85 and older) and both sexes.

The age-standardized incidence rates (ASR[E]) for Germany can be calculated from the projected number of cases. The standardizations were done with the Europe standard population.

**Example for the projection of new cancer cases for Germany and the year of diagnosis 2006 –  
All cancer sites without non-melanoma skin cancer**

<i>age group</i>	<b>Data pool</b> age-specific rate per 100,000 persons		<b>Population</b> Germany in the year 2006		<b>Projection</b> Numbers of new cancer cases in the year 2006 in Germany	
	<i>male</i>	<i>female</i>	<i>male</i>	<i>female</i>	<i>male</i>	<i>female</i>
0-4	22.6	18.0	1,814,392	1,722,424	410	310
5-9	11.2	8.2	2,017,904	1,916,361	226	157
10-14	13.7	10.9	2,089,653	1,983,531	286	216
15-19	19.8	16.2	2,460,792	2,337,956	487	379
20-24	33.7	24.5	2,461,404	2,389,216	829	585
25-29	44.9	49.6	2,474,656	2,410,893	1,111	1,196
30-34	59.4	82.3	2,488,757	2,408,257	1,478	1,982
35-39	82.4	139.4	3,350,602	3,193,230	2,761	4,451
40-44	133.9	231.0	3,691,585	3,508,400	4,943	8,104
45-49	240.5	356.2	3,273,689	3,165,857	7,873	11,277
50-54	455.4	493.6	2,832,935	2,826,599	12,901	13,952
55-59	816.7	686.9	2,478,599	2,501,151	20,243	17,180
60-64	1,343.4	892.8	2,204,673	2,281,582	29,618	20,370
65-69	1,881.1	1,065.3	2,590,255	2,825,358	48,725	30,099
70-74	2,418.4	1,241.6	1,759,243	2,105,694	42,546	26,144
75-79	2,846.3	1,458.9	1,254,517	1,803,864	35,707	26,317
80-84	3,128.6	1,763.3	676,508	1,484,466	21,165	26,176
85+	3,644.2	2,173.1	397,643	1,183,164	14,491	25,711
<b>total</b>			<b>40,317,807</b>	<b>42,048,003</b>	245,801	214,607
<b>ASR(E)</b>					<b>467.1</b>	<b>334.5</b>

## 6.2 Used data pool

The data pool results from selected registries in a consensus procedure between all population-based cancer registries. The respective registries should have a high degree of coverage and a stable time trend. Currently the pool comprises the data of the following federal states:

- Bavaria
- Brandenburg (Joint cancer registry, GKR)
- Bremen
- Hamburg
- Mecklenburg-Western Pomerania (GKR)
- Lower Saxony
- North Rhine-Westphalia (administrative district of Münster, excluded for the consideration of the DCO rate)
- Saarland

- Saxony (GKR)
- Schleswig-Holstein

The current pool covers a total population of 37.9 million inhabitants, i.e. about 46% of the German population as a whole. The proportion East-to-West Germany (former GDR and former FRG) in the pool is nearly 1 : 3.5 being comparable to 1 : 3.9 in the whole population. So a sufficient representativeness for Germany should be reached with the pool data.

The data of the pool registers will evaluate each time by an expert working group. Several indicators will be used as you see in the table below. In this table you find the indicators for all cancer sites. The working group evaluates the indicators for more cancer sites or groups (data not shown). Due to a pending complementary adjustment of the NRW Cancer Registry Act (2005) it is currently not possible to calculate a valid DCO rate for the district of Münster (NRW).

As you see in the table the indicators are similarly over time and over the registries, too. To the experts mind the used registries are appropriate for a projection of the data for Germany as whole currently.

<b>Quality indicators of the pool registers for all cancer sites</b>							
<b>Pool register</b>	<b>2003</b>	<b>2004</b>	<b>2005</b>	<b>2006</b>	<b>2007</b>	<b>2008</b>	<b>2009</b>
<b>Ratio of mortality to incidence</b>							
Bavaria	0,45	0,43	0,43	0,43	0,42	0,43	0,45
Brandenburg	0,52	0,50	0,48	0,48	0,45	0,44	0,45
Bremen	0,43	0,46	0,47	0,46	0,44	0,46	0,49
Hamburg	0,52	0,49	0,48	0,49	0,50	0,47	0,44
Mecklenburg-West. Pom	0,49	0,48	0,47	0,46	0,47	0,47	0,47
Muenster	0,47	0,48	0,49	0,48	0,48	0,48	0,47
Lower Saxony	0,42	0,41	0,43	0,44	0,43	0,42	0,44
Saarland	0,47	0,48	0,49	0,49	0,47	0,50	0,49
Saxony	0,48	0,47	0,48	0,47	0,46	0,44	0,44
Schleswig-Holstein	0,42	0,42	0,41	0,42	0,42	0,41	0,41
<b>Constancy (Change to pervious year)</b>							
Bavaria	100 %	102 %	99 %	99 %	99 %	98 %	95 %
Brandenburg	100 %	99 %	100 %	100 %	101 %	98 %	97 %
Bremen	100 %	93 %	99 %	99 %	101 %	102 %	92 %
Hamburg	100 %	101 %	103 %	97 %	100 %	102 %	105 %
Mecklenburg-West. Pom	100 %	100 %	102 %	101 %	97 %	101 %	102 %
Muenster	100 %	103 %	101 %	104 %	100 %	100 %	99 %
Lower Saxony	100 %	98 %	97 %	95 %	102 %	102 %	96 %
Saarland	100 %	98 %	99 %	102 %	103 %	95 %	98 %
Saxony	100 %	100 %	99 %	100 %	103 %	105 %	99 %
Schleswig-Holstein	100 %	98 %	94 %	101 %	98 %	102 %	98 %
<b>Constancy (2008 = 100%)</b>							
Bavaria	102 %	104 %	103 %	102 %	102 %	100 %	95 %
Brandenburg	102 %	101 %	100 %	101 %	102 %	100 %	97 %
Bremen	106 %	99 %	98 %	97 %	98 %	100 %	92 %
Hamburg	97 %	98 %	101 %	98 %	98 %	100 %	105 %
Mecklenburg-West. Pom	99 %	99 %	101 %	102 %	99 %	100 %	102 %
Muenster	93 %	96 %	97 %	100 %	100 %	100 %	99 %
Lower Saxony	106 %	104 %	101 %	96 %	98 %	100 %	96 %
Saarland	104 %	101 %	100 %	102 %	105 %	100 %	98 %
Saxony	94 %	94 %	92 %	93 %	95 %	100 %	99 %
Schleswig-Holstein	108 %	106 %	99 %	100 %	98 %	100 %	98 %
<b>Percentage of DCO</b>							
Bavaria	21,6 %	18,5 %	16,9 %	14,8 %	13,2 %	12,7 %	11,3 %
Brandenburg	13,4 %	12,0 %	11,0 %	10,8 %	10,6 %	10,3 %	10,3 %
Bremen	8,7 %	7,6 %	7,0 %	6,1 %	5,8 %	4,9 %	5,6 %
Hamburg	5,9 %	6,1 %	5,4 %	5,5 %	5,1 %	3,4 %	3,5 %
Mecklenburg-West. Pom	8,2 %	12,3 %	11,2 %	11,3 %	11,6 %	13,0 %	13,5 %
Muenster	7,7 %	9,3 %	6,7 %				
Lower Saxony	20,9 %	17,5 %	15,5 %	11,4 %	12,3 %	10,2 %	9,7 %
Saarland	3,7 %	4,5 %	4,7 %	5,9 %	5,4 %	3,8 %	6,0 %
Saxony	13,1 %	12,7 %	10,8 %	10,4 %	10,2 %	10,0 %	11,2 %
Schleswig-Holstein	12,4 %	11,4 %	11,4 %	11,4 %	10,6 %	16,6 %	16,2 %

### 6.3 The problem of different DCO rates between the federal states in the pool

The DCO rates still differ relevantly between the federal states (see above “DCO cases”). There are still artificially increased DCO rates as expected in the more populous and “younger” cancer registries of Bavaria and Lower Saxony on the one hand. On the other hand the sole use of the very low DCO rates of the older registries (e.g. Saarland, Hamburg) for Germany as a whole does not make sense because in the younger registries DCO cases compensate the absence of a coverage of 100%.

A passable solution is the use of a current median DCO rate of all pool registries together. Since the DCO rate itself show a time trend (up to lower rates), the median DCO rate of the respective last three years of all pool registers (by cancer site, sex and age group) was used.

**Transfer of the median DCO rates to the age-specific disease rates without DCO – Example: All cancer sites without non-melanoma skin cancer (2006)**

<i>age group</i>	<b>Rate without DCO</b> age-specific rate per 100,000 persons		<b>Rate including median DCO</b> <b>proportion</b> age-specific rate per 100,000 persons		<b>median DCO proportion</b>	
	<i>male</i>	<i>female</i>	<i>male</i>	<i>female</i>	<i>male</i>	<i>female</i>
0-4	21,9	17,4	22,6	18,0	3%	4%
5-9	10,8	8,2	11,2	8,2	4%	0%
10-14	13,7	10,9	13,7	10,9	0%	0%
15-19	19,8	16,2	19,8	16,2	0%	0%
20-24	33,2	24,5	33,7	24,5	1%	0%
25-29	44,0	48,6	44,9	49,6	2%	2%
30-34	58,0	81,3	59,4	82,3	2%	1%
35-39	80,3	137,6	82,4	139,4	3%	1%
40-44	127,3	226,4	133,9	231,0	5%	2%
45-49	227,0	348,8	240,5	356,2	6%	2%
50-54	423,8	479,8	455,4	493,6	7%	3%
55-59	764,5	657,7	816,7	686,9	6%	4%
60-64	1.253,7	851,7	1.343,4	892,8	7%	5%
65-69	1.724,1	994,6	1.881,1	1.065,3	8%	7%
70-74	2.162,1	1.108,6	2.418,4	1.241,6	11%	11%
75-79	2.406,0	1.211,7	2.846,3	1.458,9	15%	17%
80-84	2.308,5	1.281,4	3.128,6	1.763,3	26%	27%
85+	1.852,1	1.126,0	3.644,2	2.173,1	49%	48%
<b>Total</b>	<b>532,8</b>	<b>439,1</b>	<b>601,9</b>	<b>506,7</b>	<b>11%</b>	<b>13%</b>
<b>ASR(E)</b>	<b>406,5</b>	<b>301,05</b>	<b>467,1</b>	<b>334,5</b>		

For the calculation a cancer rate was calculated with the data of the pool for each cancer site according to each age group and each sex without DCO cases. The respective current median

proportion was added to these age and sex specific rates. So finally there are age and sex specific cancer rates including a median DCO proportion.