Local Cancer Intelligence

Frequently asked questions

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What is a Clinical Commissioning group (CCG) or Local Area Team?

- **CCG:** The 211 Clinical Commissioning Groups (CCG) are NHS organisations set up by the Health and Social Care Act 2012 to organise the delivery of NHS services in England. They are clinically led groups that include all of the general practice groups in their geographical area. The aim of this is to give GPs and other clinicians the power to influence commissioning decisions for their patients. CCGs are overseen by NHS England (including its Regional Offices and Area Teams). These structures will manage primary care commissioning, including holding the NHS Contracts for GP Practices NHS. CCGs have boundaries that are coterminous with those of lower layer super output areas.

- **LAT:** There are 25 NHS Local Area Teams (LAT) in England. LATs have responsibility of GP and dental services, pharmacy and certain aspects of optical services. Ten of the teams lead on specialised commissioning across England and a smaller number of area teams carry out the direct commissioning of prison and military health.


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What is cancer prevalence and where are the data from?

We use the term ‘cancer prevalence’ for the number of people who have been diagnosed with cancer in the past and who are still alive, on a given date. The date we use here is 31 December 2010. We present 20-year prevalence, which is the number of people still alive who were registered with a cancer diagnosis within the 20-year period 1991-2010, in England.

The cancers included are:

- All cancers: all malignant cancers excluding non-melanoma skin cancer (NMSC) (ICD10 codes C00-C97, excluding C44).
- Breast (female): C50
- Prostate: C61
- Lung (trachea, bronchus and lung): C33-34
- Colorectal (colon, rectosigmoid junction, rectum, anus and anal canal): C18-21

Cancer prevalence figures have been calculated by counting the number of people diagnosed with cancer in the given period, based on the information collected by cancer registries and using the National Cancer Data Repository (NCDR). If a person died or left the country in the given period (1991-2010), or were aged over 99 at diagnosis or over 105 at the end of 2010, they were removed from the study.
Analysis for all malignant neoplasms combined are based on the first cancer diagnosed in each person, within the period of the study. This approach aligns with the methods used to estimate the “two million” people living with or beyond a cancer diagnosis in UK (Maddams et al., 2009). The cancer type data is based on first diagnosis of each specific cancer - for example, if a person were diagnosed with lung cancer in 1991 and colorectal cancer in 2005, they would be included in counts for both lung and colorectal cancers. If that person was diagnosed with lung cancer in 1991 then with lung cancer again in 1997, that person would be counted only once in lung cancer, based on their first lung cancer diagnosis in 1991.

The numbers in this analysis may not agree with those published elsewhere due to slight differences in methodologies, data extraction methods, periods of observation, datasets, and rounding.

Work is ongoing to scale up these 20-year prevalence figures to complete prevalence, i.e. the total count of people who are alive and have ever had a cancer diagnosis, and update figures and methods first published by Maddams et al. (2009).

Sources:


Macmillan and the National Cancer Intelligence Network are working in partnership to develop robust data analysis and insight, which increases our understanding of the UK cancer survivorship population and helps make personalised care a reality. Find out more about our work here.

**Why is prevalence important?**

Cancer prevalence statistics are essential for understanding the number of people who have previously received a diagnosis of cancer and their need for care. Some people will be receiving active treatment for their cancer, some may be recovering from cancer and readjusting to life after treatment and others may be living with the on-going consequences of their cancer and its treatment.

**What does living with cancer mean for a patient and why is time since diagnosis helpful?**

The cancer prevalence numbers are defined as the number of people who are currently alive and have had a cancer diagnosis in the past - in this case for people diagnosed in the 20-year period 1991-2010. For some of these people the cancer will be influencing most aspects of their lives whilst for others the impact will be less acute.

The cancer prevalence data are provided for the total 20-year period and by periods of time after first diagnosis: 0-1 years, 1-2 years, 2-5 years, 5-10 years, 10-15 years and 15-20
years. In the UK our study shows around 1.8 million people are living with and beyond cancer, having had a cancer diagnosis in the 20-year period between 1991 and 2010. Of these, 10% (around 183,880) were diagnosed at the start of the period, between 1991 and 1995, so have been living with and beyond cancer for 15 to 20 years after their first diagnosis in that period. Of the more recently diagnosed, 13% (around 235,590) have been living with cancer for up to one year.

Segmenting the prevalent cancer population in this way provides an insight into how many people have recently been diagnosed with cancer, and how many are longer term survivors. The total prevalence figures for the 20-year period are a useful indicator of the burden of cancer as a whole, however, patient needs and experiences will vary over time after diagnosis. Segmenting the prevalent population by time since diagnosis can therefore help to inform health care service planning for the needs of people living with and beyond cancer at different time periods on their pathway.


Why is prevalence rising?

The increase in prevalence is a function of the growing and ageing population alongside the increasing number of people being diagnosed with and surviving cancer. The growth in cancer incidence and survival is due to the following main factors:

- An ageing population: life expectancy is increasing, with more elderly people alive today than ever before. Cancer is primarily a disease of older people. Hence there are more people being diagnosed with cancer.
- A greater focus on early diagnosis.
- Advances in cancer treatments.
- Changing lifestyle risk factors: for example increases in obesity rates, and decreases in smoking prevalence.

How have future prevalence estimates been calculated?

Our future CCG prevalence estimates are the estimated number of people that might be living up to 20 years with a cancer diagnosis prior to the projection date (e.g. 20-year prevalence in 2030 is the number of people diagnosed between 2011 and 2030 who are alive at the end of 2030).

Future estimates for CCGs are crude and based on Maddams et al. (2012) future cancer prevalence projections for the UK as a whole. The future estimates here take into account how many people were alive at the end of the year 2010 who had been diagnosed with cancer in the period 1991-2010, by CCG. Then UK-level future estimated trends have been applied to these locality data, based on two of the four scenarios used by Maddams et al. (2012)
Scenario 1: assumes existing trends in incidence and survival will continue in the future (except for prostate cancer), together with the continued growth and ageing of the general population. This was considered to be the most empirically based scenario by the authors.

Scenario 2: assumes age- and sex-specific incidence and survival remain constant (2008 to 2030). The growth in prevalence is therefore driven by growing and changing population demographics only. This was considered by the authors to be the most conservative scenario.

Maddams et al. (2012) growth rates used for UK total prevalence (i.e. all people currently alive who have been diagnosed with cancer, not just for a 20-year period) are then applied to each CCG’s 20-year prevalence figure, thus assuming that the rate of change for all CCGs is the same as for the UK and for complete prevalence. Future CCG estimates are not adjusted for local differences and changes in the age structure, size and movement of the local population; cancer type profiles and trends; trends in risk factors and the possibility of future advances in screening and treatment regimes. Estimates are as such indicative only but aim to provide an estimate of the number of people living with cancer for CCGs in both the short- and long-term.

Work is ongoing to scale up the 20-year prevalence figures presented here to complete prevalence and so update figures and methods first published by Maddams et al. in 2009. The simple projections presented here will in due course be scrutinised and developed as more detailed data become available.

Sources:


How accurate can you be at predicting future prevalence?

Predicting the future is difficult, particularly as there are limited data currently available for the newly-created CCGs and their resident populations. The CCG future prevalence estimates provided here are therefore based on crude calculations and provide proxy numbers. Future estimates will naturally change over time, as more data are available.

We provide these estimates to give an indication of how your local population might grow and reflects two possible future scenarios as noted in FAQ above.
However, there are some limitations to predicting future trends, while a number of assumptions need to be made in order to make any future estimates. Key points are noted below.

Our CCG estimates are based on:

- The projections calculated by Maddams et al (2012) for the UK as a whole. Therefore our estimates do not take into account unknown factors that may happen in the future e.g. factors that influence cancer incidence (e.g. smoking rates, screening programmes, risky lifestyles) or outcomes (e.g. new treatments, changes in access to care).

- Applying UK-wide projections of prevalence to CCG 20-year prevalence figures for 2010 (i.e. assuming the rate of change in the UK will be the same for each CCG). Therefore they do not take into account differences in the CCG populations and how these may evolve over time. For example, if a CCG population ages or grows faster than the UK overall, or if it is more or less socio-economically deprived relative to the rest of the UK, this would affect the future estimate for that CCG presented here.

- Where people lived at the time of their diagnosis, not where they live now or in the future – so the future estimations do not take into account population movement since time of diagnosis or in the future.

Despite these caveats, these data can be used to influence planning as there is a clear indication that the cancer population is going to increase. As such, long-term planning will need to cater for a larger, older and, most likely, a more complex cancer population i.e. potentially with more comorbidities and needs than today.

Sources:


Cancer incidence and mortality in my local area - Back to contents

What is cancer incidence and where are the data from?

Incidence is the number or rate (per head of population) of new cases of cancer diagnosed in a given population in a defined time period (in this case a year). This does not include secondary cancers or recurrences. Only rates per 100,000 have been presented here. Charts comparing different CCGs within the Local Area Team also show the Upper and Lower confidence Intervals (CI) of the CCGs incidence rate. Figures for the number of diagnosis have not been presented at this time.
Data on patients diagnosed with cancer are recorded on the National Cancer Data Repository. The data can be analysed and then presented - by single year and all age groups combined for CCGs. The population files, based on Office for National Statistics estimates, were prepared for use by Public Health England’s Knowledge and Intelligence Team (West Midlands) on behalf of the United Kingdom and Ireland Association of Cancer Registries (UKIACR). Population data have similarly been extracted by CCGs.

Data are not currently publicly available for brain or central nervous system (CNS) tumours. More detail on cancer incidence including brain or CNS tumours for NHS users can be found in the Cancer Commissioning toolkit https://www.cancertoolkit.co.uk/ (accessed May 2014).


What are the tumour groups included for incidence and mortality?

The tumour groups included for incidence and mortality along with their corresponding international classification of disease (ICD10) codes are as follows:

- All cancers: all malignant cancers excluding non-melanoma skin cancer (NMSC) (ICD10 codes C00-C97, excluding C44).
- Breast: C50
- Urology: C60-C68 (includes prostate cancer)
- Lung: C33, C34, C37, C38, C39, C45 (includes Thorax cancer)
- Lower Gastrointestinal (GI): C17-C21 (includes colorectal)

Data are not currently available separately for prostate, colorectal and lung cancer so we present higher level groupings of cancers. The majority of urological cancers will be prostate cancer, of Lower GI will be colorectal cancer and of ‘lung’ cancers the majority will be lung cancers (usually classified as C33-34). Data are not currently publicly available for brain or central nervous system (CNS) tumours. More detail on further tumour groups including brain or CNS tumours for NHS users can be found in the Cancer Commissioning toolkit https://www.cancertoolkit.co.uk/ (accessed May 2014).

What are age standardised rates and why have they been used?

Age-standardised rates take into account the variation in the age structures of populations. The age-standardised rates adjust for age to allow comparisons between different areas or time trends to be made.

The rates are directly age-standardised rates and are calculated by taking the age-specific crude rates and applying them to the age distribution of a hypothetical population (in this case, the 2013 European Standard Population (ESP)). Until recently age-standardised rates have been calculated using the 1976 ESP. This change in population for the calculations may mean that the rates presented here are higher than those in other sources, previous publications or higher than expected.
Compared to the 1976 ESP, the 2013 ESP places greater weight on older age groups, which more closely reflects the age distribution in current European populations. For this reason, and because both cancer diagnoses and deaths are more common amongst older age groups, age-standardised rates calculated with the 2013 ESP are likely to be much higher than those calculated with the 1976 ESP; the rates calculated with the 2013 ESP are also more likely to reflect the true rates in the population at the current time. Further details of the implications of using the 2013 ESP are noted by the Office for National Statistics here.

The 2013 ESP is currently being rolled out and not all published rates across England and the UK will necessarily now be using the 2013 ESP. Historical trends and past publications will have used the 1976 ESP to calculate age-standardised rates. As such data using the different ESPs will not be comparable and consideration of the ESP used to calculate age-standardised rates will be needed to ensure any comparisons between data sources are appropriate.

Source: Calculated by South West Knowledge and Intelligence Team (KIT), Public Health England (PHE), using the Network of Public Health Observatories age-standardised rate method.

What does it mean when we say ‘higher than’, 'lower than' or 'similar to' the England average for incidence and mortality?

The reference to higher than, lower than or similar to indicates whether the age-standardised rate for the locality is statistically significantly different to the England average. When looking at data sometimes differences may be due to chance and depends on the quality and random and natural variation of the subject of interest. The difference we highlight is defined by comparing if the confidence intervals for the local area with the rate for England. Confidence intervals are used to show the range around a data point where we are, in this case, 95% sure that the true value lies, so is a measure of how confident we are that the statistic is true.

‘Higher than’ indicates that the local rate is significantly higher than the England average and this difference is unlikely to be due to chance i.e. we are 95% sure that the figure is different. ‘Similar to’ indicates that local rate is not significantly different — the numbers may not be identical but we cannot be sure that the true difference is not due to chance so we say that the local figure is not significantly different to the England average. ‘Lower than’ indicates that the local rate is significantly lower than the England average and this difference is unlikely to be due to chance.

What is cancer mortality and where are the data from?

Cancer mortality is the number or rate of deaths from cancer in a given population in a defined time period (usually a year). Mortality data relate to all deaths registered with cancer mentioned as an underlying cause of death. Only rates per 100,000 have been presented here. Charts comparing different CCGs within the Local Area Team also show the Upper and Lower confidence Intervals (CI) of the CCGs mortality rate. Figures for the number of cancer deaths have not been presented at this time.
In 2012, cancers accounted for 29% of all deaths, while circulatory diseases (which includes deaths from ischaemic heart disease and strokes) and respiratory diseases (including deaths from pneumonia) accounted for 28% and 14% of all deaths respectively in England and Wales.

Source: Public Health England’s’ Cancer Analysis System and Office for National Statistics. 2008 - 2012 patients of all ages who have died of cancer by year of registered cancer death for CCGs chart extracted June 2014 from PHE National Cancer Intelligence Networks’ Cancer Commissioning Toolkit.

Data on patients dying of cancer are sent from Office for National Statistics to the National Cancer Registry which in turn updates the records.

More detail on cancer mortality for NHS users can be found in the Cancer Commissioning toolkit https://www.cancertoolkit.co.uk/ (accessed May 2014)

Cancer survival in my area - Back to contents

What is an all cancers net survival index and where are the data from?

Net survival in a population of cancer patients is their survival from the cancer of interest after adjustment for other causes of death. Presented here are one-year net survival rates by Clinical Commissioning Group (CCG) (all cancers combined) for people diagnosed with cancer in 2011 and five-year net survival rates by Local Area Team for (all cancers combined) for people diagnosed with cancer in 2007. All first, primary, invasive malignancies were eligible for inclusion. Patients diagnosed with prostate cancer or non-melanoma skin cancers were excluded.

Cancer survival is influenced by the age people get cancer, the type of cancer they have and stage at presentation. To make a fair comparison of changes in survival over time and space, a survival index has been created that adjusts for the effect of changes over time in the profile of cancer patients by age, sex and type of cancer within each CCG. This means any changes in the survival index over time are due to changes in the outcomes of people with similar ages and cancer types. For more detail on the calculations please consult the source.

Cancer of the prostate was excluded from the index, because the widespread introduction of prostate-specific antigen (PSA) testing since the early 1990s has led to difficulty in the interpretation of survival trends. More detail on prostate survival by the NCIN can be found at: http://www.ncin.org.uk/publications/data_briefings/prostate_cancer_survival (accessed May 2014)

Sources:

Why are CCG data not presented for five year net survival index and only up to 2007?

Five year survival index data are only presented for the Local Area Team as data at a CCG level are not statistically robust and hence not available. Development work on a five year survival indicator highlighted that it was not possible to develop a statistically robust measure at individual CCG level. Any year to year variation in an indicator can reflect actual improvement or deterioration in the position and not simply natural fluctuations. The smaller the number of patients, the greater the risk of this issue arising and this is a possible when dealing with CCGs.

In the case of the cancer survival indicators although there were a sufficient number of patients at the one year survival point for the indicator to be robust, this was not the case at the five year point. This reflects the smaller number of patients at the five year point due to those who have died between one and five years after diagnosis.

Data for five-year survival are for people diagnosed in 2007 and followed up to 2012.

If CCGs came into existence in April 2013, why does the tool contain data from before this for CCGs?

It is appreciated that a Clinical Commissioning Group cannot be responsible for trends in cancer outcomes that pre-date its existence. However, it is still useful for CCGs to have historical outcome measures for patients who were resident within their current boundaries at the time of diagnosis. This historical data can help the user predict what might happen in the future and to understand the historical challenges in their area.

What does it mean when we say ‘better than’, ‘poorer than’ ’similar to’ or compared to the England average for survival?

The reference to better than, poorer than or similar to indicates whether the survival figures for the CCG is significantly different to the England average. When looking at data sometimes differences may be due to chance and depends on the quality and random and natural variation of the subject of interest. The difference we highlight is defined by identifying the precision of the CCG survival compared to the figure for England. A statistical test is carried out to show how much a particular survival percentage varies from the overall survival for that year in England. For full details please refer to the source paper.

‘Better than’ indicates that the CCG rate is higher than the England average and this difference is unlikely to be due to chance. ‘Similar to’ indicates that local rate does not really vary – the numbers may not be identical but we cannot be sure that the true difference is not
due to chance so we say that the local figure is similar to the England average. ‘Poorer than’ indicates that the CCG rate is lower than the England average and this difference is unlikely to be due to chance.

For the five year survival index the precision test was not available so we present the England figure next to the Local Area Team figure. We cannot be sure how different the Local Area Team survival index is to the England average so simple present the comparative figure for England.


Patient experience in my area - Back to contents

What is patient experience and where are the data from?

Patient experience encompasses most aspects of care outside of the impact of treatment. It includes things like whether patients were treated with dignity and respect, given good information, involved in decisions, and their views and preferences listened to and taken into account, for example

- Were you properly informed about your choices for care and treatment?
- Were you given a clinical nurse specialist?
- Were you called by your preferred name?
- Were you sent for diagnostic tests early enough or did you need to keep returning to your GP?
- Were you informed about how to spot recurrence and what to do if you did?
- Were you told about any possible side effects of treatment?
- Were you given information by hospital staff about how to access financial support if need be?

All of these types of questions were included in the survey and are classed by NHS England as ‘patient experience’. A good experience would be one where people with cancer feel supported, respected and meaningfully involved in decisions about their care. This includes recognising that cancer can affect someone’s whole life, as well as the people who are important to them. Key aspects for good experience include: high quality communication, meaningful involvement and coordinated care.
NHS England’s National Cancer Patient Experience Survey (CPES), carried out by Quality Health, provides insights into the care and treatment experienced by cancer patients in 155 NHS hospital trusts across England. In the 2012–13 survey, 68,737 cancer patients treated in hospital as day cases or inpatients during September to November 2012 took part. This is the third national CPES; the previous surveys ran in 2011–12 and 2010. More details on the survey can be found here: [http://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey](http://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey) (accessed June 2014). These data show the experiences of care for people with cancer who have been a hospital inpatient or day case between September and November 2013, living in the selected CCG area. Comparisons to the national average, and highest and lowest scoring CCGs are also shown.


How have people been allocated to CCGs in the CPES?

Data for each respondent has been allocated to the Clinical Commissioning Group identified as covering the place of residence of the patient. The CCG thus identified as the place of residence of the patient is not therefore necessarily the referring CCG, although there is likely to be close similarity between data for CCG of residence and referring CCG.

There were 68,737 respondents to the 2013 CPES. All these respondents had postcodes which mapped to CCGs in the Health and Social Care Information Centre mapping system (available at [http://systems.hscic.gov.uk/data/ods/datadownloads/pcodedata](http://systems.hscic.gov.uk/data/ods/datadownloads/pcodedata) accessed June 2014).

What is the data and what do the different scores mean in the CPES?

The scoring system used in this data cut is the same as used for scoring in the national and Trust level reports on the 2013 CPES. The percentage presented in the graphs is the percentage of people who gave a positive response to the questions selected.

The data have been presented in a map and graphics to help show where your CCG sits compared to other CCGs and the average percentage score for England.

**CCG score** – displays the percentage of people reporting a positive experience for that question. The upper and lower confidence levels are also provided.

**England average** – displays the overall score for England for that question.

**Number of respondents** – displays the absolute number of respondents in respect of this CCG from all Providers in the NHS. This number is not the same for each question for legitimate reasons – for example, not all questions are applicable for all respondents and not all respondents answer all the questions.

Because many patients attend multiple hospitals for treatment, the methodology used for the CPES takes the LAST attendance in a hospital during the relevant data capture period (in this case September November 2012 inclusive) and allocates the patient to that Trust for the
purposes of analysis. The questionnaire provides detailed instructions to respondents on how to complete the survey if they have attended more than one Trust for treatment.

This analysis has been prepared by Quality Health, who organise and run the National Cancer Patient Experience Survey Programme on behalf of NHS England.

**Why are some scores not available in the CPES?**

Where the number of respondents in a particular CCG is less than 20, we have used the convention of leaving the relevant cell blank as there is insufficient data to allow display.

Some CCGs have relatively small numbers of cancer patients, so the total number of respondents to the survey may be low despite a high response rate. Data for these CCGs have been completed in the normal way, but the results for these areas need to be treated with caution due to small sample numbers. It is important to recognise, however, that the low numbers of respondents is simply the result of low numbers of cancer patients being treated and maybe dependent on the relative resident population of that CCG.

The data contained in these tables relate only to scored questions. Indicator questions (e.g. have you had an operation) are not described.

**Does experience of care vary for different people in the CPES?**

Variations in patient experience still prevail between Trusts and tumour groups. Younger patients tend to report more negative experiences across a number of different elements of patient experience, patients from ethnic minority groups consistently report less positive experiences and women tend to report more negative experiences of care across the board. These variations data are not currently available for individual CCGs but are presented in the National and Trust reports here: [http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey](http://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey) (accessed April 2014)

**Where can I find further information about patient experience?**

- Top Tips Guide for Improving Patient Experience
- Patient guide to using Cancer Patient Experience Survey
- Report - Improving care for people with cancer Course on Macmillan Values Based Standard

**Routes to and from diagnosis - Back to contents**

**What are the different measures of survival by cancer type?**

**Median survival by cancer type** is the duration of time since diagnosis when relative survival is at 50% and we interpret this as the time when half of the patients have survived (or half have died). Survival is often only presented as a count of the number or proportion of people to reach certain markers; one, five or ten years after diagnosis. By calculating the median survival time we know the actual number of years since diagnosis half of patients have survived. Median survival time is presented for those diagnosed in 2007 in England.

**One-year and five-year net survival by cancer type** are presented to give an indication of the general prognosis for people diagnosed with this cancer type. Data are for adults (aged 15–99 years) by cancer type in England during 2007–2011 and followed up to 31 December 2012.

England data are presented for one and five-year survival for individual cancers. Data by cancer type are not currently available by CCG or LAT.


**What is Routes to diagnosis and what can it tell us?**

A ‘Route to Diagnosis’ is defined as the sequence of interactions between the patient and the healthcare system which lead to a diagnosis of cancer, based on the end point, the pathway and the referral route into secondary care. Depending on context it might either be a ‘detailed’ route, e.g. IP-C-O4, or a broad summary route, e.g. “Emergency Presentation”.

The Routes to Diagnosis study by National Cancer Intelligence Network defines a methodology by which the route the patient follows to the point of diagnosis can be categorised, in order to examine demographic, organisational, service and personal reasons for delayed diagnosis. Initial Routes to Diagnosis results for patients diagnosed in 2007 were presented in the National Cancer Intelligence Network data briefing: Routes to Diagnosis, in November 2010. Since then the methodology has been reviewed and the results have been updated to include patients diagnosed from 2006 to 2008. The latest results for 2006-10 presented here follow the same methodology as the 2006-2008 study.

Administrative Hospital Episode Statistics (HES) data are combined with Cancer Waiting Times (CWT) data, data from the cancer screening programmes and cancer registration data from the National Cancer Data Repository (NCDR). Using these datasets every case of cancer registered in England which was diagnosed in 2006-2010 is categorised into one of eight ‘Routes to Diagnosis’. Results for the 2006-2010 study have fewer cases assigned to the “unknown” Route due to more complete HES data being available. Having a 5-year cohort to base results from has also enabled more cancer sites to be included in the results.

The tool also presents associated one-year survival rates. Routes to diagnosis data can be used to enhance understanding of and explore possible reasons for delayed diagnosis. It can be looked at alongside one-year survival to understand how diagnosis might impact survival rates.

Source: National Cancer Intelligence Network. *Routes to diagnosis (2006-2010).* Excel extracted June 2014 from PHE National Cancer Intelligence Network’s Cancer

More information on Routes to Diagnosis in your CCG and comparisons by cancer type can be downloaded here.

**What is Routes from Diagnosis and what can it tell us?**

Macmillan’s Routes from Diagnosis research programme is an approach which links and analyses pseudoanonymised routinely collected data, such as Cancer Registry data and Hospital Episode Statistics (HES). It allows us to map the cancer journey from diagnosis to death (or ongoing survival) describing the health outcomes that patients experience. This can include survival times as well as the rate and frequency of cancer- and non-cancer related morbidities.

The approach also lets us see how the frequency and rate of cancer diagnoses is affecting the health care system, for example the lengths of time patients spend in hospital, when they access a health care service and how much this costs.

These are the results from the first phase of a study led by Macmillan Cancer Support in partnership with research consultancy Monitor Deloitte and Public Health England’s National Cancer Intelligence Network (NCIN) as part of its Routes from Diagnosis programme.

The research provides a retrospective analysis of almost 85,000 cancer patients’ interactions with the NHS in England over a seven-year period (2004-2011). It allows us to understand the different outcomes for cancer patients and what happens to them as they travel through their clinical journey, in more detail than ever before.

**Routes from diagnosis: Outcome groups**

Routes from Diagnosis uses survivorship outcome frameworks to separate patients into mutually exclusive, collectively exhaustive groups, first by survival length and then adding layers of detail appropriate to each cancer type. These can been produced in both detailed and simplified formats. For ease of interpretation, the simplified frameworks are presented here. For more detailed information, please see the full Routes from Diagnosis report.

All patients are allocated to one outcome pathway only, using a ‘hierarchy’ to prioritise the characteristics which had the greatest bearing on patients’ lives after diagnosis. First, survival was prioritised as the most important outcome for cancer patients. This is then followed by cancer recurrence, spread or new cancers, and if these did not occur, then other inpatient morbidities. For example, if a patient experienced ‘cancer complications’ this will always take priority over ‘other inpatient morbidities’, which takes priority over ‘no other inpatient morbidities’. This means that a patient could have experienced both ‘cancer complications’ and ‘other inpatient morbidities’ but would only be categories and included in a ‘cancer complications’ pathway.

**Routes from diagnosis: Inpatient morbidities**

Routes from Diagnosis can tell us about presence of other serious health conditions recorded in inpatient records. Just because someone has survived cancer, does not
necessarily mean that they have returned to good health. The morbidity charts presented here show the percentage of each cancer population who had one, two or several of a range of morbidities recorded in their inpatient records over a period of up to seven years after diagnosis.

Routes from Diagnosis shows us that only one in five (20%) women diagnosed with breast cancer, and one in four (25%) men diagnosed with prostate cancer, will survive both long-term and in good health. The remaining long-term survivors will experience a range of other serious health conditions, have their cancer spread or come back, or get another type of cancer. Cancer survivors are more likely to develop other serious health conditions as a result of their illness and its treatment.

- Lung cancer survivors alive five years after diagnosis are three times more likely to develop a life-threatening respiratory condition, such as emphysema.
- More than a quarter (29%) of people with breast cancer will survive seven years after diagnosis and be left with health conditions serious enough to warrant a stay in hospital, such as heart disease.
- Prostate cancer survivors are 60 percent more likely to develop a chronic genitourinary condition such as incontinence.

Survival for people with brain or central nervous system (CNS) cancer varies widely depending on which specific type of cancer they have. Fewer than 2% of people with glioblastoma will live for seven years or more, compared with almost two in three (64%) people with meningioma and more than four in five (87%) people with nerve sheath cancer.

**Routes from diagnosis: Cost to the NHS**

The consequences of cancer and its treatment can lead to poor quality of life and can cost the NHS more than the cancer treatment itself. For example, the average cost of treating a breast cancer survivor who has one or more serious health conditions almost doubles from £4,500 to £7,500 the year after the bulk of their treatment has taken place.

The costs come from HES inpatient data only and exclude the large proportion of chemotherapy and radiotherapy treatment delivered in an outpatient setting. It reflects the cost to the NHS budget, i.e. what commissioners pay hospitals to provide care based on the NHS National Tariff, rather than the exact cost to hospitals of providing the care.

Costing a patient’s care is very complicated. Costs have been worked out using codes assigned to hospital inpatient activity using the Healthcare Resource Group (HRG) codes.

Costs are made up of ‘things’ that happen to patients throughout their interaction with the hospital such as:

- Where they were treated
- How they were admitted
- Types of treatment, such as operations and procedures
- How long they were in hospital for (i.e. a day or overnight)
- Who they saw (i.e. consultants and treatment specialists).
While there are some chemotherapy and radiotherapy costs included in this analysis it excludes a large proportion of chemotherapy or radiotherapy which is normally delivered in an outpatient setting. Chemotherapy and radiotherapy are known as ‘unbundled costs’. These costs are negotiated at a local level.

For the purposes of this study national average costs are included for some activity (that which happens in an inpatient setting). The costs do not include: critical care days, neonatal care, specialist palliative care and rehabilitation.

Unfortunately cancer treatment is not well recorded in the normal HES data set. New data sets are being built nationally (i.e. Radiotherapy Data Set and the Systemic Anti-Cancer Therapy data set) which will ultimately allow us to better understand what treatment is being provided and the true cost of this.