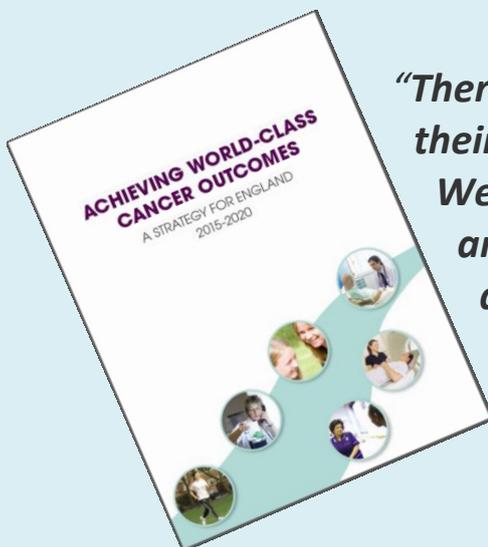




The rewards of using patient data

“I believe as a patient that I have a responsibility to the rest of society in permitting the use of my data. But I also have the right to ask clinicians and researchers, or rather demand, that my data is used – remove the barriers – used for purposes of audit, comparison, research. Ask questions and find answers, for me and for all the other patients like me.”

Margaret Grayson,
Patient advocate, use MY data



“There is extensive evidence that cancer patients want their data to be used for research and to improve care. We must harness their support, ensuring cancer patients are placed at the heart of strengthening our cancer data intelligence.”

“We never killed anyone by using their data. I’m pretty sure we have by not using data.”

Chris Carrigan,
Head, National Cancer Intelligence Network

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This is a call to action from useMYdata – a movement for cancer patients

We aim to:

- build confidence in the use of patient data for analysis and research
- increase the involvement of patients in decisions about how their data is used and in communicating the importance of this work.

Timely access to data is needed to drive improvements in:

- the prevention of cancer
- standards of cancer care
- clinical outcomes and experience for cancer patients.

The examples and cases studies within this document demonstrate the rewards of using data, highlighting where using data has changed practice, improved outcomes and saved lives.

The use of patient data is the only reason that all of this work is possible.

EUROPEAN DATA IN HEALTH RESEARCH ALLIANCE

Across Europe, research using personal data has made tangible improvements to our health and wellbeing. Find out more about some of the many studies that would be threatened if the Parliament's amendments to the Data Protection Regulation are implemented.

Using research to help prevent cancer

Prostate cancer study (part of the Collaborative Oncological Gene-environment Study)

Countries involved

Denmark, France, Spain, Sweden, Norway, Greece, Italy, Germany, Great Britain, Australia, Austria, Belgium, Canada, China, Cyprus, Czech Republic, Finland, Hungary, Iceland, Israel, Ireland, Japan, Latvia, Lithuania, Malaysia, Mexico, Netherlands, Poland, Romania, Russia, South Africa, Taiwan, Thailand, USA

What is it?

This major collaborative study has built the largest data set ever used in cancer research to investigate inherited risk factors for cancer.

Results

Thanks to the results of this study, we now know much more about how likely a person is to develop prostate cancer from their genetic make-up, which could improve the way we detect and prevent this disease.

Why it's under threat

Participants had provided broad consent for the use of their **pseudonymous genetic data**. The European Parliament amendments only allow the use of pseudonymous data without specific consent under very tough conditions: researchers would have to show that studies couldn't "possibly be carried out otherwise" and are in "high public interest" – these conditions are unclear and very difficult to prove in practice. At the same time, anonymous data cannot be used as the study involves linking data about people from different data sets. If the amendments were implemented as they stand, there is no guarantee that studies like this – with their potential to improve health – could continue.

Understanding the factors affecting cancer and chronic disease

The European Prospective Investigation into Cancer and Nutrition (EPIC)

Countries involved

Denmark, France, Germany, Greece, Italy, Norway, Spain, Sweden, Great Britain, Netherlands

What is it?

The largest study of diet and health ever undertaken. EU-funded EPIC involves over half a million people across ten European countries. EPIC investigates the relationships between diet, nutritional status, lifestyle, environmental factors and the incidence of cancer and other chronic diseases.

Results

EPIC has significantly improved our understanding of chronic diseases and how they can be prevented. For example, thanks to EPIC we now have a better grasp of pre-and post-menopausal breast cancer as well as dietary factors affecting colon cancer.

Why it's under threat

The Parliament's amendments to the Data Protection Regulation prohibit the use of **identifiable health data** without **specific consent and set tough limits on the use of pseudonymised data**. This would make the EPIC study unworkable because:

1. The data collected within EPIC is **pseudonymised** when it is used in research. There is no guarantee that the study would meet the tough requirements set for the use of pseudonymous data without consent.
2. The study's success also relies on using **identifiable data** to build its dataset by linking its own findings with data from other sources like cancer registries. Participants have given broad, not specific, consent for this linkage: going back to each participant in the study to ask for their specific consent would be incredibly burdensome in terms of time and cost, and this extra burden could delay the study or even prevent it from happening.

Countries involved

Great Britain

What is it?

We know that in the UK affluent women are more likely to get breast cancer than socially deprived women, yet socially deprived women are more likely to die from breast cancer. This study aimed to unpick this anomaly by examining whether differences in outcome were linked to differences in how patients are managed by their hospitals and doctors.

Results

The study showed that poorer survival rates of women from deprived areas are not caused by poorer access to healthcare or treatment, but are actually associated with problems unrelated to breast cancer (co-morbidities).

Why it's under threat

The study used hospital and doctor records to look at factors involved in cancer treatment like waiting times and treatment received. To ensure that the outcome was not biased, the study received special approval to allow the use of this identifiable data without consent. Despite the safeguards already in place, the Parliament's amendments to the Data Protection Regulation would make future studies like this impossible as it would prohibit the use of identifiable data without consent.

Section 2 – Achievements made possible by cancer registration data

There is no guarantee that having your information on the cancer registry will directly benefit you. However, we know that registry information is continually leading to improvements and new information on the prevention, diagnosis and treatment of cancer and so can help future generations.

In order to give each person the best possible care, we need to know how different cancers respond to different treatments - this information is held in the registry.

If you have a family history of cancer, doctors can also use the registry to find out what treatments worked best for your relatives and tailor your care accordingly. This information may also help doctors treat any of your relatives who are diagnosed with cancer in the future.

Registry information has shown that 1 in 2 people will now survive cancer for at least 10 years.

Tracking cancer rates and survival

Registry information showed that:

- Three quarters of children with cancer are now cured, compared with around a quarter in the late 1960s
- Incidence rates of malignant melanoma (the most serious type of skin cancer) have increased more than fivefold since the mid 1970s.

Enabling decisions about NHS facilities

Registry information helped the NHS decide how many proton beam therapy units (that deliver a special type of radiotherapy) to build in the UK. By 2018 there will be two proton therapy units in the UK delivering radiotherapy to up to 1,500 cancer patients a year.

International comparisons of cancer rates and survival

International comparisons such as the International Cancer Benchmarking Partnership are using registry information to help us understand how we can improve cancer survival in the UK to ensure the best possible outcomes for patients.

Understanding when and where patients are being diagnosed with cancer

Research around when and where patients are diagnosed with cancer, which showed that almost a quarter are diagnosed in an emergency and typically have poorer outcomes. This has reinforced the importance of finding ways to get more patients diagnosed early, at a time when treatments are more likely to be successful.

Impact on NHS policy

The NHS England Programme of Care (POC) for cancer is one of 6 NHS England POCs, with oversight of a total of £14 billion NHS England spend.

The Cancer POC accounts for approx £5bn of £14 Billion directly commissioned services, with a responsibility to promote collaborative commissioning approaches within relevant service areas.

The decision to implement bowel scope (a method of screening for bowel cancer) as part of the bowel cancer screening programme was made based on registry information.

Analysis of data allowed the assessment of the use and impact of high cost robotic assisted surgery (costing between £1-2m per robot). A range of analytical reviews, inequalities report, volume/outcomes analysis were possible because of the ability to utilise large linked datasets.

As a direct result of this work, national policy was changed, resulting in an investment of circa £4m investment in robotic prostatectomy surgery.

A similar programme to help surgeons learn keyhole colorectal surgery for patients with bowel cancer and other conditions was set up in 2007. It was reported that in 2008, 10% of operations on the colon involved keyhole surgery. Now that figure has reached 50% and the saving for the NHS over that period has been calculated as being around £11m.

For lung cancer, a "high spend" report on lung cancer was produced to demonstrate 'whole pathway variation'. The report was used by the POC Board in the prioritisation of lung cancer, including collaborative commissioning and regional vanguards in the North and East of England.

Improvement of national screening programmes

Registry information has been used to improve the breast cancer screening programme by enabling the NHS to identify and reduce the number of women diagnosed with breast cancer between screening appointments.

The decision to implement bowel scope (a method of screening for bowel cancer) as part of the bowel cancer screening programme was also made based on registry information.

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The NCIN's 2010 publication 'One, Five and Ten-year Cancer Prevalence' was the first time that it was possible to know the number of patients living with cancer. This work was only possible because patients could be tracked from their diagnosis robustly until their point of death, using quality assured linked data.

There are currently 2.5 million people in the UK living with and beyond their cancer diagnosis, a figure set to increase to 4 million by 2030.

Why is this number increasing?

The number of people living with or beyond cancer is increasing for a number of reasons:

- Due to an aging population and higher rates of diagnosis in older people.
- Cancer survival rates are increasing and people affected by cancer are living longer due to better treatment.
- Fewer people are dying from cancer.

What do we know about cancer survivors in the UK?

- There are three-quarters of a million people of working age with a cancer diagnosis
- 63% of people with a cancer diagnosis are 65 or over
- 10% of people in the UK aged over 65 have a cancer diagnosis
- 1.24 of the 2 million cancer survivors in the UK were diagnosed more than five years ago [1]
- 83% of cancer survivors return to work, but over half of those returning had been off work for six months or more [2]

[1] Source: Cancer prevalence in the United Kingdom: estimates for J Maddams, D Brewster, A Gavin, J Steward, J Elliot, M Utley & H Moller Br J Cancer 2009 101: 541-547

[2] Source: Amir Z, Moran T, Walsh L, Iddenden R, Luker k. Return to paid work after cancer: a British experience. J Cancer Surviv 2007

Routes to Diagnosis

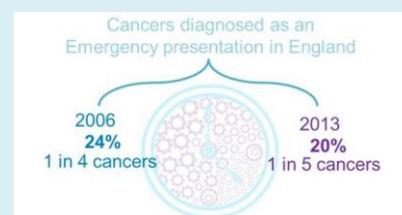
Cancer survival in England is lower than the European average, which has been at least partly attributed to later stage at diagnosis in English patients. There are substantial regional and demographic variations in cancer survival across England. The Routes to Diagnosis study defines a methodology by 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 a data briefing published in November 2010. Since then the methodology has been reviewed and the results have been updated to include patients diagnosed from 2006 to 2013. The latest results follow the same methodology as the 2006-2008 study.

Over 46,000 fewer patients have been diagnosed as an emergency presentation, helping to improve cancer survival. Without the ability to link and use large datasets, this would never have been known, and improvements could not have been identified or evaluated.

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 2006-2013 is categorised into one of eight 'Routes to Diagnosis'.

Results for the 2006-2013 study have fewer cases assigned to the "unknown" Route due to more complete HES data being available. Having an 8-year cohort to base results from has also an improved examination of time trends with changes between Routes becoming more evident.

The headline figures are encouraging: the proportion of cancers diagnosed through an emergency route has decreased from 24% to 20%, whilst the proportion of cancers diagnosed through urgent GP referral with a suspicion of cancer, the Two Week Wait route, has increased from 25% to 34%.



In big data terms, over 118 million records were used to generate the results that we are publishing today.

The results give us rich details in the variation and inequalities that the data continues to reveal. Looking behind the averages we are confronted with stark realities, for example:

- 50% of pancreatic cancer patients present through an emergency route, with only 10% of those people surviving a year after diagnosis.
- For women diagnosed with ovarian cancer, 20% of those under 50 are diagnosed as an emergency, compared to 51% of those aged over 85.
- For people with colorectal cancers, only 7% in the most deprived areas are diagnosed through screening compared to 11% in the least deprived areas.

The analyses highlights that too many people with cancer are still being diagnosed too late.

Colorectal cancer data

The main diagnostic test used to identify colorectal cancer is a colonoscopy. Unfortunately the test is not 100% accurate and some individuals may undergo a negative colonoscopy but subsequently be diagnosed with a cancer - a post-colonoscopy colorectal cancer (PCCRC).

The proportion of people undergoing colonoscopy who developed a bowel cancer within three years fell from 10.6% in 2001 to 7.3% in 2007

Such cancers may occur as a result of a rapidly growing new tumour that was not present at initial colonoscopy but, more frequently, because precancerous lesions were missed or inadequately removed or the disease was simply missed by the colonoscopist.

The rate of PCCRC occurrence is, therefore, an important quality indicator of a colonoscopy service.

Analysis of the data showed that the overall proportion of individuals who developed a bowel cancer within three years of a colonoscopy in the English NHS between 2001 and 2007 was 8.6%. The proportion of people undergoing colonoscopy who developed a bowel cancer within three years fell from 10.6% in 2001 to 7.3% in 2007.

Almost 10% of people diagnosed with colorectal cancer die within one month of diagnosis. 56% of people dying within one month are 80 or more years old.

For those that survive, 65% of the colorectal cancer survivors report one or more generic health problems, which was higher than in the general population.

Respondents with other long term conditions, those with active or recurrent disease, those with a stoma and those at the extremes of the age range (under 55 and over 85) reported a higher number of problems.

60% of early deaths present initially as emergency cases to hospital. At least 50% of patients who die within one month receive no active treatment.

Equalities

Reports published for the National Cancer Equality Initiative (NCEI) by the National Cancer Intelligence Network (NCIN) on cancer and equality groups gave a clear picture of where there are differences between groups in aspects of cancer patients' diagnosis, care and outcomes.

There are some stark health inequalities for people with cancer. For example for all cancers combined (excluding non-melanoma skin, breast, lung and sex specific) age standardised mortality for men is 70% higher than it is for women.

Age standardised mortality in the most deprived populations is 50% higher than in the least deprived. Similarly emergency presentation – a marker of late diagnosis and worse prognosis – increases with age and has a clear socioeconomic gradient that worsens with deprivation.

The report also highlights the importance of timely, good quality data collection. This includes linking different data sources to ensure the full picture is examined, from routinely collected 'basic' information, such as the number of people being diagnosed with cancer, through survey information to understand the patient experience, and patient reported outcome measures.

Important differences in patient experience are found between heterosexual and non-heterosexual groups, and patients with and without long-term conditions, however there is currently less evidence about these equality groups for other cancer metrics.

Commissioners and clinicians in local communities use the information in this report to devise strategies to tackle all inequalities that are issues in their populations.

Rare and less common cancers

Collaboration between NCIN and Cancer52 was seen as a milestone in the recognition of the number of people affected by the rare and less common cancers. Data relating to many of these sites has not been published routinely before.

Data on many more less common and rare cancers can now be reported routinely.

Rare and less common cancers make up just under half of all newly diagnosed cancers - 47% for 2013 in England for both males and females. As of 2013 there are around 2,700 more deaths annually from rare and less common cancers than in 2010. Counts and crude rates are presented for 278 rare and less common cancer sites for incidence figures and 95 sites for mortality figures.

Malignant cancer sites with the highest incidence per 100,000 population include brain, endometrioid adenocarcinoma, Non-Hodgkin Lymphoma, multiple myeloma and pancreas. Sites with the highest mortality include brain, ovary, Non-Hodgkin Lymphoma, pancreas and bladder.

A number of cancer sites stand out as having comparatively high mortality rates considering their incidence rates. Mesothelioma and bone tumours of the head and neck have relatively high mortality rates compared to their incidence rates, 3.90 vs. 4.24 and 0.09 vs. 0.10 per 100,000 population respectively.

Upper GI cancers including pancreatic cancer and biliary tract cancers (cholangiocarcinoma/bile duct cancer (intra- or extrahepatic)) also had high mortality rates given their incidence, 13.10 vs. 14.05 and 3.64 vs. 3.58 per 100,000 population respectively.

Examining these differences in more detail, and assessing any changes in the quality of cancer registration data over time may help to unpick the variation seen here.

A number of sites show both high incidence and mortality rates. Brain, rarer leukaemia types, multiple myeloma, gallbladder and primary liver (excluding intrahepatic bile duct cancer) all have crude mortality rates above many sites, but also with incidence rates no greater than double that of the mortality rate.

This work illustrates that data on many more less common and rare cancers can be reported routinely than in previous years, but also that a number require more work to break down larger generic groupings with improvements in coding completeness and quality.

Older people

In terms of prevention, older people appear less likely to practice some of the behaviours which would increase the risk of cancer. However, older people may also have the legacy of issues such as smoking or excess alcohol consumption, which may increase their risk.

They are also more likely to be overweight or obese and less physically active. We need to support older people in reducing their risk of developing cancer and taking action to be fit for more aggressive (but more effective) cancer treatments by changing their lifestyle.

Late diagnosis appears to be a major problem in older people. They are more likely to be diagnosed following an emergency admission, diminishing their chances of long term survival. They also experience poorer survival after diagnosis with a cancer that has already spread. Encouraging earlier diagnosis in older people should be a major priority.

Older patients are also less likely to receive active cancer treatment, be it surgery, radiotherapy or cancer drugs. In some cases, there will be good reasons for this. Frailty and other issues can reduce a person's ability to withstand treatment and can result in an unacceptable impact on quality of life. However age alone should never be a barrier to treatment. We must do more to help clinicians assess a person's suitability for treatment and, where necessary, tailor treatment options to suit a person's circumstances.

Older patients are also less likely to receive active cancer treatment, be it surgery, radiotherapy or cancer drugs. In some cases, there will be good reasons for this. Frailty and other issues can reduce a person's ability to withstand treatment and can result in an unacceptable impact on quality of life. However age alone should never be a barrier to treatment. We must do more to help clinicians assess a person's suitability for treatment and, where necessary, tailor treatment options to suit a person's circumstances. Overall, older people report a positive experience of cancer treatment and care and NHS services should be congratulated on their continued efforts to improve patient experience. In particular, they are more likely to have confidence in doctors and nurses and feel that they were treated with dignity and respect. Patient experience surveys do nonetheless also identify areas for improvement. In particular, older people are less likely to have access to a clinical nurse specialist or report being given information on side effects of treatment.

These issues are particularly concerning given that older people are more likely to have other health issues which will impact on their quality of life during and after treatment and may necessitate enhanced support.

For older people with cancer who are near the end of their life, there are substantial variations in the length of time they spend in hospital, suggesting that some areas of the country are better than others in supporting people in the community. There is substantial scope to improve both the quality and efficiency of care in this respect.

Older people are less likely to have opportunities to participate in cancer research, meaning that opportunities to develop the evidence base on how best to treat older people are missed.

Reassuring parents with children diagnosed with cancer about their place of care

We analysed survival of children with cancer according to the extent to which their principal treatment centre shared care with local hospitals. There was no difference in survival between centres which practised different amounts of shared care. This result applied equally to children with leukaemia, brain tumours and other cancers, to those with cancers that

have a good, intermediate or poor prognosis. Families unfortunate enough to have a child with cancer should be reassured that their child's chances of survival would be the same regardless of the amount that their principal treatment centre devolved to local hospitals.

Families unfortunate enough to have a child with cancer should be reassured that their child's chances of survival would be the same regardless of the amount that their principal treatment centre devolved to local hospitals.

Risk of bias to local analyses

Whilst national statistics on cancer are useful, sub-national data are much more useful for those responsible for the health of their local populations. For each NCIN or any publications with sub-national cancer data, we produce bespoke briefings on London for PHE London's Director and her team. She is also the health advisor to the London Mayor.

The short, bullet-pointed briefings are typically used to inform London's position compared with national figures, if there had been improvements over time or if there are areas of concern. Amongst other things, London is an area with a hugely diverse ethnic mix. The risk of certain population groups choosing to opt out more than other groups will introduce bias and decrease confidence levels, rendering much of the results uninterpretable.

The risk of certain population groups choosing to opt out more than other groups will introduce bias and decrease confidence levels, rendering much of the results uninterpretable

An inability to monitor government initiated improvement programmes

In support of the governments Accelerate, Coordinate, Evaluate (ACE) program, working with CRUK, we are starting a piece of work to look at the diagnostic pathway patients with lung cancer, to understand the number of times contact is made with the healthcare system before a diagnosis is made, via different routes, for learning about what could be improved to facilitate earlier diagnosis.

A loss of significant numbers of patients will prevent this, as the confidence intervals would become much wider, and therefore of little use.

This may be expanded out to patients with a diagnosis for colorectal cancer if there is capacity later. The analysis will include data on diagnostic imaging, outpatient episode data (hopefully) and routes to diagnosis, linking the experience of the patient with more granular data about their diagnostic process. A loss of significant numbers of patients will prevent this, as the confidence intervals would become much wider, and therefore of little use.

Who is waiting for a cancer diagnosis, and how long?

Patients regularly report that the wait between a suspicion of cancer and the point of hearing whether they have cancer or not is one of the most stressful periods in their lives.

We are using Cancer Waits data to look at this by NHS Trust, and looking at whether Trusts running the ACE programme are managing to improve better than Trusts not using ACE.

Comprehensive data allows us to generate the evidence about whether best practice initiatives are helping to get patients diagnosed earlier to bring together some learning for the wider pathway planning.

All ACE projects are running initiatives as examples of 'best practice', and we are collecting evidence about whether such best practice initiatives are helping to get patients diagnosed earlier to bring together some learning for the wider pathway planning. This is a small part of that evidence base.

Does clinical care directly affect patient experience?

We have historically measured clinical outcomes and patient experience separately. To bring these two dimensions together, we completed and tested the linkage of the English Cancer Patient Experience Survey (CPES) with the cancer registration data. A workbook describing this linkage was released in December 2015.

Data linkage allowed the direct correlation of treatments and experience, which has not been possible before.

Crucially, this linkage allowed the direct correlation of treatments and experience, which has not been possible before. The linkage will also allow patient groups to be identified where the survey is not being used, allowing further surveys to better represent the cancer population.

Publishing helps patients

Publishing in the public domain, in a format that is understandable, empowers the general public to instigate change on their own terms, terms which are often a lot more powerful and persuasive to those who have the capacity to ensure change.

Patients in a particular constituency used evidence produced by using the data to approach their councillor and lobby for better awareness among the community

The publication of the ovarian cancer profile report showed variation in survival at local level, with areas in the North West that had much poorer survival compared to the national average.

Patients in a particular constituency used this evidence to approach their councillor and lobby for better awareness among the community. This led to the councillor supporting a number of roadshows in the community to help raise awareness of the symptoms of ovarian cancer.

When working at small areas, the unknown nature of scale, and the risk of bias, with op-outs will mean this work will not be possible, and future patients will not benefit.

Targeting specific areas for improvement

It is commonly assumed that patients presenting via emergency routes have worse survival because the individuals are presenting at later stages when prognosis is worse and treatment options can be more limited. But unless we can measure this, the NHS can't confidently target its improvement actions, and can't evaluate whether such actions are having the desired effect.

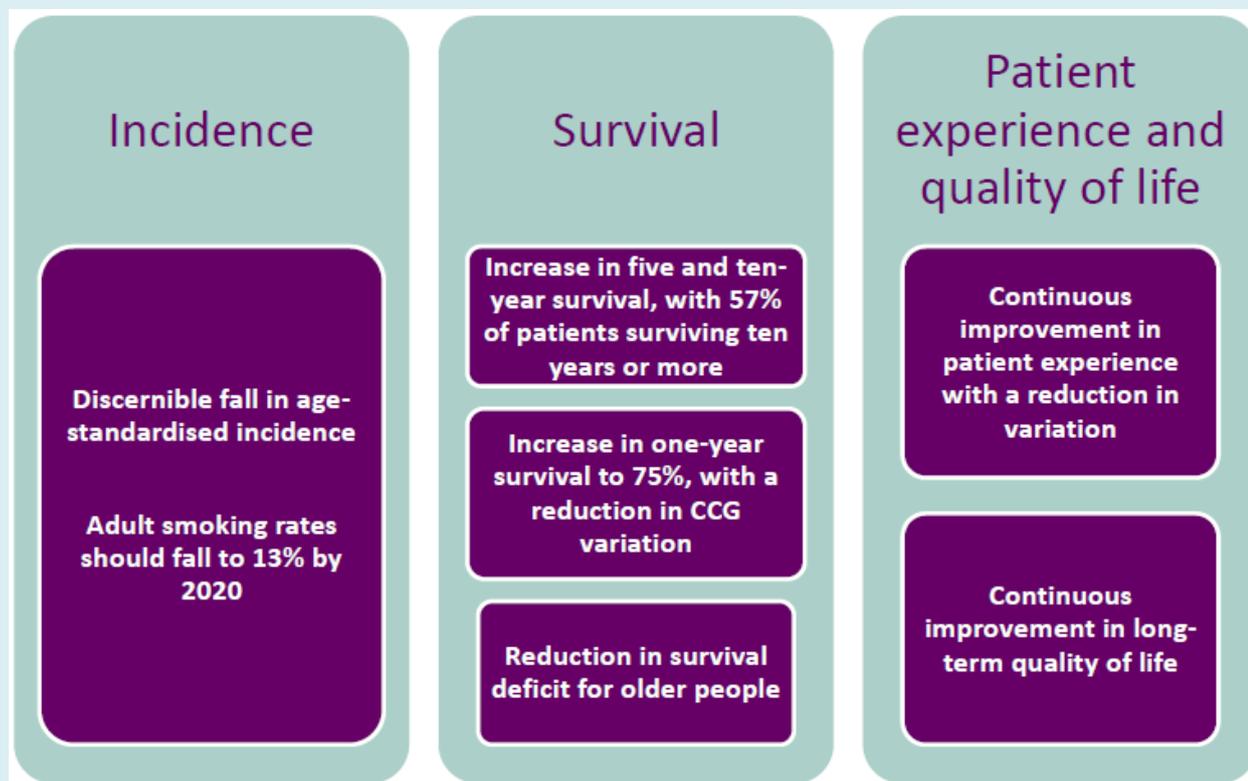
Complete data analysis is need so that the NHS can target its improvement actions, and crucially, use the data to evaluate whether such actions are having the desired effect

This is a complex area, and in December 2015 we published a short briefing, accompanied by a data workbook. Demonstrating the benefits of a partnership approach, CRUK will be using some interesting findings on this work on their post-Christmas media campaign for the public, so we are expecting some media attention. Other charities are taking similar approaches with us in early 2016.

Service Metrics and Taskforce Requirements

There are a range of commitments within the Cancer Taskforce strategy. These are listed here, with the potential impact of opt-outs being implemented:

Certain key analyses are only possible because of the use of complete data. Without that, some would be at risk.



- Age standardised incidence: Not possible. The increase in the confidence intervals for these figures will have to reflect the numbers of opt outs. Of course, the numbers of opt-outs with cancer are not known, so we will need to project the incidence figures for all years forward. We will be unable to identify whether falls in incidence are as a result of opt-outs, or reflect a true fall.
- 5 and 10 year survival: Not possible for reasons above (see incidence)
- 1 year survival: Not possible to monitor whether this is achieved. CCG level figures will not be reliable.
- Older people: Not possible.
- Patient experience: is a voluntary questionnaire, so no impact.
- Quality of Life: metric not defined, so unable to comment

Having complete, high quality data, is a requirement of several key national areas of monitoring, so that reliable results are produced which can be acted upon:

- The Consultant Outcomes Programme
- 1yr survival by provider
- Cancer Waiting Times breakdowns
- The Cancer Drugs Fund data extracted from SACT
- The Radiotherapy Centre activity and performance data on which SofS receives a monthly report
- The International Cancer Benchmarking Project (ICBP)
- Statistics on cancer incidence, survival and mortality).....

What else do we know from research on linked cancer data?

- There are 2m cancer survivors in the UK, growing by 3% each year.
- The UK has poorer cancer outcomes than comparable countries.
- Much of the excess mortality occurs soon after diagnosis and 25% of cancer patients present as an emergency.
- Rates of surgery for lung cancer are almost certainly too low.
- Overall mortality following surgery for colorectal cancer is decreasing.
- One-off screening with Flexible Sigmoidoscopy between the ages of 55 and 64 can detect pre-cancerous polyps, which when removed will prevent them becoming cancerous, significantly reducing the incidence of bowel cancer and reducing deaths from the disease

Providing the evidence base for national awareness and early diagnosis campaigns

- Gap in survival rates between the UK and other comparable countries.
- 23% of cancers diagnosed through an emergency presentation.
- Late diagnosis, due in part to patients not reporting symptoms/presenting late.
- Potential to avoid a large number of deaths.

Evaluating the effects of the campaigns: Blood in Pee

- Increased awareness with 72% mentioning blood in pee as a cancer symptom (seen or heard) compared with 23% pre-campaign.
- Increase in referrals during the campaign period, and some evidence of sustained impact. (26% increase in the number of urgent GP referrals for suspected urological cancers 2012 to 2013).
- Referrals increased from 2012 to 2013. Two-week referral increased by 8.2% bladder, 22% kidney and 14% urological respectively.
- Diagnosis rate for urological cancers increased by 2.0% for England.
- Second wave Oct – Nov 2014, 34% increase in Two-week wait referrals for compared to the same months in 2012.

Breast Cancer in Women over 70

- Awareness in women aged over 70 aware of campaign advertising rose: proportion spontaneously mentioning breast cancer from 38% to 51%.
- Large increase (67%) in referrals for suspected breast cancer and breast symptom referrals in the target age group during the campaign period.
- Statistically significant 25% increase in the number of breast cancers diagnoses after GP referral Two- week wait or breast symptom referral.
- Large increase in women self-referral to Breast screening programme during campaign period (net increase of 12,432 self-referrals compared to same period in 2011).

Regional Ovarian Pilot

- Significant increase in awareness of ovarian cancer symptoms: 23% before the campaign to 32% afterwards.
- No evidence of an impact on the number of ovarian or gynaecological cancer diagnoses through Two-week wait.
- No impact on the conversion rate to either ovarian or gynaecological cancers of Two-week wait referrals February-April 2014.

Regional Pilot Oesophago-gastric

- Awareness of warning signs increased significantly: (persistent) heartburn as from 11% to 31%, persistent indigestion from 9% to 25% and food sticking increased from 23% to 38%.
- 52% increase in referrals for suspected upper GI cancers in pilot area compared to 17% in the control area.
- The increase in upper GI referrals was larger for men (63%) than for women (44%).
- For those aged 60-69 statistically significant increase of 29% in the upper GI cancer detection rate, from 35% to 64%.

Cancer registration data extracts approved for release - November 2014

The PHE Office for Data Release (ODR) ensures that requests for potentially or explicitly identifiable data are managed in line with PHE's statutory responsibility as a data controller, so that:

- ✓ any data sharing complies with the rights of the data subject, Data Protection Act and Caldicott principles;
- ✓ there is an appropriate legal gateway for the receiving organisation to receive and process patient or personal data;
- ✓ the physical transfer of the data is secure; and,
- ✓ the receiving organisation can satisfy that they have in place comparable controls to ensure that the data is held securely.

The Office for Data Release (ODR) made 110 releases between April 2014 and October 2015. During this period, 35% of data releases were to Academic institutions and a further 33% to Care Quality Commission (CQC) Registered Health and Social Care Providers.

- 98% of data releases made by the ODR were for cancer related projects including research, clinical audit, service evaluation and direct care.
- 99 were for National Cancer Registration Service Data
- 9 were for National Cancer Screening Programmes Data (Breast, Bowel, Cervical).

The next update of the Data Release Register will be in February 2016.

To view the register go to: <https://www.gov.uk/government/collections/public-health-england-data-release-register>

Section 4 - Be Clear on Cancer

Campaign evaluation

The Department of Health started the awareness raising activity in 2010. Today, Be Clear on Cancer is a Public Health England programme of activity, but delivered in partnership with NHS England, Department of Health and Cancer Research UK.

How are Be Clear on Cancer campaigns evaluated?

Public Health England (via National Cancer Intelligence Network (NCIN)), Department of Health and NHS England collate and analyse a number of data sets relating to each campaign.

The evaluation metrics are carefully considered for each campaign. Where necessary or relevant, additional metrics are added to the evaluation plan.

| Metric | Broad questions we're seeking to answer |
|---------------------------------------|---|
| Cancer and campaign awareness | Are people seeing the campaign and is it raising awareness of the signs and symptoms? |
| GP attendance | Are we seeing more people going to their GP with the symptoms promoted by the campaign, and is there any shift in the profile of patients presenting? |
| Urgent referrals for suspected cancer | Are we seeing more people referred urgently for suspected cancer, and is there any shift in the profile of these patients? |
| Conversion rates | Of those referred urgently for suspected cancer, how many actually turn out to have that cancer? |
| Impact on investigations | Are we seeing an increase in diagnostic investigation activity, or the length of time patients are waiting for tests? |
| Cancer incidence and staging | Are we seeing an increase in the numbers of patients diagnosed with cancer, and/or a shift towards earlier stage disease? |

Anecdotal feedback from a range of experts and colleagues from all levels of campaign activity is also regularly reviewed. All of this information is used to help shape and develop the Be Clear on Cancer programme of activity.

Who evaluates the Be Clear on Cancer campaigns?

Cancer Research UK was appointed in 2011 to help develop the evaluation framework for the Be Clear on Cancer programme, and to lead the evaluation of all campaigns that took place between 2011 and March 2013.

Reflecting new structures within the NHS, NCIN has been responsible for campaign evaluation of all campaigns implemented from 1 April 2013 onwards.

Department of Health and Public Health England reports

Following the *Cancer Reform Strategy* (2007) and *Improving Outcomes: A Strategy for Cancer* (2011), the Government set it's ambition to save an additional 5, 000 lives per year by 2014/15. The aim was to achieve this through earlier diagnosis and better access to treatment. The Department of Health started the awareness raising activity in 2010. Public Health England now leads on the programme of activity in partnership with DH and NHS England. Department of Health and Public Health England reports below:



All of the research and analyses highlighted in this document have been made possible through the use of patient data.