

National Disease Registration Service



Welcome to the monthly NDRS newsletter

Each month we share the latest news from the **National Disease Registration Service (NDRS)** including new data releases, publications and events.

In this month's update, we share news about the Cancer Data Conference 2020, the latest data release from the Get Data Out programme, and we announce upcoming data releases in the new year.

The **National Disease Registration Service** is part of **Public Health England** and collects data from the NHS about cancer, rare diseases and congenital anomalies in England.

It is made up of the **National Cancer Registration and Analysis Service (NCRAS)** and the **National Congenital Anomaly and Rare Diseases Registration Service (NCARDRS)**. The NDRS uses data to detect changes in the health of the population and help the NHS improve the diagnosis and treatment of these diseases.

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Others can [sign up to our newsletter here](#).

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Data releases and publications

Head and neck cancer data published

On Wednesday, we published detailed statistics about **head and neck cancers**, as part of our **Get Data Out** programme. You can find data on incidence rates, treatments, and routes to diagnosis for head and neck cancer patients from 2013.

Data on survival statistics for patients diagnosed in 2017 was also updated for the other cancer types in the programme - **brain**, **ovarian**, **testicular**, **pancreatic**, and **prostate** tumours. And data about routes to diagnosis for prostate

Detailed Statistics from the 'Get Data Out' programme > Head and neck

You can download all the latest Get Data Out data we have published for this tumour group as a single file here:

[Download](#)

To understand more about the Get Data Out data, read our [guide for first time users](#).

Explore the tree below to understand how patients with head and neck cancer have been divided into groups. Click on the circles to expand the branches of the tree. You can also drag the tree and zoom in and out. The numbers inside the circles represent the number of patients within the group.



cancer was also added.

[Find out more](#)

Cancer survival index for CCGs in England

This month we [published](#) data on one-year survival for each CCG. This was published on gov.uk for the first time. This is accompanied by an interactive [app](#). The one-year index of cancer survival for England has increased from 62.6% in 2002 to 73.3% in 2017.

[Find out more](#)

Update of the Cancer Services Profile

We [published](#) the 2019 [update](#) of the Cancer Services Profile on the Fingertips tool. The [indicators](#) look at demographics, cancer screening, incidence, Two-Week Wait referrals, diagnostic services, emergency presentations and admissions by GP practice, CCG and at a national level.

[Find out more](#)

New paper about the National Cancer Diagnosis Audit published in Cancer Epidemiology

We published a [paper](#) about avoidable delays to patient cancer diagnoses. The paper used National Cancer Diagnosis Audit data and showed that 24% of patients were reported by GPs to have had an avoidable delay to their diagnosis. This occurred most commonly when patients had GP-led investigations before referral.

This information was picked up by the [tabloids](#) and [trade press](#).

[Find out more](#)

Two new cancer data stories released about lung and brain cancer

This month we released two new cancer data stories and an accompanying [blog](#). The [first story](#) talks about how patient data was used to compare SABR and fractionated radiotherapy for treating non-small cell lung cancer (NSCLC). The [second story](#) describes how one charity, [brainstrust](#), used patient data to change

National Statistics

Cancer survival: index for Clinical Commissioning Groups

One-year cancer survival by Clinical Commissioning Group for all-cancers combined, 3 cancers combined, breast, colorectal and lung.

Official Statistics

Cancer services profiles: 2019 annual update

Annual update of data in the cancer services profiles for the financial year 2018 to 2019.



Cancer Epidemiology
Available online 3 December 2019, 101617
In Press, Corrected Proof



The frequency, nature and impact of GP-assessed avoidable delays in a population-based cohort of cancer patients

Ruth Swann ^{a, b, c, d, e}, Georgios Lyratzopoulos ^{b, c}, Greg Rubin ^d, Elizabeth Pickworth ^b, Sean McPhail ^b

[Show more](#)

<https://doi.org/10.1016/j.canep.2019.101617>

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perceptions about non-malignant brain tumours.

These are the latest in a series of [cancer data stories](#) that explain how patient data is used to improve cancer care.

[Find out more](#)



NCRAS data was used by Macmillan to estimate how many people are living with treatable but not curable cancers

Macmillan published a [report](#) that looks at the population of people living with treatable but not curable cancers. The findings were based on our partnership work and estimate that around 136,000 people can be described as living with treatable but not curable cancers.

The charity also used our data to publish new [estimates](#) of the projected prevalence of cancer in the UK. They predict that around 3 million people now live with cancer (in 2020) which will rise to 3.5 million by 2025. These findings have gained [media coverage](#) which focus on individual nation figures and provide a reminder of cancer signs and symptoms.

[Find out more](#)

MACMILLAN
CANCER SUPPORT

Analyses of NCRAS liver cancer data included in news stories

Last month, [analyses](#) of NCRAS liver cancer data was included in [news stories](#) that linked liver cancer to unhealthy lifestyles. The data found that deaths from liver cancer have tripled in England in the last 20 years.

[Find out more](#)

Cancer statistics: availability and location

NCRAS regularly publishes statistics about cancer in England for anyone to use. For the latest data on cancer, please read our [guide](#).

[Find out more](#)

The screenshot shows the NCRAS (National Cancer Research Institute) website. At the top, there is a navigation bar with links: About us, News and events, NCRAS Cancer Research Database, Accelerating cancer research, Patient and public involvement, and Networks. A search bar is located on the right. Below the navigation bar, there is a section titled "Press release: Deaths from liver cancer have tripled in past 20 years in England". The date published is "Nov 01 2019". The text of the press release states: "More people are being diagnosed with and dying from liver cancer in England than ever before, according to new research presented at the 2019 NCRAS Cancer Conference." It also mentions that in 20 years, from 1997 to 2016, incidence and deaths from the most common form of the disease, hepatocellular carcinoma (HCC), have tripled and it is most common among the most deprived members of society.

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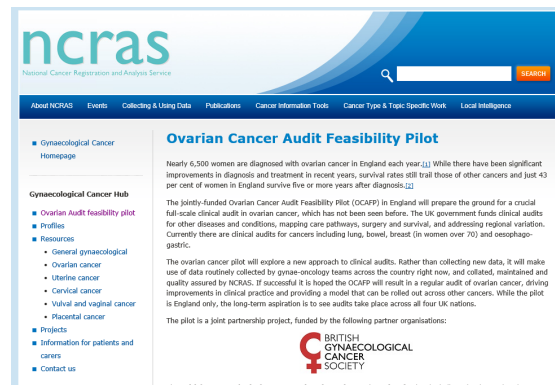
Cancer statistics: availability and location

September 2018 update

Ovarian Cancer Audit Feasibility Pilot report - January

The Ovarian Cancer Audit Feasibility Pilot is a collaboration between the gynaecological oncology clinical community, the charity sector, and the National Cancer Registration and Analysis Service, part of Public Health England, to perform meaningful analysis of routinely collected data for the purposes of improving treatment and outcomes for women diagnosed with ovarian cancer in England.

The first report of a series of analyses throughout the 2 year project will be released in January 2020. It will provide a detailed insight into the current status of this disease in England, including details of disease incidence, mortality and survival. For further information about the Ovarian Cancer Audit Feasibility Pilot and links to all outputs from the project (once released), please visit the [NCRAS website](#).



23 year cancer prevalence dashboard website - 8th January

In January we will be publishing a dashboard on [CancerData](#) to provide 23 year cancer prevalence figures for England between 1995 and 2017. This is the first time that prevalence data will be made available via the CancerData [website](#). The dashboard presents prevalence counts and rates for Clinical Commissioning Groups, Sustainability and Transformation Partnerships and Cancer Alliances across England, broken down by population demographics, stage at diagnosis and for different tumour types. This dashboard was generated by the NCRAS partnership with the Transforming Cancer Services Team for London, and is based on the 2017 London Prevalence [Dashboard](#).



Cancer registration for 2018 - 27th January

Next month we will publish our first release of the 2018 cancer [registrations](#). These statistics will look at cancer diagnoses in 2018 and age-standardised incidence rates for all types of cancer by age, sex, and region including breast, prostate, lung and colorectal cancer.



Events

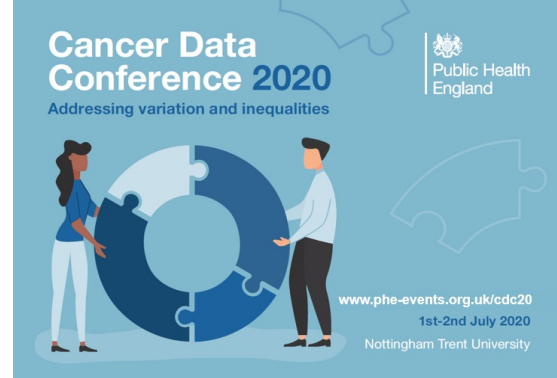
Cancer Data Conference 2020

We are excited to announce that the website for the Cancer Data Conference 2020 is now live

and can be accessed [here](#).

Registration and abstract submission are now open, and abstracts can be submitted via the [website](#) until 16th February 2020. We are also offering bursaries for patients, carers and members of the public to attend the conference. Information about the bursaries can be found [here](#).

Finally, there are opportunities to get involved via sponsorship and the conference exhibition. If you are interested, please get [in touch](#) or go to the conference [website](#).



[Find out more](#)

Other news

New design for the **CancerData** website



Our newly designed [CancerData.nhs.uk website](#) went live this month. There is now a dedicated home page with drop down menus, quick links to all the pages, and visuals to match our [NDRS website](#). Also, please note the 'Get Data Out' page has been renamed as 'Detailed Statistics'.

We would appreciate any feedback, so please do not hesitate to get [in touch](#).

[Find out more](#)

New vacancies coming soon



In the new year we will be looking to recruit four new clinical leads to support our data and analytical

work across NDRS. These will be part-time secondments.

Each will be recognised experts in their field and we are particularly seeking experts in radiotherapy, chemotherapy, haematology and congenital anomalies and rare diseases.

More detail about these posts including how to apply will be included in the next edition of this newsletter.

University of Cambridge Vice Chancellors Award for Predict Prostate Tool



In November, the Predict Prostate [Tool](#), which is based on NCRAS data, was [awarded](#) a University of Cambridge Vice Chancellors [Award](#) for research impact and public engagement. The tool is designed to help men with prostate cancer choose between active surveillance and treatment such as surgery.

[Find out more](#)

Merry Christmas!



We wish everyone a Merry Christmas and a Happy New Year!

Thank you for reading. If you have any questions or queries please get in touch. We would welcome your feedback on this newsletter too, and if you wish to unsubscribe please follow the link below.

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