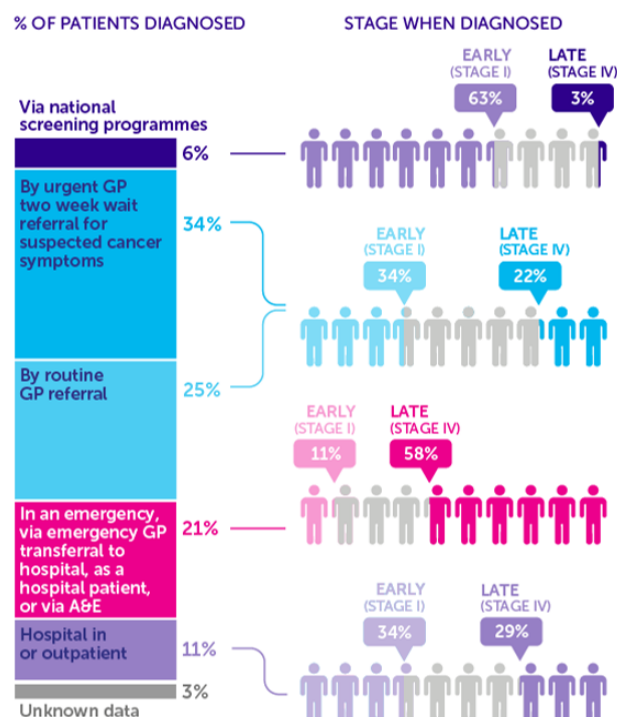


PATIENT DATA AND CANCER

Patient data is essential for improving cancer outcomes – both for research, as well as through improving NHS treatment and care. The information held about patients in their medical records, in cancer registries and other databanks can be used to research the causes of cancer, monitor survival rates, study the effectiveness of treatments and interventions such as screening, and follow up of patients in clinical trials.

HOW AND WHEN CANCER PATIENTS ARE DIAGNOSED



Source: National Cancer Intelligence Network, data for England 2012-2013

Case study: Using data to understand routes to diagnosis

This award-winning analysis combined six datasets to examine how cancer patients in England were diagnosed between 2006 and 2010.

This led to a huge shift in our understanding and drove activity to reduce the proportion of cancers diagnosed as an emergency. For example, the NHS-led ACE programme in England, supported by Cancer Research UK and Macmillan Cancer Support, which aims to promote earlier diagnosis of cancer.

This work demonstrates the potential of in-depth data analysis to inform service transformation and improve outcomes for patients.

Cancer registries should be celebrated and protected as a world-leading source of information.

The high-quality, population-based data held within cancer registries has played a vital role in efforts to improve outcomes for people affected by cancer. **It is crucial that this world-leading source of information is protected in the future.**

- England's cancer registry is internationally respected for its high quality and comprehensiveness, containing information on over 14 million historical tumours.
- A review
- Following an awareness review by Cancer Research UK and Macmillan Cancer Support, Public Health England are working to ensure that more people with cancer are made aware of the cancer registry.
- The McNeil review concluded that the cancer registry should ultimately move to NHS Digital. This is recommended to take place over a timeframe of 3-5 years – it is important that there is a clear roadmap to deliver this move without affecting the quality and completeness of the cancer registry or reducing analytical capacity.

For more information, contact publicaffairs@cancer.org.uk or 020 3469 6058.

National data programmes

Government must protect resources for NHS Digital and other data-holding organisations.

- We have been reassured by progress made by NHS Digital on managing access to data for research and **we encourage the Government to protect resources for them and other data-holding organisations, so that this vital work can continue.**
- The establishment of Health Data Research UK to develop Digital Innovation Hubs is a welcome step towards realising the potential of data collected by the NHS and allowing the UK to become a world-leading centre for innovative digital healthcare. HDR UK must ensure that the Hubs are effectively joined up with innovations in the NHS, such as the development of Local Health and Care Records.
- **The NHS must better utilise data in research, planning services, driving value by commissioning based on outcomes and empowering patients by giving them access to their records.**

Government must ensure that the new national data opt-out is not adversely affecting medical research

- We recognise and support the ambition to build public trust in the use of data and responsible use of data, with strong safeguards in place. We advised the national data opt-out programme throughout its development to ensure that the views of patients and the needs of researchers were considered and are pleased to have seen it implemented effectively.
- NHS England and NHS Digital must continue to monitor the national data opt-out to ensure that the application of the opt-out is not adversely affecting medical research.

Exiting the European Union

Ensure data flows are not impacted by the UK's departure from the EU

Many research studies rely on data being shared across borders. Cross-border data sharing is essential for research - either because the patient population size in one country is too small or the project requires large amounts of data to be processed.

Over 4,800 UK-EU clinical trials took place between 2004 and 2016, and more than a quarter (28%) of trials CRUK funds involve patients from at least one other EU country. In 2015/16 Cancer Research UK's Population Research Committee spent £11.6 million on cross-border research.

The UK Government must ensure that cross-border data flows are not impacted by the UK's departure from the EU.

It is welcome that the UK Government intends to seek an adequacy decision as part of the future relationship with the EU, and that the EU Commission is intending to make an adequacy decision before the end of the implementation period.