

The Cancer Information Service: A decade informing the NHS about cancer

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The UK Cancer Information Service (UK-CIS) provides users with the most up-to-date cancer incidence, mortality and survival data for the whole of the UK and its constituent areas.

Objective

We chronicle the development of the UK-CIS since 2001 and how it has been used in informing the National Health Service (NHS) on cancer in the last decade.

What are the key milestones?

A client server version based in the West Midlands was first presented to the UK Association of Cancer Registries Executive back in 2001. By 2003 a web-version was established in Oxford and Yorkshire. These 3 separate installations would eventually merge into one to become a national system for England in 2006. This was made available to NHS users in 2008. It was inevitable that a UK version was put together incorporating data from England, Northern Ireland, Scotland and Wales. The UK-CIS was officially launched at last year's UKACR and NCIN conference (see Figure 1).

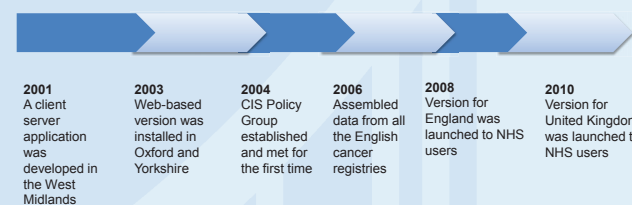


Figure 1: Significant milestones in the development of the UK-CIS

Where do the data come from?

The incidence and survival data were submitted to the UK-CIS by the cancer registries (see Figure 2). The mortality data were provided by the Office for National Statistics. The life tables used to compute the survival estimates were prepared by colleagues at the London School of Hygiene and Tropical Medicine. There are no patient identifiable data in the UK-CIS.

Governance

The UK-CIS is one of the information tools provided by the NCIN. As the CIS grew, a steering group was put together and the first meeting of the CIS Policy Group was held in 2004. This group oversees the maintenance and the development of the CIS.

Once all the data from the different cancer registries have been assembled, a testing team consisting of analysts from various registries would then validate the data and check the functionality within the CIS. Once testing has completed, the CIS Policy Group will give the go-ahead for the latest version to be made available to the users.

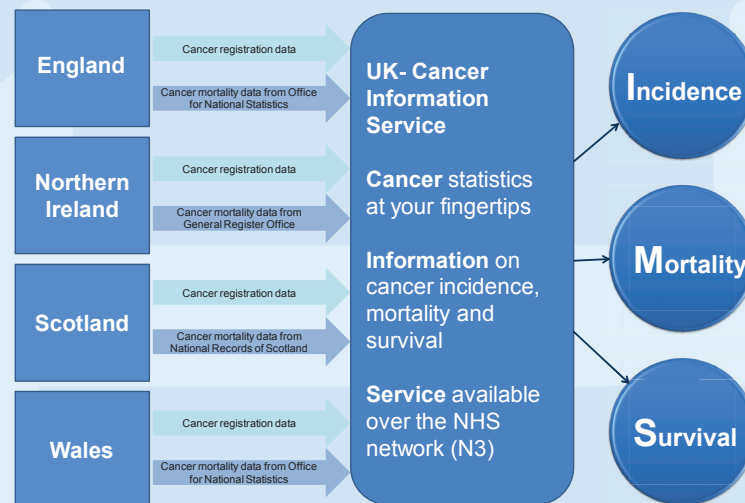


Figure 2: Types of statistics in the UK-CIS and their data source

How has the CIS been used to inform the NHS community?

The CIS is available to NHS users with N3 connection. Users are able to access cancer statistics on their locality and also national and UK wide data. It also allows the user to navigate to data at various levels of geography, tumour type and age group. It enables the user to assess variation in cancer incidence, mortality and survival over time.

The same data from the UK-CIS have been used to populate parts of the Cancer Commissioning Toolkit and cancer e-Atlas. In addition, the UK-CIS data have featured in key NCIN reports and cancer registries' tumour specific information products (see Figure 3). These information products are available to colleagues in the NHS community.

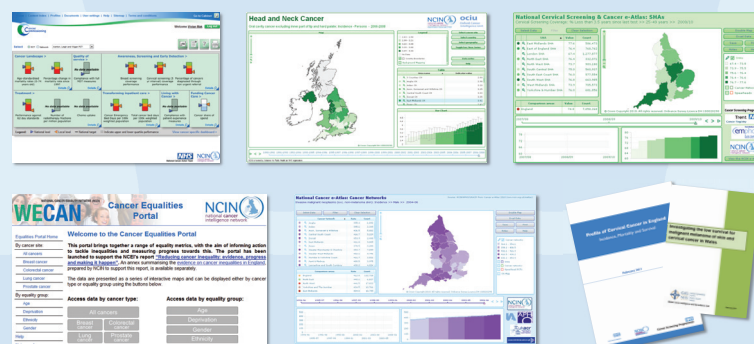


Figure 3: Electronic toolkits and recent published reports using data from the UK-CIS

Data from the UK-CIS can be used for planning healthcare services and targeted interventions for cancer

The UK-CIS enables users to query it and generate results to help us understand more about cancer.

Are more people being diagnosed with or dying of cancer? Has cancer survival improved? Are there differences in cancer incidence and mortality across the UK? How does cancer survival in my locality compare with others in the UK?

How does cancer mortality for people over 75 in my locality compare with others in the UK? What are the differences between old and young people in relation to diagnosis, survival and death due to cancer?

What are the differences between men and women in relation to diagnosis, survival and death due to cancer? Has the incidence of specific cancers changed? What are the age profiles of different cancers?

Key facts

- The cancer incidence module is based on data of over 7* million cancer registrations
- * Data of patients diagnosed with cancer since 1985 (for England, Scotland and Wales) and 1993 for Northern Ireland
- The cancer mortality module is based on data of over 3 million cancer deaths since 1985.

Future plans

We continue to develop the UK-CIS further. Over the next year it is intended to present data for the constituent areas within Wales, revised the calculation of the confidence intervals and also to present the mortality data indexed by registered year of death.

In addition, future data submissions to the UK-CIS will now be taken directly from the National Cancer Data Repository (NCDR). The NCDR contains data on cancer registrations from all 4 countries. The next iteration of the NCDR will have cancer registrations of patients diagnosed up to 2009.

The interface for the UK-CIS will also be upgraded and it will be updated to reflect new organisational configurations as they are eventually formed.

Conclusions

The UK-CIS continues to be used by colleagues in NHS organisations and also within the cancer registry community to monitor the occurrence and outcomes of those diagnosed with cancer.

The construction of the UK-CIS has involved input from dedicated colleagues from all 11 cancer registries in the UK. It has also meant that all the approaches used by cancer registries to derive the incidence, mortality rates and survival estimates are streamlined.

Acknowledgements

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