Technical note on the calculation of the baseline for the Detect Cancer Early HEAT target

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The Scottish Government
Riaghaltas na h-Alba

1.   Introduction

1.1   This Technical Note details the rationale behind the choice of data source for, and method of calculation of, the baseline for the Detect Cancer Early (DCE) HEAT target. Cancer data sources will be discussed along with their suitability for use in measuring progress towards the target. How this data was then used to calculate the baseline, set targets for individual NHS boards and publication plans will also be outlined. The official statistics which support this target and technical information regarding data validation and coding will be published separately by Information Services Division (ISD), National Services Scotland.

2.   Background

2.1   The Detect Cancer Early programme[1] was launched by the Cabinet Secretary in February 2012. Its aim was to bring improvements in survival for people with cancer in Scotland to amongst the best in Europe by diagnosing and treating the disease at an earlier stage. Current 5-year survival rates from cancer in Scotland are considerably lower than other European countries, and when analysed further, this difference occurs mostly in the first year after diagnosis, suggesting that advanced stage at disease presentation contributes to this survival deficit.

2.2   To support delivery of the aims of the programme, a HEAT[2] target was agreed for NHS Boards:

> **To increase the proportion of people diagnosed and treated in the first stage of breast, colorectal and lung cancer by 25% by 2015.**

2.3   Breast, colorectal and lung cancers were chosen to be included as they are the most common in Scotland accounting for 45% of all cancers in 2011. By using these three tumour groups, the impact of the interventions can be evaluated and lessons learned applied to other cancer types in the future.

2.4   The programme brings additional benefits which, although difficult to measure, are also important and will contribute to improvements in the quality of patient care. One of these is the timely production and better recording and reporting of data on stage at diagnosis, which helps to inform local multidisciplinary cancer team decision-making and clinical audit. Another benefit is that the various components of the Programme, in particular social marketing interventions are likely to encourage earlier diagnosis in general and result in an overall 'leftward' shift for <u>all</u> stages i.e. moving from stage 4 to stage 3, stage 3 to stage 2 and stage 2 to stage 1.

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[1] Further information on the DCE programme can be found on the Scottish Government webpage: http://www.scotland.gov.uk/Topics/Health/Services/Cancer/Detect-Cancer-Early
[2] Further information on HEAT targets can be found on the Scottish Government webpage: http://www.scotland.gov.uk/About/Performance/scotPerforms/partnerstories/NHSScotlandperformance
Specific information about the DCE HEAT target can be found by visiting:
http://www.scotland.gov.uk/About/Performance/scotPerforms/partnerstories/NHSScotlandperformance/DetectCancerEarly

3. Data sources

3.1   There are two principal datasets used to record stage of diagnosis in patients with cancer. These are cancer registry and cancer audit data.

3.2   **Cancer registry** is compiled by ISD staff and uses multiple sources of electronic data such as hospital discharge records, pathology records, death records, etc. to create individual cancer registry records. It is population-based and does not gather an over-ambitious amount of data as this may risk reducing the data quality of the most important variables. Another important benefit is that the data set remains reasonably stable over time. These characteristics (as well as a very clear set of guiding principles) also support international comparisons.

3.3   Considerable effort is expended to maximise case ascertainment including cases that may never undergo any treatment. There are a relatively high proportion of records in this data set where staging is unknown due to the complexity of pulling together the different information sources.

3.4   The intricate nature of this task also means it takes a long time to compile the data in to cancer registries. The data is therefore not able to be published until in excess of one year following derivation – for example, data for 2010 was published in Summer 2012 (and staging data was not published with this release). Such a delay in the publication of information is not ideal for use in monitoring progress against the HEAT target. Real time information is more appropriate for the operation of the DCE Programme so the impact of interventions such as the national and local public awareness campaigns and the initiatives to improve cancer screening uptake can be assessed and improved upon.

3.5   Cancer registry data have to meet the needs of many users including policy makers, epidemiologists, researchers, geneticists, and health services managers and clinicians. The data are used for a very wide array of purposes, and are collected according to international standards to facilitate international comparisons of incidence and survival.

3.6   More information on cancer registry data can be found here:
        http://www.isdscotland.org/Health-Topics/Cancer/Scottish-Cancer-Registry/

3.7   **Cancer audit** data have only been gathered much more recently and are collected directly by NHS Boards. Due to the close working relationships between clinicians and audit staff staging data is more complete for cancer audit data than for cancer registry.

3.8   A further benefit of cancer audit data is that it focuses on selected single types of cancer (and does not necessarily cover every histological subtype of cancer). This makes it easier to collect a more detailed data set without compromising the integrity of the most important data items. However, as the focus of the data collection is around monitoring performance and informing clinical decisions around treatment there is not the same requirement to collect information on all cases where there has been a diagnosis of cancer. So, for example, people diagnosed for the first time at post-mortem would not be included in the data set.

3.9   Although there is considerable overlap with data items within the Cancer Registry data set, the additional need for in-depth clinical and pathological information means the reason for collecting it is quite different in nature. The data is also used to inform Quality Performance Indicators[3], a critical work stream for the Scottish Cancer Taskforce.

3.10   The differences between cancer audit and cancer registry data are summarised in Annex A.

4.   Developments to date

4.1   In the 2012/13 Local Delivery Plan (LDP) guidance the available Cancer Registry data was used for the DCE HEAT target, using average annual performance for 2005 to 2009 as a baseline. However, due to the high proportion of "unknown" stages and the delay between collection and publication it was made clear that the use of registry data for monitoring of the target would be reviewed. Consideration was given to using the new cancer audit data instead and a workshop was held in March 2012 to assess the quality of the staging information and the feasibility of using this. Caveated with the need for further improvements to staging information, combined with the relative speed with which cancer audit data can be processed, cancer audit data emerged as the preferred source for monitoring of the DCE HEAT target. The proposal was supported by the DCE Programme Board and Scottish Cancer Taskforce.

4.2   Although cancer audit data will be the primary source for measuring progress against the HEAT target, Cancer Registry data will also be monitored throughout the programme as it is anticipated that changes in staging patterns will be reflected in both sets of data.

5.   Calculating the baseline and setting targets

5.1   Following the decision to use audit data for the baseline, the calculation method had to be established. This in turn would inform the national target – to achieve an additional 25% of the baseline proportion of those diagnosed at stage 1.

5.2   It was decided that a two year average would be more appropriate than using a single year to account for variations between years, this is particularly useful for smaller Boards which may experience large percentage changes from small numbers. The DCE priming campaign was launched in February 2012. As such the latest data prior to this would give the best reflection of the proportion of stage 1 cancers before any impact of marketing campaigns or social interventions have been realised (whilst bearing in mind the impact of steadily increasing cancer incidence and the on-going improvements in recording of stage). It was therefore agreed to use data from 2010 and 2011 combined as the baseline. Performance management against the target would then be measured using a rolling two year average i.e. 2011/2012, 2012/2013 etc. through to delivery in 2014/2015.

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[3] Information on Quality Performance Indicators is available on the Health Improvement Scotland website:
http://www.healthcareimprovementscotland.org/our_work/cancer_care_improvement/programme_resources/cancer_qpis.aspx

5.3   As noted previously, audit data was chosen partly because there was a more complete set of staging data available than with registry data. It is unlikely that staging data will be complete for all records within any data set – there will always be cases where stage cannot be determined with certainty or where it is clinically inappropriate to pursue a series of investigations for the sole purposes of determining stage. Following initial work to increase ascertainment of stage in preparation for the 2010/2011 baseline, there remains variation in the level of "unknown" (or unrecorded) stages within the audit data between different NHS boards and across the three cancer types. In order to provide the most comprehensive information it was decided to include these unknown values when reporting the baseline. The impact the inclusion of these "unknowns" had on the measurement against the target was given significant consideration and it was concluded that that their inclusion was important in understanding and reducing the variation in staging information across NHS boards.

5.4   It is expected that the inclusion of these "unknowns" (or unrecorded) will encourage boards to continue to improve the quality of their staging data for all stages – not just stage 1. From quality improvement work that was done for the 2010/2011 baseline it is known that, when staged, some of the "unknowns" become stage 1, some stage 2, etc. Good quality and timely data facilitates transparent demonstration of performance and improvements in patient experience and this will be an additional benefit of the programme.

5.5   The level of variation in the proportion of "unknowns" was taken in to account when setting targets for individual NHS Boards. NHS Boards with a lower proportion of recorded stage 1 cancers tend to have a higher proportion of unstaged data and therefore will have a higher target. All NHS Boards will be expected to reach the same proportion of cancers diagnosed at stage 1 by the end of 2015 and this will be a 25% increase of the published national 2010/2011 baseline.

5.6   There is recognition that geographic, demographic and socio-economic factors will affect regions differently and each board will have a unique challenge in overcoming these to meet their target. The work of the programme will expect boards to find solutions to address inequalities as this will be key to increasing early detection of cancer, for example, by raising the screening uptake figures amongst deprived communities.

6.   Publication and performance management

6.1   ISD published the 2010/2011 DCE baseline figures in their statistical publication '**Detect Cancer Early Baseline**' on 28th May 2013. This contained the number and percentage by stage of diagnosis for the three tumour types included in the DCE programme - breast, colorectal and lung – for the combined period 2010 and 2011. Figures were made available at national, NHS Board and Cancer Network level for both the individual and combined tumour types.

6.2   As with all HEAT targets and standards, public reporting of the DCE HEAT target will be done through the Scotland Performs website. Data will be updated annually in line with the release of ISD published data. The first measurement against the target will be for 2011/2012 and is likely to be available in Autumn 2013.

Annex A

	Cancer registration	Cancer audit
History	Longstanding – since late 1950s	More recent – last 10-15 years
Scope	All malignant neoplasms, carcinoma *in situ*, neoplasms of uncertain behaviour, benign tumours of brain and CNS	Selected major cancers (and in some cases selected histologies at any given anatomical site)
Population covered	Population-based. Includes cancers arising in elderly who die very soon after hospital admission, patients treated in private hospitals or outside Scotland (as long as Scottish residents), patients diagnosed at autopsy.	Centred around multidisciplinary teams. Unlikely to include cancers arising in elderly who die very soon after hospital admission, patients treated in private hospitals or outside Scotland (as long as Scottish residents), patients diagnosed at autopsy.
Data set	Limited and relatively stable over time. Partly focused on international population-based comparisons of cancer incidence and survival.	More extensive, very tumour-specific and clinically orientated, and less likely to remain stable over time. Not particularly geared towards international comparisons.
Data uses	Multiple, including public health surveillance, planning services, monitoring and evaluation of interventions such as primary prevention and screening programmes, epidemiological and health services research, support for genetic counselling, data to support health promotion campaigns, etc.	Primarily focused on monitoring quality of clinical care. More recently for monitoring stage of disease. Theoretically could be used for health services research.
Data credibility	Thought to be reasonably high internationally, supported by routine indicators of data quality and *ad hoc* studies of data quality. May have less credibility with some clinicians.	May have greater sense of credibility among clinicians due to local involvement in data collection (by some, at least).

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