

Statistics Commission



**NATIONAL STATISTICS TO MONITOR
THE NHS CANCER PLAN: REPORT
OF A SCOPING STUDY**

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National Statistics to Monitor the NHS Cancer Plan: Report of a Scoping Study

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Introduction

1. The Statistics Commission had several reasons for choosing this as one of the first areas for a scoping study to assess the case for further more substantial work to look at the adequacy of National Statistics for monitoring the NHS Cancer Plan. There was a desire for work with the potential to draw out wider lessons about the use of National Statistics to monitor policy implementation, as well as a need to balance other more economic statistics based projects with one from the social area was one driver. The National Statistician had drawn the Commission's attention to the difficult confidentiality issues relating to cancer registries. All these made it an obvious priority topic in the health field.

Methods of working

2. The study was identified as one suitable for carrying out in-house, by a mix of Commission members and staff. It was conducted by Janet Trewsdale and Gill Eastabrook, with administrative support from Emmy Mulla. Sir Kenneth Calman helped us with advice at various stages. We are grateful to Department of Health and Office for National Statistics staff for their help.
3. Our work was based on studying documents, in combination with discussions and correspondence with DH and ONS staff, including a meeting between one of the study team (GE) and the Professor Mike Richards (the National Clinical Director for Cancer) who is responsible for leading delivery of the NHS Cancer Plan. It also took account of discussions at and in the fringes of the Statistics Users' Council conference on Health and Care Statistics on 15/16 November 2001.
4. There was no single document setting out how the Department of Health planned to monitor implementation but they made available to us a number of relevant documents:

NHS Cancer Plan: September 2000;

Review of Cancer Registration in England (the Gillis Report): 28 April 2000;

Service and Financial Framework for 2001-02 (blank returns): January 2001;

Executive summary of the Review of Business Information Needs (RoBIN) of the NHS Executive on cancer (the full document is not in the public arena): received 12 February 2001;

Action Programme for Cancer registration (The Department's response to the Gillis Report): 26 March 2001;

RoBIN review of cancer implementation plan: 26 July 2001;

NHS Plan Implementation Programme: August 2001.

We have also accessed, via the web, the *NHS Cancer Plan – Making Progress*, November 2001. Included in that report are a series of updates on the actions and milestones set out in the Plan.

Background

5. Our consideration of the *NHS Cancer Plan* confirmed the initial rationale, set out in paragraph 1 above, for undertaking this study. The document sets out four aims, three new commitments and a large number of action and milestones. We have focused our consideration on the aims and commitments, but where we have looked at the more detailed actions and milestones, this has reinforced the overall messages. The aims and commitments are listed in annex A, which also records our findings on the specific points.
6. In our work we concentrated on the needs of the Department of Health to monitor and manage implementation of the Plan. There are however two other important stakeholder groups:
 - Parliament and the general public which expect good information on which to judge the government's progress. These needs are very much within the scope of this project but we judge that the required information is a subset of that needed by DH. What is important is that it should be published;
 - clinicians and managers within the NHS who need more detailed data. We did not attempt to consider these needs.

We return to the first point later in this report.

7. Our remit was to look at the adequacy of National Statistics to monitor the NHS Cancer Plan but it rapidly became clear that a substantial proportion of the data in current or potential use had not, for one reason or another, been "badged" as National Statistics. We felt it would be unhelpful and artificial to restrict ourselves to looking only at these so we have considered the full range of relevant official statistics. The fact that not all of these are National Statistics does however raise issues which we have considered. These are discussed in paragraph 19.

Geographical coverage

8. The NHS Cancer Plan is for England and so our specific recommendations are for the English Department of Health. There are however similar developments in the rest of the UK. The Scottish Executive published *Cancer in Scotland: Action for Change* in July 2001; the National Assembly for Wales and the Northern Ireland Executive have stated their intention to monitor cancer provision in their respective devolved administrations. We hope that our conclusions will be helpful to all those involved in the exercise throughout the United Kingdom.

Specific aims, commitments, actions and milestones

9. We have considered, for each of the aims and commitments in the Plan, whether existing data sources appear adequate to monitor implementation. The outcome

of this consideration is recorded in Annex A. We have leaned very heavily in this on information obtained by interviewing Professor Mike Richards. The conclusions are however our own.

10. We have not undertaken a similar systematic exercise for all the specific actions and milestones identified in the detail of the *NHS Cancer Plan*. The spot checking we have done suggests that our general conclusions are robust but that there may be a number of specific points where better information is needed. For example the central return which gives information on when women receive the results of smear tests in writing does not cover those who receive test results from GPs rather than direct from the health authority.
11. We recommend that DH should undertake a systematic check to ensure that any data gaps are identified and tackled appropriately, building on the work of the cancer RoBIN.

What is or will be available

12. The development of the *NHS Cancer Plan* was evidence based with three main types of source:

- cancer registry data and other related ONS data;
- DH routine data collections and ad hoc surveys including HES (hospital episode statistics), KC53/61 screening returns and regular smoking and drinking surveys;
- external (to DH) research on screening, prevention and treatment.

These sources will provide much of the basis for monitoring implementation but they do not presently cover all areas where monitoring is needed.

13. Some new data collections have already been undertaken:
 - the third patient experience survey has focused on cancer patients (following earlier ones for primary care and CHD patients);
 - the Commission for Health Improvement and the Audit Commission are carrying out a review of cancer services and their fieldwork was done in Autumn 2000 so will provide a baseline for the Plan. (We understand from DH that the CHI and Audit Commission report *National Service Framework Assessments No.1: NHS Cancer Care in England and Wales* has now been published, on 11 December 2001.);
 - the introduction of peer review site visits for all hospitals providing cancer services would provide assessment against agreed standards (a national report will be published on the 2001 exercise and future reporting arrangements will be agreed).

What more remains to be done

14. Work is underway or planned in other areas. The confidentiality issues for cancer registers are being addressed. The arrangements for setting and monitoring local smoking targets are being considered in the context of local circumstances. Work needs to continue in these areas.
15. There are however two areas, relating to waiting times and the funding of palliative care, where we have not been satisfied that work currently in hand will fill the gaps in time to meet monitoring needs. Specifically we believe that early implementation of cancer data sets is necessary if progress towards, as well as achievement of, the 2005 waiting targets is to be addressed. The quality of data used to monitor investment in palliative care needs to be assessed, and action taken if there are problems.
16. We recommend that DH should:
 - complete implementation of the cancer data sets as soon as possible;
 - satisfy itself of the quality of the out-turn data it collects on investment in palliative care.

Accountability

17. Our consideration of specific issues reinforced our initial view that Parliamentary and public needs could be met from a subset of the information required by the DH, NHS management and, in particular, the National Clinical Director for Cancer, to monitor implementation of the NHS Cancer Plan. Parliament and the public do however need to have access to that subset in a suitably user friendly form. Current arrangements do not make this easy. Some of the data we discuss above are published as National Statistics, others are not. Some of the latter may be published on an ad hoc basis (for example the recent *The NHS Cancer Plan – Making Progress* included a figure for the proportion of people with suspected cancer seen by a specialist within two weeks of urgent referral).
18. We recommend that the DH should formulate, and set out publicly, clear plans for publication of information to allow Parliament and the public to monitor progress towards and achievement of the aims, commitments, actions and milestones set out in the NHS Cancer Plan.

Scope of National Statistics

19. We note in paragraph 7 above that many of the data we have been considering are not National Statistics. In some cases these are new series which may not yet fully meet the quality standards. We make no specific recommendations but we note that there is a wider issue. If key government targets are set in areas

which are not already supported by existing National Statistics, it is possible that new data collections introduced to monitor progress will not, initially, meet NS quality standards. This has implications for public confidence in the data on whether targets have been met, but there are no easy answers to this challenge.

Wider issues

20. When the Commission asked us to look at this area it noted the potential to identify lessons about the use of National Statistics to monitor targets and hence the implementation of government policy.
21. We have already referred to the challenge presented by the need for information systems to keep up with a changing policy and management agenda. We recognise that we have no ready answers to the difficult questions which arise.
22. Since we began our work a number of issues have come to the Commission's attention which relate specifically to the use of National Statistics for monitoring achievement of targets. These include:
 - changes to the way in which Home Office expresses its targets for removal of unsuccessful applicants for asylum. These now include dependents as well as principal applicants;
 - concerns about whether the quality of regional GDP (gross domestic product) data is adequate to monitor the relevant targets.

We understand in the first case enhancements to National Statistics systems could be made and the main issue arising related to the presentation of the information. These issues too have been addressed. In the second case the issue has yet to be resolved.

23. There are two issues which related to monitoring the cancer plan but also, and in some ways more clearly, to the other examples.
24. Firstly, whether the high quality standards expected of National Statistics may lead to data which are fit for their intended purpose being excluded. We have not, at present, observed specific cases where this has happened but it is important that quality standards should be appropriate. If key government targets are to be monitored using data which do not meet National Statistics standards, the reasons for this need to be understood.
25. Secondly, target setting needs to have some regard to the practicality of monitoring. Clearly the information tail should not wag the policy dog but when quantitative targets are set which cannot be monitored from existing data collections, the feasibility of monitoring and the benefits of setting the targets in a particular form should be considered before firm commitments are made.

Conclusion

26. Proper monitoring of a major change like the NHS Cancer Plan presents a significant challenge. It requires substantial enhancement to existing DH and NHS information systems. It is important to note that some of these changes will also support patient care directly as well as overall management. Work is complete, underway or planned in many areas. Although much of this work has yet to come to fruition we do not believe at this stage further investigation by or on behalf of the Statistics Commission would be productive. We have, however, some specific recommendations for DH and in addition we raise some general issues which we recommend the Commission should consider.
27. We recommend above that the DH should continue to give priority to work to ensure that implementation and achievement of the NHS Cancer Plan's aims, commitments, actions and milestones can be properly monitored and in particular that it should:
- undertake a systematic check to ensure that any data gaps are identified and tackled appropriately;
 - complete implementation of the cancer data sets as soon as possible;
 - satisfy itself of the quality of the out-turn data it collects on investment in palliative care;
 - formulate, and set out publicly, clear plans for publication of information to allow Parliament and the public to monitor progress towards and achievement of the aims, commitments, actions and milestones set out in the *NHS Cancer Plan*.
28. We recommend also that the Statistics Commission should:
- return to the issue in early 2003, seeking a progress report from DH;
 - consider, in the light of our findings and work in other policy areas, whether National Statistics should aim to support monitoring of all key government targets, and if so, how the intrinsic difficulties might be addressed.

MONITORING THE NHS CANCER PLAN

HOW AIMS AND COMMITMENTS WILL BE MONITORED

AIMS

To save more lives

This will be monitored by looking at overall under 75-year cancer mortality rates using cancer registry and general mortality data. This depends crucially on the successful resolution of the confidentiality related problems for cancer registries. We understand the Department of Health has proposals for secondary legislation that should help cancer registries but there is a process of consultation and Parliamentary approval to go through.

To ensure people with cancer get the right professional support and care as well as the best treatments

The new cancer patient survey will be used for this. We understand no firm decision has been made to repeat this survey, pending consideration of its results. Clearly this will be necessary if this aim is to be monitored properly.

To tackle the inequalities in health that mean unskilled workers are twice as likely to die from cancer as professionals

DH intends to monitor health inequalities using a variety of sources, including:

- the ONS longitudinal study which contains social class information;
- cancer registries data which supply information on incidence, survival and mortality by socio-economic deprivation (a measure of deprivation based on Carstairs index which is an area based measure of inequality rather than a social class measure).

There is also a large programme of work being taken forward on health inequalities which will need to address monitoring issues. There may also be a management need for information to inform action on inequalities in service delivery – for example on geographical difference in provision of radiotherapy services. Ad hoc data collections have already been used in this context and may need to be repeated. Peer review has helped networks identify variations they can plan to address.

To build for the future through investment in the cancer workforce, through strong research and through preparation for the genetics revolution, so that the NHS never falls behind in cancer care again.

This aim does not lend itself to monitoring by a single figure (or even a small set of figures). There are however some related statistical issues. Good information will be needed to underpin delivery of the aim – for example to support better workforce planning. These will need to be tackled by DH but we have not attempted to address them here.

COMMITMENTS

In addition to the existing *Smoking Kills* target of reducing smoking in adults from 28% to 24% by 2010, new national and local targets to address the gap between socio-economic groups in smoking rates and the resulting risks of cancer and heart disease:

we shall reduce smoking rates among manual groups from 32% in 1998 to 26% by 2010, so that we can narrow the health gap

we shall set local targets making explicit what this means for the 20 health authorities with the highest smoking rates.

Regular smoking surveys will support monitoring of the national targets. We understand that local targets have not yet been set but that 20 health authorities selected on the basis of general deprivation rather than smoking rates have been funded to develop innovative projects. These projects will be evaluated by the Health Development Agency.

New goals and targets to reduce waiting times for diagnosis and treatment so that:

the ultimate goal is that no one should wait longer than one month from an urgent referral for suspected cancer to the beginning of treatment except for a good clinical reason or through patient choice.

for some uncommon cancers like acute leukaemia, children's cancers and testicular cancer, this is what most patients already experience.

for other cancers this will take time to achieve, so we will set milestones along the way:

by 2005 there will be a maximum one month wait from diagnosis to treatment for all cancers

by 2005 there will be a maximum two month wait from urgent GP referral to treatment for all cancers.

Current NHS patient administration systems tend to focus on time from referral to first out-patient appointment or time from decision-to-admit to hospital admission. Dates of diagnosis (or decision to treat) and date treatment begins will not necessarily be recorded in the main computer systems. Some information is currently being collected on time taken to see a specialist from urgent referral for all cancers and on the other 2001 targets for specific cancers. This requires information to be assembled locally.

We share the view of the National Clinical Director for Cancer that collecting comprehensive information for all cancers will require implementation of the cancer data sets currently being developed. This is particularly important to make sure information collection does not divert clinical and other staff from patient care. Planning of the generic (ie common to all cancers) set is almost complete with some site specific modules also well advanced. A subset for central collection on waiting times is now close to being agreed. Further site specific subsets will be agreed over the next couple of months.

We understand there is good support for these sets from most cancer clinicians but that implementation will require resources: hardware, software and some coding staff. We

understand from DH that this has been flagged up as a priority for 2002-3 in the Priorities and Planning Framework and as such is expected to be a priority call on NHS resources, including those earmarked for LIS (local information strategy) resources. The DH hopes that this will allow full implementation by 2005. We are however concerned that any slippage (and at this stage we are not aware of any detailed timed and resourced plans) will put at risk the ability to monitor achievement of these important targets, and that in any case information will not be available in time to track progress as the targets dates approach.

An extra £50 million NHS investment a year by 2004 in hospices and specialist palliative care, to improve access to these services across the country. For the first time ever, NHS investment in specialist palliative care services will match that of the voluntary sector.

Information on health authorities' plans for this money was being collected on the planning and in-year monitoring return (SAFFR – the Service and Financial Framework Return) but no similar information on out-turn was to be collected. This was surprising and we are now pleased to hear that the set of forecast/estimated out-turn figures (to be collected at the ends of the third and fourth quarters of this financial year) has been expanded to include expenditure on palliative care.

We are however concerned that, as these data have not been collected in earlier quarters and as health authorities will need to supply them some time before their accounts are finalised, it will not be possible to be confident in advance of their quality. It will be important to assess the quality of these data quickly and, if there are problems, take steps to ensure that good systems are in place to allow monitoring of spending well before 2004.

JT/GE
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