

# **Review of Cancer Registration in England**

**Final report presented to the  
Department of Health by C R Gillis, 28 April 2000**

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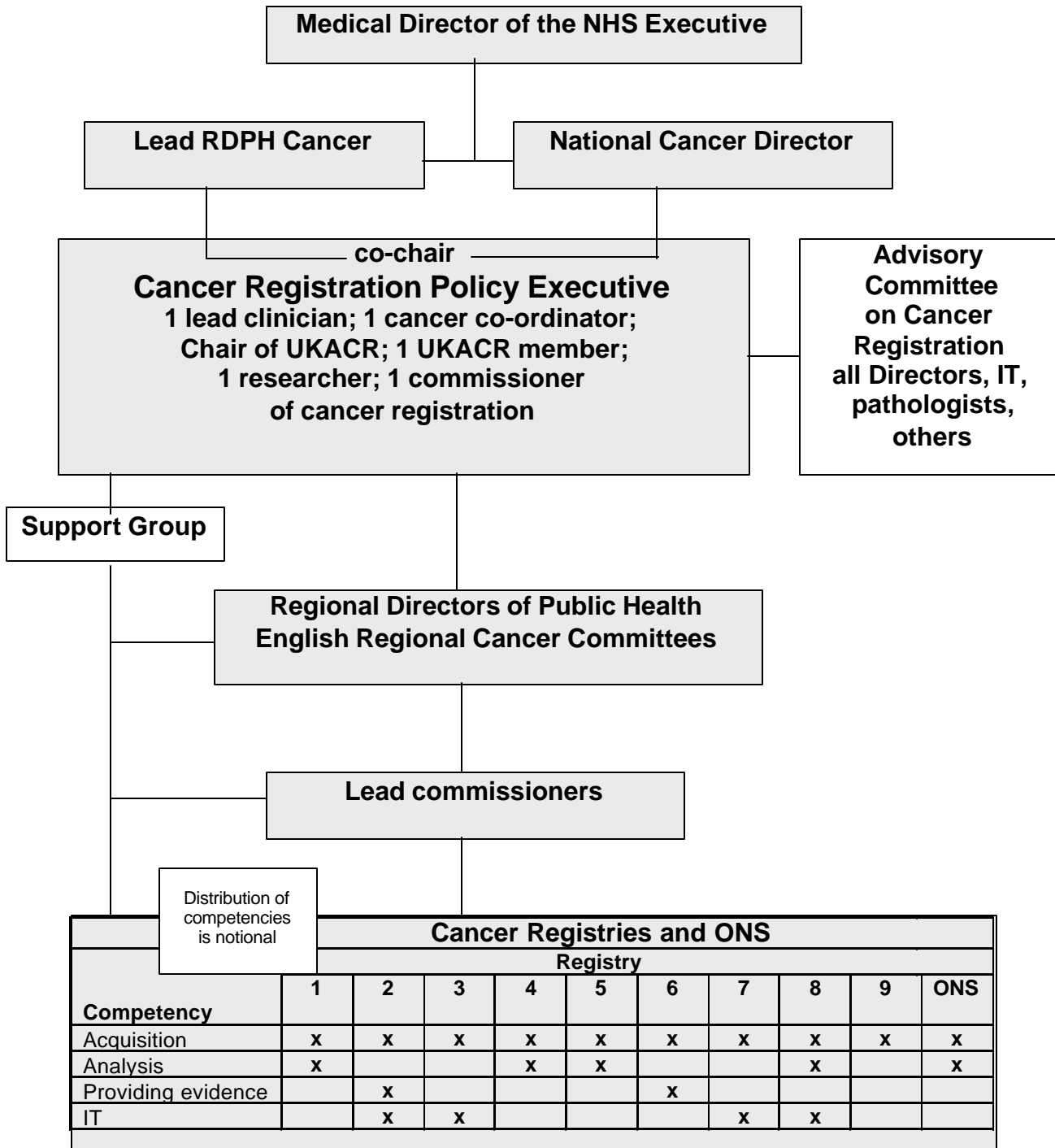
## **1. Overview of the proposed framework**

This report defines a new role for cancer registries in directly informing and improving national and local cancer strategies through the expert use of timely, complete and accurate data.

- Current arrangements for cancer registration in England are no longer sufficient for the national cancer agenda of the NHS. The present regional cancer registration system remains the cornerstone of collecting the data required to support it.
- Cancer registration should be provided by a new framework driven by and accountable to a Cancer Registration Policy Executive consisting of key individuals in cancer strategy so that information is seen to contribute to national cancer control policy.
- The Policy Executive should have the support of an Advisory Committee to aid in development of issues where detailed professional input is required.
- A small support group for the Cancer Registration Policy Executive is required to facilitate its work programme and provide co-ordination with the regional registries.
- The Directors of cancer registries should be accountable (to Regional Directors of Public Health through lead commissioners) for the conduct of the work programme set by the Cancer Registration Policy Executive.
- The key competencies for successful cancer registration now and in the future are defined as
  - data acquisition
  - analysis
  - providing evidence
  - IT
- Resources (which will differ in each Regional Registry) are required to develop and improve the competencies of cancer registration.
- Information on clinical treatment and stage of disease at diagnosis is critical to the development of cancer strategies. The performance of cancer registries in obtaining and disseminating such data, and of trusts in making it available, should be subject to regional appraisal.
- Data collection should continue on the basis of the existing geographical boundaries of cancer registries. However, their outputs however must relate to the new regional structure of the NHS in England.
- The techniques of cancer registration provide models for the new Public Health Observatories for other chronic diseases. The data from Cancer registries will provide inputs to the Regional Public Health data sets.
- Provision of up-to-date, complete and accurate basic data is critical to the users of cancer data. The Policy Executive should set and monitor performance standards in these areas, particularly to address the issue of improving timeliness.

A diagram of the proposed framework is set out below.

Proposed framework for the effective co-ordination of cancer registration in England



Cancer Registries and ONS										
Competency	Registry									ONS
	1	2	3	4	5	6	7	8	9	
Acquisition	x	x	x	x	x	x	x	x	x	x
Analysis	x			x	x			x		x
Providing evidence		x				x				
IT		x	x				x	x		

## 2. Introduction

Professor Charles Gillis, Director of the West of Scotland Cancer Surveillance Unit, Greater Glasgow Health Board, was asked by the Department of Health to undertake a review of cancer registration in England.

The review was initiated principally as a result of concerns about the timeliness of the cancer registration data reported nationally. These were raised in Parliament (*Hansard*, 21 November 1996). The research community also expressed concern about cancer data (P Twentyman (Secretary, United Kingdom Coordinating Committee for Cancer Research), personal communication).

Cancer registration has existed in England since 1929, with national coverage attempted since 1962. The basic aim has always been to collect a record of patient and tumour characteristics for every newly diagnosed primary malignancy in residents of England. The traditional uses of these data were to monitor national and local trends in cancer incidence and survival, to allow follow-up studies of individuals who may have been exposed to a carcinogenic agent (from, for example, early radiation therapy), and in planning services. In the last ten years, however, there has been a growth in demand for information from cancer registries as cancer has become a national clinical priority for the NHS. As a result, the uses to which the data are put are widening, for example to evaluate the effectiveness of breast and cervical screening programmes, to assist NHS trusts in the reorganisation of cancer services as recommended in the Calman-Hine report and to support clinical genetics services.

The keys to successful use of cancer registration data have always been:

- completeness (of population coverage);
- timeliness, and
- accuracy

However, the newer applications of the data demand ever higher standards in these aspects of data quality.

Reviews of cancer registration have taken place approximately every 10 years since 1970 (OPCS, 1990). Completeness, timeliness and accuracy have been restated as the fundamental goals of cancer registration in each review.

The terms of reference for the present review were set by the Department of Health and are shown in full at Appendix 1. In summary, they required that the review advise the Department of Health on ways of improving the overall performance of the cancer registration system in England. The scope of the review was to range from the regional cancer registry (CR) level to the National (ONS) level. For the purposes of structuring this report, the 10 elements of the terms of reference are summarised as:

- *at the individual CR level, to review:*
  - ◇ the *modus operandi* of CRs
  - ◇ the comparative performance of CRs
  - ◇ the analytical and research output of each registry

- ◇ the efficiency of use of resources
- *at Office for National Statistics (ONS) level, to review:*
  - ◇ cancer registration activity at the ONS
  - ◇ interrelationships between CRs and the ONS
  - ◇ ONS workload in relation to cancer registration
- *at the national level, to review:*
  - ◇ areas requiring the development of national guidance
  - ◇ information flow from the registries to ONS and other national bodies
  - ◇ mechanisms to improve the overall cancer registration system

The overall aim of the review is therefore to suggest means of improving the co-ordination and effectiveness of cancer registration nationally and regionally, given the changes in the purposes for which the data are being used.

The remainder of this report presents the methodology adopted for the review, the context in which the review was conducted and the main findings. Options for improvement are then discussed in the light of the context and findings. Finally, a series of recommendations is set out.

### **3. Methodology**

Professor Gillis co-opted Mr Roger Black, Head of the Scottish Cancer Intelligence Unit, Edinburgh, and Professor Peter Boyle, Director of Epidemiology and Biostatistics at the European Institute of Oncology, Milan, to aid him in the review.

The Department of Health established a Reference Panel of representatives of interested parties such as Directors of Public Health, NHS Trust Chief Executives and academic users. Membership of the Reference Panel is set out at Appendix 2. This group met three times.

Professor Gillis attended meetings of the Advisory Committee on Cancer Registration (ACCR) on two occasions and the United Kingdom Association of Cancer Registries (UKACR) on one occasion. Minutes of meetings of both of these groups were made available as background materials for the review. In addition, the UKACR agreed to make available their review of cancer registries' work: 'Resources and Outputs: Summary' (Williams, 1999). This document was used extensively in the Review.

Each registry made a written submission to augment documentation already provided by UKACR and the ACCR. In addition, Professor Gillis visited every cancer registry in England and the Office for National Statistics (ONS). Professor Gillis asked at least one senior clinician in each registry area to comment on the performance of the relevant registry during these visits.

Professor Gillis also met the Lead Clinician for Cancer Services at Kings College, Guys and St. Thomas' NHS Trust, Professor Mike Richards, now the National Cancer Director for England.

Mr Black visited the National Cancer Registration Bureau at Titchfield and the Medical Statistics Group at ONS. Mr Black also met the co-ordinator of the cancer registration section of the NHS Information Authority project on the 'Cancer Information Strategy' for the NHS in England.

The first interim report of the review was seen by the ACCR and UKACR Executive Committee in October 1999, and was described to the full membership of the UKACR at its AGM in November 1999.

A draft final report was prepared for discussion by the reference panel on 29 February 2000 and their comments included in an amended report discussed by the ACCR on 16<sup>th</sup> March. The ACCR approved the report subject to minor amendments.

This final report sets out the developments in NHS and cancer policy in the section on "drivers for change". "Requirements for the future" and "critical factors" are drawn from these developments. The critical factors include "four core competencies". After setting out the findings from this review, the report goes on to discuss options for the future using the requirements for the future and the core competencies. Finally, the report sets out a proposal for a framework for the future of cancer registration.

## 4. Drivers for change

### Introduction

This section sets out the context in which cancer registries currently operate and outlines the challenges, or 'drivers for change', which they are facing. The context and challenges are outlined under the headings set out below, together with a note of the relevant principal policy documents:

1. Cancer control;
2. The cancer agenda – including the *Calman-Hine* proposals;
3. The wider healthcare agenda – *Modernising the NHS*, the *National Planning Guidelines*, *Information for Health* and the *Cancer Information Strategy*;
4. The public health agenda – *Saving lives: our healthier nation*; and
5. The international context

Each section contains a statement setting out a requirement for the future and a set of critical factors which registries need to develop in order to underpin the relevant requirement for the future. In turn, the critical factors are grouped into four competencies for cancer registration at the end of this section.

### 1. Cancer Control

Cancer is now the commonest cause of premature death in the UK. Although survival following treatment has improved, the ageing population and increasing incidence of many types of cancer mean that the total numbers of deaths are not falling substantially year-on-year. Currently more than half of all patients die within five years of diagnosis. This underlines the importance of reducing the occurrence of cancer as well as minimising the consequences for individuals with a cancer diagnosis through the provision of quality diagnostic, treatment and palliative care services: this combined approach is known as *cancer control*. The role of information in achieving effective cancer control is embodied in current policy on public health and cancer services and recognised by the World Health Organisation and research organisations nationally and internationally.

**Requirement for the future (1):** to develop a nation-wide cancer registry service that supports the efforts of the NHS in reducing the occurrence of cancer and minimising the consequences for individuals with a cancer diagnosis through the collation and analysis of consistent, comparable and complete cancer data on prevention and care.

**Critical factors:** timeliness; completeness of ascertainment; uniformly high standards of accuracy; analytical capability; credibility of information to clinicians; communication skills.

### 2. The cancer agenda

#### *The Calman-Hine proposals*

Evidence from cancer registries was fundamental in establishing the scope for change and the subsequent recommendations of the Calman-Hine report.

The stated aim of the Calman-Hine proposals is to create a framework for cancer care in England which will enable a patient, wherever he or she lives, to be sure that treatment and care received is of a uniformly high standard. Underpinning the recommendations are

general principles that include patients having access to a uniformly high quality of care, the importance of early recognition of symptoms and screening and giving patients clear information on treatment options and outcomes. Each of these principles requires or is informed by good quality cancer data.

The proposals also include a specific statement that “cancer registration and careful monitoring of treatment and outcomes are essential”.

A National Cancer Director has been appointed and a working group led by him has been set up to develop national cancer standards. The work of cancer registries will be essential in assisting the Department of Health and Health Authorities to monitor compliance with these standards.

### ***Emergence of Clinical Datasets***

The National Cancer Director has proposed minimum data sets for the key cancers. Also, clinicians individually and collectively are now initiating and obtaining their own data on a variety of cancers and using *ad hoc* datasets to evaluate key aspects of care. The National Cancer Director is looking to the expertise in cancer registries for help with this as a priority. The interface between population-based cancer registration and information in Trusts is critical as:

- *providing evidence requires cancer registries to understand of the influence of casemix and referral patterns on variations in outcomes between Trusts; and*
- *cancer registries need information from Trusts to provide the clinical detail to understand geographical variations in outcomes.*

**Requirement for the future (2):** to develop the role and capabilities of the cancer registries to support and monitor the Calman-Hine proposals and to develop an interface between the registries and clinical data collection which allows best use of limited resources.

**Critical factors:** data acquisition; data quality (including data standards); timeliness; analytical capability; providing evidence; IT skills.

### **3. The wider health care agenda**

The *National Planning Guidelines for the NHS in 2000-2002* have reaffirmed the priority of cancer for the NHS. The White Paper *Modernising the NHS* highlighted for the first time the role of information in supporting good clinical care. It also introduced the concept of clinical governance, which in turn brought assessment of local clinical effectiveness, clinical risk management and quality assurance of services into sharp focus. All these activities rely on collecting and analysing good quality data.

For cancer services, these developments emphasise the importance of consistency in techniques of data collection and reporting by cancer registries. Complete population-based data are essential in this area because there are variations in casemix at all levels of care. Survival and other patient-centred outcome measures of treatment vary locally, regionally and nationally, but comparisons will only be taken seriously if based on valid data. In addition, clinician and management interest in the new cancer agenda has increased interest in the timeliness and quality of the data used.

*Modernising the NHS* also introduced changes to the organisation of the NHS. The development of primary care groups and primary care trusts suggests that local cancer

registry data and information will be required to support them. The white paper also introduced Health Improvement Plans and Trust Implementation Plans. Providing evidence from information is now a part of all of these plans and, as a result, has moved from a being a research activity to core NHS business.

*Modernising the NHS* also sharpened the focus on information technology. In addition, radical changes in information management and technology are currently in development in both the primary care and acute sectors of the NHS. The Electronic Health Record (EHR), as foreseen in *Information for Health*, will eventually provide person-based information for all contacts and episodes of care. However, in the medium term cancer registries need to be ready to exploit existing electronic databases at the same time as planning data collection based on the EHR. The platform for this is the *Cancer Information Strategy* but the immediate catalysts will be the clinical minimum datasets for specific cancers proposed by the National Cancer Director. Integrating these new requirements with the current cancer registration minimum data set is essential to avoid duplication of effort.

The NHS Information Authority (NHSIA) has inherited ownership of *Information for Health* and therefore of the Cancer Information Strategy. If cancer registration is to be truly “at the heart of strategic thinking in cancer” it will need input into and assistance from the NHSIA. Some specific suggestions from the NHSIA are:

- incorporation of the revised cancer registration minimum data set (MDS) into the NHS Data Model/Data Dictionary;
- development of standard interfaces between registries and suppliers of the source data both for existing systems as part of the revised MDS, and also as part of the EHR project;
- increasing involvement with the IT aspects of the Cancer Information Strategy; and
- assistance with the identification, evaluation and utilisation of new technologies.

**Requirement for the future (3):** to develop IT capability in order to exploit developments in NHS information (with strong central support) and to support proactively the clinical governance agenda and help clinicians and managers interpret the factors underlying variations in risk and outcome and to assist in the design and monitoring of care interventions.

**Critical factors:** completeness and timeliness of data; local engagement between cancer registries and clinicians; analytical capability; providing evidence; IT.

#### **4. The public health agenda**

##### ***Savings Lives – our healthier nation***

The goals of this white paper are to:

- improve the health of the population as a whole by increasing the length of people’s lives and the number of years people spend free from illness; and
- improve the health of the worst off in society and to narrow the health gap.

As cancer is the commonest cause of premature death (and is highlighted as a priority in the paper), understanding cancer control in populations is a key requirement for supporting the goals of the White Paper.

The supporting role of information in cancer control in populations involves:

- knowing the current descriptive epidemiology and aetiology of cancer.
- identifying variations in risk and outcome, and the scope for intervention; and
- monitoring the effectiveness of interventions such as screening.

All of these activities require complete, accurate and timely data allied to skilled analytical capability to be effective. These are the essential building blocks not only for cancer registration but also for the registration of other chronic diseases anticipated in the proposal to establish regional Public Health Observatories.

### ***Current position and responsibilities of the Health Authorities***

Health Authorities have a statutory responsibility for the health of the local population and each Health Authority is required to produce a Health Improvement Plan to outline their agenda for improving health in their area. Registries enable Health Authorities to monitor progress in the implementation of the local Health Improvement Programme and to play a part in ensuring that residents receive the best quality of care. In future registries will become increasingly important in assisting Health Authorities in assessing the implementation of national guidance on cancer management.

Registries must also be able to support the responsibilities of District Directors of Public Health in fulfilling their responsibilities for assessing the impact of environmental hazards such as those laid out in the current draft guidance on investigating the health impact of emissions to air from local industry.

In addition, commissioning of specialist services, which is being devolved to groups of Health Authorities, needs to be informed by data from cancer registries, particularly in relation to cancer outcomes.

Finally, cancer data has a key role to play in the national screening programmes. Public and professional interest is frequently focussed on the effectiveness of breast and cervical screening programmes and the scope for further programmes in, for example, colorectal and prostate cancer. Complete, accurate and timely cancer registration data and high analytical skills are required to provide evidence of their effectiveness.

***Requirement for the future (4):*** to ensure all cancer registries have the capability to provide skilled analytical support and that they work proactively to engage public health physicians in the use of cancer data to support cancer control, with the by-product that use of the data encourage improvement in data quality and relevance.

***Critical factors:*** data acquisition; data quality (including data standards); analytical capability; IT skills.

## **5. The international picture**

### ***General***

Five-year survival from common cancers in England (and the rest of the UK) appears to be less favourable than in many European countries (Berrino et al, 1999). Although these results may be partly due to artefacts of data quality, many clinicians and epidemiologists believe that some of the differences are due to genuine variations in the quality of care. Scientifically robust answers cannot be given until the many reasons for variation in survival

outcome are understood. Many disciplines have a role in resolving this important issue but that of the cancer registries is fundamental and unique.

### **Contribution of Cancer Registries in Europe**

There is now an important European dimension to cancer control. For example, there can be no doubt that the co-ordinating activities of the European Network of Cancer Registries and the EURO CARE project have, respectively, drawn attention to the credibility of European comparisons of data and the description in variations in survival. Furthermore, participation in international collaborative projects has underlined the scope for supporting control of cancer through the design, promotion and evaluation of interventions, for example, screening, survival outcomes. There is clear evidence of the success of this approach from the work of the cancer registries in the Nordic countries.

**Requirement for the future (5):** to maintain and enhance the capability of the UK to participate in and contribute to national and international studies of current issues in cancer.

**Critical factors:** data quality; analytical capability, credibility and communication skills.

### **Cancer registration – in summary**

In summary, the ongoing developments in cancer, health and health care policy suggest that the requirements for cancer registries of the future are:

1. to develop a nation-wide cancer registry service that supports the efforts of the NHS in reducing the occurrence of cancer and minimising the consequences for individuals with a cancer diagnosis through the collation and analysis of consistent, comparable and complete cancer data on prevention and care.
2. to develop the role and capabilities of the cancer registries to support and monitor the Calman-Hine proposals and to develop an appropriate interface between the registries and clinical work that allows best use of limited resources.
3. to develop IT capability in order to exploit developments in NHS information (with support from the NHSIA) and to support proactively the clinical governance agenda by helping clinicians and managers to interpret the factors underlying variations in risk and outcome.
4. to ensure all cancer registries have the capability to provide skilled analytical support and that they work proactively to engage public health physicians in the use of cancer data to support cancer control, with the by-product that use of the data will continue to improve quality and relevance.
5. to maintain and enhance the capability of the UK to participate in and contribute to national and international studies of current issues in cancer.

The role of cancer registration is no longer simply the collection and management of databases. Given the current context of public health and clinical governance, it is the competence of cancer registries in providing information and insight which is key. From the critical factors outlined in each section above, the competencies required to underpin cancer registration in the future can be seen to be:

**Data Acquisition skills:** Understanding technical aspects of data definitions, methods of data collection and quality assurance as well as developing good relationships with data providers. This a product of tact and trust.

**Analytical skills:** Familiarity with the current and potential scope for appropriate use of the data to contribute to policies, health services planning and to fundamental and applied research.

**Providing evidence:** Understanding how to convert the analysis of data into evidence that will improve outcomes in prevention and care. This involves knowledge of the mechanisms of clinical effectiveness and clinical and public health governance and willingness and ability to provide relevant outputs.

**Information technology skills:** The ability to exploit existing existing electronic databases to improve cancer registration data collection and to contribute to the strategic development of future systems based around the EHR.

## 5. Current Findings

### Introduction

This section describes the current situation in cancer registration in terms of the remit of the review. Much of the content is based on a review of material on the cancer registries provided by the UKACR (Williams, 1999) and the cancer registries individually.

### Comparison of *modus operandi* of cancer registries

#### *Core contract*

*The current remit of cancer registration is set out in the core contract for commissioning cancer registration (EL(96)7) and is:*

to create and maintain a comprehensive, accurate, timely and accessible register of cancers suitable for:

- management of resources for prevention, treatment and laboratory services;
- commissioning and evaluating services, including screening programmes;
- planning and evaluating clinical management and treatment (including clinical audit);
- research into the causes of, and survival from, cancer; and
- education of professionals and the public.

The core contract also specifies a series of tasks required to meet these goals, including data collection, data quality assurance and information provision. In general, all registries were able to demonstrate compliance with most requirements of the core contract. Some appeared to be doing more in the sense of acting proactively to meet emerging demands for information. A minority did not comply with the requirement to submit data to ONS within agreed timescales.

#### *Geographical*

There are 9 population-based cancer registries in England, only 3 of which are contiguous with existing NHS Regions (i.e. Trent, Northern and Yorkshire, and West Midlands). Boundary changes following the merging of Regional Health Authorities in 1994, and the 1999 changes to the NHS regions in southern England resulted in the following combinations:

- the North West Region is served by two registries, Merseyside and Cheshire and North Western Cancer Registries;
- the South Eastern Region is served by Oxford, South and West, and Thames Cancer Registries;
- the Eastern Region is served by East Anglian and Thames Cancer Registries; and
- the London Region is served by the Thames Cancer Registry.

All registries come within the framework of lead purchasing by individual health authorities. The host organisation varies: in 2 cases, the lead purchasing health authority is also the host organisation; in 6 registries the host organisation is a Trust; and in one the host organisation is a University.



*Overview of functions and management*

All registries perform the same basic functions with respect to the data being collected namely capture, validation, linkage, storage, retrieval, analysis, interpretation, reporting and dissemination. All registries provide an information service and undertake research and development and education and training, although the nature and extent of this varies. The 9 registries are variably named with 4 being called cancer registries, 4 being contained within cancer intelligence units and 2 being within larger cancer surveillance or information units.

In 2 registries, the Director function is shared between two people and in the remaining 7, one person undertakes this role. The Director holds an academic contract in 4 cancer registries, mostly in a Public Health specialty. In a further 4 registries, the Director is a Consultant in Public Health Medicine and in 2 registries, the Director is a non medical NHS Senior Manager. The contractual and budgetary arrangements for the Director function vary amongst the registries: in 2 registries, there is no funding in the budget for the Director; in 3 registries there is full funding; and in the remaining 4 there is part funding. In 6 registries, the Director is part-time, undertaking registry duties in combination with breast and cervical screening quality assurance (3) or academic duties (3). In 2 registries, the Director is full-time and in 1 registry the Director is a clinical academic with no formally contracted time. All directors split their registry duties between managerial and analytical activities.

*Data acquisition and analysis*

Over 280,000 cases of cancer are registered annually from the resident population of England. The registries vary considerably in size and cover populations ranging from 2.4 to 13.9 millions, with an average population size of around 5 millions. Most (8) registries record cases of cancer in non-residents who are treated within their geographical boundaries. Resident registrations vary (between 89-99%,) as a proportion of total registrations depending on cross-boundary flows.

Three registries receive most of their notifications electronically with the remaining 6 receiving most of their notifications on paper. Where data are received electronically, clinical notes are routinely sampled to assure the quality of the information. If the pathology text is received electronically, this is also used to validate coded data. For 5 registries, pathology is the source of over 50% of notifications. Hospital information systems and clinical case notes account for the majority of notifications in a further 3 registries, and for 2 registries, detailed information was not provided.

The coding of cancer site and morphological type is carried out exclusively by registry staff in 5 registries, and is reviewed by registry staff in the rest. The coding of treatment data by registry staff is more variable, ranging from 0% (in 1 registry) to 100% (in 3 registries). When not coded by registry staff, data are usually coded by trained records staff at hospitals.

In the 6 manual registries, staff spend most of their time extracting information either from documents sent to the registry, or from clinical case notes accessed during visits to hospitals. In the three electronic registries, staff spend up to 20% of their time extracting data from clinical notes, required for tracking cases notified by death certificates only and quality assurance. Only one cancer registry undertakes systematic and active follow-up of cases to ascertain their vital status. The remainder rely on the National Health Service Central Register for flagging the records of persons registered with cancer and notification of their deaths.

All registries manage their computer systems in-house and most have support contracts with commercial organisations. All registries are undertaking major developments, particularly in the fields of computing and information technology, to improve links with data providers or customers. Most cancer registries without electronic links with their major providers of data are in the process of developing them. The main sources are information collected for purposes other than cancer registration (for example, patient administration systems, hospital discharge systems, histopathology systems, ad hoc clinical data bases and any other relevant information on electronic media which the registry was able to obtain). A variety of record linkage techniques are used to link these together. Validation or quality assurance work was usually done by comparison of the registration record with the text of the pathology report and sometimes the case record when available.

New posts are planned in 6 registries (at April 2000), spread across the range of competencies i.e. data acquisition, analysis providing evidence and information technology.

Between 1996-98 inclusive registries undertook an average of 450 genetic enquiries (i.e. requests to validate self reported family histories of cancer) and an average of 490 *ad hoc* statistical reports (range 40-1,020). *Ad hoc* enquiries range in complexity from those answered using off-the-shelf data to those requiring complex new analyses. For all registries, both genetic and ad-hoc enquiries are increasing year-on-year.

### Costs

The following table provides a summary of the costs of the registries.

**Table 1: Summary of registry costs**

Cancer Registry	Resident population (rounded)	Registrations (typical)	Total Budget £	Adjusted* Budget £	Cost/Registration £	Adjusted* cost/Registration £
East Anglia	2650000	17979	316234	318734	17.60	17.70
Merseyside & Cheshire	2410000	17800	354639	396639	19.90	22.30
Oxford	2640000	18473	342733	342733	18.60	18.60
South & West	6640000	43000	799200	799200	18.60	18.60
Thames	13850000	70646	1602071	1757877	22.70	24.90
Trent	4780000	26416	508222	625916	19.20	23.70
West Midlands	5320000	34328	683493	683493	19.90	19.90
North Western	4030000	30936	365649	365649	11.80	11.80
Northern & Yorkshire	6650000	42000	1096300	1223332	26.10	29.10
<b>ENGLAND</b>	<b>48970000</b>	<b>301578</b>	<b>6068541</b>	<b>6513573</b>	<b>19.40</b>	<b>20.70</b>

\*The 'adjusted budget' = the registry budget plus the cost of additional staff who are funded from other sources and are engaged on registry work. The adjusted cost per registration is also based on this adjustment.

SOURCE: Williams (1999)

Excluding one registry which reported a very low cost per case, the range of costs is approximately £20 - £30 per registration.

The total cost of the registries in England was £6.1 millions (1998/9). In addition, the registry function derived support from relationships with research and university staff, breast and cervical screening programmes and with Trusts. The additional support provided by

university and research staff was estimated at approximately £450k per annum. In some cases, the support included the salary of the Director. It was not possible to quantify the support derived from the Breast and Cervical Screening Programme Quality Assurance nor from the Trusts.

Support from Trusts usually took the form of case-note retrieval and was essential for the manual registries as well as for the electronic registries when checking random samples of the data.

The average cost of a registry, over the 9 registries was approximately £650k with a range from £316k to £1.6m. Exclusion of the largest registry reduced this average to £550k.

The average cost per resident registration in England was £21.70 with a range of £12.90 to £26.70. The adjusted costs, taking into account the estimated additional £450k deriving from non-budget staff, increased these average costs to £23.20 with a range of £12.9 to £29.8. It should be noted that 6 registries received support from non-budget staff. The extent and nature of this varied. Excluding the outlying registry, the ranges became £18.50 to £26.70 and £18.60 to £29.80 for budget and adjusted costs respectively.

The Resources and Outputs report (Williams, 1999) suggests that costs appeared to be influenced by the type of processing undertaken by the registries, (either electronic or manual) and the size of the registry (derived from the population covered, arbitrarily divided into three categories). The 3 'electronic' registries had a lower average cost per resident registration than the 6 'manual' registries (£20.40 compared with £22.30) based on budget allocations. The report concluded that the relationship with size was less clear and may have implied an optimum size in the middle category that had average costs of £18.2 per resident registration, compared with £20.20 for smaller registries and £24.10 for the larger registries. However this effect disappeared on exclusion of the outlying registry bringing the average cost of the middle size category to £20.80 implying a wider range in which to find an optimum size. The report suggested that size and processing type confounded each another, for example, 2 of the 3 largest registries were also manual.

## 6. Comparative performance of cancer registries

**Table 2: Timeliness, completeness and accuracy of registrations of malignant neoplasms (excluding non-melanoma skin cancer)**

Indicator		Timeliness		Completeness		Completeness and Accuracy		Accuracy	
Registry	Year analysed	%1997 complete by 1.7.99		M:I Ratio		%DCO		%MV	
		Initial	Full MDS	Male	Female	Male	Female	Male	Female
East Anglia	1997	0	104	63.8	57.8	0.3	0.2	82.0	84.1
MCCR	1997	93	29	68.2	63.9	0.8	1.2	75.5	74.8
North Western	1997	0	100	61.7	58.2	1.1	1.3	77.5	78.7
Northern	1994	43	40	76.0	67.4	8.5	8.1	69.4	70.8
Oxford	1997	0	103	58.0	52.0	1.4	1.6	84.6	84.9
South & West	1996	61	52	60.0	54.0	8.0	9.0	77.0	77.0
Thames	1997	16	84	63.8	57.9	15.4	15.7	69.2	70.4
Trent	1997	0	98	69.0	62.0	9.0	8.5	84.0	84.0
West Midlands	1997	0	103	60.0	55.0	6.7	7.6	76.9	78.8
Yorkshire	1996	11	67	66.6	62.0	2.0	2.1	81.7	82.0
<b>(GB) Average</b>		<b>30</b>	<b>80</b>	<b>64.1</b>	<b>58.5</b>	<b>5.5</b>	<b>5.5</b>	<b>78.0</b>	<b>78.8</b>

Registry comments

Source: UKACR QA Group, (1999)

*%MDS*

Northern and Yorkshire values are low due to a postcode assigning problem.

MCCR have had to change their processing priorities due to local pressures.

*M:I ratios*

Northern M:I ratios may be high due to some cases having been missing during merging of the registries.

*%DCO*

South and West, Trent and Thames are introducing methods to reduce their high DCO rates.

West Midlands have a problem with one of their health authorities contributing to their high DCO rates.

Northern DCO rates are high due to data quality issues relating to the merging with Yorkshire registry.

### Data quality

The UKACR has adopted a set of standard indicators of registration data quality, from which four key indicators have been selected for the purposes of summarising registry performance in terms of timeliness, completeness and accuracy. The following indicators, along with comments provided by some registries, are presented above (table 2).

### *Timeliness*

- the % registrations of malignant neoplasms for a particular calendar year for which the complete national minimum dataset (i.e. with valid codes suitable for submission to ONS) had been collected within 18 months from the end of that year
- the % registrations of malignant neoplasms for a particular calendar year for which initial notifications had been received within 18 months from the end of that year are also shown as these can be useful in interpreting variations in the main MDS indicator

### *Completeness*

- The Mortality to Incidence ratio (M:I ratio) is a standard indicator of the completeness of ascertainment of cases by registries. The values observed are influenced to a limited extent by time trends in incidence and mortality, and casemix, but this ratio should be fairly constant between registries. Given recent survival statistics, one would expect male M:I ratios to be about 60-65% with lesser values for females, for whom the overall survival is slightly greater than for men (this is mainly due to casemix variations between males and females). Higher than expected values for the M:I ratio generally indicate incomplete ascertainment of cases in a registry area.

### *Completeness and accuracy*

- Death certificate only (DCO) registrations are those for which the only information available to the registry is from the death certificate. High percentages of such cases (%DCO) may indicate incomplete ascertainment of cases from other data sources (such as pathology laboratories and hospital discharge records) and a poor standard of accuracy (since death certificates contain limited information on the cancer diagnosed, and sources of more accurate information such as pathology reports are not being used). Therefore this indicator is relevant both to completeness and accuracy.

### *Accuracy*

- Registrations supported by histology, cytology, bone marrow or haematology reports are said to be microscopically verified. The percentage of cases of this type (%MV) is a standard indicator of the accuracy of data for a particular registry. Low values may mean use of less reliable data sources such as death certificates and unvalidated discharge data from Hospital Information Systems.

The 'gold standard' for cancer registration data quality internationally is the set of criteria (including those described above) for acceptance in the publication 'Cancer Incidence in Five Continents' (Parkin *et al*, 1997). It is a matter of concern that not all registries in England had data acceptable to the current editors of this standard work.

### *Comparability of data items*

All registries are capable of providing data of sufficient quality to meet needs for descriptive statistics on cancer locally. However, not all provide data of sufficient quality to support the comparative analysis of outcomes in sub-regional areas and at the level of NHS Trusts.

### *Availability of Data*

Some registries collect more data items than required for the National Minimum Dataset. There are tensions about the priority of local as opposed to national requests for data. This is because most registries see themselves as primarily responsible to their local communities. In some cases the priority accorded to national issues is unduly relegated.

Many registries report that access to medical records in some Trusts is difficult. The necessary priority for registration work in medical records departments needs to be recognised by medical records officers and managers in Trusts.

### ***Analytical and research output of each registry***

#### *Annual Reports*

All registries comply with the requirement of their core contracts to produce annual statistical reports. Comments from clinicians indicated that greater clinical content is required to increase the relevance of these reports.

#### *Public Health*

All cancer registries are involved to an extent in supplying local health authorities with process data that are relevant to the designation of Trusts as cancer centres or units. Registries are also becoming progressively involved in projects in providing evidence on the treatment of common cancers: by supplying comparative data or by offering skills in, for example, data quality assurance and statistical analysis. However, the extent to which this opportunity has been taken up by registries is variable. There was concern reported from several clinicians that some registries were not sufficiently proactive in this respect.

#### *Screening*

All cancer registries contribute to the evaluation of the breast and cervical screening programmes, either through collaboration with regional QA co-ordinators or directly through joint registration/screening appointments of directors. The data and skills found in cancer registries, for example interval cancer data and statistical analysis skills, mean that they are ideally placed to undertake the evaluation role for cancer screening programmes.

#### *Research*

There is a correlation between the involvement of registries in research, the availability of resources and research staff and the ability of registries to provide high quality outputs such as publication in peer reviewed journals, other research publications with and without commentary and websites containing accessible and useful information.

Perusal of the research output of the registries, particularly those not attached to an academic institution, shows scope for increasing involvement.

### ***Efficient use of resources***

There is no clear correlation between the costs of registries and the quality of their outputs in terms of timeliness, completeness and accuracy. Indeed three registries with relatively good data quality also have low costs. However this may be due to a history of successful clerical data collection and a lack of need to invest in developing information resources. This cannot be sustained in the long term.

There is no relationship between the population size of registries and either the quality of their output or their cost.

It should be noted for the future of cancer registration that the range of skills and competencies of staff employed through cancer registration budgets is highly variable. No registry has at its disposal optimum levels of skills in providing evidence, data administration, IT, statistical analysis and business management skills.

### ***Cancer registration activity at the ONS***

#### *Role of ONS*

It is acknowledged universally that ONS does a good job in processing data and turning these into high quality national outputs. However, co-ordination of primary data collection in the NHS, which is the key to increasing the timeliness and quality of the data, cannot be undertaken by ONS. The role of ONS in priority setting and management of registration is essentially passive. Although compliance with ONS schedules for submission of data is part of registries' core contracts, lead commissioners are unlikely to be more concerned about provision of national data than local issues. While the technical relationship of ONS with most registries is satisfactory, ONS is unable to exert any managerial influence on registry priorities.

### ***Interrelationships between CRs and the ONS***

#### *Timeliness*

All registries appreciate the need to provide ONS with up-to-date information but this comes second to local priorities for some. Some registries consider that their credibility depends on their local rather than national reputation. Directors allocate priorities according to their views on local and national issues.

#### *Interface Manual*

The ONS interface manual is not part of every registries' computing system. If it was, it would minimise the numbers of records with invalid data items in circulation between the individual registries and ONS.

#### *Working Relationships*

Good working relationships have been established with some registries so that queries can be resolved quickly. The current system is thought to be workable but too dependent on the goodwill of registry directors. A key issue is that complaints made to cancer registration purchasers by ONS do not carry much weight in relation to other local concerns. There is no individual or group who can require all registries to respond to ONS. Equally there is no individual or group who can require ONS to respond better to registries. This has resulted in an unsatisfactory tension between national and local priorities in some registries.

### **ONS workload**

The current workload of ONS in processing data submissions is manageable, but there is scope for greater efficiency if registries complied with the ONS template for such submissions. This is realistic if good working relationships can be established and sustained.

### **Areas requiring the development of national guidance**

#### *Integration of cancer registration with Public Health*

The evolution of policy for the development of cancer services in the NHS, from the Calman-Hine proposals to the appointment of a National Cancer Director, has meant that providing evidence has moved from a research basis to a core activity. Most now accept that local statistical evaluation of casemix, patterns of referral, treatment pathways and outcomes is an essential component of effective service delivery. This could be partly achieved through ad hoc local data collection in Trusts but comparative analysis and benchmarking would not be possible. Furthermore, an ad hoc approach would be inefficient if the skills of cancer registry personnel and data already being collected by registries were not deployed in this area. Clearly, there is a need to integrate cancer registration with other cancer data collection activities by

- Consolidating the national MDS for cancer registration with the clinical MDSs' being developed by the National Cancer Director.
- Setting out a framework for coordinated local data collection. A key question is whether registries should attempt to collect all information required, which might jeopardise timeliness if additional resources are not made available. An alternative would be for baseline epidemiological data to be collected by registries, augmented by detailed clinical information collected by Trusts for the subset of patients they treat.

These two developments would avoid duplication of effort in data collection and provide a population basis for comparative data analysis.

#### *Information Technology*

There was no demand for a single IT system for registration in England. However, national guidance on a 'preferred option' would be of benefit in informing local developments in the medium term. It is hoped that, in the longer term, universal use of a standard 'electronic health record' in the NHS will become the basis of a single IT system for cancer registration.

#### *Statutory basis for registration*

The credibility and utility of cancer registration data are jeopardised if even a small percentage of cases are not registered and/or there are delays in registration. If there are continuing problems in achieving timely and complete data, or there are barriers to data collection imposed by changes in legislation governing medical confidentiality, the possibility of establishing registration as a statutory function should be considered.

### **Information flow from the registries to ONS and other national bodies**

Data flows from cancer registries to ONS have already been commented on. Information flow to other national bodies is mainly in the form of aggregate data delivered through traditional ONS publications and ad hoc statistical reports. However, ONS has made progress in the exploitation of other media such as CD-ROMs and web publishing, as have some of the registries.

### **Mechanisms to improve the overall cancer registration system**

Although the timeliness of national reporting could be improved within the existing system, existing management structures and mechanisms are unlikely to be able to achieve major

improvements in overall registry performance. New arrangements need to be made regarding management and accountability and registries themselves need to develop in relation to their core competencies. It is worth repeating that no registry had all the core competencies at the highest level, but these are required to fulfil current expectations brought about by the drivers for change discussed in Section 4. The bulk of the remainder of the report is concerned with proposals for the improvement of the existing cancer registration system.

## 7. Discussion and strategic options

### Discussion

This section addresses the second aim of the review, namely to suggest means of improving the coordination and effectiveness of cancer registration nationally and regionally. The report revisits the requirements and competencies identified in Section 4, Drivers for Change, and considers the national and regional implications of these requirements. The report then sets out the possible strategic options for the future and considers which of these is most appropriate for detailed discussion.

#### **Requirement 1**

*To develop a nation-wide cancer registry service that supports the efforts of the NHS in reducing the occurrence of cancer and minimising the consequences for individuals with a cancer diagnosis through the collation and analysis of consistent, comparable and complete cancer data on prevention and care.*

The UKACR report concludes that there is variability in the budgets, organisational structures, operational procedures, staffing levels and the locations/settings of the registries. The report concedes that there are variations in costs and concludes that, although interpreting these variations is not straightforward, there are some discernible patterns and the variation in the overall costs is less than might be anticipated. Some of the differences can be explained by variations in the size and processing methods of the registries and some undoubtedly result from idiosyncratic local practice. The UKACR report also concludes that the extent and nature of outputs is variable (Williams, 1999).

The variability in data quality and in the extent and nature of the outputs of registries strongly suggests that **a greater degree of coordination and collaboration** is required if data are to be valid for comparative studies. This variability also suggests that **clear standards for methods of data collection are required at a national level**, as well as exact national definitions for individual data items.

Cancer registry data only attain high quality through consistent use and interrogation by as many constituencies as possible. It is therefore critical **to enhance the engagement of registries with local and national users** of cancer data. Although shared use of registry and clinical datasets is desirable, it is important that **ownership of the detailed clinical data is local**, although nationally defined. **Timeliness** is another critical area for improvement if the NHS is to be appropriately supported.

In order to support the efforts of the NHS it is essential to ensure that local clinicians, managers and researchers have access to suitable skills for analysis and interpretation. As a result, there is a need **to develop the analytical capability of some registries**.

#### **Requirement 2**

*to develop the role and capabilities of the cancer registries to support and monitor the Calman-Hine proposals and to develop an appropriate interface between the registries and clinical work that allows best use of limited resources.*

In order to establish dialogue with data suppliers and data users, develop trust in cancer registry capability and credibility in the output of cancer registries, cancer registry services must have **a strong local presence**. The findings suggest that this generates tension about

the priority of local and national requests for data so that future management arrangements for registration require the authority to overcome this apparent conflict.

There is tension between the need for obtaining consistent and robust basic data on cancer occurrence and finding and recording **the outcomes of treatment in the detail clinicians will accept**. The work plan of the National Cancer Director has made the latter a priority.

These issues must be resolved so that;

- duplication of effort by registration and staff for providing evidence is removed;
- the potential for registry use of clinical databases as a source of reliable information is realised; and
- comparisons using clinical data are population-based.

This will require **greater co-ordination and collaboration** and **the extension of the current minimum data set (MDS)**. However, the capability of registries to collect complete, population-based data could be jeopardised by over-ambitious extension of the MDS. An appropriate balance needs to be achieved, such as continuing to collect the basic MDS (which has served epidemiological and public health interests well) and ensuring that the extended datasets required for some (priority) cancers are properly integrated with the basic data. Adequate time must be allowed for this to take place.

There is also a need for cancer registries to either:

- make arrangements for their own staff to collect the additional information required; and/or
- ask Trusts to provide it.

However they are collected, the basic MDS and extended MDS for particular types of cancer must be delivered if cancer registries are to fulfil their responsibilities for monitoring the Calman-Hine proposals, evaluating performance and outcome, and generally becoming closer to the clinical interests of Trusts in facilitating the national cancer agenda in each region. In order to avoid *ad hoc* local solutions to information needs, **this strategy must have national support**.

### **Requirement 3**

*to develop IT capability in order to exploit developments in NHS information (with support from the NHSIA) and to support proactively the clinical governance agenda by helping clinicians and managers to interpret the factors underlying variations in risk and outcome.*

Registries must continue to support and exploit existing databases, whilst contributing to and planning for the development of the electronic health record. These processes will benefit from greater collaborative working.

The findings are that only three registries receive their data electronically and, in the context of the increasing emphasis on the use of technology, registries should be required to develop in this area. A requirement of the Calman-Hine report is to **provide information to the public** and all registries should be developing their capability to **exploit the internet** for this purpose.

#### **Requirement 4**

*to ensure all cancer registries have the capability to provide skilled analytical support and that they work proactively to engage public health physicians in the use of cancer data to support cancer control, with the by-product that use of the data will continue to improve quality and relevance.*

The cancer registry system is already well-placed to meet this requirement as the average population base of the English regions allows for a critical mass of expertise while permitting the necessary interaction between the cancer registry and the clinical community. This interaction is a necessary condition for the production of high quality data about cancer and will also be required for other chronic disease registration foreseen in the Public Health Observatories. The proposals for change should **ensure that this balance between critical mass of expertise and local interaction is maintained.**

Cancer registries need to **be better integrated into their regional cancer strategies and general public health information structures.**

To achieve this, the director of the registry must have equal influence and be of equivalent status to every other member of the regional group that decides strategy. This is the best means of ensuring that evidence will be used effectively in reaching decisions on cancer policy and will support Regional Directors of Public Health, Health Authorities and Trusts in developing their policies on cancer. This also means that there can be transparency in cancer strategy. The public too can have access to the anonymised basic data.

The analytical capability of registries resides not only in their directors. **Funding for information analysts should be part of the core budget of every registry.** Registries should also consider, as some already have, the appointment of senior research personnel with the experience to develop new applications of data and attract research funding.

Cancer registries, which possess the appropriate competencies, are well placed to continue to evaluate the effectiveness of breast and cervical screening.

#### **Requirement 5**

*to maintain and enhance the capability of the UK to participate in and contribute to national and international studies of current issues in cancer.*

This requirement further supports the need for **consistent, comparable and complete data.** It also suggests a requirement for **good links with the research community.**

The findings demonstrate that there is variability in the registries' interaction with the research community and these links should be developed and improved. The findings suggest that there is a correlation between involvement in providing evidence and the capability to publish research, which suggests that **the development of capacity in providing evidence is also important.**

#### **Competencies**

The review found that no registry had the highest levels of expertise in all the four competencies. Any proposal for the future needs to ensure that **registries are able to develop these competencies.**

## **Summary of issues for future configuration**

The approach taken in achieving the improvement in the overall performance of the cancer registration system in England as required by the terms of reference (appendix 1) should aim to:

- retain the best features of the current local registries;
- support the development of those registries where shortcomings in the core competencies are identified via the new framework for cancer registration (see later) and where justified with increased resources; and
- put in place appropriate mechanisms to ensure that credible, timely national data are available on prevention and care.

In addition, the ability to meet the following conditions may vary and the future configuration should be such that it achieves these aims:

- mechanisms for greater co-ordination and collaboration;
- an appropriate balance between a strong local presence and national standards, guidance and support;
- development of links with local clinicians and providers of appropriate local data to support clinical processes; and
- better integration into the local cancer strategy and public health agendas.

## **Options for strategic development**

There are five options for strategic development of the cancer registry service to enable the service to meet the challenges of the future:

1. dispense with the current system and start afresh;
2. make no changes;
3. establish a national registry;
4. allow for a different number of registries, for example, to match the regional structure of the NHS, allowing stronger management of registration through the existing NHS management structure; or
5. leave the existing registries in place, but ensure greater co-ordination and collaboration through a formally constituted and accountable framework.

These options are discussed below.

### ***Option 1: dispense with the current system***

Cancer registries are well established in the health care system. The product they deliver is needed now by all sections of the health service. Cancer registries have attained their current position through their own initiative. The current national cancer agenda has brought their importance into focus.

It would take time to start afresh. In the interim there would be a continuing need for data to support the Calman-Hine proposals and the public health, clinical governance and electronic health record agendas.

This option can therefore be dismissed.

***Option 2: make no changes***

The drivers for change indicate a need for greater co-ordination and collaboration to meet the challenges ahead and to keep pace with the changes in the NHS.

In particular the review concluded that although some improvements could be made in the timeliness of national data within the existing system, the existing management structures and mechanisms are unlikely to be able to achieve major improvements in overall registry performance.

These factors suggest that the status quo is not acceptable.

***Option 3: establish a national registry***

Although consistent national data are required, no individual or group wished to see the establishment of an English Cancer Registry.

There is no precedent for a successful national registry of this size. It would not be possible to have the local contacts necessary for a properly functioning registry in a single registry for a population in excess of 50 millions.

This option can therefore be dismissed.

***Option 4: Changing the number of registries***

Ideally, cancer registries should relate precisely to regional boundaries used for other aspects of NHS management. However, regional boundaries have been subject to change and may change in the future. Many of the clinical flows cross regional and other boundaries but better collaboration between registries and flexibility in data exchange and reporting should be deployed to overcome this. Therefore changing the number of registries does not have any significant advantages over the status quo.

This option can therefore be dismissed.

***Option 5: establishing a collaborative framework***

This option proposes to retain the existing registries but to enhance co-ordination and collaboration through the development of a formal administrative entity with a remit for improving the core competencies throughout England and for improving collaboration and joint working through the framework of cancer registries. The immediate expected outcome would be an improvement in the homogeneity of procedures and methodologies used in cancer registries.

Most contributions of cancer registries to improving outcomes in prevention and care have come from studies carried out on a regional basis. Establishing a framework based on existing arrangements would build on this expertise and provide the co-ordination and accountability necessary.

There are considerable strengths in the current cancer registration system across the country that could be shared to registries' mutual benefit by working together on the core competencies of cancer registration, data acquisition, analysis, providing evidence and IT.

As previously stated no registry in England possesses all these competencies at the highest level, but such high level competencies are needed by all registries.

Many registries have been working together on topics of common interest for many years and where appropriate with ONS. However, such collaboration has been *ad hoc*, usually through the UKACR. At times local priorities have conflicted with this. Thus arrangements for strengthening collaboration are required to resolve conflicting priorities.

This option also allows for the fact that cancer and other diseases do not recognise regional boundaries. It is the techniques of cancer registration that need to be working to the same high standard throughout England so that any boundary changes can be accommodated by qualified regional personnel from the regions affected working in concert to accommodate the newly defined regional boundaries. This is increasingly practical with the advent of better communications through the NHS net. No registry would be required simply to collect and report data on a single geographical basis. Their outputs would have to be presented on the basis of the boundaries of interest to the data users.

A formal framework would also lessen cancer registries' vulnerability to changes in regional boundaries because the framework would improve the distribution and thus availability of the core competencies to deal with the problems that arise from such changes. Thus all cancer registries would ultimately deliver to the same standards. As this happens staff time devoted to dealing with the consequences of boundary changes would diminish.

### ***Preferred option***

The option that most appropriately meets the requirements for developing cancer registration in England is Option 5, the introduction of a formal and accountable collaborative framework. This would be headed by a policy executive working with the National Cancer Director. The policy executive would oversee the development of cancer registration at a strategic level whilst allowing for local implementation and development of services and research within the wider cancer agenda.

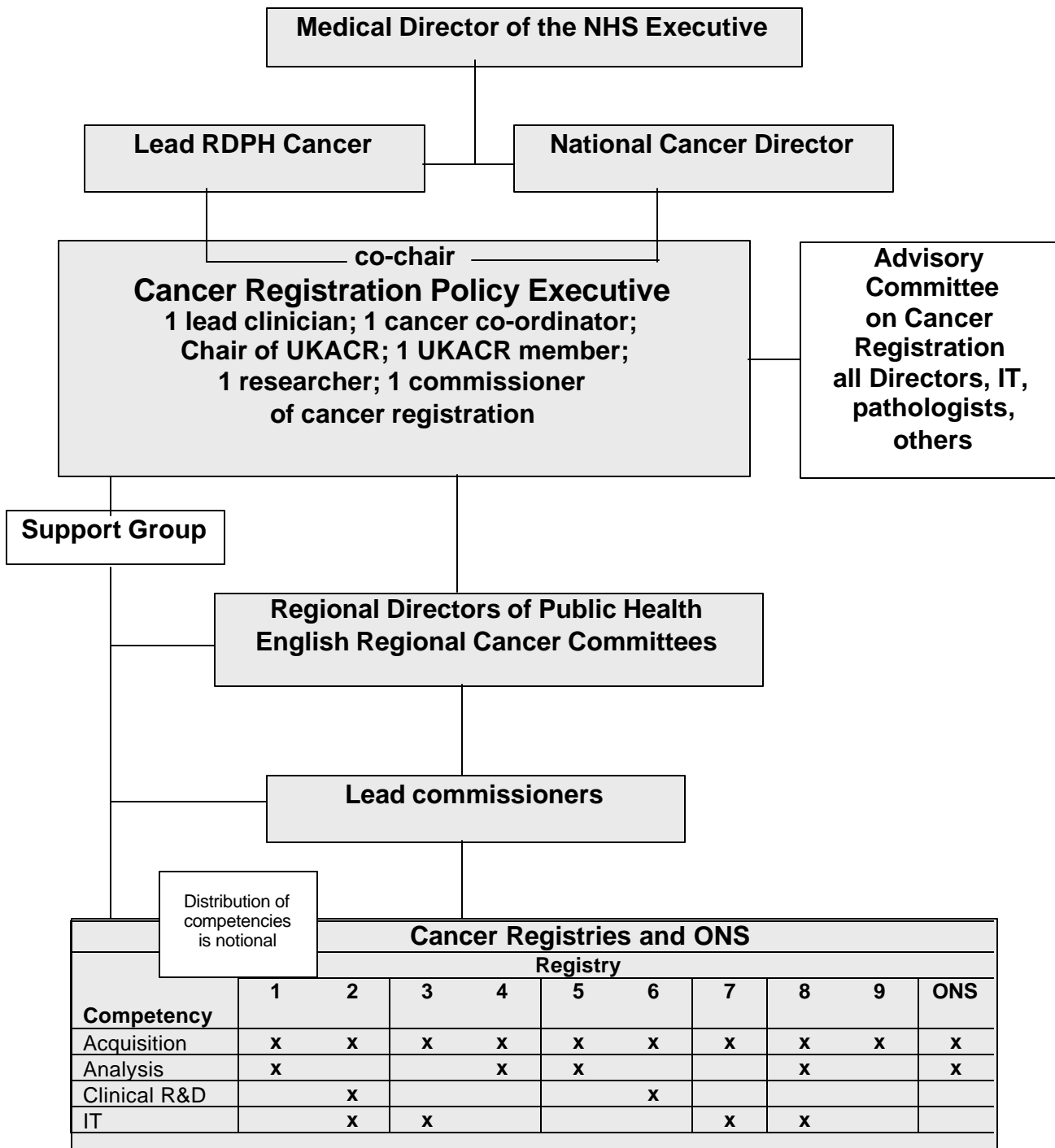
The more detailed mechanisms for the framework are set out in the next section.

## 8. Detailed proposal – a collaborative framework

### Introduction

This section of the report sets out the detail of the preferred option, the establishment of a collaborative and accountable framework for cancer registration in England. The section sets out the proposed structure as a diagram and then describes the role of each of the existing or new organisations in supporting the framework in its aim of improving the overall performance of the cancer registration system in England.

### Proposed framework for the effective co-ordination of cancer registration in England



## **Cancer Registration Policy Executive**

We advocate a small policy executive group to direct and manage cancer registration in England. The new group would be selected on the basis of expertise rather than representative status. It would be co-chaired by the Lead RDPH Cancer in the Department of Health, who is currently chair of the ACCR, and the. The Policy Executive should report to the medical director of the NHS Executive (the Deputy Chief Medical Officer).

The members of the cancer registration policy executive should include a lead clinician and a regional clinical cancer co-ordinator. The policy executive should also include the chair of the UKACR and one other member of their executive committee who would represent both cancer registration and ONS. A further member of the policy executive should be chosen to represent the research community (preferably from UKCCCR as this group has expressed interest). Finally, one member should be chosen from the lead commissioners because of the importance of accountability.

### ***Role and task of the Cancer Registration Policy Executive***

The role of the policy executive should be to improve co-ordination in the cancer registry system and to increase collaboration between all parties. Specifically, the policy executive needs to develop a nation-wide cancer registry system that supports the efforts of the NHS in the cancer control agenda.

The task of the policy executive would be to translate the cancer agenda of the Department of Health into a programme of work relating to the competencies of the cancer registry. The objective of this programme of work would be to provide evidence to support strategy in cancer control. The policy executive would aim to reduce heterogeneity in the methods of data collection, particularly in the use of IT.

### ***Terms of reference for the Cancer Registration Policy Executive***

The immediate remit of the Policy Executive would be to set out strategic objectives and appropriate milestones for cancer registries and for ONS and to:

- address issues requiring a national strategy, such as the integration of cancer registration and clinical datasets;
- set out annual priorities/planning guidance for the Regional Directors of Public Health, lead commissioners of registries and for ONS;
- formally consult with the National Cancer Forum, meetings of lead clinicians and the UKACR about their proposals and maintain informal dialogue with key stakeholders;
- take an overview of registry and ONS performance; and
- monitor the effectiveness of each commissioning process, holding the Directors of Cancer Registries and lead commissioners to account for delivering what is expected.

### **Support group**

The policy executive will require support from a small dedicated team based in the Department of Health. This would comprise individuals with some experience in the core competencies of registry work, but of more importance would be facilitating and project management skills, to ensure that national strategies for registration are seen through to a successful conclusion.



## **Advisory Committee**

It is proposed to expand the current membership of the Advisory Committee on Cancer Registration to include all cancer registry directors together with specialised information technology expertise and representation from pathology. While the policy executive would concentrate on management of the registration system, it is important that, *inter alia*, the ACCR should continue to look in detail at technical questions such as data definitions. It is anticipated that the policy executive would call upon the ACCR to prepare reports on such technical issues.

## **Lead commissioning of cancer registration services**

The responsibility for commissioning cancer registration services would be transferred to the Regional Offices of the NHS Executive. However, the system of lead commissioners for cancer registration has been successful in some regions. The experience of these commissioners should be retained and integrated into the new regional system of cancer registration with Regions being expected to continue to work with health authorities and individuals with successful track records under the existing system. The latter could be employed directly or seconded from local health authorities. Responsibility for undertaking the work on a day-to-day basis could therefore continue in a very similar manner to the current arrangements although overall responsibility would transfer to Region. Region would also be responsible for deploying the funding obtained from the Department of Health, for agreeing annual costs of the Cancer Registration Policy Executive work programme, and for local appraisal of registry performance.

Registries could be accountable to regions through a lead commissioning arrangement. The Regional Directors of Public Health would arrange for the appointment of suitable individuals where necessary.

## **Cancer Registries**

The existing remit of registries should be maintained, with an expanded role to include proactive data use, particularly in clinical governance, linkage to other datasets and research but particularly in providing evidence. Operational development is required for all registries in the following areas:

### *Competencies*

- all registries must objectively assess their capabilities in the core competencies and draw up plans to develop in areas where they have shortcomings.

### *Calman-Hine and Clinical Governance*

- all registries must be proactive in the production of data of sufficient quality to meet the future requirements of the NHS, in particular, the implementation of Calman-Hine and the development of the public health and clinical governance agendas.

### *The New Cancer Agenda*

- cancer registries must be part of the cancer team that is implementing the new cancer agenda on a basis that makes it clear they have equality with the other disciplines involved.

### *Provision of Data*

- cancer registries, through their directors, must have responsibility for providing a cancer intelligence function as well as simply collecting the data.

#### *Use of Data - Epidemiology*

- cancer registries, through their directors, must have responsibility for understanding the descriptive epidemiology of cancer and its care in their regions and be involved in the study of aetiology aspects of cancer.
- Cancer registries must also be able to present data to the public on prospects for prevention and the scope for improving services.

#### *Public Health*

- because these responsibilities relate to the population rather than to individual patients Directors of Cancer Registration should report to Regional Directors of Public Health and link into the relevant new Public Health Observatories; and

#### *Relationships*

- all registries must engage with local clinicians to encourage use of cancer data and thereby improve their quality;
- all registries should actively nurture existing relationships with a variety of University and research institutions so that data can readily be used in research on cancer aetiology and clinical epidemiology;
- where relationships with University and research institutions do not exist registries must actively build up partnerships with such bodies; and
- all registries should aim to develop their own proposals for research and compete for research funding.

#### *Boundaries*

- all registries need to be able to work together to be able to provide outputs based on the new regional boundaries even though they collect their data from different geographical boundaries, e.g. the old regions. Registries working to a common cancer registry standard will ultimately ensure that there are no differences in quality of data on either side of geographical boundaries wherever these might be placed.

#### *Appraisal*

- Regional appraisal of registries' performance is required, for example, in making available complete, timely and accurate data or progress in achieving capability in the core competencies. This would include not only the cancer registries but also the performance of Trusts in providing the required data to cancer registries.

### **Repositories of Cancer Registry Data - (ONS and Department of Health)**

Clearly, there is a continuing need for cancer registration data to be collated and published nationally. The recent appointment of the National Cancer Director means that there must be rapid access to the most recent cancer registry data and that these must be of high quality. As previously implied this does not mean establishing a new repository for cancer data rather it means making better use of existing arrangements.

ONS should continue to fulfil its current role of collecting basic national data. However, the current commissioning mechanism and Service Level Agreement between the Department of Health and ONS for work in assembling/collating and publishing cancer registry based information needs to be revisited so that ONS has an equivalent platform and scope for action as the registries.

The more detailed data required for monitoring Calman-Hine at national level should be provided directly by the registries.

### **The UKACR**

Such co-ordination of registry activities as currently exists in the UK is supplied by the UKACR. They are to be congratulated for initiating this role and sustaining it so far. However, the UKACR has had no executive authority. Their enthusiasm and willingness to collaborate should be enhanced by making their Chairman and one other member of their executive committee contribute to the proposed Policy Executive.

One of the drawbacks with the current absence of executive authority is that there is no sanction against those who default in collaboration with existing projects and no organisation with responsibility to ensure that good proposals are followed through to practical benefits. The proposed Policy Executive will determine the work programme for cancer registration and will have the power to ensure that the work programme is carried out to its satisfaction.

The UKACR should continue with its current composition and programme of activities and, through its directors, have a key role in the Advisory Committee to the Policy Executive in the proposed framework.

### **Development costs**

The review team has estimated the costs of bringing registries up to a uniform level with regard to all the competencies as a recurring increase in investment of around £3 million based on the costs indicated in the UKACR Resources and Outputs: Summary report (Williams,1999). It does not take into account the specific circumstances of each registry. Indeed, we believe that any additional resources directed to cancer registration should be based on assessment of the registries competencies and needs for development, and the work programme of the policy executive.

The costs of setting up and supporting the policy executive and its support group are not included in this estimate.

## **9. Conclusion**

The general conclusion of this review is that, essentially, the strategic roles and remits of the current organisations involved in cancer registration should not change. However, greater co-ordination and collaboration is required amongst the current organisations and a proposal has been put forward to achieve this through the establishment of a collaborative framework.

## **References**

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## Terms of reference

In the context of *Information for Health* and the *Cancer Information Strategy*, to advise the Department of Health on ways of improving the overall performance of the cancer registration system in England. This should encompass the activity of the cancer registries in England the Office for National Statistics. This should cover:

- at the individual CR level:
  - a. **comparison of modus operandi of CRs** with respect to acquisition, quality assurance and storage of data, taking into account local circumstances (as informed by the registry and lead purchaser).
  - b. **comparative performance of CRs** against the UKACR Quality and Performance Indicators and the standards and targets in the core contract for cancer registration [EL(96)7]. [This is mostly addressed by paper ACCR(98)7 “*UKACR Quality and Performance Indicators 1998. Summary*” and the timeliness aspect by the ONS progress report ACCR(98)10].
  - c. **the analytical and research output of each registry**, including assisting local Health Authorities and Trusts to monitor cancer services and QA and evaluation of breast and cervical screening programmes (interval breast cancers and invasive cervical cancers);
  - d. **the efficient use of resources** for compliance with the core contract and outputs (for example an annual report) and meeting customer needs.
- at Office for National Statistics (ONS) level
  - e. **to review cancer registration activity at the ONS** to achieve more timely publication of cancer data and to consider the optimum balance between timeliness and quality of data
  - f. **to examine the interrelationships between CRs and the ONS**, with a view to streamlining mechanisms
  - g. **to examine** to what extent **ONS workload** can be trimmed by better input from CRs
- at the national level:
  - h. **areas requiring the development of national guidance** related either to the process of registration or to information output;
  - i. **information flow from the registries to ONS and other national bodies** eg Childhood Cancer Research Group (CCRG), Small Area Health Statistics Unit (SASHU).
  - j. **to comment on mechanisms to improve the overall cancer registration system** in England.

## Reference group attendees

Professor Charles R Gillis,  
Director, West of Scotland Cancer Surveillance Unit

**Chairman**

Dr Penny Babb, Senior Research Officer, ONS London

Dr Ian Basnett, Deputy Director of Public Health,  
Camden & Islington Health Authority

Mr Roger Black, Head, Scottish Cancer Intelligence Unit,  
Information & Statistics Division, NHS in Scotland

Ms Paula Bland, Cancer Registry Commissioner,  
Bromley Health Authority

Professor Peter Boyle, Director, Division of Epidemiology and  
Biostatistics, European Institute of Oncology, Milan

Dr Mike Fry, Chief Executive, Christie Hospital NHS Trust, Manchester

Mr Moosa Patel, Department of Health **Secretary from January 2000**

Dr John Pritchard, Chief Scientific Officer, Welsh Office

Ms Chris Puckey, System Manager, ONS Titchfield

Dr Mike Quinn, Director, Demography & Health Division,  
ONS London

Dr John Radford, Director of Public Health, Doncaster Health Authority

Professor Mike Richards, Department of Palliative Medicine,  
Guys and St Thomas' Hospital, London, and National Cancer Director

Dr Monica Roche, Director, Oxford Cancer Intelligence Unit

Ms Judith Stephenson, Cancer Registration Manager,  
West Midlands Cancer Intelligence Unit

Mr Alan Waterhouse, Assistant Director (IM&T), Trent Cancer Registry

Dr John Wilkinson, Deputy Director of Public Health,  
North Yorkshire Health Authority

Dr Elizabeth Wilson, Department of Health

**Secretary to December 1999**

