

**T**he Expert Advisory Group on Cancer's report on the policy framework for commissioning cancer services has three main thrusts: strengthening links between primary and secondary care, identifying district general hospitals which will become cancer units capable of providing generic cancer care and reinforcing the role of tertiary referral centres as cancer centres.'

The central message is clear: a move to greater sub-specialisation and better integration of cancer services. But the policy framework falls a long way short of providing purchasers and providers with the practical framework required to develop and commission services locally.

How are purchasers to define populations and cases to be served by cancer units and centres? Where will centres and units be sited, what services will be provided and what volumes of activity? How can providers be guaranteed that there will be some stability in the marketplace?

In an ideal world, purchasers should be able to look to cancer needs assessments and their current contracts for information on population needs and service use to answer these questions. But purchasers have made little progress in contracting services for cancer: 85 per cent of all contracts are block contracts, which means that cancer services are part of general surgical services or part of general oncology care. Length of stay, cost, volume and *Patient's Charter* quality issues are the core of many contracts, but the relevant population focus is usually missing.

Purchasers have four information needs if they are to implement the recommendations of the group. First, they require population data on the expected number of new and prevalent cases for each cancer site; second, health services data to quantify the anticipated activity and workload for each cancer site by specialty and provider; third, data on evaluations of healthcare interventions and services; and finally the ability to monitor the outcomes of care (see table 1).

Where are purchasers to turn for this data? There are three potentially relevant data sources: the cancer registry, routine hospital Kömer systems and clinical audit systems. The strengths and weaknesses of each of these are summarised in table 2 and reviewed with specific reference to their ability to provide the information described here.

#### Routine NHS hospital data

NHS providers are obliged to collect a minimum contract data set on all hospital admissions. This data set duplicates much of the data collected by the cancer reg-



**Purchasers need a framework to develop and commission cancer services at local level, yet there is now a questionmark hanging over the future of cancer registries, says Allyson Pollock**

istry, but the minimum contract data set (MCDS) is based on finished consultant episodes of care, unlike the common data set for cancers, which is person-based.

The registry data set can provide a picture of the individual's progress through different treatment and care spells over time - the MCDS cannot. The minimum contract data set can give a measure of volume or activity and of hospital workload for the population, but it cannot easily relate this activity to individuals or to population needs. The data which purchasers need most - relating the care of individuals to a population in order to monitor trends in incidence (need) and care across populations - can only be provided by cancer registries.

Outcome measures cannot be derived using the MCDS either, since the MCDS collects no information on death or survival. But the registries are in a unique position to do so.

#### The cancer registry

Although cancer registration was introduced in the 1930s to evaluate new treatments such as radium therapy, the 12 registries in England and Wales are more frequently associated with the annual statistics of incidence and mortality and, less frequently, with cancer survival published by the Office of Population Censuses and Surveys.<sup>1</sup> Cancer incidence data is unique in that it provides purchasers with a direct measure of need. This contrasts with other common conditions, such as coronary heart disease,

where purchasers depend on using mortality as a proxy measure of need.

Most district purchasers only use registry data to monitor trends in incidence and mortality. Few have used them to look at health service needs, delivery and use, despite most of the registries being in a unique position to do so.

Since July 1993, acute NHS providers are obliged to provide their local registry with a common data set for cancer on every individual diagnosed as having cancer (NHS EL[92]95). This data set includes information on treatment, tumour stage, place of treatment, consultant, place and date of death, and date of diagnosis.

If purchasers are to evaluate health services and compare their residents' experience of healthcare with that of other districts, survival statistics are necessary. Survival statistics depend on having an accurate measure of date of diagnosis and date of death. A strict chronological sequence of clinical events must be used to define diagnosis. Cancer registry staff are trained to apply such a hierarchy rigorously. The potential for different definitions of diagnosis (and inaccurate estimates of survival time) would greatly increase if the task were to be deskilled.

OPCS automatically sends death certificates with a mention of cancer to the relevant registry, which either initiates and traces a registration or updates an existing registration. The death certificate is an integral part of case ascertainment and ensuring completeness of incidence data.

The advantage of the registry handling

death certificate returns is that through its links with both NHS and non-NHS providers and GPs, registry clerks can retrospectively retrieve data on cases missed across large geographic areas with relative ease. District purchasers currently do not have the expertise to update case records from death certificate returns.

#### Survival league tables and case-mix bias

The major advantage of cancer registries providing population survival statistics is that problems of patient selection can be eliminated. Despite attempts by many clinicians and health service researchers to prove the need for specialisation and high-volume treatment centres for cancer, the argument is still at best based on clinical consensus and inconclusive evidence.

Cancer registry data can be used to overcome this problem by providing survival statistics for purchasers based on district of residence. Patient selection problems also disappear if purchasers repeat these analyses for their residents by treat-

ment centre, since for major cancers such as breast some 80 per cent of a purchaser's cases receive treatment in local centres.

#### Clinical audit systems

Clinical audit systems are not part of routine data collecting systems. But many of them have been set up as a response to perceptions of inadequate and poor quality data collected by routine data systems. Clinical audit systems have five main weaknesses: they are usually clinician-centred and stand-alone so cannot provide cross-district or even inter-provider comparisons; the data quality is rarely standardised and data items seldom defined; they do not link with the cancer registries or with other routine data systems; access to purchasers is discretionary and subject to clinical consent; crucially, there is no population focus.

The absence of a population focus means that clinical audit systems and NHS hospital systems are biased towards collecting data on only those patients treated within the acute NHS sector. Analysis is skewed to auditing the care of a select group of patients.

The system cannot tell purchasers or providers about the appropriateness of care for their whole population, or groups that services do not reach. Population-based comparisons of treatment are as important as comparisons of survival. Without this data purchasers will not know how many of their residents clinicians might expect to treat, at what stage they will present and what treatments they might expect to receive.

Purchasers now hold the audit purse-strings. To ensure that clinical audit contributes to planning, audit must be

capable of complementing a population focus, and its systems must integrate with cancer registries and hospital data systems.<sup>1</sup>

#### The role of cancer registries

Cancer registries have the unique ability to provide purchasers with much of the data they require to assist with commissioning and reshaping services. The registries can provide data on population needs, health service use, treatment patterns and outcomes data. They also provide an essential database for monitoring *Health of the Nation* targets on cancer.

The abolition of regional health authorities raises questions about the future of cancer registries in England and Wales. HA purchasers may need to agree a purchaser lead to negotiate with registries locally. There are dangers in this approach if purchasers have different perceptions of the importance of cancer registration.

At a time when purchasing has more need of information to make informed decisions, it is essential that cancer registries are adequately resourced to support them in this difficult task. This involves recognising that registries provide a vast range of expertise and that registry data can give purchasers information that is not affected by patient selection. ■

#### REFERENCES

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- 3 Bamert I, Pollock AM, Gill M. Collecting data on cancer [letter]. *Br Med J* 1994; 309(6931): 791.

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TABLE 1. INFORMATION NEEDS FOR RESHAPING CANCER SERVICES

Population data on new and prevalent cases by cancer site

Service use data, such as number of patients treated by place of treatment, treatment type and cancer site

Service provision, eg staffing; patient ratios, beds etc.

Effectiveness of interventions  
Population-based outcome data - survival, mortality

TABLE 2. DATA FOR MONITORING AND EVALUATING SERVICES

MINIMUM CONTRACT DATA SET	CLINICAL AUDIT SYSTEMS	THAMES CANCER REGISTRY
Special features Linked to consultant episodes not hospital spell. Cannot track an individual's care programme or provide population focus. Good measure of hospital workload	Can track individuals' care. Cannot provide a population focus. Data variable in quality and collection. Measure of clinical workload	Permits a population focus. Can track an individual's care. Provides data on new cases Only six-month follow-up. Measure of annual workload on new cases
GP details	✓	✓
Place of treatment	✓ (acute NHS only)	✓
Emergency/selective presentations	✓	no
Stage at presentation (severity of disease)	no	✓
Treatments	✓ (not individual cases)	✓ (first six months only)
Place of death	no	✓
Survival	no	✓
Date of diagnosis	no/rarely	✓
Date of death	?	✓