Hospital-based cancer registry: a tool for patient care, management and quality. A focus on its use for quality assessment

Ana Ruiz[a] and Ángel Facio[b]

[a]Servicio de Oncología Médica. Hospital de Fuenlabrada. Madrid. Spain.
[b]Department of Medicine. University of A Coruña. Spain.

CONCEPT OF TUMOR REGISTRIES

Tumour registries are systems for collection, storage, analysis and interpretation of data from people with cancer. There are two main types of tumour registries: population-based and hospital-based tumour registries (from now on PBTR and HBTR). Other registries of syndromes, diseases or special situations could be of interest in order to collect information about special populations at high risk of developing cancer[1-3].

The average density of the population in areas covered by cancer registration is considerably higher than for the world as a whole[4]. The steady increase in coverage of the world's population by cancer registration has been accompanied by developments in standardization of registration methodology, definitions and coding[5,6]. Tumour registries constitute an essential part of any rational programme of cancer as well as of a modern health system information. In spite of constituting the basis for the knowledge about some important aspects in oncology (namely, tumour incidence, prevalence, aetiology of different tumours, professional risk, geographical patterns, overall survival, etc.) methodology and interpretation of data from population-based tumour registries, it is not a main objective in the training period of medical oncologists in Spain.

The objective of registries is to collect as complete and accurate information as possible. This would include clinical description of the disease, as well as the information to identify the patient, tumour, hospital, and relevant physicians. When this data is put together with the additional information describing treatment and follow-up, relapses, metastases as well as date and cause of death, a complete and invaluable database is created. This data could be used in many fields: aetiological and epidemiological investigation, care planning, primary and secondary prevention, benefiting both patients and society. The older the registry and wider the area covered, the more useful it is. Description of temporal tendencies is also an essential endpoint of cancer registries.

Promotion of tumour registries is a common policy in the USA and in Europe. In 1992 the Congress of the USA evidenced the necessity of collecting more thorough data with regard to cancer in the USA. The *National Program of Cancer Registries (NPCR)* was then created. Another significant organization is *The North American Association of Central Cancer Registries (NAACCR)* addressed to cancer registries, governmental agencies, professional associations, and private groups interested in improving the quality and use of data from registries. The procedures are available at the website (www.naaccr.org). It promotes the uniform standards of data and facilitates education, training and certifies tumour registries. *The National Cancer Database (NCDB)* is a joint project of The American College of Surgeons together with the American Society of Cancer. This database has generated essential information with data from almost 2000 hospitals and clinical reports from more than 5.5 million of patients. *The Surveillance, Epidemiology, and End Results (SEER)* programme is an authoritative source of information on cancer incidence and survival in the United States. It collects and publishes cancer incidence and survival data from different population-based cancer registries. The oldest registry was established in Connecticut in 1941.

In Europe, the *European Network of Cancer Registries (ENCR)* organizes registries coordination, workshops and geographic studies. This project was established in 1989 and is supported by *the Cancer Programme of the European Commission*. Its main objective is to improve the quality, comparability and availability of cancer incidence data. Finally it aims to widen the registry of cancer cases in Europe. The European Parliament and the European Council decided to adopt a plan named "Europe against cancer" in the third framework programme to act between 1996-2000. To evaluate the efficiency of measures, data furnished by cancer registries are needed. Among the actions to be taken: standardization and comparability of data including the development and strengthening of the European Network of Registries. Denmark is a country with a long tradition in cancer registration. The Danish Cancer Registry was founded in 1942 as a nationwide programme to register all cancer cases in the population[7]. Those registries, which have served as pioneers particularly in Europe, usually cover the

whole of a country. Reporting of cancer cases is compulsory in some countries such as Finland, Poland, Norway and Slovakia with very different results depending on the resources in each country[8]. In Germany a law was passed by the Federal Parliament that prescribed the installation of cancer registries in each of 16 Bundesländer. However other countries like Greece have lacked a population-based tumour registry for a long time. The International Agency for the research of Cancer publishes periodically "Cancer Incidence in Five Continents". Population-based tumour registries considered as contributors from Spain were: Albacete (created in 1990), Asturias (created in 1978), Basque Country (created in 1986), Granada (created in 1985), Mallorca (created in 1982), Murcia (created in 1981), Navarra (created in 1970), Tarragona (created in 1980), Zaragoza (created in 1960) and Girona (created in 1994).

One of most important sources for population-based tumour registries would be the relevant hospital-based tumour registry. This structure has traditionally been considered as a quality indicator to evaluate hospital structure quality. The American College of Surgeons requires the hospitals to have a HBTR to obtain the accreditation to train specialists. Originally they were conceived as an organ to guarantee the follow-up of people with cancer[9]. Unfortunately HBTRs have become in most of cases a mere list of patients with cancer contacting the hospital, without any further interpretation of data. Maintenance of tumour registries is expensive. Only a good exploitation of this valuable data justifies its presence.

Results obtained from a hospital-based tumour registry should never been extrapolated in terms of epidemiological descriptors such as incidence or prevalence. These are only available from population-based tumour registries. Endpoints of hospital-based tumour registries include supporting administrative aspects at hospital, the cancer programme and it arises nowadays as a tool with different utilities. Characteristics of any tumour registry are exhaustivity and validity. Exhaustivity is the grade in which all cancers contacting the hospital are registered. To guarantee exhaustivity a study of all potential sources must be done in every hospital. Validity ensures reliable results. It refers to the proportion of cases registered with a determined feature that really have it. Completeness and reliability are also essential for cancer databases.

Potential uses of hospital-based tumour registries are widely described (table 1). However it is very well known that hospital management do not know much about their possibilities[10]. In this world of competition, the necessity of making it profitable is a matter of interest for us as oncologists and as part of the public system of health. Development of a registry requires a well-defined policy as well as a huge effort. But existence and maintenance of a hospital-based tumour registry is only justified if its own data is exploited. The main problems arising from the registry are economics. The only justification for running costs would be using its data in the hospitalary realm. Unfortunately few hospitals take most advantage of available data in order to provide with an efficient care[11].

Cancer registries should observe the principles related to data quality (Directive 95/46/EC Article 6) and collect data that are adequate, relevant and not excessive in relation to the purpose, as well as being accurate, complete and up to date. The number of data items should thus be limited for two reasons: quality (the fewer data items the greater the likelihood that these will be recorded correctly) and confidentiality (the more data items the more chance of an unintended breach of confidentiality when releasing the data)[12]. The data items in the recommended minimum data set are listed in table 2.

More data are usually recorded in HBTRs than in PBTRs. Every hospital should define its own case report form according to the available information and its potential uses. The International Classification of Diseases for Oncology is the standard for recording site (topography), morphology (including grade of malignancy) and behaviour[6].

TABLE 1. **Usefulness of hospital-based tumour registries**

To describe the dimension of cancer in the area
To study the requirements of patients with cancer (through the annual frequency)
To identify the fulfilment with patterns to refer patients to specialized centres
To estimate the actual coverage of the centre
To identify other facilities where diagnosis or treatment were performed
To contribute to the economic management
To contribute to administrative aspects
Follow-up of patients with cancer
Research
Clinical research
Epidemiological research (providing with data the relevant PBTR)
To contribute to the quality care
To study outcomes
Histologic verification
Delays in diagnosis or treatment
To know the vital status of patients with cancer
To collaborate with Departments of Documentation

PBTR: population-based tumor registries

TABLE 2. **Quality programmes**

Assessment: an evaluation of the quality status care before initiating any measure. Deviations are then described
Quality assurance: a process designed to ensure standards of quality are met
Quality improvement: an iterative process designed to strengthen quality by continuosly measuring and raising target

Specific recommendations to record multiple primary tumours, bladder tumours, non-melanoma skin cancers and central nervous system tumours have been done by the International Agency for Research of Cancer (IARC). Where possible, registries should code the method of detection in relation to screening[12]. The extent of disease should be recorded in terms of the three-digit code of the TNM system[13]. This system is not used for coding the extent of lymphomas, brain tumours and childhood cancers.

There are two groups of data generated through a registry: aggregate (anonymous) and identifiable data. Identifiable data can be used to avoid duplicity of tests and to transfer data to another registry. Individual data could also be used to study causality of cancer (through cohorts or case-control studies), to evaluate screening programmes and to perform additional studies such as: toxicity, second tumours, studies in relatives, etc. Aggregated data can be used in research (histological types or different types of cancer) as well as in health planning.

The purposes for which data collected by the cancer registry are to be used should be clearly defined. The cancer registry must maintain the same standards of confidentiality as customarily apply to the doctor-patient relationship. This obligation extends indefinitely even after the death of the patient[12].

USEFULNESS OF HOSPITAL-BASED TUMOUR REGISTRIES

Follow-up of patients with cancer

To guarantee the follow-up of patients with cancer was the first intention when hospital-based tumour registries were created. Use of a unique tool to organize the follow up, would avoid the duplicity of visits (i.e. surgeon and oncologist), tests (i.e. CEA for two or more specialists), and image diagnostic.

Use of guidelines at hospital would allow the uniformity of follow up regardless of the specialist. Once all the relevant people have agreed the guidelines, a centralised department or organization could call patients for being followed and control this follow-up. It is recognized that guidelines must be implemented within a larger project that includes quality control, to show that where they are employed, patient outcome is better[14,15]. In France the implementation of guidelines across different hospitals is allowing the certainty that every patient treated in a network of hospitals will receive what is considered the standard of care by expert oncologists[16].

Clinical investigation

A forecast of potential patients to be included in a clinical trial can be obtained from the hospital-based tumour registry. Otherwise it would be difficult to anticipate the number of patients actually able to be included in a trial. Though some Departments of Medical Oncology make their forecasts based upon its own data the right way to proceed is to offer clinical trials to everyone contacting the hospital and not only one department.

Clinical management

Departments of Oncology's budgets and necessity of human resources should be established according to hospital load and not the supposed incidence obtained from published data that is the usual way to do it. Numbers of new cases diagnosed every year in a hospital can only be obtained from the hospital-based tumour registry. Other sources of information such as listing of Department of Pathology or patients admitted in a hospital, cannot distinguish between incident cases and relapses. Actually in Spain, information about ambulatory patients with cancer is really very difficult to be obtained. The "CMBD" *(conjunto mínimo básico de datos)*, the mandatory information collected for every patient admitted in a hospital, is not collected for ambulatory patients.

The HBTR generates information about: number of patients diagnosed with each type of cancer every year, percentage of these patients with early, advanced or metastatic disease. This allows management people to do the forecast for surgery rooms, candidates to adjuvant chemotherapy, adjuvant radiotherapy, candidates to palliative chemotherapy and palliative treatment. This information would allow foreseeing the budget for cytostatics, oncologists, nurses, surgeons, hospital's day slots, etc. in a realistic manner. Number of patients diagnosed with rare tumours, allows the management to calculate the expenses for referring them to other centres.

A proper clinical management requires high-quality information.

Epidemiological studies

Though incidence and prevalence figures can never be obtained from a hospital-based tumour registry, some correlations can be established. A significant difference with respect to the expected total number of cases for a determined pathology could mean that patients are not satisfied with the relevant department and look for care in a different hospital. The same conclusion can be obtained when the number of cases is higher than expected. If a Department enjoys a good reputation, patients from other geographical areas could look for care there.

In some way, changes in figures of annual cases reported for the hospital could anticipate further changes in the actual incidence. Results from a hospital-

based tumour registry should be generated in the following year whereas results from a population-based tumour registry are in fact generated with a delay of at least 2-3 years.

Quality assurance

To understand the ability of hospital-based tumour registries to contribute to the quality assurance[17], some preliminary concepts about quality of care should be explained.

What is quality cancer care?

In spite of being one of the major concerns for the general population, so far quality assurance in Oncology has deserved little literature. Quality cancer care when evaluated has shown significant deviations from the standard[18,19]. Some countries such as the USA[18], the UK[20] or Canada[21] have released reports about this topic, being the Institute of Medicine's[18] probably the best and most thorough one, an obliged reference regarding quality cancer care. Unfortunately, this topic has not deserved political attention in Spain up to now.

On the other hand, geographical differences in quality cancer care have been demonstrated in several studies[18,22,23]. From an empirical standpoint, geographic differences would also be expected in our country. This feature would go (if demonstrated) against the principles of universality and equality inherent to our public health system.

Quality cancer care has different meanings depending on the perspective. From a patient's point of view it means unimpeded access to timely care, a positive health status and a good quality of life. Patients should have the right to ask the relative success rate of one therapy compared with others. But they need to know the actual one in each centre, not figures described in the literature (only achieved in reference centres). From an economic point of view, efficiency and equity are also important aspects of quality. In cancer services (our objective now), quality is reflected in the structure of organizations, the processes of patient care and most importantly the outcomes of care.

A focus on quality care includes assessment, control and quality improvement (table 2).

Assessment of quality cancer care

If the quality cancer care can be measured or not is still in the arena. However what is clear is that some processes are measurable. Once effective care has been identified, mechanisms to develop and implement measurement systems are needed. The third recommendation of the North American report was to measure and monitor the quality care using a core set of quality measures[18].

Quality assurance needs a pattern of reference: indicator/criteria/standard.

1) Indicator: it is a parameter about which a general consensus exists it is useful to evaluate the quality cancer care. In Oncology there is agreement on: early diagnosis, information to the patient, inclusion in clinical trials and specialized care.

2) Criteria: it is the objective (or measurable) component of the quality measure. It is the pattern we apply to the indicator. It should be objective, accessible, verifiable, global, sensitive, specific, valid, reasonable and acceptable. For instance to evaluate care specialization (indicator), criteria would be the number of interventions performed by a surgeon a year.

3) Standard: it is the value of criteria that establishes the limit between what is considered as acceptable and unacceptable according to the state of the art. Standard doesn't mean absolute perfection. We must not forget we are working with human beings and freedom is an essential part of decisions. If standard for adjuvant therapy would be 100% the physician could be prone to forget these conditions inherent to the patient as free individual. Sometimes it is difficult to find standards, but the lack of benchmarks for cancer care quality is a problem not an excuse.

According to Chassin a good measure of quality should meet three characteristics[24]:

1) High sensitivity and specificity.

2) If we focus on the process, this must be related to the outcome (i.e. a process like adjuvant therapy for breast cancer is related to the outcome: survival). But we must keep in mind that an optimal process does not guarantee the good result in Oncology.

3) If we focus on the outcome, this must be related to a process that can be measured and therefore improved if deviations are detected (if the outcome is breast conserving surgery, the process can be early diagnosis because the earlier the cancer is detected the easier the sparing surgery can be done).

Methods of quality assurance

Donabedian in 1966 classified the methods in:

Methods of analysis of structure. Including physics and human resources. The best example would be accreditation.

Methods of analysis of process. It analyzes the dynamic aspects of processes of oncological care. It is based upon the analysis of documentation and it evaluates autopsies, clinical report, etc.[25]. Other specific processes of care would be use of screening for breast cancer, use of radiation therapy after breast conserving surgery, etc. It is easier to measure deviations in

processes and to check efficacy of improvement measures.

Methods of analysis of outcomes. This is the most accurate approach to quality care. However, morbidity and mortality rates are not very sensitive for small size samples. Satisfaction with care and health-related quality of life are other outcomes that can be measured. Final endpoints are to be distinguished from intermediate endpoints (early–stage breast cancer detection) and from clinical endpoints (tumour shrinkage).

Some important parameters in quality cancer care

Hospital case volume. It refers to the structural aspect of health care delivery system (physics resources). There is convincing evidence of a relationship between treatment in higher-volume hospitals and better short-term survival for several types of cancer. The most controverted recommendation from the National Cancer Policy Board was that some procedures (pancreatectomies, esophageal surgery, liver resection, pelvic exenteration and high-dose chemotherapy for germ cell tumours) should be done at facilities that perform a high volume of these procedures[18]. The Calman-Hine report even recommended that cancer surgery should be limited to "high-volume" consultants[20]. There is no agreement upon the required minimum figure for each procedure.
Lesser known but also important is the fact that pathology reports are more complete when more than 10 prostatectomies a year were done[26]. This could also be true for other malignancies.

Specialization. Specialization for cancer care has been claimed from all the organisms studying quality cancer care[18,20,21]. It has been demonstrated that infrequent interventions (surgery for rare tumours, for instance) should be performed in centres with most experience. It is very well known that surgery for rectal and ovarian cancer should be performed by specialists[27,28]. But surgical specialization is only one aspect and includes the treatment by a multidisciplinary team (supportive care and nursery). Misstaging is also more frequent in hands of non-specialists[29]. Histopathologic diagnoses are more accurate when done by specialists[30,31]. On the other hand, decisions about initial cancer management should be made by experienced medical professionals[18].

Early diagnosis. An early stage (usually considered as TNM I-II) predicts a better outcome. However, some bias cannot be excluded since some good-prognosis cancers are easily diagnosed at early stages in screening programmes. It is the called "overdiagnosis bias"[32].

An item in the registries is "method of detection" in relation to screening. Where possible, registries should code screen detected and interval cancer (according to local definition).

Clinical record. This analysis belongs to analysis of process. The clinical record is the most important source of information, not only for a registry but for audits and for other sort of studies. There is an accepted relationship between clinical record and clinical care quality, being collection of data a dimension of quality care[23,33]. However, with some exceptions, clinical record has not often been evaluated in Spain[34]. To evaluate the clinical record quality a specific study must be done. Reports, documentation of every procedure including information to the patient ("what is not documented, it has not been done"), staging, treatment administered to the patient, etc. are aspects that must be assessed.

Access to the hospital. Emergency admission has predicted a worse prognosis in patients with gastrointestinal tumours[35]. Ambulatory studies would be expected for patients with cancer. An excess of emergency admissions could reflect an insufficient specialized care.

Histologic verification. Definitive diagnosis of cancer with some exceptions (i.e. germ cell tumours, hepatocellular carcinoma, neuroblastome) requires histological confirmation. The higher the histologic verification the better the validity and the worse the exhaustivity. Some cancers will never be histologically confirmed (patient negative to biopsies, difficult access to the tumour, etc.). As oncologists, verification is always required to treat patients. However for registration purposes (mainly for population-based tumour registries), cases without histological confirmation have to be considered in order to achieve a good exhaustivity. Actual cases of cancer are more than verified ones. This is one of afore mentioned cases where 100% must not be standard.

Inclusion in clinical trials. Large, carefully designed clinical trials are usually necessary to establish which specific processes of care or treatments are actually effective[18]. Inclusion in clinical trials is one of the ways to improve quality cancer care[36]. It has been considered as an indicator to evaluate it[37]. The American College of Surgeons recommends a 6% of patients with cancer to be included in a clinical trial[38].

Tumour staging. It is the process that determines and describes the anatomic extension of tumour[13]. Primary location, histology and tumour staging are the three factors that should be considered before deci-

ding a treatment. It offers a prognostic category and facilitates the comparability of data[39] as well as uniformity in the research against cancer. Importance of staging has been recognized by countries like Canada[40]. Accuracy in staging is essential in the comparability of data[41]. It depends on the interest of the physician as well as on his specialization[42].

Intervals. Intervals between first symptom and diagnosis, between diagnosis and first treatment, and between surgical treatment and adjuvant treatment are considered as indicators of quality of care. They would be quality indicators for primary, specialized and oncological care. The European Society of Surgical Oncology proposes maximum times for diagnosis and treatment[43]. In Canada, an increase in waiting times for radiotherapy has been reported[21]. The important thing is to have the tools to detect these deviations in order to be able to modify it.

Palliative care. Cancer and its treatment bring a myriad of emotional, psychological, social and spiritual consequences. There is a growing awareness within the provider community and among the public of the need to address a broader range of patient needs and involve patients in decision-making about care. Patients must be ensured quality care at the end of life, especially to manage cancer-related pain and timely referral to palliative and hospice care. Administration of chemotherapy close to the time of death is a sign of poor performance.
A secondary focus has been on the development of practice guidelines for specific patient problems (lymphedema, breathlessness, pain, depression, psychosocial distress). The development of performance indicators for supportive care and practice guidelines would help set expectations for care delivery[21].

Necropsy. Rates of necropsy have dramatically decreased in last years. Regardless of the reasons for the decline in autopsy rates (economics, fear of malpractice litigation and technological advantages), the ethical and professional reasons for increasing the number of autopsies are far more important. Autopsy is the ultimate outcome measure and the "gold standard" for quality assurance[44].

Elderly patients. Cancer disproportionately affects the elderly. Thirty per cent of patients with cancer are 75 or older and 1% are older than 90 years old[45]. In spite of having demonstrated that elderly population get benefit from treatment for cancer, even the same than younger people, there is enough evidence they are not offered the standard treatment. They are poorly informed[46] and therefore this is a handicap to be included in clinical trials. Even staging is less frequent at diagnosis in this population[47].

Surgical quality criteria. Cancer surgery takes place in a variety of settings and is practiced by general surgeons, sub-specialty surgeons (gynaecologists, thoracic surgeons, urologists) and surgical oncologists affiliated with tertiary care teaching hospitals[21]. Referral networks should be organized in order to deliver specialized surgical care for at least gynaecological, ocular and musculoskeletal cancers.
Quality assurance in surgical oncology is a field of growing importance[48]. However, no quality assurance guidelines are yet available. It must be kept in mind that the impact of primary surgical treatments is often underestimated especially when post-operative adjuvant treatments are evaluated. This is of importance in clinical trials where the effect of adjuvant therapy may consequently be wrongly interpreted[49]. Outcomes regarding quality of surgery could be measured in terms of local relapses, surgical mortality or survival. But the need for long follow-up time (for relapses and survival) lead us to identify surrogate variables. Some processes (mainly related with the risk of local relapse) such as performance of lymphadenectomy, number of lymph nodes, etc. can be evaluated. Macroscopic investigation of the tumour specimen may serve as an important auditing variable for quality of surgery as a predictor of local recurrence[50]. Other indicators would be length of stay and readmission. Research is required on appropriateness and consistency with practice guidelines for surgery.
It is necessary to develop standard waiting time targets for cancer surgery. All these quality indicators should be monitored in a regular basis and address variations in care.

Oncological quality criteria. Use of systemic therapies is far greater than the rate of increase in the number of cancer patients overall. Some criteria such as interval between surgery and adjuvant treatment and chemotherapy dose intensity could evaluate quality of care with regard to medical oncology[51]. Other criteria refer to overuse (anti-HT3, G-CSF) or underuse (anthracyclines, or chemotherapy whenever they are indicated) of some drugs. Misuse must be specifically evaluated. Physicians have significant difficulties dealing with adverse events and human errors because of the culture of medical practice. In the USA an estimated 100-150,000 deaths are caused each year by medical error. Fortunately modern views of human errors have moved away from individual culpability to the identification of patterns of events[52,53]. Sometimes medical mishaps can be avoided with additional controls. Main problem with performance of physicians is that they are not evaluated by anyone after obtaining their degree or board. Physicians are prone to see quality assurance as a budget control more than a programme to improve their performance[36].

Radiotherapy facilities must comply with other requirements that exceed the objective of this document (guidelines for quality assurance for radiation protection). Waiting times must also be evaluated. Some patients who might benefit from radiotherapy may not be treated at all. In general where waiting lists for radiotherapy are longer, the proportion of cases that receive radiotherapy is lower. Lower rates are also observed in areas that lie further away from the nearest radiotherapy centre.

Pathological quality criteria. Information contained in pathology reports of cancer specimens is of critical importance. The quality of pathology reports has been reviewed for breast and prostate cancer in the USA. The adoption of protocols not only provides for consistency in reports across institutions but also for a comprehensiveness that can result in better quality of care for patients[54]. Pathology reports are significantly more complete when more than 10 prostatectomies a year are performed[26].

CRITERIA GENERATED BY THE HOSPITAL BASED TUMOUR REGISTRY TO ASSESS THE QUALITY CANCER CARE

Every HBTR designs its own case report form and therefore the items to be considered for the registry. Most HBTR share most of items (table 3). Including some specific items such as "inclusion in any clinical trial" can help to use the HBTR as a tool for quality assurance.

There are some criteria that will never be evaluated through a registry such as information to the patient or quality of life. Main source for audits, registries and assessment of quality cancer care is the clinical record. Quality of data of registry depends on quality of clinical record[55].

Some other criteria to evaluate quality can be clearly obtained from the registry.

1) Number of new diagnosed cancer patients (Hospitalary volume).
2) Number of rare tumours diagnosed a year in the hospital (specialization): germ cell tumours, bone tumours, thyroid tumours and eye tumours.
3) Number of infrequent procedures performed a year (specialization): pancreatectomies and esophagectomies.
4) Collection of antecedents in the clinical report (completeness of these items): toxic antecedents, familial history and professional history.
5) Early diagnosis: patients diagnosed at stages I-II and patients whose diagnosis was incident (screening, hazard, etc.).
6) Percentage of patients included in clinical trials (adding this item in the case report form and therefore in the registry).
7) Staging (percentage of patients with correct staging).
8) Percentage of patients dying in the hospital.
9) Necropsy rate.
10) Intervals: first symptom-diagnosis, diagnosis-first treatment (surgery?) and first treatment-adjuvant therapy or neoadjuvant therapy-surgery.
11) Percentage of elderly patients receiving an active treatment.

Improving the quality of cancer programmes and services cannot be put on hold while improved tracking and information systems are established. The work plan of the European Commission (2003-2008) "Community Action in the Field of Public Health" identified as a priority area for 2003 to develop and coordinate the health information system and to operate the health monitoring system. The programme shall contribute to tackle inequalities in health. A ge-

TABLE 3. **Items of information collected by registries**

Essential variables	
Personal identification	Name and/or unique personal identification number
Sex	Male or female
Date of birth	Day, month, year
Address	Usual residence
Incidence date	Date of first pathological confirmation
Most valid basis of diagnosis	Death certificate, or clinical or pathological
Topography	ICD-O
Morphology	ICD-O
Behaviour	
Source of information	
Recommended variables	
Date of last contact	
Status at last contact	
Stage or extent	TNM
First treatment	

Adapted from Jensen et al, 1991. ICD-O: International Clasification of Disease-Oncology

TABLE 4. **Criteria to evaluate quality cancer care. Registry as generator of criteria**

Indicator	Criteria	HBTR as generator
Hospital case volume	Nº new patients a year	Yes
Specialization	Procedures a year/specialist	No
	Rare tumors	Yes
	Infrequent procedures	Yes
	Certification board	No
Early diagnosis	Stage I-II	Yes
	Incident diagnosis	Yes
	Ambulatory access to diagnosis	Yes
Clinical record	Collection of antecedents	Yes
	Staging	Yes
	Lack of documents	No
	Information to patient	No
Access to the hospital	% diagnosed with cancer after being admitted through emergency department	Yes
Histologic verification	% patients with histological verification	Yes
Inclusion in clinical trials	% patients included	(some registries include this item)
Tumor staging	% patients staged	Yes
Palliative care	Pain control	No
	Symptoms control	No
	Death out of hospital	Yes
Necropsy	% of necropsies/deads	Yes
Intervals	1st symptom-diagnosis	Some registries include 1st symptom. Not widely accepted
	Diagnosis-1st treatment	Yes
	Treatment-adjuvant treatment	Yes
Elderly patients	Staging	Yes
	Surgery as 1st treatment	Yes
	Inclusion in clinical trials	Yes (if included)
	Adjuvant treatments	Yes
Surgical quality	Specialized surgeon	No
	Performance of lymphadenectomy	No
	Number of lymph nodes	If included
	Margins	No
	Mesorectal surgery (rectum cancer)	No
	Local relapses	If included
Pathological quality	Quality of clinical report	No
	Specialized pathologist	No
Oncological quality	Dose intensity	No
	Misuse of drugs	No
	Mishaps	No
	Radiotherapy facilities quality	No
	Waiting times	Yes

HBTR: hospital-based tumour registries.

neral goal is to strengthen capacity to assess and evaluate health strategies and interventions. Initially the action will have as aim to identify and assess the mechanisms and structures relating to quality standards[56].

To summarize, hospital-based tumour registry is an excellent tool to evaluate some quantitative and qualitative aspects of oncological care (table 4). It exists the obligation of exploiting HBTR data at maximum. Being quality cancer care one of most deficient aspects studied in Oncology and lacking data-systems to evaluate it, HBTR arises as generator of data related to quality. Some data regarding information to patients, pain control or their satisfaction with the care will not ever be evaluated by a registry. HBTR cannot be the only tool to examine quality cancer care but it is a good one being its data comparable, objective, and standardized. Some benchmarks should be stated in order to be able to compare every data generated through registries and therefore to adopt measures for improving deficiencies. As physicians we have the obligation of measuring our performances. This is one of best known ways of improving quality in Oncology.

References

1. Macrae FA, St John DJ, Muir EP, et al. Impact of a hospital-based registry on the management of familial adenomatous polyposis. Med J Aust 1989;151(10):546-8.
2. DeBaun MR, Tucker MA. Risk of cancer during the first four years of life in children from The Beckwith-Wiedemann Syndrome Registry. J Pediatr 1998:132(3):398-400.

3. Cardillo M, Rossini G, Scalamogna M, et al. North Italy Transplant Program. Tumor incidence in heart transplant patients: report of the North Italy Transplant Program Registry. Transplant Proc 2001;33(1-2):1840-3.
4. Raymond L. Techniques of registration. In: Parkin DM, Whelan SL, Ferlay J, Raymond L, Young J, editors. Cancer incidence in five continents. Lyon: IARC scientific publications, 1997; p. 9-11.
5. Whelan SL. Introduction. In: Parkin DM, Whelan SL, Ferlay J, Raymond L, Young J, editors. Cancer incidence in five continents. Lyon: IARC scientific publications, 1997; p. 1-2.
6. Fritz A, Percy C, Jack A, et al, editors. International Classification of Diseases, Oncology. 3rd ed. Geneva: WHO, 2000.
7. Parkin DM, Whelan SL, Ferlay J, Raymond L, Young J, editors. Cancer incidence in five continents. Lyon: IARC scientific publications, 1997; p. 462-614.
8. Parkin DM, Whelan SL, Ferlay J, Raymond L, Young J, editors. Cancer incidence in five continents. Lyon: IARC scientific publications, 1997; p. 470.
9. Young JL. El registro hospitalario de cáncer. En: Jensen OM, Parkin DM, MacLennan R, Muir CS, Skeet RG, editors. Registros de cáncer. Principios y Métodos. Lyon: International Agency for Research on Cancer, 1995.
10. Cuervo LG, Roca S, Rodríguez MN, et al. Evaluation of institutional cancer registries in Colombia. Rev Panam Salud Publica 1999;6(3):202-6.
11. Chassin MR, Galvin RW. The urgent need to improve health care quality. Institute of Medicine National Roundtable on health care quality. JAMA 1998;280(11): 1000-5.
12. Tyczynski JE, Démaret E, Parkin DM, editors. Standards and guidelines for cancer registration in Europe. Lyon: IARC technical publication Nº 40, 2003; p. 1.
13. Sobin LH, Wittekind Ch. TNM Classification of malignant tumours. 6th ed. New York: Wirley-Lin, 2002.
14. Storme G. Clinical practice guidelines in cancer: the European perspective. Br J Cancer 2001:84(Suppl 2):6-7.
15. Ray-Coquard I, Philip T, De Laroche G, et al. A controlled "before-after" study: impact of a clinical guidelines programme and regional cancer network organization on medical practice. Br J Cancer 2002;86:313-21.
16. Fervers B, Hardy J, Blanc-Vincent MP, et al. SOR: Project methodology. Br J Cancer 2001;84(Suppl 2):8-16.
17. Bickell NA, Chassin MR. Determinig the quality of breast cancer care: do tumor registries measure up? Ann Intern Med 2000;132:705-10.
18. Hewitt M, Simons P. Ensuring quality cancer care. Washington DC: Institute of Medicine, 1999.
19. Gershenson DM. Why american women are not receiving state of the art gynecologic cancer care. Cancer J 2001;7(6):450-7.
20. Expert advisory group on cancer. The Calman-Hine report. A Policy framework for commissioning cancer services: a report by the Expert Advisory Group on cancer to the Chief Medical Officers of England and Wales. London: HM Stationery Office, 1995.
21. Sullivan T, Evans W, Angus H, Hudson L. Strengthening the quality of cancer services in Ontario. Available from URL: http://www.cancercare.on.ca/pdf/Synopsis_CQCO_Report.pdf
22. Sainsbury R, Rider L, Smith A, et al. Does it matter where you live? Treatment variation for breast cancer in Yorkshire. Br J Cancer 1995;71(6):1275-8.
23. Farrow D, Hunt W, Samet J. Geographic variation in the treatment of localized breast cancer. N Engl J Med 1992; 326:1097-101.
24. Chassin MR. Quality of Care. Time to Act. JAMA 1991; 266: 3472-3.
25. Lyons TF, Payne BC. The relationship of physician's medical recording performance to their medical care performance. Med Care 1974;12:714-20.
26. Imperato PJ, Waisman J, Wallen M, et al. The use of quality indicators for assessing radical prostatectomy specimens. Am J Med Qual 2000;15(5): 212-20.
27. McCardle CS, Hole D. Impact of variability among surgeons on postoperative morbidity and mortality and ultimate survival. BMJ 1991;302:1501-5.
28. Nguyen HN, Averette HE, Hoskins W, et al. National survey of ovarian carcinoma: Part V- The impact of physician´s specialty on patients survival. Cancer 1993;72: 3663-70.
29. McGowan L, Lesher LP, Norris HJ, et al. Misstaging of ovarian cancer. Obstet Gynecol 1985;65:568-72.
30. Westra WH, Kronz JD, Eisele DW. The impact of second opinion surgical pathology on the practice of head and neck surgery: a decade experience at a large referral hospital. Head Neck 2002;24(7):684-93.
31. Lee AH, Mead GM, Theacker JM. The value of central histopathological review of testicular tumours before treatment. BJU Int 1999;84(1):75-8.
32. Morrison AS. Screening of chronic disease. Monographs in Epidemiology and Biostatistics, vol 7. New York: Oxford University Press, 1992; p. 272.
33. Sanazaro PJ. Quality assessment and quality assurance in medical care. Annu Rev Public Health 1980;1:37-68.
34. De Miguel B, Santiago M, Candía B, et al. La Historia clínica de urgencias. Un parámetro de la calidad de la asistencia. Emergencias 1997;9(1):31-4.
35. Porta M, Fernández E, Belloc J, et al. Emergency admission for cancer: a matter of survival? Br J Cancer 1998;77(3):477-84.
36. How cancer centers manage quality of care. Oncology (Hungtint) 2000;14(5):624-6.
37. Malin JL, Asch SM, Kerr EA, et al. Evaluating the quality of cancer care. Development of cancer quality indicators for a global quality assessment tool. Cancer 2000; 88:701-7.
38. Cornfeld MJ, Jadwin A, O'Grady P, et al. Feasibility of assessing quality in medical oncology practices. Cancer Pract 2001;9(5): 231-5.
39. Hewitt M, Simone JV. Enhancing data systems to improve the quality of cancer care. National Cancer Policy Board. Institute of Medicine and Commission on life sciences national research council. National Academy Press; Washington DC. Available in: http://www.nap/edu/openbook/0309071917/R1.html
40. Sobin LH. An International perspective on Canada's role in cancer staging. Cancer Prev Control 1998;2(6):310-1.
41. Brierley JD, Catton PA, O'Sullivan B, et al. Accuracy of recorded tumor, node and metastasis stage in a comprehensive cancer center. J Clin Oncol 2002;20:413-9.
42. McGowan L, Lesher LP, Norris HJ, et al. Misstaging of ovarian cancer. Obstet Gynecol 1985;65:568-72.
43. Blichert-Toft M, Snola MG, Ctaliotti L, O'Higgins N. Principles and guidelines for surgeons-management of symptomatic breast cancer. Eur J Surg Oncol 1997;23: 101-9.
44. Burton EC. The autopsy: a professional responsibility in assuring quality of care. Am J Med Qual 2002;17(2):56-60.
45. Coebergh JW. Significant trends in cancer in the elderly. Eur J Cancer 1996;32A(4):569-71.
46. Ajaj A, Singh MP, Abdulla AJJ. Should elderly patients be told they have cancer? Questionnaire survey of older people. BMJ 2001;323:1160.
47. Sant M, Eurocare Working Group. Differences in stage and therapy for breast cancer across Europe. Int J Cancer 2001;93(6):894-901.

48. Gunnarson U. Quality assurance in surgical oncology. Colorectal cancer as an example. Eur J Surg Oncol 2002;29:89-94.
49. Landheer ML, Therasse P, van de Velde CJ. The importance of quality assurance in surgical oncology. Eur J Surg Oncol 2002;28(6):571-602.
50. Nagtegaal ID, Van de Velde CJ, van der Worp E, et al. Macroscopic evaluation of rectal cancer resection specimen: clinical significance of the pathologist in quality control. J Clin Oncol 2002;20(7):1729-34.
51. Morrow T, Siegel M, Boone S, et al. Chemotherapy dose intensity determination as a quality of care measure for managed care organizations in the treatment of early-stage breast cancer. Am J Med Qual 2002;17(6):218-24.
52. About the National Quality Forum. Challenges in Health Care Quality. Available from http://www.qualityforum.org/about/home.htm
53. Barach P, Small SD. Reporting and preventing medical mishaps: lessons from non-medical near miss reporting systems. B Med J 2000;320:759-63.
54. Imperato PJ, Waisman J, Wallen MD, Llewellyn CC, Pryor V. Improvements in breast cancer pathology practices among medicare patients undergoing unilateral extended simple mastectomy. Am J Med Qual 2003;18(4):164-70.
55. Ruiz-Casado A, Facio A, Used M, et al. Hospital tumour registry as source to generate indicators of quality of cancer care. Eur J Cancer 2001;37(6):237.
56. Community action in the field of public health (2003 to 2008). Work plan 2003. Off J Eur Union C62/21-35 (Mar.15, 2003).