

analysis of the results of this venture should aim at assessing the potential impact on the conclusions of clinical trials, with worst-case and best-case scenarios for data that could not be checked against the hospital chart.

Is the quality control procedure cost effective? The estimated \$800 cost for a single site visit is modest in view of the potential gain in quality control and education, especially if this occurs early during the trial. One interpretation of the study is the need for greater clinical trial support within the institutions visited, and the level of such support is not indicated. The EORTC has an enviable record of entering large numbers of patients on important clinical trials, with rather meagre resources, but lack of support for clinical trial nurses and data managers is a frequent complaint of EORTC investigators. A report from ECOG has suggested that extensive training programmes for those involved in clinical trials is a major component contributing to the high quality participation of their community hospitals [6]. The EORTC programme should be used to study the influence of clinical trial support staff on quality of administration of chemotherapy by comparing the performance of institutions with different levels of support, and/or with support staff that have different levels of training and education.

The quality control procedures initiated by EORTC are important and should improve the quality of participation in chemotherapy trials. Further analysis of the data is awaited, but consistent improvements in administration of chemotherapy and follow-up of patients with precise recording of data may

require expansion of funding to increase the availability and education of data managers within the participating centres.

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Cancer Incidence Registration

IN A RECENT issue of this Journal, estimations of the burden of cancers of various forms in the European Community countries were presented [1] and were the subject of a commentary [2]. This analysis was based on national mortality rates, available from vital statistics schemes in many countries, combined with the information on cancer incidence available regarding several regions within countries. The latter data are available from population-based cancer registries which have been established in an increasing number of parts of the world. In this issue of the Journal there is the report from the Cancer Registry which has been established for several years in the Canton of Vaud in Switzerland (Levi *et al.*, p. 207).

Production of cancer incidence statistics is not a simple task but one which involves cooperation of cancer physicians and pathologists and hospital records staff to provide information regarding cases, and the product of the work of demographers to provide estimates of the population by age and sex in the region covered by the registration scheme. All this information has to be collected and coordinated by the staff of the cancer registry. The collected information has a variety of uses including

the calculation of the cancer incidence rates in the region, to monitor time trends in cancer occurrence, to examine geographical aspects of cancer within their region and to calculate and monitor population-based survival rates. Further uses of the data extend to their value in the passive follow-up of cohorts with a particular exposure to monitor whether their cancer rates are elevated and their use to epidemiologists conducting case-control and other epidemiological studies. Knowledge of the numbers of patients being treated for cancer provides a better basis for resource planning than merely having information available regarding the numbers of deaths from the disease.

The data regarding Vaud have certain interesting features. The rates of certain cancers (e.g. testis in males and breast cancer in females) in the Canton are among the higher levels recorded in Europe with stomach cancer rates being among the lower rates [3]. The incidence rate of breast cancer is increasing overall while the high rate of testicular cancer has apparently remained unchanged in recent years. The authors also note that the incidence rates for tobacco-related neoplasms appear to be stabilising but note that those cancers whose rates are increasing are those whose aetiology is less well understood. These are interesting observations not only for those working in the field of cancer treatment and research in the Canton but also serve as a comparison for other populations with similar data available.

The *European Journal of Cancer* is happy to invite cancer registries to submit short synopses of their recent data for publication. The articles should be in a format similar to that of the article contained in this issue (Levi *et al.*, p. 207). In particular, a short description of the registry and registration practice should be followed by pointers to recent reports from the registry and a brief description of the most important findings either regarding cancer levels, cancer trends or cancer survival. Registries should endeavour to provide a figure similar to Fig. 1 of Levi *et al.* containing annual rates age-standardised to the World Standard Population [4] together with the numbers of cases that these are based on.

Descriptive epidemiology has provided important information in the past which has led to the formulation of the environmental theory of carcinogenesis and it is currently thought that upwards of 80 and perhaps 90% of human cancers may be due to environmental factors, defining "environment" in its broadest sense to include a wide variety of aspects of lifestyle [5, 6]. The development of cancer registration in the recent past has an important role to play in refinement of the influence of environmental ("lifestyle") factors on cancer risk. Thus, it is important that cancer registries, one of the major contributors to descriptive epidemiology, have the opportunity

to present their data to a wider audience than can generally be reached by their own reports. Thus, this journal is happy to provide a forum for descriptive epidemiology whether as described above or in general terms by publishing longer articles on the subject.

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Establishment of a European Registry for Familial Ovarian Cancer

BACKGROUND

EPIDEMIOLOGICAL STUDIES have provided little data useful for the identification of women at risk of developing ovarian cancer. Furthermore, there are no cheap, reliable screens, and this malignancy is almost invariably diagnosed at an advanced stage. During the past decade, genetic evidence of the aetiology of ovarian cancer has rapidly accrued. The apparent increase in the incidence of genetically determined ovarian cancer may be due to improved data collection. We need to be able to identify risk factors and markers for early detection and control.

Three carcinoma-prone conditions have been recognised in which malignant epithelial ovarian neoplasm show significant familial concentration: (1) site-specific ovarian carcinoma, where familial risk is restricted to ovarian cancer; (2) breast/ovarian cancer syndrome, where carcinoma of the breast is associated with ovarian carcinoma; and (3) cancer family syndrome (Lynch syndrome II), consisting of hereditary non-polyposis colorectal cancer with proximal colonic cancer predominance, associated with endometrial and/or ovarian carcinoma [1]. Families with two or more first-degree relatives affected by ovarian cancer have been conventionally considered suitable for epidemiological and genetic analyses.

Studies on such families at high risk for ovarian carcinoma

showed that the hereditary pattern is consistent with the segregation of an autosomal dominant mutation with variable penetrance [1-5]. However, the data have not conclusively clarified the mode of genetic transmission. Both genetic and environmental factors, alone or in combination, could account for familial aggregation of ovarian cancer cases. However, in a subset of ovarian cancer families, genetic background plays a major role, as shown by the linear decrease in tumour incidence with lower degree of kinship. Lynch estimated that this hereditary subgroup represents 5-10% of all ovarian cancers [2]. Although the real frequency of genetically controlled ovarian cancer may be overestimated, it is clear that familial ovarian cancer should no longer be looked on as rare.

Formal genetic analysis of such kindreds has not been done systematically. Nevertheless, the available data do not show any consistent chromosomal abnormality except for *in vitro* hyperploidy associated with cancer proneness in families with hereditary single tumours, including that of the ovary [6]. Furthermore, low IgA levels and serum alpha-L-fucosidase levels have been detected in some ovarian cancer aggregates [1].

For molecular genetic studies, different research groups are trying to identify regions of the genome that are frequently rearranged in ovarian tumour samples. Once these have been characterised, the next step would be to search for predisposing mutations at these loci in high-risk families. Concurrently, a search for predisposing genetic lesions could be done by linkage