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## PERSPECTIVE

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# The role of the cancer registry in cancer control

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It has been accepted generally that the cancer registry has more of a 'back room' than a 'front line' role in cancer control, its particular responsibilities lying in description of cancer patterns, care, and outcome, in monitoring these variables in relation to control activities, and in providing a research database—often, for others to utilize. While readily justifiable, this prevailing concept of the cancer registry's role may not be sustainable in times of economic restraint. A survey of members of the International Association of Cancer Registries showed that most registries fit the accepted mold. Some, however, extend beyond it, particularly in the direct conduct of epidemiologic research and in the implementation of control programs, particularly screening. Sixteen percent appeared only to be collecting incidence statistics and may be at risk of economic rationalization. It would be consonant with their basic role and skills, and promote more rational cancer control, if cancer registries were to take on an expanded role, including direct participation in epidemiologic research, evaluation of interventions against cancer at the population level, situation analysis and cancer control planning, and implementation of aspects of cancer control—particularly coordination of screening—and monitoring the performance of cancer control programs. This expanded role could become the responsibility of specialized cancer control units of which cancer registration would be the central function.

*Key words:* Cancer control, cancer registration, health services, planning.

### Introduction

The accepted role of a general, population-based cancer registry has been summarized by Jensen and Storm:<sup>1</sup>

The main objective of the cancer registry is to collect and classify information on all cancer cases in order to produce statistics on the occurrence of cancer in a defined population and to provide a framework for assessing and controlling the impact of cancer on the community.

This definition leaves room for interpretation of what provision of "a framework for assessing and controlling the impact of cancer on the community" might mean. Is it a largely indirect role in cancer control or is a direct, front line role included? The former is the usual answer, as Muir *et al*<sup>2</sup> indicate:

In the control of cancer, registries are rarely in the forefront, their tasks being rather in the nature of intelligence gathering about the current cancer

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burden in a community, providing the data needed to uncover the cause of cancer in humans and for evaluation of the effects of steps taken to control the disease.

This largely indirect role includes:

- *Description* of incidence, mortality, prevalence, patterns of diagnosis (including stage at diagnosis), patterns of treatment, and survival both to inform the public, professions, and policy makers, and to provide essential input into the rational planning of cancer control programs;
- *Monitoring* these statistics in relation to implementation of cancer control activities to permit inferences about the success, or otherwise, of cancer control programs at the population level (a good illustration of how this can be done is given by Chu *et al*<sup>3</sup>);
- *Provision*, often only passively, of a *research data base* that can be used for epidemiologic, clinical, and health services research.

These basic roles alone are sufficient to justify the view, stated by Muir *et al*,<sup>2</sup> that:

The cancer registry is an essential part of any *rational* programme of cancer control, benefiting both the individual and the society in which he lives.

But, when times are tough, the political imperative is for front line service to the community not for back room data, or back room research. Votes are won by action, not by information and research (except, perhaps, opinion research).

A personal anecdote will help to illustrate this point. In the late 1970s, I was employed as Director of Health Research and Planning in the Health Department of Western Australia. During that time, I contributed to action which upgraded the State's Cancer Registry from one based only on routinely collected hospital-discharge information to a truly population-based Cancer Registry, working under a legislative mandate, and including notification from pathology and radiotherapy departments. The State's first population-based cancer-registry report was published in 1982. I returned to academic epidemiologic research for 10 years, during which time I made some limited use of the Registry for research purposes and then returned to the Health Department in 1988 as its Chief Executive Officer. A year later, the State was in serious financial difficulties and the 1989/90 State budget included an effective seven percent cut in the Health Department's funding. Cost-saving measures were urgently re-

quired, however the Government had said that there would be no cuts in services to patients.

Despite my original paternal role, predisposition towards cancer registries, and the use that I had made of this one, I was very seriously tempted to close the Cancer Registry as a cost-saving measure. It was producing good incidence and mortality reports, it had had some limited use for research purposes, but it had been used hardly at all for planning or monitoring purposes. It could be argued that, for planning of a prevention program at least, perfectly adequate indicative data could be obtained from the neighboring (but 2,500 km away) South Australian Cancer Registry. In the event, I could not bring myself to close the Registry. Had I not been there, someone else might have.

This anecdote illustrates what many cancer registries already know, some, perhaps, from bitter experience, that a registry that is not making continuing positive and *direct* contributions to cancer control is a registry 'at risk.' This view was well expressed, if not as bluntly, by Greenwald *et al*:<sup>4</sup>

We think that any registry—hospital, local, regional, or national—must devote at least as much resources, time, and talent to its use for research and control purposes as it does to data acquisition, computerization, and publication of annual reports. Otherwise, it is doubtful that the registry investment is being optimally used.

The cancer registry is essential to cancer control, and cancer control is essential to (the survival of) the cancer registry.

## What is cancer control?

There appears to be no accepted definition of cancer control. The following was devised in consultation with Dr Jan Stjernsward of the World Health Organization's Cancer and Palliative Care Unit and Dr Max Parkin of the Descriptive Epidemiology Program at the International Agency for Research on Cancer.

Cancer control encompasses all actions taken to reduce the frequency and impact of cancer. It includes prevention, earlier diagnosis where this may lead to a better outcome, treatment, rehabilitation, and palliative care. The totality of cancer control may be conceived of in terms of a six by nine matrix of *components* by *steps*.<sup>5</sup>

The six *components* are mutually exclusive cancer-control program areas covering the actions that can be taken to reduce the frequency and impact of cancer. They are:

- (i) *primary prevention*. Actions taken to reduce

human exposure to agents that may cause cancer or to reduce genetic predisposition to cancer;

- (ii) *screening*. Actions directed towards asymptomatic people with the objective of identifying those at high risk of development of symptomatic cancer (e.g., genetically susceptible, possess a precancerous lesion or *in situ* cancer, possess an early invasive cancer) for whom some program of continuing screening, diagnosis, and/or therapy may reduce the subsequent morbidity of or mortality from cancer;
- (iii) *early diagnosis*. Actions taken to increase the probability that a person with a symptomatic cancer will have that cancer diagnosed at a stage when treatment is likely to result in cure;
- (iv) *treatment*. Actions taken in a patient with diagnosed cancer which have cure of the cancer as their objective;
- (v) *rehabilitation*. Actions taken in a patient who has had cancer treated, which have restoration of the patient to full physical, mental, and social function as their objective;
- (vi) *palliative care*. Actions taken in a patient who has cancer that cannot be cured, which have continuing maximization of the patient's physical, mental, and social well-being as their objective.

There are nine *steps* in developing and implementing any one of these six components of a cancer control program: (1) *basic research*; (2) *development of interventions*; and (3) *evaluation of interventions* are the research steps, both pure and applied. From the perspective of a cancer registry, the most relevant example of basic research is epidemiologic research into the causes of cancer (e.g., a case-control study into the association between human papilloma virus and cancer of the cervix). It includes, however, basic research which may lead to a new method of screening, making earlier diagnoses, a more effective treatment or better subsequent care. Development takes the results of basic research (e.g., that human papilloma virus causes cancer of the cervix) and endeavors to find a potentially effective intervention against cancer (e.g., a vaccine against infection with relevant types of human papilloma virus). Evaluation aims to determine, within a research rather than implementation framework, whether or not a potentially effective intervention is actually effective in reducing the incidence of cancer. Ideally, this is done under circumstances of actual use within an appropriate target population. It may (should) also include economic evaluation of cost-effectiveness.<sup>6</sup>

The next three steps, (4) *situation analysis*, (5) *raising awareness of need*, and (6) *program planning*, lead to the preparation, for a particular population, of the most appropriate cancer control plan taking into account what is known about the occurrence, causes, and control of cancer in that population (or what can be inferred from what is known in other populations), what is already being done, and the resources that the population might be able reasonably to invest in cancer control, having regard to its wealth and the importance of other health problems. The somewhat 'political' step of raising awareness of need has been included at this level because it follows logically from publication of the situation analysis and, without it, it is unlikely that program planning will occur at a sufficiently influential level that the program will have any prospects of implementation.

The next two steps, (7) *program implementation* and (8) *program monitoring*, are the realization in practice of the cancer control plan. Monitoring, an essential component of this practical realization, is the documentation by way of appropriate process, impact, and outcome measures that the program, as implemented, is achieving its objectives in an efficient and equitable way.

Finally, (9) *future planning* combines the original situation analysis with projections of population size, characteristics, and cancer patterns, the results of program monitoring, and informed speculation regarding the results of future research and development activities to project the characteristics of the cancer control program to about a 10- to 15-year future horizon. This activity is required so that facilities, workforce planning, and financial allocations can be planned well in advance.

This matrix may be used to summarize the accepted, largely supporting role of cancer registries in cancer control outlined above, as shown by the *italic* entries in Table 1. A central role in situation analysis and program monitoring is ascribed to cancer registries in Table 1 because they are essentially the only source of population-based incidence, prevalence, clinical (stage, treatment), and survival data that are essential to these activities. Even here, though, the registries often have been cast in the role of passive providers of these data to others rather than as direct participants in the analysis and monitoring processes.

## What the registries are doing

How well does the stereotypical role described by the *italic* entries in Table 1 fit the reality for most cancer registries? To answer this question, I carried out a sur-

**Table 1.** The generally accepted and proposed expanded roles of cancer registries in cancer control<sup>a</sup>

Steps in cancer control	Components of cancer control					
	Primary prevention	Screening	Early diagnosis	Treatment	Rehabilitation	Palliative care
Basic research	<i>Support</i> <b>Central</b>	<i>None</i>	<i>None</i>	<i>None</i>	<i>None</i>	<i>None</i>
Development of interventions	<i>None</i>	<i>None</i>	<i>None</i>	<i>None</i>	<i>None</i>	<i>None</i>
Evaluation of interventions	<i>Support</i> <b>(Central)</b>	<i>Support</i> <b>Central</b>	<i>Support</i> <b>Central</b>	<i>Support</i> <b>Central</b>	<i>Support</i> <b>Central</b>	<i>Support</i> <b>Central</b>
Situation analysis	<i>Central</i> <b>Central</b>	<i>Central</i> <b>Central</b>	<i>Central</i> <b>Central</b>	<i>Central</i> <b>Central</b>	<i>Central</i> <b>Central</b>	<i>Central</i> <b>Central</b>
Raising awareness of need	<i>None</i> <b>Support</b>	<i>None</i> <b>Support</b>	<i>None</i> <b>Support</b>	<i>None</i> <b>Support</b>	<i>None</i> <b>Support</b>	<i>None</i> <b>Support</b>
Program planning	<i>Support</i> <b>Central</b>	<i>Support</i> <b>Central</b>	<i>Support</i> <b>Central</b>	<i>Support</i> <b>Central</b>	<i>Support</i> <b>Central</b>	<i>Support</i> <b>Central</b>
Program implementation	<i>None</i> <b>(Central)</b>	<i>None</i> <b>Central</b>	<i>None</i> <b>Support</b>	<i>None</i>	<i>None</i> <b>Support</b>	<i>None</i> <b>Support</b>
Program monitoring	<i>Central</i> <b>(Central)</b>	<i>Central</i> <b>Central</b>	<i>Central</i> <b>Central</b>	<i>Central</i> <b>Central</b>	<i>Central</i> <b>Central</b>	<i>Central</i> <b>Central</b>
Future planning	<i>None</i> <b>Central</b>	<i>None</i> <b>Central</b>	<i>None</i> <b>Central</b>	<i>None</i> <b>Central</b>	<i>None</i> <b>Central</b>	<i>None</i> <b>Central</b>

<sup>a</sup> *Italic entries represent the accepted role and the bold entries represent the proposed expanded role. Parenthetical entries indicate the expanded role may be beyond the registry's responsibility.*

vey of members and associate members of the International Association of Cancer Registries. A form was mailed to each of 233 registries stating the definition of cancer control given above and requesting: "On the basis of this definition of cancer control, please describe ways in which your Registry is *at present* making a contribution to cancer control." A completely open-ended approach was adopted to this inquiry, both to permit cancer registries to mention anything that they considered pertinent and to avoid prompting overstatement of very minor contributions.

Replies were received from a total of 137 registries (59 percent of those sent a form). Repeat mailing was not carried out, and some response bias (perhaps in favor of nonresponse in those not making contributions to cancer control) can be assumed. Those responding included population-based general cancer registries (the majority), some hospital registries, and some more specialized registries (e.g., childhood cancer registries, registries of specific categories of cancer). All replies were used in the following analyses.

As far as possible, each contribution to cancer control mentioned by each registry was classified into one of the 54 categories of activity implied by the cells of the matrix shown in Table 1. The results are summarized in Table 2. Not unexpectedly, nearly one-half of all registries (41 percent) were contributing to basic

research on cancer prevention—almost entirely epidemiologic research into the causes of cancer. Other contributions to research and development in cancer control were infrequent, the single largest being in the conduct of clinical trials of treatment (specified by eight percent of cancer registries). Nine percent of registries made contributions to research but did not specify the research area; it would be reasonable to assume that this was mainly epidemiologic research into the causes of cancer.

Only a small proportion of registries made specific reference to contributions to situation analysis (20 percent made any reference) although it would be reasonable to assume that nearly all were making an indirect contribution by way of producing incidence statistics. The majority of the contributions specified in Table 2 were of the nature of 'description of diagnosis,' 'description of stage,' or 'description of treatment.' Four registries specifically mentioned 'needs assessment' among their activities. It seems likely, therefore, that most of the registries were contributing their data to situation analysis rather than participating directly in it. A similar conclusion can be reached for the contribution to program planning; although the tabulated contributions appeared to be quite direct, e.g., 'setting priorities,' 'planning services.' Seventeen percent of registries made a general contribution to planning that

**Table 2.** What cancer registries are doing in cancer control; proportion of 137 cancer registries that identified a specific contribution in each of 54 cancer control activities

Steps in cancer control	Components of cancer control					
	Primary prevention (%)	Screening (%)	Early diagnosis (%)	Treatment (%)	Rehabilitation (%)	Palliative care (%)
Basic research	41 <sup>a</sup>	6 <sup>b</sup>	1	3 <sup>b</sup>	0	0
Development of interventions	0	0	0	0	0	0
Evaluation of interventions	1	0	0	8	0	0
Situation analysis	4 <sup>c</sup>	0 <sup>c</sup>	7 <sup>c</sup>	9 <sup>c</sup>	0 <sup>c</sup>	1 <sup>c</sup>
Raising awareness of need	0 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>	0 <sup>d</sup>
Program planning	2 <sup>c,e</sup>	3 <sup>c,e</sup>	0 <sup>c,e</sup>	3 <sup>c,e</sup>	0 <sup>c,e</sup>	1 <sup>c,e</sup>
Program implementation	16	16	1	5	1	0
Program monitoring	4 <sup>c</sup>	36 <sup>c</sup>	4 <sup>c</sup>	30 <sup>c</sup>	0 <sup>c</sup>	3 <sup>c</sup>
Future planning	0 <sup>f</sup>	0 <sup>f</sup>	0 <sup>f</sup>	0 <sup>f</sup>	0 <sup>f</sup>	0 <sup>f</sup>

<sup>a</sup> This entry includes all involvement in 'epidemiologic research,' 'etiologic research,' 'case-control studies,' and 'cohort studies.' It may include basic research directed towards other components of cancer control, such as screening.

<sup>b</sup> These entries were mainly research into screening and treatment without further specification. They may have included some development and evaluation activities.

<sup>c</sup> Collection of incidence (specifically mentioned by 65% of registries), mortality (17%), and survival (36%) statistics would contribute to these aspects of cancer control but have not been tabulated.

<sup>d</sup> Raising awareness of need may have been a component of the public (13% of registries) and professional (10%) education activities of registries.

<sup>e</sup> An additional 17% of registries specified a contribution to planning of cancer control generically.

<sup>f</sup> Five registries (4%) specified incidence or mortality projections which would be likely to contribute to one or more of these areas of cancer control.

could not be classified under any one of the program components of Table 2. No registry indicated a direct role in raising awareness of need, although this may have been a component of the public and professional educational activities mentioned specifically by 13 percent and 10 percent of registries, respectively.

While no role usually has been seen for cancer registries in the implementation of cancer control programs, 34 percent, in fact, were making some contribution in this area. Sixteen percent were contributing to implementation of each of primary prevention and screening, and five percent to implementation of treatment programs. These roles, in some cases, were clearly well suited to the registry environment. For example, six registries were involved in identifying cases of familial cancer and organizing subsequent follow-up of families and risk reduction activities; five were responsible for ensuring that treated patients received follow-up care; and several ensured, by follow-up contact, that women with abnormal cervical cytology had further investigation and treatment. Thirteen registries (nine percent) appeared to have responsibility for the overall coordination of screening programs. For eight percent of registries, public education

was their only contribution to the implementation of cancer control.

Many registries indicated specific contributions to program monitoring, and most would have made at least indirect contributions through incidence, mortality, or survival monitoring. Thirty-six percent of registries specifically were monitoring the results of screening programs, and 30 percent were monitoring treatment patterns or the outcome of treatment.

While no registry indicated a specific contribution to the future planning of any of the individual program components, four percent mentioned a role in projection of future incidence rates.

Twenty-two registries (16 percent) fitted my definition of seriously 'at risk' registries. That is, they appeared only to be collecting, and possibly reporting, incidence data, with or without mortality data, and, apparently, not making any additional or direct contribution to cancer control.

In summary, it appears that the role in cancer control being played by most cancer registries is similar to the one usually attributed to them. On the positive side, some registries are playing a direct role in the implementation of cancer control programs, particu-

larly screening and some aspects of treatment, and on the negative side, their role in situation analysis and program monitoring, in practice, appears to be more of a supporting than a central one. Alternatively, it may be that little adequate situation analysis and program planning actually is being carried out and so, in most populations, no central role in these activities exists. While this may be no fault of the cancer registries, it may place them in a dangerously underused position and at risk of economic rationalization.

### **An expanded view of the registry's role**

If it is true that the traditional 'back room' role of cancer registries may not be sufficient to see them through stringent economic times, and that many cancer registries may be 'at risk' in consequence, is there any strategy that they can adopt which will both preserve their essential role, and promote their survival? The answer, I believe, is 'yes.' I propose an expanded role for cancer registries in cancer control, and a model organizational framework within which that role can be practiced. In so doing, I aim to build on what are the essential skills of cancer registries—population-based collection, storage, and retrieval of data, epidemiologic research and analysis, computation with large data bases, record linkage, information presentation and dissemination, etc.—rather than proposing that they take on roles for which they may be little suited or ill-prepared.

If, in response to these proposals, cancer registries seek to expand their roles, it will be important that they only do so within the capacity provided by the resources they have or are able to obtain. It would be counterproductive if registries were to try to expand their roles within a tightly fixed budget and, thereby, put their basic functions at risk. On the other hand, registries may have to show what additional benefits they can offer before they will be granted more resources. No single prescription can be offered to solve the resulting dilemma except the exercise of prudence and wise judgement.

To the traditional role of cancer registries shown by italic entries in Table 1 have been added bold print entries which describe what I see as an appropriately expanded role. I will highlight particular aspects of this expansion.

*Cancer registries can and should be actively and directly involved in epidemiologic research that makes use of the data that they collect*

Successful examples of this approach come readily to mind: the Institute of Cancer Epidemiology in associ-

ation with the Danish Cancer Registry; the Program in Epidemiology in association with the Cancer Surveillance System of the Fred Hutchinson Cancer Research Center in Seattle (WA, USA); the Los Angeles County Cancer Surveillance Program within the Department of Preventive Medicine at the University of Southern California (USA); the British Columbia Cancer Registry in association with the Division of Epidemiology, Biometry and Occupational Oncology in the British Columbia Cancer Agency (Canada); the Shanghai Cancer Registry, etc.

The Danish Cancer Registry with its associated Institute of Cancer Epidemiology is a particularly good example of the combination of a cancer registry with an effective epidemiologic research facility. It combined, in 1988, a cancer registry unit with three research units and a biostatistics and data processing unit.<sup>7</sup> In addition to its regular incidence reports, the Registry produced during 1986-88 nearly 60 publications, of which about one-quarter were related to descriptive epidemiology of cancer and three-quarters to epidemiologic studies of cancer etiology.

*Cancer registries should participate directly in the research evaluation of interventions against cancer at the population level*

The population-based research skills possessed by cancer registries lend themselves very well to the evaluation of interventions, particularly when the outcome to be measured requires or may use cancer registration (e.g., incidence of advanced cancer in evaluation of screening, death from cancer in evaluation of treatment). The acquisition of additional skills, either directly or by way of collaboration, may be necessary to this role. For example, evaluation of primary preventive measures often requires measurement of behavior, evaluation of rehabilitative interventions requires measurement of function, and evaluation of palliative care requires measurement of quality of life. The latter two, however, are well linked to the cancer registry because of the importance of the registry in providing the population base (particular categories of cancer patients) for the research. The former is linked less readily perhaps, because the targets are not present cancer patients, and the outcomes sought most immediately are behavioral rather than directly cancer-related.

This last point regarding participation of cancer registries in activities related to primary prevention underlies my use of parentheses around designations of their expanded role in primary prevention in Table 1 (and, later, Figure 1). It is arguable that the inclusion of activities related to environmental and lifestyle change

within the program of a cancer registry may be moving too far from the registry's central function and main skills' base. They are also problematic because they are often relevant to other major disease groups as well as to cancer (e.g., tobacco use and diet to cardiovascular disease). It may be better for the cancer registry to work in collaboration with other bodies when dealing with these aspects of primary prevention of cancer than to take primary responsibility for them.

*Cancer registries should carry out periodic present-situation analyses and future projections relevant to cancer control and coordinate the processes of cancer control planning*

Adoption by cancer registries of this central role in preparation for and conduct of cancer control planning will ensure that planning is population-based, follows sound epidemiologic principles, and makes use of the best available data. It also will ensure that the cancer registry data are used to best effect. It will require that cancer registries take an interest in other data than those that they are accustomed to collect and handle, e.g., cancer-care workforce data, facility distribution and use data, patterns of access to and use of services, etc. These data are compatible with the central role of cancer registries, however, because they are related to cancer, are (or should be) population-based, and require the skills present in cancer registries for their collection and analysis.

In the planning of cancer control, the cancer registry should see itself not as the leader but as the instrument or coordinator of the process. Ideally, leadership will lie with a group representative of the major interests in cancer control—the National Cancer Society, major institutions involved in cancer control, and the National Health Authority. This will ensure that the plans developed will have credibility and the best prospects of public, political, and professional support.

*Cancer registries should develop materials that can be used to promote the need for cancer control and cancer control planning*

These materials are a logical output from situation analysis and may have to be developed before even the need for cancer control planning is recognized. The cancer registry has a central role in preparing them but only a support role (through this preparation) in using them to raise professional, public, and political awareness of need. The lead role should be taken by the institutions and non-government and government agencies referred to above.

*Cancer registries should accept responsibility for implementation of particular aspects of cancer control programs*

Cancer registries have a logical role to play in the coordination of screening programs. This is so because, ideally, a screening program has its base in the at-risk population, aims to involve all those appropriately targeted by the program, records the results of screening for monitoring and future assessment purposes, aims to ensure that appropriate action is taken on screening results, and can assess its performance by linking any advanced cancers that may occur back to screening records.

Consider the example of a cervical cytology program. The requirements for an effective cervical cytology screening program for a whole population are summarized in Table 3.<sup>8</sup> It would be both logical and efficient if the coordination and monitoring requirements—maintenance of the population register, periodic invitation of women, monitoring and prompting follow-up diagnosis and care, and monitoring coverage and outcome of the program—were all located together.

An example of how this can be done is provided by the Victorian (Australia) Cervical Cytology Register which, in 1991, obtained information on 545,000 instances of cervical cytology taken from some 498,000 women in the State of Victoria.<sup>9</sup> The Register provided

**Table 3.** Requirements for an effective cervical cytology screening program for the control of cancer of the cervix in a whole population (modified from ICRF Coordinating Committee on Cervical Screening, 1984<sup>8</sup>)

- 
- A policy on the age-group of women to be targeted.
  - A policy on the frequency with which women in different age groups will be invited for screening.
  - A target group of women who are informed about the function and value of cervical cytology.
  - A population register in which the target group can be identified.
  - A means of extending periodic invitations to women to attend for screening and rescreening.
  - Competent and acceptable facilities for the taking, examination, and reporting of cervical smears.
  - Mechanisms for maximizing the probability that a woman who has a relevant abnormality attends for diagnosis and care.
  - Effective and efficient treatment of relevant abnormalities.
  - A means of monitoring coverage of the population at risk by the screening program and other relevant process measures.
  - A means of monitoring the incidence of invasive cervical cancer in the target population and relating it to screening history.
-

information on past smear history to cytology laboratories (average 1 h response time to requests), prompted follow-up of women with abnormalities according to an agreed protocol, and extended reinvitation to women for screening at agreed intervals. It has published two monitoring reports (after two years of operation), and its results already are being used to improve the quality of the cervical cytology services. A research project has been initiated into the variation among laboratories in the reporting of smears.

For largely historical reasons, this registry is not a part of the Victorian Cancer Registry, although the two work closely together. A cancer registry, however, does have the interest, facilities, and skills necessary for all the tasks carried out by a cervical cytology registry and would be a logical and efficient host for one. However, for a cancer registry to take on these functions would require careful planning and significant changes in the style of its operation. The following are quoted, with permission, from the Director of the Victorian Cervical Cytology Registry:<sup>10</sup>

The Cancer Registries in Australia are notoriously slow in their work—registers of cancer screening tests can't afford the luxury of slowness.

Cancer Registries in Australia have not needed to be interactive to any great extent with the outside world. I think one of the reasons for the success of the Victorian Cervical Cytology Registry is that we are interactive with labs, with doctors, and with women. Cancer Registries would need staff and a mind-shift to accommodate this.

Other roles that cancer registries could play in implementation of cancer control include, for example, identification, follow-up, and coordination of screening of cancer families, prompting of clinical follow-up of patients treated for cancer where this will improve the outcome, and prompting referral to rehabilitation and palliative care services. Because of the emphasis on epidemiology and involvement in etiologic research in cancer registries, a role in coordinating primary prevention may also be considered but with the reservations expressed above.

*Cancer registries should accept responsibility for all epidemiologic (both general population and clinical) approaches to monitoring the performance of cancer control programs*

Comprehensive monitoring will require the development of data collections that have not been traditionally part of the cancer registry's set—surveys or surveillance of exposure to carcinogens, recording of

the activity of screening programs, surveys of functional state after treatment, surveys of quality of life during palliative care, etc. These are activities for which the cancer registry is basically well equipped.

Examples are available of how cancer registries have picked up several of the extended roles outlined above. I will cite two.

The Queensland (Australia) Cancer Registry became a Cancer Epidemiology and Prevention Unit with emphasis on primary prevention and screening. In addition to operating the State Cancer Registry and a National Paediatric Cancer Registry, it both funded externally and carried out internally a cancer prevention research program covering etiologic research and the development and evaluation of prevention methods. It introduced and monitored population-wide interventions for the primary prevention of smoking-related cancer, diet-related cancer, and skin cancer. It was responsible for the coordination and monitoring of pilot-phase introduction of population-based breast cancer screening, and a variety of initiatives in increasing access to and uptake of cervical cytology screening. The Unit was located within the State Health Department, and all of these activities were carried out in close association with the Queensland Cancer Fund (the local cancer charity).

In citing this example, it is appropriate to sound a warning. Because of the Unit's interest in risk factors (smoking, diet) it was broadened to become an Epidemiology and Prevention Unit which also targeted cardiovascular disease and injury as the other major lifestyle-related diseases. Not long after, the Queensland Department of Health was reorganized, the primary prevention programs went to a new Health Advancement Branch, the screening programs went to the Women's Health Unit, and the Registry is back doing its original job, plus some epidemiologic research, in an Epidemiology and Health Information Branch. As its Director notes, "the important link between information and action is not as immediate as it was".<sup>11</sup> Could this change have been partly a consequence of loss of the Unit's primary focus on population-based phenomena related to cancer?

My second example comes from the Swedish regional tumor registries as exemplified by the Southern Swedish Regional Tumor Registry.<sup>12</sup> The Swedish registries are located within regional oncologic centers (which are responsible for all aspects of cancer care within their region) and contribute their data to the National Swedish Cancer Registry. In addition to their care functions, these registries have a major role to play in the design and conduct of clinical trials, and in the design, implementation, and evaluation of cancer care programs. The latter are agreed means, within the



region or, for some tumors, nationally, of referral, diagnosis, classification, and staging of cancers; about 50 percent of all cancer patients currently are treated according to these programs. The regional cancer registry houses the secretariat for the cancer care programs and is responsible for their coordination and patient follow-up as well as for data collection and storage, and monitoring. The population-based cancer registry and cancer-care program files are linked and the latter form the basis for accrual of patients into clinical trials. While, as a result of these linkages, the Swedish regional tumor registries have a strong clinical role, they also support epidemiologic research, collaborate in primary prevention programs, and assist screening units by identifying cancers in non-attenders and interval cancers.

Dutch cancer registries similarly are located in Comprehensive Cancer Centers and have a wider role which includes support of the activities of tumor working-groups which develop regional and national guidelines for cancer care.<sup>13</sup>

### A model organizational structure

My model organizational structure for a Cancer Control Unit (a term I have adopted for the expanded cancer registry) is shown in Figure 1. It proposes six program areas: (i) cancer registration; (ii) cancer epidemiology and prevention; (iii) clinical epidemiology; (iv) cancer services research; (v) cancer control planning; and (vi) cancer information (directed mainly to disseminating appropriately the products of the work of the other five programs rather than providing general information about cancer). These program areas should not be seen as defining rigid internal structures with separate groups of staff. Ideally, an organic management structure would be adopted in which there would be substantial opportunity for staff, particularly senior staff, to make contributions in a number of different areas.

Not all of these programs will be appropriate in all populations, and the composition of each may vary depending on existing institutional arrangements and responsibilities. In particular, in poorer countries with little to spend on tertiary services, only incidence registration, epidemiology, primary prevention, description and monitoring of cancer services (particularly palliative care), and cancer control planning may be justified. Whatever the required mix, however, there is a productive synergy to be gained from bringing these elements together in one place and under one administration—the resulting whole should be greater than the sum of its parts.

It is my view that the model Cancer Control Unit

would be best located within a comprehensive cancer center. This approach would work optimally where the cancer center has a defined responsibility for cancer services to a particular, geographically defined population (as, for example, in Sweden or in Holland), and where there is a close working relationship between the cancer center and the local cancer society.

I suggest this location because:

- it brings under one roof and one administration most of the cancer control activities for a whole population;
- clinical facilities are generally well funded and have a capacity to retain support in difficult financial times;
- the senior clinical staff responsible for cancer care usually have a strong sympathy for cancer prevention activities;
- many cancer registry activities are (or should be) closely related to clinical activities, and they both would benefit from a closer relationship;
- there is a much greater danger of reorganizations (of the kind that overtook the Queensland Unit) within health authorities (the most likely alternative location) than within cancer centers;
- a Cancer Control Unit will gain public credibility and support from its association with a major care-giving institution.

Whatever the location, the Cancer Control Unit must have close ties with the major institution or institutions responsible for cancer care, the government health authority, and nongovernment organizations active in cancer control.

### Conclusion

The proposition that cancer registries should accept an expanded role in cancer control depends on three postulates:

- (i) that cancer control has benefits to offer such that every community will wish to make at least some investment in it;
- (ii) that, at any level of community investment in cancer control, greater benefit will be gained for the community if the cancer control program is based on:
  - good knowledge of the nature and extent of the problem of cancer in the community, the measures in place to combat it, and community access to and use of those measures;
  - sound scientific evidence of what particular measures can achieve in practice;

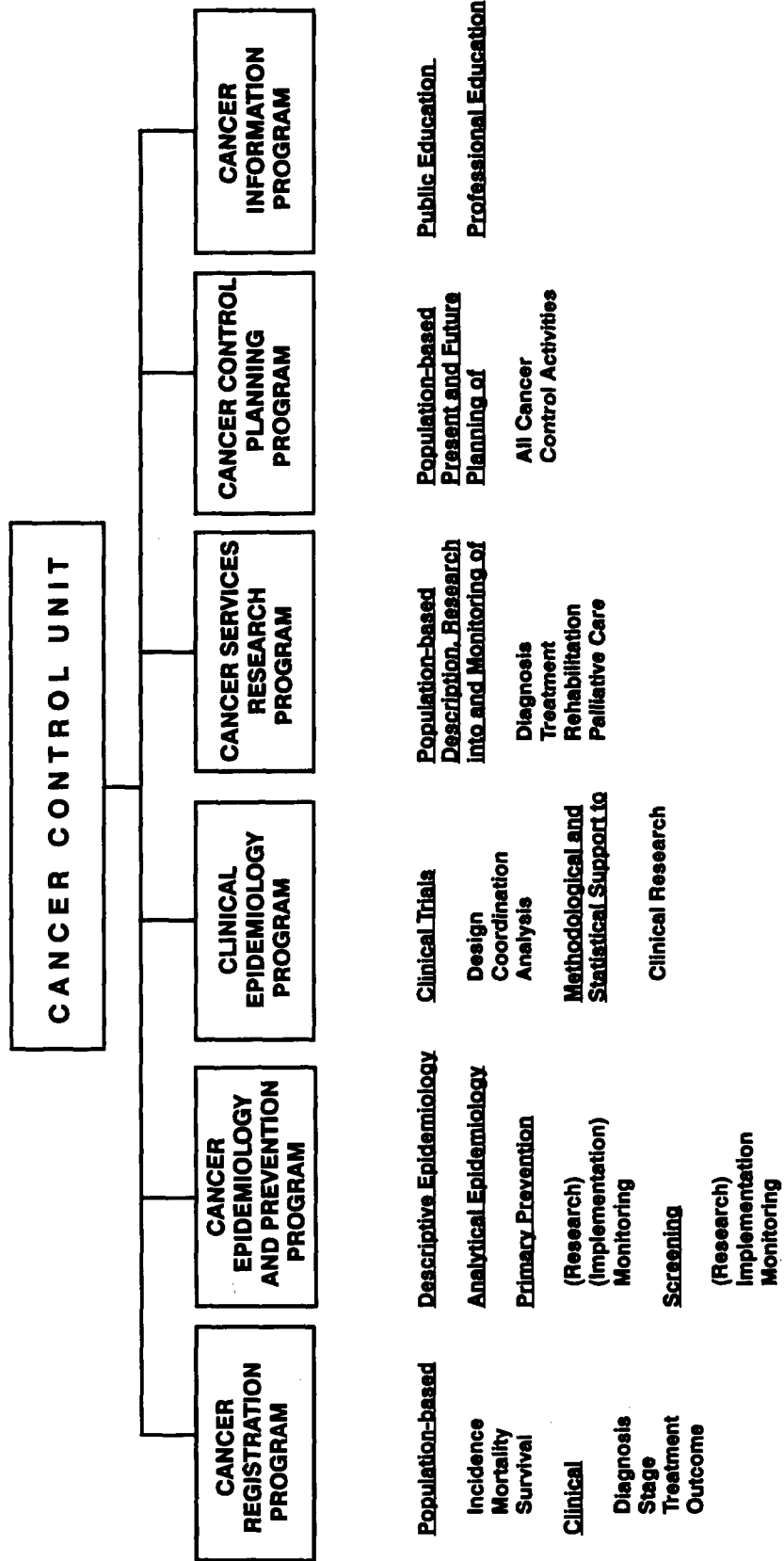


Figure 1. Model organizational structure for a Cancer Control Unit located within a Comprehensive Cancer Center.

- rational planning that takes this knowledge and evidence fully into account when deciding the range of measures and amount of each measure to be offered in the community, and;
  - monitoring of implementation of the program, and projection of the future nature and extent of the cancer problem, so that ongoing planning can continue to promote optimization of the use of cancer control resources in meeting the community's need;
- (iii) that expansion of the role of cancer registries in cancer control within their existing skills, base can increase the effectiveness and efficiency of cancer control and help to preserve the basic functions of the cancer registry in times of economic restraint.

In this paper, I have assumed the truth of the first two postulates, and argued the case for the third more from a managerial than a scientific perspective. Establishment of the role of the cancer registry in cancer control is more of an exercise in management science (if science it is) than any other form of science. Like many other propositions in management, conviction of its truth will come ultimately from the review of case studies which appear to support its truth. I hope that this paper will encourage the conduct and reporting of such studies.

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## References

1. Jensen OM, Storm HH. Purposes and uses of cancer registration. In: Jensen OM, Parkin DM, MacLennan R, Muir CS, Skeet RG, eds, *Cancer Registration, Principles and Methods*. Lyon, France: International Agency for Research on Cancer, 1991; IARC Sci. Pub. No. 95: 7-21.
2. Muir CS, Demaret E, Boyle P. The cancer registry in cancer control: an overview. In: Parkin DM, Wagner G, Muir CS, eds, *The Role of the Registry in Cancer Control*. Lyon, France: International Agency for Research on Cancer, 1985; IARC Sci. Pub. No. 66: 13-26.
3. Chu KC, Kramer BS, Smart CR. Analysis of the role of cancer prevention and control measures in reducing cancer mortality. *JNCI* 1991; **83**: 1636-43.
4. Greenwald P, Sondik EJ, Young JL. Emerging roles for cancer registries in cancer control. *Yale J Biol Med* 1986; **59**: 561-6.
5. World Health Organization. *How to Set Up National Cancer Control Programmes*. Geneva: World Health Organization, in press.
6. World Health Organization. The use of quantitative methods in planning national cancer control programmes. *Bull World Health Organization* 1986; **64**: 683-93.
7. Jensen OM, Ewertz M, Lynge E, Olsen JH, Schou G, Storm HH. *Danish Cancer Society, Danish Cancer Registry, Institute of Cancer Epidemiology: Triennial Report 1986-1988*. Copenhagen: Danish Cancer Society, 1989.
8. ICRF Coordinating Committee on Cervical Screening. Organisation of a programme for cervical cancer screening. *Br Med J* 1984; **289**: 894-5.
9. Mitchell H, Higgins V. *Victorian Cervical Cytology Registry. Statistical Report 1991*. Victoria, Australia: Victorian Cervical Cytology Registry, 1992.
10. Mitchell H. Victorian Cervical Cytology Register, Melbourne, Australia. Personal Communication, June 1992.
11. Ring I. Epidemiology and Health Information Branch, Queensland Department of Health, Brisbane, Australia. Personal Communication, June 1992.
12. Moller TR. Cancer care programmes: the Swedish experience. In: Parkin DM, Wagner G, Muir CS, eds, *The Role of the Registry in Cancer Control*. Lyon, France: International Agency for Research on Cancer, 1985; IARC Sci. Pub. No. 66: 109-19.
13. de Winter GA. Landelijk Overlegorgaan Kankercentra, Utrecht, The Netherlands. Personal Communication, May 1992.