Canadian Strategy for Cancer Control: Research Working Group

Final Report

January 2002

Subgroup Reports:
Basic Research
Clinical Research
Health Services Research
HR & Infrastructure Research
Medical Imaging Research
Palliative Care Research
Prevention Research
Socio-behavioural Research
Translational Research

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Summary

Background

- A commitment to build and sustain a strong foundation in research is vital for effective cancer control.
- A strong research culture is required for a cancer control system to respond strategically to new knowledge and technology. This enables it to evolve and continuously improve.
- The Canadian public expects that the burden of cancer can be dramatically reduced over the next two decades and there is a desire to meet this expectation by adequate investment in a broad spectrum of cancer research.
- Canada's current investment in research is grossly inadequate to attract and retain the numbers and diversity of creative and skilled research personnel needed to sustain a worldclass research effort in cancer control.
- Especially important is the need to fill existing major gaps (e.g. in health services research related to cancer control, bio-informatics, and palliative care research), to take full advantage of new opportunities arising (e.g. as is currently the case in genomics and translational research), and to facilitate the development of new interdisciplinary cancer control research programs with innovative objectives.
- Canada has a competitive advantage in many areas of research in cancer control because of its universal health care system and comprehensive cancer care systems. These features can allow Canada to become a world leader in areas like population health research and clinical trials. The current human research resource crisis in Canada is preventing this advantage from being fully exploited.

Objectives of Research Recommendations

- To reduce significantly the burden of cancer in Canada over the next two decades and beyond.
- To provide the evidence base that is needed for sound policy decisions; decisions that will enable our health systems to cope with the coming increased demands.
- To create a national resource which could underpin research activity across the cancer control continuum from prevention to early detection, diagnosis, treatment and palliative care.
- To provide a national research framework so that local cancer control activities will benefit from national activities and align with national objectives.
- To generate the largest impact on the cancer continuum by encouraging a multidisciplinary approach and attracting the best scientific minds into the cancer research arena.
- To provide an enabling platform for investigators and institutes to compete internationally, e.g. the provision of unique resources based on the Canadian health care system, coordination of funding opportunities to maximize the use of resources.

- To provide a rational framework to channel diverse resources for maximum impact, e.g., government initiatives (e.g. CFI, Genome Canada, CIHR etc), industry and volunteer organizations.

Summary of Recommendations

1. **Increase research funding to position Canada as a leader in cancer control.**
   Expansion of cancer research across Canada is essential to continued improvement in the effectiveness of all programs aimed at cancer control. We recommend a policy of national funding of cancer research at a per capita level equivalent to that in the USA (i.e. an increase from a current estimate of $ 5.00 to a target of $15.00 per person) to exploit new opportunities and to meet urgent needs.

2. **Aggressively address the human resource crisis**
   New and expanded funding, organizational, and career and training support mechanisms are needed to address the human resource crisis facing cancer control research activities in Canada. Only by introducing multiple strategies will it be possible to recruit new researchers, retain researchers, and release current capacity, to enable Canadian researchers to take advantage of the opportunities and address the needs that are developing across the cancer continuum.

3. **Foster funding mechanisms to promote breakthroughs and interdisciplinary research.**
   In order to foster interdisciplinary, breakthrough research in cancer control, innovative funding mechanisms must be established to provide: 1) competitive and stable salary support for all levels of investigators; 2) sufficient operating funds and infrastructure support for both short and long term innovative research programs; 3) a much broader base level of funding to underwrite the costs of interdisciplinary research programs. Only with such changes can Canada expect to participate in and benefit from breakthroughs that will significantly improve cancer control.

4. **Champion national priorities for cancer control research.**
   Progress towards cancer control depends on the alignment of research funding with current knowledge, needs, gaps, and opportunities. National priorities will help to co-ordinate funding initiatives, reduce duplication, and guide the development of a critical mass of research across Canada. Long-range national priorities should be developed through broad consultation, and be regularly reviewed and updated.

5. **Establish a national information resource for data collection related to patients and populations**
   A key step in capitalizing on opportunities across the research spectrum depends on the collection of, and access to, high quality data on a wide range of dimensions relating to cancer. This requires standardized and linkable data sets in a variety of areas such as risk behaviours, biological samples, health services utilization, and outcomes such as survival and quality of life. This is essential for research which informs the cancer process from prevention to palliation.

6. Establish a national voice for research in cancer control.

Government decisions have enormous potential impact on cancer research activities. A national body should be established by participants in the CSCC process that will, on an on-going basis represent to the Federal and Provincial governments the views of the public and research community on issues relevant to cancer research. At present such a body does not exist. Government decision-making may therefore be less than fully informed and consequences affecting Canada's ability to engage in this critical component of cancer control may be overlooked.

Recommendations

Recommendation 1: Increase research funding to position Canada as a leader in cancer control.

Background

- Improved cancer control (to achieve a significant impact on both individuals and Canadian society as a whole) is dependent on active research activities spanning the full spectrum of areas relevant to cancer control (screening/prevention, diagnosis, treatment, palliative care, health services, socio-behavioural, translational and basic research).
- Knowledge about the cancer problem (all aspects) has reached the point where additional interdisciplinary and applied approaches are important and relevant – BUT – these will only be effective if research strength in core disciplines is sustained.
- Funding of cancer research in Canada is currently estimated at 3-fold below the per capita level in the U.S., yet Canadians expect EQUIVALENT standards of cancer control.

Goal

To establish and sustain a level of government support for cancer research that matches public expectations and scientists' recognition of emerging needs and opportunities.

Targets

Federal and Provincial governments, private cancer fund-raising organizations (e.g. CCS, LRF, CRS), cancer agencies, hospitals, universities, CAPCA, CIHR, cancer patients, scientists, groups representing needs of science, leaders of industry.

Actions

- Target groups to persuade governments to adopt this recommendation.
- Recommend to CIHR, NCIC/CCS and other private cancer fund-raising organizations that they increase communications to the public emphasizing the importance and benefits of a strong cancer research effort being maintained in Canada.
- Circulate broadly the Research Working Group Report and its attachments.
- Create a freestanding national body to serve as a guardian of the cancer research agenda in Canada which would have professional and public members (see also Recommendation 6).

Estimated Cost

$450,000,000 per annum (2001 dollars)

Expected Outcomes

- Core disciplines will be strengthened and stabilized.
- This recommendation is crucial to address the current crisis in research manpower (see also Recommendation 2).
- Additional funds are also essential to allow creation of new mechanisms of support and the introduction of longer and larger support levels, including greater possibilities for interdisciplinary, resource-sharing, and networking activities, all of which are needed to accelerate significant research breakthroughs (see also Recommendation 3).

Priority Rank: 1

Recommendation 2: Aggressively address the human resource crisis.

Background

- Canada has a well developed cadre of researchers in certain disciplines in cancer control, however other areas of high priority are less well served. Indeed, in some areas highly qualified personnel interested in cancer control are almost totally lacking. Overall, existing expertise is being diminished by two factors: 1. Severe underutilization of qualified personnel in Canada, due to other professional pressures (e.g. patient care and teaching); 2. Failure to sustain this group due to the departure of existing scientists to more attractive positions in the USA and the lack of new recruits.
- Canada has a competitive advantage in many areas of cancer control because of its universal health care system and comprehensive cancer care systems. These features can allow Canada to become a world leader in areas like population health research and clinical trials. The current crisis in Canadian research human resources is and will continue to prevent this advantage from being fully exploited for some time, even if an increased infusion of funds occurs, unless multiple new measures are taken immediately to address the need for more personnel.
- There is a growing appreciation of the need for creating multidisciplinary teams to effectively tackle many aspects of cancer control research particularly those concerned with understanding and modifying disease incidence, as well as therapeutic effectiveness. This need is not well served by current grant and training systems. This calls for structural changes that will promote the development of researchers and research teams that will be better qualified and supported to conduct innovative, multidisciplinary research programs.

Goal

To modify and expand the Canadian cancer research funding and health system environment to stimulate personnel training, to attract, retain and make better use of existing highly qualified researchers, to foster the development of new programs that

utilize multidisciplinary and innovative approaches, and in particular to allow programs in priority underserved areas to become viable.

Targets

- NCIC
- CIHR
- SHRC
- Provincial cancer agencies
- Universities

Actions

There is no single solution that will address the human resource crisis that is currently affecting all areas of cancer control research. Each has unique problems and specific needs that will require appropriately tailored solutions. However, the general proposals listed below will go a long way to resolving some of the most common and pressing issues:

Increase trainees:

- More funded positions
- Higher stipends to make training more attractive, particularly in under-served areas and within multidisciplinary programs.
- Establish block grants that include a training component.
- Include incentives in grants that include a training component.
- Establish research chairs for developing senior mentor and training capacity.

Increase access to research opportunities for the existing cadre of investigators:

- create new mechanisms for purchasing additional time for research. This could include reducing (without necessarily eliminating or compromising) patient care and/or teaching duties.

Increase the attractiveness of research positions in Canada (see also Recommendation #3):

- Make salaries more competitive.
- Establish longer (7 yr) career awards.
- Change methods of academic evaluation to accommodate investigators involved in "team" activities, and projects with long-term end-points.
- Create new mechanisms to support training in new areas for established investigators.
- Stabilize the transition period for new investigators through the adoption of a longer (5 yr) initial grant-funding policy.

Estimated Cost

Some of the recommendations address structural issues that do not affect the current granting envelope. Research chairs, block trainee grants and new trainee positions would require significant additional funding, already recognized as a general necessity for improved research in Canada (CIHR, C21 research chairs initiative).

Expected Outcomes

- Creation of a critical mass of investigators across the spectrum of cancer control research, including the establishment of new programs in underserved areas (e.g. health services research in cancer care delivery, cancer prevention, palliative care).
- New possibilities for multidisciplinary programs and more rapid translation of basic findings to application.
- Renewed public recognition of the contributions that can be made by Canadian scientists and the benefit of these to the Canadian public.

Priority Rank: 2

Recommendation 3: Foster funding mechanisms to promote breakthroughs and interdisciplinary research.

Background

- Funding in Canada is currently insufficient to support the scope and types of interdisciplinary research that are necessary to achieve breakthroughs in cancer control.
- Cancer control research is both labour intensive and costly. It also requires adequate, stable and broad-based support of multiple activities to ensure the delivery of results that will have a profound impact on cancer control.
- Current mechanisms for accessing funds to support cancer control research are cumbersome, inefficient and discourage rather than encourage the pursuit of projects that require interdisciplinary or risk-taking approaches.

Recommendation

Goal

To revitalise and revamp current research funding mechanisms, and to establish new sources of funding and partnerships to promote interdisciplinary and innovative research in cancer control through the establishment of larger, more stable operating grants, competitive personnel stipends and increased investment in infrastructure support (see also Recommendation #2).

Targets

Provincial and national research funding agencies, current private sector research funding sources (e.g. pharmaceutical industry, philanthropic supporters of research); includes creation of new partnerships between government and non-government funding sources (e.g. the CIHR's Business Development and Partnerships Branch, partnerships with charitable & not-for-profit organizations, industry sponsored scholarships, international partnerships).

Actions

- Establish seven-year (for established career scientists) and five year (for new investigators) grants to improve stability required for long-term programs of research targeted at significant breakthroughs (see also Recommendation #2).
- Revamp current research funding mechanisms so that researchers can include investigator's time, and other infrastructure support needs in their applications for research support in addition to operating costs.
- Improve government incentives to broaden the spectrum of private sector research funding (e.g. tax advantages, public acknowledgement of sponsorship with specific designations attached to level of support, etc.). This will also facilitate larger, internationally competitive grants, ensuring that Canadian researchers remain in Canada and have the support they require for interdisciplinary, breakthrough, cancer control research.
- Maintain a balance between investigator-driven research, and strategic or targeted research (e.g. RFA's) based on National Research Priorities (e.g. end-of-life care research, behavioural research, prevention research, see also Recommendation #4).
- Provide research incentives, such as undesignated support for training or clinical scientist awards, to cancer centres demonstrating significant and innovative multidisciplinary research and research training opportunities.

Estimated Costs

While longer-term career awards, requests for investigator salary support, increased operating costs, infrastructure and indirect costs will require larger funding commitments, the new mechanisms proposed will also be more cost effective. The ability to maintain experienced researchers, rather than having to recruit less experienced individuals to replace them, is both cost effective and fosters a much more stable (and thus likely more successful) national research effort. A heightened coordination of government and private sector support will also see funding availability increase, without necessarily requiring that it be derived solely from the public purse.

Expected Outcomes

- More stable and adequate funding for all facets of research activity and for cancer control researchers at all levels. This will see Canada remain competitive with other jurisdictions, and promote retention of senior as well as entry-level investigators.

- A more appropriate and conducive working environment within which the research can take place.
- Improved ability for researchers to undertake larger, riskier and longer-term studies, which will increase the likelihood of breakthroughs in cancer control research.
- A greater sense of participation and partnership between traditional (e.g. government, agencies) and less traditional (a broadly defined private sector) sectors in the funding of cancer control research.

Priority Rank: 3

Recommendation 4: Champion national priorities for cancer control research.

Background

Links between funded cancer control research and its applications typically are weak. The NCIC (1994) framework for knowledge synthesis and decision-making has been widely endorsed but rarely is used in any systematic way. As a consequence, research consumers (e.g. the public, practitioners, program leaders, policy makers, funders) lack the tools for evidence-based decision-making and practice.

Solutions require collaboration between research producers, research consumers, and research funders. A framework for setting research priorities is an essential condition to align research funding with current knowledge needs, gaps, and opportunities. National priorities lay a foundation for coordinating funding initiatives, reducing duplication, and guiding the development of a critical mass of research across Canada. The priority setting process for Canadian cancer control research should take advantage of work in other countries while identifying areas in which Canada can provide unique vision and leadership. Long-range national priorities should be developed through broad consultation and be regularly reviewed and updated.

Goal

A broadly consultative workshop to coordinate a process of developing national priorities. The workshop must include key opinion leaders and decision-makers from research producers, research consumers, and research funders constituencies.

Target

A mechanism for priority setting and an initial statement of national priorities should be developed within two years and endorsed by all CSCC partner organizations. Partner organizations should commit to a long-term initiative and priorities, and an annual or biannual systematic review and updating, supported by a system for monitoring and evaluating progress.

Actions

1. The CSCC Secretariat should be tasked with developing the initial consultation and workshop process, including commissioning of any necessary background papers or analyses.
2. A representative stakeholder group should be appointed to serve as a Steering Committee.
3. Funding should be shared among the CSCC partner organizations.

Estimated costs

$200,000-$250,000/annum for the first two years, $150,000/annum thereafter.

Expected Outcome

National research priorities will:

- Reduce duplication, enhance efficiency and increase utilization of key basic and applied research across jurisdictions and organizations.
- Enable collaborative research initiatives with other countries with similar aims.
- Pinpoint the unique role Canada can have internationally, and encourage vision, leadership, and action towards that role.
- Encourage development of multidisciplinary teams within and across geographic settings, thereby providing the critical mass to address more complex and demanding cancer control priorities (Stokol, 1998).
- Accelerate and guide knowledge transfer and uptake.
- Encourage standardized monitoring and comparative analysis across jurisdictions, and mutual learning about best practices.
- Be subject to periodic revision based on changing needs and opportunities.

Priority Rank: 4

REFERENCES

National Cancer Institute of Canada (1994). Bridging research to action: A framework and decision making process for cancer control. Canadian Medical Association Journal, 151, 1141-1146.

Stokols, D. (May, 1998). The future of interdisciplinarity in the School of Social Ecology. Paper presented at the Social Ecology Associates Annual Awards Reception, School of Social Ecology, University of California, Irvine. www.uci.edu/98f/50990/readings/stokols.html

Recommendation 5: Establish a national information resource for data collection related to patients and populations

Background

It is absolutely essential to work constructively toward a system of data collection across the country that enables research. This implies the identification of data sets and data standards within a framework of national standards. There is currently ongoing work, by both the Canadian Institutes of Health Information (CIHI) and the Canadian Coalition on Cancer Surveillance (CCOCS) which have done important work in this regard. The area for focus within this domain is:

- to ensure that the information which is part of the Canadian cancer information 'system' (loosely defined) contains all the elements that are essential to conduct research across the spectrum, and
- collects data with sufficient intensity to meet the needs of localized regional/community monitoring and planning,
- data is collected and recorded in such a way as to produce confidence in the resource
- to enable access to that information for the benefit of those affected by cancer.

The desired outcome is a blueprint for the development of a national framework for databases that supports research requirements across the spectrum.

Goals

A National framework within which to identify national standards for cancer-related data and data sets, and to support and enable the collection of the same across the country.

Targets

A summary statement about the opportunities and deficiencies with respect to the framework/ plans of CCOCS and Federal/Provincial/Territorial Conference of Deputy Ministers (FPT) with respect to the ability to enable/support research across the spectrum is available by June 2001.

Actions

1. Voice strong support for work of CCOCS and FPT collaborative process, as it is critical to establishing an information framework within which to conduct research of relevance to the cancer burden (see also Recommendation #6).

2. Create a working group comprised of blue ribbon researchers across the cancer research spectrum to work closely with CCOCS, FPT and other pivotal initiatives, to ensure data system development that will enable and support research across the spectrum. Charge the working group with considering three areas of high potential yield (translational, population health and prevention, and health

services research) and ensure that plans for countrywide data sets support excellent research in these three key areas. A key aspect of enabling broad multidisciplinary work is to ensure the inclusion of information from biological samples from cancer patients in the data framework.

3. To create a task force to review the implications of legislation at federal and provincial levels which is created to address privacy and confidentiality issues, and to lead action (or contribute if effective mechanism is under way) with respect to ensuring public benefit from cancer related research while protecting privacy of individuals.

Intended Recipient of the Recommendation:

- CCOCS (Canadian Coalition on Cancer Surveillance)
- CAPCA (Canadian Association of Provincial Cancer Agencies)
- FPT Conference of Deputy Ministers
- CIHR/NCIC/CIHI (with respect to privacy legislation)
- CIHI

Costs

Research costs ultimately need to be distinguished from clinical and program costs, and a sufficient investment added to ensure research standards for methodology development and implementation. The short-term costs of the blue ribbon panel and other recommendations is modest.

Priority Ranking: 5

Recommendation 6: Establish a national voice for research in cancer control

Background

Federal and Provincial governments are major sources of funding for cancer research. In addition, they create legislation that may significantly affect the feasibility of conducting research, even though this is not an intended outcome. A recent example is federal privacy legislation. Finally, Provincial governments are responsible for the cancer care system within which research is conducted.

Despite the enormous potential impact of government decisions on cancer research activities, at present there is no body that has a mandate to present to governments the interests and concerns of the broad community committed to the importance of cancer research. In the absence of such a body, government decision-making may be less than fully informed and consequences affecting Canada's ability to engage in this critical component of cancer control may be overlooked.

Goals

Establishment of a group of stakeholders that will, on a continuing basis, be available to represent to governments the views of the public and research community on issues relevant to cancer research.

Targets

Creation of an appropriate body/forum as an outcome of the CSCC process.

Actions

Place on the overall CSCC agenda the responsibility for determining which constituencies/organizations should be part of a proposed "body" or forum. Participation should be drawn from a broad cross-section of stakeholders in cancer control that support and recognize the research imperative (e.g. non-government cancer organizations, private fundraising foundations, professional associations, academic research institutions). Workshops/discussion groups can be organized around specific issues/opportunities, drawing in individuals with an interest and expertise in particular areas (e.g. privacy, ethics).

Priority Ranking: 6

Appendices Following

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Basic Research: Table of Contents

1. Definition and Importance of Basic Cancer Research

Basic research involves making discoveries, developing new tools and methodologies, and generating new concepts. Through these mechanisms, basic research builds the foundation of scientific knowledge upon which all new technological developments depend. Throughout the history of civilization, the power and promise of basic research has excited mankind. In our society, basic research is now driving the creation of a knowledge-based economy through the development of biotechnology and related industries. Indeed, many believe that the socio-economic and real health of a modern nation is a direct function of its investment in basic research and the associated work force it trains.

The term “basic cancer research” reflects our ignorance until recently of what cancer really is biologically. This has spurred a tremendous drive over the last 25 years to resolve this question and has now led to a large body of evidence indicating cancer to be a family of diseases, each caused by an abnormal accumulation of cells due to their acquisition of mutations in a small subset of genes that normally regulate cell proliferation, viability, and differentiation. The result has been an even greater expectation of the potential of further studies of these processes to yield new breakthroughs in the development of more specific and effective prevention (screening), diagnostic, and treatment strategies.

At the same time, the improved understanding of what cancer is, how it is caused, proven examples of the ability of screening and prevention programs to reduce the incidence of certain cancers, and the introduction of treatments that now often prolong survival has led to an expanded concept of cancer research that embraces all aspects of cancer control. These raise many new questions about cancer prevalence, and the need to understand and address problems faced by individuals affected by cancer as well as the institutions and communities responsible for their care. As a consequence, a much more diverse portfolio of basic research activity is needed to support this enlarged cancer control research mandate.

Accordingly, basic cancer research is now viewed as including all research that seeks to obtain new insights into fundamental aspects of cellular, human and societal behaviour relevant to improving cancer prevention, diagnosis, treatment and palliation.

2. What Are We Doing Now?

The following provides a simplified overview of topics currently considered as active areas of basic cancer research in Canada:

- Identification of agents (chemicals, viruses, radiation) that can cause cancer and elucidation of the cellular and molecular mechanisms by which they do so.

- Identification of host factors (e.g. immune, vascular, endocrine, genetic) that affect cancer risk and the cellular and molecular mechanisms involved.

- Analysis of the normal processes of DNA synthesis and its fidelity, cellular development, proliferation, differentiation, survival, movement/migration and the molecular mechanisms by which these processes are regulated.

- Identification of genes whose mutation may contribute to the development of any aspect of a malignant phenotype and the mechanisms by which this occurs.

- Development of new diagnostics including improved imaging, and cellular and molecular markers of transformed cells.

- Development and preclinical evaluation of new (increasingly specific) therapeutic strategies using physical, chemical, biological and viral/genetic agents to target abnormal cell survival or proliferation control mechanisms, tumor vascular integrity, oncogene and tumor suppressor gene products, as well as strategies to exploit potential allo- and auto-immune anti-tumor effects.

- Identification of mechanisms of improved delivery of therapeutic agents to malignant cells including radiation physics, pharmacology, drug-targeting, cell therapy, gene therapy and elucidation of host as well as tumor-specific factors (physiological, genetic) that affect treatment response.

- Identification of mechanisms underlying behaviour important to exposure to risk factors (e.g. genetic factors affecting addiction), compliance (e.g. affecting screening and/or treatment), and perception of life quality (e.g. pain management).

3. How Well Are We Doing It?

Canada has a strong track record in many areas of basic cancer research. This is indicated by the international recognition of a high proportion of its cancer research scientists, the groundbreaking discoveries and methods they have pioneered, and the multiple world-class centres of training that have been established across the country. Good people attract good people and this adage is particularly relevant to the strength of basic cancer research in Canada. In addition, the creation of well funded research institutes affiliated with treatment facilities, the provision of resources to foster and maintain groups of excellent basic cancer research investigators, strong public and volunteer support for the pursuit of basic cancer research (i.e. through the dream launched by Terry Fox and the large community presence sustained by the Canadian Cancer Society), and the use of a high quality peer review mechanism for allocating funds have all been major factors in keeping Canada at the forefront in many areas of basic cancer research.

On the other hand, the overall decline in resources available to foster growth in Canadian academic biomedicine that dominated the 1990's has recently begun to stunt the continuing expansion of new science in Canada during a period of technological explosion and growth elsewhere, particularly in the USA. Moreover, this has been accompanied by a serious decline in the number of Canadian graduates and post-graduates interested in training in disciplines critical to the future of basic cancer research and a relative reduction of new investigators willing or available to join the basic cancer research community in Canada.

Relative to what has happened in the USA, science in Canada has also suffered from a lack of pharmaceutical industry support and a slow growth of its own biotechnology companies. This situation is now beginning to change, but economic disadvantages including unfavorable tax laws and inadequate availability of qualified personnel continue to hamper the strong synergism of biotech and academic research that has recently helped to fuel scientific progress in the USA.

4. Horizon Scanning

Basic cancer research has entered the scene of big time research. At the same time, there is an important need and opportunity to provide incentives and reward and recognition for individual creativity and risk taking.

- **Genomics**

The impact of human genome information and the imminent establishment of technology centres across Canada through Genome Canada will provide new capacity for tissue banking and associated clinical data management, gene discovery, single nucleotide polymorphism (SNP) analyses, and large-scale gene and protein expression studies. Such capabilities will make it possible to pursue in Canada, many studies that will clarify early stages of cancer development, who will be affected and how different types of cancer develop, as well as the identification of new and more specific targets for treatment and genes that determine many aspects of the behaviour of cells and individuals that affect their susceptibility to developing cancer and particular anti-cancer therapies.

- **Mathematics/Bio-informatics**

The explosion of information that the new genomics and proteomics technologies have made possible will require the increasing use and further development of more sophisticated mathematical and computing methodologies for many aspects of cancer research.

- **Use of Model Organisms**

Genomic parallels and the availability of complete sequence data on various lower organisms (e.g. yeast, worms and flies, as well as mice) which can be

genetically manipulated with relative ease has made all of these invaluable models for delineating the function of uncharacterized human genes, for analyzing their regulation and for determining effects of particular mutations on human gene expression and function. Given the key role of specific genes in human cancer development and in determining how different individuals respond to mutagens, treatments and other sequelae of cancer, the importance of studies of genetically manipulated model organisms is likely to increase dramatically.

- **Immunology**

The potential of harnessing knowledge about how the immune system can recognize and destroy cancer cells is now one of the fastest growing areas in cancer research. It is clear that immune cells play a major role in contributing to cures in some diseases (e.g. in leukemic recipients of allogeneic bone marrow transplants) and many additional vaccine as well as cell-based cancer therapies are now being considered. In each case, these rely on continuing basic research in all aspects of immune cell development, function, and ex vivo manipulation.

- **Tumor Biology**

Many exciting developments are occurring in this broad area. These include the creation of new xenotransplant models for analyzing the behaviour of primary samples of human malignant cells, delineation of the processes of abnormal cell signalling in the perturbed control of cancer cell proliferation, apoptosis, differentiation and movement, and identification of the molecular mechanisms underlying tumor angiogenesis and tumor cell metastasis.

- **Interdisciplinary Studies**

The potential for greater immediate impact in settings where scientists with very different training and expertise can combine their investigative efforts in “virtual” if not real working groups is clear. However, these are likely to achieve success only where their importance is recognized and supported by appropriate changes in clinical (direct patient care) duties and current academic practices for emphasizing individual research achievements.

- **New Funding Opportunities**

Several remarkable funding sources for health research have been created in the last 2-3 years. These include The Canadian Foundation for Innovation (CFI), the creation of 21st Century Chairs, and the establishment of the new Canadian Institutes of Health Research (CIHR). The latter now includes an Institute of Cancer Research. The President of CIHR has indicated the intent of CIHR to more than double health research dollars in Canada over the next few years. The impact of these resources on basic cancer research will undoubtedly be profound and create scope for new as well as expanded training and investigational programs relevant to the needs of basic cancer research.

5. Barriers

There are several barriers to progress in basic cancer research in Canada. The most important of these is a lack of trainees and highly qualified personnel. These have been mentioned above and the same issue is addressed and documented in greater detail in the Report compiled by the Research Resource Working Subgroup. Nevertheless, it warrants specific reiteration here.

A major effort will be required to increase the attraction to both science and medical and allied health professional graduates in Canada of obtaining post-graduate and post-doctoral level training in a basic cancer research field. Such individuals not only flesh out the research activities being overseen in Canada by their supervisors, these new trainees will also become the premier investigators of the future. They will play crucial roles in all areas of cancer research (not just basic research, itself) and will be particularly important to the anticipated creation of interdisciplinary projects and teams in translational and behavioral areas of cancer research.

A major effort will also be required to decrease the loss of trained personnel from Canada to better positions in the USA. Most of the best graduate students who have trained in basic cancer research in Canada go to the USA or Europe to obtain post-doctoral training in the same or a related field, often funded by a Canadian Fellowship. Few are successfully recruited back.

A second impediment to basic cancer research is inherent in the riskier nature and long delivery time required for its benefits to be realized and appreciated. This, together with increasing competition for large expenditures to address problems of greater immediacy or political relevance, places recognition of the importance of maintaining a strong basic cancer research activity in constant jeopardy.

6. What Should We Be Doing?

- Improved stipends, facilities and conditions are needed to attract, retain and stimulate Canadian scientists who will contribute to the future of basic cancer research in Canada. Longer (5-year) start-up grants for new investigators are needed to help stabilize their inauguration as “independent” scientists. Larger grants for established investigators are needed to allow them to spend more time on more creative projects.

- Improved stipends, interdisciplinary training programs and greater opportunities for involvement in broader issues of cancer control are needed to improve accrual of graduate students and postdoctoral fellows. Incentives for returning to Canada for those who are funded to train outside need to be developed.

- All changes need to retain the use of the peer review system criteria of excellence for evaluating applications for projects, program and personnel funding.

- New opportunities/incentives/funding are needed to foster networking and sharing of resources and ideas both between disciplines and institutions/loci (although not necessarily restricted to either of these).

- Mechanisms that encourage the pursuit of more ambitious and riskier projects are needed. The Terry Fox New Frontiers Initiative grants are a good example of how a relatively small investment can help a large new activity to get started (e.g. J. Woodgett establishment of micro assay technology in Ontario).

- Partnerships between organizations are needed to facilitate collection and analyses of patient material and/or data that might otherwise be provincially restricted.

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J. Slingerland	-	University of Toronto, Toronto.

Appendix B: Clinical Research Subgroup Report

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A. What are we doing now?

Within the treatment topic working group there is a sub-group with clinical trials/clinical research. At a recent meeting we agreed to try to estimate the current level of clinical trials activity in Canada by asking centres to tell us the ratio of non-NCIC CTG to NCIC CTG clinical trial enrolment in their institutions. This will allow us to have fairly good figures on the level of trials activity in the country. We don't have the numbers yet, but my guess is that we will find that somewhere between 3.5 – 5.0% of cancer patients are going on trials, a number that is comparable to other jurisdictions. That working group is likely to recommend that we aim to double this figure. The US NCI is hoping to achieve a fivefold increase in enrolment to its trials (20,000 patients per year to 100,000) over five years.

B. How well are we doing it?

There is pretty good evidence to support the statement that the quality of trials done in Canada is internationally competitive. Several review teams have said just that about the Clinical Trials Group. These review teams have particularly praised the CTG's investigational drug programme. This programme has stimulated a high level of activity in studying new anti-cancer agents. This activity has occurred within and outside the CTG. In addition, many studies outside the CTG have achieved international prominence. One such study was on the plenary session at ASCO this year. That Canadian research in this area is of high quality should not be particularly surprising given the natural advantages provided by centralized cancer systems and the leadership of institutions like McMaster.

C. Horizon Scanning

- What is the future of evidence based medicine/decision making? At present, regulators, policy makers, funders and practitioners rely (or say they rely) on the results of randomized trials to inform decisions. Unless this changes, there will be a need for RCTs for the forseeable future.
- What will be the impact in Canada of the restructuring of the US NCI clinical trials program? The US NCI is driving major changes in how trials are developed, approved, and conducted. Their intent is to include Canada in this

process. If successful, this restructuring will radically change how trials are done. What isn't clear is how successful the reform will be.

- Where will industry sponsored trials fit? The involvement of industry in cancer trials is expanding enormously. What isn't clear is whether we can continue to develop effective partnerships that allow Canadian academic leadership of national and international trials. If we can't, independent academic clinical research is in danger.
- How will we cope with the explosion of new agents requiring testing? The capacity to undertake the Initial (phase I and II) trials of these drugs is limited by organizational and institutional constraints. Further, if the drug development paradigm doesn't change, i.e., if RCTs are needed before drugs are approved, it is a real question whether there is the system capacity to conduct the studies that need to be done. Patient, investigator, support personnel and organizational resources could easily be exhausted.
- Can we do the trials needed to determine reliably whether therapy can be successfully individualized? The conventional statistical requirements to demonstrate that a treatment is selectively effective are daunting. However, if we really want to be confident that, for example, a molecular marker predicts who will benefit from a given treatment and who won't, we need this sort of evidence.

D. Barriers

- Regulatory/ethical requirements. It is almost impossible to convey how difficult it is becoming to meet the requirements of the several authorities who have a say in whether trials are approved and what must be done while they are conducted. A particular problem is the fact that US governmental requirements apply to many trials done in Canada, even when the trials originate in Canada. This regulatory/ethical burden is a problem both for organizations running trials and institutions participating in them.
- Resources at institutions participating in trials. The "infrastructure" of clinical trials is a health care system that is currently stretched to the breaking point. Clinical trials require the time of investigators, research nurses and data managers (CRAs), research pharmacists and the use of physical resources (space, drugs, diagnostic facilities). "Academic" trials have traditionally depended upon the institutions to bear at least some of these costs on the basis of an institutional commitment to research. However, that is becoming less and less possible. Most institutions now carefully "cost" trials before agreeing to them. This lengthens the local approval process already prolonged by ethics review.
- Lack of trained personnel. CRAs are now in high demand and competed for by institutions, the pharmaceutical industry and contract research organizations. The last two pay much higher salaries so it is becoming very difficult to keep qualified personnel at participating institutions.
- Overall funding. Although NCIC contributes a substantial portion of its budget to clinical trials, federal funding is very small by international standards. Competition from international industry trials. Whether this is

really a barrier depends upon one's perspective, but in at least some cases, the existence of large, well funded industry studies aimed at addressing questions of limited scientific interest has made it impossible to conduct "made in Canada" trials. This trend is likely to accelerate as more companies get involved with cancer drugs and more drugs are "me-too" copies.

E. What should we be doing?

1. There needs to be an effective national voice for cancer clinical trials, if not for clinical trials in general. (This idea comes from Dr. Sutcliffe and the Treatment Working Group). While we have a national cancer clinical trials group, its mandate is to develop and conduct trials, not to attempt to address structural and regulatory issues. Perhaps this could be a role for a CIHR cancer institute.- a primary role for such an agency would be to attempt to develop centralized mechanisms for dealing with regulatory and ethical issues

2. Institutions need to renew their commitment to including clinical research as part of their mandates.

3. Programs to train clinical investigators and clinical research personnel need to be developed and expanded.

4. There needs to be investment in programs aimed at taking advantage of the fact that cancer treatment is relatively centralized in Canada and of the opportunities for developmental and translational research this provides.

5. There should be a focused national effort to develop a realistic informatics strategy to enhance our competitiveness in trial conduct.

F. Subgroup membership

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Appendix C: Health Services Subgroup Report

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Introduction

This paper has been written under the guidance of a small group (Judy Birdsell (Chair) Charles Wright, Barbara Whylie and Bill Evans) with the input of 45 researchers and decision makers across Canada (Appendix 1). This report was written to serve as input to the deliberations of the Research Working Group of the Canadian Strategy for Cancer Control.

Scope of Health Services Research

Health Services Research (HSR) is a relatively recent focus on the landscape of health related research in Canada. There have been several attempts to define health services research. (See Appendix 2) For the purposes of this paper, health services research can be seen to be a policy-oriented field which includes the following characteristics:

- An interdisciplinary field of enquiry examining the use, costs, quality, accessibility, delivery, organization, financing and outcomes of health care services for groups of individuals or populations.
- Its goal is to improve the health services of the country by applying the knowledge gained from research. This outcome implies, indeed requires, close collaboration between researchers and research users. HSR is, therefore, as much a process as a product.
- Because of its interdisciplinary nature, HSR builds on the research methodologies of disciplines such as economics, sociology and management and fundamental research in these areas is essential to the furtherance of HSR. [1].

What are we doing now?

Because health services research is a relatively new activity in Canada, there is not an abundance of researchers working in health services research in general and even fewer whose focus is cancer. Work to date includes descriptive work showing patterns of care in different geographic locations (most of this work has been Ontario based), some costing and economic evaluation and several studies related to various aspects of breast cancer. A partial list of current research is included in Appendix 3.

Health Services Research often deals with health system issues regardless of the specific disease process involved, but within any major disease area such as cancer there are many issues in the delivery and evaluation of services and programs that require HSR attention. In the recent past, there has been emerging focus on HSR, as exemplified by the creation of the CHSRF, the addition of a panel addressing Health

[1] For example, research explicating the concept of 'access' to health care, increasing our understanding of what it means to the public and administrators, and development of methods to measure and assess 'access' to health services.

Services and Health Promotion by NCIC, the intention of CIHR to have HSR as a cross cutting theme, and a special competition in HSR sponsored by the Canadian Breast Cancer Research Initiative following a workshop on the topic.

Because most provinces have agencies that organize at least some of the cancer services and there are provincial cancer registries there are major opportunities for cancer-related HSR, which are not available for other disease types, or indeed for cancer in many other countries. These opportunities are beginning to be exploited by initiatives such as the Canadian Coalition on Cancer Surveillance and by groups such as the Institute for Clinical Evaluative Studies (ICES) and the Radiation Oncology Research Unit (RORU) at Kingston.

How well are we doing it?

Countrywide, there is a relatively small number of individuals and groups engaged in HSR in cancer, with many of these located in Ontario. Many feel the quality of health services research done in Canada is excellent, and that Canada rates in the top three (with UK and USA) with respect to quality of research done (Lomas, personal communication, 2000).In some specific areas, the cancer community has led the way in research e.g. with respect to quality of life outcomes measurement. Modeling the cost of care of common cancers is another area where Canadian research has garnered attention outside Canada.

It is difficult to make a complete assessment of how well we are doing in HSR, as sometimes this type of research is funded by organizations in order to answer questions of immediate interest, and therefore research is not 'processed' (nor often reported) through traditional peer reviewed mechanisms. Nevertheless, with respect to research that IS within the traditional peer reviewed granting system, it would appear that there are woefully inadequate numbers of HSR researchers and groups. Funding is difficult to find for this type of research, and researchers are anxious about this situation as the transition to CIHR occurs

The research that has been done to date tends to be of the descriptive nature, so that it helps to identify some areas where these may be problems (e.g. radiotherapy waiting lists, geographic variations in access) but there has been less emphasis on research that attempts to identify solutions

In addition there does not seem to be a 'community of HSR researchers' in Canada. This is exemplified by the fact that often people don't identify themselves as HSR, and there is a generally low level of awareness of cancer related HSR across the country.

What is on the horizon that will impact health services?

Factors of a general nature which may impact the future:

1. New knowledge and new technologies. Basic science advances in areas such as genetics and imaging will identify new technologies for the prevention, early detection, diagnosis and treatment of cancer. How will the system need to be organized and funded to support this, assuming societal values direct that this be done… What will happen to the groups of practitioners being trained and providing care using methods that are no longer warranted?
2. Aging population. This will create more cancer patients, and changing profiles of the population of health care providers.
3. Informed public and patients with increasingly sophisticated demands and expectations of accountability. The Internet is changing patient/doctor relationships.
4. Information technology.. Electronic health records are a reality in some jurisdictions. What will the health care system of the future look like,, with whom will individuals worried about, or with a diagnosis of cancer, interact and for what purposes and with what outcomes? The use of information technology will impact all areas of health services.
5. Complementary and alternative therapies. The increased recognition of the use of complementary and alternative therapies in cancer in the face of paucity of data about effectiveness.
6. Privacy. Increasing concern about, and legislative action regarding access to personal health data.
7. More expensive treatments, societal expectations for state of the art treatment and finite financial resources.
8. Pressure to move to integrated delivery systems (which means different things to different people).

What are the barriers?

Data Related Issues

The predominant theme relates to data issues. Although there is recognition of the potential for analysis involving cancer registry data and particularly when combined with other administrative data sources for the purposes of assessing outcomes and other dimensions, there is very little of this work done. Working with administrative data sets is very time consuming, involving numerous bureaucratic issues related to access, issues of working with data collected for other purposes and by other people, and increasingly the concern about privacy. There are no well-accepted and understood guidelines for ethical use of secondary data for research purposes across the country.

There is some sense that accessing cancer data is even more difficult than accessing other administrative data. The ability to do inter-provincial analysis is very important in order to assess the effectiveness of varying systems. There was only one study of this type identified by respondents. In addition, data collected and stored for administrative purposes is often not of a quality conducive to research.

Although respondents commonly felt that data related issues were paramount, it is noted that compared to most other countries, and most other diseases, we already have very good data related to cancer, and have had for many years in some jurisdictions, but we have not used this data to maximum advantage to this point. Caution is noted with respect to expecting huge results without adequate attention to the human/ data interface. The ability to use data critically and effectively is a large part of the solution.

Shortage of Personnel

The human resource capacity in Canada to do health services research is limited as illustrated by the comments in previous section, although this is not the only aspect. As we are now on the eve of increased availability of funds, this shortage of personnel will become critical. While there is some expertise in Canada in Health Services Research, it will be a challenge to train a new cadre of researchers in this field. As graduate students are trained, there are many opportunities for them within the delivery and policy system, so the academic community is not being strengthened.

The decision makers who provided input noted as an important feature on the horizon the shortage of specialized personnel to provide services. In so far as HSR involves the active engagement of those with expertise in service delivery the shortage of service professionals will negatively impact our ability to do HSR.

Nature of the Cancer Community

The cancer community is large and focused, and some would say, close-minded. It is large enough that there is no compelling reason to look beyond the cancer system for insights. In addition, practitioners, who are often the ones doing health services research, have very little time to seek involvement from broader communities, even though they may like to do that. There are very few outside the cancer system who study it… There is inherently a conflict of interest at some levels in looking at delivery systems in which one is a player. Whatever the reason, there seems to be a broader community of researchers who might like to be engaged in health services research related to cancer, but who perceive barriers in the cancer community.

Decision makers, in particular, are very cognizant of the varying organizational and policy arrangements within which cancer services are delivered in Canada, and of the continuing discussion about things such as integration of services, centralization/decentralization etc. There is virtually no evidence upon which to make judgments about the benefit of one system over another, but an acknowledgment that the Canadian situation provides a unique natural laboratory in which to add to international understanding about the outcomes associated with varying delivery models.

Nature of Health Services Research

By its very nature, much of health services research involves close working relationships with those responsible for making policy and delivering services. This is

time consuming business, and the traditional methods of funding research (peer reviewed, infrequent competitive mechanisms) are not conducive to effective and timely research. NHRDP is seen to have developed a degree of expertise in funding/reviewing/supporting this type of research. People have come to believe that the people reviewing proposals are competent to do so, and the importance of this type of research to the system is valued. There is concern that this will be lost as CIHR becomes established.

Health Services Research by its very nature is problem focused i.e. it is designed to help inform the system so that it can be more effective. Some would argue that it is the job of those responsible for delivering services to support this type of research. Others argue that there is research that is absolutely essential to this type of work that would never be funded by an agency responsible for services, or that there is a portion of the work that is not applicable to any one or even a group of agencies (but is relevant to the system as a whole), and therefore no agency delivering services would fund it either. Recent Canadian thinking (Hurley et all, 1999) suggests there are three dimensions which help to differentiate types of HSR. These dimensions are:

1) the time horizon for the research
2) the initiator of the research (investigator, joint, user)
3) the nature of the research question (methods, conceptual, applied).

No one would argue that a short-term, user-initiated and applied question should be funded by the user. Funding for the other types of research garners more debate.
.

Recommendations/ Directions for Action

The HSR subgroup identified three goals (and recommended actions) which we believe are important steps in moving HSR forward. These three goals were considered in the development of the six recommendations of the Research Working Group, and are congruent with the overall recommendations, while providing more specifics with respect to actions. The HSR subgroup has reflected on the six overall recommendations and provides comments in Appendix 5. The goals and recommended actions of the HSR subgroup follow:

Data

1. *Goal: Have good quality administrative data available and accessible to qualified Health Services Researchers.*

Actions:

- Support activities of Canadian Coalition for Cancer Surveillance. This initiative exists to enhance and enrich the national cancer surveillance system. Fundamental to its efforts is the attempt to define a minimum clinical data set that

would be captured by all provinces and 'rolled up' to the Canadian Cancer Registry. The data under consideration includes staging information.
- In collaboration with other research funders and those who use administrative data for research purposes, create a national task force to make recommendations with respect to standards and guidelines for access to secondary data which enable research that benefits society, while protecting the privacy of individuals.
- Make publicly available a subset of administrative data for analysis and teaching purposes.

Personnel

2. *Goal: Support the development of a healthy, vibrant and productive community of health services researchers in Canada who contribute to improvement of cancer outcomes in the country.*

   Actions:

   - That an initiative, jointly sponsored by CAPCA, NCIC, CHSRF and provincial governments be created for the purposes of determining strategic directions and areas of priority to the country in cancer health services, and in providing core funding to enable the growth of a HSR community that can effectively provide evidence to enhance decision making. We should build on the organizational learning that has taken place within the cancer community in the establishment of joint research initiatives such as have happened with respect to breast cancer, prostate cancer and tobacco use. The focus of this initiative should include (but not be limited to) strengthening the human capacity of HSR, enabling interdisciplinary groups of researchers and users, and ensuring that existing research knowledge is used within the system.
     - Consideration be given to the establishment of career renewal awards. HSR requires the active involvement of those who understand the system very well, and often they are practitioners. HSR also requires the involvement of individuals from multiple disciplines. This is seen to be a 'short term' solution to increasing the number of people engaged in the enterprise. It in essence, is a 'side ways' award, enticing individuals to change the focus of their days,, either from service delivery into research, or from disciplinary research in other substantive areas toward a cancer focus.
     - Provide incentives for interdisciplinary teams involving research among various aspects of the cancer provider community, and also among researchers working in other health related areas or disciplines.
     - Develop a strategy for ensuring Canadians benefit from existing knowledge about what works along the entire spectrum of the cancer experience from prevention to death.
     - Learn from other Canadian groups who have established international reputations in HSR (although not necessarily cancer)…

- Assess how to provide the 'human capacity' to do HSR dealing with administrative databases as they become more accessible.

- In the short run (within 18 months) host a national conference on HSR in cancer (begin to build this 'community')

Facilitating Inter-Provincial Research

3. *Goal: That research involving several provinces or being national in scope be feasible and not unduly burdened by numerous ethical and scientific reviews.*

   Action:
   - In collaboration with research funders and those doing multi-site health related studies, create a national task force to make recommendations with respect to standards and guidelines for ethical review related to research projects that involve access to records or individuals in varied jurisdictions across the country.

Topics/ Domains where Research is Required

The list of areas where researchers and decision makers feel more attention is needed are varied and are listed in Appendix 4. Although there were many specific areas mentioned, in a general sense, the overriding question to be asked is "Are Canadians receiving timely access to cancer services of high quality and achieving optimal outcomes?" While many specific areas were identified, there was convergence around four themes:

1) more HSR is needed across the spectrum, but prevention and screening, primary care, palliative care, and access to care were recurring topics
2) assessing the impact of varying organizational delivery systems
3) the importance of economic analysis (particularly if done within an environment that enabled use of the information)
4) a continued and increased effort on capitalizing on the cancer data system which exists in Canada, and in encouraging development in that area.

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Appendix 1: Individuals Providing Input

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Appendix 2: Definitions – Health Services Research

- Health services research is the use of the scientific method for acquiring information that can be used for rational decision –making in the management of the health and the health care system. It is ultimately concerned with improving the health of the community by enhancing the efficiency and effectiveness of the health system as an integral part of the overall process of socioeconomic development. (Alberta Heritage Foundation for Medical Research 1997)

- A multidisciplinary field of enquiry, both basic and applied, that examines the use, costs, quality, accessibility, delivery, organization, financing, and outcomes of health care services to increase knowledge and understanding of the structure, processes and effects of health services for individuals and populations"(Institute of Medicine)

- A field of enquiry using quantitative or qualitative methodology to examine the impact of the organization, financing and management of health care services on the access to, delivery, cost, outcomes and quality of services (Association for Health Services Research, 2000) (Efficacy studies and demonstration projects are excluded).

- Health services research examines the effectiveness of health services, the outcomes of accepted procedures, and variations in service delivery patterns and population health outcomes. The ultimate goal is not only to generate useful new knowledge but to put that knowledge to work in ways that improve health services financing, organization and delivery. (With respect to Health Services Research Foundation. MRC Website 1997)

- Health services research is a field of enquiry (not a discipline); it is driven by the questions and issues encountered by those working in field (more mission than curiosity oriented) ; is more concerned with effectiveness issues than efficacy; is arising from a paradigm other than biomedical and it is concerned with the use of the research by those working in health care. Therefore, it is more of a process than a product (Lomas 2000)

- The integration of epidemiologic, sociologic, economic, and other analytic sciences in the study of health services. Health services research is usually concerned with relationships between need, demand, supply, use, and outcome of health services. The aim of the research is evaluation, particularly in terms of structure, process, output, and outcome. (From Last, Dictionary of Epidemiology, 2d ed)

- The investigation of the health needs of the community and the efficiency and effectiveness of the provision of services to meet those needs (MRC (UK) 2000)

Appendix 3: Current Research in Health Services Related to Cancer in Canada [2]

- Descriptive work showing systemic problems with access to radiotherapy across country; marked inequities in access to care among different regions of the same province and among different age groups; interregional variation in treatment of cancer with surgery and radiotherapy. (Nature of data means you can't assess appropriateness of care, nor make recommendations for interventions).
- Linking patterns of care with outcomes (Quebec study on local recurrence according to wait times for breast radiation post lumpectomy).
- Studies (using registry data) that predict the future burden of cancer.
- CBCRI funded several grants in health services e.g. randomized trial of follow up strategies for breast cancer; An evaluation of patient and caregiver needs; Utilization of supportive care by women with breast cancer; Analysis of waiting times for surgery. Many of these were as a result of a special competition held in 1996.
- Costing and economic evaluation
- Comparison of initial management of node-negative breast cancer in two provinces.
- Descriptive research about things such as radiotherapy waiting lists and geographic variations in service in Ontario has been done. This research has focused on illuminating what may be wrong, rather than providing information about how to improve the situation.
- There have been projects in the utilization of complementary and alternative therapies
- Record linkage studies between cancer registry data and other administrative databases (BC)

Some Groups doing Health Services Research:

- Practice Guideline work in Ontario and in Canadian Breast Cancer Initiative
- Radiation Oncology Research Group (Queen's University, Kingston)
- Ontario Clinical Oncology Group (McMaster)
- ICES, Ontario
- CHSPR (BC) Group Patterns of Care
- Supportive Cancer Care Research Unit (McMaster)
- Health Analysis and Modeling Group, Statistics Canada with clinicians in Ottawa
- NCIC Clinical Trials Group. Working Group on Economic Analysis

[2] This list makes no claim to be inclusive, but rather to provide a sense of the range and types of health services research related to cancer.

Appendix 4: Areas Requiring Research in Health Services

For any given health issue (e.g. tobacco use) at which level of the system (individual, small group, community, population) are interventions more effective? In addition, what is the synergy between actions at multiple levels?

How can knowledge from behavioural sciences (e.g. with respect to salient messages for a particular age group) be incorporated into public policy with mass media campaigns, for example? (What are the effective models that ensure transfer and uptake of research knowledge?)

How can information technology be used to deliver services that are effective and accessible, and that enhance health behaviour or delivery of health services?

How quickly will findings from Ontario that 3 weeks of radiotherapy for breast cancer in women with conservative therapy provide equivalent results to 5 weeks be translated into Clinical Practice Guidelines, and subsequently into practice patterns? What are the factors influencing that uptake?

Waiting lists.

How do we improve the organization, delivery, efficiency and effectiveness of cancer services in Canada? How does the nature of the relationship of cancer agency with regional health authority impact the outcomes and efficiency of cancer services.

What is the impact of changing demographics of workers (baby boomers, health care providers choosing balance over excessive work) on the organization and delivery of health services.

More emphasis needed on effectiveness and efficiency questions

Population studies valuable because of our single payer system.

Develop meaningful measures of outcomes e.g. customer satisfaction, process quality so that we can begin to measure what we get for our investment in health care.

Compare effectiveness/ efficiency among diseases… develop disease-by-disease scorecards.

Need ‘translational’ research that takes epidemiological findings (basic findings) into behavioural research initiatives (clinical trials), and then to prevention programs (analogous to clinical programs).

Encourage and evaluate prevention programs that integrate several prevention approaches at once (legislation, community participation, public education, physician education, etc.

Most important short-term research is in providing information about outcomes analysis. How do different payment environments (public versus private) affect outcomes?

Build on strengths of databases in this country.

How does how we organize care affect what is going on? (And don't limit look to cancer…)

Cross provincial studies are very important. How does access to cancer and symptom control drugs vary among provinces?

How has the shift to community care affected access to cancer drugs? What is the most effective way to pay for drugs within the system?

Do alternative therapies belong in a publicly funded system? What role should alternative practitioners play?

Development and evaluation of strategies for the dissemination of treatment guidelines needs to be a high priority for the future.

Intervention studies needed!! Test different ways of modifying medical practice, and different ways of managing cancer programs.

Primary care – including for prevention, screening and palliative care, and not only within the treatment system.

Palliative care – for ethical reasons alone, palliative care is of special importance for cancer control.

Study the various predictors of outcomes: type of care, models of care delivery, costs, public versus private, professional versus volunteer (across all stages.. prevention to palliation).

How to enable evidence based decision making in real time.

Need to agree on a minimum data set so that monitoring/surveillance is possible.

Need to understand the role of family members in providing care.

Evaluate the different weight of equity, efficiency and individual liberties on the decision making and the influence on the other two when one is privileged, and consider the differences in systems which differ on public /private mix.

What is the nature of the value (and limitations) of integrated systems.
Integrate health services research about cancer with other chronic diseases. Don't isolate.

Better transference of knowledge (including establishing a clearinghouse).

Cost effectiveness and cost utility of various treatments.

Notes from Decision Makers' Responses

Impact on health care costs of preventative services.

Tobacco control research

Impact on caregivers of providing at home care for dying.

How to maintain adequate access to services (including screening, diagnostic and treatment)

How to move to more ambulatory and home centred care, while maintaining or improving outcomes.

Research on prevention strategies, population screening, supportive and palliative care.

Cost effectiveness research related to treatment options.

Factors affecting access to care.

Relationship of resource allocation to outcomes.

Need to have a high level framework within which to conduct economic research, and need for incentives for change in practice.

Better understanding of the contribution of an organized cancer system to the quality and effectiveness of cancer care delivery

Need to better understand competing values systems; need to address through research, not rhetoric!

In the 'natural experiment' that is Canada, do comparative, evaluative studies using 'benchmarking' approaches

Address issue of duplication in the expensive process of guideline development.

Which variables predict success of screening programs?

How to organize treatment services to reduce waiting lists and improve access to care:

Incorporation of recommendations from body of scientific knowledge into clinical guidelines re screening.

Dissemination of information on best practices in the area of prevention.

What is the impact of distance to cancer care/diagnostic services on service utilization and morbidity/mortality outcomes.

Research on ‘trade offs’ between quality and length of life.. how do people feel?

Access to treatment,

Identify optimal organizational models that identify the factors or conditions for success in setting up these models.

Relationship of outcomes to accessibility/availability of services, effectiveness of community based/at home treatment, consumer evaluation of service, effectiveness of prevention strategies.

Research into the cost of cancer to families.

Cost of treating various types of childhood cancer.

Impact of pediatric cancer on family and community.

Cancer prevention.

Effectiveness of outreach programs.

Economic evaluation and systems research.. how do we connect the pieces of the system?

How do we bring patients and families into the research enterprise? (get it out of hands of scientists)

Appendix 5: Comments Relating Health Services Research Subgroup to the Six Recommendations of Overall Research Working Group

The Research Working Group (with input from all the subgroups – clinical, palliative care, basic, health services research, socio-behavioural, translational, prevention) developed six recommendations that capture the key elements arising from the working groups. Following are comments of the HSR subgroup which help to link the work of the subgroup with the overall recommendations.

The recommendations are listed in priority order.

1. **Increase research funding to position Canada as a leader in cancer control**
   Financial resources to support research are THE key lever in moving forward. There are some unique opportunities within Health Services Research to examine the impact of such things as the impact of varying models of service delivery, using existing and improving data resources, which would be of great interest internationally.

2. **Aggressively address the human resource crisis**
   This is critical in health services research. There are very few individuals or groups in Canada engaged in health services research, and personnel development was one of three goals of the HSR subgroup.

3. **Foster funding mechanisms to promote breakthroughs and interdisciplinary research**
   Two specific actions recommended by HSR subgroup involved funding mechanisms which would foster interdisciplinary research. First, the creation of a joint initiative involving key stakeholders in the country to determine strategic priorities in HSR is seen to be a key action to enable the achievement of this recommendation. The second action recommended was the hosting of a national conference in HSR in the next 18 months. This is essential in HSR as it is very much an 'emerging' field, and as yet, there is no cohesion or even knowledge of one another across the country.

4. **Champion national priorities for cancer control research**
   A national conference in HSR is one venue through which to look at priorities within this area, and also to take stock of the interests and expertise of various individuals across the country, and to enable researchers and decision makers to connect with one another.

5. **Establish a national information resource through a framework of national standards for data collection related to patients and populations**
   All of the goals identified by the HSR subgroup referred to the issue of information resources one way or another: a concerted effort to ensure that data collection and surveillance systems under development enable research; building human capacity to use databases effectively, and facilitating inter-provincial research.

6. **Establish a national voice for Cancer Research**
   Although this aspect did not come up specifically in the deliberations of the HSR subgroup, a national voice of interested Canadians may well be effective in helping to achieve some of the goals which are essential to HSR, such as enabling research that happens in multiple jurisdictions, and facilitating access to data for secondary analysis.

Appendix D: HR & Infrastructure Subgroup Report

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A. APPROACH TO DATA COLLECTION

The resource subgroup of the CSCC Research Team has attempted to survey the resources available for cancer research in Canada. The data presented here is by no means exhaustive, but rather represents a snapshot of cancer-related resources. The approach to gathering such information has been to request relevant data from a number of organizations across Canada that support cancer research. The organizations contacted include: National Cancer Institute of Canada (NCIC); Medical Research Council of Canada (MRC); Cancer Care Ontario (CCO); McGill Cancer Centre (MCC); Fonds de la Recherche en Sante du Quebec (FRSQ); Alberta Heritage Foundation for Medical Research (AHFMR); Cross Cancer Institute (CCI); Southern Alberta Cancer Research Centre (CACRC); and the BC Cancer Agency (BCCA). The primary contacts for each organization are listed on pg. 11. The above the organizations were contacted for input on the following categories:

1. Total number of cancer investigators (breakdown into broad classes if possible)

2. Funding for cancer research and support
    - Cancer research (operating grants and major program support)
    - Infrastructure support (career support, raining awards, equipment awards. construction/building and renovation)
    - Network support
    - Industry dollars

3. Future directions for cancer research in Canada
    - brain drain
    - retention of highly qualified faculty
    - recruitment of young students into science, and especially cancer research
    - novel funding mechanisms that might stimulate multidisciplinary research

B. CURRENT PERSONNEL INVOLVED IN CANCER RESEARCH

The total number of cancer investigators in Canada is estimated to be around 2000. The current NCIC database includes 1,637 individuals who have been applicants or co-applicants in successful grant applications over the past five years. In addition there are 501 physicians in Canada who participate in conducting clinical trials through the NCIC Clinical Trials Group based at Queen's University in Kingston, Ontario. The MRC database lists approximately 650 investigators involved in cancer research, but it is expected that the majority of these have also received funding from the NCIC. In addition to the 1600 successful investigators in the NCIC database, there are 2400 investigators who were unsuccessful applicants; many of these unsuccessful applicants likely have also been successful, so we can estimate that there are perhaps and additional 800 (difference between 2400 and 1600) scientists interested in cancer research in

Canada. We were unable to breakdown the interests of these investigators any further than indicated above.

We did not attempt to determine the number of cancer investigators employed by the pharmaceutical/biotech industry in Canada.

C. FUTURE NEEDS FOR CANCER RESEARCH PERSONNEL IN CANADA

It is difficult to obtain an accurate estimate of the future personnel needs in Canada. For many years, Canada has produced fewer scientists and engineers than most G7 countries. In addition to this low production rate, Canada, like other countries, faces the need to replace large numbers of scientists and engineers during the next decade because of the aging of the faculties in Canadian Universities and research institutes. The AUCC estimates that during the next decade, Canadian Universities will need to replace 16,000 faculty members. If the proportion of the population going to universities increases as expected, even more faculty will need to be hired.

In addition to these pressures on finding new faculty, the recent restructuring of the medical care system has eroded the time that clinician investigators have available for research. This time limitation limits the amount of clinical research that can be done and consequently slows the application of new knowledge into effective new interventions to improve the health of Canadians. Although all university and hospital administrators acknowledge this problem, no one has yet generated an estimate of the number of physician scientists needed to sustain an effective health research (or cancer research) enterprise in Canada.

D. RESEARCH FUNDING FOR CANCER RESEARCH IN CANADA

In 1999-2000, the NCIC provided $54.4 million in research support. Of this amount $49.7 million directly supported research with the remainder going to support training, career awards and networks. In the same period the Medical Research Council spent $42.5 million on cancer research. Of that amount $30.2 million went to direct support of research, and $12.3 million was spent on training, career awards and networks.

The $97 million spent on cancer research by the NCIC and MRC represents by far the vast majority of cancer research funds available in Canada. Modest amounts of cancer research money are provided by the FRSQ, AHFMR, other cancer voluntary agencies and by the various provincial cancer agencies in Canada. In total we estimated that there is approximately $120 million per year available for cancer research in Canada through competitive granting mechanisms.

It is difficult to obtain an accurate estimate on industry spending on health research. Statistics Canada estimated that industry provided approximately $600 million in health research funding in 1998. Other estimates have ranged as high as $2.6 billion in 1999

(includes venture capital). If we assume that there is at present at least $1.2 billion in industry/biotech funding for health research, and that 20% of this money goes to cancer research, then there could be an additional $250 million available from the private sector for support of cancer research.

E. COMPARISON WITH FUNDING FOR CANCER RESEARCH IN THE UNITED STATES

Comparisons with the US are difficult because the nature of the funding for research is quite different. In addition to funding operating grants, the National Institutes of Health also support a large intramural research program, provides substantial overhead on almost all grants, and allow a portion of investigator salaries to be included on grants. In 2000-2001, the U.S. NCI will have a budget of approximately $3.8 billion dollars ($5.6 billion Cdn). However, only 70% or $2.7 billion goes for extramural grant support (Cdn$ 4.0 billion). According to NIH figures the average indirect costs in 1998 were 32%. Correction for indirect costs gives $1.8 billion for grants (Cdn$ 2.7 B).

In addition to the large amount of federal government funding in the US, another major difference is the relative lack of funding from the non-profit community. In Canada, voluntary agencies contribute as much to health research as the government. In the US, voluntary agencies contribute only 15% of the total government support. Therefore, we could estimate that in 2000-01, US cancer researchers will have access to $0.8 billion (15% of $3.8 billion NCI budget) or Cdn$ 1.2 billion. Adding these figures, we estimate that US cancer investigators have access to Cdn$ 3.9 billion annually in competitive grants for supporting their research.

If we use the usual 10:1 ratio in comparing US and Canada, the simple calculation would suggest that Canada should be spending $390 million on cancer research in 2000-01. In contrast, we estimate that the total available for Canada in the 2000-01 fiscal year will be $55 million from NCIC, $75 million from CIHR (15% of total budget, approximately usual amount spent by MRC on cancer research), and approximately $25 million from other sources for a total of $155 million for cancer research.

F. OTHER COMMENTS FROM RESPONDENTS

Big Picture

- need a cancer-related evaluative unit that would assess service delivery outcomes
- must learn to consistently apply existing knowledge base
- challenge is in translational research (from bench to bedside)
- consider strategies that would provide funding for large global projects which show potential for significant breakthroughs
- implement life sciences approach to cancer research (i.e. transdisciplinary rather than just interdisciplinary)

Resources

- support needed for late stage pilot studies that test novel approaches for improvement of cancer control
- NCIC might sponsor lobbying effort to government to consider indirect costs for Canadian research
- funding for clinical trials do not currently address new treatment methods
- need special funding for clinical scientists
- more support for experimental pathology to ensure movement from gross/microscopic analyses to molecular approaches
- make wages more competitive with US (e.g. AHFMR is enhancing salaries with market supplements valued at $10K/yr for AHFRM awardees in the first five years of their appointment, and $20K/yr for those beyond five years)
- narrow the gap between Canadian and US funding for research (Canadian research enterprise is about $1/10^{th}$ the size of the US)

Brain drain, faculty retention & recruitment

- establish young investigator award with start-up funds for post-doctoral fellows to encourage them to return from the US
- current initiatives that are driven by need to build capacity and retain Canadians should also target specific areas
- foster interdisciplinary cancer programs
- address space limitations for new recruits
- initiate summer programs for high school students in cancer research areas
- increase graduate training programs and special MD fellowships for oncology training and support for MD-PhD students in cancer labs or projects
- foster NCIC partnerships with Canada Research Chairs to establish Cancer Chairs
- improve marketing by universities and also to the public via the CCS
- expect 20% growth in student enrollment
- the ageing of Canada's professorate means a greater number of faculty will need to be replaced shortly
- to maintain acceptable level of quality, an estimated 2500-3000 new faculty will need to be hired over next 10 years

F. PRIMARY CONTACTS AND RESOURCES

Robert Phillips,
Executive Director, NCIC

Mark Bisby,
Director, Programs Branch, Medical Research Council

Roger Deeley
Head, Division of Research, Cancer Care Ontario

Abe Fuks
Dean of Medicine
McGill Unversity

Luc Deschenes
Director General des Affaires Medical et Universitaire
Ministere de la Sante et de Service Socio

Josee Charest
Research analyst, FRSQ

Matthew Spence
President and Chief Executive Officer
Alberta Heritage Foundation for Medical Research

Carol Cass
Associate Director of Research, Cross Cancer Institute

Randal Johnston
Director, Southern Alberta Cancer Research Centre
Faculty of Medicine, University of Calgary

Don Carlow
President & CEO, BC Cancer Agency
"Future of Cancer Research", Feb. 2000

Mamoru Watanabe
Professor Emeritus of Medicine, Department of Medicine, University of Calgary

NCIC Research Report, 1999

James Till, Report of the National Task Force on Personnel, National Cancer Institute of Canada, January 1992

Leanne Elliot
Policy Analyst, Research and Policy Analysis, Association of Universities and Colleges of Canada. "Revitalizing universities through faculty renewal", Research File 2000 Vol 4 (1)

Enriqueta C. Bond
Burroughs Welcome Fund
"The Role of Philanthropy in Medical Research", presentation at the 2000 Gala celebrating the MRC.

Appendix E: Medical Imaging Subgroup Report

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1. What are we doing now?

Canada has a well-established reputation in the development of imaging technologies as applied to cancer. There are significant publication in the areas of ultrasound, magnetic resonance, digital radiography, image verification and MR spectroscopy. There is some research on PET and nuclear medicine imaging for cancer but this is less well developed. From a broader perspective, there is significant development beginning in optical imaging such as, bronchoscope and interstitial tissue spectroscopies.

This research is located in only a few major centres in Canada, such as, Toronto, MNI, London, and Vancouver.

2. How well are we doing it?

In some areas of the technical development of medical imaging for cancer, we have a highly visible and a recognized worldwide presence. Probably the best example is digital mammography where researchers in Toronto coordinate the whole North American effort. MR imaging of breast is also well recognized. The use of MR for cancer diagnosis, staging and tumor characterization is another recognized area of Canadian leadership. Finally, the use of imaging for verification in radiation therapy is known worldwide.

What we do not do well is translate the technical developments into clinical practice. Reasons for this will be discussed subsequently. Very often the technical imaging research, which is done in Canada is applied to cancer problems in the United States or elsewhere.

3. Horizon scanning

There is a growing worldwide interest in the increased role of imaging for cancer. The NCI-US has designated $50M of tobacco money exclusively for imaging development for cancer. No similar expanded budget has yet been identified in Canada.

Some of the new development and possibilities in imaging that are attracting this attention include:

- Direct image guided treatment such as MR guided surgery, image-guided thermal or cryotherapy, and more minimally invasive forms of tumor ablation. Such treatment will have an expanding role in palliative care.
- A growing recognition that imaging can be used for more than just anatomical definition of tumors. It can provide significant information about the physiology and individuality of patient tumors; for example, imaging techniques are being developed for the measurement of oxygenation status of tumors, angiogenesis assessment, mechanical and elastographic properties of tumors, etc. There is a growing recognition that quantitative imaging can provide important additional information about the state of the tumor, which is beneficial, for either the initial treatment plan or follow response to therapy.
- Another new area on the horizon is the development of molecular imaging where imaging is used to highlight or identify specific molecular or genetic markers and the expression of genes in developing tumors. There is the strong belief that the development of this form of molecular imaging will be a necessary component to any form of gene therapy or manipulation.
- There is an opportunity to effectively use imaging for screening targeted high-risk groups (genetically predisposed).
- Finally, there is a growing recognition of the importance of imaging in the genomics research at the animal level. This has a long-term impact on the cancer problem as well as many other diseases.

4. Barriers?

The major barrier to the impact of imaging research in Canada on cancer is the problem of translation to the clinic. Most cancer treatment centres in Canada do not have sufficient access to imaging technology and services to even provide the necessary basic support for the clinical operation. These is partly due to the fact that imaging is usually a purchase service from some other institution which has many competing demands on its imaging activities.

Even if time where available, there are very few medical imaging clinicians that have both an interest in cancer and in research. The lack of academic radiology effort tied to the cancer problem is a major bottleneck.

5. What should we be doing?

a. Cancer imaging and its development should be seen as integral part of cancer management with sufficient resources and political will dedicated to cover the necessary service imaging component for cancer and then additional resources and effort to push forward the clinical research application of cancer imaging.

b. A program to train oncological imagers for cancer imaging research should be implemented and some mechanism other than simply funding put in place to ensure such individuals carry out a research mandate. This probably requires alternate payment schemes and tighter affiliations between oncological imagers and cancer treatment centres.

c. Research and cancer service agencies need to be prepared for the high developmental costs of things like image-guided therapy. This requires dedicated equipment; complex teams of personnel and initially relatively slow throughput as the techniques are worked out. Because such an enterprise is a combination of research/development and care, it often falls between the cracks in budget planning.

d. Specific budgets at the national level need to be identified for technological development. This is not hypothesis driven research nor is it technical development which will be carried out solely by industry. The profit margin is minimal in cancer therapy and diagnostic equipment. Thus, a national program in concert with industry that specifically targets the technical development of image related procedures for cancer needs to be put in place. After demonstrations of the effectiveness of such technical developments have been established, the health care system then can be prepared to absorb innovative treatment strategies.

e. There needs to be a commitment to fund research in innovative uses of imaging specifically for tumor characterization. As novel therapies are being development that target various aspects of tumor development, new imaging techniques will need to be worked out to monitor the effectiveness of these therapies. Anti-angiogenesis treatments are a good example in which one would like to monitor efficacy with something more specific than simple tumor regression. Imaging research to develop such measurements is needed.

R. Mark Henkelman, Ph.D.
June 19, 2000

Appendix F: Palliative Care Subgroup Report

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Introduction

***Definition**:* Palliative care, according to the World Health Organization, is the "active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is to achieve the best quality of life for patients and their families. Many aspects of palliative care are also applicable in the course of the illness in conjunction with anti-cancer treatment." "Terminal care" refers to care delivered at the end of life and reflects only a portion of all of palliative care.

Background: The primary source document for this report was the "Canadian Agenda for Research in Palliative Care: A report from the National Research Advisory Committee of the Canadian Palliative Care Association" (March 31st, 1999). This National Agenda was funded by Health Canada, and was assembled by a committee consisting of leading palliative care researchers in Canada, and consumer representatives, organized under the auspices of the Canadian Palliative Care Association (CPCA). Background material for the development of the research agenda included the following: 1) review of the palliative care/end of life literature - with an overview of Canadian content - highlighting gaps and priorities; 2) interviews were conducted with family and professional care givers regarding significant issues requiring research attention; focus groups were conducted both in English and in French; 3) an analysis of the current funding for palliative care research in Canada was conducted; this included a national

survey of key researchers in the field as well as obtaining data from major Canadian grant funding agencies.

More than 210,000 people die each year in Canada. According to estimates from the National Cancer Institute of Canada: Canadian Cancer Statistics 2000, cancer will account for 65,000 deaths in the year 2000; lung cancer will account for 17,700 deaths; breast cancer 5,500; colorectal cancer 6,500 deaths; and prostate cancer 4,200 deaths. The deaths/cases ratio for all cancers is estimated to be 0.49. These figures can leave no doubt that the Canadian Cancer Control Strategy must encompass the needs of the dying, and an awareness that for many patients, death will be the final outcome of the course of their cancer. Most of these patients will require health care services, and research in palliative/end of life care will ensure quality care for them and their families.

Palliative/end of life research can be distinguished from biomedical research in several ways. While the latter focuses on the discovery of fundamental mechanisms that could lead to a development of new treatments for a disease, palliative care research focuses on these mechanisms as well as the illness experience of the individual and their family. Palliative care research must be inclusive of the broad spectrum of biopsychosocial issues, aimed not only at studying the disease itself but the experience of the people who are journeying through this disease and its treatment, and the meaning of these events to the individual, family and community. Unlike traditional biomedical research, which is typically focused on the issue of cure, palliative care research involves the quest for new ways to alleviating suffering when cure is no longer possible.

What are we doing now?

Several general areas appear to dominate Canadian palliative care research, as reflected by the findings of the literature search conducted by the National Research Advisory Committee of the CPCA. These include:

1. mortality and survival associated with treatment and/or disease progression
2. the nature of the facilities and services related to end of life care
3. attitudes, opinions, knowledge and belief of health care providers
4. practice patterns of health care providers
5. decision making regarding end of life care
6. cost effectiveness of programs, services and treatments
7. the attitudes and experiences of patients and family members
8. pain and symptom etiology and therapy

The quality of the research being done is variable, depending on the experience of the investigator(s). Most palliative care research in Canada has been conducted by a small cadre of investigators, funded either by local sources or small operating grants targeted at

specific projects. In spite of that, Canadian researchers have had success in a number of diverse areas affecting end of life care. For example:

- The development and application of the subcutaneous routes for fluid and drug administration has transformed and simplified the ability to care for dying patients in their home setting.
- Studies of desire for death and its association with pain and depression in dying patients provided important information guiding Canadian Health Care Policy.
- The development of measures of family satisfaction with care and quality of end of life in the dying provided a rational basis for evaluating the effectiveness of different approaches to delivering health services in this population.

How well are we doing it?

Reports from Cancer 2000, the Senate Special Committee on Euthanasia and Assisted Suicide (1995), and NCIC sponsored workshops on palliative care have had limited impact in stimulating the development of palliative care research in Canada. While Canadian researchers have made significant contributions to palliative care research, they have been hampered by a lack of a critical mass of investigators, and the absence of dedicated funding for this type of research. Despite this, there does appear to be a strong, albeit small cadre of successful end of life care researchers in Canada.

The existing Canadian research infrastructure, however, is currently inadequate to ensure the timely production of useful knowledge, with the funding of research projects and personal being inadequate. Large sample size, multi-centered trials appear to emanate largely for the United States. Canada has clearly fallen behind the United States, where private sector funding (such as the Soros Foundation, Project on Death in America; Robert Wood Johnston Foundation) and Federal funding (The National Institute of Health) have seen palliative care research and scholarship make major, recent unprecedented strides.

Horizon Scanning

With the aging of the Canadian population and the rising cancer mortality rates, providing quality end of life care will become even more of an imperative. This will only occur if research in this area is able to develop a sound, empirically base knowledge base upon which excellent care can be informed and provided.

A Canadian palliative care research team recently received modest funding to enable some collaborative work amongst Canadian palliative care researchers (Cohen R et al. Improving quality of life and informing social policy in palliative care. Socio-behavioral Cancer Research Network Team. Centre for Behavioral Research and Program Evaluation, Canadian Cancer Society/National Cancer Institute of Canada). To expedite work in this area, collaborations of this kind will be necessary in order to rapidly generate knowledge that is sensitive and responsive to the needs of dying Canadians.

Barriers

- There are very few senior, experienced palliative care researchers in Canada. This makes it difficult to attract and develop the next generation of appropriately trained and mentored palliative care researchers.
- The existing Canadian research infrastructure is inadequate to ensure the timing production of useful knowledge. In particular the funding for research projects and personal is inadequate.
- Palliative/end-of-life care research has major methodological challenges. Current research training programs in research ethics guidelines are insufficient to address these problems successfully.
- Prior to the setting of the Canadian Agenda for Palliative Care Research, there was no agreed upon agenda of research priorities. This has hampered efforts to develop coherent, multi-centered trials under a single funding umbrella.
- There is profound cultural and social diversity in Canadian society, which is not adequately reflected in palliative and end of life care research efforts.
- Many problems that contribute to suffering at the end of life, such as pain and cachexia-anorexia, have their genesis earlier in the course of illness. These issues receive little attention, particularly by those responsible for the early care of patients with cancers that will predictable take their lives; coordinated oncology-palliative care initiatives are uncommon.

What should we be doing?

A number of priority areas have been identified for targeted research. These include:

- Pain control and symptom management
- Quality of life/end of life decision making
- Service delivery (traditional/alternative)
- Psychosocial and spiritual support
- Information/tools/research methods or practices
- Public/professional awareness/attitudes/opinions
- Ethics in palliative care research

Recommendations

(These were largely drawn from the Research section of the Palliative Working Group's report, and vetted by representatives from that committee).

Goal:

1. To establish strong palliative care research programs integrated within Canadian cancer centres. In addition to the conduct of research, these centres will train

investigators who may successfully compete for support from national granting agencies. This requires the recognition of the ethical imperative for impeccable symptom control right from the time of a cancer diagnosis and throughout the course of illness. This goal will only be achieved with enhanced availability of funding for all aspects of end-of-life care research (see recommendation # 1-3).

2. To establish collaborative research linkages between centres, ensuring the success of multi-centre clinical trials. This will be greatly enhanced by the establishment of a national information resource for data collection related to patients and populations (see recommendation #5).
3. To ensure that the coordinated NCIC – CIHR programs reflect the need for capacity building in palliative care research. This could be achieved through sponsored research fellowships or scholarships, the funding of investigator initiated operating grants, targeted requests for proposals, new ideas grants, centers of excellence grants, infrastructure grants supporting clinical research units, and programmatic funding for senior investigators (both to conduct research and mentor trainees) [see recommendation # 2,3]. In addition to designated funds ear marked for palliative care research, dedicated palliative care research review panels would be established.

Specific Targets:

1. An approved program by NCIC-CIRH for dedicated funds for capacity building in palliative care (see recommendation #2,3). Evident by 2003.
2. Provincial cancer agencies establish strong palliative care divisions within each tertiary cancer centre. Evident by 2005.
3. Active palliative care research programs in most academic cancer centres. These programs would partner with cancer centres and community palliative care programs to develop collaborative end of life research initiatives (see recommendation # 4 – 6). Evident by 2005
4. A specific amount of funding should be dedicated by NCIC-CIHR for investigator-driven palliative care research (see recommendation #3). A dedicated palliative care review panel should be responsible for the review of grants in this sector. Evident by 2003
5. A strong multi-institutional palliative care research network should be in place. This network could form part of the NCI Clinical Trials program. Evident by 2005
6. A national working group should be established through CAPCA to see to it that these goals are actualized, guided by the 1999 Canadian Agenda for Research in Palliative Care. This could be facilitated through the process recommended to champion national priorities for cancer control (see recommendation #4). Ongoing process.

Anticipated Outcomes:

- Reduction of suffering of patients with advanced chronic illness will directly correlate with the overall level of support for palliative care research nationally.
- In addition to an enhanced quality of life for patients, optimal symptom control may also correlate with prolongation of life.
- Patient's whose symptoms have been successfully controlled through the application of therapies emerging from research, will utilize fewer medical services. They will remain independent for a longer period, with consequent improvement in productivity and maintenance of dignity.
- Cross-disease research initiatives will flourish, as palliative care research outcomes are highly relevant to advanced cardiac disease, renal disease, chronic obstructive pulmonary disease, the rheumatoid disorders, AIDS, and other chronic degenerative disorders of the aged.

Committee Members:

Drs. Harvey Max Chochinov, Neil MacDonald, Neil Hagen, Pierre Allard, Robin Cohen

Appendix G - Prevention Research Subgroup

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1. Scope of cancer prevention research

- etiologic research to identify underlying causes of cancer.
- intervention research to identify effective cancer prevention interventions – primarily primary prevention.

Etiologic Research

The main focus to date of etiologic research in Canada and internationally has been the identification of modifiable factors that increase or decrease the risk of cancer. These include:

- behaviours (e.g. diet, tobacco, exercise, alcohol, risky sexual practices, recreational exposure to sun)
- occupational carcinogens (e.g. asbestos, radon, benzene)
- microbiologic agents (e.g. EBV, hepatitis B)
- environmental carcinogens (e.g. dioxins, PCBs, pesticides, ionizing radiation)

> **Identification of modifiable causes of cancer is needed to develop primary prevention i.e. interventions aimed at preventing development of cancer.**

Recently, etiologic research has broadened to include the identification of inherited cancer genes that are not modifiable at present but may be so in the future through "genetic engineering". Major inherited cancer genes, however, only cause about 10% of cancers and minor inherited cancer genes have little impact without meaningful exposures to carcinogens. For example, major inherited cancer genes such as BRCA1/BRCA2 and RB1, respectively, confer substantially increased risks of breast/ovarian cancers and retinoblastoma. The prevalence of these genes in the general population, however, is very low (e.g. RB is present in about 3 per million children) and, in their inherited form, only account for a small fraction of cancers. Less direct evidence of the importance of non-inherited factors comes from observation of the large international variations in cancer incidence rates and the relatively rapid changes in cancer risks among migrants and their offspring toward those of the country of destiny.

Intervention Research

Primary prevention interventions

Research on interventions to reduce the risk of developing cancer has focused on behavioural interventions (e.g. methods to reduce smoking, improve nutrition/weight control, increase exercise) and chemoprevention (supplements of natural products such as β-carotene, vitamin C, selenium and use of synthetic products such as tamoxifen). The gold standard to date has been the randomized intervention trial design but these are costly and there is a growing recognition of the need for alternative research methods.

Early detection interventions
Randomized screening trials (RSTs) have established the efficacy of screening for breast and colorectal cancers. The efficacy of cervical cancer screening has been supported by the results of ecologic and case-control studies. RSTs underway include those aimed at prostate, ovarian, and lung cancers. Molecular biomarkers hold the promise of being able to detect cancer very early in development with the potential for treatment with minimal morbidity.

Related Issues
Other research areas relevant to cancer prevention interventions include policy research, evaluation research and cancer surveillance methods research. Evaluation research serves to assess the effectiveness of interventions at the population level i.e. after widespread adoption of intervention strategies. Surveillance methods development is needed to accurately measure the current impact of cancer, to measure progress in cancer control, to forecast future impacts and to generate hypotheses about the causes and management of cancer.

2. What are we doing in Canada?

Etiologic research

- Systematic approaches – There have only been a few attempts to conduct ongoing, systematic cancer etiologic research programs in Canada:
    - large-scale case-control assessment of potential occupational carcinogens among residents of Montreal (PI is Jack Siemiatycki)
    - large-scale case-control assessment of environmental and behavioural causes of cancer among residents of most provinces (collaborative program between Health Canada and provincial cancer registries that is no longer funded)
    - NCIC program to stimulate cancer etiologic research (a 5-year commitment initiated in 2000.

- *Ad hoc* studies
    - Most cancer etiologic research in Canada has been conducted in a relatively *ad hoc* manner. Although these studies have provided much useful information, many of the current research questions require a more systematic approach with large sample sizes, long-term follow-up studies and well-established multidisciplinary teams e.g. to have the statistical power and sophistication needed to detect the role of low-level environmental exposures such as electromagnetic fields, ionizing radiation, pesticides and other environmental contaminants.

    - Canada has developed computerized record linkage technology that is world-class but the capacity to fully exploit this technology is severely constrained by inadequate human capacity throughout the country. The national capacity, largely at Statistics Canada, is very slow and causes substantial delays in the completion of epidemiologic research studies dependent on this technology for follow-up of study cohorts.

Intervention research
There have been only a few population-based cancer prevention intervention trials in Canada, including:

Behaviour modification
- Reduced dietary fat/breast cancer (PI = Norman Boyd)
- Smoking prevention and cessation trials (not focused on cancer prevention but clearly relevant to this goal)

Chemoprevention
- Tamoxifen for women at high-risk of breast cancer (a few Canadian centers are participating in a trial or trials initiated in the USA).
- Use of sunscreens to prevent moles (British Columbia Cancer Agency) – note: about 50% of melanomas arise in preexisting moles
- The BC Cancer Agency has completed several Phase II lung cancer chemoprevention clinical trials and is one of only two NCI (US) Master Agreement Holders for Phase II clinical trials outside of the US.
- The BC Cancer Agency is also working on chemoprevention of oral cancers.

3. How Well Are We Doing?

Canadian epidemiologists have made significant contributions to knowledge of cancer etiology in these fields:
- tobacco
- occupation
- diet
- ionizing radiation
- sun exposure
- environmental contaminants

Research evidence produced by Canadian cancer epidemiologists has facilitated health policy development such as:
- national drinking water guidelines (chlorination disinfection by-products)
- environmental tobacco smoke
- the banning of saccharin
- occupational exposure standards

The funding allocated to cancer prevention research in Canada has been extremely limited. NCIC established a National Etiologic Research Strategy Task Group in 1997. This group investigated funding of cancer etiologic research in Canada and showed that NCIC provided a total of an average of $0.65 million per year in 1996/97 and 1997/98 for etiologic research. In 1997/98, NCIC awarded grants for etiologic research to only two researchers while ten etiologic researchers received grants from CBCRI. Over the 5-year period 1993-1997, MRC funded virtually no etiologic research.

The largest early detection study undertaken in Canada to date was the Canadian Breast Cancer Screening Trial involving some 90,000 women. Ecologic studies and a case-control study to evaluate cervical cancer screening programs have also been done in Canada. A major effort to undertake a randomized screening trial for prostate cancer was not successful in attracting funding even though two of the three potential partners approved funding. This illustrates the difficulty of mounting large-scale research in a laissez-faire research environment.

The budget of the US National Cancer Institute for the current year is $3 billion but the proposed 2001 budget is $4.135 billion (US) – the Canadian equivalent of these two figures would be $450-600 million (Cdn) per year. The US NCI budget does not include a breakdown that would identify their expenditures on cancer prevention research.

4. Horizon Scanning – Next 5-10 Years

- increased availability and use of genetic markers of susceptibility and biomarkers of exposure status in epidemiologic studies.

- rapidly aging population and rapidly increasing cancer case loads that may overwhelm the health care system – this may be further aggravated by increased costs of "high-tech" drugs for which Canadians will demand universal access. This will raise the priority of cancer prevention but too late to prevent major upheavals in the cancer care system.

- The US NCI recently identified these priorities for increased funding:

    - genes and the environment
    - cancer imaging
    - defining the signatures of cancer cells
    - molecular targets
    - research on tobacco and tobacco-related cancers
    - cancer communications

5. Barriers and Opportunities

Barriers

Capacity

- Relatively small number of senior, experienced cancer epidemiologists in Canada.

- Lack of funding for large-scale long-term studies/systems. Even if long-term funding were available, the current academic evaluation and reward system makes it difficult for a researcher to contemplate a research program that might not bear fruit (i.e. publications) for many years to come. This demands some "structural" modifications on where and how such research can be conducted, or it requires some modification of academic reward systems.

Privacy/confidentiality

- Overzealous legislation and regulation in the areas of privacy/confidentiality may make it impossible to conduct needed research.

Opportunities

- Canada is the only country in the Western Hemisphere and one of the few in the world with population-based cancer registries for the entire population and a comprehensive publicly-funded health care system. These attributes make Canada an ideal setting for conducting population-based long-term health research.

- When given the opportunity, Canadians have shown tremendous willingness and even desire to participate as subjects in health research.

- The implementation of CIHR should permit increased investment in training and career development opportunities for young cancer epidemiologists.

- Mechanisms to build and sustain inter-disciplinary and international collaboration would facilitate progress in areas which demand large-scale and/or high-tech approaches e.g. assessment of cancer risks in relation to gene/viral/environmental interactions, improved exposure assessment for a wide range of factors.

- There is an ongoing need and opportunity to develop and improve epidemiologic methods to strengthen epidemiologic research and the usefulness of the results of such research for policy development and programs related to cancer prevention.

6. Recommendations

1. Human Capacity

- The whole structure of epidemiologic training and research in Canada should be examined by authorities who have an interest in the existence of a vibrant, highly qualified research community in this area.

- Provide funding to train clinical fellows in cancer prevention and funding for clinical faculty to conduct chemoprevention/cancer prevention trials. Very few academics, especially junior faculty, would want to be involved in Phase III trials as there will not be any results for publication for several years. There must be some avenue for recognition of this type of work.

- Increase substantially personnel funding for PhD students in disciplines essential to cancer prevention research, particularly epidemiology, and operating funds for their studies.

- Increase salary levels for epidemiologic career scientists in Canada to slow down the loss of such scarce human resources to the U.S. because salaries are much higher.

- Strengthen capacities to conduct computerized record linkage at the local, provincial and national levels. This includes hiring new staff and training programs for existing staff in cancer registries, universities and government agencies. Enhancement of the Statistics Canada capacity is urgently needed to remove a major bottleneck in the conduct of epidemiologic cohort studies including research not only on cancer etiology but also on early detection and survival.

2. Infrastructure

- It is critically important for investigators to begin putting blood samples (or DNA and serum) in storage in order to be able to take advantage of the avalanche of information on polymorphisms that influence the risk of cancers that will become available in the next 5-10 years.

3. Facilitation and Coordination

- Encourage research which aims to elucidate the role of environmental agents in cancer etiology, whether they be of industrial origin, personal lifestyle habits, dietary, microbiological or whatever.

- Facilitate multi-disciplinary research.

- Implement long-term, large-scale follow-up studies (cohort studies) to investigate risk factors for common cancers by reducing the barriers and capitalising on the opportunities.

- Foster randomized prevention trials (including Canadian participation in international prevention trials).

4. Funding Mechanisms

- Funding agencies should invest in long-term (10+years) etiologic and intervention studies aimed at cancer prevention.

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Appendix H: Socio-behavioural Research Subgroup

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SCOPE OF SOCIOBEHAVIOURAL RESEARCH

Research itself is seen as a crosscutting theme within the Canadian Strategy for Cancer Control (CSCC) framework, and Sociobehavioural Research in turn cuts across the research working subgroups. Recent frameworks for cancer control (e.g. Hiatt, & Rimer, 1999; NCIC, 1994) highlight the relevance of sociobehavioural research across the full range of prevention, screening, diagnosis, treatment, rehabilitation, and supportive and palliative care with key themes like information and decision-making, risk communications, illness behaviour and adaptation, lifestyle change, and social support. A second dimension of particular interest to the sociobehavioural sciences is the knowledge transfer and uptake process. Sociobehavioural research has invested significant energy in recent years to better understanding and facilitating the dissemination, adoption, implementation, and maintenance process (Parcel, et al, 1990; Rogers, 1995). This interest spans from interventions at the individual, through practice, to population and community levels. The following overview particularly highlights dissemination as a key strategic priority for which sociobehavioural research has much to offer, but for which there is little awareness of this potential in the cancer control community broadly. Finally, there is increasing interest in applying sociobehavioural research to improve health services, in particular, the management of chronic disease (cf. Von Korff, et al, 1997; Wagner, et al, 1996).

In sum, sociobehavioural research priorities will be crosscutting and must be integrated with research perspectives such as health services research, community perspectives, palliative care, and population and prevention research. There will be less extensive but nonetheless critical ties to areas such as translational research (e.g. genetic counselling) and clinical trials (e.g. quality of life measurement).

In sum, the growing breadth, significance, and synthesis of the social and behavioural sciences has progressed to the point that the term "behavioural research" is being replaced by the more comprehensive term "sociobehavioural research", defined as:

> *Sociobehavioural research covers a wide range of research activities, including behavioural epidemiology, development and testing of theoretical models to understand health behaviour, prediction of risk-relevant behaviours, research to develop and evaluate interventions, evaluation of multi-faceted community interventions, research to analyze and evaluate the impact of policy and other environmental measures, knowledge synthesis and dissemination research. It has many levels of analysis, including individual processes, biobehavioural systems, interpersonal relationships and behaviour, organizational practices and macrosocial processes.*

So what are the unique foci for sociobehavioural research? There are at least four:

- **Health Behaviours**. Smoking, nutrition, lack of physical activity, sun exposure, and sexual activity leading to exposure to some viruses all are established as significant contributors to cancer. Sociobehavioural research is key both to understand the etiology of these behaviours, and to develop effective prevention and behaviour change programs. Of equal importance is the full range of behaviour across the cancer experience: What factors influence participation in and responses to screening programmes? How do people adapt to and cope with the cancer experience? What are the predictors of successful rehabilitation? How do families deal with the unique challenges of end-of-life?

  "Sociobehavioural processes" include not only the processes affecting individual consumer behaviour, but those characterizing practitioner and health systems behaviour too. For example, (a) patient-practitioner communication and decision-making research, and (b) policy research to understand, stimulate, inform, support, direct, and/or evaluate tobacco policy making, both fall within the purview of sociobehavioural research.

- **Psychosocial Factors in Illness Behaviour and Management**. In a similar vein but more comprehensively, the broad determinants of health perspective provides insights and tools for sociobehavioural epidemiology, underscoring the critical importance of social context for understanding health behaviour and change (Emmons, in press). Throughout the prevention and treatment continuum, psychosocial factors are key for risk communications (e.g. "the giving of bad news"), psychological distress as an impact and moderator of cancer treatment, individual and family adaptation and coping, the patient's ability to understand probabilities and treatment utilities, adherence to

screening and treatment protocols, pain management, and a host of fundamental cancer control strategies.

Again, organizational research is important. For example, we know more about the efficacy of primary care prevention ~ a range of preventive procedures clearly are efficacious and cost-effective ~ than we know about the effectiveness of these procedures in routine practice, or how we can enable increased implementation of and fidelity to these best practices. At a community level, we know relatively little about the interplay between community/system/policy factors and individual factors in determining personal health practices and service utilization.

- **Biopsychosocial Models of Cancer**. The past two decades have begun to develop a firm foundation of psychoneuroimmunology research that has important implications for understanding how cancer develops and progresses. There now are well-established links between psychological states and immunocompetence laying the foundation for cancer research to investigate psychosocial factors that might result in immunocompromise. Interactions between genetic and learning factors as expressed in risk behaviour (e.g. tobacco use) currently are of keen interest, underscoring the need for innovative approaches to transdisciplinary research (e.g. Abrams, in press; Kahn, & Prager, 1994).

- **Dissemination**. We know a fair bit about the predictors of cancer-relevant behaviour from survey research and epidemiological data. Much is known about basic principles of behaviour change. However, the pressing priority is for "translational research" that bridges between basic sociobehavioural science research and small, well-controlled studies, and applications at all levels (individual, small group, community, and population) within the cancer care structure. Recent reviews suggest that careful attention to how research findings can be disseminated can indeed lead to more effective clinical and other intervention practices (e.g. Hiatt & Rimer, 1999). Creating an alliance between sociobehavioural researchers and policy experts would represent an effective avenue for transferring the technology of sociobehavioural research to a source of genuine impact. One exciting area – sure to be a growth area – is the relationship between sociobehavioural research and new information technologies. There is a rapidly developing research literature on the use of new technologies to create and deliver effective sociobehavioural interventions to the public, that are powerful, efficient, proactive, tailored to the individual, and linked to the patient's past and future health behaviours, readiness for change, and other health-relevant information. Policy research is another growth area ~ one of shared priority for sociobehavioural and health services research.

Two case scenarios will illustrate the synthesis of these research elements:

Example 1: Workplace Smoking Cessation

Combining workplace policies with promotional campaigns in the workplace, smoking cessation services, and community interventions that support non-smoking as a community norm create synergies that magnify the effect of each intervention alone. Identification of the optimal mix of initiatives, and the process of effective implementation, requires research in policy development, organizational culture, individual motivation and skill for behaviour change, and program evaluation. It requires ongoing monitoring of behavioural risk factors and service delivery/outcomes at a community level. It may even extend to translational research on how genetic and sociobehavioural factors combine to influence dependence. Unexpected disciplines like law, political sciences, community planning, information technology, adult education, economics, and geography become critically important. New, more challenging methods for synthesizing research findings are needed to support evidence-based program planning, decision-making, and resource allocation.

There are compelling reasons for multiple intervention programs in community health. The use of for multiple intervention programs has emerged from a growing understanding of multi-causality; the unravelling of epidemiological paradoxes which have been partly explained by community-level mediating variables; a systems theory view that effective interventions for change in a multi-level system require complementary changes in all the subsystems, with structural and process changes reinforcing and legitimizing each other; and an emerging understanding of interdependencies among determinants of health and illness

Example 2: Family Health

What factors influence family health at difference stages in the cancer control continuum? For example, what are the dynamics between community prevention strategies and individual/family health decisions (e.g dietary changes of midlife couples when they become "empty nested" and the focus for meal planning shifts from children to their own health needs). How is a family affected when a member becomes palliative, and how might clinical and health services adapt to better promote and support healthy coping? These questions call for a new breed of "action research", that studies these process "in real time", and that works to continuously improve practices by applying improved understanding rapidly as research progresses. This in turn requires new, more flexible approaches by researchers and research funders.

WHAT ARE WE DOING IN CANADA NOW?

The National Cancer Institute of Canada's Sociobehavioural Cancer Network (SCRN) has invested significant energy over the past five years to develop the capacity for sociobehavioural research. SCRN has just restructured to build on this enhanced capacity, by funding four national teams, each with a dedicated focus and action plan, complemented by six regional research centres that can provide access to multiple channels for priority projects.

The NCIC's sociobehavioural research panels have seen an increasing number and quality of projects over the past decade. Creation of new mechanisms like the Canadian Tobacco Research Initiative adds momentum to the trend to more applied, high impact sociobehavioural cancer control research. In some areas (e.g. palliative care), we are starting to see impacts on the ways in which research is conducted, and the uptake of psychosocial measures and practices. There certainly is a very strong demand from research consumers for prevention programs that will reduce the estimated 50% or more of cancers linked to sociobehavioural risk factors.

At the same time that this capacity development is very welcome, it should be noted that the rapid expansion has significantly depleted the pool of sociobehavioural researchers available to serve a rapidly increasing demand for this kind of research. Renewed investment in sociobehavioural human resources, and expansion of mechanisms for innovative, multidisciplinary research, are required. These strategies should be developed within the context of a co-ordinated set of research priorities aimed at reducing the gap between sociobehavioural research and application needs and opportunities.

HOW WELL ARE WE DOING IT?

Despite the recent interest and support for sociobehavioural research in cancer control, Canada is lagging behind countries like the U.S. in the commitment of dollars and structures to sociobehavioural cancer control research. The gap is growing and there is a pressing need for significant increases in sociobehavioural research capacity if we are not to fall further behind.

Canada already is missing opportunities to nurture capacity in priority areas. For example, the NCIC Cancer 2000 Task Force several years ago recognised that palliative care was a nascent field that needed protected funding to give it time to grow. Sociobehavioural research is inextricably interwoven with much of the palliative research agenda. The recommendation was ignored. In the last few years, private foundations in the US (e.g. George Soros/ “Death in America” project, the Robert Wood Johnston Foundation, the MayDay Foundation) and more recently the NIH have recognised the need to improve end-of-life care and have dedicated considerable levels of funding to research in this area.

HORIZON SCANNING

Priority areas for future research will include:

- Basic sociobehavioural research to better understand the determinants and development of health risk behaviour. While there are signs of progress in some areas, such trends as the recent increases in adolescent smoking underscore our limited understanding of the etiology of tobacco use, and how to effectively intervene in the developmental and cultural context in which tobacco use evolves. Similarly, we need more basic sociobehavioural research to understand the complex sociobehavioural patterns at each stage in the cancer continuum from prevention to palliation.
- Foundational investment in surveillance and survey systems to track and unravel trends in health risk behaviour, health systems variables, and other important psychosocial factors for planning, implementing and managing cancer control strategies.
- Major investment in the full continuum of health behaviour interventions, from hypothesis generation through efficacy and effectiveness studies, to diffusion (NCIC, 1994).

- An expanded marriage between clinical and sociobehavioural researchers, to add best practice psychosocial and other complementary interventions to cancer care, rehabilitation and survivorship, screening, genetic testing and counselling, and other emergent areas. Similarly, increased collaboration is needed between sociobehavioural researchers and other health services disciplines to impact programs and policies on a population level.
- Continuing refinement of measurement tools such as quality of life for research, clinical, and population applications, for planning, intervention monitoring, and accountability.
- Investment in research on learning and self-care: how can people learn and best be supported, to take greater responsibility for evidence-based decision-making and their role in cancer prevention and management?
- Similarly, consistent with the "closer to home" health reform trend, families and other community caregivers need innovative and effective support systems that incorporate sociobehavioural sciences best practices.
- A major role for sociobehavioural research in fostering of integrative health services, co-ordination of care, and the balancing of proven conventional, complementary, and behavioural medicine strategies.
- Within this context, a special role for the development of dissemination strategies and innovations that link sociobehavioural sciences and information technologies.
- Sociobehavioural research to evaluate cancer control policies.
- Community alliances to foster capacity building and translation of key sociobehavioural research into practice.

WHAT ARE THE BARRIERS AND OPPORTUNITIES?

We see four major barriers to achieving these priorities for the future. They relate to: structures, training, standards, and research agenda.

Structures. As noted, sociobehavioural research is crosscutting. We need structures (programs, networks, review panels, etc) that reflect this reality. For example, within the NIH, an Office of Behavioral and Social Science Research has had considerable success in working with the various Institutes to promote an appropriate, balanced, and productive emphasis on sociobehavioural research.

The size of research grants is a special problem for sociobehavioural research. In common with clinical trials, intervention research to evaluate sociobehavioural strategies requires much larger grants than basic research. Prevention is a particular problem because large cohorts often need to be followed longitudinally to see if the preventive strategy affected outcomes of interest. This problem will not get easier, given finite resources for applied research. As for clinical trials, sociobehavioural research may need to give priority to more efficient methodologies than large RCTs. At the same time, more efficient research alone cannot hope to close the gap between research needs and research production – a substantial increase in research dollars is needed.

Three additional structures of are particular interest for sociobehavioural research. First, as is widely recognised in Canada currently, we need major investment in surveillance systems. From a sociobehavioural research perspective, they must include key psychosocial variables, and must lend themselves to small area analysis, so as to study key community and social factors influencing cancer prevention, care, and outcomes. These needs must be addressed as planning for a national information resource progress. Second, as information systems develop to inform the public, professionals, and policy makers about current knowledge and best practices, these information systems both (a) must be designed to take advantage of what we know about learning and behaviour (in particular, the limitations to information alone as an intervention to change attitudes and behaviour), and (b) must themselves function as research tools, to enable priority research on decision-making, self-care, psychosocial factors influencing these behaviours, and other key cancer control delivery issues. Third, and most daunting of all, there are very limited structures to support dissemination research. Here, there is major overlap with health services research – many sociobehavioural scientists are interested in applied research and practice. However, there are very few structures and resources to support the systematic application of new knowledge to existing health systems. Roles and accountability for this transfer are absent or vaguely defined. As a consequence, useful and effective interventions are poorly disseminated and adopted. This barrier is not specific to sociobehavioural research, but it is a particular and critical problem for the application stage of sociobehavioural research.

Training. There simply are not nearly enough sociobehavioural scientists working in the cancer control arena, and those that there are find themselves scattered too widely across the country to provide a critical mass. Structures like the SCRN have provided extremely valuable focus on this issue, but the initiative is too limited to meet the pressing need for training. There are too few focused funding programs to attract top researchers and support their students.

Standards. The sociobehavioural research process would be greatly facilitated if there were concerted efforts to establish standards of two kinds, which are currently almost completely lacking. First, we need standards that define expectations for how sociobehavioural research should be operationalised as a crosscutting priority. The current focus of the Clinical Trials Group on quality of life measurement is an excellent example, but there are many other areas in which standards are needed (e.g. inclusion of known sociobehavioural moderators in epidemiological surveys; measurement of non-specific factors like treatment expectations that influence clinical outcomes). Second, applied research needs the enabling effects of appropriate clinical standards. For example, despite much research establishing the importance of social support in cancer care, there is a huge gap between “best practice” and what typically is found in cancer care settings. Appropriate service standards would set the stage for important sociobehavioural research on how best to encourage best practice, adherence,

effectiveness of interventions in real-world settings on a full range of biopsychosocial outcomes, etc.

Research Agenda. Many sociobehavioural scientists would welcome a comprehensive research agenda that set priorities from a health services perspective and encouraged research to close critical gaps in knowledge. The current Canadian Tobacco Research Initiative is an excellent example. More national research agendas of this kind will contribute significantly to reduce barriers for sociobehavioural research. Similar research agenda should be developed at the provincial and local level to align applied research efforts. Sociobehavioural research is key ~ unless we can change individuals and society, much research cannot achieve its potential impact

In addition to these barriers that must be overcome, there are important opportunities that open windows and doors for sociobehavioural research in cancer control:

- The current wave of health restructuring that is sweeping the country and cancer control provides opportunities for sociobehavioural research, both to study the process and to inject research findings to reform planning and decisions. Emerging structures and priorities (e.g. continuity of care, self-care) provide specific opportunities for sociobehavioural research to contribute.
- Sociobehavioural research internationally is "coming of age". There increasingly are proven technologies ready for wide application.
- The explosion of information technology offers for the first time the possibility of sufficiently comprehensive data sets to start modelling the health of populations in ways that integrate biopsychosocial knowledge.
- We are starting to have a science of knowledge transfer and uptake, significantly expanding the scope of sociobehavioural research to include research that examines the behaviour of cancer control decision-makers, providers, and managers.
- There is a readiness and expectation for accountability, that provides opportunities to apply the program evaluation and evaluation research methodologies that have developed greatly over the past three decades.

WHAT SHOULD WE BE DOING?

1. **Funding Mechanisms**. Work with agencies funding cancer control research, to develop and co-ordinate funding timelines, review criteria, and review processes that encourage partnerships between research producers and research consumers towards improved cancer control. The new CIHR Community Alliances for Health Research, and the CTRI Planning Grants are examples of such structures. Another worthwhile example is the CIHR Interdisciplinary Health Research Team program that encourages sustained collaboration across disciplines, universities, and relevant sectors. An important aspect of these mechanisms is they can be used to encourage the "virtual" centres needed to create a critical mass of broad multidisciplinary teams, particularly given current human resource constraints in cancer control research.

2. **Funder Collaboration**. Work with CIHR and the Canadian Strategy for Cancer Control partners to ensure appropriate structures and processes that will stimulate, enable, and co-ordinate sociobehavioural research on cancer control.
3. **Methods Development**. Support methods development research, to adapt and refine current tools (e.g. RCTs) to make them more comprehensive of sociobehavioural factors and more efficient; development of new, more comprehensive, and more probing indicators of impact. Of particular importance is the current shift to population-based intervention for prevention, with the associated need for new methodologies better suited to community versus clinical interventions. The population focus also underscores the need for data collection across national boundaries, to take advantage of natural experiments (e.g. variations in tobacco control legislation) and for surveillance across countries using standard protocols.
4. **Researcher Pool**. Expand existing innovations to accelerate development of an effective Canadian cadre of sociobehavioural researchers (e.g. expand the number of SCRN teams funded, increase dedicated funding for multiple levels of career development in the sociobehavioural sciences, provide incentives that attract key disciplines not traditionally central to health research).
5. **Strategic Linkage**. Work with surveillance, infomatics, and other major initiatives, as they relate to cancer control, to develop opportunities for sociobehavioural research.
6. **Sociobehavioural Technology**. Develop funding programs to stimulate application of proven sociobehavioural technology to cancer control systems.
7. **Reshape Care Models**. Use sociobehavioural research as an action tool for redesigning care. There are studies showing that cancer patients sometimes feel they have to co-ordinate their own care. Sociobehavioural research offers important contributions to innovative models for more integrated care to offset current fragmentation of services, through studies of patient-practitioner communication and decision-making, roles for different health providers, patient-centred comprehensive information systems, self-care skills, and natural pathways and continuity of care through the cancer control system (or lack thereof).
8. **Research Agenda**. Create processes to develop research agendas, not only at local through national levels, but also to fund international studies, and co-ordinated international research agenda so that we avoid duplication and focus efforts in areas of relative strength (e.g. a relatively well co-ordinated cancer control system). An essential first step will be a conference for sociobehavioural researchers to assess and assign priorities, and to develop a comprehensive strategy.
9. **Research and Service Standards**. Work with cancer agencies and others to achieve consensus on, and oversee development of, priority research and service standards that address sociobehavioural perspectives.

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Appendix I: Translational Research Subgroup

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Scope of Translational Research

Translational research can be considered a research philosophy that embraces multiple disciplines ranging from basic science to clinical medicine. Informatics provides a medium to enable, coordinate and analyze this interdisciplinary process. The goals of the Canadian Strategy for Cancer Control are the reduction of cancer mortality and the relief of suffering due to cancer in all communities of Canadian society. Translational research will contribute to achieving these goals by applying research knowledge to clinical situations. Since the study of cancer patients also yields important new basic research knowledge, translational research is a bi-directional process.

Translational Research and Scientific Discovery

Translational research has been successful in utilizing clinical material to advance basic understanding of cancer. Important landmarks in this process have been the identification of tumor suppressor genes and establishing the multi-step molecular mechanisms of human cancer. Such studies are facilitated by the establishment of tumour banks and realistic *in vivo* models, and the development of analytical methods that address the complexities of human cancers. Rapid progress understanding the molecular mechanisms of human cancers, coupled with increasing sophistication in drug development, offers unprecedented opportunities for the development and implementation of novel therapeutic interventions. Over the long term, this approach offers the hope of curative treatments for patients with cancer.

Translational Research and the Care of Cancer Patients

Compared to progress in scientific discovery, application of the discoveries to the routine care of cancer patients has been slow. The public, the scientists and the politicians are excited by headline discoveries, but implementation where evidence justifies is a slow process, which has been largely ignored or assumed to not need support. “Surely this is the goal of all the work?” is the public perception.

What are we doing now?

Recognizing these issues, NIH and NCI are actively promoting translational research [see www.cdp.ims.nci.gov/new.html]. The NCIC Clinical Trials Group has a Tumour Bank Working Group to coordinate Canadian tumor banks and link patient samples to clinical trials data. An increasing number of investigator-initiated projects are incorporating biological endpoints into the trial design, using a wide range of analytical techniques, based in hospital pathology departments. Some techniques, such as estrogen receptor assays and immunophenotyping of leukemias/lymphomas, have become routine tests that are reimbursed by the routine health system. Pathologists make extensive use of immunohistochemistry markers based on current understanding of the molecular basis of cancer. This has resulted in increasing refinements in cancer diagnosis that have practical effects in the clinic.

How well are we doing it?

Translational research is presently sporadic, based on the initiative of individual investigators, without much infrastructure or understanding of the issues and importance. While in the area of clinical trials Canada has strong leadership, the science of evidence-based implementation has been largely ignored. Some have felt that implementation was the prerogative of industry. Implementation of predictive tests, particularly molecular tests, has been based much more on political expediency than of scientific evidence. Even when such evidence is compelling, implementation has been impeded by political decisions and adherence to archaic bureaucracy. Such barriers impede the scientific implementation of knowledge that could positively impact on individual cancer patients.

Horizon scanning

We are at the brink of an unprecedented acceleration toward understanding the fundamental basis of human cancers, with tremendous opportunities to apply this knowledge to patients.

- Novel therapeutic agents provide opportunity for radical new approaches to cancer therapy
- Understanding cancer initiation has potential for prevention of cancer.
- Genome knowledge will impact on cancer cure and improvement in quality of life, with recognition of the impact of cancer and treatment responses due to human variation and tumor classification.
- Informatics will facilitate bi-directional flow of data between the clinical record, the life history and family history of individuals, and a vast array of molecular tests and basic research.
- Facilitated flow of data and biological endpoints in clinical trials will accelerate the timeline, expand enrollment opportunities, and reduce costs.
- The science of evidence-based implementation can enable incorporation of tests, therapies and strategies into cancer care where and when appropriate, optimally deploying health care dollars.
- Novel approaches to analysis of huge data sets and new rules for statistical evaluation and interpretation will emerge.
- Molecular targeted therapy will be based on understanding of the mechanisms of cancer and decoding of tumor and human heterogeneity, and achieve effective therapy with reduced morbidity.

What are the barriers?

- *Poor resources for translational research in Pathology Departments*

  Historically, laboratory medicine has provided the home for implementation of translational research (e.g. clinical hematology, endocrinology, clinical chemistry). To a considerable extent these disciplines evolved over the past several decades as offshoots of pathology departments. However, today, many existing Canadian academic and hospital based pathology departments are in poor health in terms of staff recruitment, morale, and training. Furthermore, they lack the resources needed to develop the new discipline of molecular analysis of human cancers. They are generally incapable of keeping pace with developments at the basic science level and meeting clinical demands.

- *Deficiency of clinical scientists*

  There is a deficiency of trained clinician scientists. Academic and institutional departmental structures reduce the opportunities for scientists and clinicians to interact. Creative and individualized training programs that would be appropriate to a rapidly changing scientific cancer agenda are impeded by the educational structures of yesterday. Additional barriers are political (including clinical turf wars), and the long time frame needed to establish training/certification programs.

- *Prospective impact analysis has been ignored in cancer*

  The scientific methodologies is an integral component of translational research. As a result, many molecular tests remain in the realm of research when the data justify full implementation.

- *Political inattention to evidence*

  Many molecular tests remain in the realm of research when the data justify full clinical implementation. There is presently a deficiency in process for the implementation of new tests into health care, even when sound data support the improvement in health outcomes.

- *Informatics*

  The power of informatics has yet to be felt in cancer translational research. Lack of, or poor data structure, in electronic medical records (e-record), where they exist, limits the e-record to a trivial extension of paper. There are no national standards in e-records, so poor communication between institutions. Privacy and security policies at the interface of clinical care and research are undeveloped.

- *Data mining*

  We are ill equipped to harness the knowledge embedded in the huge data-sets that are emerging from molecular analysis of tumors and patient genomes.

What should we be doing?

- *Long term Strategy to Cancer control*

  A comprehensive long-term strategy that links basic science to routine patient care will enable translational research at its full power. The Canadian health care system and the Cancer Care organizations present opportunities unrivalled in the world, with universal access to care. This advantage can be extended to universal access to research, which brings with it the best quality of care.

- *Inspire political endorsement*

  In order to implement a Canada-wide infrastructure in translational research with a broad consensus we need the political powers that control health care allocations to endorse the value of translational research and to respect the evidence that points to improved outcomes. A major tool to achieve this end will be a vigorous and effective lobbying campaign which educates the public and politicians about the power that translational research can bring to address cancer control.

- *Rejuvenation of Pathology*

  Whereas the discovery of new knowledge about human cancers takes place in basic research institutes, implementation of this knowledge for routine patient care is the mandate of existing pathology departments. A major investment is therefore needed to assist these departments with the demand for assessment of advanced analytical tests and implementation where appropriate in routine clinical cancer care.

  Research and training should be recognized as activities for hospital pathology departments that are vital to the future and to the provision of routine service in the face of rapidly evolving knowledge. A fresh look at training requirements will consider novel paths to Professional expertise and certification.

  Pathology Departments can lead to establish utility and cost effectiveness of new cancer tests, to provide links to e-records, and to enable national standards of laboratory practice. Forward-looking pathology departments can facilitate clinical trials and biological endpoints.

- *Impact analysis*

  We need to recruit to the job of cancer control, scientists into with expertise in analysis of outcome in health and economic impact analysis on cancer care and prevention. These leaders will develop standards, policies and processes for implementation of tests that have beneficial impact, and develop a framework for prospective evidence-based guidelines.

- *Informatics*

  The combination of molecular advancements, such as knowledge of the human genome and array technologies, and the power of computer hardware and the Internet, largely advanced by commercial opportunities, presents to those concerned with cancer control unprecedented opportunities. To harness the power of informatics we require:

  - an academic focus,
  - the development of info-structure,
  - and policies for appropriate implementation.

  Academic Informatics

  We must reach out to academic areas unaware of the needs and opportunities of cancer research, to find expertise and future genius in handling and interpreting meaning in large data sets. Change is rapidly upon us, and those of us whose early neuronal development did not include computer games may be challenged to keep up, let alone envisage the future. In recruiting and creating opportunities for rewarding careers we may be competing with a powerful commercial world. We must optimize on the attraction of academic values and freedom and the potential to make the world a better place to inspire youth to new fields with few mentors.

  Info-structure

  Technical info-structure is obvious and feasible but requires national coordination of will. For example, national e-record standards of data structure with full links to basic science data warehouses will enable research advances at both basic and translational levels. Broad-band web linkages can be open for national networking and sharing of data. Web-based clinical trials can be facilitated and made available to cancer patients while maintaining community and family ties and supports. The internet can pull into the research effort to control cancer the community physicians and care-givers, and education experts.

  Policy development

  Smooth, constructive, optimal paths to cancer control will be facilitated by prospective development of policies and standards. This will require a broad base of lay public representation with guidance from leaders in science, medicine, ethics, and law. Areas to be urgently addressed by such ad hoc committees include reciprocity of information sharing, security and confidentiality of data, informed consent, and ownership of ideas, data, samples.

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Feedback:

- There is a need to have well trained, knowledgeable personnel throughout Canada to ensure the catchment of quality documentation, data, and clinical information up front, so there is quality information/data with which to perform/support the research.
- Recommendation #5 should rank higher than #3. Rationale: Before a positive outcome can be rationalized, one needs quality data and information, gleaned by knowledgeable 'informaticians'. With good data and information, you can legitimately start to prioritize with credibility. The Canadian Health Record Association has professionals who have been educated in health information science as well as informatics, and are currently working in positions that are reflective of this higher application of education.
- The Canadian Health Records Association agrees that Recommendation # 2 is definitely a high priority.
- Recommendation #5: Establish a national information resource for data collection related to patients and populations. The Canadian Health Record Association should be high on the "Intended Recipient of the Recommendation", instead of appearing not at all. Rationale: Our membership thrust includes those who as professionals, excel in the management of health information and in the commitment to the professions clients, users, stakeholders and peers; are Data Managers, designing systems to facilitate clinical and health documentation. Our training and education has paved the way for us as Information Managers to design health information databases; collect data; classify clinical and health documentation, and secure data. As Data Providers, we retrieve and present data, from the assessment phase to the research phase. As Information Providers, we know how to regulate access to health information, to measure, manage and develop policies for all privacy legislation's, both Federal and Provincial, and develop and present such in legal forums. As Information Analysts, our membership creates health information from data and effectively contributes to decision-making. As Data Technologists, we are sought to promote the advancement of technologies for information management. As Researchers, we perform research from providing research objectives through to publishing the results. Our skills are also sought after, as we develop from the research, health information management theory and practice. Our association members serve as Advisors, serving as a health industry resource and have done so for many years. Our education has developed our skill in assessing education needs, through to evaluation and delivery of education programs. We are indeed Advocates, sought out to become partners, members of teams for health care research and initiatives (see the enclosed Position Statements developed and published for Canada, by the CHRA).
- Recommendation #6: Establish a national voice for research in cancer control. Ensure CHRA become one of the 'voices'. We are credible in the health care sector. We can and have supported the representation of public and private community issues relevant to health care research, 'report cards', and, cancer research. The knowledge base of our association is extensive and varied.
- Distribute the report Recommendations to all universities currently embarking on the Health Information Management degree initiative; strategize in partnership with the CHRA.

- Let these Universities know of the thrust to get more $$$ for training/education. As marketing strategy for the university, it will give the universities higher profiles in Macleans for increasing student catchment.
- Develop a database of education/skills of students/professionals. The Canadian Health Record Association has done this for several years with a National Resource Team whose members are skilled, competent, knowledgeable Health Information professionals, who respond to queries from CHRA members, stakeholders, and general public on issues relating to health record/health information practice. These include such issues as document standards, privacy, confidentiality, data base production, research methodologies, and data retention.
- Obstacle is the lack of a current, quality driven database. Without this sound database with information managers being involved, the outcome will be fuzzy and not as positive as it could be.
- Strong support for recommendations #1 and #2.
- Resources and commitment from those who have the responsibility for research would advance the activities. The question is who has this responsibility? Federal the provincial governments do if only to remain competitive in a global economy.
- The barriers are political will, competing interests on the national agenda and the issue of who owns this issue.