Sponsored by:

- Canadian Institutes of Health Research- Institute for Cancer Research
- National Cancer Institute of Canada
- Canadian Association of Provincial Cancer Funding Agencies
- Health Canada

A Delphi Process Undertaken by
The Praxis Group, Calgary, Alberta

September, 2002

A Delphi Process for Setting Cancer Research Priorities in Canada

VOLUME I - MAIN REPORT

Background to the Delphi Process for Setting Cancer Research Priorities

In 1999, key national health organizations working in the cancer field formed a partnership to initiate development of the *Canadian Strategy for Cancer Control.* The goal of the strategy is to reduce the burden of cancer on the health system and society by maximizing the impact of efforts aimed at fighting and preventing cancer through coordinated and collaborative action.

During the first phase of strategy development, eleven working groups examined priority issues and cross-cutting themes in the area of cancer control. The *Research Theme Working Group*, chaired by Dr. Victor Ling, developed several recommendations concerning research and cancer control. Recommendations from the *Research Theme Working Group*, along with research recommendations from other working groups, were discussed at the *Research Priority Setting Workshop* in Toronto in May 2001. Workshop participants began the task of identifying research priorities and initiatives that could lead to significant and rapid benefit for potential and current cancer patients. Consultation with a larger audience of cancer researchers and survivors was identified as a key component of this work. To facilitate this consultation, workshop participants selected a Delphi process to stimulate dialogue among a national audience.

A Delphi is a staged process for developing consensus and making group-based decisions. A Delphi process typically occurs in a series of stages, over time. Participants provide their comments regarding a particular set of issues or areas of interest. The groups' responses are then analyzed and reported back so participants can compare their own responses to those of the overall group. Participants, having benefit of the previous discussion, comment on the issues again as well as other questions that have been raised.

A new group report is generated and the process is repeated with a new series of questions.

Predominately an internet-based process, Stage I of the Cancer Research Delphi process was initiated in September 2002. 800 individuals from across Canada with some background in cancer related issues were asked to review background information and complete a questionnaire identifying research priorities within thematic areas.

Stage II of the Delphi process was conducted in January and February 2002. In this stage, the 180 participants from Stage I were invited to review Stage I results and rank priorities for: key focus areas for the Overriding Thematic Areas (2), and Priority Research Topics, infrastructure needs and human resources needs for each of the Priority Themes (12).

Stage III was completed in June 2002. The 800 individuals originally requested to participate in the Delphi process received the results of Stage I and II, and were invited to complete the Stage III questionnaire.

Overview of the Delphi Process for Setting Cancer Research Priorities Report

The report for the Delphi Process for Setting Cancer Research Priorities is presented in two Volumes. An overview of the content of each Volume is provided below:

Volume I

Stage I Backgrounder

- includes background information about the Delphi process and the 14 Research Themes used as the foundation of the process

Stage I Questionnaire

- gathered feedback about the operational descriptions, key focus areas and potential research topics for the 14 Research Themes presented in the Backgrounder

Stage II Backgrounder

- provides an overview of Stage I results including: a summary of suggested revisions for the operational descriptions; expanded lists for key focus areas and potential research topics; and, expanded lists for the infrastructure and human resources needs for each of the Research Themes

Stage II Questionnaire

- asked participants to priorize the expanded lists for each of the Research Themes

Stage III Backgrounder and Questionnaire

- the Backgrounder provides a summary overview of the results of Stage II and the Questionnaire solicited feedback about the results and collected participant feedback about the Cancer Research Alliance

Stage III Results

- presents the summary results of the Stage III Questionnaire

Volume II

Stage II Detailed Results

- provides a comprehensive reporting of the results of the Stage II Questionnaire including:
  - *Demographic Results* - provides respondents' demographic frequencies and cross tabulations by province, age, gender, type of researcher and type of organization represented.
  - *Results Rankings* - presents the ranked priorities by both frequency and weight for key focus areas, potential research topics, infrastructure needs, and human resources needs for each of the Research Themes
  - *Analysis of Infrastructure and Human Resources Needs* – compares the ranked priorities for the two Overriding Themes with the priority infrastructure and human resources need for each of the 12 Priority Themes.

A Delphi Process for: Setting Cancer Research Priorities in Canada

Stage 1: Backgrounder

Sponsored by:

- Canadian Institutes of Health Research- Institute for Cancer Research
- National Cancer Institute of Canada
- Canadian Association of Provincial Cancer Funding Agencies
- Health Canada

A Delphi Process Undertaken by Praxis Inc.

October, 2001

Evolution of the Cancer Research Priorty Setting Process

The Canadian Strategy for Cancer Control

In 1999, key national health organizations working in the cancer field formed a partnership to initiate development of the *Canadian Strategy for Cancer Control.* The goal of the strategy is to reduce the burden of cancer on the health system and society by maximizing the impact of efforts aimed at fighting and preventing cancer through coordinated and collaborative action. The strategy will identify:

- National priorities — including goals, objectives, targets, actions and milestones
- Clear roles and responsibilities for national cancer agencies
- Mechanisms to link research to policy and practice
- Mechanisms for addressing emerging issues and maintaining partnerships

The following national organizations serve as members of the Strategy's Steering Committee:

- Canadian Association of Provincial Cancer Agencies
- Canadian Cancer Society
- National Cancer Institute of Canada
- Health Canada

Provincial departments of health and regional cancer stakeholders are also involved in the process.

During the first phase of strategy development, working groups examined priority issues and cross-cutting themes in the area of cancer control. There was a group addressing each of the following topics:

- Prevention
- Screening
- Research
- Supportive Care
- Palliative Care
- Human Resource Planning
- Pediatric cancer
- Diagnosis
- Treatment
- Informatics and Technology
- Surveillance

The working groups have completed their reports, which are now being synthesized into an overall strategy.

The Research Theme Working Group

Dr. Victor Ling chaired the *Research Theme Working Group*. This group, along with its nine sub-groups, made several recommendations concerning cancer control. These recommendations are contained in the *Research Working Group Report* also referred to as the 'Ling Report'. The six key recommendations were:

- Increase research funding to position Canada as a leader in cancer control
- Aggressively address the human resource crisis
- Foster funding mechanisms to promote breakthroughs and interdisciplinary research
- Champion national priorities for cancer control research
- Establish a national information resource for data collection related to patients and populations
- Establish a national voice for research in cancer control

Setting Research Priorities

Recommendations from the *Research Theme Working Group*, along with research recommendations from other working groups, were discussed at the *Research Priority Setting Workshop* in Toronto in May 2001. This workshop involved, for the first time in history, representatives from Canada's two largest research funding organizations, the National Cancer Institute of Canada and the Canadian Institute for Health Research – Institute for Cancer Research, working in collaboration with the Canadian Association of Provincial Cancer Agencies, Health Canada and a large group of cancer research stakeholders.

Workshop participants began the task of identifying research initiatives that could lead to significant and rapid benefit for potential and current cancer patients. Consultation with a larger audience of cancer researchers and survivors was identified as a key component of this work. To facilitate this consultation, workshop participants selected a Delphi process, which can be

used to stimulate dialogue and help build consensus. This process will ensure that a larger audience reviews and comments on the research priorities identified at the *Research Priority Setting Workshop.*

In July 2001, the *Joint Research Priority Planning Subcommittee,* led by Dr. Jim Till, met in Calgary to discuss and design a Delphi process to facilitate this consultation. It is anticipated that over 800 participants will be involved in the process, which is intended to:

- Inform and educate participants about cancer research in general and the specific research areas
- Identify participants' research priorities
- Generate support for research priorities

Upon completion of the Delphi process, meetings sponsored by the organizers of the Research Priority Setting Workshop will be held to review the Delphi results and recommended cancer research initiatives to be pursued in the coming years.

An Introduction to the Delphi Process

A Delphi process is a staged process for developing consensus and making group-based decisions. A Delphi process typically occurs in a series of stages, over time. Participants provide their comments regarding a particular set of issues or areas of interest. The groups' responses are then analyzed and reported back so participants can compare their own responses to those of the overall group. Once this is done, the participants, having benefit of the previous discussion, comment on the issues again as well as other questions that have been raised. A new group report is generated and the process repeats itself with a new series of questions.

The Delphi process planned for setting cancer research priorities will be conducted in three stages:

- Stage 1 – October 2001
- Stage 2 – November-December 2001
- Stage 3 – January-February 2002

In September, at the beginning of Stage 1, individuals interested in participating in the process will be asked to review background information and complete a questionnaire. The comments from this stage will be summarized and included in the background information accompanying the Stage 2 questionnaire, which will be distributed in November. This process will be repeated for Stage 3. Following the completion of the three stages, a final report will be produced. Delphi participants will receive a summary of this final report.

This Delphi process for setting cancer research priorities will be Internet-based. For purposes of security and confidentiality, each participant will receive an log-on address and a personal password, allowing them to access all materials and the questionnaires during each stage of the process. The questionnaires can be completed and submitted on-line. Individuals without on-line access can be accommodated with hardcopy versions of the background information and questionnaires (see contact information).

Because individual questionnaire responses can only be accessed with a personal password, the confidentiality of the participant is protected. In addition, no attributions of names or organizations of affiliation will be made in the summary or final reports, further protecting participant confidentiality.

Instructions to Complete Stage 1

A variety of options are available for accessing the Backgrounder and completing the Stage 1 questionnaire:

The Backgrounder

The Backgrounder is comprised of background information necessary to complete the Stage 1 questionnaire. The Backgrounder is available on-line and can be read on-line or printed in hardcopy format. The Backgrounder is also available as a PDF file that can be downloaded printed, and read off-line at your convenience.

The Questionnaire

In the on-line version of the Backgrounder there is a link at the end of each section. That link will take you to the related section of the questionnaire where you can answer the questions on-line. You can move back and forth between the Backgrounder and the questionnaire at your convenience. If you prefer to read the entire Backgrounder prior to completing the questionnaire, you can open the first link in the Backgrounder, scroll through, and scroll through the questionnaire at your convenience.

There is also a PDF file of the questionnaire that can be downloaded,. The printed questionnaire can be used as a reference when later inputting your responses to the questionnaire on-line.

If for some reason, you cannot complete your response on-line, you can complete the questionnaire in hardcopy format and fax it back to us (see contact information). Questionnaires that are faxed back must be legibly written. Do not write in the margins and additional pages can be added.

The questionnaire can be completed in stages at your leisure. The link, log-on address and personal password allow you to enter your record as often as you want and add, delete or make any other changes.

In Section B (12 Priority Research Themes) is not compulsory. We encourage you to respond to only the Themes for which you have some knowledge or understanding.

Contact Information

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The Cutoff Date

The date for completion of Stage 1 is October 24, 2001.

Cancer Research Themes

Section A – Overriding Thematic Areas

Fourteen themes will be used as the foundation for the Delphi process. The Large Working Group originally identified thirteen themes; however, the Infrastructure theme was split into two themes – A1 Infrastructure and A2 Human Resources. Since these two themes address the tools, resources and other foundations upon which research programs are built, they are considered to be overriding topics; as a result, they comprise Section A of the questionnaire.

Section B – Priority Themes

Section B of the questionnaire deals with the other twelve research priority themes, which are:

B1. Etiologic Factors

B2. Surveillance

B3. Population Based Prevention

B4. Experimental Therapeutics

B5. Clinical Research

B6. Palliative Care/Quality of Life.

B7. Health Services and Policy Research

B8. Genome Science and Cancer

B9. Screening

B10. Cancer Biomarkers and Imaging

B11. Pediatric Cancer

B12. Sociobehavioural Cancer Research

A1
OVERRIDING THEMES

Capitalizing on opportunities across the research spectrum is dependent on the collection of, and access to, high quality data on a wide range of dimensions relating to cancer control. This requires large standardized and linkable databases in a variety of areas such as risk behaviours, biological samples, health service utilization and outcomes (i.e. survival and quality of life).

Tumor banks can facilitate the use of clinical material to advance both the basic understanding of cancer and the development and implementation of novel diagnostic and therapeutic procedures.

National multidisciplinary networks can complement and supplement the creative initiative of individuals and can foster a research philosophy that embraces multiple disciplines and enhances the translation of research knowledge into policy and practice.

Appropriate funding mechanisms and targets can create additional opportunities for innovation and risk-taking, while also maximizing accomplishments in selected strategic areas.

A national voice for research in cancer control can provide leadership and help to overcome barriers to the implementation of optimal paths to cancer control. To ensure that these paths are indeed optimal, appropriate attention must be paid to evaluation, to accountability (including attention to ethical issues) and to economic considerations.

Key focus areas include:

- Informatics databases, such as those required for policy and legislation, those required for the results of molecular-level tests arising out of basic research, etc.
- Tumor banks, with national standards and networks, and associated databases
- National multidisciplinary networks, centers, consortia
- Funding mechanisms and targets
- National voice for research in cancer control
- Evaluation, accountability, economics

Human Resources

A2

OVERRIDING THEMES

Canada has a well-developed cadre of researchers in certain disciplines of cancer control. However, other high priority areas are not as well served. In some areas there is almost a total lack of highly qualified research personnel who are interested in cancer control. As well, existing qualified research personnel are underutilized because of other professional pressures such as patient care and teaching. There has also been a failure to sustain qualified research personnel since some personnel leave for more attractive positions, especially in the USA.

Canada should have a competitive advantage in many areas of cancer control, because of its universal health care system and comprehensive cancer control systems. These features can allow Canada to become a world leader in areas such as population health research and clinical trials. However, there is a need for new and expanding funding, as well as organizational, career and training support mechanisms in order 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 and enable Canadian researchers to take advantage of the opportunities and address the needs that are developing across the cancer continuum.

There is a growing appreciation of the need to create multidisciplinary teams in order to most effectively tackle many aspects of cancer control research. Increasingly, it is recognized that enhancement of human resource capacity includes not only the recruitment, retention and support of suitably-qualified research personnel, but also of practitioners and policy-makers knowledgeable in the translation of the existing knowledge base into evidence-based policy and practice.

Key focus areas include:

- Aggressively addressing the human resource crisis
- Attracting appropriately-qualified new researchers
- Retaining existing well-qualified researchers
- Making better use of existing highly-qualified researchers
- Fostering the utilization of multidisciplinary and innovative approaches
- Stimulating programs in priority underserved areas to become viable
- Enhancing support for those who can best translate research into policy and practice

This area of research focuses on the identification of modifiable risk factors for cancer. This includes "lifestyle" risk factors (e.g. diet and physical activity) occupational and physical environmental exposures (e.g. asbestos and ionizing radiation), inherited predispositions and susceptibilities to cancer, microbiological agents (e.g. viruses) and the interactions between environmental and genetic factors. (Research considering biochemical changes intrinsic to cancer causation, and research into the application/ translation of knowledge about preventive factors into behavioral changes, are dealt with in other sections.)

While several potential protective or risk factors are known, increased detail in the identification of natural dietary factors that could prevent cancer would be helpful. Etiologic research can be carried out in the laboratory or in animals but requires validation in human populations. Human research requires careful measurement on exposure markers. This particular area would be strengthened by additional research into potential biomarkers of exposure, as an adjunct, validation, or substitute for traditional interview techniques. Increasing emphasis is being placed on prospective research, and validated markers that would predict pre-cancerous changes would be helpful to carry out this research more expeditiously.

Potential research topics include:

- Increased detail in the identification of natural dietary factors that could prevent cancer.
- Potential biomarkers of exposure, as an adjunct, validation, or substitute for traditional interview techniques.
- Validated markers that would predict pre-cancerous changes.

Surveillance

B2
PRIORITY THEMES

Surveillance requires high quality, accessible databases and assumes the existence of policy and technical resources to enable linkage of individualized information for purposes of bona fide research.

Cancer is unique in some of the databases available to it; the cancer registries provide a tracking of incidence and mortality that is unique among disease groupings. With additional resources, the comprehensiveness of these databases could be enhanced, which would improve their explanatory power.

Privacy issues related to the use of these databases must be respected. However, these concerns must not result in the inability of these databases to answer important research questions for the benefit of those whose experiences are represented there, and for other Canadians using the health care system that generated the data. Research agencies need to work to ensure appropriate accessibility for these reasons.

The linkage of registries with exposure databases or geographic exposure information could generate important hypotheses in cancer etiology and epidemiology. Good population surveys that would develop population levels of exposure would be of added value. Further development would require both the understanding and development of databases, and the development of a cadre of scientists with the high level of statistical expertise required to carry out and interpret these analyses.

Potential research topics include:

- Appropriate accessibility of data bases
- Linking of registries with exposure databases or geographic exposure information
- Population surveys that would develop population levels of exposure
- Building of research expertise on geographical exposures to map against cancer incidence maps
- Developing a cadre of scientists with a high level of statistical expertise

Population Based Prevention

B3
PRIORITY THEMES

Research in the area of primary prevention helps identify those actions and interventions, which will ultimately reduce the numbers of cases of cancer that develop in the first instance. It is estimated that up to 50% of cancers could be avoided entirely if we could implement changes early in the pathway of cancer development. Preventing cancer is a complex process, which involves interaction between biologic characteristics and processes within the body, and exposure to a variety of factors in everyday home, work and community environments.

Population based prevention focuses on those factors that are primarily behavioural and social in nature. Exposure to factors that increase risk of cancer is widespread and therefore broadly based measures targeting whole communities are warranted. Many of the risk factors for cancer also impact other major diseases, indicating that it probably makes sense to work collaboratively with other health groups.

Policy and regulatory approaches are also important in cancer prevention. In order to measure the impact of interventions targeting whole populations it is important to have population monitoring systems in place that provide information both on exposure levels and incidence of cancer.

Potential research topics include:

- Lifestyle modification (nutrition, exercise, reduced sun exposure)
- Effects of legislation on exposure to carcinogens (e.g. from tobacco use)
- Efficacy of protective devices and practices limiting exposure (sunscreen)
- Social factors affecting exposure (peer pressure, media impact)
- Interaction between biologic characteristics and exposure behaviours
- Efficacy of community based interventions e.g. social, educational
- Research into effectiveness of integrated disease prevention strategies (cancer, heart disease, etc.)
- Methods determining impact of policy/ regulatory interventions.
- Inter-relationships among risk behaviours, social determinants, community context and health outcomes
- Designs for evaluating setting of quantitative / population-specific impacts (including the interactions among influences)
- Collaboration between formal agencies / NGOS /governments /disciplines, etc.
- Identification of best mixes of interventions, and the development and dissemination of population prevention guidelines

Experimental Therapeutics

B4
PRIORITY THEMES

Rapid progress in understanding the molecular mechanisms underlying human cancers, coupled with increasing sophistication in methods for drug development, now offer unprecedented opportunities for the development and implementation of novel therapies. Examples include drugs that are simpler in chemical structure, yet are aimed specifically at the vulnerable molecular targets on cancer cells. Other novel approaches include specific gene therapy based on our expanding knowledge of the human cancer genome, and agents directed at tumor blood supply or unique immune characteristics.

An increasing number of investigator-initiated projects are utilizing increased biological knowledge to design novel agents. But, "translational research" of this kind currently is sporadic, based on the initiative of individual investigators, without adequate infrastructure, or wide understanding of the importance of this kind of research or of the issues involved in fostering it.

A coordinated national program to enhance research on new treatments is needed. Program elements would include attention to the steps leading to drug discovery, to the validation of biologically-targeted agents, to the pre-clinical testing that must precede the initiation of clinical trials, and the timely efficient conduct of clinical trials on promising new therapies. A particular research area of increasing importance is the individualization of therapy, where diagnostic tests involving molecular markers are used to predict who will benefit from a given treatment.

Potential research topics include:

- Development of a sophisticated infrastructure to foster and nourish innovation
- Creation of an organizational and regulatory environment which protects intellectual property, recognizes promising avenues of development, and efficiently moves new therapies towards clinical trial
- Individualization of therapy
- Selecting and validating gene based therapeutic targets
- Facilitating the synthesis, rapid screening, pre-clinical toxicology and evaluation of efficacy of new molecules
- The translational interface, i.e. support for Phase I clinical trials.

Clinical Research

B5
PRIORITY THEMES

Canada, because of advantages provided by centralized cancer systems and leadership provided by institutions and groups (such as the NCIC Clinical Trials Group), has done clinical trials research of high quality. However, it is estimated that only about 3-5% of adult cancer patients are enrolling in trials. Because of the acceleration of knowledge about the fundamental basis of cancer, there will be a rapid increase in the number of new drugs requiring testing in trials. There will be an increasing need for trials designed to determine whether therapy can be individualized to enhance the likelihood that specific patients will benefit from a particular treatment. Some current trials may be well funded by industry, but may be aimed at addressing questions of limited scientific interest, such as minor modifications of existing drugs. Barriers to an increased number of trials include complex regulatory requirements, restricted resources at institutions participating in trials, lack of trained personnel, and limited overall funding.

An effective national voice for clinical trials is needed, especially for addressing regulatory and ethical issues. Increased numbers of clinical investigators and support personnel (such as research nurses, data managers and research pharmacists) are needed. The potential power of informatics, based on computers and the Internet, has yet to be harnessed effectively for the support and enhancement of clinical trials, including the provision to patients of more and better information about the trials that are already underway, and about those that are being planned.

Potential research topics include:

- Regulatory issues which impact on the expeditious conduct of clinical trials and promising new agents.
- The ethical conduct of clinical trials in concert with research on the optimal infrastructure for ethical review of trials
- Manpower issues including studies on factors limiting the number of clinical investigators, support personnel and regulatory personnel
- Techniques to increase enrollment in clinical trials and patient information about trials
- Prioritization of trials to meet public needs and expectations balanced with translational research opportunities
- Enhancement of Canadian participation in international trials

Palliative Care/Quality of Life.

Palliative care aims to improve the life of patients and families through early identification and impeccable management of suffering associated with cancer and emphasis on the positive aspects of life inclusive of physical, psychosocial and spiritual sources. Palliative care is an exercise in prevention - prevention of suffering through prioritizing the diagnosis and skillful care of sources of distress throughout the course of cancer and for the family into the bereavement period. It is not simply an end of life concept separate from other aspects of cancer research and control.

Palliative care research focuses on fundamental symptom mechanisms as well as the experience of the patient and the family. While most cancer patients would benefit from the fruits of palliative care research, the existing infrastructure is inadequate. Urgently needed are supportive centres of excellence, collaborative research networks, capacity building, and integration of strong palliative care research programs within Canadian cancer centres.

Potential research topics include:

- Pathophysiology of the most difficult symptoms.
- Assessment of the multiple dimensions of symptom intensity and risk factors for symptom distress.
- Decision making regarding multiple therapeutic interventions including blood products, surgery, artificial nutrition and antineoplastic treatments near the end of life
- Assessment, management and prevention of symptoms in patients with limited ability to communicate
- Psychological and social issues which result in patient-family distress
- Ethical issues in end of life care not otherwise addressed in this list; other issues include research ethics, euthanasia and studies on health professional competence in palliative care
- Existential and spiritual concerns - development of a taxonomy and assessment tools; evaluation of strategies to help people find meaning at the end of life
- Organization and delivery of palliative care - studies on quality and access coupled with research on models
- Pediatric palliative care

Health Services and Policy Research

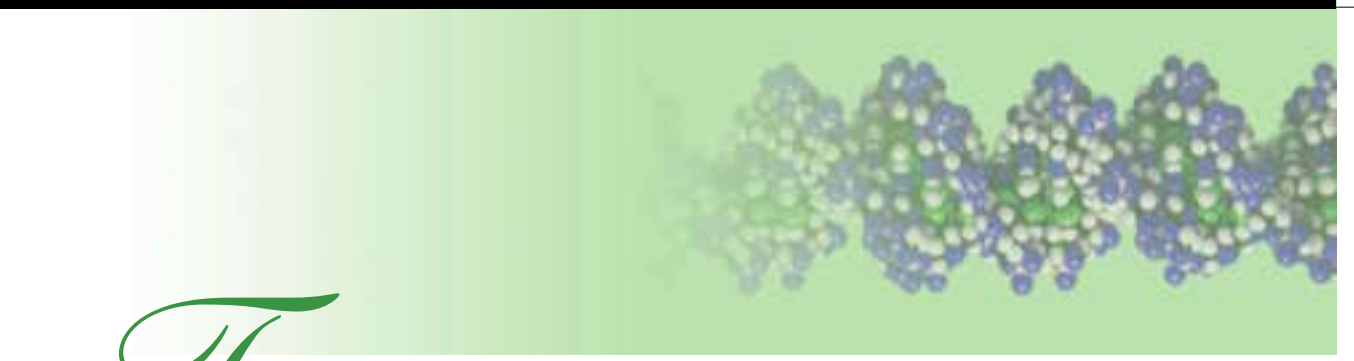
Health Services and Policy Research (HSR) is a relatively recent focus on the landscape of health related research in Canada. For the purposes of this exercise, HSR can be seen to be a policy oriented field which is interdisciplinary in nature and includes examination of the use, costs, quality, accessibility, delivery, organization, financing and outcomes of health care services for groups of individuals or populations. In a general sense, this field of research answers the question: Are Canadians receiving timely access to cancer services of high quality and achieving optimal outcomes?

The domain of interest includes the breadth of the cancer spectrum from primary prevention to palliation and supportive care. Its goal is to improve the health of the country by applying the knowledge gained from research. This outcome implies and requires close collaboration between researchers and research users. HSR is as much a process as a product. Because of its multidisciplinary 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. Often HSR research involves the analysis of data contained in administrative data systems.

Potential research topics include:

- Comparison of utilization of cancer services among geographic regions
- Economic analysis (cost effectiveness of current therapies; economic performance of delivery system)
- Outcomes measurement
- Effectiveness of varying organizational models for delivering integrated care
- Modeling cost of cancer care
- Understanding of equitable access to care and services (e.g. urban/rural; gender)
- Prevalence and impact of use of complementary therapies in health system
- Communications approaches to maximize access to cancer information (e.g. E-health)
- Policy generation, dissemination, uptake and implementation
- Identification and reduction of problems with co-ordination of patient-centred services and policies at a local community level

Genome Science and Cancer



The deciphering of the human genome (i.e. the complement of genes that contain the information necessary to determine the structure and function of all cell types in the body) has provided an unprecedented opportunity to understand the multistage processes by which a normal cell becomes malignant, to identify genes that may predispose individuals to cancer and to identify new molecular targets for the development of highly specific anti-cancer drugs.

Genome science encompasses not only studies of the structure of genes and the way in which they are organized, but also the way in which the information they contain is accessed and used to make proteins that define the structure of cells, the way in which they grow and the specialized functions they perform in the body (proteomics and functional genomics). In addition, it is possible to associate certain genetic characteristics with ways in which individuals respond to certain drugs, as well as environmental and life style factors (pharmacogenomics or pharmacogenetics).

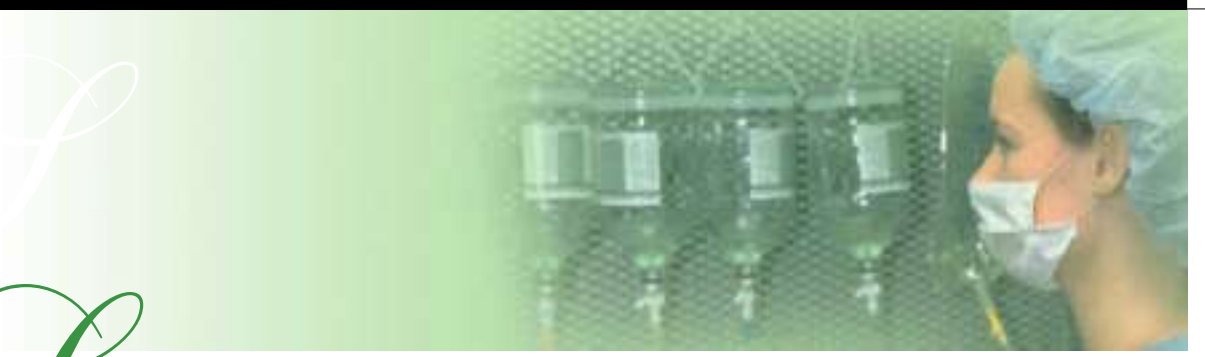
With this type of information it is possible to identify the molecular differences between cancerous and normal cells, to monitor the way in which the tumor responds to treatment and to identify markers of tumor predisposition and disease progression. This information will provide molecular signatures that can guide the individualized design of cancer treatment that is tailored both to the molecular characteristics of the tumor and the genetic characteristics of the patient. It will also provide information useful for cancer prevention and at the individual level to guide lifestyle changes to minimize cancer risk.

The ability to fully utilize the information potential of these new technologies will be markedly enhanced by the development of consortia and networks sharing with experience instrumentation and development of computing/ analytical capability.

Potential Research Topics include:

- Molecular profiling of tumours
- Functional proteomics, elucidation of molecular signalling pathways
- Pharmacogenomics, molecular profiling of populations
- Gene therapy
- Development of model systems
- Technology development
- Hardware
- Bioinformatics, analytical software

Screening



Screening is the application of tests to a presumably well population in order to separate those individuals who may have a particular condition from those who probably do not. Screening has been shown to reduce mortality in some cancer sites (notably, breast, cervix and colorectal cancers). Resources need to be available for the development and testing of new molecular and imaging tests that may prove to be useful in screening initiatives.

In order to implement new screening tests, attention needs to be directed at ways to arrive at high levels of evidence of efficacy without having to subject every new test to population based randomized controlled trials (RCTs); in the case of screening, these are extremely expensive and slow to come to conclusion. Methodologic research in this area would be of high priority.

There is also research needed into the "diffusion curve" of screening in the professional population and the public; this is dealt with in the behavioral research area. Health care research also needs to cover the means of minimizing false positives and false negatives, and the actual, and optimal, diagnostic pathways for screening tests in the general population.

Potential research topics include:

- Achieving high levels of evidence of efficacy without population based RCTs
- "Diffusion curve" of screening
- Minimization of false positive and negatives
- Actual and optimal diagnostic pathways for screening tests in the general population.

Cancer Biomarkers and Imaging

B10
PRIORITY THEMES

Rapid advances are being made in imaging technology. With existing equipment it is possible to resolve tumors at the sub-millimeter level. Molecular biomarkers combined with these advances in imaging technology offer the opportunity to identify cancer very early with the potential for treatment with minimal morbidity. The technology permits visualization of the presence of specific molecules or alterations in metabolic function that are indicative of early cancer related changes (functional imaging). In addition to providing information about the size and shape of a tumor, functional imaging can provide considerable physiological information that can influence treatment design and may provide a non-invasive means to follow or guide drug delivery to the tumor, as well as tumor response during and after treatment. At the experimental level, imaging of this type is playing an increasingly important role in the genomic studies of animal models of cancer development and progression. Currently, clinical trials of the efficacy of new imaging modalities are rare in Canada.

Potential research topics include:

- Diagnostic imaging, including anatomical, functional and qualitative
- Early detection of specific cancers through screening
- Molecular and functional imaging
- Imaging of animal models for genomics research
- Image guided therapy

Pediatric Cancer

Among children aged 0-19, cancer continues to be one of the leading causes of potential years of life lost (PYLL). Although cancer remains a major cause of PYLL, mortality rates for childhood cancer have declined by more than 50% since the early 1950s, with most of the improvement occurring after 1970. Forty years ago, very few survived childhood leukemia (the most common childhood neoplasm) but now approximately 80% of Canadian children and teenagers with acute lymphoblastic leukemia are alive five years after diagnosis.

The success of previous clinical trials in identifying new treatments has been significant, but novel treatments are still needed. The impact of current therapies on developing tissues can produce substantial long-term toxicities. More ways need to be found to reduce such late effects, and to reduce the suffering that can result from them. A better understanding is also needed of the development of tissues during childhood, and of the important differences between tumors of childhood and those of adults.

The establishment and maintenance of a multi-disciplinary research consortium, with an appropriate human and technical infrastructure, would not only enhance innovative collaborative research on childhood cancers, but would also foster the optimal use of existing knowledge.

Potential research topics include:

- Reduction of late effects in survivors of childhood cancer
- Clinical trials, including Phase I/II studies designed in Canada, and participation in Phase I-III international collaborative group trials
- Pediatric palliative care, including methodology and delivery
- Correlative studies of emerging biological and sociobehavioural information on survival, quality of life and long-term outcomes for children and families
- Optimal utilization of existing surveillance data, existing research expertise, and the unique characteristics of the Canadian health care system

Sociobehavioural Cancer Research

B12
PRIORITY THEMES

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.

Sociobehavioural research is crosscutting and must be integrated with research perspectives such as health services research, community perspectives, palliative care, and population and prevention research. There are less extensive but nonetheless critical ties to areas such as translational research (e.g. genetic counselling) and clinical trials (e.g. communications and decision making, quality of life measurement, illness behaviour and adaptation, social support).

Potential research topics include:

- Determinants and development of health risk behaviour and coping, and implications for prevention/improvement
- Ongoing regional survey and surveillance systems to unravel and monitor trends in these factors
- Psychosocial factors that influence adaptation, coping, and quality of life at each age and stage on the cancer continuum
- Increased understanding of the role of complementary medicine in a person's experience of cancer
- Coordination of care, and the balancing of proven conventional, complementary and behavioural medicine strategies.
- Factors influencing uptake behaviour of best practice knowledge by consumers, practitioners, and policy makers
- Outcomes research and program evaluation of cancer control services, to include sociobehavioural predictors, processes, and outcomes

A Delphi Process for Setting Cancer Research Priorities in Canada

Stage 1: Questionnaire

Cutoff Date: October 26, 2001

Sponsored by:

- Canadian Institutes of Health Research- Institute for Cancer Research
- National Cancer Institute of Canada
- Canadian Association of Provincial Cancer Funding Agencies
- Health Canada

A Delphi Process Undertaken by Praxis Inc.

October, 2001

Contents of Questionnaire

Section A – Overriding Thematic Areas

Fourteen themes will be used as the foundation for the Delphi process. The Large Working Group originally identified thirteen themes; however, the Infrastructure theme was split into two themes – A1 Infrastructure and A2 Human Resources. Since these two themes address the tools, resources and other foundations upon which research programs are built, they are considered to be overriding topics; as a result, they comprise Section A of the questionnaire.

Section B – Priority THemes

Section B of the questionnaire deals with the other twelve research priority themes, which are:

B1. Etiologic Factors
B2. Surveillance
B3. Population Based Prevention
B4. Experimental Therapeutics
B5. Clinical Research
B6. Palliative Care/Quality of Life.
B7. Health Services and Policy Research
B8. Genome Science and Cancer
B9. Screening
B10. Cancer Biomarkers and Imaging
B11. Pediatric Cancer
B12. Sociobehavioural Cancer Research

Section C – Comments and Other Thoughts

Section D – Contact /Demographic Information

A1 Infrastructure

1. Do you generally agree with the operational description for Infrastructure? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

2. In your opinion, should something in the operational description for Infrastructure be …

Added: _____

Deleted: _____

Changed: _____

3. Do you generally agree with the key focus areas for Infrastructure? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

4. In your opinion, should something in the key focus areas for Infrastructure be …

Added: _____

Deleted: _____

Changed: _____

A2 Human Resources

1. Do you generally agree with the operational description for Human Resources? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

2. In your opinion, should something in the operational description for Human Resources be …

Added: _____

Deleted: _____

Changed: _____

3. Do you generally agree with the key focus areas for Human Resources? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

4. In your opinion, should something in the key focus areas for Human Resources be …

Added: _____

Deleted: _____

Changed: _____

Section B – Priority Themes

B1 Etiologic Factors

1. Do you generally agree with the operational description for Etiologic Factors? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

2. In your opinion, should something in the operational description for Etiologic Factors be …

Added: _____

Deleted: _____

Changed: _____

3. Do you generally agree with the potential research topics for Etiologic Factors? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

4. In your opinion, should something in the potential research topics for Etiologic Factors be …

Added: _____

Deleted: _____

Changed: _____

5. In your opinion, what are the three most important infrastructure needs related to Etiologic Factors? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

6. In your opinion, what are the three most human resources needs related to Etiologic Factors? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

B2 Surveillance

1. Do you generally agree with the operational description for Surveillance? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

2. In your opinion, should something in the operational description for Surveillance be …

Added: _____

Deleted: _____

Changed: _____

3. Do you generally agree with the potential research topics for Surveillance? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

4. In your opinion, should something in the potential research topics for Surveillance be …

Added: _____

Deleted: _____

Changed: _____

5. In your opinion, what are the three most important infrastructure needs related to Surveillance? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

6. In your opinion, what are the three most human resources needs related to Surveillance? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

B3 Population Based Prevention

1. Do you generally agree with the operational description for Population Based Prevention? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

2. In your opinion, should something in the operational description for Population Based Prevention be …

Added: _____

Deleted: _____

Changed: _____

3. Do you generally agree with the potential research topics for Population Based Prevention? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

4. In your opinion, should something in the potential research topics for Population Based Prevention be …

Added: _____

Deleted: _____

Changed: _____

5. In your opinion, what are the three most important infrastructure needs related to Population Based Prevention? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

6. In your opinion, what are the three most human resources needs related to Population Based Prevention? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

B4 Experimental Therapeutics

1. Do you generally agree with the operational description for Experimental Therapeutics? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

2. In your opinion, should something in the operational description for Experimental Therapeutics be …

Added: _____

Deleted: _____

Changed: _____

3. Do you generally agree with the potential research topics for Experimental Therapeutics? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

4. In your opinion, should something in the potential research topics for Experimental Therapeutics be …

Added: _____

Deleted: _____

Changed: _____

5. In your opinion, what are the three most important infrastructure needs related to Experimental Therapeutics? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

6. In your opinion, what are the three most human resources needs related to Experimental Therapeutics? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

B5 Clinical Research

1. Do you generally agree with the operational description for Clinical Research? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

2. In your opinion, should something in the operational description for Clinical Research? be …

Added: _____

Deleted: _____

Changed: _____

3. Do you generally agree with the potential research topics for Clinical Research? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

4. In your opinion, should something in the potential research topics for Clinical Research be …

Added: _____

Deleted: _____

Changed: _____

5. In your opinion, what are the three most important infrastructure needs related to Clinical Research? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

6. In your opinion, what are the three most human resources needs related to Clinical Research? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

B6 Palliative Care/Quality of Life

1. Do you generally agree with the operational description for Palliative Care/Quality of Life? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

2. In your opinion, should something in the operational description for Palliative Care/Quality of Life be …

Added: _____

Deleted: _____

Changed: _____

3. Do you generally agree with the potential research topics for Palliative Care/Quality of Life? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

4. In your opinion, should something in the potential research topics for Palliative Care/Quality of Life be …

Added: _____

Deleted: _____

Changed: _____

5. In your opinion, what are the three most important infrastructure needs related to Palliative Care/Quality of Life? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

6. In your opinion, what are the three most human resources needs related to Palliative Care/Quality of Life? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

B7 Health Services and Policy Research

1. Do you generally agree with the operational description for Health Services and Policy Research? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

2. In your opinion, should something in the operational description for Health Services and Policy Research be …

Added: _____

Deleted: _____

Changed: _____

3. Do you generally agree with the potential research topics for Health Services and Policy Research? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

4. In your opinion, should something in the potential research topics for Health Services and Policy Research be …

Added: _____

Deleted: _____

Changed: _____

5. In your opinion, what are the three most important infrastructure needs related to Health Services and Policy Research? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

6. In your opinion, what are the three most human resources needs related to Health Services and Policy Research? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

B8 Genome Science and Cancer

1. Do you generally agree with the operational description for Genome Science and Cancer? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

2. In your opinion, should something in the operational description for Genome Science and Cancer be …

Added: _____

Deleted: _____

Changed: _____

3. Do you generally agree with the potential research topics for Genome Science and Cancer? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

4. In your opinion, should something in the potential research topics for Genome Science and Cancer be …

Added: _____

Deleted: _____

Changed: _____

5. In your opinion, what are the three most important infrastructure needs related to Genome Science and Cancer? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

6. In your opinion, what are the three most human resources needs related to Genome Science and Cancer? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

B9 Screening

1. Do you generally agree with the operational description for Screening? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

2. In your opinion, should something in the operational description for Screening be …

Added: _____

Deleted: _____

Changed: _____

3. Do you generally agree with the potential research topics for Screening? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

4. In your opinion, should something in the potential research topics for Screening be …

Added: _____

Deleted: _____

Changed: _____

5. In your opinion, what are the three most important infrastructure needs related to Screening? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

6. In your opinion, what are the three most human resources needs related to Screening? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

B10 Cancer Biomarkers and Imaging

1. Do you generally agree with the operational description for Cancer Biomarkers and Imaging? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

2. In your opinion, should something in the operational description for Cancer Biomarkers and Imaging be …

Added: _____

Deleted: _____

Changed: _____

3. Do you generally agree with the potential research topics for Cancer Biomarkers and Imaging? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

4. In your opinion, should something in the potential research topics for Cancer Biomarkers and Imaging be …

Added: _____

Deleted: _____

Changed: _____

5. In your opinion, what are the three most important infrastructure needs related to Cancer Biomarkers and Imaging? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

6. In your opinion, what are the three most human resources needs related to Cancer Biomarkers and Imaging? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

B11 Pediatric Cancer

1. Do you generally agree with the operational description for Pediatric Cancer? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

2. In your opinion, should something in the operational description for Pediatric Cancer? be …

Added: _____

Deleted: _____

Changed: _____

3. Do you generally agree with the potential research topics for Pediatric Cancer? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

4. In your opinion, should something in the potential research topics for Pediatric Cancer be …

Added: _____

Deleted: _____

Changed: _____

5. In your opinion, what are the three most important infrastructure needs related to Pediatric Cancer? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

6. In your opinion, what are the three most human resources needs related to Pediatric Cancer? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

B12 Sociobehavioural Cancer Research

1. Do you generally agree with the operational description for Sociobehavioural Cancer Research? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

2. In your opinion, should something in the operational description for Sociobehavioural Cancer Research be …

Added: _____

Deleted: _____

Changed: _____

3. Do you generally agree with the potential research topics for Sociobehavioural Cancer Research? Please circle your choice from 1 (strongly disagree) to 5 (strongly agree) or N/A (no opinion).

Strongly Disagree				Strongly Agree	N/A
1	2	3	4	5	

4. In your opinion, should something in the potential research topics for Sociobehavioural Cancer Research be …

Added: _____

Deleted: _____

Changed: _____

5. In your opinion, what are the three most important infrastructure needs related to Sociobehavioural Cancer Research? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

6. In your opinion, what are the three most human resources needs related to Sociobehavioural Cancer Research? Please priorize your answers with 1 being most important.

Priority 1 _____

Priority 2 _____

Priority 3 _____

Section C – Comments and Other Thoughts

In your opinion, are there other priority research themes which should have been included?

Do you have additional comments?

Section D – Contact/Demographic Information

In order to assist us in grouping responses we need to have you classify yourself into one of the following areas. Please select one category which most strongly represents your work.

Currently-active researcher:

____Basic biological research
____Other basic research
____Clinical research
____Health services research
____Population heath research
____Psychosocial research
____Other (please specify) _____

Not currently-active researcher:

____Advocacy
____Health care
____Policy analysis and development
____Regulatory review
____Other (please specify) _____

Please select one category which most strongly represents the type of organization to whom you work or belong.

____Academic institution
____Healthcare institution
____Volunteer organization
____Consumer organization
____Federal Government
____Provincial Government
____Local or Regional Health Authority
____Individual
____Other (please specify) _____

A Delphi Process for Setting Cancer Research Priorities in Canada

Stage II: Backgrounder and Questionnaire

Cutoff Date: February 12 - 5:00 p. m. MST, 2002

Sponsored by:

- Canadian Institutes of Health Research- Institute for Cancer Research
- National Cancer Institute of Canada
- Canadian Association of Provincial Cancer Funding Agencies
- Health Canada

A Delphi Process Undertaken by Praxis Inc.

January, 2002

An Introduction to the Delphi Process: Stage II

A Delphi process is a staged process for developing consensus and making group-based decisions. A Delphi process typically occurs in a series of stages, over time. Participants provide their comments regarding a particular set of issues or areas of interest. The groups' responses are then analyzed and reported back so participants can compare their own responses to those of the overall group. Participants, having benefit of the previous discussion, comment on the issues again as well as other questions that have been raised. A new group report is generated and the process is repeated with a new series of questions.

The Delphi process for setting cancer research priorities is being conducted in three stages:

Revised Schedule

- Stage 1 – October 2001
- **Stage 2 – January - February, 2002**
- **Stage 3 – March, 2002**

For the most part, Stage II of the Delphi process is internet-based. To ensure security and confidentiality, each participant has received a log-on link and a personal password, allowing access to all materials including the questionnaire. The questionnaire can be completed and submitted on-line. Because individual questionnaire responses can only be accessed with a personal password, the confidentiality of the participant is protected. As well, personal names, organizations or affiliations will not be identified in the summary or final reports.

We Have Heard You!!

We knew that Stage I would include a lot of information – some of it fairly complex and lengthy - but it was important to get this information to participants. There were a number of complaints about this. Stage II, although requiring as much reading, will be simpler. There is only one document. It is the Stage II Backgrounder and Questionnaire. We have reduced the graphics so that the access time on-line or downloading via modem will be quicker. Finally, the questionnaire requires you to prioritize a number of topic areas. As a result, this questionnaire should take from 20 to 40 minutes to complete, depending on the number of topics (themes) you want to address.

Overview of Stage I

In Stage 1, over 800 names were provided to the Delphi team. We were unable to obtain email or fax numbers for 110 of the potential participants. An almost equal number signed on to the process, but indicated that they did not want to participate and were deleted from the database. This resulted in 181 final participants for Stage I as presented in the following table.

Original database	846
No contact info	110
Declined participation	102
Non-Participants (no response)	453
Participants	181

Instructions to Complete Stage II

Please Read Thoroughly Before Proceeding!!!

Stage II is comprised of only one document, which includes a summary of participants' comments from Stage I and a series of lists to be prioritized by you. For each of the research themes there is:

- A table summarizing agreement/disagreement with the operational description for the research theme.
- A summary of the suggested revisions to the operational description. (Comments were grouped into categories based on common or similar responses.)
- An expanded list of Potential Research Topics - **for you to prioritize**.
- A table summarizing the categories of infrastructure needs pertaining to the research theme as suggested by participants.
- An expanded list of infrastructure needs pertaining to the theme - **for you to prioritize**.
- A table summarizing the categories of human resource needs pertaining to the research theme as suggested by participants.
- An expended list of human resource needs - **for you to prioritize**.

LOGGING ONTO THE WEBSITE

When you log on to the Website, you will be presented with a window that has the original demographic information you completed as well as three new questions. **You must complete this information before you will be able to proceed.** In the case of hardcopy responses, we will not be able to include your response in the analysis if this information is not completed. Following this, a window will open and provide *A Summary of Section C from Stage I, "Other Themes and Comments"* that many Stage I participants completed followed by the *Table of Contents* for the rest of Stage II. You will be able to click on the Table of Contents to go directly to the themes that you wish to address.

When you go into each theme you will see a button at the top right hand corner that says *"Print this Section"*. If you want a hard copy please click on this button and a copy of only that theme will be printed out. If you would like to print a copy of the entire document, a PDF file has been created. Click on this link to download the PDF file: *Stage II - Backgrounder and Questionnaire*. We have reduced the size of this document for easier downloading and use. Print in black-only to accelerate printing. You can then read the section and complete the prioritizing off-line, then come back on line to finish the process. If at any time, you need to review the original *Stage I - Backgrounder*, you can download the file by clicking here on it.

If for some reason, you cannot complete your response on-line, you can download and print the PDF file, complete the questionnaire in hardcopy format and fax only the completed pages back to us. To ensure that we can use your comments, **questionnaires that are faxed back must be written legibly and include your name and password so that we can identify your material.** Please do not write in the margins but feel free to add extra pages.

Contact Information:
Fax: 403 229-3037
Email: cancer_delphi@praxis.ca

The link and personal password allow you to enter your file at your convenience and add, delete or make any changes you wish. When you click the submit button at each stage you will receive a message advising that your information has been received.

Finally, you do not have to complete all the sections. Please complete those that are relevant to you and your view of cancer research in the future.

The final cutoff date for the survey is February 12th, 2002 at 5:00 p.m. MST. There will be no extensions!
Thank you for your participation!

Comments and Other Thoughts from Stage 1 Section C

In this section, participants commented about the Delphi process or suggested new research themes and/or additional research topics. Wherever possible, suggested research topics were incorporated into the appropriate research theme.

The Delphi Process

Some participants identified problems downloading large documents or expressed concerns that completion of the questionnaire required considerable time. In response to these concerns, the files are smaller and the questionnaires are simpler - Participants provide feedback by ranking various topics.

Additional Cancer Research Themes

Participants suggested addition of the following research themes:

Overriding Themes:

Basic Research Areas - The importance of basic cell and molecular biology, immunology, computational biology and statistics was understated. It was suggested that an overriding theme be identified to address these basic research areas.

Ethics - The issue of ethics including privacy regulation, access to human subjects and data is inadequately covered. It was suggested that this be an overriding theme called "*Access to human subjects and private data*" or included as part of the Infrastructure theme

Public Education and Outreach - There were a number of suggestions pertaining to enhancing public awareness of aspects such as cancer prevention, diagnosis and treatment.

Comments and Other Thoughts from Stage 1 Section C

Additional Research Themes:

Surgery and Radiation Therapy Research - These are the most common and effective methods of intervention yet they are almost ignored. Optimization of surgery and radiation therapy would result in immediate and substantial improvements in outcomes.

The Study of Sub-Groups of the Population (e.g. Aboriginal, immigrant, gender) - There must be a clearer recognition of the need to integrate into studies the differing aspects of cancer control in the management of individuals and communities.

Complementary Therapies - The role of complementary medicine is marginalized yet front and centre in the daily reality of patients. Complementary cancer care - approaches that can help support the mind, body and spirit (and thus, the immune system) - deserves its own category. Historically, the conventional research community has all but ignored this important field. The majority of cancer patients use one or more complementary therapies and the general public is demanding that research in complementary therapies be funded.

Late Effects of Treatment and Follow-Up Care - Follow-up care is largely ignored in cancer research. Enormous clinical resources are used for follow-up, optimization of this process could potentially save resources, improve the outcomes and quality of life.

Basic Cancer Research - For example: basic informatics research, statistical research needed to enhance the collection and analyses of data highly relevant to cancer control, signal transduction, tumour invasion and metastasis.

Specialized Training of Health Care Professionals - The impact of specialized training of health care professionals on patient care and outcomes should be considered.

Contact/Demographic Information

Please complete the following contact information. Participants from Stage I who are completing this in hard copy are asked to re-submit their contact information and complete the three new questions at the end of the section that are highlighed in italics.

Participants who have not submitted contact information will not be included in Stage III of the Delphi process.

In order to assist us in grouping responses we need to have you classify yourself into one of the following areas. Please select one category which most strongly represents your work or acitivities.

Currently-active researcher:

____ Basic biological research
____ Other basic research
____ Clinical research
____ Health services research
____ Population health research
____ Psychosocial research

Non-researchers and not currently active researchers:

____ Advocacy
____ Health care
____ Policy analysis and development
____ Regulatory review
____ Other (please specify) _____

Please select one category which most strongly represents the type of organization in which you work, or to which you belong.

____ Academic institution
____ Health care institution
____ Volunteer organization
____ Consumer organization
____ Federal Government
____ Provincial Government
____ Local or Reginal Health Authority
____ Individual
____ Other (please specify) _____

Please indicate where province or territory you reside

____ *British Columbia*
____ *Alberta*
____ *Saskatchewan*
____ *Manitoba*
____ *Ontario*
____ *Quebec*
____ *New Brunswick*
____ *Nova Scotia*
____ *Prince Edward Island*
____ *Yukon*
____ *Northwest Territories*
____ *Nunavut*

Please indicate your gender

____ Male ____ Female

Please indicate your age group

____ Less than 30 years
____ 31 to 40 years
____ 41 to 50 years
____ 51 to 60 years
____ 61 to 70 years
____ *over 70*

A1 Infrastructure

Agreement/Disagreement with Operational Description

The majority of respondents agreed or strongly agreed with the operational description. The results are summarized below:

Operational Description Response Frequency (n = 164)

Response	# of Respondents	% of Respondents
Strongly Disagree	**1**	**.6**
Disagree	**7**	**4.4**
Neutral	**20**	**12.5**
Agree	**77**	**48.1**
Strongly Agree	**55**	**34.4**
Not Applicable	**4**	

Suggested Revisions to the Operational Description

Infrastructure Description

- Operational description requires a general overview that explains infrastructure in the context of cancer research. What is it? Why is it important? What are the implications?

National Voice

- Define more specifically - too vague.
- Does not fit under infrastructure - should be removed.
- Indicate that laypersons should be included in networks as part of the national voice; inclusion of a broad group of non-scientists.
- Highlight the advisory role of the national voice.

Supply of Physical Space and Equipment

- Need for physical buildings/research facilities, personnel, electronic facilities for research.
- Access and supply of adequate equipment.
- Problems with reference physical space in academia.

Mechanism for Knowledge Transfer/Communications

- Formal methodology or forum for sharing research findings.
- Transfer of research to practice.
- Mechanism for public education, communication and discussion about research programs.

Evaluation, Accountability and Economics

- Not appropriate topics for infrastructure.
- Less emphasis on economics.

Key Focus Areas

The following is a list of Key Focus Areas. The items in green were included in the Stage 1 Backgrounder while the items in **black** are the topics most frequently suggested by participants during Stage 1.

Please select up to five priority Key Focus Areas from the amalgamated list (both the green and the **black**) below. In the space provided, indicate your ranking with one (1) as the highest priority.

____ Informatics databases, such as those required for policy and legislation and those required for the results of molecular-level tests arising out of basic research

____ Tumour banks, with national standards and networks, centres, consortia

____ Funding mechanisms and targets

____ National voice for research in cancer control

____ **Research targeted at overcoming infrastructure barriers (e.g. privacy legislation, impacts on surveillance, simplifying access)**

____ **Focus should not be limited to databases; include all types of data**

____ **Standards for databases to facilitate linkages and improve access**

____ **Integrated and coordinated system to link databases and help streamline and simplify access**

____ **Development of clinical research networks**

____ **Development of networks that are multidisciplinary and multisectoral and include those who are under represented and laypersons**

____ **Provision of sufficient physical space, labs and equipment to conduct research**

If you would like to add one additional Key Focus Area, please write it in the space provided below.

Other (please specify) _____

_____

_____

Agreement/Disagreement with Operational Description

The majority of respondents agreed or strongly agreed with the operational description. The results are summarized below:

Operational Description Response Frequency (n = 137)

Response	# Of Respondents	% Of Respondents
Strongly Disagree	**1**	**.7**
Disagree	**5**	**3.7**
Neutral	**13**	**9.6**
Agree	**52**	**38.2**
Strongly Agree	**65**	**47.8**
Not Applicable	**1**	

Suggested Revisions to the Operational Description

Recruitment and Retention

- Capture, educate and train the next generation of basic and clinical researchers; attract uncommitted trainees (undergrads, grads).
- Stable funding for career researchers; all researchers should be provided with a baseline budget.
- Recruitment and retention of scientists to work in federal/provincial organizations.
- Career stability and development for research support staff; more emphasis on clinical support staff.

Expansion of Research Teams/Human Resources Scope

- Community partners should be part of the research team.
- Human resources should include all health and social services professionals, patients and their families.
- Development of strong multidisciplinary, international teams.

Key Focus Areas

The following is a list of Key Focus Areas. The items in green were included in the Stage 1 Backgrounder while the items in **black** are the topics most frequently suggested by participants during Stage 1.

Please select up to five priority Key Focus Areas from the amalgamated list (both the green and the **black**) below. In the space provided, indicate your ranking with one (1) as the highest priority.

____ Aggressively addressing the human resources crisis

____ Attracting appropriately qualified new researchers

____ Retaining existing well-qualified researchers

____ Making better use of existing highly qualified researchers

____ Fostering the utilization of multidisciplinary and innovative approaches

____ Stimulating programs in priority underserved areas to become viable

____ Enhancing support for these who can best translate research into policy and practice

____ Providing opportunities and support for career retraining and transition to new research

____ More funding for, and emphasis on, training and development of researchers

____ Enhancing the training related to research in medical schools and education programs

____ Offering training for researchers in underserved areas, technical support areas; training for new researchers

____ Enhancing interactions between clinicians, researchers and practitioners

____ Improving system of communication between basic researchers, laboratory bench, clinicians

If you would like to add one additional Key Focus Area, please write it in the space provided below.

Other (please specify) _____

_____

_____

B1 Etiologic Factors

Agreement/Disagreement with Operational Description

The majority of respondents agreed or strongly agreed with the operational description. The results are summarized below:

Operational Description Response Distribution (n = 117)

Response	# of Respondents	% of Respondents
Strongly Disagree	**2**	**1.7**
Disagree	**6**	**5.2**
Neutral	**18**	**15.7**
Agree	**61**	**53.0**
Strongly Agree	**28**	**24.3**
‡'drvNot Applicable	**2**	

Suggested Revisions to the Operational Description

Description Needs More Careful Delineation

- Not focused on the right issue - understanding why people respond the way they do to known risks is more important and more cost effective than focusing on identifying more risks.
- Age, inheritance, sex and ethnic group are important and need to be included in research.
- Age, inheritance, sex and ethnicity are not modifiable risks and should therefore be excluded.
- Etiology needs to be carefully delineated from other related topics such as population-based prevention and genome science.

Description is Too Narrow

- Operational description is too narrow; broaden the description to include chemical, biological, mental, spiritual and emotional factors.
- Too much emphasis on dietary factors to the exclusion of other important lifestyles issues, such as exercise and tobacco use.

Potential Research Topics

The following is a list of Potential Research Topics. The items in green were included in the Stage 1 Backgrounder while the items in **black** are the topics most frequently suggested by participants during Stage 1.

Please select up to five priority Potential Research Topics from the amalgamated list (both the green and the **black**) below. In the space provided, indicate your ranking with one (1) as the highest priority.

____ Increased detail in the identification of natural dietary factors that could prevent cancer

____ Potential biomarkers of exposure as an adjunct, validation, or substitute for traditional interview techniques

____ Validated markers that would predict pre-cancerous change

____ **Model of research that would allow for greater examination of multiple interactions**

____ **Research related to the impact of lifestyle factors (e.g. sun exposure, smoking, diet, exercise etc.)**

____ **Genetic research (e.g. gene environment interactions, epigenetic alterations, genomic research to identify potential etiologic factors and functional genomic and proteomics,**

modifier genes in cancer and genetic risk markers)

____ Environmental carcinogens and contaminants, environmental/occupational exposure, household (e.g. industrial emissions, pesticides, food additives)

____ Improve effectiveness of current research (e.g. more accuracy in measurements of exposure; more large, long-term research cohort studies; more good exposure data)

If you would like to add one additional Potential Research Topic, please write it in the space provided below.

Other (please specify) _____

_____

_____

Suggested Infrastructure Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 63 means that the first, second or third priority suggestions of 63 participants pertained to the theme.

Infrastructure Needs Key Themes	Priority Response (Combined Totals)
Coordination and Distribution of Research and Information	**63**
Database Creation, Use and Access	**44**
Funding	**35**
Research Methods Approaches and Procedures	**33**
Other Research Needs	**16**
Other	**8**

Most Important Infrastructure Needs

The following is a list of the most frequently suggested infrastructure needs related to etiological factors. The items describing each need are examples taken from respondents' comments. Please select up to five priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Networks** - development of multidisciplinary and interdisciplinary research and information networks

____ **Tumour/Tissue Banks** - national coordination, standards and networks; associated databases; evaluation and distribution of research findings

____ **Data Base Informatics** - design, development and management of databases

____ **National Data Sets** - large-scale, comprehensive, accessible data sets

____ **Standardized, Linked Databases** - e.g. data and tumour warehouses linked to exposure databases, environmental databases linked to cancer incidence databases

____ **Funding** - adequacy, structure, mechanisms and targets

____ **Population-Based Cohort Studies** - large-scale, long-term, including sub-populations

If you would like to add one infrastructure need, please write it in the space provided below.

Other (please specify) _____

_____

Suggested Human Resource Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 112 means that the first, second or third priority suggestions of 112 participants pertained to the theme.

Human Resource Needs – Key Themes	Priority Response (Combined Totals)
Knowledge and Training Needs	**112**
Recruitment	**31**
Retention, Support and Use of Existing Personnel	**13**
Team Building and Information Sharing	**11**
Other	**10**

Most Important Human Resource Needs

The following is a list of the most frequently suggested human resource needs related to etiological factors. The items describing each need are examples taken from respondents' comments. Please select up to five priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Multidisciplinary and Multisectoral Networks** - teams of qualified people with innovative approaches; cross discipline training; researchers who can straddle areas; epidemiology and clinical intervention trials

____ **More Epidemiologists** - cancer, molecular, population based, genetic, clinical

____ **Staff Statisticians** - involved with data collection, database generation and management, computer programming; bioinformatics experts

____ **Genetics** - technologists skilled in biomarker and genetic testing; geneticists/molecular biologists; cancer geneticists/ genetic counsellors; genome scientists; "epigeneticists"

____ **Attracting and Retaining Researchers** - sufficient highly qualified researchers

____ **Networks** - more effective multi-agency, multi-province research networks; stronger connections between cancer centres and departments responsible for epidemiology

If you would like to add one human resource need, please write it in the space provided below.

Other (please specify) _____

_____

_____

Agreement/Disagreement with Operational Description

The majority of respondents agreed or strongly agreed with the operational description. The results are summarized below:

Operational Description Response Distribution (n=110)

Response	# of Respondents	% of Respondents
Strongly Disagree	**3**	**2.8**
Disagree	**4**	**3.7**
Neutral	**18**	**16.8**
Agree	**42**	**39.3**
Strongly Agree	**40**	**37.4**
Not Applicable	**3**	

Suggested Revisions to the Operational Description

Development of Networks/Databases

- National network of registries and databases that encourages a common method for the collection and dissemination of data.
- Implementation of surveillance project and development of surveillance networks .
- Development of the necessary infrastructure that will support standardized data collection.
- Linkages including administrative databases with registries and exposure databases to enable studies that include health care system use.

Definition of Surveillance

- Weak definition of surveillance; surveillance should be defined as activities defined to monitor the health of the population.
- Definition should be expanded to relate to specific populations, outcomes, risk factors and behaviours.
- Elaboration of the notion of privacy issues required.

Potential Research Topics

The following is a list of Potential Research Topics. The items in green were included in the Stage 1 Backgrounder while the items in **black** are the topics most frequently suggested by participants during Stage 1.

Please select up to five priority Potential Research Topics from the amalgamated list (both the green and the **black**) below. In the space provided, indicate your ranking with one (1) as the highest priority.

____ Appropriate accessibility of databases

____ Linking of registries with exposure databases or geographic exposure information

____ Population surveys that would develop population levels of exposure

____ Building of research expertise on geographical exposures to map against cancer incidence maps

____ Developing a cadre of scientists with a high level of statistical expertise

____ **Support for the maintenance and improvement of cancer registries**

____ **Surveys of risk factors and of causes of exposures**

____ **Creation of linkages with other chronic disease databases (e.g. diabetes, heart)**

____ **Research into best practices for data collection, ensuring data quality at various levels (e.g. completeness, validity)**

____ **Professional development of scientists with bioinformatics and computer science expertise**

____ **Obtaining information related to incidence,**

causes, and treatment of specific cancers in specific populations for specific genes/ genotypes through surveillance

____ Enhanced surveillance methodology (e.g. more sophisticated forecasting; more systematic surveillance for changing patterns, better record linkage and processing of very large data bases, etc.)

____ Improvements in informatics technology (e.g. standard interface, common edits, etc.)

____ Regular population surveillance of risk conditions/behaviours to permit studies of macro population level interventions on risk conditions/behaviours

____ Impact of screening intervention, impact of preventative strategies and application of treatment according to disease type and stage

____ Support (shared with other diseases, health promotion) of long term databases on tobacco use/exposure, dietary intake, physical activity levels, etc.

If you would like to add one additional Potential Research Topic, please write it in the space provided below.

Other (please specify) _____

_____

_____

Suggested Infrastructure Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 73 means that the first, second or third priority suggestions of 73 participants pertained to the theme.

Infrastructure Needs Key Themes	Priority Response (Combined Totals)
Databases and Data Management	**73**
Research Methods and Procedures	**33**
Networks and Coordination	**31**
Funding	**21**
Legislation	**8**
Other	**10**

Most Important Infrastructure Needs

The following is a list of the most frequently suggested infrastructure needs related to surveillance. The items describing each need are examples taken from respondents' comments. Please select up to five priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Databases and Data Management** - accessible, comprehensive, integrated databases; registries linked to exposure and geographic exposure information, to staging and treatment databases, to national clinical trials networks; common, national standards for data storage and sharing; more collaboration between surveillance database managers and users; incorporation into census data gathering; inclusion of rural populations; common computer hardware and software

____ **Research Methods and Procedures** - on-going population surveys; local socio-behavioural monitoring tools; long-term surveillance systems for risk factors; population based cancer registries to identify, classify and track the outcomes for each case; update Enhanced Cancer Surveillance System database; periodic collection, analysis and dissemination of information on behavioural risk factors; comprehensive markers for surveillance; separate pediatric surveillance system

____ **Networks and Coordination** - multidisciplinary, national networks; national goals for reducing risk behaviours/conditions;

steering group for cancer surveillance connected to a national cancer strategy; collaboration with Health Canada and Statistics Canada; regional standardized registries; national intake coordinating centre

____ **Funding** - funding for: cancer registry activities, strategic plan developed by the Canadian Coalition on Cancer Surveillance; "surveillance" proposals become eligible for research funding.

____ **Legislation** - policies that allow linkage and access; resolving issues of privacy and access; interprovincial agreement to enable standardization, merging and linkage of databases; standardized population surveys at regular intervals to enable research on macro population level preventive interventions

If you would like to add one infrastructure need, please write it in the space provided below.

Other (please specify) _____

_____

_____

Suggested Human Resource Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 75 means that the first, second or third priority suggestions of 75 participants pertained to the theme.

Human Resources Needs Key Themes	Priority Response (Combined Totals)
New Skills Required	**75**
Attracting and Retaining Personnel	**25**
Training and Supporting Personnel	**20**
Networks	**28**
Funding	**5**
Data	**2**
Legislation	**2**
Other	**6**

Most Important Human Resource Needs

The following is a list of the most frequently suggested human resource needs related to surveillance. The items describing each need are examples taken from respondents' comments. Please select up to five priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **New Skills Required** - include: epidemiologists; public health practitioners/ scientists-survey expertise; training data managers; statisticians, with a knowledge of cancer ; public health practitioners/scientists with survey expertise; high level statisticians; molecular epidemiologists; ethicists to address privacy issues; information technology staffing; trained tumour registrars in each geographic area or hospital; occupational hygienists; cancer informatics specialists; human resources expertise in surveillance

____ **Attracting and Retaining Personnel** - attracting appropriately qualified new researchers; retaining existing researchers

____ **Training and Supporting Personnel** - capacity building; making training programs in this area more attractive; enhancing support for those can translate research into policy/ practice

____ **Networks** - transdisciplinary research teams, with both strong critical mass locally and multicentre links; willingness to collaborate and share information

____ **Funding** - increased funding; funding support for key trained people to help with data interpretation

If you would like to add one human resource need, please write it in the space provided below.

Other (please specify) _____

_____

_____

B3 Population Based Prevention

Agreement/Disagreement with Operational Description

The majority of respondents agreed or strongly agreed with the operational description. The results are summarized below:

Operational Description Response Distribution (n = 112)

Response	# of Respondents	% of Respondents
Strongly Disagree	**2**	**1.8**
Disagree	**3**	**2.7**
Neutral	**14**	**12.7**
Agree	**45**	**40.9**
Strongly Agree	**46**	**41.8**
Not Applicable	**2**	

Suggested Revisions to the Operational Description

Population Health

- Several respondents interpreted "population health" in a broader health promotion framework and recommended that intervention strategies include the broader determinants of health.

Preventable Cancers

- Emphasize that more than 50%, and possibly up to 70%, of cancers are preventable.
- More focus on cancer prevention through the reduction of tobacco usage.
- Greater emphasis on other behavioural and environmental factors that are or may be cancer related.

Improved Evaluation

- Need to evaluate the effectiveness of interventions, both in terms of lifestyle changes and incidence, prevalence, and mortality rates.

Potential Research Topics

The following is a list of Potential Research Topics. The items in green were included in the Stage 1 Backgrounder while the items in **black** are the topics most frequently suggested by participants during Stage 1.

Please select up to five priority Potential Research Topics from the amalgamated list (both the green and the **black**) below. In the space provided, indicate your ranking with one (1) as the highest priority.

____ Lifestyle modification (nutrition, exercise, reduced sun exposure)

____ Effects of legislation on exposures to carcinogens

____ Efficacy of protective devices and practices limiting exposure (sunscreen)

____ Efficacy of community based interventions e.g. social, educational

____ Research into the effectiveness of integrated disease prevention strategies (cancer, heart disease, etc.)

____ Methods determining impact of policy/ regulatory interventions

____ Interrelationships among risk behaviours, social determinates, community context and health outcomes

____ Designs for evaluating setting of quantitative/ population-specific impacts (including the interactions among influences)

____ Collaboration between formal agencies/NGOs/ governments/disciplines, etc.

____ Identification of best mixes of interventions and the development and dissemination of population prevention guidelines

____ Greater emphasis on evaluation of prevention strategies, including the effects of prevention education on behavioural change and the effects of all interventions

____ More focus on preventing use of tobacco smoking and determinants of nicotine addiction

____ More focus on relationships between the physical environment and cancer

____ Assess the best ways of putting current knowledge into practice

____ More emphasis on prevention strategies

If you would like to add one additional Potential Research Topic, please write it in the space provided below.

Other (please specify) _____

_____

_____

Suggested Infrastructure Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 28 means that the first, second or third priority suggestions of 28 participants pertained to the theme.

Infrastructure Needs Key Themes	Priority Response (combined totals)
Funding	**28**
Data	**21**
Networks	**21**
Evaluation	**16**
Advocacy/Policy/Legislation	**15**
Dissemination of research	**6**
Other	**11**

Most Important Infrastructure Needs

The following is a list of the most frequently suggested infrastructure needs related to population based prevention. The items describing each need are examples taken from respondents' comments. Please select up to five priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Funding** - funding for: facilities; longitudinal research; randomized trials; community-based research; policy research; cross-discipline studies; education and travel; translating research into practice

____ **Data and Databases** - national databases; linkages; standardized and multi-level measures/databases; surveillance systems to monitor behaviours and initiatives; national and provincial databases that include risk behaviours; exposures; prevalence and incidence data

____ **Multi-Disciplinary Network** - national, multidisciplinary networks addressing moving research into deliverables; community health network and cancer prevention centres; study coordination; prevention research

____ **Evaluation** - assessing interventions; evaluation guidelines

____ **Advocacy/Public Policy** - researchers speaking with one national voice about cancer control; higher government priority for cancer control; links between researchers and legislators; stronger legislation

____ **Dissemination of Information** - models for dissemination; central clearing house to assure quality information is available to both researchers and the public; mechanism for identifying, promoting, and updating recommendations for "best practices" and research needs related to these practices; better public communication of current knowledge; community access to risk estimates in their own areas

If you would like to add one infrastructure need, please write it in the space provided next.

Other (please specify) _____

_____

_____

Suggested Human Resource Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 28 means that the first, second or third priority suggestions of 28 participants pertained to the theme.

Human Resource Needs Key Themes	Priority Response (combined totals)
Recruitment, training, retention of researchers	**28**
Multi-disciplinary approach	**16**
Human resources, general	**13**
Translating research into practice	**12**
Epidemiologists/statisticians/ methodologists	**10**
Prevention educators	**10**
Other professionals	**19**
Other	**15**

Most Important Human Resource Needs

The following is a list of the most frequently suggested human resource needs related to population based prevention. The items describing each need are examples taken from respondents' comments. Please select up to five priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Attracting new researchers** - new, appropriately qualified researchers including PhD fellows and Post-doctorates; researchers with expertise in community-based research; behavioural science/behaviour modification researchers; health economists

____ **Training** - training new researchers; keeping the existing researchers trained; population based research and methodologies; post-doctoral transdisciplinary training; broad non-disease specific training

____ **Retaining** - retaining and making better use of existing researchers

____ **Multi-Disciplinary Approach** - multi-disciplinary teams and approach(es); cross-discipline interaction among researchers; transdisciplinary teams with local critical mass and multicentre links; enhanced partnerships among all sectors (research-policy-practice); individuals who link research, surveillance, and government intervention

____ **Enhancing Human Resources in the Health Sector (General)** - address the human resource crisis - lack of trained people and lack of positions for trained people; need well-trained prevention scientists/methodologists; health care professionals with training and commitment to cancer prevention; better utilization of public health personnel; enhanced human resources for social services and medicine

____ **Translating Research Into Practice** - enhance support for those who can translate research into practice or policy and practice

____ **Epidemiologists/Statisticians/ Methodologists** - cancer epidemiologists; increased availability of epidemiology specialists; epidemiologists knowledgeable about social and behavioural sciences (and vice versa); statistical model builders

____ **Prevention Educators** - community-based cancer prevention educators; public health educators; community facilitators; personnel trained in behaviour modification; media expertise and involvement

f you would like to add one human resource need, please write it in the space provided below.

Other (please specify) _____

_____

_____

B4 Experimental Therapeutics

Agreement/Disagreement with Operational Description

The majority of respondents agreed or strongly agreed with the operational description. The results are summarized below:

Operational Description Response Frequency (n = 97)

Response	# of Respondents	% of Respondents
Strongly Disagree	**3**	**3.4**
Disagree	**3**	**3.4**
Neutral	**12**	**13.6**
Agree	**31**	**35.2**
Strongly Agree	**39**	**44.3**
Not Applicable	**9**	

Suggested Revisions to the Operational Description

Relationship with Private Sector

- Need for less dependence on pharmaceutical companies.
- Private/public partnerships should be acknowledged and discussed in the operational description.
- Discussion of the relationship of this research to pharmaceutical companies, the conflict of interest controversy and the importance of arms-length research.

Less Emphasis Drug-focused Therapies

- Too focused on drug therapies; equal attention should be paid to other treatments, e.g. radiation, surgery, nutritional therapies.

Potential Research Topics

The following is a list of Potential Research Topics. The items in green were included in the Stage 1 Backgrounder while the items in **black** are the topics most frequently suggested by participants during Stage 1.

Please select up to five priority Potential Research Topics from the amalgamated list (both the green and the **black**) below. In the space provided, indicate your ranking with one (1) as the highest priority.

____ Development of a sophisticated infrastructure to foster and nourish innovation

____ Creation of an organizational and regulatory environment that protects intellectual property, recognizes promising avenues of development, and efficiently moves new therapies towards clinical trials

____ Individualization of therapy

____ Selecting and validating gene based therapeutic targets

____ Facilitating the synthesis, rapid screening, pre-clinical toxicology and evaluation of efficacy of new molecules

____ The translational interface, i.e. support for Phase I clinical trials.

____ Immune therapy of cancer and evaluation of host-tumour interactions

____ Research on novel surgical approaches

____ Research on innovative radiation therapies

____ Development of new paradigms for clinical efficacy testing

____ Research into the economics of therapies with new biologic approaches

____ Creation, validation and exploitation of better models of human malignancies

____ Stem cell research to facilitate healing of normal tissues after various cancer treatments

If you would like to add one additional Potential Research Topic, please write it in the space provided below.

Other (please specify) _____

_____

_____

Suggested Infrastructure Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 26 means that the first, second or third priority suggestions of 26 participants pertained to the theme.

Infrastructure Needs – Key Themes	Priority Response (Combined Totals)
Coordinated Networks/Centres	**26**
Funding	**18**
Clinical Trials	**17**
Translational Research	**12**
Relationship with Private Sector	**11**
Regulatory Environment/Accountability	**8**
Pre-clinical Work/New Discoveries	**7**
Databases	**5**
Other	**20**

Most Important Infrastructure Needs

The following is a list of the most frequently suggested infrastructure needs related to experimental therapeutics. The items describing each need are examples taken from the respondents' comments. Please select up to five priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Co-ordinated Networks/Centres** - centres of excellence; national multidisciplinary programs, networks, centres or consortia to: serve as a national voice, prioritize, ensure scientific validity and rigor, foster innovation, increase communications, coordinate experimental research and link researchers

____ **Funding** - mechanisms to provide adequate and sustained support; funding for non-proprietary nutritional approaches and non-proprietary immuno-stimulative approaches to cancer treatment; development of funding opportunities for highly innovative projects

____ **Clinical Trials** - more and better access to clinical trials; increased support for phase I infrastructure and trials; greater patient base for clinical trials; clinical trials network for each tumour group; more laboratories providing biologic assessments; expanded access to phase I clinical trials for centres not traditionally involved

____ **Translational Research** - encouragement for translational research and research labs; better translational interface; new funding programs for translational research and for the protection of intellectual properties; development of a translational research network for interacting scientists and clinicians

____ **Relationship With Private Sector** - recognition and clarification of ethical issues involved in private sector collaboration; enhancement of coordinated university - pharmaceutical firm research; recognition that emphasis on private sector research must not impede research on promising topics unlikely to yield profit; recognition of the relative responsibilities of the public and private sectors

____ **Regulatory Environment/ Accountability** - creation of an organizational and regulatory environment which protects intellectual property, recognizes promising avenues of development and efficiently moves therapies towards clinical trial; creation of an industry friendly environment

____ **Pre-Clinical Work/New Discoveries** - more funding for proof of concept of new discoveries; support for pre-clinical model research and testing; mechanisms to facilitate the development, screening and pre-clinical testing of new agents; improved access to pre-clinical models and research support targeted to the development of animal models; facility for pre-clinical toxicology and pharmacokinetics studies

____ **Databases** - development of databases

If you would like to add one infrastructure need, please write it in the space provided below.

Other (please specify) _____

_____

_____

Suggested Human Resource Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 37 means that the first, second or third priority suggestions of 37 participants pertained to the theme.

Human Resources Needs Key Themes	Priority Response (Combined Totals)
Need for Specific Skills	**37**
Recruitment and Retention	**18**
Support Researchers (workload)	**11**
Networks	**11**
Training	**9**
Funding	**5**
Other	**16**

Most Important Human Resource Needs

The following is a list of the most frequently suggested human resource needs related to experimental therapeutics. The items describing each need are examples taken from the respondents' comments. Please select up to five priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Need For Specific Skills** – including: clinician scientists; research support personnel such as trials assistants, pharmacists, nurses, data managers; pharmacologists; chemists; research scientists; translational scientists; lab-based individuals who work with and understand tumours, in addition to genes and proteins

____ **Recruitment and Retention** - attract new and retain existing researchers; make research in Canada attractive

____ **Support Researchers** - make better use of existing researchers; protected time for research activity; time for clinicians to participate in research; support translational researchers; reduce clinical pressures on talented researchers

____ **Networks** - multidisciplinary and innovative approaches; national networks and record linkages of researchers; better coordination of research projects; communication between professionals; sharing of scientific results, including failures

____ **Training** - adequate training of individuals working in this area of research and/or new researchers; training in nutritional therapies, immuno-stimulative therapies; translating research into practice; develop stimulating educational programs that would facilitate desire to explore this form of research

____ **Funding** - funding for research personnel in nutritional and immuno-stimulative therapies, translational researchers, research nurses, data managers

If you would like to add one human resource need, please write it in the space provided below.

Other (please specify) _____

_____

_____

Agreement/Disagreement with Operational Description

The majority of respondents agreed or strongly agreed with the operational description. The results are summarized below:

Operational Description Response Frequency (n = 103)

Response	# of Respondents	% of Respondents
Strongly Disagree	**1**	**1.0**
Disagree	**1**	**1.0**
Neutral	**19**	**19.4**
Agree	**37**	**37.8**
Strongly Agree	**40**	**40.8**
Not Applicable	**5**	

Suggested Revisions to the Operational Description

Need to Broaden Description

- Description is too focused on drug trials. It does not sufficiently acknowledge other clinical research such as studies of best treatments, trials on diagnostics and prevention of relapse, sociobehavioural research and a range of other topics.
- Include statement about desired clinical trials endpoints and explain the phases of clinical trials.

Involvement of Patients

- More analysis of the barriers to patient participation in clinical trials including discussion with patients about the best ways to carry out trials.
- No enrolment and participation problems with the pediatric population.

Potential Research Topics

The following is a list of Potential Research Topics. The items in red were included in the Stage 1 Backgrounder while the items in black are the topics most frequently suggested by participants during Stage 1.

Please select up to five priority Potential Research Topics from the amalgamated list (both the red and the black) below. In the space provided, indicate your ranking with one (1) as the highest priority.

____ Regulatory issues that impact on the expeditious conduct of clinical trials and promising new agents

____ The ethical conduct of clinical trials in concert with research on the optima infrastructure for ethical review of trials

____ Manpower issues including studies on factors limiting the number of clinical investigators, support personnel and regulatory personnel

____ Techniques to increase enrolment in clinical trials and patient information about trials

____ Prioritization of trials to meet public needs and expectations balanced with translational research opportunities

____ Enhancement of Canadian participation in international trials

____ Implementation of trials information into practice

____ Studies on herbal medications and other complementary and alternative therapies

____ Studies on nutrition and its role in preventing or modifying cancer incidence and cancer progress

____ Information technology to improve acquisition and utility of clinical data

____ Research on the role of pharmaceutical companies in affecting the nature and types of clinical research

If you would like to add one additional Potential Research Topic, please write it in the space provided below.

Other (please specify) _____

_____

_____

Suggested Infrastructure Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 23 means that the first, second or third priority suggestions of 23 participants pertained to the theme.

Infrastructure Needs Key Themes	Priority Response (Combined Totals)
Funding	**23**
Databases, Data Management	**23**
Clinical Trials	**20**
Ethics, Evaluation and Regulation	**19**
National Leadership and Networks	**16**
Patient Enrolment	**13**
Other	**17**

Most Important Infrastructure Needs

The following is a list of the most frequently suggested infrastructure needs related to clinical research. The items describing each need are examples taken from respondents' comments. Please select up to five priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Funding** - funding mechanisms and targets; independent funding; funding for: clinical trials including infrastructure such as computers and patient databases, non-proprietary treatments, salaries of clinical investigators, administrative support in universities and agencies to run clinical trials, costs incurred by hospitals for participation in a clinical trial, sufficient funding by public agencies to assure that the pharmaceutical industry does not unduly set the agenda for clinical trials

____ **Databases and Data Management** - more national/international networks; readily accessible databases of trials active in Canada; national electronic database system; better informatics support of clinical trials (linking investigators and centres); accessible banks of stored clinical material; clinical trials data managers to support the conduct of trials

____ **Clinical Trials** - increased clinical trials; support for investigators; more phase I research facilities; support of infrastructure at local institutions to allow them to participate; more space in hospitals to facilitate clinical trials; major expansion of clinical trials group or establishment of additional clinical research organizations

____ **Ethics, Evaluation and Regulation** - clarification of ethical frameworks and regulatory issues; less cumbersome, more efficient regulatory processes; increased support of research ethics committees; uniform standards for ethics, design and reporting protocols; coordinated, centralized ethics review processes

____ **National Leadership and Networks** - national, multidisciplinary networks; effective national voice; national clinical trials group to coordinate new academic trials; clinical trial networks; networks between researchers, clinicians, biotech companies and pharmaceutical companies

____ **Patient Enrolment** - increased community involvement; mechanisms to increase access of patients to clinical trials (national networks to more rapidly accrue patients to clinical trials, rapid identification of patients who may be eligible for trials through nightly

notification of positive biopsies to central clinical data warehouse); enrolling community-based patients; site-specific goals for proportion of cancer patients enrolled in clinical trials

If you would like to add one infrastructure need, please write it in the space provided below.

Other (please specify) _____

_____

_____

Suggested Human Resource Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 57 means that the first, second or third priority suggestions of 57 participants pertained to the theme.

Human Resources Needs Key Themes	Priority Response (Combined Totals)
Need for Specific Skills	**57**
Workload Issues	**20**
Recruitment and Retention	**14**
Training	**11**
Funding	**11**
Other	**17**

Most Important Human Resource Needs

The following is a list of the most frequently suggested human resource needs related to clinical research. The items describing each need are examples taken from respondents' comments. Please select up to five priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Need for Specific Skills** - *i*ncluding: clinical scientists, research nurses, data managers, clinical trials investigators, support staff (particularly for participating hospitals), cancer pathologists, research support personnel, translational researchers, biostatisticians

____ **Workload Issues** - ensure protected time to allow clinicians/investigators to engage in research; address human resources shortage; make better use of existing researchers

____ **Recruitment and Retention** - recruit new researchers especially those with the training and skills to attract competitive research grant funding; retain existing researchers

____ **Training** - training support, especially for clinical researchers and for new personnel; clinician education regarding trials and the importance of research; more training opportunities, reward and recognition; cross-discipline training in research methodologies; research training for physicians; training to increase communication between researchers, practitioners and patients

____ **Funding** - funding for: clinical researchers, infrastructure in major cancer centres to allow seamless operation of clinical research projects, research in a holistic mind/body/spirit multifactoral approach to cancer treatment, multicentre trials, more clinical research support staff for centres and networks

If you would like to add one human resource need, please write it in the space provided below.

Other (please specify) _____

_____

_____

B6 Palliative Care/Quality of Life

Agreement/Disagreement with Operational Description

The majority of respondents agreed or strongly agreed with the operational description. The results are summarized below:

Operational Description Response Distribution (n = 106)

Response	# of Respondents	% of Respondents
Strongly Disagree	**1**	**1.0**
Disagree	**3**	**3.0**
Neutral	**9**	**8.9**
Agree	**39**	**38.6**
Strongly Agree	**49**	**48.5**
Not Applicable	**5**	

Suggested Revisions to the Operational Description

Palliative versus Supportive Care

- Disagreement about whether or not palliative care should be defined as care of terminally ill patients.
- Some respondents suggested "supportive care", including symptom control and pain management, at all stages of cancer.

Quality of Life

- Greater emphasis on quality of life during all stages of cancer and for those at risk of cancer because of genetic susceptibility.

Cancer and Palliative Care

- Palliative care is not unique to cancer.
- Some suggest integrating palliative care into the section on oncology or into clinical research and sociobehavioural research.
- Disagreement about considering palliative care as a form of cancer prevention.

Potential Research Topics

The following is a list of Potential Research Topics. The items in green were included in the Stage 1 Backgrounder while the items in **black** are the topics most frequently suggested by participants during Stage 1.

Please select up to five priority Potential Research Topics from the amalgamated list (both the green and the **black**) below. In the space provided, indicate your ranking with one (1) as the highest priority.

____ The pathopsysiology and treatment of the most common and difficult symptoms, including pain, chachexia-anorexia, asthenia, depression, anxiety and delirium collectively present in more than 80% of patients who die of cancer

____ Assessment of the multiple dimensions of symptom intensity and risk factors for symptom distress

____ Decision-making regarding multiple therapeutic interventions including blood products, surgery, artificial nutrition and antineoplastic treatments near the end of life

____ Assessment, management and prevention of symptoms in patients with limited ability to communicate

____ Psychological and social issues that result in patient-family distress

____ Ethical issues in end of life care not otherwise addressed in this list; other issues include research ethics, euthanasia and studies and health professional competence in palliative care

____ Existential and spiritual concerns – development of a taxonomy and assessment tools; evaluation of strategies to help people find meaning at the end of life

____ Organization and delivery of palliative care – studies on integration of palliative care with other aspects of oncology care throughout the trajectory of illness; studies on quality and access coupled with research on models

____ Pediatric palliative care

____ Greater emphasis on pain control or management for cancer patients (e.g. development of more effective medications with fewer side effects)

____ Development of objective criteria for pain assessment

____ Further integration of palliative care with oncology, particularly at earlier stages of cancer, and with acute care

____ Increased coordination of patient care and support among the multiple players (i.e., family and other home caregivers and medical staff) to enhance delivery

____ Investigate and support complementary therapies with a view to improving quality of life

If you would like to add one additional Potential Research Topic, please write it in the space provided below.

Other (please specify) _____

_____

_____

Suggested Infrastructure Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 28 means that the first, second or third priority suggestions of 28 participants pertained to the theme.

Infrastructure Needs Key Themes	Priority Response (combined totals)
Funding	**28**
Networks/Centres of Excellence	**25**
Coordinated/Integrated Delivery	**16**
Research and Evaluation	**17**
National Voice	**8**
Facilities/Beds	**6**
Other	**17**

Most Important Infrastructure Needs

The following is a list of the most frequently suggested infrastructure needs related to palliative care/quality of life. The items describing each need are examples taken from respondents' comments. Please select up to five priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Funding** - adequacy; mechanisms and targets; funding for: medicare to address palliative care, care in communities, palliative care developments, pediatric palliative care research, pain management and spiritual issues; alternate funding to support palliative care delivery; proportion of health care dollars allocated to palliative care

____ **Networks and Centres of Excellence** - community, regional, national and international, multi-disciplinary networks and centres of excellence; centres of excellence that model excellent palliative care and develop strong research programs; strengthened links between clinical researchers, social science researchers, nutrition and metabolism researchers, service

delivery people

____ **Coordination/Integration of Delivery** - developing community capacity; coordinated standardized palliative care programs; research-centred palliative care structure that coordinates in-patient care with community work; linkages between oncologists and palliative care providers

____ **Databases** - regional, national databases; national palliative data network linking care programs; rural medical and nursing practitioners and larger systems such as provincial cancer agency networks

____ **Research and Evaluation** - linking/translating research into practice; clinical trials in palliative care; population-based studies; academic divisions of palliative care at research-oriented universities; identifying and monitoring supportive care needs and evaluating supportive care programs

____ **National voice** - for research in palliative care

____ **Facilities/Beds** - more facilities i.e. beds, hospices, palliative care units in all major medical centres

If you would like to add one infrastructure need, please write it in the space provided below.

Other (please specify) _____

_____

_____

Suggested Human Resource Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 46 means that the first, second or third priority suggestions of 46 participants pertained to the theme.

Human Resource Needs Key Themes	Priority Response (combined totals)
Care Providers	**46**
Researchers	**40**
Training/Education	**27**
Multidisciplinary Approach to Delivery	**11**
Other	**14**

Most Important Human Resource Needs

The following is a list of the most frequently suggested human resource needs related to palliative care/quality of life. The items describing each need are examples taken from respondents' comments. Please select up to three priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Attracting, Retaining and Supporting Researchers** - attracting new and retaining existing researchers; secure funding for established clinician/researchers; better use of current qualified researchers; more practitioner-researchers; involving research specialists in epidemiology, psychometrics with existing palliative care programs to build research capacity

____ **Increasing Numbers, Expertise and Skill Range of Care Providers** - more providers; more palliative care specialists (e.g. physicians, nurses); expansion of the cadre of all palliative care disciplines; more physicians (family doctors, pediatricians, oncologists) interested in palliative care; nurses who serve as community-based links between hospital

and home

____ **Multi-disciplinary Approach** - collaborative, multi-disciplinary approach**;** networks linking translational researchers and clinical palliative care researchers

____ **Training/Education** - training in effective palliative methods for physicians and nurses; integrated multidisciplinary training for clinical and research work; training grants; helping funders understand a holistic mind/body/spirit multifactoral approach to palliative care; curriculum changes for all health professionals; creation of an institute for the study of symptom control and end-of-life care; mentorship

If you would like to add one human resource need, please write it in the space provided below.

Other (please specify) _____

_____

_____

Agreement/Disagreement with Operational Description

The majority of respondents agreed or strongly agreed with the operational description. The results are summarized below:

Operational Description Response Distribution (n = 103)

Response	# of Respondents	% of Respondents
Strongly Disagree	**2**	**2.1**
Disagree	**5**	**5.2**
Neutral	**8**	**8.2**
Agree	**40**	**41.2**
Strongly Agree	**42**	**43.3**
Not Applicable	**6**	

Suggested Revisions to the Operational Description

Development of Networks/Partnerships

- Stress collaboration between researchers, direct users of research and those dealing specifically with areas of cancer. "Integration and coordination" are key.
- Inter-provincial and international comparisons are an important element to health services and research.

Key Additions to the Operational Description

- Prevention and patient care need to be included.
- Changes to practice are as important as policy changes.
- Increase various domains/disciplines mentioned.

Potential Research Topics

The following is a list of Potential Research Topics. The items in green were included in the Stage 1 Backgrounder while the items in **black** are the topics most frequently suggested by participants during Stage 1.

Please select up to five priority Potential Research Topics from the amalgamated list (both the green and the **black**) below. In the space provided, indicate your ranking with one (1) as the highest priority.

____ Comparison of utilization of cancer services among geographic regions

____ Economic analysis (cost effectiveness of current therapies; economic performance of delivery system)

____ Outcomes measurement

____ Effectiveness of varying organizational models for delivering integrated care

____ Modelling cost of cancer care

____ Understanding of equitable access to care and services (e.g. urban/rural; gender)

____ Prevalence and impact of use of complementary therapies in health system

____ Communications approaches to maximize access to cancer information (e.g. E-health)

____ Policy generation, dissemination, uptake and implementation

____ Identification and reduction of problems with co-ordination of patient-centred services and policies at a local community level

____ Prevention services

____ Benchmarks and standards for comprehensive cancer control planning, implementation and monitoring

____ Ethical issues around providing genetic based treatment and services

____ Information technology applied to cancer control systems.

____ Modelling of cancer services delivery based on evidence-based best practices to predict future resource needs

____ Public health systems research to take advantage of natural experiments in the population interventions

____ Research into the importance of continuing professional education and development

If you would like to add one additional Potential Research Topic, please write it in the space provided below.

Other (please specify) _____

_____

_____

Suggested Infrastructure Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 73 means that the first, second or third priority suggestions of 73 participants pertained to the theme.

Infrastructure Needs Key Themes	Priority Response (Combined Totals)
Research Methods and Procedures	**73**
Coordination and Distribution of Research And Information	**28**
Data	**26**
Funding	**15**
Legislation	**1**
Other	**7**

Most Important Infrastructure Needs

The following is a list of the most frequently suggested infrastructure needs related to health services and policy research. The items describing each need are examples taken from respondents' comments. Please select up to three priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Research Methods and Procedures** - outcome measures and technologies; evaluation, accountability, standardization; better translation and evaluation of research into policy and practice; multidisciplinary team approach to research analysis of data; development of models, theories and methods

____ **Coordination and Distribution of Research and Information** - national, multidisciplinary voice/network in cancer control; province-wide coordination of cancer care services in every province; health services research network

____ **Databases** - informatics databases; comprehensive database development and national linked databases related to health care utilization; access to administrative databases; adequate, efficient, accessible databases

____ **Funding** - development of funding structure, including mechanisms and targets; priority funding for health services and policy research; funding for: researchers and policy makers, chart level review, sociobehavioural research

If you would like to add one infrastructure need, please write it in the space provided below.

Other (please specify) _____

_____

_____

Suggested Human Resource Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 71 means that the first, second or third priority suggestions of 71 participants pertained to the theme.

Human Resources Needs Key Themes	Priority Response (Combined Totals)
Research Methods and Procedures	**71**
Coordination and Distribution of Research and Information	**11**
Funding	**5**
Data	
Other	**5**

Most Important Human Resource Needs

The following is a list of the most frequently suggested human resource needs related to health services and policy research. The items describing each need are examples taken from respondents' comments. Please select up to five priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Recruit Personnel** - attract: researchers, radiation oncologists, radiation therapists, case managers, health economists, scientists who can do outcome research, research support staff

____ **Train and Support Personnel** - support personnel who can translate research into practice and police; protect time for clinicians to become engaged in health services and policy research; make better use of existing researchers; train cancer informatics specialists

____ **Multi-disciplinary innovative approaches** - to research and policy

____ **Coordination and Distribution of Research and Information** - expertise network in health services research; collaborative nucleus of oncologists trained in health service research and policy research and strategically placed across the country; better linkage of "front-line" researchers and policy makers; research to identify how best to serve the needs of potential recipients of care

____ **Funding** - funding for training/retraining researchers in a holistic mind/body/spirit multifactoral approach and the value of healthful complementary approaches; funding so that research findings about quality of care and care delivery can be put into place

____ **Data (Databases and Expertise)** - expertise in large databases, statistics; support personnel to collect and handle data

If you would like to add one human resource need, please write it in the space provided below.

Other (please specify) _____

_____

_____

Agreement/Disagreement with Operational Description

The majority of respondents agreed or strongly agreed with the operational description. The results are summarized below:

Operational Description Response Distribution (n = 90)

Response	# of Respondents	% of Respondents
Strongly Disagree	**0**	**0**
Disagree	**3**	**3.7**
Neutral	**8**	**9.9**
Agree	**27**	**33.3**
Strongly Agree	**43**	**53.1**
Not Applicable	**9**	

Suggested Revisions to the Operational Description

Description is Not Balanced

- Too optimistic about what genome science can achieve; does not account for ethical, legal, and social issues or other potentially negative consequences.
- Makes too many assumptions; needs to be more realistic in terms of expectations and prioritization.

Description Needs to Reflect Better Integration with Other Research Areas

- This area of research cannot be separated from others. It must be studied and understood within a wider context.
- Description should reflect better integration with overall cancer research, clinical information, health service application, environmental factors, molecular biology, and computer science.

Potential Research Topics

The following is a list of Potential Research Topics. The items in green were included in the Stage 1 Backgrounder while the items in **black** are the topics most frequently suggested by participants during Stage 1.

Please select up to five priority Potential Research Topics from the amalgamated list (both the green and the **black**) below. In the space provided, indicate your ranking with one (1) as the highest priority.

____ Molecular profiling of tumours

____ Functional proteomic, elucidation of molecular signalling pathways

____ Pharmacogenomic, molecular profiling of populations

____ Gene therapy

____ Development of model systems

____ Technology development

____ Hardware

____ Bioinformatics, analytical software

____ **Legal, social, ethical issues associated with increased use of genetic information in cancer care**

____ **Tumour stem cell characterization and biology**

____ **Control of cell differentiation, programming of gene expression**

____ **Mathematical modelling of molecular networks and cell behaviour**

____ **Tumour vaccines**

If you would like to add one additional Potential Research Topic, please write it in the space provided next.

Other (please specify) _____

Suggested Infrastructure Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 49 means that the first, second or third priority suggestions of 49 participants pertained to the theme.

Infrastructure Needs Key Themes	Priority Response (Combined Totals)
Coordination and Distribution of Information	**49**
Funding	**14**
Facilities and Training	**13**
Research Method and Management	**9**
Other	**6**

Most Important Infrastructure Needs

The following is a list of the most frequently suggested infrastructure needs related to genome science. The items describing each need are examples taken from respondents' comments. Please select up to five priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Tumour/Tissue Banks** - tissue banks with linkage to clinical history and outcome; standardized acquisition and preservation methodologies; nationally available access; linked provincial, regional or national tumour banks; legislation changes

____ **Databases** - design; management, linkage; capacity; database to link gene discovery with drug pathway data and status of clinical trials of relevant new drugs

____ **Networks** - multidisciplinary; regional, national and international; linkages to epidemiologists; overcoming provincial barriers to genetic information flow; networks to support legal, social, ethical research related to use of genetics in cancer prevention and care

____ **Funding** - funding mechanisms and targets; adequate, sustained funding; increased research funding; funding technology development such as gene chip technologies; funding research that is not hypothesis driven, protein sequencing facilities

____ **Facilities** - DNA/protein microarray; proteomics; genomics "core" laboratories; protein sequencing facilities; technology development; training centres; laboratory infrastructure; centres of excellence

____ **Research Methods and Procedures** - development of genome science spectrum (informatics, functional genomics, genetic polymorphism, proteomics); development of model systems; legislation/regulations to manage genomic research; translation of research into policy and practice

If you would like to add one infrastructure need, please write it in the space provided below.

Other (please specify) _____

Suggested Human Resource Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 29 means that the first, second or third priority suggestions of 29 participants pertained to the theme.

Human Resource Needs Key Themes	Priority Response (Combined Totals)
Training and Skills	**29**
Retention and Use of Existing Personnel	**12**
Knowledge Sharing	**9**
Recruitment	**7**
Other	**12**

Most Important Human Resource Needs

The following is a list of the most frequently suggested human resource needs related to genome science. The items describing each need are examples taken from respondents' comments. Please select up to three priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Requirement for Well-Qualified Personnel** - need for expertise in a range of skills including computational biology, biostatisticians/bioinformatics specialists, translational researchers who can collaborate with clinical

____ **Recruitment of New Researchers** - attracting new researchers; recruitment costs to compete with larger centres; increased resources for training of new investigators

____ **Retention and Use of Existing Personnel** - retaining and sustaining current expertise; making better use of existing qualified researchers

____ **Sharing Knowledge** - networks of multidisciplinary researchers; utilization of multidisciplinary and innovative approaches; support for multidisciplinary centres; knowledge sharing/collaboration opportunities; more inter-laboratory efforts; less emphasis on individual labs, more on team efforts

If you would like to add one human resource need, please write it in the space provided below.

Other (please specify) _____

_____

_____

Agreement/Disagreement with Operational Description

The majority of respondents agreed or strongly agreed with the operational description. The results are summarized below:

Operational Description Response Distribution (n = 97)

Response	# of Respondents	% of Respondents
Strongly Disagree	**1**	**1.1**
Disagree	**5**	**5.6**
Neutral	**19**	**21.1**
Agree	**34**	**37.8**
Strongly Agree	**31**	**34.4**
Not Applicable	**7**	

Suggested Revisions to the Operational Description

Expanded Research Scope

- Need for good quality evidence, thatcan be obtained by both experimental and observational approaches.
- Need for randomized trials to establish the validity of population screening.
- Monitoring is required at the population level.
- Also need to look at "diffusion curve" and actual and optimal diagnostic pathways for screening tests in sub-groups within the general population.

Awareness/Public Education

- The public should be aware of the importance of screening.
- Potential screening candidates need to be fully aware of all impacts of screening.
- Funding agencies and decision makers need to be made aware of the importance of screening.
- Need to educate the public about screening - its advantages and its limitations; when it is appropriate and when it is not; what is diagnostic and what is screening.

Potential Research Topics

The following is a list of Potential Research Topics. The items in green were included in the Stage 1 Backgrounder while the items in **black** are the topics most frequently suggested by participants during Stage 1.

Please select up to five priority Potential Research Topics from the amalgamated list (both the green and the **black**) below. In the space provided, indicate your ranking with one (1) as the highest priority.

____ Achieving high levels of evidence of efficacy without population based RCTs

____ "Diffusion curve" of screening

____ Minimization of false positive and negatives

____ Actual and optimal diagnostic pathways for screening tests in the general population

____ **Integrating effective screening into the primary care system**

____ **Development of novel candidate testing procedures**

____ **Research into cost-effectiveness/cost-benefit of both current and new and improved screening methods**

____ **Population-based screening research including encouraging those in need of screening to get screened; the emotional impact of screening**

____ **Development of a screening strategy**

If you would like to add one additional Potential Research Topic, please write it in the space provided next.

Other (please specify) _____

Suggested Infrastructure Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 35 means that the first, second or third priority suggestions of 35 participants pertained to the theme.

Infrastructure Needs Key Themes	Priority Response (Combined Totals)
Research Methods and Procedures	**35**
Networks and Linkages	**20**
Funding	**17**
Data	**12**
Other	**2**

Most Important Infrastructure Needs

The following is a list of the most frequently suggested infrastructure needs related to screening. The items describing each need are examples taken from respondents' comments. Please select up to three priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Research Methods and Procedures** - increased number and access of sites for screening or travelling vans (rural or high-risk populations); screening test development and refinement; infrastructure for systematic review and synthesis of research on screening; support for translation of research ideas to clinical testing; more widespread availability of screening; evaluation

____ **Networks and Linkages** - National multidisciplinary networks; national voice for cancer control; international collaborative RCTs to evaluate screening; establishment of Cancer Prevention Centres; linkage to surveillance; collaboration between clinician, provincial health systems and basic researchers

____ **Funding** - new, innovative and long-term funding mechanisms; baseline funding; funding for the design, development and implementation of organized screening programs; remove responsibility for screening from budget-sensitive institutions; resources need to be available for the development and testing of new molecular and imaging tests that may prove to be useful in screening initiatives

____ **Databases** - data base/informatics; tumour banks; common database designs; data on efficacy of screening; bio informatics; access of researchers to data

If you would like to add one infrastructure need, please write it in the space provided below.

Other (please specify) _____

Suggested Human Resource Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 27 means that the first, second or third priority suggestions of 27 participants pertained to the theme.

Human Resource Needs Key Themes	Priority Response (Combined Totals)
Need for Specific Skills	**27**
Research Methods and Procedures	**21**
Retain and Support Personnel	**7**
Coordination & Distribution Of Research And Information	**2**
Funding	**1**
Other	**2**

Most Important Human Resource Needs

The following is a list of the most frequently suggested human resource needs related to screening. The items describing each need are examples taken from respondents' comments. Please select up to five priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Need for Specific Skills** - attract: new researchers in all areas; radiologists; lab technicians, epidemiological, clinical investigators, statisticians, health economists, specialists in automation, cancer pathology, cytotechnologists, professional educators

____ **Research Methods and Procedures** - enhance support to translate research into policy; support long-term research; foster multidisciplinary and innovative approaches; stimulate programs in priority-underserved areas; train research personal to recognize risks associated with any screening program; investigate reasons for low uptake of screening; more time for research by clinicians

____ **Retain and Support Personnel** - retaining existing personnel; support personnel through on going training and upgrading of skills

____ **Coordination and Distribution of Research and Information** - public education and community outreach personnel

____ **Funding** - financial and training support for clinicians and technicians doing screening.

If you would like to add one human resource need, please write it in the space provided below.

Other (please specify) _____

_____

_____

B10 Cancer Biomarkers and Imaging

Agreement/Disagreement with Operational Description

The majority of respondents agreed or strongly agreed with the operational description. The results are summarized below:

Operational Description Response Distribution (n = 88)

Response	# of Respondents	% of Respondents
Strongly Disagree	**3**	**3.8**
Disagree	**3**	**3.8**
Neutral	**11**	**14.1**
Agree	**36**	**46.2**
Strongly Agree	**25**	**32.1**
Not Applicable	10	

Suggested Revisions to the Operational Description

Inclusion of Other Kinds of Treatments

- The description places emphasis on drug treatment - it should include surgery and radiation.
- The description should also recognize that early detection - the goal of biomarkers - may enable more natural interventions (such as lifestyle changes) that could reverse the disease process and avoid more invasive, costly treatments.

Too Much Emphasis on Imaging

- Include other types of early diagnosis, such as molecular or genomics.
- Add 'molecular markers and pathological samples'.

Description Not Clearly Distinct From Other Themes

- The description suggests that biomarkers are part of nearly every other 'Priority Theme'. Biomarkers do not refer only to disease detection.

Potential Research Topics

The following is a list of Potential Research Topics. The items in green were included in the Stage 1 Backgrounder while the items in **black** are the topics most frequently suggested by participants during Stage 1.

Please select up to five priority Potential Research Topics from the amalgamated list (both the green and the **black**) below. In the space provided, indicate your ranking with one (1) as the highest priority.

____ Diagnostic imaging, including anatomical, functional and qualitative

____ Early detection of specific cancers through screening

____ Molecular and functional imaging

____ Imaging of animal models for genomics research

____ Image guided therapy

____ **Health service implications of new diagnostic imaging**

____ **Identification of molecular biomarkers to assist in new imaging modalities and to guide new treatment strategies**

____ **Optical imaging**

____ **Computer assisted image analysis technologies**

If you would like to add one additional Potential Research Topic, please write it in the space provided below.

Other (please specify) _____

_____

_____

Suggested Infrastructure Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 27 means that the first, second or third priority suggestions of 27 participants pertained to the theme.

Cancer Biomarkers and Imaging Needs Key Themes	Priority Response (Combined Totals)
Coordination of Research and Technology (networks, centres, databases)	27
Equipment and Technology	15
Funding	15
Access to Equipment and Technology	10
Other	9

Most Important Infrastructure Needs

The following is a list of the most frequently suggested infrastructure needs related to cancer biomarkers and imaging. The items describing each need are examples taken from respondents' comments. Please select up to five priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Centres of Excellence/Networks** - centres of excellence for functional imaging in cancer research across the country; centres from where the research can be coordinated; national and international networks; CBCRI as a cancer research group that promotes development of new or improved methods of detection

____ **Databases** - bioinformatics databases; tumour tissue repository

____ **Equipment and Technology** - more well equipped, networked and staffed imaging centres; modern imaging equipment; additional MRI facilities for use by researchers; more PET scanners; laboratory infrastructure; genome sequencing and microarray facility; ability of system to implement current best practices for imaging (e.g. image-guided biopsy).

____ **Accessibility of Technology** - availability of new imaging technology and equipment (e.g. in all geographical areas - rural/ urban centres); equal access; mechanisms to facilitate/regulate access

____ **Funding** - funding structure, mechanisms and targets; funding for equipment, training, instrumentation; new imaging-based screening methods; clinical trials to examine the impact of enhanced imaging techniques on clinical outcome

If you would like to add one infrastructure need, please write it in the space provided below.

Other (please specify) _____

_____

_____

Suggested Human Resource Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 26 means that the first, second or third priority suggestions of 26 participants pertained to the theme.

Cancer Biomarkers and Imaging Needs Key Themes	Priority RespJïSe (Combined Totals)
Training and Skills	26
Recruitment, Retention and Use of Personnel	21
Other	14

Most Important Human Resource Needs

The following is a list of the most frequently suggested human resource needs related to cancer biomarkers and imaging. The items describing each need are examples taken from respondents' comments. Please select up to three priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Shortage of Trained Professionals, Need for Training** – need for clinical scientist training centres; need for more trained professionals including MRI/PET technicians, radiologists, informatics people, computer scientists, statisticians, clinical epidemiologists, cross-trained personnel (lab/epi), biophysicists, biomedical engineers and technologists, support staff

____ **Support for Research** – more medical physics imaging expertise collected in centres of excellence; support for translational research by clinician/scientist teams; training and protection of research time for pathologists with interest in molecular diagnostic and prognostic markers; nuclear medicine/radiology research to support PET

____ **Recruitment, Retention and Use of Personnel** – attracting new researchers and qualified personnel; retaining existing qualified personnel; use of financial incentives; making better use of existing researchers

If you would like to add one human resource need, please write it in the space provided below.

Other (please specify) _____

_____

_____

Agreement/Disagreement with Operational Description

The majority of respondents agreed or strongly agreed with the operational description. The results are summarized below:

Operational Description Response Distribution (n = 94)

Response	# of Respondents	% of Respondents
Strongly Disagree	**2**	**2.5**
Disagree	**1**	**1.2**
Neutral	**10**	**12.3**
Agree	**25**	**30.9**
Strongly Agree	**43**	**53.1**
Not Applicable	**13**	

Suggested Revisions to the Operational Description

More Emphasis on Long-Term

- Emphasize initiatives to follow-up on pediatric cancer survivors over the long-term.
- Assessment of the role of supporting the mind, body and spirit and a complementary approach to maintaining well-being, reducing the risk of recurrence, and long-term late effects of conventional treatments

Including Adolescents/Young Adults

- The need to explore the effects of cancer on adolescents and young adults; important to develop infrastructure to study the late effects and also to support the childhood cancer survivor.
- There must also be some focus on adolescent cancer issues, including behavioural, compliance and health-related quality of life outcomes.

Description Needs Sharper Focus

- Description falsely implies that we have experienced all around progress for all pediatric cancers.
- This section is not fundamentally distinct from the other sections.
- Pediatric cancer is a small but critical area with a specific contribution to make to the larger cancer research arena; important to identify a coherent programmatic approach to the funding of pediatric cancer research across the spectrum of cancer control.

Potential Research Topics

The following is a list of Potential Research Topics. The items in green were included in the Stage 1 Backgrounder while the items in **black** are the topics most frequently suggested by participants during Stage 1.

Please select up to five priority Potential Research Topics from the amalgamated list (both the green and the **black**) below. In the space provided, indicate your ranking with one (1) as the highest priority.

____ Reduction of late effects in survivors of childhood cancer

____ Clinical trials, including Phase I/II studies designed in Canada, and participation in Phase I-III international collaborative group trials

____ Pediatric palliative care, including methodology and delivery

____ Correlative studies of emerging biological and sociobehavioural information on survival, quality of life and long-term outcomes for children and families

____ Optimal utilization of existing surveillance data, existing research expertise, and the unique characteristics of the Canadian health care system

____ Etiologic studies related to pediatric cancer (e.g. genetic determinants/ predisposition, basic, modifiable and other risk factors)

____ Research into the basic biology of developmental tumours, including genetic predisposition

____ Assessment of the role of supporting the mind, body and spirit and a complementary approach to maintaining well being

____ Research related to school issues of pediatric cancer patients (e.g. re-entry during treatment, transplant, palliative situation etc.)

____ Studies related to the effects of pediatric cancer on the family, particularly the parents/ caregivers (e.g. financial, emotional, siblings, etc.)

____ Optimizing preventive interventions in pediatric populations (e.g. smoking-related diseases)

____ Adolescent treatment and outcome issues

____ Intervention studies for prevention of new cancers in survivors of childhood cancer

If you would like to add one additional Potential Research Topic, please write it in the space provided below.

Other (please specify) _____

_____

_____

Suggested Infrastructure Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 49 means that the first, second or third priority suggestions of 49 participants pertained to the theme.

Infrastructure Needs Key Themes	Priority Response (Combined Totals)
Coordination and Collaboration (networks, centres of excellence, databases)	**49**
Funding	**19**
Research Related Issues	**12**
Other	**5**

Most Important Infrastructure Needs

The following is a list of the most frequently suggested infrastructure needs related to pediatric cancer. The items describing each$"eed are examples taken from respondents' comments. Please select up to five priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Networks and Centres of Excellence** - national and/or international multidisciplinary networks, centres, consortia; multi-disciplinary research; institutions that incorporate units of cancer epidemiology; networks of pediatric oncology researchers and pediatric clinical trials; multi-centre research programs; IS support for the networks; national voice for pediatric cancer; centres of excellence in pediatric research

____ **Databases** - databases/informatics; Canadian data base focused on childhood cancer incidence; data on long term impact; expand existing database at Health Canada; optimal utilization of existing surveillance data

____ **Tissue/tumour banks** - national tumour and developing tissue banks

____ **Funding** - funding structure, mechanisms, targets, stability; access to funding for etiology as well as therapy studies; funding of: peer reviewed North American studies, infrastructure at pediatric centres, clinical research, longitudinal research, national consortium or trials group

____ **Research Related Issues -** evaluation; accountability; legal consent for longitudinal studies; support for correlative research, pre-clinical models, prevention

If you would like to add one infrastructure need, please write it in the space provided below.

Other (please specify) _____

_____

_____

Suggested Human Resource Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 35 means that the first, second or third priority suggestions of 35 participants pertained to the theme.

Human Resource Needs Key Themes	Priority Response (Combined Totals)
Training and Skills	**35**
Recruitment	**16**
Networking and Multidisciplinary Approaches	**8**
Retention and Use of Existing Personnel	**7**
Stimulation of New Programs	**4**
Other	**4**

Most Important Human Resource Needs

The following is a list of the most frequently suggested human resource needs related to pediatric cancer. The items describing each need are examples taken from respondents' comments. Please select up to five priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Training** - training about: the mind, body and spirit role, complementary approaches, pediatric clinical and base research, development of tissues during childhood; more involvement of survivors and families; address human resource crisis through aggressive training; expand positions in general pediatric residency training

____ **Recruitment** - attracting: new researchers, pediatric oncologists, data managers, research personnel, nurses (front line, investigators, community), epidemiologists with interests in childhood cancer; aggressively addressing the human resource crisis

____ **Retention and Use of Existing Personnel** - retaining existing well-qualified researchers and experts; making better use of existing researchers

____ **Networking and Multidisciplinary Approaches** - fostering multidisciplinary and innovative approaches, multi-disciplinary research consortium; more interlaboratory efforts; linking translational pediatric researchers with front line pediatric oncologists; improving linkages between doctors who deal with pediatric cancer and those who deal with late effects in survivors

____ **Stimulation of New Programs** - stimulating programs in priority under served or under funded areas

If you would like to add one human resource need, please write it in the space provided below.

Other (please specify) _____

_____

_____

Agreement/Disagreement with Operational Description

The majority of respondents agreed or strongly agreed with the operational description. The results are summarized below:

Operational Description Response Distribution (n = 94)

Response	# of Respondents	% of Respondents
Strongly Disagree	**2**	**2.3**
Disagree	**1**	**1.1**
Neutral	**19**	**21.8**
Agree	**28**	**32.2**
Strongly Agree	**37**	**42.5**

Suggested Revisions to the Operational Description

Emphasize Scope of Research

- Recognition that this kind of research involves understanding the individual in a complex environment of family and community, spirituality, and personal empowerment; very difficult to isolate these factors for study.

Changes to Description

- Sociobehavioural research needs to be clarified; better defined.
- Topic area overlaps with others; should be integrated into other research themes.

Potential Research Topics

The following is a list of Potential Research Topics. The items in green were included in the Stage 1 Backgrounder while the items in **black** are the topics most frequently suggested by participants during Stage 1.

Please select up to five priority Potential Research Topics from the amalgamated list (both the green and the **black**) below. In the space provided, indicate your ranking with one as the highest priority.

____ Determinants and development of health risk behaviour and coping, and implications for prevention/improvement

____ Ongoing regional survey and surveillance systems to unravel and monitor trends in these factors

____ Psychosocial factors that influence adaptation, coping and quality of life at each age and stage along the cancer continuum

____ Increased understanding of the role of complementary medicine in a person's experience of cancer

____ Coordination of care, and the balancing of proven conventional, complementary and behavioural medicine strategies

____ Factors influencing uptake behaviour of best practice knowledge by consumers, practitioners and policy makers

____ Outcomes research and program evaluation of cancer control services, to include sociobehavioural predictors, processes and outcomes

____ Understanding determinants of lifestyle (e.g. tobacco use, diet, exercise)

____ Need for new research methods/paradigms to capture complexity of this kind of research

____ Role of spirituality in healing, prayer and personal empowerment in healing

____ Impact of economic, educational, social support factors and gender

____ Effects of psychosocial factors on the etiology and clinical progression of cancer (mind-body effects)

____ Investigation of factors relating to "patient delay" at pre-diagnosis, diagnosis and treatment stages

____ Understanding the 'transitional' issues faced by patients, families and cancer professionals when cancer progresses and treatment is ineffective.

____ Integrative care models to be tested. Dissemination of research on evidence-based interventions that are not systematically implemented with all newly diagnosed patients

____ Relative effectiveness of single-factor vs. multifactor approaches to behaviour change, especially in adolescence

____ Importance of rapid KAB surveillance of health professionals as well as population, including children

If you would like to add one additional Potential Research Topic, please write it in the space provided below.

Other (please specify) _____

_____

_____

Suggested Infrastructure Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 29 means that the first, second or third priority suggestions of 29 participants pertained to the theme.

Infrastructure Needs **Key Themes**	Priority Response (Combined Totals)
Coordination and Distribution of Research and Information (centres, networks)	**29**
Research Methods and Procedures	**20**
Funding	**21**
Databases	**3**
Other	**3**

Most Important Infrastructure Needs

The following is a list of the most frequently suggested infrastructure needs related to sociobehavioural cancer research. The items describing each need are examples taken from respondents' comments. Please select up to three priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Research Methods and Procedures** - evaluation, accountability, economics; standardized measures of key determinants and outcomes; units that perform cancer-related behavioural science research; access of qualified behavioural scientists to cancer epidemiology units; complementary and alternative medicine centres; defining highest priority areas of focus

____ **Centres of Excellence/Networks** - national, multidisciplinary networks; national voice to promote work in this area; centres of excellence to support the development of sociobehavioural cancer research; linkage programs across universities; building bridges to other disciplines/groups

____ **Funding** - funding mechanisms and targets; funding for research initiatives including RFA's for key issues; implementation of the psychosocial standards developed by the Canadian Association of Psychosocial Oncology; qualitative and quantitative research; large-scale community intervention trials

____ **Databases** - comprehensive databases; informatics databases

If you would like to add one infrastructure need, please write it in the space provided below.

Other (please specify) _____

_____

_____

Suggested Human Resource Needs

The following table summarizes the key themes suggested by respondents and the frequency of response. For instance, a priority response rating of 77 means that the first, second or third priority suggestions of 77 participants pertained to the theme.

Human Resource Needs Key Themes	Priority Response (Combined Totals)
Research Methods and Procedures (attracting and retaining researchers, need for some professions, training, research approaches)	**77**
Coordination and Distribution of Research and Information	**4**
Other	**1**

Most Important Human Resource Needs

The following is a list of the most frequently suggested human resource needs related to sociobehavioural cancer research. The items describing each need are examples taken from respondents' comments. Please select up to five priority needs. In the space provided, indicate your ranking with one (1) as the highest priority.

____ **Attracting and Retaining Researchers** - attracting new and retaining existing, qualified existing researchers

____ **Need for Some Professions** - social scientists who understand cancer; statisticians; biostaticians; clinician researchers; qualitative researchers; persons with expertise in survey design; social workers

____ **Training** - training multidisciplinary personnel

____ **Fostering Multidisciplinary and Innovative Approaches** - primary care health professionals to carry out the necessary research; educating researchers about the role that the mind and spirit can play in the healing process; stimulating programs in priority underserved areas; having practitioners participate in the research

____ **Supporting Researchers** - enhancing support for those who can best translate research into policy and practice; protected time for clinicians and academics to work together.

____ **Coordination and Distribution of Research and Information** - development of national teams and a strong voice; linking with other relevant health groups; community partnership projects

If you would like to add one human resource need, please write it in the space provided below.

Other (please specify) _____

_____

_____

A Delphi Process for Setting Cancer Research Priorities in Canada

Stage III: Backgrounder and Questionnaire

Cutoff Date: June 14 - 5:00 p. m. MST, 2002

Sponsored by:

- Canadian Institutes of Health Research- Institute for Cancer Research
- National Cancer Institute of Canada
- Canadian Association of Provincial Cancer Funding Agencies
- Health Canada

A Delphi Process Undertaken by Praxis Inc.

May, 2001

Section I:
An Introduction to the Stage III Delphi Process

A Delphi is a staged process for developing consensus and making group-based decisions. A Delphi process typically occurs in a series of stages, over time. Participants provide their comments regarding a particular set of issues or areas of interest. The groups' responses are then analyzed and reported back so participants can compare their own responses to those of the overall group. Participants, having benefit of the previous discussion, comment on the issues again as well as other questions that have been raised. A new group report is generated and the process is repeated with a new series of questions.

The Delphi process for setting cancer research priorities is being conducted in three stages:

- **Stage I – October, 2001**
- **Stage II – January - March, 2002**
- **Stage III – May - June, 2002**

Once again, Stage III of the Delphi process is internet-based. To ensure security and confidentiality, each participant has received a log-on web link and a personal password, allowing access to all materials including the questionnaire. The questionnaire can be completed and submitted on-line. Because individual questionnaire responses can only be accessed with a personal password, the confidentiality of the participant is protected. As well, personal names, organizations or affiliations will not be identified in the summary or final reports.

Please Read Thoroughly Before Proceeding!!!

Stage III will require less of your time than Stage II. We estimate that it will take approximately 20 minutes to complete. Stage III includes the following:

* Demographic/contact information – please update or complete
* Questions about the future of the Research Alliance – please complete
* Stage II Results – please review and complete the final questions at the conclusion

When you log on to proceed, your demographic information from Stage II will appear. You can review it and update it if you so desire. If you did not participate in Stage II, you will need to complete this information before you will be able to proceed. We will not be able to include your submission (online or hard copy) if this information is not complete. No confidential information is asked and no names or attributions will be included in the final report. Your response is totally confidential.

Following completion of the demographic information, a window will open with four questions about the future of the Research Alliance. A description of the Alliance is included in the questionnaire. Please complete these questions and then click on the submit button.

Once you have done this, another window will appear with the results of Stage II Delphi. These results are presented as tables highlighting the priorities that were identified for each of the fourteen research from Stage II. Please answer two questions at the end of the results.

When you go into each theme you will see a button at the top right hand corner that says, *"Print this Section"*. If you want a hard copy please click on this button and a copy of only that theme will be printed out. If you want to print a copy of the entire document, a PDF file has been created. Click on this link (right here) to download the PDF file: *Results of Stage II*. We have reduced the size of this document for easier downloading and use. Print in black-only to accelerate printing. If at any time, you would like to review any of the earlier documents, *Stage I - Backgrounder*, *Stage I Questionnaire*, or *Stage II Backgrounder and Questionnaire*, you can download the file by clicking on any of the links provided here.

If you cannot complete your response on-line, you can download and print the PDF file, complete the questionnaire in hardcopy format and fax the completed pages back to us. To ensure that we can use your comments, questionnaires that are faxed back must be written legibly and include your name and password. Please do not write in the margins but feel free to add extra pages.

The final cut off date of the survey is June 14th, 2002 5:00pm MDT.

Contact Information:
Fax: 403 229-3037
Email: cancer_delphi@praxis.ca

The link and personal password allow you to enter your file whenever you wish to make changes, additions or deletions. When you click the submit button you will receive a message advising that your information has been received.

Thank you for your participation!

Section II
Contact/Demographic Information

Please complete or verify the following contact information. Participants who have not submitted contact information will not be included in future communication about this process.

Please identify the one category that most strongly represents your work or activities.

Currently-active researcher:

____ Basic biological research
____ Other basic research
____ Clinical research
____ Health services research
____ Population health research
____ Psychosocial research
____ Other (please specify) _____

Non-researchers and not currently-active researchers:

____ Advocacy
____ Health care
____ Policy analysis and development
____ Regulatory review
____ Other (please specify) _____

Please select one category that most closely represents the type of organization in which you work or belong.

____ Academic institution
____ Volunteer organization
____ Health care institution
____ Consumer organization
____ Federal government
____ Provincial government
____ Local or regional health authority
____ Individual
____ Other (please specify) _____

Please indicate the province or territory where you reside

____ British Columbia
____ Alberta
____ Saskatchewan
____ Manitoba
____ Ontario
____ Quebec
____ New Brunswick
____ Nova Scotia
____ Prince Edward Island
____ Newfoundland
____ Yukon
____ Northwest Territories
____ Nunavut

Please indicate your gender

____ Male
____ Female

Please indicate your age group

____ Less than 30 years
____ 31 to 40 years
____ 41 to 50 years
____ 51 to 60 years
____ 61 to 70 years
____ over 70 years

Section III
Questions About the Research Alliance

A Brief Description of the Cancer Research Alliance

The Canadian Strategy on Cancer Control is a broad-based coalition that is evolving national strategies to enhance the care of cancer patients and their families, and to further research on cancer. Out of this framework has emerged a Cancer Research Alliance made up of senior representatives from the National Cancer Institute of Canada (NCIC), Health Canada, the Canadian Association of Provincial Cancer Agencies (CAPCA) and the CIHR Institute of Cancer Research (ICR). This group has been working together to examine the current status of cancer research in Canada and to begin a process of identifying national priorities for cancer research. Part of this effort was the launching of the current Delphi process in which a broad base of individuals with an interest in cancer research have been invited to voice opinions on research priorities. The proposed goal of this alliance is to coordinate ongoing and future research initiatives across the whole spectrum of research, including basic biomedical, prevention, screening, diagnosis, treatment, psycho-social and palliative care, in order to optimize new opportunities and to hasten progress. The purpose of the questions in this Stage III of the Delphi process is to seek feedback from the cancer community about these efforts.

Please answer the following questions:

1. Should members of the Research Alliance (CIHR-ICR, NCIC, CAPCA & Health Canada) take any further steps to foster consensus on Canadian cancer research priorities?

   YES ___ NO ___

2. If your answer to Question 1 is "NO", then what is the basis for your response?

   _____

   _____

   _____

3. If your answer to Question 1 is "YES", then is an ongoing "coordinating group" needed for the Research Alliance (for example, a group that meets at least once per year)?

   YES___ NO___

4. If your answer to Question 3 is "YES", then should such a "coordinating group" seek to link its efforts (on cancer control research priorities) internationally?

   YES___ NO___

Section III : Results from Stage II of the Cancer Delphi

I. Demographic Frequencies

Based on the demographic information received, Stage II participants represented a reasonably valid cross section of researcher types, organizations, provinces, gender and age. Participation in the Stage II process appears representative of the larger population.

Researcher Type

About half of the participants were involved with basic biological research, clinical research or population health services. The remainder of participants were distributed among other types of research.

Respondent Type	Count	%
Basic Biological Research	25	22.7
Other Basic Research	2	1.8
Clinical Research	17	15.5
Health Services Research	6	5.5
Population Health Services	13	11.8
Psychosocial Research	7	6.4
Other Currently Active Research	3	2.7
Advocacy	8	7.3
Health Care	7	6.4
Policy Analysis Development	10	9.1
Other Not Currently Active Research	12	10.9
TOTAL	110	100.0

Type of Organization

Slightly over half of the participants were from academic institutions. The next largest group worked at health care institutions.

Type of Organization	Count	%
Academic Institution	57	51.8
Health Care Institution	14	12.7
Consumer Organization	1	.9
Federal Government	7	6.4
Provincial Government	8	7.3
Local or Regional Health Authority	5	4.5
Individual	4	3.6
Other Organization	11	10.0
Volunteer Organization	3	2.7
TOTAL	110	100.0

Province, Gender and Age

Almost half of the participants were from Ontario. 87% of participants resided in Ontario, Quebec, Alberta or British Columbia. About two-thirds of participants were male and one-third female. Over 80% of participants were between the ages of 41 and 60.

Province	Count	%
British Columbia	15	13.6
Alberta	16	14.5
Saskatchewan	5	4.5
Manitoba	7	6.4
Ontario	44	40.0
Quebec	15	13.6
New Brunswick	1	.9
Nova Scotia	2	1.8
Prince Edward Island	2	1.8
Newfoundland	3	2.7
TOTAL	110	100.0

Gender	Count	%
Male	70	64.2
Female	39	35.8
TOTAL	109	100.0

Age	Count	%
Less than 30 years of age	1	.9
31 – 40 years old	10	9.2
41 – 50 years old	34	31.2
51 – 60 years old	49	45.0
61 – 70 years old	13	11.9
Over 70 years old	2	1.8
TOTAL	109	100.0

II. Response Frequencies – Overriding Themes and Priority Themes

Following the completion of Stage I of the Delphi process, participants' comments were analyzed and expanded lists were generated for the 'Key Focus Areas' for the Overriding Thematic Areas (2), and the 'Priority Research Topics' for the Priority Themes (12). In Stage II, participants were asked to rank order their top five priorities for each of the expanded lists.

The following tables summarize the frequency of number one (1) rankings for each of the two Overriding Themes (Infrastructure and Human Resources) and twelve Priority Themes. For example, the option from each list that received the most number one rankings was placed first, the option that received the second most number one rankings was placed second, through to the option with the fifth most number one rankings being placed fifth. To simplify the tables, only the options that placed in the top five are shown. In some cases there were several options that received the same number of rankings - in these cases, more than five options are shown. For example, three different options may have received the same number of first rankings so all three options are shown.

Note: Following these tables are a series of questions regarding the findings. Please do not forget to review and complete any of those questions that are of interest to you.

A1 Infrastructure

Ranking	Key Focus Area	Frequency Ranked as Number 1
1	Funding mechanisms and targets	21
2	Informatics databases, such as those required for policy and legislation and those required for the results of molecular-level tests arising out of basic research	18
3	Integrated and coordinated system to link databases and help streamline and simplify access	14
4	Provision of sufficient physical space, labs and equipment to conduct research	12
4	Tumour banks, with national standards and networks, centres, consortia	12
5	Development of networks that are multidisciplinary and multisectoral and include those who are under represented and lay persons	11

Response to Theme Results

1. Do you agree with the results for this theme?

   YES ____ NO____

2. If you have any comments regarding this theme please provide them below.

A2 Human Resources

Ranking	Key Focus Area	Frequency Ranked as Number 1
1	**Aggressively addressing the human resources crisis**	**36**
2	**Retaining existing well-qualified researchers**	**19**
3	**More funding for, and emphasis on, training and development of researchers**	**12**
4	**Attracting appropriately qualified new researchers**	**10**
5	**Enhancing support for those who can best translate research into policy and practice**	**9**

Response to Theme Results

1. Do you agree with the results for this theme?

   YES ____ NO____

2. If you have any comments regarding this theme please provide them below.

B1 Etiologic Factors

Ranking	Potential Research Topic	Frequency Ranked as Number 1
1	Validated markers that would predict pre-cancerous change	22
2	Genetic research (e.g. gene environment interactions, epigenetic alterations, genomic research to identify potential etiologic factors and functional genomic and proteomics, modifier genes in cancer and genetic risk markers)	18
3	Model of research that would allow for greater examination of multiple interactions	13
4	Environmental carcinogens and contaminants, environmental/ occupational exposure, household (e.g. industrial emissions, pesticides, food additives)	12
5	Improve effectiveness of current research (e.g. more accuracy in measurements of exposure; more large, long-term research cohort studies; more good exposure data)	11

Response to Theme Results

1. Do you agree with the results for this theme?

   YES ____ NO____

2. If you have any comments regarding this theme please provide them below.

B2 Surveillance

Ranking	Potential Research Topic	Frequency Ranked as Number 1
1	Appropriate accessibility of databases	14
2	Enhanced surveillance methodology (e.g. more sophisticated forecasting, more systematic surveillance for changing patterns, better record linkage and processing of very large databases, etc.)	8
3	Support (shared with other diseases, health promotion) of long term databases on tobacco use/exposure, dietary intake, physical activity levels, etc.	6
3	Obtaining information related to incidence, causes, and treatment of specific cancers in specific populations for specific genes/genotypes through surveillance	6
4	Surveys of risk factors and of causes of exposure	5
4	Impact of screening intervention, impact of preventative strategies and application of treatment according to disease type and stage	5
5	Linking registries with exposure databases or geographic resource information	4
5	Improvements in informatics technology (e.g. standard interface, common edits, etc.)	4
5	Regular population surveillance of risk conditions/behaviours to permit studies of macro population level interventions on risk conditions/ behaviours	4
5	Research into best practices for data collection, ensuring data quality at various levels (e.g. completeness, validity)	4

Response to Theme Results

1. Do you agree with the results for this theme?

   YES ____ NO____

2. If you have any comments regarding this theme please provide them below.

B3 Population Based Prevention

Ranking	Potential Research Topic	Frequency Ranked as Number 1
1	Research into the effectiveness of integrated disease prevention strategies (cancer, heart disease, etc.)	17
2	Greater emphasis on evaluation of prevention strategies, including the effects of prevention education on behavioural change and the effects of all interventions	14
3	Lifestyle modification (nutrition, exercise, reduced sun exposure)	13
4	More focus on preventing use of tobacco smoking and determinants of nicotine addiction	9
5	More emphasis on prevention strategies	6
5	Interrelationships among risk behaviours, social determinates, community context and health outcomes	6

Response to Theme Results

1. Do you agree with the results for this theme?

   YES ____ NO____

2. If you have any comments regarding this theme please provide them below.

B4 Experimental Therapeutics

Ranking	Potential Research Topic	Frequency Ranked as Number 1
1	Development of a sophisticated infrastructure to foster and nourish innovation	17
2	Individualization of therapy	11
3	Selecting and validating gene based therapeutic targets	7
3	Creation of an organizational and regulatory environment that protects intellectual property, recognizes promising avenues of development, and efficiently moves new therapies towards clinical trials	7
4	The translational interface (i.e. support for Phase I clinical trials)	6
4	Creation, validation and exploration of better models of human malignancies	6
5	Facilitating the synthesis, rapid screening pre-clinical toxicology and evaluation of efficacy of new molecules	5
5	Development of new paradigms for clinical efficacy testing	5

Response to Theme Results

1. Do you agree with the results for this theme?

   YES ____ NO____

2. If you have any comments regarding this theme please provide them below.

B5 Clinical Research

Ranking	Potential Research Topic	Frequency Ranked as Number 1
1	Techniques to increase enrolment in clinical trials and patient information about trials	16
2	Prioritization of trials to meet public needs and expectations balanced with translational research opportunities	14
3	Regulatory issues that impact on the expeditious conduct of clinical trials and promising new agents	12
4	Manpower issues including studies on factors limiting the number of clinical investigators, support personnel and regulatory personnel	11
5	The ethical conduct of clinical trials in concert with research on the optimal infrastructure for ethical review of trials	7

Response to Theme Results

1. Do you agree with the results for this theme?

   YES ____ NO____

2. If you have any comments regarding this theme please provide them below.

B6 Palliative Care/Quality of Life

Ranking	Potential Research Topic	Frequency Ranked as Number 1
1	The pathopsysiology and treatment of the most common and difficult symptoms, including pain, cachexia-anorexia, asthenia, depression, anxiety and delirium collectively present in more than 80% of patients who die of cancer	21
2	Organization and delivery of palliative care – studies on integration of palliative care with other aspects of oncology care throughout the trajectory of illness; studies on quality and access coupled with research on models	16
3	Greater emphasis on pain control or management for cancer patients (e.g. development of more effective medications with fewer side effects)	8
4	Increased coordination of patient care and support among the multiple players (i.e. family and other home caregivers and medical staff) to enhance delivery	5
4	Pediatric palliative care	5
5	Assessment of the multiple dimensions of symptom intensity and risk factors for symptom distress	4
5	Psychological and social issues that result in patient-family distress	4
5	Further integration of palliative care with oncology, particularly at earlier stages of cancer and with acute care	4

Response to Theme Results

1. Do you agree with the results for this theme?

   YES ____ NO____

2. If you have any comments regarding this theme please provide them below.

B7 Health Services and Policy Research

Ranking	Potential Research Topic	Frequency Ranked as Number 1
1	**Outcomes measurement**	**15**
2	**Economic analysis (cost effectiveness of current therapies, economic performance of delivery system)**	**9**
3	**Effectiveness of varying organizational models for delivering integrated care**	**8**
4	**Prevention services**	**7**
5	**Modeling of cancer services delivery based on evidence-based best practices to predict future resource needs**	**6**

Response to Theme Results

1. Do you agree with the results for this theme?

   YES ____ NO____

2. If you have any comments regarding this theme please provide them below.

Ranking	Potential Research Topic	Frequency Ranked as Number 1
1	**Molecular profiling of tumours**	**15**
2	**Legal, social, ethical issues associated with increased use of genetic information in cancer care**	**12**
3	**Functional proteomic, elucidation of molecular signaling pathways**	**11**
4	**Gene therapy**	**7**
5	**Bioinformatics, analytical software**	**6**

Response to Theme Results

1. Do you agree with the results for this theme?

   YES ____ NO____

2. If you have any comments regarding this theme please provide them below.

B9 Screening

Ranking	Potential Research Topic	Frequency Ranked as Number 1
1	Integrating effective screening into the primary care system	20
2	Achieving high levels of evidence of efficacy without population based RCTs	10
2	Research into cost-effectiveness/cost-benefit of both current and new and improved screening methods	10
3	Development of screening strategy	9
4	Minimization of false positive and negatives	6
4	Actual and optimal diagnostic pathways for screening tests in the general population	6
5	Development of novel candidate testing procedures	3

Response to Theme Results

1. Do you agree with the results for this theme?

   YES ____ NO____

2. If you have any comments regarding this theme please provide them below.

B10 Cancer Biomarkers and Imaging

Ranking	Potential Research Topic	Frequency Ranked as Number 1
1	Early detection of specific cancers through screening	21
2	Molecular and functional imaging	15
3	Identification of molecular biomarkers to assist in new imaging modalities and to guide new treatment strategies	9
3	Computer assisted image analysis technologies	9
3	Diagnostic imaging, including anatomical, functional and qualitative	9
4	Health service implication of new diagnostic imaging	5
5	Image guided therapy	3

Response to Theme Results

1. Do you agree with the results for this theme?

   YES ____ NO____

2. If you have any comments regarding this theme please provide them below.

B11 Pediatric Cancer

Ranking	Potential Research Topic	Frequency Ranked as Number 1
1	Reduction of late effects in survivors of childhood cancer	15
2	Clinical trials, including Phase I/II studies designed in Canada, and participation in Phase I-III international collaborative group trials	10
2	Research into the basic biology of developmental tumours, including genetic predisposition	10
3	Etiologic studies related to pediatric cancer (e.g. genetic determinants/ predisposition, basic, modifiable and other risk factors)	9
4	Optimal utilization of existing surveillance data, existing research expertise, and the unique characteristics of the Canadian health care system	7
5	Intervention studies for prevention of new cancers in survivors of childhood cancer	4
5	Correlative studies of emerging biological and sociobehavioural information on survival, quality of life and long-term outcomes for children and families	4

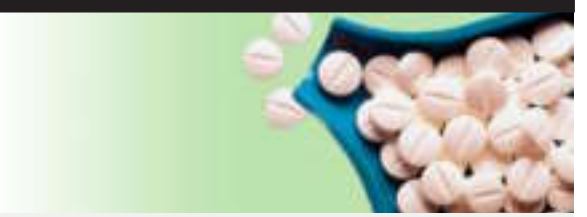
Response to Theme Results

1. Do you agree with the results for this theme?

   YES ____ NO____

2. If you have any comments regarding this theme please provide them below.

B12 Sociobehavioural Cancer Research



Ranking	Potential Research Topic	Frequency Ranked as Number 1
1	Determinants and development of health risk behaviour and coping, and implications for prevention/ improvement	21
2	Psychosocial factors that influence adaptation, coping and quality of life at each age and stage along the cancer continuum	9
3	Outcomes research and program evaluation of cancer control services, to include sociobehavioural predictors, processes and outcomes	7
4	Investigation of factors relating to "patient delay" at pre-diagnosis, diagnosis and treatment stages	6
4	Role of spirituality in healing, prayer and personal empowerment in healing	6
4	Understanding determinants of lifestyle (e.g. tobacco use, diet, exercise)	6
5	Increased understanding of the role of complementary medicine in a person's experience of cancer	5
5	Need for new research methods/paradigms to capture complexity of this kind of research	5

Response to Theme Results

1. Do you agree with the results for this theme?

   YES ____ NO____

2. If you have any comments regarding this theme please provide them below.

A Delphi Process for Setting Cancer Research Priorities in Canada

Stage III Results

Sponsored by:

- Canadian Institutes of Health Research- Institute for Cancer Research
- National Cancer Institute of Canada
- Canadian Association of Provincial Cancer Agencies
- Health Canada

A Delphi Process Undertaken by Praxis Inc.

August, 2002

Cancer Research Delphi Process – Stage III Results

Stage III of the Cancer Research Delphi process was electronically distributed to 606 individuals from the original Stage I contact list and a further 29 individuals whorequested to be added during the process of Stage III. The Delphi announcement was distributed on June 6th, 2002 and a reminder was distributed on June 17th, 2002. 147 emails were returned as undeliverable. In total, 104 completed responses were received by the June 24th cutoff date.

The Stage III questionnaire provided an overview of the of the Stage II results, including: participants' demographic information, the top five ranked Key Focus Areas for the two Overriding Thematic Areas, and the top five ranked Priority Research Topics for the 12 Priority Themes.

In Stage III, participants were asked to indicate their agreement with the results for each theme and to provide any additional comments related to each theme. In addition, participants were asked a series of questions about the Cancer Research Alliance.

The Stage III results are presented in the following sections.

I/ Demographic Results

Based on the demographic results, respondents in Stage III of the Delphi process represented a reasonably valid cross section of respondent types, types of organization, provinces and gender.

Respondent Type	Frequency	Percent
Currently Active Researchers:		
Basic biological research	16	15.5
Other basic research	2	1.9
Clinical research	22	21.4
Health services research	4	3.8
Population health research	9	8.7
Psychosocial research	7	6.8
Other	2	1.9
Currently Not Active Researchers:		
Advocacy	11	10.7
Health care	8	7.8
Policy analysis and development	8	7.8
Other currently not active research	14	13.6
TOTAL	103	100

Academic institution	45	43.7
Volunteer organization	17	16.5
Health care institution	1	1.0
Consumer organization	5	4.9
Federal government	7	6.7
Provincial government	4	3.8
Local or regional health authority	2	1.9
Individual	6	5.8
Other	16	15.5
TOTAL	103	100

British Columbia	17	16.3
Alberta	14	13.5
Saskatchewan	5	4.8
Manitoba	4	3.8
Ontario	45	43.3
Quebec	9	8.7
New Brunswick	5	4.8
Nova Scotia	3	2.9
Prince Edward Island	1	1.0
Newfoundland	1	1.0
Yukon, Northwest Territores and Nunuvut	0	0.0
TOTAL	104	100

Male	60	57.7
Female	44	42.3
TOTAL	104	100

II/ The Cancer Research Alliance

Participants in the Stage III questionnaire were provided with a brief description of the Cancer Research Alliance and request to provide feedback. Over 90% of respondents agreed that the Research Alliance should take future action toward building consensus on Canadian research priorities. Over 97% indicated that an ongoing coordinating group for the Research Alliance is needed. Just under 90% suggested that the efforts of a coordinating group should be linked internationally.

The results for each question are highlighted in the following section. 'Quotable quotes' or representative examples of verbatim comments from participants who did not support further consensus building steps have been provided.

1. Should members of the Research Alliance (CIHR-ICR, NCIC, CAPCA & Health Canada) take any further steps to foster consensus on Canadian research priorities?

	Frequency	Percent
Yes	95	91.3
No	9	8.7
Total	104	100

2. If your answer to question 1 is 'no', then what is the basis for your response?

   "The traditions of research require freedom of action. We do not know where or when the next major advance will occur nor what it will bring. Continuing to try and achieve consensus risks stifling individual initiative. We should be supporting excellence in research from whatever source it derives."

   "It would seem that almost 700 of the original 800 have opted out of more consensus building. Move on."

   "A tremendous amount of time and energy has been spent already on this. Many opportunities have been given for input and consensus seeking activity. There has been a delay in proceeding with research activity on the priorities identified. The time is now ripe to proceed with things."

   "However it is vital to ensure that all needs are represented. It is a major concern that whenever there is consensus there is also compromisation, this compromisation must not be allowed to direct all focus to large vocal groups at the expense of groups that are underrepresented such as pediatrics."

3. If your answer to question 1 is 'yes', then is an ongoing 'coordinating group' needed for the Research Alliance (for example, a group that meets at least once per year)?

	Frequency	Percent
Yes	94	97.9
No	2	2.1
Total	96	100

4. If your answer to question 3 is 'yes', then should such a 'coordinating group' seek to link its efforts (on cancer control research priorities) internationally?

	Frequency	Percent
Yes	81	87.1
No	12	12.9
Total	103	100

III/ Overriding Themes

The majority of respondents agreed with the top five Key Focus Areas identified for Infrastructure and Human Resources. Comments were predominately related to reordering the ranking.

A1 Infrastructure

Do you agree with the results of the Key Focus Areas for Infrastructure?

	Frequency	Percent
Yes	87	87
No	13	13
Total	100	100

A2 Human Resources

Do you agree with the results of the Key Focus Areas for Human Resources?

	Frequency	Percent
Yes	79	89.8
No	9	10.2
Total	88	100

VII Priority Themes

Generally Stage III participants were in agreement with top five ranked Potential Research Topics for each of the Priority Themes. All received over 80% agreement with the exception of Genomic Science and Cancer and Experimental Therapeutics, which received 79.9% and 72.2% agreement respectively. Notably, the Potential Research Topics identified for Screening received 100% agreement.

The quantitative results for each Priority Theme are provided in the following section. Written comments were predominately related to reordering the ranking.

B1 Etiologic Factors

Do you agree with the results of the Potential Research Topics for Etiologic Factors?

	Frequency	Percent
Yes	74	88.1
No	10	11.9
Total	84	100

B2 Surveillance

Do you agree with the results of the Potential Research Topics for Surveillance?

	Frequency	Percent
Yes	72	90.0
No	8	10.0
Total	80	100

B3 Population Based Prevention

Do you agree with the results of the Potential Research Topics for Population Based Prevention?

	Frequency	Percent
Yes	67	84.8
No	12	15.2
Total	79	100

B4 Experimental Therapeutics

Do you agree with the results of the Potential Research Topics for Experimental Therapeutics?

	Frequency	Percent
Yes	61	79.2
No	12	20.8
Total	79	100

B5 Clinical Research

Do you agree with the results of the Potential Research Topics for Clinical Research?

	Frequency	Percent
Yes	68	86.1
No	11	13.9
Total	79	100

B6 Palliative Care/Quality of Life

Do you agree with the results of the Potential Research Topics for Palliative Care/Quality of Life?

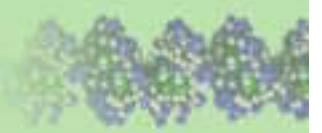
	Frequency	Percent
Yes	72	88.9
No	9	11.1
Total	81	100

B7 Health Services and Policy Research

Do you agree with the results of the Potential Research Topics for Health Services and Policy Research?

	Frequency	Percent
Yes	71	87.7
No	10	12.3
Total	81	100

B8 Genome Science and Cancer



Do you agree with the results of the Potential Research Topics for Genome Science and Cancer?

	Frequency	Percent
Yes	59	79.7
No	15	20.3
Total	74	100

B9 Screening

Do you agree with the results of the Potential Research Topics for Screening?

	Frequency	Percent
Yes	72	100
No	0	0
Total	72	100

B10 Cancer Biomarkers and Imaging

Do you agree with the results of the Potential Research Topics for Cancer Biomarkers and Imaging?

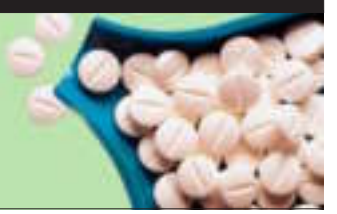
	Frequency	Percent
Yes	64	90.1
No	7	9.9
Total	71	100

B11 Pediatric Cancer

Do you agree with the results of the Potential Research Topics for Pediatric Cancer?

	Frequency	Percent
Yes	62	84.9
No	11	15.1
Total	73	100

B12 Sociobehavioural Cancer Research



Do you agree with the results of the Potential Research Topics for Sociobehavioural Cancer Research?

	Frequency	Percent
Yes	72	88.9
No	9	11.1
Total	81	100