



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

Survivorship at the BC Cancer Agency

Research & Practice

Richard Doll MSc, MSW

Cancer Survivorship & Sociobehavioural Research

British Columbia Cancer Agency



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority



CIHR IRSC



Public Health
Agency of Canada

Agence de la santé
publique du Canada



CANADIAN PARTNERSHIP
AGAINST CANCER

PARTENARIAT CANADIEN
CONTRE LE CANCER





BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

Defining Survivorship

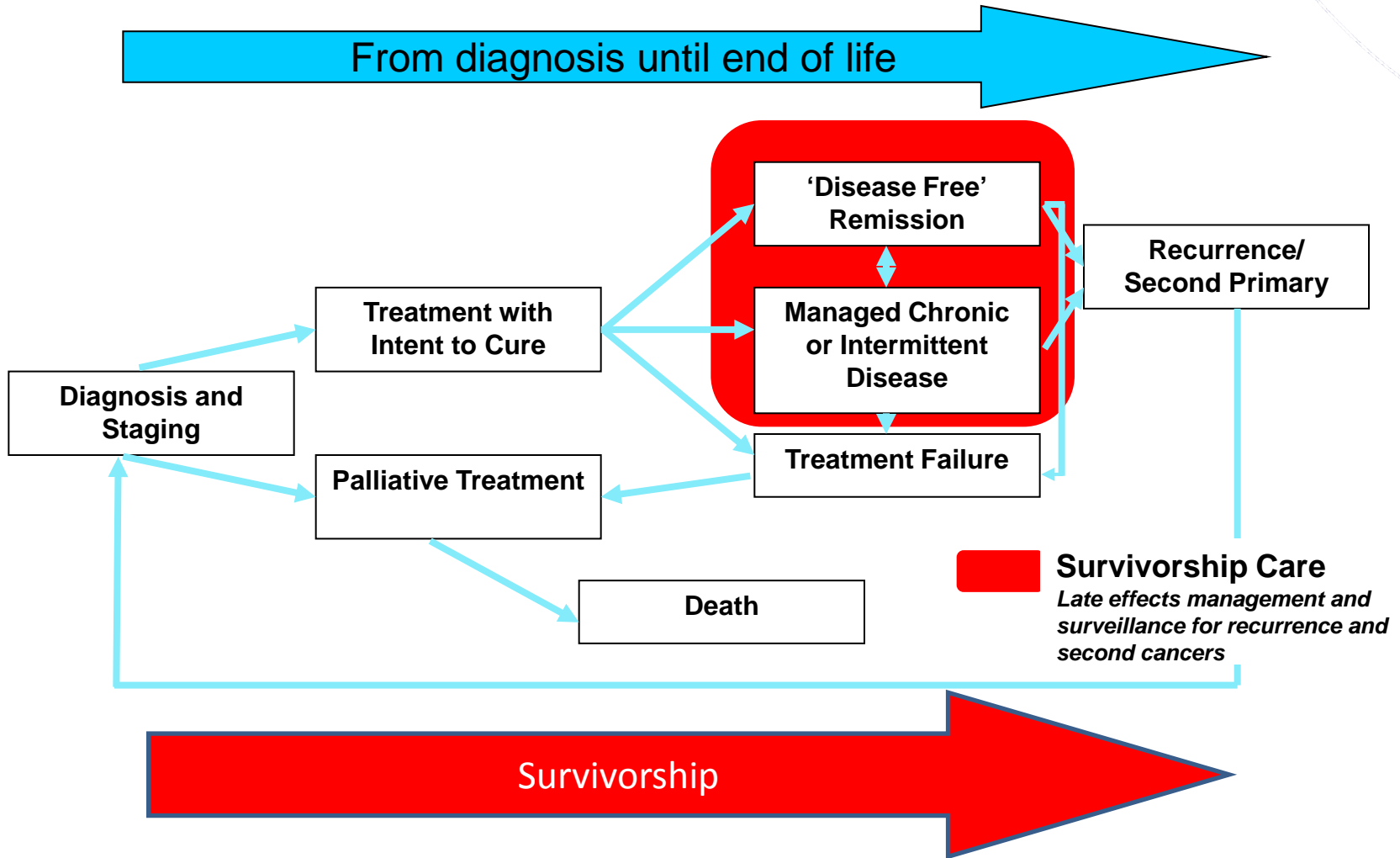
- Having no disease after the completion of treatment
- The phase following post-initial treatment living five years or more post-diagnosis
- USA Survivorship Coalition: “At the point of diagnosis “(survivor or survivorship?)
- Institute of Medicine> The distinct phase in the cancer trajectory between the end of primary treatment and recurrence or end of life*
- How one defines survivorship and the approach for care is heavily influenced by one’s values, experiences, philosophy & conceptual framework



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority





BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

Mandate

- Identify state/evidence in survivorship provincially, nationally, internationally
- Incorporate broad input for BCCA plan
- Provide broad recommendations for survivorship approach/activities
- Integrate research plan
- Recommendations for immediate action



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

Key Principles

- Transitioning care, managing uncertainty
- Coordinating care
- Integrating medical management, follow-up and quality of life
- Patient/caregiver involvement
- Identification of measureable outcomes
- Integration of research and evaluation
- Attention to “economics” in demonstrating value



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

The Imperative for Cancer Survivorship

Active treatment creates risks of long-term adverse physical effects or worry that threatens quality of life, creates anxiety, complicates communication (Clark, JCO, 2006)

We need to understand the impact but beyond, to develop strategies to improve quality of life

“Being disease free does not mean being free of your disease”
(Rowland, Director, Office of Cancer Survivorship NIH)



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

Objectives of Cancer Survivorship?

- Helping to effectively manage the patients experience with cancer through the trajectory from diagnosis to end of life
- Helping to optimize and sustain the benefits of cancer treatment
- Helping to overcome the adverse outcomes of cancer treatment such as late effects
- Address the four dimensions of quality of life (physical, psychological, social, functional)
- Creating opportunities to enhance “survivor” (and the person’s support system) skills, capabilities and attitudes in attaining or preserving health



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

IOM Recommendations (2006)

- Establish as a distinct phase of cancer care
- Evidence based clinical practice guidelines
- Test models of coordinated interdisciplinary care in diverse communities
- Developing comprehensive care plans
- Educational opportunities for providers
- Health insurance
- Follow-up care



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

International Priority Setting

LIVESTRONG, Washington D.C. (September, 2011)

THEMES:

1. Survivorship Care Plans (treatment summary and psychosocial supports)
2. Screening for new cancers/ recurrence
3. Care Coordination – Oncologists and GPs
4. Prevention/ health promotion
5. Interventions- symptom management, palliative care
9. Navigation



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

Review of Evidence for Priorities UK

- Understanding the extent of psychological, social and physical needs of survivors
- Development of testing of interventions to address symptoms, long & late effects, sexual issues
- Service organization and delivery, outcome measurement
- Developing and testing psychosocial interventions
- Addressing the needs of caregivers/ families
- Self management approaches



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

National Priority Setting in Cancer Survivorship (2008, funded by CPAC)

- Establishment of national standards & guidelines
- Development of models of care delivery
- Creation and implementation of care plans
- Research development
- Knowledge translation models
- Consortium for national survivor advocacy groups
- Creation of a national office for cancer survivorship



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

Quality of Life Domains in Survivorship

Physical

- Fatigue, pain, cognitive, recurrence, co-morbidities

Functional

- Capacity to engage in activities of daily living, return to work

Emotional

- Impact on mood/affect, cognitive

Social Role

- Role functioning & support, financial burden



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

BCCA Plan

- Provincial Program
- Provincial Steering/Workgroup
- Establishing an Endowed Chair in Cancer Survivorship
- Building a Canadian Consortium for Survivorship Research



BC Cancer Agency

CARE + RESEARCH

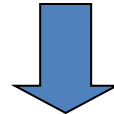
An agency of the Provincial Health Services Authority

Research and Practice Model

Vision and Leadership in Survivorship



Practice Development and Application



Generation of Evidence Based Research



Recognition of Importance
Awareness and Receptiveness

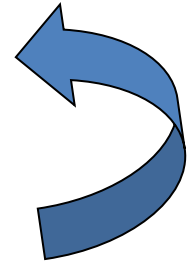


Health Practice Priority
Investment and Sustainability

Discovery

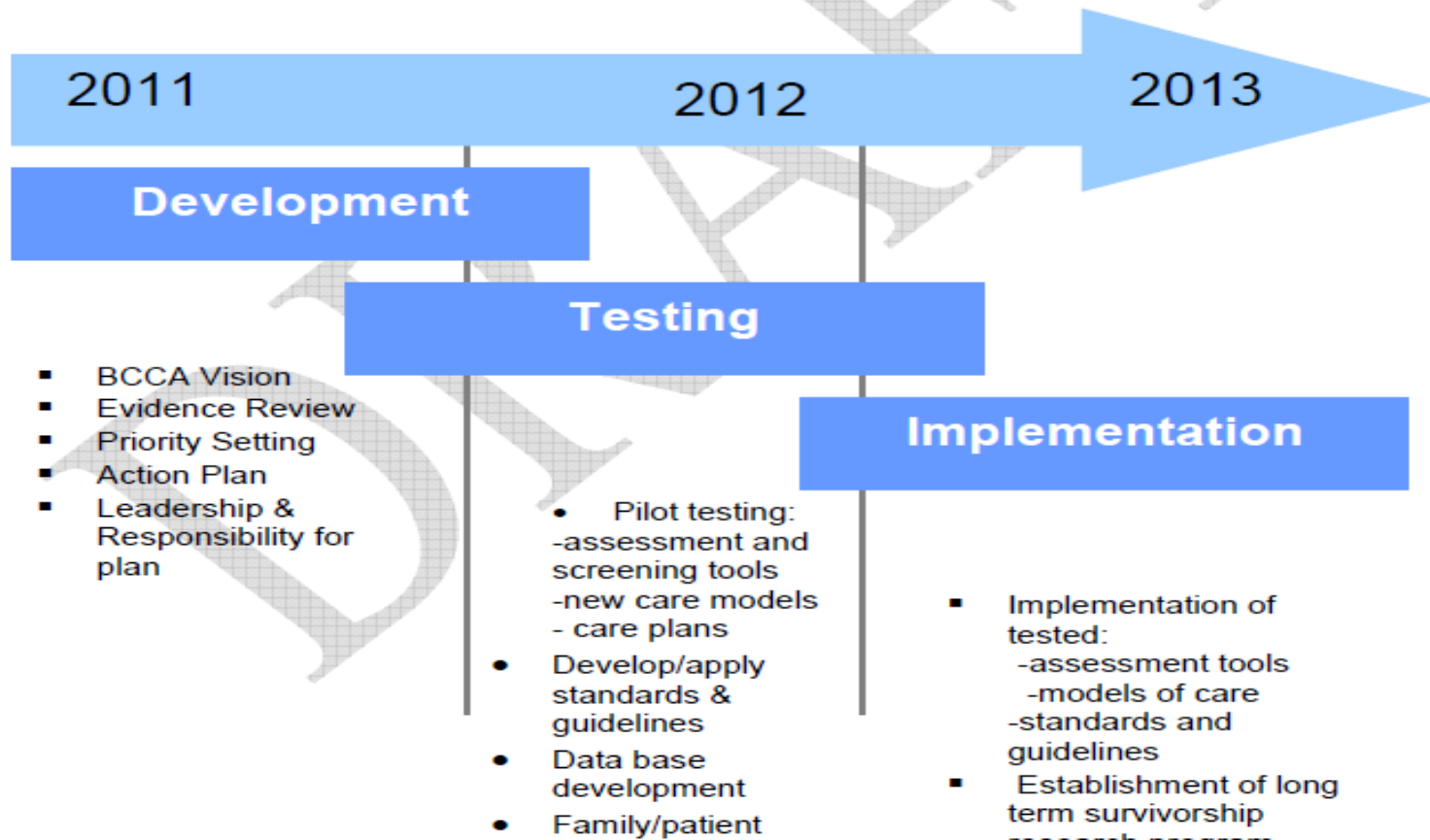
Clinical
Validation

Population
Application





BCCA 3 Year Survivorship Plan: Research, Policy & Practice





BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

Approach/Consultations

- Cancer Survivorship Steering Group
- Survivor Reference Group
- Survivorship Literature including grey literature
- Environmental Scan- National, International approaches
- Patient forums and Centre presentations
- Executive committee
- Expert informants external to BCCA
- Tumor Group Leaders consultations
- International Priority Setting meeting (**LIVESTRONG**, Sept, 2011)
- Disease/Advocacy Groups e.g. Prostate, Breast etc.
- Health Authorities



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

Suggestions for Priority Setting

- Pathways
- Care plans
- Data base
- Post-treatment assessment
- Framework e.g. uncertainty
- Post-treatment “discharge planning”
- Primary care pathway
- Navigation



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

Theme Areas in Transitioning Care

1. Care Planning (Amanda Ward & Frances Wong)
2. Post-treatment Assessment (Wolfgang Linden & Ryna Levy-Milne)
3. Post-treatment Interventions (Gina Mackenzie & Mary Flaherty)
4. Primary care/Oncologist post-treatment summary (Phil White & and Rob Olsen)



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

Transfer of Care to Primary Care Physicians

- Awareness of treatment/issues
- Out of the loop
- Time/remuneration
- Patient/oncologist/PCP lack of confidence
- Competing demands
- Shortage of PCP' s



BC Cancer Agency

CARE + RESEARCH

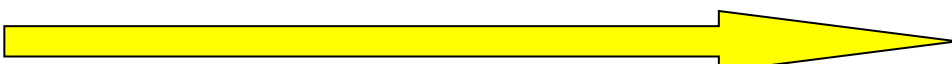
An agency of the Provincial Health Services Authority

Handoffs to Primary Care Physicians

- Treatment protocols
- Recommendations from oncologist
- Surveillance expectations
- Prevention and behavioural management strategies
- Risks for recurrence and second primaries
- Resources available

Survivorship Research Program

Research Priorities



Practice

Measurement/Tool Development

Needs/Characteristics of Unique Pop

Evaluation of Effective Models of Care

Development of Effective Interventions

Mechanisms Underlying Long-term Effects

Survivorship Database

Screening

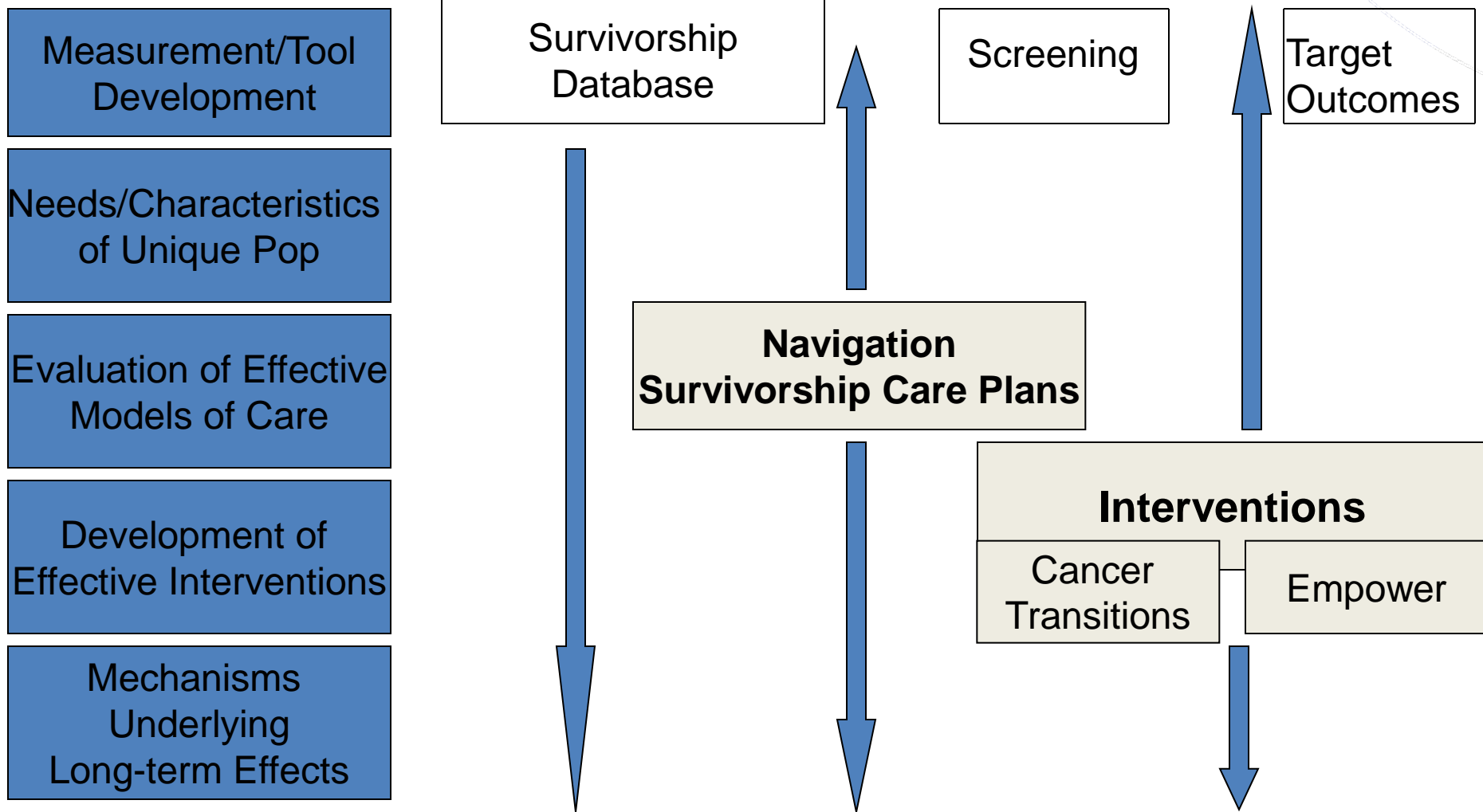
Target Outcomes

Navigation Survivorship Care Plans

Interventions

Cancer Transitions

Empower





BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

Sociobehavioural Research Center

- Director, support staff
- ~ 20 Adjunct Research Scientists
- Two CIHR funded national research teams 2005- 2014
- Leadership in Canadian Center for Applied Research in Cancer
- Project work funded by CPAC and PHAC
- Canadian Cancer Survivorship Research Consortium
- Rural and remote focus in Northern Health
- The Lesley Diamond Endowed Chair in Cancer Survivorship ~ \$5.12 million SFU/BCCA/BCCRF



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

Why a Consortium?

- Undertake research that otherwise would be difficult: large national studies, pooling of unique skills
- Opportunity for fast turn-around to transfer knowledge to clinical practice
- Less resistance to implement proven approaches when there is broad collaboration
- Minimize duplication & competition



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

Consortium's Mission

- The Research Consortium will enhance capacity through creating new knowledge by addressing current gaps in the evidence, facilitating the synthesis and exchange of this knowledge between stakeholders, and applying this knowledge to improve the survivorship experience.



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

Research Themes

- Needs assessment: to identify and measure the proportion of those in need (who is in need, what the needs are and how to address them).
- Late effects: identification and interventions for management.
- Pediatric and young adults: the long term effects of cancer
- Determine effective interventions including psychosocial, physical, nutritional, lifestyle.
- Focus on lifestyle, wellness and the chronic nature of cancer.
- Potential of technology support/web-based information.
- Development of data bases to support national research
- Evaluating the models of care.
- Focus on “unique” populations



BC Cancer Agency

CANCER RESEARCH

An agency of the Provincial Health Services Authority

Canadian Cancer Survivorship Consortium

Organization	Research Theme	Lead Researchers
UBC/BCCA	Survivorship Research Centre	Kazanjian, Doll, Ward, Linden + 20, Chair
Princess Margaret	Survivorship, Oncology	Jones, Hodgson, Catton
McMaster/U of Toronto	Health Economics	Longo
Canadian Partnership (CPAC)	Cancer Journey Action	Fitch
Propel (Waterloo)	Epidemiology	Campbell
Ontario Institute of Cancer Research	Policy	Grunfeld
Universite Laval	Survivorship/navigation, Family Practice	Fillion, Aubin
McGill/Jewish	Psychosocial Oncology	Loiselle
Can. Care Man. University of Man.	Family Practice	Sisler, Taylor-Brown
University of Calgary/Tom Baker	Survivorship/ Oncology psychosocial	Carlson, Giese-Davis, Wu
University of Ottawa/ Ottawa Cancer Centre	Palliative Care/family practice	Chasen



BC Cancer Agency

CARE + RESEARCH

An agency of the Provincial Health Services Authority

Nursing Team Consortium/CIHR/ARCC Members

- Lise Fillion, Laval > Navigation
- Carmen Loiselle, McGill > PORT
- Marg Fitch, Toronto > CPAC
- Maya Shaya, Switzerland > Modeling (uncertainty)
- Sally Thorne, Vancouver > Multi-theme
- Lynda Balneaves, Vancouver > CAM
- Fuchsia Howard, Vancouver > Post Pediatric
- Carole Robinson, Kelowna > Caregivers