Submission to the

Conversation on Health

The BC Cancer Agency mission:

• To reduce the incidence of cancer
• To reduce the mortality rate of cancer
• To improve the quality of life for those living with cancer
Introduction

In September 2006, Premier Gordon Campbell launched the Conversation on Health to invite British Columbians into a dialogue about the challenges and solutions to issues facing our health care system.

One of the growing challenges is cancer. It is estimated that one in three people will develop cancer in their lifetime. In B.C., that means 20,000 people will be newly diagnosed in 2007, and 9,000 will die from this disease. By 2020, these numbers will have increased to 28,000 and 12,000. Clearly, this will place a great burden – both in human and fiscal terms – on our province.

The BC Cancer Agency has a three-fold mission to address this burden:

- To reduce the incidence of cancer
- To reduce the mortality rate of cancer
- To improve the quality of life for those living with cancer

While this is the BC Cancer Agency’s mission, we cannot achieve it alone. Our stakeholders and partners in the local and global community play an important role in shaping a system to help reach these goals. Their experiences, frustrations, achievements and advice can help shape a vision for cancer control in this province.

It is therefore the input of those partners – patients, families, health professionals, health authorities, advocacy groups and researchers, to name a few – that we present, in its entirety, the following document: the BC Cancer Agency’s submission to the Conversation On Health.

Dr. Simon Sutcliffe,
President
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Background

In May 2007, the BC Cancer Agency’s Vancouver Island Centre received a request to provide a written submission to the Conversation on Health. Recognizing that the cancer control system in British Columbia comprises a wide range of stakeholders, BC Cancer Agency leadership determined that input to the Conversation specifically on cancer care and control needed to come from a range of care providers and clients, not simply BC Cancer Agency staff.

By inviting patients, families, health care professionals, regional health authorities, advocacy and support groups, volunteers, and the public to participate, it was possible to solicit opinions and suggestions from a variety of perspectives.

In July 2007, the BC Cancer Agency solicited feedback from the public about its vision of the future of cancer care and control across the province of British Columbia. Public forums were held in the four regions where the BC Cancer Agency currently has regional centres, and written submissions were accepted from across the province. Participation in the forums and in the written submissions included input from patients, their families and caregivers, cancer survivors, support group members, advocacy and interest groups, regional health authorities, researchers, and members of the well public.

This report is not designed to provide analysis or recommendations from the BC Cancer Agency, rather it is the unedited content from the public forums and written submissions from across the province – the messages that the public have indicated they wish to have included in the Conversation on Health.
Methodology

The BC Cancer Agency’s public forums were designed to present a submission to the Conversation on Health, comprised entirely of feedback from a variety of stakeholders across the cancer care and control spectrum.

The provincial Conversation on Health was structured around three questions:

- How do we better define the principles of the Canada Health Act?
- How do we make our health care sustainable?
- How can we improve health care delivery?

The BC Cancer Agency’s public forums were designed to echo, though not duplicate, the Conversation on Health format. Three key subject areas based on the BC Cancer Agency’s mission formed the framework for the discussion: incidence, mortality, and quality of life. Four questions were put to participants in the public forums in each of the mission statement categories:

- What is working well?
- What do we need to rethink?
- How do we improve?
- Who do we need to partner with?

While the BC Cancer Agency was hosting the forums, the “we” refers to the system as a whole. BC Cancer Agency is a partner in the cancer control system across our province, and recognizes that such a system needs the cooperation and input from all of its partners to provide care.

Public forum participants worked in break-out groups, each representing one of the three topic areas: incidence, mortality and quality of life. The aim was not to reach agreement, consensus, or even to correct misapprehension or misinformation. The aim was for everyone to be heard, respected, and given an opportunity to have their views and suggestions expressed.

The BC Cancer Agency’s goal was to present feedback from stakeholders in the cancer care system as it was recorded during the public forums, for the Province to see the full range of ideas and expectations of the public. The following report presents the thoughts and ideas of the public forum participants exactly as they were captured, without editing or analysis.
Key Themes Emerging

In preparing this report - particularly noting the key messages - a number of themes appear in each of the discussion areas, and indeed, across the entire report.

Incidence
- Regulation/monitoring of environmental agents – pollutions, toxins, etc
- Early life education in prevention
- Support for healthy lifestyles
- Increase the number of cancer screening programs – colorectal, skin

Mortality
- Access to, and funding for, alternative/complementary/non-traditional medicine
- The need for patient navigation through the cancer care system
- Delay from diagnosis to treatment
- Support for hospice/palliative care
- Holistic approach to health care

Quality of life
- Shorter wait times needed from diagnosis to treatment
- The need for patient navigation through the cancer care system
- Support for hospice/palliative care
- Access to alternative/complementary/non-traditional medicine
- Better communication between family physicians and specialists
- See patient as a person, not a disease
- Increased services such as financial support and home care for patients
Reducing the Incidence of Cancer

What is working well?

- Access good – wait time
- There is more public information available on cancer on websites, and in the public.
- Respect, caring from healthcare professional
- Screening Mammography Program
- Smoking cessation and prevention programs/policy/laws/taxation, etc
- Early intervention
  - e.g. in schools – Education re: smoking
- Focus on less well-known cancers
  - e.g. Underwear affair
- Research on HPV vaccine
- Registry for Bone Marrow Transplant
- Encouraging people not to smoke
  - Regulations for smoke-free environment
- Screening for breast and cervical cancers and prostate
  - Screening reminder system (e.g. mammography) works well – use it for other screening programs
- Good communication
- Family doctors promoting screening
- Vehicle emission controls (AirCare)
- Access from North Shore to BC Cancer Agency services
- Respect for patients throughout agency
- Promoting healthy lifestyles and incentives
- Exposure to carcinogens
- Awareness of obesity – related illnesses, importance of healthy diet and exercise
- Stricter nutrition and additive labeling on food
- Variety of produce
- Spectrum of the cancer control program
- Screening programs for breast cancer, cervical cancer
- Success in some screening programs
  - Mammography, cervical
- Dieticians effect on consumer food choices
- Gov’t legislation on smoking bylaws
  - e.g. banning smoking on outdoor patios
- BC Cancer Agency increasing awareness
  - Sunscreen, exposure, diet
  - Canadian Cancer Society
- Early education – schools
- Dermatology research and awareness of chemicals in sunscreen shown to be carcinogens
- Municipalities banning commercial use of pesticides
- Use of websites, toll free numbers on cancer info
- Schools replacing junk food with healthy food
- Municipalities improving parks and paths to promote healthy activity
- CBC and others informing about the hazards of cleaning products – alternatives
- Media increasing interest and awareness in health issues
  - More grass roots approach, more investigative
- Legislation to help make health choices the easier choices
• Prevention Chair at UBC
• Prohibiting smoking in public places
• Promotion of health awareness
• Media contributing to awareness, a receptive public to the message
  - Cultural/attitudes changing
• Preliminary screening
  - Mammography rates okay, much room for improvement
• Researching causes of cancer and opportunities for prevention
  - Media coverage and explanation of research – clearly, in a way people can understand
  - Public demand for this info
• Provincial targets on tobacco use reduction
• Support local agencies that promote healthy lifestyles and health education – kids, rec centres
• Definition: Prevention
• Papilloma virus vaccine – is it available here?
• Sun protection – education
• Mammogram screening program
• More promotion of healthy lifestyle – TV ads
• Research – Herceptin available quickly = benefits in incidence and relative to occurrence
• Centre [for the Southern Interior] has done well – sincere, compassionate, supportive
• Medication provided here
• Information – audiovisual
• Reducing cancer
  - Prevention information
• Educating general public
• We’ve gotten the message on lifestyle factors
• More efforts working toward prevention activities – workplace, schools, individuals
• Screening & beyond
• The last 10 years have been very important (i.e. support groups)
• More socially acceptable
• Prevention efforts have moved beyond health care
• Early prevention
• Skill level of surgeons, improvement of treatments
• Having a centre in the southern interior
• Having oncologists here SI
• Collegiality of cancer care
• Professional nationally
• Supportive groups – a lifeline
• Access to medications coverage
• Gene marker technology
• General organization & delivery of care
• Educational opportunities
• Mammography screening program
• Yearly doctor check-up and tests
  - ie blood, Pap
• Education that the Centre provides
  - ie healthier lifestyle, nutrition
• IT’S FREE
• Skin screening program at the beaches
- MRI screening
- The location of the Surrey site
- Screening Mammography program
- Lots of exposure on eating healthy
  - Magazine ads, newspaper, media
- Lots of info on early detection in magazines, TV
- Lot of info available at the Agency
  - Pamphlets available
- Prostate, Breast cancer awareness
- Support groups HELP – info from this area for detection
- Limiting smoking indoors/outdoor
- Getting the right info and how it is delivered through the media
- Encourage books (library)
- Romanow Report to USE
What do we need to rethink?

- What is causing increase in incidence?
- Age at diagnosis – younger patients
- Longer range consequences
- Policies on:
  - Healthy eating
  - Carcinogens in environment
  - Exercise (especially in schools)
  - Smoking
- Empowering people in rural areas, poorer socioeconomic groups
- Pollution – effect of exposure in environment
- Awareness of effects of hormonal therapies
- Hereditary Cancer Screening
  - Other screening tests
- What is the evidence for the guidelines?
- Cost-effectiveness
- Patient getting pathology results
- Broader education to First Nations, and First Nations communities
- Understanding of your own cancer and what drives it
- Information to prevent incidence and recurrence
- How can the patient take responsibility
- How health professionals can encourage understanding
- Tracking workplace exposure over time
- Epidemiology
- Screening for colon cancer, prostate cancer
- Health education regarding diet, exercise
- Exposure to radiation during diagnosis and treatment
- How we modify the way we eat?
  - e.g. junk food in schools
- Relationship to food
- Society needs to take responsibility
  - e.g. for health of children
- Use of automobiles
  - Pollution
  - Lack of exercise
- Controls of additives etc put into foods
  - Taking another look at our standards and learning from other jurisdictions
- Food labeling
- Role of psychological/psychosocial stress
- Priority/funding that prevention receives in our healthcare system
- More implementation of what we do know
  - More research into those things we don’t
- Coordination in programs of research
- It could have saved the system and our family a lot to have prevented this delay in surgery
- Set targets w/consequences about tobacco use reduction
- More regulation of industrial carcinogens – burden of proof on industry
- “Triple bottom line” social, economic responsibility
• Need a ‘wholistic’ prevention, screening strategy across Canada
• Pan-Canadian symposiums/expert critical mass on best practices in prevention
• Make health lifestyles fun!
• Attitude of industry of “anything goes” re: products and their testing, research on health effects
• Accountability
• Precautionary principle of regulations
• Foster idea of corporate responsibility
• More awareness of and testing for less prevalent forms of cancer e.g. not just breast and prostate
• Equity issue of funding, research and focus
• Lack of holistic approach
• Planning packages for different groups/ages
• Coordination of groups; health care providers, advocates
• E.g. things to prevent cancer also prevent diabetes
• Health care focus on health rather than disease
• Education of health issues at much younger age
• Screening fails at times
  - Misdiagnosis
  - Level playing field among health professionals (equally qualified to diagnose)
  - Equal access for patient, particularly by location
  - Lack of screening for certain kinds of cancers
  - Programatic (sic) screening lacks
• Legislate: no cigarettes in pharmacy, “power walls,” parks, health authority campuses
  - Financial interests in the above, conflict of interest
• More receptive to treating and working with other cultures
  - First Nations
• Physicians shouldn’t ask patients if they have a good diet
  - Many patients don’t know
  - Get dieticians involved
• Tax breaks to people growing healthy food, organic
  - Rethink subsidization, support
  - Makes healthy food more accessible
• Increased protection of agricultural land
• Lessen cost of healthy choices
• Employers providing opportunities for healthy lifestyles
  - e.g. gym equip at Health Ministry
  - assist employees with stress management education - better health
• Mammograms
  - Diagnostic alternative to present procedure
  - Don’t know damage done
  - False/negatives
  - Better screening
• Increased use of colonoscopes for screening
• PSA baseline testing at 35 for men with family history of cancer. 40 for others
• Earlier diagnosis, screening by use of technology e.g. PET scan
• Increased availability of genetic counseling & testing
• No one in charge: gap
• Knowledge on part of doctor & patient
  - Need automatic reminders
- Consistency
  - Different process for screening and diagnostic mammograms
  - Smoking incidence still high esp teenage girls
  - More ed for GP’s
  - Better way of getting information for patient from Dr
  - Rethink link between/beyond chronic disease and poverty
  - It’s not an individual’s fault (i.e. poverty). Problem with transportation, food
  - Job may expose them to chemicals
  - Rethink judgments around lung cancer – as it’s connected to smoking
  - Cervical cancer
  - Health is the responsibility of more than one ministry i.e. housing
  - Low income people are seldom able to access alternative health care practices due to cost
  - i.e. cost of housing and food for people can reduce the cost of health care (including cancer) and decrease incidence of cancer
  - alternative health approach – more ‘holistic’ approach
  - Compensation to pay for
  - How are we communicating information – not everyone has a computer
  - Not all the information is reliable
  - Have to be sensitive to people who don’t have early information on prevention
  - Who are we reaching? Are we effective?
  - How are we communicating?
  - Reaching healthy people
  - The role of WCB – targeting specific industry
  - Wait times – diagnosis to surgery
  - Research to find the cause
  - Inpatient care in the Centre for the Southern Interior
  - Dovetail services with Kelowna General Hospital
  - Coordination of care/who’s driving the bus?
  - Caseload – fragmented care
  - Better communication amidst those providing care
  - Rethinking drugs/how to integrate alternative medicines
  - Collaboration with alternate & and traditional medicine
  - Coordinated team of experts with holistic approach
  - The issue of milk fat of 1% or less in consumption of milk
  - Big boost in money for education in smoking, diet, exercises from the government, especially smoking
    - MORE PUSH NEEDED!
  - Doctors actively educating patients
  - Make it a easier for people to make healthier choices
  - Support group for smokers
    - How to motivate people to change
  - Sensation programs
  - Payment for services for prevention for GP’s
  - How to involve local politicians in regards to Long Range Planning of Health Care
    - Make changes QUICKLY
  - Need MORE physicians doing prevention
  - Need other health professionals in the delivery of prevention
    - Example nurse, practitioner
• Research and safety of meds HRT and potential risks
• Research on more methods on early detection
• Mammography is only one tool others available
• Screening programs for smokers/non-smokers to detect lung cancer; or Xrays yearly
• Clarifying issues in respect to diet, health
• The role of birth control pills in the rise of breast and ovarian cancer in young women
• The role of environmental pollution in all types of cancer from heavy industry into the atmosphere and in the workplace
• The notion that each person is solely responsible for the cause of their cancer
How do we improve?

- Taking holistic view of patient
- Previous exposure to carcinogens
- Tailor treatments to the individual
- If the BC Cancer Clinic partnered with First Nations in the various regions of the province
- Become more accessible to populations that normally don’t venture into the cancer clinics
- Personalized medicine
  - Can the system handle this
  - Better use of resources
- Moving research into practice in a faster way
- Giving some specific information on how to prevent recurrence
- Other options available elsewhere in the world
- Coordination of information on types of treatment
- Funding for patients to use complementary therapies
- Create public education regarding health
- Tax credits for using exercise/lifestyle programs
- Research on complementary and alternative therapies
- Time between screening and diagnostic
- Anticipate number of abnormal findings so can fast track
- Cancer education for family physicians
- Access to family physicians
  - Especially in rural areas
- Scheduling system that anticipates number of abnormal findings
- More advanced techniques for diagnosis and treatment
  - Incorporating new treatments
- Integrating health education into the school system
- Funding to family physicians for health education
- Strict environmental regulations
- Holding industrial polluters accountable
- Stronger prevention education in medical training
- Improved food standards
- Physicians should be encouraged and enabled to address prevention with patients
- Screening for other forms of cancer
- More money for screening programs, education
  - Prevention saves money in the long run – investment
  - Less people require treatment, treatment expensive!
- Increase legislation: make healthy choices the easier and cheaper choices create
  - Second hand smoke
  - Public parks
  - Healthy foods
- Examine efficiencies in prevention programs, techniques, approaches
  - Bottom up approach
- Increasing prevention re: prevention
- Education!!!
  - Evaluating what is taught and what isn’t, and why?
  - Life skills
  - Early education on prevention
• Change the Canada Food Guide; wrongly discourages fats
• Community gardens
• Need to focus on all population – bring it out in the open
• Curriculum with/LHSOL
• Other comm. Grps/rec centres/daycares
• Ministry of Lifestyles
• Use motivated volunteer in ethnic communities to reach all audiences
• Disincentives/incentives to live a healthy lifestyle
• Implement new screening tools as they become available
• Advocate with other countries to reduce environmental contributors to cancer
• Advocate with gov’t
• Grass roots org – healthy lifestyle
• Education curriculum
• Include community centres, rec centres, day cares
• Evaluate existing programs
• Promote and support volunteers to focus on prevention
• Get the message out consistently to all groups and populations
• Tax breaks and other incentive for health practices, both personal and professional
  - To those who promote healthy (sic)
• Increased emphasis on physical activity
• More accessible nurses and professionals for individual, communities, schools
  - Key figure for cancer prevention info
• Reach out more to patients and people in the system for input
• Apply discoveries in research e.g. genetic markers
• Create networks linking partners and groups
• Clear pathway to get screening streamlining system
• Funding for HPV vaccine Screening
  - Free PSAs (cost prohibitive)
  - Province-wide screening database for each patient and on each patient’s chart. Must be initiated by BP who has been trained for this
• Genetic counseling
  - Advocate to get money for this
• Smoking
  - Education school
• Decreasing toxins in environment
• Orchard sprays
• Pesticides – orchard, grass
• Communication & education of GPs
• GP
• Access to alternative therapies
• Cooperation between agencies, practitioners,
  • Information sharing
• Provide patient-centred care
• Coordination within cancer centre – case counselor
• Drs have open mind to alternative therapies (family physician & oncologists)
• Specific education – shopping, cooking, more practical ‘hands on’ activities to change habits
• Collaboration
• Bring soup kitchen/food banks
• Policy & legislation enforcement – government commitment to improve – relates to chronic disease and poverty
• The right to know what one is being exposed to
• Right to clear air as opposed to the right to smoke
• A living wage
• Improvement doesn’t stop
• Better coordination of services right from diagnosis
• Inpatient care for chemotherapy at Centre for the Southern Interior
• Navigator/coach system to assist patient through the cancer journey
• Designated people helping with the financial obstacles
• Letting people know about financial support
• Setting up a fund that’s supported beyond donated money
• Shorten wait times – transparency through the media about wait times
• Equal access
• Investigative experts/team as soon as there is a suspicion of cancer
• Rapid access clinics
• Breast – diagnosis to plan in one week
• Prostate
• Universal screening
• Colonoscopy program over 50
• Get more information to the GP
• More screening for skin cancer
• Tax structure
  - E.g. tax of cigarettes, cars
• Better coordination, too fragmented
• Consistency of messages re: food
• Treatment of food
  - ie pesticides, chemicals
• Education on nutrition; food prep
• Resources – easier access
• Pesticides by-law for cosmetic use “Provincial Legislation”
  - Discourage – ban use
• Look to other countries in what is working in nutrition education
• Walking Briskly UP HILLS
• Create supportive environments not just education
• Ban sales and use of cosmetic pesticides
• Participation program bring it back
• Tobacco prevention
  - Especially young
  - Sue tobacco companies
• Improve prevention of exposures to carcinogens in the workplace; at home;
  - ie second hand smoke
• TV commercials “Shock Commercials”
• Labeling all products
• FOCUS ON YOUTH!
• Sue McDonald’s for effects of their junk food
• Identifying environmental causes of cancer
• Stress the importance of early detection, screening, diet, choices
• Teach the young people diet choices
  - ie fruits and vegetables
• Improving quality of healthy eating
• Genetic testing, accessibility
  - Length of time to get results
  - Cost
  - Education
• Exercise in reducing cancer
  - Education
• Education in diet/healthy lifestyles in primary/high school
• Avoiding carcinogens
• Education in not to start smoking
  - Especially the youth
• Disney not allowing smoking in movies
• Incentives (Federal) Tax credits for healthy living programs
• Disincentives for poor choices
• Increase age to purchase tobacco products
• It would also have helped us to have been more aware of the importance of routine screening with colon cancer running in the family
• Incorporate the latest techniques for diagnosis, surgery and treatment regimes, in use elsewhere in the world
• Include patients in their treatment regimes and individualize to their particular situation and values
Who do we need to partner with?

- With non-profit organizations
- Coordination of research activity
- Worksafe BC
- Canadian Cancer Society
- CFIH
  - Alternative healthcare
  - Inspire health
- Schools
- Industry including pharmaceuticals
- Epidemiology
  - Cancer registry databases
- Across levels of government
  - Between Ministries
- Industry and government
- Physicians association
- Research funders
  - E.g. CIHR and Prevention
- Post secondary institutions and schools
- Community centres/library
- Community organizations
- Media
- Public health agencies
- Federal partners
- BC Centre for Disease Controls
- Ministry of Education
- Other health authorities
- BC Cancer Agency, CCS, health providers
- TLC, Organic farmers assn.
- Schools, universities
- Health providers including hospitals, doctors, nurses
- Government
- Industry
- Nutritionists, naturopaths (sic), alternative medicines
- Industry, business
- Corporate sector
- School system
- Industry
- Media
- Universities
- All levels of government
- Volunteers
- Groups with shared interests e.g. heart & stroke, diabetes assn.s
- Holistic practitioners, Alternative health care providers
- Network of health care practitioners
- Government ministries, health authority
- Ministry of Employment and Income Assistance, EI
• Churches, universities, colleges
• School districts, First Nations
• Business, WCB
• Countries that run more socialized medicine
• Health professionals – patients – public
  - Drs, nurses, NGO’s
• Municipal government; politicians
• Ministry of Health – Ministry of Education
• Support groups
• Alternative healthcare to research, evaluate and include their products and services in treatments for cancer when valid
• The food industry for safety of preservatives, dyes, etc.
• Employers to ensure worker safety from carcinogens
• Heavy industries that pollute air and water locally
• International bodies in regard to nuclear testing, nuclear plants, war weaponry, industrial pollutants of oceans and air that circulate throughout the world
Key Messages

- Understanding causes
  - New areas of prevention
- Role of all modifiable exposures and how we can prevent
- Multiple ways of effecting changes
  - Policy
  - Education
- Making screening programs accessible
- Make prevention a priority
  - Education, funding, research
- Broad approach
  - Multiple levels/sectors of government
- Shifting balance between prevention and cure
- Key role of environment (regulation)
- Balance between individual and social responsibility
- Access to services that promote health
- Let’s make healthier choices the easier choices
- 50% of cancers are preventable
- Personal responsibility
- Paradigm shift of business – accountability
- Public awareness
- Promote healthy lifestyle
- Educate people at a young age and make it fun
- Accessibility – info available to all
- Accessible to less franchised communities
- Need better:
  - Networking, education, collaboration, communication between health care providers and patients
  - Screening – standardized approach; funding unrestricted
  - Focus on primary prevention – more emphasis including poverty issues
  - Rethink link between chronic disease & poverty
  - Policy/legislation/enforcement for the social/environmental issues
  - More collaboration with partners
  - Let’s use the cancer clinic 24 hours/7 days
  - Commitment to: Reduce wait time, Do research to find the cause, coordinate services
  - Rethink treatment re: drugs & how we can integrate approaches including alternate medicine
  - Navigator/coach to assist patient through the system which includes financial issues

- Healthy lifestyle – promoting it
- Reducing exposure to carcinogens
- Incentives to change lifestyle
- Early detection
- Money into research for early detection
- Promote healthy lifestyle diet/exercise
  - Incentives
  - Disincentives
Reducing the Mortality Rate of Cancer

What is working well?

- Good statistics in B.C.
- Burnaby Hospital – outstanding, personable care – wonderful staff
  - Equal care
- Continuity in care
- Better research
- Vancouver Centre – participation in studies
- Overall needs met
- Willingness of staff to help
- Free care – public
- Screening for some cancer (breast, cervix)
- Treatments
- Cancer Agency Nurse Help line
- New treatments available
- Treatment given in timely manner for some cancers
- Good communication within the cancer centre
- Screening Mammography Program
- Paying attention to different cultural group
  - Cervical screening
- Pediatric cancer
  - Successful advances
- Awareness of skin cancer
  - Population
- Dentist aware of oral cancer
  - Screening
- Link between smoking and lung cancer
- Anti-smoking legislation
- Connection between healthy living and prevention
- Videoconferencing between cancer agencies
- Quality of nurses, building protocols
- High reputation and quality of care
- Applying state of the art technology etc
- Treatment of common cancer, location and its effect on treatment
- Nice building, environment
- Some served well (esp. w/a common cancer) – efficient
- Support services when accessed e.g. library, support groups
- Availability of chemo/radiation/medication
- Team approach
- Provincial website
- Rethink downloading of GP website database (for doctors)
- Research
- Tumour registry
- Nurses
- Long term follow up (childhood cancers) following to adulthood
- Nutrition services to prevent recurrence
- Palliative care benefits program
- Early prevention, skill level of surgeons, improvement of treatments
• Having a centre in Interior
• Having oncologists here (Southern Interior)
• Collegiality of cancer care professional nationally
• Supportive groups – a lifeline
• Access to medications coverage
• Gene marker technology
• General organization and delivery of care
• Educational opportunities
• Mammogram screening program
• Available information support groups for patients to get info and support
• Research
• Access to tried and true drugs treatment and drugs "old" tried and true
• New treatments available
• Treatment given in timely manner for some cancers
• Good communication within centre
• Fewer teens are smoking
What do we need to rethink?

- 1. Separate surgery from other treatment as in False Creek Surgical Centre
- 2. Time taken to diagnose too long
- 3. Look to treatment in other countries to improve
- 4. Improve care for foreign or other language speakers
- Slow diagnosis because of failure to recognize symptoms
- No hospital chaplain – need for spiritual support
- Psycho sociable support about talking about
- Create openness about talking about death
- Waiting time too long
- Coordination between agency and Drs outside of agency system
- More education
- Childhood cancer follow up
  - Lack agency to pass on
- GP’s don’t have hospital privileges
- Delays for diagnostic tests
  - Referrals
  - Treatments
  - Surgeries
- Lack of public info – accountability for money
- Public confused – cancer agency, cancer foundation
- Need identification of what the different organizations do
- Some hospitals don’t welcome hospice
- Patients req. to aggressively pursue option and treatments
  - Harder for elderly
  - Adds stress to patients
- Doctors too busy
  - Not open to patient input
- Emphasis on particular cancers. Less focus on certain cancers broaden focus e.g. breast cancer
- Doctors have hard time discussing palliative care, palliation
- Early detection - prescreening (caught too late) e.g. lung cancer – knowledge available to patient
- Public policy on anti-smoking – need more
- Partnerships with caregivers, family
- Body, mind, spirit – support and connection
- Avoid talking about palliative care
- Errors in recording test results
- Doctors too busy – follow-ups not acted upon
- Rethink pay parking
  - Added stress, cost
- Other cancers not being focused on – advocacy
- GAP b/w diagnosis and treatment (access to oncologist)
- Access to the agency – getting into the agency referred
- Professionals working together
- Lack of knowledge, referrals
- Subspecialty expertise (access to in the region)
- Early in diagnosis
1st surgery admission: maintenance anti-depressant medication interrupted, 2nd surgery admission: maintenance morphine pain medication was interrupted

Perhaps Pharmanet or some other information system could be utilized to streamline protocol around the issue of maintenance medications for hospital patients

Access to post treatment resources (tap into resources, publicity e.g. support)

Too many ‘little’ groups

Focus on cancer as a whole

Where is the money going? Fundraising
  - going into on pocket not divided
  - public perception of where the money is going (administration costs)

Cancer patients are almost helpless to find their way ‘into the loop,’ they are diverted by the professional jealousies of ass’ld health practitioners

Aren’t listening (and listen well) (people at the clinic)
  - Stress

Major source of stress (bad experience – not encouraged to voice concern, opinion)

Practitioners in practices don’t refer to agency (professional jealousy?)
  - Specialists won’t change

Patients have to ask for information, not given by doctors
  - Moral, psychological stress

Lessen stress

Listen well

People in decision making roles lack of training in healthcare or experience

More input from nurses and doctors in field

Projects not being effectively managed

Guidelines

Communication with family physicians

General practice level
  - Diagnosis needs to be before patient gets really sick

Lack of referral

Diagnostic process and protocol

Examine GP priorities

Pay more attention to patient
  - Patient and family know more about their condition
  - Listen to patient

How does the community physician learn guidelines and best practices in cancer diagnosis

Rethink diagnostic tests
  - Costs of tests and the time it takes to get them all

Doctors only have time to answer one or two questions
  - Diagnosis made at emergency time rather than before that stage is reached

More funding for screening programs
  - Making colorectal as efficient as mammography

Utilize advanced technology
  - Study effects
  - E.g. U.S. in between each treatment – MRI to look at what is working and what isn’t

Ensuring that everyone gets equal treatment and equal care
  - Underserved population
  - Rural communities, culture, gender
  - Screening Mammography doing this well – other screening programs should expand based on example
• Gender discrepancy in access to screening programs
• Patient control of test
  - Mammography example of good program
• Education initiatives among minority economically deprived and underserved populations
• More emphasis on research into individual and cancer causing conditions that impact them as individuals
• Patients should be made aware of all treatment options not just those funded locally
• How important is mortality to patient?
  - Quality of life also a consideration
• Importance to patient should be considered
  - Patient should make decisions
• Take holistic approach to patient care
  - Consider spirituality, culture, values
• Physicians not addressing risks or performing tests need to be looked at
• Patients aware of all treatment options and have information
• Agency needs to give patients direction and ability to research other avenues
• Rethink best methods by taking into consideration all newest research and technologies
• Wait times – diagnostic, surgery
• Research to find the cause
• Inpatient care in CSI
• Coordination of care/Who's driving the bus
• Caseload – fragmented care
• Better communication amongst those providing care
• Rethinking drugs – how to integrate alternate medicines
• Collaboration with alternate & traditional medicine
• Research
• Coordinated team of experts with holistic approach
• Individualize treatment
  - Using techniques and research available
• Germany: individual treatment (paid for personally) harvest cancer cells, tests, find best treatment
  - Here intense chemo; Germany lowest dosage of drug combined with complementary medicines
• Overall education on screening process limitations
• Availability of new treatments and methods and consistency across Canada
• Need access to better diagnostics
  - ie not just using x-rays to make diagnosis
• Lack of communication between primary care and Cancer Agency
• Disconnect between cancer agency and surgeon at first diagnosis: better coordination needed
• Coordinated system to follow cancer patients through care journey
• Wrong assumptions about what BCCA does: patients feel abandoned after treatment
  - Don’t feel like agency is involved in recovery
• Sonograms made mandatory
• No hospital chaplain
  - Spiritual support important to healing
• Create openness about talking about death
• Waiting time too long
• Women's issues is still not high on the priority or it seems so
It seems that prostate cancer is still a mystery in First Nations communities.

Coordination between cancer agency’s and doctors outside of agency system.

More education for physicians about cancer.

The wait that people must endure to find out about the test results.

Organization of continuity of care.
  - Care seems to be fragmented.

Quality of info physicians can give to patients about their cancer.
  - ie what are my chances?
  - What does a suspicious lump mean?
How do we improve?

- People out of medical school trained in diagnosis, patients needs
- Look at cancer control systems in other countries
  - What works, what they do differently
- More creative discussions
  - Between public healthcare workers and advocates of private
  - To help improve public cancer control system
- Universal PSA testing
- Early bronchoscopy or test for lung cancer
- Mammography early screening
- Public information at all social levels/cultural
- 'Scared straight' method doesn’t work
- Common culture, barriers
  - lack of communication
- Individual patients – info sheet give as soon as diagnosis mandatory (right, access, bill of rights, informed at initial stage)
- Getting info from source that is reliable
- Nurse navigator
- Coordinate efforts
- Better planning and accountability for research topics by researchers
- Exploring the usefulness of holistic medicines
- Embrace holistic approach including complementary/alternative
- Need to focus more public education on ovarian cancer as there is good info now about breast cancer but with ovarian cancer, the info isn’t as accessible or out there (at least in the First Nations communities)
- Leadership role for MoH in educating practitioners to the whole system
- Central located diagnostic – one physical diagnostic centre
  - 1 – 2 day intensive then sent back to location
- Then referral to cancer agency
- Harder for older people
- Access, lack of help
- Advocate
- Rural areas – traveling GPO’s
- Access, monitoring progress
- Inaccurate, not updated website (accessible, updated)
- Handouts – specific to cancers
- Gap at surgeon level – immediate access to oncologists, rights
- Politics (government hurdles)
- PSA
- Treatments available, not expensive but not being used here
  - Lack of political will
- Resources to make more available
- International sharing of info, treatments (clinical trials)
- Send patients to international centres
- Partnering
- Alternative treatments
  - Explore successes
- Research (general)
  - Have follow up in place – with Dr’s office when a diagnosis (positive test result) to ensure patient gets treatment
  - Look wider for cures not just focus on what we know today
  - What are other choices?
    - Holistic
    - Complementary – hyperbaric, etc (BCCA)
    - Integrated care (e.g. Inspired Health organization)

- Survivorship
  - Care plan for survivorship
  - Guidelines for health surveillance
  - Give to patient, caregiver, doctor/physician

- See patient as a family unit and cancer affects entire family unit
- Provide support to caregivers
- Health promotion and disease prevention at an early age (education at schools, community, etc)
- Genetic testing/screening
  - Effective for breast cancer?
  - Family history therefore early screening

- Follow up for cancer patients
- Awareness of programs especially for families
- Direction to get to the support program when you (caregiver) needs it
- Prevention: regulation of environmental toxins, radiation, pollution, etc

- Hospice in hospitals
  - Recognize/accept
  - Increased hospice availability
  - At home
  - Provide hospices money to do so
  - More options for hospice

- Have the organization coordinated so not competing with each other for money
- The support provider organization to focus on what they do best
- Pediatric oncologist on the Island
- Normal follow-up times and ongoing support by family physician
- Government funding of research
  - Independent
  - Varying
  - Not tied into pharmaceutical

- Both quality of life/mortality things done well
  - Option for treatment close to home (esp children @VGH coming from BCCH)

- Palliative care benefits
- Need extended services
- Need access to meds for palliative, curative
- Benefits cover – cancer meds
- Salaried doctors to reduce competition – could tie education loans (forgiven) if go as salaried
- Need patient navigator/case manager through follow-up stay (possibly specialist)
- Extended hours of op’s @BCCA and personnel
  - Cancer lodge hours as well
  - Weekends
  - Hours same at BCCA
- Would relieve strain on some parts of the system
  - Supply chain of providing health practitioners (universities, # doctors and nurses)
  - Resources directed to necessities
  - Examine priorities
  - Improve availability to tests to catch cancer early and improve mortality rates
  - Send patients for treatment in other countries
  - Healthcare money should be focuses on care not support staff
  - Put priority on diagnostic level so less will be required for hospitalization
  - Tailor diagnostics/treatment for individuals and individual factors
  - Find balance between evidence administration and patient administration
  - Empower GP to go through testing process quicker
  - Patient driven healthcare
  - Guide GP
  - Eliminate any favouritism
    - Politicians moving to the front of the line
  - Identifying probabilities
  - Empower patients to self manage chronic illnesses
  - Cancer education for family physicians
  - Increase number of family physicians
  - Taking a holistic approach to treatment
  - Presenting risk in a comprehensive way for patients
  - Incorporating complimentary care
  - Fund available to patients to use for treatment that they feel would benefit them
  - Advice from healthcare professionals about non-standard care
  - Encourage patients to do their own research
  - Improve family physicians knowledge of cancer
    - What’s new and recent trends
  - Availability/opportunity for healthy population to participate in clinical trials
  - Awareness of population that are at risk
    - What services are available
  - Improve (shorten) time between screening to diagnosis
  - Better diagnostic in between treatments
  - Need a responsive screening system that anticipates a number of abnormal results and related scheduling needs and develops a fast-track system to access services
  - Scheduling for occurrence so that wait times are reduced
  - Emphasis on importance of choice and hope
  - Individualization of patient care and treatment
  - Ask patients how they want to be given opinions and results
  - Better coordination of services right from diagnosis
  - Inpatient care for chemo CCSI
  - Navigator/coach system to assist patient through cancer journey
  - Designated people helping with the financial obstacles
  - Letting people know about financial support
  - Setting up a fund that’s supported beyond donated $
  - Shorten wait times – transparency through the media about wait times
  - Equal access
  - Investigative expert/team as soon as there’s a suspicion of cancer
  - Rapid access clinic – breast – diagnosis to plan in one week
- Prostate
- Colonoscopy
- Universal screening program over 50
- Get more info to the GP
- More screening for skin cancer
- Recognition of doctors, nurses, caregivers, etc
  - Because it’s easy to get burnt out in this system, but they provide excellent care
- Surveys after treatment
- Complimentary medicine available to help treat whole person
  - Should be available in/from agency
- Individualized treatment plans
- Professional patient advocates to help patients navigate system
  - Nurses would be great to find answers and solutions
  - Unknown is scariest
  - Need someone to say you need to call doctor
  - Older people get overwhelmed by information
  - Coach, manager of care, guide
  - Help make connections
  - Scientific understanding of process-based treatments
- Especially for lesser known/uncommon cancers
- Pharmaceutical research that’s “not for profit”
- More government funded research for non-lucrative processes/meds
- Better co-ordination of care between healthcare providers
- Funding for treatments which are recommended (by oncologists) but have not gone to Clinical Trials (so individuals need to cover cost of drugs)
- Educate doctors better on dealing with terminal diagnosis
- Emphasize to health professional that quality of life outweighs quantity of life
- Process based treatment protocols
  - Treatment based on scientific understanding of process
  - Particularly for rare cancers for which there are not sufficient patients for clinical studies
- Embrace holistic approach incl. complementary, alternative
- More variety in choice of treatments/medication
- More gov’t funded holistic/alternative treatments
- Exploring usefulness of complementary treatments
- Provide more treatments/aids to have a positive attitude
- Better coordination of care
- Navigator/guide for patient (nurse?) through process/treatment/after care
- More hospices: taken care of = longer life
- Navigators in specific areas
  - Mortality
  - Quality of life, etc
- More patient information
- Supplement the federal compassionate leave provisions, and offer additional support (in terms of extending the eligible time period beyond 6 weeks and supplementing federal benefits during the first 6 weeks) to people caring for family members with cancer and other major illnesses.
- The provincial government should also use its influence to promote improvements to the compassionate leave program nationally.
Who do we need to partner with?

- Cooperation with University animal researchers
  - Drug research
- Medical institutions in other countries especially research institutions
- Patients pay part of cost
- Family physicians to improve their education around cancer
- Epidemiologists
- Pharmaceutical companies
- Researchers
- Institutions: Universities, hospitals
- Finance providers: pharmaceutical companies, government
- Partner with patients
- BCCA w/universities – more doctors (pay as you go education)
- Hospice societies
- Home care
- Funding agencies
- More hospices: taken care of longer life
  - E.g., Palliative designation: more medical coverage
- Complementary medicine – researchers, practitioners
- Why are some people surviving?
- Variation of outcome (esp alternative measures)
- Research
- Would be useful to partner with First Nations organizations.
- Alternative lifestyle education
- Ministry of Health
- Practitioners
  - Lack of knowledge
  - Not referring
- Agencies
  - Leadership, PHSA, Health Authorities
- Getting into ‘the loop’ and help getting knowledge (prof ppl)
- Conferencing between professionals – why not w/patients
- Focus on bigger concepts – not mini projects
- Alternative practitioners
- “Inspire Health”
- International partnerships (medical communities)
- Leaders of other cultures
- Education system for health professional
- Education for all levels – younger children
- Complementary medicines/practitioners
  - Naturopaths, acupuncture, massage therapists
- Partner with everyone except pharmaceutical cos. and equipment suppliers
- Home care
- Public funding agencies (ie palliative designation = more medical coverage)
- BC Palliative Care Association
- Physicians
Key Messages

- Empower GP to go through diagnostic process faster
- Primary focus should be patient driven
- Better doctor training
- Pay more attention to patient rather than throw text book
  - Patient and family know more about their condition
  - Listen to patient
  - “Something is wrong with me”
- Reaching at risk population for screening and diagnosis
- Individualize treatment
- Importance of choice and hope
- Listen to patients
- Better information
- Timely care
- Getting into the loop
- Doctors have to be more empathetic and compassionate
- Doctors need to be able to earn a living
- Combine the patchwork quilt
  - See the pattern
  - Let the best at something be their best
- Fee for service
- Use the cancer clinic 24 hours/7 days
- Commitment to
- Reduce wait time
- Do research to find the cause
- Coordinate services
- Rethink treatment re:drugs and how we can integrate approaches including alternate medicine
- Navigator/coach to assist patient through system which includes financial issues
- More information on screening programs
- Patient (guide, mentor)
- Better co-ordination between surgeons and cancer agency
- Better emphasis on process-based treatment protocols
- Better coordination of services
- More funding
- Increase psychosocial, spiritual support
Quality of Life

What is working well?

- “Team” approach
- Library
- Interpreters for minority groups
- Coverage for new medications
- Centralization of cancer care
  - Different points of care
- Counseling services
- Participant studies
  - Therapy and care
- Support at home
  - Choice to stay at home
- Internet resource
- Breast cancer information kit
  - Distributed by surgeons
- Nurse, clinician, clinic
- Screening
- Library Services
- Financing cancer treatments
- Excellent at Burnaby hospital
- UVic program
  - Workshops on quality of life
- Involving people in discussion about quality of life
- Symptom management
  - Pain
- Looking at quality of life holistically
- Opportunity to have family involved
- Nurse specialists
- Team approach
- Environment
- Info package
- Breast health navigator
- Caring staff
- Drs in BC spend more time than other provinces
- Chemo nurses
- Volunteer drivers
- Researchers
- Cancer Lodge
- Peer support
- Support services, nutrition, peer support
- MoH funds drugs
- Cancer Lodge support in (some) communities
- Cancer Connection (CCS)
- Wig/salon area is excellent
- Funding chemo medications on protocol
- Educational resources, library, courses, education sessions
- Coordinator
• Computer
• Can find out sequence of patient treatment
• Sharing clinical notes between provincial system authorities
• Acceptance of alternative therapy
• Long term follow-up program
• Patient advisory committee
• Family patient counseling
• Referring clients in financial need – drugs, etc, lodging, travel
• TAPS program for ferry/travel
• Interdisciplinary approach in one centre
• Cancer Information Service line
• Research Centre on Vancouver Island
• Treatment accessibility
• Short waiting times (relative to other provinces)
• Client friendly environment
• Information package
• Interdisciplinary approach
• Radiation Therapy very well organized
• Volunteer support
• Teaching in chemo new patient
• Patient and Family Counselling Dept at centre
• Library
• Quality of care at BCCA and tx are fantastic
  - But there are areas that can be improved
• Wants to be aware of what’s around to make it easier for others
• Appreciates getting together with Fraser Valley cancer centre
  - Leads a support group in the community
• Open communication between BCCA and CCS (Canadian Cancer Society)
• Getting a puppy the “best piece of medicine”
• Staff at BCCA
  - Takes a special person to work with people who have the dx
  - They are exceptional and understanding and caring and have a great attitude
• Aiming to achieve equality of service delivery
• Allowed sister to come in when I had chemo
• Good communication with oncologist and answered questions
• Good communication with staff and oncologist
• Cancer runs and meetings excellent
• GP’s are supportive of patients as they go through the tx
• The chemo nurses and the education they give is phenomenal and their patience
  - Puts the teaching in their workload at initial chemo
• Relaxation sessions at BCCA
• Education and support from BCCA
• Support groups for different illnesses
• Surgeon referring the patients to support groups
• The BCCA makes the patients feel cared for really well
What do we need to rethink?

- Patient education
  - Not enough offered
  - Access to terminology
- Physician knowledge
  - End of care
- Care packages/plan
  - Palliative
  - New patient
  - Transitions
- Communication between family doctors and specialists
  - Coordination of care
- Palliative vs. Curative care
  - (Cancer care givers) deny [?]
- Discussion re: end of life
- Needs to be patient centered not disease centered
- Patient education
- Access to supportive services
- Availability of services
- Patient navigation through system
- Information about new technology
  - Access
- Knowledge translation
  - Technology
- Cultural sensitivity
- Is there a way to reach out to the First Nations community better?
- Palliative care has not been supported
  - Particularly for cancer patients
- Opportunities to learn
- Education for patients and family
  - Re: condition/navigate the system/rights
- Access to system
  - Helpline
  - Books
  - Guides
- Communication between general practitioners and specialists
- Continue to give care
- Patients need education on communicating between doctors
- Implement a nurse specialist into system to communicate between doctors and patient
- Staff doctors have low concern
- No feedback system
- Delays in diagnosis/treatment and follow-up
- Lack of knowledge in CAM & patronizing attitude
- Drs are busy to answer questions
- Patients have to manage their cases
- Radiology/pathology errors in test reports
- Not responsive about error
• Administrative mistakes; communication/schedule
• No feedback mechanism that has effect
• Doctors and their staff abrupt/rapid/low concern and apparent lack of interest
• Level of emotional support for families once home from acute care, including extended family and young siblings
• Parental support network (on the Island) for parents of children dx’d w/ca
• Appt’s changed frequently on moments notice
• People traveling from up Island get overwhelmed when appts delayed
• Lack of patient control over appointments
• Inconsistent appointments for treatment (patients that come from the upper Island)
• Communications; oncologist – patient; admin – patient
• Attentive listening
• Quicker access to new technologies/drugs/therapies – approval process is time consuming
• Lack of efficiency/professional expertise
• Lack of respect
• Administrative mistakes
• No input into scheduling appts
• Comm’n amongst health care providers (e.g. Dr – Dr) and between facilities
• Sharing info between carers – issues with privacy of info
• Administrative protocol – inconsistency with what people at the centre tell you
• Patient flow
• Promptness
• Make the patient’s experience less stressful
• Explore/be open to non-traditional therapies
• Respect for choice
• Better communication between family physicians and Agency healthcare professionals
• Family physicians listening to patient and being aware of symptoms (i.e. back pain led to metastasis as was not muscle pain)
• Being patient-focused (not treating disease) but treating patient (holistically)
• Not reaching people soon enough (lots of programs to help ie CCS)
• Need patient assessment early on
• Not everyone receive the info they need
• Living with cancer group good – need one for care-givers and children whose families have cancer
• Support for people who are alone
  - Patients who live alone
  - Help available for care or household
  - Commercial care expensive
• Going forward with the Navigator role is imperative
• Nurses line said person was outside of her jurisdiction and would not answer question
  - Re: pain medication
• Communication between family Dr. and oncologist
  - Need a liaison between the 2
• Gap from (between) surgery and BCCA when no more curative tx options were available
  - And felt therefore, uncared for
• Communication gap between oncologist tx and what is received in the notes of a referring institution
  - Need notes from oncologist to hospital
• For people who are deaf receiving chemo in the arm takes away their means of communication
  - They would rather have chemo elsewhere on their body
• Some doctors do follow-up and some are not consistent
• Positioning of chemo tx
  - Sitting up leads to neuropathy in legs
  - Lying down would be better
• Chemo treatment
  - Alternative treatment to minimize side effects
• Patients who live alone – hard time without support
• Culture sensitive advocacy on site
• Chemo teach info when
  - 2 diff. chemos in 1 regime
• More education about support services/groups
• People have a lot of questions
  - But people do not always realize they need support nor where to go to get the support
• Need to empower patients to take responsibility for their own health rather than giving all control to the system
• Further support and education for patients who are given contradictory diagnosis, prognosis and tx protocols
  - Find a way for the medical professionals to come to come to a consensus
• The way the Agency represents itself to the public
  - And the government needs to reflect the actual services it delivers
• Patients need to be treated as individuals
• I was very disturbed to learn that the agency has a very specific protocol for treating certain cancers
• I find it very hard to accept that treatments do exist, and that someones life depends on the type of cancer they have and the agency protocol (politics)
• Defining the BCCA’s care
  - Early detection, diagnosis, treatment, follow-up care, etc – continuing care
• Care from beginning to end
  - Whole
How do we improve?

- Information kits/information
- Models of care in other countries
  - Adopting/accepting
- Introducing patient navigation
- Strong commitment to fund services
- Provide patients with educational programs
- Hire a nurse clinician/nurse practitioner for each specific cancer (breast, brain, lymphoma, etc)
- Develop publications that are geared to First Nations families.
- Make a commitment to see all patients in all services needed
- Introduction to services
  - Library
  - Terminology
- Accountability from centres
- Feedback loop
- Need electronic health information system
  - With maintaining privacy
- Emphasis on communication with in healthcare providers
- Funding following patients
- More time from family physicians
  - Follow-up
- Integration of nurses into system
- Improve multi-disciplinary care
- Recognize and address the unique needs of various ages and stages
  - ie. Pediatric, adolescents, young adults, mid-life, seniors
- Transitions between stages
  - Dx
  - Tx
  - Palliative
  - Or “successful” end of treatment survivorship
- Home care support is not sufficient
- Before treatment is over, address survivorship –
  - Letting people know that there is a range of post-treatment reactions
    - Emotionally
    - Cognitively
    - Physically
- Education
  - Breast cancer information kit
- Pt communication
- More staff (too much workload)
- Decrease wait times/monitor
- Public education
- Palliative care
- Decrease barriers to care for economically stressed families
  - Cover funding for accommodation/travel/loss of income
- Social safety net
  - Advice to patients
• Support for caregivers
  - Family/caregivers
• Physician funding
  - Model needs to change – can’t look after a cancer survivor in 10 minutes
• Navigation of the system
• Information on websites (for public)
  - Holistic care
  - Expectations
  - Advice
  - Treatment plans
  - FAQs
• Helplines
  - Advice, etc.
• Give better knowledge on who the primary physician is
• Phone lines
  - Expectations
• Wait times
• Communication to patients/families
• Website (run by cancer agency)
  - Personal information
  - Chart condition
  - Personal log in ID
  - Access by healthcare
  - Providers and patient
  - Ask questions to doctors
• Specialization for ethnic groups
  - Information
  - Translation
  - Recruit volunteers in communities
  - Knowledge to doctors
  - Brochures given out during events
• Give information about different perspectives
• People skills from doctors Better integration of research and traditional medicine from around the world
• Inspire Health (free)
• Funding research
• Integrated treatment program of traditional and non-traditional cancer care
• Holistic cancer care
• Earlier referrals to palliative care
• Better handling of information to the patient/transfer of knowledge to the public
• Isolation – patients from up Island often must go through process along without partner or parents or siblings if they go to Vancouver
• Holistic support to family/caregivers
• Spend time w/family, not just patient
• Financial support for primary care giver
• Home support for family
• Printed version of funding guidelines/options either charity or gov’t
• Formal navigator/care manager for every patient
• Educate H.C. professionals about support programs available to patients
• Support groups – cancer connection (CCS programs)
• Funding to improve isolation of families
• Family support program
• Re-imbursement program for loss of income
• Full range of human experience - spiritual, social
• Direct impact (for patient)
  - Feedback mechanism patient gives feedback and sees results directly
• Cancer patient ombudsman/advocate
• Acknowledge about support groups
• More hours (24/7) for BCCA
• Reducing waiting times for diagnostics/treatment
• Parking passes (free) for an initial period of time
  - Financial burden
• Doctor training in human communications
• More admin capacity at BCCA
• More staff
• Earlier registration to palliative care
• More compassionate communication – teach positive vocabulary
• Communication between authorities/system and patients should be taken care of by physicians more effectively
• A program from BCCA reaching out to physicians (education program…)
• Improvement on knowledge about how to assess palliative care and pain clinic
• Improve information accessibility about available programs to the patient
• Earlier access to palliative
• Shortening the gap between diagnosis and cancer specialist
• More efficient use of the money
• More education of the public (through Drs?) of support services
• Expedite referrals to specialist from the time of diagnosis
• Lack of knowledge of pain clinic (educate pts about it)
• Make is easier to access P&S mgmt
• Communication training
  - Compassion
  - Positive
  - Listening
• Ongoing training for HCPs
• Health care skills
  - Education at high schools and elementary schools
• Communication between health care practitioners
• Health care practitioners
• What resources are available to support emotional & physical needs
• One point of entry for continuum of care
• Give information about support services at time of diagnosis, so patient doesn’t need to search for self
• Patient-focused care rather than disease-focused - is this money centred?
• Patient centred training course for Dr education
• Tap into CME so physicians have better understanding of what patient experiences
• Offer “Living with Cancer” to caregivers and family
• Funding subsidized for home care
• Variety of delivery modes as client needs. Personalize: individual or group
• Remove stigma of word “counseling”
• Financial issues
  - Paying for parking when you have no income a hardship
  - Very expensive medications (ie nausea pill)
  - Costs of living
• There is no cancer tx leave
  - $ from the government such as exists for maternity benefits
• Patients going through tx do not have the energy to advocate to the government
  - Need an advocate
• Emergency wait times too long
  - People with cancer problems need to be triaged better by someone who understands cancer
  - Need some way to be flagged as a cancer patient rather than wait, for an hour, for triage, and be exposed to others in waiting room
• Breast cancer physiotherapy services and massage therapy, manual lymph drainage, centralized and together to support breast cancer patients
• Non-hodgkins lympho. Patients do not get many support groups as compared with breast and other cancers
• Centralized outpatient cancer follow-up by physiotherapist
• Alternative therapies
  - Example of how a puppy helped a patient cope
• Inform cancer patients about funding for drugs that are available
• Home visits to assess situation (financial and psychological) that patients are in
• Telephone friend
  - Someone who could relate to cancer and symptom
  - Telephone connection – advertise
• Management of lymphedema
  - Centralize therapist for all problems related to it
• Advertise more the telephone cancer connection from CCS
• Emergency room have too long waits for cancer patients
  - They should be flagged and triaged early
• More representative to come out to speak to support/patient groups on topics like counseling and educational
  - More personal than forums
  - General public – intimidating to attend educational sessions at hospital
  - Easier to understand
• Gap to services to caregivers – family or spouses – equal
• More discussions and access forums
• Ability to be able to provide competent care
  - Caregivers/healthcare
• Building relationships to ensure education
• Promote healthy lifestyle choices
• Provide lymphedema service in Abbotsford for women with breast cancer
• Improved financial support for “hidden costs” of cancer
  - Drugs, transport, etc.
• Assign an advocate to every patient
• People to answer telephone rather than machines
Volunteer driver program to add wheelchair accessibility

- Ensure that support includes side effects post treatment for how ever long it takes
- There are lots of people involved in a patient's care – it would be nice to have one person to be a guide throughout the system and to guide the patient
  - Navigator, care manager
- Everyone should be informed of and have access to alternative therapies
  - Stop treating the patient as a disease but tx the whole person
- Need a centre for integrated healing in the Fraser Valley
- More funding for quality of life initiatives
- Gov't needs to spend more $ for doctors to actively promote healthy lifestyles, as well for the school system
- Training physicians on healthy lifestyle education
- Find a way to financially support caregivers
- Not paying for parking at the BCCA
  - Giving patients parking in the lots and having the construction persons not take up spots
- More coordination of professional advice
  - Consensus of opinion on diag and treatment
- Create a comprehensive system from diagnosis until end
  - Or change how the Agency presents itself to public
- Connection with nutritionist to help improve health
- Advice on healthy lifestyle choices
- Treat the whole person and not just the disease
Who do we need to partner with?

- Librarians
- Physicians
- Medical school
- Nursing
- Social workers
- Community based organizations
- Government!!!
- Family physicians
- Communities
- Leaders of cancer care
- Doctors, nurses, patients
- Cancer agencies across the country
- Outside the cancer organization traditional authorities and non traditional alternatives
- Patients!
- Would be useful to partner with First Nations, perhaps start with one region, and test it out
  - Health care professionals
  - Ministry of Health
  - Canadian Cancer Society
  - Community organizations
Key Messages

- Supportive care needs to be given upon discharge
- Rethink walk-in clinics (get rid of?)
- Balanced funding
- Palliative care education for patients/public
- Patient education is patient support
- Communication skills need to improve
- Communication between patients and doctors
- Need better access to system and coordination between providers and patients
- Education to ethnic communities
- Education regarding extra care and helping families
- Better communication/organization/integration through the cancer continuum
- Financial resources for people experiencing cancer in any sense
- Be more compassionate
- 4 Cs: Communication, compassion, coordination, consistency
- Patients are partners in their care
- Patients are people first
- Develop communication
- Patient focused care
- Network between patient and health care professionals
- One stop shopping for information. Web?
- Patient centred care as a requirement for doctor’s education
- Physical, emotional, financial support for patients and family
  - ie patient living alone or with caregiver with own health challenges
- Proud of what we offer in B.C.
- More open networking between organizations
- Listen to consumer/client
- Attention to patients who live alone
- Treat the whole person and not just the disease
- Care navigator to help the patient through the system
- Money for quality of life initiatives
  - ie physician and youth education, lifestyle counseling, financial support
  - Health education – school age
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