

# Let the People Speak: Innovative Approaches to Community Engagement in a Regional Cancer Research Framework

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# We need research based care, wherever we live.....

**CureSearch**


National Childhood Cancer Foundation  
Children's Oncology Group





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***Form pairs and have one person tell the other in 3 minutes about a health research story that impressed them.***



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***The person who listened should tell the story back and pick out what they heard as being the important elements that impressed the story teller***

***Form groups of 4 to 6; it is now 2019  
and your community has a  
successful community cancer  
research program:***

***In 5 minutes, find at least one answer  
to –***

***Who is involved?***

***What has been achieved?***

***What is the program known for?***

***How does the program benefit the  
community?***

***How does the program benefit the  
researchers?***



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What do communities want,  
really, really want.....?



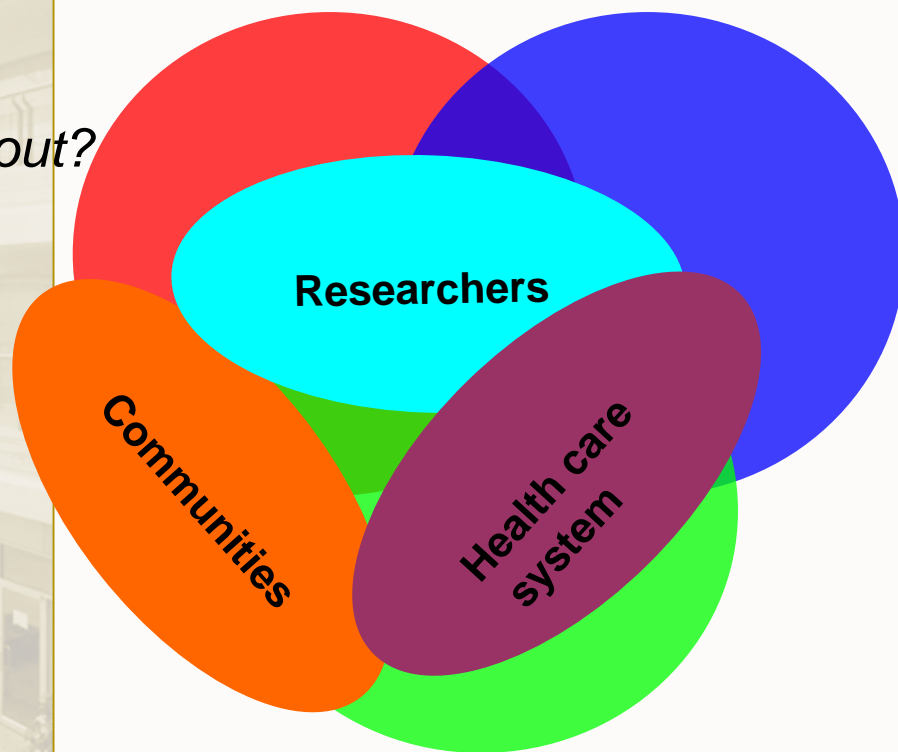
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What do researchers want,  
really, really want.....?

# Finding and mapping common ground - the hedgehog concept

*What are we  
passionate about?*

*What are we  
best in the world at?*



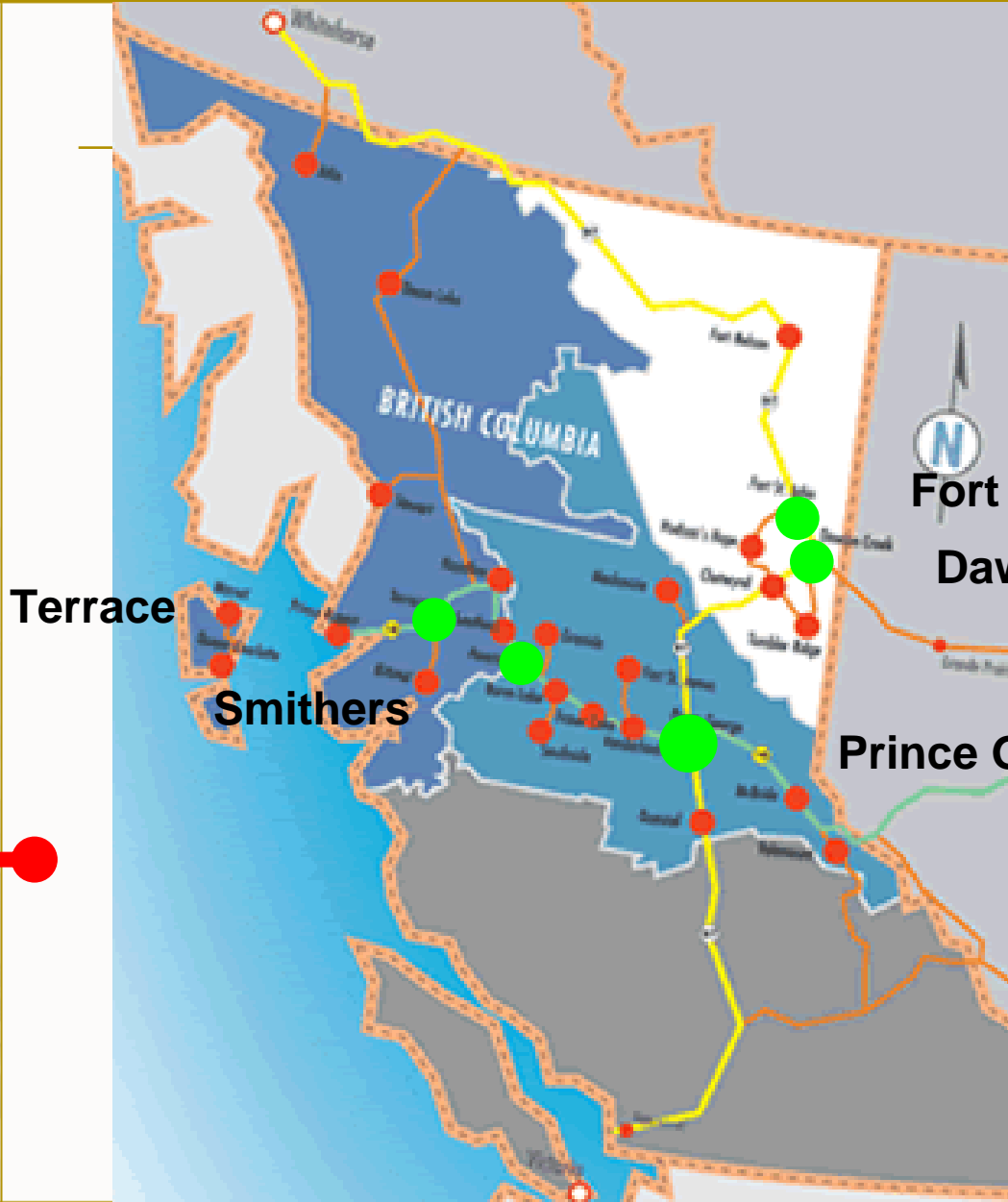
*What drives our economic engine?*

**Jim Collins**  
**“Good to Great”**

# Finding the passion – Community consultation in the NCCS Research Framework



- **UNBC, NMP owe their existence to recent community activism – community engagement held to be very important**
- **Community consultations undertaken in 2008 to establish direction and subsequent structural design of the research framework**
- **1 day Appreciative Inquiry events; one on site at UNBC, 1 done as a 5 way, day long video conference linkage of 5 sites separated by 1200 km; 80 participants from health care, education and community – vast majority not researchers**
- **Participants sought through ads in clinics, local media**



**Fort St John**

**Dawson Creek**

**Terrace**

**Smithers**

**Prince George**

500 km

# Research Values

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- Research that engages and fits the context the community
- Research that leads to knowledge translation, exchange and best practice in the North
- Research that will improve access to cancer care
- Research that improves patient outcomes/is patient focused
- Passion/researcher that excites passion; researchers go the extra distance
- Research that contributes to a knowledge base for our processes
- Research that attracts a critical mass of talented people

# Who is involved?

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- Researchers from UNBC, BCCA and Northern Health
- Oncology care providers
- Community based health professionals
- Private sector partnerships
- Cancer society and philanthropic organizations and Foundations
- Aboriginal organizations
- Traditional healers
- Community groups
- Educators
- Researchers from other universities in Canada and elsewhere
- National and international funding council
- Other Canadian health authorities, particularly ones facing similar challenges
- WIKI and other internet based communities
- Public health agencies
- Researchers with interests across the whole cancer care spectrum

# What is achieved?

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- Developed a seamless mechanism to translate knowledge into practice
- Established 3 key priorities,
- Have established appropriate research infrastructure
- Methodology for clinical trials that is applicable to the special sociologic and geographic realities of the North
- Every oncology related profession will have research integrated into its practice
- Increased community involvement in cancer research
- “One stop” approach to clinics/maps/supports/diagnosis
- Improved access to care
- Decreased cancer morbidity and mortality
- Decreased rates of cancer
- Better quality of life focus in palliative/end of life care
- Better understanding of cancer and risk factors distribution
- Better understanding of community impacts and needs
- Better understanding of disease
- Greater awareness and better funding of Northern cancer research
- Better regional and national collaboration and more partnerships

# What is it known for?

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- Knowledge is widespread and transparent; in schools, physician offices and health units
- It is helping the community, everybody is involved
- Know who the researchers are
- That the research is for them and by them
- What the processes and organization are
- What's going on in research
- They can be involved in setting research priorities
- What is best practice
- Empowered community – informed and able to act
- Where to find a user friendly database of research findings “how will the research affect me”
- Research outcomes
- How to get involved in research

# Setting Priorities



# The Cancer Continuum

Prevention

Screening

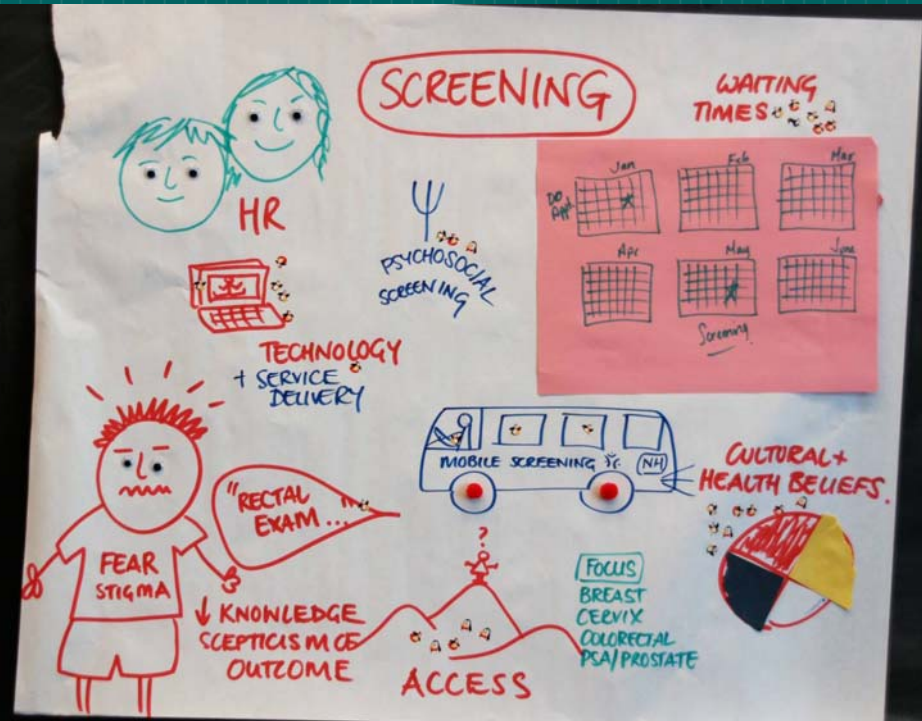
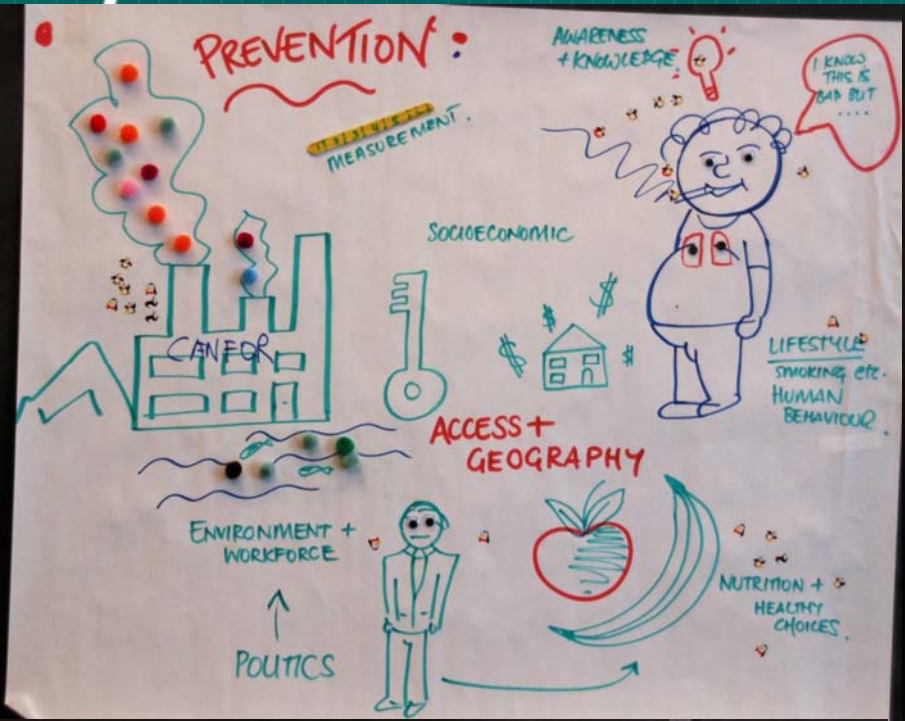
Diagnosis

Treatment

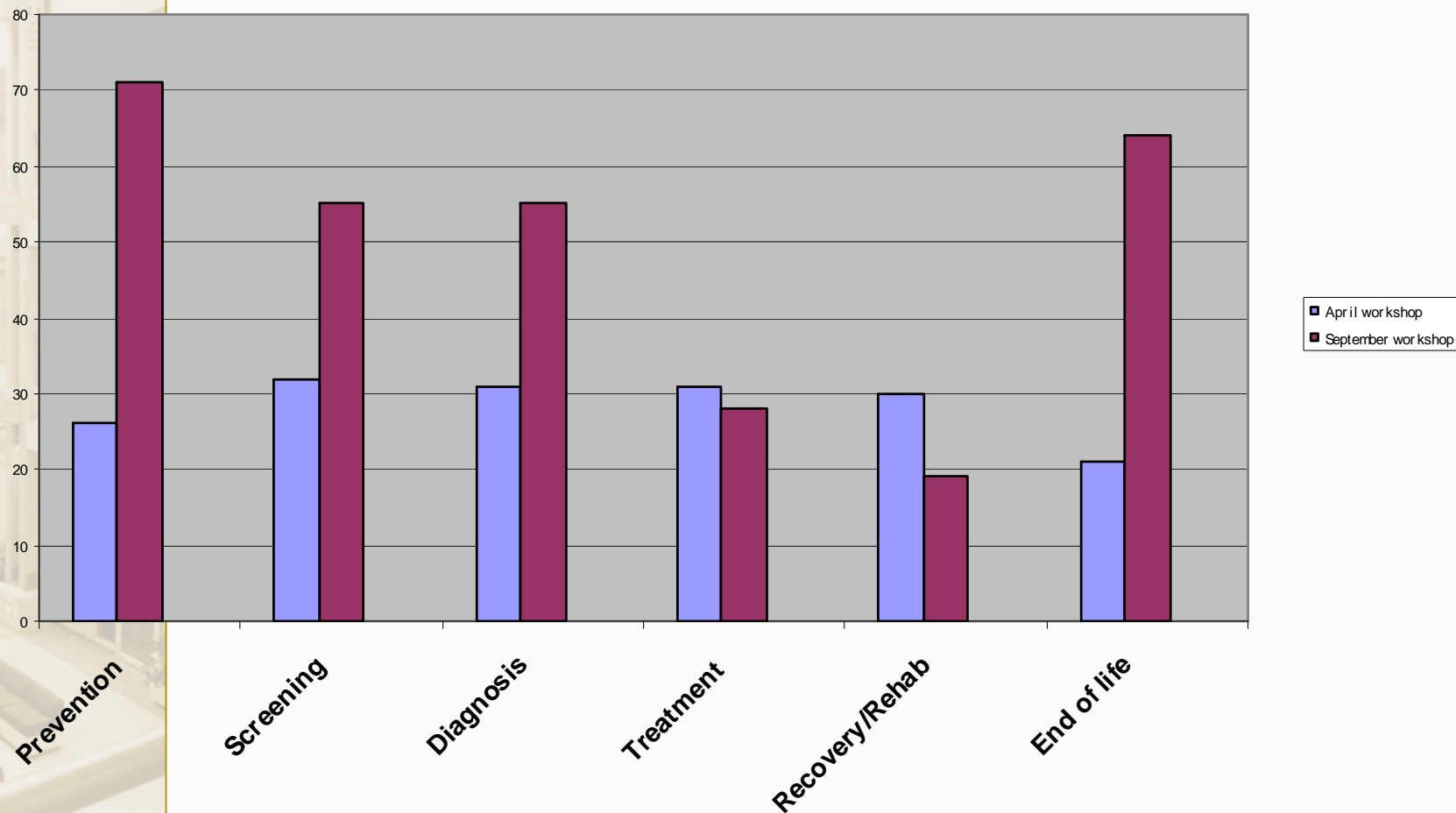
Rehabilitation

Palliation

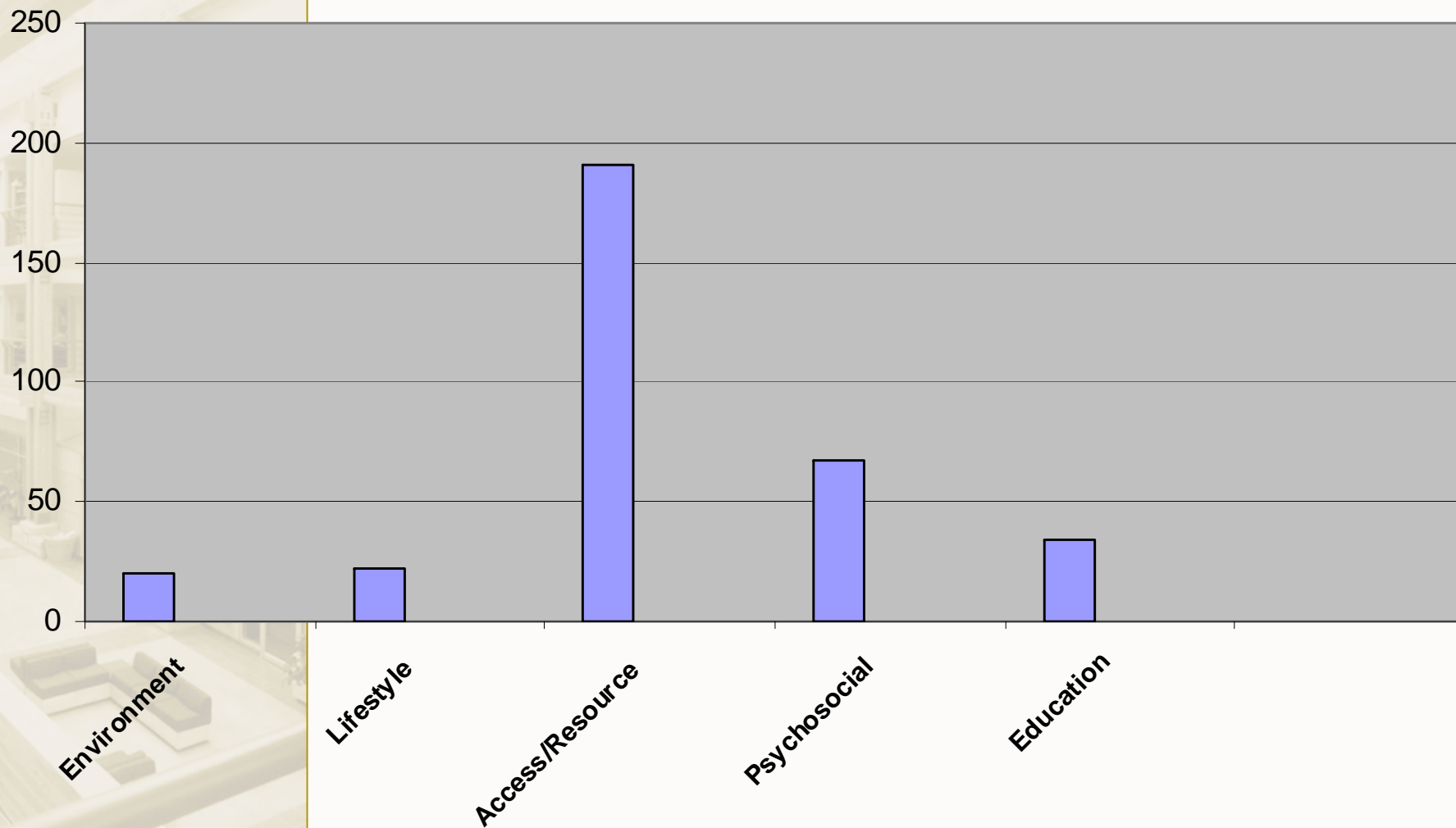
- Groups split up at random and asked to identify issues in one or two areas of the continuum.
- Asked to demonstrate ideas visually rather than in text.
- Each individual was assigned 12 voting dots and could place as many or as few against any of the ideas expressed by all the groups
- Images shared by teleconference – titles written up for voting at each site
- Issues selected analyzed by organizing group for common underlying themes after the consultation




# Votes for Research focus within the cancer continuum



# Cross cutting themes





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**Does picking a theme exclude  
researchers or research  
disciplines?**

# Access, for example.....



- Application of portable genomic technologies to diagnosis and risk screening
- Specific population risks and care maps
- Self care
- Transport systems
- Telehealth
- Mobile care systems
- Community program development
- Integration with traditional practices



# Access, for example.....



- Basic science needed for understanding of disease and treatment response determinants
- Applied science/engineering needed for new technology development assessment
- Clinical science needed for clinical outcomes research of novel approaches
- Social science needed for study of systems and evaluation of community based approaches
- Something for everybody!

# Conclusions

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- Community inputs are a valuable way of setting directions in health research
- True advances in health outcomes will not occur without community participation
- Community consultation is not as daunting as it sometimes made out to be

