

**Patients' Association of Canada
Association des Patients du Canada**

**Why Patients Must Participate
in our Health Care System
And Why This is So Difficult**

To be Posted on www.patientsassociation.ca
November 4 2011



How the System will improve patient experience with ICT

1. Patient control over individual record
2. Patient electronic access to provider through mobile phones, PCs, land lines
3. Renew Prescriptions on Line
4. Make Appointments on Line
5. Patient-patient communication for peer support
6. Fax machine is disassembled and reborn as the android mobile device of the future.



Population Health 1800-1850

- Longevity at Birth \approx 36 years (Britain)
- Longevity at 20 years \approx 70 years
- Everyone @ 40 had at least one Chronic NCD
- Vast majority of deaths due to infectious diseases at all ages



Birth of Current Health Care Systems

- 1865 – Joseph Lister and modern sterile surgery
 - Anaesthetic plus asepsis makes modern surgery possible
- 1880 - Louis Pasteur (1822-95) & Robert Koch (1843-1910)
 - Anthrax, Tuberculosis etc. caused by identifiable micro-organisms.
 - Vaccines were developed
 - Identify microbes causing infection after surgery
 - Sterile operating rooms and procedures begin
 - Modern laboratories are built everywhere
- 1880 – Prosperous times: New Hospitals are built
 - New housing, New sanitation etc.
- 1910 – Flexner Report on medical education
 - In US and Canada
 - Drs Professionalize



Success of the System by 1950

- 1850-1950 Rapid decline of death by infectious diseases: The Mortality Shift
More deaths due to NCDs like heart disease, COPD and cancer \
- Longevity & birth Canada: 66-M 71-F
- Minority deaths from infectious diseases
- Mortality shift attributed to success of scientific medicine



Acute Scientific Health Care 1960

- The “Big C” and Heart Attacks are acute diseases that science will cure
- Body is separated from the person
- Expert based, acute hospital focused
- The scientific health care system grows
- Science will ID cause & cure of diseases
- Patient has little or no role in system



Population Health 2008

- Life expectancy at birth 2008:
 - Canada 79-Male 83-Female
- 90% of deaths due to Chronic NCDs
- Less than 5% deaths due to IDs (WHO)
- 40% of people with chronic NCDs have more than one – good reason for speaking of complex chronic NCDs

From United Nations Volume on NCDs: Canada

NCD mortality

2008 estimates	males	females
Total NCD deaths (000s)	103.1	105.1
NCD deaths under age 60 (percent of all NCD deaths)	15.5	10.9
<i>Age-standardized death rate per 100 000</i>		
All NCDs	386.5	265.0
Cancers	142.2	106.6
Chronic respiratory diseases	26.9	16.0
Cardiovascular diseases and diabetes	151.6	90.1

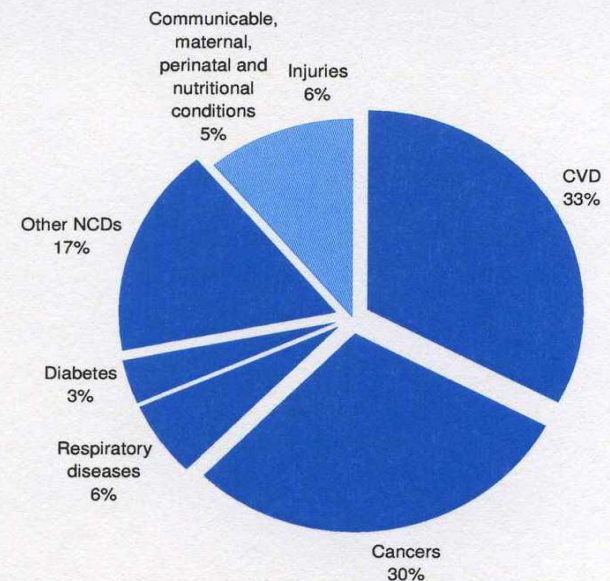
Behavioural risk factors

2008 estimated prevalence (%)	males	females	total
Current daily tobacco smoking	15.4	11.6	13.5
Physical inactivity	34.0	37.4	35.7

Metabolic risk factors

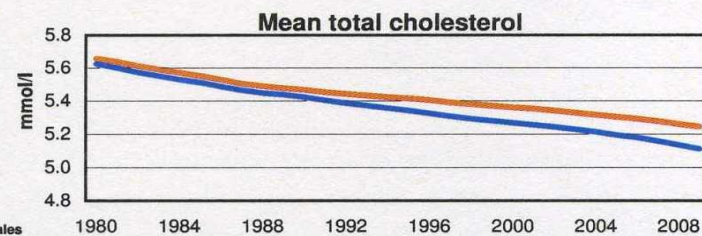
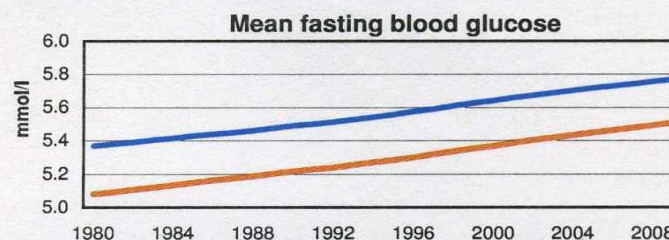
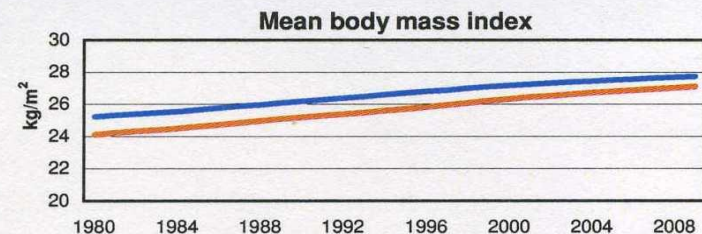
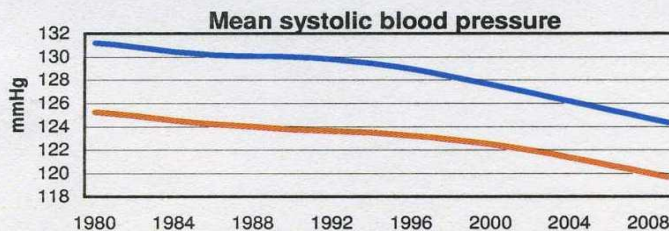
2008 estimated prevalence (%)	males	females	total
Raised blood pressure	35.8	31.6	33.6
Raised blood glucose
Overweight	67.8	58.7	63.2
Obesity	26.0	26.4	26.2
Raised cholesterol	54.8	57.6	56.2

Proportional mortality (% of total deaths, all ages)



NCDs are estimated to account for 89% of all deaths.

Metabolic risk factor trends



■ Males
■ Females



The Shift from Acute to Complex

Variable	1850	1950	2008
Longevity at Birth Male	35	66	79
Longevity at Birth Female	32	71	83
% Infectious Diseases Deaths	70%+	40%+	5%-
Age of Population with at least 1 NCD	40	?	65
% with Complex NCDs (2 or more)	?	?	40-50%
Reasons for Mortality Shift		Science	Complex



System is Slow to Catch Up

- Continued emphasis on acute episodes
 - Hospitals continue to grow in size and cost
- Constant expansion of body categorization
 - More than 100 specialties and subspecialties
 - Increased drive for protocol based care
- Overall little inclusion of patients as people
- Why it's hard for hospitals to be patient centred



How Cancer is Becoming Recognized as a Chronic Disease

- NY Times Oct 29 Article questions screening and early detection
 - “P.S.A. screening test for prostate cancer does not save lives and causes enormous harm”
 - “many, if not most, cancers are indolent. They grow very slowly or stop growing altogether. Some even regress and do not need to be treated — they are harmless.”



Simple

Following a Recipe

- The recipe is critical to success
- Recipes are tested to assure replicability of later efforts
- No particular expertise; knowing how to cook increases success
- Recipes produce standard products
- Certainty of same results every time
- Optimism re results

Complicated

A Rocket to the Moon

- Formulae are critical and necessary
- Sending one rocket increases assurance that next will be ok
- High level of expertise in many specialized fields + coordination
- Rockets similar in critical ways
- High degree of certainty of outcome
- Optimism re results

Complex

Raising a Second Child

- Formulae have a use. But not alone
- Raising one child gives no assurance of success with the next
- Expertise however multi-disciplined can help but is not sufficient
- Every child is unique in critical ways
- Uncertainty of outcome remains
- Optimism re results



Complicated Acute Diseases

- Abrupt onset
- Often all causes can be identified and measured
- Diagnosis and prognosis are often accurate
- Specific therapy or treatment is often available
- Protocol-based intervention is usually effective: cure is likely with return to normal health
- Profession is knowledgeable while laity is inexperienced and dependent
- Patient's contribution largely unnecessary

Complex Chronic NCDs

- Gradual onset over time
- Multivariate cause, changing over time
- Diagnosis is uncertain and prognosis obscure
- Specific treatment is available but also requires judgment
- No cure, pervasive uncertainty: support & self care over time is needed to maintain health
- Professionals & patients must share knowledge to maintain or improve health
- Patient's contribution critical



What is a Patient?

Complicated Acute Disease

- A diseased body to be diagnosed and treated
- An autonomous individual with no relevant links to others
- Focus on the disease or organ
- Prescribed treatment
- The person named on the OHIP card

Complex Chronic Condition

- A person with a particular history and personality
- A group of people including the person and those close
- Broad interest in history and lifestyle
- n of 1 trials
- Anyone who has had a significant health care experience themselves or as a companion



What is a Patient Centred System

- Responds to the morbidity of the population
- Increases capacity to self-assess and self-manage with mutual support
- Continuous care to maintain health
- Avert acute episodes of chronic conditions
 - Self-monitoring signs of acute onset
 - Easier access to mutual & professional support
 - Rapid response to indications



Selections from CMA and CNA PRINCIPLES TO GUIDE HEALTH CARE TRANSFORMATION IN CANADA

- Improving the patient experience and the health of Canadians must be at the heart of any reforms...
- Improved health literacy (the ability to access, understand and act on information for health) to help mitigate inequalities
- Patients, families and providers must be partners in the governance of the system.



Patients' Association of Canada Mission Statement

As a patient led and patient governed organization, the Patients' Association of Canada promotes the patient voice and the patient perspective in health care in order to improve everyone's health care experience.



Some of our activities

- At the Clinical Level
 - Patients' Choice Awards (with OMA)
 - User Guide How to Navigate the System
- At the Service Delivery Level
 - Training front line ER staff to deal with patient anxiety
 - Redesigning the day of moving in at Baycrest
- At the Policy Level
 - Supporting board members who want to assume the patient perspective: A Trillium project



To Join Us

- Look at the web site
 - www.patientsassociation.ca
 - If you find good reason to,
 - Sign up for the newsletter
- To contribute
 - Write to communications@patientsassociation.ca
 - Or donate on our web site