

From Data to Health Information

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February 25, 2004

Presentation outline

- **Background: health information needs in Canada**
 - **Record linkage: description and example**
 - **Privacy versus public good**
 - **An example of a microsimulation model**
 - **Discussion**
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Health information needs in Canada

- **Management of service delivery programs**
 - **Surveillance systems**
 - **Understanding and monitoring of population health**
 - **Understanding of etiology for specific conditions**
 - **Prevention**
 - **Health and health services research**
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Health services research

- **Do waiting times for procedures have an impact on the effectiveness of the treatments?**
 - **Are there non-financial barriers to access to appropriate treatment?**
 - **Is antibiotic resistance SES blind?**
 - **Are preventive services reaching those who need them most?**
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Population and occupational health

- **What is the nature and extent of socio-economic disparities in mortality and morbidity in Canada?**
 - **Why are some communities healthier than others?**
 - **Which jobs are killing Canadian workers?**
 - **Are shift workers more susceptible to injury when they are off the work site?**
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What is record linkage?

The combining of person-specific data from more than one data source

Deterministic record linkage

The combining of information by the use of common unique identifiers.

Example:

Relationship between annual volume of patients treated by admitting physician and mortality after acute myocardial infarction. Tu JV, Austin PC, Chan BTB; JAMA 2001;285(24):3116-3122

Probabilistic record linkage

The combining of information using probabilistic methods, when common unique identifiers are not available

→ A much more technically difficult problem

Manitoba-Census linkage pilot project

- To create using, record linkage, an analytical database for a sample of 20,000 Manitoban households including:
 - Socio-demographic information from the 1986 Census
 - Longitudinally-linked health records
 - To study the association between SES and disability, and health and health care utilization
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The linkage

- Authorized under the Statistics Act
 - No common unique identifier available
 - Names are not captured on the Census
 - Names not available on Manitoba Health Registration file used
 - Record linkage performed without the use of names
 - Used postal code, gender, month and year of birth, and family structure
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Assumptions in matching

- **Information for only some characteristics on both files**
 - **Information is incomplete and subject to error**
 - **Records with same information may correspond to different individuals**
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Putting the files together

	Census	Manitoba	Agreement
Postal Code	K1A OT6	K8C 0P6	0
Sex	F	F	1
Year of birth	1959	1959	1
Month of birth	June	October	0
Family structure	Couple	Couple	1
		Total Score	3

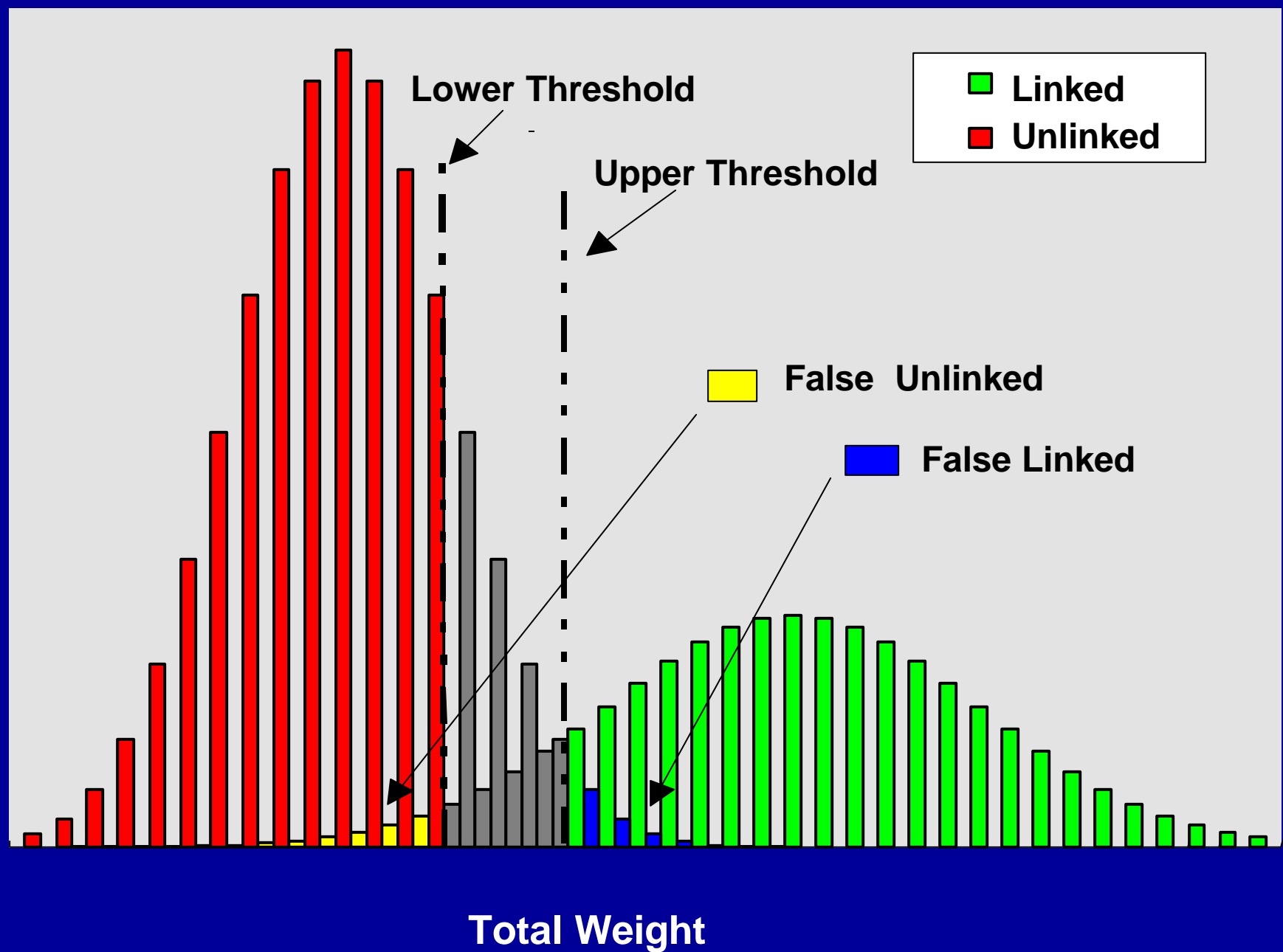
Assessing certainty: the “rule” of M/P/U

Matched (M): We have high confidence that the 2 records correspond to the same individual.

Probable (P): We really aren't sure if the 2 records correspond to the same individual .

Unmatched (U): We have high confidence that the 2 records correspond to different individuals.

Number of Links

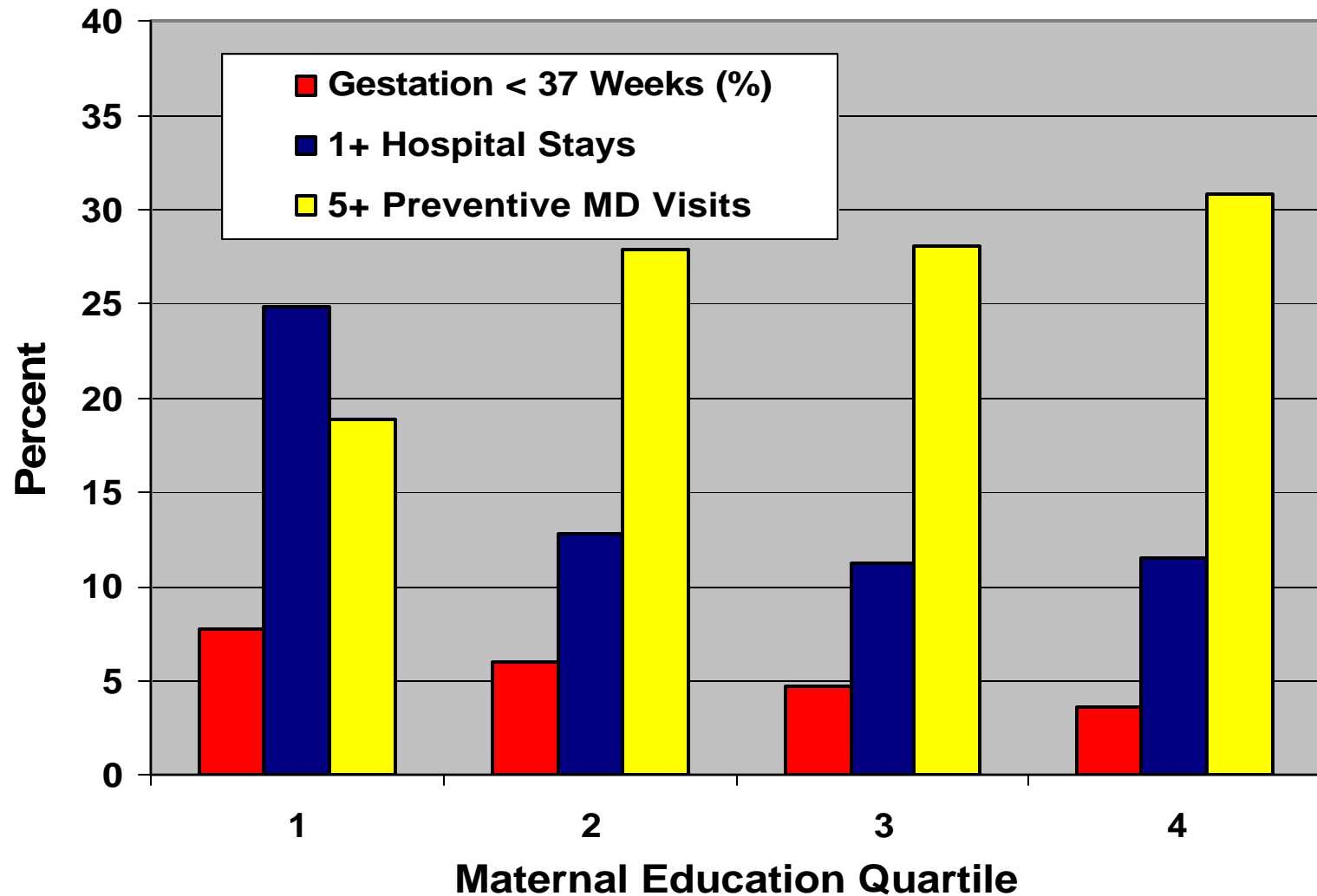


Total Weight

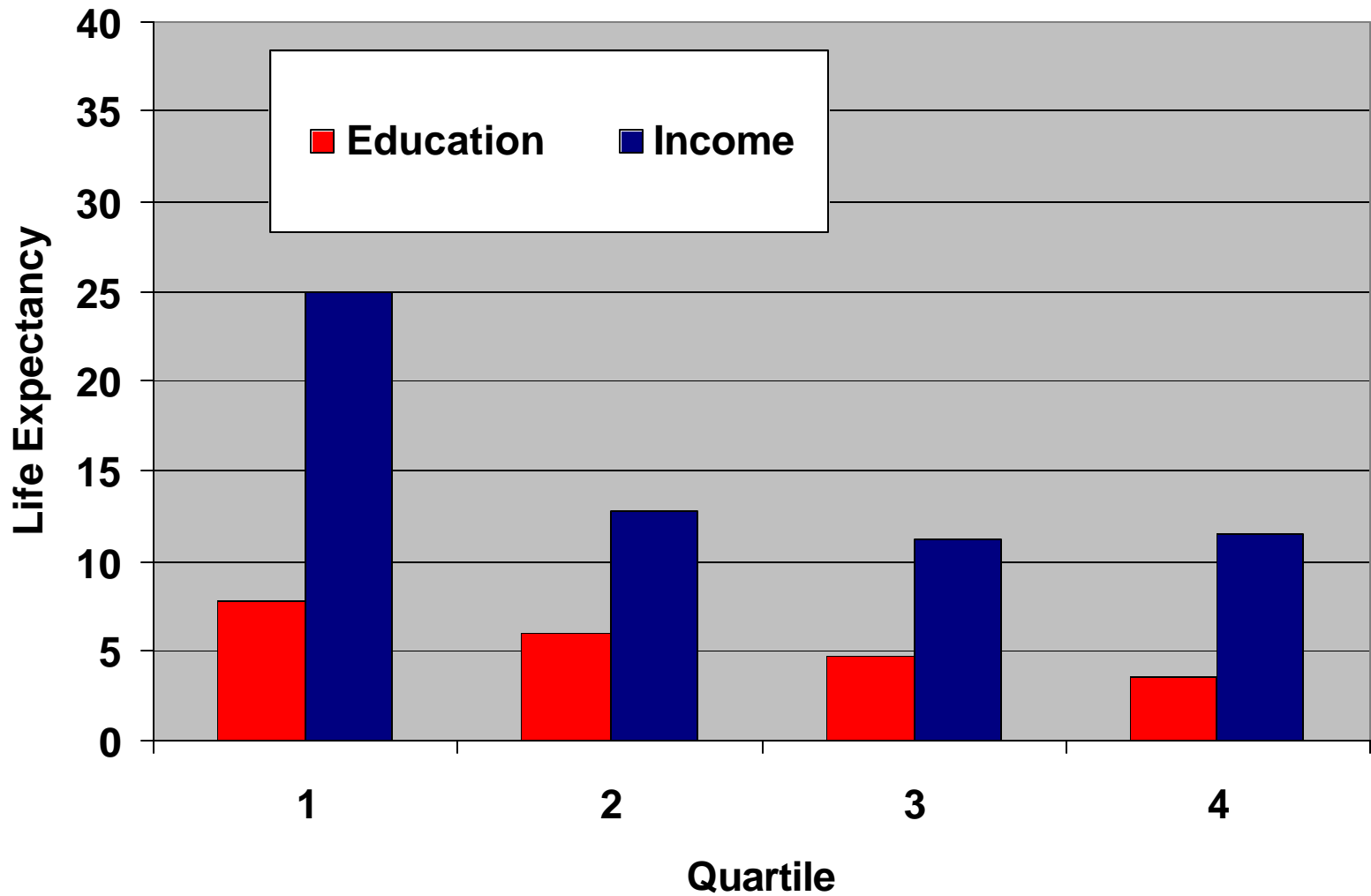
Back to the Manitoba-Census linkage

- **Match rate**
 - 74% in households (95% accuracy)
 - 55% in collective institutions
 - 39% in collective non-institutions
 - **New database of 48,000 Manitobans incorporating**
 - 1986 Census (2B) detailed questionnaire
 - Longitudinally-linked Manitoba Health data on ambulatory, hospital services and entry to nursing homes
 - Mortality from vital statistics records
 - HALS 1986-1987 (for a sub-sample only, n=4,400)
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Socio-economic gradients of health care use during the first year of life



Life expectancy at age 30 by education quartile and income quartile



Privacy is a right



“Privacy is our fundamental right as individuals to control information about ourselves - including controlling the collection, use and disclosure of that information.”

Alwyn Child, 1999

Health is a central value of Canadians

“The primary objective of Canadian health care policy is to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers.”

Canada Health Act

“... parliament recognizes that Canadians value health as central to happiness and fulfilment,”

Canadian Institutes of Health Research Act

Ethics and health research

“The benefits of medical knowledge that we enjoy today are due to research that has been conducted using information about millions of people in the past, mostly without their being aware that such information has been used. ... Does our generation have a right to benefit from the past, if it is not willing to allow future generations to benefit from our experience?”

Jack Siemiatycki, 2001

An example of an ethical issue

Vaccination is the greatest public achievement of the 20th century (Informed, December 1999)

Safety of MMR vaccine being questioned

MMR rate of immunization below 80% in some US counties

What should we do about it?



Excerpts from the Federal Privacy Act

personal information ... may be disclosed ... (j) to any person or body for research or statistical purposes if the head of the government institution

i) is satisfied that the purpose for which the information is disclosed cannot **reasonably** be accomplished unless the information is provided in a form that would identify the individual to whom it relates, and

(ii) obtains ... a written undertaking that no subsequent disclosure of the information will be made in a form that could **reasonably** be expected to identify the individual...;

Needs a balance



Thorough review process

- **Public good**
 - **Privacy**
 - **Confidentiality and security**
 - **Transparency**
 - **Conflicts of interests**
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Colorectal cancer: 2003

The second cause of cancer deaths in Canada



Estimated

Incidence

Deaths

MEN

9,800

4,400

WOMEN

8,300

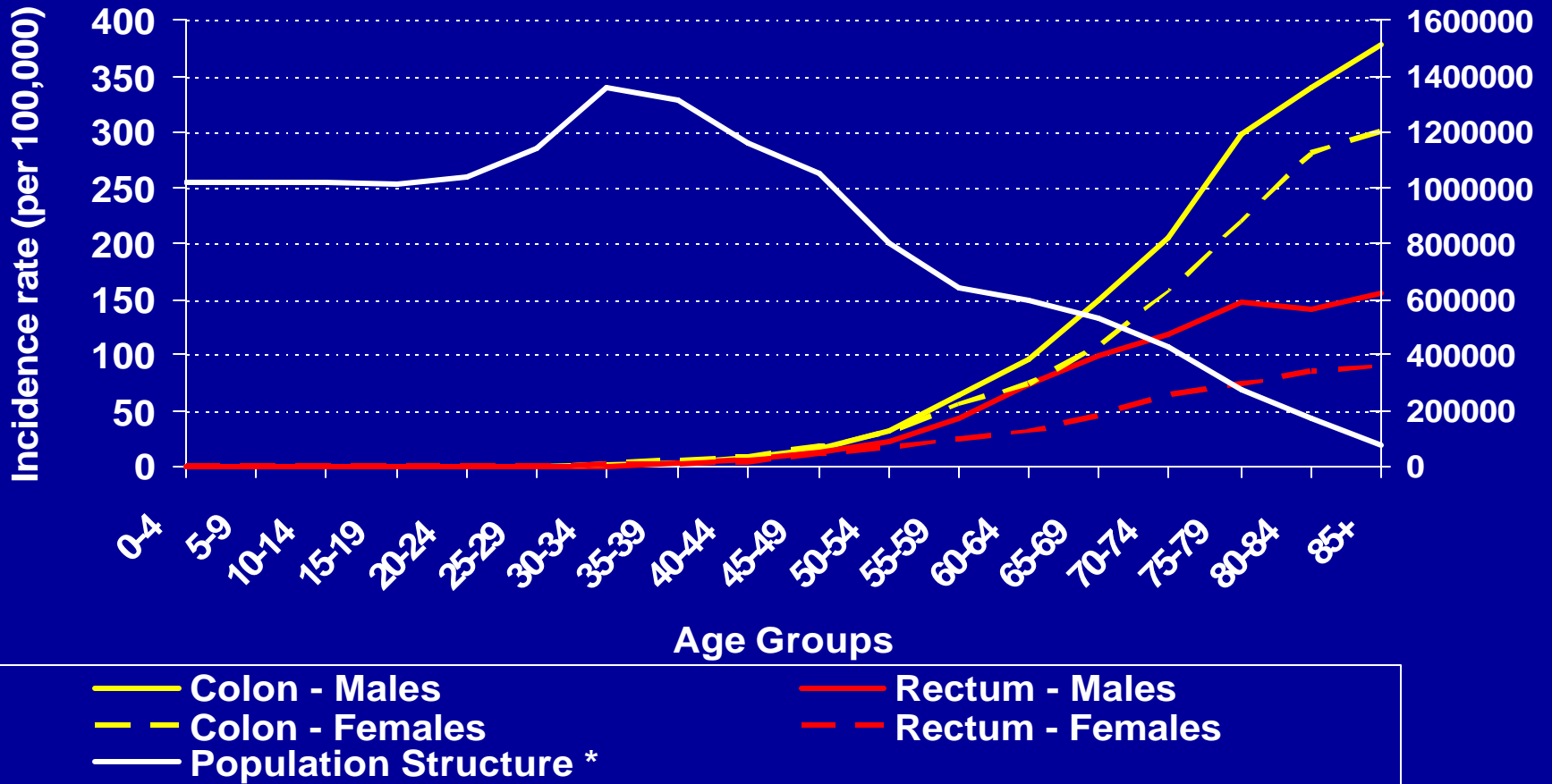
3,800

TOTAL

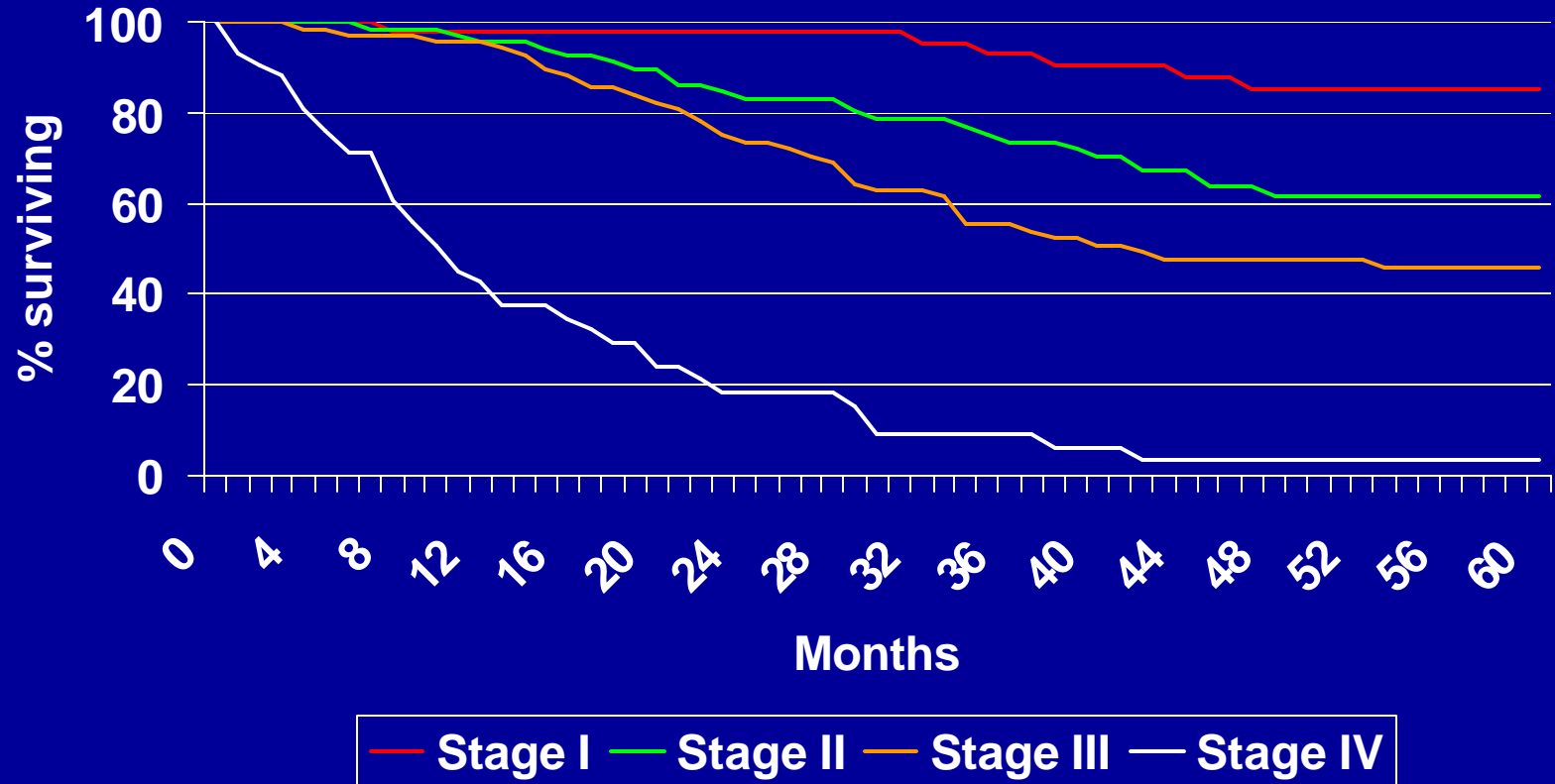
18,100

8,200

Incidence rate increases with age



Late stage means lower survival



Context

- Randomized controlled trials have shown efficacy of screening for colorectal cancer with faecal occult blood test (FOBT) combined with colonoscopy
 - National Committee on Colorectal Cancer Screening was established in 1998 by Health Canada to study the feasibility of colorectal cancer screening in Canada
 - Issue: What would be the impacts of such a screening program in Canada?
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Policy-related questions

- What would be the expected mortality reduction under a population based screening program?
 - What is the most appropriate age range?
 - What would be the estimated cost and resource impacts?
 - Is it cost-effective?
 - How sensitive are the results to the program parameters?
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POpulation HEalth Model (POHEM)

- A framework for organizing health information for representative samples of synthetic persons
 - A simulation model which creates synthetic human populations and ages them while exposing them to risk factors and diseases using computer Monte Carlo simulation techniques
 - POHEM was used to evaluate the potential impacts of colorectal cancer screening
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Evaluating breast cancer incidence

Age 51

Risk Factors



Age at menarche
11



RR = 1.2

X

Obesity
BMI = 29



RR = 1.3

X

Age at first live birth
33



RR = 1.9

=

RR = 2.96

X

Baseline incidence =
0.00084

=

Probability of incidence =
0.0025

Random number =
0.56



If random number < probability, event occurs



GO ON TO NEXT EVENT

(false)

Evaluating breast cancer incidence

Age 52

Risk Factors



Age at menarche
11



RR = 1.2

X

Obesity
BMI = 30



RR = 1.4

X

Age at first live birth
33



RR = 1.9

=

RR = 3.19

X

Baseline incidence =
0.00095

=

Probability of incidence =
0.0030

next event
is birthday



GO ON TO
NEXT EVENT

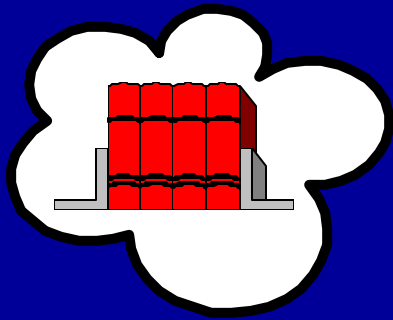
(true)



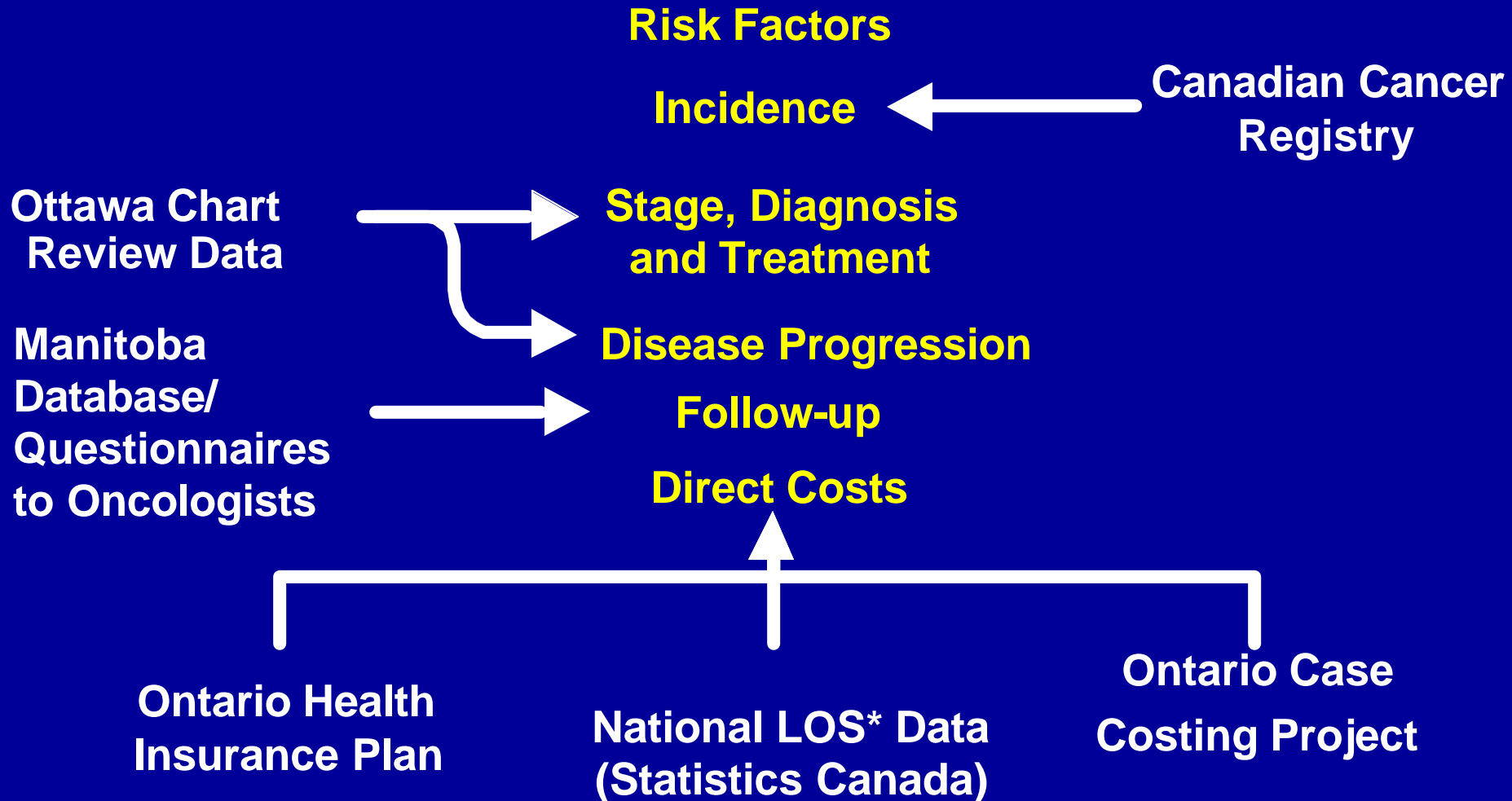
If random
number <
probability,
event occurs

Random
number =
0.001





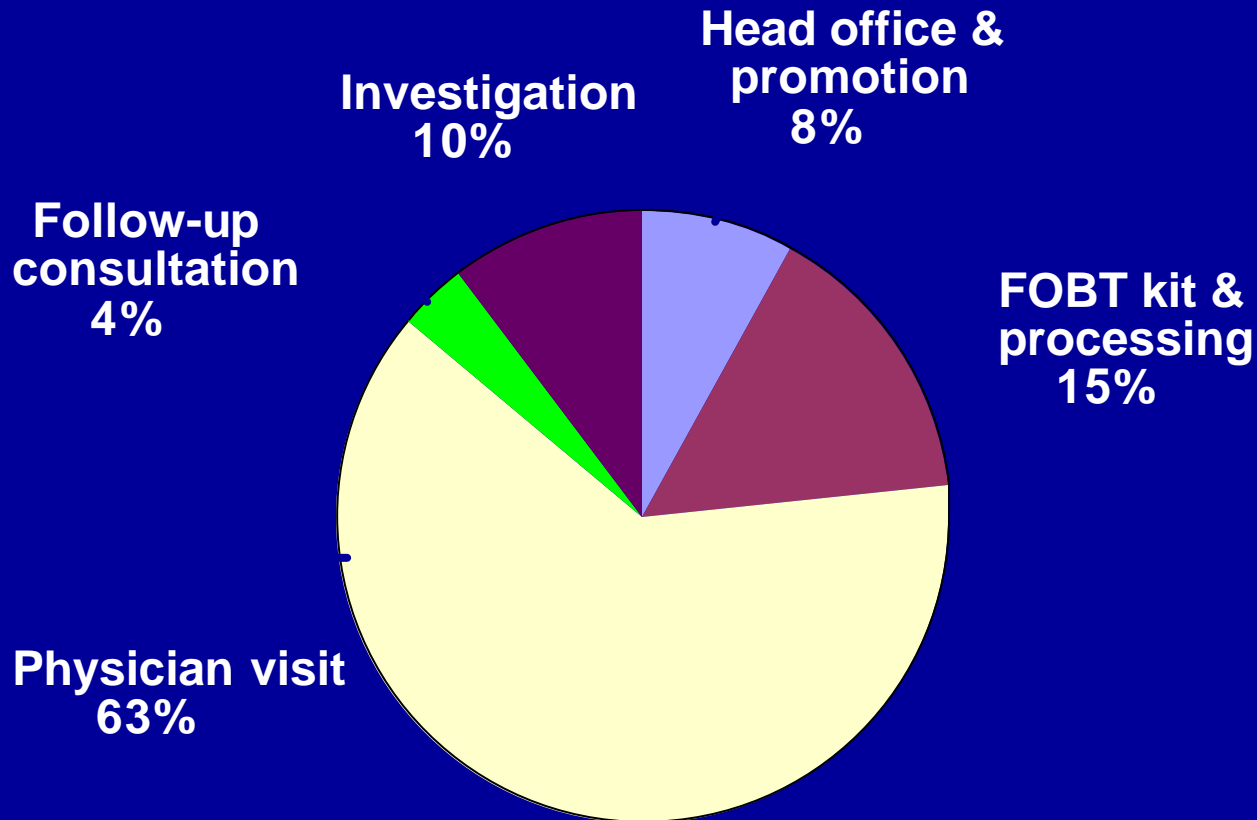
Data Sources



Estimated mortality impacts

Frequency	Biennial	<i>Annual</i>	Biennial
Participation	67%	67%	50%
10 Year CRC Mortality Reduction	16.7%	26.0%	10.0%
25 Year CRC Mortality Reduction	14.2%	22.5%	8.7%
CRC Deaths Avoided (lifetime)	23,668	40,110	13,964
Deaths from complications	133	265	106

Estimated cost of biennial screening



- \$112 million per year on average (discounted at 5%)
 - 33% of the direct treatment costs associated with colorectal cancer
 - Increase colonoscopy needs by at least 15%
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Population based screening is estimated to be cost-effective

Frequency Participation	Biennial 67%	<i>Annual</i> 67%	Biennial 50%
Years (days) of life saved for the cohort	0.040 (15)	0.065 (24)	0.025 (9)
CE-Core scenario*	\$6,202	\$7,129	\$8,262
CE- High Cost Scenario*	\$10,001	\$10,750	\$13,502

At what age is it cost-effective to begin screening ?

	Age screening started	Discounted at 5% (\$/LYG)
X	40 vs 45	133,325
?	45 vs 50	49,647
→	50 vs 55	24,643
	55 vs 60	17,681

Potential gains for a 50 year old fully participating

- Percent CRC Mortality Reduction:
 - 34.5% after 10 years, 31.4% after 25 years
 - Potential life expectancy gains
 - 0.10 years (37 days) for cohort
 - 1.75 years for CRC cases
 - 25% probability of having a colonoscopy
 - Lifetime probability of complications:
 - Death 0.005%, Perforations 0.043% and Haemorrhage 0.008%
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Colorectal cancer screening summary

- Participation rate is the major driver of mortality reduction of CRC
 - Screening from 50-74 was shown to be a good target age group
 - Annual and Biennial FOBT screening of 50-74 year olds were cost-effective
 - Annual screening doubles the number of colonoscopies and FOBTs
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Limitations

- A computer model is not reality
 - Highly dependent on the assumptions used to build the model
 - Sub-committee of experts
 - Type of test
 - Participation rate
 - Clinical trials data
 - Data sometimes limited to a province or a region (staging, costs, etc.)
 - Difficult to validate such a model
 - Reproduce the results of a clinical trial
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**« It is tough to make predictions,
especially about the future»**

Yogi Berra

Thank You!
