



Understanding Attitudes to Health Research or “Who can phone you at dinner time?”

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population-based research, back in the old days . . .

Voters List,
Medical Insurance List
issued to researchers,
subjects selected



letter mailed
to subject
by researchers
to introduce study



followed by call
to subject
to invite participation



in 2003 . . .

~~Voters List,
Medical Insurance List
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Freedom of Information and Protection of Privacy Act

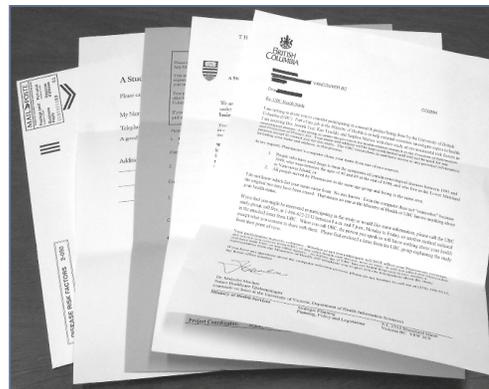
- expressly forbids the use of individual identifying information for contacting study subjects

the new regime, scenario 1 . . .

selection made by government agency



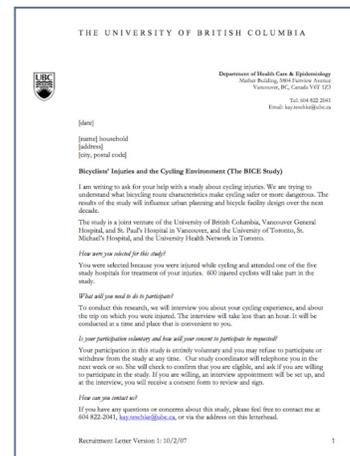
letters of introduction sent from government



government agent calls subject for permission to release name to researchers



participation



process turned over to researcher

the new regime, scenario 2 . . .

- No release of names to researchers
 - Scenario 1 very cumbersome for government, and
 - does not comply with the legislation

rationale for legislation change



- Government personnel occasionally received angry complaints about release of contact info without permission
 - feeling that this was the tip of the iceberg
 - In contrast, researchers often hear thanks that research is being conducted
-
- Considerable legal & ethical scholarship on privacy issues
 - But little literature on public opinions about participation in health research

survey of public opinions



Four questions:

1. Are you **willing to participate in health research**?
2. How would the **organization contacting you** affect whether you felt comfortable and willing to participate in health research?
3. How would the **method of selecting you** affect whether you felt comfortable and willing to participate in health research?
4. Would other factors **make you feel better or worse about participating** in health research?

study methods



Sample of 3000 Metro Vancouver and rural Vancouver Island households, drawn from electronic telephone directory file, represents ~ 50% of population of province of British Columbia

Adult with next birthday asked to respond

Questionnaire mailed to respondents, with return-mail envelope

Non-responders followed up with 2nd and 3rd mailings, and telephone calls



1st mailing

N=854

+



2nd mailing

N=414

+



3rd mailing

N=207

=

Total

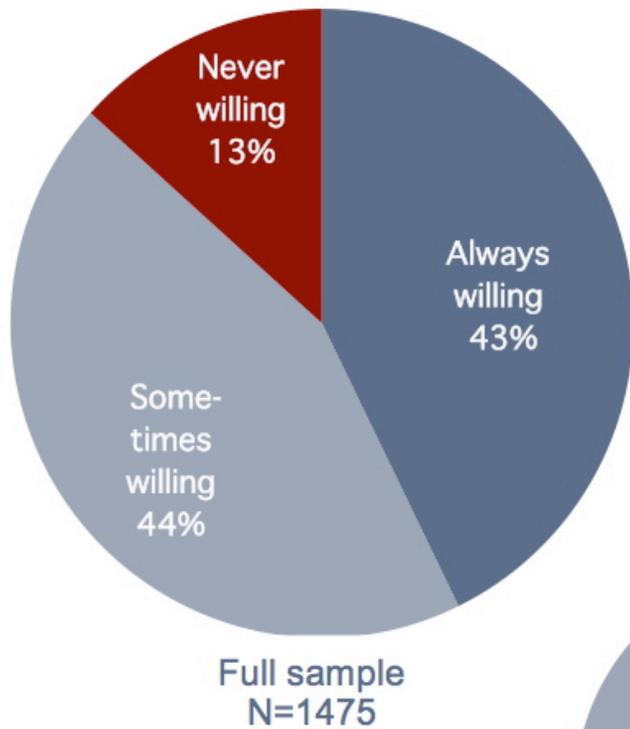
1475 (55%)

314 = ineligible

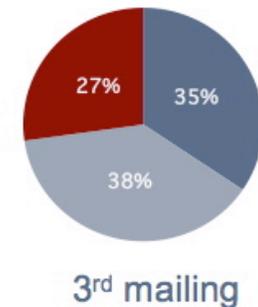
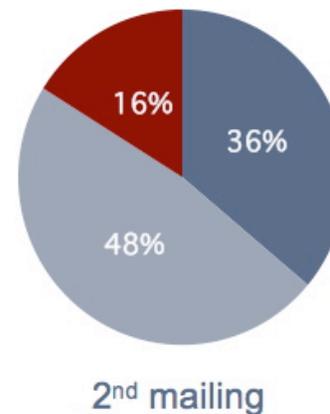
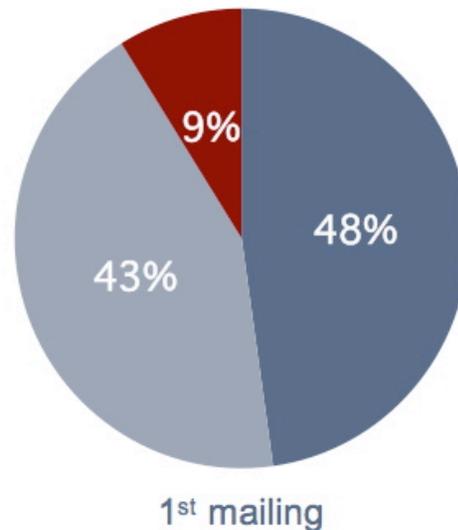
183 = refused

1028 = no contact

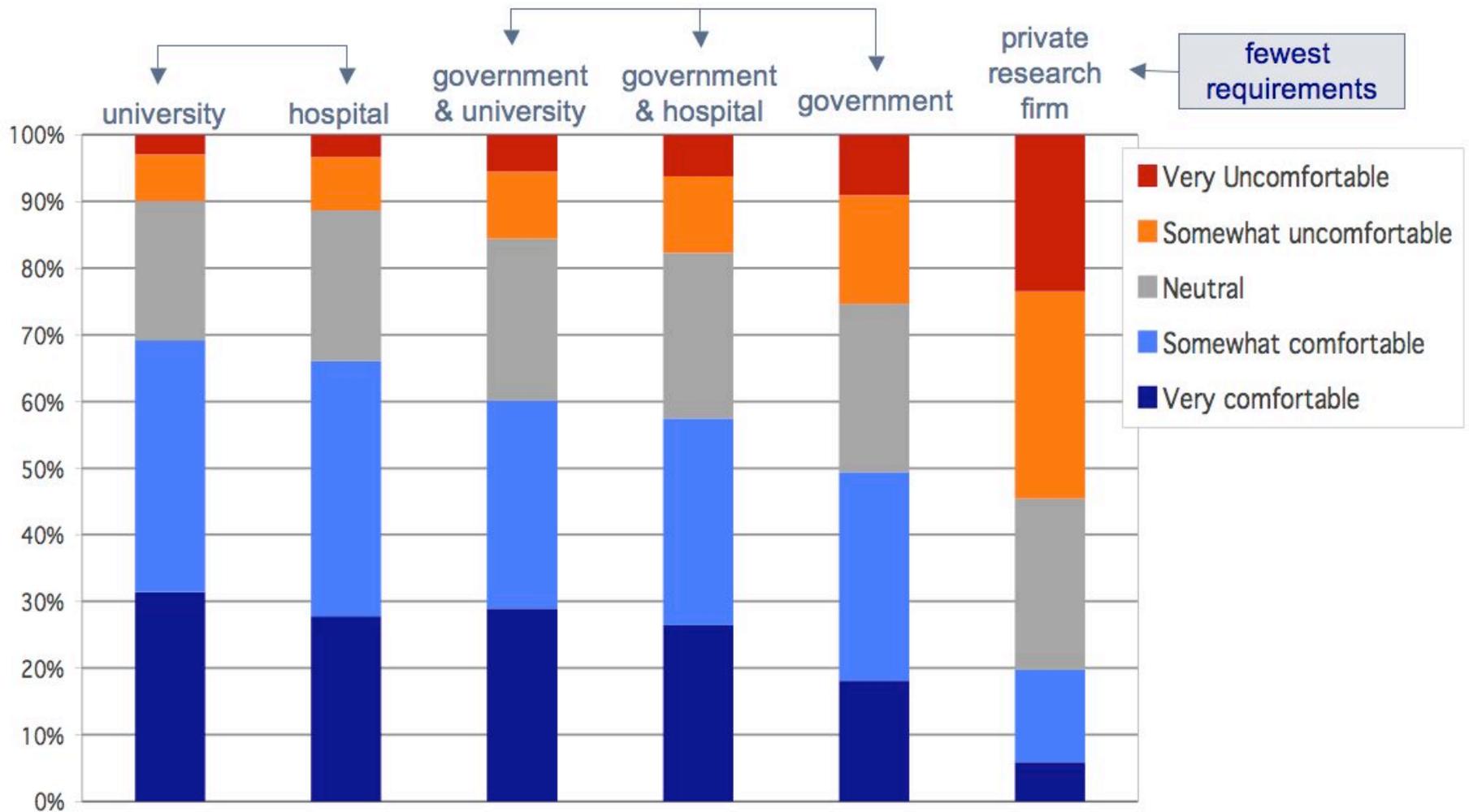
1. Are you willing to participate in health research?



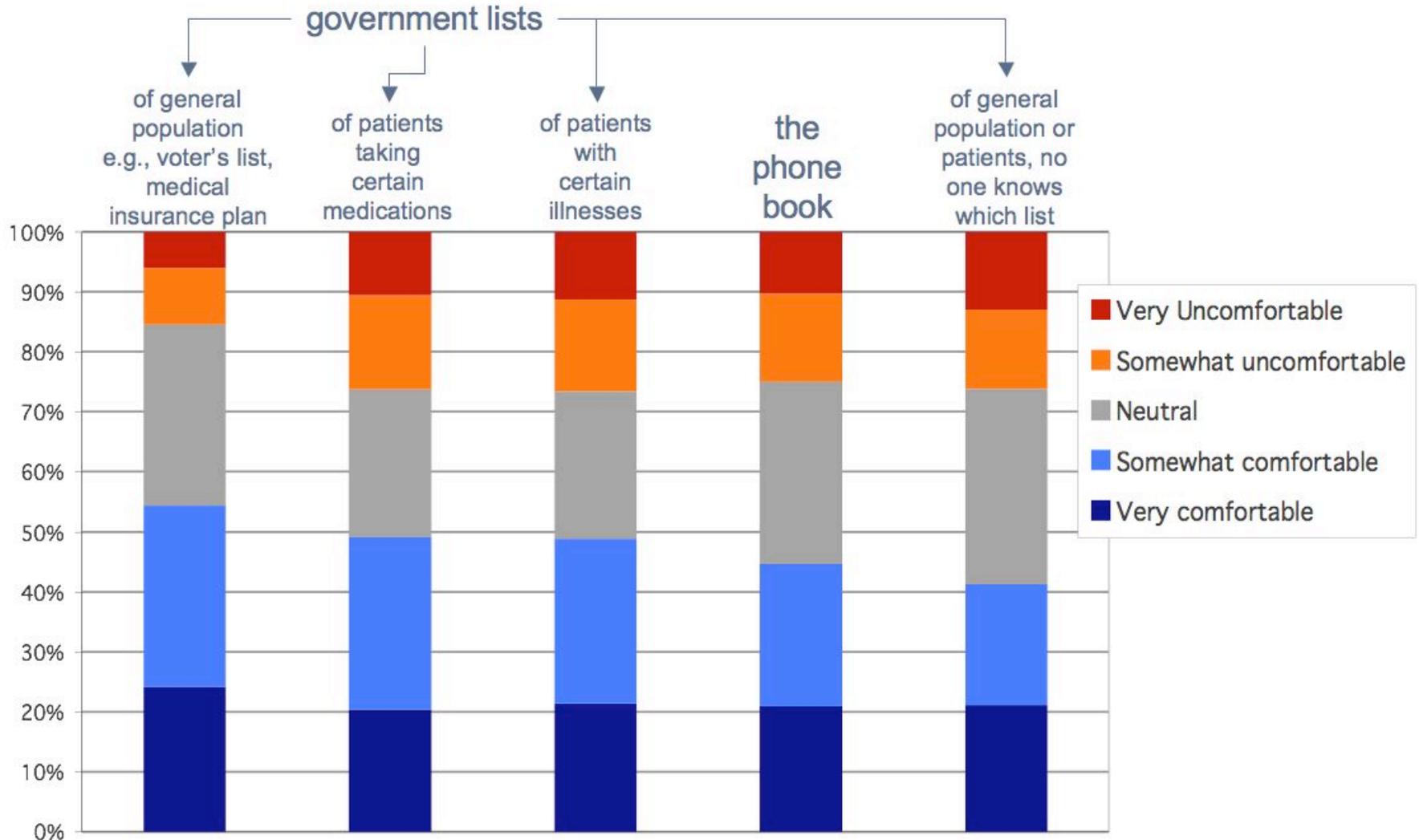
- 87% of respondents willing to participate in health research, at least sometimes
 - Women slightly more willing than men
 - Women less willing with increasing age
 - Men more willing with increasing age
- More of those who responded later were never willing; willingness of non-respondents unknown, but certain to be lower



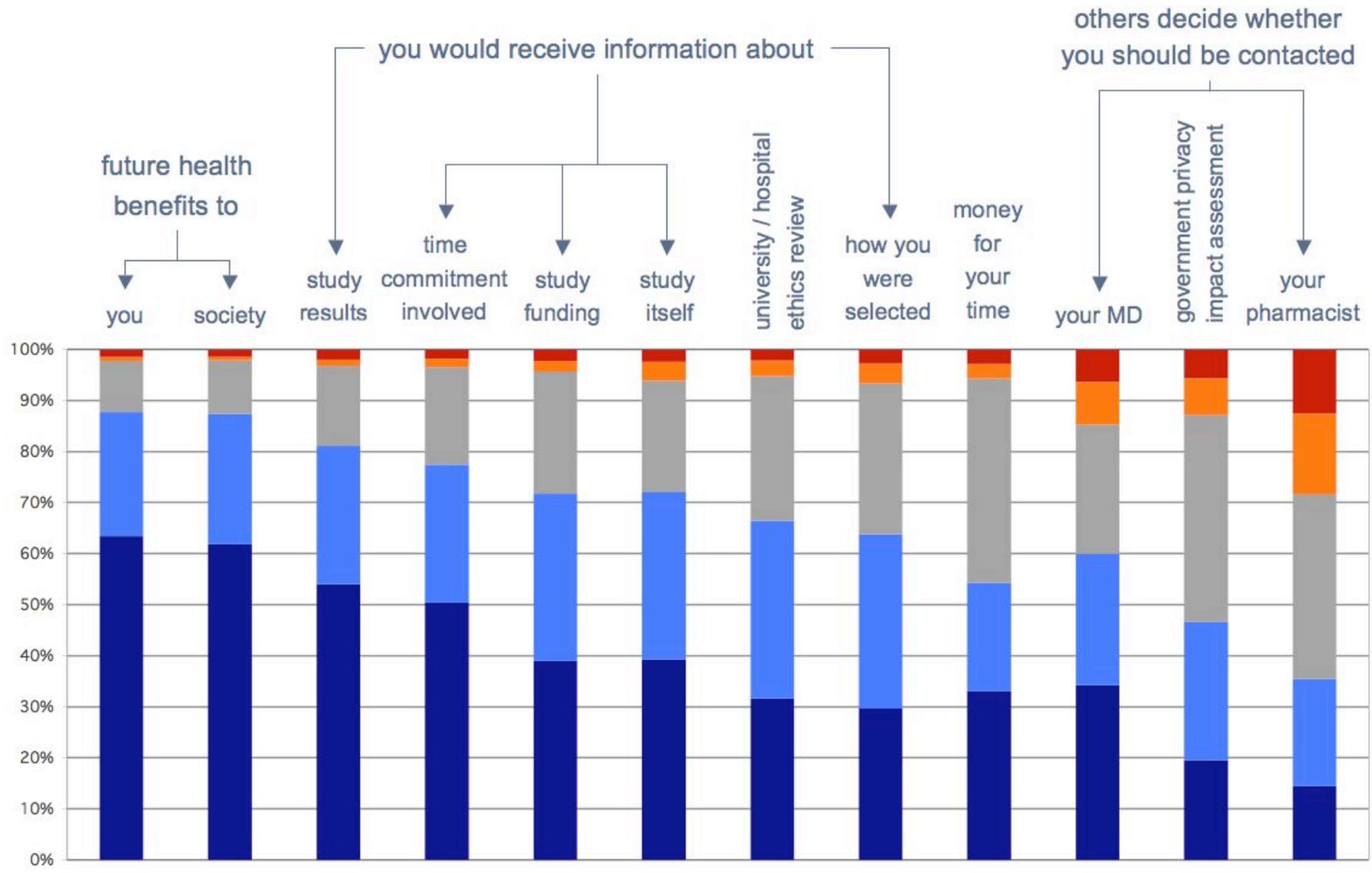
2. How would the **organization contacting you** affect whether you felt comfortable and willing to participate in health research?



3. How would the **method of selecting you** affect whether you felt comfortable and willing to participate in health research?



4. Would any of the following make you feel better or worse about participating in health research?



limitations . . .



- Effect of participation rate on results unknown
 - main effect likely to be on overall willingness
 - those who answered in the 1st, 2nd, and 3rd mailings had little difference in their answers to questions 2, 3, and 4
- Effect of the fact that a university conducted this research is unknown
 - another sample, not reported here, was initially contacted by the Ministry of Health, and had little difference in their answers to questions 2, 3, and 4

conclusions . . .



- Great majority of respondents willing to take part in health research
- Organization contacting participants makes a difference to participation
 - universities and hospitals > government >> private research firms
- Modes of selection similar in effect on participation
- Strongest motivators for participating are future health benefits of the research

thanks



- Study participants
- Research assistants
 - Saleema Dhalla
 - Hasina Jamal
- Malcolm Maclure
- Lianne Warren
- BC Ministry of Health
- BC Medical Services Foundation