



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

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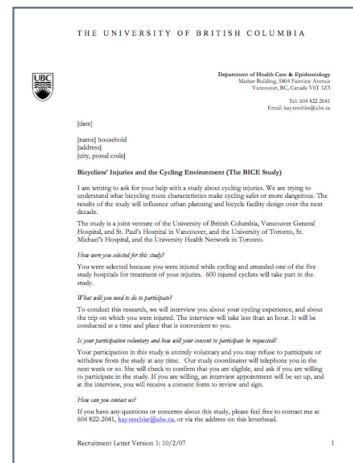
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population-based research, back in the old days . . .

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

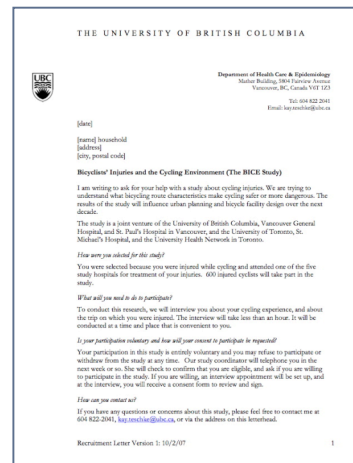


in 2003 . . .

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

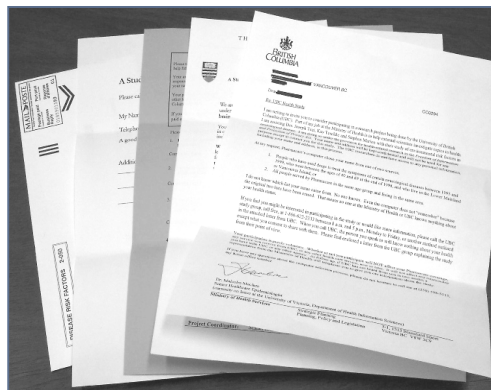
- expressly forbids the use of individual identifying information for contacting study subjects

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



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Bicycles' Injuries and the Cycling Environment (The BICE Study)

I am writing to ask for your help with a study about cycling injuries. We are trying to understand what bicycling more characteristics make cycling safer or more dangerous. The results of this study will influence urban planning and bicycle facility design over the next decade.

The study is a joint venture of the University of British Columbia, Vancouver General Hospital, and St. Paul's Hospital in Vancouver, and the University of Toronto, St. Michael's Hospital, and the University Health Network in Toronto.

How are you asked for the study?
You were selected because you were injured while cycling and attended one of the five study hospitals for treatment of your injuries. 400 injured cyclists will take part in the study.

What will you need to do to participate?
To conduct this research, we will interview you about your cycling experience, and about the trip on which you were injured. The interview will take less than an hour. It will be conducted at a time and place that is convenient to you.

Is your participation voluntary and how will your consent to participate be requested?
Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time. Our study coordinator will telephone you in the next week or so. She will check to confirm that you are eligible, and ask if you are willing to participate in the study. If you are willing, an interview appointment will be set up, and at the interview, you will receive a consent form to review and sign.

How can you contact us?
If you have any questions or concerns about this study, please feel free to contact me at 604 822-2041, hcy@hsc.ubc.ca, or via the address on this letterhead.

Recruitment Letter Version 1: 10/2/07

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

rational 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

Survey: Opinions about Participating in Health Research

The following table shows the results of a survey of 100 people who were asked to participate in a health research study. The table shows the number of people who responded "Yes", "No", or "Don't Know" to each of the following questions. The table also shows the percentage of people who responded "Yes", "No", or "Don't Know" to each question.

Question	Yes	No	Don't Know
1. Would you be willing to participate in a health research study?	65	25	10
2. Would you be willing to participate in a health research study if you were paid for it?	75	15	10
3. Would you be willing to participate in a health research study if you were paid for it and you were guaranteed to be paid?	85	5	10
4. Would you be willing to participate in a health research study if you were paid for it and you were guaranteed to be paid and you were guaranteed to be paid?	90	5	5
5. Would you be willing to participate in a health research study if you were paid for it and you were guaranteed to be paid and you were guaranteed to be paid and you were guaranteed to be paid?	95	5	0

Percentages are based on the total number of people who responded to each question. Percentages may not add up to 100% due to rounding.



1st mailing

N=854

+

Survey Opinions about Participating in Health Research

Participants in the survey were asked to indicate their level of agreement with the following statements to a degree of strongly agree, agree, neutral, disagree, or strongly disagree. The results of the survey are shown in the following table.

Statement	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
It is important to participate in health research to help improve health care.	85	10	5	0	0
Participating in health research is a good way to learn more about health care.	75	20	5	0	0
Participating in health research is a good way to help others.	70	25	5	0	0
Participating in health research is a good way to help the community.	65	30	5	0	0
Participating in health research is a good way to help the world.	60	35	5	0	0
Participating in health research is a good way to help the future.	55	40	5	0	0
Participating in health research is a good way to help the past.	50	45	5	0	0
Participating in health research is a good way to help the present.	45	50	5	0	0
Participating in health research is a good way to help the future and the past.	40	55	5	0	0
Participating in health research is a good way to help the future and the present.	35	60	5	0	0
Participating in health research is a good way to help the future, the past, and the present.	30	65	5	0	0
Participating in health research is a good way to help the future, the past, and the present, and the world.	25	70	5	0	0
Participating in health research is a good way to help the future, the past, and the present, and the world, and the community.	20	75	5	0	0
Participating in health research is a good way to help the future, the past, and the present, and the world, and the community, and the health care system.	15	80	5	0	0
Participating in health research is a good way to help the future, the past, and the present, and the world, and the community, and the health care system, and the government.	10	85	5	0	0
Participating in health research is a good way to help the future, the past, and the present, and the world, and the community, and the health care system, and the government, and the future.	5	90	5	0	0
Participating in health research is a good way to help the future, the past, and the present, and the world, and the community, and the health care system, and the government, and the future, and the past.	0	95	5	0	0
Participating in health research is a good way to help the future, the past, and the present, and the world, and the community, and the health care system, and the government, and the future, and the past, and the present.	0	100	0	0	0



2nd mailing

N=414

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[illegible]

3rd mailing

N=207

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Total

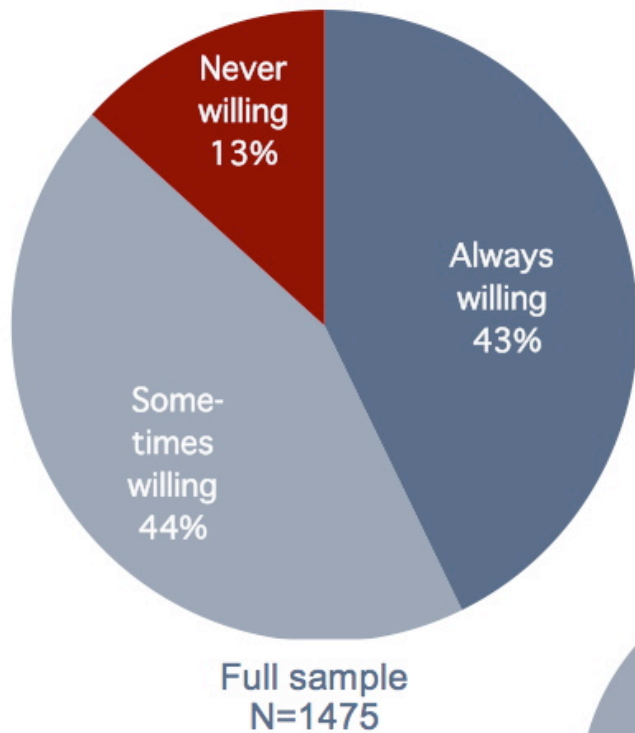
1475 (55%)

314 = ineligible

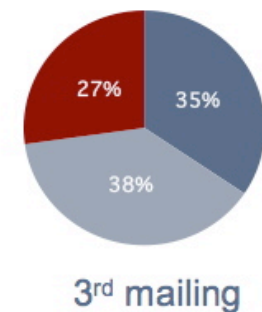
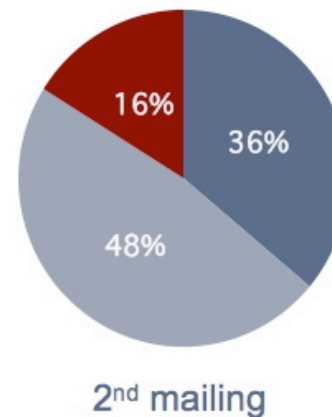
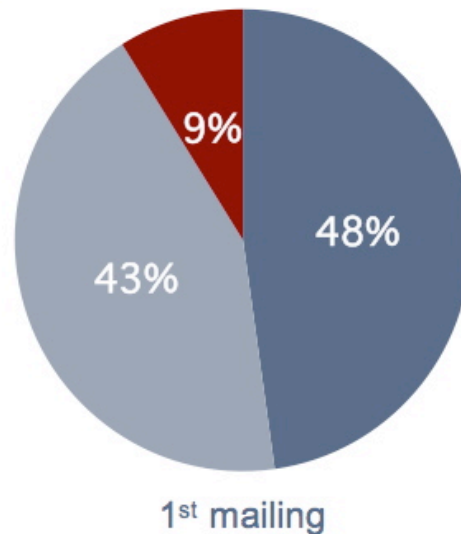
183 = refused

1028 = no contact

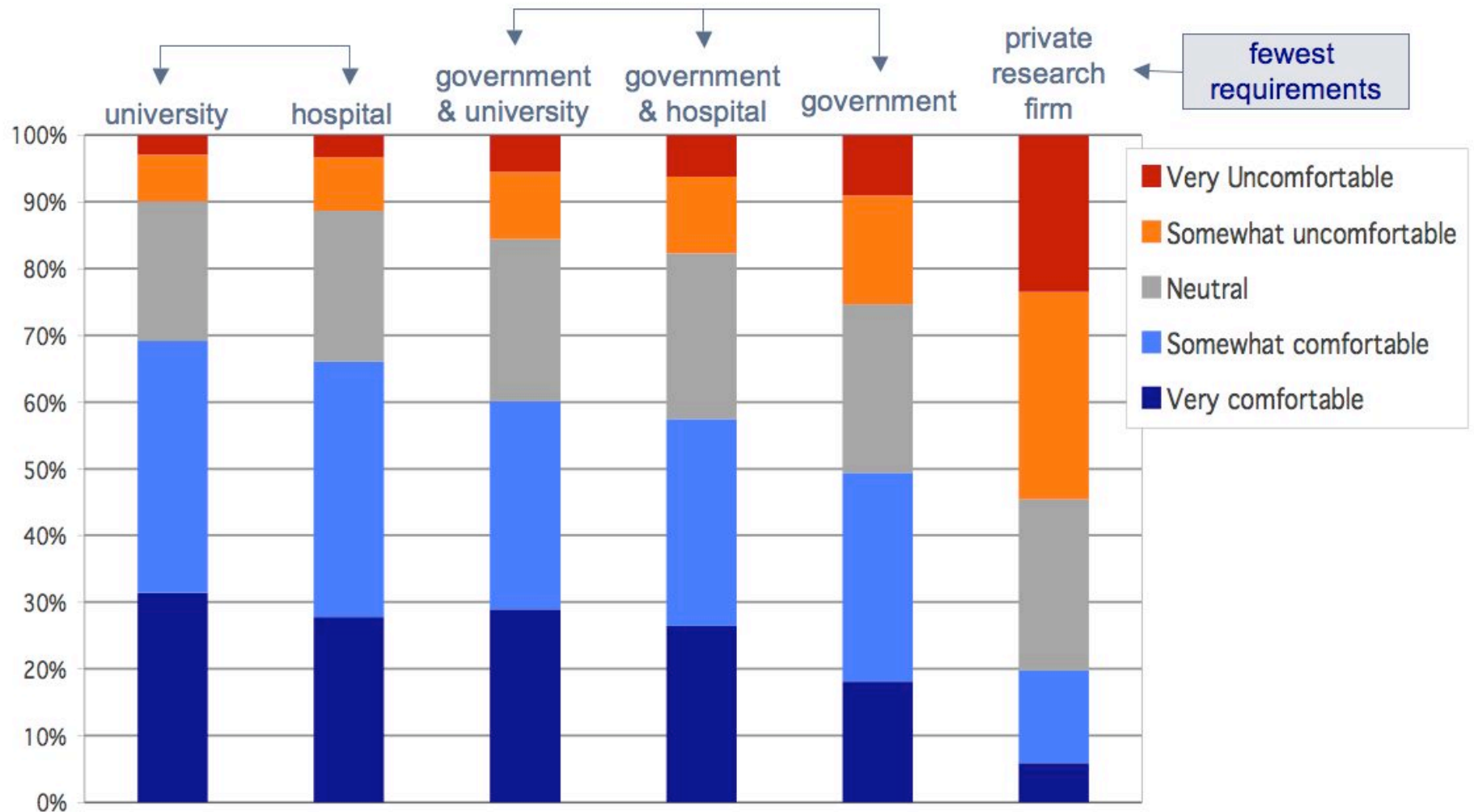
1. Are you willing to participate in health research?



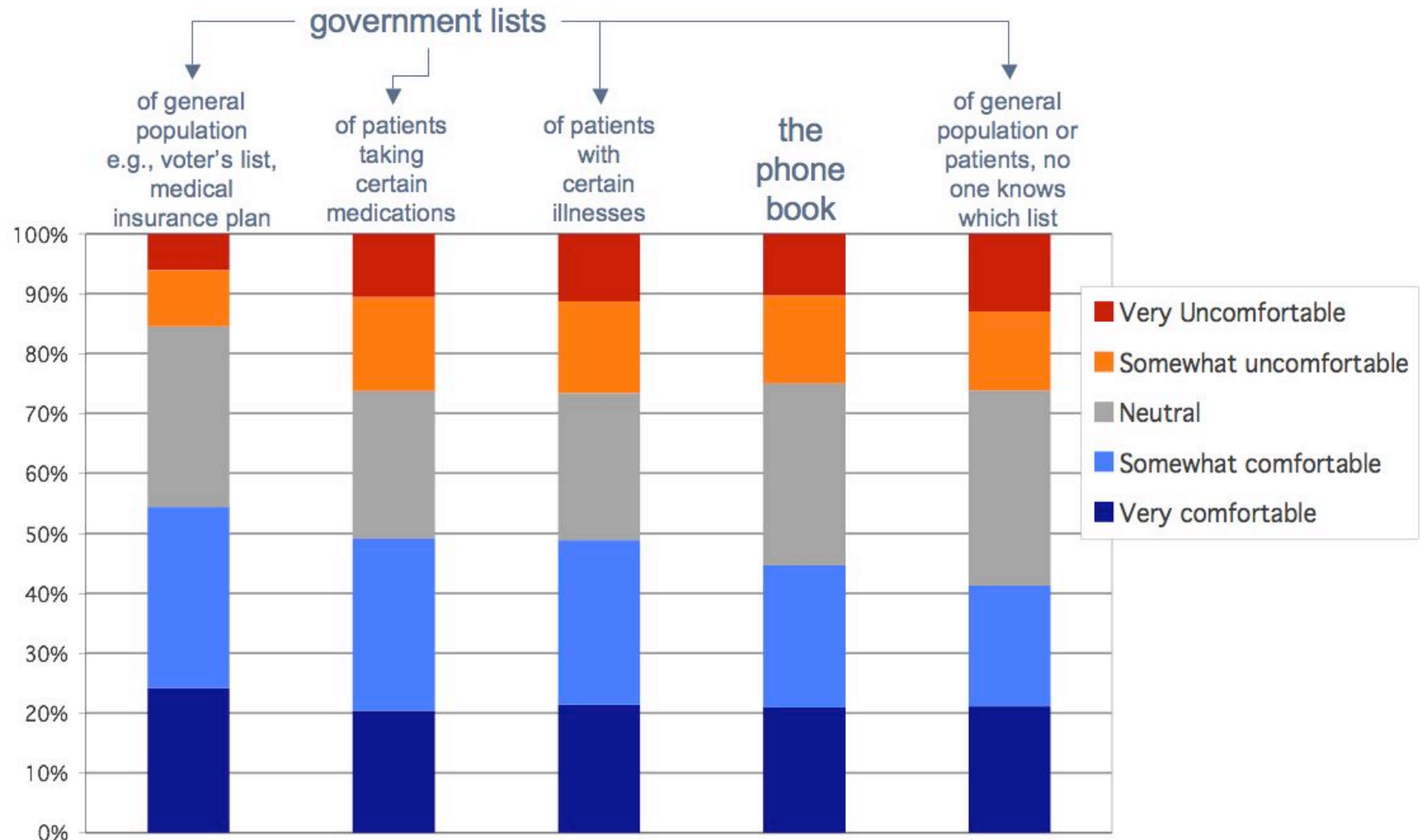
- 87% of respondents willing to participate in health research, at least sometimes
 - Women slightly more willing than men
 - Women less willing with increasing age
 - Men more willing with increasing age
- More of those who responded later were never willing; willingness of non-respondents unknown,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



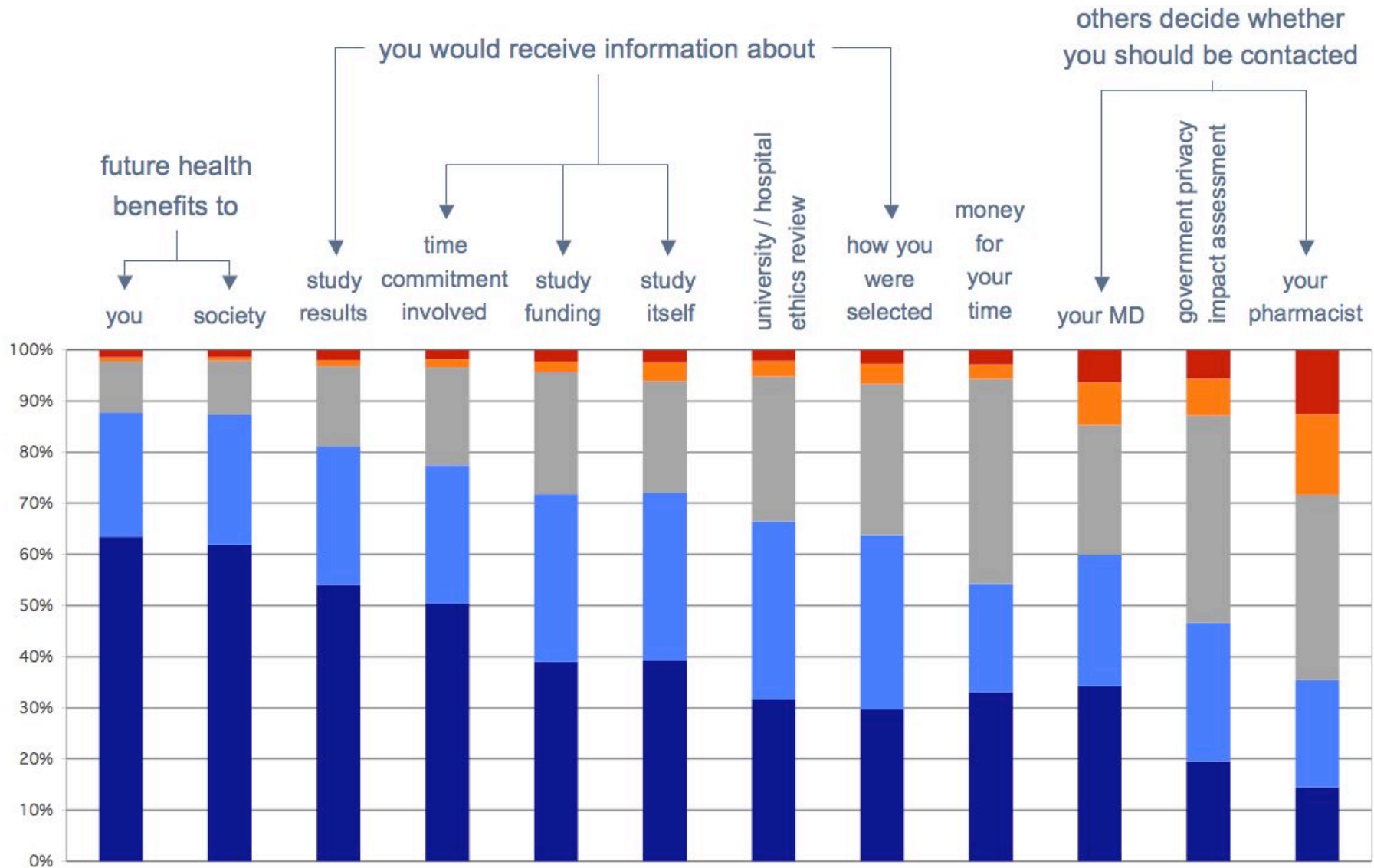
2. How would the **organization contacting you** affect whether you felt comfortable and willing to participate in health research?



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