Public Opinion on Privacy and Data Sharing in Biobank Research

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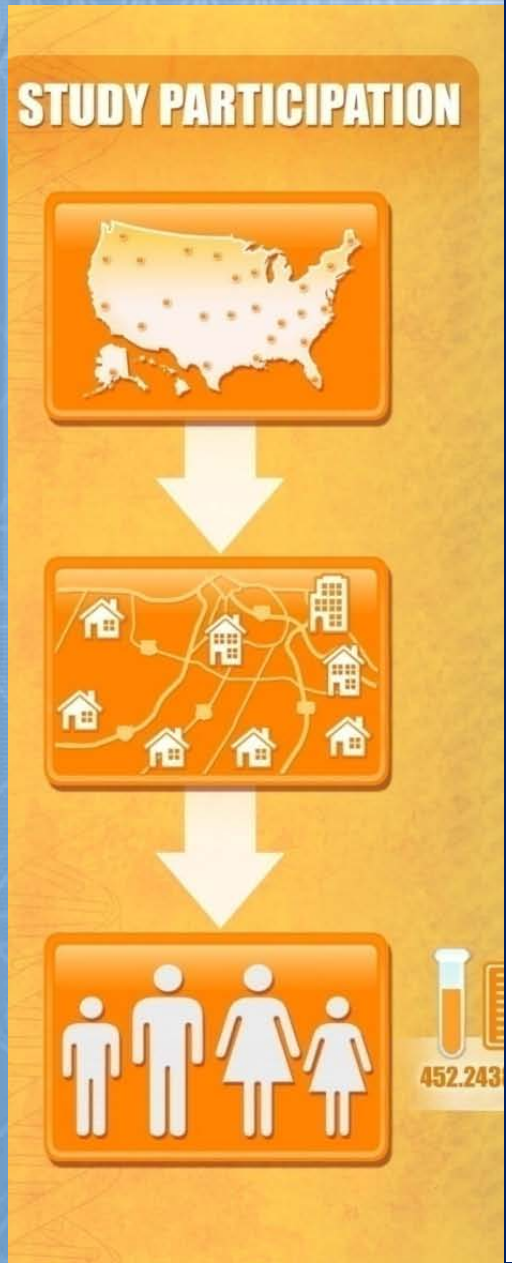
Proposed U.S. Prospective Cohort Study



- Informed by the NIH document "Design Considerations…."
- Enroll 500,000 individuals representative of the U.S. population
  - Recruit across the U.S.
  - Enroll individuals and 30% households
  - Collect DNA and other specimens
  - Physical/developmental/psychological exam
  - Lifestyle and behavioral information
  - Environmental exposures
  - Follow for a decade
  - Contact for periodic updates and a second exam

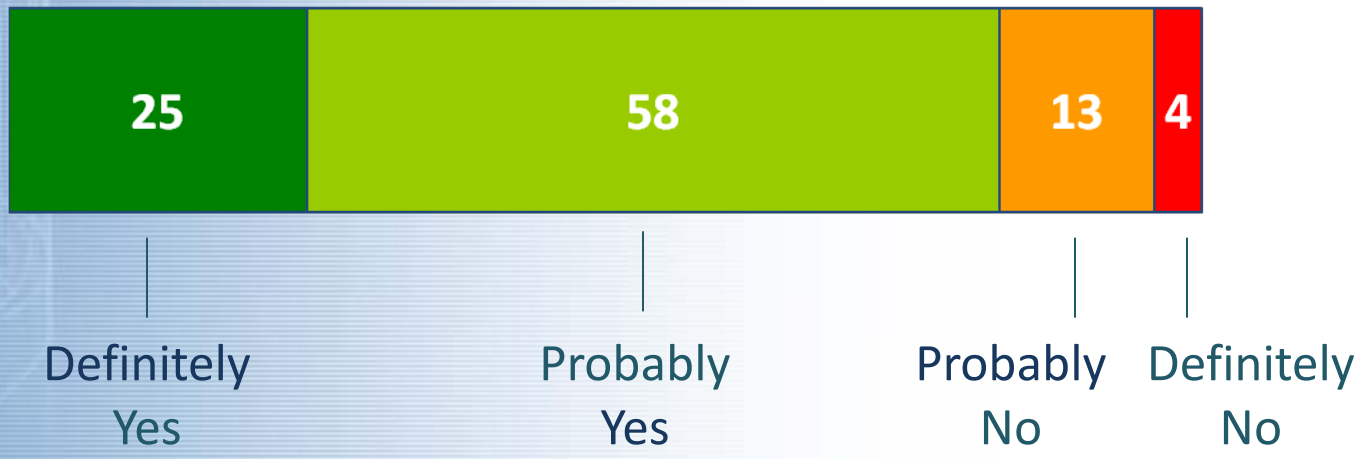
Public Consultation

- Making Every Voice Count: Public Consultation on Genetics, Environment and Health (9/06 – 8/08)
  - Attitudes about the proposed study
  - Inform design and implementation
  - Focus groups, community leader interviews, population-based survey, and town halls
- Follow Up Public Consultation Project (8/09-6/11)
  - Focusing on return of research results, privacy, and consent
  - Focus groups (online and in-person) and a population-based survey

Initial Consultation Data

General Support for the Study

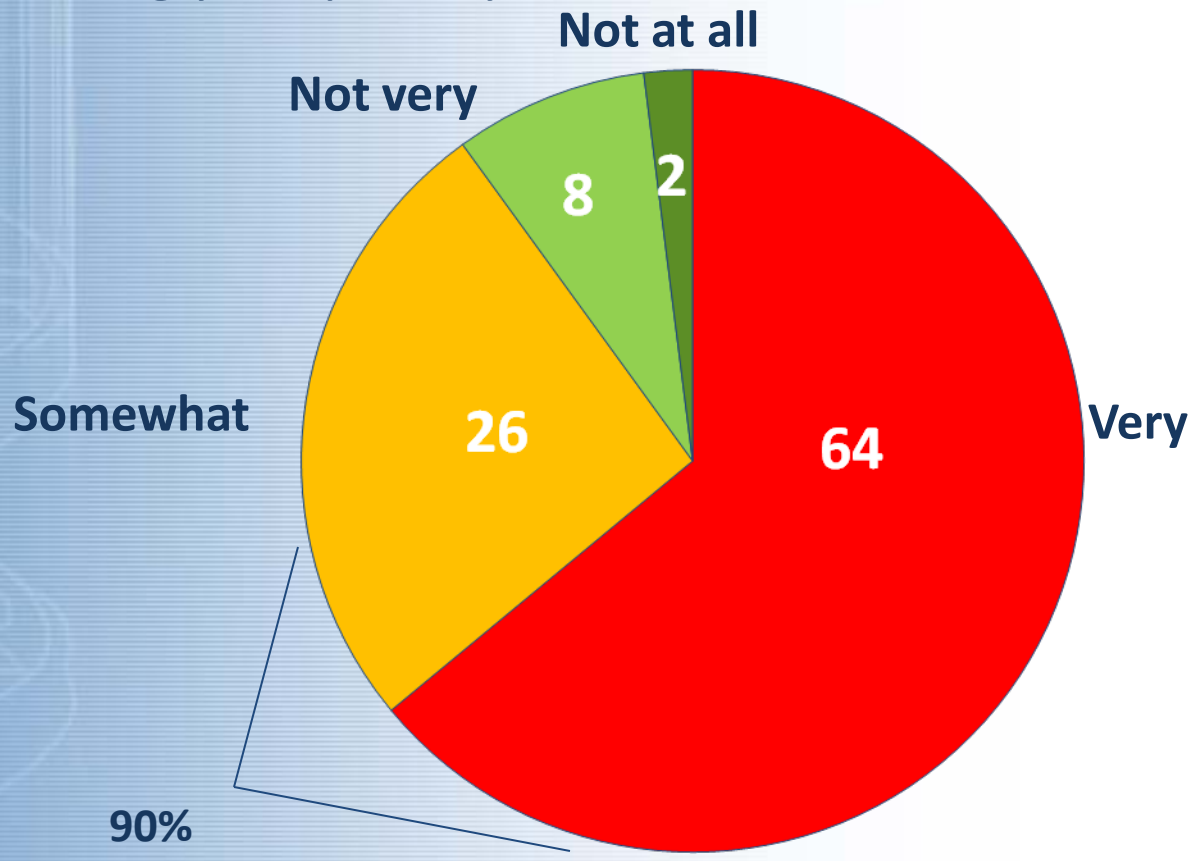
"Based on what you've just learned, do you think this study should be done?"



Privacy

People would be concerned about protection of their privacy if they participated.

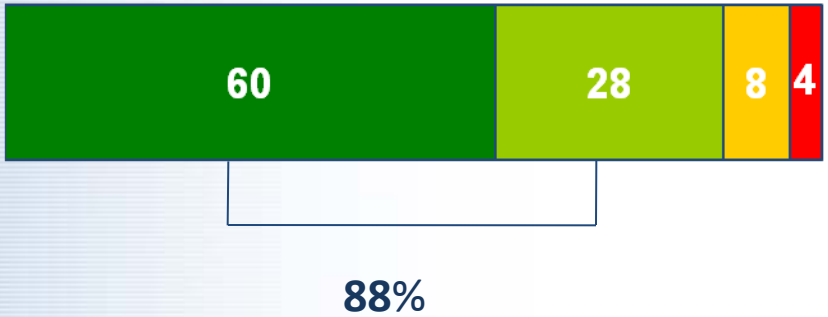
"If you were a participant, how concerned would you be about protecting your privacy?"



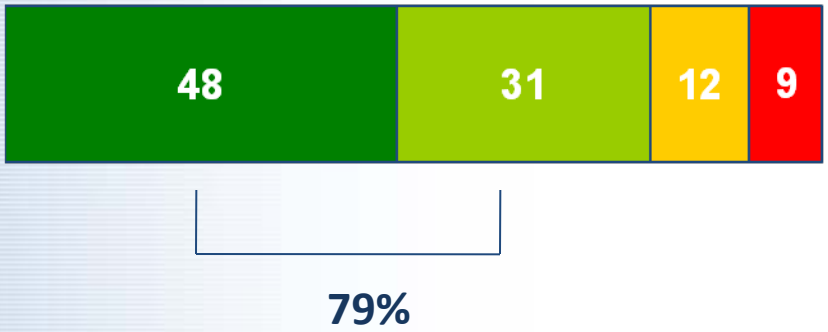
General Opinions about Privacy

How concerned are you about the privacy of your…

…financial information?

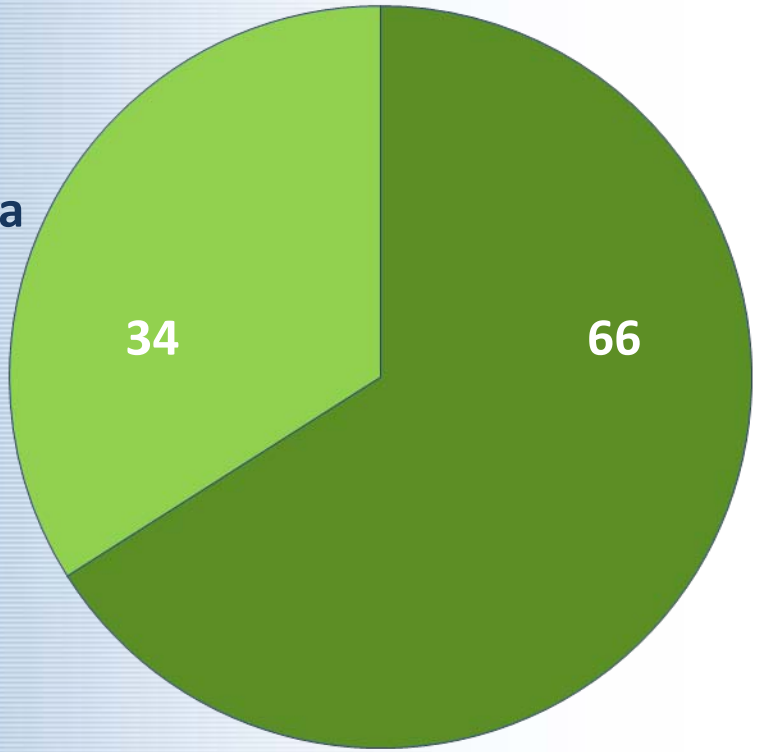


…medical information?



Does some information on medical records need extra privacy protection?

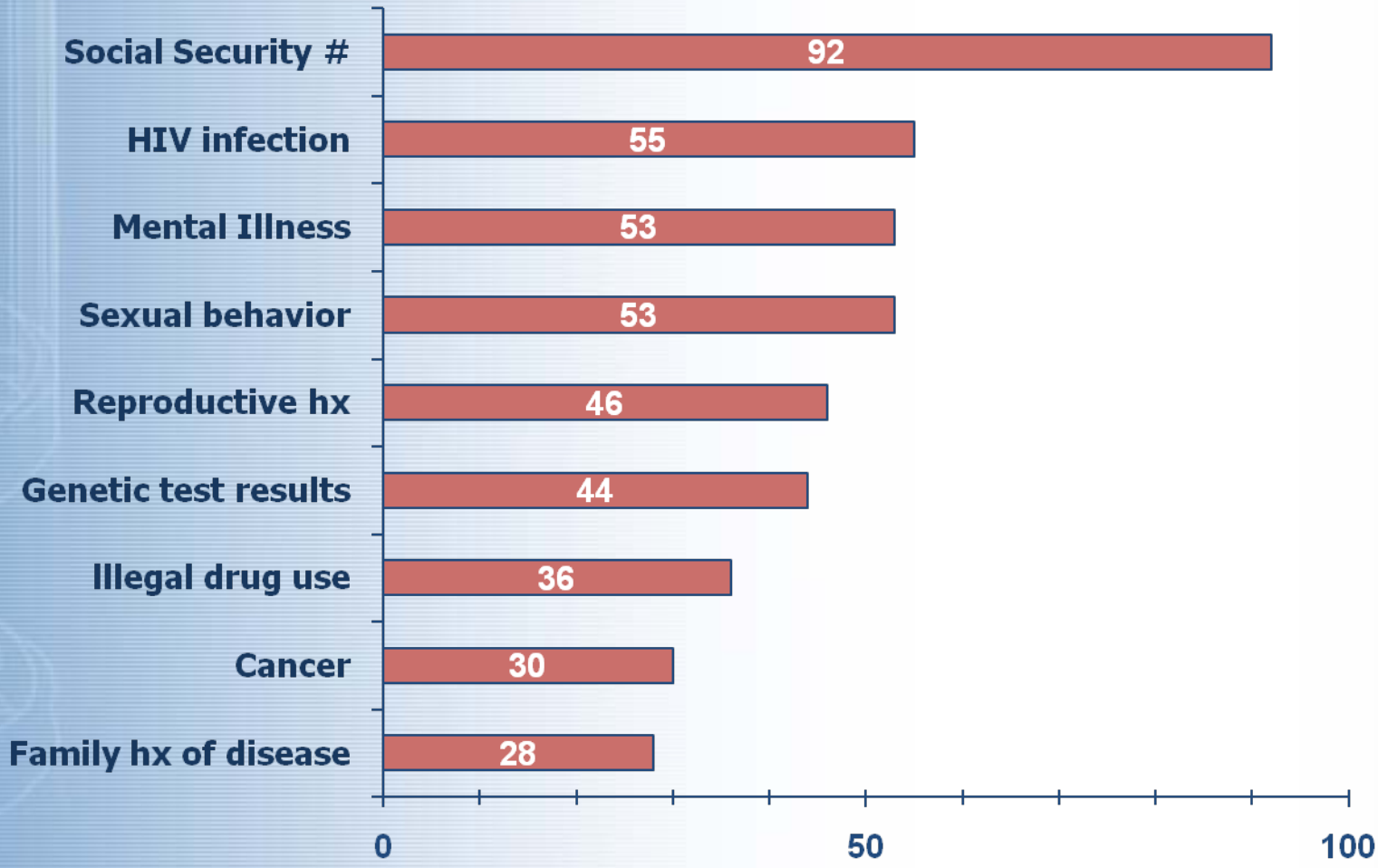
Yes, some information in medical records needs extra privacy protections.



It all should be protected equally.

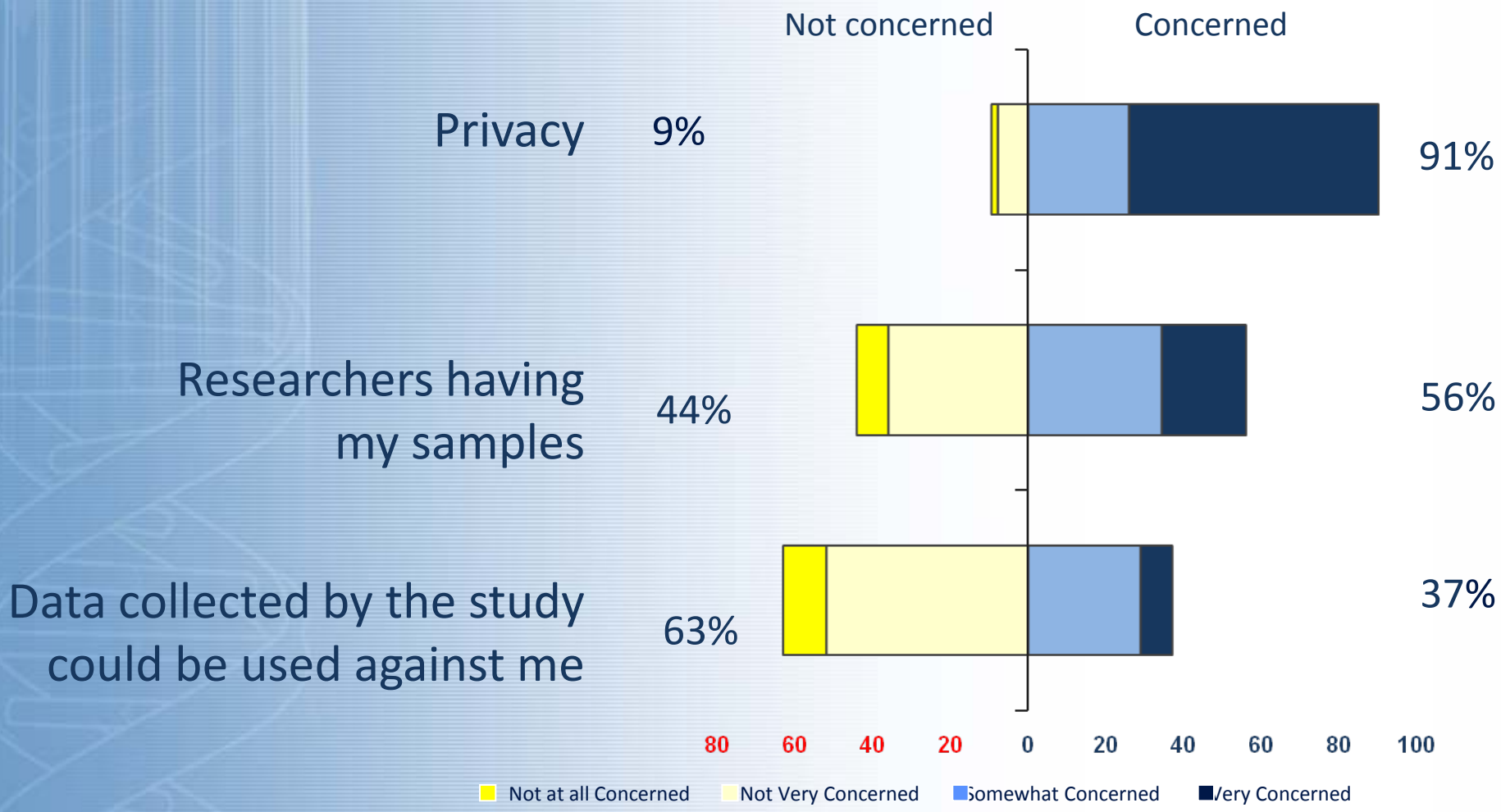
Confidential. N=4,659. Weighted. GPPC 2008

What types of information in a medical record do you think need extra privacy protections? (n=1574)

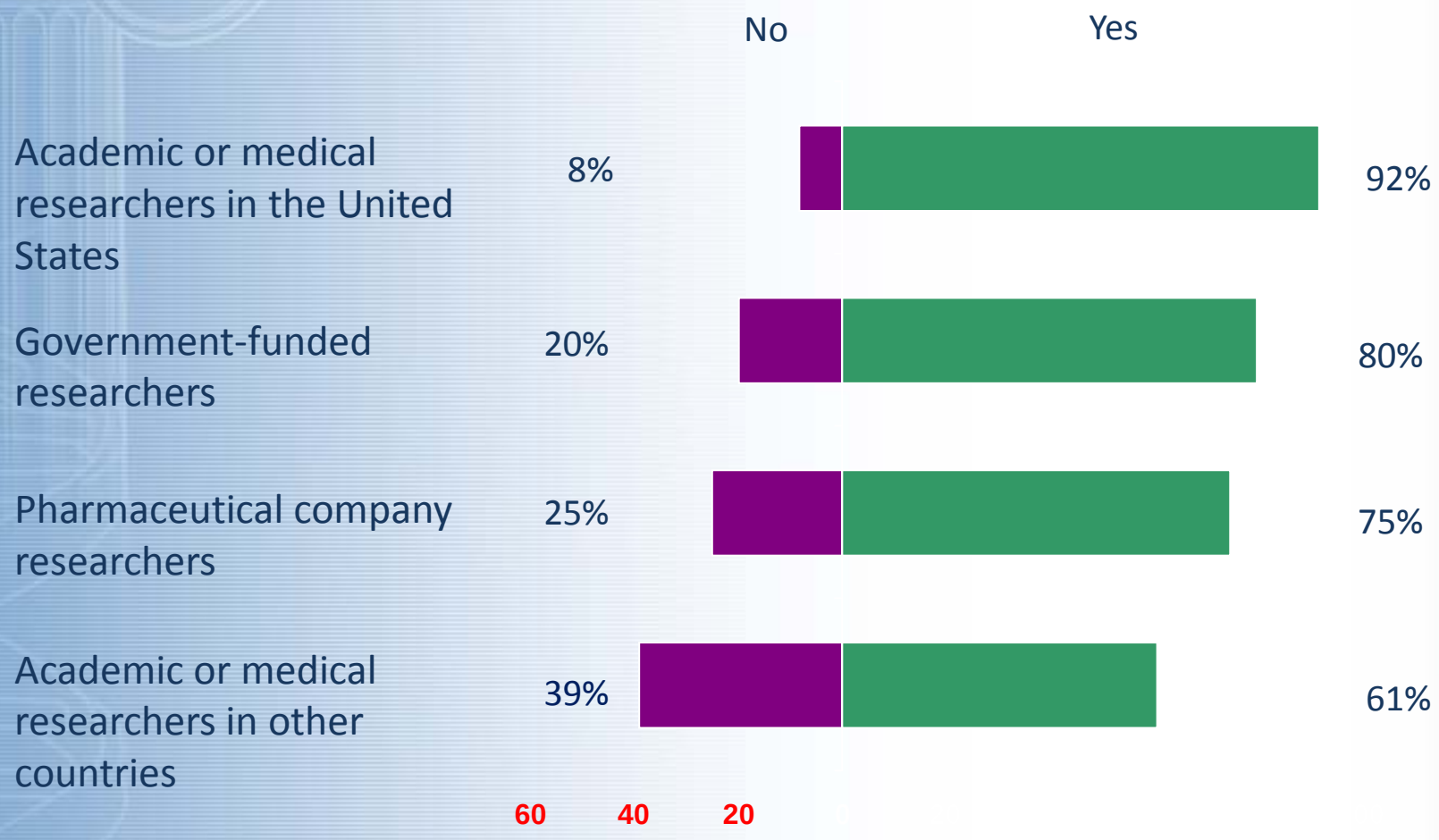


Confidential. N=4,659. Weighted. GPPC 2008

How concerned would you be about the following if you participated?



Would you allow the following types of researchers to use your samples and information for research?



Current Consultation Data

Privacy

Privacy

- General thoughts on privacy
  - Privacy is dead

    F1: Basically, you don't have privacy

    F2: Not with the internet (DC, Cauc, Low SES)

  - For some, this made them less concerned when thinking about participating in the biobank.

    Honestly, I don't have an issue with privacy. My belief is that anyone can find out anything about anybody. I don't worry about it. (Female, ONL 1, Mixed, SN)

Privacy

Risks if privacy protections are violated

- ✓ Discrimination (insurance, employment)
- ✓ Identity fraud

I am really concerned about identity fraud…because all that you are talking about, people can gather, get, and use against you. (Female, DC, Cauc, N-SN)

I worry about people stealing my identity and taking all of my money. (Female, ONL 1, Mixed, SN)

Privacy

Risks if privacy protections are violated

- ✓ Being stigmatized

  If it were known that many of these participants have HIV, then they would get labeled. (Female, DEN, Hisp, SS)

- ✓ Fear of being cloned

  Anybody could clone you in Europe. (Male, DC, Mixed, N-SN)

Privacy

Risks if privacy protections are violated

- ✓ Being spammed by drug company marketing

> *F: I think the risk of criminal activity based [on this is] much less than that of commercial activity…that you are going to start getting mailings from pharmaceutical firms saying, you know, you should be taking this pill, or, you know –*
> *M: "Tired of your blue eyes?"* (DC, Mixed, N-SN)

Privacy

Privacy breaches

- Are inevitable

- Some participants were not overly concerned
  - Coding provided adequate protection
  - The data would only appeal to a very small segment of people.

It's [data breach] always going to happen. (Male, DC, Cauc, Low SES)

GINA

- Most focus group participants never heard about GINA

- Most were not reassured by the protections it offered.

MOD: Does the fact that GINA is in effect give you any reassurance?
F: No, not really

(DC, Cauc, Low SES)

GINA

But it's just a law, right? In ten years down the road, some cowboy gets elected…and he changes the law.

(*Male, DC, Mixed, N-SN)*

MOD: Would [GINA] help your concern around insurance companies having access?
F: No, because insurance companies are large organizations. They have ways of getting information, whatever law comes out.

(DC, Mixed, N-SN)

MOD: Having that information [about GINA], does that change anything about what you have thought so far?
F: There is always red tape and there is always a way around things.

(PHL, AA, Mid-High SES)

General discussion about study protections

- Some felt that despite NIH's best intentions, it would be difficult to control access to and use of the data.

  An insurance company could be attached to another research firm and they are obtaining information from NIH, and – maybe NIH doesn't know that they are involved with insurance. (Male, PHL, AA, Mid-High SES)

Access to the data

- Others who should not have access
  - Scientists performing cloning

    The people who clone. I don't want them to get a hold of me. (Female, PHL, Mixed, SN)

  - Individuals seeking transplant/donor matches

    What is going to prevent somebody from saying, my child is deathly ill with whatever, leukemia, we need a bone marrow. You have got to let me into this database to find people who are compatible. (Female, DC, Mixed, N-SN)

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