

Big Desire to Share Big Health Data: A Shift in Consumer Attitudes toward Personal Health Information

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Figures

Figure 1. Number of responses

- 128 Respondents
- Maximum number of responses: 91
- Average number of responses: 72

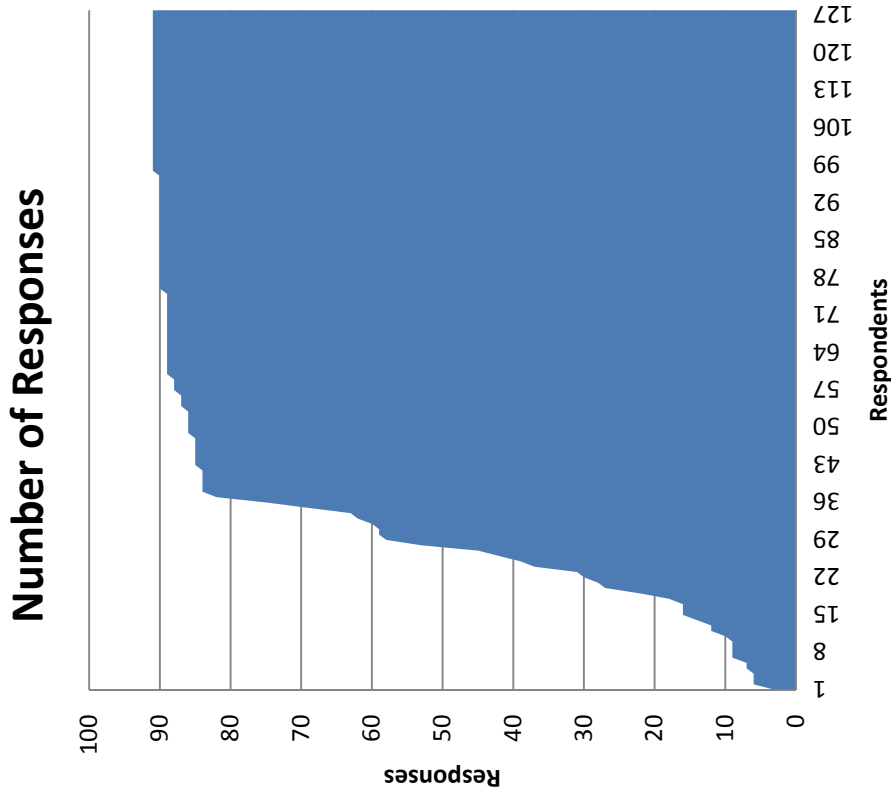


Figure 2. Response distribution

- Over 73% of participants answered more than 90% of all survey questions.

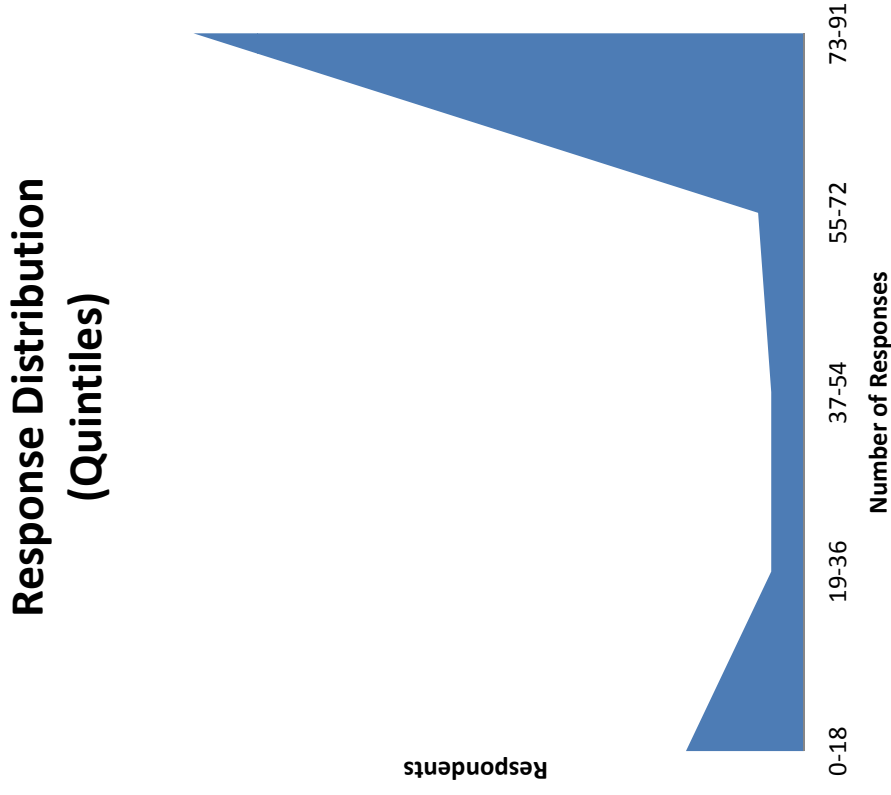


Figure 3. Country

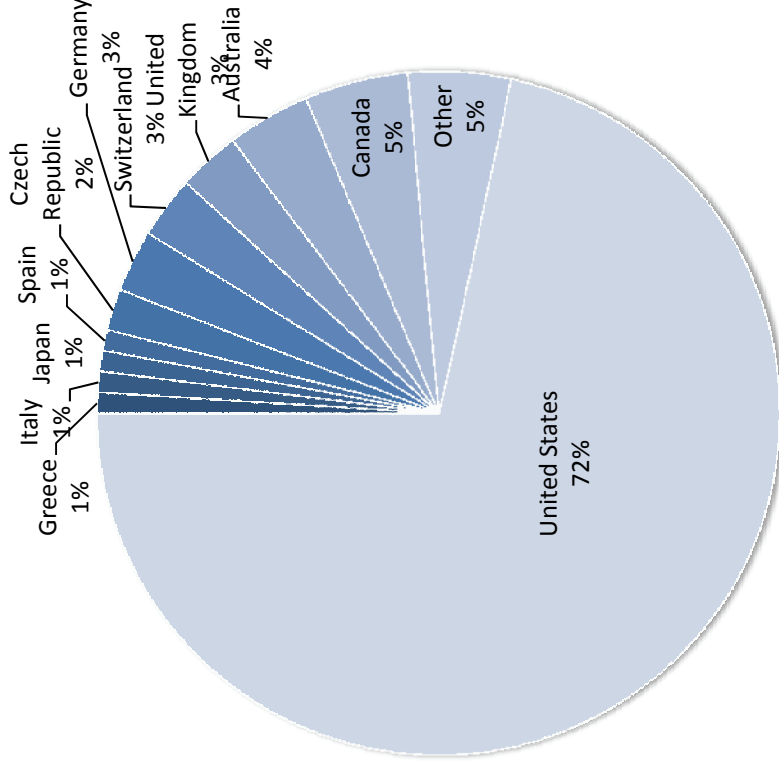
1. Question 383: Country

- Number of responses: 102
- No response: 22
- Skipped question: 4

Responses:

- United States (72%)
- Canada (5%)
- Australia (4%)
- United Kingdom (3%)
- Switzerland (3%)
- Germany (3%)
- Czech Republic (2%)
- Spain (1%)
- Japan (1%)
- Italy (1%)
- Greece (1%)
- Other (5%)

The country I currently live in is...



Over 12 countries represented
By region: North America (77%), Europe (14%), Australia (4%), Asia (1%), other (5%) (>100% due to rounding)

Figure 4. Employment status

2. Question 575: Employment Status

- Number of responses: 101
- No response: 25
- Skipped question: 2

Responses:

- Employed, full-time (53%)
- Self-employed (20%)
- Student (12%)
- Employed, part-time (6%)
- Retired (5%)
- Not employed, but looking for work (4%)

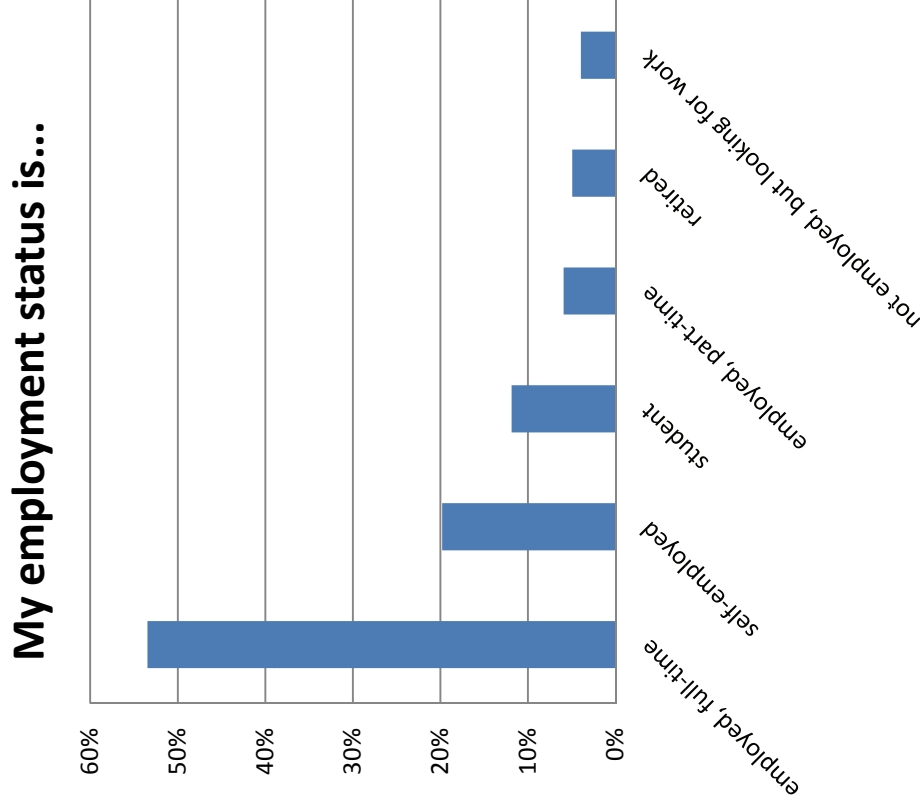


Figure 5. Education

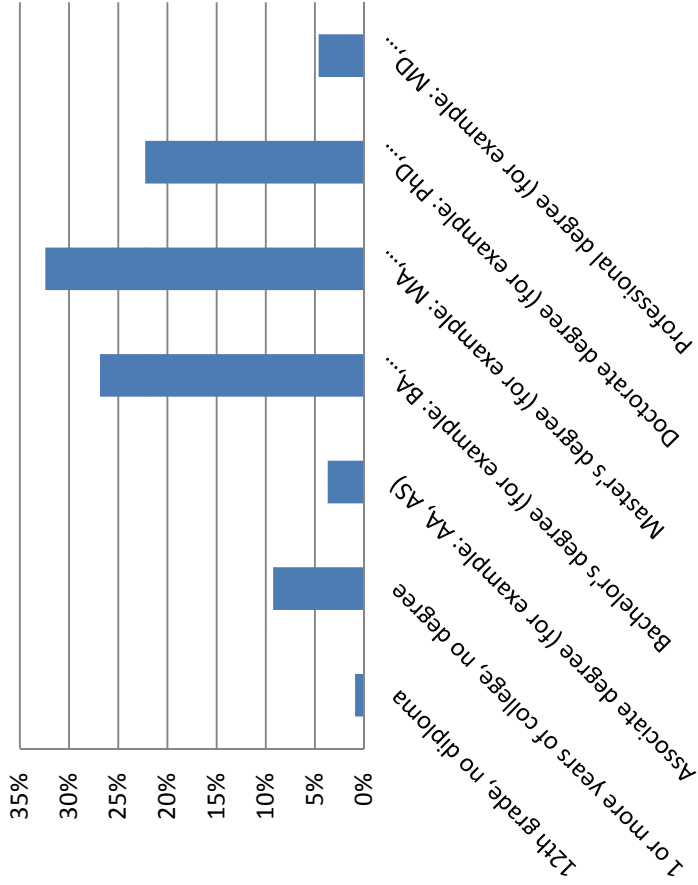
3. Question 689: Education

- Number of responses: 108
- No response: 18
- Skipped question: 2

Responses:

- 12th grade, no diploma (1%)
- 1 or more years of college, no degree (9%)
- Associate degree (4%)
- Bachelor's degree (27%)
- Master's degree (32%)
- Doctorate degree (22%)
- Professional degree (5%)

The highest degree or level of school I have completed is...



59% of respondents have Master's level education or higher.

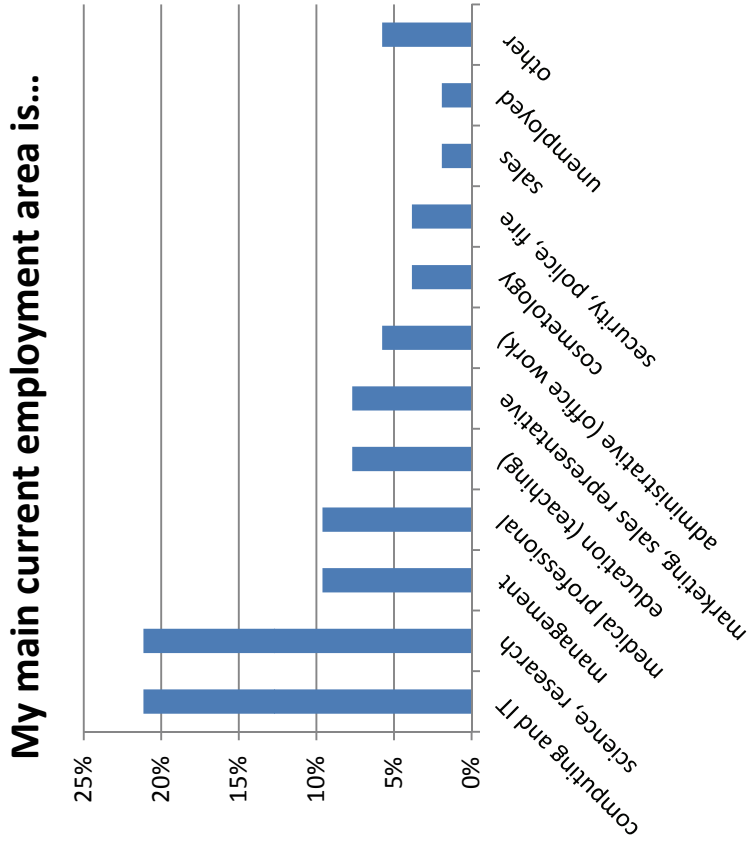
Figure 6. Employment area

4. Question 3472: Employment Area

- Number of responses: 52
- No response: 75
- Skipped question: 1

Responses:

- computing and IT (21%)
- science, research (21%)
- management (10%)
- medical professional (10%)
- education (8%)
- marketing, sales representative (8%)
- administrative (6%)
- cosmetology (4%)
- security, police, fire (4%)
- sales (2%)
- unemployed (2%)
- other (6%)



**Top employment areas are
computing/IT and science/research**

Figure 7. Gender

5. Question 5632: Gender

- Number of responses: 102
- No response: 25
- Skipped question: 1

Responses:

- Female (50%)
- Male (50%)

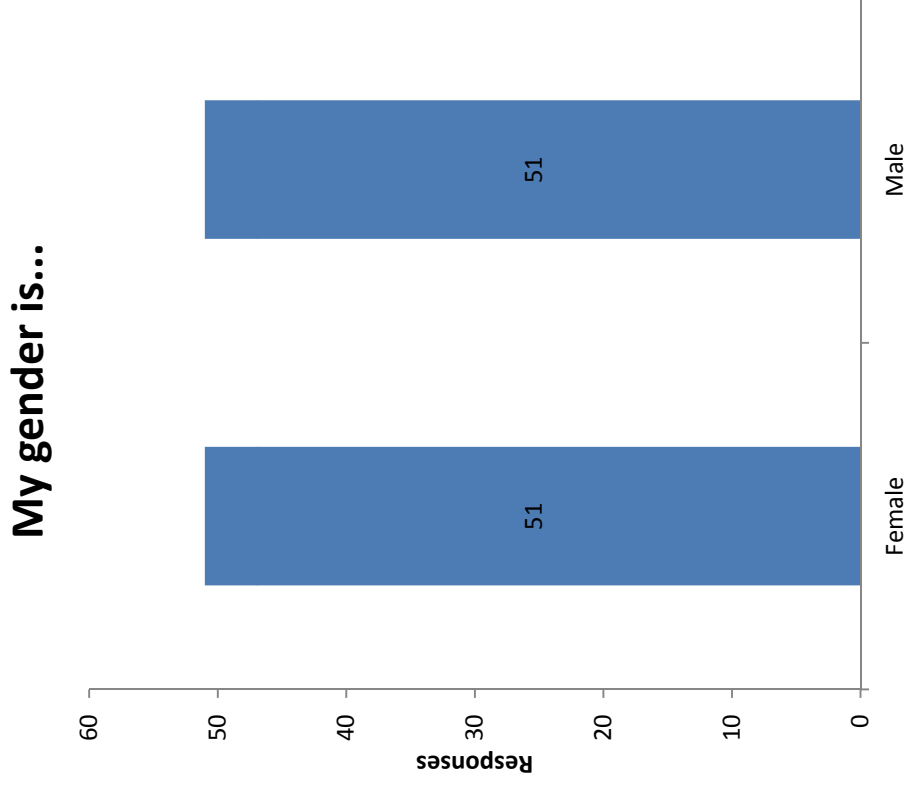


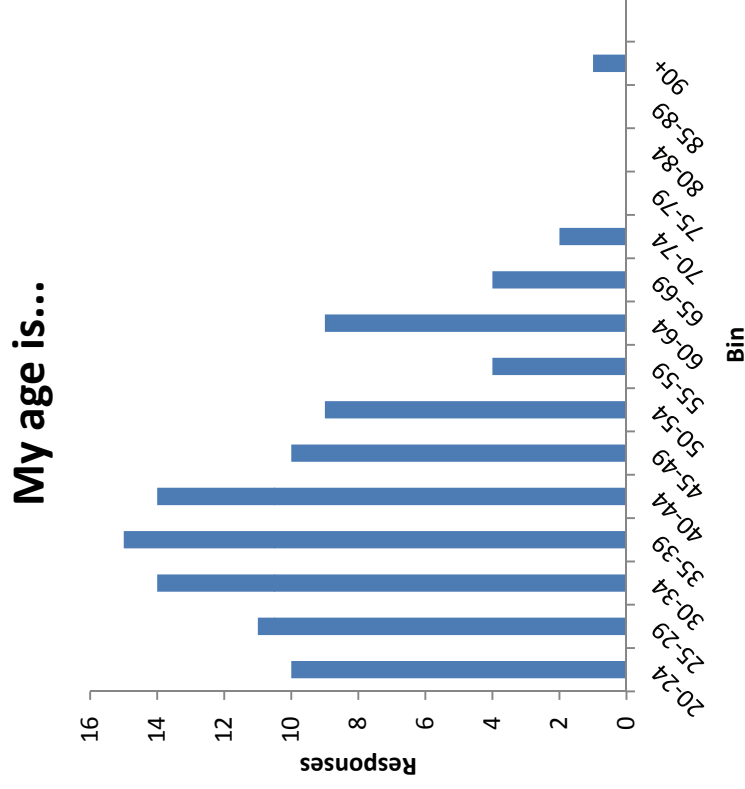
Figure 8. Age

6. Question 12085: Age

- Number of responses: 103
- No response: 25

Responses:

- 20-24 (10%) – 60-64 (9%)
- 25-29 (11%) – 65-69 (4%)
- 30-34 (14%) – 70-74 (2%)
- 35-39 (15%) – 75-79 (0%)
- 40-44 (14%) – 80-84 (0%)
- 45-49 (10%) – 85-89 (0%)
- 50-54 (9%) – 90+ (1%)
- 55-59 (4%)



Age ranges from 20 to 90+
Average age cohort is 40-44.

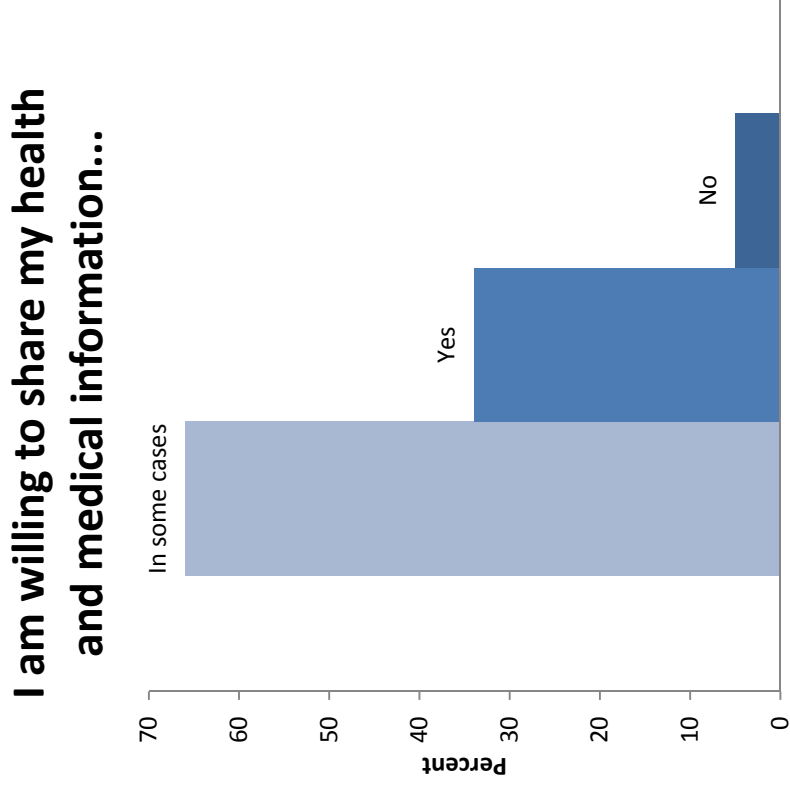
Figure 9. Willing to share...

14. Question 245651: I am willing to share my health and medical information...

- Number of responses: 105
- No response: 23

Responses:

- In some cases (63%)
- Yes (32%)
- No (5%)



When asked about sharing, 95% responded “Yes” or “In some cases.”

Figure 10. Share info with...

12. Question 245521: I am willing to share my health and medical information with...

- Number of responses: 100
- No response: 28

Responses:

- Personal physician or healthcare provider (88%)
- Non-profit research organizations (for example, National Psoriasis Foundation) (84%)
- Family member (83%)
- Universities or academic institution (79%)
- Government (28%)
- For-profit companies (24%)
- Others (23%)
- Insurance companies (14%)

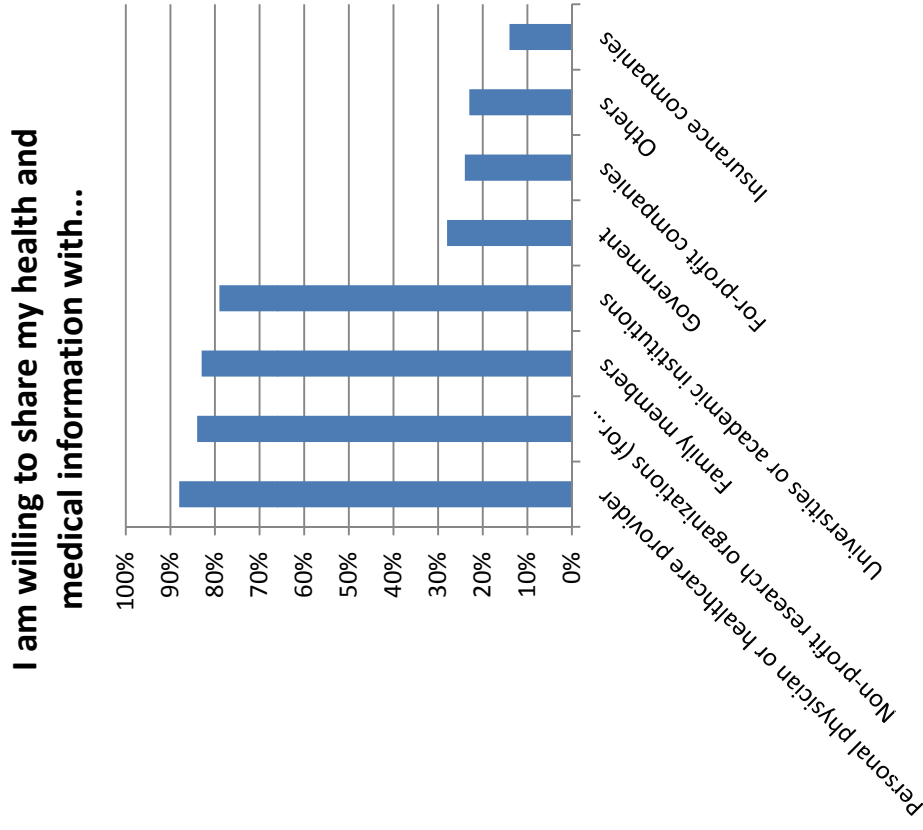


Figure 11. Motivation

11. Question 245411: I am motivated to share my health information for the following reasons...

- Number of responses: 106
- No response: 22

Responses:

- Make new health discoveries (88%)
- Learn more about personal health risks (82%)
- Desire to change current system (73%)
- Health condition (66%)
- Learn more about my ancestry (31%)
- Want something in return (15%)
- Bragging rights (11%)

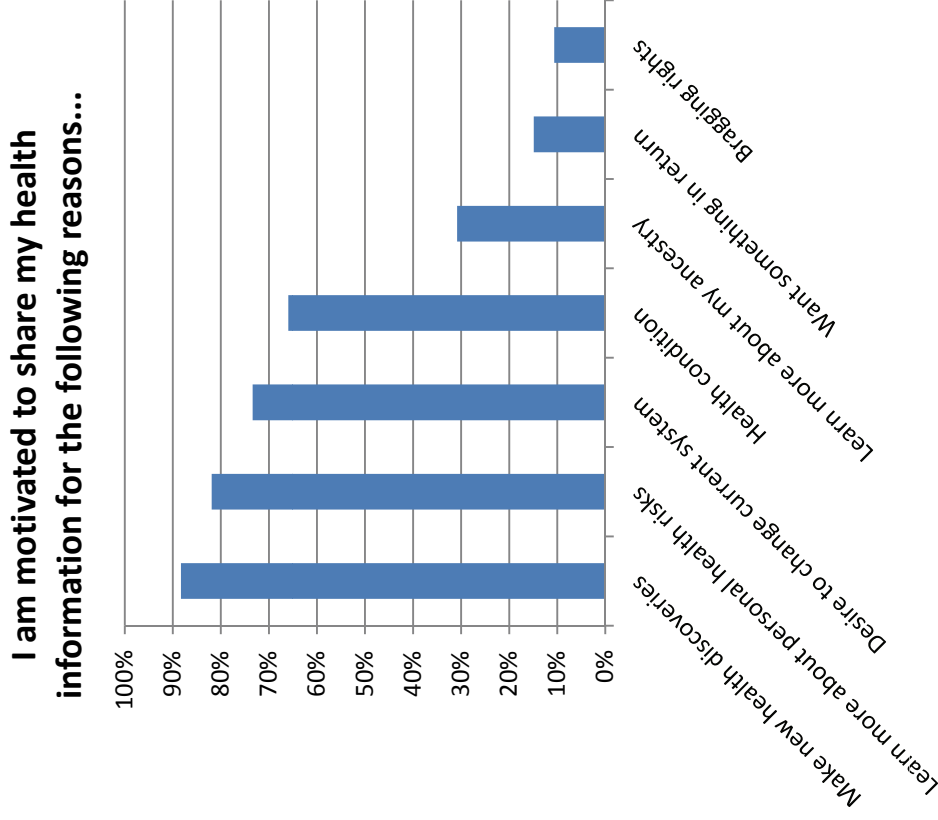


Figure 12. Want to know...

25. Question 246051: Based on the information I share, I would like to know...

- Number of responses: 95
- No response: 33

Responses:

- Actionable things I can do to improve my health (93%)
- My likelihood to develop a disease (86%)
- What others like me are doing to stay healthy (82%)
- My current state of health (81%)
- My health relative to peers or others (71%)
- How my health may affect my children (62%)
- Other (17%)

Based on the information I share, I would like to know...

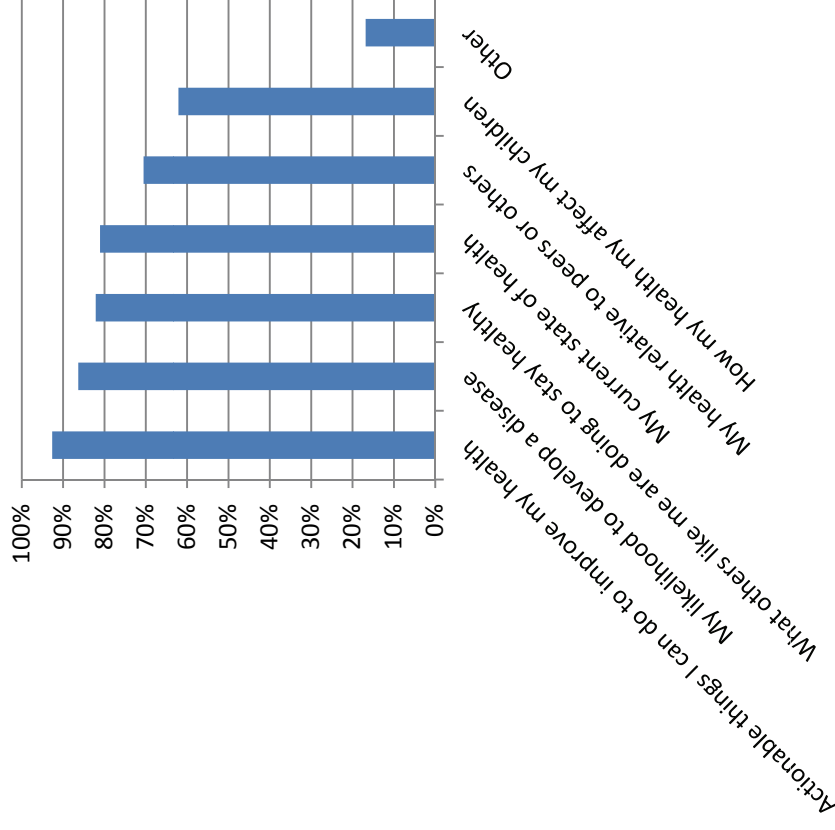


Figure 13. Connect with others

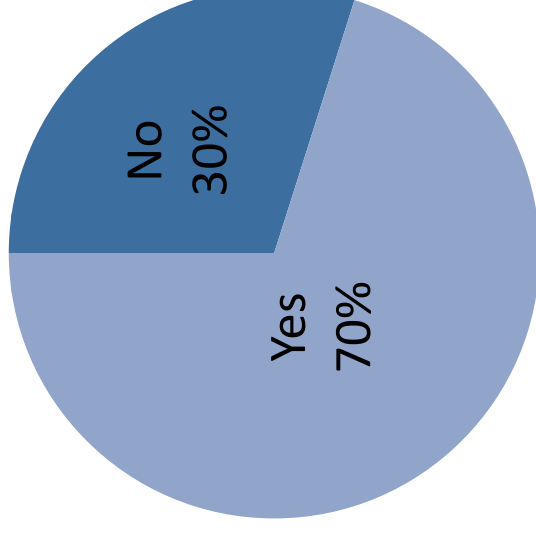
26. Question 246141: After sharing my health and medical information, I would like to connect with other people who have similar health conditions...

- Number of responses: 97
- No response: 31

Responses:

- Yes (70%)
- No (30%)

After sharing my health and medical information, I would like to connect with other people who have similar health conditions...



70% of respondents would like to connect with others who have similar health conditions.

Figure 14. Share identified info

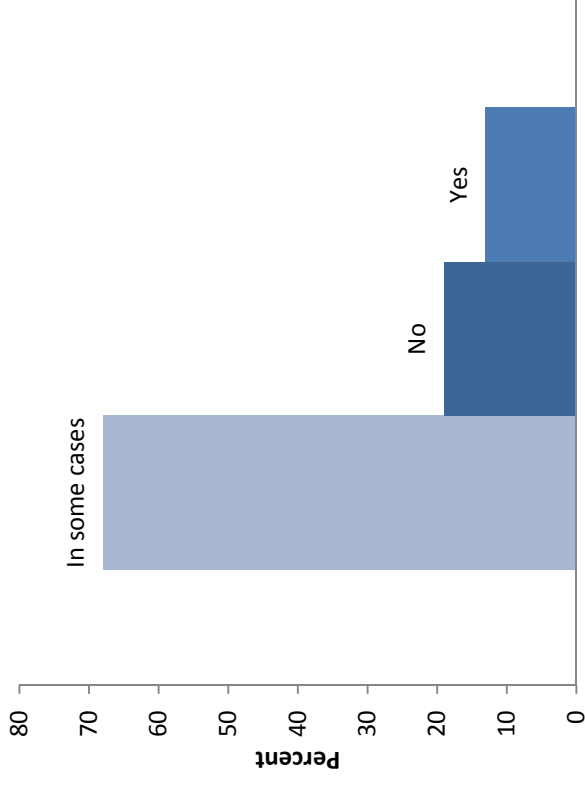
15. Question 245671: I would share my health and medical information even if it were not anonymized...

- Number of responses: 100
- No response: 28

Responses:

- In some cases (68%)
- No (19%)
- Yes (13%)

I would share my health and medical information even if it were not anonymized...



68% would share fully identified information in some cases.

Figure 15. Share irreversibly data

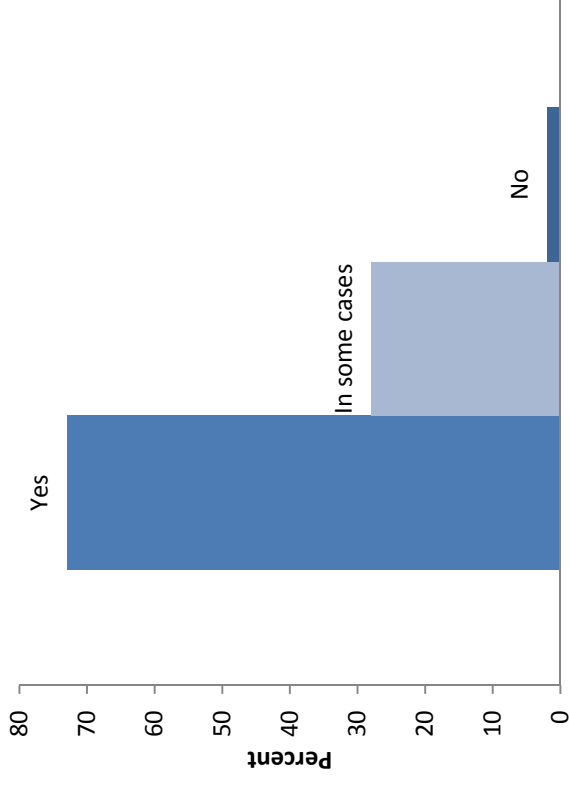
13. Question 245631: I am willing to let researchers use my information if it is irreversibly anonymized...

- Number of responses: 103
- No response: 25

Responses:

- Yes (71%)
- In some cases (21%)
- No (2%)

I am willing to let researchers use my information if it is irreversibly anonymized...



71% are willing to share irreversibly anonymized information.

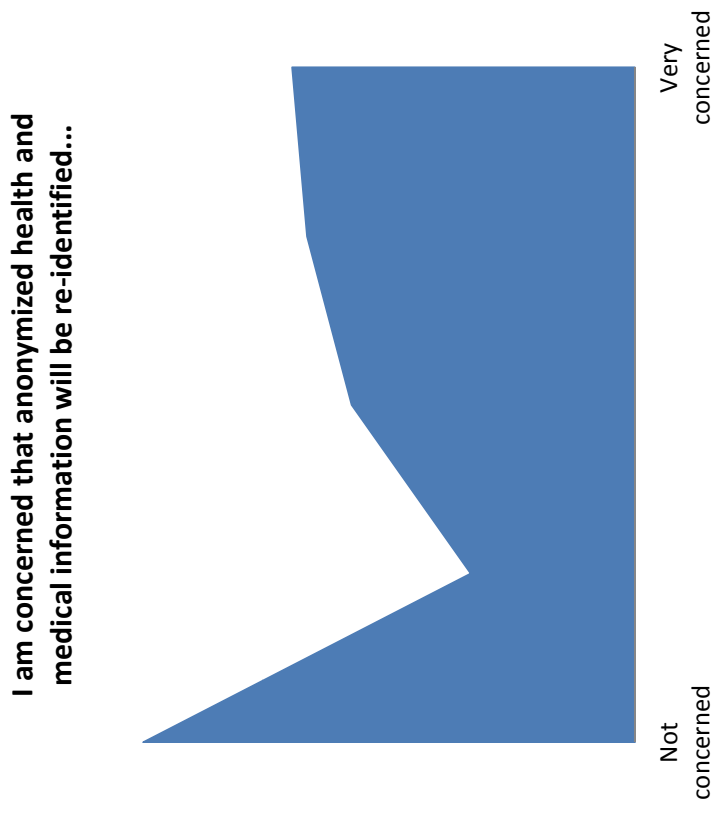
Figure 16. Re-identify concern

18. Question 245781: I am concerned that anonymized health and medical information will be re-identified...

- Number of responses: 108
- No response: 20

Responses:

- Bottom quintile (33%) – Not concerned
- Second quintile (11%)
- Middle quintile (19%)
- Fourth quintile (22%)
- Top quintile (23%) – Very concerned



One-third of respondents are not concerned, and about half are concerned or very concerned about the re-identification of anonymized information.

Figure 17. Sharing data types

7. Question 245051: Under the right circumstances, I would be willing to share the following health and medical information...

- Number of responses: 106
- No response: 22

Responses:

- Diet (88%)
- Exercise (88%)
- Traits (85%)
- Diseases and conditions (81%)
- Genomic data (80%)
- Fitness tracking information (80%)
- Medications (79%)
- Environmental factors (78%)
- Electronic medical records (72%)
- Other (27%)

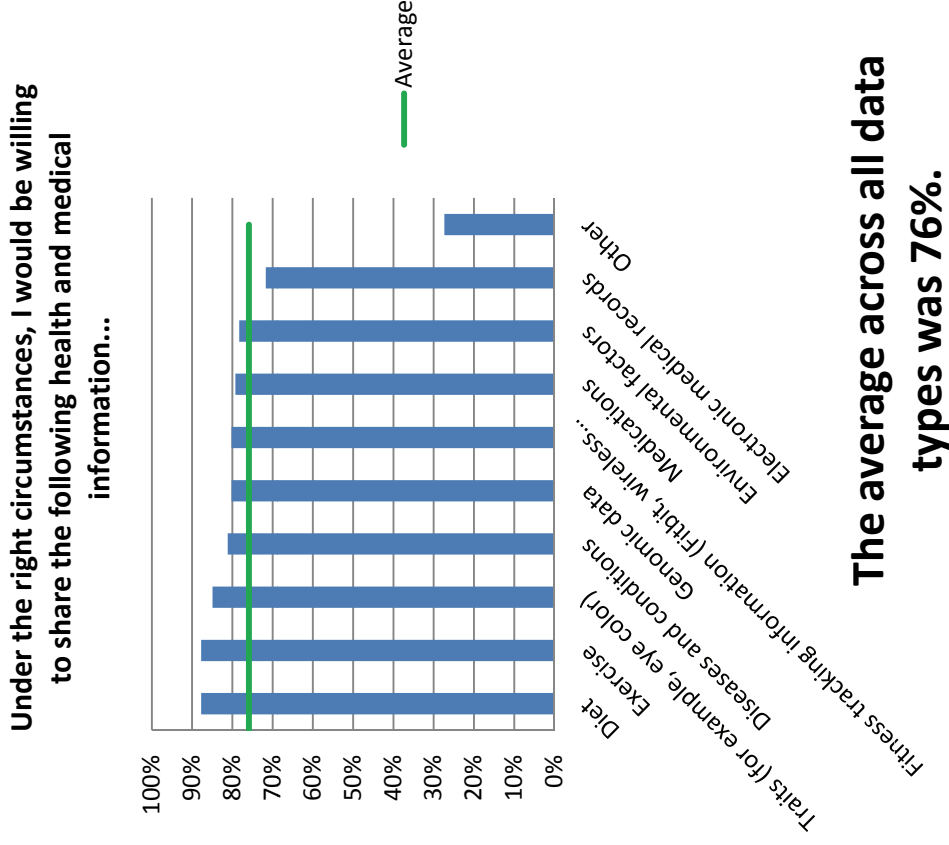


Figure 18. Tracking devices

8. Question 245251: I own one or more health/fitness tracking devices...

- Number of responses: 103
- No response: 25

Results:

- Fitbit or other activity tracking (28%)
- Blood pressure cuff (27%)
- Wireless scale (17%)
- Blood glucose monitor (16%)
- Zeo or other sleep monitoring device (12%)
- Other (18%)

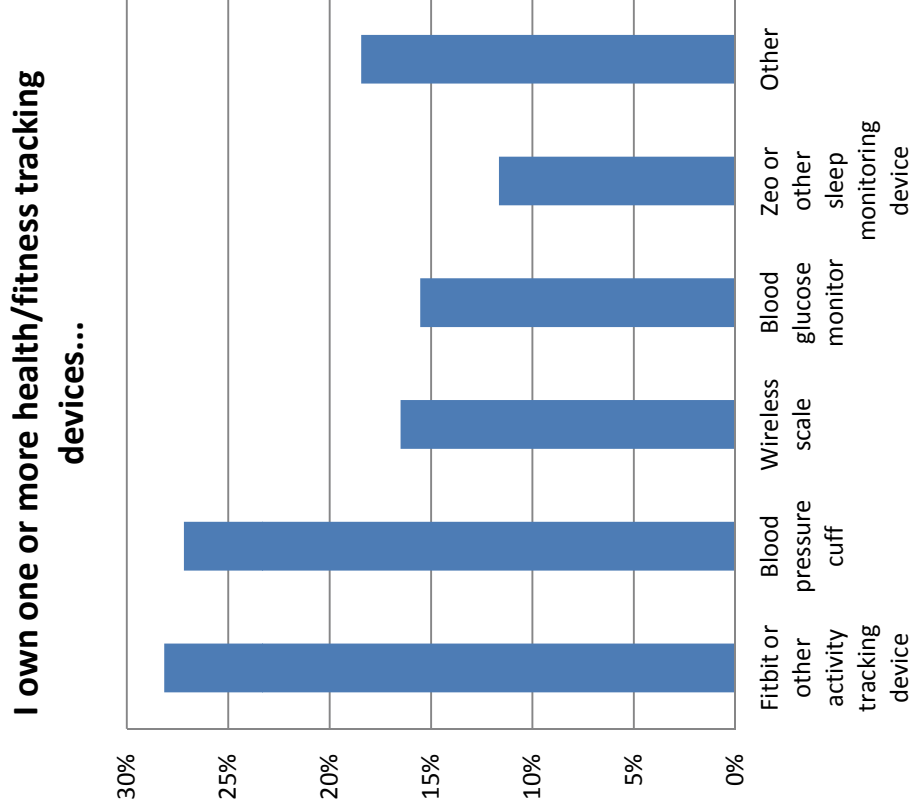
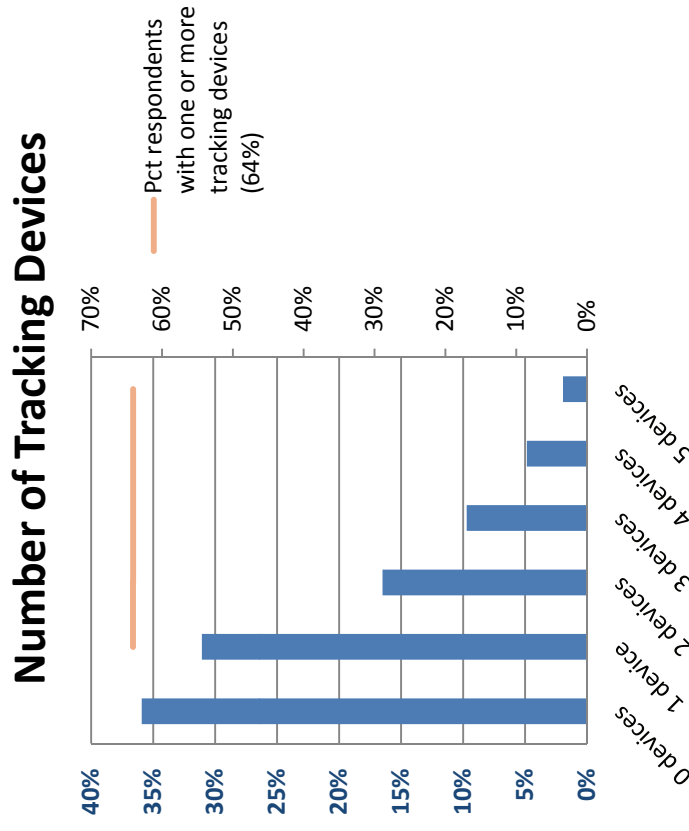


Figure 19. Number of tracking devices

Number of devices owned

- No devices (36%)
- 1 device (31%)
- 2 devices (17%)
- 3 devices (10%)
- 4 devices (5%)
- 5 devices (2%)



64% of respondents reported owning one or more tracking devices.

Figure 20. Genotyping

10. Question 245371: I have been genotyped through a company like 23andMe, Navigenics, Pathway Genomics, etc....

I have been genotyped through a company like 23andMe, Navigenics, Pathway Genomics, etc....

- Number of responses: 106
- No response: 22

Responses:

- No (66%)
- Yes (34%)

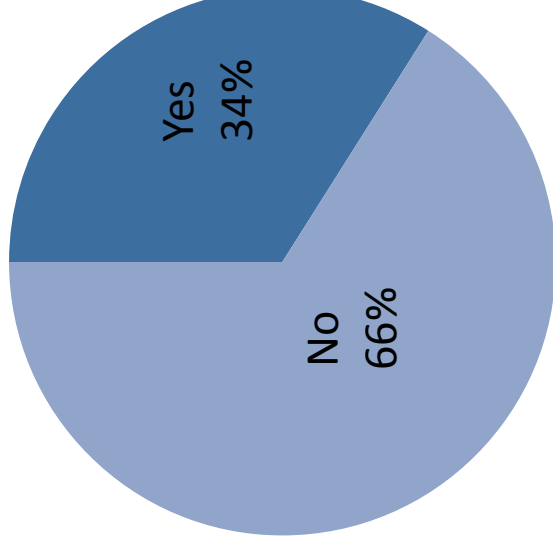


Figure 21. View of doctor

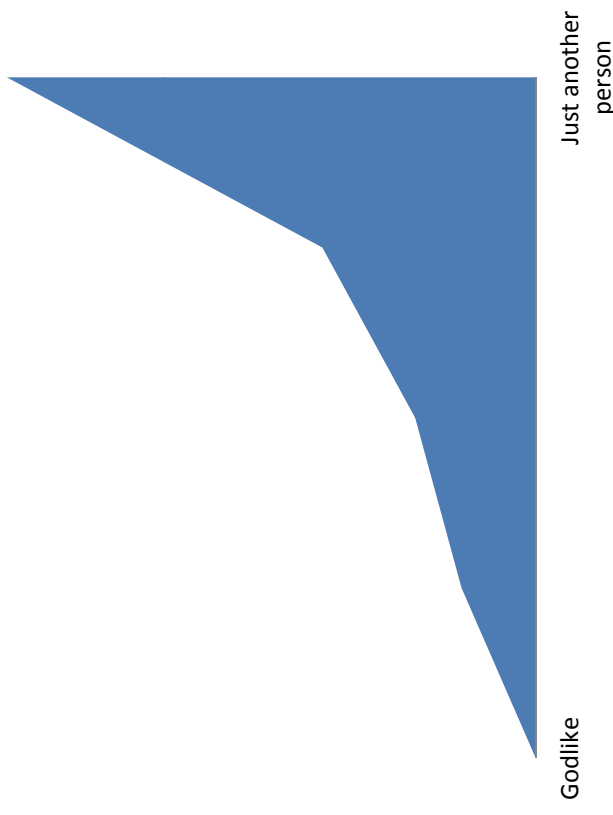
9. Question 245371: I see my doctor as...

I see my doctor as...

- Number of responses: 101
- No response: 27

Responses:

- Bottom quintile (0%) - Godlike
- Second quintile (8%)
- Middle quintile (13%)
- Fourth quintile (23%)
- Top quintile (56%) – Just another person



**Most respondents see their doctor as “just another person.”
(56% in top quintile)**

Figure 22. Doc-recommend sharing

24. Question 246031: I would be more likely or less likely to share my health and medical information for research if my physician told me it was safe...

- Number of responses: 103
- No response: 25

Responses:

- Bottom quintile (9%)
- Second quintile (4%)
- Middle quintile (41%)
- Fourth quintile (17%)
- Top quintile (29%)

I would be more likely or less likely to share my health and medical information for research if my physician told me it was safe...



Most respondents are indifferent, but about 30% are more likely to share if their physicians told them it was safe.

Figure 23. Access control

16. Question 245691: For research purposes, I believe that access to anonymized medical data should be controlled by...

- Number of responses: 100
- No response: 28

Responses:

- Myself (69%)
- Non-profit organizations (45%)
- Universities and academic institutions (38%)
- National databanks (34%)
- Government (25%)
- For-profit companies (6%)
- Insurance companies (3%)

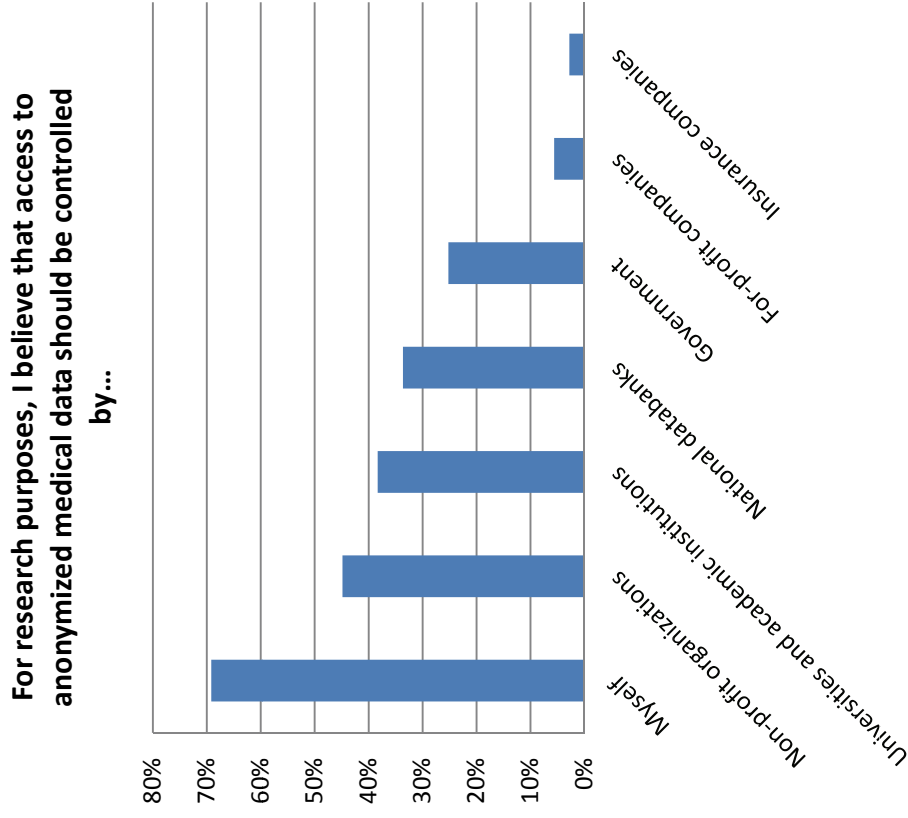


Figure 24. Pay to review

27. Question 246161: After uploading my health and medical information, I would pay one of the following to review my data and provide recommendations...

- Number of responses: 103
- No response: 25

Responses:

- Non-profit organization with recommendations based on scientifically validated algorithms (63%)
- Physician or healthcare provider (59%)
- Genetic counselor (52%)
- For-profit company with recommendations based on scientifically validated algorithms (40%)

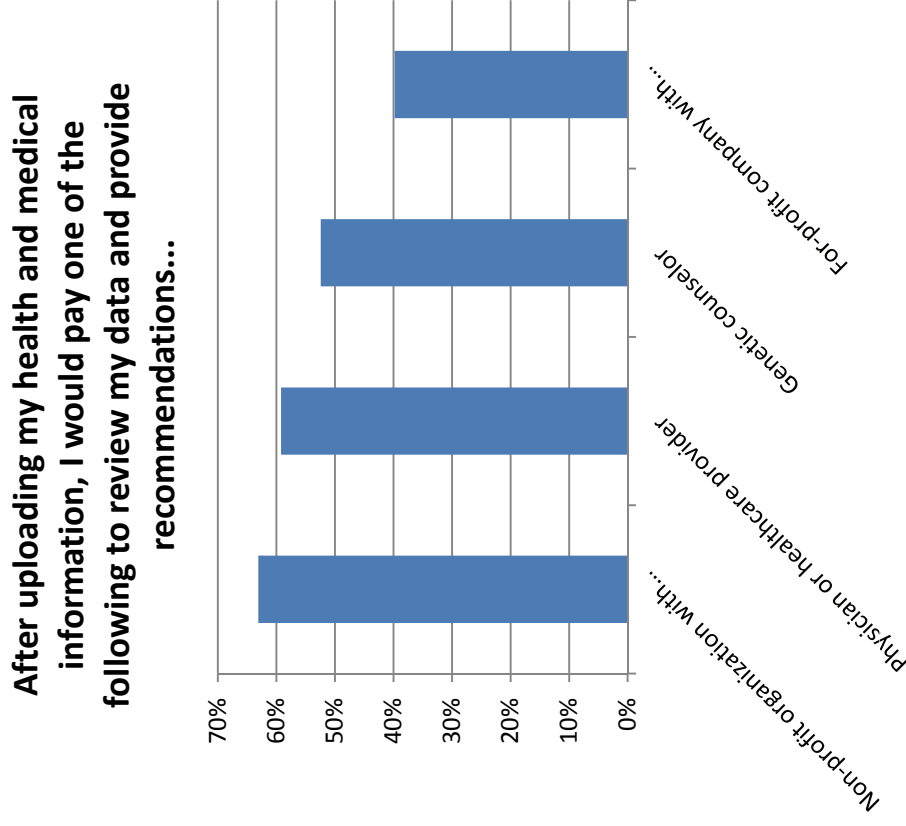


Figure 25. Share with feedback

17. Question 245761: I would be more likely to share my health and medical information if I received personalized recommendations based on discoveries made from my data...

- Number of responses: 105
- No response: 23

Responses:

- Bottom quintile (3%) – Less likely
- Second quintile (4%)
- Middle quintile (15%)
- Fourth quintile (25%)
- Top quintile (53%) – More likely

I would be more likely to share my health and medical information if I received personalized recommendations based on discoveries made from my data...



Respondents are more likely to share if they receive personalized recommendations based on discoveries made from their data. (53% in top quintile)

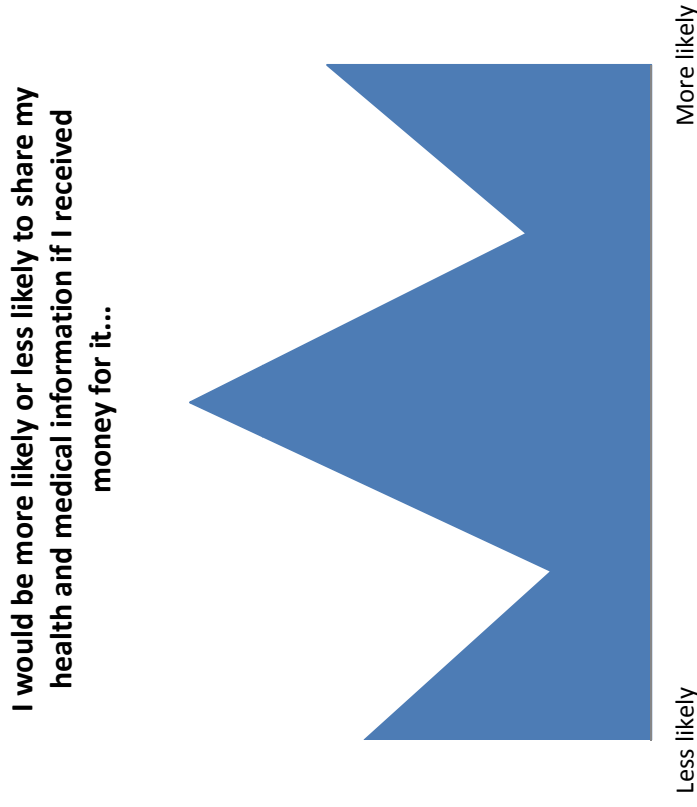
Figure 26. Share for money

23. Question 246011: I would be more likely or less likely to share my health and medical information if I received money for it...

- Number of responses: 104
- No response: 24

Responses:

- Bottom quintile (22%) – Less likely
- Second quintile (8%)
- Middle quintile (36%)
- Fourth quintile (10%)
- Top quintile (25%) – More likely



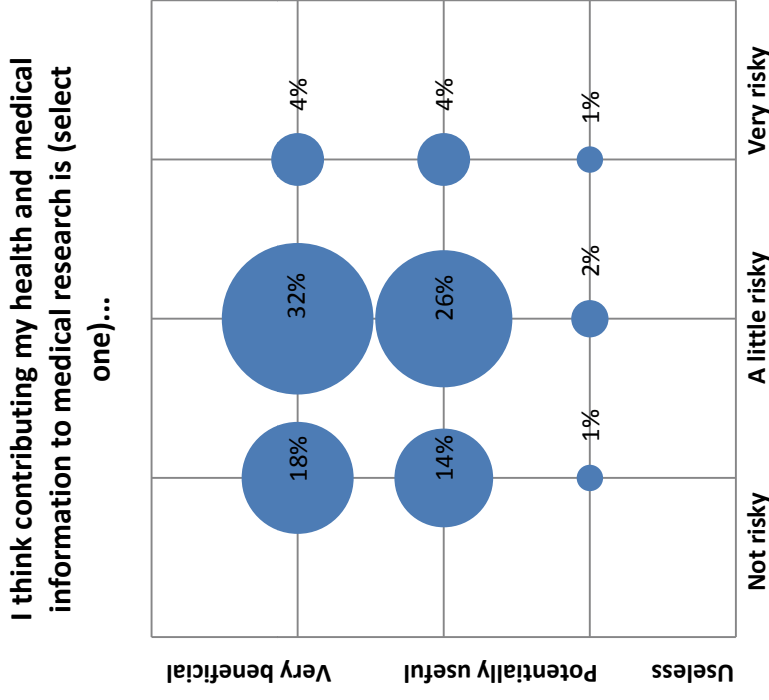
Most respondents are indifferent to receiving money in exchange for sharing. About one-quarter would be less motivated, and one-quarter would be more motivated.

Figure 27. Contribution and risk

21. Question 245901 - I think contributing my health and medical information to medical research is (select one)...

- Number of responses: 102
- No response: 26

Responses: see chart



58% of respondents think that contributing to medical research is a little risky, but potentially or very beneficial.

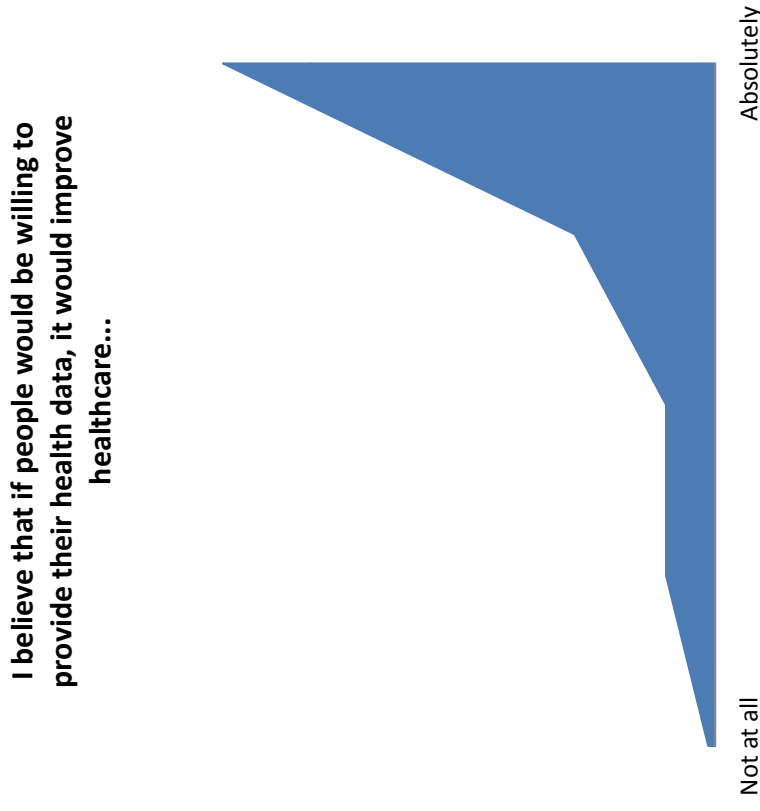
Figure 28. Share to improve

20. Question 245861: I believe that if people would be willing to provide their health data, it would improve healthcare...

- Number of responses: 105
- No response: 23

Responses:

- Bottom quintile (1%) – Not at all
- Second quintile (7%)
- Middle quintile (7%)
- Fourth quintile (19%)
- Top quintile (67%) – Absolutely



Two-thirds of respondents believe it would improve healthcare “absolutely” if people would be willing to provide their data.

Figure 29. Sharing barriers

19. Question 245801: I believe the barriers that prevent people from sharing genomic and medical data for research are...

- Number of responses: 105
- No response: 23

Responses:

- Privacy concerns (85%)
- Lack of awareness of value of contribution (77%)
- Concern about data being used for profit (58%)
- No easy way to share data (45%)
- Other (13%)

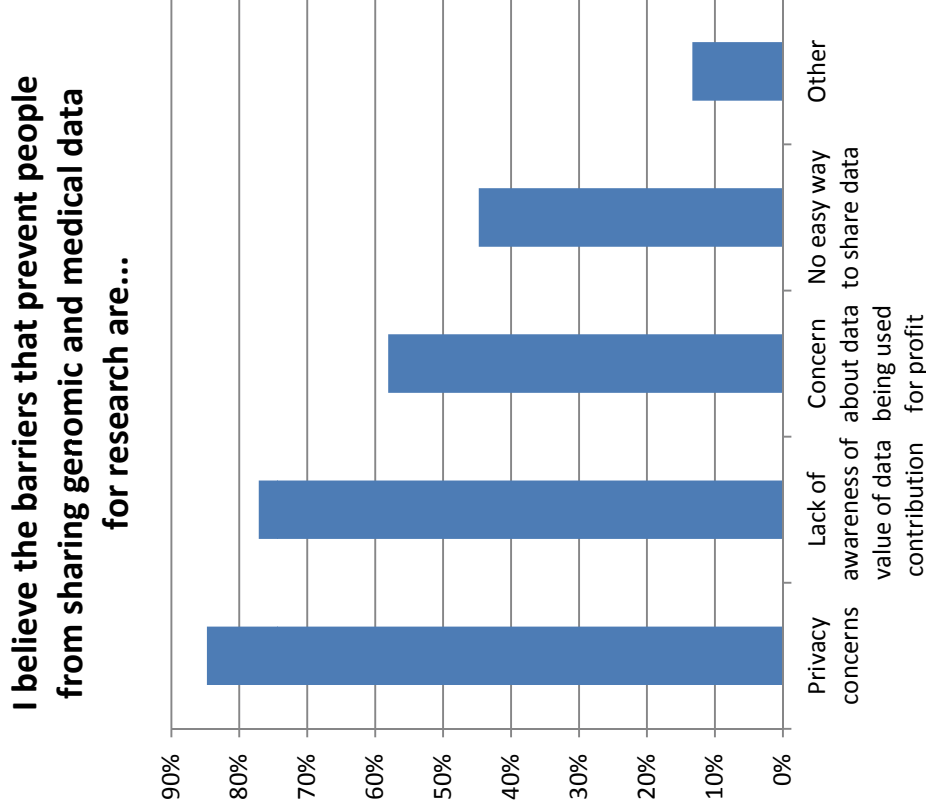


Figure 30. Concerns about sharing

22. Question 245941: My concern with sharing my genomic data is...

- Number of responses: 106
- No response: 22

Responses:

- Insurance discrimination (67%)
- Personal or family privacy (43%)
- Employment discrimination (40%)
- Racial discrimination (11%)
- Other (20%)

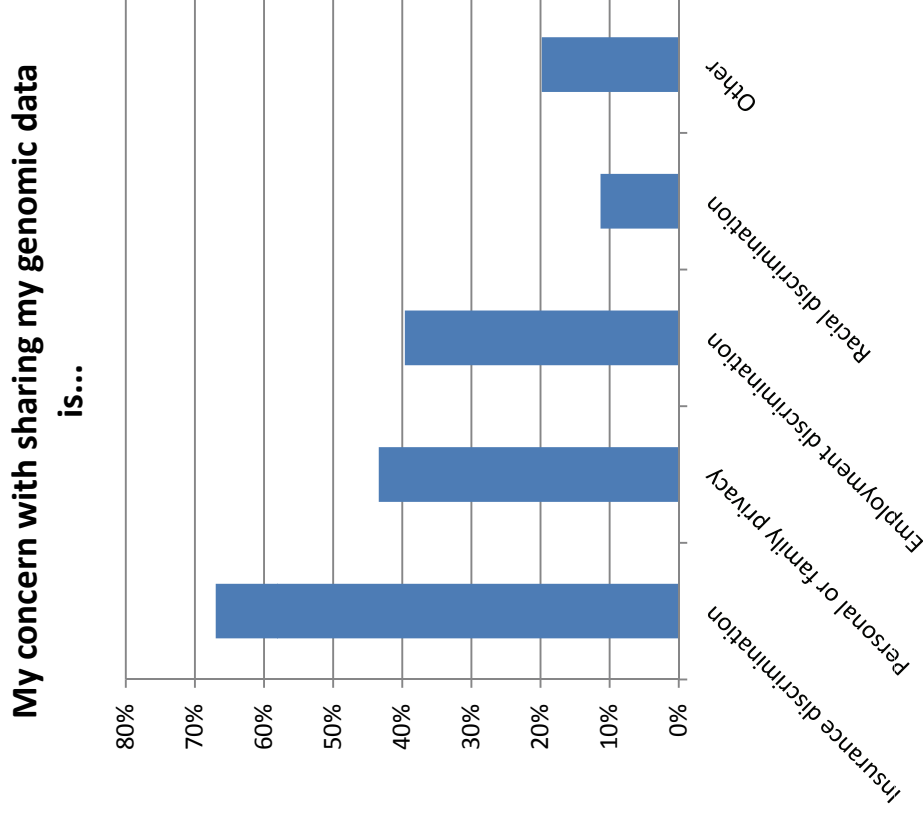


Figure 31. Traitwise Survey Platform



Figure 32. Health Information
Sharing Model

