

Privacy, storage and usage: A look at how older adults view big data in health care

2020 AARP Big Health Data Survey of Adults
Ages 50 and Older

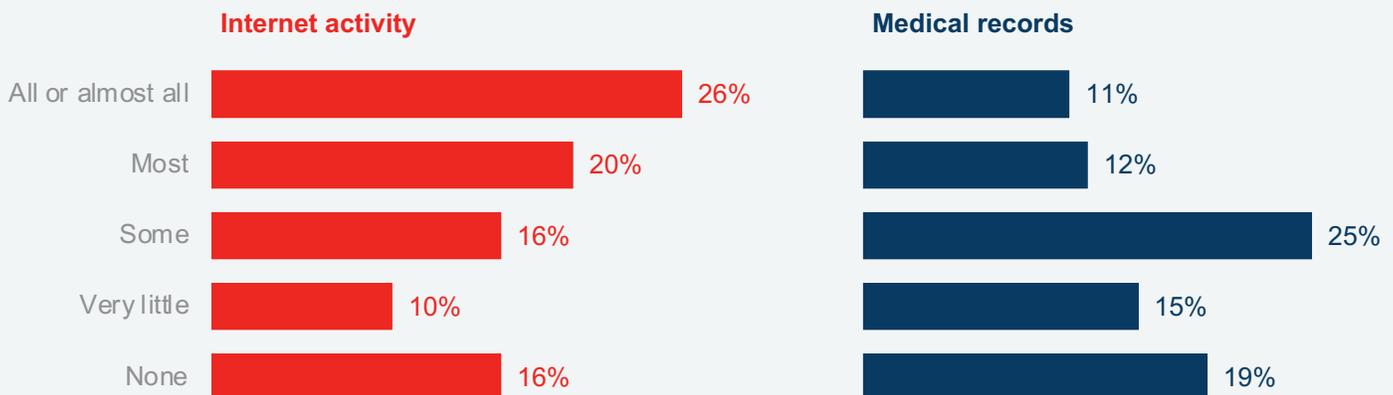


While many older adults think most of their internet activity is being tracked and shared, few believe their personal medical information is shared. Most say data policy transparency is important.

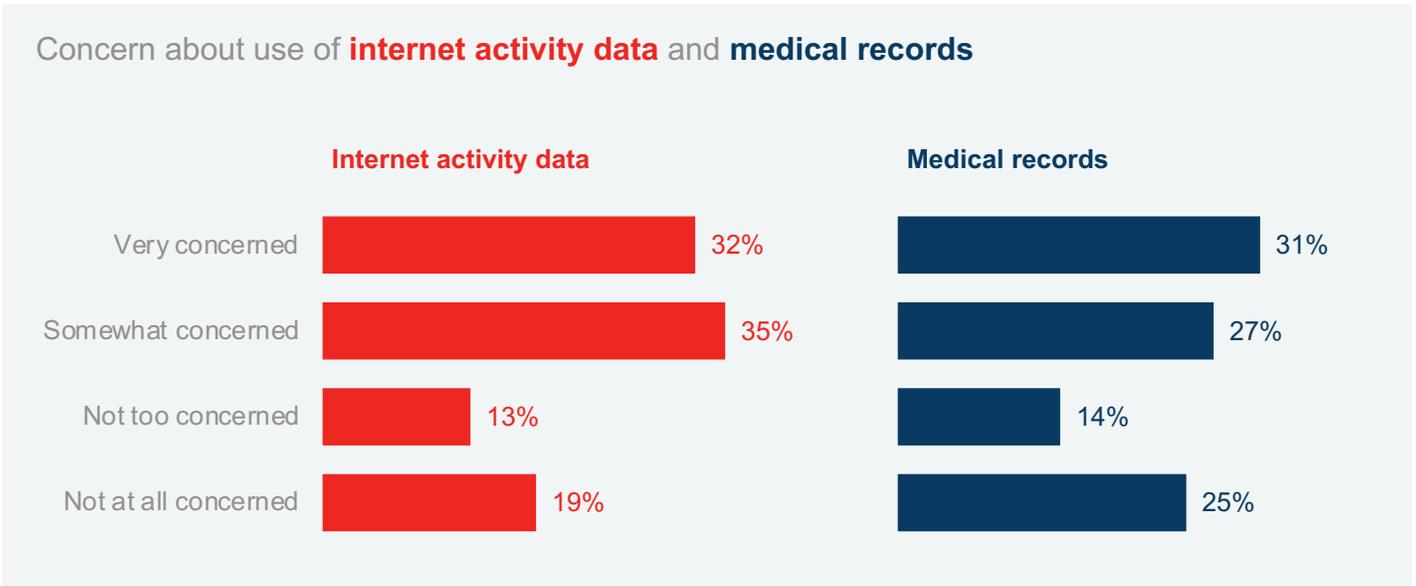
More than two in five (46%) adults ages 50-plus believe most, if not all, of their internet and/or phone activity is tracked by advertisers, technology firms, and related companies. Comparatively, a majority (59%) think only some (25%), very little (15%), or no (19%) information from their medical records is being tracked.

A recent survey on **big health data** shows that **older adults lack knowledge** about **how much personal data is collected, analyzed, and shared.**

Beliefs about the amount of **internet activity tracked** and **medical records shared**

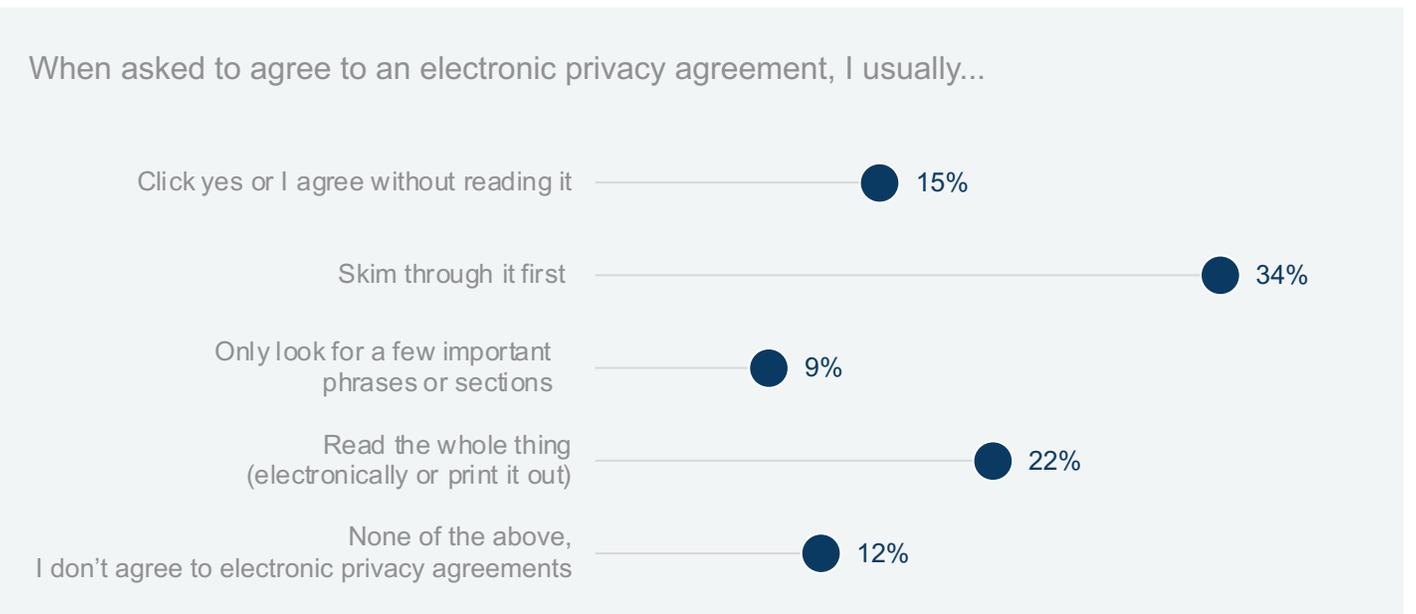


A majority say they are concerned (either very or somewhat) about the use of their internet activity data (67%) and their medical records data (58%). In conjunction with this concern, most say organizations should be transparent about data privacy policies. In a recent AARP Privacy and Personal Data survey, most older adults said organizations' transparency about data privacy and security is important (92%,) and websites' transparency about the information that is collected when users are on the page (e.g., via cookies) is important (89%).



Despite their concern about the use of their personal data, very few older adults read electronic privacy agreements.

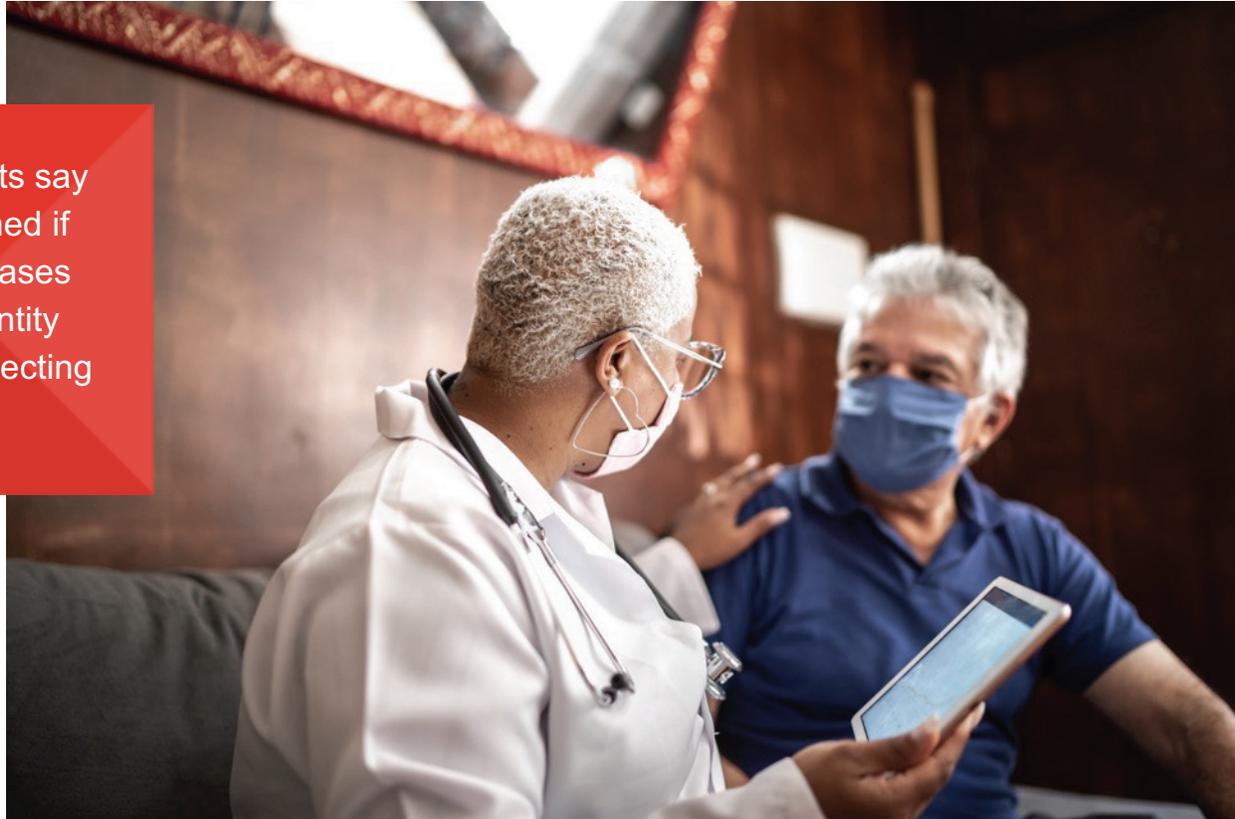
Only about one in five (22%) older adults say they actually read an entire electronic privacy agreement. In about half of the cases, older adults agree to an electronic privacy agreement without reading it (15%) or only skimming through it first (34%). According to the AARP Privacy and Personal Data survey, between 32% and 45% older adults say these policies from various industries (e.g., tech, healthcare, insurance) are not easy to understand, which could explain why most don't read them.



Sharing specific health-related information raises concern.

When asked about their level of concern if certain types of health-related information were shared with an entity other than the one collecting it, more than half (54%) say they would be concerned if their medication purchases were shared. More than two in five (44%) say they would be concerned if information about their heart rate were shared and two in five (40%) say they would be concerned if information about their weight loss, sleep patterns, and/or food purchases were shared.

Over half of older adults say they would be concerned if their medication purchases were shared with an entity other than the one collecting the information.



Very or somewhat concerned if data was shared about...

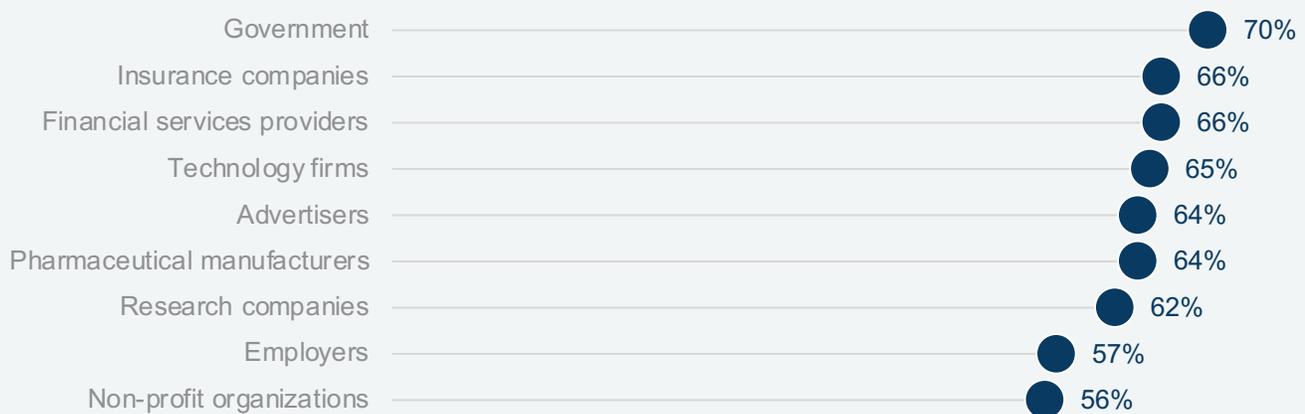


Trust is an issue: A majority of older adults would be concerned if companies or their employer collected and analyzed their health data.

The majority say they would be concerned (very or somewhat) if any of the entities listed in the survey collected and analyzed their health data. Seven in ten (70%) say they would be concerned if the government collected and analyzed their health data, and two-thirds (66%) would be concerned if insurance companies and/or financial companies collected and/or analyzed their health data.

To be considered trustworthy regarding data privacy and security, most older adults say the company must be **transparent** about what data is collected and allow customers to **be able to control** what data is collected and how it is used.

Very or somewhat concerned if data was collected and analyzed by...



This concern indicates a lack of trust. According to the AARP Privacy and Personal Data survey, nearly all older adults ages 50+ believe in order for an organization to be considered trustworthy regarding their data privacy and security, they must adopt the following policies:

91%



Being transparent in what data is collected and why

91%



Allowing customers to control what data is collected and how it is used

91%



Allowing customers to “opt out” or take steps to prevent collection of personal data

Most say potential risks of personal data collection in general outweigh possible benefits.

Whether they actually read privacy agreements or not, most older adults say the risks of personal data collection outweigh any possible benefits. Nearly six in ten (57%) say the potential risks of companies collecting data outweigh the possible benefits, while three in ten (29%) say the benefits would outweigh the risks. About one in seven (14%) isn't sure which statement comes closest to their thoughts on the matter.

57% agree with the statement: *"The potential risks of companies collecting data about me outweigh the benefits I get."*



29% agree with the statement: *"The benefits I get from companies collecting data about me outweigh the potential risks."*



Similarly, more say big health data will erode privacy rather than enable better diagnoses.

When asked about big health data specifically, a slight majority (54%) say they agree with the statement outlining possible problems with collecting personal health data, such as the erosion of privacy. One-third (33%) agree with the statement outlining possible benefits, such as faster research and cures. Another 13% say they aren't sure which statement comes closest to their thoughts on the matter.

For this study, we defined big health data as very large databases that contain information from health care providers as well as data from stores where people shop and apps and websites that track people's sleep, diet, and exercise habits.

54%
Agree

"The collection, sharing, and use of big health data could erode our privacy. We have little control over the data and it can be sold without our consent. It could be used by entities for surveillance or discrimination, rather than to promote well-being."

33%
Agree

"Increased the use and sharing of data could enable better diagnoses more targeted prevention and treatments, faster research and cures, the creation of new tools to help us make healthier choices, and economic growth from the creation of health data business."



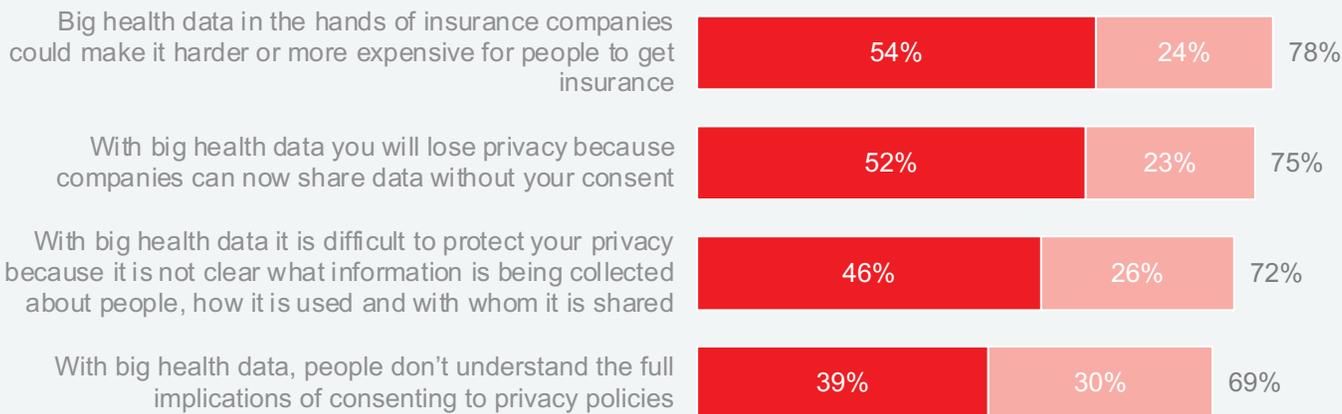
Many older adults are concerned that the use of big health data may negatively impact people on a personal level such as making it harder for people to get insurance.

Older adults are concerned that big health data use could affect access to insurance and overall privacy.

More than seven in 10 older adults say they are either very or somewhat concerned that the use of big health data may negatively impact people on a personal level. The vast majority (78%) are concerned that the use of big health data may limit access to insurance and three out of four (75%) worry about companies using their data without their consent.

Concerns regarding the use of big health data

■ Very concerned ■ Somewhat concerned



Possible benefits: Some older adults are concerned that restricting big health data may curtail disease prevention and cures.

Conversely, many older adults also say they are either very or somewhat concerned that restricting the use of big health data may inhibit the management of public health, such as preventing the development of better ways to avert outbreaks (59%) and cost-effective treatments (56%). About half believe restricting the use of big health data could prevent the development of better cures and treatments for diseases (53%) and/or slow the development of products and services that could help them better manage their health (52%).

Most older adults are concerned that restricting the use of big health data may negatively impact national healthcare management such as preventing the development of better ways to avert outbreaks.



Concern regarding restricting the use of big health data

■ Very concerned ■ Somewhat concerned



Implications

We are in the middle of a data collection and usage revolution. While many argue that more data is useful and making data accessible to a wider array of entities may yield important results, some point out potential hazards, especially related to the handling of medical data. Medical offices collect health-related data, but so do a variety of devices, websites, and applications. These big health data are being generated, collected, analyzed, shared, and sold with little-to-no regulation or oversight—and certainly without the consumers’ knowledge.

The objective of this survey was to garner opinions, attitudes, and experiences of adults ages 50-plus relating to internet usage/privacy and big health data concepts. While the vast majority of older adults are not aware of the term “big health data,” many are concerned about how companies use data once they are collected. When provided with a definition of big health data, most say concerns outweigh possible benefits; some say they are also concerned that in some cases, restricting the use of big health data may negatively impact the nation. The vast majority of older adults say they are concerned that the use of big health data may negatively affect people on a personal level, such as limiting access to insurance and companies using their data without their consent.

Health care providers and policymakers must ensure that policies regarding data collection and usage are transparent. Older adults demand easy-to-understand information that enables them to make informed decisions about how their personal health data is collected and used.

Methodology

The AARP Big Health Data survey was conducted via telephone (37% cell phone) by American Directions Group with sample targeting people ages 50 or older. The sample of 800 included an oversample of African American and Hispanic/Latino respondents. The interviews were conducted in English and Spanish, February 4–25, 2020. The margin of error for the national survey is ± 3.46 percent.

The AARP Privacy and Personal Data survey was conducted online by Magid with 2,000 respondents ages 50+. The interviews were conducted December 1–11, 2020. The margin of error for the national survey is ± 2.20 percent.



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