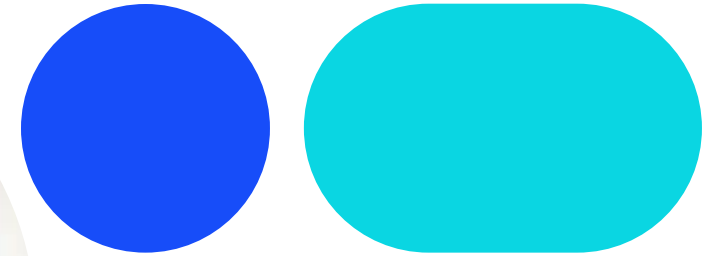
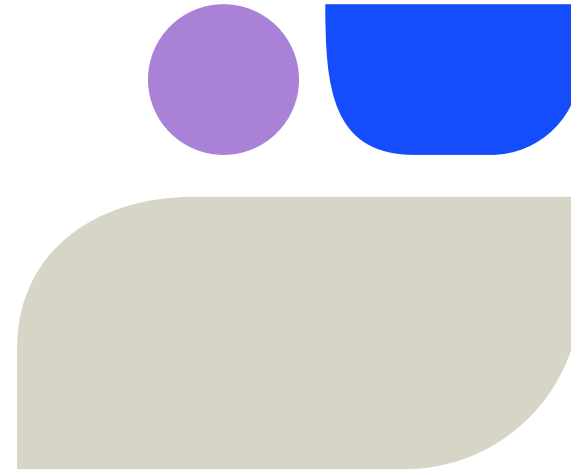


Understanding, Access and Use of Health Information in America

An AHIMA Foundation Study

OCTOBER 2021



Introduction

At AHIMA Foundation, we believe in a future where health information serves people, and where better health outcomes are powered by health information for all.

We launched our Health Literacy for Health Equity initiative to draw attention to the issue of limited health literacy and its associated poor outcomes, especially in underserved communities.

This survey was conducted as a first step to understanding consumer behaviors and identifying solutions that empower consumers with information so they can make more informed decisions about their care.

We encourage you to use and share these findings to inform important discussions around health literacy for health equity. Together, we can help people take control of their health, and improve health outcomes for all.

Sincerely,



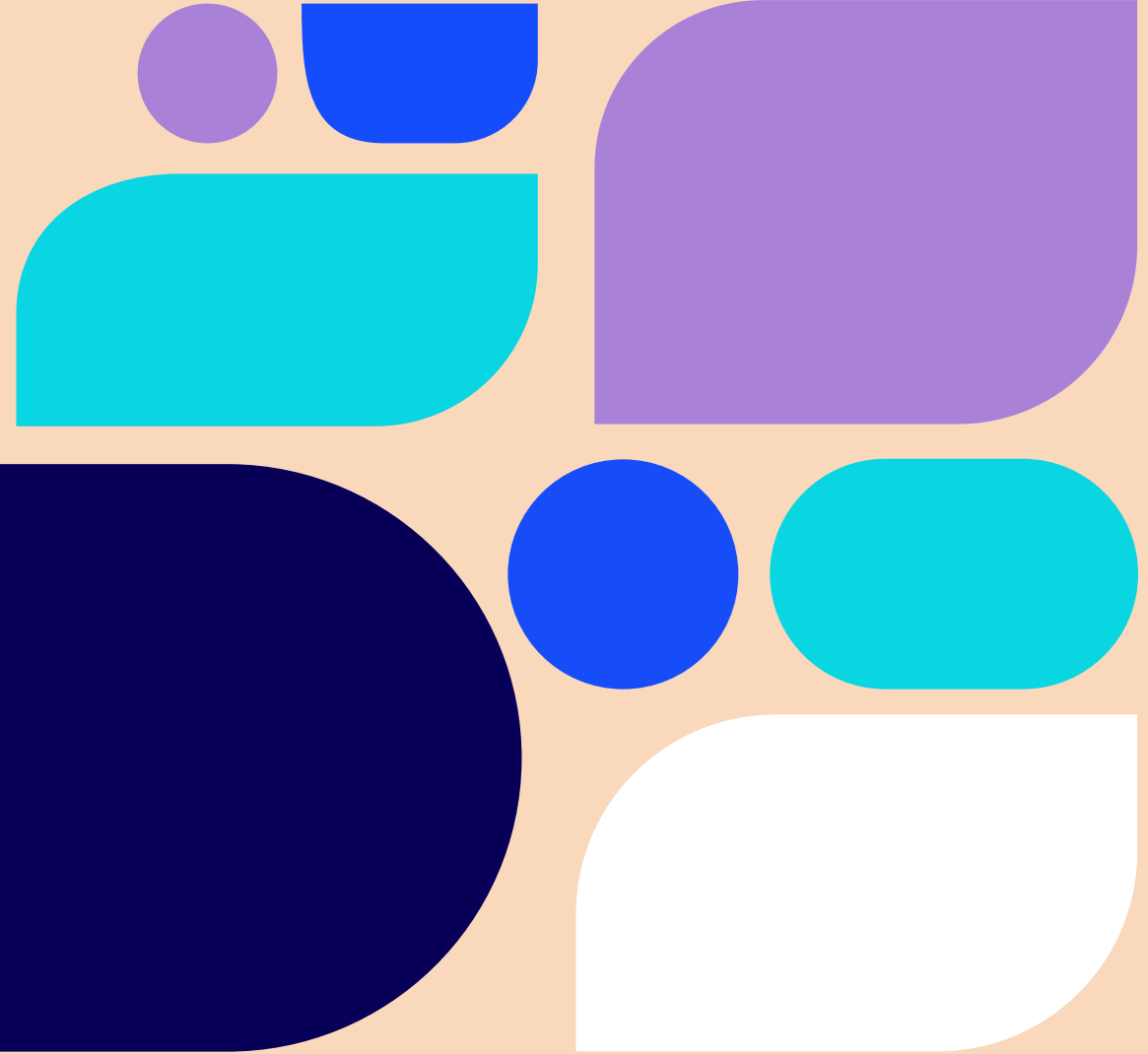
Anisa Tootla
Executive Director
AHIMA Foundation



As an initial response to these findings, AHIMA Foundation has developed easy-to-access [tools and resources](#) in English and Spanish to help consumers access, understand and use their health information with confidence.

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Executive Summary

Communication is key for any relationship and especially true for the relationship between doctor and patient. According to a recent study* commissioned by AHIMA Foundation and conducted by Kelton Global, a Material company, there is a clear disconnect in the information being shared and understood when patients and doctors are together. A majority of Americans report they aren't fully grasping the information discussed with their health care provider, leaving many confused and unsure of how to proceed. This is also true among caregivers who express concern about their loved ones' understanding and ability to access important information about their own health. This communication breakdown prompts many patients and caregivers to turn to other resources, like the Internet, to fill in the holes and take their health management into their own hands. While millions report that they've found

success going this route, many are lacking a key piece of the health management equation: access to and an understanding of their personal medical information and records.

In fact, millions of Americans have difficulty accessing their information and even question the security of their data. It's critical that Americans are able to retrieve their medical information. Getting a whole picture of their health would produce positive outcomes and allow Americans to feel confident in their understanding of their health, their ability to better manage their health, and to trust their doctor's recommendations.



*a survey to 1,059 nationally representative American adults, ages 18+

Our Study Uncovered the Following Key Findings:

1

A majority of Americans don't fully grasp the information discussed with their doctor during visits, leaving many in the dark about their health

2

Americans trust the Internet to strengthen their grasp on their health

3

Medical records are a key component of health management, but millions of Americans have difficulty accessing their information and question the security of their data





1



A majority of Americans don't fully grasp the information discussed with their doctor during visits, leaving many in the dark about their health

Many Americans struggle with having a clear picture of their health. 3 in 4 (76%) – or 187 million* – Americans report that they do not leave their doctor's office on a positive note, including disappointment in the level of Q&A they have with their doctor, their confusion about their health, and their need to do more research.

For many, there seems to be a communication breakdown when they are with their health care provider. Nearly 1 in 4 (22%) Americans confess that they do not feel comfortable asking their doctor certain health questions.

And this lack of communication can have a detrimental impact on their ability to have a strong grasp on their health. In fact, many are unable to have the proper dialogue and report that they sometimes leave the appointment without getting clear answers to their questions (24%) or that they didn't have the opportunity to ask any questions at all (17%).

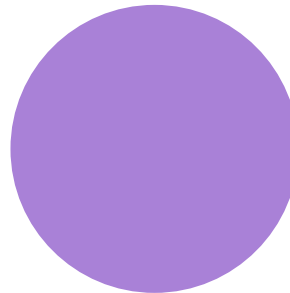
- Caregivers are more likely than their counterparts who are not caregivers to feel they do not get clear answers to their questions (29% vs. 20%) or to feel they didn't have the opportunity to ask questions (22% vs 13%).



*Extrapolated from 246,324,983 Americans aged 18+ (Source: U.S. Census Bureau, Current Population Survey 2018)



Nearly
2/3 of Americans are not extremely confident in their understanding of the health information they discuss with their doctor



After these visits, many are left feeling confused and unsure of the information they were given. Nearly 2 in 3 (62%) Americans are not extremely confident in their understanding of the health information they discuss with their doctor.

In fact, many don't understand all the medical information their doctor provides (24%) – or even remember it immediately following a visit (31%).

Perhaps this is why 15% – or nearly 37 million* – Americans admit they sometimes feel more confused about their health than they did before their appointment.

*Extrapolated from 246,324,983 Americans aged 18+ (Source: U.S. Census Bureau, Current Population Survey 2018)

And these feelings are not isolated to how they feel about their own health; many have concerns about the health of the loved ones under their care. More than 2 in 5 (43%) Americans are caregivers, meaning they are solely or partially responsible for someone else's health and medical needs, such as a parent, child, loved one, or friend. Among them, 91% play an active role in managing their loved one's health.

Millennials (65%) and Gen Xers (50%) are significantly more likely than Gen Z (39%) and Boomers (20%) to be a caregiver.



91% of caregivers play an active role in managing their loved one's health

Most have concerns about their loved ones' ability to manage their own health. While most (84%) believe doctors are providing enough information to ensure that they are able to manage the health of the person under their care, it is not without its challenges.

For starters, many worry about the lack of communication. In fact, many don't agree that the doctor can communicate with the patient if they are unavailable (38%) or that their loved one can communicate independently with their doctor on any questions regarding their medical and health information (34%).

Others worry about a lack of understanding and accessibility to critical health information. More than 2 in 5 (43%) caretakers don't feel their loved one is able to understand all of their medical and health information independently. And about 1 in 3 (31%) don't believe the health and medical information of the person they care for is easily accessible to them.

Caregivers don't agree that...

Their loved one can communicate independently with their doctor on any questions regarding their medical and health information

43%

Their loved one is able to understand all of their medical and health information independently

43%

The doctor can communicate with their loved one in their absence

38%

The health and medical information of their loved one is easily accessible

31%

2

Americans trust the Internet to strengthen their grasp on their health



Many need to do their own digging to make sense of their doctor's counsel. More than 2 in 5 (42%) Americans report they research their doctors' recommendations to understand them better after an appointment.

- Caregivers are significantly more likely than their counterparts who do not provide care to feel confused after appointments (20% vs. 11%).
- Caregivers are more likely than their peers who are not caregivers to research the doctor's recommendations following an appointment (47% vs. 38%).
- Younger generations are more likely than older generations to report feeling confused after their doctor visits (Gen X 28%, Millennials 19% vs. Gen X 13%, Boomers 9%).



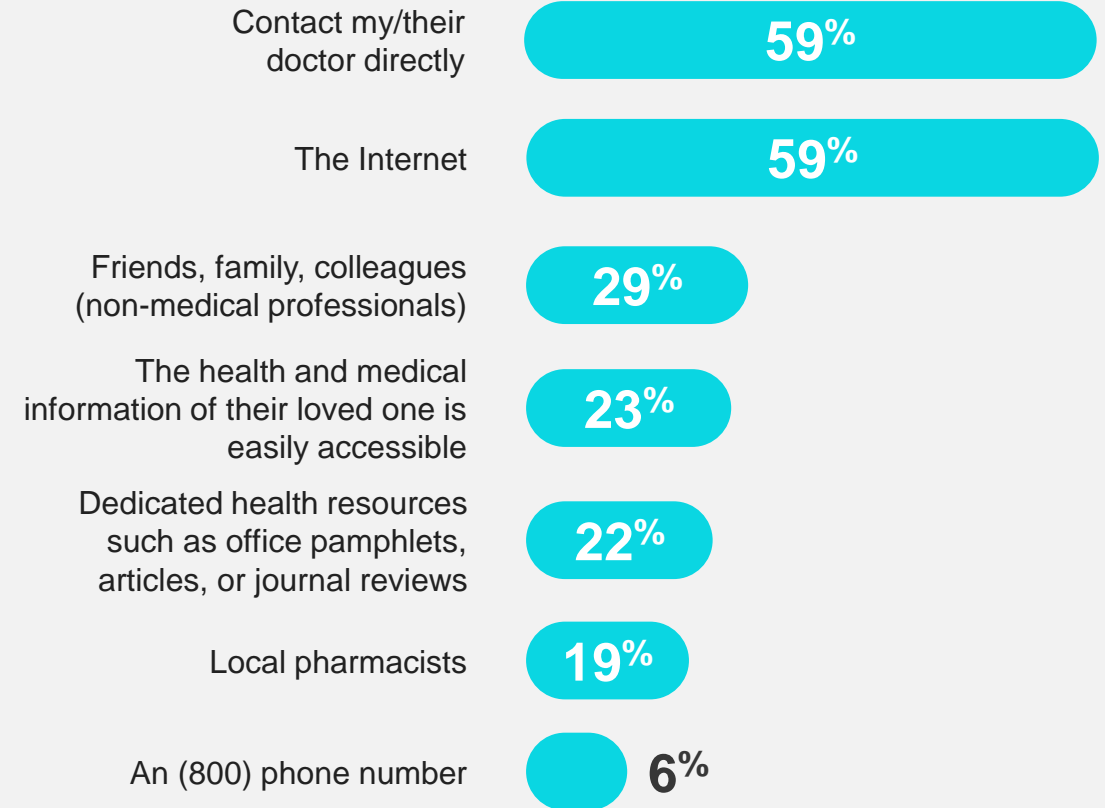
42%

of Americans research their doctor's recommendations after an appointment

The Internet is a place where Americans feel they can find the information they need. Nearly all (94%) Americans seek out health information about specific medical questions or conditions. While 3 in 5 (59%) of them would contact their doctor directly, just as many (59%) turn to the Internet to find the information they are seeking. In fact, 4 in 5 (80%) Americans are likely to research their medical recommendations online following an appointment with their doctor.

Caregivers are more likely than their counterparts who are not caregivers to explore medical recommendations online after a visit with the doctor (88% vs. 74%).

How Americans typically seek out health information or answers about specific medical questions or conditions



Americans feel secure in the information they find on the Internet. Among those who use the Internet to find information, nearly 9 in 10 (86%) are confident that the information is credible. More than 2 in 5 (42%) report they are usually relieved that there was a lot of information on what they were researching. Others say the information they gather allows them to feel more confident in their doctor's recommendations (35%) and to feel better that they learned more than the information the doctor provided (33%).

When Americans seek out medical information on the Internet...*



86% believe the information is credible



42% are relieved there is a lot of information



35% are more confident in their doctor's recommendations



33% feel better that they learned more than what their doctor shared



42 million

Americans* feel determined to make their health a priority after seeking out health information on the Internet

After searching on the Internet, many are empowered to take their health into their own hands. In fact, about 1 in 3 (31%) – or 42 million* – Americans report that when they seek out health information on the Internet, they end up feeling determined to make their health a priority and to seek answers from their doctor. Far fewer associate their use of the Internet with feelings of nervousness that they or a loved one is suffering from a serious medical issue (17%), or greater confusion compared to before they researched (13%).

- Caregivers are more likely than their peers who do not provide care to feel nervous that a loved one is suffering from a serious medical issue after they do research on the Internet (23% vs. 13%).
- Men are more likely than women to report that their confidence in their doctor's recommendations increases after researching online (40% vs. 30%).

* Extrapolated from 135,478,741 Americans who seek out information online, which was derived from taking 55% of those who report they go online for medical information in the total population of 246,324,983 Americans aged 18+ (Source: U.S. Census Bureau, Current Population Survey 2018)



3

Medical records are a key component of health management, but millions of Americans have difficulty accessing their information and question the security of their data

Americans don't actively pursue their medical records. Nearly half (48%) of Americans admit they don't usually review their medical records until much later after an appointment with their doctor. Even more (52%) report that they rarely access their medical records to review their health information.

- Caregivers are more likely than non-caregivers to review medical records shortly after meeting with a doctor to find the information that was shared (69% vs. 59%).

Part of this passiveness may be because millions don't know where the information they need is located. In fact, 1 in 4 (24%) – or 59 million* – Americans don't know where to go to access their health and medical information.



59 million

Americans don't know where to go to access their health and medical information



42 million

Americans** don't know if their information is shared with people/organizations or if it is kept safe

** Extrapolated from 199,523,236 Americans who use an online portal, which was derived from taking 81% of those who report they use an online portal to access their information in the total population of 246,324,983 Americans aged 18+ (Source: U.S. Census Bureau, Current Population Survey 2018)

For others, the process of locating their records can be a tedious one. 89% of Americans have collected their personal health information or records at some point in time. Among them, about 1 in 4 (24%) – or 59 million* – didn't find the process easy. And more than twice as many (53%) of those who have never had to locate their records anticipate that the process wouldn't be easy if they had to try.

- Caregivers, with the added responsibility for more than just themselves, find the process significantly easier than non-caregivers (72% vs. 63%).

While a majority of the population uses a portal to access their health information, millions question its security.

4 in 5 (81%) Americans utilize an online platform or portal to access their medical records or health information. Among them, 21% – or nearly 42 million** – are unaware of whether their information is shared with other people or organizations or if it is kept safe.

*Extrapolated from 246,324,983 Americans aged 18+ (Source: U.S. Census Bureau, Current Population Survey 2018)

While many say they have faith that their personal data is safe and protected on the online portal, the reasons they feel this way are not universally shared. 2 in 3 (66%)

Americans who use an online portal trust that their medical information is kept completely safe and not shared with other people or organizations.

But the source of this trust may leave a lot to be desired. In fact, a majority of portal-using Americans did not report that this trust is because their doctor recommended and/or endorses the online platform so they trust their information is safe (60%), the online platform makes its data policy very clear (61%), that they have to give consent if that platform wants to use their information in any way (61%), or because they've never been made to feel that their information was anything less than safe and protected (64%).

Reasons Americans May Not Trust Their Information on the Online Portal is Safe*

I've not been made to feel that my information is safe and protected

64%

The online platform or portal does not make its data policy very clear

61%

I do not have to give consent if the platform wants to use my information in any way

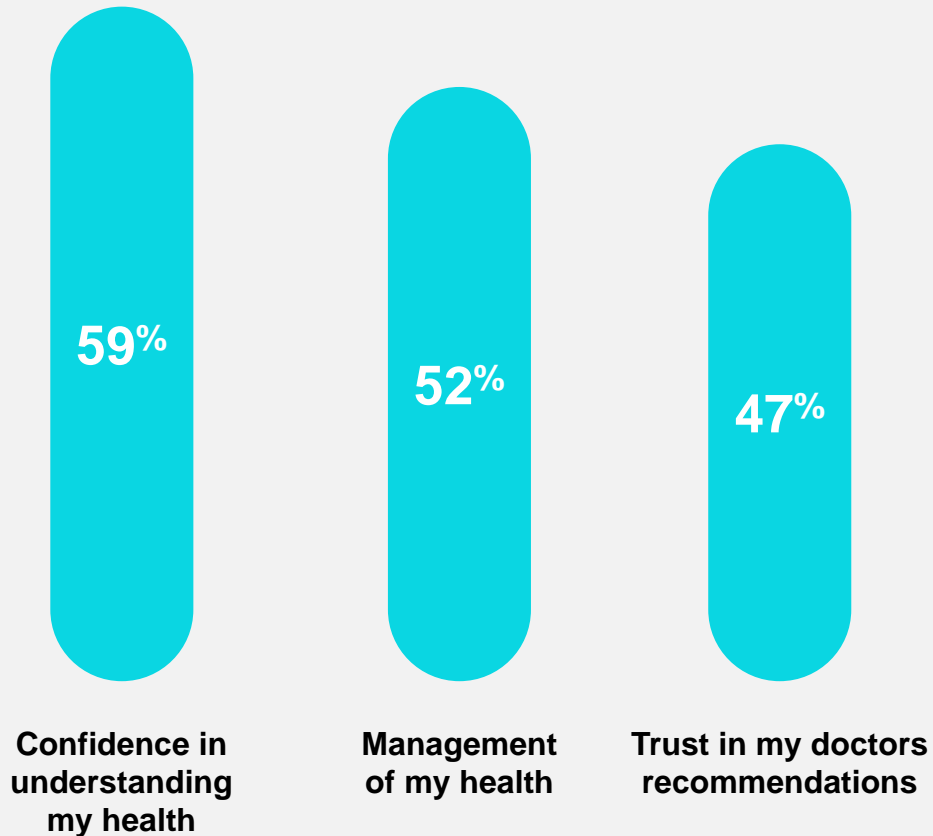
61%

My doctor did not recommend and/or endorse the online platform or portal

60%

*Among Americans who use a portal to access their health information

Improvements Americans Would See if They Had Access to All Their Health Information



One thing is for certain: If Americans were able to have a whole picture of their health, they'd see noticeable changes. 4 in 5 (81%) Americans agree that if they had access to all their health information, including medical records, recommendations, conditions, and test results, they'd see at least one improvement in their health management. Among them, about 3 in 5 (59%) believe they'd see such a change in their confidence in understanding their health. Others say the same about the management of their health (52%) and their trust in their doctor's recommendations (47%).

- Caregivers are more likely than their peers who are not caregivers to believe that access to all health information would improve confidence (53% vs. 44%), management of health (46% vs. 39%), and trust in doctor's recommendations (44% vs. 33%).
- Men are more likely than women to believe that a whole picture of their health would improve their trust in their doctor's recommendations (44% vs. 32%).

Disparities



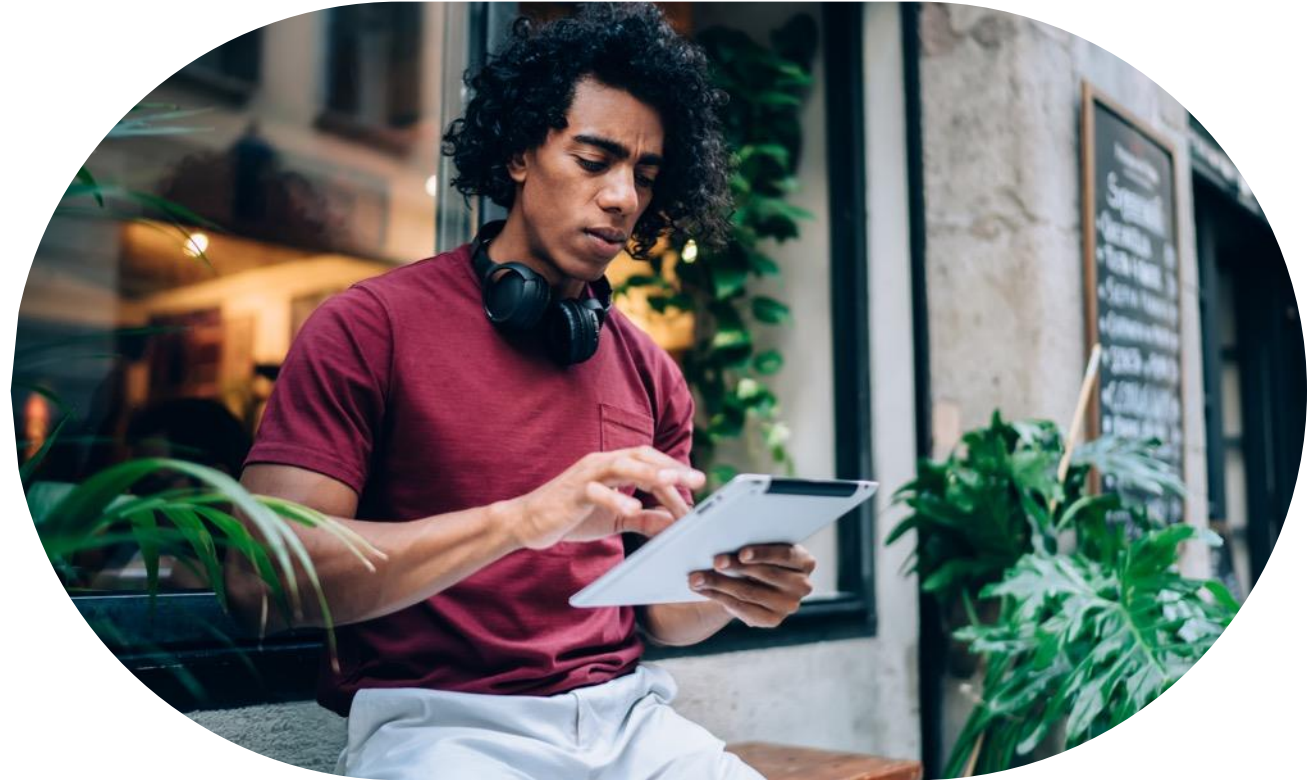
Generation

Younger generations are more likely than their older counterparts to report a greater disconnect with their doctor and to not feel as confident in their understanding of their medical information.

Consequently, they're more likely than their older peers to believe having a whole picture of their health information could lead to improvements in how they manage their health and trust in their doctor's recommendations.

Younger Americans are more likely than their older counterparts to:

- Leave their doctor visits not feeling positively about the visit (This means they experience feelings of confusion, unanswered questions, lacking clarity around their questions, or not feeling comfortable bringing up certain questions to a greater degree) (Gen Z 86%, Millennial 86%, and Gen X 81% vs. Boomers 61%).
- Leave their appointments without getting clear answers to their questions (Gen Z 33% and Millennials 31% vs. Gen X 23%, Boomers 16%).
- Feel more confused about their own health than before their appointments (Gen Z 28% and Millennials 19% vs. Gen X 13%, Boomers 9%).





Boomers, on the other hand, are more likely than their younger counterparts to:

- Not be able to retain the information they discussed with their doctor (Gen Z 19%, Millennials 24%, Gen X 21%, Boomers 26%).
- Feel extremely confident in their understanding of their health information (Gen Z 31%, Millennials 36%, Gen X 37%, Boomers 43%).

Younger generations are more likely than older counterparts to:

- Rarely access their medical records after a visit (Gen Z 59%, Millennials 55%, Gen X 53%, Boomers 44%).
- Research their doctor's recommendations online following a doctor's appointment (Gen Z 86%, Millennials 89%, Gen X 81%, Boomers 71%).

Millennials are more likely than any other generation to take on the caregiver role (Gen Z 39%, Millennials 65%, Gen X 50%, Boomers 20%).

There are many differences in the ways in which different generations seek out health information:

- Boomers and Gen X are more likely than Millennials or Gen Z to reach out to their doctor directly to seek out health information or answers about specific medical questions or concerns (Boomers 60%, Gen X 60% vs. Millennials 53%, Gen Z 41%).
- Gen Z and Millennials are more likely than their older counterparts to reach out to family, friends, and colleagues for this information (Gen Z 31%, Millennials 33% vs. Gen X 27%, Boomers 22%).
- Older Americans seek out this information on the Internet to a greater degree than younger generations (Gen X 58%, Boomers 60% vs. Gen Z 44%, Millennials 52%).



When it comes to the improvements they'd see if they had access to all their health information:

- Boomers are more likely than other generations to not feel that anything would improve in their life (Boomers 31% vs. Gen Z 12%, Millennials 12%, Gen X 17%).

Younger Americans are more likely than older generations to use an online platform or portal to access medical records (Gen X 88%, Millennials 86% vs. Gen Z 76%, Boomers 78%).

Education

Those Americans who hold a high school degree at most are more likely than their peers with more education to have issues accessing and understanding their health information.

They're also less likely to feel comfortable asking their doctor questions or even seeking out medical information from their providers.





Those with a high school degree, at most, are less likely than their more educated peers to:

- Feel comfortable asking their doctor medical questions (HS or Less 24%, Some College 22% vs. College Graduate 34%).
- Understand all of their medical information (HS or Less 72%, Some College 72% vs. College Graduate 80%).
- Review their own medical records after meeting with their doctor (HS or Less 59%, Some College 55% vs. College Graduate 72%)
- Know where to go to find their medical information (HS or Less 72%, Some College 71%, College Graduate 82%)
- Find the process of collecting their medical information to be easy (HS or Less 62%, Some College 64%, College Graduate 72%)

Those with a high school degree, at most, are less likely than their more educated peers to:

- Find the data policies of online portals clear (HS or Less 29% vs. Some College 40%, College Graduate 45%).
- Go directly to their doctor when they are seeking information (HS or Less 50%, Some College 53%, College Graduate 60%).
- Feel that having a whole picture of their health and medical information would improve their confidence in their health management (HS or Less 41% vs. Some College 52% vs. College Graduate 49%).





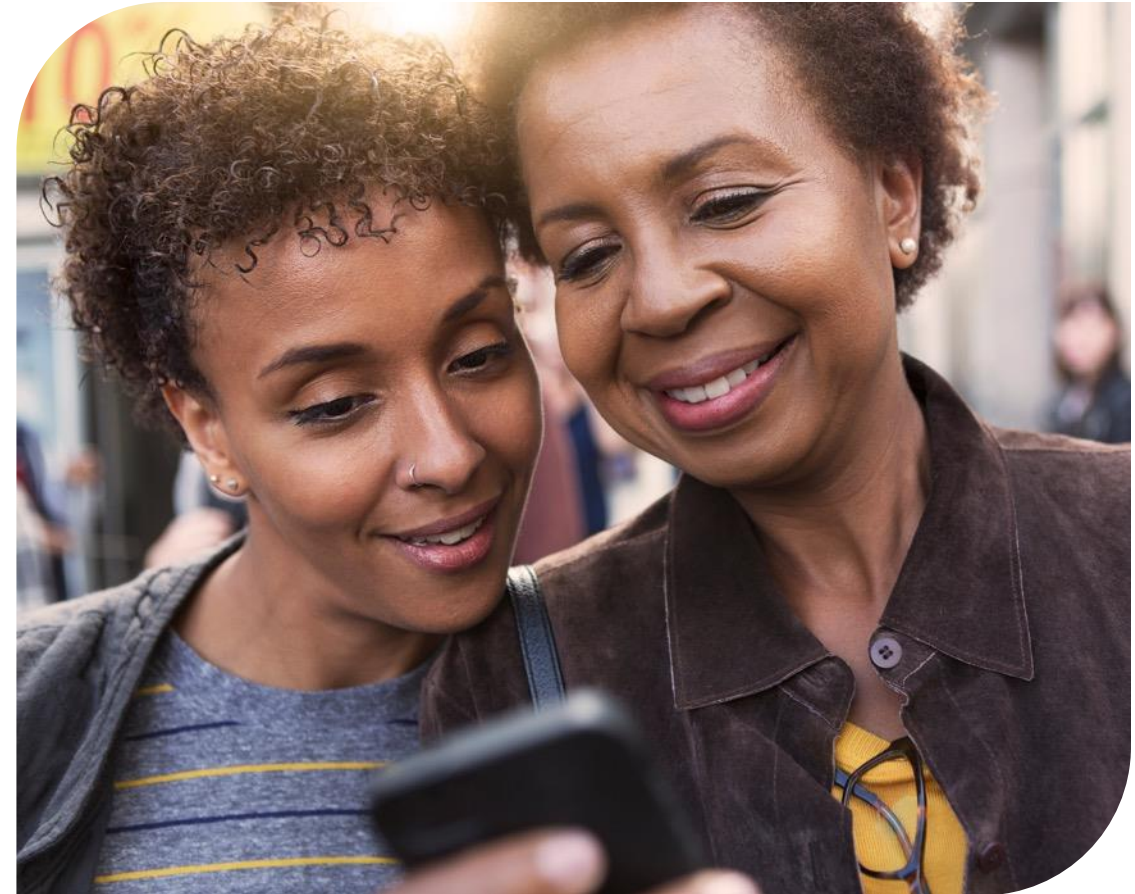
Income

Lower income earners (<\$50K) are more likely than those earning more to struggle with understanding and retaining the medical information their doctor shares.

They're also less likely to have accessed their personal health information, let alone to even know where to find it.

Lower income individuals are less likely than those earning more to:

- At least somewhat agree that they understand the medical information their doctor shares (LT 50K 71% vs. 50-100K 79%, MT 100K 84%).
- Research their doctor's recommendations (LT 50K 37%, 50-LT 100K 44% vs. MT 100K 53%).
- Remember all of the medical recommendations shared during a doctor's visit (LT 50K 65% vs. 50-LT 100K 71%, MT 100K 78%).
- Immediately look at their medical records after a visit with their doctor (LT 50K 59%, 50-LT 100K 64% vs. MT 100K 79%).
- Have ever accessed their medical records (LT 50K 62% vs. 50-LT 100K 71%, MT 100K 75%).
- Know where to go to access their medical information and health data (LT 50K 71% vs. 50-LT 100K 81%, MT 100K 84%).
- Use an online platform or portal to access their medical records (LT 50K 76% vs. 50-LT 100K 86%, MT 100K 88%).



Ethnicity

People of color struggle with their relationship with their doctor or to feel satisfied with the information they discuss.

They're more likely than their White peers to feel optimistic that if they had access to all of their health information, they'd see improvements in the management of their health and their trust in their doctor's recommendations.





Hispanics are more likely than their peers to:

- Leave their doctor's appointment not feeling positively (This means they experience feelings of confusion, unanswered questions, lacking clarity around their questions, or not feeling comfortable bringing up certain questions to a greater degree) (White 75%, Black 75%, Hispanic 83%).
- Review their medical records shortly after meeting with their doctors (Hispanics 76% vs. White 61%, Black 62%).
- Believe their data on a portal is being shared with other people/organizations (Hispanic 20% vs. Black 9%, White 13%).

When it comes to the improvements they'd see if they had access to all their health information, Blacks and Hispanics are more likely than their White counterparts to believe it would:

- Improve the management of their health (White 50%, Black 56%, Hispanic 54%).
- Improve their trust in their doctor's recommendations (White 44%, Black 56%, Hispanic 51%).

Black Americans are more likely than their peers to find the process of collecting their personal health records to be easy (Black 78% vs. White 66% vs. Hispanic 64%)

White Americans are more likely than other groups to use the Internet to seek out health information or answers about specific medical questions or conditions (White 59%, Black 40%, Hispanic 48%).



Methodology

Quantitative Methodology

Sample

Panel Sample: n=1,059

- U.S. resident
- Nationally representative sample
- 18+ years old

Fielding Dates: 7/26/21 – 8/2/21

Methodology

Results of any sample are subject to sampling variation. The magnitude of the variation is measurable and is affected by the number of interviews and the level of the percentages expressing the results.

In this particular study, the chances are 95 in 100 that a survey result does not vary, plus or minus, by more than 3 percent from the result that would be obtained if interviews had been conducted with all personas in the universe represented by the sample. The margin of error for any subgroups will be slightly higher.

About Kelton Global

Kelton Global, a Material company, is a leading global insights firm serving as a partner to more than 100 of the Fortune 500 and thousands of smaller companies and organizations. For more information about Kelton Global please call 1.888.8.KELTON or visit www.keltonglobal.com.

Thank You

