Access, Understanding, and Use of Electronic Health Information in America

AHIMA Foundation Consumer Pulse Survey

FEBRUARY 2023
Introduction

Making electronic health information easy to access, understand, and use is key to improving health and wellness outcomes, yet millions of Americans have difficulty accessing their information. In 2022, armed with this knowledge and anchored on Health Literacy for Health Equity™, the American Health Information Association (AHIMA) Foundation established research aims aligning with specific Healthy People 2030 objectives developed by the Health Communication and Health Information Technology (HC/HIT) Workgroup:

- Increase the proportion of adults offered online access to their medical record.
- Increase the proportion of adults who use IT to track healthcare data or communicate with providers.
- Increase the proportion of people who can view, download, and send their electronic health information.
- Increase the proportion of people who say their online medical record is easy to understand.
- Increase the health literacy of the population.

Baseline data findings included in this report can be used to inform future strategies intended to help consumers make informed health decisions using their online medical record, guide evidence-based healthcare system IT policies and practices and educate, and train aspiring and current health information professionals about known disparities.
Table of Contents

- Executive Summary
- Methodology
- Key Findings
- Report Narratives
Executive Summary

We know people who use IT to keep track of their health information and talk with healthcare providers are more likely to have better health outcomes, and fortunately the results in this survey show the majority of Americans have accessed their personal health information electronically at some point in time – many for the first time during the COVID-19 pandemic.

While this data shows progress is being made toward Healthy People 2030’s objective to "increase the number of adults offered online access to their medical record," many disparities still exist. There are still people who have never tried to access their personal health information electronically. Some tried but were unsuccessful in gaining access. Some have no desire. Some don't know how.

The 21st Century Cures Act aims to improve access to online medical records in a secure, easy-to-understand way. As healthcare data breaches continue to make national headlines – threatening patient care and private data – the results of this survey also indicate a profound gap in consumer health information literacy specific to the privacy and security of their electronic personal health information.

Additionally, this survey also found Americans with chronic conditions were less likely to understand their personal health information than those without a chronic condition. These results show continued and targeted efforts are needed to reduce health misinformation among this population specifically if we are to improve the health literacy of the population overall – a Healthy People 2030 objective.
Survey Methodology
Methodology

The AHIMA Foundation survey items were embedded in the AmeriSpeak® omnibus survey, funded and operated by NORC at the University of Chicago. AmeriSpeak® is a probability-based panel designed to be representative of the US household population. Randomly selected US households are sampled using area probability and address-based sampling, with a known, non-zero probability of selection from the NORC National Sample Frame. These sampled households are then contacted by US mail, telephone, and field interviewers (face to face). The, panel provides sample coverage of approximately 97% of the U.S. household population. Those excluded from the sample include people with P.O. Box only addresses, some addresses not listed in the USPS Delivery Sequence File, and some newly constructed dwellings. While most AmeriSpeak® households participate in surveys by web, non-internet households can participate in AmeriSpeak® surveys by telephone. Households without conventional internet access but having web access via smartphones are allowed to participate in AmeriSpeak® surveys by web. AmeriSpeak® panelists participate in NORC studies or studies conducted by NORC on behalf of governmental agencies, academic researchers, and media and commercial organizations. For more information, email AmeriSpeak-BD@norc.org or visit AmeriSpeak.norc.org.
Personal health information includes your age, sex, race, ethnicity, marital status, education, employment, insurance, and income; your physical and mental health conditions and histories; your test and laboratory results; and other information that a healthcare professional collects to identify you and determine appropriate care.

Accessing personal health information electronically means using your healthcare provider or hospital’s website, online patient portal, app on your phone, or another electronic device to access your health information.

Chronic conditions are those that last for a year or more and require ongoing medical attention. Chronic conditions include, but are not limited to long COVID, arthritis, asthma, atrial fibrillation (a-fib), cancer, heart disease, Chronic Obstructive Pulmonary Disease (COPD), depression, high blood pressure, diabetes, obesity, and HIV/AIDS.
Key Findings
Key Findings:

1. The majority of Americans have accessed their personal health information electronically, at some point in time.

2. Although most Americans say they understand their health information when it’s accessed electronically, 2 in 3 still engage in Google searches and 1 in 2 call or message their healthcare provider for additional insight.

3. Many Americans are not worried at all about the privacy and security of their electronic personal health information.

4. Many Americans accessed their personal health information electronically for the first time during the COVID-19 pandemic.
How Many Americans Access Their Personal Health Information Electronically?
The majority of Americans have accessed their personal health information electronically, at some point in time.
70% of adult Americans (~180 million) have accessed their personal health information electronically, at some point in time.*

Of the 30% of adult Americans who have never accessed their personal health information electronically:

- 26% never tried
- 4% tried but were unsuccessful in gaining access

Among the 26% of adult Americans who have never tried to access their personal health information electronically,

- 44% have no desire
- 33% do not know how

* Extrapolated using U.S. Census Bureau estimates of 258,418,467 adults, 18 and older, living in the United States in 2021.
In the United States, substantial progress in the adoption of electronic health records has been made over the past decade – especially among office-based physicians and hospitals.

An electronic health record (EHR) is an electronic version of a patient's medical history, that is maintained by the provider over time, and may include all of the key administrative clinical data relevant to that person's care under a particular provider, including:

- demographics
- progress notes
- problems
- medications
- vital signs
- past medical history
- immunizations
- laboratory data
- radiology reports

Many Americans reported that all their healthcare providers use electronic health records

- All: 76.5%
- Some: 18.1%
- None: 5.4%

n = 1,070

- U.S. resident
- Nationally representative sample
- 18+ years old
1 in 3 adult Americans have accessed their own health information or that of a child or senior loved one 5 or more times electronically within the past 12 months.

<table>
<thead>
<tr>
<th>In the past 12 months......</th>
<th>Accessed one’s own information</th>
<th>Accessed child or senior loved one’s information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fewer than 5 times</td>
<td>60.1%</td>
<td>63.5%</td>
</tr>
<tr>
<td>5 to 9 times</td>
<td>22.5%</td>
<td>21.0%</td>
</tr>
<tr>
<td>10 times or more</td>
<td>17.4%</td>
<td>15.5%</td>
</tr>
</tbody>
</table>
Most Americans access their personal health information to review health care provider’s notes following a visit and to review current laboratory or other test results. Although many report checking their current results, only 35% review how their laboratory or test results have changed over time.

For what reasons do you access your own personal health information electronically?

<table>
<thead>
<tr>
<th>Reason</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Review my health care provider’s notes about my visit and/or my after-visit instructions</td>
<td>75.6%</td>
</tr>
<tr>
<td>Review my current lab or other test results</td>
<td>71.3%</td>
</tr>
<tr>
<td>Review and/or order medication refills</td>
<td>41.2%</td>
</tr>
<tr>
<td>Send messages to and/or receive messages from my healthcare provider(s)</td>
<td>41.0%</td>
</tr>
<tr>
<td>Make appointments with my healthcare provider(s)</td>
<td>39.0%</td>
</tr>
<tr>
<td>Review how my lab or other test results have changed over time</td>
<td>35.1%</td>
</tr>
<tr>
<td>Check when I am due for screenings and vaccinations (e.g., mammogram, COVID-19 shot, flu shot, etc.)</td>
<td>20.2%</td>
</tr>
<tr>
<td>Share information about my health with others (e.g., family, caregivers, etc.)</td>
<td>7.0%</td>
</tr>
<tr>
<td>Get information to send to my insurance company</td>
<td>6.0%</td>
</tr>
</tbody>
</table>
Types of electronic devices used to access personal health information

- One-half of Americans use a smartphone to access their personal health information.
- 42% of Americans use a laptop or desktop to access their personal health information.
- Only 8% of Americans use a tablet to access their personal health information.
Disparities to accessing personal health information electronically were found to vary most by gender, education, age, health status, and employment.
Gender

Women were slightly more likely to have ever accessed their personal health information electronically.

History of Accessing Personal Health Information Electronically

- **Have accessed personal information electronically**
  - Women: 74.4%
  - Men: 65.8%

- **Have not accessed personal information electronically**
  - Women: 25.6%
  - Men: 34.1%
Those with higher education levels were slightly more likely to have ever accessed their personal health information electronically and did so at a slightly higher frequency (5 or more times in the past 12 months) than their counterparts with less education.
**Age**

Americans ages 45 through 59 years of age were slightly more likely to have ever accessed their personal health information electronically and did so at a slightly higher frequency (5 or more times in the past 12 months) than counterparts outside that age window.
Americans with chronic conditions were much more likely to access their personal health information and at a higher frequency than their counterparts living without chronic conditions (5 or more times in the past 12 months).
Compared to those not working, Americans currently employed were more likely to have ever accessed their personal health information electronically (75.6% vs. 63.1%).
Do Americans **Understand** Their Personal Health Information When it is Accessed Electronically?
Although most Americans say they understand their health information when it’s accessed electronically, 2 in 3 still engage in Google searches and 1 in 2 call or message their healthcare provider for additional insight.
It can be harder for people to use technology for health-related tasks when they have low health digital literacy.

**Digital health literacy** (also known as eHealth literacy) brings digital literacy and health literacy together and focuses on the ability to find relevant and reliable health information from electronic sources to solve health problems. It also includes adding in your own health-related content and protecting your privacy online.
Smartphones, tablets, and other devices make it simple to read, watch, and share health information. But, the convenience comes with a big trade-off. The internet is filled with misleading and false information.

Health misinformation is a health-related claim that is based on anecdotal, false, or misleading evidence. Many healthcare professionals agree health misinformation can be dangerous; getting misleading or incorrect information about a chronic condition or a medication can have serious repercussions.

![ infographic showing percentage of people taking actions to understand health information ]

80% of Americans take a number of actions to understand the personal health information they access electronically.

- 63% do a Google search or ask Google a question
- 53% call or send a message to their healthcare provider
- 30% ask friends or family to help explain
- 15% do a search on social media sites (e.g., TikTok, Facebook, Twitter, etc.)
Disparities to understanding personal health information accessed electronically were found to vary most by gender, education, age, health status, and employment.

Overall, women, those with higher levels of education, adults 45 and older, and those employed were slightly more likely to understand their personal health information.

Those with chronic conditions were less likely to understand their personal health information.
Women were slightly more likely to understand their personal health information.
Those with higher levels of education were slightly more likely to understand their personal health information.

**Understanding of Personal Health Information Accessed Electronically**

- **Understand most of the information (75% or more)**
  - Highschool or less: 75.3%
  - Some college: 78.1%
  - Bachelor’s degree or higher: 85.4%
- **Understand some of the information (around 50%)**
  - Highschool or less: 21.6%
  - Some college: 19.2%
  - Bachelor’s degree or higher: 12.2%
- **Understand very little of the information (25% or less)**
  - Highschool or less: 3.1%
  - Some college: 2.7%
  - Bachelor’s degree or higher: 2.4%
Adults age 45 and older were slightly more likely to understand their personal health information.
Americans with chronic conditions were less likely to understand their personal health information than those without a chronic condition.

Understanding of Personal Health Information Accessed Electronically

- Understand most of the information (75% or more)
- Understand some of the information (around 50%)
- Understand very little of the information (25% or less)

Living with Chronic Condition

- Chronic condition: 75.5% (Most), 23.1% (Some), 0.4% (Little)
- No chronic condition: 84.5% (Most), 11.6% (Some), 3.9% (Little)
Employment

Americans currently employed were slightly more likely to understand most of the personal health information accessed electronically than those not working (81.5% vs. 78.3%).

<table>
<thead>
<tr>
<th>Currently employed</th>
<th>Currently unemployed</th>
</tr>
</thead>
<tbody>
<tr>
<td>18.5% Does not understand most of the personal health information</td>
<td>78.3% Understands most of the personal health information</td>
</tr>
<tr>
<td>81.5% Understands most of the personal health information</td>
<td>21.7% Does not understand most of the personal health information</td>
</tr>
</tbody>
</table>
What Do Americans Know About the Privacy and Security of Their Electronic Health Information?
Many Americans were not worried at all about the privacy and security of their electronic personal health information.
or more – most Americans – are not worried at all about the privacy and security of their electronic personal health information when it is shared by their healthcare providers.

<table>
<thead>
<tr>
<th>How worried are you about the privacy and security of your electronic personal health information when it is shared by your healthcare provider?</th>
<th>Very worried</th>
<th>Somewhat worried</th>
<th>Not worried at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical health</td>
<td>8%</td>
<td>28%</td>
<td>63%</td>
</tr>
<tr>
<td>Mental health</td>
<td>9%</td>
<td>24%</td>
<td>65%</td>
</tr>
<tr>
<td>Drug and alcohol use</td>
<td>7%</td>
<td>17%</td>
<td>74%</td>
</tr>
<tr>
<td>Prescription medications</td>
<td>7%</td>
<td>23%</td>
<td>69%</td>
</tr>
</tbody>
</table>
As many as two-thirds to one-half of Americans do not know if information about their physical health, mental health, drug and alcohol use, and prescription medications is shared with other providers to whom they are referred.

A referral, in the most basic sense, is written order from a primary care provider to see a specialist for a specific medical service.

<table>
<thead>
<tr>
<th>When a healthcare provider refers or sends you to someone else for care, what information do they share with that provider before your appointment?</th>
<th>Information IS shared</th>
<th>Information IS NOT shared</th>
<th>Don’t know if information is shared</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical health</td>
<td>49%</td>
<td>12%</td>
<td>37%</td>
</tr>
<tr>
<td>Mental health</td>
<td>25%</td>
<td>19%</td>
<td>54%</td>
</tr>
<tr>
<td>Drug and alcohol use</td>
<td>28%</td>
<td>18%</td>
<td>52%</td>
</tr>
<tr>
<td>Prescription medications</td>
<td>47%</td>
<td>13%</td>
<td>37%</td>
</tr>
</tbody>
</table>
Disparities in Americans knowledge about the privacy and security of their electronic personal health information varied most by age and health status.
Compared to younger generations, Americans age 60 and over were less likely to know if their mental health information was shared with a provider to whom they were referred and were the age group least worried about the privacy and security of their electronic personal health information pertaining to mental health.
Compared to Americans in “very good to excellent health,” Americans in “good, fair, or poor health” were slightly less likely to know if their physical health information was shared with a provider to whom they were referred and were more worried about the privacy and security of their electronic personal health information pertaining to their physical health.
What Do We Know About Americans Use of Technology During the COVID-19 Pandemic?
Many Americans accessed their personal health information electronically for the first time during the COVID-19 pandemic.
43% of Americans (~111 million) indicated that their use of technology increased as a result of the COVID-19 pandemic. Among those citing increased use, nearly 30% (~33 million) accessed their personal health information online, for the first time during the COVID-19 pandemic.*

* Extrapolated using U.S. Census Bureau estimates of 258,418,467 adults, 18 and older, living in the United States in 2021.
Since the COVID-19 pandemic started in early 2020, Americans have increased their use of technology for their health.

- **71%** had one or more telehealth visits or appointments with healthcare providers.
- **47%** searched online to find a place where the COVID-19 vaccine was available and **45%** scheduled an appointment.
- **45%** sent one or more messages to their healthcare provider through a portal or messaging app.
- **26%** checked the results of one or more COVID-19 tests online.

**Key Finding 4**

The use of telehealth expanded rapidly as providers pivoted their work to address patient care needs due to the emergence of COVID-19.

**Telehealth** (sometimes called telemedicine) is the use of electronic information and communication technologies to provide and support healthcare.
1 in 3 Americans reported using ‘wearables’ such as Fitbit, smart watches, or heart rate monitors at least once a month.

1 in 3 Americans reported searching for and reading health information on websites or social media at least once a month.

Most Americans do not use health or wellness apps or online mental health counseling services.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Use at least once a month</th>
<th>Use but less than once a month</th>
<th>Do not use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health or wellness apps (e.g., Calm, Noom, HealthTap, iFit, etc.)</td>
<td>22.8%</td>
<td>6.5%</td>
<td>70.8%</td>
</tr>
<tr>
<td>Online mental health counseling services (e.g., Talkspace, BetterHelp, etc.)</td>
<td>7.8%</td>
<td>1.9%</td>
<td>90.3%</td>
</tr>
<tr>
<td>Search for and read health information on websites or social media sites</td>
<td>36.2%</td>
<td>24.6%</td>
<td>39.3%</td>
</tr>
<tr>
<td>Wearables (e.g., smart watch, Fitbit, heart rate monitor, etc.)</td>
<td>37.5%</td>
<td>3.5%</td>
<td>59.1%</td>
</tr>
</tbody>
</table>
Disparities to Technology Use During the COVID-19 Pandemic

Disparities to technology use during the COVID-19 pandemic varied most by health status, employment, and household internet access.
Health Status

45% of adult Americans surveyed (a nationally representative sample of 1,070) reported having a chronic condition.

Those with chronic conditions were more likely to rely on technology to find and schedule COVID-19 vaccine appointments and more likely to use technology to access COVID-19 test results.

- 58% Searched online to find a place where the COVID-19 vaccine was available*
- 56% Scheduled an appointment online to receive the COVID-19 vaccine or booster shot*
- 31% Showed proof of COVID-19 vaccination status by accessing a portal or online database**
- 22% Checked results of one or more COVID-19 tests online**

*p < .0001, **p <= .05
Employment

As compared to those not working, individuals who are currently employed were

- More likely to have ever had a telehealth visit or appointment with a healthcare provider using Zoom, Skype, Webex, Microsoft Teams, or some other video conferencing tool (52.2% vs. 42.1%)
- More likely to have increased their use of technology due to COVID-19 (46.0% vs. 38.6%)
- More likely to use health or wellness apps like Calm, Noom, iFit, and HealthTap (11.3% vs. 7.0%)

Survey Respondents Employment Status

Working 57.9%
Not working 42.1%

n = 1,070
- U.S. resident
- Nationally representative sample
- 18+ years old
Health equity in telehealth is the opportunity for everyone to receive the healthcare they need and deserve, regardless of social or economic status. Providing health equity in telehealth means making changes in digital literacy, technology, and analytics. This will help telehealth providers reach the underserved communities that need it the most.

Advocating for broadband access for all is a vital first step to ensuring that the benefits of online technologies can equitably improve health. There are currently many initiatives to make broadband internet more accessible and affordable for people across the U.S.

Survey Respondents with Household Internet

<table>
<thead>
<tr>
<th>Internet Household</th>
<th>87.5%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Internet Household</td>
<td>12.5%</td>
</tr>
</tbody>
</table>

n = 1,070
• U.S. resident
• Nationally representative sample
• 18+ years old

Non-internet households were able to participate in this survey by telephone. Households without conventional internet access but having web access via smartphones were also allowed to participate in this survey by web.
Thank You