AMERICAN BABY BOOMERS' SOURCING OF HEALTH INFORMATION

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ABSTRACT

Background

When health issues arise, individuals often aim to learn about the condition: seeking advice from professionals, family, or medical literature. The American elderly population will double between 2012 and 2050 with Baby Boomers central to this growth. They are considered a culturally pivotal generation in American history and experienced the explosion of widespread Internet use as working adults. To support this unique generation health professionals need to know where Baby Boomers get information and what sources they trust.

Aims

- 1. Where did Baby Boomers access health information before the Internet became readily available?
- 2. Where does the Baby Boomer generation look to find information to help make decisions about their own health?
- 3. How do Baby Boomers prioritize different sources of information?

Method

A 22 question anonymous survey was created and distributed via the Qualtrics Survey System to participants born between 1946 and 1964 (n=222).

Results

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As children and young adults, most participants reported going to physicians and/or family members. 99% reported current weekly Internet use, and 66% reported the same for social media use. The most frequently used sources were physicians (98%), Internet sources (84%) and family members (67%). More participants reported using for-profit health information websites such as WebMD (86%) than hospital or university-affiliated (68%) or government-affiliated (50%) sites. Physicians and other healthcare professionals were considered trustworthy (95%) together with health information websites (67%). Other media sources received significantly lower trust rankings. Most participants considered hospital- or university-affiliated sites (89%), health information websites such as WebMD (80%) and government-affiliated sites (77%) to be trustworthy, while social media (32%) was less frequently considered trustworthy.

Conclusion

The Baby Boomer generation will become the largest age bracket of healthcare recipients in American history. The past few decades have seen an explosion of online health information sources available to this public. Compared to previous generations, Baby Boomers are less likely to rely solely on their healthcare provider for information and are more likely to research health information independently. This could cause conflicts between sources of information but may also be indicative of motivation and engagement in their care process.

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I hope the information provided in this thesis will spark thought and conversation about a generation in which quite a few members are people whom I care deeply about and look up to.

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1.0 INTRODUCTION

When you start experiencing symptoms of an illness or are diagnosed with a condition you are unfamiliar with, where is the first place you seek information? Do you prioritize the advice of your physician, the Internet, or your own judgment and experience? As new sources of health information become increasingly available, both providers and patients have greater choice as to where to go for that so-called wisdom.

The aging Baby Boomer generation is a special topic of interest related to this phenomenon. Within the next decades there will be an influx of geriatric patients who have potential access to health information that is different to that accessed by older generations. This project focused on learning more about how the Baby Boomer generation accesses health-related information and what factors lead to prioritization of certain sources. This knowledge will hopefully supplement clinicians' understanding of a rapidly growing patient population and benefit patient-provider communication.

1.1 SOURCES OF HEALTH INFORMATION

Many health professionals believe that in an uncomplicated world, patients or individuals concerned with their health would look only to sources of institutional authority for health information. In this ideal world, when a mysterious rash appears on your chest, the first and only

action to take would involve consulting a medical professional for an evaluation. If a medical professional is not readily available, you may consult a government-reviewed pamphlet on skin disorders to try to pin down whatever is ailing you. But the reality of healthcare is far more complicated than that hypothetical scenario, and multiple, sometimes conflicting sources of health information compete with each other to be in the forefront of Americans' minds (Carpenter et al., 2016).

An incredibly diverse pool of health information sources are accessible to Americans. This paper will separate sources into three categories: (1) *Physicians, Healthcare Professionals and Authoritative Sources,* (2) *Family and Community,* and (3) the *Media.* These categories are reflective of Paul Starr's separations found in his 1982 book *Social Transformation of American Medicine: the Rise of a Sovereign Profession and the Making of a Vast Industry.* Starr discusses America's long history of relying solely on family and community members for healthcare and information (Starr, 1982). He argues that in the 19th century, medical institutions began to establish their authority as America's primary source of care and information (Starr, 1982). But his book was published in 1982 and was unable to discuss the importance of the media (especially the Internet) to American health information gathering which increased in the 21st century. The following section will review literature and research related to health information sources commonly used by Americans in the past and today.

1.1.1 Physicians, Healthcare Professionals and Authoritative Sources

Traditionally, physicians have been the primary source of trusted health information and served a gatekeeping role between the worlds of the knowledge of the established medical community and the common knowledge of patients (Arora, 2003). A study of the information-seeking

behaviors of older adults (mean age in years 78, SD 910) found that respondents consistently listed healthcare providers as their most trusted source of health information, followed by pharmacists (Chaudhuri et al., 2013).

In Paul Starr's 1982 Social Transformation of American Medicine, historical perspectives on the formation of the authority of the medical community is researched in depth. Starr writes that before institutional medical authority was established in the United States, healthcare was maintained at a familial or community level, which he refers to as "domestic medicine." Hospitals and healthcare institutions were solely reserved for those who did not have access to family or community units, such as the homeless or mentally ill, and doctors were often mistrusted. In the 19th century, a consolidation of professional and educational authority began, which marked the advent of modern medical authority that is the dominant paradigm of America's health system (Starr, 1982). Americans began to trust the medical expertise of physicians and research from medical universities over the advice of their families and communities. Still, Starr emphasizes that despite the significant effects of the consolidation of medical authority and the shift in trust, the grassroots, community-based health informationseeking ways of Americans still persist in American society today (Starr, 1982).

Paul Starr's 1982 book largely discusses the history of America's majority culture from the founding of the country to the late 20th century. He argues that a shift occurred that caused the majority of Americans to view physicians as the most trustworthy source of healthcare and health information. But the United States is a diverse nation with large communities of individuals from different cultural and ethnic backgrounds. Some of these individuals do not match Starr's narrative of the acceptance of medical authority by the public. For example, individuals in communities of Black/African American and Hispanic/Latino Americans (which

have existed in America for centuries) express distrust of physicians at higher rates than the total population (Armstrong et al., 2007). In addition to this, many citizens who immigrated to the United States may also hold views that differ from the majority population. It is important to acknowledge that there can be significant variation in trust and belief about health and medicine depending on an individual's cultural background.

Despite cultural variation, physicians and other healthcare providers are considered to be among the most trustworthy sources of health information to Americans (Starr, 1982). A study examining the information-seeking behaviors of older adults (mean age 78 years, SD 10) asked participants to rank sources of health information from most to least trustworthy and found that healthcare providers were considered the most trustworthy source of information by a considerable margin (Chaudhuri et al., 2013). In line with Starr's argument, physicians are considered by many to be the most trustworthy healthcare professional. Survey research of around 8,500 patients diagnosed with multiple sclerosis revealed that 98% of participants trusted physicians to some degree (Marrie et al., 2013).

1.1.2 Family and Community

Community dwelling participants from retirement homes, mean age 78, were asked to rate sources of health information in terms of trust (Chaudhuri et al., 2013. The results were as follows, from highest to lowest reported trust: *health care providers, pharmacists, friends and relatives, retirement community staff, newspapers, the Internet, television,* and lastly *radio* (Chaudhuri et al. 2013). Considering the authoritative power and financial resources of the government and the medical community, it is no surprise that those two sources were regularly considered the most reliable. But the third result, 'friends and relatives,' is a source of health

information that receives zero dollars of funding, has no institutional agenda and no organizational structure. Why did older adults rank friends and relatives over Internet and media sources?

America has a long history of placing trust in one's family and community when making health decisions and providing care (Starr, 1982). Starr writes that this trust can be traced back to America's agricultural roots, where family members provided care out of necessity, and were the most knowledgeable about, and familiar with, the health history of the individual (Starr, 1982). Today, contacting family members and friends continues to be common for health worries. For example, when a resident in a retirement community begins to experience cold and flu-like symptoms, their first action may be to call their child for advice on the next step.

A 2007 study aimed to learn about the use and preference of health information sources of cancer patients (Pecchioni & Sparks, 2007). Physicians were both the most frequently used and most important information source (88%), the majority of patients stated that they were most satisfied by friends and family as sources of information, followed by nurses, other patients, and doctors (Pecchioni & Sparks, 2007). This study reflects Starr's argument that family and community members are considered valuable providers of health-related advice by many Americans.

1.1.3 Media and the Rise of the Internet

For much of the history of the United States, information about health and illness was transmitted orally. This often occurred between members of one's family and their community (Starr, 1982). Starr argues that during the 19th century institutions of medical authority surpassed family and community members as America's primary source of healthcare. Although unable to

provide healthcare itself, a new source emerged in the 20th century that began to play a large role in providing health information to millions of Americans: the media.

The development of the media as a source of health information led to far greater ease of access, as health information was no longer only transmitted orally but was distributed through print publications and electrical signals into American homes. When a disease outbreak occurred, the media helped inform Americans about its existence and recommended what precautions to take. Often, media sources such as newspapers or television news programs presented information provided by sources of authority such as government warnings and research studies (Carpenter, 1995). Despite this cooperation, the media's growing role in informing the public coincided with a growing distrust in sources of institutional authority (Carpenter, 1995).

In the 20th century the early developing mass media began to play a role in informing the public about topics related to health in ways that were not always considered helpful by sources of authority (Carpenter, 1995). For-profit media sources such as newspapers, magazines, television shows and radio programs presented information to media consumers with the goal of maintaining ratings and maximizing profit. Often, the media has focused on health situations that garner mass attention such as infectious disease outbreaks and epidemics while ignoring more widespread epidemic diseases (Carpenter, 1995). Furthermore, the effects of media outlets' reporting of health information has been evident in print media in the past century where there has often been conflicting reported information between that of medical researchers and media outlets (Carpenter, 1995). Conflicts such as these require Americans to prioritize one source of health information over another.

Another issue is the health literacy of media outlets and reporters. The health literacy and quality of information reported by journalists has direct effects on the health literacy and health

outcomes of those who access their media (Lopes & Araujo, 2017). Members of the public who regularly consume mass media may be likely to follow advice provided by these sources. This concern about the media's influence is evidenced by government bodies' regulation of televised health information, such as the monitoring of media sensationalism in response to disease outbreaks (Lopes & Araujo, 2017).

Before the Internet media health information was often presented by for-profit companies such as print publications and radio shows. Now, a plethora of health information sources is available to Americans at the click of a button. The widespread use of the Internet has affected aspects of health and medicine, particularly in the way Americans with Internet access acquire and share information about health issues.

The Internet has experienced unprecedented growth in usage in a relatively short period of time. Since 1997, Americans' Internet usage has increased 70% to 150% every year (Coffman et al., 2011). In 2018 89% of American adults were estimated to regularly use the Internet (Pew Research Center, 2018). The Internet is home to many sources of health information presenting the American public with far more sources than ever before. Individuals are able to share sources far easier through email, instant messaging, and social media. It is not only the increase in source availability that has impacted how Americans learn about their health.

Compared to other forms of media, huge variation exists between different online sources. Older mass media sources such as television programs and newspaper articles generally share the health advice of individuals who are considered experts in the reported subject. The Internet gives every user a platform to share health information through social media, discussion forums, and blogs. This has resulted in an increase in health information sources with questionable, if any, evidence behind them. The Internet is home to information ranging from

peer-reviewed research articles to opinion blogs. Below I will discuss in detail the history and prevalence of various online sources.

As the Internet became increasingly popular and more easily accessible for the average American, the United States (U.S.) government became more aware of its potential as a channel of communication with the public. Although there are numerous historical examples of the U.S. government sharing health information with the public, including print publications such as *The Medical and Health Information Directory (MHID)* and *The Health Care Directory (HCD)* (Carroad, 1978), the ease of transmission of government-approved health information via the Internet has allowed for more numerous and diverse information sharing. Examples of government sources of health information include the online database of the National Institutes of Health, the Centers for Disease Control, and the National Library of Medicine's *MedLine Plus*, which links users to a variety of peer-reviewed online health resources.

The U.S. government has solidified its position as a trustworthy source of health information in the eyes of many. Americans consistently reported that health information found on the Internet is more trustworthy when obtained from government sources, as opposed to non-government sources (Eysenbach et al., 2009). Quasi-governmental international agencies such as the United Nations and the World Health Organization (WHO) have also been invested in online health information. The WHO has created online databases of health information and researched international information seeking habits. For example, a 2014 project funded by the WHO emphasized concern in research trends indicating that "1. Experts and authorities are less trusted... 2. The way the public seek health advice has shifted to the public on-line sources, and social networks... [and] 3. The way the media works has changed to embrace 24-hour journalism" (Gamhewage, 2014). Another issue at the forefront of discussion by the WHO is the

assessment of individuals' reported trust of health information sources, especially related to health risk (Gamhewage, 2014).

In addition to government-related sources of online health information, many independent health information sources can be accessed on the Internet. These sources can be divided into three broad categories: nonprofit and academic sources, for-profit sources, and social media platforms. Popular nonprofit sources are websites like Mayoclinic.org, and popular academic sources include Harvard Health Publishing and Hopkins Medicine's Health Library. These university resources are technically private run under a non-profit model, receive indirect funding from the government, and do not have shareholders (United States Department of the Treasury, 2012).

In contrast, for-profit companies that run health information services focus on maximizing profit through their platforms. This may have an effect on the health information presented on their websites, as the provided information is dependent on what is most profitable for the company and its shareholders. A prime example of this type of source is WebMD. WebMD has been accused of leading individuals to falsely diagnose themselves with serious ailments as a result of the way their platform leads users to conclusions about their symptoms (Heffernan, 2011). It has also been criticized for receiving funding from pharmaceutical companies to encourage use of specific drugs and for "frame[ing] information commercially" (Heffernan, 2011).

All of the above health information websites can be accessed by entering their unique Uniform Resource Locator (URL) into an Internet browser. Another popular method exists to help persons access these websites: search engine keyword queries. Although some individuals do save trusted websites, it is very common for people interested in a health condition to search

keywords related to their condition on a search engine, a website hosted by a for-profit company such as Google (Stockman, 2008). Search engine queries allow for quick and easy access to articles that specifically cater to an individual's topic of interest.

A research project titled *Googling for a diagnosis – use of Google as a diagnostic aid* focused on how effective Google queries are at leading healthcare professionals to a correct diagnosis (Stockman, 2008). This study is particularly interesting as it asks experts to use an information source that is frequently used by non-experts. Results of the study showed that without any other diagnostic measures, Google searches revealed the correct diagnosis 58% of the time (95% confidence interval 38% to 77%) (Stockman, 2008). The authors concluded that the results indicated the possibility of Google as an effective diagnostic tool (Stockman, 2008). It is unclear exactly what terms each professional used in the search and if a success rate of 58% should be considered valuable compared to other available diagnostic tools. The study failed to explain which websites the professionals accessed after Googling, which could be a considerable variable in the success rate of search engines as a diagnostic tool.

Social media platforms have become an increasingly popular source of health information. Facebook, Twitter, and health forums like Patient.info are popular examples of social media platforms that Americans may use to access health information. These sources rely on user discussion and article sharing, resulting in varying levels of accuracy and sourcing of health information, ranging from government health resources and research articles to the personal opinions of users. An incredibly diverse range of sources of social media-based health information sources exists in the 21st century, and many Americans are faced with the task of deciding which sources to trust to help make decisions about their health and the health of their loved ones.

Social media platforms have allowed for rapid sharing of health information and usually require only a registered email address to allow individuals to post and share content. Websites like Facebook, Twitter, and Pinterest allow users to post original content or share links to articles related to health. This results in a wide variety of scientific credibility of health information from these sites. An example of this is the rise of the anti-vaccination movement, which is largely attributed to massive online sharing of a non-credible research article linking vaccines with autism (Matt, 2016).

Social media also allows for health-related online support groups. These groups function similarly to in-person support groups, where members "meet others with the same diagnosis and gain more information about their diagnosis" (Purk, 2004). Online support groups are often more accessible than in-person groups, as members can participate regardless of physical and geographical constraints. In addition to information sharing, support groups allow individuals receive and share emotional support and mutually benefit from discussing their condition with others (Purk, 2004). Online support groups exist on social media platforms like Facebook or specific websites that host discussion forums about a specific condition.

Widespread Internet access has resulted in more sources of health information being available to Americans than ever before. But medical authority figures and family members remain important sources to Americans. With so many sources to decide between, where will Americans look for health information? As older adults are among the largest populations of healthcare service recipients (World Health Organization, 2018), researchers have been interested in how they learn about illness. In recent years, numerous studies have focused on the health information seeking habits and trust patterns of the nation's older generations.

1.2 INFORMATION SEEKING HABITS OF OLDER GENERATIONS

The Silent Generation refers to those born between 1928 and 1945 (Goodkind, 2016). This generation was born during the Great Depression and World War II, but moved into adulthood during post-depression and post-war America, and prospered from America's strong economy (Zuehlke, 2008). A 2013 survey of older adults living in retirement communities (mean age 77.7, SD 9.8) asked participants to identify and rank sources on a scale of trustworthiness, and describe difficulties in finding health information (Chaudhuri et al., 2013). Out of 1,520 individuals who received surveys distributed to retirement communities, 403 participants completed the survey (Chaudhuri et al., 2013). The majority of the participants identified as Caucasian (91%) and female (70%). Participants came from diverse socioeconomic and educational backgrounds, with varying levels of self-reported financial stability. Participants were asked how often they use the Internet and 37.5% responded "never." When asked to rank various sources in terms of trustworthiness, *health care providers* and *pharmacists* were by consistently ranked as the most trustworthy. Friends and relatives were among the more trustworthy sources, while the Internet was ranked 5th out of 8, and received an average trust score that was roughly half of the average score for healthcare providers (Chaudhuri et al., 2013). Figure 1 Older adults' ranking of health information sources (Chaudhuri et al., 2013) provides a graphical representation of the data that was provided by the research article. Another relevant finding from the study was that as economic status of residents increased, reported trust in healthcare providers increased (Chaudhuri et al., 2013).

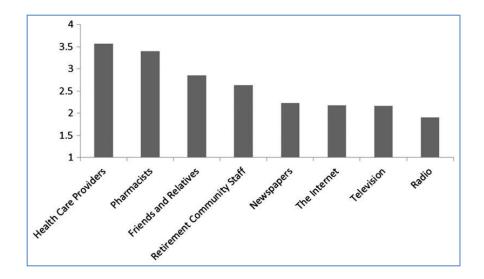


Figure 1 Older adults' ranking of health information sources (Chaudhuri et al., 2013).

Chaudhuri co-authored another article titled *Trust in Health Information Sources Differs Between Young/Middle and Oldest Old.* In this study, 353 adults over the age of 65 living in retirement communities were separated into two age groups and completed a survey asking them to rank health information sources in terms of trust (Le et al., 2014). Two age groups were created: "Young/Middle Old" (65 to 84 years) and "Oldest Old" (>85 years). The article (published in the *American Journal of Health Promotion*) did not provide an explanation or evidence to support dividing age groups into these specific categories. The "Oldest Old" age group (>85 years old) were less likely to trust the Internet for health information than the younger group (Le et al., 2014). Younger residents also reported higher use and trust of the Internet as a source of information. Members of the "Young/Middle Old" category, some of them Baby Boomers, trusted and used the Internet for health information more than their older retirement community neighbors. Does this suggest a generational difference in health information sourcing?

1.3 BABY BOOMERS

The aging Baby Boomer generation is a significant population related to the future of America's healthcare system. Baby Boomers are the largest generation in American history; the 2015 U.S. Census reported that around 71 million Baby Boomers lived in the United States, making up 23% of the total population with the average age being 58 in 2018 (Gao, 2016). As Baby Boomers reach the age of retirement, there will be an increase in these individuals seeking healthcare for conditions commonly associated with aging (World Health Organization, 2018). This influx is predicted to occur within the next ten years (Libbey et al., 2016).

There is no official universal consensus on the specific age parameters for the Baby Boomer generation, but the group is often defined as individuals born between 1946 and 1964 (Goodkind, 2016). The term "boom" refers to the increase in the birth rate in the United States and Europe following the post-World II economic success of the Silent Generation's growing middle class. Families became more affluent and healthcare accessibility greatly improved, resulting in an increase of births as well as lower infant mortality rates (Jones, 1980).

The term "Baby Boomer" is often considered to be a label of cultural significance, with commonly attributed features of the group including a rejection of traditional values, higher affluence and educational status, and an increased desire for independence (Owram, 1997). Baby Boomers experienced the largest increase in wealth from a previous generation than ever previously recorded; as they began working and starting families, the United States' middle class grew substantially (Owram, 1997). In addition to differences in financial status from older generations, Baby Boomers reported higher levels of health and fitness than previous generations (Jones, 1980). The generation is also known for challenging authority in various forms, including challenges to conventional medical authority such as ignoring the government and medical

warnings related to recreational drugs and casual sex (Owram, 1997). When observing these trends, it is important to acknowledge that these are generalizations and do not represent the entire population of Baby Boomers.

This population will require healthcare services associated with aging. Not only must the American healthcare system be prepared for a large increase in the number of patients, healthcare professionals must be prepared to treat and communicate with patients who may have different expectations for their care and seek health information differently.

1.3.1 The 'Silver Tsunami'

The predicted increased in the American elderly population related to aging Baby Boomers and the associated implications for healthcare is popularly referred to as the Silver Tsunami (Libby et al., 2016). Similar to how the government and population of a coastal town must prepare for the effects of an incoming giant wave brought by a tsunami, many experts in economics and healthcare have been repeating a similar warning to government and industry leaders: we must be prepared for the aging Baby Boomer generation. Unlike many issues related to the future of healthcare, statistics help us to know roughly what is to be expected. Census Bureau research conducted in 2014 indicates that the American elderly population will double in size from 2012 to 2050 as a result of aging Baby Boomers (Goodkind, 2016). Purely in terms of numbers, this issue should be at the forefront of the minds of legislators and healthcare professionals.

This issue exists outside of the United States. In Japan, the impact of a wave of aging individuals has already led to what many refer to as a crisis. Currently over 25% of people in Japan are above the age of 65, and by 2050, the proportion is estimated to skyrocket to the point where one in every three people is 65 or older (Wakamatsu-cho et al., 1996). This has led to a

healthcare crisis, where there is a disparity between the number of individuals requiring agingrelated services and individuals able to care for them. Similarly, Japan's economy faced a struggle to afford provision of healthcare and social services for these citizens.

Japan has had to adapt and evolve to accommodate this change in population. A popularly circulated news article titled 'Dementia Towns': How Japan is Evolving for its Aging Population, suggests that one in five elderly Japanese persons is estimated to have dementia, and Japan is coping with this problem by creating highly regulated communities of people with dementia with various support services for these individuals (McCurry, 2018). It is important to not conflate aging with dementia, as many individuals age with no cognitive deficits, but this news article highlights the government's concern.

Years of research on Japan's aging population led to the government tripling the nation's financial allocation for dementia management and assisted the creation of the "Orange Plan," described as "a comprehensive package of measures to tackle dementia" (McCurry, 2018). In the same way that Japan has been forced to accommodate this boom of aging individuals, the United States must begin to plan for the future. In 2015, Americans 70 or older only made up 10% of the total population (Gao, 2016), compared to Japan's 25%. The United States is predicted to experience a shift similar to that of Japan's.

Once it has been established that the aging population will increase substantially in the United States, the next question to be asked is how these individuals may differ from previous aging generations. The topic of the aging Baby Boomers is unique: the sheer number of people, and the characteristics associated with this generation.

1.3.2 Health Characteristics of Aging: a Normal Future

Speculating about the implications of the aging Baby Boomer generation requires a basic understanding of the effects of normal aging on the human body. The WHO writes that due to gradual damage or 'wear and tear' at a molecular and biological level, various functions of the body begin to significantly decline around the age of 70 years (World Health Organization, 2018). Common conditions associated with aging include bone, muscle and joint pain, loss in sensory functions, cardiovascular conditions, and cognitive conditions such as dementia (World Health Organization, 2018). These conditions become debilitating and may require intense levels of care that can create financial burden on patient, family, provider, and government as well as an emotional burden on the individual and their families. In addition to physical conditions, aging is associated with psychological effects that are a result of life changes such as retirement, death of family and friends, and changes in living situations.

It is important to note that these conditions and life events do not define the entire population. An 80 year old could very well be running marathons while a 40 year old could be on the verge of death due to heart disease. Similarly a young adult could experience crippling depression as a result of the death of a loved one while an older person could play an important role in professional and community functions well into old age.

1.3.3 Health Characteristics of Baby Boomers

There are many components of health, including longevity, absence of illness, and overall wellbeing. Longevity, or life expectancy, is a commonly discussed factor in determining a population's health. It is a common trend in human history for populations to experience higher

life expectancy as time goes on due to improvements in medicine and quality of life. The Baby Boomer generation experienced increased life expectancy due to greater access to healthcare and medical advancements as well as a decrease in hazardous occupations (Jones, 1980). The average life expectancy for Americans was 47 years in 1900, 68 years in 1950, and 77 in 1998, showing huge increases in a relatively short amount of time (University of California Berkeley, 2005).

Other aspects of health include absence of illness and an individual's perception of their own health. As young adults, Baby Boomers reported that they felt they lived healthier lifestyles with higher levels of fitness than their parents and preceding generations (Jones, 1980). But are Baby Boomers 'healthier' than their parents? A 2013 study comparing statistics on the health of Baby Boomers with the health of the previous generation at the same age found that the ''overall health status'' (meaning incidence of medical complications with considerable risk) of Baby Boomers was worse than previous generations (King, 2013). More Baby Boomers were obese (39% vs. 29%), had hypertension (43% vs. 36%) and reported a functional limitation (14% vs. 9%) (King, 2013). The most significant difference was found in hypercholesterolemia, or 'high cholesterol,' where 74% of Baby Boomers reported having the condition compared to 34% of members of the Silent Generation (King, 2013). All of these conditions are associated with decreases in life expectancy and overall quality of life.

What might explain this increase in conditions associated with poor health, especially in diseases related to the cardiovascular system, the leading cause of death in the United States? (Centers for Disease Control and Prevention, 2017). It is important to acknowledge that a variety of factors may affect data that is collected on Baby Boomers' health, such as socioeconomic status and geographic spread. Research only shows trends and averages but discernable

differences exist between the trends of Baby Boomers compared to those of older generations. Only 17% of Baby Boomers reported consistent physical exercise, either recreationally or professionally, compared to 52% of members of the previous generation when they were between the ages of 46 and 64 (King, 2013). Moderate drinking was also reported by Baby Boomers at much higher rates (67% vs. 37%) (King, 2013). Both of these are considerable risk factors for heart disease (Centers for Disease Control and Prevention, 2017). Despite these trends Baby Boomers smoke less than the previous generation (21% vs. 28%) and have a higher life expectancy (King, 2013). Although Baby Boomers are expected to live longer, data suggest that more members of this generation will experience life-altering illnesses such as cardiovascular diseases and their co-occurring conditions. As more health issues arise people will be increasingly looking for information. Sources of information and perhaps approaches to this may have changed over the last century.

1.3.4 Information Seeking Characteristics of Baby Boomers

Baby Boomers are among the largest consumers of online health information in the United States; early 21st century research found that 52% of individuals querying about health online were between the ages of 40 and 60 years (Cline & Haynes, 2001). Much of this is explained by the size of the generation in proportion to the rest of the United States. But what other factors may affect the Baby Boomers' large rates of health information consumption? A commonly repeated model of explanation, often filled with stereotypical characteristics of the generation, relates to the Baby Boomers' increased involvement in their health status. Baby Boomers were born during a period of time where the world was experiencing significant change. The

generation was born during America's post-World War II period of high economic success, and thus grew up in a different economic climate than was experienced by previous generations. Similarly, a shifting cultural climate may have influenced the generation's way of thinking. Baby Boomers are often associated with free, independent thinkers, who were heavily shaped by prosperity, 1960s youth culture and "free love," and the Vietnam War (Blauth et al., 2011). Characteristics relevant to health information seeking habits that are often included in the model are a tendency to be driven and idealistic, a belief in change and a desire to micromanage those around them (Blauth et al. 2011). Another commonly reported characteristic is a desire for independence, particularly in living situations and during failing health (Anderson, 2015). These characteristics may be broadly accurate but not the only factor involved in how Baby Boomers seek health information.

In addition to potential differences that define Baby Boomers as a culturally unique generation, different sources of health information are available to them that may distinguish their information seeking habits from previous generations. Technology has become increasingly available during the Baby Boomer generation's lifetime, which may impact their information seeking habits. The Baby Boomer generation experienced the rapid growth of technology and the "Dot Com Bubble" in their young and middle adulthood.

Unlike the Silent Generation before them, the average Baby Boomer grew up with televisions, landline phones, and other modern technology in their homes. Baby Boomers entered adulthood (18+) between 1964 and 1982 (Goodkind, 2016), and the Internet became widely available to the public in 1995 (Greenstein, 2017). Unlike their parents' generation, who were around the age of retirement when the Internet became available to the public, many Baby Boomers were forced to adapt to its increasing use in the workplace as working adults.

A 2007 study reviewed common stereotypes about Baby Boomers' access to and use of technology and polled participants on their usage (Niemelä-Nyrhinen, 2007). The polls found that the majority of participants had little to no anxiety about technology and the Internet, and a majority of participants were comfortable with and regularly used the Internet and instant messaging. A 2015 study of the online health information seeking habits of different age groups polled participants about their use of web-based social networks, drug review websites, and health discussion forums (Sadah et al., 2015). The results indicated that the age range of 45-64 years, roughly the parameter of the Baby Boomer generation, used general social networks like Facebook and Twitter, drug review websites like Drugs.com, and health web forums like WebMD more frequently, relative to their proportion of the total population, than any other age range (Sadah et al., 2015). The Baby Boomers are of significant interest to healthcare providers, as the generation is not only large in size, but accesses health information in different ways than any previous generation.

1.4 IMPLICATIONS

Many members of the Baby Boomer generation have needed to help their parents make healthcare decisions. The Baby Boomers have also witnessed the financial and emotional burdens associated with caretaking of their parents when long-term health problems arise. Often Baby Boomers have needed to make health decisions on behalf of a seriously ill or cognitively impaired parent and sought health information from various sources. When a parent is not able to make decisions for themselves, their children often become their most important representative in the healthcare process. Soon there will be an increase in Baby Boomers accessing information regarding their own health. Visits to the doctor, discussions with pharmacists, and decisions about power-of-attorney and advance directives will become more frequent. Where will this generation look for information and how will healthcare providers handle their information seeking habits?

1.4.1 Importance of engagement, compliance, and patient education

The health information-seeking habits of Baby Boomers is relevant to clinical practice, patient education, and decision-making. Increasing our understanding of these patterns will allow clinicians to be more aware of Baby Boomers' expectations for engagement and participation in their own healthcare process. Understanding patient expectations and values is a very important aspect of a successful patient-provider relationship.

Engagement is active participation and involvement in the process of learning about a condition and taking steps toward improving one's own health (Vahdat et al., 2014). If the Baby Boomer generation values taking the initiative in researching their own health condition, they will expect more in-depth explanations of their provider's decision-making process. This may be different to members of the previous generation who place greater trust in their healthcare providers and are not as engaged in researching their own condition (Chaudhuri et al., 2013). An interest in researching one's own health is likely connected to engagement in one's overall healthcare process. If a patient had no interest in their health and treatment, they would be unlikely to take the time to conduct independent online research.

Knowledge about health information-seeking habits will also help prepare the clinician to be involved in education, an essential part of healthcare service. An informed clinician would be

more prepared to discuss with the patient inaccurate health information from an unreliable source. A few decades ago the majority of health information was accessed from healthcare professionals and trusted family members (Starr, 1982). Health information conflicting with professional advice was usually only provided by family members (Starr, 1982). Today, the public receives potentially conflicting advice from family members who get information from potentially dubious sources. They are exposed to countless online information sources, some of which provide information lacking in robust evidence and accuracy. Members of this generation could hypothetically need to prioritize different advice given by family members, healthcare professionals, and the Internet.

Healthcare professionals must be prepared to educate and support a wave of patients who may independently research their health condition more than previous generations of patients. Successful education improves health outcomes by making information easier to understand and increases patient engagement. A positive patient-provider relationship is associated with greater engagement and better health outcomes (Vahdat, 2014). When a patient understands health information rather than just receiving it, they are more likely to be engaged in the entire recovery process (Vahdat, 2014).

There may be concerns that patients will refute the advice of their healthcare provider based on information they find online. This is especially true for sources that do not rely on peerreviewed research such as opinion articles and social media groups. An example of this is the rise of the anti-vaccination movement following the rapid online sharing of articles connecting vaccines with autism. Almost every healthcare professional is aware that the original article was based on false claims, and the physician researcher was penalized by the General Medical Counsel for falsifying data, but the long-term effects are real and troubling. The anti-vaccination

movement has contributed to a recent rise in measles and pertussis (whooping cough), diseases that are easily preventable with vaccines (Matt, 2016).

2.0 STUDY AIM

The aim of this study is to learn more about how a unique generation, the Baby Boomers, approach their health information needs. The specific research questions are:

1. Where did Baby Boomers access health information before the Internet became readily available?

2. Where do Baby Boomers look to find information to help make decisions about their own health?

3. How do Baby Boomers prioritize different sources of information?

The purpose of this study is to gather information about where members of this generation look for health information and why they chose these sources. The data will provide valuable information for both healthcare professional and healthcare consumer. Learning more about Baby Boomers will also help to inform us about future generations as the Boomers were in many ways a transitional generation in terms of culture and technology usage.

3.0 METHODS

The study used survey research involving volunteers born between the years 1946 and 1964. These individuals were accessed through Pitt + Me, a database of research participant volunteers.

The survey was hosted on Qualtrics Survey Service. The University of Pittsburgh's Human Research Protection Office (HRPO – formerly known as the Institutional Review Board) reviewed and classified this study under the category of "Tests, Surveys, Interviews, Observations," which is minimal risk exempt status. The study met the requirements for exempt status under section 45 CFR 46.101(b)(2) on June 25, 2018. The survey contains four main sections. The first three sections correspond to the study's research questions. The following sections will provide further detail about the study's participants and survey.

3.1 PARTICIPANTS

All survey participants were accessed through Pitt + Me, a database of voluntary individuals interested in supporting research. Pitt + Me is operated by the University of Pittsburgh's Clinical and Translational Science Institute (CTSI). Pitt + me is supported by the National Institutes of Health through Grant Number UL1 TR001857; this information was requested to be included by CTSI. The only inclusion criterion for participation was year of birth: all individuals were born between the years 1946 and 1964.

Participants indicated interest in the study on the Pitt + Me website, serving as a gatekeeper, which prompted an email from the author with a link to the survey. Survey distribution began on August 20, 2018, and although data collection is still active, this thesis will only look at responses collected between August 20, 2018 and December 1, 2018. As of that date, 222 participants initiated the survey and 216 completed every question. 263 individuals, including the 222 who began the survey, expressed interest in participating in the project on the Pitt + Me website. An unknown number of individuals saw the study information on Pitt + Me.

3.2 SURVEY

The survey was hosted on Qualtrics Survey Service, a secure web-based survey system. Surveys were available both electronically (via email) and in printed physical copies, to avoid the potential sampling bias of omitting participants who do not frequently use the Internet. No paper surveys were requested so all results were collected electronically.

The survey included both fixed response and open-ended questions. Open-ended questions were included throughout the survey in an effort to collect information that is potentially outside of the fixed questions. Participants were asked to recall where they have accessed health information in the past. They were then prompted to rank various sources of health information on a scale of trustworthiness.

3.3 DATA ANALYSIS

The first three sections of the survey correspond to the study's research questions while the fourth covered demographic information. All questions will be labeled Q[n] to allow the reader to reference specific questions from the survey. The first section, which included Q2 and Q3, asked participants to identify where health information was sourced at two stages of their younger life. The second section, which included Q6, Q8, Q9, Q10, Q12, Q13, and Q14, asked participants to identify, describe or explain sources of health information they have accessed. The third section, which included Q4, Q5, Q7, Q11, and Q15, asked participants to identify, describe or explain sources. Finally, Q16 through Q22 were included to create a section of demographic questions.

The numerical order of survey questions did not match the order of research questions for a number of reasons. First, the survey was divided into sections of questions that were nonspecific to Internet use, followed by specific to Internet use. This allowed for Qualtrics' branch logic to prevent individuals who answered "No" to *having Internet access* from answering question related to the Internet and reduced survey burden of irrelevant questions. In addition to this, questions about sourcing were asked before questions about prioritization, leading to a divide in the order of survey questions matching to research questions.

Q2 through Q11 focused on sources of health information, including human advice, print media and online media. Q12 asked participants about their Internet use. Participants who reported regularly using the Internet in Q12 were asked to identify and rank online sources of health information in Q 13-15.

The first question of the survey, labeled Q1 by Qualtrics, asked participants to confirm that they were willing to take the survey. Because it is not relevant to the research aims, it will

not be included in the report and the first discussed question will be Q2. A full copy of the Qualtrics survey listing all questions as they were presented to participants can be found in Appendix A.

3.3.1 Research Question 1

Where did Baby Boomers access health information before the Internet became readily available?

Q2 and Q3 addressed where Baby Boomers received health information when they were young and before the Internet was a common source. Baby Boomers entered adulthood (18+) between 1964 and 1982 (Goodkind, 2016) and the Internet only became widely available to the public in 1995 (Greenstein, 2017); thus there was a 31-year period where Baby Boomers needed to research health information without Internet availability. As discussed earlier, the Baby Boomers represent a transitional generation who grew up without the Internet but needed to adapt to its increased use as adults.

Both questions provided the non-age-specific terms "child" and "young adult," which allowed participants to determine what these terms meant to them. "Child" was intended to prompt recollection of memories of a time when their parents, members of the previous generation, were responsible for seeking health information. Use of the term "young adult" was intended to learn where Baby Boomers looked for health information as independent young adults. The primary purpose of both of these questions was to assess where this generation recalled seeking health information before Internet sources were readily available.

3.3.2 Research Question 2

Where does the Baby Boomer generation look to find information to help make decisions about their own health?

Q6, Q8, Q9, Q10, Q12, Q13, and Q14 addressed where Baby Boomers look for health information. Q6 and Q8 provided lists of common health information sources. Many of these sources reflected the sources provided to participants in the Chaudhuri et al. (2013) study of the information-seeking habits of older adults. In Q6 participants were asked to identify sources of health information they have used in the past. An open-ended answer titled "other" allowed participants to identify a source they felt was not included in the list.

Q8 provided a similar list of health information sources, but asked participants to identify which source they would seek first if a health problem arose. The sources provided in Q8 were the same as in Q6, except Internet sources were divided into "Social Media," "Websites," and "Wikipedia" to create more detailed categories of Internet sources. Wikipedia was included separately as the author perceived its distinct status as an online encyclopedia, rather than a health information website. This question was designed to be compared with Q9, to see if a difference existed between what participants reported doing in the past and what they would hypothetically do in the present.

Q9 and Q10 were open-ended questions that asked participants to remember the last time they needed to learn about a health condition, and identify which information they accessed first and which they accessed second if necessary. These questions aimed to increase understanding of where Baby Boomers recently sought health information when aiming to learn about a

condition or symptom. Q10 allowed participants to state that they only sought information from one source.

Q12, Q13, and Q14 were focused on the Internet use of Baby Boomers. Q12 asked participants if they regularly use the Internet, and defined "regularly" as "at least once a week on average." Q13 asked participants the same question but focused on social media use rather than general Internet use. The author defined "regularly" as weekly given that some participants may not use the Internet or social media daily, but weekly use would be a good indicator of enough familiarity with these sources to use it them as a health information source. Q14 presented a list of categories of online health information sources that was chosen by the author and asked participants to identify which source categories they have used in the past to learn about health and illness.

3.3.3 Research Question 3

How do Baby Boomers prioritize different sources of information?

Q4, Q5, Q7, Q11, and Q15 addressed how Baby Boomers trust and prioritize different sources of health information. Q4 asked participants how important they consider being involved in one's own health decision-making process, and Q5 asked the same about one's family's health decision-making process. Information-seeking is an important aspect of involvement in healthcare.

Both Q4 and Q5 allowed participants to rank their perception on a scale as follows: "Extremely important," "Very important," Moderately important," "Slightly important" and "Not at all important." Q7 and Q15 asked participants to rank a variety of information sources on a scale of trustworthiness that included: "Very Untrustworthy," "Untrustworthy," "Unsure," "Trustworthy" and "Very Trustworthy." Unsure was included so participants would not be forced into ranking a source they have not used or were not familiar with. Q7 provided the same list of health information sources that was used in Q8. Q15 provided the same list of online health information sources that was used in Q14.

Q11 was an open-ended question that asked participants to state whether they believe the Internet or healthcare professionals are valuable sources of health information. "Why?" was included at the end of the question so participants could state their interpretation of the term "valuable" and explain their selection. While the majority of questions regarding prioritization of sources were fixed-response questions, Q15 encouraged participants to provide their own explanation for their preference.

3.3.4 Demographic Information

Q16 through Q22 aimed to collect demographic information about the surveyed population. Racial Identity categories (Q18) were based on recommendations provided by the University of Florida's Institutional Planning of Research department (University of Florida, 2016). Demographic questions were included to increase understanding of the population that accessed the survey. Q16, Q17 and Q22 are discussed in the text below, while Q18-21 are reported in * Table 1 Q18-Q21: Demographics.

This section contained the only questions that allowed participants to choose not to provide a response. Demographic questions were asked at the end of survey. This decision was based on the rationale that participants would have more energy and motivation to answer questions at the beginning rather than the end. Demographic questions require less effort in thoughtful response than the questions that comprise the other sections of the survey. These questions were also asked at the end to avoid beginning the survey with potentially sensitive questions. Q16 through Q21 asked basic demographic questions: year of birth, gender, racial identity, nationality, state residence, and highest attained education level. Individual participant responses will not be compared to their demographic information.

4.0 **RESULTS**

As the survey included both fixed response and open-ended questions, there will two primary forms of reporting data. The answers to fixed response questions will be presented as frequency counts. Responses to open-ended questions will be categorized by similarity and frequency counts will be reported for responses that dominate a question.

4.1 **DEMOGRAPHICS**

Of the 222 individuals who initiated the survey, 216 began the Demographics section and 213 completed every question. Q16 asked participants to identify their year of birth, to which 216 answered. The median age of participants was 64 years (range = 54 - 72). Q17 requested gender identification and of the 216 that answered, 158 (73%) identified as female, 57 (26%) identified as male, and 1 (<1%) selected "I prefer not to say." Q22 asked participants "Have you ever worked in a healthcare profession?" and 78 (36%) selected "Yes (if so, in what profession/s)." Of those 78 the most common selection was some form of experience as a nurse (n=12). Responses to Q18-Q21 are displayed in Table 1 Q18-Q21: Demographics

The largest population of participants were white women who achieved at least a college degree, followed by white men. Almost all of the participants were residents of Pennsylvania, USA. Around one third of all participants indicated experience as a healthcare professional.

Table 1 Q18-Q21: Demographics

Q18: Racial identity (n=214)	
Hispanic or Latino	0 (0%)
Black or Afro-Caribbean	9 (4%)
Asian	1 (0.5%)
Caucasian or non-Hispanic White	200 (93.5%)
Native American or Alaska Native	2 (1%)
Native Hawaiian or Pacific Islander	0 (0%)
Two or more races	2 (1%)
Q19: Nationality (n=215)	
USA	208 (96.5%)
China	1 (0.5%)
Guinea	1 (0.5%)
Jamaica	1 (0.5%)
Russia	1 (0.5%)
Switzerland	1 (0.5%)
United Kingdom	2 (1%)
Q20: State of Residence (n=213)	
Alabama	1 (0.5%)
North Carolina	1 (0.5%)
Ohio	2 (1%)
Pennsylvania	209 (98%)
Q21: Highest Level of Education Attained (n=216)	
High school degree	12 (6%)
College/university partially completed	30 (14%)
College/university degree	86 (40%)
Technical/trade degree	9 (4%)
Master's degree	59 (27%)
Professional degree	5 (2%)
Doctorate degree	12 (6%)
Other	3 (1%)

4.2 **RESEARCH QUESTION 1**

Where did baby boomers access health information before the internet became readily available?

Q2 and Q3 asked participants to provide an open-ended answer about where they sought health information at two different stages of their lives: childhood and young adulthood.

Q2: "When you were a child, where do you remember your family going for information about health and illness?" (n=222)

The majority of answers (n=141) specifically mentioned a physician, especially in the form of a family physician or primary care physician. Multiple answers specifically mentioned family doctors that made house calls or visited their family to provide treatment. Below are examples of these responses:

-The family doctor provided all information about illnesses. I don't remember any discussions about health.

-We saw our local doctor only when needed.

-The family doctor. He actually made housecalls until I was middle school age.

-We went to family doctors. My father would ask questions at his church.

Another trend was the high occurrence of answers including family members (n=46). These responses listed both family members who were physicians or healthcare providers, or family members without healthcare experience. Examples of these responses are listed below:

-My mom went to her family and neighbors.

-No one was sick. Mom for little miseries.

-Family doctor until mom went to nursing school then she became the primary source. -My father worked for the railroad[.] I believe they relied on the company's benefits people for information

-My aunt was a nurse so she was our first line of defense. After her were local doctors who made house calls.

Various other responses reflect popular print sources at the time. For example, 6 participants mentioned books by Dr. Benjamin Spock. Other examples included:

- grandma first then a medical encyclopedia -Family doctor and dentist. TV and probably magazine articles -PDR, Merck's Manual, TV

There were 21 participants who answered "No," suggesting that they did not remember where their family looked for health information as a child.

Q3: "When you were a young adult, where do you remember your family going for information about health and illness?" (n=222)

Although not as frequent as in the previous question, the majority of responses (n=111) mentioned a trusted physician. Another common answer was seeking the advice of a family member, often the mother. A change from the previous question was an increase in responses where participants indicated seeking out a primary source of information that was not a physician, healthcare provider, or family member. Below are examples:

-Myself

-Medical books -My nursing reference books. I am an RN. -I would read about from a library. -I usually used a Merck Manual or went to the library. -library, text books -Books, Encyclopedias, Teen Magazines -Again, always professional medical sources – got degree and worked in health care so consulted colleagues, textbooks, research, etc.

Ten participants answered "No," suggesting that they did not remember where their family looked for health information as a young adult.

4.3 **RESEARCH QUESTION 2**

Where does the Baby Boomer generation look to find information to help make decisions about their own health?

Seven questions (Q6, Q8, Q9, Q10, Q12, Q13, and Q14) were intended to meet the goals of Research Question 2 Q6, Q9, and Q10 prompted participants to think of where they accessed health information more recently. Q8 asked a hypothetical question about where the participant would look now. Q12 asked if they regularly use the Internet. If the participant responded "Yes"

to Q12, Qualtrics branch logic prompted access to Q13 and Q14, questions related to Internet usage.

Q6: "Select all of the following that you have consulted in the past when needing to make a decision about your health" (n=219)

Participants were asked to identify common sources of health information that they have used at any point in their lives to make a decision about their own health. As can be seen in Figure 2 Q6: Reported health information sources used in the past, nearly every participant reported using their physician as a source of health information. Physicians were the only source used more frequently than the Internet, with 217 participants indicating they have consulted physicians for health information and 187 recalling use of the Internet. The Internet was followed by family (149). Only 116, or slightly over 50% of respondents reported using a healthcare professional as a source of health information. If "Healthcare professional" was selected, participants were given the option to enter an open-ended response indicating which healthcare professionals they spoke with. The most frequently occuring open-ended responses listed nurses (55), followed by physical therapists (21).

Twenty participants selected "other" and gave an open-ended response. There was great variety in this category: from chiropractors to "prayer, spirit." Eight of these answers could be considered Internet sources. For example, four open-ended answers listed online research databases such as PubMed and NIH.

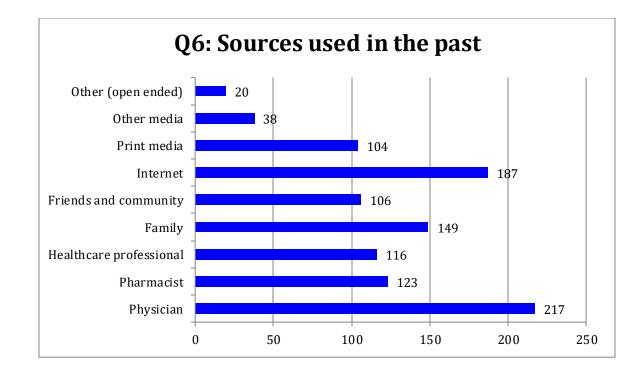


Figure 2 Q6: Reported health information sources used in the past

Q9: "Think of the last problem you've had with your health that you needed to learn more about. Where did you look and/or whom did you consult first to learn more about this condition? (n=219)

This open-ended question prompted participants to remember the last source of health information they used. The overwhelming majority of answers fell into two categories: physician/doctor (90) or an Internet source (88). Although most answers only listed "website" or "Internet," some participants specified which website they accessed on the Internet, with the majority of these being either health information sites such as WebMD, or hospital and government-affiliated sites such as MayoClinic and NIH. The third most common category was family (18). In the majority of answers indicating a family member, participants elaborated that this family member was a healthcare professional such as a nurse.

Q10 – "Did you seek information from a second source or individual? If so, who or where did you seek this information? Which source ended up providing the most valuable information?" (n=219)

Of the 160 participants who selected "Yes," physicians (112) were the most commonly provided example. Internet sources (47) were selected less frequently than in Q9 while other sources such as healthcare professionals (14) and friends (12) appeared more frequently.

Q8: "Select which source you would likely talk to/access first if you needed information about a health condition." (n=219)

The majority of responses fell into two categories: physician (90) or health information website (75). Family (29) and healthcare professional (15) were the next two most common responses.

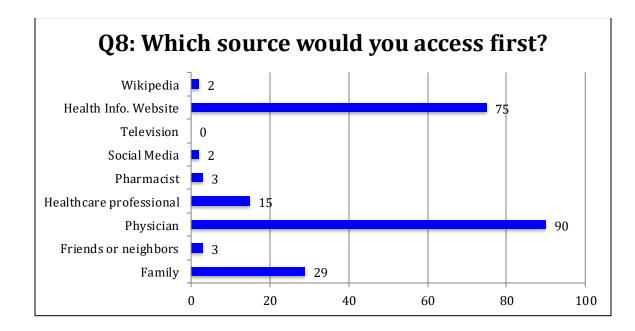


Figure 3 Q8: Which source participants would access first to learn about health condition

Q12: "Do you have access to and regularly use the Internet (at least once a week on average)?" (n=219)

218 of 219 participants answered yes to Q12 regarding regular access and use of the Internet.

Q13: "Do you regularly use social media platforms (at least once a week on average)?" (n=219)

Two thirds of participants (66%) reported weekly social media use, as is displayed in Q13: Selfreported regular (weekly) social media use below.

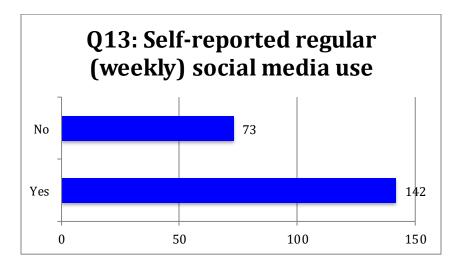


Figure 4 Q13: Self-reported regular (weekly) social media use

Q14: "Select all the sites that you have used to learn about health and illness" (n=218)

This question asked participants to report which types of online sources of health information they have used in the past. Fixed-response answers included examples of each category of source. For-profit health information websites were most frequently selected (190), followed by hospital and university-affiliated websites (152). Government-affiliated sites (111) were the third most commonly selected option. Full response data for Q14 is displayed below in Figure 5.

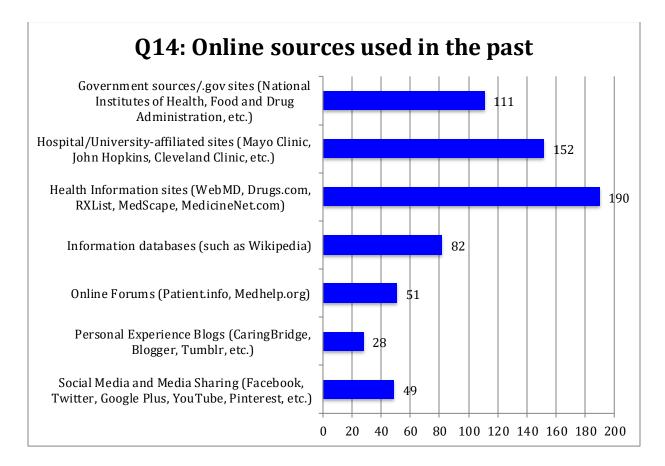


Figure 5 Q14: Reported online sources used in the past

4.4 **RESEARCH QUESTION 3**

How do Baby Boomers prioritize different sources of information?

Q4 and Q5 asked participants to rate the importance of being involved in their own and their family's healthcare process. Q7 and Q15 asked participants to provide a trust ranking of general health information sources and online sources. Q11 asked participants whether they believe healthcare professionals or the Internet are more valuable, and required an open-ended response.

Q4: "How important do you think it is to be involved in the process of making decisions about your own health?" (n=219)

218 of 219 participants indicated that being involved in their own health decision-making process is "Extremely important" (201) or "Very important" (17).

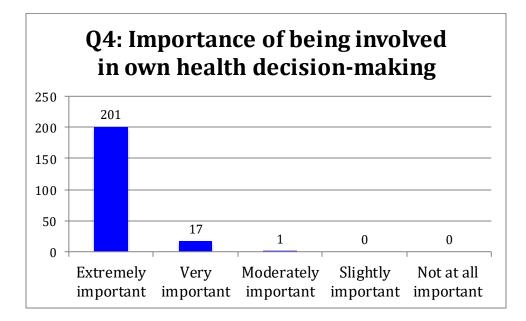


Figure 6 Q4: Importance of being involved in own health decision-making

Q5: "How important do you think it is to be involved in the process of making decisions about the health of an immediate family member?" (n=219)

There was more variation in responses from this question compared to Q4, as can be seen in Q5: Importance of being involved in family's health decision-making. 121 selected "Extremely important," 73 selected "Very important," and 21 selected "Moderately important." Participants were less likely to consider being involved in the health decision-making process of a family member "Extremely important" than being involved in decision-making about their own health.

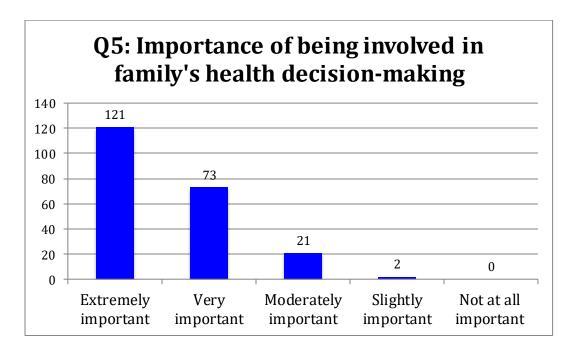


Figure 7 Q5: Importance of being involved in family's health decision-making

Q7: "If you are looking for information about your health, illness, or medication, rate the following sources in terms of how trustworthy you think the information will be." (n=219) Q7: Ranking sources by trustworthiness presents the data collected from Q7, with points of

interest being high trust rankings for healthcare professionals, family and health information websites, and low rankings for social

media and television

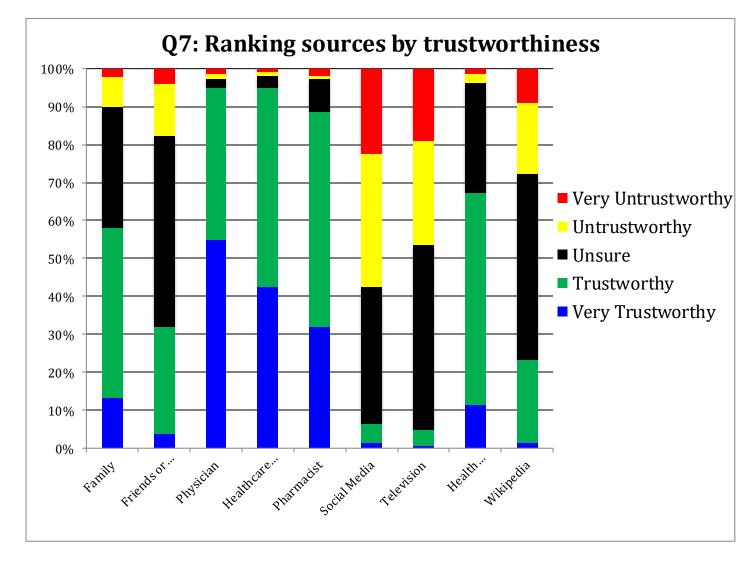


Figure 8 Q7: Ranking sources by trustworthiness

*Source categories in Figure 8 from left to right: (1) Family, (2) Friends or Community Members, (3) Physician, (4) Healthcare Professional, (5) Pharmacist, (6) Social Media, (7) Television, (8) Health Information Websites, and (9) Wikipedia.

Q7 presented participants with a list of health information sources and asked them to rank them in terms of trustworthiness. Participants were also presented with the option "Unsure." This was intended to prevent collection of trust rankings where participants had no opinion on an item's trustworthiness. Three sources received a significant number of "Unsure" responses: *Friends or Neighbors* (110), *Wikipedia* (107), and *Television* (102).

The three most trusted sources were healthcare providers: *Physicians, Healthcare Professionals, and Pharmacists. Physicians* were the most trusted source of health information with 95% of participants ranking them as either "Very Trustworthy" (120) or "Trustworthy" (88). *Healthcare Professionals* were ranked as "Very Trustworthy" (93) or "Trustworthy" (115) by 95%, although fewer participants viewed them as very trustworthy.

The only media-based source to receive more positive than negative trust rankings were *Health Information Websites*; 67% (147) considered this category to be "Very Trustworthy" (25) or "Trustworthy" (122). This category was followed by *Wikipedia* (51), *Social Media* (14), *and Television* (10). *Social Media* and *Television* were the only two sources with sizable (close to 50%) numbers of untrustworthiness rankings, with 126 ranking *Social Media* as "Untrustworthy" or "Very Untrustworthy," and 97 ranking *Television* the same.

Family and *Friends or Neighbors* were considered more trustworthy than every mediabased source besides *Health Information Websites*. 58% of participants ranked *Family* as either "Very Trustworthy" (29) or "Trustworthy" (98) while 32% ranked *Friends or Neighbors* as "Very Trustworthy" (8) or "Trustworthy" (62).

Q11: "Which information is more valuable when learning about a health condition: information from the Internet or advice from a physician or healthcare professional? Why?" (n=219)

This question prompted participants to provide an open-text response about whether they think health information from the Internet or advice of a physician or healthcare professional is more valuable. It also asked them to provide an explanation for their answer. Responses can be organized into three broad categories: physician or healthcare professional (154), Internet (35), or responses that describe a complementary relationship (28). Two responses did not fit into any of these categories.

The advice of physicians or healthcare professionals was described as more valuable by 154 participants (70%). A common theme was the expression that physicians have a better understanding of the individual and their unique health status. Examples of this are listed below:

- Physician or health care worker ... these individuals know me, my needs and issues. Even good sources on the Internet speak in generalities. In addition, it can be hard determining 'good' sources on the Internet.

- physician: because the doctor can tailor information to my specific situation

- Physician because they are the ones that know my health background and can make the better decision for me

- Real healthcare professional- tailored response to me

Another trend in responses was that the advice of physicians and healthcare professionals is most trustworthy due to their status as an expert as a result of their educational background, license requirements, and personal experience. Below are examples:

- "Physician. Reliability, training, nuanced understanding"

- Educational background, and licensing requirement

- Physician because he/she has the training and resources, plus experience, to draw upon.

- Advice from physician, that is what the[y] went to school for.

- Physician/healthcare professional due to their education, training, and state board requirements

- Physician. They have been educated and seen other patients with similar problems

A third trend in this group's selection was distrust in Internet sources, as expressed in the below responses:

- Physician - sometimes very confusing, and scary, on the Internet.

- I think it's more valuable to get advice from a physician or healthcare professional. It's scary reading unfiltered information found on the Internet.

- Physician; you cannot trust everything you read on the Internet

- Healthcare professional. With the exception of professional literature, information from the Internet is unreliable.

Information from the Internet was described as more valuable than a physician or healthcare professional's advice by 35 participants (16%). A common explanation for this answer was the diversity of sources available from the Internet. Examples of these responses include:

- Internet includes more and recent sources

- Internet – it gives you choices and I make my own decision and if necessary I seek a physician.

- Internet... I can gather information from many different points of view.

- Internet. Because there are various sources that you can compare and decipher. Sometimes the physician doesn't explain everything or go into depth

- Internet because one has all the sources and time. Individuals are very limited in the time and information they have.

Another trend in responses was concern about the accuracy of information or time constraints of physicians and healthcare professionals:

- Internet. You actually get many sides of information. Doctors tend to be one sided and I think most are in it to push certain drugs. They need to keep ordering test and things to keep you coming back to get a bigger co pay/ money in their practice/wallet

- Internet, because most times drs just blanket an illness not tailor to individual

- We should say the healthcare professional, and in years past that would be the case. But in today's medical system, appointments with physicians are so very brief that they simply do not have time to convey sufficient information and educate the patient. Patients now must take getting informed into their own hands"

- The Internet is more valuable because there is more information to consider and I can take all of time that I want to on the Internet. The Dr.'s time and knowledge is limited. I have been mis-diagnosed on several occa[s]ions

- I generally educate myself and then seek out a physician for diagnostic tests and prescriptions I cannot get on my own. I trust my own research and I somewhat trust my physician In addition to the previously discussed trends, a number of responses emphasized the importance of seeking out reliable Internet sources:

- The Internet is much more valuable BUT you have to be sure it is a trustworthy site for there are many pages with misleading and false information.

- Internet because you can seek out several reliable sites; with physician or healthcare prof. you have limited time for discussion

- Internet then pcp because certain Internet sources are not funded by drug company[ies]

- The Internet when there is a reputable site. I found it easier to read and reread the information. Then I can research points that confuse me and I can take my time.

The final group of responses did not fit into either of the previous categories. Within this category, responses either indicated that their preference depends on the specific health situation or that they use both sources in a complementary fashion. Below are examples of the former:

- Depends--I usually trust my physician, but we get conflic[t]ing information from various sources, so we have to make an informed decision as to which source is more valuable.

- depends. physician should have more accurate info, but you may need to get more complete information

- It depends. I'm fighting a multi-decade battle with cancer; I've frequently found studies (by which I mean real, peer-reviewed work, not Dr Oz) that my physicians weren't aware of.

- depends upon what I feel about the severity of the issue

Examples of the importance of using both healthcare providers and the Internet in a complementary fashion include the below:

- Internet first, gives you just the facts, where once see a doctor, she can advise me how the condition impacts me

- Both. Internet for background, then physician. Doc doesn't have time to do full background on a condition

- Combination. Physic[i]ans, etc. know the most about what they're doing, but they often don't give you the bigger picture such as more info about the illness, possible causes, different treatments.

- For me they both need to be used together. As a nurse, I would not necessarily believe what a MD recommends without having a confirming source of information. MDs now are too busy and too much under the control of health plans to be totally unbiased. Q15:"If you are looking for information about health, illness, or medication, rate the following sources in terms of how trustworthy you think the information will be." (n=219) Q15: Ranking online sources by trustworthiness presents data collected from Q15, showing high trust rankings for health information sites, hospital/university sites, and government sites, and low rankings for social media.

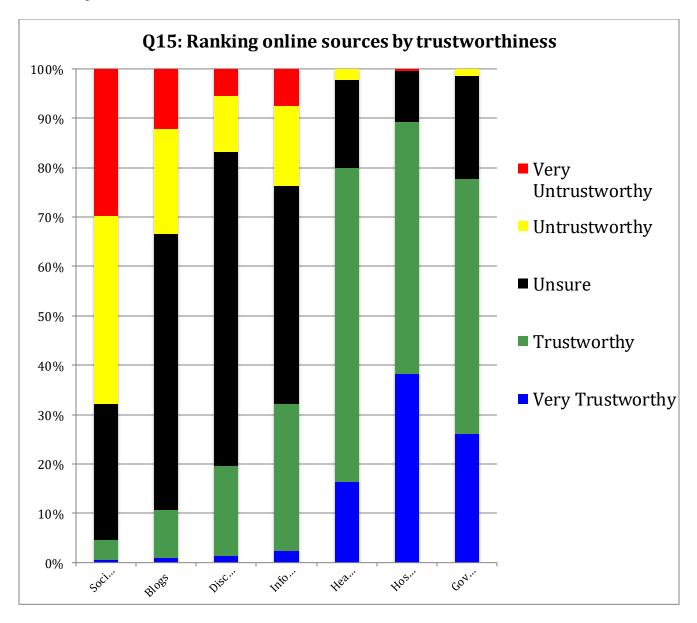


Figure 9 Q15: Ranking online sources by trustworthiness

*Source categories in Figure 9 from left to right: (1) Social Media and Media Sharing, (2) Personal Experience Blogs, (3) Online Forums, (4) Information Databases, (5) Health Information Sites, (6) Hospital/University sites, and (7) Government sources/.gov sites.

Q15 presented participants with a list of online health information sources and asked them to rank them in terms of trustworthiness. Similar to Q7, participants were able to select "Unsure." 215 individuals answered this question. "Unsure" was the most selected answer for three source categories: *Discussion Forums* (137), *Blogs* (120), and *Information Databases* (95).

Hospital/University Websites, Government Websites, and Health Information Websites were the most trusted sources of online health information. 89% (192) of participants ranked Hospital/University Websites as "Very Trustworthy" (82) or "Trustworthy" (110). Government Websites were considered trustworthy by 77% (167) and 80% (172) considered Health Information Websites the same, although the latter received 21 fewer rankings of "Very Trustworthy." The three websites associated with medical authority were the most trusted. 69 participants considered Information Databases to be trustworthy and 42 ranked Discussion Forums trustworthy, with a significant majority of selections for both categories being "Unsure."

Social Media and Blogs were the least trusted sources of online health information. 68% ranked Social Media sources as untrustworthy, with 82 selecting "Untrustworthy" and 64 selecting "Very Untrustworthy." 33% ranked Blogs as untrustworthy, with 46 selecting "Untrustworthy" and 26 selecting "Very Untrustworthy."

5.0 **DISCUSSION**

This is the first study exploring the health information seeking *and* trust ranking patterns of members of the Baby Boomer generation. Although the participant population may not represent the entire generation, their characteristics represent millions of future healthcare recipients. The novel findings of this study have the potential to increase awareness of the information seeking habits and preferences of what will be the largest population of healthcare recipients in American history. Healthcare providers will find this of interest to support learning and discussing how their future patients look for health information and which sources they trust.

5.1 CHARACTERISTICS OF SURVEY PARTICIPANT SAMPLE

The median age of surveyed Baby Boomers was 64 years. The majority of survey participants were white (94%), female (73%), and pursued post-high school education (93%). Almost all (98%) were residents of the state of Pennsylvania. Around 36% of participants reported having experience working as a healthcare professional. These characteristics are reflective of the population, who were individuals volunteering to participate in online research studies.

5.2 **RESEARCH QUESTION 1**

Where did Baby Boomers access health information before the Internet became readily available?

When asked to remember where their family sought health information as a child, the large majority of participants indicated their parents spoke to a physician or talked to a family member. Their parents largely relied on the advice of others. Asked the same question about young adulthood, physicians and family members remained common sources, but many participants stated that they began to independently research health information with text sources such as the Merck Manual, which appeared multiple times in response to Q3.

5.3 **RESEARCH QUESTION 2**

Where does the Baby Boomer generation look to find information to help make decisions about their own health?

Paul Starr (1982) discussed the establishment of America's institutions of medical authority as trustworthy sources of health information and provision. Before this shift in the 19th century, individuals mostly relied on family and community members for these needs (Starr, 1982). In the late 20th century, widespread public Internet use led to its integration into the lives of working Americans who were required to adapt to this technology (Greenstein, 2017). These three

sources reflect distinct changes in America's history of health information seeking, which are evident in the responses to this survey.

Physicians (99%), Internet sources (85%) and family members (65%) were the three most frequently used health information sources. The surveys revealed that almost every Baby Boomer participant has used the Internet to access health information in some form. This attribute differs significantly from previous generations, who rely more heavily on physicians and family members and access the Internet less frequently (Chaudhuri et al., 2013). Unlike older generations, when an average Baby Boomer starts experiencing symptoms or receives a diagnosis, they are very likely to use the Internet for information at some point. This variation in access could be due to differences in the older generation's access habits and preferences, less available technology during the majority of their lifetime, another explanation, or a combination of these factors.

Around two thirds of participants reported weekly social media use, meaning that the majority of this population may be exposed to unfiltered health information from these platforms, unlike older generations that use the Internet less frequently. Asking to confirm weekly use did not separate individuals who only use social media platforms once a week from those who spend hours a day using them. Individuals who heavily use social media use would more be more likely to access health information there than those who do not, as they are more frequently exposed to health-related articles and opinions.

Baby Boomers reported using the Internet for health information research more than they use healthcare professionals (53%) and pharmacists (56%). This difference is likely due to the easy accessibility of online sources compared to that of a professional. The third most commonly selected source was family (68%). As revealed in the open-ended answers, there may be

crossover between the categories of healthcare professional and family, as many trusted family members may have experience working in a healthcare profession. Friends and community members (48%) and print media (46%) were commonly accessed sources. Other media sources such as television and podcasts were only reported as used by 17%.

It is important to note that "The Internet" as a source could be interpreted differently depending on an individual's interpretation of the term. Some may have viewed the Internet as simply entering terms in a search engine like Google. This could explain the numerous individuals who selected "Other" and entered specific online sources like PubMed and NIH.

5.4 RESEARCH QUESTION 3

How do Baby Boomers prioritize different sources of information?

Roughly 99% of participants indicated that being involved in one's own health-decision making is either "extremely important" (92%) or "very important" (7%). This generation views themselves as crucial decision-makers in their own healthcare process, potentially differing from the traditional authoritative relationship with providers associated with the previous generation (Starr, 1982). In contrast, only 59% considered being involved in the decision-making process of a family member "extremely important," although most considered it "very important."

Q7 and Q15 allowed participants to select "Unsure" instead of ranking a sources trustworthiness. This resulted in a few source categories receiving a majority of "unsure" answers, which did not allow for recording of a participant's 'gut feeling' assessment of trustworthiness. On the other hand, allowing "unsure" prevented the collection of responses in

which the participant truly did not have a trust preference and simply selected an answer out of necessity.

Similar to the previous generation, Baby Boomers consider physicians to be the most trustworthy source of health information, followed by healthcare professionals and pharmacists. The key distinction between the previous generation is that Baby Boomers also consider certain Internet sources trustworthy, whereas many members of older generations did not as shown in Chaudhuri et al.'s 2013 study. Roughly 67% of participants identified health information websites as either trustworthy or very trustworthy. Trust in both professional and Internet sources could lead to conflicts in information between a person's two most trusted sources of information, and Baby Boomers may find themselves having to choose between these. Health information sites were the only media source that was found trustworthy by the majority of participants. The majority of participants also identified family members as a trustworthy source.

When asked whether physicians or the Internet provided more valuable health information, 70% selected physicians as being most valuable. Common reasons given were the physicians' knowledge of one's unique health history, physicians' training or expertise, and participants' distrust in Internet sources. As stated earlier, physicians are the most trustworthy information providers to the majority of Baby Boomers. A small proportion (16%) answered that more valuable information could be found from Internet sources, giving reasons that included distrust in physicians or healthcare professionals and concern about the time constraints of scheduling appointments with a professional. Many participants stressed the importance of seeking out reliable sources of information. Roughly 13% stated that they use both in a complementary fashion or that their preference depends on the specific health situation.

Around 80% rated health information websites such as WebMD as "Trustworthy" or "Very Trustworthy." When asked to identify types of online sources they have used in the past, participants reported using for-profit online sources such as WebMD more frequently than government affiliated sources (e.g. WHO) or university affiliated sources (e.g. MayoClinic). Use did not match trust though, as more participants considered government and university-affiliated online sources to be "very trustworthy," compared to the majority of participants who ranked websites like WebMD as simply "trustworthy." For-profit sites such as WebMD were considered trustworthy by the large majority of participants, which is problematic. WebMD has been criticized in the media for its tendency to lead individuals to falsely diagnose themselves with serious ailments (Heffernan, 2011). They have also been criticized for receiving funding from pharmaceutical companies to encourage use of their drugs and to "frame information commercially" (Heffernan, 2011). It is very possible that most individuals, regardless of their generation, are unaware of the for-profit or non-profit status of online information sources, and do not consider it to be a factor in source preference.

5.5 IMPLICATIONS FOR HEALTHCARE PROFESSIONALS

This study reinforces the prediction (Krahn, 2013) that Baby Boomers, the largest incoming wave of patients in American history, use the Internet for health information more than any previous generation. This may be due to characteristics unique to the generation, but is also likely due to the explosion of online sources of health information within the past few decades. Baby Boomers are also likely to trust Internet sources more than previous generations. This will likely lead to an increase in situations where patients are coming into healthcare settings with

prior knowledge of their condition or symptoms. Previous generations were more likely to only access and trust the expertise of physicians and other healthcare professionals. If the information this population accesses conflicts with the information provided by a professional, the professional may need to educate the patient on the reasoning behind health assessments.

Some healthcare providers may fear that seeking health information on the Internet leads to more challenging patients. While Baby Boomers use the Internet to seek health information more than older generations (Chaudhuri et al., 2013), this should not necessarily be interpreted as negative factor. It is important to prioritize an individual's own goals and motivation in care and engage them in the therapeutic process. In addition to this, the survey revealed that physicians, followed by other healthcare professionals, are considered to be the most trustworthy sources of information. Increased Internet use should not be considered a threat to the authority of healthcare professionals.

There are potentially positive effects of online health information sourcing. The Internet as a source of health information should not be viewed as a blanket threat to providers for two main reasons. First it is inevitable that the future of health information seeking will involve patients researching and self-diagnosing through the Internet and professionals should be prepared for this. Online health-related research could lead to some misinformed patients, but is far more likely to lead to patients who have a greater understanding of their condition than if they had not engaged in any independent research. An increase in the number of self-informed patients will make education about basic concepts easier. It may also be an important task of healthcare professionals to help guide patients to online sources they consider trustworthy. A future study could be done on how professionals can educate patients about online health information seeking.

There are other potential positive effects to independent online research such as the possibility that putting energy into researching one's illness is a good indicator of motivation to improve one's health status and engagement. Especially for disorders treated by health rehabilitation professionals, patient self-motivation is extremely important for improving health outcomes. Successful recovery relies heavily on patients being actively involved in the process and using therapeutic techniques taught by the provider.

Using the Internet as a health information tool can provide psychological and emotional benefits. The results of a longitudinal study indicated that searching the Internet for information about a diagnosis creates a more positive outlook of one's own health when the individual was diagnosed with a severe illness (Sassenberg & Greving, 2016). Online support groups also provide social support and emotional comfort (Purk, 2004). They can be accessed at any time and regardless of an individual's mobility status, making social support functions more readily accessible than traditional support group gatherings.

5.6 LIMITATIONS

There are limitations present in the design of this study. First is a lack of sample diversity. Over 90% of participants identified as white or Caucasian. Around 70% completed either a college degree or graduate degree program. Variations in culture and socioeconomic status can affect which sources an individual has access to and how they place trust in these sources. There was also a lack of geographic diversity, as almost all participants were recruited from the Pittsburgh area. The homogeny of this survey's participant population led to results that may not represent the entire population of American Baby Boomers. These limitations were a result of where participants were pooled from: a University of Pittsburgh voluntary research participant database.

Another potential limitation was the study's sole reliance on participants who were accessed via an Internet database. This could potentially have skewed the results towards increased reported Internet use. A paper survey option was offered to participants although none requested it. These weaknesses do not diminish the value of the study, as the participants represent what will be a significant patient population in the future: Caucasian, college-educated and Internet-using Baby Boomers.

This study did not compare answers with the age of participants. It is possible that the preferences and habits of younger Baby Boomers different from those of the older. Q4 and Q5 asked participants to identify the importance with answer options: "Extremely important," "Very important," "Moderately important," "Slightly important," or "Not at all." These answers were selected with the author's belief that most participants would consider being involved in their own and their family member's healthcare process to be important, and with the intent of giving participants a large scale of identifying importance to allow comparison between questions. Although there was a difference in response between Q4 and Q5 in selection of the first two options, the majority of responses fell within these options. Having the majority of options emphasize "importance" may have slanted participants to believe they are expected to identify the provided belief as important. In addition to this, terms such as "extremely" and "very" are ambiguous and interpretation may differ greatly from person to person.

5.7 RECOMMENDATIONS FOR FUTURE STUDY

The age range of the Baby Boomer generation spans 18 years matching this study's participants. One avenue for further study would involve looking at differences in responses between participants depending on their age within this range. Generational parameters do not define an entire population and there may be differences in source use and trust between younger and older Baby Boomers. For example, this could reveal if a specific age range within this generation experienced an increase in trust of the Internet or decrease in trust of physicians.

Another recommendation for future study would be to target different or more diverse participant populations. The majority of participants were white, college-educated professionals or retired professionals from western Pennsylvania. Targeting different populations could potentially identify differences in source usage and trust. Individuals from different racial and cultural backgrounds can perceive health and illness differently from one another. There is also a well-documented racial disparity in Internet access in the United States, particularly among African-Americans and Latino Americans living in challenging socioeconomic situations (Lewis, 2017). If the Internet is being discussed as a potential tool for improving patient engagement and health outcomes, then yet another racial health disparity may exist.

It is unlikely that unequal access to Internet is only confined to race, as access is expensive; future studies should aim to contact lower SES individuals. Similarly, there is a welldocumented disparity in access to healthcare professionals and resources in many of America's rural and underserved areas (Hartley, 2004). Another potential barrier to access for Baby Boomers is providing care for their aging parents, limiting time resources that would allow them to see healthcare professionals in person. A grant-funded study providing incentives for survey completion could help expand the demographic makeup of participants and address potential

barriers to both Internet and healthcare access. Only researching a slice of America's demographic population does not provide the whole picture of how American Baby Boomers access and trust health information.

In addition to addressing different populations, it would be valuable to ask participants how frequently they use social media (weekly, daily, hourly) to compare with their trust of online sources. Trust preferences may differ between individuals who check social media infrequently and those who spend hours a day on social media platforms. Another emerging topic this study did not cover was telehealth and telepractice. The survey separated physicians and healthcare professionals from Internet sources but did not ask participants about the increasingly common combination of the two. Future studies would benefit from aiming to learn more about how Baby Boomers perceive health advice from professionals on the Internet, especially in situations where the professionals are not familiar with the patient's health history.

Q22 asked participants to state if they have ever worked in a healthcare profession and if so to state the position. Q22 was initially intended to be compared to responses in the other sections. The necessity of the December 1 data cutoff for this thesis required the author to look at responses through a Qualtrics data report in the form of a pdf, which did not allow for participant answer comparison. As the survey is still active, it was not possible to compare and separate responses from before and after the cutoff date. There is still potential for future comparison of Q22 to other responses through Qualtrics' data analysis function of an active survey. A future study would benefit from comparing information like this to responses.

5.8 LOOKING TOWARD THE FUTURE

This thesis aimed to learn more about a generation that will soon constitute the majority of American healthcare recipients. The information collected by this study was intended to help healthcare professionals and educators better understand this population, with the ultimate goal being improved patient-provider relationships and better health outcomes. A new wave of patients is less likely to rely solely on the advice of their provider and more likely to research their health condition on the Internet. Healthcare professionals should understand that this is not a threat to their authority, but an opportunity for increased patient engagement and self-advocacy. Use of the Internet has potential to function as a valuable supplementary education tool in an individual's care process. Patients can also receive emotional support from online support groups.

The survey results indicate that there is a need for increased understanding of online health information sources. For example, some participants did not differentiate trustworthiness of information provided by for-profit sites such as webmd.com and non-profit sites like mayoclinic.org. Increased understanding of the information provided by these sources is necessary for healthcare professionals, educators, and patients. Healthcare professionals are responsible for equipping patients with tools and skills that will benefit their health, and educators are responsible for teaching future professionals to be prepared for this task. This necessitates increased education regarding which reliable sources they should recommend to their patients dependent on the situation. And although nearly every participant in this survey reported regular Internet access, other studies have indicated that not all American populations share this privilege. Future studies should aim to learn more about differences in populations access to information resources, and healthcare professionals can empower individuals lacking in

these resources by informing them not only about which sources to access, but where they can be accessed (e.g. a public library).

6.0 CONCLUSION

The Baby Boomer generation will soon become the largest population of healthcare recipients in American history. Within the past few decades an explosion of online health information sources have become readily available. The Baby Boomers use the Internet and these sources more frequently than any previous generation. They are less likely to rely solely on their healthcare provider for information and are more likely to research health information independently. This may lead to conflicts between sources of information but may also motivate members of this generation to be more proactive about their health. Rather than simply being scared of potential conflicts from Internet sources and patients with potentially stronger opinions, healthcare professionals should be prepared to research and recommend valuable online sources and engage with patients in a way that facilitates trust-building, positive patient-provider relationships, and improved health outcomes.

APPENDIX A : SURVEY

Ben Zook BPhil

Survey Flow

Standard: Introduction + Past Experiences with Seeking Health Information (3 Questions)

Standard: Current Experiences with Seeking Health Information (9 Questions)

Branch: New Branch

If

If Do you have access to and regularly use the Internet (at least once a week on average)?

Yes Is Selected

Block: Internet Usage (3 Questions)

Block: Demographics (8 Questions)

Page Break

Start of Block: Introduction + Past Experiences with Seeking Health Information

Q1 Thank you for agreeing to participate in this survey. I am an undergraduate Speech-Language Pathology student, aiming to gather information that will help healthcare professionals be better prepared to provide the best possible care and be more aware of your expectations. The survey will ask you some questions about where you prefer to get information about health issues, and will end with basic demographic questions. All responses and information will remain completely anonymous. If you would prefer to fill out a paper copy of this survey, please contact me by email at bjz9@pitt.edu.

Q2 When you were a child, where do you remember your family going to for information about health and illness?

 \bigcirc Please describe what you remember in a few sentences or less: (1)

 \bigcirc I do not remember where my family sought out information about health and illness (2)

Q3 When you were a young adult, where do you remember going for information about health and illness?

 \bigcirc Please describe what you remember in a few sentences or less: (1)

○ I do not remember where I sought out information about health and illness when I was a young adult (2)

End of Block: Introduction + Past Experiences with Seeking Health Information

Start of Block: Current Experiences with Seeking Health Information

Q4 How important do you think it is to be involved in the process of making decisions about your own health?

 \bigcirc Extremely important (1)

 \bigcirc Very important (2)

 \bigcirc Moderately important (3)

 \bigcirc Slightly important (4)

 \bigcirc Not at all important (5)

Q5 How important do you think it is to be involved in making decisions about the health of an immediate family member?

 \bigcirc Extremely important (1)

 \bigcirc Very important (2)

 \bigcirc Moderately important (3)

 \bigcirc Slightly important (4)

 \bigcirc Not at all important (5)

Q6 Select all of the following that you have consulted in the past when needing to make a decision about your health

Physician (1) Pharmacist (2)

Healthcare professional other than pharmacists, such as... (3)

Family (4)

Friends and community members (5)

The Internet (6)

Print media (books, magazines, newspapers, etc.) (7)

Other media (television, podcasts, etc.) (8)

Other (9) _____

Q7 If you are looking for information about your health, illness, or medication, rate the following sources in terms of how trustworthy you think the information will be.

	Very	Untrustworthy	Unsure (3)	Trustworthy	Very
	Untrustworthy	(2)		(4)	Trustworthy
	(1)				(5)
Family (1)	0	0	\bigcirc	\bigcirc	\bigcirc
Friends or neighbors (2)	0	0	0	\bigcirc	0
Physician (3)	\bigcirc	\bigcirc	0	\bigcirc	0
Healthcare professional	0	\bigcirc	0	0	\bigcirc
(such as					
nurse,					
physical					
therapist, etc.)					
(4)					
Pharmacist	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
(5)					
Social Media (6)	0	0	\bigcirc	\bigcirc	\bigcirc
Television (7)	\bigcirc	0	0	\bigcirc	0

Websites	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
(such	as				
WebMD,					
Mayoclinic,					
Drugs.com)					
(8)					
Wikipedia (9)	\bigcirc	\bigcirc	\bigcirc	\bigcirc

Q8 Select which source you would likely talk to/access *first* if you needed information about a health condition.

 \bigcirc Family (1)

 \bigcirc Friends or neighbors (2)

 \bigcirc Physician (3)

O Healthcare professional (such as nurse, physical therapist, etc.) (4)

 \bigcirc Pharmacist (5)

O Social Media (6)

 \bigcirc Television (7)

• Websites (such as WebMD, Mayoclinic, Drugs.com) (8)

O Wikipedia (9)

Q9 Think of the last problem you had with your health that you needed to learn more about. Where did you look and/or whom did you consult *first* to learn more about this condition?

Q10 Did you seek information from a *second* source or individual? If so, who or where did you seek this information? Which source ended up providing the most valuable information?

 \bigcirc I only consulted one source/individual (1)

O (2)_____

Q11 Which information is more valuable when learning more about a health condition: information from the Internet *or* advice from a physician or healthcare professional? Why?

Q12 Do you have access to and regularly use the Internet (at least once a week on average)?

 \bigcirc Yes (1)

 \bigcirc No (2)

End of Block: Current Experiences with Seeking Health Information

Start of Block: Internet Usage

Q13 Do you regularly use social media platforms (at least once a week on average)?

 \bigcirc Yes (1)

 \bigcirc No (2)

Q14 Select all the sites that you have used to learn about health and illness.

Social Media and Media Sharing (Facebook, Twitter, Google Plus, YouTube, Pinterest, etc.) (1)

Personal Experience Blogs (CaringBridge, Blogger, Tumblr, etc.) (2)

Online Forums (Patient.info, Medhelp.org) (3)

Information databases (such as Wikipedia) (4)

Health Information sites (WebMD, Drugs.com, RXList, MedScape, MedicineNet.com) (5)

Hospital/University-affiliated sites (Mayo Clinic, John Hopkins, Cleveland Clinic, etc.) (6)

Government sources/.gov sites (National Institutes of Health, Food and Drug Administration, etc.) (7)

Q15 If you are looking for information about your health, illness, or medication, rate the following sources in terms of how trustworthy you think the information will be.

	Very	Untrustworthy	Unsure	Trustworthy	Very
	Untrustworthy	(2)	(3)	(4)	Trustworthy
	(1)				(5)
Social Media and	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
Media Sharing	Ŭ	Ŭ	0	0	0
(Facebook, Twitter,					
Google Plus,					
YouTube, Pinterest,					
etc.) (1)					
Personal Experience	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
Blogs		0	0	0	0
(CaringBridge,					
Blogger, Tumblr,					
etc.) (2)					
Online Forums	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
(Patient.info,	_				
Medhelp.org) (3)					
Information	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
databases (such as					
Wikipedia) (4)					
Health Information	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
sites (WebMD,	-	-	-	~	-

Drugs.com, RXList,					
MedScape,					
MedicineNet.com)					
(5)					
Hospital/University-	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
affiliated sites					
(Mayo Clinic, John					
Hopkins, Cleveland					
Clinic, etc.) (6)					
Government	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
sources/.gov sites					
(National Institutes					
of Health, Food and					
Drug					
Administration,					
etc.) (7)					

End of Block: Internet Usage

Start of Block: Demographics

Q16 What is your year of birth? (if you were not born during any of the listed years, you may exit the survey)

▼ 1946 (1) ... 1964 (19)

Q17 What is your gender?

 \bigcirc Male (1)

 \bigcirc Female (2)

 \bigcirc I prefer to not say (3)

Other (4) _____

Q18 Which of the following best represents your racial identity?

 \bigcirc Hispanic or Latino (1)

 \bigcirc Black or Afro-Carribean (2)

 \bigcirc Asian (3)

 \bigcirc Caucasian or Non-Hispanic White (4)

O Native American or Alaska Native (5)

O Native Hawaiian or Pacific Islander (6)

 \bigcirc Two or more races (7)

- Q19 What is your country of birth?
- ▼ Afghanistan (1) ... Zimbabwe (1357)

Q20 In which state do you currently reside?

▼ Alabama (1) ... I do not reside in the United States (53)

Q21 What is your highest level of attained education?

 \bigcirc No schooling completed (1)

O Completed elementary school (2)

 \bigcirc High School partially completed (3)

 \bigcirc High School degree (4)

O College/university partially completed (5)

O College/university degree (6)

O Technical/Trade degre (7)

O Master's Degree (8)

- O Professional Degree (9)
- \bigcirc Doctorate Degree (10)

Other (11)

Q22 Have you ever worked in a healthcare profession?

○ Yes	(if	so,	in	what	profession/s)	(1)
O No (2)						
○ Not sure	e (3)					

Q23 Thank you for your time. You are about to finish the survey. If you would like to review your answers please go back.

End of Block: Demographics

APPENDIX B : TABLES FOR Q7 AND Q15

	Very Untrustworthy	Untrustworthy	Unsure	Trustworthy	Very Trustworthy
Family	5	17	70	98	29
Friends or Neighbors	9	30	110	62	8
Physician	3	3	5	88	120
Healthcare professional	2	2	7	115	93
Pharmacist	4	2	19	124	70
Social Media	49	77	79	11	3
Television	40	57	102	9	1
Health Information Websites	3	5	64	122	25
Wikipedia	20	41	107	48	3

	Very				Very
	Untrustworthy	Untrustworthy	Unsure	Trustworthy	Trustworthy
Social Media	64	82	59	9	1
Blogs	26	46	120	21	2
Discussion Forums	12	24	137	39	3
Information Databases (such as wikipedia)	16	35	95	64	5
Health Information Websites	0	5	38	137	35
Hospital/University Websites	1	0	22	110	82
Government Websites	0	3	45	111	56

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