

Delaware Health Literacy Report 2023



**DELAWARE HEALTH
AND SOCIAL SERVICES**
Division of Public Health



ChristianaCare®

**Partnership for Healthy
Communities**
UNIVERSITY OF DELAWARE
COMMUNITY ENGAGEMENT
INITIATIVE



**PMG
CONSULTING**

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 - Focus group members
 - Survey participants
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 - Delaware Division of Libraries
 - Sussex County Health Coalition
 - Delaware Alliance for Nonprofit Advancement
 - United Way of Delaware
- All interviewees, focus group participants, and survey participants who shared their time, and perspectives. ***All quotes provided in this report have been approved for release by the individual.***

FOREWORD

The Delaware Division of Public Health, under the auspices of the Department of Health and Social Services, intends to continue its support of the Health Literacy Council's strategic planning efforts by implementing a contract with PMG Consulting. Through their guidance, facilitation, and management, the Council can effectively stabilize and drive forward momentum of the Health Literacy initiatives across the state. The Division will make sure these efforts are also in alignment with the CCR-2109 grant and the Community Health Workers Association of Delaware activities, by participating and communicating with the Health Literacy Council Executive Leadership Board.

Continuing to elevate health literacy throughout partnering agencies and sectors across Delaware will, in turn, assist all Delawareans, particularly vulnerable residents, with addressing their medical and social health needs so as to reduce health inefficiencies and inequities. By continuing to leverage the work of so many associated professions working within healthcare and medical capacities, health literacy will be promoted to and utilized by all who call Delaware their home.



- **Laura Saperstein**
Bureau Chief, Population Health
Delaware Division of Public Health

It has been nearly 20 years since the Institute of Medicine published a *Prescription to End Confusion*¹. The time has come to fill that prescription in Delaware. One million people (roughly the population of Delaware) are counting on it. That may not sound like a huge number; however, these are real people in our community. **We are still missing the mark to help empower the people of Delaware to navigate the complexities of health.**

In that landmark publication, the Institute of Medicine (now the National Academies of Science, Engineering and Medicine) laid out all the changes necessary within our institutions, including the skills, tools, expectations, and priorities that were needed to help people find, process, and utilize health information more effectively. The last 20 years have shown that without a coordinated effort, the work of well-intentioned people and programs can only do so much to address this need.

Furthermore, it has been 20 years since the National Assessment of Adult Literacy revealed that one third of adults lack the necessary skills to utilize even basic health information and many more struggle on some level². Clearly, there are few things impacting health like the phenomenon of misunderstanding. **The time has come for Delaware to answer the call to action with a strategic plan to improve health literacy.**

This report represents years of collaboration and discussion, culminating in a multi-institution, cross-sector strategic planning session to identify the initial steps that health, education, and community-based stakeholders can take to improve the health of individuals *and* systems through coordinated health literacy initiatives. By hearing the voice of the community alongside those of our state partners, perhaps we can start to move the needle on the health literacy crisis facing the one million people depending on us.



- **Greg O'Neill, MSN, APRN, AGCNS-BC, NPD-BC**
Patient & Family Health Education Director
ChristianaCare

¹ From Health Literacy: A Prescription to End Confusion, 2004: <https://nap.nationalacademies.org/catalog/10883/health-literacy-a-prescription-to-end-confusion>

² From National Center for Education Statistics: <https://nces.ed.gov/naal/health.asp>

INTRODUCTION

The Delaware Division of Public Health, under the charge of the Delaware Department of Health and Social Services, partnered with ChristianaCare and the University of Delaware Health Sciences to spearhead efforts to address the rampant health literacy deficiencies statewide. ***Ensuring patients understand their health information, and that of their family and loved ones, is integral to ensuring positive medical outcomes for the short and long-term.*** By addressing the need for better comprehension of health information, we help ensure the wellbeing of all Delaware residents.

In order to ensure clarity of the issues discussed in this report, it is imperative to establish a foundational understanding of terminology. The definitions of health literacy utilized for this work were taken directly from the United States government's **Healthy People 2030** initiative³. Health literacy is defined as follows:

- **Personal health literacy** is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.
- **Organizational health literacy** is the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

These key terms guided our work as we researched national precedents and current efforts, and they informed our endeavors as we navigated Delaware's current health literacy landscape.

Delaware is comprised of three counties, 19 school districts, and a total of 57 municipalities⁴. Northern Delaware (New Castle County) is considerably more urban, while central and southern Delaware (Kent and Sussex counties) consist of rural areas. The healthcare footprint of Delaware consists of the following: There are six separate hospital systems across the state (excluding the Veterans Administration Medical Center), three federally qualified healthcare systems, 11 community health centers⁵, and numerous medical clinics. Additionally, there are three major health insurance companies represented in the state. See **Table 1** for a list of hospital systems, federally qualified health centers, and health insurance companies within Delaware.

³ Office of Disease Prevention and Health Promotion: <https://health.gov/healthypeople/priority-areas/health-literacy-healthy-people-2030>

⁴ <https://delaware.gov/guides/municipalities>

⁵ <https://www.dhss.delaware.gov/dhss/dph/chs/chsservicecenters.html>

Name	Location(s)
Hospital Systems	
Bayhealth	95 locations across Camden, Dover, Felton, Georgetown, Greenwood, Harrington, Lewes, Middletown, Milford, Milton, Smyrna, and Woodside
Beebe Healthcare	Frankford, Lewes, and Rehoboth
ChristianaCare	Middletown (2), Newark (4), Smyrna, and Wilmington (2)
Tidal Health	Bridgeville, Delmar, Georgetown, Laurel, Millsboro (2), Seaford (5)
Nemours Children's Health	Bear, Dover, Lewes, Middletown, Milford, Millsboro, Newark, Seaford, and Wilmington (6)
Trinity Health Mid-Atlantic (Saint Francis)	Wilmington
Federally Qualified Health Centers⁶	
Henrietta Johnson Medical Center	Claymont, Wilmington (2)
La Red Health Center, Inc.	Georgetown (2), Milford, Millsboro, Ocean View, Seaford
Westside Family Health	Bear, Dover (3 including a mobile unit), Newark, New Castle, Wilmington (3)
Health Insurance Companies Located Within Delaware	
AmeriHealth Caritas	Newark
Highmark Blue Cross Blue Shield	Wilmington
Centene (serves Medicaid members)	Wilmington
Division of Public Health Clinics⁷	
New Castle County	Floyd I. Hudson State Service Center
	Porter State Service Center
	University Plaza - Chopin Building
Kent County	Milford Riverwalk
	Williams State Service Center
Sussex County	Adams State Service Center
	Anna C. Shipley State Service Center
	Edward W. Pyle State Service Center

Table 1
List of Healthcare Establishments Within Delaware.

We solicited involvement from key leaders within these establishments, as well as community partners and other state health care champions. Many of these stakeholders coalesced to create the ***Health Literacy Council of Delaware***. The council established the overarching mission and vision of the Health Literacy state initiative. This backbone mission will inform all goals, objectives, and decisions that steer the initiative forward.

It is imperative that health literacy be acknowledged as a patient safety issue and a prerequisite to healthcare education. The recommendations provided in this report affirm this truth and help remedy the miscommunication of medical information. This report expounds upon the needs for health knowledge access for all Delaware residents across the continuum of

⁶ From the Health Resources and Services Administration: <https://data.hrsa.gov/data/reports/datagrid?gridName=FQHCs>

⁷ From Division of Public Health Office Locations: <https://www.dhss.delaware.gov/dhss/dph/ofclocations.html>

care. By implementing the recommended strategies, health and wellness can improve for the vast majority of Delaware residents.

We look welcome your participation in this vital work.

OVERVIEW OF METHODOLOGY

This investigation is a mixed-methods study of the health literacy landscape within Delaware as it relates to the vast majority of the state population.

For the quantitative aspect of this research, we searched for authoritative data to describe the size and demographics of the state's population, delineate the scope of current understanding of health information within health sectors, and bolster our comprehension and comparison of state data as it relates to national metrics. We also included any other data in this report that was considered useful in describing the current health literacy and education practices in the Delaware landscape as accurately as is possible.

For the qualitative aspect of this research, our design employed a three-pronged approach consisting of key informant interviews, focus group sessions, and a community survey. These culminated into a statewide strategic planning work group in which we deployed the **SOAR** (Strengths, Opportunities, Aspirations, Results) methodology. The qualitative data adds a crucial measure of depth to the data collected in the quantitative step of this study.

RELEVANT STATE DATA

Our landscape analysis focuses on confronting and resolving the health literacy deficits across all populations within the state. To do this, we must describe the demographics of those living in Delaware. Here, we briefly examine factors that, statistically speaking, may place persons at-risk for low health literacy. These variables were selected based on the availability of data and their correlation to health literacy according to national research. They provide a high-level description of a growing yet incongruent state.

POPULATION

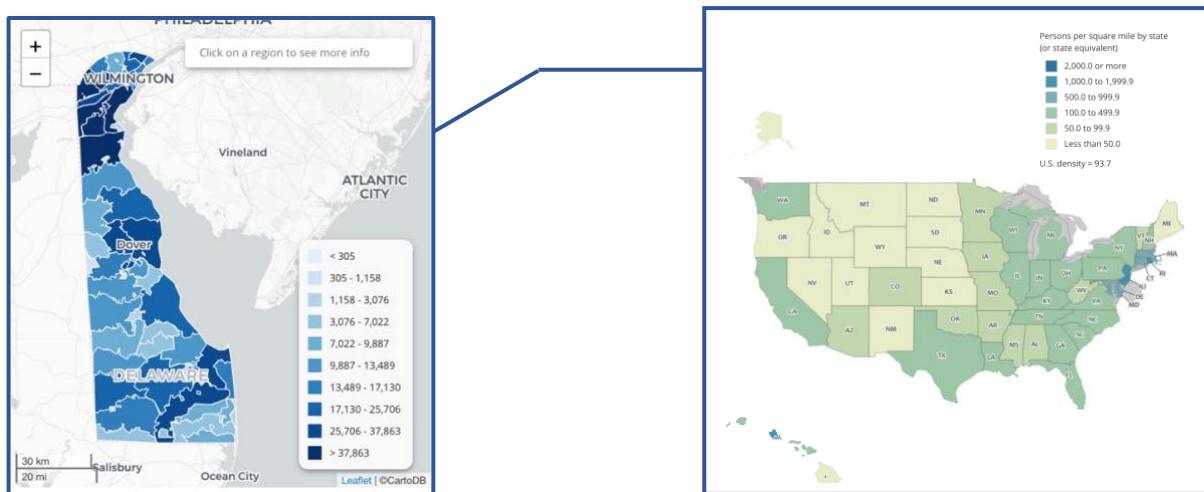


Figure 1

Population Distribution Within Delaware and National Comparison:

https://myhealthycommunity.dhss.delaware.gov/portals/ecdc/locations/state/community-overview#POPULATION_TOTAL ; <https://mtgis-portal.geo.census.gov/arcgis/apps/MapSeries/index.html?appid=2566121a73de463995ed2b2fd7ff6eb7>

We see in **Figure 1** that the most densely populated areas within the state are in the northern and southeastern parts of the state. There are a total of **957,248** persons living within the state, with a population density of 491 people per square mile. This places Delaware as one of the most densely populated states in the country. Subsequent figures describe in more detail the nature of Delaware's population as it relates to income, insurance, and literacy levels.

HOUSEHOLD INCOME

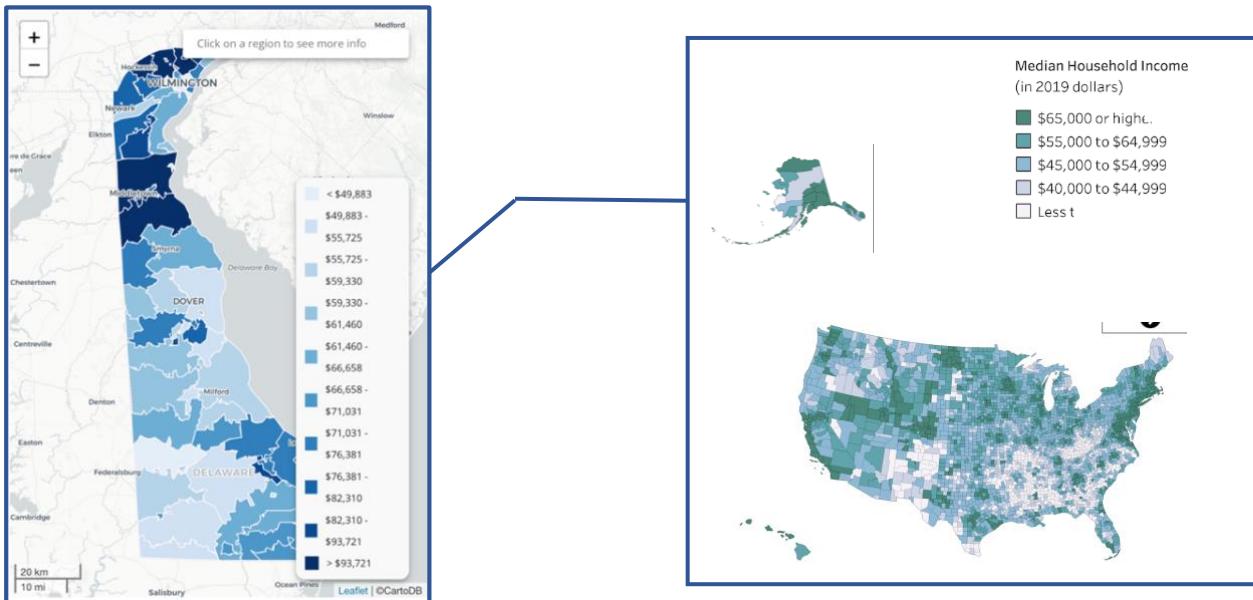


Figure 2

Household Income Distribution within Delaware and National Comparison:

https://myhealthycommunity.dhss.delaware.gov/portals/ecdc/locations/state/wealth-creation#MEDIAN_FAMILY_INCOME_CENSUS_TOTAL_DOLLARS;

<https://www.census.gov/library/visualizations/interactive/acs-median-household-income-2015-2019.html>

Figure 2 shows the distribution of household incomes across the state and provides a national comparison map. The median household income within Delaware is **\$69,110**, with higher income households residing across New Castle County and southeast Sussex County. The state's median income falls slightly below the national median of **\$70,784** (from 2021 data)⁸.

⁸ From the United States Census Bureau: <https://www.census.gov/library/visualizations/2022/comm/median-household-income.html>

INSURANCE COVERAGE

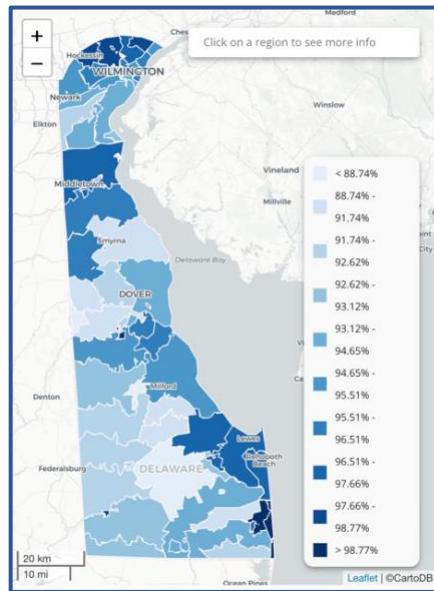


Figure 3

Insurance Coverage within Delaware:

https://myhealthycommunity.dhss.delaware.gov/portals/ecdc/locations/state/health#HEALTH_INSURANCE_CENS_US_TOTAL_PERCENT

Figure 3 displays the percentage of individuals who report having health insurance coverage across the state. Approximately 8.3% of United States residents are uninsured⁹; Delaware's data parallels this national statistic. Although 94.16% of residents report having health insurance, the highest rates of coverage are located at the extreme north and southeast of the state. It should be noted that there is a high correlation of health insurance coverage to the aforementioned income levels, as well as literacy levels across the state. Although this data is insufficient to speculate causation, we recommend further investigation, as the congruence of metrics begs for deeper analysis.

⁹ From the United States Census Bureau: <https://www.census.gov/library/visualizations/2022/comm/health-insurance.html>

HEALTH LITERACY LEVELS

Through research for the larger Communities of Excellence initiative, we have found that **at least 341,293 Delawareans aged 16 to 74 are not proficient readers (56 percent)**¹⁰. At least **211,644** Delawareans read below a sixth-grade level, and **129,649** Delawareans read below a third-grade level. Two of the state's counties, Kent County and Sussex County, have populations where **20 percent** or more of the populations have below basic literacy levels. Although these figures address basic, foundational literacy, they are integral to our understanding of the disparities regarding health literacy as well. As the **Figure 4** indicates, health literacy disparities within Delaware coincide with basic literacy rates for the majority of the state.

In 2003, the United States Department of Health and Human Services partnered with the Department of Education to release the [National Assessment of Adult Literacy \(NAAL\)](#). This assessment included 28 health related items. This, alongside Harvard University's population-based health literacy analysis, [Literacy and Health in America](#) in 2004, have served as the foundation for current state analysis applied in creating the Health Literacy Map, provided by the University of North Carolina at Chapel Hill. The map also utilizes the 2010 US Census Bureau data and American Community Survey summary files to calculate health literacy estimates by state. All of these resources detail the imperative connection between socio-economic dynamics, health literacy, and health outcomes.

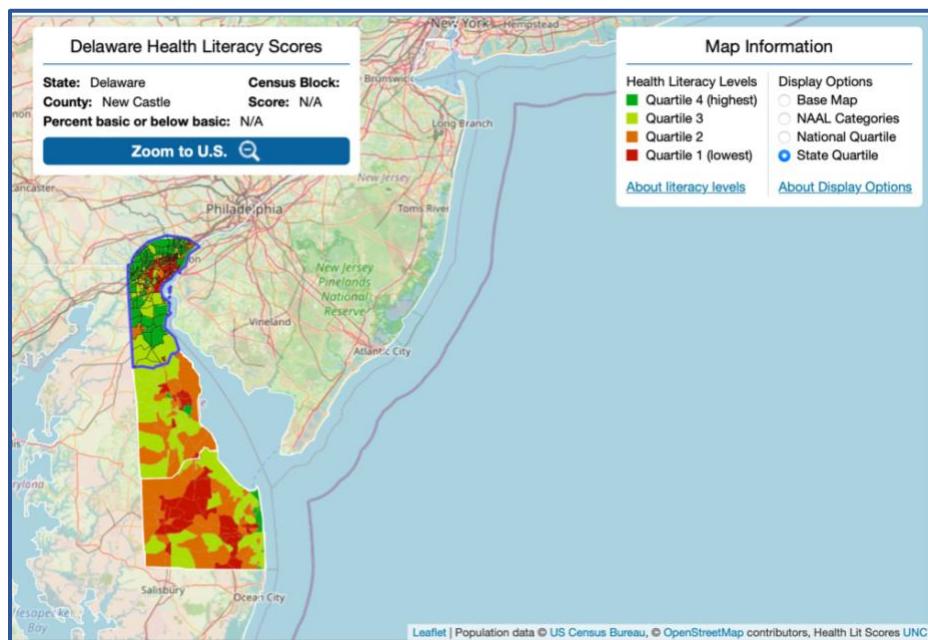


Figure 4
Health Literacy Map of Delaware: <http://healthliteracymap.unc.edu>

Figure 4 depicts the Health Literacy Map for Delaware. Health Literacy estimates range from 177-280, with the higher scores indicating higher health literacy and displayed as quartiles

¹⁰ <https://map.barbarabush.org/assets/cards/BBFL-Literacy-Card-DE.pdf>

three and four, with four being the highest. Lower scores indicate lower health literacy and are displayed as quartiles one and two, with one being the lowest. All health literacy estimates were divided evenly into four quartiles based on the range for scores calculated for the specific state.

- Quartile 1 (lowest): 235 or lower
- Quartile 2: 235-247
- Quartile 3: 247-254
- Quartile 4: 254 or over

As evidenced by the location of the majority of lower quartile scores, **more intentional work is needed to address the deficits in health literacy across the southernmost part of Delaware.** Both universal and targeted approaches should be deployed more robustly to effectively mitigate this trend. Recommended strategies, as well as the Health Literacy Map for the United States, are provided later in this report.

CURRENT NATIONAL BENCHMARKS

Through the first portion of this report, we have presented information that contributes to understanding the variables within the Delaware population and demographics as they relate to health literacy. We now turn to national benchmarks to conclude the quantitative portion of the report. The [National Action Plan to Improve Health Literacy](#) sets the trajectory for this work. Listed below are key findings from several national research cohorts:

- According to the NAAL assessment¹¹, people were *more likely to have poor (Below Basic) health literacy skills if they:*
 - Self-reported poor health.
 - Were age 65 or older.
 - Had health insurance from Medicare or Medicaid or had no insurance.
 - Lived below the poverty level.
 - Were Hispanic or Black.
- According to the Centers for Disease Control and Prevention (CDC), **nine out of 10 adults struggle to understand and use health information when it is unfamiliar, complex, or jargon filled**¹².

¹¹ https://health.gov/sites/default/files/2019-09/Health_Literacy_Action_Plan.pdf

¹² Kutner, M., Greenberg, E., Jin, Y., & Paulsen, C. (2006). *The health literacy of America's adults: Results from the 2003 National Assessment of Adult Literacy* (NCES 2006-483). Washington, DC: U.S. Department of Education, National Center for Education Statistics.

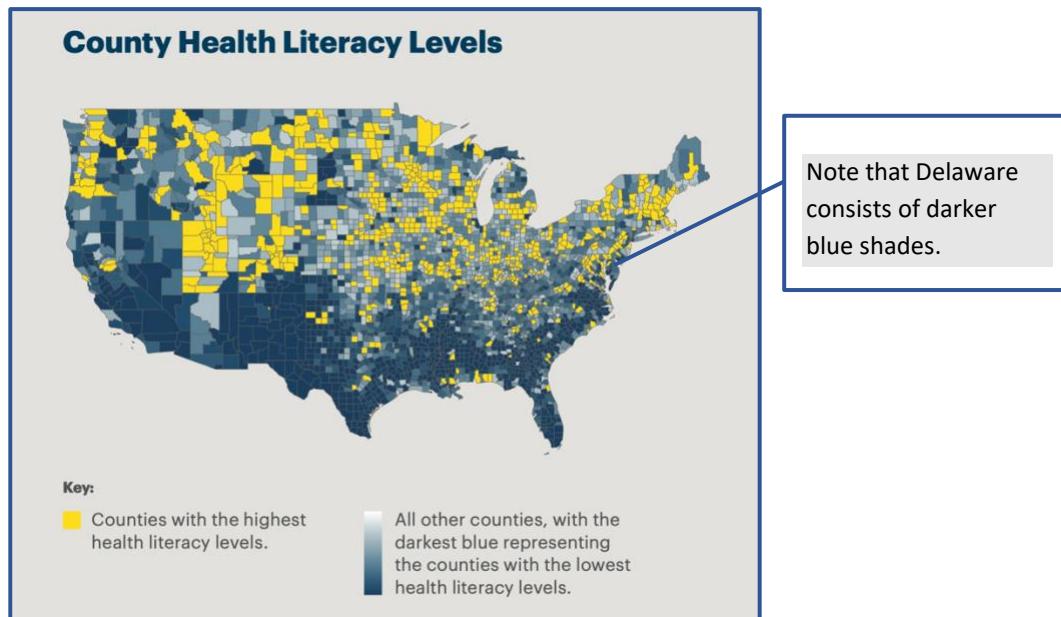


Figure 5
 County Health Literacy Levels:
<https://www.unitedhealthgroup.com/content/dam/UHG/PDF/About/Health-Literacy-Brief.pdf>

In **Figure 5**, we see the distribution of counties across the United States according to their estimated health literacy levels. Counties with the highest health literacy levels are shaded yellow. This means that **15 to 27** percent of the population in these locations is predicted to have “limited health literacy;” these counties have a predicted percent above basic health literacy values at and above the **80th** percentile. The remaining counties have varying levels of health literacy, with the darkest shade of blue representing a population in which **36 to 59** percent have limited health literacy. “Lowest health literacy level” counties have “predicted percent above basic health literacy” values at and below the **20th** percentile value.

Differences in education, languages spoken, health behaviors, and health system characteristics contribute to significant variation in the health literacy level of each county¹³. Several national reports have concluded that limited health literacy is negatively associated with the use of preventive services such as mammograms or vaccines, as well as the management of chronic conditions such as diabetes¹⁴. An association between limited health literacy and an increase in preventable hospital visits and admissions has also been discovered.

Delaware counties are comprised of mostly darker blue shades; there are no areas of yellow. Many of the recommendations provided later in this report stemmed from areas shaded yellow in other parts of the nation. Our intent is not to devalue the healthcare efforts that take place in our state; rather, we seek to emulate the specific health literacy successes that have occurred in spaces across the nation. It is imperative that we utilize the successful strategies initiated in counties shaded yellow and learn from their practices.

¹³ <https://www.unitedhealthgroup.com/content/dam/UHG/PDF/About/Health-Literacy-Brief.pdf>

¹⁴ https://health.gov/sites/default/files/2019-09/Health_Literacy_Action_Plan.pdf

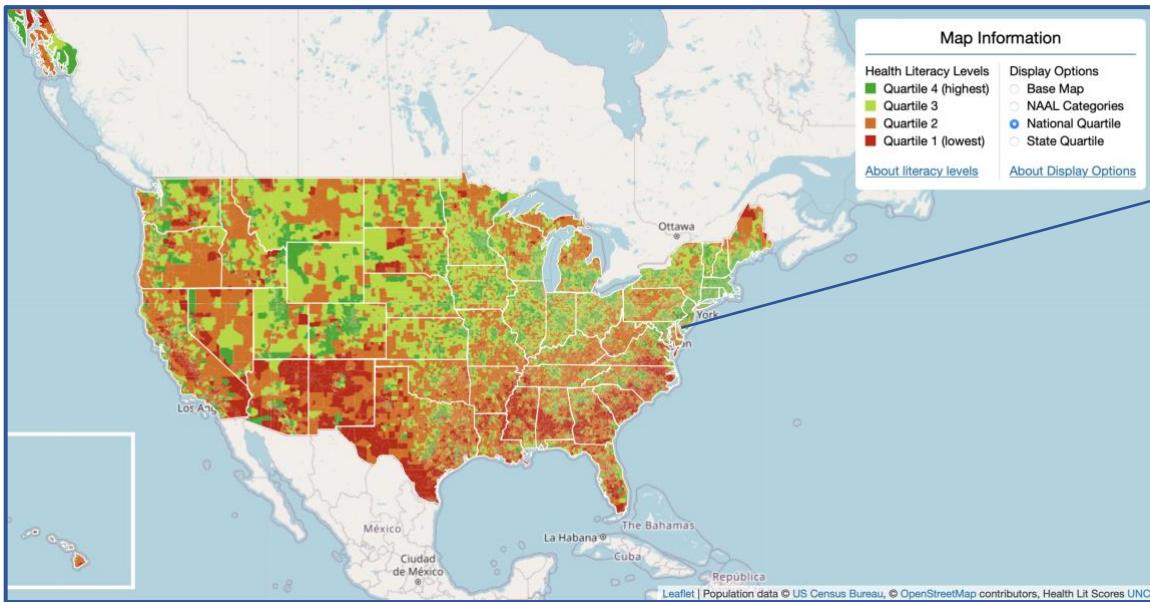


Figure 6

National Health Literacy Mapping to Inform Health Care Policy. Health Literacy Data Map. University of North Carolina at Chapel Hill, 2014. Web. 03 November 2022: <http://healthliteracymap.unc.edu>

Figure 6 shows the Health Literacy Map for the United States, provided by the University of North Carolina at Chapel Hill. This map utilizes the 2010 US Census Bureau data and American Community Survey summary files to calculate health literacy estimates by state. The above image shows health literacy levels for 216,864 census block groups across the country. As with the state map (Figure 4), health literacy estimates range from 177-280. The higher scores indicate higher health literacy and are displayed as quartiles three and four, with four being the highest. Lower scores indicate lower health literacy and are displayed as quartiles one and two, with one being the lowest. All health literacy estimates were then divided into four even quartiles based on the range of scores for the nation.

- Quartile 1 (lowest): 235 or lower
- Quartile 2: 235-247
- Quartile 3: 247-254
- Quartile 4: 254 or over

An analysis for Delaware was provided earlier; however, when comparing the state to the national map, **it is evident that Delaware is behind much of the northeast and western regions regarding health literacy levels.** To be clear, a lot of great work has been done to improve the health of Delawareans, but this analysis illustrates the need for specific health literacy pursuits and processes within the state.

STAKEHOLDER ENGAGEMENT

A three-pronged approach to elicit feedback was utilized for this study. Key informant interviews were designed and executed at both the state and national levels. Guided by those findings, focus groups were held to deepen our understanding of health literacy issues as they relate to direct healthcare professionals and community authorities within the state. These groups allowed for open, transparent discussion and uncovered impactful perspectives. In conjunction to the focus groups, an online community survey was promoted through multiple channels to gather input directly from the community at large. These three approaches helped provide a holistic understanding of the current health literacy landscape within Delaware, particularly as it relates to larger national initiatives.

KEY INFORMANT INTERVIEWS

The national stakeholders we interviewed illuminated current health literacy landscapes and endeavors across the United States, thus providing a foundational and replicable standard. These interviews also emphasized the need for consistent efforts toward advocacy and legislative policy to ensure sustainability of implemented strategies. **Twenty national interviews were completed.**

The interviews with state personnel, ranging from frontline healthcare providers and caregivers to healthcare system CEOs and state legislators, highlighted the detrimental voids of health education and information within Delaware and expounded on practical strategies that can improve the current trajectory. **Thirty-one state interviews were completed.**

A list of both national and state interviewees can be found in **Appendix A (upon request)**. Below we share poignant quotes that help frame the experiences and observations of many within the health literacy landscape.

RECOGNITION OF NEED

“We are the only country on the planet that does not incorporate health literacy into their healthcare.”

- Dr. Omar Khan, President and CEO, Delaware Health Sciences Alliance

“It would be ideal to have a universal health literacy plan and approach that meets patients where they are, with no expectations.”

- Nursing Program Lead

“There needs to be equity of awareness, starting at the high school level and progressing beyond. Equity of awareness breeds equity of opportunity.”

- Pam Gardner, Lead Program Manager of Delaware Health Sciences Alliance

COMMUNICATION

“The linguistic piece within health literacy is crucial. The responsibility, and therefore the investment, is on the medical community to effectively articulate information to patients and guardians.”

- John Comings, Senior Technical Consultant, World Education

“Federally funded health centers are major culprits of using inaccessible and difficult medical jargon with patients and in patient resources and not communicating effectively...You need buy in from doctors, health-care teams, administration, and patients in order for things to change.”

- Jamie Stanfield, Head of Gulf Coast Libraries, University of Southern Mississippi

“It seems that health is not important, rather, the cost of health is. There is a significant disconnect as a result of the differences between [the counties]; it’s ‘versus’ instead of being a united front of hospital systems.”

- Dr. Tam, CEO, Beebe Healthcare

INVESTMENT

“[Health literacy work] can’t be a one year or year and a half pilot. There needs to be an investment. A lot of initiatives have come and gone because there is no state commitment, they have short timelines, and there is no long-term investment.”

- Maricel Santos, Associate Professor of English, San Francisco State University

“There tends to be not enough people who can allocate the focus and time needed to really make a statewide change. It will take lots of partnerships and communication. But you don’t need your own state solution and trainings. You just need a group of people who are willing to tap into resources and move things along.”

- Susan Bockrath, Executive Director, Nebraska Association of Local Health Directors

FOCUS GROUPS

Seven focus groups were conducted for the purposes of soliciting information from specific touchpoints within healthcare systems and society at large. Participants represented all counties and spanned an array of communities and demographics throughout the state. Focus group categories were as follows:

- ***Librarians/library system staff***
- ***Nurses***
- ***Community Health Workers***
- ***First Responders***
- ***Community Outreach Organizations***
- ***Senior Citizens***
- ***Funders***
- ***Disability Community Members***

Focus groups consisted of an average of six participants; they lasted approximately 60 minutes. During this time, participants were asked a series of vetted questions; one consultant moderated the conversation, while another took notes. All participation was anonymous, unless specifically requested otherwise. At the end of the discussion, participants were asked if they would like to stay involved with the state's Health Literacy initiative; **100% of participants from all focus groups opted to remain involved.** Below are a few substantive quotes that help conceptualize the conversations from these focus groups.

COMMUNICATION NEEDS

“Despite my background [in healthcare] and my current position, navigating the landscape was still difficult [while caring for my mother] ...There needs to be a better conduit of information and distinct points of contacts for assistance and resources within the facilities to help when patients have questions or concerns.”

- Senior Population Representative

“Many people don’t trust [medical providers.] There needs to be more education about health for faith based and community leaders.”

- Community Outreach Representative

“One client threw all the paperwork down out of frustration. They ended up right back in the hospital.”

- Local Nurse

CULTURAL AWARENESS

“There are large Haitian, Dominican Republican, and Venezuelan populations in Sussex [County]. It can be difficult to get an interpreter, and I often use an iPad to link to online interpreter systems. It’s difficult to find culturally diverse materials. [My concern] is the inability to connect with the patients.”

- Local Nurse

“Community workers and community-based organizations need to penetrate these communities in need who otherwise would use urgent care or ER resources...When patients are with you, there is a captive audience and a significant opportunity to get a patient’s trust.”

– Local Nurse

TRAINING NEEDS

“The biggest issue [for EMT personnel] is explaining the medical terminology in a simplistic way... There is no training, tools, or resources for how to talk through their traumatic events and experiences...Many suicides most likely could have been prevented if we knew how to talk to the person in the moment.”

- First Responder

“We need better tools to keep the conversation at the simplest, most basic level to alleviate intimidation...Simple, clean and good information, be it written or oral, would help us do a better job.” – State Police Officer

“Some [health literacy] training is held at department level [for nurses], but it’s sporadic.”

- Local Nurse

ACCOUNTABILITY

“There are too many people filling the gaps of what should be expected services...Accountability is in the wrong place.”

–Village Volunteer

“While working for Hospice, many people didn’t know the medications they were taking and why. No explanations were ever really given. That was frustrating.”

– Disability Community Representative

“We need a delivery conduit of information that is standard, consistent, reliable, and accurate.”

- Community Outreach Organization Representative

“There is no accountability in communicating information and education; there is no prescribed process.”

- Senior Population Representative

“If you don’t have health literacy, there is no way to fully understand. That’s not only inconvenient, it’s a dangerous situation.”

- Disability Community Representative

“Someone needs to be available to help meld the information all together, because doctors don’t always talk to each other.”

- Disability Community Representative

COMMUNITY RESIDENT SURVEY SUMMARY

An online survey was designed to capture perspectives directly from Delaware residents. It aligned with several nationally recognized health literacy and equity surveys. It was written at a fifth-grade reading level and was reviewed by the Health Literacy Council of Delaware prior to dissemination. The survey was distributed through multiple channels that included the Delaware Department of Libraries, Sussex County Health Coalition, all major hospital systems within Delaware, United Way of Delaware, and several nonprofit organizations via the Delaware Alliance for Nonprofit Advancement. A copy of the survey can be found in **Appendix B (upon request)**.

Our research of historical and archived state data showed that this type of survey has never been conducted within Delaware. Future efforts may need to deploy different methods of data collection which are typically more costly than online surveys to access more diverse respondents and increase participation from across the state. This data serves as a benchmark for our future health literacy assessment and progress. The reader is asked to bear in mind that the purpose of the survey was to begin to understand the lived experiences of residents as they encounter health and medical choices, not conduct a major research project. These results form a beginning point to learn how needs across different populations vary, if at all, with regard to health literacy practices.

FINDINGS

Although there were **795** participants, this effort yielded **599 completed surveys** from respondents who live in Delaware. Only complete surveys were utilized for the data calculations. Respondents tended to self-identify as female (**80.4%**); Caucasian or European American (**70.6%**); and homeowners (**83.3%**). The majority of respondents were 65 or older (**42.6%**), with those aged 55 to 64 following (**22%**). Roughly **6%** of respondents identified as disabled, and **98%** of respondents selected English as their primary language. The income for the majority of respondents (**57.4%**) fell between **\$40,000** and **\$139,999**.

The majority of respondents have completed a level of education higher than high school graduation or equivalency; most (**39.3%**) stated they earned a master's degree, with those achieving a Bachelors, Trade School, or certification program following (**37%**).

The survey conveyed minimal issues with access to care; **93.7% of respondents stated they have a primary care doctor and 58.5% travel 10 miles or less to their provider's office.** A resounding **98% of respondents currently have health insurance.** This measure of access helps account for the **86.2%** of respondents who complete an annual checkup.

Although only **14.3%** of respondents selected that they struggle with meeting their health care needs, **one third of participants (33.33%) responded that they find it difficult to understand their healthcare;** this measure speaks directly to personal health literacy.

The responses to an open-ended question, "***What resources do you believe would help adults like yourself or others you love better understand and engage in healthcare across Delaware?***" centered on cost of care, staff communication, and more simplified explanations for patients on their conditions and care instructions during and after appointments.

These findings align with national benchmark data, in general, and findings from the key informant interview and focus groups.

We recognize that certain populations that would significantly impact the response metrics are not included in this survey. By the very nature of survey access and self-selection, state residents with lower literacy and/or limited technological access are unintentionally precluded from participation. Admittedly, our processes are currently limited. We ask that the reader keep this fact in mind, and we recommend future efforts include more diverse avenues for information solicitation.

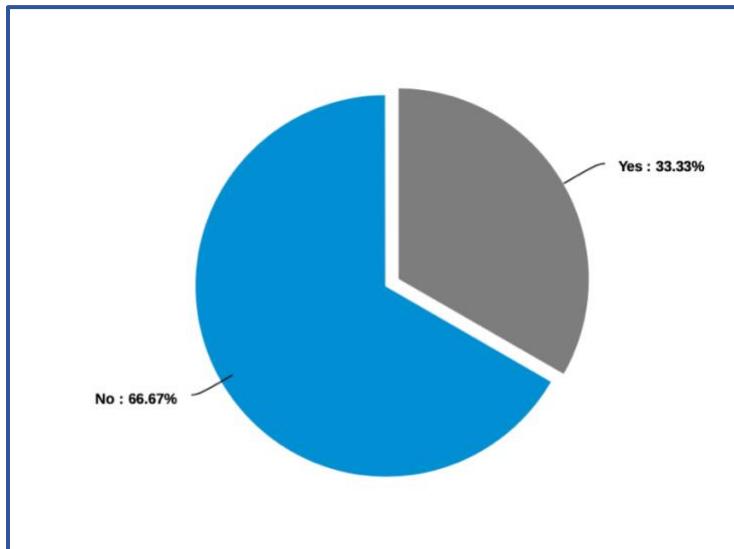


Figure 7
Percentage of Survey Participants Who Find It Difficult to Understand Their Healthcare

Figure 7 shows the percentage of survey participants who find it difficult to understand their healthcare. As the figure indicates, **33.33% of respondents indicated they face difficulty understanding their healthcare.**

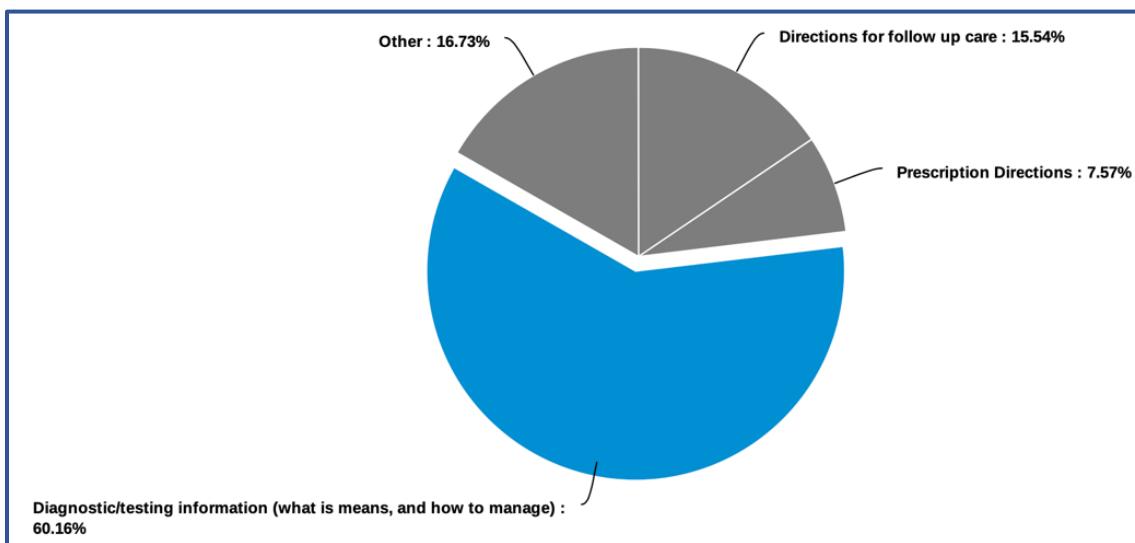


Figure 8
Information Respondents Find Difficult to Understand

Figure 8 shows a breakdown of information respondents find difficult to understand, in relation to the aforementioned question regarding their ability to understand their healthcare. The graph shows that diagnostic information (**60.1%**), followed by directions for follow up care (**15.5%**) prove most difficult for respondents to comprehend.

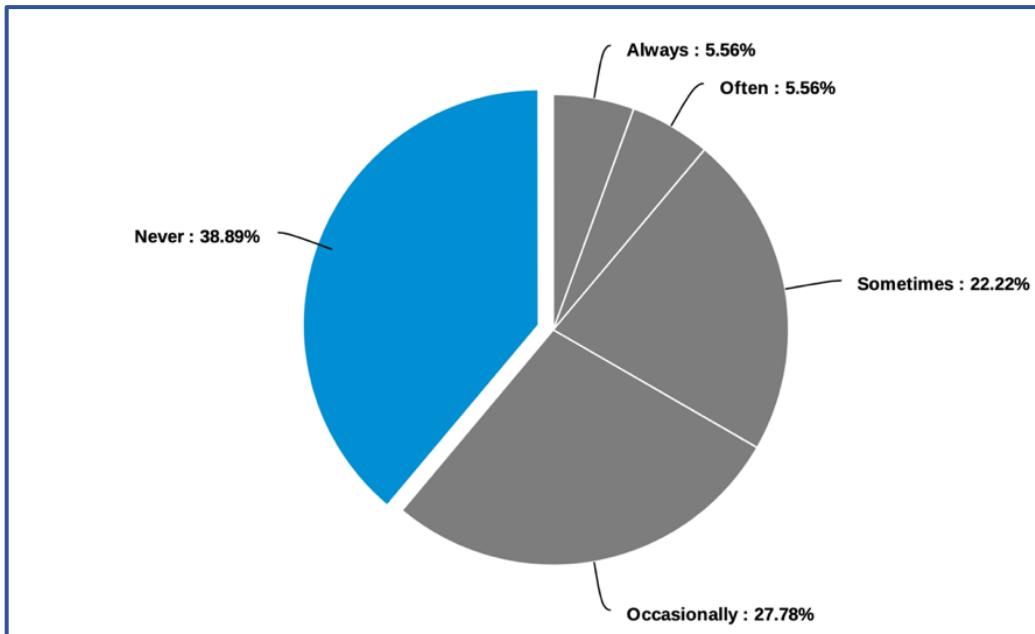


Figure 9
Percentage Who Utilizes Assistance to Read Materials from Doctor

Figure 9 shows the breakdown of respondents who utilize assistance to read materials from their doctor. **The majority of respondents selected they have someone help them read healthcare materials at some point, be it occasionally (27.8%), sometimes (22.2%), often (5.6%), or always (5.6%).** This staggering statistic should give the reader considerable pause. It can be extrapolated that the health literacy voids within our state complicate the medical understanding for most state residents; this is a patient safety issue that must be addressed.

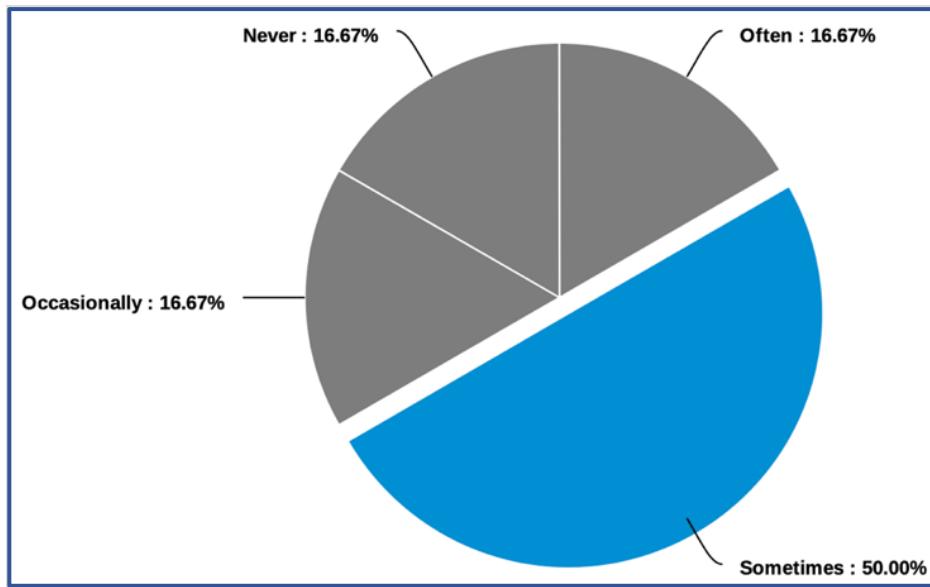


Figure 10
Frequency of Respondents Who Encounter Problems Understanding Their Medical Condition(s)

Figure 10 displays the frequency with which respondents encounter problems understanding what is told to them about their medical condition(s). Exactly half of respondents stated they have a problem “sometimes,” whereas 16.7% selected often or occasionally. **Based on the survey responses, we can infer that people across these demographics are struggling/need assistance to understand their healthcare.**

STRATEGIC ANALYSIS

PMG Consulting applied its “SOAR” methodology for solidifying what should and can be done to elevate health literacy in the medical community and promote communication and understanding for patients. This analysis accompanies the qualitative and quantitative research findings, and it gives voice to the mission and desired outcomes agreed upon by the Health Literacy Leadership Council. As such, it directly informs the recommendations and strategies of this report.

SOAR is an acronym standing for Strengths, Opportunities, Aspirations, and Results. The SOAR analysis process focuses on organization or community strengths and how those strengths can be leveraged to take advantage of the opportunities facing the organization or landscape in which it exists. The tool is used to collect information and utilize that information to guide a team brainstorming session. Strengths and opportunities focus on your present situation, whereas aspirations and results focus on your desired future situation.

A SOAR analysis is a 2×2 matrix. The top row on the matrix focuses on the present, and the bottom row focuses on your desired future. The left column focuses on internal factors, and the right column focuses on factors that are external to your organization.

We focused on high level themes in the SOAR analysis for this report due to the richness of data; a more detailed SOAR analysis can be found in ***Appendix C (upon request)***.

<u>Strengths:</u> <i>What can we build on?</i>	<u>Opportunities:</u> <i>What is being asked for?</i>	<u>Aspirations:</u> <i>Where are we going?</i>	<u>Results:</u> <i>How do we know we're succeeding?</i>
<ul style="list-style-type: none"> • Delaware's diminutive size serves as a strength when considering health literacy and health equity initiatives. With just under 1 million residents, information dissemination strategies can be readily implemented, and the subsequent outcomes are easily measurable. • The demographic diversity serves as a microcosm of the nation. In all national interviews, the health literacy representatives mentioned the potential for Delaware to serve as a testing ground for experimentation of health literacy strategies, as the diversity in communities reflects key populations across all states. • There are 6 hospital systems in the state. The plethora of healthcare systems provide numerous opportunities to connect with patients, caregivers, and healthcare providers. There is a robust network of healthcare providers who desire to affect change. 	<ul style="list-style-type: none"> • Presently, there are no state policies or protocols, or funding streams dedicated to addressing health literacy in any capacity. Without legislative support, health literacy initiatives of any sort are not sustainable, as they require substantial funding and support to ensure long-term implementation. • There is no common language utilized among healthcare providers, community health workers, and caregivers. This increases the risk of miscommunication of healthcare information. • Health Literacy is often confused with and compounded by social determinants of health. There is confusion amongst healthcare providers and frontline caregivers regarding the definition of health literacy and how it differentiates from social determinants of health. 	<ul style="list-style-type: none"> • Create a universal awareness, education, and training for the anchor systems for healthcare, with a targeted focus on community deployment, such as curriculum for all community health workers, navigators, and positions that have direct contact with community members in relation to their healthcare needs. This will convey a sense of unity and priority for health literacy within healthcare education. • Establish standardized policy and protocols for state and anchor organizations with regard to health literacy. This will fortify joint efforts to implement health literacy initiatives across hospital systems. This includes implementing teach back, appointment question checklists, etc. 	<ul style="list-style-type: none"> • The findings culminate into one substantive issue, which is that health literacy is not recognized as a priority within the state government, and as such is not elevated to the necessary level of recognition within the healthcare and medical arenas. As such, there is minimal understanding, and therefore minimal movement, toward change. • The health literacy pursuits we initiate now will indelibly impact the state of Delaware and its residents in the short and long term. Our efforts will posture Delaware as a leader in the health landscape for the nation as well as ensure a positive trajectory for the residents for years to come.

Table 2
High level SOAR analysis. The exhaustive list is in *Appendix C (upon request)*.

HIGH LEVEL, UNIVERSAL RECOMMENDATIONS

The recommendations, and subsequent goals and objectives, shared here are a consolidation of proposals and suggestions extrapolated from our research and iterated via discussions held during the Statewide Strategic Planning Session held on 24 January 2023. We have enforced and expanded the recommendations to align with tenets explicated in the Healthy People 2030 national initiative. We recommend The Health Literacy Council of Delaware create a mission and vision for the state, as well as set goals and objectives. Additionally, it is recommended that The Council develop infrastructure that emulates best practices from across the nation. Once approved by The Council, these recommendations will be used to draft a formalized strategic plan.

PMG Consulting recognizes the crucial need to view this work within an equitable and inclusive lens.

The most encompassing goal and recommendation is to ensure the equitability, cultural sensitivity, diversity, and inclusion in all processes.

When reviewing, please keep in mind this vital perspective.

Recommendation 1: Establish legislative policy that provides consistent funding for Delaware's health literacy initiatives.

- Institutionalized policy would ensure the longevity and continual elevation of health literacy across the state in addition to setting standards, suggested interventions and prioritization for organizational responsibility.

Recommendation 2: Solicit high level leadership within healthcare organizations and state systems to standardize Health Literacy policy and practices.

- These key stakeholders will serve as conduits of bold, sustainable energy within high level leadership to enact change within organizational policy/practices within state systems and critical anchor institutions.

Recommendation 3: Develop a health literacy awareness campaign for public and private consumers.

- This goal speaks to the need for unified messaging and education both externally to patients/consumers and internally to organizational staff.

Recommendation 4: Facilitate and support the identification and utilization of health literate materials under the Health Literacy Council's guidance to promote access to relevant, accurate quality materials for partners and consumers.

- This would include digital health literacy resources, self-advocacy materials, and other pertinent information for patients and providers.

Recommendation 5: Streamline and standardized all health literacy education within the state, to include primary and secondary education as well as professional medical training programs.

- This goal helps ensure consistency in language and messaging at earlier ages and throughout the educational pathways of all residents.

Goal 1: Operationalize, bolster, and institutionalize the Health Literacy Council of Delaware.	
Objective 1:	Create the vision and mission and adopt initial core goals and objectives as part of the Health Literacy Council's (HLC) workflow. <ul style="list-style-type: none"> • Convene and gain consensus by the current committee on its vision and mission. • Adopt or modify consultant recommendations with regard to goals and objectives.
Objective 2:	Establish HLC infrastructure to include the functions and roles that serve the council. <ul style="list-style-type: none"> • Expand infrastructure, to include subcommittees, in order to operationalize goals and objectives set before the group (advocacy, communication, programmatic). <ul style="list-style-type: none"> ○ Establish a resource development committee and task them with executing specific objectives based on the statewide strategic plan's goals. <ul style="list-style-type: none"> ▪ Solicit funding to ensure <i>programmatic goal attainment, sustainability, and impact.</i> ○ Establish advocacy, communication, and programmatic subcommittees to create goals for each of these subsections
Objective 3:	Develop, sanction, and implement a statewide strategic plan. <ul style="list-style-type: none"> • A Statewide Strategic Planning Session, held on 24 January 2023, served as the catalyst for the development of an official health literacy plan for Delaware. • Complete a statewide strategic plan in alignment and communicated with state and local officials, institutions and partners.

Goal 2: Increase urgency and awareness around health literacy across Delaware.	
Objective 1:	Create an awareness campaign that establishes health literacy as a priority in the state.
	<ul style="list-style-type: none"> • Create a communications committee to deploy a robust awareness and communication plan around health literacy. • Create a robust communication plan with universal and targeted messaging. <ul style="list-style-type: none"> ○ Advocate for a statewide declaration of health literacy as a patient safety issue and primary healthcare pursuit. ○ Advocate for a proclamation declaring October as Health Literacy month, beginning in 2023. ○ Create media materials that help inform and promote messaging by community partners.
Objective 2:	<p>Develop and promote potential legislation, as well as organizational policy/processes, to incorporate health literacy awareness, strategies, and practices into educational systems, state systems, anchor organizations, and large CBOs. (Examples include nursing/medical provider, CTE, and public-school curricula.)</p> <ul style="list-style-type: none"> • Identify key educational and training institutes and their initiatives to deploy health literacy awareness and education. • Create an advocacy committee that will identify state level best practice policies and advocate for legislative change. <ul style="list-style-type: none"> ○ Evaluate current legislative policies and practices for the state of Delaware. ○ Advocate for policy changes within anchor hospital systems/healthcare systems based on national best practices. ○ Create evaluation to track progress and shifts in legislative policies and practices. ○ Provide technical assistance with implementing organizational and legislative policy changes.
Objective 3:	<p>Host a yearly convening to include national advisors.</p> <ul style="list-style-type: none"> • Annually replicate the inaugural forum completed in 2022. (This event served as a means of spreading awareness and engaging the healthcare community across the state. Consisting of three focused panels and one keynote speaker, the forum addressed health literacy concerns across the state and advancements that could be utilized to fill current voids.)

Goal 3: Develop universal and standardized educational strategies that reach individuals, families, providers, and systems of care. Initial emphasis will be placed on hospital systems, FQHCs, anchor CBOs, health insurance providers, educational pipelines, and consumers.

Objective 1:	<p>Develop a statewide training system on health literacy that includes hospital systems, FQHCs, anchor CBOs, health insurance providers, educational pipelines, and consumers.</p>
	<ul style="list-style-type: none"> • Create a programmatic committee that will assess and develop a statewide training curriculum for hospital systems, FQHCs, anchor CBOs, health insurance providers, educational pipelines, and consumers. <ul style="list-style-type: none"> ○ Assess the educational and training needs across the landscape. <ul style="list-style-type: none"> ▪ Assess education and training needs for hospital systems, FQHCs, anchor CBOs, and health insurance providers. ▪ Assess education and training needs for educational pipelines. ▪ Assess education and training needs for consumers. ○ Curate or develop a community toolbox. <ul style="list-style-type: none"> ▪ Curate templates, resources, and supports that help organizations and direct consumers.
Objective 2:	<p>Identify and promote educational resources that support hospital systems, FQHCs, anchor CBOs, health insurance providers, educational pipelines, and consumers.</p>
	<ul style="list-style-type: none"> • Identify and promote educational resources around health literacy for anchor organizations' usage. <ul style="list-style-type: none"> ○ Assess the educational and training needs across the landscape. <ul style="list-style-type: none"> ▪ Identify training needs for hospital systems, FQHCs, anchor CBOs, and health insurance providers. ▪ Identify training needs for educational pipelines. ▪ Identify training needs for consumers. ○ Sample activities include: <ul style="list-style-type: none"> ▪ <i>Implement a statewide teach-back campaign as an initial foray into communicative efforts for health literacy.</i> <ul style="list-style-type: none"> • <i>Teach-back is one of the best practices for health literacy; by initiating efforts with this campaign, we tie in awareness and education with immediate trackable progress. Furthermore, the successes and lessons learned from this campaign would inform all future efforts.</i> ▪ <i>Develop a leading questionnaire document that providers can give to patients to stimulate questions during an appointment.</i> ▪ <i>Incorporate graphic medicine into frontline patient interactions, such as intake forms and discharge documentation.</i> <ul style="list-style-type: none"> • <i>For example, utilize materials from the Graphic Medicine Toolkit and IHA resources to create a communication graphic for emergency situations between first responders and the person(s) in crisis.</i> ○ Create a technical assistance arm to support this work. • Curate, vet, and create equitable and accessible materials that support and train networks of providers. <ul style="list-style-type: none"> ○ This would include resources for community facing health providers, such as doulas, CHWs, Peer Navigators, etc.

Objective 3:	Develop funding pipelines through grants and other resources for partner deployment of health literacy initiatives.
	<ul style="list-style-type: none"> • Identify resource needs of partners to support health literacy initiatives. • Elevate funding needs to the resource development committee. • Provide and distribute funding through partners to help develop learning opportunities for individuals and communities across the state.

NATIONAL BEST PRACTICES

The best practices that emerged from our research aligned with three main categories: **Policy, Awareness, and Education and Engagement**. Implementing pilots from within these three strategy groups will help ensure a measure of sustainability and impact within the health literacy landscape for the state.

POLICY

- The Horowitz Center received an official designation from the Maryland General Assembly via HB 1082 to be the state's official Consumer Health Information Hub
 - The bill also requires state and local agencies to use plain language in public communications about health, safety, and social services benefits and establishes grant requirements related to health literacy.
- Safe Care Texas has continuously advocated for more inclusion of health literacy language into state health regulations. At the End of Session in 2017, the Texas State Health Coordinating Council added Health Literacy to the State Health Plan
 - They have also written three separate House bills that have been consistently lobbied for in congress.

AWARENESS

- The Maryland Horowitz Center sponsors the Health Literacy in Action (HLiA) Conference for health literacy professionals and newcomers. The purpose of the conference is to connect participants with ongoing research, policy, and practice.
 - Various states have followed the Horowitz Center's example and hosted forums, conferences, and summits all revolving around the topic of health literacy (FL, PA, CA, etc.)
- Wisconsin Health Literacy developed key partnerships within state pharmacies to make them aware of their prescription drug labelling campaign. They also developed a

quarterly e-newsletter and distributed to pharmacy opinion leaders in the state to inform them of the initiative and its progress.

- They also hosted a Labeling Summit in 2017, during which the latest research was shared and pharmacists from the pilot organizations shared experiences with other pharmacies who may want to participate in the future.
 - This focused communication tactic establishes buy-in for a specific strategy.
- The IHA has developed an extensive health literacy toolkit.
 - Other states have emulated this model to varying degrees (PA, MD, and FL most notably)

EDUCATION AND ENGAGEMENT

- The Maryland Horowitz Center provides technical assistance to Maryland Local Health Improvement Coalitions (LHICs)¹⁵. LHICs are voluntary, community-driven groups focused on local health priorities and solutions.
 - The Center also collaborates on community health projects across Maryland, such as the Lifting All Voices program in Frederick, to ensure all resources and information shared aligns with plain language and literacy level standards.
- The IHA hosts a Solutions Center, which serves as a hub of publications, conference recordings, and an interactive chat room for members to solicit feedback on their health literacy programs/concerns/initiatives.
- The Pennsylvania Health Coalition and the IHA offer online training for health professionals and community members to increase their health literacy skills.
- Safer Care Texas offers on- and off-site training and education opportunities as well as consultations for community and government organizations to assess their health literacy environment.

¹⁵ University of Maryland's School of Public Health: <https://sph.umd.edu/research-impact/research-centers/horowitz-center-health-literacy/projects-center-health-literacy/center-health-literacy-health-departments-and-community-coalitions/center-health-literacy-local-health-improvement-coalitions>

ATTACHMENTS

Contact PMG Consulting at ascholl@pmgconsulting.net or ebraun@pmgconsulting.net for a copy of related support documents (attachments).

Appendix A- National and State interviewees

Appendix B- Community Survey Responses

Appendix C- Detailed SOAR Analysis

Appendix D- Strategic Planning Session Organizational Attendance

Appendix E- National Forum Organizational Attendance

Virtual Forum Attendance

PMG Consulting, LLC

University of Delaware

St. Vincent Charity Medical Center

Christiana Care

Basic Education Consultant

Central Susquehanna Intermediate Unit

State of Delaware

Delaware Office of the Lt. Governor (State of Delaware)

Delaware Capital School District

Bayhealth

Healthwise

Harvard School of Public Health

Polytech

University of Delaware

Department of Health Services (State of Delaware)

Beebe Healthcare

Northeast Pennsylvania Area Health Education Center

Literacy Delaware

Delaware Division of Libraries

University of Pittsburgh Medical Center

Highmark Health

TidalHealth

Nemours Children's Health

Glidden ADR, LLC

American Lung Association

Delaware Healthcare Association

San Francisco State University

The Healthcare Improvement Foundation

Illinois Public Health Association

Worcester State University

Eastern Seals of Delaware and Maryland's Eastern Shore

University of Pennsylvania Health System

New York State Department of Health

Silverman Treatment Solution

La Red Health Center

Quality Insights

Health Literacy Connections

Help Initiative, Inc.

Institute for Healthcare Advancement

Sussex County Habitat for Humanity

Northshore University Health System

Delaware State University

Delaware HIV Consortium

Children and Families First

Neighbor Good Partners

League of Women Voters of Delaware

Detroit Recovery Project, Inc.

Delaware Academy of Medicine

Standford Medicine Children's Health

University of Southern Mississippi

Open Door Collective

Delaware Psychiatry Access Program

DHSS Library

Tapp Network

GBA Consulting

Wisconsin Literacy

Chesapeake Utilities

Contact Lifeline

Minnesota University School of Public Health

The University of Texas Health Science Center at Fort Worth

Health Literacy Statewide Planning Session Attendance

