Paterson-Passaic County/ Bergen County HIV Health Services Planning Council

2015

HEALTH LITERACY ASSESMENT REPORT

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Bergen-Passaic Transitional Grant Area
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EXECUTIVE SUMMARY

In 2015, the Planning Council determined that an assessment of health literacy among persons living with HIV/AIDS (PLWH) in the Bergen-Passaic Transitional Grant Area (TGA) is needed in order to assist a population that not only may have educational and verbal challenges but also must contend with difficult medical terminology associated with serious chronic illness. With health literacy skills, adherence and ultimately health status are likely to improve.

Once recognized as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions,"[1] the definition of health literacy now focuses more on the skills required to navigate the health care system and the importance of clear communication between providers and patients. Health literacy requires a complex group of reading, listening, analytical, and decision-making skills, and the ability to apply these skills in health situations. It includes the ability to understand instructions on prescription drug bottles, appointment slips, medical education brochures, doctor's directions and consent forms, and the ability to negotiate complex health care systems.

This study aims to assess current levels of health literacy among PLWH receiving Ryan White care and services in the Bergen and Passaic TGA and to assess the level of proficiency among Ryan White providers to assist with building health literacy skills. The goal is *to determine whether existing capacity is adequate to address health literacy skills in the TGA*. The assessment attempts to provide a baseline of information about health literacy among Bergen-Passaic PLWH, leading to self-efficacy with informed decision-making related to HIV care and support.

Five objectives frame the assessment:

1. Assess the current level of health literacy among Bergen-Passaic PLWH.
2. Review available health literacy resources available and distributed by the Part A providers.
3. Assess the extent to which Bergen-Passaic Ryan White providers receive training and/or technical assistance as professionals dealing with health literacy.
4. Identify the major areas of health literacy deficiencies and recommend solutions.
5. Develop an action plan for improved health literacy.

The methodology consisted of a literature review, key informant interviews, focus groups and a consumer survey.

KEY INFORMANT PERSPECTIVES

Four personal interviews with experts in health literacy were conducted, each of one hour duration and one with written correspondence. Key informants spoke with authority about the present state of health literacy, both locally and regionally. Their observations were considered equally valid in Bergen-Passaic. They assessed health literacy levels among PLWH as generally

[1] T. Selden et al, *Health Literacy: A Prescription to End Confusion."* Institute of Medicine (2004).

below average. Numeracy presents the greater challenge, but all aspects of health literacy need to be addressed as well.

Key informants spoke about health literacy levels across special populations, identifying foreign language speakers, low income and low educational attainment among those with lowest health literacy competencies.

According to key informants, improving health literacy is a provider's responsibility. It is one that has not received sufficient attention, however. Provider training in health literacy is a relatively new offering and one that many providers have not yet taken.

PROVIDER PERSPECTIVES

To gain information about the views and knowledge surrounding health literacy, two focus groups were conducted with supportive service professionals in the Ryan White Program. Topics included assessment of clients' health literacy, case manager capacity and training and consumer resources.

Clinical staff and case management providers expressed concern about their patients' abilities to understand medical forms, prescriptions, written directions, etc. Most important, however, providers felt that insurance health literacy constitutes the most common and urgent issue for their patients. Other forms of health literacy, while not to diminish their importance, are less urgent. The implementation of the Affordable Care Act leading to insurance options, previously a rare concern to Ryan White enrollees, presents new challenges that require basic understanding of insurance coverage and terminology.

According to focus group respondents, improving health literacy is a provider's responsibility Focus group participants uniformly spoke of the need for additional training.

Focus group participants also indicated that health literacy assessment was not a formal or required component of the case management care plan. While case managers may informally review their clients' health literacy, a structured assessment tool is not in place.

CONSUMER CAPACITY

To measure the health literacy capacity of persons living with HIV/AIDS, a short survey was undertaken with enrollees of the Bergen-Passaic Part A Program. Questions were derived from validated surveys available in the public domain. The sample consisted of 129 respondents; 92 (71%) took the survey in English and 37 (29%) completed it in Spanish. Ninety-four (69%) resided in Paterson or other parts of Passaic County. Bergen County was home for 35 (27%) of the respondents.

In general, survey respondents displayed average or below average competencies with regard to health, numeracy and health insurance literacy. While variations were noted, the overall results were consistent:

- Comprehension of simple reading materials were mostly adequate.
- Although respondents felt comfortable with reading health related materials, marginal or inadequate literacy levels were identified for more than fifty percent of respondents.
- Numeracy proficiency posed the greatest challenge for nearly all respondents.
- Health insurance literacy presented challenges to most respondents. For nine of ten questions pertaining to insurance health literacy, survey respondents scored below the national average.

The survey included an analysis of eight special populations:

- Residents from Paterson scored consistently lower when compared with other Passaic County and Bergen County residents.
- We compared race by White, Black and Other Race (as reported by respondents). Results were not uniform across the four health indicators. More often, Whites scored higher than Blacks but this did not hold true for all questions.
- We compared Hispanic respondents with Non-Hispanic respondents. Sixty-four respondents identified themselves as Hispanic. Results across the four health literacy indicators varied, with non-Hispanic respondents recording slightly higher scores on most questions.
- For all health indicators, females scored higher than males with one exception.[2] Differences, however, were not significant.
- Respondents were asked to identify their average annual income. Answers were grouped into four categories ranging from less to $10,000 to greater than $40,000. Respondents were allowed to answer "Don't know" as well. Respondents with incomes below $10,000 scored worse for all questions. Respondents ranging between $20,000 and $40,000 generally scored did not score better than those with lower incomes.
- As might be expected, health literacy correlated directly with educational levels of the respondents. Across all levels of education, Respondents with a Vocational Tech, College or higher education performed better on the survey than their counterparts with a lower level of education.
- We compared responses from those recently diagnosed (after 2010) to those who have been living with HIV/AIDS longer than five years. In general, those recently diagnosed scored higher although not uniformly across all questions. While not statistically proven, we observe that those living with HIV disease for more than five years were generally less health literate than those more recently diagnosed.
- We compared responses of persons infected with HIV through male sex with men (MSM), injected drugs and heterosexual transmission. Overall, results varied.[3] No clear distinctions emerged among the major transmission categories.

[2] Less than five transgender respondents completed the survey. Results are not reported to protect confidentiality.
[3] The sample contained 15 respondents injected by drugs using a needle and 15 with "Other" responses. Because of the small sample size, firm conclusions cannot be made for these special populations.

DISCUSSION, RECOMMENDATIONS AND WORK PLAN

Discussion

The study reveals issues anticipated in the literature and concerns expressed by clinical and case management providers. Key informants spoke with authority about the present state of health literacy, both locally and regionally. Their observations are equally valid in Bergen-Passaic where health literacy levels among PLWH are generally below the average. Numeracy presents the greater challenge, but all aspects of health literacy need to be addressed as well. The consumer health literacy survey results are consistent with key informant opinion.

So, too, are the clinical and case management providers who expressed concern about their patients' ability to understand medical forms, prescriptions and written directions. Most important, however, providers felt that insurance health literacy represents the most common and urgent issue for their patients. Other forms of health literacy, while not to diminish their importance, are less urgent. The implementation of the Affordable Care Act leading to insurance options, previously rarely of concern to Ryan White enrollees, presents new challenges that require basic understanding of insurance coverage and terminology. They are often confusing, not just to PLWH but to the general public as well. However, according to this study, PLWH have greater needs.

The consumer health literacy survey confirms the opinions expressed by both key informants and providers. In general, survey respondents displayed average or below average competencies with regard to health numeracy and health insurance literacy. While variations were noted, the overall results were consistent.

It is safe to conclude that very low income levels and low educational attainment were the most significant contributing factors of health literacy. Language did not emerge as a significant barrier. Hispanics, who were able to complete the survey in Spanish, scored slightly but not significantly lower than Non-Hispanics for the majority of indicator. This may be attributed to the availability of bi-lingual personnel at the provider sites and to attention paid by this TGA to cultural competency.

Recommendations

In 2010, the Planning Council commissioned a two-year task force on cultural competency that culminated in a set of nineteen recommendations to the Part A Program. As health literacy and cultural competency are related, these recommendations are relevant to the discussion here. Bi-lingual assistance, while available across the entire provider network, needs to be tied into health literacy assistance as part of the routine services of the Part A Program. The 2011 Cultural Competency Task Force Recommendations acknowledged this relationship and was explicit in endorsing health literacy improvement in the TGA.

With this in mind, the following recommendations for improving health literacy are offered.

1. Establish health insurance literacy as the priority training needed by consumers and supported by clinicians and case managers.
2. Assess all case management clients for health literacy using a standardized assessment tool. Communicate results to the clinicians providing care. Tools may be selected by the individual agency based on the preponderance of special populations. However, the selected tool should utilize a scoring method for objective measurement.
3. Incorporate health literacy improvement into every case management care plan.
4. Require case managers to obtain health literacy training. Internet trainings are available at no cost and can be completed conveniently.
5. Provide access to health literacy learning aids for all Part A enrollees, and encourage the use of online courses for consumers. Providers should consider having online bi-lingual programs available for viewing at their site.
6. Implement health literacy improvement recommendations from the Cultural Competency Task Force recommendations of 2011.

Members of the Planning & Development Committee of the Paterson-Passaic County-Bergen County HIV/AIDS Planning Council formulated a work plan based on the findings of this assessment and the recommendations offered. The work plan is presented as part of the full report.

I. INTRODUCTION

A. OVERVIEW OF HEALTH LITERACY

According to the U.S. Department of Education National Center for Education Statistics, 12% of American adults possess "below basic" health literacy proficiency.[4] Since this finding was reported in 2003, over 1,000 studies have demonstrated that most health materials are written at levels of complexity far beyond the reading skills of average high-school graduates.[5] Health literacy is a problem for the general population and not exclusively for those with HIV/AIDs.

Non-English speakers are traditionally among those with low educational attainment and often are severely compromised in their ability to understand health related materials. In the Bergen-Passaic Transitional Grant Area (TGA), 2010 census estimates indicate 30% of the population is foreign born, and more than fifty languages are spoken in the home. Between 36% and 44% speak a language other than English at home; and, of those residents, 38% to 50% speak English less than well.[6] Nine percent of Bergen and 13% of Passaic households are linguistically isolated, compared to 5% nationally.[7] Passaic County is home to ten percentage points more Spanish language speakers then the statewide average and ranks second highest among the 21 New Jersey counties for those who speak English less than well. Undocumented immigrants, difficult to quantify, are found in substantial numbers. With its extraordinary diversity and widespread dependence on foreign languages, problems associated with language comprehension are inevitable.

A 2014 study commissioned by the Paterson-Passaic County – Bergen County HIV Health Services Planning Council found that Spanish-speaking respondents made little mention of language problems, indicating they felt that translation services were adequate for them. However, with low educational attainment common among this population, translation does not equate to adequate health literacy. The study recommended further investigation of health literacy among PLWH, in particular those with limited English proficiency. While that needs assessment focused exclusively on Spanish-speakers, it is generally recognized that health literacy is a barrier to all non-English speakers.

Persons with low educational attainment and low income are also vulnerable to inadequate health literacy. According the Planning Council's 2012 Comprehensive Needs Assessment, over 20% of Bergen-Passaic PLWH did not complete high school, and over 67% live at or below 300% of the federal poverty level.

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[4] M. Kutner, E. Greenberg, Y. Jin,Y and C. Paulsen, C. (2006). *The Health Literacy of America's Adults: Results From the 2003 National Assessment of Adult Literacy* (NCES 2006–483). U.S. Department of Education. Washington, DC: National Center for Education Statistics.

[5] Ibid.

[6] U.S. Bureau of the Census. 2010 Census of the Population.

[7] Linguistic isolation is defined as a household where no one age 14 and over speaks English only or speaks English "very well." U.S. Bureau of the Census.

Attention to health literacy is burgeoning throughout the nation and in New Jersey as well. In 2015, the New Jersey Department of Health Division of HIV/AIDS, STD and TB Services (NJ-DHSTS) announced an initiative to improve health literacy among persons living with HIV/AIDS (PLWH). It will emphasize provider training, particularly for case managers, in assessing and improving levels of health literacy for Ryan White enrollees as well as requiring health literacy screening by Part B case managers. Additionally, academic and professional organizations are raising awareness about health literacy through presentations and full-day workshops held at various clinical sites. Thus, the decision by the Planning Council to address health literacy for Part A/MAI clients is timely and apt.

A complete definition of health literacy is evolving. One of the earliest authorities defines health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[8]More recent definitions focus on specific skills needed to navigate the health care system and the importance of clear communication between the health care providers and their patients, both of whom play important roles in health literacy. Health literacy is not simply the ability to read. It requires a complex group of reading, listening, analytical, and decision-making skills, and the ability to apply these skills to health situations. For example, it includes the ability to understand instructions on prescription drug bottles, appointment slips, medical education brochures, doctor's directions and consent forms, and the ability to negotiate complex health care systems. This expanded definition is articulated by the Calgary Charter on Health Literacy:[9]

> Health literacy allows the public and personal working in all health-related contexts to find, understand, evaluate, communicate and use information. Health literacy is the use of a wide range of skills that improve the ability of people to act on information in order to live health lives. These skills include reading, writing, listening, speaking, numeracy, and critical analysis, as well as communication and interaction skills.

Health literacy is measured by numerous components that must be understood in order to address its full import. Among them are the following.

- Prose – The ability to search, comprehend and use continuous text, such as pamphlets and newspaper articles.
- Document – The ability to search, comprehend and use non-continuous texts in various formats, such as train schedules, food labels, prescription labels, appointment slips, forms, etc.
- Numeracy – The ability to identify and perform computations, alone or sequentially, using numbers embedded in printed materials, such as completing an order form, balancing a checkbook, understanding graphs, understanding food labels, etc.
- Health Insurance – The ability to understand basic health insurance terms and concepts, such as when choosing or using a health plan.

[8] T. Selden et al, *Health Literacy: A Prescription to End Confusion."* Institute of Medicine. 2004.
[9] The Calgary Charter on Health Literacy, sponsored by the Centre for Literacy of Quebec. October 2008.

Further, research has shown that poor health literacy directly affects health status. Persons with limited health literacy skills consistently:[10]

- Participate in negative health behaviors;
- Hold health beliefs that interfere with adherence;
- Present in later stages of disease;
- Need to be hospitalized or re-hospitalized;
- Misunderstand instructions needed for self-care;
- Die at an earlier age;
- Neglect preventive behaviors or services such as mammograms, flu shots, etc.;
- Poorly manage chronic disease (such as HIV/AIDS).

With this as a backdrop, the Planning Council determined that an assessment of health literacy among PLWH in the Bergen-Passaic TGA is needed in order to assist a population that not only may have educational and language challenges but also must contend with difficult medical terminology associated with serious chronic illness. With health literacy skills, adherence and ultimately health status are likely to improve. Thus, attention to this important subject is most appropriate.

B. METHODOLOGY

Goals and Objectives

This study aims to assess current levels of health literacy among PLWH receiving Ryan White care and services in the Bergen and Passaic TGA. The study also assesses the level of proficiency among Ryan White providers to assist with building health literacy skills. The aim is to determine whether current capacity exists and is adequate to address health literacy skills in this TGA.

Project Goal:

To provide a baseline of information about health literacy among Bergen-Passaic PLWH, leading to self-efficacy with informed decision-making related to HIV care and support.

Objectives:

1. Assess the current level of health literacy among Bergen-Passaic PLWH.
2. Review available health literacy resources available and distributed by the Part A providers.
3. Assess the extent to which Bergen-Passaic Ryan White providers receive training and/or technical assistance as professionals dealing with health literacy.
4. Identify the major areas of health literacy deficiencies and recommend solutions.
5. Develop an action plan for improved health literacy.

[10] Elissa Director, "Health Literacy: The Link Between Better Communication and Better Health Outcomes." Presentation. Rutgers University, Office of Continuing Professional Education, 2015.

Research Methodology

This assessment includes the following components.

- A literature search of the status of health literacy among PLWH to determine various levels of proficiency, training resources available to Ryan White providers, online and written resources for PLWH, best practices and other topics of interest.

  Health literacy has many definitions and applications specific to various segments of the population. While health literacy has been a topic of interest for over a decade, recent research and discourse continue to become available. The study reviews relevant resources related to health literacy, screening tools and materials available to assist with health literacy skills.

- A consumer survey to measure PLWH current levels of health literacy as related to document comprehension, numeracy and health insurance.

  Consultants conducted a short survey of Ryan White Part A clients to determine prevailing levels of health literacy. Consultants researched available validated survey instruments suitable for the population and developed a multi-faceted survey instrument with input from the Planning & Development Committee. The instrument contained 25 questions, exclusive of screening and demographic questions, and covered reading, health, numeracy, insurance and HIV/AIDs literacy. Being a short survey, no attempt was made to cover each area comprehensively or in detail.

  The survey was conducted on line or with pen and pencil depending on the preference of the survey respondent. All Part A medical and medical case management providers were asked to participate by identifying respondents and assisting with administration. Instructions for recruiting respondents and conducting the survey were provided prior to the survey period. The survey was administered in English and Spanish. Additional information pertaining to the survey methodology is contained in Section II of this report.

- Interviews with key informants to assess health literacy issues and identify best practices.

  Four personal interviews of one hour duration and one written correspondence were conducted with experts in health literacy. Key informants experienced with persons with serious chronic illness and/or persons with HIV/AIDS were selected from recommendations of health care professionals. Key informants were asked about the prevalence of low health literacy and best educational practices available to health professionals.

- Provider focus groups to determine how health literacy is currently addressed at Ryan White care sites.

  Two two-hour focus groups were conducted with Part A medical providers and medical case managers, especially those who provide treatment adherence, to answer:
  - To what extent are your clients currently below basic levels of health literacy?
  - How do providers help clients with below basic health literacy?
  - What materials are used to support health literacy?
  - What training do providers receive related to health literacy?
  - What are the major barriers to improving health literacy?
  - What is needed from providers to help with health literacy?

  The focus groups, one in each county, consisted of six to twelve participants from case management agencies. The sessions were two hours in duration with a short pen and pencil survey. Discussions were audio taped and transcribed to assure accurate reporting. A focus group guide was developed and approved by the Planning & Development Committee prior to the session. Prior to each session, participants were asked to complete a short survey intended to summarize their current levels of knowledge and experience with health literacy client support.

- An inventory of materials and resources currently available to PLWH and to Ryan White providers intended to enhance health literacy skills, particularly for those who do not speak English well.

  Consultants prepared an inventory of consumer oriented health literacy materials and resources available in English and foreign languages for PLWH as well as professional materials and resources for providers. The inventory was helpful in developing the health literacy action plan contained in this report.

II. KEY INFORMANT PERSPECTIVES

To gain insights into the current situation with regard to health literacy among PLWH, personal interviews were undertaken with leaders in the field with knowledge of the special needs of persons with HIV/AIDS. Key informants were asked about the prevalence of low health literacy, current thinking on how to address literacy among persons of low educational attainment, and best educational practices available to health professionals.

The key informants represented:

- The New Jersey Department of Health Division of HIV/AIDS, TB and STD Services;
- The New York/New Jersey AIDS Education and Training Center Southern New Jersey Local Performance Site, and
- Rutgers University School of Nursing.

Their collective experiences included direct contact with PLWH in clinical settings, HIV planning, health literacy research and professional training. One-hour interviews were conducted by telephone, which were audio recorded and transcribed. A fifth key informant provided written comments based on the interview guide.

The following summarizes their comments.

A. ASSESSING HEALTH LITERACY AMONG PERSONS WITH HIV/AIDS

In the opinion of the key informants, the level of health literacy among persons with HIV/AIDS is generally low. However, the spectrum of comprehension levels can be relatively wide. Those who have been engaged in care for a period of time often have a fairly high level of health literacy specific to HIV. On the other end, the newly diagnosed or those not engaged in care usually have major health literacy deficits. Key informants agreed that the length of time in care affects health literacy. For the more recently diagnosed, the problem is more acute.

Low health literacy would be measured in terms of language and mathematics. For the most part, most patients are fairly clear about some of the language, i.e., understanding the virus, the immune system, etc. Both language and mathematics need to be addressed.

Mathematics, i.e., numeracy, is much more difficult to comprehend than language comprehension. Lab values, such as CD-4 cell counts and viral load, tend to be intimidating and therefore less comprehensible. Prescription adherence is directly affected by health literacy and numeracy in particular. Key informants spoke about specific examples when their patients were unable to sort out the number of doses, when and how they should be taken, what to do about contra-indications and other potentially serious matters. These challenges often lead to poor adherence, often with the patient refusing to take the medication at all. One key informant tested her patients on the number and frequency of taking their prescribed dosages. She found that, out of 100 patients, about five percent answered correctly. If prescription usage is complex in any

way, or if there are multiple medications to be taken at various times, the patient is challenged to know and understand what, when and how much to take.

Misinformation is one of the problems key informants talked about when identifying barriers to health literacy. Myths about HIV treatments, stigma or unreliable sources of information can often affect patients' understanding of their disease and their treatment needs. Peers, while often helpful in providing support, may not always have accurate information affecting engagement and adherence as a result.

Low health literacy is not always the patient's fault. Often, information is provided far above their reading level. In general, the problem is not so much the patient's reading level but how the information is presented. "If there is a lot of text, a lot of writing, people get frustrated – that's too much to read, it takes too long to get to the message... "

> *Albert Einstein once said, "If you can't explain it simply, then you don't know it well enough."*

Medicaid advises providing materials between grade levels of 3-5; and the reading level of the average American is between 5-8 grades. Yet it is very difficult to write below sixth grade level.

Pictures help people with low literacy understand the text. Many in the community are visual learners. When patients receive information sheets when they leave the visit, most of it is written, and often there is no visual cue to go with that. Pictures help a great deal in this respect.

One key informant stated, "In general, a simple form is ridiculously complicated." Consent forms are usually written in a language well above the understanding of the average person. The form itself, especially with insurance and referrals, is as difficult for the person to understand as are the verbal instructions. Computer generated forms are especially difficult. As a result, when a patient does not show for a visit, the reason may be that he or she didn't understand the form received in the mail with appointment information.

When a patient does not read, the situation worsens considerably. Some patients will not reveal that they cannot read, and others comprehend only to a limited degree. Information on prescription drugs are particularly difficult for the low literacy reader inasmuch as very little account is taken for those who do not or cannot read labels properly.

Foreign-born patients obviously struggle more with health literacy simply from the fact that English is not their primary language. The words used by Americans, i.e., the words we are accustomed to hearing, have different meanings to people who don't clearly understand American colloquialisms or the way they speak; and that is misinterpreted many times when speaking to a foreign-born person.

The problem goes beyond literacy levels and onto cultural distinctions. Words we may use in English may be different words in other cultures. Clearly, culturally and linguistically appropriate health information is critical. Health care professionals are not always culturally competent when talking to their patients. Clearly, culturally and linguistically appropriate health

information is critical, and providers need to be aware of cultural differences. "If agencies are not teaching their care givers to be aware of what they are saying, then [they're] going to miss the boat."

As one key informant described, "It's not that they don't understand the concept as much as they just have learned a different word for it. Also, when you look at some of the sub-populations, it's not so much the word as how the information is delivered."

One key informant spoke about values. Sometimes people think, "Oh they must not understand what I'm saying;" versus "No, they just disagree with me." I think that has to be pulled apart as well.

> *"Where is the line between what someone comprehends versus where someone just differs in opinion?"*

When discussing prevalence of low health literacy among special populations, one key informant identified income levels as a significant determinant. Low educational attainment, a byproduct of poverty, would directly affect health literacy. Further, the low income population is likely to have less access to other informational resources such as the internet or media. While they mostly depend on their health provider, they also tend to use their peers for information, which can be both positive and negative. Peer support for persons with HIV should be strengthened by proper education so that shared information is accurate.

One key informant discussed low educational attainment somewhat differently. She sees a problem with how people were taught in school, with dependence on standardized tests or multiple choice questions and answers. Patients, particularly those of low socioeconomic status, were not taught how to take in information, synthesize and understand how to make a decision from it.

> *"One of the biggest barriers to literacy is not the words but the process around the use of those words."*

Key informants did not identify differences across genders. Age groups, on the other hand, have differences. Younger and middle-age patients, especially those that use the internet, are likely to be more in tune with medical information. Seniors, on the other hand, depend on their doctor or nurse and more often find themselves at a loss. The elderly may also be affected by cognitive deficits. One key informant identified the mentally ill because they are disenfranchised.

Health insurance literacy is an area of immediate concern, according to key informants. A population living at or below the poverty level never had insurance prior to the Affordable Care Act and usually did not work within the insurance system. Further, they tend not to understand the difference between insurance and grant programs such as Ryan White. So, when they get Medicaid or private insurance, they may not know what to do with it.

Those who qualify for marketplace plans may not know differences in coverage and can find themselves underinsured. For example, people with HIV need to know that the Bronze plan is

not sufficient for their needs and that supplemental assistance to obtain the Silver plan, which is better suited to their health needs, is available under Ryan White.

There are many levels of health insurance literacy that are not well understood – co-pays, deductibles, in- and out-of-network requirements, managed care options, formularies, payment policies and appeals processes to name a few. As one key informant stated, it's now imperative to understand precisely what the plan covers. Conversely, the insurance company needs to better understand HIV patients including differences in medications, their efficacy, resistances and other medical concerns, rather than simply apply the rule of lowest cost to the prescription claim.

The implications of low health insurance literacy are evident. If patients don't understand basic concepts such as deductible or co-pays, they are prone to skip their appointments and not receive their medications on a regular basis. "Someone has to teach them how to access appointments, how to access specialty care, how to work with the co-pay, how to understand deductibles…then, if something happens in their lives, they can protect themselves."

B. PROVIDER COMPETENCY

Current Health Literacy Practices

Key informants were unaware of standardized practices to assist patients with health literacy. Systematic health literacy screening is not usually part of a provider's intake process and would be included in the treatment plan only incidentally. Actual health literacy is usually provided as needed, but utilizing measure tools to determine actual health literacy levels or outcomes are generally not done. There are exceptions however, thus variations exist across the various providers. The New Jersey Department of Health is moving toward formalizing health literacy assessment and interventions at the provider level.

When asked if medical and case managers need special health literacy training, key informants answered affirmatively. Training is needed on how to assess health literacy and how to deliver health information to people with low literacy. "Whether case managers, linkage coordinators, peers…I think somebody needs to be trained in how to lift that literacy level. It's a barrier that, if overcome, the person can move towards self-sufficiency."

Available Resources to Assess Health Literacy

According to key informants, health professionals have an array of standardized tools to assess their patients' health literacy levels. Many originate from government sources and many from educational centers.

Tools for Health Professionals

Key informants agreed that responsibility for improving health literacy for their patients and/or clients lies with the health professional. This includes not only clinical personnel but social workers and case managers. Most do not have specific training in health literacy. Nor were

informants aware of structured trainings targeting this topic. They did state that interest appears to be widespread.

Key informants cited a number of tool kits available to assist health professionals improve their patients' health literacy. One informant spoke of videos, in Spanish and English, to help professionals work with persons with lower literacy levels.

The National Action Plan to Improve Health Literacy[11] released in 2010 by the United States Department of Health and Human Services seeks to provide a framework for organizations, professionals, policymakers, communities, individuals, and families in a linked, multi-sector effort to improve health literacy. Key informants expressed concern that providers are not meeting the objectives of the Plan.

The Centers for Medicare Services (CMS) offers a very substantial manual around document literacy and how to design documents to make them readable. Other "plain language" tools are useful when translating documents to sixth grade level. Internet tools such as Google Plain Language are immediately available at no cost.

Health Literacy Training

Key informants collectively agreed that health literacy training was needed for medical professionals and medical case managers in particular. Continuing education programs are available from numerous sources, both in written and on-line formats. They recommended a teach-back approach where educating about specific skills includes total health literacy skills. Such skills include teaching patients where to get information, how to process that information, how to make a decision using that information and then where to go for follow-up. Such teach-back skills need to be taught to health care professionals. Informants also emphasized the need to go beyond surface level understanding to rigorous skills building. One approach to health literacy looks at how information from the medical record can be easily understood, considering how the information changes to meet the needs of the physician to those of the patient.

Key informants recommended valuable trainings available from Literacy Volunteers of America, Centers for Medicare Services, the Office of Minority Health, National Quality Center, and other organizations. Numeracy training, however, is a relatively new topic, and still in the formative stages.

NJ-DHSTS is actively supporting health literacy training and will require a certificate of completion for any health professional but especially for medical case managers. This relatively recent step underscores a new recognition of the importance of health literacy and the need for a proactive approach to training. Other key informants endorsed health literacy training targeted directly to HIV/AIDS.

One key informant advocated for a statewide health literacy campaign with Ryan White Part A and Part B professionals joining forces as a collaboration.

[11] http://www.health.gov/communication/HLActionPlan/

C. CONSUMER RESOURCES

Consumer Access to Health Literacy Tools

Health literacy tools are abundantly available, and some are very good, according to one key informant. For the most part, HIV/AIDS patients do not have access to structured courses to improve health literacy even though they would certainly benefit from them. One key informant observed that other groups, such as cancer patients, have more and better access to systematic information sharing.

Key informants spoke about tool kits aimed at consumer understanding. Kaiser Family Foundation offers resources on the internet. It also includes a video about basic health insurance.

Foreign Language Resources

Spanish resources are the most common form of foreign language print aids. Interpreters would be ideal; however, smaller agencies do not have the resources to hire. Family members who act as translators are not the best solution, either. Even when agencies have bi-lingual staff, many are not in a position to interpret or understand the needs of the patients. One informant explained: Interpreting should include understanding the context of HIV, and most interpreters are not going to be able to have the kind of insight or are not trained to have this insight.

D. ORGANIZATIONAL POLICY

Key informants collectively agreed that organizations need to be aware of health literacy as a provider's responsibility, much like the movement in cultural competency. Credentials, certifications, and trainings should be explicitly endorsed in the agency's policy and procedures documents. Roles and responsibilities need to be defined as part of their standards of care.

One key informant believes that health literacy gets "lip service" at the agency level; that is, they think the work is done but they don't look with a critical eye to determine what really works for clients or patients. "We don't really reach the people where they need to be reached to really make a difference on how they approach their health care or manage their lives."

Informants believed that Ryan White agencies are more sensitive to the issue than primary care providers. One informant believes that medical case managers can fill the void at most practices, relieving doctors from this time-consuming work. However, only patients who are case managed would benefit; thus, a broader level of health literacy still needs to be in place.

Key informants believe there are not enough bi-lingual nurses to meet the needs of the HIV population. One informant believes that there are more culturally competent providers in HIV clinics than in primary care practices. Another informant described a recent study that found nurses to be very focused on patient education but ill-informed about health literacy.

There is a disconnect between public health concepts and clinical practice.

One key informant suggested a statewide health literacy campaign conceived as a collaboration across various types of providers. Case managers, for example, could work together to re-define their roles to include more than addressing social service needs. An informant recommended a holistic approach incorporating knowledge of health and risk behaviors, how the health care system works and how to work within the system. In doing so, case managers can be effective in "filling the void" left by doctors who do not have time to work more closely with their patients.

III. PROVIDER PERSPECTIVES

While every provider of HIV/AIDS health services is involved with client education, it falls to the medical and non-medical case manager, as well as clinical staff, to work most directly in advancing health literacy. To gain information about the views and knowledge surrounding health literacy, focus groups were conducted with supportive service professionals in the Ryan White Program. Discussions centered on the state of health literacy among their clients/patients, the extent to which personnel are themselves equipped with assisting health literacy and suggestions for meeting the health literacy needs of their constituents.

Two focus groups were conducted: one in Bergen and one in Passaic County, on March 25, 2015. Thirteen direct service providers were selected to participate, nine of whom were medical or non-medical case managers, representing seven Ryan White agencies. Experience and caseloads varied, but in general the case managers were considered to be knowledgeable about the special needs of HIV/AIDS clients. Experience averaged 11.7 years and ranged from less than one to 26 years. Average caseloads also varied from six to 150, averaging 84 clients per case manager.

Prior to discussions, participants completed a short twelve-question survey pertaining to client evaluation and education procedures currently in place. Twelve of the thirteen participants completed the survey. Responses are tabulated and presented below and at the end of this chapter.

Focus group discussions centered on four main topics:

- The current status of health literacy among HIV/AIDS clients;
- Prose, document, numeracy and health insurance literacy;
- Professional health literacy training;
- Screening and learning tools for consumers.

The following summarizes the major points of the discussion.

A. ASSESSING CLIENTS' HEALTH LITERACY

Health literacy evaluation is not standard practice in the Bergen-Passaic TGA. Fifty-eight percent of focus group participants stated they do not evaluate their client's health literacy using a standard assessment tool. Of those who do evaluate regularly, follow-up and re-evaluation are usually done but not with regularity. When asked how often clients are evaluated or re-evaluated, answers ranged equally from every visit to twice per year to "as needed." Only one-quarter of the focus group participants indicated their agency provides formal health literacy education for their patients or clients.

According to focus group participants, the level of health literacy is not uniform for all clients. HIV community as a whole, compared to those with other illnesses, even chronic illnesses, are usually well informed on instructions with labs, medicine, tests, etc. Focus group participants observed some clients, particularly gay men, are on the high end of comprehension. However, this is not always the case.

While health literacy is an issue across the entire general population, focus group participants felt it is worse for persons with chronic diseases such as HIV/AIDS. Medications and complexities of their diseases make it more difficult to understand underlying symptoms, indications, medications, etc.

Participants made a strong point regarding literacy in general. Some clients have little or no reading skills and therefore are at severe disadvantage to understand and act upon medical information. Literacy (i.e., reading skill) is the baseline and needs to be addressed before medical information can be understood. Literacy, especially in urban Paterson, is the first problem. Health literacy follows.

Understanding the doctor is not always easy for many HIV/AIDS patients, according to the participants. Many patients say "yes" to the doctor's questions just to finish their appointment, and they feel the doctor doesn't do good follow-up with the patient. According to the participants, this happens often.

Participants observed that certain populations have lower levels of health literacy. Often those who need extra help are:

- The newly diagnosed;
- Substance abusers and mentally ill have greater problems;
- Elderly with dementia causes forgetfulness;
- Non-English speakers. All focus group participants have some clients with issues understanding the English language. Their clients need an interpreter, not just a translator, and medical translators are in short supply. There is a need for Asian speakers. One quarter of focus group participants stated they provide health literacy assistance in foreign languages, Spanish and Polish being most common.

Low educational attainment is not necessarily universal in this TGA, however. It does directly affect health literacy, but not all are in that situation according to the participants, particularly those in Bergen County. Persons with average to high intelligence but without reading ability will find health literacy a barrier. Others are able to seek out educational tools to raise their level of comprehension.

There was general agreement that low health literacy affects adherence, retention, and health status. Research has shown this to be true.

Levels of Health Literacy

Reading (prose) and document literacy

Case managers observe that understanding and acting upon written materials related to HIV/AIDS can often be overwhelming, causing the client to rely on the case manager for interpretation. Many clients are so overwhelmed with the disease itself and all the different pieces that go with it, such as stigma, filling out forms, etc.

Forms are threatening, according to case managers. A client just diagnosed doesn't understand the full impact of what is going on. Some lack confidence when submitting a claim themselves and tend to rely on the case manager. Once a client learns that it's not as threatening, confidence rises.

Case managers stated that some forms themselves were not easy to complete. Many are left to do their own research before assisting the client. They cited a lack of training as a barrier to health literacy.

Numeracy/prescription directions

Focus group participants believe that basic HIV information is generally understood. CD4 and viral load are easy to understand. Yet, their clients don't fully understand what else the doctor says.

Prescription directions can be confusing, although the pharmacist usually will explain the labels. Often, the patient's emotional state plays into comprehension.

Participants also stated there is a level lacking in nutritional literacy.

Health insurance literacy

Focus group participants felt that health insurance literacy is currently the most urgent issue facing their clients today. Half of focus group participants provide some form of health insurance literacy assistance to their clients.

Not having health insurance means not getting treatment. Not understanding the rules of health insurance can have a domino effect on overall care and treatment. With the Affordable Care Act, patients need to do extra work, will get confused, could lose their adherence routines and get frustrated with trying to communicate with doctors. The need depends on whether they understand enough to ask questions.

First, choosing the right insurance plan is very difficult. If the case managers find it confusing, imagine how the client feels. Uniformly and generally unanimously, focus group participants consider the problem critical to the care and treatment of PLWH.

Basic insurance terminology is generally understood, but knowing what the plan covers is needed more. Medicaid HMOs are the most difficult with which to work. "Insurance is going to be the death of everybody," said one participant.

Case managers walk clients through the process but are not always confident in their own skills. "We're not all that literate ourselves about insurance. We have had to use trial and error to get things done."

Focus group participants noted insufficient understanding of the appeals process. The system is overwhelmed, which makes it difficult to navigate.

HMOs may not always understand the special needs of HIV patients, especially with supportive services. There is a gap between perception of medical needs between the patient, case manager and the insurer. For example, substance abuse is not considered a "symptom" but is often perceived by insurers as an "illness" that interferes with treatment regimens. Case managers believe there is a need to address the whole person and addressing the problems and barriers that do not allow their clients to understand their health problems.

B. CASE MANAGER TRAINING AND ASSESSMENT

Universally, focus group participants stated there is no formal procedure or standard in place for assessing the health literacy of their clients. Further, no specific or uniform screening tool is used nor is health literacy specifically addressed at intake. Screening may be done by the nurse, but non-medical case managers do not usually work directly with the medical case manager.

Health literacy training is not widely received, according to focus group participants. Only one participant ever attended training on health literacy. Most go through Basic Facts (fundamental instruction on HIV/AIDS), but they stated they need much more.

Focus group participants expressed strong interest in course work, training, and screening tools related to health literacy. There was strong support for a health literacy assessment as part of the case management intake. The majority felt assessments should be done at least every six months, although opinions varied on this.

One participant stated understanding billing codes would help the case manager to guide the patient.

Consumer Training

According to focus group participants, consumers have access to health literacy educational presentations. Pharmaceutical companies provide representatives with presentations for patients. Many are well attended, but not always. State-sponsored programs touch upon health literacy but usually have a different purpose.

Printed materials were not rated highly by focus group participants. On the other hand, videos are excellent. Health literacy classes also received high grades.

The internet, especially YouTube and other social media, is helpful with explaining complex subjects in plain language. Focus group participants find it a great tool. Some warned, however, that without proper caution, information from the internet can be misunderstood. They considered the website www.cdc.gov a comprehensive resource for expanding consumer capacity.

In the opinion of focus group participants, pictures, visuals, etc. are worthwhile tools. Using real-life examples are also effective. Be imaginative, they advised.

Case managers need to focus on support along with training. It takes a lot of energy to balance the two.

Community organizations, libraries, etc., also offer worthwhile programs. Participants urged each other to take good advantage of them.

Participants suggested investigating smart phone apps for medication reminders. It helps to keep a diary and a list of questions for the doctor. They urged training with asking questions "the right way."

IV. CONSUMER CAPACITY

To measure the health literacy capacity of persons living with HIV/AIDS, a short survey was undertaken from April 20, 2015 through May 20, 2015 with enrollees of the Bergen-Passaic Part A Program. Questions were derived from validated surveys available in the public domain. In total, 129 (N) respondents completed the survey, either on line or in hard copy. The survey was available in English (n=92) and Spanish (n=37). Results are presented as follow.

A. SURVEY SAMPLE

- The survey sample consisted of 129 respondents; 92(71%) were English speakers.
- Ninety-four (69%) resided in Paterson or other parts of Passaic County. Bergen County was home for 35 (27%) of the respondents.
- Nearly 35% of respondents were age 25 to 44, and 40% were over age 55.
- Males outnumbered females by approximately 54%.
- Whites and blacks were nearly equally represented. Hispanics accounted for 50% of survey respondents.

Respondent Characteristics

Demographics

Table IV.1
Survey Respondents by Demographic Characteristic

Residence	Count	%
Paterson	38	29.5%
Passaic County (not Paterson)	52	40.3%
Bergen County	35	27.1%
Other	4	3.1%
Total	129	100.0%
Age	**Count**	**%**
<=24	2	1.6%
25-34	23	17.8%
35-44	22	17.1%
45-54	30	23.3%
55+	52	40.3%
Total	129	
Gender	**Count**	**%**
Male	83	64.3%
Female	45	34.9%
Transgender	1	0.8%
Total	129	100.0%

Race/Ethnicity	Count	%
White	45	35%
Black	50	39%
Other	34	26%
Total	129	100.0%
Hispanic	64	49.6%

Economic and Educational Status

- Sixty-two percent of respondents earned less than $20,000 per year, placing them at or close to the federal poverty level.
- Thirty-seven percent did not complete high school.
- Fifth-eight percent were either not working or disabled.

Table IV.2
Survey Respondents by Economic and Educational Status

Annual Income	**Count**	**%**
Less than $10,000	51	40%
$10,000-$19,000	29	22%
$20,000-$39,000	16	12%
$40,000+	6	5%
Don't know/Declined	27	21%
Total	129	100.0%
Education Completed	**Count**	**%**
Less than third grade	1	1%
Fourth to eighth grade	14	11%
Some high school	32	25%
High school/GED	48	37%
Vocational training, college or other higher education	28	22%
Other	6	5%
Total	129	100.0%
Work Status	**Count**	**%**
Full time	28	22%
Part Time	19	15%
Retired	4	3%
Disabled	38	29%
Currently not working	37	29%
Other	3	2%
Total	129	100%

HIV Status

- Nearly 60% were diagnosed with HIV/AIDS since 2000, and 12% were diagnosed after 2010.
- Respondents were nearly equally infected by male sex with men or by heterosexual contact. Injecting drugs accounted for 12 percent of the respondents.

Table IV.3
HIV Status

When were you diagnosed with HIV?	**Count**	**%**
Before 2000	50	39%
Between 2000 and 2010	60	47%
After 2010	16	12%
Don't know	3	2%
Total	129	100%
How were you infected with HIV? (May answer more than one)	**Count**	**%**
Male sex with a man	49	38%
Injecting drugs using a needle	15	12%
Female sex with a man or male sex with a female	50	39%
Other	15	12%
Total	129	100%

B. OVERALL SCORES

Literacy

Five questions focused on the respondents' reading comprehension.[12] Respondents were provided with a sentence (or phrase) with a word missing. They were then asked to choose which word best fit the meaning of the sentence. Respondents were allowed to skip the question and go on to the next. Only English speaking respondents (92) completed questions D and E.

- Of the five questions asked, four were answered correctly by 90% or more of the total respondents, and one question (English only) was answered correctly by 63%.
- From these results, it appears that respondents demonstrated an adequate level of reading comprehension. The one question with below average results "the x-ray will …" was answered correctly by 63% with 40% answering incorrectly ("viewed").
- Very few (<5) respondents chose to skip these questions, indicating a general comprehension of the question and willingness to answer.

[12] Joanne R. Nurss, Ruth M. Parker, Mark V. Williams and David W. Baker, Short Test of Functional Health Literacy in Adults (STOFLA). Funded by the Robert Wood Johnson Foundation (August 2001).

Table IV.4
Literacy

a. Your doctor has sent you to have a _____ X-ray.

Answer	Total	% Total
Correct (stomach)	117	90.7%
Incorrect	9	7.0%
Skipped	3	2.3%
Total	129	100.0%

b. You must have an _____ stomach

Answer	Total	% Total
Correct (empty)	123	95.3%
Incorrect	3	2.3%
Skipped	3	2.3%
Total	129	100.0%

c. when you come for _____.

Answer	Total	% Total
Correct (it)	119	92.2%
Incorrect	6	4.7%
Skipped	4	3.1%
Total	129	100.0%

d. The X-ray will _____

Answer	Total	% Total
Correct (take)	58	63.0%
Incorrect	32	34.8%
Skipped	2	2.2%
Total	92	100.0%

e. from 1 to 3 _____ to do.

Answer	Total	% Total
Correct (hours)	86	93.5%
Incorrect	3	3.3%
Skipped	3	3.3%
Total	92	100.0%

Health Literacy

Three questions were asked about the respondent's perceived comprehension of health related information.[13] Answers were subjective and based solely on the respondent's opinion. Questions pertained to ability to understand health information without assistance, ability to complete health related forms, and difficulties with learning about health related conditions.

- Over one-quarter of respondents sought help when reading hospital materials. By contrast, 39% never asked for help and 35% used help sometimes or occasionally.
- Apparently experienced with medical forms, nearly 60% of respondents felt confident that they could fill them out alone. Sixteen percent expressed little or no confidence with completing medical forms.
- When asked about difficulties understanding written information, two-thirds of respondents replied they never or occasionally experienced problems learning about their medical condition. Twelve percent either always or often experienced such problems.

Table IV.5

a. How often do you have someone (like a family member, friend, hospital/clinic worker, or caregiver) help you read hospital materials?

Answer	Count	% Total
Always	21	16.3%
Often	12	9.3%
Sometimes	28	21.7%
Occasionally	17	13.2%
Never	50	38.8%
Skipped	1	0.8%
Total	129	100.0%

b. How confident are you filling out medical forms by yourself?

Answer	Count	% Total
Extremely	44	34.1%
Quite a bit	33	25.6%
Somewhat	29	22.5%
A little bit	19	14.7%
Not at all	2	1.6%
Skipped	2	1.6%
Total	129	100.0%

[13] Lisa D. Chew, Katharine A. Bradley and Edward J. Boyko, "Brief Questions to Identify Patients with Inadequate Health Literacy," Family Medicine 36(8): 588-94. 2004.

c. How often do you have problems learning about your medical condition because of difficulty understanding written information?

Answer	Count	% Total
Always	3	2.3%
Often	12	9.3%
Sometimes	28	21.7%
Occasionally	28	21.7%
Never	57	44.2%
Skipped	1	0.08%
Total	129	100.0%

Document Literacy/Numeracy

Numeracy is considered one of the most difficult parts of health literacy for most consumers. To test the level of document/numeracy literacy, respondents were provided with a standard label from an ice cream container.[14] (See Figure 1) Respondents were asked five questions about how to interpret the information on the label. The following tables show the number and percent who answered correctly, incorrectly or skipped to the next question.

Figure 1
Ice Cream Label

[14] The Newest Vital Sign, www.pfizerhealthliteracy.com. February 2011.

- Clearly, this set of questions posed the greatest problems for respondents. The percentage of respondents with correct answers ranged from 24% to 60%.
- The greatest difficulty pertained to the questions requiring the respondents to calculate an answer to a complex question. For these questions, correct answers ranged from 24% to 30% (Questions 3 and 4).

Table IV.6

a. If you eat the entire container, how many calories will you eat?

Answer	Total	% Total
Correct (1,000)	52	40.3%
Incorrect	75	58.1%
Skipped	2	1.6%
Total	129	100.0%

b. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?

Answer	Total	% Total
Correct (One cup / 2 portions)	47	36.4%
Incorrect	80	62.0%
Skipped	2	1.6%
Total	129	100.0%

c. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 grams of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?

Answer	Total	% Total
Correct (33 grams)	31	24.0%
Incorrect	91	70.5%
Skipped	7	5.5%
Total	129	100.0%

d. If you usually eat 2,500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?

Answer	Total	% Total
Correct (Ten percent)	39	30.2%
Incorrect	85	65.9%
Skipped	5	3.9%
Total	129	100.0%

e. Pretend that you are allergic to the following substances: penicillin, peanuts, latex gloves, and bee stings. Is it safe for you to eat this ice cream?

Answer	Total	% Total
Correct (No)	77	59.7%
Incorrect	50	38.8%
Skipped	2	1.6%
Total	129	100.0%

Insurance Health Literacy

Ten questions were asked to determine the level of health insurance literacy among PLWH. Questions were derived from a national validated survey developed by Kaiser Family Foundation.[15]

- Over half of the respondents knew the definition of "health insurance premium." One-quarter incorrectly said it was the best type of health insurance you can buy.
- Nearly three-quarters of all respondents understood that a premium must be paid every month.
- Knowledge of the health care deductible was demonstrated by less than one-quarter of all respondents, indicating this term is not well understood.
- Only 27% of respondents were able to correctly calculate out-of-pocket costs for a four-day hospital stay.
- Slightly more than half of respondents correctly identified "annual out-of-pocket limits."
- Only 12% knew the definition of a formulary.
- Respondents demonstrated a reasonable knowledge of a provider network with 61% answering correctly.
- When asked whether all doctors in a hospital participate in a specific provider network, respondents were nearly equally divided between positive and negative responses.
- Less than 4% of respondents correctly demonstrated an ability to calculate out-of-network expenses.
- Eighty-four percent of respondents demonstrated knowledge of appeals allowed for a denied claim.

[15] Mira Norton, Liz Hamel and Mollyann Brodie, Assessing Familiarity with Health Insurance Terms and Concepts," Kaiser Family Foundation, 2014. http://kff.org/health-reform/poll-finding/assessing-americans-familiarity-with-health-insurance-terms-and-concepts/

Table IV.7

Note: Correct answer is shown in *italics*.

a. Which of the following is the best definition of the term "health insurance premium"?

Answer	Count	% Total
The best type of health insurance you can buy	32	24.8%
The amount health insurance companies charge each month for coverage	69	53.5%
A bonus you get at the end of the year if you stay covered	6	4.7%
Don't know	19	14.7%
Skipped question	3	2.3%
Total	129	100.0%

b. Is a health insurance premium something you must pay every month, regardless of whether you use health care services, or do you only have to pay your health insurance premium during months when you use health care services?

Answer	Count	% Total
Must pay every month, regardless of whether you use services	95	73.6%
Only have to pay in months when you use health care services	12	9.3%
Don't know	16	12.4%
Skipped question	6	4.7%
Total	129	100.0%

c. Which of the following is the best definition of the term "annual health insurance deductible"?

Answer	Count	% Total
The amount that is deducted from your paycheck each year to pay for your policy	58	45.0%
The amount of health expenses you can subtract from income on your yearly tax return	17	13.2%
The amount of covered health care expenses you must pay yourself each year before your insurance will begin to pay	33	25.6%
Don't know	18	14.0%
Skipped question	3	2.3%
Total	129	100.0%

d. Suppose that under your health insurance policy, hospital expenses are subject to a $1,000 deductible and $250 per day co-pay. You get sick and are hospitalized for 4 days, and the bill comes to $6,000. How much of that hospital bill will you have to pay yourself?

Answer	Count	% Total
$0	10	7.8%
$1,000	46	35.7%
$2,000	35	27.1%
$4,000	6	4.7%
$6,000	2	1.6%
Don't know	27	20.9%
Skipped question	3	2.3%
Total	129	100.0%

e. Which of the following best describes the "annual out-of-pocket limit" under a health insurance policy?

Answer	Count	% Total
The most you will have to pay in deductibles, co-pays and coinsurance for covered care received in network for the year	68	52.7%
The most your insurance policy will pay for covered services in a year	10	7.8%
The most you will have to pay for premiums in a year	16	12.4%
Don't know	29	22.5%
Skipped question	6	4.7%
Total	129	100.0%

f. Which of the following best describes a "health insurance formulary"?

Answer	Count	% Total
The form you send to your insurance company when you need to have a medical bill paid	62	48.1%
The name for permission you must get from your insurance company before surgery will be covered	12	9.3%
The list of prescription drugs your health plan will cover	15	11.6%
Don't know	34	26.4%
Skipped question	6	4.7%
Total	129	100.0%

g. Which of the following best describes a health plan "provider network"?

Answer	Count	% Total
The hospitals and doctors that contract with your health plan to provide services for an agreed-upon rate or fee schedule	79	61.2%
The computer system doctors and hospitals use to submit bills to insurance companies	9	7.0%
A website where consumers can find information about the best doctors	13	10.1%
Don't know	23	17.8%
skipped question	5	3.9%
Total	129	100.0%

h. True or false: If you receive inpatient care at a hospital that participates in your health plan's provider network, all the doctors who care for you while you're in the hospital will also be in network.

Answer	Count	% Total
True	54	41.9%
False	51	39.5%
Don't know	20	15.5%
Skipped question	4	3.1%
Total	129	100.0%

i. Suppose your health plan covers lab tests in full if you go to an in-network lab, but only pays 60% of allowed charges if you go out of network. You forget to check and get your blood test at a lab that turns out to be out of network. The lab bills you $100 for the blood test. Your health insurance allows only $20 charge for that test. How much would you have to pay out of pocket for that lab test?

Answer	Count	% Total
$0	4	3.1%
$40	8	6.2%
$80	84	65.1%
$88	5	3.9%
$100	2	1.6%
Don't know	22	17.1%
Skipped question	4	3.1%
Total	129	100.0%

j. True or false? If your health insurance plan refuses to pay for a service that you think is covered and your doctor says you need, you can appeal the denial and possibly get the insurance company to pay the claim.

Answer	Count	% Total
True	108	83.7%
False	15	11.6%
Skipped question	6	4.7%
Total	129	100.0%

HIV Knowledge

Two basic questions about HIV/AIDS were asked to assess fundamental understanding of HIV clinical information. [16] These questions were added solely to assist providers with their patients and were not included as markers of health literacy.

- Eighty-six percent of respondents understood that HIV treatment is intended to increase CD4 counts.
- Eighty-seven percent of respondents understood that HIV treatment is intended to reduce viral load.

Table IV.8

a. Is the goal of HIV treatment to make the CD4 count go up or down?

Answer	Count	% Total
Up	111	86.0%
Down	14	10.9%
Don't know	3	2.3%
Skipped	1	0.8%
Total	129	100.0%

b. Is the goal of HIV treatment to make the viral load go up or down?

Answer	Count	% Total
Up	12	9.3%
Down	112	86.8%
Don't know	2	1.6%
Skipped	3	2.3%
Total	129	100.0%

[16] CY Osborn,TC Davis, SC Bailey and MS Wolf. Health Literacy in the Context of HIV Treatment: Introducing the Brief Estimate of Health Knowledge and Action (BEKHA)-HIV Version. AIDS Behavior14(1): 181-8 (2010).

C. INTERPRETATION

To interpret the survey results, we assigned three levels of competency: adequate, marginal and inadequate. Where benchmarks were unavailable, levels were measured by percentage of correct responses. Questions with only two options, correct or incorrect, were interpreted as adequate (correct) or inadequate (incorrect):

1. Correct/Incorrect

Interpretation	Range (% Correct)
Adequate	61-100%
Inadequate	60-0%

Questions with a range of answers based on respondents' qualitative opinion, were interpreted as adequate, marginal or inadequate based on a Likert scale of one to five with one as the worst and five as the best, as follows:

2. Range of answers

Interpretation	Answer: How often do you have someone help you read hospital materials?	Answer: How confident are you filling out medical forms by yourself?	Answer: How often do you have problems…because of difficulty understanding written materials?
Adequate	Never (score=5)	Extremely (score=5)	Never (score=5)
Adequate	Occasionally (score = 4)	Quite a bit (score = 4)	Occasionally (score = 4)
Marginal	Sometimes (score =3)	Somewhat (score =3)	Sometimes (score =3)
Inadequate	Often (score =2)	A little bit (score =2)	Often (score =2)
Inadequate	Always (score =1)	Not at all (score =1)	Always (score =1)

For survey questions on Insurance Health Literature, scores were compared to a national benchmark obtained from a 2014 nationwide survey of the general population.

Results indicate the survey population exhibited adequate literacy ability, adequate or marginal health literacy, mostly inadequate document/numeracy literacy and below average health insurance literacy.

Literacy

- Four of the five questions pertaining to literacy or basic reading comprehension were correctly answered by greater than ninety percent of respondents, indicating this set of questions points to adequate reading comprehension among respondents. Only one question (d) left respondents uncertain.

Question	% Adequate	% Inadequate
a. Your doctor has sent you to have a ___ x-ray	90.7%	9.3%
b. You must have an ___ stomach	96.1%	3.9%%
c. when you come for ___	92.2%	7.8%
d. The x-ray will ___	63.0%	37.0%
e. from 1 to 3 ___ to do	93.5%	13.2%

Health Literacy

- Scores varied depending on the question asked. Health literacy levels were determined to be adequate only when asked about filling out medical forms.
- When asked about needing help reading hospital materials and having problems understanding written information, literacy levels were considered marginal or inadequate for more than fifty percent of respondents.
- Nearly 60% of respondents scored well when asked about filling out medical forms alone, indicating a relatively high level of health literacy. Only two percent could be considered inadequately literate.

Question	% Adequate (Likert score = 5 or 4)	% Marginal (Likert score = 3 or 2)	% Inadequate (Likert score = 1)
a. How often do you have someone help you read hospital materials?	25.6%	34.9%	38.8%
b. How confident are you filling out medical forms by yourself?	59.7%	37.2%	1.6%
c. How often do you have problems learning about your medical condition because of difficulty understanding written information?	11.6%	43.4%	44.2%

Document Literacy/Numeracy

- This set of questions yielded the lowest literacy levels in the survey, predictive of the common difficulties with reading food labels or making calculations from information on the labels.
- Of the five questions related to document literacy/numeracy, responses for only one “is it safe for you to eat this ice cream” can be considered adequate.
- Results of the remaining four indicated inadequate document or numeracy literacy among survey respondents.

Question	% Adequate	% Inadequate
a. If you eat the entire container, how many calories will you eat?	40.3%	59.7%
b. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?	36.4%	63.6%
c. …if you stop eating ice cream, how many grams of saturated fat would you be consuming each day?	24.0%	76.0%
d. …what percentage of your daily value of calories will you be eating if you eat one serving?	30.2%	69.8%
e. …is it safe for you to eat this ice cream?	59.7%	40.3%

Insurance Health Literacy

For this set of questions, national survey results were compared to the sample. Generally, the sample revealed less understanding of health insurance and, at times, significantly higher levels of inadequate literacy.

- For all but one question, sample results were consistently below national averages. Some sample responses were more than twenty percentage points below national averages.
- Sample respondents scored most poorly when asked about health insurance premiums, deductibles, out-of-pocket expenses and formularies, indicating generally inadequate of understanding about insurance terminology and applications.

Question	% Answered Correctly	National Benchmark
a. Which is the best definition of the term "health insurance premium"	53.5%	76%
b. Is a health insurance premium something you must pay every month…	73.6%	79%
c. Which is the best definition of the term "annual health insurance deductible"	25.6%	72%
d. How much of that hospital bill will you have to pay yourself?	27.1%	51%
e. Which best describes the "annual out-of-pocket limit"…	52.7%	67%
f. Which best describes a "health insurance formulary"	11.6%	33%
g. Which best describes a health plan "provider network"	61.2%	76%
h. …all the doctors who care for you while you're in the hospital will also be in the network	39.5%	41%
i. …How much would you have to pay out of pocket…	3.9%	16%
j. …you can appeal the denial and possibly get the insurance company to pay the claim	83.7%	68%

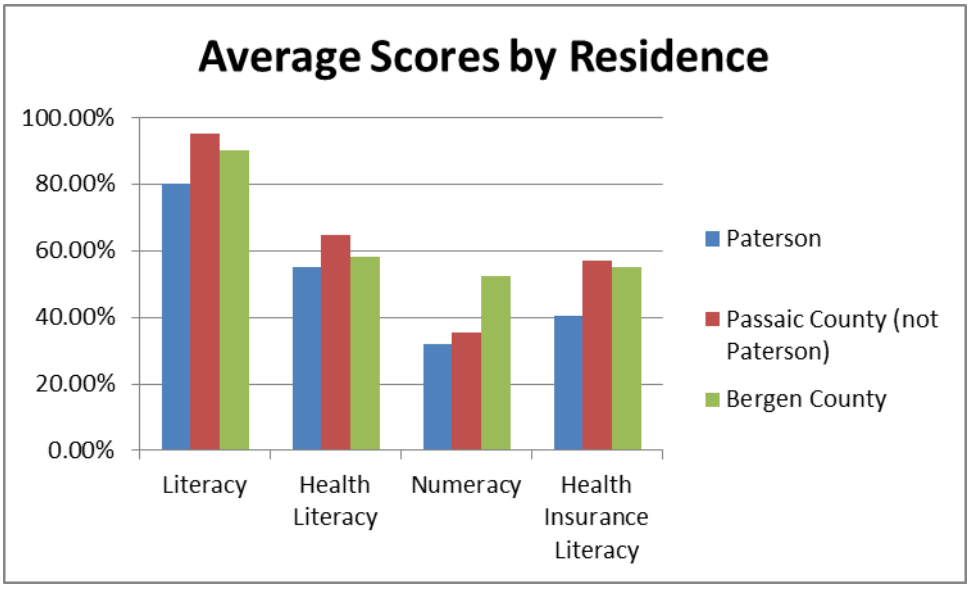
V. SPECIAL POPULATION SCORES

Eight special populations were studied to determine variations across demographic variables. For a broad overview, average scores were calculated for each of the four indicators of health literacy and displayed in tabular and graphical formats.[17] The tables provide summary results for each special population expressed as the percentage of correct answers. Detailed tables for each special population are provided under separate cover.

A. RESIDENCE

Residents from Paterson scored consistently lower when compared with other Passaic County and Bergen County residents. Differences, in some cases, were significant.

- A greater percentage of Paterson residents sought assistance with reading hospital materials than the remainder of the Passaic County or Bergen County residents. Paterson residents most frequently had problems with written information regarding their medical condition, and Paterson residents were less confident in completing medical forms.
- Residents of Passaic County excluding Paterson scored highest in overall literacy/reading comprehension compared to Paterson and Bergen County residents.
- Irrespective of residence, health numeracy questions posed a challenge for respondents with Bergen County residents performing best overall.
- Paterson residents had the least accurate responses to insurance health literacy questions compared to the remainder of Passaic County residents and Bergen County residents.

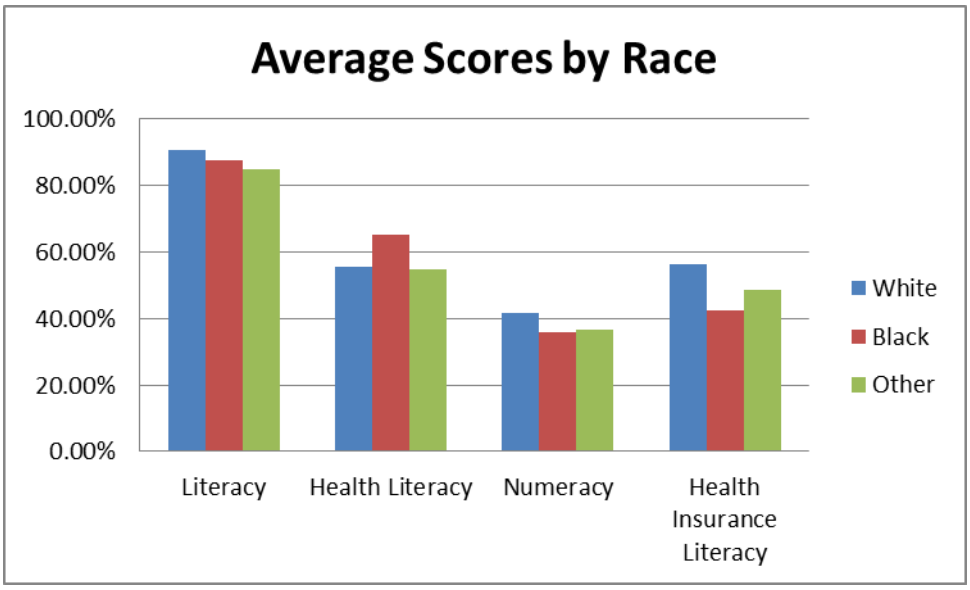


[17] In this report, age was not included in the subpopulations. While respondent age was recorded, calculation of cross-tabs was not feasible. Year of diagnosis is considered a suitable surrogate.

B. RACE

We compared race by White, Black and Other as reported by respondents. Results were not uniform across the four health indicators. More often, Whites scored higher than Blacks. Comparisons with Other Race category are open to interpretation due to the small sample size of these respondents.

- White respondents demonstrated a slightly higher level of overall literacy/reading comprehension than Blacks. More Blacks than Whites sought assistance with reading hospital materials while Blacks demonstrated greater self-confidence in completing medical forms. Little variation was observed when measuring understanding of written information regarding their medical condition.
- Irrespective of race, health numeracy questions posed a challenge for all respondents, with Whites performing marginally better than Blacks.
- Whites had more accurate responses to insurance health literacy questions than Blacks; knowledge of appeals across all races was greater than 78%.

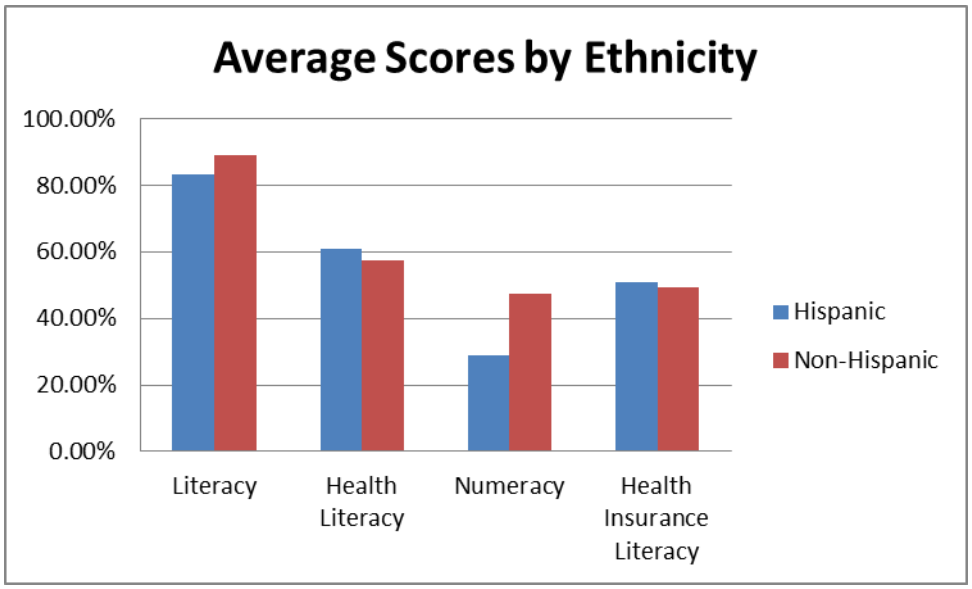


C. HISPANIC/NON-HISPANIC

Hispanic respondents were compared with Non-Hispanic respondents. Sixty-four respondents answered in Spanish, the remainder in English. Both Spanish and English speakers were combined in this report. Results across the four health literacy indicators varied, with non-Hispanic respondents recording slightly higher scores on most questions.

- Non-Hispanic respondents demonstrated a slightly higher level of overall literacy and reading comprehension than Hispanics.
- More Hispanic participants sought assistance with reading hospital materials than Non-Hispanics; Hispanics and Non-Hispanics were equally confident in their ability to fill-in the forms without assistance; and Hispanics indicated less difficulty understanding written information regarding their medical condition than Non-Hispanics.

- Hispanics exhibited considerably more difficulty with numeracy questions than Non-Hispanics.
- Non-Hispanics performed slightly better than Hispanics on questions relating to Health Insurance literacy.

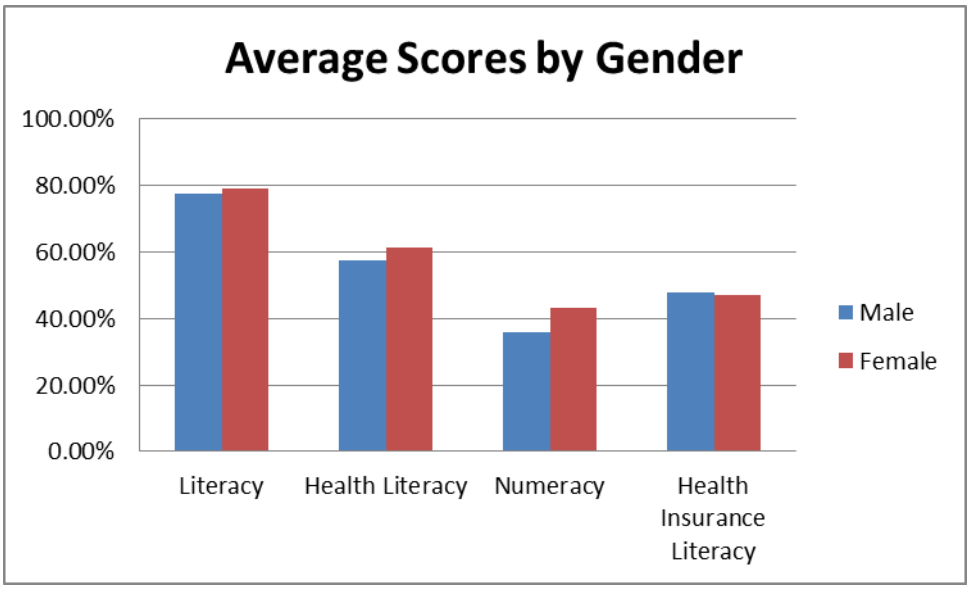


D. GENDER

For all health indicators, females scored higher than males with one exception.[18] Differences, however, were not significant.

- Females performed slightly better than Males in overall literacy and reading comprehension.
- Approximately half of men and half of women sought assistance with reading hospital materials, women were more confident than men in completing medical forms and more women had problems understanding written information regarding their medical condition.
- Health numeracy questions posed a challenge for all respondents, but females outperformed males.
- Men had slightly more accurate responses to insurance health literacy questions compared to women.

[18] Less than five transgender respondents completed the survey. Results are not reported to protect confidentiality.

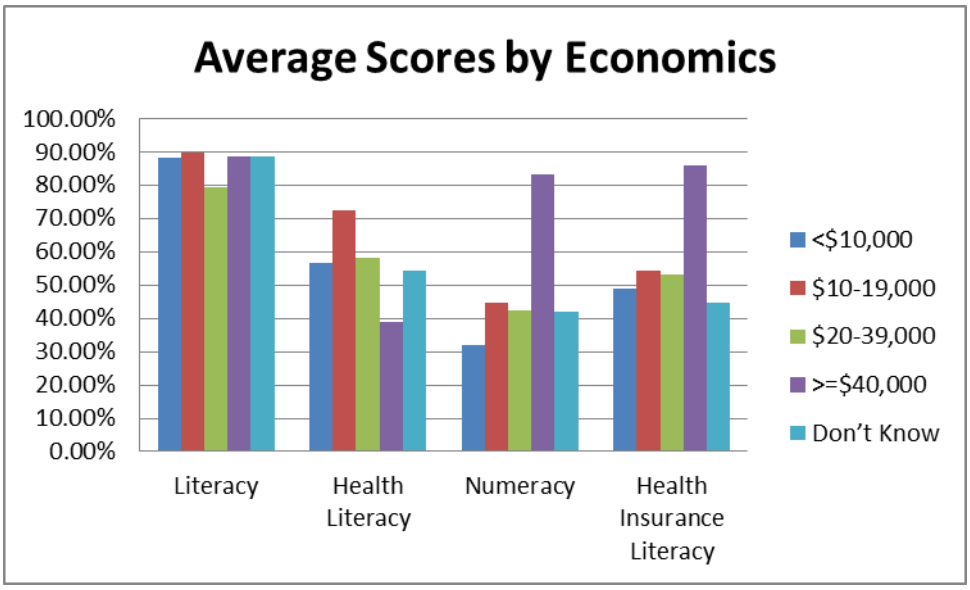


E. ECONOMIC STATUS

Respondents were asked to identify their average annual income. Answers were grouped into four categories ranging from less to $10,000 to greater than $40,000. Respondents were allowed to answer "Don't know" as well. Respondents with incomes ranging between $20,000 and $39,999 generally scored worse than those with lower incomes although this was not true for all health literacy indicators.[19]

- Respondents earning between $20,000 and $39,999 performed the poorest of all financial incomes in overall literacy and reading comprehension.
- Respondents earning between $20,000 and $39,999 sought the most assistance with reading hospital materials, those that earned less than $10,000 had the least confidence in completing medical forms and between two-thirds and three-quarters of all respondents did not have problems understanding written information regarding their medical condition.
- Health numeracy questions posed a challenge for all respondents regardless of income.
- Insurance health literacy was similar for both those earning less than $10,000 and between $10,000 and $19,999.

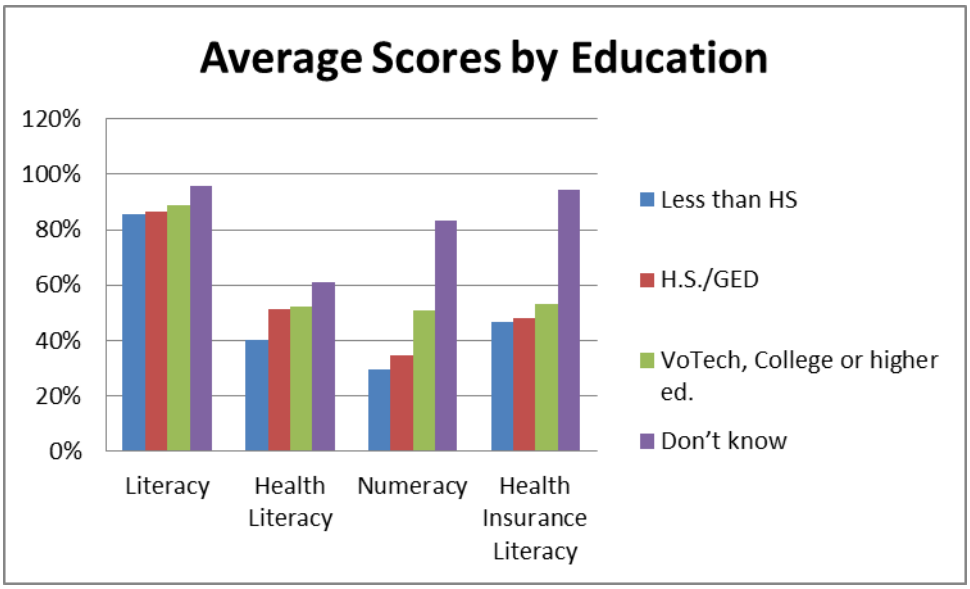
[19] Because only six respondents reported incomes over $40,000, comparisons with the other income groups are considered unreliable.



F. EDUCATION

As might be expected, health literacy correlated directly with educational levels of the respondents. Across all levels of education, respondents with a VoTech, College or higher education performed better on the survey than their counterparts with a lower level of education.

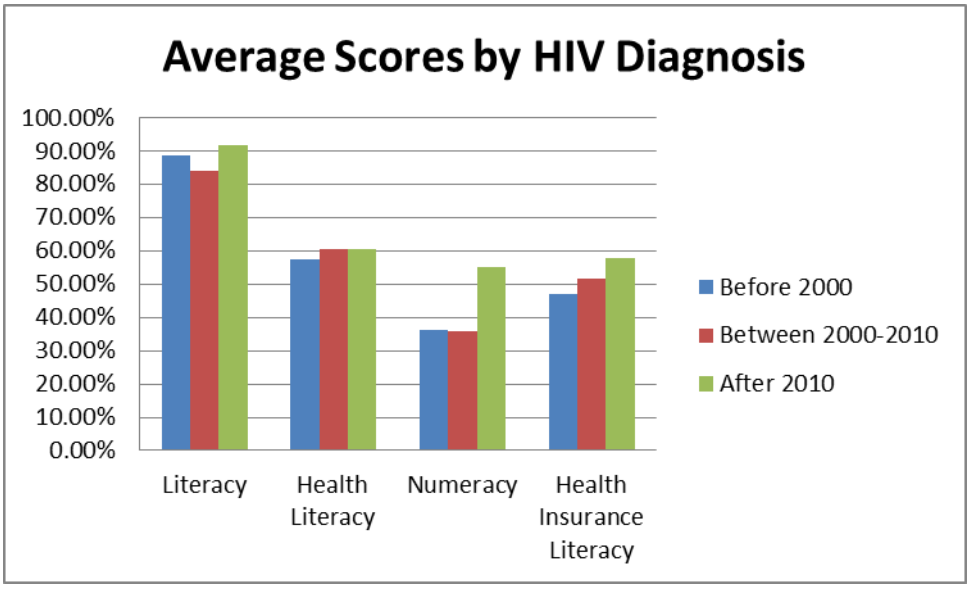
- Respondents with less than High School Diploma performed the poorest of all educational categories in overall literacy and reading comprehension.
- Respondents with less than a High School Education sought the most assistance with reading hospital materials, had the least confidence in completing medical forms and had problems understanding written information regarding their medical condition.
- Health numeracy questions posed the greatest challenge for the least educated.
- Insurance health literacy improved with level of education.



G. HIV DIAGNOSIS

We compared responses from those recently diagnosed (after 2010) to those who have been living with HIV/AIDS longer than five years. In general, those recently diagnosed scored higher although not uniformly across all four health literacy indicators. While not statistically proven, we observe that those living with HIV disease for more than five years were generally less health literate than those more recently diagnosed.

- Respondents diagnosed after 2010 performed the best in overall literacy and reading comprehension.
- Regardless of diagnosis year, approximately half of the respondents never or occasionally had others help them read hospital materials, Respondents diagnosed between 2000 and 2010 showed the most confidence in completing medical forms, and those diagnosed before 2000 required the most help understanding written information regarding their medical condition.
- Health numeracy questions posed a challenge for all respondents regardless of when diagnosed with HIV; however, those diagnosed after 2010 performed best.
- Respondents diagnosed after 2010 responded correctly more often than those diagnosed before them on insurance health literacy questions.



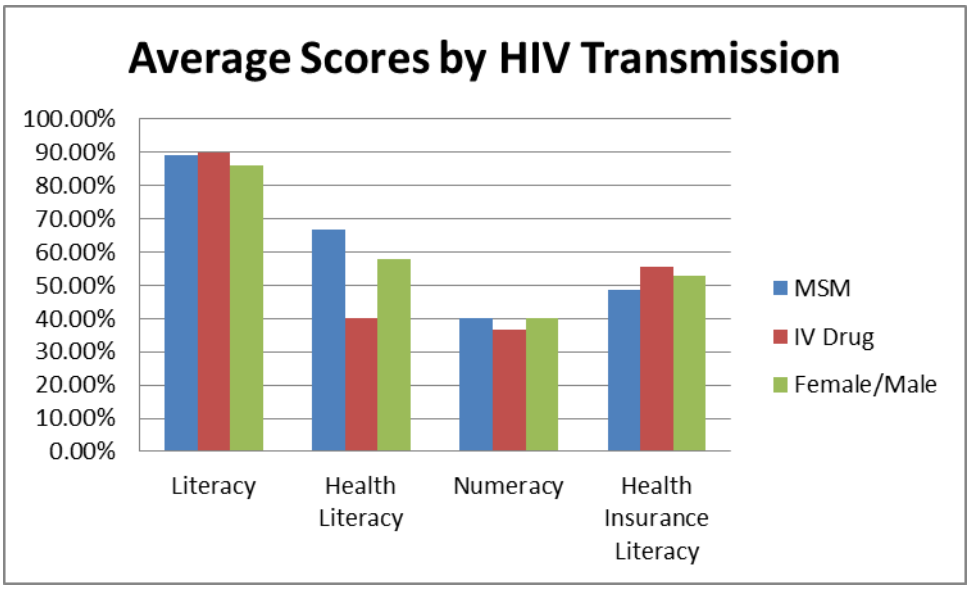
H. HIV TRANSMISSION

We compared responses of persons infected with HIV through male sex with men (MSM), injected drugs and heterosexual transmission. Overall, results varied with each health literacy indicator.[20] No clear distinctions emerged among the major transmission categories.

- IV Drug and MSM had similar overall literacy and reading comprehension, higher than those that contracted HIV through Female/Male transmission.

[20] The sample contained 15 respondents injected by drugs using a needle and 15 with "Other" responses. Because of the small sample size, firm conclusions cannot be made for these special populations.

- Persons infected by IV drug use most often required assistance reading hospital materials, were least confident in completing medical forms alone and had the greatest difficulty learning about their medical condition from written materials. Overall, MSM infected individuals performed best on Health Literacy questions.
- Health numeracy questions posed a challenge for all respondents regardless of mode of transmission.
- Respondents infected through IV Drug Use performed better on insurance health literacy questions than those infected by MSM or Female/Male transmission.



Residence

Literacy

Correct answers in percent:

Question	Paterson	Passaic County (not Paterson)	Bergen County	Other
a. Your doctor has sent you to have a ___ x-ray	81.6%	98.1%	94.3%	*
b. You must have an ___ stomach	94.7%	98.1%	97.1%	*
c. when you come for ___	86.8%	100.0%	91.4%	*
d. The x-ray will ___	50.0%	80.0%	67.7%	*
e. from 1 to 3 ___ to do	87.5%	100.0%	100.0%	*
Average score	80.1%	95.2%	90.1%	*

*Quantities less than five are not reported.

Health Literacy

Likert scale = 5 or 4 (i.e., percentage of answers = Never or Occasionally for question a and c) and Extremely or Quite a Bit for question b:

Question	Paterson	Passaic County (not Paterson)	Bergen County	Other
a. How often do you have someone help you read hospital materials?	42.1%	51.9%	65.7%	25.0%
b. How confident are you filling out medical forms by yourself?	68.4%	59.6%	51.4%	50.0%
c. How often do you have problems learning about your medical condition because of difficulty understanding written information?	55.3%	82.7%	57.1%	25.0%
Average score	55.3%	64.7%	58.1%	33.3%

Document Literacy/Numeracy

Correct answers in percent:

Question	Paterson	Passaic County (not Paterson)	Bergen County	Other
a. If you eat the entire container, how many calories will you eat?	23.7%	46.2%	54.3%	*
b. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?	44.7%	25.0%	45.7%	*
c. …if you stop eating ice cream, how many grams of saturated fat would you be consuming each day?	13.2%	15.4%	51.4%	*
d. …what percentage of your daily value of calories will you be eating if you eat one serving?	26.3%	21.2%	51.4%	*
e. …is it safe for you to eat this ice cream?	52.6%	69.2%	60.0%	*
Average score	81.6%	88.5%	85.7%	*

*Quantities less than five are not reported.

Health Insurance Literacy

Correct answers in percent:

Question	Paterson	Passaic County (not Paterson)	Bergen County	Other
a. Which is the best definition of the term "health insurance premium"	47.4%	50.0%	71.4%	*
b. Is a health insurance premium something you must pay every month…	65.8%	80.8%	80.0%	*
c. Which is the best definition of the term "annual health insurance deductible"	36.8%	11.5%	37.1%	*
d. How much of that hospital bill will you have to pay yourself?	15.8%	36.5%	28.6%	*
e. Which best describes the "annual out-of-pocket limit"…	28.9%	71.2%	57.1%	*
f. Which best describes a "health insurance formulary"	18.4%	*	17.1%	*
g. Which best describes a health plan "provider	50.0%	67.3%	71.4%	*

Question	Paterson	Passaic County (not Paterson)	Bergen County	Other
network"				
h. …all the doctors who care for you while you're in the hospital will also be in the network	21.1%	50.0%	48.6%	*
i. …How much would you have to pay out of pocket…	*	*	*	*
j. …you can appeal the denial and possibly get the insurance company to pay the claim	81.6%	88.5%	85.7%	*
Average score	40.6%	57.0%	55.2%	*

*Quantities less than five are not reported.

HIV Knowledge

Correct answers in percent:

Question	Paterson	Passaic County (not Paterson)	Bergen County	Other
a. Goal of treatment is to make CD4 levels go up or down	86.8%	84.6%	91.4%	*
b. Goal of treatment is to make viral loads go up or down	81.6%	96.2%	85.7%	*
Average score	84.2%	90.4%	88.6%	*

*Quantities less than five are not reported.

Race

Literacy

Correct answers in percent:

Question	White	Black	Other
a. Your doctor has sent you to have a ___ x-ray	93.3%	90.0%	88.2%
b. You must have an ___ stomach	95.6%	92.0%	100.0%
c. when you come for ___	95.6%	92.0%	88.2%
d. The x-ray will ___	73.1%	63.3%	47.1%
e. from 1 to 3 ___ to do	96.2%	100.0%	100.0%
Average score	90.8%	87.5%	84.7%

Health Literacy

Likert scale = 5 or 4 (i.e., percentage of answers = Never or Occasionally for question a and c) and Extremely or Quite a Bit for question b:

Question	White	Black	Other
a. How often do you have someone help you read hospital materials?	48.9%	62.0%	41.2%
b. How confident are you filling out medical forms by yourself?	53.3%	70.0%	52.9%
c. How often do you have problems learning about your medical condition because of difficulty understanding written information?	64.4%	64.0%	70.6%
Average score	55.5%	65.3%	54.9%

Document Literacy/Numeracy

Correct answers in percent:

Question	White	Black	Other
a. If you eat the entire container, how many calories will you eat?	44.4%	38.0%	38.2%
b. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?	33.3%	38.0%	38.2%
c. …if you stop eating ice cream, how many grams of saturated fat would you be consuming each day?	24.4%	28.0%	17.6%
d. …what percentage of your daily value of calories will you be eating if you eat one serving?	31.1%	28.0%	32.4%
e. …is it safe for you to eat this ice cream?	75.6%	48.0%	55.9%
Average score	41.8%	36.0%	36.5%

Health Insurance Literacy

Correct answers in percent:

Question	White	Black	Other
a. Which is the best definition of the term "health insurance premium"	66.7%	50.0%	41.2%
b. Is a health insurance premium something you must pay every month…	77.8%	76.0%	64.7%
c. Which is the best definition of the term "annual health insurance deductible"	31.1%	20.0%	26.5%
d. How much of that hospital bill will you have to pay yourself?	37.8%	16.0%	29.4%
e. Which best describes the "annual out-of-pocket limit"…	68.9%	42.0%	47.1%
f. Which best describes a "health insurance formulary"	11.1%	16.0%	*
g. Which best describes a health plan "provider network"	75.6%	50.0%	58.8%
h. …all the doctors who care for you while you're in the hospital will also be in the network	46.7%	34.0%	38.2%
i. …How much would you have to pay out of pocket…	*	*	*
j. …you can appeal the denial and possibly get the insurance company to pay the claim	91.1%	78.0%	82.4%
Average score	56.3%	42.4%	48.5%

*Quantities less than five are not reported.

HIV Knowledge

Correct answers in percent:

Question	White	Black	Other
a. Goal of treatment is to make CD4 levels go up or down	91.1%	82.0%	85.3%
b. Goal of treatment is to make viral loads go up or down	93.3%	80.0%	88.2%

Ethnicity

Literacy

Correct answers in percent:

Question	Hispanic	Non-Hispanic
a. Your doctor has sent you to have a ___ x-ray	89.1%	92.3%
b. You must have an ___ stomach	95.3%	96.9%
c. when you come for ___	90.6%	93.8%
d. The x-ray will ___	51.9%	67.7%
e. from 1 to 3 ___ to do	88.9%	95.4%
Average score	83.2%	89.2%

Health Literacy

Likert scale = 5 or 4 (i.e., percentage of answers = Never or Occasionally for question a and c) and Extremely or Quite a Bit for question b:

Question	Hispanic	Non-Hispanic
a. How often do you have someone help you read hospital materials?	48.4%	55.4%
b. How confident are you filling out medical forms by yourself?	59.4%	60.0%
c. How often do you have problems learning about your medical condition because of difficulty understanding written information?	75.0%	56.9%
Average score	60.9%	57.4%

Document Literacy/Numeracy

Correct answers in percent:

Question	Hispanic	Non-Hispanic
a. If you eat the entire container, how many calories will you eat?	26.6%	53.8%
b. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?	25.0%	47.7%
c. …if you stop eating ice cream, how many grams of saturated fat would you be consuming each day?	10.9%	36.9%
d. …what percentage of your daily value of calories will you be eating if you eat one serving?	17.2%	43.1%
e. …is it safe for you to eat this ice cream?	64.1%	55.4%
Average score	28.8%	47.4%

Health Insurance Literacy

Correct answers in percent:

Question	Hispanic	Non-Hispanic
a. Which is the best definition of the term "health insurance premium"	50.0%	56.9%
b. Is a health insurance premium something you must pay every month…	64.1%	83.1%
c. Which is the best definition of the term "annual health insurance deductible"	21.9%	29.2%
d. How much of that hospital bill will you have to pay yourself?	29.7%	24.6%

Question	Hispanic	Non-Hispanic
e. Which best describes the "annual out-of-pocket limit"…	54.7%	50.8%
f. Which best describes a "health insurance formulary"	*	16.9%
g. Which best describes a health plan "provider network"	62.5%	60.0%
h. …all the doctors who care for you while you're in the hospital will also be in the network	40.6%	38.5%
i. …How much would you have to pay out of pocket…	*	*
j. …you can appeal the denial and possibly get the insurance company to pay the claim	82.8%	84.6%
Average score	50.8%	49.4%

*Quantities less than five are not reported.

HIV Knowledge

Correct answers in percent:

Question	Hispanic	Non-Hispanic
a. Goal of treatment is to make CD4 levels go up or down	85.9%	86.2%
b. Goal of treatment is to make viral loads go up or down	89.1%	84.6%

Gender

Literacy

Correct answers in percent:

Question	Male	Female	Transgender
a. Your doctor has sent you to have a ___ x-ray	91.6%	88.9%	*
b. You must have an ___ stomach	97.6%	93.3%	*
c. when you come for ___	90.4%	95.6%	*
d. The x-ray will ___	44.6%	46.7%	*
e. from 1 to 3 ___ to do	63.9%	71.1%	*
Average score	77.6%	79.1%	*

*Quantities less than five are not reported.

Health Literacy

Likert scale = 5 or 4 (i.e., percentage of answers = Never or Occasionally for question a and c) and Extremely or Quite a Bit for question b:

Question	Male	Female	Transgender
a. How often do you have someone help you read hospital materials?	50.6%	53.3%	*
b. How confident are you filling out medical forms by yourself?	53.0%	71.1%	*
c. How often do you have problems learning about your medical condition because of difficulty understanding written information?	68.7%	60.0%	*
Average score	57.4%	61.5%	*

*Quantities less than five are not reported.

Document Literacy/Numeracy

Correct answers in percent:

Question	Male	Female	Transgender
a. If you eat the entire container, how many calories will you eat?	38.6%	44.4%	*
b. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?	31.3%	46.7%	*
c. …if you stop eating ice cream, how many grams of saturated fat would you be consuming each day?	22.9%	26.7%	*
d. …what percentage of your daily value of calories will you be eating if you eat one serving?	28.9%	33.3%	*
e. …is it safe for you to eat this ice cream?	56.6%	64.4%	*
Average	35.7%	43.1%	*

*Quantities less than five are not reported.

Health Insurance Literacy

Correct answers in percent:

Question	Male	Female	Transgender
a. Which is the best definition of the term "health insurance premium"	55.4%	51.1%	*
b. Is a health insurance premium something you must pay every month…	73.5%	73.3%	*
c. Which is the best definition of the term "annual health insurance deductible"	28.9%	20.0%	*
d. How much of that hospital bill will you have to pay yourself?	22.9%	33.3%	*
e. Which best describes the "annual out-of-pocket limit"…	54.2%	48.9%	*
f. Which best describes a "health insurance formulary"	12.0%	11.1%	*
g. Which best describes a health plan "provider network"	59.0%	64.4%	*
h. …all the doctors who care for you while you're in the hospital will also be in the network	39.8%	40.0%	*
i. …How much would you have to pay out of pocket…	*	*	*
j. …you can appeal the denial and possibly get the insurance company to pay the claim	85.5%	80.0%	*
Average score	47.9%	46.9%	*

*Quantities less than five are not reported.

HIV Knowledge

Correct answers in percent

Question	Male	Female	Transgender
a. Goal of treatment is to make CD4 levels go up or down	83.1%	91.1%	*
b. Goal of treatment is to make viral loads go up or down	88.0%	84.4%	*

*Quantities less than five are not reported.

Economic Status

Literacy

Correct answers in percent:

Question	<$10,000	$10-19,999	$20-39,999	>=$40,000	Don't Know
a. Your doctor has sent you to have a ___ x-ray	88.2%	100.0%	68.8%	100.0%	96.3%
b. You must have an ___ stomach	98.0%	93.1%	93.8%	83.3%	100.0%
c. when you come for ___	96.1%	89.7%	87.5%	*	96.3%
d. The x-ray will ___	66.7%	66.7%	61.5%	*	54.5%
e. from 1 to 3 ___ to do	93.3%	100.0%	84.6%	83.3%	95.5%
Average score	88.5%	89.9%	79.2%	88.9%	88.5%

*Quantities less than five are not reported.

Health Literacy

Likert scale = 5 or 4 (i.e., percentage of answers = Never or Occasionally for question a and c) and Extremely or Quite a Bit for question b:

Question	<$10,000	$10-19,999	$20-39,999	>=$40,000	Don't Know
a. How often do you have someone help you read hospital materials?	51.0%	65.5%	43.8%	33.3%	48.1%
b. How confident are you filling out medical forms by yourself?	54.9%	75.9%	62.5%	50.0%	51.9%
c. How often do you have problems learning about your medical condition because of difficulty understanding written information?	64.7%	75.9%	68.8%	33.3%	63.0%
Average score	56.9%	72.4%	58.4%	38.9%	54.3%

Document Literacy/Numeracy

Correct answers in percent:

Question	<$10,000	$10-19,999	$20-39,999	>=$40,000	Don't Know
a. If you eat the entire container, how many calories will you eat?	37.3%	44.8%	31.3%	83.3%	37.0%
b. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?	25.5%	41.4%	56.3%	*	37.0%
c. …if you stop eating ice cream, how many grams of saturated fat would you	15.7%	*	*	83.3%	44.4%

Question	<$10,000	$10-19,999	$20-39,999	>=$40,000	Don't Know
be consuming each day?					
d. …what percentage of your daily value of calories will you be eating if you eat one serving?	21.6%	37.9%	31.3%	*	29.6%
e. …is it safe for you to eat this ice cream?	60.8%	55.2%	50.0%	83.3%	63.0%
Average score	32.2%	44.8%	42.2%	83.3%	42.2%

*Quantities less than five are not reported.

Health Insurance Literacy

Correct answers in percent:

Question	<$10,000	$10-19,000	$20-39,000	>=$40,000	Don't Know
a. Which is the best definition of the term "health insurance premium"	49.0%	62.1%	43.8%	83.3%	51.9%
b. Is a health insurance premium something you must pay every month…	82.4%	69.0%	68.8%	83.3%	63.0%
c. Which is the best definition of the term "annual health insurance deductible"	13.7%	34.5%	*	83.3%	29.6%
d. How much of that hospital bill will you have to pay yourself?	31.4%	17.2%	*	*	22.2%
e. Which best describes the "annual out-of-pocket limit"…	56.9%	58.6%	50.0%	83.3%	33.3%
f. Which best describes a "health insurance formulary"	11.8%	*	*	*	*
g. Which best describes a health plan "provider network"	62.7%	69.0%	56.3%	83.3%	48.1%
h. …all the doctors who care for you while you're in the hospital will also be in the network	47.1%	34.5%	31.3%	*	29.6%
i. …How much would you have to pay out of pocket…	*	*	*	*	*
j. …you can appeal the denial and possibly get the insurance company to pay the claim	84.3%	89.7%	68.8%	100.0%	81.5%
Average score	48.8%	54.3%	53.2%	86.1%	44.9%

*Quantities less than five are not reported.

HIV Knowledge

Correct answers in percent:

Question	<$10,000	$10-19,000	$20-39,000	>=$40,000	Don't Know
a. Goal of treatment is to make CD4 levels go up or down	88.2%	79.3%	75.0%	100.0%	92.6%
b. Goal of treatment is to make viral loads go up or down	84.3%	93.1%	81.3%	100.0%	85.2%

Education

Literacy

Correct answers in percent:

Question	<3rd Grade	4th-8th Grade	Some H.S.	H.S./GED	VoTech, College or higher ed.	Don't know
a. Your doctor has sent you to have a ___ x-ray	*	100.0%	87.5%	89.6%	89.3%	100.0%
b. You must have an ___ stomach	*	100.0%	96.9%	93.8%	96.4%	100.0%
c. when you come for ___	*	100.0%	90.6%	95.8%	89.3%	83.3%
d. The x-ray will ___	*	100.0%	47.6%	54.3%	78.3%	*
e. from 1 to 3 ___ to do	*	100.0%	81.0%	100.0%	91.3%	100.0%
Average score	*	100.0%	86.7%	88.9%	95.8%	85.5%

*Quantities less than five are not reported.

Health Literacy

Likert scale = 5 or 4 (i.e., percentage of answers = Never or Occasionally for question a and c) and Extremely or Quite a Bit for question b:

Question	<3rd Grade	4th-8th Grade	Some H.S.	H.S./GED	VoTech, College or higher ed.	Don't know
a. How often do you have someone help you read hospital materials?	0.0%	28.6%	28.1%	47.9%	42.9%	50.0%
b. How confident are you filling out medical forms by yourself?	0.0%	35.7%	56.3%	58.3%	75.0%	83.3%
c. How often do you have problems learning about your medical condition because of difficulty understanding written information?	0.0%	35.7%	50.0%	47.9%	39.3%	50.0%
Average score	0.0%	33.3%	44.8%	40.4%	51.4%	52.4%

Document Literacy/Numeracy

Correct answers in percent

Question	<3rd Grade	4th-8th Grade	Some H.S.	H.S./GED	VoTech, College or higher ed.	Don't know
a. If you eat the entire container, how many calories will you eat?	*	*	25.0%	43.8%	57.1%	83.3%
b. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?	*	*	34.4%	35.4%	53.6%	*
c. …if you stop eating ice cream, how many grams of saturated fat would you be consuming each day?	*	*	15.6%	16.7%	42.9%	*
d. …what percentage of your daily value of calories will you be eating if you eat one serving?	*	*	21.9%	22.9%	42.9%	83.3%
e. …is it safe for you to eat this ice cream?	*	57.1%	68.8%	54.2%	57.1%	83.3%
Average score	*	57.1%	33.1%	29.8%	34.6%	50.7%

*Quantities less than five are not reported.

Health Insurance Literacy

Correct answers in percent

Question	<3rd Grade	4th-8th Grade	Some H.S.	H.S./GED	VoTech, College or higher ed.	Don't know
a. Which is the best definition of the term "health insurance premium"	*	*	50.0%	47.9%	78.6%	83.3%
b. Is a health insurance premium something you must pay every month…	*	85.7%	68.8%	68.8%	75.0%	100.0%
c. Which is the best definition of the term "annual health insurance deductible"	*	*	28.1%	16.7%	42.9%	*
d. How much of that hospital bill will you have to pay yourself?	*	35.7%	21.9%	31.3%	17.9%	*
e. Which best describes the "annual out-of-pocket limit"…	*	78.6%	46.9%	56.3%	42.9%	*
f. Which best describes a "health insurance formulary"	*	*	*	*	25.0%	*

Question	<3rd Grade	4th-8th Grade	Some H.S.	H.S./GED	VoTech, College or higher ed.	Don't know
g. Which best describes a health plan "provider network"	*	78.6%	62.5%	52.1%	67.9%	*
h. …all the doctors who care for you while you're in the hospital will also be in the network	*	64.3%	31.3%	31.3%	46.4%	*
i. …How much would you have to pay out of pocket…	*	*	*	*	*	*
j. …you can appeal the denial and possibly get the insurance company to pay the claim	*	100.0%	81.3%	79.2%	82.1%	100.0%
Average score	*	73.8%	48.9%	46.6%	48.0%	53.2%

*Quantities less than five are not reported.

HIV Knowledge

Correct answers in percent

Question	<3rd Grade	4th-8th Grade	Some H.S.	H.S./GED	VoTech, College or higher ed.	Don't know
a. Goal of treatment is to make CD4 levels go up or down	*	100.0%	87.5%	79.2%	89.3%	83.3%
b. Goal of treatment is to make viral loads go up or down	*	100.0%	84.4%	85.4%	85.7%	83.3%

*Quantities less than five are not reported.

HIV Diagnosis

Literacy

Correct answers in percent:

Question	Before 2000	Between 2000-2010	After 2010	Don't Know
a. Your doctor has sent you to have a ___ x-ray	90.0%	91.7%	93.8%	*
b. You must have an ___ stomach	96.0%	95.0%	100.0%	*
c. when you come for ___	94.0%	90.0%	93.8%	*
d. The x-ray will ___	70.7%	48.6%	78.6%	*
e. from 1 to 3 ___ to do	92.7%	94.3%	92.9%	*
Average score	88.7%	83.9%	91.8%	*

*Quantities less than five are not reported.

Health Literacy

Likert scale = 5 or 4 (i.e., percentage of answers = Never or Occasionally for question a and c) and Extremely or Quite a Bit for question b:

Question	Before 2000	Between 2000-2010	After 2010	Don't Know
a. How often do you have someone help you read hospital materials?	54.0%	50.0%	56.3%	33.3%
b. How confident are you filling out medical forms by yourself?	58.0%	63.3%	50.0%	66.7%
c. How often do you have problems learning about your medical condition because of difficulty understanding written information?	60.0%	68.3%	75.0%	66.7%
Average score	57.3%	60.5%	60.4%	55.6%

Document Literacy/Numeracy

Correct answers in percent:

Question	Before 2000	Between 2000-2010	After 2010	Don't Know
a. If you eat the entire container, how many calories will you eat?	38.0%	36.7%	68.8%	*
b. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?	34.0%	35.0%	56.3%	*
c. …if you stop eating ice cream, how many grams of saturated fat would you be consuming each day?	14.0%	23.3%	56.3%	*
d. …what percentage of your daily value of calories will you be eating if you eat one serving?	36.0%	23.3%	37.5%	*
e. …is it safe for you to eat this ice cream?	60.0%	60.0%	56.3%	*
Average score	36.4%	35.7%	55.0%	*

*Quantities less than five are not reported.

Health Insurance Literacy

Correct answers in percent:

Question	Before 2000	Between 2000-2010	After 2010	Don't Know
a. Which is the best definition of the term "health insurance premium"	54.0%	50.0%	62.5%	*
b. Is a health insurance premium something you must pay every month…	80.0%	73.3%	68.8%	*
c. Which is the best definition of the term "annual health insurance deductible"	26.0%	21.7%	31.3%	*
d. How much of that hospital bill will you have to pay yourself?	24.0%	28.3%	37.5%	*
e. Which best describes the "annual out-of-pocket limit"…	50.0%	51.7%	68.8%	*

Question	Before 2000	Between 2000-2010	After 2010	Don't Know
f. Which best describes a "health insurance formulary"	12.0%	*	*	*
g. Which best describes a health plan "provider network"	66.0%	60.0%	56.3%	*
h. …all the doctors who care for you while you're in the hospital will also be in the network	28.0%	45.0%	56.3%	*
i. …How much would you have to pay out of pocket…	*	*	*	*
j. …you can appeal the denial and possibly get the insurance company to pay the claim	84.0%	83.3%	81.3%	*
Average score	47.1%	51.7%	57.9%	*

*Quantities less than five are not reported.

HIV Knowledge

Correct answers in percent:

Question	Before 2000	Between 2000-2010	After 2010	Don't Know
a. Goal of treatment is to make CD4 levels go up or down	90.0%	83.3%	87.5%	*
b. Goal of treatment is to make viral loads go up or down	88.0%	85.0%	87.5%	*

*Quantities less than five are not reported.

HIV Transmission

Literacy

Correct answers in percent:

Question	MSM	IV Drug	Female/Male	Other
a. Your doctor has sent you to have a ___ x-ray	89.8%	100.0%	92.0%	80.0%
b. You must have an ___ stomach	95.9%	100.0%	96.0%	93.3%
c. when you come for ___	93.9%	100.0%	90.0%	86.7%
d. The x-ray will ___	68.6%	57.1%	58.1%	66.7%
e. from 1 to 3 ___ to do	97.1%	92.9%	93.5%	83.3%
Average score	89.1%	90.0%	85.9%	82.0%

Health Literacy

Likert scale = 5 or 4 (i.e., percentage of answers = Never or Occasionally for question a and c) and Extremely or Quite a Bit for question b:

Question	MSM	IV Drug	Female/Male	Other
a. How often do you have someone help you read hospital materials?	65.3%	40.0%	44.0%	46.7%
b. How confident are you filling out medical forms by yourself?	69.4%	46.7%	56.0%	53.3%
c. How often do you have problems learning about your medical condition because of difficulty understanding written information?	65.3%	33.3%	74.0%	73.3%
Average score	66.7%	40.0%	58.0%	57.8%

Document Literacy/Numeracy

Correct answers in percent:

Question	MSM	IV Drug	Female/Male	Other
a. If you eat the entire container, how many calories will you eat?	42.9%	33.3%	40.0%	40.0%
b. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?	40.8%	*	32.0%	46.7%
c. …if you stop eating ice cream, how many grams of saturated fat would you be consuming each day?	26.5%	*	24.0%	*
d. …what percentage of your daily value of calories will you be eating if you eat one serving?	26.5%	40.0%	36.0%	*
e. …is it safe for you to eat this ice cream?	63.3%	*	68.0%	60.0%
Average score	40.0%	36.7%	40.0%	48.9%

*Quantities less than five are not reported.

Health Insurance Literacy

Correct answers in percent

Question	MSM	IV Drug	Female/Male	Other
a. Which is the best definition of the term "health insurance premium"	55.1%	60.0%	58.0%	*
b. Is a health insurance premium something you must pay every month…	75.5%	60.0%	80.0%	60.0%
c. Which is the best definition of the term "annual health insurance deductible"	24.5%	33.3%	24.0%	*
d. How much of that hospital bill will you have to pay yourself?	28.6%	*	28.0%	*
e. Which best describes the "annual out-of-pocket limit"…	57.1%	46.7%	60.0%	*
f. Which best describes a "health insurance formulary"	14.3%	*	10.0%	*

Question	MSM	IV Drug	Female/Male	Other
g. Which best describes a health plan "provider network"	57.1%	60.0%	74.0%	33.3%
h. …all the doctors who care for you while you're in the hospital will also be in the network	38.8%	*	52.0%	*
i. …How much would you have to pay out of pocket…	*	*	*	*
j. …you can appeal the denial and possibly get the insurance company to pay the claim	85.7%	73.3%	90.0%	66.7%
Average score	48.5%	55.6%	52.9%	53.3%

*Quantities less than five are not reported.

HIV Knowledge

Correct answers in percent

Question	MSM	IV Drug	Female/Male	Other
a. Goal of treatment is to make CD4 levels go up or down	89.8%	93.3%	82.0%	80.0%
b. Goal of treatment is to make viral loads go up or down	85.7%	80.0%	92.0%	80.0%

VI. DISCUSSION, RECOMMENDATIONS AND WORK PLAN

A. DISCUSSION

From the results of this study, we learned that health literacy in the Bergen-Passaic Transitional Grant Area is a matter of concern for persons living with HIV/AIDS. This conclusion is supported by key informant interviews, provider focus groups and the consumer survey of health literacy. All aspects lead to a conclusion that health literacy needs greater attention at the provider level. Above all, health insurance literacy must be considered a priority and an urgent need.

The study reveals issues anticipated in the literature and concerns expressed by clinical and case management providers. Key informants spoke with authority about the present state of health literacy, both locally and regionally. Their observations are equally valid in Bergen-Passaic where health literacy levels among PLWH are generally below the average. Numeracy presents the greater challenge, but all aspects of health literacy need to be addressed as well. The consumer health literacy survey results are consistent with key informant opinion.

So, too, are the clinical and case management providers who expressed concern about their patients' ability to understand medical forms, prescriptions and written directions. Most important, however, providers felt that insurance health literacy represents the most common and urgent issue for their patients. Other forms of health literacy, while not to diminish their importance, are less urgent. The implementation of the Affordable Care Act leading to insurance options, previously rarely of concern to Ryan White enrollees, presents new challenges that require basic understanding of insurance coverage and terminology. They are often confusing, not just to PLWH but to the general public as well. However, according to this study, PLWH have greater needs.

The consumer health literacy survey confirms the opinions expressed by both key informants and providers. In general, survey respondents displayed average or below average competencies with regard to health, numeracy, and health insurance literacy. While variations were noted, the overall results were consistent:

- Comprehension of simple reading materials were mostly adequate.
- Although respondents felt comfortable with reading health related materials, marginal or inadequate literacy levels were identified for more than fifty percent of respondents.
- Numeracy proficiency posed the greatest challenge for nearly all respondents.
- Health insurance literacy presented challenges to most respondents. For nine of ten questions pertaining to insurance health literacy, survey respondents rated below the national average.

Key informants spoke about health literacy levels in special populations, identifying foreign language speakers, low income and low educational attainment among those with lowest health literacy competencies. The consumer survey confirmed their opinions in this TGA.

Of the special populations studied in the consumer survey, some scored consistently low, namely:

- Paterson residents scored low in all four health literacy indicators.
- Respondents with low economic status, ranging between $10,000 and $40,000 annual income performed more poorly than those of higher income.
- Respondents with low educational attainment consistently correlated with poor health literacy.

Some special populations scored better than others, although differences were less notable:

- PLWH diagnosed after 2000 generally displayed higher levels of health literacy. This may be attributed to broader understanding of the virus and greater attention paid by the providers to encourage self-sufficiency.
- Whites were more proficient with health insurance literacy than other races.
- Females tended to be more literate than males.
- Non-Hispanics scored somewhat better than Hispanics, but differences were not notable.

It is safe to conclude that low income levels and low educational attainment were the most significant contributing factors of health literacy. Language did not emerge as a significant barrier. Hispanics, who were able to complete the survey in Spanish, scored slightly but not significantly lower than Non-Hispanics for the majority of indicator. This may be attributed to the availability of bi-lingual personnel at the provider sites and to attention paid by this TGA to cultural competency.

According to key informants and focus group respondents, improving health literacy is a provider's responsibility. It is one that has not received sufficient attention,however. Provider training in health literacy is a relatively new offering and one that many providers have not yet taken. Focus group participants uniformly spoke of the need for additional training. All expressed interest in health literacy and were eager for additional training.

Focus group participants also indicated that health literacy assessment was not a formal or required component of the case management care plan. While case managers may informally review their clients' health literacy, a structured assessment tool is not in place. With the results of the consumer survey as evidence, health literacy has not received sufficient attention at intake or while rendering case management services.

Their comments are born out from an earlier survey conducted on behalf of the Cultural Competency Task Force in 2011. The Cultural and Linguistic Competency Policy Assessment (CLCPA) was administered to all Part A providers and included questions pertaining to health literacy of the consumer population. When asked if your agency assesses health literacy of the consumer population, 45% replied "never/seldom" or "sometimes." Second, when asked if your agency employs specific interventions based on the health literacy levels of consumers, 38% replied "never/seldom" or "sometimes." Third, when asked if your agency evaluates the quality and effectiveness of interpretation and translation services it either contracts for or provides, 33% replied "never/seldom" or "sometimes." Finally, when asked if your agency has a supporting policy that addresses translation services, literacy and health literacy, 29% said "none or informal" and 41% replied "don't know." These results indicated a clear lack of uniformity, attention to and provision of health literacy services across Part A providers.

Health literacy resources are abundantly available from a variety of sources. Case managers and clinicians would be well served to explore the various websites featuring health literacy training and information materials. Additionally, client assessment tools are available for incorporation into client intake procedures.

B. RECOMMENDATIONS

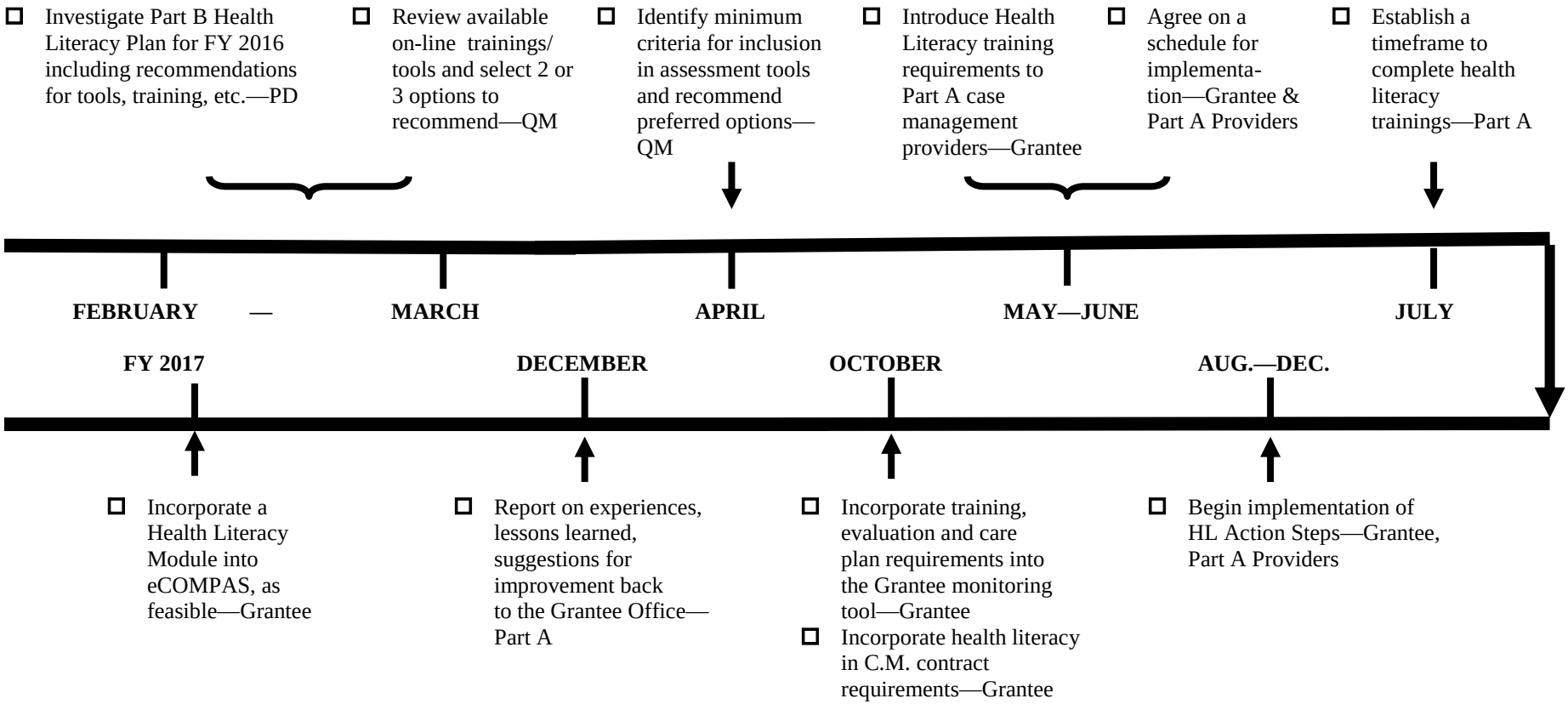
In 2010, the Planning Council commissioned a two-year task force on cultural competency that culminated in a set of nineteen recommendations to the Part A Program. As health literacy and cultural competency are related, these recommendations are relevant to the discussion here. Bi-lingual assistance, while available across the entire provider network, needs to be tied into health literacy assistance as part of the routine services of the Part A Program. The 2011 Cultural Competency Task Force Recommendations acknowledged this relationship and was explicit in endorsing health literacy improvement in the TGA.

The Planning Council commissioned the present assessment of health literacy with the stipulation that it include a work plan for Part A providers. This is presented in the following pages and incorporates the following recommendations.

1. Establish health insurance literacy as the priority training needed by consumers and supported by clinicians and case managers.
2. Assess all case management clients for health literacy using a standardized assessment tool. Communicate results to the clinicians providing care. Tools may be selected by the individual agency based on the preponderance of special populations. However, the selected tool should utilize a scoring method for objective measurement.
3. Incorporate health literacy improvement into every case management care plan.
4. Require case managers to obtain health literacy training. Internet trainings are available at no cost and can be completed conveniently.
5. Provide access to health literacy learning aids for all Part A enrollees, and encourage the use of online courses for consumers. Providers should consider having online bi-lingual programs available for viewing at their site.
6. Implement health literacy improvement recommendations from the Cultural Competency Task Force recommendations of 2011.

C. WORK PLAN

PATERSON-PASSAIC COUNTY – BERGEN COUNTY HIV HEALTH SERVICES PLANNING COUNCIL
FY 2016 HEALTH LITERACY TIMELINE



PD = Planning & Development Committee
QM = QM Team
Grantee = Grantee
Part A = Part A Providers

VII. APPENDICES

APPENDIX A – Inventory of Health Literacy Resources

Professional Health Literacy Training Materials Inventory

AAP (American Academy of Pediatrics)
Culturally Effective Care Toolkit: Literacy and Health Literacy
https://www.aap.org/en-us/professional-resources/practice-support/Patient-Management/Pages/Culturally-Effective-Care-Toolkit-Literacy-and-Health-Literacy.aspx

AHRQ (Agency for Healthcare Research and Quality)
The AHRQ Health Literacy Universal Precautions Toolkit, 2nd edition, can help primary care practices reduce the complexity of health care, increase patient understanding of health information, and enhance support for patients of all health literacy levels.
http://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/index.html

AMA (American Medical Association) Health Literacy Kit
Health Literacy and Patient Safety: Help Patients Understand Manual for Clinicians 2nd Edition
http://med.fsu.edu/userFiles/file/ahec_health_clinicians_manual.pdf

AmeriHealth
The Health Literacy & Plain Language Resource Guide
https://www.amerihealthcaritas.com/pdf/health-literacy-guide.pdf

CDC (Centers for Disease Control and Prevention)
This site provides information and tools to improve health literacy and public health. These resources are for all organizations that interact and communicate with people about health.
http://www.cdc.gov/healthliteracy/index.html

Training in health literacy, plain language, and culture and communication is essential for anyone working in health information and services. Whether you are new to these topics, need a refresher, or want to train your entire staff, the following courses are a good place to start.
http://www.cdc.gov/healthliteracy/gettraining.html

Harvard School of Public Health - Health Literacy Studies
The HSPH Health Literacy website was designed for professionals in health and education who are interested in health literacy to provide unique tools as well as links to key documents, articles, and materials.
http://www.hsph.harvard.edu/healthliteracy/

HRSA (Health Resources and Services Administration)
http://www.hrsa.gov/publichealth/healthliteracy/healthlitabout.html
Free online course for professionals:
http://www.hrsa.gov/publichealth/healthliteracy/

Minnesota Health Literacy Partnership
The Minnesota Health Literacy Partnership has developed a variety of training and presentations materials to help educate individuals and health care professionals about the importance of health literacy. These materials are free.
http://healthliteracymn.org/resources/presentations-and-training

National Center for Education Statistics
The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy
http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2006483

NIH National Institutes of Health
Provides information in the form and with the content that is accessible to specific audiences based on cultural competence, and incorporates plain language approaches and new technologies.
http://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/health-literacy

Public Health Foundation TRAIN
TRAIN is a free service of Public Health Foundation and operates through collaborative partnerships with state and federal agencies, local and national organizations, and educational institutions to quickly find and register for many courses.
https://www.train.org/DesktopShell.aspx?tabId=62&goto=browse&browse=keyword&keyword=Health+Literacy&keyoption=Both&clinical=Both&local=All&ByCost=0

The Council of State Governments
State Official's Guide to Health Literacy
http://www.csg.org/knowledgecenter/docs/SOG02HealthLiteracy.PDF

US Department of Health and Human Services
National Action Plan to Improve Health Literacy
http://health.gov/communication/hlactionplan/pdf/Health_Literacy_Action_Plan.pdf
This research-based guide will help you learn how to design health websites and other digital health information tools. Use it to create effective products for all users, including the millions of Americans who don't have strong literacy or health literacy skills—as well as those who don't have a lot of time to find, process, and use complex health information.
http://health.gov/healthliteracyonline/

US Food and Drug Administration
FDA assists consumers with making good health decisions by providing information to know how to get and understand basic health information and services
http://www.fda.gov/forconsumers/consumerupdates/ucm424523.htm

VA Library Network
www.va.gov/library/docs/consumer_health/health_literacy_resources_2014.docx
Health Literacy Resources compiled by the Consumer Health Library Panel to assist VHA staff in working more effectively with our veteran patients.

Consumer Health Literacy Training Materials Inventory

MedlinePlus
Trusted health information for consumers
https://www.nlm.nih.gov/medlineplus/healthliteracy.html

Office on Women's Health
Assist consumers with how to read drug labels
http://womenshealth.gov/aging/drugs-alternative-medicine/how-to-read-drug-labels.html

Health Literacy Assessment Tools

HIV Specific Tools

BEHKA-HIV - Brief Estimate of Health Knowledge and Action- HIV Version (Osborne et al)
8 item instrument
0-3 low literacy, 4-5 marginal, 6-8 adequate
Scores were significantly associated with self-reported medication adherence
Assesses knowledge of CD4 lymphocyte count, viral load and current HIV medications as well as medication adherence
2 questions address health numeracy

HIV-HL HIV-Related Health Literacy Scale (Ownby et al)
Computer administered 20 item instrument
Assesses skills in taking medications properly and has several items related to HIV infection and treatment
Includes some health numeracy
Source: Development and Validation of a Brief Computer-Administered HIV-Related Health Literacy Scale (HIV-HL) (available on line for $39.95)

General Health Literacy Tools

SAHL – Short Assessment of Health Literacy (Spanish & English)
18 test term flash cards including a key word with related meaning to test term AND a distractor word unrelated to test term meaning
Tests comprehension and pronunciation (decoding)
2-3 minutes to administer
Score of 0-14 indicates low health literacy
Source: AHQR Agency for Healthcare Research and Quality
http://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy/index.html#sahletest

REALM – Rapid Estimate of Adult Literacy in Medicine
66 item word recognition arranged in order of increasing difficulty
Provides reading level grade estimate for patients below 9th grade level
Administered in 3-6 minutes
Limitations: does not measure comprehension or numeracy

REALM-R – Rapid Estimate of Adult Literacy in Medicine – Revised
8 item word recognition - read each term in 5 seconds
Administered in 2 minutes
Score: 0=<3rd grade; 1-3=4-6th grade; 4-6=7-8th grade; 7+= high school
Source: AHQR Agency for Healthcare Research and Quality
http://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy/index.html#sahletest

SAHLSA-50 – Short Assessment of Health Literacy for Spanish Adults
50 Spanish test term flash cards including a key word with related meaning to test term AND a distractor word unrelated to test term meaning
3-6 minutes to administer
Source: AHQR Agency for Healthcare Research and Quality
http://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy/index.html#sahletest

TOFHLA – Test of Functional Health Literacy in Adults
Timed test
2 part assessment:
Provide client medical information / instructions. Participants review information and answer questions that test their understanding of the information provided.
Multiple choice items in which selecting the correct word among 4 options completes sentences from standard medical instructions
0-59 inadequate literacy, 60-74 marginal, 75-100 adequate
Spanish version available
22-25 minutes to administer

S-TOHLA - Short Test of Functional Health Literacy in Adults
2 reading comprehension passages (4th & 10th grade level) Multiple choice items in which selecting the correct word among 4 options completes sentences from standard medical instructions
8-12 minutes to administer
0-53 inadequate literacy, 54-66 marginal, 67-100 adequate
Does not include numeracy

NVS- Newest Vital Sign
6 item assessment measures reading and comprehension of a nutrition label
Administer in 3-6 minutes
Tests numeracy, reading & comprehension
Available in English and Spanish
May overestimate low literacy

Single Item Literacy Screen
A single item question intended to identify adults in need of help with printed materials: "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?" Never, Rarely, Sometimes, Often, Always
Scores above Rarely are positive for difficulty with reading printed materials

How confident are you filling out medical forms by yourself?
3 questions to detect health literacy:
How often do you have problems learning about your medical condition because of difficulty understanding written information?
How often do you have someone help you read hospital materials?
How confident are you filling out medical forms by yourself?
Always, often, sometimes, occasionally or never. Responses if sometimes, occasionally or never indicate limited health literacy.

APPENDIX B – 2011 Cultural Competency Task Force Recommendations

Paterson-Passaic County-Bergen County
HIV Health Services Planning Council
Cultural Competency Task Force

RECOMMENDATIONS

Goals

I. Create a culture of competency within the organizations.
II. Achieve competency at all levels of the organizations.
III. Establish a deeper involvement with communities served.
IV. Achieve a deeper respect for cultural differences.

Recommendations

A. Policy

1. Create and incorporate within the Bergen-Passaic TGA standards of care a universal policy statement of cultural competency.
2. Incorporate the universal policy statement of cultural competency into contractual requirements for Part A providers.
3. Expand agency policies by broadening the practice of cultural competency to include:
    - Knowledge of diverse communities,
    - Organizational philosophy,
    - Personal Involvement in diverse communities,
    - Resources and linkages,
    - Human resources,
    - Clinical practice,
    - Engagement of diverse communities.
4. Develop and adopt a cultural competency policy for the Planning Council.

B. Linguistic Competency and Health Literacy

5. Provide linguistically competent services for the major ethnic communities served by the providers in the Bergen-Passaic TGA. Major communities will defined by the provider.
6. Empower consumers to express their values, attitudes and belief systems around health practices.
7. Empower consumers to understand their health choices through enhanced health literacy.

C. Training

8. Provide training to supervisory and staff employees on each of the following:
    - Knowledge of Diverse Communities,
    - Organizational Philosophy,
    - Personal Involvement in Diverse Communities,

- Resources and Linkages,
- Human Resources,
- Clinical Practice,
- Engagement of Diverse Communities.

9. Provide agency-specific training to supervisory and staff employees on the following:
    - Addressing gaps revealed in the Cultural and Linguistic Competence Policy Assessment;
    - Improving communication throughout the organization;
    - Working through cultural differences within the communities served;
    - Measuring effectiveness through Quality Improvement.
10. Provide training employing the following approaches:
    - In depth; beyond the basics;;
    - Interactive and concrete
    - Methods that are incorporated into the daily operations of the organization;
    - Experiential at some level (not solely lecture oriented);
    - Results oriented – measurable.
11. Invite community stakeholders to participate in training activities, both at the TGA and agency levels.

D. Consumer Involvement

12. Obtain ongoing input from clients on their specific cultural needs.
13. Work with consumers to develop insightful client satisfaction surveys.
14. Reinforce and encourage client/provider communication to ensure the provision of culturally competent services.

E. Community Involvement

15. Educate the community to help achieve the goals of the TGA through:
    - Direct involvement in community activities to foster deeper understanding of the diverse cultures;
    - Social marketing/community education to reduce stigma;
    - Reducing resistance to HIV testing;
    - Educating community leaders on stigma, cultural respectfulness, and the need for an improved quality of life.
16. Build constructive relationships with key diverse communities of each agency, to be identified by the agency itself. Extend the dialogue with cultural brokers through interaction, involvement and support of local initiatives.

F. Quality and Measurement

17. Establish a Cultural Competency Quality Improvement Program (Comprehensive Plan Objective II.3) to include:
    - Quality Indicators
    - Benchmarks
    - Analysis
    - Improvement Methods (Plan-Do-Study-Act; Peer Learning, etc.)

- Ongoing Review

18. Allow the funded agencies to select improvement methods most amenable to their needs and abilities, following a general orientation to the various methods available to them.
19. Incorporate cultural competency quality improvement requirements into the Part A contracting process. Require providers to identify a minimum of one cultural competency QI indicator per year and establish an improvement plan that includes outcome measurement.

APPENDIX C – Client Survey Instrument (English and Spanish)

For office use only.
Agency _____
Date_____
Number_____

PATERSON-PASSAIC COUNTY – BERGEN COUNTY
HIV HEALTH SERVICES PLANNING COUNCIL
HEALTH LITERACY ASSESSMENT
CONSUMER SURVEY

This survey is part of the Planning Council's assessment of the needs of persons with HIV. Thank you for your answers and your help. ALL RESPONSES ARE STRICTLY CONFIDENTIAL.

1. Are you HIV-positive?
   - ☐ Yes
   - ☐ No

   If No, **STOP**. You are not eligible for this survey.

2. Did you complete this survey in the last month?
   - ☐ Yes
   - ☐ No

   If Yes, **STOP**. You are not eligible for this survey.

Part I. Literacy. Here are some medical instructions that you or anybody might see around the hospital. These instructions are in sentences that have some of the words missing. Where a word is missing, a blank line is drawn and four possible words that could go in the blank appear just below it. Please figure out which of those four words should go in the blank, which word makes the sentence make sense.

1. Your doctor has sent you to have a _____ X-ray.
   - ☐ stomach
   - ☐ diabetes
   - ☐ stitches
   - ☐ germs

2. You must have an _____ stomach
   - ☐ asthma
   - ☐ empty
   - ☐ incest
   - ☐ anemia

3. when you come for _____.
   - ☐ is
   - ☐ am
   - ☐ if
   - ☐ it

4. The X-ray will _____
   - ☐ take
   - ☐ view
   - ☐ talk
   - ☐ look

5. from 1 to 3 _____ to do.
   - ☐ beds
   - ☐ brains
   - ☐ hours
   - ☐ diets

Part II: Health Literacy. Please mark one answer for each question below.

1. How often do you have someone (like a family member, friend, hospital/clinic worker, or caregiver) help you read hospital materials?
   - ☐ Always
   - ☐ Often
   - ☐ Sometimes
   - ☐ Occasionally
   - ☐ Never

2. How confident are you filling out medical forms by yourself?
   - ☐ Extremely
   - ☐ Quite a bit
   - ☐ Somewhat
   - ☐ A little bit
   - ☐ Not at all

3. How often do you have problems learning about your medical condition because of difficulty understanding written information?
   - ☐ Always
   - ☐ Often
   - ☐ Sometimes
   - ☐ Occasionally
   - ☐ Never

Part III: Document Literacy

Nutrition Facts	
Serving Size	½ cup
Servings per container	4
Amount per serving	
Calories 250	Fat Cal 120
	%DV
Total Fat 13g	20%
Sat Fat 9g	40%
Cholesterol 28mg	12%
Sodium 55mg	2%
Total Carbohydrate 30g	12%
Dietary Fiber 2g	
Sugars 23g	
Protein 4g	8%

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

Ingredients: Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.

This information is on the back of a container of a pint of ice cream.

1. If you eat the entire container, how many calories will you eat?
   - ☐ None
   - ☐ 250
   - ☐ 1,000
   - ☐ I don't know

2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?
   - ☐ Half the container
   - ☐ One cup
   - ☐ Two cups
   - ☐ I don't know

3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 grams of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?
   - ☐ 51 grams
   - ☐ 33 grams
   - ☐ 24 grams
   - ☐ I don't know

4. If you usually eat 2,500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?
   - ☐ Ten percent
   - ☐ Fifty percent
   - ☐ One hundred percent
   - ☐ I don't know

Pretend that you are allergic to the following substances: penicillin, peanuts, latex gloves, and bee stings.

5. Is it safe for you to eat this ice cream?
   - ☐ Yes
   - ☐ No
   - ☐ I don't know

Part IV. Insurance Literacy

1. Which of the following is the best definition of the term "health insurance premium"?
   - ☐ The best type of health insurance you can buy
   - ☐ The amount health insurance companies charge each month for coverage
   - ☐ A bonus you get at the end of the year if you stay covered
   - ☐ Don't know

2. Is a health insurance premium something you must pay every month, regardless of whether you use health care services, or do you only have to pay your health insurance premium during months when you use health care services?
   - ☐ Must pay every month, regardless of whether you use services
   - ☐ Only have to pay in months when you use health care services
   - ☐ Don't know

3. Which of the following is the best definition of the term "annual health insurance deductible"?
   - ☐ The amount that is deducted from your paycheck each year to pay for your policy
   - ☐ The amount of health expenses you can subtract from income on your yearly tax return
   - ☐ The amount of covered health care expenses you must pay yourself each year before your insurance will begin to pay
   - ☐ Don't know

4. Suppose that under your health insurance policy, hospital expenses are subject to a $1,000 deductible and $250 per day co-pay. You get sick and are hospitalized for 4 days, and the bill comes to $6,000. How much of that hospital bill will you have to pay yourself?
   - ☐ $0
   - ☐ $1,000
   - ☐ $2,000
   - ☐ $4,000
   - ☐ $6,000
   - ☐ Don't know

5. Which of the following best describes the "annual out-of-pocket limit" under a health insurance policy?
   - ☐ The most you will have to pay in deductibles, co-pays and coinsurance for covered care received in network for the year
   - ☐ The most your insurance policy will pay for covered services in a year
   - ☐ The most you will have to pay for premiums in a year
   - ☐ Don't know

6. Which of the following best describes a "health insurance formulary"?
   - ☐ The form you send to your insurance company when you need to have a medical bill paid
   - ☐ The name for permission you must get from your insurance company before surgery will be covered
   - ☐ The list of prescription drugs your health plan will cover
   - ☐ Don't know

7. Which of the following best describes a health plan "provider network"?
   - ☐ The hospitals and doctors that contract with your health plan to provide services for an agreed-upon rate or fee schedule
   - ☐ The computer system doctors and hospitals use to submit bills to insurance companies
   - ☐ A website where consumers can find information about the best doctors
   - ☐ Don't know

8. True or false: If you receive inpatient care at a hospital that participates in your health plan's provider network, all the doctors who care for you while you're in the hospital will also be in network.
   - ☐ True
   - ☐ False
   - ☐ Don't know

9. Suppose your health plan covers lab tests in full if you go to an in-network lab, but only pays 60% of allowed charges if you go out of network. You forget to check and get your blood test at a lab that turns out to be out of network. The lab bills you $100 for the blood test. Your health insurance allows only $20 charge for that test. How much would you have to pay out of pocket for that lab test?
   - ☐ $0
   - ☐ $40
   - ☐ $80
   - ☐ $88
   - ☐ $100
   - ☐ Don't know

10. True or false? If your health insurance plan refuses to pay for a service that you think is covered and your doctor says you need, you can appeal the denial and possibly get the insurance company to pay the claim.
   - ☐ True
   - ☐ False

Part V: HIV Knowledge

1. Is the goal of HIV treatment to make the CD4 count go up or down?
   - ☐ Up
   - ☐ Down
   - ☐ Don't know

2. Is the goal of HIV treatment to make the viral load go up or down?
   - ☐ Up
   - ☐ Down
   - ☐ Don't know

Part VI: Respondent Characteristics

1. What is your birthday? (Month/Day/Year) _____

2. What is your gender?
   - ☐ Male
   - ☐ Female
   - ☐ Transgender

3. What is your race?
   - ☐ White
   - ☐ Black
   - ☐ Other

4. Are you Hispanic?
   - ☐ Yes
   - ☐ No

5. What is your annual gross income? (Income before taxes or other deductions)
   - ☐ Less than $10,000
   - ☐ $10,000-$19,000
   - ☐ $20,000-$39,000
   - ☐ $40,000+
   - ☐ Don't know/Declined

6. What education level did you complete?
   - ☐ Less than third grade
   - ☐ Fourth to eighth grade
   - ☐ Some high school
   - ☐ High school/GED
   - ☐ Vocational training, college or other higher education
   - ☐ Other (Specify) _____

7. What is your work status?
   - ☐ Full time
   - ☐ Part Time
   - ☐ Retired
   - ☐ Disabled
   - ☐ Currently not working
   - ☐ Other (Specify) _____

8. What city or county do you live in?
   - ☐ Paterson
   - ☐ Passaic County (not Paterson)
   - ☐ Bergen County
   - ☐ Other (Specify) _____

9. When were you diagnosed with HIV?
   - ☐ Before 2000
   - ☐ Between 2000 and 2010
   - ☐ After 2010
   - ☐ Don't know

10. How were you infected with HIV? (May answer more than one)
    - ☐ Male sex with a man
    - ☐ Injecting drugs using a needle
    - ☐ Female sex with a man or male sex with a female
    - ☐ Other (Specify) _____

11. Where did you complete this survey:
    - ☐ Bergen Family Center
    - ☐ Buddies of New Jersey
    - ☐ CAPCO
    - ☐ City of Passaic Alliance
    - ☐ Hackensack University Medical Center
    - ☐ Hispanic Multi-Purpose Service Center
    - ☐ Hyacinth Foundation
    - ☐ Northeast Life Skills
    - ☐ Legal Services of North Jersey
    - ☐ Paterson Counseling Center
    - ☐ Paterson Division of Health
    - ☐ St. Joseph's Medical Center – 21 Market Street
    - ☐ St Joseph's Comprehensive Care Center – 160 Market Street
    - ☐ St. Mary's Hospital
    - ☐ Straight & Narrow
    - ☐ Team Management 2000
    - ☐ Well of Hope
    - ☐ Other/I did not complete this survey at a service site.

For office use only.

Agency _____
Date_____
Number_____

PATERSON-PASSAIC COUNTY – BERGEN COUNTY
HIV HEALTH SERVICES PLANNING COUNCIL
HEALTH LITERACY ASSESSMENT
CONSUMER SURVEY

Este cuestionario es parte del asesoramiento a necesidades por el Consejo de Planificación para VIH. Gracias por su opinión y su ayuda. SUS RESPUESTAS SON ESTRICTAMENTE CONFIDENCIALES.

1. Es usted VIH positivo?
   - ☐ Si
   - ☐ No

   Si no, pare aqui. No complete la encuesta.

2. Completó esta encuesta en el último mes?
   - ☐ Si
   - ☐ No

   En caso afirmativo, por favor pare aqui. No complete la encuesta.

Lectura I. Conocimiento. Estas son ALGUNAS instrucciones médicas que Ud. o cualquier puedo encontrar aquí en el hospital. En cada frase faltan algunas palabras; donde falta la palabra, hay un espacio en blanco y luego hay 4 posibles palabras para escogar. Quisiera que Ud. lea la frase y decida cuál de estas cuatro palabras es la palabra que falta en las frase, o que le da major sentido a la frase. Cuando Ud. decida cuál es la palabra correcta para aquel espacio, marque con un círculo la palabra que Ud. ha escogido y siga leyendo. Cuando termine la página, continue en la página siguiente hasta terminar todas.

6. Su doctor le ha _____ a sacarse Rayos X del _____.

☐ distinguido	☐ estómago
☐ mandado	☐ caminar
☐ corrido	☐ vestido
☐ formalmente	☐ comunmente

7. Cuando venga por los _____ debe de tener el estómago _____.

☐ libros	☐ volar
☐ fiel	☐ cabeza
☐ Rayos X	☐ vacío
☐ dormir	☐ contento

8. Este examen de Rayos X _____ de 1 a 3 _____.

☐ Durará	☐ millas
☐ cantará	☐ luz
☐ permanente	☐ Rayos X
☐ silla	☐ horas

9. El día antes de _____ radiografiá, cene solamente alguna _____.

☐ del	☐ bailar
☐ alguna	☐ inteligente
☐ la	☐ fruta
☐ botón	☐ receta

Parte 2: Conocimientos sobre la salud. Por favor marque una respuesta para cada pregunta que sigue.

1. Con qué frecuencia tiene a alguien (como un familiar, amigo, trabajador del hospital/clínica o cuidador) ayudará a leer los materiales del hospital?
   - ☐ Siempre
   - ☐ A menudo
   - ☐ A veces
   - ☐ De vez en cuando
   - ☐ Nunca

2. Qué tan seguro está llenando formularios médicos por ti mismo?
   - ☐ Extremadamente
   - ☐ Bastante
   - ☐ Algo
   - ☐ Un poco
   - ☐ Para nada

3. Con qué frecuencia tiene problemas aprendiendo acerca de su estado de salud debido a la dificultad en entender la información escrita?
   - ☐ Siempre
   - ☐ A menudo
   - ☐ A veces
   - ☐ De vez en cuando
   - ☐ Nunca

Lectura III: Lea Al Paciente

Información Nutricional	
Tamaño de la Porción	½ taza
Porciones por envase	4
Cantidad por porción	
Calorías 250	Cal Grasa 120
	%DV
Grasa Total 13g	20%
Grasas Sat. 9g	40%
Colesterol 23mg	12%
Sodio 55mg	2%
Total Carbohidratos 30g	12%
Fibras Dietéticas 2g	
Azúcares 23g	
Proteína 4g	8%

*Porcentaje de Valores Diarios (DV) se basan en una dieta de 2.000 calorías. Sus valores diarios pueden ser mayores o menores dependiendo de las calorías que usted necesite.

Ingredientes: Crema, Leche Descremada, Azúcar Líquida, Agua, Yemas de Huevo, Azúcar Morena, Aceite de Cacahuate (Maní), Azúcar, Mantequilla, Sal, Carragenina, Extracto de Vainilla

Esta información aparece en el reverso de un envase de helado.

6. Si usted se come todo el helado en el envase, ¿cuántas calorías habrá consumido?

7. Si a usted le recomendaron consumir 60 gramos de carbohidratos en la merienda, ¿cuánto helado puede comer?

8. Su médico le aconseja reducir la cantidad de grasas saturadas en su dieta. Usted normalmente consume 42 gramos de grasa saturada al día, que incluye una porcion de helado. Si deja de comer helado, ¿cuántos gramos de grasa saturada consumiría cada dia?

9. Si usted normalmente come 2500 calorías habrá consumido si se come una porción?

Imagine que es alérgico/a a las siguientes sustancias: Penicillina, cachuate (maní), guantes de latex y picaduras de abeja.

10. ¿Puede comer este halado con seguridad?

Parte 4. Conocimientos de Seguro

7. Cuál de las siguientes es la mejor definición del término "prima de seguro de salud"?
   - ☐ El mejor tipo de seguro de salud que puede comprar
   - ☐ La cantidad que cobran cada mes las compañías de seguros de salud por la cobertura
   - ☐ Un bono que usted obtiene al final del año si permanece cubierto
   - ☐ No se

8. Es una prima de seguro de salud algo que debe pagar cada mes, independientemente de si utiliza los servicios de salud, o usted sólo tiene que pagar la prima de su seguro de salud durante meses que utiliza los servicios de salud?
   - ☐ Debe pagar cada mes, independientemente de si usted utiliza los servicios
   - ☐ Sólo tiene que pagar en meses que utiliza los servicios de salud
   - ☐ No se

9. Cuál de las siguientes es la mejor definición del término "deducible anual de seguro de salud"?
   - ☐ La cantidad que se deduce de su sueldo cada año para pagar su póliza
   - ☐ La cantidad de gastos de salud que puede restar de los ingresos en su declaración anual de impuestos
   - ☐ La cantidad de gastos medicos cubiertos que debe pagar usted cada año antes de que su seguro comience a pagar
   - ☐ No se

10. Supongamos que por su póliza de seguro de salud, gastos de hospital están sujetos a un deducible de $1,000 y $250 por día copago. Usted se enferma y está hospitalizado durante 4 días, y recive una factura de $6,000. Cuánto de esa factura del hospital tenria que pagar usted?
    - ☐ $0
    - ☐ $1,000
    - ☐ $2,000
    - ☐ $4,000
    - ☐ $6,000
    - ☐ No se

11. Cuál de las siguientes opciones describe mejor el "límite de desembolso anual" bajo una póliza de seguro de salud?
    - ☐ El máximo que tendrá que pagar en los deducibles, copagos y coseguro por servicios cubiertos recibidos en la red para el año
    - ☐ El máximo que pagaria su póliza de seguros por servicios cubiertos en un año
    - ☐ El máximo que tendrá que pagar por las primas en un año
    - ☐ No se

12. Cuál de las siguientes opciones describe mejor el "formulario de seguro de salud?"
    - ☐ El formulario que enviara a su compañía de seguros cuando usted necesita tener una cuenta médica pagada
    - ☐ El nombre de permiso que debe obtener de su compañía de seguros antes de que cirugia sea cubrierta
    - ☐ La lista de medicamentos recetados que su plan de salud cubriera
    - ☐ No se

11. Cuál de las siguientes opciones describe mejor un "red de provedores" de plan de salud?
    - ☐ Los hospitales y los médicos que tienen contrato con su plan de salud para ofrecerle servicios segun a un acuerdo de tasas o cuota
    - ☐ El sistema de computadoras que usan los médicos y hospitales para presentar facturas a las compañías de seguros
    - ☐ Una pagina de Internet donde los consumidores pueden encontrar información sobre los mejores médicos
    - ☐ No se

12. Verdadero o falso: Si recibe atención hospitalaria en un hospital que participa en la red de provedores de su plan de salud, todos los médicos que lo atenderan mientras usted está en el hospital también estarán en la red.
    - ☐ Verdadero
    - ☐ Falso
    - ☐ No se

9. Suponga que su plan de salud cubre las pruebas de laboratorio en su totalidad si usted va a un laboratorio que es un proveedor de su plan de salud. Pero solo paga el 60% de los cargos si va a un laboratorio que no es un proveedor de su plan. Si usted se olvida y va a un laboratorio fuera de su plan de salud, el laboratorio le cobra $100. por la prueba de sangre. Su seguro de salud cubre solo el pago de $20. para esa prueba. ¿Cuánto pagaría usted de su bolsillo para esa prueba de laboratorio?
   - ☐ $0
   - ☐ $40
   - ☐ $80
   - ☐ $88
   - ☐ $100
   - ☐ No se

10. Verdadero o falso? Si su plan de seguro de salud se niega a pagar por un servicio que usted piensa que está cubierto y su médico le dice que necesita, puede apelar la negación y conseguir que posiblemente la compañía de seguros page la reclamación.
   - ☐ Verdadero
   - ☐ Falso

Lectura V: VIH Conocimiento

Quisiera saber si está familiarizado con dos términos del VIH: Conteo CD4 y carga viral. ¿Le puedo hacer algunas preguntas sobre esto?

3. ¿El objetivo del tratamiento es lograr que el conteo CD4 suba o baje?
   - ☐ Suba
   - ☐ Baje

4. ¿El objetivo del tratamiento es lograr que la carga viral suba o baje?
   - ☐ Suba
   - ☐ Baje

Parte 6: Características de los Encuestados

12. Cuando es su cumpleaños? (Mes/Día/Año) _____

13. Cual es su género ?
   - ☐ Masculino
   - ☐ Femenino
   - ☐ Transgénero

14. Cuál es su raza?
    - ☐ Blanco
    - ☐ Negro
    - ☐ Otro

15. Es usted Hispano?
    - ☐ Si
    - ☐ No

16. Cuál es su ingreso bruto anual? (Ingreso antes de impuestos u otras deducciones)
    - ☐ Menos de $10,000
    - ☐ $10,000-$19,000
    - ☐ $20,000-$39,000
    - ☐ $40,000+
    - ☐ No se/Se Niega

17. Qué nivel de educación completó?
    - ☐ Menos de tercer grado
    - ☐ Cuarto a octavo grado
    - ☐ Alguna escuela secundaria
    - ☐ Escuela secundaria/GED
    - ☐ Entrenamiento vocacional, universidad o otros estudios superiores
    - ☐ Otro (Especifique) _____

18. Cuál es su situación laboral?
    - ☐ Tiempo completo
    - ☐ Tiempo parcial
    - ☐ Retirado
    - ☐ Discapacitado
    - ☐ Actualmente no esta empleado
    - ☐ Otro (Especifique)_____

19. En qué ciudad o condado vive usted?
    - ☐ Paterson
    - ☐ Condado de Passaic (no en Paterson)
    - ☐ Condado de Bergen
    - ☐ Otro (Especifique)_____

20. Cuándo se le diagnosticó el VIH?
    - ☐ Antes del año 2000
    - ☐ Entre los años 2000 y 2010
    - ☐ Después del año 2010
    - ☐ No se

21. Cómo fue infectado con el VIH? (Puede responder más de una)
    - ☐ Hombre sexo con un hombre
    - ☐ La inyección de drogas con una aguja
    - ☐ Mujer sexo con un hombre o Hombre sexo con una mujer
    - ☐ Otro (Especifique)_____

22. Favor escoja el lugar desde el cual está completando este cuestionario.
    - ☐ Centro Familiar de Bergen
    - ☐ Buddies de New Jersey
    - ☐ CAPCO
    - ☐ Ciudad de Passaic Alianza de Passaic
    - ☐ Centro Médico de la Universidad de Hackensack
    - ☐ Centro de Servicios Múltiples para Hispanos
    - ☐ Fundación Hyacinth
    - ☐ Northeast Habilidades para la Vida
    - ☐ Servicios Legales de North Jersey
    - ☐ Centro de Asesoramiento de Paterson
    - ☐ División de Salud de Paterson
    - ☐ Hospital y Centro Médico St. Joseph – 21 Market Street
    - ☐ Centro de Atención Integral St. Joseph's– 160 Market Street
    - ☐ Hospital St. Mary's
    - ☐ Straight & Narrow (El Buen Camino)
    - ☐ Team Management 2000
    - ☐ Well of Hope
    - ☐ Este cuestionario no se completó en el sitio del Proveedor

APPENDIX D – Key Informant Discussion Guide

PATERSON-PASSAIC COUNTY – BERGEN COUNTY HIV HEALTH SERVICES PLANNING COUNCIL
HEALTH LITERACY ASSESSMENT

KEY INFORMANT INTERVIEW GUIDE

Name _____ Date _____

Organization _____

Title _____ Phone/e-mail_____

Interviewer _____

Introduction: Hello, my name is _____. I am calling on behalf of the Paterson-Passaic County – Bergen County HIV Health Services Planning Council. I appreciate your willingness to serve as a key informant and will try not to take too much of your time.

We are conducting a comprehensive assessment of health literacy of persons living with HIV/AIDS in Bergen and Passaic counties. The study aims to assess the level of health literacy in this population and resources available to address their needs.

BACKGROUND

1. What is your title and position? Do you work directly with PLWH or as an administrator?

   ☐ Directly with PLWH ☐ Administrator ☐ Both

   Please describe health literacy services provided by your agency.

   Other related services?

2. In your opinion, how would you assess the current level of health literacy among persons living with HIV/AIDS in [geographic region]?

   Probe Types of literacy and different populations:

   Literacy: reading (prose), documents, numeracy, insurance

   Populations: Foreign-born, minority status, educational attainment, gender, age, length of time since diagnosed, other factors

3. Are there sufficient resources available to PLWH with low health literacy? Please describe resources most significant or helpful for this population. I'm interested in knowing your assessment of these resources.
   Probe: What resources are lacking?

4. Do you feel that medical and case management providers need special health literacy training in dealing with persons living with HIV? Explain.

5. What health literacy training is available to medical and case management providers?

6. What types of training do you recommend for HIV providers?

7. What recommendations do you have for organizations when instituting health literacy programs for persons living with HIV/AIDS?
   Probe: Policy and procedures, professional certifications, standards.

8. What other comments, suggestions or concerns do you have regarding health literacy for persons living with HIV/AIDS?

Thank you.

APPENDIX E – Focus Group Discussion Guide

PATERSON-PASSAIC COUNTY – BERGEN COUNTY HIV HEALTH SERVICES PLANNING COUNCIL
HEALTH LITERACY ASSESSMENT
FOCUS GROUP GUIDE

Focus Group Name: _____ Date _____

Facilitator: _____

Introduction: Thank you for coming today. My name is Pat Virga and I am a consultant with New Solutions, Inc. My company is working with the Paterson-Passaic County – Bergen County HIV Health Services Planning Council on an assessment of the health literacy of Ryan White patients and clients. This assessment will ultimately allow the Planning Council to develop an action plan for health literacy improvement. The first step in this process is to gather information about your patients' and clients' literacy needs, and that will be the focus of our discussion today.

Our objectives for this focus group are:

1. To assess health literacy levels, competencies and needs of Ryan White patients and clients.
2. To gain insights into how health literacy is handled at your agency and what, if any, procedures would help to improve literacy.
3. To identify the resources available to assist providers with improving health literacy.

Before we begin, please understand that this focus group is completely confidential. None of your statements will be reported in any way that would identify you. We are audiotaping the session purely to give us an accurate record of what is being said.

Also, we asked you to complete the short survey as you came in. The purpose of that is to gather basic information in order to leave time for discussions. We have a lot of information to cover, and we want this group to be fast paced. Since we want everyone to participate, I might limit the time provided for answers. I appreciate your understanding.

Let's begin with introductions. *[Go round the table and ask each to identify him/herself.]*

Questions:

We define health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." Please keep this in mind during our discussions.

1. Please describe the average health literacy levels of your patients or clients.

   Probe: Communication, Reading Comprehension, Documents, Numeracy, Navigation, Information Seeking, Function, Decision-making/Critical Thinking, Need for Assistance

2. What are the most common reasons for low health literacy among your patients or clients?

   Probe: Foreign language speakers, low educational attainment, complicated subject matter, cognitive barriers, anything else?

3. How would you assess health literacy levels specific to HIV/AIDS?

   Probe: Medical terminology, medication names

4. Health insurance literacy has been identified as one of the most critical literacy issues facing people today regardless of health status. Please discuss the problems your patients/clients are having today with health insurance literacy.

   Probe: Understanding terminology, selecting health plans, submitting claims and paying co-pays and deductibles, appeal procedures, etc.

5. Please describe the types of problems you encounter when your patient/client has low health literacy.

   Probe: Retention in care, ability to keep appointments, treatment adherence, health status, etc.

6. Please describe the procedures you use to evaluate and remediate low health literacy.

   Probe: Screening/testing frequency, standardized testing tools (name them), computer assisted tools, etc.

7. What do you consider the best ways to assist your clients or patients to improve their health literacy?

   Probe: What written or visual educational materials do you use or are aware of that are effective in providing health literacy assistance for your patients and clients?

8. What tools do you use or need to assist clients with low health literacy?

   Probe: Training, assessment materials, etc., videos, translators

9. Have you ever had a health literacy (or literacy) training course?

   Probe: What type, when, where, etc. What types of health literacy training would you be interested in?

10. Do you have any suggestions or other comments for improving health literacy for your patients/clients?

Thank you for talking with us today.

APPENDIX F – Focus Group Survey Results

Case Manager Focus Group
Short Survey Responses

1. Do you evaluate your patients'/clients' health literacy using a standard assessment tool at any time during their enrollment?

No	7	58%
Yes	4	33%
No answer	1	8%

2. If yes, approximately how many of your patients/clients are evaluated?

<10%	2	17%
26-50%	1	8%
75-99%	1	8%
100%	3	25%
No answer	4	33%
Do not know	1	8%
	12	17%

3. Do you re-evaluate your patients'/clients' health literacy using a standard assessment tool at follow-up visits?

No	7	58%
Yes	3	25%
No answer	1	8%
Do not know	1	8%
	12	

4. If yes, how many of your patients or clients with low health literacy do you re-evaluate?

<10%	2	17%
26-50%	1	8%
75-99%	1	8%
100%	1	8%
No answer	6	50%
N/A	1	8%
	12	

5. How often are your patients/clients re-evaluated?

As needed	4	33%
No answer	4	33%
Twice a year	4	33%

6. Does your agency have policies and procedures in place regarding health literacy?

No	5	42%
Yes	2	17%
Do not know	5	42%

7. Have you ever attended a training on health literacy?

No	9	75%
Yes	1	8%
Do not know	1	8%
No answer	1	8%
	12	

8. Does your agency provide formal health literacy education for your patients or clients?

No	5	42%
Yes	3	25%
Do not know	2	17%
No answer	2	17%
	12	

9. If yes, how often do you provide the education?

Other : Never	1	8%
Monthly	1	8%
As Needed	3	25%
No answer	7	58%
	12	

10. Do you provide health insurance literacy assistance?

No	4	33%
Yes	6	50%
Do not know	1	8%
No answer	1	8%
	12	

11. Do you provide health literacy assistance in foreign languages?

No	7	58%
Yes	4	33%
No answer	1	8%
	12	

12. If yes, what languages are spoken at your clinic/agency? (May answer more than one.)

Spanish	7	54%
Polish	1	8%
No answer	5	38%

APPENDIX G -- Acknowledgements

The Paterson-Passaic County – Bergen County HIV Health Services Planning Council thanks those who participated in this study.

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