WHY HEALTH INFORMATION IS HARD TO READ: A MIXED METHODS STUDY INVESTIGATING THE READABILITY OF HEALTH INFORMATION

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ABSTRACT OF THE DISSERTATION

Why Health Information Is Hard to Read: A mixed methods study investigating the readability of health information

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To investigate how readability affects the way adults who are learning to read evaluate health information, a mixed methods research study was designed based on a sociotechnical framework and using theories of everyday life information seeking. The study analyzed a corpus of consumer health information documents (N=501) using the CohMetrix text analysis tool (McNamara, Graesser, McCarthy & Cai, 2014) and a set of NLP-based tools developed by Educational Testing Service (ETS) called SourceRater and Language Muse® to identify specific linguistic features that contribute to readability. In this study, these tools were used to assess the difficulty of reading health information. In the next phase of the study, adults who are learning to read (N=20) assessed the readability of the documents in the corpus as part of a usability study. The study found that the documents' low narrativity, limited concept and word overlap, and low cohesion contribute to the difficulty of reading health information for adults who are learning to read. It also identified differences in perceptions of reading difficulty among adults who are learning to read. The findings highlight the limitations of current health literacy guidelines and of using readability formulas like the Flesch-Kincaid Grade Level formula to determine the readability of consumer health information, and questions the reliability

of “Easy to Read” health information collections. Health information documents that are easier to read can improve access to health information that supports and addresses the needs of communities with poor health outcomes, including adults who are learning to read.

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1. Introduction

Providing better access to good quality health information for members of communities who are disproportionately affected by health disparities means that health information materials need to be informative, relevant, useful, and easy to read. Since poverty, adult reading levels, and negative health outcomes converge in many of these communities, the need for health information that is easy to read for adults who are learning to read is paramount (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; National Center for Education Statistics, 2002). When adults who are learning to read evaluate health information, the ease of reading that document—what researchers term readability (DuBay, 2004)—is a potentially crucial factor in how they judge its quality and usefulness. The quality that makes text easy to read (readability) has been operationalized by different readability formulas, such as the Flesch-Kincaid Grade Level formula (DuBay, 2004), which are often recommended in professional guidelines for creating easy to read health materials (U.S. National Library of Medicine, 2016). The effective use of these "classic" formulas for determining the readability of consumer health information documents is limited for several reasons. Some of these limitations are: (1) these formulas were not developed for these types of texts; (2) they do not measure other aspects of language beyond vocabulary frequency and sentence length that might account for ease or difficulty of reading; (3) and they do not account for reader characteristics that might affect how easy a document is to read, such as prior knowledge of a topic (Redish, 2000).

Health agencies and community organizations including libraries, who are concerned with providing access to good quality health information, tend to do so by

prescribing criteria, checklists and other tools to help individuals determine the authority and credibility of consumer health information resources (Fritch and Cromwell, 2001). These criteria include how easy it is to identify the author or publisher of the information (e.g. whether a government agency or a private corporation such as a pharmaceutical company), how frequently the information is updated, and how health information presents evidence for health claims. Examples include the National Library of Medicine's tutorial on evaluating Internet health information resources,[1] the National Institutes of Health's Q&A site on evaluating online health resources,[2] the Medical Library Association's Guidelines for Evaluating Content[3], and the National Network of Libraries of Medicine's checklist for evaluating health information.[4] Many of these same agencies also provide content creators with guidelines on writing "easy-to-read" health information. It is important to understand whether the implementation of these recommendations result in health information documents that are easy to read for adult beginning readers.

To investigate how these professional practices affect the way adults who are learning to read evaluate health information that has been created specifically for users like them, this proposal describes a multi-phase mixed methods study that critically examines health literacy as a sociotechnical system in which social constructs and technical artifacts are mutually and recursively shaped (Leonardi, 2012). It will examine on the one hand how sociomaterial practices such as implementing writing guidelines and applying traditional readability formulas, affect the classification of health information

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[1] See https://www.nlm.nih.gov/medlineplus/webeval/webeval.html
[2] See https://ods.od.nih.gov/Health_Information/How_To_Evaluate_Health_Information_on_the_Internet_Questions_and_Answers.aspx
[3] http://www.mlanet.org/resources/userguide.html#guidelines
[4] See http://nnlm.gov/pnr/hip/criteria.html

materials as "easy to read," and on the other, how adult beginning readers evaluate the resulting documents. Since many of the readability formulas used to assess the readability of health information, such as the Flesch-Kincaid Grade Level formula, were developed for school and educational use (DuBay, 2004), exploring the social function of these formulas in health literacy practices uncovers the way such practices, which were originally developed for school-aged children learning to read, actually create barriers to information access for adults who are learning to read. A sociotechnical approach to investigating health literacy provides an analytical lens through which to gain a deeper understanding of the way in which socially constructed professional values and contextual factors affect readability judgments. This focused analysis seeks to further enrich automatic methods of assessment and the guidelines used when creating health information materials for these users.

To do so, Phase I of this study analyzed the readability of 501 publicly available consumer health information documents using both traditional tools (e.g. Flesch-Kincaid Grade Level formula). The analysis in Phase I also uses newer computational tools such as Coh-Metrix[5] and NLP tools developed by Educational Testing Service (ETS). These more newer tools take into account more sophisticated linguistic features of text such as narrativity and cohesion (discussed in Chapter 3). In Phase II, the study investigated how adults who are learning to read evaluate the readability of these health information documents through a series of case studies based on usability testing methods. The integrated analysis from each phase of this study revealed that health information documents are characterized by long but structurally simple sentences, and that linguistic factors such as the type of vocabulary used, and the documents' poor narrativity and low

[5] Coh-Metrix tool is available at http://cohmetrix.com/

cohesion are factors that contribute to their poor readability. Furthermore, this study also found that specific reading practices of adults who are learning to read also sometimes affect the readability of health information. Specifically, this research study (1) investigated how adults who are learning to read evaluate "easy to read" health information in the context of everyday life information seeking and (2) investigated the practice of health literacy by focusing on the uses of readability for adults who are learning to read.

The remainder of this first section discusses in greater detail this study's problem statement, the work's significance, the research objectives, and the research questions that are the focus of this study. A short note disambiguating important terms used in this paper concludes Chapter 1. This is followed by a literature review that discusses the theoretical basis for the conceptual framework that underpins this work. After this discussion, the mixed methods research design that was developed to answer these research questions is described, including a discussion of Phase I and II of this study. Chapter 4 discusses the integrated findings of this research study, and the conclusion in Chapter 5 synthesizes a discussion of the implications of this work, its limitations, and directions for future work.

1.1 Problem Statement

Recognizing that health information needs to be informative, relevant, useful, and easy to read, different organizations have created formal guidelines that emphasize readability and the importance of assessing reading grade level when creating health information materials. Guidelines like Medline Plus' *How to Write Easy-to-Read Health Materials* mention different readability formulas available to content creators to assess

the readability of their health information materials (U.S. National Library of Medicine, 2016). These guidelines are problematic for two main reasons. First, the readability formulas such as Flesch-Kincaid Grade Level formula, which are endorsed by the guidelines, have an overly simplistic way of defining readability as only a function of sentence and word length. Researchers have coined the term "simplicity paradox" to describe the effects of over-emphasizing the role of sentence and word length to determine readability, pointing out that simplifying text by making sentences shorter paradoxically leads to text that is harder to read, mainly because this way of shortening sentences often creates gaps in cohesion and requires readers to make inferences without the aid of linguistic clues such as connective words or phrases (Zarcadoolas, 2011).

A second problematic aspect of these guidelines is the assumption that all readers of Easy to Read materials have a similar set of needs with respect to consumer health information. A main concern in this research is that adults who are learning to read are not the same as children who are learning to read, and that not all adults who are learning to read have the same reading practices nor the same level of domain or background knowledge (Carey, 1985). Consider, for instance, the difference between an adult for whom English is a second language, but who regularly reads the newspaper in another language, and adult for whom English is a dominant or native language, but who is learning to read and write in English as an adult. Determining what makes health information easy to read for these different types of adult readers is not as straight-forward as the guidelines suggest. To improve the readability of health information for adults who are learning to read and to improve the guidelines that inform the creation of these materials, user feedback is essential. Determining what features beyond word and

sentence length might make health information texts easy to read for someone remains understudied, particularly with respect to adult new and developing readers. A better understanding of how adults who are learning to read assess the readability of health information resources will not only help improve these guidelines, but also will ultimately improve access to health information that is easy to read for this group of users as well.

1.2 Significance

The link between poverty, adult reading levels, and negative health outcomes has led to a growing public health concern about the ability of members of at-risk communities to access, understand and use health information to manage their health (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; National Center for Education Statistics, 2002). This is not surprising considering that a high incidence of hospital and emergency service use correspond with low levels of health literacy among adults (Howard, Gazmararian, & Parker, 2005), and that adults from ethnic minority groups tend to have lower health literacy than White adults (National Center for Education Statistics, 2003[6]). Two important factors contribute to the severity of this situation: (1) the state of adult literacy in the U.S. and (2) the expertise needed to read and use health information.

Roughly 30 million adults (14%) in the United States tested at the lowest levels of literacy and health literacy (National Center for Education Statistics, 2003). At the same time, research shows that consumer health information is very difficult to read, and this difficulty constitutes a health risk factor (Baker et al., 2002; Baker, Parker, Williams, &

[6] This is the last population-wide survey of health literacy that exists at the time of this writing.

Clark, 1998; Berland, Elliott, Morales, Algazy, Kravitz, Broder, & McGlynn, 2001; Walsh and Volsko, 2008; Dollahite, Thompson, and McNew, 1996). Developing ways to make health information more accessible and easier to read for members of communities most affected by health disparities requires a research agenda that includes a focus on community members' perspectives about the readability and utility of the health information available to them. Without a better understanding of how these adults evaluate consumer health information, the effectiveness of public health mandates to improve access to health information, such as the U.S. Department of Health and Human Services' National Action Plan to Improve Health Literacy (2010) and recommendations for creating health information materials for members of at-risk communities, remains in question.

1.3 Research Objectives

To investigate how professional practices related to the creation, standardization, assessment, and dissemination of consumer health information affect the way these materials are ultimately evaluated by adults who are learning to read, this mixed methods study conducted (1) a linguistic analysis of consumer health information documents using computational methods for assessing readability and (2) a series of usability case studies that investigated how adults who are learning to read evaluate these documents and assess their readability. Integration of the mixed methods occured during the sampling, data collection, and data analysis phases to optimize the trustworthiness of the research findings, and to help maximize the study's validity (Johnson, Onwuegbuzie, & Turner, 2007). The first point of integration informed the sampling of documents that were analyzed during the usability case study. In order to select documents in a way that

minimizes researcher bias, the corpus of health information documents was grouped into statistically derived clusters and prototypical documents from each cluster were identified and selected for user evaluation. The second point of integration was at the data collection phase, which included an interview protocol that was developed based on the findings from Phase I. Finally, an integrated analysis of findings from each phase of the study helped to provide additional context and to corroborate the findings from Phase I with the experiences of who are learning to read, which were collected and analyzed as part of Phase II.

1.4 Research Questions

In order to better understand what accounts for the readability of health information and how readability affects the way members of at-risk communities evaluate health information, this study undertakes a critical analysis of health literacy as a sociotechnical system (Leonardi, 2012) involving the use of writing guidelines, readability formulas, and the classification of health information as "easy to read." The following research questions drive the study:

RQ1. What linguistic features affect the readability of consumer health information documents for adult emerging readers?

a. What linguistic features of consumer health information documents are characteristic of these documents according to computational linguistic analysis?
b. What features of text and reader, besides those identified by the "classic" readability formulas, account for the ease of reading consumer health information documents?

RQ2. How do adults who are learning to read perceive the readability of "easy to read" consumer health information documents?

a. To what extent does the "easy to read" classification of health materials affect the way adults who are learning to read evaluate them?

RQ3. What assumptions do the measures of readability recommended by professional guidelines make about the characteristics of adults who are learning to read?

1.5 A Note on Terms

Before going further, it is important to define some important terms that will be discussed throughout this paper. First, to properly delineate the scope of this research, health information needs to be defined and specified within the context of this study. **Health information** is a term that encompasses a broad range of resources, documents, and tools used by practitioners and the public that are related to health and wellness. Examples of health information include prescription medication labels, pre- and post-surgery instructions, patient health records, and public health materials such as posters, worksheets, and pamphlets. Health information also includes a group of documents and resources called **consumer health information**, which are user-focused information resources on a variety of health topics. These documents are also often called **patient education materials**. Patient education materials are generally created by hospitals, healthcare organizations, physician organizations, and institutions such as the Centers for Disease Control and the American College of Physicians. Recognizing that not all users of consumer health information are patients, however, this study uses the term **consumer health information documents** to refer to print-based literature about a variety of health

topics, and focuses on health information created for the public, which is increasingly described as a consumer in the healthcare marketplace movement.

Another set of terms that must be defined are those that describe the adults who participated in this study and who represent a larger group of adult readers for whom "easy to read" health materials are created. The research literature and many public health resources often describe these adults as adults who have low literacy skills, who lack literacy skills, or even adults who are illiterate. The research study presented here is not an investigation of cognitive factors. Terms that describe cognitive abilities, such as literacy skills, are therefore not used in this work except when describing the focus of other related research.

A growing practice in related work is to describe this group of adults as **emerging readers**, which is a term that originates in the education literature that focuses on the stages of reading development (Chall, 1996). Because the term "emerging readers" can also be used to refer to children who are learning to read, it is not used in this paper. Instead, the phrase this paper will use to describe this group of adult readers is **adults who are learning to read**. The study described here is grounded in critical methodologies that aim to elevate the role of the participant, especially when participants are members of communities that have been historically marginalized, neglected, treated unethically, or abused (see Section 2.3). Primarily for this reason, using language that describes qualities that participants have, instead of focusing on characteristics that dominant social groups feel these participants lack, is important for this work.

In addition to using a framework rooted in critical methodologies, this study also applies a sociotechnical practice framework to investigate health information and reading

practices (see Section 2.2). When asked why they are receiving tutoring at the library, I have often heard adults say, “so I can work on my reading and writing.” In the course of my volunteer work with these adults, I have never heard them describe themselves as someone who can’t read or as someone who lacks reading skills. Instead, they use positive, affirming language that describes their learning practices: working on reading and writing. For all of these reasons, it is important to use terms derived from the way these adults describe themselves as a way to ensure that the adults who participated in this research study do not feel further marginalized based on the language I use to describe them in this dissertation.

2. Literature Review

To obtain a multifaceted understanding of how readability affects the usability of consumer health information, this study conceptualizes this phenomenon as a set of interconnecting health literacy practices. The practice of evaluating consumer health information is part of broader everyday health literacy practices that includes people’s assessments of these documents’ usability and readability. Evaluating health information is socially embedded in value systems and related practices like reading and health management. At the same time, creating health information documents that are easy to read is also part of a broader set of professional practices for health literacy professionals. This research integrates several theoretical frameworks in order to understand the relationship between the professional practice of creating health information documents and the everyday practice of evaluating these materials. Applying the theories of everyday life information seeking (Savolainen, 1995), literacy as social practice (Gee, 2015), and sociomateriality (Leonardi, 2013) to the health literacy practice of evaluating

health information results in a conceptual framework that supports an analysis of consumer health information documents as sociotechnical artifacts created through the use and manipulation of other sociotechnical tools, such as readability formulas and writing guidelines. The health information document, itself a sociotechnical artifact, is then embedded in other sociotechnical practices that are carried out when people seek, read, evaluate and ultimately use them. To collect the data needed to make this type of analysis, the research design for Phase II of this mixed methods work is based on critical methodology (Israel, Schulz, Parker, & Becker, 1998) and usability theory (Marcus, 2011), and integrates these with the methods of data collection and analysis of Phase I of the study including tools based on natural language processing techniques and research on readability. The rest of this section discusses each of these theoretical approaches in more detail and how they each inform the design of this research study.

2.1 The Everyday Life Information Seeking Practice of Evaluating Health Information

Everyday life information seeking practices, such as information searching, monitoring, sharing, and evaluating, are often implicated in literacy practices. Some of these practices, such as reading health information to help manage one's health, are social instances in which people negotiate the meaning of language in print, such as interpreting an ad (Gee, 2015). This research study combines the theory of everyday life information seeking (Savolainen, 1995) and the theory of literacy as social practice (Gee, 2015) with a sociotechnical approach (Leonardi, 2013) to critically examine the practice of evaluating health information. Without denying that reading is a cognitive process, they offer a conceptual framework that frames this study's object of analysis as a social and, more specifically, a sociotechnical practice. As such, this study design uses a usability

case study method as a way to observe health literacy practices rather than as a way to assess participants' abilities or skills. This section more fully develops concepts related to everyday life information seeking as a lens through which to study health literacy practices such as evaluating consumer health information.

Research in library and information science has traditionally studied information evaluation almost exclusively as a cognitive process (Hilligoss & Rieh, 2008; Eysenbach & Kohler, 2002). These cognitive studies have found great variability in the way people evaluate the quality and credibility of information, but no way to account for it. One way to account for this variability, however, is to recognize the role of social influences or social practices on this phenomenon (Yi, Stvilia, & Mon, 2012; Kim, Kreps, & Shin, 2015). People's values are constructed, sanctioned and negotiated through the social structures and interactions that organize their daily lives (Giddens, 1984; Bourdieu, 1990; Savolainen, 1995). The evaluation of health information is, accordingly, a socially created, sanctioned and reproducible process located outside the mind of individuals and squarely in the observable practices of everyday life. Based on the theories of practice, habitus, and social structures (Bourdieu, 1990; Giddens, 1984; Schatzki, Knorr-Cetina, & Von Savigny, 2001), Savolainen's theory of everyday life information seeking (ELIS) emphasizes the situational and structural aspects of information practices (1995). By applying ELIS to health literacy practices, this study investigates the role of reading and readability in the everyday life information practice of evaluating health information.

Conceptualizing literacy-related practices such as evaluating health information as social and discursive practices rather than as purely cognitive processes opens up new ways of understanding health literacy. If knowledge, or what counts as evidence for belief, develops within a social context (Fallis, 2006), it stands to reason that ways of

evaluating that knowledge are also socially constructed and reproduced. Information practices like evaluation are linked to prior experiences and to other related practices such as health practices and language use through a social system that organizes people's way of life known as the habitus (Bourdieu, 1990). The social structure that orients evaluation practices is constituted through language and discourse (Tuominen, Talja, & Savolainen, 2002). According to this framework, knowledge, language, information and beliefs are never neutral or objective, but rather products of discourses that develop from subjective social positions (Hepburn, 2006). This discursive (social) subjectivity helps to explain, for instance, why prescriptive approaches to evaluating information, such as checklists and tutorials, are sometimes ineffective, since they ignore social practices that influence how people make judgments.

Individuals have different ways of defining credibility, and how they define credibility affects the way they evaluate information (Hilligoss, & Rieh ,2008; Eysenbach, *&* Kohler, 2002). Likewise, people's definitions of quality also vary (Arazy and Kopak, 2011*;* Marshall and Williams, 2006; Stvilia, Gasser, Twidale, & Smith, 2007; Yi, Stvilia, & Mon, 2012*)*. Aspects of the information source itself also affect how participants assess its credibility. These characteristics include—but are surely not limited to—document readability, writing quality, amount of jargon, the use of appropriate use of tone, and the use of plain language (Eysenbach, *&* Kohler, 2002; Hilligoss & Rieh's (2008). When they read information in order to evaluate its quality, credibility, relevance, or usefulness, people seem to pay attention to certain cues present in the text and use these cues in their evaluation. Though these studies have shown that language evidently plays a role in the way people evaluate information, *how* language use

affects the way people evaluate information, however, has been understudied. This research study makes important contributions to this area of research by conducting usability studies of consumer health information from the perspective of adults who are learning to read, a group that is at greater risk of negative health outcomes partly because of their lack of access to health information that is easy to read (Walsh and Volsko, 2008).

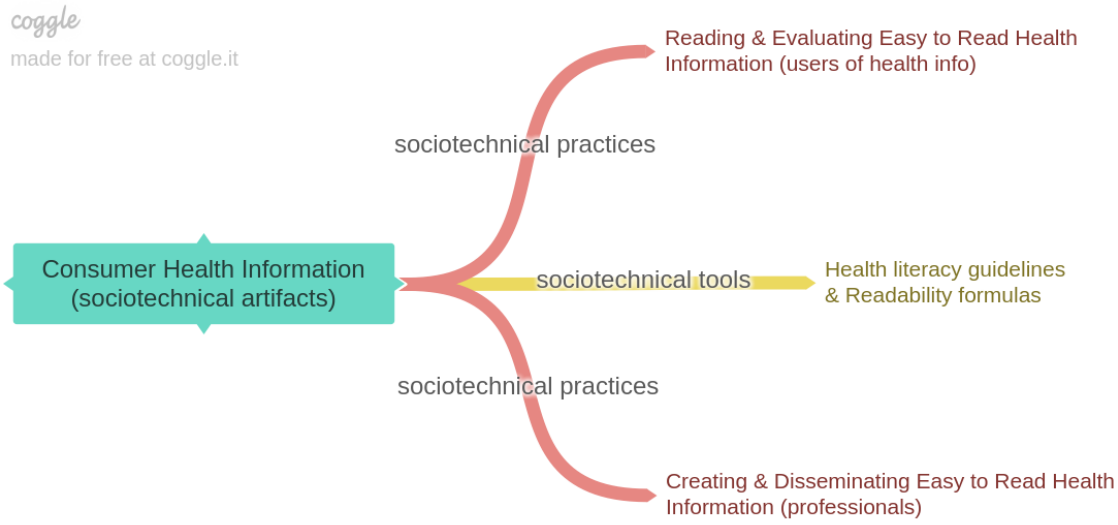
2.2 Health Literacy as Sociotechnical Practice

Services for adults who are learning to read are a common component of many public library community outreach and education programs. Fitzgibbons (2001) offers a historical overview of literacy work in public libraries, including literacy policies and guidelines developed by international and professional organizations such as UNESCO, the American Library Association (ALA), and the International Federation of Library Associations (IFLA). Though less prevalent, health literacy programs more specifically have been gaining traction in public libraries, particularly since the publication of the report, *Health Literacy: A Prescription to End Confusion* (Kindig, Panzer, & Nielsen-Bohlman, 2004). This report not only claims that half of all adults in the United States have trouble with health information, but more importantly, it correlates the high incidence of hospital and emergency service use with low levels of health literacy. Some early articles on health literacy in libraries published around this time offered prescriptive strategies for health literacy program development (Burnham & Peterson, 2005). The launch of *Healthy People 2010* and of *Healthy People 2020,* national plans to improve the health of American adults, highlighted the importance of increasing health literacy levels among adults (U.S. Department of Health and Human Services; Huber, Shapiro, &

Gillaspy, 2012). Recent efforts are taking a less prescriptive approach to health literacy in libraries. Some important findings in this area claim that adults tend to self-report being adept at finding health information and that they are good or excellent judges of the quality of the health information they find (Yi, 2015). What many of these studies fail to do, however, is conceptualize health literacy as a broader sociotechnical system in which professional practices and everyday health information practices interact with sociotechnical tools and artifacts when someone seeks, finds, reads, evaluates, and ultimately uses health information to manage their health.

Framing health literacy practices as sociotechnical practices facilitates the observation and analysis of this complex phenomenon (Leonardi, 2013). Increasingly, health literacy is a social practice in which health professionals, librarians, and members of different communities use or manipulate different artifacts in order to manage and make decisions about their health and wellbeing.

Figure 2.2 Sociotechnical model of health literacy



The figure above shows the interaction between the sociotechnical practices involved in creating, evaluating, sharing, and using health information, and the sociotechnical tools that are shaped and also themselves shape these practices. This sociotechnical system also includes the development and implementation of standards for creating so-called easy-to-read health information, the endorsement of certain linguistic features as gold standards for what makes text easy to read, and the use of certain technical tools for measuring the readability of consumer health information. Of singular interest to the present study are those technologies used to assess the readability of consumer health information, such as the Flesch-Kincaid Grade Level formula and the writing guidelines for developing so-called "Easy-to-Read" health information materials. All of this is embedded within a set of professional health literacy practices that practitioners strive to implement with the ultimate goal of improving the health literacy of different communities (Koh, Berwick, Clancy, Baur, Brach, Harris, & Zerhusen, 2012). It is not clear, however, that the specific professional health literacy practices concerned with creating easy-to-read health information are in fact accomplishing this goal or even providing greater access to health information. This study, then, seeks to better understand, from the point of view of adults who are learning to read, whether and to what extent consumer health information is in fact useful, usable, and easy to read by using a sociotechnical approach to exploring this complex phenomenon.

Reframing health literacy practices and related technologies as a mutually shaping system (Leonardi, 2012) challenges two dominant conceptualizations of health literacy: (1) the behavioral model of health literacy, which defines health literacy as a set of competencies that individuals either have or lack (Sørensen, Van den Broucke, Fullam, Doyle, Pelikan, Slonska, & Brand, 2012), and (2) the social movement model of health

literacy, which conceptualizes health literacy as an individual good, encompassing a person's right to make decisions about one's own body and health (Huber, Shapiro, & Gillaspy, 2012). Instead, the sociotechnical approach looks at the social context in which health literacy practices occurs, taking into consideration the people, practices, technologies, and artifacts involved in providing access to easy-to-read health information, as well as the characteristics of the system that make health literacy an important social agenda. Health literacy is, according to a sociotechnical approach (Leonardi, 2013), a set of socially embedded practices involving not just the intended users of consumer health information resources, but also library professionals, health practitioners, and content creators. This approach identifies the interdependencies between the professional practices involved in providing access to easy-to-read health information, the technologies implicated in these practices—such as the use of guidelines and readability formulas—the documents created according to these guidelines, and the ultimate users of these materials.

2.2.1 Using Readability Formulas in Health Literacy Practices.

Several agencies and institutions are involved in defining health literacy as a public health issue. The Institute of Medicine defines health literacy as the ability to find, process and understand health information needed to make decisions related to one's health (2004). To help professionals create health information that satisfies these health literacy criteria, the U.S. National Library of Medicine and the federal government have codified what it means for a consumer health information document to be "easy to read." Practices to avoid include the use of technical vocabulary and writing long sentences, while practices endorsed include the use of bulleted lists whenever possible (PLAIN, 2011; U.S. National Library of Medicine, 2016). Often, these guidelines recommend that content creators use readability formulas as a way to assess and subsequently classify

consumer health information as "easy to read" (U.S. National Library of Medicine, 2016). The National Library of Medicine, for instance, recommends a reading level of 7th or 8th grade (2016). Once it has been determined that a document meets these guidelines, agencies may submit it to the "Easy to Read" collection of MedlinePlus where librarians and public health professionals can access them for distribution to members of communities they serve (U.S. National Library of Medicine, 2016).

As useful and well intentioned as these definitions and recommendations are, they are mostly derived from empirical research based on adults reading websites (Office of Disease Prevention and Health Promotion, 2016). It is unclear whether any studies exist that focus on the different reading practices of different kinds of adults who are learning to read—for instance, reading health information in print as opposed to online. Health literacy guidelines do not reflect the diversity of reading practices among adults, individual differences among adult readers, or the variety of their experiences reading different kinds of texts. This study collected data representing differences in adults who are learning to read as they evaluate health information in order to address this gap in the research.

2.2.2 Readability and Readability Formulas.

The present study makes an important contribution to our understanding of health literacy as a sociotechnical practice by conducting usability case studies with members of communities for whom these resources are intended. From a sociotechnical perspective, it explores (1) how members of these communities evaluate and determine the readability of consumer health information documents, and (2) the role of writing guidelines and readability formulas to designate these documents as "easy to read" for members of

already marginalized and at-risk communities. To do so first requires a discussion of the development, use, and limitations of readability formulas, which follows in the next sections.

2.2.2.1 What is Readability?

Readability has been defined as a quality that determines how easy texts are to read for a particular individual (DuBay, 2004). Based on this definition, a number of important findings have had a lasting impact on current understandings of reading, literacy, and readability:

- Easy-to-read texts benefit individuals who have low topic knowledge and/or low motivation,
- Improved readability increases the likelihood that someone will continue reading, and
- Texts that are easy to read increase reading speed and retention (DuBay, 2004).

Despite these findings, defining just what makes something "easy to read" remains a complicated research problem.

2.2.2.2 How Readability Formulas Operationalize Readability.

The modern concept of readability which resulted in the development of many of the readability formulas used today, is the outcome of research that began in the United States in the 1920's stemming from the field of education (DuBay, 2004). During this early period, teachers were increasingly concerned with the reading difficulty of textbooks for middle school and high school students, a group that was staying in school longer than generations before the first World War (Zakaluk and Samuels, 1988). It was at this time that the first English word frequency list, *The Teacher's Word Book*,

operationalized word difficulty for the first time (Zakaluk and Samuels, 1988; DuBay, 2004). Not long after, an important study published in *Library Quarterly* conceptualized literacy as a set of skills, which remains a common characterization of reading even today (Dale and Tyler, 1934). This study was an early attempt to identify factors that affect the readability of text. It explored the readability of health information documents specifically, and focused on a specific group of readers: African American adults with limited reading skills. Dale and Tyler used a vocabulary test and a multiple choice reading comprehension test to assess the reading skills of participants, and found that vocabulary was most closely correlated to reading difficulty as measured by technical vocabulary and the number of easy and difficult words in the samples. When the researchers compared the reading scores of adults with those of children in different grade levels, they found that adults in their study were most familiar with words known by children in the 6^{th} and 8^{th} grades. Sentence length and complexity were also found to be important determinants of reading difficulty, as were the number of pronouns, prepositions, and clauses in the sample reading materials. This study provides strong evidence that helps to account for the weight given lexical features in many readability formulas and statistical models.

Based on these and many subsequent studies, early readability formulas like the Flesch-Kincaid Grade Level (Flesch, 1948), the Fry Readability Graph (Fry, 1968; Fry, 1977), the SMOG formula (McLaughlin, 1969), and the New Dale-Chall readability formula (Chall and Dale, 1995), many of which are still used today, emphasize the effect of vocabulary and sentence length on readability. Because in English longer words tend to occur less frequently, readability formulas tend to score texts with a high incidence of

long words as difficult to read (Sigurd, Eeg-Olofsson, & Van Weijer, 2004). This observed correlation between the frequency and length of words in English has also been used to develop health literacy assessment tools. For example, the Rapid Estimate of Adult Literacy in Medicine and the Short Assessment of Health Literacy (Agency for Healthcare Research and Quality, 2016)—two tests widely used in healthcare settings to measure people's health literacy—are both based on the assumption that people are likely to recognize shorter, more frequently used words.

There is an inherent problem with the way these tools assess an individual's level of health literacy: they ignore the difference between being able to recognize a word as it is written or read and being able to understand a word's meaning in context. These assessments conflate word recognition and vocabulary knowledge. For example, an adult who is learning to read might not be able to read the word "pneumonia," but she may very well know what pneumonia is due to prior life experience. In other words, just because someone cannot read a word does not mean that person does not know the word's meaning. Health literacy assessment tools based on this assumption like the Rapid Estimate of Adult Literacy in Medicine and the Short Assessment of Health Literacy are therefore insufficient indicators of health literacy.

Sentence length has also been used in a number of different readability formulas as a simple way to account for syntactic structure (Flesch, 1948; Zarcadoolas, 2011). The assumption here is that short sentences tend to exhibit a simple syntactic structure, which tend to be easier for readers to understand. Sentences with more complex structure, such as those containing dependent clauses, tend to be longer sentences, and the number of subordinate clauses in a text has been validated as a measure that predicts text difficulty

in Dale and Tyler (1934). Accordingly, the average length of sentences in a document has been used in a number of readability formulas including the Flesch-Kincaid Grade Level (Flesch, 1948), the Dale-Chall (Chall and Dale, 1995), and the SMOG formulas (McLaughlin, 1969).

The assumption that longer sentences are more difficult to read than short ones, however, is not always correct (Feng, Elhadad & Huenerfauth, 2009). Consumer health information documents include many long sentences simply because they tend to list symptoms, directions, or lists of examples that help to further define important concepts. Example 2.2.2.2.a What I Need to Know About Irritable Bowel Syndrome, pg. 14

> Fiber is found in foods such as whole-grain breads and cereals, beans, fruits, and vegetables.

The example sentence above is relatively long, with 15 words, but has a simple structure. Its length is the result of a list of items that are high in fiber. Findings related to this limitation are discussed in greater detail in section 4.4.

Using the classic readability formulas to assess consumer health information documents can also lead to inflated reading grade levels because the formulas cannot adequately handle linguistic features that often characterize these types of documents, such as specialized vocabulary, lists, or phrases not presented as complete sentences. These formulas are also unable to account for factors that affect the way people read such as reading ability, topic knowledge, motivation, context, and genre (Schriver, 2000). Another important limitation of these formulas—and one that speaks to their external validity—is that they were developed by using training corpora (also known as criterion passages) that were very short and not representative of a wide variety of texts (Klare, 1984; Redish, 2000). Because they were initially developed for use in educational

contexts, these formulas were trained on textbooks and other educational materials intended for school-aged children, and this limits their applicability to texts developed for adults, texts with longer passages, and to texts from different genres, such as health information. For these reasons, simply following guidelines that recommend the use of the classic formulas is not enough to ensure the readability of consumer health information.

2.2.2.3 Applying Natural Language Processing Techniques to Assess Readability.

Readability research using computational methods is a rich area of study. This work identifies specific features within a corpus that represent linguistic characteristics such as semantics and syntactic structures that are used to make readability predictions (Collins-Thompson, 2014). Applying natural language processing (NLP) techniques to build more sophisticated language models than the traditional readability formulas has led to some recent developments in readability research. An important finding is that the selection of features used to predict the readability of text is more significant than the selection of the computational method itself (Collins-Thompson, 2014). Research based on semantic network analysis has been able to extend the earlier readability formulas based on word length and frequency. This research has found that relative word length—or the difference in length between semantically related terms (broader terms vs. narrower terms)—can better account for variability in text difficulty (Benjamin, 2012). This makes intuitive sense, at least for English language texts, since not only do basic nouns tend to be shorter than their variants, but they also tend to be less morphologically complex (e.g. sofa vs. chesterfield and sod vs. sodden) (Feldman, 2013). A likely

hypothesis is that texts that are easier to read tend to include more basic forms of nouns and that, as difficulty increases, so too does the use of more complex noun variants.

Latent semantic analysis, a technique used to analyze the relationships between concepts in a document, has also been used to measure text cohesion, which refers to the way concepts and ideas are developed in a text (Benjamin, 2012; Deerwester, Dumais, Furnas, Landauer, & Harshman, 1990). A more recent advance in the understanding of what makes text easy to read is that text cohesion plays an important role in the reading process. Cohesion refers to the semantic relationship between sentences. That is, it represents how ideas are strung together in a text. Since the traditional readability formulas like Flesch-Kincaid Grade Level (Flesch, 1948), the Dale-Chall (Chall and Dale, 1995), and the SMOG formulas (McLaughlin, 1969) do not take meaning into account, they are unable to identify or measure features like cohesion that are closely related to readability. Researchers have been able to detect and model cohesion in text by using natural language processing (NLP) methods (Klebanov, Diermeier, & Beigman, 2008). A study by Louis and Nenkova (2012) also found that these automatic methods of detecting text cohesion are as reliable as human annotators. Though not primarily a readability study per se, this study shows that discourse cues can help to identify the level of cohesion in a text. In other words, it is possible to observe and measure the level of cohesion in a text (McNamara, et al., 2014).

Another important aspect of research on cohesion is its relationship to syntactic complexity (i.e. sentence structure). Siddharthan (2006), for instance, examined ways to simplify text while preserving cohesion as a way to make text more readable by making explicit the relationship between discourse and syntax. Paradoxically, simplifying text by

making sentences shorter can lead to text that is harder to read due to the gaps in cohesion that characterize text with an abundance of short sentences (Zarcadoolas, 2011; Petersen & Ostendorf, 2007). An example of this type of simplification is the use of bulleted lists in health information documents. Medline's guidelines recommend, "[w]here appropriate, use bulleted lists instead of blocks of text to make information more readable." (U.S. National Library of Medicine, 2016). Bulleted lists are frequently used to enhance the readability of consumer health information. However, bulleted lists often omit function words and other cues that help to explain the relationship between items in the bulleted list. These gaps require readers to make inferences without the aid of linguistic clues such as connective words or phrases (McNamara, Kintsch, Songer, & Kintsch, 1996). This is not ideal for adults who are inexperienced readers. Inexperienced readers and readers who have low domain knowledge actually benefit from text that makes explicit connections between concepts presented across sentences and paragraphs (McNamara et al., 1996).

Using computational linguistic methods to analyze readability raises some methodological issues that must be resolved in order to maximize the validity of research results based on these methods. Reading practices and other processes involved in reading text are not always so easy to observe and quantify. A combination of factors including cognitive, affective, discursive, pragmatic, and social, are at play when people read text. When selecting and using any method or formula to assess readability, researchers as well as practitioners must be clear as to what aspect of reading and readability their chosen method is able to measure (Snatchschneider & Petscher, 2011). This is why simply relying on readability formulas to assess a document's readability is not enough to support the health information practices of adults who are learning to read.

It is important that practitioners understand the limitations of traditional readability formulas and that they begin to implement other methods of assessing readability as part of their health literacy efforts.

Readability assessment methods based on computational methods have yielded important results when applied to health information. A study of the effects of simplifying health information found that while lexical simplification diminishes perceived difficulty, it increases actual difficulty since it can make text less coherent (Leroy, Kauchak, & Mouradi, 2013). This inverse relationship between perceived and actual difficulty of health information suggests that simplifying text by focusing on vocabulary and sentence length alone—as recommended by the standard writing guidelines—might not have the desired effect of making health information easier to read. This also raises questions about the relationship between the reader and the text. When a reader evaluates an information resource such as a health information document, she brings certain expectations to that practice. At least some of these expectations are socially constituted, such as that a document have a certain structure or that it use a respectful tone (not childish, demeaning or condescending). At the same time, the text itself brings with it the codification and embodiment of the creators' communicative goals. Many of these are socially constructed through professional practice. In the case of a health information document, for instance, these codified constructions include conceptions of health, accuracy and authority, as well as instantiations of what "easy to read" language is. All of these factors interact when someone reads a health information document, and they affect the way that person evaluates the document itself. The present study further investigates the sociotechnical relationship between features of the text and

those of the reader by analyzing consumer health information materials that have been classified as "Easy to Read." This analysis involves the use of computational linguistic methods which are based on studies of reading and readability that make certain assumptions about what it is to read a text. The next section discusses this foundational work and what it means for this research study.

2.2.2.4 Reading Research.

Tools for automatically assessing the readability of text, such as Coh-Metrix, are based on a series of recent studies on reading difficulty and comprehension. Such studies have found that a reader's level of prior knowledge, world knowledge, and domain knowledge affect their reading of different types of text (Chin et al., 2011; McNamara, Kitsch & Kintsch, 1996; McNamara et al., 1996). Specifically, readers who lack background knowledge tend to have difficulty understanding what they read (McNamara et al., 2014). Another set of studies found that prior knowledge of a topic (e.g. science or biology) explained half the variance in reading comprehension of science texts among students (Ozuru et al., 2009; Tarchi, 2010). A common thread through many of these studies is their emphasis on reading comprehension as a cognitive process. Though none of these studies explicitly defines reading, many are based on a cognitive view of reading as a set of skills or abilities. More than just decoding the meanings of words, however, reading involves higher level processes of meaning making, which the research literature defines as comprehension (Duke & Carlisle, 2011). Making meaning, however, is in part a social process involving socially constructed norms and values. What it means to follow a healthy way of life or health practices, for example, varies among different social groups or communities (Cockerham, 2006). Like meaning making, reading is a social

practice and is situated in social action (Gee, 2001). While acknowledging the cognitive aspects of reading, this mixed methods study frames reading and evaluating health information as a situated social practice in order to further expand theories of reading and readability, specifically with respect to health information.

2.2.2.5 Limitations of Reading Research.

When doing any kind of reading or readability study, researchers must be able to account for how much the measurement tool itself might be interfering with any measure of a participant's knowledge or reading ability (Ozuru et al., 2009). This is especially important when studying reading difficulties and when focusing on participants with a low level of domain knowledge or adults who are inexperienced readers. An experiment that elegantly addressed this issue investigated which features affect the readability of text for adults with intellectual disabilities (Feng et al., 2009). This study challenges the generalizability of some of the earlier claims of readability research based on the reading and comprehension scores of school-aged children and the readability of school texts. It found that readability assessment models trained on children's texts are not always adequate models of text readability for text intended for adults. This puts into question the professional practice of using traditional readability formulas to assess the readability of texts developed for adults.

Much of the research on health literacy includes studies that measure literacy skills or reading abilities (Berkman et al., 2011). These studies implicitly ask how *well* someone reads based on attaining optimal comprehension. Asking this question assumes a gold standard, baseline, or expertise in terms of reading and comprehension. It is not necessarily the case that the process of meaning construction involved in reading can be

characterized this way. Making meaning is not an all or nothing endeavor since the relationship between words and meaning is not one to one. Meaning is social and, consequently, the same text can have different interpretations (Gee, 1992). More recent approaches that look at *the way people read* acknowledge a diversity of social practices and experiences involved in the process of reading. Instead of asking how well someone reads, these studies focus on language use as socially situated. Written and spoken language are linked through social practices involving discourses that guide ways of speaking, believing, evaluating, and interpreting (Gee, 1992; 2001).

An approach to reading that takes into account the way language is socially situated can also help to determine features of written language that account for how easy it is to read for an individual. A study of reading in the workplace and in leisure time found that occupation and social setting are correlated with the use, content, amount, and type of document read (Kirsch & Guthrie, 1984). What people read and how much they read varies not only between work and leisure, but also by type of occupation. Specifically, it reported that professionals in upper management positions spend more time at work reading society and science topics as opposed to technicians, clerical workers, and service workers who tend to do more reference reading. Reading outside of work also varied by type of material: regardless of occupation, participants spent most of their leisure reading time reading prose as opposed to the other categories investigated in the study such as notices, announcements, comics, or labels. These findings suggest that an individual's reading practices have something to do with how difficult or easy it is for them to read a sample of text. It is also likely that an adult's reading practices are affected by her attitudes towards reading and the reading practices of the people around her. If an

adult, for example, spends little time at work or at home reading informational texts or has very little experience reading in general, she might experience difficulty reading consumer health information regardless of it being labeled as "easy to read." The discourses in that document about health, medicine, science, risk, and scientific evidence might be unfamiliar to her and might, therefore, make the document difficult for her to read.

Taking a social approach to reading is underrepresented in readability research, which has remained closely tied to cognitive theories of language use and comprehension. To carry out a study that addresses this gap by investigating the health literacy and information practices of adult new readers, it is important to firmly ground this work on critical methodologies, which interrogate dominant narratives such as what it means to be literate as well as health literate. The following section discusses the use of critical methodologies in this research study, paying special attention to the methods in Phase II.

2.3 Applying a Critical Lens to Health Literacy Practices

This research study is based on a critical methodology that not only frames the research problem itself, but one that also guided the collaborative effort between the researcher and the research participants, including both community members and community-based organizations (Israel, Schulz, Parker, & Becker, 1998). A critical approach to this phenomenon puts into question dominant narratives about access to health information (Dunbar, 2008). According to such dominant narratives, there are those who need easy to read health materials and those who can create and provide access to them. In order to provide better access to health information for those who need it,

professional guidelines stemming from this dominant stance suggest health materials stay within a 7th-8th grade reading level, and they recommend the use of widely available readability formulas including the Flesch-Kincaid Grade Level to assess document readability (U.S. National Library of Medicine, 2016).

Applying a critical lens to this practice reveals the way in which health literacy practices are embedded within a system that reproduces inequities through the use of technologies like automatic readability formulas that make assumptions about the characteristics of adults who experience greater health inequities. Using a formula that assigns a 7th grade reading level to content written for adults is a way of demarcating a group of adults as "others" who are in some ways similar to 7th grade children. Likewise, the practice of giving a literacy test that assigns to an adult a reading grade level of 6th grade, for example, might marginalize adults who are learning to read as someone who is considered to be outside the norm. This research study uses data collection methods that flip this power imbalance. Rather than measuring the reading skills or comprehension of study participants who constitute a vulnerable class in this research, this study instead asked them to make judgments about the usability and readability of consumer health information resources. In this way, this study treated participants as experts on the utility and readability of health information documents. This can have a transformative effect on members of communities affected by poverty, marginalization and other factors that compound health disparities (Tuhiwai Smith, 1999). The following sections discuss in more detail how several theoretical frameworks and recent research findings were used in this study to develop a research design that addresses the objectives of critical research methodologies.

2.4 Usability Studies on the Readability of Health Information

In design theory, usability represents the characteristics of a product or system that users identify as facilitating the efficiency, effectiveness, and satisfaction experienced during their use of it (Marcus, 2011). Because of its focus on ease of use, usefulness, and user satisfaction, a usability study is a reliable way to observe and analyze how people evaluate consumer health information (Bevan, 2009; Nardi, 1996). If language use has something to do with how easy a document is to read, this suggests that a relationship exists between usability and readability. Based on this assumption, this study design includes a usability case study of health information documents by adults who are learning to read that asked them to evaluate consumer health information documents. These usability case studies also asked participants to mark up the documents they evaluated and to participate in an interview in order to collect data about their experiences evaluating the usability and readability of consumer health information.

Usability studies are further expanding readability models by introducing user perspectives that are evidently related to reading, such as affect, use, perceptions, and expectations (Leroy et al., 2013; Sluis, Broek, Glassey, Dijk, & Jong, 2014). As a research method, usability studies are not only well suited to observing sociotechnical practices and yielding rich descriptions of how people use technology, but they are also an ideal method of collecting deep data about different cases representative of a single phenomenon (Nardi, 1996; Rosson & Carroll, 2002). Additionally, usability methods are a viable way to empower vulnerable participants—an important aim of critical methodologies (Tuhiwai Smith, 1999)—by recognizing the agency that adults who are learning to read have to assess the readability of health information documents. Rather than focusing only on participants' skills or abilities, the usability study presented here investigated the readability of health information documents from their point of view.

2.5 Resulting Conceptual Framework

The objective of the research design on which this study is based is to better understand how people evaluate consumer health information and what role readability plays during this evaluation. Using a sociotechnical framework and a theory of everyday life information seeking, this phenomenon is cast as part of a larger health literacy event that is socially embedded in value systems and practices like language use and health management (Leonardi, 2012; Gee, 2015; Savolainen, 1995). These two theoretical frameworks show us that health literacy guidelines, readability formulas, and the resulting consumer health information documents are all products of social practices. The sociotechnical literature stems from an approach to studying science that focuses attention on the tools used to make scientific observations (Leonardi, 2013). According to this theoretical approach, scientific findings are not objective or neutral facts, but rather, they are the product of professional practices (by scientists). And the tools created to observe the natural world are also products of these practices. Hence, what these tools are able to observe and measure, and what data scientists are able to analyze, are the result of these social practices. Reality, or what we know, is shaped by the practice of science and the use of scientific tools. Similarly, the theory of everyday life information seeking departs from a constructivist perspective to show how social factors influence information practices like seeking and evaluating information (Savolainen, 2009). Of particular relevance to the present study is Savolainen's finding that credibility judgments are highly dependent on the topic at hand and on one's own ways of knowing and thinking (2007).

To undertake this project in a manner that is in keeping with the general aims of critical studies (Denzin, Lincoln, Tuhiwai Smith, 2008), and to collect rich observations of participants' own judgments on the usability and readability of consumer health information, this study comprises a series of usability case studies that treat participants as experts with respect to the readability of these documents (Suchman, 1987; Nardi, 1996). The following section presents the methods used in the linguistic analysis of a corpus of consumer health information documents (Phase I) and the methods used in the health information usability study (Phase II).

3. Mixed Methods Research Design

This study is designed as a two-part, sequential mixed methods study. First, a quantitative linguistic analysis (Phase I) assessed the readability of the Health Text Readability Corpus, which includes "easy to read" health information materials, using different computational tools: Coh-Metrix (see Section 3.1.2), developed by a team at the University of Memphis, and a suite of NLP tools developed by ETS for developed to evaluate linguistic features in well-formed text to, respectively, evaluate readability, and generate reading activities to support ELL or struggling reader populations: SourceRater and Language Muse® ® (see Section 3.1.3). These analyses identified linguistic features of health information documents that affect their readability. I then used a statistical clustering method to group the documents in the HTRC into clusters based on linguistic features related to readability, and identified prototypical documents in each cluster. Next, a usability study investigated how adults who are learning to read evaluate these prototypical documents (Phase II). Only three documents were selected to minimize the cognitive demands of this usability task for adults who are learning to read. Additionally,

to minimize researcher bias in the selection of documents, the results of Phase I were used to statistically identify prototypical documents in the health corpus that are likely to be representative of other documents in each of the three clusters. Once identified, these prototypical consumer health information documents were used to gather data about participants' evaluation of the readability of health information. This method of sampling documents for user evaluation maximizes the trustworthiness of the qualitative findings and their transferability to the larger collection of "easy to read" patient education materials. Ultimately, these results will help to determine which features enhance or detract from the readability of consumer health information for adults who are learning to read.

A crucial advantage of the sequential mixed methods approach is that the findings from Phase I (the linguistic analysis) were integrated into the design of Phase II (the usability case study) (Creswell, Klassen, Plano Clark, & Smith, 2011). Specifically, the interview protocol for the usability case studies included questions about features identified during the linguistic analysis (Phase I). This allowed the researcher to gather participants' perspectives on the computationally derived readability measures. The next point of integration in this study occurred during data analysis to expand the definition of readability by including features identified through the usability case studies that were not captured by the analysis in Phase I. Findings from the usability case studies were then used to further explain the findings of the linguistic analysis. By integrating diverse methods in this way, this study ensures the complementarity of the findings from each phase of the study (Johnson, Onwuegbuzie, & Turner, 2007) thereby providing a multifaceted understanding of the relationship between the features identified by

readability assessment tools and the way members of at-risk communities—in this study, adults who are learning to read—evaluate the readability of health information.

The rest of this chapter discusses the methods used in each phase of this study in more detail. It begins with a description of the corpus of health information documents analyzed in Phase I, and continues with a description of the linguistic tools used for this analysis. The chapter then discusses the linguistic features identified by each tool that were used to analyze the readability of these documents, and concludes with a description of the quantitative analysis performed, including the statistical clustering that divided the corpus into three groups, and the identification of the prototypical documents that were then used to gather data from participants during the usability studies conducted in Phase II. The chapter then discusses the methods used in Phase II, including the usability case study design, the use of health information documents to gather participant data, the participants who volunteered for this study, and the methods used to analyze the qualitative data gathered during this phase. The chapter ends with a recapitulation of the integrated analysis of data collected in both phases of this study.

3.1 Phase I: Linguistic Analysis of Consumer Health Information Documents

This section describes the creation of a machine-readable corpus of health information documents, which includes easy-to-read materials (Section 3.1.1), a linguistic analysis of this corpus using a computational tool called CohMetrix (Section 3.1.2), a linguistic analysis of the corpus using natural language processing (NLP) tools developed by by ETS (Section 3.1.3), and a series of statistical analyses (Section 3.1.4). To determine the features of consumer health information resources that affect their readability, such as text cohesion, psycholinguistic factors like how concrete or abstract a

word is, and syntactic complexity, the Coh-Metrix[7] software was used to analyze a corpus of 501 consumer health information documents[8] that are freely available online from a number of information, government and public health agencies.[9] Coh-Metrix identified features of these documents that may affect their readability, including cohesion, narrativity, connectivity, and syntactic complexity. The corpus was also analyzed using tools developed by ETS based on natural language processing methods, and these results helped to support the trustworthiness of the linguistic analysis. A subsequent statistical analysis of the linguistic features of these documents was then conducted to identify relationships between these features and to understand their effects on the documents' readability. Next, the documents in this health corpus were classified into statistically significant groups using a k-means cluster analysis. Prototypical documents from each cluster were selected and used as data collection tools during Phase II of this study (Tan, Steinbach, & Kumar, 2006). In addition to describing the Health Text Readability Corpus and the linguistic methods used to analyze it, this section also presents the results of the cluster analysis, including the selection of prototypical documents that were used as data collection tools in Phase II of the study.

3.1.1 Creating the Health Text Readability Corpus.

This section describes the methods used to create a corpus of consumer health information documents intended to help adults manage their health or the health of family members. Because this research study is solely interested in characteristics of health information resources, I collected a non-probabilistic, purposive sample (Krippendorff,

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[7] Coh-Metrix tool is available at http://cohmetrix.com/
[8] Sometimes also called patient education materials.
[9] See Appendix for list of sources

2004) of consumer health information documents. The collection includes health information documents that are in "Easy to Read" collections (N=294) as well as documents not found in these collections (N=207). To create the corpus, I first selected all pdf documents available through Medline Plus[10], including those that were labeled Easy-to-Read[11] as well as those not included in the Easy-to-Read collection. Then, I conducted a Google search for "patient education materials" and collected consumer health information pdf documents freely available online from different health organization such as the CDC, NIH, American Heart Association, and American Diabetes Association. Only pdf documents were included in the corpus since adults who have low health literacy scores tend to rely on print-based media rather than on digital resources as a source of health information (U.S. Department of Health and Human Services, 2008). No websites, worksheets, posters, infographics, or handouts in table or chart format were included in the corpus.

In total, 501 consumer health information documents were collected. Both, "Easy to Read" documents and those not classified this way were included in the corpus in order to capture as much linguistic variability as possible, which is important for cluster analysis (Tan, Steinbach & Kumar, 2006). This collection of consumer health information documents is referred to as the Health Text Readability Corpus (HTRC). The collected pdf documents were then converted into machine-readable txt files for linguistic analysis. The final sample consists of 496 health information documents after removing 5 documents that did not convert properly from pdf to txt format, which was necessary for analysis. The following sub-section describes the methods of linguistic analysis

[10] https://medlineplus.gov/healthtopics.html
[11] https://medlineplus.gov/all_easytoread.html

conducted on this corpus using both CohMetrix as well as the ETS tools, and the results of the statistical analyses used to classify the documents.

3.1.2 Coh-Metrix Tool.

Coh-Metrix[12] is an automatic text evaluation tool developed at the University of Memphis by a research team led by Danielle McNamara and Arthur Graesser between 2012-2014. Coh-Metrix was used in this study to measure 108 features associated with text easability[13] and text cohesion[14] for the documents in the HTRC such as type-token ratios, adjacent noun overlap, and the use of cohesive cues such as the presence of connectives in the texts (McNamara et al., 2014). Coh-Metrix is designed to capture more sophisticated features, such as argument and concept overlap, than the traditional readability formulas do (Benjamin, 2012), and has been extensively validated as a tool that is able to identify variation between high- and low-cohesion texts, as well as variations between spoken and written speech, and between authors or writing styles (Louwerse et al., 2004; McCarthy et al., 2006; McNamara et al., 2006). It uses computational techniques such as part-of-speech tagging and latent semantic analysis, among others, to produce quantitative indices representing different linguistic features and discourse structures of text. These indices were used as the linguistic variables of interest in the statistical analysis conducted on the documents in the HTRC to identify what variables besides vocabulary and sentence length are likely to affect the readability of health information.

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[12] Coh-Metrix tool is available at http://cohmetrix.com/

[13] Easability are sources of ease or difficulty in a text. (McNamara, et al., 2014)

[14] Cohesion is a measure of how well connected are different parts of the text. (Greaser, et al., 2003; McNamara, et al., 2014).

The research that led to the development of Coh-Metrix found that readers with less prior domain knowledge benefit from cohesive texts (McNamara et al., 2014). In cohesive texts, concepts are deliberated repeated, which supports readers as they make inferences when reading. By using specific discourse phrases or deliberately repeating concepts, cohesiveness prevents ambiguity, which can be problematic for inexperienced readers. Text in which important concepts are repeated across sentences is better able to support readers that lack background knowledge. The researchers also point out that the use of a series of short sentences can sometimes be less cohesive because connective concepts are implicit rather than explicit.

In addition to characteristics of the text itself, related research has also found that reading skill affects the way people make inferences when reading (as opposed to cohesion, which is a characteristic of the text that's being read). Individuals for whom reading is a relatively new practice, or who have low domain knowledge, tend to ignore conceptual gaps rather than make the appropriate inferences. This failure to make correct inferences is a sign of lack of comprehension (McNamara et al., 2014, p. 22). Research suggests that cohesive text includes a set of cues that allow the reader to form a coherent understanding of what he or she is reading. Cohesive cues such as connectives are explicitly present in the text as specific words and phrases (e.g. "until," "although," "and," "or," "but," "however," "on the other hand," etc.). This means they can be automatically identified with computational linguistic methods and analyzed.

Unlike traditional readability formulas like the Flesch-Kincaid Grade Level, CohMetrix does not suggest a reading grade level for text. Instead, it provides individual scores for each of the features extracted from the documents. An analysis of this output of

feature scores helps to provide a more nuanced understanding of how these features contribute to the ease or difficulty of reading the documents based on syntax, cohesion, and semantics. The following section discusses the specific linguistic features identified by CohMetrix which were used to analyze the documents in the HTRC.

3.1.2.1 Coh-Metrix Easability Measures.

Though they can be useful in identifying text that might be difficult to read for certain readers, traditional readability formulas such as the Flesch-Kincaid Grade Level formula do not reveal *which* linguistic features of a text account for reading ease or difficulty. This is because these traditional formulas are based on only two features: word length and sentence length. To address this limitation, the researchers who developed Coh-Metrix set out to identify those features of text that actually account for its readability (McNamara, Graesser, McCarthy & Cai, 2014). These "easability" measures together account for 67.3% of the variance in text reading ease (p. 86).

Table 3.1.2.1.a CohMetrix Easability Features

Feature*	**Description**
Narrativity	Corresponds with features of oral, everyday language and, as such, is associated with world knowledge and word familiarity. It also tends to characterize texts that tell a story.
Syntactic Simplicity	Indicates familiar, less complex and more familiar syntactic structures that are easier to process.
Word Concreteness	Indicates the presence of words that are easy to visualize and are therefore less abstract. Abstract, less concrete words, make text more difficult to understand. For example, the word "milk" is more concrete than the word "hope."

Referential Cohesion	Measures the amount of concept overlap between sentences and throughout the text, which helps readers to make inferences not present in the text. Referential cohesion is crucial for readers with low domain knowledge (McNamara et al., 2014; Ozuru, Briner, Best, & McNamara, 2010).
Deep Cohesion	Indicates the presence of causal and intentional connectives in the text that represent causal and logical relationships. As with referential cohesion, texts that score high on this measure help readers form inferences based on what they read.
Connectivity	Indicates the presence of adversative, additive, and comparative connectives that reflect relationships in the text. Examples are "and," "or," "also," "but."

The table above presents six easability meausures[15] identified by CohMetrix that affect the ease or difficulty of reading a text. To derive these easability measures, Coh-Metrix researchers conducted a principal component analysis (p. 78) which identified the following easability factors: narrativity, syntactic simplicity, word concreteness, referential cohesion, deep cohesion, verb cohesion, connectivity, and temporality. According to the principal component analysis conducted by the CohMetrix researchers, the first five of these—narrativity, syntactic simplicity, word concreteness, referential cohesion, deep cohesion— account for 54% variance (p. 86). For this reason, they are the main focus of the linguistic analysis conducted for the present study's analysis of documents in the Health Text Readability Corpus.

Connectivity is also included in my analysis as a way to measure whether and to what extent the presence or absence of connective words or phrases in the health corpus might affect the readability of the documents. Medline's guidelines for writing easy-to-

[15] The full index is available online at http://cohmetrix.com/documentation_indices.html

read health materials recommend the use of bulleted lists, and many documents in the health corpus include bulleted lists. Bulleted lists often omit connective words such as "and," "or," "because," "however," "although," "also," and "but." A previous exploratory pilot study showed that adult developing readers find such lists problematic because they have trouble parsing them (Morales, 2017). This might be due to the absence of connectives that help readers make inferences between sentences and ideas. Connectives help link together different parts of the text and, thereby help readers make inferences (Graesser, McNamara, Louwerse, 2003). Because of this function, they are considered cohesive cues, and their presence or absence is an indication of the text's cohesion (McNamara, et al., 2014). It is important for this study, then, to also analyze the connectivity of these documents. Out of the 108 total features that CohMetrix measures, the present study only focuses on the easability features listed above since they strongly account for a document's readability.

3.1.2.2 Word Information Features.

In addition to the easability measures discussed in the prior section, CohMetrix also provides an analysis of word information for the health information documents in the HTRC that is more sophisticated than the Flesch-Kincaid Grade Level formula in that it goes beyond word length and frequency. Word information refers to a set of semantic features related to the way in which readers mentally process words and word meaning. Examples of such features are word familiarity, concreteness, imageability, meaningfulness, and hypernymy. The table below provides a more detailed definition of the lexical features identified by CohMetrix that were used to analyze the HTRC (McNamara et al., 2014).

Table 3.1.2.2.a Word Information Features Measured by CohMetrix

Feature	Description
Familiarity	This is a measure of how familiar a word seems to an adult. Scores range from 100-700 with the maximum entry of 657, a mean of 488 and a standard deviation of 99. Sentences with familiar words are easier to read.
Concreteness	This measures the level of abstractness in a word. Concrete words represent things you can hear, taste, or touch. The range of scores is 100-700.
Imageability	This feature refers to the ease with which a reader can construct a mental image of a word. For example, 'ambulance' has a higher imageability score than 'ache.' The range of scores is 100-700.
Meaningfulness	Meaningful words are highly associated with other words. Words that are weakly associated with other words might contribute to low readability. There is a relationship between concreteness and meaningfulness. Scores range from 100 to 700 with a minimum of 127, a maximum of 667, a mean of 415, and a standard deviation of 78.
Hypernymy	This feature represents the level of semantic specificity of a word. For instance, 'chair' is more specific than 'furniture.' The higher the hypernymy count, the more specific the term.

CohMetrix provides a measure of these psycholinguistic features in its output because they can affect the readability of text (McNamara et al., 2014). For example, the concreteness or familiarity of a word can make text easier to read. CohMetrix derives the measures for the features listed in the table above from two sources. It uses the MRC

Psycholinguistic Database[16] to derive familiarity, concreteness, imageability, and meaningfulness scores. To derive scores for hypernymy, CohMetrix uses the WordNet[17] lexical database.

3.1.2.2 Limitations of Coh-Metrix.

Though Coh-Metrix goes far beyond the Flesch Kincaid Grade Level formula in the features that it identifies and has been extensively validated as a tool that is able to identify variation between high- and low-cohesion texts (Louwerse et al., 2004; McCarthy et al., 2006; McNamara et al., 2006), its training corpus is an important limitation for the present study (Benjamin, 2012). A training corpus is the collection of texts or documents that a computational linguistic tool uses to learn how to score features in order to accurately score new, unseen texts. CohMetrix's training corpus is a collection of K-12 academic texts, which is not at all representative of health information documents which are developed for adults. This limitation is partly offset by the size of the training corpus (32,520 texts) and its variability in terms of subject matter or domain, as it includes science, history, language arts, as well as business, health, home economics, and industrial arts (McNamara et al., 2014). Additionally, CohMetrix continues to add a variety of texts to its training corpus in order to continually improve the validity of its output. When analyzing the Coh-Metrix output, it is important to keep in mind that variable scores are relative to texts in its training corpus. Because of this inherent limitation (which is a limitation to any corpus since it is impossible to include all available documents in a corpus), I used another set of tools developed by Educational Testing Service to analyze the HTRC.

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[16] http://websites.psychology.uwa.edu.au/school/MRCDatabase/uwa_mrc.htm
[17] https://wordnet.princeton.edu/

3.1.3 ETS' NLP Analysis Tools.

In order to enhance the linguistic analysis facilitated by CohMetrix, and to minimize the effect of its limitations, the HTRC was also analyzed by a set of text analysis tools developed by Educational Testing Service (ETS), including Language Muse® (Madnani, Burstein, Sabatini, Biggers, & Andreyev, 2016) which identifies features related to syntax and discourse relations and SourceRater which assesses text complexity by analyzing a number of features that contribute to this measure of reading difficulty (Napolitano, Sheehan, & Mundkowsky, 2015). Though many of these features overlap with those identified by Coh-Metrix, the ETS tools identify a number of additional features of particular interest to the present study; these include text complexity, organizational features, and specific discourse relations. Documents in the HTRC corpus were prepared for analysis. This involved converting pdf files to .txt files. A number of documents that the ETS tools were not able to analyze due to their format were removed from the corpus (N_{ETS}=430)[18]. The following sections discuss in more detail the linguistic features measured by ETS' SourceRater and Language Muse® tools that were used to analyze the HTRC.

3.1.3.1 SourceRater Features.

SourceRater is a tool developed by ETS that provides a measure of text complexity (Napolitano, Sheehan, & Mundkowsky, 2015). It has been validated as a tool that is highly correlated with human judgments of text complexity, and can reliably predict differences between different genres: informational, literary, and mixed genre texts (Sheehan, 2016). What makes SourceRater unique is that it not only provides a

[18] Compare to the CohMetrix analysis of N=496 documents in the HTRC.

holistic complexity score for the document, but it also provides a more granular view of those features that contribute to this complexity score. Another unique aspect of this tool is that it provides a correspondence between the level of complexity in a text and acceptable ranges of complexity for grades 2-12 based on the Common Core standards, and this has been externally validated (Napolitano, Sheehan, & Mundkowsky, 2015). The overall complexity is scored from 0-2000, and is a composite score based on contributing features, which are scored from 0-100 (the higher the score, the more complex the text is). The following table summarizes the complexity features computed by SourceRater in this analysis.

Table 3.1.3.1.a SourceRater Complexity Features.

Feature*	**Description**
Academic Vocabulary	Words more commonly found in academic writing rather than spoken language or fiction.
Argumentation	Presence of words and phrases commonly found in informational text such as “although,” “however,” “as a result,” “for this reason,” etc.
Lexical Cohesion	A measure of the number of overlapping lemmas between pairs of sentences in each paragraph.
Concreteness and Imageability	Describes how difficult it is to imagine the word.
Conversational Style	Reflects the use of words and style associated with spoken language.
Narrativity	Reflects the amount of text found within quotation marks, referential pronouns, and use of past-tense verbs, all of which are primary features of written narratives, as opposed to spoken discourse.

Syntactic Complexity	Measures the complexity of sentence structure in a text.
Word Unfamiliarity	A measure of rare words in a text based on word frequency.
Final Complexity	Overall complexity score for the text based on the scores for contributing features listed above.

*All scored from 0-100, where 100 indicates maximum complexity.

The features in the table above contribute to the final complexity score include measures of syntax, vocabulary difficulty, and organizational features such as argumentation and narrativity. More specifically, they represent the complexity of sentences in the documents, the documents' use of academic and rare words, the use of concrete words, the use of words associated with spoken language, the presence of words and phrases associated with informational text such as "although" and "for example," and a measure of how closely the text conforms to linguistic features common of written texts.

3.1.3.2 Language Muse® Features.

The health information documents in the HTRC were also analyzed using a tool developed for educators by ETS called Language Muse®, which relies on NLP techniques to identify features having to do with syntactic structures (structure of sentences) and discourse relations (which represent logical relationships such as cause and effect) (Madnani, Burstein, Sabatini, Biggers & Andreyev, 2016). The Language Muse® tool is intended for use primarily by educators. The tool is intended for classroom use with English language learners, and is designed to generate language-based activities on K-12 classroom texts. For purpose of this study, the back-end NLP features used to generate the activities were re-purposed, and were generated on the HTRC corpus.

Table 3.1.3.2.a. ETS Language Muse® Features

Feature	Description
Complex Clauses	Complex noun phrases or verb phrases.
Cause and Effect	Terms representing a cause-effect relation between text segments.
Contrast	Terms that represent a comparison or contrast between text segments.
Evidence and Details	Terms that represent specific evidence or details in a text segment.
Opinion and Inferences	Terms that indicate opinions and inferences between text segments.
Persuasion	Terms that represent persuasion in a text segment.
Summary	Terms representing a summary of ideas or concepts in a text.

The table above presents a summary of the features identified by Language Muse® that were used in the analysis of health documents in the HTRC. The Language Muse® output used in the analysis of the HTRC generates raw counts of the presence of these features in the text. The results of this analysis were integrated with the Coh-Metrix analysis in order to provide a deeper understanding of the relationships between different linguistic features and their effects on the documents' readability. Language Muse® was used specifically to identify discourse structures present in informational texts (and that are likely to be present in health information documents) such as contrast, evidence and details, cause and effect, and persuasion. The use of the three distinct tools to identify linguistic features in the HTRC provides a more broad and varied set of analyses with which to work.

3.1.4 Quantitative Analysis of HTRC based on Coh-Metrix Easability Features.

A series of statistical analyses was performed on the documents in the HTRC using the CohMetrix output of easability measures listed in Section 3.1.2.1 to investigate the relationship between readability and different linguistic features. More specifically, this includes a quantitative linguistic analysis using features identified by Coh-Metrix that goes beyond vocabulary frequency and sentence length, the only features used in traditional readability formulas such as the Flesch-Kincaid Grade Level formula. First, I conducted an exploratory descriptive analysis of the six easability measures of interest. Next, I performed a k-means cluster analysis to classify the documents in the corpus into statistically meaningful categories based on the variables of interest listed in Table 3.1.2.1.a by a subsequent discriminant analysis based on these same variables. The resulting clustering model facilitated the identification and selection of a prototypical health information document from each cluster, which were then used to collect participant data in the subsequent qualitative phase of this mixed methods work. The clustering model also allows for the prediction of cluster membership for new texts. Finally, the discriminant analysis confirmed the goodness of fit of the clustering model for the documents in the health corpus. The following section discusses in more detail the classification of the documents into clusters, how prototypical documents were sampled for Phase II, and describes the prototypical documents selected.

3.1.4.1 Sampling Health Information Documents for Participant Evaluations.

To sample documents for participants to evaluate during Phase II of this study, a k-means cluster analysis classified the documents in the health corpus into three distinct

groups representing varying degrees of reading difficulty based on the six easability measures of interest listed in Section 3.1.2.1. Most of the documents in the health corpus belong to Clusters 3 (N_3=228) and 2 (N_2=178), while 59 documents (N_1) were assigned to Cluster 1. Because k-means are sensitive to outliers in the data, these were removed in order to make the final clusters more reliable (Hautamäki, Cherednichenko, Kärkkäinen, Kinnunen, & Fränti, 2005). After outliers were removed to prepare the HTRC for the cluster analysis, the new total number of documents is 465.

Table 3.1.4.1.a. Final Cluster Centers, N=465

Easability Feature	Cluster 1	Cluster 2	Cluster 3
Narrativity	-.6259	**-.5868**	-.7918
Syntactic Simplicity	.6974	**.8271**	.5911
Word Concreteness	**1.583**	.5949	.6814
Referential Cohesion	-.5934	-.2099	**.0592**
Deep Cohesion	.9842	**1.076**	.4290
Connectivity	-4.939	-3.569	**-2.329**

The table above shows the final cluster centers for the six variables for each of the three clusters. The easability feature scores used in this clustering model were z-scores provided by the CohMetrix output. These are standardized scores that represent the number of standard deviations a raw data point is from the mean. Negative z-scores represent scores that are less than the mean. Figures in black bold font indicate highest scores while figures in red indicate the lowest scores among the clusters. According to

this table, documents in Cluster 1 use more **concrete words** than documents in the other 2 clusters. On the other hand, Cluster 1 documents have the lowest **referential cohesion** and **connectivity** scores, indicating the low presence of adversative, additive, and comparative connectives such as "and," "or," "but" in these documents. Documents in Cluster 2 (N=178) have the lowest **word concreteness** scores, but have the highest **narrativity**, **syntactic simplicity** and **deep cohesion** scores out of the three clusters. Documents in this cluster are characterized by simpler sentences, are written in a style that more closely resembles spoken language, and explicitly represent causal and logical relationships, the presence of which helps readers make logical inferences when reading. Documents in Cluster 3, meanwhile, have the lowest **narrativity**, **syntactic simplicity**, and **deep cohesion** scores of all three clusters. Documents in this cluster are written in a less conversational style, have more complex sentence structure, and lack the presence of connective words or phrases that represent causal and logical relationships. Important to note for this study, all three clusters scored quite low on the **connectivity** measure. The low use of these types of **connectives** may explain why some participants negatively evaluated these documents because of gaps in cohesion and problems interpreting what they read, (see Section 4.5). Based on this clustering analysis, it is reasonable to hypothesize the following order of reading difficulty: Cluster 2 (easiest), Cluster 1 (moderate), Cluster 3 (more difficult). Considering the membership of documents in each cluster, this model suggests that most documents in this corpus are members of the most difficult to read cluster, Cluster 3.

A discriminant analysis was subsequently conducted to determine how well the six easability measures of interest could predict cluster membership for the documents in the

HTRC. The three groups being compared in the discriminant analysis were Cluster 1 (N=59), Cluster 2 (N=178), and Cluster 3 (N=228). Because there were three clusters, two discriminant functions were created. The canonical correlation for Discriminant Function 1 was .863, indicating it is highly related to group membership. The test for the combined predictive value of Discriminant Functions 1 and 2 was statistically significant: X2 (12) = 726.351, $p < .001$. The canonical correlation for Discriminant Function 2 was .442, indicating it is also highly related to group membership, though not as highly as Function 1. The Wilks' Lambda was significant, $\lambda = .804.$, X2 (5) = 100.037, $p < .001$, partial $\eta 2 = .07$, indicating a larger than typical effect size. The model using the six easability measures discussed above was able to significantly discriminate between clusters.

According to the Standardized Canonical Discriminant Function Coefficients table (below), **connectivity** is weighted most heavily to maximize the discrimination between clusters for standardized Discriminant Function 1, and **deep cohesion** is weighted most heavily to maximize discrimination between clusters for standardized Discriminant Function 2.

Table 3.1.4.1.b. Standardized Canonical Discriminant Function Coefficients

Easability Feature	Function 1	Function 2
Narrativity	-.260	-.099
Syntactic Simplicity	.009	.163
Word Concreteness	-.257	-.765
Referential Cohesion	.384	.320

Deep Cohesion	-.280	.588
Connectivity	.896	-.040

Overall, the discriminant analysis using the six easability measures listed above correctly classified 96.1% of documents into the 3 clusters according to the statistical method used.

Table 3.1.4.1.c. Classification Results

		Predicted Group Membership			
	Cluster	1	2	3	Total
Count	1	57	2	0	59
	2	3	169	6	178
	3	0	7	221	228
%	1	96.6	3.4	.0	100
	2	1.7	94.9	3.4	100
	3	.0	3.1	96.9	100
a. 96.1% of original grouped cases correctly classified					

A discriminant function that primarily represented information on connectivity scores predicted cluster membership at levels much higher than chance. Important to note is that the percent of documents that are correctly classified into each cluster does not vary greatly, indicating that the model based on these six easability measures is able to significantly discriminate between the three clusters.

3.1.4.1.1 Identifying Prototypical Health Information Documents.

Once the documents in the HTRC were grouped into k-means clusters, it was possible to identify prototypical documents from each cluster that were subsequently

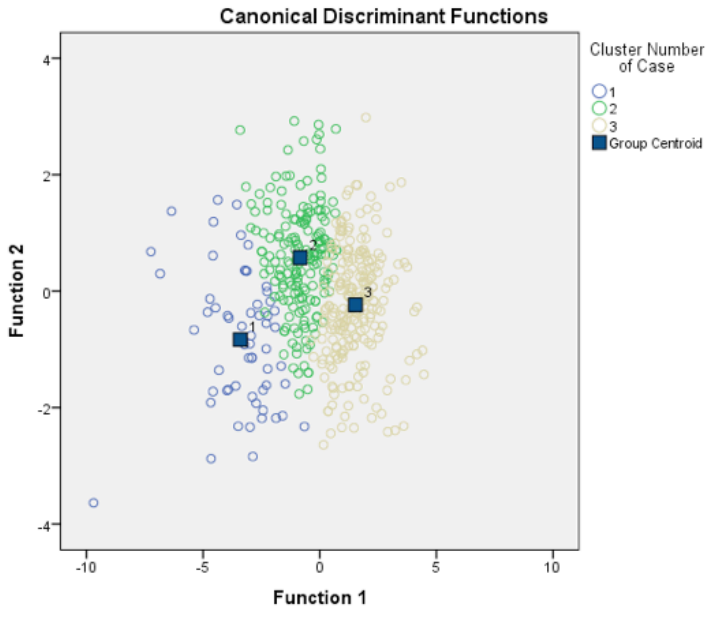
used as data collection tools in the usability case studies to elicit participant evaluations (Phase II).

Table 3.1.4.2.a. Functions at Group Centroids

Cluster	Function 1	Function 2
1	-3.405	-.833
2	-.834	.576
3	1.533	-.234
Unstandardized canonical discriminant functions evaluated at group means.		

The table above shows the cluster centroids, or group means, for each document cluster. Prototypical documents from each cluster were selected by identifying those that lie closest to each cluster centroid. This method of selecting documents for participants to evaluate during the usability studies was used in order to minimize researcher bias in the selection of data collection tools, thereby maximizing the trustworthiness of this mixed methods work.

Graph 4.1.4.2.a. Group Centroids



Graph 4.1.4.2.a. above is a visual representation of the documents in each cluster, and locates the centroid for each cluster. This graph shows three distinct clusters with centroids that are far away from each other, and far away from cluster boundaries. Documents that lie close to these centroids are not only representative of other documents that lie nearby, but are also sufficiently distinct from the documents that lie near the other two cluster centers. This is confirming evidence that the prototypical document from Cluster 3 should be more difficult to read than the other prototypical documents, while the Cluster 2 prototype should be the easiest to read.

3.1.4.2 Prototypical Health Information Documents.

The k-means cluster analysis identified three prototypical health information documents from each cluster that were used to elicit participant data during Phase II of this study.[19] These documents varied in length, topic, and reading grade level.

Table 3.1.4.2.a. Prototypical Health Information Documents

Cluster	Document Title	Source Agency	Page Count	Word Count	Flesh Kincaid Grade Level
1	Managing Chemotherapy Side Effects: Anemia	National Cancer Institute	2	405	8th
2	What I Need to Know About Irritable Bowel Syndrome	National Institute of Diabetes and Digestive and Kidney Diseases	26	3033	12th
3	What I Need to Know About Hepatitis A	National Institute of Diabetes and Digestive and Kidney Diseases	15	2015	11th-12th

The prototypical documents used for data collection with participants are listed in table 3.1.4.2.a. above. The three prototypical documents are all part of Medline Plus' Easy to

[19] PDFs of these documents are included in the appendix.

Read health information collection[20]. Despite being part of this easy-to-read collection, only one of these documents scores at the reading grade level recommended by the Medline health literacy guidelines (U.S. National Library of Medicine, 2016). The Cluster 1 prototype has an 8th grade reading level, according to the Flesch Kincaid Reading Grade Level formula, while the other two prototypical documents score at a 12th grade reading level. The prototypical documents from clusters 2 and 3 are also much longer than the prototypical document from cluster 1.

Perhaps due to their length and their high reading grade level scores, these two documents include several tools intended to help the reader to use them effectively such as a table of contents and a pronunciation guide. Words that a reader can find in the pronunciation guide are highlighted in bold type font throughout the documents. All three prototypical documents include bulleted lists, section headers presented as questions, and illustrations such as pictures of people or anatomical diagrams. The Cluster 1 prototype uses stock photographs of people doing a variety of activites, while the prototypical documents from Clusters 2 and 3 use line drawings and diagrams of different organs. Another key difference between the documents has to do with their content. The prototypical document from Cluster 1 includes a brief definition of the health topic—one small paragraph of three sentences total. The rest of the document provides advice for managing symptoms, information about diet and nutrition, and information on when to call a medical professional for help. The longer documents from Clusters 2 and 3 include much more detailed information on the health topic than provided by Prototype 1 and

[20] This collection can be found at https://medlineplus.gov/all_easytoread.html

include definitions of organs involved, information on risk factors, transmission, diagnosis, and treatment, as well as information on clinical trials.

To prepare them for the usability sessions with participants, these documents were printed in color on white paper to ensure that highlights, diagrams, and pictures appeared as originally designed, and were stapled. Each participant received one stapled color copy of each of the three prototypical documents to read, evaluate, and mark up during the user evaluation session conducted in Phase II of this study, discussed in Section 3.2.

3.2 Phase II: User Evaluations of Consumer Health Information

To investigate how adults who are learning to read evaluate consumer health information documents, Phase II of this study engaged participants in a usability case study. Usability testing is a method of user interface and product design in which a designer observes an individual's interaction with a design prototype[21] or finished product in order to identify obstacles encountered when using the product to accomplish a specified task (Lewis, 2006). Based on standard usability testing methods (Lewis, 2006), the usability sessions designed for this study included three tasks: (1) a readability evaluation task of sample documents from the HTRC during which participants marked up parts of the prototypical documents they found hard or easy to understand, (2) a follow-up semi-structured interview, and (3) a short participant questionnaire.

The research protocol[22] for Phase II of this study was approved by the Institutional Review Board, and funds for participant compensation were provided by the Rutgers University School of Communication & Information. The rest of this section describes in

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[21] Prototype here does not refer to a statistical prototype as discussed in Section 3.1.4.3. A design prototype refers to a simulation of a final product.

[22] See Appendix X.

more detail the methods of data collection and analysis that were part of this second phase.

3.2.1 Usability Case Study Design.

The usability case study method used in this research design allows the researcher to collect rich observational data about the particulars of the phenomenon of interest, which in this study comprises a participant's evaluation of a consumer health information document (Baxter and Jack, 2008; Hammersley, Gomm & Foster, 2000; Lewis, 2006). Usability testing is a method of user interface and product design in which a designer observes an individual's interaction with a prototype or finished product in order to identify obstacles encountered when using the product to accomplish a specified task (Lewis, 2006). Each usability test case constitutes an individual unit of analysis and consists of a participant's (1) evaluation of a consumer health information document, (2) responses to a semi-structured, open-ended interview, and (3) responses to a short survey questionnaire.[23] Collecting data on a case-by-case basis facilitates the discovery of variability in the features that contribute to the ease or difficulty of reading health information documents as assessed by individual adults who are learning to read. It is important to capture this variability of experience to critically interpret the effectiveness of health information guidelines that make recommendations that affect these adults. Each case yielded rich observational data about the way adults who are learning to read evaluate consumer health information, a perspective that is lacking in health literacy research.

[23] The protocol for the usability sessions is included in the appendix.

3.2.2 Usability Data Collection Methods.

The usability sessions with participants took place at the Brooklyn Public Library's Adult Literacy Center, where all participants receive free educational support and services (Section 3.2.3 discusses this in more detail). This made it easier for participants since it did not interfere with work or other responsibilities, and it did not require them to make additional travel arrangements. Both of these can be hardships to adults who are members of this community since they very often have limited financial means. Since adults who are learning to read rely more on print-based media rather than on digital resources as a source of health information, this study focuses exclusively on printed consumer health information documents such as brochures and fact sheets (U.S. Department of Health and Human Services, 2008). This was indeed the case for participants in this study, according to their responses to a post-task survey (see Section 3.2.3.3). Other considerations were the study participants' level of comfort using digital technology to make annotations, and the need to minimize the cognitive load of the task. Adults who participate in the Brooklyn Public Library's Adult Learning Center have very limited experience using computers and many are learning basic computer skills such as turning on the computer, opening a file, and saving their work. In order to avoid overcomplicating the task for participants and to make sure their challenges using digital technology did not affect the results of the evaluation task itself, this study design included only print-based materials for participants to read, evaluate, and mark up. It was also important for this study, which is based on critical methodologies, to treat participants as experts of their own lived experience and to allow for them to have control over the way they deliver responses. Giving them the authority to mark up documents

helped to promote a sense of self-efficacy and empowerment for the participants in this study who are so often marginalized.

Because the goal of usability testing is not to test participants, but rather to evaluate a product in order to improve its design and functionality (Lewis, 2006), this is a sound method for collecting participant data during the consumer health information evaluation task and conforms to the guiding principles of work based on critical methodologies (See Section 2.3). An important aim of this phase of the study is to minimize the participants' perception of being a test subject. The evaluation task required participants to mark up the health information documents with colored pens. Participants were verbally instructed to use the green pen to mark "good," "helpful," or "useful" document features, and to use the red pen to mark "bad," "confusing," or "not useful" document features. They were also given a task instruction sheet with written instructions of the task. After explaining the informed consent process, explaining the study, and giving instructions for the task, I remained nearby in order to take observation notes during the tasks and to be available in case participants needed assistance. For instance, some participants requested that I read to them the survey questionnaire questions or take down their responses. Others would ask me questions during the task itself, such as to verify if they were reading a word correctly. Since this last example is an instance related to readability and literacy, I did not intervene by giving affirmation or correcting participants. Instead, I took note of these instances of reading challenges while asking that participants do their best to guess what an unknown word might be in a sentence. The instructions as well as the complete study protocol are available in Appendix A.

To further enrich the data collected during the evaluation task, the research study also included a pre-task interview question to gauge participants' knowledge of the health topics presented in each of the documents, a semi-structured, open-ended, follow-up interview, and a short demographic survey questionnaire which was conducted immediately after completing the task. These pre- and post-task methods allow for data verification by participants themselves. This form of member checking is a common technique in qualitative work used to enhance the trustworthiness of the analysis and subsequent findings (Lincoln and Guba, 1985). The interview and then the survey questionnaire were administered immediately following the evaluation task in order to optimize the trustworthiness of the findings. During the follow-up interview, I asked each participant to walk me through the documents, pointing out features of each document the participant found useful or not, and explaining what made these features helpful or not during the evaluation. Appendix D shows documents marked up during the usability sessions by three different participants.

3.2.2.1 Documents.

The prototypical documents from the Health Text Readability Corpus were statistically identified and selected for the user evaluations with study participants.[24] Because the topic of the document was not a variable used in document clustering, documents selected as data collection tools were not selected according to health topic. In the interest of brevity, these documents will be subsequently referred to as Anemia document, IBS document, and Hepatitis A document[25]. Participants in this study were

[24] Section 3.1.4.2 Discusses the method of statistically selecting prototypical documents from the corpus for use in the usability studies with participants.
[25] See Appendix.

asked to evaluate the documents, paying special attention to how easy to read they find them to be. The order in which participants read and evaluated the documents varied by participant to minimize any effect that reading the documents in a certain order might introduce into the data. During the usability case studies, participants used colored pens to mark up aspects of these documents they determined as pertaining to the documents' usability and readability (see Section 3.2.2).

3.2.3 Participants.

This study engaged 20 adults who were all students at the Brooklyn Public Library Adult Learning Center[26] where they received free adult literacy education at the time of this study. Most students at the Adult Learning Center are employed and are taking literacy classes in order to advance at work or get a better paying job. Insofar as they are actively engaged in a literacy program and are proactive in improving their own reading and writing, these adults are highly motivated readers. Though many cannot yet take or even study for the High School Equivalency exam because of their level of reading and writing proficiency (for example, the exam is timed, and these readers might run out of time due to their reading speed), the usability data showed that participants were, on the whole, adept at managing their health in terms of their ability to identify good, useful information—an important goal of health literacy—and they had a layperson's grasp of practices associated with maintaining a healthy lifestyle (e.g. maintaining a good diet, avoiding fatty or processed foods, and incorporating exercise and physical activity into their daily life). The rest of this section discusses how participants were recruited, the special ethical considerations involved in their participation, and ends with a review of

[26] https://www.bklynlibrary.org/locations/central-learning-center

participant characteristics, including demographic information, they volunteered by filling out a survey questionnaire during the usability case study sessions.

3.2.3.1 Participant Recruitment.

The study protocol called for recruiting 20 individuals. Making provisions to recruit 20 participants ensures the collection of rich data for within-case and across-case analysis, even if not all 20 recruited participants are able to yield usable data. In fact, one participant in this study, Lois[27], was not able to finish the entire usability study, though she did fill out the survey questionnaire and answered the pre-task interview question. This participant stayed to read the materials, but did not stay for the post-task interview. Established qualitative sampling methods stress that the goal of sampling is to provide as much detail, richness, variation and information on a phenomenon as possible as a way to establish credibility and transferability, rather than to ensure generalizability (Lincoln and Guba, 1985). Qualitative studies sample until they reach saturation to maximize the richness of the data collected (Charmaz, 2014; Lincoln and Guba, 1985). Consequently, it is often difficult to anticipate the sample size that will yield saturation (Charmaz, 2014). Research that uses the case study method tends to analyze a small number of cases—from a single case to a handful—in order to gather rich data and conduct deep analysis on select or special cases (Creswell, 2013). That said, however, a novice researcher might need to see more cases than a more experienced investigator in order to be confident that theoretical saturation has been reached (Charmaz, 2014). Bounding the recruitment process of this proposed project at 20 participants aimed to maximize the likelihood that

[27] This is a pseudonym used to protect the anonymity of participants.

enough rich case data would be collected to allow for theoretical saturation at both the within-case as well as the across-case analytical level.

Since this study focuses on the way adults who are learning to read evaluate so-called “easy to read” consumer health information documents, this study undertook a purposive sampling of participants (Teddlie & Yu, 2007). The key criterion used to sample potential participants was reading expertise, and this was determined by their enrollment in literacy classes at the Brooklyn Public Library’s Adult Learning Center. To maximize the variability of experiences among the group, which is important for qualitative work, students with different levels of reading experience were recruited for participation in this study (Lincoln and Guba, 1985). Besides reading experience, additional participant characteristics of interest to this study include experience with consumer health information, languages spoken, education, and reading practices.

With IRB approval[28] and with the help of key community informants including staff of the BPL’s Adult Learning Center, the recruitment process identified potential participants who are learning to read in English as adults. These participants are not easy to locate and recruit. Because of the stigma often associated with emerging adult literacy, adults who are learning to read often avoid certain social interactions or fully disclosing their reading aptitude to avoid negative social interactions (Ozanne, Adkins, & Sandlin, 2005). To identify participants from this somewhat "invisible" or hidden group and to gain entry into this community, I contacted free adult literacy programs offered by public libraries in the New York and New Jersey area, and found a program where I could participate as a volunteer on a long-term basis. I worked as a volunteer literacy tutor at

[28] IRB approval was received on September 22, 2016.

the Brooklyn Public Library, a large urban public library system, for three years. During my time as a volunteer literacy tutor, I forged strong relationships not only with the adult learners in the program, but also with the program staff. Early on, I disclosed to the program staff my research interest in health literacy as well as my focus on readability and adult literacy, and they invited me to speak to the adult learners about my work. This prolonged engagement (Lincoln and Guba, 1985) allowed me to establish trust as well as to foster awareness of my research interest among the students and staff at the BPL Adult Learning Center. The perspective gained throughout this long-term engagement with this community of adult new readers contributes credibility to the final analysis (Lincoln and Guba, 1985). Research with adults who are learning to read often characterizes them as child-like, lacking self-esteem, and being less capable than other adults (Belzer & Pickard, 2015; Jaffee, 2001). My prolonged engagement with adults enrolled in the literacy center has shown me that many adults who are learning to read are highly motivated, avid learners who are also strong advocates for themselves and their families. Conducting research from this perspective on the experiences of members of this community seeks to have an emancipatory effect. By reminding the research community that adults who are learning to read are not inferior to other adults simply because they are learning to read later in life, this research seeks to de-stigmatize an often marginalized group.

It is important to remember that, despite not being considered a vulnerable class by the Institutional Review Board's standards, the participants in this study nonetheless constitute a vulnerable class of participants due to this study's design and focus on reading and readability. Adults who met the study criteria are learning to read and in this

study they were tasked with reading and evaluating health information—a genre of documents empirically found to be difficult to read for many people (Davis et al., 2001). To minimize the vulnerability of participants, including any potential sense of shame that might be associated with reading, this study followed a protocol that explicitly addresses a number of ethical issues. The following section discusses these in further detail.

3.2.3.2 Ethical Considerations.

Health literacy studies that involve members of vulnerable communities, such as the current study, require special considerations at every stage of the research process in order to safeguard the integrity of the findings and the dignity of the participants themselves. These special measures help protect participants by minimizing a number of risks they potentially encounter as a result of participating in a research study. These risks include exploitation, not adequately obtaining informed consent, and lack of autonomy to make decisions that affect their life (Zion, Gillam & Loff, 2000). Collecting data from vulnerable participants in an ethical manner requires a research protocol that is not only mindful of bias, but that also mitigates the potential risks to participants, protects their rights, and empowers them by preserving their agency to engage and to determine their manner and level of engagement with the research process (Denzin et al., 2008). The usability testing protocol for this study was designed to minimize participants' risks of exploitation, lack of autonomy, and their perception of being tested on their reading abilities or medical knowledge.

In addition to the risks mentioned above, this study protocol was mindful of the participants' potential lack of confidence in reading health information documents. To address this potential risk, this protocol engaged participants as experts tasked with assessing the usability of consumer health information documents rather than as the object under observation, thereby empowering them to critically engage with health

information and make expert judgments of their quality, usefulness, and readability. Because usability testing methods focus on the qualities of a product under evaluation rather than on evaluating participant characteristics (Lewis, 2006), methods developed for usability testing can help to ensure this critically mindful aspect of the present research study (Denzin et al., 2008). In this way, the study protocol also sought to avoid situations that might overwhelm or embarrass participants or that might seem coercive, by neutralizing as much as possible the inherent power dynamics in the researcher-participant relationship. By using these methods, a key aim of this study was to support participants in developing a sense of agency and a belief that they are capable of evaluating health information in order to make decisions about their health, their life, and their body. A prior pilot study was conducted to ensure that such an approach would indeed preserve participants' agency, elicit rich, usable data, and minimize risks for the participants (Morales, 2017).

Many adults who are learning to read have low levels of income (Berkman et al., 2011); this generalization likely applies to the participants in this study. An ethical calculation of the appropriate, non-coercive amount of participant compensation was therefore critical for this study. Poverty also means many potential participants have no reliable method of transportation, and compensation might need to include reimbursement for public transit. Participants might also suffer from chronic health conditions, which may contribute to participants' difficulty with mobility, reading or comprehension. To address these challenges, the researcher discussed recommended amounts and methods of compensation with the Learning Center staff who are more closely linked with the community of adult learners from which participants were

recruited. For these reasons, the usability case study sessions took place at the Brooklyn Public Library's Adult Learning Center on days when the study participants would already be at the library to receive literacy tutoring support.

Perhaps the most obvious challenge for a study focusing on reading health information is that participants are adults who are learning to read. Cognitive load can affect an individual's ability to recall information (Wilson, Wolf, Curtis, Clayman, Cameron, Eigen, & Makoul, 2010). To minimize cognitive load for the participants, all research materials developed by the researcher to be used in this study were written in clear, concise language that is straightforward and does not rely on technical language. These materials include the informed consent form, study descriptions, instructions, interview questions, and survey questions. Participants were verbally informed about their rights and protections as voluntary participants in the study. To avoid overwhelming participants with too many reading related tasks—which may result in incomplete or otherwise unusable data—instructions and survey questionnaires were read aloud to participants when they requested it. In this way, the study design aimed to present a cognitively appropriate evaluation task as part of the usability case study. The following section presents characteristics of the adult readers who participated in Phase II of this research study.

3.2.3.3 Participant Characteristics.

Participants in this study included 8 women and 12 men ranging in age from 25-75 years old, all of whom are enrolled in adult literacy tutoring sessions at the Brooklyn Public Library's Adult Learning Center. Pseudonyms are used throughout this dissertation as a way of ensuring the participants' confidentiality and privacy. Below is a

table listing all participants by pseudonym and corresponding demographic information gathered through the survey questionnaire during the usability study.

Table 3.2.3.3.a. Participants

Participant Name	Gender	Age	Languages Spoken
Grayson	Male	56	English
Wilson	Male	58	English
Ana	Female	60	English
Robert	Male	43	English
Anthony	Male	51	English, French
Joan	Female	64	English
Peter	Male	56	English
Robinson	Male	35	English
Jerome	Male	34	English, French
Elliot	Male	46	English
Esther	Female	39	English
Lucy	Female	69	English
Claire	Female	75	English
Thomas	Male	32	English
Grace	Female	59	English, Igbo
Simon	Male	51	English

Christopher	Male	56	English
Mary	Female	53	English
Curtis	Male	25	English
Lois	Female	27	English, French, Creol[sic]

The table above shows that only 4 of the 20 participants speak another language in addition to English. Most participants are native English speakers, and most are immigrants from the West Indies, while two are from Africa. Three participants have lived in the United States their entire lives. The other participants' time living in the U.S. ranged from 8 months to 30 years. Two participants reported never having attended school, while most reported having attended only grade school.

Table 3.2.3.3.b. Highest Level of School Attended by Participants

Elementary School	**Middle School**	**Some High School**	**No School**	**Can't Remember**
5	2	10	2	1

The table above shows that the highest level of education attended that was reported among participants was high school, though none of the participants have a high school diploma. Two participants reported not having ever attended school, and one participant, a 32-year-old male, reported not remembering what level of school he last completed. It is possible that he might not have attended school at all, but said he could not remember due to the stigma associated with such an admission. This participant could not read independently and needed my help in filling out the survey.

Though participants in this study share some common experiences regarding language, literacy, education, and social situations such as immigration experiences, they did not all share the same reading experiences or exhibit the same reading practices. Although all participants have experience reading books and completing writing assignments as part of their participation in the library's Adult Learning Center literacy programs, their reading experiences outside the learning center vary greatly.

Table 3.2.3.3.c. Types of Resources Most Read by Participants

Reading Materials	No. Of Participants
Books	16
Flyers	14
Information from Doctor	13
Train or Bus Schedules	13
Newspapers	12
Magazines	12
Maps	12
Forms to Fill Out	12
Websites	5

The table above shows the types of information materials participants have the most experience using. Considering that these participants are all students in the Brooklyn Public Library's Adult Learning Center, it is not surprising that 16 participants reported having some experience regularly using books. Flyers are the next most reported information resource used by participants. Thirteen participants reported having some experience using print-based information they receive from a doctor or clinic, meaning they are familiar with the types of materials they were asked to read and evaluate as part

of this research study. Overall, most participants reported having some experience with magazines, brochures, flyers, advertisements, maps, train or bus schedules, and filling out forms. Six participants reported very limited experience with any of these sources of information. When answering this section of the survey questionnaire, two participants—Claire and Peter—qualified their responses by saying they read and fill out forms, including information received from a doctor, with the aid of a family member such as a spouse or an adult son or daughter. Both Claire and Peter are native English speakers who read aloud. Claire is 75 years old and reported never having attended school. Peter is 56 years old and reported having completed the 6th grade. The information practices of at least some adults who are learning to read, then, include access to a trusted and more experienced reader when they evaluate and use information to manage their own health. According to the survey data, these participants are indeed the types of individuals for whom "easy-to-read" health information is intended. To be sure, there are adults for whom text-based health information might not be an appropriate format. It is important to keep in mind that participants in this study, however, are highly motivated adult learners who are actively engaged with their ongoing education and who have varying, if limited, levels of experience with different types of texts including health information.

3.2.4 Study Site.

The usability sessions with participants took place at the Central branch of the Brooklyn Public Library's Adult Learning Center. Conducting the sessions there made it easier for participants to engage in the study since it did not interfere with work or other responsibilities, and it did not require them to make additional travel arrangements. Both of these can be hardships to adults who are members of this community since they very

often have limited means. The supervisor at the Adult Learning Center allowed me to perform the usability studies in an area usually reserved for tutoring sessions. This ensured participants had a comfortable, quiet place to sit and ample room at a table where they could make their annotations, without interference from staff, volunteers, or other students.

The Adult Learning Center offers free educational opportunities and support to individuals who are at least 17 years old. These include levels from basic literacy and education through obtaining the high school equivalency diploma. The Learning Center also helps students to prepare for the citizenship exam, driver's exam, basic computer literacy, and offers a variety of workshops about financial literacy, health literacy, and navigating the different city agencies and regulations such as those dealing with housing. The Learning Center staff conducts periodic testing of all students and reviews of student portfolios to monitor student progress. These assessments are ultimately used to move students from one level to the next as their reading speed, comprehension, and writing improve. In addition to the permanent staff, the Learning Center uses volunteer tutors and workshop moderators to deliver educational content. All volunteers must first complete a training program for eight weeks in which they are introduced to the Learning Center's pedagogical approach and preferred methods for supporting the ongoing development of adult literacy.

While ultimately beneficial, conducting the usability sessions at the Brooklyn Public Library's Adult Literacy Center did introduce some limitations to the study. An important limitation is that participants may have interpreted the study as one of the educational opportunities or assessments they receive at the Center. As much as the study

design attempted to minimize participants' perceptions that they were being tested, it is still possible that by conducting the sessions at the Learning Center, some participants might have felt this way anyway. Additionally, even though I explained my work at the beginning of each session, because of my affiliation with the Center and the location of the study, participants may have felt this was a research study conducted by the Learning Center. To minimize the effects of these misinterpretations as much as possible, I reiterated that the study was in no way affiliated with the Brooklyn Public Library and that it was a study conducted as part of my graduate school program. I allowed participants to ask me questions about my program and my work more generally at the conclusion of each usability session to make it clear what my motivations and affiliations were in conducting this study. The Learning Center staff reiterated this as well to all participants. The compensation given to participants (discussed in Section 3.2.3.2) also served to show this study was not part of the Learning Center's activities, since the Learning Center never compensates students for participating in its programs.

3.2.4 Usability Case Study Data Analysis Methods.

Data collected in Phase II of the study was organized by case and each case constituted (1) the evaluation task, (2) the follow-up semi-structured and open-ended interview, (3) the participant survey questionnaire, as well as (4) field notes and observations to facilitate within-case and across-case analysis following the method recommended by Miles, Huberman, & Saldana (2013). Organizing data this way facilitates an analysis based on case particulars in order to arrive at an idiographic generalization that synthesizes the experience of adults who are learning to read when evaluating consumer health information documents (Ayres, Kavanaugh, & Knafl, 2003).

Rather than aiming for statistical generalization, this study attempted to capture the variation of the phenomenon of interest (how adults who are learning to read evaluate health information documents) in order to enhance the field's current understanding of the complexity of health literacy as demonstrated through an analysis of different cases (Smaling, 2003). This study expected this across-case variation to be somewhat related to participant characteristics such as age, gender, knowledge of health topics, education, language use, and reading practices, but also to characteristics of this particular genre of health texts. During analysis, particular attention was paid to participants' assessments of the overall usability of the document, as well as to specific linguistic features that participants identified as aiding or hindering the readability of the documents. To this end, case study data was coded using a values coding method to identify and subsequently analyze participants' evaluation of the consumer health information documents (Saldaña, 2015). A value in this coding scheme refers to the importance participants place on something. For the analysis of the data collected in this study, values referred to participants' judgments about the usefulness or helpfulness of different aspects of the health information documents they evaluated. Values were coded manually based on the green and red markings that participants made on the health information documents they evaluated during the usability case study sessions, and based on the responses they give during the post-task interview. As noted above, participants used the red marker to identify features of the documents that were unhelpful or confusing and the green marker to identify features that were helpful or useful (see Section 3.2.2). Each case was also manually coded according to linguistic features that participants identified during their evaluation as having to do with the documents' readability, as well as

according to features that were observed to challenge the participants during their reading and evaluation.

Memoing is an important methodological tool for qualitative research that allows the researcher to become immersed in the data, explore assumptions and subjective stances, facilitate planning, and ultimately, identify concepts and extract meaning from the data (Birks, Chapman, & Francis, 2008). Qualitative research often conducts data collection and analysis iteratively. Memos are a long-form synthesis of the researcher's reflections about the research process, data collected, observations, or theories and frameworks used. Three types of memos were created to facilitate the data analysis process: (1) process memos, (2) observational memos, and (3) analytical memos. These memos were a critical way for me to identify key findings and their implications for this study. Process memos were used to plan the usability case study sessions, and to organize the iterative data collection and analysis phases. These types of memos included to-do lists and reflections intended to document the data collection and analysis process at each step. Observational memos were created after conducting usability sessions as a way to organize field note observations, identify patterns among observations, and to help remind the researcher to further explore ideas or emerging themes identified in previous usability sessions. For example, after the first five usability sessions, I wrote a process memo to remind me to ask participants questions about their familiarity with reading aids such as pronunciation guides included in the documents they evaluated. I had observed that these aids were sometimes ignored by participants when reading the documents, but were included in many health information documents. I created an observational memo in which I identified the value that creators of these documents presumed them to provide to

readers. Analytical memos were used when analyzing data on a case-by-case basis in order to then facilitate across case analysis. Analytical memos were then collapsed into categories of themes that collected evidence from multiple cases as patterns were identified in the data. Memoing was used in the analysis phase of this research study to focus an analytical lens on the data as it was being collected, but it also facilitated the documenting of observations and interactions between the researcher and the participants in this study. This way of documenting the research process can help future researchers develop protocols for engaging with research participants who are members of marginalized, stigmatized, or vulnerable communities in ways that bolster mutual trust and respect.

3.3 Integration of Mixed Methods Findings

Once the data collected through the usability case studies was analyzed, the findings from Phase II of the study were integrated with the findings of the linguistic analysis carried out in Phase I. This integrated analysis provides a more comprehensive analysis of the readability of health information documents as sociotechnical artifacts (Leonardi, 2012) from the perspective of adults who are learning to read. Integrating the findings of Phase II strengthen the findings from the linguistic and statistical analysis by incorporating the experiences of adults who are learning to read. This phase of the analysis also included an integration of the results from the ETS linguistic analysis of the Health Corpus which not only confirmed but also provided more explanatory power to the findings. Integrating the findings from each phase of this mixed methods study enriched the findings from the linguistic and statistical analysis with the experiences of adults who are learning to read. This integration helps to maximize the confirmability and

dependability of the overall study (Johnson, Onwuegbuzie, & Turner, 2007; Lincoln and Guba, 1985). Mixed methods studies like this one that integrate the experiences of participants with findings related to document readability are rare. The next chapter reports the findings of this integrated analysis in order to answer the study's research questions.

4. Findings

This chapter reports the integrated findings from Phase I and Phase II of this research study on the readability of "easy to read" health documents for adults who are learning to read. The results presented in this section advance our understanding of why health information is difficult to read despite professional efforts to improve the readability of health documents for adults who are learning to read. Most participants found at least some of the health information documents they evaluated difficult to read even though all the documents they evaluated were part of Medline Plus' Easy to Read Health Information collection[29]. This difficulty was identified by the frequently used Flesch-Kincaid Grade Level formula, but it did not prevent the health information documents from appearing in the Easy to Read health information collection. There are several possible reasons for this. For instance, content creators may not know what changes to make to the documents to lower the grade level. The more sophisticated linguistic analysis of these health information documents using the CohMetrix and ETS tools identified features such as vocabulary use, cohesion, and writing style which help to explain why these documents are difficult to read in a way that Flesch-Kincaid cannot do. This study concludes that the "Easy to Read" label used by Medline Plus is not a reliable

[29] Section 4.7.1 presents a more detailed discussion of the participants' perception of the ease or difficulty of reading these documents.

method of identifying health information that is easy to read for adults who are learning to read. Newer tools that integrate natural language processing methods do a much better job of pointing out specific problems with "Easy to read" documents.

The usability studies confirmed the difficulty adults who are learning to read have when reading health information documents from Medline Plus' Easy to Read collection. This is important because librarians and health professionals rely on this "easy to read" label to identify health information that they assume adults who are learning to read can use and understand. Knowing which linguistic features to change to make these documents easier to read for these adults could help improve access to these documents for adults who are learning to read.

It is important to keep in mind that the findings of the research study reported here represent the experiences of a specific group of adults who are highly motivated, receive consistent support, and are part of a community of adult learners who have access to resources such as tutors and literacy specialists. Many adults who are learning to read and for whom easy to read health information resources are developed, are not necessarily members of learning communities, and might not have the same level of access to resources that can help them make sense of the health information they receive. The participants in this study cannot yet read independently enough to pass the high school equivalency exam, but attend twice-weekly reading and writing tutoring sessions in order to be able to prepare for the exam in the future. It is therefore important to consider how much more challenging must be the task of reading and evaluating health information for adults who are not receiving this type of support.

This chapter is organized to reflect three main sets of findings:

1. Findings resulting from the analysis of data collected in Phase I of the study.
2. Findings resulting from the integrated analysis of Phase I and II.
3. Findings resulting from the analysis of data collected in Phase II, but which were not identified by methods used in Phase I.

First, Section 4.1 presents the readability scores for HTRC documents according to the Flesch Kincaid Grade Level formula. This analysis shows not only that health information documents do not meet the standards recommended by professional guidelines, but also that the tools these guidelines recommend do not address the specific linguistic features that make these documents difficult to read. Since the Flesch-Kincaid readability formula does not identify specific linguistic features that can lower their readability score, Section 4.2 reports on the findings of the CohMetrix analysis which identified the linguistic features that account for the ease or difficulty of reading the documents in the HTRC. Sections 4.3, 4.4, 4.5, and 4.6 delve into these features in much more detail, including an analysis of the ETS output and results from the usability studies conducted in Phase II that are related to these features. Sections 4.7, 4.8, and 4.9 report on the findings that resulted from the usability studies (Phase II) but which were not part of the Phase I analysis, including how reading practices, prior knowledge, and personal experience affect the readability of health information documents for adults who are learning to read. For a summary of these findings, see the beginning of Chapter 5.

4.1 The Readability of Health Information Documents.

As mentioned earlier, there is currently no process in place to verify that health information documents submitted to collections like this are indeed easy to read or that they even abide by the easy-to-read guidelines. One objective of this analysis is to show

to what extent professionals can trust the "easy to read" label for health information. On average, all documents in the HTRC score above a 10th grade reading level on the Flesch-Kincaid Grade Level. This is not surprising because documents in HTRC have an average of 18.5 words per sentence and an average of 1.62 syllables per word. Table 4.1b shows the descriptive statistics for the variables used by the Flesch-Kincaid Grade Level formula for the documents in this corpus as well as the predicted reading grade level calculated by the Flesch-Kincaid readability formula.

Table 4.1.a Features Used by Flesch-Kincaid Grade Level Formula, N=496

Features	**Min**	**Max**	**Mean**	**Standard Deviation**
Sentence length by number of words	8.02	163.2	18.5	8.95
Word length by number of syllables	1.22	2.60	1.62	.147
Flesch-Kincaid Grade Level	4.01	65.75	10.5	4.06

Even by traditional metrics recommended by the professional guidelines, the average reading grade level for documents in the health corpus is rather high. It is important here to mention that, contrary to what is expected, the Flesch-Kincaid Grade Level formula does not have an upper bound (Kincaid, Fishburne, Rogers & Chissom, 1975). This means that very long documents can often score well above the 12th grade, which explains the wide range in Flesch-Kincaid grade level reported in table 4.1.a.

Example 4.1.a Mathematical Formula Used to Calculate the Flesch-Kincaid Grade Level

0.39 (total words / total sentences) + 11.8 (total syllables / total words) - 15.59

Example 4.1.a shows the formula used to derive the Flesch-Kincaid Grade Level. This is another reason why formulas like this are not well suited for long documents like those in

the HTRC. Health information documents can often score higher than 12th grade reading level just because of their length, as was the case with some of the documents in the HTRC.

Furthermore, a comparison of the Flesch-Kincaid Grade Level for HTRC documents from ETR collections and those from non-ETR collections shows that their respective average reading grade levels only varies by one grade level.

Table 4.1.b Flesch-Kincaid Grade Level for HTRC, ETR & Non-ETR corpora

Corpus	Flesch-Kincaid Grade Level
All documents (N=496)	10th
Easy-to-Read (N=293)	10th
Non-Easy-to-Read (N=203)	11th

The HTRC includes documents found in Easy-to-Read (ETR) collections as well as documents not explicitly labeled as being easy to read, as detailed in Section 3.1.1. The corpus was split accordingly and each subcorpus was analyzed separately to determine whether ETR documents indeed follow the professional recommendations regarding reading grade level and readability. Table 4.1.b shows the average Flesch-Kincaid Grade Level for all documents in the HTRC is 10th grade. More importantly, the reading grade level for ETR documents is 10th grade, well above the recommendations in the professional guidelines. The Medline guidelines for writing ETR (Easy to Read) health materials recommend that health information documents score between a 7th and 8th grade level (U.S. National Library of Medicine, 2016). Keeping in mind the discrepancy between the Flesch-Kincaid Grade Level scores of these documents and the readability grade level recommended by the guidelines, it is not surprising that documents in the

HTRC were difficult to read for the participants in this study, adults who are learning to read.

The problem with using the Flesch-Kincaid Grade Level formula to assess the readability of health information is not its ability to predict whether a document is hard to read. Rather, the issue is that once a readability score has been determined, there is no analysis that helps content creators identify ways to improve that score in order to make a document easier to read. This is an important limitation of the Flesch-Kincaid Grade Level formula and readability formulas like it. A more sophisticated analysis of linguistic features, including the use of certain types of words, syntax, concept and word overlap, and the presence of discourse relationships, provides a better understanding of what factors make health information difficult to read, especially for people who need easy to read health materials. To this end, the following section presents the results of the linguistic analysis of the documents in the HTRC conducted during Phase I of this study.

4.2 Linguistic Features Beyond Word Length and Word Count Related to the Readability of Consumer Health Information

The analysis of the CohMetrix' easability features for documents in the HTRC (N=496) found that some linguistic features help to make these documents easy to read and others contribute to these documents' poor readability. Features that contribute to the difficulty of reading these documents are their low **narrativity**, **referential cohesion**, and **connectivity.** Features that contribute to the ease of reading these documents are **syntactic simplicity**, **word concreteness**, and **deep cohesion**. The good news is that documents in the HTRC tend to have sentences with simple syntax, they tend to use vocabulary that is highly specific, and they make explicit causal and logical relationships

in the text, which are important for readers who have little knowledge of the topics presented in the documents (McNamara et al., 2014; Ozuru, Briner, Best, & McNamara, 2010). The bad news is these documents lack narrativity, they have little concept overlap, and they generally lack other important types of connectives such as "and," "or," "but," and "because," which help readers to form inferences when reading.

Since CohMetrix does not predict a reading grade level the way the Flesch-Kincaid Grade Level formula does, it is important to keep in mind as a reference the average Flesch-Kincaid Grade level for documents in this corpus is 10th grade as we consider the results of the CohMetrix analysis.

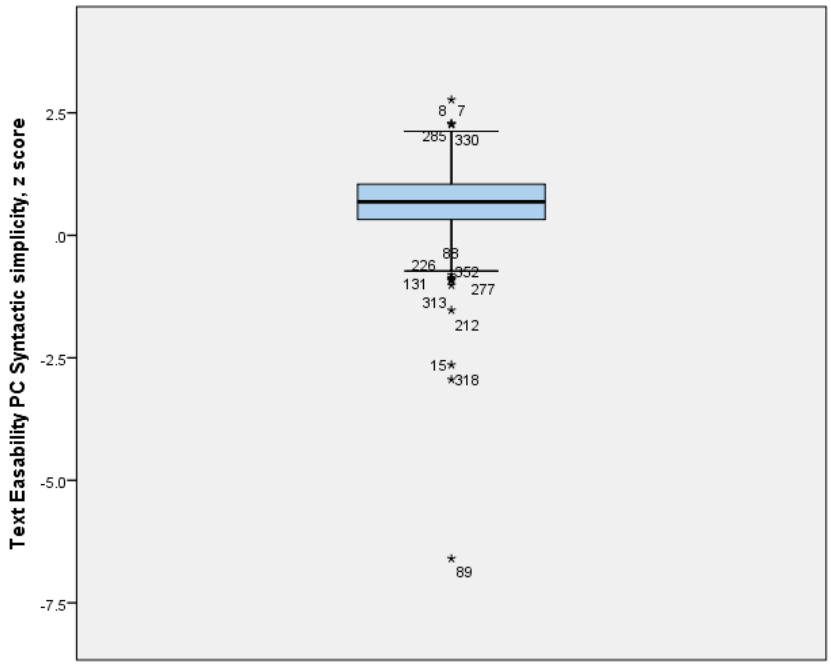
Table 4.2.a Descriptive Statistics for CohMetrix Easability Features, z-scores*, N=496

Feature	Range	Mean	Standard Deviation
Narrativity	-2.37 - .885	-.068	.585
Syntactic Simplicity	-6.60 - 2.77	.676	.697
Word Concreteness	-2.07 - 5.36	.785	.752
Referential Cohesion	-2.10 - 3.10	-.107	.853
Deep Cohesion	-1.94 - 3.46	.744	.656
Connectivity	-9.09 - .446	-3.12	1.12

*Scores are given as z-scores which represent the number of standard deviations from the mean for the training corpus. Negative scores refer to the number of standard deviations less than the mean.

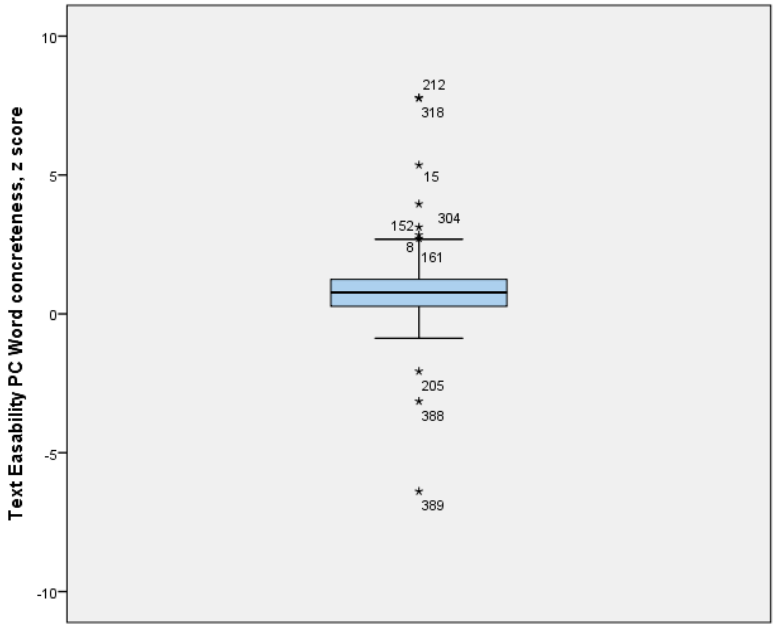
This data shows that the structure of the sentences in these documents (measured by **syntactic simplicity**) does not deviate greatly from the average for documents in the training corpus.

Graph 4.2.a Boxplot of CohMetrix Syntactic Simplicity Scores for documents in HTRC, N=496



The low standard deviation for this feature (s=.607) also indicates the corpus is pretty uniform with respect to this feature despite the wide range in scores (-6.60-2.77), as Graph 4.2.a also shows. The scores for **word concreteness** and **deep cohesion** suggest a similar pattern: documents in the HTRC use words that are close to the average level of concreteness and explicitly contain a near-average amount of causal and logical connectives compared to documents in the training corpus.

Graph 4.2.b Boxplot of CohMetrix Word Concreteness Scores for documents in HTRC, N=496



Graph 4.2.c Boxplot of CohMetrix Deep Cohesion Scores for documents in HTRC, N=496

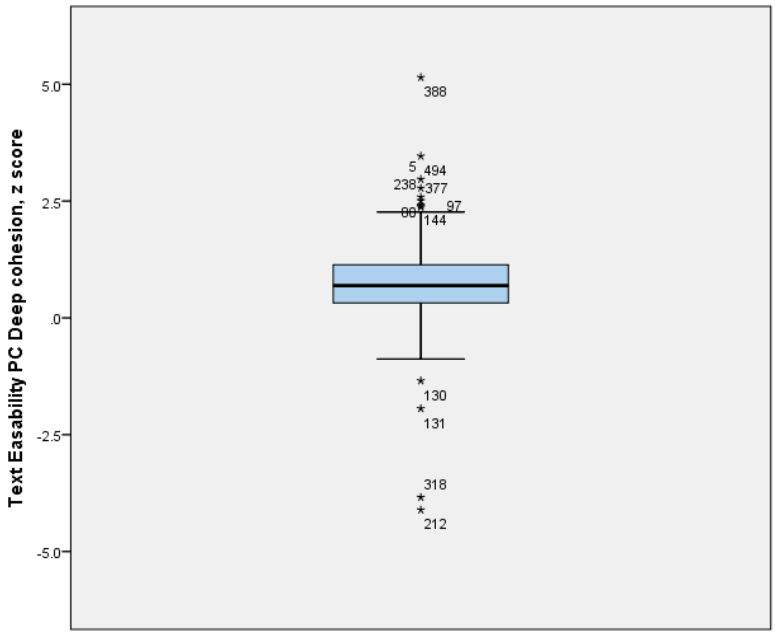
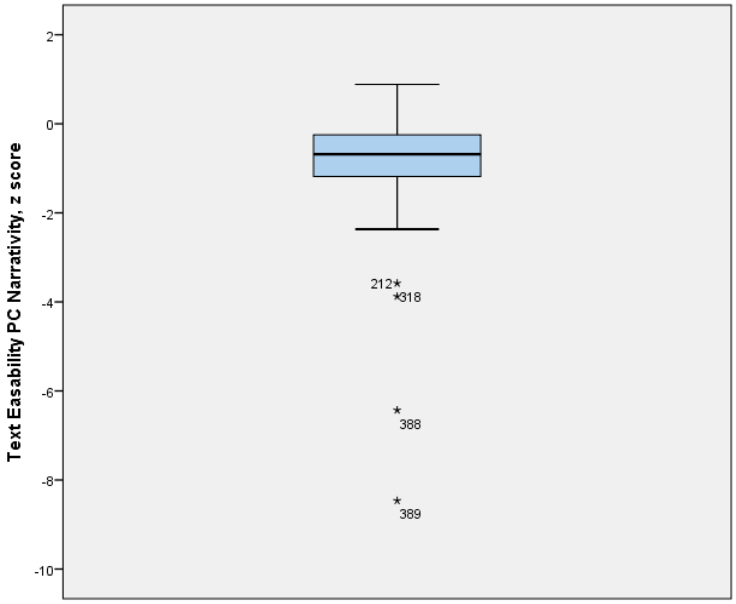


Table 4.2.a and Graphs 4.2.b and 4.2.c above also show these features deviate by less than one standard deviation from the mean, suggesting very little variation for these features among the documents in the HTRC. As discussed in Section 3.1.2.2, the CohMetrix training corpus is a collection of K-12 academic texts. This means that with respect to syntactic simplicity, word concreteness, and deep cohesion, documents in the HTRC are within the range of K-12 texts.

Documents in the HTRC might nevertheless be difficult for adults who are learning to read due to their low **narrativity, referential cohesion,** and **connectivity** scores. The average **narrativity** score for documents in the HTRC is -.068, slightly less than the average for the CohMetrix training corpus.

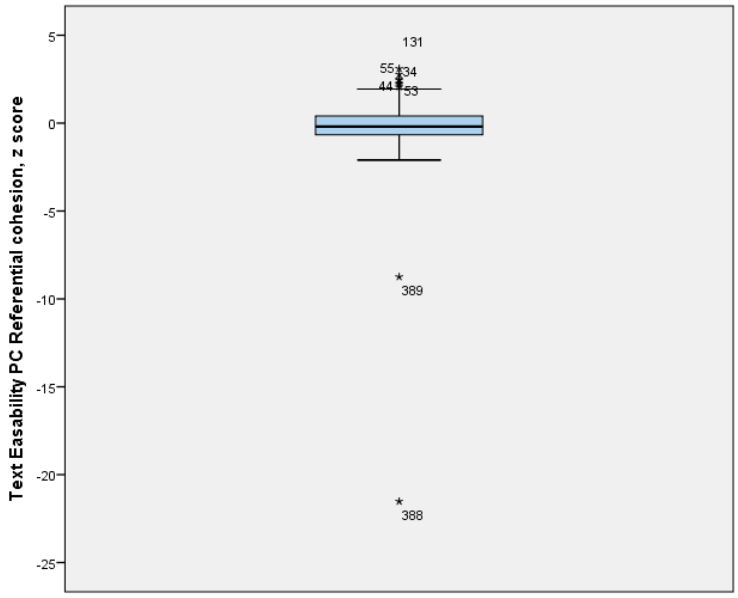
Graph 4.2.d Boxplot of CohMetrix Narrativity Scores for documents in HTRC, N=496



Graph 4.2.d above also shows the uniformity of the HTRC with respect to narrativity. That health information documents have slightly low narrative qualities is probably unavoidable since **narrativity**, as measured by Cohmetrix, corresponds with features of oral, everyday language (see Section 3.1.2.1). Documents in the HTRC contain

explanations and definitions that do not readily lend themselves to narrativity. Similarly, the **referential cohesion** score for documents in the HTRC is only slightly less than the average for documents in the training corpus ($M_{\textbf{referential cohesion}}$ = -.107), which indicates sentences and concepts in these documents do not overlap very much.

Graph 4.2.e Boxplot of CohMetrix Referential Cohesion Scores for documents in HTRC, N=496

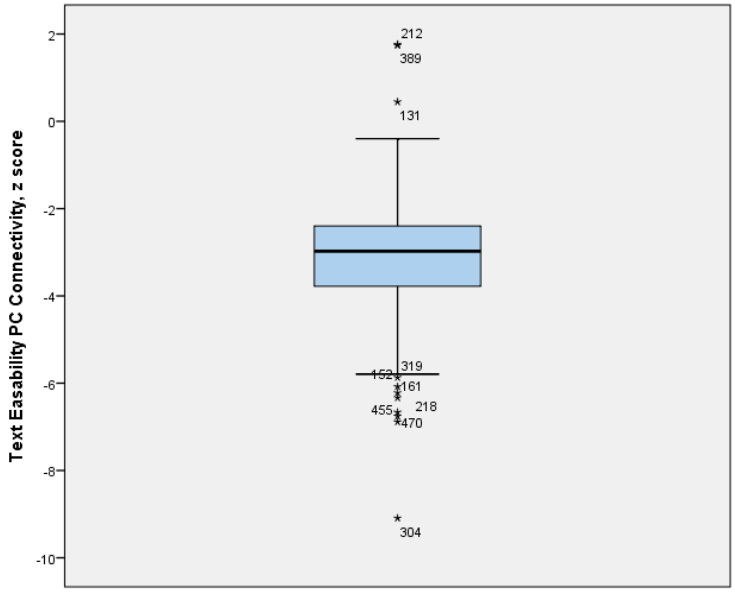


Graph 4.2.e above shows very little variability among documents in the HTRC with respect to **referential cohesion**. A key finding of prior research is that if readers have low domain knowledge, and if the text they are reading has low narrativity and low referential cohesion, comprehension can suffer (Graesser, Olde, Klettke, 2002; McNamara et al., 2014).

The feature score for the documents in the HTRC that most deviates from the average for documents in the CohMetrix training corpus is **connectivity**. This feature measures the amount of adversative, additive, and comparative connectives that are explicitly used in the text. Examples of these connectives are “and,” “or,” “also,” and

"however." Documents in the HTRC have an average **connectivity** score of -3.12. This is also the only easability feature with a standard deviation of more than one point, suggesting some variability among documents in this corpus with respect to connectivity.

Graph 4.2.f Boxplot of CohMetrix Connectivity Scores for documents in HTRC, N=496



Graph 4.2.f above shows a wider range for this feature among documents in the HTRC. The large range for this feature (-9.09 - .446) also skews far below the average for documents in the training corpus which indicates that documents in the HTRC are more likely to lack these types of **connectives** than are the average K-12 text in the training corpus (See Table 4.2.a). The lack of **connectives** in the HTRC represents a serious obstacle to the readability of these documents. In other words, adults who are learning to read must infer the way that concepts and ideas are related in the text. This is especially problematic for adults with little reading experience and for low knowledge readers in general. Based on earlier research and considering the easability scores for the documents in the HTRC (see Table 4.2.a), a reasonable hypothesis is that these documents are in fact

challenging for adults who are learning to read. The following subsection (4.2.1) compares each subcorpus of the HTRC with respect to these features in order to better understand whether and to what extent Easy to Read health information documents perform better than non-ETR documents with respect to the features discussed above.

4.2.1 Comparison of Easy-to-Read and Non-Easy-to-Read Health Documents.

A comparison of the CohMetrix Easability feature scores for the HTRC documents labeled "easy to read" and those documents not included in "easy to read" collections, shows that features that account for the ease and difficulty of reading health information are similar across the two sub-corpora. As mentioned in Section 4.1, it is useful to keep in mind that the Flesch-Kincaid Grade Level for ETR documents is 10th grade while non-ETR documents have a 11th grade Flesch-Kincaid Grade Level.

Table 4.2.1.a CohMetrix Easability Features for Sub-corpora ETR & Non-ETR, z-scores*

Feature	Mean ETR N=293	Standard Deviation ETR	Mean Non-ETR N=203	Standard Deviation Non-ETR
Narrativity	-0.589	0.546	-0.822	0.613
Syntactic Simplicity	0.721	0.63	0.61	0.781
Word Concreteness	0.808	0.73	0.752	0.784
Referential Cohesion	-0.189	0.791	0.01	0.924
Deep Cohesion	0.713	0.625	0.789	0.696
Connectivity	-3.12	1.18	-3.12	1.02

*Scores are given as z-scores which represent the number of standard deviations from the mean for the training corpus. Negative scores refer to the number of standard deviations less than the mean.

The tables above show that documents in each sub-corpus (ETR vs. Non-ETR) share similar scores for most measures. More specifically, documents in each subgroup have poor **narrativity** and **connectivity** scores, which contribute to their reading difficulty. What is more, they have the same mean **connectivity** score: -3.12. Documents in each subcorpus also have similar scores for **syntactic simplicity, word concreteness,** and **deep cohesion**, which contribute to the ease of reading these documents. The scores for **referential cohesion** are an important difference between the subcorpora. The non-ETR documents in the HTRC deviate less than ETR documents from the mean for this measure when compared to documents in the CohMetrix training corpus. In other words, the documents in the ETR subcorpus actually score worse than non-ETR for this measure, which contributes to the poor readability of ETR documents. This comparison between the ETR and non-ETR subcorpora indicates that just because a document has been labeled as Easy to Read does not guarantee that it will indeed be so.

The next four sections (4.3-4.6) discuss these results in greater detail and further contextualize how the easability features identified by CohMetrix affect the readability of heath information for adults who are learning to read by integrating the results from the usability studies conducted during Phase II. Since vocabulary and sentence structure have long been considered to contribute to readability, the next two sections focus on these features with special attention given to the limitations of how these have been operationalized by traditional readability formulas. First, Section 4.3 discusses how vocabulary features, including semantics (the meaning of language), as well as the use of technical terms and acronyms, affect the readability of health information.

4.3 How Vocabulary Use Affects the Readability of Health Information

Consumer health information documents represent a special case of documents to study because of the lexical issues that are unique to this type of document. Health information documents like those in the HTRC contain specialized language related to health, medicine, and anatomy. These documents must balance the need to use this type of language with the needs of their users, most of whom are laypersons with different levels of education, reading experiences, and knowledge of health topics. The intrinsic difficulty of medical vocabulary reduces the readability of these documents. An analysis of data collected in both phases of this study found that the vocabulary used in consumer health information documents contributes to their poor readability particularly for adults who are learning to read. This section discusses the extent to which vocabulary use, including the use of certain types of content words, technical language, contractions, and acronyms, affects the readability of health information.

Readability formulas like the Flesch Kincaid Grade Level operationalize vocabulary as a measure of word length or syllable count (see Section 2.2.2.2). As previously discussed, these traditional readability formulas are built on the assumption that longer words, which in English tend to be increasingly rare as a function of their length (Sigurd, Eeg-Olofsson, & Van Weijer, 2004), are less likely to be known by students in lower grades. Texts with a high incidence of long words therefore tend to score at a higher reading grade level than a document with a lower average word length. This metric assumes that children learn longer, more rarely used words, as they mature; and that they develop their reading skills as they also learn and acquire new vocabulary.

Therefore, it is likely that a child in the 8th grade will know how to read longer words than a child in the 2nd grade.

Adults who are learning to read, however, do not learn vocabulary in the same way as children. Adults, regardless of their reading experience, tend to have a larger vocabulary and recognize longer words than do children. It is also important to distinguish between the words a reader *knows*, regardless of age, and words someone can *read*. Simply because an adult cannot read a word does not mean that same adult does not know the word's meaning. For instance, an adult who is learning to read might know what pneumonia is even if he cannot read the word. Adults are also likely to have more experience with health than children, regardless of reading ability. For this reason, the Flesch-Kincaid Grade Level formula is not a good method for assessing the readability of health documents created for adults.

An analysis of data collected during both Phase I and Phase II of this study reveals aspects of vocabulary beyond word length that affect the readability of documents in the HTRC. Importantly, some of the features identified by CohMetrix, SourceRater and Language Muse® are more explanatory than using the Flesch-Kincaid Grade Level formula. That is, though the more sophisticated tools may still be measuring the effect of longer words in a document, the ETS tools provide more information about the type of longer words. This level of detail helps us to better understand what types of longer words or what it is about longer words that affects readability. Specifically, sub-section 4.3.1 reports on the semantic features analyzed during Phase I of the study that contribute to the readability of documents in the HTRC. Sub-section 4.3.2 presents findings related to the use of academic vocabulary resulting from Phase I and Section 4.3.3 discusses how

the academic vocabulary in these documents contributed to the difficulty of reading them for participants. The final sub-section, 4.3.4, presents findings related to vocabulary use that were not identified by the methods used in Phase I, but which nevertheless contributed to the difficulty of reading health information for adults who are learning to read according to the analysis of data collected during Phase II.

4.3.1 Semantic features contribute to the difficulty of reading health information.

According to the linguistic analysis conducted as part of Phase I of the study, the health information documents in the HTRC have an average of only 1.62 syllables per word, which indicates that the presence of very long words are relatively infrequent and do not necessarily contribute to the difficulty of reading these documents. A semantic analysis of the HTRC explains how the vocabulary in these documents contributes to their low readability. Specifically, semantic information including type of vocabulary and word frequency are factors that affect the readability of health information.

Table 4.3.1. presents the descriptive statistics for semantic word information features measured by Coh-Metrix for the health information documents in the HTRC.[30] These semantic word information feature scores calculated by Coh-Metrix are based on the MRC Psycholinguistic Database[31], which includes a lexicon and associated scores based on human judgments for each of these measures. The MRC Psycholinguistic Database contains information on the linguistic properties of words derived from experimental data with adults who have a college-level education rather than on predictive models based on assumptions (Cortese & Fugett, 2004; Coltheart, 1981).

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[30] See Section 3.1.2.2 for an index of these features and their score ranges.
[31] http://websites.psychology.uwa.edu.au/school/MRCDatabase/mrc2.html

Table 4.3.1. Semantic Word Information Features Computed by CohMetrix for documents in HTRC, N =496

Feature*	Range	Mean	Standard Deviation
Concreteness of content words	345-514	404	24.2
Familiarity of content words	535-589	572	6.78
Hypernymy of nouns	3.82-7.67	6.34	.491
Imageability of content words	383-516	429	19.4
Meaningfulness of content words	396-481	438	10.9

*Scores for these features can range from 100-700; 100 is low and 700 is high.

This table shows that mean scores for **concreteness** and **imageability** for the HTRC documents are slightly below the average for words in the MRC Psycholinguistic Database (scores for these lexical features can range from 100-700). Their large standard deviation values indicate these features vary widely for HTRC documents. **Concreteness** and **imageability** refer to the level of abstractness of a word and how easy it is to form a mental image of the word. According to these scores, health information documents in the HTRC contain words that are somewhat concrete but still difficult to conceptualize even for adults, which might contribute to their reading difficulty.

To better understand this finding, it is important to interpret them along with the **hypernymy** values for the documents in this corpus, which CohMetrix computes based on WordNet data. WordNet[32] is a lexical database of words in the English language grouped by synonym sets based on psycholinguistic theories that claim that we mentally store our lexicon (the words we know) in groups related by associated meanings (Miller, Beckwith, Fellbaum, Gross & Miller, 1990). **Hypernymy** scores indicate the level of specificity of a word by identifying a word's location in a hierarchy of terms from

[32] WordNet is a lexical database of English words: https://wordnet.princeton.edu/

broadest term (most general) to more specific. Somewhat counterintuitively, the higher the **hypernymy** value, the more specific the term. For example, 'heart' has a higher **hypernymy** value and is a more specific term than 'internal organ,' a more general term. The average **hypernymy** value for nouns and verbs for documents in the HTRC is 6.34, and the standard deviation (s=.491) indicates low variability for this measure among documents in this corpus. This means that nouns and verbs in the HTRC documents tend to be rather specific with respect to the WordNet lexicon. Considered along with the **concreteness** and **imageability** scores discussed above, this indicates that the vocabulary used in these health information documents is specific and also somewhat difficult to conceptualize. An example of highly specific and difficult to conceptualize vocabulary might be technical, scientific, medical or anatomical terms. More generally, highly specific vocabulary that is hard to conceptualize is a useful way of identifying words likely to be unfamiliar to a reader. In this way, using a tool like CohMetrix is more useful than using the Flesch-Kincaid Grade Level for identifying documents that can be difficult to read for adults who are learning to read based on these types of semantic features.

Two other important findings of the CohMetrix analysis were the high mean **familiarity** score (see Table 4.3.1.a above) for health information documents in the HTRC ($M_{familiarity}$=572), and the slightly higher than average **meaningfulness** score ($M_{meaningfulness}$=438). These features indicate whether an adult is likely to have encountered that word before (**familiarity**) and how meaningful the term is—it is not a measure of vocabulary knowledge or of word frequency (i.e. it does not indicate whether the reader knows the meaning of the word or how rare the word is in the English language). The higher the Coh-Metrix **familiarity** score, the more familiar a word is

likely to be to an adult. Likewise, the higher the **meaningfulness**[33] score, the more meaningful a word is likely to be to an adult. The relatively high mean **familiarity** score for health information documents in the HTRC indicates that adults are likely to be familiar with the vocabulary used in these documents. The somewhat high mean **meaningfulness** score indicates that the vocabulary used in these documents is likely 'to make sense' to an adult with a college-level education (Nickerson & Cartwright, 1984). **Familiarity** and **meaningfulness** scores provided by CohMetrix are based on ratings given by adults who are more experienced readers than adults who are learning to read for whom "easy to read" health information has been developed, such as the adults who participated in this study. Despite these high **familiarity** and **meaningfulness** scores, the vocabulary used in health information documents might nevertheless be less familiar to adults who are learning to read, as the next section will explain.

4.3.2 Academic vocabulary contributes to the complexity of health information.

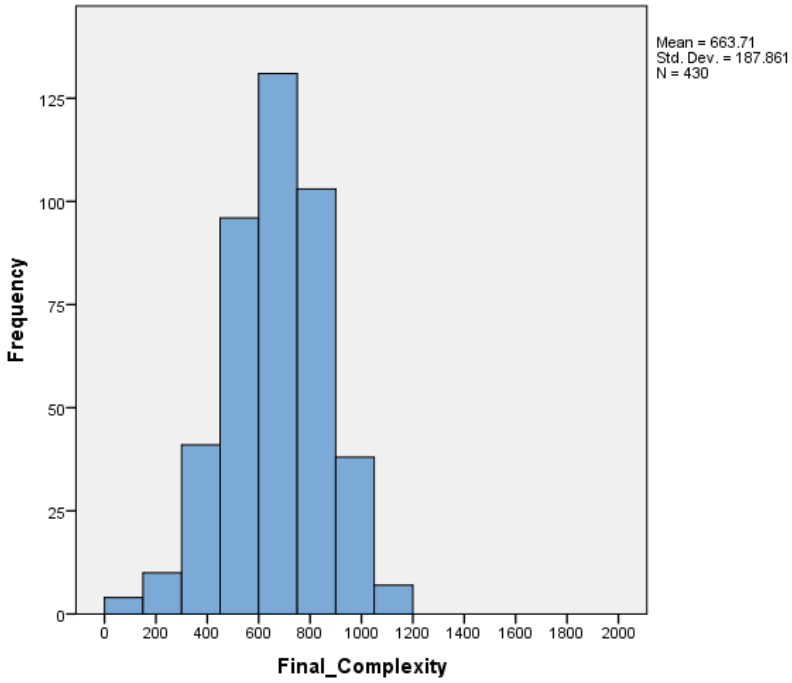
The linguistic analysis of documents in the HTRC conducted using ETS' SourceRater[34] tool identifies additional features related to vocabulary difficulty which are likely to contribute to their reading difficulty. This tool provides a **final complexity** score for the documents in the corpus, as well as an analysis of the specific linguistic features that contribute to final complexity, including the use of **academic language**, **word**

[33] Based on the experimental methods used to develop meaningfulness scores (such as electing word associations for target words), this measure tends to indicate how closely related a word is to other words.

[34] See Section 3.1.3.1 for an index of these features and their score ranges.

unfamiliarity[35], and **concreteness and imageability**. Graph 4.3.2.a shows the frequency distribution for the **final complexity** score derived by SourceRater for the health information documents in the HTRC.

Graph 4.3.2.a Distribution of Complexity Score Computed by ETS' SourceRater for documents in HTRC, N=430



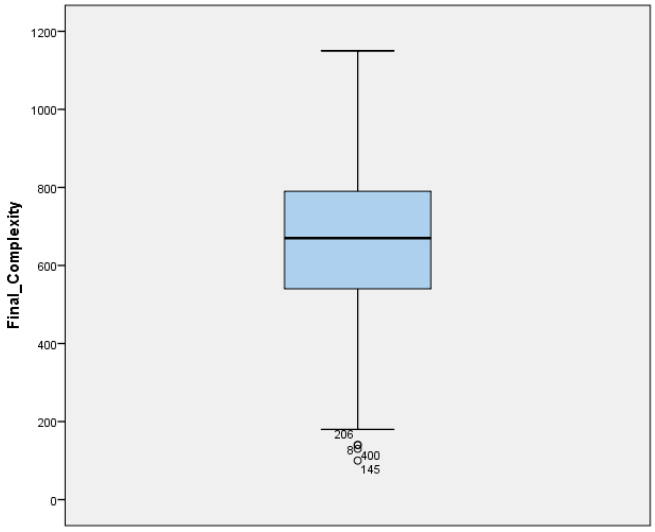
This graph shows that documents in the HTRC have a mean **final complexity** score of 664 with wide variability among documents in the corpus (measured on a scale between 0-2000; higher scores indicate higher levels of complexity), indicating that these documents are appropriate for the 7th grade according to the Common Core standards[36] (Napolitano, Sheehan, & Mundkowsky, 2015). It is important to remember that Common Core standards represent what students are *supposed* to know at each grade level based on an educational framework focused on college readiness, rather than what they actually

[35] SourceRater **word unfamiliarity** score, which indicates the quantity of rare words in a text and is computed using two different word frequency lists, is different from the Coh-Metrix **familiarity** score discussed in Section 4.3.1.

[36] SourceRater provides an alignment table showing the expected ranges of complexity relative to a targeted grade level, which has been externally validated by the Common Core (Sheehan et al., 2015).

know. Considering that the participants in this study have limited experience with formal education, this **final complexity** score based on the Common Core standards suggests that documents in the HTRC have a level of complexity that might be too difficult for adults who are learning to read (Napolitano, Sheehan, & Mundkowsky, 2015). Sections 4.3.3, 4.3.4, 4.5.2, and 4.5.3 will discuss the difficulty participants experienced when reading these documents due to some of these factors, such as the medical and scientific language used in these documents, the use of abbreviations, and the use bulleted lists.

Graph 4.3.2.b Boxplot of Complexity Scores Computed by ETS' SourceRater for documents in HTRC, N=430



The graph above shows that **final complexity** scores for 50% of the health information documents in the HTRC fall in the 600-800 range, which indicates that many of these documents contain vocabulary that is conceptually difficult. This characteristic contributes to the reading difficulty of the documents, particularly for adults who are learning to read.

Vocabulary features that contribute to the **final complexity** score provided by SourceRater for the documents in the HTRC include the use of **academic vocabulary**,

abstract words, and a measure of how **rare words** are in the English language (based on the assumption that the rarer a word is, the less likely someone is to have encountered it before).

Table 4.3.2.a SourceRater Vocabulary Features, N=430

Feature	Range*	Mean	Standard Deviation
Academic Vocabulary	34 - 87	62	10
Concreteness and Imageability	25 - 89	51	11
Word Unfamiliarity	44 - 101	75	10
Final Complexity	100 - 1150	664	188

*All scored from 0-100, where 100 indicates maximum complexity.

Consistent with the CohMetrix analysis, the ETS data shows that content words used in these health information documents tend to be rather somewhat difficult to conceptualize (reflected by the mean **concreteness** and **imageability** score of 51 in Table 4.3.2.a). Content words are words that carry meaning including nouns, verbs, adjectives, as opposed to function words which serve grammatical, discourse or structural purposes such as ‘however’ or ‘not.’ More importantly, health information documents in this corpus have a mean **academic vocabulary** score of 62, and a mean **word unfamiliarity** score of 75, all out of a possible 100. This data indicates the presence of highly specific yet conceptually difficulty vocabulary in the HTRC documents. This is unsurprising given the use of specialized vocabulary related to anatomy, treatments, drugs, and medical procedures in health information documents that is not well known to participants in this study. Remember, these scores are based on studies with human subjects who can read college-level texts. This finding indicates that these terms are so rare that adults who are learning to read might not have encountered them before. These

readers are also likely to have difficulty associating this highly specific and technical vocabulary to their known vocabulary. The next section presents results of the usability data collected during Phase II which help to contextualize the Phase I findings related to how the vocabulary used in these documents contributes to their reading difficulty for adults who are learning to read.

4.3.3 The use of academic vocabulary makes health information difficulty to read for adults who are learning to read.

Usability data collected during Phase II of this study shows the extent to which participants experienced the impact of technical words and specialized vocabulary on the difficulty of reading health information. (A full description of adults who participated in this study is available in Section 3.2.3.3). When evaluating the IBS document for this study, for example, Mary, a 53 year old woman who reads independently found the generic drug name, Loperamide, problematic (What I Need to Know About Irritable Bowel Syndrome, p.15). Though she could read Immodium, the brand name of that drug, she had not previously encountered the generic drug name, and this was a challenge for her when reading the document. Her knowledge of Immodium shows that she knows words that most children might not know while her lack of familiarity with the generic name reflects her position of knowing some words that children are unlikely to know but still having gaps. In addition to generic drug names, when evaluating health information documents for this study, most participants also found that anatomical and medical terms were problematic. Fourteen participants including phonics readers and adults who read aloud had trouble with medical, anatomical or otherwise health-related vocabulary including “chemotherapy,” “anemia,” “virus,” “vaccine,” “organs,” and “jaundice.” For

example, Peter, a 56 year old man who reads aloud, could not read the word “organs” in this passage from the Hepatitis A document: “Inflammation is swelling that occurs when tissues of the body become injured or infected. Inflammation can cause organs to not work properly.”

In the example above, Peter had no trouble reading the word “inflammation.” Like Mary, above, who could read another 4-syllable word (Immodium), their usability data contradicts the assumption of traditional readability formulas that longer words (e.g. ‘inflammation’) are more difficult to read than are shorter words (e.g. ‘organs’). Tools like CohMetrix and ETS offer a more sophisticated measure of vocabulary for adults who are learning to read. It is possible that broad scientific terms with low **hypernymy** scores such as ‘organ,’ might be more difficult for adults who are learning to read than are more specific health terms such as ‘inflammation.’ Even **word frequency** itself is a more useful measure of reading difficulty than word length (Brysbaert, Mandera, McCormick, Keuleers, 2018). It is reasonable to assume that the word “organ,” though considerably shorter than “inflammation,” is simply less frequently encountered than the word “inflammation” in the everyday health information practices of adults who are learning to read. The word “organ,” after all, is a scientific term that classifies an anatomical part of the human body, and this term might be commonly used in certain contexts such as scientific or medical literature that are less familiar to adults who are learning to read. Adults who are learning to read often have not completed formal secondary education, which means many have not taken a secondary level education in science and therefore might not have encountered the word “organ” in its scientific context very often if at all. The word “inflammation,” on the other hand, is a common condition that many adults

who are learning to read are likely to have experienced in their lifetime and therefore, they might have seen it written in a document before. In fact, a comparison between 'internal organ' and 'inflammation' on the Google Ngram Viewer[37] revealed that 'inflammation' occurs much more in its corpus than 'internal organ.'

In addition to anatomical and medical language, vocabulary related to health topics was also problematic for participants in this study. Words that describe what the documents are about such as "anemia," "chemotherapy," "irritable bowel syndrome," and "hepatitis" are especially challenging for phonics readers. One participant who is a phonics reader, for instance, read "hospital" instead of "hepatitis." Nine participants including phonics readers and adults who read aloud also had difficulty reading "irritable bowel syndrome" and "anemia." Again, it is important to stress that just because a participant could not read content words did not mean he did not know what these words meant. Five participants had heard of anemia before and could offer a layperson's definition of the condition as having to do with a problem with your blood that could be treated by eating leafy greens. This is a good example of the discrepancy between vocabulary knowledge and reading ability, especially for adults who are phonics readers and for adults who read aloud.

4.3.4 Acronyms and contractions contribute to the difficulty of reading health information for adults who are learning to read.

The results of Phase II yielded findings related to vocabulary use that were not part of the results of Phase I, but that are nevertheless important factors that affect the readability of health information. In addition to experiencing difficulty with medical and

[37] https://books.google.com/ngrams

scientific vocabulary as discussed in the previous section (4.3.3), several participants in Phase II of this study also found reading acronyms and contractions problematic. For example, Wilson and Ana (phonics readers) and Elliot (who reads aloud) all had trouble reading acronyms such as IBS, a common abbreviation of irritable bowel syndrome, despite the inclusion of the abbreviation after its unabbreviated form, as is conventional in these documents:

Figure 4.3.4.a

The image in Figure 4.3.3.a shows the heading of the section on page 1 which introduces the health topic of the document. This is the only place in the document where there is an explicit link between the full name of the health condition and its medical abbreviation. It is therefore not surprising that participants who had trouble reading IBS did not make the connection between the acronym and its unabbreviated form, especially if they are also unfamiliar with the convention of presenting the abbreviation in parentheses after the unabbreviated name of the health condition. Though IBS is a commonly used term within this health information context—particularly for practitioners and people who have been diagnosed by this condition—reading acronyms is not a common practice among adults who are learning to read according to my training as a tutor at the Brooklyn Public Library's Adult Learning Center. Reading abbreviations in general, and knowing that acronyms are a common type of abbreviation, requires more experience with reading and writing than that of participants in this study. In fact, learning to read common abbreviations related to titles, salutations, dates, and addresses, for example, are part of

the literacy curriculum at the Brooklyn Public Library's Adult Learning Center for more advanced learners. Medical abbreviations and other specialized abbreviations, however, are not explicitly part of this curriculum. This is important considering the specialized abbreviations regularly used in the healthcare context. In addition to the IBS example mentioned above, commonly used medical abbreviations for health conditions include COPD, HPV, ADD, and AIDS, just to name a few. This finding suggests, unsurprisingly, that health information materials that include commonly used healthcare abbreviations are likely to pose a challenge for adults who are learning to read. Remarkably, this is not specified in the professional guidelines for writing easy-to-read health materials.

In addition to having trouble reading acronyms in the health information documents they evaluated, participants who are phonics readers and those who read aloud also had difficulty reading contractions and their related adverbs, prepositions, and conjunctions. Ana, a phonics reader, as well as Peter and Claire, who read aloud, often read "can" instead of "cannot," "do" instead "don't" or "doesn't," and "of" instead of "for." These high-frequency words are considered "sight words," referring to words that more experienced readers identify on sight instead of having to sound them out. To be sure, misreading sight words is a problem for anyone, regardless of age, who is learning to read (Torgesen, 2002). That said, misreading sight words such as the ones that gave trouble to participants in this study may constitute a critical error for readers of health information documents. The documents in the HTRC often include health advice on ways to manage a health condition by implementing certain practices or advice regarding decisions that affect the way people carry out their daily health practices such as ways of managing symptoms. Misreading this advice by essentially reading the opposite of what

is written (e.g. reading “do” instead of “don’t”) can have serious negative and sometimes dangerous consequences.

4.4 How Syntax Affects the Readability of Health Information

In addition to vocabulary, the structure of sentences has long been known to be a key factor that contributes to text readability. Sentences with many clauses tend to be longer and also more complex than short sentences without relative or dependent clauses. As noted above, the Flesch Kincaid readability formula uses sentence length as an indicator of sentence complexity (Flesch, 1948). This formula, however, is not able to identify a difference in readability for sentences that are the same length but with different syntactic structures. More sophisticated tools that can identify sentence structure, such as CohMetrix, are better suited to analyze how syntax affects document readability.

An important finding of the Phase I linguistic analysis for documents in the HTRC is that, despite having long sentences, documents in the corpus are, on average, structurally simple, which contributes positively to the readability of the documents in the corpus. This is to say, though the documents in the HTRC have long sentences, these long sentences have simple syntax, which contradicts the assumption on which traditional readability formulas are based. As reported in Section 4.2, the mean CohMetrix **syntactic simplicity** score for the documents in this corpus is .68 (SD=.70), which indicates that documents in the HTRC contain sentences with relatively simple syntax. Similarly, the results of the SourceRater analysis found that documents in this corpus have a relatively low mean **syntactic complexity** score of 37 out of a possible 100. Keep in mind that SourceRater’s syntactic complexity feature measures the opposite of CohMetrix’s

syntactic simplicity. The Language Muse® analysis of HTRC documents indicates the average number of **complex clauses** per document lies near the bottom of the range (20.7), which is consistent with both CohMetrix and SourceRater. All this indicates that sentences in the HTRC documents are structurally simple, though the large standard deviation (17.6) for complex clauses indicates there is large variability for this measure among documents in the corpus.

A more granular look at two example sentences from the Hepatitis A document in this corpus illustrates the advantage of using syntactic analysis instead of relying on sentence length to identify syntactic complexity.

Table 4.4.a Sentence Length, Syntax, and Flesch Kincaid Grade Level for Example Sentences

Ex #	Example Sentence	Sentence length, number of words	CohMetrix Syntactic Simplicity, z-score*	Flesch Kincaid Grade Level
4.4.a	See a doctor right away if you or a child in your care has symptoms of hepatitis A.	18	-0.079	7th grade
4.4.b	A blood sample is taken using a needle inserted into a vein in your arm or hand.	17	0.957	7th grade

*CohMetrix syntactic complexity scores are not based on a range, but are given as z-scores which represent standard deviations from the mean for the training corpus.

Table 4.4.a shows the number words in each sample sentence (used by the Flesch Kincaid formula as a measure of syntactic complexity), the syntactic simplicity score provided by CohMetrix, and the Flesch Kincaid Grade Level. As expected, examples 4.4.a and 4.4.b, which do not vary greatly in sentence length, also do not differ in reading grade level assigned by the Flesch Kincaid Grade Level formula. However, the CohMetrix results show that these sentences indeed vary in terms of the complexity of their syntactic

structure. The CohMetrix syntactic simplicity scores indicate that example 4.4.b is easier to read than 4.4.a as 4.4.b's z-score deviates more from the mean for documents in the CohMetrix training corpus in a positive direction. This means that it has a more simple sentence structure than sentences in the K-12 documents in the CohMetrix training corpus. The z-score for syntactic simplicity for example 4.4.a is slightly less than the mean for documents in the CohMetrix training corpus. Although 4.4.a and 4.4.b are almost the same length and have the same 7th grade Flesch Kincaid Grade Level (which corresponds with the recommendations in the MedlinePlus Easy-to-Read guidelines), the CohMetrix scores show a difference in readability due to syntax. These examples again highlight the limitations of using the traditional readability formulas to assess the readability of health information documents, and at the same time, they show the usefulness of tools like CohMetrix that are better able to identify linguistic features directly associated with sentence structure rather than using indirect measures of syntax such as sentence length.

As this analysis has shown, sentence length is not a sufficiently specific measure of syntactic simplicity, which puts into question the professional practice of using traditional readability formulas to assess the readability of health information documents. That professionals use simple syntax when creating these health information materials for adults who are learning to read is reassuring, but it does not explain why these documents are still considered difficult to read by adults who are learning to read (see Section 4.7.1). Though data collected during Phase II of the study did not yield findings that are directly related to the effects of sentence structure on readability, participants did report issues related to cohesion, some of which, at least, are related to syntax. The following section

discusses how features related to overall **text cohesion** and **narrativity** affect the readability of documents in the HTRC.

4.5 Cohesion Contributes to the Difficulty of Reading Health Information

An integrated analysis of the data collected in both phases of the study found that part of what makes reading consumer health information documents difficult for adults who are learning to read is their lack of cohesion. Cohesion, simply put, indicates the degree to which relationships between concepts and ideas are explicit throughout a text (McNamara, Graesser, McCarthy, & Cai, 2014). Several linguistic features contribute to the cohesion of text. Function words or phrases such as "although," "however," and "also" connect ideas and help users make inferences when reading. Words or phrases that represents discourse relationships in text, such as cause and effect relationships such as "because," as well as concept overlap, which represents the development of an idea across segments of text or across sentences, also help the reader to connect ideas present in the text in specific ways. The amount of cohesion in a text, which helps readers to make inferences when reading, affects how easy or difficult it is to read. This section will first present findings related to cohesion resulting from the analysis of Phase I of this study, and will subsequently present evidence of reading difficulty that participants experienced due to the HTRC documents' low cohesion.

4.5.1 Health Information Documents Lack Cohesion

CohMetrix and ETS' SourceRater both provide measures of linguistic features associated with cohesion, including referential cohesion, deep cohesion, connectivity, argumentation, and lexical cohesion features. The tables below present the scores for features related to cohesion measured by each tool.

Table 4.5.1.a CohMetrix Cohesion Feature Scores for HTRC, z-scores, N=496

Feature	Range*	Mean	Standard Deviation
Referential cohesion	-2.10 - 3.10	-.107	.853
Deep cohesion	-1.94 - 3.46	.744	.656
Connectivity	-9.09 - .446	-3.12	1.12

*Scores are reported as z-scores which represent the number of standard deviations a raw data point is from the mean of the training corpus.

Table 4.5.1.b SourceRater Complexity Feature Scores for HTRC, N = 430

Feature	Range*	Mean	Standard Deviation
Argumentation	7 - 100	35	14
Lexical Cohesion	29 - 100	66	17

*All scored from 0-100.

The data in table 4.5.1.a shows that, although documents in the HTRC tend to explicitly contain connectives that represent causal and logical relationships as measured by **deep cohesion**, their low connectivity and referential cohesion scores indicate they nevertheless generally lack specific words that explicitly express logical relationships among concepts. As discussed in Section 4.2, the CohMetrix analysis indicates that this lack of **connectivity,** which measures the presence of connective words such as "and," "or," "also," and "but," contributes to the difficulty of reading health information documents (See Table 4.5.1.a above). Similarly, the SourceRater analysis found that documents in this corpus have a low mean **argumentation** score of 35 out of a possible 100, indicating an overall lack of words and phrases common in informational text such as "although," "however," "as a result," and "for this reason.[38]" When these connective words are missing from text, the reader must guess what type of logical relationship

[38] See section 3.1.3.1 for a description of SourceRater features.

exists between text segments or ideas presented in the text. The reader must decide, with little support from the text, whether ideas are complementary or contrasting, for example. This is challenging for readers who have little experience reading or who have low domain knowledge. Adults who are learning to read might have both little reading experience and low knowledge of the health topic described in the document. When reading health information, this can contribute to reading difficulty and to negative evaluations of health information. This was evident in the data collected during Phase II of the study, discussed in Section 4.5.2.

Example 4.5.1.a Health text that with low cohesion

> **Mental health issues**. **Psychological**, or mental health, issues such as anxiety or depression may be related to IBS in some people. Stress can make the nerves of your gut more sensitive, causing more discomfort and emotional distress.
> (IBS document, pg. 6)

The example above shows an excerpt from a document in the HTRC with a **connectivity** score of -5.869, which indicates it lacks words or phrases that make connections between sentences, in this case words that connect 'stress' in the third sentence to the concepts introduced in the second sentence. It is important to note that the phrase that appears in blue is a subsection heading, but is presented as a sentence that is part of that block of text. Only the bold type and color treatment distinguish it from the rest of the sentences in the section—a cue that an inexperienced reader might miss when reading, especially since the word "psychological" also appears in bold type to signal its inclusion in a pronunciation guide provided at the end of the pamphlet. The low connectivity score for Example 4.5.1.a is a contributing factor to the lack of cohesion in this text segment.

Discourse relations can also indicate the level of cohesion in text. It is reasonable to expect that consumer health information, which provides a certain amount of medical advice, should include certain types of discourse relations associated with informational texts such as cause and effect, evidence, and persuasion (Madnani, Burstein, Sabatini, Biggers, & Andreyev, 2016). Table 4.5.1c below shows the raw counts of different **discourse relationships** represented in the health information documents that form part of the HTRC.

Table 4.5.1.c Counts of Discourse Relations in HTRC by Language Muse® , N=430

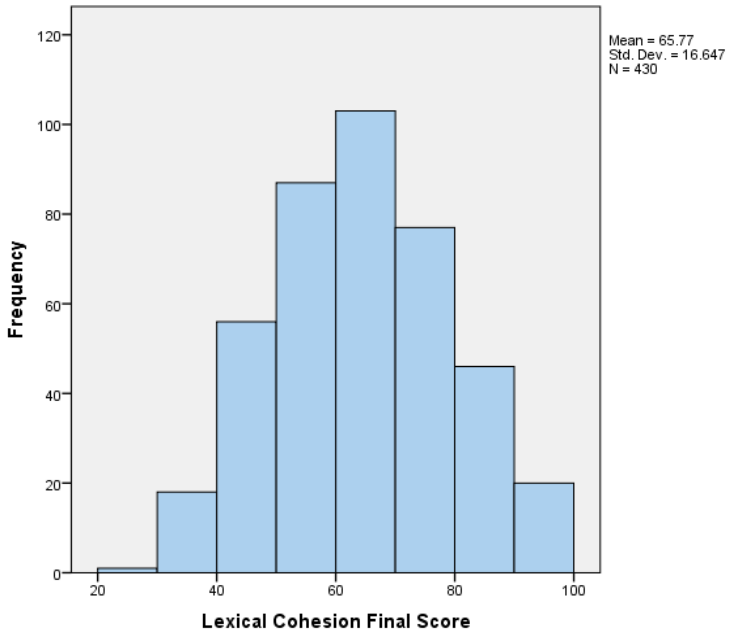
Discourse Relation	Range	Mean	Standard Deviation
Cause and Effect	0 - 19	1.71	2.50
Contrast	0 - 41	5.18	5.53
Evidence and Details	0 - 106	19.2	17.1
Opinion and Inferences	0 - 20	1.51	2.22
Persuasion	0 - 6	.40	.854
Summary	0 - 3	.11	.401

The table above shows that documents in the HTRC have a very low mean number of **cause and effect relationships** ($M_{cause\&effect}$= 1.71) and an even lower mean number of **persuasive relationships** ($M_{persuasion}$= .40) and **summary relations (** $M_{summary}$= .11). This suggests, documents in the HTRC do not contain language that makes explicit the development of ideas that represent cause and effect, persuasion, or summarization of information, all of which can help inexperienced readers and those who lack sufficient topic knowledge make inferences when they read. Documents in this corpus also vary greatly with respect to discourse relations that represent evidence and supporting details ($M_{evidence}$= 19, s=17.1). Though **evidence and detail relationships** are more explicit in

these documents than are other discourse relations commonly found in informational texts, they are still rather infrequent. The lack of discourse relationships found in the HTRC means that health information lacks explicit cohesive cues that help readers make inferences. This is especially problematic in the context of health information for adults who are learning to read.

In addition to connective words and phrases that explicitly state logical relationships, the way ideas and concepts are developed in a text also affects cohesion. The CohMetrix analysis found that part of what makes health information documents in this corpus difficult to read is their low **referential cohesion** scores, which refers to the amount of concept overlap between sentences, ($M_{\text{referential cohesion}} = -.107$). The SourceRater analysis measured a related feature called **lexical cohesion**, which refers to the overlap in meaning across sentences, and found documents in this corpus have a mean **lexical cohesion** score of 66 out of 100.

Graph 4.5.1.a Frequency Distribution Histogram for SourceRater's Lexical Complexity



As the graph above shows, almost half of the documents in the HTRC score below 60 for **lexical cohesion**. A likely hypothesis is that health information documents that score poorly on these measures, such as the documents in the HTRC, do not adequately support adults who are learning to read or those with low topic knowledge as they make inferences when reading. The following section presents findings from the usability studies conducted during Phase II that shows how cohesion contributed to the difficulty participants experienced when reading health information documents.

4.5.2 How Cohesion Affects the Readability of Health Information for Adults Who Are Learning to Read

Cohesion was a factor in the way five participants evaluated health information during this study. When evaluating the Anemia document, Grace agreed with the statement, "Balance rest with activity," but she interpreted the following statement as advising the patient to get a lot of rest: "Take short naps during the day. Short naps of less than 1 hour are best. Too much bed rest can make you feel weak." (Managing Chemotherapy Side Effects: Anemia, p. 1). She asked, "When you are weak, what can you do?" Grace further explained that if one is already weak, there is not much you can do to feel less tired other than to rest. Because of this, she gave this section a negative evaluation. Thomas and Joan had similar negative reactions to this section in the same document, and explained that the advice presented was inconsistent with their understanding of weakness resulting from chemotherapy.

A possible explanation for these negative evaluations is the lack of cohesion in that text passage, the result of relatively short sentences that are not linked by connective words. The use of explicit causal connectives would clarify the connections between the

ideas, and would help the reader make the proper inference, diminishing the risk of misinterpretation. In the alternate versions of this passage below, the suggested version uses the logical connectives ‘because’ and ‘in order to’ and alters the order of the arguments that are presented.

Example 4.5.2.a Managing Chemotherapy Side Effects: Anemia, page 1

Original: Balance rest with activity. Take short naps during the day. Short naps of less than 1 hour are best. Too much bed rest can make you feel weak.

Suggested: Balance rest with activity. Take short naps during the day because you can feel weak from too much bed rest. You can avoid feeling weak by taking naps that last less than 1 hour.

The last two sentences in the suggested version above deliberately repeat an important idea in this passage: that sleeping too much can cause fatigue. The third sentence links back to the first, providing information that supports and develops the main idea. Developing an idea by overlapping words and concepts across segments or sentences reduces the burden on the reader when making inferences (Graesser, McNamara & Louwerse, 2003). It diminishes how much a reader must guess at the relationships between ideas. When concepts, words, and ideas do not overlap like this, reading health information can be more difficult.

An example of how gaps in cohesion affect the way adults who are learning to read evaluate health information was evident in Mary’s negative evaluation of information on how people can contract Hepatitis A. In the passage below, Mary did not understand what coming in contact with stool has to do with drinking untreated water or eating food washed in untreated water:

Example 4.5.2.b What I need to know about Hepatitis A, page 3

You could get hepatitis A through contact with an infected person's stool. This contact could occur by

● eating food made by an infected person who didn't wash his or her hands after using the bathroom

● drinking untreated water or eating food washed in untreated water.

In 4.5.2.b, the relationship between untreated water and human waste or stool is implied but not explicitly stated—there is no explicit concept overlap or connection between the first sentence in this passage and the last phrase. This text should explain that untreated water can include bacteria found in stool as a way of eliminating this gap in cohesion. This participant's negative evaluation of this passage highlights the importance of reducing the number of inferences an emerging reader needs to make when reading a text. Underlying assumptions need to be made explicit in text written for these adults. The less information the reader must fill in on her own, the better—especially when the topic is unfamiliar or related to health information. This can help to diminish misinterpretations and will make the information easier to read and, ultimately, to use.

Text that has low cohesion, such as the documents in the Health Text Readability Corpus, requires that a reader fill in the gaps in the text with little or no support from the text itself. This is especially challenging for less experienced readers including adults who are learning to read, and often results in their experiencing difficulty when reading health information, as was the case during the usability studies conducted in Phase II. Importantly, making the wrong inferences when reading health information can not only result in a reader determining that health information is not useful, as the findings from

the user studies show, but it can also lead to critically misunderstanding the health advice provided by these documents.

4.5.2.1 Skipping Over Unknown Words Can Affect Cohesion.

A common practice among adults who are learning to read is skipping over unknown words. This practice contributed to the difficulty of reading health information documents for participants in this study. Though this is a common practice among readers in general regardless of reading experience, adults who are learning to read do it more often. How less experienced readers resolve these skipped words tends to result in more errors than when other, more experienced, readers do this (Nicholson, Bailey, & McArthur, 2006; Nicholson, 1993). When participants skipped or jumped over words they could not read, this spotty reading resulted in coherence gaps that affected the way they made inferences. Gaps in cohesion, whether they are gaps already present in the text as discussed in section 4.5, or whether they are the result of this skipping practice, ultimately affect the meaning a reader can construct when reading. Claire, who reads aloud, explains that she skips words she cannot read as she reads aloud: “It’s hard because some words I have to jump over so I don’t get the full understanding, but I’m still reading.” This explicit distinction between reading and understanding, echoes prior research that conceptualizes reading as a complex process encompassing more than decoding letters into sounds (Duke and Carlisle, 2011). In other words, sounding out words and forming meaning while reading are different aspects of the reading process, as Claire reports.

To fill in cohesion gaps that result from skipping over unfamiliar words, participants who read aloud often substitute a known word for the unknown word based

on contextual cues. Fortunately, this practice often resulted in a sentence that was grammatical since participants tended to substitute for a word that is the same part of speech as the target word (i.e. a noun for a noun). What is more, the resulting sentence also often maintained a similar meaning to the original sentence if the adult emerging reader substitutes a word that is synonymous with the unknown word. For example, Elliot read "belly" instead of "abdomen" in the following sentence when evaluating the IBS document:

Example 4.5.2.1.a What I need to know about Irritable Bowel Syndrome, page 2

The most common symptoms of IBS include pain or discomfort in your **abdomen**—the area between your chest and hips—and changes in your bowel habits.

During the usability sessions, this often resulted in a grammatical sentence that maintained close fidelity with the original sentence. Sometimes, however, this practice caused coherence problems or gaps. If the reader does not know much about the topic discussed in the text or if the text is not very cohesive, there are few contextual cues available to the reader to use as a way of finding an appropriate synonym. In this case, an adult who is learning to read may substitute a word that is the same part of speech as the target word, but that is not synonymous with it. There is no way for the reader to know with certainty that the new meaning of the sentence is not the intended or most likely meaning. To the adult who is learning to read, it sounds like a grammatical sentence, so it sounds correct, but may not make much sense. An example of this phenomenon was when Anthony read "herpes" instead of "hepatits:" "You could get [**hepatitis/herpes**] A through contact with an infected person's stool" (What I need to know about Hepatitis A, p. 3). Later in that same page, the same participant read "breakfast" instead of "bathroom:" "…eating food made by an infected person who didn't wash his or her hands

after using the [**bathroom/breakfast**]" (What I need to know about Hepatitis A, page 3). Other examples of this include Curtis, who also read "herpes" instead of "hepatitis," and Claire who read "protein" instead of "cholesterol" (Hep A document). Cohesion gaps like these that result in altered meanings have serious implications when considering the delicate nature of health information and the reader's ability to use health information to manage his or her health. These errors that adults who are learning to read make when reading, and the resulting cohesion gaps, are difficult if not impossible for computational methods to identify. This highlights the importance of conducting qualitative work with adults who are learning to read.

4.5.3 The Use of Lists in Health Information Documents Affects Their Readability

An important characteristic of the health information documents used in this analysis was the use of lists. In these documents, lists were either embedded in paragraphs or they were presented as bulleted lists. Regardless of the way the lists were presented in the documents, reading lists was challenging for the participants in this study. Grace, for instance, misread the following list as all inclusive instead of as a list of options: 'Would taking medicine, iron pills, or getting a blood transfusion help me?" She seemed to ignore or fail to notice the word "or," and responded, "I don't think *all* these will help you…" Lists that present a number of options or choices, and that include the word "and," such as the list in the following passage, were also problematic for participants:

Example 4.5.3.a Excerpt from Anemia document, pg. 2

> You may need to eat foods with iron. Red meat, leafy greens (such as collard greens and spinach), and cooked dried beans are good choices."

Mary gave this section a negative evaluation and explained, "people on chemotherapy cannot eat ***all*** of this." Instead of inferring that these are options from which to choose one or two foods that will help someone suffering from anemia, this participant inferred that a patient must eat all of these foods. Lists that use conjunctions seem to be problematic for adult emerging readers.

Health literacy guidelines for writing easy to read health information explicitly recommend the use of bulleted lists in order to make health information easier to read and this may account for their abundance in these types of documents: "Where appropriate, use bulleted lists instead of blocks of text to make information more readable. Dense blocks of text can be difficult to read" (U.S. National Library of Medicine, 2017). Bulleted lists, however, often omit connective words such as "and," "or," "because," "however," "although," "also," and "but" that help readers make inferences between sentences and ideas (Graesser, McNamara, & Louwerse, 2003). As reported in Section 4.2, the CohMetrix **connectivity** score for documents in the HTRC is -3.12 (s=1.12), which reflects the lack of such connective words.

Bulleted lists are particularly problematic for readers who have little experience reading information presented in this condensed format (Morales, 2017). This underscores the role that literacy, the learned practice of reading certain types of text, plays in the evaluation of health information. Participants in this study did not always know what to do with a bulleted list. Three participants (Claire, Anthony, and Curtis)

interpreted bulleted lists as multiple choice questions or fill in the blank exercises. Anthony was unsure what to do with a section of the Anemia document listing reasons you should call a doctor: “Do I circle one of these? Do I fill in the blank? What do I do?” He thought this was a fill-in-the-blank exercise and asked me to add the word ‘sick’ as his response. This might be because in his experience in the library’s adult literacy program, he completes exercises and answers test questions that are formatted in a similar way using colons followed by a list of response choices or followed by a blank space that students must fill in with the correct response. Curtis reported also having “seen boxes like this before on tests,” referring to the purple box of bulleted items on page 3 of the Hepatitis A document. Bulleted lists were especially problematic for adults who read aloud since, when reading aloud, these sound like questions the readers ask of themselves.

Participants generally perceived bullets as helpful even when they misinterpreted bulleted lists. Robert, Thomas, and Mary correctly assumed that bullet points signal information that is important and that they should pay attention to. Adults who read silently and independently had less trouble with bulleted lists. This suggests that being able to use bulleted information is a learned practice and is associated with more reading experience. Health literacy professionals who develop materials for phonics readers and for those who read aloud need to carefully consider the use of bulleted lists since presenting information in this format does not support the reading practices of adults who do not read independently.

The analysis of the health information documents in the HTRC using both CohMetrix and ETS’ SourceRater tools suggests that readers might need to infer more

from the text than what is explicitly stated, and this has serious implications for health information and for adult emerging readers specifically (McNamara et al., 2014; Ozuru et al., 2009; Tarchi, 2010). If readers have low domain knowledge, as can often be the case with health information, and if the text they are reading has low cohesion, comprehension can suffer (Graesser, Olde & Klettke, 2002; McNamara et al, 2014). Indeed, gaps in cohesion made the health information documents they were evaluating difficult to read for participants who are phonics readers and those who read aloud.

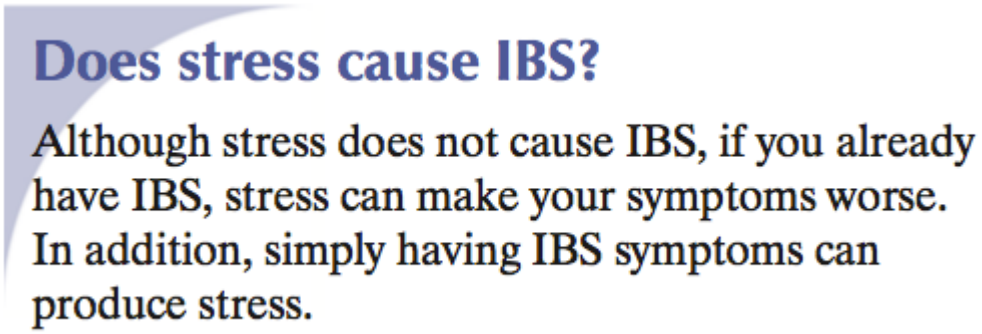
4.6 Writing Style Contributes to the Difficulty of Reading Health Information

In addition to having low cohesion, another feature that contributes to the difficulty of reading health information is writing style. Evidence for this observation comes from the CohMetrix analysis of the documents in the HTRC conducted in Phase I of the study, which found documents in this corpus have a low **narrativity** score ($M_{narrativity}$ = -.684, s = -.5852). As mentioned in Section 4.2, CohMetrix's **narrativity** feature measures how closely text resembles oral, everyday speech and, as such, is associated with world knowledge and word familiarity (McNamara, et al., 2014). High **narrativity** tends to characterize texts that tell a story. The assumption is that, regardless of reading experience, people have more experience with spoken language than with written language, so text that reads the way we speak tends to be easier to read. The SourceRater analysis similarly found that health information documents in this corpus have a mean **conversational style** score of 40 out of a possible 100 (s= 12). For inexperienced readers, such as adults who are learning to read, text that deviates too much from everyday language can be difficult to read. This analysis indicates that the lack of narrativity or a

conversational style in consumer health information documents contributes to the difficulty of reading these materials, particularly for these adults.

An important example of how the conversational style appears in HTRC documents is the question-and-answer format used to organize information. Section headers are often posed in the form of a question.

Figure 4.6.a



As recommended by the guidelines, professionals use this Q&A format as a way to present information in a more engaging way. Nevertheless, information presented in the form of questions in the text was often confusing for participants. Participants, especially those who read aloud, interpreted these as questions they needed to answer, as in a test. For example, under the section "Questions to ask your doctor or nurse" of the Anemia document, Grace, who reads independently, wrote an answer to the question: "Would taking medicine, iron pills, or getting a blood transfusion help me?" She wrote, "I don't think all these will help you, rather eat healthy food will help you." This was especially evident in adults who read aloud since, when reading aloud, it sounded like the participants were posing the questions to themselves. Information presented in the form of questions followed by a set of bullets was also confusing for Robinson, who reads aloud. He thought these were questions he needed to answer, as in a test. As an answer to the question, "What problems should I call you about?" (appearing under the section,

"Questions to ask your doctor or nurse,") Robinson wrote in, "a brook harm" [a broken arm] (Anemia document, p. 2). It is important to remember that participants in this study are familiar with testing (See Section 4.5.3), and they may associate informational texts, or even their experience in the usability study, with tests they have taken in the past. This may account for the way they interpreted the questions they found in the health information documents they evaluated.

The usability study, as much as it was designed to minimize the perception that it was a testing environment, nevertheless resembled one in an important respect: a reader was given a text to read, and then answered questions about that text, just as they do when they take standardized reading comprehension tests at the Adult Learning Center. It is important, then, for professionals to carefully consider the way they implement a more conversational style when they create these types of documents. The Q&A format, as was evident in this study, can confuse adults who are learning to read. A writing style that better resembles spoken language might indeed improve the readability of health information, but what exactly characterizes such a style in the context of health information documents and the extent to which this is helpful for adults who are learning to read still needs more research.

Despite recommendations to write health information documents in a style that is personal, engaging, and that includes stories by way of providing examples (U.S. National Library of Medicine, 2017), most of these documents are not written in an everyday conversational style. Health literacy guidelines fail to explain how professionals can accomplish this difficult task in order to turn an informational text into a text that reads more like a story. Further research is needed to investigate the specific narrative

structures that can improve the readability of health information and that better supports adults who are learning to read.

Though beyond the scope of this work, research suggests there is a relationship between narrativity, writing style, and cohesion that would make informational texts such as health information easier to read for adults who are learning to read. What is evident from the integrated analysis of Phase I and Phase II of this study is that the type of vocabulary used in these documents, their overall lack of cohesion, and their writing style contribute to their reading difficulty despite the simple syntax used in these documents. For this reason, it is imperative that practitioners recognize the limitations of using traditional readability formulas as indicators of readability. Equally important is that health information professionals also understand that linguistic analysis alone does not capture the complexity of this problem. As Sections 4.7-4.9 discuss, sociotechnical practices like learning to read and the personal characteristics of the reader also affect the readability of health information.

4.7 Reading Practices of Adults Who Are Learning to Read

In addition to linguistic features that affect the readability of health information which can be identified by computational methods and by adults who are learning to read, this study also investigated factors such as participant characteristics which are difficult for computational methods to measure. The rest of this chapter reports on findings that resulted from an analysis of Phase II, but which were not part of the Phase I findings, including how participants' reading practices, perceptions of readability, prior knowledge, and personal experience affect the readability of health information for adults who are learning to read. The analysis conducted as part of this study also included the

perceptions of adult emerging readers about the readability of easy-to-read health information and an examination of how health literacy guidelines conceptualize adult emerging readers. This section discusses these findings in more detail with the goal of providing a holistic understanding of this complex phenomenon.

Because learning to read is linked with cognitive development in childhood, there is not a lot of research that confirms its applicability to adult learners. For this reason, and because this study is based on a socio-technical practices framework, during analysis it became necessary to classify participants by the practices they exhibited during the usability study phase, rather than by their cognitive development or reading development stages. Participants whose reading practices lie at the opposite ends of the reading development continuum had very different ways of reading, and this was evident in the way they marked up the documents during the usability sessions. Appendix D includes examples of documents marked up by the three different types of participants: phonics readers, adults who read aloud, and independent readers. The classifications under the column labeled Reader Type in Table 4.7.a are based on observational data collected during the usability sessions.

Table 4.7.a Participants by Type of Reader[39] Stage

Reader Type	Number of Participants
Phonics Readers	3
Adults who read aloud	10
Independent Readers	6

[39] Though 20 participants enrolled in the study, 2 participants decided they did not wish to participate in the evaluation task of the study. It was therefore not possible to classify their reading practices.

Among the participants who completed the study, three readers sounded out words as they read. This way of reading is called phonics (Suggate, 2016), which is why I chose to describe them as phonics readers. Phonics readers, often called new or beginning readers in the literature, needed substantial support when reading the health information documents and when filling out the survey questionnaire. As they read, these participants sounded out letter patterns in a word, and they tended to read word by word, resulting in a slow staccato cadence with many stops and starts. These participants requested that I read the health information material aloud to them as they tried to silently follow along. They reported routinely receiving help from family members (wife, son, daughter, etc.) when they need to read or fill out health information. For these participants, the evaluation task was the most difficult and many were not able to evaluate all three health information documents during the time allowed for our session.

Participants also included ten adults who read aloud, and five independent readers who read silently, with very little, if any, support from other adults. Independent readers were able to fill out the survey questionnaire on their own and interacted with the documents at a deeper level, evident in the types of annotations they made on the health information documents they evaluated. Refer to example 4.5.2.1.a in which Elliot read "belly" instead of "abdomen." See Appendix D for a sample of these annotations.

The largest number of participants (10) included adults who read aloud. Reading aloud is a learned practice and is a key method of support and instruction used at the Adult Learning Center where these participants take literacy courses. Participants who read aloud often asked me to confirm a word they read. These adults read more fluently than phonics readers and they read words in context. That is, when they encounter a word

with which they are not familiar, they use contextual cues and other words they recognize in order to fill in the blank of the target word with a word that makes sense in that context, as is consistent with readers in this stage of reading development regardless of age (Chall, 1996). During Phase II of this study, the participants' practice of skipping over words or filling in meaning from contextual cues sometimes resulted in cohesion gaps even when none were explicit in the text itself. Section 4.5.2.1 discussed this specific practice and the resulting problems with cohesion that computational methods are unable to detect.

The task of evaluating health information documents was challenging for the participants in this study for several reasons. Primarily, participants were asked to read three consumer health information documents (a total of 54 pages of text and images), mark-up the documents, and to answer questions about what they read. A typical session with a participant lasted 1.5 hours. In addition to these challenges, participants were not always familiar with the health topics discussed (see Section 4.8) or with the language used in the documents (see Section 4.3). The documents themselves lacked the presence of cohesive cues that support readers when making inferences when reading (Section 4.5), and this proved problematic, especially for participants who needed substantial support when reading.

The results of this study show that adults who are learning to read are not members of a single, homogenous group, nor do they all exhibit the same reading practices. This study supports prominent theories about reading development that conceptualize the process of gaining fluency when reading and of constructing meaning from reading as a set of stages (Chall, 1996; Stall & Kuhn, 2002). Perhaps because reading is a learned

practice and is often a goal of institutionalized teaching, these stages have long been associated with grade levels and with developmental stages that coincide with age in children. The association of reading difficulty of a text with a school grade level as in the Flesch-Kincaid Grade Level formula is an example of how integrated these notions of reading development have become. One of the problems with equating reading development stages with school levels is that school levels are discrete. That is, they begin and end at specified times of the academic year, and a student's progression from one grade to the next is perceived as a discrete step. The theories of reading development stages, however, present a much more dynamic and fluid continuum of reading suggests a continuum along which reading practices develop as a reader gains greater experience with reading and writing a variety of texts (Chall, 1996; Stall & Kuhn, 2000). As readers become more experienced with certain reading practices, they do not cleanly jump a level and leave another behind. Rather, they gradually transition from one set of reading practices into another as they adopt new practices that build on earlier ones.

4.7.1 How Adults Who Are Learning to Read Emerging Perceive the Readability of Easy-to-Read Health Information

When asked during the post-task interview how difficulty each of the three test documents was to read, half of the participants found at least some of the documents they evaluated hard to read despite all documents being part of MedlinePlus' "Easy to Read" health information collection. More specifically, the three phonics readers generally felt all documents were equally difficult to read and therefore expressed no preference between the documents. The independent readers also expressed no preference for one document over another since for them, all documents were fairly easy to read. Two

important variables for participants when asked which document they found most helpful were document length and word length. When asked which document was most helpful, for example, Mary, an independent reader, identified the Anemia document because it was the shortest. Another independent reader, Thomas, explained that the Anemia document was easier because it has shorter words.

Table 4.7.1.a Syllable Counts for Documents Evaluated by Participants

Document	Mean Word Length by Syllable Count
Managing Chemotherapy Side Effects: Anemia	1.536
What I Need to Know About Irritable Bowel Syndrome	1.706
What I Need to Know About Hepatitis A	1.702

While the Anemia document indeed has the shortest words among the three prototypical documents Table 4.7.1.a shows that the average difference among the three documents is small.

Opinions about document readability varied the most among the ten participants who read aloud. Within this group, three participants expressed having no preference, but the majority of the participants in this group (n=6) had a clear preference for the Anemia document, which was the shortest of the three health information documents participants were asked to evaluate. Reasons given for this preference included the perception among participants who read aloud that the Anemia document was easiest, that it is “more to the point” (Robert), that “it got to the point faster” (Robinson), and that “less is more” (Peter). Peter and Joan made the distinction that whether or not the health information document is easy to read depends on qualities of the reader, rather than qualities of the

document, such as prior knowledge about the topics discussed in the documents, the reader's reading speed, or vocabulary knowledge. A unique finding among participants who read aloud came from Esther. She found all documents equally easy to read yet preferred the longer document because, "I learn more from the longer document."

"Too much information."

Three participants who read aloud and one independent reader felt the longer documents were too long and included "too much information." Mary, an independent reader, explained: "If I got this from my doctor, I'd shake my head. I have to read all this?" When asked how these documents could be improved, Robinson said, "Cut down information. Just get to the point. Include easy to follow recommendations on what to avoid, stay away from and what to do." Similarly, Robert explained: "Anemia is more useful. It's more to the point. It tells what to do next. Longer document is too much information. Longer document has information that is still relevant, but when you are sick you just need to know what to do." The longer documents are part of a series of health information materials published by the National Institutes of Health titled, "What I need to know about…" These health information documents are comprehensive in their coverage of specific health topics. The document on Hepatitis A, for example, not only covers what is Hepatitis A, symptoms associated with the disease, and treatment options, but it also discusses what is the liver, who is more at risk to contract Hepatitis A, and how it is diagnosed. To echo Robert's comment above, not all the information presented in these more comprehensive and, consequently, longer documents has the same level of priority for an adult who has just been diagnosed with this health condition. Two important factors to consider when striking a balance between the amount of information

to provide and what information a reader needs are personal characteristics such as prior knowledge and personal experience, each of which is discussed in the final sections of this chapter.

4.8 How the Reader's Prior Knowledge Affects the Readability of Health Information

This study conceptualizes consumer health information documents as instantiations of professional health literacy practices concerned with readability. In this way, reading involves more than simply the language used in the document by health literacy professionals. A reader's prior knowledge also plays an important role in reading and in the way readers evaluate health information. When text lacks cohesion, as is the case for documents in the HTRC, prior knowledge is instrumental in helping readers make inferences as they read, which ultimately affects the way readers evaluate health information. Making inferences from text that lacks cohesion is especially difficult for inexperienced readers and for those with low topic knowledge.

According to the pre-task interview question asking about the participant's knowledge of the health topics, most participants had no specific knowledge of any of the three main topics represented in the health information documents they were asked to evaluate. Nevertheless, they used what prior knowledge of health they did have to evaluate the usefulness and quality of the health information documents they read. Participants in this study had a layperson's understanding of what health practices are necessary to lead a healthy life, such as maintaining a healthy diet. Out of the three main document topics—Anemia, Hepatitis A, and Irritable Bowel Syndrome—Anemia was the most commonly recognized (4 participants reported having at least heard of anemia

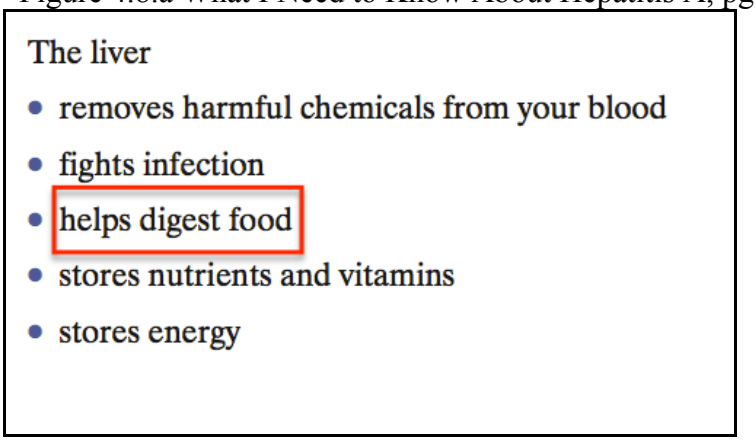
before). That said, only Anthony and Claire explicitly stated that Anemia was a condition having to do with the blood; Claire also mentioned that it was managed by eating "plenty of greens."

If a participant said that their prior knowledge was consistent with information presented in the text, this was often accompanied by a positive evaluation of the health information document. If, on the other hand, information in these documents was incongruous with a participant's prior knowledge, she gave the document a negative evaluation. When evaluating the Anemia document, for instance, Grace declared: "Anemia makes you feel weak or tired is true so I mark it green." (Referring to the "What is Anemia?" section on top of page 1.) Because what this participant knows about anemia and its relationship to fatigue supports this statement, she found this information to be of good quality and therefore useful. Information that is in accordance with a reader's prior knowledge can help to establish the credibility of health information.

Prior knowledge, however, sometimes came into conflict with the health information provided in some of these documents. Mary noticed that the information about anemia in the Anemia document was presented within the context of cancer and chemotherapy. Referring to the recommendation that a patient suffering from anemia during chemotherapy should eat red meat and eggs, she said, "Some people on chemotherapy cannot eat all of this" (Anemia document, p. 2). She was able to use her knowledge of cancer treatment and its side effects to make a judgment that the information in this document is not accurate or useful for all cancer patients. Another example of how prior knowledge could lead to negatively evaluating health information

was when Grace read that the liver "helps digest food." She said, "food is in the stomach," not in the liver (Hep A doc p. 2).

Figure 4.8.a What I Need to Know About Hepatitis A, pg. 2


The liver

- removes harmful chemicals from your blood
- fights infection
- helps digest food
- stores nutrients and vitamins
- stores energy

Figure 4.8.a highlights the section of the text discussing the liver that Grace identified as incorrect in the Hepatitis document. Grace lacked knowledge about the liver's function, and the document does not include information explaining the relationship between the liver and the digestive system. Consequently, she marked this information as not correct and therefore not useful as health information. Omitting information or assuming background knowledge about topics such as anatomy can result in users negatively evaluating the usefulness of health information.

An analysis of the vocabulary used documents in the HTRC (See Section 4.3) suggests that writers of easy-to-read health information documents tend to assume that adult emerging readers have a greater level of prior knowledge about health topics, illnesses, medicine, and the human body than they actually have. Though a few participants were familiar with specific health topics such as inflammation and chemotherapy, many concepts related to organ functions and anatomy were unfamiliar to participants. Concepts about the primary functions of different organs or how they work

together to carry out biological processes are generally part of a formal science education, such as biology or chemistry courses offered in secondary school. Many adult emerging readers, like the participants in this study, however, may not have completed a high school or secondary level education (See Section 3.2.3.3). Most adults for whom so-called "easy to read" health information materials have been created have a different type of prior knowledge about health and the human body than does someone who has taken a high school biology class. These adults also have a different type of prior knowledge than the professionals who create these documents. Participants' prior knowledge about these health topics was dependent on their own experiences with health issues. Joan, a participant who reads aloud, explained that, "by knowing already about some of these [topics], it made it easier to pick it up." More specifically, because she was somewhat familiar with hepatitis, she found this document fairly easy to read. The Hepatitis document "was ok," she said. During the pre-task interview, she said it was some kind of virus and that some people can catch it. By contrast, another participant who reads aloud, Robinson, was not familiar with any of the three health topics in the documents he evaluated. He explained these documents were difficult to read, used words that were too long and unfamiliar, and included too much information. He described reading these documents as "stressful." Though this is a preliminary finding that needs further investigation, this is nevertheless important within the context of this study. As explained in Section 4.5, health information documents analyzed in this study are not cohesive, which requires that readers fill in these cohesion gaps with their own background knowledge. When participants have low domain knowledge, as was the case with most participants in this study, they are not able to fill in these gaps in the text, which

contributes to the difficulty they experience when reading health information documents. Prior knowledge of health topics is acquired in different ways including past experiences. The next section discusses how personal experiences can also affect the way adults who are learning to read evaluate health information.

4.9 The Role of Personal Experience in Reading Difficulty

In addition to using their prior knowledge, participants in this research study often relied on personal life experience when they evaluated health information documents. To be sure, this is a common practice of all readers when reading any kind of text. What is important about this observation within the context of the present study is that when adults in this study encountered difficulty in reading the documents they evaluated, they often used their personal experience as a way to make sense of what they were reading. Participants in this study often ignored or misinterpreted critical health information such as medical advice when it was not consistent with their personal experience. This practice of using personal experience when evaluating health information that is already difficult to read often resulted in problems of interpretation, inference-making, or problems making meaning. For example, Grace prioritized her own experience of not eating meat and ignored the context of the health topic in the Hepatitis A document. For her, the health advice to eat "red meat is not useful because I don't eat meat," and this resulted in her finding this recommendation about how to manage anemia not useful (Anemia document, p. 2).

Most adults who are learning to read have different experiences with health, with the healthcare system, and with formal education than do other adults who are not members of at-risk communities. This is an important difference between children who

are learning to read and adults who are learning to read. It is important for health literacy professionals to have a better understanding of these adults' types of health experiences and how they might contradict the information that is being presented in health information documents that are created for members of these communities. Four participants in this study compared what they read in the health information documents they evaluated to their own experience with different health topics. The extent to which the information they read matched their own experience often determined whether they evaluated health information as useful or not. Esther, for example, found the list of symptoms of hepatitis A useful and explained, "These are things I've felt" (Hepatitis A document, pg. 4). When reading the IBS document, Mary found useful the information about "medical history" under the section, "How is IBS diagnosed," and explained this matched her experience of doctor's visits and that taking a medical history is how a doctor's visit begins. Similarly, when reading about fiber as a way to manage IBS-related constipation, Mary recalled her past experience using a fiber-fortified supplement to help her grandson manage constipation. She explained that using Pediasure with fiber did not help, but that using Pediasure without fiber did help, so "fiber is not 100%" (IBS document, p. 14). Comparing the information in the documents with their personal experience was a way for participants to validate the health information they read, and an important method of determining the usefulness and quality of health information. Presenting information that contradicts a reader's personal experience with her own health can limit how that reader interprets meaning and perceives the usefulness of the information, a challenging problem for content creators.

4.10 Conclusion of Findings

The findings from this study advance our understanding of a sociotechnical phenomenon in which health literacy principles such as readability and access to health information are put into practice by creating consumer health information documents for adults who are learning to read. This perspective focuses an analytical lens on so-called "easy to read" health information materials and the tools and technologies used to create and manipulate these sociotechnical artifacts, such as readability formulas and health literacy guidelines. In defining the problem of the readability of consumer health information, health literacy guidelines construct concepts such as what it means for health information to be easy to read and what constitutes a low literacy adult, and endorse specific tools for professionals to use in order to create health information that is easy to read for members of this group. The underlying assumptions that such conceptualizations make about language use, health information, and adults who are learning to read reveal the professional values and principles of health literacy as a field of professional practice. These findings show that such assumptions do not accurately reflect the experiences of adults who are learning to read.

The findings from this research study open up several avenues for further work, particularly to further enrich the linguistic analysis with more in-depth studies of how adults who are learning to read use health information. This future work and the limitations of the present study are discussed in Chapter 5. The findings from this research nevertheless have serious implications for health information practices both professional and personal. I will discuss these implications in more detail, and will also synthesize this study's significance and its contributions to research on information

practices. First, Chapter 5 will contextualize these findings within the specific health literacy practice of making recommendations for creating easy-to-read health information documents.

5. Conclusion

The study reported in this dissertation was designed as a two-part, sequential mixed methods study. Phase I of the study assessed the readability of health information documents by conducting a quantitative linguistic analysis of the Health Text Readability Corpus using a computational tool called Coh-Metrix (see Section 3.1.2) and a suite of NLP tools called SourceRater and Language Muse® developed by ETS for automatically analyzing student writing: (see Section 3.1.3). The analysis conducted in Phase I of the study identified linguistic features of health information documents that affect their readability. These features were then used to divide the corpus into three document clusters in order to identify prototypical documents from each cluster to use as data collection tools in Phase II of the study. Phase II consisted of a usability study to investigate how adults who are learning to read evaluate these prototypical documents (Phase II). Specifically, participants were asked to read and evaluate the usefulness and readability of prototypical consumer health information documents from the Health Text Readability Corpus that are labeled "Easy to Read."

This study breaks new ground with respect to the health information practices of an under-studied group and represents a new approach to an important social problem involving access to good quality health information for adults who are at higher risk of poor health outcomes. This chapter will discuss in more detail the implications of this study's findings for research and for professional practice. Section 5.2 will present the

contributions of this work to the field of library and information science. After a discussion of the contributions of this research and its implications for professional practice, Section 5.3 will discuss the study's limitations. This is followed in Section 5.4 by a presentation of areas for future work that will extend the findings of this study.

This study found that despite the recommendations in professional guidelines, health information documents score at a 10th grade Flesch-Kincaid Grade Level on average. This predicts that adults who have not completed high school will find these documents difficult to read, which is consistent with the experiences of the participants in this study. As noted in Section 4.1, there is not a significant difference in Flesch-Kincaid Grade Level between HTRC documents that are labeled "Easy-to-Read" and those that are not. However, this study found that documents in HTRC have low narrativity, referential cohesion, and connectivity scores, indicating that documents lack words that overlap across sentences and connective words that help readers form relations among concepts and arguments in the text (inferences). It is not surprising, then, that participants found documents in this corpus difficult to read, as the lack of such features requires readers to infer more from the text than what is explicitly stated. The rest of this section will summarize the study's main findings to answer the research questions laid out in Chapter 1 and show how they advance our knowledge and open up potential paths for more research to better understand this problem.

RQ1. What linguistic features affect the readability of consumer health information documents for adult emerging readers?

a. **What linguistic features of consumer health information documents are characteristic of these documents according to computational linguistic analysis?**

The vocabulary used in health information documents contributes to these documents' poor readability. Though the Flesch-Kincaid Grade Level formula measures only word length to operationalize the role of vocabulary in predicting readability, the more sophisticated linguistic methods used in this study revealed that semantic features such as word concreteness, imageability, meaningfulness, familiarity, and hypernymy provide a deeper understanding of vocabulary features beyond simply word length that contribute to the difficulty of reading health information. More specifically, the findings of this study show that the vocabulary used in HTRC documents is specific yet difficult to conceptualize. Examples of this type of vocabulary are technical, scientific, or medical terms which are specific, but can be unfamiliar and hard to conceptualize. Though certainly challenging for all lay readers, this is especially problematic within the context of health information created for adults who are learning to read as it presents an additional barrier to reading and to information seeking more generally. Acronyms and contractions in health information documents also contributed to the difficulty participants had reading this information.

A key finding of this study is that despite being long, sentences in these documents have simple syntax. This finding highlights an important limitation of readability formulas like the Flesch-Flesch-KincaidKincaid Grade Level, which use sentence length as an indicator of syntactic complexity. To understand why documents with simple sentences are nevertheless difficult for adults who are learning to read, this study analyzed the level of cohesion in these documents. Cohesion refers to explicit relationships between concepts and ideas that are present in a text (McNamara, Graesser, McCarthy, & Cai, 2014). The linguistic analysis found that documents in the HTRC lack

cohesion. Specific features that contribute to this lack of cohesion are the general lack of connectives and the lack of discourse features in the documents that help readers infer relationships such as argumentation, cause and effect, evidence and details, and persuasion.

RQ1b. What features of text and reader, besides those identified by the "classic" readability formulas, account for the ease of reading consumer health information documents?

Another key factor affecting the cohesion of these documents, and their low readability, was the participants' practice of skipping over unknown words. Skipping over unknown words, though a common practice for readers in general, is much more frequent for adults who are learning to read, causing gaps in the text that they often resolve with a high degree of errors. This leads to misreading or misinterpreting health information, which has serious implications for the health information practices of adults who are learning to read. This finding supports previous research claiming that reading practices can affect the readability of text (Kirsch & Guthrie, 1984).

Another factor related to low cohesion and which affects the readability of health information is the use of lists in these documents. Bulleted lists in particular contribute to low cohesion because they often omit connective words and phrases that help readers make inferences. Readability guidelines unfortunately recommend the use of bulleted lists in health information as a way of making text more readable (U.S. National Library of Medicine, 2017). This finding provides evidence from adults who are learning to read that contradicts this widely adopted recommendation.

Readability guidelines for health information also stress the importance of using a conversational style. The linguistic analysis of documents in the HTRC found they score

low on narrativity and conversational style. One way in which documents in the HTRC do incorporate a conversational style is by using a question-and-answer format to organize sections. Often, headings are presented as questions. Somewhat unexpectedly, participants often misinterpreted these as questions they needed to answer rather than as section headings.

RQ2. How do adults who are learning to read perceive the readability of "easy to read" consumer health information documents?

a. **To what extent does the "easy to read" classification of health materials affect the way adults who are learning to read evaluate them?**

The usability studies yielded a number of important findings about what factors affect readability that the automated linguistic analysis was not able to capture. First, an analysis of the observational data from these sessions revealed three distinct reading practices among participants. These reading practices became a useful way to classify adults who are learning to read as phonics readers, adults who read aloud, and independent readers, and is consistent with theories of reading development stages, according to which readers gradually progress from stage to stage as they gain reading experience (Chall, 1996; Kuhn & Stall, 2000). Participants who are phonics readers and those who are independent readers found no difference in readability among the three HTRC documents they evaluated. Phonics readers generally found all documents equally hard to read whereas independent readers found all documents equally easy to read. Most adults who read aloud, however, reported that the shortest document (Anemia) was the easiest to read. Four participants went on to explain that longer documents simply have too much information, some of which is not immediately relevant or necessarily important for adults who need to find specific information to help them manage their health.

Finally, the results of the usability studies found that participants' prior knowledge and personal experiences sometimes had a negative impact on the readability of health information. Whenever the information in these documents was inconsistent with their prior knowledge, participants evaluated the health information as nonsensical, false or inaccurate. Similarly, participants often ignored or misinterpreted critical health information such as medical advice when it was not consistent with their personal experience. When information did not seem to make sense vis-a-vis prior knowledge or personal experience, participants found the information to be of poor quality. This finding suggests a relationship exists between prior knowledge, personal experience, readability, and misinformation, though further research is needed to make definitive conclusions

RQ3. What assumptions do the measures of readability recommended by professional guidelines make about the characteristics of adults who are learning to read?

The MedlinePlus guidelines for writing "easy to read" health materials refer to adults who are learning to read as "users with limited literacy" who have certain cognitive and learning disabilities (U.S. National Library of Medicine, 2016). They do not focus on adults whose reading difficulty is due to a lack of education. These guidelines recommend the use of traditional readability tools like the Flesch-Kincaid Grade Level formula to evaluate health information in order to ensure it reads at a 7th or 8th grade level. By matching adults' reading experiences with those of middle school-aged children, these health literacy practices ignore the ways in which these groups of readers differ. The experiences of the participants in this study were often at odds with the way in which these guidelines conceptualize adults who are learning to read. For example, their reading practices and their experiences with a formal system of education were not

similar to those of middle school students. Another difference was their vocabulary knowledge. Some participants were familiar with medicines or conditions such as Immodium, anemia or inflammation, which are not as likely to be commonly known to children.

How these guidelines conceptualize readability also results in health information documents that do not support the reading practices of adults who are learning to read. The guidelines recommend that health information avoid being "too wordy," avoid using long sentences, and avoid using medical jargon. Findings from this study show, however, that when health information documents oversimplify sentences by omitting certain words, cohesion suffers. This often results in reading difficulty for adults who are learning to read. This study's findings also provide a deeper and more nuanced understanding of how vocabulary use can affect the readability of consumer health information beyond the simple characterization of what the Guidelines call "medical jargon" and wordiness (U.S. National Library of Medicine, 2016). Examples discussed in section 4.3 include the problems associated with the use of anatomical terms, the names of medications, and the use of contractions. At a deeper level of meaning, certain psycholinguistic features of words such as how easy it is to form a mental image of a word or how closely associated a word is with other words can also affect the readability of health information, features that health literacy guidelines altogether ignore.

Often, health literacy guidelines conflate reading comprehension with general comprehension. For example, Health Literacy Online's website states that "users with limited literacy skills…may struggle to decode challenging words and remember their meanings" (Office of Disease Prevention and Health Promotion, 2016). This contributes

to a way of conceptualizing these readers as adults who have trouble understanding information, which is not necessarily the case. An adult who is learning to read and who is developing reading practices that support reading comprehension, such as reading fluency and analysis, can indeed understand information that is told to him or that is read aloud to him. Just because an adult experiences difficulty when reading health information does not mean this same adult cannot understand it when such information is read aloud.

Likewise, someone's reading experience does not necessarily indicate her knowledge of a topic nor does it indicate her vocabulary knowledge. Knowing how to read a word and knowing what a word means are not the same thing. It is important to distinguish an adult reader's vocabulary knowledge and her ability to recognize these words when written. Most participants in this study, for instance, could not recognize some of the words in the pronunciation guide found at the end of the Hepatitis and IBS documents. Specifically, six participants in this study—five who read aloud and one independent reader—could not read the word "jaundice," but they recognized the word when I read it to them during the usability sessions. Other words that participants could not recognize in print, but which they recognized if read aloud included "virus" and "vaccine." Additionally, participants in this study had a general understanding of relevant health topics such as anemia, jaundice, hepatitis, and chemotherapy even if they could not read the words. Participants in this study were also able to evaluate the usefulness or readability of the health information documents they read regardless of their reading experience, indicating they were able to determine whether these documents could help them manage their health. But when participants misunderstood information in these

documents due to a misreading or misinterpretation, they determined the documents were not useful to them.

Even those participants who needed the most support when reading health information were able to determine that the documents did include relevant information even if it was too hard for them to read. These participants also reported relying on others for help when reading health information. In fact, two participants, a phonics readers and an adult who reads aloud, reported that they ask family members such as adult children or spouses for help when reading health information. This reveals another misconception of health literacy that is evident in the way health information documents are designed: that reading is a solitary practice for all adults. As they develop reading independence, adults who are learning to read develop a number of reading practices such as reading aloud and asking others for help. Health information is often written as if for a single independent reader under the assumption that reading information is done without the aid or support of others. Health literacy professionals should rethink this assumption when they develop health information resources for adults who are learning to read. At least some adults who are learning to read have a support network of trusted and more experienced readers on whom they rely for help when using and reading health information. It is important to investigate whether this is the case, generally, for adults who are learning to read regardless of their participation in formal learning programs such as the one in which participants in this study are enrolled.

Medline's guidelines for writing "easy-to-read" health information suggest that health literacy professionals "consider reading level, cultural background, age group and English Language Proficiency (ELP)" when developing health information materials

(2017). After gathering this information about the intended audience, these guidelines go on to explain:

> Now that you have learned about your audience, consider them carefully when writing. Cultural, age, and gender differences may have an impact on your content. For example, the writing style and graphics may be different for an HIV/AIDS brochure for teens than for adults over age 50. (U.S. National Library of Medicine, 2017).

But beyond explaining that health information materials should be designed differently for readers of different ages, this recommendation does not sufficiently explain to a health literacy professional what it is about age, gender, or cultural background that is important or the how these characteristics might affect the readability of these documents. It is not clear from this recommendation that health literacy professionals consider differences in personal life experiences, such as different experiences with health or the practice of seeking help from more experienced readers.

The professional guidelines' focus on demographic data as a way to frame health information materials is often treated as part of health literacy efforts that fall under the umbrella of "cultural competence" (Betancourt, Green, Carrillo & Ananeh-Firempong, 2016). Beyond requiring that health information be culturally appropriate and available in multiple languages, cultural competence does not definitively include an awareness of literacy, educational attainment, or reading practices in its mandate. Using demographic data such as race, ethnicity, and age ignores important differences within these same groups, such as the experiences of adult emerging readers. Adults who are learning to read have very different experiences than others in their same so-called cultural or racial group especially when it comes to their education, their interactions with the healthcare system, and their experience with different types of reading materials. In order to create

health information resources that are better able to support the needs of members of these communities, it is important for health literacy professionals to recognize more variability in the personal life experience of adults who are learning to read than are currently described in the "easy-to-read" guidelines.

5.1 Implications

This study's findings have serious implications not only for professional practice, but more importantly, for the health information practices of adults who are learning to read. First, the findings of this study indicate that health literacy professionals should reconsider and redraft guidelines that endorse the use of traditional readability formulas like the Flesch-Kincaid Grade Level as a way of identifying so-called "Easy to Read" health information. This study shows that traditional readability formulas such as the Flesch-Kincaid Grade Level are not adequate tools for measuring the readability of consumer health information. The Flesch-Kincaid Grade Level formula does provide a readability prediction, but it does not provide ways for health literacy professionals to lower the readability score of the document they created. The analysis of the HTRC corpus demonstrates that, despite their wide availability and professional recommendations to use readability formulas like the Flesch Kincaid Grade Level formula to ensure a 7th grade reading level, health information documents are written at a high school reading level. Though these formulas can determine that health information documents are not easy to read, they do not explain which linguistic variables affect readability and to what extent. Without a better understanding of the factors that affect readability, practitioners do not have the necessary tools to improve the readability of health information for adults who are learning to read.

Another important implication of these findings concerns the trustworthiness of the "Easy-to-Read" label. Health information documents that are labeled as "easy to read" by practitioners or health organizations are not so easy to read after all. This finding puts into the question not only the accuracy and usefulness of these labels, but also the professional practice by which these documents are created, assessed, and selected for inclusion in "Easy-to-Read" collections. It also asks just how dependable or useful are, for instance, the Medline guidelines for creating health information that is easy to read (U.S. National Library of Medicine, 2016). Either content creators and health agencies are not properly following these guidelines, or if they do, they do not know how to adapt or simplify health information to make it easier to read after it has already been drafted. Evidently, these guidelines are not explicit enough in making suggestions that help to increase the readability of health information. A formal process of verification might also be necessary to ensure that documents submitted to Easy-to-Read collections do conform to revised guidelines.

This study also shows that health information documents are characterized by linguistic features that make these documents rather difficult to read due to their low narrativity, limited overlap between words, sentences, and concepts in the text, and a lack of connectives that help a reader make connections and inferences when reading a text. Health literacy professionals should consider ways to improve the cohesion and narrative qualities of health information documents they create. This means they should avoid condensing text into bulleted lists or otherwise simplifying text by removing words and concepts that help readers to make connections between ideas when they read. What the right level of content is before it is considered too lengthy remains a question that needs

more research. Improving the narrative qualities of these documents is also a challenge considering the informational nature of the content. More research is needed to identify ways in which the writing style of these documents can be improved to make them easier to read. An important implication of this work is that professionals need more training to help them identify ways they can improve the readability of health information by focusing on linguistic features such as cohesion, narrativity, connectivity, and what vocabulary to use. For instance, health literacy professionals who develop materials for these adults need to carefully consider the use of bulleted lists since presenting information in this format does not support the reading practices of adults who do not read independently.

The linguistic characteristics of health information documents identified in this study are of particular concern with respect to adults who are learning to read for at least two reasons: (1) these adults especially need texts that support them in deriving meaning while reading, and (2) the medical vocabulary used in these health information documents is hard to conceptualize for adults who do not have a formal education, a barrier that might be minimized by text that is easier to read. This last point is of benefit to all users of health information, not only those adults who are learning to read. That said, however, the purpose of this mixed methods research study was to investigate how adults who are learning to read assess the usability and readability of health information documents created specifically for them, and it showed that these documents are not considered easy to read by this group of readers.

This study underscores the lack of access to health information that supports and addresses the needs of adults who are learning to read. Considering that this group also

experiences relatively high rates of poverty and lower health outcomes (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011), this lack of access to health information that is easy to read constitutes a serious barrier to well-being. The field of library and information science is well positioned to not only investigate the nature of barriers related to health information seeking for members of these communities, but it is also equipped with the metatheoretical and methodological approaches necessary to understand the social factors related to information seeking and use. These are necessary to the development of innovative solutions for health information practitioners, educators, and for users of health information. Though many disciplines and researchers struggle to identify and engage participants like the ones in this study, libraries and librarians have been deeply embedded in these communities for a long time. Health literacy research stands to benefit from a stronger collaboration with library and information science researchers in order to continue to advance research in this area. The following section discusses the contributions the present study makes to this research area.

5.2 Contributions

This mixed methods research makes several important contributions to library and information science and to health literacy research. To begin, it explicitly links reading practices to information evaluation practices, a conceptual link that is often assumed in theoretical work, but remains under-explored. It also turns a critical eye to health literacy practices involved in the creation, assessment, classification, and dissemination of health information documents that are easy to read for adults. By developing a conceptual framework that casts the everyday life information practice of evaluating health information as part of a broader sociotechnical system that involves professional health literacy practices, this work shows that sociotechnical tools and artifacts like readability formulas, writing guidelines, and consumer health information materials do not

sufficiently support practitioners or the adults they intend to serve. At a theoretical level, this study demonstrates that tools like readability formulas and health literacy guidelines do not provide an objective or neutral perspective on what it means to be literate, healthy, or well informed. Instead, these tools represent socially constructed ideas of what these concepts mean, and further entrench a power dynamic between those who need "easy to read" health information and those who create and claim authority over it. Importantly, this work extends the theory of ELIS by showing its applicability, not only outside the context of work, but by using health information practices to show that information practices are not neatly separated between the spheres of work and leisure. This work shows the interconnectedness and even interdependence between professional health literacy practices and non-work health information practices.

This study's main contribution is a more concrete understanding of the specific linguistic features that affect the readability of health information, which is currently lacking in health literacy guidelines for creating easy-to-read materials (RQ1). Not only does the type of vocabulary used in health information matter, but so does the way in which language helps readers to form inferences as they read (RQ1a). The language used in so-called "easy to read" consumer health information documents, and the reading practices of adults who are learning to read, result in many gaps that readers must fill as they make sense of what they read (RQ1b). This study indicates that creating health information documents that are more cohesive should improve the readability of these types of documents. Improving the readability of these documents also includes re-examining the writing style and length of these documents, the use of lists, contractions, and abbreviations, as well as reconsidering how best to clarify medical, scientific, and anatomical terms. In the end, what is more useful for adults who are learning to read, according to the results reported in this thesis, is a document that includes information that is actionable and that provides guidance on how best to manage their health vis-a-vis

a new diagnosis. This should be the main guidepost for professionals who create these materials. The extent to which the type of vocabulary used in health information and the participants' vocabulary knowledge affect the readability of health information underscores the limitations of traditional readability tools such as the Flesch Kincaid Grade Level formula, which only measure vocabulary by word length. The use of more advanced linguistic methods like CohMetrix and those developed by ETS provide a clearer analysis of the role of linguistic features in the readability of health information.

Another contribution of this mixed methods study is a critical examination of the professional recommendations for creating health information that is easy to read. This is a much needed critique in health literacy since these guidelines are an important professional standard used by many public health organizations in the United States. By integrating the data collected during both phases of this mixed methods design, this study calls into question the claims and assumptions made in these guidelines about readability, literacy, and adults who stand to benefit the most from health information that is easy to read. This study provides evidence from intended users of these documents as well as from a linguistic analysis of health information documents that challenges the main claims and recommendations in professional health literacy guidelines like the MedlinePlus.

The mixed methods design worked well for testing and verifying how linguistic features do or do not support the health information practices of adults who are learning to read. Specifically, an important observation was that the reading practices of adults who are learning to read change as they become more independent readers, and this affects how they read and evaluate health information. This study underscores the value

of doing mixed methods work to investigate the usability and readability of health information for specific users. Each phase of the study informed and further contextualized the other. Specifically, the protocol for the usability case studies included questions about features identified during the linguistic analysis (Phase I) as a way to narrowly focus the scope of the data being collected in Phase II. The analysis in Phase I also helped to minimize researcher bias in the sampling of documents for the usability sessions in Phase II. Additionally, including participants and examining their interactions with these documents provided concrete instances of the readability barriers identified by the linguistic analysis conducted in Phase I. Each phase of the study answered different research questions which together give us a more complete understanding of the readability of health information for adults who are learning to read. Data collected during Phase II also helped to identify features that affect the readability of health information that were not identified by the automated or computational tools used in Phase I of this study. Findings from this type of work can be used to further iterate and improve the tools used to assess the readability of health information documents. More specifically, these methods help to uncover linguistic qualities that are, if not unique to health information, at least characteristic of these documents and that might present difficulties for their intended users.

An important contribution of this research study is the protocol designed for the usability studies conducted in Phase II. A main goal of this study was to minimize the power imbalance between the participants and me, the researcher. For this reason, the protocol I designed for the participant evaluations of the health information documents was carefully developed and tested in a pilot study (Morales, 2017). This portion of the

study was designed to address participants' vulnerabilities during the study, and to minimize their perceptions of being a test subject, while preserving the integrity and quality of the data being collected. Because usability study designs with vulnerable participants like the adults who are learning to read are not very common, this protocol and design deserve further study.

This study also adds to the literature the experiences of members of a group that has been woefully under-examined in library and information science research (Sørensen et al., 2012), despite the active support many libraries provide in the form of outreach and education programs for adults who are learning to read. By including the experiences of these adults, this work strives to challenge the stigma and biases often associated with marginalized communities that disproportionately experience poverty and negative health outcomes compared with other groups. Tackling and addressing the stigma associated with poverty and, more specifically, with learning to read as an adult is the first step in fixing barriers associated with access to health information discussed in this work (Chew, Bradley, & Boyko, 2004). It is primarily for this reason that this study does not characterize adults who are learning to read by identifying skills they lack or presumed deficiencies in their cognitive abilities, as terms like illiteracy or low literacy do. Including the perspectives and experiences of adults who are learning to read collected in Phase II helps to cast a critical lens on the professional practice of health literacy itself. Professional health literacy practices that fail to consider the lived experiences of members of marginalized communities not only risk perpetuating the same inequities, bias and power dynamics they aim to break down, but they also fail to provide better

access to health information for those who are at greater risk of having poor health, an important professional goal of health literacy (Coleman, Hudson, & Maine, 2013).

Another contribution of this work is the preparation of a machine-readable corpus of 501 consumer health information documents, known here as the Health Text Readability Corpus (HTRC) which includes documents that are considered "easy to read" by different agencies and organizations such as the National Library of Medicine. Section 3.1.1 describes the corpus in more detail including the methods used to collect documents for inclusion and prepare them for analysis. This corpus can undergo other types of computational and qualitative analysis to yield even more findings related to the way language is used in consumer health information.

5.3 Limitations

This work has a number of limitations which are important to discuss in order to contextualize the contributions and implications discussed above. One important limitation that affects how study results are compared and interpreted concerns the use of CohMetrix whose training corpus is a collection of K-12 texts, not consumer health information documents written for adults. To address this limitation, it is important to understand the size (32,520 texts) and representation of documents in the corpus used to develop CohMetrix, which includes school subjects like science, history, health, industrial arts, and language arts. This is discussed in greater detail in Section 3.1.2.2. Another important limitation of this tool is that CohMetrix does not provide a predictive readability score the way that traditional formulas do. The CohMetrix output requires much more analysis in order to identify what the output means for the readability of health information. To better contextualize the CohMetrix data, this study also included an analysis of the same corpus by a set of tools developed by ETS. This helped to not

only confirm the interpretation of CohMetrix results, but it also provided additional features such as discourse relations that contribute to cohesion and readability. The ETS tools used in this study provided explanations that accompany the output of the linguistic analysis, which better supports the interpretation of results.

The participant pool is another important limitation of this study. The study recruited 20 participants to enable the collection of rich data for analysis (Charmaz, 2014; Lincoln and Guba, 1985). Study participants are not representative of all adult emerging readers. This is due to two main factors. First, the number of participants does not allow for statistical generalization. The goal of this study, however, was not to make predictions but rather, to better understand the experiences of members of this group vis-a-vis health information designed specifically for them. Second, not all adult emerging readers participate in an adult education program. The adults who participated in this study were evidently highly motivated to read, evaluate, understand, and use health information that is hard to read. Other readers may not be so motivated, may not have access to programs that offer this level of support, or may experience other personal barriers. This study also did not observe how adults who are learning to read and who have been diagnosed with the conditions discussed in the documents use consumer health information to manage their condition, so conclusions to that level of specificity are not possible.

This study focuses primarily on the experiences of the end-user of "easy-to-read" consumer health information and therefore did not include the experiences of health literacy professionals who create these documents. To address this limitation, I conducted an extensive review of the relevant health literacy literature (See Section 2.2). Additionally, I made observations about health literacy professionals by attending

meetings and forums conducted by the National Network of Libraries of Medicine and by the New York City Department of Health and Human Services where practitioners discussed best practices and the challenges of creating health information that is easy to read for members of different at-risk communities.

As mentioned in more detail in Section 3.2.1, the study site itself also constituted an important limitation to this study. The library setting and my active role as a volunteer tutor in the adult literacy program might have contributed to creating a standardized test-taking environment common of educational settings. The usability study design aimed to minimize the effects of this limitation primarily by asking participants to make their own annotations, determinations, and recommendations on how they assess the readability of the documents. As researcher, I also had to balance the need to establish trust with members of this learning community against the risk that they would see me as a tutor during the usability sessions. Recognizing that I had limited options for entering such a community (for instance, I can never be a member of this community the way that adults who are learning to read are), I made the determination to enter the community as a volunteer tutor to establish trust and to have access to daily field observations over the course of two years in order to better inform the findings.

Finally, the study did not experiment with different sentence constructions or test the use of certain vocabulary, so conclusions and recommendations about which specific syntactic structure or vocabulary improves the readability of these types of materials are still preliminary. This study, however, does point to areas of future research that are more targeted based on findings related to vocabulary use, syntax, cohesion, writing style, as

well as non-linguistic factors such as participant characteristics that affect the readability of health information. These will be discussed in the following section.

5.4 Future Work

This study opens up a rich field of research that investigates the extent to which consumer health information supports the needs of adults who are members of at-risk communities. Rather than asking whether an adult can read a document, a better question is, to what extent do adults who are learning to read find health information usable, and what can practitioners do make these documents easier to read? To answer these questions, a larger user study is first required that analyzes how these adults use consumer health information in their daily lives.

Extensions of this work must also investigate the relationship between non-verbal features of health information, such as diagrams, charts and figures, and the accompanying text. There were indications during the usability studies that tables of content, footnotes, and pronunciation guides were not helpful for participants. Future studies that investigate more closely the usability of such aids as well as the effectiveness of design features in health information documents are necessary to understand the extent to which these aids contribute to the readability of health information. The findings from the study reported here suggest that these aids do not always support adults who are learning to read.

More specifically, future work will include studies that investigate cohesion gaps in health information by testing specific vocabulary and different syntactic structures with participants based on the findings from this work to understand the effects of contractions, connectives, sight words, abbreviations, and scientific language on the

readability of these documents. This can be done using methods similar to the Cloze test in which certain words in a text are removed and participants are asked to fill them in.

Though the scope of this study did not examine the collaborative aspect of health information practices for adult emerging readers, this study suggests that reading and using health information is sometimes a collaborative practice for adults who are learning to read. Adults who do not read independently rely on more experienced readers for help reading and filling out forms. It is worth investigating this phenomenon in future work in order to better understand how to develop health information materials that support and make the most of such collaborative health information practices for the target audience. To develop health information materials that are easy to read, health literacy professionals need to better understand the larger network of support (not just health professionals) that adults who are learning to read routinely access as they carry out different health information practices including reading, information seeking, evaluating, and managing their health.

Another important avenue for future work is to investigate the practices of health literacy practitioners as they go through the process of creating these materials and determining their readability for adult emerging readers. Future work needs to be conducted to better understand these processes including the challenges and barriers these professionals themselves face when creating health information for adults like those who participated in this study. This type of research needs to include the perspectives and collaboration of public librarians as well since they are often an important link between authoritative health information resources and the communities that health literacy practitioners aim to reach

The work discussed herein provides a much-needed understanding of the health information practices of adults who are learning to read, specifically how they evaluate consumer health information that practitioners believe is "easy to read." It also further expands readability models by including the perspectives of the intended users of these documents. Not enough research has been done to provide solutions to the challenges related to reading health information or to creating health information that is easy to read, but my research lays out the nature of this problem. Ultimately, this research aims to improve access to quality consumer health information for members of communities that face greater health disparities. Adults who are learning to read and write are disproportionately members of these communities, and improving their access to good quality, authoritative, and actionable health information that is easy to read is imperative as we tackle health disparities and the high cost of healthcare for people who need it the most.

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Appendix A: Research Protocol

Task Instructions
This task is not a test of your abilities. There is no right or wrong answer. I simply wish to determine whether you find these health information resources useful or not. Please read the following documents at your own pace and take as long as you need. I am providing you with some colored pens. With the green pens, please mark features, phrases or words in the document that you find helpful in evaluating the usefulness of the information. With the red pens, mark features, phrases or words in the document you find unhelpful, confusing or difficult to understand.

Survey
Participants will be asked to fill out this survey upon completion of the task and interview. Participants may decline to answer any or all questions with no risk of penalty.

1. Gender (circle one): Male Female Other: _____

2. Age: _____

3. List the language(s) you speak, and the age when you learned it/them.
_____
_____
_____
_____

4. List the language(s) you read and write, and the age at which you learned it/them.

_____
_____
_____
_____

5. What language(s) do you prefer when reading health-related information?
_____
_____

6. What types of materials do you typically read? Check with an X all that apply:

___Newspaper
___Magazines
___Maps
___Train or Bus Schedules
___Notes or letters from your childrens' school or teachers
___Information your doctor gives you
___Instructions for installing new technology (like using your new cell phone)

___Information about your hobbies
___Information you get at the library
___Forms to fill out (health insurance forms, job applications, etc.)
___Books (not e-books)
___E-books
___Websites
___Brochures
___Flyers
___Posters
___Advertisements
___Catalogs
___Recipes

7. How would you describe or characterize your level of proficiency with reading in English?

_____
_____
_____

8. What is your last level of school completed?

_____

9. How long have you lived in the United States?

_____

Interview Questions

The PI, Miraida Morales, will ask participants the following questions upon completion of the evaluation task. Participants may decline to answer, or may ask that a question be repeated or restated if not understood.

For each document:
1. Could you show me parts of this document, [showing or pointing] that you found confusing or gave you trouble? Why do you say that?

2. Could you show me parts of this document [showing or pointing] that you found clear in meaning? Why do you say that?

3. Tell me about the parts of this document you found helpful when reading it.

4. What design features (colors, font size, layout) did you find most helpful? Why do you say that?

5. What design features (colors, font size, layout) did you find troublesome or confusing? Why do you say that?

6. What phrases or words did you find most helpful? Why do you say that?

7. What phrases or words did you find most difficult to understand? Why do you say that?

8. Which format(s) (print, website, etc.) did you find most useful? Why do you say that?

9. Which format(s) (print, website, etc) did you find most difficult to use? Why do you say that?

10. Overall, how do you rate the usefulness of this document? Why do you say that?

11. How do you rate how easy or difficult this document was to read? Why do you say that?

12. Have you ever received a document like this from a doctor, nurse, hospital, or clinic? Describe the document, if you remember it, and how you used it. Was it labeled as Easy-to-Read?

13. How do you feel about the Easy-to-Read label on these documents? Do you find this label helpful or not? Why?

Sample Email to Key Informants in the Community

From: Miraida Morales <miraidam@scarletmail.rutgers.edu>
To:
Subject: Health Literacy Study - Kindly requesting your help finding participants

----Message Text----
Dear [Informant],

As you know from our previous conversations, I am working on a health literacy research project to investigate how adult new readers evaluate consumer health information resources. Because of your close ties to the community and your dedication to health literacy outreach efforts, I wanted to ask for your help in recruiting adult new readers to participate in this study.

Participants in this study will be paid $30, and they will be asked to evaluate health information documents, participate in a follow-up interview, and fill out a short survey questionnaire. Participation will last approximately 1.5 hours. Participation in the study is voluntary and confidential. No identifying information about the participants will be linked to study materials.

If you are able to identify participants who are interested, please have them call me at 917-407-6289 or email me at miraidam@scarletmail.rutgers.edu so we can schedule a time to meet that is most convenient for them.

Thank you for your time and your help.

Sincerely,
Miraida Morales
Ph.D. Candidate
School of Communication and Information
Rutgers, The State University of New Jersey

Consent Form

You are invited to participate in a research study that is being conducted by Miraida Morales, who is a Ph.D. student in the Department of Library and Information Science at Rutgers University. The purpose of this research is to determine how adults who are new or developing readers evaluate health information resources.

Approximately 15 people will participate in the study, and each individual's participation will last approximately 1.5 hours.

The study procedures include the following: reading and evaluating three (3) health information documents, a follow-up interview, and a short survey.

This research is confidential. Confidential means that the research records will include some information about you and this information will be stored in such a manner that some linkage between your identity and the response in the research exists. Some of the information collected about you includes your name and telephone number. This information will be kept confidential by limiting access to the research data and keeping it in a secure location. Information that can identify you will be stored separately, and the key linking your responses to your identity will be stored on its own password protected flash drive. Data collected on paper will be stored in a locked file cabinet located in the Principal Investigator's office. Data that is subsequently entered into an electronic format for analysis will be stored in an external hard drive that is password protected.

The research team and the Institutional Review Board at Rutgers University are the only parties that will be allowed to see the data, except as may be required by law. If a report of this study is published, or the results are presented at a professional conference, only group results will be stated. All study data will be kept for 3 years.

The research results will also be made available to you once analysis is complete.

There are no foreseeable risks to participation in this study.

You may receive no direct benefit from taking part in this study. You will receive $30 for participating in the study even if you withdraw from the study after you have begun participation.

Participation in this study is voluntary. You may choose not to participate, and you may withdraw at any time during the study procedures without any penalty to you. In addition, you may choose not to answer any questions for any reason.

If you have any questions about the study or study procedures, you may contact me at:
Miraida Morales
Email: miraidam@gmail.com
Phone: (917)407-6289
Address: 4 Huntington Street, New Brunswick, NJ 08901

You may also contact my faculty advisor:
Nina Wacholder
Email: ninwac@rutgers.edu
Phone: 848-932-8784
Address: 4 Huntington Street, New Brunswick, NJ 08901
If you have any questions about your rights as a research subject, please contact an IRB Administrator at the Rutgers University, Arts and Sciences IRB:

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Email: humansubjects@orsp.rutgers.edu

By participating in the above stated procedures, then you agree to participate in this study. You will be given a copy of this consent form for your records.

Sign below if you agree to participate in this research study:

Participant Signature _____ Date

_____

Principal Investigator Signature _____ Date

_____

Appendix B: List of Documents in HTRC	
Source	**Document Title**
American Diabetes Association	The Diabetes Advisor: Eye Exams for People with Diabetes
American Diabetes Association	The Diabetes Advisor: Factors Affecting Blood Glucose
Agency for Healthcare Research and Quality	Reducing the Risk of Breast Cancer with Medicine: The Basic Facts
American Diabetes Association	The Diabetes Advisor: Gestational Diabetes
Alzheimer's Association	Basic Facts About Alzheimer's Disease: What It Is and What You can do
American Diabetes Association	The Diabetes Advisor: Gestational Diabetes: What to Expect
Alzheimer's Association	FDA-approved Treatments for Alzheimer's
American Diabetes Association	The Diabetes Advisor: Getting the Most Out of Health Care Visits
Alzheimer's Association	Know the 10 Signs: Early Detection Matters
American Diabetes Association	The Diabetes Advisor: Hypoglycemia
Alzheimer's Association	take care of yourself How to recognize and manage caregiver stress
American Diabetes Association	The Diabetes Advisor: Kidney Disease- Signs and Treatment
American Academy of Allergy, Asthma & Immunology	Colds, Allergies and Sinusitis — How to Tell the Difference
American Diabetes Association	The Diabetes Advisor: Medications for Treating Type 2 Diabetes
American Academy of Pediatrics	Pediatric Endocrinology Fact Sheet: Acquired Hypothyroidism in Children
American Diabetes Association	The Diabetes Advisor: Nerve Damage and Diabetes
American Academy of Pediatrics	Vitamin D Deficiency and Rickets
American Diabetes Association	The Diabetes Advisor: Peripheral (Sensorimotor) Neuropathy
American Cancer Society	Radiation Therapy What It Is, How It Helps
American Diabetes Association	The Diabetes Advisor: Planning for Pregnancy
American Diabetes Association	Are You At Risk for Type 2 Diabetes?
American Diabetes Association	The Diabetes Advisor: Planning for Pregnancy
American Diabetes Association	Diabetes: An Introduction
American Diabetes Association	The Diabetes Advisor: Pregnancy - Physical Exam Before Getting Pregnant
American Diabetes Association	Fast Facts: Data and Statistics about Diabetes
American Diabetes Association	Prediabetes: What Is It and What Can I Do?
American Diabetes Association	The Diabetes Advisor: Pregnancy - Physical Exam Before Getting Pregnant
American Diabetes Association	Standards of Care
American Diabetes Association	The Diabetes Advisor: Type 2 Diabetes
American Diabetes Association	The Diabetes Advisor: Preventing or Delaying Kidney Disease
American Diabetes Association	The Diabetes Advisor: A1C/eAG
American Diabetes Association	The Diabetes Advisor: Skin Care and Infections
American Diabetes Association	The Diabetes Advisor: Autonomic Neuropathy
American Diabetes Association	The Diabetes Advisor: Taking Care of Your Feet
American Diabetes Association	The Diabetes Advisor: Checking Blood Glucose
American Diabetes Association	The Diabetes Advisor: Tracking Blood Glucose
American Diabetes Association	The Diabetes Advisor: Diabetes and Kidney Disease
American Diabetes Association	The Diabetes Advisor: Treating Gestational Diabetes
American Diabetes Association	The Diabetes Advisor: Diabetes and Oral Health
American Diabetes Association	The Diabetes Advisor: Type 1 Diabetes
American Diabetes Association	The Diabetes Advisor: Diabetes and Stress
American Diabetes Association	Toolkit No. 6: All About Cholesterol
American Diabetes Association	The Diabetes Advisor: Diabetes and Your Emotional Well-Being
American Diabetes Association	What Can I Eat? Alcohol
American Diabetes Association	The Diabetes Advisor: Diabetes and Your Eyes
American Diabetes Association	What Can I Eat? Be More Active
American Diabetes Association	The Diabetes Advisor: Diabetes Symptoms
American Diabetes Association	What Can I Eat? Fast Food Tips
American Diabetes Association	The Diabetes Advisor: Diagnosing Diabetes
American Diabetes Association	What Can I Eat? Healthy and Low Cost Using Canned and Dry Foods

American Diabetes Association	What Can I Eat? Healthy Eating When Dining Out
American Heart Association	A Patient's Guide to Living With Atrial Fibrillation
American Heart Association	How Can I Handle the Stress of Not Smoking?
American Heart Association	How Can I Improve My Cholesterol?
American Heart Association	How Can I Keep Track of Physical Activity and Healthy Eating?
American Heart Association	How Can I Make My Lifestyle Healthier?
American Heart Association	How Can I Monitor My Cholesterol, Blood Pressure and Weight?
American Heart Association	How Can I Prepare for Heart Surgery?
American Heart Association	How Can Physical Activity Become a Way of Life?
American Heart Association	How Do I Change Recipes?
American Heart Association	How Will I Be Monitored After Heart Surgery?
American Heart Association	let's talk about High Blood Pressure and Stroke
American Heart Association	The ABCD's of Blood Pressure Measurement
American Heart Association	Understanding and Managing High Blood Pressure
American Heart Association	What About My Child and Rheumatic Fever?
American Heart Association	What About African Americans and High Blood Pressure?
American Heart Association	What About African Americans and High Blood Pressure?
American Heart Association	What Are Anticoagulants and Antiplatelet Agents?
American Heart Association	What Are High Blood Cholesterol and Triglycerides?
American Heart Association	What Are the Caregiver's Rights?
American Heart Association	What Are the Warning Signs of Stroke?
American Heart Association	What Happens After Heart Surgery?
American Heart Association	What Is Atrial Fibrillation?
American Heart Association	What Is Cardiac Rehabilitation?
American Heart Association	What Is Caregiver Burnout?
American Heart Association	What Is Heart Valve Surgery?
American Heart Association	What Is High Blood Pressure Medicine?
American Heart Association	What Is High Blood Pressure Medicine?
American Heart Association	What Is Kawasaki Disease?
American Heart Association	What Is Peripheral Vascular Disease?

American Heart Association	Why Should I Lose Weight?
American Thoracic Society	What Is Obstructive Sleep Apnea In Adults?
Amputee Coalition of America	Body Image, Relationships and Sexuality after Amputation
Amputee Coalition of America	Cosmesis: The Art of Making Artificial Limbs Look Lifelike
Amputee Coalition of America	Notes from the Medical Director Senior Health: Older Adults and Newer Technology
Amputee Coalition of America	Notes from the Medical Director: Limb Loss in Children: Prosthetic Issues
Amputee Coalition of America	Pain Management and the Amputee
Amputee Coalition of America	Peripheral Arterial Disease (PAD) and Limb Loss
Amputee Coalition of America	Prosthetic Feet
Amputee Coalition of America	Prosthetic Knee Systems
Amputee Coalition of America	Special Report: Senior Health When Are Prostheses the Right Choice for Older Amputees?
American Heart Association	Why Should I Be Physically Active?
Amputee Coalition of America	Ways Children Adjust to Limb Loss
Amputee Coalition of America	When a Parent Loses a Limb: Helping Children Cope
Association of Clinicians for the Underserved	Starting Insulin-a patient guide
Association of Clinicians for the Underserved	Starting Insulin-a patient guide: Measuring Your Blood Sugar
Association of Clinicians for the Underserved	Starting Insulin-a patient guide: Using Insulin to Treat Your Diabetes: What It Means For You
Association of Clinicians for the Underserved	Starting Insulin: a patient guide - Using Insulin to Treat Your Diabetes
National Institute of Diabetes and Digestive and Kidney Diseases	Celebrate the Beauty of Youth
Centers for Disease Control and Prevention	American Indian and Alaska Native Heart Disease and Stroke Fact Sheet
American Heart Association	Why Should I Be Physically Active?
American Heart Association	Why Should I Limit Sodium?

Centers for Disease Control and Prevention	Hepatitis B: General Information
Centers for Disease Control and Prevention	Hepatitis B: When Someone in the Family has Hepatitis B
Centers for Disease Control and Prevention	An Alcohol-Free Pregnancy Is the Best Choice for Your Baby
Centers for Disease Control and Prevention	Aortic Aneurysm Fact Sheet
Centers for Disease Control and Prevention	Breast Cancer In Young Women
Centers for Disease Control and Prevention	Cervical Cancer
Centers for Disease Control and Prevention	Cervical Cancer Screening with the HPV test and the Pap test in women ages 30 and older
Centers for Disease Control and Prevention	Childhood Sunburns Can Cause Skin Cancer: What You Can Do
Centers for Disease Control and Prevention	Cholesterol Fact Sheet
Centers for Disease Control and Prevention	Choose Your Cover
Centers for Disease Control and Prevention	Gestational Diabetes
Centers for Disease Control and Prevention	Heart Disease Fact Sheet
Centers for Disease Control and Prevention	Heart Failure Fact Sheet
Centers for Disease Control and Prevention	Hepatitis A: General Information
Centers for Disease Control and Prevention	Hepatitis B and Sexual Health
Centers for Disease Control and Prevention	Hepatitis B and Your Family: Information for People from Africa
Centers for Disease Control and Prevention	Hepatitis B: Are You At Risk?
Centers for Disease Control and Prevention	Hepatitis B: Are You At Risk? Information for People from Africa
Centers for Disease Control and Prevention	Hepatitis B: Are You At Risk? Information for People from Africa

Centers for Disease Control and Prevention	Hepatitis C & Injection Drug Use
Centers for Disease Control and Prevention	Hepatitis C: General Information
Centers for Disease Control and Prevention	Hepatitis C: Information on Testing & Diagnosis
Centers for Disease Control and Prevention	Hepatitis C: What to Expect When Getting Tested
Centers for Disease Control and Prevention	Hepatitis C: Why Baby Boomers Should Get Tested
Centers for Disease Control and Prevention	High Blood Pressure Fact Sheet
Centers for Disease Control and Prevention	HIV and Viral Hepatitis
Centers for Disease Control and Prevention	Influenza (Flu) Vaccine (Inactivated or Recombinant): What you need to know
Centers for Disease Control and Prevention	Know the Facts About Heart Disease
Centers for Disease Control and Prevention	Know the Facts About High Blood Pressure
Centers for Disease Control and Prevention	Know the Facts About High Cholesterol
Centers for Disease Control and Prevention	Know the Signs and Symptoms of a Stroke
Centers for Disease Control and Prevention	Men and Heart Disease Fact Sheet
Centers for Disease Control and Prevention	Parents' Influence on the Health of Lesbian, Gay, and Bisexual Teens: What Parents and Families Should Know
Centers for Disease Control and Prevention	Peripheral Arterial Disease in the Legs
Centers for Disease Control and Prevention	Play It Safe In the Sun: A Guide for Parents
Centers for Disease Control and Prevention	Protect Your Baby for Life
Centers for Disease Control and Prevention	Hepatitis C & Incarceration

Centers for Disease Control and Prevention	Protect Your Baby for Life: Hepatitis B and Your Baby
Centers for Disease Control and Prevention	Protect Your Baby for Life: When a Pregnant Woman Has Hepatitis B
Centers for Disease Control and Prevention	Pulmonary Hypertension Fact Sheet
Centers for Disease Control and Prevention	Share the Fun Not the Germs
Centers for Disease Control and Prevention	Sodium: the facts
Centers for Disease Control and Prevention	State Heart Disease and Stroke Prevention Programs Address High Blood Cholesterol
Centers for Disease Control and Prevention	Stroke Fact Sheet
Centers for Disease Control and Prevention	Sunscreen for Your Sun Day
Centers for Disease Control and Prevention	Take Control of Your Heart: It's all in the ABCS
Centers for Disease Control and Prevention	Talking to Your Teens About Sex
Centers for Disease Control and Prevention	Viral Hepatitis: Information for Gay and Bisexual Men
Centers for Disease Control and Prevention	When Someone Close To You Has Hepatitis B
Centers for Disease Control and Prevention	Women and Heart Disease Fact Sheet
Consumer Reports	Adult Vaccines: Protect Yourself and Your Family
Consumer Reports	Treating High Blood Pressure: Is a Calcium Channel Blocker Drug Right for You?
Consumer Reports Health	Allergy tests: When you need them—and when you don't
Consumer Reports Health	Choosing a type 2 diabetes drug: Why generic metformin is often the best choice
Consumer Reports Health	Imaging tests for lower-back pain Why you probably don't need them.
Consumer Reports Health	Take control of your health: You have the power to manage your health
Consumer Reports Health	Testing for Alzheimer's disease: When you need a brain scan—and when you don't
Consumer Reports Health	Treating Sinus Problems
Consumer Reports Health	Upper endoscopy for frequent heartburn or GERD: When you need it—and when you don't
Consumer Reports Health	Where to go for healthcare when you need it
FDA's Office of Women's Health	4 Basic Steps to Food Safety at Home
FDA's Office of Women's Health	Clinical Trials
FDA's Office of Women's Health	Contact Lens Care
FDA's Office of Women's Health	Depression
FDA's Office of Women's Health	Diabetes Medicines
FDA's Office of Women's Health	Dietary Supplements
FDA's Office of Women's Health	Dietary Supplements
FDA's Office of Women's Health	Hair Dyes and Relaxers
FDA's Office of Women's Health	Health Scams: Don't Take the Risk
FDA's Office of Women's Health	Heart Health for Women
FDA's Office of Women's Health	High Blood Pressure (Hypertension)
FDA's Office of Women's Health	HPV (human papillomavirus)
FDA's Office of Women's Health	Mammograms
FDA's Office of Women's Health	Medicine and Pregnancy
FDA's Office of Women's Health	Medicine and Pregnancy
FDA's Office of Women's Health	Medicines to help you: Cholesterol
FDA's Office of Women's Health	Medicines to help you: Depression
FDA's Office of Women's Health	Medicines to Help You: HIV and AIDS
FDA's Office of Women's Health	Medicines to Help You: Menopause
FDA's Office of Women's Health	Osteoporosis
FDA's Office of Women's Health	Sleep Problems
FDA's Office of Women's Health	Smoking: Medicines to Help You Quit
FDA's Office of Women's Health	Tattoos and Permanent Makeup
FDA's Office of Women's Health	Use Medicines Wisely
FDA's Office of Women's Health	Women and HIV
FDA's Office of Women's Health	Women in Clinical Trials
FDA's Office of Women's Health	Your Glucose Meter

Immunization Action Coalition	Summary of Recommendations for Child/Teen Immunization
Immunization Action Coalition	Vaccinations for Adults
Immunization Action Coalition	Vaccinations for Preteens and Teens, Age 11–19 Years
Massachusetts Department of Public Health	Understanding Lead Poisoning A guide for parents of children with high lead levels
Mine Safety and Health Administration	Proper Lifting Techniques - How to Lift Safely
Narcotics Anonymous World Services	Am I an Addict?
National Cancer Institute	Managing Chemotherapy Side Effects : Nerve Changes
National Cancer Institute	Managing Chemotherapy Side Effects: Anemia
National Cancer Institute	Managing Chemotherapy Side Effects: Appetite Changes
National Cancer Institute	Managing Chemotherapy Side Effects: Bleeding Problems
National Cancer Institute	Managing Chemotherapy Side Effects: Constipation
National Cancer Institute	Managing Chemotherapy Side Effects: Diarrhea
National Cancer Institute	Managing Chemotherapy Side Effects: Fatigue (feeling weak and tired)
National Cancer Institute	Managing Chemotherapy Side Effects: Hair Loss (Alopecia)
National Cancer Institute	Managing Chemotherapy Side Effects: Infection
National Cancer Institute	Managing Chemotherapy Side Effects: Memory Changes
National Cancer Institute	Managing Chemotherapy Side Effects: Mouth and Throat Changes
National Cancer Institute	Managing Chemotherapy Side Effects: Nausea and Vomiting
National Cancer Institute	Managing Chemotherapy Side Effects: Pain
National Cancer Institute	Managing Chemotherapy Side Effects: Sexual and Fertility Changes in Men
National Cancer Institute	Managing Chemotherapy Side Effects: Sexual and Fertility Changes in Women
National Cancer Institute	Managing Chemotherapy Side Effects: Skin and Nail Changes
National Cancer Institute	Managing Chemotherapy Side Effects: Swelling

National Diabetes Education Program	Take Care of Your Feet for a Lifetime
National Diabetes Education Program	Tips for Kids With Type 2 Diabetes
National Cancer Institute	Managing Chemotherapy Side Effects: Urination Changes
National Cancer Institute	Managing Radiation Therapy Side Effects: What to do about changes when you urinate
National Cancer Institute	Managing Radiation Therapy Side Effects: What to do when you have loose stools (diarrhea)
National Cancer Institute	Managing Radiation Therapy Side Effects: What To Do About Feeling Sick to Your Stomach and Throwing Up (Nausea and Vomiting)
National Cancer Institute	Understanding Chemotherapy
National Cancer Institute	Understanding Radiation Therapy: What To Know About Brachytherapy (A Type of Internal Radiation Therapy)
National Cancer Institute	Understanding Radiation Therapy: What To Know About External Beam Radiation Therapy
National Center for Chronic Disease Prevention and Health Promotion	Breast Cancer: What You Need To Know
National Center for PTSD	Assessing and Responding to Suicidal Intent: A fact sheet for providers
National Center for PTSD	Treatment of PTSD
National Center for PTSD	What is PTSD?
National Cholesterol Education Program	High Blood Cholesterol What you need to know
National Diabetes Education Program	4 Steps to Manage Your Diabetes for Life
National Diabetes Education Program	Choose More than 50 Ways to Prevent Type 2 Diabetes
National Diabetes Education Program	Did You Have Gestational Diabetes When You Were Pregnant?
National Diabetes Education Program	Eat Healthy Foods
National Diabetes Education Program	How to Help Your Children Stay Healthy
National Diabetes Education Program	It’s Not Too Late to Prevent Type 2 Diabetes
National Diabetes Education Program	Know Your Blood Sugar Numbers
National Diabetes Education Program	Lower Your Risk for Type 2 Diabetes
National Diabetes Education Program	Make Healthy Food Choices
National Diabetes Education Program	Take Care of Your Feet for a Lifetime

National Eye Institute	Don’t lose sight of Cataracts
National Heart, Lung, and Blood Institute	A Pocket Guide to Blood Pressure Measurement in Children
National Heart, Lung, and Blood Institute	Atherosclerosis
National Heart, Lung, and Blood Institute	Coronary Heart Disease
National Heart, Lung, and Blood Institute	Facts About Menopausal Hormone Therapy
National Heart, Lung, and Blood Institute	Facts About Peripheral Arterial Disease (PAD)
National Heart, Lung, and Blood Institute	Facts About Peripheral Arterial Disease (PAD) for African Americans
National Heart, Lung, and Blood Institute	Heart Attack: Know the Symptoms
National Heart, Lung, and Blood Institute	High Blood Pressure and Children: What Parents Need to Know
National Heart, Lung, and Blood Institute	Learn What a Heart Attack Feels Like— It Could Save Your Life.
National Heart, Lung, and Blood Institute	Lowering Your Blood Pressure With DASH
National Heart, Lung, and Blood Institute	The Heart Truth for African American Women: Take Action to Protect Your Heart
National Heart, Lung, and Blood Institute	The Heart Truth for Latinas: Take Action to Protect Your Heart
National Heart, Lung, and Blood Institute	The Heart Truth for Women
National Heart, Lung, and Blood Institute	What You Need To Know About High Blood Cholesterol
National Heart, Lung, and Blood Institute	Your Guide to a Healthy Heart
National Heart, Lung, and Blood Institute	Your Guide to Living Well with Heart Disease
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Are Bursitis and Tendinitis?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Acne?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Back Pain?
National Eye Institute	Astigmatism

National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Alopecia Areata?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Epidermolysis Bullosa?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Juvenile Arthritis?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Lichen Sclerosus?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Lupus?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Marfan Syndrome?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Pemphigus?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Psoriasis?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Raynaud's Phenomenon?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Vitiligo?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	Healthy Bones Matter
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Are Growth Plate Injuries?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Are Heritable Disorders of Connective Tissue?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Are Knee Problems?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Are Osteoporosis and Arthritis and How Are They Different?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Are Shoulder Problems?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Are Sports Injuries?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Are Sprains and Strains?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is a Hip Replacement?

National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Atopic Dermatitis?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Behçet's Disease?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Fibromyalgia?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Gout?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Osteoarthritis?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Osteogenesis Imperfecta?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Osteonecrosis?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Paget's Disease of Bone?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Reactive Arthritis?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Rheumatoid Arthritis?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Rosacea?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Scleroderma?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Scoliosis?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Sjögren's Syndrome?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Spinal Stenosis?
National Institute of Arthritis and Musculoskeletal and Skin Diseases	What Is Ankylosing Spondylitis?

National Institute of Dental and Craniofacial Research	A Healthy Mouth for Your Baby
National Institute of Dental and Craniofacial Research	Plaque: What it is and how to get rid of it
National Institute of Dental and Craniofacial Research	Three Good Reasons to See A Dentist Before Cancer Treatment
National Institute of Diabetes and Digestive and Kidney Diseases	Prevent diabetes problems: Keep your diabetes under control
National Institute of Diabetes and Digestive and Kidney Diseases	Abdominal Adhesions
National Institute of Diabetes and Digestive and Kidney Diseases	Abdominal Adhesions
National Institute of Diabetes and Digestive and Kidney Diseases	Alagille Syndrome
National Institute of Diabetes and Digestive and Kidney Diseases	Anatomic Problems of the Lower GI Tract
National Institute of Diabetes and Digestive and Kidney Diseases	Appendicitis
National Institute of Diabetes and Digestive and Kidney Diseases	Autoimmune Hepatitis
National Institute of Diabetes and Digestive and Kidney Diseases	Barrett's Esophagus
National Institute of Diabetes and Digestive and Kidney Diseases	Be Active When You Have Diabetes
National Institute of Diabetes and Digestive and Kidney Diseases	Biliary Atresia
National Institute of Diabetes and Digestive and Kidney Diseases	Bleeding in the Digestive Tract
National Institute of Diabetes and Digestive and Kidney Diseases	Celiac Disease
National Institute of Diabetes and Digestive and Kidney Diseases	Colonoscopy
National Institute of Diabetes and Digestive and Kidney Diseases	Energize Yourself and Your Family
National Institute of Diabetes and Digestive and Kidney Diseases	Fit and Fabulous as You Mature
National Institute of Diabetes and Digestive and Kidney Diseases	Gastroesophageal Reflux (GER) and Gastroesophageal Reflux Disease (GERD) in Adults
National Institute of Diabetes and Digestive and Kidney Diseases	Gastroesophageal Reflux Disease (GERD) in Children and Adolescents

National Institute of Diabetes and Digestive and Kidney Diseases	Gastroesophageal Reflux (GER) and Gastroesophageal Reflux Disease (GERD) in Infants
National Institute of Diabetes and Digestive and Kidney Diseases	Healthy Eating & Physical Activity Across Your Lifespan: Fit for Two
National Institute of Diabetes and Digestive and Kidney Diseases	Healthy Eating and Physical Activity Across Your Lifespan: Better Health and You
National Institute of Diabetes and Digestive and Kidney Diseases	Healthy Eating and Physical Activity Across Your Lifespan: Helping Your Child
National Institute of Diabetes and Digestive and Kidney Diseases	Helping Your Overweight Child
National Institute of Diabetes and Digestive and Kidney Diseases	Indigestion
National Institute of Diabetes and Digestive and Kidney Diseases	Irritable Bowel Syndrome
National Institute of Diabetes and Digestive and Kidney Diseases	Irritable Bowel Syndrome in Children
National Institute of Diabetes and Digestive and Kidney Diseases	Just Enough For You: About Food Portions
National Institute of Diabetes and Digestive and Kidney Diseases	Kidney Failure: Choosing a Treatment that's Right for You
National Institute of Diabetes and Digestive and Kidney Diseases	Kidney Failure: Eat Right to Feel Right On Hemodialysis
National Institute of Diabetes and Digestive and Kidney Diseases	Learn About Diabetes
National Institute of Diabetes and Digestive and Kidney Diseases	Liver Biopsy
National Institute of Diabetes and Digestive and Kidney Diseases	Liver Transplantation
National Institute of Diabetes and Digestive and Kidney Diseases	Lower GI Series
National Institute of Diabetes and Digestive and Kidney Diseases	National Institute of Diabetes and Digestive and Kidney Diseases
National Institute of Diabetes and Digestive and Kidney Diseases	Ostomy Surgery of the Bowel
National Institute of Diabetes and Digestive and Kidney Diseases	Peptic Ulcer Disease and H. pylori
National Institute of Diabetes and Digestive and Kidney Diseases	Pancreatitis

National Institute of Diabetes and Digestive and Kidney Diseases	Prevent diabetes problems: Keep your eyes healthy
National Institute of Diabetes and Digestive and Kidney Diseases	Prevent diabetes problems: Keep your feet healthy
National Institute of Diabetes and Digestive and Kidney Diseases	Prevent diabetes problems: Keep your heart and blood vessels healthy
National Institute of Diabetes and Digestive and Kidney Diseases	Prevent diabetes problems: Keep your kidneys healthy
National Institute of Diabetes and Digestive and Kidney Diseases	Prevent diabetes problems: Keep your mouth healthy
National Institute of Diabetes and Digestive and Kidney Diseases	Prevent diabetes problems: Keep your nervous system healthy
National Institute of Diabetes and Digestive and Kidney Diseases	Prostatitis: Inflammation of the Prostate
National Institute of Diabetes and Digestive and Kidney Diseases	The World Around You: Use What You Have to Stay Healthy and Fit
National Institute of Diabetes and Digestive and Kidney Diseases	Tips to Help You Get Active
National Institute of Diabetes and Digestive and Kidney Diseases	Treatment Methods for Kidney Failure HEMODIALYSIS
National Institute of Diabetes and Digestive and Kidney Diseases	Ulcerative Colitis
National Institute of Diabetes and Digestive and Kidney Diseases	Upper GI Endoscopy
National Institute of Diabetes and Digestive and Kidney Diseases	Upper GI Series
National Institute of Diabetes and Digestive and Kidney Diseases	Viral Gastroenteritis
National Institute of Diabetes and Digestive and Kidney Diseases	Viral Hepatitis: A through E and Beyond
National Institute of Diabetes and Digestive and Kidney Diseases	Virtual Colonoscopy
National Institute of Diabetes and Digestive and Kidney Diseases	Peptic Ulcer Disease and NSAIDs
National Institute of Diabetes and Digestive and Kidney Diseases	Walking: A Step in the Right Direction

National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Bowel Control
National Institute of Diabetes and Digestive and Kidney Diseases	What I Need to Know About Celiac Disease
National Institute of Diabetes and Digestive and Kidney Diseases	What I Need to Know About Cirrhosis
National Institute of Diabetes and Digestive and Kidney Diseases	What I Need to Know About Constipation
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Diabetes Medicines
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Diverticular Disease
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Erectile Dysfunction
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Gas
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Hepatitis A
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Hepatitis B
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Hepatitis C
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Hirschsprung Disease
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Irritable Bowel Syndrome
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Lactose Intolerance
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Liver Transplantation
National Institute of Diabetes and Digestive and Kidney Diseases	What I Need to Know About My Child's Bedwetting
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Peptic Ulcer Disease
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Physical Activity and Diabetes
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Preparing for Pregnancy if I Have Diabetes
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Urinary Tract Infections

National Institute of Diabetes and Digestive and Kidney Diseases	Hemochromatosis
National Institute of Diabetes and Digestive and Kidney Diseases	Whipple Disease
National Institute of Diabetes and Digestive and Kidney Diseases	Hemorrhoids
National Institute of Diabetes and Digestive and Kidney Diseases	Wilson Disease
National Institute of Diabetes and Digestive and Kidney Diseases	Hepatitis B What Asian and Pacific Islander Americans Need to Know
National Institute of Diabetes and Digestive and Kidney Diseases	Young at Heart
National Institute of Diabetes and Digestive and Kidney Diseases	Take Charge of Your Health
National Institute of Diabetes and Digestive and Kidney Diseases	Your Guide to Diabetes: Type 1 and Type 2
National Institute of Diabetes and Digestive and Kidney Diseases	The Digestive System and How It Works
National Institute of Diabetes and Digestive and Kidney Diseases	Chronic Diarrhea in Children
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Bladder Control for Women
National Institute of Diabetes and Digestive and Kidney Diseases	Cirrhosis
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Carbohydrate Counting and Diabetes
National Institute of Diabetes and Digestive and Kidney Diseases	Constipation
National Institute of Diabetes and Digestive and Kidney Diseases	What I Need to Know About Colon Polyps
National Institute of Diabetes and Digestive and Kidney Diseases	Constipation in Children
National Institute of Diabetes and Digestive and Kidney Diseases	What I Need to Know About Crohn's Disease
National Institute of Diabetes and Digestive and Kidney Diseases	Crohn’s Disease
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Diarrhea
National Institute of Diabetes and Digestive and Kidney Diseases	Cyclic Vomiting Syndrome
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about Kidney Stones
National Institute of Diabetes and Digestive and Kidney Diseases	ERCP (Endoscopic Retrograde Cholangiopancreatography)
National Institute of Diabetes and Digestive and Kidney Diseases	What I Need to Know About Living with Kidney Failure
National Institute of Diabetes and Digestive and Kidney Diseases	Fecal Incontinence
National Institute of Diabetes and Digestive and Kidney Diseases	What I need to know about My Child’s Urinary Tract Infection
National Institute of Diabetes and Digestive and Kidney Diseases	Flexible Sigmoidoscopy
National Institute of Mental Health	Schizophrenia
National Institute of Diabetes and Digestive and Kidney Diseases	Always Embarassed: Social Phobia (Social Anxiety Disorder)
National Institute of Mental Health	Foodborne Illnesses
National Institute of Diabetes and Digestive and Kidney Diseases	Anxiety Disorders
National Institute of Mental Health	Gallstones
National Institute of Diabetes and Digestive and Kidney Diseases	Attention Deficit/Hyperactivity Disorder
National Institute of Mental Health	Attention Deficit/Hyperactivity Disorder
National Institute of Diabetes and Digestive and Kidney Diseases	Gas in the Digestive Tract
National Institute of Mental Health	Autism Spectrum Disorder
National Institute of Diabetes and Digestive and Kidney Diseases	Gastritis
National Institute of Mental Health	Bipolar Disorder
National Institute of Diabetes and Digestive and Kidney Diseases	Getting on Track : Physical Activity and Healthy Eating for Men
National Institute of Mental Health	Bipolar Disorder in Children and Teens
National Institute of Diabetes and	Bipolar Disorder in Children: A Parents' Guide

National Institute of Mental Health	Chronic Illness and Mental Health: Recognizing and Treating Depression
National Institute of Mental Health	Depression
National Institute of Mental Health	Depression
National Institute of Mental Health	Depression
National Institute of Mental Health	Depression and College Students
National Institute of Mental Health	Depression in Women
National Institute of Mental Health	Depression: What You Need to Know
National Institute of Mental Health	Eating Disorders: About More than Food
National Institute of Mental Health	Generalized Anxiety Disorder: When Worry Gets Out of Control
National Institute of Mental Health	Helping Children and Adolescents Cope with Violence and Disasters
National Institute of Mental Health	Men and Depression
National Institute of Mental Health	Men and Depression
National Institute of Mental Health	Obsessive Compulsive Disorder: When Unwanted Thoughts Take Over
National Institute of Mental Health	Older Adults and Depression
National Institute of Mental Health	Panic Disorder: When Pain Overwhelms
National Institute of Mental Health	Post-Traumatic Stress Disorder
National Institute of Mental Health	Postpartum Depression Facts
National Institute of Mental Health	Social Phobia (Social Anxiety Disorder): Always Embarassed
National Institute of Mental Health	Suicide in America: Frequently Asked Questions
National Institute of Mental Health	Suicide: A Major, Preventable Mental Health Problem
National Institute of Mental Health	Teen Depression
National Institute of Mental Health	The Teen Brain: Still Under Construction
National Institute of Mental Health	Treatment of Children with Mental Illness
National Institute of Mental Health	When Worry Gets Out of Control: Generalized Anxiety Disorder
National Institute on Aging	A Guide for Older People: Talking with your doctor
National Institute on Aging	Alzheimer’s Disease Medications
National Institute on Aging	Caring for a person with Alzheimer's Disease
National Institute on Aging	Dietary Supplements

National Institute on Alcohol Abuse and Alcoholism	Women and Alcohol
National Institute on Aging	Exercising in Cold Weather
National Institute on Aging	Medicines: Use Them Safely
National Institute on Aging	Older Adults and Alcohol: You can get help
National Institute on Aging	Real-Life Benefits of Exercise and Physical Activity
National Institute on Aging	Safe Use of Medicines
National Institute on Aging	Stay Safe In Cold Weather!
National Institute on Aging	Understanding Alzheimer's Disease
National Institute on Aging	Understanding Memory Loss
National Institute on Alcohol Abuse and Alcoholism	A Family History of Alcoholism: Are You At Risk?
National Institute on Alcohol Abuse and Alcoholism	Alcohol Overdose: The Dangers of Drinking Too Much
National Institute on Alcohol Abuse and Alcoholism	Alcohol: A Women's Health Issue
National Institute on Alcohol Abuse and Alcoholism	Beyond Hangovers
National Institute on Alcohol Abuse and Alcoholism	College Drinking
National Institute on Alcohol Abuse and Alcoholism	Drinking and Your Pregnancy
National Institute on Alcohol Abuse and Alcoholism	Fetal Alcohol Exposure
National Institute on Alcohol Abuse and Alcoholism	Harmful Interactions
National Institute on Alcohol Abuse and Alcoholism	Rethinking Drinking: Alcohol and your health
National Institute on Alcohol Abuse and Alcoholism	Risky Drinking Can Put a Chill on Your Summer Fun
National Institute on Alcohol Abuse and Alcoholism	Talk to Your Child About Alcohol
National Institute on Alcohol Abuse and Alcoholism	Treatment for Alcohol Problems: Finding and Getting Help
National Institute on Alcohol Abuse and Alcoholism	Using Alcohol to Relieve Your Pain: What Are the Risks?

National Institute on Drug Abuse	Marijuana: Facts Parents Need to Know
National Institute on Drug Abuse	Seeking Drug Abuse Treatment: Know What to Ask
National Institutes of Health	Healthy Bones
New York City Department of Health and Mental Hygiene	Screening and Brief Intervention for Alcohol Problems
New York City Department of Health and Mental Hygiene	Travel Warning: Zika and Pregnancy
NIH Osteoporosis and Related Bone Diseases	Once Is Enough: A Guide to Preventing Future Fractures
NIH Osteoporosis and Related Bone Diseases	What Are Ways to Prevent Falls and Fractures?
Substance Abuse and Mental Health Services Administration	Healthy Babies, Strong Futures: How Men Can Help Pregnant Women Be Alcohol Free
Substance Abuse and Mental Health Services Administration	Marijuana
Substance Abuse and Mental Health Services Administration	Prescription Drug Abuse
Substance Abuse and Mental Health Services Administration	Preventing FASD: Healthy Women, Healthy Babies
Substance Abuse and Mental Health Services Administration	Treatment Options
The National Institutes of Health Osteoporosis and Related Bone Diseases	What Is Bone?
U.S. Department of Health and Human Services	A Healthy Mouth for Your Baby
U.S. Department of Health and Human Services	Men: Stay Healthy at 50+
U.S. Department of Health and Human Services	Men: Stay Healthy at Any Age
U.S. Department of Health and Human Services	Seal Out Tooth Decay
U.S. Department of Health and Human Services	The Power of Our Youth
U.S. Department of Health and Human Services, Office on Women's Health	Breastfeeding
U.S. Department of Health and Human	Healthy Pregnancy Do's and Don'ts
National Institute on Deafness and Other Communication Disorders	Ear Infections in Children

U.S. Department of Health and Human Services, Office on Women's Health	Healthy Pregnancy Do's and Don'ts
U.S. Department of Health and Human Services, Office on Women's Health	Healthy Pregnancy Food Don'ts
U.S. Department of Health and Human Services, Office on Women's Health	Your Guide to Breastfeeding
U.S. Department of Health and Human Services, Office on Women's Health	Your Guide to Breastfeeding for African American Women
U.S. Department of Veteran Affairs	Taking Aspirin to Prevent Heart Attacks
U.S. Department of Veteran Affairs	Taking Aspirin to Prevent Stroke
U.S. Department of Veterans Affairs	Flu Shots: General Information
U.S. Department of Veterans Affairs	Flu Symptoms When to Seek Medical Care
U.S. Department of Veterans Affairs	Home Care Guide for Flu
U.S. Department of Veterans Affairs	How to Help Control the Spread of Flu
U.S. Food and Drug Administration	Food Facts: Raw Produce Selecting and Serving it Safely
U.S. Food and Drug Administration	Food Safety for People with HIV/AIDS
U.S. Food and Drug Administration	Improving Your Odds for Cervical Health
U.S. Food and Drug Administration	Medicines In My Home
U.S. Food and Drug Administration	Menopause & Hormones Common Question
U.S. Preventive Services Task Force	Women: Stay Healthy at 50+
	Women: Stay Healthy at Any Age

Appendix C: Documents Marked Up by Participants in Phase II

IBS is a group of symptoms that occur together, not a disease. Symptoms can come and go repeatedly without signs of damage to the GI tract.

What are the symptoms of IBS?

The most common symptoms of IBS include pain or discomfort in your **abdomen**—the area between your chest and hips—and changes in your bowel habits. The pain or discomfort of IBS may be reported as cramping and

- starts when you have bowel movements more or less often than usual
- starts when your stool appears looser and more watery or harder and more lumpy than usual
- goes away after a bowel movement

2

Phonics Reader Mark-up of IBS Document

Managing Chemotherapy Side Effects: **Anemia**

Eat and drink well.

- Talk with your doctor or nurse to learn what foods and drinks are best for you.
  - You may need to eat high-protein foods. Meat, peanut butter, and eggs are good choices.
  - You may need to eat foods with iron. Red meat, leafy greens (such as collard greens and spinach), and cooked dried beans are good choices.
- Most people need to drink at least 8 cups of liquid every day. Water and juice with extra water added are good choices.

Questions to ask your doctor or nurse:

1. What problems should I call you about? A brook harm.
2. What is causing the anemia?
3. Would taking medicine, iron pills, or getting a blood transfusion help me?
4. Could you give me the name of a nutritionist, so I can learn more about what foods might help?

Your doctor or nurse will order blood tests. If you have anemia, you may need medicine. Or you may need a blood transfusion to help you feel better.

How can we help?

National Cancer Institute's Cancer Information Service

Phone: 1-800-422-6237 (1-800-4-CANCER)
Web: www.cancer.gov
Online Chat: www.cancer.gov/livehelp

NCI has a series of 18 Chemotherapy Side Effects Sheets at:
www.cancer.gov/chemo-side-effects

NATIONAL CANCER INSTITUTE

Revised February 2012

Reads Aloud Participant Mark-up of Anemia Document

Managing Chemotherapy Side Effects: **Anemia**

Eat and drink well.

Even though some

- Talk with your doctor or nurse to learn what foods and drinks are best for you. Nurses knows better than the doctors
  - You may need to eat high-protein foods. Meat, peanut butter, and eggs are good choices. you should ask the nurses.
  - You may need to eat foods with iron. Red meat, leafy greens (such as collard greens and spinach), and cooked dried beans are good choices.

- Most people need to drink at least 8 cups of liquid every day. Water and juice with extra water added are good choices.

Questions to ask your doctor or nurse:

1. What problems should I call you about?
2. What is causing the anemia?
3. Would taking medicine, iron pills, or getting a blood transfusion help me? I don't think all these will help you, rather eat healthy food will help you.
4. Could you give me the name of a nutritionist, so I can learn more about what foods might help?

Your doctor or nurse will order blood tests. If you have anemia, you may need medicine. Or you may need a blood transfusion to help you feel better.

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Independent Reader Mark-up of Anemia Document