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Improving Patients' Understanding of their Electronic Medical Record Data in Order to Improve Self-Management - A Quality Improvement Project

Erin Amelia Roth

University of Massachusetts Amherst

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Improving Patients' Understanding of their Electronic Medical Record Data in Order to Improve
Self-Management - A Quality Improvement Project

Erin Amelia Roth

University of Massachusetts College of Nursing

DNP Project Chair:

Dr. Pamela Aselton

University of Massachusetts - Amherst

DNP Project Mentors:

Debra Stavarski, PhD, RN

Director, Nursing Research, Reading Hospital

Hong Yu, PhD, FACMI

Quantitative Health Sciences, University of

Massachusetts - Lowell

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Abstract

Background: Patients are increasingly given access to their electronic medical records (EMRs) to help them keep track of their care, but many may have a difficult time understanding what is in them. Programs such as NoteAid assist in translating medical records and may increase the number of patients who actively use their EMRs, a development which may improve the management of chronic diseases.

Purpose: To work on a translation system developed by the University of Massachusetts Informatics group to make outpatient records more understandable for adult patients with chronic disease by using and testing a machine-learning database (NoteAid). Patients' self-management of chronic disease may improve, as they increase their understanding of medical terminology.

Methods: A test version of NoteAid was used with volunteer adult patients during face-to-face sessions in an outpatient office at a health system in Southeastern Pennsylvania. These sessions were used to test NoteAid's effectiveness as a tool to improve patients' understanding of their EMRs. Patients read their own office note from a recent visit without the use of NoteAid, and then interpreted the same note using it.

Results: 13 participants participated over a two-month period with 85% reporting they would use the system from a patient portal and 100% answering *strongly agree* or *agree* when asked if the NoteAid system helped them comprehend their clinical EMR notes.

Conclusions: Machine-learning databases like NoteAid have the potential to improve the management of chronic diseases. By integrating these systems into an informative and user-friendly portal, patients are afforded the opportunity to improve understanding of their EMRs.

Keywords: *medical terms, patient understanding, health literacy, chronic disease, and electronic health record usability*

Improving Patients' Understanding of their Electronic Medical Record Data in Order to Improve
Self-Management - A Quality Improvement Project

Introduction

With the enactment of the American Reinvestment & Recovery Act (ARRA), including the Health Information Technology for Economic and Clinical Health (HITECH) Act, there were several national goals developed (Centers for Disease Control and Prevention [CDC], 2017). One of the goals of the HITECH Act is to implement meaningful use of electronic health records throughout the United States. Meaningful use is defined as using an electronic health record in a meaningful way, such as electronic prescribing or using the EHR to exchange health information. The Centers for Medicare & Medicaid Services (CMS) offers incentive payments to eligible professionals or eligible hospitals who are able to demonstrate that they have made an effort to adopt, implement, or improve certified EHR technology. This act was enacted with three phases spanning 2011-2015. Eligible professionals or eligible hospitals who declined to participate by 2015 are currently facing negative adjustments made to their Medicare/Medicaid fees in the amount of a 3% reduction.

Health literacy can be described as, “the degree to which individuals have the capacity to obtain, process, and understand basic health information needed to make appropriate health decisions” (U.S. Department of Health and Human Services, n.d., p. 1). Low health literacy is more common in older individuals, minority populations, individuals who have low socioeconomic status, and medically underserved individuals (U.S. Department of Health and Human Services, n.d.). Low health literacy can have negative effects on many different areas of healthcare, including having difficulty understanding medical information, whether verbal or

written, having difficulty managing chronic health conditions, and creating a barrier to communicating effectively with healthcare providers.

With the movement toward patients and consumers becoming more involved in their health care, individuals can now be actively and effectively engaged in activities that were traditionally carried out only by health care providers only, such as reading medical documents and lab results (Keselman & Arnott Smith, 2012). Unfortunately, however, patients' engagement with electronic health records is low, even though there are many potential benefits to patients accessing and using their electronic health records. As one explanation, Keselman and Arnott Smith (2012) determined that difficulty with terminology was one of the barriers to increased use of electronic health records.

Background

Patient satisfaction and quality of life can be negatively impacted by lack of patient understanding of their health information (Pieterse, Jager, Smets, & Henselmans, 2012). A study investigated the impact of minimizing medical terminology in medical documents and whether it improved patient understanding and anxiety/depression scores (Wernick et al., 2016). Participants were divided into two groups and read either an original letter with medical terminology or a translated letter which minimized medical terminology. Each participant then returned in two weeks for another meeting, in which they read whichever letter they did not read at the first meeting. The authors found that patients preferred the translated letter, as opposed to the letter with medical terminology, and suggested that minimizing the use of medical terminology in medical correspondence has the ability to improve patient-provider relationships and management of chronic diseases.

The creation of easily accessible simplified definitions of medical terms with appropriate reading grade level should increase patients' understanding of their electronic medical records. A system, such as NoteAid, also has the potential to increase the number of patients who actively use their electronic medical records, a benefit which may improve the management of chronic diseases overall.

Problem Statement

With the enactment of recent legislation which is promoting making patients' electronic medical records available to them in the primary care setting, adult patients with chronic diseases may have difficulty understanding certain terms and jargon in their medical records. This results from a medical record system that is not consumer-friendly, does not include definitions of terms, and does not include assistance for patients to learn the medical record system. These factors place patients at risk for not having complete information to manage their chronic health conditions and having decreased patient satisfaction due to barriers in communication between patients and providers.

The purpose of this project was to work on a translation system developed by the University of Massachusetts (UMASS) Medical School Informatics group to make outpatient records more understandable by using a machine-learning database, which gives definitions of medical terms and medications tailored to assisting individuals with understanding their medical records. A test version NoteAid was implemented with adult patients in an outpatient office at a health system in Southeastern Pennsylvania, with the objective to improve patient understanding of their office encounters.

Review of the Literature

A comprehensive search of the literature was conducted using the Ovid, PubMed, and CINAHL databases. The key terms used for the literature search included the following: medical terms, patient understanding, health literacy, chronic disease, and electronic health record. Results were limited to the past five years. One-hundred ninety-eight results were retrieved using PubMed by searching these key terms: medical terms and patient understanding. These results were limited to humans and adults over the age of 19. One-hundred seventy-six results were retrieved using PubMed with the key terms health literacy and chronic disease. These results were limited to humans and adults over the age of 19. Twenty-seven results were retrieved using PubMed with the key terms electronic health record and patient understanding.

One-hundred twelve results were retrieved using OVID with the key terms health literacy and chronic disease. Forty-five results were retrieved using CINAHL with the key terms health literacy and chronic disease. Inclusion criteria for articles were human studies, English language, and studies conducted with the adult population. Exclusion criteria were studies that did not focus on the use of electronic medical records and those studies that focused on eHealth literacy relating to online health information. Seven results were retrieved using CINAHL with the key terms electronic health record and patient understanding. These results were limited to humans, English language, and all adult population.

A study was conducted that developed a classification system of comprehension errors of medical documents (Keselman & Arnott Smith, 2012). Lay individuals were included in the study and they read two documents using medical terminology including a description of a clinical trial and an office visit note. The authors found that terminology was one of the barriers to increased use of accessing electronic medical records. It is important to note that the goal for

patients' understanding of medical records is not intended to be at the level of a health care practitioner's level of understanding.

There is a language gap between health care providers and patients (Hong, Ehlers, Gillis, Patrick, & Zhang, 2010). This language gap and misunderstandings related to medical terminology can cause problems in communication between health care providers and patients, as well as affect patients' access to health information and could result in poor patient and provider satisfaction (Hong et al., 2010). Patients' lack of understanding of health information they receive has the potential to influence their level of involvement in the interaction, leading to lack of engagement with their health care provider (Pieterse et al., 2012). Lack of engagement between patients and providers may lower patient satisfaction and have a negative impact on quality of life.

Patients and families are expected to use a large number of health and medical documents (Keselman & Arnott Smith, 2012). There are benefits from having patients access their medical documents however, they often have difficulty understanding the information found in these documents. The field of informatics can help to address this problem by developing health-related tools that are consumer-friendly.

Readability of Medical Records

A non-blinded, randomized crossover study was conducted to examine health literacy and the impact it has on chronic disease management (Wernick et al., 2016). The goal of the study of 59 participants was to determine whether decreasing the use of medical terminology in health correspondence improved patient understanding and anxiety/depression scores. The Rapid Estimate of Adult Literacy in Medicine (REALM) was used to measure health literacy and the self-reported EQ-5D questionnaire was used to measure depression and anxiety. Patients had

their most recent correspondence from their provider translated by one of the study authors to minimize the medical terminology. The Flesch-Kincaid readability level tool was applied for the translation of medical terms. The study found that participants were 78% more likely to prefer the translated letter, and 79.7% of the participants reported that their perceived ability to manage their chronic health condition significantly improved with the translated letter.

The researchers showed that decreasing the Flesch-Kincaid level in medical correspondence has the ability to improve patient-provider relationships and management of chronic diseases (Wernick et al., 2016). As the authors stated, “minimizing medical terminology in secondary care correspondence is one avenue that can contribute greatly to patient understanding and empowerment of chronic disease management in an era of an ever increasing chronic disease burden and an ageing population” (Wernick et al., 2016, p. 600).

Fage-Butler and Nisbeth Jensen (2015) conducted a study that investigated medical terminology that was used in online patient-patient communication, without input from healthcare professionals. These researchers found that health literacy should be determined on an individual basis, as patients with chronic health conditions may have a better understanding of medical terminology relating to their specific chronic condition (Fage-Butler & Nisbeth Jensen, 2015). This study offered useful information, as the results showed that a machine-learning database can be used with patients who have a variety of health literacy levels.

Patient-Friendly Terms

Another study was conducted that included 80 participants and assessed their comprehension errors based on two medical documents (Keselman & Arnott Smith, 2012). Participants were asked to read two documents, a description of a clinical trial and a physician’s office visit note. They were then evaluated on their comprehension of the two documents.

Errors found included incorrectly recalling brand names of medicine, misunderstanding clinical concepts, misunderstanding the objective of a clinical research study, and misunderstanding, confusing or misspelling clinical terms. As the authors stated, “understanding categories and causes of lay comprehension errors is essential for development of informatics support for the task and designing useful, usable PHR’s” [personal health records] (Keselman & Arnott Smith, 2012, p. 2).

Usability of Medical Records

A usability study was conducted by Hong et al. (2010) that explored patient-friendly terms and their use in an electronic medical record portal. They found that using patient-friendly terms has the potential to bridge the language gap between health care providers and patients. The authors randomly chose 50 participants who were active in MyChart, which is an ambulatory electronic medical record portal. A total of 340 terms were identified from MyChart and analyzed based on patients’ search data. The authors found that participants tended to use simplified terms to express medical concepts, rather than formal medical terms.

Being able to write patient-friendly health materials involves several important steps (National Institutes of Health / U.S. National Library of Medicine, 2016). The first step includes knowing the target audience, including reading level, cultural background, age, and primary language. Determining the goals and objectives of the health materials is the next step. There are certain aspects of health materials that make them more difficult to understand, including materials being written at greater than an 8th grade reading level, long sentences that are wordy, use of complex words, medical jargon, abbreviations, and acronyms. If these cannot be avoided, explaining terms and concepts in plain language will help the reader to understand the material.

It is important to avoid abstract language when giving instructions. This can be avoided by being specific. In addition, sentences should be limited to less than 15 words.

Health Literacy

There are several readability assessment tools to help determine reading level of the language used in the health materials, including Readability-Score.com, New Dale-Chall Readability formula, Fry Readability Graph, SMOG, Gunning FOG, and Flesch-Kincaid Grade Level in addition to software programs that can be used to determine reading level (National Institutes of Health / U.S. National Library of Medicine, 2016). The Flesch-Kincaid tool can be found in the Microsoft Word grammar checker and can also at Readability-Score.com.

A cross-sectional study was conducted that investigated the effect of health literacy on quality of life for patients with ischemic heart disease (IHD) (Gonzalez-Chica et al., 2016). The study included patients with ischemic heart disease in general practices in two Australian states, Queensland and South Australia. Data were gathered between 2007 and 2009. A total of 587 patients with IHD were included in the study, from 24 practices. Investigators also explored the role of sociodemographic and clinical variables as potential confounders. Health literacy was measured using a validated questionnaire and was classified as inadequate, marginal, or adequate, using a validated 16-item questionnaire. Health-related quality of life was measured using the Medical Outcomes Study Short Form 12, which includes a physical and mental component.

The authors found that advanced age, lower educational level, disadvantaged socioeconomic status, and a larger number of cardiovascular disease comorbidities had a negative effect on health literacy and health-related quality of life (HRQoL) (Gonzalez-Chica et al., 2016). Furthermore, inadequate health literacy is a contributing factor to poor physical

functioning in patients with a diagnosis of ischemic heart disease. This is the only study currently completed that examined the effects of health literacy on HRQoL in patients with ischemic heart disease.

Patient Portal Characteristics

A systematic review was performed with the goal of determining characteristics of patient portals that are favorable from the standpoint of patients and providers and to determine areas of the portals that need improvement (Kruse, Argueta, Lopez, & Nair, 2015). Successful portals were those found to be user-friendly and that allow patients to take responsibility in managing their health. Portals vary in their design, as one portal may offer access to laboratory results without an explanation of the results, while another portal may provide an explanation of the results but the terminology may cause the patient confusion.

Patients over the age of 65 are more likely to have difficulty using patient portals (Kruse et al., 2015). A common finding in the systematic review was patients' difficulty in understanding the medical terminology and patients not having an understanding of their medical condition. Well-designed portals have the potential to provide patients access to their health records, improve communication between patients and providers, and to allow patients to have control in managing their chronic conditions.

Patient Engagement

A state of the science review was conducted that investigated patient portals and patient engagement (Irizarry et al., 2015). The authors found that the use of patient portals is influenced by many different personal factors, including age, ethnicity, education level, health literacy, health status, and the individual's role as a caregiver. Irizarry et al. (2015) found certain characteristics in the literature that were associated with lower use of patient portals, including

ethnic minorities, individuals under the age of 35, and individuals who are healthier and less educated. Individuals who have the most interest in patient portals include those with disabilities and chronic health conditions, those who use healthcare services frequently, and individuals who act as caregivers for elderly parents or children (Irizarry et al., 2015).

Social Network

A longitudinal qualitative interview and observation study included 44 participants from four community education venues in South Wales, UK (Edwards, Wood, Davies, & Edwards, 2013). The purpose of the study was to explain health literacy and how it relates to people living with a long-term condition who use their social network for support with health literacy-related tasks, including managing their condition, interacting with health professionals, and making health-related decisions. The authors conducted detailed qualitative interviews to determine how participants used their support systems. Participants often used their family and social networks in order to seek, understand, and use health information.

This distribution of health literacy helped participants manage their chronic condition, become more active in health-related decisions, communicate more effectively with healthcare professionals, and to accept living with a chronic condition (Edwards et al., 2013). The results from this study show that patients can benefit from a strong support system while managing their chronic conditions, through the distribution of health literacy.

Urban Versus Rural

Another cross-sectional study was performed with the purpose of the study being to use the Health Literacy Questionnaire (HLQ) to describe the health literacy of adults in urban and rural Victoria, Australia (Beauchamp et al., 2015). Participants completed the HLQ and the data were analyzed to describe differences between demographic sub-groups. The study included 813

clients from eight health and community care organizations in Victoria, Australia. The HLQ is a 44-item measure that uses nine domains. Groups with lower health literacy included those born in another country or those who spoke a different language other than English at home, those with a lower education level, no private health insurance, those with multiple chronic conditions, and women. These groups reported having difficulties communicating with healthcare providers, navigating the healthcare system, finding or understanding information about health, and in having a social support system.

A longitudinal study was performed that investigated whether the relationship between age and health outcomes can be explained by the severity of heart failure, evidence-based medication use, and health literacy in patients with the chronic condition of heart failure (Wu, Moser, DeWalt, Rayens, & Dracup, 2016). The study included 575 patients from outpatient clinics and hospitals in rural areas of California, Nevada, and Kentucky. The researchers attempted to explain the disparity that increasing age predicts worse heart failure outcomes.

Wu et al. (2016) tested an education and counseling intervention on the process of detecting and managing increasing symptoms of heart failure. They used the Short Test of Functional Health Literacy in Adults (S-TOFHLA) to measure the health literacy of participants. This tool measures an individual's ability to read and understand health-related literature. The S-TOFHLA has been validated with several thousand patients. Health literacy is then categorized by three levels: inadequate (0-16 correct answers), marginal (17-22 correct answers), or adequate (23-36 correct answers). The authors grouped participants into a lower group (inadequate and marginal) and a higher group (adequate). Participants were divided into a younger group (less than 65) and an older group (greater than or equal to 65). The average age of participants was 66.

The authors found that increased age was associated with worse health outcomes (Wu et al., 2016). Health literacy, as opposed to severity of heart failure or medications to control heart failure, mediated the effects of age of survival without cardiac events. Therefore, the relationship between older age and worse health outcomes may be partially explained by health literacy. This data offers valuable information, as it showed that improving health literacy may have a positive effect on health outcomes in patients with chronic health conditions.

As the review of the literature indicates, there have been many studies performed that investigated health literacy and chronic disease. The results of these studies show that improved health literacy may lead to better management of chronic disease. Therefore, a machine-learning database has the potential to help patients improve their understanding of their electronic medical record, a capability which may have a positive impact on the management of long-term chronic diseases.

Evidence-Based Practice: Verification of Chosen Option

Based on the literature review, it was determined that there was a need for a tool to assist patients in improving their understanding of their electronic medical records. The UMASS Medical School Informatics group has developed a machine-learning database called NoteAid. NoteAid currently includes over 10,000 medical terms, with a goal of increasing that to 100,000 terms (Richman, 2017). Each definition has been created to be between a fourth and seventh grade readability level, based on the Flesch-Kincaid grade level system. After working with the informatics group, a test version of NoteAid was used with adult patients in an outpatient office setting at a health system in Southeastern Pennsylvania.

Theoretical Framework/Evidence Based Practice Model

Knowles' Adult Learning Theory, along with Edwards' Health Literacy Pathway Model were used as the frameworks for this project. The diagrams for both can be found in Appendix A and Appendix B, respectively. Knowles' theory involves six assumptions related to adult learners, including need to know, self-concept, experience, readiness, orientation, and motivation (McEwen & Wills, 2014). The goal is to guide learners to become self-directed, lifelong learners who understand and can use technology. In addition to Knowles' theory, the Health Literacy Pathway Model was also used as part of this project. The Health Literacy Pathway Model, created by Edwards, explores health literacy in patients with a chronic health condition (Edwards et al., 2013). In this model patients develop health literacy through a process including five stages.

Knowles' Adult Learning Theory

The focus of Knowles' Adult Learning Theory is on adult learning, rather than youth learning, with the most important aspect of this theory being to create a climate of physical comfort, mutual trust and respect, openness, and acceptance of differences (McEwen & Wills, 2014). Knowles postulated that adults need to know the reason why they need to learn something. Typically, as adults mature, they like to become self-directed and want to be more independent when it comes to the concept of learning. The theorist believed that adults learn better when their own experiences are included when learning, as they contribute to self-identity. He also believed that real-life situations cause an adult learner to be ready to learn, since they are problem-oriented learners, as compared to subject-oriented learners. As people mature, they become oriented to the immediate application of learning, rather than postponed application.

Finally, as people mature, they also become motivated to learn by internal stimuli with the goal to solve current problems.

Edwards' Health Literacy Pathway Model

The Health Literacy Pathway Model explores health literacy in individuals with chronic disease using five stages of development (Edwards et al., 2013). These stages include health knowledge, health literacy skills and practices, health literacy actions, production of informed options, and making an informed decision or shared decision. This project applied the first two stages, health knowledge and health literacy skills and practices, as the final stages would be beyond the scope of this project.

A longitudinal qualitative study was conducted that explored experiences of participants with chronic health conditions as they related to health literacy and participation in healthcare processes (Edwards, Wood, Davies, & Edwards, 2012). The authors used the Health Literacy Pathway Model for their study. They were able to map a set of stages that each individual progressed through as they increased their knowledge and understanding of their chronic condition, increased their knowledge on managing it, actively communicated with health care providers, and made decisions regarding their health. The authors found that health literacy is a multidimensional process that “develops over time, across different health contexts and through social interactions” (Edwards et al., 2012, p. 12). The goal of the Health Literacy Pathway Model is to improve knowledge, self-management, and participation in the decision-making process (Edwards et al., 2012). The results of the study showed that participants who followed each stage of the model found themselves to be more empowered regarding their chronic condition.

Stage one of the Health Literacy Model focuses on building health knowledge. This includes the individual's basic knowledge about overall health issues in addition to his or her own health concerns. This knowledge is gained by reading, interacting with health care professionals, discussions with family and friends, and information gained from media (Edwards et al., 2012). The second stage focuses on developing health literacy skills and practices. Health literacy skills include listening, speaking, arithmetic, problem-solving, and decision making as they relate to information seeking and using that information. Health literacy tasks relate to tasks that individuals carry out by using their health literacy skills. An example of a health literacy task includes self-monitoring blood sugar and searching for health information.

Goals, Objectives and Expected Outcomes

The purpose of this quality improvement project was to work on a translation system with the UMASS Medical School Informatics group to make outpatient records more understandable by using and testing NoteAid, which gives definitions of medical terms tailored to specific chronic diseases. After working with the informatics group, a test version of this system was used with adult patients in an outpatient setting at a health system in Southeastern Pennsylvania.

Patients who agreed to participate in the project tested NoteAid, with the expected outcome being that NoteAid has the potential to improve patient satisfaction and improve patients' understanding of their office notes and electronic medical record. Health care providers may benefit from this information, as they will gain an understanding of patients' thoughts and attitudes regarding having access to and viewing their personal office notes as well as the language used in their clinical notes and how patients interpret and understand this information. There is also the potential benefit of improving the self-management of chronic disease, as patients may increase their understanding of medical terminology.

Methods

This was a quality improvement project, with the goal to make outpatient records more understandable for adult patients by using NoteAid. For the purpose of this project, the Flesch-Kincaid Grade Level tool was used to determine reading level for the instruments used throughout this project (created by UMASS). The intent of this DNP student was to offer feedback to physicians and stakeholders to improve patient understanding of their own office notes.

Patients tested NoteAid and its effectiveness as a user-friendly tool to improve patients' understanding of their electronic medical records. Permission was given by the University of Massachusetts Medical School to use NoteAid and surveys, from a larger research project that already has IRB approval, for the intent of this project (Appendix C).

Project Site and Population

The setting for project implementation was an outpatient office in a health system in Southeastern Pennsylvania. A support letter from the facility was received and the support letter from the UMASS Doctor of Nursing Practice program can be found in Appendix H. The health system serves a population of 2.5 million people (Tower Health, 2017). Individuals over the age of 18 represent approximately 77.3% of the population, as of July 1, 2015 (United States Census Bureau, n.d.). The health system consists of six hospitals, a rehabilitation hospital, an inpatient rehabilitation unit, office-based primary and specialty care (with over 300 providers), and a home health agency (Tower Health, 2017).

Setting Facilitators and Barriers

The health system is a teaching facility that offers assistance for projects such as this to be completed, providing resources that assist in successfully implementing projects. A barrier

for this project was difficulty obtaining a sufficient number of patients that were agreeable to participate in the project. An anticipated barrier was getting a sufficient number of patients who speak English as their primary language, as 17% of the population of Berks County primarily speaks a language other than English at home (United States Census Bureau, n.d.). In this instance, however, language was not a barrier for project implementation, as all patients spoke English as their primary language.

In a project of this nature there is the possibility that the DNP student may have heard a patient safety concern during a face-to-face session requiring that the patient's physician be notified. However, this situation did not occur during any of the sessions held. There was also the potential for patients to request to meet with the health care provider again, if they had further questions about their office note, a situation that also did not occur during implementation.

Potential risks of participating in this project included the discomfort from looking at a computer screen for the time needed to read the office note and the possibility of the patient feeling upset or embarrassed from reading their own note or from the DNP student seeing the patient's note. Sessions were expected to be approximately 30-45 minutes in length; however they ended up being approximately 20 minutes in length.

Stress was another potential barrier of this project, as it took approximately 20 minutes per patient to participate, and this was personal time spent away from their chosen activities in order to participate. This was the largest barrier identified during project implementation, as it was difficult for the DNP student to get patients to agree to take part in the project. The initial goal was to have approximately 20 patients for the project; however, only 13 patients agreed to participate.

Inclusion/Exclusion Criteria

The physicians and office staff at the outpatient office helped to determine who the DNP student could contact regarding participation in the project. Criteria for inclusion included patients who spoke English as their primary language, were active in MyChart and OpenNotes, and were over the age of 18. If a patient in this outpatient office was active in MyChart (meaning they have accessed the portal), they were also automatically active in OpenNotes. OpenNotes is an organizational initiative allowing patients to see office visit notes, as they are written (<https://www.opennotes.org/>). Patients with a primary language other than English were excluded from the project, as the NoteAid web interface is not available in languages other than English at this time.

Sample

Only 13 of the contacted patients agreed to participate in the project over a two-month period, out of approximately 80-100 patients who met criteria for inclusion and were asked to participate. This was a voluntary quality improvement project and each patient received a letter explaining the project (Appendix I) prior to the beginning of the session. The DNP student reached out to patients that met criteria via phone two days prior to their scheduled appointment or through a face-to-face interaction as they checked in for their office visit. The DNP student had access to the schedule and patient contact information through EPIC. If the patient was interested, a face-to-face session was scheduled for the day of the office visit, directly following the end of the appointment.

Intervention

The DNP student met face-to-face with participant volunteers for approximately 20 minutes following their scheduled office visit. These sessions were used to test NoteAid and its

effectiveness as a user-friendly tool to improve patients' understanding of their electronic medical records. Each patient was asked to complete a survey at the beginning of the session to gather demographic information, information-seeking behaviors, and a few health-related questions (Appendix D).

A short educational session was then held by the DNP student on how to use NoteAid, using a printed PowerPoint presentation (Appendix E). An office note, specific for each patient, was used to demonstrate the use of NoteAid. Since not all notes were completed at the end of each appointment, the most recent office note available through MyChart was used. Each patient read his or her medical record office note without using NoteAid on the DNP student's MacBook laptop computer. The office note was then imported into NoteAid, and the patient re-read the office note using NoteAid. The DNP student was available if the patient needed assistance navigating the tool. Several patients were used to using either a desktop computer or an iPad; therefore, many needed assistance in using NoteAid. The DNP student assisted when needed to copy and paste the text from MyChart into the NoteAid system.

Measurements

A Likert-type scale survey was then completed at the end of the session by each patient in order to assess whether they liked using NoteAid, whether they were able to effectively use it, if they were able to understand the medical terms used, and the likelihood that they would use a database similar to this regularly (Appendix F). An informal discussion between patients and the DNP student was then held, prior to the end of the session. During this informal discussion patients were able to ask questions relating to the database and any other questions relating to the sessions. Qualitative verbal responses from patients on their thoughts on using NoteAid were recorded by the DNP student.

Ethical Considerations/Protection of Human Subjects

The University of Massachusetts (UMASS), Amherst Institutional Review Board (IRB) approval was obtained prior to initiating the DNP project. The Human Subjects Determination form was approved by the facility and was then approved by the UMASS IRB. Patients in the project were protected under the Health Insurance and Accountability Act (HIPAA), and assured that their health information was protected and kept private (U.S. Department of Health & Human Services, 2017). Family members were included in the project if the patient wanted a family member present; however, since these family members would then have access to the patient's medical record, patients were informed about that.

The confidentiality of patients in the project was protected by not having any identifying information on the written surveys and the fact that the sessions were held in a private conference room at the outpatient office. The note used for each session was intended to be the patient's own office note from their recent (within 24-48 hours) office visit. However, due to office notes not being completed at the end of their office visit, the most recent office note available was used instead.

Data Collection Procedures

The DNP student gave each patient who agreed to participate in the project the letter for patients, which had a Flesch-Kincaid grade level of 7.9 (Appendix I). The DNP student explained to each patient that family members may be included in the project with the understanding that these family members would have access to the patient's medical record. With patients' permission, family members were encouraged to participate in the face-to-face sessions, especially if they currently help the patients manage their chronic conditions, with the understanding that they would have access to the medical record during the session.

Data from the surveys were analyzed by the DNP student using Statistical Package for the Social Sciences (SPSS), and the results will be presented to the Director of Nursing Research, physicians at the outpatient office, stakeholders, and the UMASS Informatics group. The DNP student analyzed the survey results gathered prior to the educational session, data gathered from the survey at the end of the session, and the responses from the post session discussion prompts. No patient identifiers were included with data.

Data Analysis

The DNP student collectively gathered information from the sessions and the results from the surveys using version 25 of SPSS and Excel to generate descriptive statistics. During the face-to-face sessions, there were no concerns relating to patient safety that needed to be promptly shared with the physicians.

After all sessions were completed qualitative comments from patients based on prompts from the face-to-face sessions were reviewed for themes and also reported. Data from sessions were gathered and collectively shared with providers once all sessions were completed, as there were no patient concerns identified during the sessions. The prompts for the discussion at the end of each session included: changes patients would like to see in NoteAid, whether family or caregivers would use this tool, what they liked about it, what they did not like about it, if they had trouble reading on the computer screen, and if they felt as though they improved their knowledge on medical terminology during the session (Appendix G).

The aggregate data will be shared with the UMASS Informatics Group. They will use this data to help plan the next phase of their research and to help determine the usability of NoteAid.

Results

Among the 13 volunteer participants included in the project, there was a variety of demographic information, including five females (38%) and eight males (62%). Of the 13 participants, two rated their health as *fair*, six rated their health as *good*, and five rated their health as *very good*. None of the patients rated their health as either *excellent* or *poor*.

When asked how many office visits participants had in the past 12 months, two stated that they had nine or more office visits, seven stated that they had three to four office visits, and four stated that they had zero to two office visits. Participants were limited to one racial group, with all participants identifying as White, non-Hispanic. The highest grade level of school completed varied throughout the participant group, with responses in all categories except for *some high school, but did not graduate*. The results are summarized in Table 1.

Table 1

Highest grade or level of school completed by participants

Highest grade or level of school completed	Patient Response	%
8th grade or less	1	7.69%
Some high school, but did not graduate	0	0.00%
High school graduate or GED	3	23.08%
Some college or 2-year degree	5	38.46%
4-year college graduate	2	15.38%
More than 4-year college degree	2	15.38%

A majority of the participants were over the age of 65 (84.62%). One participant identified as between the ages of 45 and 54, one identified as between the ages of 55 and 64, eight participants were between the ages of 65 and 74, and three participants were above the age of 75. There were not any participants who were under the age of 45. These results are summarized in Table 2.

Table 2

Participant age ranges

Age Ranges (in years)	Participant Responses	%
18-24	0	0.00%
25-34	0	0.00%
35-44	0	0.00%
45-54	1	7.69%
55-64	1	7.69%
65-74	8	61.54%
75+	3	23.08%

Participants' self-reported chronic diseases included a variety of conditions, which are summarized below (Table 3). The majority of patients (84.62%) identified as having high blood pressure. Arthritis/gout and diabetes were the second and third most-identified diagnoses by the participants, 46.15% and 38.46% respectively. Diagnoses in which there were no patient responses were removed from this table; however, all diagnoses can be found in Appendix D.

Table 3

Participant diagnoses

Diagnosis	Number of participants	Percentage of participants
Anemia	1	7.69%
Angina	1	7.69%
Arthritis/Gout	6	46.15%
Artificial Joint	3	23.08%
Asthma	4	30.77%
Cancer	3	23.08%
Congenital Heart Disorder	1	7.69%
Diabetes	5	38.46%
Emphysema	1	7.69%
Glaucoma	1	7.69%
Heart Attack/Failure	3	23.08%
Hepatitis	1	7.69%

High Blood Pressure	11	84.62%
Liver Disease	2	15.38%
Lung Disease	2	15.38%
Thyroid Disease	1	7.69%
Ulcers	3	23.08%
Prefer not to say	1	7.69%

Most participants (69.23%) included in the project had three or more chronic diseases they have been diagnosed with. One patient had three chronic diseases, four patients had four chronic diseases, and four patients had five or more chronic diseases. These are summarized below (Table 4). Results from Table 4 show that patients with multiple chronic diseases would be likely to use a system like NoteAid, as 84.6% of participants stated that they would be very likely or likely to use NoteAid from the patient portal if it were available to them.

Table 4

Chronic diseases present in sample

Number of chronic diseases identified by participants	Patient responses	%
Number of patients with 3 chronic diseases	1	7.69%
Number of patients with 4 chronic diseases	4	30.77%
Number of patients with 5 or more chronic diseases	4	30.77%

Results from the project showed that 100% of participants reported that they liked the NoteAid system, that the NoteAid system helped them comprehend their clinical note, and that the NoteAid system helped them understand their medications. The participant responses from the post educational session survey are summarized in Table 5. Age does seem to have an impact, as 100% of patients between the ages of 45 and 64 stated that they were very likely or likely to use the NoteAid system from the patient portal, compared to 87.5% of patients between the ages of 65 and 74, and 66.67% of patients over the age of 75.

Table 5

Patient responses to select post educational session survey questions

	45-64 yrs	65-74 yrs	75+ yrs
Participants who reported that they liked the NoteAid system (strongly agreed or agreed)	2 (100%)	8 (100%)	3 (100%)
Participants who reported that the NoteAid system helped them comprehend their clinical note (strongly agreed or agreed)	2 (100%)	8 (100%)	3 (100%)
Participants who reported that the NoteAid system was user friendly (strongly agreed or agreed)	2 (100%)	8 (100%)	2 (66.67%)
Participants who reported that the NoteAid system's output was accurate (strongly agreed or agreed)	1 (50%)	7 (87.5%)	3 (100%)
Participants who reported that the NoteAid system helped them understand clinical concepts (strongly agreed or agreed)	2 (100%)	7 (87.5%)	3 (100%)
Participants who reported that the NoteAid system helped them understand their medication (strongly agreed or agreed)	2 (100%)	8 (100%)	3 (100%)
Participants who reported that they were very likely or likely to use the NoteAid system from the patient portal	2 (100%)	7 (87.5%)	2 (66.67%)

Results also showed that 84.6% of participants would use the NoteAid system from the patient portal if it were available to them, compared to 15.4% who were unlikely to use it. These results are displayed in more detail in Table 6. This result correlates with age, in that as age increases the percentage of likelihood that patients would use the system decreases.

Table 6

Patient responses: To what extent would you use the NoteAid system from the patient portal

	Frequency	Percent
Unlikely	2	15.40%
Likely	3	23.10%
Very Likely	8	61.50%
Total	13	100.00%

The post session discussion prompts provided some valuable information and themes pertaining to NoteAid. Eight participants stated that they had difficulty reading the text through NoteAid, particularly citing that the blue text (medical terms) looked the same as the black text and that the font was too small for easy readability. A summary of the comments made by patients based on the post session discussion prompts can be found in Table 7.

Table 7

Patient comments from post session discussion prompts

Would you like to see any changes made to the test version of this machine-learning database?	What did you like about the machine-learning database?
No	Seems easy to use
No	Informative
Blue text looks black, brighter would be better	User friendly, like that you can hover over and not have to click to get definition
Blue looks black, font should be larger	Easy to use
Bigger font, medical terms don't look blue	Informative
Size of font too small	Would find it useful overall
No	Seems easy to use
Difference in color for words, bigger font	Likes hovering over rather than clicking
Can't see different color, should be more of a contrast	Would eliminate need to do additional research
Like the layout, this is good. Normal lab values should be included	Easy to use, would help a lot of people
Font too small, medical terms don't stand out, they look black, very hard to read	Wouldn't have to go to internet as much
Larger font	User friendly, but would have to get used to it. Use iPad at home
No	Pretty neat tool, especially with a long list of medications

Of note, seven participants were wearing glasses during their sessions. Based on patient comments, it would appear that changing the shade of blue or switching to a different color of the medical terms and increasing the size of the font would make it easier for patients to read, especially if they have vision difficulties. When asked what patients thought of NoteAid, several responded that they felt the system was user-friendly and easy to use. Other responses included that the system was informative and they liked that they could hover over a term, rather than having to click on it.

Discussion

There is the potential of a great benefit by implementing a machine-learning database such as NoteAid in helping patients to understand their own medical records. Interestingly, despite the large variation in education level, 85% of the participants stated that they would use the NoteAid system from the patient portal if it were available to them. This shows that this would be a tool that patients from less than a high school education up to more than a 4-year college degree would use the system.

The facility where the project took place had a total of 98,546 patients (29.1%) who were active in MyChart, out of 338,800 patients who had an access code to activate MyChart (MyChart HelpDesk, personal communication, May 3, 2018). Therefore, using the same ratio, this tool would help at least 16,000 patients, as approximately 16.2% (13 participants out of 80) of participants who were asked to participate agreed to be included in the project. We would expect that 84.6% of patients would find it helpful, as found in this project. However, it can be assumed that this number would be higher due to the difficulty of obtaining the sample in this project. As Keselman and Arnott Smith found in their results, terminology was one of the barriers to increased use of electronic health records (2012). By implementing a system such as

NoteAid, overall use of patient portals may increase, since this barrier would decrease due to access of simplified definitions of medical terminology and medications provided by NoteAid.

Age did have an effect on whether a patient would be likely to use a system such as NoteAid with participants included in this project. Results from this project showed that age had an impact on likelihood of use from this sample, as 7.69% of participants were between the ages of 45 and 54, 7.69% were between the ages of 55 and 64, 61.54% were between the ages of 65 and 74, and 23.08% were over the age of 75. Although all age groups were more likely than not to want to use it, the younger age groups indicated they are more likely to use it. This probably has to do with the higher level of familiarity with technology of younger age groups. This is similar to the results from Kruse et al., who found that patients over the age of 65 are more likely to have difficulty using patient portals (2015). It would be expected that a larger sample size would demonstrate similar results based on age.

The DNP student used stage one of the Health Literacy Model by spending one-on-one time with each patient and used a PowerPoint presentation and verbal explanation to educate each patient on NoteAid and how it is used. The second stage of the Health Literacy Model was integrated by allowing each patient to have the opportunity to ask questions, read information about NoteAid, read his or her recent office note as it was written, and read that office note using NoteAid. Providers may be able to implement these two stages of the Health Literacy Model through office visits, which may improve likelihood that more patients will become actively involved in their healthcare, through a patient portal.

Overall, patients provided positive feedback regarding NoteAid. In particular, patients stated that they could go to one place and get a lot of information without having to click on anything; they could hover over the terms to get definitions, rather than clicking on the terms.

As Kruse et al. stated, well-designed portals have the potential to provide patients access to their health records while improving communication between patients and providers and allowing patients to have control in managing their chronic conditions (2015). This project demonstrated these conclusions as well, since 92.31% of participants evaluated NoteAid as user-friendly in the post educational session survey.

As Hong et al. stated, there is often a language gap between health care providers and patients (2010). Implementation of a machine-learning database such as NoteAid could help to bridge this gap, providing the potential to ultimately improve the management of chronic diseases, by improving patients' understanding of those chronic diseases and their medications. Results from this project show that patients with multiple chronic diseases would be likely to use a system like NoteAid, as 84.6% of participants stated that they would be very likely or likely to use NoteAid from the patient portal if it were available to them. Of the 13 project participants, nine had a diagnosis of three or more chronic conditions. By engaging patients, giving them access to their electronic medical records, and providing an effective tool to help them understand this information, the use of systems such as NoteAid may have a positive impact on the management of chronic diseases.

Cost-Benefit Analysis

The only expenses associated with this project were printing costs for the letter for patients and the participant surveys that patients received if they agreed to participate in the project. Related to the use of a system to providers overall, there is a potential cost savings, as implementation of a machine-learning database could improve the management of chronic diseases, a development which has the potential to decrease costs associated with chronic health conditions. However, this specific quality improvement project was not that broad in scope.

Limitations

Although there was positive feedback regarding NoteAid and accessing office notes, there were several identified limitations of this project. Due to the busy office setting, no office notes were completed at the conclusion of the visit. Therefore, the most recent patient's note, from a prior office visit, was used to test the system. In practice when patients would access their record that office note should be available for them to view. For the first few sessions there were a couple identified problems with NoteAid, including the system not identifying blank spaces and difficulty with access. However, these issues were resolved quickly by the informatics team and did not occur in any subsequent sessions.

Limitations to participation included patients not being active in MyChart and patients not agreeing to participate primarily due to the time needed to participate in the project, and they were not interested in returning at another time to participate. With a goal of 20 participants, the DNP student was only able to meet with 13 participants, since many patients were not interested in participating.

Another limitation was a possibility of selection bias, in that people who were computer literate would be more willing to participate in the project and would then be more likely to use a system like this. The sample may not be representative of the entire population of patients for that reason, as this group of people was computer savvy, since they were active in MyChart. As the population ages, it can be assumed that more patients will be more adept at using technology and therefore more likely to use a system such as NoteAid. It can be assumed that the population of aging adults will be increasingly more technologically savvy.

Conclusion

If a facility is looking to implement a machine-learning database such as NoteAid, it would be beneficial to test the system through a patient portal with a larger group of participants. It would also be important for patients to have access to their current office visit notes at the conclusion of their scheduled appointments if possible.

Since patients also were found to not be interested in returning to the office at a later date to participate in the project, being able to complete the sessions directly following the office visit was most appealing to patients, since they would not have to make a separate trip to the office. Additionally, it would be beneficial for the patients to be able to test the system on a desktop, as many of the participants in this project were not used to using a laptop, especially a MacBook.

In general, patients and consumers are becoming more active and involved in their health care, a trend which demonstrates a need for patients and consumers to be able to understand the information found in their electronic medical records. Of the participants, nine stated that they use the Internet or email at least once per day, with 46% using the Internet or email several times per day. Therefore, if patients have access to their records in a user-friendly system, they are more likely to use a system such as NoteAid to access their office notes. Studies have found that there is a lack of patient understanding of their electronic medical records, primarily relating to terminology (Keselman & Arnott Smith, 2012). By creating simplified definitions of medical terms, patients' understanding of their electronic medical records may be improved upon, a fact shown to be true based on the results of this project, as 100% of participants reported that the NoteAid system helped them comprehend their clinical notes. The results also showed that 85% of the participants reported that they would use the NoteAid system from a patient portal.

This project involved working on a translation system with the UMASS Informatics group to make outpatient records more understandable by using and testing NoteAid, a machine-learning database, which gives simplified definitions of medical terms. After working with the informatics group, a test version of NoteAid was used with adult patients in an outpatient setting at a health system in Southeastern Pennsylvania. Health care providers gained an understanding of patients' thoughts and attitudes regarding having access to and viewing their personal office notes.

Health care providers can also gain an understanding of the language used in their clinical notes and how patients interpret and understand this information. The goal of this project was to provide information from face-to-face sessions to health care providers and the University of Massachusetts that may be used to improve adult patients' understanding of their medical records. Thus, this information may then have a potential positive impact on the management of patients' chronic diseases, patient satisfaction and communication between patients and providers. By integrating a machine-learning database into a patient portal, patients have access to their health records, as well as access to a user-friendly tool to help them understand the important information those records provide.

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Appendix A

Knowles' Six Assumptions

1. Need to know



2. Self-concept



3. Experience



4. Readiness to learn



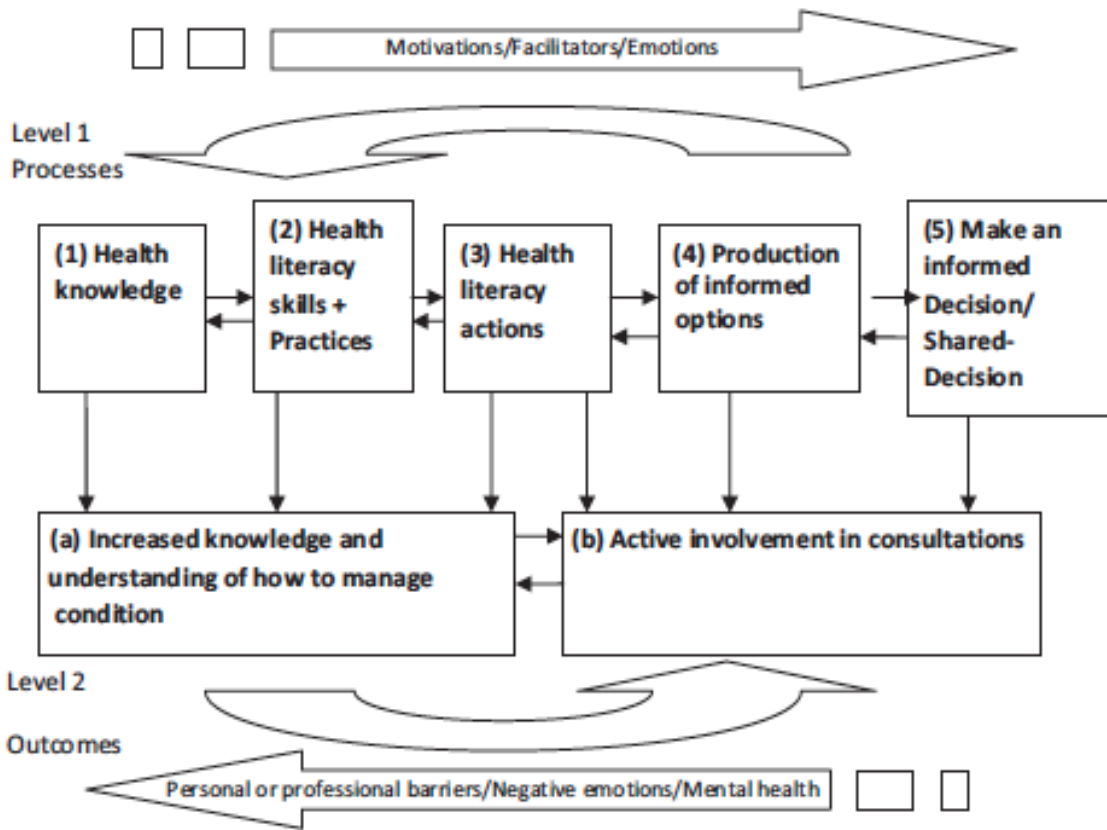
5. Orientation to learning



6. Motivation

Appendix B

Edwards' Health Literacy Pathway



(Edwards et al., 2012)

Appendix C

Permission Letter



Department of Quantitative Health Sciences
University of Massachusetts Medical School
368 Plantation Street
Albert Sherman Center
Worcester, MA 01605 USA

October 31, 2017

Reading Hospital

To Whom It May Concern:

I am giving permission for Erin Roth to use the following instruments as she works on her DNP project at Reading Hospital; Pre-assessment survey, NoteAid Survey and the web interface NoteAid.

Sincerely,

A handwritten signature in black ink, appearing to be 'H. Yu'.

Hong Yu, MS, MA, PhD, FAMCI
Professor, Department of Quantitative Health Sciences,
University of Massachusetts Medical School
Adjunct Professor, College of Information and Computer Science,
University of Massachusetts, Amherst
Research Health Scientist, Bedford VAMC
Tel. 508-856-3474
Fax 508-856-8993

Appendix D

Pre Educational Session Survey

HEALTH HISTORY

Check if you have or have ever had the following:

- | | |
|--|---|
| <input type="checkbox"/> AIDS/HIV positive | <input type="checkbox"/> Glaucoma |
| <input type="checkbox"/> Alzheimer's disease | <input type="checkbox"/> Heart Attack/Failure |
| <input type="checkbox"/> Anemia | <input type="checkbox"/> Hemophilia |
| <input type="checkbox"/> Angina | <input type="checkbox"/> Hepatitis |
| <input type="checkbox"/> Arthritis/Gout | <input type="checkbox"/> High Blood Pressure |
| <input type="checkbox"/> Artificial Heart Valve | <input type="checkbox"/> Hypoglycemia |
| <input type="checkbox"/> Artificial Joint | <input type="checkbox"/> Kidney Problems |
| <input type="checkbox"/> Asthma | <input type="checkbox"/> Liver Disease |
| <input type="checkbox"/> Cancer | <input type="checkbox"/> Lung Disease |
| <input type="checkbox"/> Congenital Heart Disorder | <input type="checkbox"/> Stroke |
| <input type="checkbox"/> Diabetes | <input type="checkbox"/> Thyroid Disease |
| <input type="checkbox"/> Drug Addiction | <input type="checkbox"/> Tuberculosis |
| <input type="checkbox"/> Emphysema | <input type="checkbox"/> Ulcers |
| <input type="checkbox"/> Epilepsy/Seizures | <input type="checkbox"/> Prefer not to say |

INFORMATION SEEKING

1. Have you ever looked into information about health or medical topics from any source?

- Yes
 No (**skip to question 4**)

2. The most recent time you looked for information about health or medical topics, where did you go first? Choose only one.

- | | |
|--|---|
| <input type="checkbox"/> Books | <input type="checkbox"/> Newspapers |
| <input type="checkbox"/> Brochures, pamphlets, etc | <input type="checkbox"/> Telephone information number |
| <input type="checkbox"/> Public Health Organization | <input type="checkbox"/> Complementary, alternative, or unconventional practitioner |
| <input type="checkbox"/> Family | |
| <input type="checkbox"/> Friend/Co-worker | |
| <input type="checkbox"/> Doctor/health care provider | <input type="checkbox"/> Other (please describe): |
| <input type="checkbox"/> Internet | |
| <input type="checkbox"/> Library | |
| <input type="checkbox"/> Magazines | |
-

3. Based on the results of your most recent search for information about health or medical topics, how much do you agree or disagree with each of the following statements?

a. It took a lot of effort to get the information you needed.

5 Strongly Agree	4 Agree	3 Neither Or N/A	2 Disagree	1 Strongly Disagree
---------------------	------------	---------------------	---------------	------------------------

b. You felt frustrated during your search for information.

5 Strongly Agree	4 Agree	3 Neither Or N/A	2 Disagree	1 Strongly Disagree
---------------------	------------	---------------------	---------------	------------------------

c. You were concerned about the quality of information.

5 Strongly Agree	4 Agree	3 Neither Or N/A	2 Disagree	1 Strongly Disagree
---------------------	------------	---------------------	---------------	------------------------

d. The information you found was hard to understand.

5 Strongly Agree	4 Agree	3 Neither Or N/A	2 Disagree	1 Strongly Disagree
---------------------	------------	---------------------	---------------	------------------------

4. In general, how much would you trust information about health or medical topics from each of the following?

a. A doctor

4 A lot	3 Some	2 A little	1 Not at all
------------	-----------	---------------	-----------------

b. Family or friends

4 A lot	3 Some	2 A little	1 Not at all
------------	-----------	---------------	-----------------

c. Government health agencies

4 A lot	3 Some	2 A little	1 Not at all
------------	-----------	---------------	-----------------

d. Health organizations or groups

4 A lot	3 Some	2 A little	1 Not at all
------------	-----------	---------------	-----------------

e. Charitable organizations

4 A lot	3 Some	2 A little	1 Not at all
------------	-----------	---------------	-----------------

f. Religious organizations and leaders

4 A lot	3 Some	2 A little	1 Not at all
------------	-----------	---------------	-----------------

DEMOGRAPHICS

1. About how often do you use the Internet or e-mail?

- Several times a day
- About once a day
- 3-5 days a week
- 1-2 days a week
- Every few weeks
- Less often
- Never

2. In general, would you say your health is:

- | | | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Excellent | Very good | Good | Fair | Poor |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

3. What is your race? Please mark one or more:

- White
- Black or African American
- Asian
- Native Hawaiian or Other Pacific Islander
- American Indian or Alaskan Native
- Other

4. Are you of Hispanic or Latino origin or descent?

- Yes, Hispanic or Latino
- No, not Hispanic or Latino

5. What is the highest grade or level of school that you have completed?

- 8th grade or less
- Some high school, but did not graduate
- High school graduate or GED
- Some college or 2-year degree
- 4-year college graduate
- More than 4-year college degree

6. How many minutes does it usually take you to get to your healthcare practitioner's office (your primary care doctor's office)?

- Less than 15
- 16 to 30

- 31 to 60
- 60 to 120
- More than 120

7. How many visits to your doctors have you had in the past 12 months?

- 0-2
- 3-4
- 5-6
- 7-8
- 9+

8. How hard is it for you (and your family) to pay for the very basics like food and heating/cooling? Would you say it is:

- Very hard
- Hard
- Somewhat hard
- Not very hard
- Don't know

9. What is your age?

- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75+

10. What is your marital status?

- Divorced
- Married
- Widowed
- Single

11. What is your gender?

- Female
- Male
- Non-binary/third gender
- Prefer to self-describe _____
- Prefer not to say

Appendix E

Outline of PowerPoint Presentation for Patients

- I. Overview of NoteAid
 - a. NoteAid is a tool used to make medical words easier to understand.
 - b. NoteAid was made by a group at the University of Massachusetts.
 - c. NoteAid gives definitions of medical words.
 - d. NoteAid can help to make your medical records easier to understand with the click of a button.
- II. How NoteAid Works
 - a. Text can be copied and pasted into a text box in NoteAid.
 - b. Click the *simplify* button at the bottom of the text box.
 - c. The system finds medical words included in the text.
 - d. The medical words will turn blue.
 - e. You can hover over each word with the mouse to see the simplified definition of each medical word.
 - f. The following slides will show examples of what this will look like.
- III. Example of simplified note using NoteAid
- IV. Example of definition given in NoteAid
- V. Conclusion
 - a. Questions?
 - b. Thank you for agreeing to be involved in this DNP project.

Appendix F

Post Educational Session Survey

NoteAid Patient Survey

Please indicate how much you agree with the following statements about NoteAid.

Q1) I like the NoteAid system:

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree
- Do not know

Q2) The NoteAid system helps you comprehend your clinical EHR notes:

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree
- Do not know

Q3) The NoteAid system is user friendly:

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree
- Do not know

Q4) The NoteAid system's output is accurate:

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree
- Do not know

Q5) To what extent would you use the NoteAid system from the patient portal?

- Very likely
- Likely
- Note Sure
- Unlikely
- Very Unlikely

Q6) The NoteAid system helps you understand clinical concepts:

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree
- Do not know

Q7) The NoteAid system helps you understand your medication:

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree
- Do not know

Q8) The NoteAid system helps you improve the communication between you and your doctor:

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree
- Do not know

Q9) Using the NoteAid system is stressful:

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree
- Do not know

Q10) You are uncertain on how to use the NoteAid system:

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree
- Do not know

Appendix G

Post Session Discussion Prompts

1. Would you like to see any changes made to the test version of this machine-learning database?
2. Would your family or caregivers use this machine-learning database or help you use it?
3. What did you like about the machine-learning database?
4. What didn't you like about the machine-learning database?
5. Did you have trouble reading the information on the screen? If so, do you use glasses and are you wearing them now?
6. Do you feel as though you learned medical terminology definitions through this session that you didn't know prior to this session?

Appendix H

Support Letter from the UMASS DNP Program

From Pamela Aselton

To Erin Roth

Date 11/28/17 18:36

Message Body

To Whom it May concern,

The proposal submitted by Erin Roth has received final approval from the UMASS DNP Program.

Pamela Aselton PhD, MPH, FNP-BC
DNP and CNL Program Director
College of Nursing
UMASS Amherst
413 545-5089
paselton@nursing.umass.edu

Appendix I

Letter for Patients

Project Coordinator: Erin Roth, Doctor of Nursing Practice (DNP) student

Title of Project: Improving Patients' Understanding of their Electronic Medical Record Data in Order to Improve Self-Management - A Quality Improvement Project

We invite you to be a part of a project. The aim of the project is to test a system being developed to help patients have a better understanding of their own office notes. These are the notes that providers write and put in their patients' Electronic Health Records (EHR). The notes have medical terms that may be hard for patients to understand. The system being tested links medical words to definitions written in simple everyday words that are easier to understand.

You need to understand the risks and benefits of this project before you participate.

You will test a system that was created that may help patients understand their office notes. We will use your office note from your recent office visit and have you test the system. We will ask you to read the clinical note as it is written. Then you will be asked to read it again while using the system.

If you agree to participate, you will do the following things:

Description of the project:

Your participation will take about 10-15 minutes to complete. You will fill out two surveys throughout the session. One survey will be filled out at the beginning of the session and the other one will be filled out at the end of the session. You will read your own office note as it is written. Then you will read the office note using the system. You will also be asked a few questions about the session.

Description of any procedures that may result in discomfort or inconvenience:

Discomforts from your participation in this project are small. Your personal time for the session will be spent away from your normal activities. You will be looking at a computer screen for the time needed to read your office note. You may feel upset or embarrassed from reading your own note or from the DNP student seeing your note.

You may stop reading your note at any time if you become upset and do not wish to continue.

Confidentiality of information:

Participation in this project requires that the DNP student who is conducting this project will see your medical record (specifically your note from your recent office visit). Your participation in this project means that you are willing to permit the DNP student to read the note from your recent office visit. Your identifiers will not be used for this project. Your privacy will be protected by not having any identifying information on the written surveys. However, if there is a safety concern during the session, your provider will be notified. Data will be shared with the UMASS Informatics Group. They will use this data to help plan the next phase of their research. There will be no patient identifiers shared with UMASS.

We will be encouraging family members to participate in this project. The choice (about whether to allow family to participate) is your choice to make. If you choose to allow family to participate in this project, you do so with the understanding that personal information in your medical record will be made available to your participating family members.

Expected benefits of project:

You may not personally be helped by taking part in this project. However, your participation may lead to knowledge that may benefit others in the future.

You can choose not to participate. If you decide not to participate in this project, it will have no effect on you or on the healthcare that you receive. You are also free to leave the session at any time.