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## Noteaid: A Comprehension Tool to Improve Patient Understanding

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**Noteaid: A Comprehension Tool to Improve Patient Understanding**

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June 2, 2020

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## Table of Contents

Abstract .....	3
Introduction .....	4
Background .....	4
Problem Statement .....	7
Organizational “Gap” Analysis of Project Site.....	7
Review of the Literature (related to evidence based practice/s to address the problem).....	8
Theoretical Framework/Evidence Based Practice Model.....	14
Goals & Objectives .....	16
Methods .....	16
Project Site and Population.....	17
Measurement Instrument(s) .....	18
Data Analysis .....	18
Results .....	19
Discussion .....	25
Conclusion .....	28
References.....	29
Appendix A (Andragogy Theory) .....	35
Appendix B (PDSA).....	36
Appendix C (Pre intervention and Post intervention Survey) .....	37
Appendix D (Timeline).....	39

## Abstract

*Background:* Meaningful use mandates allow patients access to provider notes, however, there remain many barriers including the inability of the patient to understand the notes.

This project surveyed clinicians on the informatics committee of a large tertiary care facility about their thoughts regarding the Noteaid translation system after presenting examples of translated patient notes and education about the meaningful use mandate.

*Methods:* An online PowerPoint presentation and preintervention survey was distributed, followed by a live educational intervention. The members were emailed a post intervention survey about the effectiveness, likeability, usability, and practicality of the Noteaid software tool to translate medical jargon.

*Results:* Of the 20 participants, 45% stated they spent more than 40% of their *time* on patient education and teaching. Most were unaware of the meaningful use mandate, and 68% believed that the release of provider notes alone could not improve the quality of care and/or effect patient outcomes. After the presentation, 100% liked the Noteaid system and 75% believed the system could improve outcomes by improving patient understanding. The majority (80%) rated both of the translated note examples as a 4 on a 5-point rating scale.

*Conclusion:* Solutions to patient understanding of medical notes are needed. Noteaid, is a systematic solution that was positively reviewed by this group of clinicians as being a helpful tool for patients in understanding their own medical notes. The meaningful use mandate has the potential to improve patient care and better educate patients.

*Keywords:* Noteaid, Patient portal, terminology, Health literacy, Meaningful use

## **Noteaid: A Comprehension Tool to Improve Patient Understanding**

### **Introduction**

The American healthcare system is one that can be considered robust, with advancements in technology, however innovations in healthcare can take time to be accepted. As an aspect of patient center care, the healthcare informatics foundational role is to create systems that advance existing structures into a patient-friendly system that improves care and understanding (Snyder et al., 2011). The conceptual challenges presented by allowing patients to view provider notes can be solved by utilizing technology to create solutions. The problem of patients not being able to understand their provider notes, which they have access to through the electronic health record (EHR) is the focus of this project.

The goal of this project is to help healthcare providers understand the medical software translation system Noteaid as an independent open access tool which has the capability to improve the patient's understanding of their provider notes by simplifying medical jargon (Lalor et al., 2019).

### **Background**

Advanced Practice Registered Nurses (APRN) and Medical Doctors (M.D) are highly trained and educated professionals. Lengthy educational programs and years of clinical experience allow clinicians to navigate complex medical problems and ideas, while utilizing medical language continuously and repetitively. The existing gap between patient and provider communication is highlighted by lack of insight, as “many doctors

tend to overestimate their ability in communication” (Ha & Longnecker, 2010, section abstract).

The use of medical jargon utilized by clinicians creates additional barriers. The differences between peer-to-peer communication as compared to provider patient conversations are plentiful. However, these differences do not override the responsibility of the clinician to be a competent educator. The competent clinician would not carry out a patient educational session utilizing the same jargon they would use with peers either verbally or written. However, this partnership with the patient to translate medical information into easily understood concepts “is a central clinical function in building a therapeutic doctor-patient relationship, which is the heart and art of medicine” (Arora (2003), Stewart (1995), Roter (1983), as cited in Ha & Longnecker (2010) section, Benefits of Effective Communication).

Healthcare disparities and social determinants of health remain a significant problem and burden for this nation, highlighting the existence of healthcare inequality hence ongoing programs such as the Healthy People Initiatives (“Healthy People 2010”, 2019). The problem is interventions that are designed to close these gaps, often fall short and instead “reinforce obstacles and propagate disparities while employing the same technologies aimed at improving access to health-related information” (Smith & Magnani, 2019, section. 4). From a public health perspective these existing gaps regarding portal accessibility and usability present both ethical and legal burdens that threaten negative impact, disproportionately affecting vulnerable populations (Smith & Magnani (2019), Lyles et al., 2017). It is important for all individuals to have access to their medical records and understand the content.

According to the Centers for Disease Control and Prevention (CDC), the federally funded program Health Information Technology for Economic and Clinical Health (HITECH) required the implementation of the EHR and is foundational to the work that is ahead (“Public Health and Promoting Interoperability Programs”, 2020). Major public health stakeholders such as Centers for Medicare and Medicaid (CMS) and (ONC) Office of National Coordinator are mandating phases designed to close gaps and advance healthcare by way of incentive programs aimed at decreasing disparities and establishing meaningful use of the medical record. These programs goals are accomplished in various stages (“Public Health and Promoting Interoperability Programs”, 2020).

Currently, level three is focused on improving patient and provider candidness, including the visibility of provider notes via EHR. This area alone represents more than a third of the scoring methodology of the current level ("Public Health and Promoting Interoperability Programs," 2020). There are many barriers to the successful implementation and net benefit of stage three (Chen et al., 2018). Without adequate support, these barriers threaten to minimize the overall benefit of this level of transparency.

The gaps in patient education exist for several reasons including psychological and emotional factors, as well as fundamental health literacy limitations as supported by the Agency for Healthcare Research and Quality (AHRQ). In-office patient education for both simple and complex disorders quickly reach a level of inundation (Brega et al, 2015). However, patient education is a vital component to sharing health knowledge and improving long and short-term outcomes.

Using discharge summaries alone may not be the answer to patients understanding their conditions. The potential emotional barrier and level of overload must be considered (Martin et al 2005, Brega et al 2015). The information must be provided to the patient in a way that is acceptable to the patient and allows them to retain the knowledge. Patient education is a snapshot of time and can lack the simplification required for laypersons' benefit. A level one grade A study by Pavlik et al., 2014, found that although patients were overall satisfied with after visit summaries, there was very little effect on information retention regardless of the extent of information included in the summary (Pavlik et al., 2014). Therefore, discharge summaries that have been used in the past to bridge this gap are perhaps insufficient.

### **Problem Statement**

The problem of patient's lack of understanding the medical jargon in providers notes, which they now have access to, needs a systematic solution. The Noteaid system can help to satisfy federal mandates, for meaningful use and benefit patient care by helping patients understand the medical records. This project seeks to educate providers, on this open-source software, in order to improve overall healthcare quality and eliminate disparities in making medical information useful for more individuals.

### **Organizational Analysis of Project Site**

The hospital system can be one that is influenced by different silos of knowledge which have their own unique areas of focus and influence. Change for the adult learner is not always a concept that is well received by all and the idea of buy-in for adults' learners is well known to be invaluable to the success and failure of any project. Nonetheless, high quality patient education is always of utmost importance.



An informatics committee meeting consisting of each unit's technologically advanced members who are well-versed in in-patient education examines the problems and a potential solution. The goals of this project are to educate, members of the informatics committee about Noteaid and assess the effectiveness of the software technology. Facilitators include: committee members engagement, familiarization with upstream changes, and a potential improvement to a systems problem.

### **Review of the Literature**

A comprehensive literature review was conducted by searching for key terms associated with the three main pillars of the clinical question; clinical informatics, health literacy, and Noteaid. The exact keywords utilized include: *patient assess to record or meaningful use or patient portal or OpenNotes*, AND *clinical information systems or information technology or systems* AND *Noteaid or natural language processing or understanding provider notes, or health literacy*.

The goal was to cast a wide net incorporating the main pillars of the problem. The limiters included Boolean/Phrase, full text, academic journal format, and publication years 2014-2020. The databases; academic search premier (23), Science citation index (36), Social science citation (30), Library, information science & technology abstract (21), Complementary index 9, Cumulative Index to Nursing and Allied Health (CINAH) complete (17), Gala academic OneFile (9), and American Physiological Association (APA) PsycInfo (10) yielding 155 results.

All titles and abstracts were read and non-applicable or duplicate articles were excluded. Thirteen articles were selected for use in this literature review. Each article was evaluated using the Johns Hopkins Nursing Evidence-based Practice Rating Scale for

strength and grade. The thirteen articles selected were all journal articles consisting of a mixture of types including quantitative randomized studies (level 1 & 2), qualitative studies (level 3), organization experiences (level 5 evidence), and non-experimental studies (level 6 evidence).

### **Patient Portals**

Historically, there have been many barriers to accessing medical records. The previous paper system needed to evolve due to its “cumbersome and time-intensive functions of collection, compilation, storage, retrieval, and reproduction”, therefore scoring low in terms of utility (Cahill et al, 2014, section Electronic medical record access by patients). In the past, patients needed to request their record in writing and then wait for this information. Once the documents arrived at the new area it would need to be internally processed and the turnaround time could take several weeks. This system was primarily a form of early provider to provider information sharing facilitated and carried out by patients, providing little to no information to benefit the patient directly.

A major barrier, at this time, included questions surrounding ownership of the information, privacy, and confidentiality related to underlying HIPAA restrictions (Beard et al, 2011). These barriers directly impaired forward movement of the emerging concept of patient engagement until healthcare adopted security protocols from other arenas, such as banking (Beard et al.,2011). The AHRQ defines patient engagement as “the involvement in their own care by individuals (and others they designate to engage on their behalf), with the goal that they make competent, well-informed decisions about their health and health care and take action to support those decisions” (Maurer et al, 2012, as cite by Irizarry et al., 2015 section Patient Engagement and Patient Portals). Having

overcome these barriers, the revivification of the patient portal began. Key points that have come to light include the fact that advancements in technology can make the internet secure enough to support information sharing in the healthcare arena as record security has been an area of concern for some patients (Dontje et al., 2014, p. 826, Tieu et al., 2015, “Security and Privacy of Information” section).

Today, having overcome the barrier of cyber security other problems evolved including but not limited to the issue of utility of patient portals. The problems have been an area of focus and problem solving. Portals offer the ability to access “easy-to-read, printer-friendly summaries ...also viewed as helpful for sharing information with family members and providers who did not have patient portal access” (Irizarry et al., 2015, section utility). Moreover, the demand for EHR has happened at the same time patients increasingly look to the internet for health information as information is more widely available (Lalor et al, 2019). However, some providers expressed concern for the legitimacy and trustworthiness of patient-initiated internet accessed health information (Volk & Obeid, 2019).

Madrigal & Escoffery, 2019 found that “seventy-five percent of the participants have searched for health information on the web” (Madrigal & Escoffery, 2019, section results). Despite this ongoing debate, patients have a positive view about accessing their health information for personal use and accessing their health information could potentially benefit the patients’ health management (Tieu et al., 2015, Dalrymple et al., 2016). As a result of this foundational work on EHR development through HITECH the ability to obtain health information has expanded and patients now can obtain the information and utilize it to help themselves. This level of transparency gives the patient

a new level of control that can be utilized to overcome the barriers that prevent portal usage.

Despite the benefits of patient portal use significant barriers remain, effecting overall success. These barriers can be difficult to study since access to patient portal can be variable amongst institutions which can make a direct comparison difficult (Dontje et al., 2014). However, the literature reports many recommendations to mitigate these barriers such as improving patient engagement, increasing portal usability, and simplifying shared information and data as these barriers threaten the overall benefit of improving accessibility and usability for all (Smith & Magnani, 2019, Dontje et al., 2014). Given the meaningful use mandate to incorporate patient and provider collaboration, patient engagement has now transitioned from an opportunity to a responsibility.

### **Health Literacy**

Health literacy is a major barrier and fundamental problem that has a considerable effect on personal engagement and ability to manage one's own health (Levy et al., 2015, Irizarry et al., 2015, Lalor et al., 2019, Dalrymple et al., 2016). The evidence related to social determinates of health and the existence of healthcare disparities demonstrates the need for shared responsibility between individual and collective responsibility.

Smith & Magnani, 2019, writes that health literacy is a social determinate, while Woods et al., 2017, writes that digital inclusion is another. Therefore, as we progress in the arena of digital health it is essential to level the playing field so that the alleviation of sickness and suffering can be attainable for all (Smith & Magnani, 2019).

“Health literacy is defined as the degree to which an individual can access, process, and comprehend basic health information and services and thereby participate in health-related decisions” (Smith & Magnani, 2019, section, Digital Health Literacy).

It is important to note that health literacy is different from formal education (Graham and Brookley, 2008). High academic levels do not always correlate with a high health literacy level or vice versa; moreover, “limited health literacy is common and is hard to recognize” (Brega et al, 2015, P1). One example, is a highly educated community health nurse who may still struggle with her postpartum aftercare instructions. In contrast, an undereducated caregiver of a twenty-year sufferer of diabetes may understand more about managing the disease than many others and have a high health literacy level in that arena. As a means to satisfy the needs of most people, healthcare providers are taught to provide written and verbal education at a 6<sup>th</sup> grade level (Janiak et al., 2013, Mcinnes & Haglund, 2011). However, this clause is perhaps insufficient because beyond education remains many areas that hinder a person's ability to fully make informed health decisions. Therefore, best practice guidelines recommends using “health literacy universal precautions” (Brega et al., 2015, p.1). The use of universal precautions does not remove the need to understand each client's literacy level individually; instead, it prevents any miscommunication by keeping communication simple (Brega et al., 2015, p.1).

### **Terminology**

Beyond health literacy, a contributing component that impairs note comprehension is the use of medical terminology, which is a significant barrier to portal accessibility and usability (Dontje et al., 2014, Dalrymple et al., 2016). The provider's note contains vital information such as the diagnosis, symptoms, recommendations, and

the plan which are imperative to the progression of care as “patients are expected to navigate a complex medical system and then manage more and more of their often complex care at home” (Graham & Brookley, 2008 section, background). New providers face the challenge of this learning curve as they enter the workforce. However, clinicians gain momentum and improve their own comprehension while advancing through years of complete submersion into clinical practice where ultimately, they “find themselves in the small minority of the population with high-level literacy skills” (Graham and Brookley, 2008, section background).

Medical terminology is also not flawless, as there is some degree of variation in terms of abbreviations from provider to provider (Chen et al, 2018). Given the underlying deficit in health literacy, it would be unreasonable to believe that improving health literacy alone could bridge this gap. It is more logical that an intermediary systematic approach that helps the average patient understand medical terminology can connect these two distinct, yet intricate worlds. For patients to benefit completely from having their medical records available to read, the problem of understanding medical terminology must be overcome, regardless of health literacy level.

### **Noteaid**

According to Chen et al., 2018 Noteaid is a “natural language processing system” created by the University of Massachusetts Medical School (Chen et al, 2018 section, Title). Although the overall research for this system is limited, there is strong preliminary evidence of its effectiveness. Noteaid, uses two systems CoDMED and Med link, simplification language systems to serve as an intermediary that minimizes the barrier of health literacy versus medical terminology on patient ability to comprehend provider

notes (Chen et al., 2018). The overall goal of this qualitative study was to glean expert advice regarding usability and effectiveness of the system. Although physician's overall review was mixed, physicians found the system to provide adequate translation.

Moreover, the recommendations of these experts were implemented to expand the system to reflect changes, and additional definitions were added making the system increasingly robust (Chen et al., 2018).

However, physician expert opinion is only a segment of the required expertise. It is important to study the other experts and lay persons regarding the effectiveness and usability on Noteaid. Lalor et al., 2019 determined that patient comprehension improved in a quasi-experimental study. When compared to the control group they did not find improvement in comprehension when utilizing MedlinePlus alone and patient initiated searches. This study further adds that Noteaids Wikipedia linkage was most significant (Lalor et al., 2019). The Noteaid system does not create additional work for provider or patient and is a reasonable solution to dissolving barriers and arriving at the true potential of allowing patient access to their medical records.

### **Theoretical Framework or Evidence Based Practice Model**

The theoretical framework that will be used for this quality improvement project is the Adult Learning Theory also known as the Andragogy Theory. This theory was created by Malcolm Knowles in 1984. The four core concepts of adult learning according to this theory is need to know, learning through doing, problem solving, and immediate use (Knowles et al., 2014). This theory is important to this quality improvement project because although Noteaid can be utilized in any area of care including pediatrics, benefits of this systematic solution will be gleaned from adult users seeking to help themselves,

adult caregivers seeking to help another person, or adult parents seeking to help their children. Therefore, Andragogy Theory is highly applicable and a diagram of the model can be viewed in Appendix A.

The first concept of the Andragogy Theory is the “need to know concept”. This means that adult learners benefit from understanding the reasoning behind new learning (Knowles et al., 2014). It is important to inform learners that provider notes contain information that they will need to understand and implement in order to prevent disabling and debilitating conditions, as well as prevent exacerbation of chronic diseases an idea known as provider endorsement. The Noteaid system links a patient directly to pertinent information in order to understand more about their conditions. These links are intended to be easy to understand, simple, focused without a lot of extraneous information, therefore satisfying the adults learners need to know concept.

The second concept, is “learning through doing”, this concept is accomplished by navigation through the Noteaid system (Knowles et al., 2014). With its Kindle like appearance, Noteaid allows adult learners to take a hands-on approach to navigate their record system. The patient can also be fully involved in their care through self-directed, system guided education. The third concept of “problem solving” is best exhibited by the goals of the program (Knowles et al., 2014). The goal of Noteaid is to help patients understand their medical records. It has the potential to help patients solve problems with their health that may be affecting their quality of life.

The final concept of “immediate use” is satisfied with this program because being able to understand health information allows adult learners to utilize the knowledge they have gleaned immediately (Knowles et al., 2014).



## **Goals, and Objectives**

The overall aim of this DNP proposal was to educate and survey an expert panel about an informatics-based solution (Noteaid) for the clinical problem of patients not being able to understand provider notes. The long-term goal for this DNP project was to improve patients and family members of individual's medical records understanding of provider notes shared in patient portal to help improve care. The DNP student objectives accomplished in order to complete this project included:

1. Participating in annotation of medical terms and developing internet resources for patients on specific disease topics in the software.
2. Obtaining demonstration software and sample notes from Noteaid developers.
3. Creating PowerPoint presentations and surveys.
4. Presenting PowerPoint presentation and surveys to informatics committee on two separate occasions.
5. Analyzing pre- and post-education surveys and disseminating survey results.

## **Methods**

This DNP Project involved educating a group of on the Noteaid system. This was accomplished through PowerPoint presentations and through system demonstration with permission from the creators. These clinicians on the Informatics committee work closely with patients and their expertise is demonstrated by their ability to assess patient needs, navigate health literacy levels, effectively educate patients, and determine the effectiveness of their teaching. They were surveyed to share their professional judgment

regarding Noteaid's potential to improve patient's understanding of their own medical records.

The Plan/Do/Study/Act PDSA was the implementation theory that was utilized in this quality improvement project (see Appendix B). This implementation strategy was used as a template to complete the educational intervention. The *plan* was to gather information needed by creating PowerPoint presentations while educating medical professionals and utilizing de-identified patient notes to demonstrate Noteaid's effect to the medical professionals. The *do* was presenting and distributing surveys. The results of the survey questions were then *studied* and the data presented back to Noteaid creators and the general public has the potential to *act* as expert opinion and/or improve both the individual system and the healthcare system.

### **Project Site and Population**

This DNP project took place during an informatics committee meeting at a large tertiary care facility. This DNP student provided PowerPoint presentations, education time, and administrative time. The micro-community of the informatics committee represents professionals from different areas throughout the hospital. All members apply annually to participate in this form of shared governance. In order to qualify and be selected to participate the volunteers have to be recommended by their leaders, be in good standing within the institution, and have a heart for informatics. The goal of the committee is to represent the many roles within the institution.

The participants included clinicians from Social Work, Nursing, Nutrition, Occupation Therapy, Physical Therapy, Nursing Informatics, Nursing Research, and Nursing Administration from both inpatient and outpatient areas. The committee meets

twice a month to discuss, provide feedback for, brainstorm ideas, and review processes of anything information that may be implemented in the institution.

This committee has been on the front lines of many technological implementations and changes, including the implementation Epic an electronic medical record system as part of a continuous improvement process. It also uses “Safe Affair” as a framework which is a hospital wide initiative to educate patients, families, and staff members. Since all specialty areas utilize Epic this micro community represents the voice of each unique specialty.

### **Measurement Instruments**

In order to measure the responses to this educational presentation, a pre-intervention and post intervention survey were created to be given to committee members (see Appendix C). The pre-intervention survey along with the initial pre-recorded PowerPoint presentation were sent one month prior to the live education series. The committee members who had not submitted their preintervention surveys were reminded each week for one month. After the prerecorded PowerPoint presentation and preintervention surveys were sent, the committee members were presented a 2<sup>nd</sup> more condensed presentation and live demo, virtually. The post intervention surveys were collected electronically by this DNP student. The committee members were emailed weekly to complete the post intervention surveys.

### **Data Analysis**

The data collected were presented as tables utilizing descriptive analysis due to the relatively small sample size. The data came from pre- and post-intervention surveys which included several open-ended questions which were categorized and grouped by

theme for feedback and discussion presented as qualitative data. The quantitative data were represented by averages or number of participants.

### **Ethical Considerations/Protection of Human Subjects**

The University of Massachusetts, Amherst (UMass) Internal Review Board (IRB) approval approved this project and the DNP student was added to the grant's IRB at UMASS Amherst. In accordance with the Health Insurance Portability and Accountability Act of 1996 (HIPAA), the data is already de-identified that was used with the software and under an IRB for part of the Noteaid improvement project. Participants being expert professionals were protected by de-identifying the surveys.

### **Results**

Twenty members of the informatics committee at a large tertiary care facility participated in an educational series focused on meaningful use mandates and an informatics-based solution. These participants who spend much of their time educating and teaching patients and families represent a group that will be directly affected by this mandate.

The pre intervention surveys were sent out four weeks prior to the live PowerPoint presentation and post intervention surveys. The online delivery of the pre-intervention survey allowed for more participants than the post- intervention and more than an in person meeting typically would have in attendance.

There were twenty members who participated in the pre-intervention survey and there were ten participants in the post intervention survey. The demographics of the group members can be found in Table 1 which outlines occupation, years of experience, and percent of time in current roles focused on patient and family education.

**Table 1*****Participant Demographics: Pre-intervention***

Occupation	Yrs. of Experience	Time in patient education
Nursing N= 15	0-10 Yrs N=6	<0-5 % N= 3
Nursing specialty area N=3	11-20 Yrs N= 4	6-39 % N=8
Dietician N=1	> 21 yrs N= 8	40-70 % N=9
Social Work N=1		

Of the 20 participants who completed the pre intervention surveys, 90% were registered nurses as well as nurses in technological roles such as informatics and project management with another 10% in other healthcare roles such as dieticians and social workers. On average their years of experience equaled 17.4 years with a range of experience of 5-35 years with 45% of them spending over 40% of their time educating patients and families.

Significant pre- intervention survey questions are outlined in table 2 below.

**Table 2*****Quantitative Data: Pre intervention***

Question	Pre/Post intervention	Result
Awareness of meaningful use mandates?	Pre	aware: 45% unaware: 55%

Can patients alone understand provider notes, given your clinical experience?	Pre	Yes: 10% No: 55% Maybe: 35%
Do you have the time to help patients understand your notes?	Pre	Yes: Nil No: 100%
Access to notes alone can improve the quality of care and/or change outcomes?	Pre	No: 63% Maybe: 37% Yes: Nil

Of the 20 original participants, 55% were unaware of the current mandate despite being in an active roll out phase. While many clinicians were receptive and hopeful about this new mandate. They also voiced many areas of concern which were primarily focus on effectiveness of the mandate, and later categorized by theme and presented below. Over 50% of the participants believed that the release of notes alone could not improve the quality of care and/or effect patient outcomes and 55% of them believed that access alone would not yield understanding.

Open responses both pre and post intervention were analyzed for themes and are presented in Table 3.

### **Table 3**

#### ***Themes of Open-Ended Responses Pre and post Intervention***

Themes:

Response From Clinicians

Patients alone can't understand provider notes.	“They may end up confusing patients, especially things on the differential diagnosis that may not have been explained to the patient.”
	“If you are not in medical field it can be hard to understand the medical terminology.”
	"Medical terminology is specific to healthcare and patients may have difficulty understanding it"
Ambiguity about net effect of open notes without intervention.	“just knowing the results without understanding them in context makes it difficult as a provider.”
	"I feel it may create unnecessary concern (and hysteria) when reading a result, they don't understand and before providers are able to talk about the results. I think this can become a slippery slope.”
	“this will create more health disparity between those with access + knowledge to understand the complexity of health, vs non-English speakers and low literacy patients.”
Clinician receptiveness to the goal of 21 <sup>st</sup> Century Cures Act.	“Think it {OpenNotes} gives more transparency for patients”
	“step in a good direction but will need some work for clinicians and patients to be comfortable with it”
	“This may help patients participate in their care in a more meaningful way and improve compliance with treatment.”
	“As both a provider and a patient, I hope that it will allow patients to stay more engaged in their care. I hope it will also facilitate better communication between providers and their patients.
	“it is a worthwhile mandate”
	“I feel it is a right and can be beneficial for both parties.”
Fear of additional work for healthcare providers.	{patients} “will need increased attention by healthcare personal to answer questions.”
Fear of effects of censorship on the provider.	“I think that this will help create much more transparency between HCPs and patients; however, I worry about what may be censored out of HCP notes now that patients are able to view them (i.e. nuances of a patient, worries of the team, etc)”

“As a provider I worry that note sharing with patient will change what is shared among providers since as a support service I depend on RN notes and MD notes to determine patient's temperament and specifics of plan since I can't physically round with everyone.”

“I think that there are areas where provider inpatient notes can contradict each other, are not updated properly, and private patient information may be written about that pertains to staff care plan for difficult behavior that should not be directly shared with the pt.”

“I know that patient facing notes will change the content of the notes, and that will affect in house communication and record, which is a concerning outcome to me”

---

Noteaid can be of benefit.

“Makes the notes easy to consume--- actually valuable”

“a great service to empower patients/families”

“I feel like it'll help patients to be able to interpret medical jargon and notes w/ more ease”

Many were concerned that the notes would “end up confusing the patients”. Open ended statements included “if you're not in the medical field, it can be hard to understand medical terminology”. While lack of understanding of medical terminology was their identified primary area of concern, there were also seven identified common themes and concerns about the mandate. After receiving education about the goals of the mandate open text comments made on surveys were variable, but remained largely receptive and hopeful.

Noteaid as a translation system was supported by statements such as “it simplifies the medical terminology”, “it's nice to have more explanation for the patient in the note”, “I feel like it'll help patients to be able to interpret medical jargon and notes w/ more ease”,



“a great service to empower patients/families”, and Noteaid “makes the note easy to consume—actually valuable”.

Table 4 below summarized the post intervention qualitative data.

**Table 4**

***Quantitative Data: Post intervention***

Question	Survey	Results
Do you like the Noteaid system?	Post	Yes 100 % No: Nil
Noteaid would increase the understanding of provider notes?	Post	Yes 100% No: Nil
Access to these notes alone can improve the quality of care and/or change outcomes?	Post	Yes 75 % No: 25%
Noteaid will improve outcomes by increasing understanding of notes.		Yes:70 No Maybe
Rate translated notes, two examples.	Post	80% 4 of 5 stars

After the presentation, 100% of the participants liked the Noteaid system and 75% believed that Noteaid could improve outcomes by improving patient understanding. The majority (80%) rated both of the translated note examples as a 4 on a 5-point rating scale and believed that Noteaid would increase the understanding of the average patient. All of the surveyed clinicians agreed that they did not have additional time to spend educating the patients about the content of their notes. The clinicians spoke highly of the system, many of them surprised by both the immediacy and the accuracy of the translation.

Overall, 70% believed that Noteaid could improve outcomes by improving patient understanding with 30% stating that there was a possibility that Noteaid could have a direct

effect on understanding and could improve outcomes. No participants thought that Noteaid could *not* improve outcomes by its direct effects on increasing understanding. Finally, 80% of the participants rated the two translated note examples as a four on a five points scale.

### **Discussion**

Initially over half of the participants believed that the release of notes alone could not improve the quality of care and/or effect patient outcomes and over half of them believed that access alone would not yield understanding. After the presentation they were much more positive. This translation system was selected for this project as the literature highlighted many barriers that affect patient understanding of provider notes. Those reasons included the medical jargon used, the education level of the writers, as well as health literacy levels (Graham & Brookey, 2008, Dontje et al., 2014, Dalrymple et al., 2016, Levy et al., 2015, Irizarry et al., 2015, Lalor et al., 2019).

The findings of the preintervention surveys, that so many of the clinicians thought that patients could not understand provider notes, was a potential barrier to the goals of the meaningful use mandate. The overarching goal of meaningful use is to create programs that have the capacity to effect real and measurable change for population health (“Public Health and Promoting Interoperability Programs”, 2020).

The historical foundation where the health care system assumes that patients can understand complex written information needs to be re-examined. (Graham & Brookey, 2008). Provider notes are really a form of peer-to-peer communication written to an audience of other clinicians. Without the addition of an intermediary system such as Noteaid, provider notes may be less useful to patients affecting this mandate’s ability to bring about real change. It is likely that at the time of roll out of the meaningful use

mandates many clinicians were unaware of the directive. Clinicians are concerned about the success or failure of new ideas and should be viewed as major stakeholders to the successful uptake of any program.

The theoretical framework of the adult learner applies to the goals of the meaningful use mandate. The goal is not simply to improve understanding of any individual providers notes, but to have a lasting effect on population health decreasing disparities and improving care. This framework supports educating learners that provider notes contain information that they will need to understand and implement in order to prevent disabling and debilitating conditions, as well as prevent exacerbation of chronic diseases.

Provider endorsement of any new program is identified as a key facilitator in its success (Logue & Effken, 2012, Wald et al., 2010). An example of this is highlighted by a clinician who because of the new mandate has started closing appointments with 'Don't forget to read your note later,' (MD Millen as cited by Mulcahy, 2020). This statement can help the client to understand that there is something important in their note for them and of importance to their health care.

The Noteaid system links a patient directly to pertinent information in order to understand more about their conditions by translating the terms being used. These links are intended to be easy to understand, simple, and focused without a lot of extraneous information, therefore satisfying the needs of adult's learners as identified by Knowles et al as "need to know", "learning through doing", "problem solving" and "immediate use" (Knowles et al., 2014).

Population health mandates, such as this one, often come from the top-down which can have a negative effect on stakeholder buy-in. The gap that exists from research into translation into clinical practice can perhaps be explained by this top-down approach. These changes ultimately have an effect on specific healthcare roles, so soliciting opinions from those who are largely affected by this change is important.

Experience, specifically within nursing is variable and it is the diversity of thought in which our strength dwells. In order to effect real change to population health we must pull from these strengths. Valuable expert opinion from all clinicians is important. Administrative professionals with a nursing background will not share the same experiences and/or value the same systems that a bedside nurse will. Therefore, soliciting the opinions of those carrying out the actual work, in large volumes, will not only improve buy-in it will also increase awareness and be foundational to the success of any program such as meaningful use mandates.

One significant barrier emphasized by the clinicians was the lack of continuity with embedding the Noteaid system, which is largely dependent on institutions buy- in. Although Noteaid is now an open access tool, having to exit patient portal and take any additional steps utilizing a separate website threatens to create additional friction. Likely, patients and families will not be carrying this out and the friction will become a major barrier to utilization ultimately impacting the overall effectiveness of the mandate. Many patients may also be concerned again with privacy issues which must be assured by the institution to support the use of the website.

The strength of this project includes the surveyed clinicians, a professional relationship with the group's members and the DNP student were a key facilitator. The

setting was a large academic medical group where clinicians are highly regarded for their level of expertise. Since this group discusses possible institutional rollouts, it is through relationship alone that this educational series and surveys were permitted.

Additional strengths were the professional characteristics of the participants, who were analytical and investigative problem solvers. This was a major facilitator as the members were free to voice their opinions even when they did not agree with certain initiatives. Despite the small number of participants in this project, the qualitative data and unanimous agreement on the potential for this tool can be used to direct future efforts toward achieving the full scope of the meaningful use mandate.

### **Conclusion**

Although some may take issue with the meaningful use mandate; the goal of this project is to identify the usefulness of a tool to help make it more effective. It would be futile to create a mandate, implement all the changes associated with it, and fail to results in a net positive improvement. The gaps that exist between patient understanding and provider notes need to be addressed systematically.

The goal of this project was to determine where systems can interact to bridge the gap that exists in order to improve the chance of positive outcomes. Following this brief educational intervention and demonstration of the Noteaid system, this small project lends credence to the idea that Noteaid has as strong chance to be the intermediary technological solution to bridge the gap between patient and provider.

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## Appendix A

### Theoretical Framework

Adult Learning Theory

# Knowles' 4 Principles Of Andragogy

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## Train to Your Audience

Malcolm Shepherd Knowles (1913 – 1997) was an American educator who identified the characteristics of adult learners and created the principles of adult learning theory.

Using the adult learning theory principles that Knowles identified helps you deliver effective training by helping you meet the unique needs of your audience.

## These are the principles

- 

**#1**  
Adults need to know why they are learning something.
- 

**#2**  
Adults learn through doing (even if they make mistakes).
- 

**#3**  
Adults are problem-solvers.
- 

**#4**  
Adults learn best when the subject is of immediate use.

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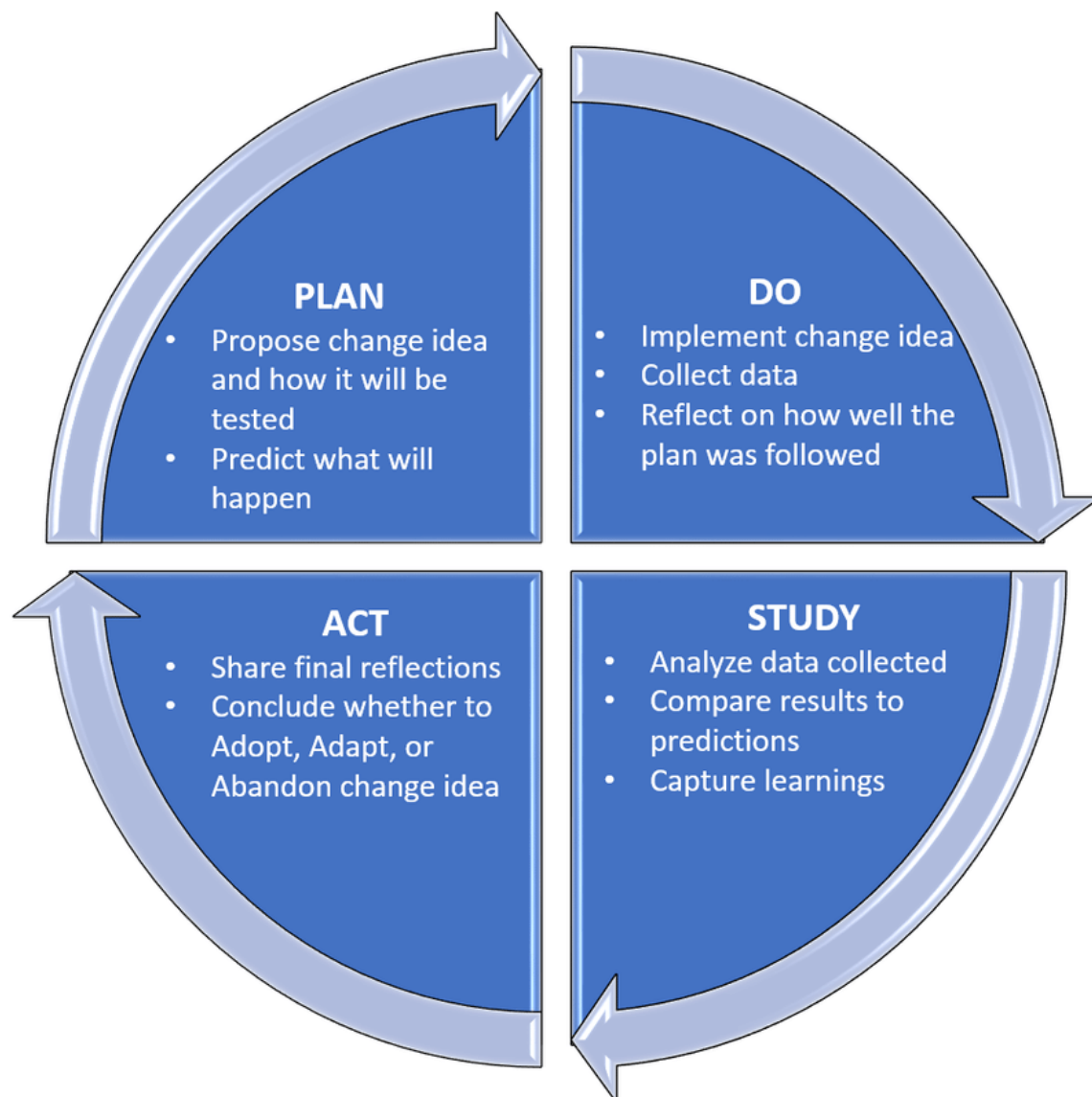


Adult learning improves individual knowledge and skill. This in turn can improve organizational performance as learners apply that knowledge directly to their work.

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## Appendix B

### Implementation Theory PDSA



## Appendix C Pre intervention Surveys

*Please do not put your name in the survey*

### **Demographics:**

Occupation:

Years of experience:

What percent of your current job is spent on patient education or improving patient education?

1. Are you aware of meaningful use phase three mandate? Yes/No
2. What are your thoughts about meaningful use and the mandate to allow patients access to provider notes as a provider and as a patient of healthcare systems?
3. Do you think that access to these notes alone can improve the quality of care and/or change outcomes? why or why not?
4. Based on your clinical experience, do you think that patients alone can understand your notes? Yes/No/maybe
5. Do you have the time to personally help patients understand your notes in order to bridge the gap? Yes/ No
6. Do you think that discharge summaries are effective in helping patients follow the plan which take place outside of the healthcare area? Yes, no.
7. Where do you think a gap exists between patient education and plan actualization outside of the health care setting?
8. How well do you think the following statement explains this key term excerpted from a provider note? Note:“RECOMMENDATIONS: Recommend a course of extracorporeal shockwave lithotripsy and a stent exchange within the next 1 to 2 months.”Translation in patient view regarding the term Lithotripsy"The most common treatment for kidney stones. It uses sound waves to break up the stones."  
\* As above rate how well you believe the following definition of the term "snapping hip" would help the patient better understand the sentence and term. Excerpt from note: “Indications: the patient is a 15-year-old female who is a competitive ballet dancer who preforms at the Metropolitan ballet, who has been bothered by a snapping hip for the last one year. “Term translation: “A condition in which one can hear a noise when the hip joint is moved. It can cause pain and weakness that makes it hard to move the hip. Massage and improved posture can help reduce the pain.”

## Appendix C Post intervention Survey

*Please do not put your name in the survey*

Post intervention Survey:

**Demographics:**

Occupation:

Years of experience:

What percent of your current job is spent on patient education or improving patient education?

1. Do you like the noteaid system? Yes/no  
Explain
2. Given the current mandate where patient will have access to provider notes do you agree that noteAid would help improve patient understanding?  
Yes/no/ maybe            Why
3. What suggestion would you make to improve the system?
4. Do you think that noteaids software allow provider notes to be more understandable to the average patient? Yes/no  
Comments:
5. Will Noteaid improve outcomes by improving patient understanding and comprehension of provider notes? Yes/ No/ Maybe
6. Example 1 - How well do you think the Noteaid system translated the note
7. Example 2- How well do you think the Noteaid system translated the note

## Appendix D

### Timeline

Task	July	August	September	October	November	December
Recruitment of informatic committee	X					
Project finalization mentorship and guidance		X	X			
Request permission for sample database use and demo sheets			X			
Educational PowerPoint and sample database play. Pre and post tests administration.				X		
Data analysis of outcomes					X	
Results presented in this Quality improvement Project						X