

Social Justice and Readability:

What Consent Forms Hide & Choose to Reveal

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## **I. Summary**

When looking at social justice in the medical field you need to look at the readability in consent forms. So our group looked at that intersection to try and determine how much the readability actually affects social justice. Our group was able to do this by reviewing works on the connection between social justice and document readability, by making an overview of the readability in the consent forms and recommendations for next steps to the people in charge. Our group will be done and ready to give our recommendations by the end of the day on Friday the 18th. By doing this our group hopes that our research and presentation will spark a conversation surrounding the readability of medical consent forms which will lead to changes in the way that consent forms are written and how they are delivered to people when they need to sign them. In the appendix, you will find our annotated bibliography and other documents that we used.

## **II. Introduction**

As students this topic affects us because we can't sign things ourselves so just learning to read the documents doesn't help as much as making a change. The majority of our guardians do not or can not read these consent forms that are dictating over the procedure that can be performed. Due to this we have decided that the consent forms need to be updated to fit the U.S. population which they currently are not. This has also become a social justice issue because people are suffering the consequences of not reading the consent forms fully. Normally this would be the fault of the person reading for not reading it carefully enough but due to the college reading level that is required to understand what is being said and that America has an average reading level of 8th grade. We can not move forward as a society if we can't even read about what we are signing away in a consent form.

## **III. Needs/Problems**

The consent forms surrounding healthcare in America are at a reading level that most Americans are not at making it pretty much unreadable to them. This is a problem because it bars people from being able to get proper healthcare because either they will sign a consent form for

something that traps them or they know what it says and sign something that doesn't cover them fully.

In a 2018 by Zachary W. Taylor which talks about the readability of the college instructions on how to report sexual assaults and how it prevents people from getting the help they need. Taylor claims that 90% of all sexual assault victims do not report is because they don't comprehend how to report sexual assault via college campus instructions of "How to Report Sexual Assault". This essentially means that not every college student is at the reading level of the instructions. Turns out that "the difficulty of these instructions is especially problematic for two groups of college students: English-language learners and students with reading disabilities, such as dyslexia." (Taylor, 2018) making the readability level of these instructions limited to certain college students. Although this source uncovers the truth about readability levels in "How to Report Sexual Assault", it is also hypocritical because the readability of the information is high, leaving those who do not read at the same educational level and entering or in college, confused and in doubt. This article is appropriate for social justice and readability problems because it proves that a limited amount of college students are able to comprehend how to report sexual assault—making it a privilege—leaving more than half of students not able to use their voice to speak up. It further shows that readability isn't as simple as someone graduating college or being in college then they have a college reading level which isn't true.

The 2017 article "Informed consent and the readability of the written consent form" by Sivanadarajah, et. al (2017) talks about the readability relating to consent forms in the medical field. The author argues that the medical consent forms relating to invasive procedures are written at too high of a reading level. He argues that because not enough people understand what they are saying and the important information that has to do with their health is being missed.

The authors do this by taking multiple different standardized consent forms and comparing them to determine which ones are easier to read as shown in one of their studies. “This study demonstrates that the BOA endorsed standardised consent forms are much easier to read and understand than the NHS Consent Form 1, with the detailed BOA forms being the easiest to read.”(Sivanadarajah et al., 2017) This article intends to show certain standardized medical consent forms are at too high of a level where on the other hand there are some that are at the right level. In order to change this there needs to be one single standard in terms of medical consent forms and they need to be at a level where the majority of people if not all can read.

The 2003 article "Readability Standards for Informed-Consent Forms as Compared with Actual Readability" by Paasche-Orlow, et. al (2003) talks about the readability standards and how different the actual readability is when it comes to consent forms in the medical field. “The mean Flesch–Kincaid scores for the readability of sample text provided by IRBs exceeded the stated standard by 2.8 grade levels (95 percent confidence interval, 2.4 to 3.2;  $P < 0.001$ ).”(Paasche-Orlow, et al., 2003). The authors intend to inform the reader that the readability of consent forms are too high for the average person. Despite the article being difficult to read at times, I think the author achieved his intended goal of informing people that the current medical consent forms do not work and put people in harm's way. The more complicated scores and numbers can cause some confusion but the article does a very good job at showing directly what's wrong with the readability in consent forms. This article successfully serves its purpose to inform people about the problem with readability.

The 2012 paper “Roadblocks, Stop Signs”: Health Literacy, Education and Communication at a Free Medical Clinic” by Sally J. Huntington talks about the lack of understanding in health literacy in free healthcare clinics: “which takes place in a free medical

clinic for low-income and uninsured patients, addresses the patients' health literacy and access to health information inside and outside of the clinic setting, as well as the strategies clinic providers use to effectively communicate health information" (Huntington, 1970). Huntington uses this paper to discuss the medical language used in and out of a free health care clinic. This paper is a good source of information regarding the understanding or lack thereof regarding healthcare. Even if the readability levels are lowered there is still vocabulary that can cause confusion within consent form. This is another problem within medical consent forms that can be solved to try to help the majority of people get an understanding of what they are signing.

All of these articles and papers show the social justice issues that the readability consent forms and other medical documents are causing. The articles also show that there are possible solutions out there that can be taken to help the readability in consent forms.

#### **IV. Goals/Objectives**

- Decrease readability by the recommended reading level of the National Institutes of Health (NIA) and the American Medical Association (AMA).
- Look for details and errors that need to be fixed in order to improve the readers comprehension based on their reading level and use gathered information to prove high readability levels throughout consent forms.
- Create and present a powerpoint that further guides clients into the overall discussion of decreasing readability levels of consent forms, information regarding consent and readability levels that connect with social justice.

#### **V. Timetable**

Phases	Description	Dates
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1	Read the consent form and decide what parts need improvement and what parts we need to work on	November 30 - December 1
2	Formulate a plan on how we are going to go forward on fixing the consent forms	December 2
3	Create a timeline detailing what needs to be done by what day	December 3-4
4	Create the plan by making the proposal	December 4-7
5	Put that plan into action by making a presentation	December 7-10

**VI. Key Personnel**

Description	People
Clients	Manual Students and Families and Denver Health stakeholders and Manual staff.
Sponsors	Whitney Weathers
Group Leader	Ethan Zimmerman
Group Members	Laila Carroll, Natalie González & Tommie Mack

**VII. Evaluation**

As with anything, we are going to need benchmarkers to make sure we are hitting our goals as we go along. To do this we will meet as a group and based on the tables above we will decide whether or not we have met or deadline for each of the phases. For phase 1, we will check to make sure that we all have a good understanding of the consent form by having a conversation showing that we are on the same page. We will do this on December 1st because it still will give

us time to get on the same page if we aren't and if we are it will give us time to start on the next phase. For phase 2, based on our understanding of the consent forms, we will create ideas on how to help fix the readability. We will do this by December 2nd and we will know that we have done this by being able to write down as a group the problem we are going to tackle. For phase 3, based on the ideas put forward in phase 2 we will create a timeline to make those ideas into a reality. This phase we will have done by December 4th and we will know when we have met this goal when we have created a timeline on paper of what we need to accomplish going forward. For phase 4, we are going to put all the phases prior into one proposal to make sure our ideas can be accomplished in a timely manner. We will have this done by December 7th and we will know we are done when we turn it in to Ms. Weathers. For phase 5, the last phase we are going to put our ideas into our final presentation that will consist of everything up to this point.

### **VIII. Next Steps-What Should Change?**

- Show up on presentation day and listen to our presentation that consists of everything that has to do with consent, readability, and social justice.
- According to the information gathered in the powerpoint, decide whether this information has impacted the reader either by experience or from someone they know.
- Use information from powerpoint to understand how consent and readability is connected with one's social justice.

### **IX. Appendix**

Huntington, S. (1970, January 01). [PDF] "Roadblocks, Stop Signs": Health Literacy, Education and Communication at a Free Medical Clinic: Semantic Scholar. Retrieved November 20,

2020, from

[https://www.semanticscholar.org/paper/"Roadblocks,-Stop-Signs":-Health-Literacy,-and-at-a-Huntington/d6489b0009e4b3b15b48041bd7f7d62f41100351](https://www.semanticscholar.org/paper/)

The 2012 paper “Roadblocks, Stop Signs”: Health Literacy, Education and Communication at a Free Medical Clinic” by Sally J. Huntington talks about the lack of understanding in health literacy in free healthcare clinics: “which takes place in a free medical clinic for low-income and uninsured patients, addresses the patients’ health literacy and access to health information inside and outside of the clinic setting, as well as the strategies clinic providers use to effectively communicate health information” (Huntington, 1970). Huntington uses this paper to discuss the medical language used in and out of a free health care clinic. This paper is a good source of information regarding the understanding or lack thereof regarding healthcare.

Paasche-Orlow, M., Author Affiliations From the Departments of Medicine (M.K.P.-O., A. G.

Letizia and Others, J. H. Beigel and Others, & L. A. Jackson and Others. (2003, May

29). Readability Standards for Informed-Consent Forms as Compared with Actual

Readability: NEJM. Retrieved November 19, 2020, from

<https://www.nejm.org/doi/full/10.1056/NEJMsa021212>

The 2003 article "Readability Standards for Informed-Consent Forms as Compared with Actual Readability” by Paasche-Orlow, et. al (2003) talks about the readability standards and how different the actual readability is when it comes to consent forms in the medical field. “The mean Flesch–Kincaid scores for the readability of sample text provided by IRBs exceeded the stated standard by 2.8 grade levels (95 percent confidence interval, 2.4 to 3.2;  $P < 0.001$ ).” (Paasche-Orlow, et al., 2003). The authors intend to inform the reader that the

readability of consent forms are too high for the average person. Unlike other articles on this subject this article is easier to read as well as they use a lot of models to help the reader understand what is going on. This article serves its purpose to inform people about the problem with readability.

Sivanadarajah, N., El-Daly, I., Mamarelis, G., Sohail, M., & Bates, P. (2017, November). ~~ojjk~~  
 Informed consent and the readability of the written consent form. Retrieved November  
 19, 2020, from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5696940/>

The 2017 article "Informed consent and the readability of the written consent form" by Sivanadarajah, et. al (2017) talks about the readability relating to consent forms in the medical field, "This study demonstrates that the BOA endorsed standardised consent forms are much easier to read and understand than the NHS Consent Form 1, with the detailed BOA forms being the easiest to read."(Sivanadarajah et al., 2017) This article intends to show certain standardized medical consent forms are at too high of a level where on the other hand there are some that are at the right level.

Taylor, Z. W. (2018). Unreadable and Underreported: Can College Students Comprehend How to Report Sexual Assault? *Journal of College Student Development*, 59(2), 248–253.  
<https://doi.org/10.1353/csd.2018.0023>

Taylor claims that 90% of all sexual assault victims do not report is because they don't comprehend how to report sexual assault via college campus instructions of "How to Report Sexual Assault". This essentially means that not every college student is at the reading level of the instructions. Turns out that "the difficulty of these instructions is especially problematic for two groups of college students: English-language learners and students with reading disabilities,

such as dyslexia.” (Taylor, 2018) making the readability level of these instructions limited to certain college students. Although this source uncovers the truth about readability levels in “How to Report Sexual Assault”, it is also hypocritical because the readability of the information is high, leaving those who do not read at the same educational level and entering or in college, confused and in doubt. This source is appropriate for social justice and readability problems because it proves that a limited amount of college students are able to comprehend how to report sexual assault—making it a privilege—leaving more than half of students not able to use their voice to speak up.