

# **A Medical Communicators Role In Digital Patient Advocacy**

Reflection Essay  
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## REFLECTION

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When reflecting back on my time spent in the Master's in Professional Writing and Communication program, my thesis "[A Medical Communicators Role in Digital Patient Advocacy](#)" holds some of my most valued work that I composed throughout my graduate career. The portfolio was created to showcase the importance of a medical communicator's role to the field of digital patient advocacy with a special focus on rare diseases. My thesis was designed in the medium of a blog website that works to define myself in the field. The website reaches out to several different types of audiences, one being patients and caregivers and the other future employers in the field of medical communication. All the different stages and building blocks while composing my portfolio were rewarding as I navigated through each section. From attending conferences, networking with medical communicators from The American Partnership for Eosinophilic Disorders (APFED), listening to people's stories and the culture of the industry, curating the material, and meeting with my chair each part helped me to see the layers of my portfolio come together. When developing my thesis, I felt like this work was critical to shine light to rare diseases in order to efficiently help to bridge the gap between patients/caregivers and physicians/specialists. I learned that in order for effective communication we need more medical communicators filling the areas of media relations, healthcare journalists, educators, supervisors, writers, and editors to name a few. When thinking of the whole picture an ideal medical communicator would be someone who is not only efficient in breaking down dense medical documentation but building a digital space where these patients and their families can come together, where they will not be silenced and rather given a chance. A chance to speak, a chance for change and a chance to address their needs, wants and desires.

## SPECIAL FOCUS

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Medical communicators are assets to the field as they are the gatekeepers that should work to support patient advocacy. They help to breakdown medical jargon and advocate for patient needs. My website works to resemble this mission, when visiting my site, one will notice it is broken down into the following categories:

- Blog
- About
- Social Media
- Advocacy
- Reflection

- Works Cited

Furthermore, my website hosts the following materials that works to deliver just how critical digital patient advocacy is and how one can go about doing it successfully. It is bad enough that these patients and their families are facing a rare diagnosis the last thing they need is to feel as if they are alone and that no one is taking the time to listen to them. Rather, there should be a sense of community and a relationship built between the patients and their medical team along with a space that they feel comfortable in going to, to talk about these diagnosis's, in order to establish a community. My website's goal is to adhere to this standard and works to create a space that is inclusive; not something that is a one size fits all approach but a landing spot where people can congregate together into a space that works to advocate and educate in the following ways:

I. Blog Posts.....

*The blog features a series of stories that are unique to the field. They work to educate, inspire and at some points even tear at the heart strings. This includes spotlights on medical communicators, in which we hear from APFED's Executive Director, Mary Jo Strobel and Communications Manager, Amity Chaves. Similarly, I feature stories from patients and caregivers that divulge into their own personal stories as it brings patient voice to the industry. Furthermore, other areas of interest include posts about industry standards, advocacy, conference takeaways and more.*

II. Instagram Account [@lunalung2018](#).....

*The social media account @lunalung2018 spotlights posts that are relevant to the field of rare diseases, most notably this one is geared towards hypereosinophilic syndrome (HES); however, anyone can adapt to this site for rare diseases. The posts reflect advocacy campaigns such as #EosAware & #LunasGreetings, spotlights, information about my children's book Luna Lung...Meets HES, facts and more. When working with Instagram I used the promotion tool to help boost posts to allot a more diverse exposure. Other stylistic choices included formatting photos, breaking down posts into descriptions with information that is easy to understand. By creating this virtual space on social media, I wanted to create a spot where those could come for inspiration and when looking back at all the photos, quotes, facts and support it is so rewarding to see what happens when you all come together.*

III. Research Paper "Defining New Media...In the World of Technical Communication" .....

*"Defining New Media...In the World of Technical Communication" I research the*

*definition behind new media and how new media and technical communications comes together in the field of medical documentation (via the Internet). In my study we interview Executive Director for The American Partnership for Eosinophilic Disorders, Mary Jo Strobel and University of Massachusetts Dartmouth English professor, Katherine DeLuca. I chose to interview these two individuals because they have firsthand professional experience that shows multiple aspects to the field. The following paper explores theories given from theorists such as Douglass Eyman, Barry Thatcher, Alison Reynold and more. When selecting my articles, I made my choices based on what would enhance my paper and add to my argument. The overarching goal of this paper is to uncover a better understanding of new media and its important role in technical communications for medical writing. In conclusion, I want to explore the many definitions and portray how like rhetoric, there is not just one definition. Nor is new media just new media...we will learn that it is far more.*

IV. Document Design Medical Labeling Lesson.....

*The Document Design Medical Labeling Lesson was developed in order to look at the issues associated with a medicine labels document design. Ineffective design in medical labeling can poses a plethora of issues: overdose, death and more. This lesson helps to educate one on these issues and ways in which medicine should be labeled in order to affectively educate patients and caregivers who may administer it. This includes freeing the text from medical jargon with easy-to-understand terms, using font that is easy to read, colors that are cohesive to the brand, and more. Likewise, placement of information on a medicine label is critical as well in order to effectively produce a label that is accessible to all patients.*

V. Digital Remix of children’s book “Luna Lung...Meets HES” .....

*My digital remix of “Luna Lung...Meets HES” transforms the originally published book (in 2018) into an interactive experience for readers to access on their computers and or tablets. “Luna Lung Meets...HES” is a book in which I wrote based on the inspiration that stemmed from my mom and our family’s journey through her diagnosis of Hypereosinophilic Syndrome (HES). The book is delivered in a children’s book format working to educate both those old and young about the importance of advocacy and community support for rare diseases such as HES. The remix works to incorporate animation across the images and pages, voice over components placed on various pages, alt. text for images, external links to further the conversation and connect one another.*

VI. Patient Advocacy Vision Board.....

*The Patient Advocacy Vision Board works to express what can happen when a medical communicator uses the power of patient story and patient advocacy to come together. The volume of support can be viewed in an instant and works to unite the community into creating an inclusive space. This vision board is made up of a series of pictures in which I have collected over the years and placed into a template on Canva where I worked to puzzle piece them together to create a digital board overlaid with music and various animation. Creating a digital vision board is one way in which medical communicators can produce advocacy in the digital space as it can be posted to blogs, websites and on social media which in turn creates a chain reaction between shares, reposts and more.*

VII. Resume.....

*The last component to my portfolio encloses my professional resume. I have tailored and revised my resume to define myself in the field over the course of my time spent in the MPW program. It is broken down into various categories such as education, experience, employment, community service and skills that will help to place me in the field. Each portion works to portray my credibility and will give my employers a glimpse of who I am.*

When conducting each medium a rhetorical lens was used in combination with critical thinking. I used research and reflection based on conferences, my case study interviews with [The American Partnership for Eosinophilic Disorders \(APFED\)](#), my patient story interviews, as well as knowledge gained from coursework and industry standards to help guide me in my design approach. I worked to unscramble medical jargon into simpler terms and sentence structures making it easier for the average reader to understand. In conjunction, I used images that worked to tell a story which creates a more humanized approach... It is critical that medical communicators listen to patient needs, share their stories, listen to doctors and physicians, and communicate their findings at an eye level. The color palette was carefully chosen to maintain a color balance that is visually appealing to the eye and maintains a professional outlook. When doing this in the virtual space it needs close attention to detail, you want to let people know that there is an actual human on the other side and not just a computer executing all the work. In doing so I kept in mind the Aristotelian appeals of ethos, pathos and logos when conforming my examples.

**REVISION**

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As I went through this process there are a few aspects in which I revised from previously submitted course work completed within our program. This included editing my video on “Physical Disability & The Embodied Experience” this worked on trimming down unnecessary content that was class specific and tailoring it to be more of a professional piece rather than academic, which has been placed in the blog section of my website. Likewise, I continued to revise my digital remix “Luna Lung...Meets HES” children’s book into a digital remix where it went through a few revisions before the final submission. This included ironing out the overall production of the book: making sure that images, text, and animations were in synch. I incorporated feedback from my instructors and chair while refining and putting the final finishing touches on my supporting documents.

## **CONCLUSION**

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In conclusion, “A Medical Communicators Role in Digital Patient Advocacy” works to support two overarching goals: 1. Helping to stress the importance medical communicators carry in digital patient advocacy for rare diseases. And 2. To help define myself in the job market and deliver examples of what the industry should be doing in order to be successful. As I continue to be inspired the process has been rewarding and being able to reflect back on my thesis and see how each piece has come together to help support a multitude of areas has created such a rich experience. Looking to the future I hope others can take away something from my initiative and work towards achieving their own hopes, goals, and dreams to advocate for a better medical system. To keep patients at the forefront and to create household names for rare diseases.