Lorrie Hayes

1. What world problem are you concerned about?

There are many people who have diseases or other medical conditions that require treatment such as medications, surgery, or some form of therapy. All of these people have to adapt their lives to accommodate their condition and at one point or another need the advice of someone who has lived through a similar situation.

2. Why is this problem important?

There are countless rare diseases in the world with only a handful of living people infected[1]. This poses a problem for the patients and their families when trying to adapt their lives to accommodate the disease if they can not speak to others who have dealt with a similar situation. The lack of people to discuss these questions with could lead to the patient feeling isolated and even more confused. Also having only the medical advice of doctors and nurses nearby, might limit the number of options the patients have.

3. What aspect of this problem seems particularly important to you?

The need that patients have for information is very important. Patients need many different opinions to make an informed decision about what they should do. It is also important to be able to have conversations with people who have had similar experiences to you. This would be of vital importance when dealing with diseases that are less common.

In the case of rare diseases that infect children, it is really important that the parents can get information about how to deal with a situation that seems so daunting. It could help the families see that their situation is not as hopeless as they might feel that it is.

 4. How could a new software system help to solve this aspect of the problem?

A software system that provides a convenient way for a patient to talk with both doctors and other patients from around the world would be very beneficial.
There would be a few parts in the software.

One of the parts would be to get a list of doctors will to give advice to patients through the Internet. There could be a section where interested doctors and nurses could register. Once they have registered, they could list any specialties that they have so that patients could connect with the appropriate doctor or nurse. They could post general information on their page that patients might find useful. They could also advertise any medical trials they are researching to see if any of the registered patients want to take part.

There would have to be a similar section for patients to register. There should be a place for the patients to list any condition or procedure they have or have had. Similar to the doctors and nurses, they could also post anything they feel might be useful to others dealing with the same stuff they have.

There would be a way for members to search through the database of doctors, nurses, and patients to find people who could help them. There should be a way to search through the

members by location and by particular conditions.

There would also be a section where all of the members could talk about anything they choose, such as books, TV shows, movies, etc. This would be important to allow people who might not have the same condition but have other things in common, to become friends. This would be useful if a patient has a very rare condition that no one who lives near them has, but someone close by who has another disease, could be there for them during particularly hard times.

5. Why do you think that this idea will make a big impact on the world?

This software will help the world by making it easier for patients to get vital information to help them make the best decision for their health. It will also allow people who do not know anybody else who has their disease or condition to become friends with others who have the same disease or condition. This could make dealing with any disease a little bit easier and more manageable.

This would also make it easier for doctors to conduct research. Doctors are already using social media to find patients to take part in research studies, and this software would all them to just do one simple search on on website to find possible patients. [2]

6. What sources did you use in writing this Vision Statement?

Information found on rarediseases.org

Moore, Elizabeth. "How Social Media Helps Us Study Rare Diseases" CNET. http://news.cnet.com/8301-27083_3-20099540-247/how-social-media-helps-us-study-rare-diseases/