Designing for Dispersed Populations with Rare Diseases

There are more than 7,000 different rare diseases.

Approach:

Study 1: Exploratory interviews with people with rare diseases

We conducted interviews with 19 people about their experiences living with their condition, relationships and support, use of technology and information management, and sense making practices. We discuss how having a disease that is invisible or unfamiliar influences many roles.

MacLeod, H., Oakes, K., Connelly, K., and Siek, K. (2015). Rare World: Towards Technology for People with Rare Diseases. In CHI 2015. - Honourable Mention Award

Study 2: Survey with people with common chronic illnesses and rare diseases

We distributed a survey with questions about demographics, use of technology for health information and support, and perception of healthcare providers to people with common chronic illnesses and people with rare diseases. We adapt and apply a machine learning algorithm to distinguish between these two groups.


Study 3: Asynchronous, Remote, Community Research with people with rare diseases

We conducted a study in a private Facebook group over several months where participants responded to discussion prompts and completed a variety of research activities. We analyzed this data to better understand the role of the disease in their relationships with friends and family.


10% of People have a Rare Disease

10% of People have a Rare Disease

There are more than 7,000 different rare diseases.

Key Findings:

People with rare diseases face a unique set of challenges, different from what we know about people with common chronic illnesses:

- They have a hard time expressing what they are going through to friends, who haven’t heard of the disease or don’t see visible symptoms. Common chronic illnesses tend to be more recognizable or familiar to these friends.
- They tend to strongly identify with their disease, and it moderates most other aspects of their life. In common chronic illnesses, there is an emphasis on “the whole person” outside of just the disease that is not the same in the case of rare diseases.
- They often lie about how they’re feeling, downplay their symptoms, or even tell people they have a different disease than they actually do (typically a common disease the friend would have heard of).
- Friends & family often don’t believe that they are actually sick or think they are exaggerating their symptoms.

Next Steps:

- Speculative design, design futuring: how might digital technologies address these needs now and in the future?
- Deploying & evaluating: how can we evaluate technologies when populations are geographically distributed?