

Designing a web portal for persons with serious mental illness

Design considerations based on the literature, focus groups and an expert users survey

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People with serious mental illness die 25 years earlier, on average, than the general population. Much of this disparity in life expectancy can be attributed to modifiable lifestyle factors or psychotropic medications that increase the risk for developing obesity, diabetes, and/or cardiovascular diseases. (Parks, Svendsen, Singer, & Foti, 2006; Viron & Stern, 2010) While many websites and mobile apps have been developed to support persons with mental illness, very few link this information with similar resources on physical health. Plus, research shows that

persons with serious mental illness often have a more difficult time using online resources. (Cohen & Adams, 2011; Nicholson & Rotondi, 2010; Swan, 2009)

In 2015, the University of Massachusetts Medical School's Lamar Soutter Library, in conjunction with the university's Department of Psychiatry and the Dartmouth Psychiatric Research Center, received a three-year grant from the National Library of Medicine/National Institutes of Health to address this issue. The end product of this

grant will be an online resource that persons with mental illness can use to learn skills to more fully understand and address physical health issues they experience.

In order to build an effective tool for this population and this purpose, significant research and preparation was conducted. Year one (2015-2016) of the grant was dedicated to information and data gathering. In order to learn specifically what persons with serious mental illness would want to find in this type of online resource, focus groups were convened. Three focus groups (N=42) were conducted with people having lived experience. One was conducted in an inpatient psychiatric facility, another is an outpatient setting and a third with young adults that are part of a social psychiatric research group. Three additional focus groups were conducted with mental health professionals. These groups consisted of librarians working in mental health academic institutions or hospitals, researchers, educators, and practitioners. One of these focus groups was held at a conference of health information professionals and the other two were conducted at universities. Results of these focus groups are currently being reviewed using Dedoose, an online qualitative data analysis tool. It is anticipated that these results will be published in 2018. A poster documenting this process and initial findings was presented at the annual meeting of the American Psychological Association and can be found at

http://escholarship.umassmed.edu/lib_articles/202/.

While the focus groups helped the project team understand need, an online survey was also created and distributed to experts in mental and physical health seeking input of best practices in website formatting, navigation and content. A 64-question survey was designed using RedCAP, an online survey

and database application. The initial design of the survey was based upon a validated tool entitled the DISCERN survey, which was designed to evaluate web sites created for our target population. Additional questions were developed based on design and format elements that would be vital to address as part of this project. 68 responses were received. Highlighted findings from this survey can be found in a poster discussing this project that was presented at the annual meeting of the Medical Library Association in Seattle, Washington in May of 2017. The full text of the poster can be found at http://escholarship.umassmed.edu/lib_articles/199/.

In late 2017 - early 2018, this project will enter the design phase. By mid-2018, it is anticipated that we will initiate usability testing with potential users, these being groups similar to those that participated in the focus groups and the survey. The site will be launched by the fall of 2018 and marketing and training efforts will get underway.

References

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