

To: SI 405 Instructional Team

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Subject: U-M Precision Health External Research Report

Stakeholder Analysis

U-M Precision Health has numerous stakeholders we need to be considering while planning and executing our project. The main users of the U-M Precision Health website include Precision Health researchers and the general public. Researchers, mainly graduate students, go to the website to find tools and data about specific projects, as well as to find collaborators to aid them in future research projects. The general public uses the site to gather information about what U-M Precision Health does, its projects, and ways in which they can get involved. Another stakeholder that U-M Precision Health is trying to target more directly is the participants of the studies. Participants are an integral part of the aforementioned research projects, but as it stands now, the site doesn't provide these participants with as many resources as it could. One of our client's goals with this project is to provide access to patient-specific information in a user-friendly way.

After speaking with our client during our second meeting, we were reminded that other important stakeholders to keep in mind include schools that work with and help fund U-M Precision Health (Pharmacy and Medical Schools), partnering organizations (Medical School Data Office, Central Biorepository, Institute for Social Research), precision health members, University of Michigan deans and department heads, and potential donors. While these groups may not be the primary users of the site, they are still important to take into consideration. Funding schools and potential donors are looking for U-M Precision Health to succeed, as they have already or plan to donate money in order to fund the research projects. Partnering organizations, precision health members, and university deans and department heads are looking for U-M Precision Health to make an impact on the broader community, public health, and to find innovative solutions to existing problems. While these stakeholders don't necessarily use U-M Precision Health's website as often as our primary users, meeting their needs is still fundamental to the organization's success.

Competitive Analysis

U-M Precision Health's main competitors include other precision health organizations at different universities, specifically those who speak at the [Precision Medicine World Conference](#).

With for-profit companies, healthy competition drives up quality and drives down costs. Similarly, this kind of competition can exist among non-profits. Theoretically, if donors have multiple nonprofits to choose from, they will donate to the one that is the "best." However, competition among nonprofits isn't always as beneficial as it is to for-profit companies. This is because "instead of feeling pressure to create better and better products, [nonprofits] worry that [they] may not be able to provide a product or service at all ... If donors and volunteers are spreading their time and energy across multiple organizations with the same mission, nonprofits might not be able to continue certain programs" (Creal). U-M Precision health also relies on external funding and donations, so it's important for us to take note of what similar organizations promote and focus on in order to be able to better emphasize what makes U-M Precision Health unique and most deserving of donations and funding.

Additionally, since one of our main goals is to support U-M Precision Health's researchers and patients, we can use our competitive analysis to surface the things that our competitors do well to support these stakeholders, so as not to reinvent the wheel and to learn from what's working already. Additionally, since our project revolves around redesigning the U-M Precision Health website, we will be focusing our analysis on the ways in which our competitors present themselves through their own websites.

Competitive Analysis

Competitor	Mission Statement	Resources for Researchers	Resources for Patients	Access to General Information	Standout Website Features
Precision Medicine at UCSF	[On Home Page] "UCSF's vision is to fulfill the promise of precision medicine by pioneering a knowledge network that yields the seeds for new discoveries, better outcomes, and greater value and equity to improve health for all."	No obvious resources for researchers. Lots of links to other UCSF health departments that <i>do</i> have resources for researchers.	Only descriptions of their programs but no resources for how to participate or information for current participants.	Homepage provides clear mission statement, event listings, and recent news.	Minimal scrolling required on each page. Home page has a clear mission statement. Clearly segmented navigation.
Duke Center for Applied Genomics & Precision Medicine	[On 'About' Page] The major missions of the Center, carried out by its Programs in Applied Genomics and Programs in Precision Medicine are discovery research, implementation science, and outcomes and education.	Second tab in navigation is clearly labeled as 'Researchers' Provides a listing of research programs with links to each.	'Resources for Patients' is listed on the 'Education' page and includes information about 'Advocacy,' 'Data Sharing,' and 'Family History.'	'Resources for the Public' is listed under the 'Education' tab and includes ways to learn about precision medicine, how to access precision medicine programs at duke, and resources for patients.	Clearest navigation of all four sites. Very well-sorted and labeled content.
University of Pittsburgh & UPMC Institute for Precision Medicine	[On Home Page] "The IPM facilitates the movement of biomedical research into personalized clinical care. The over-arching goal is to help researchers and clinicians discover and exploit clinically actionable individual features about risk of disease, optimal treatment, disease course, and response to treatment."	Provides brief descriptions of just a few research initiatives, no actual resources for researchers. Briefly mentions that their UPMC Genome Center can be used for 'research needs.'	Provides an external link to their Genome Center that separately provides some clinical services to patients.	Very little content with information for the general public. Some brief paragraphs and videos.	Lots of videos break up the text content.
Stanford Precision Health	[On Home Page] "Precision Health reimagines medicine to focus on predicting, preventing, and curing disease precisely. Marrying two seemingly different approaches — high-tech and high-touch — this Stanford Medicine vision tailors health care to the unique biology and life circumstances of each individual, with an emphasis on catching disease before it strikes. Precision Health represents a fundamental shift to more proactive and personalized care that empowers people to lead healthy lives."	Extensive resources for researchers including funding opportunities, professional training, a research center directory, and more.	Extensive resources for patients. First tab in navigation is labeled as 'Health Care' and is broken into two sections: 'Find a Doctor' and 'Clinics and Services.'	Very little content specific to the Precision Health department. Most links navigate to the main, Stanford Medicine site.	Cool use of grid on the home page. Clear and detailed navigation. Clear mission statement on home page.

Subject Matter Interview

Our group had the opportunity to interview Dr. Colin Halverson as our subject matter expert. In 2017, Dr. Halverson received his PhD in (Linguistic) Anthropology from the University of Chicago where he also received his MA in Social Sciences in 2010. He is currently an Assistant Professor of Medicine at the Indiana University School of Medicine where he specializes in the bioethics of precision health. Within his research, he broadly focuses on bioethics, medical anthropology and the history and philosophy of science with focuses in medical and cancer genetics, communication of risk and uncertainty, and patient education. His focus on ethics provides us with a unique perspective into the considerations precision health researchers should keep in mind when working with patients.

Throughout our interview, we inquired about the current state and public sentiment regarding precision health as well as the future of the industry. Dr. Halverson shared that currently, the field primarily focuses on genetics, however there is a clear potential for growth surrounding actionable issues which are not being addressed as the emphasis remains on genetics. Focusing attention on these other issues would “have greater potential to affect greater numbers of individuals’ health” (Halverson). He mentioned that although many are unaware of what precision health is, those who do are very enthusiastic about all it has to offer.

Looking into the next five to ten years of precision health and its related fields, Halverson sees a more fully integrated system within mainstream healthcare. There will be an increase in targeted genetic tests ordered by primary care physicians with the inclusion of “streamlined algorithmic interpretation and explanations” of results (Halverson). That being said, he imagines there will be an uptake in “inappropriate” ordering for patients whether they be unnecessary or excessive orders.

Dr. Halverson explored the patient perspective of enrolling in and receiving results from a biobank. In response to this and an array of his research into the field, he shared important ethical considerations and questions for precision health researchers to keep in mind and consider when working with patients. He brought up the idea of “how to consent and whether to return.” He strongly supports the idea that less is more and that there are multiple questions to consider when working with patients including “whether inundating patients with results is frightening” and also understanding what the role of medicine and research is within this field.

Throughout our interview with Dr. Halverson, we were able to explore the current and future states of precision health and understand the unique and important perspective of the role bioethics plays within the industry.

Works Cited

Creal, Spencer. "Why Competition in the Nonprofit Sector is Frustrating." Nonprofit Hub, 15 Nov. 2017,
<https://nonprofithub.org/starting-a-nonprofit/strange-and-frustrating-competition-of-non-profit-sector/>.

Duke Center for Applied Genomics & Precision Medicine, <https://precisionmedicine.duke.edu/>.

Precision Medicine at UCSF, <https://precisionmedicine.ucsf.edu/>.

Stanford Medicine Precision Health, <http://med.stanford.edu/precisionhealth.html>.

The Institute for Precision Medicine (IPM), <https://ipm.pitt.edu/>.