Medicine and Identity

Genomics Salon, July 14, 2016, 4:30pm (Foege S-110)
https://genomicssalon.wordpress.com/
Jolie Carlisle and Hugh Haddox

Upcoming events:
Thursday, August 4 2016
Biotechnology and the rhetoric of change (Foege S-110)

*** To limit email traffic on department lists, announcements and reminders about the genomics salon will be sent through the UW genomics salon google group. ***
To join, go to https://groups.google.com/forum/#!forum/uw-genomics-salon

Medicine is suffering from a "one-size-treat-all" treatment strategy. A desire for better treatment options has generated initiatives to develop medicines for demographic groups based on characteristics like race, sex, and age. This session will examine the pros and cons of such approaches and how culture has influenced the design of clinical trials. It will also examine the potential to use genetic information from individual patients to design personalized medical treatments: where has this approach been successful and what obstacles stand in its way?

Discussion point #1: How has culture influenced clinical trial design?

It is assumed that the results of a clinical trial performed on a set of individuals can lead to generalizable conclusions that can be applied to most people, but when is this assumption inappropriate? Historically, most clinical trials have been performed on white, middle-aged males. Is it reasonable that these results can be extended to other genders, ages, and races? In recent years, cultural shifts have informed scientific policy changes concerning representation in clinical studies. Funding for clinical studies is often contingent on the inclusion of diversity and the investigation of potential differences in treatment response between groups. However, accomplishing these goals is often dependent on the formation of categories which may not reflect reliable genetic distinctions. Although biological differences are strongly associated with sex and age, the relevance of race is less clear. Race is not a biological term. There is more genetic variation within racial groups than across them. Is there a responsible way to utilize categories to create diverse clinical trials?

Discussion point #2: What are the challenges for personalized medicine?

Using genetics to tailor medical treatments to individual patients has greatly improved our ability to treat diseases like cancer and cystic fibrosis. As scientists uncover more genetic determinants of disease, the window for personalized medicine is broadening. However, this approach also faces a variety of challenges. Many medical doctors were trained before the human genome was sequenced and lack the expertise to interpret and communicate genetic data with patients, creating a need for trained medical geneticists. Although personalized medicine is likely to provide the most effective treatments, how much will higher costs of treatments and research and development impede progress on this front?

Further reading/viewing

Dorothy Roberts "**The problem with race-based medicine**" *TED talk* (March 2016)
https://www.youtube.com/watch?v=KxLMjn4WPBY
"[Race] is a crude but convenient proxy for more important factors, like muscle mass, enzyme level, genetic traits [doctors] just don't have time to look for. But race is a bad proxy. In many cases race adds no relevant information at all; it's just a distraction."

Cynthia Graber "**The problem with precision medicine**" *The New Yorker* (February 2015)
http://www.newyorker.com/tech/elements/problem-precision-medicine
"As scientists continue to draw connections between DNA data and health outcomes, the problem of interpretability continues to grow. Many doctors are simply not qualified to make sense of genetic tests, or to communicate the results accurately to their patients."

Gina Kolata "**A path for precision medicine**" *The New York Times* (February 2015)
http://www.nytimes.com/2015/02/03/health/a-path-for-precision-medicine.html?_r=0
"Some patients have already benefited as doctors discover genes driving their tumor's growth and prescribe drugs aimed at those genes."

Nicholas J. Schork "**Personalized medicine: Time for one-person trials**" *Nature Comment* (April 2015)
http://www.nature.com/news/personalized-medicine-time-for-one-person-trials-1.17411
"Every day, millions of people are taking medications that will not help them. The top ten highest-grossing drugs in the United States help between 1 in 25 and 1 in 4 of the people who take them."

Howard Brody and Linda Hunt "**BiDil: Assessing a Race-Based Pharmaceutical**" *Annals of Family Medicine* (November 2006)
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1687161/
"Race as a biological-medical construct is increasingly controversial; BiDil offers a good example of how sociocultural factors in disease causation may be overlooked as a result of an overly simplistic assumption of a racial and hence presumed genetic difference."

Angus Chen "**Is It Time To Stop Using Race In Medical Research?**" *National Public Radio* (February 2016)
http://www.npr.org/sections/health-shots/2016/02/05/465616472/is-it-time-to-stop-using-race-in-medical-research
"The NIH guidelines require the use of race in recruiting research subjects. There's a history of advocating for that in order to increase the participation of minorities in clinical research. Then it gets confusing, because the researchers continue to use these categories in conducting the research."

Michael Yudell "**Taking Race out of Human Genetics**" *Science* (February 2016)
http://science.sciencemag.org/content/351/6273/564.full
"It is important to distinguish ancestry from a taxonomic notion such as race. Ancestry is a process-based concept, a statement about an individual's relationship to other individuals in their genealogical history; thus, it is a very personal understanding of one's genomic heritage."

Michelle Llamas "**How the FDA let women down**" *Drug Watch*
https://www.drugwatch.com/fda-let-women-down/
"According to the FDA's Office of Women's Health, females have nearly double the risk of developing an adverse drug reaction compared to men. Yet, for decades, women were underrepresented in clinical trials, and the FDA didn't start looking into the problem of gender equality in studies until the late 1990s."