MS Mosaic: First Steps (and Stumbles) Toward a Patient-Centered Mobile Platform for Multiple Sclerosis Research and Care

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Background and Objective

MS Mosaic is a longitudinal study (NCT02845635) designed to gather a robust dataset describing the experience of multiple sclerosis and then utilize novel machine learning techniques to discover hidden subpopulations, evaluate treatment response, and predict clinical course. Initial study emphasis was placed on characterizing the seemingly random symptoms of multiple sclerosis. The research team therefore developed a mobile application that collects daily symptom and medication data, weekly study tasks, and continuous physiologic data, from multiple sclerosis patients. While the investigators believe this patient-centered approach is best, significant challenges to this approach exist that must be addressed.

Development History, Challenges, and Lessons Learned

Initial planning for MS Mosaic began in March 2015. Significant time was committed to drafting an IRB protocol and receiving approval, as well as identifying and finalizing agreements with the study's mobile and website developers. Subsequent app and website development and testing required sixteen months and approximately eighty pages of original content. Given the sensitivity of the study's data and the investigators' desire to restrict access exclusively to Mosaic research team members, securing a data storage vendor willing to assume liability, and thus sign an agreement with our institution for the mobile app "back end", has proven especially challenging. From this experience, the investigators recommend early identification of the mobile development partner to inform the IRB protocol, recruit future study subjects in application design, and halt application development after initial test build completion until all legal agreements and IRB protocols are approved.

Planned Analyses and Near-Future Directions

Given the significant effort and challenges facing the team's preferred approach to patient-centered research, MS Mosaic is only now about to launch. Initial focus will be on improving symptom characterization through a Bayesian generative hierarchical model that uses a Dirichlet process at a higher level and then represents the observed data at a lower level, providing a particular patient's group memberships. With this approach, we can also forecast symptom change, which we hope to one day incorporate into the mobile platform. A supplemental approach to symptom sub-typing under review is leveraging our companion community building initiative, Mosaic Artisans, for the provision of labels in supervised classification, via a recurrent neural network. Concurrent with symptom characterization, the investigators will launch a sub-study, Mosaic Tesserae, whose aim is to incorporate MRI data into models for relapse characterization, and the development of joint mobile and imaging models. We begin with MRI feature exploration. Of particular interest to MS are features that identify lesions from raw MRI data. Features that mark the location, size and number of lesions in a scan can be used in downstream joint models to assess a patient's overall likelihood of experiencing a relapse or of experiencing deteriorating symptoms. We will leverage recent advances from the deep learning community and employ convolutional neural networks to extract salient features from the images. Expert judgment by clinicians (as part of Mosaic Artisans) will be used to validate of our approach. Joint modeling can then predict relapses from MRI data, or to predict MRI features leveraging mobile app data. We will also explore causal explanations for observed symptoms based on imaging data.