**What is the purpose of your project? What will you achieve?**

While research in Systematic Lupus Erythematosus (SLE) has advanced significantly over the decade, biomedical researchers are still perplexed by the complexity and varying symptoms of the disease.1 On top of this obscurity, it is not known how stress from the Covid-19 pandemic can affect the overall well-bring of lupus (SLE) patients. Initial research suggests that stressful events such as the pandemic may cause flare ups of Type 2 SLE symptoms.2

Surprisingly, the current lupus detection framework primarily relies on Type 1 SLE symptoms and fails to address Type 2 SLE symptoms that currently are the major concern for lupus patients seeking healthcare.3 Thus, with this project, we seek to improve the rheumatologist’s approach to characterizing lupus patients by studying the Type 2 SLE. Being able to define lupus endotypes using clinical characteristics and biomarkers for Type 2 SLE will eventually aid rheumatologists to offer personalized and precision-based care to patients and transform overall health and quality of life of these patients.

To accomplish this, there are two main topics we aim to study in the project. First, we will deep-dive into understanding the impact of pandemic on lupus patients, especially analyzing the roles of geography and demographic factors that may have caused or added stress during the pandemic. Second, we intend to analyze the importance of telehealth visits which has started since the pandemic. Although there was a drop from ~75% (during pandemic peak) to ~15% in these visits, studying their appropriateness based on patient’s symptoms can be extremely helpful for a better overall patient satisfaction.4 For instance, it would make more sense to schedule a telehealth visit for a patient who lives far and has no severe symptoms.

**Why is this project a valuable pursuit and who will it serve?**

The covid-19 pandemic has magnified the impact of socioeconomic status, ethnicity, age, and other factors, pushing even more researchers to study the influence of these factors on the physical and emotional health of lupus patients. Another factor that is extremely helpful and is frequently used in the healthcare system is telehealth; virtually providing patient care with a healthcare professional via a phone call or video chat. The advantages of telehealth include reduced travel time and providing patients without reliable transportation with a convenient approach to attending a clinical visit. However, it also includes disadvantages, such as loss of physical exam opportunities and difficulty connecting at the same therapeutic level, that can lead rheumatologists to miss early signs of depression or anxiety in lupus patients. Telehealth also lets patients and doctors lose the ability to perform procedures or gather immediate data from x-rays and labs. Thus, diving into telehealth statistics of lupus patients is worth the deeper analysis for overall patient satisfaction.

To support our project pursuit, we have access to data from the Lupus Foundation of America (LPA), Duke Lupus Clinic, and Lupus National Registry. Our first dataset is a part of the CovIdentify study at LPA which aims to detect coronavirus infections early by patient’s own health report. It also brings researchers more understanding of the impact of the pandemic on patients. This data allowed patients to provide their demographic details and weekly updates about their experiences, including Type 2 SLE symptoms such as widespread pain, polysymptomatic distress, physical function, medication adherence, anxiety and depression, perceived stress, and the ability to recognize positive experiences. 1701 individuals have enrolled in this study since May 2020, and 662 patients are treated in Duke Health System (DHS). This also allows us to rely on clinical informatics data provided by Duke Lupus Clinic to analyze telehealth statistics. Moreover, the rich medical data of the treated patients at DHS and patients’ reported survey outcomes in the CovIdentify study will allow us to categorize Type 1 SLE and Type 2 SLE symptoms as part of our third goal, i.e. helping researchers develop a common framework of diagnosing lupus symptoms.

**What similar work has already been done?**

Since the beginning of the pandemic, little research has been done to understand the impact of pandemic factors on patients with systemic lupus erythematosus (SLE). Ramirez, Giuseppe et al. conducted research on the infection rate of COVID-19 symptoms, as well as on the vaccine prospect for lupus patients.5 Based on their study, “in the timeframes January–April and May–December 2020, we found that among 334/518 responders, 28 had COVID-19 in 2020. And only 31% of patients with infected relatives developed COVID-19”, which indicates the impact of COVID-19 on lupus patients is non-negligible, including the risk of infection within families. However, the study also shows that lupus patients are more likely to have COVID-like symptoms, and “it might further support the hypothesis of shared mechanisms of aberrant inflammation between COVID-19 and SLE.” Further, these COVID cases were higher in the second half of the year. Furthermore, the authors imply that the willingness to vaccination increases over time with the development of counseling, while “data from this study also show that most patients with SLE are favorable to engage in public efforts including vaccination campaigns and suggests that cases of vaccine hesitancy might possibly be overcome with adequate counseling.” In general, COVID cases and symptoms are more severe among lupus patients than in healthy cohorts of the population, but on the good side, the willingness of vaccination performs better than expected before.

In another research, Pisetsky, Clowse, and Rogers6 state that type 2 SLE is harder to diagnose because of its non-inflammatory nature. The symptoms of this SLE type include fatigue and cognitive dysfunction. While the paper discusses medical approaches to detect type 2 SLE, we plan to use semi-supervised learning frameworks to identify different endotypes of Type 2 SLE. For this purpose, we plan to use the data from Duke Lupus Registry.

**Plan for the Project**

This semester, our team focuses on the understanding and analysis of the data we obtained from the Lupus Foundation of America (LPA). The dataset has 240 variables, including lupus patients’ demographic information, belief in the vaccine, and their FSS score (Fatigue Severity Scale which is a clinically relevant way to distinguish fatigue as a symptom of lupus from depression and other symptoms). First, we worked on getting a basic understanding of the data after we got the resource and discussed with our clients more technical explanations for medical terminologies. Based on their feedback, we have done several exploratory data analyses from different perspectives, including geographic and demographic information.

For the geographic information, we visualized the lupus patient’s geographic information in the map and we combined the Rural-Urban Commuting Areas (RUCA) with LPA’s data and get more insight into the relationship between lupus patients’ FSS scores and their living locations. Based on it, we further use Area Deprivation Index (ADI) to link RUCA, and we will use the linear regression to predict patients’ FSS from ADI. This can help us get more idea about the Telehealth usage. For instance, if we can find strong relationship between the ADI and FSS score, we can build model based on the data focusing on specific locations and study what self-reported symptoms by patients can imply the patient has the necessary to see the doctor in person and get further technical examinations.

For the demographic information, from the political party affiliation part, there exist significant differences among patients’ attitudes to the vaccine. Around 70% of people of the democratic party want the vaccine, and the remaining 30% people do not want the vaccine. Adversely, 70% of people in the republican party do not want the vaccine, and 30% of people want the vaccine. In our survey data, there are 40% of patients indicate them as “Independent or unaffiliated”, and 60% of them do not want to get the vaccine. This result gives our clients more insights about their target groups of people for them to encourage taking the vaccine. We also analyzed the relationships among patients’ income, their attitudes to the vaccine, their education levels, ethnicity, race, etc. These results give us more insight into removing outliers and categorizing patients effectively while building models for data analysis. For example, in the case of analyzing the impact of political party affiliation on patients’ attitudes to the vaccine, we find that 2.6% of them belong to minor parties, which is a small portion of our original data. Therefore, we remove these people to keep the data purer for further analysis. For the next step, we will use Fisher’s exact and Chi-square tests to find significant factors in our study and build models based on the processed data. This can help us to narrow down the scope and focus on specific groups of people. For example, for people in the same political party affiliation part, they could have some similar behaviors, and we can dive into their data to find whether they have similar symptom of Type 2 SLE. This approach could help us identify distinct endotypes of Type 2 SL. Furthermore, to predict patients’ attitudes to the vaccine, we plan to use logistic regression because the clinical results are binary.

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