Characterization of the Lupus Patient Experience Based on Longitudinal Patient Generated Real World Data from a Digital Health APP (HEALTH STORYLINE)

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CONTEXT

Lupus is a chronic autoimmune disease with several sub-types that can cause symptoms such as pain, fevers, rashes, and kidney problems. The heterogeneity of Lupus poses challenges for timely and accurate diagnosis, understanding flares and symptom fluctuations, and effect of the disease and treatment on the patient experience and quality of life. Digital tools are increasingly used in research and care and have become a growing source of patient reported real-world data (RWD) that can include contextual data to complement validated tools such as ePROs/digital endpoints.

METHODOLOGY

Data from Health Storylines (HSL, a disease-agnostic, publicly available self-care management app) from patients reporting a Lupus diagnosis from 2017 – 2023 were analyzed. User demographics, tool/widget data, interaction/engagement data, use of synced external devices, and qualitative analyses of free-text data are described. Patent data was gathered during user interactions with the app, which were organized into sessions. Tools are modules within the application that share information or collect data. A session is defined as the duration in which a user interacts with an in-app tool and concludes after 30 minutes of user inactivity.

OBJECTIVES

The aim of this study was to explore how data from apps can be leveraged in the study and management of patients with Lupus.

RESULTS

App utilization

The Health Storylines^{TM} app supports patients in the management of their condition(s) by offering health tracking tools, education, opportunities to connect to their circle of support for accountability and social connection, as well as opening opportunities to participate in research.

The cohort of adult patients with Lupus (self declared) described in this study are among those patients who downloaded and used the app at their own will. This organic interaction is in contrast with other therapeutic areas that have white-labeled versions of the app tailored to share or collect specific information to foster communities of patients or execute a study, that are often be developed through partnerships with patient advocacy organizations or sponsors.

Patients in the cohort: **3 029**

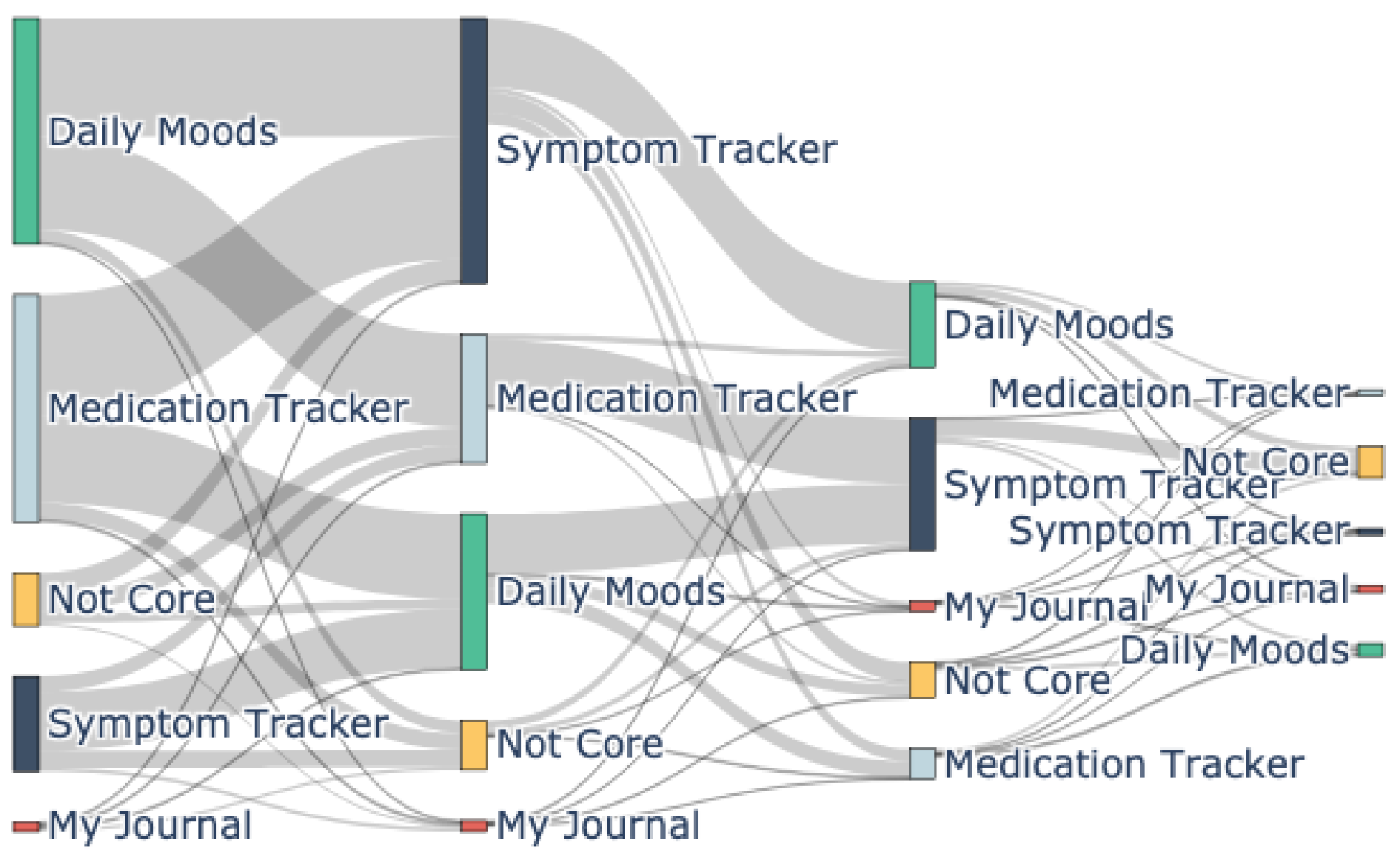
Average use of **2,9** tools

Patients who used at least one tool: **2 323**

Average use of **3,7** tools

2,323 patients used disease management tools. The most commonly reported tools were Daily moods (1,911 users), Symptom tracker (1,553 users) and Medication tracker (1,153 users).

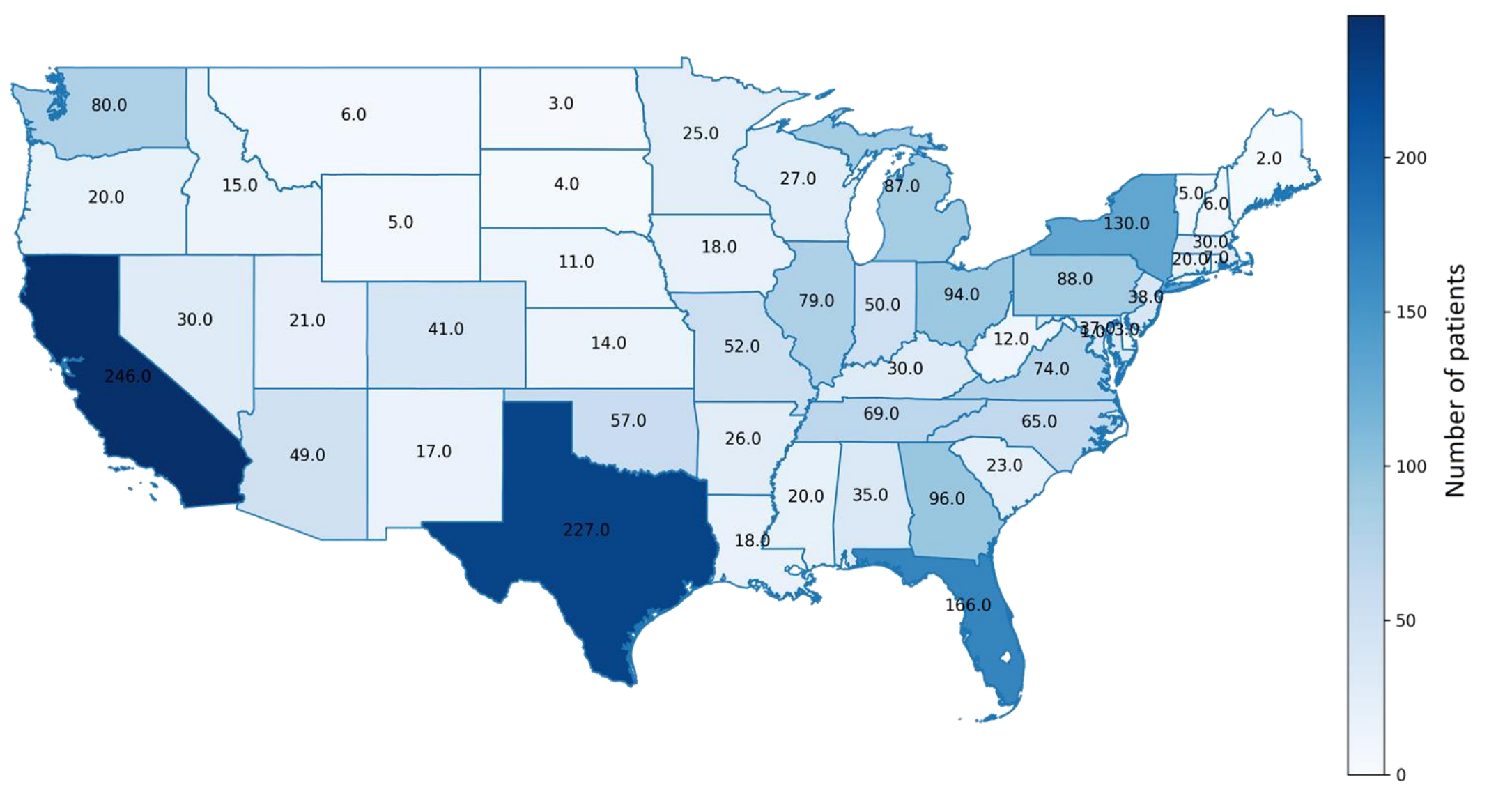
Patients' journeys observed in the application were analyzed to gain a better understanding of how patients use the application. Usage patterns of the tools during a session are presented below.



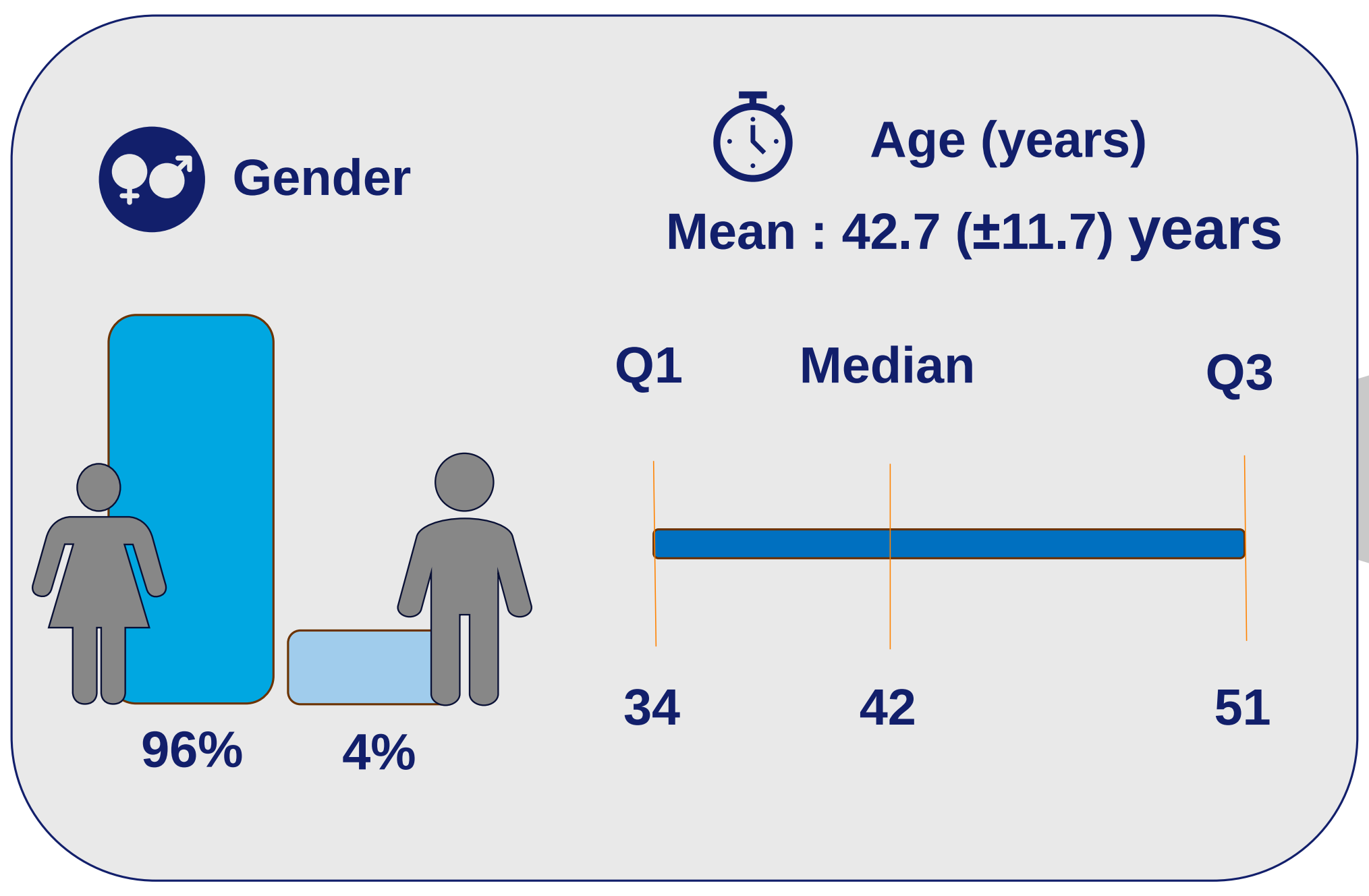
If a tool is used more than once within a session, only the **first** occurrence is considered. For sake of clarity, we grouped all the tools that must be intentionally added from a discretionary tool library into "Not Core".

Patient characteristics

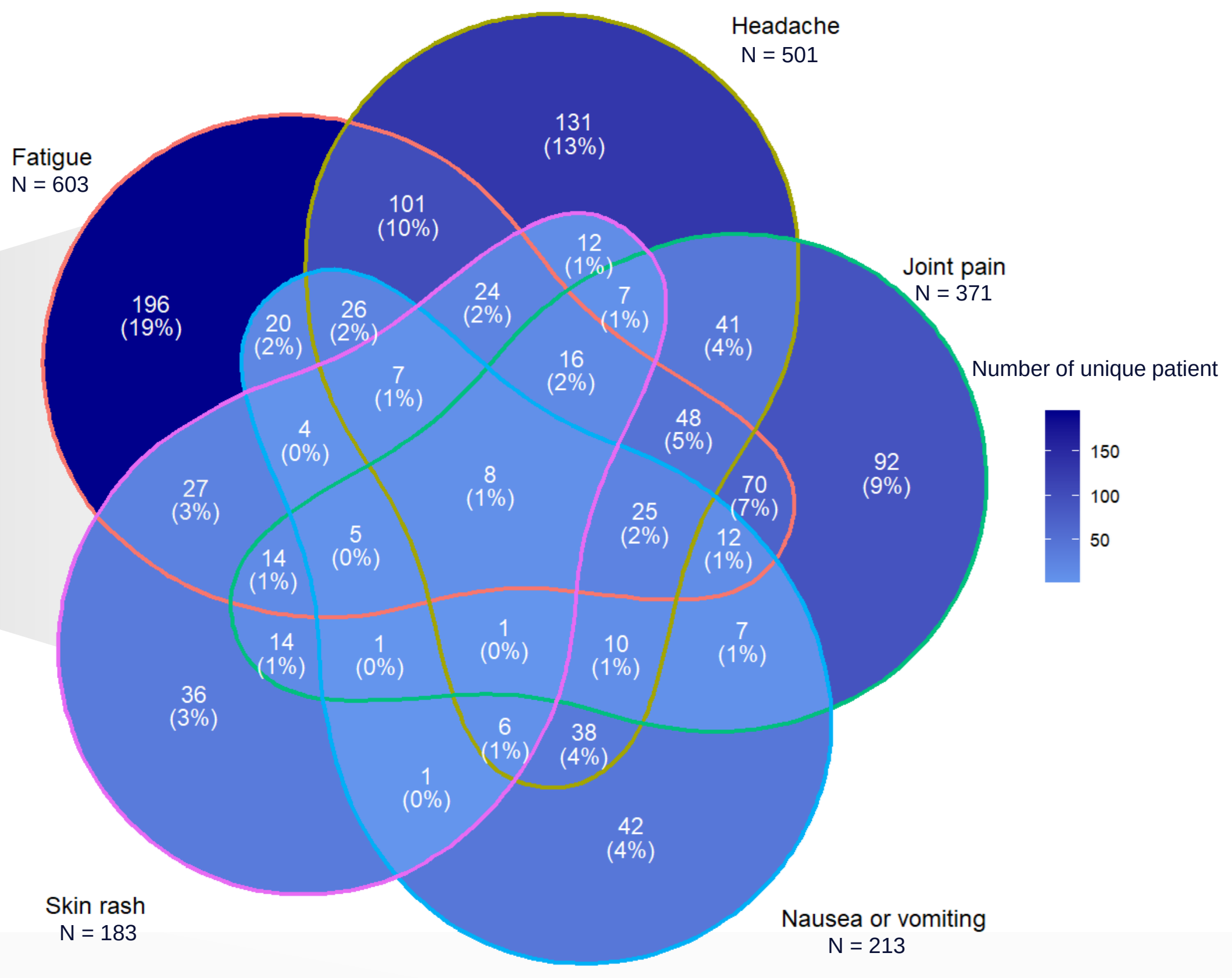
The patients were distributed across 35 different countries, with the majority situated in the United States (76%).



Patients with lupus were predominantly female (96%), with an overall average age was 42.7 years (±11.7).



Patients recorded their symptoms through the "Symptom Tracker" tool. The most frequently reported symptoms were fatigue, headaches, and joint pain (as presented in the Venn diagram).



More than 2,300 symptoms were cataloged by the users. In this figure, we have only included the 5 symptoms that were reported at least once by the largest number of patients.

Users mood

Word clouds describing « Sad mood »

Word clouds describing « Neutral mood »

Word clouds describing « Happy mood »

Word clouds describing « Frustrated mood »

Patients recorded their daily moods via the "Daily Moods" tool. The first step is to describe their emotional state by selecting a single word from a pre-defined list (such as Sad, Happy, Neutral, Frustrated, Victorious, etc.). Then, patients had the option to write a brief text to provide more detailed insights into how they felt. The word clouds represented to the left represent the most commonly reported moods. The size of the words in each word clouds represents the proportional occurrence of the word in the free text entry expanding on each selected mood.

The words "pain" and "tire" are frequently employed, reflecting the "fatigue" symptom, which is the most frequently reported.

CONCLUSION

Data from apps can generate valuable insights that help better characterize the patient experience, and decision-making drivers, symptom patterns, treatment adherence, quality of life, and impact of lifestyle factors on disease management. The common use of daily moods emphases the importance of understanding the psychosocial dimension Lupus has on patient experience. Apps can add real-time longitudinal context to enrich existing sources of patient-reported RWD, such as standardized PROs.