

Abstract

Objectives

Cardiovascular disease is the leading cause of mortality in patients with systemic lupus erythematosus. Therefore, using diet to control blood lipid levels and modify cardiovascular disease risk could be a promising therapeutic strategy to control disease symptoms. The primary objective of this study was to learn about systemic lupus erythematosus patient experiences with diet, including their opinion on considering diet as a therapeutic option. The secondary objective was to obtain this information in a cost- and time-effective manner.

Methods

A lay summary and a 15-question diet-based online survey were publicly available for 3 weeks. Social media was used to promote the survey through relevant charities, hospitals and research groups.

Results

A total of 300 responses were received, 284 from patients with systemic lupus erythematosus. Patients reported that there was a lack of clinical counselling regarding diet, with only 24% stating their doctor had spoken to them about diet. Despite this, 100% of patients stated they would change their diet if they knew it would help their symptoms and 83% would take part in a future diet-based clinical trial. Text analysis of patient research suggestions identified a particular interest in using diet to treat fatigue and manage disease flares.

Conclusions

This project successfully gathered patient information regarding diet and systemic lupus erythematosus over a short timeframe using an anonymous social media platform. The survey provided evidence that patients support further research and potential diet intervention studies investigating the effect of diet on the symptoms of systemic lupus erythematosus.

Keywords Lupus, diet, therapy, patient public involvement engagement, patient opinion, social media, survey