‘A Vision for Lupus’ report:
A US-focused addendum

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Systematic Lupus Erythematosus (SLE), or lupus, is a chronic, inflammatory, autoimmune disease that can affect many different parts of the body – including the skin, joints and multiple organs¹.

The Lupus Foundation of America (LFA) estimates that 1.5 million Americans have some form of lupus². Approximately 90% of cases are in women – most often young women³,⁴. There are more cases of lupus amongst Asians, African-Americans, African-Caribbean people, and Hispanic Americans than in Caucasians⁵,⁶,⁷. In fact, evidence suggests that lupus affects 1 in 537 young African-American women⁸.

In the United States (US), lupus is ranked amongst the top 20 leading causes of death in females⁸.

The LFA suggests that mean annual costs for people living with lupus, including direct and indirect costs, can be as much as $50,000². Evidence shows that socioeconomic-demographic, as well as behavioral and psychological, factors are a mediator of high disease activity in lupus⁹.
Awareness of lupus in the United States

Current situation

According to a survey conducted by the LFA in 2019, more than half of Americans have not heard of lupus (63%). Just 16% said they were familiar with lupus and understood its symptoms. However, 54% of African-Americans and 43% of Hispanic individuals indicated being somewhat familiar with lupus, compared with 39% of Caucasians. Most respondents did not know that minority populations tend to be disproportionately affected by lupus; and many did not know that lupus tends to affect young people. Even so, a third reported personally knowing someone who has lupus.

Of a cohort of 196 patients from the California Lupus Epidemiology Study, approximately half waited over 6 months to receive a diagnosis, with up to 32% waiting up to 1 year.

“We see a lot of ‘maybe’ cases, so we wade through patients who don’t have lupus to get to the really sick patients”
– Dr Patricia Cagnoli, Rheumatologist, University of Michigan, US.

The aim for the future: calls to action

Short-term: Build on the success of engagements with celebrities with lupus, cultivating a group of public figures who are willing to publicly talk about lupus.

Since more than half the US population do not know of lupus, there is great opportunity for public education via social media. For example, Selena Gomez’s public disclosure of her lupus diagnosis is an example of the potential success of social media engagement. Gomez’s public announcements led to increased public interest in lupus, evidenced by notable surges in the search term “What is lupus?”.

Long-term: Find sustainable ways to disseminate information gathered by lupus initiatives across the US, to ensure findings are reaching the people who could benefit from them the most.

In the US, there are numerous ongoing initiatives aiming to raise awareness, co-ordinate public health priorities, and raise the patient voice for people living with lupus. However, often only a select group of well-educated patients are involved in such initiatives; findings must be widely disseminated to reach a larger, representative population of lupus patients. This could be achieved via communication directly with physicians who are, in turn, encouraged to pass the information to their patients. For example, via conferences such as the American College of Rheumatology (ACR), ACR e-mailers, or via patient advocacy groups such as the LFA.
Service delivery for people with lupus in the United States

Current situation

Patients who receive care at a dedicated lupus clinic or from a specialist rheumatologist are more likely to receive care consistent with the SLE quality of care indicators. However, data derived from the California Lupus Epidemiology Study indicate that access to speciality care varies significantly, with racial/ethnic minorities and those with lower levels of education waiting longer to see a specialist.

Moreover, there is a maldistribution of rheumatologists with the majority practicing in metropolitan areas. The geography and transport infrastructure in the US mean people with lupus may have to travel long distances to appointments. Longer distance and time to travel to medical appointments are associated with negative outcomes, such as missed appointments, increased pressure at appointments or discontinuation of medications. Since ~25% of patients in the US receive their healthcare through a government-sponsored program like Medicare or Medicaid (according to the LFA), people may be further limited in terms of which hospitals they can attend.

“The aim for the future: calls to action

Short term: Focus on development of satellite outreach programs, with the aim of reaching patients in communities with little current access to lupus care

Lupus foundations should invest in outreach programs aiming to reach patients who may otherwise find it difficult to attend medical appointments in the city, find information about lupus, or connect with other patients. This may take the form of locally based social workers with contacts, information and resources, such as which hospitals patients can be seen at with their insurance. They may also arrange transportation to appointments or make connections with patient groups.

Long term: Encourage more doctors to become rheumatologists

According to members of the Vision for Lupus Steering Committee working in the US, there are currently not enough rheumatologists in the US to support patients beyond the big cities. This is projected to worsen, with the estimated excess demand for rheumatology providers to be over 4,000 by 2030. There should be an increased focus in the long term on encouraging medical students to pursue this rewarding speciality. Financial incentive programs such as scholarships, loans with service requirements and loan repayment have been shown to increase the number of healthcare providers in under-served areas.
Clinical research into lupus in the United States

Current situation

An online survey of 1621 people with chronic conditions, including lupus, showed a willingness to take part in trials, but a low degree of participation experience. Respondents indicated the main reason for not taking part is lack of awareness, with most patients not being invited to take part by their physicians. Common reasons for non-participation were inconvenient trial sites, concerns over side effects and eligibility criteria.

Describing their experience of recruitment and retention for a cardiovascular disease prevention trial in patients with lupus, one research team described a lack of enthusiasm among clinicians and patients to participate. Both parties cited concerns over randomization and health status, and many patients did not want to take additional medication or felt they were too ill to participate.

Clinical trial participants should represent the patients who will receive the medical product; people of different ages, races and ethnicities may respond differently to the products being tested. However, racial/ethnic minorities are often under-represented in clinical research, which is concerning for conditions like lupus, for which minority populations tend to be disproportionately affected.

The aim for the future: calls to action

Short term: Raise awareness of ongoing clinical trials to facilitate access to research participation enabling people with lupus to make autonomous decisions in the management of their condition.

Awareness around the importance of clinical research and current opportunities is vital to encourage greater trial participation. This may take the form of education provided by patient advocates who have first-hand experience with clinical trials. Physicians could encourage patients to participate in registries / symptom libraries, so they become more comfortable with the concept of research and are more open to participating in clinical trials. Patient advocacy groups can also play a role in advertising clinical trial research opportunities.

Long-term: Focus on improving participation of minority populations in clinical trials

Patient participation is key to furthering understanding of lupus and improving diagnosis and treatment; however, racial/ethnic minorities are not adequately represented in lupus clinical research. It is important to understand the underlying reasons for this imbalance, and work to encourage change. For example, through encouragement by trusted physicians, especially if they belong to a minority group; through culturally relevant and transparent communication to enable individuals to make an informed decision, including details of the study in language that is appropriate to the community; and through strengthening of trust in the health care system in general.
References
1. Lupus Foundation of America. What is lupus? Available at: https://www.lupus.org/resources/what-is-lupus (Last accessed September 2019)