

2018 World Lupus Day Survey

Key Survey Findings

Background

Since 2004, lupus organisations around the globe have conducted activities on 10th May to raise awareness and educate the public about the symptoms and health effects of lupus.¹

Thursday 10th May 2018 marks the 15th World Lupus Day, a global awareness day which serves to unite people affected by the disease and lupus organizations around the world for the common purpose of raising awareness of this disabling and potentially fatal autoimmune disease.¹ GSK are committed to supporting the World Lupus Federation (WLF) to raise awareness of this disease and improve the lives of patients.

The 2018 World Lupus Day Survey has been conducted to:

1. Assess levels of awareness and understanding of lupus across the world
2. Highlight common misconceptions and the stigmatisation of lupus patients
3. Support the lupus community around the official World Lupus Day campaign

Key external introductory messages

1. Thursday 10th May marks the 15th World Lupus Day, an annual event supported by the [World Lupus Federation](#), a coalition of patient organizations united to improve lupus sufferers' quality of life.¹
2. As part of World Lupus Day, the World Lupus Federation are urging individuals to show their support by signing a [petition](#) urging the World Health Organization to make lupus an international health priority and ensure that people with lupus around the world are diagnosed and treated effectively.²
3. Systemic lupus erythematosus is the most common form of lupus³, whereby the body's immune system wrongly identifies healthy tissue and organs as foreign invaders and attacks them.⁴ It is a chronic autoimmune disease that can result in inflammation and organ damage over time.⁵
4. Although people with lupus may have a variety of different symptoms, some of the most common include extreme fatigue, painful or swollen joints (arthritis), unexplained fever, skin rashes and kidney problems.⁴
5. As lupus is such a highly complex and individualised disease, there are many challenges associated with the diagnosis and effective management of the condition.^{3,6}
6. Key challenges facing the lupus community include the low level of public understanding and common misconceptions of the disease, which has been highlighted by a recent global survey.⁷
7. The survey has provided new and insightful data which illustrates that there is a need to educate the general public about the disease to increase understanding, dispel myths and tackle the stigma surrounding lupus.

Key survey findings⁷

At least five million people worldwide have a form of lupus.³ It is a debilitating disease with symptoms affecting every aspect of the lives of those with the condition.³ It has no geographical boundaries, affecting people of all nationalities, races, ethnicities, genders and ages.²

- The World Lupus Federation expanded on a disease awareness survey conducted in 2016 to assess public opinion of lupus; this year a larger number of respondents answered question 1.* (Question 1: ‘When you hear the term ‘lupus’ – what do you think it is?)
- Despite the fact that lupus is a global health problem, more than half (51%) of survey respondents across the world were not aware that lupus is a disease.

The cause of lupus is believed to be in response to a combination of factors both inside and outside the body, including hormones, genetics, and environment.⁸ It is not contagious, you cannot “catch” lupus from someone or “give” lupus to someone.^{4,8}

Despite this, of those people who were aware that lupus is a disease:

- 1 in 10 (11%) respondents believed that unprotected sex might contribute to the development of lupus.

Lupus has been found to have a severe impact on a person’s self-esteem and physical and social functioning.⁹

- In 2017, the WLF conducted a twitter poll among 12 patient groups and found that almost half (43%) of people living with lupus indicated that they worry the most about physical inactivity and social isolation due to the debilitating effects the disease has on the body.¹⁰

The lack of understanding of the condition is contributing to the stigmatization of lupus patients, leaving people with lupus feeling isolated.⁹

Of those people who were aware that lupus is a disease:

- Only 57% were very comfortable or comfortable **hugging** someone with lupus.
- 49% were very comfortable or comfortable **sharing food** with someone with lupus.

Level of comfort interacting socially with someone with lupus increased with age.

Of those people who were aware that lupus is a disease:

- Almost 40% (37%) of people over the age of 55 reported being very comfortable sharing food with someone with lupus, compared to just 1 in 4 (25%) people aged 18-24.
- Just 1 in 3 (33%) people aged 18-24 reported being very comfortable hugging someone with lupus, compared to 43% of people over 55.

Out of all the lupus complications, respondents were most familiar with kidney failure as a complication of having lupus. The reason for the increased statistic could be attributed to celebrities like Selena Gomez speaking out about certain aspects of the disease and shining a spotlight on lupus amongst the general public.

Of those people who were aware that lupus is a disease:

- 37% of respondents said that kidney failure was a complication of having lupus.

Younger respondents were more aware of certain complications associated with lupus than older people, specifically kidney failure.

Of those people who were aware that lupus is a disease:

- More than 40% of respondents aged 18-34 (41% of 18-24, 42% 25-34) were aware that kidney failure can be a complication of lupus, which could be because of greater exposure to discussions on social media.
- Almost half (48%) of all survey respondents over the age of 55 did not know any complications associated with lupus.

It is clear that there is a need to increase understanding of lupus to prevent misconceptions, tackle the stigma and help to encourage social integration for those living with the disease.

- In this survey, almost 8 out of 10 (76%) respondents thought that more should be done to highlight and explain to the general public the impact lupus has on patients.
- 65% of respondents felt that the best way to increase awareness and understanding of lupus is by sharing more information online, on social media and via traditional media.

This call to action is supported by The World Lupus Federation who aims to raise awareness of lupus, bring global recognition of its life-changing impact and elevate lupus on the world's healthcare agenda.¹¹

***Q1: When you hear the term 'lupus' – what do you think it is?**

- **Number of respondents (2016) = 18,459**
- **Number of respondents (2018) = 35,506**

Country trends

In Brazil and the USA, there is a correlation between the level of understanding and adults being comfortable engaging in social activities with people with lupus. The correlation suggests that high levels of understanding can reduce misconceptions about the disease.

Brazil

There were high levels of understanding in Brazil compared to rest of the data set:

- 43% knew that lupus could cause kidney failure.
- 69% said that defective genes could contribute to someone developing lupus.
- More than 50% of Brazilians are very comfortable hugging (55%), shaking hands (57%) and sitting next to someone on a bus who has lupus (58%).

Across all Brazilians who completed the survey:

- 93% of Brazilians said more should be done to highlight and explain to the general public the impact lupus has on patients – suggesting they believe disease awareness is important.

USA

In the USA, there were high levels of understanding about what can cause lupus and which parts of the body it affects compared to rest of the data set:

- 64% of people said defective genes could contribute to someone developing lupus.
- 45% knew that lupus could cause kidney failure.

- People in the USA were also comfortable taking part in social activities with someone who has lupus; 70% were very comfortable or comfortable hugging someone with lupus and 73% were very comfortable or comfortable shaking hands with a person with lupus.

General points of interest

- Lupus was believed to be more common than cystic fibrosis, viral meningitis and Crohn's disease in Australia (35%), Brazil (46%), Spain (31%) and the USA (39%). In Indonesia, 46% of people said lupus was the most common disease however, an equal number of respondents (46%) thought that viral meningitis was the most common disease.
- In Japan, 50% of people knew kidney failure could be a complication of lupus (the highest percentage in the data set), however 28% believed unprotected sex could contribute to the development of the disease.
- In Australia (56%), Canada (62%) UK (57%) and the USA (67%) more than 50% of people surveyed said lupus could affect the joints – in all other countries the majority of people thought it affected the skin.
- More than 85% of people in Brazil (93%) and Indonesia (88%) think more should be done to raise awareness of lupus among the general public.
- The thoughts on how to raise awareness of lupus were consistent among all countries.

About the Survey Data

- An online, nine-question public opinion survey was conducted by Yolo Communications for GSK and involved adults from 16 countries from across the world.
- The 2018 World Lupus Day Survey generated 35,506 respondents over the age of 18
 - Question 1 was answered by 35,506 adults.*
 - Questions 3-7 were answered by 16,814 adults* (1000+ from each country) who were aware that lupus is a disease.
 - Questions 8-9 were answered by approx. 20,191 adults* (1000+ from each country who were aware that lupus is a disease and 200+ from each country who were not aware that lupus is a disease).
 - 16,814 who were aware that lupus is a disease*
 - 3,377 who were not aware lupus is a disease*
 - The market research company capped the number of respondents progressing to questions 8&9 at approx. 200 per market for those who were not aware lupus is a disease.

**people without lupus*

A full data report is available upon request. Please contact Duane Peters at peters@lupus.org.

About the World Lupus Federation

The World Lupus Federation (WLF) is a coalition of approximately 250 lupus patient organizations from around the world, united to improve the quality of life for all people affected by lupus. Through coordinated efforts among its global affiliates, the Federation works to create greater awareness and understanding of lupus, provide education and services to people living with the disease, and advocate on their behalf.

References

- ¹ World Lupus Day. About us. Available at: <http://www.worldlupusday.org/about-us.html> Last accessed March 2018
- ² World Lupus Day. World Lupus Day 2018. Available at: <http://www.worldlupusday.org/index.html> Last accessed March 2018
- ³ Lupus Foundation of America. Statistics on Lupus. Available at: <https://resources.lupus.org/entry/facts-and-statistics> Last accessed March 2018
- ⁴ NIH National Institute of Arthritis and Musculoskeletal Diseases. Handout on health: systemic lupus erythematosus. Available at: http://www.niams.nih.gov/Health_Info/Lupus/. Last accessed March 2018
- ⁵ Tsokos GC. Systemic lupus erythematosus. *N Engl J Med*. 2011;365:2110-21.
- ⁶ Zeng J, et al. Novel biomarkers for systemic lupus erythematosus. *Biomark Med*. 2017.doi: 10.2217/bmm-2016-0379. Last accessed March 2018
- ⁷ GSK 2018 World Lupus Day Survey
- ⁸ Lupus Foundation of America. Get Answers. Available at: <http://www.lupus.org/answers/entry/is-lupus-contagious> Last accessed: March 2018
- ⁹ Sutanto, B, et al. Experiences and Perspectives of Adults Living With Systemic Lupus Erythematosus: Thematic Synthesis of Qualitative Studies. *Arthritis Care & Research*. 2013; 65(11): 1752-1765.
- ¹⁰ World Lupus Federation. World Lupus Day. Available at: <http://www.worldlupusfederation.org/world-lupus-day.html> Accessed March 2018
- ¹¹ World Lupus Federation. About the WLF. Available at: <http://www.worldlupusfederation.org/about.html> Accessed March 2018