

ANALYSING GOOGLE TRENDS TO DISCERN INFORMATION NEEDS FOR CANADIANS WITH LUPUS

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BACKGROUND:

- Knowledge gaps in public awareness of SLE worsens delays
- Lupus patients perceive that there is little understanding/knowledge of their illness
- SLE patients regularly use online sources for health information¹

What is Google Trends?

Google Trends (GT) offers real-time, anonymous insights into public search interest by time and location. It tracks both search queries (exact terms entered to Google) and topics (related terms grouped by GT) which are measured by RV.

- Relative Search Volume (RV): Measures popularity on a 0–100 scale; 100 = highest interest.
- Shows top searches (most popular overtime) and rising searches (fastest growing).

Average time to SLE diagnosis in Canada¹ **47 months**



How can we use GT in lupus research?

- Analyzing public interest³
- Understanding behavioural trends related to diseases⁴
- Providing insight around information needs to key stakeholders²

OBJECTIVES:

Investigate SLE-related awareness and knowledge gaps in Canada to generate targeted interventions that integrate health disparity reduction strategies, shortening the path to diagnosis for Canadians living with SLE.

Examine Temporal Trends

Evaluate Spatial Variation

Engage in integrated knowledge translation (iKT)

METHODS:

GT data collection was guided by methodological insights from Nuti et al.'s (2014) systematic review of 70 studies, which evaluated the use of GT in health research to ensure relevance and specificity.

This research used an iKT approach, which included key stakeholders including policy makers, advocacy groups, SLE foundations/organizations, researchers, clinical experts, and patient partners.

1. National Search Interest

- Searched "lupus" and "SLE" (2004– November 2024) using the Disease topic filter.
- Identified peaks (RV >0.50) and troughs (RV <0.25) in search activity.
- Cross-referenced peaks with major news/events (Google News and key lupus milestones).

2. Sub-Regional Analysis

- Mapped top provinces/territories, and cities with the highest lupus-related search volumes.
- Collected and analyzed the top 25 overall and rising search terms and queries per region.

3. Thematic Analysis of Search Queries

- Analyzed search terms using NVIVO software.
- Themes identified both from the data and informed by literature and patient insights.

Key themes:

- Deductive: testing, symptoms, causes, gender, diagnosis, language, etc.
- Inductive: animals, celebrity, affected body parts, etc.

RESULTS:

Table 1 Examines peaks in the search term "lupus" across Canada (2004-2024). Peaks were defined as RV >0.50. Associated news events were collected by performing additional searches for "lupus, [month, year]" and investigating top hits for relevance.

Time Period	Peaks	Associated News/Events
July 2009	Peak (0.58)	GSK announces positive Phase 3 study results for Benlysta News headlines speculate that musician Michael Jackson struggled with lupus prior to his death
June 2010	Peak (0.60)	9 th International Congress on SLE held in Vancouver, BC
October 2015	Peak (1.0)	Selena Gomez announces diagnosis with lupus
August 2016	Peak (0.66)	Positive Phase II trials for voclosporin announced
September 2016	Peak (0.69)	Selena Gomez makes news headlines as she announces she is taking time off due to her lupus diagnosis Civil Servants' walk for lupus awareness in Washington, DC
September 2017	Peak (0.78)	Selena Gomez undergoes kidney transplant surgery on September 14, 2017, which she shares on social media Benlysta (belimumab) autoinjectors approved in Europe and Japan
March 2023	Peak (0.50)	Lupus Nexus study begins enrolling patients at 24 sites across the Lupus Clinical Investigators Network (LCIN)

Table 2 RV for "lupus" across Canada from 2004-2024 separated by sub-regional interest.

Rank based on population size	Region	RV for lupus
1	Ontario	78
2	Quebec	54
3	British Columbia	75
4	Alberta	77
5	Manitoba	75
6	Saskatchewan	75
7	Nova Scotia	81
8	New Brunswick	84
9	Newfoundland and Labrador	100
10	Prince Edward Island	70
11	Yukon	73
12	Northwest Territories	61
13	Nunavut	66

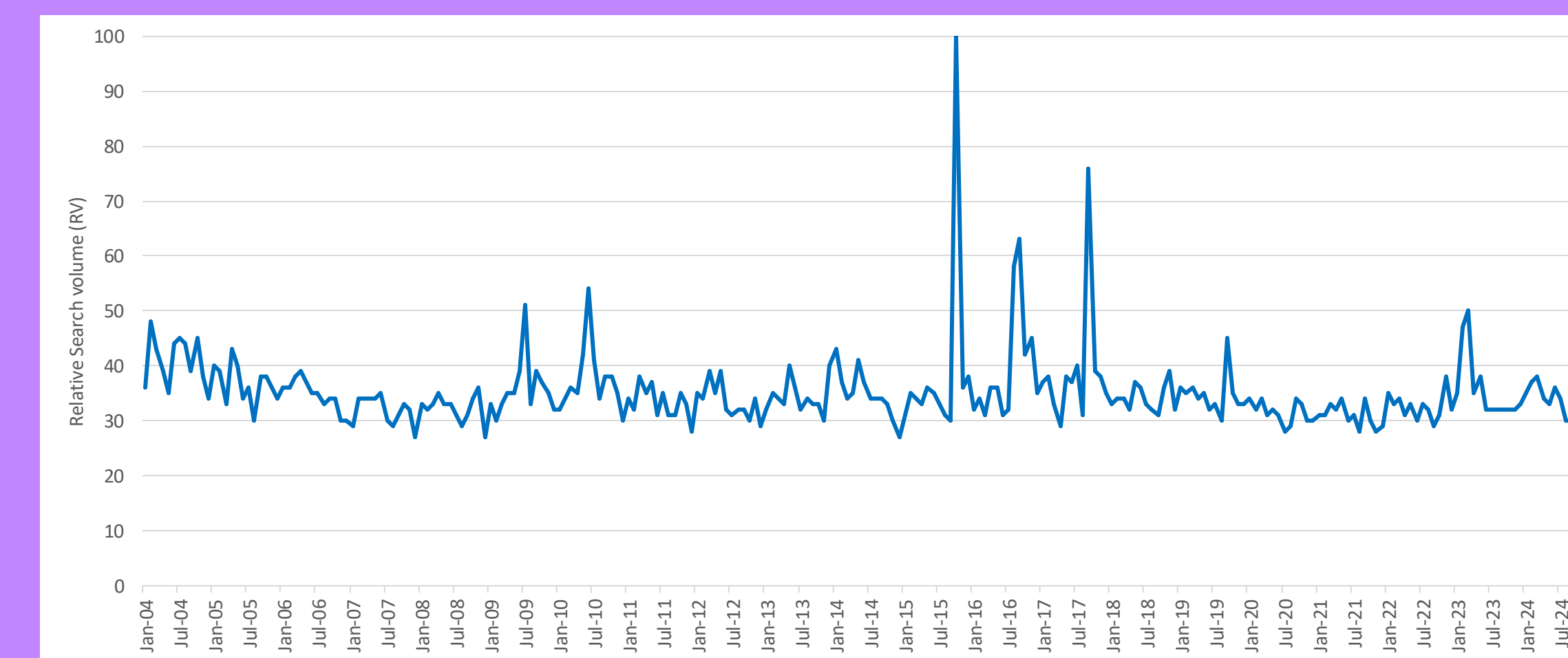


Fig. 1 Illustrates search interest in 'lupus' across Canada (Jan 2004–Nov 2024). The y-axis represents RV (0–100), with 100 marking peak interest. Key peaks align with major media events (see Table 1).

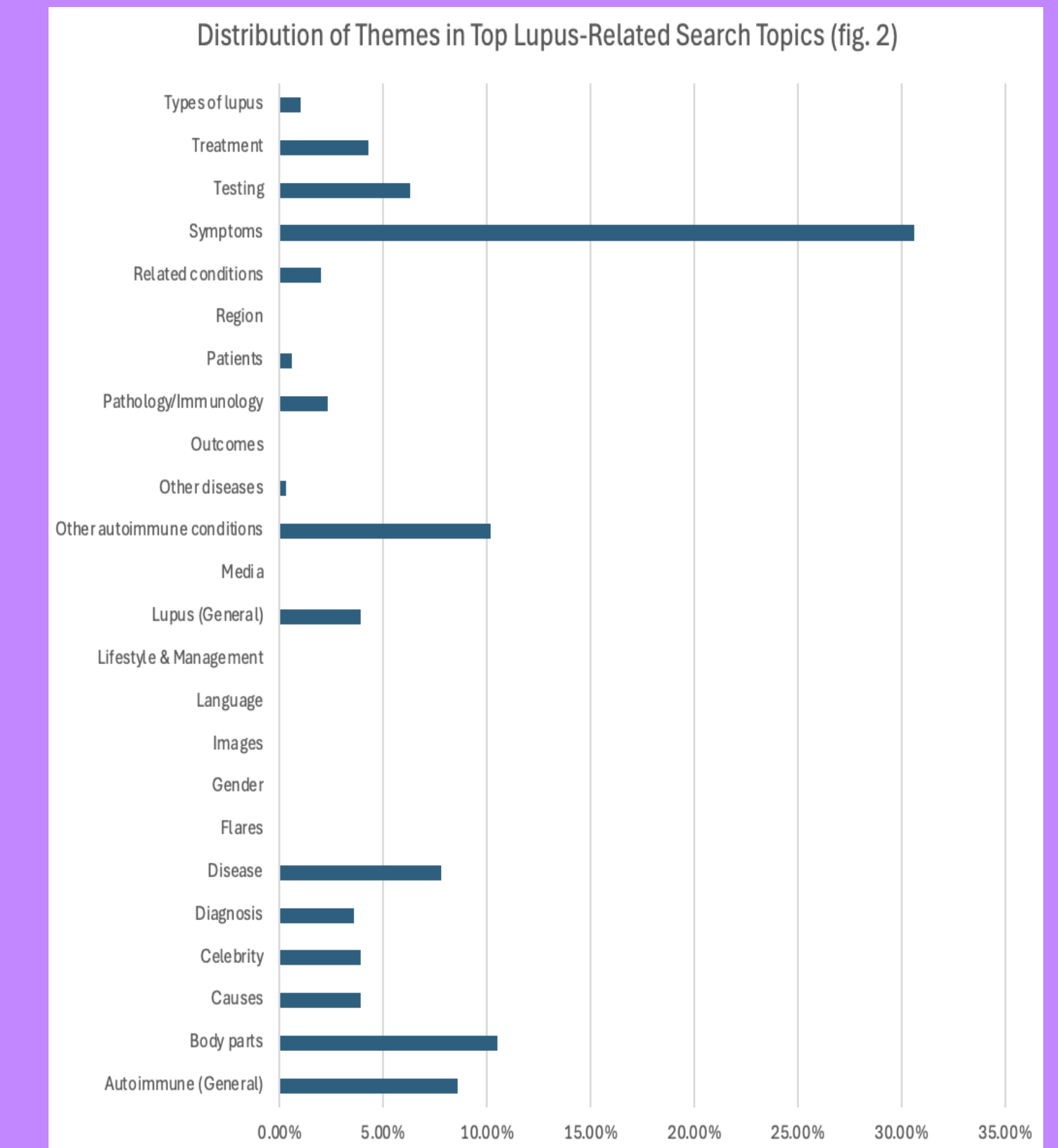


Fig. 2 presents the thematic breakdown of top "lupus" search topics in Canada from Google Trends. The x-axis shows the percentage of total coverage out of 304 terms, while the y-axis lists NVIVO-coded themes. The same method was used to analyze top/rising topics and queries, though each yielded slightly different patterns.

DISCUSSION:

Regional and Temporal Search Patterns

- Newfoundland and Labrador showed the highest search volume for "lupus" (RV=100).
- Several smaller towns also ranked highly, despite lacking active lupus advocacy organizations.
- Online engagement may reflect regional differences in awareness, lived experience, or unmet informational needs.

Thematic Insights from Search Terms

- Symptoms consistently emerged as the most searched theme, particularly in top and rising topics.
- Rising queries spiked in interest around celebrities and general lupus information, likely influenced by media coverage.

Event-Driven Search Activity

- Significant increase in search interest may not align with major milestones in the lupus community (drug trials/approvals, SLE classifications, etc).
- A peak was seen during voclosporin's Phase 2 trials, suggesting early community attention.
- The 2019 EULAR SLE criteria release did not generate significant search interest.

Limitations of Google Trends Data

- GT excludes individuals with limited internet access and those that do not use Google search engines, leading to sampling bias.
- Searches may reflect curiosity or media exposure rather than lived experience.
- Search terms can be vague or overlap with other conditions (e.g., RA vs. SLE).

NEXT STEPS:

- Results will be shared and triangulated through a deliberative dialogue with key knowledge users in the SLE community. This deliberative dialogue will take place in May 2025.
- The results will also be shared with Lupus Canada through a strategic report to develop targeted interventions that to meet patient and public education needs, and increase awareness and knowledge related to SLE across Canada.
- Next steps may include international comparison to offer additional insights.

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