



Swiss Knife Survey 2024

COUNTRY LEVEL DATA

Lithuania

For full text european analysis, please refer to:

*Cornet A., Karakikla-Mitsakou Z., Andersen J. et al. - Experiences and unmet needs of persons living with systemic lupus erythematosus in Europe: Lupus Europe's 2024 Swiss knife survey, Autoimmunity Reviews, Volume 24, Issue 8, 2025, 103838, ISSN 1568-9972,*

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### DEMOGRAPHICS:

|                              | Lithuania        | EUROPE        | Age              | Lithuania        | EUROPE        |
|------------------------------|------------------|---------------|------------------|------------------|---------------|
| Total number of responses    | 110              | 4525          | Up to 25         | 3.6%             | 5.5%          |
|                              |                  |               | 26 to 35         | 23.6%            | 15.8%         |
| <u>Gender</u>                | <u>Lithuania</u> | <u>EUROPE</u> | 36 to 45         | 25.5%            | 26.9%         |
| Man                          | 1.9%             | 4.1%          | 46 to 55         | 19.1%            | 28.0%         |
| Woman                        | 98.1%            | 95.5%         | 56 to 65         | 22.7%            | 16.0%         |
| Other / prefer not to answer | 0.0%             | 0.4%          | above 65         | 4.5%             | 6.2%          |
| Total                        | 100.0%           | 100.0%        | NA               | 0.9%             | 1.5%          |
|                              |                  |               | Grand Total      | 100.0%           | 100.0%        |
| <u>Diagnosis</u>             | <u>Lithuania</u> | <u>EUROPE</u> | <u>Diagnosis</u> | <u>Lithuania</u> | <u>EUROPE</u> |
| SLE                          | 90.0%            | 92.5%         | Lupus Nephritis  | 22.0%            | 19.5%         |
| Child onset SLE              | 10.0%            | 7.5%          | APS              | 14.7%            | 19.2%         |
| Grand Total                  | 100.0%           | 100.0%        | LN+APS           | 6.4%             | 6.2%          |
|                              |                  |               | None of the 2    | 56.9%            | 55.2%         |
|                              |                  |               | Grand Total      | 100.0%           | 100.0%        |

### BURDEN

|                                    |                  |               |   |                  |               |
|------------------------------------|------------------|---------------|---|------------------|---------------|
| <u>Lupus under control past3mo</u> | <u>Lithuania</u> | <u>EUROPE</u> | <u>Satisfied with current state</u>       | <u>Lithuania</u> | <u>EUROPE</u> |
| Yes                                | 77.3%            | 66.5%         | Yes                                       | 60.6%            | 47.6%         |
| No                                 | 22.7%            | 33.5%         | No  | 31.3%            | 47.4%         |
| n=                                 | 110              | 4360          | Prefer not to answer                      | 8.1%             | 5.0%          |
|                                    |                  |               | n=  | 99               | 3957          |
| <u>Flares over 5 years</u>         | <u>Lithuania</u> | <u>EUROPE</u> | <u>Burden</u>                             | <u>Lithuania</u> | <u>EUROPE</u> |
| A. Never                           | 8.6%             | 7.9%          | Overall burden of lupus on life           | 6.62             | 6.94          |
| B. Once                            | 7.6%             | 12.7%         | activity of disease itself                | 6.54             | 6.63          |
| C. Twice                           | 10.5%            | 11.0%         | physical conseq.of disease                | 7.00             | 7.41          |
| D. 3 or 4 times                    | 18.1%            | 13.3%         | side effects of treatment                 | 6.24             | 6.02          |
| E. Annually                        | 13.3%            | 9.7%          | fatigue                                   | 7.72             | 7.95          |
| F. Several times a year            | 28.6%            | 34.8%         | Pain                                      | 6.52             | 6.79          |
| G. Don't know                      | 13.3%            | 10.6%         | Psychological impact                      | 6.90             | 6.99          |
| n=                                 | 105              | 4124          | Social impact                             | 6.20             | 6.48          |
|                                    |                  |               | Work / education impact                   | 6.67             | 7.08          |
|                                    |                  |               | Financial impact                          | 6.70             | 6.46          |
|                                    |                  |               | 0= no burden at all / 10 = extreme burden |                  |               |

|  |                  |               |
|--|------------------|---------------|
| <u>Lupus life Experience:</u>  | <u>Lithuania</u> | <u>EUROPE</u> |
| A. Lupus very active, preventing from having an active (professional,...) life - THE most significant impact on QoL  | 4.0%             | 9.7%          |
| B. Lupus very active, major burden day in/day out. Can handle (professional,...) obligations but is THE most significant impact on QoL                               | 8.9%             | 9.5%          |
| C. Lupus quite active, significant impact on QoL, but can manage most often to have a reasonable QoL   | 9.9%             | 11.0%         |
| D. Lupus story of flares and remission, flares are frequent and impact significantly QoL   | 8.9%             | 5.5%          |
| E. Lupus story of flares and remission, flares not too frequent, Even when not flaring, side effects of lupus/medication, anxiety or fatigue are major burden on QoL | 21.8%            | 19.6%         |
| F. Lupus story of flares and remission, flares not too frequent impacting significantly QoL, when not flaring can have a good life                                   | 5.0%             | 9.1%          |
| G. Lupus rarely flaring, most often under control but anxiety, fatigue, concerns or side effects / medication are significant burden on QoL                          | 18.8%            | 16.4%         |
| H. Lupus not very aggressive, even when flaring, can live a normal life  | 8.9%             | 3.9%          |
| I. Lupus rarely flaring. Most of the time, can live a normal life  | 4.0%             | 6.5%          |
| J. Lupus in long term remission (possibly with the use of ongoing medication), so not a significant burden on QoL  | 9.9%             | 7.0%          |
| K. Prefer not to answer  | 0.0%             | 1.9%          |
| n=   | 101              | 4,057         |

### Patient Doctor Communication

| Most missing                                 | Lithuania | EUROPE |  |      |      |
|--|-----------|--------|--|------|------|
| Time   | 34.7%     | 31.6%  | Doctor takes into account my opinion         |      |      |
| Empathy                                      | 13.7%     | 14.0%  | when managing my treatment                   | 6.65 | 7.44 |
| Communication within team                    | 13.7%     | 22.3%  | I am a key contributor to Sh. Dec. Mak.      |      |      |
| Acknowledge the symptoms I mention           | 30.5%     | 22.9%  | about my treatment mngt                      | 5.97 | 6.96 |
| Personalised info                            | 13.7%     | 10.6%  | I have an active role in controlling my      |      |      |
| lay language                                 | 13.7%     | 6.4%   | disease                                      | 7.49 | 7.47 |
| An invite to ask                             | 5.3%      | 5.7%   | I have a trustful relationship with my       |      |      |
| Answers                                      | 16.8%     | 8.3%   | doctor                                       | 7.10 | 7.56 |
| Consider non measurable                      | 30.5%     | 25.0%  | I say "the truth, all the truth and only the |      |      |
| What symptoms mean for my life               | 14.7%     | 16.7%  | truth" to my HCP with regards to my          | 8.73 | 8.82 |
| Clear info on Meds                           | 29.5%     | 21.2%  | I can share all my problems with my          |      |      |
| Certainty I can talk anything                | 6.3%      | 4.3%   | doctor                                       | 7.45 | 7.71 |
| Holistic approach                            | 22.1%     | 17.9%  | My doctor takes into account my              |      |      |
| Info on Clinical Trials                      | 15.8%     | 15.5%  | psychological well-being                     | 6.40 | 6.94 |
| Nothing                                      | 14.7%     | 23.7%  |  |      |      |
| Other  | 2.1%      | 3.5%   | n=   | 113  | 3773 |
| n=   | 95        | 3,841  | 0 = fully disagree : 10 = fully agree        |      |      |
|  |           |        |  |      |      |
| Satisfaction with HealthCare team            | 6.83      | 7.33   |  |      |      |
| 0 = fully unsatisfied / 10 = fully satisfied |           |        |  |      |      |

### Unmet needs

| Unmet Needs                  | Lithuania | EUROPE | Satisfaction with treatment:        | Lithuania | EUROPE |
|------------------------------|-----------|--------|-------------------------------------|-----------|--------|
| A. effic Clinic measured     | 15.1%     | 13.9%  | A. Satisfied, AND I believe this is |           |        |
| B. Effic NON Measured sympt  | 22.1%     | 25.3%  | the best that can be achieved for   | 31.0%     | 37.1%  |
| C. reduc Steroids            | 10.5%     | 18.8%  | B. Satisfied, BUT I believe better  |           |        |
| D. Lower side Eff            | 25.6%     | 23.7%  | control could be achieved for my    | 34.5%     | 30.4%  |
| E. less fatigue              | 37.2%     | 53.2%  | C. Not satisfied, BUT I believe     |           |        |
| F. LT kidney prot.           | 16.3%     | 19.1%  | this is the best that can be        | 19.5%     | 18.4%  |
| G. Easier to take            | 10.5%     | 5.4%   | D. Not satisfied AND I believe      |           |        |
| H. Access to existing        | 12.8%     | 7.7%   | better control could be achieved    | 14.9%     | 14.2%  |
| I. Access non Pharma treatm. | 33.7%     | 32.0%  |                                     |           |        |
| J. edu & access to support   | 17.4%     | 9.5%   | n=                                  | 87        | 3503   |
| K. Financial burd            | 22.1%     | 19.8%  |                                     |           |        |
| L. Other                     | 1.2%      | 3.5%   |                                     |           |        |
| n=                           | 86        | 3,502  |                                     |           |        |

### Symptoms or Features experienced / Most bothersome

| Patient reported Symptoms or features | Lithuania            |                               |                  |                      | Lithuania                |       |
|---------------------------------------|----------------------|-------------------------------|------------------|----------------------|--------------------------|-------|
|                                       | Regularly experience | most prevent live to the full | most worry today | most worry long term | least taken into account |       |
| A.None                                | 2.2%                 | 0.0%                          | 1.1%             | 0.0%                 | A.None                   | 5.8%  |
| B.Rash                                | 39.8%                | 15.9%                         | 12.6%            | 13.8%                | B.Rash                   | 15.1% |
| C.Sun                                 | 46.2%                | 17.0%                         | 8.0%             | 10.3%                | C.Sun                    | 18.6% |
| D. Ulcers                             | 25.8%                | 4.5%                          | 2.3%             | 2.3%                 | D. Ulcers                | 5.8%  |
| E.DryEyes                             | 44.1%                | 17.0%                         | 11.5%            | 13.8%                | E.DryEyes                | 18.6% |
| F.dryskin                             | 57.0%                | 8.0%                          | 6.9%             | 4.6%                 | F.dryskin                | 17.4% |
| G.Hairloss                            | 61.3%                | 18.2%                         | 19.5%            | 19.5%                | G.Hairloss               | 29.1% |
| H. Joints                             | 66.7%                | 38.6%                         | 29.9%            | 34.5%                | H. Joints                | 9.3%  |
| I.Jaccoud                             | 10.8%                | 1.1%                          | 2.3%             | 2.3%                 | I.Jaccoud                | 3.5%  |
| J.Musclpain/weak                      | 55.9%                | 33.0%                         | 27.6%            | 18.4%                | J.Musclpain/weak         | 7.0%  |
| K. Headache                           | 47.3%                | 18.2%                         | 14.9%            | 18.4%                | K. Headache              | 8.1%  |
| L.Fatigue                             | 77.4%                | 46.6%                         | 43.7%            | 40.2%                | L.Fatigue                | 44.2% |
| M. Flu-like                           | 20.4%                | 5.7%                          | 6.9%             | 2.3%                 | M. Flu-like              | 5.8%  |
| N. Shrot Breath                       | 21.5%                | 3.4%                          | 8.0%             | 6.9%                 | N. Shrot Breath          | 1.2%  |
| O. depres/anxiety                     | 43.0%                | 17.0%                         | 18.4%            | 19.5%                | O. depres/anxiety        | 18.6% |
| P. Heamatologic                       | 16.1%                | 1.1%                          | 2.3%             | 5.7%                 | P. Heamatologic          | 2.3%  |
| Q. Raynaud                            | 19.4%                | 1.1%                          | 3.4%             | 3.4%                 | Q. Raynaud               | 4.7%  |
| R. Kidney                             | 20.4%                | 9.1%                          | 11.5%            | 16.1%                | R. Kidney                | 2.3%  |
| S. Chestpain                          | 19.4%                | 2.3%                          | 2.3%             | 1.1%                 | S. Chestpain             | 2.3%  |
| T. Hiugh, Blood Pres                  | 22.6%                | 2.3%                          | 4.6%             | 5.7%                 | T. Hiugh, Blood Pres     | 2.3%  |
| U. Cardiovasc                         | 15.1%                | 6.8%                          | 9.2%             | 6.9%                 | U. Cardiovasc            | 5.8%  |
| V. Osteoporosis                       | 25.8%                | 8.0%                          | 8.0%             | 9.2%                 | V. Osteoporosis          | 9.3%  |
| W. Brainfog                           | 26.9%                | 4.5%                          | 6.9%             | 5.7%                 | W. Brainfog              | 8.1%  |
| n=                                    | 93                   | 88                            | 87               | 87                   | n=                       | 86    |

# Symptoms or Features experienced / Most bothersome

| Patient reported Symptoms or features | EUROPE               |                               |                  |                      | EUROPE                   |       |
|---------------------------------------|----------------------|-------------------------------|------------------|----------------------|--------------------------|-------|
|                                       | Regularly experience | most prevent live to the full | most worry today | most worry long term | least taken into account |       |
| A.None                                | 1.4%                 | 2.9%                          | 3.1%             | 1.5%                 | A.None                   | 16.0% |
| B.Rash                                | 42.6%                | 9.2%                          | 8.3%             | 6.6%                 | B.Rash                   | 10.5% |
| C.Sun                                 | 60.4%                | 25.9%                         | 13.0%            | 11.0%                | C.Sun                    | 13.4% |
| D. Ulcers                             | 36.1%                | 4.4%                          | 2.7%             | 1.6%                 | D. Ulcers                | 8.6%  |
| E.DryEyes                             | 56.1%                | 10.4%                         | 7.6%             | 6.1%                 | E.DryEyes                | 14.0% |
| F.dryskin                             | 50.4%                | 3.8%                          | 2.9%             | 1.9%                 | F.dryskin                | 11.3% |
| G.Hairloss                            | 48.7%                | 10.6%                         | 12.4%            | 9.9%                 | G.Hairloss               | 22.1% |
| H. Joints                             | 72.8%                | 44.8%                         | 33.0%            | 32.3%                | H. Joints                | 8.7%  |
| I.Jaccoud                             | 9.4%                 | 3.1%                          | 3.4%             | 4.7%                 | I.Jaccoud                | 3.6%  |
| J.Musclpain/weak                      | 62.6%                | 33.5%                         | 26.2%            | 24.9%                | J.Musclpain/weak         | 11.7% |
| K. Headache                           | 49.4%                | 17.0%                         | 12.8%            | 10.3%                | K. Headache              | 8.5%  |
| L.Fatigue                             | 84.9%                | 59.0%                         | 44.7%            | 36.7%                | L.Fatigue                | 34.8% |
| M. Flu-like                           | 29.4%                | 4.5%                          | 3.3%             | 2.3%                 | M. Flu-like              | 4.0%  |
| N. Shrot Breath                       | 29.2%                | 5.6%                          | 7.5%             | 6.6%                 | N. Shrot Breath          | 4.7%  |
| O. depres/anxiety                     | 43.8%                | 13.4%                         | 16.0%            | 14.8%                | O. depres/anxiety        | 17.8% |
| P. Heamatologic                       | 23.6%                | 3.0%                          | 5.5%             | 8.4%                 | P. Heamatologic          | 2.2%  |
| Q. Raynaud                            | 35.0%                | 5.1%                          | 3.4%             | 3.1%                 | Q. Raynaud               | 5.5%  |
| R. Kidney                             | 17.0%                | 5.3%                          | 12.0%            | 22.8%                | R. Kidney                | 2.3%  |
| S. Chestpain                          | 22.7%                | 2.8%                          | 5.4%             | 4.8%                 | S. Chestpain             | 2.7%  |
| T. Hiugh, Blood Pres                  | 20.6%                | 2.4%                          | 4.7%             | 5.9%                 | T. Hiugh, Blood Pres     | 2.6%  |
| U. Cardiovasc                         | 7.7%                 | 2.8%                          | 7.3%             | 19.3%                | U. Cardiovasc            | 2.4%  |
| V. Osteoporosis                       | 17.2%                | 2.9%                          | 4.8%             | 9.1%                 | V. Osteoporosis          | 3.7%  |
| W. Brainfog                           | 41.7%                | 10.0%                         | 14.1%            | 14.5%                | W. Brainfog              | 17.5% |
| n=                                    | 3,848                | 3,584                         | 3,564            | 3,534                | n=                       | 3,397 |

Swiss Knife Survey - Country level data

DATA FOR: Lithuania

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