



Swiss Knife Survey 2024

COUNTRY LEVEL DATA

Belgium

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,
For more information, contact: secretariat@lupus-europe.org



DEMOGRAPHICS:

| | <u>Belgium</u> | <u>EUROPE</u> | <u>Age</u> | <u>Belgium</u> | <u>EUROPE</u> |
|------------------------------|----------------|---------------|------------------|----------------|---------------|
| Total number of responses | 127 | 4525 | Up to 25 | 3.9% | 5.5% |
| | | | 26 to 35 | 14.2% | 15.8% |
| Gender | <u>Belgium</u> | <u>EUROPE</u> | 36 to 45 | 27.6% | 26.9% |
| Man | 4.0% | 4.1% | 46 to 55 | 29.9% | 28.0% |
| Woman | 96.0% | 95.5% | 56 to 65 | 18.1% | 16.0% |
| Other / prefer not to answer | 0.0% | 0.4% | above 65 | 4.7% | 6.2% |
| Total | 100.0% | 100.0% | NA | 1.6% | 1.5% |
| | | | Grand Total | 100.0% | 100.0% |
| Diagnosis | <u>Belgium</u> | <u>EUROPE</u> | <u>Diagnosis</u> | <u>Belgium</u> | <u>EUROPE</u> |
| SLE | 90.6% | 92.5% | Lupus Nephritis | 18.0% | 19.5% |
| Child onset SLE | 9.4% | 7.5% | APS | 15.6% | 19.2% |
| Grand Total | 100.0% | 100.0% | LN+APS | 7.4% | 6.2% |
| | | | None of the 2 | 59.0% | 55.2% |
| | | | Grand Total | 100.0% | 100.0% |

BURDEN

| <u>Lupus under control past3mo</u> | <u>Belgium</u> | <u>EUROPE</u> | <u>Satisfied with current state</u> | <u>Belgium</u> | <u>EUROPE</u> |
|------------------------------------|----------------|---------------|-------------------------------------|----------------|---------------|
| Yes | 66.7% | 66.5% | Yes | 47.4% | 47.6% |
| No | 33.3% | 33.5% | No | 47.4% | 47.4% |
| n= | 123 | 4360 | Prefer not to answer | 5.3% | 5.0% |
| | | | n= | 114 | 3957 |
| <u>Flares over 5 years</u> | <u>Belgium</u> | <u>EUROPE</u> | <u>Burden</u> | <u>Belgium</u> | <u>EUROPE</u> |
| A. Never | 11.7% | 7.9% | Overall burden of lupus on life | 6.50 | 6.94 |
| B. Once | 14.2% | 12.7% | activity of disease itself | 6.36 | 6.63 |
| C. Twice | 11.7% | 11.0% | physical conseq.of disease | 7.33 | 7.41 |
| D. 3 or 4 times | 13.3% | 13.3% | side effects of treatment | 5.77 | 6.02 |
| E. Annually | 4.2% | 9.7% | fatigue | 7.99 | 7.95 |
| F. Several times a year | 34.2% | 34.8% | Pain | 6.72 | 6.79 |
| G. Don't know | 10.8% | 10.6% | Psychological impact | 6.97 | 6.99 |
| n= | 120 | 4124 | Social impact | 6.59 | 6.48 |
| | | | Work / education impact | 6.83 | 7.08 |
| | | | Financial impact | 6.07 | 6.46 |

0= no burden at all / 10 = extreme burden

| <u>Lupus life Experience:</u> | | <u>Belgium</u> | <u>EUROPE</u> |
|--|-----|----------------|---------------|
| A. Lupus very active, preventing from having an active (professional,...) life - THE most significant impact on QoL | | 4.2% | 9.7% |
| B. Lupus very active, major burden day in/day out. Can handle (professional,...) obligations but is THE most significant impact on QoL | | 5.9% | 9.5% |
| C. Lupus quite active, significant impact on QoL, but can manage most often to have a reasonable QoL | | 11.9% | 11.0% |
| D. Lupus story of flares and remission, flares are frequent and impact significantly QoL | | 5.1% | 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 | | 31.4% | 19.6% |
| F. Lupus story of flares and remission, flares not too frequent impacting significantly QoL, when not flaring can have a good life | | 13.6% | 9.1% |
| G. Lupus rarely flaring, most often under control but anxiety, fatigue, concerns or side effects / medication are significant burden on QoL | | 14.4% | 16.4% |
| H. Lupus not very aggressive, even when flaring, can live a normal life | | 1.7% | 3.9% |
| I. Lupus rarely flaring. Most of the time, can live a normal life | | 5.9% | 6.5% |
| J. Lupus in long term remission (possibly with the use of ongoing medication), so not a significant burden on QoL | | 1.7% | 7.0% |
| K. Prefer not to answer | | 4.2% | 1.9% |
| n= | 118 | 4,057 | |

Patient Doctor Communication

| <u>Most missing</u> | Belgium | EUROPE | | | | |
|------------------------------------|----------------|---------------|--|------|------|--|
| Time | 25.9% | 31.6% | Doctor takes into account my opinion | | | |
| Empathy | 14.7% | 14.0% | when managing my treatment | 7.66 | 7.44 | |
| Communication within team | 15.5% | 22.3% | I am a key contributor to Sh. Dec. Mak. | | | |
| Acknwoledge the symptoms I mention | 26.7% | 22.9% | about my treatment mgnt | 7.04 | 6.96 | |
| Personalised info | 6.9% | 10.6% | I have an active role in controlling my | | | |
| lay language | 10.3% | 6.4% | disease | 7.65 | 7.47 | |
| An invite to ask | 7.8% | 5.7% | I have a trustful relationship with my | | | |
| Answers | 7.8% | 8.3% | doctor | 7.97 | 7.56 | |
| Consider non measurable | 31.0% | 25.0% | I say "the truth, all the truth and only the | | | |
| What symptoms mean for my life | 19.8% | 16.7% | truth" to my HCP with regards to my | 8.86 | 8.82 | |
| Clear info on Meds | 26.7% | 21.2% | I can share all my problems with my | | | |
| Certainty I can talk anything | 1.7% | 4.3% | doctor | 8.02 | 7.71 | |
| Holistic approach | 16.4% | 17.9% | My doctor takes into account my | | | |
| Info on Clinical Trials | 14.7% | 15.5% | psychological well-being | 7.28 | 6.94 | |
| Nothing | 20.7% | 23.7% | | | | |
| Other | 2.6% | 3.5% | | | | |
| n= | 116 | 3,841 | n= | 113 | 3773 | |
| | | | 0 = fully disagree : 10 = fully agree | | | |

Satisfaction with HealthCare team 7.57 7.33
0 = fully unsatisfied / 10 = fully satisfied

Unmet needs

| <u>Unmet Needs</u> | Belgium | EUROPE | <u>Satisfaction with treatment:</u> | Belgium | EUROPE |
|------------------------------|----------------|---------------|-------------------------------------|----------------|---------------|
| A. effic Clinic measured | 10.6% | 13.9% | A. Satisfied, AND I believe this is | | |
| B. Effic NON Measured sympt | 19.2% | 25.3% | the best that can be achieved for | 43.3% | 37.1% |
| C. reduc Steroids | 16.3% | 18.8% | B. Satisfied, BUT I believe better | | |
| D. Lower side Eff | 19.2% | 23.7% | control could be achieved for my | 18.3% | 30.4% |
| E. less fatigue | 64.4% | 53.2% | C. Not satisfied, BUT I believe | | |
| F. LT kidney prot. | 18.3% | 19.1% | this is the best that can be | 28.8% | 18.4% |
| G. Easier to take | 0.0% | 5.4% | D. Not satisfied AND I believe | | |
| H. Access to existing | 6.7% | 7.7% | better control could be achieved | 9.6% | 14.2% |
| I. Access non Pharma treatm. | 28.8% | 32.0% | | | |
| J. edu & access to support | 7.7% | 9.5% | n= | 104 | 3503 |
| K. Financial burd | 15.4% | 19.8% | | | |
| L. Other | 6.7% | 3.5% | | | |
| n= | 104 | 3,502 | | | |

Symptoms or Features experienced / Most bothersome

| <u>Patient reported Symptoms or features</u> | Belgium | | | | Belgium | |
|--|---------------------------------------|--|-----------------------------------|---------------------------------------|----------------------|-------|
| | <u>Regularly</u> <u>experience</u> | <u>most prevent</u> <u>live to the full</u> | <u>most worry</u> <u>today</u> | <u>most worry</u> <u>long term</u> | | |
| A.None | 0.9% | 0.9% | 1.8% | 0.0% | A.None | 16.0% |
| B.Rash | 41.4% | 8.8% | 9.6% | 8.8% | B.Rash | 9.4% |
| C.Sun | 57.8% | 18.4% | 10.5% | 9.7% | C.Sun | 11.3% |
| D. Ulcers | 31.9% | 1.8% | 0.9% | 0.9% | D. Ulcers | 12.3% |
| E.DryEyes | 50.0% | 8.8% | 5.3% | 7.1% | E.DryEyes | 18.9% |
| F.dryskin | 37.9% | 3.5% | 1.8% | 0.0% | F.dryskin | 10.4% |
| G.Hairloss | 46.6% | 10.5% | 14.9% | 8.0% | G.Hairloss | 19.8% |
| H. Joints | 75.9% | 50.9% | 31.6% | 36.3% | H. Joints | 10.4% |
| I.Jaccoud | 15.5% | 5.3% | 7.0% | 3.5% | I.Jaccoud | 4.7% |
| J.Muscpain/weak | 63.8% | 37.7% | 34.2% | 29.2% | J.Muscpain/weak | 16.0% |
| K. Headache | 43.1% | 20.2% | 12.3% | 13.3% | K. Headache | 10.4% |
| L.Fatigue | 89.7% | 57.9% | 43.0% | 35.4% | L.Fatigue | 43.4% |
| M. Flu-like | 24.1% | 2.6% | 0.0% | 0.9% | M. Flu-like | 0.9% |
| N. Shrot Breath | 38.8% | 6.1% | 13.2% | 9.7% | N. Shrot Breath | 7.5% |
| O. depres/anxiety | 46.6% | 14.0% | 11.4% | 14.2% | O. depres/anxiety | 16.0% |
| P. Heamatologic | 18.1% | 0.9% | 2.6% | 5.3% | P. Heamatologic | 0.9% |
| Q. Raynaud | 37.1% | 1.8% | 1.8% | 1.8% | Q. Raynaud | 3.8% |
| R. Kidney | 15.5% | 4.4% | 9.6% | 19.5% | R. Kidney | 0.9% |
| S. Chestpain | 25.9% | 2.6% | 7.0% | 7.1% | S. Chestpain | 2.8% |
| T. Hiugh, Blood Pres | 20.7% | 2.6% | 2.6% | 8.0% | T. Hiugh, Blood Pres | 1.9% |
| U. Cardiovasc | 10.3% | 0.9% | 5.3% | 11.5% | U. Cardiovasc | 0.0% |
| V. Osteoporosis | 12.9% | 0.9% | 3.5% | 8.8% | V. Osteoporosis | 1.9% |
| W. Brainfog | 33.6% | 9.6% | 12.3% | 13.3% | W. Brainfog | 11.3% |
| n= | 116 | 114 | 114 | 113 | n= | 106 |

Symptoms or Features experienced / Most bothersome

| <u>Patient reported Symptoms or features</u> | <u>EUROPE</u> | | | | <u>EUROPE</u> | |
|--|-----------------------------|--------------------------------------|-------------------------|-----------------------------|---------------------------------|-------|
| | <u>Regularly experience</u> | <u>most prevent live to the full</u> | <u>most worry today</u> | <u>most worry long term</u> | <u>least taken into account</u> | |
| 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 | n= | 3,397 |

Swiss Knife Survey - Country level data

DATA FOR: Belgium

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, <https://doi.org/10.1016/j.autrev.2025.103838>.

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