



Swiss Knife Survey 2024

COUNTRY LEVEL DATA

Portugal

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:

| | Portugal | EUROPE | Age | Portugal | EUROPE |
|------------------------------|-----------------|---------------|------------------|-----------------|---------------|
| Total number of responses | 172 | 4525 | Up to 25 | 4.1% | 5.5% |
| | | | 26 to 35 | 14.5% | 15.8% |
| <u>Gender</u> | <u>Portugal</u> | <u>EUROPE</u> | 36 to 45 | 32.6% | 26.9% |
| Man | 4.7% | 4.1% | 46 to 55 | 31.4% | 28.0% |
| Woman | 95.3% | 95.5% | 56 to 65 | 10.5% | 16.0% |
| Other / prefer not to answer | 0.0% | 0.4% | above 65 | 5.2% | 6.2% |
| Total | 100.0% | 100.0% | NA | 1.7% | 1.5% |
| | | | Grand Total | 100.0% | 100.0% |
| <u>Diagnosis</u> | <u>Portugal</u> | <u>EUROPE</u> | <u>Diagnosis</u> | <u>Portugal</u> | <u>EUROPE</u> |
| SLE | 95.3% | 92.5% | Lupus Nephritis | 17.0% | 19.5% |
| Child onset SLE | 4.7% | 7.5% | APS | 11.3% | 19.2% |
| Grand Total | 100.0% | 100.0% | LN+APS | 5.0% | 6.2% |
| | | | None of the 2 | 66.7% | 55.2% |
| | | | Grand Total | 100.0% | 100.0% |

BURDEN

| | | | | | |
|------------------------------------|-----------------|---------------|---|-----------------|---------------|
| <u>Lupus under control past3mo</u> | <u>Portugal</u> | <u>EUROPE</u> | <u>Satisfied with current state</u> | <u>Portugal</u> | <u>EUROPE</u> |
| Yes | 70.5% | 66.5% | Yes | 52.4% | 47.6% |
| No | 29.5% | 33.5% | No | 42.8% | 47.4% |
| n= | 166 | 4360 | Prefer not to answer | 4.8% | 5.0% |
| | | | n= | 145 | 3957 |
| <u>Flares over 5 years</u> | <u>Portugal</u> | <u>EUROPE</u> | <u>Burden</u> | <u>Portugal</u> | <u>EUROPE</u> |
| A. Never | 9.1% | 7.9% | Overall burden of lupus on life | 7.30 | 6.94 |
| B. Once | 13.6% | 12.7% | activity of disease itself | 7.19 | 6.63 |
| C. Twice | 12.3% | 11.0% | physical conseq.of disease | 7.65 | 7.41 |
| D. 3 or 4 times | 18.8% | 13.3% | side effects of treatment | 6.46 | 6.02 |
| E. Annually | 5.2% | 9.7% | fatigue | 8.33 | 7.95 |
| F. Several times a year | 27.9% | 34.8% | Pain | 7.44 | 6.79 |
| G. Don't know | 13.0% | 10.6% | Psychological impact | 7.52 | 6.99 |
| n= | 154 | 4124 | Social impact | 6.43 | 6.48 |
| | | | Work / education impact | 7.40 | 7.08 |
| | | | Financial impact | 6.79 | 6.46 |
| | | | 0= no burden at all / 10 = extreme burden | | |

| | | |
|--|-----------------|---------------|
| <u>Lupus life Experience:</u> | <u>Portugal</u> | <u>EUROPE</u> |
| A. Lupus very active, preventing from having an active (professional,...) life - THE most significant impact on QoL | 7.3% | 9.7% |
| B. Lupus very active, major burden day in/day out. Can handle (professional,...) obligations but is THE most significant impact on QoL | 9.3% | 9.5% |
| C. Lupus quite active, significant impact on QoL, but can manage most often to have a reasonable QoL | 8.6% | 11.0% |
| D. Lupus story of flares and remission, flares are frequent and impact significantly QoL | 6.0% | 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 | 21.9% | 19.6% |
| F. Lupus story of flares and remission, flares not too frequent impacting significantly QoL, when not flaring can have a good life | 7.3% | 9.1% |
| G. Lupus rarely flaring, most often under control but anxiety, fatigue, concerns or side effects / medication are significant burden on QoL | 21.2% | 16.4% |
| H. Lupus not very aggressive, even when flaring, can live a normal life | 4.6% | 3.9% |
| I. Lupus rarely flaring. Most of the time, can live a normal life | 10.6% | 6.5% |
| J. Lupus in long term remission (possibly with the use of ongoing medication), so not a significant burden on QoL | 3.3% | 7.0% |
| K. Prefer not to answer | 0.0% | 1.9% |
| n= | 151 | 4,057 |

Patient Doctor Communication

| Most missing | Portugal | EUROPE | | | |
|--|----------|--------|--|------|------|
| Time | 23.8% | 31.6% | Doctor takes into account my opinion | | |
| Empathy | 14.0% | 14.0% | when managing my treatment | 7.96 | 7.44 |
| Communication within team | 19.6% | 22.3% | I am a key contributor to Sh. Dec. Mak. | | |
| Acknowledge the symptoms I mention | 25.9% | 22.9% | about my treatment mngt | 7.47 | 6.96 |
| Personalised info | 5.6% | 10.6% | I have an active role in controlling my | | |
| lay language | 8.4% | 6.4% | disease | 8.27 | 7.47 |
| An invite to ask | 4.9% | 5.7% | I have a trustful relationship with my | | |
| Answers | 7.0% | 8.3% | doctor | 8.28 | 7.56 |
| Consider non measurable | 14.0% | 25.0% | I say "the truth, all the truth and only the | | |
| What symptoms mean for my life | 15.4% | 16.7% | truth" to my HCP with regards to my | 8.94 | 8.82 |
| Clear info on Meds | 18.2% | 21.2% | I can share all my problems with my | | |
| Certainty I can talk anything | 2.8% | 4.3% | doctor | 8.43 | 7.71 |
| Holistic approach | 12.6% | 17.9% | My doctor takes into account my | | |
| Info on Clinical Trials | 14.0% | 15.5% | psychological well-being | 8.02 | 6.94 |
| Nothing | 33.6% | 23.7% | | | |
| Other | 1.4% | 3.5% | n= | 113 | 3773 |
| n= | 143 | 3,841 | 0 = fully disagree : 10 = fully agree | | |
| | | | | | |
| Satisfaction with HealthCare team | 7.98 | 7.33 | | | |
| 0 = fully unsatisfied / 10 = fully satisfied | | | | | |

Unmet needs

| Unmet Needs | Portugal | EUROPE | Satisfaction with treatment: | Portugal | EUROPE |
|------------------------------|----------|--------|-------------------------------------|----------|--------|
| A. effic Clinic measured | 16.9% | 13.9% | A. Satisfied, AND I believe this is | | |
| B. Effic NON Measured sympt | 26.2% | 25.3% | the best that can be achieved for | 48.8% | 37.1% |
| C. reduc Steroids | 30.0% | 18.8% | B. Satisfied, BUT I believe better | | |
| D. Lower side Eff | 20.8% | 23.7% | control could be achieved for my | 28.3% | 30.4% |
| E. less fatigue | 50.8% | 53.2% | C. Not satisfied, BUT I believe | | |
| F. LT kidney prot. | 28.5% | 19.1% | this is the best that can be | 17.3% | 18.4% |
| G. Easier to take | 6.2% | 5.4% | D. Not satisfied AND I believe | | |
| H. Access to existing | 2.3% | 7.7% | better control could be achieved | 5.5% | 14.2% |
| I. Access non Pharma treatm. | 30.8% | 32.0% | | | |
| J. edu & access to support | 6.9% | 9.5% | n= | 127 | 3503 |
| K. Financial burd | 17.7% | 19.8% | | | |
| L. Other | 2.3% | 3.5% | | | |
| n= | 130 | 3,502 | | | |

Symptoms or Features experienced / Most bothersome

| | Portugal | | | | Portugal | |
|---------------------------------------|----------------------|-------------------------------|------------------|----------------------|--------------------------|-------|
| Patient reported Symptoms or features | Regularly experience | most prevent live to the full | most worry today | most worry long term | least taken into account | |
| A.None | 0.7% | 0.7% | 0.7% | 0.0% | A.None | 21.6% |
| B.Rash | 27.7% | 11.7% | 7.4% | 6.7% | B.Rash | 12.0% |
| C.Sun | 66.7% | 34.3% | 11.9% | 10.4% | C.Sun | 9.6% |
| D. Ulcers | 28.4% | 8.0% | 6.7% | 4.5% | D. Ulcers | 8.0% |
| E.DryEyes | 57.4% | 13.1% | 14.1% | 9.7% | E.DryEyes | 17.6% |
| F.dryskin | 45.4% | 3.6% | 4.4% | 3.0% | F.dryskin | 11.2% |
| G.Hairloss | 46.8% | 12.4% | 13.3% | 10.4% | G.Hairloss | 19.2% |
| H. Joints | 65.2% | 52.6% | 37.0% | 36.6% | H. Joints | 9.6% |
| I.Jaccoud | 11.3% | 0.7% | 2.2% | 6.0% | I.Jaccoud | 4.0% |
| J.Musclpain/weak | 51.1% | 25.5% | 23.7% | 24.6% | J.Musclpain/weak | 6.4% |
| K. Headache | 46.1% | 16.8% | 14.8% | 11.2% | K. Headache | 7.2% |
| L.Fatigue | 87.9% | 52.6% | 41.5% | 33.6% | L.Fatigue | 24.8% |
| M. Flu-like | 15.6% | 1.5% | 0.7% | 0.7% | M. Flu-like | 8.0% |
| N. Shrot Breath | 11.3% | 2.2% | 3.7% | 2.2% | N. Shrot Breath | 6.4% |
| O. depres/anxiety | 51.8% | 11.7% | 20.0% | 15.7% | O. depres/anxiety | 12.8% |
| P. Heamatologic | 17.7% | 1.5% | 3.7% | 11.2% | P. Heamatologic | 2.4% |
| Q. Raynaud | 21.3% | 4.4% | 2.2% | 4.5% | Q. Raynaud | 1.6% |
| R. Kidney | 12.8% | 4.4% | 7.4% | 23.9% | R. Kidney | 0.0% |
| S. Chestpain | 14.2% | 1.5% | 4.4% | 2.2% | S. Chestpain | 0.0% |
| T. Hiugh, Blood Pres | 20.6% | 1.5% | 5.9% | 4.5% | T. Hiugh, Blood Pres | 6.4% |
| U. Cardiovasc | 7.8% | 1.5% | 7.4% | 23.9% | U. Cardiovasc | 0.8% |
| V. Osteoporosis | 19.9% | 2.9% | 5.2% | 9.0% | V. Osteoporosis | 3.2% |
| W. Brainfog | 22.7% | 7.3% | 10.4% | 11.2% | W. Brainfog | 8.0% |
| n= | 141 | 137 | 135 | 134 | n= | 125 |

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: Portugal

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>.

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