European Survey on the Burden of the Disease and Access Barriers for individuals living with Systemic Sclerosis

Participant FAQ

Who can take part?

Adults aged 18 or over who live in Europe or Israel and have systemic sclerosis confirmed by a doctor. Adult family members or friends can also take part on behalf of someone with systemic sclerosis.

Why can I not answer for my child?

This survey is only for adults. Both the patient and the person answering must be 18 or over. Children's care is organised differently and comes with different impacts, on the child and the family. This survey wouldn't do right to those experiences.

Which language and country should I choose?

Choose the language you understand best. Then choose the country where you live, even if it is different from the country of your language. For example, you may live in Italy, but French is your native language. That option is possible.

I am a caregiver. Whose experience should I describe?

Answer for the person you care for. Ideally, you can go over the survey questions together. When you read "you" or "your", this means them. A few questions ask about you. These are marked with a message before the question. In those questions, "the person assisting you" or "your caregiver" means you.

What is the difference between a local centre and a specialist referral centre?

Your local centre is the nearby centre where you go for routine check-ups and symptom management. A specialist referral centre has systemic sclerosis experts

and specialist services, for example advanced tests and a team of different professionals who decide together on your care. Usually, people go to their local centre more frequently than to the specialist referral centre, but this doesn't have to be the case for you. If your nearest centre happens to be a specialist referral centre, please provide your answers under 'specialist referral centre'.

None of the answers fits my situation. What should I do?

Choose the answer that is closest to your situation. Where there is an "Other" option, you can describe your situation in your own words. For questions about numbers or costs, your best estimate is enough.

Can I take a break?

Yes. You can leave the survey window open and continue later the same day. If you close the window, your answers may be lost.

Is the survey anonymous?

Yes. The survey does not collect your name or contact details. Results are only reported for groups of people, never for individuals.

Who can I contact with questions?

Email the FESCA Secretariat at **secretariatoffice@fesca-scleroderma.eu**.

I am a family member or friend and receive a carer allowance. Am I a professional care provider? (Question 4)

If you are a family member or friend, choose one of the family member or friend options, even if you receive a carer allowance or payment for the care you give. The option "professional care provider" is only for people who care for patients as their job, for example nurses or home care staff.

I do not recognise my region in the list. Which one should I choose? (Question 10)

The regions in this list are those used for European statistics. They may group several counties or provinces together, or have different names from the ones you know. Choose the region that includes the town or city where you live.

Which type of healthcare coverage should I choose? (Question 14)

Health systems differ a lot across Europe, and not every option exists in every country. Choose the option that best describes your own situation.

Public healthcare only: Your care is funded mainly through general taxes. You are covered as a resident and do not belong to a health insurance fund or company. Examples: the NHS in the UK, or the national health services in Spain, Italy, Portugal, Sweden or Denmark.

Mandatory health insurance only: You are legally required to be insured with a health insurance fund or company, and you have no extra policy on top. This applies even if contributions are deducted automatically from your salary, and even if the insurer is a private company. Examples: statutory insurance (GKV) or substitutive private insurance (PKV) in Germany, a mutualité/ziekenfonds in Belgium, the basic policy (basisverzekering) in the Netherlands, or basic insurance (LAMal/KVG) in Switzerland.

Private health insurance in addition: You have extra insurance on top of the public or mandatory system, whether you pay for it yourself or your employer provides it. This includes policies that cover only dental care, hospital stays, faster access or private clinics. Examples: a mutuelle in France, an aanvullende verzekering in the Netherlands, private insurance in Ireland, Spain or the UK.

If you are covered through a family member's insurance, choose the option that describes that insurance. A quick tip: if you have a card or membership number from a health insurance fund or company, you probably have mandatory insurance, not "public healthcare only."

What does "private healthcare" mean in this survey? (Question 15)

Private healthcare is care that you pay for yourself or through private insurance, and that is not paid by a public or mandatory health system. A privately run clinic or practice that treats you under the public or mandatory system is not private.

Who is the central person in managing my care? (Question 18)

Choose the professional who mainly decides on your systemic sclerosis care and treatment, even if another doctor writes repeat prescriptions. If your doctor is an internist who specialises in rheumatology, choose "Rheumatologist".

How do I answer the travel distance question if I use miles or travel abroad? (Question 26)

Distances are in kilometres. As a guide, 10 km is about 6 miles, 20 km is about 12 miles and 50 km is about 31 miles. If you travel to another country or island for care, choose "More than 50 km".

What is a "hospital drug"? (Question 30)

A “hospital drug” is a medicine you can only get through a hospital, not from a regular pharmacy. Some are given to you at the hospital or clinic, for example as an injection or drip. Others you collect from the hospital pharmacy and take or inject yourself at home. If you are not sure, choose “Don’t know / can’t remember.”

How do I know if hospital drugs can be delivered to my home or local pharmacy? (Question 31)

Some hospitals or health systems can send these medicines to your home or to a pharmacy near you. Answer based on what you know. If you are not sure whether this is possible where you live, choose "I don't know whether this is possible".

Do prescription charges or co-payments count as paying for medicines? (Question 37)

Include any medicine where you pay something yourself, for example a prescription charge, a co-payment or a yearly deductible. Choose "I do not pay anything for my pharmacological therapies" only if all your medicines are completely free for you.

The amounts are in euros, but I pay in another currency. What should I do? (Question 39)

If the amount in the survey is in euros, but you pay in another currency, use the conversion table below. Rates are approximate and only need to give you the right range. If you spent less than 100 euros, choose one of the two "I hardly spent money myself" options. Give your best estimate.

Currency conversion for question 39

Currency	100 EUR	500 EUR	1,000 EUR	5,000 EUR	10,000 EUR
Albanian lek (ALL)	~9,700 ALL	~48,500 ALL	~97,000 ALL	~485,000 ALL	~970,000 ALL
Armenian dram (AMD)	~44,000 AMD	~220,000 AMD	~440,000 AMD	~2,200,000 AMD	~4,400,000 AMD
Azerbaijani manat (AZN)	~195 AZN	~975 AZN	~1,950 AZN	~9,750 AZN	~19,500 AZN
Belarusian ruble (BYN)	~370 BYN	~1,850 BYN	~3,700 BYN	~18,500 BYN	~37,000 BYN
Bosnia and Herzegovina convertible mark (BAM)	~196 BAM	~980 BAM	~1,960 BAM	~9,800 BAM	~19,600 BAM
Czech koruna (CZK)	~2,500 CZK	~12,500 CZK	~25,000 CZK	~125,000 CZK	~250,000 CZK
Danish krone (DKK)	~750 DKK	~3,700 DKK	~7,500 DKK	~37,000 DKK	~75,000 DKK
Georgian lari (GEL)	~310 GEL	~1,550 GEL	~3,100 GEL	~15,500 GEL	~31,000 GEL

Currency	100 EUR	500 EUR	1,000 EUR	5,000 EUR	10,000 EUR
Hungarian forint (HUF)	~36,000 HUF	~180,000 HUF	~360,000 HUF	~1,800,000 HUF	~3,600,000 HUF
Icelandic króna (ISK)	~14,400 ISK	~72,000 ISK	~144,000 ISK	~720,000 ISK	~1,440,000 ISK
Israeli shekel (ILS)	~350 ILS	~1,750 ILS	~3,500 ILS	~17,500 ILS	~35,000 ILS
Kazakhstani tenge (KZT)	~60,000 KZT	~300,000 KZT	~600,000 KZT	~3,000,000 KZT	~6,000,000 KZT
Kyrgyzstani som (KGS)	~10,000 KGS	~50,000 KGS	~100,000 KGS	~500,000 KGS	~1,000,000 KGS
Moldovan leu (MDL)	~2,000 MDL	~10,000 MDL	~20,000 MDL	~100,000 MDL	~200,000 MDL
North Macedonian denar (MKD)	~6,150 MKD	~30,750 MKD	~61,500 MKD	~307,500 MKD	~615,000 MKD
Norwegian krone (NOK)	~1,000 NOK	~5,000 NOK	~10,000 NOK	~50,000 NOK	~100,000 NOK
Polish złoty (PLN)	~440 PLN	~2,200 PLN	~4,400 PLN	~22,000 PLN	~44,000 PLN
Pound sterling (GBP)	~85 GBP	~430 GBP	~860 GBP	~4,300 GBP	~8,600 GBP
Romanian leu (RON)	~530 RON	~2,650 RON	~5,300 RON	~26,500 RON	~53,000 RON
Russian ruble (RUB)	~9,500 RUB	~47,500 RUB	~95,000 RUB	~475,000 RUB	~950,000 RUB
Serbian dinar (RSD)	~11,700 RSD	~58,500 RSD	~117,000 RSD	~585,000 RSD	~1,170,000 RSD
Swedish krona (SEK)	~1,000 SEK	~5,000 SEK	~10,000 SEK	~50,000 SEK	~100,000 SEK
Swiss franc (CHF)	~95 CHF	~470 CHF	~930 CHF	~4,700 CHF	~9,300 CHF
Tajikistani somoni (TJS)	~1,100 TJS	~5,500 TJS	~11,000 TJS	~55,000 TJS	~110,000 TJS
Turkish lira (TRY)	~5,300 TRY	~26,500 TRY	~53,000 TRY	~265,000 TRY	~530,000 TRY
Turkmenistan manat (TMT)	~400 TMT	~2,000 TMT	~4,000 TMT	~20,000 TMT	~40,000 TMT
Ukrainian hryvnia (UAH)	~4,800 UAH	~24,000 UAH	~48,000 UAH	~240,000 UAH	~480,000 UAH
Uzbekistani som (UZS)	~1,400,000 UZS	~7,000,000 UZS	~14,000,000 UZS	~70,000,000 UZS	~140,000,000 UZS