



CONTEXT

Number of survey respondents¹ **4**

Sex of respondents² **4 F**
0 M

Age of respondents³ **4 between 18 and 64 years**

18 64

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

Yes 100%

No 0%

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ **100% Yes**
0% No

Access to non-drug treatment⁶ **100% Yes**
0% No

Main non-drug treatment accessed

Access to physiotherapy **100%**

Access to psychological support **100%**

Access to dietary advice **25%**

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial **50% No**
50% Yes

Participated in a clinical trial **50% No**
50% Yes

Main barriers to accessing drug treatment

Lack of referral **0%**

Late diagnosis **25%**

Not qualifying for treatment **0%**

Lack of marketing authorisation **0%**

Lack of reimbursement **0%**

TIMELY DIAGNOSIS

Time to diagnosis **100%**
between 6 months & several years

Main reasons for delayed diagnosis

Incorrect diagnosis received before correct one **25%**

Consultations required before referral to a systemic sclerosis specialist **75%**
between 2 & 10

FINANCIAL IMPACT

Full coverage of drug treatment⁷ 0%

Out-of-pocket spend for drug treatment 0%

NO > €500/year

Full coverage of non-drug treatment⁷ 25%

Out-of-pocket spend for non-drug treatment 100%

NO > €500/year

1. Target of responses: 10.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multi-professional-team-pdf-6955526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.

CONTEXT

Number of survey respondents¹ **15**

Sex of respondents² **15 F**
0 M

Age of respondents³ **13 between 18 and 64 years**
 18 **64**

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

Yes 67%

No 33%

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ **80% Yes**
20% No

Access to non-drug treatment⁶ **67% Yes**
33% No

Main non-drug treatment accessed

Access to psychological support **20%**

Access to physiotherapy **60%**

Access to dietary advice **7%**

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial **67% No**
33% Yes

Participated in a clinical trial **87% No**
13% Yes

Main barriers to accessing drug treatment

Lack of referral **13%**

Late diagnosis **7%**

Not qualifying for treatment **20%**

Lack of marketing authorisation **0%**

Lack of reimbursement **0%**

TIMELY DIAGNOSIS

Time to diagnosis **57%**
between 6 months & several years

Main reasons for delayed diagnosis

Incorrect diagnosis received before correct one **27%**

Consultations required before referral to a systemic sclerosis specialist **50%**
between 2 & 10

FINANCIAL IMPACT

Full coverage of drug treatment⁷ **60%**

Out-of-pocket spend for drug treatment **33%**
> €500/year

Full coverage of non-drug treatment⁷ **80%**

Out-of-pocket spend for non-drug treatment **67%**
> €500/year

1. Target of responses: 10.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multi-professional-team-pdf-6955526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.

CONTEXT

Number of survey respondents¹ 23

Sex of respondents² 18 F
5 M

Age of respondents³ 22 between 18 and 64 years

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

Yes 57%

No 43%

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ 74% Yes
26% No

Access to non-drug treatment⁶ 39% No
61% Yes

Main non-drug treatment accessed

Access to psychological support 22%

Access to physiotherapy 52%

Access to dietary advice 9%

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial 83% No
17% Yes

Participated in a clinical trial 83% No
17% Yes

Main barriers to accessing drug treatment

Lack of referral 22%

Late diagnosis 13%

Not qualifying for treatment 17%

Lack of marketing authorisation 0%

Lack of reimbursement 0%

TIMELY DIAGNOSIS

Time to diagnosis 78% between 6 months & several years

Main reasons for delayed diagnosis

Incorrect diagnosis received before correct one 42%

Consultations required before referral to a systemic sclerosis specialist 64% between 2 & 10

FINANCIAL IMPACT

Full coverage of drug treatment⁷ 52% NO

Out-of-pocket spend for drug treatment 45% > €500/year

Full coverage of non-drug treatment⁷ 57% NO

Out-of-pocket spend for non-drug treatment 35% > €500/year

1. Target of responses: 5.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multi-professional-team-pdf-6955526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.



CONTEXT

Number of survey respondents¹ **3**

Sex of respondents² **3 F 0 M**

Age of respondents³ **3 between 18 and 64 years**

18 64

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

Yes 67%

No 33%

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ **67% No 33% Yes**

Access to non-drug treatment⁶ **100% No 0% Yes**

Main non-drug treatment accessed

Access to physiotherapy **0%**

Access to psychological support **0%**

Access to dietary advice **0%**

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial **100% No 0% Yes**

Participated in a clinical trial **100% No 0% Yes**

Main barriers to accessing drug treatment

Lack of referral **0%**

Late diagnosis **0%**

Not qualifying for treatment **33%**

Lack of marketing authorisation **33%**

Lack of reimbursement **0%**

TIMELY DIAGNOSIS

Time to diagnosis **100% between 6 months & several years**

Main reasons for delayed diagnosis

Incorrect diagnosis received before correct one **33%**

Consultations required before referral to a systemic sclerosis specialist **33% between 2 & 10**

FINANCIAL IMPACT

Full coverage of drug treatment⁷ **33%**

Out-of-pocket spend for drug treatment **0%**

NO > €500/year

Full coverage of non-drug treatment⁷ **67%**

Out-of-pocket spend for non-drug treatment **0%**

NO > €500/year

1. Target of responses: 3.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multi-professional-team-pdf-6955526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.



CONTEXT

Number of survey respondents¹ **20**

Sex of respondents² **17 F**
3 M

Age of respondents³ **20 between 18 and 64 years**

18 **64**

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

No **55%**

Yes **45%**

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ **75% Yes**
25% No

Access to non-drug treatment⁶ **70% Yes**
30% No

Main non-drug treatment accessed

Access to psychological support **40%**

Access to physiotherapy **55%**

Access to dietary advice **0%**

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial **70% No**
30% Yes

Participated in a clinical trial **80% No**
20% Yes

Main barriers to accessing drug treatment

Lack of referral **15%**

Late diagnosis **15%**

Not qualifying for treatment **20%**

Lack of marketing authorisation **0%**

Lack of reimbursement **5%**

TIMELY DIAGNOSIS

Time to diagnosis **50%**
between 6 months & several years

Main reasons for delayed diagnosis

Incorrect diagnosis received before correct one **35%**

Consultations required before referral to a systemic sclerosis specialist **26%**
between 2 & 10

FINANCIAL IMPACT

Full coverage of drug treatment⁷ **50%**

Out-of-pocket spend for drug treatment **25%**
> €500/year

Full coverage of non-drug treatment⁷ **25%**

Out-of-pocket spend for non-drug treatment **25%**
> €500/year

1. Target of responses: 10.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multi-professional-team-pdf-6955526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.

CONTEXT

Number of survey respondents¹ **69**

Sex of respondents² **68 F**
1 M

Age of respondents³ **80% between 18 and 64 years**

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

Yes 74%

No 26%

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ **70% Yes**
30% No

Access to non-drug treatment⁶ **67% Yes**
33% No

Main non-drug treatment accessed

Access to psychological support **12%**

Access to physiotherapy **58%**

Access to dietary advice **6%**

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial **51% Yes**
49% No

Participated in a clinical trial **64% No**
36% Yes

Main barriers to accessing drug treatment

Lack of referral **16%**

Late diagnosis **17%**

Not qualifying for treatment **9%**

Lack of marketing authorisation **0%**

Lack of reimbursement **0%**

TIMELY DIAGNOSIS

Time to diagnosis **70%**
between 6 months & several years

Main reasons for delayed diagnosis

Incorrect diagnosis received before correct one **39%**

Consultations required before referral to a systemic sclerosis specialist **60%**
between 2 & 10

FINANCIAL IMPACT

Full coverage of drug treatment⁷ **46%**
NO

Out-of-pocket spend for drug treatment **60%**
> €500/year

Full coverage of non-drug treatment⁷ **43%**
NO

Out-of-pocket spend for non-drug treatment **46%**
> €500/year

1. Target of responses: 15.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multi-professional-team-pdf-6955526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.

CONTEXT

Number of survey respondents¹ **76**

Sex of respondents² **72 F**
4 M

Age of respondents³ **54** between 18 and 64 years
 18 64

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

No **62%**

Yes **38%**

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ **72% Yes**
28% No

Access to non-drug treatment⁶ **57% No**
43% Yes

Main non-drug treatment accessed

Access to psychological support **14%**

Access to physiotherapy **34%**

Access to dietary advice **16%**

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial **99% No**
1% Yes

Participated in a clinical trial **99% No**
1% Yes

Main barriers to accessing drug treatment

Lack of referral **16%**

Late diagnosis **26%**

Not qualifying for treatment **13%**

Lack of marketing authorisation **0%**

Lack of reimbursement **0%**

TIMELY DIAGNOSIS

Time to diagnosis **67%**
between 6 months & several years

Main reasons for delayed diagnosis

Incorrect diagnosis received before correct one **37%**

Consultations required before referral to a systemic sclerosis specialist **56%**
between 2 & 10

FINANCIAL IMPACT

Full coverage of drug treatment⁷ **89%**

Out-of-pocket spend for drug treatment **44%**
> €500/year

Full coverage of non-drug treatment⁷ **92%**

Out-of-pocket spend for non-drug treatment **30%**
> €500/year

1. Target of responses: 15.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multi-professional-team-pdf-6955526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.

CONTEXT

Number of survey respondents¹ **202**

Sex of respondents²

- 184 F
- 17 M
- 1 Prefers not to answer

Age of respondents³

137 between 18 and 64 years

18 64

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

No **51%**

Yes **49%**

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ **77% Yes**
23% No

Access to non-drug treatment⁶ **58% Yes**
42% No

Main non-drug treatment accessed

- Access to psychological support **14%**
- Access to physiotherapy **51%**
- Access to dietary advice **13%**

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial **73% No**
27% Yes

Participated in a clinical trial **80% No**
20% Yes

Main barriers to accessing drug treatment

- Lack of referral **19%**
- Late diagnosis **31%**
- Not qualifying for treatment **9%**
- Lack of marketing authorisation **2%**
- Lack of reimbursement **2%**

TIMELY DIAGNOSIS

Time to diagnosis **45%**
between 6 months & several years

Main reasons for delayed diagnosis

- Incorrect diagnosis received before correct one **29%**
- Consultations required before referral to a systemic sclerosis specialist **63%**
between 2 & 10

FINANCIAL IMPACT

Full coverage of drug treatment⁷ **10%**
NO

Out-of-pocket spend for drug treatment **29%**
> €500/year

Full coverage of non-drug treatment⁷ **36%**
NO

Out-of-pocket spend for non-drug treatment **38%**
> €500/year

1. Target of responses: 70.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multi-professional-team-pdf-6955526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.

CONTEXT

Number of survey respondents¹ 127

Sex of respondents² **116 F**
11 M

Age of respondents³ 100 between 18 and 64 years
 18 **64**

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

Yes **54%**

No **46%**

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ **59% Yes**
41% No

Access to non-drug treatment⁶ **76% Yes**
24% No

Main non-drug treatment accessed

Access to psychological support **16%**

Access to physiotherapy **65%**

Access to dietary advice **9%**

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial **64% No**
36% Yes

Participated in a clinical trial **72% No**
28% Yes

Main barriers to accessing drug treatment

Lack of referral **26%**

Late diagnosis **24%**

Not qualifying for treatment **37%**

Lack of marketing authorisation **3%**

Lack of reimbursement **3%**

TIMELY DIAGNOSIS

Time to diagnosis **75%**
between 6 months & several years

Main reasons for delayed diagnosis

Incorrect diagnosis received before correct one **46%**

Consultations required before referral to a systemic sclerosis specialist **57%**
between 2 & 10

FINANCIAL IMPACT

Full coverage of drug treatment⁷ **17%**

Out-of-pocket spend for drug treatment **38%**
> €500/year

Full coverage of non-drug treatment⁷ **37%**

Out-of-pocket spend for non-drug treatment **55%**
> €500/year

1. Target of responses: 90.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multi-professional-team-pdf-6955526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.



CONTEXT

Number of survey respondents¹ **17**

Sex of respondents² **17 F**
0 M

Age of respondents³ **17 between 18 and 64 years**

18 64

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

No 65%

Yes 35%

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ **53% No**
47% Yes

Access to non-drug treatment⁶ **76% No**
24% Yes

Main non-drug treatment accessed

Access to psychological support **18%**

Access to physiotherapy **12%**

Access to dietary advice **6%**

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial **71% No**
29% Yes

Participated in a clinical trial **82% No**
18% Yes

Main barriers to accessing drug treatment

Lack of referral **18%**

Late diagnosis **53%**

Not qualifying for treatment **6%**

Lack of marketing authorisation **6%**

Lack of reimbursement **6%**

TIMELY DIAGNOSIS

Time to diagnosis **69%**
between 6 months & several years

Main reasons for delayed diagnosis

Incorrect diagnosis received before correct one **53%**

Consultations required before referral to a systemic sclerosis specialist **50%**
between 2 & 10

FINANCIAL IMPACT

Full coverage of drug treatment⁷ 41%

Out-of-pocket spend for drug treatment 43%

NO **> €500/year**

Full coverage of non-drug treatment⁷ 82%

Out-of-pocket spend for non-drug treatment 83%

NO **> €500/year**

1. Target of responses: 10.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multi-professional-team-pdf-6955526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.

CONTEXT

Number of survey respondents¹ **54**

Sex of respondents² **49 F**
5 M

Age of respondents³ **47** between 18 and 64 years
 18 64

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

Yes **61%**

No **39%**

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ **69% Yes**
31% No

Access to non-drug treatment⁶ **59% Yes**
41% No

Main non-drug treatment accessed

Access to psychological support **19%**

Access to physiotherapy **44%**

Access to dietary advice **13%**

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial **54% Yes**
46% No

Participated in a clinical trial **54% No**
46% Yes

Main barriers to accessing drug treatment

Lack of referral **17%**

Late diagnosis **31%**

Not qualifying for treatment **6%**

Lack of marketing authorisation **2%**

Lack of reimbursement **2%**

TIMELY DIAGNOSIS

Time to diagnosis **64%**
between 6 months & several years

Main reasons for delayed diagnosis

Incorrect diagnosis received before correct one **28%**

Consultations required before referral to a systemic sclerosis specialist **56%**
between 2 & 10

FINANCIAL IMPACT

Full coverage of drug treatment⁷ **56%**
NO

Out-of-pocket spend for drug treatment **41%**
> €500/year

Full coverage of non-drug treatment⁷ **48%**
NO

Out-of-pocket spend for non-drug treatment **42%**
> €500/year

1. Target of responses: 10.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multi-professional-team-pdf-6955526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.

CONTEXT

Number of survey respondents¹ 140

Sex of respondents² 135 F 5 M

Age of respondents³ 125 between 18 and 64 years

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

No 50%

Yes 50%

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ **44% No** 56% Yes

Access to non-drug treatment⁶ **66% No** 34% Yes

Main non-drug treatment accessed

Access to psychological support 18%

Access to physiotherapy 24%

Access to dietary advice 6%

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial **81% No** 19% Yes

Participated in a clinical trial **86% No** 14% Yes

Main barriers to accessing drug treatment

Lack of referral 26%

Late diagnosis 24%

Not qualifying for treatment 11%

Lack of marketing authorisation 4%

Lack of reimbursement 1%

TIMELY DIAGNOSIS

Time to diagnosis 66% between 6 months & several years

Main reasons for delayed diagnosis

Incorrect diagnosis received before correct one 39%

Consultations required before referral to a systemic sclerosis specialist 56% between 2 & 10

FINANCIAL IMPACT

Full coverage of drug treatment⁷ 49%

Out-of-pocket spend for drug treatment 50%

NO **> €500/year**

Full coverage of non-drug treatment⁷ 73%

Out-of-pocket spend for non-drug treatment 44%

NO **> €500/year**

1. Target of responses: 60.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multiprofessional-team-pdf-6955526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.



CONTEXT

Number of survey respondents¹ **47**

Sex of respondents² **38 F**
9 M

Age of respondents³ **35 between 18 and 64 years**

18 64

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

Yes 68%

No 32%

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ **72% Yes**
28% No

Access to non-drug treatment⁶ **70% Yes**
30% No

Main non-drug treatment accessed

Access to psychological support **28%**

Access to physiotherapy **60%**

Access to dietary advice **17%**

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial **70% No**
30% Yes

Participated in a clinical trial **81% No**
19% Yes

Main barriers to accessing drug treatment

Lack of referral **17%**

Late diagnosis **30%**

Not qualifying for treatment **15%**

Lack of marketing authorisation **2%**

Lack of reimbursement **4%**

TIMELY DIAGNOSIS

Time to diagnosis **71%**
between 6 months & several years

Main reasons for delayed diagnosis

Incorrect diagnosis received before correct one **32%**

Consultations required before referral to a systemic sclerosis specialist **60%**
between 2 & 10

FINANCIAL IMPACT

Full coverage of drug treatment⁷ **32%**
NO

Out-of-pocket spend for drug treatment **33%**
> €500/year

Full coverage of non-drug treatment⁷ **49%**
NO

Out-of-pocket spend for non-drug treatment **39%**
> €500/year

1. Target of responses: 20.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multi-professional-team-pdf-695526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.

CONTEXT

Number of survey respondents¹ **21**

Sex of respondents² **20 F**
1 M

Age of respondents³ **19** between 18 and 64 years
18 **64**

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

No **67%**

Yes **33%**

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ **67% Yes**
33% No

Access to non-drug treatment⁶ **57% Yes**
43% No

Main non-drug treatment accessed

Access to psychological support **5%**

Access to physiotherapy **57%**

Access to dietary advice **10%**

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial **67% Yes**
33% No

Participated in a clinical trial **71% No**
29% Yes

Main barriers to accessing drug treatment

Lack of referral **5%**

Late diagnosis **19%**

Not qualifying for treatment **19%**

Lack of marketing authorisation **5%**

Lack of reimbursement **5%**

TIMELY DIAGNOSIS

Time to diagnosis **88%**
between 6 months & several years

Main reasons for delayed diagnosis

Incorrect diagnosis received before correct one **29%**

Consultations required before referral to a systemic sclerosis specialist **67%**
between 2 & 10

FINANCIAL IMPACT

Full coverage of drug treatment⁷ **29%**
NO

Out-of-pocket spend for drug treatment **0%**
> €500/year

Full coverage of non-drug treatment⁷ **76%**
NO

Out-of-pocket spend for non-drug treatment **42%**
> €500/year

1. Target of responses: 15.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multi-professional-team-pdf-6955526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.

CONTEXT

Number of survey respondents¹ **18**

Sex of respondents² **15 F**
3 M

Age of respondents³ **18 between 18 and 64 years**

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

Yes 89%

No 11%

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ **94% Yes**
6% No

Access to non-drug treatment⁶ **61% No**
39% Yes

Main non-drug treatment accessed

Access to physiotherapy **17%**

Access to psychological support **17%**

Access to dietary advice **0%**

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial **72% No**
28% Yes

Participated in a clinical trial **72% No**
28% Yes

Main barriers to accessing drug treatment

Lack of referral **6%**

Late diagnosis **17%**

Not qualifying for treatment **11%**

Lack of marketing authorisation **11%**

Lack of reimbursement **6%**

TIMELY DIAGNOSIS

Time to diagnosis **57%**
between 6 months & several years

Main reasons for delayed diagnosis

Incorrect diagnosis received before correct one **33%**

Consultations required before referral to a systemic sclerosis specialist **50%**
between 2 & 10

FINANCIAL IMPACT

Full coverage of drug treatment⁷ **50%**
NO

Out-of-pocket spend for drug treatment **78%**
> €500/year

Full coverage of non-drug treatment⁷ **44%**
NO

Out-of-pocket spend for non-drug treatment **57%**
> €500/year

1. Target of responses: 10.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multi-professional-team-pdf-6955526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.

CONTEXT

Number of survey respondents¹ **40**

Sex of respondents² **39 F**
1 M

Age of respondents³ **36 between 18 and 64 years**

18 64

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

Yes 92%

No 8%

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ **80% Yes**
20% No

Access to non-drug treatment⁶ **50% No**
50% Yes

Main non-drug treatment accessed

Access to psychological support **28%**

Access to physiotherapy **25%**

Access to dietary advice **20%**

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial **55% Yes**
45% No

Participated in a clinical trial **75% No**
25% Yes

Main barriers to accessing drug treatment

Lack of referral **25%**

Late diagnosis **40%**

Not qualifying for treatment **10%**

Lack of marketing authorisation **18%**

Lack of reimbursement **8%**

TIMELY DIAGNOSIS

Time to diagnosis **74%**
between 6 months & several years

Main reasons for delayed diagnosis

Incorrect diagnosis received before correct one **38%**

Consultations required before referral to a systemic sclerosis specialist **75%**
between 2 & 10

FINANCIAL IMPACT

Full coverage of drug treatment⁷ 55%

Out-of-pocket spend for drug treatment 68%
> €500/year

Full coverage of non-drug treatment⁷ 73%

Out-of-pocket spend for non-drug treatment 56%
> €500/year

1. Target of responses: 20.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multi-professional-team-pdf-6955526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.

CONTEXT

Number of survey respondents¹ **122**

Sex of respondents² **120 F**
2 M

Age of respondents³ **114 between 18 and 64 years**

18 64

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

Yes **26%**

No **74%**

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ **83% Yes**
17% No

Access to non-drug treatment⁶ **59% No**
41% Yes

Main non-drug treatment accessed

Access to psychological support **32%**

Access to physiotherapy **25%**

Access to dietary advice **11%**

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial **75% No**
25% Yes

Participated in a clinical trial **84% No**
16% Yes

Main barriers to accessing drug treatment

Lack of referral **14%**

Late diagnosis **28%**

Not qualifying for treatment **13%**

Lack of marketing authorisation **3%**

Lack of reimbursement **2%**

TIMELY DIAGNOSIS

Time to diagnosis **68%**
between 6 months & several years

Main reasons for delayed diagnosis

Incorrect diagnosis received before correct one **62%**

Consultations required before referral to a systemic sclerosis specialist **59%**
between 2 & 10

FINANCIAL IMPACT

Full coverage of drug treatment⁷ **30%**
NO

Out-of-pocket spend for drug treatment **42%**
> €500/year

Full coverage of non-drug treatment⁷ **66%**
NO

Out-of-pocket spend for non-drug treatment **58%**
> €500/year

1. Target of responses: 50.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multi-professional-team-pdf-6955526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.

CONTEXT

Number of survey respondents¹ **58**

Sex of respondents² **55 F**
3 M

Age of respondents³ **42 between 18 and 64 years**
 18 64

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

No **66%**

Yes **34%**

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ **60% Yes**
40% No

Access to non-drug treatment⁶ **64% Yes**
36% No

Main non-drug treatment accessed

Access to psychological support **28%**

Access to physiotherapy **60%**

Access to dietary advice **19%**

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial **62% No**
38% Yes

Participated in a clinical trial **66% No**
34% Yes

Main barriers to accessing drug treatment

Lack of referral **24%**

Late diagnosis **33%**

Not qualifying for treatment **5%**

Lack of marketing authorisation **3%**

Lack of reimbursement **2%**

TIMELY DIAGNOSIS

Time to diagnosis **71%**
between 6 months & several years

Main reasons for delayed diagnosis

Incorrect diagnosis received before correct one **38%**

Consultations required before referral to a systemic sclerosis specialist **63%**
between 2 & 10

FINANCIAL IMPACT

Full coverage of drug treatment⁷ **52%**
NO

Out-of-pocket spend for drug treatment **30%**
> €500/year

Full coverage of non-drug treatment⁷ **60%**
NO

Out-of-pocket spend for non-drug treatment **24%**
> €500/year

1. Target of responses: 10.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multi-professional-team-pdf-6955526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.

CONTEXT

Number of survey respondents¹ **17**

Sex of respondents² **16 F**
1 M

Age of respondents³ **15 between 18 and 64 years**
 18 **64**

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

Yes 76%

No 24%

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ **65% Yes**
35% No

Access to non-drug treatment⁶ **71% Yes**
29% No

Main non-drug treatment accessed

Access to psychological support **29%**

Access to physiotherapy **47%**

Access to dietary advice **29%**

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial **59% No**
41% Yes

Participated in a clinical trial **71% No**
29% Yes

Main barriers to accessing drug treatment

Lack of referral **12%**

Late diagnosis **18%**

Not qualifying for treatment **12%**

Lack of marketing authorisation **6%**

Lack of reimbursement **0%**

TIMELY DIAGNOSIS

Time to diagnosis **44%**
between 6 months & several years

Main reasons for delayed diagnosis

Incorrect diagnosis received before correct one **41%**

Consultations required before referral to a systemic sclerosis specialist **59%**
between 2 & 10

FINANCIAL IMPACT

Full coverage of drug treatment⁷ 18%
NO

Out-of-pocket spend for drug treatment 100%
> €500/year

Full coverage of non-drug treatment⁷ 35%
NO

Out-of-pocket spend for non-drug treatment 75%
> €500/year

1. Target of responses: 8.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multi-professional-team-pdf-695526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.

CONTEXT

Number of survey respondents¹ 150

Sex of respondents² 141 F, 8 M, 1 Prefers not to answer

Age of respondents³ 122 between 18 and 64 years 18 to 64

SHARED DECISION-MAKING AND PATIENT SUPPORT

Patients were involved in developing their treatment plan⁴

No 57%

Yes 43%

ACCESS TO MULTIPROFESSIONAL CARE

Access to multiprofessional team⁵ **72% Yes** 28% No

Access to non-drug treatment⁶ **56% No** 44% Yes

Main non-drug treatment accessed

Access to psychological support **13%**

Access to physiotherapy **37%**

Access to dietary advice **7%**

ACCESS TO CLINICAL TRIALS AND APPROVED TREATMENT

Received information about participating in a clinical trial **65% No** 35% Yes

Participated in a clinical trial **76% No** 24% Yes

Main barriers to accessing drug treatment

Lack of referral **19%**

Late diagnosis **27%**

Not qualifying for treatment **12%**

Lack of marketing authorisation **3%**

Lack of reimbursement **1%**

TIMELY DIAGNOSIS

Time to diagnosis **76%** between 6 months & several years

Main reasons for delayed diagnosis

Incorrect diagnosis received before correct one **48%**

Consultations required before referral to a systemic sclerosis specialist **57%** between 2 & 10

FINANCIAL IMPACT

Full coverage of drug treatment⁷ **19%** NO

Out-of-pocket spend for drug treatment **18%** > €500/year

Full coverage of non-drug treatment⁷ **24%** NO

Out-of-pocket spend for non-drug treatment **44%** > €500/year

1. Target of responses: 70.
 2. Multiple-choice answers provided: Male; Female; Prefer not to answer.
 3. Multiple-choice answers provided: 18 to 24; 25 to 34; 35 to 44; 45 to 54; 55 to 64; 65 or over.
 4. Shared decision-making is defined as an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences - National Institute for Health and Care Excellence (NICE), <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>.
 5. A multiprofessional team is defined as one where health and care professionals work together. The aim of a multiprofessional team is to appropriately utilise knowledge, skills and best practice from multiple disciplines and across all services provider boundaries (i.e. health, social care or voluntary and private sector). Multiprofessional teams work together to define, re scope and reframe health and social care delivery issues and reach solutions based on an improved collective understanding of complex patient need(s). - National Institute for Health and Care Excellence (NICE), www.nice.org.uk/guidance/ng142/evidence/e-multi-professional-team-pdf-6955526994.
 6. Drugs are pharmaceutical medicines used to restore, correct, or modify a physiological function; non-pharmacological options include everything else such as patient education, self-management, physical exercise, lifestyle or behaviour interventions, psychological counselling, relaxation, dietary, nutritional or microbiome interventions, stretching, hand and foot interventions, mouth exercise therapy. - Parodis I, Girard-Guyonvarc'h C, Arnaud L, et al. EULAR recommendations for the non-pharmacological management of systemic lupus erythematosus and systemic sclerosis. Annals of the Rheumatic Diseases. Published Online First: 10 July 2023. doi: 10.1136/ard-2023-224416.
 7. By statutory health authority or health insurance.
 Methodology note: FESCA launched a patient survey across 20 countries to understand socio-economic challenges for people living with systemic sclerosis. Reported insights are based on responses provided to multiple-choice questions.