THERAPEUTIC ADVANCES in
Respiratory Disease

Plain Language Summary of Publication

How do doctors and patients communicate about the treatment of systemic sclerosis-associated interstitial lung disease? A plain language summary of publication

Ther Adv Respir Dis

2025, Vol. 19: 1–9

DOI: 10.1177/17534666251371814

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Summary

What is this summary about?

Systemic sclerosis (SSc) is a condition that affects the immune system (the body's natural defence system) and causes the skin to harden and thicken in large patches. Research shows that 30% to 90% of people with SSc also have **interstitial lung disease** (ILD), a condition that causes inflammation and scarring of the lungs. When people have SSc and ILD, it is known as SSc-associated ILD or SSc-ILD. The authors of this plain language summary of publication (PLS-P) reviewed different articles to find out what the key issues were in the way doctors and patients with SSc-ILD communicate with each other.

How to say

- **Cyclophosphamide:** sy-kloh-fos-fuh-mide
- **Glucocorticoid:** gloo-koh-kor-tih-koyd
- **Haematopoietic stem cell:** hee-muh-toh-poi-et-ik stem sel
- **Interstitial lung disease:** in-tur-stish-ul luh-ng duh-zeez
- **Interstitium:** in-tur-stish-um
- **Mycophenolate:** my-koh-feh-noh-layt
- **Nintedanib:** nin-teh-duh-nib
- **Prednisone:** pred-nih-sone
- **Pulmonologist:** pul-muh-nah-loh-jist
- **Rheumatologist:** roo-muh-tah-loh-jist
- **Systemic sclerosis:** sihs-tem-ihk skluh-rohw-suhs
- **Tacrolimus:** tak-roh-lih-mus
- **Tocilizumab:** toh-suh-lee-zoo-mab

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Received: 21 May 2025; revised manuscript accepted: 11 August 2025.

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What were the results?

The key messages from the studies were:

1. Most patients felt uneasy when they were diagnosed with SSc-ILD
2. Good communication between doctors and patients at the first visit is crucial as it sets the tone for future relationships
3. Both doctors and patients avoid talking about how SSc-ILD symptoms may get worse (prognosis) or the subject of death. Patients should be encouraged to ask questions to address important and personal topics that would not be talked about otherwise
4. Patients may feel intimidated by a doctor, which could interfere with communication
5. Doctors must be able to listen and show empathy to build a relationship with patients and be aware that different communication styles may suit a patient during different stages in their journey
6. Doctors should avoid using a lot of technical terms. Patients felt metaphors helped them understand their condition better
7. Patients have different awareness, thoughts, and feelings about SSc-ILD than doctors. If doctors understand this, it may improve the communication between doctors and patients

Ways to close the gap between the way doctors and patients communicate include patients having the opportunity to access:

- Self-learning and patient organizations
- Peer-mentoring (patients mentoring other patients)
- Information technology
- Shared decision-making, where the doctor and patient work together to come to a decision about treatment and care

What do the results mean?

The best way to improve the feelings patients have when they are diagnosed with SSc, including SSc-ILD, is to improve the quality of the communication between doctors and patients. The quality of the first meeting between a doctor and patient sets the tone for future checkups, especially if the doctor can listen, show empathy, and allow the patient to ask questions. Improving the patient's knowledge about SSc-ILD, for example by using websites, reading printed materials, or taking part in peer-mentoring schemes, may also contribute to a better conversation.

Keywords: **interstitial lung disease**, physician–patient communication, plain language summary of publications, shared decision-making, **systemic sclerosis**

Where can I find the original article on which this summary is based?

You can read the original article in the *Journal of Scleroderma and Related Disorders* at https://journals.sagepub.com/doi/10.1177/23971983251324803.

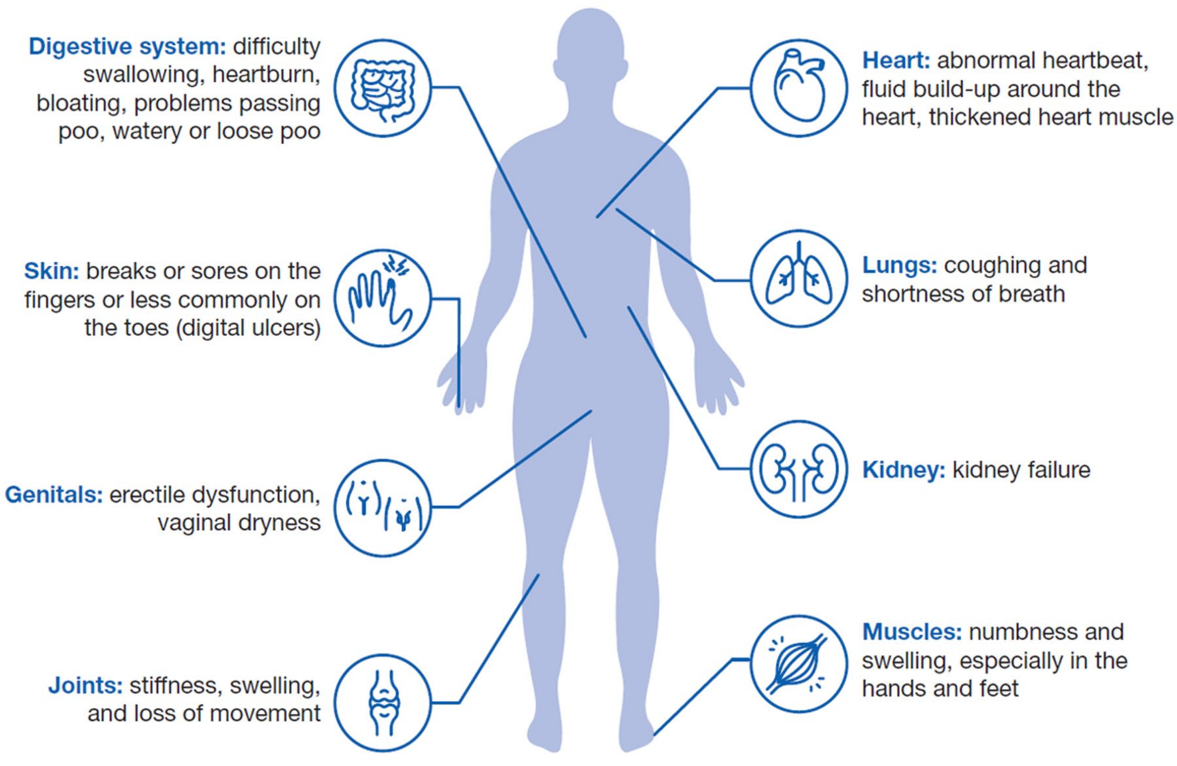
Kuwana M, Saito A, Farrington S, Galetti I, Denton CP, Khanna D. Physician–patient communication in the treatment of **systemic sclerosis**-associated **interstitial lung disease**: A narrative review and recommendations. *Journal of Scleroderma and Related Disorders*. 2025;0(0). doi:10.1177/23971983251324803

Who is this article for?

This summary may help people with **systemic sclerosis** or **systemic sclerosis**-associated interstitial disease, their families and caregivers, patient advocates, and healthcare professionals to improve communication between patients and their doctors.

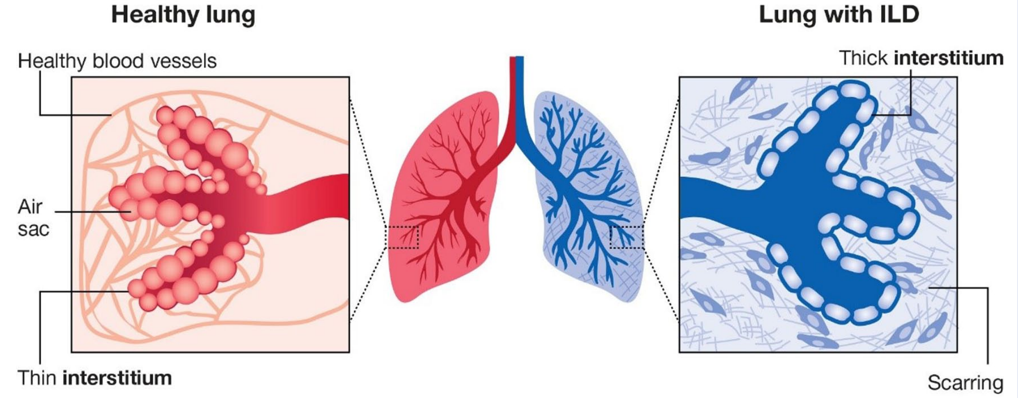
What is systemic sclerosis (SSc)?

SSc is a condition that affects the immune system, which is the body's natural defence system against germs and infections. In SSc, the immune system mistakes its own healthy tissue for something foreign and attacks them (known as an autoimmune condition). This causes the skin to harden and thicken in large patches. SSc may affect the following organs:



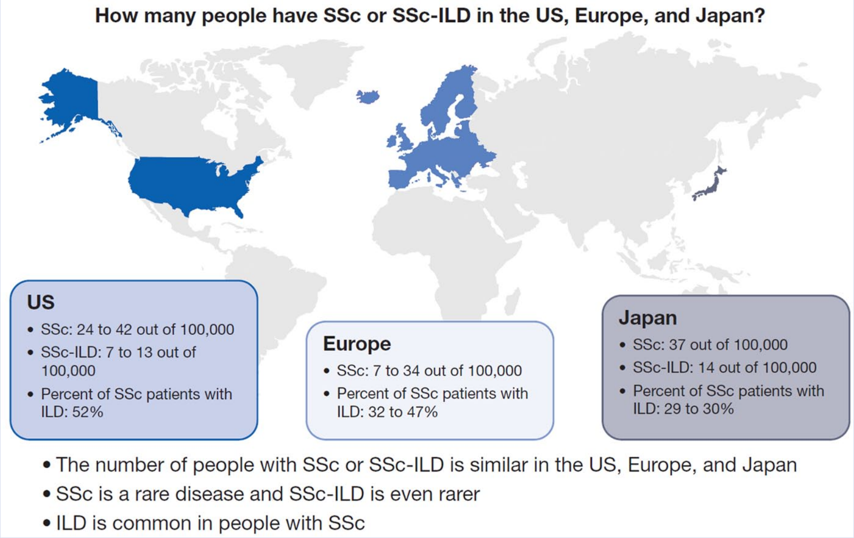
What is interstitial lung disease (ILD)?

ILD describes a large group of conditions that causes inflammation and scarring of the lungs. ILD affects a part of the lung called the **interstitium**, which is the tissue and space around the air sacs of the lungs.



- Research shows that 30%–90% of people with SSc have ILD, also known as SSc-associated ILD or SSc-ILD.
- The disease progression of SSc-ILD is very varied. Some patients can remain stable in their condition but around 30% of people with SSc die from respiratory failure.
  - Respiratory failure is when a person's lungs cannot get enough oxygen or remove enough carbon dioxide.

How many people have SSc or SSc-ILD in the US, Europe, and Japan?



US
- SSc: 24 to 42 out of 100,000
- SSc-ILD: 7 to 13 out of 100,000
- Percent of SSc patients with ILD: 52%

Europe
- SSc: 7 to 34 out of 100,000
- Percent of SSc patients with ILD: 32 to 47%

Japan
- SSc: 37 out of 100,000
- SSc-ILD: 14 out of 100,000
- Percent of SSc patients with ILD: 29 to 30%

- The number of people with SSc or SSc-ILD is similar in the US, Europe, and Japan
- SSc is a rare disease and SSc-ILD is even rarer
- ILD is common in people with SSc

What are the treatment options for SSc-ILD?

- **Haematopoietic stem cell** transplantation:
  - A transplant of stem cells, which are special types of cells that can turn into any other type of cell in the body.
  - Normally given to people during early stages of the disease who have a very high chance of developing respiratory failure.
- Lung transplantation:
  - A transplant of the lung is given to people who do not respond to any treatment and have a high chance of dying soon from respiratory failure.

- Medications:
    - Medications are the most common treatment for SSc-ILD. The three drugs currently approved for treatment of SSc-ILD are:
        - **Nintedanib**, a drug taken by mouth twice a day. It slows the development of scarring in the lungs but cannot get rid of any scarring that has already happened.
            - This drug was approved for use in people with SSc-ILD in 2019 in the United States and Japan, and was approved for use in the European Union in 2020.
        - **Tocilizumab**, an injection under the skin taken once a week. It decreases the body's immune response (it stops or slows the body attacking itself).
            - This drug was approved for use in people with SSc-ILD in the United States in 2021.
        - **Rituximab**, an injection under the skin taken once a week. It improves how the lungs work.
            - This drug was approved for use in people with SSc in Japan in 2021.
    - Doctors also prescribe other medications to decrease the body's immune response. However, these are "off-label prescriptions" in most countries. This means that they have been approved to treat other conditions, but not SSc-ILD:
        - **Mycophenolate**, a drug taken by mouth twice a day. It decreases the body's immune response.
            - This drug was approved for use in people with SSc-ILD in Japan in 2024.
        - **Cyclophosphamide**, a drug taken by the mouth or by an injection into a person's vein (intravenous injection). It decreases the body's immune response.
            - This drug was approved for use in people with SSc in Japan in 2011.
        - **Prednisone**, a drug taken by mouth once a day. It decreases the body's immune response.

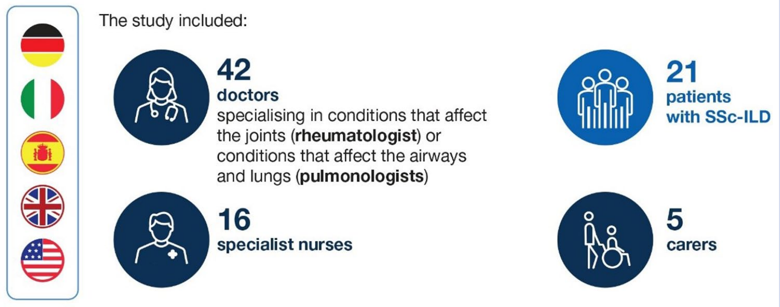
What is this study about?

- Medical societies (organizations that represent a particular group of medical professionals) and experts in the US, Europe, and Japan, have published recommendations and guidelines for managing SSc-ILD. However, these studies do not focus on how well doctors and patients communicate with each other during checkups.
- The authors looked through different articles to find out what the key issues were in the way doctors and patients with SSc-ILD communicate with each other.

How do doctors and patients communicate in the United States, Europe, and Japan?

Researchers focussed on the results of two articles:

- A study in Germany, Italy, Spain, the United Kingdom, and the United States to look at how doctors and patients with SSc-ILD communicated with each other.
    - The aim of the article was to understand the communication needs of patients with SSc-ILD to see if they are being met.
    - The study involved doing interviews and watching conversations between doctors, patients, nurses, and carers.


The study included:

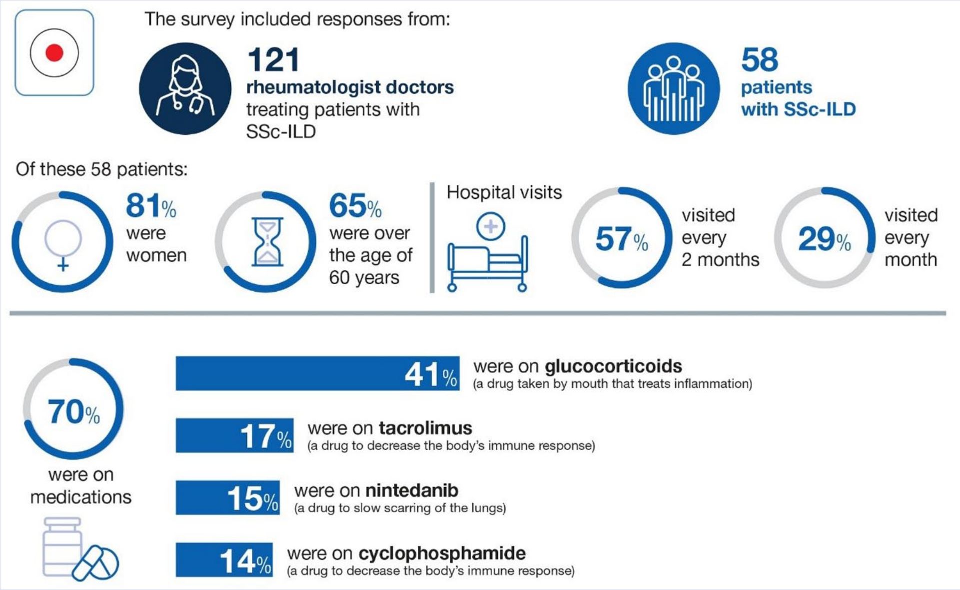
42
doctors
specialising in conditions that affect the joints (**rheumatologist**) or conditions that affect the airways and lungs (**pulmonologists**)

21
patients with SSc-ILD

16
specialist nurses

5
carers

- A survey of doctors and patients with SSc-ILD in Japan to look at the consistencies and inconsistencies in how doctors and patients communicate with each other.



The survey included responses from:

121
rheumatologist doctors
treating patients with SSc-ILD

58
patients with SSc-ILD

Of these 58 patients:

81% were women

65% were over the age of 60 years

Hospital visits

57% visited every 2 months

29% visited every month

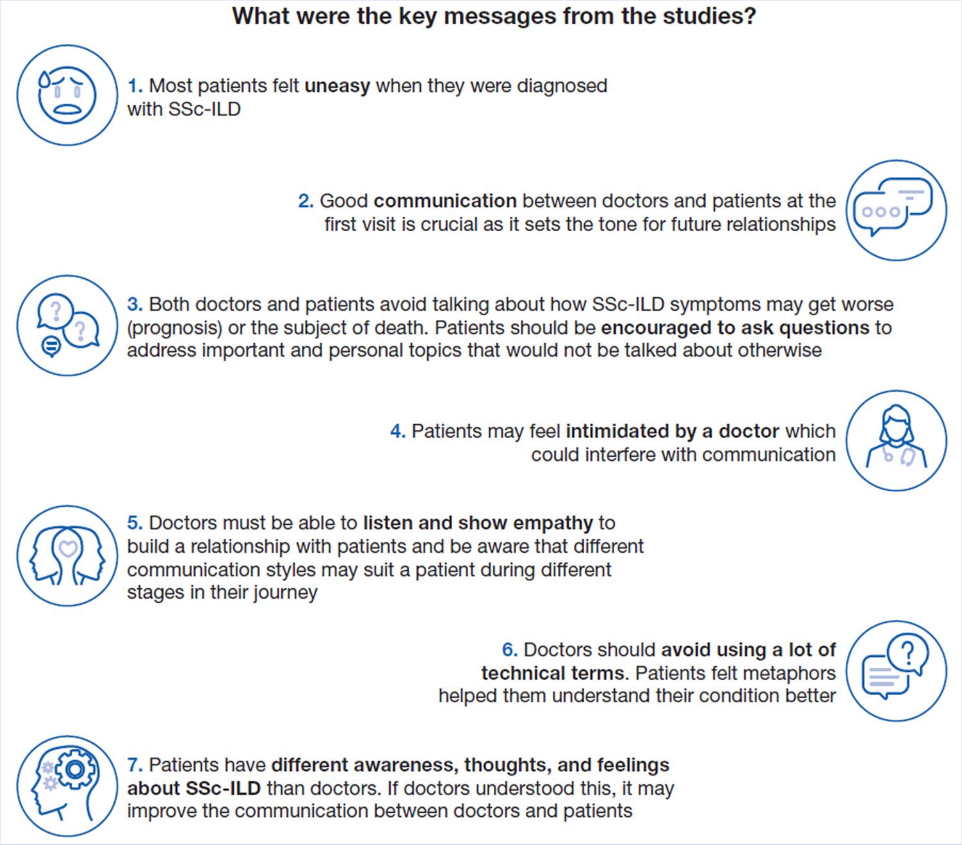
70% were on medications

41% were on **glucocorticoids**
(a drug taken by mouth that treats inflammation)

17% were on **tacrolimus**
(a drug to decrease the body's immune response)

15% were on **nintedanib**
(a drug to slow scarring of the lungs)

14% were on **cyclophosphamide**
(a drug to decrease the body's immune response)



What were the key messages from the studies?

1. Most patients felt **uneasy** when they were diagnosed with SSc-ILD
2. Good **communication** between doctors and patients at the first visit is crucial as it sets the tone for future relationships
3. Both doctors and patients avoid talking about how SSc-ILD symptoms may get worse (prognosis) or the subject of death. Patients should be **encouraged to ask questions** to address important and personal topics that would not be talked about otherwise
4. Patients may feel **intimidated by a doctor** which could interfere with communication
5. Doctors must be able to **listen and show empathy** to build a relationship with patients and be aware that different communication styles may suit a patient during different stages in their journey
6. Doctors should **avoid using a lot of technical terms**. Patients felt metaphors helped them understand their condition better
7. Patients have **different awareness, thoughts, and feelings about SSc-ILD** than doctors. If doctors understood this, it may improve the communication between doctors and patients

What did the patient authors (Sue Farrington and Ilaria Galetti) think were the most important issues in communication between doctors and patients?

The first visit is very important for creating trust and building a relationship with the doctor but sometimes the opportunity is missed

Doctors should communicate that they are on the patient's side

There are some topics that patients want to discuss but are not mentioned, such as changes in facial features and issues relating to sex life

Some doctors may talk *at* patients rather than have a back-and-forth conversation and patients are not encouraged to ask questions

SSc-ILD is a rare and complex disease and so patients need to understand that doctors do not have all the answers about the disease

How can we close the gap between the way doctors and patients communicate?

Self-learning and patient organisations

- Self-learning can include looking at websites, pamphlets, and other materials so patients can learn about SSc-ILD on their own
- Patient organisations have lots of educational tools such as websites to provide accurate information about SSc-ILD
- Patient education is important to reduce false or incorrect information

Peer-mentoring

- Patients with SSc can act as mentors for newly diagnosed patients
- Mentors can understand what it is like for new patients and can support them

Information technology and social media

- Visits could be made virtually and important information could be sent in an email
- In the US, doctors have been encouraged to use Twitter (now called "X") to promote their research
- Social media also contains false or incorrect information and fake news so readers should remain cautious

Shared decision-making

- Shared decision-making is where the doctor and patient work together to come to a decision about treatment and care
- For example, doctors could describe some treatment options for SSc-ILD but tell the patient to think about it before agreeing to a treatment option

What do the results mean?

- Other studies have shown that when patients participated in their checkups and trusted their doctors, they were happy with their treatment, and had fewer side effects, lower disease activity, and less damage to their organs.
- There are still a few ways to improve the way doctors and patients with SSc-ILD communicate with each other:
    - Improve the patient's knowledge about SSc-ILD: this is the best way to improve the way doctors and patients communicate with each other. Ways to improve a patient's knowledge include disease-awareness campaigns (such as websites and printed materials or pamphlets) and peer-mentoring schemes.
        - Healthcare organizations, patient organizations, and pharmaceutical companies need to do more to educate patients.
        - Different cultures and healthcare systems between countries can cause differences in how doctors and patients communicate. So not all patient education activities used in one country will be suitable for use in another country.
    - The quality of the first meeting between a doctor and patient has an important impact on communication especially if the doctor listens, shows empathy, and allows the patient to ask questions.

Where can you find the original article on which this summary is based?

The original article is entitled "Physician-patient communication in the treatment of **systemic sclerosis**-associated **interstitial lung disease** (SSc-ILD): A narrative review and recommendations" and is available free of charge at https://journals.sagepub.com/doi/10.1177/23971983251324803.

Where can I find more information?

- Peer-mentoring programmes:
    - https://www.uofmhealth.org/conditions-treatments/rheumatology/peer-mentors-scleroderma
- Patient self-learning:
    - https://sites.google.com/umich.edu/selfmanagescleroderma/home
- Patient organizations:
    - https://scleroderma.org/
    - https://www.sruk.co.uk/scleroderma/
    - https://fesca-scleroderma.eu/
- Disease awareness websites by pharmaceutical companies
    - https://hai-senishou.jp/ssc

Declarations

Ethics approval and consent to participate
Not applicable.

Consent for publication
Not applicable.

Author contributions

Masataka Kuwana: Conceptualization; Writing – original draft; Writing – review & editing.

Aiko Saito: Writing – review & editing.

Sue Farrington: Writing – review & editing.

Ilaria Galetti: Writing – review & editing.

Christopher P. Denton: Conceptualization; Writing – review & editing.

Dinesh Khanna: Conceptualization; Writing – review & editing.

Acknowledgements

The authors meet criteria for authorship as recommended by the International Committee of Medical Journal Editors (ICMJE) and were fully responsible for all content and editorial decisions, and were involved at all stages of manuscript development. Medical writing assistance was provided by Nikita Vekaria, PhD, of Envision Ignite, an Envision Medical Communications agency, a part of Envision Pharma Group under the authors' conceptual direction and based on feedback from the authors, and was contracted and compensated by Nippon Boehringer Ingelheim Co. Ltd. Nippon Boehringer Ingelheim was given the opportunity to review the manuscript for medical and scientific accuracy as well as intellectual property considerations.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: this review is based on roundtable discussions between the authors in Tokyo, Japan (3 December 2022) and at the 8th Systemic Sclerosis World Congress in Prague, Czech Republic (14–16 March 2024), sponsored by Nippon Boehringer Ingelheim Co. Ltd. and Boehringer Ingelheim, respectively.

Competing interests

The authors received no direct compensation related to the development of the manuscript. M.K. has received consulting fees, speaking fees, and research grants from Argenx, Asahi Kasei, AstraZeneca, Boehringer Ingelheim, Chugai, GlaxoSmithKline, Janssen, Kissei, MBL, Mitsubishi Tanabe, Mochida, Nippon Shinyaku, Ono Pharmaceuticals, and Taisho. A.S. is an employee of Nippon Boehringer Ingelheim Co. Ltd. S.F. and I.G. have nothing to disclose. C.P.D. reports consulting fees from Roche, Boehringer Ingelheim, GlaxoSmithKline, Horizon Therapeutics, CSL Behring; honoraria from Boehringer Ingelheim and Janssen; and grants from Horizon Therapeutics, GlaxoSmithKline, and Servier. D.K. reports consultancies with Amgen, Argnx, Astra Zeneca BMS, Boehringer Ingelheim, Genentech/Roche, GSK, Mitsubishi Tanabi, Merck, Novartis, and Zura Bio.

Availability of data and materials

Not applicable.

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