Scleroderma Health Care Survey 2026

In May 2026 Scleroderma New Zealand surveyed its members about access to health services. This survey looked at what was working well and access to health providers through the public or private health sector.

This survey repeated some questions from a similar survey of Scleroderma NZ members in 2018.

The survey was completed online. A link to the survey was emailed to Scleroderma NZ members and placed on the Scleroderma NZ facebook pages. At the end of May people were reminded about the survey.

There were 99 New Zealand resident responders. 89% were members of Scleroderma NZ, a 33% response rate among Scleroderma NZ members.

Most, 93%, were female. They were aged between 30 and 85 years old, mean 64, with half of the responders aged between 55 and 74 (the interquartile range – ages with 25% younger than 55 years old and 25% older than 74 years old).

There were people from across New Zealand.

Northland	4	4%
Auckland	17	17%
Waikato	15	15%
Bay of Plenty	9	9%
Hawke's Bay	6	6%
Taranaki	6	6%
Manawatu/Whanganui	8	8%
Wairarapa	1	1%
Wellington	18	18%
Nelson-Marlborough	1	1%
Canterbury	6	6%
Southern	8	8%

Most responders were European.

Maori	5	5%
Pacific	1	1%
Asian	4	4%
European	88	89%
Other	1	1%

People had been diagnosed with scleroderma ranging from recently, to more than 40 years ago. The median duration was 10 years, with 50% (the interquartile range) between 5 and 20 years.

The time between when people first saw a doctor for their symptoms of scleroderma and their scleroderma diagnosis ranged from immediately to 30 years. The median duration was six months, with 50% (the interquartile range) between three months and two years, with 10% diagnosed immediately. One person was diagnosed within a short time as they asked for blood tests to determine whether they had primary or secondary Raymaud’s. Someone else commented that it took four years and they were going back to the doctor all the time about their pain and joints before the doctor did anything about it.

Most, 96%, see a rheumatologist and 3% see an immunologist. 2% saw both a rheumatologist and an immunologist. 3% do not see either a rheumatologist or an immunologist. They do not live in regions with a tertiary hospital. Of those who see a rheumatologist, 89% only saw them in the public health service, 5% only privately and 5% in both the public health service and privately. Of the three who see and immunologist one does so in the public health service and two privately. 16% see their rheumatologist or immunologist 3 monthly, 26% 6 monthly, 48% yearly, 6% 2 yearly and 4% less than 2 yearly.

94% have had a lung function test. Of those, 2% have one 3 monthly, 9% have one 6 monthly, 47% yearly, 25% 2 yearly and 17% less often. 95% have their lung function test through the public health service and 6% privately (two people have both).

47% have had a six-minute walk test. Of those, 2% have one 3 monthly, 11% 6 monthly, 29% yearly, 18% 2 yearly and 40% less often. 91% have their six-minute walk test through the public health service and 11% privately (two people have both).

88% have had an echocardiogram (an ultrasound scan of heart). Of those, 3% have one 6 monthly, 45% yearly, 22% 2 yearly and 29% less often. 89% have their echocardiogram through the public health service and 12% privately (three people have both).

49% monitor their blood pressure at home. Of those, 14% daily, 39% weekly, 22% monthly, 14% 3 monthly and 10% less often.

For 58% their rheumatologist / immunologist checked their blood pressure. and for 46% their rheumatologist / immunologist nurse checked their blood pressure. For 76% their rheumatologist / immunologist or their nurse checked their blood pressure. A GP or medical centre nurse check their blood pressure for 78%. 4% were checked monthly, 35% 3 monthly and 61% less often. 9% of people did not have their blood pressure checked by these. Two of these nine people monitored their blood pressure at home, leaving seven who did not have their blood pressure monitored.

36% see their GP for Scleroderma health related checks. Among those 36% see them 1–3 monthly, 5% 3–6 monthly, 15% 6–12 monthly and 3% less often.

Most people have regular blood tests from their GP, rheumatologist or immunologist to monitor their health.

Blood test monitoring	Percent having blood test
Kidney function	66%
Liver function	63%
ANA panel	29%
Thyroid	29%
Inflammatory markers (CRP)	44%
Vitamin D	20%
Sugar levels	21%
Cholesterol levels	29%
Full blood count	63%

People have regular blood tests from their GP to monitor their kidney function (66%), liver function (63%), ANA Panel (29%), thyroid (29%), inflammatory markers (CRP) (44%), vitamin D (20%), sugar levels (21%), cholesterol levels (29%) and full blood count (63%).

6% did not have any of the above tests. 16% were unsure what test they had and a further 9% had one or more of the above tests and were unsure what else.

8% are on care-plus (funding provided to general practices to improve chronic care management, 3 monthly GP visits at reduced fee), 2% just for scleroderma, 3% just for another chronic health condition and 3% for both scleroderma and another chronic health condition.

61% have straightforward access to medical professionals and the care they need in the public health system.

8% knew about the Access and Choice programme (publicly funded mental wellbeing support services, provided by some GP services and other providers in New Zealand). They all used the Access and Choice programme. None received their services related to Scleroderma.

Health services accessed for Scleroderma related diagnosis through the public or private health system

	Accessed	Public only	Public and private	Private only
Ophthalmology (eye clinic)	27%	12%	4%	11%
Gastroenterology	51%	33%	7%	10%
Cardiology	59%	44%	9%	5%
Respiratory Clinic	63%	54%	6%	3%
Orthopaedic Clinic	14%	6%	3%	5%
Renal Clinic	5%	4%	1%	0%
Physiotherapy	30%	16%	4%	10%
Hand Therapy	31%	22%	3%	6%
Podiatry	22%	6%	2%	14%
Dietician	21%	16%	1%	4%
Dentistry	25%	6%	0%	19%
Neurology	5%	2%	0%	3%
Dermatology	19%	11%	1%	7%
ENT (Ear Nose and Throat)	13%	7%	1%	5%
Exercise programme	9%	6%	0%	3%
Home help	8%	4%	1%	3%
Mobility parking permit	30%	30%	-	-

35% have been told that they have Lung Fibrosis (Interstitial Lung disease, ILD). They had the following treatments.

	Currently	Previously	Not had
Cyclophosphamide	0%	20%	80%
Mycophenolate mofetil (CellCept)	40%	9%	46% (51%*)
Nintedanib	0%	0%	89% (100%*)
Pirfenidone	0%	0%	91% (100%*)
Rituximab	3%	6%	83% (91%*)
Tocilizumab	3%	0%	89% (97%*)
Any of the above	46%	11%†	34% (43%*)

* including not answered as not had.

† not including those currently on treatment.

Of the 17 who had mycophenolate for 3 months or more, 15 said they receive benefit from it. One of them experienced intolerable side effects. The two who said they did not receive benefit from it experienced intolerable side effects. One other person did not have mycophenolate because it might be harmful for them.

Fourteen, 14%, reported having lung deterioration without a diagnosis of ILD. Four people said they might have lung fibrosis and four said their deterioration was due to another cause.

20% have ulcers on their fingers (but not their toes), 3% have ulcers on the fingers and toes and 1% have ulcers only on their toes. Of the 24 people with ulcers, 8 were treated with sildenafil (1 also with nifedipine, 1 also with rectogesic, to treat fissures, and 1 also with an antibiotic and CBD balm, a herbal cream), 1 other was treated with nifedipine and iloprost, 2 were treated with antibiotics, 2 were treated surgically, and 1 with an anaesthetic. Seven were not on treatment and three did not say what treatment they were on.

7% have lost fingers and 1% their toes. Most losing one finger, with one losing two and one losing three. The person who lost their toes is a double amputee.

People were asked if they had any concerns or helpful information they would like to share about their scleroderma care. About half, 49 people, responded with comments.

A common concern was that people thought there were not enough health care services available. Concern was expressed about staffing workloads *'our health care system is so under resourced they can't give us the treatment and care we need'*, *'long delay between rheumatology appointments'* and *'I waited nearly a year to see a dermatologist'*. Some areas of New Zealand like Northland, Taranaki and Palmerston North have poor access for patients to see a rheumatologist and the patients had to travel to other centres. Tauranga is without a rheumatology nurse, *'They were the go between and would pass a concern on to the rheumatologist. No way to contact now'*. Concern was expressed about a lack funds for podiatry, dentistry and opticians. One person has *'been wondering if it would be worth going to a scleroderma clinic in Australia'*.

Serval expressed concern that they felt there was a lack of knowledge about scleroderma among their health professionals and others. *'Too little is known by too few'*. *'There is a lack of knowledge from health services regarding Scleroderma'*. A GP said *'I don't look like I Have Scleroderma'*. *'My GP doesn't seem engaged or interested'*. *'It's an unknown disease and wish more people would understand the silent pain we go through'*. One implying that more research is needed *'Still not enough understood on treating Scleroderma'*.

People also felt they need to know more about scleroderma and its care. *'I don't know what's available and how to access it'*. *'It's the unknown that gets to me, like am I going to grow old with my family I know it's life limiting but how limiting?'*. *'Not sure how serious scleroderma is or should be treated by medical professionals'*. *'Not informed of care-plus program'*. *'No information given on support group or help available from the rheumatologists'*. *'I'm still working through everything and quite confused and to be honest scared'*.

People expressed concern about delays and long wait times. *'Health system issues: - Very slow, long waiting times'*. *'there was a delay of 21 days before the prescription reached my chemist'*.

Some felt there was a lack of coordination. *'No real co-ordinator between rheumatologist and other specialists'*. *'I feel there is no coordinated care'*.

A few had private health care, one saying *'I seem to have to pay to get any treatments privately'*.

Some expressed appreciation for the health professionals. *'The docs I see are great'*. *'most doctors and very kind but not that knowledgeable about treatment'*, *'While the local rheumatology team are fantastic, our health care system is so under resourced they can't give us the treatment and care we need'*.

A few express appreciation for the support that Scleroderma New Zealand provides. *'I am glad there is a scleroderma NZ because sometimes you feel isolated as people around you don't really understand the extent of this chronic condition'*. *'I do like the newsletter you put out'*. *'I am only starting hand therapy next week as I went to Te Awamutu for a Scleroderma seminar last year and they said to get referred sooner rather than later'*.

Comparison with 2018

There were similar responses to most comparable questions in 2018. The response rate among Scleroderma NZ members was similar in both surveys, 30% in 2018 and 33% in 2026. A higher proportion of 2026 responders are members of Scleroderma NZ (89% in 2026 and 71% in 2018).

Responders were, on average, four and a half years older in 2026 than 2018.

More people saw either a rheumatologist or an immunologist in the 2026 survey (97%) than the 2018 survey (88%). With more seeing a rheumatologist in 2026, 96%, than in 2018, 76%. They were being seen by a rheumatologist or an immunologist more frequently in 2026.

People who monitored their blood pressure at home were doing so more frequently in 2026. In 2018 more people reported that their GP monitored their blood pressure (92%) than said in 2026 that their GP or medical centre nurse checked their blood pressure (78%).

Fewer people see their GP in 2026 for scleroderma health related checks (36%) than in 2018 (75%). Fewer people are you on care-plus in 2026 (5%) than in 2018 (26%).

Summary

Responders to the surveys reported and increase in access to rheumatologists. However, many responders said they needed more and better access to rheumatologists.

There were lower proportions reporting GP care for scleroderma in 2026.

In 2026 half have had a six-minute walk test. This is still a low proportion, although higher than in 2018 when a third had had a six-minute walk test.

Seven percent of responders did not have their blood pressure monitored.

About a third of responders, 36%, said they did not have straightforward access to medical professionals and the care they need in the public health system.

There was an amputation rate of 8%.

Conclusion

There is a need for more rheumatologists and increased funding and scope of the public health service.

People were concerned about the level of care they received and the knowledge about scleroderma, among health professionals, themselves and generally.