

Final Report - 2023 Arthritis Australia Grant-in-Aid

Application Title: Development of a patient global assessment for systemic sclerosis

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Lay summary

Systemic sclerosis, or scleroderma, is an autoimmune disease that causes scarring of the skin and internal organs. This multi-organ system involvement has meant that measuring important changes in disease status in clinical trials of novel therapies has remained challenging. In this project, we have addressed how patients and physician perceive overall disease and how they assess the totality of systemic sclerosis and its effects on patients. These results are being used to develop new global assessment instruments to use in clinical trials to better measure patients' response to treatment. We have demonstrated that physicians evaluate multiple components, including patient symptoms, examination findings and test results when making their global assessment. Interviews of physicians and patients have highlighted significant uncertainty about the overall assessment of systemic sclerosis despite the perceived importance of global assessment instruments as a tool to evaluate disease progression.