



**School of Medicine
and Public Health**
UNIVERSITY OF WISCONSIN-MADISON

Title of Study: Blood Type Distribution in Autoimmune Diseases: A Large-Scale, Self-Report, Anonymous Survey

UW Madison IRB Exempt Project: 2017-0545

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Background

In Spring 2017, the Scleroderma Education Project, a 501c3 non-profit organization focused on systemic scleroderma education and research, conducted a large-scale, anonymous, self-report survey of blood types in patients diagnosed with systemic sclerosis (scleroderma). A total of 924 responses were obtained over a six-week period. About 62% were from the US. The survey asked only two questions:

- What is your blood type?
- What is your country of birth?

While the detailed statistical analysis of these results is still underway, it is very clear that the survey results are significantly different than the weighted population norms of the survey respondents.

Study Goals

To determine if these anomalous results were specific to systemic sclerosis, a follow-on large-scale study is being done by the University of Wisconsin, Madison. Four additional autoimmune diseases are being surveyed as part of this new study:

- Systemic Lupus Erythematosus (SLE)
- Rheumatoid Arthritis
- Psoriasis
- Ankylosing Spondylitis

Upon completion of this study, we should have preliminary answers to two important questions:

- 1) Is the distribution of blood types in each of these five autoimmune diseases the same as in the general population?

2) Does blood type distribution differ among these different autoimmune diseases?

Systemic sclerosis (SSc), systemic lupus erythematosus (SLE), and rheumatoid arthritis (RA) are similar in that patients with these diseases are usually middle-aged women and almost always test positive for anti-nuclear (ANA) antibodies. In contrast, while psoriasis is also a heavily female-dominant autoimmune disease, patients with psoriasis are almost always ANA-negative. Ankylosing spondylitis was included in this study as it is one of the few autoimmune diseases that is male-dominant and is also ANA-negative.

Because of concerns that self-report survey data can inherently be subject to either self-selection bias or inaccurate reporting of diagnosis or blood type information, these surveys are being conducted with very large study populations (minimum: 1000 respondents per disease). Depending on the results of this pilot study, a follow-on study is planned using actual patient records to eliminate these self-report survey concerns and to examine potential additional data that may help to explain the results of the pilot study.

Since the previous pilot study conducted by the Scleroderma Education Project suggests that patients with systemic sclerosis have an unexpected distribution of blood types as compared to population norms, it becomes very important to understand if this phenomenon is isolated to this one autoimmune disease or may occur in other autoimmune diseases as well. When there is a relationship between blood types and disease susceptibility or resistance, this can provide important information that may be useful in understanding the pathogenesis of the disease and may lead to improved treatment approaches.

Inclusion and Exclusion Criteria and Survey Links

Each of the four additional study diseases has its own specific inclusion and exclusion criteria. In all cases, however, survey participants need to know their blood type (A, B, AB, or O) and RH factor (positive or negative) to participate in the survey. Here are the specific inclusion and exclusion criteria for each disease, as well as links to the individual surveys:

Systemic Lupus Erythematosus (SLE)

Who Should Take This Survey

You should complete this survey only if you have been formally diagnosed with Systemic Lupus Erythematosus (SLE).

Who Should Not Take This Survey

- Patients with a tentative diagnosis such as UCTD (Undifferentiated Connective Tissue Disease).

- Patients with a lupus/scleroderma overlap syndrome such as Mixed Connective Tissue Disorder (MCTD)

Survey Link: <https://www.surveymonkey.com/r/8F57BC6>

Rheumatoid Arthritis

Who Should Take This Survey

You should complete this survey only if you have been formally diagnosed with Rheumatoid Arthritis.

Who Should Not Take This Survey

- Patients with a diagnosis of osteoarthritis.
- Patients with a tentative diagnosis such as UCTD (Undifferentiated Connective Tissue Disease).

Survey Link: <https://www.surveymonkey.com/r/76VYXYL>

Psoriasis

Who Should Take This Survey

You should complete this survey only if you have been formally diagnosed with Psoriasis.

Who Should Not Take This Survey

This survey is restricted to Psoriasis patients who do not also have Psoriatic Arthritis. If you have Psoriatic Arthritis or your doctor believes that you may have this complication, please do not take this survey.

Survey Link: <https://www.surveymonkey.com/r/5LBBMQL>

Ankylosing Spondylitis

Who Should Take This Survey

You should complete this survey only if you have been formally diagnosed with Ankylosing Spondylitis.

Who Should Not Take This Survey

Patients with Enteropathic Arthritis, Psoriatic Arthritis, Reactive Arthritis, or Undifferentiated Spondyloarthritis.

Survey Link: <https://www.surveymonkey.com/r/DWHVWXZ>

If you have any questions about this study, please contact:

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