

**SICCA Sjögren's International Collaborative Clinical Alliance**  
**Data Request Form**

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**SJÖGREN'S SYNDROME CASE DEFINITION:** based on the new American College of Rheumatology Classification Criteria for Sjögren's syndrome (Shiboski et al, 2012)\*

A "case" is defined as having two out of three of the following objective tests:

- Serology positive for anti-SSA and/or SSB antibodies **OR** (positive rheumatoid factor **and** ANA titer  $\geq 1:320$ ).
- Ocular staining score  $\geq 3$
- Presence of focal lymphocytic sialadenitis with a focus score  $\geq 1$  focus/4 mm<sup>2</sup>;

A "control" *may* be defined as being negative for all objective tests included in the case definition above, however, applicants may wish to propose an alternative definition for a control in their proposed plan.

Please check data requested.

<input type="checkbox"/> Case status (ACR SS phenotype versus control phenotype)	
<input type="checkbox"/> Race/ethnicity (see list below)	
Caucasian, Native American, Asian or Pacific Islander, Hispanic/Latino African-American, Afro-Caribbean or other African Heritage	
<input type="checkbox"/> Age	<input type="checkbox"/> Gender
<input type="checkbox"/> Labial salivary gland (LSG) biopsy diagnosis	
<input type="checkbox"/> LSG biopsy Focus Score (0 - 12)	<input type="checkbox"/> Ocular Staining Score (0 – 12)
<input type="checkbox"/> SSA (negative or positive)	
<input type="checkbox"/> SSB (negative or positive)	
<input type="checkbox"/> ANA (negative or positive, if positive, includes titer and pattern)	
<input type="checkbox"/> Rheumatoid factor (negative or positive)	
<input type="checkbox"/> Recruitment site (Argentina, China, Denmark, India, Japan, UK, US)	
<input type="checkbox"/> Other, please explore our data collection forms on the SICCA website: <a href="https://sicca-online.ucsf.edu/">https://sicca-online.ucsf.edu/</a>	

\*\*This data request form has a limited number of variables. Additional variables are available for dissemination. These can be explored by using the Data Services section of our website: <https://sicca-online.ucsf.edu/>

A detailed plan of the proposed statistical analysis and evidence that a statistician will be performing these analyses must be included in the proposal. The applicant would also need to be able to provide data analyses output as needed for quality control by the SICCA Statistical team. If the applicant does not have access to local statistical support, they would need to collaborate with the UCSF SICCA team for analyses to be performed by the SICCA Statistical team.

### **DELIVERY INFORMATION**

**We will deliver data via a secure server to the recipient and email address specified below:**

**Recipient:** \_\_\_\_\_

**Email:** \_\_\_\_\_

**Phone:** \_\_\_\_\_

\* Shiboski SC, Shiboski CH, Criswell LA, Baer AN, Challacombe S, Lanfranchi H, *et al.* American college of rheumatology classification criteria for Sjogren's syndrome: a data-driven, expert consensus approach in the Sjogren's international collaborative clinical alliance cohort. *Arthritis Care Res* 2012;64:475-487.