SICCA *Sjögren's International Collaborative Clinical Alliance Next Generation Studies*

Data Request Form

Joanne Nititham, UCSF, 513 Parnassus Avenue, San Francisco, CA
94143-0500 415-502-1995 (voice) • 415-476-9370 (fax) •
Joanne.Nititham@ucsf.edu

SJÖGREN'S SYNDROME CASE DEFINITION: based on the 2016 ACR-EULAR Classification Criteria for Sjögren's syndrome (Shiboski et al, 2017).*

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

Item	Weight / Score
LSG with FLS and FS ≥ 1[3]	3
Anti-SSA (Ro) +	3
OSS ≥ 5 (or VB ≥ 4) on at least one eye[4]	1
Schirmer ≤ 5 mm/5min on at least one eye	1
UWS[5] flow rate ≤ 0.1 ml/min	1

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.

☐ Case status (ACR SS phenotype versus control phenotype)

☐ Race/ethnicity (see list below)

Caucasian, Native American, Asian or Pacific Islander, Hispanic/Latino African-American, Afro-Caribbean or other African Heritage

☐ Age ☐ Gender

☐ Labial salivary gland (LSG) biopsy diagnosis

☐ LSG biopsy Focus Score (0 - 12) ☐ Ocular Staining Score (0 – 12)

☐ SSA (negative or positive)

☐ SSB (negative or positive)

☐ ANA (negative or positive, if positive, includes titer and pattern)

☐ Rheumatoid factor (negative or positive)

☐ Recruitment site (Argentina, China, Denmark, India, Japan, UK, US)

☐ Other, please explore our data collection forms on the SICCA website:
https://siccaonline.ucsf.edu/

**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://siccaonline.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 CH**, Shiboski SC, Seror R, Criswell LA, Labetoulle M, Lietman TM, Rasmussen A, Scofield H, Vitali C, Bowman SJ, Mariette X and the International SS Criteria Working Group. 2016 ACR-EULAR Classification Criteria for primary Sjögren's Syndrome: A Consensus and Data-Driven Methodology Involving Three International Patient Cohorts. *Arthritis & Rheum* 2017;69(1):35-45