

Conditions for using SCAPIS data

SCAPIS is a collaborative project and a result of the hard work of many people and the generous contributions of the study participants. To make best possible use of the data, the following conditions apply:

Application

1. Data is provided only for the purposes described in the project application to SCAPIS *(Petition-XXX — Titel)* to the receiving Principal Investigator *(Namn)*.

Responsibility

2. The receiving Principal Investigator (PI) is responsible for downloading the approved dataset within 30 days after receiving the confirmation email that data are ready for delivery. After 30 days the data set will no longer be available for downloading. Upon receipt of the data, the PI's responsible research organization will take over as the **data controller** for the personal data received and is thereby responsible for compliance with applicable legislation and respect for the consent of the participants. The data constitutes sensitive personal data and shall be processed in accordance with applicable personal data legislation, the guidelines of the responsible research organization and the Public Access to Information and Secrecy Act. The data may not be deposited in a database that is using open access. Open access in these conditions means published freely available on the Internet. Please note that the data obtained from SCAPIS must not be processed or stored outside Sweden in any way. Also note that SCAPIS data must not be used for linkage to other registers or for prospective follow up analyses.

Data exclusivity and return to SCAPIS Data Service

- 3. SCAPIS offers **no exclusivity to** data. However, cooperation between groups with similar projects is encouraged.
- 4. Where appropriate, the Principal Investigator shall be prepared to make newly generated data from the project available via the SCAPIS Portal. In these cases, SCAPIS will need a description of the generated data after completion of the analysis. Once imported into the SCAPIS Portal, the new data will be available for other researchers to apply for in accordance with ordinary SCAPIS procedures. However, it may be decided that newly imported data should be protected by embargo in favour of the Principal Investigator for a limited period of time.

Publications and communication

- 5. The project summary, title, name of the Principal Investigator and responsible research organization will be published on www.scapis.org at the time of the application's approval, to promote transparency and cooperation. The project's popular scientific summary, title, the name of Principal Investigator and responsible research organization will be published on www.scapis.se at the time of the application's approval, for information to members of society in general and study participants in particular.
- 6. In accordance with established practice in the scientific community all authors must fulfil the ICMJE recommendations for authorship (ICMJE). SCAPIS encourage offering of **co-authorship** to



individuals who contributed to the creation of SCAPIS. In the cases so agreed, the Principal Investigator ensures that the persons concerned are given the opportunity to contribute to the research to such an extent that co-authorship can be justified.

- 7. In the scientific publication of research based on SCAPIS data, the following text shall be included:
 - If possible, SCAPIS shall be mentioned in the title and/or abstract.
 - In acknowledgement:

"The main funding body of The Swedish CArdioPulmonary bioImage Study (SCAPIS) is the Swedish Heart-Lung Foundation. The study is also funded by the Knut and Alice Wallenberg Foundation, the Swedish Research Council and VINNOVA (Sweden's Innovation agency) the University of Gothenburg and Sahlgrenska University Hospital, Karolinska Institutet and Stockholm county council, Linköping University and University Hospital, Lund University and Skåne University Hospital, Umeå University and University Hospital, Uppsala University and University Hospital."

- 8. SCAPIS encourages open access publishing.
- 9. At the same time as the scientific **publication** of the project, the Principal Investigator is encouraged to **notify the SCAPIS office** to facilitate follow-up and communication on current publications.
- 10. The Principal Investigator is expected to be available and helpful for any popular science communication about the project, coordinated by the Heart-Lung Foundation, without compensation.

Applications involving register data

11. If the approved dataset involves data from register, the Principal Investigator is responsible for that register data is not used for prospective analyses.

Medical image material

12. If the application concerns a project involving analysis of SCAPIS medical images currently stored within regional IT/IS image storage systems, the Principal Investigator is responsible for obtaining the necessary permits to access these images and when necessary, arrange for the images to be pseudonymised prior to scientific analysis.

Acceptance of the terms and conditions

To accept the terms and conditions: Confirm the email with the conditions from the SCAPIS office with "OK". Acceptance of the conditions must be sent from the same email address that received the email with the conditions. The accepted conditions will be saved together with other application documents. The Principal Investigator is also encouraged to save the conditions herself.