

USER MANUAL

Idiopathic Interstitial Pneumonia Registry

USER MANUAL – IIP LUNG REGISTRY

Internet access: <https://lung.swissrdl.unibe.ch/timeout.jsf>

Idiopathic Interstitial Pneumonia Registry

Username

Password

 Login

[Forgot password](#) [New user](#)

Welcome to the Swiss Lung Registry

The Swiss Lung Registry includes patients from the Swiss IIP registry with idiopathic interstitial pneumonias (IIPs), other interstitial lung diseases (ILDs), and survivors of SARS-Cov-2 infection (COVID-19). This prospective cohort study aims to investigate the natural course of disease, response to specific treatments, and risk factors for the development and progression. We collect potentially related exposures and risk factors, clinical data, patient reported outcomes, pulmonary function, and physical performance test. The ongoing collection of blood samples and storage in our bio bank facilitates the investigation of underlying biological mechanisms.

www.swissiip.ch/

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Webinar

In consultation with the responsible persons of the Lung Registry we accomplish webinars. If you are interested about any information, please contact PD Dr. med. Manuela Funke-Chambour.

[Webinar in how to enter data \(english\)](#)

This registry is managed by SwissRDL, a group of the University of Bern, specialized in registries and data linkage.

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If you have questions about storage, data transfer and encryption, feel free to contact our IT team:

[Swissrdl_it\[at\]ispm.unibe.ch](mailto:Swissrdl_it[at]ispm.unibe.ch)

For more information about SwissRDL visit our website www.swissrdl.unibe.ch.

TABLE OF CONTENTS

This table of contents is a dynamic PDF file. The chapter you click on will guide you to the corresponding page.

USER MANUAL – IIP LUNG REGISTRY	1
TABLE OF CONTENTS	2
1. GENERAL INFORMATION	3
1.1. Help	3
1.2. Patient-based System	3
1.3. Obligatory Demographic Data	3
1.4. Features of the IIP Registry	3
1.5. Languages and Font Size.....	4
1.6. Processing Status of the Forms	4
1.7. Profiles in the IIP Registry – Access Authorization	4
1.8. Tools	5
1.9. Employment in Multiple Clinics.....	5
2. REGISTRATION	6
2.1. Create a User Account.....	6
2.2. Activation of Your Access	6
2.3. Inactivated User Account	6
2.4. Forgot Password	6
3. DATA ENTRY	7
3.1. Patient Data.....	7
3.1.1. Search Patient.....	7
3.1.2. Create a Patient Record	7
3.1.3. Edit a Patient Record	7
3.1.4. Delete a Patient Record	8
3.2. Case Data.....	9
3.2.1. Create New Form.....	9
3.2.2. Different versions in the registry	9
3.2.3. Enter Data.....	9
3.2.4. Submit a Form	11
3.2.5. Modify or Complete a Form	11
3.2.6. More than one Visit: Document case-based	11
4. DOWNLOAD DATA	12
5. ONLINE STATISTICS	13

1. GENERAL INFORMATION

1.1. Help

- F5** In case of any problem, press F5 on your keyboard to refresh the page.
-  You will find assistance to a specific page by clicking on «?».
- Mouse roll over** By positioning your cursor on a symbol, you can view the symbol's function.

1.2. Patient-based System

This medical internet-based documentation registry system is a patient-based system. The demographic data of patients are registered once per clinic and with the specification of a unique medical record number (MRN) in an anonymized way. Therefore, the sensitive data is refrained on a local server and only a one-way hash code sent to the central server.

1.3. Obligatory Demographic Data

The following demographic data are obligatory:

- **Date of birth**
- **Gender**

The information above is collected with the objective of a cross-institutional long-term observation. It is sent as a one-way hash code of level 1 to the central server in order to keep all demographic personal data (clinic, doctor, patient) on a local module server.

1.4. Features of the IIP Registry

You can see the features of the following symbols by rolling over them with the mouse:

In General:

- | | | |
|---|-------|---------------------------|
|  | Open | Open a drop-down list |
|  | Plus | Add a form or a component |
|  | Arrow | Back to search |

On the list of patients:

- | | | |
|---|--------------|--|
|  | Form list | View the list of attached forms |
|  | Demographics | View and modify the demographic data |
|  | E-Form | Add an electronic form |
|  | Delete | Delete the patient (only possible if all forms are deleted beforehand) |

On the form list:

- | | | |
|---|--------|--|
|  | Edit | View / edit / complete a form |
|  | Print | Print a form |
|  | Delete | Delete a form (only possible by entering the password) |
|  | Submit | Submit a form |

1.5. Languages and Font Size

The application is available in the following six languages: English, German, French, Italian, Spanish and Polish. In this regard, the preferred system language can be activated by clicking on the equivalent icon at the bottom right corner. In the top right corner, you can change the font size of the page.

1.6. Processing Status of the Forms

There are three different statuses of a form and five of a subform:

Subform Processing status	Form Processing status	Description
		Subform has not been filled yet
		Subform has been filled partially, but has not been saved. **By closing the open case (going back to form list) without saving and reopening it again, the entered data will be lost. By switching to another subform without saving a modified subform, and switching back to the modified subform again, the data will still be there.
		Subform has been saved, but there is missing data.
		Subform is complete and saved.
		Data modification in a previously saved subform. Save again to make it turn green.
		Form incomplete - not all the subforms are completed and saved.
		Form completed - all the subforms are completed and saved and the form is ready for submission.
		Form completed and submitted – its information is regarded for online statistics queries. You can only view the data but not edit it anymore. There is no possibility to change the data or to add data to a submitted e-form, at the exception of having a profile allowing to reopen a submitted case again (Administrator Profile).

1.7. Profiles in the IIP Registry – Access Authorization

The registry provides different types of profiles with different authorities. The following are the most important:

- **Lung Administrator:** Manage users, open cases after submitting, online statistics, compare data with an anonymized pool
- **Clinic Administrator:** Download/Export of data, online statistics of the own clinic, manage users, activate profiles of personnel at the own clinic
- **Doctor:** Data entry, submitting of forms, online statistics of the own cases
- **Data Entry Clerk:** Data entry, submitting of forms

By registering a user, a specific profile as Lung Administrator, Clinic Administrator, Doctor or Data Entry Clerk is distributed. One user can hold multiple profiles simultaneously but not more than one user account.

- For example: Dr. John is registered with the username 'JohnDoctor'. He performs surgery in two different clinics and needs therefore two different Doctor profiles. Both profiles are attached to one user name, "JohnDoctor".

The coordinator of the study validates each profile. The access to the tools of the IIP Registry depends on the profile of the user.

1.8. Tools

After you log in, you will find the navigation bar on the left side of the page. The provided tools may be limited depending on the user's profile.

- **Enter data:** New patient, search patient
- **Clinical tools:** Download data, Online statistic, Form viewer, Follow-up calendar, Documents
- **Admin tools:** Validate user, Clinic settings, User activity, Manage users, Manage clinics...
- **My Account:** Modify account
- **Logout**

A user can view a summary of its cases and their status under **Admin tools** → **User activity**

1.9. Employment in Multiple Clinics

If you are employed and registered in multiple clinics, choose the clinic you want to enter data in by clicking on the drop-down list to the right of your name.

2. REGISTRATION

2.1. Create a User Account

The registration of a new user is done in a single step. Open the login page (<https://lung.swissrdl.unibe.ch/timeout.jsf>) and click on **New user** (1).

Idiopathic Interstitial Pneumonia Registry

Username

Password

 Login

2 [Forgot password](#) [New user](#) **1**

Welcome to the Swiss Lung Registry

The Swiss Lung Registry includes patients from the Swiss IIP registry with idiopathic interstitial pneumonias (IIPs), other interstitial lung diseases (ILDs), and survivors of SARS-Cov-2 infection (COVID-19). This prospective cohort study aims to investigate the natural course of disease, response to specific treatments, and risk factors for the development and progression. We collect potentially related exposures and risk factors, clinical data, patient reported outcomes, pulmonary function, and physical performance test. The ongoing collection of blood samples and storage in our bio bank facilitates the investigation of underlying biological mechanisms.

Complete your registration by filling in the information with a *:

- **Username and Password** (upper and lower case will be considered)
- **First name, Last name, Date of birth, Email, Language**
- **Profile, Country, City, Clinic, Department**

Please do not forget that you need only one user account even if you are employed in more than one clinic. If you need multiple profiles (for different clinics or authority levels), you will be able to add them to your user afterwards. Please tell us, if you are changing your position, so that we can avoid duplicates. Do not delete user accounts in any case because if you do so, the patient data will be deleted too, since it is connected to the users. And, please do not create user accounts for other people.

2.2. Activation of Your Access

Your registration will be checked and validated by the Clinic Administrator or the Study Coordinator. After that, you will receive an Email regarding the activation of your profile. Finally, you can start your documentation activity.

2.3. Inactivated User Account

If you do not log in to your user account for over six months, your account will get inactivated. Please contact the Study Coordinator (kurt.dejaegere@extern.insel.ch) to reactivate it instead of creating a second user account. This is something you should avoid in any case. In case of doubt, do not hesitate to contact the support team of SwissRDL by calling **031 684 5 66** or writing an Email to swissrdl@ispm.unibe.ch.

2.4. Forgot Password

If you have forgot your password, please click on **Forgot password** (2) to renew it.

3. DATA ENTRY

3.1. Patient Data

The collection of medical data requires best care and attention regarding the data security. This is why we make high demands on our information security. The SwissRDL Management – operating company of the medical documentation platform IIP Registry – has decided to invest in an internationally acknowledged certification for information security.

3.1.1. Search Patient

Check in a first step, if the patient you want to register already exists in the registry to avoid duplicate registration. If you have profiles for different clinics, check also, whether you have chosen the appropriate one (1). In case you are entering data instead of a doctor, make sure to choose his or her name in the top-left corner (2).

After that, click on **Enter data** and then **Search patient** (3) on the navigation bar. You can now search a patient based on the medical record number (**MRN**), **date of birth** (4). Search with one information only, otherwise the search machine will not be able to find any results. We recommend the search by the date of birth, since names can easily be misspelled.

The screenshot shows the user interface for searching patients. On the left is a navigation menu with 'User, Test' (2), 'Enter data', 'Search patient' (3), 'Clinical tools', 'Admin tools', and 'My Account'. The top status bar shows 'Logged into: MEMdoc: dept, Bern Schweiz' (1). The main search area has a 'Search' (4) header, radio buttons for 'Patient' (selected) and 'Form', and input fields for 'M.R.N.' and 'Date of birth' (format dd.mm.yyyy). 'Search' and 'Reset' buttons are at the bottom right.

If you find more than one patient, please choose the appropriate patient on the **form list**. 

You can also extend your search by clicking on  **Extended search** to search, based on gender, treating doctor and several forms. However, in general, the simple search will be successful.

Please search a patient before creating a new patient record, so you may only create a new record if the person is not already registered.

3.1.2. Create a Patient Record

Please respect that each one of the patients (to be registered) have to sign an **informed consent**.

To create a new patient record, click on the navigation bar on **Enter data** and then **New patient**. Complete the record by filling in the obligatory information with a *.

- **Important:** The medical record number (MRN) is created by the system. Please note the MRN in the patient data in your clinic. Otherwise, it will be difficult to find the right patient again during a Follow-up.
- Submit the record by saving the information.

3.1.3. Edit a Patient Record

If you want to edit a patient's information after creating the record, search the patient and open the drop-down list called **Demographics**, edit the information and save the record.

3.1.4. Delete a Patient Record

It is possible to delete a patient record in the drop-down list of the *demographics*.

→ *A reason to delete a patient record is for example the cancellation of an operation.*

You must enter your password to delete a record. The intention here is to prevent the deleting of records by accident. Furthermore, it is only possible to delete a record if there are no more forms attached to the patient (see the form list).

3.2. Case Data

3.2.1. Create New Form

If you find a patient through search, you can add an E-form to the record by clicking on . Another option is to open the patient record first by clicking on  and then add the E-Form with .

You will then be able to choose the form you want to add. There are two options:

- Swiss Lung Registry: ILD (V1) - deactivated
- **Swiss Lung Registry: ILD (V2) – March 2021**
- Swiss Lung Registry: Post-COVID-19 (V1) - deactivated
- **Swiss Lung Registry: Post-COVID-19 (V2) – March 2021**

3.2.2. Different versions in the registry

Version 1

This version is now deactivated. Existing visits in this version can, however, still be completed and submitted. New visits for cases, which started with version 1, must be continued with version 2. At the moment, data transfer from visit 1 to future visits is not working for different versions of the form. We are trying to fix the problem as soon as possible.

Version 2

All new cases must be documented with version 2. The handling remains the same as with version 1. Data from visit 1 will be transferred to future visits.

3.2.3. Enter Data

The following **subforms** must be filled in for a **complete form**. You will find the obligatory questions to the individual subforms marked in blue, whereas all subforms include some obligatory questions.

Swiss Lung Registry: ILD form

<input checked="" type="checkbox"/> Baseline
<input checked="" type="checkbox"/> General
<input checked="" type="checkbox"/> General ILD
<input checked="" type="checkbox"/> Symptoms
<input checked="" type="checkbox"/> Tests
<input checked="" type="checkbox"/> Tests ILD
<input checked="" type="checkbox"/> Frailty

Swiss Lung Registry: Post-COVID-19 form

<input checked="" type="checkbox"/> Baseline
<input checked="" type="checkbox"/> COVID19 Initial
<input checked="" type="checkbox"/> General
<input checked="" type="checkbox"/> Symptoms
<input checked="" type="checkbox"/> Tests
<input checked="" type="checkbox"/> Frailty

Do not forget to save the subforms after entering the data. If there is information missing to complete the form, save the subforms by clicking on “save incomplete” to keep the entered data saved. Please remember to complete the missing information afterwards and submit the form. Unsubmitted forms will not be considered

The circles on the left side represents the processing status of the subforms. If you want to know more about the individual statuses, see **1.6. Processing Status of the Forms**.

3.2.4. Submit a Form

After entering all required information, all the circles will be fully marked in green. If this not the case, there is still information missing. After completing the information, you must submit the form by clicking on . The form is submitted when instead of the green circle, a lock  appears on the form list.



Swiss Lung Registry: ILD (V1) Complete 

Submit 

-  Baseline
-  General
-  General ILD
-  Symptoms
-  Tests
-  Tests ILD
-  Frailty

Save  Reset 

Submitted forms are protected against subsequent manipulations. Furthermore, the forms will not be included in the statistics if they are not submitted, since they are only saved on our server by being submitted. Therefore, please always check if you have submitted a form.

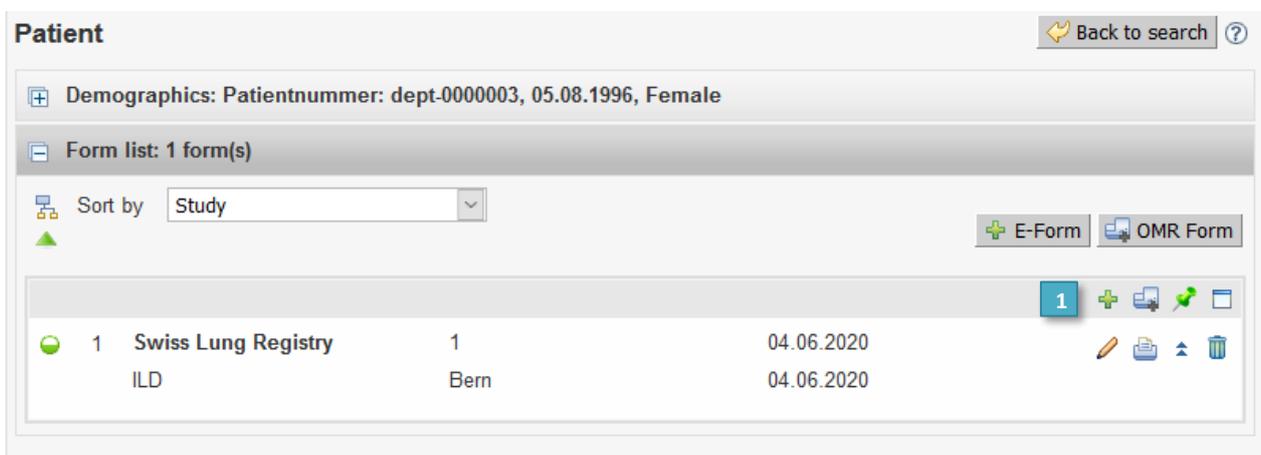
→ Complete but not submitted forms  will not be included.

3.2.5. Modify or Complete a Form

To modify or complete an existing but not submitted form, choose the correspondent patient record and click on . Do not forget to save the changes.

3.2.6. More than one Visit: Document case-based

The documentation of a second, third etc. visit should be documented case-based. This means that you have to add all follow-up forms to the first visit by clicking on  at the grey bar on the first visit (1). In this case, do not use . If you enter data case-based, some of the data in the form (e.g. **Date of registry inclusion**) have to be entered only once. Some data from the first visit are copied to the subsequent visits automatically.



Patient  Back to search 

 Demographics: Patientnummer: dept-0000003, 05.08.1996, Female

 Form list: 1 form(s)

Sort by Study 

 E-Form  OMR Form

	1	Swiss Lung Registry	1	04.06.2020				
		ILD	Bern	04.06.2020				

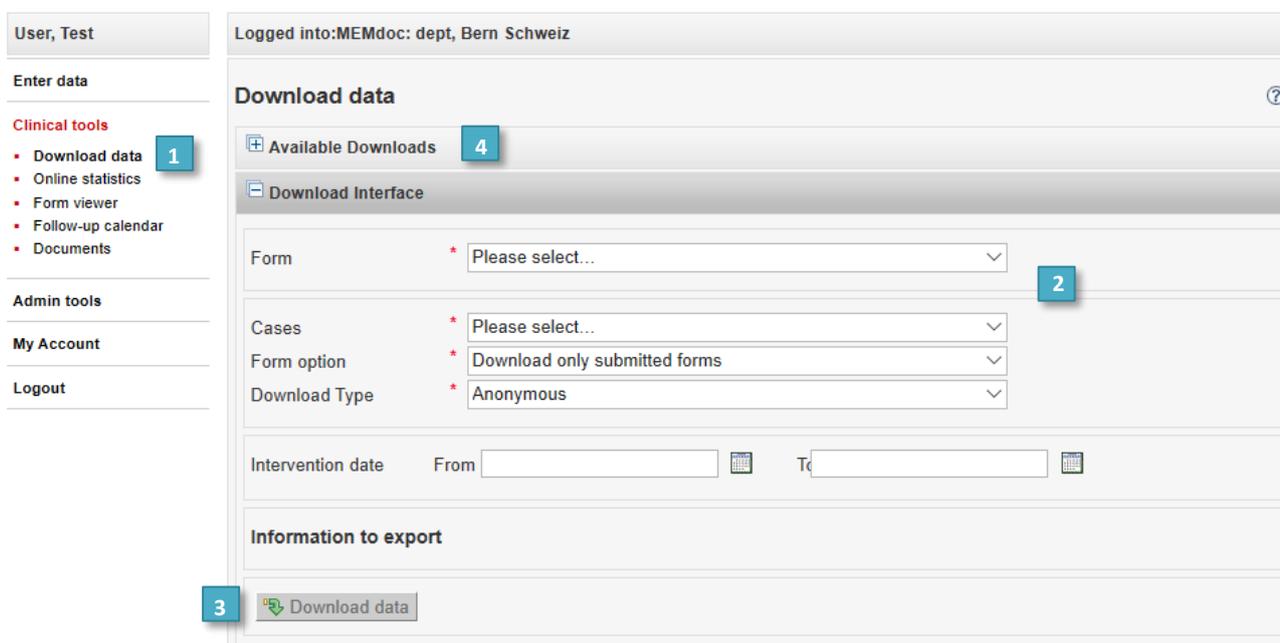
4. DOWNLOAD DATA

Only users with an administrator profile are authorized to export all data from a clinic. Besides, it is only possible to export clinic internal data, which you can download as an Excel sheet. Please consider, that the passing of those data to third parties is strictly forbidden. You can only pass the data to their owner. In case of this interdiction not being observed, legal consequences could follow.

- Doctor B would like to view all data that has been registered in his clinic, though he is not authorized to do so. The reason for this is that there are also the cases that were registered by other doctors included in the data export. As an Administrator, you have to call Doctor B's attention to the data security measures, such as this interdiction, and are **not** allowed to hand out the complete data set. He is only allowed to view the data that he registered himself.

How to download data

Choose **Clinical tools** on the navigation bar and click on **Download data** (1). Under the drop-down list **Download Interface** choose the Form, Cases, Form option and Download type (marked with a *) (2). Finally, you can limit the data that you want to export by entering a time interval and download the data (3) . The duration of the download depends on the amount of data. As soon as the download is completed, you can download the data set under the drop-down list **Available Downloads** (4) .

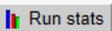


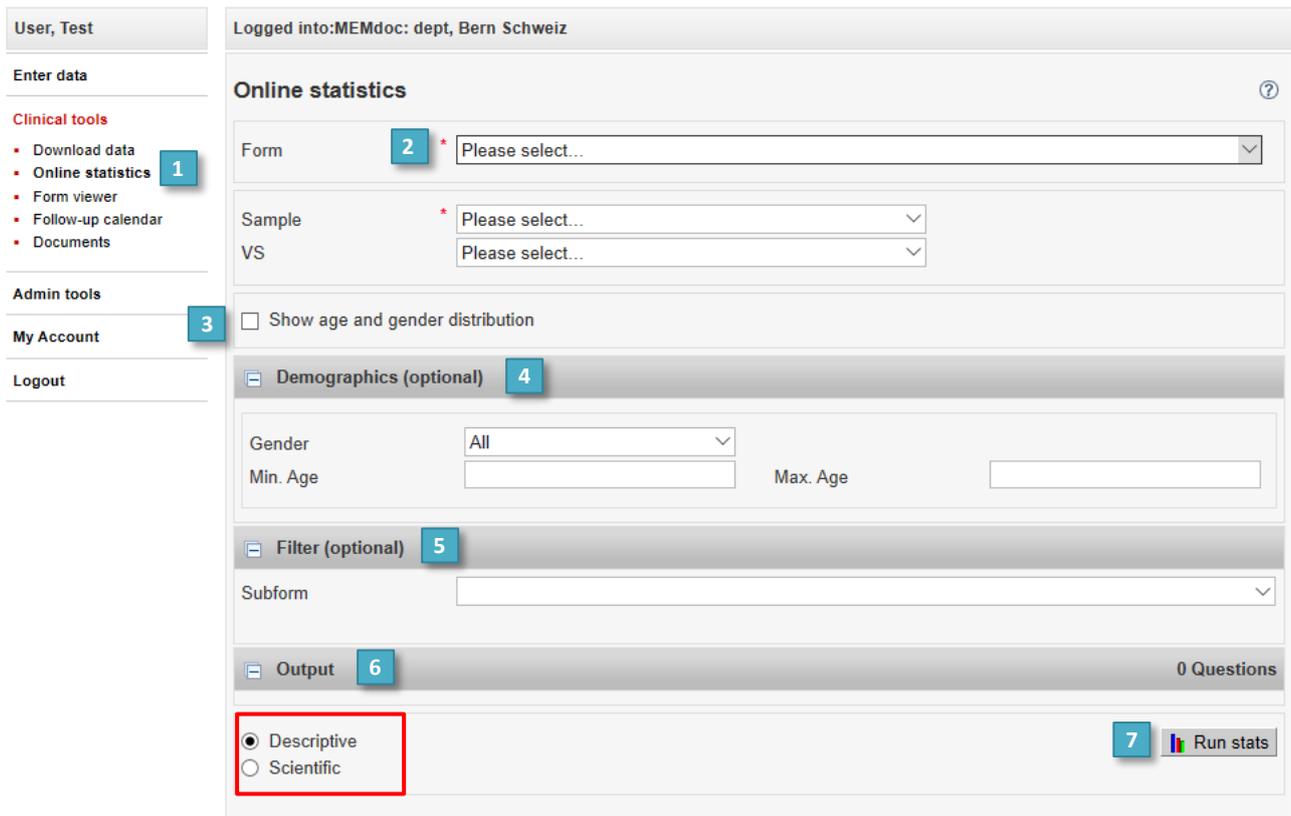
You will receive two files per download (as an Excel-file and a text document). Pay attention to the names of the downloaded documents.

1. Document with the annex **_dept**: An extract of the chosen data
2. Document with the annex **_dep_legend**: A list of decryption codes for the data

5. ONLINE STATISTICS

The online statistics tool, are only for administrators available. By using this tool, you will not only see an extract of variables but for example also a frequency analysis.

Click on **Clinical tools** on the navigation bar and **Online statistics** afterwards (1). Fill in the boxes (marked with a*) with the information (Form, Sample) you prefer to view (2). If you want the gender and age to be evaluated too, mark the box **Show age and gender distribution** with a tick (3). You can search based on gender and age if you open the optional drop-down list **Demographics** (4) and choose a subform under **Filter** (5). If you would like to compare your data with data from another clinic, choose the corresponding area under **VS** (6). The comparative data can only be chosen from a geographically stretched area, such as the own canton or Switzerland (respectively, all the cases in the pool). Lastly, you can choose between a descriptive and a scientific comparison. The data will remain anonymous. Complete the process by clicking on  (7).



The screenshot shows the 'Online statistics' interface. On the left is a navigation menu with 'Clinical tools' containing 'Online statistics' (1). The main area is titled 'Online statistics' and contains several sections: 'Form' (2) with a dropdown menu; 'Sample' and 'VS' (6) with dropdown menus; a checkbox for 'Show age and gender distribution' (3); a 'Demographics (optional)' section (4) with 'Gender' (dropdown: All) and 'Min. Age'/'Max. Age' (input fields); a 'Filter (optional)' section (5) with a 'Subform' dropdown; an 'Output' section (6) with '0 Questions'; and a comparison type selection (7) with radio buttons for 'Descriptive' (selected) and 'Scientific'. A 'Run stats' button with a bar chart icon is at the bottom right.