

Information on new software platform

European Anaphylaxis Registry

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Motivation for Changing Software

The European Anaphylaxis Registry collects information on anaphylactic reactions through a web-based data entry system. The software, which has been used, was created solely for this project and has served for over 10 years very well.

Considering the new possibilities of up to date IT architectures and complying with current IT security standards, the association NORA e.V., which supports the Anaphylaxis Registry decided to develop an entirely new software platform. As a result of long-standing successful cooperation with the company "FRIEDMANN Kommunikation GmbH" from Cologne, Germany, we decided to commission the new development there as well.

What does this mean for the **continuation** of the present Anaphylaxis Registry?

- Data entry continues via a web-based interface.
- Access (password, username) and the support team remain unchanged.
- The survey's content remains unchanged.
- NEW: Faster data entry with the survey now organized in item groups.
- NEW: Detailed patient management functionality through features such as print, export, sort, filter and delete.
- NEW: Patient-ID without sensitive data. If not already available, it is advisable to maintain your own patient-ID-list locally.

What does this mean for the **development** of the Anaphylaxis Registry in future?

- For a single patient, several surveys (=questionnaires) can be created. Which allows ...
 - ... to capture details for important aspects of the disease without extending the basic survey (e.g. medical intervention, immunotherapy, challenge testing).
 - ... to gain a better understanding on repeated reactions and the impact of the disease on the life quality of the patients through follow-up-assessments.
 - ... to record more detailed lab data, if available
 - ... patients to enter data themselves, e.g. about their medical history.
- The new software platform can be used to collect data in other (related, partnering) research projects with minimal effort.

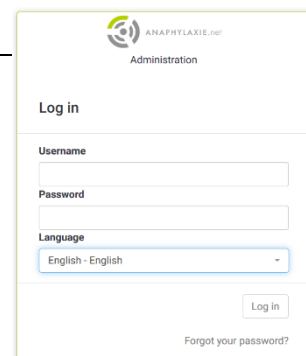
System requirements

Web browsers such as Mozilla Firefox or Microsoft Edge should be used to perform data entry to the Anaphylaxis Registry. Please do not use Internet Explorer as this browser no longer has the technical requirements for the new system.

Login


You can login on the website www.anaphylaxie.net either via **Login** or via the tap **Questionnaire - User Login**.

This opens a window where you can enter your access data.








The screenshot shows the login interface for the Anaphylaxis Registry Administration. At the top, there is a logo for ANAPHYLAXIE.NET and the word "Administration". Below this, the text "Log in" is displayed. The form contains three input fields: "Username", "Password", and "Language". The "Language" field is a dropdown menu currently set to "English - English". At the bottom right of the form is a "Log in" button. Below the button, there is a link that says "Forgot your password?".

Part 1: How do I enter data of a new patient (=participant)?

- 1- Choose the widget "New participant" on the home screen.
 - 2- Select the "Save" button in the "Add participant" popup.
 - The data asked in the popup can be entered directly when the patient is created or edited later.
 - "Comment"-field: Do not enter free text information on the reaction or any other information about the patient. This is only for information on study participation or logistics (e.g. withdrawal, dead, change of clinic).
 - 3- A new participant has been created and will automatically appear at the top entry of the list of participants ("Central participant management").
 - Each participant is assigned a series of action buttons located on the left side of the line.  (for more detail see Part II)
 - 4- Create a new questionnaire (=survey) using the button "Add participant to survey"
 - In future projects, several different surveys can be completed for a single participant, e.g. for follow-up assessment.
 - 5- Choose „Next“ in the “Module selection” popup.
 - The basic survey for the Anaphylaxis Registry has already been chosen.
 - New popup “list active survey” appears – select “create tokens” – select “data entry”.
 - 6- Change the language (=Sprache) via the drop down menu.
 - 7- Confirm the information text on the first page of the survey by selecting “Next”.
 - 8- Complete the entire survey.
 - Button top left “Resume later”: saves data entered so far and allows continuation of data entry later.
 - Button top center “Exit and clear survey”: discards ALL entries in this module, including those on the previous pages.
 - Button top right “Question index”: jumps to a chapter (group of items, page) of the current survey for further data entry.
 - Questions highlighted with a red star are mandatory, i.e. a regular skip to the next section is not possible without response, as well as completing the entire **survey**. Jumping to another chapter (button “Question index”) or intermediate saving (button “Resume later”) is possible without answering the mandatory questions.
 - 9- Save the survey using the “Submit” button in the last section.
 - Mandatory fields must be completed. In the case of missing information, there are always options in the mandatory fields to indicate the absence of data (e.g. “unknown”).
 - 10- Upon completion, the entire survey can be printed and/or exported as PDF.
- ... to add next participant start again at the home screen.

Part 2 – How do I display and use the data of a participant (=patient)?

Choose the widget “List of participants “ to access “Central participant management”.

- Selecting a **column heading** allows sorting.
- Selecting the **dropdown-menus** located beneath the column headings allows filtering. For example, if you choose “unknown” in the column “informed consent”, only the patients with missing data on informed consent will be displayed.
- **Search fields** located beneath the column headings help to **find** specific data in that column. For example, by entering an exact Participant ID, the given case will be displayed immediately.
- Action button “**Edit this participant**” , one can display and edit data such as informed consent or bio-samples.
- Action button “**Delete this participant**” , deletes all the information on the chosen participant permanently.
- Action button “**List active surveys**” , displays any completed or uncompleted surveys of the participant.
- Action button “**Add participant to survey**” , one can assign the participant to a survey (only in projects with multiple surveys).
- The participant ID and all the other data of a participant in the project (e.g. informed consent, blood-samples) can be printed by selecting “**Print participant data**” .
- By selecting single participant (**Checkbox** in every line/row) or all participants (Checkbox left on the column headings’ line), one can carry out actions for **multiple participants**. **Exporting data** in e.g. in CSV-format is also possible. *(This option will be activated later in the project)*

SCREENSHOT DER TEILNEHMERLISTE

Own account information

Participants overview FAQ ACC-Derma -

Central participant database

Return to admin home

Central participant management

Search field

Dropdown-menu

Add new participant

Checkbox

<input type="checkbox"/>	Action	Created	Active surveys	Modulstatus	Participant ID	Comment	Willingness for FU questions	Bio-samples	Informed consent	Survey's language
<input type="checkbox"/>	    	07.03.2019			4932-9545-7208		No	Yes	Yes	German
<input type="checkbox"/>	    	07.03.2019			9477-3156-4775		Yes	Available on request	Yes	German
<input type="checkbox"/>	    	07.03.2019			4984-5676-1599		No	Yes	Unknown	German

Selected participant(s)...

Displaying 1-3 of 3 result(s). 10 rows per page



Dropdown menu