

ESID registry:

Standard Operating Procedure (SOP) for already registered patients with a consent prior to version 3.0 (pre-GDPR)

Objective:

All living patients should be informed about their rights under the DSGVO, in particular contact information from data protection and supervisory authorities.

Procedure:

In the system, the status of the patients is noted in the last documentation ("alive", "deceased", "lost-to-follow", "discharged after complete recovery").

- For all patients who are documented as **'deceased'** in the system, no further action is required, especially no message, for example, to surviving family members.
- Patients with status **'discharged after complete recovery'** will be sent the information sheet.
- For all patients who are marked as **'alive'** in the system
 - and are expected to visit to the Documenting Centre within the next **2 years**, it is sufficient to hand out the information sheet **or** have the current declaration of consent (PIC) signed again (version at least 3.0) on the occasion of the next visit to the Documentation Centre.
 - All other live patients will be sent the information sheet.
- Patients who are documented in the Registry as 'lost to follow' will be sent the information sheet.

The information sheet is to be sent by the respective documenting centre and dispatch is to be documented in the registry with date. The information is to be sent to the last known address of the patient. An acknowledgement of receipt or signature by the patient is not required. The information sheet is usually sent regular mail. Only if a centre has already established a method of secure (electronic) communication with patients, e.g. a patient portal, it is also possible to send the information via this system.