ESID registry:

Standard Operating Procedure (SOP) for **already registered patients** with a Patient Informed Consent prior to version 3.0 (pre-GDPR) (All patients who are newly registered to the ESID registry must sign a GDPR-compliant PIC!)

Objective:

All living patients should be informed about their rights under the GDPR (General Data Protection Regulation), 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" as"alive", "deceased", "lost-to-follow", or "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 (i.e. "supplement to data protection" in the respective language version).

- For all patients who are marked as **'alive'** in the system
  - **and** are expected to visit to the Documenting Centre **before 2020-12-31**, it is sufficient to have the current declaration of consent (PIC) signed again (GDPR-compliant version) on the occasion of the next visit to the Documentation Centre.

  - All other living patients will be sent the information sheet (i.e. "supplement to data protection" in the respective language version).

- Patients who are documented in the Registry as **'lost to follow'** will be immediately sent the information sheet (i.e. "supplement to data protection" in the respective language version)

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 by 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.