

Subject: Call for participation: Malignancies in IEI – an ESID registry study

Dear ESID registry participants, Dear colleagues and friends,

Malignancies may pose a serious challenge in IEI patients. We wish to assess the incidence of malignancies in IEI and learn about management challenges, using the ESID registry. So far, we already know from your entries that at least 4.7% of ESID-registered patients suffer from malignancy as first manifestation or during follow-up of IEI. However, this number is derived from only about a quarter of all registered patients.

We now ask for your help to increase the resolution and the size of this dataset. The incidence of malignancies in patients with IEI is increased and their outcome is worse than in patients without IEI. There is a clinical need to better understand which IEI carry the highest risks for malignancies, which patients with a malignancy need to be screened for IEI, and how the presence of an IEI affects treatment and prognosis of the malignancy.

With this email, we would like to ask all ESID registry participants to register if a patient has ever suffered from a malignancy (Y / N) . You can complete the level 1 fields regarding the occurrence of a malignancy. for all registered patients thus far. Please also enter the type of malignancy OR tick “no” if –to your knowledge– the patient has not yet suffered from cancer at time point of entry/follow-up. We ask to complete this by August 31st 2022.

After completion of the level 1 data acquisition, we will send out a brief level 2 survey to collect additional details on those IEI patients who developed a malignancy, including treatment and outcome, later this year or early 2023.

We sincerely thank you for your time and effort, and are happy to answer any question you may have.

Kind regards,

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