

Registries in immune thrombocytopenia (ITP) in Europe: the European Research Consortium on ITP (ERCI) network

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Registries are essential tools for a better comprehension of rare disease epidemiology and management.¹ Immune thrombocytopenia (ITP) is a rare disease with an annual incidence rate of about three per 100 000 individuals.² Knowledge has been generated in ITP epidemiology during the last decade thanks to large cohorts of patients with ITP, including the recognition of factors related to variations in incidence, clinical course, predictors of chronicity, risk factors for bleeding, infection and thrombosis, as well as the determination of real-world treatment strategies.³ Nevertheless, many issues remain unknown in ITP (Table S1). Linkage of registries presents several interests (Table 1). In June 2019, the European Research Consortium on ITP (ERCI) was founded by 10 experts in ITP in order to promote research in ITP among other objectives (Material S1).⁴ One project supported by ERCI is to promote linkage of existing ITP registries in Europe. The first step of this project was to identify and describe the characteristics of available registries of patients with ITP in Europe. This was the aim of this study.
