RARE ANAEMIA DISORDERS EUROPEAN EPIDEMIOLOGICAL PLATFORM (RADEEP): DISTRIBUTION OF PATIENTS IN EUROPE

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BACKGROUND

Due to complications of the disease but also the treatment, rare anaemia disorders (RADs), over time, become multi-organ disorders, requiring the involvement of several medical specialties. This creates an important burden on the health systems and requires surveillance to ensure a health policy that provides adequate allocation of resources.

AIMS

This study aimed to assess the distribution of RADs in Europe, to improve diagnosis and follow-up protocols, as well as to facilitate research and access to available therapeutic options for patients with RADs.

METHOD

The study was conducted through the Rare Anaemia Disorders European Epidemiological Platform (RADeep), endorsed by ERN-EuroBloodNet.

Two epidemiological mappings were performed in 2020 and 2023, including 235 centres from 19 European countries.

Data on RADs patients in regular follow-ups were included, stratified by sex and age range. Diseases included: sickle cell disease (SCD), thalassaemia (THAL), pyruvate kinase deficiency (PKD), membrane disorders (MbD), congenital dyserythropoietic anaemia (CDA), and iron-related anaemia disorders (IRAD).

RESULTS

A total of 43,838 RAD patients were reported. The most frequently reported RAD was SCD with 26,892 (61%) patients, followed by THAL, MbD, PKD, IRAD, and CDA with 11,418 (26%), 3 983 (9.1%), 794 (1.8%), 523 (1.2%) and 228 (0.5%) patients, respectively. (Fig 1)

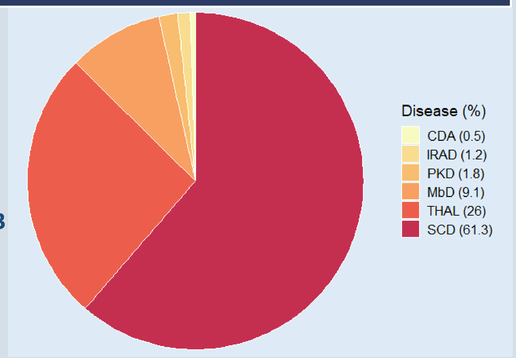
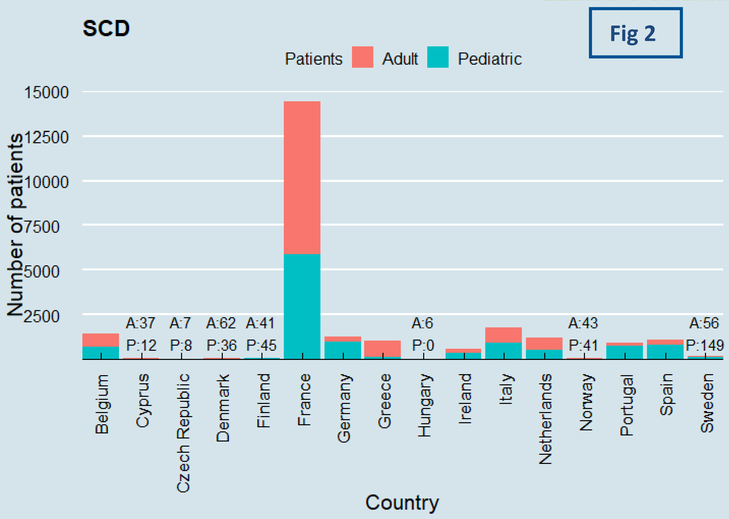
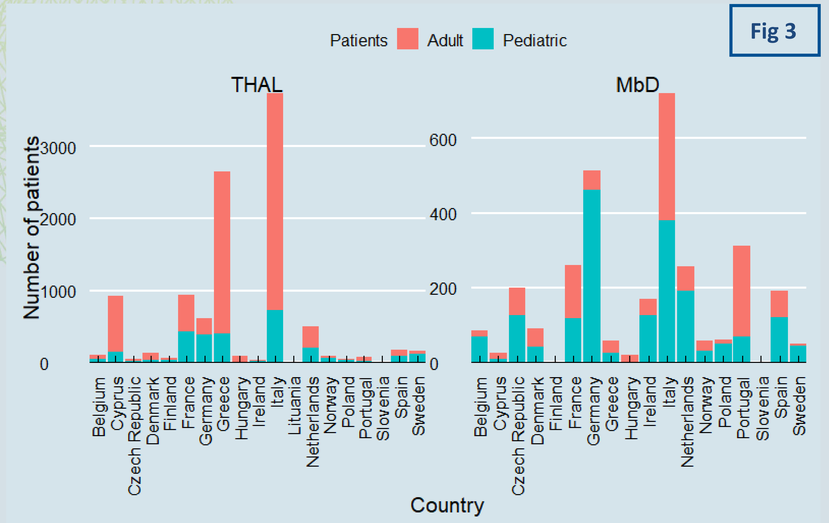


Fig 1: RAD distribution in Europe





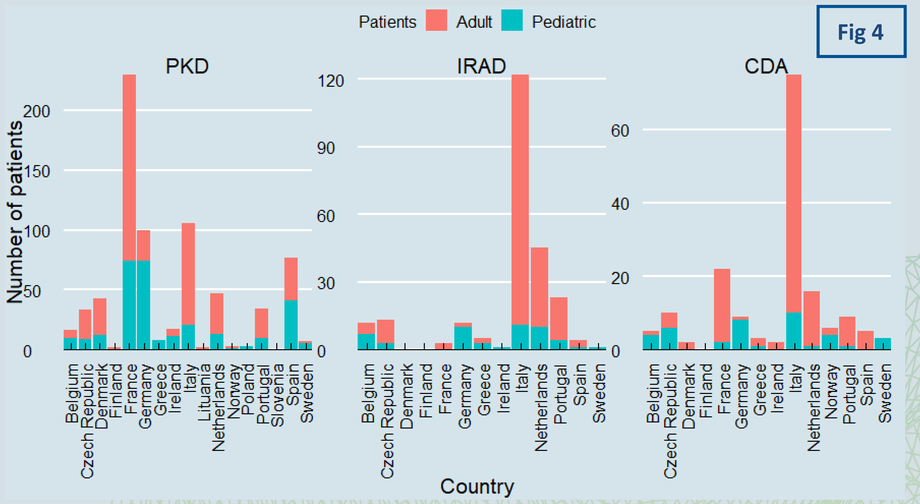
For SCD patients, 53% were adults with significant variations at country level ranging from more than 75% adults in Cyprus, Greece or Hungary to less than 25% in Germany, Portugal, and Spain (Fig 2).

For those with THAL, 74% were adults with national variations and a predominance of pediatric patients were in Sweden, Poland, Norway, and Germany (Fig 3).

For the other RADs, adult patients represented 39% for MbD, 55% for PKD, 79% for IRAD, and 76% for CDA. (Fig 3 and 4).

In general, men and women were evenly distributed.

Fig 2: SCD reported patients per country
Fig 3: THAL and MbD reported patients per country
Fig 4: PKD, IRAD and CDA reported patients per country



CONCLUSION

This study showed the heterogeneous geographic distribution of patients with various RADs in Europe. This heterogeneity relies on:

- Different prevalence of ethnic origin populations at risk for SCD or THAL
- Presence of preventive programs, patient registries, or centres of expertise for diagnosis, as for PKD or CDA

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