RWE pathway
The State-of-the-art of Patient Registries in Portugal

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ISPOR Europe 2022
6 – 9 November 2022
Vienna, Austria
Poster code: SA9

BACKGROUND

- Across the world, healthcare environment is becoming more specialized, competitive, and cost sensitive than ever before with a major focus in outcomes and value. This new era is now more focused in Real-World Evidence (RWE) to complement epidemiological gaps and support decision-making.
- Patient registries are one of the main sources of Real-World Data (RWD), enabling different healthcare stakeholders to analyze clinical practice, benchmark them and foster better patient care[1].
- RWD collected through registries may support clinical research by generating hypotheses, facilitating descriptive studies and health service research.
- Despite the growing need and importance of RWE and RWD, the current situation in Portugal regarding patient registries is still not fully studied.

OBJECTIVES

- The aim of this study is to identify and make an overview of patient registries in Portugal to set a baseline to document future developments in this domain.

METHODS

2-PHASE APPROACH

Phase I – Registries identification

- Systematic Literature Research (SLR) using PRISMA methodology was applied for the development of Phase I during May 2021.
- Identification of studies via databases, using OVID® software, was conducted in Embase®, Medline© and Cochrane© to identify registries used in Portugal between January 1955 to March 2021. A search strategy using a set of rules and search terms (both Portuguese and English) were implemented.
- A set of inclusion/exclusion criteria were defined in advance for the review. Portuguese patient registries, articles, conference papers and observational studies were included. Randomized Clinical Trials (RCTs) were excluded from the analysis.
- Manual review for validation and a final analysis was performed to compile and identify unique registries.
- An additional search from other sources was conducted using the Google® search engine to complement SLR.
- This step allowed the identification of registries that possibly did not publish their results in indexed journals and therefore were not identified in databases.
- The results were manually analyzed to relate to patient registries in Portugal.
- After the registries' selection, the number of mentions in literature was assessed for each one.

Phase II – Registries overview

- Search in publications and among websites to support the description of registries with relevance to Portugal was then developed.
- Descriptive statistics was performed according to the following criteria:
  - ✓ Geography: National *vs.* International;
  - ✓ Ownership: Health Authorities/ Research Centers/ Patient Associations/ Medical Societies/ Hospital/ Pharma Industry;
  - ✓ Setting: Hospital, Primary Care or directly in the community;
  - ✓ Medical domain*.
  (* classification according to Colégio de Especialidade - Ordem dos Médicos[2])

RESULTS

Phase I – Registries identification

- 1.927 relevant records were identified but 4 were removed due to duplication. From these, 1.628 were not specific to patient registries in Portugal, and therefore were excluded (N=295).
- From this point, full-text articles were analyzed, and 18 studies were excluded (N=277). Manual seriation by registry was then performed reaching 80 patient registries in Portugal.
- The Google® search identified additional 48 registries. Combining these search results, a total of 108 unique registries present in Portugal were listed (Figure 1).
- Reuma.pt stands out as the most documented registry with 34 mentions in publications. Portugal Oncology Registry (RON) follows next with 24 mentions in papers, and the Portuguese Registry on Acute Coronary Syndromes/ProACS, referred in 21 publications (Figure 2).
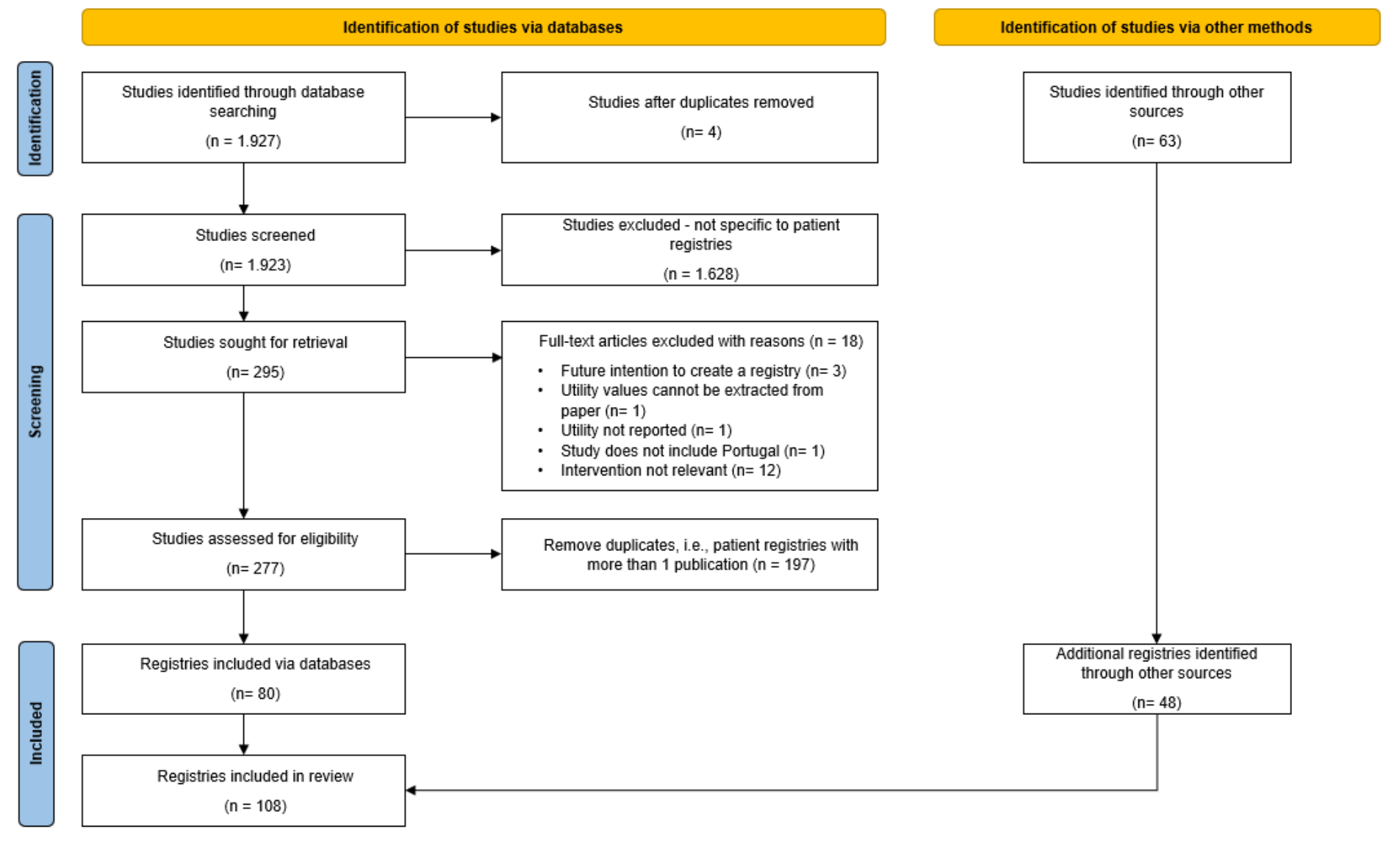

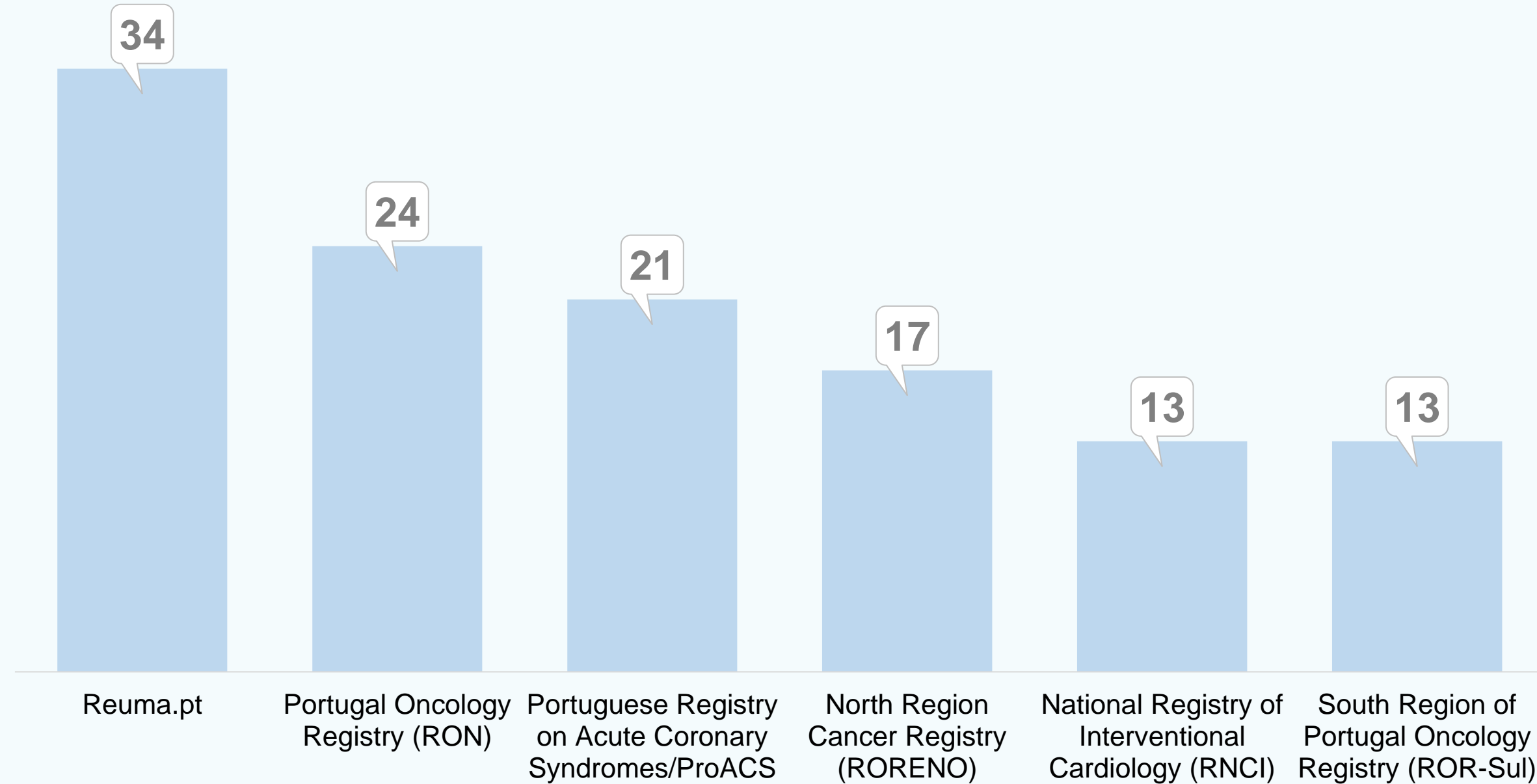Figure 1. PRISMA flow chart of selection process to identify the registries

Figure 2. Number of mentions in publications per registry (top 6)

Phase II – Registries overview

- From the 108 unique registries, 76 (70%) were classified as national and 32 (30%) as international that collect data for Portuguese population (Figure 3).
- The vast majority of national registries are owned by medical societies (46%) and health authorities (42%). Research centers own 7% while hospitals and patient associations are the owners of 3% and 1%, respectively (Figure 4).
- Registries are mostly implemented in hospitals (82%) while the ones promoted in primary healthcare setting only represent 7% (Figure 5).
- National registries cover 18 different specialties. Cardiology has the highest number of registries (21, i.e., 28%) followed by Medical Oncology (9, i.e., 12%).
- Some registries are specific to Pneumology (6, i.e., 8%) and the remaining registries cover specialties such as Endocrinology, Hematology, Dermatology, among others (Figure 6).
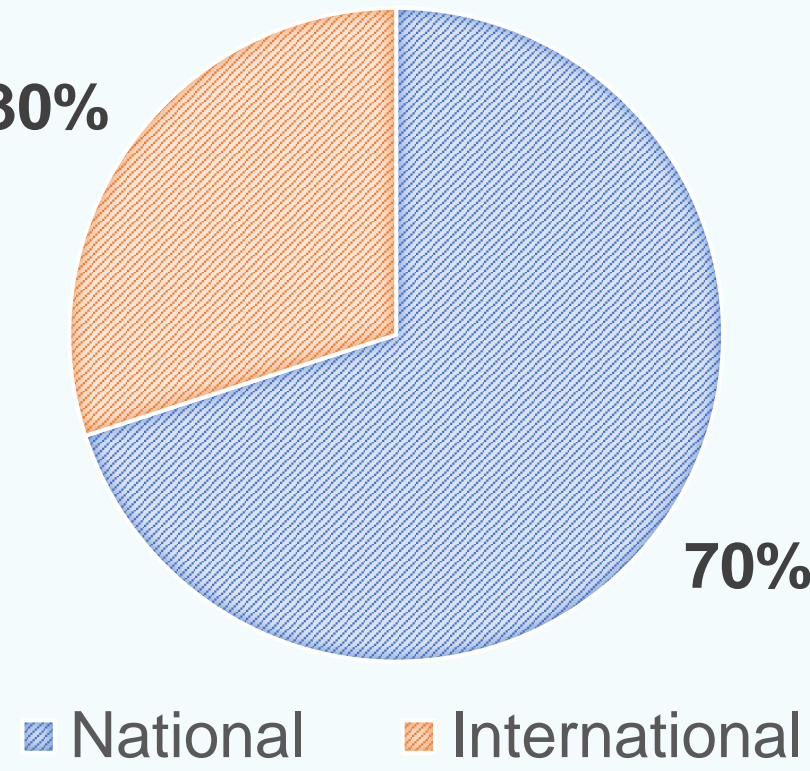

Figure 3. National *vs.* International registries (% of registries, N=108 registries)
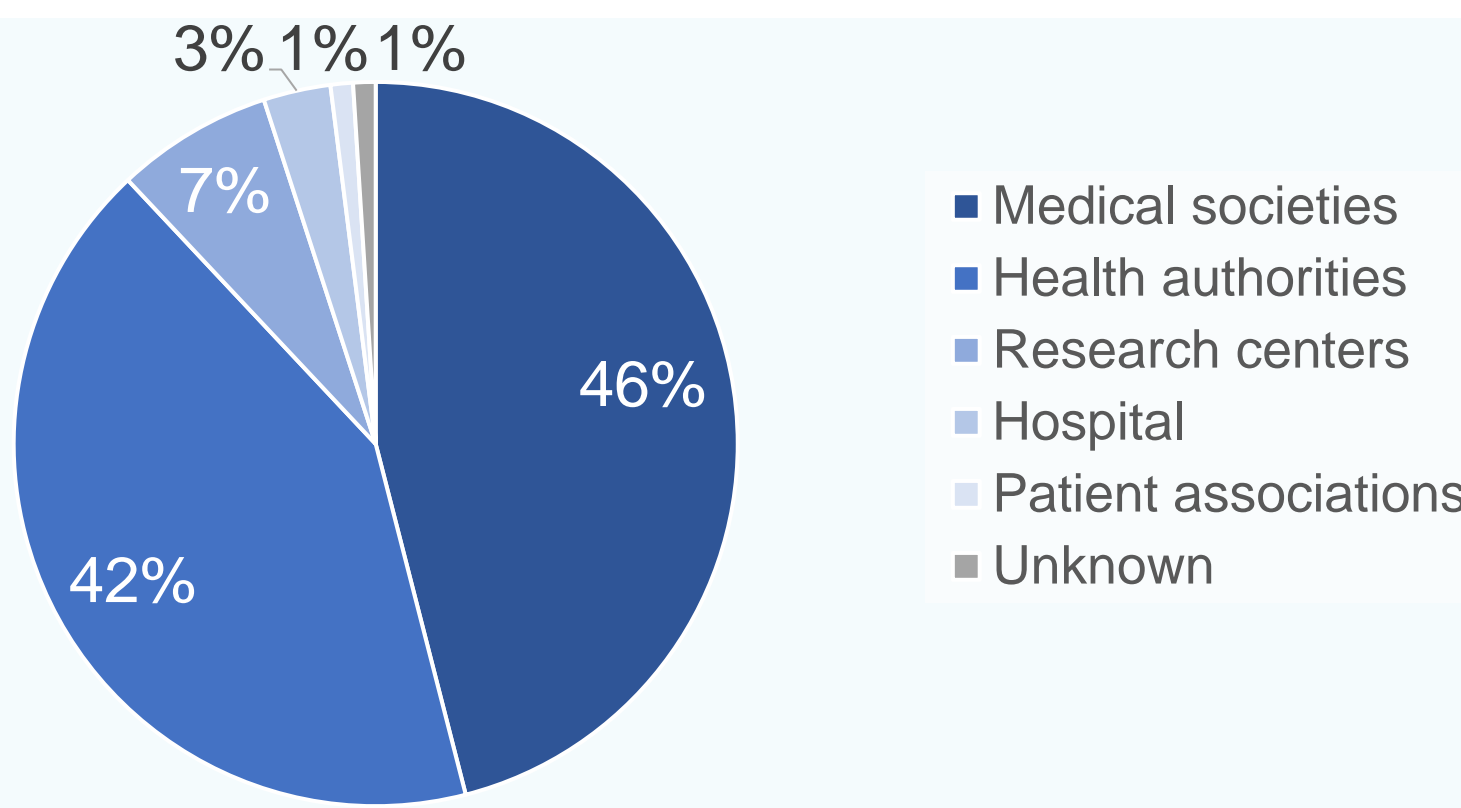

Figure 4. Ownership of national registries (% of registries, N=76 registries)

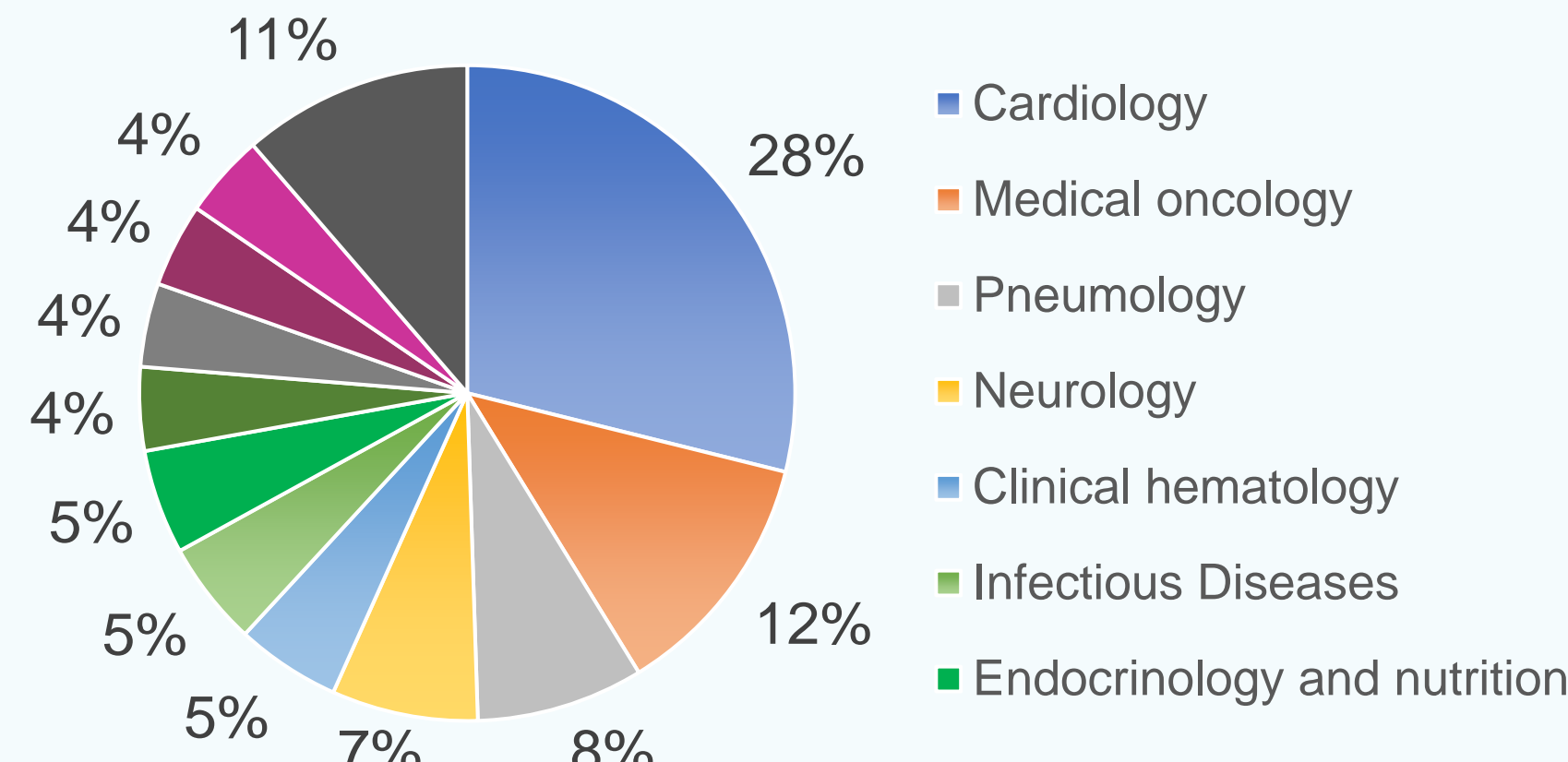Figure 5. Data collection site (N=76 registries)

Figure 6. Registries medical domains (N=76 registries)

CONCLUSIONS

- RWE has gained preponderance being a useful tool to support the validation of medical treatments and clinical procedures. An important source of RWD are patient registries. Based on IQVIA findings, Portugal lacks a systematized public list of patient registries, and its detailed characterization is essential.
- This study allowed the identification and an overview of the registries that collect data for Portuguese population. Besides the 76 national registries identified, other registries also collect national data and provide information to international data archives.
- For medical societies, RWE is critical to benchmark clinical practice and support in guidelines review. On the other hand, Health Authorities may use it to obtain epidemiological data, compare the quality of care between institutions and support the evaluation of health technologies. These two entities are an example of how to take advantage of RWD to support in decision-making.
- Registries are mainly implemented in hospitals. Therefore, it would be interesting in the future the key implementation difficulties to start developing more registries in primary healthcare setting.
- To keep an easy track of the existing registries and to promote the use of RWD, an easily centralized repository should be created in Portugal.
- In the future, an in-depth characterization of the 76 national registries must be done to better understand and clarify their potential, usefulness to the different stakeholders involved and to shape which key factors will emerge as essential.

REFERENCES

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[2] Colégio de Especialidade, Ordem dos Médicos, https://ordemdosmedicos.pt/especialidades/, accessed July, 2021