European Atlas on Clinical Trials in Cancer and Hematology (EuroACT): Patient Access Disparities and Underuse of Patient Reported Outcome Measures

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INTRODUCTION

Patient communities have long expressed concerns about limited access to clinical trials in cancer, hematology as well as the inconsistent use and reporting of patient-reported outcome measures (PROMs). [1] With inconsistent adherence to reporting standards and variability in patient-reported outcomes (PROs) usage and collection methods, highlighting the need for standardized protocols to improve the reliability and the impact of PROs in oncology research. [2]

OBJECTIVES

- The primary objective of EuroACT is to comprehensively analyze the landscape of clinical trials in the European region, encompassing 27 disease areas in oncology and hematology.
- This analysis focuses on three main aspects: geographical distribution of clinical trial sites across Europe; extent to which PROs are collected in clinical trials; and publication rates of PRO data gathered during trials.

METHODS

- Predefined searches were conducted on EU EudraCT, the US ClinicalTrials, and other datasets to compile a fit-for-purpose database on interventional and observational trials.
- Only trials completed between 2017-2022 were included, which investigated at least one of the 27 disease areas registered in at least one European country (as defined by WHO) and excluding Phase I studies.
- PROs were identified based on preliminary literature search and publication data derived from PubMed.

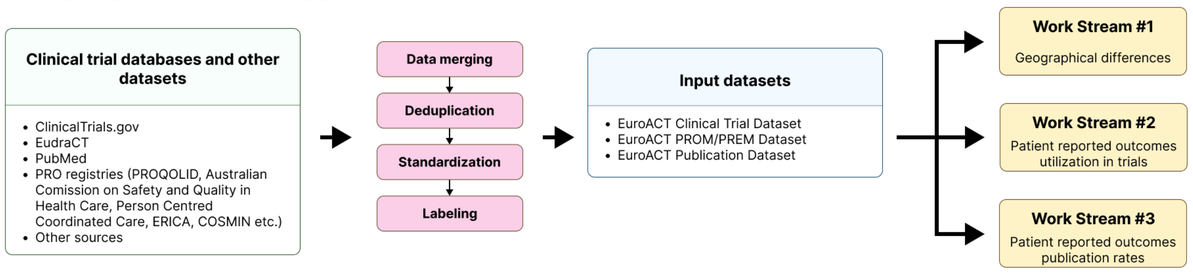

Figure 1. Data integration and analysis workflow.

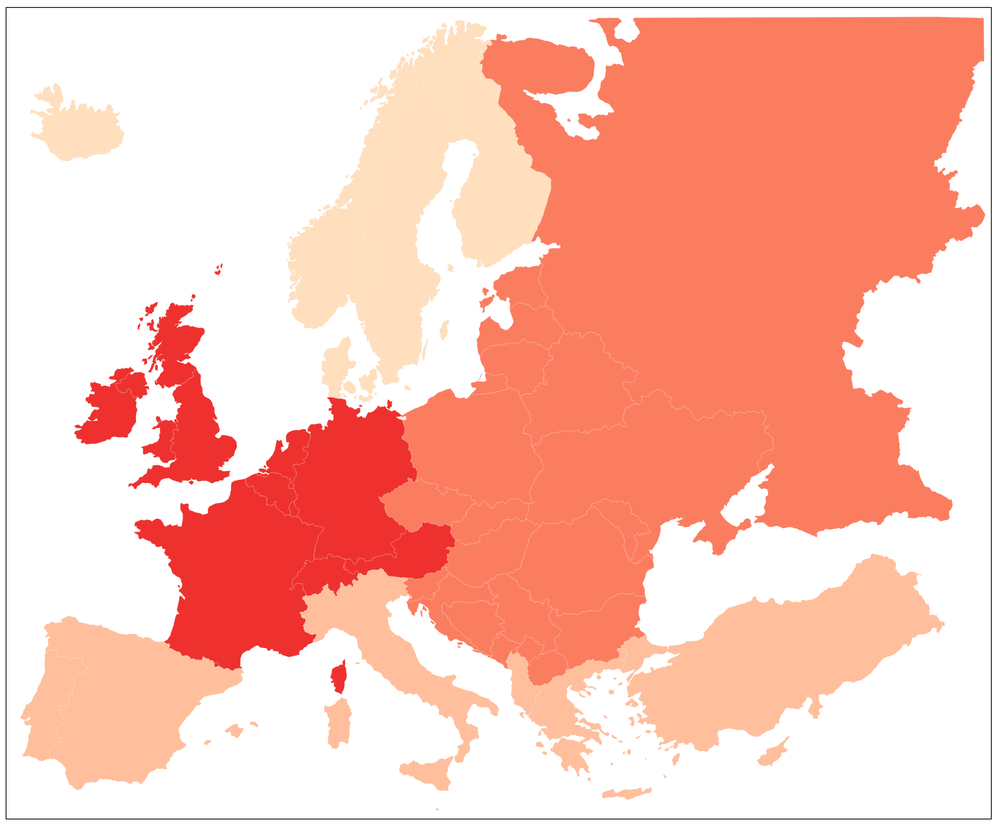

Figure 3. Regional disparities in clinical trials across 27 disease areas. Color density indicates the number of clinical trials.

RESULTS

- Analysis of 5,171 completed trials revealed substantial geographical disparities. Western Europe hosted the highest proportion of trials (73,4%), followed by Central and Eastern Europe (57%), Southern Europe (56,5%) and Northern Europe (31,4%).
- Only 19% of trials incorporated PROMs.
- The most frequently used PROMs were the EORTC-QLQ-C30, EQ-5D and SF-36.
- Fewer than 17% of trials had associated publications on PubMed, out of which only a few trials included PRO data.

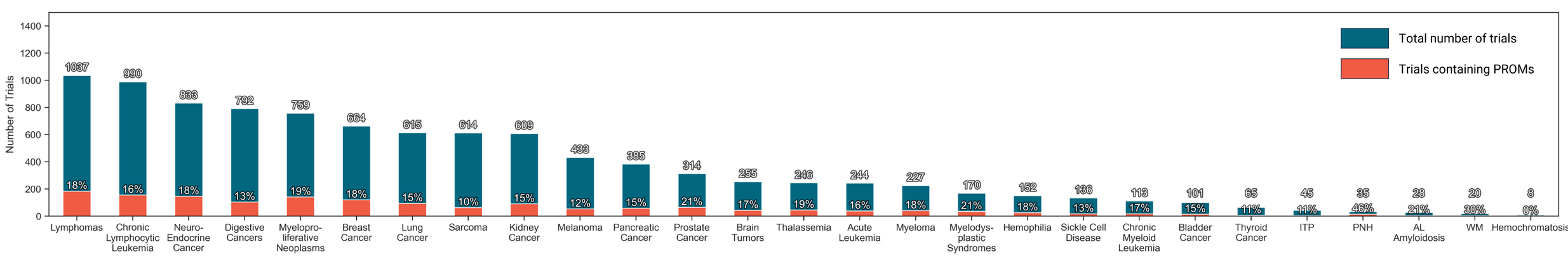

Figure 2. Number of clinical trials across 27 disease areas, total number of trials (blue bar) and trials containing PROMs in their outcomes (red).
Abbreviations: ITP: Idiopathic Thrombocytopenic Purpura; PNH: Paroxysmal Nocturnal Hemoglobinuria; WM: Waldenström Macroglobulinemia

CONCLUSION

- Significant geographical disparities in access to oncology and hematology clinical trials create substantial barriers to innovative treatments across various regions in Europe.
- Publication of trial results is inconsistent and can contribute to patient mistrust in the clinical trial landscape.
- Only a subset of trials incorporated PRO measures, and their data is infrequently published.
- Collectively, this analysis highlights a critical gap in capturing the patient voice, which is indispensable for improving treatment strategies.

REFERENCES

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2. O. Bylicki, H. K. Gan, F. Joly, et al. (2015) Poor patient-reported outcomes reporting according to CONSORT guidelines in randomized clinical trials evaluating systemic cancer therapy. Annals of Oncology 26: 231–237.

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