Sickle cell disease patient registries are not collecting enough data

A targeted review of the data registries collect

Objectives

- Patient registries can be a good source of evidence for health-care providers, payers and regulators requiring real-world data for evidence-based decision-making.
- This review aimed to identify and assess key characteristics of sickle cell disease (SCD) registries across the globe reporting patient data.

Methods

1. SCD registries identified through targeted searches (no date restrictions applied) of the ClinicalTrials.gov, European Directory of Registries, Orphanet, and PubMed databases
2. Publications and websites assessed for availability of information (including comorbidities, diagnosis and disease classification, mortality, treatments, hospitalizations, and funding agencies).

Results

- 22 registries identified, 15 active
- 23% multinational, 77% national-level
  - National registries most commonly found in the USA (n=9) and Spain (n=4)
- Number of patients per registry: 62 to 102,163
- Data collection period: 1 to 99 years
- 82% of registries initiated during the last 10 years, 22% of these were industry-funded

Figure 1:
Types of data collected by SCD registries

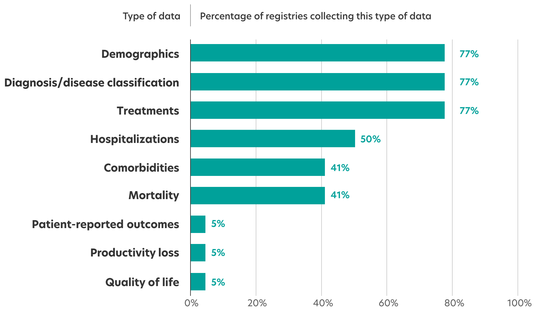
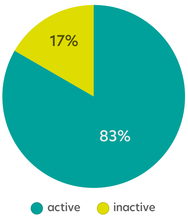


Figure 2:
Split of active/inactive registries initiated in the past 10 years



Discussion/Conclusion

- A rise in the number of industry-funded registries during the last 10 years correlates with increased interest of stakeholders (e.g., health technology assessment bodies) in the data.
- **While a good source of real-world information, SCD patient registries are not collecting enough data on quality of life, patient-reported outcomes, or productivity losses.**

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