

# Patient and Disease Registry Publications: An Online Survey of Medical Publication Professionals

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## Background

- Registry-based scientific publications are associated with a unique set of challenges.
- Due to the large variety in type, location, and size it is difficult to share best practices with others involved in these publications.

## Research Design and Methods

- A 23-question online survey was sent to medical publication professionals (MPPs) and responses were collected from October to December 2016.
- Respondents were not required to answer all questions and only data from those with registry experience were analyzed.

## Objective

- To understand the details, potential challenges, and perceived value of publications based on disease, safety, or treatment registry data from MPPs with registry experience (MPPREs).

## Results

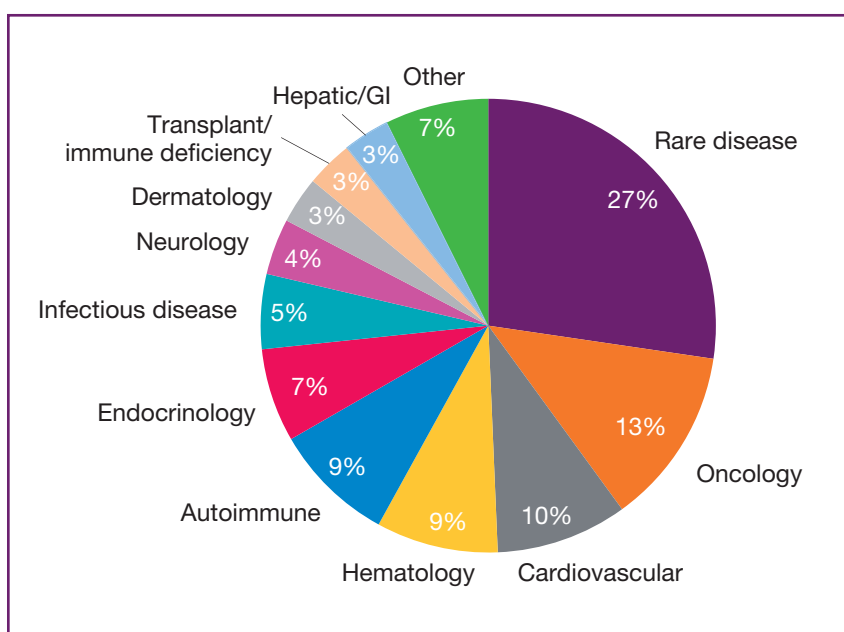
### Respondents

136/266 (51%) of respondents had experience working with registries (N=266)



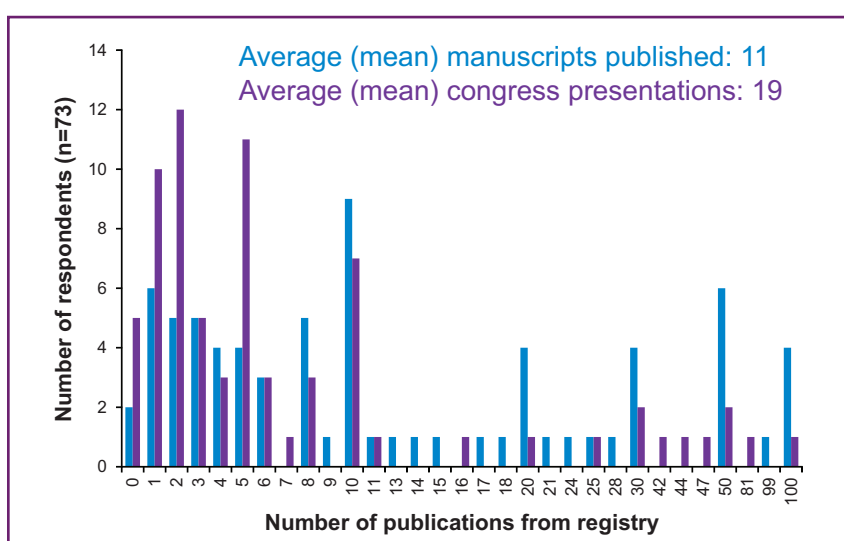
### Registry Focus

- 96 MPPREs reported the disease/therapeutic area focus of their registries.

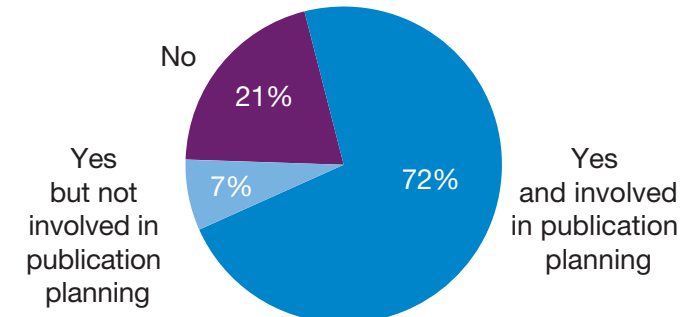


### Publications Produced From Registry Data

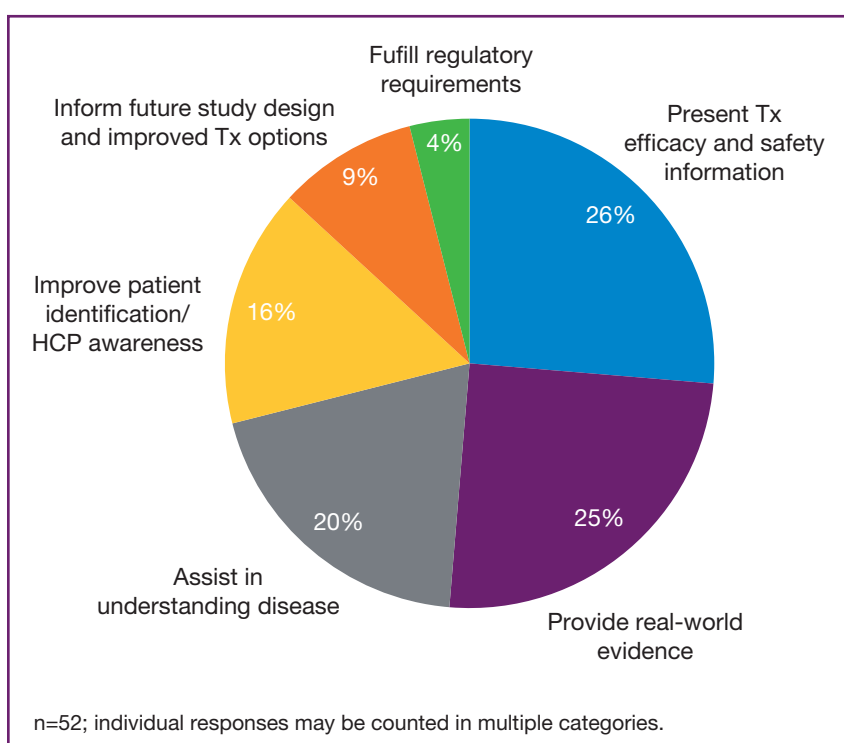
- The majority of registries produced publications (85/93; 91%).



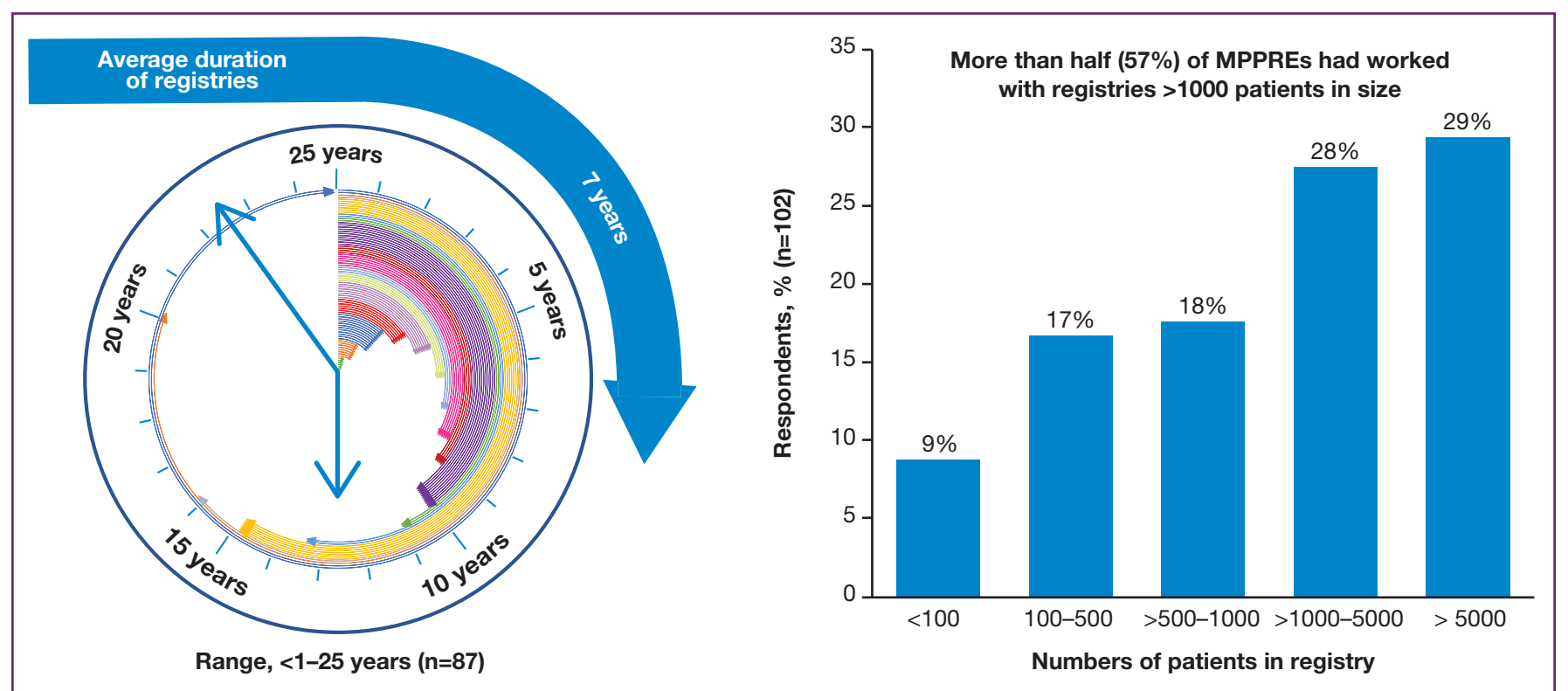
Was there a steering committee associated with the registry (n=83 responses)



### Perceived Primary Goal of Registries

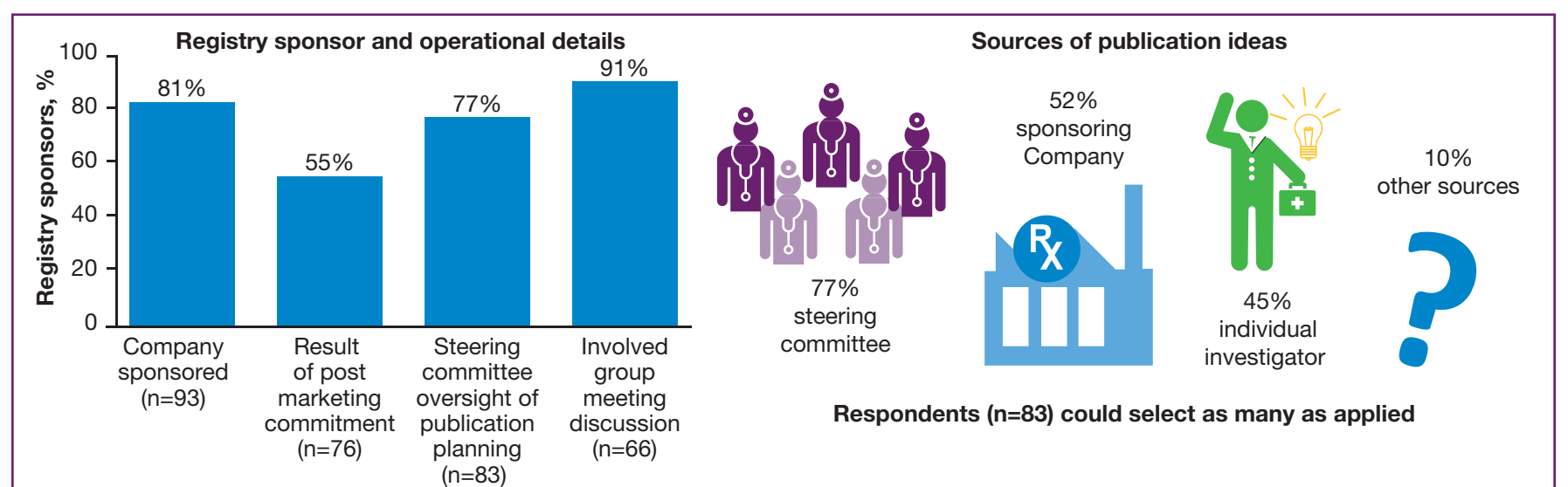


### Registry Duration and Size

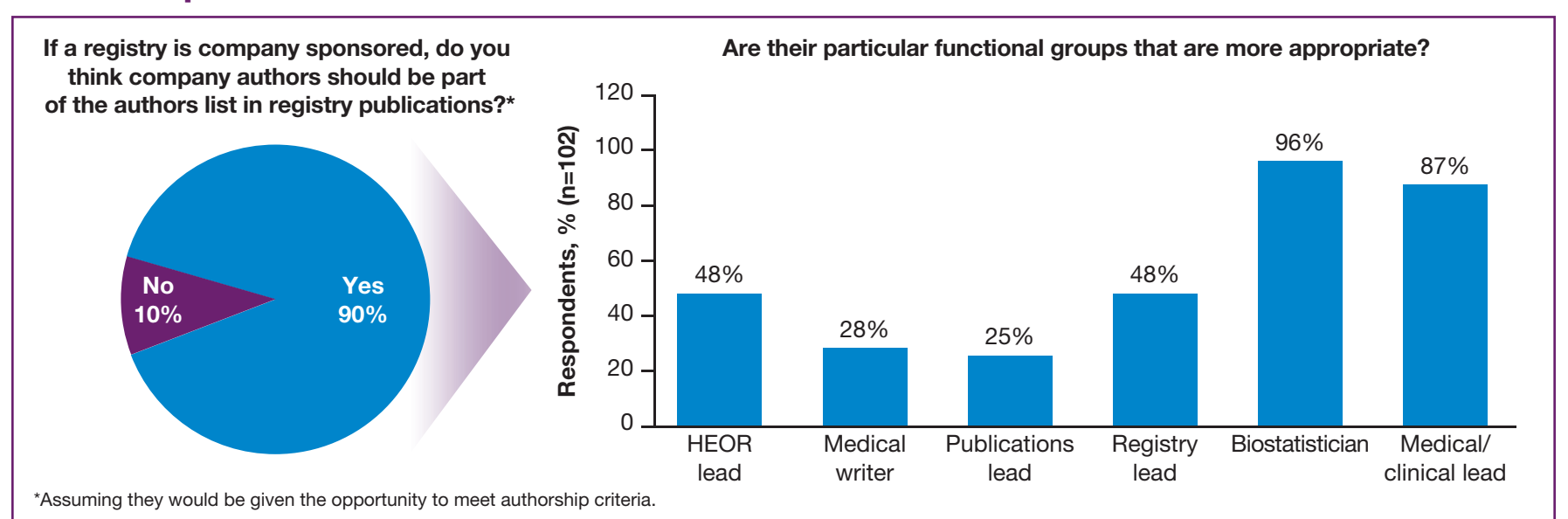


### Registry Sponsor and Operational Details

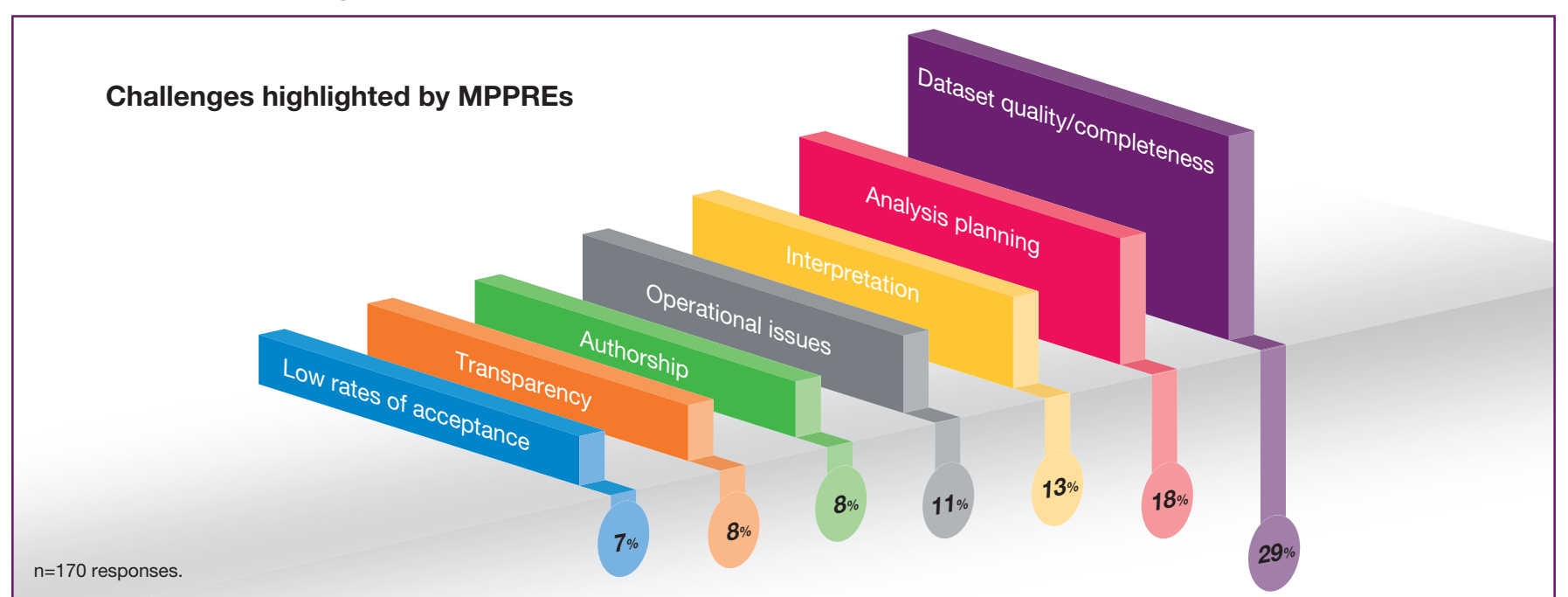
- The majority were company-sponsored and a result of postmarketing commitments.
- Steering committee oversight of publication planning was common and typically involved group meetings to foster discussion and debate.



### Authorship Issues



### Perceived Challenges



## Conclusions

- Half of surveyed 266 MPPs had registry experience.
- >80% of registries were company sponsored; over half had regulatory postapproval commitments.
- Nearly all produced publications (on average 11).
- Steering committees commonly in place to drive publication planning and generation.
- The 3 most commonly cited goals of a registry were to provide real-world treatment data, assist in understanding (rare) diseases, and present the safety and effectiveness of treatments.
- The 3 most commonly identified challenges associated with registries were data quality/completeness, analysis planning, and interpretation of results.