Stakeholders' perspectives toward the use of patient registry data for decision-making on medicines: a cross-sectional survey

HPR167

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Introduction

The use of patient registries in regulatory, Health Technology Assessment (HTA), and payer decision-making has gained increasing attention in recent years. Thus, this study's objective was to assess stakeholders' perspectives towards the use of RWE from patient registries in decision-making on medicines, and to explore factors influencing their intention to use registry data in the future.

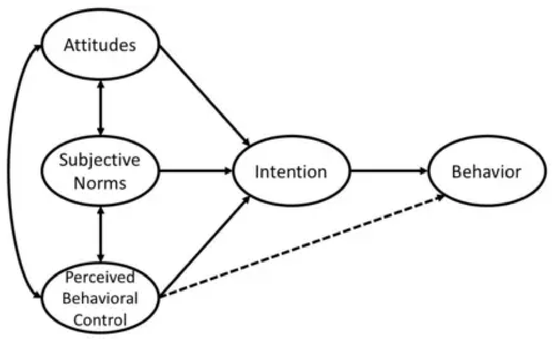
Methods

- Web-based Survey (24 questions)
  - Demographics
  - Perspectives towards registry data
    - Based on Theory of Planned Behavior
    - 5-point Likert scales

1210 invites

Target population:

1. Regulators
2. HTA & payer representatives
3. Other stakeholders (pharmaceutical industry, academia, healthcare providers, patient representatives)



Analyses

- Descriptive analyses
- Logistic regression analysis (outcome: intention, determinants: demographics, attitudes, subjective norm, behavioral control)

Results

191 responses were included in the analyses (response rate 16%; Table 1). Disease epidemiology, long term effects, and safety were generally viewed as the most informative aspects to investigate with a registry-based study (Figure 1, top panel). Covering the relevant patient population and cost were seen as registry-based studies biggest strengths, whereas data access and quality were seen as their biggest weaknesses (Figure 1, bottom panel). Compared to regulators, HTA/payers had a similar intention to use registry data, while other stakeholders were more frequently very open to using registry data in the future. Respondents with a high perceived behavioral control concerning the use of registry data were more often very open to using registry data in the future than respondents with a neutral or low perceived behavioral control (Figure 2). Respondents most often were familiar with and used the EMA guideline on registry-based studies, though a large group also reported not using any guidance document (Figure 3).

Table 1: *Respondents' demographics*

	N=191 (%)
Stakeholder[1]	
Regulators	110 (58)
HTA/payers	24 (13)
Others	54 (28)
Work experience[2]	
≤10 years	101 (53)
>10 years	89 (47)
Gender[3]	
Women	124 (65)
Region[4]	
Northern Europe	35 (18)
Eastern Europe	15 (8)
Southern Europe	38 (20)
Western Europe	69 (36)
Multinational org.	26 (14)

[1]3 missing, [2]1 missing [3]2 missing, [4]8 missing

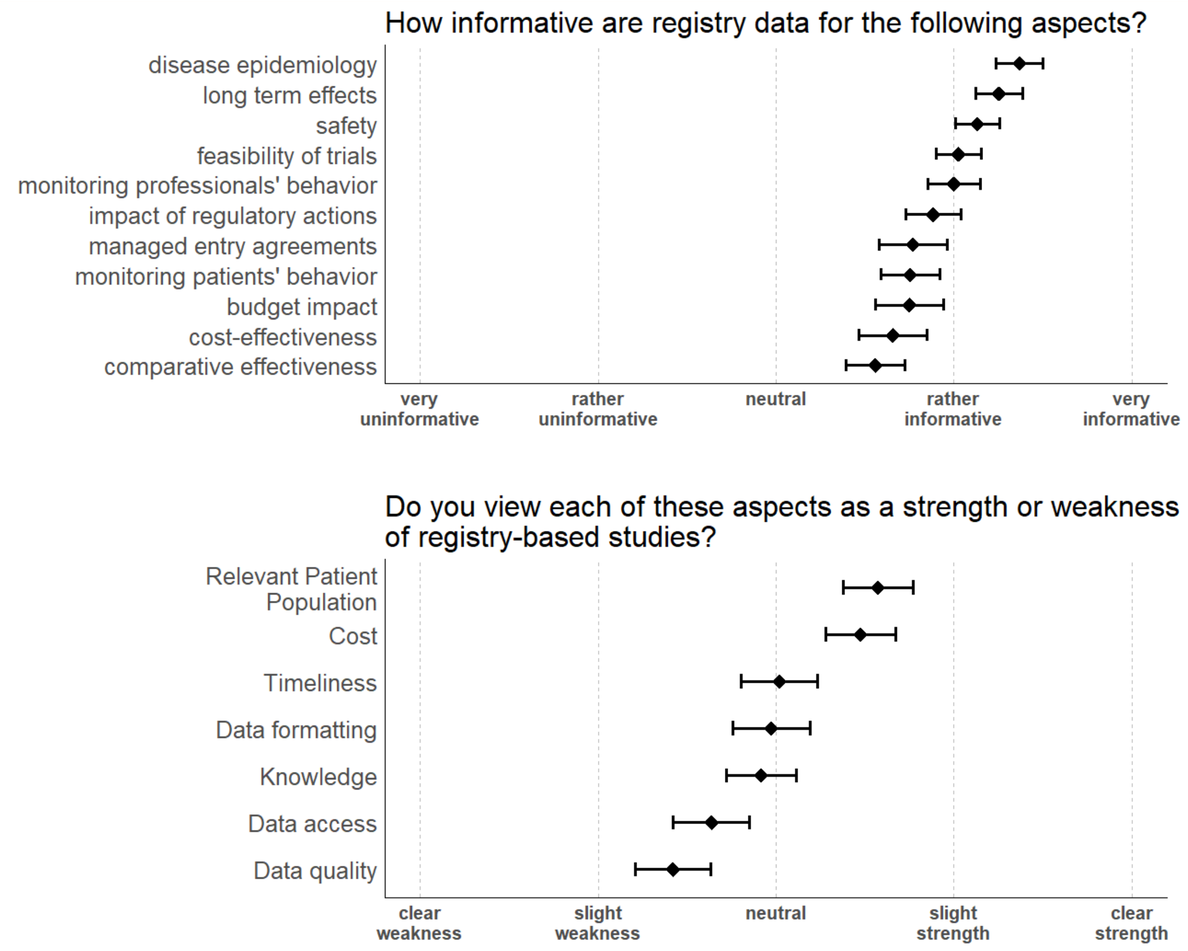


Figure 1*: Perceived informativeness (top panel), and perceived strengths and weaknesses of registry-based studies (bottom panel); means and 95%-CI's*

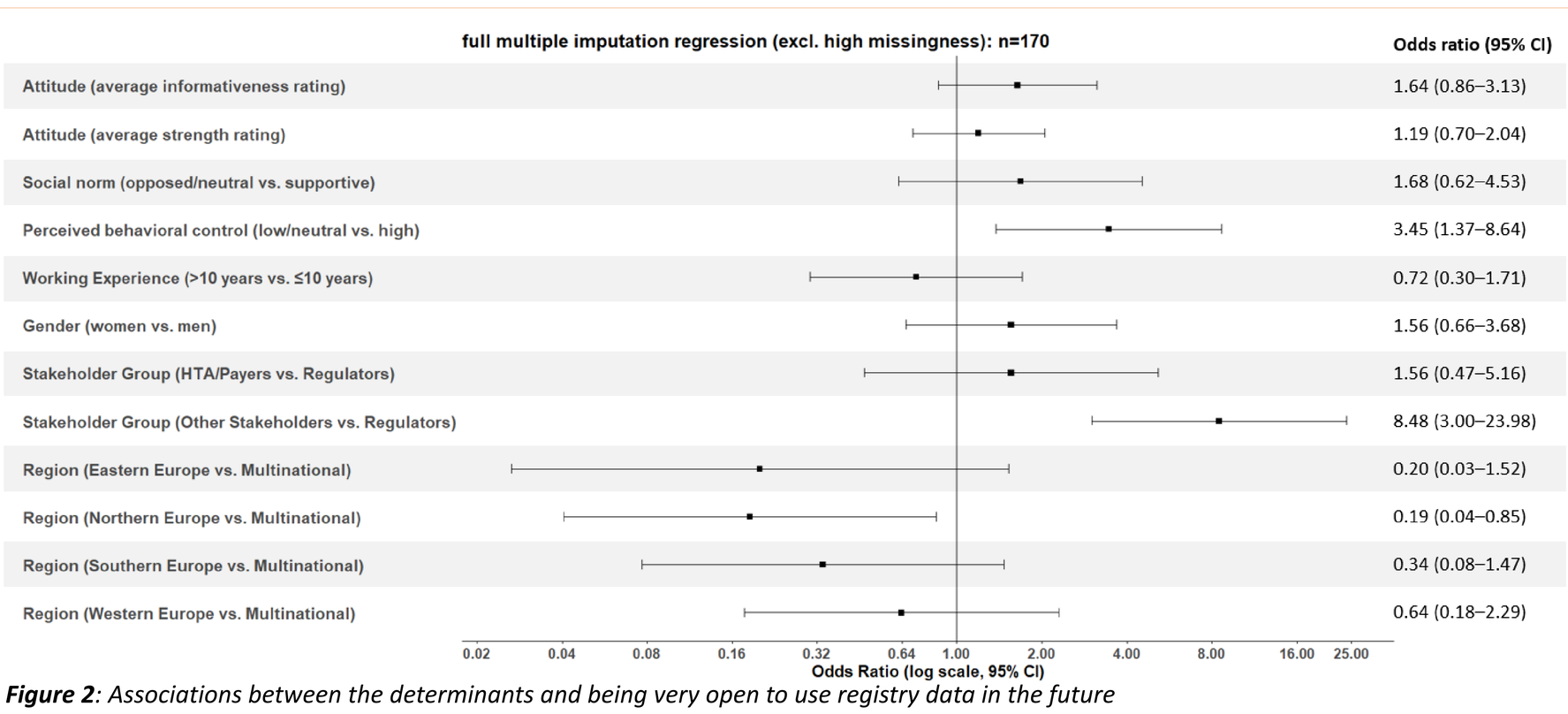


Figure 2*: Associations between the determinants and being very open to use registry data in the future*

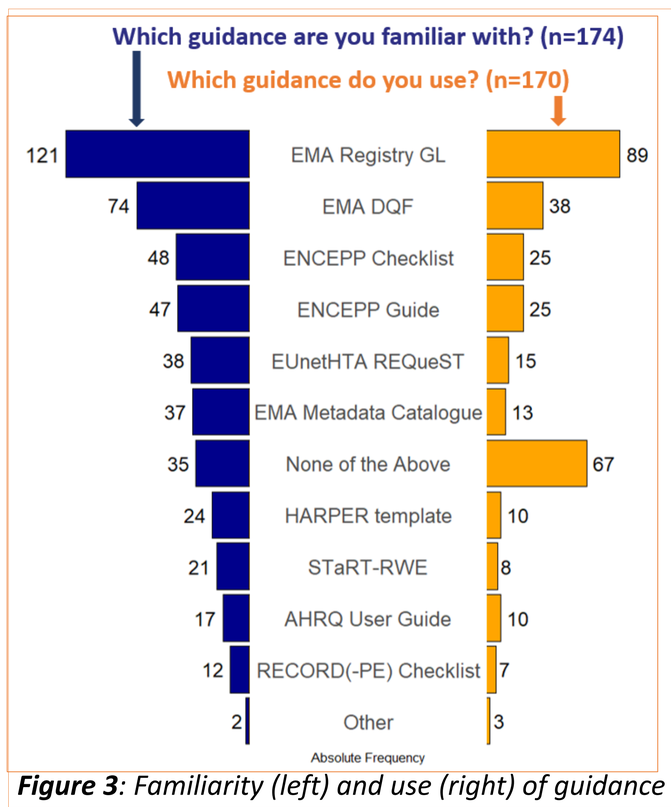


Figure 3*: Familiarity (left) and use (right) of guidance*

Conclusions

Stakeholders are open to increase the use of registry data in the future. Nevertheless, perceived weaknesses such as data quality and accessibility will need to be addressed to align and improve stakeholders' perspectives on the use of patient registries as an evidence basis for medicines decision-making.

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Participate in our new survey!

Survey Link

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