



# PATIENT DATA USE IN MEDICAL RESEARCH VERSUS DATA PRIVACY: PERSPECTIVE FROM FIVE PATIENT ASSOCIATION REPRESENTATIVES

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## Background

- Nearly 30% of the world's data is generated by the healthcare industry and this number is estimated to reach 36% by 2025.<sup>1</sup> Although patient data has the potential to significantly improve healthcare, patients have to be ensured that their data are protected.
- The objective of this study was to assess the views of patient association representatives (PARs) on the use of patient data in healthcare and the protection of patient data privacy

## Methods

- PARs who attended the European Patient Forum 2022 were contacted and offered to be interviewed. A total of 81 PARs were contacted, and five were interviewed.
- Interviews consisted in 19 questions divided into three sections: General section (1), data protection (2), and commercial companies (3). We used a 7-points Likert scale for questions where scorings were required from the interviewee (1= low/strongly disagree, 7= high/strongly agree).



30 minutes interviews



19 items questionnaire



7-points Likert scale

## Results

- Five PARs representing Spain (n=1), Malta (n=2), Bosnia (n=1) and Europe (n=1) were interviewed. Populations represented by the PARs ranged between 4 and 200 million patients.

### Section 1 (General Section)

- PARs viewed data from routine clinical care as useful for medical research. Additionally, they believed patients should contribute to medical research when possible and that research involving patient data should be systematically published (Figure 1).

### Section 2 (Data Protection)

- Clinicians and health care professionals were seen as the most trustworthy stakeholders to handle health data (Figure 2). Additionally, genetic information was considered to be the most sensitive type of health data (Figure 3).
  - Although PARs acknowledged the importance of patient data protection (mean= 6.8), they recognized it could also represent a barrier to medical research (mean= 4.9)
  - Three out of five PARs believed patient data are sufficiently protected from a privacy standpoint, however four reported patients felt having no control over their health data (Figure 4).

### Section 3 (Commercial Companies)

- PARs acknowledged commercial entities are key stakeholders in medical research due to their expertise, however, a lack of confidence persists (Figure 3)

Figure 1: PARs opinion on patient data and its applicability to medical research (mean score on a 7-points Likert scale)

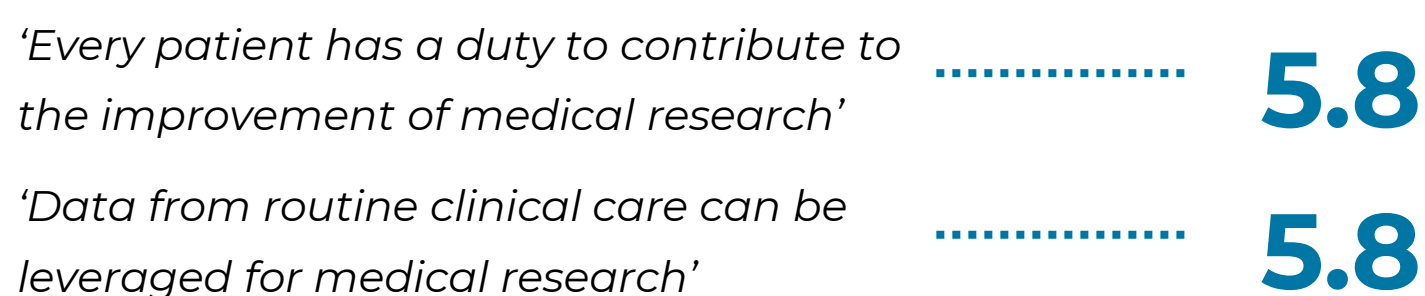


Figure 2: 'What type of patient data do you consider sensitive?'

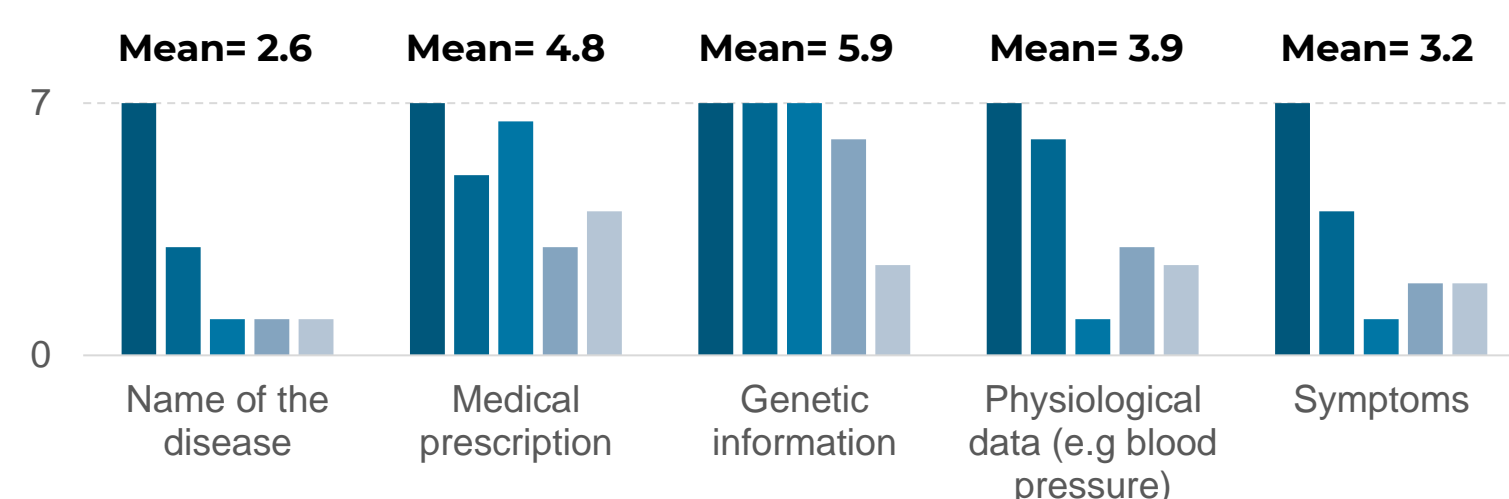


Figure 3: 'Who do you trust most to handle health data?'

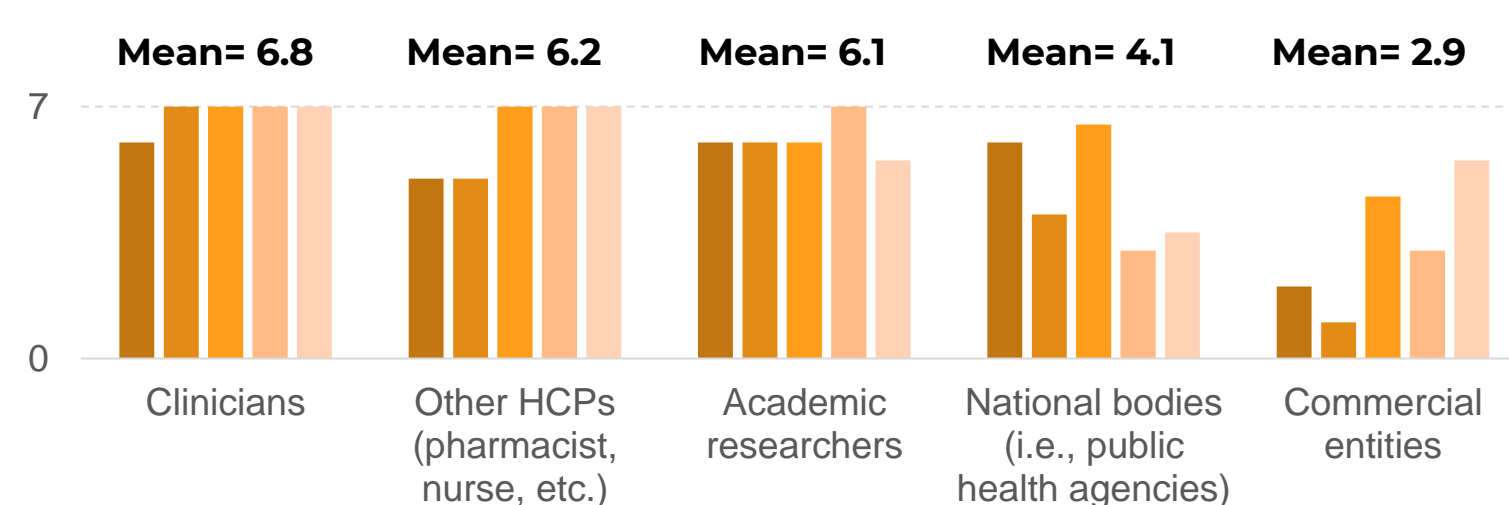


Figure 4: PARs quotes on patient data privacy



## Discussion

- PARs are aware of the importance of patient data in medical research. Patients are willing to share their data provided all stakeholders guarantee privacy. However, concerns remain as patients report having little control over their data and doubt it is adequately protected.
- Data protection will become even more critical as we see a rising trend in real-world data and artificial intelligence use for medical research

1. Coughlin S, Roberts D, O'Neill K, Brooks P. Looking to tomorrow's healthcare today: a participatory health perspective. Intern Med J. 2018 Jan;48(1):92-6.