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The EU Patient Community's Perspectives on Data Protection and Data Control

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BACKGROUND & OBJECTIVES

The EU General Data Protection Regulation **(GDPR)** is the subject of **sensitive debates,** particularly with regard to the **challenges** it poses **for health research (1-3).** However, there has been **little empirical investigation of patients' perspectives on data protection and data control.**

- **Objectives of the study:**

1. to provide information about the **EU/EEA patient community's knowledge** of the GDPR, experiences of exercising their GDPR rights, and views on data control.
2. To **inform ongoing debates on the European Health Data Space proposal** with insights into patients' perspectives on the use of their personal data for health research.

METHODS

- **Online survey:**
  - Available in English
  - Question types: multiple-choice, Likert-scale,and open-ended
  - Consisted of two parts: 1) Introductory questions, 2) Data protection and data control, with focus on a) GDPR awareness, b) data subject rights, c) data control, d) data altruism.
- **Distributed from December 2022 to March 2023 through:**
  - International organizations, e.g.: WECAN, Patvocates, EUPATI, EAHL, EORTC, EPF, etc. Social media (paid advertisement campaigns on Facebook and LinkedIn). The research team's professional networks.
- **Data analysis:** descriptive (in Excel) and inferential (in SPSS).

RESULTS

1. Demographics

- In total, **n=220 participants:**
  - **77% patients,** 16% carers, 7% members of patient organizations who are neither patients nor carers.
  - Most had experience in the disease areas of cancer (39%), infectious diseases (17%), and rare diseases (17%).
  - More than half of all participants (64%): followed courses on the topics of medicines development, clinical research or patient engagement.
- Based in **28 European Member States:**
  - The majority resided in **Western and Northern Europe.**

2. Awareness about the GDPR & exercising of data subject rights

- The **majority of participants** (90%) had **previously heard about the GDPR**.
  - **Main sources of information** about the GDPR: **training** (45%), the **news** (37%), notifications on websites (31%), **experience as participants in health research** (27%).
- **Few patients (22%) had exercised** their data subject rights.
- **Almost half** of the patients (47%) **planned to exercise** their data subject rights in the next 1 year, in medical research context.

3. Data control

- **Respondents valued** both individual (e.g. data subject rights) and collective (e.g., data intermediaries) **control tools.**
- **Positive and negative outcomes to exercising control** were identified by respondents, e.g.:
  - **Positive outcomes:** benefits for individual patients (e.g., better diagnosis), benefits for society (e.g., more data available for scientific research), fostering trust in research, etc.
  - **Negative outcomes:** jeopardizing research (e.g., limiting data sharing), psychological burden for individuals, administrative burden for researchers, etc.

4. Data altruism

- **Data altruism means the voluntary sharing of personal or non-personal data**, based on consent or permission, for purposes of general interest, such as health research. **Data altruism organizations** will be managing consents and permissions, and will be able to use the data or make it available to other data users.(Article 2(8) and Chapter IV of the Data Governance Act)
- **Survey respondents were more likely to altruistically share their personal data** with data altruism organizations **when imagining that patient representatives would be involved** in the decision-making.

References:

1. Lalova-Spinks T et al. Challenges related to data protection in clinical research before and during the COVID-19 pandemic: an exploratory study, Frontiers in Medicine, 2022
2. Peloquin D et al. Disruptive and Avoidable: GDPR Challenges to Secondary Research Uses of Data, European Journal of Human Genetics, 2020, 28:697-705
3. Hansen J et al. Assessment of the EU Member States' rules on health data in the light of GDPR, report produced for the European Commission, 2021

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CONCLUSIONS

The findings highlighted the importance of awareness raising and training on the application of the GDPR in the context of health research, and provided important points to consider when building the future European Health Data Space.