



PATIENT VIEWS ON USE OF THEIR DATA IN PHARMACOEPIDEMIOLOGICAL STUDIES

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PATIENT VOICE

World Health Organization. (2021).
Nothing for us, without us:
opportunities for meaningful engagement of
people living with NCDs: meeting report.





PHARMACOEPIDEMOLOGICAL STUDIES FOR THE PATIENT



- Pharmacoepidemiological studies are integral to patient safety.



- Studies affect other patients with similar illnesses by influencing the availability of such drugs and the ability to make informed decisions about drug suitability given knowledge about patient experiences.



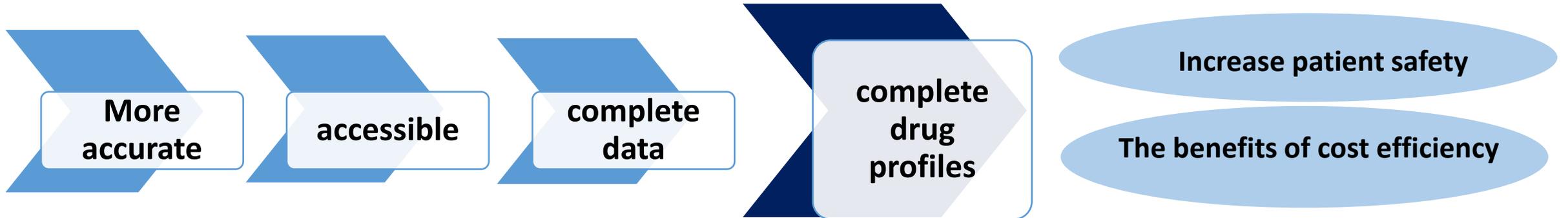
- Pharmacoepidemiology studies have the numerous benefits of the discipline in terms of enhancing patient safety.



- For these activities patient data have crucial importance.



PATIENTS DATA



Sharing of health data opens the door to the study of the so-called 'Big Data', which holds great promise for improving patient-centered care.

PATIENTS' VIEWS AND ATTITUDES TOWARDS THE SHARING OF HEALTH DATA FOR RESEARCH

- ❖ Results suggest widespread—though conditional—support among patients and the public for data sharing for health research.
- ❖ Despite the fact that participants **recognise actual or potential benefits** of data research, they expressed concerns about **breaches of confidentiality and potential abuses of the data.**



THE VIEWS OF PATIENTS AND THE PUBLIC REPORT THAT **WILLINGNESS FOR DATA TO BE LINKED AND SHARED FOR RESEARCH PURPOSES IS HIGH AND THAT PEOPLE ARE GENERALLY OPEN TO AND UNDERSTAND THE BENEFITS OF DATA SHARING.**

- ❖ Outpatients from a German university hospital who participated in a questionnaire study expressed a strong willingness (93%) to give broad consent for secondary use of data.
- ❖ 93% of a sample of UK citizens with Parkinson's disease were willing to share their data. Wide support for sharing of data internationally and in multicentre studies was reported among patient participants.
- ❖ Most participants in a sample of US patients with cancer were willing to have their data made available for 'as many research studies as possible'.
- ❖ Study found UK rheumatology patients and patient representatives in support of data sharing.
- ❖ 78.8% of surveyed Canadians felt positive about the use of routinely collected data for health research.



STUDIES SHOWED AGREEMENT ON THE FOLLOWING CONDITIONS:

value

privacy

risk minimisation

data security

transparency

control

information

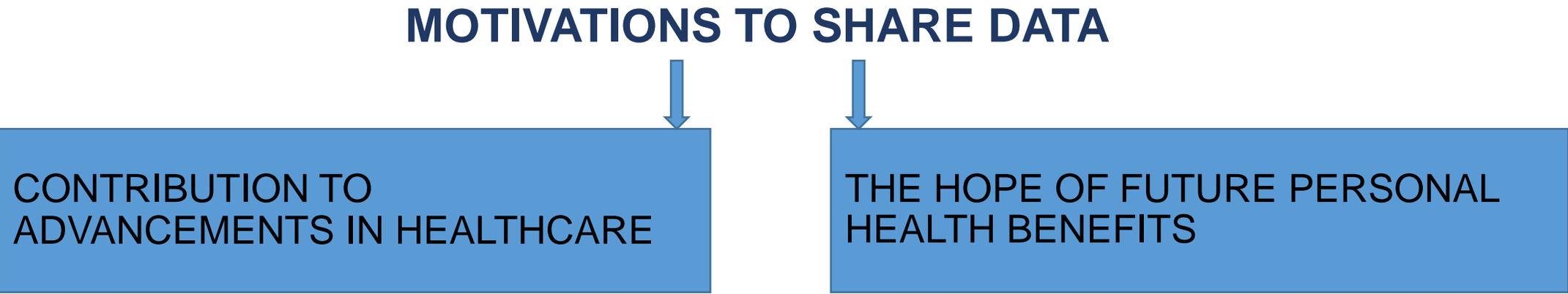
trust

responsibility

accountability

- [doi:10.1136/ medethics-2019-105651](https://doi.org/10.1136/medethics-2019-105651)

MOTIVATIONS TO SHARE DATA



CONTRIBUTION TO
ADVANCEMENTS IN HEALTHCARE

THE HOPE OF FUTURE PERSONAL
HEALTH BENEFITS

- ❖ Sharing data for ‘the common good’ or ‘the greater good’ was identified as one of the most prevalent motivations.
- ❖ Data sharing could help their doctor ‘make better decisions’ about their health or result in an increased chance of receiving personalised health information.
- ❖ Data sharing was believed to enable the study of long-term treatment effects and rare events, as well as the study of large numbers of people, to improve diagnosis, and treatment quality, as well as to stimulate innovation and identify new treatment options. .



MOTIVATIONS TO SHARE DATA

Motivations for data sharing—views of research participants from four European countries: A DIRECT study

Nisha Shah¹ · Victoria Coathup¹ · Harriet Teare¹ · Ian Forgie² · Giuseppe Nicola Giordano³ · Tue Haldor Hansen⁴ · Lenka Groeneveld⁵ · Michelle Hudson⁶ · Ewan Pearson⁷ · Hartmut Ruetten⁸ · Jane Kaye^{1,9}

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- ❖ Research participants expect in terms of control over data sharing needs to be considered and aligned with sharing for future research and re-use of data.
- ❖ Even with de-identified data, respondents prioritise privacy above all else.



PERCEIVED RISKS OF DATA SHARING

- ❖ The most significant risks of data sharing were perceived to results from **breaches of confidentiality, commercial use and potential abuse of the data.**
- ❖ Patients' concerns about confidentiality in general, sometimes linked to the risk of reidentification, concerns about a party's **competence in keeping data secure**, and concerns that personal information **could be mined from genomic data.**
- ❖ Patients perceived '**detrimental**' consequences of data 'falling into the wrong hands', such as insurance companies.
- ❖ Respondents were fearful of health data being '**stolen by hackers**' .
- ❖ Patients are concerned about **different levels of access by third parties** and about **the use of their data for commercial purposes.**
- ❖ Concerns about **control and ownership of data** and about **re-use of data for purposes that participants do not agree on.**
- ❖ Fear of **discrimination, stigmatisation, exploitation or other repercussions** as a consequence of data being shared

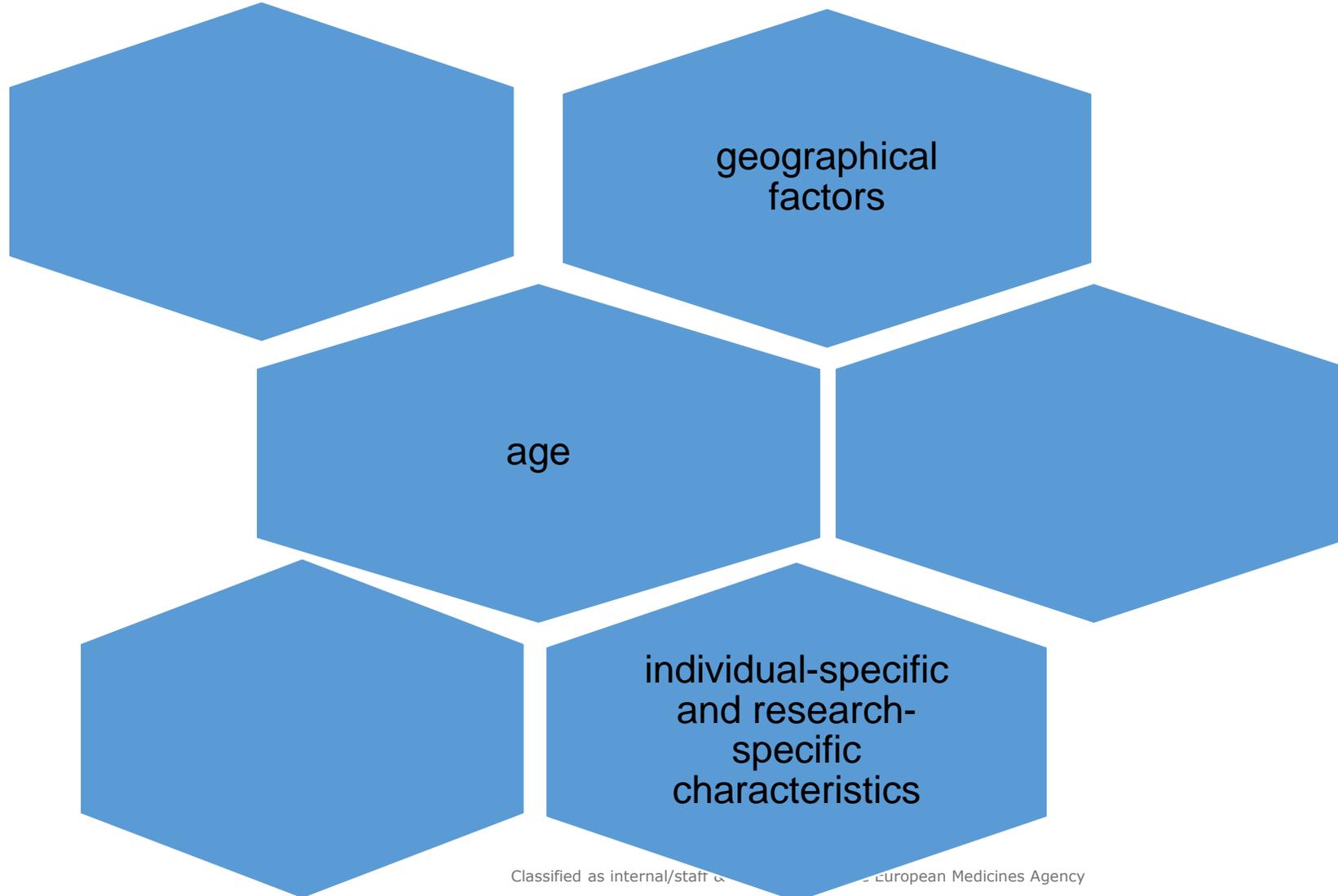


BARRIERS TO SHARE DATA

- ❖ Individuals often opposed data sharing if it was motivated by financial gain or profit or if the data were shared with commercial/private companies.
- ❖ Lack of understanding and awareness around the use of data was as a barrier to data sharing.
- ❖ Lack of transparency and controllability in releasing data as factors of lack public trust in data sharing activities.



FACTORS AFFECTING WILLINGNESS TO SHARE DATA





CONCLUSIONS

Despite the fact that patients recognise actual or potential benefits of health research, **they report a number of significant concerns and related conditions.**

The ENCePP Code of Conduct may be a tool to reinforce patient's trust, we could work to improve this.



THANK YOU FOR YOUR ATTENTION !

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