

DOES THE MANDATORY CONTRIBUTION OF MEDICAL RECORDS FOR RESEARCH USE VIOLATE THE MORAL RIGHT TO PRIVACY?

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INTRODUCTION AND OVERVIEW

INTRODUCTION AND SCOPE

Importance of Medical Databases

National medical record databases support research in epidemiology, treatment development, and personalized medicine.

Privacy and Ethical Concerns

Using records without patient consent raises privacy intrusion concerns and ethical debates in research use.

Scope and Assumptions

Focus is on privacy in research, assuming government-managed databases and use within secure Data Safe Havens.

Rights vs. Interests

Different bar of moral justification

ASSUMED CONDITIONS FOR RESEARCH USE

De-identified Records Only

Researchers access de-identified medical data remotely with strict controls preventing raw data export.

Government-owned

Only managed by elected governmental or regulatory bodies rather than unelected or private organisations and corporations

Data Safe Havens

Import & export restriction.

Cybersecurity and Privacy Measures

Approved IPs, network segmentation, session monitoring, and penetration testing ensure data safety and privacy.

MY MAIN ARGUMENT

DE-IDENTIFIED MEDICAL RECORD IS NOT PERSONAL INFORMATION

Personal Information

Your personal information must be ABOUT you.

About-ness

Information α is Absolutely about A = α is explicitly and directly points at A.

Information α is Relatively about A = α , when combined with SOME OTHER INFO (β), the combined info ($\alpha+\beta$) is absolutely about A.

Relative aboutness is always relative to some other information (α is about A relative to β)

I.e., Relative aboutness is **contextual**

E.g.

"Phone D is at location X" is **not absolutely** about A;

"Phone D is at location X" combined with "D is A's phone" is **absolutely** about A .

"Phone D is at location X" is **relatively** about A relative to "D is A's phone" .

Søe et al. (2021): ANY information has the POTENTIAL to become personal information

DE-IDENTIFIED MEDICAL RECORD IS NOT PERSONAL INFORMATION

De-identified Medical Record

“Record No. 114514 shows a patient with condition Z”

NEITHER absolutely about A

NOR relatively about A

Thus: NOT A’s personal information

How Risk Comes In

De-identified medical records are always AT RISK OF BECOMING personal information

RIGHT AGAINST PRIVACY RISK?

Problem of Paralysis

IF people have the right against risk imposition
THEN all daily activities become right-violating.

High Risk?

Risk of privacy breach (EXTREMELY liberal estimate): 6.48% per person per
year

Risk of road injury: 7.7% for the same period in the U.S.

Is U.S. traffic right-violating?

DISCUSSION AND CONCLUSION

BROADER ETHICAL CONSIDERATIONS

Ethical Challenges

Mandatory contributions raise concerns like trust erosion, data misuse risks, and unequal research benefit distribution.

FINAL POSITION AND RECOMMENDATIONS

Privacy and Data Protection

Mandatory medical record contribution under strict de-identification can be consistent with privacy rights.

Ethical Conditions

Ethical justifiability depends on societal concerns and fair distribution of research benefits.