



Use of health information in research

- The patient's perspective

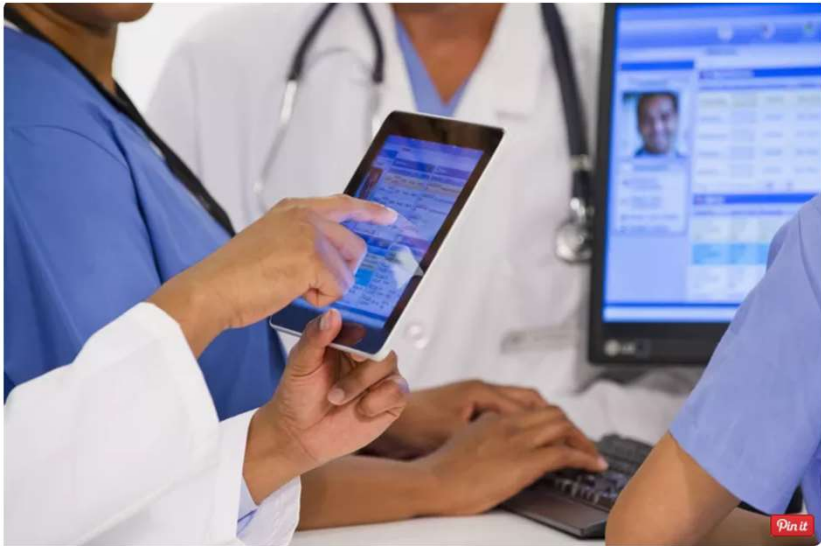
PRESENTATION CREATED BY TIA CARMON



Outline

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Background



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- ▶ Use of EHRs has increased the amount of data available for research.
- ▶ Researchers are conducting studies with de-identified health information from electronic health records.
- ▶ Use of health information for research is valuable to help further clinical research & development. This type of research can be support the advancement of medicine

Research related to patient perspective on use of their health information for research purposes



Comparison of knowledge, attitudes, and trust for the use of personal health information in clinical research

"Most participants were comfortable with the unconsented use of de-identified health information (63.5 %) or biospecimens (61.2 %). " **1**

BMC Medical Ethics

A survey of patient perspectives on the research use of health information and biospecimens

"Many respondents supported the use of their information and biospecimens for health research and also preferred consent be sought for use of health information and biospecimens." **2**



Patient Views on the Use of Personal Health Information and Biological Samples for Biobank Research

"Participants generally expressed a willingness to participate in a hypothetical biobank, and they acknowledged the benefits of this type of research. " **3**

Patient attitudes

Table 4 Participant opinions on research use of health information and biospecimens

| Statement | Strongly Disagree % | Disagree % | Neutral % | Agree % | Strongly Agree % |
|--|---------------------|------------|-----------|---------|------------------|
| 1. I would always give medical researchers consent to use my identifiable health information or biospecimens for any medical research purpose | | | | | |
| health information | 4.7 | 18.0 | 15.2 | 43.1 | 18.0 |
| biospecimen | 3.8 | 14.2 | 22.7 | 41.7 | 15.6 |
| 2. I need to know the exact medical research purpose for which my identifiable health information or biospecimen is being used before I would give consent | | | | | |
| health information | 9.0 | 21.8 | 21.8 | 33.2 | 12.3 |
| biospecimen | 10.4 | 34.1 | 23.2 | 23.7 | 6.2 |
| 3. It is enough for me to know my identifiable health information or biospecimen is being used for medical research in general | | | | | |
| health information | 3.3 | 15.6 | 20.4 | 46.9 | 12.0 |
| biospecimen | 3.8 | 14.2 | 17.1 | 47.4 | 14.7 |
| 4. I would consent to have my identifiable health information or biospecimens held in a research repository, data library or biobank and used as needed by researchers | | | | | |
| health information | 1.9 | 12.8 | 14.2 | 50.2 | 18.0 |
| biospecimen | 3.3 | 9.0 | 15.2 | 53.1 | 17.1 |



Consent options

No consent

This route simply advises patients that their health information could be used for research. The patient does not have the option to say yes or no, an example of this is a posted sign informing patients that their health information could be used for research

Negative consent

This route gives is when the patient is advised that their health information could be used for research and gives the patient the option to say yes or no, as to whether the patient wants to give their consent for their health information to be used for research or not

Positive Consent

This route is when the patient must give written or verbal consent to have their health information used for research purposes

Consent options-patient responses

Box 1 Patients' comments relating to different consent options

Advise only ($n = 3$)

... one assumes if a doctor is taking part in research he's trying to do the best for his patients. And as far as I am concerned, you should trust him enough to rely on him to do that. (Patient 15)

Negative consent (advise and have option to say no) ($n = 1$)

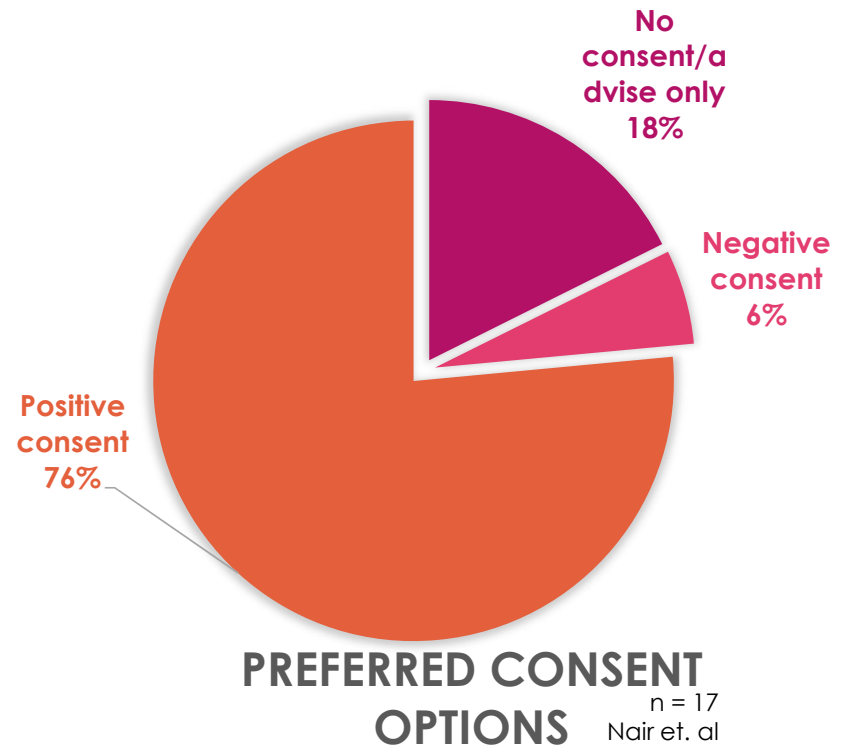
... send me something in the mail saying, 'We're going into your file, unless you say no'. (Patient 8)

Positive consent ($n = 13$)

If the verbal one carried as much weight as the other one [written consent], then I would go with the verbal. (Patient 11)

I think asking for consent and signing a consent form explaining the research will probably be the best option for me. Um, it would give me a good idea as to what's involved and I would have the option of getting involved or not. (Patient 16)

I think you need to give conscious consent to having any data, any personal data used, whether you are identified or not. That's certainly a right. That's your information, it's your medical history. Whether it's identified or not, you should control it. (Patient 14)





Conclusion

- ▶ Overall patients are accepting of the use of health information for research purposes.
- ▶ Patient acceptance of use of their health information for research purposes can depend on patient trust of their healthcare provider and/or health institution.
- ▶ Patients want to be aware that their health information is being used for research purposes.
- ▶ Patients prefer to be asked to consent to having their health information used for research purposes.
- ▶ Patients generally acknowledge that the use of health information for research purposes as beneficial.

References

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Other resources

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