

Communicating Privacy and Confidentiality Issues to Physicians and Patients in a Research Study using Electronic Medical Records

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Background

The COMPETE study (Computerization of Medical Practices for the Enhancement of Therapeutic Effectiveness) is studying how medicines are prescribed in small, community family practice offices. The implementation of electronic medical records in these practices as part of the study has raised issues of confidentiality, security and privacy. Communicating information about privacy and confidentiality to patients in a non-threatening way is particularly challenging.¹

Methodology

We conducted two focus groups each for three different groups (total N = 44): 1. Family physicians in the Hamilton area (N = 13); 2. Younger consumers (Age 35-55; N = 15) and 3. Older consumers (Age 56-80; N = 16) All consumer participants had interacted with the healthcare system at least twice in the past year and had expressed an interest in participating in focus groups on "health issues."

Physician and consumer participants were asked about their concerns regarding computerization of health records as well as secondary access to anonymized patient data for research purposes.

A brochure to explain privacy and confidentiality issues was provided to all participants. Feedback on 'tone and manner', appropriate-ness of language and 'believability' was solicited.

Results

Physicians in general felt that patients would not want to know much about the COMPETE project. They also felt that patients were satisfied with the confidentiality afforded to them by their physician. They did not anticipate any privacy or confidentiality concerns for their patients with use of anonymized patient data in the COMPETE project or with the introduction of EMRs into their practice.

In contrast, consumers worried about a loss of control over their health information with computerization. They felt that anonymization of health information was not adequate protection. Consumers also expressed concern about information usage creep and inadequate security practices to keep their health information confidential. Older consumers in particular were concerned about access by government and the insurance industry. Although both physicians and consumers raised realistic concerns regarding electronic data, they displayed an unwarranted confidence in the security offered by current paper record systems.

Consumers felt that a simple, plain language brochure would be adequate for most people, but that a more detailed booklet be provided for those who needed more information. Some consumers felt they would like to be able to discuss concerns about the study with their physician in greater depth.

Conclusion

Consumers would like more control over their health information and would like to have a say in how the information is used, even if it is anonymized.

Physicians by and large are not aware of these consumer views. Both groups require education to be able to judge advantages and disadvantages of EMR vs paper systems. As EMRs proliferate in clinical practice, these issues must be addressed.

References

1. Goldman J, Mulligan D. Privacy and Health Information Systems: A Guide to Protecting Patient Confidentiality. Washington DC: Centre for Democracy and Technology; 1996

