

JERHRE NOTES

Skills for Solving Ethical Problems in Human Research

How Effective are Your HIPAA Authorization Forms?

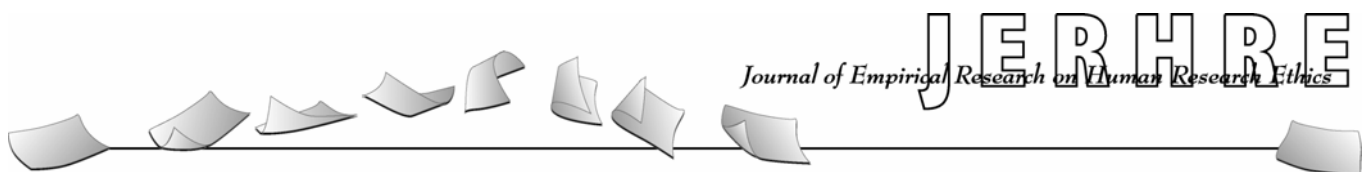
So, your HIPAA authorization forms include the required elements. But do they say what subjects need to know? Are they understandable and reasonably brief?

A survey of HIPAA authorization forms from 111 institutions, including medical centers and commercial IRBs, revealed that all of the forms fulfilled the requirement of describing the data to be collected, and 95% of the forms adequately described the intended uses of the data. However, many were ineffective from the perspective of a potential research participant, and even illegal if one considers whether they tell participants what they would want to know in understandable language.

- Only 19% of the forms distinguished between data containing personal identifiers versus coded or aggregate data.
- Complex legalistic language was typically employed, as well as defensive language that seemed to negate the right to revoke the authorization.
- 62% of the forms provided detailed lists of entities that might have access to protected health information, but did not distinguish the short list of persons with access to personally identified data (e.g., site monitors) versus the long list of entities whose access is limited to coded data (e.g., other study sites).
- Only 5% indicated when the personal health data would be destroyed.
- Most of the forms were at least two pages long.

For details, see:

Breese, P., Rietmeijer, C., & Burman, W. (2007). Content among locally approved HIPAA authorization forms for research. *Journal of Empirical Research on Human Research Ethics*, 2(1), 43-46.



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