Case Reports on the Web Redux: Confidentiality Still in Jeopardy

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Summary: We reported at AMIA 1999 on the apparent lack of privacy protection for the subjects of case reports at 32 websites. It has been clear for some time that print journal editors and Institutional Review Boards require informed consent from patients or their surrogates if they can be potentially identified in publications.[1-3] We found in 1999 that this level of confidentiality protection was not being applied to case reports on the Internet.[4] This report is a follow up evaluation of those and 26 other websites with case reports to see if confidentiality protection practices have improved.

Methods: From December 2002 through January 2003 we revisited the 32 case report websites reported on at AMIA 1999. Included sites were those that presented a minimum of one paragraph of clinical history or physical examination findings of a patient. Each site was examined thoroughly (via existing links) to answer the following three questions (same questions as our 1999 report; possible answers in parentheses): 1. Are these cases real patients? (yes, no, unclear), 2. If the cases are real patients, is there a clear statement of confidentiality protection? (yes, no), and 3. If the cases are real patients, is there a statement of informed consent? (yes, no). Cases were assumed to be real if actual images (photographs, radiographs, etc.) were presented. Reports were classified as "unclear" if there was no explicit statement that case descriptions were fictional and images were not included, or if patients were described as fictional but images were presented. Finally, 26 additional websites presenting case reports were identified and the same methodology was applied to them.

Results: Of the 32 original sites reported in 1999, 31 had real cases, only 4 of those mentioned confidentiality protection, and only one noted obtaining consent from patients. On follow up, 15 of these sites are no longer functioning, and of the remaining 17, only 3 included a confidentiality statement with one obtaining consent from cases. Of 26 new websites with case reports identified, all appeared to present real cases and none of them included statements of privacy protection of subjects nor mentioned obtaining consent from subjects for publication.

Conclusions: This survey of medical websites that offer case reports provides evidence of persistent inattention to subjects' confidentiality. Authors of these reports or sponsoring institutions continue to fail to provide safeguards for patient/subject health information and fail to obtain adequate consent from subjects before publishing potentially identifiable information.

References:

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