

## Messages from AMIA

# AMIA's code of professional and ethical conduct 2018

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## INTRODUCTION

AMIA has a longstanding interest in and a professional obligation to promote a strong ethical framework for the field of biomedical and health informatics. This white paper presents the latest AMIA Code of Professional and Ethical Conduct. The original Code was approved in 2007<sup>1</sup> by the AMIA Board of Directors. Recognizing the need to update the Code to ensure that it remains current and relevant, this document constitutes a revision of and update to the second code, approved in 2012 and published in the *Journal of the American Medical Informatics Association* in 2013.<sup>2</sup> The code presented here remains an evolving document, with modifications expected as the in-

formation technology, informatics, and healthcare environments change over time. AMIA will publish on its web site the most recent version of the Code of Ethics as part of a process that seeks ongoing response from and involvement by AMIA members.

Because the Code is meant to be practical, applicable in real life, and easily understood, it is compact and uses general language. The AMIA Code of Ethics is not intended to be prescriptive or legislative; it is aspirational and extends beyond regulatory and legal obligations to provide the broad strokes of a set of important ethical principles pertinent to the field of biomedical and health informatics.

The Code is organized around the common roles of AMIA members and the constituents they serve, including patients, caregivers,

clinicians, researchers, students, agencies, hospitals and practices, medical organizations, vendors, insurance companies, and others with whom they interact. The AMIA Board and the AMIA Ethics Committee encourage members to offer suggestions for improvements and changes. In this way, the Code will continue to evolve to best serve AMIA and the larger informatics community.

The Code's authors are aware that all professionals will, from time to time, find themselves in situations shaped by what has been called "dual agency" or "multiple agency." In these circumstances, a professional encounters conflicting commitments, duties, or loyalties. An informatics professional may have conflicting duties to patients, to colleagues, to society, and to an employer. Few, if any, codes of ethics are nimble enough to provide guidance in such situations. Further, AMIA's Ethics Committee is a resource to members who find themselves in ethically unclear or challenging situations.

AMIA members may contact the AMIA Ethics Committee, which can provide guidance in some circumstances. AMIA members are professionally diverse,<sup>3,4</sup> and include those who are, or are in training to be, nurses, physicians, pharmacists, dentists, informaticians, computer scientists, and others. In many cases, these professions have their own codes of ethics.<sup>5-12</sup> The International Medical Informatics Association, an international federation for which AMIA serves as the U.S. membership organization, also has a revised "Code of Ethics for Health Information Professionals."<sup>13</sup>

This document incorporates issues covered by other documents and laws bearing on ethics and professional conduct:

- AMIA's "Conflict of Interest Policy," which governs the organization's employees and leaders in regard to some of their financial and other interactions with outside entities.<sup>14</sup>
- AMIA's "Meeting Anti-Harassment Policy," which describes AMIA's commitment to providing an atmosphere that is welcoming to all members and supports learning and professional growth.<sup>15</sup>
- The International Committee of Medical Journal Editors' "Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals."<sup>16</sup> This document is widely accepted as identifying standards for publication and authorship, and is paralleled by the editorial policies for the past<sup>17</sup> and current<sup>18</sup> publishers of the *Journal of the American Medical Informatics Association*, as well as the publisher of *Applied Clinical Informatics*.<sup>19</sup>
- Privacy laws. Several sections herein address patient privacy or the rights of patients to view and control access to their health information. These sections are intended to parallel and make explicit duties under the law. In the United States, for instance, the Privacy Rule under the Health Insurance Portability and Accountability Act<sup>20</sup> lays out many duties for those who are entrusted with health information. Many other countries have similar laws to protect patient data. Informatics professionals are expected to be familiar with and follow the laws governing their practice.

Members of the Ethics Committee are unanimous in their view that those who work in informatics, much as in other health professions, are duty-bound to embrace a patient-centered approach to their work, even if that work does not involve direct patient care or human subjects research. As elsewhere in the health professions, vulnerable populations or those with special needs may be entitled to additional considerations.

The importance of professionalism and ethics has been recognized for millennia by health professionals and organizations,<sup>21</sup> now including information technology professionals. This code of ethics

emphasizes AMIA's commitment to adhere to and promote the highest standard of ethical and professional behavior.

## PRINCIPLES OF PROFESSIONAL AND ETHICAL CONDUCT FOR AMIA MEMBERS

AMIA members acknowledge as their professional duty to uphold the following principles of and guidelines for ethical conduct. AMIA members are expected to know to seek the advice of institutional ethics committees, AMIA's Ethics Committee, or appropriate institutional review boards, as necessary. The following code details address patient care, interactions with colleagues, responsibilities to employers, and roles regarding society and research.

I. Key ethical guidelines regarding patients, guardians, and their authorized representatives (called here collectively "patients")

AMIA members involved in patient care should:

- A. Recognize that patients and their loved ones and caregivers have the right to know about the existence and use of electronic records containing their personal healthcare information, and have the right to create and maintain their own personal health records and manage personal health information using a variety of platforms including mobile devices. In this context AMIA members should:
  1. Not mislead patients about the collection, use, or communication of their healthcare information.
  2. Enable and — as appropriate, within reason and the scope of their position and in accord with independent ethical and legal standards — facilitate patients' rights and ability to access, review, and correct their electronic health information.
  3. Recognize that patient-provided/generated health data, such as those collected on mobile devices, deserve the same diligence and protection as biomedical and health data gathered in the process of providing health care.

B. Advocate and work as appropriate to ensure that protected health information (PHI),<sup>20</sup> personally identifiable information (PII), and other biomedical data are transmitted, acquired, recorded, stored, maintained, analyzed, and communicated in an appropriately safe, reliable, secure, and confidential manner, and that such data management is consistent with applicable laws, local privacy and security policies, and accepted informatics standards.

C. Never knowingly disclose PHI, PII, or biomedical or health data in violation of legal requirements or accepted local confidentiality practices, or in ways that are inconsistent with the explanation of data disclosure and use to the patient. AMIA members should understand that inappropriate disclosure of biomedical information can cause harm, and so should work to prevent such disclosures. AMIA members should avoid acquiring data through means that run the risk of, or fail to prevent, inappropriate disclosure. Likewise, even if an action does not involve disclosure, one should not use — or through negligence permit the use of — patient information and data in ways inconsistent with the stated purposes, goals, or intentions of the patient or organization responsible for these data, except as appropriate for public health, previously approved and communicated research uses, or reporting as required under the law.

II. Key ethical guidelines regarding colleagues

AMIA members should:

A. Endeavor, as appropriate, to support and foster colleagues' and/or team members' work, in a timely, respectful, and conscientious way to support their roles in healthcare and/or research and education.

B. Support and foster the efforts of patients to be actively involved in the collection, management, and curation of their health data.

C. Advise colleagues and others, as appropriate, about actual or potential information or systems issues (including system flaws, bugs, usability issues, etc.) that negatively affect patient safety, privacy, data security, or outcomes or could hinder colleagues' ability to delegate responsibilities to patients, other colleagues, involved institutions, or other stakeholders.

D. If a leader, an AMIA member should:

1. Be familiar with these guidelines and their applicability to their practice, unit, or organization.
2. Communicate as appropriate about these ethical guidelines to those they lead.
3. Strive to promote familiarity with, and use of, these ethical guidelines.

III. Key ethical guidelines regarding institutions, employers, business partners, and clients (called here collectively "employers")

AMIA members should:

A. Understand their duties and obligations to current and former employers and fulfill them to the best of their abilities within the bounds of ethical and legal norms.

B. Understand and appreciate that employers have legal and ethical rights and obligations, including those related to intellectual property. Understand and respect the obligations of their employers, and comply with local policies and procedures to the extent that they do not violate ethical and legal norms. Consider the tradeoffs that occur with the configuration and use of technologies (eg, decision support systems) before implementation, and monitor and manage results when the optimal approach is unclear.

C. Inform the employer and act in accordance with ethico-legal mandates and patient rights when employer actions, policies, or procedures would violate ethical or legal obligations, contracts, or other agreements made with patients. Maintain a safe and high-quality environment even while implementing innovation, recognizing that all changes in a complex adaptive environment generate unanticipated consequences and potential harm.

IV. Key ethical guidelines regarding society and regarding research

AMIA members involved in research should:

A. Be aware of the Declaration of Helsinki (Ethical Principles for Medical Research Involving Human Subjects), which should guide all human subject research, including research that involves users of informatics tools and interventions as human subjects (eg, workflow analysis studies, clinical decision support systems analysis, patient care innovations, analysis, etc.).<sup>22,23</sup> Recognize that duty and care to colleagues exist regardless of whether such responsibilities are acknowledged by institutional review boards, vendors, and others involved in informatics activities.

B. Be mindful and respectful of the social or public health implications of their work, ensuring that the greatest good for society is balanced by ethical obligations to individual patients.

C. Avoid any plagiarism or self-plagiarism or other misrepresentations of the truth in the publication of research and other work.

D. Disseminate new knowledge — both positive and negative — expeditiously, to allow the field to advance and to permit others to take advantage of novel discoveries to improve patient care.

E. Strive as appropriate in the context of one's position to foster the generation of knowledge and biomedical advances through appropriate support for ethical and institutionally approved research efforts facilitated through informed consent and disclosure processes and procedures, particularly when third-party entities not meeting the definition of business associates are involved.

F. Know and abide by the applicable governmental regulations and local policies that define ethical research in their professional environment.

V. General professional and ethical guidelines

AMIA members should:

A. Maintain competence as informatics professionals:

1. Obtain applicable continuing education and be dedicated to a culture of lifelong learning and improvement;
2. Recognize technical and ethical limitations and seek consultation when needed, particularly in ethically conflicting situations;
3. Contribute to the education and mentoring of students, junior members, and others, as appropriate;
4. Promote a culture of inclusivity in their work and professional conduct.

B. Strive to encourage the adoption of informatics approaches supported by adequate evidence to improve health and health-care; and to encourage and support efforts to improve the amount and quality of such evidence.

C. Be mindful that their work and actions reflect on the profession and on AMIA.

## CONCLUSION

As a matter of personal and professional integrity, adherence to the principles laid out here is expected of all who have the privilege of serving in the field of biomedical and health informatics. Those whose skills allow them to contribute in one way or another to the health of individuals and populations carry important responsibilities, and this Code of Ethics delineates how informaticians may best do so.

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