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Research Ethics: What Nurses Need to Know

**To: Ethics Advisory Board**

**From: Conscientious RN**

**Subject: Patient care during research**

I’ve been asked to care for patients who are participating in a research study. What are the ethical guidelines for this type of practice?

**From: ANA Center for Ethics and Human Rights**

Nurses frequently are called upon to provide care for patients who are participating in scientific and medical research studies, which are a primary source of evidence-based practice. These patients have dual roles: They’re hospital/clinic patients and human subjects participating in research studies. Nurses should be aware of the special concerns raised by research involving patients and other vulnerable groups, including children, people who are cognitively impaired, those who are economically or educationally disadvantaged, older adults, pregnant women, prisoners, and underserved populations.

Nurses who are asked to assist in a research study or engage in research activities in any capacity must take care to ensure that research is soundly constructed, significant, worthwhile, and in conformity with ethical standards. Federal regulations direct that, before initiation, all research proposals must be approved by a formally constituted and qualified institutional review board (IRB) to ensure participant protection and the ethical integrity of the research. Nurses also should be fully informed about the qualifications of the principal investigator, the rights and obligations of all those involved in the study, and the ethical conduct of research in general.

The *Code of Ethics for Nurses with Interpretive Statements* (the *Code*) states that the principle of respect for autonomy, respect for persons, and respect for self-determination provides individuals with the right to choose whether to participate in research as a human subject. In addition, research participants or legal surrogates must receive sufficient and materially relevant information to make informed decisions and to understand that they have the right to decline to participate or to withdraw at any time without fear of adverse consequences or reprisal.

Information needed for informed research consent includes the nature of participation; potential risks and benefits; available alternatives to taking part in the study; disclosure of incidental findings; return of research results; and an explanation of how the data will be used, managed, and protected. Details about the nature of consent must be communicated in a manner that is comprehensible to the patient or a legally authorized representative.

According to the *Code*, nurses remain committed to patients throughout the continuum of care and during their research participation. Patients who are in research studies may perceive that they don’t have a choice of whether to participate since they’re currently in the hospital and depend on their providers (who may also be the principal study investigators) for care. An individual’s human rights, however, are not altered because of participation in a research study. A patient’s welfare may never be sacrificed for research ends.

Nurses should be aware of threats to integrity, including requests to deceive a patient, withhold information, falsify records, or misrepresent research aims. Nurses may see researchers seemingly pressuring patients to stay in a study when the patients have clearly stated that they wish to withdraw. The *Code* states that nurses have a duty to question and, if necessary, to report to appropriate oversight bodies, such as the IRB, any researcher who violates participants’ rights or is involved in research that is ethically questionable. Nurses also have a duty to advocate for participants who wish to decline to participate or to withdraw from a study before completion.

— Response by Kathryn Schroeter, PhD, MA-Bioethics, RN, CNOR, CNE, chair of the ANA Ethics and Human Rights Advisory Board