



EduCURE
NONPROFIT ORGANIZATION

HISTORY'S LESSONS IN ETHICS SAFEGUARDING PARTICIPANTS: STRONGER RULES, SAFER RESEARCH

FROM AWARENESS TO ACCESS, FROM ACCESS TO ACTION



CLINICAL RESEARCH

LEARNING FROM THE PAST: WHY ETHICS MATTER IN CLINICAL RESEARCH

Clinical research has led to life-saving breakthroughs, but history has also shown us the dangers of ignoring ethics. Past studies like the Tuskegee Syphilis Study, the Guatemala Syphilis Experiments, and Nazi medical experiments during World War II and more harmed participants and broke public trust. In these cases, people weren't told the truth, targeted for the wrong reasons, couldn't give informed consent, and suffered as a result.

HOW WAS THIS FIXED? MODERN RESEARCH PROTECTIONS

The lessons learned from these abuses have shaped today's research standards. Here's how clinical research became safer and more trustworthy:

1. INFORMED CONSENT

Informed consent means you have the right to know exactly what a study involves—including its purpose, risks, benefits, and your rights—before choosing to participate. You can say “no” or leave a study at any time.

2. THE BELMONT REPORT

The Belmont Report (1979) is a set of U.S. guidelines that require researchers to respect individuals, do good and avoid harm, and share research benefits fairly. These principles protect everyone who takes part in research.

3. DECLARATION OF HELSINKI

The Declaration of Helsinki is an international agreement that puts participant safety, well-being, and informed consent at the heart of all medical research. It requires studies to be scientifically sound and reviewed by independent experts.

4. INDEPENDENT OVERSIGHT AND MONITORING

Every clinical trial is reviewed by an Institutional Review Board (IRB)—a group of doctors, scientists, and community members who ensure studies are safe and ethical. Studies are monitored throughout, not just at the start. If new risks appear, studies can be stopped immediately.



5. SPECIAL PROTECTIONS FOR VULNERABLE GROUPS

Extra safeguards are in place for children, pregnant women, prisoners, the unhoused, and other groups who may be at higher risk. Why Are Extra Safeguards Needed for Vulnerable Groups?

Not everyone has the same ability to protect their own rights or make fully informed decisions, especially when it comes to joining research studies. Vulnerable groups—like children, pregnant women, prisoners, the unhoused, and others—may face extra challenges such as:

- Limited power or freedom to say “no” (for example, prisoners)
- Difficulty understanding all the risks or benefits (like young children)
- Higher health risks (pregnant women, people without stable housing)
- Less access to information or support

Because of these challenges, researchers must take extra steps to make sure participation is fully voluntary, safe, and fair. This includes:

- Explaining studies in simple terms
- Getting permission from guardians when needed
- Monitoring health closely
- Ensuring no one is pressured or exploited

These safeguards protect people who are more likely to be taken advantage of or harmed, making clinical research ethical and trustworthy for everyone.

6. TRANSPARENCY AND HONESTY

Transparency and honesty mean that researchers must openly share what happens in their studies—no matter the outcome. Here’s how this is done:

Registering Studies Publicly:

Before studies begin, researchers must register them on public websites like ClinicalTrials.gov. This means anyone—patients, families, or the public—can look up what studies are happening, who can join, and what the goals are.

Reporting All Results:

After the study ends, researchers must share the results, whether the treatment worked or not. This helps prevent hiding negative or disappointing results and ensures doctors and patients get the full picture.

Independent Oversight:

Review boards and regulators check that results are reported honestly and in a timely way.



SAFER RESEARCH, BETTER OUTCOMES



MORE PEOPLE, MORE DIVERSITY:

In the past decade, the percentage of women and minority volunteers in U.S. clinical trials has risen by over 25%, making results more relevant to everyone.



RAPID MEDICAL PROGRESS:

Since the introduction of ethical guidelines, the average time to bring a new, safe medicine to patients has dropped from over 10 years to about 7 years—without compromising safety.



IMPROVED TRUST:

Surveys show that over 70% of Americans now express confidence in the clinical research process due to transparency and strong oversight.



LIFE-CHANGING DISCOVERIES:

Research into HIV/AIDS, conducted under strict ethical rules, has turned what was once a fatal disease into a manageable condition for millions.



SAFE TREATMENTS FOR ALL AGES:

Today, more than 60% of clinical trials include children and seniors, leading to safer, age-appropriate care.



FEWER HARMFUL SIDE EFFECTS:

New monitoring systems have helped reduce severe side effects in approved drugs by over 40% compared to the 1980s.



WHY DOES THIS MATTER?

Being open builds trust, helps doctors and patients make better decisions, and prevents repeating mistakes. It ensures that research truly serves the public good.



ABOUT EDUCURE

EduCure is a nonprofit organization dedicated to making clinical research understandable and accessible for everyone. We provide information about your rights as a trial participant and how to get involved safely.

Be a Part of the Cure

WANT TO LEARN MORE OR GET INVOLVED?

Questions? Want to Learn More?

Visit EduCureActNow.org

Visit ClinicalTrials.gov for current research studies.

Contact EduCure at info@educureactnow.org or

833-428-7348

Your donation—just \$5

helps EduCure deliver vital information to expand medical advancement through clinical research and clinical trials.

Together, we can drive innovation and improve healthcare for all. Donate today and be a part of the cure!



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