c:\teach\ge ethics assignment

Jesús A. Díaz, *Ph.D.*
Philosophy
Kean University
Union, NJ 07083-7131

ETHICS ASSIGNMENT

NARROWING YOUR TOPIC

All assignments in this course are rehearsals to your Final Paper. This assignment stands midway between the Cultural Event and your Final Paper. The Cultural Event was your initial opportunity to apply what the course had covered up to the date of that assignment. In the Final Paper, you should display your mastery of all the skills taught during the entire semester. These are:

- Identify problems as prerequisites to research
- Narrow your topic—this assignment's purpose
- Awareness of moral problems in research
- Retrieve information (data) from databases
- Assess the reliability of sources
- Understand the difference between data and interpretation. Interpret the data you or others gathered
- Know when to paraphrase and when to quote directly
- Avoid plagiarism
- Format your scholarly apparatus correctly. "Scholarly apparatus" refers to the totality of endnotes, footnotes, in-text citations, notes, and bibliography

Previous assignments required me to narrow the topic; *you* narrowing the topic is this assignment's goal. Reinforcing the difference between data and interpretation is a secondary objective. I mimic the situation of a person who has read extensively about the intersection of health and social justice. Specifically, that person has read about the topics the section titled THE DATA covers:

A) Medical care and research in developed and developing nations

B) How economic, educational, social and other factors affect people's ability to receive medical care, give informed consent to such care or to participate in research trials

C) Research involving underserved populations and risks of exploiting them

D) Reasonable Benefits and Fair Treatment as competing proposals for biomedical research in developing nations to comply with the standards Nuremberg, Helsinki, and Belmont enunciate.

That person wants to write a paper, but she or he has collected more data and possible topics than a paper can contain; hence, after reading this document, *narrowing your topic* is your first step.

Occasionally, while surveying the bibliography, some students have found topics that interest them more than those I've outlined. Consult with me if that's the case with you. Whatever your choice, the assignment's purpose and requirements would not change.

In this course's website, review *Instructions for Selecting the Topic of Your Final Paper*. The advice there also applies to this assignment.

GUIDELINES FOR THIS ASSIGNMENT

A) No more than four pages typed, double spaced. Do not count the bibliography in the four-page limit. If your paper has four pages of text and a bibliography, your paper has four pages, not five. A sheet has two pages, front and back.

B) Retrieve from library databases and cite at least three peer-reviewed sources, none older than five years, dealing with your topic. Your bibliography may contain no more than one source I cite in this document or in its bibliography.

C) Use the citation format you prefer: APA, Chicago, MLA or any other.

D) The symbol ■ precedes sources you should read.

TURN TO PAGE 3

ETHICAL FRAMEWORK

Because they express recognized research norms, familiarity with the following three documents should help you frame your approach:

A) *Nuremberg Code*

https://drive.google.com/file/d/0B4c7pHi2WdWjOVU1TGo5alNMcEk/edit

Focus on points 1, 4, 5, 7, 9, & 10

B) *Declaration of Helsinki*

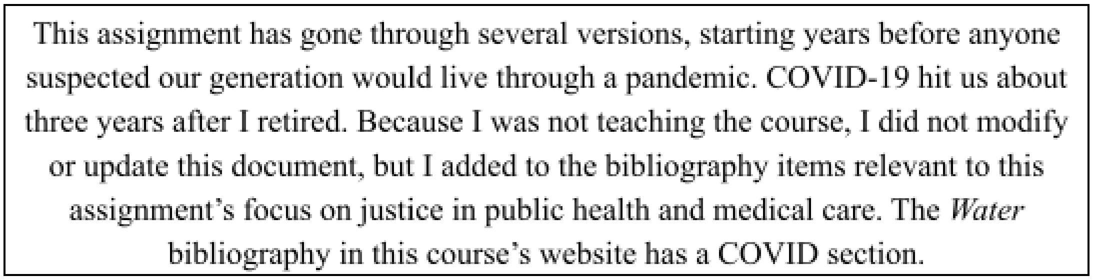
https://drive.google.com/file/d/0B4c7pHi2WdWjZFEtUEtVRTBwZFU/view

Focus on *General Principles*; *Risks, Burdens and Benefits*; *Vulnerable Groups and Individuals*; *Informed Consent*; *Use of Placebo*

C) *Belmont Report*

https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/

Focus on *Beneficence*, *Comprehension,* and *Selection of Subjects*



This assignment has gone through several versions, starting years before anyone suspected our generation would live through a pandemic. COVID-19 hit us about three years after I retired. Because I was not teaching the course, I did not modify or update this document, but I added to the bibliography items relevant to this assignment's focus on justice in public health and medical care. The *Water* bibliography in this course's website has a COVID section.

TURN TO PAGE 4

THE DATA

I. /SITUATION IN THE USA

(i)

We watched *The Deadly Deception* in class, about The Tuskegee Syphilis Experiment:

- WGBH, Boston, for NOVA (Producer), & Dilami, D. (Director). (1993). *The Deadly Deception* [documentary]. VHS & DVD. Retrieved April 9, 2017, from https://www.youtube.com/watch?v=qNa8CnC4sSU

Even after *Nuremberg* and penicillin becoming available, the American government denied syphilis treatment to African American men who did not know the federal government was using them as research subjects (see *Nuremberg*, point 1; *Helsinki*, points 19 & 20).

(ii)

Read Gerth et al. (2000); Ryan (2024); Jordan et al. (2017); Richtel et al. (2016); Grady (2016); Rogers et al. (2018):

- Gerth, J. et al. (2000, Apr. 23). Drug makers reap profits on tax-backed research. *New York Times*. The story is part of a series titled *Medicine Mechants*.

Gerth et al. describe the development of Xalatan, a breakthrough in the treatment of glaucoma, a leading cause of blindness. Despite financing the research, American taxpayers without insurance or with insufficient coverage may not benefit from the eye drops. Albert Russell is an example [see *Helsinki*, point 34; Belluck, et al. (2021, Jul. 19); Robins et al. (2023, Jul. 22).]

- Ryan, L. (2024, Apr. 11). Many patients don't survive end-stage poverty. *New York Times*.

A story similar to Albert Russell's. Physicians tell a homeless man with a life-threatening infection that antibiotics are not eradicating the malady; amputating his arm in the only treatment. He refuses, unless he finds housing. Homeless in the streets, lacking an arm would make him vulnerable to assault and robbery. Psychiatric evaluation revealed the man thought processes were logical and he was not suicidal. Unable to find housing, the patient died in a hospice. His death certificate will say sepsis is the cause of death; it should add end-stage poverty. The letter presents this and another case as examples of situations common in safety-net hospitals: "Medical textbooks usually don't discuss fixing your patients' housing. They seldom include making sure your patients have enough food or some way to get to a clinic. But textbooks miss what my medical students don't: that people die for lack of these things."

- Jordan, M. et al. (2017, May 13). The painful truth about your teeth: You can work full time but not have the money to fix your teeth—visible reinders of the divide between rich and poor. *Washington Post*.

Some Americans pay over $1 billion/year for cosmetic dental procedures while others, lacking dental insurance or with insufficient coverage, have just one option: have their teeth pulled. Geographical areas populated by the working-poor suffer from a shortage of dentists and tend to lack fluoridated water. The story describes a free dental clinic where, for two days, volunteer dentists provided free care. During that period, they treated 1,165 patients, many with full-time jobs but uninsured.

- Richtel, M. et al. (2016, Dec. 19). Harnessing the U.S. taxpayer to fight cancer and make profits. *New York Times*.

As with Xalatan, American taxpayers financed the initial research leading to CAR-T, an immunotherapy. Critics argue that patients buying the $200,000 treatment pay twice: first for the early tax-payer financed National Institutes of Health (NIH) research, later for the drug marketed by a for-profit pharmaceutical. Some argue it is unethical for industry to profit from NIH-financed research when taxpayers' access to the therapy depends on their ability to pay.[1]

- Grady, D. (2016, Dec. 24). In cancer trials, minorities face extra hurdles. *New York Times*.

According to Grady, immunotherapy is the new frontier in the fight against cancer but most research subjects in oncology and other fields are white. Without a diverse group of subjects, investigators cannot find out if distinct populations react to treatment differently (see *Helsinki*, point 13). Also, Black men are underrepresented in prostate cancer research despite being diagnosed with and dying from the disease at twice the rate of their white counterparts:

- Rogers, C. et al. (2018). Attitudes toward genomic testing and prostate cancer research among black men. *American Journal of Preventive Medicine, 55*(5S1), S103-S11. DOI: https://doi.org/10.1016/j.amepre.2018.05.028

---

[1] For more on immunotherapy see McGinley, L. (2017, May 28). "This is not the end": Using immunotherapy and a genetic glitch to give cancer patients hope. *The Washington Post*.

II. / SITUATION IN DEVELOPING COUNTRIES

(i)

Read the following with *Helsinki*, points 19, 20, & 34:

- McNeil, D. (2010, Oct. 1). U.S. apologizes for syphilis tests in Guatemala. *New York Times*.
- Carroll, R. (2011, Jun. 8). Guatemala victims of US syphilis study still hunted by the "devil's experiment." *The Guardian*.

As World War II ended, American public health officials worried about service members with sexually transmitted diseases returning home. To test penicillin's effectiveness, from 1946 to 1948 NIH physicians infected seven hundred Guatemalan prison inmates. As the Tuskegee men, these prisoners did not know they were being used as research subjects. NIH paid syphilis-infected prostitutes to have sex with the male prisoners. If this did not infect the men, researchers injected syphilis bacteria in them. Dr. John Cutler, who participated in the Tuskegee project and appears in *The Deadly Deception*, led the Guatemala study.[2] McNeil (2010) mentions two other studies where consent was absent: In the 1960s, investigators infected retarded children with hepatitis; in 1963, elderly patients were injected liver cancer cells.

During the Cold War, the American government, concerned about biological warfare, conducted experiments affecting thousands of unsuspecting Americans:

- Rubin, J. et al. (Producers & Directors). (2007). *The living weapon* [Documentary]. PBS Home Video. Retrieved May 4, 2024, from https://www.pbs.org/wgbh/americanexperience/films/weapon/

(ii)

In parts of Africa and Asia, the percentage of the population infected with HIV and the rates of HIV transmission are higher than in developed countries. Connor et al. (1994) report that from 1 to 2 mg. of AZT orally five times/day to the mother before and during labor, and to the infant during the first six weeks of life outside the womb, reduce by two-thirds the transmission of HIV from mother to infant. As of 1998, these dosages cost $800 in the United States. The annual public health budget in many developing countries is $5-22 per capita (Glantz et al., 1998b, footnote 11).

Mothers taking AZT must refrain from breast-feeding, so families with limited resources would have to buy baby formula. Due to water contamination, breast-feeding is the method of child rearing health experts in developing countries recommend. These circumstances bring to mind the 1970s allegations that multinationals marketing infant formulas in developing countries

---

[2] McNeil, D. (2011, Aug. 30). Panel hears grim details of venereal disease tests. *New York Times.*

led to increased infant mortality in those nations (Garson, 1977; Molander 1980; Newton 2000; Sasson (2016); Vogell, 2024):

https://www.unwater.org/our-work/integrated-monitoring-initiative-sdg-6/indicator-611-proportion-population-using-safely

https://www.youtube.com/watch?v=LCKsU4bPFOQ

https://www.youtube.com/watch?v=fgCwHD5SeHc&oref=https%3A%2F%2Fwww.youtube.com%2Fwatch%3Fv%3DfgCwHD5SeHc&has_verified=1

The third link requires signing in with a Google account. I accessed all three on April 9, 2017.

Health authorities in Africa and Asia thought that a more limited course of AZT might be effective; finding out required a trial. That trial raised three ethical problems:

1. Randomized trials, the gold standard in clinical research, have placebo arms (persons who do not receive the substance or treatment tested). This is not a moral problem when the trial's purpose is to discover if what is tested cures or manages a disease. This was the purpose with the investigations involving Xalatan and CAR-T. But experts knew that AZT combats HIV/AIDS. Assigning African and Asian women to the placebo group—to deprive them of effective treatment—was to let the natural progression of HIV/AIDS unchecked.[3]

Angell (1997, p. 847) explains this point:

> An essential ethical condition for a randomized clinical trial comparing two treatments for a disease is that there is no good reason for thinking one is better than the other. Usually, investigators hope and even expect that the new treatment will be better, but there should not be solid evidence one way or the other. If there is, not only would the trial be scientifically redundant, but the investigators would be guilty of knowingly giving inferior treatment to some participants in the trial. The necessity for investigators to be in this state of equipoise applies to placebo-controlled trials, as well. Only when there is no known effective treatment is it ethical to compare a potential new treatment with a placebo. When effective treatment exists, a placebo may not be used. Instead, subjects in the control group of the study must receive the best-known treatment. Investigators are responsible for all subjects enrolled in the trial, not just some of them, and the goals of the research are always secondary to the well-being of the participants.

☐ Was assigning African and Asian women to the placebo group ethical?

The women in the placebo group were not getting AZT because they were poor and their countries lacked the resources to buy it and/or the infrastructure and personnel to distribute it (see *Helsinki,* point 33; *Belmont*, Beneficence). Developed counties showed no willingness to defray the cost. That's why the investigators wanted to find out if a lower (presumably cheaper) dosage than used in developed countries would be safe and effective.

---

[3] "Natural progression" refers to the sequence of disease stages without medical intervention. With rare exceptions, untreated HIV infection leads to death.

2. Living in poverty, with little or no health care or education, were the women who volunteered for the AZT study able to provide the uncoerced informed consent *Nuremberg*, *Helsinki*, and *Belmont* require? Informed consent requires an elementary scientific understanding, which people with little or no education may lack (see *Belmont*, *Comprehension*). Living where medical resources are inadequate, mothers eager to protect their children from HIV/ADS are vulnerable to manipulation (Tafesse et al., 1998). French (1997) reports that despite briefings, participants in the African studies did not understand what a placebo is or why researchers use them; others did not know AZT existed. Their need to receive medical care for them and their offspring led them to join the study. Finding that ethics rules may not allow the trial in the United States surprised an Ivory Coast health official. See *Helsinki*, points 19 & 20 and *Belmont*, Selection of Subjects.

■ Titanji, B. K. (2012, May). TED: Ideas worth spreading. Retrieved April 9, 2017, from Ethical Riddles in HIV Research:

https://www.ted.com/talks/boghuma_kabisen_titanji_ethical_riddles_in_hiv_research

If link does not work, try:

https://drive.google.com/file/d/0B4c7pHi2WdWjSjdLMTViRDdBSVk/view?usp=sharing

The effects of education on research subjects are not limited to developing countries. Grady (2016) reports that, in New York City, lower educational attainment correlates with not understanding explanations or consents, having language barriers, not knowing about trials, and lacking transportation.

REASONABLE AVAILABILITY AND FAIR BENEFITS

3. Effective treatments should be available to all needing them (see *Helsinki*, point 34). Even if trials proved the hypothesis that lower AZT dosages block the transmission of HIV from mother to child, developing countries lack the resources to buy and distribute AZT. In other words, if lower AZT dosages work, developed nations will continue to provide treatment to their citizens without having placed them at risk. But developing nations may not benefit from trials in which their citizens participated (Glantz et al., 1998a).

Years ago, research in developing countries showed that vitamin A decreases infant mortality and a hepatitis B vaccine prevents perinatal transmission of the infection. These inexpensive interventions remain unavailable in the countries needing them but unable to pay; it is unlikely that expensive AZT would be (Lallemant, M., 1998).

The United States has the resources and the infrastructure to make medical treatment available to all within its borders. The profit motive and lack of insurance or insufficient coverage leads to cases like those described above (pp. 3-4). For developing countries, ethicists have proposed two ways of dealing with the ethical challenge: Reasonable Availability and Fair Benefits.

REASONABLE AVAILABILITY

Council of International Organizations (2002, p. 51) states, "any intervention or product developed, or knowledge generated (by research in poor communities) will be made reasonably available for the benefit of the population or community."

■ Council of International Organizations of Medical Science. (2002). *International Ethical Guidelines for Biomedical Research Involving Human Subjects.* Geneva: CIOMS. Guideline 10: Research in Populations and Communities with Limited Resources. Retrieved Mar. 3, 2017 from

https://cioms.ch/publications/product/international-ethical-guidelines-for-biomedical-research-involving-human-subjects-2/

Admitting we cannot correct global injustices overnight, Consensus Statement (1999, p. 833) adds:

> To define the highest standard of care practically attainable in the host country is difficult and may be different from the existing standard of care. A majority of us agree that, at the very least, the highest standard of care practically attainable in the host country should be provided to all study participants. There is no obligation to provide study participants with the highest standard of care attainable elsewhere in the world.

■ Consensus Statement. (1999, Mar. 6). Science, ethics, and the future of research into maternal infant transmission of HIV-1. *Lance*t, *353*(9155), 832-835.
DOI: https://doi.org/10.1016/S0140-6736(98)10414-2

In other words, if developing country X hosts a trial, X's citizens who participated in the study must have access to X's highest standard of care, not to a higher standard of care in developed countries. A problem afflicts this view: The products of biomedical research should be available equally to all who need them. Moreover, whether or not therapeutic findings result from investigations, Reasonable Availability does not leave developing countries better off than they were before participating in biomedical investigations.

FAIR BENEFITS

Clinical research often proceeds in three phases, sometimes more: Phase I is the first human exposure to the substance or therapy investigated; often, Phase 1 aims is to find out if humans react as nonhuman animals did. Involving a group larger than Phase I, Phase II aims to confirm dosages and compare the drug or treatment under investigation with existing therapies; side effects found in Phase I are examined. Phase III, involving the largest number of participants, intends to confirm and refine earlier findings. Passing Phase III is necessary for the substance or treatment to reach the public.

https://www.nccn.org/patients/resources/clinical_trials/phases.aspx (accessed Oct. 6, 2019)

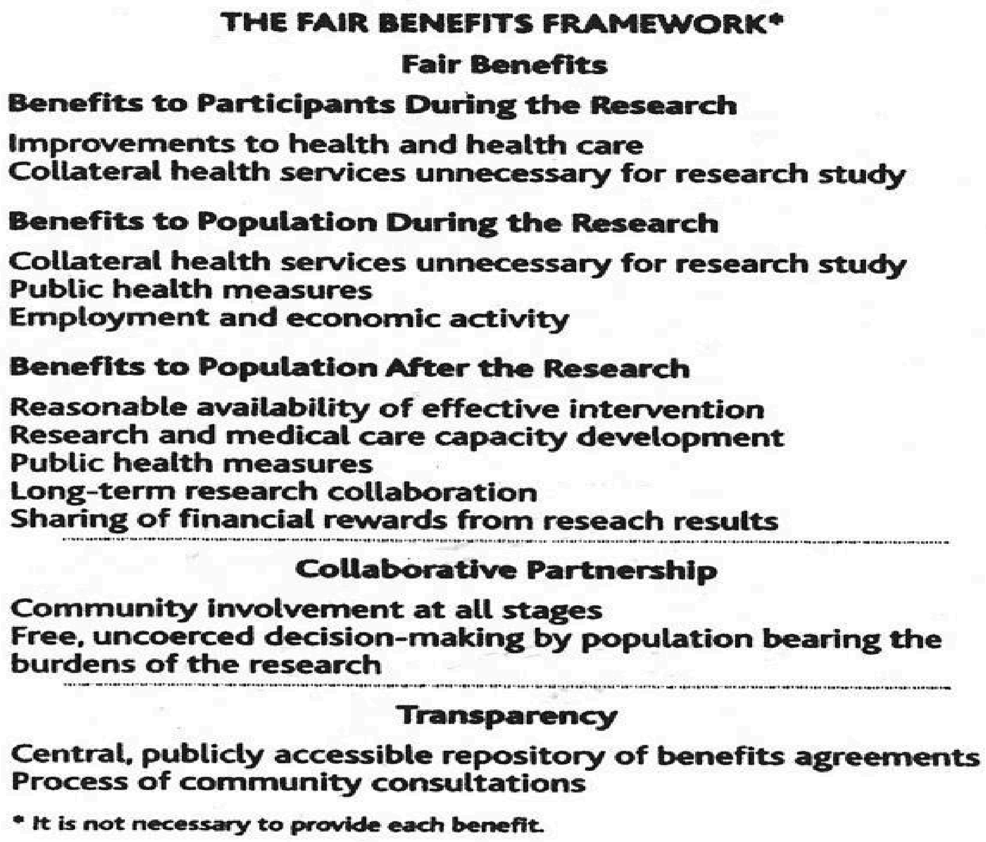
Reasonable Availability guides us only when phase III leads to new findings. We cannot apply it to phases I and II—when risks to research subjects are higher—or when Phase III is futile.

The Fair Benefits standard goes further:

> A exploits B when B receives an unfair level of benefits as a result of B's interactions with A.
>
> . . . .
>
> They (populations in developing countries that have been subjects in medical research) may be exposed to the risks of research, while access to the benefits of new, effective drugs and vaccines goes predominantly to the people in developed countries and the profits go to the biopharmaceutical industry. This situation fails to provide fair benefits and thus constitutes the paradigm of exploitation (Participants in the 2001 conference, 2002, p. 2133).

■ Participants in the 2001 conference on ethical aspects of research in developing counties. (2002, Dec. 13). Fair benefits for research in developing countries. *Science, 298*(5601), 2133-2134.DOI: 10.1126/science.1076899

Avoiding exploitation requires that underdeveloped countries participating in clinical research benefit regardless of the knowledge that may or may not emerge from the trials conducted within their borders. We must help those nations train health professionals, construct public health infrastructures, etc. The following chart, from [Participants in the 2001 conference. (2002), p. 2134] explains Fair Benefits:



THE FAIR BENEFITS FRAMEWORK*

Fair Benefits

Benefits to Participants During the Research

Improvements to health and health care
Collateral health services unnecessary for research study

Benefits to Population During the Research

Collateral health services unnecessary for research study
Public health measures
Employment and economic activity

Benefits to Population After the Research

Reasonable availability of effective intervention
Research and medical care capacity development
Public health measures
Long-term research collaboration
Sharing of financial rewards from reseach results

Collaborative Partnership

Community involvement at all stages
Free, uncoerced decision-making by population bearing the burdens of the research

Transparency

Central, publicly accessible repository of benefits agreements
Process of community consultations

* It is not necessary to provide each benefit.

For an expanded Fair Benefits chart see pg. 23 in:

Participants in 2001 Conference on the Ethical Aspects of Research in Developing Countries. (2004, May- Jun.). Moral standards for research in developing countries: From “Reasonable Availability” to “Fair Benefits.” *Hastings Center Report 34*(3), 17-27. DOI: https://doi.org/10.2307/3528416

TURN TO PAGE 12

References[4]

DEVELOPING COUNTRIES

Angell, M. (2000, 30 March). Investigators' responsibility for human subjects in developing countries. *Journal of the American Medical Association 342*(13), 967-969. DOI: 10.1056/NEJM200003303421309

------------. (1997, Sep. 18). Editorial: The ethics of clinical research in the Third World. *New England Journal of Medicine 337*(12), 847-849. DOI: 10.1056/NEJM199709183371209

Ballantyne, A. (2008, Jul. 31). 'Fair benefits" accounts of exploitation require a normative principle of fairness: Response to Gbadegesin, and Wendler, and Emanuel et al. *Bioethics 22*(4), 239-244. DOI: 10.1111/j.1467-8519.2007.00622.x

Emanuel, E. et al. (2004, Mar. 1). What makes clinical research in developing countries ethical? The benchmarks of ethical research. *Journal of Infectious Diseases 189*(5), 930-937. DOI: 10.1086/381709

French, H. (1997, Oct. 9). AIDS research in Africa: Juggling risks and hopes. *New York Times*.

Garson, B. (1977, December). The bottle baby scandal: Milking the Third World for all it's worth. *Mother Jones 2*(10), 33-44.

Glantz, et al. (1998a, Mar. 19). Letter. *New England Journal of Medicine 338*(12), 839.

---------------. (1998b). Research in developing countries: Taking benefits seriously. *Hastings Center Reports, 28*(6), 38-42. DOI: https://doi.org/10.2307/3528268

Kuritzkes, D. (2004, Mar. 1). Ethical conduct of research in resource-limited settings. *Journal of Infectious Diseases 189*(5), 764-765. DOI: 10.1086/381711

Lallemant, M. et al. (1998, Mar. 19). Letter. *New England Journal of Medicine 338*(12), 839-840.

Lo, N. et al. (2017, Apr. 13). The perils of trumping science in global health—the Mexico City policy and beyond. *New England Journal of Medicine 376*(15), 1399-1401. DOI: 10.1056/NEJMp1701294

---

[4] (1) As I wrote in *Instructions for Selecting the Topic of Your Final Paper*, DOIs often lead to publishers' websites, which invite you to buy what you can get for free in library databases. But publishers' websites often have, without charge, important information about the papers, e.g., how often they have been downloaded, cited, etc. Some publications lack DOIs.

(2) If a DOI does not work as it should, copy and paste it to your browser's search box.

Lurie, P. et al. (1997, Sep. 18). Unethical trials of interventions to reduce perinatal transmission of the human immunodeficiency virus in developing countries. *New England Journal of Medicine 337*(12), 853-856. DOI: 10.1056/NEJM199709183371212

Millum, J, (2012). Sharing the benefits of research fairly. *Journal of Medical Ethics 38*(4), 219-223. DOI: 10.1136/medethics-2011-100118

Molander, E. (1980). *Responsive capitalism: Case studies in corporate social conduct.* New York: Mc-Graw-Hill.

Neitzke, A. (2012). Globalizing research ethics: Justice and biomedical research in developing countries. *Perspectives on Global Development and Technology 11*(1), 145-153. DOI: h://doi.org/10.1163/156914912X620798

Newton, L. (2000, summer). A new power agenda: Tracking the emergence of a new global polity in the infant formula controversy. *Business & Professional Ethics Journal, 19*(2), 5-39. DOI: https://www.jstor.org/stable/27801219

Sasson, T. (2016, Oct. 3). Milking the Third World? Humanitarianism, capitalism, and the moral economy of the Nestlé boycott. *The American Historical Review 121*(4), 1196-1224. DOI: https://doi.org/10.1093/ahr/121.4.1196

Tafesse, E. et al. (1998, Mar. 19). Letter. *New England Journal of Medicine 338*(12), 838.

Vogell, H. (2024, Mar. 21). How the U.S. waged a global campaign against baby formula regulation. ProPublica.

Documents Show Internal Clash Before U.S. Officials Pushed to Weaken Toddler Formula Rules — ProPublica

ETHNICITY AND RACE

⁎ Abi-Rached, J. et al. (2024, Apr. 4). Nazism and the *Journal*. *New England Journal of Medicine, 390*(13), 1157-1161.[5] DOI: 10.1056/NEJMp2307319

Alohan, D. et al. (2020, Jun. 3). COVID-19 outbreaks at correctional facilities demand a health equity approach to criminal justice reform. *Journal of Urban Health 97*(3). 342-347. DOI: https://doi.org/10.1007/s11524-020-00459-1

Bassett, M. et al. (2023, Nov. 26). Reparations as a public health priority—a strategy for ending Black-White health disparities. *New England Journal of Medicine, 383*(22), 2101-2103. DOI: 10.1056/NEJMp2026170

---

[5] With the heading *Recognizing Historical Injustices in Medicine and the Journal*, in 2024 *The New England Journal of Medicine* began publishing a series of articles dealing with the issues the heading covers. In this bibliography, ⁎ precedes articles in the- series.

Bichell, R. et al. (2021, Jun. 6). For Black patients, an algorithm may help perpetuate harmful racial disparities. *Washington Post*.

Bosman, J. et al. (2021, Jul. 22). Virus widens a racial gap in longevity. *New York Times*.

⁎ Chowkwanyn, M. (2024, May 2). *Journal* voices in the Civil Rights era—New horizonns and limits in medical publishing. *New England Journal of Medicine, 390*(17), 1541-1546. DOI: 10.1056/NEJMp2307360

Cooper, H. et al. (2020). *From enforcers to guardians: A public health primer on ending police violence*. Baltimore, MD: Johns Hopkins Press.

Healy, M. (2020, Jun. 2). Cause of death: COVID-19, police violence, or racism. *Los Angeles Times*.

⁎ Jones, D. et al. (2024, Jan. 4). Indigenous Americans—The *Journal*'s historical "Indian problem". *New England Journal of Medicine, 390*(1), 1-7. DOI: 10.1056/NEJMp2307311

Laurencin, C. et al. (2020, Apr. 6). Racial profiling is a public health and health disparity issue. *Journal of Racial and Ethnic Health Disparities 7*(3). 393-397. DOI: 10.1007/s40615-020-00738-2

Llorente, E. (2022, Aug. 28). Flawed device may help explain racial disparity in COVID death. *Star-Ledger*.

McGinley, L. et al. (2022, Dec. 19). Weight-loss drugs are a milestone for the obese but expose health inequity. *Washington Post*.

Mizellle, R. (2023, Jun.15). A slow-moving disaster—the Jackson water crisis and the health effects of racism. *New England Journal of Medicine, 388*(24), 2212-2214.DOI: https://doi.org/10.1056/NEJMp2212978

Proctor, R. (1990). *Racial hygiene: Medicine under the Nazis.* Cambridge: Harvard University Press.

Ramirez, M. (2024, Jan. 31). Americans don’t sleep enough. The long-term effects are dire, especially for Black people. *USA Today*.

Black people are more sleep-deprived, and it's hurting their health (usatoday.com)

Robin, R. (2023, Dec. 30). How bias endangers pregnant Black women. *New York Times*.

Salas, R. (2021, Sep. 9). Environmental racism and climate change—missed diagnoses. *New England Journal of Medicine 385*(11), 967-969. DOI: 10.1056/NEJMp2109160

Scheffer, D. (2016, Oct. 9). Nuremberg's lessons 70 years later. *Los Angeles Times*.

TUSKEGEE

Brandon, DT. et al. (2005, Jul.). The legacy of Tuskegee and trust in medical care: Is Tuskegee responsible for race differeces in mistrust of medical care? *Journal of the National Medical Association 97*(7), 951-956. PMCID: PMC2569322

Jones, J. (1993). *Bad blood: The Tuskegee syphilis experiment.* New York: Free Press.

Maupin, J. et al. (2012). Transformational Medical Education Leadership: Ethics, Justice and Equity—The U.S. Public Health Service Syphillis Study at Tuskegee Provides Insight for Health Reform. *Ethics & Behavior, 22*(6), 501-504. DOI: https://doi.org/10.1080/10508422.2012.730790

Reverby, S. (2000). *Tuskegee's truths: Rethinking the Tuskegee syphillis study.* Chapel Hill : University of North Carolina Press.

----------------. (2009). *Examining Tuskegee: The infamous syphillis study and its legacy* . Chapel Hill: University of North Carolina Press.

-------------. S. (2011). "Normal exposure" to inoculation syphilis: A PHS "Tuskegee" doctor in Guatemala, 1946-1948. *Journal of Policy History, 23*(1), 6-28. DOI: https://doi.org/10.1080/10508422.2012.730790

Washington, H. (2006). *Medical apartheid: The dark history of medical experimentation on Black Americans from colonial times to the present.* New York: Doubleday.

IS THERE A RIGHT TO HEALTH CARE?

Blake, V. (2016, Jun.). An opening for civil rights insurance after the Affordable Care Act. *Boston College Journal of Law & Social Justice, 36*(2), 235-286. https://ssrn.com/abstract=3305419

Blumenthal, D. et al. (2020, Oct. 8). Covid-19-Implications for the health care system. *New England Journal of Medicine, 383*(15), 1483-1488. DOI: 10.1056/NEJMsb2021088

Braveman, P. e. (2011, Dec 1). Health disparities and health equity: The issue is justice. *American Journal of Public Health, 101*(S1), S149-S155. DOI: 10.2105/AJPH.2010.300062

Evans, M. (2020, Sep. 10). Health equity—Are we finally on the edge of a new frontier. *New England Journal of Medicine, 383*(11), 997-999. DOI: 10.1056/NEJMp2005944

Greer, S. (2013, Apr. 15). Rules for rights: European law, health care and social citizenship. *European Law Journal, 20*(1), 66-87. DOI: https://doi.org/10.1111/eulj.12036

Jones, C. (2010). The moral problem of health disparities. *American Journal of Public Health,100*(S1), S47-51. DOI: 10.2105/AJPH.2009.171181

King, J. (2020, Jun. 25). Covid-19 and the need for health care reform. *New England Journal of Medicine, 382*(26), e104(1)-e104(3). DOI: 10.1056/NEJMp2000821

Machan, T. (2016). Rights, values, regulation and health care: To be well is not a fundamental right but a value. *American Journal of Medical Research, 3*(2), 115-125. DOI: 10.22381/AJMR3220165

Mariner, W. et al. (2016, Nov.). A culture of health and human rights. *Health Affairs, 35*(11), 1999-2004. DOI: DOI: 10.1377/hlthaff.2016.0700

Palmisano, D. et al. (2004, May 12). Expanding insurance coverage through tax credits, consumer choice, and market enhancements: The American Medical Association proposal for health care insurance reform. *Journal of the American Medical Association, 291*(18), 2237-2239.DOI: 10.1001/jama.291.18.2237

Reutter, L. e. (2010, Aug. 16). 'Health care equity through action on the social determinants of health': Taking up the challenge in nursing. *Nursing Inquiry, 17*(3), 269-280. DOI: 10.1111/j.1440-1800.2010.00500.x

Yearby, R. (2015). Sick and tired of being sick and tired: Putting an end to separate and unequal health care in the United States 50 years after the Civil Rights Act of 1964. *Health Matrix: Journal of Law-Medicine,25,* 1-32. Available at: https://scholarlycommons.law.case.edu/healthmatrix/vol25/iss1/3

TURN TO PAGE 17

UNDERSERVED POPULATIONS[6]

American Public Health Association. (2018, Nov. 13). Addressing law enforcement violence as a public health issue. Apha.org

Addressing Law Enforcement Violence as a Public Health Issue (apha.org)

Angus, L. et al. (2010). Evidence that citizenship mandate curtailed participation in Oregon's Medicaid family planning program. *Health Affairs, 104*(3), 690-698. DOI: 10.1377/hlthaff.2008.0843

Barton, A. (2023, Oct. 6). Addiction treatment: Florida shuffle: Failure to oversee treatment leaves patiets adrift in addiction. *USA Today* (Weekend Edition). Pp. 1D-5D.

Brown, T. e. (2023). The future of the social determinants of health: Looking upstream to structural drivers. *Milbank Quarterly, 101*(S1), 36-60. DOI: 10.1111/1468-0009.12641

Brush, B. et al. (2016, Aug.). The data dilemma in family homelessness. *Journal of Health Care for the Poor and Underserved, 27*(3), 1046-1052. DOI: 10.1353/hpu.2016.0122

National Health Care for the Homeless Council: http://nhchc.org/

Dean, L. et al. (2000, Sep.). Lesbian, gay, bisexual, and transgender health: Findings and concerns. *Journal of the Gay and Lesbian Medical Association, 4*(3), 102-151. DOI: https://doi.org/10.1023/A:1009573800168

Drikell, J. E. (2008, Oct. 11). Barriers and facilitators of HIV disclosure: Perspectives from HIV-infected men who have sex with men. *Journal of HIV/AIDS & Social Services, 7*(2), 135-156. DOI: 10.1080/15381500802006573

Farber, L. et al. (2015, Jun. 4). Advocacy for health care: A synthesis review. *The Milbank Quarterly, 93*(2), 392-437. DOI: 10.1111/1468-0009.12112

Garbarino, J. (2022, Sep. 29). The war-zone mentality-Mental health effects of gun violence on U.S. children and adolescents. *New England Journal of Medicine, 387*(13), 1149-1151. DOI: 10.1056/NEJMp2209422

Garcia-Castillo, D. et al. (2007, Feb.). Quality in medical translations: A review. *Journal of Health Care for the Poor and Underserved, 18*(1), 74-84. DOI: 10.1353/hpu.2007.0009

---

[6] As you can see in this bibliography, some use "vulnerable" to refer to these populations, so you have to include the word in database searches. However, the trend is to use "underserved." "Vulnerable" implies helplessness. "Underserved" reflects the fact that these groups' situation results from policy choices and social factors.

Goodren, L. (2011, Mar. 31). Care of transsexual persons. *New England Journal of Medicine, 364*(13), 1251-1257. DOI: 10.1056/NEJMcp1008161

⁎ Jones, D. et al. (2024, Feb. 1). Explaining health inequities—The enduring legacy of historical bias. *New England Jouranl of Medicine, 390*(5), 389-395. DOI: 10.1056/NEJMp2307312

Heckler, M. (1986). *Report of the Secretary's Task Force on Black and Minority Health.* Washington, DC: Government Printing Office.Retrieved November 18, 2016 from http://minorityhealth.hhs.gov/assets/pdf/checked/1/ANDERSON.pdf

Keen R et al. (2024, May 29). Criminalizing Homelessness—The Grants Pass, Oregon, Supreme Court Case. *New England Journal of Medicine, 390*(22), e57. DOI: 10.1056/NEJMp2405434

⁎ Maldonado, B. et al. (2024, Jun. 6). Malicious midwives, fruitful vines, and bearded women—Sex, gender, and medical expertise in the *Journal*. *New England Journal of Medicine, 390*(21), 1941-1947. DOI: 10.1056/NEJMp2404784

Marmot, M. (2018, Jun). Medical care, social determinants of health, and health equity. *WMHP: World Medical & Health Policy, 10*(2), 195-197. DOI: https://doi.org/10.1002/wmh3.261

Schwirtz, et al. (2020, May 20). These NYC neighborhoods have the highest rates of virus deaths: Race and income are the key factors that decide who dies from COVID-19 and who survives, city data shows. *New York Times*.

Singh, J. (2016, Aug. 15). Ethical issues to consider in the design of HIV prevention trials involving transgender people. *JAIDS: Journal of Acquired Immune Deficiency Syndromes, 72*[Suppl. 3], S252-S255. DOI: [10.1097/QAI.0000000000001089](10.1097/QAI.0000000000001089)

White, K. et al. (2014, Feb. 12). Impact of Alabama's immigration law on access to health care among Latina immigrants and children: Implications for national reform. *American Journal of Public Health, 104*(3), 397-405. DOI: 10.2105/AJPH.2013.301560

Zagorac, I. (2016, Nov.). How should we treat the vulnerable?: Qualitative study of authoritative ethics documents. *Journal of Health Care for the Poor and Underserved, 27*(4), 1656-1673. DOI: [10.1353/hpu.2016.0154](10.1353/hpu.2016.0154)

Zimmerman, M. et al. (1999). Health care as a gendered system. In J. Saltzman-Chafetz. *Handbook of the Sociology of Gender* (pp. 483-518). New York: Plenum.

HIV/AIDS

Annas, G. et al. (1998, Apr.). Human rights and maternal-fetal HIV transmission prevention trials in Africa. *American Journal of Public Health, 88*(4), 560-563. DOI: 10.2105/ajph.88.4.560

Bendavid, E. et al. (2012, May 16). HIV development assistance and adult mortality in Africa. *Journal of the American Medical Association, 307*(19), 2060-2067. DOI: 10.1001/jama.2012.2001

Connor, E. et al. (1994, Nov. 3). Reduction of maternal-infant transmission of human immunodeficiency virus type 1 with zidowdine treatment. *New England Journal of Medicine, 331*(18), 1173-1180. DOI: 10.1056/NEJM199411033311801

Emanuel, E. (2012, May 16). PEPFAR and maximizing the effects of global health assistance. *Journal of the American Medical Association, 307*(19), 2097 -2100. DOI: 10.1001/jama.2012.4989

Leyva-Moral, J. et al. (2016, Oct. 11). Participants' safety versus confidentiality: A case study in HIV research. *Nursing Ethics, 24*(8), 376-380. DOI: 10.1177/0969733016669865

Robins, R. et al. (2023, Jul. 22). How a drug maker profited by slow-walking a promising H.I.V. therapy. *New York Times*.

GENERAL

Alexander, L. (1949, Jul. 14). Medical science under dictatorship. *New England Journal of Medicine, 241*(2), 39-47. DOI: 10.1056/NEJM194907142410201

Anders, G. (1996). *Health against wealth: HMOs and the breakdown of medical trust*. Boston: Houghton Miffling.

Authers, J. (2020, May 30). The golden rule is dying of Covid-19. Bloomberg.com[7]

--------------. (2020, Mar. 28). How coronavirus is shaking up the moral universe. Bloomberg.com

Beaver, J. et al. (2017). Reevaluating eligibility criteria—Balancing patient protection and participation in oncology trials. *New England Journal of Medicine 376*(16), 1504-1505. DOI: 10.1056/NEJMp1615879

---

[7] Bloomberg.com is an online-only newspaper. Its website has a paywall, but all or most of its content is available in library databases about a week after online publication. That's why, when referring to it, I don't follow the conventions for citing websites.

Belluck, P. et al. (2021, Jul. 19). How an unproven Alzheimer drug got approved. *New York Times.*

Bramble, B. (2020). *Pandemic Ethics: 8 big questions of COVID-19*. Bartleby books. Microsoft Word - Pandemic Ethics_FINAL VERSION.docx (philpapers.org)

Christian, N. et al. (2022, Sep. 1). What *Dobbs* means for patients with breast cancer. *New England Journal of Medicine.* DOI: 10.1056/NEJMp2209249

Friedman, R. (2006). *Children in medical research: Access versus protection*. New York: Oxford University Press.

Garbarino, J. (2022, Sep. 29). The war-zone mentality – Mental effects of gun violence in U.S. children and adolescents. *New England Journal of Medicine 387*(13), 1149-1151. DOI: https://doi.org/10.1056/NEJMp2209422

Ghooi, R. (2011, Apr-Jun.). The Nuremberg Code – A critique. *Perspectives in Clinical Research 2*(2), 72-76. DOI: 10.4103/2229-3485.80371

Goliszek, A. (2003). *In the name of science: A History of secret programs, medical research and human experimentation.* New York: St. Martin.

Herzhinger, R. (1997). *Market Driven Healthcare: Who Wins, Who Loses in the Transformation of America's Largest Service Industry*. New York: Basic Books.

Jarvis, L. (2022, Apr. 8). Medicine is clearing up the FDA's mess on Biogen's Alzheimer's drug. Bloomberg.com

Jewett, C. (2022, Mar. 25). F.D.A. rushed a rug for preterm births. Did it put speed over science? *New York Times*.

Litton, P. et al. (2005). A normative justification for distinguishing the ethics of clinical research from the ethics of medical care. *Journal of Law, Medicine & Ethics, 33*(3), 566-574. DOI: 10.1111/j.1748-720x.2005.tb00519.x

Lobato-Victoria, A. et al. (2013, Jan/Jun.). ¿En qué medida es verdad que los sujetos de investigación comprenden sus derechos? *Persona y Bioética, 17*(1), 49-57.

¿EN QUÉ MEDIDA ES VERDAD QUE LOS SUJETOS DE INVESTIGACIÓN COMPRENDEN SUS DERECHOS? (scielo.org.co)

London, A. (2013). Justification, coherence and consistecy of provisions in the revised Declaration of Helsiki. *World Medical Journal 59*(5), 188-192. Available at (PDF) Justification, Coherence and Consistency of Provisions in the Revised Declaration of Helsinki (researchgate.net)

Maitland, K. et al. (2011). Use of deferred consent for severely ill children in a multi-centre phase III trial. *Trials, 12*(1), 90-93. DOI: 10.1186/1745-6215-12-90

Marquis, D. (1999, Aug. 26). How to resolve an ethical dilemma concerning randomized clinical trials. *New England Journal of Medicine, 341*(9), 691-693. DOI: 10.1056/NEJM199908263410912

Marya, R. el al. (2021). *Inflamed: Deep medicine and the anatomy of injustice*. New York: Farrar, Straus, & Giroux. Interviewed in: Marya, R. et al. (2021, Aug. 2). "Inflamed": Dr. Rupa Marya & Raj Patel on Deep Medicine & How Capitalism Primes Us for Sickness. (A. Goodman, Interviewer). *Democracy Now*! Retrieved May 16, 2024, from https://www.democracynow.org/2021/8/2/inflamed_rupa_marya_raj_patel_interview

Okall, D. et al. (2014, Sep. 25). Men who have sex with men in Kisumu, Kenya: Comfort in accessing health services and willingness to participate in HIV prevention services. *Journal of Homosexuality, 61*(12), 1712-1726. DOI: 10.1080/00918369.2014.951261

Peebles, A. (2022, Apr. 9). Medicare's strict Alzheimer policy raises ante for drugmakers. Bloomberg.com

Rajan, K. (2017). *Pharmocracy: Value, politics, and knowledge in global biomedicine*. Durham & London: Duke University Press.

Schwartz, , M. (Ed.). (2020). *The ethics of pandemics.* Ontario: Broadview Press. Companion website: The Ethics of Pandemics – Supplemental Resources (broadviewpress.com)

Wender, D. (2005). Protecting subjects who cannot give consent: Toward a better standard for "minimal" risks. *Hastings Center Report, 35*(5), 37-43. DOI: https://doi.org/10.1353/hcr.2005.0087

World Medical Association. (2015). *Medical Ethics Manual (*3rd ed.). France: Ferney-Voltaire Cedex. Retrieved May 16, 2024 from

Medical Ethics Manual – WMA – The World Medical Association

Yiyi, C. et al. (2014, May 1). Suggestions to ameliorate the inequity in urban/rural allocation of healthcare resources in China. *International Journal for Equity in Health, 13*(1), 1-12. DOI: 10.1186/1475-9276-13-34

(1990, fall/winter). *Business and Professional Ethics Journal, 9*(3 & 4). Special issue*: Justice and the Health Care Industry*. Entire issue devoted to justice in health care.

PODCASTS

Transcripts available in library database with bibliographic references shown

- Investigating injustices in the *Journal's* history. (2024, Jan. 18). *New England Jounal of Medicine, 390*(3). DOI: 10.1056/NEJMp2311329

- Investigating injustices in the *Journal*'s history, part 2. (2024, Feb 1). *New England Journal of Medicine, 390*(5). DOI: https://doi.org/10.1056/NEJMp2314000

VACCINES

historyofvaccines.org

Your bibliography must contain at least five bibliographic sources. No more than two can be sources I cite in this document or in this bibliography.

THIS VERSION: 6/17/2024

PREVIOUS VERSIONS: 7/15/2023; 10/10/2022; 8/15/2023; 12/27/2020; 10/16/2019; 10/9/2018; 6/23/2017; 5/3/2017; 6/27/2016; 1/13/2015; 5/31/2014; 6/1/2013; 7/5/2012; 6/9/2010; 12/27/2009; 8/5/2008; 9/1/2007.