

TOP BIOETHICS NEWS STORIES: JUNE—AUGUST, 2019

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“Ebola Cases Pass 2,000 as Crisis Escalates” by Amy Maxmen, *Nature*, June 4, 2019

The number of Ebola cases in the Democratic Republic of the Congo (DRC) has doubled in just over two months and has now passed 2,000, according to the World Health Organization (WHO). An estimated 2,008 people have been infected with Ebola in the North Kivu and Ituri provinces since the start of the outbreak in late July 2018, and 1,346 of those individuals have died. (<https://tinyurl.com/y5ekf4mp>)

The number of people infected by Ebola in the Democratic Republic of Congo escalated last spring due to mistrust and attacks on healthcare workers. Two reasons for the spread of the disease are (1) the belief that Ebola was invented by politicians as a way to oppress and control the citizens of DRC and (2) distrust of foreign healthcare workers.

“Russian Biologist Plans More CRISPR-Edited Babies” by David Cyranoski, *Nature*, June 10, 2019

A Russian scientist says he is planning to produce gene-edited babies, an act that would make him only the second person known to have done this. It would also fly in the face of the scientific consensus that such experiments should be banned until an international ethical framework has agreed on the circumstances and safety measures that would justify them. Molecular biologist Denis Rebrikov has told *Nature* he is considering implanting gene-edited embryos into women,

possibly before the end of the year if he can get approval by then. (<https://tinyurl.com/y3ehg8ey>)

“The World Health Organization Says No More Gene-Edited Babies” by Megan Molteni, *Wired*, July 30, 2019

The world’s largest public health authority has weighed in with the most authoritative statement yet on the use of Crispr to alter the DNA of human babies. Eight months after a rogue Chinese scientist revealed he had secretly created the world’s first gene-edited children, the World Health Organization is asking countries to put a stop to any experiments that would lead to the births of more gene-edited humans. (<https://tinyurl.com/yaaqtc54>)

In November 2018, Chinese scientist He Jiankui made headlines for announcing the birth of two babies who were genetically altered at the embryonic stage. Many members of the scientific community called for a moratorium on this kind of research until scientists can determine the long-term, generational implications of genetically-editing an embryo. In July 2019, the WHO asked all countries to put a stop to this research, which came one month after Russian scientist Denis Rebrikov announced his plans to implant gene-edited embryos into two women.

“New Evidence Points to Possible Causes of Puzzling Paralysis in Kids” by Maggie Fox, *STAT News*, June 14, 2019

Researchers say they have strong new evidence that a virus is involved in a rare and puzzling polio-like condition that began

affecting children in the U.S. about five years ago. The researchers hope their work will lead to a better test for the paralyzing condition, called acute flaccid myelitis (AFM), which has been diagnosed in more than 500 kids since 2014. (<https://tinyurl.com/y6j33gqx>)

Scientists looked at the spinal fluid of 42 children with AFM and found antibodies for enteroviruses, a general group of viruses that includes the polio virus and a new respiratory virus, EV-D68. AFM tends to affect young children on an every other year schedule and will sometimes result in neurological issues and paralysis. This study confirms that AFM is associated with one or more types of enteroviruses.

“China Is Harvesting Organs from Detainees, Tribunal Concludes” by Owen Bowcott, *The Guardian*, June 17, 2019

An independent tribunal sitting in London has concluded that the killing of detainees in China for organ transplants is continuing, and victims include imprisoned followers of the Falun Gong movement. (<https://tinyurl.com/y6qxuk5z>)

“15 Studies Retracted Due to Fears They Used Chinese Prisoners’ Organs” by Clare Wilson, *New Scientist*, August 16, 2019

Fifteen studies about transplanted organs by researchers in China have been retracted this month due to concerns the work may have used organs from executed prisoners. Three other papers have been the subject of expressions of concern

for the same reason, according to the website Retraction Watch which monitors questions raised over published research. (<https://tinyurl.com/yablckmw>)

A tribunal, initiated by the International Coalition to End Transplant Abuse in China, found in a unanimous determination that China continues to harvest organs from prisoners of conscious, namely those of the Falon Gong. Additional reports show that they may have also harvested organs from Uyghurs, Tibetans, and people who belong to Christian sects. Several research journals are now looking at whether studies have been published using organs from prisoners. Fifteen papers have, thus far, been retracted, and approximately 400 papers are in question.

“Three Euthanasia Cases Face Investigation in Netherlands” by Senay Boztas, *The Guardian*, June 23, 2019

Three euthanasia cases involving women with psychiatric conditions and dementia are under investigation in the Netherlands, the Observer can reveal. Prosecutors confirmed that the deaths, in 2017 and 2018, were being investigated for potentially breaching strict conditions in the 2002 law that allows people in the Netherlands to ask a doctor to help them die. (<https://tinyurl.com/yxbdafw8>)

“Dutch Doctor Faces Trial in Landmark Euthanasia Case” *BBC*, August 27, 2019

A Dutch doctor has appeared in court after performing euthanasia on a patient suffering with severe dementia. Prosecutors say the doctor did not do enough to verify consent. It is the first such case since the Netherlands legalised euthanasia in 2002. The 74-year-old patient was suffering from Alzheimer’s disease when she died in 2016. The doctor allegedly sedated the woman and asked her family to hold her down as

she administered a lethal drug. (<https://tinyurl.com/y9svxuff>)

Euthanasia has been legal in the Netherlands since 2002, and during that time, there have been few legal cases questioning whether the law has been followed properly. In 2019, three cases were investigated to determine whether doctors breached the law. One of those cases involving an elderly dementia patient went to trial. In this case, the doctor asked family members to hold the woman down as he administered the lethal drugs. The doctor was eventually acquitted.

“In a 1st, Doctors in U.S. Use CRISPR Tool to Treat Patient with Genetic Disorder” by Rob Stein, *NPR*, July 29, 2019

For the first time, doctors in the U.S. have used the powerful gene-editing technique CRISPR to try to treat a patient with a genetic disorder. “It is just amazing how far things have come,” says Victoria Gray, 34, of Forest, Miss. “It is wonderful,” she told *NPR* in an exclusive interview after undergoing the landmark treatment for sickle cell disease. Gray is the first patient ever to be publicly identified as being involved in a study testing the use of CRISPR for a genetic disease. (<https://tinyurl.com/y3gxgxbb>)

While genetically modifying embryos is ethically unsound, genetically-modified stem cells have fewer ethical issues. The U.S. conducted a trial involving genetically-modified bone marrow cells retrieved from a patient with sickle-cell disease. These modified bone marrow cells were then re-infused into the patient in hopes that her blood stem cells will make healthy red blood cells. A similar trial was conducted in Germany for beta-thalassemia. It will take quite some time to see if the trial was successful.

“Scientists Are Making Human-Monkey Hybrids in China” by Antonio Regalado, *MIT Technology Review*, August 2, 2019

In a controversial first, a team of researchers have been creating embryos that are part human and part monkey, reports the Spanish daily *El País*. . . . Their objective is to create “human-animal chimeras,” in this case monkey embryos to which human cells are added. (<https://tinyurl.com/yxnzy2zr>)

“Japan Approves First Human-Animal Embryo Experiments” by David Cyranoski, *Nature*, July 26, 2019

A Japanese stem-cell scientist is the first to receive government support to create animal embryos that contain human cells and transplant them into surrogate animals since a ban on the practice was overturned earlier this year. Hiromitsu Nakauchi, who leads teams at the University of Tokyo and Stanford University in California, plans to grow human cells in mouse and rat embryos and then transplant those embryos into surrogate animals. (<https://tinyurl.com/y2wbjt4o>)

Human-animal chimeras could be a promising alternative to obtaining organs from human donors; however, the ethics around this research is hazy. In both China and Japan, researchers are exploring the addition of human pluripotent stem cells to animal embryos. In China, the researchers are adding human embryonic stem cells to monkey embryos, a technique that is prohibited from receiving federal funding in the U.S. In Japan, the researchers are taking a more tempered approach and creating human induced pluripotent stem cells that are programmed to become a particular organ and then injecting them into mouse embryos. Aside from the stem cell source in the China case, another ethical concern is whether the animal brain will contain human neurological cells. ●●●

TOP BIOETHICS NEWS STORIES: SEPTEMBER—NOVEMBER, 2019

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“23andMe, Moving Beyond Consumer DNA Tests, Is Building a Clinical Trial Recruitment Business” by Rebecca Robbins, *STAT News*, September 26, 2019

Consumer genetics giant 23andMe announced Thursday that it would move deeper into the business of clinical trial recruitment, partnering with a fast-growing startup to help match its customers with nearby study sites based on their diseases, demographics, and DNA. The Silicon Valley company has for months been quietly making inroads into clinical trial recruitment by emailing customers who've opted in with recommendations about studies that might be appropriate for them. (<https://tinyurl.com/y6qtnnh9>)

“There’s No Such Thing as Anonymity’: With Consumer DNA Tests, Sperm Banks Reconsider Long-Held Promises to Donors” by Meghana Keshavan, *STAT News*, September 11, 2019

For generations, it was a basic tenet of donating sperm: Clinics could forever protect their clients' identities. But, increasingly, donor anonymity is dead. The rise of consumer genetic tests—which allow people to connect with relatives they never knew they had, including some who never intended to be found in the first place—is forcing sperm donation clinics to confront the fact that it is now virtually impossible to guarantee anonymity to their clients. Instead, sites like 23andMe and Ancestry.com are giving customers the genetic clues they need to identify biological parents on their own. (<https://tinyurl.com/ywyoprn>)

Consumer DNA testing continues to be a source of debate among bioethicists because of the privacy issues it poses. 23andMe was in the news for entering the clinical trial recruitment business. Patients who opt-in will be offered clinical trials near them. Additionally, consumer DNA testing has posed problems for the assisted reproductive industry. Sperm donors, past and present, are no longer guaranteed anonymity now that DNA testing is inexpensive and widely used.

“U.N. Urged to Investigate Organ Harvesting in China” by Emma Batha, *Reuters*, September 24, 2019

A senior lawyer called on Tuesday for the top United Nations human rights body to investigate evidence that China is murdering members of the Falun Gong spiritual group and harvesting their organs for transplant. Hamid Sabi called for urgent action as he presented the findings of the China Tribunal, an independent panel set up to examine the issue, which concluded in June that China's organ harvesting amounted to crimes against humanity. (<https://tinyurl.com/y47kxmgw>)

“Chinese Government May Have Falsified Organ Donation Numbers, Study Says” by Ben Doherty, *The Guardian*, November 14, 2019

The Chinese government may have been systematically falsifying its organ donation numbers, raising renewed concerns over the use of executed prisoners and other forced donors for transplants, a new academic paper says. In 2015, China publicly promised it would no longer source organs from

executed prisoners, previously almost its sole source. But a study led by Australian National University PhD student Matthew Robertson, published in the *BMC Medical Ethics* journal on Friday, says Chinese-government supplied datasets on organ donations show “highly compelling evidence they are being falsified”. (<https://tinyurl.com/vz4mjqu>)

An international tribunal found China guilty of crimes against humanity for forced organ harvesting of prisoners, including prisoners of conscience and detainees. The tribunal's counsel presented the findings at the United Nations Human Rights Council. The fallout has been the retraction of dozens of journal articles because the organs used may not have been obtained ethically.

“The Worst Public Health Crisis in Decades’: First Federal Opioid Trial Slated to Begin Monday by Jorge L. Ortiz *USA Today*, October 20, 2019

The landmark opioid litigation pitting state and local governments against makers and distributors of the highly addictive painkillers is set to go to trial Monday after attempts at a settlement broke down last week. An offer of \$48 billion in cash, treatment drugs and services was rejected as lawyers for the 2,400 cities and counties involved clashed with states attorneys general over the distribution of the settlement. (<https://tinyurl.com/y4xtbpma>)

Cuyahoga and Summit Counties in Ohio have initiated the first of what will be several lawsuits against pharmaceutical

companies Teva Pharmaceuticals, Johnson & Johnson, and Purdue Pharma. The lawsuits are over false claims that opioids are not addictive and can be taken long-term for pain management. These lawsuits, brought by state and local authorities, will continue into 2020. However, some patients believe new federal guidelines regulating the prescription of opioid pain meds are overkill, resulting in patients not getting the pain medicine they require.

“Google’s Secret ‘Project Nightingale’ Gathers Personal Health Data on Millions of Americans” by Rob Copeland, *The Wall Street Journal*, November 11, 2019

Google is engaged in a secret project with one of the country’s largest health-care systems to collect and crunch the detailed personal health information of millions of Americans across 21 states, according to people familiar with the matter and internal documents. The initiative, code-named “Project Nightingale,” appears to be the largest in a series of efforts by Silicon Valley giants to gain access to personal health data and establish a toehold in the massive health-care industry. (<https://tinyurl.com/wzkr768>, by subscription)

Last fall Google made strides to enter the health data industry. The company partnered with the Mayo Clinic to store patient data in the cloud and use AI to analyze that data. Then Google partnered with Ascension Health Network, a network of Catholic Hospitals, to store and study patient data. Additionally, Google acquired Fitbit for \$2.1 billion, which gives Google access to user data. A whistle-blower working with the Google/Ascension project, called “Project Nightingale,” outed the companies for potentially violating privacy laws because Ascension did not acquire patient permission to give health data to a tech company. This has led to a federal investigation.

“DR Congo Measles: Nearly 5,000 Dead in Major Outbreak,” *BBC*, November 21, 2019

Measles has killed nearly 5,000 people in the Democratic Republic of Congo in 2019, authorities said, after the disease spread to all the provinces in the country. Close to a quarter of a million people have been infected this year alone. The World Health Organization (WHO) says this is the world’s largest and fastest-moving epidemic. Measles in DR Congo has now killed more than twice the number who have died of Ebola there in the last 15 months. (<https://tinyurl.com/rs275uj>)

“Two Ebola Treatments Yield ‘Substantial Decrease’ in Mortality, Landmark Trial Shows” by Helen Branswell, *STAT News*, November 27, 2019

Final data from a landmark clinical trial of four Ebola therapies conducted in the current outbreak in the Democratic Republic of the Congo show two of the drugs dramatically reduced the risk of dying from the disease, especially in people who started treatment quickly after onset of their illness. Findings of the PALM trial, published in the *New England Journal of Medicine* on Wednesday, show that two treatments based on Ebola antibodies led to a survival rate of about 65% in treated patients, compared to 33% in the outbreak overall. (<https://tinyurl.com/y4q493qx>)

The Democratic Republic of Congo had an on-going Ebola epidemic. The extent of the outbreak was unclear and DRC’s health minister was arrested. Additionally, a measles epidemic spread throughout the country. By November, antibody drug therapies proved to decrease mortality in patients with Ebola.

“New CDC Report Offers a Possible Clue about Why Vaping Illness Sprang Up in 2019” by Megan Thielking, *STAT News*, November 26, 2019

A new report adds to the evidence that vitamin E acetate might play a role in a spate of vaping-related illnesses that have sickened thousands. It could also offer an early clue about why the illnesses appeared seemingly suddenly this year—though experts caution it’s too soon to rule out other potential culprits. The chemical—used as an additive or thickener in some vaping products—was found in vaping products used by 11 of 12 patients sickened with vaping-related illness in Minnesota, the Centers for Disease Control and Prevention reported Tuesday. (<https://tinyurl.com/yxsrbsnj>)

Numerous teens and young adults started to become sick with a vaping-related illness, landing in the hospital for lung damage. Oddly, this outbreak of illnesses was unique to the U.S. Last fall, over two thousand people became severely ill and almost fifty people died, including a seventeen-year-old who was the youngest person to die. Another seventeen-year-old required a double lung transplant. Scientists believe the lung damage is related to an ingredient in marijuana products. Teen vaping fell appreciably in 2020.

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