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Freedom from Unwarranted Experimentation

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Abstract

This is a declaration of the fundamental human right of all people, simply by virtue of being human, to be free from subjection to all forms of experimentation unless they voluntarily consent to participate after being fully informed of all risks by qualified experts in all relevant fields. Further, it asserts that everyone retains the right to opt out of any experiment, each of their own accord, and at any time, even after consent has been freely given and the experiment is underway. This paper argues for the urgent need to broadly expand the definition of human research in order to extend protections against illicit experimentation far beyond the boundaries of formal medical and scientific research; to recognize the full scope of ethical principles embodied in the Nuremberg Code of 1947; and, ultimately, to enact these protections into law. In support of these contentions, three primary examples have been chosen to illustrate recent and widespread violations of these fundamental rights. Examples have been chosen from social media, the tobacco industry, and wind energy production precisely because they fall well outside this boundary of formal human research as conventionally defined, and they demonstrate the need for wider protections in all walks of life, as a fundamental dictate of social justice.

Keywords

Unwarranted Experimentation, Human, Rights, Research, Nuremberg Code, Facebook, Tobacco, Wind Energy

1. Introduction

All human beings have a fundamental and inalienable right to be free from subjection to any form of experimentation against their will, or without their knowledge. This right is closely related to, but distinctly different from the widely recognized right to health. Any experimental research or activity which puts a person's health or wellbeing at the risk of harm without his or her fully informed consent and voluntary participation must be considered a violation of this right.

When any sustained experiment of any kind poses even the faintest possibility of harm to any person, he or she must be provided with all the relevant information necessary to make a fully informed decision to voluntarily participate or refuse. Even when a subject has been properly informed and agrees to participate, he or she retains the right to revoke consent and stop participating at any time during the course of the experiment. Experiments which are not designed to provide every legitimate means of egress for subjects without further unavoidable harm are also a violation of this right.

The Nuremberg Code forged in 1947 is among the first and perhaps most well-known efforts to articulate this ethical principle explicitly ("Tribunals", 1949) [1]. A circular published by the Weimar Government prior to the start of WWII, known as the "German Guidelines on Human Experimentation 1931" preceded the Nuremberg doctrine and espouses some of the same principles, but it notably lacks any recognition of the subject's right to opt out ("Guidelines," 1931) [2]. Unlike these guidelines, the Nuremberg Code was written specifically as a tool for prosecuting crimes against humanity perpetrated by Nazi doctors and researchers during WWII. They had subjected concentration camp prisoners to horrific experiments that no one would ever consent to voluntarily.

To briefly summarize some of its most important provisions, the Nuremberg Code asserts that an ethical experiment on humans must:

- Obtain voluntary, informed consent of all subjects
- Allow subjects to leave if they choose
- Make every effort to minimize potential harm
- Be conducted by experts in the field
- Be stopped if injury, disability, or death becomes likely

Contrary to what one might hope, these provisions have been largely ignored outside the realms of science and medicine, and seldom enacted into law. Outside medical research, these principles have become "More honor'd in the breach than the observance" as Shakespeare so aptly put it (Branagh, 1996, *Hamlet* Act 1, scene 4, 7-16) [3].

What follows is a discussion of the Nuremberg Code in some its historical context to show why the protections for human subjects embodied in it must be treated as a fundamental human right and why it should be more broadly applied. This discussion draws upon some recent examples of illicit experimentation on human subjects outside of medical research; such as tobacco products and psychological experiments conducted on Facebook. It then focuses most specifically on the development of wind energy as a case study of widespread but hitherto unrecognized human experimentation. Finally, it attempts to call attention to some shortcomings of the Nuremberg Code and offers some suggested improvements in the hope of renewing interest in it and applying it across its proper breadth as a fundamental human right and principle of social justice.

2. Historical Background

Placed in its historical context, the Nuremberg Code must be seen both as a

framework for defining ethical experimentation, and as the assertion of a fundamental human right to protection from unethical or unwarranted experimentation. On the occasion of its fiftieth anniversary, ethicist Evelyne Shuster (1997) [4] wrote that "Informed consent, the core of the Nuremberg Code, has rightly been viewed as the protection of subjects' human rights." Nonetheless, the true scope and importance of this doctrine has yet to be fully understood and embraced.

More and more frequently in the industrialized world, illicit experimentation on human subjects is conducted by public agencies and/or private industries in order to test the efficacy of new technologies, products, or social policies. Such practices have become commonplace to a degree that the authors of Nuremberg could have scarcely anticipated. The subtle but important historical fact is that even some of the experiments conducted by the Nazi doctors were, themselves, not intended for the purpose of medical research or to improve human health in any way. For example, some of those sponsored by the Schutzstaffel (SS) and German air force on prisoners at Dachau were undertaken solely to determine the limits of human endurance to extreme cold, very low pressure, or drinking seawater (Rozett & Spector, 2000, p. 307) [5]. Their main intent was to prepare and equip German military personnel for war in extreme conditions.

Since these infamous experiments, the right to informed consent has continued to be routinely violated with impunity by government agencies, the military, prison administrations, schools—and, perhaps less conspicuously, but more pervasively--private industry. This impunity seems partly due to the erroneous conclusion that the provisions of the Nuremberg Code apply only to formal scientific experiments on human subjects *i.e.* those conducted for medical or health related purposes. These other types of research on human subjects have been allowed to proliferate without consequence because we, as a society, do not hold these other perpetrators to the same stringent ethical standards. This underscores the urgent imperative to further refine and inject these principles into any and all public and private debates and policy decisions where experimental proposals hold the potential to cause people harm.

As with some forms of torture, the harm caused by some experiments may not be obvious or immediately evident. It is crucial to realize that the absence of severe or acute symptoms in experimental subjects does not mean that no harm has been committed. For decades, the tobacco industry subjected unwitting smokers to experimental tobacco products designed to enhance their addictive qualities (Stevenson & Proctor, 2008) [6]. It was easy for the public, the government, and the medical community to ignore this harm because the deadly impacts of smoking are neither immediate nor initially obvious. Often, the most serious harm is not evident until it reaches the stage where it becomes difficult, if not impossible, to treat or arrest the diseases that smoking causes. In many cases, the most serious health effects of tobacco products take decades to manifest themselves. By the time that the dangers of lung cancer and heart disease were realized, many smokers were already far too addicted to stop smoking—even

though they realized it might eventually cost them their lives! To put it succinctly, the experiment in nicotine addiction was wildly successful; but the health outcomes were devastating, accentuating the need to protect people from such experimentation whether harm is manifest or not.

How, then, should we weigh the true impact of such experiments? The U.S. Centers for Disease Control and Prevention (CDC) estimates that smoking causes 480,000 deaths annually ("Tobacco", 2016) [7]. Based on this average, it is reasonable to conclude that the experiments to enhance addiction were the cause of a very large portion of some 26 million deaths and the incalculable suffering of millions more since 1960—and these statistics apply only to the US. Most notably for this discussion, the punitive litigation that has been brought against the tobacco industry has included product liability, manufacturing negligence, fraudulent advertising, and violations of consumer protections; but never illicit experimentation on human subjects without their informed consent. Presumably, this is because there is, so far, no law which prohibits such experiments or assigns any punishment for conducting them on the general public.

As recently as 2014, Facebook sponsored an experiment in social psychology conducted on its users to determine whether negative content could spread a mood-altering contagion through social media. Nearly 700,000 users were deliberately subjected to emotionally negative content while completely unaware that they were subjects of a wide ranging social experiment (Kramer, Guillory, & Hancock, 2014) [8]. Apparently, those who conducted this experiment did not carefully consider the potentially serious health risks it created, despite a growing body of published studies that show social media can contribute to depression and suicidal ideation (Dunlop, More, & Romer, 2011) [9]. Since the conclusion of this experiment, no effort has been made to determine what harm may have been caused to these online subjects; and, therefore, there is no way to determine the extent of serious emotional damage that may have been inflicted on unwitting users.

In this behavioral study, the authors claimed "[The experiment] was consistent with Facebook's Data Use Policy, to which all users agree prior to creating an account on Facebook, constituting informed consent for this research" (Kramer *et al*., 2014). After publishing this study, however, the Editor-in-Chief of the Proceedings of the National Academy of Science, Inder M. Verma (July 3, 2014) [10], issued an "Editorial Expression of Concern and Correction" in which he states that

> …**as a private company Facebook was under no obligation to conform to the provisions of the Common Rule** when it collected the data used by the authors, and the Common Rule does not preclude their use of the data….It is nevertheless a matter of concern that the collection of the data by Facebook may have involved **practices that were not fully consistent with the principles of obtaining informed consent and allowing participants to opt out** [emphasis added].

The Common Rule referred to here is Title 45 of the U.S. Code of Federal

Regulations for the Department of Health and Human Services (HHS) pertaining to the protection of human research subjects. These regulations were derived from the principles of the Nuremberg Code as outlined in The Belmont Report (1979) [11]. Generally, these regulations are only applied to areas that HHS oversees, such as heath, food, and drugs. Technically, therefore, Verma is correct to say that Facebook was not legally obligated to comply with these policies. Nonetheless, his expressed concern that subjects had a right to informed consent and an opportunity to opt out is very well placed, indeed.

It is difficult to understand why Facebook, or any other private company, should be ethically or legally exempt from the responsibility to tell users that they were being subjected to experimentation that could cause serious harm, or be allowed dereliction from their duty to give users an opportunity to opt out of the study. In absence of any repercussions, Facebook has essentially reserved the right to conduct further social, or behavioral experiments on its users without first obtaining genuine informed consent and without regard for the danger to its subjects—based, presumably, on the dubious claim that users have given their informed consent by accepting the terms of Facebook's Data Use Policy (which almost exclusively addresses data use and privacy). In point of fact, the term *experiment* or its derivatives does not even appear in the online policy statement to this day ("Facebook", 2017) [12]. The claim that in conceding their online privacy of personal data, users have also given informed consent to potentially dangerous emotional manipulation is shameless casuistry and an ethical travesty. Why should this experiment be viewed any differently than those in which, for example, users were intentionally exposed without consent to a physical contagion which causes negative emotions? Would a physical contagion have sparked greater public outrage or action?

These examples illustrate why the time has come to hold all research on human subjects to the same ethical standards, regardless of who or where it is conducted. The protections afforded by the Nuremberg Code must be applied even in cyberspace.

3. Deciphering the Code

If we accept the premise that the Nuremberg Code is more than a set of ethical guidelines for researchers, but also a doctrine for the protection of all experimental subjects as a fundamental human right, there can be no rational grounds for artificially limiting these rights solely to formal experiments conducted by qualified medical researchers and scientists. It would be absurd to suppose, for example, that such rights are fully in force for controlled medical research, but utterly forfeit when experimenters are not properly qualified or when the protocol is ill-designed. Regardless of who conducts an experiment, the safety of human subjects must be held paramount in all cases. Tenet 7 of the Nuremberg Code states without qualification that "Proper preparations should be made and adequate facilities provided to protect the experimental subject against even remote possibilities of injury, disability, or death." Accordingly, no person or

group who engages in experimentation of any kind should be exempt from the obligation to obtain the fully informed consent of all subjects when there is the faintest reason to believe it will put them at risk. Whether experimentation is done to advance government programs, test new products and technologies, or improve the psychological impacts of an advertising campaign; it must be held to the same standards of safety and informed consent for all subjects without exception.

After nearly seventy years in existence, recognition of the full breadth of protections embodied in the Nuremberg Code is long overdue. Regardless of purpose, anyone who conducts an experiment of any kind on human subjects must acknowledge that "The voluntary consent of the human subject is absolutely essential (tenet 1)." And, anyone who is in charge of an experiment "must be prepared to terminate the experiment at any stage, if he has probable cause to believe, in the exercise of the good faith, superior skill, and careful judgment required of him, that a continuation of the experiment is likely to result in injury, disability, or death to the experimental subject (tenet 10)." In all cases, it must be the exclusive right of each individual subject "to bring the experiment to an end if he has reached the physical or mental state where continuation of the experiment seems to him to be impossible (tenet 9)" ("Tribunals," 1949).

Since its authors, Leo Alexander, Werner Leibbrand, and Andrew Ivy were doctors and medical researchers themselves; and since the defendants at Nuremberg Trial were also doctors; perhaps it is not surprising that the language used to express this code is written from the perspective of medical science. Even so, science is specifically mentioned only twice. Everywhere else, the authors chose to use the more general terms *experiment or experimental.* Some form of this term is used no less that twenty-six times in this brief document, suggesting that the authors recognized the applicability of these principles far beyond the Trial and the domains of pure science or medicine.

Notably, tenet 8 stringently states that "The experiment should be conducted only by scientifically qualified persons. The highest degree of skill and care should be required through all stages of the experiment of those who conduct or engage in the experiment" ("Tribunals", 1949). By this definition, therefore, research on any human subject which is not designed and conducted with the highest degree of skill and expertise is simply unethical. Lack of expertise may disqualify an experiment as an ethical one, but this does not disqualify it as an experiment *per se*—and does not exempt such experimentation from any other ethical dictates. Hence, the rights of the human subject to be protected from them are ubiquitous. Though not expressly stated, the expression "highest degree of skill and care" is a requirement designed to ensure the safety of human subjects. Experiments conducted without them are a manifest violation of human rights. Consent is meaningless unless subjects are fully informed of the true dangers, but this is not possible if the expertise necessary to identify the full potential for harm is absent.

As a foundation for the protection of human subjects, the Nuremberg Code is

indispensable; but it is nonetheless imperfect. Perhaps its most glaring deficiency is that it fails to precisely define what constitutes an experiment on human subjects. Yet, this definition is critically necessary for correctly determining when and how these principles are properly applied. Within the medical research community, many efforts have been made to refine the definition of human research. As noted earlier, however, these tend to focus their attention almost exclusively on medical and scientific research *pro per se*; and tend to focus on formal investigation only. For example, the Research Ethics Committee (of the World Health Organization (WHO) (2009) [13] has published the following:

> Any social science, biomedical, behavioural or epidemiological activity that entails systematic collection or analysis of data with the intent to generate new knowledge; in which human beings:
> 1) are exposed to manipulation, intervention, observation or other interaction with investigators, either directly or through alteration of their environment; or
> 2) become individually identifiable through investigators' collection, preparation or use of biological material or medical or other records.

It begins by limiting the definition to formal scientific fields of inquiry, thereby overlooking human research which may be unsystematic, completely non-scientific in nature, or devoid of requisite expertise; but which still may impose genuine risks to human health and welfare. Definitions which ignore informal investigations involving human beings inadvertently exempt them from the solemn responsibilities to take every available precaution to ensure the safety of subjects. If ignored, we fail to fully recognize and protect the fundamental right of all human beings to be free from all illicit or unwarranted experimentation.

In a white paper entitled "Experiments in Torture," Physicians for Human Rights (PHR) has emphasized the need to define human research more inclusively, and thereby extend these full protections.

> Activities that constitute human subject research and experimentation do not require a particular research study design, the testing of hypotheses, or the use of control groups….The systematic collection of personalized information from any human subjects, whether patients, volunteers, soldier-subjects, prisoners, or any other group, for purposes other than their direct benefit requires human subject protections, such as informed consent, and prospective review of and approval by an institutional review board (IRB), regardless of the information-gathering methods used or the stated purpose of the inquiry (Allen & Raymond, 2010) [14].

Embracing a broader definition such as this can help to remedy our ethical blind spot. We must consider any sustained or widespread investigation to be human experimentation if there is reason to believe it could adversely effecting human beings' health, wellbeing, or environment. This definition includes all

investigations regardless of whether they are systematic or not, regardless of whether they affect human beings directly or indirectly; and regardless of whether they are designed for the primary purpose of determining human impacts or not. Any investigation which involving human beings should be held accountable for the human safety whether conducted by acknowledged experts or not. To clarify, the term "sustained" in this context implies any investigation or study which occurs over an extended period of time, which involves a non-trivial number of subjects, or which requires the application of significant resources to conduct it. This definition should not exclude brief experiments on a few people; but it is intended to include and call attention to an important class of human research which tends to be hidden in plain sight. In general, therefore, the rights and obligations defined in the Nuremberg Code should be applied to all these classes of experimentation.

Another notable defect of the Nuremberg Code can be found in tenet 9, which states that "During the course of the experiment, the human subject should be at liberty to bring the experiment to an end, if he has reached the physical or mental state, where continuation of the experiment seemed to him to be impossible." According to this tenet, the right of the subject to opt out is virtually absolute; but, again, a definition for what constitutes a legitimate means of egress remains undefined. The subject's right to leave an experiment is absolutely critical because it defines and extends the true meaning of voluntary consent. Even if consent is fully informed and freely given, each subject still retains an undiminished right to revoke consent and end participation at any time. Moreover, this imposes an ethical obligation on human researchers to design protocols which afford subjects every reasonable opportunity to leave the experiment at any time. Did smokers, for example, have a legitimate opportunity to opt out by simply quitting once they learned of the dangers? Though sometimes asserted that they did, this proposition seems highly dubious given that tobacco companies were secretly experimenting with enhancements that make cigarettes more addictive. Facebook users clearly had no real chance to opt out or bring the experiment to an end, because they were not even aware that their emotions were being secretly manipulated by unseen experimenters.

Based on the nature of some experiments, it may be nearly impossible to provide subjects with the opportunity to stop the experiment once it goes beyond a certain point. Neither the donor nor the recipient had a chance to opt out once anesthesia was administered, for example, in the first kidney transplant experiments conducted by Dr. Joseph Murray. In such cases, especially those in which this danger is less obvious, informed consent means that subjects must be told that it will be difficult or impossible to leave once a certain point in the experiment is reached. In addition, if it can be reasonably anticipated that subjects might incur harm during the process of withdrawing, this risk must also be made indelibly clear to every subject. Though the practical means to leave or stop an experiment are not well-defined in the Nuremberg Code, it strongly emphasizes the duty of the experimenter to err on the side of full disclosure. Te-

net 1 asserts that

> "…before the acceptance of an affirmative decision by the experimental subject, there should be made known to him the nature, duration, and purpose of the experiment; the method and means by which it is to be conducted; **all inconveniences and hazards reasonably to be expected**; and the effects upon his health or person, which may possibly come from his participation in the experiment [emphasis added] ("Tribunals", 1949).

When we focus on the subject's right to opt out, it sheds a clear light on the true meaning and extent of voluntary consent because the right to withdraw consent remains in force at all times.

Equipped with this deepening understanding, we can now consider the subtle form of experimentation that occurs during development and deployment of wind energy technology in proximity to people.

4. Wind Energy: A Case Study

Due to inherent economic advantages, the wind industry has sought to build its massive, wind-driven power generators as close to existing power grids as possible. It is much less expensive to build, operate, and maintain land-based systems; and more economical to generate power as close to the point of consumption as possible *i.e.* the grid ("Renewable Energy", 2012) [15]. These economic forces have made it almost inevitable that wind energy suppliers would bring their power generators into close proximity to residential consumers.

Since the inception of wind power, however, it was soon discovered that such industrial-scale wind turbines (IWTs), in addition to producing electrical energy, also radiate dangerously intense sound energy created by the rotation of the massive blades in turbulent air. This radiation of sound pulsations has a direct, perceptible, and adverse effect on some IWT neighbors.

One of the earliest attempts to place an IWT close to residential homes occurred near Boone, North Carolina, U.S.A in 1979. It immediately produced complaints from many people living nearby who suffered disturbances, sleep disruption, and a variety of adverse health effects in their daily lives. A highly controlled study of the Boone site was conducted by Neil Kelley and other scientists from the Solar Energy Research Institute (SERI), sponsored by the U.S. Department of Energy. The study determined that complaints were a direct result of the IWT-produced impulsive sound energy emissions. The conclusion of this study specifically states that "The greater part of the impulse acoustic energy responsible for the annoyance was very low frequency, and the observed peak was generally below the "normally" audible lower limit of 20 Hz" (Kelley *et al.*, 1985) [16]. It is critical to note that infrasound and low frequency noise (ILFN) was found to be the cause of complaints. Sound waves in the frequency range below 20 Hz fall below the limit of detection of the human ear—a conclusion contrary to common sense—Boone residents were being adversely impacted by a form of sound energy that they were not aware of in any conventional sense. Kelley's

study was completed in 1985 and then presented at the American Wind Energy Association Conference in San Francisco in 1987.

In an unrelated investigation which also began in 1979, a longitudinal medical study of human pathologies caused by ILFN and low frequency vibration (LFV) was undertaken by Dr. Nuno Castelo Branco and Mariana Alves-Pereira (2004) [17]. This ongoing study began to report very serious human impacts from occupational exposure patterns to ILFN and LFV on a large cohort of Portuguese air force technicians as early as 1984. Since then, this research team has continued to publish on these very serious whole body pathologies, collectively referred to as vibroacoustic disease (VAD) for over three decades, using both human and animal studies. As early as 1985, therefore, there was ample published evidence, based on expert medical and acoustic research that prolonged exposure to the ILFN and LFV of the kind created by wind IWTs was highly detrimental to human health.

Despite the growing chorus of complaints and adverse health reports on the public record from neighbors, as well as solid scientific evidence that IWTs were the cause—or perhaps because of these them—the wind industry has steadfastly chosen to ignore them and accelerate the siting of industrial-scale wind farms near residents. This process has been marked by a staggering variety of design changes, operational changes, and mitigation tactics intended, in the main, to reduce human health impacts or discredit the findings that indicated IWTs were dangerous. By siting new designs in ever closer proximity to residents, they are effectively testing these experimental changes at the hazard of human subjects who live near them.

As further evidence mounted to support the seminal studies mentioned, the wind industry sought to confound the issue and experimented with mitigation of the most prominent complaints, while continuing to inflict acute, serious, and widespread damage to the health and wellbeing of nearby residents—many of whom lacked the economic, legal, or political means to escape these hazards.

Design changes included converting to upwind rotors; changing the size, number, angle, and configuration of blades; changes to blade tip and edge configurations; new gearbox designs, changes to tower shape, configuration, and height; and changes to wind farm site layouts. Throughout all these changes, IWTs have gradually but steadily grown larger, and have been placed ever closer to people—despite the obvious increases in damaging human impacts and the acute symptoms and complaints from neighbors that invariably accompany them as soon as they begin operation.

Undoubtedly, some modifications were also intended to improve power output or cost efficiency, but many can only be explained as tests to determine or reduce human impact. For example, efforts to feather the blade angles actually de-power turbines, making them less efficient generators. Reducing noise is the far more probable explanation for such attempts. Similarly, other design changes such as installing air foils or serrated blade edging would tend to disrupt laminar air flow and thus reduce power, again suggesting that noise reduction and the

abatement of adverse effects on human beings is the primary aim. These modifications amount to tacit experiments on human subjects to determine whether adverse effects could actually be mitigated. No other explanation is possible.

Often, these experimental changes were measured by microphones to gauge sound volume in the human audible range, using the A-weighting scale which wholly discounts sub-audible noise (Oerlemans, Fisher, Maeder, & Koegler, 2008) [18]. Industry acoustic engineers assumed, without consulting clinical experts, and contrary to established scientific foundation, that such measurements would accurately reflect the actual human experience of IWT noise. Measuring audible sound only, and then estimating impact with computer modeling grossly misrepresents the full range of human experience and health impacts from IWTs (Salt & Lichtenhan, 2014; Cooper, 2015) [19] [20].

Under a misguided confidence that the new design will ameliorate the worst human consequences of IWT sound emissions, they are then sited near residential homes. Based on such studies, wind developers assure local communities that there is no risk and no harm will occur. Residents who live near IWTs soon find themselves to be the uninformed subjects of ongoing industry experimentation which exposes hundreds (and sometimes thousands) of them to very serious health and safety risks from a hazardously polluted soundscape—for decades.

Wind developers have also experimented with noise mitigation for individual residents by planting trees on the turbine-facing side of their homes, provisioning homes with white noise machines intended to mask audible noise, and furnishing air-conditioning units so that windows can be kept shut tight in summer months. Efforts have been made to soundproof nearby homes by tightly sealing them and adding dense materials such as stone, tiling, and double glazing on walls, floors and roofs. There is little scientific or engineering foundation to suggest that such mitigation efforts are effective against the whole-body effects of ILFN and LFV; but there is considerable evidence to show the contrary (Phipps, 2007) [21]. Moreover, there are many acoustic studies (including Kelley cited above) that show tightly sealed rooms, which are typically allocated to children, may actually amplify ILFN indoors (Ambrose, Rand, & Krogh, 2012) [22]. As a last resort, wind developers have often bought nearby properties outright from the worst affected neighbors in exchange for their silence, but such non-disclosure agreements merely deprive others in the community from learning the true dangers to health and safety caused by these colossal power generators.

One mitigation tactic used by the wind industry is especially telling for this discussion. Most industrial wind facilities systematically collect operational data about IWT performance and operating conditions, known as supervisory control and data acquisition (SCADA). When complaints about adverse health effects mount, developers or public officials sometimes collect health information from complainants about the associated time, location, and environmental conditions. Ostensibly, these data are then correlated with the SCADA data and analyzed for patterns to guide mitigation tactics, such as depowering under

those conditions. Typically, the analysis is done in complete absence of any training in public health or true clinical expertise, based on the patently absurd claim that exposing the SCADA data to such scrutiny would compromise trade secrets. Intentionally withholding or suppressing information about the causes of adverse health effects for this reason is flagrantly unethical and a manifest violation of informed consent.

When injuries are sustained from chronic exposure to dangerous levels of ILFN and vital information about their causes is withheld from public view, they are often compounded by doctors and clinicians who fail to take patient complaints seriously. Ironically, the oath to "do no harm" is sometimes violated by doing nothing. Injury is proliferated by lax government regulations such as IWT setback requirements, as well as the dismissive attitudes of a myopic public bent on promoting renewable energy at any cost. All are complicit in this widespread and ongoing violation of human rights.

Tracking complaints, compiling public health records, and recording SCADA data, all fall easily within the systematic data collection identified by the WHO Ethics Committee as a hallmark of human research in the definition cited early—except that it falls outside the boundaries of formal scientific inquiry. Even if such data collection did not occur, most land-based wind projects are sustained in duration and widespread in terms of the sheer numbers of people who are put at risk. As a result, the uncertain outcomes, the sustained nature of inquiry, and the potential for widespread impacts on health and well-being still qualify wind projects as experiments on human subjects.

5. Analysis

By almost any thoughtful definition of the term, the behavior of the wind industry over the past three decades constitutes a sustained and unwarranted experiment on human subjects and, therefore, a widespread and ongoing violation of their fundamental rights to protection—this remains true regardless of how unscientific or poorly designed these experiments have been. Perhaps a simple thought experiment can dispel any skepticism about this. If we were to omit only the identity of the experimenter, and then submit a proposal for public health research on human subjects which intentionally exposed individuals to dangerous levels of ILFN or LFV, any accredited Institutional Review Board would summarily reject it as unethical and unworthy of public funding.

Our hypothetical proposal utterly fails the test of informed consent. As we shall see in a moment, if the actual risks to health and safety were fully disclosed, it would be rejected on this basis alone. Second, the scientific expertise necessary to understand the full spectrum of impacts inflicted by ILFN on the human body is especially high. The wind industry has consistently sought to avoid or stymy rigorous, multidisciplinary investigations that involve both acoustic experts and clinicians working in concert. Those clinicians and researchers who have studied the human impacts of IWTs often point to the crucial need for a multidisciplinary approach due the inherent pathogenic complexities of ILFN impacts (Lau-

rie, 2014) [23], as well as the acoustic challenges of accurately measuring dose response to exposure of ILFN and LFV. Such measurement requires very high levels of expertise and experience in acoustic science and engineering, as well as deep clinical knowledge of whole body responses to ILFN and LFV.

In absence of such proficiency, it is impossible to provide sufficiently reliable information for anyone to make a sound decision about living near IWTs. Experimenters who lack the requisite expertise to furnish accurate and comprehensible accounts of potential harm, also lack the expertise to recognize or prevent harm. Without these, such experiments are grotesquely unethical from the outset.

When human experimentation is undertaken for the purpose of developing new products or technologies like wind power, the tenet 2 of the Nuremberg Code takes on a special meaning and importance. It reads: "The experiment should be such as to yield fruitful results for the good of society, unprocurable by other methods or means of study, and not random and unnecessary in nature." This tenet places the burden on would-be experimenters to show that any risk of harm is justified by the potential benefits to society—and not the benefits to experimenters! Thus, even when informed consent is properly obtained, an experiment may still be unwarranted if it imposes unjustifiable risk. The grand claims of reduced energy costs, a cleaner environment, and preventing global climate change that are advanced by the wind industry and its proponents have no basis in fact. On the contrary, there is strong evidence to suggest that wind power drives energy costs up dramatically (Nowell, 2010) [24], pollutes the local environment with ILFN and LFV (Walker, Hessler, Hessler, & Schomer, 2012) [25], and is utterly incapable of stemming climate change in any appreciable way (Bryce, 2013) [26].

In addition, risk must be a justified by a social good that cannot be obtained by means other than putting human subjects in harm's way. This principle is reinforced by the language of tenet 6 which states that "The degree of risk to be taken should never exceed that determined by the humanitarian importance of the problem to be solved by the experiment" ("Tribunals", 1949) Taken alone, tenet 6 sets up a scale of social justice that balances risks and potential benefits, requiring that the two are commensurate with one another. Taken together, these tenets set a very high bar for determining whether research on human subjects is justified. The experiment must be sufficiently justified by its promise of social good; but this conclusion leads one to ask who should be the judge of this balance?

Within institutions dedicated to formal medical and health research, especially those which are publicly funded; the responsibility of assessing whether an experiment is ethical falls to the Institutional Review Board (IRB). Typically, IRB members have both scientific and non-scientific expertise, the latter including relevant engineering or ethical training, for example. An IRB is intended to provide an independent oversight of human research to help ensure that participants are not exposed to unnecessary risk. If, for example, an experimental pro-

tocol is deemed too risky or otherwise unethical, the IRB has the power to ask for a change of protocol, or even to reject the study outright. When human experiments are conducted outside these auspices, however, independent expert oversight is often non-existent.

In absence of an equivalent "Community Review Board", key decisions for highly experimental technology such as wind projects are generally made by a small handful of local officials with little or no expertise in the areas of science, health, or engineering necessary to accurately assess health and safety risks. They are ill-equipped to carefully weigh the risks to individuals against the true benefits for the community. As a result, for most wind projects, IWT hosts and neighbors are told there is no risk whatsoever—a complete misrepresentation of the true dangers that await. In addition to trivializing the danger, proponents tend to grossly exaggerate the potential benefits that will accrue.

Perhaps worst of all, since neighbors are not typically apprised that they will be subjected to hazardous experimental technology; they are also unaware that there may be no practical opportunity to stop the experiment or escape for years once it begins.

6. Experiments with No Exit

The primary thrust of the Nuremberg Code is that any experiment must hold paramount the safety and wellbeing of its human subjects. As we have seen, the subject's right to know the true risks, as well as the right to opt out at any time, do not expire once consent is given. This right remains in force throughout the experiment. This is why the definition of a sustained investigation becomes central for understanding these rights. The greater the number of subjects, and the longer the duration of the study, the more likely that new risks and dangers, not evident at the outset, will appear after a prolonged experiment begins. Even when the protocol is well designed by a highly expert researcher in the appropriate field, and full disclosure has been made in good faith to all subjects, therefore; if new dangers are discovered in the course of the study, subjects must be informed and allowed to reconsider their continued participation. If serious or widespread dangers become evident, a burden of deciding whether to stop the experiment is also placed on the experimenter—who may be the only party in a position to recognize the emerging danger. This obligation is made quite clear in tenet 10, which states

> During the course of the experiment, the scientist in charge must be prepared to terminate the experiment at any stage, if he has probable cause to believe, in the exercise of the good faith, superior skill and careful judgement required of him, that a continuation of the experiment is likely to result in injury, disability, or death to the experimental subject ("Tribunals," 1949).

When deep investment of time, money, and public or private resources; conflict of interest inevitably arises between the motivation to complete the study

and the ethical obligation to curtail it in the face of newly discovered dangers. Under these circumstances, especially when human research is conducted in the private sector, or in cooperation between public and private institutions; there is a tendency to ignore the precautionary principle. The momentum of the experiment overshadows sound ethical judgement. This tendency often manifests itself in the form of a demand for certainty that the experiment is causing harm before stopping it. For many years, tobacco companies argued that there was insufficient evidence to prove with certainty that smoking caused harm. Typically, this demand for etiological certainty, far exceeds the capabilities of science. As a result, the experimentation with nicotine addiction went on unabated for decades in the face of manifest harm.

The precautionary principle, which was originally formulated with environmental damage in mind, is rooted in the much older principle enshrined in the Hippocratic Aphorism (first do no harm); but it has often been defeated in these scenarios because the burden of proof gets subtly shifted to those who allege harm. The principle of precaution is intended to place the burden of proof on those who cause harm to demonstrate that proposed products, technologies, or operations are safe. In this respect, it is consistent with the Nuremberg Code, which clearly puts the burden and responsibility to ensure the safety of human subjects squarely on the experimenter. Tenet 7 stringently states that the experimenter must "…protect the experimental subject against even remote possibilities of injury, disability, or death." To insist on scientific certainty that harm is being caused by the conditions of the experiment before it is stopped, therefore, is a patent violation of the subject's human right to protection.

Viewed as an ongoing experiment as we have defined it, the track record of wind energy over more than three decades has been one of total disregard for the harm it has inflicted on those who live near industrial IWTs. Unlike smoking, however, the harm caused by IWTs is both immediate and obvious for some. Though it may take decades before smokers begin to manifest heart and lung diseases, the symptoms caused by IWTs are both serious and acute for those who are most susceptible to them.

The studies cited earlier provided more than sufficient evidence to show that experimental wind projects impose much more than remote possibilities of harm. Since then, however, other studies have produced an enormous and growing body of evidence that support the earlier studies and further demonstrate the inherent danger of exposure to the ILFN and LFV emitted by IWTs—more than enough to justify a moratorium on the use of wind energy in the vicinity of human beings.

In 2009, Dr. Nina Pierpont concluded a simple but elegant case-crossover study of the impacts of IWTs on neighbors. Case-crossover design is a widely used and accepted design in epidemiology, population biology, psychology and many social sciences; when the effects to be studied manifest immediately upon exposure and then quickly subside when exposure is eliminated. By comparing each individual to himself or herself before during and after exposure, a strong

correlation between exposure and its effects can be identified. Since some portion of IWT neighbors are affected immediately, the case-crossover design is well-suited for studying the most immediate impacts of IWTs on humans.

Since we have emphasized the stringent requirement that human research must be conducted by an expert in the relevant field of study, and since the wind industry has taken special pains to denigrate Pierpont's expertise in order to undermine her conclusions, it is appropriate to note that Pierpont is eminently qualified to conduct experiments of this kind. She holds a BA in Biology from Yale, a PhD in behavioral ecology from Princeton. She did a post-doctoral fellowship in ornithology at the American Museum of Natural History and earned her MD at Johns Hopkins University School of Medicine in 1991. She has extensive experience both in field work and as a practicing pediatrician.

In the clinical portion of her report, entitled *Wind Turbine Syndrome*, Pierpont (2009, p. 48) [27] notes that the core symptoms of turbine exposure "…include sleep disturbance, headache, tinnitus, other ear and hearing sensations, disturbance to balance and equilibrium, nausea, anxiety, irritability, energy loss, motivation loss, and disturbances to memory and concentration" Based on her simple but meticulously executed protocol, Pierpont draws a very strong connection between these symptoms and their source:

> Core symptoms are closely correlated with exposure, including being at home, the direction and strength of the wind, whether turbines are facing the home, and the presence of moving blade shadows. Core symptoms all resolve immediately or within hours away from the turbines, with the exception of disturbances of concentration and memory, which resolved immediately in some cases or improved over weeks to months in others (Pierpont, 2009, p. 48-49).

Those susceptible to these effects often quickly discover the cause of their symptoms in much the same way that Pierpont's protocol works. They notice that when they are near spinning IWTs they soon begin to feel sick and when the spinning stops or they get away from the IWTs they begin to feel better. Once the source of their problems becomes obvious, however, they find themselves trapped in a brutal experiment with no exit.

Farming families, who are usually told by wind developers that there is no danger or annoyance whatever, typically sign lengthy lease agreements to host IWTs on their farms, only to discover that living near them is unendurable ("Gare testimony", 2015) [28]. In some cases, they notice that livestock is adversely affected as well (Knuth, 2010; Castelo Branco, Alves-Pereira, Pimenta, & Ferreira, 2015) [29] [30]. They are sometimes forced to decide whether to abandon their homes and family livelihoods for generations; or place their health at deepening risk by living with chronic sleeplessness, headaches, nausea, and more. Suburban and rural residences who make this discovery too late, may be left with no other choice but to live in torment or abandon their homes which are sometimes rendered unsalable by their proximity to the IWTs. Many who find them-

selves in this predicament have no way to halt the experiment or leave it without incurring catastrophic financial harm.

Under these circumstances, wind developers and public officials who are responsible for siting IWTs too close to residents without first obtaining informed consent and providing them with a means to opt out, bear full responsibility for the harm and damage to health which invariably ensues. The fact that a public vote was taken or that a contract was signed does not alter this obligation in any way. A vote which results in violations of human rights is still a violation of human rights. When people sign leases to host IWTs on their homestead, without being fully informed—or, as often the case, intentionally misinformed—do not furnish a license to violate their basic human rights to health, to trap them in unwarranted experimentation, or to treat them with cruelty. When IWT hosts realize that living near them has become humanly intolerable, they have an inalienable human right to escape from it which overrides the terms of any lease or contract.

Though it is unlikely that Pierpont (2009, p. 122) considered her recommendations in light of the Nuremberg Code, her ethical conclusion is perfectly consistent with its principles.

> With regard to families already affected, developers and permitting agencies share the responsibility for turbines built to close to homes, and together need to provide the financial means for these families to re-establish their lives at their previous levels of health, comfort, and prosperity.

Human beings retain the right to safely opt out of any experiment they can no longer tolerate, and to do so without incurring undue harm. The obligation to ensure a safe departure falls on those who design and conduct such experiments at human expense. If the benefits to society of this sweeping human experiment in wind energy are as great as proponents claim, such relief would be a very small price to pay to achieve them without infringing on human rights. In any case, Pierpont's work furnishes sufficient and undeniable evidence of danger well beyond the 'remote possibility' of harm required by the Nuremberg Code.

As we shall see in a moment, however, re-establishing the families immediately affected is not a long term solution to this problem any more than low-nicotine or filtered cigarettes are a solution to the long-term effects of smoking. For wind energy, the only known solution is to keep IWTs away from people altogether.

7. What Is the Harm?

Though estimates vary, the epidemiologist Carl Phillips has pointed out that only a relatively small percentage of those who live close to IWTs suffer from immediate and palpable detrimental effects; but some of those who do, may experience debilitating health consequences (Phillips, 2011) [31]. The wind industry and its proponents have seized upon the minority status of those who are first affected to diminish, dismiss, and ultimately deny the findings of science and the

public complaints of its victims, as though these are utterly irrelevant or insignificant. Since most people are not impacted immediately, it is relatively easy for the wind industry to convince a voting public that health concerns about wind projects are overblown or completely groundless. Those IWT neighbors who are not initially affected, and other residents who live outside the impact radius, often readily trust such industry "experts". The overwhelming majority of community members do not experience harm—at least initially—and so, based on the assurances given by developers, they mistakenly believe that they never will.

Even if a conservative estimate of only 5% of residents suffer immediately from IWT exposure, however; and even if sleeplessness—the most commonly reported symptom—were the only one; the public health consequences could still be considered extremely serious; especially in light of the widespread and growing encroachment of wind projects at the edge of the grid in the industrialized world, and more recently in the developing world. Here, again, a working definition of experimentation as a sustained or widespread investigation focuses attention on the size of the affected population and the prolonged duration of otherwise transient effects. It is crucial to realize that, over time, the mildest of adverse health effects can lead to the most serious of consequences when exposure is chronic.

Sleep has been widely recognized as a necessity to good health and life itself. Conversely, chronic sleep deprivation has been recognized for its devastatingly adverse health effects.

> The public health consequences of sleep loss and sleep-related disorders are far from benign. The most visible consequences are errors in judgment contributing to disastrous events such as the space shuttle Challenger (Walsh *et al.*, 2005). **Less visible consequences of sleep conditions are far more prevalent, and they take a toll on nearly every key indicator of public health: mortality, morbidity, performance, accidents and injuries, functioning and quality of life, family well-being, and health care utilization.** Some of these consequences, such as automobile crashes, occur acutely within hours (or minutes) of the sleep disorder, and thus are relatively easy to link to sleep problems. Others—for example, obesity and hypertension—develop more insidiously over months and years of chronic sleep problems. After decades of research, the case can be confidently made that **sleep loss and sleep disorders have profound and widespread effects on human health** [emphasis added] (Colten & Altevogt, 2006) [32].

If IWT-inflicted sleeplessness were an infectious disease, it might well meet some definitions of a pandemic. Though it is suspected that the unreported incidence is much higher because uninformed victims do not associate symptoms with ILFN exposure; even 5% of the people who live within a few miles of IWTs is not a trivial number. Since this particular form of sleep deprivation is man-made, however, we must also weigh the cost of this experiment in terms of human pain and suffering.

Consciously inflicting prolonged sleep deprivation is an internationally recognized form of torture. In a powerful indictment of the CIA "enhanced interrogation" program, Physicians for Human Rights (PHR) and Human Rights First (HRF) have published a description of how various interrogation techniques are enhanced by combining them with one another:

> These techniques, moreover, are generally used in combination— prolonged isolation, for example, combined **with sleep deprivation, light and sound bombardment, and exposure to cold—compounding their devastating psychological impact** [emphasis added] (Allen, 2007) [33].

It is striking how closely this description of torture also describes some of the direct human impacts of IWTs on some of those who live near them—especially when the flicker effect is considered in conjunction with the impacts of both audible and inaudible sound energy, and LFV. When IWT victims describe the intermittent assault as torture, it is not exaggeration; but testimony (B. Funfar, open letter, September, 2010) [34]. In a legal analysis in "Leave No Marks," also published by PHR, it is asserted that "The psychological impact of sleep deprivation supports the conclusion that it would constitute torture cruel or inhuman treatment for the purposes of criminal prosecution" (Allen, 2007).

By discounting or dismissing such personal reports, the wind industry, like the asbestos and tobacco industries, would have us ignore palpable human suffering as merely anecdotal, and somehow irrelevant. But if we choose to deny or ignore the human anguish caused by such technological experimentation, we undermine the very foundation of the Nuremberg Code and any doctrine which seeks to establish or protect fundamental human rights based on respect for persons, beneficence, and social justice.

As debilitating as sleep deprivation is to both physical and psychological health and wellbeing, it is hardly the only deleterious outcome created by nearby IWT. In addition to the early onset effects documented by Pierpont, there is substantial evidence that long-term exposure to ILFN and LFV can lead to gradual but potentially life-threatening and irreversible damage to health for a much larger percentage of those exposed over prolonged periods of time. As we shall see, at sufficient dosage, some adverse effects are virtually pervasive.

In the Alves-Pereira and Castelo Branco studies of pathologies induced by ILFN and LFV mentioned at the outset of this discussion, the health of the aircraft technician cohort was carefully tracked over the course of fifteen years. In 1992, they also began studies based on animal models (Wistar rats) as well (Antunes *et al.*, 2013) [35]. Among their reported findings, all of the 140 technicians exhibited pericardial thickening—a serious and potentially life-threatening cardiovascular condition. Similar results were obtained in the animal studies.

In addition, many other serious pathologies were correlated to long-term exposure to ILFN and LFV. The incidence of late-onset epilepsy was twenty times that of the general population. Twenty-eight of technicians had malignant tumors including squamous cell carcinomas in their respiratory system, adenocar-

cinomas in their digestive system, and in some cases, both. Thyroid dysfunction was observed at 7.5 times the incidence in the national adult Portuguese population. Virtually all subjects exhibited some degree of cognitive impairment, and some were so debilitated by it that they had to leave work on permanent disability. At least 50% of the cohort experienced one or more of the following after ten years of exposure,: psychiatric disturbances, nose bleeds, varicose veins and hemorrhoids, reduced visual acuity, ulcers, colitis, headaches, severe joint pain, intense muscle pain, and neurological disturbances (Castelo Branco & Alves-Pereira, 2004).

Too little is known about dose response to predict accurately whether IWT neighbors will develop similar pathologies in similar time frames. The aircraft technicians were exposed in an occupational pattern, while IWT exposure is intermittent around-the-clock based on the vicissitudes of the natural wind. Unlike the aircraft technicians, exposure to IWTs may be sustained for longer periods of time without relief and recovery time. There is currently no means to accurately track the cumulative dose exposure to low-frequency sound in the way that a radiation dosimeter works, for instance. The critical point about cumulative dose exposure for this discussion, is that it represents only one of the many crucial health parameters ignored by wind industry because it has never applied the proper clinical and scientific expertise necessary to understand the true impact of its experimentation on human subjects—and few pay heed to the incalculable toll in human suffering it imposes.

Nonetheless, the best scientific evidence provides more than sufficient reason to conclude "that a continuation of the experiment is likely to result in injury, disability, or death to the experimental subject." Both science and common sense dictate precaution. Just as the dangers of long-term exposure to cigarette smoke were not immediately evident to smokers; so too the insidious hazards of prolonged exposure to ILFN and LFV are not obvious. And, just as the health hazards of prolonged smoking are cumulative, so are the effects of prolonged exposure to IWT noise. Insisting on absolute certainty that harm is occurring, or that it will ensue, is simply a ploy used by both industries for decades to distract attention from the looming health crisis, and continuing violation of the rights of their unsuspecting subjects.

Ironically, the siren call for more science, more evidence, and more data collection while testing new products and technologies, amounts to nothing more than an unethical call for accelerated misery, suffering, damage to health, and trampling of human rights.

Tenet 3 of the Nuremberg Code states that ethical research on human subjects must be grounded in, and justified by, prior knowledge obtained from non-human research and/or previous study.

> The experiment should be so designed and based on the results of animal experimentation and a knowledge of the natural history of the disease or other problem under study, that the anticipated results will justify the performance of the experiment ("Tribunals, 1949").

If industry were held to the same standards of responsibility for their experimental activities as those conducting formal scientific and medical research, many such experiments would be curtailed. If, for example, communities were fully informed of the overwhelming evidence that sustained exposure to IWT noise is extremely dangerous, very few people would voluntarily opt to subject themselves to it. Very few projects would be sited as close to residents as those which have proliferated over the last thirty years. If forced to provide those residents who could not tolerate IWT exposure with the financial means to opt out and fully restore their lives and health elsewhere, wind developers would soon lose their appetite for building IWTs near people. If the subjects to such experimental activities were fully informed about the known risks of IWT exposure, perhaps they too would be less tempted by the financial inducements to expose themselves to potentially life-altering health effects.

Given the insidious nature of prolonged exposure to IWTs, it may well be asked whether there is any way to develop wind energy and still hold paramount the human right to protection from such hazardous experimental technology. Although ILFN is a form of sound energy, it propagates in a manner that is dramatically different from ordinary sound in other frequency ranges of the spectrum. ILFN attenuates (fades, for those unfamiliar with acoustics) much more slowly than higher frequency and it is capable of bending around and penetrating solid objects such as buildings. Simply stated, it is much more difficult to mitigate the effects of ILFN than those of conventional sound. This is a fact well known to acoustic scientists and, of course, the ILFN produced by large IWTs is no different in this regard (Møller & Bajers, 2011) [36].

It is also well-established that, although humans cannot ordinarily hear ILFN (unless is very intense); most large mammals including humans are, nevertheless, highly sensitive to it. The vestibular (inner ear) hair cells are directly affected (Salt & Hullar, 2010) [37]. The surface of our body is highly sensitive to the vibrations induced when ILFN strikes it (Takahashi, Kanada, Yonekawa, & Harada, 2005) [38]. ILFN can be amplified by the low-frequency resonance in homes (Kelley, 1987) [39], and in the human body itself (Pierpont, 2009, p. 87). In short, living a very great distance away may be the only effective means to mitigate the human impacts of IWTs. Cross-sectional health studies which have taken this into account, tend to corroborate the conclusion that sufficient distance is the only known prophylactic against the worst effects of ILFN and LFV (Nissenbaum, Aramini, & Hanning, C. 2012) [40].

Technically, it is perfectly feasible to build wind farms far from human habitation. The wind industry itself has proven this by building wind farms offshore. As noted earlier, however, offshore farms are far more costly to build, operate, and maintain. This leaves us with a stark choice between recognizing and securing basic human rights to health and to protection from unauthorized experimentation, on one hand; or enjoying the economic advantages to be gained by ignoring these responsibilities, on the other.

8. Conclusions

The world we live in today is quite different from the one in which the Nuremberg Code was first conceived. The experiments this doctrine was first designed to identify and proscribe were horrifying, unimaginably cruel, and inhumane. Perhaps it is difficult for some to understand, therefore, how ethical standards so conceived could possibly be relevant to the experiments described here. Or, perhaps, this type of experimentation has simply become so pervasive in society since then that we have become inured to such gross transgressions of basic human rights.

Certainly, many of the medical and therapeutic benefits enjoyed today could not have been achieved without conducting research on human subjects. For example, it is unlikely that the breakthrough in curtailing tissue rejection derived from the experimental kidney transplants performed by Nobel Prize winner, Dr. Joseph Murray, could have been achieved in absence of trials with human subjects. Transplants involve grave risks to donors as well as recipients. Yet earlier attempts to transplant kidneys from cadavers resulted in grievous suffering and death for recipients in every case. Since then, however, organ transplants have saved countless lives and restored health in cases which would be hopeless otherwise. It bears reminding, however, that many of the advances in medicine, health, clean water, and food production were obtained within the ethical guidelines rooted in the Nuremberg Code. Perhaps, such successes have made us too complacent about safeguarding the right to informed consent and the right to decide for ourselves whether to participate in an experiment or not.

Nevertheless, since the advent of the Nuremberg Code, history has been rife with egregious examples of illicit human experimentation. The infamous Tuskegee Syphilis experiment by the US Public Health Service was begun long before the Nuremberg Code, but amazingly continued until 1972—twenty-five years after this code was written. Still more remarkably, it was discovered in that same year, 1947, that penicillin could cure syphilis, but the subjects were never treated or even informed that they had this communicable disease. The Tuskegee subjects were not told they were the subjects of an experiment, just as the Facebook users were not told that they were the subjects of an experiment in emotional contagions. The Tuskegee victims were denied access to the known prophylactic drugs for decades, just as IWT neighbors have been denied the only known preventive—distance.

Examples of unwarranted human research abound. Drinking water has been fluoridated since 1940, when it could have been delivered easily in other vehicles such as toothpaste, thus providing an opportunity for some to simply opt out. Multi-dose vaccines are tested to ensure they are safe and effective, but were laced with the controversial component, ethylmercury (thimerosal), a known neurotoxin, in concentrations so high that the EPA requires unused doses to be treated as hazardous waste. Yet the US CDC now condones the removal of this

information from vaccine labels (when not considered a preservative), making it difficult, if not impossible, for prospective recipients to opt out without refusing the vaccine altogether. Again, GMO products have been introduced into the general food supply without labelling, making informed decision about whether to eat them or not, virtually impossible. Many other breaches of informed consent and the right to opt out can be found in prisons, school systems, the military, and other sectors of private industry.

We have reached an ethical crossroads in which we must decide whether we can afford to continue ignoring the right to informed consent to all human subjects, regardless of whether experimentation is formal or not. Perhaps the first step toward full acknowledgement of this right is to embrace and hold open the Nuremberg Code itself as a living document, subject to further scrutiny, refinement, and enhancement. Next, its principles must be enacted into laws that fully recognize the rights of all to be free from involuntary subjection to experimentation and the right to fully and genuinely informed about potential harm to health and wellbeing. These ethical principles must become legal protections—but even this, taken alone, is not sufficient.

In absence of the "highest degree of skill and care" which can only be furnished by scientific, clinical, and engineering experts; legal protections will be both blind and impotent. It is incumbent upon these professions, many of whom have already embraced some of these ideas in their own ethical canons, to champion them throughout the broader community, and to supply the supporting expertise necessary to ensure proper oversight and guidance for all human research, whether formal or otherwise.

PHR, cited several times here, deserves credit for leading the way in this regard. Just as the IRB provides oversight over formal experimentation, a general or community review board would bring desperately needed expertise and oversight to the broader community, and inject expert influence over public policy wherever human experimentation is concerned. Society must learn to hold paramount the safety and wellbeing of all human subjects in all cases, just as the medical community has begun to do. Without this, we will remain forever at the mercy of experimentation without conscience or means of escape.

If the past is prelude to the future, it is unlikely that private industry will ever voluntarily respect these rights; so long as they portend increased regulation, cost, or time-to-market. It will be argued that oversight will stifle innovation and result in damaging economic consequences. Such dire predictions, however, fly in the face of the unparalleled advancements in modern science and medicine which have been accomplished in accordance with full respect and due consideration for these human rights.

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Dedication

This work is dedicated to all those persons who have suffered physical or psychological harm, or death while being subjected to experimentation against their will; and to all those who have courageously exposed themselves to personal peril attempting to help them escape from such harm.

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