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Hacking humans, upgrading Homo sapiens: the role of the Huntington's disease community and the consequences for life

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At Risk for Huntington's Disease

HD is a genetically caused brain disorder that causes uncontrollable bodily movements and robs people's ability to walk, talk, eat, and think. The final result is a slow, ugly death. Children of parents with HD have a 50-50 chance of inheriting the disease. There is no cure or treatment.

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Hacking humans, upgrading Homo sapiens: the role of the Huntington's disease community and the consequences for life

An influential book by best-selling historian Yuval Noah Harari, *Homo Deus: A Brief History of Tomorrow*, looks broadly at potential medical advances, thus providing hope for the Huntington's disease community's quest for a cure, but it also warns of the vast consequences for human life caused by the advance of biotechnology and the accumulation and control of data.

A professor in the History Department at the Hebrew University of Jerusalem and holder of a Ph.D. from the University of Oxford, England, Dr. Harari published the international blockbuster *Sapiens: A Brief History of Humankind*. *Sapiens* was first published in Hebrew in 2011 and was translated into nearly 50 languages, selling over 10 million copies by 2018.

In *Sapiens*, Dr. Harari uses macro-history (also known as "big history") and biological evolution to explain the development of human society over the past several hundred thousand years. He focuses in particular on the "cognitive revolution" that began 70,000 years ago. During this period, the modern human species, *Homo sapiens*, came to dominate Earth.

"Homo sapiens" is Latin for "wise man." "Deus" means "god." In *Homo Deus*, first published in English in 2016, Dr. Harari projects current trends deep into the 21st century and speculates that humanity could double average life expectancy to 150 years. He also considers the profound changes longer lives would bring such as people in positions of authority stretching out their careers and thus cutting off opportunities for younger individuals.

Ultimately, in this century humanity may seek immortality by developing new biomedical tools and implants, fusing our bodies with high-tech machines, and perhaps also creating non-organic beings.

"You may debate whether it is good or bad," Dr. Harari writes, "but it seems that [...] the twenty-first century will [...] involve re-engineering *Homo sapiens* so that it can enjoy everlasting pleasure. In seeking bliss and immortality humans are in fact trying to upgrade themselves into gods. Not because these are divine qualities, but because in order to overcome old age and misery humans will first have to acquire godlike control of their own biological substratum [bedrock]."

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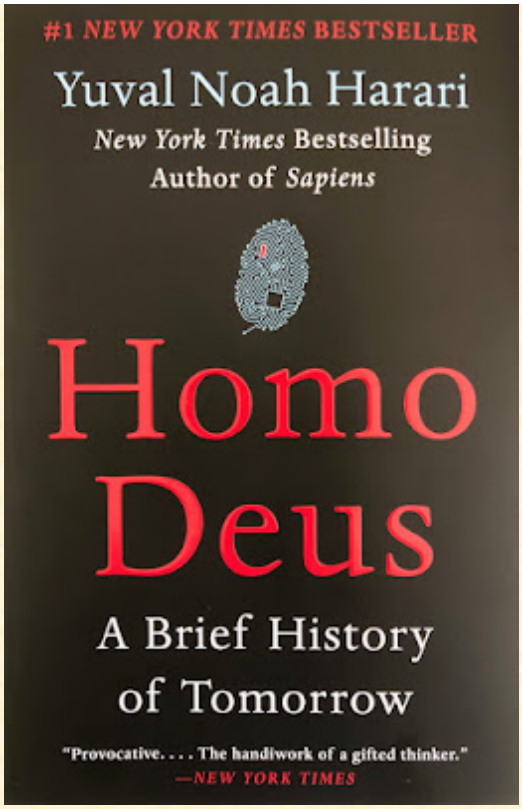


A new scientific dogma: we are algorithms

The idea of ending disease and extending life, even if by only a few years, stirred the depths of my being. The fear of death propels our psyches and civilization. In the Huntington's community, where the disease's devastating and fatal symptoms cut off down lives early, the fear of death is ever-present and more acute. I recalled my mother's death from HD in 2006 at 68 and my condition as an HD gene carrier. At 59, each day without symptoms is a blessing.

Homo Deus also reminded me of my 2010 article "God, Huntington's disease and the meaning of life," in which I examined the Catholic Church's little-known and little-understand acceptance of evolutionary theory and the notion that the Resurrection of Christ could be seen as a genetic mutation.

However, in *Homo Deus* Dr. Harari also warns that current trends in biotechnology and the gathering and control of data could also lead to the creation of a super-human elite taking control of the rest of humanity, threatening privacy, democracy, and human and civil rights.

"If indeed we succeed in hacking and engineering life, this will be not just the greatest revolution in the history of humanity," Dr. Harari told the audience at the 2018 World Economic Forum Annual Meeting in Davos, Switzerland. "This will be the greatest revolution in biology since the very beginning of life 4 billion years ago.[...]

"Science is replacing evolution by natural selection with evolution by intelligent design. Not the intelligent design of some god above the clouds, but *our* intelligent design, and the intelligent design of our clouds, the IBM cloud, the Microsoft cloud. These are the new driving forces of evolution."

Yuval Noah Harari in 2017 (photo from Wikimedia Commons)

In *Homo Deus*, Dr. Harari explains that "science is converging on an all-encompassing dogma, which says that organisms are algorithms" – a method or list of instructions for making calculations – "and life is data processing."

"Humans are algorithms that produce [...] copies of themselves," he adds. The influence of computer algorithms designed by organizations such as Google has grown vastly, taking in fantastic sums of personal data for users of the Internet and personal devices. "Non-conscious but highly intelligent algorithms may soon know us better than we know ourselves."

In their digital lives, over 2 billion Facebook members have encountered that organization's problematic algorithm, which a company study found to be a better reader of people's personalities than even their friends, parents, and spouses, Dr. Harari points out.

Crucial data from HD families

Homo Deus doesn't mention HD. However, it recognizes the importance of Alzheimer's disease and the need to prevent it and disease in general. Dr. Harari explains that upgrading humanity would include attempts to expand the abilities of the brain – which, of course, is an organ severely debilitated by HD.

The history of the search for HD treatments is key to the biotechnological revolution. HD-affected individuals and their families have both witnessed and participated in that revolution, starting with the hunt for the huntingtin gene in the 1970s, 1980s, and 1990s, and since then with a growing number of research studies and clinical trials involving thousands of individuals.

At the start of this decade, CHDI Foundation, Inc., the nonprofit virtual biotech focused on defeating HD, pioneered the use of systems biology, which includes the deciphering of vast amounts of biological data, in disease treatment (click here to read more).

CHDI has also collaborated with IBM to seek deeper understanding of the huntingtin protein's role in the disease. In this effort, IBM has provided its immense computational power and the tools of big data analytics.

Enroll-HD, the CHDI-sponsored worldwide database of HD-affected individuals and family members, has more than 17,000 participants.

Thousands of HD-affected individuals and gene carriers have also participated in the research involving the search for so-called modifier genes that affect the age of onset. The scientists have analyzed millions of small variations in these people's genes.

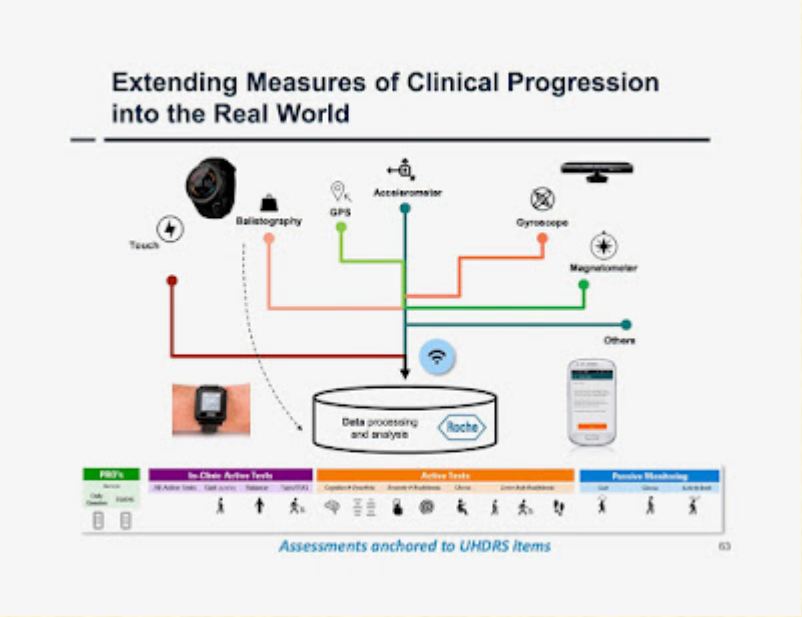
Digital monitoring and algorithms

An increasing number of researchers and companies are in effect trying to hack HD's genetic causes. The most prominent is the gene-silencing drug developed by Ionis Pharmaceuticals, Inc., in collaboration with CHDI and other researchers. On December 19, pharma giant Roche, now the drug's license-holder, announced the first 26 planned sites for the crucial global Phase 3 trial to test the drug's efficacy.

In that trial, participants will receive the drug via lumbar puncture (spinal tap), the first time this delivery method is being used extensively in an attempt to treat a neurological disorder.

For the study, Roche has designed an HD Digital Monitoring Platform, which will continually measure participants' biometric data using smartphones and watches.

"The software is what's special, and the analytics engine behind it," Erik Lundgren, the Roche lifecycle leader of the HD team, said in an interview last March. "A tremendous amount of data comes in. The algorithms and how you make sense of that is what our team has been working hard on developing."



A graphic illustrating the Roche HD Digital Monitoring Platform (source: Roche)

Privacy versus healthcare systems

As Dr. Harari warns, the purpose and uses of technologies and information-gathering techniques originally developed for something positive such as curing a disease could result in unintended, perhaps negative, consequences.

Companies such as Google "want to go much deeper than wearables," he explains.

"If we give Google and its competitors free access to our biometric devices, to our DNA scans and to our medical records, we will get an all-knowing

medical health service that will not only fight epidemics, but will also shield us from cancer, heart attacks and Alzheimer's," he writes.

However, he observes, "imagine a system that, in the words of the famous Police song, watches every breath you take, every more you make and every bond you break; a system that monitors your bank account and your heartbeat, your sugar levels and your sexual escapades. It will definitely know you much better than you know yourself."

Google and these other algorithm-based systems could make decisions for us, from selecting which movie to watch to choosing a spouse to settling on a candidate in the voting booth.

In a world in where the stress on data takes on a religious fervor, the demand for the free and massive flow of information could trump freedom of expression and, by extension, people's right to control their own information, Dr. Harari asserts. He cites pressure from "Dataist missionaries" for free access to all information, including copyrighted materials.

The danger is that "we will just have to give up the idea that humans are individuals, and that each human has a free will determining what's good, what's beautiful and what is the meaning of life."

"The big battle over what we today call 'privacy' will be between privacy and health," Dr. Harari asserted at the World Economic Forum. "Do you give access to what is happening inside your body and brain in exchange for far better health care? And my guess is that health will win, hands down.[...] Maybe in many places [people] won't have a choice. They won't get insurance if they are unwilling to give access to what is happening inside their body."

What kind of world are we creating?

Because of the many critical issues it touches on regarding humanity's future, *Homo Deus* is a must-read book.

For the HD community, it provides valuable context for the difficult medical, social, and ethical challenges involved in the disease and the quest for treatments.

As many in science strive, in Dr. Harari's words, to "defeat death and grant humans eternal youth," the complexities of HD and the close collaboration between HD scientists and families may serve as a reminder that the biotechnological and medical sectors should consult disease communities and the rest of society.

Yes, despite having back problems, to avoid HD onset I would take a drug via recurring spinal taps. I would also wear a data monitor, as do people with type 1 diabetes, for example.

However, I'm also concerned about the dystopian scenarios outlined by Dr. Harari for this century.

What kind of world are we creating for our children and grandchildren?

Posted by Gene Veritas at 1:56 PM

Labels: big history , biology , biotechnology , evolution , gene , God , hacking , Homo Deus , Homo sapiens , human data , Huntington's disease , immortality , life expectancy , revolution , systems biology , treatments , Yuval Noah Harari

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