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viewpoint

Genomics for citizens

Providing the public with more and better knowledge to address the challenges of the twenty-first century

Jacques Dubochet

Enlightenment, the German philosopher Immanuel Kant (1724–1804) surmised, is Man's emergence from self-imposed immaturity. From the ancient Greeks and the philosophers of the Roman republic, to the thinkers of the European Enlightenment and the great scientists of the nineteenth and twentieth centuries, philosophers and scientists have used science and reason to fight the superstitious belief that our lives are ruled by supernatural entities. Reason and science have enlightened and empowered us to become the masters of our own fate.

Yet, it took a long time to get to where we are today. It has only been in the advanced democratic societies of the late twentieth century that the ideas of the Enlightenment have become fully integrated with our lives: we enjoy the fruits of research and expect to determine our own fate by regularly electing those we trust to represent us. It is ironic, then, that with the rejection of supernatural forces, we have witnessed a schism between biologists and social scientists over what determines the fate and the nature of humankind.

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Social scientists consider education and culture to be the major factors that shape our beliefs, our actions and our lives. By contrast, ever since the biologists Charles Darwin (1809–1882) and Gregor Mendel (1822–1884) established the role of genes in determining what we are, genetics has stood as the central tenet of the life sciences. By the end of the twentieth century, this gap between biology and social sciences—between 'nature' and 'nurture'—had grown immensely (Ridley, 2003): on one side, social scientists see humans as "blank slates" (Pinker, 2002) onto which education and culture inscribe the fate of the individual (Guillebaud, 1999); on the other side, biologists have focused on heredity and the transfer of genetic information as being responsible for determining the future of an individual. Moreover, biologists have embraced Darwin's insight that *Homo sapiens* is deeply related to all other species and have discovered that human behaviour has important genetic components (Bouchard & McGue, 2003) that are not always very different from those found in animals (Wilson, 1975).

Recent years have seen major changes take place in this debate. The completed sequence of the human genome has given us an unprecedented, complete overview of our genetic make-up, and scientists in academia and industry are busy accumulating genome data from many different organisms. Sequencing methods have become so powerful and inexpensive that personal genomics becomes a promising and worrying reality (see, for instance, the services offered by companies such as 23andMe, deCODE genetics and Navigenics). However, reading the genome does not mean understanding it; most of us are well aware that it will take time and considerable effort before we are able to understand how genetic information translates into the physical or mental properties—the phenotype—that can be observed in real life. In fact, short of a limited number of diseases that are genetically well characterized, genetics does not and will never provide clear-cut answers. In general, genetics provides probabilities, predispositions or susceptibilities that may or may not become facts later in life, depending on lifestyle, culture and education. Nonetheless, the increasing amount of genomic data available means that the nature versus nurture debate can finally be addressed on factual grounds.

Just as nature and nurture come together, so too do science and society. The time when scientific research—including biology—took place at a safe distance from any possible application or societal benefits is long gone. Society—that is, the taxpayer—funds scientists because they expect research to yield benefits in the long term, such as new products or services and business or job opportunities. In turn, scientists have become used to the fields and check boxes in grant application forms that require them to demonstrate the potential societal benefit of their projects.

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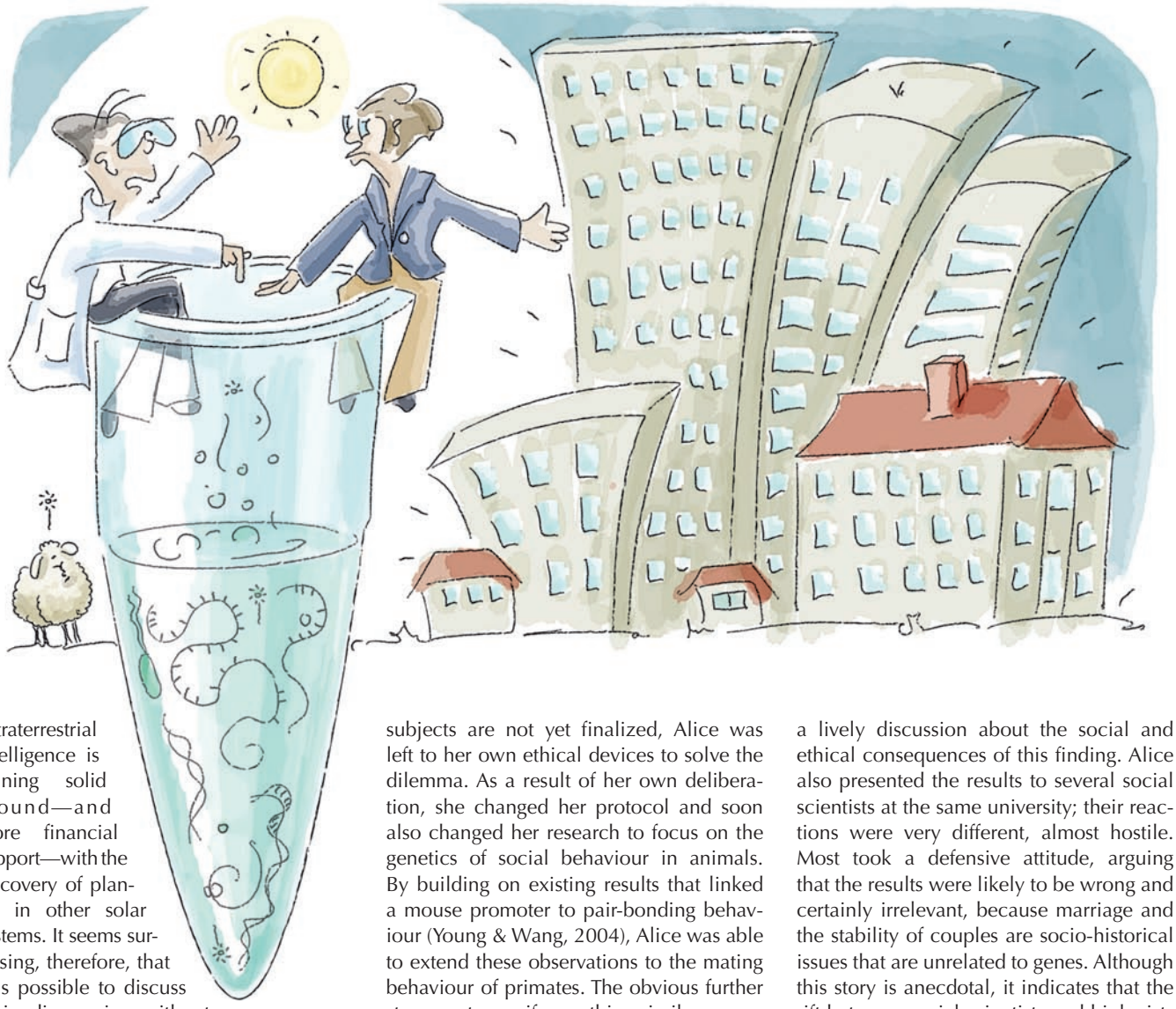
At the same time, however, too many natural scientists remain happy to retreat into their laboratory once they have secured the funding, completely ignoring the wider repercussions of their work. By way of example, the chemical synthesis of a virus from scratch is an impressive achievement that should certainly raise important medical, ethical and security questions. Why then, did the journal that published the research feel it inappropriate for the authors to discuss these questions? Similarly, once considered the realm of exalt scientists, the search for



extraterrestrial intelligence is gaining solid ground—and more financial support—with the discovery of planets in other solar systems. It seems surprising, therefore, that it is possible to discuss their discoveries without systematically considering the consequences of the discovery of alien life.

A third example concerns a scientist whom we will call 'Alice': an anonymous researcher caught in a maze of ethical difficulties at the beginning of her scientific carrier. Alice's project began as a study of differential gene expression in the human brain; work that required *post mortem* brain extracts that she purchased from a commercial firm. Over time, Alice became uneasy about the origins of the extracts; the supplier told her that they were taken from dead people that had been found by the police, meaning that the donors were obviously unable to give 'informed consent'. This information troubled Alice: was it ethical to use non-consensual samples? As the Swiss laws governing scientific research on human subjects are not yet finalized, Alice was left to her own ethical devices to solve the dilemma. As a result of her own deliberation, she changed her protocol and soon also changed her research to focus on the genetics of social behaviour in animals. By building on existing results that linked a mouse promoter to pair-bonding behaviour (Young & Wang, 2004), Alice was able to extend these observations to the mating behaviour of primates. The obvious further step was to see if something similar occurs in humans. Alice was well aware that her work would eventually raise thorny social questions, but in the end, another group of scientists was quicker. They showed that Swedish males with a certain variant of the gene promoter were twice as likely to be unmarried or to report a recent marital crisis (Walum *et al*, 2008).

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Alice once again changed the direction of her research but presented the Swedish case to biology students at the Université de Lausanne, Switzerland, which triggered a lively discussion about the social and ethical consequences of this finding. Alice also presented the results to several social scientists at the same university; their reactions were very different, almost hostile. Most took a defensive attitude, arguing that the results were likely to be wrong and certainly irrelevant, because marriage and the stability of couples are socio-historical issues that are unrelated to genes. Although this story is anecdotal, it indicates that the rift between social scientists and biologists seems to remain very wide indeed, at least at Lausanne (Dubochet, 2008).

Whether substantiated or not, the results showing the partnering behaviour of Swedish males with a certain genetic make-up are certainly relevant if we look at the broader picture. The full sequence of the human genome and the rapidly increasing ability to cheaply sequence individual genomes will eventually provide sufficient data to establish a correlation between certain genetic variables and personality traits. Whether the relationships are real or not, people will still be confronted with probabilistic data about themselves, which could lead to serious misunderstandings, as most people prefer black and white answers

Fig 1| L'Eprouvette at a scientific festival in Paris, 2007, with a forensic DNA test. Photo credit: Severine Trouilloud, Interface Sciences Societe, UNIL.

from science rather than shades of probable grey. There is also a risk that genetics and the interpretation of it will become dangerously entangled: the data will undoubtedly be analysed and presented by someone in terms of ethnic or social groups, which could foster or affirm unpleasant and unfounded prejudices against other nations or races.

What can scientists do to ensure that this knowledge is used for the common good, rather than misunderstood or misused?

How will individuals and society react to this forthcoming avalanche of genomic data and the resulting correlation of genes with disease and behavioural traits? What can scientists do to ensure that this knowledge is used for the common good, rather than misunderstood or misused? These are formidable questions, the answers to which will require effort and contributions from all sides: biologists, social scientists and philosophers, but also from society at large. It is therefore no longer possible for anyone—biologist or social scientist—to remain entrenched in their particular area of interest; we must all work together to find answers.

In response to this challenge, at the Université de Lausanne we have established a mandatory Biology and Society curriculum for biology students, which begins at the very start of a bachelor of science degree and continues throughout (www.unil.ch/biologiesociete/page48286.html; Dubochet, 2008). The curriculum involves not only members of the biology department, but also social scientists, philosophers and ethicists, as well as experts in a range of specific research fields and ethical or legal areas. The workload is not heavy—it corresponds to about one hour each week—but our experience shows that it fosters considerable voluntary extracurricular work and discussion. The first year explores the history and philosophy of science and the second year consists mainly of group work to consider themes in biology and medicine that raise ethical or social questions, such as "personal genomics" and "human genetics, race and IQ".

The third year of the course is the most ambitious as it exposes biology students to the methods and ways of thinking used in the social sciences and humanities. The course professor is drawn from one of these departments and has the challenging goal of demonstrating to aspiring biologists that the social sciences and humanities have a different, but nonetheless relevant view of biology, and that the questions thus raised are both meaningful and important. In some way, the students are asked to put aside their own prejudices and pick up another set of prejudices to look back at their own field. In reciprocation, a similar course is offered for social scientists and aims to show young students in the social sciences that biology is relevant to their studies and to themselves. As a consequence, students graduating in the social sciences from Lausanne today have a much firmer grip of biology and do not see a general problem with biologically grounded ideas, such as that altruism in humans has evolutionary and genetic roots that are similar to the same trait in animals, or that aggressive racist behaviour might have, in part, evolutionary origins.

It is because students are the next generation of scientists and researchers that we make such efforts to teach them to look actively beyond their own area of expertise. However, students do not make decisions about which projects should be funded, which problems research should address, or how to deal with the knowledge that research produces. In a democracy it is the politicians and, through them, the population at large who make such decisions.

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This is why the Université de Lausanne has developed the Science–Society Interface (www.unil.ch/interface), which is a platform aimed at improving the public understanding of science, as well as helping scientists to gain a better understanding of public attitudes towards scientific research. One element of the interface is a public laboratory called l'Éprouvette—literally 'the test tube'—where adults and children can gain first-hand experience of how biologists work (Fig 1). It also contains all the standard biology tools and machinery—such as microscopes, culture facilities, centrifuges, spectrometers, electrophoresis and PCR apparatus—in sufficient numbers for a school class to perform experiments, with additional space for conferences and discussions.

About 3,500 people visited l'Éprouvette last year: 60% were school students who generally came with their biology

teachers, with the remaining visitors comprising families and social or professional associations. So far, politicians and other public officials have not been keen to visit, which is regrettable as it would be beneficial for all if politicians and decision-makers had a solid understanding of science. Indeed, we are making efforts to attract them. We are also able to take the laboratory beyond the confines of the university, taking a specially equipped bus to schools in remote regions and to fairs and markets to give more people an opportunity to consider the societal implications of science. The success enjoyed by each trip the bus has made demonstrates its usefulness in taking science to the people.

Providing the public with more and better knowledge about science [has] become an unprecedented challenge for education

In general, a session at l'Éprouvette takes one day or less. In addition to the well-known experiment of extracting DNA by using everyday kitchen equipment, or some light-hearted examples of molecular gastronomy, l'Éprouvette facilitates more ambitious experiments. For example, visitors perform a pseudo-genetic test to identify a carrier of Duchenne muscular dystrophy, or use DNA to identify a 'criminal' from samples secured on the spot. The "genomic identity" experiment involves a DNA fingerprint based on repetitive Alu sequences; cells are harvested from the participant's saliva, DNA is extracted and purified before PCR and gel electrophoresis. In practice, the whole experiment lasts between 5 and 6 hours and leaves ample time for discussion.

Indeed, discussing the social and ethical issues surrounding genomics is the *raison d'être* of l'Éprouvette. After the experiments have provided the biological experience, the participants debate the broader implications. Visitors might, for example, realise how much a single genetic marker can reveal about an individual's health risks, or they might discuss the implications of a father and his son discovering that they are not actually related as a result of DNA fingerprinting at l'Éprouvette. The staff ensure that such a situation would not arise, but the very possibility serves to highlight the implications of genomics for privacy and family life. It also acts as a starting point for telling visitors about the possibilities and limits of DNA fingerprinting. The discussions typically encompass themes as broad and complicated as genetic determinism, nature versus nurture, or choice and free will. It is always an impressive and rewarding experience to observe how laypeople, who might never have experienced or had any real interest in science, discover not only how biologists work, but also how their work raises questions about the very nature of being human.

Running l'Éprouvette is time-consuming and labour-intensive. Many of our advanced biology students help either for a small remuneration or mostly as volunteers. Students who take time to teach at l'Éprouvette can earn additional credits for the advanced Science and Society curriculum; more importantly, however, l'Éprouvette gives young researchers and students the occasion to practice communication with the public and to contribute to a better understanding and appreciation of science.

I began by declaring that science and reason are the tools that have been used to enlighten; that have liberated humankind from ignorance and superstitious beliefs and have encouraged us to become masters of our own lives. Reason and knowledge have become the cornerstones on which modern democracies are built; yet, modern scientific advances proceed at an impressively fast rate, providing new products, services and benefits, but also creating challenges and risks that arise before we have even thought to consider them. The result is that politicians and the electorate alike are often faced with the problem of making decisions about scientific research and insight without the necessary understanding of the research itself or what it means. Providing the public with more and better knowledge about science—how it works at a practical level, as well as its social implications—has therefore become an unprecedented challenge for education. The Science and Society programme in Lausanne is one contribution towards this goal.

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CONFLICT OF INTEREST

The author declares that he has no conflict of interest.

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