Information can kill

Steffen Huck*

University College London & ELSE

Kai A. Konrad

Social Science Research Center Berlin (WZB) and Free University of Berlin

April 28, 2004

Abstract

Background. Recent advances in understanding links between genes and the susceptibility to particular diseases have considerably increased the scope for predictive diagnosis. *Methods.* We analyse how the introduction of predictive diagnosis affects patients' decisions to undergo medical screenings relying on a "rational choice" model. *Findings.* We show that predictive diagnosis can *increase* the number of fatalities from a deadly disease. *Interpretation.* Our result shows the necessity of careful further analysis and debate about the pros and cons of predictive diagnosis and the publication of medical research in general.

(1787 words.)

1 Introduction

Recent advances in understanding links between genes and the susceptibility to particular diseases have made it possible to warn certain parts of the population about their increased risk of contracting diseases. Prominent examples for predictive genetic diagnosis are Huntington's disease, morbus Crohn, or an inherited predisposition to breast cancer. For a survey see, e.g., Burke [1]. Such information should make a carrier of traits that are linked to a disease more likely to take precautions, for example, to undergo regular medical screening that enable early treatment for the disease if diagnosed. Intuitively, one would think that because of this, such information should lower the number of people who develop and die from a disease and, thus, increase average health in the population. In this note we show that this need not necessarily be true.

In fact, information about a link between a certain trait (like sex of the patient) and a particular disease can *increase* the number of people developing and dying from a disease. The reason for this counterintuitive finding is that the bad news for some parts of the population (who learn that they are more likely to develop a disease) is good news for the remaining part of the population (who, by the law of average, find themselves less likely to develop the disease). Accordingly, learning about how certain traits are linked to certain diseases has a differential impact on the population: Some parts of the population will go more frequently to medical screening, others go *less* frequently. Here we show that the latter effect may outweigh the former.

We obtain this result by studying a rational choice framework where patients decide in a fully rational manner whether or not to undergo medical screening. They weigh the costs and benefits of undergoing the screening and decide to go a

screening if and only if the benefits outweigh the costs [2, 3]. Rational economic decision making in this fashion can operate on a concious or a subconcious level [3].

Earlier, Marteau and Lerman [4] have warned of adverse effects similar to those analysed here by invoking psychological arguments. They write (p. 1058): "It will also be important to ensure that people who are found not to be at increased risk do not develop a false sense of reassurance, feeling invulnerable to the adverse effects of their risky behaviour. Such people need to understand that they have a residual (albeit lower) risk of developing the condition and to be encouraged to engage in risk reducing behaviours relevant for the general public." In some sense, we show that predictive genetic diagnosis and, more generally, any information about certain traits and diseases can have adverse effects even if people do *not* develop a "a false sense of reassurance". People might process the provided information perfectly well and this alone might cause additional deaths. Psychological biases as suggested by Marteu and Lerman might then, of course, aggravate the problem further.

We think our analysis raises important questions regarding both, genetic testing and the publication of medical research. Widespread publication of certain findings about the risk of contracting diseases can cause higher incidents of the disease and, if the disease is dangerous, more deaths.

2   Analysis

Consider a potentially deadly disease that we shall simply call D. To keep things as simple and illustrative as possible we make some assumptions about how D can be diagnosed and treated. D can be diagnosed before it breaks out. The diagnosis is perfect and if a patient is diagnosed she can be treated. However, there is no treatment once D has broken out, and the patient will die. To be more specific, consider an example with a population of 100 individuals, each depicted as one cell in Figure 1. Only ten percent of the population will develop the disease D, the others will not. In the figure, these are the red and white cells, respectively. Individuals in the population do not know whether they belong to the group of red cells or white cells; hence, the average risk of contracting the disease in this case is 10 percent for each individual.

Each individual in this population has to make a decision about whether to attend regular health checks/screenings. To describe this decision problem we need to know how the patient evaluates different health outcomes. Following the standard approach in health economics, we employ the notion that with each outcome a patient associates a "utility" level [3]. For simplicity, let us assume that there are only three possible health outcomes: (1) A patient does not contract the disease. This is the best outcome associated with the highest utitility level, say, 1. (2) A patient develops D before it was diagnosed and dies. This is the worst outcome, with utility level 0. (3) A patient with D is diagnosed before the disease breaks out and treated accordingly. This is the intermediate outcome associated with a utility level b between the first two. If there is a good treatment for D (almost) restoring perfect health, b will be close to 1. If the treatment has many side effects and only partially restores health,

b will be much closer to zero.

Individuals must decide whether to undergo regular screening, which imposes some costs upon the patient. These costs can be material (for example, fees and transport) but also psychological (for example, embarassment and pain) [2], and may also differ between patients depending on where they live and what cost is covered by their health insurance. To go back to our illustrative example, let us assume that there are 60 individuals who have low cost c of screening, and 40 individuals who have high cost C. These costs are measured in the same units as the "utility" from the various health outcomes above. The risk of contracting the disease is independent of the individual costs for undergoing screening. In Figure 1, the individuals to the left of the bold dividing line have low cost, and the ones to the right have high cost.

Individuals will undergo screening if their cost is lower than the *expected* benefit of screening. There is no benefit of screening for those who do not contract the disease. For those who would contract the disease, the benefit equals b, i.e., the difference between their utility from being diagnosed and treated and their utility from contracting the disease and dying. To an individual who does not know whether she is one of the red or one of the white cells, this benefit occurs with a 10 percent probability. Hence, the expected benefit is $\frac{b}{10}$. Individuals will now compare the expected benefit from screening with their costs. Now consider the following case where the low costs c are smaller than $\frac{b}{10}$, and the large costs C are greater than $\frac{b}{10}$. In this case all individuals with low costs undergo the screening, and all individuals with high cost do not. Accordingly, the total number of deaths will be equal to 4, represented by the four red cells among the high cost individuals in Figure 1.

5

Next, let us examine what happens in this example where there is some sort of predictive medicine. Let some 10 percent of the population carry some (genetic) trait that increases the likelihood of contracting the disease by a factor of 5, i.e., from 10 percent to 50 percent, and let us assume that everybody knows their trait. Individuals will know their trait either if it is easily observable like as the case of sex or if the whole population is subjected to the predictive genetic testing, say, at birth. In any case, in our example this means that there are now 10 individuals who carry the trait and have a 50% chance of contracting D. These individuals are represented as the cells labelled 'T'(for "trait") in Figure 2. The other 90 individuals are captured by the 90 cells labelled '0'. The trait is unrelated to the costs of undergoing a health check. Hence, among the 10 individuals who carry the trait there 6 individuals with low costs and 4 individuals with high costs, as depicted in Figure 2.

Consider now how the genetic information changes decision behavior. The group of carriers of the dangerous gene is likely to undergo screening (unless C is very high). Hence, all 5 lives of individuals in this group who would contract the disease will be saved. On the other hand, the individuals with high cost who do not carry the dangerous gene will not screen. Hence, the two (red) individuals in this group who are at risk will contract the disease and will die. These are shown by the two red cells in the bottom right corner of Figure 2. In some sense, these two individuals cannot be saved: They die with and without the predictive test.

Finally, consider the group of individuals who have low cost of screening, but have learned that they do not carry the dangerous gene (all cells labelled '0' to the left of the dividing line). They know now that they are at lower risk. In

fact, they have the benefit b of screening only in 5 of 90 cases. Hence, they will not screen unless their costs are very low, $c \leq b/18$, (compared to $c \leq b/10$ in the case without predictive diagnostics). Therefore, if c is in the range between $b/10$ and $b/18$, the genetic test will change their behavior from 'screen' to 'not screen', and this will cause three more deaths. These are shown by the red cells in the bottom left corner of Figure 2.

On balance, we find that with genetic testing there will be 5 deaths while we only 4 deaths occured without genetic testing. Note that the individuals act fully rationally here; i.e., they choose actions that maximize their ex-ante expected utility. But still, the number of deaths increases.

3 Conclusion

The widespread availability of predictive genetic diagnosis and information about genetic susceptibility to diseases will induce major changes of individuals' willingness to undergo medical screening. We show that the total number of victims of a curable disease can increase as a consequence of predictive genetic diagnosis.

In a next step we plan to analyse the problem in a more general framework that allows us to make inferences about when and where the release of information about links between traits and diseases is perticularly dangerous. Our results so far indicate that the negative effect of predictive diagnosis is particularly powerful if the number of patients with comparatively low psychological and/or monetary costs for undergoing a health check is large. This, of course, means that the problem that we sketch is more pronounced in populations where most individuals have good medical insurance.

Both authors contributed to the idea of this paper, the analysis, and the write-up.

We have no conflicts of interest to declare.

.

References

[1] Burke, W, 2002, Genetic testing, *New England Journal of Medicine*, 347, 1867-1875.

[2] Mansley, EC and MT McKenna, 2001, Importance of perspective in economic analyses of cancer screening decisions, *Lancet*, 358, 1169-73.

[3] Meltzer, MI, 2001, Introduction to health economics for physicians, *Lancet*, 358, 993-98.

[4] Marteau, TM. and C Lerman, 2001, Genetic risk and behavioral change, *British Medical Journal*, 322, 1056-1059.

Individuals with
low screening cost c | Individuals with
high screening cost C

Figure 1

Figure 2