SOFTWARE

MOONSHOT

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At Linkedin there is an interesting discussion about “personalized medicine” (I need quotation marks here as I always thought that good medicine is personalized). One commenter says

> I believe precision medicine is a term to be use in grants, to indicate personalized medicine based on genetic information. Incomplete and imprecise. But funding agencies and bureaucrats need to see these words. I hear on the grapevine the US American President’s use of it is the start of this rather imprecise term. http://www.nih.gov/precisionmedicine/

referring to a short essay published in the New York Times already in January.

> But for most common diseases, hundreds of genetic risk variants with small effects have been identified, and it is hard to develop a clear picture of who is really at risk for what. This was actually one of the major and unexpected findings of the Human Genome Project […] A second unexpected finding of the Human Genome Project was the problem of “missing heritability.” While the statistics suggest that there is a genetic explanation for common conditions and diseases running in families or populations, it turns out that the information on genetic variants doesn’t explain that increased risk.

Maybe the familiar risk can be explained by rare variants, (inherited!) epigenetic DNA modifications or just shared early environment and it’s just not in the genes – making the whole approach of personalized medicine a well-meant but meaningless enterprise. Until now, I didn’t even consider side effects. But as the NYT article goes on, there might be - some

> The push toward precision medicine could also lead to unintended consequences based on how humans respond to perceptions of risk. There is evidence that if people believe they are less at risk for a given disease, they feel excessively protected and their behavior gets worse, putting them at increased risk. Likewise, those who feel they are at greater risk, even if the increased risk is small, might become fatalistic, making their behavior worse as well. Then there are the worriers, who might embark on a course of excessive tests and biopsies “just in case.” In a medical system already marked by the overuse of diagnostic tests and procedures, this could lead to even more wasteful spending.

Maybe earlier genetic research has been always accompanied by some ELSI research program, all the ethical, legal and social implications. Now this is all left to a NY articles and the 700 comments under it.