The Revolution of Personalized Medicine

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Personalized medicine: the “-omics and data revolution”

The **Digital YOU**: the sum of your genomic, proteomic, microbiomic, metabolomics data, *combined with* a digital record of your vital signs over time ...

This data will be informative – to say the least – particularly when you compare your digital self with the digital versions of others in your situation.

*Peter Cullis, The Personalized Medicine Revolution*
Science megatrend

Convergence of computer science, nanotechnology, biotechnology and cognitive science (« info-nano-bio-cogno » convergence),

-> leading to a deluge of data (big data)

+  

-> the capacity to extract meaning (smart data)
The aging challenge

Increase of life expectancy

The proportion of older persons (over sixty) will more than double over the next fifty years. 2 billion human beings will be > 60 years in 2050 (20% of the world population)
Consequences on personalized medicine

- Sequencing of individual genomes will be a commodity. Making sense of the genomes will require huge cohorts.

- Personalized medicine will become a major industry of the future, particularly as the health-maintenance industry increasingly engages in an anti-aging agenda.

- Identification (and soon correction?) of predisposing genes and risk factors

- Tailored prevention program (life style, nutrition, drugs) with continuous recording of many bio-parameters by integrated biosensors (watches, glasses, contact lenses, clothes...):
Challenges in personalized medicine

Data
• Quality of data collected
• Making sense of data: to understand complex traits massive cohorts are required.
• Danger of «spurious correlations» in data analysis;
• Data privacy and security concerns

Doctors
• Genetic and «probalistic» counselling is difficult and unfamiliar to many doctors.
• Medical curriculum today lacks crucial parts to understand and practise genomic medicine (math, bioinformatics …)

Technology
• Driver of personalized medicine. Expect more «game changers» (like crispr/cas9 ↑)
Dangers for precision medicine

1. Underestimating the precision medicine revolution
   - Generalized use of non-health data for health purposes with privacy and security concerns
   - Incidence on clinical trials and health insurance

2. Not benefitting from precision medicine
   - «data silos» due to privacy or national regulations or commercial interests
   - Right balance between individual rights and public health concerns, between protection and innovation

3. Bypassing the health system
   - Probable rise of DTC and gene-hype
   - The «data cowboys» might bypass and neutralize the health system
Beijing IRGC expert workshop (Aug 2015):

Strong Baseline Protections While Promoting Data Access and Sharing

- Personal medicine is a **global** phenomenon
- **Quality of data** as first ethical imperative, implying certification of providers, controlled and tiered access etc
- **Informed consent** seen as dynamic, adaptive, and the patient as an **active user**
- Use-based view of **privacy** : focus on what is used not what is collected
- **Accountable** systems: data cannot be used against the individual (+incidental findings)

Workshop report available at irgc.org
International (adaptive) regulation ...

- «Framework for responsible sharing of genomic and health-related data» by the «Global Alliance For Genomic And Health»
- Universal Declaration of Human Genome and Human Rights (UNESCO 1998)
- Need for a «Nagoya protocol» for human genetic data and resources?

JOIN the two major codes of the 20th century: Genetic Code and the Universal Declaration of Human Rights.