

Genetic Testing



Issues and Recommendations

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Pharmacogenomics and Patient Stratification

From Predictive to Personalized Medicine

- What should be the priorities:
 - In terms of public healthcare?
 - From the point of view of the individual?
- How can fair and equitable access to personalized medicine be made compatible with the overall costs of healthcare system?
- When and how does a risk for discrimination appear? How can we overcome this?

Previous Recommendations for Genetic Testing

- Council of Europe:
 - Additional Protocol to the Convention on Human rights and Biomedicine concerning Genetic Testing for Health Purposes (2008)
- European Expert Group STRATA:
 - 25 recommendations on the Ethical, Legal and Social Implications of Genetic Testing

Progress in Diagnostic Testing

- What is the clinical utility of these diagnostic tests when no medical follow up or treatment is possible?
 - A continuous dialogue between patients and physicians (counselling pre- and post-test) is necessary.
 - The result by itself is insufficient.**
- The problem of the result:
 - From an individual point of view, it is important that the patient is able to understand and absorb the result
 - From a societal point of view, the risks of “self-service” tests are increasing with multiple drawbacks in terms of healthcare management and costs.
- Conditions for results delivery and genetic counselling need to be clear

Recommendations for Pharmacogenomics and Personalized Medicine

- Technical issues:
 - A clear differentiation should be made for the management of genetic tests in the research stage versus the diagnostic routine.
- The eventual issue of patents:
 - To ensure that patents do not block the possibility of studying factors that underlie or are associated with the functioning of a certain gene or its interaction with other factors, such as the environment.
- Issues related to the patients and the individual:
 - Stratification vs discrimination
 - Exclusion of certain type of patients? Unresolved problem...