The Public Health (Genomics) Challenge

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... not only beyond the 4 P’s, but also (A. Brand, 2008) ...

1. from common complex diseases to “multiple rare diseases”
2. from diseases to “diseasomes”
3. from risk factor to “risk pattern”
4. from clinical utility to “personal utility”
..... and also

(1) highly (in space & time) dynamic personal (health) information

(2) from statistical risks within groups to “individualized evidence”

(3) “virtual individual models”

ITFoM (www.itfom.eu) – ”ICT for health & health for ICT”: a radically new vision for healthcare!
“From Stratified Medicine to truly Individualized Medicine“

• No existing groups, only individuals
  ➔ Every test will be part of treatment. No result can be transferred to another patient.
  Every therapy is unique, not reproducible.

• No existing method on how to evaluate the new kind of technology
  ➔ How can we fulfill the hierarchy of evidence, the golden standard to prove the efficacy of a treatment?

• The patient is not only consumer of the technology, but also part of it
  ➔ There is no boundary between patient and treatment.
  The patient is a unique part of the technology itself.
"European Best Practice Guidelines for Quality Assurance, Provision and Use of Genome-based Information and Technologies”


www.phgen.eu
Angela Brand* and Jonathan Lal for the Public Health Genomics European Network (PHGEN II)

European Best Practice Guidelines for Quality Assurance, Provision and Use of Genome-based Information and Technologies: the 2012 Declaration of Rome
1. Research

- Keep up with new insights from basic sciences.
- Generate evidence to demonstrate when the use of genome-based information and technologies (GBIT) in public health can improve health outcomes in a safe, effective and cost-effective manner.

2. Monitor Health

- Develop surveillance systems of personal health data: accurate and ongoing assessment of highly dynamic health information changing over space and time on the individual level with a life-course perspective is needed.
- Promote personal files that contain comprehensive personal health information including ‘omics data and its interaction with all other health determinants.

3. Diagnose and Investigate

- Move from symptom- and phenotype-based approach to pathway-based cloud diagnostics for early identification of health problems on individual level.
- Move from “clinical utility” to “personal utility”.

4. Inform, Educate, Empower

- Promote health literacy of all stakeholders: enable citizens (including health professionals), individually and cooperatively, to access, understand, appraise, and apply information that will facilitate the application of GBIT for the benefit of individual citizens and their communities.
- Promote person-centred healthcare.

5. Mobilize Community Partnerships

- Promote Public Private Partnerships (PPP): Mechanisms, tools and models are required to link the needs of healthcare systems to those of the private sector and to foster the development of individualized technologies (e.g., Learning Adapting Levelling model).
6. Develop Policies

- Treat GBIT as the most holistic approach of health information when developing health policies.

7. Enforce Laws

- Use the dynamics of GBIT as a unique opportunity to frame and enforce laws and regulations pro-actively.

8. Link to / Provide Care

- Develop systems that sustain the interoperability between personal health management and public health management.

9. Assure Competent Workforce

- Integrate GBI and GBT into the professional training and life-long learning (LLL) curricula of health professionals.

10. Evaluate

- Establish and support a holistic and systems based evaluation of the impact of GBIT, taking into account economic issues and the different European health systems.
- Promote a system where technology transfer (TT) activities and policy-based Public Health Assessment tools (HNA, HTA, HIA) run in parallel for the timely, effective and efficient evaluation of GBIT.
Thanks for your attention!

“Future perspective
Personal health drives a fundamental change not just in what is known, but also in how we think of ourselves and the way we are living, thus redefining our society. The political will is there, but we have to prepare for all the various organizational changes…. in time.”

Personalized Medicine
(doi:10.2217/pme.12.16)

Public health perspective: from personalized medicine to personal health
Tomris Cesuroglu, Ben van Ommen, Núria Malats, Ralf Sudbrak, Hans Lehrach & Angela Brand