The ESF Forward Look Personalised Medicine for the European Citizen: Welcome to the Launch and Implementation event!
The promise of personalised medicine

- More effective medicines
- Safer medicines
- Cheaper medicines
- Better healthcare
- Cheaper healthcare
- Less (rather than more) healthcare disparity
Forward Look on Personalised Medicine

ESF Position Paper
May 2011

Technology
19-20 Sept 2011
London, UK

Disease Summit
18-20 Oct 2011
The Hague, NL
1) CV & metabolic diseases
2) Oncology
3) Rare Diseases

“Big picture” Summit on clustered issues
13-14 Feb 2012
Dubrovnik, HR
Identify grand challenges and recommendation

Stakeholder conference
18 April 2012
Rome, IT
Consensus discussion on Grand Challenges and overall recommendations

In-depth expert interviews
Forward Look on Personalised Medicine

“At the heart of personalised medicine lies the individual citizen…”
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“… the citizen’s health status will be reflected by a new disease taxonomy informed by the multi-layered characterisation of physiological and pathological processes”

Move from reactive to proactive, including include disease prevention.
“Comprehensive, accessible, and interoperable datasets must be generated to support the development of a new disease taxonomy and allow for its ongoing refinement and application"
“Models and decision-making processes must be revised to reflect a focus on the individual citizen at all levels, from assessment of the safety and efficacy of interventions, through HTA and reimbursement, to diagnosis, treatment and prevention.”

New trial designs: n of 1, targeted populations, monitoring biomarkers, etc.
“Models and decision-making processes must be revised to reflect a focus on the individual citizen at all levels, from assessment of the safety and efficacy of interventions, through HTA and reimbursement, to diagnosis, treatment and prevention.”

Creation of Europe-wide and wider networks.
Biomarkers including imaging linked to specific phenotypes, altered drug development.
"Emphasis must be placed on stakeholder participation, interdisciplinary interaction, public-private and precompetitive partnerships, and translational research in order to develop the frameworks that support the vision of personalised medicine and healthcare"

Patient engagement.
Importance of language. Avoid hyperbole. Avoid “victims”, “survivors”.
Personalized Medicine is more than Genomic Medicine.
"Emphasis must be placed on stakeholder participation, interdisciplinary interaction, public-private and precompetitive partnerships, and translational research in order to develop the frameworks that support the vision of personalised medicine and healthcare."

Analogy of Google maps applied to information around patients: exposures, genome, microbiome, other patients, ....
“Emphasis must be placed on stakeholder participation, interdisciplinary interaction, public-private and precompetitive partnerships, and translational research in order to develop the frameworks that support the vision of personalised medicine and healthcare”

Examples – IT tools to ensure f/u. Cloud sourcing what the best treatment might be, allow patients to have access to MD notes?
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“Dedicated funding and governmental support must be provided to ensure the availability of core infrastructure, including access to core technology and frameworks for education and training of professionals and the wider community”

EMR: data follow the patient. Especially an issue in Europe across borders
Promote public-private partnerships.
“Dedicated funding and governmental support must be provided to ensure the availability of core infrastructure, including access to core technology and frameworks for education and training of professionals and the wider community.”

Patients have a right to manage their own data; controversial across the continent, e.g. not in Germany. Balance between individual use of data and contributing data to a greater commons.
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“Dedicated funding and governmental support must be provided to ensure the availability of core infrastructure, including access to core technology and frameworks for education and training of professionals and the wider community.”

Education also a central recommendation. Health care providers, public, .. Biology, IT, lifelong learning
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80 recommendations
Personalised medicine: the time for action is now

- Rapidly emerging area with high potential for Europe
- Raising questions along the full innovation cycle
- Potentially great benefits for patients
- Potentially large economic impact across public and private sectors
Global Reach – Personalized Medicine

- Rare Diseases
- Cancer
- Personalized Medicine

Logos of various organizations related to rare diseases, cancer, and personalized medicine.
Break-out groups:
How can we implement the recommendations?

1. **Prioritize**
   *What are the first steps?*

2. **Stakeholders**
   *Who will do it?*

3. **Action points**
   *Who does what?*
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Phase 1
- Public dialogue
- Education
- Regulatory frameworks
- Testing and reimbursement models
- Infrastructure planning
- Stakeholder participation
- Collection of reference data
- Proof of principle
- Data standardisation
- Biomarker validation

Phase 2
- Responsible governance frameworks
- Apply metrics
- Harmonisation of procedures
- Patient-centred partnerships
- Interaction networks (molecular and environmental)
- Infrastructure testing
- Data integration
- Data sharing
- Dynamic monitoring

Phase 3
- In silico models
- Remote sensing
- E-learning and adaptable interfaces
- Real-time monitoring
- Systematic data collection
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IMPLEMENTATION PHASE

- Final Report publication
- Dissemination
  - Additional publications (scientific, policy, etc.)
  - COST Conference
- Launch and implementation event: Jan. 2013
  - Key stakeholders
  - Action plan
- Go global: OECD, NIH, FDA, CIHR, etc.
- Take over from ESF…