Alfons Bora

Genetics and Public Health – Challenges for Science and Technology Studies

International Symposium „Public Health Genetics – Experiences and Challenges“
Bielefeld, Feb. 19-21, 2004
Summarising my impressions

Still confused, but on a higher level.

Some remarks on:

1. Fields of public relevance – Questions
2. Issues raised by PH community (pilot study)
3. STS Implications
### Fields

<table>
<thead>
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<th>Questions</th>
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<td><strong>1. Research</strong></td>
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<td>- Research as a public task</td>
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<td>- Research (population based data, pharmacogenetics) could touch rights/values, which are of public interest:</td>
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<td>(- besides all usual questions of research ethics…)</td>
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<td>- biobanks: informed consent, voluntary participation, data protection, public control</td>
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<td>- pharmacogenetics: follow up studies, monitoring</td>
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<td><strong>2. Individual diagnostics/therapy</strong></td>
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<td>- Availability</td>
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<td>- Equal access</td>
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<td>- Right not to know, informed choice</td>
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<td>- Professional training (science &amp; art)</td>
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<td>- Voluntary/mandatory (with respect to employers, insurances)?</td>
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<td>- Risks of “individualisation” (pharmacogenetics)?</td>
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<td>- Social environment (family)</td>
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<td>- Eugenics?</td>
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3. Prevention  - Possibilities? (“Rare Mendelian” – More complex diseases)
   - Potential measures of prevention? Efficiency?
   - Different levels of screening as public health measures?
   - Questions of consent, informed choice
   - Coercion - Autonomy
   - Enforced information – Right not to know
   - “Active” counselling – Family decision making

4. Privatisation  - Regulation and providing for publicly available diagnostics

5. Public debate  - Information, education, empowerment, but also…
   - … responsivity (bi-directional communication)
   - many studies show: attitude is not a direct function of information, behaviour is not a direct function of attitude
Issues raised by PH community (pilot study)

- Learn about potentials and chances, more information and knowledge needed
- Critically accompany the development
- Assess impacts
- Relate findings to social sciences oriented approaches in PH

Message: Critical co-operation, broadening the knowledge base, mutual responsivity. Matches the tendency of questions raised by PHG.
STS Implications

1. Research:
- Social conditions of technology development (information technology as basis, specific form of innovation networks)
- Social effects (inequality)

2. Technology Assessment:
- Knowledge issues touched = Assessment
- Public debate issues touched = Appraisal
- Decision-making touched issues = Appraisal

3. Policy recommendations:
- Regulatory framework (legal context, policy goals)
- Options

Message: Complex matter, open questions, difficult regulation. We are rather far from conclusions. TA still has to be done, case-by-case. Involve TA-institutions.