The social challenges of genomics and Personalised Medicine

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I. Who is talking about it?
II. What is being said?
III. What’s hot?
Social dimensions of biomedicine

A. Medical ethics
   - originally a sub-discipline of philosophy
   - codifications: Nuremberg Code 1949, Declaration of Helsinki 1964, etc.

B. Bioethics
   - Human Genome Project: 3-5% of funding dedicated to ELSA
Social dimensions of biomedicine

C. Social sciences

- Initially strong objections against normative stances

- Understanding the political conditions and the social and individual practices that influence the progress and the acceptance/uptake of biomedicine and bioscience
The social challenge of genomics and personalised medicine – perspectives from the social sciences and bioethics

(1) Identity
(2) Justice, Equity, Access
(3) Participation
1. Identity

1990s: geneticization (A. Lippman 1991)

2000s: enlightened geneticisation (A. Hedgecoe 2001)
biosociality (P. Rabinow 1996 [1992])
Davos, Switzerland, 1912

1924
“It is not hard to imagine groups formed around the chromosome 17, locus 16,256, site 654,376 allele variant with a guanine substitution... These are new biological groupings that will crosscut, partially supersede, and eventually redefine the older categories [of disease, race and sex] in ways that are well worth monitoring.”

Davos, Switzerland, 2008

23andMe is represented at the World Economic Forum
"Seems Accurate To Me!"

Posted by EllaCig on Hypospadias Health

I have the AA gene for hypospadias and one of my two sons has a slightly hypospadias opening. I've been told by doctors he has no complications from it and won't need any surgery. It also shouldn't affect his ability to have children some day. Still, very interesting to know how it got there.

Feb 7, 2011

11 Responses (reply)

AndreaBador

Very interesting! Thanks for sharing. My sister has AA for this gene but had only daughters.

Feb 8, 2011

mykitop

Whoa, I have mild hypospadias... They got this one right. I'm impressed.

A - Substantially increased odds of hypospadias.

Feb 20, 2011

MadeinBrazil

I have also, but I'm G. May be it was something else.

Feb 20, 2011
1. Identity

2010s: *Empirical evidence* of how people understand, and act on, genetic information:

(1) Information on genetic predispositions is typically assimilated into existing identities and practices
(2) Evidence from genetic susceptibility testing has neither confirmed our fears nor our hopes
1. Identity

2010s: A. Focus on **oppressive effects:**
Patients-in-Waiting (S. Timmermans & M. Buchbinder 2010)
Pre-patients

B. Focus on **empowerment:**
P4 medicine (L. Hood)

C. **Middle ground:**
somatic individual (C. Novas & N. Rose 2010)
2. Justice, equity, access

- Deborah Stone: The “chocolate cake” problem of justice
- Just resource allocation is one of the core questions of bioethics and social science
2. Justice, equity, access

Most pertinent to cancer genomics:
- Lower income groups have higher risks;
- Fear of genetic discrimination;
- Fear that scarce resources are spent on preventive services and diagnostic tests with low utility;
- Minority groups are not well characterised (genomic information)
- Currently: “Lifestyle solidarity” debate

3. Participation

- Hans Jonas (1903-1993): The doctor is “alone with his patient and God”
- Post WWII: Scope of legitimate expertise of doctors became gradually smaller
- Late 20th century: Increasing calls for the participation/“empowerment” of patients
3. Participation

- 2010s: More and more practices move out of the clinic: diagnosis (*direct-to-consumer* DTC)
  data collection (e.g. "*Quantified Self*” QS)
  data analysis (e.g. "*Cure Together*”)
  (self-)treatment decisions
<table>
<thead>
<tr>
<th>Symptom</th>
<th>Member Ratings (num votes)</th>
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<tbody>
<tr>
<td>Pounding head</td>
<td>1.27</td>
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<tr>
<td>Nagging pain in one side of head</td>
<td>1.27</td>
</tr>
<tr>
<td>Photophobia (sensitivity to light)</td>
<td>1.30</td>
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<tr>
<td>Fatigue</td>
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<tr>
<td>Pulsating, Intractable Pain</td>
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<td>Nausea</td>
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<tr>
<td>Sensitivity to flashing lights</td>
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<td>Trouble concentrating</td>
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<td>Impotency</td>
<td>1.19</td>
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<tr>
<td>Feeling like head is going to explode</td>
<td>1.37</td>
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<tr>
<td>Neck pain</td>
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<td>Photophobia (sensitivity to sound)</td>
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<td>Neck muscle stiffness</td>
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<td>Extreme pressure/throbbing behind eyes</td>
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<tr>
<td>Pain in above one eye</td>
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<tr>
<td>Sinus pressure</td>
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<td>Trouble communicating</td>
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<td>Intense throbbing on both sides of head</td>
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<td>Dizziness</td>
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<td>Continuous migraines once after another</td>
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<tr>
<td>Shoulder / Back pain</td>
<td>0.65</td>
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<tr>
<td>Blurred vision</td>
<td>1.17</td>
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<tr>
<td>Head pain upon waking</td>
<td>0.69</td>
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<tr>
<td>Headache</td>
<td>1.19</td>
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<tr>
<td>Sensitivity to movement</td>
<td>0.63</td>
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Avoidance of Triggers is Best for Migraine: Results of Patient Study Comparing 180 Treatments

September 12th, 2011 Alexandra Gamichael

180 Migraine Treatments Compared
by 3,455 Patients

Popular but less helpful
Modes of citizen participation

data collection/generation
analysis
interpretation
application
Toward Precision Medicine
Building a Knowledge Network for Biomedical Research and a New Taxonomy of Disease

[© National Academy of Sciences, 2011]
European Science Foundation (ESF) *Forward Look on Personalised Medicine for the European Citizen: Report (in press)*
The social challenge of genomics and personalised medicine

To achieve more socially and politically robust solutions, we need
- rigorous empirical research into what people really need and want
- multi- and interdisciplinary collaborations in tackling open challenges (e.g. data integration)
Thank you very much for your attention!