PERSONALIZED HEALTH CARE: THE GENETIC CHALLENGE

Preventative strategies for addressing chronic diseases...

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Selection of Issues
(all need work!)

- DTC Testing and Popular Culture
- Impact on Health Systems
- Health Benefits?
- Patent Problems
- Confidentiality/Privacy
- Consent Challenges
In 2001 Collins and Mansoura declared that the “most critical measure of the success of the HGP will be determined by the answer to this question: To what extent did the scientific and medical advances derived from the HGP reduce the burden of disease for all people?”
The Future?

Oberg touts 'right to know' in promoting DNA test firm

By Keith Gerein, Edmonton Journal June 3, 2010

A Decade Later, Genetic Map Yields Few New Cures

By Nicholas Wade

June 12, 2010

Ten years after President Bill Clinton announced that the future of medicine has yet to see any large part of the promised benefits of the Human Genome Project, the scientist who led the Human Genome Project says the genome has yielded few cure.

Gene Test for Dosage of Warfarin Is Rebuffed

By Andrew Pollack

Published May 5, 2010

In a setback for the fledgling field of personalized medicine, Medicare has decided not to pay for genetic tests intended to help doctors determine the best dose of the blood thinner warfarin for a particular patient.

World still waiting for genome DNA map to unlock secrets

By Richard Gray, Daily Telegraph June 20, 2010
### Table 3: Willingness to Pay for Genetic Tests

<table>
<thead>
<tr>
<th>Willingness to Pay for Genetic Testing</th>
<th>Manageable Disease</th>
<th>Serious, Unpreventable Disease</th>
<th>Determining Healthy Foods</th>
<th>Psychiatric Condition</th>
<th>Baldness (men only)</th>
<th>Risk of Gaining Weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>nothing</td>
<td>36.9</td>
<td>48.3</td>
<td><strong>54.5</strong></td>
<td>50.1</td>
<td><strong>83.9</strong></td>
<td>72.5</td>
</tr>
<tr>
<td>$1-$499</td>
<td><strong>36.6</strong></td>
<td>32.2</td>
<td>32.9</td>
<td>30.5</td>
<td>11.8</td>
<td>19.8</td>
</tr>
<tr>
<td>$500-$1999</td>
<td>17.5</td>
<td>12.6</td>
<td>8.7</td>
<td>12.5</td>
<td>2.5</td>
<td>5.2</td>
</tr>
<tr>
<td>$2000+</td>
<td>9.0</td>
<td>7.0</td>
<td>3.9</td>
<td>6.9</td>
<td>1.8</td>
<td>2.5</td>
</tr>
</tbody>
</table>

**Public Health System Should Pay**

<table>
<thead>
<tr>
<th></th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disagree</td>
<td>21.9</td>
<td>37.0</td>
<td>41.1</td>
</tr>
<tr>
<td>Neutral</td>
<td>16.5</td>
<td>18.9</td>
<td>20.0</td>
</tr>
<tr>
<td>Agree</td>
<td>61.7</td>
<td>44.1</td>
<td>41.1</td>
</tr>
</tbody>
</table>

*Respondents were only asked about publicly insured testing for the three tests indicated. The percentages for disagree and agree include responses of ‘disagree/agree’ and ‘strongly disagree/agree’.
### Table 4: Factors that Influence Interest in Genetic Testing

<table>
<thead>
<tr>
<th></th>
<th>No effect</th>
<th>Strong effect</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Availability of treatment</td>
<td>16.1</td>
<td>5</td>
</tr>
<tr>
<td>Curiosity</td>
<td>41</td>
<td>14</td>
</tr>
<tr>
<td>Reproductive decisions</td>
<td>44.4</td>
<td>7</td>
</tr>
<tr>
<td>Fear of discrimination</td>
<td>32.9</td>
<td>6.4</td>
</tr>
<tr>
<td>Healthy lifestyle choices</td>
<td>24.3</td>
<td>7.5</td>
</tr>
</tbody>
</table>

Reported as percentage of all respondents.

- Across all test categories, few respondents expressed willingness to pay more than $500 out of their own pocket.
- Curiosity about genetic risk had only a modest impact on consumer interest.
Direct-to-consumer genetic testing is at an increased or decreased risk of, say, heart disease, is a fool’s hope — in spite of years away. The idea that you will benefit in any tangible manner from knowing whether you are at risk is a fool’s hope. There is absolutely no question, he said, that the whole hope of personalized medicine, the dream has been just about as bleak as it could be.

But any direct-to-consumer genetic testing is a fool’s hope — in spite of years away. The idea that you will benefit in any tangible manner from knowing whether you are at risk is a fool’s hope. There is absolutely no question, he said, that the whole hope of personalized medicine, the dream has been just about as bleak as it could be.
Has the revolution arrived?

Looking back over the past decade of human genomics, Francis Collins finds five key lessons for the future of personalized medicine — for technology, policy, partnerships and pharmacogenomics.

Third, the success of personalized medicine will depend on continued accurate identification of genetic and environmental risk factors, and the ability to utilize this information in the real world to influence health behaviours and achieve better outcomes. This will require...
Health Behaviour Change
Genes and Behaviour

The Behavioral Response

“Any risk communication expert would laugh at the suggestion [that genetic risk information would motivate behaviour change] … We have long known from other areas of research that the communication of risk is necessary but rarely sufficient. And even if people do change, they all relapse.”

Colleen McBride, Chief and Senior Investigator for the Social and Behavior Research Group at the National Human Genome Research Institute.

The few studies conducted to date have achieved only small changes in behaviour, and based on single-gene disease risks assessed by probabilistic risk information may be less likely to influence behaviour. The difficulty of health behaviour change and the need for effective risk communication have been recognized for many years. Marteau, T. M., and J. Weinman. 2006. Self-regulation and the behavioural response to single-gene disease risks assessment: A theoretical analysis and framework for future research. Social Science & Medicine 62: p.1360-1368.
Motivated Users?

Characteristics of users of online personalized genomic risk assessment: Implications for physician-patient interactions.

Lee, J. C., F. J. J., P. D. 2, Sharon Hensley Alford, PhD 2, Robert J. Reid, MD, PhD 3, Eric B. Larson, MD, MPH 1, J. J. 3, B. Nevanis, PhD 4, and Lawrence C. Brody, PhD 4

Conclusions: Individuals who present to health care providers with online genetics information may be more likely to be motivated to take steps to alter their health. These motives might be leveraged by health care providers to promote positive health outcomes. Genet Med 2009:11(8):582–587.

Understand Risks?

Broad Public Benefits?

How Many Motivated Users?
Most Heart Patients Skimp on Exercise After Rehab

A year later, only 37 percent were doing cardio exercises 3 times a week, study finds

-- Robert Preidt
Dr. Joel Hirschhorn, a genetics and obesity researcher at Children's Hospital Boston, said people should not interpret the study to mean, "I don't have this gene variant so I don't need to be physically active."

"This is great… This means we are doomed so we might as well live it up. We don't need to quit smoking or change or diets."

Fighting the gene takes 3-4 hours a day
Or you can always live like the Amish, new research shows

Maybe you CAN blame being fat on your genes. But there's a way to overcome that family history — just get three to four hours of moderate activity a day.

Sound pretty daunting?

Not for the Amish of Lancaster County, Pa., who were the focus of a new study on a common genetic variation that makes people more likely to gain weight. It turns out the variant's effects
Impact on Health Systems
Impact on healthcare costs?

74% report they would use it to gain disease knowledge.

34% consider the information to be a medical diagnosis.

78% would ask their physician for help interpreting test results.

61% thought professional responsibility.

Research article

Technology assessment and resource allocation for predictive genetic testing: A study of the perspectives of Canadian genetic health care providers

Alethea Adair†1, Robyn Hyde-Lay*†1, Edna Einsiedel2 and Timothy Caulfield1
ELSI ISSUES?

- Commercialization
- Privacy
- Anxiety
- Research priorities
- Patents
- Discrimination
- Stigmatization
- Genetisization
- Marketing
- Education
- Hype/Public Trust
- Educa=on
Conclusions

- Don’t oversell (communication issues)
- Scientific progress is uncertain and iterative
  - Translation research
- Behaviour change?
- Fatalistic behaviour?
- Increase healthcare costs?
Thank you!

• Amy Zarzeczny, Robyn Hyde-Lay, Ubaka Ogbogu, Nola Ries, Tania Bubela, Jim Evans, Amy McGuire, Wylie Burke, Therese Marteau, Eric Meslin and the HLI research team.