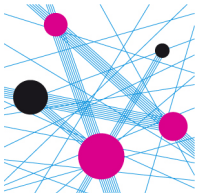
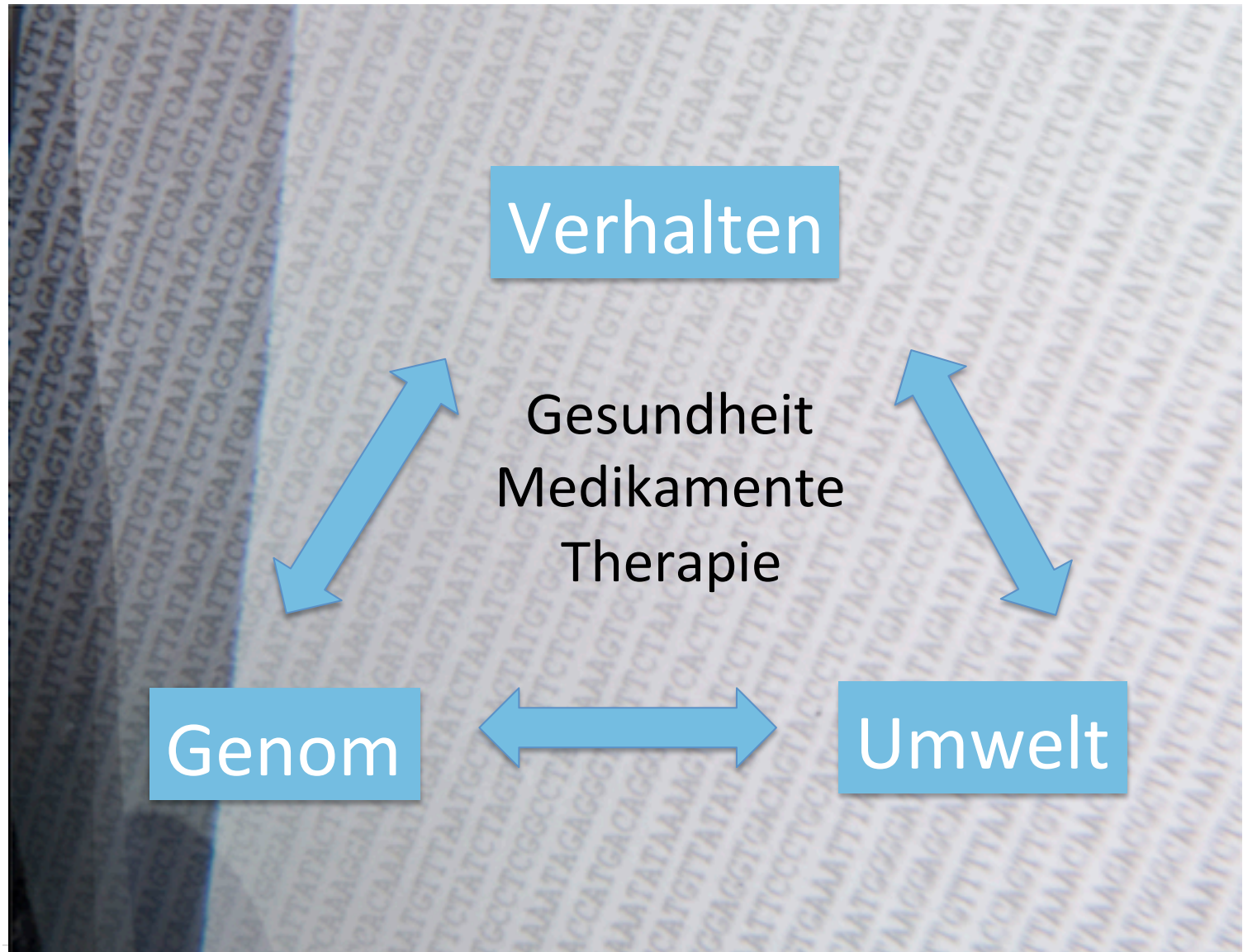
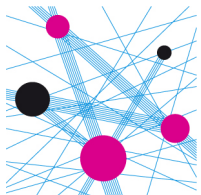


The Future of Personalized Health – Genome meets iPhone

OpenData.ch 2012-Konferenz, 28. Juni 2012

Prof. Ernst Hafen





40'000 Health Apps

KHN
KAISER HEALTH NEWS

FDA Seeks To Tame Exploding Medical App Market

TOPICS: [HEALTH IT](#)

By **JENNY GOLD**

KHN Staff Writer

JUN 26, 2012

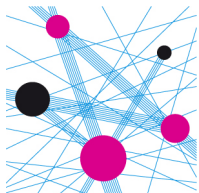
This story was produced in collaboration with 

Want to monitor your blood pressure and sugar level? Eat healthier meals? Screen yourself for depression? Find out if you need glasses? Now you can do it all with apps on your smartphone.

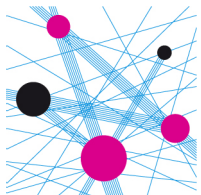
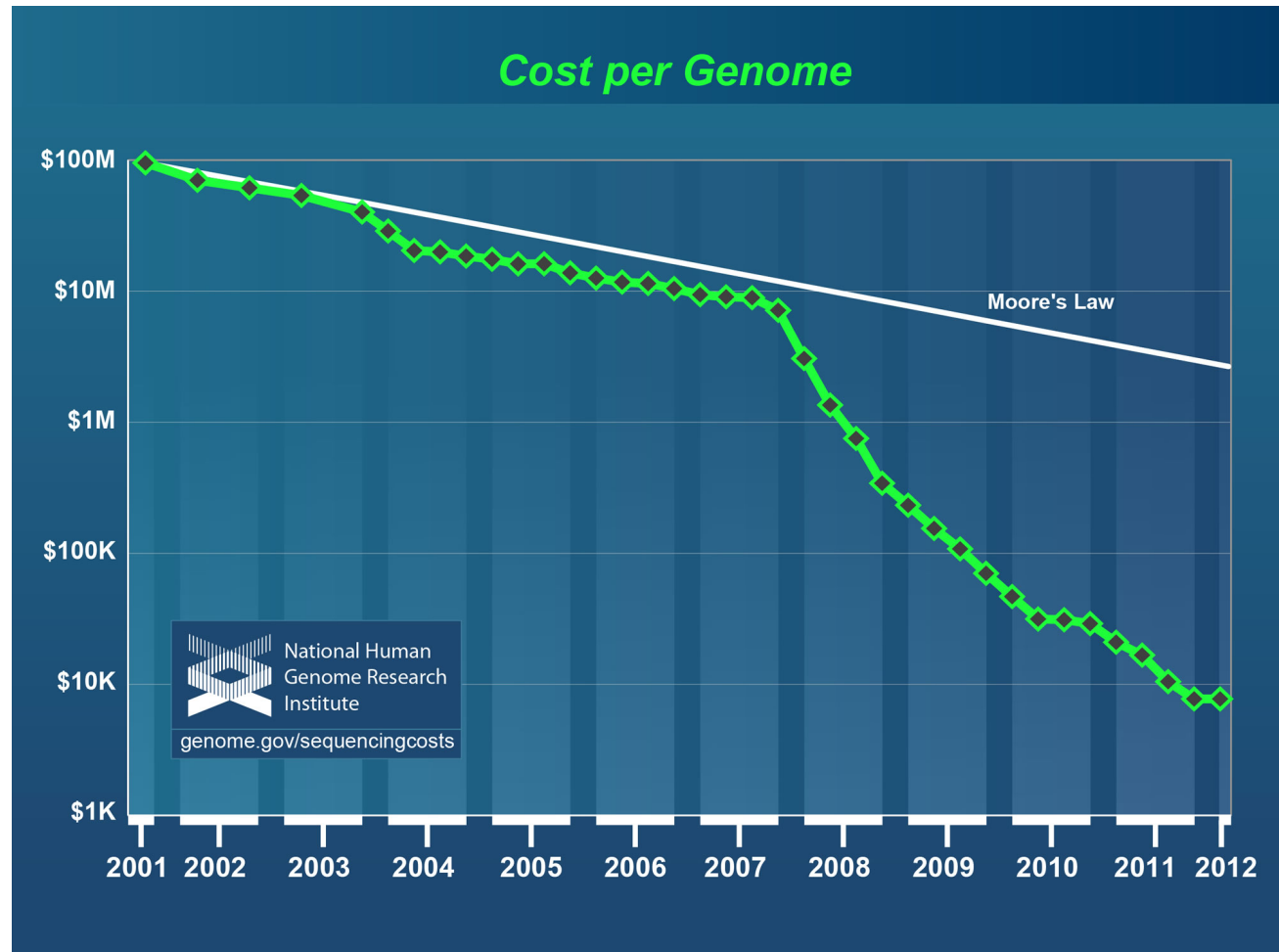


In fact, there are 40,000 medical applications available for download on smartphones and tablets—and the market is still in its infancy. But that growth is in the crosshairs of new regulatory efforts from the Food and Drug Administration.

Medical apps offer the opportunity to monitor health and encourage patient wellness on a moment-to-moment basis, instead of only during the occasional visit to the doctor's office. Some even replace devices used in hospitals and doctors' offices, such as glucometers and

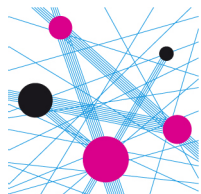
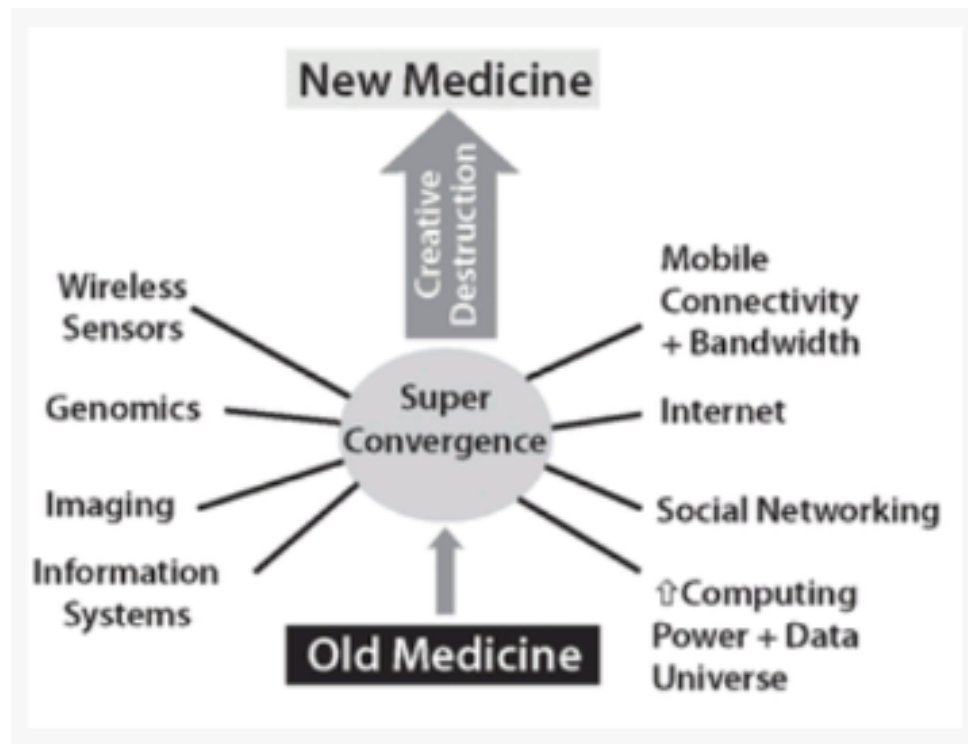


Preissturz beim Sequenzieren von Genomen





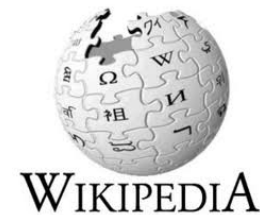
February 2012



Der Beginn einer Revolution

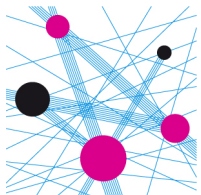


28 Jahre



1984 Commodore 64

2012

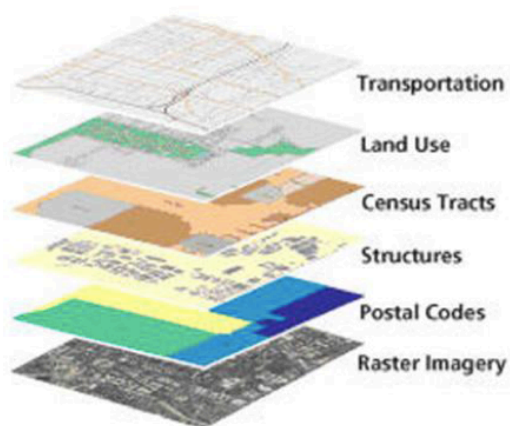


Google Maps der Gesundheit

Toward Precision Medicine: Building a Knowledge Network for Biomedical Research and a New Taxonomy of Disease

15

Google Maps: GIS layers Organized by Geographical Positioning



Information Commons Organized Around Individual Patients

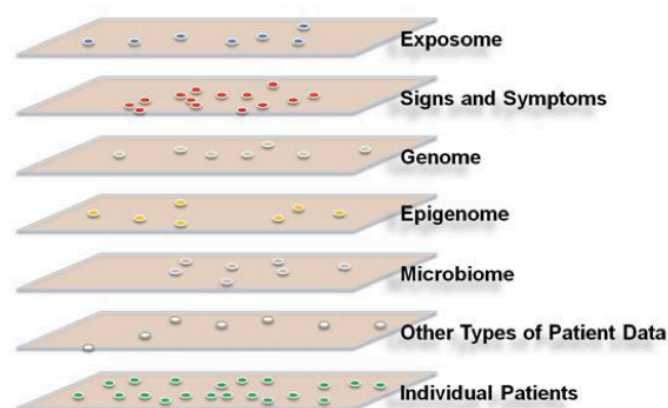
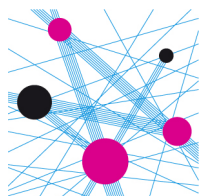
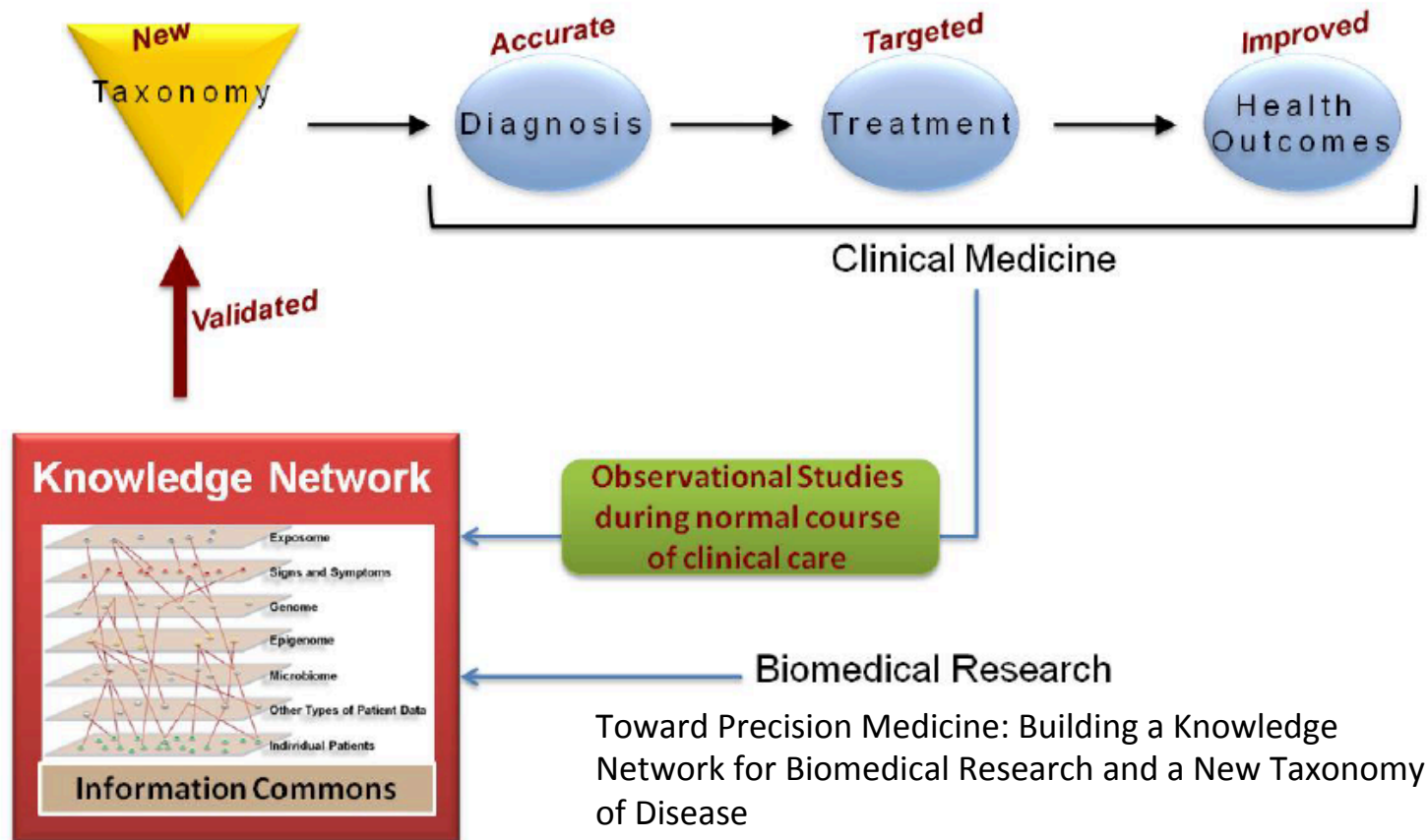


Figure 1-2: The proposed, individual-centric Information Commons (right panel) is somewhat analogous to a layered Geographical Information System (left panel). In both cases, the bottom layer defines the organization of all the overlays. However, in a GIS, any vertical line through the layers connects related snippets of information since all the layers are organized by geographical position. In contrast, data in each of the higher layers of the Information Commons will overlay on the patient layer in complex ways (e.g., patients with similar microbiomes and symptoms may have very different genome sequences). Source: FPA 2011 (left panel).

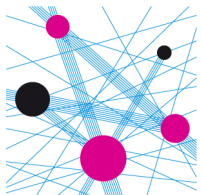
Ref: Toward Precision Medicine: Building a Knowledge Network for Biomedical Research and a New Taxonomy of Disease National Research Council of the National Academies of Sciences, USA 2012



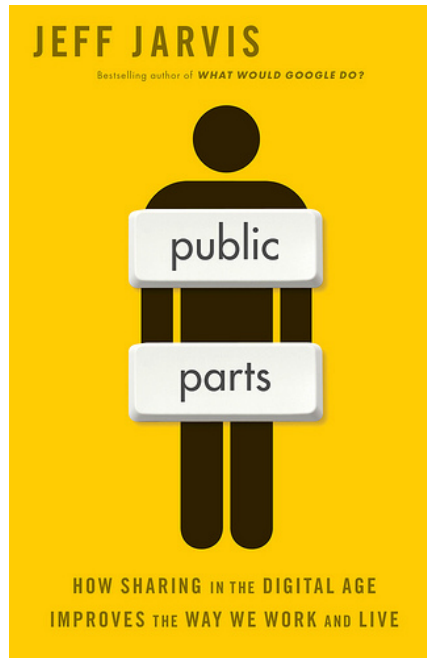
NRC 2012: Towards Precision Medicine



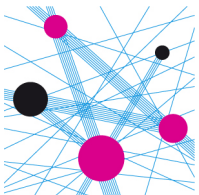
Toward Precision Medicine: Building a Knowledge Network for Biomedical Research and a New Taxonomy of Disease
National Research Council of the National Academies of Sciences, USA 2012



Die Privatsphäre im Zeitalter des Internets und der sozialen Netzwerke



- Eine neue Ethik des Teilens
- Teilen hat Vorteile: z.B.: Wikipedia, Khan Academy
- Neue Definition der Privatsphäre: (z.B: Facebook; Google Street View)
- *Publicness* als neuer Begriff
- Beispiel Gesundheit: Ergebnisse aus einer Konsultation beim Arzt kann für andere relevant sein



Call for a new social contract



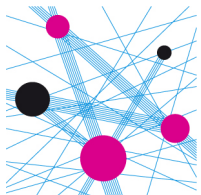
Susan Desmond-Hellmann
is the Chancellor of the
University of California, San
Francisco, San Francisco, CA
94143, USA.

out by Amy Dockser Marcus in the Wall Street Journal in 2006 (6). A unified group of patient advocates pushing government, academia, private industry, and caregivers to create a new social contract in which patients both contribute and benefit would be a powerful force. I cannot imagine a more effective way to create the world we imagined in “Precision Medicine” a reality.

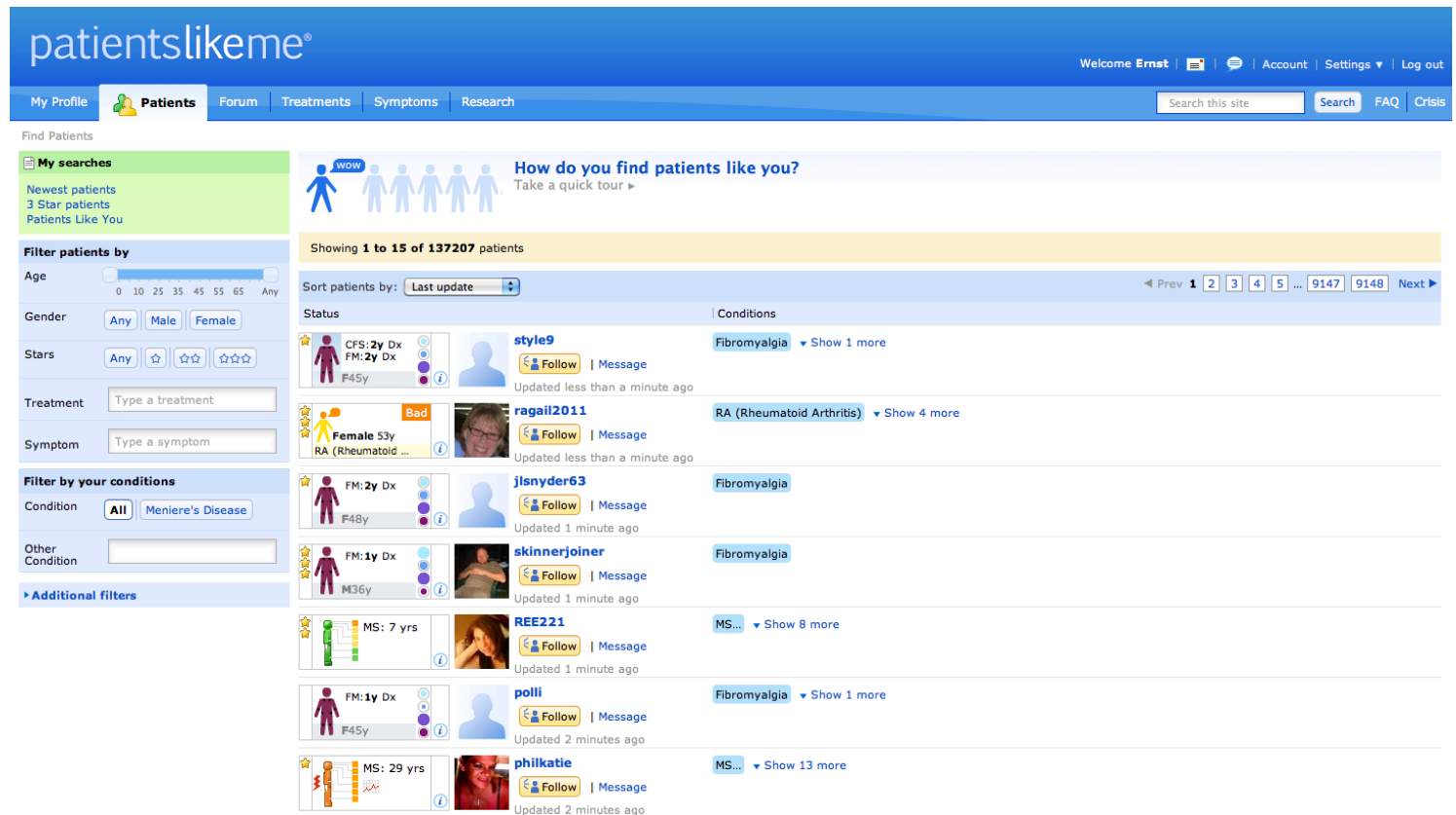
- Susan Desmond-Hellmann

Citation:

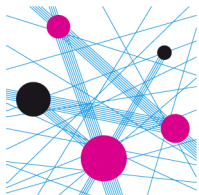
S. Desmond-Hellmann,
Toward Precision Medicine:
A New Social Contract? *Sci.
Transl. Med.* **4**, 127ed3 (2012).



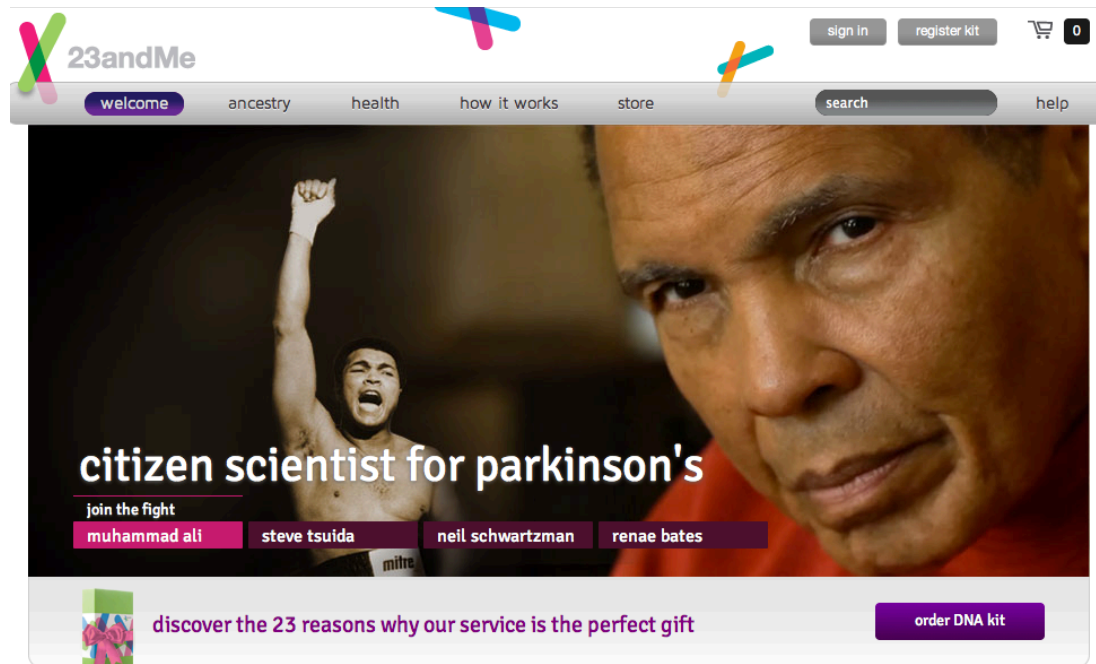
Beispiel **Patientslikeme**: Soziales Netzwerk für chronisch kranke Patienten – Patientendaten dienen der besseren Behandlung von Krankheiten (Fall Lithium und ALS)



The screenshot displays the Patientslikeme website interface. At the top, the header includes the site name "patientslikeme®" and navigation links for "My Profile", "Patients", "Forum", "Treatments", "Symptoms", and "Research". A search bar and links for "Search", "FAQ", and "Crisis" are also present. Below the header, the "Find Patients" section shows "My searches" with options for "Newest patients", "3 Star patients", and "Patients Like You". A filter section allows users to filter patients by age (0 to 65+), gender (Any, Male, Female), stars (Any, 1 to 5), treatment, and symptom. A "Filter by your conditions" section includes a condition dropdown (set to "All") and a text input for "Other Condition". The main content area displays a list of 137,207 patients, showing the first 15. Each patient entry includes a profile picture, a list of conditions (e.g., "CFS: 2y Dx", "FM: 2y Dx", "F45y"), a star rating, a name (e.g., "style9", "ragail2011", "jlsnyder63", "skinnerjoiner", "REE221", "polli", "philkatie"), and a "Follow" button. The list is sorted by "Last update" and includes pagination controls at the bottom.



Beispiel **23andme**: The Citizen Scientist – Crowd Sourcing medizinische Forschung (Bsp: Parkinson Krankheit)



the spittoon

MAR
03

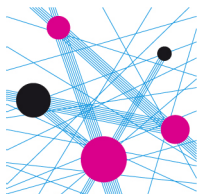
Thank You For Helping to Fight Rare Disease!

On Monday we kicked off a campaign for Rare Disease Day to raise awareness of research, especially into two rare diseases, myeloproliferative neoplasms (MPN) and sarcoma. We hoped to reach 500 participants in our MPN research initiative and 800 participants in our Sarcoma Community by today, and are happy to say that with your help [...]

video tutorials



explore our collection of
education materials



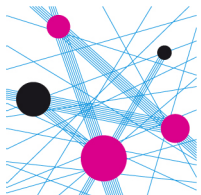
Beispiel **Neurimmune AG** (Zürich Schlieren): Antikörper aus gesunden älteren Menschen gegen Alzheimer als Medikamente



Old age – life worth living for everyone.
Margit Haase (1904). She can teach us so much.

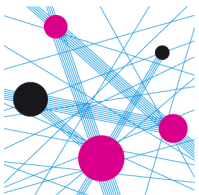
neurimmune
Prominent antibody therapeutics

The image shows a portrait of an elderly woman, Margit Haase (1904), on the left. To the right is a green rectangular area containing a white right-pointing arrow and the text 'Old age – life worth living for everyone. Margit Haase (1904). She can teach us so much.' Below this is the Neurimmune logo, which consists of a stylized 'Y' shape and the text 'neurimmune Prominent antibody therapeutics'.



Crowd Sourcing von Gesundheitsdaten

- Jedes Individuum ist verschieden (Genom – Umwelt – Verhalten).
- Sinkende Genomkosten erlauben Einsicht in die persönliche Grundlagen von Gesundheit und Krankheit (Medikamentendosierung, Krebsbehandlung).
- Smartphones ermöglichen kontinuierliches Monitoring von persönlichen Gesundheitsdaten.
- Zusammenhänge zwischen Genom, Umwelt und Gesundheit können nur durch die Analyse grosser Datensätze gefunden werden.
- Jeder kann mit seinen anonymisierten Daten einen Beitrag zu einer personalisierten Gesundheit leisten (Bsp. Blutspenden). > Wikipedia Prinzip in der Gesundheit.



Diskussionspunkte

- Wie können die Chancen dieses Ansatzes genutzt und die Risiken gleichzeitig minimiert werden?
- Wem gehören Gesundheitsdaten?
- Wie sicher sind sie?
- Wie kann Diskriminierung verhindert werden?
- Wer soll davon profitieren können?
- Welche Rolle sollen der Staat und Private spielen können?
- Würden Sie Ihre Gesundheits- und Genomdaten in anonymisierter Form zur Verfügung stellen > Ein Wikipedia der Gesundheit?

