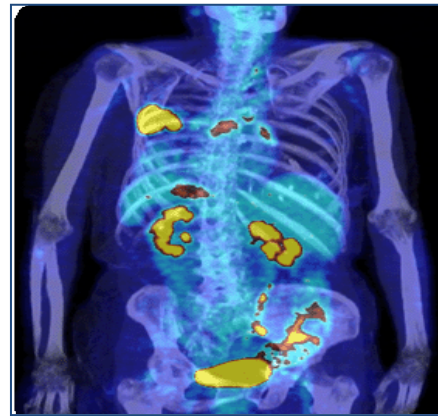


Personalisierte Medizin aus Patientensicht: Nutzen oder Überforderung?



Barbara Prainsack Dr phil FRSA
Professor of Sociology and Politics of Bioscience, Brunel University,
London

Personalised Medicine for the European Citizen - towards more precise medicine for the diagnosis, treatment and prevention of disease

ACTIVITIES - Timeline

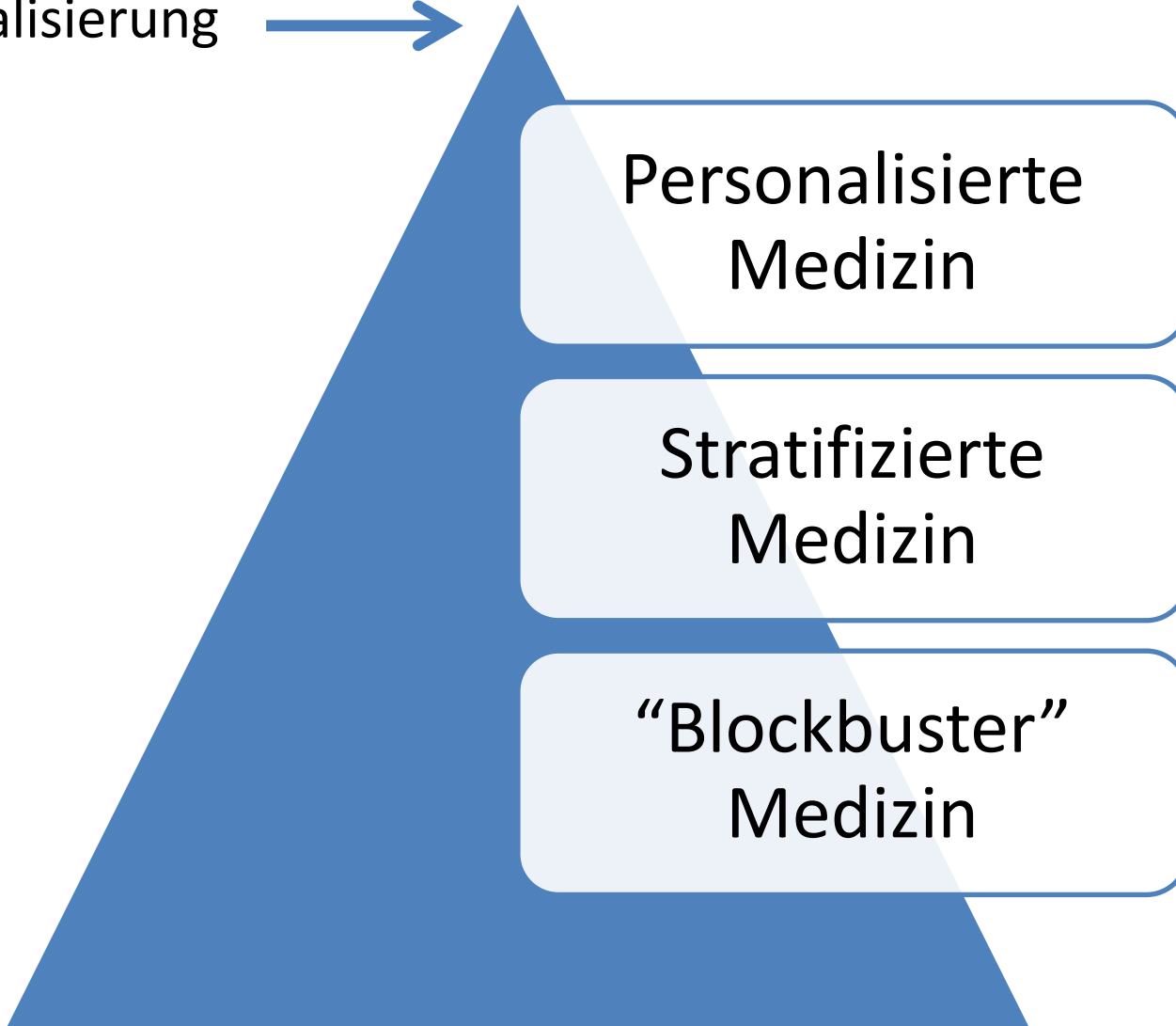
Activity	Date	Location
Technology Workshop	19-20 September 2011	London, UK
1st meeting of the Scientific Committee	20 September 2011	London, UK
Disease Summit	18-20 October 2011	The Hague, NL
2nd meeting of the Scientific Committee	20 October 2011	The Hague, NL
Interview phase	October - November 2011	
3rd meeting of the Scientific Committee - Clustering/ filtering of big picture topics	21 November 2011	London, UK
Big Pictures Workshops	13-14 February	Dubrovnik, HR

Further pages:

- [Summary](#)
- [More information](#)
- [Scientific Committee](#)
- [Management Committee](#)
- [Contacts](#)

- ▶ EuroBioFund
- ▶ EUROCORES
- ▶ Exploratory Workshops
- ▶ **Forward Looks**
- News
- All Current and Completed Forward Looks
- Space Sciences (SSU)
- Humanities (SCH)
- Life, Earth and Environmental Sciences (LESC)
- Medical Sciences (EMRC)**
- Presentations Library
- Physical and Engineering Sciences (PESC)
- Social Sciences (SCSS)
- Workshop scheme
- ▶ Calls and Funding
- ▶ MO Fora
- ▶ Research Networking Programmes
- ▶ ESF Research Conferences
- ▶ Science Policy
- ▶ ESF Meetings
- ▶ European Latsis Prize 2012
- ▶ Peer Review
- ▶ ESF Symposia

Individualisierung



Personalisierte
Medizin

Stratifizierte
Medizin

“Blockbuster”
Medizin

Personalisierte Medizin (ESF FL “working definition”, 2012):

Eine Medizin, die individuelle Unterschiede soweit wie möglich berücksichtigt (in allen Phasen der medizinischen Forschung und Praxis)

Herausforderungen der datenintensiven Medizin:

- Qualität
- Integration
- Interpretation
- Auswertung

Patientinnen und Patienten spielen hier
eine immer bedeutsamere Rolle, auch in
der Generierung der Daten



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video tutorials





RESEARCH ARTICLE



Efficient Replication of over 180 Genetic Associations with Self-Reported Medical Data

Article

Metrics

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Comments: 0

Joyce Y. Tung^{1*}, Chuong B. Do¹, David A. Hinds¹, Amy K. Kiefer¹, J. Michael Macpherson¹, Arnab B. Chowdry¹, Uta Francke^{1,2}, Brian T. Naughton¹, Joanna L. Mountain¹, Anne Wojcicki¹, Nicholas Eriksson¹

1 23andMe, Inc., Mountain View, California, United States of America, **2** Department of Genetics, Stanford University, Stanford, California, United States of America

Abstract [Top](#)

While the cost and speed of generating genomic data have come

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Perspective

The Missing Voice of Patients in Drug-Safety Reporting

Ethan Basch, M.D.

N Engl J Med 2010; 362:865-869 | [March 11, 2010](#)

[Article](#)[References](#)[Citing Articles \(38\)](#)

A patient wants to know about symptoms she may have from a prescription drug she is taking. Consulting the label's "Adverse Reactions" section, she finds a wealth of data. Little does she

MachaDesu
shared basic info



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Accelerated clinical discovery using self-reported patient data collected online and a patient-matching algorithm

Paul Wicks, Timothy E Vaughan, Michael P Massagli & James Heywood

[Affiliations](#) | [Contributions](#) | [Corresponding author](#)

Nature Biotechnology 29, 411–414 (2011) | doi:10.1038/nbt.1837

Received 02 April 2010 | Accepted 10 March 2011 | Published online 24 April 2011

Abstract

[Abstract](#) • [Author information](#) • [Supplementary information](#)

Patients with serious diseases may experiment with drugs that have not received regulatory approval. Online patient communities structured around quantitative outcome data have the potential to provide an observational environment to monitor such drug usage and its consequences. Here we describe an analysis of data reported on the website PatientsLikeMe by patients with amyotrophic lateral sclerosis (ALS) who experimented with lithium carbonate treatment. To reduce potential bias owing to lack of randomization, we developed an algorithm to match 149 treated patients to multiple controls (447 total) based on the progression of their disease course. At 12 months after treatment, we found no effect of lithium on disease progression. Although observational studies using unblinded data are not a substitute for double-blind randomized control trials, this study reached the same conclusion as subsequent randomized trials, suggesting that data reported by patients over the internet may be useful for accelerating clinical discovery and evaluating the effectiveness of drugs already in use.

Das quantifizierte Selbst



Search

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Your Health

- Personal information
- Condition scores
- Daily tracking
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Connect

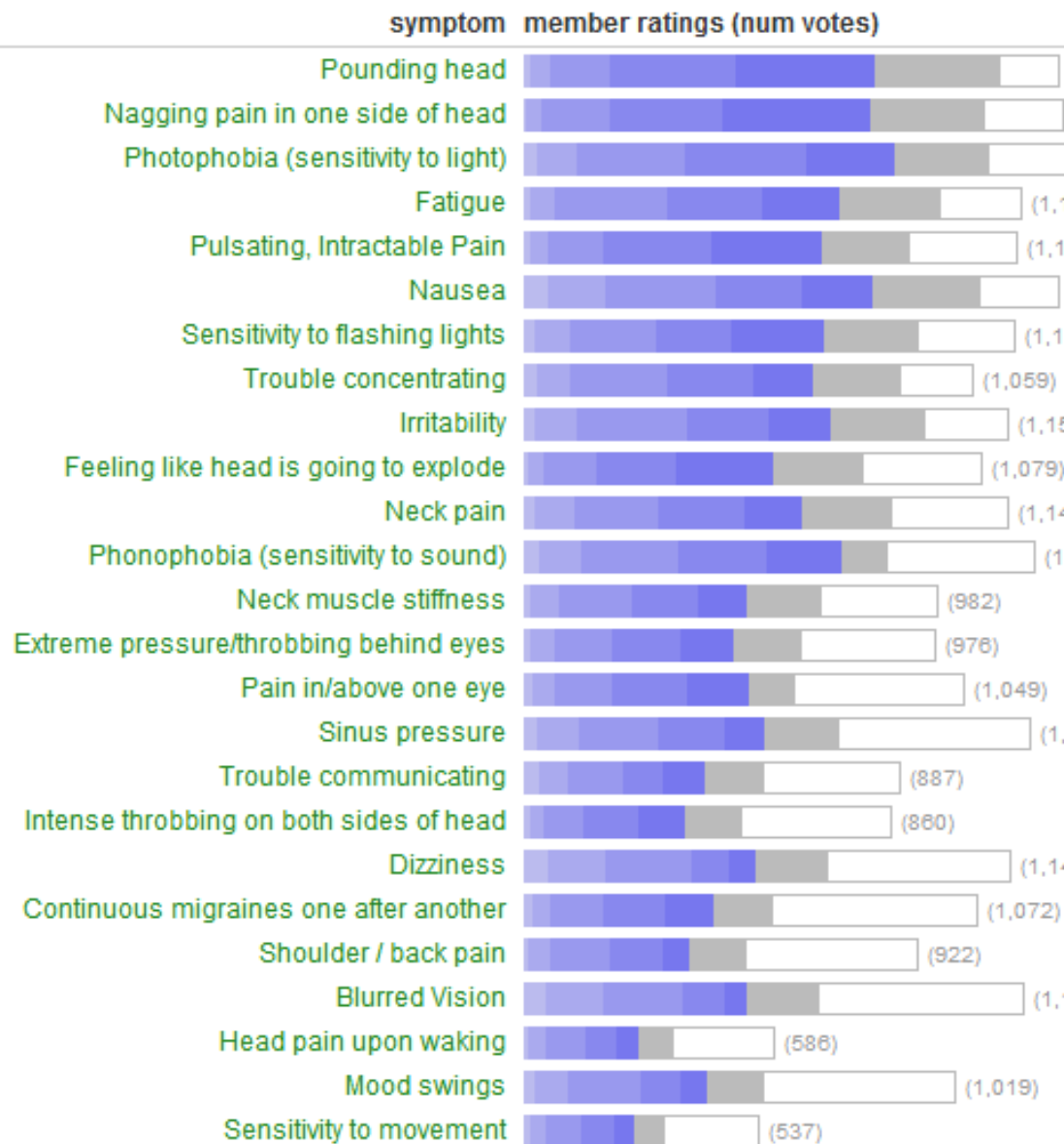
- Members like you
- Inbox
- Invite

Settings

- Sign out

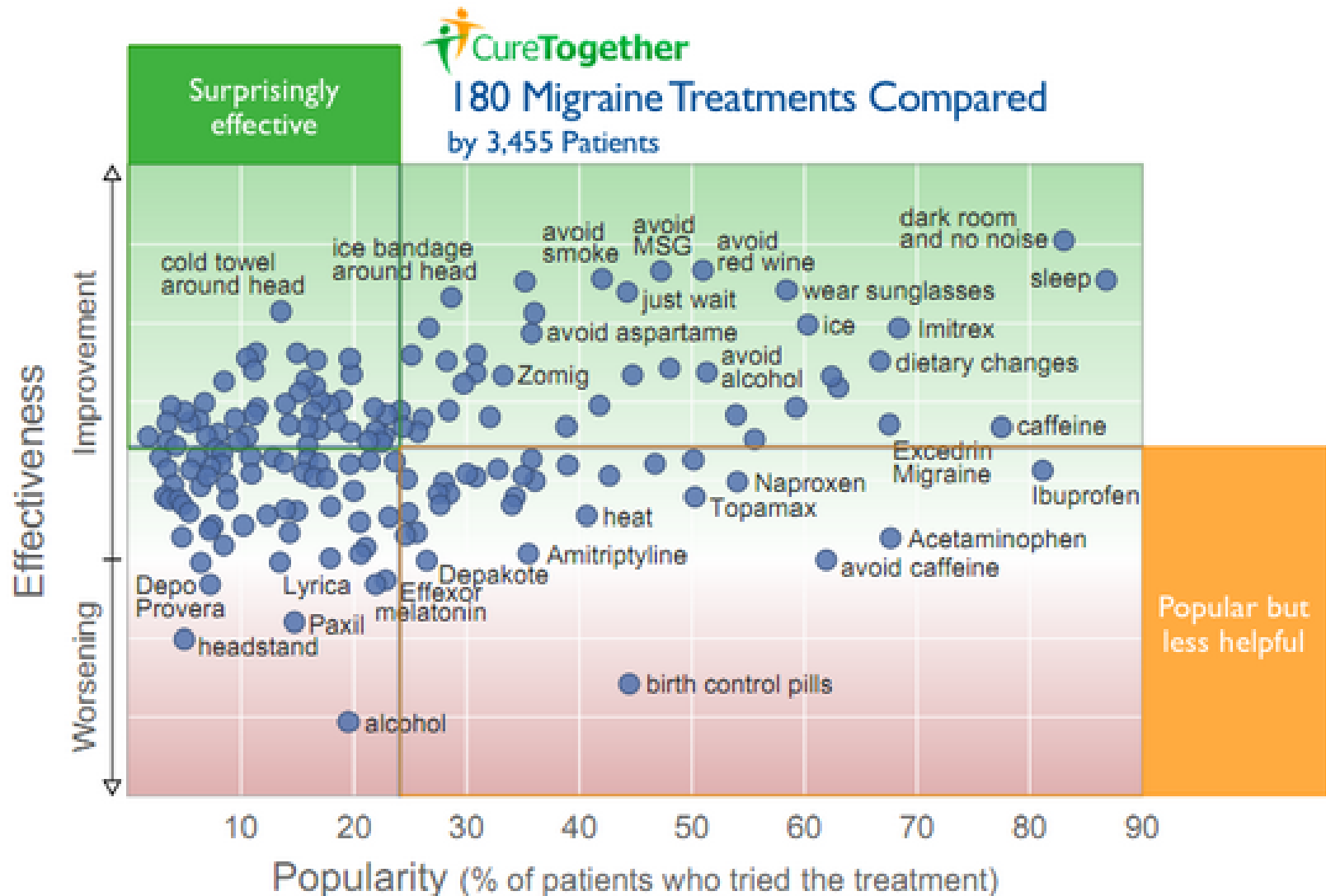
Symptom Severity Scale

-  extreme
-  severe
-  moderate
-  mild
-  minimal
-  no rating
-  did not have symptom



Avoidance of Triggers is Best for Migraine: Results of Patient Study Comparing 180 Treatments

September 12th, 2011 Alexandra Carmichael Posted in [Infographics](#), [Research Findings](#) | [13 Comments](#)



LORENZO'S BRAIN

THIS WEBPAGE IS INTENDED TO BE READ BY A SPECIALIST IN NEURORADIOLOGY OR NEUROSURGERY. I PUBLISH THESE PERSONAL DATA OF MINE WITH THE PURPOSE TO HAVE EXPERT OPINIONS AND GET USEFUL TECHNICAL SUGGESTIONS ON HOW TO SAFELY GET RID OF THIS 3 CM AVM SITTING IN THE DOMINANT HEMISPHERE OF MY BRAIN.

THURSDAY

What's the best decision to make?

Hi there,

my name is Lorenzo, I'm a biotechnology researcher, I am 27 and I'm writing from Italy. Since I was a child I have experienced the occurrence of generalized seizures, however such phenomena were rather sporadic and resembling normal faintings, so I haven't investigated the problem for long time. When I was 22 I went to see a neurologist after a new epileptic fit and she prescribed an MRI exam. So did I, discovering an **arteriovenous malformation** in the left frontal area of my brain. My reaction was rather careless about it, so I didn't take care of the AVM nor did I want to take an anti-epileptic medication. I just continued my normal life without any trouble.



Hello, here I am!



concerned about my lesion and decided to do so.
Fortunately my AVM has never bled, and who knows
and especially the constant thought of such risk.
So at this point I have my mind made up: I will
turns up: what treatment? I have a choice to make
been offered different solutions and many of them
is: "there's more than one option, it's up to you to
But I am in a funny situation where I have to decide
even have one symptom. What am I gonna do?
Basically I should pick one of three options:

1. Direct surgical excision of the AVM
2. Partial embolization to achieve a flow reduction
nidus.
3. Nidal embolization as a cure, eventually in multiple
obliteration.



What do you suggest?

Die partizipative Wende



Datensammlung



Analyse



Interpretation/Anwendung

Nutzen oder Überforderung?

- Patientengenerierte Daten sind in mancher Hinsicht nuancierter und sensibler
- Patientengenerierte Daten außerhalb des Gesundheitssystems lassen sich für Prävention, Diagnose, oder Therapie nutzbar machen
- Selbstbestimmtere Patienten
- Spareffekt durch „Delegation“ bestimmter Aufgaben auf Patienten

Nutzen oder Überforderung?

- Zugangsschranken zu internetbasierten Hilfsmitteln
- Die Integration verschiedener Datensätze bringt immer auch Risiken mit sich
- Datensicherheit
- Qualitätskontrolle
- Wird das Recht auf mehr Kontrolle zur Pflicht, diese auch auszuüben?

Neue Formen von
Mitwirkung von
Patientinnen und
Patienten in allen
Bereichen der
medizinischen
Forschung und Praxis

Personalisierte
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“Blockbuster”
Medizin

Vielen Dank für Ihre
Aufmerksamkeit!

barbara.prainsack@brunel.ac.uk