

Das Forum für ICT im Gesundheitswesen
Le forum pour les TIC dans le système de santé




SGMI SSIM SSMI
Schweizerische Gesellschaft für Medizinische Informatik
Société Suisse d'Informatique Médicale
Società Svizzera d'Informatica Medica
Swiss Society for Medical Informatics

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SwissTech Convention
Center, Lausanne
21.-22. September 2017

“May I Please Have My Data? A polite request from a Swiss patient”

Karin Holm, President, Patient Advocates for Cancer Research & Treatment (PACRT)

 @ karinholmjr

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“May I Please Have My Data? A Polite Request from a Swiss Patient”

- Patient perspective on digital health in Switzerland.
- Patient empowerment via a portal to electronic health records.
- Benefits of research data control by citizens/patients.
- Concerns about and asks to improve digital health

Breast Cancer Survivor thanks to all the science, clinical research, and women who came before me.



Geneva, Switzerland

My experience with digital health in Switzerland

- Diagnosed early stage breast cancer in 2012.
- Great medical team in Geneva, treated successfully, great outcome.
- No information provided in writing. Trust me. Fine.
- Internet www.breastcancer.org women sharing with women
- Second opinion, interviewed 3 surgeons before selecting.
- Oncologist gave me article by Hood & Friend on P4 cancer medicine (preventive, predictive, personalized, participatory).
- Involved EUPATI-CH, Swissethics committee Geneva, SBP WG, etc.

My Own And Other Patient's Research Questions



Wilbanks TEDTalk:
Let's Pool Our
Medical Data



5

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Breast Cancer in Switzerland



*estimation 2015**
(incl. invasive BC only)

76,500 women currently living with BC

1/8 ♀ Swiss Women

6,200 new women diagnosed annually

1,400 deaths annually

1st cause of death in women in age range 40-50 years old



association savoir patient
réseau cancer du sein
comité qualité de vie
et cancer du sein
observatoire des
effets adverses



krebsliga schweiz
ligue suisse contre le cancer
lega svizzera contro il cancro



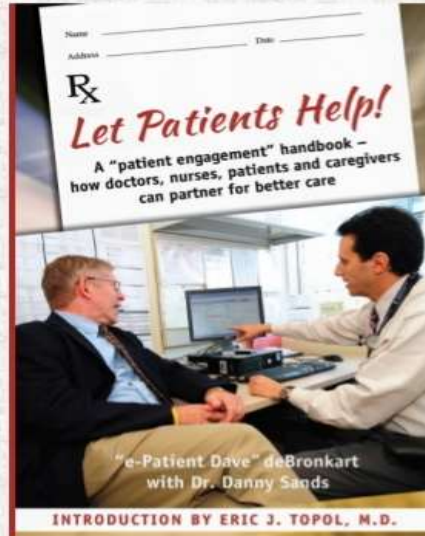
To family and friends lost to breast cancer in Switzerland,
U.S., UK, France, Denmark, The Gambia, Ghana, the world...



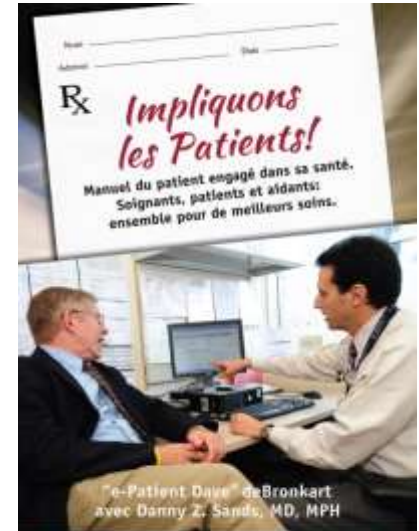
American approach: bold, quick,
customer is always right



“Gimme my
damn data.”
e-Patient Dave
deBronkart




Swiss culture : diplomacy,
cooperation, careful
analysis



INTRODUCTION ÉCRITE PAR ERIC J. TOPOL, MD

bH

Swiss Patient Portal to Electronic Health Records?


Connecté à ma santé

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RANDALL Karin Holm

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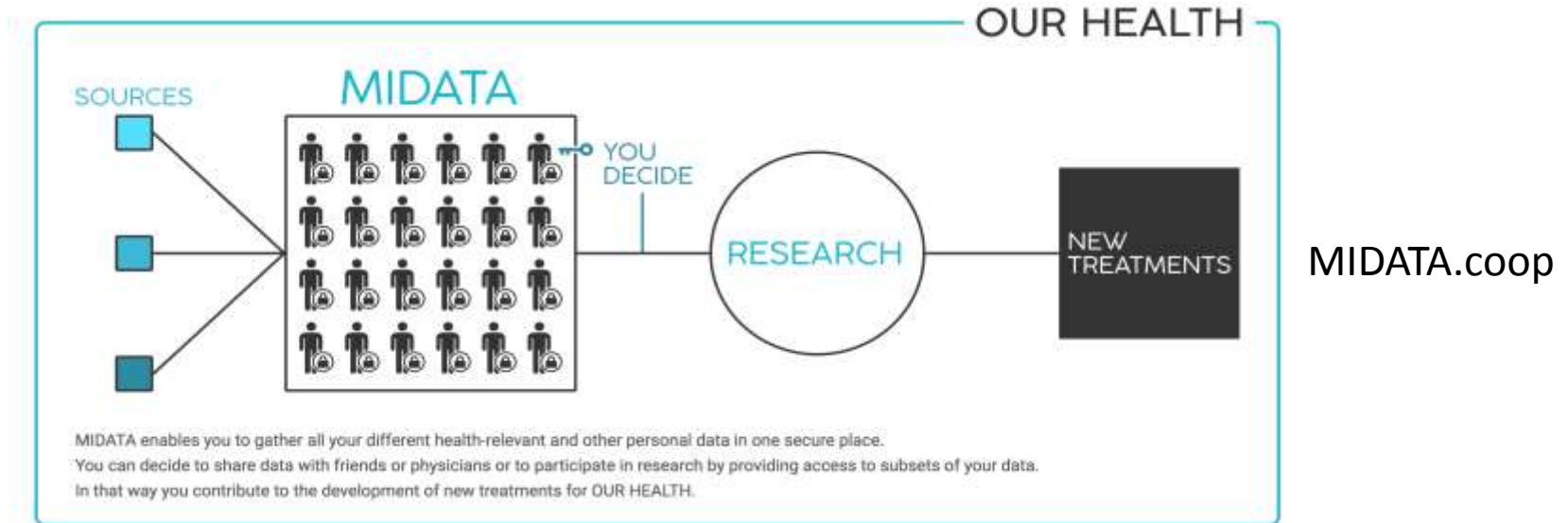

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My Private Medical Data Is Valuable

The screenshot shows the Guardian website interface. At the top, there are navigation links for 'sign in', 'become a supporter', 'subscribe', and 'search'. The Guardian logo is prominently displayed on the right. Below the logo, there are category links: 'UK', 'world', 'sport', 'football', 'opinion', 'culture', 'business', 'lifestyle', 'fashion', 'environment', 'tech', and 'travel'. A 'browse all sections' button is also visible. The main content area features a 'Big data' sub-header and the article title 'Your private medical data is for sale - and it's driving a business worth billions'. The author is identified as 'Sam Thierman in New York' with a Twitter handle '@samthierman'. The article is dated 'Thursday 10 January 2017 13:00 GMT'. Below the text, there is a photograph of a person lying in a hospital bed with an IV drip. To the right of the article, there is an advertisement titled 'Governed Self' with a red background and a white arrow pointing right.

MIDATA.coop Citizen-controlled Data Storage and Sharing



Please Give Me My Data - We are asking politely now...

- Let me access my health records electronically and securely from home or mobile device (e.g. mondossiermedical.ch).
- Allow me to decide who has access to my data and who will benefit from it.
- Permit me to efficiently donate my data to benefit other patients and society at large (e.g. MIDATA.coop).
- Let most research be patient-driven (even pharma, biotech, academic research) to answer questions that are most important to patients to prevent disease, get healthy, and stay healthy -- as naturally as possible.