“May I Please Have My Data? A polite request from a Swiss patient”
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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.
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](http://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
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
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
Swiss Patient Portal to Electronic Health Records?
My Private Medical Data Is Valuable

Your private medical data is for sale – and it’s driving a business worth billions

Although information is anonymized, data miners and brokers can build up detailed dossiers on individual patients by cross-referencing with other sources.
MIDATA.coop Citizen-controlled Data Storage and Sharing

MIDATA enables you to gather all your different health-relevant and other personal data in one secure place. You can decide to share data with friends or physicians or to participate in research by providing access to subsets of your data. In that way you contribute to the development of new treatments for OUR HEALTH.

MIDATA.coop
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.