



My Medical Record Rare Diseases Day 2016

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"MY Medical Record" The problem

- Elvira has CMTC
- She has a medical problem during the weekend
- The GP replacement doesn't have her data: can't help
- Professor offered help at the weekend
- All she needs is a referral









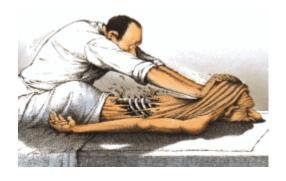
My Medial records (1)

Data is currently not in one place (fact)











Out of Hours?





My medical record (2)

Potential consequences of non-centralised data

Medical mistakes (not up-to date and not a complete overview)
Time consuming and awkward (e.g. At another hospital)
Data not available 24 hrs (in case of accidents, when abroad)
Rare diseases (what to do and what NOT to do)



Why can I access my bank accounts worldwide at any time Why can I access my tax records worldwide at any time.

Why can't I access my medical records?







My medical records(3)

Consequences for the patient (and their family)

(Serious / Permanent) physical damage or even death Psychological damage Lack of confidence in medical personell



Ownership and Responsibility

Who is actually the owner of MY medical record?
Who is actually responsible for the accuracy of my medical data?



Cost of Health care (meaning: insurance costs)

What are the costs of medical mistakes as a result of.... What are the costs of all the duplicated databases....







In development and existing - EPHR's









And more ??







The Solution







The Question

Who is ACTUALLY going to do what and when?



Highlights

- The patient is central
- 2. Less bureaucracy
- 3. Lower cost





