Making a case for easily accessible electronic health records
- A patient perspective on lack of availability of health information in critical situations

A basic problem: There are many research articles out there that investigate the effects of patient accessible electronic health records, but very few of these are written from a patient perspective. Since I’m both a researcher and a patient, suffering from a chronic rheumatic disease, I therefore chose to make a workshop contribution from the patient’s perspective!

Main point: For patients dependent on immunosuppressive medication, like I am, there could be a potential danger in not having access to one’s own electronic health records.

A scenario:

Monday
- Ordinary checkup with basic blood work

Thursday
- Physician calls in the afternoon to tell me the immune system is way too low

Friday
- Cancelled conference trip to Portugal (due to obvious health risks)

Identified problems:
• I felt fine the entire week → no reason for me to call the hospital!
• I was dependent on this particular physician’s calling hours
• I could have become very sick while abroad or during a flight

There are situations in which patient access to electronic health records, and especially test results, could make all the difference, especially for patients who could regularly be in a bad shape without noticing it!