
DIGITAL HEALTH VS. PATIENT PRIVACY (GENERAL DATA PROTECTION REGULATION): IS THE FUTURE HERE TO STAY?

ISPOR EU 2018 Conference
Issues Panel



ISSUE

- Healthcare systems stakeholders are looking to reduce inefficiencies, remove redundancies, personalize treatments, improve healthcare quality, and patient access, whilst trying to reduce healthcare costs.
- For digital health to function, end users (patients) are required to provide all of their tracking data.
- As of May 2018, European patients are protected by General Data Protection Regulation (GDPR).



PANEL

- **Moderator:** Carl V. Asche, PhD, Professor of Medicine, Director, Center for Outcomes Research, University of Illinois College of Medicine;
- **Panelist(s):**
 - Katarzyna Kolasa, PhD, Professor of Health Economics, Head of Department, Health Economics and Healthcare Management, Kozminski University.
 - Ken Redekop, PhD, Associate Professor, Erasmus School of Health Policy & Management, Erasmus University Rotterdam.
 - Vladimir Zah, DPhil, Visiting Professor of Health Economics, Health Economics and Healthcare Management, Kozminski University.
- Debate the pros and cons of GDPR and whether digital health is in survival mode.



BACKGROUND

- General Data Protection Regulation (GDPR) .
- GDPR will be directly applicable in all EU Member States.
- GDPR remains under negotiation.





GDPR FEATURES

- Worldwide territorial scope.
- Enhancements.
- One-stop shop.
- Sanctions.

WAYS BY WHICH GDPR WILL AFFECT THE HEALTHCARE INDUSTRY



THE UNIVERSITY OF ILLINOIS
COLLEGE OF MEDICINE
PEORIA CHICAGO ROCKFORD URBANA

COR
CENTER FOR OUTCOMES RESEARCH

SAFER PERSONAL DATA

- The GDPR mandates that data breaches must be reported.
- Concern that GDPR will severely impact ability to engage with customers and prospects.
- GDPR presents a great opportunity to build trust.



THE UNIVERSITY OF ILLINOIS
COLLEGE OF MEDICINE
PEORIA CHICAGO ROCKFORD URBANA



DETAILED PATIENT PROFILES

- The data footprint of an individual is usually highly fragmented.
- Healthcare providers will have a more detailed view.
- GDPR enshrines the right to be forgotten, which could emerge as a barrier to improved diagnosis.
- Legal requirement for all healthcare providers to retain records for a prescribed period in case of query.
- The GDPR places a framework around this data.



THE UNIVERSITY OF ILLINOIS
COLLEGE OF MEDICINE
PEORIA CHICAGO ROCKFORD URBANA



PUTTING PATIENTS IN CONTROL

- Healthcare is the one area of our lives that has remained highly sensitive and private.
- Some of the new data-subject rights also help customers feel in control.
- The framework is there to give the user control; but how?



THE UNIVERSITY OF ILLINOIS
COLLEGE OF MEDICINE
PEORIA CHICAGO ROCKFORD URBANA



USING NEW DATA SOURCES

- Research has found that healthcare is the industry the general public most trusts with its personal data.
- Technologies from social networking are increasingly being used to deliver patient care and support.
- Hospify encrypts and delivers text messages from phone-to-phone.



THE UNIVERSITY OF ILLINOIS
COLLEGE OF MEDICINE
PEORIA CHICAGO ROCKFORD URBANA



FROM DATA INSIGHTS TO BETTER PREVENTION

- The success of ERNs also depends on big data.
- The masses of data that healthcare organizations have been collecting for decades is still often unstructured and inaccessible.
- The GDPR is a reason for the health sector to be excited.



THE UNIVERSITY OF ILLINOIS
COLLEGE OF MEDICINE
PEORIA CHICAGO ROCKFORD URBANA

