

Data Privacy/Ethics in Telemedicine

W231 Final Project
(Behind the Data: Humans & Values Course)
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Executive Summary

- Telemedicine scope and information flow
- Growth and Use cases
- Regulations in Place
- Data leakage and Security Issues
- Perspective of Privacy Frameworks
- Cost Benefit versus Privacy
- Recommendations

Uber : Transportation / Telemedicine : Healthcare

Defining Telemedicine

- According to the American Telemedicine Organization
 - “Telemedicine is the use of medical information exchanged from one site to another via electronic communications to improve a patient’s clinical health status. Telemedicine includes a growing variety of applications and services using two-way video, email, smart phones, wireless tools and other forms of telecommunications technology”.

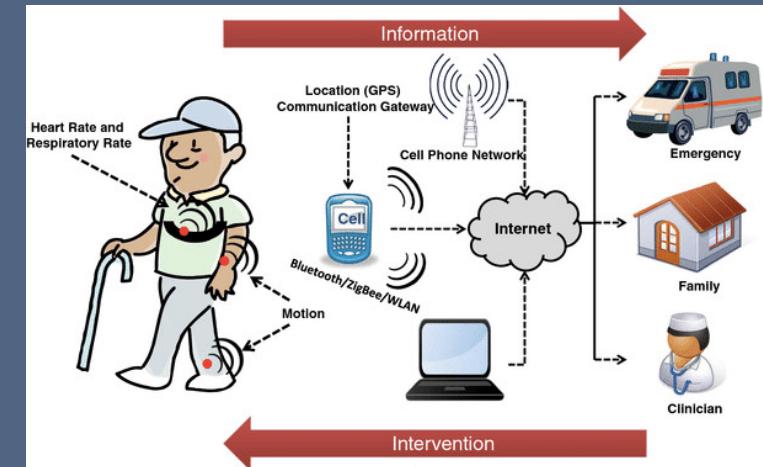
Four Engagement Models



1. Live Interaction



2. Store and forward

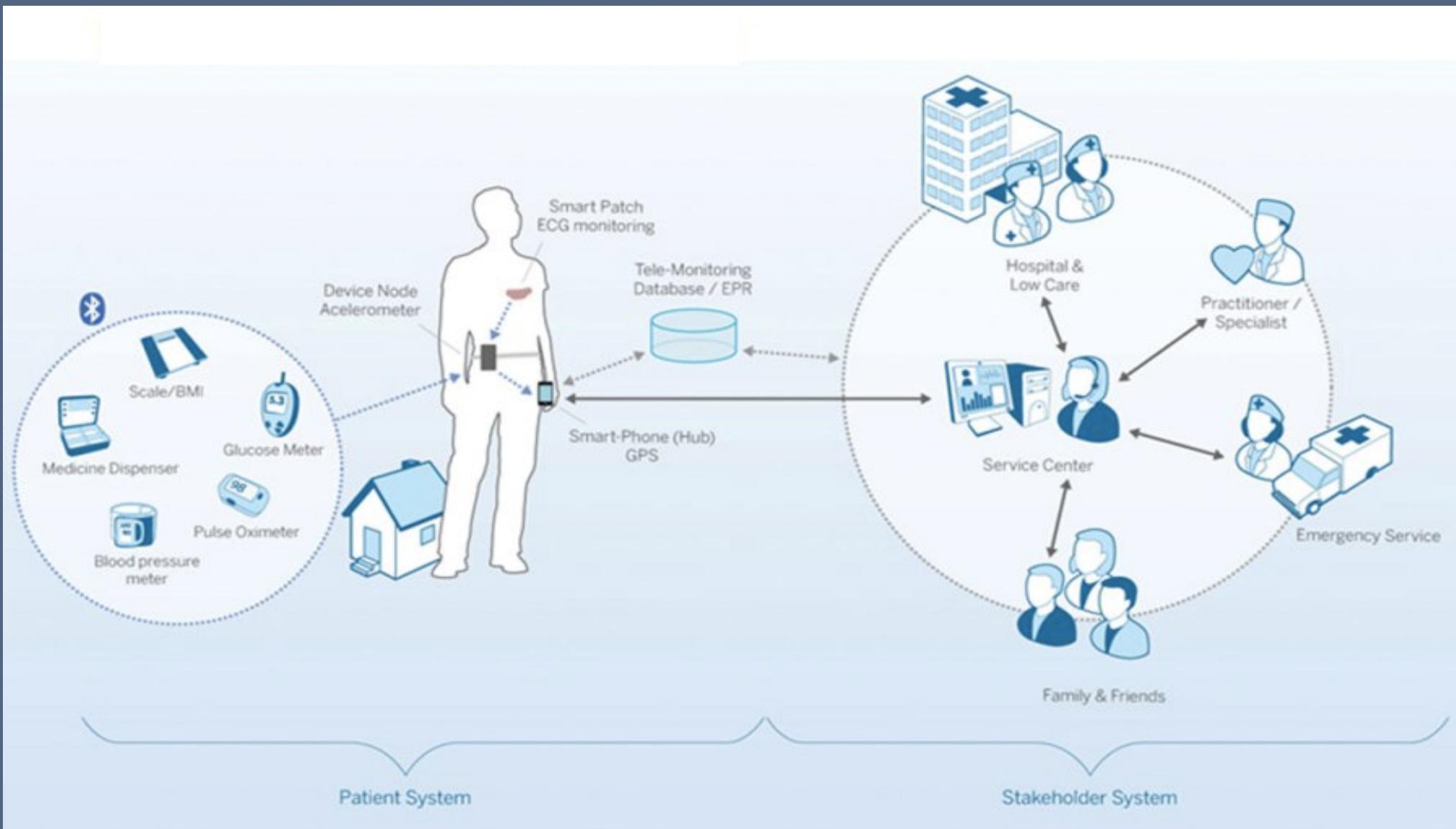


3. Remote Patient Monitoring

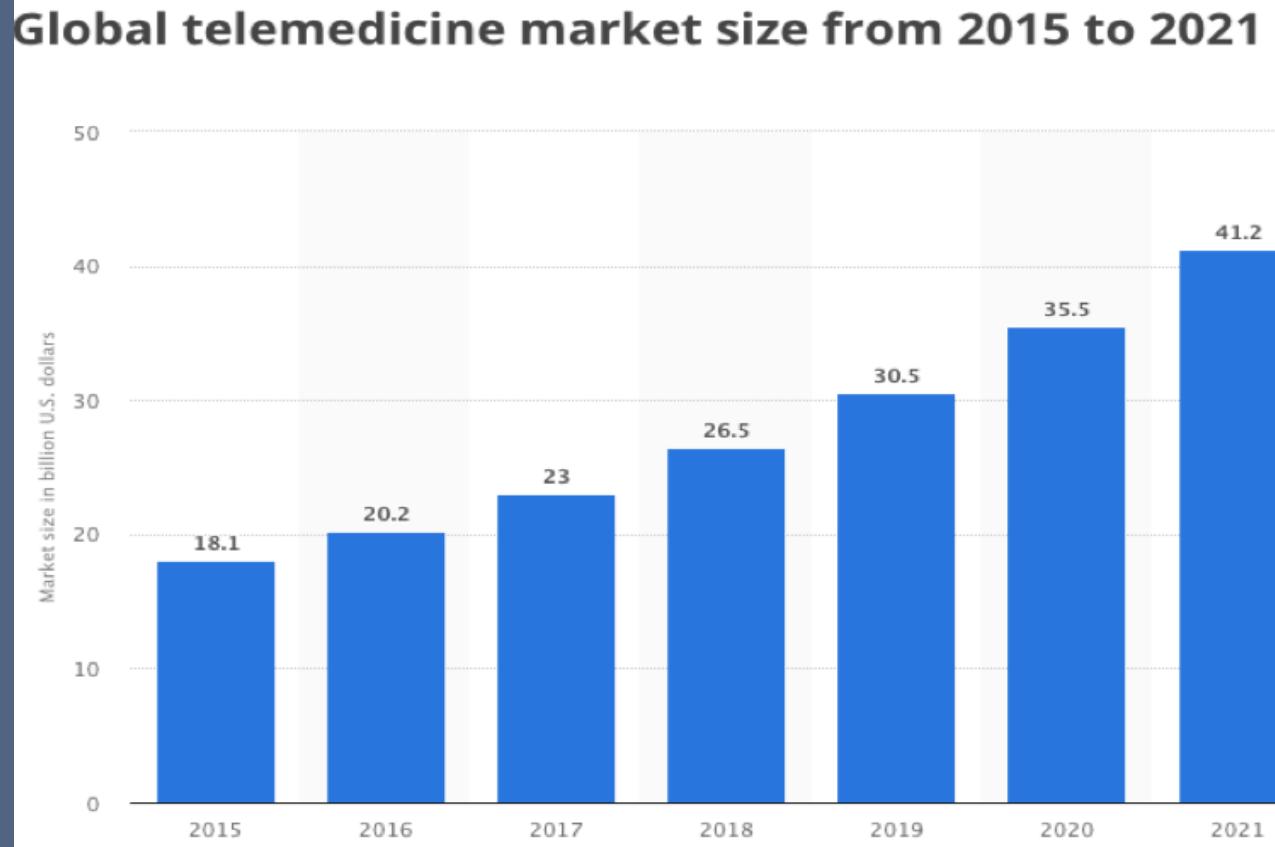


4. Provider initiated Health gadget

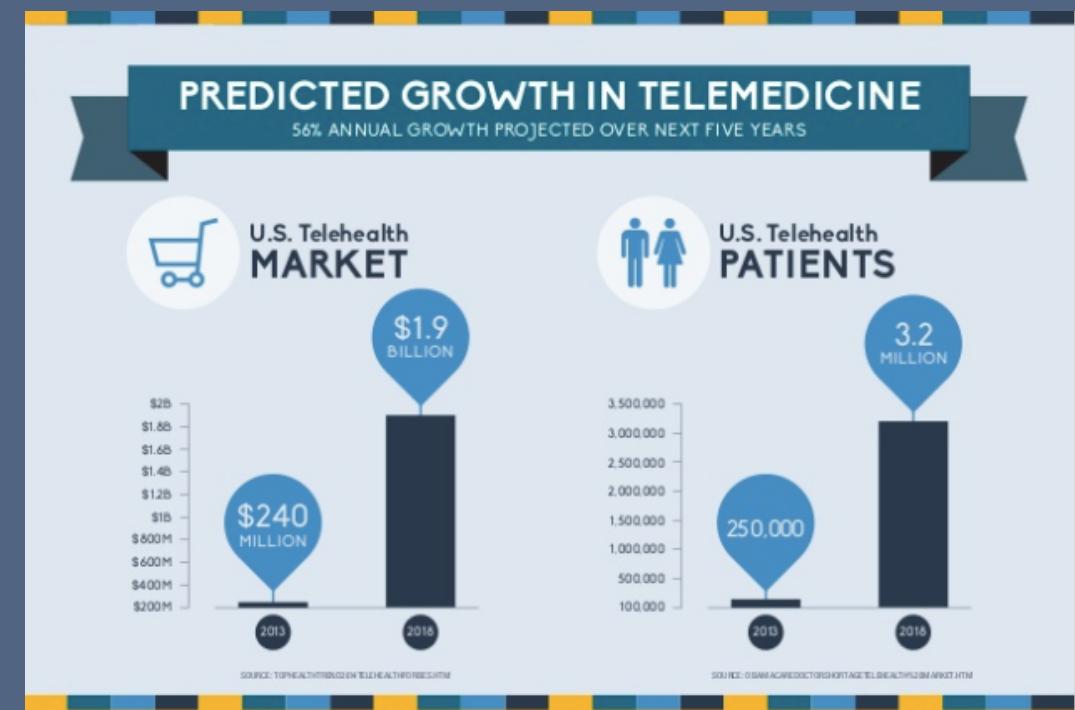
Information Flow



Growth in Telemedicine

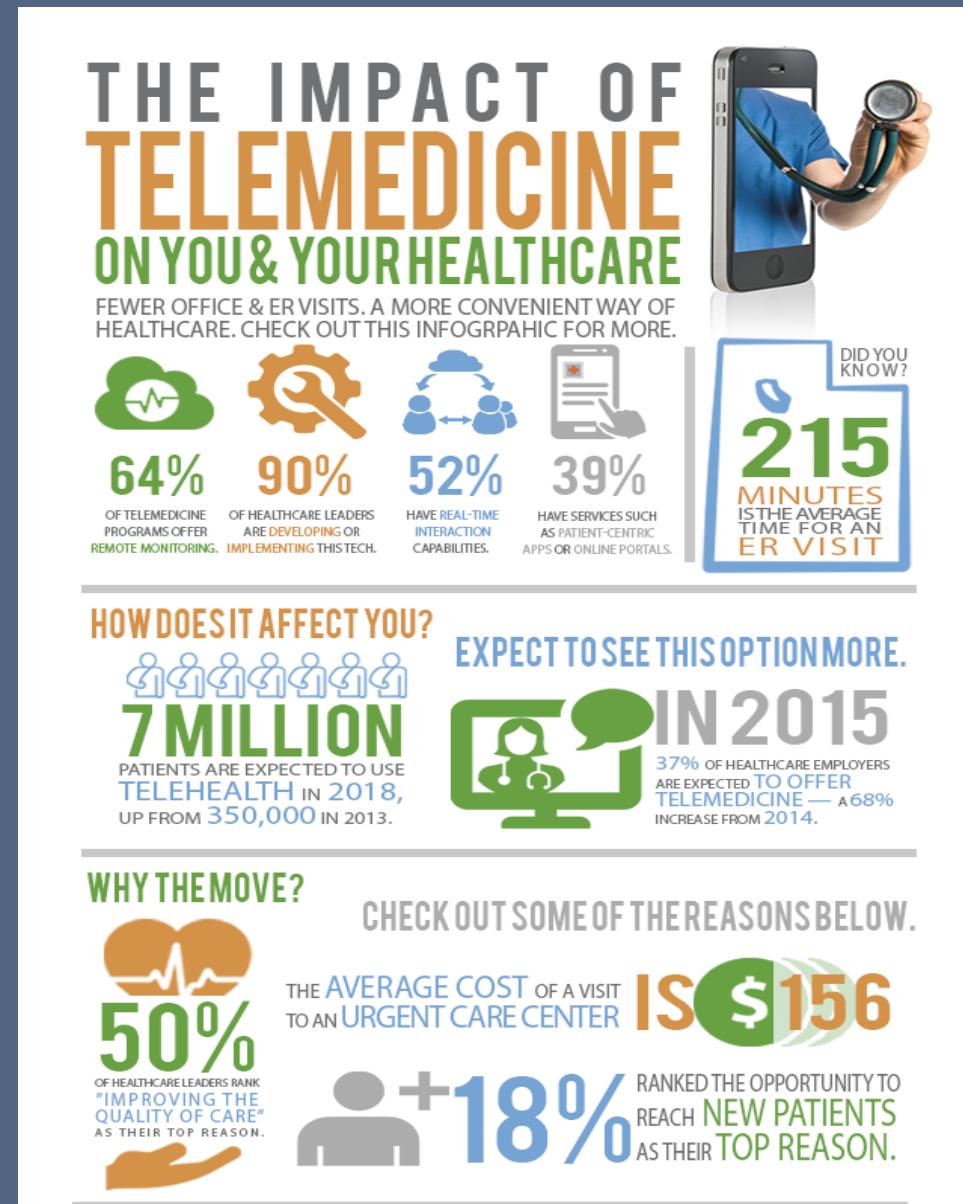
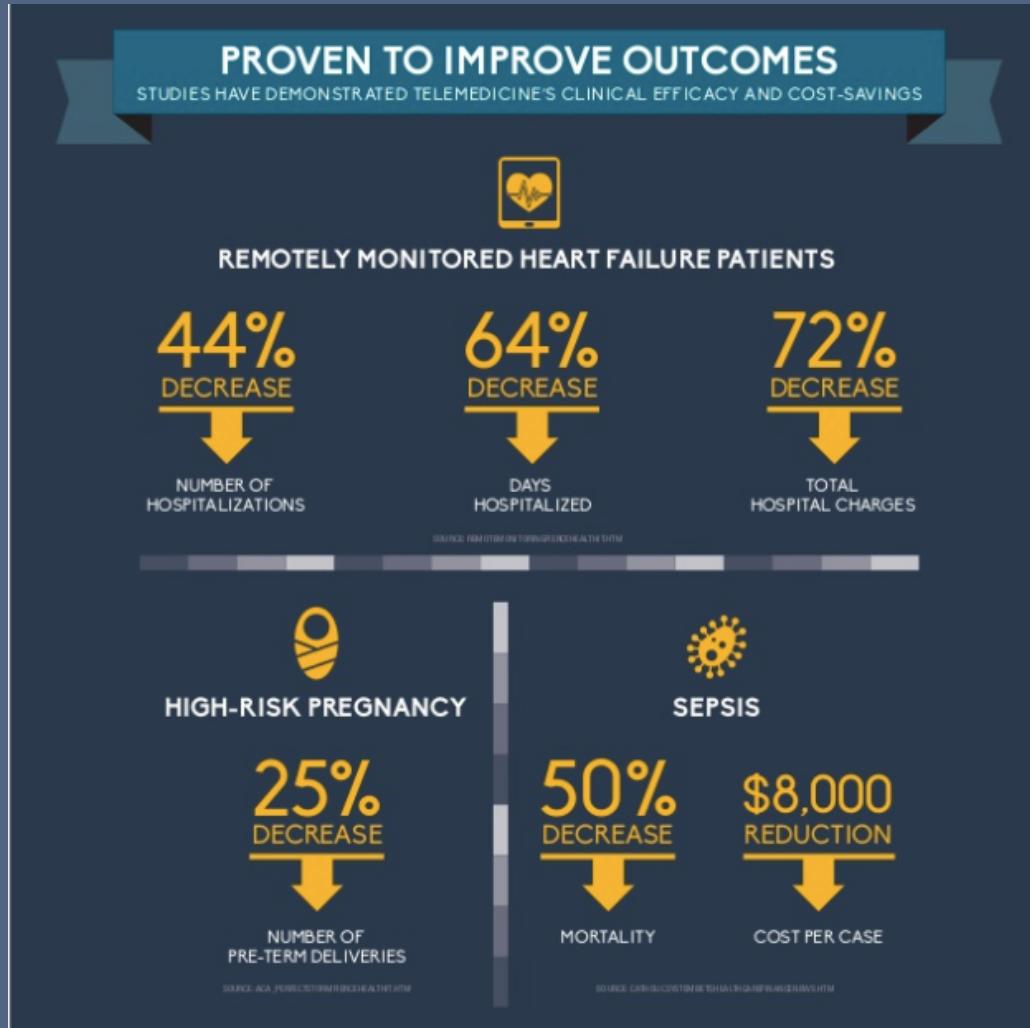


Global market in US billion dollars



US Market

Value Proposition



Use Cases

Industry moving towards value based delivery model

Shortage of doctors in general. Only 10% of nation's doctors practice in rural areas



Care for growing aged population



Aids mental health and opioid crisis



Keeping schools healthy

Regulations & Standards in place



- HIPAA(Health Insurance Portability and Accountability Act of 1996)
 - Protects all "*individually identifiable health information(PHI)*" held or transmitted by a covered entity, in any form or media, whether electronic, paper, or oral.
 - No restrictions on the disclosure of de-identified health information.
 - Data Breach: *Notify all affected individuals that their Protected Health Information has been exposed, whether it was due to a hacking incident, a lost laptop or Smartphone, or any other device that contained unencrypted PHI.*

No specific requirements related to Telemedicine

Regulations & Standards in place



- HITECH(Health Information Technology for Economic and Clinical Health) Act of 2009 – Extended HIPAA to “business associates,” entities that “create, receive, maintain, or transmit” PHI. A business associate agreement is needed with third party vendors.
- FHIR (Fast Healthcare Interoperability Resources) Specification, which is a standard for exchanging healthcare information electronically.
- Furthermore, some 167 bills active in state legislatures this year, according to the Center for Connected Health Policy.

Ethical Challenges

- **Is patient consent required?**
 - Not required by federal law,
 - Certain states require informed consent from the patient.
- **Exclusion bias based on affordability of devices.**
- **Opacity of machine learning apps like autism**
- Insurance companies can use personal behavior patterns to offer rates.

Security and Privacy issues

- More Complexity - States have different privacy laws
- More hardware, software and people stakeholders that need to be HIPAA compliant
- PHI may be compromised by insecure connection at patient end. Such individual cases go undetected for long
- Medical identity fraud easier with a remote patient. Medical information is **worth ten times** more than credit card numbers on the black market.

Security and Privacy issues Continued

- De-identified data is already worth lots in secondary market.
- File download on devices at the provider as well as patient end. Leads to more security issues.
- Study shows a dearth of standardization security in telemedicine security across all chronic illnesses.
- Thin line between health trackers and remote monitoring instruments—more confusion for patients as to when their data is protected

Perspective of Privacy frameworks

- Nissenbaum's Contextual Privacy framework
 - Sender of information – Patient
 - Recipient – Doctor.
 - HIPAA – framework that guides the transmission principle(ensuring Trust)
 - Context – Patient Welfare/Treatment
 - Telemedicine – Medium of communication
- If this medium is not compromised and the communication(network, systems and people), are governed by HIPAA, then the patient's privacy
- Deidentified data is still up for grabs

Benefits versus Ethics/privacy

Benefits



- Two studies by Center for Disease Control(CDC)
 - A 2015 Study of Tele monitoring Program for Underserved Chronic Disease Patients: 50% reduction in 30-day readmission and a 13-19% decrease in 180-day readmission rates
 - 2016 Study looked at telemedicine Emergency Medical Services initiative: 6.7% absolute reduction in potentially medically unnecessary Emergency department visits, and a 44-minute reduction in total ambulance back-in-service times. A \$103 in patient saving.

Benefits

- Courts supportive of Telemedicine
 - In 2015, the Iowa SC ruled against ban of telemedicine abortions stating that the restriction limits accessibility to women in remote areas
 - In yet another case in Texas, the court issued a stay on regulations that would have rolled back the use of telemedicine in that state.



Privacy factors unique to healthcare

- The nature and variety of risks inherent in the compromise of sensitive information. Unauthorized disclosures can create enormous harms, including
 - social stigma,
 - employment discrimination,
 - insurance discrimination, and
 - other types of injuries.
- The emotion linked to one's medical state. Prior research suggests that people tend to be more emotional and exhibit greater risk-seeking behavior when faced with a life-death choice than with problems in other life domains such as personal finances or public property

Recommendations

- Exclusion due to affordability can be addressed by providing subsidies for smartphones
- Implement simple steps that a patient can take in the event of a breach.
- Blockchain technology
- Data encryption(in addition to network encryption)

Recommendations(Continued)

- Certification of third party apps by cybersecurity experts
- Collaboration between telemedicine experts and security researchers
- Effective patient education
-



Are you flossing
every day?



Be honest now.
That's not consistent
with the data from
your tooth implant.

Of course!

Image Sources

- <https://www.statista.com/statistics/671374/global-telemedicine-market-size>
- https://abm-website-assets.s3.amazonaws.com/mdtmag.com/s3fs-public/legacyimages/Figure1_0.jpg
- <https://chironhealth.com/blog/from-around-the-web-11-fabulous-infographics-about-telemedicine/>