Data Privacy and Ethics of Healthcare in the Digital Era

Data Privacy and Ethics (WS 2020/21)

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01

The Future of Healthcare:

Outlook & Relevance

The future of healthcare

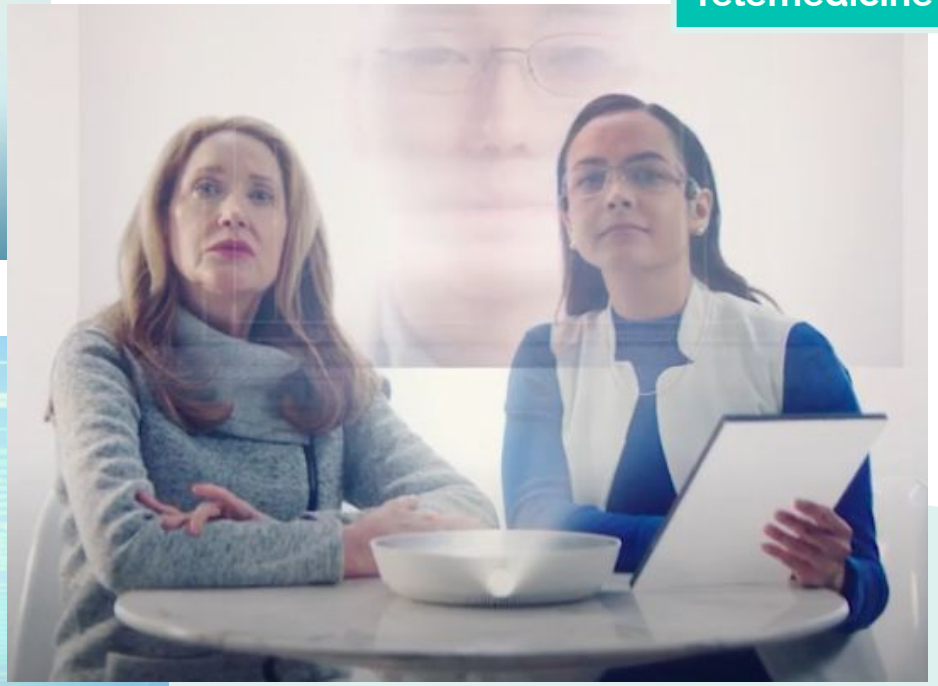
A story of Sofie

Source: GE, 2019

Source: GE, 2019


Good morning, Sophie!
7:20AM
24°C
120
TODAY'S SCHEDULE
MUSIC LESSONS
REMINDERS
Mom's Birthday
CHANGE DETEC
IN PROGRESS
collection
sharing
Data
analysis
consent
PATIENT NAME
PATIENT NO.
CONFIRMED
IGNORE
WOULD YOU LIKE TO
DR. LIZ
PRIMARY
Asteroid mining race heats up
YOUR CONSENT FORMS
8:52 AM
CONSENT GRANTED FOR TRANSFER OF ALL RELEVANT PERSONAL HEALTHCARE DATA

Real-time analysis



Telemedicine

“The good news is that we caught it early”

- Doctor via telemedecine

Visions of healthcare in the digital era

with the usage of data and technologies...

Facilitating Preventive Care
Prevention instead of curing

Consumer-centric
In response to empowered customers,

consumerization of healthcare

Preventing human errors

IoT, ML, AI offering clinical supports, eg. insights from real-time analysis

Costs & efficiency

Better operational efficiency

Source:Hitachi Vantara, 2019 ; Kraus et al., 2020

Tech companies in healthcare :

disruptions ? innovation?

Google

Google Fit

health-tracking platform

Apple

Apple Health

Mobile access to electronic health record (EHR)

Uber

Uber Health

Shuttle patients to hospitals

Amazon

Non-prescription medicine

Facebook

Preventive Health

connects people to health resources.

source: PwC Health Research Institute, 2019

The future of health will be driven by digital transformation enabled by radically **interoperable data** and **open, secure platforms**.

- Deloitte Analysis, 2019

Data security and privacy concerns impede the **efficient usage of health information** to maximize *value creation* for all healthcare stakeholders.

- Gopal et al. , 2018

Patient safety

Data security

Privacy

Ethics

Health promotion

Disease prevention

cost-effectiveness

affordability

intellectual property

interoperability

patient engagement

Dimensions of **appropriate use of digital health**

source: World Health Organization, n.d.

02

Ethical Problems

of Digitalization in Healthcare

Medical Data & Biobank

- World Medical Association (WMA) - Declaration of Taipei on Ethical Considerations regarding Health Databases and Biobanks (revised in 2016)
- Protect and enhance participants' rights to privacy, confidentiality, and self-determination of their information for research
- Define requirements for broad consent

Source: WMA - The World Medical Association-WMA Declaration of Taipei on Ethical Considerations regarding Healt Databases and Biobanks

Medical Data & Biobank

- **Health data definition?**
  - Clinical & non-clinical domain
  - Can be linked with administrative & commercial databases:
    - Patient-reported outcomes
    - Environmental sensors
    - Social media
    - Wearables & smart speakers
  - All data = health data?

Source: Borowski, L. (2015) Using Non-Clinical Data Can Increase Impact of Analytics

Content

What kind of data?

Intended uses of data

Non-profit research or more?

Security standards

Safety & control policies?

Actual uses of data

Who and for what?

Mode of governance

Administrational decisions

Dimensions of biobanks and health databases

Source: Aicardi, C., Del Savio, L., Dove, E. S., Lucivero, F., Tempini, N., & Prainsack, B. (2016)

Medical Data & Biobank

- **Personal data vs Individual data**
  - Not synonymous but oftentimes treated as such
  - Eg.: genetic data is personal, but not individual (provide information about more than one individual)
  - Reevaluate the notion of data privacy and consent due to this broader understanding

Source: Aicardi, C., Del Savio, L., Dove, E. S., Lucivero, F., Tempini, N., & Prainsack, B. (2016). Emerging ethical issues regarding digital health data.

Medical Data & Biobank

- **Anonymization is not guaranteed forever**
  - Anonymization: modify a dataset to remove or encrypt personal identifiable information (PII)
  - Cannot be promised with current technological development velocity
  - Big data & ubiquitous data collection foster deanonymization, with multiple incentives
  - Eg.: Re-identification of patients in Maine and Vermont, USA
    - Match redacted hospital data with news stories
    - Recovers around 30% of inpatient identities (10% with HIPAA standard)

Source: Frasher, E. (2018). Addressing the Failure of Anonymization: Guidance from the European Union's General Data Protection Regulation

Accountability of AI

- Algorithms are normally a black box, decisions are inexplicable
- Assistive system, clinician make final choice, but still uncertain about the validity of the recommendations → how far a clinician is accountable for patient harm?
  - Developers cannot foresee adversarial consequences
  - Missing aspects / inputs in the model
  - Biased data → possible misdiagnosis
  - Critical reasoning skills of human

Source: Habli, I., Lawton, T., & Porter, Z. (2020). Artificial intelligence in healthcare: accountability and safety.

03

Legal Aspects

of Data Privacy in Healthcare

Legal Perspectives on Data Privacy

Two polar approaches to data protection:

- EU
  - GDPR: overarching framework
- USA
  - HIPAA: sector-specific + state driven laws

Source: Coos, 2018

Differences in Defining Data Privacy

European Union:

- The European Union's Charter of Fundamental Rights addresses privacy as a fundamental freedom
- Chapter 3 of the GDPR on data privacy rights

USA:

- No explicit right to privacy stated in the US Constitution
- The Fourth Amendment of Constitution:
  - *"The right of the people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures."*

Sources: EU Charter of Fundamental Rights, n.d.; Sharp, 2013; GDPR.eu, n.d.; U.S. Constitution - Fourth Amendment, n.d.

Differences in Approach to Data Privacy

European Union:

- Data privacy as an individual right
  - Applies only to “natural” persons
- Prioritizes interests of regular citizens

USA:

- A majority of the GDPR data protection standards are not found in US law
- National security interests tend to trump individual interests
- Considers privacy a commercial asset

Sources: Coos, 2018; Boehm, 2015

GDPR vs HIPAA

	GDPR	HIPAA
Protected Data	Any information relating to an identified or identifiable natural person	Any information regarding health status, provision of healthcare, or healthcare payment
Scope	All controllers and processors of personal data	Applies only to “covered entities”
Data Processing	Explicit consent is required Exception: the conditions of Article 9 of the GDPR and a legal basis applies	Data can be disclosed without consent under certain purposes
Data Breaches	All breaches of personal data protection reported within 72 hours	All breaches affecting >500 records reported within 60 days

Sources: Jones, 2020; Art. 4 GDPR – Definitions, n.d.; GDPR vs HIPAA – What Are the Differences and How to Comply, n.d.

“We need to use our collective prowess and power to protect (the) most vulnerable of populations, and it requires not just our industry but also nation states to be part of that.”

—Satya Nadella, Microsoft CEO

Benefits of Stricter Data Privacy Regulations

- Better awareness of which data you provide, how it will be used
  - eg. a case of health insurance Allgemeine Ortskrankenkasse (AOK)
    - Outcome: fine 1,24 million EUR
- Ensure that your data will be processed only with your consent
  - eg. a case of Google and UChicago Med
    - *UChicago Med has shared thousands of patient data records without their consent*
    - Outcome: case was dismissed

Sources: European Data Protection Board, 2020; Davis, 2020

“We entered into a research partnership with Google as part of the medical center's continuing efforts to improve the lives of its patients.”

— UChicago Medicine spokesperson

Drawbacks of Stricter Data Privacy Regulations

- Obstacles for AI in medical research:
    1) Increased cost of AI implementation
    2) The right to explanation
    3) The prohibition of repurposing data
- Sharing data becomes difficult which prevents research partnerships

"In EU law every transfer of data to other agencies interferes with fundamental rights and requires specific justification"

~ European Parliament's Policy Department for Citizens' Rights and Constitutional Affairs

Sources: Wallace & Castro, 2018; Boehm, 2015

04

Ethical Theories

applied to Data Privacy

The case of Google and UChicago Medicine

- Partnership between the UChicago Medical Center and Google
  - Use machine learning approaches on historical data from electronic health records
  - Goal to predict medical issues and improve healthcare outcomes
- Case filed by a former patient at UChicago Medicine
  - Claim: improper de-identification of data and deceptive business practices
  - Free text notes and dates of services not removed from data
  - Possibility of re-identification as Google is an expert in the AI domain

Sources: Davis, 2019; Wakabayashi, 2019

Case outcome

- UChicago and Google claimed that they adhered to HIPAA guidelines regarding de-identification of records
- Outcome:
  - Case was dismissed as the plaintiff failed to prove that the contract breach caused him economic damages
  - Plaintiff also could not prove that the value of his medical data had been diminished by the Google and UChicago partnership

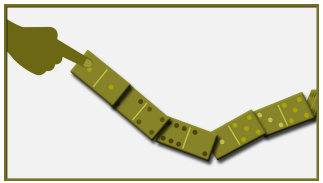
HIPAA
Health Insurance Portability and Accountability Act

Sources: Davis, 2019; Wakabayashi, 2019

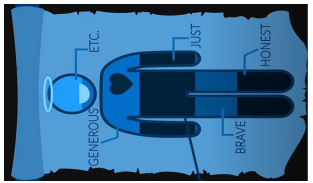
Case analysis

Deontological ethics

Consequentialism



Virtue ethics



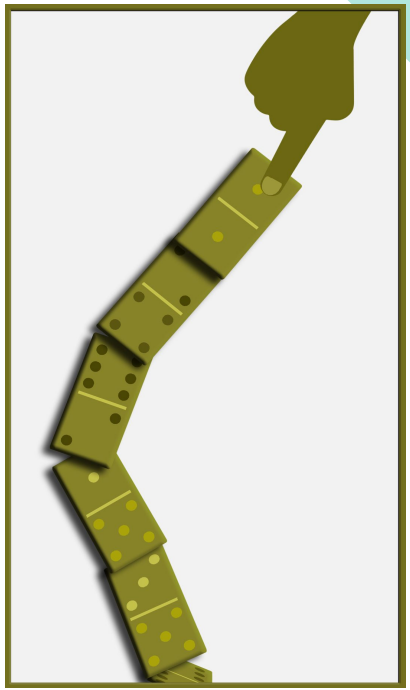
Schools of thought: Deontological ethics

- Based on identification of moral rules that serve to guide individuals
- Connected to the ideas of duties and rights of people
- Intention matters more than the outcome and consequence of an action
- Easy to apply as it is based on rules, but a double edged sword as consequences are disregarded
- Eg. UN declaration of human rights

Sources: Alexander & Moore, 2020; (McCombs School of Business at the University of Texas at Austin, 2020)

Consequentialism

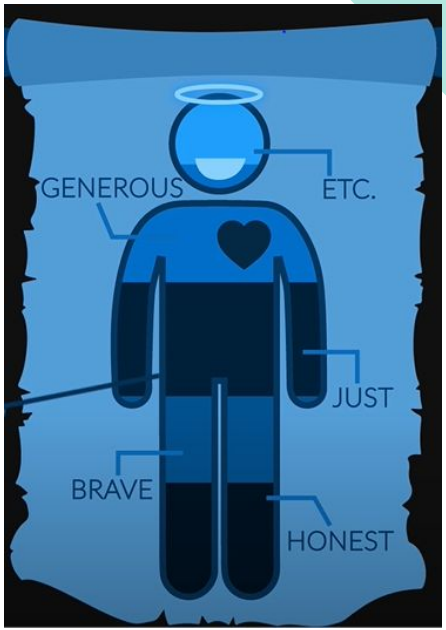
- Focus on aggregating social outcome and the net good resulting from an action
- Connected to the idea of Utilitarianism - greatest good for the greatest number
- Experiences of individuals do not hold much value and actions may be considered ethically sound, even if they violate rights of some people
- The end justifies the means; cost-benefit analysis required
- Eg. consequentialism can be used to justify war



Sources: Sinnott-Armstrong, 2019; (McCombs School of Business at the University of Texas at Austin, 2018a)

Virtue ethics

- Based on virtues of individuals that are defined by their inner character (morals)
- No explicit rules or outcome aggregation
- Virtue is acquired through practice
- Virtuous people would make the right choices when faced with ethical challenges
- Eg. caring for the environment is a virtue



Sources: Hursthouse, R., & Pettigrove, G., 2016; McCombs School of Business at the University of Texas at Austin, 2018b

Dark Knight example - White et al. (2008)

Consequentialist

Deontologist

Virtue ethicist

Sources: McCombs School of Business at the University of Texas at Austin, 2018b ; White et al., 2008, pp. 5-10

Case: Deontological ethics

- Plaintiff's argument - violation of a set of rules by Google and UChicago regarding data privacy
- Court ruling: "**breach of contract**, without monetary harm, does not confer standing"
- Google and the UChicago claimed that they acted within the rules set by HIPAA during the contract process
- However, Google and UChicago breached the privacy contract and thus violated a set of rules - against deontology

Case: Consequentialism

- The district court judgement has strong elements of a decision based on consequentialism
- Court ruling: “breach of contract, **without monetary harm**, does not confer standing”
- Based on net social outcome - plaintiff was not caused any economic damages from the partnership and breach of contract
- Costs and benefits of the situation were weighed and the case was dismissed
- Google and UChicago’s argument was also based on the positive net benefits of using the data for machine learning in healthcare

Case: Virtue ethics

- Google and UChicago claim a virtuous position - working to improve healthcare outcomes and assist in various healthcare support functions
- However, the case exhibits elements of **secrecy and concealment of information** - not virtuous behaviour
- If Google and UChicago were virtuous, then why would they not seek “explicit consent” from patients regarding sharing of their health data
- Why secrecy? People may object to sharing of their data after reading about inclusion of patient notes, and dates of admission and discharge

THANKS

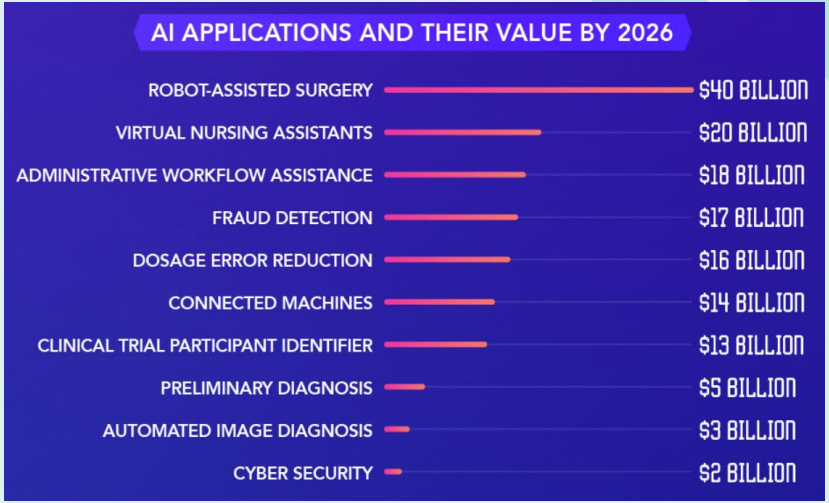
Do you have any questions?

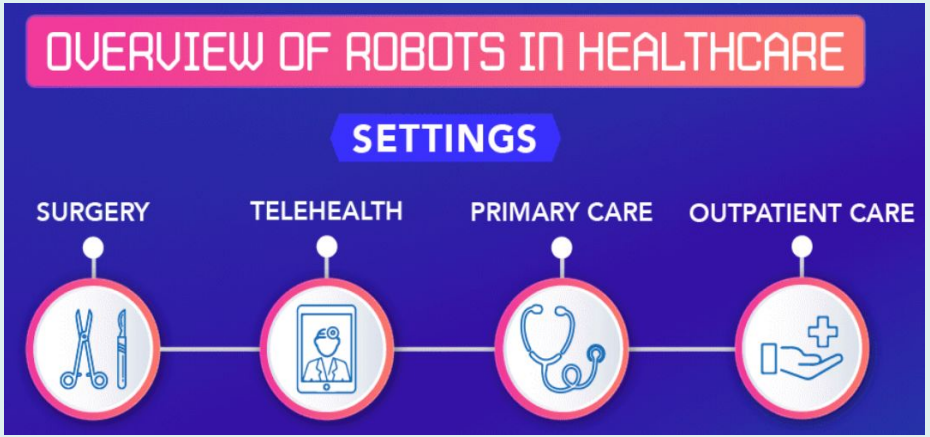
Discussion

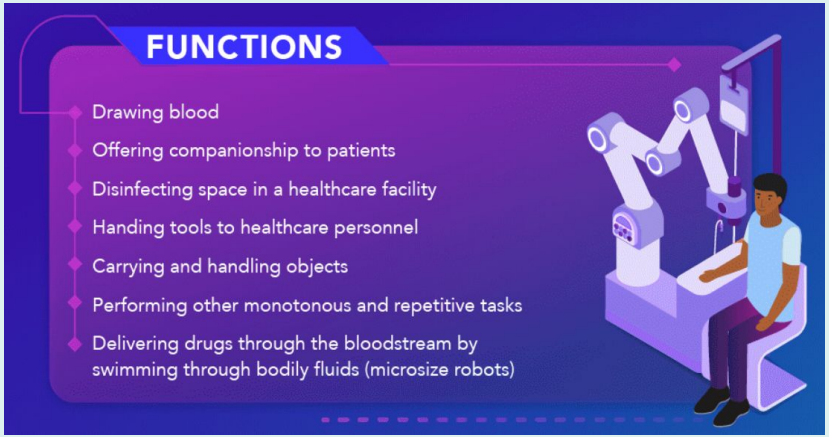
Robotics

AI in healthcare...

Question: What do you think are the drawbacks of robotics (including AI) in healthcare?



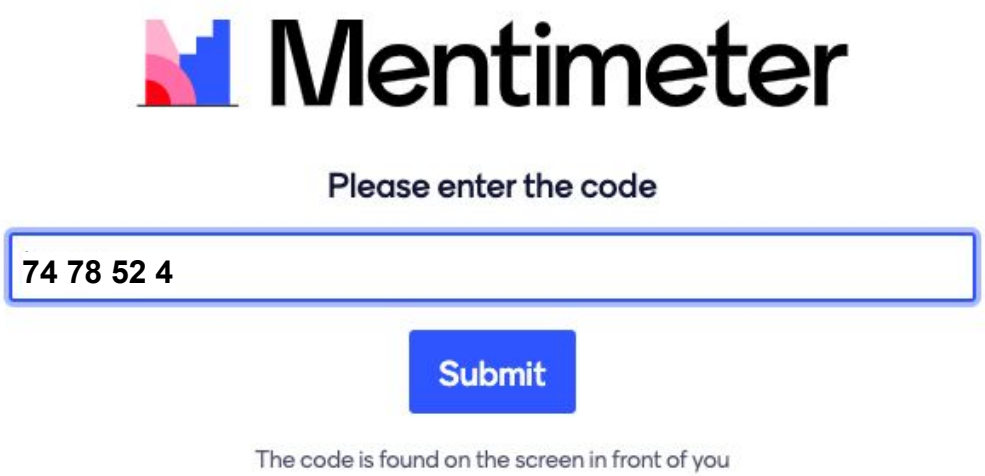




Source: Maryville University , Managing the Future of Healthcare: How Robot Nurses and AI Will Shift Healthcare n.d.

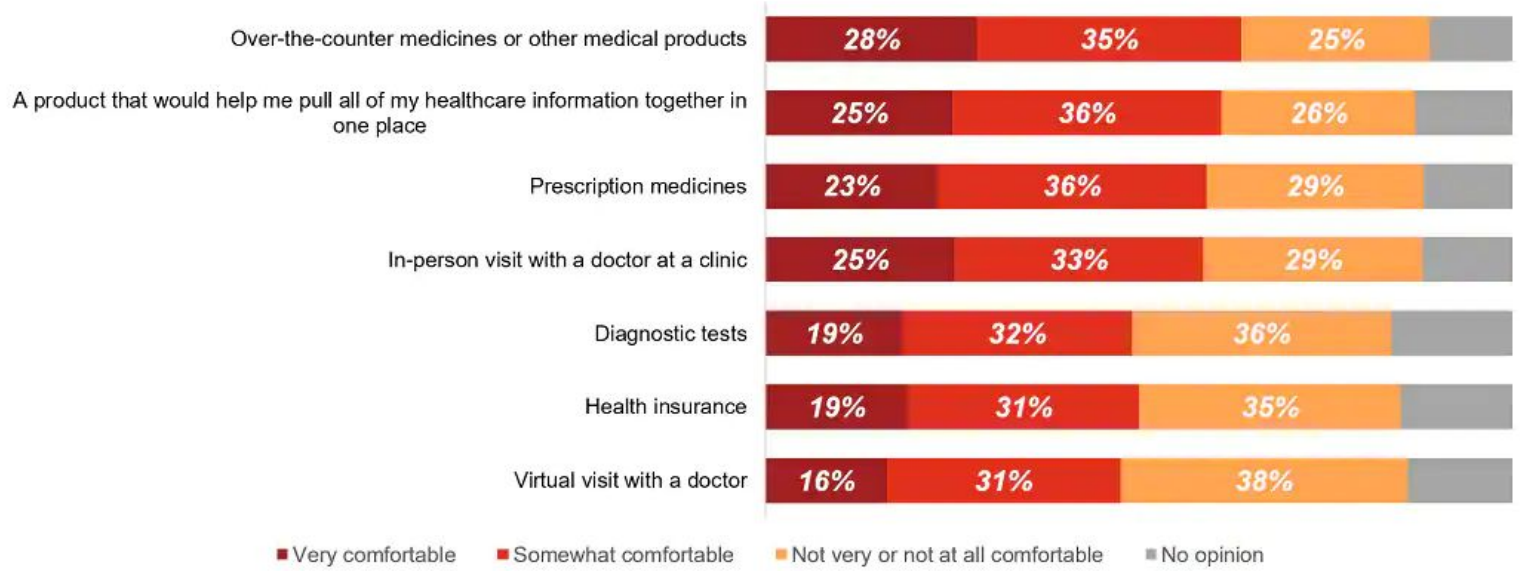
Tech applications in healthcare

Step 1: Go to : https://www.menti.com/
Step 2: enter the code as shown below or use the QR code



Would you see a doctor or buy health insurance from a technology company?

Consumers say they are generally more comfortable buying products from tech companies than buying healthcare services from them

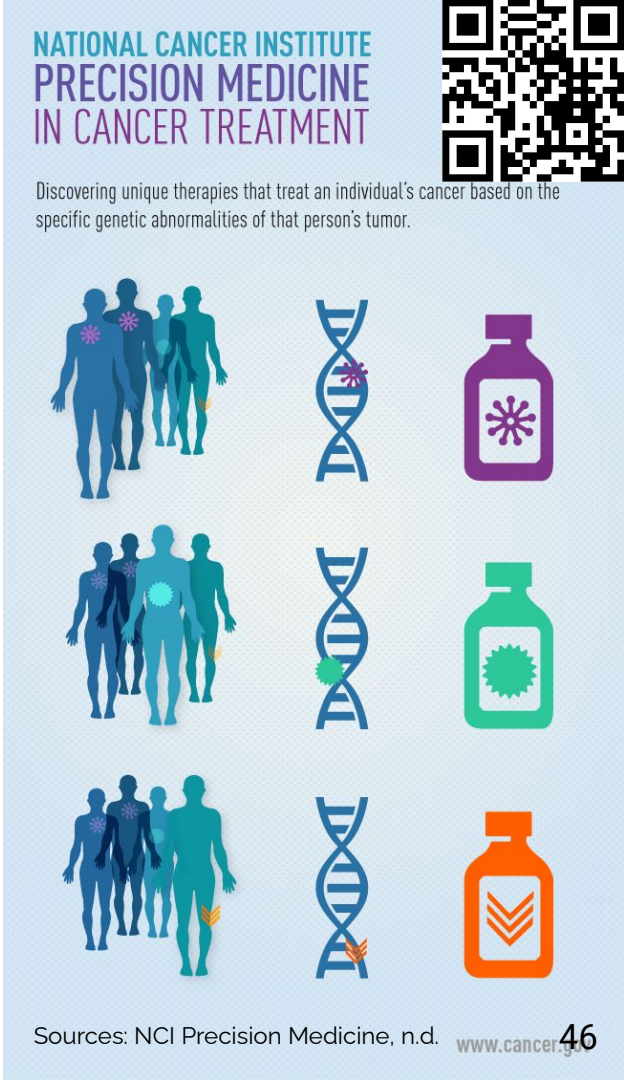


Source: PwC Health Research Institute survey of 1,501 respondents. Question: "To what extent would you feel comfortable purchasing the following healthcare products or services from a non-traditional healthcare company, such as Google, Apple or Amazon?"

pwc.com/hri

Precision Medicine and Data Privacy

- Pharmacogenomics - the use of an individual's genetic data to predict a response to particular drug treatments.
  - ➢ Identifiability problem: genome sequence is unique for each person
- Question 1: Would you consent to share your sensitive data for a better quality treatment?
- Question 2: Would you consent to share your data for medical research purposes?



Sources: NCI Precision Medicine, n.d.

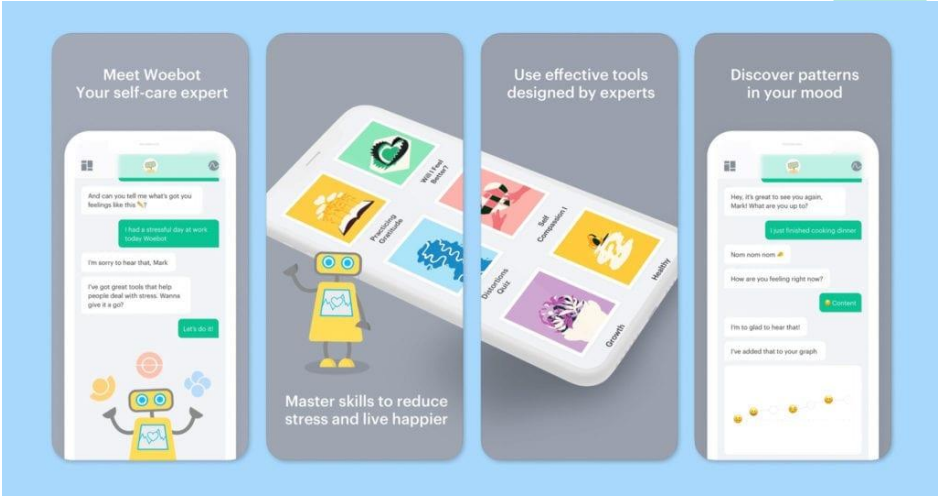
AI Therapy Apps

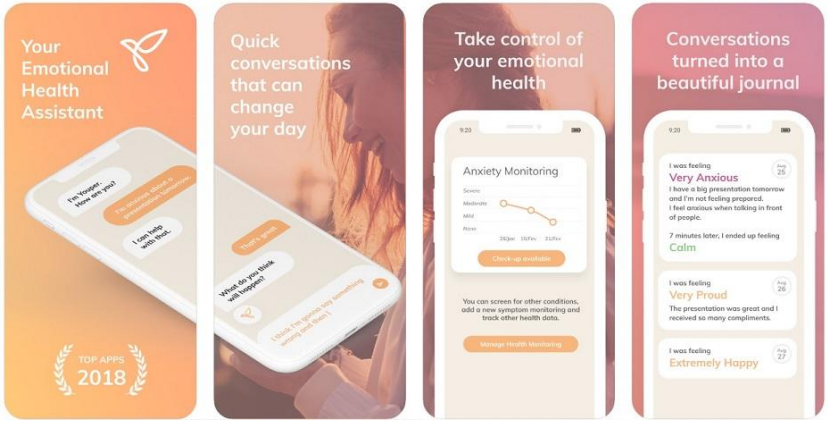
Interactive chat experiences with bots programmed with artificial intelligence

Set health goals, track mood, tool packs for anxiety, depression and isolation support

Cheap, convenient, accessible

Woebot®

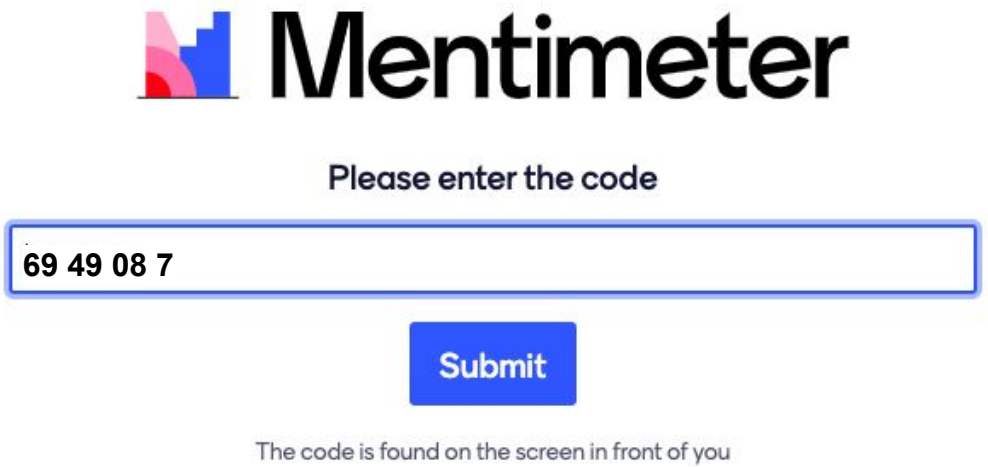




youper

AI Therapy Apps: Are they ready?

Step 1: Go to : https://www.menti.com/
Step 2: enter the code as shown below



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