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**Manage Your Health Data — EIT Health**

DJ's Notes

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# Contents

<b>1 Week 1: What is healthcare data?</b>	<b>3</b>
1.1 Health data . . . . .	3
1.2 Electronic Health Records . . . . .	3
1.3 e-Prescriptions . . . . .	3
<b>2 Week 2: Devices, Apps, and websites with health information</b>	<b>4</b>
2.1 Trustworthy Websites with Health Information . . . . .	4
2.2 Your health data outside the hospital . . . . .	5
<b>3 Week 3: Self-management of health data - Does it really work?</b>	<b>7</b>
3.1 Security, Legal and Ethical issues . . . . .	7
3.2 Health data - Advantages and disadvantages . . . . .	7
<b>4 Read</b>	<b>8</b>
<b>5 Resources</b>	<b>9</b>
<b>6 Questions</b>	<b>10</b>
<b>7 Answers</b>	<b>11</b>
<b>8 Think</b>	<b>12</b>
<b>9 Survey</b>	<b>13</b>

## List of Figures

1 Where patients sought health information first . . . . .	4
2 Wearables . . . . .	6
3 Data Protection Issues . . . . .	8
4 Do you or people you know use any of the following tools for this? . . . . .	13
5 What do you think is the most important use of health data? . . . . .	14
6 Is it ethical for a patient to refuse the anonymous use of his/her data for research? . . . . .	14
7 What do you think of managing your own health data? . . . . .	15

Course Link <https://www.futurelearn.com/courses/managing-your-health-data/2/todo/44502>

# 1 Week 1: What is healthcare data?

## 1.1 Health data

1. **What is data?** Facts and statistics collected together for a reference or analysis. Data is the basic platform to get information.
2. **What is information?** The result obtained after the data analysis
3. **What is health data?** All the data related to health conditions, laboratory results, metrics and medical research, is known as clinical or health data.
4. **Who generates the health data?** Hospitals, medical organizations, pharmacies and citizens... they all generate data.
5. **What is health data used for?** The main purpose of collecting health data is to store the information related to a patient. The data is also used for research, clinical trials or in some cases billing.
6. **Why should we manage our healthcare data?** Dietary habits, physical exercise, activity logs, self-generated observations, and other types of lifestyle information can have **a significant impact on our clinical care and can influence decisions healthcare professionals make about our health**. To exploit such data, citizens must adopt a more proactive role and become essential players in managing their own health data.

## 1.2 Electronic Health Records

1. **What is EHR?** EHR is defined as a digital repository of patient data that is stored and exchanged securely in hospitals.
2. **Who can access EHR?** Storing, managing and analysing patient data in the EHRs can be accessed by both physicians and patients anytime when required and using a secure online system.
3. **Why is EHR useful?** EHRs can store data securely and track a patient's health over time. As they are digital they are searchable, so reduces time and the need for duplicate records.

## 1.3 e-Prescriptions

1. **What is e-prescription used?**
  - (a) Electronic medical prescriptions aims to facilitate the **management** of patients' health data,
  - (b) whilst also ensuring the whole process of prescribing is **secure**.
2. **How does e-prescription work?**
  - (a) When a clinician prescribed medication to a patient, that prescription is registered in **a central system in a country**.

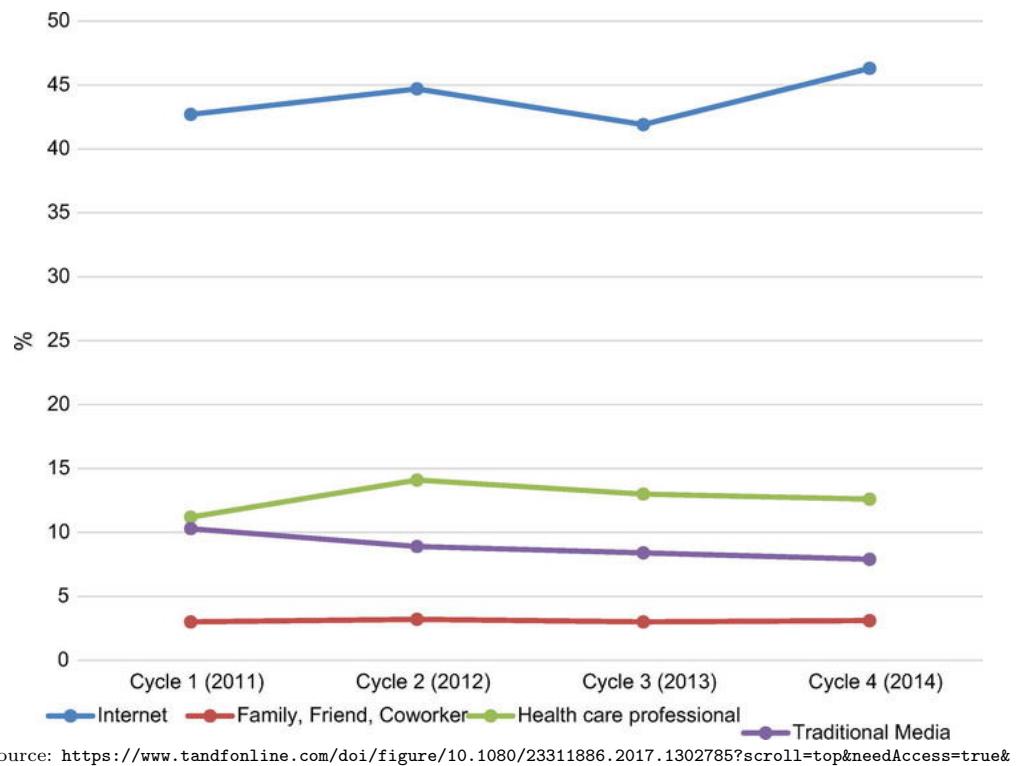


Figure 1: Where patients sought health information first

- (b) Patient then goes to a pharmacy to pick up his prescribed medication, he uses his health identity card as ID and the pharmacist then accesses the electronic prescriptions that have been assigned to that patient.

### 3. What are the benefits of e-prescription?

- (a) Commodity of patients (ease of use for patients)
- (b) avoiding duplicate prescriptions
- (c) enabling repeat prescriptions to chronic patients
- (d) empowering the authentication of prescription dispenses

## 2 Week 2: Devices, Apps, and websites with health information

### 2.1 Trustworthy Websites with Health Information

#### 1. Clinical Information over Internet

- (a) **Patient empowerment** is an essential concept in the latest approach in healthcare. This a concept related to health literacy and the quality of information available for patients.
- (b) When asked how important they considered Internet as source of health information, **around half of the users** reported to be important or very important.

(c) **What kind of information do patients need** We need sources of information adapted for patients but curated by health professionals. Always taking into account that health professionals should be our main source of information in relation to our health.

(d) **Fact from fiction - Who can we trust?** What are the alternative sources to clinical institutions to search for information. Websites with health related information intended for patients, and tools to produce and store health data.

## 2. Managing data outside hospital

(a) There is a plethora of information and tools available online that allow us to search, produce and manage data related to our health, outside of our clinical institution.

## 3. Self-diagnosis and the internet

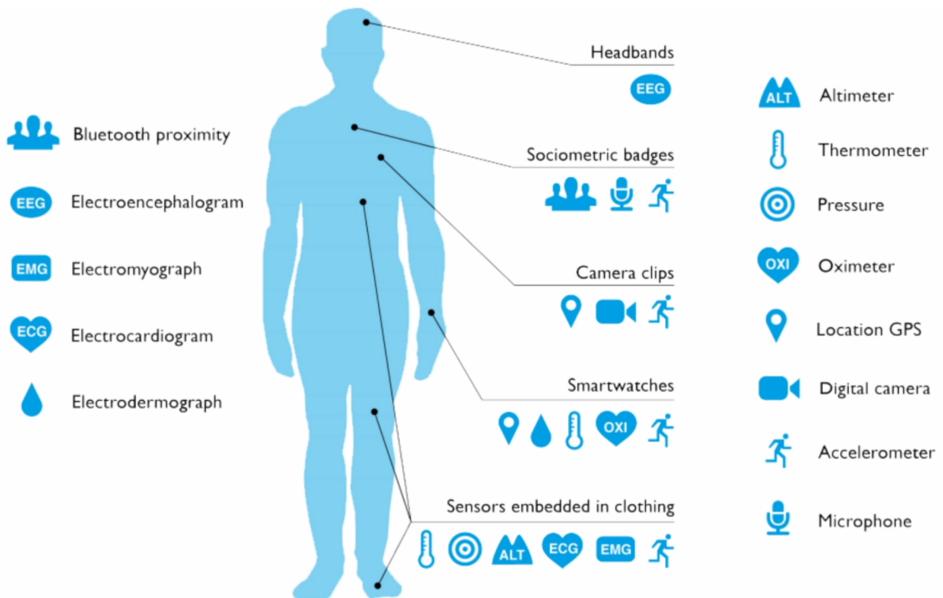
## 2.2 Your health data outside the hospital

### 1. The expansion of data enrichment

- (a) The traditional way of generating and managing health data was through paper records.
- (b) Clinical institutions, doctors and other healthcare professionals will always be the cornerstone of our treatment,
- (c) Today, we can greatly enrich the data related to our health with wearable devices, mobile apps and other websites or tools.

### 2. What is wearables?

- (a) Wearables are a technological gadget with a sensor.
- (b) They can monitor
- (c) These gadgets can be connected to smart phones with lots of apps available, that keep a log of your vital signs and physical activities, daily habits, diet, etc.
- (d) Information from wearables can be collected at home, at work or as we go about our day. It **avoids the use of uncomfortable alternatives** and the data is collected 24 hours a day and can be accessed by most citizens.



#### Thermometers

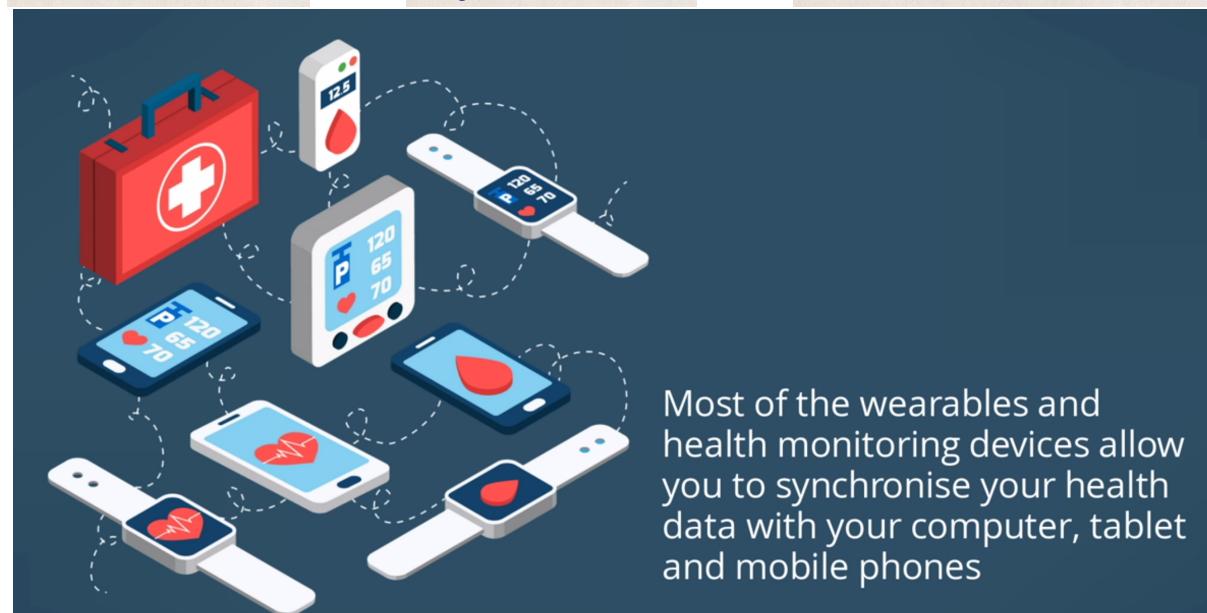
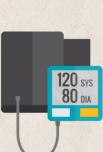
Most are digital and have sensors that measure body temperature.

The great development of the technologies has allowed the production of intelligent thermometers that are faster and with better accuracy.



#### Blood pressure monitor

The blood pressure is another vital sign that can be measured at home.



The information can be obtained at home



Source: <https://www.futurelearn.com/courses/managing-your-health-data/2/steps/473546>

Figure 2: Wearables

### **3 Week 3: Self-management of health data - Does it really work?**

#### **3.1 Security, Legal and Ethical issues**

##### **1. The data protection directive from the EU**

(a) **How is health and genetic data classified?** A special category of data requiring a higher level of data protection

(b) The technology used for clinical data protection and encryption must be taken to the greatest consideration because of the sensitivity of the information.

(c) **What issues do we need to consider regarding health data?**

###### i. Security issue

- How is our data protected against unauthorized use or modification?
- To protect the data, encryption techniques are used to prevent attacks and access by unauthorized persons.

###### ii. Ethics issues

- Concerned with privacy, confidentiality and consent.
- Data privacy: the private communication between patients and healthcare specialists must be guaranteed and any information about patients must be confidential.
- Confidentiality: any information about a patient must be confidential.
- Consent: collecting and processing patient's data requires their permission.

iii. Legal Privacy: All the information about laws and directives to protect individuals' privacy is related to legal issues.

(d) **Sharing your data**

i. It is forbidden to share personal data unless the person gives his consent.

ii. If a patient gives permission, then their health data can be processed.

iii. Exceptions:

- In case of emergency, no consent is required since sharing health data is vital for the patient.
- It is allowed to share health data between health specialists that are treating the patient.
- Consents forms must be clear and unambiguous for patients.

#### **3.2 Health data - Advantages and disadvantages**

##### **1. Technology - friend or Foe?**

##### **2. Barriers to health data self-management**



Source: <https://www.futurelearn.com/courses/managing-your-health-data/2/steps/473546>

Figure 3: Data Protection Issues

#### (a) Technology

- i. Barriers come from how data is generated and stored.
- ii. EHR clinical data generated in hospitals is coded using different terminologies and formats, depending on the software used. As a consequence, compiling all our health information is not just a matter of putting it in the same place, but also we have to be able to gather it all in the same coding ‘language’.
- iii. Similarly, devices like wearables or mobile applications store the data in different ways and formats. And data about dietary habits or exercise is usually generated in proprietary formats.
- iv. Usually data can be interpreted only by those applications which have generated the data, and users are only allowed to export parts of this information.

#### (b) Legal and Security

- i. It is crucial to be aware on **how data is managed within third-party applications** we use.
- ii. When we download our personal health data and use a third-party application, we must **be sure that the application is secure and reliable**.
- iii. We should use applications that **maintain the user’s data unaltered**. And we need to be aware of any potential security and privacy issues. For example, some free applications receive benefits from our data. **Blockchain?**

### 3. Do you want to manage your health data?

- (a) As we have seen many areas of healthcare could benefit from analysing our personal health data, and there is increasing interest from clinical research.
- (b) At the centre of all of this, is us and our willingness to take a more proactive role in managing our health data.

## 4 Read

1. Electronic Health Records: Then, Now, and in the Future <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5171496/>

2. Overview of the national laws on electronic health records in the EU Member States [https://ec.europa.eu/health/ehealth/projects/nationallaws\\_electronichealthrecords\\_en/](https://ec.europa.eu/health/ehealth/projects/nationallaws_electronichealthrecords_en/)
3. Gimme My DaM Data video from the American College of Medical Informatimusicology <https://www.youtube.com/watch?v=0gpk-fbfg4Y&feature=youtu.be>
4. Plante and Colleagues Say High Ratings Don't Mean Blood Pressure App Works [https://www.meduvm.edu/com/news/2018/06/22/plante\\_and\\_colleagues\\_say\\_high\\_ratings\\_don\\_t\\_mean\\_blood\\_pressure\\_app\\_works](https://www.meduvm.edu/com/news/2018/06/22/plante_and_colleagues_say_high_ratings_don_t_mean_blood_pressure_app_works)
5. Health information on the Internet (Gold mine or minefield?) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4020634/>
6. The Global WannaCry cyber attack in May 2017 which targeted healthcare systems. <https://www.england.nhs.uk/wp-content/uploads/2018/02/lessons-learned-review-wannacry-ransomware-cyber-attack.pdf>

## 5 Resources

1. WebMD
  - a <https://www.webmd.com/>
  - b a verified health information services website from the US
  - c The site publishes content relating to health, including a symptom checklist, drugs information and blogs from doctors who share their thoughts about specific topics. It also provides a means of storing personal medical information.
2. Medlineplus
  - a <https://medlineplus.gov/>
  - b MMedlineplus is written by health professionals but with content adapted to be accessed by patients.
  - c It pulls together information from the US National Library of Medicine, National Institutes of Health and other US government agencies and healthcare organisations.
  - d All the content is provided by clinical professionals.
  - e Optimised to be used on mobile devices, around 400 million people around the world have used the site. It can also use patient data within EHR systems and connect this data to related information on conditions and medications.
3. HealthVault
  - a Microsoft <https://international.healthvault.com/de/en>
  - b Can manage **Personal Health Record(PHR)**

- c Entry all the data manually?! by the patients?!
- d The site allows individuals to share their entire health record or just selected data with others, such as doctors, healthcare professionals or relatives.
- e It allows health and fitness data to be collected from selected devices like blood pressure monitors, heart rate watches and wifi bodyscales.

4. Google Fit Android App

- a Google and WHO <https://www.google.com/fit/>
- b Movements management using accelerometer.
- c More moves, more heart points

5. Qoolife

## 6 Questions

1. What health data is mainly used for?

- a Clinical research
- b Patient treatment (Electronic Health Records)
- c Keep fit

2. The results obtained from a glucose blood tests are data or information?

- a Data
- b Information

3. The diagnosis “Diabetes” is data or information?

- a Data
- b Information

4. The Electronic Health Records use:

- a Medical standards
- b Clinical terminologies
- c PC
- d Mobile phones

5. What are the benefits of using Electronic Prescriptions?

- a Avoids duplicated prescriptions
- b Periodic prescriptions for chronic patients

- c No authentication is required
6. Some wearable devices can:
- a monitor different vital signs
  - b count steps
  - c track sleeping
7. Which devices can be considered as Health Monitoring?
- a Thermometer
  - b Blood pressure monitor
  - c Computer
8. Why are some health monitoring devices used alongside mobile applications?
- a To visualise your health data in your mobile
  - b Share health data with others
  - c It is more secure
  - d To store your health data in the cloud

## 7 Answers

1. What health data is mainly used for?
- a Clinical research is based on the analysis of health data from multiple patients
  - b Patient treatment (frequently using EHRs) is the main way of generating and storing health data
2. The results obtained from a glucose blood tests are data or information?
- a Clinical research is based on the analysis of health data from multiple patients
  - b Patient treatment (frequently using EHRs) is the main way of generating and storing health data
3. The diagnosis “Diabetes” is data or information?
- a Diabetes is a diagnosis provided by a doctor based on symptoms and results from a laboratory test, it is therefore Information.
4. The Electronic Health Records use:
- a To facilitate appropriate analysis of data, EHR systems need to use standards in medicine to be homogeneous across regions and systems

b Terminologies like the International Classification of Diseases (ICD) by the World Health Organization are generally used to store your health data in an EHR

5. What are the benefits of using Electronic Prescriptions?

a Typos, duplicates and other mistakes associated with paper records can be avoided when data is stored in an electronic form; potentially avoiding life threatening problems.

b When patients need to be dispensed the same drug periodically, e-prescription can help facilitate this process and save time for health professionals and patients.

6. Some wearable devices can:

a Wearables are electronic devices that can be embedded into clothes or worn as accessories. Modern smartwatches can measure heart rate, for example.

b Mobile phones or smartwatches include GPS. Taking into account speed and distance, they can estimate the number of steps you take.

c If worn during the night, some devices can estimate periods and levels of sleep.

7. Which devices can be considered as Health Monitoring?

a Devices with a sensor to measure the temperature and a display to show the numerical value are very common to check if we have fever.

b Blood pressure is an important vital sign measuring the pressure on the wall of vessels that can be monitored with devices at home

8. Why are some health monitoring devices used alongside mobile applications?

a Mobile displays are usually better than wearables with built-in displays, as they are able to show the gathered data

b Since mobile phones are generally connected to the internet, we can upload the corresponding data to the cloud and share it with other users.

c Connecting to a mobile facilitate sharing of your health data, but there are more opportunities to share the data with undesired people, so it is in fact more insecure

d With data uploaded to the cloud, we can store it for future consultation or gather it from different applications and devices.

## 8 Think

1. What is the difference between EHR and e-prescription?

2. What is the importance of health data security?

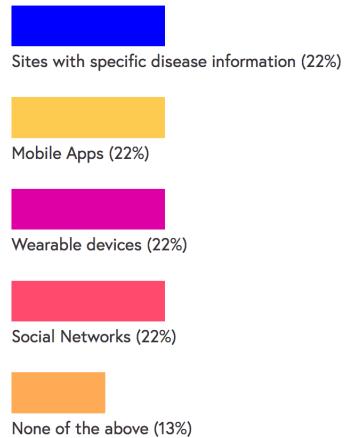
3. What are the technological barriers of managing our health information today?

4. What are your main concerns on privacy related to your health data?
5. What are the consequences to giving citizens more control over their own data? Or do you think that it will disconnect people from healthcare professionals?
6. How do you plan to change your behaviour in regards to managing your personal health and activity data?

## 9 Survey

### Do you or people you know use any of the following tools for this?

You selected Mobile Apps. See how your answer compares below.



Source: <https://www.futurelearn.com/courses/managing-your-health-data/2/steps/473553>

Figure 4: Do you or people you know use any of the following tools for this?

## What do you think is the most important use of health data?

You selected Treatment of the patient. See how your answer compares below.



Treatment of the patient (44%)



Research for new treatments (19%)



Epidemiology / Surveillance / Alerts (19%)



Distribution of healthcare resources (19%)

Source: <https://www.futurelearn.com/courses/managing-your-health-data/2/steps/473567>

Figure 5: What do you think is the most important use of health data?

## Do you think it is ethical for a patient to refuse the anonymous use of his/her data for research?

You selected Yes, we should be able to refuse. See how your answer compares below.



Yes, we should be able to refuse (59%)



No, we should not be able to refuse (41%)

Source: <https://www.futurelearn.com/courses/managing-your-health-data/2/steps/473568>

Figure 6: Is it ethical for a patient to refuse the anonymous use of his/her data for research?

## What do you think of managing your own health data now?

You selected We need access to our EHR. See how your answer compares below.



We shouldn't manage our health data (6%)



We already have tools to manage our data (29%)



We need access to our EHR (65%)

Source: <https://www.futurelearn.com/courses/managing-your-health-data/2/steps/473560>

Figure 7: What do you think of managing your own health data?