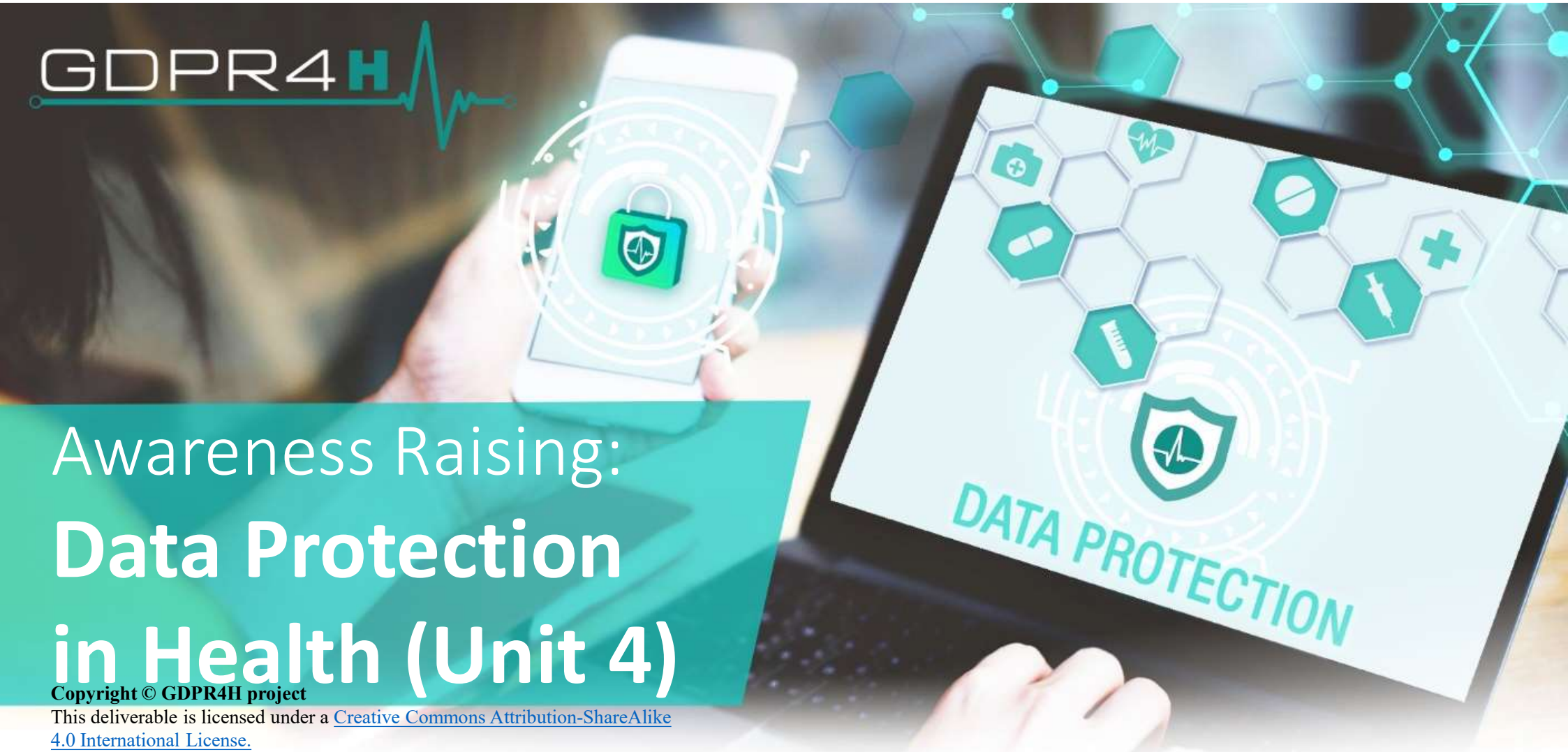

Awareness Raising:
Data Protection in Health (Unit 4)

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GDPR4H

Aims & Objectives

- Description of the basic historical aspects of GDPR
- Description of the typical doctors' responsibilities related to the GDPR
- Analysis of the framework of raising awareness for employees

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GDPR4H

Learning Outcomes

- *List at least 3 historical aspects of GDPR*
- *Analyze the 3 pillars of the new E-Health plan*
- *Describe 3 doctors' responsibilities*
- *List the key aspects of employees awareness*
- *Describe the reasons why data protection is important for raising awareness*

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Terms and Keywords

-E-health
-EU Directives
-Processing
-Awareness
-Data minimization

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History of EU Data Protection

- 1970 - Germany - Land of Hessen - First data protection law
- 1973 - Sweden - Data Act - First national data protection law
- 1977 - Germany - Federal Data Protection Law
- 1978 - France - Law on Data Processing, Data Files and Individual Liberties
- 1978 - Denmark - Private Registers Act and Public Registers Act
- 1978 - Norway - Personal Registers Act
- 1989 - Luxembourg - Act Concerning the Use of Nominal Data in Computer Processing
- 1984 - United Kingdom - Data Protection Act

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EU Data protection directives

EU Data Directives (1995; 2002 and 2006) intended to:

- **harmonize the data protection laws** of the Member States
- create the binding principles that must be put in use in the national laws of the 28 EU Member States

These principles were also implemented by three members of the EEA that are not members of the EU (Iceland, Liechtenstein and Norway). BUT:

- Disparities among the laws of the 27 EU Member States (and the three EEA States), and how the data protection laws are enforced.
- Each country has put in use the EU directives in its own way, and according to its own cultural elements

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E-Health Plans

On **25 April**, the European Commission suggested its Communication on Digital Transformation of Health and Care. This document sets out measures to make it possible for citizens to have access and share health data in a safe way. Moreover, it puts forward actions to pool data across Europe to boost research and the development of personalized medicine.

The three pillars of the new strategy are:

1. *Providing citizens with better and equitable access to their health data, everywhere in the EU*
2. *Making use of digital services for citizen empowerment*
3. *Offering connection and sharing of health data for research*

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Pillar 1

Currently, patients are not able to have access to their health records. In particular, access is often considered as not easy, timely, or free. Under this perspective, the recognition process suggests that ***"citizens have the right to access and share their health data"*,** as well as all the current issues regarding accessibility and interoperability. The European Patients Forum underlines that **access to one's own health information** remains as the core patient's right and precondition for patients' empowerment. Based on the above, solutions exist to enable patients not only to access but also to add their own comments to their health records.

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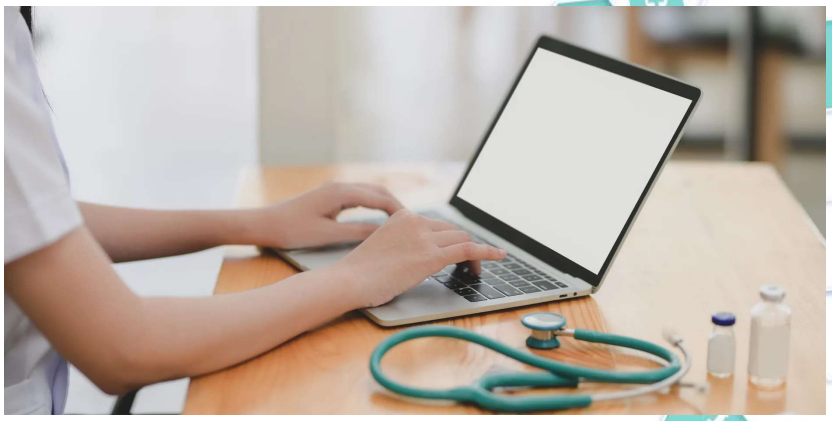
Pillar 2

Digital health should:

-enable care to be structured around a person's needs and preferences

-offer improvements on the coordination of care

-provide effective exchange of information between care professionals and patients



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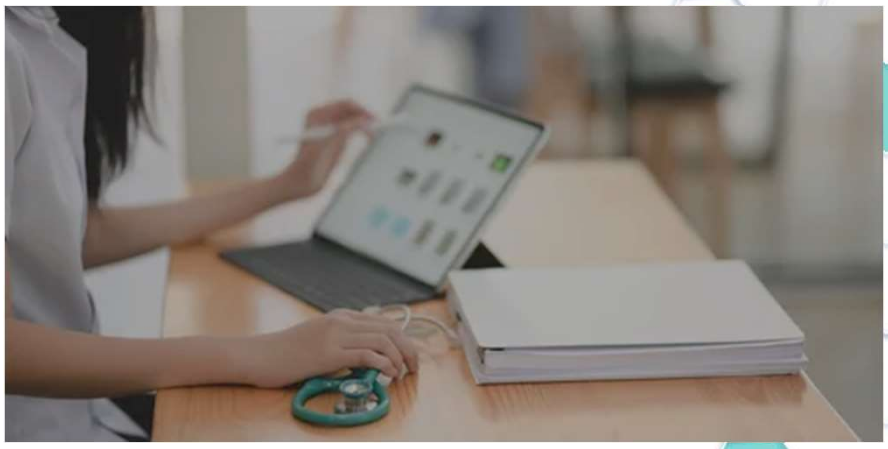
Pillar 3

To build trust, **protection of personal data** should be protected, and its use should not result in any discrimination related to health status. This pillar recognizes also the fact that patients should also have a view in how their data is shared and used. The European Patients Forum welcomes the fact that cybersecurity is addressed, as this is an important area of vulnerability for patients who rely on secure transfers of very personal data.



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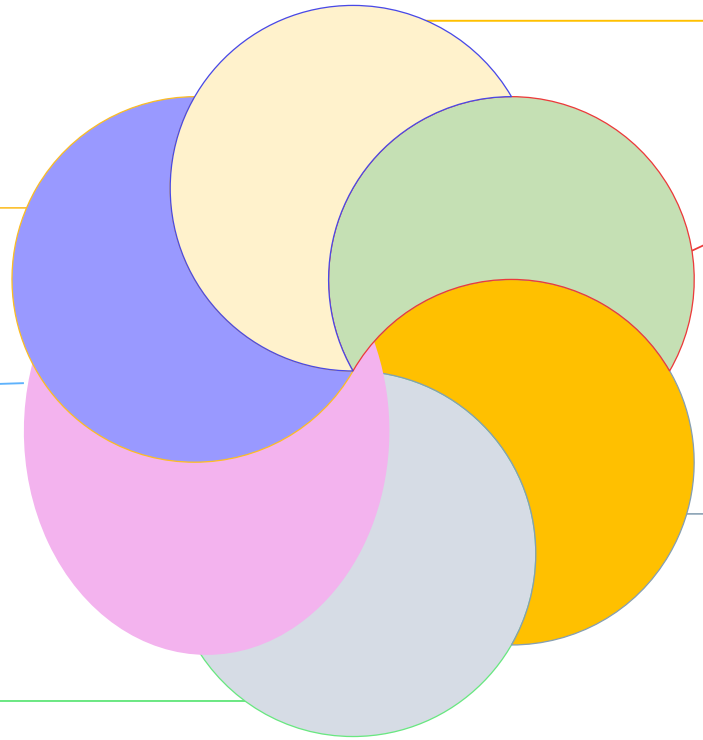
Doctor's responsibilities



To keep a processing file for the sensitive health data of his/her patients

To keep an information form and obtain the consent of his/her patients, if he/she intends to use the data for purposes other than medical records

To put in use technical security mesures

To protect the data processing procedures in view of being transparent

To ensure that personal data of patients are kept up to date.

To ensure lawful, fair and transparent processing of personal data

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Doctor's responsibilities: Categories of Recipients

Recipients are broken down into four categories:

- **sharing data** related to provision of medical care
- **sharing data** in cooperation with data processors where a contract is required
- **sharing data** if legal arrangements exist
- **sharing data** in view of public health purposes.

TYPES OF RECIPIENTS	DESCRIPTION
Social and Health Care	Doctors, Voluntary Hospitals, Private Hospitals and Clinics, Physiotherapists, Occupational Therapists, Speech and Language Therapists, Social Workers, Pharmacies, Nursing Homes
Data Processors with a contract	Online backup companies
Public Health	National agencies
Third parties and stakeholders	Insurance companies
Legal arrangements	Social Protection

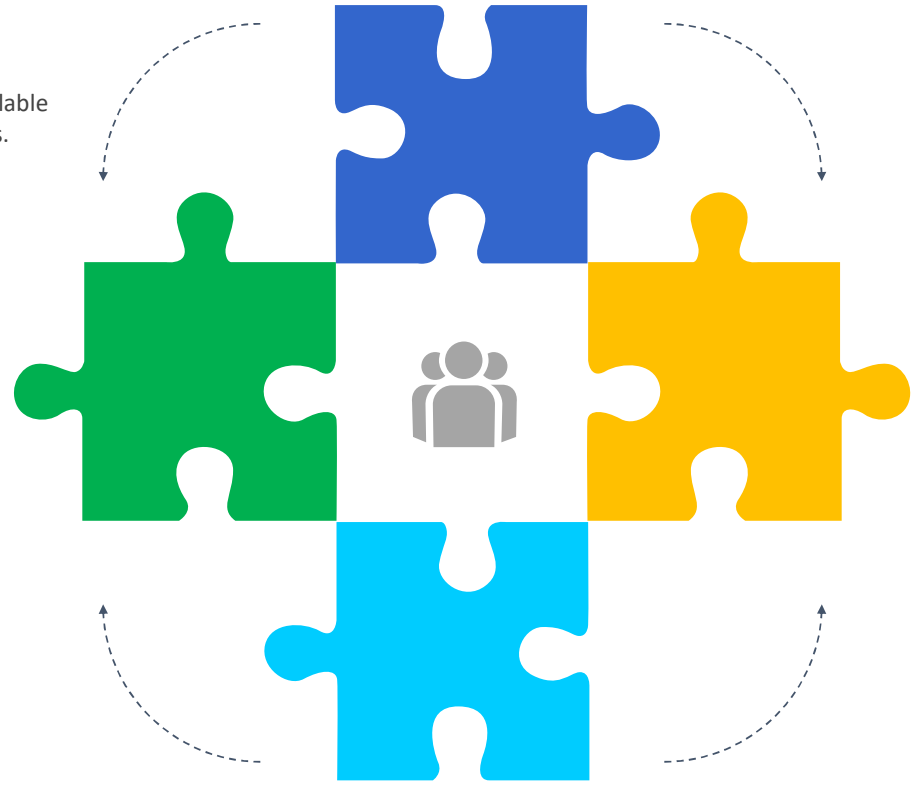
Doctor's responsibilities: Compliance with Data Protection Principles

Lawfulness and Transparency

The practice privacy statement should be made available to data subjects, when they register for care services.

Purpose Limitation

Doctors are permitted to gather and process information for a specific purpose. If doctor's practice is carrying out any additional processing beyond the normal practice, then it must be included in the Record of Processing Activities



Data Minimasitation

Personal data should be relevant and limited to what is necessary in relation to the purposes for which they are processed.

Accuracy

Every reasonable step should be taken into account, in view of ensuring that personal data are inaccurate, having regard the purposes for which they are processed, erased or rectified without any delay.

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Doctor's responsibilities: Compliance with basic individual's rights

1. Right to Access:

Under ***Article 15 of GDPR***, the patient can access a copy of their medical record. The doctor shall provide a copy of the patient's medical record. The access request should be carried out as soon as possible, and no later than **30 days after the access request**. They will not charged with a fee for providing a copy of the medical record. The individual can make an Access Request for their own personal data.

2. Right to Rectification:

Having based on the ***Article 16 of GDPR***, the patient can obtain rectification of records which are inaccurate. Nevertheless, this is not an unqualified right and depends on the circumstances of each case. If there is a disagreement between the doctor and the patient, due to the inaccuracy of the record, a possible dispute may be resolved by the addition of a supplementary statement in the patient record.

3. Right to portable data:

The right to data portability, under **Article 20 of GDPR**, deals with the circumstances where the processing procedure is based on consent or a contract. The patient is entitled to receive a copy of their medical record in a format that allows them to transfer the data to another health care provider.

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Creating employees awareness about GDPR on Health

- Human error is the lead factor for causing data breaches
- Financial risk
- Proactive and preventive behavior
- Legal requirement
- Key of the demonstration of GDPR compliance
- Organizational measures
- The improvement of workflows

WHY DATA AWARENESS IS IMPORTANT?

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Creating employees awareness about GDPR on Health

- Policies are the most important part
- Awareness involves knowing the procedures
- Engagement of everyone ; from executives to employees and developers
- Allocation of specific responsibilities according to departments
- Assignment of a Point of Contact

UNDERSTANDING RESPONSIBILITIES

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Synopsis

In this unit, the learner will gain knowledge on the historical aspects of EU Data Protection and the directives of the new GDPR Regulation. Moreover, learners will gain insight into the Communication on Digital Transformation of Health and Care which sets out measures for access and sharing health data in a safe way.

This unit also introduces learners to the **3 pillars**(digital health, protection of the health data and right to access the health data). The unit also creates the basic framework for analyzing doctors' responsibilities, as well as the categories of their responsibilities.

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