

DILEMMA 1. DESCRIPTION

The Health Information System in Peru needs technical training at all levels of use of the SIS. This training must include a deep reflection on confidentiality and privacy issues.

Privacy is an ethical problem, which arises when someone collect and manage personal data, specially health personal data. Privacy is also a human right. When you use personal data, you have some restrictions.

The Universal Declaration of Human Rights (article 12) establishes that: “No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks”.

Perú has a Data Protection Law (2011) which establishes the right to data protection in Peru. The controller (natural or legal person in charge of the data) have some data protection duties (see ANNEX2-Dilemma1-DOC1_DataProtectionLawPeru.pdf).

There is a “Declaration on privacy rights in a digital world” (see ANNEX2-Dilemma1-DOC2_UN-PrivacyRights.pdf, from http://www.un.org/ga/search/view_doc.asp?symbol=A/C.3/68/L.45/Rev.1)

When you manage health personal data, you must take care of them. People who are not in charge of the health services can´t use these data.

The health services can´t transfer personal data to third parties (private companies, for example). You must ask for consent and inform carefully to the data subject. You must implement security measures to avoid thefts or forbidden access to data. The controller or processor shall evaluate the risks inherent to the processing and implement measures to mitigate those risks.

These measures should ensure an appropriate level of security, taking into account the state of the art and the costs of their implementation in relation to the risks and the nature of the personal data to be protected.

You cannot store data longer than it is necessary for achieving the purpose for which they have been collected. After achieving the purpose of data processing (e.g. after the

performance of a contract), the collected data shall be erased, anonymised, or transferred to the entity legally authorised to receive them from the controller.

The Data Protection Principles are:

Personal data must be:

- a) **processed lawfully, fairly and in a transparent manner** in relation to the data subject;
- b) **collected for specified, explicit and legitimate purposes** and may only be further processed for another compatible purpose
- c) **adequate, relevant, and limited to the minimum necessary** in relation to the purposes for which they are processed
- d) **accurate and kept up to date**; every reasonable step must be taken to ensure that personal data that are inaccurate, having regard to the purposes for which they are processed, are erased or rectified without delay;
- e) **kept in a form which permits identification of data subjects for no longer than is necessary** for the purposes for which the personal data are processed;
- f) **processed under the responsibility and liability of the controller**, who shall ensure and demonstrate for each processing operation the compliance with the provisions of this Regulation.

Imagine the Public Health System (PHS) in Peru receives a good economical offer from a private insurance company: if PHS sells them the personal data about citizens, they will pay a great amount of money.

The PHS meets a great dilemma, as some more budget to improve health public services would strengthen his capacity to protect people's right to health people in the country".

DILEMMA 1. WORKSHEET

1. READING AND COMPREHENSION OF THE SITUATION

Read carefully the description of both the context and the given situation.

2. ANALYSIS OF THE SITUATION

Considering the documents provided:

- ANNEX1-DOC1_ACM-Moral_Imperatives: ACM (Association for Computing Machinery)
- ANNEX1-DOC2_FEANI-Code of Conduct Ethics approved GA 2006: FEANI (Federation of european professionals of engineering)
- ANNEX1-DOC3_RAE-UK-Statement_of_Ethical_Principles. RAE-UK (Royal Academy of Engineering of the United Kindom)
- ANNEX2-Dilemma1-DOC1_DataProtectionLawPeru
- ANNEX2-Dilemma1-DOC2_UN-PrivacyRights (“Declaration on privacy rights in a digital world”)

Follow the next steps:

- identify and describe the major either ethical or social problematic issues that appear in this situation, and point out the posed dilemma.
- identify into the ethical codes and laws provided either the principles or articles that may be related to the situation, explaining these relations.
- analyze the identified problems taking into account every stakeholder (individuals, institutions, groups, society at large,...), how are they affected, how the different possible options would affect. Explain the situation from different points of view.
- Some reflections might help with the analisis:
 - Do you agree with privacy being a human right? Why?
 - Is there some other right which would legitimate the sale of personal data?
 - Who is responsible in the Public Health System in Perú from the data protection perspective?
 - Do citizens in Peru have the right to privacy? Do they know it?

- Bearing in mind the Data Protection Law from 2011, which will be the ethical and legal implications if the PHS finally sells personal data to the insurance company?
- Reach an agreement on what a good professional should do and give and argue it (assess their potential risks and consequences of it, compare it with other options, identify ethical principles or values that underlie it, give references of ethical codes and laws that support, etc.)

3. EXPOSITION TO THE WHOLE GROUP

Choose a group representative to present your ideas and proposals to the class.