SCENARIOS AND USERS REQUIREMENTS

IEHR 1ST ESB MEETING – NOVEMBER 7TH 2019, BERLIN

STEFANO DALMIANI - FTGM

FONDAZIONE TOSCANA GABRIELE MONASTERIO/CNR PISA

USERS' PROBLEM

- **Different types of users, with different needs, knowledge, backgrounds, behavior, tools (apps)**
  - Somehow HCPs and patients needs are dependent and sometimes complementary
  - Many HCP use IT tools for (part of) their daily work
  - Some Patients use IT tools to manage their health (or wellness)
  - IT tools of HCP and Patients are often not connected nor able to communicate something
    - Use of communication standards may foster an effective communication, but some standards are "too flexible". We are far from a "plug>&play" paradigm in general.
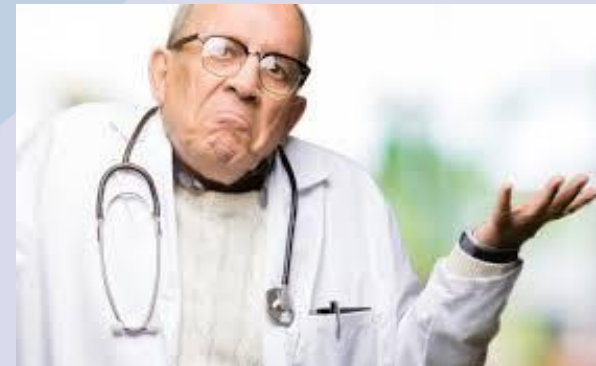
APPROACH TO THE PROBLEM

- **Critical step: define an IT solution (ERHS) implementing an effective model of data exchange and management**
  - *In respect of medicolegal regulation*

- **In order to simplify the communication with final users, the analysis of requirements is based on the specification of user scenarios.**

- **A "user scenario" is a storyboard describing the interactions of different actors in a particular situation to solve a specific problem.**
  - *In medicine scenarios are currently used in clinical practice teaching, both for physicians and nurses*

- **User scenarios involve access, by authorized people, to health data of patients coming from different European countries.**
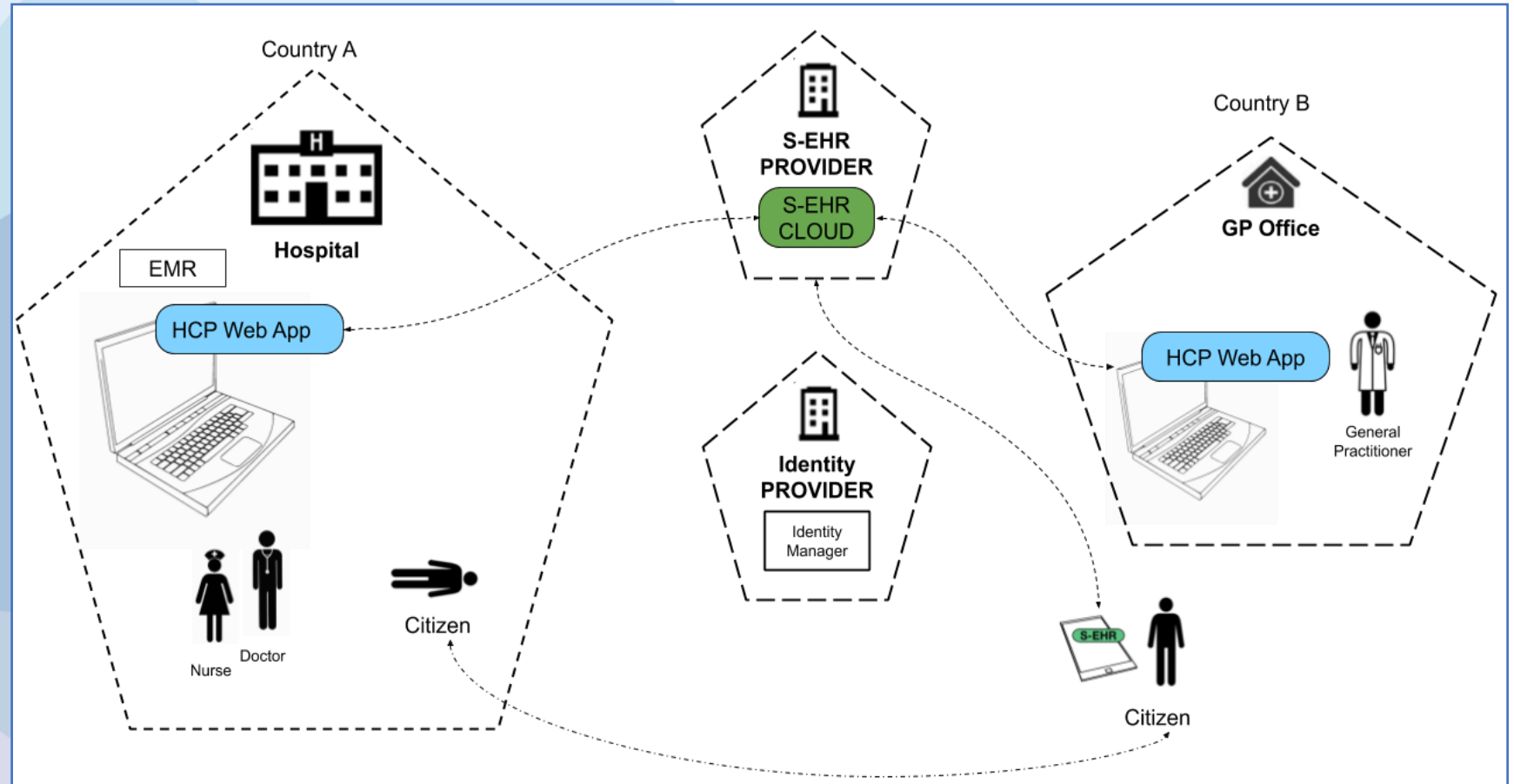
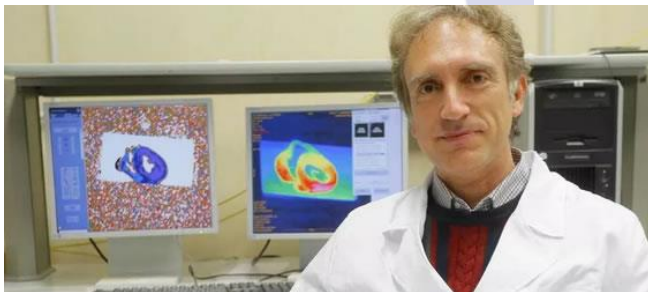# SCENARIO 1 - DEVICE TO DEVICE LOCAL HR EXCHANGE
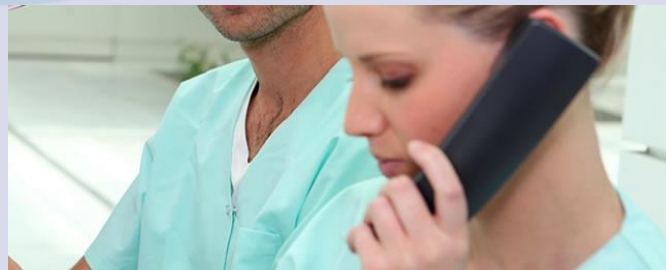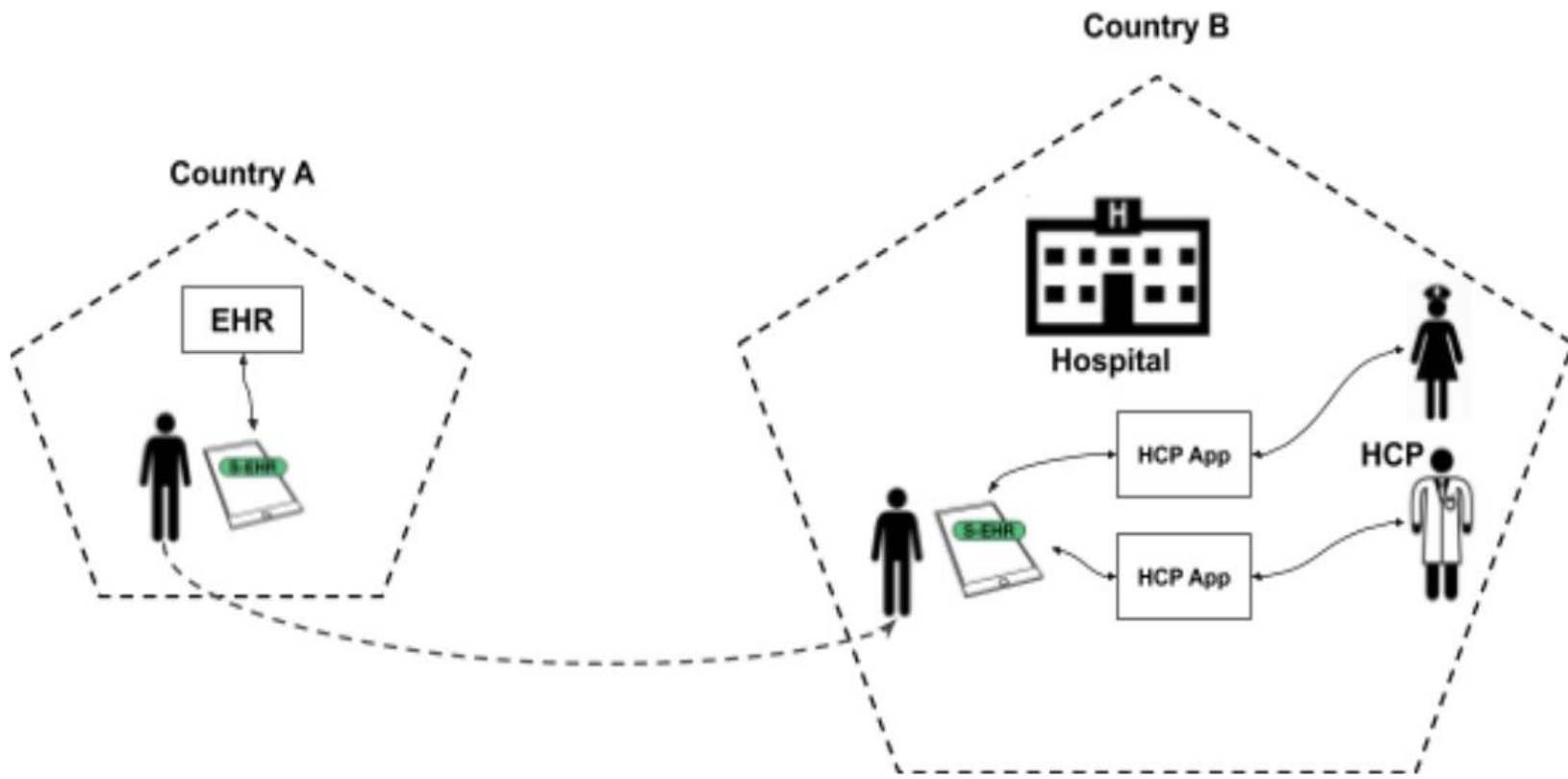
SCENARIO 2 – EMERGENCY ACCESS

SCENARIO 3 - RESEARCH PROTOCOLS
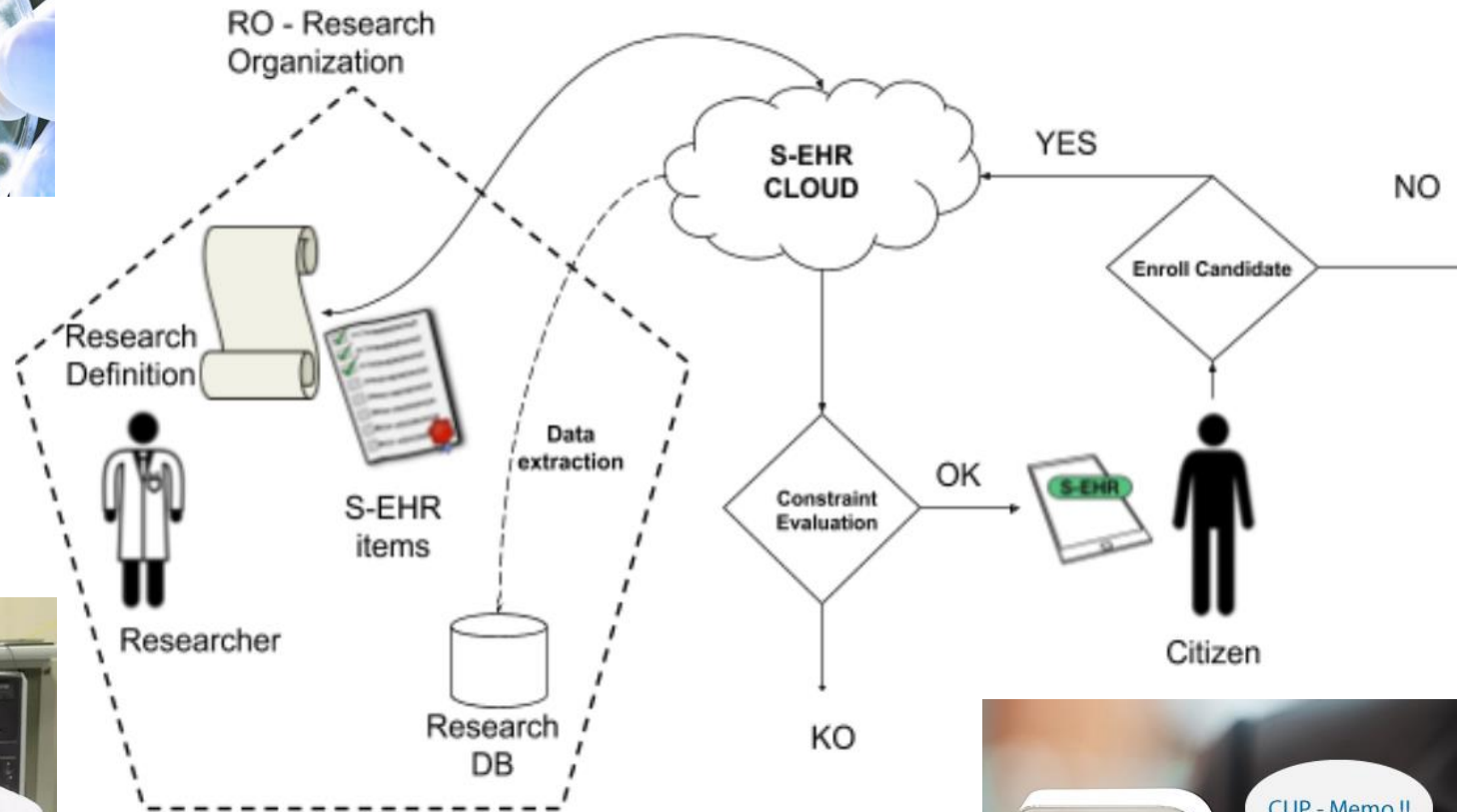
SMART- EHR CONTENT

- **In order to have a meaningful use S-EHR should be able to contain at least:**
  - *Patient Summary; (Emergency Dataset)*
  - *ePrescription;*
  - *Laboratory results;*
  - *Clinical imaging and bio-signals:*
    - contains DICOM images and movies;
    - contains bio-signals (e.g. SCP and Dicom waveform);
  - *Reports and digitally signed documents;*
  - *Hospital discharge reports.*
  - *personal notes of the patient (wellness and activity data)*

USERS' PROBLEM

- Focus on 3 reference scenario
  - *D2D*
  - *R2D*
  - *Research (Data Donation)*

- 3 kinds of final users
  - Patients/persons (& family informal Caregivers)
  - Healthcare Professionals
  - Researchers

- Reference (scoping) Organizations
  - None
  - Healthcare Providers
  - Research Organization

USERS FOCUS GROUPS

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PAOLO MARCHESCHI - FTGM

FONDAZIONE TOSCANA GABRIELE MONASTERIO/CNR PISA

IEHR FOCUS GROUPS

Focus Group	Description
Patients	Persons who travel abroad and are affected by chronic cardiovascular disease
Healthcare Professionals	Employee of Healthcare service provider (Hospital, Outpatient facility, territorial service) and Stakeholder representatives
Researchers	Investigators interested in, or promoting a, research protocol in clinical or social field

FOCUS GROUP INTERACTION

- One initial, introductory, meeting, where project was explained and scenario described, and were questionnaire was introduced and explained.

- One final meeting, usually at 7-10 days from the initial one, where patient's suggestions and comments were discussed and reported, and where paper or electronic compiled questionnaires were collected.

PATIENTS FOCUS GROUPS

For every hospital (FTGM, SCUBA, HYG and CHU) was assigned a focus group manager, in charge of conducting every focus group activity: from selection of candidates, to proposals for participation up to answers collection.

- **BAGDASAR-ARSEN EMERGENCY CLINICAL HOSPITAL (SCUBA): 5 patients from the Cardiology Department.**
- **ATHENS DIAGNOSTIC AND TREATMENT CENTERS (HYG): 7 patients.**
- **GABRIELE MONASTERIO TUSCANY FOUNDATION (FTGM): 5 cardiological patients.**
- **UNIVERSITY HOSPITAL CENTER OF LIEGE (CHU): 8 patients.**

HEALTH CARE PROFESSIONALS FOCUS GROUPS

Health Care Professionals Focus Groups was representing employees of healthcare service providers (Hospital, Outpatient facilities, territorial services) and included Stakeholder representatives and members.

- **BAGDASAR-ARSEN EMERGENCY CLINICAL HOSPITAL (SCUBA): 3 physicians and 3 nurses from the Cardiology Department.**

- **ATHENS DIAGNOSTIC AND TREATMENT CENTERS (HYG): 5 nurses and 4 physicians.**

- **GABRIELE MONASTERIO TUSCANY FOUNDATION (FTGM): 3 nurse and 4 physicians.**

- **UNIVERSITY HOSPITAL CENTER OF LIEGE (CHU): 3 nurses and 10 physicians.**

- **MEDICAL ASSOCIATION OF ATHENS (ISA): 100 physicians.**

RESEARCHER FOCUS GROUP

The researchers' focus group was formed by professionals performing clinical research in different settings, from pneumology, cardiology, gynaecology, neurosurgery, and cardiac surgery:

- **BAGDASAR-ARSEN EMERGENCY CLINICAL HOSPITAL (SCUBA): 5 researchers physicians.**

- **ATHENS DIAGNOSTIC AND TREATMENT CENTERS (HYG): 7 researchers.**

- **GABRIELE MONASTERIO TUSCANY FOUNDATION (FTGM): 5 researchers.**

- **UNIVERSITY HOSPITAL CENTER OF LIEGE (CHU): 5 researchers.**

RESPONSE ANALYSIS AND INTERPRETATION (PATIENTS)

- Patients have shown some distrust to share their healthcare data via software. Fear of data theft often associated with data cloud sharing.

- Patients differ completely in their opinion on the proposition to enter health data by themselves or Share data with relatives.

- Patients like better management of health but they fear technical problems could arise. They are wondering if hospitals could assist them with technical issues.

- Several patients pointed out that elderly people(> 65 y) do not have a smart-phones and those who have one use it only for calling or sending text messages.

RESPONSE ANALYSIS AND INTERPRETATION (HCP 1/2)

- **Some hospitals have a complete Clinical Information System, while other hospitals do not have such facilities, HCPs strongly ask for a wider spectrum of functionalities and system integrations.**

- **They embraced the idea of an S-EHR platform that could help them also in their daily clinical practice.**

- **The main concern was about the possible overwhelming of information.**

RESPONSE ANALYSIS AND INTERPRETATION (HCP 2/2)

- **Several physicians accept that the transfer of patient data takes up to 10 min in scenario 1. They argue that this is a small price to pay for obtaining a big quantity of healthcare data which moreover will avoid to repeat exams. These same physicians accept the biggest delay (up to 1 min) for the data transfer during emergency (scenario 2).**

- **They are aware that in an emergency they will not have time to go through the whole patient's healthcare history, but once the emergency is controlled, they will rely on the whole healthcare history to take future health decisions.**

- **There has been a reluctance to allow patients to enter data by themselves. They suggested adoption of a colour code differentiating data registered by patients/family caregivers from other ones certified by hospitals and professional healthcare providers.**

RESPONSE ANALYSIS AND INTERPRETATION (RESEARCHERS)

- Most researchers like very much the idea of getting their data directly from patients. However, they fear that elderly patients do not adhere to this solution.

- They liked the possibility of allowing individual patients to apply for a research study, who saw a way of increasing, in a simple manner, the number of participants in the study.

- Some researchers do not always consider it useful as they often perform studies with follow-up research and consider it important to perform studies on a local population, suitable for performing instrumental control examinations at regular intervals.

- Receiving data through mobile devices has aroused some interest, especially if these data are certified by hospitals, and do not use manually entered data.

RESULTS

- **Patients do not trust completely to put data in the cloud. Cloud is often synonym of data leakage.**
  - *Carrying data in the Mobile phone could solve this problem of trust, D2D allows to share data privately without cloud.*
- **Patients fear that technological problems could arise without having someone to help them.**
  - *Commitment to make technology as easy as possible, through a co-design approach.*
- **Patients however trust completely HCPs and agree that they will provide better care based on their complete health record.**
- **HCPs and researchers liked the idea to use such technological innovations in order to reduce errors and increase the success of patient care.**

NEXT STEPS

- **The definition of requirements is aligned with the incremental development approach of InteropEHRate, composed by three cycles:**

  - *Each development cycle lasts one year and incrementally adds results and improvements to results produced in the previous cycle, on the basis of feedback coming from final users and external stakeholders.*

  - *During each year, a set of candidate user requirements are defined in the first 6 months of the year, to be possibly implemented during the following 6 months of the project*

Thank you!

Paolo Marcheschi

Stefano Dalmiani

FTGM - Monasterio Foundation Research Hospitals

Q&A time.

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