Patient Summary

Moving clinical data from country to country in Europe

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Standards and Profiles in Action for Europe and beyond

Our vision is that of a global eHealth ecosystem where people receive safe and informed health care and interoperability assets fueling creativity, entrepreneurship, and innovation, and eStandards nurture digital health innovation, strengthen Europe's voice & impact, enabling co-creation and trusted provider-user relationships.

In the eStandards project (www.estandards-project.eu), standards developing organizations join up with eHealth stakeholders to build consensus on eHealth standards

- to create and adopt a Roadmap for alignment, iterative consolidation, and broad adoption of eStandards,
- to contribute to the eHealth European Interoperability Framework by resolving ambiguities & embedding quality management, and
- to explore the socio-economic aspects of interoperability standards.

Patient Summary: Information for Physicians

Testimonial

Jan, a 70 year old patient from Belgium, was brought into my emergency department. He was in shock, unable to speak, and his wife only spoke Dutch.

Fortunately, I had rapid access to his online Patient Summary. From this I could quickly learn that he had an aortic aneurysm! So, it was clear for me that rupture was a major diagnostic hypothesis. I think this saved his life!

What is a patient summary?

A Patient Summary is a concise clinical document. It provides an electronic set of clinical data. It is applicable for unexpected healthcare contacts.

A Patient Summary provides a health professional with essential information needed for healthcare coordination. In case of an unexpected situation, it can be vital for the continuity of care. It does not include a detailed medical history or details on each of the clinical conditions.

What clinical scenarios is the Patient Summary for?

The Patient Summery is particularly useful when your patient needs unplanned care. It provides important clinical information to the attending emergency department physician or GP, like allergies, current medication and medical conditions.

The summary data are collected and presented in a concise form, gathering basic information for the clinician.

Thereby it will increase safety and may add valuable insight for clinical decisions, as well as speed up a patient's journey through the health care process.

What does the Patient Summary contain?

It contains:

- General information about the patient (name, birth date, gender, etc.)
- Information about the Patient Summary itself (e.g. when and how it was created, last updated and by whom)
- A Medical Summary consisting of the most important clinical patient data:
    - allergies
    - current medical problems
    - medical implants
    - major surgical procedures during the last six months list of the current medication.

Who fills the Patient Summary?

In principle, the data come from the patient's general practitioner, and may be supplemented by other sources such as hospital and pharmacy records. The clinical data are recorded, as they are now, during routine medical care in the Electronic Health Record (EHR). If the EHR System is well structured, and the physician has entered coded information correctly, the Patient Summary can be automatically constructed. Medical specialists may also contribute. The physician may choose to validate the Patient Summary, whenever needed, before it is made accessible to others. This provides a final check by a physician who is familiar with the patient.

Is permission needed to fill in the Patient Summary?

Yes. Only a practitioner who has a therapeutic relationship with the patient will be able to fill the Patient Summary with information derived from the electronic health records.

Is the Patient Summary only useful for cross border patient care?

No, it is also useful and accessible on the national level. It is an important step to access vital patient information when you need it for clinical decision making when caring for a patient for the first time.

Can I trust the information?

Yes, you can trust the information of the Patient Summary.

The clinical data were filled in by your colleagues who previously cared for your patient. You can see when it was last updated and by whom.

Can I trust the translation into my language?

Yes, you can. The Patient Summary uses exclusively coded data (for example using the International Classification of Diseases (ICD) for diseases and Anatomic Therapeutic Chemical Classifications for drugs, or SNOMED-CT). These code systems have validated equivalents in all European languages.

Example: "Heart failure" has an international ICD code (150-) or SNOMED-CT code (42343007). Translation files will indicate the Dutch term (hartfalen) or French term (défaillance cardiaque), or the Portuguese term (insuficiência cardíaca).

That means, of course, that every responsible clinician has to fill in the right, coded, information into his/her patient's EHR! Which is, by the way, also very important for sharing good quality information among colleagues in your own country.

Do I need permission to look at a Patient Summary of a patient outside my practice?

Yes, you can only look at the Patient Summary when you have a trusted therapeutic relationship with the patient and his/her permission. In an emergency situation you may access it without explicit permission when the patient is not able to give it (e.g. when unconscious). All accesses will be logged

and may be subject to a later audit, requiring you to demonstrate that the therapeutic relationship did exist. The patient should be able to see who has accessed their Patient Summary when.

How do I access a Patient Summary?

Your Electronic Health Record System will allow you to record the contact with the patient. The system will record the permission to access the Patient Summary, and provide access to that Patient Summary.

What is the future for the Patient Summary?

- In the future, its accessibility will not be limited to European Countries. It will also be accessible in other continents;
- It is expected that the use of Patient Summaries will increase the quality of medical record keeping in general;
- It is intended that the range of clinical data in it will progressively be extended to include data that are specific to long term conditions.

Patient Summary: Information for Patients

Testimonial

My wife and I live in the Dutch speaking part of Belgium.

For my 70th birthday, we made a trip to Lisbon, to visit our son, his wife and our grandchildren.

There I suddenly and unexpectedly turned seriously ill. I had a very heavy pain in my chest and soon lost consciousness. I was rushed to the hospital. My wife, who only speaks Dutch, tried to explain what happened to me. The doctor in the emergency room asked her about my medical history, but she was not able to explain that in English or Portuguese. Then, she remembered I had my Patient Summary on the Internet. She authorized the doctor to look at it. The doctor quickly accessed that information and found out my main artery (the aorta) was severely widened (I had what is called an "aortic aneurysm").

This has put the doctor on the road to check whether my widened aorta was ruptured. And so, he made the diagnosis. That, I think, saved my life.

What is a patient summary?

It contains clinical information that could be vital when unexpectedly you need help:

- Whether you are allergic, and if so, the nature of your allergy
- The name of your most important clinical problems
- Whether you had major surgical procedures in the past six months (and for what reason)

- Whether you carry any implants, and if so, what kind of implants
- Whether you currently take medicines, and if so, which ones

When will it be useful?

My Patient Summary is particularly useful if I ever need unplanned or emergency care. It will give important clinical information to the attending emergency physician or general practitioner. These doctors can check what my medical conditions are, what medicines I take, whether I have serious allergies. If I am seriously ill, I will not always be able to provide this information myself. Even if I could, when I am abroad, it is not sure that the attending doctor will speak my language.

It makes a big difference when the doctor can access my Patient Summary. All the important information is there, gathered in a concise form. Because it is coded information, it can be translated in any language that the doctor understands.

I feel a lot safer now to travel and to visit my loved ones abroad.

Who is responsible for making sure that my Patient Summary is complete and up to date?

I trust my general practitioner to document in the electronic health record all important medical information. My GP is expected to update that information every time he/she gets a medical report, for instance from my cardiologist. My medical specialist and the pharmacist can also contribute.

Will I be able to look at the Patient Summary and ask for changes ?

I can always ask my GP to share that Patient Summary with me and to check whether all important information is there. I can also view my own Patient Summary.

This means that I can also check whether a new important development in my medical condition is well reflected. So, I know that my medication list is up to date. If necessary, I can ask my GP to update anything that I think is missing or may be useful in an emergency situation.

Can I trust that this information will be only visible to the doctors I can trust?

My doctor explained to me that all my medical information is encrypted and safely guarded, including this online Patient Summary. Only doctors who have asked my permission to access that information can see it. In case I am unconscious, and in case of an emergency, the treating physician exceptionally may access the crucial information without gaining my permission at the time. I can always look up who has accessed my Patient Summary. If I am not happy with a certain access, I can ask for an investigation.

Will physicians in other countries understand the content of the Patient Summary?

Yes, they will be able to. The Patient Summary uses only medical terms that have been professionally translated into every European language. The computer of the emergency doctor can display these medical terms in his or her preferred language.

PATIENT ADMINISTRATIVE DATA			
Variable (nesting level 1)	Variables (nesting level 2)	Variables (nesting level 3)	DEFINITION AND COMMENTS
Identification	National Health Care patient ID	National Health Care patient ID	Country ID, unique for the patient in that country. Example: ID for United Kingdom patient
Personal information	Full Name	Given name	The Name of the patient (Example: John). This field can contain more than one element
		Family name/Surname	This field can contain more than one element. Example: Español Smith Note: some countries require surname to be the birth name [to avoid potential problems with married women names).
	Date of Birth	Date of Birth	This field may contain only the year if day and month are not available. E.g.: 01/01/2009
	Gender	Gender Code	This field must contain a recognized valid value
Contact information	Address	Street	Example: Oxford
		Number of Street	Example: 221
		City	Example: London
		Post Code	Example: W1W 8LG
		State or Province	Example: London
		Country	Example: UK
	Telephone No	Telephone No	Example: +45 20 7025 6161
	Email	Email	Example: jens@hotmail.com
	Preferred HP/HPO to contact[1]	Name of the HP/HPO	Name of the HP/name of the HPO that has been treating the patient. If it is a HP, the structure of the name will be the same as described in 'Full name' (Given name, family name/surname)
		Telephone No	Example: +45 20 7025 6161
		Email	Email of the HP/legal organization
	Contact Person/ legal guardian (if available)	Role of that person	Legal guardian or Contact person
		Given name	The Name of the Contact Person/ guardian (example: Peter. This field can contain more than one element)
		Family name/Surname	This field can contain more than one element. Example: Español Smith
		Telephone No	Example: +45 20 7025 6161
		E-mail	E-mail of the contact person/legal guardian
Insurance information	Insurance Number	Insurance Number	Example: QQ 12 34 56 A

PATIENT CLINICAL DATA			
Variable 1)	**Variables (nesting level 2)**	**Variables (nesting level 3)**	**DEFINITION AND COMMENTS**
Alerts	Allergy	Allergy description	Description of the clinical manifestation of the allergic reaction (Example: anaphylactic shock, angioedema (the clinical manifestation also gives information about the severity of the observed reaction)
		Allergy description id code	Normalized identifier
		Onset date	Date of the observation of the reaction
		Agent	Describes the agent (drug, food, chemical agent, etc.) that is responsible for the adverse reaction
		Agent id code	Normalized identifier
	Medical Alert Information (other alerts not included in allergies)	Health Care Alert description	Medical Alert Information: any other clinical information that is imperative to know so that the life or health of the patient does not come under threat. Example 1: Intolerance to aspirin due to gastrointestinal bleeding. Example 2: intolerance to captopril because of cough (the patient is not allergic but can't tolerate it because of persistent cough)
		Health Care Alert id code	Normalized identifier
Medical History	Vaccinations	Vaccinations	Contains each disease against which immunizations has been given
		Brand name	
		Vaccinations id code	Normalized identifier
		Vaccination Date	the date when the immunization was received
	List of resolved, closed or inactive problems	Problem description	Problems or diagnoses not included under the definition of "current problems or diagnosis".

[1] A Health Professional in country A may need a contact (Health Professional/Healthcare Provider) who knows the patient

			Example: hepatic cyst (the patient has been treated with an hepatic cystectomy that solved the problem and therefore it's a closed problem)
		Problem id code	Normalized identifier
		On set time	Date of problem onset
		End date	Problem resolution date
		Resolution Circumstances	Describes the reason by which the problem changed the status from current to inactive (e.g. surgical procedure, medical treatment, etc.) This field includes "free text" if the resolution circumstances are not already included in other fields like surgical procedure. medical device, etc. e.g. hepatic cystectomy (this will be the resolution circumstances for the problem "hepatic cyst" and will be included in surgical procedures)
	Surgical Procedures prior to the past six months	Procedure Description	Describes the type of procedure
		Procedure Id (code)	Normalized identifier
		Procedure date	Date when procedure was performed
Medical Problems	List of current problems / diagnoses	Problem/Diagnosis Description	Problems / diagnoses that fit under these conditions: conditions that may have a chronic or relapsing course (e.g. irritable bowel syndrome, otitis media), conditions for which the patient receives repeat medications (e.g. diabetes mellitus, hypertension) and conditions that are persistent and serious contraindications for classes of medication (e.g. dyspepsia, migraine and asthma)
		Problem Id (code)	Normalized identifier
		Onset time	Date of problem onset

	Medical Devices and implants	Device and Implant description	Describes the patient's implanted and external medical devices and equipment that their health status depends on. Includes devices as cardiac pacemakers, implantable fibrillator, prosthesis, ferromagnetic bone implants, etc. that are important to be known by the HP
		Device Id code	Normalized identifier
		Implant date	Date when procedure was performed
	Major Surgical Procedures in the past six months	Procedure Description	Describes the type of procedure
		Procedure Id (code)	Normalized identifier
		Procedure date	Date when procedure was performed
	Treatment Recommendations	Recommendations Description	Therapeutic recommendations that do not include drugs (diet, physical exercise constraints, etc)
		Recommendation ID (code)	Normalized identifier
	Autonomy / Invalidity	Description	Need of the patient to be continuously assessed by third parties, invalidity status may influence decisions about how to administer treatments
		Invalidity Id code	Normalized invalidity identifier (if any, otherwise free text)
Medication Summary	List of current medicines	Active ingredient Exemption: brand name	Substance that alone or in combination with one or more other ingredients produces the intended activity of a medicinal product. Example "paracetamol". Brand name if a biological medicinal product or when justified by the health professional (ref. Commission Directive 2012/52/EU)
		Active ingredient id code	Code that identifies the active ingredient

	(All prescribed medicines whose period of time indicated	Strength	the content of the active ingredient expressed quantifiably per dosage unit, per unit of volume or per unit of weight, according to the pharmaceutical dose form. Example 500 mg per tablet
	for the treatment has not yet expired whether it has been dispensed or not)	Pharmaceutical dose form	the form in which a pharmaceutical product is presented in the medicinal product package (e.g. tablet, syrup)
		Number of units per intake	the number of units per intake that the patient is taking. Example 1 tablet
		Frequency of intakes	Frequency of intakes per hour/day/week/month. Example each 24 hours
		Duration of treatment	Example: 14 days
		Date of onset of treatment	Date when patient needs to start taking the medicine prescribed
Social History	Social History Observations	Social History Observations related to smoking, alcohol, diet	Health related “life-style factors" or "life style observations" Example: cigarette smoker, alcohol consumption
		Reference date range	Example: from 1974 thru 2004
Pregnancy history	Expected date of delivery	Expected date of delivery	Date in which the woman is due to give birth. Year, month day are required (e.g. 01/01/2014)
Physical findings	Vital Signs Observations	Blood pressure	One value of blood pressure which includes: systolic blood pressure and diastolic blood pressure
		Date when blood pressure was measured	Date when blood pressure was measured
Diagnostic tests	Blood group	Result of blood group	Result of blood group test made to the patient
		Date	Date on which the blood group was done. This field may contain only the year if day and month are not available (e.g. 01/01/2009)

METADATA			
Variable (nesting 1)	**Variables (nesting 2)**	**Variables (nesting 3)**	**DEFINITION AND COMMENTS**
Country	Country	Country	Name of country A
Patient Summary	Date Created	Date Created	Date on which PS was generated
	Date of last update	Date of last update	Date on which PS was updated (date of most recent version)
Nature of the PS	Nature of the PS	Nature of the PS	Define the context in which it was generated. Distinguish among three methodological approaches to build the PS: direct human intervention of an HP, automatically generated and mixed approach
Author organization	Author organization	Author organization	At least an author organization (HCP) shall be listed. In case there is no HCP, at least an HP shall be listed

eStandards supported by	Coordinators
 	***Scientific coordinator:*** ***Catherine Chronaki***  ***Coordinator:*** ***Geert Thienpont*** 
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Consortium

1	RAMIT Research in Advanced Medical Information and Telematics vzw (BE)
2	HL7 International HL7 International Foundation (BE/EU)
3	NEN (CEN TC/251) Stichting Nederlands Normalisatie Instituut (NL/EU)
4	IHE-EUR Integrating the Healthcare Enterprise-Europe aisbl (BE/EU)
5	EuroRec European Institute for Health Records (FR/EU)
6	MEDIQ Mediq AS (DK)
7	OFFIS OFFIS EV (DE)
8	Lombardy Regione Lombardia (IT)
9	NICTIZ Stichting Nationaal ICT Instituut In De Zorg (NL)
10	HOPE European Hospital and Healthcare Federation (BE/EU)
11	COCIR European Coordination Committee of the Radiological, Electromedical and Healthcare IT Industry (BE/EU)
12	SPMS Serviços Partilhados do Ministério da Saúde, E.P.E.(PT)