TRILLIUM II

Reinforcing the Bridges and Scaling up EU/US Cooperation on Patient Summary

WP4

D4.3 v2019-06-28 Education and training material for the international patient summary and
associated standards in three languages-WP4-MEDCOM

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Lead beneficiary:	MedCom				
Contact:	Mie Hjorth Matthiesen, MedCom, mhm@medcom.dk				
Contributors:	Mie Hjorth Matthiesen, Dipak Kalra, Elaine Blechman, Valentina Tageo, Robert Stegwee, Shirin Golyardi, Jan Petersen, Willem-Jan Jacobs, Hans Gille, Janne Rasmussen				
Editors:	Mie Hjorth Matthiesen				

Statement of originality

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Change History

Version	Date	Author	Organisation	Description
0.1	14.05.2018	Dipak Kalra	I~HD	First outline and content of the document
0.2	21.06.2018	Elaine Blechman	SmartPHR	Input regarding learning objectives
0.3	11.09.2018	Mie H. Matthiesen	MedCom	Input from Valentina Tageo, Robert Stegwee Additional input + restructuring of the document
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0.5	11.12.2018	Jan Petersen	MedCom	Review of the deliverable and input to several sections, especially the ethics section.
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1.0	20.12.2018	Mie H. Matthiesen	MedCom	Final corrections before submission
2.0	28.06.2019	Janne Rasmussen	MedCom	Updated information in Appendix II

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Deliverable Overview

Objectives

D4.3 is the outcome of task 4.4: Collect and Revise educational and training material of relevance to the international patient summary.

This task will address awareness, education, and thus understanding and support amongst patients and healthy citizens in the use and benefits of the IPS. Specific online materials will include topics on how to access, understand, use and securely update their summary, how they may use it to make personal health and wellness decisions, how to share their summary(ies) for decision making in care planning and access to care (in case of patient mediated access).

Content

Educational and training material for IPS is addressed in D4.3 as follows:

- Importance of educating patients and HCPs (Chapter 2)
- Main topics of public and professional education (Chapter 3)
- Different strategies that could be adopted to design and deliver educational resources to different stakeholders (Chapter 4)

Deviations

V1 was submitted as planned in M24. Due to activities taking place after delivery that are of relevance to the content of D4.1, the deliverable has been updated at the end of the project and a v2 is submitted M30. The updates constitute update of Annex II in terms of number of language available.

1. Executive summary

This deliverable complements other activities of the Trillium II work packages and deliverables in supporting the successful scale up of the adoption and benefits from pan-European exchange of patient medical summaries. This deliverable emphasises the importance of well-educated patients and health professionals, about the purpose, content, use and trust of patient summaries, of the value summaries can have for the care given to individuals and by individuals in self-care. Although Trillium II primarily supports the adoption of a European or International patient summary conforming to the European Guidelines and/or to an emerging International Patient Summary specification, this deliverable recognises that progress is being made in parallel within some countries on the implementation and scale up of nationally defined patient summary specifications. Since these summaries have rather similar information content, this deliverable does not strongly distinguish which patient summary specification might be offered to professionals, patients and the public in individual countries, since the educational needs are considered to be almost identical.

An accurate and up to date summary of a person's health and care history and current status has the potential to contribute to better quality and safer healthcare decisions, especially in situations where that information is not otherwise available. Widening access and good quality use of health summary information by patients will require investments in health literacy and digital health literacy. In the case of health professionals, the educational challenge may be around the quality of their own documentation which will be needed to allow good quality summaries (complete enough, accurate, up to date) to be generated or created. All stakeholders will need to trust in the summary content enough or rely on it for decision making.

Chapter 2 of this report explains why it is important to educate patients and health professionals about the IPS. Chapter 3 lists the main topics that public and professional education should cover:

- The health and care scenarios for patient summary use
- The PS benefits across the health system
- Content of the patient summary
- Information flows
- Information governance and data protection
- Empowering patients through their summary

The purpose and scope that should be covered for each of these topics is discussed.

Chapter 4 describes a range of strategies that could be adopted, usually at Member State level, to design and deliver educational resources to different stakeholders, especially the public and professionals. There is no single strategy that will achieve this education, especially given diverse population health literacy and access to digital tools, and so a mixed model is recommended. This chapter closes by proposing a series of educational objectives that might be used to shape specific programmes, and to assess their effectiveness.

Despite numerous contacts with health ministry eHealth contact points across Europe, including the eHealth Network, and national standardisation bodies through CEN, it is apparent that the efforts made to educate the public and healthcare professionals about the patient summary are at best patchy and sometimes non-existent. It has therefore proved more relevant and potentially useful to Member States and the European Commission for this deliverable to consolidate expert inputs on the educational topics that are most needed for the successful scale up of patient summaries and for the realisation of its anticipated benefits. Appendix I to this report presents examples of educational resources offered in different Member States. This is not a

comprehensive view of what is available, since it is at times difficult to discover such resources. It is rather an illustration of the diversity of what exists, and of its fragmented nature.

If the scale up, adoption, and realisation of benefits from the patient summary, and later the IPS, are to be realised there is now a vital need to invest in workforce and public education that systematically addresses the topics presented here, using a diversity of modalities.

2. The importance of educating patients and HCPs about the IPS

The successful implementation of a patient summary is heavily dependent on the education and training for both citizens/patients and health professionals. By facilitating education and training, citizens/patients and health professionals are made aware of the existence of the patient summary and the information it contains, engagement to actively use and update the patient summary and all parties (including health care organisations and insurance brokers) are made aware of the benefits such a patient summary includes. If the involved parties are aware, engaged and convinced of the potential benefits, the following benefits are to be expected:

1. Health professionals and patients will be better motivated to capture high quality data that is incorporated into summaries;
2. Health professionals will be encouraged to access, trust and use patient summaries to enable safer and more effective care decisions;
3. Patients will be encouraged to contribute relevant data to their summaries, to access and check their summaries and make use of them for personal care and decision making;
4. Patients will be in a position to make better informed decisions about the control of their summaries, such as authorisations for their communication and access, including consent management;
5. EHR vendors will perceive a greater market value in patient summaries and their exchange, stimulating better applications and interfaces to support summary maintenance, smarter use of summary data and the greater adoption of patient summary exchange standards;
6. Healthcare funders and healthcare providers will identify better returns on investments that support wide-scale patient summary creation and exchange;
7. Health outcomes and healthcare value may, as a consequence, improve.

To achieve above benefits, this deliverable focuses on the educational strategies and topics that should be prioritised by health systems for educating the public and professionals. Although Trillium II primarily supports the adoption of a European or International patient summary conforming to the European Guidelines and/or to an emerging International Patient Summary specification, this deliverable recognises that progress is being made in parallel within some countries on the implementation and scale up of nationally defined patient summary specifications. Since these summaries have rather similar information content, this deliverable does not strongly distinguish which patient summary specification might be offered to professionals, patients and the public in individual countries, since the educational needs to be considered here are almost identical.

2.1 The opportunities from better educated summary users

As outlined above, wider access to an accurate and up to date summary of a person's health and care history and current status has the potential to contribute to better quality and safer healthcare decisions, especially in situations where that information is not otherwise available or is only available in a human-readable form e.g. on paper. Most summaries, especially for cross-border use, have been designed to target the clinical information needs for managing adult patient care in unscheduled care scenarios for which no background health records are available. However, earlier work reported in Deliverable 4.1 has indicated a high relevance of this summary information for more significant disaster and rescue situations, albeit with a different prioritisation of some information headings within the summary. It also seems likely that a child-relevant version of the summary might be constructed and rolled out with only modest addition to the current EU Guidelines.

Widening access and good quality use of health summary information by patients will require investments in health literacy and digital health literacy. In the case of health professionals, the educational challenge may be around the quality of their own documentation will be needed to produce good quality summaries which are complete enough, accurate and up to date. All stakeholders will need to trust in the summary content enough to rely on it for decision making.

2.2 The availability of patient summary education programmes within Europe

The original intention of this deliverable, when it was defined in the Description of Action, was to identify good educational programmes within Europe about the patient summary, targeting the public and patients on one side, healthcare professionals on the other. It was expected that this deliverable would function as an inventory of resources, highlighting good examples and drawing from these a synthesis of the most important topics for education.

Despite numerous contacts with health ministry eHealth contact points across Europe, including the eHealth Network, and national standardisation bodies through CEN, it is apparent that the efforts made to educate the public and healthcare professionals about the patient summary are at best patchy and sometimes non-existent. It has therefore proved more relevant and potentially useful to Member States and the European Commission for this deliverable to consolidate expert inputs on the educational topics that are most needed for the successful scale up of patient summaries and for the realisation of its anticipated benefits.

The next section describes those educational topics and why each of them is important for awareness, engagement, endorsement and support of a patient summary ecosystem. Later parts of this deliverable outline strategies that could be adopted for delivering such education. Appendix I to this deliverable lists some examples of different member state or institutional educational resources. However, these are only examples as a comprehensive collation of educational resources was not possible.

Appendix II provides links to material about what the IPS is in three languages: English, Danish and Italian.

3. Topics on which IPS educational programmes are needed

In order for the public support, patient engagement and empowerment through the patient summary, healthcare professional commitment to create and use good quality summaries, and for wide-scale adoption of the IPS standard, there are several areas of patient, public education and healthcare professional education that need to be provided.

1. **The health and care scenarios for patient summary use:** The health and care scenarios for which secure online access to an individual's patient summary by authorised professionals for specific purposes is of care safety benefit to those individuals.
2. **The PS benefits across the health system:** The benefits across the health system from the successful scaling up of patient summary availability and use.
3. **Content of the patient summary:** The information content of the patient summary, and the source systems from which this information is derived. Individuals must be guided on how they can correct errors and omissions in the summary that they access. There is a specific need for healthcare professional education about the creation and maintenance of patient summary information.
4. **Information flows:** The potential information flows that would enable that summary to be accessible at some other global point of care or emergency situation.
5. **Information governance and data protection:** How the summary and these information flows are governed, in terms of data protection and information security, and how the rights of European citizens are protected through these arrangements. This includes how individuals might exercise their right to opt out, if this is permitted, and to reverse that decision later if they wish to. Also the patient's right to transfer the summary to third party (data portability).
6. **Empowering patients through their summary:** How an individual can review their own health summary, and what options they have for downloading it, and offering access to it to approved third-party vendors of ICT products and services that they wish to take advantage of. This should include how individuals can take advantage of the summary themselves to become more informed and empowered actors in managing and improving their own health and prevention. The possibility of delegating access to the summery to next of kin or other trusted persons should be addresses.

Although all of these topics are expressed with the patient or member of the public as target, in practice healthcare professionals need an equivalent level of understanding for their own confidence in contributing to and using patient summaries, and in advising their patients if asked for advice.

Whilst there may be a need for education about the IPS as an internationally endorsed specification, the difficulty of international standards adoption suggests that this is perhaps the least important educational need. However, if multiple stakeholders and decision makers are convinced that patient summaries are vital to health systems, that they need to be exchanged across borders and that it is cost effective from a business point of view to implement systems that have global markets, the business model for IPS adoption will follow naturally.

3.1 The health and care scenarios for patient summary use

In order for patients, and health professionals, to be confident about the information that should be in a patient summary, and how it may subsequently be used, it is important for all of these actors to appreciate the healthcare contexts that it is designed to serve, and the knowledge gaps that treating healthcare professionals face without adequate knowledge of a patient's health history.

The different healthcare scenarios in which an urgent clinical encounter may arise needs to be specified to the public, since resistance to an online summary seems often to arise from persons who regard themselves

as relatively healthy, and resistance is lower among who people recognize that they do have health issues that emergency professionals may need to know about.

Clearly there will be many unplanned care encounters where a summary is not available, in national and cross-border situations, and it will be important for patient awareness of the importance of the summary not to create any undue alarm for patients having unplanned care where a summary is not available. However, it is equally important to emphasise how awareness of allergies, current medication, ongoing conditions and recent procedures may influence care decisions and either avoid safety complications or accelerate accurate diagnosis and the most effective treatment.

Also, of great importance is the need to educate health professionals about the critical dependence that other professionals will place on the information they read in a patient summary, which may direct diagnostic and treatment decisions. HCPs need to appreciate how important it is for the content of the patient summary to be as complete a and as up-to-date as possible, which may impact their clinical documentation practices. As an example, it is common for an electronic health record system to have a summary or dashboard screen which contains a problem list of recent and ongoing conditions. This overview has to be maintained manually (even if this is by dragging and dropping diagnoses from another screen into the summary). Obviously, such curation efforts require time. There is a recognised problem of clinicians not removing irrelevant or outdated information from a summary, such as old conditions that are not of current concern, and especially the removal of suspected allergies that are now considered to be highly unlikely.

Maintaining an accurate patient summary takes effort, and clinicians will need education about why it is important to consider it as a worthy investment of time and effort, for the sake of other health professionals in other countries providing care to their patients. This is a non-trivial matter, which has been highlighted over some years in workshops and events, such as in the Trillium Bridge project. However, it seems not to have been taken seriously by many Member States within national or cross-border patient summary initiatives.

Deliverable 4.1 has highlighted two important use cases, emergency/disaster situations and the case of children and immunisation, as additions to the unplanned care use case for which most health systems are today implementing their patient summary solutions. Additional use cases are also mentioned in that deliverable, and others have been highlighted by the VALUeHEALTH project. Education about these additional use cases might be premature, but some level of stakeholder engagement is required to ascertain which additional use cases should be added in the future. This topic is briefly discussed later in this deliverable.

3.2 The PS benefits across the health system

This section considers the different actors in the health ecosystem, and which benefits of a patient summary might be communicated to them.

Health Systems

With inefficiencies in the care of individual patients identified, such as duplications of tests and delays in the optimal delivery of healthcare interventions, or as there is a shift towards outcomes-based commissioning, there will be a greater need for more complete health data on which to evaluate clinical outcomes.

Concrete benefits of access to a Patient Summary:

a) Increased safety, quality care and universal access;
b) Faster integration of health information across care providers, therefore enabling care decisions based on more complete information;
c) The increased interoperability between procured components of national, regional and local eHealth architectures and applications, is likely to improve quality and reduce costs, making the EU market more competitive on the global scale;
d) Better alignment of the eHealth standardization process with digital Health policy development in Europe, the US and globally, will lead to availability of just-in-time standards and specifications for agreed policy decisions or initiatives.

Citizens/Patients: Why the Patient Summary

Patient Summaries are increasingly important to ensure that patients receive the best possible care. A cross-border electronic healthcare record system (including Patient Summaries) can ensure that the patients' relevant data is available to clinicians, therefore increasing factors of success for treatment.

Concrete benefits of access to a Patient Summary:

a) Increased safety in administration of treatment in emergencies
b) Increased trust in provided health care
c) Increased access and quality of care
d) Increased information on patients' clinical history

Emergency doctors (clinical)

Providing the appropriate treatment for patients in case of emergencies is particularly difficult. In addition, comprehensible medical documentation on patients is likely to be lacking.

A cross-border electronic Patient Summary can provide clinicians working on emergencies with all the relevant patient data, therefore facilitating administration of the best possible healthcare.

Concrete benefits of access to a Patient Summary:

a) Facilitate the identification of patients and consult their essential healthcare data;
b) Improve the decision-making process in diagnosis, based on the patient's relevant clinical data, available in own language (with an original copy);
c) Increased likelihood of obtaining patient consent for healthcare services;
d) Better patient care through cross-border healthcare data exchange;
e) More efficient use of resources when providing healthcare to foreign patients;
f) Security increase deriving from the use of a paperless electronic patient data system;

Standards developers and SDOs

Activities on IPS standards bridge the gap between strategic intent and capability for action by Standards Development Organization (SDOs) striving for interoperability, quality, and safety through standards adoption.

Concrete benefits of a Patient Summary:

a) Support in validating and receiving endorsements on the accuracy of cross-border clinical information structures and associated terminology value sets;
b) Bridge the gap between standardization and adoption - collaboration between development teams are likely to achieve a result that standards are more widely adopted.

    c)   Increased funding resulting from engagement with open innovation and from the evolution of governance of the international patient summary.

Vendors and developers

It is presently difficult and expensive for healthcare organizations to change system supplier or to take best of breed mixed-vendor solutions. Competitiveness is therefore stifled, and SMEs are disadvantaged because they are rarely able to provide a comprehensive solution to a health care provider. The results of Trillium-II are therefore expected to have a substantial positive impact on competitiveness and innovation.

Concrete benefits of a patient summary:

    a)   Increased understanding of use cases will contribute to reduce dependency upon locked-in solutions and to open-up the market to innovative products from SMEs;

    b)   Use of Harmonized standards will likely decrease unnecessary regulatory divergences, which constitute barriers in key economic sectors such as health and health IT

    c)   Development of solutions based on Open Source codes and Standards (e.g. CDA)

    d)   Likely advance of EU-US innovation capacity on industry development and market growth (eHealth and pharma)

    e)   Impact on the mobile Health industry, an industry that, in general, is driven by low budgets and cannot afford adoption of complex standards, through the delivery of interoperability assets in the form of libraries for FHIR, building blocks that dynamic developers can rapidly adopt.

3.3 Content of the patient summary

Trust in the value of a patient summary, and the willingness of patients and professionals to correctly balance the need to protect privacy with the need to provide relevant information in an emergency, critically hinge upon the content of the international patient summary. Therefore, it is vital that patients and health professionals have ready access to accurate information about the kind of health care data that is included within the patient summary, and the kind of potentially sensitive information that should not routinely be exported from electronic health record systems into a shared patient summary.

For this purpose, a simple list of patent summary headings is not enough. It is important that all stakeholders are aware of the query or filter criteria that are applied to each of the headings in order to generate the data set that is exported into a patient summary. It is also important, especially for the public, to know if there are mechanisms for them to mask certain information, either directly or through request to their healthcare professionals. Masking could be used to exclude personally sensitive information unlikely to be of significant decision-making value.

For the education of patients, it may be helpful to illustrate for each of the headings the kinds of clinical care decisions that can be made more accurately and safely if such information is available in an emergency situation. In the search of educational resources about patient summaries, no good examples illustrating this clinical care benefit, on a heading by heading basis. It is nevertheless their view that a cumulative demonstration of the benefit of the patient summary, on a heading by heading basis, would help greatly to reinforce its value and strengthen public confidence in the importance of tipping the balance in favour of sharing such information rather than restricting it.

The value of patients accessing their personal summaries, and making use of that information personally, is discussed below. Another aspect of patient access is the ability to detect errors and omissions. Patient education about the summary information content, including which source provider EHR systems have

contributed to it, should also include guidance on how to identify the relevant source EHRs that might contain an error, and how the patient can enable its correction.

There is a specific need to invest in workforce skills in summary creation, maintenance, and trust, which was first investigated and highlighted by the Trillium Bridge project in its 2015 recommendations[1].

The development of training for all health professional disciplines and specialties who will create or use data items that are contributing to the Patient Summary is vital, so that they use terms and information structures consistently and will make best use of summary data coming from other provider systems. This includes promoting the development of guidance and training for all health professional disciplines and specialties, and patients, about the creation, maintenance and use of good quality health record documentation, and helping clinicians to understand the extent of reliance they should place on health information received through a transatlantic summary from another country.

There is no shared practice in creating, and especially in maintaining the clinical documentation within EHR systems that is needed to generate patient summaries, such as maintaining up to date problem lists, partly because of differing perceptions of how valuable such summaries are to colleagues. There is limited consensus on what levels of problem severity and detail should be included, which acute or short-term events to include and whether non-medical health factors belong in summaries. There is poor guidance or consensus on when items should be removed from a summary or declared inactive, and summaries therefore tend to accumulate content rather than being carefully curated. This is especially a risk if patient summaries are generated automatically rather than manually curated. Furthermore, different specialities have different concerns, and therefore value different kinds of content in a patient summary - and are not always good at considering future users from other professions and care settings. Few professionals actually have experience of sharing patient summaries with patients, colleagues, and vice versa.

Clinicians have a tendency to not trust information which is "not collected here", and they re-take histories, duplicate tests etc. Clinicians trust information even less if they do not know the authors and countries of data they receive, such as the seniority of the author and the healthcare context in that country. Professionals have concerns that they may be liable for errors in a source document that they rely on. For an International Patient Summary to deliver direct care benefits, clinicians need to be able to determine the provenance of received information, rely on it appropriately and re-collect only the data necessary to support robust decision-making.

3.4 Information flows

It is probably not clear to many health professionals, or to the public, how information from their general practitioner system, or hospital system, can arrive in another country as a structured clinical document, with some concepts even translated into the local language. Recognising the notion that detailed architecture diagrams are bewildering to most people, there is a need for simple diagrams, preferably animations to show how information leaves their local health care provider system and is securely stored in a national or regional repository until an emergency need is declared. It is important to convey how that access by overseas professionals is verified, so that only authorised persons are able to access the information, and how it is communicated to them. It may be helpful to explain how multilingual terminologies contribute to the readability of critical information in another country. The existence of audit trails, and how these are monitored, is also important to convey to the public and to healthcare professionals. For example, the

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[1] http://trilliumbridge.eu

Swedish NPÖ (Nationell Patientenöversikt) registers each event of someone accessing a patient summary to keep track who is accessing information and on what grounds.

We have not seen much material that explains to the public how they might in the future be able to discover who has accessed their summary, within their national health system and across borders, in order to verify that these excesses were genuinely in support of their emergency health care. This transparency is a critical acceptance factor.

3.5 Information governance and data protection

One of the important topics on which ethical issues need to be explored with patients, the wider public and healthcare professionals, regarding education, is data protection. The EU General Data Protection Regulation (GDPR) gives patients greater control over the movement and use of personal health information, including their patient summary. There is an important balance to be found between the rights of citizens to have their privacy protected when it comes to accessing their personal health information in unplanned and emergency contacts, and at the same time and context their needs and rights must be respected. For patients to make informed and sound decisions about such access, especially across borders, they need to properly understand its purpose and potential value to them via health professional access.

In order for the public to be confident that extracts of their electronic health records can securely be placed into a summary that is held at a national, international, European or even global level, they need to be informed about the data protection rights that they have, for example under GDPR. They need to be educated about the principles of data protection, the risks from which they are protected by such legislation, and what specific measures of security and access control can be applied to their shared summary. This generic education needs to be complemented by direct information about the various roles and controls are being applied in their country, when their summary is accessible within Europe, and when their summary is accessible outside of Europe.

Trust in sharing health information in unscheduled care scenarios, which will almost always mean granting access to "strangers", is likely to be greater if the individual knows what their summary contains and is comfortable that the information is accurate. This in turn implies that patient access to their own summary may help with trusting its access in an emergency.

Although the primary target audience should be patients and the public, health professionals may be asked by their patients for an opinion on the trustworthiness of a national patient summary repository and cross-border access. Additionally, the health professionals themselves will need to be confident in supporting the export of data that they are responsible for.

Another issue that will need education to the public and health professionals is what options might be offered for opting out of shared access to summaries. The implementation of any opt out arrangements seem to vary among countries, ranging from a block on export so that there is no summary at all, to a block on access so the summary exists but is "virtually" invisible to most actors. Individuals offered an opt out should know what exactly takes place if they do opt out.

These matters are also ethical issues because the promotion of an international patient summary to the public without these important areas of education and assurance may challenge the legitimacy, under GDPR, of enabling legitimate distributed access to these summaries.

3.6 Empowering patients through their summary

Although initially developed for unplanned care healthcare encounters that might, for example, occur at a hospital emergency department or general practice, there are a growing number of added value services, especially for patients, that are emerging in the marketplace if the patient summary can be accessed directly by the patient. Examples of this include medication reminder alerts on a mobile phone, the ability for patients to link self-management activities to conditions in their medical summary, personalised prevention and wellness strategies, and the ability of patients to show their medical summary to other persons if they wish, such as a gym instructor or an employer.

There are some important pre-requisites to the trustworthy use of third-party applications and services.

1. That the patient summary accessed through, for example, a national portal, is accurate and up-to-date, and also that it does not include any information that the patient has specifically requested to be masked from the summary;
2. That the interoperability interface is sufficiently standardised, preferably in the future adopting the IPS, so that the application vendor is best placed to import accurately the summary of the patient, irrespective of the country in which it resides;
3. That the patient is able to be confident about the data protections offered by third party application vendors, such as cloud storage arrangements.

Patients will not be in a position to make founded choices about applications and services that could bring them added value from the IPS unless they are educated about these three prerequisite areas.

They will also not obtain the best benefit they could from their patient summary and added value services unless they are educated enough about their health condition, the various ways they could contribute to self-management and relevant prevention measures.

In summary, the vision for the future is for patients to be empowered knowledge workers that play an active role in managing the data and use of their (international) patient summary.

During the investigation of this topic across European member states, no published educational syllabus or programmes that cover the above topics were found. Therefore, a set of learning objectives was developed as a guide to member states about programmes they should give serious consideration to developing for their public. This set of learning objectives is described on the following page.

4. Strategy for raising the awareness

As mentioned earlier, no single educational format will address the diverse needs of health professionals and patients and the public, which is the focus of this deliverable. Furthermore, it should be noted that education to the ICT sector, and other industry sectors such as clinical research, are not included in this deliverable but should be planned for as part of a national and European multi-stakeholder engagement strategy.

Figure 1 below illustrates many of the different dimensions that need to be considered when developing a comprehensive strategy at regional, national levels or through multi-national collaborations. This figure also references the learning objectives described later in this chapter.

Educational topics	National or regional perspectives	Design / Delivery		Learning objectives
• health and care scenarios for patient summary use • PS benefits across the health system • content of the patient summary • information flows • information governance and data protection • empowering patients through their summary	• language • cultures • kind of health system • kind of PS • opt in/out models • patient access • local features	**Design** — **Health professionals** • professions and specialities • care settings • role in PS creation • role in PS use • role in patient advocacy **Patients, caregivers, the public** • disease severities • educational level • digital literacy • digital technology access • caregiving role	**Levels of detail** • Overviews and key concepts • topic specific understanding, FAQ • creator/user expertise • comprehensive courses **Delivery** — **Channels** • Leaflets, web pages • News, magazine, TV articles • Animations, interviews, apps • Online courses • Workshops, seminars • MOOCs	1. knowledge worker 2. professional knowledge worker 3. patient knowledge worker 4. PS information benefits 5. harms from lack of PS 6. obstacles to patients 7. role of the information content 8. how errors might arise 9. enable timely access to the PS 10. patient health contributions

Figure 1: Dimensions to consider when developing a patient summary education strategy

Any educational resource and its delivery relating to the patient summary should clearly address one or more of the topics shown on the left of this figure and discussed in Chapter 3. Other topics may, of course be identified. The education will need to be tailored for any country or region, taking into account many issues of which several examples are indicated in the figure. The design of educational resources will usually need to be differentiated regarding the target audience, not only the role of the health professional but what role they may need to play in summary creation or use. For example, an emergency department physician will have a different exposure to patient summaries to a cardio-thoracic surgeon. A diversity will also exist amongst patients, caregivers or other members of the public: there may be a wish to cater for different health history situations (those with a severe condition or a complex history, or those with just one well managed condition). Resources will need to take account of educational levels, digital literacy and if (perhaps for economic reasons) some communities will have less easy access to digital tools such as computers. Multiple levels of detail should be catered for, ranging from those who might only want to learn about key concepts to those wanting an in depth course because of specific leadership or decision making roles that they may

need to play (for example if procuring a new EHR system that must be patient-summary-ready). Perhaps obviously, multiple delivery channels need to be catered for. Finally, any resource should identify at the outset what learning objectives are aimed for, taken from the examples presented in this chapter, or others.

As indicated previously, a mixture of resources will inevitably be required, but the overall coverage of a portfolio of resources can only be determined if they are mapped onto an overall educational strategy, so that gaps in the offerings can be avoided.

It should also be noted that investments in education about the patient summary will rarely be isolated from other investments in improving the digital health literacy of community sectors, and so this educational strategy is likely to be included into a larger strategy.

4.1 Learning objectives for digital health literacy about the patient summary

The following learning objectives are offered as high-level outcomes that an educational strategy might target, or select from, or add to.

At the conclusion of educational activities, learners (such as patients, informal caregivers, professional healthcare providers, and patient advocates) should be able to:

Objective 1. Define "knowledge work" and "knowledge worker." Demonstrate understanding of why it is important for healthcare professionals and patients to seek out new information and to apply this to their practice and lifestyle.

Objective 2. Explain why competent healthcare providers are professional knowledge workers. Show insight into the importance of continuing professional education, and in particular how enriching the understanding of patient summary curation, sharing and use improves the safety and effectiveness of their practice.

Objective 3. Explain why competent patients and caregivers must become personal knowledge workers. Show insight into why better informed patients, illustrated through awareness of their health summary information, are better able to contribute to the management of their conditions, prevention of complications and wider wellness management.

Objective 4. List (e.g. ~3) benefits to patients and caregivers becoming knowledge workers, relating to greater use of their patient summary. (These may include those described in earlier parts of this deliverable.)

Objective 5. List 3 challenges or harms to patients and caregivers of relying exclusively on healthcare professionals for their health knowledge. Show understanding of the resource limitations on health systems in providing detailed self-care and health educational support, and also the value of self-discovery providing that trustworthy sources of information are used.

Objective 6. List 3 obstacles to patients and caregivers becoming personal knowledge workers. For professionals and other healthcare system workers this objective helps them to appreciate the diversity of resources, levels of detail and channels that may be required to personalise the optimal way for each patient to learn from their patient summary, and for patients and caregivers this objective helps them to discover how to circumvent any obstacles they may face in accessing educational information about their health summary.

Objective 7. List (e.g. up to 12 types of) personal health information that patients are asked to present before, during and after planned, unplanned and emergency healthcare encounters to familiar, and unfamiliar providers. This objective focuses on the content of the patient summary, and illustrate understanding of the different types of information (headings) that it covers.

Objective 8. Explain how treatment errors might result when a healthcare professional may be missing background health information from each of the patient summary headings. This objective emphasises why each heading within the patient summary is important, and also why it is important for that information to be complete, accurate and up to date.

Objective 9. Explain how you could enable timely access to 12 types of always-necessary personal health information before, during and after planned, unplanned and emergency healthcare encounters to familiar, and unfamiliar providers, even when you (or the patient you care for) is unconscious. This objective focuses on preparation: the patient summary has to be ready when needed, which requires patients and professional to collaborate on the accuracy and maintenance of the source data (usually in a patient's GP EHR system) and to have discussed in advance, given consent if necessary, to the generation and accessibility of this summary, world-wide. This objective also requires insight, on both side, of the importance of the professional-patient relationship to maintain accurate medication records, notify of new conditions or complications, and of health risks, so that the summary is enriched by both patients and professionals.

Objective 10. Explain how patients can contribute to the maintenance of their own health through use of the patient summary. This objective requires understanding of the empowerment opportunity that the patient summary presents, including awareness of the kinds of value-added products and services that patients might take advantage of to exploit the summary information in support of their own health care and wellness strategies.

Following implementation of these recommendations, the impact of these educational activities on learners' performance as formal and informal knowledge workers requires scientifically rigorous evaluation.

5. Future patient summary use cases

Previous work in VALUeHEALTH has suggested that there would be societal and sustainable business value in condition specific summary extensions to elaborate on the clinical content most relevant for commonly occurring long-term conditions, and possibly also for rare diseases.

Looking beyond unscheduled care, a rich summary that includes a focused data set about each long-term condition has the potential to be a useful holistic overview to support continuity of care even in planned situations. A summary could prove a useful starting point for professionals to review even if detailed records are available: offering a perspective across all current health issues as well as an at-a-glance update on the condition being managed in that encounter.

Patient empowerment is still at an early stage in most health systems. Self-use of the European Patient Summary has not been a strong element of its design. Anecdotally it seems that patients have been little consulted in other health summary specification initiatives across Europe. Patient consultation work undertaken in SemanticHealthNet showed that there are several areas of possible extension to the summary that would add value to patients - not just for self-completion but for joint completion with care professionals to support lifestyle choices and self-management strategies.

The rapid growth of health-related applications, especially for mobile use, shows that consumer interest for accessing and using personal health information is strong. There is also experience that many patients make good use of online portals provided by their providers to access portions of their electronic health record in order to perform healthcare related transactions, online consultations with their healthcare professionals and to provide self-monitoring information. Online access to an individual's full electronic health record seems - again anecdotally - not to be as extensively used. It is therefore a hypothesis of this deliverable that access to a health summary might prove a more manageable and useful set of information for many patients to access and use in improved health understanding, joint decision making with professionals and for self-management strategies.

Having summary information, especially as it becomes enriched, opens opportunities for the ICT sector to design innovative products that tailor how the summary is displayed to different users of contexts, highlighting information of highest priority for that user, or highlighting recent changes etc. For patients there are many possibilities for assigning goals and tasks linked to summary data and tracking personal health status against those. If large pollutions of summaries are permitted to be analysed for research, presumably anonymously or with patient consent, further value to multiple stakeholders can be anticipated, as discussed in VALUeHEALTH's recommendations.

6. Ethics considerations

This deliverable has no sensitive content and ethics issues to be addressed, as it is focused on training not on real specific patient sensitive data treatment.

However, it rises important issues related to education of citizens and health professionals. As mentioned earlier, it is important when educating citizens about the benefits of the shared patient summary and its potential positive impact on the outcome of unplanned care, we do not create anxiety. It should be underlined, that the absence of an accessible patient summary, does not pose any threat to the patient safety.

When drafting education and training material for the various stakeholders with access to the patient summary, special attention is required for the citizens/patients. It is not provided that all patients have the

same resources to understand the use, content and benefits of the patient summary. This variance among the population confronted with understanding the (international) patient summary can be described as (e)health illiteracy and the unequal access to information. This may be caused by variance regarding education, familiarity with the used language, basic health knowledge or even simple things such as age. However, according to the U.S. Department of Health & Services, even persons with strong literacy skills face health literacy challenges, such as when[2]:

- Unfamiliarity with medical terms and how human bodies work;
- They have to interpret numbers or complex situations to understand their situation;
- They are diagnosed with a serious illness which scares them.

The examples above illustrate the complexity associated with the information in patient summaries and corresponding general education and training; there needs to be a significant amount of attention to make sure the information provided is widely understandable for the general public. It is not possible to elaborate on every aspect of a patient summary. However, the notion of general understandable language should be emphasized.

The importance of the rights according to general data protection regulation (GDPR) and any additional national legislation should be made very clear in all efforts to promote the sharing and use of shared patient summary. Uncertainty concerning protection and management of patient right to privacy, could be a severe obstacle to the acceptance of the mere concept of a shared patient summary.

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[2] https://health.gov/communication/literacy/issuebrief/

Appendix I: Examples of educational resources for patients and health professionals

In this appendix, a number of existing national patient summaries will be discussed regarding their coverage of the topics below. These are defined during course of this deliverable in chapter 3 (3.1 – 3.5).

- The health and care scenarios for patient summary use
- The PS benefits across the health system
- Content of the patient summary
- Information flows
- Information governance and data protection
- Empowering patients through their summary

The case of Denmark – Sundhed.dk

The Danish eHealth portal "Sundhed.dk" is the Danish equivalent to a PS.

Sundhed.dk is the official portal for the public Danish Healthcare Services and enables citizens and healthcare professionals to find information and communicate. The portal facilitates patient-centred digital services that provide access to and information about the Danish healthcare services.

The purpose of the portal is to:

- Bring together relevant information from all parts of the health service
- Offer a shared platform of communication
- Empower patients by offering maximum insight and transparency in the health care sector
- Offer health care providers easy access to clinical information about their patients' medical history.

Sundhed.dk is a public, internet-based portal and infrastructure platform that collects and distributes health care information among citizens and health care professionals. It is unique in bringing the entire Danish health care sector together on the Internet and providing an accessible setting for citizens and health care professionals to meet and efficiently exchange information.

Additionally, every citizen has a personal page (available upon identification), which is dedicated to the specific situation of this citizen, e.g.:

- view treatments and diagnoses from his/her hospital patient record
- book appointments with his/her general practitioner (GP)
- renew prescription of drugs
- monitor his/her drug compliance
- seek for shortest waiting lists for operations and quality ratings of hospitals
- register as organ donor
- get access to local disease management systems in out-patient Clinics.

Health professionals can also log on and gain secure and controlled access to personal data regarding patients they are actively treating.

Training and education material

Even though all Danish citizens have had access to their own page on Sundhed.dk since 2003, the effort to teach and train citizens has historically not been very visible. When visiting a GP, they might explain how you can access your health information on the portal. Flyers are available being used for this purpose. The latest one is from 2016 (in Danish)[3]. It explains how to find a practitioner/specialist/hospital, public treatment opportunities and what kind of health information is available on the portal. In the beginning of 2018, a campaign was launched called "Influenza or just Monday" to inform citizens on how to access the Medication Record, Patient Handbook, Vaccination overview, "find treatment provider" and what information is available in the eRecord. A video in Danish[4] was launched as a TV advertisement and on social media and visualised on posters in the public sphere.

The case of the UK – Summary Care Records

The Summary Care Records (SCR) is an electronic record of important patient information, created from GP medical records. It can be seen and used by authorised staff in other areas of the health and care system involved in the patient's direct care.

The English NHS National Programme for IT (NPfIT) project was an ambitious attempt to introduce IT across the health service including the goal of making a summary electronic patient record accessible to all physicians involved in the management of a patient and also made summary access available to patients online.

The SCR was planned to be universally accessible to health service professionals and to patients who signed up to join "HealthSpace". However, due to low uptake and negative evaluation findings, a decision was taken to close HealthSpace[5]. The scope of the SCR was originally planned to be: Summary of accident and emergency attendances; Inpatient discharge summaries; Outpatient attendances; Out of hours primary care encounters; Health and social care common assessments; and patients own contributions made via HealthSpace. Its scope has now been restricted to medication, allergies, and adverse reactions to drugs. The consent model for the SCR was created post development according to an "opt-out" model. To opt-out either the patient applies centrally or this is coded in primary care.

The NHS provides **information materials both for patients and healthcare professionals**.

Training and education material: patients

Patients can find explanation of the SCR content, goals and uses in a **dedicated webpage[6]**. Here they can learn what is the aim of the SCR, how they can include additional information and how they can opt out by

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[3] https://www.sundhed.dk/content/cms/9/76009_kom-i-gang-med-sundheddk_dec2016_web.pdf

[4] https://www.sundhed.dk/borger/service/nyt-og-presse/presserum/pressemeddelelser/ny-kampagne/

[5] de Lusignan, S.; Ross, P.; Shifrin, M.; Hercigonja-Szekeres, M.; Seroussi, B. (2013). A comparison of approaches to providing patients access to summary care records across old and new Europe: an exploration of facilitators and barriers to implementation. In: Lehmann, C.U., Ammenwerth, E., Nøhr, C. (Ed.). MEDINFO 2013 : Proceedings of the 14th World Congress on Medical and Health Informatics (397–401).. IOS Press. (Studies in Health Technology and Informatics; 192).

[6] https://digital.nhs.uk/services/summary-care-records-scr/summary-care-records-scr-information-for-patients#section-3

accessing an online opt out form[7]. Moreover, NHS Digital produced and published on YouTube a **video series** to inform citizens on:

- How SCR works if UK citizens are away from UK[8];
- How SCR works if there is an emergency hospital admission[9];
- How SCR works if emergency access to the record is needed[10].

Moreover, other video materials are produced by the local NHS Clinical Commissioning Groups (CCG), such as NHS Norwich[11].

Training and education material: health professionals
NHS Digital collects all relevant information about SCR in a **dedicated webpage[12]**. Here professionals can retrieve instructions on how to create SCR, how to add information, and how to view it in the Spine portal (which is supporting the IT infrastructure for health and social care in England), including information about security and data governance. **Examples of SCR** and **brief guides in pdf format** are downloadable.

There is also a specific section providing information for Clinical Commissioning Groups and others responsible for health planning.

Most importantly, an **interactive e-learning course** is offered by e-Learning for Healthcare (e-LfH) that is a Health Education England (HEE) Programme working in partnership with the NHS and professional bodies to support patient care by providing e-learning to educate and train the health and social care workforce[13].

The purpose of this training is to give NHS clinical staff a clear understanding of:

- What SCR is and how it is used;
- How SCR are created;
- What a SCR looks like;
- The pre-requisite to gain access to the portal;
- How to view a SCR, ask permission, etc.;
- What is contained in a SCR that is enriched with additional information.

Moreover, they are to test the knowledge they acquired at the end of the training modules.

The case of France - Dossier Médical Partagé

Training and education material
The French public health system provides extensive information on their shared medical record (i.e. the Dossier Médical Partagé (DMP) both through the **official website of the French welfare system[14]** in a specific Q&A section dedicated to citizens' rights. It is important to remark that the DMP is not a universal patient summary. It is the personal health record that each French citizen can possess (by opting in) and personalize according to his/her specific preferences.

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[7] Online opt-out form https://digital.nhs.uk/binaries/content/assets/legacy/pdf/q/q/opt_out_scr_form.pdf
[8] https://www.youtube.com/watch?v=3FDlA036_Os
[9] https://www.youtube.com/watch?v=JMgVblVuXSk
[10] https://www.youtube.com/watch?v=TpLdbH-GXLM
[11] https://www.youtube.com/watch?v=F2DB4F-R-dM
[12] https://digital.nhs.uk/services/summary-care-records-scr#section-1
[13] https://www.e-lfh.org.uk/programmes/summary-care-records/
[14] https://www.service-public.fr/particuliers/vosdroits/F10872

From the link above, the patient can consult an extensive **Q&A section** and download a set of informative document including a **brochure** illustrating how the DMP can be created, enriched and consulted as well as the rights and obligations of both patients and professional[15].

The same information included in the brochure is also made available in a more synthetic way in a **video** downloadable from YouTube[16].

More recently, a **dedicated website** has been released[17] including specific information depending on the user's profile (either a patient, a healthcare professional or a healthcare organization).

Moreover, video materials are made available on YouTube by some of the "Groupements de Coopération Sanitaire en e-santé" (GCS), which are specific type of organization that facilitates cooperation between the public and private sectors, and also between community health facilities and hospitals. They brings together public and private healthcare institutions, healthcare centres, care homes and independent medical professionals, and also medico-social stakeholders, and are established under public law or private law, depending on the case.

Within e-health, GCSs have become the preferred vehicle for the regional healthcare agencies (ARS) for developing the DMP, telemedicine and healthcare information systems in general.

Two interesting examples of **audio-visual materials developed for certain types of patients** are the following:

- "Dossier Médical Personnel: DMP patient l' histoire de Julie", which is illustrating the advantages of DMP for a pregnant woman[18]
- "DMP / dossier médical Personnel patient: l'histoire de Michel diabétique", addressing the needs of a patient suffering from diabetes[19].

The case of Italy - Fascicolo Sanitario Elettronico

The Fascicolo Sanitario Elettronico (FSE) is the online collection of health data and information that builds up a person's health and clinical history. Moreover, from the FSE it is possible to access the online health services made available by the Emilia-Romagna Region. Access to the ESF takes place in a protected and confidential form through the use of personal credentials.

It is important to remark that it is not a "shared" health record yet and it doesn't serve as a patient summary itself, since at the moment only the patient and up to 5 delegates can access.

The deployment of the patient summary in Italy is planned in 2019.

Training and education material
The Italian region 'Emilia Romagna Region' has developed a dedicated **webpage[20]** and an informative **campaign** including a **video** published on YouTube[21] to illustrate the functionalities of the personal health record (called "Fascicolo Sanitario Elettronico" (FSE)) and the requirements to access and use it.

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[15] https://www.ameli.fr/sites/default/files/210280_depliant_dmp_148x210_2016-stc_01.pdf
[16] https://www.youtube.com/watch?v=dBmsf-Sdy6M
[17] http://www.dmp.gouv.fr/
[18] https://www.youtube.com/watch?v=6fSlStA47Y8&t=2s
[19] https://www.youtube.com/watch?v=Pa8trIAvBjg
[20] https://www.fascicolo-sanitario.it/
[21] https://www.youtube.com/watch?v=dWOGluPgMIs

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The deployment of the patient summary in Italy is planned in 2019.

Nevertheless, to the purpose of this scope review of educational strategies, it is interesting to point out that the Emilia Romagna Region has also included **specific workshops to inform and train citizens** about the FSE **in a wider digital literacy regional project**, titled "Pane e Internet"[22], within the framework of the Regional Digital Agenda, to encourage the development of digital skills of citizens in order to ensure full digital citizenship.

The case of Spain/Catalonia - La Meva Salut

La Meva Salut ('My Health'[23]) is a patient portal setup as a digital, personal and non-transferable online space that allows Catalan citizens to access their personal health information and includes the healthcare information generated by the public health centers (CAP) where the citizens are attended and have assigned their own GP, e.g. the current medication plan, the administered vaccines, the diagnoses, the clinical reports and the results of the tests and the complementary explorations.

This information can only be consulted if the healthcare center has already published it on the computer system.

In order to guarantee security and confidentiality in the accessibility of the data, only people older than 18 years with an individual health card (TSI), a digital certificate, and from October 2014 a user code provided by the CAP will have access to it.

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[22] https://www.paneeinternet.it/public/dettaglio-corso?id=724
[23] http://catsalut.gencat.cat/ca/serveis-sanitaris/la-meva-salut/

The Badalona Experience

Connecta't

la meva salut

La Meva Salut és un espai digital, personal i intransferible de consulta que us permet disposar de la vostra informació personal de salut.

Voleu donar-vos d'alta a La Meva Salut i teniu dubtes?

Veniu a les sessions informatives.

Demaneu informació al personal administratiu.

CAP Apenins-Montigalà: 3 i 17 de juliol
CAP Morera-Pomar: 5 i 19 de juliol
CAP Nova Lloreda: 10 i 24 de juliol
CAP Progrés-Raval: 11 i 25 de juliol

HORARI 9.30 A 11.30

Badalona Serveis Assistencials

In 2015 the Citizen Access Unit of Badalona Servicios Asistenciales (one of the local public healthcare providers in Catalonia), started carrying out a project to promote the use and understanding of 'la Meva Salut'.

Since its launch, various educational and dissemination initiatives have been carried out such as:

- Theoretical-practical talks in different nursing homes and in the monthly meetings of the local Health Councils;
- Training campaign for professionals in Primary Care centers so that they can inform the patients;
- Campaign for communication of the new initiative through posters in the centers, participation and dissemination in radio and television programs, etc. Also, social media (Twitter) have been largely used to this purposes and hoc materials (e.g. brochures) have been made available in the Primary Care centers for the patients to read it.

In addition to the aforementioned actions, during the second half of 2018, they started to implement, in all the CAPs, practical workshops, aimed at solving users' doubts and train them on the use of the patient portal. The operation of these workshops is channelled through an offer of participation to patients when they come to the center for other issues. The sessions are conducted by expert technicians. The figure shows the infographic used to produce posters and leaflets to invite patients to join the session.

The case of the Netherlands – Waarneemdossier Huisartsen

The Dutch National GP Professional Summary, Waarneemdossier, aims at the electronic exchange of a basic selection of patient records between GPs and general GP out-of-hours offices. GPs use the National Exchange Point or *Landelijk Schakelpunt*[24], for the exchange of these summaries. The Waarneemdossier has been operational for a number of years[25]. The purpose of Waarneemdossier is to enable temporary GPs to view the professional summary of the patient and return the observation information of the patient to the standard GP.

Patients do not have direct access to the professional summaries, only an overview of the sorts of data that is exchanged between GPs and pharmacies, and have to opt-in for the exchange of their information. This means the patient is not able to review his or her own health data or add any additional information regarding newly discovered conditions or over the counter medications.

Training and education material: patients

For patients, there is a dedicated website regarding the use, benefits and permissions for the exchange of professional summaries between GPs and/or pharmacies[26].

On this website there is elaborate information about the following topics:

- The benefits of the exchange of health information;

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[24] National Exchange Point https://www.volgjezorg.nl/het-lsp
[25] Information originates from an interview with a government official conducted for Deliverable 5.2
[26] Dedicated website VZVZ https://www.volgjezorg.nl

- The actual exchange of health information;
- Privacy and security of the exchange of health information;
- Healthcare professionals which are connected to the national exchange point;
- Organizations which have access to your health information.

On the website of VZVZ, healthcare organizations can order information leaflets, promotional material and consent forms for their patients regarding the Waarneemdossier[27].

Furthermore, there is a YouTube channel with multiple videos regarding the use and benefits of the exchange of health information[28].

Training and education material: health professionals

The GP Professional Summary is accompanied by an elaborate training programme in various forms such as in person training and online sources of information. During the basic training, the health professionals (in this case the GPs) are informed on the following topics:

- What is the National Exchange Point (NEP) and how does it work;
- Which caregivers are able to connect to the NEP;
- How to explain the NEP to patients;
- How to answer the most common questions regarding the NEP;
- How to ask for an opt-in.

Furthermore, via the learning center of Accredidact[29], various in-depth training and educational material aimed at health professionals is offered in the form of plenary training events, E-learning modules and in-company training meetings. These provide the health professional with stepping stones to implement the LSP and Waarneemdossier in its current process and procedures.

The case of Sweden - Nationall Patientenöversikt (NPÖ)

In Sweden a number of (local) initiatives are being developed regarding the exchange and accessibility of health records. The Swedish Nationall Patientenöversikt (NPÖ)[30] or *Journalen* is the portal to an electronic record of patient information and is being implemented step by step since 2009. It is accessible for all health professionals via the network for the Swedish health sector called Sjunet and is linked to the Swedish Prescribed Drug Register. Only health professionals that have a relationship with you can access the information, they need to be authorized and have a valid e-service Identity card. This required relationship functions as a safeguard regarding privacy but it is a limitation for the objective of emergency care as well.

This access offers the health professionals the following:

- An extensive overview of the health record of the patient which can be used to improve quality of care;

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[27] VZVZ information for patients https://www.vzvz.nl/huisartsenpraktijken/ondersteuning/materiaal-volgjezorg
[28] YouTube-channel regarding the LSP https://www.youtube.com/user/infoVZVZ
[29] In-depth training and education material of Accredidact regarding the LSP
https://www.vzvz.nl/huisartsenpraktijken/ondersteuning/trainingen
[30] Inera website https://www.inera.se/tjanster/nationell-patientoversikt-npo/

- Access to information which can be used to reduce the costs and time-consuming administration of care;
- Improved tools for planning and coordination between health professionals;
- The use of *Journalen* means that various health professionals will work based on the same data.

Although the NPÖ facilitates the access to Swedish patient summaries, this access is limited to health professionals. Swedish citizens are not able to access their patient records via this portal. However, there are several parallel initiatives such as 1177.se[31], which allows the Swedish citizens to view their medical/health data[32].

Training and education material

Inera has **dedicated a section of its website** to the NPÖ and the potential benefits that might come forth from the implementation of the portal. This section includes several **downloadable elaborations** on the various aspects of the NPÖ such as the widespread implementation, national guidelines and other developments. Inera owns a corporate YouTube-channel on which **instruction videos** are discussed regarding the various uses of the NPÖ and general instructions are provided[33]. Furthermore, local regions are performing **own educational initiatives** to train health professionals to use the NPÖ as efficient as possible[34]

The case of Estonia - Estonian National Health Information System (ENHIS)

The Estonian Electronic Health Record is created and implemented as an integrated section of the Estonian Health Information System. Via the portal Estonians health professionals and patients are able to view the health data. Data from all Estonians who have been to a doctor is stored in the database. This includes medical data of children, which is often not the case in other countries. The guardian/carer of the children is able to view the data on their behalf. Furthermore, it is possible to authorize others to view your data. This can be of use when the individual is not able to use and understand the patient portal and the information stored on it. An example of such a situation is when a senior authorizes family to view the data on their behalf.

It is noteworthy that only finalized clinical documents are added to the database. This means that citizens/patients are not able to add additional information themselves for the health professionals to use. By facilitating the access to the medical/history of patients, Estonia kept the following objectives in mind:

- Improve quality and efficiency of care;
- Faster and more adequate care;
- patients will be better informed;
- Availability of medical statistics will improve;
- Less paperwork used in administration,

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[31] 1177.se website login page https://www.1177.se

[32] https://www.regeringen.se/contentassets/632b4d05795549bc98a45cc5321db1c8/national-ehealth---the-strategy-for-accessible-and-secure-information-in-health-and-social-care-s2011.023

[33] Inera YouTube-channel https://www.youtube.com/channel/UC08DN1EQAhXlylATjSVbkQA

[34] Evaluation of the usage of NPÖ per Swedish region https://plus.rjl.se/info_files/infosida43035/Anvandningen_av_NPO_i_kommunerna_i_Jonkopings_lan_2015.pdf

Exchanging medical information by Estonian health professionals is done by using a standardized messaging format. The format and standards for exchange of Electronic Health records are based on the internationally recognised standard of HL7 V3.

Training and education material

The Estonian government and corresponding parties have invested a great deal of effort in educational and informative initiatives. On the website dedicated to the digitalization of Estonia, **general information** is provided about the electronic patient records and, according to presented number, a significant amount of the health communications is currently going via ENHIS[35]. There is also a **dedicated website** regarding the use, possible benefits and content of the Estonian patient summary. This website[36] elaborately discusses the various aspects of the patient summary and **provides a link to the actual portal[37]**.

The site of the portal includes several **downloadable elaborations** covering the topics of e.g. legal aspects, security and organ donor registration. The website also provides a number of informative **brochures** and E-Estonia manages a YouTube channel on which **instruction videos** and general information regarding the patient summary can be found[38].

The case of Australia - My Health Record

The Australian *My Health Record* provides an online portal for health professionals[39] and patients[40] to access their summary of the key health information. It is used by both healthcare professionals and patients. Healthcare professionals which are involved in the care of a patient can access important health information of the patient. This includes accidents or emergency situations. It is currently in the final stage of development and will go live after January 31st 2019.

Several sorts of health information of a patient can be stored on My Health Record such as allergies, medicines, medical conditions and pathological tests. Healthcare providers such as GPs, specialists and pharmacists can add documents and information to the record including hospital discharge, reports from tests and scans, medication prescriptions and referral letters. When patients do not want to participate in My Health Record they need to opt-out.

The deployment of My Health Record contributes with the following:

- Better connected care;
- Personally controlled health records;
- A secure environment;
- Access to key health information in an emergency;

Training and education material

My Health Record has a **dedicated website** that provides information about the use and benefits of the initiative. The website

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[35] General website about Estonian digitalization https://e-estonia.com/solutions/healthcare/e-health-record
[36] Website about Ehealth http://www.e-tervis.ee/index.php/en/international-projects/finished-projects/training-project
[37] Estonian patient portal https://www.digilugu.ee/login?locale=en
[38] Estonian YouTube channel https://www.youtube.com/user/EstonianICT/videos
[39] Portal for health professionals https://portal.ehealth.gov.au
[40] Portal for citizens https://my.gov.au/LoginServices/main/login?execution=e1s1

is divided in a section for citizens/patients and for healthcare professionals.

The sections for citizens provides information on the following topics[41]:

- What's in a My Health Record?
- How is My Health Record used in an emergency?
- Who can see my record?
- What privacy and security controls can I set?
- How secure is My Health Record?
- How do I find out about opting out?

Furthermore, there are **downloadable articles** on the relevant topics of My Health Records.

On the section for healthcare professionals[42], one can choose the setting it works in such as a general practice or a hospital. For each setting, elaborate information in provided regarding:

- What is My Health Record;
- Benefits of My Health Record for healthcare professionals;
- Clinical governance;
- What is in a My Health Record?

Furthermore, there are **extensive instructions** for each setting regarding how to:

- Register and set up access
- View and upload clinical information
- Understand privacy, security and consent
- Access training and resources
- Support and inform patients
- Get help and support.

There are also various **online training programs** healthcare professionals can follow including a general training about My Health Record[43]

Finally, there is a **YouTube channel**[44] containing dozens of educational videos about My Health Records for both health professionals and citizens/patients. These videos also elaborately discuss the benefits of My Health Record based on personal stories and experiences of Australian health professionals and citizens.

The case of Scotland – Key Information Summary

The Key Information Summary – also known as KIS – in Scotland is an electronic collection of information about a patient extracted from the patient's general practice record.

A KIS has to be specifically created for each patient. This is a task normally carried out by a doctor, and with the consent of the patient or their carers. The KIS information is shared by the GP's computer system twice a day, making this information available to other people and services looking after the patient. For example, out of hours services, Scottish Ambulance Service or NHS24 may use the KIS to gain more

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[41] Section for citizens https://www.myhealthrecord.gov.au/for-you-your-family
[42] Section for healtcare proffesionals https://www.myhealthrecord.gov.au/for-healthcare-professionals
[43] Online training My Health Record https://training.digitalhealth.gov.au/login/index.php
[44] My Health Record YouTube channel https://www.youtube.com/channel/UC2FLSV2THQY5bqc2uh2cEUQ/featured

information about people they are in contact with. KIS is accessible directly in the local system of the healthcare providers, e.g. the A&E department at a hospital or the 111 service (run by NHS24), which provides urgent health advice out of hours, when the patient's GP Practice or Dentist is closed.

Using the KIS formed part of the GP Contract requirements from 2012-2013 and GPs were encouraged to use KIS to create 'Anticipatory Care Plans' (ACPs) for vulnerable patients at risk of admission to hospital. The hope is that better information and planning for these patients can help keep them at home or in the community, reducing unnecessary hospital care.

KIS contains information on the following:

- Medication
- Allergies and reactions to medicines
- Contact information
- Care plans
- Next of kin and carer details
- Wishes or special instructions
- Management plans if you have a long term condition (such as diabetes)
- Preferred place of care

Training and education material

KIS was launched in 2013 and in that connection a range of information material was published. A particular focus was on providing material for patients.

Among others, a Patient Leaflet was developed. The leaflet is available in the following languages: English, Mandarin Chinese, Polish, Scottish Gaelic as well as in Easy Read and sign language to account for large populations of immigrants and those with reading and hearing disabilities. In NHS Scotland, there is dedicated focus on equality and diversity compliance. Specifically for patients also, a targeted patient poster and patient FAQ were developed and made available publicly.[45]

Poster and FAQ for a wider and non-patient audience were also developed and published.[46] In addition, a visual demonstration of KIS is available.

All material highlights the overall purpose of the KIS, what it contains, how it is populated and by whom, who has access to the information and for which purposes, and the patient's rights (consent and withdrawal).

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[45] https://www.scimp.scot.nhs.uk/kis
[46] https://www.scimp.scot.nhs.uk/kis

Topic → Country ↓	Is there a description of the health and care scenarios for Patient Summary use?	Are the benefits of a PS across the health system discussed?	Is there information about the content of the PS?	Does the initiative provide information regarding the flow of information?	Is information provided regarding governance and data protection?	Does it empower patients through their summary?
Denmark	Yes	Yes	Yes	Yes	Yes	Yes
United Kingdom	Yes	Yes	Yes	Yes	Yes	Yes
France	Yes	Yes	Yes	Yes	Yes	Yes
Italy[1]	Yes	Yes	Yes	Unknown	Unknown	Yes
Spain/Catalonia	Yes	Yes	Yes	Unknown	Yes	Yes
Netherlands	Yes	Yes	Yes	Yes	Yes	No
Sweden	Yes	Yes	Yes	Yes	No	No
Estonia	Yes	Yes	Yes		Yes	Yes
Australia[2]	Yes	Yes	Yes	Yes	Yes	Yes
Scotland (UK)	Yes	Yes	Yes	Yes	Yes	Yes

[1]*Not yet operational (starting from 2019). Currently only patient plus five others can access the information.*
[2]*Not yet operational (starting from January 31st 2019).*
Due to a lack of proficiency in Italian, French and Spanish, it might not be 100% accurate and it is more as a kind of indication.

Figure 2: Overview of patient summaries and coverage of topics

Appendix II: Education about the IPS in six languages

As explained earlier in this deliverable, it has not been possible to collect best practices on national IPS education material as this material has been sparse. The material found from example sites, described in Appendix I, focuses on specific solutions (usually regional or national implementations of a locally-defined summary) and, therefore, it is not possible to consider this as generic IPS material.

Instead, the project has developed information about what the international patient summary is, in English, Danish, Italian, French, Spanish and Catalan. The material is available on the Trillium-II website: https://trillium2.eu/education-material/