

The International Patient Summary and the Summarization Requirement

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Abstract. The ‘patient summary’ has an important role in delivering continuity and coordination of a person’s health and care. ‘patient summary’ implementations are pervasive and important to both healthcare providers and to their subjects of care. The digital version of the patient summary, however, often falls short of its intended functionality and its potential value. The requirements of summarization and what they mean for the communication situation in which the summarization of health and care data takes place has been analyzed. The purpose is to understand the limitations and potential of current digital solutions for communicating a ‘patient summary’. The International Patient Summary (IPS) standard is a step towards communicating safe, relevant patient summaries for use throughout the world. To meet this grand challenge, the IPS can capitalize upon the inherent capacity and competence of all people to produce and consume summaries.

Keywords. IPS, Standard, Summarization, Patient Summary

1. Introduction

The ‘patient summary’ plays an important role in the healthcare domain. Patient summaries are used by all specialties and for all health conditions, from emergency to elected care situations, and consequently they are ‘present, appearing, or found everywhere’ in all types of oral, written, and digital communications within healthcare. Its pervasive nature partly explains why patient summaries are so attractive as a health informatics application. A central well-known concept, and a deceptively simple one at that, sees variants of the patient summary implemented in most, if not all provider systems. The implementation of a patient summary is still contentious, which detracts from its value as a shared and safe resource for healthcare providers and subjects of care alike.

The International Patient Summary (IPS) Standard [1] (ISO IS 27269:2021)² is a reference standard for describing and defining the data that a patient summary might contain. The expectations placed on the IPS standard and the importance of understanding the summarization requirement for its sustainability and success are considered. The main thrust of this paper posits the importance of summarization in general for everyday communication before considering its specialized application to the patient summary, to the healthcare domain, and to the applications of Digital Health.

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² ISO IS 27269: 2021 is the fast-tracked version from CEN’s EN 17269 [2] that was published in late 2019. This step was taken to ensure that the global requirements were taken into consideration. The process improved the original document by applying editorial comments whilst retaining the same scope of the original. ISO IS 27269 is the single international standard for the reference data model superseding EN 17269.

2. Patient Summary Concerns

2.1. *The Problems of a Non-standard Patient Summary*

Patient summaries are not overly complex. They use a relatively small amount of healthcare data to complete a defined purpose. Nevertheless, despite this form of communication being common, and the amount of data within the summary being miniscule (c.f., even the smallest of Big Data applications), it has been extraordinarily difficult to reach agreement about what data should be included and what should be discarded from any standard ‘Patient Summary’. The purpose of the ‘patient summary’ is essential for determining what data is relevant for any given situation. The lack of consensus about its purpose, however, has resulted in many, non-standard variants of patient summaries being generated and deployed.

Although non-standard summaries can be sufficient for local needs, it is recognized that these have serious limitations when a patient summary is required to be shared outside of its original context. Different specialists, different conditions, and different purposes, all of which, no doubt, are important, all vie for attention; their many advocates argue for other data to be included within ‘their patient summary’ either as additional data or as a replacement for data that they regard as less important. This makes any agreement difficult to reach regarding the patient summary’s definition and complicates the intended use, making sharing difficult and undermining the clinical needs for brevity and relevance. These problems are significantly amplified when agreement is required to exchange healthcare data cross-border, where different contexts may require a different set of policy rules, legal regulations, cultural and ethical requirements to be taken into consideration.

2.2. *Multiple, Eclectic Stakeholders*

Multiple stakeholders engaging with a problem is usually a good thing, but in the case of the ‘patient summary’ the stakeholders’ actions have tended to make any solution more difficult than it should be. This is surprising given that a good quality ‘patient summary’ is held to be in everyone’s interest. Governments, healthcare providers, vendors and, not least the individual person in need of care, attest to the importance of the patient summary. In the formative eHealth Network (eHN) guideline, a patient summary is described as an identifiable “dataset of essential and understandable health information at the point of care to deliver safe patient care during unscheduled care [and planned care] with its maximal impact in the unscheduled care”. [3]

The lack of agreement about the content of a ‘patient summary’ and the proliferation of multiple agreements necessary to achieve local success, damage the goal of achieving sustainable interoperability within the healthcare domain. Consequently, the quality of shared data needed for effective continuity of care is put at risk. Any attempt to address these communication problems, however, is exacerbated by the reluctance to make changes to an artefact that plays such a central role within the healthcare domain.

Some of the problems can be laid at the door of the Digital Health ‘solutions’ on offer, as they focus to manage the diversity of need by meeting each local requirement. The considerable investment made in such applications can also obstruct any necessary change, even if that means the adoption of an open standard. Stakeholder’ resistance can arise when alternative ways of working need to be considered and these can be both daunting and costly.

It has been said that “digitizing effectively is not simply about the technology, it’s mostly about the people.” [4] A truism, but perhaps one which glosses over the fact that ‘people’ have many different roles to play, e.g., the stakeholders are vital in recognizing the need, in setting the requirements, in reaching consensus about what and how to implement, as well as being the ultimate beneficiaries and critics with respect to their own life and care. Unfortunately, the wide range and large number of existing interested parties offer no guarantee that any standard for a patient summary will be even known by them let alone adopted.

If we assume the stakeholders are doing their level best to share essential clinical data, yet failing, then it follows that the simple concept of a ‘patient summary’ is probably more complex than first impressions would suggest. Furthermore, the complexity of the ecosystem surrounding the patient summary mounts a considerable technical challenge, albeit one with the potential for immense social and economic benefit. The ‘patient summary’, however, is not just “mostly about the people”; it is a special case of summarization, which is at the core of what it means to be human. This realization gives substantive hope for achieving a sustainable, global standard with relevance to the patient summary.

2.3. The Expected Value of a Standard ‘Patient Summary’

Standardization is a generic consensus process that should help to realize a common purpose, agreed content, and coherent semantics of a standard ‘patient summary’. The process is intended to facilitate formal agreements between stakeholders; the outputs from such agreements are, by definition, consensus products. The main objective of open standardization is to simplify matters; to produce just a few agreements, better still to produce a single agreement, to replace the proliferation of numerous ad hoc ones.

The advantages of standardization are many and obvious; they include better governance opportunities, savings, reduced effort, elimination of wasteful duplication, fewer interfaces, and easier maintenance. Unfortunately, there is also a well-known downside; too many standards can be incompatible, conflicting, and competing, they can be too complicated or impenetrable, and are often slow to develop. Standardization Development Organizations (SDO) often fail to identify and engage with the relevant interested parties. They tend to overlook the powerful, wider audiences beyond just the immediate and technical one, and thereby inevitably hinder their work’s future acceptance and adoption. An on-going challenge facing the new IPS standard is to maximize the upside of standardization whilst minimizing the downside.

CEN/ TC 251 [5], a regional, European SDO, was contracted by the EC to make an existing guideline for exchanging patient summaries [6] an international standard. Specifically, the initial standardization focus was to normalize the embedded dataset outlined in that guideline. The ‘International’ prefix was chosen for the Patient Summary (IPS) to strengthen its claim to be something new, targeted at a global scope, to be the epitome of healthcare without borders. The new would-be ‘global’ IPS standard was positioned to be that standard, one which would solve urgent local and national needs as well as international ones.

2.4. Managing Expectations

This inclusive yet global aspiration contributes to the current interest around IPS. Whilst helpful, it was initially just an ‘aspiration’ and, by itself, naming is not sufficient to

stimulate engagement or convince stakeholders that it can succeed. From the outset, there was a need to differentiate the proposed standardization of the ‘patient summary’ from existing offerings. It was (and still is) important to offer something ‘new’, and to avoid the fate of being dismissed as just one more patient summary amongst many.

However, the history, and the pervasive and ubiquitous nature of the ‘patient summary concept’ would seem to defeat any attempt to describe IPS as being something ‘new’. Kleppe, in her book on Software Language Engineering [7], remarked how “deceptive the difference between the old and new is”. Kleppe quotes,

“(to) make something that was not there before, ... is deceptive, because the separate elements already existed and floated through history, but they were never before assembled in this manner. Joining, assembling, the new will always consist of that.” [8].

This dual emphasis, on ‘purpose’ and ‘assembly’, can be applied to the IPS and serves the standard well; it substantiates the claim of being ‘new’ and, more importantly, indicates how it will work and be developed in an incremental fashion to be usable and useful.

The commitment of the SDOs is to implement a fully sharable, single solution for the patient summary, one that provides efficient and relevant communication. The decision to base the standard upon an existing guideline on patient summary exchange helped, as did the decision to focus the initial scope of the standard on just the dataset in the guideline [9]. The success of this standardization initiative, however, cannot just be attributed to these decisions, important as they were to its development and important as they remain for its progress in the future. Ironically, it seems that offering something ‘new’ in ‘patient summaries’ may largely be attributed to the past (i.e., ‘floated through history’) and this history is of fundamental importance to the success of the IPS standard going forward.

The IPS unconsciously mimics and utilizes what is known about the way humans communicate with each other through summaries; this human competence in summarization precedes the idea of a computer-based application and even the paper-based precursors used within the health and care domain. The following quote taken from Winston Churchill [10] seems especially applicable to the patient summary and the requirement of summarization, “The farther back you can look, the farther forward you are likely to see.”

It is suggested here that a better understanding of the ‘summarization’ act and its results, i.e., the ‘summaries’, will provide stakeholders with a rich source of foundational requirements to confirm, to challenge, and to improve the present IPS. In part, this review explains the success of the standard’s development and offers a promissory note to support its future dissemination, its adoption, and its use. The underlying foundation of the summarization requirement offers the hope that the IPS will be sustainable, making the project’s earliest aspiration a reality.

3. Summarization in Everyday and Professional Communication³

Summarization is an integral part of both every day and professional types of human communication. Professional summarization in healthcare, and especially the ‘patient summary’, are considered here to be domain-specific specializations of the more general concepts.

Figure 1 illustrates some fundamental aspects of generic ‘summarization’, including the summary production and consumption, the principal actors involved in the process, the summarization situation, external input(s) and output(s) and the summary object itself; all of which are relevant to the healthcare domain and are clearly within the scope of Digital Health applications.

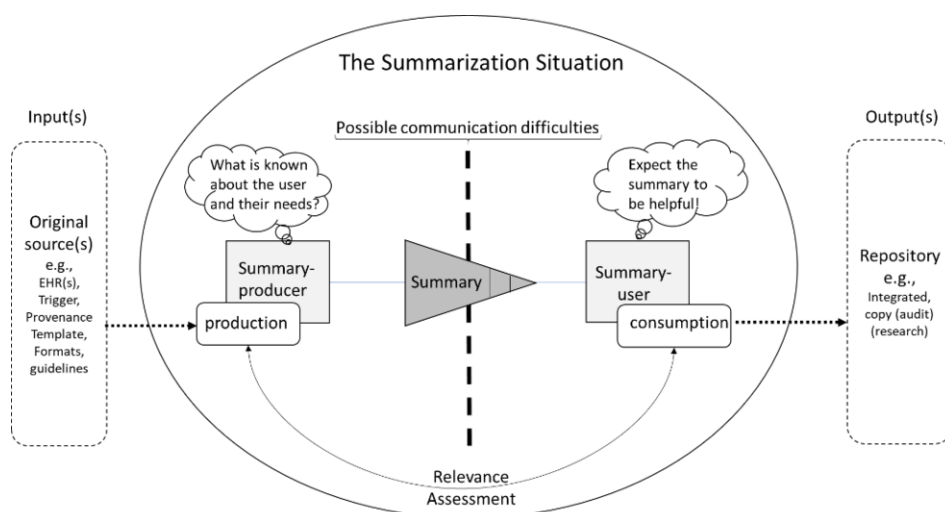


Figure 1. A Simplified Model of Summarization⁴

3.1. Summarization and the IPS

‘Summarization’ is a practical skill, an integral and versatile part of human communication. As Endres-Niggemeyer comments in her introduction of *Summarizing Information* [11],

“We all summarize, very often, when reporting about the movie we saw yesterday or the negotiations during a meeting, recoding an accident, or wring a resume’ of a stage play at school. Everyday summarizing skills belong to everybody’s communication competence.”

³ Section 2 of this paper owes much to Endres-Niggemeyer B. *Summarizing Information*. Springer-Verlag, Berlin Heidelberg, 1998 [11].

⁴ In Figure 1, the single, vertical dashed line represents one or more barriers that the Summary must go through. The barriers may impact the quality of the summary produced, affecting the usefulness.

This human competence is motivated. Sperber and Wilson claim in their book on “Relevance, Communication and Cognition” [12], “that all human beings automatically aim at the most efficient information processing possible. This is so whether they are conscious of it or not.” [12, p49].

‘Summarization’ is a good example; indeed, it may be the best example of such efficiency-driven, unconscious behavior in humans. In essence, it is the reduction of information to its most essential points; it retains what is relevant and discards the irrelevant for the purpose of effective, efficient communication.

The core requirement of summarization is to concentrate on the important points. However, determining what is important enough to include in the summary is non-trivial. What is deemed to be essential or important, or conversely what is deemed inessential or unimportant, is coupled to the idea of relevance assessment and this is part of both the production and consumption processes of the producer and user of the summary.

Summarization has always been deployed in the healthcare domain, i.e., from the first time it was necessary to report, document and/or share clinical data and “to express the most important facts or ideas about something or someone in a short and clear form” [13]. This summarization act goes largely unnoticed but is integral to all note taking, the quality of the note reflecting directly on the training, experience, and professionalism of the clinician. The patient’s longitudinal record then is an aggregation of one or more ‘summaries’ of this kind entered into notes taken from clinician/patient encounters.

The IPS can be regarded as a summarization function applied to the known healthcare history of the patient. IPS defines the core dataset for a patient summary. It uses the eHN guideline as the initial source of requirements but takes into consideration other international efforts, providing a dataset specification for global application. IPS provides an abstract definition of a Patient Summary from which derived models can be made and assessed as being conformant and interoperable.

The IPS, Dataset and the associated business rules, is a norm for what data is required in a patient summary, but the first iteration of the standard explicitly excludes details of workflow and therefore does not detail the summarization process itself. The IPS standard openly states what is not in its present scope:

“This document does not cover the workflow processes of data entry, data collection, data summarization, subsequent data presentation, assimilation, or aggregation. Furthermore, this document does not cover the summarization act itself, i.e., the intelligence/skill/competence that results in the data summarization workflow.” [1, Scope clause]

Except for the first ever interaction with the subject of care, a patient summary will probably be produced with reference to some pre-existing source or sources of existing patient information. This may include extracts from one or more EHRs, possibly clinical guidelines, templates/formats, and even other local patient summaries if relevant. The inputs would also include information about the trigger-event and the agent responsible for starting the process for producing the summary (e.g., an information request from a clinician or a patient managing their own care). This data may be directly available from the sources or part of the provenance meta-data required for any health data exchange.

The main output is the patient summary that is produced within the summarization situation, but there may also be related outputs, that might be considered as being secondary. A patient summary might be only used within the immediate communication

situation, but it is probable that it will also be stored as a persistent copy, at least for the purposes of audit if not research. The extent to which the content can or should be retained in a patient's record or integrated into the recipient's system itself varies and is subject to policy, regulation, and ethics as well as the technological sophistication of the information systems used.

It is possible too that Digital Health applications [14] may include the end-to-end sources as being part of a single communication situation. In that case, the scope of interest will include the Summarization Situation in Figure 1 and the associated inputs and outputs. The computer-based information systems are pervasive, providing an indispensable framework and tools that summarizers use. These information environments impose fixed roles, particularly if producer and user of the summaries are physically remote. The functionality and sophistication of these tools will be of paramount importance to the quality of the patient summaries in the future as efficient health information systems are a major objective of Digital Health. Further on, Summarization, whilst remaining a 'person skill', is likely to be assisted by the application of Artificial Intelligence within the clinical systems of the future.

3.2. The Summarization Situation and the IPS

The 'communication situation' is the context in which the summarization takes place; it is also especially important to the outcome of a summarization effort. Summarization is bound to the communication situation which brings the necessary communication parties together for some purpose:

- The interaction may not necessarily be face to face. For the primary patient summary use case that requires a patient summary to be accessible at the point of care, the parties will generally be location-remote to each other and if so, they will almost certainly be producing/using summaries in different contexts with different constraints dependent on their circumstances.
- A patient summary can also be produced at any time if there is no urgency (for example, a person requesting a recent summary before going on a future business trip), but a more urgent request, perhaps due to an accident, will determine whether timeliness is an important requirement for the consumer.

Summarization, then, is an example of situated communication, wherein time and space can be stretched, and what is possible may reflect the sophistication of the technology being used. Physical distance, for example, often precludes a real conversation and consequently the parties will rely on technical media to send and receive the summary using a messaging paradigm. In these cases, the information system provides a framework for their work and can be part of the production (e.g., the reduction/condensing activities), the exchange, and the consumption (e.g., the presentation/use) of the summary.

The Summarization Situation is particularly important to the outcome of a person's treatment. In one of the IPS scenarios, that of required but unscheduled care, the situation is likely to be urgent and may even be life threatening. This pressurized situation can impact both the summarizers, but it is particularly stressful for the Summary-user. Endres-Niggemeyer explicitly calls attention to the burden on the recipient who is "expected to pick up the content, to restructure it with respect to their own prior

knowledge, to integrate it into their own knowledge structure and finally to use it” [11, p86].

Furthermore, summarization situations may cause communication problems that affect the quality and usability of the summary; some of the communication difficulties are shown in Table 1. These difficulties are generic and are not healthcare domain specific [11]. This congruence gives hope of wider problem-solving collaborations beyond the healthcare domain, which may be mutually beneficial.

Table 1. Summarization situations may cause communication problems

1.	Disturbance from the situation, related perhaps to the urgency of the request on the producer or the stress for the user to assimilate the summary content. The recipient may be unable to determine chronology and timeliness of data content provided.
2.	A lack of common shared knowledge or consensus between the parties on how to handle each other and/or the transferred knowledge. If for some reason the shared, common background becomes too weak, communication problems will increase. With respect to patient summaries, the Summary-user may be unable to establish confidence in the trustworthiness, accuracy, and integrity of data content. Furthermore, specialised conditions, such as Rare Diseases, may require expertise that the Summary-user does not have.
3.	Content related inadequacies, perhaps due to terminology or structural differences. For example, unable to verify context including vital inter-relationships between clinical data content. Given that a patient summary will be a snapshot, extracted from one or more source documents at a point in time, it is vital that the original context is not lost, to ensure faithful and safe communication.
4.	Frustrated reader expectations, because of differences, between how the parties assess relevance. For example, the amount of data received may contain too much to take in, with too much irrelevant data being exchanged (information overload). This may be critical in unplanned care scenarios, where the patient is likely to be a complete ‘unknown as far as the attending clinician is concerned.
5.	Insufficient adaptation to the use situation. Policies may not exist to establish confidence in externally sourced content sufficient to allow such content to be fully integrated into their local health record and instead must keep it segregated, managed, and accessed separately.
6.	Interoperability and technology filters; The Summary-user may be overwhelmed by a plethora of conflicting and/or duplicative fragments of data from many sources (information overload).
7.	Different contexts, such as attempting to communicate effectively between different cultures. Differences in usage between unplanned and planned care.
8.	Boundaries and borders, and the associated rules, can impact the summarization process and the content of the summary. Cross-border exchange may mean that the healthcare provider as the Summary-user finds themselves unable to ascertain provenance of data content and discrete elements.

Digital Health solutions will need to counter the socio-technology problems in the Communication and Summarization Situations. The IPS as a reference model of the content can assist by supporting conformant implementations that should be interoperable, but much will depend on the infrastructure and sophistication of the technology in use.

Provenance⁵ is a key element to support ‘trust’ and for providing confidence in the data to be used. Common, shared understanding, consensus and knowledge can be strengthened, and this will help to overcome some of the other problems associated within the complex Summarization situations in the healthcare domain [15].

3.3. *The Summarizers and the IPS*

The terms ‘Summary-producer’ and ‘Summary-user’ are used here to distinguish their roles in the communication situation, albeit both parties are capable of producing and consuming summaries⁶. In the healthcare domain, the Summary-producer and Summary-user would typically be healthcare providers, i.e., healthcare organizations and healthcare professionals [16]. Increasingly, the Subject of Care (SoC) may also have a role to play in validating and/or adding a personal perspective on their own story.⁷ If the SoC becomes the mediator, taking response for the summary exchange themselves, many of the existing consent issues, for data and infrastructure to safeguard the summary, are greatly simplified or simply not required.

In the most general case, it is the Summary-producer who determines what goes in or what is left out of the summary. With the application of computers to healthcare, support can also come from third parties (e.g., clinical guidelines from professional bodies [17]), in the form of predefined templates that constrain what is summarized by the Summary-producer. These inputs may have the authority of a de jure standard of international standing or be non-standard, operating exclusively at the local level. Furthermore, the situation in which a summary is to be used is often not precisely known by the Summary-producer, nor the details of what the user requires. Even though the summaries are usually produced for the recipient, it is not necessarily the case that the user will have prior knowledge about the content. The Summary-user is hopeful that the received summary will help them in their current situation. In general, the Summary-producer will not know the specific situation that the attending clinician(s) face, nor the precise problem(s) besetting the patient.

The recipient of the content may be the intended user of the summary, but there is no guarantee that will be the case. In scenarios, where the summary is the result of a health information request, the recipient is likely to be the intended user, but that still means the content might provide surprises for the recipient given the degrees of freedom of a non-standard summary. Either way, it would be wrong to think of the Summary-user as being just a passive consumer of information. The value of the summary to the actual recipient may be judged by “looking at the incoming information and its semantic structure, in relation to the communication needs, or considering it from the viewpoint of the Summary-user” and “Summarizing is an intelligent skill, roughly comparable to translation.” [11 p47].

In the first IPS scenarios, it is the would-be recipient or Summary-user that requests or initiates the patient summary. The assumption is that this is an IPS-on-demand,

⁵ Provenance is a common requirement for all health data exchange, and ideally the common part should be a separate standard that the IPS can use rather than be embedded within the standard as it is in the first iteration. It may however be necessary to specify summary-specific provenance data, and this will need researching.

⁶ These general terms also allow AI and human agents to be deployed without discrimination. Also, Endres-Niggemeyer uses the term *Summary-consumer* rather than *Summary-user*, which is the term used in this paper to better align with Digital Health.

⁷ In traditional Digital Health settings, it is usual to consider summarization as an interaction between clinical actors. However, increasingly the patient as a Summary-user, and to a lesser extent, the patient as the Summary-producer may have a greater role to play in this type of communication in the future.

although other scenarios can be envisaged such as chronic patients or patients with rare diseases whose planned care may require communication between specialists without the patient in attendance.

The Summary-producer acts on the request and may use the IPS as-is, as a source, as a template or checklist for what to say, as a framework to add annotation to the content. In addition, specialized content not defined by the IPS, may usefully extend the IPS before the summary request is answered. The Summary-user is the attending clinician(s)⁸ and depending on the time (i.e., scheduled/unscheduled), the location (i.e., point of care) and the patient state (e.g., conscious, or not), the IPS may be the only relevant healthcare information available to support the treatment of an unknown patient.

Digital Health can play an important role, in the production, exchange, and consumption processes of the patient summary. The summarizers too are reliant upon technology to send, receive and/or present the patient summary, as typically the two parties are in different geographic locations. Further ahead, Digital Health may well consider computational agents as assistants if not replacements for the human Summary-producer and the Summary-user. The Summary-producer would be the earlier and probably the easier option to automate in any given Summarization situation. The advanced technology environment will lead to much more machine-readable data being present and available to the computerized information system.

The advent of summarization assistants does not make the idea of the IPS obsolete as the IPS Dataset will help any agent, human or computational, to select the relevant data for exchange conforming to its headings and business rules. Perception and knowledge of the received content, likely to be the standardized data from the IPS together with the non-standard extensions, would be much more difficult to automate the Summary-user, who, as noted, is more than a passive recipient of information. These future options may sound far-fetched but the requirement for information extraction tools to assist automatic summarization in the healthcare domain will be driven, in part, by the disparity between the diminishing number of healthcare professionals relative to the increase in the world's population [18].

3.4. *The Summary and the IPS*

Information from any representation can be summarized. Summarization is versatile and can be multi-media. However, the output summary does restrict itself to conveying important information, and in the patient summary especially the data will necessarily be much more constrained and focused than summaries in more general every day communications.

The original input(s) or information source(s) are reduced in the final summary but that does not stop original content from finding its way to the summary; indeed, the information source(s) can determine the main content of the summary:

“When the source is a well-organized document, the information organization in the summary should conform to the original presentation ... If the source information is not well organized, there is a tension between faithfully reflecting the source and producing a well-structured summary.” [11, p47]

⁸ The Summary-user may be a multi-disciplinary team.

Even so, the intent is that the final summary is usually reduced in size from the original source to be more easily and quickly assimilated. Summarization provides a filter and must strike a balance between offering too little or too much data to the Summary-user. “The source information or input may become important in a follow-up situation, however, when the users want to know in more detail and first-hand what the summary has told them in brief” [11, p47].

The amount of information in a summary is not fixed and can vary (represented by the graduated triangle in Figure 1). Typically, a small summary with few words will convey less information than a larger one all things being equal, but relevance decisions and the needs of the Summary-user to manage the summary are paramount. A single term, perhaps a scientific fact or a labeled diagnosis that carries weight with the Summary-user, may convey much in a very condensed form.

In everyday communication, people often vary what they present in their summarizations, saying the same things in different ways to evoke interest. In professional summarizing, the motivation is different and variety in presentation is discouraged. The variety expressed, or maybe the lack of it, will be mainly determined by the sophistication of the medium being used and the tools that are available to help the clinicians with their tasks.

Typically, a patient summary implementation will support the healthcare provider by limiting redundancy, avoiding repetition, and avoiding a variety of presentation, to convey condensed information. Summaries have a motivation and a goal and are valued for their utility; however, their functionality and success will be ultimately assessed on their ability to inform or help the Summary-user to solve problems.

The success of a summary does not just depend on its content alone, but also on the communication convention, i.e., the Summary-producer and the Summary-user must have a common basis, a largely consistent knowledge base about the intent of the communication for it to succeed. The IPS Dataset contributes to this; one of the original, key principles for the IPS is that core data should be easy to understand by all clinicians, and therefore the content is always to be generally applicable and specialty agnostic, in as far as that is possible. The ‘planned care’ scenario of IPS, however, may mean that a patient summary for that purpose includes specialist knowledge for example with respect to Rare Diseases and this might require the creation and use of optional IPS Sections related to specialist conditions, which may not be relevant or even understood by clinicians in different communication situations.

The IPS is a specification of a patient summary but many of the properties of a ‘summary’ are applicable to the IPS itself. For example, it aims for a concise representation and indicates what is the most important data to be processed and what is left out. It can specify multimedia data and the resulting summary can be represented in many forms. The IPS is implementation independent. Whilst IPS uses the common ‘document’ metaphor to explain its content, it does not require any conformant implementation to represent the data as a document. For example, the actual data can be represented in a messaging paradigm such as a document (e.g., CDA [19]) and as a set of resources (e.g., HL7 FHIR [20]). Furthermore, the IPS may serve as a dashboard, an aide memoir, as a library or source for reusable data blocks, and even be incorporated in its entirety within another type of summary document, e.g., within a discharge summary⁹, although it is unlikely that a full summary will be required. However, for any IPS conformant implementation, the purpose of the IPS must be immutable (i.e., it provides

⁹ But note the IPS is not a Discharge Summary, which has a distinct and different purpose.

a formal snapshot of the patient's longitudinal data) and it specifies the IPS data conforming with the associated, defined business rules. Other recommended data are also defined in the standard as being a legitimate option for inclusion in the IPS, but they are not mandatory or necessary for every instance.

How the summary is consumed depends greatly upon the situation and the requirements of the Summary-user. It may be entirely consumed in situ and then discarded, or it may also be retained in some persistent form. Endres-Niggemeyer noted the difficulties of identifying the target user, commenting that at that time, "there is no global definition of summaries that are suited to groups of people or individuals in specific use situations." [11, p48]. The International Patient Summary (IPS) Standard is perhaps the first global definition of a summary suited to healthcare providers for specific care situations, albeit it is still in its infancy, and that hypothesis must be tested.

There are still the inevitable disagreements concerning the choice of data blocks and elements within the current IPS Dataset. However, the IPS Dataset standard now provides a global focal point, one that is tangible, subject to greater scrutiny and is flexible, it can be changed by consensus as required. It is some ways on from a blank sheet of paper; it is now a *de jure* standard and starter set that can provide consistency and an opportunity to manage change in a coherent way, gaining agreement concerning the contents meaning and use.

As with Summary-production, Summary-consumption may also be helped by the information system used by either Summarizer. Personal documents such as a diary, or professional ones such as an engineering logbook, or even medical records are not expected to capture the totality and substance of what is communicated; even if it were practical to record everything, the result would be unhelpful if not completely unmanageable. The typical output from a consulting room visit, for example, is usually just a partial representation of the whole encounter between a clinician and a patient. That is not to denigrate the result in any way, but rather to emphasize the author's intent and skill, enabling them to make a clear record of the important points whilst omitting the unimportant detail.

The amount of information in the IPS is not fixed; structure, content and associated rules are defined within the standard, but the size and volume are not explicitly prescribed. Implicitly however, the intended scope of IPS is to provide the Summary-user with a concise summary. This utility would be one of the main objectives of IPS given that the Summarization Situation is one that may require the recipient to more easily absorb the summary information to treat the patient in the quickest and in the most effective way as possible.

It is possible that the Summary-producer might be required to send all the data that they had as a safety precaution (that is, unless they had some knowledge of stricter requirements). However, this begs the question as to why not send the complete EHR rather than an extract?

3.5. The IPS and the EHR

Figure 1 shows one or more Electronic Health Records (EHRs) as being important, but distinct sources for a patient summary. The IPS should not be regarded as an EHR; it is not a full-blown longitudinal record. IPS is a point in time extract of the important parts of that record, discarding the inessential. IPS is, in general, a much smaller artefact. The European project for exchanging health records across Europe reflects the difference in scale [21]. Consequently, it is also simpler, one that offers a much reduced, condensed

form, which is generated explicitly by request and purposed on delivering relevant data for a patient's safe continuity of care.

Although the IPS is extensible by design [22], the extensions are not intended to create a full EHR. In some cases, where no national or organizational EHR exists, the IPS data definitions can be used as a starter template from which an EHR could in theory be constructed. It is important, however, to emphasize that a full health record application would require much more functionality and data than the IPS and, to restate, it fulfils a fundamental different purpose. If IPS needed another reason for being created, it would surely be to mitigate the burden placed on the EHR would-be user, for example a front cover or dashboard for a record, that may be too large or poorly structured to be of much use to the clinician with no prior knowledge of the patient demanding treatment.

The IPS standard uses the ISO definition from a 2009 technical report [23], i.e.,

“Health record extract comprising a standardized collection of clinical and contextual information (retrospective, concurrent, prospective) that provides a snapshot in time of a subject of care's health information and healthcare”

The definition makes it clear that the IPS is an ‘extract’, but an extract can also be a ‘summary’. ISO 13940:2015 defines the ‘electronic patient summary’ as an “electronic health record extract containing essential healthcare information intended for specific uses.” [24]. Humans are wired to communicate efficiently, and summarization is one of their key competences to achieve this aim. It is part of the clinician's workflow to summarize, to produce and consume summaries and the summary, as filter, should be expected to ease some of the information burden on clinicians in these tasks.

4. Conclusion

This paper re-enforces just how foundational the summarization requirement is to the healthcare domain as a whole and especially to the ‘patient summary’. To summarize is a fundamental requirement within healthcare and the aim of the IPS standard.

Summarization finds ways of representing the important, relevant facts from a patient's entire healthcare history in an efficient manner. The pervasive nature of summarization and its underpinning of what is a basic human competence, lends credence to the IPS ideal of one single standard solution being feasible across the globe.

The value of data, however, is found in its use and, furthermore, “data by itself has no value. It's the ever-changing ecosystem surrounding data that gives it meaning” [25]. Summarization, at some level, underpins all clinical communication, regarding every patient, whatever their health condition, wherever and whenever! The summarization of patient-level information is still a challenge. Patient Summaries can be considered as being clinical tools, and of providing a basic level of clinical decision support (CDS, 2008) [26], one that might be able to productively use the existing free text portions found in today's records:

“The CDS challenge is to intelligently and automatically summarize all of a patient's electronically available clinical data, both free text and coded, and to create one or more brief (e.g., 1–2 page) synopses of the patient's pertinent past medical history,

current conditions, physiologic parameters, and current treatment(s).”

The IPS is a late start, and a small but necessary contribution towards that goal, providing the data model standard for an IPS to be used for planned and unplanned care and for local and cross-border use. The IPS Datablocks will also provide the reusability to support other applications in a more coherent and consistent fashion. The on-going challenge is to make the IPS and its implementations as optimal and effective for information sharing within healthcare as everyday summarization is for humankind.

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