H

Global Standards, Local Application

PS

International Patient Summary

& the Summarization Requirement

Stephen Kay, pHealth, Genoa 2021

Presentation Outline

PS
International Patient Summary

Expectations

Everyday summarization

Being human (before digital)

The IPS and the EHR

The IPS and Digital Health

The IPS and its future

Acknowledgements

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Expectations

1. No standard Patient Summaries (PS)
2. Stakeholders
3. Standard PS
4. New IPS

Everyday summarization

Being human (before digital)

1. Summarization and the IPS
2. Summarization Situation and the IPS
3. Summarizers and the IPS
4. The Summary and the IPS

The IPS and the EHR

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Expectations:
No Standard PS

Variants of a PS are implemented in all provider systems …

How can you say that?

PS are important for communication in Healthcare,

- For all specialties and for all health conditions
- For emergency and elective care situations
- For all patients, wherever and whenever

and independent of media, i.e., all types of oral, written, and digital communication forms.

'Local perfection' is the enemy of the good!
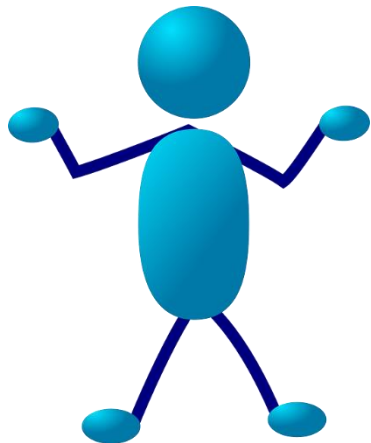
PS are not overly complex.

- A central, well-known concept
- A small dataset compared to any 'Big Data' application
- Easy to construct as required

However, disagreement on what content should be in or out, makes sharing beyond the local context very difficult.

Expectations:
Stakeholders

The PS is perhaps more complex than first impressions would suggest

Too many stakeholders! And all with valid cases for including their 'preferred' content... a good quality PS is in everyone's interest, e.g.

- Governments, healthcare organizations, vendors, clinicians and patients.
- "digitizing effectively is not simply about the technology, its mostly about the people"
- Defining a PS that people can agree on is difficult and achieving consensus is challenging...

"dataset of essential and understandable health information"

eHN guideline on PS, 2016.

Expectations:
Standard PS

"**A sum can be put right: but only by going back till you find the error and working it afresh from that point, never by simply going on.**"
-- C. S. Lewis,
The Great Divorce

"*A summary can be put right: …*"

The standardization process is intended to facilitate stakeholder agreement, by defining consensus products.

- Simplify matters; to produce a few, or better still, a single agreement in preference to multiple ad hoc ones.
- To remove obstacles and overcome barriers to business
- Standardization has substantive downsides too… e.g., proliferation!

Yet Another Patient Summary!

Expectations:
The 'new' IPS

"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."

-- A. Kleppe, Software Language Engineering

The IPS: An International Standard – ISO 27269: 2021

- Stand out from the crowd, 'international' was a goal but an aspiration too - now a reality.

- SDO collaboration on the shared vision of a single IPS from the start

- A 'new' abstract reference specification that comprises a dataset for IPS, with associated rules and reusable, scalable data blocks.

For local, regional and global use, for planned and unplanned care

Managing Expectations

Why has the IPS been so successful (thus far)?

- ➢ **The 'International' aspiration played its part**
- ➢ **The 'new', innovation and reuse strategy worked**
- ➢ **The 'must be implementable' principle brought to the fore, established focus**
- ➢ **The SDO collaborations were and are an important factor, so**

Will global take-up and use of the IPS actually happen?

- ➢ *My hypothesis:* **The fact that Summarization is an integral part of what it means to be human, gives hope to that possibility.**
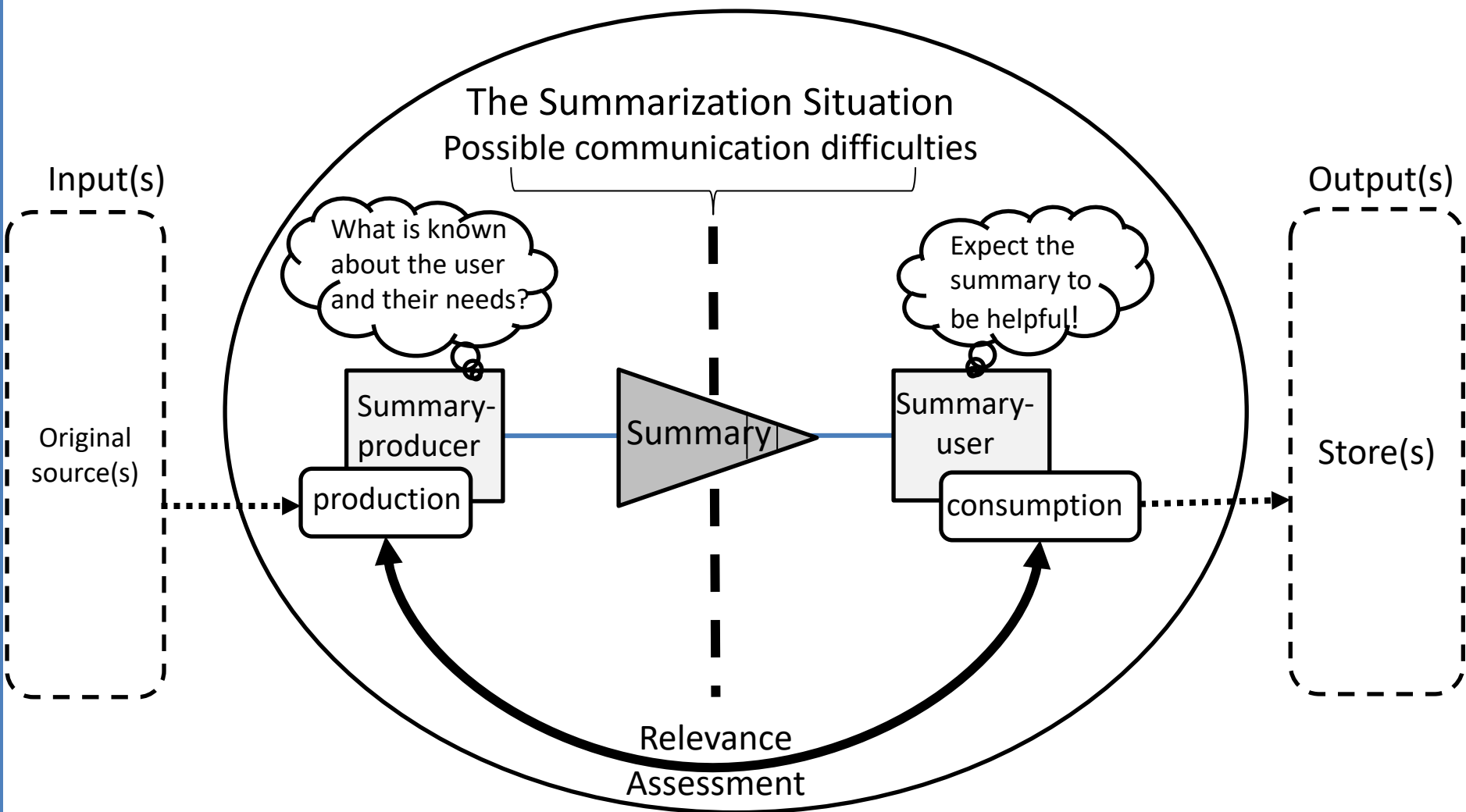
Everyday Summarization

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

Endres-Niggemeyer B. Summarizing Information. Springer-Verlag, Berlin Heidelberg, 1998.

Being Human (before Digital)

❑ This communication competence is motivated…

"all human beings automatically aim at the most efficient information processing possible. This is so whether they are conscious of it or not."

Sperber and Wilson. "Relevance, Communication and Cognition"

❑ <u>Summarization</u> is an integral part of both every day and professional types of human communication that produce a <u>summary</u>.

❑ 'Summarization in healthcare', and the 'Patient Summary', are domain-specializations of the more general concepts.

A simplified model of Summarization

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Summarization

Summarization and the IPS (1)

- The reduction of information to its most essential points; it retains the relevant and discards the irrelevant for the purpose of effective, efficient communication.

- Determining what is important and assessing what is relevant is non-trivial.

- Both the producer and user of the summary actively engage in relevance assessment, which goes largely unnoticed.

Summarization and the IPS (2)

Definition: "to express the most important facts or ideas about something or someone in a short and clear form".   Applicable to healthcare, for example:

➢ Note-taking … the quality of the note reflecting training, experience, and professionalism of the clinician.

➢ The longitudinal record is, in part, an aggregation of summaries of notes taken from one or more clinician-patient encounters.

➢ Computer information systems will increasingly be part of the summarization process … co-construction.

  ➢ Summarization, whilst remaining a 'person skill', is likely to be assisted by the application of Artificial Intelligence within the clinical systems of the future.
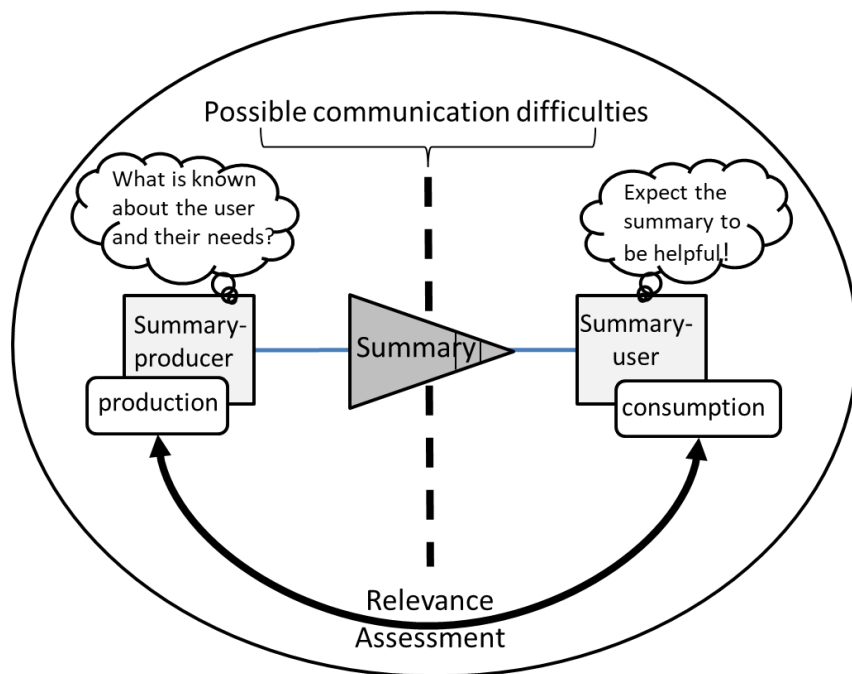
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Summarization Situation

The Summarization Situation and the IPS (1)

The Summarization Situation

Possible communication difficulties

What is known about the user and their needs?

Expect the summary to be helpful!

Summary-producer — production

Summary

Summary-user — consumption

Relevance Assessment

- The Communication Situation:
  - is the context in which the Summarization takes place.
  - may not be helpful and it may be beyond the summarizers' control.
- But it brings the necessary communication parties 'together' for some purpose.
- Time, place and more generally 'noise', including external barriers, might adversely impact the quality of the communication.

The Summarization Situation and the IPS (2)

➢ Summarization situations may cause communication problems...

  ➢ The parties will be producing/consuming patient summaries in different contexts, with different constraints.

  ➢ The patient may speak a different language (literally!) and be completely unknown to the Summary-user. Content (e.g., Rare Disease) may be unrecognized, creating further problems.

➢ The 'unscheduled care' scenario can be stressful for all parties, particularly the Summary-user 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".
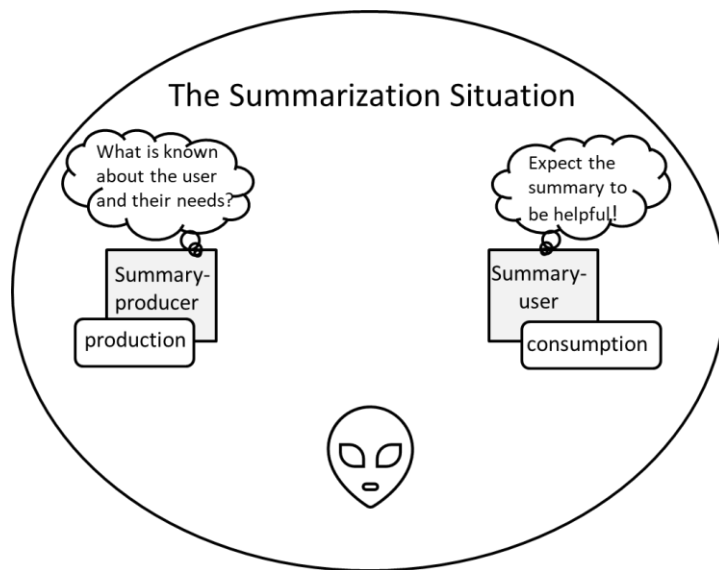
(Quickly!)

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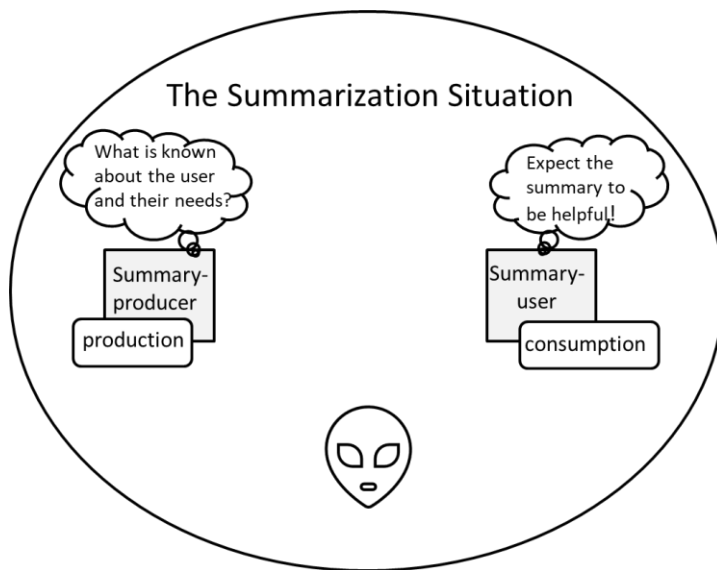International Patient Summary

Being human (before digital)

The Summarizers

The Summarizers and the IPS (1)

The Summarization Situation

What is known about the user and their needs?

Expect the summary to be helpful!

Summary-producer
production

Summary-user
consumption

- 'Summary-producer' and '-user' have different roles but both are capable of producing and consuming summaries
  - The Summary-producer may not precisely know the situation in which it will be used.
  - The Summary-user has an expectation that the summary will be helpful.
- In IPS settings, the Subject of Care(SoC) may be alien to the Summary-user.
  - In IPS, the SoC may also have a mediator role to play in sharing, validating and/or adding a personal perspective on their story.

The Summarizers and the IPS (2)

The Summarization Situation

What is known about the user and their needs?

Expect the summary to be helpful!

Summary-producer — production

Summary-user — consumption

➢ "Summarization is an intelligent skill, roughly comparable to translation"

  ➢ The 'Summary-producer' may not create the summary from scratch.

  ➢ The recipient of the content may be the intended user of the summary, but there is no guarantee that will be the case.

➢ The computer system might be considered a new actant...

  ➢ Data Entry, preferred terminologies …

  ➢ Digital Health agents for the Summarizers … probably beginning with the 'easier' Summary-producer.

  ➢ Automatic summarization in healthcare will be driven by the shortage of clinicians relative to high demand.
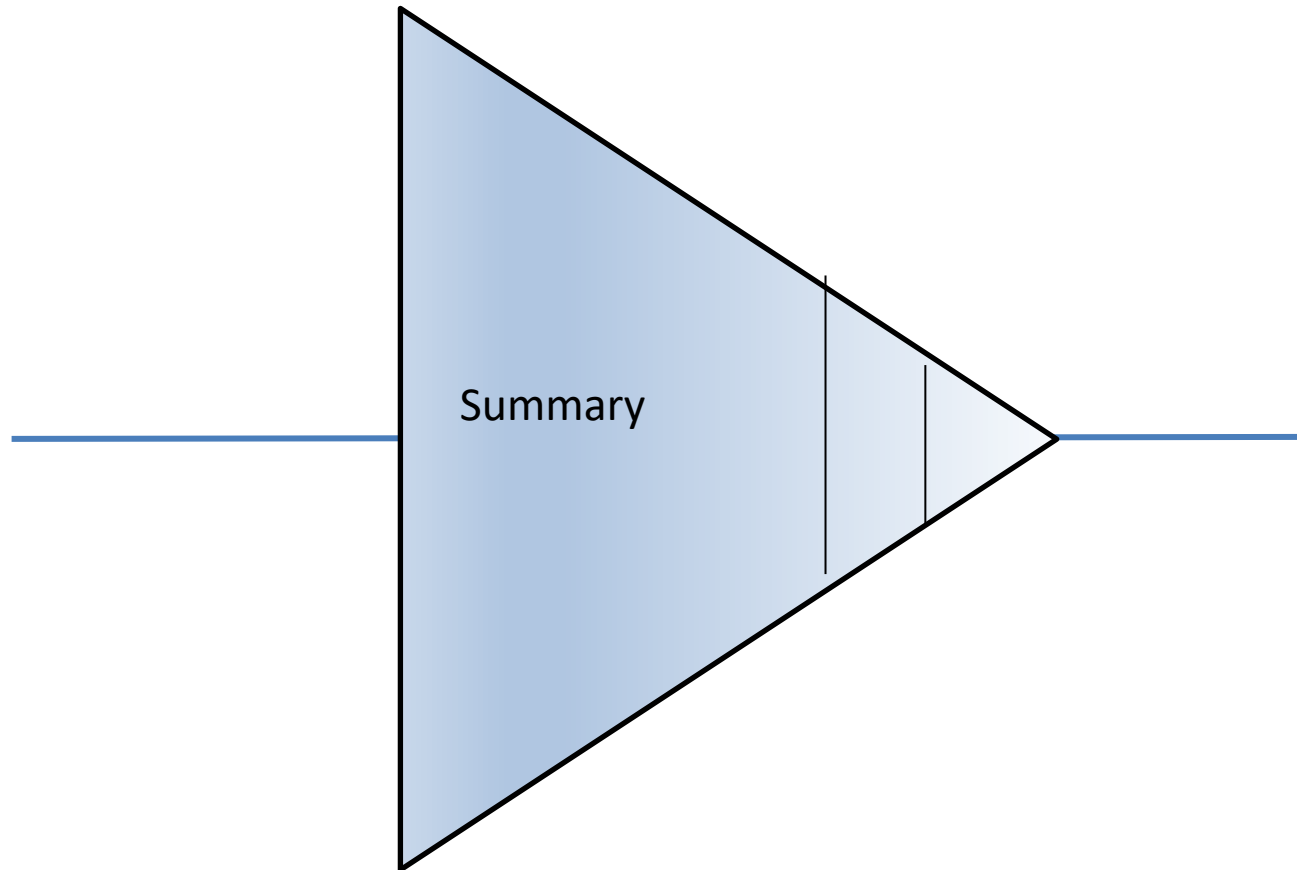
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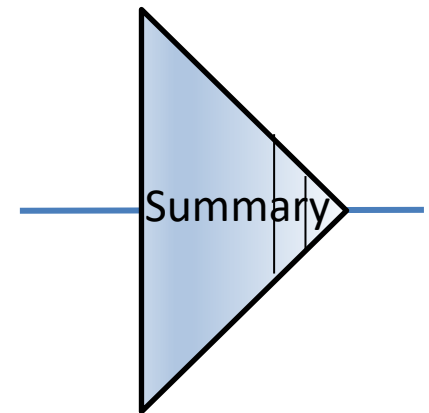
Being human (before digital)

The Summary

The Summary and the IPS

The Summary and the IPS (1)

- The amount of information in a summary is not fixed, but typically it is smaller than the original source(s).
- The professional summary is constrained and focussed. An IPS implementation should, at least, support the healthcare provider by:
    - Being relevant
    - Being brief
    - Limiting redundancy
    - Avoiding repetition
    - Minimising variety in presentation

The Summary and the IPS (2)

➢ The IPS is valued for its utility, but ultimately will be assessed on whether it helps the Summary-user to help the SoC.

➢ For this to be achieved, the 'communication convention' is vital. The IPS Dataset helps by:

- having a core that should be understood by all clinicians, providing general content and by being specialty agnostic.

- being flexible to address new requirements, e.g., Rare Diseases.

- being a global focal point, an open, de jure standard which is tangible, and extensible to manage changes

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The IPS and the EHR

The IPS and the EHR (1)

➢ The EHR is one source, perhaps the only source, for producing a summary. A summary is essentially a derivative.

➢ In planned care, why not always use the full EHR?
  ➢ If IPS needed another reason for existing, it would surely be that it has the potential to mitigate the burden placed on the clinician by trying to assimilate an EHR.
  ➢ The IPS can function as an anchor or dashboard for a record

➢ Although the IPS has extensible design, the extensions are not intended to create the full EHR

➢ The IPS fulfils a fundamentally different purpose to an EHR.

The IPS and the EHR (2)

■ **I**nternational

> It emphasizes the need to provide generic solutions for global application beyond a particular region or country.

• **P**atient
• **S**ummary

> **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**

SOURCE: ISO/TR 12773-1:2009 (en) Business requirements for health summary records — Part 1: Requirements]

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International Patient Summary

Being human (before digital)

The IPS and Digital Health

The IPS and Digital Health (1)

- Implementations of non-standard summaries detract from its value as a shared and safe resource for healthcare providers and subjects of care alike.
  - Digital Health has increased the utility of IPS by enabling reuse of the IPS Datablocks for other applications. Digital Health's interest is the whole communication situation, including Sources, Repositories and Workflows.
  - ISO 27269: 2021 constrains its present scope to the IPS Dataset. The developing *IPS* ecosystem is addressing all the summarization scenarios.
  - IPS Summarization represents 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 IPS and Digital Health (2)

- To summarize is a fundamental requirement within healthcare and the aim of the IPS is to recognize that fact and move towards realizing its value for all patients.

- The summarization of patient-level information has long been recognized as a challenge to Health Informatics and patient summaries can be considered as clinical tools, providing unique support for clinical decision making.
  - Sittig D F., et al. (2008) Grand Challenges in clinical decision support

- Digital Health has the opportunity to prioritize IPS, recognising a coherent beginning, which establishes an evolving reference standard.
  - If not, multiple, non-conformant ps implementations will exacerbate the present situation by repeating the mistakes of the past.
  - Claims to be a learning discipline/approach are forfeit.

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Being human (before digital)

The IPS and its future

The IPS and G7

➢ The value of data is found in its use; "data by itself has no value. It's the ever-changing ecosystem surrounding data that gives it meaning".

- Borgman C, L. (2015) Big Data, Little Data, No Data.

➢ There does seem to be momentum with respect to the IPS. In June, the G7 health ministers made the following commitments in relation to digital health:

"38. We commit to work towards adopting a standardized minimum health dataset for patients' health information, including through the International Patient Summary (IPS) standard, with the shared objectives of facilitating health interoperability within and between countries, … To achieve this goal, we will work with the Global Digital Health Partnership (GDHP) as they are already advancing IPS efforts."

The International Patient Summary

➤ 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 necessary workflow will need to complement the IPS ecosystem.

➤ 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.

"The farther back you can look, the farther forward you are likely to see."

Winston Churchill

Acknowledgements …

… a summary

Brigitte Endres-Niggemeyer

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Stephen Kay
http://bit.ly/IPS-Story