LOOKING INTO THE FUTURE …

LOOK BACK IN ANGER, &
LOOK FORWARD WITH HOPE

International Patient Summary Workshop - Bridging projects & Initiatives

DG Connect, Beaulieu 33, Room 0/54
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Stephen Kay, CEN IPS project team lead
Train of thought… IPS Workshop

The meaning and use of the ‘window metaphor’… hmm

The English language-word window originates from the Old Norse 'vindauga', from 'vindr – wind' and 'auga – eye', i.e., wind eye.

Windows of Opportunity…

The Eyes are the window to your soul
~ William Shakespeare

The Patient Summaries are the window to your health data
~ Catherine Chronaki
If Patient Summaries are the ‘eyes’…

What can we learn about a person and their health data by looking through the summary?

Seen from the perspective of:
   a person/patient?
   a clinician?
   an organisation?
   the vendors?
   public health?
   research?
   ...

Seen from the IPS standardization perspective?
Look back in anger…

We can do marvellous, amazing things, e.g.

- Keyhole surgery facilitated by optical instruments!
- Brain wave analysis of patients with ‘locked-in syndrome’ motor neuron disease, enabling them to communicate!!

But we cannot yet interchange a concise patient summary in a standard way affording meaningful information to benefit millions of people at a national level, let alone an international one!!
Historical, and international provenance...

The IPS builds upon solid PS experiences and requirements e.g.

National and organisational implementations
- Numerous!

Within Europe:
- epSOS
- eHN guidelines 2013
- eHN guidelines v2 2016

International activities:
- EU/US MOU & joint project work
- Trillium Bridge and EU/US roadmap
- HI7 INTERPAS
- Joint Initiative Council

... leading to standardization
JIC is developing an informative Standards Set for a Patient Summary whilst SDO members begin projects on normative content and guidance for implementations in different contexts.

The user need is for the collaboration to be effective and to provide a safe, useful, usable and coherent set of Patient Summary artefacts for the benefit of both the global and local stakeholders in the healthcare domain.
The Shared Vision of IPS

CEN/TC 251 and HL7 agree on a shared vision for the IPS:

“In order to further the care for citizens across the globe, we agree to collaborate on a single, common International Patient Summary (IPS) specification that is readily usable by all clinicians for the (cross-border) unscheduled care of a patient.”

draft, 17th November, 2016. OSLO
The information the clinician sees in cases of unscheduled care...

A window is an opening in an otherwise solid, opaque surface, through which light can pass (and, if not closed or sealed, air and sound).
The information made available may be of limited use for unscheduled care…
The information the clinician SHOULD see in cases of unscheduled care…
Standardization is a ‘viewing instrument’

- Standardization supports a ‘sharing’ and ‘open’ vision (here, the agreed CEN IPS and HL7 IPS Vision to collaborate)
  - BUT it does not solve ‘everything’, rather
- It is a specialised, engineering instrument designed to:
  - provide formal definition of requirements, achieving consensus
  - permit measurement and testing, satisfying conformance criteria
  - widen interoperable use, delivering value over time

- It frames the question, scopes the problem, and focuses by providing mechanisms to:
  - filter and illuminate
  - bring attention to detail and
  - make the picture clearer
Standardization frames the question…

Patient summaries are pervasive, in use and useful, BUT they can be made much more useful and safer…

The focus here is away from the ‘pervasive Patient Summary’ which is currently:

- **ill defined** with unclear meanings and wide-ranging scope
- **Ambiguous** with many misunderstandings
- **Confused** with the EHR and PHR applications
- **Unhelpful** with combinations of mixed containers and mixed up content
- **Inconvenient** for the clinical process and workflow
- **Is a pain for interoperable solutions** within and between organisations

The ‘pervasive Patient Summary’ is grossly **unfocused**.

The International Patient Summary (IPS) **has to be** focused.
A Viewing Instrument used to filter and focus... IPS Standardization

- The eHN has produced guide-lines for the PS dataset and has assessed that the maximum benefit is its use in urgent unscheduled care... to facilitate the same quality of care across Europe by supporting continuity of care across borders and within countries.

- The **IPS** deploys the same concepts on an international scale
Focuses on ‘Little Data’…

• “Data exist within a knowledge infrastructure- an ecosystem comprising stakeholders, technologies, organisations, objects and relationships between them.”

• “Having the right data is usually better than having more data”

Extracts from “Big Data, Little Data, No Data” by Christine L. Borgman, 2015
Towards a definition of the IPS (1)

Term: international patient summary dataset
Synonym: IPS dataset

Definition: minimal, non-exhaustive set of data elements required for the IPS

Note 1 to entry: ‘Minimal’ and ‘Non-exhaustive’ criteria are from the eHN guidelines for the patient summary.

Note 2 to entry: ‘Minimal’ reflects the ideas of ‘summary’ and the need to be concise, but also alludes to the existence of a core set of data items that all health care professionals can use; it is intended to be specialty agnostic and condition independent set. It does not imply that all the items in the dataset will be used in every patient summary. IPS items can be supplemented as required.

Note 3 to entry: ‘Non-exhaustive’ recognises that the dataset is not closed, and is likely to be extended, not just in terms of requirement evolution, but also pragmatically in instances of use.

Note 4 to entry: The focus of use for IPS is unscheduled care but the IPS dataset elements can also be used to provide a base-line within scheduled care scenarios; scheduled care, or planned care, would probably have access to the full EHR; a more extensive set of data that would include the IPS dataset elements.

Draft EN 2017 from CEN IPS, Feb. 2017
Towards a definition of the IPS (2)

Term: patient summary

Definition: subset of a health record, comprising identification, demographic and healthcare data, of a person requiring continuity of care

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Term: international patient summary
Acronym: IPS

Definition: electronic patient summary, comprising data from the IPS dataset, focussed on unscheduled, cross-border data interchange

Draft EN 2017 from CEN IPS Feb. 2017
Open process…

- **Ensuring Relevance?**
  - Adding value, getting buy-in by stakeholders throughout the process
  - Synchronising outputs with other initiatives/roadmaps, different time-lines
  - What ‘extensions’ can be considered… are worthwhile? Concise?
  - Which principles and products to include as outputs this time round
  - Jurisdiction considerations, e.g. consent
  - Governance of the IPS e.g. dataset (refinements and additions), maintenance

- **Maximizing usability?**
  - The use and value of interoperability assets
  - Terminologies and bindings
  - Clinical validation of future content
  - Guidance, consistency and education
  - Licensing and costs
  - Conformance criteria, testing
  - Quality… the PS vs the source(s) of data
  - Interactive, updateable, not just immutable ‘viewer’?
  - Proper summarisation rather than ‘simple selection’…

- **Managing change efficiently?**
  - Formalisation and sustainability
  - Agility and responsiveness to change
  - Implementation experiences; incremental enhancement
  - Managing expectations and feedback on quality and outcomes (not just outputs)

... Both CEN/HL7 IPS teams would appreciate your input!
The IPS Standards

An important technology first creates a problem then solves it.

- Alan Kay

Thank you for listening.

Stephen Kay, CEN IPS project team lead