The Future of IPS as a Global Public Good

a discussion paper from the

Joint Initiative Council for Global Health Informatics Standardisation

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Introduction

The International Patient Summary (IPS) is a unique suite of standards from several standards development organisations (SDOs) that together enable the availability of pertinent personal health information at the point of care to ensure the safe and secure provision of healthcare. It has been developed from the premise of a patient needing (emergency) care outside of their home health system. In such a case, attending clinicians may have little or no access to the patient's previous health information. Hence the need to provide a minimal and non-exhaustive set of essential clinical data for a patient: specialty-agnostic, condition-independent, but readily usable by all clinicians to initiate the delivery of safe and secure unscheduled (cross-border) patient care. While this data was originally intended to aid health professionals in providing unscheduled care, a clear desire is developing across the community for the IPS to also be used to provide planned health care, e.g. in the case of citizen movements or cross-organizational care paths. Additionally, it has been demonstrated that the IPS can be equally useful in a "cross-jurisdictional" use case (not just across international borders, but any geographic border/boundary), as well as across "organisational" borders (for example, two hospitals from different health systems who provide care to some of the same patients).

The Joint Initiative Council on Global Health Informatics Standardization (JIC) is a collaboration of SDOs that seeks to enable common, timely health informatics standards by addressing and resolving issues, gaps, overlaps, and counterproductive standardisation efforts. Members of the JIC, who include the SDOs that originated the IPS suite of standards, feel there may be a need to improve the collaborative responsiveness of the SDOs towards its stakeholders on the IPS, beyond the existing stakeholder engagement of the individual SDOs that are contributing to the IPS. This possible need for improved collaborative responsiveness will be explored by the JIC in conjunction with larger IPS stakeholder groups, using this JIC discussion paper as guidance.

This discussion paper is intended to facilitate a conversation with the global stakeholders of the IPS about how to optimally steward the IPS and its ongoing advancement.

The need for collective stewardship

It has become apparent that the "International" aspect of the IPS is not exclusive to cross-border exchange and use of personal health data across international borders. Increasingly, the IPS is also adopted within nations to create a common basis for transitions of care anywhere in their healthcare system, including across internal borders. With this broad interest, we (the collaborating SDOs) see a tremendous increase in the number and diversity of stakeholders engaged in the adoption, implementation, and further development of the IPS.

Currently, the **IPS Suite** of standards consists of six distinct specifications, managed by five collaborating SDOs (see Figure 1) and explicitly designed to work together. Collaboration among these SDOs has been a hallmark from the beginning, first between HL7 and CEN TC251, then joined by SNOMED International, ISO TC215, and IHE. As the IPS Suite of

standards continues to evolve, we seek to ensure continued alignment. For this purpose, the Cross-SDO IPS Collaboration group was started in late 2020 and has been effectively managing the mutual dependencies between the specifications. The IPS website has been created as the single go-to place for information on the IPS, which helps users find their way across the IPS standards landscape.

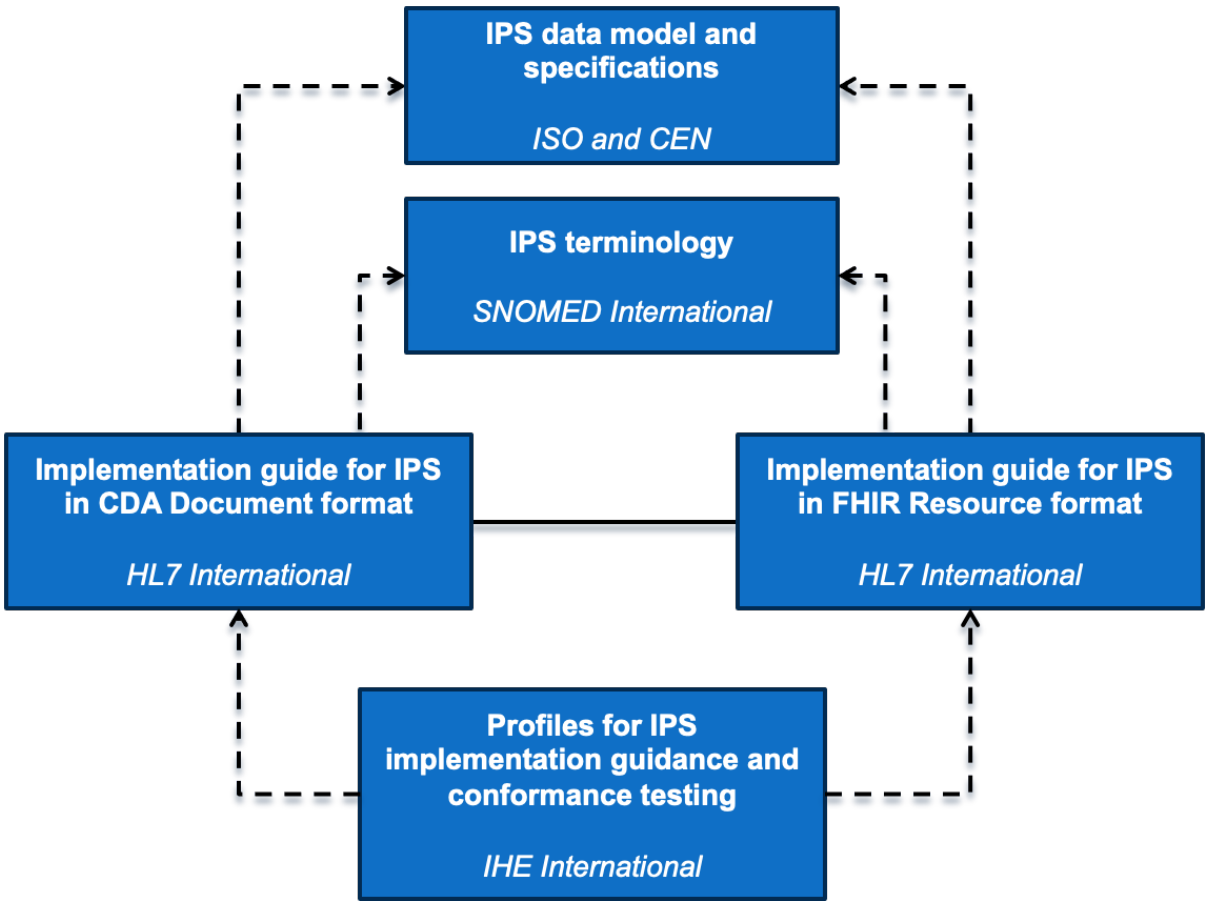

Figure 1: Current set of specifications making up the IPS Suite of standards and the respective SDOs that maintain these specifications (simplified from the IPS website)

The SDOs developing the IPS Suite are inspired by the diversity and cooperation among and between the many stakeholders that have contributed to its success. This success was not driven by a central authority; it was achieved organically. The driving forces are the overall will for the public good and the compelling needs that the patient summary use cases satisfy.

As the IPS Suite gains users and simultaneously evolves its potential uses, the JIC wishes to foster effective coordination of the parties involved so that the IPS Suite continues to effectively enable interoperability. Such coordination does not require a central authority, as various forms of federations have proven successful in business, politics, and international collaboration.

As the importance of the IPS Suite of standards to our stakeholders across the globe increases, participating SDOs also need to find ways to be more responsive, reliable, and accountable in our coordinated effort to incorporate new requirements and change requests in the IPS Suite as a whole. This requires a solid framework for the coordination work. Advancing the IPS will be best served by stewardship which facilitates and sustains the diverse stakeholder community. The aim is to develop this IPS stewardship and coordination framework in close collaboration with a broad representation of IPS stakeholders (e.g. patients, healthcare professionals, healthcare provider organisations, vendors, payers, and government organisations). A more elaborate discussion of the IPS stakeholders can be found below.

The nature of IPS stewardship

This discussion paper intends to catalyse a process for establishing shared principles, collective decision-making structures, mechanisms for coordination and communication, and cooperative accountability that continue advancing the IPS Suite as a global public good. To develop these capabilities, the JIC seeks to engage others who want to participate in the shared responsibility for creating, maintaining, and using the IPS Suite in a manner that preserves its integrity and usefulness as an interoperability enabler.

The primary measure of success of the IPS is through its implementations, where it is demonstrated that a patient summary is fit for purpose in (clinical) reality for the safe delivery of care (or other objectives related to the specific use case the patient summary is being used for). Implementation success should guide the decisions to be taken as part of IPS stewardship.

The Health Informatics Standards Development Life Cycle model (see Figure 2) is used to help understand the different phases in the development and use of the IPS Suite.

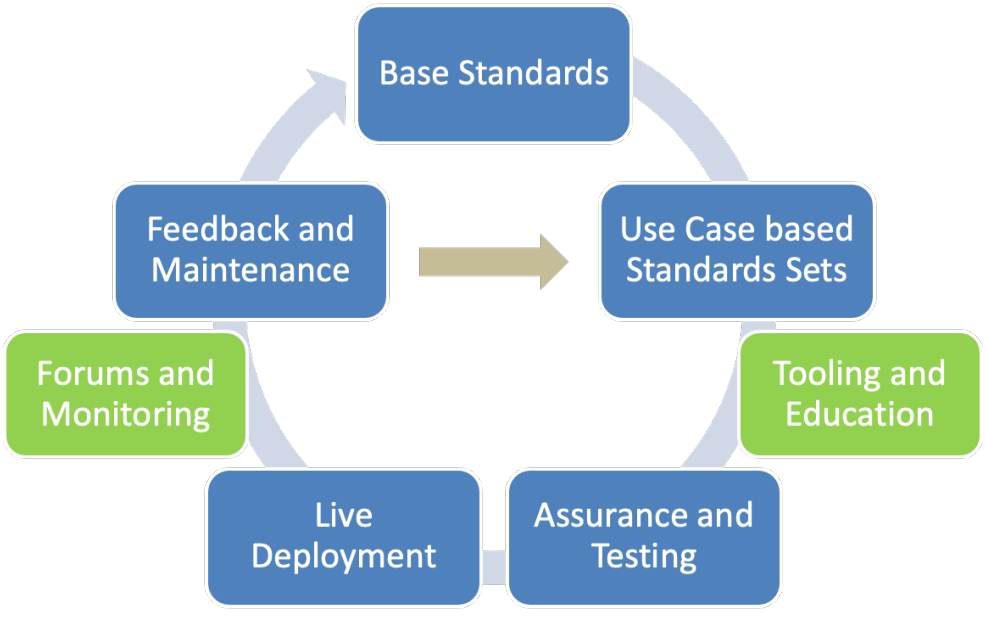

Figure 2: Health Informatics Standards Development Life Cycle[1,2]

The IPS Suite intends to support a set of use cases, each of which will have its specific requirements. In terms of the stewardship across the Health Informatics Standards Development Life Cycle, it needs to be clear who has the following decision rights:

- Make changes to the base standards, which are included in the IPS Suite or to which the IPS standards and specifications refer;
- Make changes to the standard sets within the IPS Suite, which support a particular use case or set of use cases;
- Award certificates of conformance with the IPS Suite of standards and specifications, based on agreed assurance and testing procedures;
- Support and incentivize the live deployment of processes and systems implementing the IPS Suite;
- Organise user forums and monitor the uptake of the IPS Suite;
- Provide feedback and incorporate this feedback in the maintenance of the IPS Suite;
- Define minimum requirements for alignment to the IPS which must be maintained without modification across local implementations of the IPS.

Of course, many activities can be carried out and decisions can be made by anyone wishing to do so, especially in the lower part of the Health Informatics Standards Development Life Cycle. The upper part of the Health Informatics Standards Development Life Cycle is, by nature, the domain of the SDOs. For that part, the JIC has created a JIC IPS Coordination Committee (IPSCC).

However, discussions have made it clear that our efforts need to go beyond that and address the full life cycle. A key objective of IPS stewardship is to make sure that all activities and decisions to be made concerning the individual standards and specifications, as well as the IPS Suite as a whole, take into account the impact they have across the entire life cycle. We anticipate that the specific content requirements and guidance for generating IPS instances may vary by jurisdiction and use case. For example, imagine the case where a local health authority decides to use a different terminology or value set for a particular data element in the IPS because it fits better with their local installed base. Such a decision should also be met with a responsibility to provide a mapping with the agreed terminology or value set at the global level, in order to enable easy generation of a truly IPS-compliant summary for global sharing.

Another example comes from current discussions on extending the IPS with additional data elements. Within ISO, as part of the revision process, several suggestions have been made

[1] Explained in: Schulz, S., Stegwee, R., Chronaki, C. (2019). Standards in Healthcare Data. In: Kubben, P., Dumontier, M., Dekker, A. (eds) Fundamentals of Clinical Data Science. Springer, Cham. https://doi.org/10.1007/978-3-319-99713-1_3

[2] Please note that the Health Informatics Standards Development Life Cycle is distinct from the life cycle of the actual instances of data that conform to these standards. For the purposes of the IPS, a separate life cycle will, for example, apply to the creation, consumption and deprecation of an individual patient summary (IPS instance).

for such extensions. Through an internal process of prioritisation, a few have been identified to be included in the next version. Whether these priorities truly reflect the requirements of the global clinical community is, of course, not known. At the same time, discussions are taking place in the HL7 community on how to better represent certain data elements within the HL7 FHIR Implementation Guide for the IPS. Whether those initiatives are aligned with and incorporated in the ISO specification is currently up to the individuals participating in both groups. Through a framework for collective stewardship, standards development priorities can be aligned with the global needs of a broad set of stakeholders.

The objective is to create a global community in which local variations have a minimal impact on the technical implementation and global use of any of the instances of personal health data conforming to the IPS Suite of standards and specifications.

The IPS stakeholder landscape

Each SDO has their pool of stakeholders that contribute to the development and maintenance of standards that together address health data interoperability use cases (such as the IPS). In establishing a framework that gives all potential stakeholders representation in the processes that drive the ongoing development, creation, modification, evaluation, application and regulation of health data standards, it is important to identify (groups of) stakeholders, their roles and the types of decisions they make concerning the successful adoption and deployment of solutions based on these standards. The following section considers the potential roles and influence of major stakeholder groups with a focus on the IPS.

Identification of stakeholders in the IPS

Primary use stakeholders are those directly involved in the origination, exchange, and use of patient summary data for the purpose of healthcare delivery. These stakeholders may access patient summary data through various means, such as standalone applications (desktop or mobile), embedded in health IT systems like electronic health record systems (EHRs), or fixed media (e.g. paper). Primary use stakeholders include:

- **Patients and their relatives**; can either bring their patient summary to the (first) encounter with a healthcare professional or consent to the exchange of their patient summary by their “home” healthcare provider with others; they also have a stake in what is included in the patient summary, in particular by providing corrections to their data, advance directives of care, their preferences and treatment goals, as well as their story about their health and health history.
- **Healthcare professionals**; through their use of an EHR, the healthcare professionals provide the key data that is captured in the patient summary; they may also play an active role in providing the patient summary, either to the patient or to another healthcare professional; on the receiving end, they can decide whether to ask for a patient summary and whether to trust and use the data that is provided in the patient summary for the delivery of care to the patient.

- **Healthcare provider organisations**; need to procure, implement, and maintain EHRs to support the delivery of care, making choices about the data to be captured and how this data can be shared with patients, healthcare professionals within their organisation, and other healthcare provider organisations.

Other stakeholders may include those that enable, support, mandate, or even regulate the direct use of patient summary data in healthcare delivery, as follows:

- **Vendors of EHR and PHR systems**, as well as vendors of applications that either contribute to or use patient summary data, need to provide the functionality for healthcare provider organisations, healthcare professionals, and/or patients and their relatives to capture, generate, share, request, validate, and incorporate patient summary data across the various workflows within their systems.
- **Payer organisations**, both private and public, can incentivise the use of patient summary data through financial benefits, or they can mandate the use of patient summary data as part of their policies when contracting healthcare provider organisations to deliver healthcare services for their population.
- **Government organisations**, including health authorities, digital health agencies, and ministries of health, can adopt the use of patient summary data in their policies, guide and finance the implementation of patient summary data by healthcare provider organisations, regulate the market for EHR and PHR systems to include the ability to share and use patient summary data, and/or include the use of patient summary data in the regulations for (and audits of) healthcare provider organisations.

Secondary use of patient summary data (i.e. for purposes such as public health, population health, health statistics, health system reporting, AI learning, or a wide variety of research and innovation activity) is another important driver of the adoption of standards. Some of these organisations can mandate the use of specific data standards, whereas others are dependent on the willingness of data providers to conform to relevant standards that enable efficient data processing as part of their work. Both can lead to extra efforts, either on the part of the data providers or by the data processors, trying to fit or transform the available data to the applicable data standards for that particular purpose. Without robust primary usage, the opportunities for secondary use are limited. Thus, we expect many stakeholders to be initially focused on boosting the primary use of patient summary data.

SDOs provide a service to the healthcare industry as a whole (i.e. all stakeholders listed above), by making sure the IPS Suite of standards and specifications is well aligned and fit for the purposes that the various stakeholders attribute to the IPS.

Roles of stakeholders in IPS stewardship

The effective engagement of individuals in the development of IPS standards and specifications can take many forms. First and foremost, it is the engagement of individuals that contribute their knowledge and expertise to the actual development of IPS standards and specifications. They just “roll up their sleeves and get their hands dirty” to make the standards and specifications work. That attitude and commitment will also be needed to

implement the IPS, to demonstrate what it takes to make it work in the everyday life of a patient and their healthcare professionals, or the IT departments, ensuring the connections with the outside world are safe, secure, and operational. Learning from the lessons of implementation experience will help improve the IPS Suite.

Other, more indirect, contributions are also necessary for standards development, maintenance, coordination, and communication. Providing comments and suggestions for improvement on documents being balloted, delivering education on the IPS, and deciding on the next steps in the development of the IPS Suite of standards and specifications are just a few examples of what is needed. SDOs do not all provide such additional types of engagement, nor are they geared toward the combined set of IPS artefacts that make up the IPS Suite. Here is where the collaboration with diverse stakeholders can truly make a difference. We may also expect consultants to be authorised by specific stakeholders to represent the views of stakeholders that may employ their services.

Some of these roles go beyond individual expertise and knowledge and require a representative function on behalf of a group of stakeholders. It is important to ensure and respect proper delegation of responsibility to those whose scope of expertise matches the actual issue(s) being addressed, in particular where it pertains to clinical content and context. This is where the associations, federations of associations, voluntary collaborations, and global organisations come in. They are created to support and embody the voices of individuals, organisations, or nations. Stakeholder engagement for IPS stewardship can make use of their experience in organising complex cooperation across their members to arrive at a meaningful position that reflects the interests of their members. Such organisations may include:

- Health Authorities, including Ministries of Health;
- Clinical Societies;
- Professional Societies;
- Patient Organisations;
- Healthcare Provider Associations;
- Health-IT Vendor Associations;
- eHealth Competence Centres;
- Payer Associations;
- Investment Partners for health startups.

Particularly in the global context, we see the Global Digital Health Partnership (GDHP), the World Health Organization (WHO), and the Organization for Economic Cooperation and Development (OECD) as key stakeholders to further drive the adoption, use and future development of the IPS. However, without providing a means of input and comment (using communities of practice and open topics sessions) from the patient, professional, and vendor communities, the ongoing development and realisation of the IPS may be compromised.

Principal aspects of strategic IPS stewardship

Enabling effective stewardship of IPS will include structuring the accountability across the global community, defining which stakeholders are engaged with which activities, and establishing approaches for how to operate in areas of overlapping scope and mutual dependencies. IPS stewardship entails strategic oversight of processes that allow for bottom-up standards innovation and top-down standards alignment and propagation.

Central to being a global community is to have clarity of, and commitment to, a joint way forward. This could, in part, be realised through the creation and ongoing maintenance of an IPS Roadmap. Such an IPS Roadmap prioritises new requirements and change requests pertaining to the IPS Suite and provides an indicative timeline for the incorporation of these changes in the standards and specifications that are affected by them. Principles of joint version management and backwards compatibility need to be taken into account when maintaining an IPS Roadmap. In addition, a strategic management approach should be applied in the development of an IPS Roadmap, including the assessment of perceived opportunities and mitigation of perceived risks.

In addition, IPS stewardship involves the following activities, which should reinforce and inform the strategic direction of the joint efforts around the IPS standards and specifications:

- Tracking adoption, evolution, and sustainability of the IPS;
- Facilitating best-practice patient and provider identification and sharing;
- Providing a joint conduit for communication and engagement;
- Capturing learnings from implementation and feeding them into the maintenance process of the IPS standards, specifications, implementation guidance, educational materials, assessment methods, and any other assets that are provided;
- Minimising unnecessary variance among IPS specifications and implementations;
- Maintaining joint assets (such as the IPS website);
- Providing clarity on the position of the IPS within the broader set of health data standards and interoperability governance for primary and secondary uses within and across borders

Accountability principles in IPS stewardship

One of the key attributes of the IPS, contributing to its success, is that it has been developed in a highly collaborative way across multiple SDOs. It has taken the strengths of each of the collaborating SDOs and has built upon them to produce a truly aligned IPS Suite of standards and specifications. It is important that this principle of “collaboration of peers” be maintained for the future of the IPS and its successful adoption across the globe. The core values and charter of the JIC are the embodiment of this way of working as peers.

When extending the stewardship of the IPS to include stakeholders beyond the SDOs represented in the JIC, maintaining this spirit of collaboration among peers will be crucial. The SDOs retain exclusive accountability for the standards and specifications that they have developed and which they maintain as part of the IPS Suite. Their established processes for

dealing with the revision, publication, and deprecation of standards will be fully respected by all parties involved in IPS stewardship. The need for strategic alignment with IPS stakeholders beyond the SDO and cross-SDO communities, as addressed in this discussion paper, is recognized and supported by the members of the JIC.

Stewarding the scope of IPS

An important topic that has dominated the cross-SDO discussion on the IPS for some time, is the actual scope of the IPS. Part of the success of the IPS Suite seems to be the fact that its scope is very clear and limited. That has enabled the developers to focus on working out the details necessary to the full extent needed for implementation. However, the future may require changes in scope for the IPS to remain relevant and successful.

The current scope of the IPS Suite is taken from the EN ISO 27269 standard:

- It defines a core data set for a patient summary document that supports continuity of care for a person and coordination of their healthcare.
- It is specifically aimed at supporting the use case scenario for ‘unplanned, cross border care’ and is intended to be an international patient summary (IPS).
- Whilst the data set is minimal and non-exhaustive, it provides a robust, well-defined core set of data items.

The scope statement adds: “The tight focus on this use case also enables the IPS to be used in planned care. This means that both unplanned and planned care can be supported by this data set within local and national contexts, thereby increasing its utility and value.”

Looking back at the Health Informatics Standards Life Cycle model (Figure 2), there are roughly two ways of changing the scope of the IPS:

1. Extending the number of use cases that the IPS Suite needs to cover;
2. Extending the requirements for the IPS beyond a data model, through ongoing learnings from IPS implementation experiences.

Establishing global IPS stewardship

The JIC is keen on establishing a global IPS stewardship, together with their stakeholders, to take on the further development and maintenance of the IPS Suite of standards and specifications. This includes the extension of the scope of the IPS to other use cases and the inclusion of other types of standards and specifications to meet the requirements from the live deployment of the IPS.

IPS stewardship aims to convene community members, organisations, and institutions to foster collective impact by collaboratively advancing the IPS through shared learning, strategic alignment, and integrated actions, ultimately enabling population and systems-level

change.[3] In essence, the **decision rights** of each of the stakeholders engaged in IPS stewardship follow from the **roles** as set out in the respective paragraphs above. These roles are also linked to the **use cases** that are within the scope of the IPS Suite of standards and specifications. Each of the stakeholder organisations retains **full autonomy** in making their own decisions. However, by engaging in the global IPS stewardship, each stakeholder organisation **commits** to actively communicate, participate, and collaborate with the other organisations to ensure the IPS continues to develop as a truly global asset. This includes striving to reconcile differences of opinion and conflicting requirements so that a common way forward can be followed. Communication enables a culture of collaboration.

Recognizing that local adaptation of the IPS Suite may at times be necessary, a shared objective is that local variations have minimal impact on technical implementation and global use of the instances of personal health data conforming to the IPS Suite. Therefore, our model for IPS stewardship should facilitate feedback from the global community on where, when, and why decisions by stakeholders deviate from (or even totally ignore) the IPS Suite. Such deviations may indicate shortcomings in the practical implementation of the IPS, which, if illuminated, could be resolved in future versions of the IPS suite (thus creating a full feedback loop).

A priority for enabling IPS stewardship is to establish and sustain one or more **communities of practice** around the IPS. Such a community is key to keeping the specifications alive, as it needs a critical mass of people wanting to work with the IPS. People in the community who are raising their hands have a voice at the table, including accountability towards their stakeholder group.

As there is presently no global representative organisation for many of the stakeholders involved, IPS stewardship needs to provide **open (topical) sessions** where any organisation, even when representing members from the same global group of stakeholders, can join and be part of the collaboration. These sessions and the communities of practice serve as mutually reinforcing activities. Effective IPS stewardship should provide a balance of interest across the community (or communities).

From this effort in community building, a "**Global IPS Stewardship Group"** (or another appropriately named entity) should be formed, which takes on the strategic and leadership role as outlined in this discussion paper. This Global IPS Stewardship Group would be dedicated to aligning and coordinating the work of the participants. Such a group can strategically formulate assignments/expectations for participating organisations to carry out. Evaluation is then to take place after a certain period and become part of a periodic publication of an **IPS Roadmap**, which identifies the global priorities and milestones in the future development and implementation of the IPS. Milestones could include, for example, the publication of future versions of IPS standards and specifications. Where such a Global IPS Stewardship Group is to be positioned in the global landscape of stakeholders, is up for discussion. An IPS Roadmap would help shape a common agenda to keep all parties

[3] https://collectiveimpactforum.org/what-is-collective-impact/

moving towards the same goal.

At the global level of IPS stewardship, a variety of considerations need to be weighed against one another when establishing such a roadmap. It needs to take into account what effort is required and what conditions need to be met to make it through a full life cycle of Health Informatics Standards Development, including:

- Energy, people and inspiration to work on this
- Financial means to cover the implementation
- Bandwidth within operations to adopt the change
- Perceived impact of the changes in terms of “health” outcomes
- Preconditions to implementation in the systems landscape

These efforts need to translate into value for the stakeholders involved. Where the value and efforts are misaligned for specific stakeholder groups, payer and government organisations may be able to step in and alleviate some of these misalignments. Such cost/benefit analyses are typically conducted as localised projects because they are highly dependent on the individual/local/national context of the stakeholders involved. Hence the need to have an open discussion with all parties concerned (as is the rule across the membership of the JIC) to strive for consensus about the roadmap for IPS development.

In the end, what counts is the value of the adoption of the IPS Suite of standards in the context of healthcare delivery and health system management. Developing a common set of measures of progress would facilitate tracking and allow for continuous learning and accountability. These include tracking of adoption, evolution, and sustainability of the IPS, as well as facilitating best-practice identification and sharing. These measures need to be developed and considered by the Global IPS Stewardship Group and communicated across the global community.