Aligning Policy, Standardization and Future Sustainability

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on behalf of Workpackage 5
Scope of the work on policy alignment, standardisation and sustainability

- Consider the multi stakeholder commitments, efforts and investments that are needed to scale up the development, adoption, use and benefits realisation from transatlantic shared patient summaries.
- Consider these under seven priority topic areas.
- Publish the final strategy brief document with an outline analysis and key recommendations for each of the topic areas.
Priority topic areas

- **Incentives**: financial and non-financial incentives to encourage high levels of completeness of summaries, and for the implementation and deployment of conforming EHR systems
- **Innovation**: stimulation of a market in applications that capture and deliver patient summaries e.g. mobile device apps
- **Cross-vendor integration**: enable each vendor to generate and export a valid summary, and combine summaries with other data
- **Future standardisation**: engage SDOs in adopting the summary as a standard and interfacing it with other relevant standards
- **Education**: foster the development of training for all health professional disciplines and specialties who will create or use the summary, and patients
- **Privacy and security**: strategies for addressing legal issues, identification, security and privacy protection
- **Research**: in developing other summaries for specific disease or care scenarios
Incentives

- Safe clinical decision making on the basis of a communicated patient summary relies upon its accuracy and completeness (e.g. allergy list, medications).
- Clinicians are not currently very motivated to maintain summary data within their own systems (they often know their own patients well).
- Will we be able to incentivise clinicians to invest the time and effort in completing and regulatory updating the summary of every patient on their books just in case a small number need that summary to be communicated elsewhere?
Innovative business models

- Hosting the infrastructure to communicate patient summaries across borders is expensive to establish and maintain, including the various governance and translation services and liability costs.

Who should pay?

- The summary sender is not responsible for the care required urgently elsewhere, or its costs. Why should they pay?
- The receiver will get paid for delivering care, and might actually be paid more for performing tests that duplicate recently performed tests. They may lose money through using the PS.
- Should national governments pay, when they are already struggling to budget for local priority healthcare needs?
- Why should the taxpayer subsidise healthcare for wealthy business people when they travel?
Future standardisation

• Standards have traditionally been developed in silos, within individual SDOs.

• The JIC has enabled some degree of mutual awareness of forthcoming standards across SDOs, and cross-balloting of them if relevant.

• However, the Patient Summary, and other similar assets of the future, use multiple standards together.

• How will SDOs help to better enable the easy and reliable bundling of multiple SDO standards that do need to be used together to deliver specific interoperability solutions? Who should be the steward of standards bundles? Will they be sustainable?
1. Almost every national IT programme has made Cinderella investments in the education of its health workforce. We know that the introduction of novel ICT solutions usually does require business process (workflow) changes and up-skilling the ICT workforce. How do we ensure that innovations such as the transatlantic patient summary are backed up by adequate investments in workforce education?

2. Clinicians have a tendency to not trust information “not collected here”, and they re-take histories, duplicate tests etc. How can we educate clinicians to have an appropriate level of trust in the information received in a patient summary?

3. Mediating the exchange of summaries via the patient will inevitably mean that more patients will read more about their own healthcare. Clinicians may not welcome urgent phone calls from worried or confused patients who cannot understand their summary or read unexpected details about themselves. How can we prepare the population across both continents to become happy vectors of their patient summaries, reading it along the way?
Cross-vendor integration

• Exporting data that an EHR system vendor holds into a patient summary structure is not difficult. It requires a data mapping and an export interface.

• Importing can by much more challenging, and may require handing received data that the system does not routinely store, and potentially displaying to users data items that they do not usually see or record.

• How completely should we require vendors to handle the information they import from a received patient summary?
Security and privacy

- Assuming that end to end information security can be made robust
- and assuming that the privacy policies that relate to a sender’s EHR can be interoperably communicated to a receiver
- and the receiver could map the policy stipulations to the local policies for EHR access
- how should the receiver handle conflicting policy stipulations
- e.g. a diagnosis only intended to be seen by doctors, received by a speciality that works as a multi professional team?
Research

• The epSOS patient summary has been designed to meet the requirements of unscheduled care.

• As we move, at least in Europe, to planned care, for procedures or chronic disease care, what sources of funding might support the necessary requirements analysis, design, standardisation, implementation and transatlantic adoption of a wide range of patient summaries?