

How well does the Global Patient Set cover the terms needed in an International Patient Summary?

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INTRODUCTION



Abstract

This research piloted mapping the inaugural SNOMED International Global Patient Set (GPS) Release 2019 (R.2019), including the March 2020 COVID-19 terms, into value sets for the International Patient Summary (IPS) data elements. The research leveraged the use case of a child with chronic asthma travelling from Canada to Portugal with a paper IPS document. Comparisons were made with previous GPS-IPS work and pediatric recommendations. Future research includes identifying granular IPS data elements, addressing gaps in the GPS terms, and mapping the GPS R.2020 into IPS data element value sets, including identifying alternate terminologies. Out-of-scope were an independent review of the IPS value sets and developing and implementing the value sets in an electronic health record (EHR).

Background

In February 2019, SNOMED International announced they were providing the GPS flat file of 21,782 Systematized Nomenclature of Medicine-Clinical Terms (SNOMED CT) terms free of charge in order to make the GPS available to Member, Affiliate, and Non-member countries.(1) The first release was September 2019 (GPS R.2019) and the next release is Fall 2020.

The GPS is comprised of terms from existing SNOMED CT reference sets, and includes only the identifiers, whether active, fully specified names, and the United States (US) preferred terms, and not the full ontology relationships of SNOMED CT. As GPS R.2019 is the first release all terms are active.(1)

In the GPS Implementation Guide (IG) Scenario #3 describes mapping the GPS terms into IPS data element value sets.(1)

The IPS, based upon the Patient Summary (PS), is a snapshot of an individual's medical and health information at a point in time and has been in development since 2017 (http://ihic.info/wp-content/uploads/2019/10/IHIC_2019_Cangioli.pdf, Slide 17).

The IPS is comprised of component blocks. The recommended and optional blocks are now "required if known"(Figure 1) (https://wiki.ihe.net/index.php/International_Patient_Summary).

The IPS was originally developed for emergency cross-border adult care with the intent to expand other types of care, including for children (<https://www.devdays.com/wp-content/uploads/2019/12/Robert-Hausam-International-Patient-Summary-DevDays-2019-Redmond.pdf>). Research on IPS has been published.(2)

Various organizations have taken the lead and/or collaborated on the work including the Joint Initiative Council (JIC), Health Level Seven (HL7), and the Integrating the Healthcare Enterprise (IHE) (https://hacking-health.org/wp-content/uploads/2019/02/G_Cangioli_HHA_Hackathon_Feb2019_Webinar.pdf).

Figure 2 shows the progress advancing the IPS from the European Union Guidelines to the current IHE and HL7 Fast Healthcare Interoperability Resources (FHIR) work (https://na.eventscloud.com/file_uploads/611c5c97f4e8446fccf3f3303c7f5346_Stephen-Kay_The-Patient-Summary-is-here.pdf). Most recently, IHE has taken the lead in collaboration with HL7 (https://wiki.ihe.net/index.php/Patient_Care_Coordination_Technical_Committee#Detailed_Proposed_Profile_Review_for_2019-2020_Cycle_-_F2F_Meeting).

The recent IHE June 17, 2020, report provides IPS guidance (https://www.ihe.net/uploadedFiles/Documents/PCC/IHE_PCC_Suppl_IPS_Rev1-1_TI_2020-06-17.pdf).

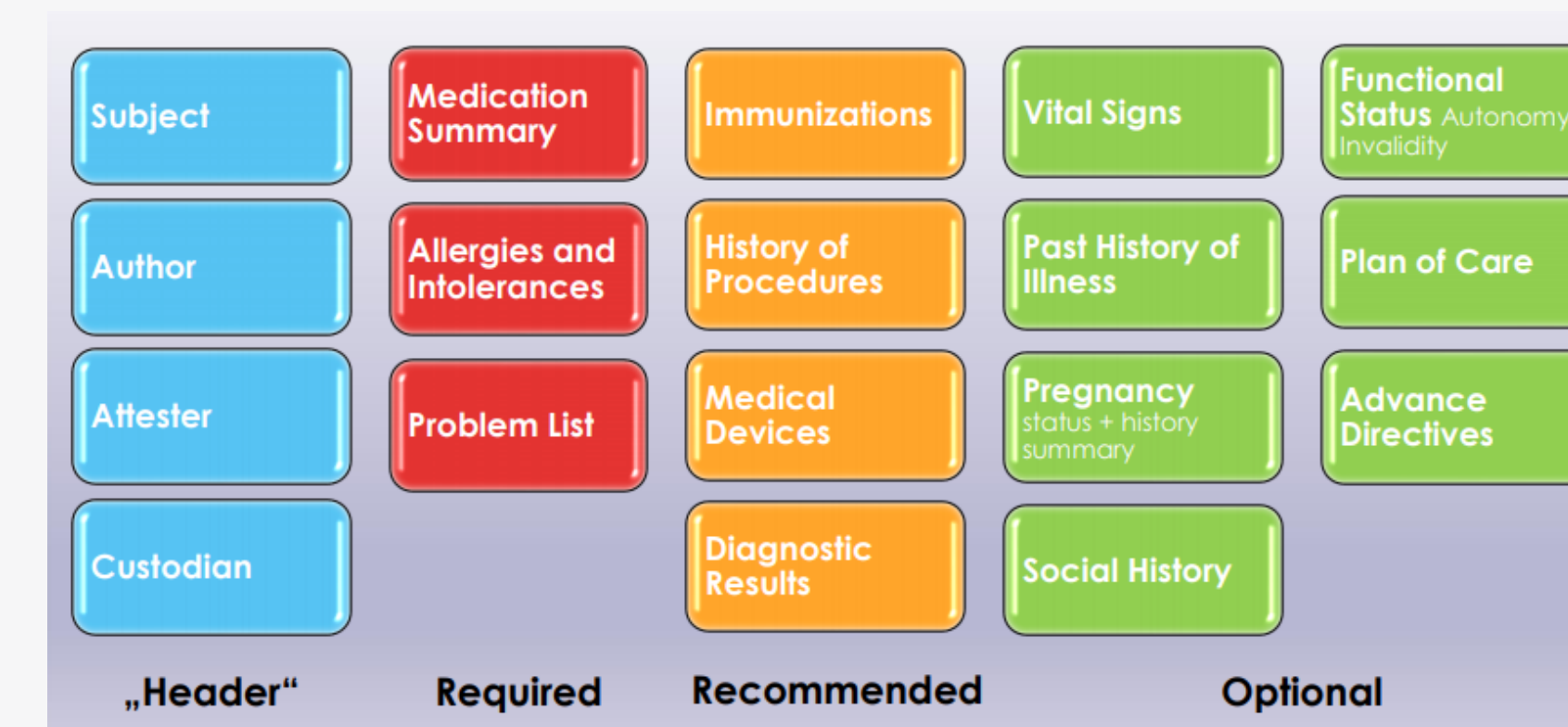


Figure 1 – IPS blocks

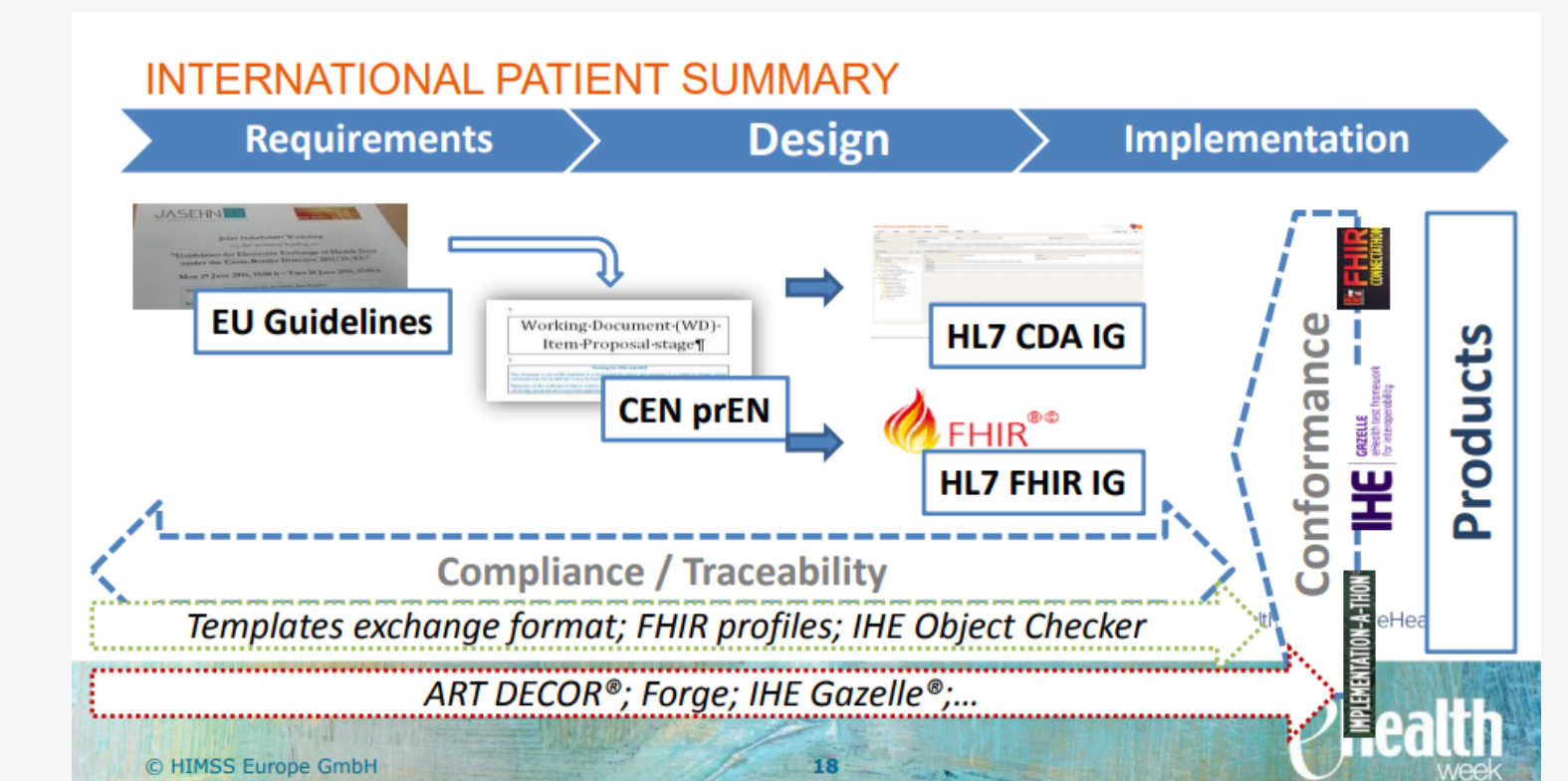


Figure 2 – IPS development progress

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METHODS



Method

Figure 3 details the research process:

- The GPS R.2019 was downloaded from IG (1), including SNOMED CT COVID-19 terms (<https://confluence.ihtsdotools.org/display/snomed/SNOMED%2BCT%2BCOVID-19%2BRelated%2BContent>), and formatted into an Excel Spreadsheet
- Figure 2 IPS block names leveraged for IPS data element labels for IPS value sets
- Health Level Seven (HL7) Fast Healthcare Interoperability Resources (FHIR) version 4.0.1 (e.g., <http://hl7.org/fhir/versions.html#maturity>), Health Informatics Standards Lifecycle (Figure 4)(3) and IPS governance model(4) were relied on
- A table of common medical terminologies was adapted to identify Canada-endorsed terminologies.(3, Table 3.1)

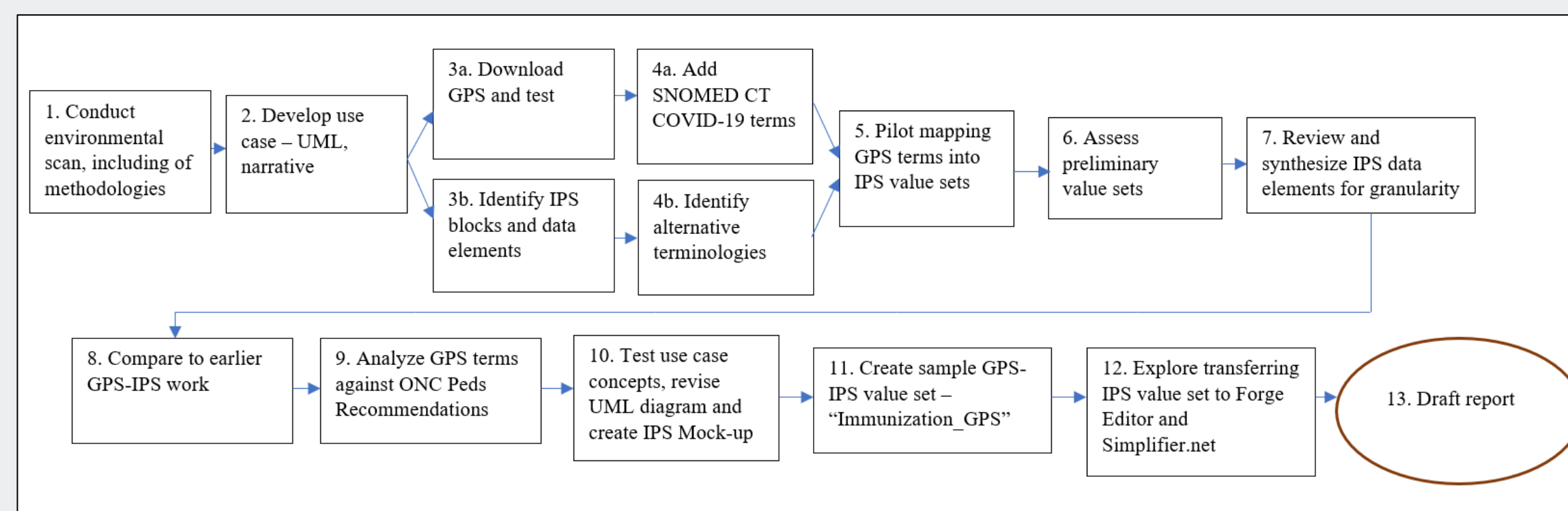


Figure 3 – Research process

- A use case was developed:
 - 8-year old male child, Sydney, with chronic asthma (<https://asthma.ca/what-is-asthma/>)
 - exhibited COVID-19 symptoms in August 2020 but tested negative
 - early October 2020 he and his family traveled from Canada to Portugal, where he again presented with COVID-19 symptoms (high fever, shortness of breath).
 - Prior to leaving Canada, his mother obtained paper copies of the IPS for each family member from their family doctor

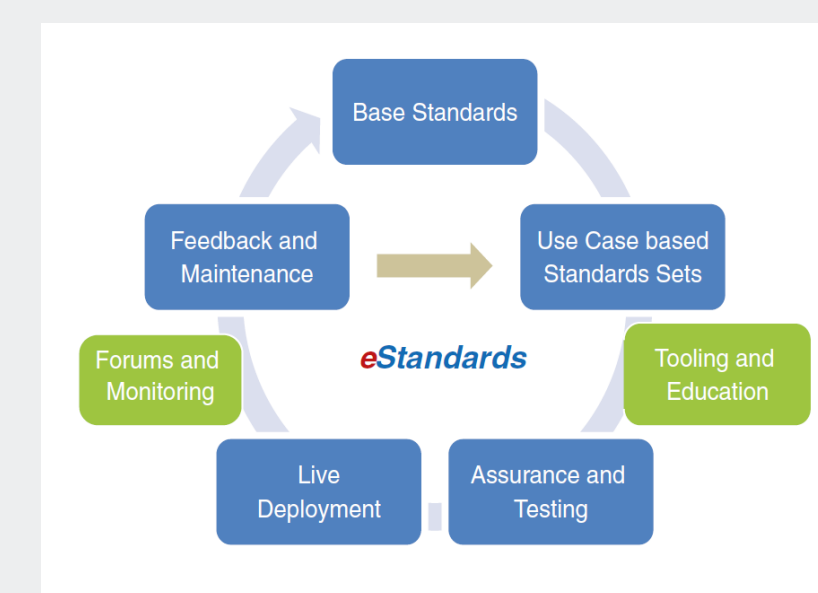


Figure 4 – Standards Life cycle

- Sydney’s mother takes him to a walk-in primary care clinic in Lisbon and has Sydney's IPS document to provide to the doctor.
- Unified modeling language (UML; <https://www.uml.org/>) was used to model the use case (Figure 5)

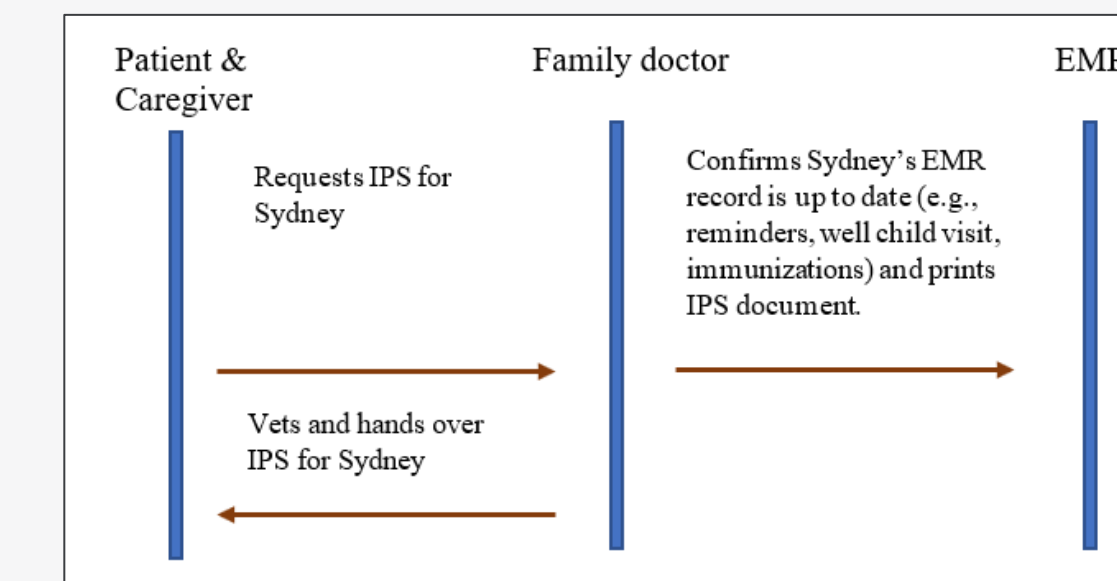


Figure 5 – Pre study UML use case

Results

During the mapping it was found that the IPS blocks as value set labels did not provide enough granularity to group like with like. For example, dog and flower pollen might both be allergens, but they are dissimilar. Therefore, SNOMED CT concepts such as “body site” were leveraged but, again, these groupings did not provide sufficient granularity (Figure 6). To better understand the ecosystem, the FHIR IPS value sets were reviewed (<https://build.fhir.org/ig/HL7/fhir-ips/terminology.html>). It was found that 14 IPS data elements had GPS-IPS value sets (Figure 7).

ConceptID	SN	USPreferredTerm	IPS Block / value set 1	IPS Block / value set 2
111002	Parathyroid structure (body structure)	Parathyroid structure	Target site	History of Procedures
125001	Ferrous (59-Fe) sulfate (substance)	Ferrous (59-Fe) sulfate	Allergies and Intolerances	
140004	Chronic pharyngitis (disorder)	Chronic pharyngitis	Problem List	History of Past Illness
187006	Cyanocobalamin (57-Co) (substance)	Cyanocobalamin (57-Co)	Diagnostic results	indicated in the diagnosis of pernicious anemia
219006	Current drinker of alcohol (finding)	Current drinker	Problem List	
252000	Acinetobacter johnsonii (organism)	Acinetobacter johnsonii	Diagnostic results	a bacterial species of the genus Acinetobacter
270002	Female first cousin (person)	Female first cousin	Social History	
271003	Bone plate, device (physical object)	Bone plate	History of Procedures	
281004	Dementia associated with alcoholism (disorder)	Dementia associated with alcoholism	Problem List	History of Past Illness
283001	Structure of central axillary lymph node (body structure)	Structure of central axillary lymph node	Target site	History of Procedures
290006	Meckel-Blau syndrome (disorder)	Meckel-Blau syndrome	Problem List	
297009	Acute myringitis (disorder)	Acute myringitis	Problem List	
300004	Miniature schnauzer (organism)	Miniature schnauzer	Allergies and Intolerances	
315003	Skin structure of umbilicus (body structure)	Skin structure of umbilicus	Target site	
317006	Reactive hypoglycemia (disorder)	Reactive hypoglycemia	Problem List	
330007	Occipital headache (finding)	Occipital headache	Problem List	
345000	Atroventricular bundle structure (body structure)	Atroventricular bundle structure	Target site	
350003	Levamisole, drug, for immunomodulation (drug)	Levamisole, drug, for immunomodulation	Problem List	

Figure 6 – Pilot mapping GPS terms into IPS value sets

Allergy intolerance substance condition (GPS) - IPS
Allergy Reaction (GPS) - IPS
CORE Problem List Finding/Situation/Event (GPS) - IPS
Results ABO+RH Group (GPS) - IPS
Results Coded Values Laboratory (GPS) - IPS
Results Coded Values Pathology (GPS) - IPS
Results Organism (GPS) - IPS
Results Laboratory Presence/Absence (GPS) - IPS
Results Radiology Measurements (GPS-DICOM) - IPS
Results Radiology Textual Observations (GPS-DICOM-LOINC) - IPS
Results Specimen Collection Method (GPS) - IPS
Results Specimen Type (GPS) - IPS
Vaccines (GPS) - IPS
Vaccine Target Diseases (GPS) - IPS

Figure 7 – GPS-IPS value sets

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RESULTS

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The issues in the prior GPS-IPS work ((L.F, personal communication, 2020 Mar 17) appear to persist (Figure 8). For example, the GPS does not contain all the needed vaccinations.

Figure 9 shows results of searching for GPS R.2019 concepts suggested by the 10 ONC recommendations for functionality in a pediatric EHR (https://www.healthit.gov/sites/default/files/facas/03-29-19_HITCC_TF_MeetingNotes_508.pdf)

No.	Short title	Description of issue	Findings and comments
1	Immunization values	review of the SNOMED-CT concepts under 398527000 Vaccine (substance) seems to be missing a few concepts for vaccines – are there plans to update the list? <ul style="list-style-type: none"> dengue fever vaccine hantavirus vaccine hepatitis C vaccine hepatitis E vaccine herpes simplex virus, type 2 vaccine human immunodeficiency virus vaccine malaria vaccine Venezuelan equine encephalitis vaccine Also, this tree only covers the antigens, but not the vaccine product which as indicated gets into the same pathway as the medicinal products (IDMP identifiers)	Infant child immunizations appears to be in GPS. The immunizations are not all in GPS (e.g., Dengue Fever is not in GPS as vaccine). Raises additional question – are all global vaccinations in GPS? Recommend: in-depth review and comparison against a range of countries' recommended immunization schedules for disparate age groups, including ranges set out in the under-18-age pediatric domain.
2	Medical devices – intentional value set	https://build.fhir.org/ig/HL7/fhir-ips/ValueSet-medical-devices-us-ips.html Includes concepts that don't appear to belong like: Molten lava, Oil well rig, Hand saw, Motor home. Discussion in response is what is the cost benefit/maintenance consideration behind teasing out those concepts that are not really medical devices.	All medical devices (e.g., Spirometer) are not included, and it appears some equipment and toys (possibly as therapeutic equipment e.g., baseball) are listed. Recommend: review of terms and creation of granular IPS value set labels (e.g., medical implant devices, tools, equipment (e.g., beds, transfer lifts), therapeutic interventions, toys).
3	For Target Disease under Immunization	FHIR specifies: http://hl7.org/fhir/R4/valueset-immunization-target-disease.html - this value set is VERY incomplete – missing key concepts in this list (e.g. HepA, HepB, polio, influenza, meningitis, varicella, dengue, cholera, hantavirus, leprosy, leishmaniasis, rabies, tularemia, smallpox, yellow fever, etc.)	Related to issue #2. Suggest reviewing in parallel for completeness (e.g., Dengue fever is not in GPS as vaccine, but Dengue is present as a disorder and as a symptom).
4	Concepts supporting some social history metrics are not included.	<ul style="list-style-type: none"> 229819007 SNOMED CT Tobacco use and exposure 256235009 SNOMED CT Exercise 160573003 SNOMED CT Alcohol intake 364193001 SNOMED CT Nutritional observable 364703007 SNOMED CT Employment detail 425400000 SNOMED CT Toxic exposure status 365900000 SNOMED CT Details of drug misuse behavior 228272008 SNOMED CT Health-related behavior 105421008 SNOMED CT Educational Achievement 	Spot check: Smoking concepts – exist in GPS. 160573003 – Alcohol intake - does exist in GPS. 256235009 – Exercise - does exist in GPS. Issue: these concepts do not represent an individual's full social history. Recommend: full review of values.

Figure 8 – Prior GPS-IPS mapping work analysis

Recommendation	Short title	Description	Comments	2019 GPS R.1 plus COVID-19 terms findings	Analysis comments
Recommendation 1	Growth charts	Use biometric-specific norms for growth curves and support growth charts for children	Allow unknown patient sex, Record Gestational Age Assessment and Persist in the EHR, Support growth charts for children; also Common Clinical Data Set (CCDS), Demographic, Clinical Decision Support (CDS), and United States Core Data for Interoperability (USCDI), Application Programming Interface (API).	height - no, weight - no, partially head circumference - yes as a procedure (56792006 - Measurement of skull circumference (procedure)) but not as an "observable entity" as included for "chest circumference." Some growth and aging concepts are present (e.g., 709479007 - Assessment of fetal gestational age (procedure)).	Review needed to ascertain whether all pediatric measurements are present, or are added to the IPS using other terminologies. In addition, an assessment is needed to compare the CCDS, CDS, and USCDI datum elements are present in form that enables
Recommendation 2	Compute weight-based drug		Out of scope for SNOMED CT?	weight not present in GPS	Unable to calculate without "weight"
Recommendation 3	Ability to document all guardians and caregivers		Include Document decisionmaking authority of patient representative	Caregiver roles present (e.g., 65656005 - Natural mother (person))	Unknown if all caregiver roles are included
Recommendation 4	Segmented access to information		Problem-specific age of consent - does it also say to remove this? Also, meeting discussion included need to know if information has been removed.	Consent concept present	Review of SNOMED CT consent concepts needed to determine if all age-consent concepts are present and if SNOMED CT is correct terminology system. Concept mapping between IPS and SNOMED CT includes "unknown" concepts such as Unknown if allergic. Consideration might be given to whether concept mapping for "information removed" is needed?
Recommendation 5	Synchronize immunization histories with registries			Mandatory immunizations appear present	Are mandatory immunizations different between countries? E.g., Malaria in Ghana versus in Canada.
Recommendation 6	Age and weight-specific single-dose range checking		[Relevant for SNOMED CT?]	Related to Recommendation 2	
Recommendation 7	Transferable access authority		Associate maternal health information and demographics with newborn	Social, Psychological, and Behavioral Data	Related to Recommendation 4
Recommendation 8	Track incomplete preventative care opportunities				
Recommendation 9	Flag special health care needs (NB: Neonatal abstinence syndrome (NAS) was also discussed)				
Recommendation 10					

Figure 9 – Concepts in ONC 10 pediatric recommendations compared to GPS R.2019

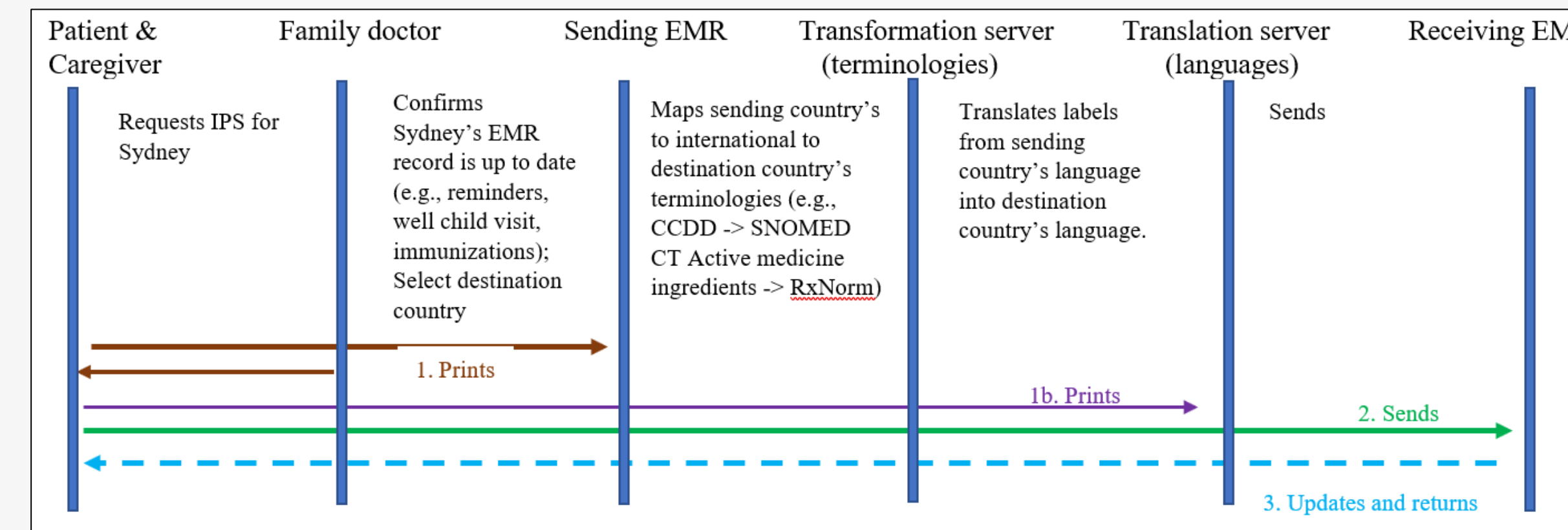


Figure 10 – Revised UML diagram adding workflow permutations

Datum	In 2019 GPS R.1 (incl. COVID-19 terms)	Alternate terminology	Comment
Male	248153007 Male (finding)		
Child	[Not listed]		
Age – 8 years old		Unified Code for Units of Measurement UCUM paragraph §31	Year https://units-of-measure.org/ucum.html#para-31
Well child visits	2020 Aug 19 410620009		
Immunizations	171258008 Up to date		
Allergy/Intolerance	716186003 No known allergy 91936005 Penicillin		No known allergy – alternative value included to show exists in GPS R2019
Mother	65656005 Natural mother (person)		
Asthma (diagnosis)	195967001 Asthma (disorder)		
Spirometry (asthma diagnostic test)	[Not listed]	LOINC – 19866-3 – Vital capacity [Volume] Respiratory system by Spirometry	A code for "Spirometry Test" did not appear to be listed. There are several LOINC codes. This code and description seem the best fit.
Spirometer (asthma medical test device)	[Not listed]		
COVID-19 test		LOINC 94722-6 COVID-19 Initial Evaluation form	Seems to be in ontology domain but only active non-ED form available. https://fhir.loinc.org/CodeSystem/\$lookup?system=http://loinc.org&code=94722-6
Saliva - specimen	119342007 Saliva specimen (specimen)		
COVID-19 test results (negative)	84387000 Asymptomatic (finding)		
Difficulty breathing	(reason for Lisbon clinic visit – would be completed in response IPS)		
High temperature	(reason for Lisbon clinic visit – would be completed in response IPS)		

Figure 13 – Testing use case concepts to GPS R.2019

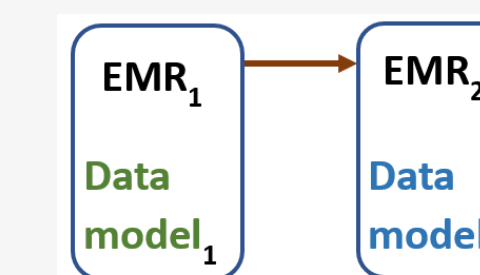


Figure 11 – EMR_{n+1} Data model

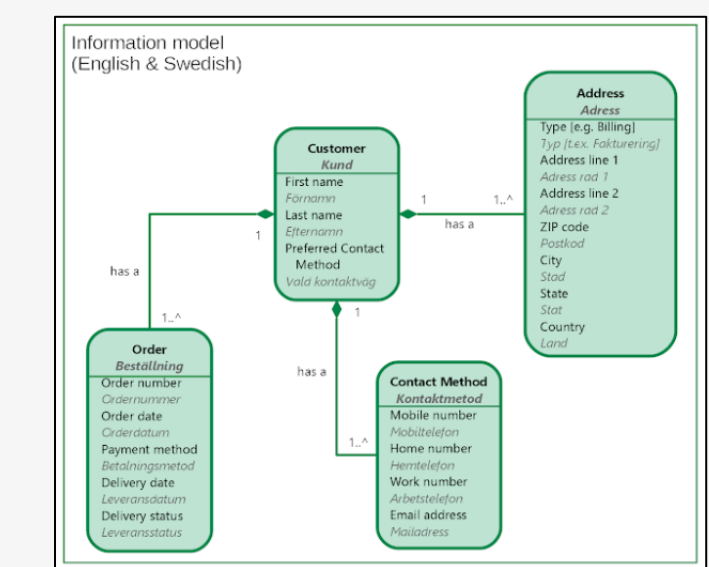


Figure 12 – Dual language data model

The IPS workflow permutations: generate in paper, hybrid, or send data only electronically; if fully interoperable EMR₂ could return data to EMR₁ (Figure 10)

Depending on the workflow permutation, the electronic medical record (EMR) data models for data exchange including terminology transformation (Figure 11) and dual language data model for language translation (Figure 12). (<https://www.softwaresuperglue.com/2018/11/information-model-vs-data-model.html>; [international-patient-summary.net/mediawiki/index.php?title=IPS_implementation_guide_1](https://www.international-patient-summary.net/mediawiki/index.php?title=IPS_implementation_guide_1)).

Figure 13 tested the narrative of Sydney against the GPS R.2019 terms and found some gaps including "child" and "spirometer" to test asthma.

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DISCUSSION



Figure 14 shows a sample IPS mock-up. For structure, a PS template and model were leveraged (<https://art-decor.org/art-decor/decor-templates--hl7ips-?section=templates&id=2.16.840.1.113883.10.22.3.2&effectiveDate=2016-11-11T00:00:00&language=en-US>; <https://www.slideshare.net/TrilliumIIHorizon/international-patient-summary-workshop>, Slide 31).

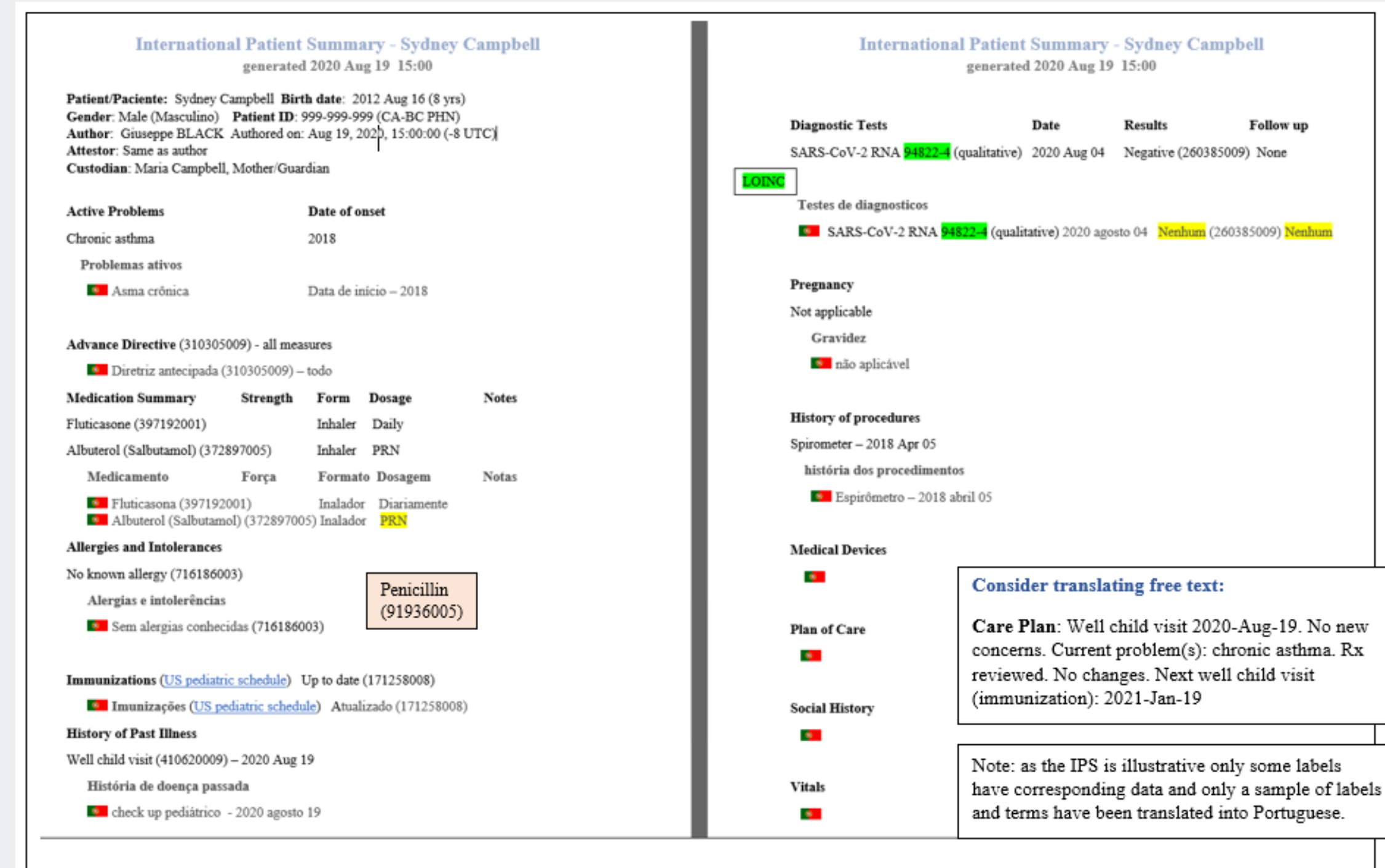


Figure 14 – IPS mock-up for Sydney

Highlights:

- Country flag may indicate translated-to language while keeping originating language
- “No known allergies” concept indicates allergies assessed but no allergies found rather than leave field blank
- A challenge to translate any free text (e.g., inset Care Plan narrative)
- An automatic translator (i.e., Google translator) would not translate the meaning accurately

Future Direction

The IPS projects to date have set a solid framework for realizing the benefit of implementing an interoperable IPS. For creating the IPS, a hybrid approach may be needed while interoperability is fully developed and implemented. Future research includes mapping the GPS R.2020 into more granular IPS data element value sets. Once the granular IPS data element value sets have been mapped using GPS and other terminologies, the IPS value sets could be formatted in a tool such as the Ontario Clinical Document Header template (<https://www.ehealthontario.on.ca/en/standards/view/provincial-clinical-document-architecture-cda-header-standard>). Next, the IPS value sets need transferred into software for profiling and then publishing as an IG in such tools as Forge Editor and Simplifier (<https://fire.ly/products/>).

References

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Discussion

Considerations in addition to mapping IPS data element value sets to realize globally interoperability:

- the GPS and IPS are in their infancy and the ecosystem is constantly changing
- Formal request for change to add new terms to GPS is needed
- Granular IPS data elements needed
- International reference table of health terminology and interoperability standards would support transformations
- Bridging strategy might be paper IPS with human medical and language translator

Of note, limitations include that one researcher designed, conducted, and reported on the research.

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