Joint Initiative Council

Template for comments

Date: 2017-09-25	Document: **JIC Patient Summary Standards Set**	Version:0.02

SDO/ person	Line	Clause/ Subclause (e.g. 3.1)	Paragraph/ Figure/ Table/ (e.g. Table 1)	Type of comment[2]	Comments	Proposed change	Observations of the developers
	David McKillop AU		1.8.1	2nd paragraph	Ed	Fullstop missing at the end of the first sentence ie "…used by different stakeholders The Guidance…" add a fullstop after "stakeholders".	Add a fullstop after the word "stakeholders" ie "…used by different stakeholders. The Guidance…"	Accepted, updated
	David McKillop		1.8.2	Last sentence	Ed	Fullstop missing at the end of the paragraph ie "… that clinical needs are met"	Add a fullstop to the end of the paragraph ie "… that clinical needs are met."	Accepted, updated
	David Mc		1.8.6	2nd last sentence	Ed	There are 2 fullstops after the second last sentence ie …"Patient Summary Standards Set.."	Remove the second fullstop.	Accepted, updated
	David Mc		1.8.6	Last sentence	Ed	The "(link here)" text is not associated with a url.	Add the appropriate url to the words "(link here)".	Accepted, updated
	David Mc		2.4	Table 2	Ge	Lab providers are missing from the list of "Other Healthcare Technology Vendors/Suppliers" where as the diagnostic imaging service provider is included.	Add "Laboratory Providers" to the list of example vendors/suppliers. Query change "diagnostic imagine service provider" to "diagnostic imaging and laboratory service providers" or just add, "laboratory service providers".	Accepted, updated
	David Mc		3.0	Last paragraph	Ed	At the end of the section the "(link here)" text is not associated with a url.	Add the appropriate url to the words "(link here)".	Accepted, updated
	David Mc		3.1.2	Procedures (investigative, diagnostic or treatment)	Ed	In the comments section of "Surgical Procedure, Non-Invasive Procedure or Intervention and Other Procedure Description", there is a closing bracket ")" after the words "limited to last 6 months", but there isn't a corresponding opening bracket "(".	Suggest deleting the closing bracket as the sentence reads fine without the closing bracket.	Accepted, updated
	David Mc		Information sheet: Readiness and Peer Audit	Last sentence	Ed	The word "though" should be "through" in the last sentence: "…actor and decisions that need to be enabled though the communicated information."	Suggest changing the word "though" to "through".	Accepted, updated
	Rob E, AU		3.1.2	Social History	Ge	Section 3.1.2 Clinical data items, Social History Observations (pages 40 – 41)	Have the risk factors of smoking, nutrition, alcohol and physical activity categorised as risk factors	This is added in to the Option column. Accepted

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				Observations	The text states "*Social history observations related to smoking, alcohol and diet*" The RACGP has done a lot of work defining lifestyle risk factors of smoking, nutrition, alcohol and physical activity (SNAP) as a separate entity to "social history". And the notion that risk factors and social history are distinctly different is supported by my own clinical practice. Historically from my experience though, comments regarding smoking, alcohol etc were often found within a social history heading but this practice is certainly not considered best practice. Refer to the RACGP Standards for general practices (4th edition), in its description of social history as: *The recording of recent important events covers a wide range of social events of importance to the patient, which may include changes in accommodation, family structure (eg. birth of children, separation or divorce, death of family members) and employment. Recent important events can alter patient preferences and values and the context of care.* Other social history factors that would be important to record are things such as whether the person is a carer for someone or whether they themselves have a carer, their employment status, Smoking, alcohol and diet on the other	rather than social history.	

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					hand are not a social history but a health risk factor and given their importance should be elevated to be within a dedicated section as the RACGP have advocated. Refer to the RACGP SNAP guide which details how primary care clinicians can work with patients on the lifestyle risk factors of smoking, nutrition, alcohol and physical activity. Previous work with the RACGP on drafting a simple model of what risk factor details to capture included this: - Category of risk (smoking, alcohol, nutrition, physical activity, substance abuse, unsafe sex, etc – the WHO has identified a few others such as unsafe water, sanitation and hygiene) - At risk? (yes / no) - Description (free text) Note: There is significant detail on Risk Assessment in the FHIR STU3 Risk Assessment Resource.		
	Camilla Wiberg Danielsen, DK				Ge	I have had a look at the Patient Summary Standards Set and think that this is a very good initiative that I am sure will be helpful for us. I especially like that it is a live document that will be reviewed and updated periodically		No response necessary
	Camilla Wiberg Danielsen, DK				Te	When referring to the clinical data, information or content of for instance a patient record I would suggest that the guidance document uses the preferred terms and definitions from the standards in the Standard Set or makes a reference to these e.g. ISO 13940 – System of concepts to support continuity of care (ContSys).		The use of terms is designed for readability o the document and does r reflect any specific standards. For further information, please consu

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					An example is 3.0 Patient Summary Standards Set Dataset where the JIC Care Sections are called for instance Patient and Contact Person/Legal Guardian/Next of Kin. In ContSys the preferred term for *patient* is 'subject of care' and *contact person* is 'next of kin' and they both have descriptions that should be the exact meaning used in in the Dataset so that the JIC Core Data Elements are attributes to this concept.		SKMT
	Jeremy Thorp UK	P2	ToC		ge	Overall I like the structure and can see how this might be re-usable.	Two thoughts: - Can we separate the introduction from ch 2 – 8 (so ch 1 is generic) - Can we add a short section that describes what might be needed to produce an extended form dataset ?	It is correct that there generic aspects incorporated in to this firs version of a SS for ease reading. The generic aspects will be extracted form a reference docume for future SS work and others to use. We will be happy to add short section re an extended dataset in the next version based on feedback from usage.
	Jeremy Thorp UK	P7	1	1	Ge	I understand why this is guidance (and agree) but who produces the underlying standard and where is it published ?	[apologies if I missed it, but this would be helpful to know]	This is in the tables
	Jeremy Thorp UK	P7	1	1	ge	Similarly, who is the audience for each section ?	Implementors will typically start at ch 6 for instance	This is covered in the introduction, section 1.4
	Jeremy Thorp	P16	2	2	Ge	In Joint Action work we have re-used the Antilope structure for defining use cases – it wasn't clear if	Can references be added (if applicable)	The team considered a number of Use Case

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	UK				a specific structure was being used here or not		templates and opted to u the ISO standard as referenced. Antilope will b referenced as one considered
	Jeremy Thorp UK	P21	2.7	ge	I would expect to see confirmation of patient identity plus confirmation and authentication of health professional id – otherwise I can't see how we can be assured of appropriate authorisation and access	Either include or – if out of scope – explain why	This is meant in 2.7 no.1 but has been updated to include 'confirmation'. Accepted
	Jeremy Thorp UK	P29	3	3	ge	Who would be expected to carry out this step ?	I think this is important for expectation management	Out of scope of the guidance provided in this PSSS
	Jeremy Thorp UK	P29	3.1		ge	Does Required include / imply "null flavour" ?	For instance, if the allergy field is null, this means there are no recorded allergies for this patient	Out of scope of this work. We have defined the data element but not the associated value sets
	Jeremy Thorp UK	P44	4	4	Ge	The categorisation framework is generic, and could usefully be added to comment no. 1 above	But … equally the European ReIF and US ONC framework are alternatives: can we add a bit of explanation about how / when the JIC version was produced ?	This is covered in detail i the referenced categorization document.
	Jeremy Thorp UK	P44	4.1		Ge	Similarly, the principles for standards identification and assessment have been developed elsewhere (e.g. in epSOS) and could usefully be referenced		The team would request this information so that it can be added to the next version of the PSSS
	Jeremy Thorp UK	P68	6	6	ge	I have a major question on this section: - Who / what is to be assessed? It could be any / all of - The supplier	At present it reads like the first two or – possibly – just the second It may be that what is needed is a separate section between 7 and 8 on audit / assessment of health provider and application implementation,	Correct, this was designe based on the application. The additional audit/assessment aspect can be picked in an information sheet in the

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					- The application - The healthcare provider - The healthcare provider's implementation of the application	but I would point to the audit process used by epSOS and now in CEF. Knowing the application meets the specification is necessary but not sufficient for ensuring safe interchange of data	future based on a post implementation audit.
	Jeremy Thorp UK	P87	8	8	Ge	I like the idea of the implementation sheets but was not clear who produces these or how many are expected for each standard	For instance, each implementor could usefully complete a sheet outlining details of optionality in their instance – to serve as a reference point for testing, audit and (if necessary) subsequent checking	The plan is that Implementation sheets be added and organisations will be identified to help others.
	Catherine Chronaki HL7				Ge	The process/workflow presented makes assumptions about the health system that may not apply globally, e.g. GP as gate keeper. Incidentally, we are considering referencing the PSSS document in Trillium II as it pertains to unplanned care and we would like to neutral to the health system and rather person-centered.	A possible solution is to separate the clinical content considerations from the process/workflow aspects. Indicate this limitation and present alternative process(es) /workflows as supported by specific systems around the world (?) Provide examples from other health systems (?) Alternatively, allow the option where the patient or next of kin carries the patient summary Looking at the individual as the holder/carrier/steward would raise provenance questions and would certainly change the basic use case.	The document currently references 1 scenario for the Use Case. Future editions could include additional scenarios against the Use Case and we would welcome these form different health systems.
	Eric Rose, M.D., IMO	n/a	n/a	n/a	ge	The JIC and its member SDOs is to be commended on this initial work product and for their commitment to coordinating efforts and practices in the use of technical standards in healthcare. The Patient Summary Standards Set contains a great degree of useful information and numerous valuable insights.	I realize that the document was explicitly not intended to be a formal implementation guide; What I'm suggesting is that, in future revisions, there be a movement in that direction, based on the real-world experience of relevant stakeholders.	Because this work covers multiple standards, guidance is deliberately non-prescriptive. Through the use of the information sheets we can obtain further information based on implementation experience and make the

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					The greatest challenge I see to successful use of this document, in its present form, is that it seems to lie in a somewhat gray area between general guidance and a formal Implementation Guide. While it may serve as a useful starting point for entities who wish to start exchanging patient summaries and aren't sure where to begin, a more fully-specified guide would go farther to enabling successful implementations.		available to further enhance the guidance.
	Eric Rose, M.D., INO	n/a	n/a	n/a	ge	It is a bit unclear to what degree, and in what manner, the Patient Summary Standards Set overlaps with, or resolves gaps in, other efforts to achieve the same goal. The Information Sheet " International Patient Summary projects from 2009 to 2020" provides some very useful background information, but it isn't clear to what degree the JIC's proposal dovetails with these other efforts, or other similar efforts not mentioned (like the U.S.' "Interoperability Standards Advisory".	If possible, some expansion on this issue in the introduction and/or referenced information sheet would be helpful.	This work used the US Interoperability Standards Advisory as an informatic source, as we used other national and international source. It is felt that historical references are useful for background onl and so has included curre and work in developmen has been referenced for which the outcomes will b included in future version of this document e.g. HL7 IPS, CEN IPS, ISO Transnational health record.
	Eric Rose, M.D., IMO	n/a	n/a	n/a	te	One issue I didn't see addressed is that the patient summary may come from an EHR system that uses a different language from that used by the recipient. In such cases, the ability for coded data to be displayed in multiple languages could	Incorporate considerations about cross-language capabilities in the document.	Patient language codes, and document language codes are included. Displ of information in multiple

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					be critical to making the data comprehensible to the treating provider.		languages is out of scope
	CIHI			ge	Support the use of User Story to describe the application of the use case in a real world scenario		No response required
	CIHI			ge	While there is general support for the data set's selection of elements and associated standards, there are potential issues with its size and scope. For example, the number of elements is quite large and it may be difficult for Primary Care clinicians to collect complete sets for required elements. Also, there is no mention of interRAI standards in the document that for example can be used to specify results of the functional assessment of the patient rather than providing a diagnosis		The data items provides detail of required and optional and covers 1 scenario. There will be multiple ways of covering which can be adjusted accordingly. InterRAI is a tool and not an international health informatics standard.
	CIHI			ge	Support the principles for standard identification and assessment described and used to select standards for PSSS.		No response required
	CIHI			ge	Strongly support the use of information sheets as a concise method to assist with informed decision making		No response required
	CIHI			ge	Suggest simplifying the language used in section 1.0 to make it easier to understand for the broader audience the paper is focusing on		The team have ma considerable effort to ma this readable and v continue to do each relea so based on feedback
	CIHI	Line 4	1.7	Paragraph 4	ed		Suggest changing ***underway a new project*** to ***there is a new project underway***	Accepted, updated
	CIHI	Line	1.8.6		ed	Potentially broken/missing link		Accepted, updated

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		6					
	CIHI		2.1	Paragraph 1	ed	Colour of text is different from the rest of the document	Change colour for consistency	Accepted, updated
	CIHI	Line 3	2.1	Paragraph 2	ed	Missing closing quote after word ***activity***	Add closing quote (‘activity’)	Accepted, updated
	CIHI	Line 9	2.1	Paragraph 2	ed	Suggest adding explicit in text references to the abbreviations (e.g Technical Report (TR)) for better readability	Consider spelling out the abbreviation TR as the reference to the term *Technical Report* is ambiguous	Accepted, updated
	CIHI		2.11.2	Figure 3: Activity Diagram	ed		Suggest including a higher resolution image for better readability	Accepted, updated
	CIHI		2.12		te	Since the focus is on both primary care and acute care systems we recommend including primary care related issues to this section	Suggest adding following points to the section 2.12 • Standardization of data in primary care (PC) sector • Prevalence of free text non-standardized records in PC environment • Maturity of EMR systems and variation in utilization of advanced functionality of such systems (including integration and exchange of data with hospital EHRs)	Accepted, updated
	CIHI	Line 8	3.0	Paragraph 4	ed	Link is potentially broken/missing		Accepted, updated
	CIHI		3.1.2	Table 7: Clinical data items	ed	Suggest checking for small inconsistencies in font colour across the document	different colour of font in “Required or Optional” column	Accepted, updated

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	CIHI		3.1.2	Table 7: Clinical data items	ed	p.37, Problems – problem code …"SNOMED preferable". p.38, Procedures – procedure code … "SNOMED preferable". In some countries SNOMED CT has not yet been comprehensively adopted in primary care. As such, commenting that "SNOMED (is) preferable" for certain data elements (above) while not providing the user with other options (e.g. ICD-10) takes away from the usability of the document.		We have made these statements based on advice from our clinicians
	CIHI			Table 9		We note that on p.55, ICD-10: 2016 is listed as an alternate semantic-related standard that is "usable and for certain use cases ICD-10 does not have needed granularity". However, it is difficult to ascertain whether this comment refers to the specific use case for the PSSS.	Suggest ""usable but for certain use cases ICD-10 does not have needed granularity". Suggest indicating whether it applies to the specific use case associated with the PSSS.	Accepted, change made
	CIHI		Information sheet: Life-Cycle of Patient Summaries	Figure 1: The patient Summary Record life-cycle	ed		Suggest including a higher resolution image for better readability	Accepted, updated
	JEfron, WCI		1.3		ge	One of the main factors defining success will be the extent to which providers share the information in an interoperable manner such that the Patient Summary may be built. A paragraph speaking to this at the beginning of the document would be useful.		We aim to provide details standards to achieve interoperability. Wording reinforced. Accepted
	JEfron, WCI		1.4		ed	Add "Patient" to the list titled "This Standards Set has been developed with a number of stakeholders in mind"		Accepted, updated

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	JEfron, WCI	1.4		ed	With the list of stakeholders followed by the Table 1, consider listing which of the 4 Table 1 category(ies) each stakeholders occupies		This will be considered fo future versions based on feedback
	JEfron, WCI	1.x		ed	The phrase “standards, standards artefacts and profiles” and its individual components are used throughout section 1 without defining what the 3 things are. While well understood by many, to ensure everyone uses the same definition, a brief overview would be worthy in section 1 rather than waiting for Section 5.		This has been clarified ar changes made in initial paragraph. Accepted
	JEfron, WCI	1.8.6		te	At least for me and I am using Adobe Reader DC		Accepted, updated
	JEfron, WCI	2.11		ge	The scenario doesn’t identify how the patient information is obtained when the patient doesn’t have a medication label when entering the acute provider. The ability to access information on the patient without either medication label or physician contact information likely is out of scope. Consider adding this to section 2.3.2		This is the way the use case was defined and we are happy to receive additional scenarios that may apply.
	JEfron, WCI	2.11.2		te	The text that is found in Figure #3 is not clear		Accepted, updated
	JEfron, WCI	2.11.5		ge	The text that is found in Figure #4 is not clear. Also I am not certain this figure it adds much more than Figure #3.		This is part of the ISO standard on which the us case was formatted and i included for information only
	JEfron, WCI	2.6 and 2.11.4		Ge	Consider providing a timestamp each time the unit is persisted		This is assumed in the document metadata
	JEfron,	2.11.4		Ed	In Item #5, do you mean “persisted” rather than		Accepted, change made

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	WCI					“persistent”?		
	JEfron, WCI		3.0		te	At least for me and I am using Adobe Reader DC		Accepted, updated
	JEfron, WCI		3.1.x		Ge	Consider adding a column that explicitly states the “applicable standards” and/or “preferred standard”.		This SS does not include any statements of preference
	JEfron, WCI		4.5		Ge	The usage of underlined content in this section is confusing		In this instance the underlining has been use as an additional form of emphasis
	JEfron, WCI		5.x		ge	The text that is found in these figures are not clear.		Accepted, updated
	JEfron, WCI		6.1		Ed	Consider explicitly stating what CASCO stands for		Accepted, updated
	JEfron, WCI		6.5.1		Ed	Consider explicitly stating what RSP stands for		First reference is now full enumerated Accepted
	JEfron, WCI		6.5.1		Ed	First sentence is confusing starting “The basic building block…” Not sure what the basic building block.		This is part of the RSP ar will be edited as such Accepted
	JEfron, WCI		6.5.1 & 6.5.2		Ed	A number of run-on sentences making point less clear than desired.		Noted and will be update based on feedback/usage
	JEfron, WCI		N/A		Ge	Consider adding a number examples of a Patient Summary that conforms with the spec		This will be included in information sheets in the future as the PSSS is use
	JEfron, WCI		Page 95	Figure 1 (Patient Summary		Extremely hard to read Figure 1		Accepted, updated

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			Record Life Cycle)				
	David Rowlands			Ge	To me, there is confusion in the articulation of the requirements being met, and the use case, which is likely to confuse readers who are not practiced in working with such documentation (e.g. many of the people who will actually use the document, since the standards referred to will be used by the techies, while this seems to me in significant part a management-oriented document – especially clinical management).	I think it would read better to articulate, as early as possible, that the standards set is designed to meet the needs of both planned and unplanned health care across the health-care continuum, and that the use case (an unplanned episode) is presented to illustrate how the set meets such a scenario. This of course begs the question – why is there not a planned care use-case as well?	Additional scenarios will b considered for future versions based on feedback
	David Rowlands			Ge	I think the explicit decision to exclude patients viewing their own summaries is a huge mistake. To me, it sends all the wrong messages for contemporary care, and sends a signal that the standards community is focused on yesterday's care models. There is ample evidence around that where patients can access their own records (e.g via portals), they do so. Often, summaries are accessed much more by patients than by clinicians. And there is also ample evidence of better outcomes and more efficient processes where patients are engaged in this way. So, to deliberately exclude this scenario seems to me grossly at odds with health care trends, and greatly reduces the document's utility. If I were a health care or health informatics manager receiving it, I would straight away say its scope does not fit our future, and I would either just shelve it as a "nice to know, may be useful some time", or ask someone to review and extend it. And the purpose of such as set is that not everyone has to do their own (likely inconsistent)	So I would strongly urge the JIC to re-consider this scope limitation, and take the relatively small extra steps of addressing these requirements, and including a 3rd use case – include use cases for examples of unplanned care, planned care and patient access.	Additional scenarios will b considered for future versions based on feedback

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					reviewing and extending.		
	Alastair Kenworthy, MoH, NZ				The document is certainly of practical use, ie I could see myself actually referring to it, quoting it, applying parts of it		No response required
	Alastair Kenworthy, MoH, NZ				The patient summary use case is a good choice (even in a country where we don't have the same cross-border issues as some others)		No response required
	Alastair Kenworthy, MoH, NZ				The detailed data set specification is very useful and I'm glad to see the liberal references to FHIR and SNOMED value sets		No response required
	Alastair Kenworthy, MoH, NZ				Some of the standards referenced are yesterday's news, e.g. HL7 v3 and IHE profiles		These standards are still high use across the worlc
	Alastair Kenworthy, MoH, NZ				The conformity assessment framework is useful		No response required
	Alastair Kenworthy, MoH, NZ				The lists of standards are useful (even when some of the standards themselves are out of date)		No response required
	Alastair Kenworthy, MoH, NZ				Perhaps the document could be published with a liberal Creative Commons licence that allows copy and paste		Accepted, updated

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