**Representing Problem Lists in FHIR**

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# Origin of Problem Lists

50 years ago, in March 1968, [Larry Weed](https://en.wikipedia.org/wiki/Lawrence_Weed) wrote that '[*a complete and accurate list of problems should play a central part in the understanding and management of patients*](https://books.google.co.uk/books?id=Ao-ZBQAAQBAJ&pg=PA27&lpg=PA27&dq=a+complete+and+accurate+list+of+problems+should+play+a+central+part+in+the+understanding+and+management+of+patients&source=bl&ots=k_pRjV9ibz&sig=8fRuN0o3dmIz5OeI1iXBE2-1C68&hl=en&sa=X&ved=0ahUKEwiFmZ7YlOzYAhWCUlAKHQpwDsAQ6AEIKTAA#v=onepage&q=a%20complete%20and%20accurate%20list%20of%20problems%20should%20play%20a%20central%20part%20in%20the%20understanding%20and%20management%20of%20patients&f=false)'. Back then, clinical documentation didn't typically follow this revolutionary ideal; Weed vividly described the consequences in his seminal [1971 Grand Round](https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&cad=rja&uact=8&ved=0ahUKEwjA4PaDlezYAhVHL1AKHeGACqcQtwIIKTAA&url=https%3A%2F%2Fwww.youtube.com%2Fwatch%3Fv%3DqMsPXSMTpFI&usg=AOvVaw1lrHRsEhg7B6u-dwfF3-ES).

Weed gave us [SOAP notes and the Problem Oriented Medical Record](https://en.wikipedia.org/wiki/SOAP_note), ideas that have guided clinical system design and development ever since. A 'current problem list' (or its first cousin, the 'patient summary') is a core component of most modern primary care systems - though its content is admittedly not *always* well curated. Despite his best efforts right up to his [death last June](https://www.nytimes.com/2017/06/21/science/obituary-lawrence-weed-dead-patient-information.html), aged 93, hospital clinicians perhaps remain to be convinced by – or empowered by technology to use - Weed's Problem List idea.

But a reasonable question therefore, is: how should FHIR carry Problem Lists or Patient Summaries?

# Problem Lists in FHIR : all problems are conditions?

The obvious (but, I hope to convince, wrong) answer is to send all Problem List items using exclusively the FHIR [Condition](https://www.hl7.org/fhir/condition.html) resource, whose [Scope Notes](https://www.hl7.org/fhir/condition.html#scope) states:

[Condition] is used to record detailed information about a condition, problem, diagnosis, or other event, situation, issue, or clinical concept that has risen to a level of concern. The condition .. could be an item on the practitioner’s Problem List, or a concern that doesn't exist on the practitioner’s Problem List. It can be a .. diagnosis .. problem .. health issue or concern.

The Condition resource further offers the Condition.category element, whose [currently suggested valueset](https://www.hl7.org/fhir/codesystem-condition-category.html#4.2.12.154.2https://www.hl7.org/fhir/valueset-condition-category.html) would divide all Conditions into being either a 'problem-list-item' or an 'encounter diagnosis' (or unstated). We might conclude from this valueset that whilst not all Conditions are necessarily also Problems, all Problems are definitely Conditions: we've come to the right place.

So, why might encoding all of a given Problem List’s ‘Problems’ exclusively as Condition resources **not** be the right approach, and what’s the alternative?

# Problems that are not conditions

A popular oversimplification of the clinical process and its documentation attempts to reduce it all to sets of signs/symptoms/findings/results (Observation) for diseases/diagnoses (Condition) that become the target of treatments/investigations/interventions (Procedure). In this naïve model, all Problems are indeed Conditions.

Out in the real world of clinical documentation and the case management thought processes it reflects, Problem or Summary Lists include many things that are neither diagnoses nor classical signs, symptoms or results. For example:

Procedures whose planning (e.g. [Colonoscopy](https://termbrowser.nhs.uk/?perspective=full&conceptId1=703993001&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104)), [cancellation](https://termbrowser.nhs.uk/?perspective=full&conceptId1=29242007&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104) or [refusal to accept](https://termbrowser.nhs.uk/?perspective=full&conceptId1=781191000000101&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104) are the cause of patient or practitioner anxiety; or whose completion always implies a clinically significant pre- or postsurgical state or diagnosis (e.g. [through-knee amputation](https://termbrowser.nhs.uk/?perspective=full&conceptId1=265736004&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104) *implies* [limb amputee](https://termbrowser.nhs.uk/?perspective=full&conceptId1=275530009&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104); [radical mastectomy](https://termbrowser.nhs.uk/?perspective=full&conceptId1=384723003&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104) *implies* [breast cancer](https://termbrowser.nhs.uk/?perspective=full&conceptId1=254837009&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104)) that may therefore not always also be separately documented.

Socioeconomic circumstances or significant life events that may influence or inform the management of current or future health needs, such as [getting engaged](https://termbrowser.nhs.uk/?perspective=full&conceptId1=54986009&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104), [eloping](https://termbrowser.nhs.uk/?perspective=full&conceptId1=302756003&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104), [trying](https://termbrowser.nhs.uk/?perspective=full&conceptId1=169449001&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104) and [succeeding](https://termbrowser.nhs.uk/?perspective=full&conceptId1=169566002&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104) in getting pregnant, [parental worrying](225640002), [family bereavement](https://termbrowser.nhs.uk/?perspective=full&conceptId1=105444006&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104), recent [travel](https://termbrowser.nhs.uk/?perspective=full&conceptId1=445000002&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104), [combat experience](https://termbrowser.nhs.uk/?perspective=full&conceptId1=224358008&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104), [retirement](https://termbrowser.nhs.uk/?perspective=full&conceptId1=105494007&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104), [carer abuse](https://termbrowser.nhs.uk/?perspective=full&conceptId1=225802003&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104), [housing](https://termbrowser.nhs.uk/?perspective=full&conceptId1=160751007&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104) and [employment status](https://termbrowser.nhs.uk/?perspective=full&conceptId1=354581000000101&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104), the [local crime rate](https://termbrowser.nhs.uk/?perspective=full&conceptId1=406133002&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104), own [criminal record](https://termbrowser.nhs.uk/?perspective=full&conceptId1=266948004&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104), [ability to access health services](https://termbrowser.nhs.uk/?perspective=full&conceptId1=160695008&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104), problems with their [financial](https://termbrowser.nhs.uk/?perspective=full&conceptId1=300704000&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104), [personal](https://termbrowser.nhs.uk/?perspective=full&conceptId1=276073003&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104), [online](https://termbrowser.nhs.uk/?perspective=full&conceptId1=1071211000000106&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104), [love](https://termbrowser.nhs.uk/?perspective=full&conceptId1=160824003&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104) or [sex](https://termbrowser.nhs.uk/?perspective=full&conceptId1=91525005&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104) lives.

Significant allergies and intolerances (e.g. to [milk](https://termbrowser.nhs.uk/?perspective=full&conceptId1=15911003&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104https://termbrowser.nhs.uk/?perspective=full&conceptId1=300912001&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104)) that explain to other clinicians viewing the record why the ‘usual’ therapy was not used, and should not be in future e.g. [injectables](http://www.ema.europa.eu/ema/index.jsp?curl=pages/news_and_events/news/2017/07/news_detail_002790.jsp&mid=WC0b01ac058004d5c1) or [inhalers](https://www.ncbi.nlm.nih.gov/pubmed/27193929) containing milk protein excipients. Leaving these less immediately visible under a separate Allergies tab of the EPR may cause them to be overlooked; promoting/duplicating these entries to the Summary or Problem list ‘front sheet’ can be clinically desirable.

Family histories of heritable conditions that at least *some* family members (e.g. [FH of Huntington's chorea](https://termbrowser.nhs.uk/?perspective=full&conceptId1=160336000&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104)) or some specific *types* of family members have (e.g. [FH hip # in 1st degree relative](https://termbrowser.nhs.uk/?perspective=full&conceptId1=759351000000104&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104)) .

Patient Summaries can go beyond Weed’s narrower definition and purpose of collating only those Problems currently being actively managed : they may include clinically significant *absences* of problems that clinicians should be aware of because they explain previous atypical diagnostic or therapeutic choices, and should similarly inform future ones. For example:

The *absence* of significant allergies and intolerances (e.g to [milk](https://termbrowser.nhs.uk/?perspective=full&conceptId1=927741000000100&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104) or to peanuts) that would otherwise prohibit avoidable exposure (e.g. entry to a school environment possibly containing peanuts in packed lunches).

The *absence* of significant family histories (e.g. [no FH of glaucoma](https://termbrowser.nhs.uk/?perspective=full&conceptId1=160267000&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104), [no FH of hearing loss](https://termbrowser.nhs.uk/?perspective=full&conceptId1=777581000000106&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104))

# Problem vs Condition : one size doesn’t fit all

The primary reason all disparate coded phenomena from a Problem List or Patient Summary can’t simply be recast as Conditions for the purposes of interoperation is the same reason each has their own dedicated FHIR resource in the first place: the Condition resource is optimised for passing diagnoses; it offers elements to qualify the diagnosis by e.g. its [severity](http://build.fhir.org/condition-definitions.html#Condition.severity), [staging](http://build.fhir.org/condition-definitions.html#Condition.stage) or disease activity (condition.[clinicalStatus](http://build.fhir.org/condition-definitions.html#Condition.clinicalStatus) active vs inactive vs recurrent) – none of which are semantically sensible properties of procedures, family histories or socioeconomic circumstances. And, of course, only the Condition resource currently offers an obvious and off-the-shelf resource element by which to annotate it as *also* a member of a problem list.

By contrast, the [Procedure](https://www.hl7.org/fhir/procedure.html#resource) resource offers up both procedure.[status](https://www.hl7.org/fhir/procedure-definitions.html#Procedure.status) values to declare where the procedure is in its act lifecycle of e.g. preparation, suspended, completed, and a procedure.[outcome](https://www.hl7.org/fhir/valueset-procedure-outcome.html) element. [FamilyMemberHistory](https://www.hl7.org/fhir/familymemberhistory.html#resource) resources may have elements for [gender](https://www.hl7.org/fhir/familymemberhistory-definitions.html#FamilyMemberHistory.gender) of the family member, their [relationship](https://www.hl7.org/fhir/familymemberhistory-definitions.html#FamilyMemberHistory.relationship) to the patient, and whether they’re [still alive](https://www.hl7.org/fhir/familymemberhistory-definitions.html#FamilyMemberHistory.deceased_x_).

These additional resource-specific elements do not become irrelevant when considering the underlying clinical phenomenon as a problem: they’re often what makes them a problem. A maternal family history of breast cancer, for example, is far more of a problem if the patient’s mother was 35 rather than 80 when she succumbed.

Jettisoning these additional elements can not only degrade but also substantially alter the clinical meaning: consider a patient whose problem is some aspect of a planned colonoscopy. Perhaps the transport challenges of getting there; whether the pre-op bowel prep will dramatically worsen the symptoms they’ve already got; whether it will be a painful or embarrassing procedure.

Cast as a Procedure, the ‘planned’ aspect of the problem procedure could be captured as:

procedure.Code = 73761001|[Colonoscopy](https://termbrowser.nhs.uk/?perspective=full&conceptId1=703993001&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104) (procedure)|   
procedure.[status](https://www.hl7.org/fhir/procedure-definitions.html#Procedure.status) = preparation

…but if we recast it as a Condition resource then, although we *can* now capture its membership of the problem list:

condition.Code = 73761001|[Colonoscopy](https://termbrowser.nhs.uk/?perspective=full&conceptId1=703993001&edition=uk-edition&release=v20171001&server=https://termbrowser.nhs.uk/sct-browser-api/snomed&langRefset=999001261000000100,999000691000001104) (procedure)|   
condition.Category = problem-list-item

…we’re forced to jettison the fact that it’s planned to occur in the future.

But this jettisoning has an important consequence: the *default* interpretation of an unqualified procedure code in SNOMED CT is as a procedure that *has* happened. Within the problem list encoding, the planned colonoscopy thus becomes now technically indistinguishable from entries recording a colonoscopy that has been performed. Going forward, it must either be interpreted in that default but altered sense (so, we’ve just changed the record..) or, when cast as conditions, all procedures must be interpreted as inherently ambiguous in respect of which stage of their lifecycle the problem occurred at, from requested through planned, cancelled to completed.

Whilst it would technically be possible to add an extension to the Condition resource, providing an additional element to replicate e.g. the semantic s of procedure.status, the approach is clearly silly: in order to achieve the same for all flavours of problem that aren’t conditions, the condition resource itself would need to grow a confusing array of extension elements, with the use of many being dependent on the type of concept passed as condition.Code.

# Problem Lists as a FHIR List of mixed Resources

Fortunately, there is another approach that avoids the above problem, and its one that FHIR already explicitly supports as an option:

Each item within a Problem or Summary list should be represented using its appropriate class of FHIR resource and all its optimised elements as appropriate (Condition, Procedure, Observation, FamilyMemberHistory, AllergyIntolerance etc). The resulting set of different resources is then wrapped up within a [List](https://www.hl7.org/fhir/list.html) resource where list.code = problems, a value already within the example valueset for that element.

Using the above approach, the condition.Category = problem-list-item pattern becomes redundant. The notion of ‘problem’ becomes an annotation on the list as a whole, not separately on each of its members.

For the reasons set out above, therefore, I would recommend that 'problem-list-item' be routinely removed from the from the valueset for the Condition.category element.

More radically, it may in fact be appropriate to profile out the entire element: the surviving value of 'encounter diagnosis' suggests a goal of partitioning the set of all true Conditions into those explaining or otherwise justifying the current encounter, and those incidental to it - possibly but not necessarily predating it. This relationship – between an encounter and its diagnosis – is however already and more sensibly representable via Encounter.diagnosis.condition, and so a reciprocal but incomplete reference back to the encounter entity itself on the part of the Condition is redundant.