Finnish PHR Profiling Guidelines

My Kanta Pages PHR

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Change history

Versio	Muutos	Tekijä	PVM
1.0	First published version	Kanta services	20.11.2017
1.1	CodeSystem, ValueSet and Questionnaire guidelines added	Kanta services	9.5.2019
1.2	Identifier element (Business Identifier)	Kanta services	17.5.2019
1.3	Using of language element in Questionnaires (Chapter 5) and valueQuantity in Observation (Chapter 15)	Kanta services	14.8.2019
1.4	Updated document to cover R4 requirements	Kanta services	07.08.2020

Contents

1 Introduction

This document describes the profiling guidelines for Finnish PHR. Finnish PHR is also known as My Kanta Pages Personal Health Record (Kanta PHR). You can find more information at Kanta pages (kanta.fi).

2 HL7 FHIR profiling guidelines

Profile implementers are expected to be familiar with the HL7 FHIR profiling guidelines (hl7.org).

3 Generic profiling guidelines

All resources used in the Finnish PHR SHALL have a profile (including the contained resources)**.** For interoperability reasons the profile SHALL have strict data structure requirements:

- Sub-elements of the resource, that are not used, SHALL NOT be disabled. The main lever elements that are not used in profile SHALL be disabled by setting cardinality to 0..0. Please note that changes can be made to profiles is there is a need for that.
- Value set binding SHALL be ”extensible”
- Value unit SHALL have a fixed value

4 Snapshot and differential of Structure Definition

Each profile and extension SHALL contain both the snapshot and differential statements. Read more about the snapshot here (hl7.org) and more about the structure definition here (hl7.org).

5 Elements and properties for all profiles

Resource.language SHALL be defined in all profiles except of Questionnaires. If the questionnaire has different language versions, the language element isn’t mandatory.

- Resource.language SHALL be mandatory 1..1. Read more about the languages valueset (hl7.org).

- Value set binding SHALL be required

- Read more about the elements (hl7.org)

Resource.meta.profile SHALL be defined in all profiles. Resource.meta.profile SHALL be mandatory 1...* and the element SHALL contain one mandatory 1..1 slice called fiphrProfile. That slice SHALL refer to the Finnish PHR profile and it is used to validate resource instance. In addition to this, other profile references can be used in resource instance, but the resource instance will not validate against it in Finnish PHR.

When the profile element is sliced, the discriminator must be set. The discriminator contains two fields: type and path. The type SHALL be set to value and the path SHALL be set to $this.

Slicing is also used in codeableConcept data type elements, this is described in more detail in chapter 14.

- Read more about the meta-element here (hl7.org) and more about slicing here (hl7.org)

6 Format of the Structure Definition, Value Set, Code System

Profiles, extensions, value sets, and code systems SHALL be in JSON format when uploaded to the Finnish PHR platform.

7 Documenting the profile and the elements of the profile

Profile SHALL include all mandatory elements of the StructureDefinition

- Id (logical id), url (logical url), name, status, etc

Profile SHALL include also these elements of the StructureDefinition

- title

- description

- experimental (in testing phase set to value ”true”)
- FHIR Version (fhirVersion) the profile targets
- Publisher (Profile creator in the sandbox environment)

Profile element definitions contain elements describing the element, why it exists, and how it is used. Read more about elementDefenition here (hl7.org) :

- these elements include: short, definition, comment, requirements,
- all modifications to the FHIR resource’s base documentation of these elements SHALL start with tag ”FinnishPHR:”
- For example, the "category" element of the Finnish PHR Vital Signs profile:
    - definition (no modifications to the base definition): "Classification of type of observation."
    - comment (Finnish PHR specific modification): "FinnishPHR: Only value vital-signs valid in FinnishPHR (defined by the value set). More fine-grained filtering can be performed using the Observation.code."

8 The naming of the artefact elements

Note! This guidance is for the profiles that are in the official development process for the data content of the Finnish PHR. In a testing phase of the profiles, which are outside of the official development process, the identifier “fiphr” SHALL not be used in the artefact naming.

Artefact

= structure definitions: profile, extension

= value set, code system

= Questionnaire

8.1 Artefact id (Resource.id)

- id SHALL be unique
- id SHALL start with identifier "fiphr"
- id SHALL contain the artefact name (for example “bloodglucose”)
- Non-normative profiles, extensions, and Questionnaires SHALL contain the used version of FHIR, now in R4 phase ”R4”. NB! Does not apply to normative resources! Read more about normative resources (hl7.org)
- structure definitions SHALL contain identifier “sd” after “fiphr”
- extensions SHALL contain identifier “ext” after “fiphr”
- value sets SHALL contain identifier ”vs” after ”fiphr”
- code systems SHALL contain identifier ”cs” after ”fiphr”
- •questionnaires SHALL contain identifier ”qu” after ”fiphr”
- all the parts of the id SHALL be separated by hyphen (“-“)
- examples:
    - normative profile: fiphr-sd-bloodglucose
    - non-normative profile: fiphr-sd-medicationstatementR4
    - extension: fiphr-ext-activesymptoms- r4
    - value set: fiphr-vs-confidentiality
    - code system: fiphr-cs-consentcategory
    - Questionnaire: fiphr-qu-DANPSS1- r4

    {

    "resourceType": "StructureDefinition",

    "id": "fiphr-sd-bloodglucose- r4**",**

    …

8.2 Artefact title (StructureDefinition.title, ValueSet.title, CodeSystem.title)

- ” A short, descriptive, user-friendly title for the structure definition. / This name does not need to be machine-processing friendly and may contain punctuation, white-space, etc. Applications don't have to use this name, but can always fall back to it. The title also corresponds to the label for the root element.”
- Title SHALL contain ”Finnish PHR”
- Title SHALL contain descriptive artefact name, for example ”Blood Glucose”
- Title SHALL contain the type of artefact (”profile”, ”extension”, ”value set”, ”code system”)
    - NB! These instructions related to the title DO NOT apply to Questionnaires.
- example:

  ” Finnish PHR Blood Glucose profile”

  {

  "resourceType": "StructureDefinition",

  …

  "title": " Finnish PHR Blood Glucose profile ",

8.3 Artefact name (StructureDefinition.name, ValueSet.name, CodeSystem.name, Questionnaire.name)

- Name SHALL contain “FIPHR”
- structure definitions SHALL contain identifier “SD” after “FIPHR”
- extensions SHALL contain identifier “EXT” after “FIPHR”
- value sets SHALL contain identifier ”VS” after ” FIPHR”

- code systems SHALL contain identifier ”CS” after ” FIPHR”
- questionnaires SHALL contain identifier ”QU” after ” FIPHR”
- artifact SHALL contain the artefact name (for example “bloodglucose”)
- Non-normative profiles, extensions, and Questionnaires SHALL contain the used version of FHIR, now in R4 phase ”R4”. NB! Does not apply to normative resources! Read more about normative resources (hl7.org)
- examples:
    - Normative profile: FIPHRBloodglucose
    - Non-normative profile: FIPHRMedicationStatementR4
    - extension: FIPHREXTActivesymptomsR4

8.4 Artefact url (StructureDefinition.url, ValueSet.url, CodeSystem.url, Questionnaire.url)

- url SHALL start with http://phr.kanta.fi/
- Profiles SHALL contain specifier ”StructureDefinition” and the artefact id:
    - example: http://phr.kanta.fi/StructureDefinition/fiphr-sd-bloodglucose
- Extensions SHALL contain specifier ”StructureDefinition” and the artefact id:
    - example: http://phr.kanta.fi/StructureDefinition/fiphr-ext-activesymptoms-r4
- Value Sets SHALL contain specifier ”ValueSet” and the artefact id: http://phr.kanta.fi/ValueSet/

  - example: http://phr.kanta.fi/ValueSet/fiphr-vs-confidentiality

- Code Systems SHALL contain specifier ”CodeSystem” and the artefact id:
  - example: http://phr.kanta.fi/CodeSystem/fiphr-cs-consentcategory

- Questionnaires SHALL contain specifier ”Questionnaire” and the artefact id and the major version of the Questionnaire:
  - example: http://phr.kanta.fi/Questionnaire/fiphr-qu-DANPSS1-r4-v1

- **NB!** The simplifier cannot handle multiple profiles on the same URL correctly, even if they are in different projects -> The data content proposer should add a “-draft” to the end of the URL when exporting it to its own project.

{
"resourceType": "StructureDefinition",
…
"url": "http://phr.kanta.fi/StructureDefinition/fiphr-sd-bloodglucose ",
…

9 Value set binding of the coded elements

All coded elements in FHIR profiles SHALL be “binded” to Value Set with value set binding (ElementDefinition.binding.valueset)

- value set binding strength SHALL be extensible (ElementDefinition.binding.strength)
- read more about terminology here (hl7.org).

10 Choice of data types

- for example effective[x]: dateTime / Period -> effectiveDateTime
- read more about the choice data element here (hl7.org).

11 Identifier element (business identifier)

Business identifier SHALL be mandatory 1..*. At least one of the identifiers SHALL be globally unique (e.g. an uuid as the value and 'urn:ietf:rfc:3986' as the system).

If, because of some technical problem, the client doesn’t get operation outcome message from PHR after create and therefore doesn’t get logical id of the resource the client can use this business identifier to make conditional create call to phr to make sure that the resource has been stored.

11.1 Subelements of the identifier

- Use of the identifier SHALL be optional and the code 'official' SHALL be only used if the given identifier value is truly globally unique (e.g. an uuid as the value and 'urn:ietf:rfc:3986' as the system, binding strength required).
- System of the identifier SHALL be mandatory 1..1.
- Value of the identifier SHALL be mandatory 1..1 and at least one of the identifiers SHALL be truly globally unique (e.g. an UUID as the value and 'urn:ietf:rfc:3986' as the system).
- read more about the identifier here (hl7.org)

12 Aggregation of the references

In reference to another resource, aggregation defines how the resource is or can be aggregated

- Type of the aggregation (ElementDefinition.type.aggregation) SHALL be defined
- If the referenced resource can be stored in the Finnish PHR as an independent resource, type of the aggregation can be ”referenced”
- If the referenced resource can be only contained, type of the reference SHALL be ”contained”

- read more about the aggregation here (hl7.org).

13 Resource reference subelements

- Reference.reference SHALL be mandatory 1..1

- read more about the references here (hl7.org).

14 Coding (+ codeableConcept) data type element and subelements

14.1 CodeableConcept

R4 profiles allow the usage of multiple codes: the profile defines one required code element which contains fixed values for code and system. In addition to this element, it is allowed to use other code elements as well. This element can contain code from any codesystem. NB! If multiple codes are used, they all SHOULD have the same semantic meaning as the mandatory code. More details are given in chapter 14.3.

- codeableConcept.coding
    - SHALL be mandatory 1..*
    - if not mandatory, the optionality SHALL be justified

14.2 Coding (+ CodeableConcept.coding)

- coding.system SHALL be mandatory 1..*
- if the value set binding defines only one code system, the system SHALL be fixed
- coding.code SHALL be mandatory 1..1
- if the code could be fixed, the fixed code SHALL be used
- coding.display SHALL be mandatory 1..1

- read more about codeableConcept here (hl7.org) and read more about coding here (hl7.org).

14.3 Slicing in coding data type element

Slicing is a FHIR feature which is widely used in coded elements in Finnish PHR. With slicing, it is possible to split elements into sub-elements and all sub-elements may include separate constraints. When using slicing, definitions SHOULD be read closely. Read more about HL7 definitions (hl7.org). Sliced element contains always at least one mandatory slice in Finnish PHR.

- Example: Observation.code.coding element includes a mandatory slice called fiphrCode. In addition, there is an optional slice that can be used with different codesystems. FiphrCode SHALL always be used

When the element is sliced, a discriminator must be set. The discriminator contains two fields: type and path. Values of these fields are used to identify the slice and the slices SHALL be separated from each other with it.

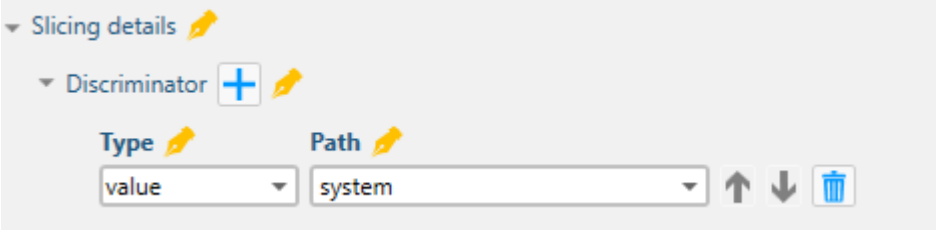

Figure 1 Example of a discriminator in Observation.

Figure 1 is from Observation.code.coding element and it uses Observation.code.coding.system's value to identify and separate slices. Read more about slicing from profiling academy (simplifier.net).

15 Quantity data type element and subelements

- Quantity.value SHALL be mandatory 1..1
- Quantity.unit SHALL be mandatory 1..1
    - unit SHOULD be fixed when applicable

- If the resource is an observation, unit SHALL be fixed
- If the unit can be coded in UCUM, it SHALL be a UCUM unit
- when using UCUM and there is not needed unit, unit gets default unit 1.

- Quantity.system SHALL be mandatory 1..1
- If the resource is an observation, system SHALL be fixed
- If the unit can be coded in UCUM, the system SHALL be fixed to UCUM (read more about UCUM here (unitsofmeasure.org))
- Quantity.code SHALL be mandatory 1..1
  - code SHOULD be fixed when applicable
  - if the resource is an observation, system SHALL be fixed
  - if the code can be coded in UCUM, it SHALL be fixed to UCUM unit
  - when using UCUM and there is not needed code for unit, code gets default unit 1.
- read more about quantity here (hl7.org).

16 Base profile

If there is defined a base profile for other profiles, the abstract element of the base profile SHALL be set to value “true”(the resource instance referencing to base profile SHALL not be stored in the Finnish PHR). Read more about abstract here (hl7.org).

17 Extensions

If there is need for an extension, first SHALL be checked if there is a suitable existing extension (FHIR, national etc.)

If there is no suitable existing extension, then the extension can be defined with extension element. The definition of the extension SHALL follow rules defined in FHIR. Read more about extensions here (hl7.org).

17.1 Finnish PHR Application information extension

Finnish PHR Application information extensio SHALL be added to the profile with cardinality 0..1 (Information about the application that created the resource instance which is generated by Finnish PHR)

18 ValueSets

A ValueSet contains a set of codes from one or more code systems, to be used in a particular context (Read more about valuesets here (hl7.org)).

A ValueSet resource SHALL include at least the following elements:

- id (follow the instructions in chapter 8 Naming of the artefact elements)
- url (follow the instructions in chapter 8 Naming of the artefact elements)
- version
- name (follow the instructions in chapter 8 Naming of the artefact elements)
- title (follow the instructions in chapter 8 Naming of the artefact elements)
- status
- experimental (in testing phase set to value ”true”)
- date
- publisher
- description

19 CodeSystems

A CodeSystem describes the existence of a code system and its key properties, and how the codes are understood (Read more about codesystems here (hl7.org)).

A CodeSystem resource SHALL include at least the following elements:

- id (follow the instructions in chapter 8 Naming of the artefact elements)
- url (follow the instructions in chapter 8 Naming of the artefact elements)
- version
- name (follow the instructions in chapter 8 Naming of the artefact elements)
- title (follow the instructions in chapter 8 Naming of the artefact elements)
- status
- experimental
- date
- publisher
- description
- caseSensitive
- content

20 Questionnaires

All Questionnaires SHALL conform to the Finnish PHR Questionnaire profile.

In addition, for display or question items the item.text is mandatory (not mandatory for group items).

21 Observation specific guidelines

In the Finnish PHR, if the category of the observation is vital-signs, the profile SHALL be derived from the Finnish PHR Vital Signs base profile

- NB! If there is a FHIR a profile for Observation under vital signs category, the profile defined SHALL be conformant to FHIR profile.

Note, that Finnish PHR has multiple base profile options for the observation profile. These base profiles can be found from Finnish PHR implementation guide (simplifier.net)

21.1 Observation grouping

When using Observation.component, defenitions described here (hl7.org) SHOULD be read

22 Examples

For each profile there SHALL be also an example resource instance in JSON format. The example resource instance demonstrates how the data elements are used.

There SHALL be an example of minimum data content and an example of maximum data content.

Each example SHALL contain narrative (instructions what the narrative SHALL contain)

- example resource instances SHALL refer to a profile by including a meta reference to profile's URL:

"meta": {

"profile": [

" http://phr.kanta.fi/StructureDefinition/fiphr-sd-bloodglucose "

```
    ]

}
```