

Finnish PHR Profiling Guidelines

My Kanta Pages PHR

17.5.2019 Kanta Services



Change history

Version	Change	Author	Date
1.0	First published version	Kanta services	20.11.2017
1.1	CodeSystem, ValueSet and Questionnaire guidelines added	Kanta services	9.5.2019
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Contents

1	Introduction	4
2	HL7 FHIR profiling guidelines	4
3	Generic profiling guidelines.....	4
4	Snapshot and differential of Structure Definition	4
5	Elements and properties for all profiles.....	4
6	Format of the Structure Definition, Value Set, Code System	5
7	Documenting the profile and the elements of the profile	5
8	Naming of the artefact elements	6
9	Value set binding of the coded elements	8
10	Choice of data types	8
11	Identifier element (business identifier)	8
12	Aggregation of the references.....	9
13	Resource reference subelements	9
14	Coding (+ codeableConcept) data type element and subelements.....	9
15	Quantity data type element and subelements	10
16	Base profile	11
17	Extensions.....	11
18	Finnish PHR Application information extension.....	11
19	ValueSets.....	11
20	CodeSystems.....	12
21	Questionnaires	12
22	Observation specific guidelines	12
23	Examples	13



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 www.kanta.fi/phr.

2 HL7 FHIR profiling guidelines

Profile implementers are expected to be familiar with the HL7 FHIR profiling guidelines: <http://hl7.org/fhir/profiling.html>

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:

- Elements and subelements of the resource, that are not used in profile, SHALL be disabled by setting cardinality to 0..0
- Value set binding SHALL be "required",
- Value unit SHALL have fixed value

4 Snapshot and differential of Structure Definition

Each profile and extension SHALL contain both the snapshot and differential statements

- <http://hl7.org/fhir/profiling.html#snapshot>
- <http://hl7.org/fhir/structuredefinition.html>

5 Elements and properties for all profiles

Resource.language SHALL be defined in all profiles

- Resource.language SHALL be mandatory 1..1
- Value set binding SHALL be required (<http://hl7.org/fhir/ValueSet/languages>)
- <http://hl7.org/fhir/resource.html>

Resource.meta.profile SHALL be defined in all profiles

- Resource.meta.profile SHALL be mandatory 1..1 and SHALL be fixed to the url of the profile
- Resource instances SHALL refer to a profile by including a meta reference to the profile
- <http://hl7.org/fhir/resource.html#Meta>

Resource.meta.security

- The user can restrict healthcare professional's access to user's data giving consent exceptions. The consent exceptions are specified with security labels mechanism of the FHIR standard. A security label is attached to a resource to provide the specific security metadata about the information in the resource.
- Resource.meta.security SHALL be defined in all profiles
 - Value set binding SHALL be Value Set Finnish PHR Confidentiality (<https://simplifier.net/FinnishPHR/fiphr-vs-confidentiality>)
 - Value set binding SHALL be required
 - security.system SHALL be mandatory 1..1 and SHALL be fixed to <http://hl7.org/fhir/v3/Confidentiality>
 - security.code SHALL be mandatory 1..1
 - security.display SHALL be mandatory 1..1
 - security.version SHALL be removed 0..0
 - security.userSelected SHALL be removed 0..0
- <http://hl7.org/fhir/resource.html#Meta>

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. (<http://hl7.org/fhir/elementdefinition.html>):

- 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 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

Artefact id (Resource.id)

- id SHALL be unique
- id SHALL start with identifier "fiphr"
- id SHALL contain the artefact name (for example "bloodglucose")
- profiles, extensions and Questionnaires SHALL contain the used version of FHIR, now in STU3 phase "stu3"
- 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:
 - profile: fiphr-sd-bloodglucose-stu3
 - extension: fiphr-ext-activesymptoms-stu3
 - value set: fiphr-vs-confidentiality
 - code system: fiphr-cs-consentcategory



- Questionnaire: fiphr-qu-DANPSS1-stu3

```
{
  "resourceType": "StructureDefinition",
  "id": "fiphr-sd-bloodglucose-stu3",
  ...
}
```

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

- "A natural language name identifying the structure definition. This name should be usable as an identifier for the module by machine processing applications such as code generation. / Support human navigation and code generation. / The name is not expected to be globally unique. The name should be a simple alpha-numeric type name to ensure that it is computable friendly."
- Artefact name SHALL be the same as artefact id
- examples:
 - profile: fiphr-sd-bloodglucose-stu3
 - extension: fiphr-ext-activesymptoms-stu3
 - value set: fiphr-vs-confidentiality
 - code system: fiphr-cs-consentcategory
 - Questionnaire: fiphr-qu-DANPSS1-stu3

```
{
  "resourceType": "StructureDefinition",
  ...
  "name": " fiphr-sd-bloodglucose-stu3",
  ...
}
```

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 type of artefact ("profile", "extension", "value set", "code system")
- NB! These instructions related to title DO NOT apply to Questionnaires.
- example:
 - " Finnish PHR Blood Glucose profile"

```
{
  "resourceType": "StructureDefinition",
  ...
  "title": " Finnish PHR Blood Glucose profile ",
  ...
}
```

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

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- 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-stu3>
 - Extensions SHALL contain specifier "StructureDefinition" and the artefact id:
 - example: <http://phr.kanta.fi/StructureDefinition/fiphr-ext-activesymptoms-stu3>
 - 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-stu3-v1>
- ```
{
 "resourceType": "StructureDefinition",
 ...
 "url": "http://phr.kanta.fi/StructureDefinition/fiphr-sd-bloodglucose-stu3",
 ...
}
```

## 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 required (ElementDefinition.binding.strength)
- <http://hl7.org/fhir/terminologies.html>

## 10 Choice of data types

Few elements have a choice of more than one data type for their content. If only one data type is needed, the choice SHALL be restricted to needed data type

- for example effective[x]: dateTime / Period -> effectiveDateTime
- <http://hl7.org/fhir/formats.html#choice>

## 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).

Usage in Observations: If, because of some technical problem, 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.

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).
- Other elements of the identifier SHALL be removed 0..0
- <http://hl7.org/fhir/datatypes.html#Identifier>
- for example Observation.identifier: <http://hl7.org/fhir/observation-definitions.html#Observation.identifier>

## 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"
- <http://hl7.org/fhir/elementdefinition-definitions.html#ElementDefinition.type.aggregation>

## 13 Resource reference subelements

Reference.reference SHALL be mandatory 1..1

- Reference.identifier SHALL not be used 0..0
- Reference.display SHOULD be removed 0..0
  - if not removed the use of the display SHALL be justified
- <http://hl7.org/fhir/references.html>

## 14 Coding (+ codeableConcept) data type element and subelements

CodeableConcept

- codeableConcept.coding
  - mainly SHALL be mandatory 1..1
  - if not mandatory, the optionality SHALL be justified
- codeableConcept.text
  - mainly SHALL be removed 0..0
  - if not removed, the use of the text SHALL be justified

#### Coding (+ CodeableConcept.coding)

- coding.system SHALL be mandatory 1..1
  - if the value set binding defines only one code system, the system SHALL be fixed
- coding.version SHALL be removed 0..0
- 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
- coding.userSelected SHALL be removed 0..0
- <http://hl7.org/fhir/datatypes.html#CodeableConcept>
- <http://hl7.org/fhir/datatypes.html#Coding>

## 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 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 unit can be coded in UCUM, the system SHALL be fixed to UCUM (<http://unitsofmeasure.org>)

Quantity.code SHALL be mandatory 1..1

- code SHOULD be fixed when applicable
- 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.

Quantity.comparator SHALL be removed 0..0

- if not removed, the use of the comparator SHALL be justified

<http://hl7.org/fhir/datatypes.html#Quantity>

## 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)

- <http://hl7.org/fhir/structureddefinition-definitions.html#StructureDefinition.abstract>

## 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 not suitable existing extension, then the extension can be defined with extension element. The definition of the extension SHALL follow rules defined in FHIR (<http://hl7.org/fhir/extensibility.html>)

## 18 Finnish PHR Application information extension

Finnish PHR Application information extension (<http://phr.kanta.fi/StructureDefinition/fiphr-ext-creatingapplication>) 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)

## 19 ValueSets

A ValueSet contains a set of codes from one or more code systems, to be used in a particular context (<http://hl7.org/fhir/valueset.html>).

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

## 20 CodeSystems

A CodeSystem describes the existence of a code system and its key properties, and how the codes are understood (<http://hl7.org/fhir/codesystem.html>).

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

## 21 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).

## 22 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

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

Observation grouping:

- When using Observation.component, definitions described here <http://hl7.org/fhir/observation.html#10.1.4.1> SHOULD be read

Observation.code.coding slicing

- In some observations there is a need to give in the Observation.code.coding the main code and the more specific code
  - For example FinnishPHR Body Temperature profile: the main code 8310-5/Body temperature is mandatory, the more specific code , for example 76011-6 / Ear temperature, is optional
- This could be done by slicing the Observation.code.coding element
  - When using Observation.code slicing, definitions described here <http://hl7.org/fhir/profiling.html#slicing> SHOULD be read

## 23 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-stu3"
]
}
```