Implementation guidelines for clinical cancer notifications

## Data submission interval

* The data are sent to the Finnish Cancer Registry at specified intervals.
  + Data submission format: encoding = “UTF-8”
  + The data are transferred to the Cancer Registry’s SFTP server in the ‘Import’ subfolder of each data provider’s own folder.
  + The files are named as follows:
    - The data provider’s *user ID* for the SFTP server; 3–6 characters (e.g. KBU).
    - File content identifier: CLI = clinical
    - Four-digit number sequence running consecutively and maintained by the data provider, with leading zeros “0000”
    - file creation time according to ISO 8601 in the format “YYYYYMMDDTHHmmss”, without time zone designator
    - Underscore between previous sections
    - File extension: .xml
    - Example: **KBU\_CLI\_0001\_20230201T093028.xml**
* Submission schedule (see also ‘Data selection from system’ and the 30-day rule):
  + 1 May: 1 Jan–31 Mar
  + 1 Aug: 1 Apr–30 Jun
  + 1 Nov: 1 Jul–30 Sep
  + 1 Feb: 1 Oct–31 Dec

## Data selection from system

* Cases to be selected
  + All new cancer cases and certain other tumours and tumour-like conditions shall be reported to the Cancer Registry.
  + Specifications for the cases to be selected are given in the attached document “When to make a clinical cancer notification”.
* Select all notifications that have been entered in the system during the period in question. In order not to leave the data incomplete, the period between the notification date (last editing date) and the date of transmission must be at least one month.
  + Select the cases whose data have not been updated for at least 30 days.
    - For example, on 1 May 2022, send as a single file all notifications of new cancer cases with a reporting date between 1 January and 31 March 2022.

## Functionalities of the data model

* Notifications may be added (new notification), edited and deleted
  + New: new cancer notification
  + Edit: a change to a previously sent notification. The notification contains a correction to previously sent cancer information. In this case, resubmit the entire notification with the corrected information. In practice, this is treated as overwriting. An edit notification cannot be used to supplement previous submissions; any supplements will be submitted as a new notification.
  + Deletion: a deletion of a previously sent notification. Only used in exceptional circumstances, e.g. entering information for the wrong patient or a completely wrong diagnosis. All data in the previously sent notification will be deleted.
    - In the case of a notification of deletion, also fill in the error\_code field.

## Data structure

* The hierarchy of the data structure follows the following model:
* Heading details
* Cancer notification 1–n times
  + Method of diagnosis 1–15 times

## Code sets used

* The diagnosis of the disease is indicated according to the diagnosis code set *THL - Tautiluokitus ICD-10 (THL – classification of diseases ICD-10)*.
* The topography and morphology can be indicated according to *SSR-ICD-O-3-Topografiat* and *SSR-Morfologia (SSR-ICD-O-3 topographies* and *SSR morphology).*
* The PAD (pathological-anatomical diagnosis) is indicated in the text field. If the histology of the tumour is not available, a description of the tumour type is requested (e.g. ocular melanoma/retinoblastoma).
* The cancer diagnosis or tumour detection method follows international guidelines (see Excel appendix with parameters “Syopailmoitus parametristot.xlsx”). Several diagnosis methods may be reported.

Methods:

1=Clinical, premortem, unconfirmed

2=Clinical, confirmed X-ray or similar

4=Specific tumour marker

5=Cytology

6=Histology from metastasis

7= Histology from primary tumour

8= Obduction, including histological sample

9=Unknown

10=Flow cytometry

12=Molecular genetics

13=Immunophenotyping

14=Cell morphology, haematology

15=Cytogenetics.

* Information on the spread of the cancer/tumour at diagnosis is reported according to one of the following:
  + the organ-specific TNM classification (separate variables for T, N and M codes, see Excel appendix with parameters) OR
  + the verbal code set indicating stage (see Excel appendix with parameters) OR
  + the organ-specific stage classification (see Excel appendix with parameters)
  + the organ-specific Stage Ann Arbor classification (see Excel appendix with parameters).
* The tumour grading system follows the classification given in the Excel appendix according to the tab ‘Gradus’.