The long-term accessibility of cancer registry data using the CITS ehealth2 guidelines and specifications

Thursday January 18, 2024

eArchiving Initiative training webinar

European Commission

Welcome to this live webinar on The long-term accessibility of cancer registry data using the CITS eHealth2 guidelines and specifications

Start 10:00

18 January 2024

Audience notes for the Live Webinar

Your **cameras have been turned off** and **microphones muted**.

If you have any technical issues during the event, please use the chat function.

Please **use the Q&A for questions to speakers**. These will be addressed at the end of the event.

Please note that this webinar is recorded. No attendee personal information will be captured in these recordings.

Agenda

1. Short introduction to cancer registration
   Vesna Zadnik, Slovenian Cancer Registry

2. Role of European Cancer Information System
   Joanna Bartnicka, Joint Research Centre

3. eHealth2 specification
   *Jože Škofljanec, eArchiving Initiative &
   Slovenian National Archives*

4. Example of the ENCR/JRC Data Call 2022
   Tina Žagar, Slovenian Cancer Registry

5. Q&A Session

European Commission

The aim and content of the CITS eHealth2

Jože Škofljanec
eArchiving Initiative & Archives of the Republic of Slovenia

Aim of the eHealth2 specifications and guidelines

To support maintenance of the cancer burden data and their (re)use

Preserve
Retention of cancer burden data that reflects the introduction of new treatment methods and influences changes in health policies

Trust
Clear and easily verifiable cancer burden related data

Usability
Specifications and guidelines can be used for all types of data exports from cancer registries

Information package includes all key elements that end users may need
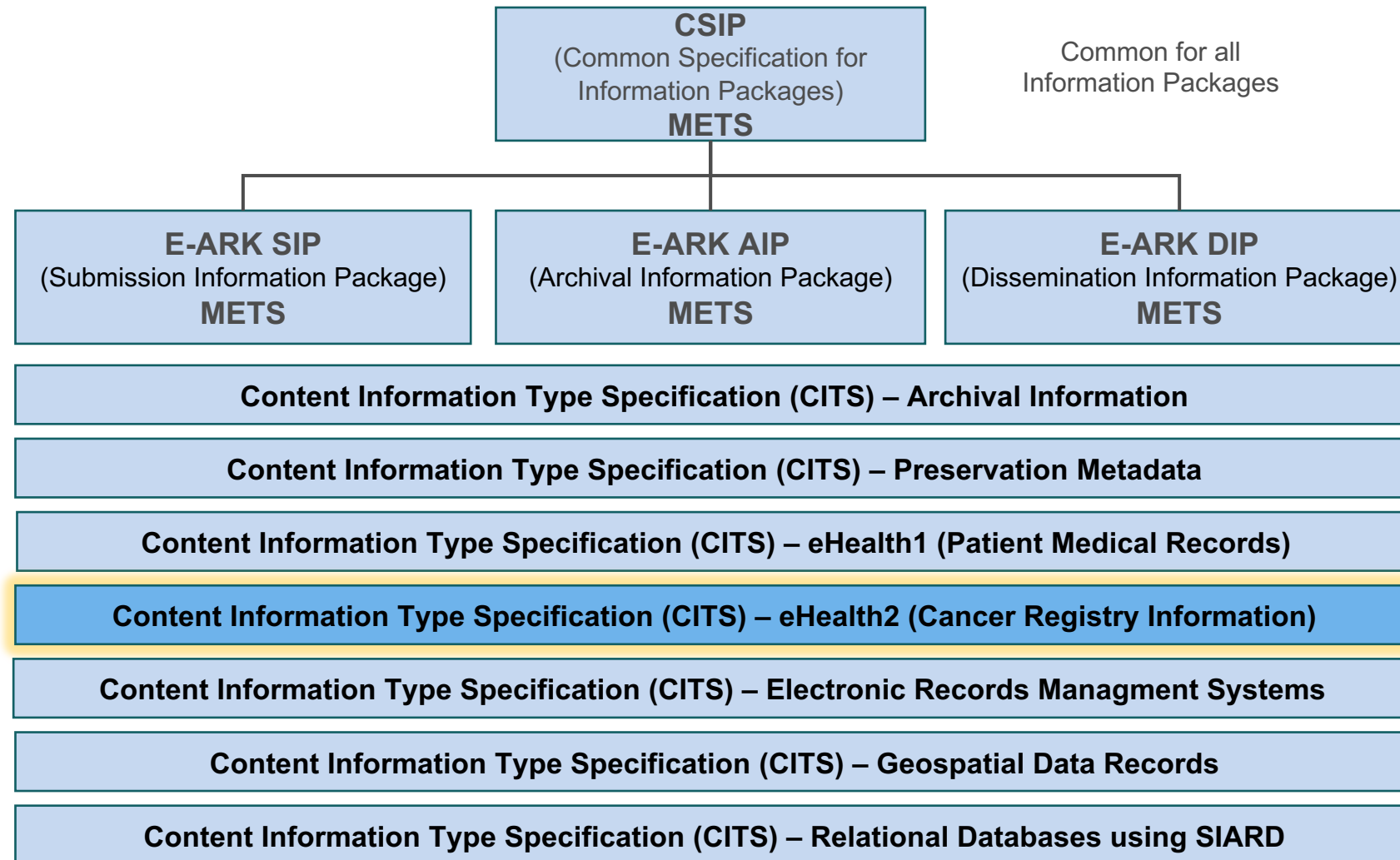
Cancer Registries
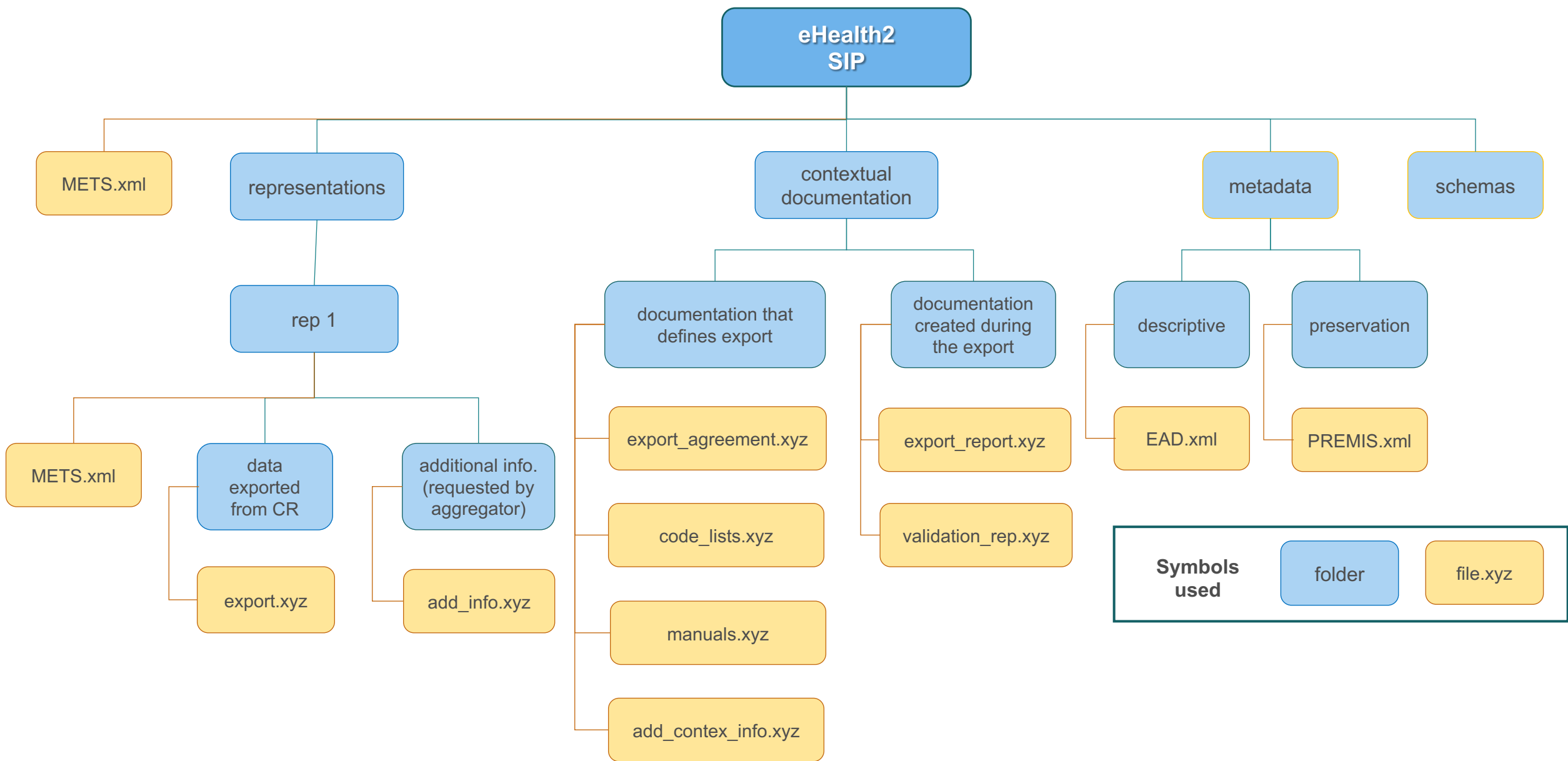
Aggregators, Academic and other Researchers

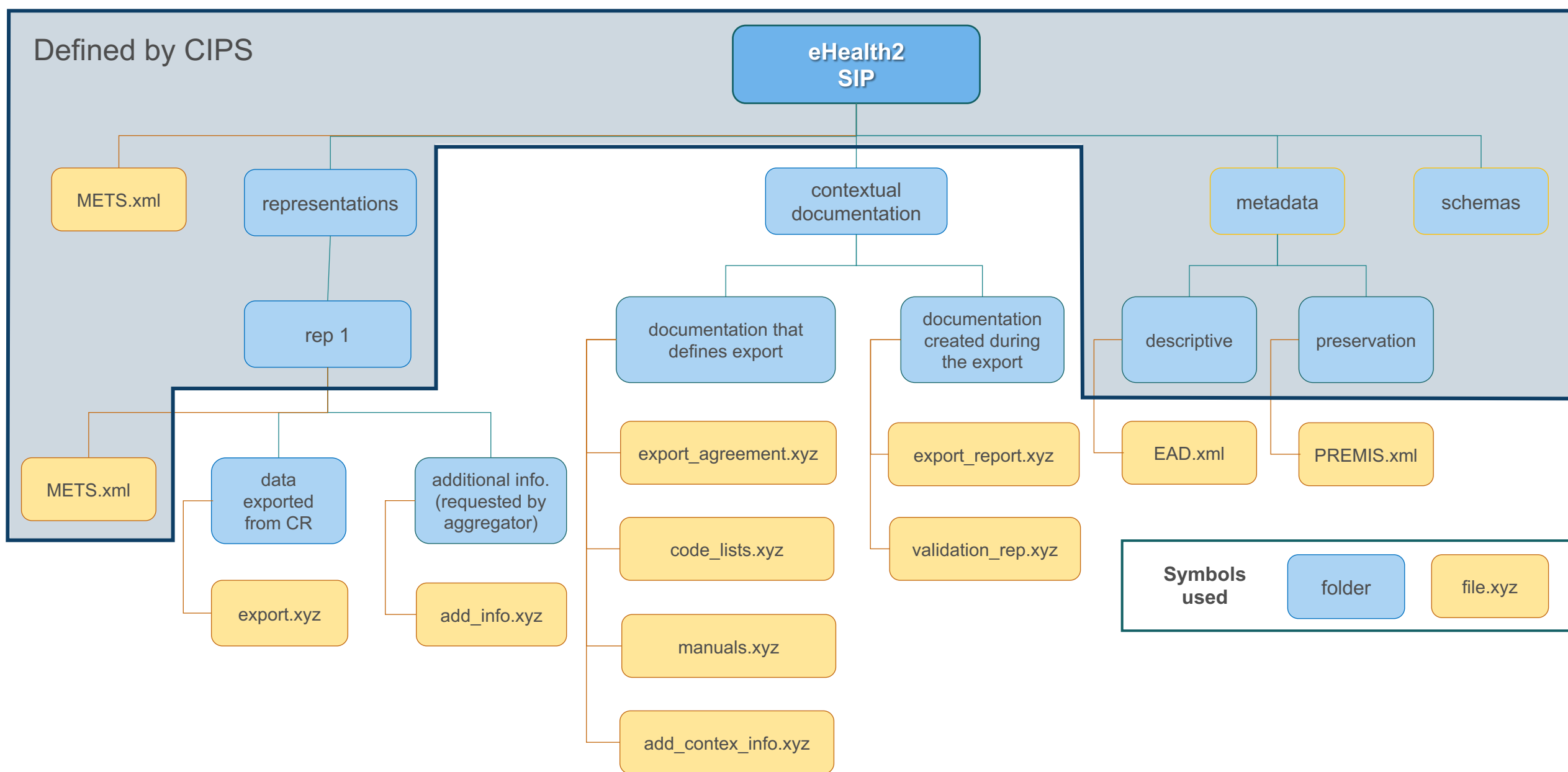**Archives and other Record Keepers**

eArchiving specifications

eHealth2 Specifications in the eArchiving Framework

```
                    ┌─────────────────────────┐
                    │          CSIP           │      Common for all
                    │ (Common Specification for│   Information Packages
                    │   Information Packages)  │
                    │          METS           │
                    └─────────────────────────┘
           ┌──────────────────┼──────────────────┐
┌────────────────────┐ ┌────────────────────┐ ┌────────────────────┐
│     E-ARK SIP      │ │     E-ARK AIP      │ │     E-ARK DIP      │
│(Submission         │ │(Archival           │ │(Dissemination      │
│ Information Package)│ │ Information Package)│ │ Information Package)│
│       METS         │ │       METS         │ │       METS         │
└────────────────────┘ └────────────────────┘ └────────────────────┘
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Content Information Type Specification (CITS) – Archival Information

Content Information Type Specification (CITS) – Preservation Metadata

Content Information Type Specification (CITS) – eHealth1 (Patient Medical Records)

Content Information Type Specification (CITS) – eHealth2 (Cancer Registry Information)

Content Information Type Specification (CITS) – Electronic Records Managment Systems

Content Information Type Specification (CITS) – Geospatial Data Records

Content Information Type Specification (CITS) – Relational Databases using SIARD

eHealth2 SIP

- METS.xml
- representations
  - rep 1
    - METS.xml
    - data exported from CR
      - export.xyz
    - additional info. (requested by aggregator)
      - add_info.xyz
- contextual documentation
  - documentation that defines export
    - export_agreement.xyz
    - code_lists.xyz
    - manuals.xyz
    - add_contex_info.xyz
  - documentation created during the export
    - export_report.xyz
    - validation_rep.xyz
- metadata
  - descriptive
    - EAD.xml
  - preservation
    - PREMIS.xml
- schemas

Symbols used   folder   file.xyz

CITS eHealth2 Information Package Schema

European Commission

Defined by CIPS

eHealth2
SIP

METS.xml

representations

rep 1

METS.xml

data exported from CR

export.xyz

additional info. (requested by aggregator)

add_info.xyz

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schemas

Symbols used

folder

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CITS eHealth2 Information Package Schema

European Commission

CITS eHealth2 Information Package Schema

How to explore eHealth2

Where to find specification and implementation assistance

Specification Guidelines

https://github.com/DILCISBoard/CITS-EHEALTH2

Support

support@e-ark-foundation.eu

info@dilcis.eu

Other useful materials

https://www.youtube.com/@e-ark

https://github.com/DILCISBoard

http://kc.dlmforum.eu/eark-products

https://digital-strategy.ec.europa.eu/en/activities/earchiving

Digitalbevaring.dk

eHealth2 going forward

Advancing the eHealth2 specification

DIGITAL PRESERVATION

Improvement and extension of the specification and guidelines — **1**

Archiving of complete cancer registry — **2**

Application of the specification to other health registries — **3**
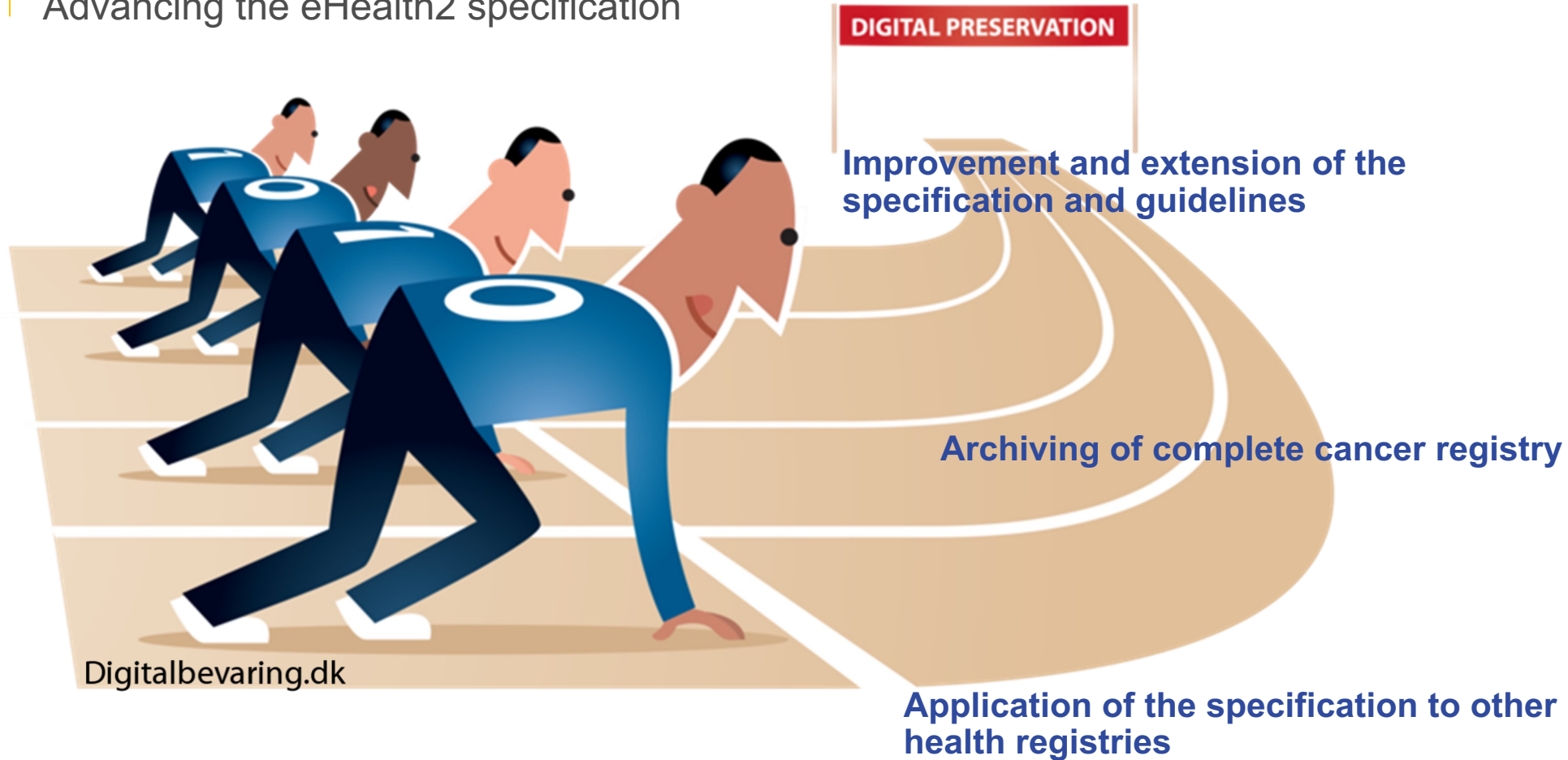
Digitalbevaring.dk

Thank you

Contact

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𝕏 @EU_eArchiving

in https://www.linkedin.com/company/eu-earchiving-initiative

▶️ https://www.youtube.com/@e-ark

Thank you

joze.skofljanec@gov.si

https://digital-strategy.ec.europa.eu/en/activities/earchiving

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