

# NAACCR XML Data Exchange Standard Implementation Guide

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# NAACCR XML Data Exchange Standard Implementation Guide

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## 1 Introduction and History

The NAACCR XML Task Force was created in August of 2014 to define and demonstrate an XML based data exchange standard for the NAACCR community. During the second half of 2014 and the first few months of 2015, a draft standard was developed, called the NAACCR XML Draft Standard.

In June of 2015, the NAACCR XML Draft Standard made its public debut at the NAACCR Annual Conference in Charlotte, NC, starting with a plenary session followed by three successive informational sessions. The XML Task Force also hosted an informational booth at the conference where feedback was recorded and questions answered.

On July 27, 2015, a public webinar was hosted by the NAACCR where the draft standard was presented by the Task Force and feedback was solicited.

On September 23, 2015, the NAACCR Board approved the Draft Standard as an official NAACCR Standard, making it version 1.0.

In August of 2016, version 1.1 of the standard was approved by the NAACCR Standardization and Registry Development Steering Committee with the following changes:

1. Remove the 1,000 characters size limits on most of the standard text data items.
2. Allow local/state data items to be defined in a user-defined dictionary without being tied to a specific location in the State Requestor items.
3. Make the NAACCR version optional in the user-defined dictionaries (in which case the base version will be assumed).
4. Add a "specificationVersion" to both the data and the dictionary XML files allowing libraries to know which version of the specification they are dealing with.

The changes are intended to allow the community to make better use of the XML features of the standard while trying to stay compatible with the fixed-columns format as much as possible.

## 2 Background

Developing this standard was undertaken with the benefit of several years of previous efforts to replace the NAACCR Volume II data exchange standard with something more extensible and easier to maintain. These previous efforts included NAACCR Workgroups dedicated to the task, a private consulting contract with healthcare data experts, and at least one grant application to obtain funding through the NCI U24 funding mechanism. Details of these previous efforts are out of scope for this document but a summary of their conclusions and lessons learned include:

- XML is an appropriate syntax for the standard
- Modeling the standard on the HL7 clinical document architecture (CDA) can be problematic
- Cost of implementation is a major concern to the NAACCR community

With the benefit of hindsight, the task force made the following assumptions during the development of the standard:

- The syntax of the standard will be XML
- The standard will be maintainable by the NAACCR community without reliance on external standards bodies or an external balloting process
- The first version of a new XML standard will be easily convertible to the existing fixed-width standard and back, without loss of data
- Once the standard is adopted by the NAACCR community, there will be a period of time where the new XML standard and the existing fixed-width standard will easily co-exist
- The use cases supported by the new XML standard will closely follow those of the current NAACCR Volume II Data Exchange Standard, namely, Registry to Registry, Registry to Submission Agency, and Registry to Researcher. As a result, generic transactional healthcare record use cases such as physician reporting to a cancer registry are not a design goal
- The new XML standard will primarily support existing NAACCR data items defined by the current Volume II standard while providing a well-defined method for handling State/Requestor Items and arbitrary embedded data

## 3 Overview

The NAACCR XML standard defines a data exchange format where NAACCR Standards Volume II data items are encoded in XML <Item> elements. These <Item> elements are placed at one of 3 levels of a nested structure within a NAACCR XML data exchange document: the root <NaaccrData> XML element, the <Patient> XML element, or the <Tumor> XML element. The <NaaccrData> element is the root element of a data exchange document and can only occur once, the <Patient> element can occur any number of times as a child of the <NaaccrData> element, and the <Tumor> element can occur any number of times as a child of the <Patient> element:

**<NaaccrData>**  
**<Patient>**  
**<Tumor>**

Every Standards Volume II data item encoded as <Item> can belong to one and only one level of the nested structure; for example, the patient's last name can only appear as a child of the <Patient> element, while the diagnosis date can only be a child of a <Tumor> element. The mapping of all <Item> elements to their parent XML elements is defined in the Base Dictionary, described later in this document.

During development of the standard, multiple levels of structure beyond Patient and Tumor were discussed, such as Treatment, Hospital Admission, and Pathology Report. These additional levels of structure were omitted from this first standard so that the transition from fixed-width file to XML would be simpler. With the fixed-width file, there is only one level of structure, the Tumor record, so limiting the additional levels of structure for this first version will give some of the advantages that a nested structure provides while easing the transition from the current data model. Future versions of the NAACCR XML standard can easily add additional levels of structure without breaking compatibility with this standard.

The NAACCR XML standard has 3 components:

1. **Data Exchange Specification:** Defines the overall structure of a NAACCR XML data exchange document and some basic syntax conventions
2. **Base Dictionary Specification:** Defines Standards Volume II data items as XML <Item> elements, their mapping between XML and the fixed-width format, and their location in the NAACCR XML hierarchy
3. **User Dictionary Specification:** Provides a way to define custom State/Requestor items compatible with the NAACCR XML standard

## 4 Data Exchange Specification

All NAACCR Data Items from the current Standards Volume II standard are encoded as <Item> elements, placed at one of 3 levels in an XML data exchange document: <NaaccrData>, <Patient>, or <Tumor>. The <NaaccrData> element occurs once per document, the <Patient> elements occur once per patient, and the <Tumor> elements occur once per tumor record for a given <Patient>. When creating a NAACCR XML data exchange document, line termination is optional and can be any combination of carriage-return and line-feed characters. Grouped data items from the current Standards Volume II Appendix E are not supported, but since they overlap with other Standards Volume II data items, their data will be retained in a conversion from XML to a fixed-width file and back.

### 4.1 <Item> Element

Each data item defined in the current NAACCR Volume II data exchange standard (Standards Volume II) is encoded as an <Item> element where the value of the data item goes in the text value of the XML element. A required attribute on every <Item> element,

the “naaccrId”, represents the “Item Name” of the Standards Volume II data item in a manner that conforms to XML naming standards. An optional attribute, called “naaccrNum” indicates the Standards Volume II item number. For example, a patient with the last name of SMITH would have this <Item> as a child of the <Patient> element:

```
<Item naaccrId="nameLast">SMITH</Item>
```

Optionally including the naaccrNum attribute:

```
<Item naaccrId="nameLast" naaccrNum="2230">SMITH</Item>
```

<Item> elements can only be placed under a <NaaccrData>, <Patient>, or <Tumor> element as defined in the NAACCR XML Base Dictionary. The order of <Item> elements under their parent does not matter, and their item value can contain newline characters without disrupting the syntax of the XML document. If an <Item> element does not have a value, it can be omitted entirely from the data exchange document.

#### 4.2 <NaaccrData> Element

Every NAACCR XML data exchange document has <NaaccrData> as the root XML element. This element must contain an attribute called “recordType”, corresponding to the Standards Volume II item number 10, “Record Type”. The recordType attribute defines the set of data items that will be valid for this XML data exchange document, much like the current Standards Volume II Record Type item defines the valid set of data items in a fixed-width record. Another required root level attribute, “baseDictionaryUri”, defines the version of the XML data exchange specification used to create this XML data document. For example, a version 15 data exchange document with confidential record types would start with:

```
<NaaccrData  
  recordType="C"  
  baseDictionaryUri="http://naaccr.org/naaccrxml/naaccr-dictionary-150.xml"  
  specificationVersion="1.1"  
  ...>
```

The baseDictionaryUri attribute does not represent an actual website that can be visited by a web browser, it is simply a unique string defined by the standard that defines a version of the XML specification. Valid values currently include:

- <http://naaccr.org/naaccrxml/naaccr-dictionary-140.xml>, corresponding to NAACCR Standards Volume II version 14.0
- <http://naaccr.org/naaccrxml/naaccr-dictionary-150.xml>, corresponding to NAACCR Standards Volume II version 15.0

An optional attribute, “timeGenerated”, can be included on the root element to indicate the date and time that a XML data exchange document was created:

```

<NaaccrData
  recordType="C"
  baseDictionaryUri="http://naaccr.org/naaccrxml/naaccr-dictionary-150.xml"
  specificationVersion="1.1"
  timeGenerated="2015-05-30T15:32:47.253-04:00"
  ... >

```

The <NaaccrData> element also contains 5 child <Item> elements that apply to the entire data exchange document. The following <Item> elements are defined in the Base Dictionary as children of “NaaccrData”:

**<Item naaccrId="recordType">...**

The recordType <Item> is redundant with the “recordType” attribute on the root <NaaccrData> element and must have the same value. It is included for backward compatibility with the existing Standards Volume II fixed-width standard. There can be only one record type included in a XML data exchange document.

**<Item naaccrId="naaccrRecordVersion">...**

This element is included for backward compatibility with the existing Standards Volume II fixed-width standard and should name the version of the Standards Volume II standard used to create records in this file. Its purpose has been superseded by the “baseDictionaryUri” attribute on the <NaaccrData> element.

**<Item naaccrId="registryType">...**

**<Item naaccrId="npiRegistryId">...**

**<Item naaccrId="registryId">...**

These 3 items describe the registry where the XML data exchange document originated and apply to all patients and tumors included in the document.

### 4.3 <Patient> Element

A <NaaccrData> element can contain any number of <Patient> elements as children. Each <Patient> element can have one or more <Item> children as long as they are defined in the Base or User Dictionary with a parentXmlElement attribute set to “Patient”. <Patient> elements can also contain any number of <Tumor> elements.

<Item> elements that are direct children of a <Patient> element apply to all <Tumor> elements underneath that <Patient>. For example, the social security number of a patient defined in <Item naaccrId="socialSecurityNumber"> will apply to every <Tumor> underneath that <Patient>. For a complete list of <Item> elements that are valid children of <Patient>, see the Base Dictionary description and file.

### 4.4 <Tumor> Element

A <Patient> element can have any number of <Tumor> elements as children. Each <Tumor> element can have one or more <Item> children as long as they are defined in the Base or User Dictionary with a parentXmlElement attribute set to “Tumor”. Each <Tumor> element corresponds to a separate tumor record for its parent <Patient> element. For a

complete list of all <Item> elements that are valid children of <Tumor>, see the Base Dictionary description and file.

#### 4.5 Consolidated Data and Nested Elements

Since the standard defines a nested structure for patients and tumors, registries with consolidated patient information can send a single set of patient data in a <Patient> element when multiple tumors are included in <Tumor> elements. If a registry does not have consolidated patient information, then a separate <Patient> and <Tumor> element will be sent for every tumor record. The standard does not enforce <Patient> or <Tumor> element uniqueness, for example, multiple <Patient> elements can be sent with the same Patient ID and multiple <Tumor> elements can be sent for the same tumor record to represent a patient visit history. The standard has been designed to be flexible enough to accommodate many data collection scenarios, while also supporting consolidated, heavily curated cancer abstracts. In any scenario, <Item> elements must be nested under the appropriate parent, <Patient> or <Tumor>, according to the Base Dictionary.

#### 4.6 XSD for the Data Exchange Specification

The standard includes a W3C-compliant XML Schema Definition (XSD) file called “naaccr\_data.xsd” that defines the valid elements and attributes in a NAACCR XML data exchange file. Some XML parsers can use the XSD to validate the basic syntax of a NAACCR XML data exchange file.

The XSD was specifically designed to avoid both data type validation and <Item> parent-child validation because of two limitations inherent in most XSD validation software. First, many XSD validators read an entire XML file before reporting its validity, making them inappropriate for large registry data exchange files. Second, most XSD validators will reject an entire XML file as soon as they encounter any portion that is non-complaint with the XSD. This behavior is problematic for most NAACCR data exchange use cases that need an overall picture of the portions of a file that are invalid rather than a Boolean valid-invalid result, as well as the ability to ignore certain validation errors based on special circumstances. For these reasons, sophisticated validation of NAACCR XML data exchange files was left to a custom software tool instead of the XSD.

## 5 Base Dictionary Specification

The Base Dictionary is an XML file that defines data items and their characteristics for processing NAACCR XML data, including:

- All Standards Volume II data items that can be used as <Item> elements
- Parameters for converting from NAACCR XML to fixed-width format and back
- Valid record types for each <Item> element
- List of valid parent-child relationships between <Item> elements and <NaaccrData>, <Patient>, and <Tumor> elements

There is a separate base dictionary file for each version of the Standards Volume II, currently including:

- naaccr-dictionary-150.xml (NAACCR Version 15.0)
- naaccr-dictionary-140.xml (NAACCR Version 14.0)

Each Base Dictionary file has three XML elements: a root element called <NaaccrDictionary>, a container element called <ItemDefs>, and a separate <ItemDef> element for each Standards Volume II data item.

### 5.1 <NaaccrDictionary>

The root element in the Base Dictionary, <NaaccrDictionary> has a “naaccrVersion” attribute corresponding to the Standards Volume II record version where its data item definitions were taken and a “description” attribute with a brief text summary of the version. It also contains an attribute called “dictionaryUri” with a unique string that will appear in the “baseDictionaryUri” attribute of every NAACCR XML data exchange document that is created from this Base Dictionary. For example, the NAACCR version 15.0 Base Dictionary root element is defined as follows:

```
<NaaccrDictionary
  dictionaryUri=http://naaccr.org/naaccrxml/naaccr-dictionary-150.xml
  naaccrVersion="150"
  specificationVersion="1.1"
  description="NAACCR 15 base dictionary"
...>
```

Consequently, every NAACCR XML data exchange file that is created from this Base Dictionary will have the following root element:

```
<NaaccrData
  baseDictionaryUri=http://naaccr.org/naaccrxml/naaccr-dictionary-150.xml
...>
```

### 5.2 <ItemDefs> and <ItemDef>

The Base Dictionary for a particular NAACCR record version contains an <ItemDef> element for every Standards Volume II data item defined in that record version, except for the State/Requestor Items, the NPCR Specific Field, and all Reserved items. All of the <ItemDef> elements are inside of a <ItemDefs> container, which has no attributes. Each <ItemDef> element has an attribute called, “parentXmlElement”, which names a single XML element that can be its parent, either “NaaccrData”, “Patient”, or “Tumor”. This parent element is what defines the nested structure of a NAACCR XML data exchange document. The Base Dictionary is the only place that this relationship is defined, and therefore relies on a separate piece of software to enforce the nesting rules and validate a NAACCR XML file. In addition to the parent XML element, <ItemDef> contains the following attributes derived from the Standards Volume II standard:

**naaccrId** – a unique text value that identifies a data item, derived from the NAACCR Name in Standards Volume II but stripped of punctuation and whitespace

characters. This text value must appear exactly as defined in the Base Dictionary as the `naaccrId` attribute in every `<Item>` of a NAACCR XML data exchange document.

**naaccrName** – the NAACCR Name from the Standards Volume II standard

**naaccrNum** – the NAACCR Number from the Standards Volume II standard

**recordTypes** – a comma-separated list of the record types from Standards Volume II where this data item can appear

**startColumn** – the starting column where this data item will be read or written from a fixed-width file; optional in the user-defined dictionaries

**length** – the character length of this item when it is written or read from a fixed-width file, also used as the maximum length of data to read from an `<Item>` element when converting XML to a fixed-width file

**dataType** – a name for the type of data contained in a data item, maps directly to a regular expression that can be used to validate the value.

<b>Data Type</b>	<b>Regular Expression</b>	<b>Usage</b>
digits	<code>^\d{n}\$</code>	Codes composed of digits only, which always occupy the full width of the field
mixed	<code>^[A-Z\d]{n}\$</code>	Codes composed of digits and uppercase characters, which always occupy the full width of the field
alpha	<code>^[A-Z]{n}\$</code>	Codes composed on uppercase characters only, which always occupy the full width of the field
numeric	<code>^\d+(\.d+)?\$</code>	Variable length numbers that require padding or justification in a fixed-width file
date	<code>^(18 19 20)\d\d((0[1-9] 1[012])(0[1-9] [12]\d 3[01])?)?\$</code>	A NAACCR-style full or partial date (20110101)
text	<code>^[.]{1,n}\$</code>	Variable length text that requires padding or justification in a fixed-width file

**regexValidation** –attribute used instead of a dataType attribute for defining a custom Regular Expression that does not fit any of the predefined data types.

**padding** – a name for the text padding rules when writing a fixed-width file, can be: rightBlank, leftBlank, rightZero, or leftZero, defaults to rightBlank.

**trim** – a name for the text trimming rules when converting a fixed-width file to XML, can be: none or all, defaults to all.

**allowUnlimitedText** – if set true, the standard allows the value to be longer than the defined item length. Defaults to false.

## 6 User Dictionary

The User Dictionary of the NAACCR XML standard provides a way to define custom XML <Item> elements that fit within the unused spaces of a fixed-width file. It has exactly the same elements and attributes as the Base Dictionary, but defines <ItemDef> elements for the State/Requestor Items, NPCR Specific Field, and the Reserved item spaces of a fixed-width file. To define a custom data item, a registry starts with the Default User Dictionary file and then edits the <ItemDef> elements to include as many custom data items as will fit within the unused spaces of a fixed-width file. When the Default User Dictionary file is modified to contain custom <ItemDef> elements, it is called a “Custom” User Dictionary instead of the “Default” User Dictionary since it is overriding the unused item spaces.

For example, in the Default User Dictionary for NAACCR record version 15.0, the State/Requestor <ItemDef> is defined as 1000 characters starting at position 2340 as follows:

```
<ItemDef naaccrId="stateRequestorItems"
  naaccrNum="2220"
  naaccrName="State/Requestor Items"
  startColumn="2340"
  length="1000"
  recordTypes="A,M,C,I"
  parentXmlElement="Tumor"
  trim="none"/>
```

If a registry wanted to add two items for patient height and weight to the State/Requestor area of a NAACCR record, a Custom User Dictionary would redefine the standard State/Requestor <ItemDef> as two new <ItemDef> elements. One of these new <ItemDef> elements would be for the patient height and one for the patient weight, the remaining characters from the 1000 character State/Requestor Items would be unused:

```
<ItemDef naaccrId="heightAtDiagnosis"
  naaccrNum="9500"
  naaccrName="State/Requestor Items"
  startColumn="2340"
  length="10"
```

```
        recordTypes="A,M,C,I"  
        parentXmlElement="Tumor"  
        trim="none"/>  
<ItemDef naaccrId="weightAtDiagnosis"  
        naaccrNum="9501"  
        naaccrName="State/Requestor Items"  
        startColumn="2350"  
        length="10"  
        recordTypes="A,M,C,I"  
        parentXmlElement="Tumor"  
        trim="none"/>
```

In this example, two new <ItemDef> elements with naaccrIds of “heightAtDiagnosis” and “weightAtDiagnosis” were created at position 2340 and 2350 respectively, each with a length of 10 characters.

Many new custom <ItemDef> elements can be created in the same way as the example above, provided that the overall length of these items does not extend beyond the length of the original <ItemDef> they are replacing. Once all of the custom <ItemDef> elements have been added to a Custom User Dictionary, this new file can be shared with other registries to communicate how a data exchange file should be parsed. Note that only <ItemDef> elements from a Default User Dictionary can be redefined, the <ItemDef> elements in a Base Dictionary cannot be changed. New data items defined with an appropriate Custom User Dictionary file will be preserved in conversions from XML to fixed-width file and back.

### 6.3 XSD for the Base and Default User Dictionary

The standard provides an XSD file for the Base and Default User Dictionary called “naaccr\_dictionary.xsd”. In conjunction with a W3C compliant validating parser, it can validate a Custom User Dictionary to ensure that any new <ItemDef> definitions follow the NAACCR XML standard.

## 7 Validation

The NAACCR XML standard defines a stepwise approach to XML data validation where each step provides an increasing level of validation complexity:

### Step 1. Element and Attribute Validation

XSDs provide basic validation of the correct element and attribute naming conventions in a NAACCR XML data exchange file. This step relies on W3C standards-compliant XML parsing software.

### Step 2. Data Type and Nesting Structure

The Base Dictionary and User Dictionary files contain all of the information necessary to validate the data types of data items and their nested structure within <Patient> and <Tumor> elements. This step relies on an XML software tool provided by the NAACCR XML Task Force to process NAACCR XML files.

### Step 3. Coding and Context

After conversion of a NAACCR XML file into a standard fixed-width format using software provided by the NAACCR XML Task Force, standard Edits metafiles can be used the same way they are currently used to validate a NAACCR data exchange file.

## 8 Extending the NAACCR XML Standard

The NAACCR XML standard allows custom, user-defined data and metadata at multiple insertion points in a data exchange document or the Base and User Dictionaries. This built-in extensibility is a forward-looking feature of the standard that encourages experimentation with new data types and structures while supporting the development of registry software where the details of an individual registry does not need to be known to the entire NAACCR community. All of these extensibility features can be used without any change to the XSDs.

One means of extending a NAACCR XML data exchange document is to add custom attributes to an element. For example, if a researcher wanted to link a gene sequence file to a tumor record, an attribute named “sequenceFile” could be added to the <Tumor> element with a direct link to the file.

Another extensibility option is the ability to add attributes to the <ItemDef> definitions in the Base and User Dictionary. As an example, if a registry had software that defined its own set of variable names for NAACCR items, different from the “naaccrId” defined in the standard, an attribute called “alternateName” could be added to the <ItemDef> element to map between the “naaccrId” and the registry item name.

A third extensibility feature allows the inclusion of arbitrary XML data in a NAACCR XML data exchange document at the <NaaccrData>, <Patient>, or <Tumor> levels. This extension method allows sophisticated data exchange scenarios where biomarker data, synoptic pathology reports, or anything else that can be encoded as valid XML can be included in a NAACCR XML file. Including data in this manner is different from defining a new <Item> in a custom User Dictionary because it is not bound by the same space limitations. These new data inclusions can be any size and do not have to be defined as <Item> elements with a NAACCR Item Number, but they do have some important limitations. First, the extra data cannot be read or saved into a fixed-width format file. And second, these data extensions require some kind of external data dictionary outside of the NAACCR XML specification to define their semantics and syntax for communication to other registries.

The fourth extensibility feature allows the inclusion of arbitrary XML data in the Base and User Dictionaries. For example, a software developer might want to keep context-sensitive help text or some other metadata for each <ItemDef> in the Dictionary files, in order to display these details to a user.

While these extensions are powerful, custom data that can be contained in an <Item> element and defined in a custom User Dictionary is preferable because it will be preserved in a conversion to and from the fixed-width format. However, when the custom data is too large to fit within an <Item> element, or it has a sophisticated structure that needs to be retained, the extensibility features of the standard permit advanced users to satisfy those needs.

## 9 Placement of Items at the Patient or Tumor Level

One of the most commonly discussed aspects of the standard during its development was how to place the current Standards Volume II data items at the correct level in the Patient/Tumor hierarchy. The current Standards Volume II data exchange standard clearly alludes to some patient and tumor delineations, but can be ambiguous and confusing about whether some data items should appear once per patient or once per tumor record. As a result, the NAACCR XML Task Force decided to rely on a document produced by the NAACCR Consolidated Items workgroup for an initial mapping of patients and tumor items, while realizing that future versions of this standard may need to change those designations. The NAACCR XML standard is designed in such a way such that changing the parent element of a data item can be done quickly and with few side effects.

## 10 Converting Between Flat File to XML

The NAACCR XML Task Force has created a software tool that converts current Standards Volume II fixed-width format files into NAACCR XML and back. This tool, the NAACCR XML Conversion Utility, provides validation of data item values according to the data types defined in the Base Dictionary and validates the nesting structure of <Item> elements within a NAACCR XML file. It can also handle compression and decompression of large data exchange files. To download the software and learn more about how it works, go to the website:

<http://naaccrxml.org>

## 11 Document History

<b>Revision Date</b>	<b>Contributing Authors</b>
<b>June 2015</b>	Isaac Hands, Roger Friedman, Gemma Lee, Fabian Depry
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<b>August 2016</b>	Fabian Depry, Lori Havener