# Accessing AGNIS Metadata Using the caDSR



#### Agenda

- Metadata
- caDSR
- Structure of a Form Builder Report
- Accessing metadata common to all module types
- Accessing metadata specific to a particular module type
- Downloading metadata from Form Builder
- Obtaining module public ID and version numbers

#### Goal

□ To provide the skills necessary to access the basic metadata required to submit data via AGNIS 2.x

#### Agenda

- Metadata
- caDSR
- □ Structure of a Form Builder Report
- Accessing metadata common to all module types
- Accessing metadata specific to a particular module type
- □ Downloading metadata from Form Builder
- Obtaining module public ID and version numbers

## Topics

- What is metadata?
- Data element fundamentals

#### What is Metadata?

- Metadata is data about data
- Metadata describes the content, quality, and other characteristics of data
- Example: If a question on a form reads: "Enter the Patient's Age"
  - What is the data?
  - What is the metadata?

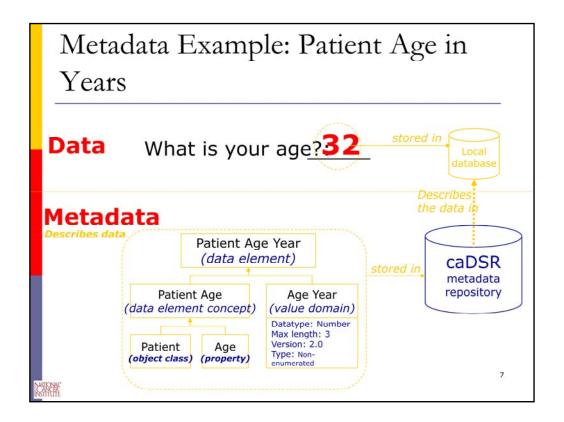
妍.

3

This slide is used with permission from the NCI. It is from a caDSR training presentation.

The data is the actual patient's age: 32

The metadata defines what you mean by patient age (a measurement in years of the duration of a person's life from birth to current year), how you want to represent that information – as a positive integer, between 0 and 150.



#### **EXAMPLE:**

Data (the piece of data you store)

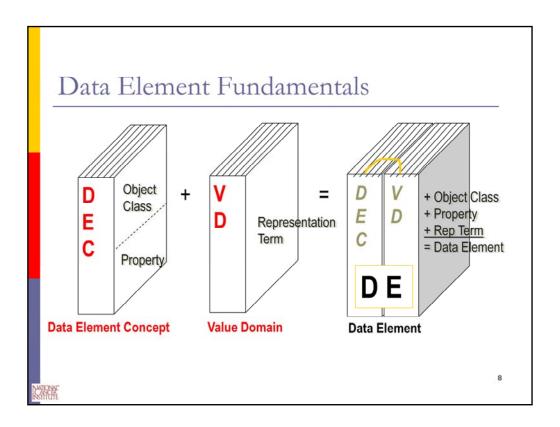
A question on a form reads: "Patient Race" with a list of selections

You enter "Asian" into a table in a database

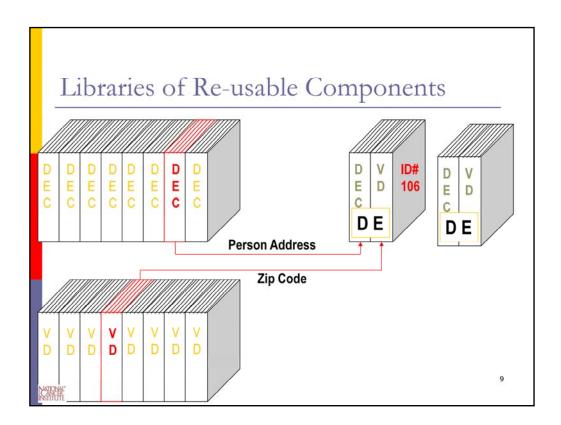
Metadata (information about that data)

Object: Patient Property: Race

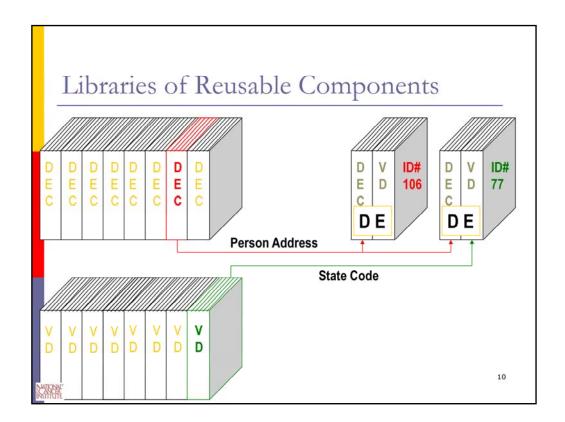
Representation: Category



As you should recall, at the high level, Data Element is made up of a Data Element Concept and Value Domain. The Data Element Concept is composed from an Object Class and Property. The Value Domain has a Representation Term. These components together form a Data Element.



Using the Person Address Zip Code example from the last slide, this slide again show how the Data Element was made. It is important to remember that these components (DEC and VD) can be used to make other Data Elements with unique Public IDs.



Here is an example of reusing Person Address with a different Value Domain of State Code to form a new DE of Person Address State Code with a Public ID of 77.

#### Agenda

- Metadata
- caDSR
- □ Structure of a Form Builder Report
- Accessing metadata common to all module types
- Accessing metadata specific to a particular module type
- □ Downloading metadata from Form Builder
- Obtaining module public ID and version numbers

## Topics

- What is the caDSR?
- Benefits
- $\hfill\Box$  Ways to access metadata in the caDSR

#### What is the caDSR?

- Cancer Data Standards Registry and Repository
- Metadata repository
- □ Uses ISO 11179 model
- Uses a standard vocabulary: Enterprise Vocabulary Services (EVS)

#### Benefits of the caDSR

- Standard vocabulary
- Standard method of representing metadata
- Existing software and resources

## Ways to Access Form Metadata Using the caDSR

#### Form Builder

- contains detailed information about each form
- https://formbuilder.nci.nih.gov/FormBuilder/

#### CDE Browser

- contains detailed information about each CDE (Common Data Element)
- https://cdebrowser.nci.nih.gov/CDEBrowser/

#### caDSR API

- Provides interactive browsing of the caDSR
- http://cadsrapi.nci.nih.gov/cadsrapi40/Home.a ction

This presentation does not show how to access form metadata using the CDE Browser. The CDE Browser returns information about the CDE that is not available in Form Builder, but does not contain form specific information. For the following reasons, using the CDE Browser to retrieve form information is not recommended:

- CDEs are not displayed in the order in which they appear on the form
- Form instructions and other form specific information is not available
- For choice list CDEs, there may be permissible values displayed that are not allowed on a specific form
- The preferred question text may not match the question text on a specific form

#### Agenda

- Metadata
- caDSR
- Structure of a Form Builder Report
- Accessing metadata common to all module types
- Accessing metadata specific to a particular module type
- □ Downloading metadata from Form Builder
- Obtaining module public ID and version numbers

## Topics

- □ Structure of a Form Builder report
- □ Types of modules
- Types of CDEs

## Structure of a Form Builder Report

#### Contains two main sections:

- General form information
  - Equivalent to form header on the PDF version of the form
- Form contents
  - Equivalent to questions on the PDF version of the form
  - Consists of modules that contain groups of CDEs

#### Types of Modules

- Non-repeating modules
  - Used to group related CDEs that can occur only once on a form.
  - Most frequently used type of module
- Non-normalized repeating modules
  - Used to group CDEs that can occur more than once on a form.
- Normalized repeating modules
  - Used to group a list or table of questions

1

Module types will be discussed in detail later in the presentation

## Types of CDEs

- □ Free text
  - Does not have a list of permissible values
  - The CDE contains detailed information about
    - Data type
      - Character
      - Number
      - Date
    - Display format
    - Unit of measure
- Choice list
  - Answers are restricted to a list of permissible values

#### Agenda

- Metadata
- caDSR
- □ Structure of a Form Builder Report
- Accessing metadata common to all module types
- Accessing metadata specific to a particular module type
- □ Downloading metadata from Form Builder
- Obtaining module public ID and version numbers

## Topics

- □ Finding a form
- Metadata required for all forms
- Accessing form information
- Accessing question information
  - Free-Text CDEs
  - Choice list CDEs

#### How to Find a Form

- The easiest way to find a form is to use the navigation tree within the Form Builder application.
- The following slides will show you how to login to the Form Builder application and navigate to a form using the navigation tree.



Access a Form Builder Report

- Go to URL https://formbuilder.nci.nih.gov/FormBuilder/
- •Login using the instructions for a guest user

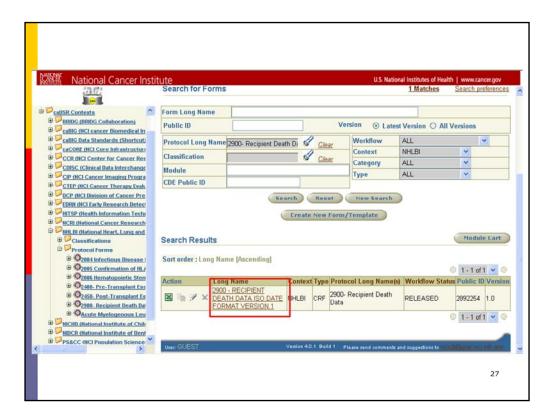


Form Builder - main page

Navigate to a form using the navigation tree on the left-hand side of the screen NHLBI (National Heart, Lung, and Blood Institute) -> Protocol Forms -> Desired form



Click on the link for the form that you desire



- •The search results will be displayed on the right-hand side of the screen.
- •The search results contain the following information:
  - Long name: The name and number of the form
  - Context: The organization associated with the form. All NMDP forms are in the NHLBI (National Heart, Lung, and Blood Institute) context.
  - Protocol Long Name: The name and number of the form
  - Workflow status:
    - Released: Form version is available for use. Only use those form versions that have a released status
    - Retired: Form version is no longer being used
    - Draft New: Form version is being developed and should not be used.
  - Public ID
    - Identifier associated with a particular form
  - Version number
    - Indentifies a particular instance of a form
- A form is uniquely identified by the combination of its public ID and version number
- •To view a form, click on the long name of the specific form that you want to view.
- •It can take a long time for the Form Builder report to appear

## Required metadata for All Module Types

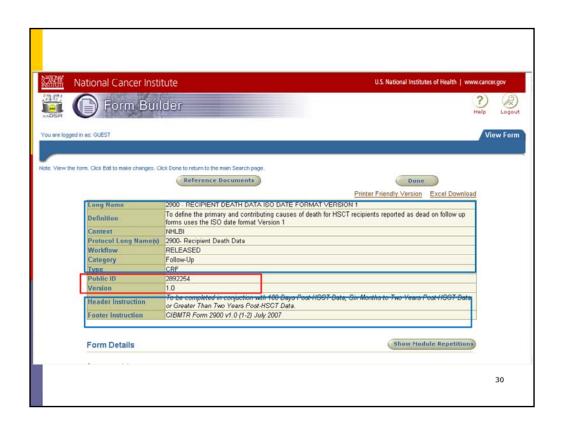
- Form public ID and version number
- CDE public ID and version number
- □ Permissible values (if applicable)
- Module public ID and version number
  - This information is not available in Form Builder
  - Instructions on how to obtain this information is given later in this presentation

28

Module public ID and version number can be found

## Accessing Form Level Information

- Required metadata (noted in red box)
  - Form public ID
  - Form version number
- Additional metadata (noted in blue boxes)
  - Long name
  - Definition
  - Context
  - Workflow status
  - Category
  - Instructions



#### Reference Documents

- Contain additional information associated with the Form Builder report
- Examples of reference documents
  - PDF version of the form
  - Change notes associated with the form



- •A Form Builder report may be associated with reference documents
- •To access the reference documents, click on the "Reference Documents" button at the top of the page



- •The most common types of reference documents that the NMDP uses are
  - •PDF version of the form
  - •PDF document describing the changes made in each version of the Form Builder report

## Form Change Notes

#### Change Notes

#### Form 2900 - RECIPIENT DEATH DATA ISO DATE FORMAT VERSION 1

Public ID: 2892254 Version: 1.0

Form	Change Note
2900 - RECIPIENT DEATH DATA (Public	Replaced by 2900 - RECIPIENT DEATH
ID 2481311 Version 3.0) – US date format	DATA ISO DATE FORMAT VERSION
	1(Public ID 2892254 Version 1.0)
2900 - RECIPIENT DEATH DATA ISO	
DATE FORMAT VERSION 1 (Public ID	Protocol Long Name added: "2900 – Recipient
2892254 Version 1.0)	Death Data"
	Footer Instruction added: "CIBMTR Form
	2900 v1.0 (1-2) July 2007"
	Header instruction changed to: "To be
	completed in conjuction with 100 Days Post-
	HSCT Data, Six Months to Two Years Post-
	HSCT Data, or Greater Than Two Years Post-
	HSCT Data."
	Module "Registry Use Only" CDE 2527891 –
	Changed to CDE 2866943

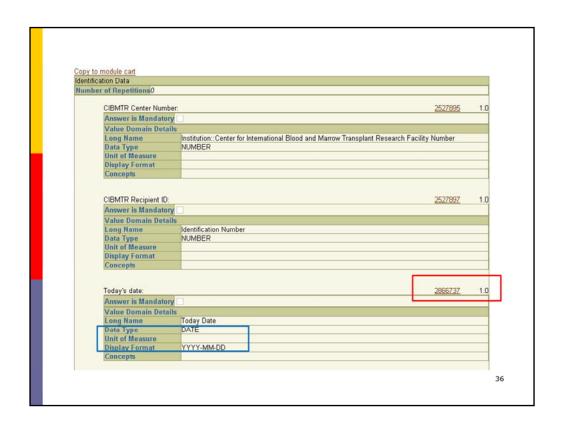
Sample form change notes.

#### Accessing Metadata for Free Text CDEs

- Required metadata (noted in red box)
  - CDE public ID
  - CDE version number
- Additional metadata (noted in blue box)
  - Data type
  - Display format
  - Unit of measure

3.

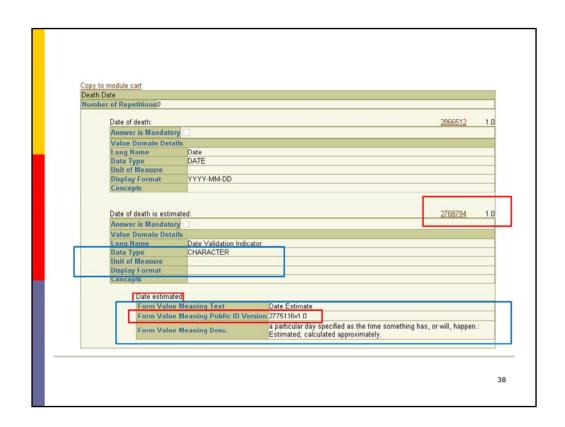
- •Required metadata
  - •CDE public ID: number that identifies a particular CDE
  - •CDE version number: number that identifies a version of a CDE
  - •A CDE is uniquely identified by the combination of its public ID and version number
- Additional metadata
  - Data type: Character, number, or date
  - •Display format: the way in which an answer is displayed such as "999.9" to indicate that an answer has 1 decimal place
  - •Unit of measure: the specified unit of measure such as "mg"



# Accessing Metadata for Choice List CDEs

- Required metadata (noted in red box)
  - CDE public ID
  - CDE version number
  - Permissible values
    - Text or
    - Value meaning public ID and version number
- Additional metadata (noted in blue box)
  - Data type
  - Display format
  - Unit of measure
  - Value meaning text
  - Value meaning description

- •Required metadata
  - •CDE public ID: number that identifies a particular CDE
  - •CDE version number: number that identifies a version of a CDE
  - Permissible values: the valid answers associated with a CDE
  - •A CDE is uniquely identified by the combination of its public ID and version number
- Additional metadata
  - Data type: Character, number, or date
  - •Display format: the way in which an answer is displayed such as "999.9" to indicate that an answer has 1 decimal place
  - Unit of measure: the specified unit of measure such as "mg"
  - Value meaning text: a string of concept names that describes the permissible value
  - Value meaning public ID version: the public ID and version number that uniquely identify a value meaning
  - Value meaning description: the definition of each concept in the value meaning text



#### Agenda

- Metadata
- caDSR
- □ Structure of a Form Builder Report
- Accessing metadata common to all module types
- Accessing metadata specific to a particular module type
- □ Downloading metadata from Form Builder
- Obtaining module public ID and version numbers

## Topics

- Non-repeating modules
- Non-normalized repeating modules
- Normalized repeating modules

- Used to group related CDEs that can occur only once on a form.
- Most frequently used type of module
- Please refer to the AGNIS Data Submission Procedures document for additional information and example XML

Accessing the metadata

Non-repeating modules do not require additional metadata

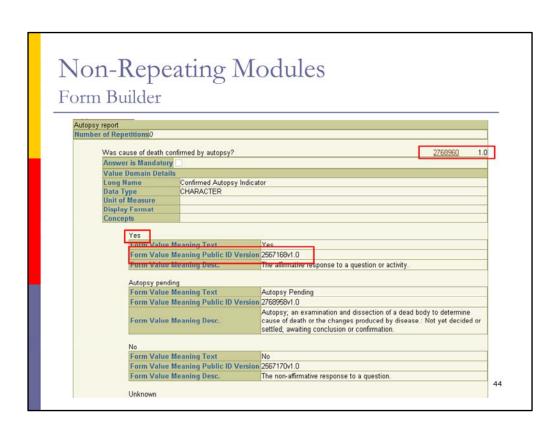


Illustration of the mapping

#### caDSR

#### Example Local Database

Death Occurrence Date ——— death\_dte

Death Occurrence Date Validation Indicator death\_dte\_est\_ind

Translation of sample data

#### caDSR

#### Example Local Database

Death Occurrence Date = 12/31/2008 death\_dte = 12/31/2008

Death Occurrence Date Validation Indicator = Yes death\_dte\_est\_ind = Yes

#### Non-Normalized Repeating Modules

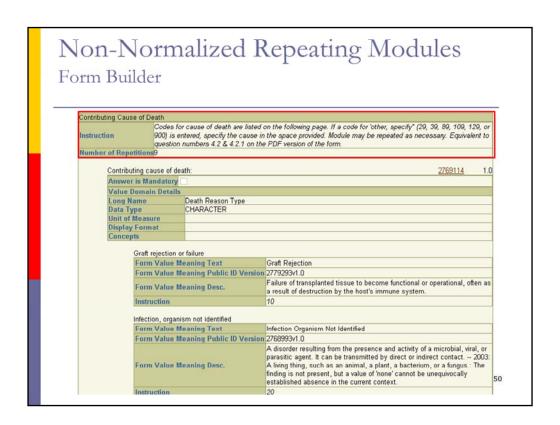
- □ Used to group CDEs that can occur more than once on a form.
- Corresponds to questions on the paper form that can have more than one answer.
- Repeat sequence number used in AGNIS XML to identify instances.
- Please refer to the AGNIS Data Submission Procedures document for additional information and example XML

Non-Nor	malized Repeating Modules	
PDF Version	of Form	
Form 2900 Q	Question 4.2	
4. Cause of death: LD Codes for cause of death a specify the cause in the sps Primary: Contributing:	re listed on the following page. If a code for "other, specify" (29, 39, 89, 109, 129, or 900) is ente ace provided.  Specify:  Specify:  Specify:  Specify:  Specify:  Specify:	red,
		48

#### Non-Normalized Repeating Modules

Accessing the metadata

- Non-normalized repeating modules in Form Builder will have the following
  - Module level instructions that state that the module may be repeated as needed
  - Number of repetitions equal to one less than the total number of instances allowed
    - For example, if you can have a maximum of 10 contributing causes of death on form 2900, the number of repetitions will be 9.



- Modules may also contain CDEs that can occur more than once on a form.
- For example, on form 2900 Recipient Death Data, a patient may have more than one contributing cause of death.
- Repeating modules will have the following
  - Module level instructions that state that the module may be repeated as needed
  - Number of repetitions equal to one less than the total number of instances allowed

# Non-Normalized Repeating Modules Illustration of the mapping

#### caDSR

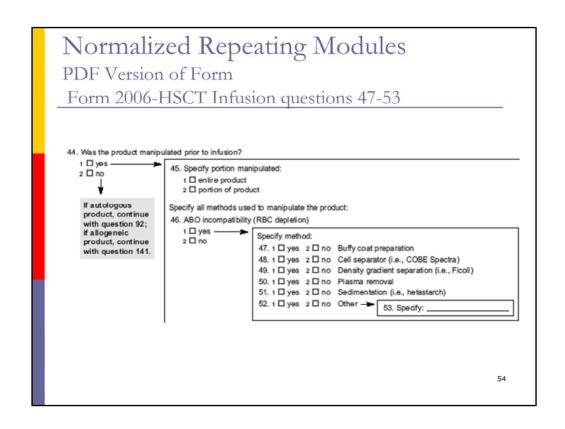
#### Example Local Database

# Non-Normalized Repeating Modules

#### Translation of sample data Example Local Database caDSR uence # Contributing Cause of Death Type = accidental death cod\_contrib = accidental death Contributing Cause of Death Type = other infection cod\_contrib = other infection Contributing Cause of Death Specify = viral infection cod\_specify = viral infection Contributing Cause of Death Type = other organ failure cod\_contrib = other organ failure Contributing Cause of Death Specify = renal failure cod\_specify = renal failure

#### Normalized Repeating Modules

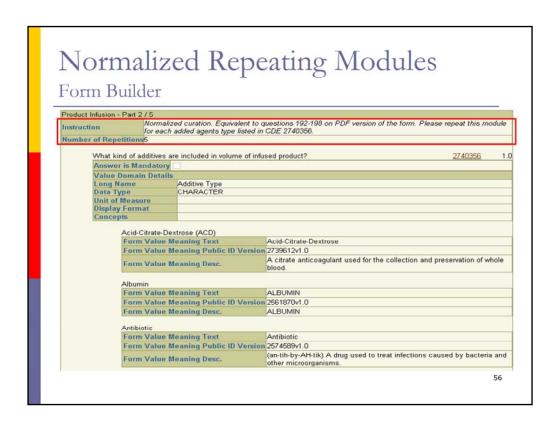
- Used to group a list or table of questions.
- One CDE is used for each column
- Value of one CDE (the mapping CDE) is used to identify the row (or question number).
- Please refer to the AGNIS Data Submission Procedures document for additional information and example XML



#### Normalized Repeating Modules

Accessing the metadata

- Each normalized module will have the following
  - Module level instructions that clearly identifies it as being normalized.
  - Number of repetitions equal to one less than the total number of rows
    - □ For example, if the table contains 6 rows, the number of repetitions will be 5



- •A module may be used to contain normalized CDEs.
- Each normalized module will have the following
  - Module level instructions that clearly identifies it as being normalized.
  - Number of repetitions equal to one less than the total number of instances allowed

# Normalized Repeating Modules Illustration of the mapping

# caDSR Infusion Agent Type Infusion Agent Administered Infusion Agent Type Infusion Agent Specify Infusion Agent Specify

#### Normalized Repeating Modules Translation of sample data Example Local Database caDSR Infusion Agent Type = heparin inf\_prod\_add\_agt\_heprn\_yn = yes 1 Infusion Agent Administered = yes Infusion Agent Type = dextran inf\_prod\_add\_agt\_dextr\_yn = no 2 Infusion Agent Administered = no inf\_prod\_add\_agt\_othr\_yn = yes Infusion Agent Type = other 3 Infusion Agent Administered = yes inf\_prod\_add\_agt\_oth\_spec = drug A Infusion Agent Specify= drug A

#### Agenda

- Metadata
- caDSR
- □ Structure of a Form Builder Report
- Accessing metadata common to all module types
- Accessing metadata specific to a particular module type
- Downloading metadata from Form Builder
- Obtaining module public ID and version numbers

## Topics

- Download formats
- Ways to download
  - From within the Form Builder report
  - From search results
- Example Excel spreadsheet

#### **Download Formats**

- Excel
- Printer friendly
  - not technically a download
  - contains all repetitions of a module
  - may be very long
- XML format is not available

# Ways to Download CDEs using Form Builder

- From within the Form Builder report
  - Excel download
  - Printer friendly web page
    - not recommended because it displays each instance of a module and creates a much longer version of the form
- From the search results
  - · Excel download only

## Downloading CDEs From Within A Form Builder Report

- Click on the hyperlinks for either:
  - Printer Friendly Version
  - Excel Downloads



2 ways to download CDEs using Form Builder

- •From within the Form Builder report
  - Excel download
  - Printer friendly web page not recommended because it displays each instance of a module and creates a much longer version of the form
- •From the search results
  - Excel download only

# Downloading CDEs From the Search Results

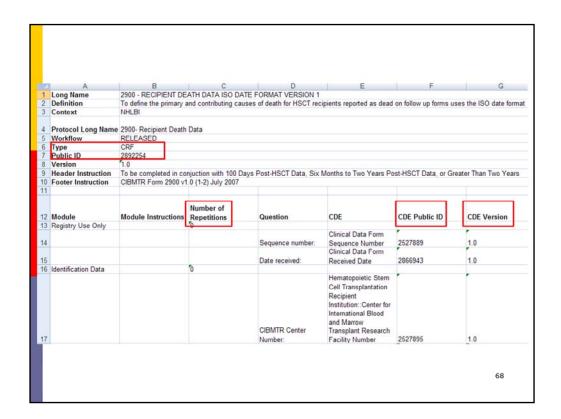
Click on the Excel icon



To download an Excel version of the form from the search results, click on the Excel icon

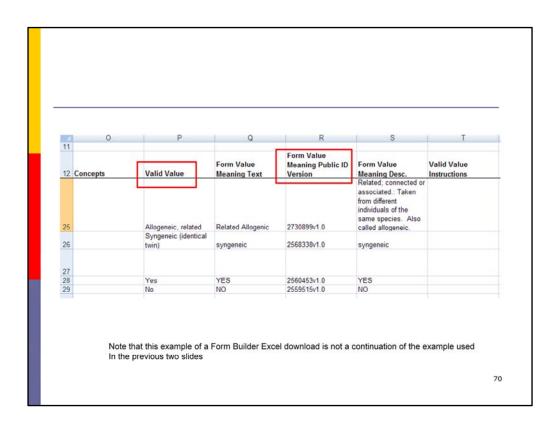
## Example Excel Spreadsheet

□ The column headers for required metadata are in a red box



The Excel spreadsheet downloaded from the Form Builder contains information about the CDEs in the order in which they appear in the form. Only form specific information is displayed.

	н	13	J	K	L	M	N
1							
)							
1							
	Question Instructions	Answer is Mandatory	Question Default Value	Value Domain Long Name	Value Domain Data Type	Value Domain Unit of Measure	Display Format
		No		Sequence Number	NUMBER		
5		No		Received Date	DATE		YYYY-MM-DD
7		No		Institution::Center for International Blood and Marrow Transplant Research Facility Number	NUMBER		



#### Agenda

- Metadata
- caDSR
- □ Structure of a Form Builder Report
- Accessing metadata common to all module types
- Accessing metadata specific to a particular module type
- □ Downloading metadata from Form Builder
- Obtaining module public ID and version numbers

# Topics

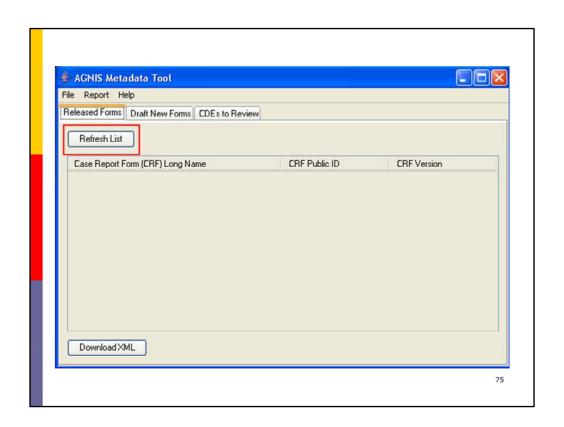
- □ Ways of obtaining module public ID and version numbers
- Using the metadata tool
- Using the caDSR API

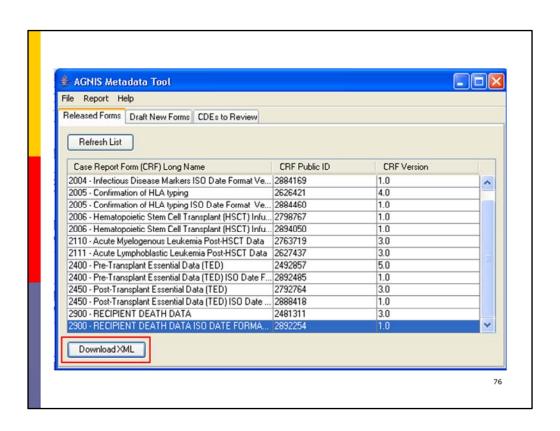
# Ways of Obtaining Module Public ID and Version Numbers

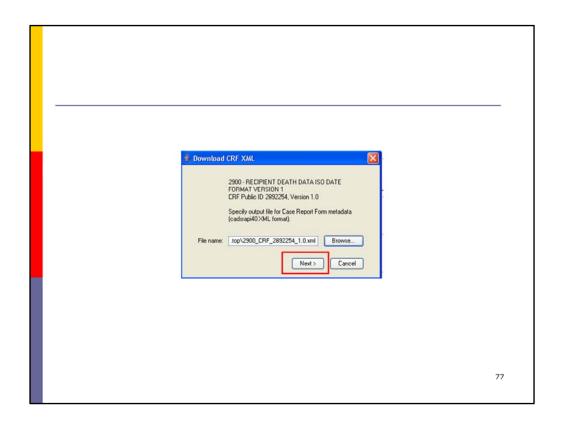
- AGNIS metadata tool
  - Download beta version from: http://www.agnis.net
- caDSR API
  - http://cadsrapi.nci.nih.gov/cadsrapi40/Home.a ction

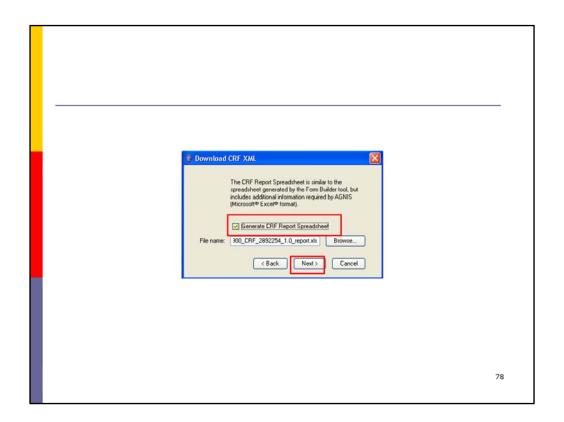
# AGNIS Metadata Tool

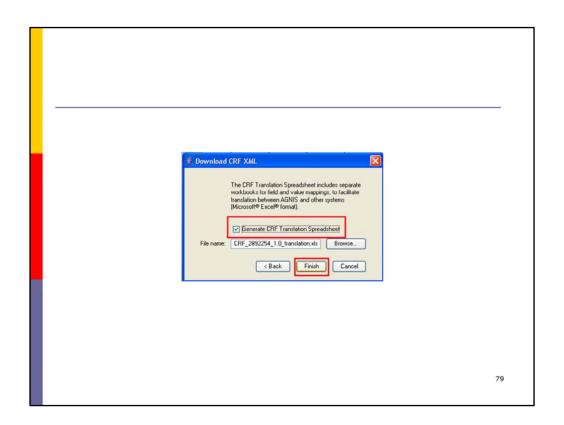
- Recommended method for obtaining module public ID and version numbers
  - Can download data in either Excel or XML formats
  - Metadata presented in a user-friendly manner







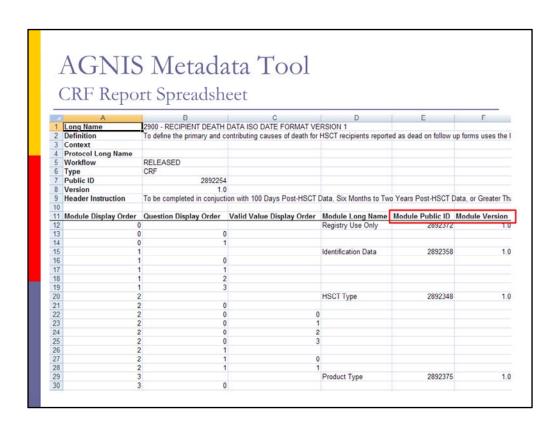


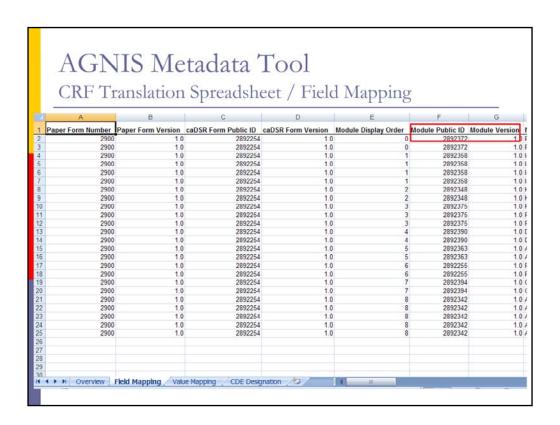


# AGNIS Metadata Tool

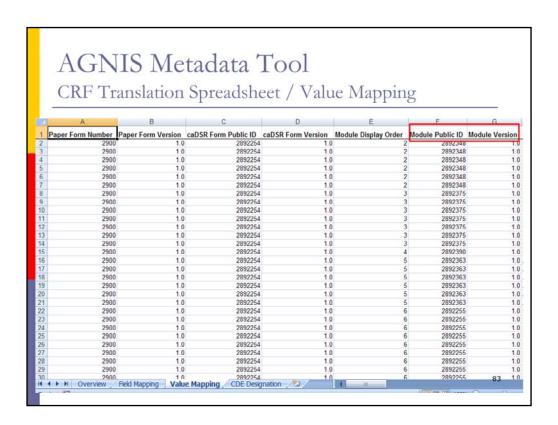
#### Output

- □ caDSR XML
- Microsoft Excel
  - CRF Report Spreadsheet
    - Mimics Form Builder output
    - □ Includes information not in Form Builder
  - CRF Translation Spreadsheet





This screenshot does not display all of the information available in the Field Mapping tab of the CRF Translation spreadsheet.



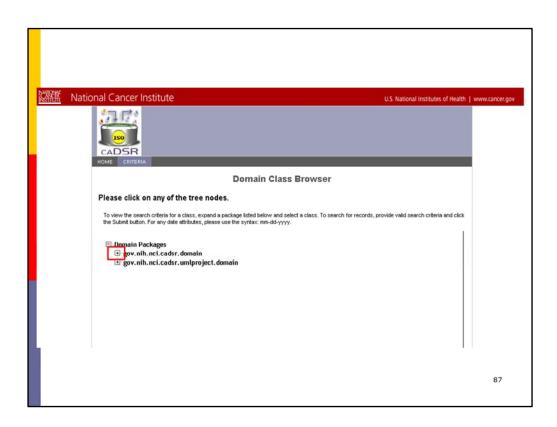
This screen-shot does not display all of the information available in the Value Mapping tab of the CRF Translation spreadsheet.

### caDSR API

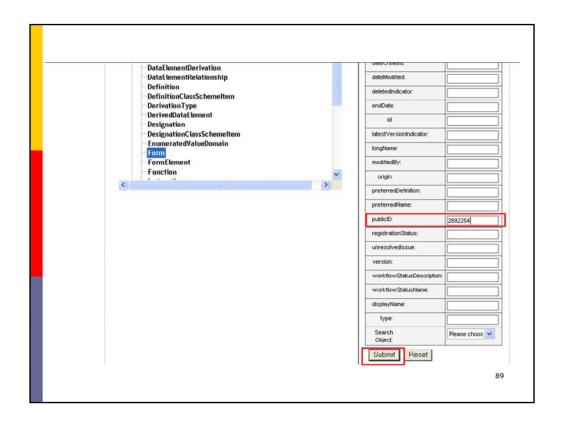
- Not the recommended method for obtaining module public ID and version numbers
  - Numerous steps involved
  - Metadata not presented in a user-friendly manner
- □ The following slides show how to obtain the information

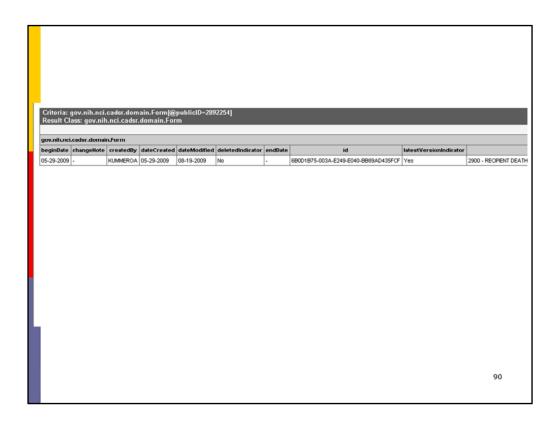


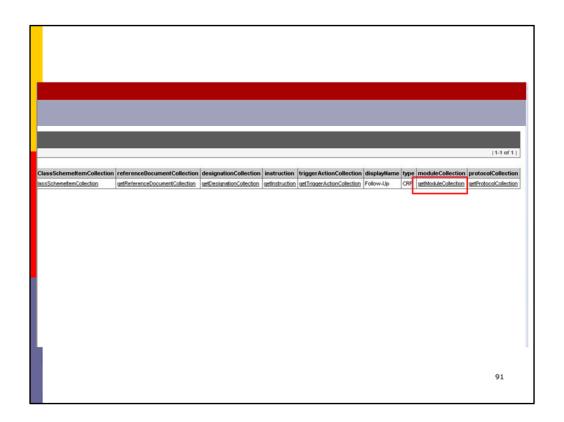


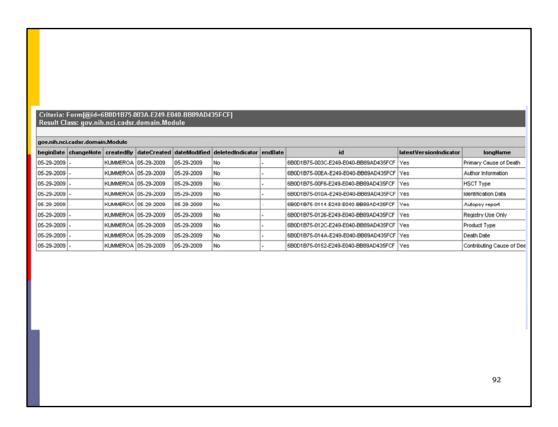


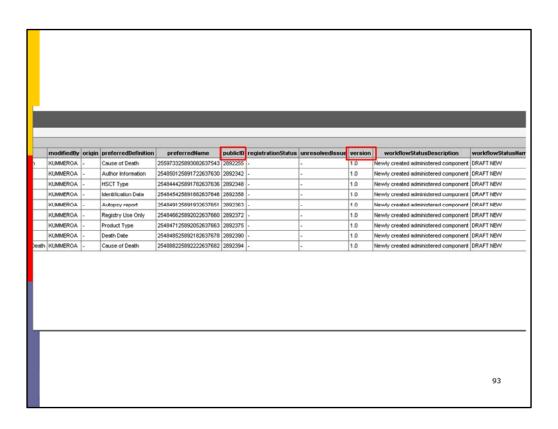












# Sources of Additional Information

AGNIS website:

http://www.agnis.net/DOCUMENTATION/i
ndex.html

- Metadata Tool User Guide
- AGNIS Data Submission Procedures
- caCORE and caDSR