Interchangeable Data-Collection Instruments:

Enabling Rapid Response throughout the Public Health Information Network (PHIN)

Tim Morris
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Interchangeable Data-Collection Instruments Agenda

- Business Problem
- Architectural Vision
- Demonstration Context: SARS Scenario
- Technology Demonstration
- Future Directions

Business Problem

Problem: An emerging disease, a new cluster of a known disease agent, or the suspicion of a new disease or health event that is manifest through a combination of suspicious symptoms.

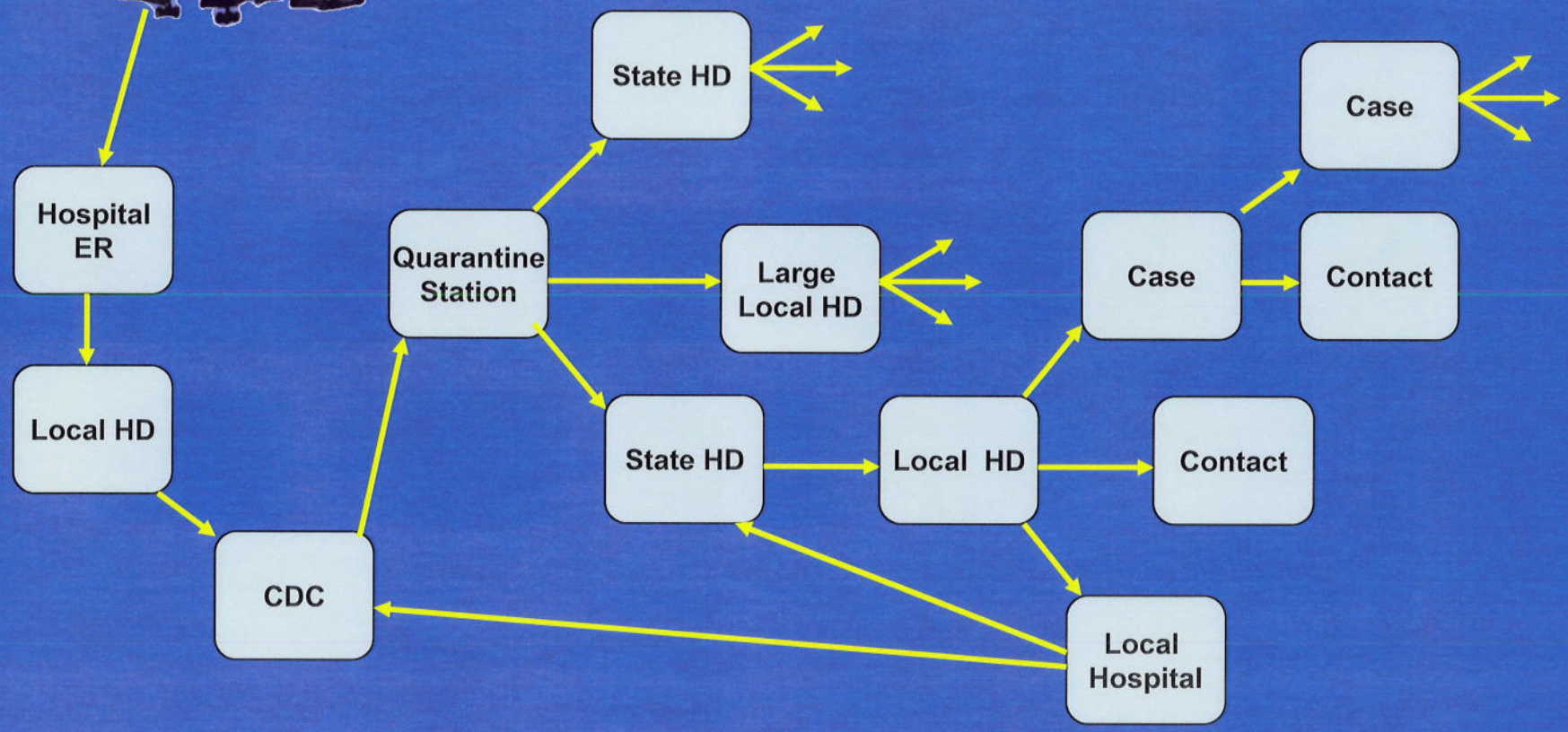
Need: Rapidly create and distribute data-collection instruments containing a standard set of questions and responses that are bound to a standard schema and standard vocabulary.

Instruments must be usable by a broad range of devices and application software, and must capture and exchange data in a consistent way. Further, the instruments must be capable of being modified as new knowledge emerges during the course of the investigation.

SARS Scenario

- An American couple traveling overseas visits an area where SARS has been reported.
- Upon their return, the couple becomes ill with worsening respiratory symptoms, and checks in at the hospital emergency room.
- Upon diagnosis of SARS, the hospital reports the case to the local health department and CDC.
- CDC notifies the quarantine station, which pulls the travel manifest for the couple's return flight, and notifies the health departments for the passengers' jurisdictions.

Containing the Outbreak



Architectural Vision

Rapid access to reusable, meta-model-driven instruments, fragments, and schemas facilitates instrument construction.

Source Content Data Stores

- Edit, Manage, & Control Content & Ontology Data Stores
- Provision Data

Content Objects
Vocabulary Objects
Queries/Responses
Publish/Subscribe

Authoring Toolset

- Create & Edit Schemas
- Distribute Schemas

Authoring tools enable SMEs to construct & customize instruments using simple graphical interfaces.

Referenced Vocabulary Objects

XML Schemas
Schema Updates

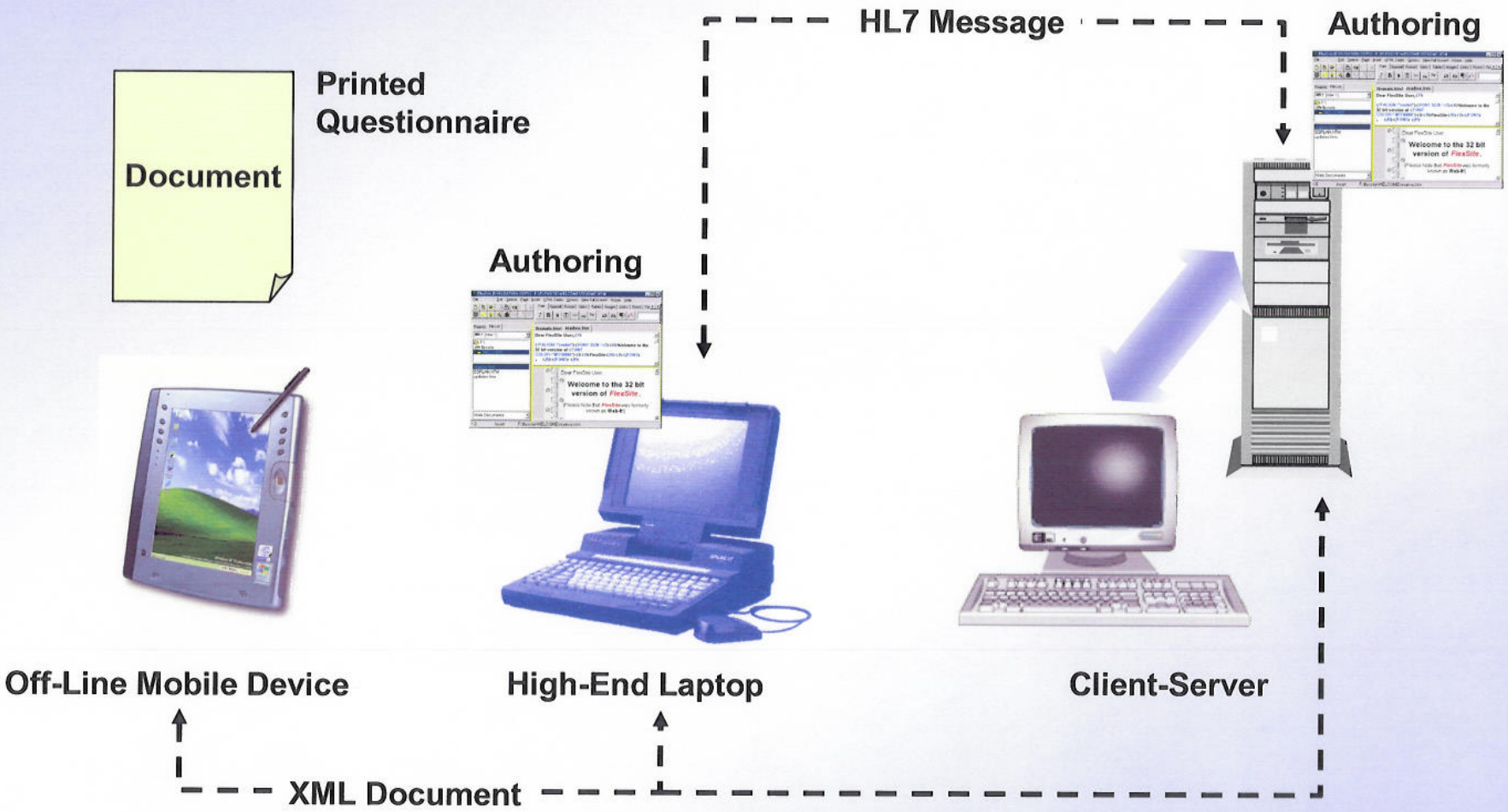
Investigation Application

- Consume Schema
- Collect Data
- Persist Data
- Analyze Data
- Report Data

HL7 Messages

Investigators use standard instrument in either on-line or off-line mode to collect and submit data.

Implementation Options



Challenges

- Binding of questions to schemas and vocabulary
- Checking and validating response values in real time
- Indicating required fields
- Bounding response values, such as requiring that they be within a specific range
- Integration with Web Services, such as PHIN VADS
- Calculating and validating a response value across multiple data fields
- Navigation based on responses
- Running the same XML markup on a range of devices, using device-appropriate UIs

XForms Provides Standard, Metadata-Driven Solution While Preserving Choice

- W3C Recommendation (October, 2003)
- Intended ultimately to replace HTML forms
- Uses XML to model, collect, and serialize user input by splitting forms into three parts – data model, instance data, and user interface
- Uses XML for data collection and exchange
- Declarative – eliminates need for scripting
- Uses XSL and XPath for input format, type validation, and skip patterns

Any Paper Form Can Be an "XForm"

CDC

SEVERE ACUTE RESPIRATORY SYNDROME

Public Health Guidance for Community-Level Preparedness and Response to Severe Acute Respiratory Syndrome (SARS) Version 2

Supplement B: SARS Surveillance

Appendix B2: SARS Domestic Case Reporting Form

Form Approved
OMB No. 0920-
xxxx

Person Details

1. IDs	
CDC ID #: *CDC ID WILL BE AUTOMATICALLY GENERATED*	Date reported to CDC: ___ / ___ / ___ (m m d d y y y y)
State ID #: _____	Jurisdiction:
Date reported to state or local health department: ___ / ___ / ___ (m m d d y y y y)	
2. Submitted By	
Last Name:	First Name:
State:	Affiliation:
Phone:	E-mail:
3. Patient Information	
City of Residence:	
County of Residence:	
State of Residence:	
Age at onset: _____ ☐ Years ☐ Months	Sex: ☐ Male ☐ Female
Ethnicity: ☐ Non Hispanic ☐ Hispanic	Race (*Mark one or more*) ☐ American Indian/Alaska Native ☐ Asian ☐ Black ☐ Native Hawaiian/Other Pacific Islande ☐ White ☐ Unknown
Nationality/Citizenship:	
Residency: ☐ US Residency ☐ Non-US Residency	
4. Optional Patient Information	
Last Name:	First Name:

January 8, 2004

DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION
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Michigan SARS Screening Form (12-4-2003)

MDCH Use Only
CDC #: _____

1. Today's Date	(mm/dd/yyyy): ___ / ___ / ___		
2. Clinician Information	Physician's Name:	Hospital/Clinic:	
County:	Phone: ( )	Pager: ( )	Other:( )
Contact Name:	Phone: ( )	Other:( )	
3. Patient Information	Last Name:	First Name:	Date of Onset: ___ / ___ / ___
City of residence:	State:	ZIP:	Phone: ( )	Date of Birth: ___ / ___ / ___	Occupation:

A. Abnormal chest radiograph? See attached CDC Appendix C3 for Infection Control Guidelines.

Yes No Unknown Date _____ *Interpretation* _____

Hospitalized Date _____ *Facility Name* _____

B. Travel in a previously SARS-affected area* during the 10-day period before symptom onset?

Mainland China, Beijing, China, Hong Kong, Taiwan, Hanoi, Vietnam, Singapore, and Toronto, Canada

Yes No Unknown

Date of return to the US (mm/dd/yyyy): ___ / ___ / ___

Date	Departing from	Arriving to	Airline Name & Flight Number	Other (Car, Bus, etc.)

IDNUM		Case	Control	SEX	AGE	SMOKE	MBGR	MBGR1WD	GRTK	GRTKWD	TARGET	KOHLS	CINEMA	OFFICEMAX	CLBOWLING	GROUD1
1		1	0	F	74	N	1	d	1	w	0	0	0	0	0	1
1	a	0	1	F	71	N	1	d	1	d	0	0	0	0	0	1
1	b	0	1	M	81	N	0	0	1	d	0	0	0	0	0	1
2		1	0	F	48	Y	0	0	1	w	0	0	0	1	0	1
2	a	0	1	M	49	N	0	0	0	0	0	0	0	0	0	0
2	b	0	1	F	41	N	0	0	0	0	0	0	0	0	0	1
3		1	0	M	62	Y	1	w	1	w	0	0	0	0	1	1
3	b	0	1	F	69	Y	0	0	0	0	0	0	0	0	0	0
3	a	0	1	?	72	N	0	0	0	0	0	0	0	0	0	0
4		1	0	M	56	Y	0	0	1	w	1	0	0	0	0	1
4	a	0	1	F	[illegible]	[illegible]	[illegible]	0	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	0	0
4	b	0	1	M	6[illegible]	N	[illegible]	d	[illegible]	[illegible]	[illegible]	0	[illegible]	[illegible]	0	0
[illegible]		[illegible]	[illegible]	M	[illegible]	[illegible]	[illegible]	d	[illegible]	[illegible]	[illegible]	0	0	[illegible]	0	1
5	a	0	1	M	62	N	1	d	0	[illegible]	[illegible]	0	0	0	0	1
5	b	0	1	M	69	N	1	d	1	d	0	0	0	0	0	1
6		1	0	F	76	Y	1	w	1	w	0	1	0	0	0	1
[illegible]		[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	0	0	0	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	0	0
[illegible]	b	[illegible]	[illegible]	[illegible]	67	N	0	[illegible]	1	w	0	0	[illegible]	[illegible]	0	1
[illegible]		[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	1	d	1	d	[illegible]	[illegible]	[illegible]	[illegible]	0	1
7	a	0	1	F	37	Y	1	d	1	w	0	0	1	0	0	1
7	b	0	1	M	49	N	1	w	1	w	0	0	1	0	0	1
[illegible]		1	0	F	73	Y	0	0	1	w	1	1	0	0	0	1
[illegible]	a	0	1	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	0	0	0	0	0	1
[illegible]	b	0	1	N	[illegible]	[illegible]	[illegible]	0	[illegible]	[illegible]	[illegible]	0	0	0	0	0
[illegible]		1	0	[illegible]	[illegible]	[illegible]	1	d	[illegible]	[illegible]	0	0	0	0	0	1
9	a	0	1	F	31	N	1	w	1	w	1	0	1	0	0	1
9	b	0	1	M	33	N	1	w	1	w	1	1	1	0	0	1
10		1	0	M	54	Y	1	d	1	d	0	0	0	0	0	1
10	a	0	1	M	60	N	0	0	1	w	1	0	0	0	0	0
10	b	0	1	M	58	N	0	0	0	0	0	0	0	0	0	0
11		1	0	F	34	Y	1	w	1	w	1	0	0	0	0	1
11	a	0	1	F	29	N	1	w	1	w	0	0	0	0	0	1
11	b	0	1	F	37	N	1	d	1	w	0	0	0	1	0	1
12		1	0	M	72	N	0	0	0	0	0	0	0	0	0	1
12	a	0	1	F	75	N	0	0	0	0	0	0	0	0	0	0
12	b	0	1	F	66	N	1	d	1	w	1	1	0	1	0	1
13		1	0	M	57	Y	0	0	1	w	0	0	0	0	0	1
13	a	0	1	M	62	N	1	w	1	w	1	1	0	0	0	1
13	b	0	1	F	48	N	1	w	0	0	0	0	0	0	0	0
14		1	0	F	65	N	0	0	0	0	0	0	0	0	0	0
14	a	0	1	M	65	N	0	0	0	0	0	0	0	0	0	0
14	b	0	1	M	71	N	1	w	1	w	0	0	0	0	0	0
15		1	0	F	70	Y	0	0	1	w	1	0	0	0	0	1

...or can supply data that can be imported into an XForm.

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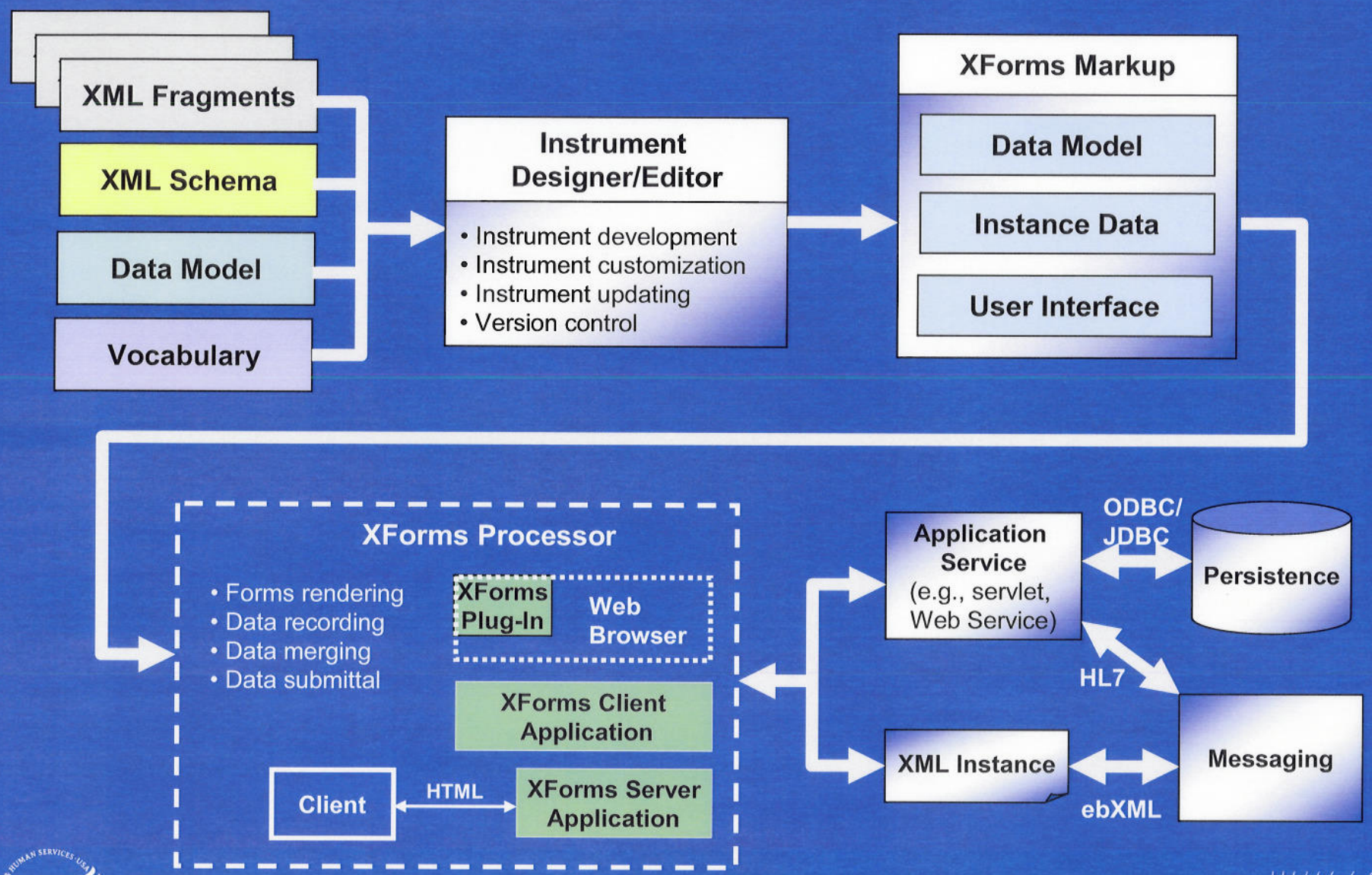
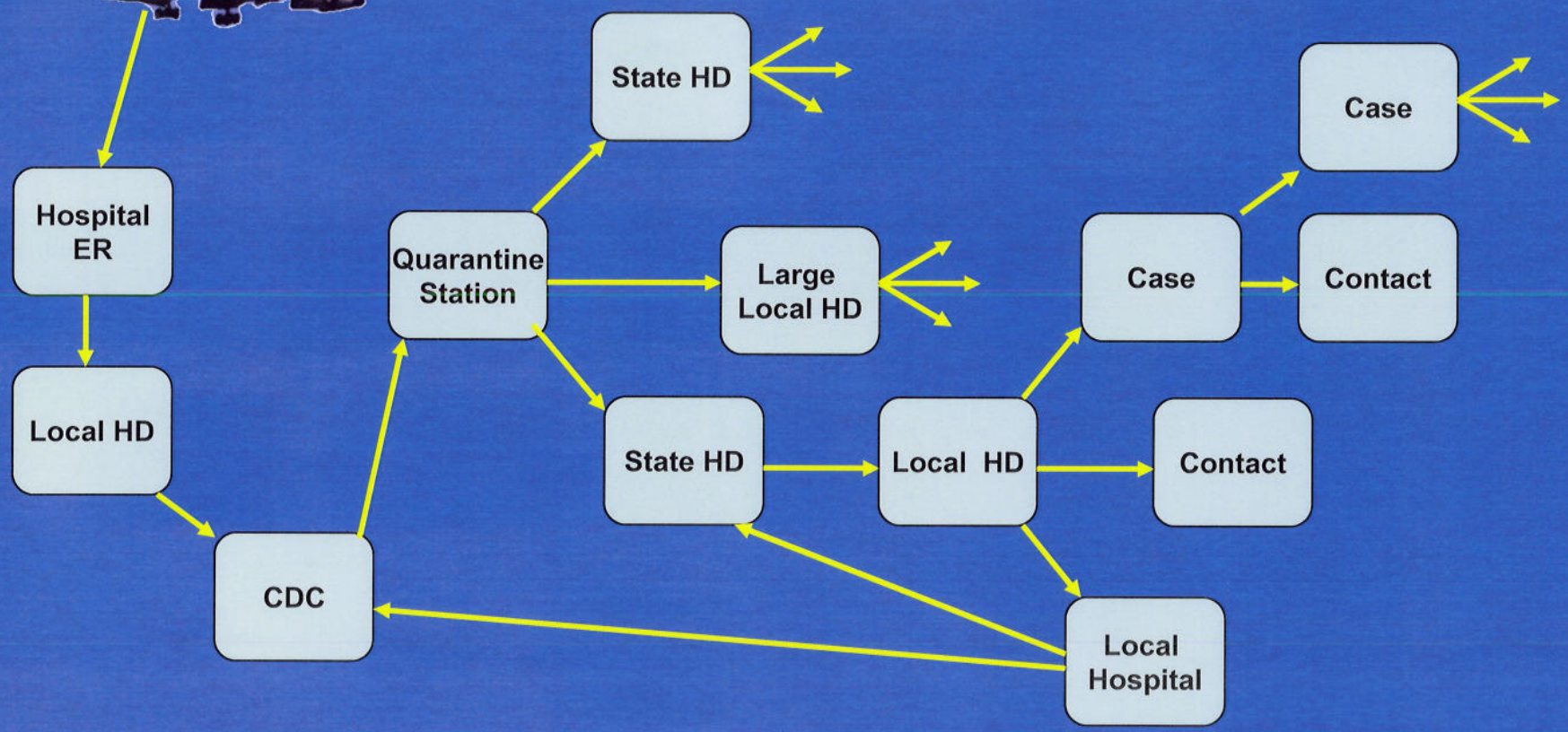
XForms Architecture



The Business Case for XForms

- Open standard – no proprietary lock-in
- SME can construct single instrument for all platforms – leaving rendering as a client decision
- Off-line and on-line data collection
- Implements public-health business rules
  - Required fields
  - "Skip patterns" based on user response, such as branch, reveal/hide fields
  - Binding of questions to schema and vocabulary
- Integrated instrument submittal
- No scripting – faster creation of instruments

Containing the Outbreak



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SARS Scenario

Time

Scenario : Conduct SARS Investigation

SARS data-collection instrument is developed & published

Hospital uses standard SARS instrument to report case

Quarantine is notified & pulls flight manifest

Quarantine notifies state & local health departments

State customizes SARS instrument as required

Provision form to local HDs

Provision form to hospitals

Provision form to emergency response teams

Render form in off-line device

Render form on laptop

Render form in client-server envir

Persist data in XML document

Persist data as name:value pairs

Persist data in database tables

Report data to State

Report data to CDC

Aggregate data

Provide data for AVR

XForms Authoring

1. Select content fragments and value sets from shared repository.
2. Use intuitive authoring tool to create an XML "instance" document
   - "Instance" becomes the document repository for the collected data
3. Edit the content and presentation as required.
4. Bind questions to schema, business rules, and vocabulary.
5. Distribute XForms markup.

XForms Authoring Demonstration

PureEdge Designer

File Edit View Insert Arrange Tools Window Help

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Person Details | Person Details (continued) | Person Details (continued) | Person Details (continued) | Person Details (continued) | Clinical Information | Clinical Information (contin

Department of Health and Human Services

Centers for Disease Control and Prevention

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Go to... Severe Acute Respiratory Syndrome (SARS) << Back Next >>

Person Details

Page 1 of 5

- Person Details
- Clinical Information
- Epidemiologic Risk Factors
- Classification of Patient

To begin, please provide the information requested below.

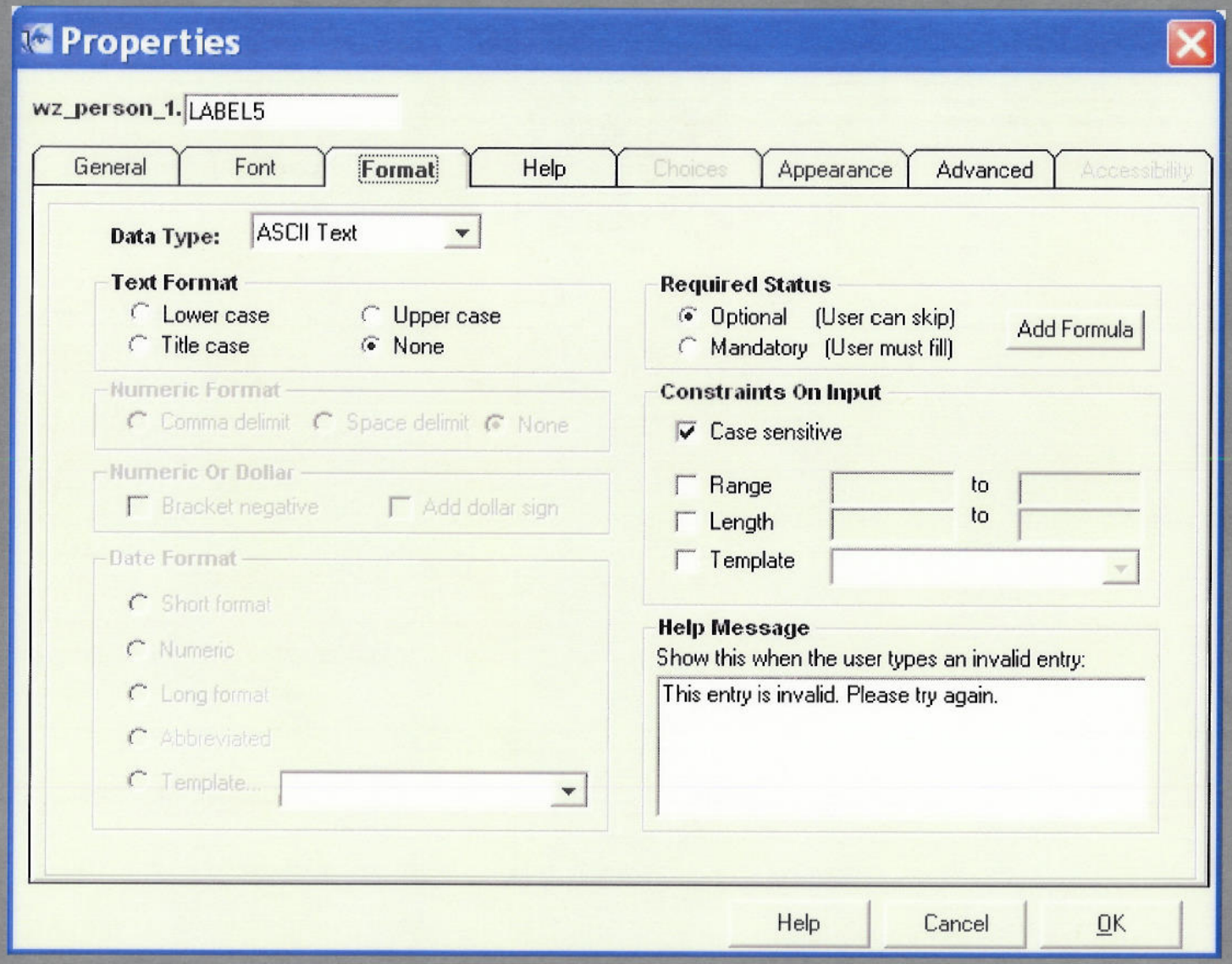
1. IDs

CDC ID #:	CDC ID WILL BE AUTOMATICALLY GENERATED
State ID #:	
Date reported to CDC:	MM/DD/YYYY
Jurisdiction:	
Date reported to state or local	MM/DD/YYYY

Tree View

- wz_person_1
  - global: global
  - line: titleLine1
  - button: menu1
  - button: menu2
  - line: LINE3
  - box: mainBox
  - line: LINE8
  - line: LINE9
  - line: LINE2
  - line: LINE11
  - line: LINE12
  - button: menu3
  - button: menu5
  - label: LABEL11
  - line: LINE1
  - label: pageTitle
  - label: LABEL2
  - label: LABEL3
  - label: LABEL5
  - label: LABEL6
  - label: LABEL9
  - label: LABEL10

Item: mainBox | Type: box | X: 204 | Y: 149 | W: 589 | H: 408


Properties
wz_person_1.LABEL5
General
Font
Format
Help
Choices
Appearance
Advanced
Accessibility
Data Type:
ASCII Text
Text Format
Lower case
Upper case
Title case
None
Numeric Format
Comma delimit
Space delimit
None
Numeric Or Dollar
Bracket negative
Add dollar sign
Date Format
Short format
Numeric
Long format
Abbreviated
Template...
Required Status
Optional (User can skip)
Mandatory (User must fill)
Add Formula
Constraints On Input
Case sensitive
Range
to
Length
to
Template
Help Message
Show this when the user types an invalid entry:
This entry is invalid. Please try again.
Help
Cancel
OK

PureEdge Designer

File Edit View Insert Arrange Tools Window Help

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Person Details (continued) | Person Details (continued) | Clinical Information | Clinical Information (continued) | Clinical Information (continued) | Clinical Information (continued)

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CDC Department of Health and Human Services
Centers for Disease Control and Prevention

Go to... | Severe Acute Respiratory Syndrome (SARS) | << Back | Next >>

Clinical Information

Page 1 of 5

Person Details
Clinical Information
Epidemiologic Risk Factors
Classification of Patient

Please provide signs and symptoms information in the following two pages.

5. Signs and Symptoms

Date of symptom onset: MM/DD/YYYY

Did the person have a fever (subjective or objective)? Yes / No / Unknown

If yes:

Date of fever onset: MM/DD/YYYY

Was temperature > 38° C (100.4° F)? Yes / No / Unknown

Tree View

- global: global
- line: titleLine1
- data: DATA1
- button: menu1
- button: menu2
- combobox: feverDate
- line: LINE3
- box: mainBox
- line: LINE9
- line: LINE2
- line: LINE7
- line: LINE12
- line: LINE1
- label: pageTitle
- label: LABEL2
- label: LABEL3
- label: LABEL1
- label: LABEL4
- combobox: onsetDate
- check: feverYES_CHK
- check: feverNO_CHK
- check: feverUNKNOWN_CHK
- label: LABEL5

Item: wz_clinical_5.global | Type: Page Global

SARS Scenario

Time

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Quarantine notifies state & local health departments

State customizes SARS instrument as required

- Provision form to local HDs
- Provision form to hospitals
- Provision form to emergency response teams

- Render form in off-line device
- Render form on laptop
- Render form in client-server envir

- Persist data in XML document
- Persist data as name:value pairs
- Persist data in database tables

- Report data to State
- Report data to CDC

Aggregate data

Provide data for AVR

Form Customization Demonstration

PureEdge Designer

File Edit View Insert Arrange Tools Window Help

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Person Details | Person Details (continued) | Person Details (continued) | Person Details (continued) | Person Details (continued) | Clinical Information | Clinical Information (contin

FLORIDA DEPARTMENT OF HEALTH

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Go to...

Severe Acute Respiratory Syndrome (SARS) << Back Next >>

Person Details

Page 1 of 5

- Person Details
- Clinical Information
- Epidemiologic Risk Factors
- Classification of Patient

To begin, please provide the information requested below.

1. IDs

CDC ID #:	CDC ID WILL BE AUTOMATICALLY GENERATED
State ID #:	
Date reported to CDC:	MM/DD/YYYY
Jurisdiction:	
Date reported to state or local	MM/DD/YYYY

Tree View

- popup: navigate_popup
- cell: CELL1
- cell: CELL2
- cell: CELL3
- cell: CELL4
- cell: CELL5
- cell: CELL6
- cell: CELL7
- cell: CELL8
- cell: CELL9
- cell: CELL10
- cell: CELL11
- cell: CELL12
- cell: CELL13
- cell: CELL14
- cell: CELL15
- cell: CELL16
- cell: CELL17
- button: nextButton
- button: backButton
- data: DATA2
- label: LABEL1
- spacer: vfd_spacer

Item: LABEL1 | Type: label | X: 16 | Y: 10 | W: 237 | H: 98

SARS Scenario

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Data Persistence

- Off-Line Mobile Device
  - Data persisted as XML instance
- Laptop
  - Data persisted as table entries and name:value pairs in local data store
- Client-Server
  - Data persisted as table entries and name:value pairs in local data store

XForms Rendering & Persistence Demonstration

Person Details

Department of Health and Human Services
Centers for Disease Control and Prevention

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Go to...

Severe Acute Respiratory Syndrome (SARS)

Next >>

Person Details

Page 1 of 5

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1. IDs

CDC ID #: *CDC ID WILL BE AUTOMATICALLY GENERATED*

State ID #:

Date reported to CDC: MM/DD/YYYY

Jurisdiction:

Date reported to state or local MM/DD/YYYY

NUM

PAGE1

100%

CDC Department of Health and Human Services
Centers for Disease Control and Prevention

Submit Form

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Go to...

Severe Acute Respiratory Syndrome (SARS) << Back Next >>

Supplement B: SARS Surveillance - SARS Domestic Case Reporting Form

Person Details

1. IDs

CDC ID #: *CDC ID WILL BE AUTOMATICALLY GENERATED*
State ID #: 45879
Date reported to CDC: 06/15/2005 MM/DD/YYYY
Jurisdiction: Los Angeles
Date reported to state or local health department: 06/01/2005 MM/DD/YYYY

2. Submitted By

Last Name: Baker
First Name: Dixie
State: California
Affiliation: CDC
Phone: (310) 123-4556
E-mail: bty5@cdc.gov

3. Patient Information

City of Residence: Los Angeles
Country of Residence USA
State of Residence: California

Age of onset: 21 ☑ Years ☐ Months

Ethnicity: ☐ Non Hispanic ☑ Hispanic

Nationality/Citizenship:

Residency: ☑ US Residency ☐ Non-US Resident

Sex: ☐ Male ☑ Female

Race: *(Mark one or more)*
☐ American Indian / Alaska Native
☐ Asian
☐ Black
☐ Native Hawaiian / Other Pacific Islander
☐ White
☑ Unknown

4. Optional Patient Infomation

Last Name:
First Name:

Clinical Information

5. Signs and Symptoms

SARS Scenario

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Data Aggregation

- Data collected using mobile, off-line device and exported as an XML instance
- Instance imported into laptop or client-server environment
- Data extracted from XML instance and persisted in local data store as table entries or name:value pairs

Data Aggregation Demonstration

CompletedInstance.xfd - Microsoft Word

```
<xmlmodel xmlns:xforms="http://www.w3.org/2003/xforms">
   <instances>
      <xforms:instance xmlns="http://www.PureEdge.com/XFDL/Custom"
id="sars">
         <SARSNotificationInformation>
            <GeneralDiseaseInformation>
               <FormInformation>
                  <DateReportedToCDC>20050615</DateReportedToCDC>
                  <StateId>45879</StateId>
                  <Jurisdiction>Los Angeles</Jurisdiction>
                  <DateReportedToState>20050601</DateReportedToState>
               </FormInformation>
               <SubmittedBy>
                  <LastName>Baker</LastName>
                  <FirstName>Dixie</FirstName>
                  <State codeListId="state_code_list.xml"
codeListName="STATE CODE LIST" codeListVersion="" codeName="">California</State>
                  <Affiliation>CDC</Affiliation>
                  <Phone>3101234556</Phone>
                  <Email>bty5@cdc.gov</Email>
               </SubmittedBy>
               <PatientInformation>
                  <CityOfResidence>Los Angeles</CityOfResidence>
                  <CountyOfResidence codeListId="county_code_list.xml"
codeListName="COUNTY CODE LIST" codeListVersion=""
codeName="">USA</CountyOfResidence>
                  <StateOfResidence codeListId="state_code_list.xml"
codeListName="STATE CODE LIST" codeListVersion=""
codeName="">California</StateOfResidence>
                  <AgeAtOnset>21</AgeAtOnset>
                  <AgeAtOnsetYearMonth
codeListId="calendar_code_list.xml" codeListName="CALENDAR CODE LIST"
codeListVersion="" codeName="">Years</AgeAtOnsetYearMonth>
                  <Sex codeListId="gender_code_list.xml"
codeListName="GENDER CODE LIST" codeListVersion="" codeName="">female</Sex>
                  <Ethnicity codeListId="ethnicity_code_list.xml"
codeListName="ETHNICITY CODE LIST" codeListVersion=""
codeName="">hispanic</Ethnicity>
                  <Race codeListId="race_code_list.xml"
codeListName="RACE CODE LIST" codeListVersion="" codeName="">unknown</Race>
                  <Residency>us</Residency>
               </PatientInformation>
               <OptionalPatientInformation>
                  <OptLastName></OptLastName>
                  <OptFirstName></OptFirstName>
               </OptionalPatientInformation>
            </GeneralDiseaseInformation>
```

Input data are captured in an XML instance document, from which they can be extracted and persisted in a relational data store.

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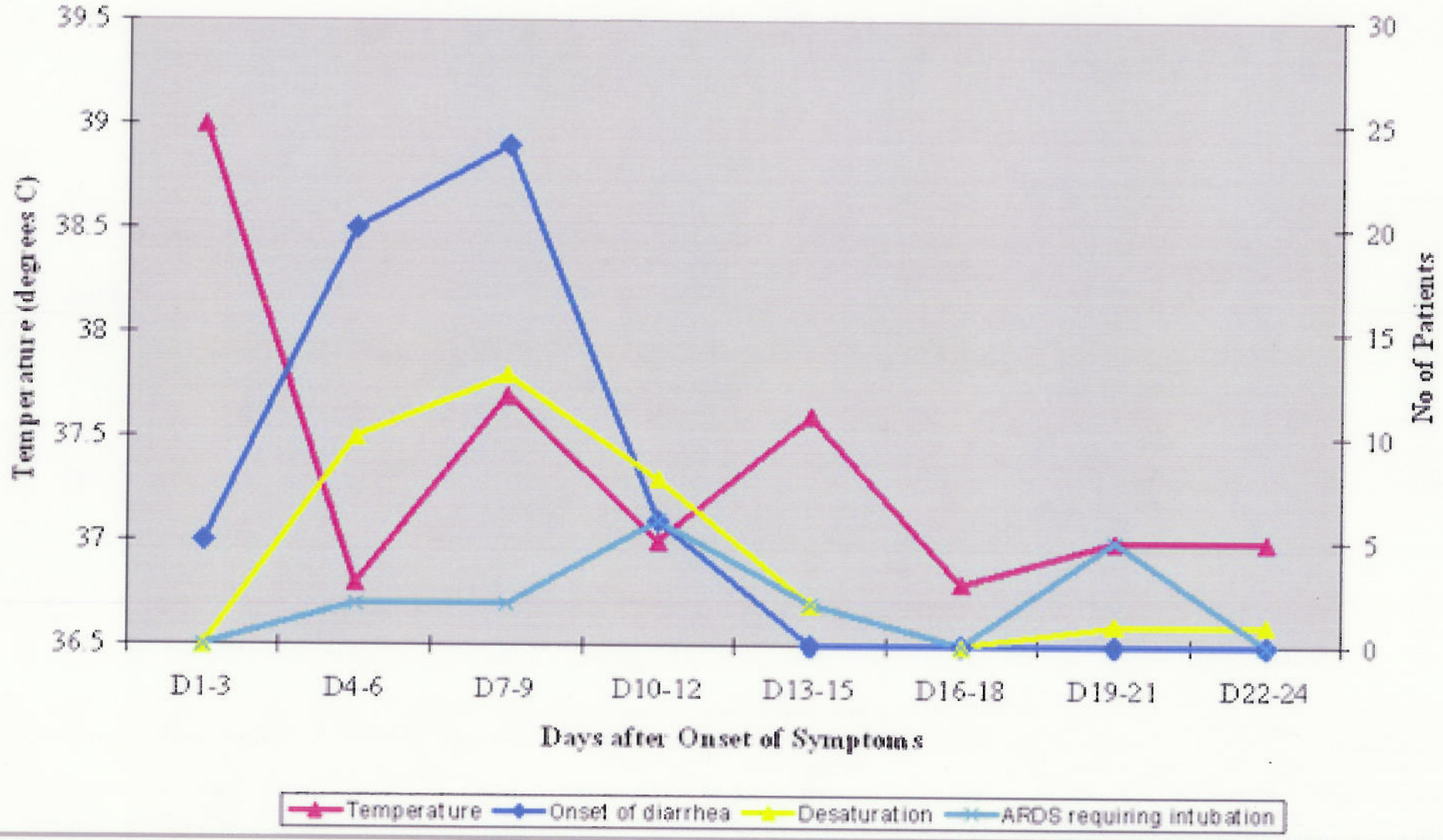
- Persist data in XML document
- Persist data as name:value pairs
- Persist data in database tables
- Report data to State
- Report data to CDC
- Aggregate data
- Provide data for AVR

AVR Demonstration

Figure 1. Temporal Clinical Profiles in 75 Patients with SARS



Benefits to Public Health

- Rapid creation of surveillance instruments
- Standard markup usable across all platforms
- On- and off-line data collection
- Standard instance data can be exchanged, displayed, and used across all jurisdictions

Future Directions

- Future work within current implementation
  - Implement versioning
  - Specify full architecture for producing, distributing, using, and managing XForms instruments
- Implement full architecture
  - Deployable full-featured authoring tool
  - Source data stores
  - Web Services integration with PHIN VADS & content stores
  - Binding of questions to schemas and vocabulary
  - Full integration with NEDSS, OMS, and PHIN-compliant partner systems