

EHDI Data Integration Across Heterogeneous Systems

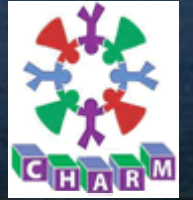
*An Experience Report
on CHARM*

March 1, 2010

*James Fritzler and Dr. Stephen Clyde
Utah State University*



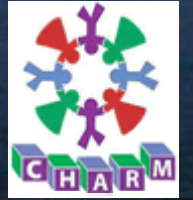
Overall Objectives for Sharing Data



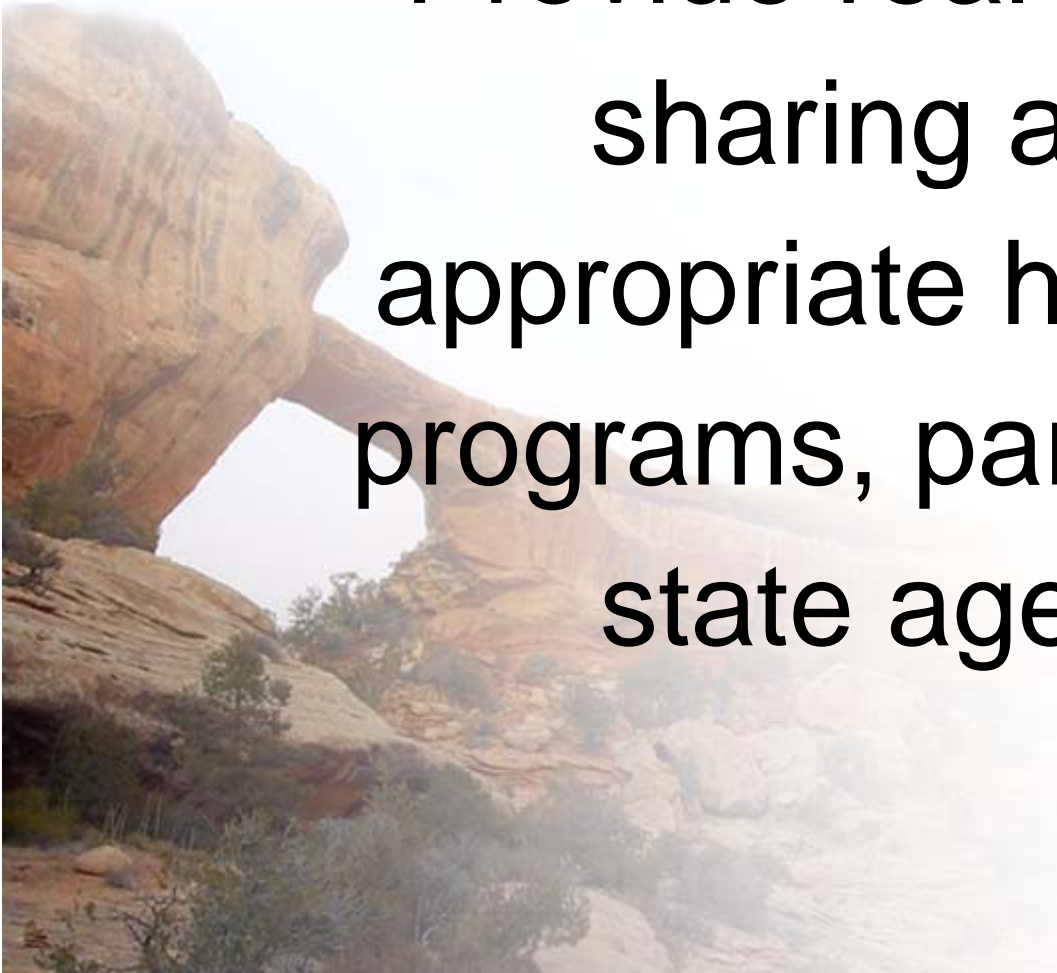
- Improve health-care services
- Improve data quality
- Reduce costs



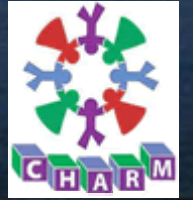
Purpose of CHARM



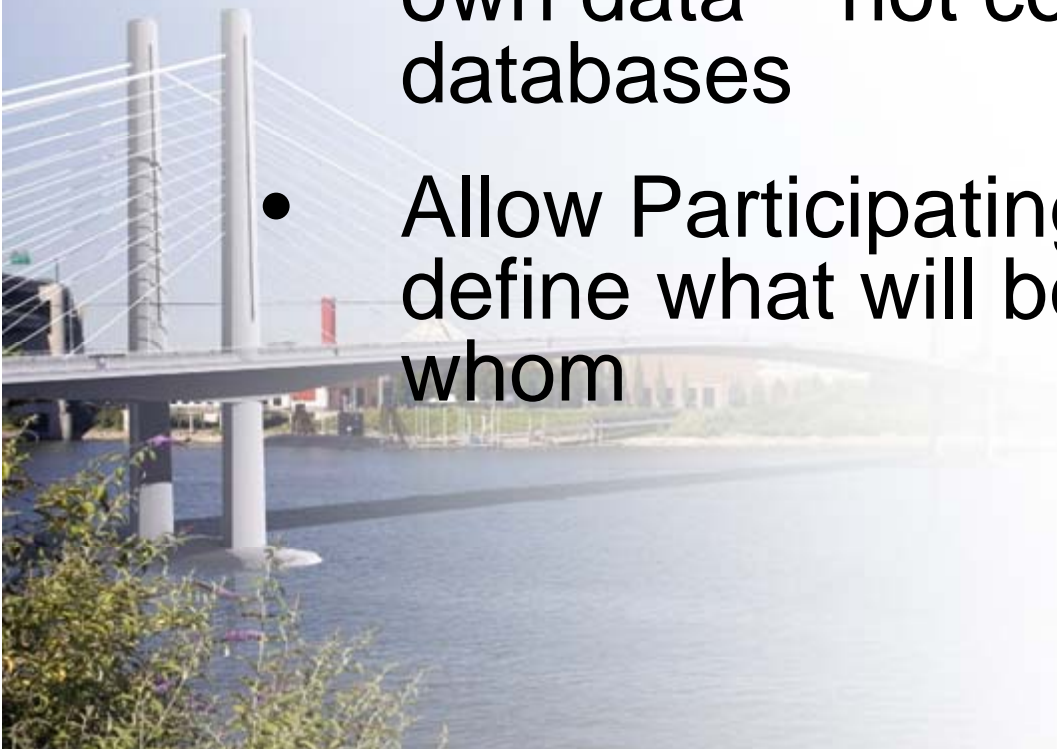
Provide real-time data
sharing among
appropriate health care
programs, partners, and
state agencies



Goals of CHARM



- Alert users of exceptional conditions
- Ensure that Participating Programs (PP) retain stewardship over their own data – not copied into other databases
- Allow Participating Programs to define what will be shared and with whom



Goals of CHARM



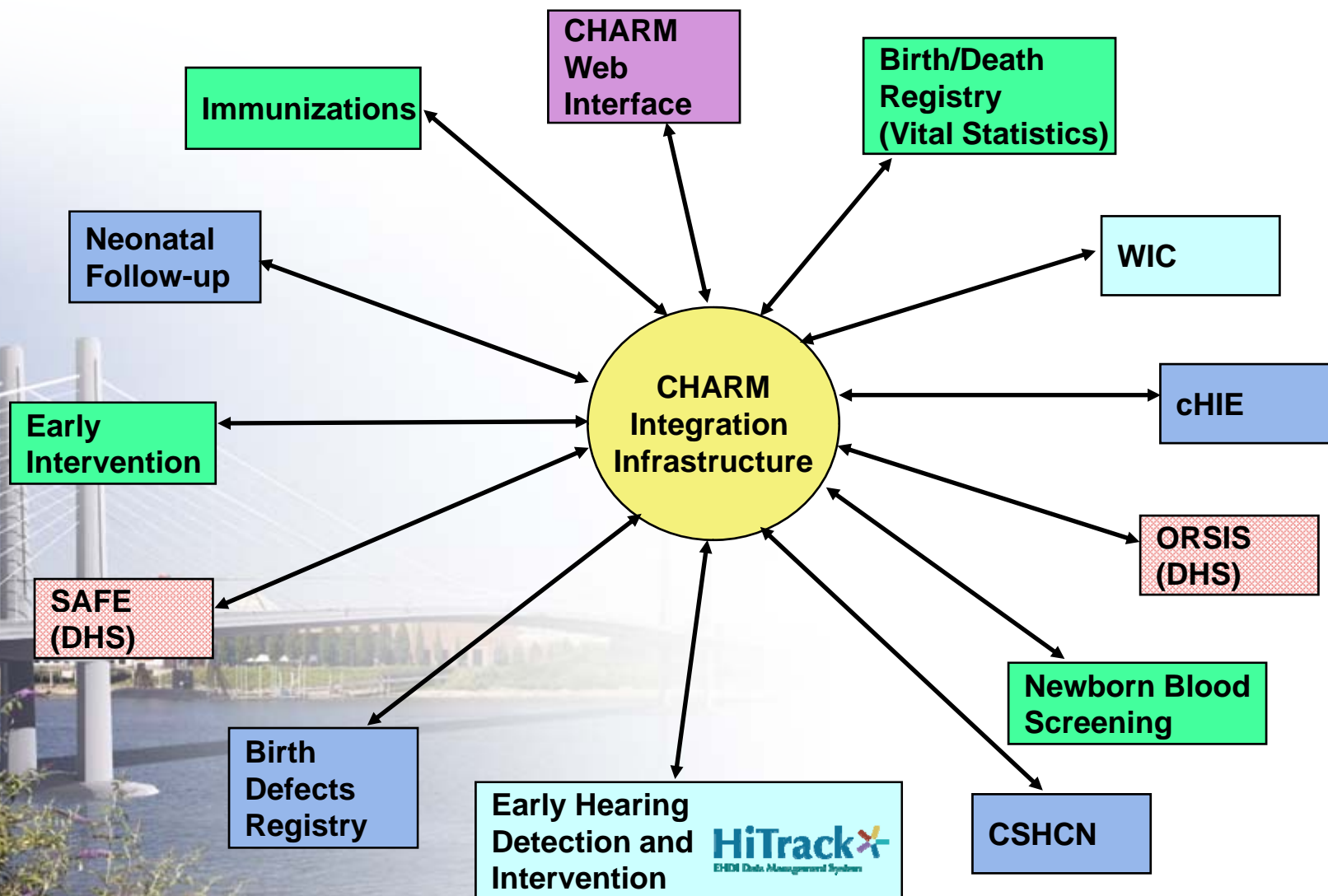
- Ensure security and confidentiality of all data
- Satisfy HIPAA and FERPA requirements
- Allow for individual information systems to evolve independently
- Facilitate CHARM's growth in scope & size

Some Guiding Principles and Concepts

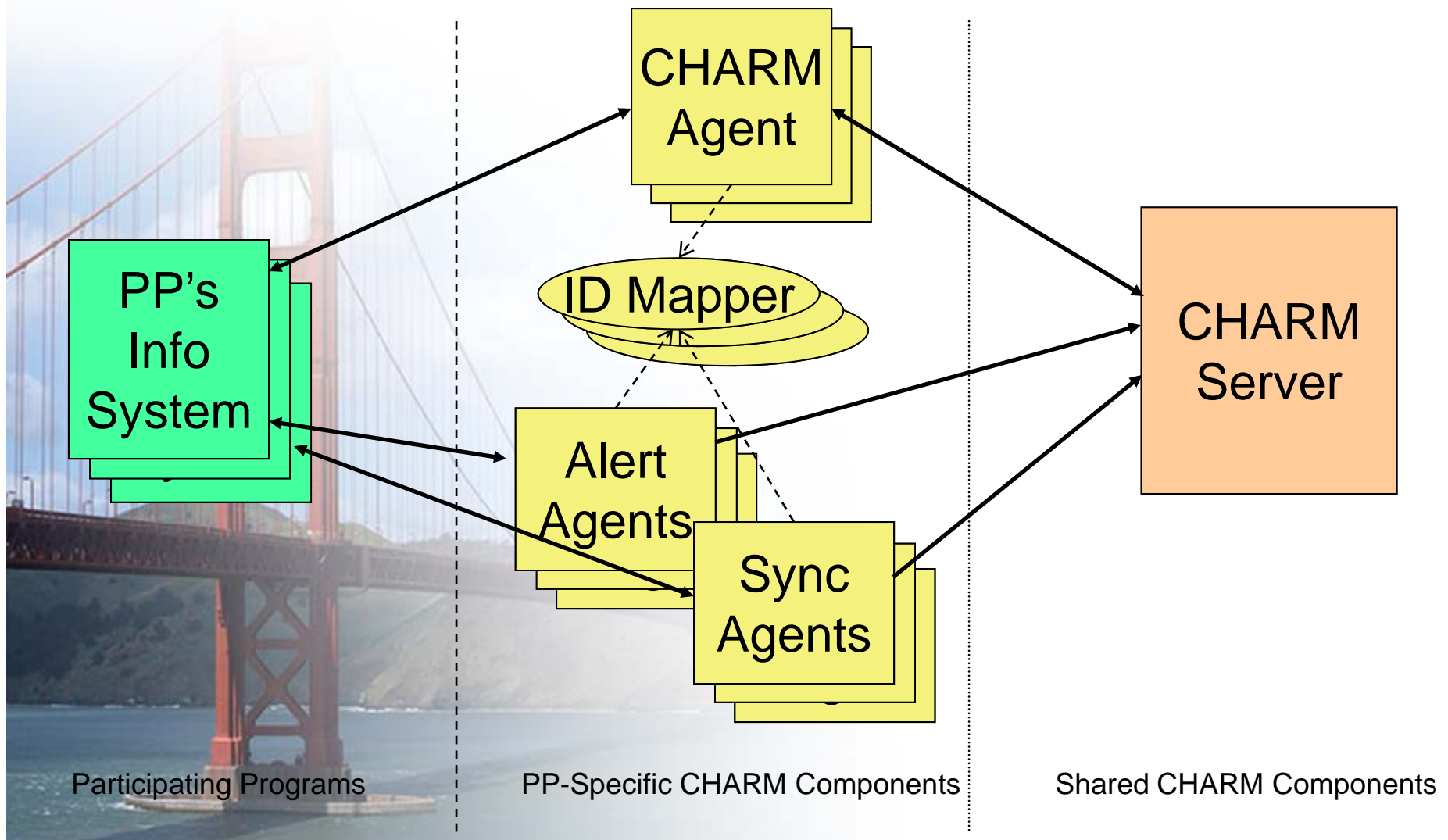


- Maintain security, confidentiality, and privacy
- Respect organizational boundaries and policies
- Minimize impact on participating programs' information systems
- Keep data close to the data stewards
- Stay true to the long-term architectural design (service-oriented architecture)
- Tune record matching to data sources
- Ongoing monitoring and adjustment

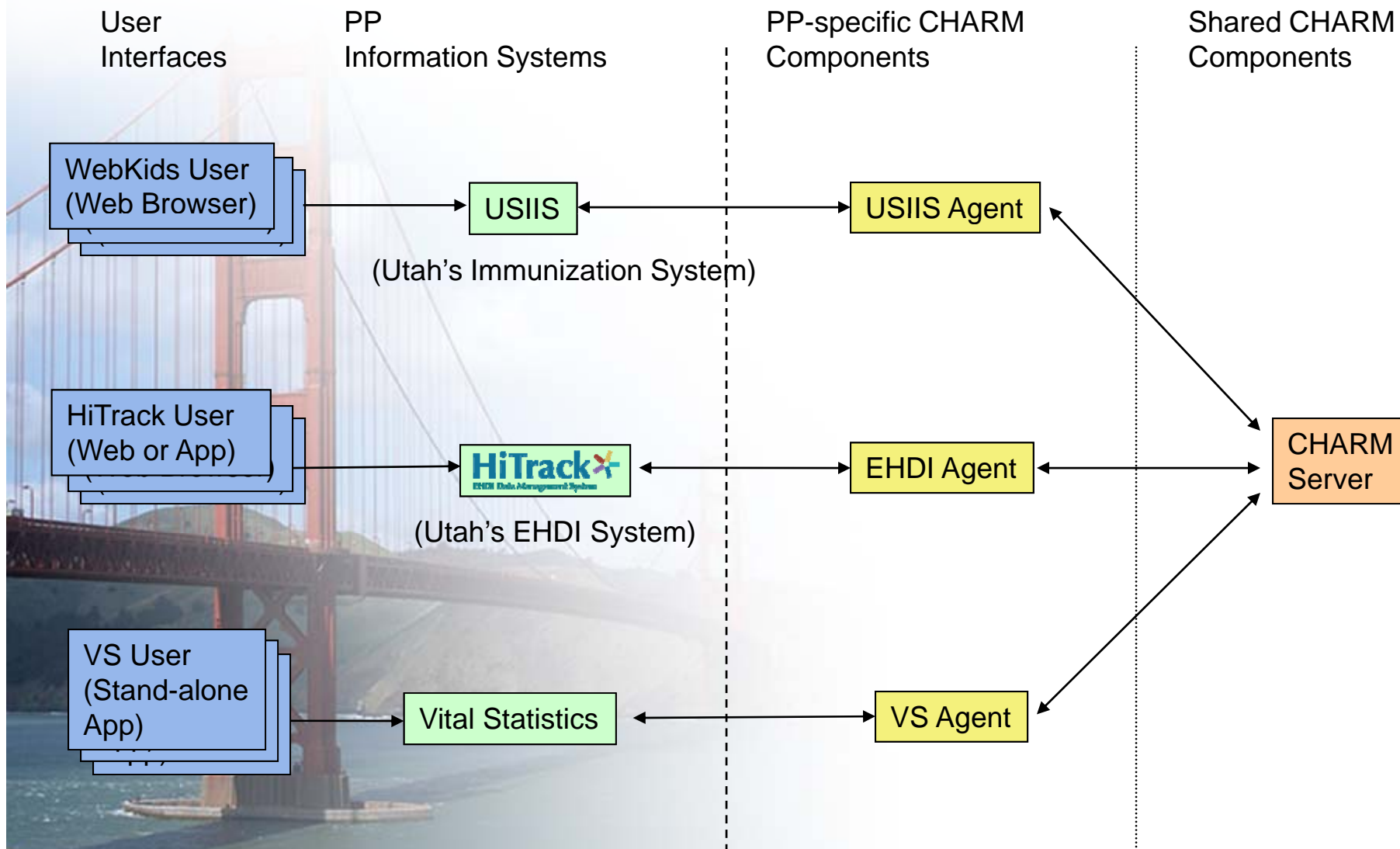
CHARM Integration Infrastructure



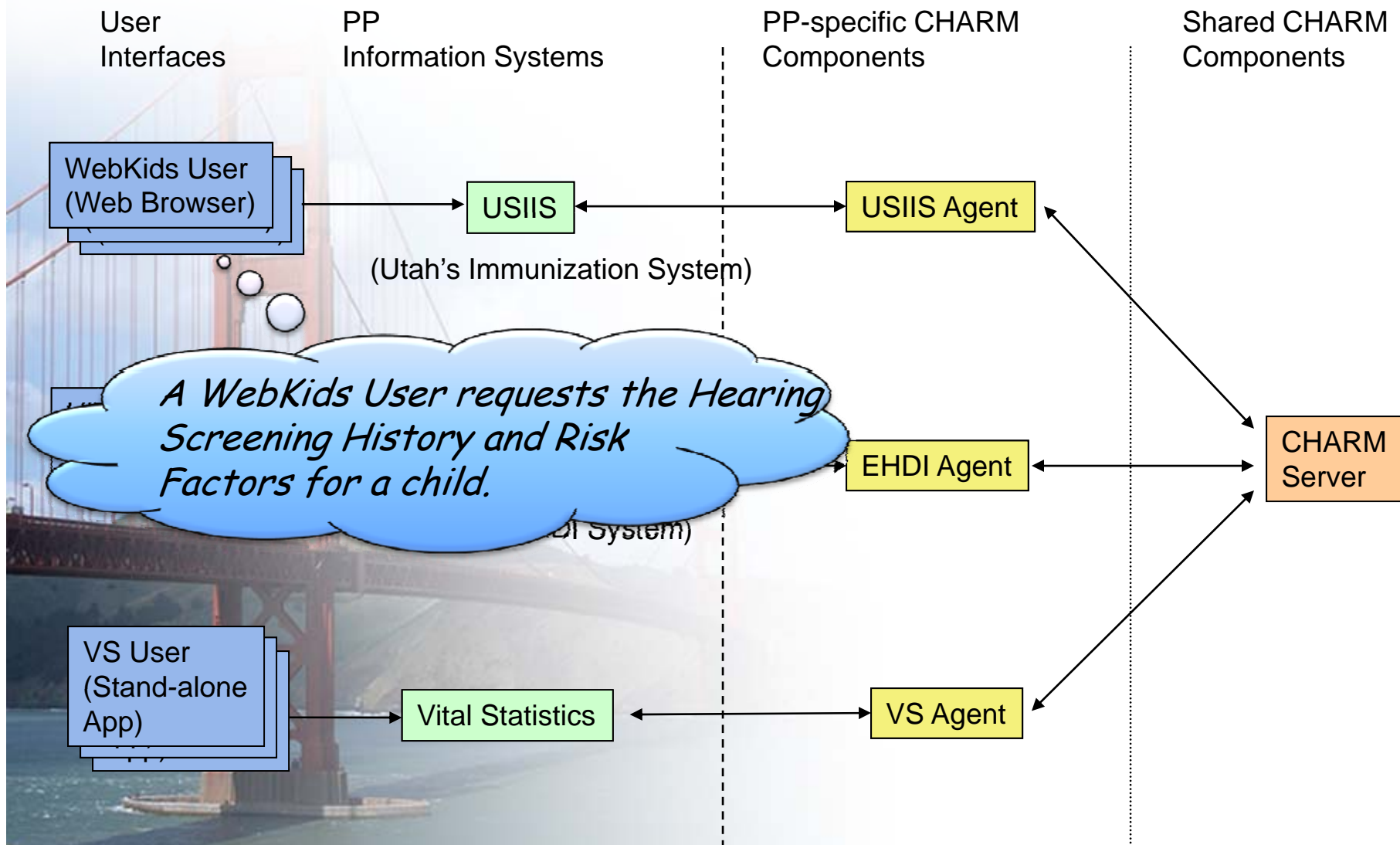
Primary CHARM-II Components



Sample Data Query




Sample Data Query –Step 1



Sample Data Query –Step 1



Address  Go Links >>

Patient Info. Age: 4 Years 7 Months ● Patient ID USIIS ID 471125

Save Delete Clinic Affiliation Delete Web Record CHARM Reset

Last Name First Name Middle N. Suffix Birth Date 05/25/2000 SSN Gender ☐ F ☒ M Mother's First Mother's Maiden

Patient's Middle Name BRENT Suffix Gender ☐ F ☒ M SSN Mother's Maiden

Street City CLEARFIELD State UT Zip 80058 Status Race U UNKNOWN Ethnicity NH NOT OF HISPANIC ORIGIN

Phone County 8 DAVIS Birth State UT UTAH Confidential flag No Release Date 05/25/2000 Physician

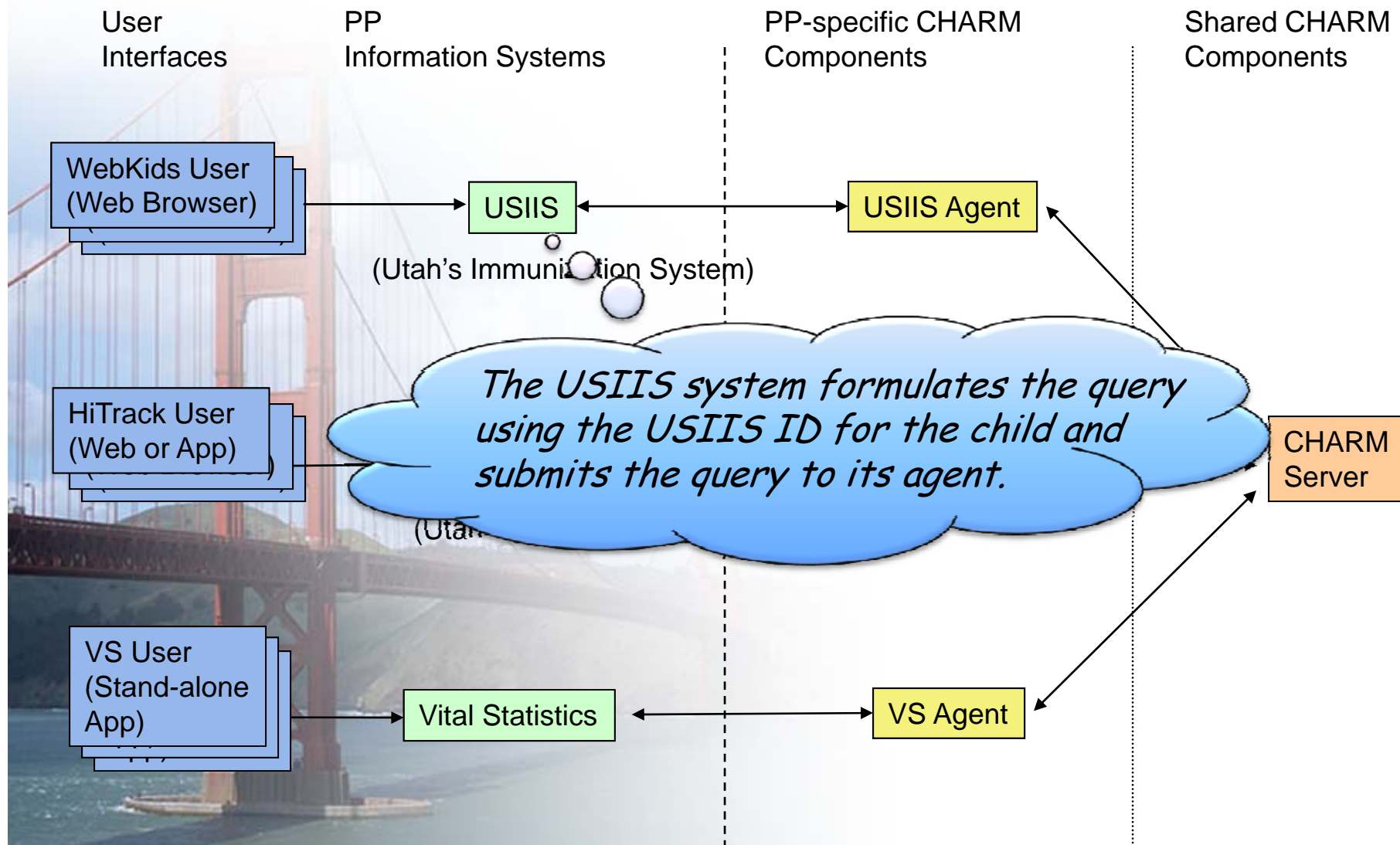
Provider 801 USIIS PROGRAM Send Reminder Card No

Comments

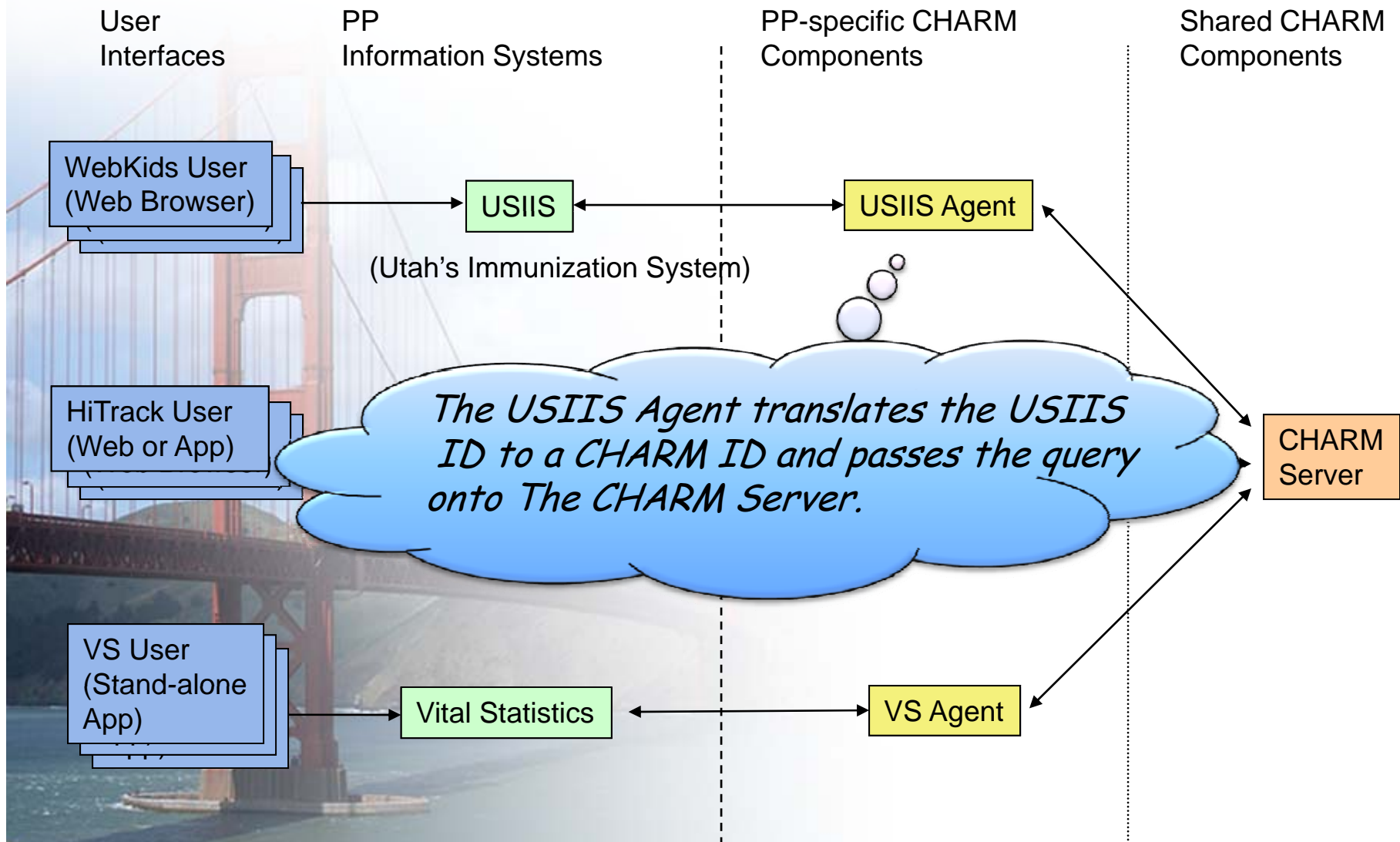
Mother's Last Father's Last Guardian's Last
Mother's First WENDY Father's First BRENT Guardian's First
Mother's Middle Father's Middle JUSTIN Guardian's Middle
Mother's SSN Father's SSN Guardian's SSN

Logout Pat. Search Pat. Info. Comm/Phy. Immun. Contra.-Ept Forecast CASA Report Admin.

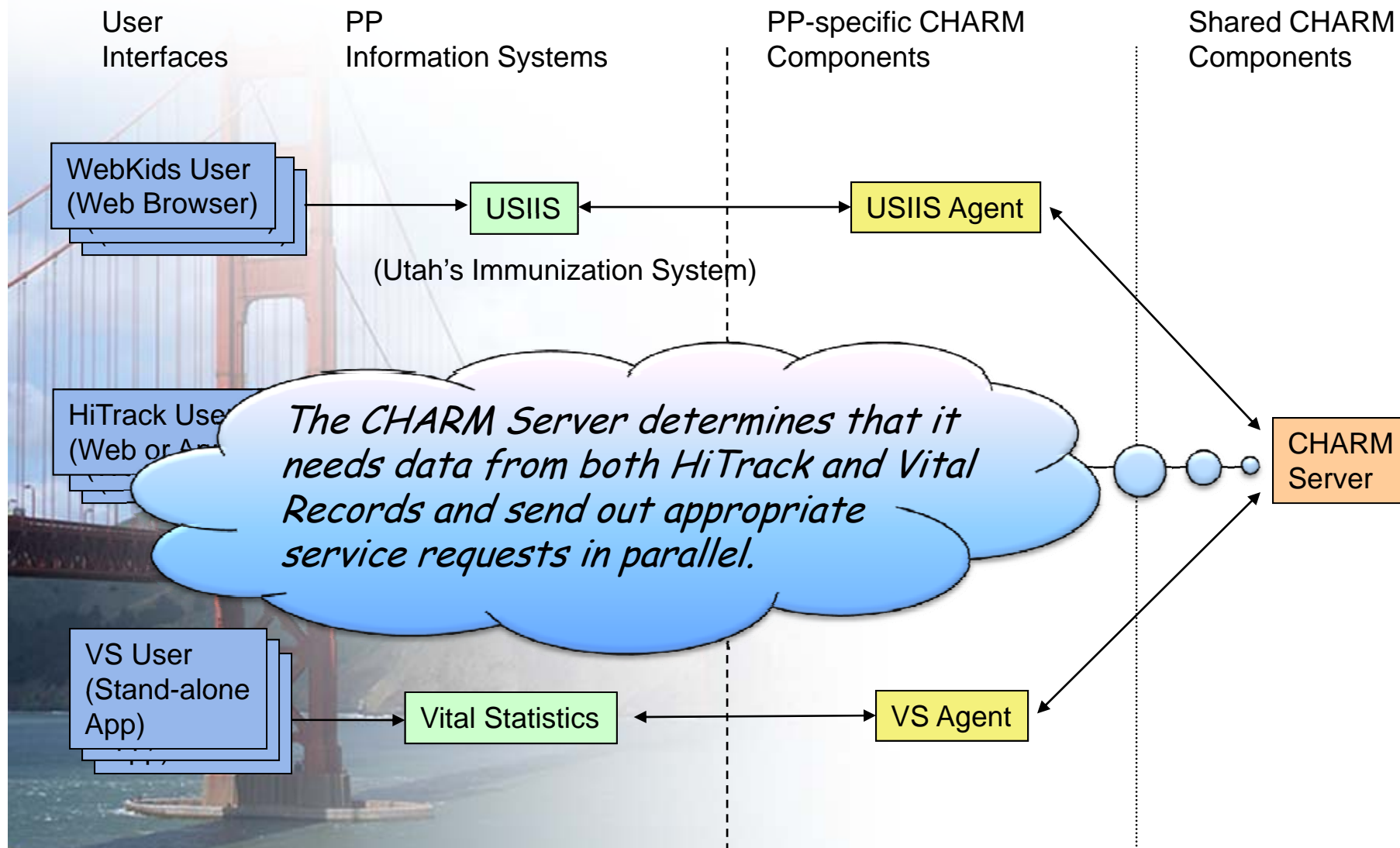
Sample Data Query – Step 2



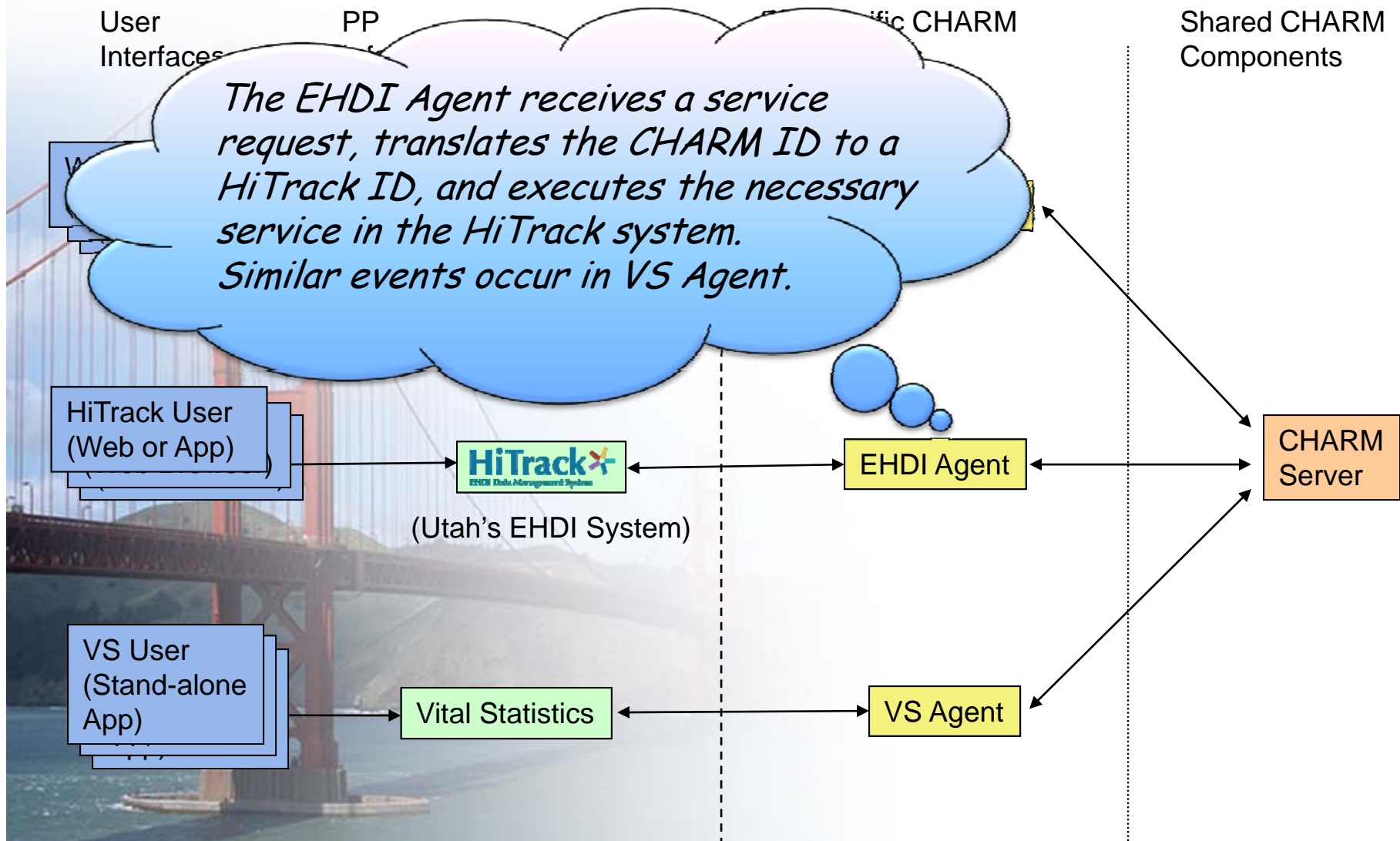
Sample Data Query – Step 3



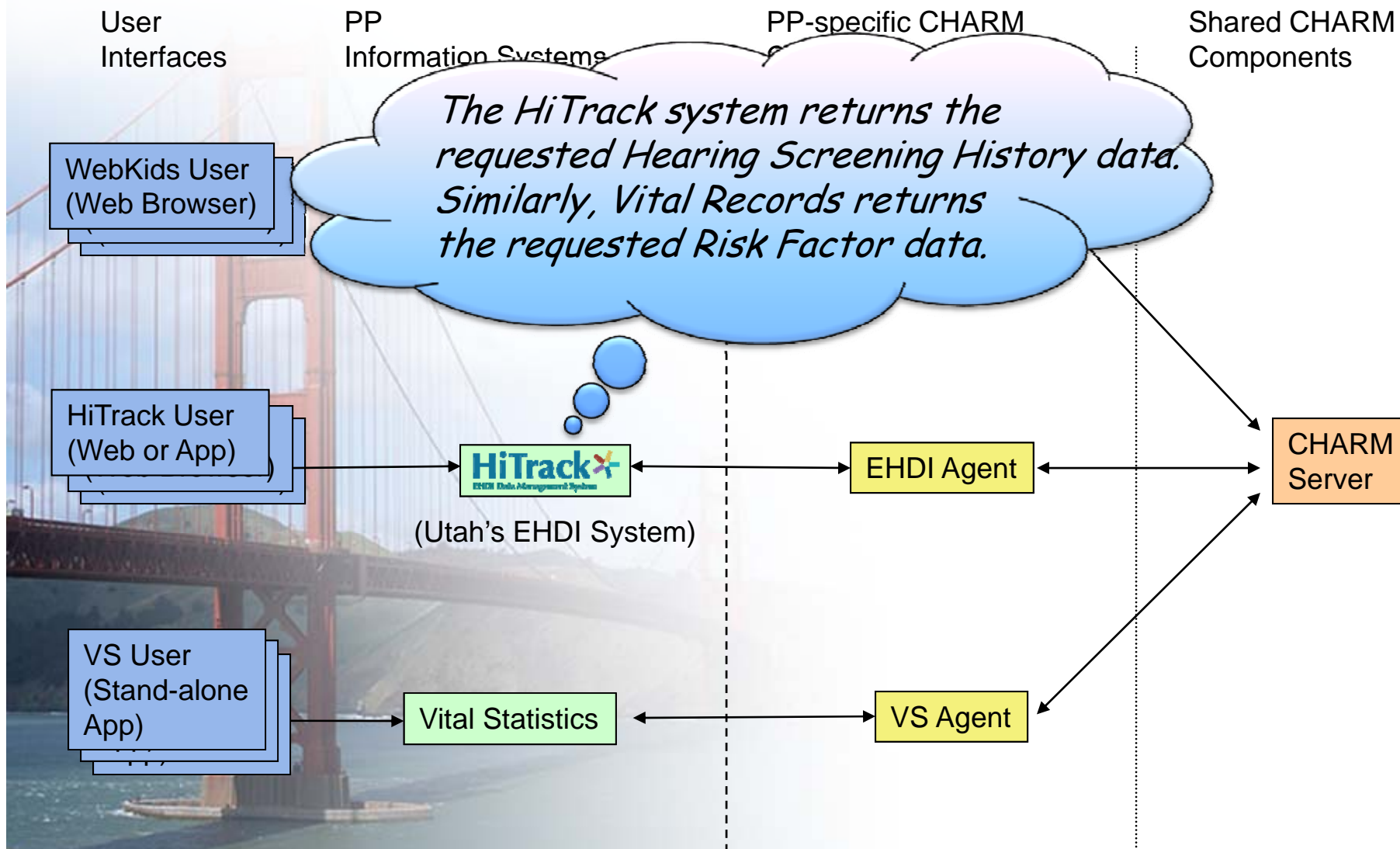
Sample Data Query – Step 4



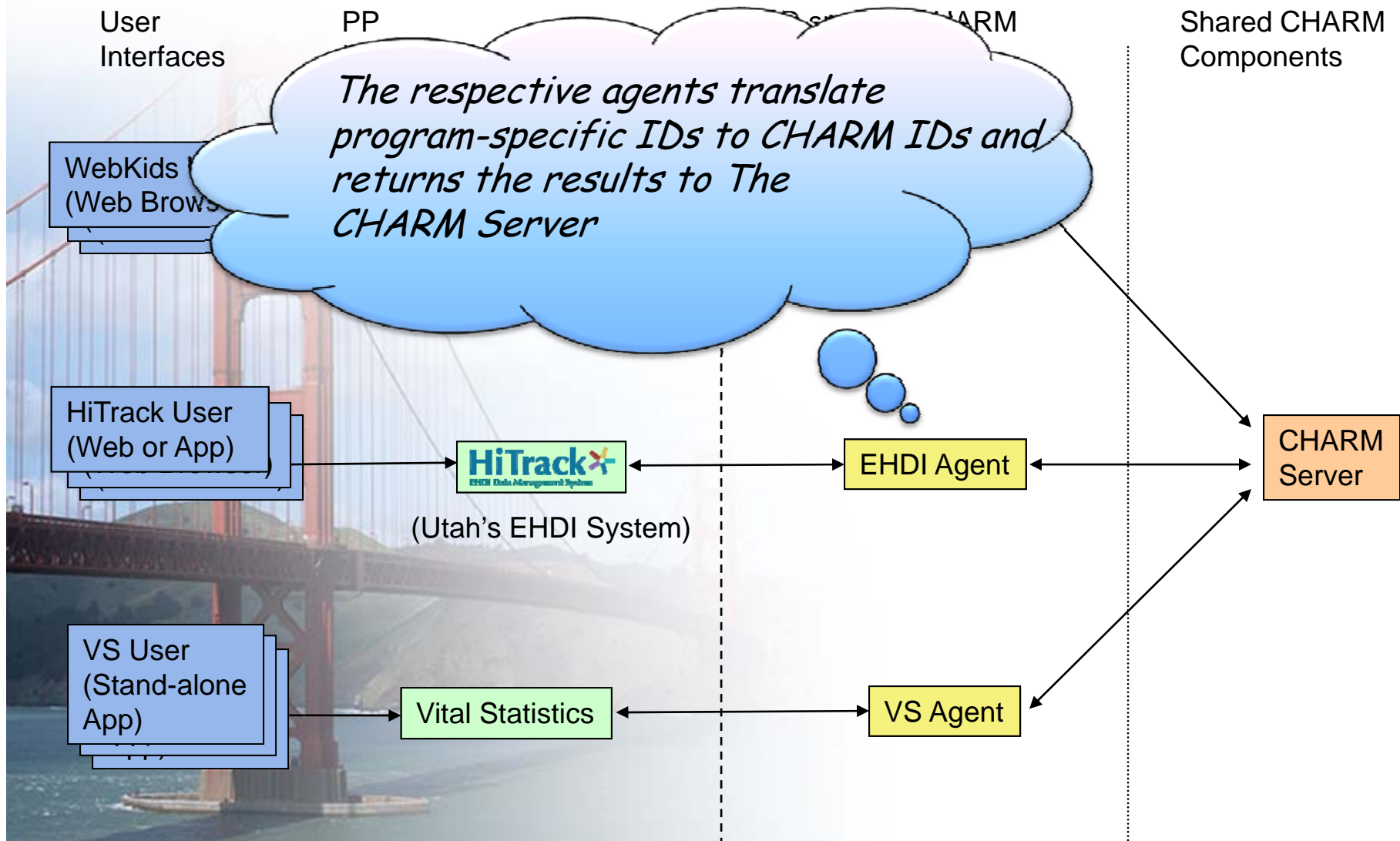
Sample Scenario – Step 5



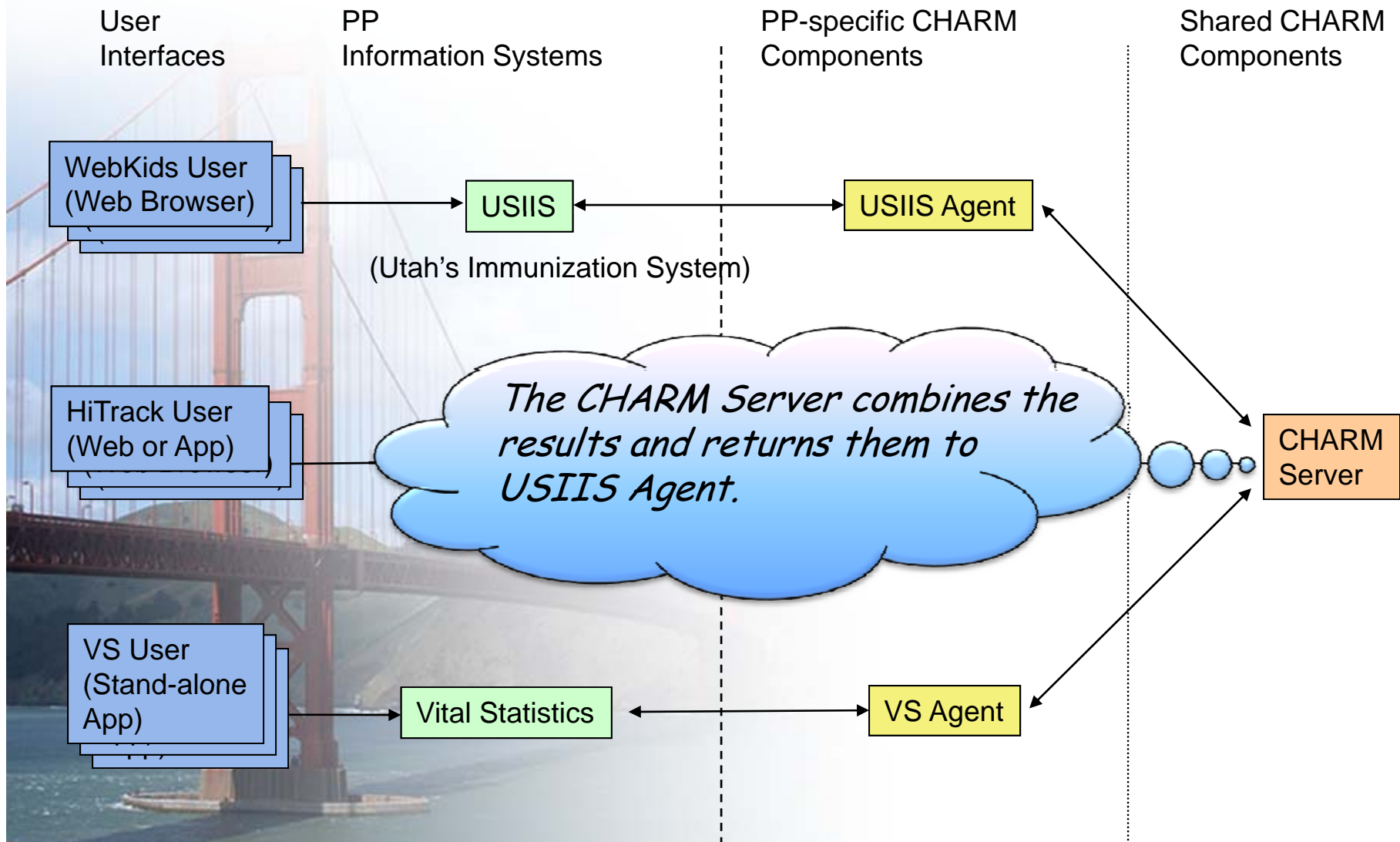
Sample Scenario – Step 6



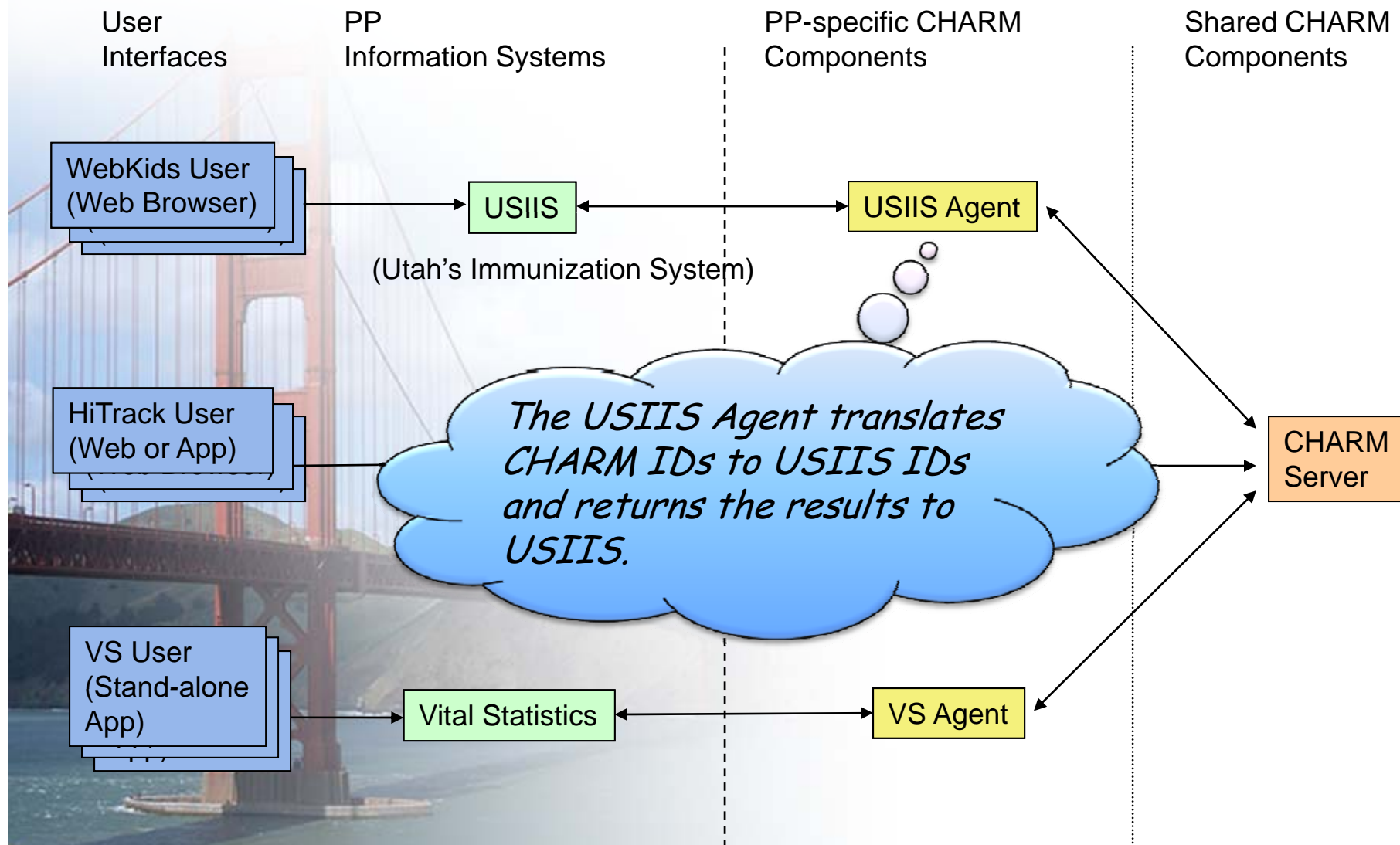
Sample Scenario – Step 7



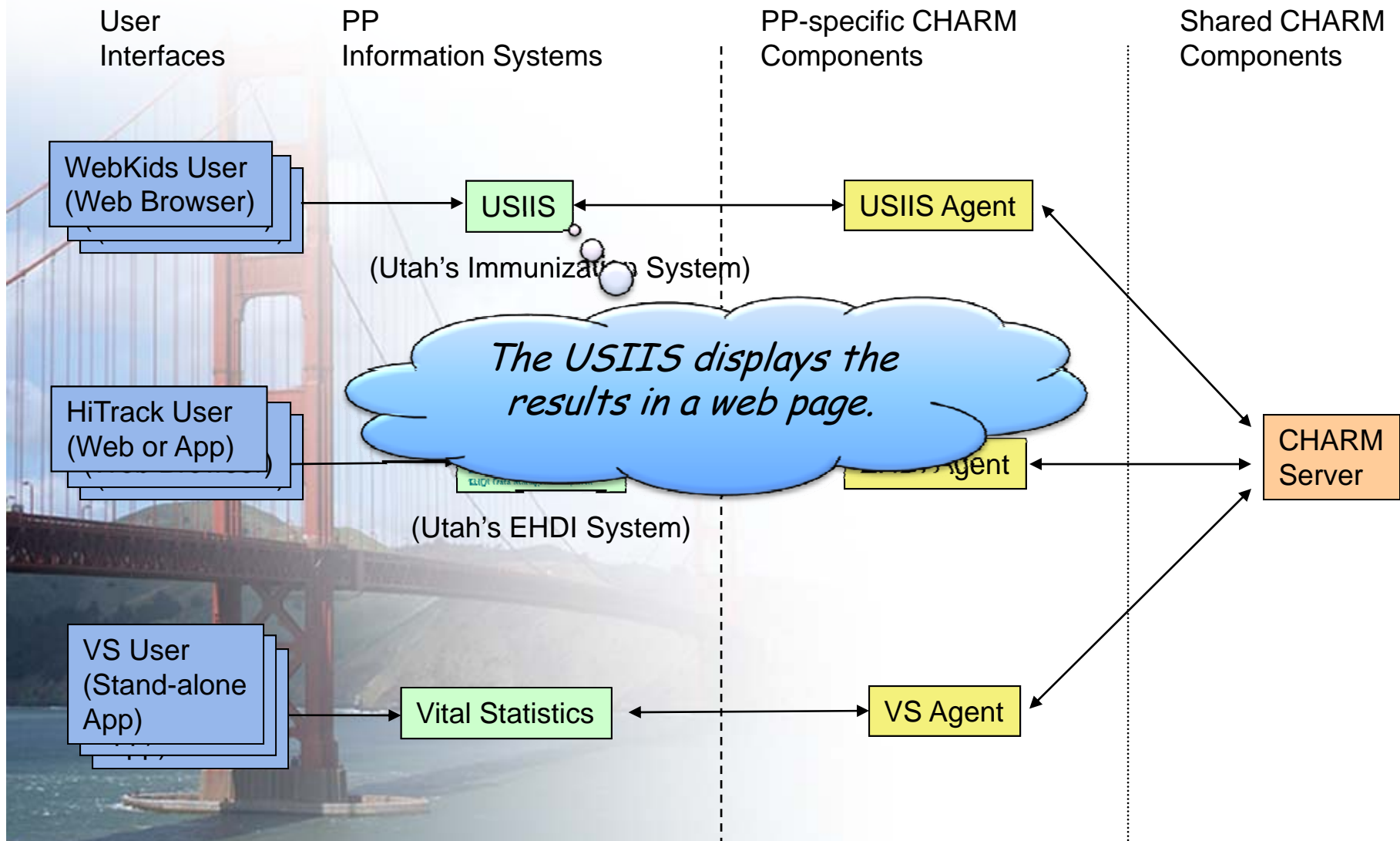
Sample Scenario – Step 8



Sample Data Query – Step 9



Sample Data Query – Step 10



Sample Data Query – Step 10



This information is brought to you by CHARM...

Hearing Test History From HiTrack

[Redacted], [Redacted]
(last, first middle)
Male, Birth Date: 05/25/2000 (mm/dd/yyyy)

Hearing Test History		
Date (mm/dd/yyyy)	Test/Ear	Result
05/30/2000	TEOAE(L)	Pass More info
05/30/2000	TEOAE(R)	Pass More info

Sample Data Query – Step 10



All Data for *All Facilities (48)

HI-TRACK
Version 4.5.1 (C) 2004 - 2009
HI-TRACK

Facility: *All Facilities

Letters Reports Merge Tools Settings Log Out

User: demo

All Data for *All Facilities (48 of 48)

DOB From: 7/ 1/2003 To: 3/ 1/2010

☐ Advanced Find ☐ Milestones

Refresh Reset Auto-Filters

Baby Name	Medical...	Birth ...	Inpati...	IP Da...	Outpatient	OP D...
Benson, Dianne	2934-79563	8/17/2006	Referred	8/18/2006	No Out. Scrn...	9/10/2006
Chao, Anthony	5432-63471	8/19/2006	Missed	8/19/2006	No Out. Scrn...	8/13/2006
Brenner, Bronson	7924-98736	5/30/2006	Referred	5/31/2006	Referred	6/02/2006
Casteel, Jayne	5432-83471	8/29/2006	Inconclusive	8/29/2006	No Out. Scrn...	8/14/2007
Hunter, Sherms	4934-70563	8/22/2006	Inconclusive	8/22/2006	Inconclusive	
Have, Asher	8169-63402	7/04/2006	Referred	7/04/2006	Referred	7/18/2006
Garbo, Gretchen	8657-29840	5/30/2006	Referred	6/08/2006	Referred	6/18/2006
Jones, Mike	3457-77121	7/12/2006	Referred	7/13/2006	Referred	7/28/2006
Lehman, Ross	7920-98722	5/31/2006	Inconclusive	6/01/2006	Passed	6/08/2006
Lesse, Patty	8657-29849	6/28/2006	Missed	6/28/2006	Passed	7/12/2006
Ozborne, Kelly	4934-71563	8/23/2006	Referred	8/23/2006	No Out. Scrn...	9/13/2006
Poppleton, Roger	8619-63442	7/05/2006	Referred	7/05/2006	Referred	7/19/2006
Myers, Todd	3457-77123	7/10/2006	Referred	7/10/2006	Refused	7/24/2006
Manilow, Mandy	8657-39846	7/17/2006	Referred	7/18/2006	Referred	8/02/2006
Smiles, Sherry	8619-63432	7/28/2006	Referred	7/01/2006	Referred	8/12/2006
Snifter, Brandi	8657-29843	6/13/2006	Referred	6/13/2006	Referred	6/27/2006
Stoud, Manny	5432-13471	8/15/2006	Referred	8/16/2006	Referred	8/29/2006
Why, Dixie	3457-77127	7/12/2006	Referred	7/12/2006	Referred	7/26/2006
Swain, Jannette	4934-79563	8/02/2006	Referred	8/02/2006	Referred	8/16/2006
Winger, Robin	5432-33471	8/17/2006	Referred	8/17/2006		

Add Baby Delete Baby Print List ☐ Combine:

Lesse, Patty
Medical ID: 8657-29849
Birth Date: 6/28/2006
Action: Passed Screening
Status: Complete

Record Overview

Tracking Options
Demographics
Screening

Risk Indicators
Diagnostics
Hearing Disposition
Amplification
EI Services

Letters
Transfer

Recommended Actions:
Add/Edit

Messages:
CONFIRMED LOSS. 07/08/06
Milestones: 0/0/-
Inactive record. Use Tracking
Options to re-activate this record.

External Links:
Vital Records
Immunizations

Sample Data Query – Step 10



Address Go Links

This information is brought to you by CHARM...

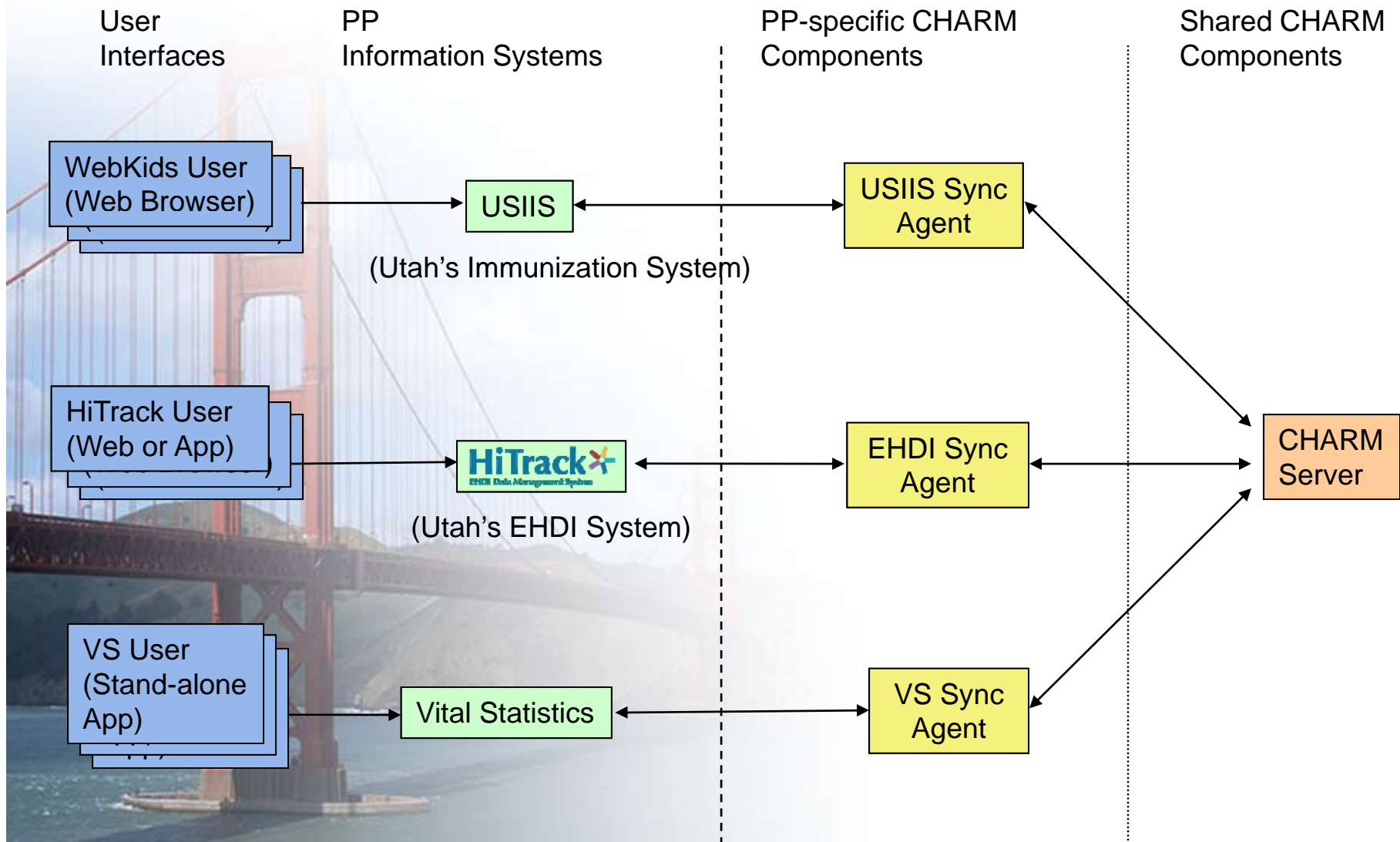
Immunization History from USIIS

██████, ██████ ██████ (last, first middle)
Gender: Male
Birth Date: 05/25/2000 (mm/dd/yyyy)
Deceased: No

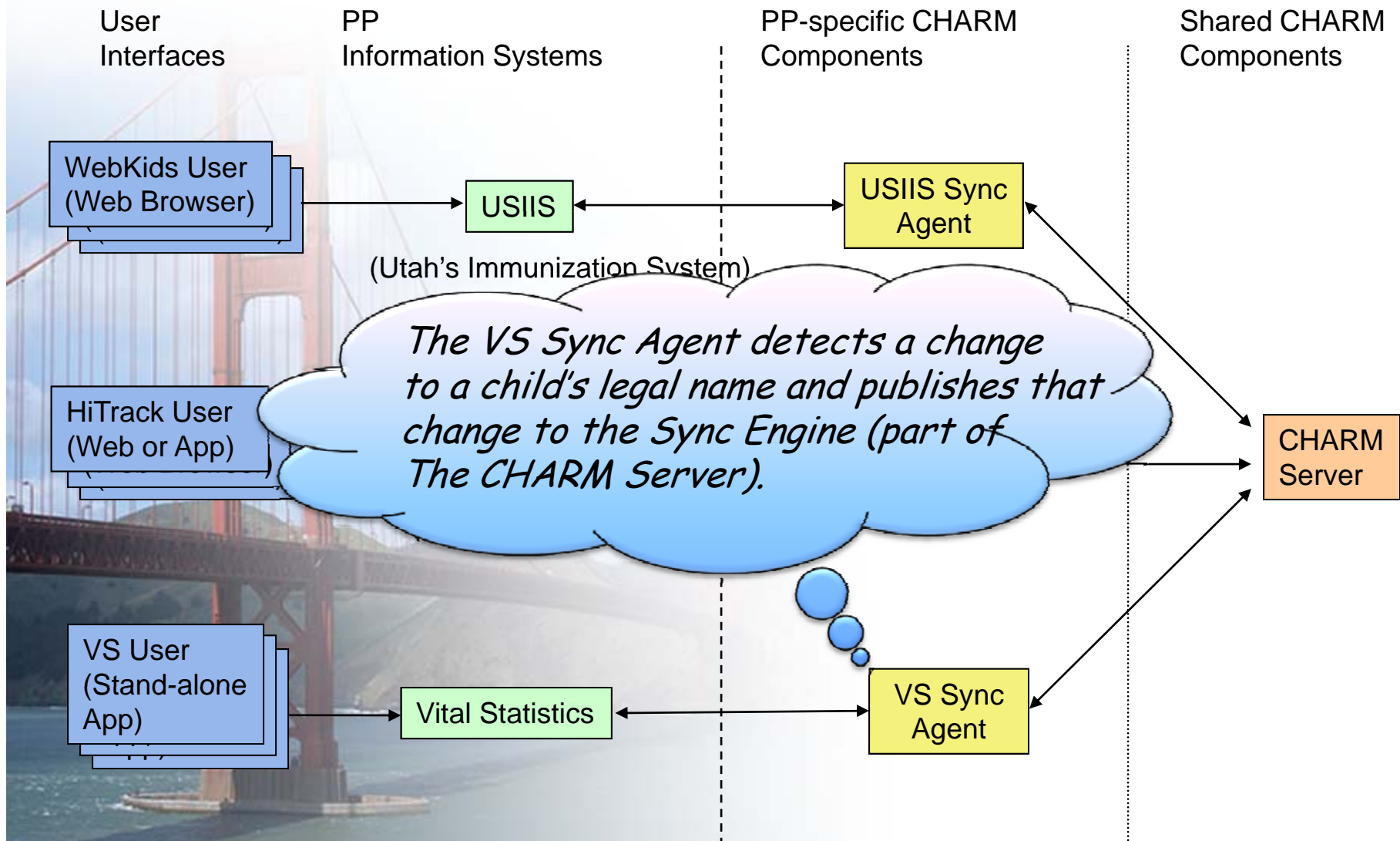
Immunization History:

Vaccination Date (mm/dd/yyyy)	Vaccination Name	Vaccination Series	
05/25/2000	HEPATITIS B - PEDIATRIC OR ADOLESCENT	HEP-B	More info
11/19/2002	INFLUENZA - SPLIT	FLU	More info

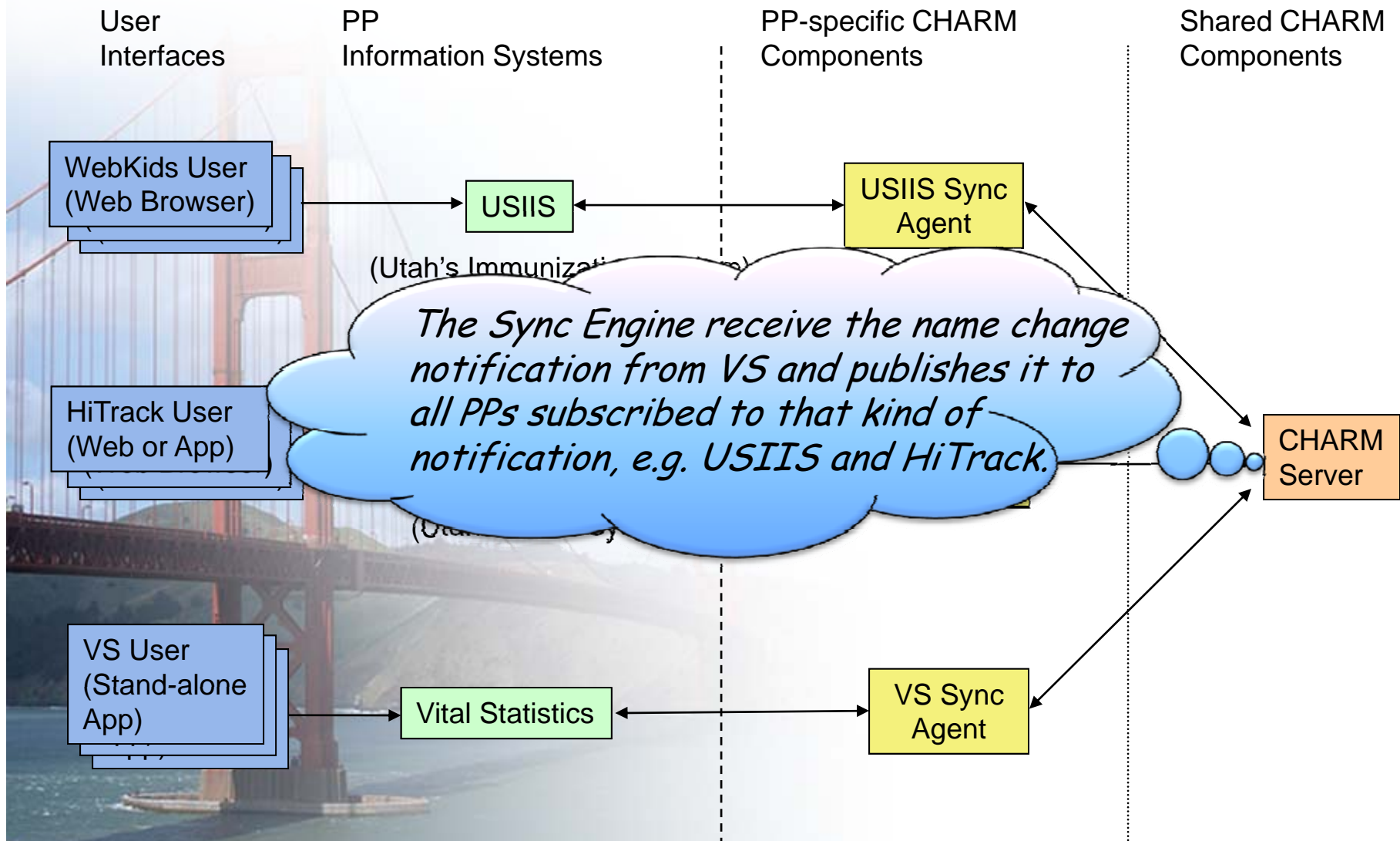
Data monitoring example



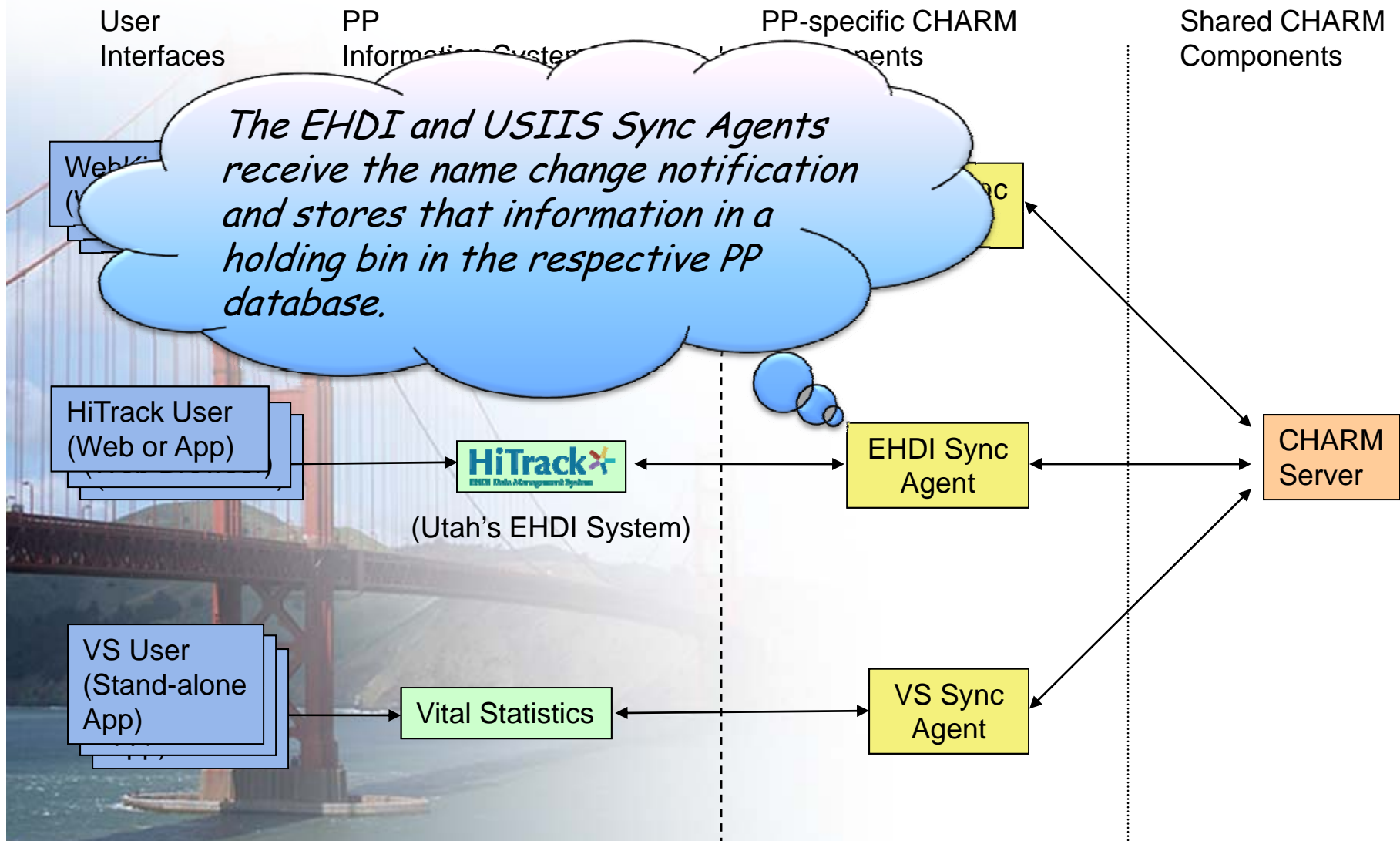
Data monitoring example – Step 1



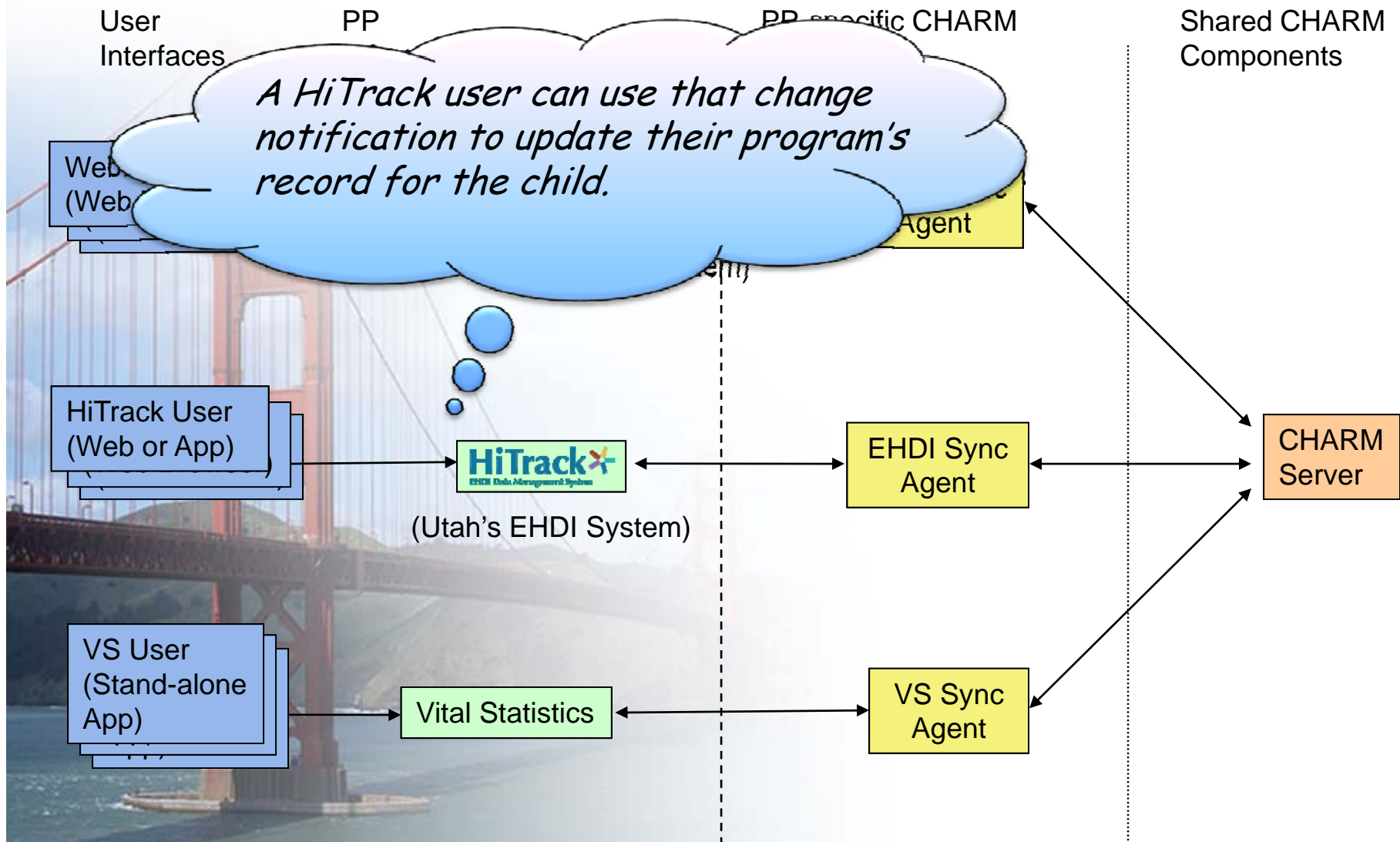
Data monitoring example – Step 2



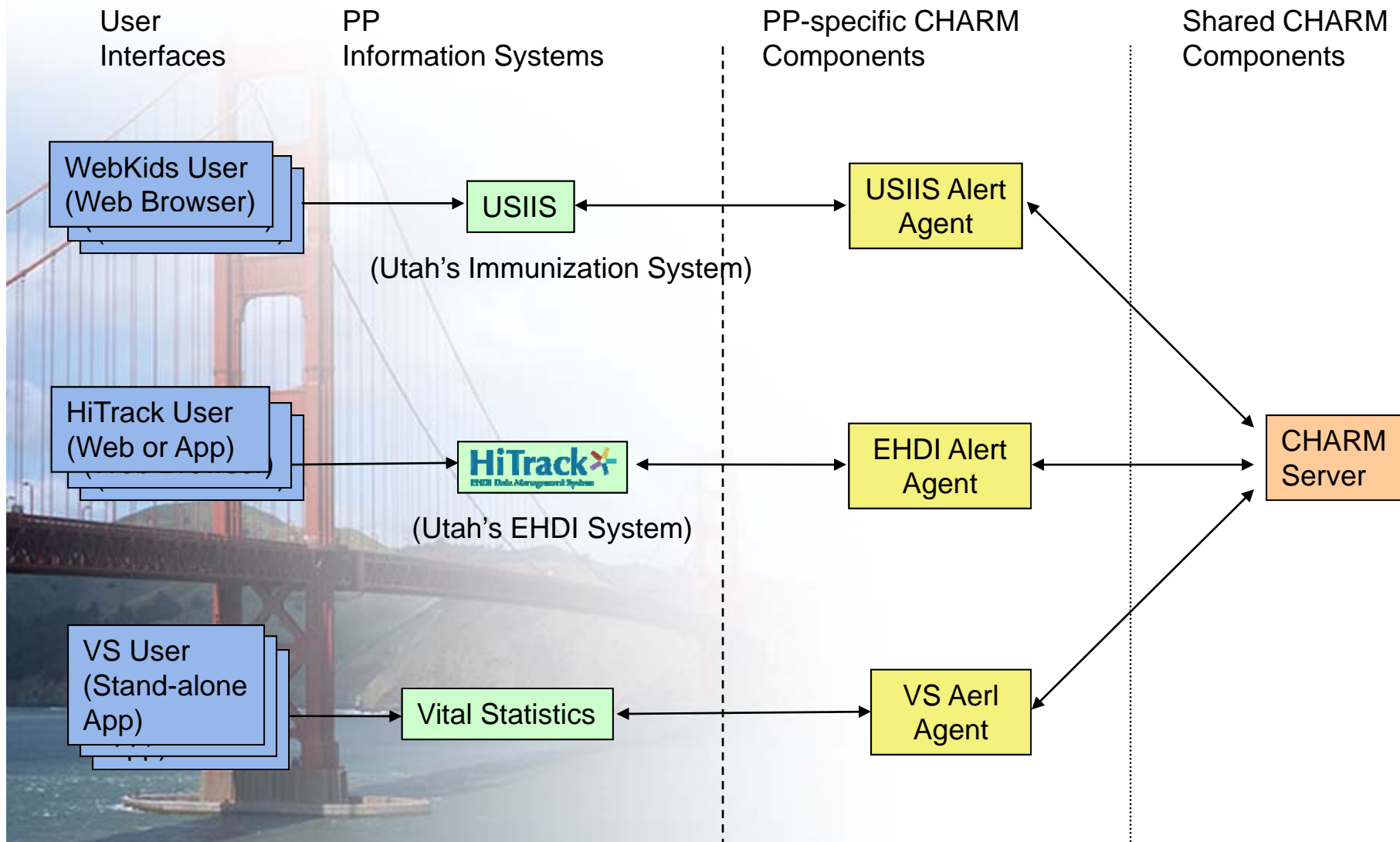
Data monitoring example – Step 3



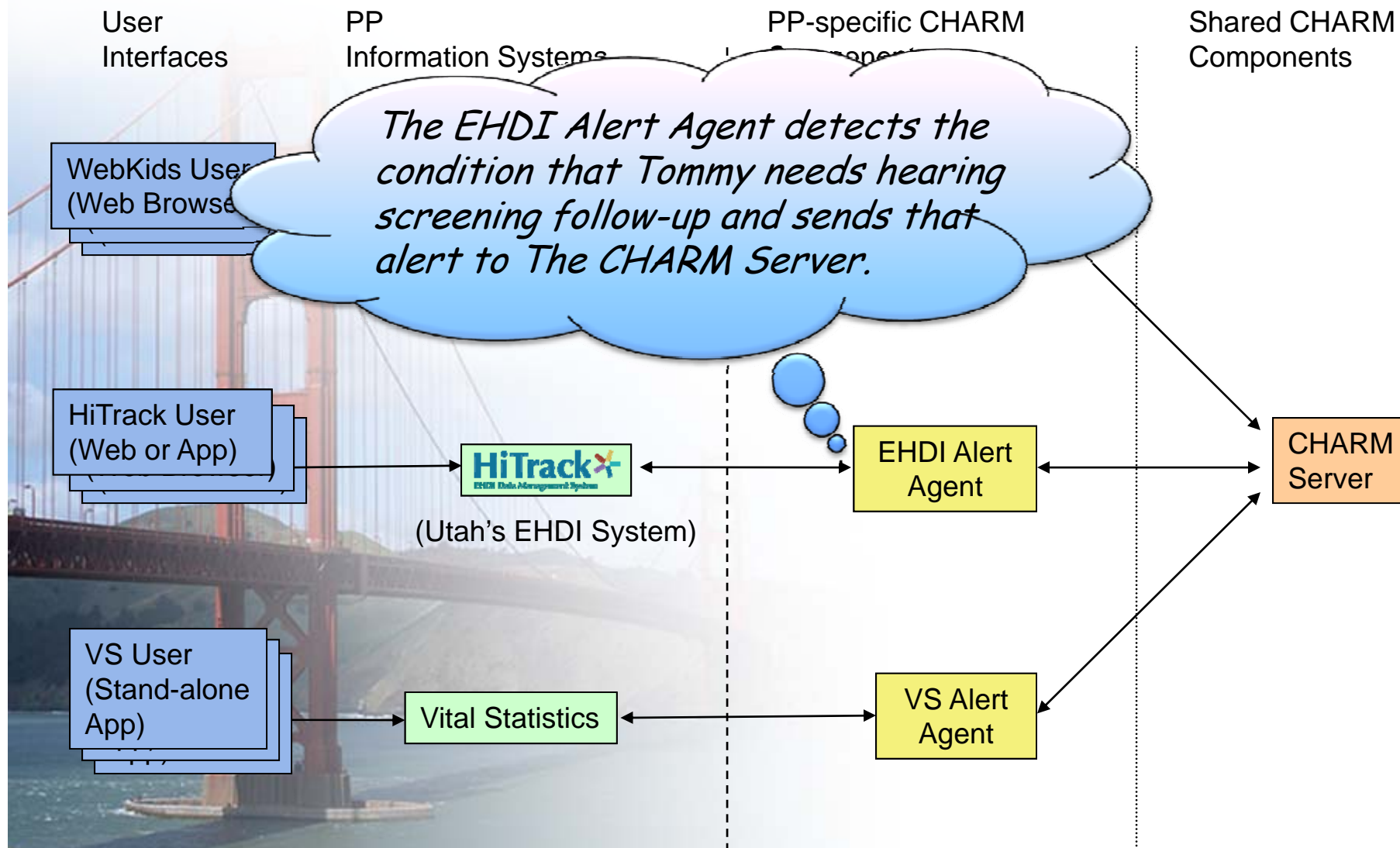
Data monitoring example – Step 4



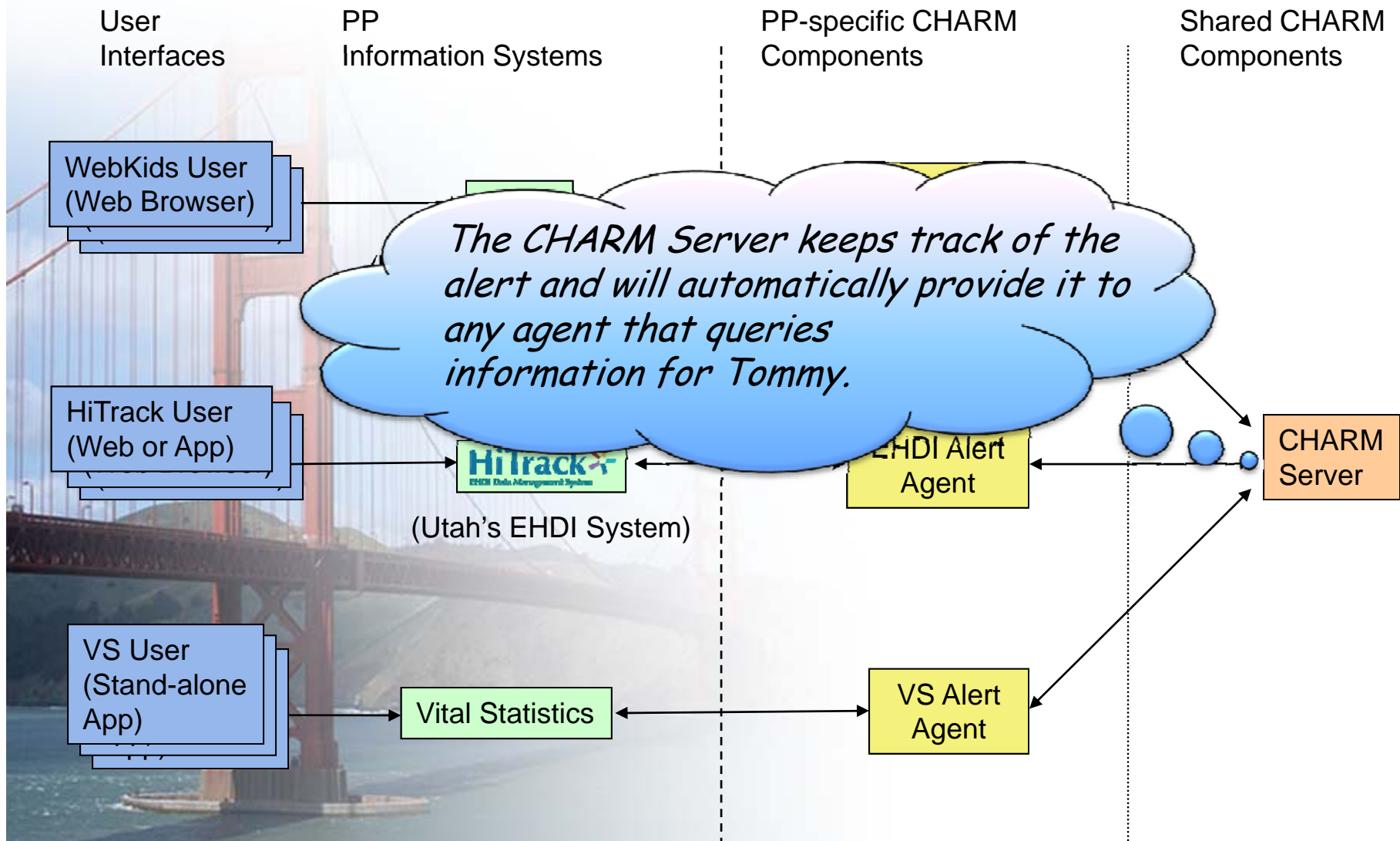
Alert example



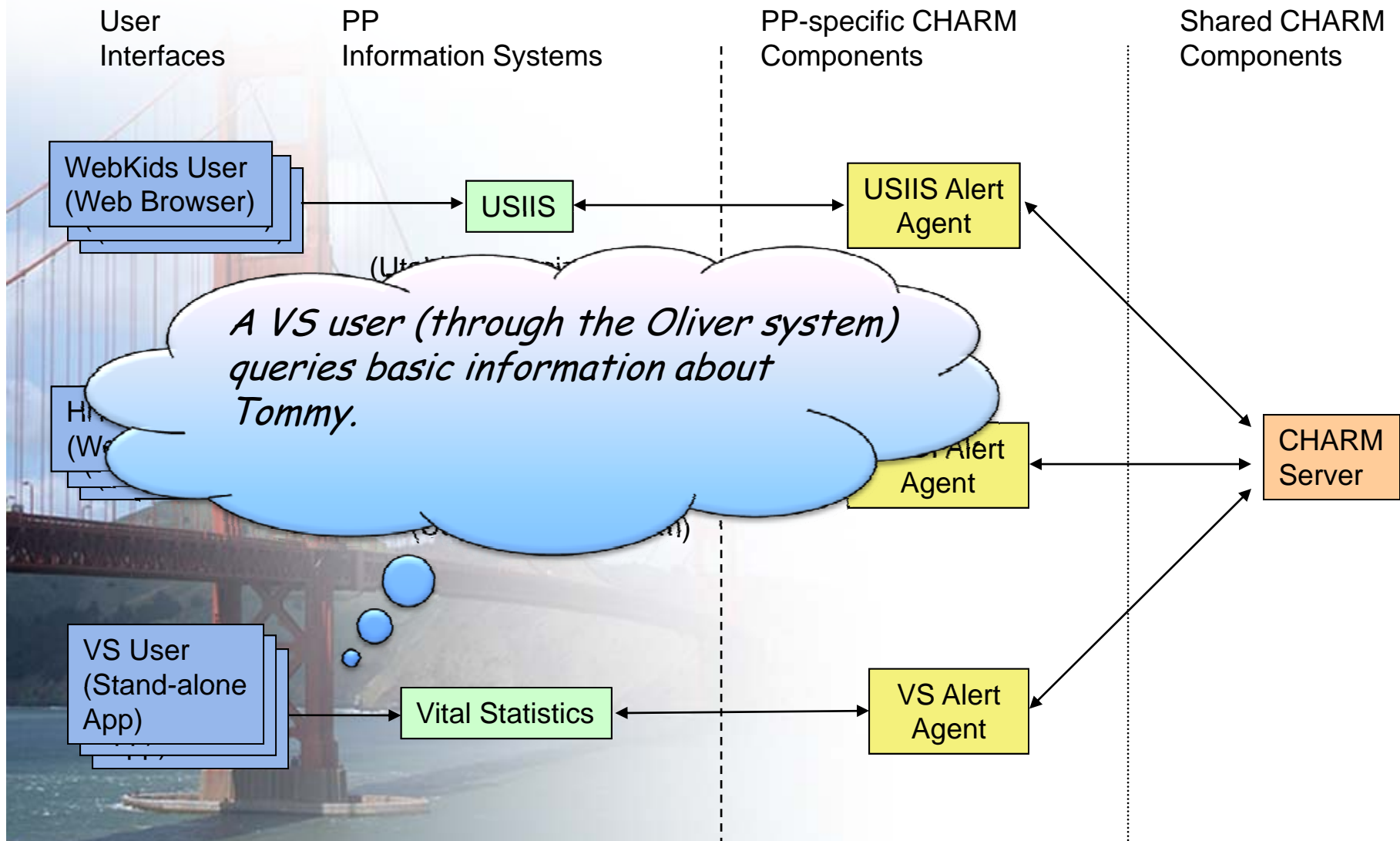
Alert example – Step 1



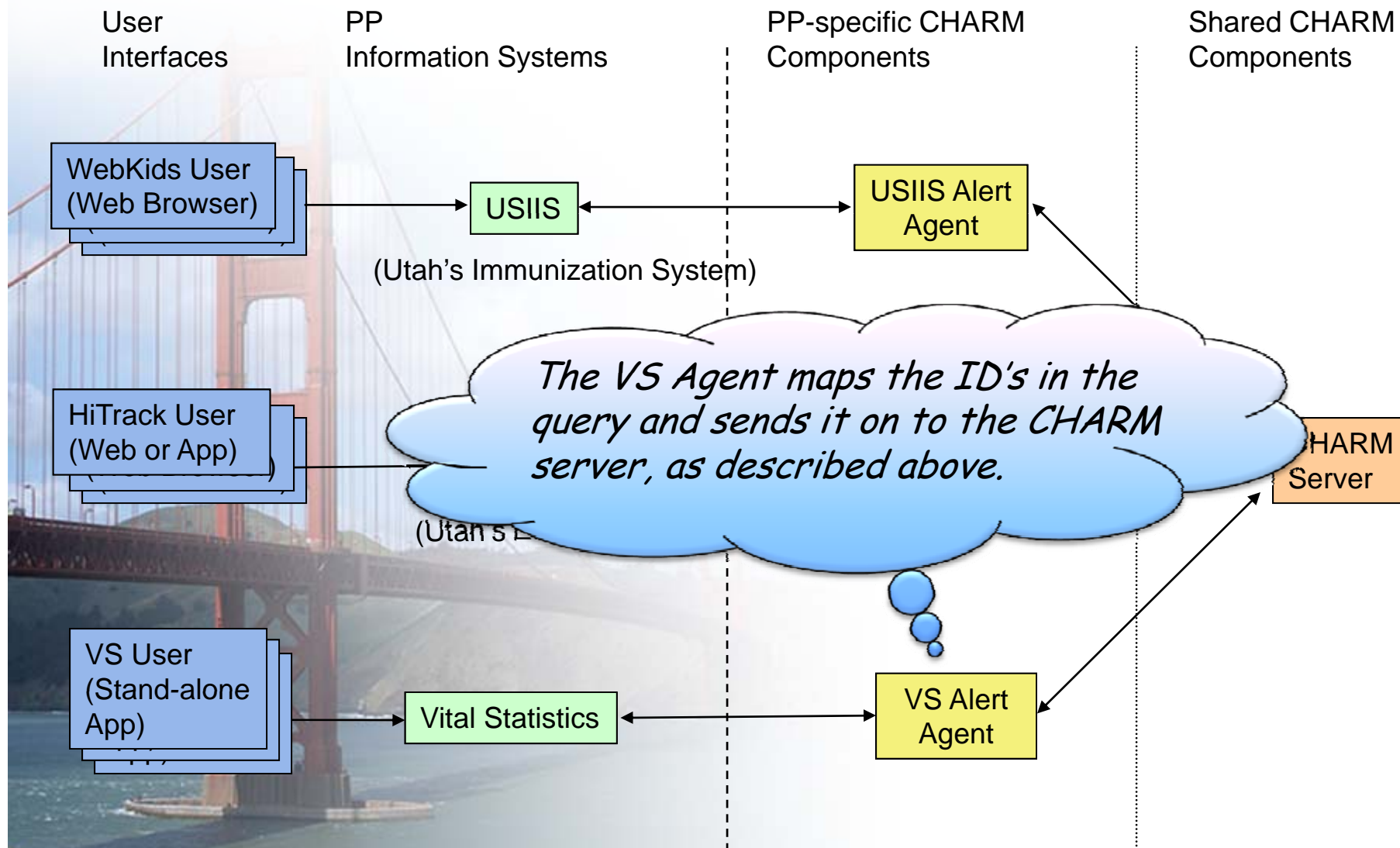
Alert example – Step 2



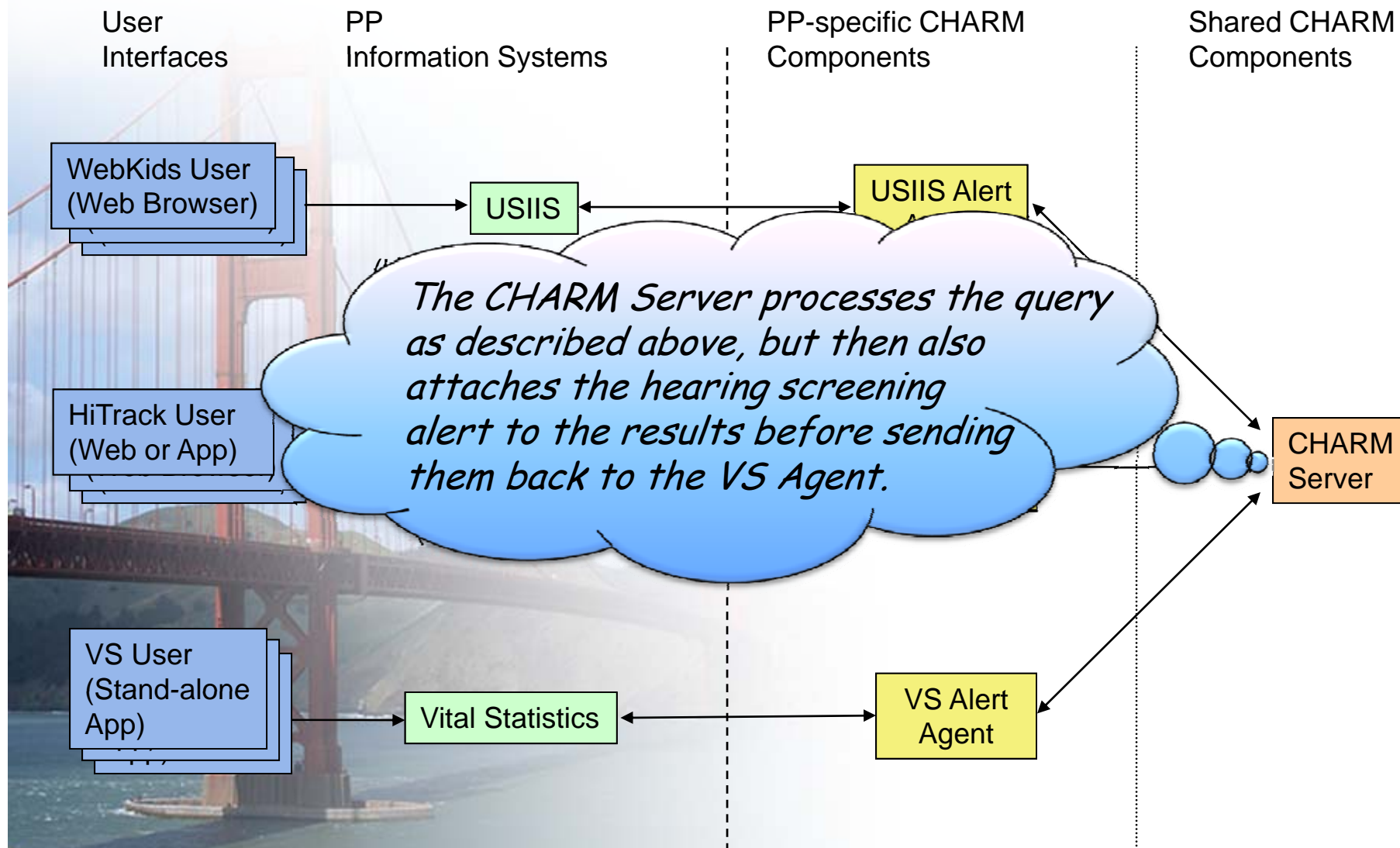
Alert example – Step 3



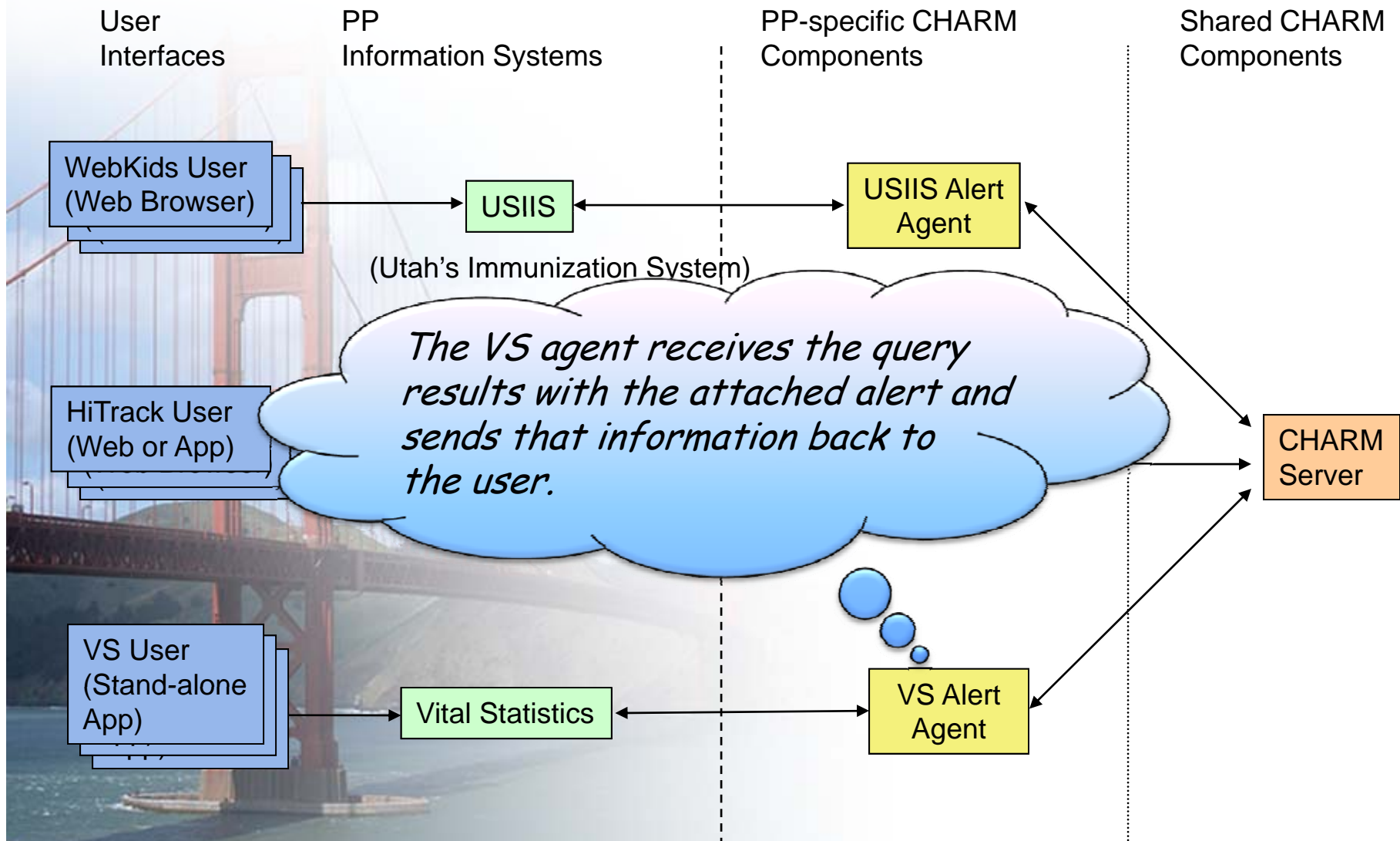
Alert example – Step 4



Alert example – Step 5



Alert example – Step 6



Alert example – Step 6



All Data for *All Facilities (48)

HI-TRACK
Version 4.5.1 (C) 2004 - 2009
HI-TRACK

Facility: *All Facilities

Letters Reports Merge Tools Settings Log Out

User: demo

All Data for *All Facilities (48 of 48)

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☐ Advanced Find ☐ Milestones

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Have, Asher	8169-63402	7/04/2006	Referred	7/04/2006	Referred	7/18/2006
Garbo, Gretchen	8657-29840	5/30/2006	Referred	6/08/2006	Referred	6/18/2006
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Winger, Robin	5432-33471	8/17/2006	Referred	8/17/2006		

☐ Combine:

Lesse, Patty

Medical ID: 8657-29849
Birth Date: 6/28/2006
Action: Passed Screening
Status: Complete

Record Overview

- Tracking Options
- Demographics
- Screening
- Risk Indicators
- Diagnostics
- Hearing Disposition
- Amplification
- EI Services
- Letters
- Transfer

Recommended Actions:
[Add/Edit](#)

Messages:
CONFIRMED LOSS. 07/08/06
Milestones: 0/0/-
Inactive record. Use Tracking
Options to re-activate this record.

External Links:
[Vital Records](#)
[Immunizations](#)

Alert example – Step 6



This information is brought to you by CHARM...

Risk Factors from VS

Alert Info:

Date (mm/dd/yyyy)	Severity	Message	From
12/03/2003	Urgent	Child has an overdue on HepB	USIIS

[More info](#)

██████, ██████ ██████ (last, first middle)
Gender: Male
Birth Date: 05/25/2000 (mm/dd/yyyy)
Deceased: No

Risk Factor Info:
Does the Family have a history of hearing loss?
false

[More info](#)

Alert example – Step 6

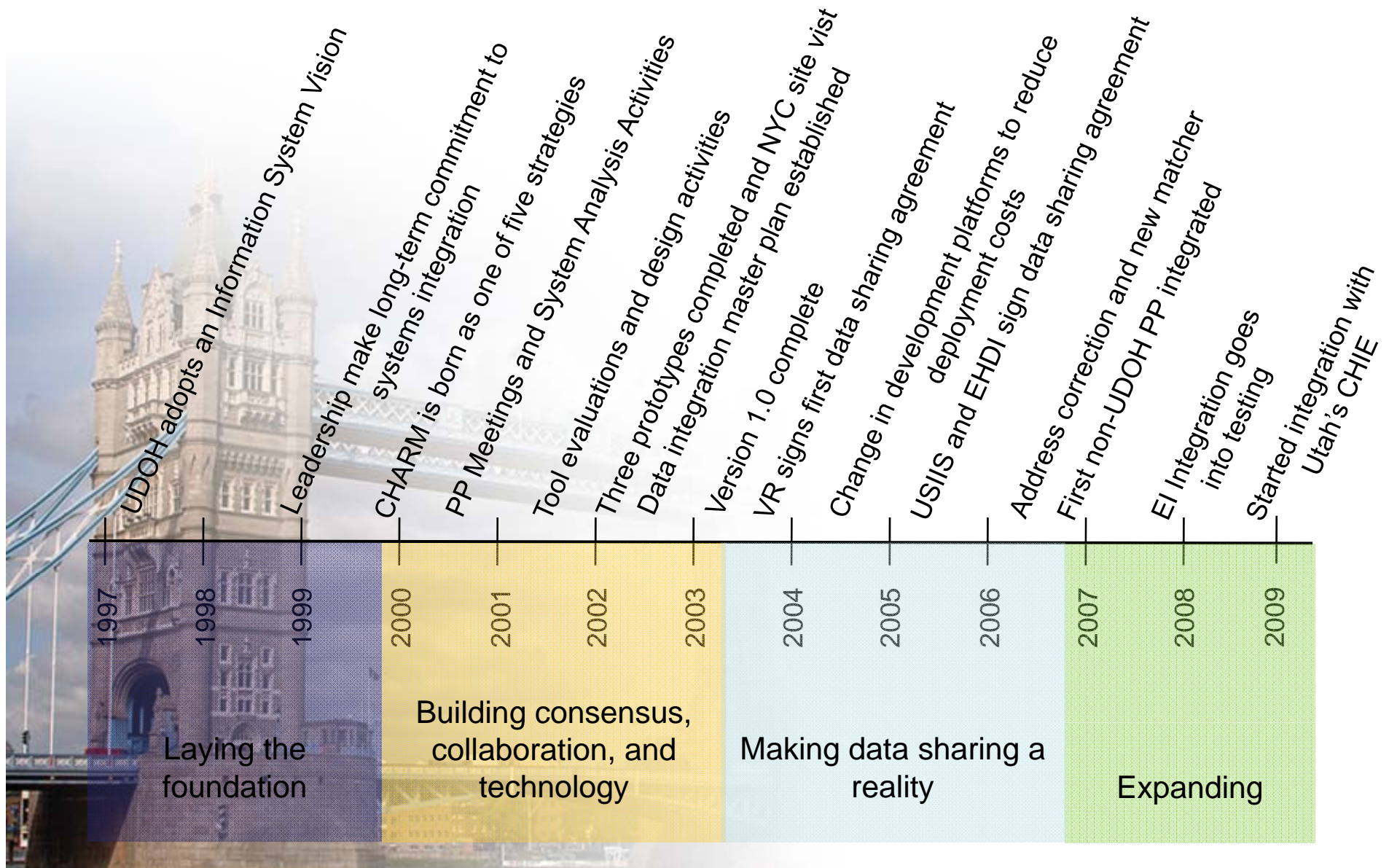


Risk Factors/Delivery Information/Birth Abnormalities

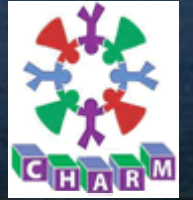
Name:	Opssjt, Nfsdfeft Lbuimffo (<i>last, first middle</i>)	
Anemia:	false	Cardiac Disease: false
Acute Or Chronic Lung disease:	false	Genital Herpes: false
Hemoglobinopathy:	false	Polyhydramnios: true
Chronic Hypertension:	false	Pregnancy Associate Hypertension: false
Eclampsia:	false	Incompetent Cervix: false
Previous Infant 4000+ Grams:	false	Previous Preterm Infant: false
Previous Small for Gestational Age Infant:	false	Renal Disease: false
RH Sensitation:	false	Rubella: false
Uterine Bleeding:	false	None: false
Other:	false	Unknown: true
Pre Existing Diabetes:	false	Gestational Diabetes: false
Specify:	false	Vaginal: IUGR
Vaginal Cessarian:	true	Primary Cessarian: false
Repeat Cessarian:	false	Forceps: false
Vaccum:	true	Birth Weight(gr):
Birth Weight(lbs):	6	Birth Weight(oz):
Birth Location:	Birth Order:	
APGAR 1:	07	APGAR 5: 08
Neonatal Meningitis:	false	Congenital Infection: false
Assisted Ventilation (Less than 30 minutes):	false	Assisted Ventilation (More than 30 minutes): false

Internet

A Look Back



Better Tracking & Follow-up



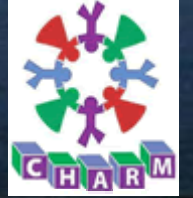
- Vital Statistics data for EHDI users
- EHDI data for EI Part-C users
- NBS data for EHDI users
- EI Part-C data for EHDI users
- Obtain Parent Opt Out information for EHDI data

Improved EHDI Data Quality



- Notification of new, unknown children from Vital Records
- Notification of name changes and deaths from Vital Records
- Notification of address changes from EI Part-C

Challenges addressed by CHARM



- Data Stewardship
- Record Matching, linking and merging
- Data Accuracy (in the face of shifting semantics)
- Confidentiality of patient data



Data Stewardship – Push vs. Pull?



- Two general techniques for accessing shared data:

- **Pushing:** copies of data to data consumers

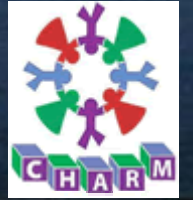
- The data consumer becomes responsible for the copy
- Data consumers must be able to accept data on demand and handle that data with confidentiality
- Data consumers must stay-updated with data sources



- **Pulling:** retrieves data from data sources as needed

- Data steward remains responsible for the data
- Data is “live” and up-to-date

Data Stewardship – Retained vs. On Demand



- Two approaches for managing shared data:
 - **Retaining Data**
 - Requires knowledge about data integrity and domain specific logic
 - Requires physical resources to keep data
 - Introduces data expiration issues
 - The data steward is disconnected from the copy; it is not necessarily updated when the data steward makes changes
 - **Retrieving Data on demand**
 - Available as needed
 - Data is “live” and up-to-date



Data Stewardship – Direct vs. Brokered



- Two approaches to handling communication for data sharing:

- **Direct Communication**

- Requires data consumers to communicate directly with data providers
 - Requires data consumers to have “domain specific knowledge” about other providers



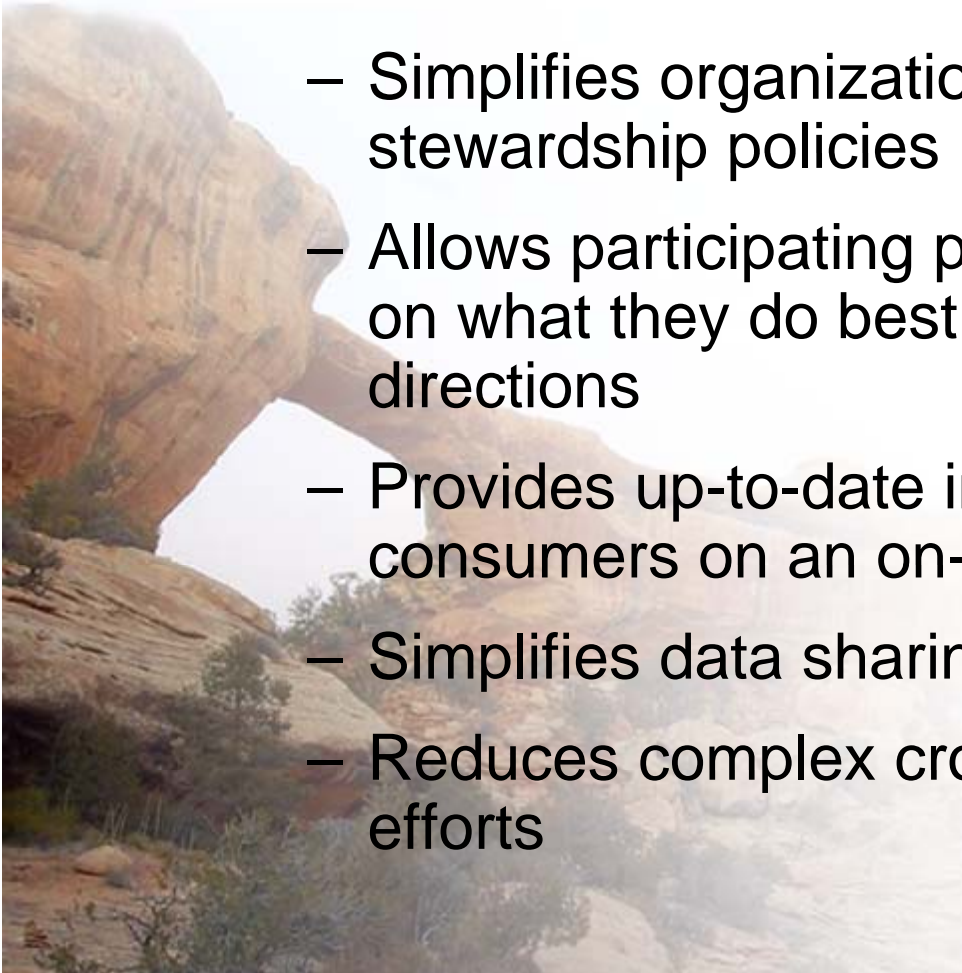
- **Data Brokering**

- “Arms length” data access reduces impact on data providers
 - Gives a buffer that protects data providers
 - Fosters “Plug and Play” architecture

Data Stewardship – Doing it right



- Benefits of keeping data close to the stewards:
 - Simplifies organizational boundaries and data stewardship policies
 - Allows participating programs to specialize: focus on what they do best and grow in their own directions
 - Provides up-to-date information for all data consumers on an on-demand basis
 - Simplifies data sharing arrangements
 - Reduces complex cross-program integration efforts



Data Quality



- The value of an integrated system depends on the quality of the data in the individual PPs and on the quality of the matching of records among these PPs
 - Matching must be tuned to the characteristics of the individual data sources
 - The characteristics can involve subtle data semantics, e.g. the encoding of race
 - These characteristics can shift over time, due to software changes, procedural changes, user turnover, or new policies

Confidentiality of patient data



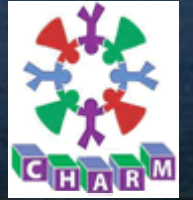
- An integrated system must preserve patient privacy
- Two general approaches for allowing or restricting data sharing across HIT systems
 - Opt-in
 - By default no data is shared. Patients must explicitly grant permission for their information to be shared with other health-care system
 - Opt-out
 - By default data is shared, but patients are always given the ability to choose not to have their data shared.

Ongoing Challenges & Next Steps



- Expansion
 - Additional participating programs within the DOH
 - Participating programs outside the DOH
 - Other Health Information Exchanges
- Data provenance
- Operations
 - Setting systems, networks, firewalls, etc.

Summary



- CHARM is the culmination of a decade of data sharing experience
- CHARM provides a real-time data sharing system that accommodates existing programs
- CHARM promotes effective data stewardship
- CHARM “bridges the gap” between today’s public health information systems