

An Information Sharing ~~Platform~~ Prototype for Hadron Therapy

Faustin Laurentiu Roman*, Daniel Abler, Vassiliki Kanellopoulos
CERN

IFIC, Univ. of Oxford, Univ. of Surrey
partner-grid@cern.ch

*presently ebg MedAustron GmbH

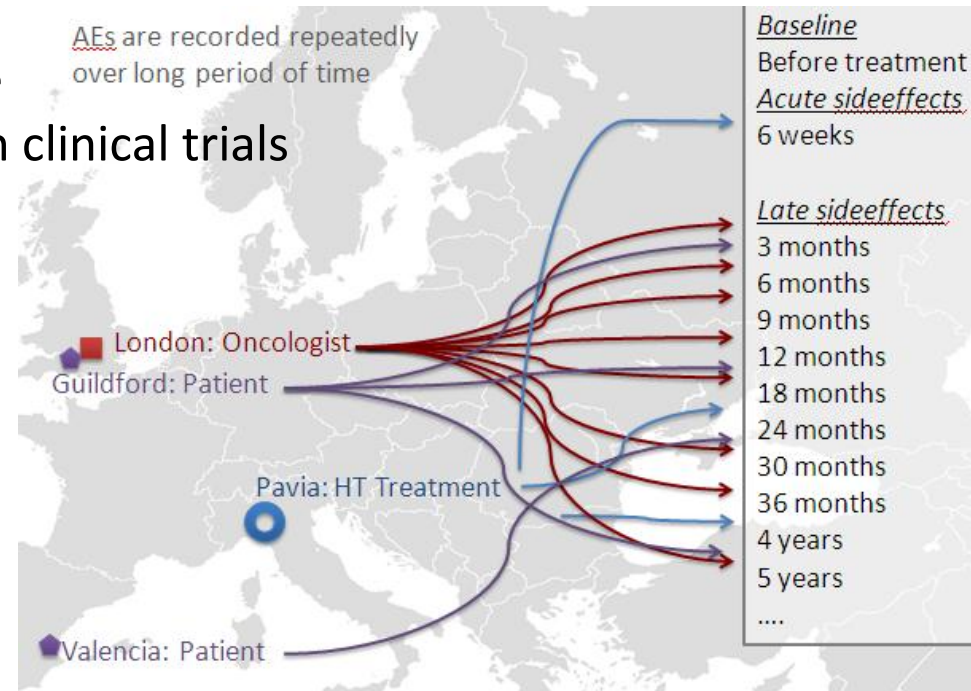
- Reporting side effects
- Hadron Therapy Information Sharing Platform (HISP)
- Data Federation and Presentation
- Data Capture and Semantics
- Data analysis
- Outlook

Why

- part of treatment quality assurance
- study effects of specific therapies in clinical trials
- research strategies for prevention

How

- Scoring systems
- differ in type, modality, grades...
- recording in multiple locations
- over many years



Project Goal

- **Doctors** and **patient** report **side effects**
- **Doctors** can view a record of the patient's side effects **across institutions**.
- **Researchers** can request access to statistical information

HISP (Hadrontherapy Information Sharing Platform)

Data Federation
and Presentation

- Unified view over distributed data sources
- Secure and intuitive portal



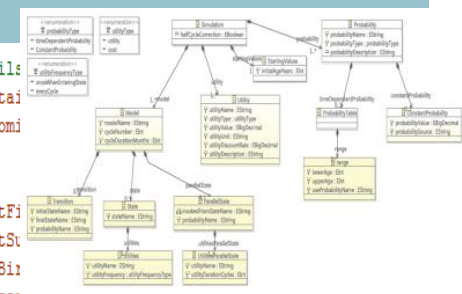
hispse - PATIENT

	First name	Surname	Date of birth	Gender	Diagnosis
status	status	status			status
	JASON	ALLEN	2/04/53	M	Anal Cancer
	JESUS	RUIZ	11/03/62	M	Anal Cancer
	TONYA	LANE	5/9/49	F	Anal Cancer
	MATTHEW	CLARK	2/03/58	M	Anal Cancer

Data Collection
Services and
Semantic
Interoperability

- Semantics of data capturing forms
- Services for electronic data capture

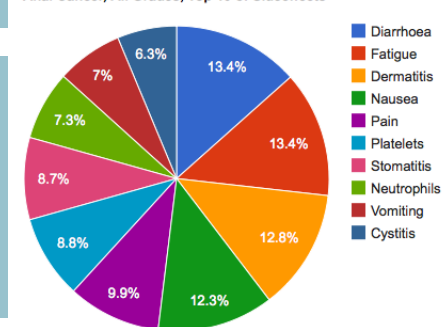
```
<!-- model for Patient Details -->
<xforms:model id="PatientDetails">
  <xforms:instance id="submit" data="PatientDetails"/>
  <!-- BINDINGS -->
  <!-- PatientDetails -->
  <xforms:bind id="PatientFirst" type="text" data="PatientDetails/first"/>
  <xforms:bind id="PatientSurname" type="text" data="PatientDetails/surname"/>
  <xforms:bind id="DateOfBirth" type="text" data="PatientDetails/dob"/>
  <xforms:bind id="DateRecorded" type="text" data="PatientDetails/recorded"/>
  <!-- PainHeadAndNeck -->
</xforms:model>
```

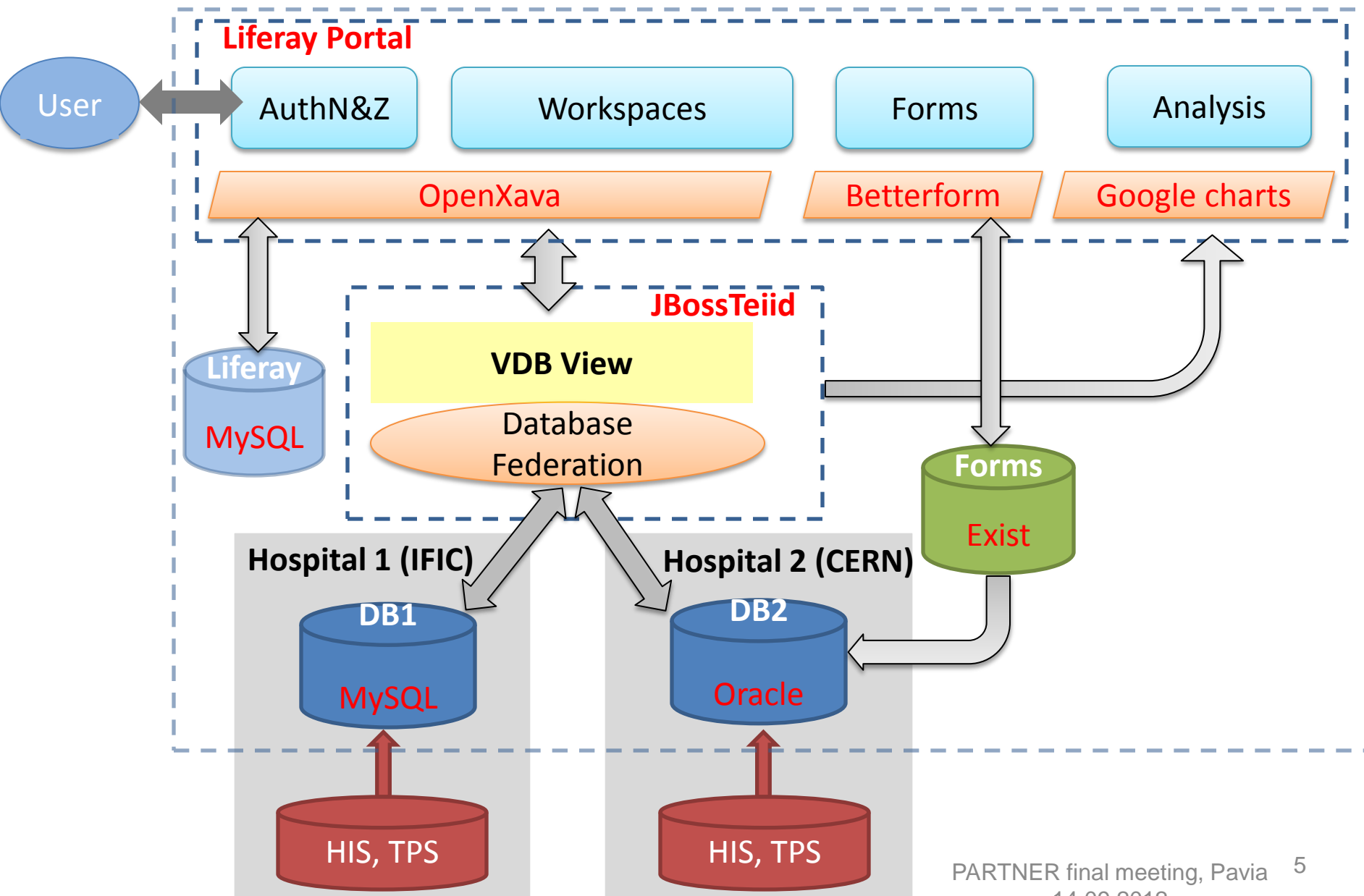


Analyzing medical
information

- HT treatment indication
- Predict treatment outcome

Anal Cancer, All Grades, Top 10 of Sideeffects



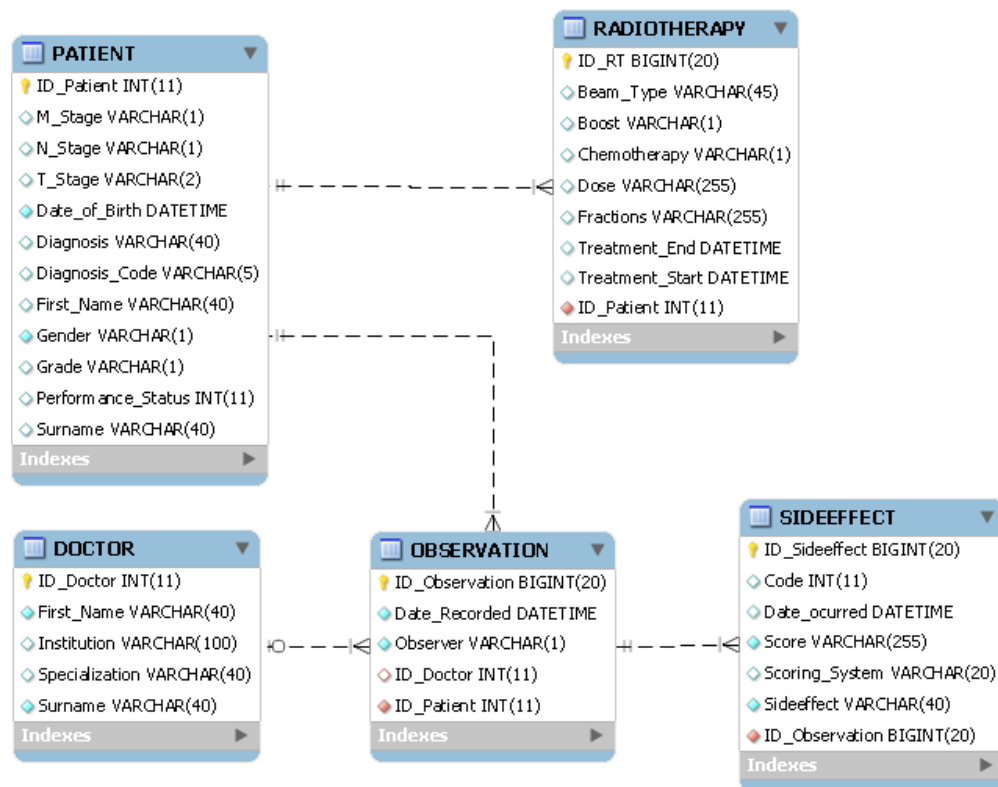


Information

- Patient (+ diagnosis)
- Treatment
- Doctor
- Side effect observations

Data

- Generated from published clinical trials
- Different characteristics



Hospital Information Systems (HIS)

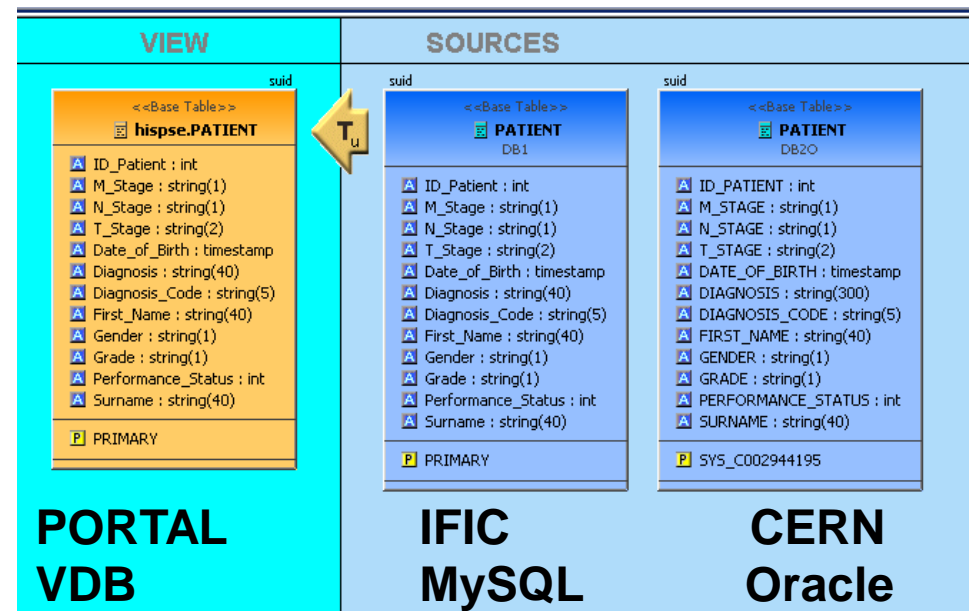
- unusual to be linked (except if parts of a single entity)
- medical data rarely shared
- undesirable to central storage/local copy

PARTNER setup:

- DB1: [MySQL](#) – popular free DB
- DB2: [Oracle](#) – popular comm. DB
 - used by hospitals systems

Location

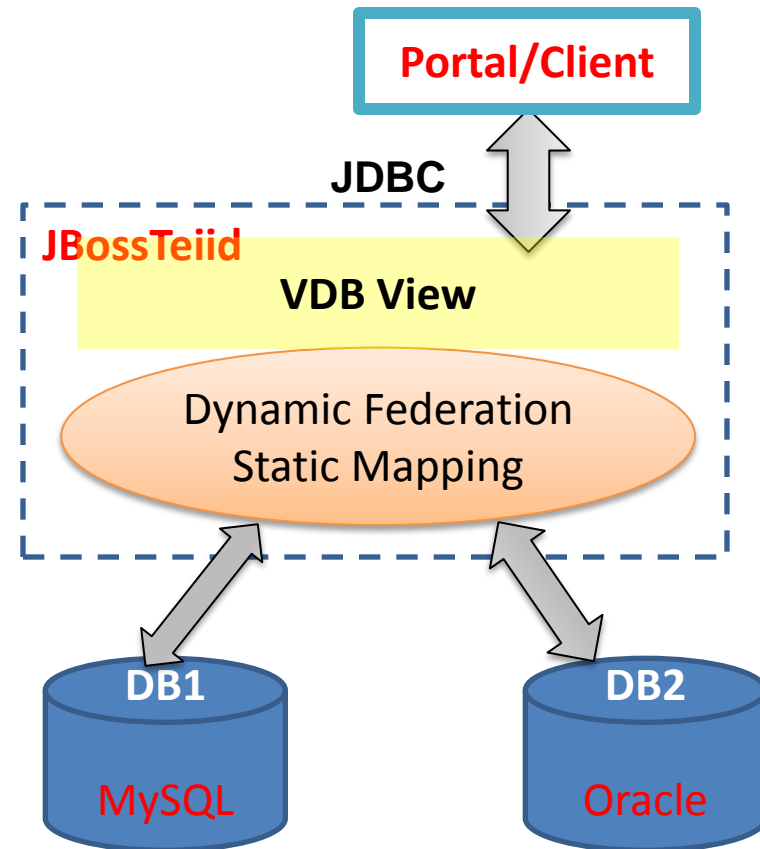
- DB1: IFIC, Valencia
- DB2: CERN, Geneva



- A virtual database(VDB) over distributed databases
- Leave data where it was created, not copy it centrally
- Mediates access to heterogeneous repositories

Jboss Teiid(/Designer)

- Open source, free
- Connects databases, files, services
- Designer for custom virtual views



Goal

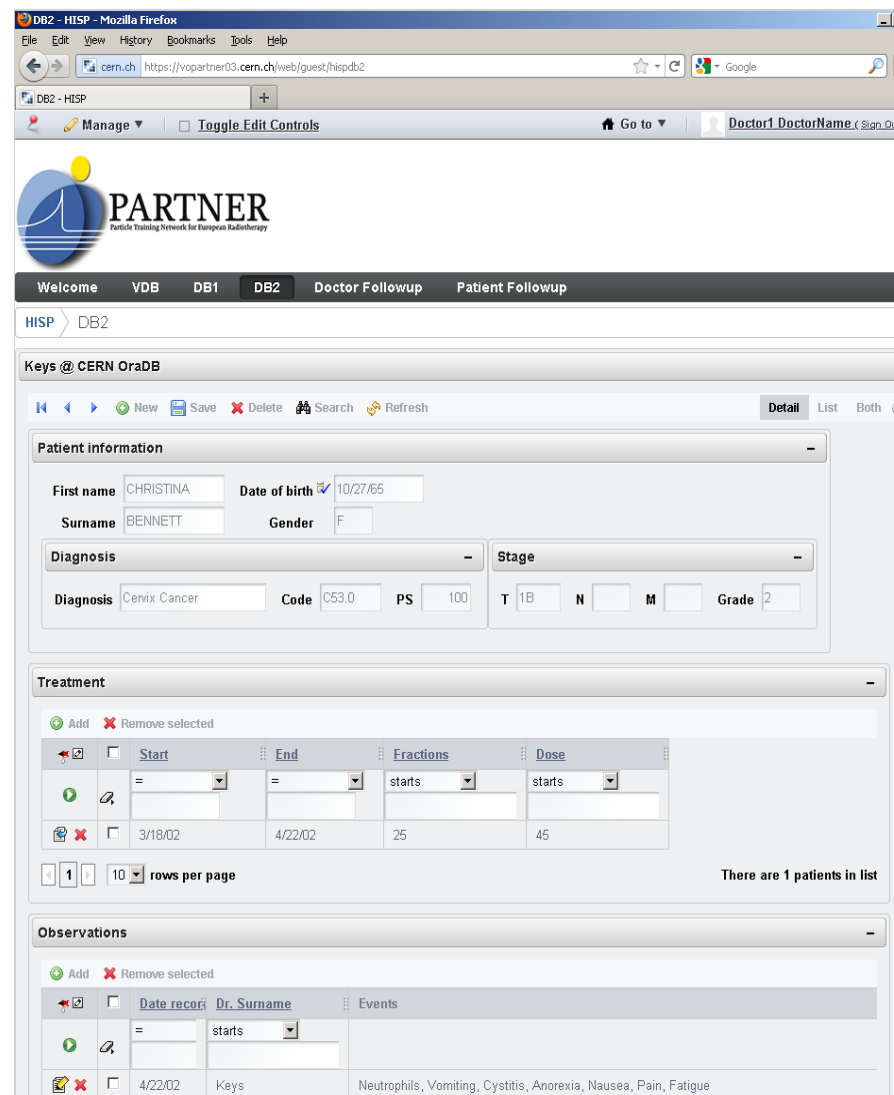
- Web2.0 secure and intuitive portal
- Easy to develop interfaces

Portal: [Liferay](#)

- User and content management
- Standard for Portlet 2.0

User interface: [OpenXava](#)

- Easy Java development framework
- Liferay compatible
- Provides a nice DB interface



DB2 - HISP - Mozilla Firefox

File Edit View History Bookmarks Tools Help

cern.ch https://vopartner03.cern.ch/web/guest/hispdb2

DB2 - HISP

Manage Toggle Edit Controls

Go to Doctor1 DoctorName (Sign Out)

PARTNER Particle Training Network for European Radiotherapy

Welcome VDB DB1 DB2 Doctor Followup Patient Followup

HISP DB2

Keys @ CERN OraDB

New Save Delete Search Refresh Detail List Both

Patient Information

First name CHRISTINA Date of birth 10/27/65

Surname BENNETT Gender F

Diagnosis

Diagnosis Cervix Cancer Code C53.0 PS 100 Stage T 1B N M Grade 2

Treatment

Add Remove selected

Start	End	Fractions	Dose
=	=	starts	starts
3/18/02	4/22/02	25	45

rows per page

There are 1 patients in list

Observations

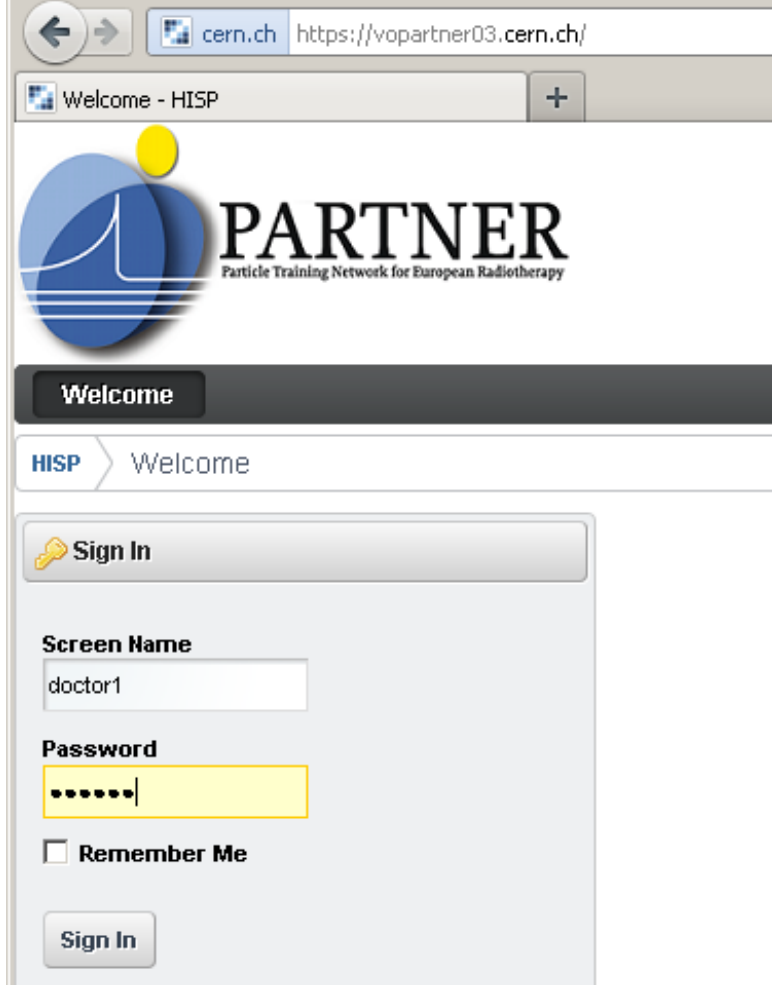
Add Remove selected

Date record	Dr. Surname	Events
=	starts	
4/22/02	Keys	Neutrophils, Vomiting, Cystitis, Anorexia, Nausea, Pain, Fatigue

- TLS encrypted connection
- Login based on
 - password
 - X509 (grid-compatible) certificates

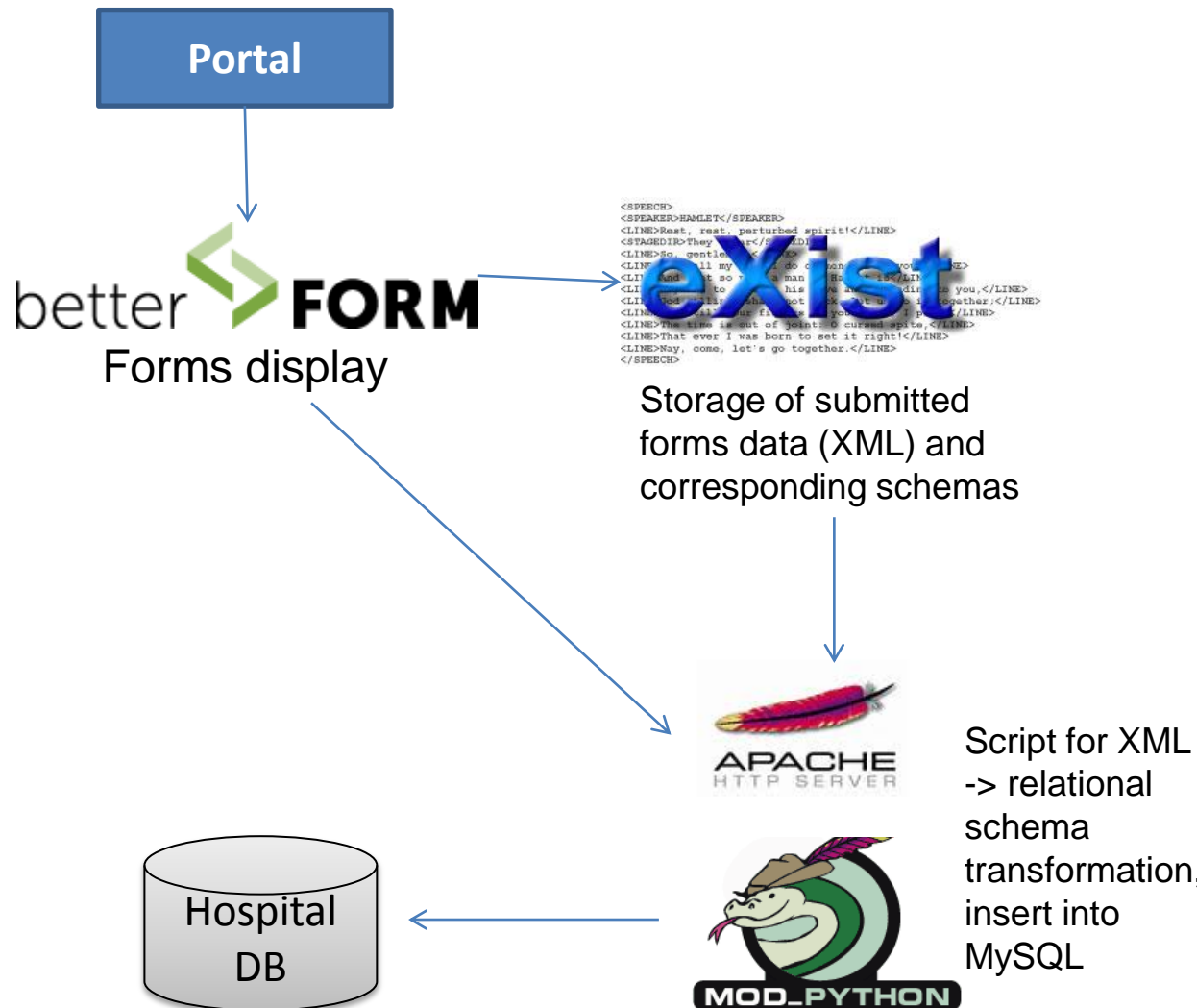
Role based access control

- Doctor
- Patient
- Researcher
- Admin



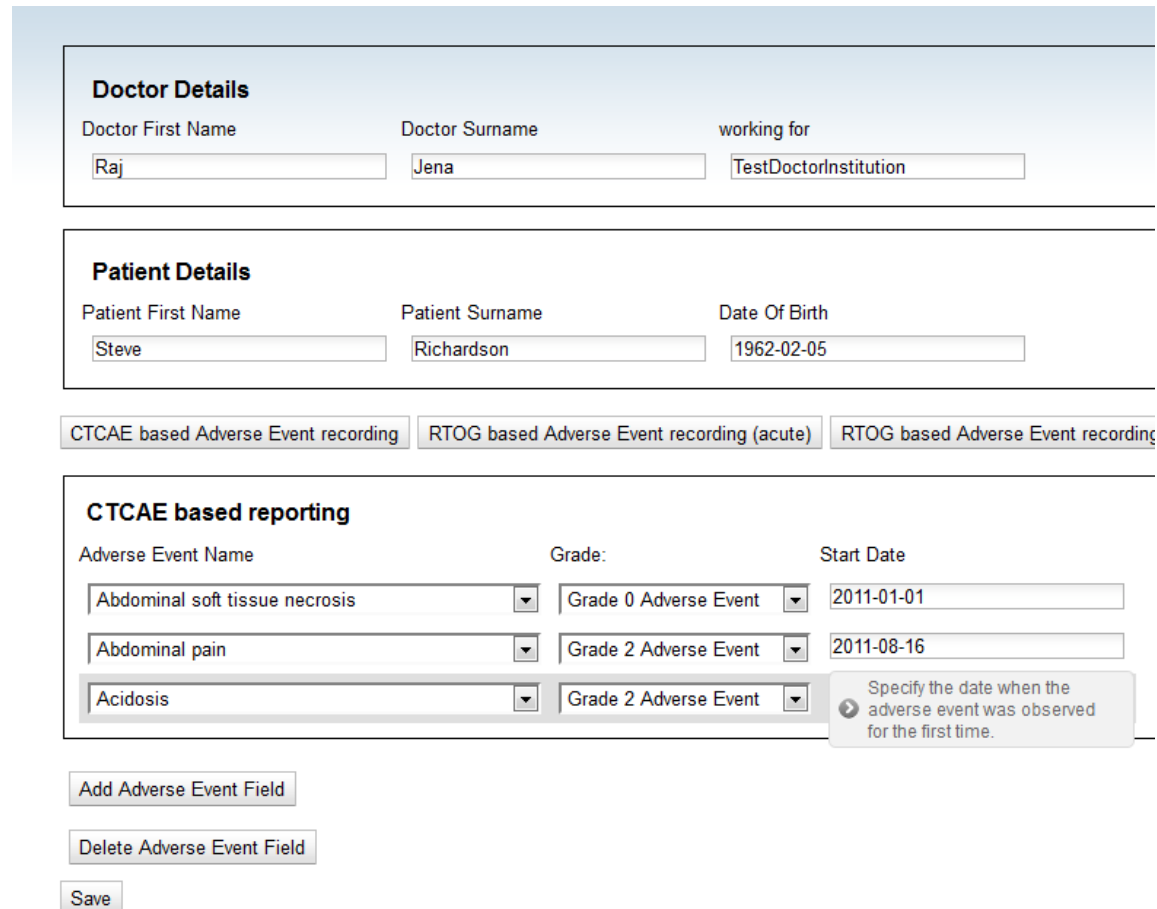
The screenshot shows a web browser window with the address bar displaying 'cern.ch' and the URL 'https://vopartner03.cern.ch/'. The browser tab is titled 'Welcome - HISP'. The page features the PARTNER logo and the text 'Particle Training Network for European Radiotherapy'. Below the logo, there is a 'Welcome' button. A navigation bar shows 'HISP' and 'Welcome'. The main content area contains a 'Sign In' section with a key icon. It includes a 'Screen Name' field with the text 'doctor1', a 'Password' field with masked characters '.....', and a 'Remember Me' checkbox. A 'Sign In' button is located at the bottom of the form.

- Forms based on W3C *Xforms*
- XForms rendered by *betterFORM* and accessed through portal
- Form data submitted to *eXistXML* database
- Data inserted in corresponding hospital DB



Web forms for doctor reporting:

- coded terms for CTCAE and RTOG scoring systems
- Input verification before submission
- Data is sent to database as observation entries



Doctor Details

Doctor First Name: Doctor Surname: working for:

Patient Details

Patient First Name: Patient Surname: Date Of Birth:

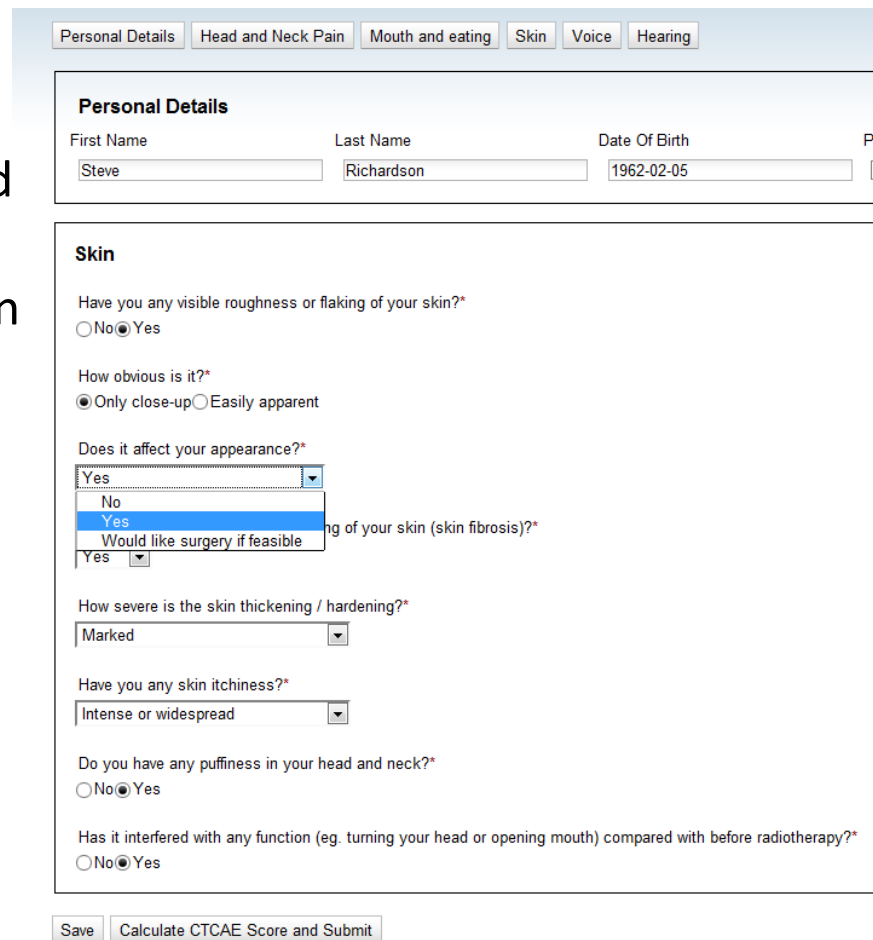
CTCAE based reporting

Adverse Event Name	Grade:	Start Date
<input type="text" value="Abdominal soft tissue necrosis"/>	<input type="text" value="Grade 0 Adverse Event"/>	<input type="text" value="2011-01-01"/>
<input type="text" value="Abdominal pain"/>	<input type="text" value="Grade 2 Adverse Event"/>	<input type="text" value="2011-08-16"/>
<input type="text" value="Acidosis"/>	<input type="text" value="Grade 2 Adverse Event"/>	

Specify the date when the adverse event was observed for the first time.

Web forms for patient reporting:

- Implements questions for CTCAE based PROM questionnaire for radiotherapy adverse events in head and neck region
- Input verification before submission
- “raw data” is saved to dedicated database
- CTCAE score could be calculated from PROM replies and is sent to database



Personal Details Head and Neck Pain Mouth and eating Skin Voice Hearing

Personal Details

First Name Last Name Date Of Birth

Steve Richardson 1962-02-05

Skin

Have you any visible roughness or flaking of your skin?*

☐ No ☒ Yes

How obvious is it?*

☒ Only close-up ☐ Easily apparent

Does it affect your appearance?*

Yes No

Yes

Would like surgery if feasible

Yes

How severe is the skin thickening / hardening?*

Marked

Have you any skin itchiness?*

Intense or widespread

Do you have any puffiness in your head and neck?*

☐ No ☒ Yes

Has it interfered with any function (eg. turning your head or opening mouth) compared with before radiotherapy?*

☐ No ☒ Yes

Save Calculate CTCAE Score and Submit

Questions taken from:

http://www.christie.nhs.uk/pro/depts/clinonc/lent_soma/docs/Raphnsubj.pdf

Patient reported outcome measures for head and neck region, Christie's hospital, Manchester, UK

Realtime statistics

- Anonymous query of all DBs
- Selection of desired query via drop down menus
- Query of the VDB via ODBC connection
- Display of results with Google Charts

Adverse Events for tumour entities

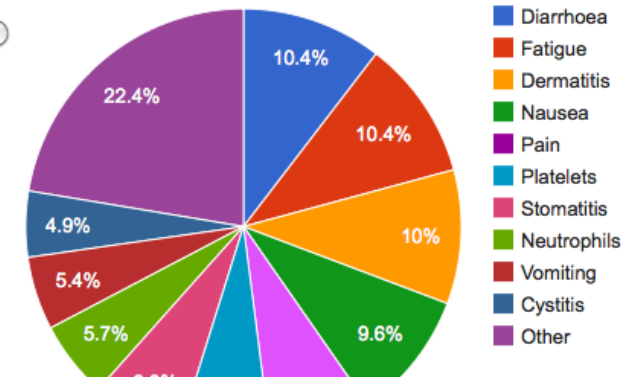
Please pick the disease of your choice

Anal Cancer All Grades

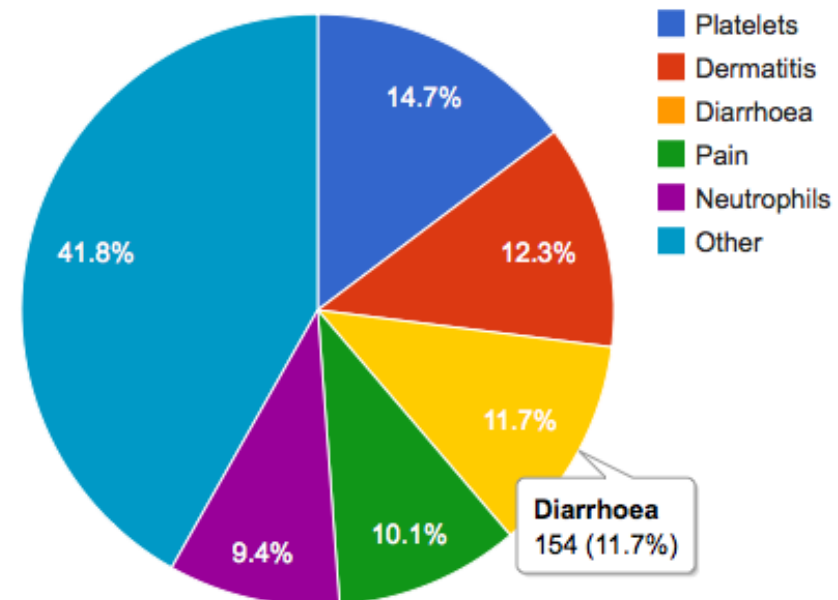
Number of Sideeffects displayed: Top 10 Submit Query

All
Top 5
Top 10

Anal Cancer, All Grades, Top 10 of Adverse Events



Anal Cancer, severe Adverse Events, Top 5 of Adverse Events



Results – prototype ready:

- Data-driven collaborative portal
- Heterogeneous database federation
- Forms for data taking
- Integrated statistics

Features:

- Free and open source
- Community supported
- Enterprise ready

DEMO: <http://bit.ly/poVWbg>

Outlook:

- Search patterns in federation: algorithms, data privacy
- Formalizing data capturing forms
- Prediction model for side effects

Acknowledgements

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<http://partner.web.cern.ch>
<https://vopartner05.cern.ch>

PARTNER final meeting, Pavia
14.09.2012

Sharing health data: good intentions are not enough

E. Pisani, C. AbouZahr

Bulletin of the World Health Organization 2010;88:462-466. doi:10.2471/BLT.09.074393

“As they prepare for careers in science, today’s students doubtless hear the same clichés as we did a generation ago: *science advances collaboratively, we reproduce and extend the work of others, we stand on the shoulders of giants.*

In some fields, such as genomics, these axioms are becoming true. **In epidemiology and public health, however, data sharing and collaboration remain more aspirational than real.”**

“Technically, the challenges are not trivial, but they have been overcome[...] We maintain that the major constraints to feasibility are a cultural resistance to change from within our own scientific community, and a reluctance of any institution to take leadership of the data sharing agenda.”

source: <http://www.who.int/bulletin/volumes/88/6/09-074393/en/index.html>