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UNICANCER

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European Commission

#### **The 20 French Comprehensive Cancer Centers**

#### Private nonprofit hospitals

- Threefold mission: care, research, education
- No overrunning fees
- A particular statute created by French Government after World War II

#### • Care for many types of cancer:

- standard cancers
- rare cancers

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- complex situations
- Leaders in senology
- Innovation and research:
  - 12 early-phase clinical trial centers
  - Unicancer Centers take part in 44% of Governmental Hospital Program for Clinical Research

### **UNICANCER : a French Reference Network**



#### The only French hospital group entirely devoted

to :

- healthcare
- research
- teaching
- ...in oncology

20 centers 18,000 employees More than 300 clinical trials 18% patients included in clinical trials 120,000 patients hospitalized per year

# UNICANCER and medical data a long story

- 1975: UNICANCER created a database for subjects treated in the Centers: "Enquête Permanente Cancer"
- Data collected are exclusively structured and completed manually
- 2008: analysis of survival data for patients with breast cancer showed an heterogeneity of data quality that lead to the decision to stop data collection in 2009
- 2011: Visit to the US of the French Cancer Centers Directors to study data mining tools (e.g. CA-BIG - CAncer Biomedical Informatics Grid)
- 2011: Centers asked UNICANCER to develop a data mining tool for their
   databases: ConSoRe

## **ConSoRe's landscape**

- In each Comprehensive Cancer Center
  - Approximately one million of patients and several millions documents (cumulated data for 20 hospitals)
  - Data concerning healthcare and research
  - Data in multiple databases
  - Text and Structured data
  - Different information systems and software (between databases and between hospitals)
  - Ethical and security framework (sensitive personalized data)

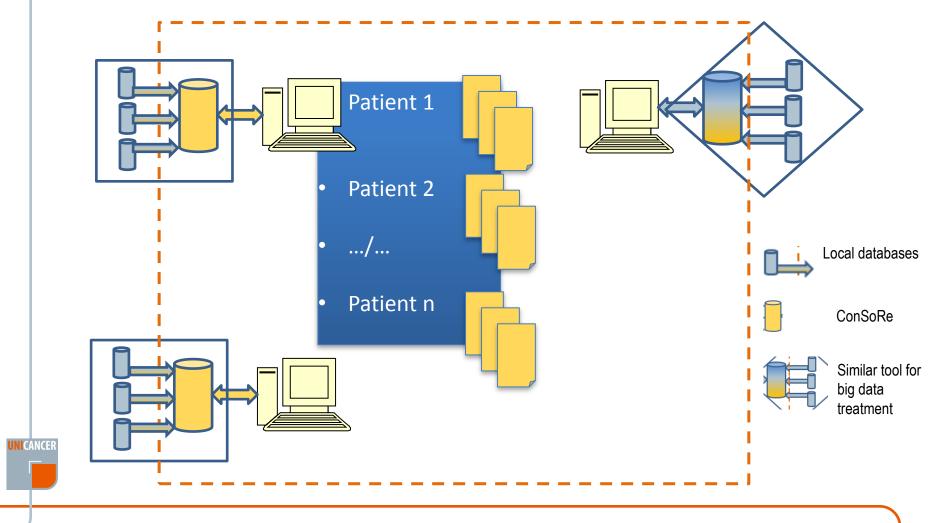
## **ConSoRe's goals**

- For a better use of data
  - Facilitate access to all data available in the group
  - Accelerate research for the patients' benefits
  - Increase collaborations
  - Improve patients' care
  - Respect the ethical and security framework

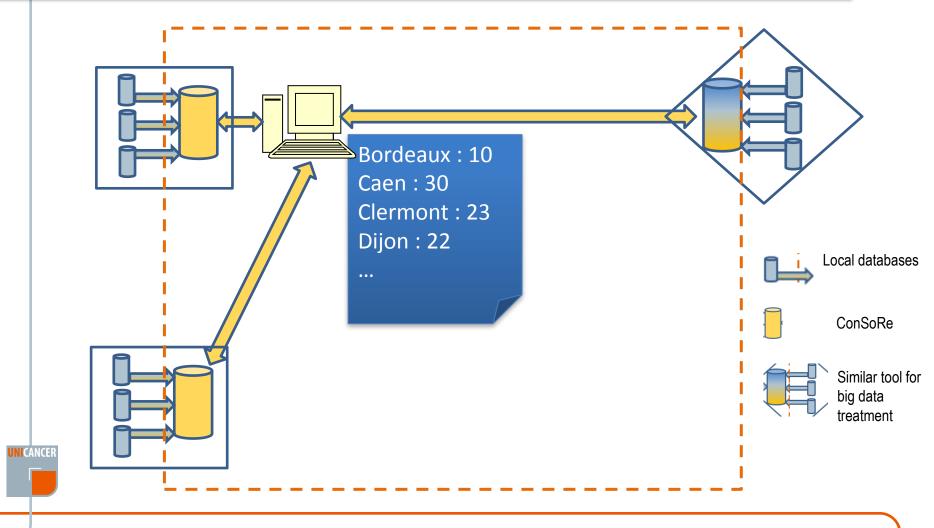
### **ConSoRe's Specifications needs**

- A local-search software to access all data related to a request / patient(s)
- A national, localization and counting tool
- Management of access according to users' profile and sites' rules
- A software that must interact with other comparable tools
- No change of original data and no new data created
- Automatic data treatment (no impact on the site activity)
- Must progress with advances in computer science and users' need

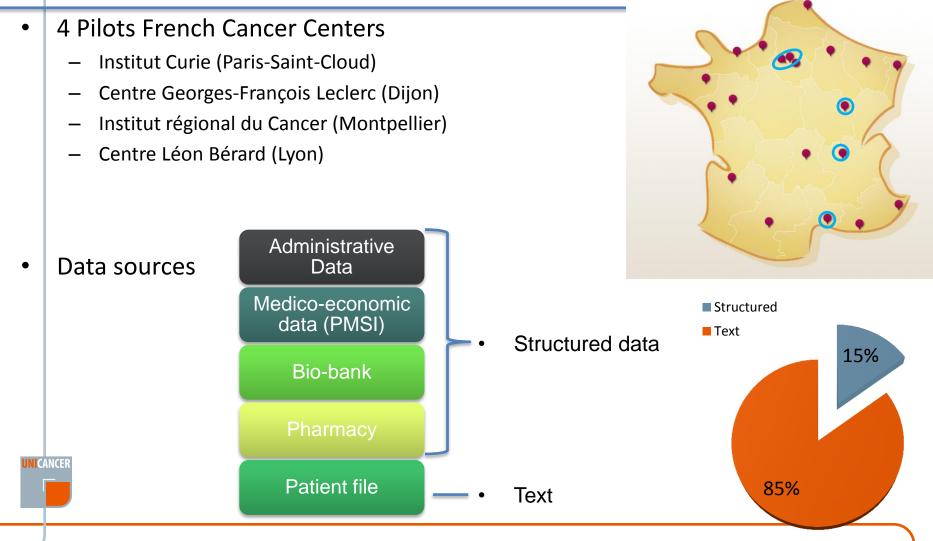
## ConSoRe A local-search software



### ConSoRe A national, localization and counting tool



### 2013 - 2014 : The Proof of Concept



# Simultaneous research in text & structured database

All sources	Pharmacy source	Pharmacy source	
Recherche Multi. Vêr	s Recherche simple utes sources.Localisations = V C50 - Tume in maligne du se	in (cim10)	
ET	OU    Chimio Composants Administrés = M440	3 - paclitaxel (vidal) 3 - paclitaxel (vidal)	×+ ×+
	Possier patient.Fulltext     =      mutation brca1	<b>X</b> +	Réchercher
	"Text" da	ta from patient visit co	onclusion letter

- From the same home page, we can simultaneously question
  - Several data-bases

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- Structured and textual data
- And use Boolean operators (AND, OR) for narrowing down the search

## A local-search software

#### 199 patient(s) trouvé(s)

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	Votre recherche : Midicaments - Antinicipitatiques x		List of pre-defined items to	
	1 2 3 4 5 >	► Localisations	help us in our request	
List of subjects	209 : CARA Aleksandar née le 09/09/1943	Localisations Fiche Tumeur		
	Siège: C56.9 - Ovaire - droit Catègorie : maigne Morphologie : M-84413 - cystadénocarinome séreux, SAI TNMs cT2c N0 M8 pT N Siège : 17440 - 17440 - gauche Catégorie : maligne Morphologie : M-85003 - adénocarcinome canalaire infiltrant TNMs cT2 N0 M0 pT N M Cycle N° 1 Jour 1, 31-12-2001	▼ Médicaments		
		<ul> <li>Cancérologie - Hématologie (199)</li> <li>Anticéophagues (199)</li> <li>Anticorps monoclonaux (64)</li> <li>Bevaczumab (53)</li> <li>Cétuximab (1)</li> <li>Panitumurnab (1)</li> <li>Pertuzumab (2)</li> <li>Rituximab (1)</li> <li>Trastuzumab (13)</li> <li>Antimitotiques locaux (54)</li> </ul>		
	Add to			
	"basket"			

- The local search provides a list of subjects that answers the request, and provides:
  - A short summary of information on each patient available in source database
  - "Patients" could be identified and added in a basket for a later work
  - A list of interesting items for narrowing down the search

### A national, localization and counting tool

Consore		
Pecherole Muderkins         ? Toules sources. Localisations         = • C50 - Tumeur maligne du sein (cim10)         X +         ET w         OU w         ? Dossier patient Medicaments         = • Mu403 - paciltaxel (vidal)         ET w         ? Dossier patient Fulltext         = • mutation brca1	X+ X+ X+ O Reductor	
Centers           Paris - Instant Curie           CD [Din - Centre Georges Prançois Ladeirs           Wongsteller - Instant Algoral du Cancer Mongeller - Var d'Aurelia           Vergetaler - Instant Algoral du Cancer Mongeller - Var d'Aurelia           Vergetaler - Ladeir Liden Edinard		Results are compiled
Total dea résuluts 54 patient(s) Para - Institut Curre 17 patient(s) Dipri - Centre Georges-François Lecore	Cone           F (54)           Mape air disproate           Entre 30 of 43 ans (9)           (20 - 50(1))           (20 - 50(1))           Entre 50 of 017 ans (4)           Entre 50 of 20 ans (4)	When a site does not respond to a specified criteria
E centre interrogé ne prend pas en compte votre recherche. Le(s) champ(s) suivant(s) ne sort pas permi(s) : Chimio.Composants Administrés Norgetier - hattut régional du Cancer Montpetier - Val d'Aurete 37 patient(s)	Localisations Localisations 17420 (1) 17440 (1) GANCLION DE L'ANSE DU RECURRENT GAUCHE - GANGLION SOUS (1) AQULHE (1) CORRE VOCALE (1)	For confidentiality reasons, only a sum is available

 The national request provides the count of patients that correspond to our request and the centers where these patients are treated.

### **Difficulties met during POC development**

 Discussion with the French data privacy agency about new domains of data treatment

 Concerns from the users about the access to their data without control – Access tracking & Written best practice rules have been established



## Status up-date mid-2015

- September 2014 the first version of ConSoRe was evaluated by future users
  - → The tool is operational but will require functional evolutions to be practical for a daily use
- From October 2014 to date
  - Identification of evolutions needed
  - Research of funding for improvements
  - Research of public & private partnerships for next steps
  - Planning for installation in other FCCC before the end of 2017

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### **Evolutions needed according users**

- Development of an intuitive and user-friendly interface for research & results
- Identify data for subjects who had several tumors or who have relapsed, with respect to chronological aspects
- New searchable databases
- Interfacing with other platforms like TRANSmart or similar
- Development of a shared bio-bank catalogue

### **ConSoRe is a possible solution for ERN**

- Possibility to access archives
  - Millions of patients and data of interest
- Avoid double work for the physicians
  - Only "one" database to fill in, the mandatory national one
- Reduce risks linked to sensitive personalized data
  - The data are maintained locally (national framework)
  - There is a necessary agreement from the local physician, in accordance with the patient's agreement, to access the data

However there is still some work to do!

# Any questions ? Contact information

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