



Portail
Epidémiologie
France
Health Databases

European Data Access Forum 24-25 March, 2015

EPIDEMIOLOGY France portal – *Health databases*

aviesan





What do we do in Public Health Research

2009 : AVIESAN, the French National Alliance for Life Sciences and Health groups together the main stakeholders of life and health sciences in France.

- Encourage use of open archives
- Raise awareness about data sharing as an asset
- Promote re-use of existing data
- Stimulate cross-fertilization and sharing across large epidemiological cohorts
- Strengthen the infrastructure for data-management
- Foster cooperation between research teams, stimulate new partnerships
- Address data linkages with other data sources

2011 : Under the authority of the Strategic Council of Health Industries (CSIS), the Epidemiology-France web portal was established.

Description of the project

An internet-based tool which offers a detailed description of existing French health databases (personal data – excepted clinical trials), and provides access to meta-data and point of contact.

- ▶ Characteristics of the databases available: objectives, topics, populations covered, type of information collected, conditions of access to the data, management structure.

Major types of databases described:

- Administrative sources
- Morbidity registries
- Databases from studies :
 - Cohorts
 - Case-control studies
 - Other longitudinal studies
 - Other cross-sectional studies (repeated or not)

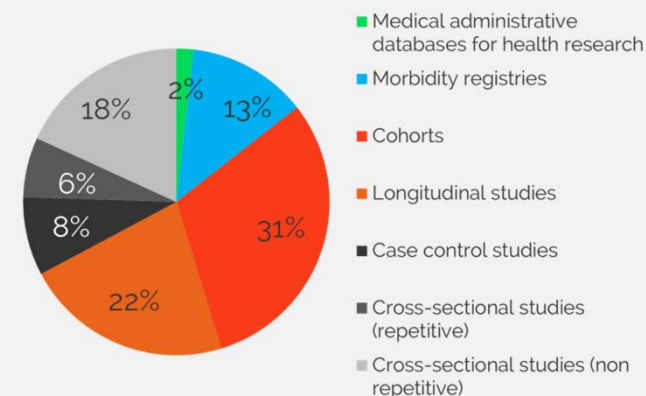


Fig 1, Repartition of the 661 databases online, March 2015 - Aviesan



Objectives

- Locate existing expertise and data by thematic
- Improve the access to health databases for researchers and the general public and encourage transparency
- Contribute to cooperation between research networks, foster a generation of new research projects, and reinforce research quality
- Improve the visibility of the French expertise in this field on a national and international scale



Key figures

More than 650 databases described so far

- 33 medical fields covered
- 80% of records translated to English
- More than 1300 unique visitors each month

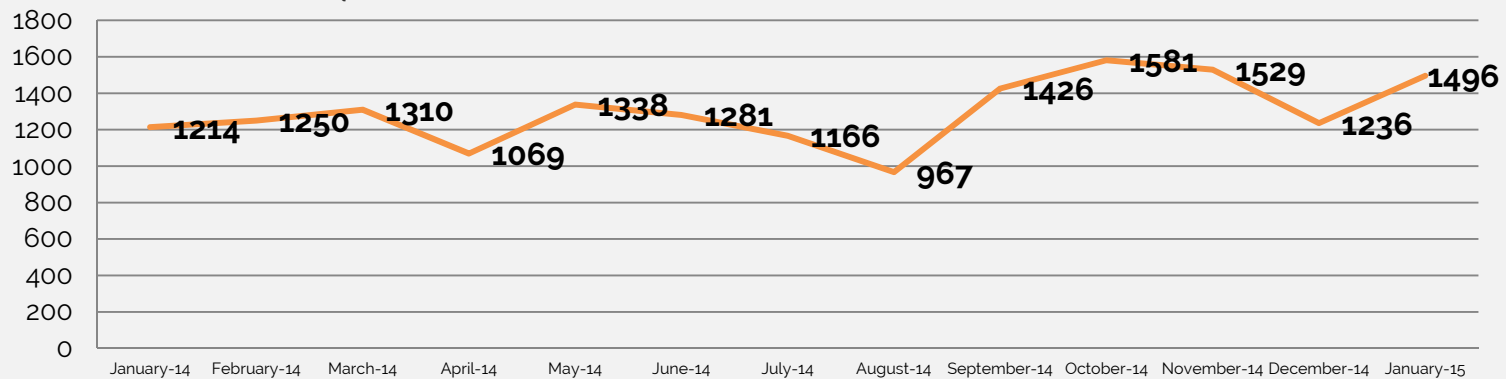
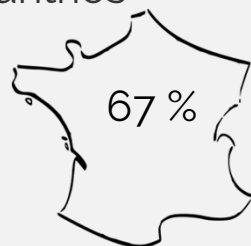
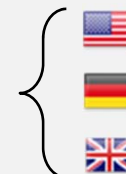


Fig 2, Epidemiology France portail frequentation by month, 2014 - Aviesan

- From 112 countries



33 %
abroad



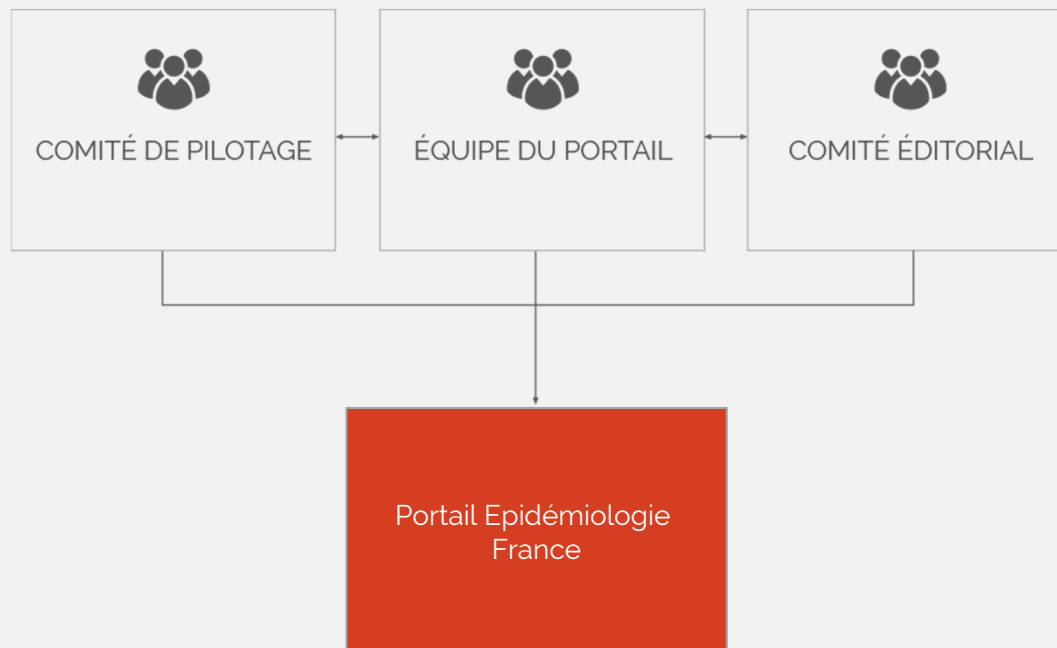
United States : 3,5 %

Germany : 3 %

Great Britain : 2,6 %



Governance



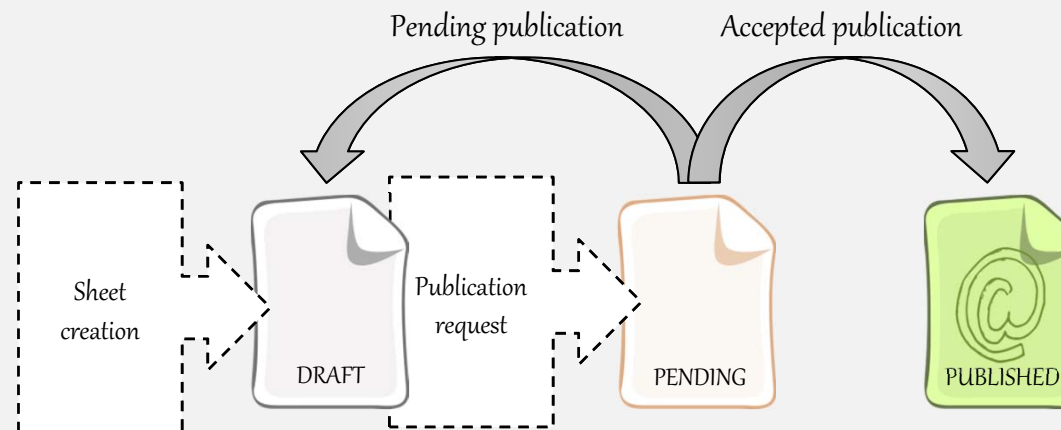
- **Steering committee**
(project supervision)
- **Web portal team**
(project execution)
- **Editorial committee**
(quality of publication)



How it works

To submit a database description:

- 1 / Complete a form in the indicated area and submit it for publication on portal
- 2 / The web portal team retain the right to the decision to publish the form
- 3 / A new version of the form can be resubmitted based on the recommendations of the web portal team





Prospects for the project

- Promote information sharing – new tab « mutualisation area » (listed database skills and best practices)
- Project of metadata harmonization to international standards (DDI) – new site version (for 2015, April)
 - XSL mapping module
 - XML import/export
 - OAI server as metadata harvester
- Include medico-economic metadata into the sheets
- Work with foreign counterparts managing similar platforms

Objective : make progress towards the identification of specialized data and existing competencies, and develop partnerships with similar projects abroad.



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<https://epidemiologie-france.aviesan.fr/?lang=en>

[New version](#)

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