



OVERALL PRESENTATION OF THE INSTITUT DES DONNEES DE SANTE (IDS)

The mission of the Institut des Données de Santé (institute on health data) is to ensure the consistency and quality of information systems used for managing health risks and to make sure that its members, the Haute Autorité de Santé, regional unions of private medical practitioners, and organizations designated by Council of State decree, have access to data produced by its members' information systems, to be used for managing health risk or for public health issues, in conditions that guarantee anonymity as decreed by the Council of State following consultation with the Commission Nationale de l'Informatique et des Libertés (national commission on data privacy). Each year, the Institut des Données de Santé transmits a report to parliament.

Act No. 2004-810 of 13 August 2004 art. 64 I; Journal officiel (official gazette) of 17 August 2004 ; article L. 161-36-5 of the French Social Security Code

“A public interest group called the “Institut des Données de Santé”, governed by the provisions of the 1st chapter of title IV of book III of the research code, is constituted between the State, the Caisses Nationales d'Assurance Maladie (national health insurance funds), the Union Nationale des Organismes d'Assurance Maladie Complémentaire (national union of complementary insurance health funds) and the Union Nationale des Professionnels de Santé (national union of health professionals) mentioned in chapter II bis of title VIII of the 1st book. The Institut des Données de Santé's mission is to ensure the consistency and quality of information systems used for managing health risk and to make sure that its members, the Haute Autorité de Santé, regional unions of private medical practitioners, and organizations designated by Council of State, have access to data produced by its members' information systems, to be used for managing health risk or for public health issues, in conditions that guarantee anonymity as decreed by the Council of State following consultation with the Commission Nationale de l'Informatique et des Libertés. Each year, the Institut des Données de Santé transmits a report to parliament.”

KEY DATES

13 August 2004 : Act creating the Institut des Données de Santé (IDS)

30 March 2007 : The IDS was set up and adopted its founding agreement

11 May 2007 : The IDS founding agreement was published in the Journal officiel de la République Française (official gazette).

MEMBERS OF THE INSTITUT DES DONNEES DE SANTE

The IDS comprises 13 members.



1. The government represented by:
 - 1.1. The Ministry for health, health insurance and handicap
 - 1.2. The Ministry for economy, finance and industry
2. La Caisse Nationale de l'Assurance Maladie des Travailleurs Salariés (national health insurance fund for salaried workers - CNAMTS)
3. La Caisse Centrale de la Mutualité Sociale Agricole (central agricultural mutual insurance fund - CCMSA)
4. La Caisse Nationale du Régime Social des Indépendants (national fund for self-employed workers - RSI)
5. La Caisse Nationale de Solidarité pour l'Autonomie (national solidarity fund for autonomy - CNSA)
6. L'Union Nationale des Régimes Spéciaux (national union of special health schemes - UNRS)
7. L'Union Nationale des Professionnels de Santé (national union of health professionals - UNPS)
8. L'Union Nationale des Organismes d'Assurance Maladie Complémentaire (national union of complementary health insurance organizations - UNOCAM)
9. Le Collectif Inter associatif Sur la Santé (inter-association health group - CISS)
10. La Fédération Hospitalière de France (French hospital federation - FHF)
11. La Fédération des Etablissements Hospitaliers et d'Aide à la Personne (federation of hospitals assisting individuals - FEHAP)
12. La Fédération de l'Hospitalisation Privée (federation of private hospitals - FHP)
13. La Fédération Nationale des Centres de Lutte Contre le Cancer (national federation of cancer control centres - FNCLCC).



ASSOCIATE MEMBERS OF THE INSTITUT DES DONNEES DE SANTE

Some organizations are associate members of the IDS.



1. La Haute Autorité de Santé (national health authority - HAS)
2. L'Union Nationale des Médecins Libéraux (national union of private medical practitioners - UNML)
3. La Conférence Nationale des Présidents des URML (national conference of URML chairmen - CNP)
4. L'Institut de Recherche et Documentation en Économie de la Santé (institute for research and documentation on health economics - IRDES)
5. L'Institut National du Cancer (national cancer institute - INCa)
6. La Fédération Nationale des Observatoires Régionaux de Santé (national federation of regional health observatories)
7. Le Fonds CMU (universal health cover fund - CMU)
8. L'École des Hautes Études en Santé Publique (institute of advanced studies on public health - EHESP)
9. Le Haut Conseil pour l'Avenir de l'Assurance Maladie (high council for the future of health insurance - HCAAM).

MANAGEMENT TEAM OF THE INSTITUT DES DONNEES DE SANTE

Christian Babusiaux
Chairman

Christian Babusiaux has been the chairman of the Institut des Données de Santé since 30 March 2007



Danièle Desclerc-Dulac
Vice-chairwoman

Danièle Desclerc-Dulac has been the vice-chairwoman of the Institut des Données de Santé since 30 March 2007. She is also vice-chairwoman of the Collectif inter associatif sur la santé (CISS).

Didier Sicard
Chairman of the Expert Committee

Didier Sicard has been chairman of the Expert Committee since May 2008. The committee advises the Institut des Données de Santé on ethical and deontological issues. Mr Sicard is honorary chairman of the national consultative committee on ethics, which he chaired from 1999 to 2008.

Richard Decottignies
Director

Richard Decottignies has been the director of the Institut des Données de Santé since 30 March 2007.

MISSIONS OF THE INSTITUT DES DONNEES DE SANTE

Improving the health system's governance entails sharing knowledge of how it operates and how it is funded between stakeholders. The Institut des Données de Santé's mission is to bring together the right conditions for acquiring this knowledge. Its mission involves in particular:

- Encouraging use of health databases by IDS members and organizations for their studies and research;
- Encourage pooling of health data from different sources and sharing of these enriched data;
- Surveying the consistency and quality of databases used for managing risk and public health.



Data base access

Setting up health databases involves considerable investment. The Institute makes the data in these bases easy to use for its members and organizations carrying out studies and research. It also provides them with the necessary expertise.

Four databases are currently shared at the IDS:

- Data from the *Système National d'Information Inter Régimes de l'Assurance Maladie* (national health insurance information system – SNIIRAM)
- Data from the *Programme de Médicalisation des Systèmes d'Information* (information systems medicalization programme – PMSI)
- Data from the *Direction Générale des Finances Publiques* (general directorate of public finance – DGFIP)
- Data from the *Système National d'Information sur l'Hospitalisation* (national information system on hospitalization – SNATIH)

Other databases will gradually be shared within the IDS:

- Data from the *Caisse Nationale de Solidarité pour l'Autonomie* (CNSA) relating to handicap and dependency
- Samples built up from data from the *Assurance Maladie Obligatoire* (obligatory health insurance scheme), the *Système National des Données Mutualistes* (national mutual data system) and other complementary health insurance organizations.

Pooling health data

Encouraging the pooling of health data between the obligatory health insurance and complementary health insurers is central to the IDS's missions. All IDS stakeholders have signed a charter. The institute also makes a methodological contribution to this domain. Two data pooling methods are put into practice:

- Pooling of anonymized personal data;
- Pooling of aggregated data.

Quality and consistency of health databases

The IDS has created the *Commission pour l'Analyse et la Diffusion d'Information Statistique* (commission for analyzing and disseminating statistical information – CADIS). The CADIS processes statistics produced by stakeholders in the health system with a focus on quality and consistency.



TRUST

Deontology

To oversee the sharing of health data, the IDS has drawn up a deontology charter. The charter covers conditions for using the databases, conditions for extracting, using and disseminating the data, conditions for disseminating results of studies done, and issues of data ownership. The IDS expert committee is responsible for ensuring that the charter is respected.

Users

The IDS involves patients, represented by the CISS, in its work as closely as possible. The CISS gathers 32 associations working in the health domain. The group places itself as a contact body between government authorities and health stakeholders in defending optimal support for users. The Collectif Inter associatif Sur la Santé (CISS) occupies vice-chairmanship of the IDS.

CNIL

Since its creation, the Institut des Données de Santé has built up close relations with the Commission Nationale de l'Informatique et des Libertés (CNIL). All of its work entails constant dialogue with the commission.

Expert committee

The expert committee advises the IDS on ethical and deontological issues relating to using and sharing health data. It ensures respect of the institute's deontological charter. This strategic role requires experts with solid capabilities in the domains of ethics, health economics, statistics, epidemiology and the medical sector. The expert committee is made up of thirteen independent, recognized figures.