

Living up to Improved Performance

The role of international databases and projects

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Need for data for comparative policy analysis

- Health system comparison is a powerful resource for better health policy
- Performance data is essential for assuring
 - Accountability, identifying good practice, management

Challenge of turning data into knowledge

“Information is not knowledge”

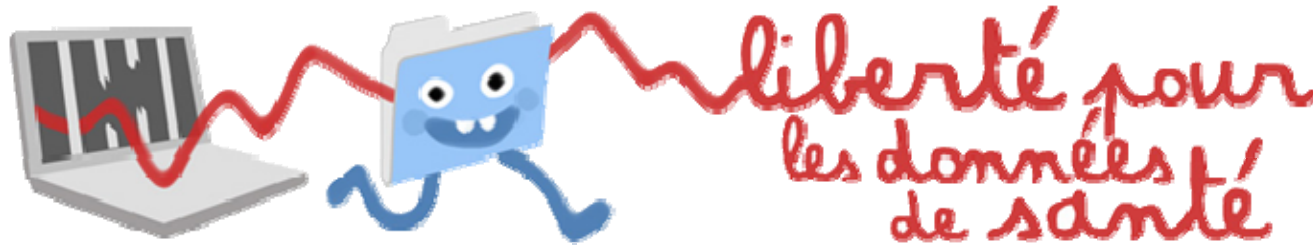
Albert Einstein

*“It is a very sad thing that nowadays
there is so little useless information”*

Oscar Wilde

- Growing number of national and international organisations collect and provide health data with different objectives
- It is ever more difficult to maintain a global view of what is available /accessible/ reliable/ comparable
- Which hinders meaningful performance analysis

Increasing demand for data & information



- Databases produced (with public money) are not always accessible to public & researchers
- Not always presented meaningfully
- And so not used to their full capacity



Euroreach objectives

*“Creativity often consists of merely turning up
what is already there”*

- Systematic review and assessment of existing health data and information systems and European projects for their contribution to comparative performance analysis
 - what is available / what is accessible
- To identify areas where more investment is necessary for improving research data at national and international level
- For assessing and improving the performance of health care systems

Review of international data and projects

- Analyze available data & information from the perspective of researchers interested in the performance of health systems
 - Some subjectivity and expert evaluation of what is available
 - Not an exhaustive inventory of all projects and data
- Promote transparency, accessibility & knowledge sharing
- Guidance for using/understanding available data

Using the HDN : an example

Mr. Curious is a young ambitious policy adviser in the Dutch Ministry of Health. The Minister will give a press conference next week.



Mr. Curious



The following items are on the agenda of the Minister's press conference :

- Rise in public health expenditure
- Re-emergence of tuberculosis death cases in some deprived areas

→ To prepare the conference, he wishes to benchmark the Dutch situation with other European countries

GHO Indicator Table

Health Status	Indicators	Decomposition
	Standardised Mortality Rates	Age, Gender, Disease, Maternal, Infant, Non Communicable Diseases, Cancer
	Incidence Rates and Mortality	Influenza, cholera, meningococcal meningitis, malaria, tuberculosis and neglected tropical diseases
	Years of Life Lost (YYL)	Cause, Age, Gender
	Disability Adjusted Life Years (DALY's)	
	Life Expectancy	Gender
	Healthy Life Expectancy	
	% of Children Aged <5 Stunted	Rural/Urban, Income, Education Level
Quality	Indicators	Decomposition
Appropriateness	N/A	
Safety	N/A	
Responsiveness	N/A	
Efficiency/Economy	Indicators	Decomposition
Outputs/Activities	TB Treatment Success Rate	

- by WHO region (2007 - present)
- by WHO region (all years)
- by World Bank income groups (2007 - present)
- by World Bank income groups (all years)

Hide filters

Filter by: Indicator | **Country** | Year | WHO region | World Bank income group

Georgia
Germany
 Ghana
 Greece

Current selection:

Deaths due to tuberculosis among HIV-negative people (per 100 000 population), Prevalence of tuberculosis (per 100 000 population), France, Germany, Netherlands

Apply

Clear filters

Filtered for Deaths due to tuberculosis among HIV-negative people (per 100 000 population), Prevalence of tuberculosis (per 100 000 population), France, Germany, Netherlands

Download this data as

[CSV \(codes only\)](#) | [CSV \(text only\)](#) | [CSV \(text and codes\)](#) | [Excel \(SpreadsheetML\)](#) | [HTML \(flat table\)](#) | [GHO XML](#)

Details: off

Country	Deaths due to tuberculosis among HIV-negative people (per 100 000 population)					Prevalence of tuberculosis (per 100 000 population)		
	2011	2010	2009	2008	2007	2011	2010	2009
France	0.45 [0.44-0.47]	0.49 [0.47-0.5]	0.52 [0.5-0.54]	0.56 [0.54-0.58]	0.61 [0.58-0.63]	5.6 [2.6-9.7]	7.2 [3.4-12]	8.7 [4.1-14]
Germany	0.34 [0.34-0.35]	0.35 [0.34-0.35]	0.36 [0.35-0.36]	0.37 [0.37-0.38]	0.38 [0.38-0.39]	5.7 [2.2-11]	6.1 [2.4-11]	6.6 [2.6-11]
Netherlands	0.21 [0.2-0.21]	0.2 [0.19-0.2]	0.19 [0.19-0.19]	0.19 [0.18-0.19]	0.19 [0.18-0.19]	8.5 [3.4-16]	8.6 [3.4-16]	8.8 [3.5-14]

Mr. Curious

- Thanks to the Health Data Navigator, Mr. Curious has found information relevant to the Minister's press conference, in a timely fashion
- He has added this comparative information to the Minister's file
- He got a promotion !

Ms. Highbrow

Mrs. Highbrow is a senior researcher in Berlin in comparative European healthcare policies, preparing a research proposal for the National Cancer Institute.



Ms. Highbrow

She wants to explore relationships between the prevention and cost of breast cancer in Germany with similar European countries

→ Individual-level cost data

→ Country-specific policy context information

Austria
Estonia
Finland
France
Germany
Israel
Luxembourg
United Kingdom

HDN Toolkit
[Download here](#)

National

| PRINT | EMAIL

Here you find a detailed inventory of specific databases commonly used for health services research in EuroREACH partner countries. Information of national data sources is organized on the basis of [performance domains](#). Further and where pertinent aggregate level data as well individual level data sources are assessed to cater research needs and to promote a better understanding of the adequacy of these national data sets. Currently the information presented is limited to [EuroREACH partners](#) but can be and should be expanded to other countries.



Cost and Expenditure

Aggregate data

- . **Eco Santé IRDES** at the **national** and **regional** levels : fees for practitioners in ambulatory sector, providers' income, macro-level expenditure data by source of funding and by setting and provider
- . **National Health Accounts** are published every year by the research and statistics branch of Ministry (DREES) : macrolevel data on main sources of healthcare financing and expenditure areas

Individual level data

- . **Etude Nationale des Coûts (National Costs Study)**: patient level cost data from about 90 volunteer public and private hospitals. It is used to calculate DRG cost-weights. ➡
- . **SNIIR-AM reimbursement database** of the **National Health Insurance Fund**. Public expenditure in the ambulatory setting and in private hospitals (fee for service payments), excluding private out-of-pockets payments ➡

● ● Access/Equity

Individual/Person level data

- . **Health, Healthcare and Insurance Survey (ESPS)**, contains information on the socio-economic background (education, occupation) and income. Allows assessing the distribution of health status and consumption. ➡
- . **Enquête décennale de santé** provides information on socio-economic background and income. ➡
- . **ENTRED survey** directed at people with diabetes has several questions on income levels and financial barriers to access to healthcare **by the patients**

● Non-health care determinants

Aggregate data

- . **Eco Santé IRDES**, at the **national** and **regional** levels : data on some **risk factors** (tobacco, alcohol consumption), road accidents and **occupational hazards**.

Individual/Person level data

- . **Baromètre santé** surveys has been designed specifically to study non healthcare determinants of health (addictions, nutrition, physical activity, occupational risk factors) ➡

- . SNIIR-AM reimbursement database of the National Health Insurance Fund. Public expenditure in the ambulatory setting and in private hospitals (fee for service payments), excluding private out-of-pockets payments 🚫

Système National d'Information Inter-Régime de l'Assurance Maladie (SNIIR-AM)

This exhaustive nationwide database is at the heart of the financing system of diagnostics, pharmaceuticals, and physicians in the ambulatory care setting and of independent practitioners in private hospitals (essentially fee for service). It provides data on claims paid by the Social Security System is therefore the main source of information on ambulatory setting activity and associated expenditure.

Governance	<ul style="list-style-type: none"> . National Health Insurance Fund http://www.ameli.fr . Information request for use should be addressed to the Institut des Données de Santé
Access to database	<ul style="list-style-type: none"> . In French only . Some aggregate data and studies available online. A good presentation in French on its design and content can be found here. . Access to the raw database requires pre-authorization with the CNIL, public agency responsible for data confidentiality and is tightly controlled.
Coverage	<ul style="list-style-type: none"> . 2 years + current year . Patient data : age, gender, town, long term and chronic diseases, date of birth, date of death, lower income indicator, healthcare care consumption and date . All consultations and visits to GPs and ambulatory care specialists but nothing about their content . All medical technical procedures . All dispensed drugs . All lab and diagnostics tests but not their results . All medical devices . Provider level data: their activity and sales turnover, geography, prescribing behaviors.

Ms. Highbrow

Mrs. Highbrow needs to know more on the healthcare systems features of the countries in her comparison

- She can access such qualitative information via the « health system profiles » page
- Or via each country's page in the « health system design section »

[Home](#) ▶ [International](#) ▶ [Health System Profiles](#)

Health System Profiles

| [PRINT](#) | [EMAIL](#)

The [European Observatory on Health Systems and Policies](#) is a major source of free information on trends in European healthcare systems, including Central Asia and Russia.

- . Country-specific [monographs](#) : all monographs have the same chapter structure to enable easy comparison between them
- . [Thematic studies](#) that cut-across several countries on a variety of topics: health technology assessments, capacity-building, chronic diseases, provider payment systems...
- . A [quarterly publication](#) on healthcare reforms and current policy developments. Issues prior to 2011 are also [available](#).
- . A set of [policy briefs](#) on a variety of subjects, prepared to inform inter-ministerial conferences and policy dialogues
- . The [Health Policy Monitor](#) describes current reforms, policies, projects and developments in European healthcare systems in a uniform, accessible and synthetic feature article.

The [Organization for Economic Cooperation and Development](#)

- . Reviews of healthcare systems : in-depth [monographs](#) that focus on the financial and economic aspects (Russia, Switzerland, Turkey, Finland, Mexico, Korea)
- . A series of [thematic working papers](#) : new professions, facing the economic crisis, comparing prices across countries...
- . Full in depth [policy studies](#) on emerging themes: multi-morbidity, long-term care, avoidable hospitalizations...[Individual country briefings](#) that benchmark OECD data with other countries

The [Commonwealth Fund](#)

- . [Regular international benchmarking studies](#)

Ms. Highbrow

- Mrs. Highbrow has sound enough background information to draft a convincing proposal
 - While the HDN *per se* cannot offer everything she needs for a complex project, she has sense of information available
 - She knows how to get more information with links to further local assistance
- She gets the grant !



Ms. Purse

- Ms Purse – working in the Finish Science Ministry’s health services research unit – is charged with making a proposal how to spend the remaining €8 mn on research funding for the coming three years
- The money should go to an area which has been under-researched in the past on the EU level, i.e. she needs to know exactly what has been researched so far (which disease areas, which dimensions, ...)



Ms. Purse

- She goes to the «international tab», find «projects» and the table which provides information about projects
 - across at least 2 countries,
 - using individual-level and
 - disease-oriented data
- She decides to have a closer look at cancer, CVD, diabetes

Table 2 Projects providing individual-level data information; classified by disease areas

	Disease-specific						Non-disease-specific
	Asthma	Cancer	Cardiovascular Diseases	Diabetes	Mental Health	Various Diseases	(Allows disaggregation into disease entities)
Population-based							
	ISAAC, GA ² LEN, PDCAAE	EPIC	MONICA	De-PLAN	WMH Survey Initiative		GBD, I2SARE, SHARE project, Compare, JA EHLEIS, EuroTHINE
Patient-based							
across sectors	ECRHS III	EuroCARE Project, HAEMACARE, RARECARE, EUNICE, EUROCHIP-3	EROS, EUROCISS, EPIC-CVD, MANAGED OUTCOMES	BIRO, EUBIROD, MANAGED OUTCOMES	EPSILON	MANAGED OUTCOMES	EPIC-Elderly, HALE, ECHIM
within hospitals only		ONCOPOOL, EuroDRG (certain countries), euroHOPE, EUPHORIC	OECD Study, EurHOBOP, EuroDRG (certain countries), euroHOPE, EUPHORIC, DuQue			EuroDRG (certain countries), euroHOPE, ECHO, EUPHORIC, DuQue	
within primary care only							EUPrimeCare

Ms. Purse

- She is surprised by the assessment tables (compared with the short & incomplete project descriptions which she found on Cordis)

EuroCARE

EUROCARE, EUROpean Cancer Registry-based study on survival and care of cancer patients, was an epidemiology research project that had collected and analyzed survival data on patients diagnosed from 1978 to 1984 (EUROCARE-1), from 1978 to 1989 (EUROCARE-2), from 1983 to 1994 (EUROCARE-3) and from 1988 to 2002 (EUROCARE-4). The main aim of EUROCARE-4 was to update survival of cancer patients in Europe and to detect timely substantial changes across regions and over time. EUROCARE-5 (up to 2007) continued the activity of surveillance and the comparison between survival and care of cancer patients.

Governance

- . Funded through the BIOMED Programme of the European Community and by the "Europe against Cancer" programm
- . The EUROCARE Co-ordinating Centre operates at the Department of Preventive and Predictive Medicine, Fondazione Istituto Nazionale per lo Studio e la Cura dei Tumori, while the database implementation and analyses are performed at the Cancer Epidemiology Unit and Data Analysis Centre, Istituto Superiore di Sanità, Rome.
- . Contact: Roberta De Angelis, Tel. +39.06.49904289, Email: roberta.deangelis@iss.it
- . Website: <http://www.eurocure.it>

Coverage

- . Data from 93 population-based Cancer Registries in 23 European countries (Austria, Belgium, Czech Republic, Denmark, Finland, France, Germany, Iceland, Ireland, Italy, Malta, Norway, Poland, Portugal, Slovenia, Spain, Sweden, Switzerland, The Netherlands, England, Northern Ireland, Scotland, Wales)
- . Analysis of survival of cancer patients by means of conventional and more innovative methods: e.g. cohort relative survival; period survival analysis to estimate survival of patients with recent diagnosis; mixture survival model to estimate the proportion of patients cured.
- . Survival data of adult patients, cross-classified according to cancer site, population, sex, age, and period of follow-up (from 1- to 5-year) - observed, expected and relative survival rates are given.
- . Comparison of cancer survival between Europe and USA will be made available. Until now survival of the EUROCARE patients has been compared with patients included in the SEER network (<http://seer.cancer.gov/>). This comparison will now be extended to the US registries of the NCR (National Cancer Registry)

Ms. Purse

- She is surprised by the assessment tables (compared with the short & incomplete project descriptions which she found on Cordis)

Output and results	<ul style="list-style-type: none">. More than 100 published articles available on website (http://www.eurocare.it). EUROCARE-4: Accordingly, survival of European cancer patients varies markedly by country, region, age and sex. Relative excess risk of death is 28% higher in Eastern Europe than central Europe; the relative excess risk of death is much higher for patients of age 55–99 years than those of age 15–54 years.. EUROCARE-5: Comparing diagnostic and therapeutic procedures for cancer patients in Italy with those in other European countries at high survival by means of high resolution studies (HR).. Important long-term outcomes (from the whole EUROCARE project): Reduce inequalities in cancer care and survival across Europe and provide information and increase standards.. Increasing and promote the use of cancer survival registry data. The EUROCARE results will be diffused among the medical, public health and scientific communities, to the public in general, to tumour patients and to health planners.
Access to data	<ul style="list-style-type: none">. Only access to EUROCARE-3 (1990-1994) and EUROCARE-4 (1995-1999) data sorted by cancer, population, age class, time from diagnosis, sex, output indicators possible.
Data quality	<ul style="list-style-type: none">. An algorithm assigned standardized sequence numbers to multiple cancers → only first malignant cancers were used to estimate relative survival from registry, year, sex and age-specific life tables. Age-adjusted and Europe-wide survival were also estimated
Linkage	<ul style="list-style-type: none">. Linkage of cohort data from the outside possible to a limited extend (xls, txt) for EUROCARE -3 (1990-1994) and EUROCARE -4 (1995-1999)
Strengths and Weaknesses	<p>Strengths:</p> <ul style="list-style-type: none">. There exist related projects: CONCORD (http://www.lshtm.ac.uk/eph/ncde/cancersurvival/research/concord/phase1.html),. EUROCHIP (http://www.tumori.net/eurochip/),. HAEMACARE (http://www.haemacare.eu),. RARECARE (http://www.rarecare.eu). Project process can be reconstructed by protocols.

Ms. Purse

- After checking all relevant projects, she is able to provide information about the scope of the various projects and the gaps in existing research - CANCER

	Benchmark Hospital Performance			Comparing Health System Performance	Investigating conditions to disease monitoring			Equity (tackling inequality)	Patient needs and satisfaction with service	Improving quality of treatment	Developing/collecting indicators	Establishing networks
	Statistical Function	Treatments / Costs/ Outcomes	Financing (DRG's)		Studying risk factors	Improving registry use	Surveillance (Incidence, survival, prevalence,					
Hospital administrative data , Medical Records	EUPHORIC	EUPHORIC, EuroDRG, EuroHOPE	EuroDRG	EuroDRG, EuroHOPE			ONCOPOOL, EUPHORIC			ONCOPOOL, EuroDRG, EuroHOPE		
Surveys (incl.self assessment)				Managed Outcomes	EPIC				EuroHOPE	EuroHOPE, Managed Outcomes	EUPHORIC	
Registry use	EUPHORIC	EuroHOPE		EuroHOPE		EUROCHIP3	EuroCARE, RARECARE, EUNICE, HAEMACARE, EUROCHIP3	EuroCARE, EUNICE, EUROCHIP3		EuroCARE, EuroHOPE	EUNICE, HAEMACARE , EUROCHIP3	EUNICE, EUROCHIP3

green = based on a previous project blue = cooperation with other projects

Ms. Purse

• CARDIO-VASCULAR DISEASES

	Benchmark Hospital Performance			Comparing Health System Performance	Investigating conditions to disease monitoring			Equity (tackling inequality)	Patient needs and satisfaction with service	Improving quality of treatment	Developing/collecting indicators	Establishing networks
	Statistical Function	Treatments/ Costs/ Outcomes	Financing (DRG's)		Studying risk factors	Improving registry use	Surveillance (Incidence, survival, prevalence, mortality;					
Hospital administrative data , Medical Records	EUPHORIC, EurHOBOP	EUPHORIC, EurHOBOP, EuroDRG, EuroHOPE, DuQue	EuroDRG	EuroDRG, EuroHOPE		EUROCISS	EUPHORIC, EUROCISS	EurHOBOP		EurHOBOP, OECD Study, EuroDRG, EuroHOPE, DuQue	EUROCISS	EUROCISS
Surveys (incl.self assessment)		DuQue		Managed Outcomes	Monica	EUROCISS	EROS, Monica, EUROCISS		EuroHOPE	EROS, EuroHOPE, DuQue, Managed Outcomes	EUPHORIC, EUROCISS	EUROCISS
Interviews, Focus -groups					EPIC-CVD							
Biomarkers					EPIC-CVD							
Registry use	EUPHORIC	EuroHOPE		EuroHOPE		EUROCISS	EROS, EUROCISS			EROS, EuroHOPE	EUROCISS	EUROCISS
Aggregated statistics data										OECD Study		

green = based on a previous project blue = cooperation with other projects

Ms. Purse

- **DIABETES**

	Comparing Health System Performance	Investigating conditions to disease monitoring		Improving quality of treatment
		<i>Studying risk factors</i>	<i>Surveillance (Incidence, survival, prevalence, mortality; stimulating Registries to collect data)</i>	
Surveys (incl.self assessment)	Managed Outcomes	DE-Plan		Managed Outcomes
Registry use		BIRO/EU BIROD	BIRO/EUBIROD	

- Already many projects, but partly overlapping (e.g. disease monitoring) and leaving visible gaps (e.g. primary care, costs of services and along pathways, patient satisfaction)
- Ms Purse can therefore identify areas for future research



Observations from our experience/Projects

- By analyzing all projects it becomes obvious that :
 - A project website hosting all relevant information is essential for information users and researchers (but bad project webpage does not mean bad project)
 - New projects should
 - aim at filling gaps in previous research (not duplicate)
 - build on experiences, success factors of previous projects
 - create collaborative research networks
 - Targeting health conditions on different levels and ideally investigating the quality of care and linking it to costs
 - Sustainability of efforts is always a problem

Observations from our experience

- Despite the multitude of initiatives, data are scarce on:
 - Care quality (effective care pathways, patient experience)
 - Disparities in health and healthcare utilisation
 - Healthcare costs and expenditure
- Access to national and international databases should be simplified both for researchers and public
 - Administrative databases are rich but often underused



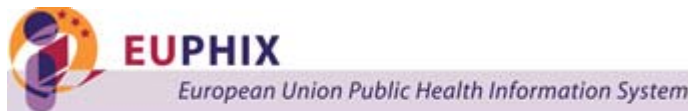
Investment in tools for improving knowledge

“When your only tool is a hammer, every problem looks like a nail”

- Good communication of data is crucial to attain the benefits of comparative information
- Resources such as HDN helps avoiding duplication of work, identifying relevant data and information
- Facilitates sharing “knowledge”
- Assists cross-country collaboration in health research

Sustainability

HDN face the same problem of sustainability common to many European projects and initiatives (lack of funding after a couple of years)



EUPHIX: EU Public Health Information & Knowledge System

Important message:

EUPHIX, the European Union Public Health Information and Knowledge System, had to be taken off line due to discontinuation of funding. We apologize for any inconvenience this may cause.

For information on the ECHI indicators we refer to:

- [DG SANCO's HEIDI data tool](#)
- [ECHIM project website](#)
- [Healthindicators.eu](#)

For information on public health topics we refer to:

- [DG SANCO's HEIDI wiki](#)
- [Health-EU Portal](#)

The EUPHIX team

To conclude

*“Knowing is not enough; we must apply.
Willing is not enough; we must do”*

Goethe