



Improved access to  
health care data through  
cross-country comparisons

# HEALTH DATA NAVIGATOR



The Health Data Navigator

**Your toolkit for  
comparative performance analysis**

A EuroREACH product

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*[www.healthdatanavigator.eu](http://www.healthdatanavigator.eu)*

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## Executive Summary

The Health Data Navigator (HDN) was developed as part of the EuroREACH project, funded by the European Commission's FP7 Health programme [Grant Agreement Nr. 242099]. The ultimate objective of the HDN is to promote generic **standards** for conceptualizing performance assessment and for evaluating the quality of relevant data sources used for the comparative evaluation of health systems.

The Health Data Navigator (HDN) offers a number of **entry points** to find and access data for comparative performance analysis:

- **European and international health information systems**
- **European projects** that have addressed aspects of performance for particular diseases, population groups and/or settings
- **National health information systems** including best practice examples of comprehensive, patient-level data for health services research
- A review of **Performance Assessment frameworks**, outlining the different performance domains and including a glossary of frequently used terms as well as an inventory of **methods** used.

The HDN organizes information about the health care system in EuroREACH countries to facilitate the **appropriate use of data** for comparative analysis by

- enabling users to systematically access databases through relevant domains of performance and/or disease areas and/or settings
- allowing users to identify whether data are patient-level (vs. aggregate only) and/or disease-based, what the quality of the data is and whether they are accessible
- guiding users in making meaningful cross-country comparisons including information about:
  - gaps in existing data, encouraging data collection in under-represented areas and
  - key health data challenges such as data protection, data linkage and comparability.

Ideally, users browsing the HDN might hope to find access to data that are patient-level and longitudinal, detailed enough to allow analysis on individual diseases, health care utilization, costs and quality across sectors, and across performance dimensions. While information on a wide range of such issues exists, it is usually confined to one or few condition(s), setting(s), health care or performance dimension(s) and availability varies considerably across countries.

The HDN offers an operational prototype website that systematically reports sources of health information. It is a starting point for identifying commonalities and variations and for bringing shortcomings to the attention of data producers and users. Through reporting standards and guidance in performance assessment developed by EuroREACH, the HDN has considerable future potential. In particular, it should include databases and information from other countries, and information stored in the HDN should be regularly up-dated. Furthermore, issues relating to data management and engineering should be regularly up-dated and elaborated. As policy makers everywhere are increasingly seeking out evidence on the comparative performance of health systems to inform “good practice” policies, we believe that it is crucial that the HDN should be sustained and developed further.

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## 1 Objective and added value of the Health Data Navigator (HDN)

The Health Data Navigator (HDN) was developed as part of the EuroREACH project, funded by the European Commission's FP7 Health programme [Grant Agreement Nr. 242099]. As an operational prototype website for researchers, policy makers, and healthcare professionals the HDN aims to ensure access to health data and to enhance cross-country comparison of European health systems. The ultimate objective of the HDN is to promote generic **standards** for conceptualizing performance assessment and for evaluating the quality of relevant data sources in the area of health. The need to develop such standards has emerged in light of the importance of harnessing information generated in the health sector to improve health outcomes and levels of efficiency (EC, 2012; World Economic Forum, 2013; Friends of Europe, 2013). As a toolbox for researchers and analysts the HDN provides guidance for accessing data, understanding the quality of data, and assessing their appropriateness for comparative performance analysis. The creation of the HDN is an important endeavour for promoting good practice in data use in the area of health. It seeks to add value to existing initiatives by combining structured database information with tools for assessing the performance of health systems both within and across countries. The rationale for developing the HDN is as follows.

First, while a growing number of national and international organisations collect and provide data on different health and health service domains, the objectives of data collection vary. The conditions for access, including information about the adequacy of data for evaluation purposes, are not always apparent.

Second, the fast growing ICT capacity to process large data sets has helped to speed up the production of available data and has encouraged a variety of methods to assemble and analyse these data. This often also involves large scale international projects that have produced valuable approaches and results. However, there exists no overview of available data or validated methods to analyse them.

Third, individual level data are becoming increasingly available, sometimes even publicly, permitting examination of cross country performance of health systems at the level of episodes of care. It is crucial to have a clear understanding of conceptual issues and issues related to privacy and security when using such data for policy purposes.

Finally, there is a need for a source of good research practices and a reliable information base for enhanced policy making, with the aim of using information to improve health and healthcare delivery. In light of intensified national and global efforts to make health systems sustainable and resilient, knowing how to access and use the fast-growing body of relevant data to best effect is crucial.

## The HDN aids your understanding of performance measurement in health care

The HDN uses a conceptual framework based on the OECD HCQI initiative, and described more fully in Chapter 2. The framework highlights the importance of the quality of health care within a wider performance framework. The focus within the health system performance is on quality, access, and efficiency, which are referred to as performance domains. These are thoroughly defined, along with other important concepts, so as to promote better standards in data collection, management and use.

While the EuroREACH framework (Chapter 2) forms the basis for the design of the HDN, the HDN also provides an overview of other established **frameworks** that have proved useful when comparing the performance of health systems. A **glossary** of frequently used terms in performance analysis provides key concepts and references to promote comparable use of data. Furthermore the HDN provides an inventory of **methods** used in performance analysis. This section features a conceptual framework that was developed for the **EuroREACH case study on diabetes care** to identify barriers and facilitators when using individual level data to compare diabetes care across countries, see also Chapter 3 and 5.

**Figure 1: Databases may be mapped using performance domains as developed by EuroREACH**



Source: EuroREACH, 2012

## The HDN helps you accessing data via performance domains

The performance domains of the HDN data section can be browsed to examine information on both internationally available data sources and data from individual countries (Figure 1). For example, clicking on **health status** when searching national data the HDN lists existing data sources that can be accessed via links to retrieve data commonly used to compare the health status of the population. This listing contains not only data sources where **aggregate data** are stored, but also sources containing **individual level data** where such data exist. This differentiation is found in each of the performance domains. Also, relevant international databases and EU projects are reported and classified according to these performance domains.



## The HDN gives systematic guidance about the appropriateness of databases for research

An important added value of the HDN website is to inform visitors of the appropriateness and quality of data they may want to use. In particular, data sources reported in the Health Data Navigator are described in greater detail where information exists. The assessment is done systematically throughout the HDN and draws on the Global Health Data Charter prepared by the World Economic Forum 2011. Table 1 summarizes these assessment criteria and provides broad explanations of what EuroREACH partners considered when classifying databases according to the criteria of interest.

**Table 1: EuroREACH appraisal criteria for databases reported in the HDN**

<b>Governance</b>	<b>Contact information:</b> who can be contacted to ask for data, ask for help... <b>Transparency:</b> e.g. most data collected are out of date to some degree by the time they are published and made available
<b>Access to database</b>	<b>Ease:</b> Can data be downloaded directly; if motions need to be filed, persons responsible contacted etc. <b>Conditions of access:</b> e.g. data protection issues, fee <b>Language issues</b>
<b>Coverage</b>	Number of variables and number of years available <b>Sample size</b> <b>Geographical coverage</b> (national, some regions, etc.). For surveys, <b>population</b> covered (representative or not)
<b>Linkage</b>	<b>Standardization:</b> harmonized standards, taxonomies, terminologies that could help codify data, but also the number and range of technical systems present challenges in terms of interoperability <b>Possibility of linkage among national databases:</b> Is there a common variable (e.g. Person ID) that makes data assignable to specific persons, providers etc. across databases
<b>Data quality</b>	<b>Entry errors:</b> databases often contain entry errors, multiple common entries, other redundancies that have led to incorrect /incomplete data <b>Breaks:</b> changing reporting standards leads to data incompatibility <b>Consistency of terminology:</b> differences in how data are described when collected
<b>Strengths and weaknesses</b>	<b>Expert opinion</b>

Source: EuroREACH 2012, adapted from the Global Health Data Charter

Assessments are also made of international and EU projects so as to enhance the utilization of project results, including arrangements for securing access to project data for new or extended research. The assessment of data quality broadly aims to identify major issues relevant for data users. While attempts were made to assess databases and project as comprehensively as possible, not all aspects of the appraisal criteria listed in Table 1 could be considered. For example, entry errors were only identified if the database was known in great detail by involved EuroREACH partners.

Where available, the assessment procedure includes expert opinion on the “strengths and weaknesses” of the database under scrutiny. Where possible and relevant, expert opinion is provided to enable database users to quickly appreciate the strengths and limitations of the data.

### **The HDN reports micro-data sources suitable for disease based comparative research**

The use of micro-data in the area of health and their potential to inform decision makers about comparative resource needs, utilization, costs and outcomes of episodes of care is increasingly becoming a “gold-standard” when assessing comparative performance. For example, the Future Elderly Model (FEM) – developed by the RAND cooperation in 1997 uses a representative sample of approximately 100.000 Medicare beneficiaries age 65 and over drawn from the Medicare Current Beneficiary Surveys, national surveys that ask Medicare beneficiaries about chronic conditions, use of health care services, medical care spending, and health insurance coverage. Each beneficiary in the sample is linked to Medicare claims records to track actual medical care use and costs over time (Goldmann et al., 2008). Future trends can then be modeled using micro-simulation methods.

While micro-simulation models are increasingly being used at national levels (OECD 2012), little is known about issues arising when individual-level data are compared across countries. Thus the EuroREACH case study on diabetes care was undertaken to illustrate potentials and barriers in comparing individual level data across countries (Box 1; see also Chapter 3 & 5). In this context, the HDN could be extended to enhance the capacity of research using data generated through the increasing use of Electronic Health Records data (Schoen, 2012; The Commonwealth Fund, 2013) including gene data (Chapter 5). The HDN framework has the potential for capturing the digital dimension of health care to help accelerating the health care evidence base including relevant information on patient confidentiality and data sharing (Halvorson et al., 2012). The EuroREACH case study on diabetes provides some lessons in this context (Box 1, Chapter 3 & 5).

**BOX 1: The EuroREACH Case Study on diabetes care uses person-level data in three countries**

The purpose of the case study was to test the feasibility of using **administrative data to compare diabetes care and outcomes in three countries**. Even though the intention was to involve more countries, the lack of appropriate data or limited access to such data restricted the case study to three EuroREACH partner countries. As a consequence the case study made use of data from the *Finnish* and *Estonian* health care systems and from the *Maccabi Healthcare Services HMO* in *Israel*. The case study team performed the following tasks:

1. Comparison of the data elements available in the three countries.
2. Development of quality and outcome measures to be calculated using data common to the three countries.
3. Establishing a common definition for new onset diabetes based on pharmacy purchasing data.
4. Establishing common data sets for hospital, physician, pharmacy, laboratory and demographic data.
5. Developing SAS scripts to be used by all participants for calculation of the agreed-upon measures
6. Pooling the data and comparing the results.

In the course of the case study, we encountered a number of issues that may affect the **comparability of data** from different health systems, for example:

- Variations in the way health care is delivered in different systems must be considered in determining the sources of required data. For example, a system with a centralized laboratory is more likely to have laboratory results data available for quality monitoring than one in which many laboratories contract with payers.
- Different coding systems may be in use in different countries. Therefore, considerable effort is required to compile a complete list of all the codes that may be used to identify the diagnoses of interest.
- Reimbursement may drive the level of detail with which diagnoses and procedures are coded. For example, systems using prospective payment formulas to determine hospital reimbursement may produce data with more exact coding of procedures and diagnoses than those using a per-day payment rate.

## **This Toolkit**

This Toolkit summarizes the rationale for and functioning of the HDN. Chapter 2 highlights key issues of measuring health system performance and proposes a comprehensive framework. Issues related to organizing data for cross country comparison are discussed in Chapter 3 while Chapter 4 illustrates the functionality of the HDN by defining objectives and information needs of analysts browsing the website through different entry points. Chapter 5 points out important findings related to the EuroREACH case study on diabetes care and discusses the future potential of the HDN. Key recommendations for the use of the HDN and areas for improvement of data standards to facilitate comparative performance assessment are presented in Chapter 6.

## **2 Importance of high quality data for comparative policy analysis**

Performance information is essential in assuring the health system's ability to provide improved health to its population. It serves many different purposes, including the promotion of transparency and accountability, determining appropriate treatment for patients, facilitating patient choice and for managerial control. Individual nations are increasingly seeking to introduce more systematic ways of assessing the performance of their health systems, and of benchmarking performance against other countries (Papanicolas and Smith, 2013). Policymakers recognize that, without measurement and comparison, it is difficult to identify good and bad delivery practice or good or bad practitioners ("what or who works"), to design health system reforms, to protect patients and payers, or to make the case for investing in health care. Measurement is also central to promoting accountability to citizens, patients and payers for health system actions and outcomes. This focus on assessment coincides with the enormous increase in the capacity for measurement and analysis of the last decade, driven in no small part by massive changes in information technology and associated advances in measurement methodology.

Whatever the ultimate aim of collecting performance information, in order to reach the desired end-point, users of this information need to be able to understand what data are being collected and how they relate to the architecture and performance of the health system. The purpose of the EuroREACH project was to provide tools to health care researchers to better enable them to access well-organized health care data that allow for comparability between countries. These tools are presented in the form of a Navigator containing a toolbox of guidance on national and international health information systems, which is one of the major tangible outcomes of the project. In order to create this tool, a health system performance assessment framework was required, that can be used to organize performance information relating to the health system's objectives, functions and processes.

### **What is the state of development of cross-country performance assessments?**

If undertaken carefully, health system performance comparison offers a powerful resource for suggesting relevant health system reforms. The progress that has been achieved is impressive, both in the scope of areas for which comparable international data on health are now available and in the degree to which comparability has been improved (Papanicolas and Smith, 2013). However, the science of international comparison is still at a developmental stage. Policy-makers therefore need to be made aware of both the strengths and limitations of the data and methods used for health system comparison.

There are various ongoing initiatives and developments that have the potential to benefit further international comparisons. However, certain challenges remain in securing comparability across conceptualizations, definitions and indicators in the international setting. A recent review of the data available for health system comparison (Fahy, 2013) identified five areas in particular where progress will benefit comparative performance assessments. First the coverage and quality of data need to be improved. One very large area of development that brings health systems closer to this goal is the investment in information and communication technologies (ICT), often described within the EU context in particular as “e-health”. A second concern for comparative assessments of health system is making existing data more relevant for policy. As increasing numbers of people seek health care outside their own country, at least within the EU setting, there is a growing requirement for better comparability at the international level (Legido-Quigely et al., 2011). The third area of development that would assist health system comparisons is to extend information coverage to other relevant issues where data are currently lacking. For example, comparative analysis of efficiency and responsiveness are in earlier stages of development, in part due to their complex, multifaceted and sometimes intangible nature. Finally, innovation in analytical methods is needed to account for the variety of data types in health care, e.g. mixed method approaches (Creswell and Plano Clark, 2010) and to complement existing approaches. In undertaking international comparisons it is important to have a broad idea of the strengths and limitations of existing metrics, and how useful they are for the purpose of assessing system performance and helping to design system reforms.

Finally, to facilitate the use of international comparisons there needs to be more and better communication of the data needed to facilitate health system performance comparisons. Despite the growing interest in health system performance measurement, there is still considerable variation, and often confusion, as to what entities or goals are being measured, and how the data collection within regions and countries enables the scope for comparison.

Through the creation of the interactive Health Data Navigator the EuroREACH project aims to address all these areas of concern. In particular, the HDN seeks to provide guidance to users of national and international health information systems that allows them to better understand the opportunities, strengths, weaknesses and gaps of existing data. In order to begin to collect, organize, evaluate and present the vast amount of health information collected in a systematic and accessible fashion, the first step of the EuroREACH project was to create a shared conceptual framework. The purpose of such a framework is to promote a common understanding amongst all collaborators of the structure and design of the health system, the linkages between various domains, and how to map existing data onto different health system domains. This framework also forms the basis for the structure of the Navigator.

## The EuroREACH Framework for performance assessment in the area of health and healthcare

A clear conceptual framework can help to clarify the way in which stakeholders understand health systems. Over the last decade, several different conceptual health system frameworks have been proposed (Aday et al., 2004; Atun, 2008; Commonwealth Fund, 2006; Hurst & Jee-Hughes, 2001; IHP, 1999; Murray & Frenk, 2000; Roberts et al., 2008; Sicotte et al., 1998). While the ultimate goal of the different frameworks may vary, each attempts to provide a common starting point - a clear and simple conceptualization of the health system - from which its users can make further progress. Yet the existence of a number of competing frameworks indicates a lack of common understanding as to what a health system comprises. Indeed, the use of different frameworks by different stakeholders for similar purposes often results in misunderstandings, when each party conceptualizes important terms in different ways.

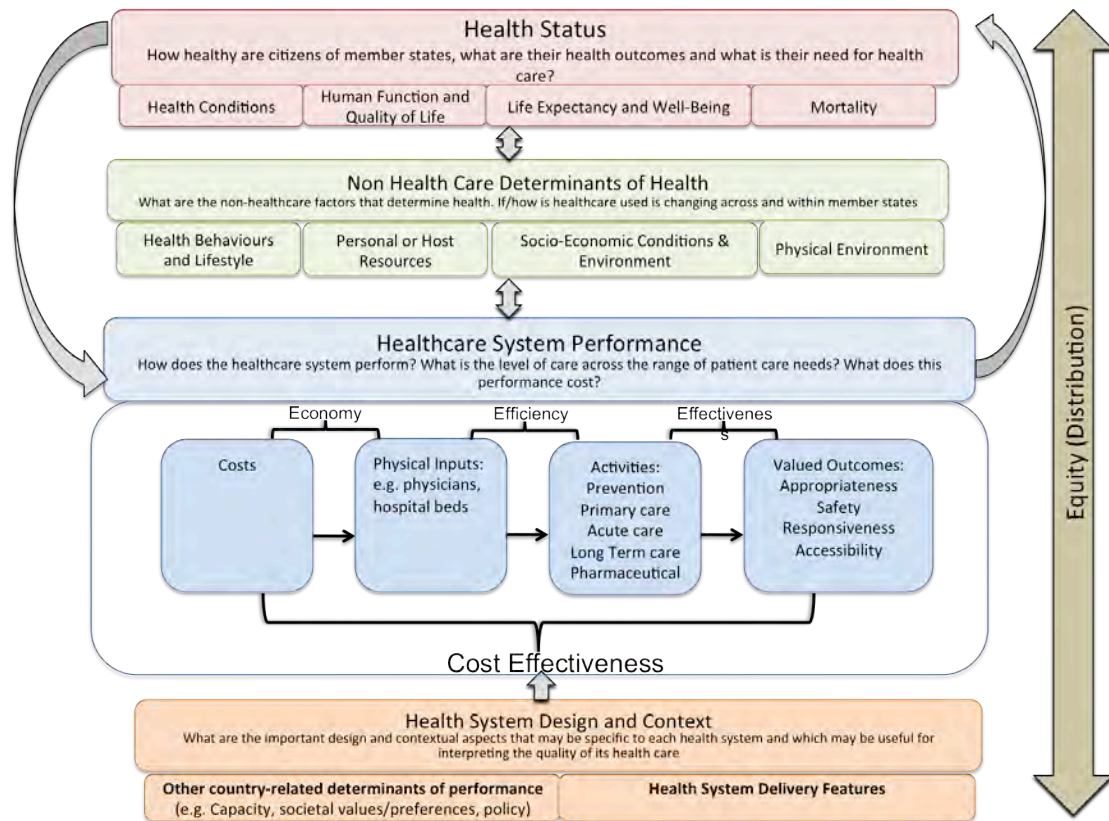
The competing frameworks nevertheless all aim to provide a better understanding as to what comprises a health system, its goals, and the underlying structure and factors that drive its performance. While all the international frameworks reviewed are subject to debate, we feel that it would not be productive to create an entirely new framework for the EuroREACH project. Instead, we sought to adapt an existing international framework as the basis of the EuroREACH project.

In identifying which framework was best suited to the needs of the EuroREACH project we reviewed ten widely used international frameworks. The performance criteria being considered for each of the international frameworks considered, *relative to the needs of the EuroREACH project*, were:

1. What was the *purpose* of the framework upon creation?
2. How does the framework conceptualize the *boundaries* of the health system?
3. How does the framework conceptualize the *goals* of the health systems?
4. How does the framework conceptualize the *architecture* of the health system?
5. Has the framework been used and had it been 'exposed' to *external review*?

Based on the performance of the different international frameworks with regards to the criteria identified above, we chose to use the OCED Health Care Quality Indicators (HCQI) Framework. However, as our project was not focusing only on quality we modified it accordingly (Figure 2). The main modification has been to the area of 'Healthcare System Performance'. This area has been altered so that we are better able to demonstrate the production process of a health care system and identify the distinct performance domains we are interested in measuring: quality, efficiency, and access (Figure 1). These modifications were made over an extended period of time and benefited from the feedback of numerous experts in the area who kindly participated in our Sounding Board project meetings ([www.euroreach.net](http://www.euroreach.net)).

**Figure 2: EuroREACH framework**



Source: EuroREACH, 2011

As indicated in Figure 2, healthcare system performance is represented by a production process, whereby physical inputs are translated into valued outcomes. The process itself is broken down into four distinct components that can be measured to facilitate performance comparisons of all components across and within countries.

The first and second boxes in the figure represent the physical inputs that go into the healthcare system, and their associated costs. By investigating these two areas, stakeholders are able to identify the potential savings that can be made by purchasing different physical inputs of different cost. For example, they may wish to examine the labour input across categories of labour or labour inputs relative to capital input where possible in health care. Hence these two boxes are important to look at in order to evaluate economy, as indicated in Figure 2.

The next box in the production process represents the activities produced by the physical and human inputs of the system. These activities span across the diverse types of services provided in the healthcare system, including preventive activities, primary care services, acute care services and so forth. By investigating the amount of activities produced by the system in relation to the inputs put into the system, stakeholders are able to better

understand how efficient the healthcare system is, i.e. technical efficiency of hospital production (Jacobs et al., 2006).

Finally, the last box in the production process represents the valued outcomes of the healthcare system. These valued outcomes represent high quality healthcare and include appropriateness, safety, responsiveness and acceptability of care. By evaluating the extent to which the activities undertaken with the healthcare system resources are able to produce the valued outcomes, stakeholders are able to assess the effectiveness of the system. The OECD (2010) approach is an important beginning in the context of assessing cost effectiveness across countries which was also applied to compare the performance of regions in Austria (Gönenc et al., 2011).

While conceptual issues in comparing the performance of health care systems are critical to enable good practice in research, careful attention also needs to be paid the appropriateness of data and how these data may be engineered to achieve research objectives. The following section provides an overview of approaches to foster the appropriate use of data and briefly discusses issues of data protection.



### **3 Organizing data for cross country comparison**

Health data are a valuable resource in many countries that could be used to improve population health, the quality of health care and the performance of health systems. Within any organizational unit (country, state, insurer, province or regional authority) numerous public and private entities may generate and maintain data that potentially contribute to comparative effectiveness research, quality monitoring and other purposes. Secondary use of data to address policy concerns often requires linking individual level data from multiple sources, raising issues of data protection. This chapter provides information about potential sources of data for system comparison, a brief description of different linkage methods, and regulations regarding the protection of data privacy.

#### **Identify appropriate data sources**

The breadth and level of detail available for each data system dictate the research and policy objectives that it can help to address. For example, aggregate data on hospital discharges could facilitate comparisons of admission rates or length of stay across regions or countries, but would on its own be insufficient for investigating the underlying factors that account for the differences. A comparison of quality and effectiveness of healthcare systems in many cases requires person-level data from multiple sources.

Data generated in the course of delivery of and reimbursement for health care offer a valuable resource for health services and comparative effectiveness research. The use of electronic medical records and automated claims processing facilitates access to the information required to identify exposures and outcomes of interest in large populations (see also Chapter 5).

Administrative data are usually collected and maintained to support the operations of the organization, rather than for the purposes of research. This fact can have an adverse impact on data quality and availability relevant for policy and research. For example, administrative files usually capture utilization of those services that the organization has an interest in tracking for purposes of payment or management. Services obtained outside the system or those for which a separate payment is not generated may not be captured. Precision in diagnostic and procedure coding is often limited by the coding system and practices of the organization and providers.

In order to understand the underlying factors responsible for variations in performance between countries, however, uniform specification and collection of data are required. From a research perspective, person-level data may be required to identify treatment modalities and other factors contributing to successful disease management so that countries can learn from one another. The EUBIROD project which is also featured in the HDN compares diabetes outcome across 20 countries is an example of the use of linked person-level data for cross-country comparisons (The BIRO Consortium, 2009).

Many policy questions require the use of multiple data to address the issues of interest. In this context, the value of data is often further enhanced when one or more data sources are linked. Such linkage might be comprehensive (at an individual level) or partial (for example linking some individual data with relevant small area data). The following are examples of potentially useful data sources that could be linked to form an information resource capable of informing a wide range of research and policy questions:

- Census data
- Vital records (birth and death registries)
- Health care membership and administrative data
- Eligibility/membership files
- Claims, including date and place of service, identity of provider/patient, diagnoses, treatment provided
- Pharmacy purchases
- Laboratory test results
- Clinical data from electronic medical records
- Communicable disease/adverse event reporting systems
- Chronic disease registries
- Large-scaled population-based surveys

Furthermore, in compiling any dataset, it is usually crucial to define the population covered by the system, thereby facilitating calculation of rates of events that can be compared between jurisdictions or over time.

### **When data linkage becomes an option**

When data from a number of different sources are used, methods of data linkage become a prime concern. For example, in comparisons of the long term outcomes associated with a specific surgical procedure, it may be necessary to supplement hospital records documenting the procedure itself with reports of health outcomes in the form of vital status, measures of functional status, and service utilization in the follow-up period, including hospital, physician, emergency services, pharmacy, and long-term care. In short, whenever quality of care is under scrutiny, data may be needed for the entire episode of care, starting with the procedure and ending with the completion of the follow-up period. The project PERFECT-Performance, effectiveness and cost of treatment episodes (Peltola et al., 2011) is an example of linking individual level hospital in-patient, out-patient, birth records, medications and disease-specific records.

Preparation of a linked data set involves identifying the sources and quality of the required data elements and establishing a method of combining them to create a more complete picture of the experience of individuals than could be obtained from any single data source. Data linkage requires not only a thorough understanding of the component databases to be linked, but also expertise in statistics and programming in order to establish a methodology for identifying matches between files, while minimizing errors (Bradley et al., 2010). Linkage of data is simplest when all of the data sources use a common unique key to identify

individual members. The ideal identifier is unique, permanent, and applicable to the entire population of interest. Unique identifiers assigned at birth exist in a number of countries, including Sweden, Norway, Denmark, and Israel (Lunde, 1975; Lunde et al., 1980). In practice, however, many data systems are not universal, even within health systems, and may not be used comprehensively (Gill et al., 1993). Therefore, other identifying information, such as name, birth date, gender, and residence may be taken into consideration in order to identify matching records. When the purpose of the project is to identify discrete episodes of care, dates of service may also be of importance in linking different services related to a single episode of care.

There are two basic methods for linkage of disparate data sets: deterministic and probabilistic (Gostin and Nass, 2009). Deterministic linkage requires an exact match between linkage variables (identity number, last name/first name, etc.). In cases in which data entry errors, name changes and other factors have resulted in differences between linkage variables in the two files (incorrect coding of identity number, or the appearance of a maiden name in one file and a married name in the other), true matches between records will be missed. In probabilistic linkage, in contrast, less than exact matches may be accepted, according to a predetermined method that assigns a score to the level of the match. The level of acceptable error depends on how crucial identification of a specific person is. Different fields may be given different weight (matched birth date may be more important than matching spelling of last name). In cases in which the goal is to link data collected by multiple agencies, probabilistic matching may allow more complete matching of records related to the same individual, at the expense of an increased risk of incorrect matches.

## **Data protection is always an issue**

One of the great strengths of administrative data systems is the availability of personal identifiers such as identification numbers, name and gender, date of birth, address and postal code. These identifiers are essential for meaningful research in that they enable linkage between data sources, permit analysis of outcomes according to socio-demographic factors, and allow for characterization of the underlying study population, essential for determining the extent to which the study results are generalizable (Black, 2003). In addition to personal identifiers, health care records will necessarily include sensitive data regarding medical and family history, personal behaviours and risk factors for disease (Chapter 5).

In general terms, the processing of health care records, or health data from other sources, is prohibited in Europe (Article 8(1) of the European Data Protection Directive 95/46/EC). The fact that such data are not specifically collected for research raises the question of whether it is in fact ethical and appropriate to use them for secondary purposes. Establishing the circumstances in which personal health data can be used for research requires balancing the good to the public to be achieved through such research with the individual's right to privacy (Gostin and Nass, 2009; Institute of Medicine, 2009).

There are a number of exemptions to the general prohibitions in Articles 8(2) and (3) of the European Directive. In general, it is acceptable for organizations to use their own data for internal purposes, for example for auditing, quality monitoring, utilization review and other activities to support the mission of the organization, without prior consent of the subject. In contrast, research involving human subjects, even when such research is based entirely on patient care data and does not involve patient contact or treatment interventions, requires explicit consideration of the risks and benefits to the individual, and the steps to be taken to protect patient privacy. Distinguishing between such internal monitoring activities and research can be difficult.

New research methods are always evolving, which demand new operations with the set of data. A former explicit consent needs to be renewed and can by no means be considered valid in a sense of an implied vague or broad consent. Shifting to the use of anonymized data offers a potential solution, as the data protection rules do not apply to data where "... the data subject is no longer identifiable ...".

Additional information is provided by recital 26 of the Privacy Directive which states that "to determine whether a person is identifiable, account should be taken of all the means likely reasonably to be used either by the controller or by any other person to identify the said person".

For health data however, complete anonymization is rarely feasible, as there can be many reasons for retaining the potential to re-identify data and true anonymization would remove nearly all data of interest for statistical research. In 2008, the International Standardization Organization (ISO) published Technical Specification (TS) No. 25237 which defines the basic concept of pseudonymisation and includes technical and organizational aspects of de-identification as well as guidelines for re-identification risk-assessment. The Article 29 Working Party defines this last concept as follows: "Pseudonymisation means transposing identifiers (like names and date of birth etc) into a new designation, preferably by encryption, so that the recipient of the information cannot identify the data subject".

Even if there is no consensus about the interpretation of what constitutes de-identification data, this practice is widely used as part of efforts to strike an appropriate balance between protection of data confidentiality and the use of data (OECD, 2012). Data to monitor and compare performance within and across countries are central to the assessment of the population health and the quality and efficiency of healthcare services. However, the use of person-level data requires special attention to the protecting the privacy of individuals. In light of these challenges, the HDN offers users a section about issues in data management which features a page related to data protection. This page discusses key aspects of the European Data Protection Directive 95/46/EC and gives systematic insights in corresponding legislation in EuroREACH countries. On the basis of a defined set of issues developed by EuroREACH, the data protection page presents a summary of national regulations concerning e.g. person level data and linkage activities.

While the data management page of the HDN is an entry point in its own right, the following section gives more insights into the functionality of the HDN from various other entry points. Chapter 4 starts out with describing briefly the current geographical coverage of the HDN and its main building blocks (Figure 4). Two case vignettes are presented to illustrate the potential of the HDN for analysts and researchers. Their searching of the health information landscape has different starting points as their research question differ. Thus, they use different entry points of the HDN and cruise data bases and other information they deem relevant for their task.

## 4 Functionality and structure of the Health Data Navigator

As a prototype website, the HDN is developed to respond to a wide range of research needs and users of health care data: from epidemiologists to economists, policy advisers to academics. Anybody who is interested in health systems should easily navigate the HDN. Effort is made to present available data and information by different entry points which are made concurrent with the EuroREACH performance framework (Chapter 2) and information related to data management including data protection (Chapter 3). Currently the HDN provides detailed information for EuroREACH partner countries. In particular, databases and related information are identified and widely described in Austria, Estonia, Finland, France, Germany, Israel, and Luxemburg and in the United Kingdom (Figure 3). In the future, data mapping can be easily extended to other countries as the architecture of the HDN website is flexible and permits further development through defined reporting standards (Chapter 1).

**Figure 3: Improved access to health care data in EuroREACH partner countries**



Source: [www.healthdatanavigator.eu](http://www.healthdatanavigator.eu)

By clicking on EuroREACH partner countries as displayed in light orange in Figure 3 website users may quickly enter country specific inventories of databases mapped along performance domains (Figure 1). Furthermore, existing databases in these countries are mapped by a defined set of disease categories (Infectious, Non-communicable diseases, Mental Health and End of Life care) and by care providers (Primary/Ambulatory Care,

Hospital/Inpatient Care, Long-Term Care, Medical Goods), also utilizing performance domains for displaying relevant data sources (Figure 1 and Figure 4).

This mapping at the national level is complemented with a comprehensive listing of existing international databases and projects that are judged suitable for comparative performance assessment. While wide-ranging attempts were made to create an inclusive inventory of data information at the international level and in EuroREACH partner countries, database and project assessments could not be provided for all displayed datasets. However, the multidimensional navigation structure of the HDN and database assessment tables are designed to be applied to all data sources. Thus, maintenance of the HDN - including the incorporation of other countries and projects not yet featured in the HDN - is crucial in ensuring an exhaustive inventory of health system information.

### The HDN features various entry points to accommodate research needs

Users can approach the information provided in the HDN from a variety of entry points. Figure 4 exhibits the *Performance* concepts and *Data Management* issues used for the organisation and storage of data and information at the *International* level, at the *National* level and at the level of *Disease areas and Care provision*. The main features of the HDN building blocks are described below.

**Figure 4: HDN building blocks are concurrent tabs which serve as entry points**



Source: EuroREACH, 2012

### The PERFORMANCE tab provides conceptual standards guiding the measurement of health system performance

The central focus of the HDN is on performance evaluation of healthcare systems (Chapter 1 and Chapter 2). Data and information contained in the HDN are structured around the EuroREACH performance framework dimensions. The *Performance* tab introduces the EuroREACH performance framework, which describes the building blocks that contribute to the overall performance of a healthcare system (Figure 2). Performance domains, displayed in a stylized way within the *Performance* tab of the HDN, are coloured to foster usability of the HDN. When users click on performance domains they are provided with conceptual information. For example, by clicking on the dimension “quality” users find working definitions of quality currently employed to capture the underlying concept (Screenshot 1).

## Screenshot 1: Key concepts of *Quality* as provided in the HDN

**HEALTH DATA NAVIGATOR**

Share your ideas for improving health data and system analysis at the international level

HOME **PERFORMANCE** INTERNATIONAL NATIONAL DISEASE AREA CARE PROVISION DATA MANAGEMENT

Search...

Home > Performance > HealthDataNav > Quality

Frameworks  
Methods

## Quality

| PRINT | EMAIL

### Key Issues in Conceptualization

There is an overall consensus that quality encompasses several dimensions; however there is no agreement on which dimensions. Dimensions vary among definitions and although effectiveness or responsiveness seems to be common to most, others are unique to one definition, such as sustainability or capacity (Kelley & Hurst)."

### Definitions

- . Quality of care: "The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge (Institute of Medicine, 2001; OECD, 2004)".
- . Quality of care: "The provision of the right (effective), coordinated, safe, responsive/patient centred and timely care (Commonwealth Fund, 2006)".
- . Quality of care: "Is captured through the dimensions of accessibility, equity, effectiveness, safety and responsiveness/centeredness (OECD, 2006)"
- . Clinical Quality: "Involves the appropriate combination of human inputs, non-human inputs and production systems (Hsiao, 2003)".

Austria | Estonia | Finland | France | Germany | Israel | Luxembourg | UK

International Data & Indicators

Source: [www.healthdatanavigator.eu](http://www.healthdatanavigator.eu)

As a guiding principle, performance domains used to map existing databases are assigned coloured dots that correspond to the colour of the respective domain. For example, "Quality" is assigned the colour blue (see also Figure 1) and so is the dot next to "Quality" when data are mapped on other pages of the website, e.g. the *National* tab.

### The **INTERNATIONAL** tab provides organized access to internationally available data

The *International* tab provides an inventory of databases, international surveys, European and international projects and initiatives as well as metadata that are commonly used and that EuroREACH has evaluated as suitable for health system comparisons. In all pages information is laid out consistent with the performance dimensions described above.

The **Data & Indicators** page provides links to the most important international data sources, with a systematic review of their content and information for assessing different performance domains (Screenshot 2). For each international database, assessment tables provide information about access to data, time period and countries covered, including an expert assessment of advantages and limitations for research, see also Table 1. The **Projects** page gives an overview of EU and international projects organised by themes with clickable assessment tables detailing each project's content, objectives, project outcomes, strengths and weaknesses. Projects were selected according to predefined criteria and are classified



both by their content as to performance analysis and by the disease areas covered. In the **Survey** page similar information is provided for international surveys important for health analysis. In order to put international data in the context of particular healthcare systems, the **Health system profiles** page provides links to information sources on the design and institutional features of individual health care systems.

### Screenshot 2: Find Data & Indicators in the HDN

**HEALTH DATA NAVIGATOR** 

*Share your ideas for improving health data and system analysis at the international level*

HOME PERFORMANCE **INTERNATIONAL** NATIONAL DISEASE AREA CARE PROVISION DATA MANAGEMENT

Search...

Home > International

**International** | PRINT | EMAIL

This tab guides you through databases widely used for cross-country comparison of performance. In this section you find detailed information including assessment on:

- . health and disease specific databases and indicators as well as general databases.
- . International projects: in most of these projects patient-level and/or disease-oriented data are comparatively used.
- . links to non-health specific surveys and
- . information sources which provide descriptive insights into health system profiles.

**HEALTH DATA NAVIGATOR** 

*Understand strengths and weaknesses of existing data bases and projects*

HOME PERFORMANCE **INTERNATIONAL** NATIONAL DISEASE AREA CARE PROVISION DATA MANAGEMENT

Search...

Home > International > Data & Indicators > Global Health Observatory (WHO)

**WHO Global Health Observatory Data Repository** | PRINT | EMAIL

**Assessment table** 

The **Global Health Observatory Data Repository** groups all the data collected by the WHO in a unique platform. It contains a wide range of data organised by WHO's priority themes: health related millennium development goals, environmental health, health equity, substance use, infectious diseases and violence and injuries.

**GHO Indicator Table**

Health Status	Indicators	Decomposition
	Standardised Mortality Rates	Age, Gender, Disease, Maternal, Infant, Non Communicable Diseases, Cancer
	Incidence Rates	Influenza, cholera, meningococcal meningitis, malaria, tuberculosis and neglected tropical diseases

Source: [www.healthdatanavigator.eu](http://www.healthdatanavigator.eu)

**The NATIONAL tab provides organized access to nationally available data in EuroREACH countries**

The *National* tab helps users to quickly find the range of data sources available in one of the EuroREACH countries (Figure 3). To facilitate understanding of the content and utilisation of national databases for cross-country comparison, standardized appraisal criteria are used (Table 1) to assess the quality of data and information of the respective source, see Screenshot 3. These appraisals aim to cater specific information needs of researchers in addressing e.g. Who produces and manages the data?, What are the requirements for accessing the data?, or Are there gaps in data? Strengths and weaknesses of the respective database are assessed by expert opinion where such information is available.

**Screenshot 3: Assessment of available costs weights for French hospitals**

**Echelle Nationale des Coûts (ENC)**

This survey of the cost weights for approximately 90 private and public hospitals is at the heart of the financing system of the hospital sector, as it is used by the Ministry to set the fee schedule of the DRG system.

Governance	<ul style="list-style-type: none"> <li>Hosted by the Ministry of Health's technical agency on hospital information systems <a href="http://www.atih.sante.fr">http://www.atih.sante.fr</a></li> </ul>
Access to database	<ul style="list-style-type: none"> <li>In French only</li> <li>Some aggregate cost-weights data is available <a href="#">online</a>.</li> <li>Access to patient level cost data requires an authorization from <a href="#">CNIL</a> (the public agency responsible for data confidentiality) and ATIH and very difficult to obtain.</li> </ul>
Coverage	<ul style="list-style-type: none"> <li>3 separate databases: <a href="#">acute care and obstetrics</a> from 1997, <a href="#">post-operative and rehabilitation</a> from 2009 and <a href="#">home based hospital care</a> from 2009.</li> <li>For acute care and obstetrics, a distinction is made between public and private hospitals (2 different scales) but from 2007 a common methodology</li> <li>Cost weights are broken down at the DRG level and derived from management accounting of surveyed hospitals</li> </ul>
Data quality	<ul style="list-style-type: none"> <li>Interpretation of data requires expertise of the French hospital funding system in France</li> <li>Some manuals of utilization provide guidance</li> <li>Access to patient level data is very difficult to obtain</li> </ul>
Strengths and weaknesses	<ul style="list-style-type: none"> <li>Detailed cost weights at the DRG level of a representative survey of public and private hospitals</li> <li>However, interpretation and access remain very difficult</li> </ul>

Source: [www.healthdatanavigator.eu](http://www.healthdatanavigator.eu)

### **The DISEASE AREA tab provides organized access to databases by disease categories**

Database information and related material is organized through a defined set of diseases via the *Disease area* tab. In particular, users may access relevant data sources by clicking on *infectious diseases*, *non-communicable diseases*, *mental health and end of life care*. Databases identified in EuroREACH partner countries are listed according to performance domains in each relevant disease category. This listing is organized for aggregate level data and individual level data and may be also retrieved through a search function. Also, EU and international projects and initiatives relevant for specific diseases are displayed. Further, users can find links to sources describing the design and the context of the health care system in the country of interest.

### **The CARE PROVISION tab provides organized access to databases by provider categories**

By entering the HDN through this tab, national and international data sources of interest are classified according to care providers. EuroREACH defined the most important providers of care as providers of *primary/ambulatory care*, of *hospital/inpatient care*, of *long-term care* and of *medical goods*. While increasingly important in organizing the supply of health care systems, no differentiation between public and private providers is made in the HDN. Thus, currently databases in this tab are categorised only according to performance domains and the degree of granularity of data. These databases may be retrieved via a search function as well as through performance domains.

### **The DATA MANAGEMENT tab provides guidance when working with health data**

Under *Data Management*, users find information on major data issues in performance comparisons including *data governance* and *data protection*. Both aspects are crucial for access to healthcare data, in particular when individual level data are concerned. In this context the EuroREACH comparative case study on diabetes care (Box 1) provided important lessons for researchers aiming to work with individual level data across countries. The page *Lessons from EuroREACH* within this tab summarizes main issues, including important aspects related to data linkage. The latter subject is also more generally documented on the page *data linkage*. Issues addressed in the page on *data comparability* help users to ask themselves relevant questions when seeking to undertake comparative analysis. Without such reflection, and associated analytic methods, comparing data across healthcare systems may lead to inappropriate conclusions.

## **How can you use the HDN for your research and what can the HDN do for you?**

To illustrate the function and potential of the HDN, two case vignettes were defined. Boxes 2 and 3 describe how two notional users, Mr. Curious and Mrs. Highbrow, find their way through the HDN. While both want to look up relevant information on health care data, their research questions differ, with implications for the breadth of information they are looking for. They therefore use different entry points and pathways within the HDN.

**BOX 2: Mr. Curious navigates through the HDN in preparation for a press conference at the Ministry of Health**

**Mr. Curious** is a young and ambitious policy adviser working for the Dutch Ministry of Health. He will attend to his first press conference next week. On the agenda of the press conference are the following items:

1. Rise in public healthcare expenditure between 2008 and 2009 from 7.4% to 9.5% of GDP in the Netherlands.
2. Modification of the Dutch DRG payment system in hospitals.
3. Re-emergence of tuberculosis death cases in some deprived areas.

Mr. Curious wants to make sure he is well-prepared in case the Minister turns to him for support. He would like to understand how other European countries compare with the Dutch situation and therefore consults the HDN to address the following questions:

**1. Mr. Curious wants to know whether public expenditure in countries around the Netherlands has grown as much between 2008 and 2009?**

- From the **International** tab, Mr. Curious navigates to *Data & Indicators* and browses through the various *indicator tables* of international databases to see whether he can find the data he is looking for (i.e. share of public health expenditure as a % of GDP between 2008 and 2009 in France and Germany). As Mr. Curious is very quick, he uses the shortcut Ctrl+F to search for “health expenditure” in the indicator tables.
- He sees that the OECD provides the data he needs. In the *efficiency/economy* section of the *indicator table* he clicks on the link ‘Costs’ which directs him to the expenditure data tables in OECD stats page. This database is public and he can thus quickly access the information needed.

Efficiency/Economy	Indicators	Decomposition
Outputs/Activities	Length of Stay	
	Number of Discharges	Diagnostic
	Bed occupation rates	
	Turnover rates	
	Number of Surgical Procedures	Disease, Age, gender
	Pharmaceutical Consumption by DDD's	Type of drug (ATC Classification)
	Long-term care recipients	Home, institutions
	Number of Diagnostic Exams	CT Scans, MRI
	Number of Consultations	Doctor, Dentists
	Physical Inputs	Human Resources
Long-term care workers		Formal and informal, Head counts and FTE
Personnel		Physicians, Nurses, Midwives, Caring Personnel, Dentists, Pharmacists, Physiotherapists, Graduates. Breakdown for most by Practising/Professionally acqwerlicensed to practice
Infrastructure		Number of Hospitals Number of Beds
Costs	Devices	CT Scans, MRI, Others
	Health Expenditure (% of GDP, Exchange rate, PPP, NCU, Total Current Expenditure on Health)	Age, Gender, Private, Public, Out-of-pocket, Cost Sharing, Corporations, Insurances, Services, Pharmaceuticals. Also presented by providers (hospital, ambulatory).

*In France, public health expenditure as a percentage of GDP went from 8.2% to 8.6% between 2008 and 2011 while in Germany, figures were 7.9 and 8.8% respectively. The Netherlands is the country with the fastest growth rate and became the second highest spender after the US in OECD area.*

## 2. Mr. Curious wants to know how DRG systems function in other countries and compare them.

There are a few different ways Mr. Curious can obtain this information:

- This time he chooses to go through the **Care Provision** tab as he knows the DRG system is used for financing hospitals. In *Hospital/Inpatient care*, he discovers the *Euro DRG project* which brings him to the description of the international hospital project. Without reading everything, he quickly discovers that almost all European countries have currently some kind of activity-based mechanism in place to fund hospital care but that DRG models vary.
- Alternatively, as he is interested in international comparisons, he browses through the **International** tab. On the *Projects* page (using Ctrl+F to search the pages with “DRG” as the keyword) he identifies that the Euro DRG project might contain the information he is looking for.

## 3. Mr. Curious finally wants to know how the Netherlands compare in terms of survival and prevention activities to the rest of Europe.

- He first goes to the **Disease** tab and clicks on *infectious diseases* as he assumes he will find relevant information on tuberculosis under this category. In *Infectious disease*, he navigates to the *International projects & data* section, where he can find different descriptions of databases. There he discovers the *Centralized Information on Infectious Diseases (CISID)*, a WHO database. He clicks on the *assessment table* and sees that data on “tuberculosis” are available from this database. He accesses the database quickly from the access link. Under Tuberculosis – Cases - Mortality and prevalence he finds the relevant figures for a number of European countries.

He discovers that while *tuberculosis death rates have seen a slight increase in the past years in the Netherlands, prevalence levels still remain lower in the Netherlands than in Germany or France.*

**BOX 3: Mrs. Highbrow seeks to compare quality and costs of breast cancer care in European countries**

**Mrs. Highbrow** is a senior researcher in Berlin working on comparative European healthcare policies. She would like to prepare a research proposal on cancer care to reply to a call from the National Cancer Institute. She is interested in comparing costs and quality of breast cancer treatment in Germany with similar European countries. She wants to find information for at least three other countries and chooses France, England, and Israel where she also hopes to access available data. She needs to use individual level data to explore whether there is a relationship between expenditure and quality/outcomes. She also wants to know if there are research projects that have addressed similar research questions. The following navigations outline how Mrs. Highbrow finds the information for her research with the help of the HDN:


**1. Mrs. Highbrow needs to obtain data on quality of cancer care in the countries of interest:**

- She goes to the **Performance** tab and clicks on the domain *Quality* of the framework. As she is well informed about conceptual aspects of quality measurement she directly jumps to the page *Data & Indicators* which guides her to different databases. In each database she can see available quality indicators. She browses through the *indicator tables* of the different databases using the word “cancer”. In the OECD database she follows the link to *Quality* and identifies two quality indicators: 5 year survival rate (effectiveness) and breast cancer screening rates (prevention) which allows her to make a quick assessment of available data on quality of cancer care in selected countries.

The screenshot shows a webpage with the following content:

- 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.

**2. She wants to find out if there is individual level data on costs of cancer care available:**

- Mrs. Highbrow goes to the **National** tab and selects the country pages of France, Israel, Germany and UK (see Screenshot above). Let's take the example of France. Mrs. Highbrow clicks on *Efficiency/Economy* and sees under *Cost and Expenditure* that there are databases providing individual level data. She is interested in *SNIR-AM reimbursement database* which provides data on healthcare consumption costs. She accesses the assessment table of the database by clicking the assessment table sign  and finds out what data are covered in the database and who to contact to obtain them (see Screenshot 2). She searches for similar data access in all other countries she had chosen.

**3. Now Mrs. Highbrow has data on quality of care and is in the process of obtaining individual level cost data for breast cancer in four countries. Her colleague told her a few weeks about research projects on cancer care and she would like to find out whether her research questions are addressed in these projects.**

- In the tab **International** she goes to *Projects* where projects are classified according to diseases. She identifies patient level data on cancer care across healthcare sectors and within hospitals only. By browsing through these different projects, she has a better sense of ongoing research in this area.
- She sees that the project *ONCOPOOL* provides data on diagnosis, pathology, therapies and outcome measures of primary operable invasive breast cancers treated in the 1990s in 10 European breast cancer Units. The project results provide her with valuable information on quality of breast cancer care in several European countries. Further, by triangulating the cancer projects (e.g. EuroCARE project, HAEMACARE, RARECARE and EUNICE), she can analyze data on e.g. risk factors, development of disease, monitoring, treatment on a comparative basis.

**4. Finally, Mrs. Highbrow wants to understand the healthcare systems of these countries to answer questions concerning policies towards breast cancer, organization of screening etc.**

- She goes to the **National** tab and clicks on the countries she has chosen. There she finds under *Health System Design and Context* relevant material to access in each country. She also cross-checks the *International* tab where she realizes that the *European Observatory* has a rich body of information on European health care systems. She goes to *country monographs* and finds that some of them contain specific information on breast cancer.

With the help of the HDN, Mrs. Highbrow can now start preparing her research proposal. Of course, as she is interested in individual level data analysis, some of the data she needs cannot be found directly online. However, the HDN allowed her to identify existing data and information sources in selected countries and provided her with links for further local assistance. While the HDN *per se* cannot offer everything she needs for such a complex research project, she has a better sense of available information and the state of the knowledge on this area thanks to the HDN.

While the case of Mrs. Highbrow illustrates well the importance of access to detailed information about existing databases to support her research, the identification of available individual level data for comparative research is only a first step. In particular, researchers or analysts comparing individual level data across countries may face substantial barriers to access due to data governance issues and data protection legislation (Chapter 3). The following section explores some of the issues researcher encounter in comparative studies with person-level data. These issues were identified through the EuroREACH case study comparing diabetes care in Estonia, in Finland and in Israel (Box 1). The chapter closes with a brief outlook of new data sources, e.g. data from Electronic Health Records that may have potential for fostering comparative research and supporting best practice.



## 5 Future potential of the Health Data Navigator as a research tool

One important role of the diabetes case study (Box 1) was to explore the practical problems encountered when administrative (national register) data are used to compare the performance of chronic care in an international context. The case study also served as a 'test-case' for the desired features of HDN and therefore in this section we pursue to illustrate the present situation and future opportunities for enhancing the value of the HDN. While the HDN aims to provide links to all data and information sources relevant for assessing health system performance, it can also be used to provide various types of metadata and important observations concerning the comparability and usefulness of the potential data sources. In this chapter we illustrate the main practical challenges in comparative performance studies based on our findings in the case study and observations made in other similar projects, e.g. EuroHOPE, EuroDRG, Managed outcomes, Nordic Hospital Study Group. We also suggest future enhancements needed to improve the HDN as a research tool.

### A case example: the EuroREACH case study on Diabetes

We illustrate the typical questions faced in comparative studies by assuming that the objective for the researcher was to compare diabetes care internationally. Due to problems in the comparability and availability of data in other EuroREACH countries, only Estonia, Israel (Maccabi) and Finland could be considered. The researcher is primarily interested in the incidences of cardio-vascular disease (CVD) events and use of health care services for a representative cohort of diabetics in a follow-up setting.

The first concern for the researcher is how to define the representative cohort of diabetics. Is it possible to use the existing data to derive a satisfactory and comparable definition for a newly diagnosed diabetic? The definition for incident diabetic persons could for example be achieved using medication data if they were available on a comparable basis in the participating countries. However, there still may exist differences in how many diabetics are identified by the health care system/health care registers. If there is variation in the average severity or disease stage of the incident cases, the challenges in outcome and cost comparisons increase. Is it then possible to link the individuals to hospital discharge registers using a unique patient identification code? What is the common possible time period for the follow-up? Do the compared countries share common standards and definitions for health care services (e.g. similar DRGs) and are there cost data available for these services?

The HDN reveals there are no functional disease registries in *Estonia* (except for the Cancer Registry). However, the data from the administrative health service database of the Estonia Health Insurance can be used for the purposes of the study and no linkage with other databases is necessary since it records all contacts in secondary/tertiary care and the cohort

of diabetics can be identified. Furthermore the database covers all years from year 2000 onwards.

*Finland* has a comprehensive system of medical registers and administrative databases, where person-level data are collected and can be linked using a unique national personal identification number. Yet the HDN reveals that the registers for primary care have been established quite recently (in 2011) and the quality of diagnosis coding is not always satisfactory. Thus the diabetic population needs to be defined using the medication data from the Social Insurance Institution and linkages to collect the cardiovascular disease (CVD) incidents and resource use are required. Fortunately, for the purposes of the present study example, a linkage-based research database of Finnish diabetic patients was already available, hosted by the National Institute for Health and Welfare and its partners. A follow-up could be conducted starting from year 2000.

*Maccabi's* patient information systems cover visits to hospitals, physicians and other health professionals, prescription drug purchases, laboratory testing (including results) and imaging studies. For this case study all databases were linked using the national identifier to create the episodes necessary for this international comparison since the year 2003.

### **Challenges and remedies in data comparability**

Our example showed how the HDN can help in finding the obvious administrative databases and relevant variables to be used to answer the specific research questions. Based on the list of data specifications a common data structure could be defined and used to develop common data scripts for the statistical programs to be used in each country. In this way the calculations and reporting could be performed locally without needing to share the data.

However, during the course of the research many challenges arose and had to be resolved using much more detailed knowledge of the data. Here, the HDN provides the contact information for the register keeper in each country. Yet it must be noted that the most experienced experts in the use of local register data can sometimes be found outside the organisations hosting the data sources. A successful comparative study requires networking between key experts and interactive (and always iterative) working process.

Electronic health records in Maccabi Healthcare could provide information on person-level health status and health determinants (i.e. smoking and body weight) whereas the databases in Estonia and Finland were based on less detailed abstractions of the patient administration systems. To increase the comparability of CVD incidence rates the researcher could perform the analysis adjusted or stratified by gender and age. Co-morbidities based on the patient's history of health care use could also be used as an adjustment. However, many important adjustment variables were not available. The data sources in Estonia and Finland lacked data necessary to evaluate properly the health needs of the study populations, i.e. data about health status (disability) and quality of life, as well as socio-economic and lifestyle health determinants.

In addition, due to lack of common service definitions and challenges arising from input price conversion meaningful comparison of cost between countries and over time was difficult. In the case study it was thus necessary to address many of the typical issues of comparability that are often encountered in such exercises. Table 2 presents broad categories of common issues of comparability: identification of the data generating process, data definition unification, cost and resource calculation and the implementation of proper risk adjustments. Table 2 also highlights how the HDN may provide assistance in tackling some of these problems.

**Table 2: Issues of data comparability**

<b>Issues of comparability</b>	<b>Example</b>	<b>HDN Solution</b>
<b>Identification of data generating process</b>	Data source: administrative systems or electronic health record?	HDN assessment of the usability and liability of each data source
<b>Data definitions</b>	Use of primary classifications: data specifications defined nationally by the authorities are not similar.	HDN assessments include information on classification, though not in detail.
<b>Comparisons of costs and resource use</b>	Prices or costs? Cost accounting methodology? Cost items included?	HDN informs about resource data but costing descriptions not available at detailed level
<b>Stratification/Risk adjustments</b>	Ensuring comparability in cost and outcome comparisons	HDN may offer rough guidance on the data available for standardisation based on sex, age, diagnoses.

*Source: EuroREACH 2012*

The diabetes case study showed that by using national registries it was possible to calculate and compare several important performance indicators between the countries. The methodology seemed promising, but the comparability issues to be solved were many and the process quite demanding and time-consuming, even for the experienced experts undertaking the study. Thus one important challenge for the HDN is how to aid researchers interested in cross-country evaluations to avoid unnecessary phases, to give guidance, to point towards potential collaborators, and to help resolve the numerous questions arising in the course of the study.

The example from the case study showed that international performance assessment requires sufficiently detailed data specifications to generate standardized data sets and assuring comparability may depend on the detail and extent of information available. In the future, important supplementary sources of data could be sought from electronic health

records, personal health records and databanks providing gene and phenotype information. The key will be the extent to which internationally agreed standard definitions and classifications are in place (see recommendations by the World Economic Forum, 2011).

## **Potential new data sources for international comparative performance assessment**

While national registers provide rich sources of data for performance comparisons, there are other potentially interesting collections of information: electronic health records (EHR), personal health records (PHR) and gene/biobank data repositories. Below, the relevant features and potential benefits of EHRs, PHRs and gene/biobanks are discussed.

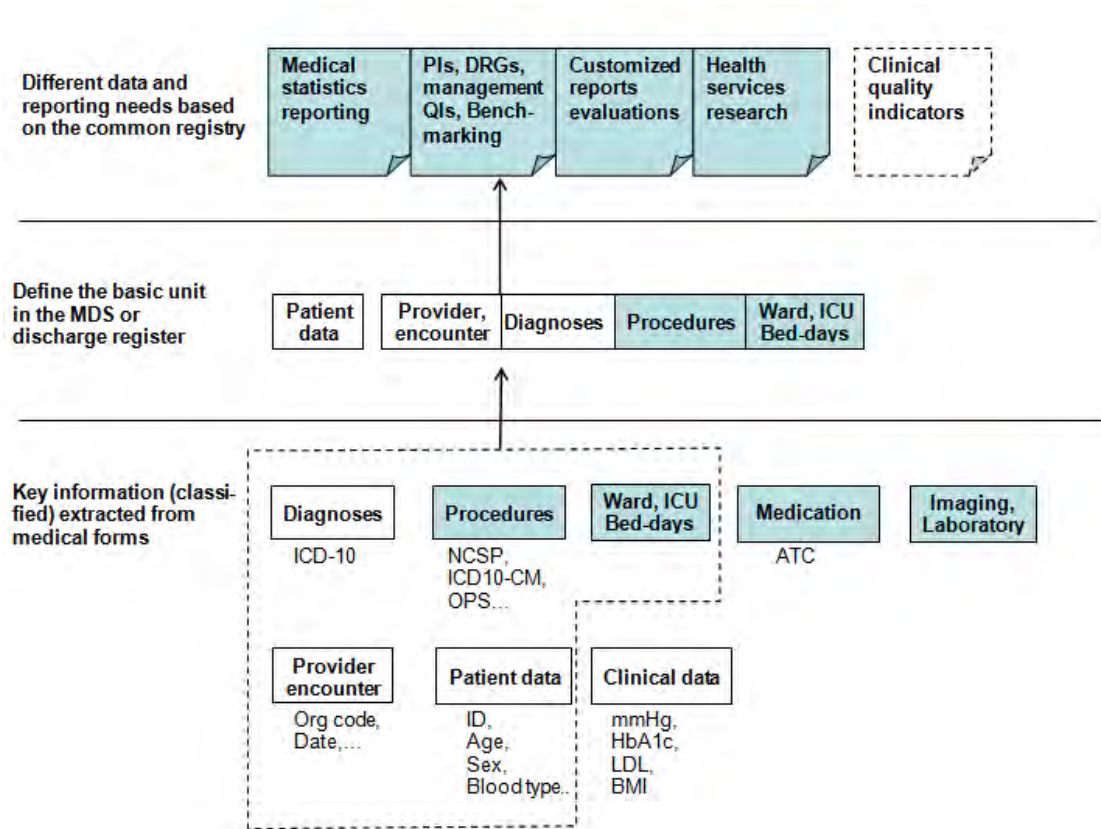
### **Electronic health records (EHR)**

Many relevant clinical variables are missing in national-level register data, main and secondary diagnoses may be recorded poorly and the administrative databases lack the data on medication and allergies, immunization status, laboratory test results, radiology images and other classified data typically found in EHRs. Medical personnel are responsible for feeding in the key medical record information (age, sex, primary and secondary diagnoses) in the health care unit's system. After discharging the patient, the unit's data administration may merge datasets from several systems (e.g. the procedures from the operating room information technology systems, systems for medical diagnostics, patient administration systems for the wards, outpatient records) to create a standardized discharge abstract. As illustrated in the Figure 5, national discharge registries and medical statistics are based on restricted information compared to the full set of data elements in the EHR. The typical data contents in national discharge registries could be developed to include a more complete set of clinical measurements. In many countries e.g. in Finland, nationally or regionally collected EHRs are used as the basis for developing integrated data warehouses that serve various information needs.

### **Personal health records (PHR)**

It is also important to recognize that, for interpreting data on quality of care and performance of providers or health systems in the treatment of most chronic diseases (including diabetes), the patient-related factors, especially adherence to treatment and lifestyle changes, are at least as important as proper use of medical interventions and services. Until now this important information have been mostly lacking in the national data registries (although surveys may contain some lifestyle or compliance related data) but emerging technologies already make it easier to collect and use relevant patient specific measurements that are recorded outside the healthcare provider organizations. Personal health records (PHRs) therefore offer new potential for performance comparisons; the co-production of services and co-creation of value (health outcomes) may contribute significantly to the understanding of observed differences in various aspects of health care performance. However, since the implementation and use of PHRs is in infancy, still variable and contents are not yet standardized, currently this type of information source cannot be included in the HDN.

**Figure 5: Defining data contents and data structures for the Minimum Data Set (MDS) as basis for national discharge registry.**



ATC : Anatomical Therapeutic Chemical), BMI: Body Mass Index, HbA1: Glycosylated haemoglobin, ICD-10: International Statistical Classification of Diseases, version 10, LDL: Low-density lipoprotein, mmHg: Millimeter of mercury (a unit of pressure), NCSP: Nordic Classification of Surgical Procedures, OPS: Operationen- und Prozedurenschlüssel (surgery and procedure ratio)

Source: EuroREACH (Linna, Miika), 2012

### Geno- and phenotype data (e.g. biobanks)

Geno- and phenotype data may become increasingly important in linking disease progression to optimal treatment processes and clinical outcomes, e.g. cancer care. The data requirements of ‘personalized medicine’ will bring new challenges and areas to international comparisons and data administration, but also offer better opportunities to stratify cohorts and adjust risks at the patient level. For example, the outcome (and cost) comparisons in today’s oncology and preventive care may improve using data on patients’ geno- and phenotype (Epstein et al., 2010; Moyer et al., 2010; Goetz et al., 2005). In many countries the discussion on the organization and protocols of use of gene information has only started. However, in the future, proper performance comparisons may need the integration of EHRs, PHRs, administrative data and geno- and phenotype databanks.

## 6 Recommendations and outlook for improved access to health care data

The objective of this section is twofold. First, we summarize findings and key recommendations arising from the experience of the EuroREACH project. Second, we address areas of improvement for better access to health care data and highlight gaps where more data and information are needed to enhance comparative research in the area of health and health care. The role of the HDN as an operational prototype inventory offers crucial experience in this context.

### Key recommendation for the use of the Health Data Navigator

- Resources such as the HDN act as important mechanisms for avoiding duplication of work, which researchers interested in analyzing the performance of health systems for particular diseases, population groups or settings are advised to interrogate before embarking on studies.
- The HDN allows the identification not only of relevant international and national databases but also of all relevant EU projects that used certain types of methodology, such as surveys or registry data. For information already collected and processed by others, this resource can obviate considerable time-consuming research.
- The comprehensive nature of the HDN database allows identification of gaps in available data. New projects should wherever appropriate build on the resources created by previous projects, possibly even through collaborative research agreements with those projects and studies. An example of this is EUNICE (the European Network for Indicators on Cancer), which uses survival data collection through cooperation with the EURO CARE project and indicators defined by ECHI (with input from EUROCHIP).
- By documenting contact points for comparative data projects, the HDN assists with finding potential collaborators for cross-country research, in particular when person-level data are used. Even though comparability issues were challenging, the EuroREACH case study on diabetes care showed that use of a consistent methodology and national registries permitted calculation and comparison of several important performance indicators.
- Data mapping in the HDN can be easily extended to other countries as the architecture of the HDN website is clear but flexible, and permits further development through defined reporting standards. A fundamental challenge common to many projects and initiatives in health care is the issue of sustainability. This is partly due to the time-limited construction of the projects and partly to lack of funding. Initiatives such as the HDN can act as a resource for sustaining interest beyond the formal lifetime of projects.

## Future potential of the Health Data Navigator

- We believe that the EuroREACH project has demonstrated the operational feasibility and usefulness of the HDN, and that the HDN should be maintained and developed further. Good communication of data availability is crucial in order to maximise the benefits of comparative information, particularly in light of rapidly increasing IT capacity. Access to international and national databases should be simplified for both researchers and the general public. It is important to provide a platform such as the HDN that is user friendly and addresses the needs of users in terms of exporting data, access to charts, maps, briefs, etc. The HDN can enhance the use of administrative databases that are rich sources of information but are often underused. Data are often collected for the management purposes of one institution and access for researchers and other institutions can be quite difficult. Centralised data management – which should not be confused with centralised ownership of data – can help satisfy the data needs of different institutions and researchers.
- The HDN should become an important inventory of validated and accessible information relating to data management, including data protection, especially in light of the increasing availability of person-level data. Although access to data should be extended to the widest possible group of appropriate users, safeguards to ensure the privacy of subjects is essential. These include strict review and data use agreements, limitations on access to identified data, preparation of de-identified or encrypted datasets for outside researchers, and prohibitions on publications of identified data by researchers.
- The HDN could promote the transparency of definitions of indicators, data sources and methods. International databases often use different definitions, sources and methodologies for the same indicator. For the user, it is essential to find easily the sources and methods used in the database. This will improve the reliability of cross-country comparisons. A good example is the OECD HCQI project, supported by the Commonwealth Fund and the Nordic Council, which has developed a set of quality indicators that have been validated by an increasing number of countries.
- The HDN offers a vehicle for supporting the development of comprehensive linked data systems. Such projects entail a considerable investment in researcher time and information technology, but they also require coordination and cooperation between the many data custodians in the private and public sector. Central funding of activities required for the development and maintenance of linked datasets can lessen the burden on organizations collecting data, improve the potential for cooperation, and reduce the cost of research.

## Where we need more information that could be also featured on the HDN

- While important initiatives are under way or already established, such as the Eurobarometer Surveys, data on health care quality are scarce both at national level and for international comparisons. In particular, investment is necessary to improve data on effective care pathways, on patient experience, on disparities in care utilisation as well as costs of care.
  - With a growing number of patients suffering chronic and multiple health problems, it becomes increasingly important to identify effective care pathways for improving system performance. This requires following patients in the health system with linked data from different providers and sectors (hospital, ambulatory care, pharmaceuticals etc.). The EuroREACH case study evaluating diabetes care is an important starting point in this context.
  - Patient feedback is essential for improving health care provision, but data on patient experience are weak in many countries. At the European level, mandating patient surveys using common measures is necessary to guide regular and comparable collection of data.
  - Information on the disparities in health care utilisation by different socio-economic and age groups as well as by gender, within and across European countries, is scarce and fragmented. Collection of improved data on health care consumption by different population groups should be supported, either through enhanced use of existing surveys or through new survey instruments.
  - Information on health care costs and health expenditure for particular services and goods is often limited in scope and comparability, even though important efforts are made in this context, such as the joint data collection on health care expenditure coordinated by OECD, WHO and European Commission. At a national level, data on costs of healthcare providers, healthcare expenditure by different socio-economic groups and by disease are often particularly difficult to obtain for research purposes. Data governance and ownership plays a crucial role here. Improving the transparency of these data is necessary for a better understanding of health system performance and efficiency.



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