

The role of HIS/HES/DIS[1] for measuring the health dimension

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Abstract

The availability of representative population-based health data is a prerequisite for identifying public health problems. Rather than basing their health policies on health determinants, most countries continue to rely on mortality figures and service-based data due to the lack of data for many key health indicators. A National Health Information System (NHIS) integrates health data from various sources, such as vital registration, health care service utilisation and survey data.

Postal questionnaire surveys and health/disability interview surveys (HIS/DIS) are an essential part of NHIS. They provide information e.g. on diseases and conditions not requiring contact to health care system, self-rated health, opinions, experiences, and health behaviour. Health examination surveys (HES) are used to gather information on clinical measurements and diseases and medical conditions diagnosed by health care professionals. These kinds of surveys face problems related to sampling, inclusion/exclusion criteria, reporting bias and low response rates. Cultural differences in questioning and answering affect international comparisons.

The advantage of HIS/DIS/HES surveys is the combination of measured health status, self-reported health determinants and socio-economic conditions. This allows in-depth analysis with personal level data to estimate distributions and inequalities between various sub-populations.

Keywords: Disability survey (DIS), Health examination survey (HES), Health interview survey (HIS), National Health Information System (NHIS)

1. Introduction

The existence of high level Health Information is essential to good governance. Therefore, the Health Information System (HIS) has a central function in the health system by feeding into all its components. Decision makers need a systematic way of increasing their capacity to access and synthesise the growing volume of information, which is part of contemporary Public Health (WHO 2000, RIVM 2004, Peticrew et al. 2004, LÖGD 2003, Gissler et al. 2005).

Reliable and timely information is necessary at facility, local, sub-national and national levels, in order to respond to rapidly-evolving health needs, to design and monitor policies and health care reforms, to evaluate the impact of services, and to define budget priorities. The HIS can be defined as a dynamic and flexible infrastructure for the monitoring of health activities and population health outcomes that is active at the national or sub-national level, and it includes the collection, analysis, storage, transmission, display, dissemination, and further utilisation of data and information from complementary sources. The goal of the HIS is to allow all professional and lay users within and outside the health sector to use, interpret and share information in order to transform it into knowledge.

National Health Information Systems (NHIS) face several challenges if they are to become a comprehensive platform for information exchange, and a real instrument for decision making (WHO 2000).

First, NHIS are often built on traditional data collections that reflect old public health problems and past health care structures. Public Health Monitoring and Reporting still consists mainly of lengthy statistical tables with little or no interpretation of the data for the users, which may explain much of the under-use of often plethoric data collected without a clear purpose. NHIS should define themselves in the continuum of flexibility (being more responsive to new information needs) vs. stability, since their strength lies in their sustainability and the availability of time series.

Second, health planners and politicians are not the only users of health information. Advocacy groups, researchers, and media reporters - also from other countries - are increasingly interested in accurate and reliable data on health and health-related issues. These users may have conflicting needs, for example pushing for 'vertical' programme-specific data collection, which often duplicates and overloads existing routine systems operating 'horizontally' across all areas of the health system.

Third, despite the wide availability of advanced information technologies (IT), NHIS may appear to lag behind the systems of private industries. This is in part explained by the specific characteristics of the health system: the complexity of the data, the specific rules that the health sector must comply with compared to conventional market goods and services, the lack of recognition of information as a full area of the health system (including financially), and the weight of traditional processes in Public Health Monitoring as well as scientific and other reporting. Furthermore, competitive interests and the current distribution of responsibilities result in fragmented data and databases that do not communicate easily, leading to biases and duplications. An illustration of the growing fragmentation of NHIS is the participation of the private health sector, which most often remains sporadic. Effective tools for the geographical representation of data are insufficiently used. In recent years, the increased awareness of confidentiality and privacy issues has led to a tightening of the legislation on data protection in conflict with increasing health information needs and the developments in IT.

Yet the principal problem is the lack of relevance and timeliness of the information to decision-makers and to the political agenda. The major aim of public health policies is to improve and maintain the health of citizens. These policies have to be based on reliable information drawn from relevant data and comparable indicators. Relevant health indicators enable correctly targeted policy measures and assessing their impact (Kilpeläinen et al. 2012).

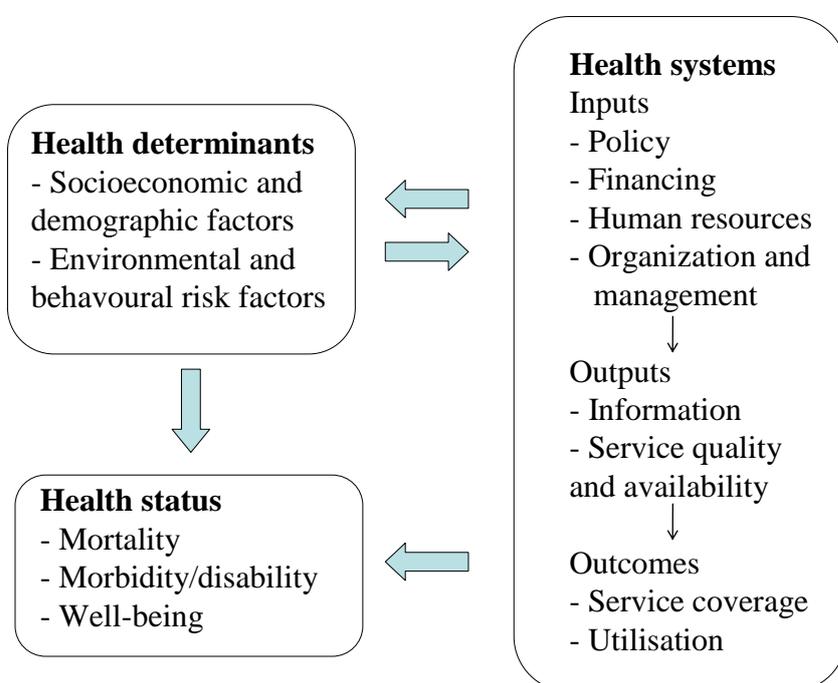
The availability of representative population-based health data is a prerequisite for identifying public health problems, health indicators have to be comparable between points in time, countries and areas to support planning and policy needs (Kilpeläinen et al. 2012). Rather than basing their health policies on health

determinants, most countries continue to rely on mortality figures and service-based data due to the lack of data for many key health indicators.

An NHIS integrates health data from various sources, such as vital registration, health care service utilisation and survey data. Internationally, causes-of-death data remain to be the most complete and comparable statistics. Data on hospital discharges have been collected for a long time, increasingly completed with data on surgical procedures and hospital outpatient visits. Information on primary health care has been scarce, but data on prescribed medicine and primary health visits are increasingly collected. These data, however, are based on utilisation of health care services, and they do not provide a complete picture on health status. Therefore, surveys are necessary to gather more detailed information on population health and its determinants.

2. Surveys as a part of NHIS

Figure 1: Measurement in National Health Information System according to WHO Health Metrics Network



The NHIS consists of information on health systems, health determinants and health status (Figure 1). Statistical and register data are routinely collected on inputs, outputs and outcomes within health care system. Information on health status is also routinely collected, but its coverage is usually limited. Data are collected on all deaths and their causes, but data on morbidity usually cover only some major diseases and medical conditions, such as cancers, infectious diseases and congenital anomalies. Otherwise, data on health status and health determinants have to be collected by other means.

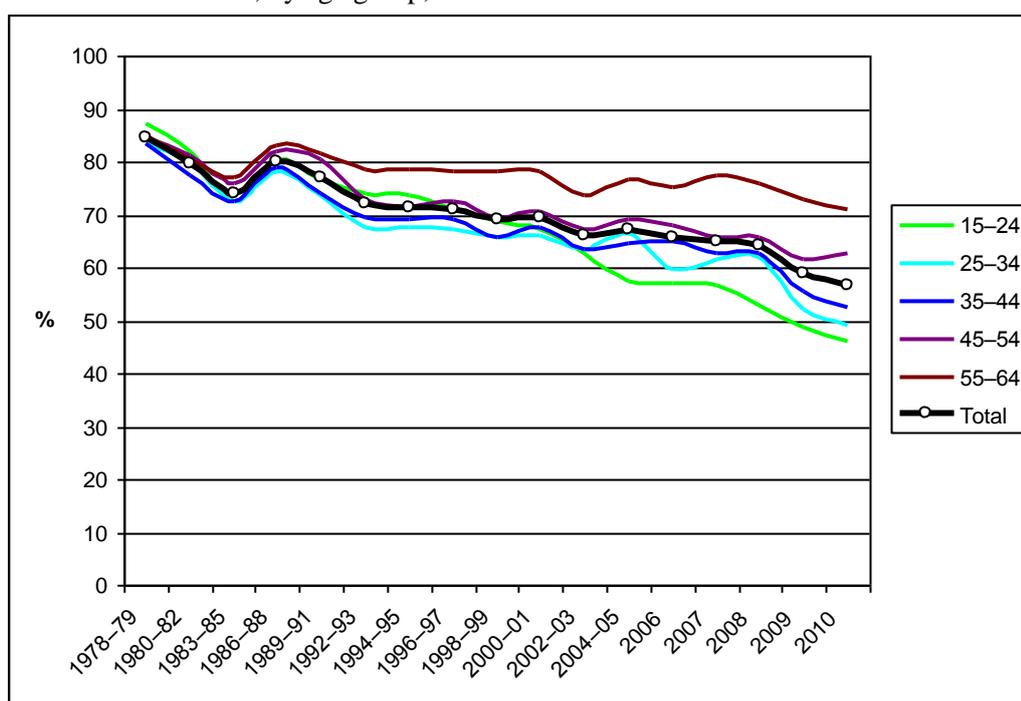
Postal questionnaire surveys and health/disability interview surveys (HIS/DIS) are an essential part of health information system, since they provide information on general population level for example on diseases and conditions not requiring contact to health care system, self-rated health, opinions, experiences, and health behaviour. The advantage of HIS/HES surveys is the combination of measured health status, self-reported health determinants, and socio-economic conditions. This allows in-depth analysis with personal level data in estimating incidences, prevalences, distributions and inequalities between various sub-populations. Similar analysis can be performed in countries, which have a register-based NHIS and unique personal identifier code, but it may take a long time to get the permission and the data for data linkages, and the process may turn out to be expensive. In some countries strict regulations and rules on confidentiality and privacy may hinder such exercises impossible, which make surveys the only way to gather this kind of data.

Health and disability surveys face problems related to sampling and variation in inclusion/exclusion criteria. Samples are usually taken in non-institutionalised population, which underestimates morbidity and disability in the target population especially among the elderly and people with disability. Also (recent) migrants may be excluded, if they are not (yet) included address or population registers, which are used to take the samples. The same may also be true for ethnical minorities, if the survey is not adjusted for their culture and/or language.

As for every survey, reporting bias may affect the results. For health surveys, the respondents may report their behaviour as better than it is in fact. A good example is self-reported weight and height (Gissler 2003). According to the Finnish Health Behaviour among Adult Population in 2000, 11% of men aged 35–64 years and 14% of women in the same age group were obese with a body mass index of 30 or more (weight in kilos per squared height in metres). The Health 2000- Health Examination Survey collected the same year revealed, however, that the real obesity rates based on clinical measurements were 96% higher among men and 64% among women, respectively. Men tend to report themselves taller and women thinner than they actually are.

Data collection based on surveys faces declining participation rates. The participation rates in epidemiological studies have declined approximately 1% per year over the last decades from 80% to 30% in many countries (Nohr et al. 2006). In general, a low response rate may increase the risk of respondents being systematically different from non-respondents, and thus, increasing the chance that the results do not reflect the study population (Hohwü et al. 2013). For example the Finnish Health Behaviour among Adult Population Survey had high response rates (83% for men and 84% for women) in 1978–1979, but decreased to 48% and 57%, respectively in 2010 (Figure 2). For men aged 15–34 years, the response rates are already less than 40%, hampering the generalisation of results. Monetary or lottery incentives may increase the response rates and they can be used to improve the representativity of the participants, but not always successfully (Hohwü et al. 2013, Griffin et al 2011, Edwards et al. 2009, Wilson et al. 2010, Gates et al. 2009, Ulrich et al. 2005, Olsen et al. 2012). Also the use of internet instead of paper-based data collection has given mixed results (Hohwü et al. 2013, Kongsved et al. 2007, Wyrick and Bond 2011).

Figure 2: Participation rates in the Finnish Health Behaviour among Adult Population Survey from 1978–1979 and 2010, by age group, both sexes.



Cultural differences in questioning and answering affect international comparisons. An example is the proportion of people responding their health as good. In Finland, two out of three respondents rated their health as good, while the proportion was one out of three in the three Baltic countries: Estonia, Latvia and Lithuania (Kasmel et al. 2004). Cultural differences in responding may explain this phenomenon, since the proportions of respondents rating their health as bad are quite similar: 8% in Finland, 10% in Estonia and Lithuania and 13% in Latvia. For historical reasons, respondents in the Baltic countries seem to rate their health as average much more often than the Finnish respondents do.

3. Health examination surveys

The first national health examination surveys (HES) in Europe were carried out in the late 1950s and early 1960s in Romania, Finland and Sweden. Since 2000 there has been a fast increasing number of new national HESs in Europe, and e.g. Croatia, Czech Republic, Poland, Spain, Denmark, Italy and France have initiated a national HES study. Some countries have conducted a national survey in regular intervals, but some others have performed their HES as an isolated survey. Finland has a long history of ongoing HESs. The Mobile Clinic of Social Insurance Institution examined adult population in 1966–1972 and since then the FINRISKI Survey (every five years since 1972), the Mini-Finland Health Survey (1978–1980) and Health 2000 Survey (2000–2001 with a follow-up survey in 2011) have been carried out.

The ultimate strength of HES is that the data are not based on self-reports only, but on clinical measurements and diseases and medical conditions diagnosed by health care professionals, as the example of obesity rates in Finland showed. The main limitation is their high costs. The Joint Action for European HES (EHES) estimated that the collection of a pilot sample of 350 and a final sample of 4000 would cost some 800 000 € for each country (EHES 2013). The European HES is being piloted in 12 countries (Czech Republic, Finland, Germany, Greece, Italy, Malta, the Netherlands, Norway, Poland, Portugal, Slovakia and the United Kingdom/England), but there is currently no funding for a full-size sample at European level.

4. Conclusions

HIS/HES/DISs are an important part of NHIS. Budget cuts and falling participation rates are the main challenges that health and disability interview and health examination surveys are facing. International collaboration is required to harmonise the survey methods and questionnaires in order to enable comparisons of survey data between countries.

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