

# Data Needs in Studies on Equity in Health and Access to Care

## *Ethical Considerations*

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In order to study equity in health and access to care in an appropriate way, data are needed on an individual level and must include information about health, mortality, morbidity, utilization of care, age, sex, residential area, family situation and the social and economic circumstances of each individual. These data must be collected at several points of time during a life cycle. This is a demanding task requiring many resources and methodological and ethical considerations. The ethical and political trade-off is between our demand for knowledge and a fair distribution of resources in order to achieve equity in health and access to care and the need to administrate sensitive data without threatening personal integrity. In presenting results from Swedish studies, it is argued that the benefits of using registers for this kind of epidemiological research by far outweigh the risk of using registers.

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Measuring a specific activity is one way of making it visible and emphasizing the importance of the task. This has long been a well-known fact among those involved in organizational processes (1, 2) or, in the words of Haire, 'Those parts of the work that are not considered important enough for regular measuring are easily disregarded' (2). This is also one of the ideas behind the process of data collection. Another is mankind striving for knowledge and understanding. Without knowledge it is difficult to take appropriate action in making good use of scarce resources.

The prerequisites for this analysis are based on well-known ethical principles established in the health legislation of many countries; namely, the right of all humans to live a healthy life and the right of equal access to medical care for equal need.

In order to assess whether these objectives are fulfilled, data on health and utilization of care are needed for different subgroups of the population. The data must have been continuously up-dated and individual-based if they are to be effective in health monitoring. According to these principles it is an ethical obligation that differentials in health and utilization of care are followed up and analysed. These benefits must, however, be valued against the potential risk that registered data on individuals are misused.

This article focuses on data need, problems in analysing health differentials and on presenting some empirical examples on how to tackle these problems with the use of register-based data.

### **DATA NEED**

Measuring health inequalities and inequity in access to medical care is an important step in the process of identifying problems for further actions and at a later stage in assessing those interventions. Data on morbidity and mortality for many diseases and aspects of health or ill-health must therefore be collected. On an individual basis, data on background characteristics and health conditions are needed, too. In general, important background characteristics are level of education, occupation, family situation, area of residence, living habits, and social and economic circumstances. Since living conditions change over time, these data are also needed at different time periods during the life cycle. Without this longitudinal approach the temporal relationship of the association between health and social conditions is not known.

### **DATA COLLECTION**

In order to answer questions on equity in health, equity in access to medical care and a fair distribution of resources,

two approaches to data collection can be taken. In one, appropriate methods for data collection and study design are chosen for each specific research question. The other approach is based on already available data in registers. There are advantages and disadvantages with both approaches. The register-based tradition, often applied in the Nordic countries, is usually cost-effective and examples on how this method can be used in the analysis of health differentials are presented.

Many health registers in Sweden and the other Nordic countries, e.g. the cause of death register, the cancer register, the medical birth register, the hospital discharge register, etc., are based on the total population of the country and include practically all deaths, cancer cases, births and all patients discharged from hospitals. From a research point of view, problems of sample size are minor and the bias from population or patient selection is relatively small. The use of a unique personal identification number facilitates the linking of information from different data sources. Information doesn't all have to be collected at one point in time. It is also possible to record linkage data from sources collected for different purposes.

The potential drawbacks of a register-based approach are the costs of data collection, the quality of routine-collected data and the trespass of privacy. The total costs of collection and registration of medical data are massive. However, it is necessary anyway to document data about the patient in medical records for adequate treatment. This means that the extra or marginal costs for managing a national register and providing a service to researchers are fairly moderate. The risk that the quality of routine-collected data may deteriorate cannot be dismissed; the continuous process of quality assurance is very important in this respect. The most important measure in maintaining consistently high quality data is the feedback of information. Those who collect and register data must be informed of their use and have easy access to them. The availability of data for research and statistical purposes must be first-rate. Keeping large databases with sensitive information on individuals is a great responsibility that demands good legal and technical protection. Experiences from Sweden and the other Nordic countries of handling large national registers is so far very good. After decades of administering these registers there is not a single known case of misuse at the central level. However, the issue of administering national epidemiological registers has to be continuously under scrutiny.

## METHODOLOGICAL PROBLEMS

Some of the methodological problems in analysing this kind of issues are:

- the situation for socio-economic groups varies over time;
- many disadvantaged groups have small sample sizes;
- disadvantaged groups are more often non-responders;
- there is a lack of repeat measurements on the same individuals; i.e. a longitudinal approach;
- identifying the population at risk can be a problem;
- identifying needs of care is a problem.

Data on the individual's background characteristics are a prerequisite for studies on health inequalities. The availability of data of this kind is still limited in most countries, and the indicators used are usually of little value in identifying the 'real' problems and causes behind the health differentials found. The socio-economic classifications used give only a broad picture of social status, i.e. educational and occupational status, and the consequences vary depending on conditions during childhood and adolescence, family situation as a grown up, geographical area of residence, social network, sex and age, and the kind of society the subject lives in. A study from Finland shows, for example, that the present socio-economic classification system is not as discriminating for women as for men (3). For women, being a single mother is probably more troublesome for future health than socio-economic status.

In attempting to identify problems and causes of inequalities in health, we need data on many subgroups of the population, which means problems concerning sample sizes and response rates, particularly in dealing with interview surveys. In research based on national population registers, sample size is not really a problem. However, the fact that socially and economically disadvantaged groups are more often non-responders is a real problem in all kinds of research.

Since the social and economic situations of an individual change throughout life's course, it is important to measure at several points during the life-span. Repeated measurement is also important in order to identify the temporal relationships between social conditions and health. Do poor social conditions constitute bad health or vice versa?

Two other problems are how to identify the denominator in an appropriate way and how to identify needs of care. The relative risks for different socio-economic groups are dependent on the population at risk. To estimate population at risk is not always easy, as is illustrated with an example later. Identifying needs of care has received much attention from researchers and planners during recent decades. Allocating more resources to deprived areas with more health problems is one way of tackling inequalities in health. Another reason for identifying needs of care is in connection with the problem of analysing equity in access to care. Many studies focus only on the utilization of care, irrespective of health status and needs of care. The central issue, however, is that utilization of care is in accordance with needs.

This brief analysis of methodological problems leads to the following conclusions about data need in studies on inequalities in health and equity of access to care. We need a wider range of socio-economic indicators that are followed-up continuously; those indicators must be measured at different time intervals; efforts must be made to estimate the population at risk properly and to identify needs of care. These arguments are illustrated with practical examples from using epidemiological registers in Sweden.

#### **A WIDER RANGE OF SOCIO-ECONOMIC INDICATORS**

In spite of the fact that mortality is highest in the case of the non-working population, the systems for classifying socio-economic indicators are usually focused on the workforce, thus creating a problem for our attempts to identify vulnerable groups most in need of support. More than 15% of the Swedish population belonged to the non-workforce in the mid-1980s and the figures have increased during the last decade. This is a heterogeneous group comprising students, housewives, early retired, unemployed, etc., each category requiring its own analysis and causal explanations.

In times of rapid societal change, the groups most in need of support will vary over time. In the past, the elderly in Sweden have lived under poorer living conditions than other groups in society, but in the past decade their economic situation has improved substantially due to the impact of better pensions (4). The economic situation of young people on the contrary has deteriorated during the last 10 years. These societal changes could have health consequences in the future.

As a consequence of our interest in identifying socially disadvantaged groups in society, we must measure a wider range of socio-economic indicators, and not just professionals or manual workers. Important and potentially vulnerable groups to follow-up are, for example, those who need social benefits, have long-term sick leave, are early retired, unemployed, immigrants or have psychiatric disorders or impairment. Other studies have shown that people living alone have more health problems. During recent years, single mothers in particular have been identified as a group with a risky lifestyle and suffer from more ill-health (5).

#### **EXCESS MORTALITY AMONG SINGLE MOTHERS**

In an ongoing study, we have preliminary results showing that single mothers with children below the age of 15 have an excess mortality in most causes of death compared to cohabitant mothers (Ringbäck et al., pers comm). For all causes of death the standardized mortality rate ratio is 1.6 and it is particularly pronounced for respiratory diseases, suicides and assaults/homicides and alcohol-related diseases.

#### **AVOIDABLE MORTALITY AMONG PSYCHIATRIC PATIENTS**

It is a well-known fact from many studies that psychiatric patients have an overall excess mortality compared to the general population (6, 7). This excess mortality is not just due to a higher mortality risk for psychiatric diagnoses and suicides, it is also evident for other causes of deaths, e.g. lifestyle behaviour related to smoking and/or alcohol abuse (7). Psychiatric patients are a vulnerable group who need specific attention and follow-up. Results from a study in the Stockholm area show that psychiatric patients also have an excess mortality in causes of death considered to be amenable to medical care, e.g. hypertension, stroke, diabetes, asthma, etc., and diagnoses possibly related to side effects of treatment with psychotropic drugs (7). This indicates that somatic problems among psychiatric patients are not dealt with appropriately by the health services. The psychiatric disorder may interfere with effective management. Deficiency in the perception of physical symptoms and a limited ability to communicate symptoms of illness may lead to a higher degree of untreated physical illness, and incapacity in taking medicines may influence the outcome of a disease. While warranting further attention from those responsible for psychiatric care, the study also supports the need to monitor health of vulnerable groups in the community.

#### **REPEATED MEASUREMENTS**

The situation for an individual changes throughout the life-cycle and so the necessity to measure social and economic situation as well as health status at different stages of a lifetime. In recent years much research interest has been devoted to circumstances of early life and how these may affect our health even as adults. Many studies show that poor social and economic conditions during childhood and adolescence increase the risk of adopting unhealthy behaviour, becoming ill, being unemployed or having a boring job, etc. The most likely explanation for the great social differences we see in ill health is that the risk factors accumulate during an individual's entire life. In order to understand the causal explanations behind social differences in health, we must therefore measure these conditions repeatedly. This longitudinal approach is the only way we will understand the temporal relationship between social conditions and health. Does unemployment cause ill-health or does ill-health lead to unemployment? Another reason behind the need for repeated measurement is the demand to measure long-time exposure. This could be illustrated by measuring the relationship between long-time occupational exposure and cancer risk.

## LONG-TIME OCCUPATIONAL EXPOSURE AND CANCER RISK

The risk of cancer in different occupational groups can be estimated by connecting data on the individual's occupation with cancer incidence, and one way of conducting such an analysis is to record-link the population census and the cancer register. This has been done regularly in Sweden over time with different censuses. One problem is that a single census measures the occupation at a specific time during the year of the census, and it is not then possible to obtain data on long-time job exposure. In order partly to overcome this problem, we record-linked two population censuses of 1960 and 1970 to the cancer register of 1971 to 1990 (8). By doing so, we created an indicator of long-time exposure, i.e. people who had the same occupation at 10-year intervals. The results from this analysis confirmed some risks and rejected others earlier formulated in the literature. For example, the associations between lip cancer and farmers and between lung cancer and miners, chimney workers and insulators were confirmed, while suspected risks between stomach cancer and plumbers and bladder cancer and dental technicians were rejected.

## ESTIMATING THE POPULATION AT RISK

In many studies, it is not easy to estimate the population at risk, i.e. the denominator, properly. This is a methodological problem that is more pronounced in the case of studies where the non-response rates could be high, e.g. in interview surveys. The problem exists even in register-based studies with a good follow-up system. For example, it is difficult to carry out fair comparisons of the mortality of different ethnic groups because of the fact that sizeable numbers of immigrants who subsequently leave their new homeland fail to register this fact with the national registration authorities. According to Nilsson, around 10% of non-Nordic immigrants may no longer be in Sweden even though they are registered there (9). The consequence of this problem is that the size of the immigrant population is overestimated and relative risks in terms of mortality are underestimated.

## MORTALITY AMONG IMMIGRANTS

In addressing the problem concerning the denominator, information about income and social benefits was used in a study to put together a population which could be more safely assumed not to have left the country (10). The results demonstrated that even after adjusting the denominator, non-Nordic immigrants in Sweden have a general mortality on a par with those born in Sweden. Persons born outside the Nordic countries run a smaller risk of dying of diabetes, ischaemic heart disease or alcohol-related diseases (10).

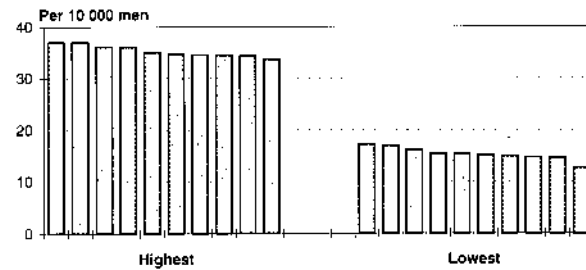


Fig. 1. Mortality from ischaemic heart disease 1992–1996 in municipalities of Sweden with the 10 highest and lowest rates. Deaths per 10000 population. Men. Age standardized rate ratios.

## IDENTIFYING NEEDS OF CARE

Identifying needs of care is a very tricky business, depending as it does on the health status of the population and also on whether there are preventive interventions or medical technologies available that can prevent or improve the prognosis of the disease. From an ethical point of view, it is important to develop tools that can allocate resources according to needs and can assess whether the target of equity in access to care is achieved. Two examples can illustrate the potential of trying to estimate needs.

## REGIONAL VARIATIONS IN HEALTH

With few exceptions, studies of geographical variations in health between or within countries have shown large differences in mortality or morbidity. Some attempts in Britain and Sweden have also used formulas for allocating resources according to needs. Mortality, utilization of care and socio-economic indicators have then be used as proxies for need. At our Centre for Epidemiology in Sweden, we have developed a computer-based statistical programme 'How are you Sweden?' with about 500 indicators of health and social conditions that can be displayed for all counties and municipalities in Sweden. This programme will soon be available on the Internet and reveals big variations in health. Mortality for ischaemic heart disease and alcohol-related deaths are 4- and 12-fold larger, respectively, in the municipalities with the highest standardized rate ratios than in those with the lowest rates (Figs. 1 and 2). Such variations are seldom considered in the

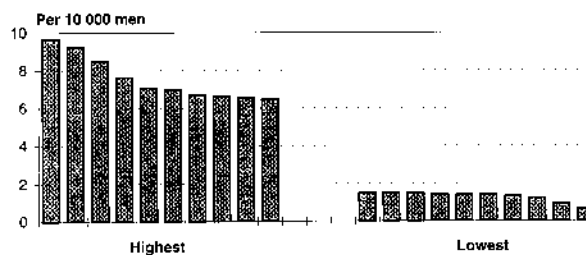


Fig. 2. Mortality from alcohol-related deaths 1992–1996 in municipalities of Sweden with the 10 highest and lowest rates. Deaths per 10000 population. Men. Age standardized rate ratios.

allocation of scarce resources, which is not in accordance with standard ethical principles. There are, of course, also several methodological problems inherent in studies of regional variations that must be considered before resources are allocated according to these regional variations.

### EQUITY IN ACCESS TO CARE

Equity in access to medical care for equal needs is a cornerstone in the Swedish Health Service Act of 1983. The crucial question, however, is how to estimate need of care in individuals. In interview surveys, long-standing illness or perceived good health can be used as proxies for need. Before the Seven Crowns Reform in 1970, which gave Swedish citizens the right to visit a doctor for seven Swedish crowns, utilization of care was not in accordance with need. Those most in need of care, e.g. low-educated people in poor health, visited doctors less often than well-educated people. After the reform in the mid-1970s, a shift in the distribution of utilized care towards equity in access to medical care took place. Less educated people visited doctors more often than well-educated people. After standardization for age and long-standing illness as a proxy for need, there were no differences in utilization of care between socio-economic groups (11). Since the mid-1970s we have, in broad terms, achieved the target of equity in access to medical care up to now. Recent studies indicate some alarming signals, however (12). A lower use in relation to health status among manual workers had developed by 1993–1994. Whether this is a temporary or more permanent change in utilization of care is open to debate. In the 1990s, occupational services, providing quite a lot of primary health care in Sweden, have experienced cuts and privatization. This is one likely factor behind the change, but might be temporary until our manual workers find other providers of outpatient care.

### CONCLUSIONS

In answering questions on equity in health, equity in access to medical care and a fair distribution of resources, different methods for data collection are possible. Results from studies in which a register-based approach has been taken are presented in this article. The potential drawbacks of a register-based approach are the high costs of data collection, the quality of routine-collected data and the trespass of privacy. It is argued that the marginal costs of administering national registers are modest and many studies have shown high quality and validity of collected data. The trespass of privacy is important to consider, and after long experience of using these registers in the Nordic countries, legal and technical protection, as well as administrative routine and regulation, are well developed. After decades of administering these registers, there is still not a single case of misuse.

Equity-oriented research from Sweden shows large socio-economic and geographic variations in health, but less pronounced differences in equity of access to care. The potential of using registers for this kind of epidemiological research, however, is far from wholly exploited.

It is obvious that for this kind of analysis data are needed on an individual level and that they must include data about health, mortality, morbidity, utilization of care, age, sex, residential area, family situation, lifestyle and social and economic circumstances for each individual. Furthermore, the data must be collected at several points of time during the life-cycle—indeed a demanding task requiring manifold resources and methodological and ethical considerations. The ethical and political trade-off is then between our demand for knowledge and a fair distribution of resources in order to achieve equity in health and access to care and the need to administer sensitive data without threatening personal integrity.

The need for data may be hampered by current debate on assumptions that registers threaten personal integrity. The conclusion from the analysis, however, is that the benefits by far outweigh the risks. It would be unethical not to use our knowledge.

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