

How to Maintain Good Quality Register Systems?

Como Manter Sistemas de Registo com Boa Qualidade?



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Good health information is essential for good governance and national health information systems have a central function in the health systems. Decision makers and health professionals need a systematic way of increasing their ability to access and synthesise the growing volume of information as a part of public health, clinical medicine and management of health care services. The availability of representative population-based health data is a prerequisite for identifying public health problems, for improving clinical outcomes and for building up a sustainable and equitable health care system.^{1,2}

A well-functioning health information system includes statistical information on health care services, but also detailed information from health surveys.³ Health interview and examination surveys are necessary to gather information on population health and its determinants as well as other health-related issues not covered by health care services.^{4,5}

The Nordic way

The management, organisation, planning, evaluation, control and protection of individuals as well as the identification, selection and enumeration of cases have been listed as relevant reasons to collect administrative health and welfare data.⁶

Record keeping has a long tradition in the Nordic countries. These five countries – Denmark, Iceland, Finland, Norway and Sweden – have based their health information systems on registers, which cover the total population. Examples of computerised health registers include national cancer registers (from the 1940s), registers on infectious diseases (from the 1950s), hospital discharge registers (from the 1960s), cause-of-death registers (from the 1960s), birth and birth defect registers (from the 1960s) and health care quality registers (from the 1990s). Nordic countries were also pioneers in moving from paper-based census to register-based census compiling all required information for example on education, income, socioeconomic position, housing and family background from existing administrative registers.

There is less registration in primary health care. All Nordic countries do have prescription registers, which were started in Denmark and Finland in the mid-1990s.⁷ Finland was the first Nordic country to initiate a nationwide primary health care register in 2011. This register includes all patients visiting public primary health care. The data collection includes also information on the visits, diagnoses, and interventions, but also height and weight as well as smoking status can be reported.⁸

The progress in social welfare registers has been much slower. The Nordic countries have registers on pensions, social benefits (such as sick leaves and social assistance), children taken into custody, and care in the social institutions (such as elderly care homes and institutions for people with intellectual disabilities). The register data on other social welfare care, especially on open, non-institutionalised care, is still non-existent.

There are several reasons why there is a strong register culture in the Nordic countries. First, there is a long tradition to collect public information: population statistics have been collected more than 250 years and health statistics also more than 150 years. One of the oldest health registers was on leprosy, started in 1856 in Norway.⁹

Second, unique personal identity codes were introduced early for all citizens and permanent residents: 1947 in Sweden, 1953 in Iceland, 1964 in Finland and Norway, and 1968 in Denmark. In general, the existence of personal identity codes and their use in the registers improves the completeness and quality of any statistics and expands the available information, for example on the aggregation of service utilisation. It also enables the more efficient secondary use of data for example in research. Finally, several data quality studies have shown the high quality of routinely collected registers.

Data protection

All Nordic countries have special legislation, which allows the collection of national health and social welfare registers without informed consent. The legislation also states that all public and private health care institutions and health

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care personnel have to report to the national registers. Authorities have to inform all citizens which kind of personal data is collected and stored and how these are used. Citizens have the right to check their personal data either at local level (hospitals and social welfare services) or national level (register keepers). The Nordic people have no right to remove their own data from national registers. In Sweden, however, people can use their right to get their complete personal identity code removed. A very important principle is that the register data must not be used in decision-making for a single registered person.

The Nordic data protection laws allow research use of register data. However, the rules applied for secondary use of register data in research are very strict. Each study will be carefully evaluated: the hypothesis has to be scientifically sound and the use of register can be allowed only if the study questions can be answered by using existing register data with good completeness and high quality. Even though the Nordic countries have the personal identity codes in their registers and data linkages between different data sources are technically easy, researchers can get only anonymised (no individual can be identified) or pseudonymised (the link between personal identity codes and study numbers are kept for example by the register keeper) data. Increasingly, the data are analysed in safe environments, and the researchers get only access to the data, but do not get a copy of it.

The General Data Protection Regulation (GDPR) on the protection of natural persons with regards to the processing of personal data and on the free movement of such data replaced the 1995 Data Protection Directive in May 2018¹⁰. Data processing can be done only with lawful basis, especially when dealing with sensitive information as health. The main principle is that the data subject gives consent to the processing of personal data for specific purpose(s). It is, however, possible to process health data without informed consent, if the processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller. These include health services, social welfare services and public health. Furthermore, statistics and scientific research have given specific status. Processing for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes is not considered to be incompatible with the initial purposes, as the Article 89 of the GDPR states.

The exemption for research is well accepted in the Nordic countries, and the administrative registers are widely used in research. The use of registers may face challenges, since the interpretation of data protection legislation and

rules varies by time and place, the process to get permission and the research data may be complicated and long, and data costs may be high. A further problem is the data sharing. The data are not freely moving within the EU countries, and it may be difficult or even impossible to send anonymised data to some countries, including United States and Australia.

How to maintain a good register-based health information system?

It may be a difficult task to build up a well-functioning health information system, and a good system may be destroyed with unwise decisions. Seven general prerequisites can be listed for a register-based information system:

1. The national legislation should allow collection of individual level data, either with or without informed consent. The GDPR does not hinder this.
2. Good infrastructure is required for registers. This includes enough qualified personnel with diverse background. Governments have to ensure sustainable funding for each register.
3. Systematic use of unique identifiers increases the completeness of data and increases the data quality.
4. Register data has to be evaluated and validated frequently. The content of any health register must be updated regularly to reflect the changes for example in the society, health care system and clinical practices.
5. The data providers, especially the clinicians and public health experts have to be interested in the data to ensure high quality data. Collaborating with hospital and health experts is more effective than naming and shaming for poor data.
6. Citizens have to trust the registers and their keepers. Most people trust authorities' capability to collect and store personal information¹¹. For health and medical institutions the share is 74%. This percentage is the highest in the Nordic countries (88 to 90%), but also in Portugal higher than the EU average (79%).
7. The possibility to use register information in scientific research increases the data usefulness and tends to improve its quality. The use of such administrative data in research is attractive, since the total study costs and the time spent on data collection can be reduced significantly. The use of sensitive health information in research is justifiable only when the studies serve widely acceptable aims and are designed and carried out to the highest possible standards of quality.

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