

DOI: 10.5327/Z1679443520191751014

Semi-plenary #14**INFORMATION SYSTEMS FOR OCCUPATIONAL HEALTH**Vilma Sousa Santana¹¹Institute of Collective Health, Federal University of Bahia, Salvador, Brazil. e-mail: <vilma@ufba.br>

As is endlessly repeated, we are living in the age of information. Indeed, this is a unique time in history. Never before there was so much knowledge, never before we had access to so many sources of data or spent so much time reading, listening to, watching news or looking for information about everything. And never before we were the target of parties interested in providing us information, counter-information or fake information to induce us to adopt behaviors useful to or profitable for someone else.

This explosion of information through different media is also a source of illness, mental distress, and even physical problems, such as musculoskeletal and eye diseases and disorders. Yet, well before the current explosion of media, information, data collection and processing, the search for useful knowledge to control epidemics has in John Snow's study of the cholera outbreak in London in 1854, one of the major and visionary examples. The Snow's study remains today as one of the Public Health pillars, particularly in Epidemiology. At that time, impregnated by miasma theory, unaware of the role of microorganisms, without computers or Internet, Snow used simple handwriting records and maps. However, he was plenty of curiosity, able to observe, reflect, and to use logic reasoning and intelligence, to succeed in controlling a lethal and transmissible pandemic, thus saving thousands of lives. More than 160 years later, epidemiology is acknowledged as a unique science essential to the knowledge on the causes of diseases, associated factors, interactions and confounding factors, as well as preventive policies and practices.

This epidemiological knowledge is not only resulting from research, but above all from strategic monitoring of health information, health determinants, associated factors and disorders, as well as on social responses, such as healthcare. All these aspects are embodied in systematic and continuous data collection. They allow us just as Snow did, learn, understand, predict and efficiently develop actions to prevent and avoid illness and suffering. Much more than a mere data monitoring, this process, known as surveillance, make feasible to accomplish its main purposes depending on the availability of information systems — not only for health.

The health information systems from social security institutions, responsible for granting compensation benefits, such as pension or disability leaves are the most popular data source for Occupational Health and Occupational Medicine worldwide. These information systems cover cases of general or work-related health problems, the use of services such as outpatient medical visits, hospital admissions and vaccination, among other several distinct data type. Nevertheless, records of exposures, such as hazards known to cause diseases, are of utmost value for healthcare providers, because they are required to comply with professional ethics: to employ all possible means for prevention when causes of diseases are known; to act before disease onset, avoiding the occurrence of new cases.

Almost all the information systems useful for Occupational Health in Brazil are under the responsibility of the Unified Health System — SUS (SUS Department of Informatics — DATASUS) and the Social Security. SUS enables public online access to anonymous databases, comprising a number of descriptors potentially useful for surveillance and research. Distinctively, the Social Security open data interface only allow plotting tables of aggregated data, which hinders the required treatment of variables for analysis. In addition, these data are limited to workers covered by occupational-related accident insurance and long-lasting severe work disability: 15 days at least, and for those who succeeded in having benefits granted. Therefore the use of Social Security database leads to expressive underestimations of morbidity indicators. In addition, data from the Work Accident Reports (CAT) the other Social Security information system are severely underreported.

However, the lack of exposures and associated factors records, i.e. the so-called determinants of health, might be worst problem. As in many countries, in Brazil employers are responsible for collecting data on occupational exposures. Workers, workplaces and job posts likely to be exposed to health hazards are targeted by specific regulatory standards. The underlying conflict of interest is obvious, and imply independent supervision and control mechanisms to ensure worker and workplace representativeness in the sampled data, and high quality (reliability and validity) of (eventually required) measurements and laboratory facilities compulsorily required, as occur in advanced countries. Moreover, while these data need to be part of the

annual and mandatory Environmental Hazard Prevention Program (PPRA) (Regulatory Norm No. 9), they are not incorporated into information systems or used for routine monitoring. They are merely presented to labor inspectorates, upon request, as proof of safety norms compliance. This is a concrete example of how a valuable process to produce information and intelligence to be used by occupational health teams practice, became useless.

Recent changes in the federal government organization — which resulted in the extinction of the Ministry of Labor and the Ministry of Social Security — can make the situation even worse. The eSocial, an ambitious and very much expected information system, presented as the solution to detect occupational exposed workers and unhealthy job posts (a requirement for special retirement conditions). However, little is known about its full implementation expected to occur this June, followed by the Social Security Occupational Profile (PPP) disappearance.

The SUS Information System for Notifiable Diseases (SINAN) has occupational exposures data, however, only for individual cases of notified work-related injuries or diseases. The development of occupational exposure matrices used to enhance, through projected estimates, measurements available only from a few sampled workers or job posts obtained by refined and expensive techniques — is hindered by the lack of knowledge about their methods and concepts. In addition to poor acceptance of many of those who advocate for better information needed for workers protection. The Asbestos and Health Effects Interdisciplinary Project team had access to quantitative air asbestos measurements at from an asbestos-containing product manufacturer from 1980 through 2015. After the data analysis, results were inconclusive given sampling selection problems and potential bias due to the aim at providing proof of compliance with safety norms and their historical over time changes.

Limited access to non-anonymous data is another problem faced by occupational health surveillance teams and researchers. In surveillance, this problem raises some odd situations. For instance, if a firm requests a list of all cases of diseases associated with carcinogenic substances used in its production process, to compensate potential victims, commonly the health surveillance authority is not able to provide these data. The reason why it happens, even when the firm provides the employees' identification data, is the limited access to non-anonymous databases. In other words, full names are not recorded or cases are not given a unique ID enabling tracking or locating workers exposed to hazards in the past knowing that many work-related diseases have very long latency and often occur during retirement. No records of similar situation were found in the literature of limited access of health surveillance agencies to identified data. Although narrow-scoped and circumscribed, this information should be known to be adequately managed, as it can lead to destitute victims of their rights, which is unfair.

The restrictions to researchers access to non-anonymous data are also difficult to understand. They limit the combination of multiple data sources, thus reducing underreporting and making it possible to achieving more precise estimates of epidemiological indicators. There are no reports of misuse of non-anonymous data by investigators, who might comply with Brazilian rigorous ethics in research requirements. Linking databases and granting access to anonymized merged databases by public institutions to researchers have been pointed out as a way out. This would be, indeed, a solution in research grounds, and there are already some successful experiences reported. Hopefully it will become widespread soon overcoming this hindrance to the advance of science in Brazil.

Finally, it is worth mention the extraordinary advance that the addition of work-related injuries and diseases into SINAN represents; and as well the inclusion in death certificates of data on “work-related injury”. These initiatives resulted from long and intense efforts of many social actors committed to the consolidation of Occupational Health within SUS over decades. We hope they will continue struggling for to extend these achievements to other equally relevant work-related diseases, as for cancer in particular, which is the most frequent among them in other regions. This is the case in countries much ahead of us in terms of detection and reporting of cases based on adequate health information systems. Will it be our own future?

REFERENCES

1. Santana VS et al. Projeto Interdisciplinar de Pesquisa sobre a Exposição Ocupacional ao Asbesto e seus Efeitos na Saúde – Relatório de Pesquisa Fev/2019. Instituto de Saúde Coletiva, Universidade Federal da Bahia e Fundacentro-SP. 2019, 156 pp.