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### Registries of occupational diseases and their use for preventive policy

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# **Chapter 1**

## **Introduction**

## Historical introduction

The history of occupational diseases goes back to antiquity, and advances in understanding work and disease paralleled the social and technical development of mankind (1). The impact of work on health can be traced to the *Edwin Smith Surgical Papyrus*, which was written in approximately 1700 BC (2). Some of the neurosurgical and orthopaedic cases discussed in the *Papyrus* probably resulted from construction injuries from the age of the Egyptian pyramids. Although Hippocrates (ca. 460-377 BC) emphasizes the relation between the environment (air and water) and health, he has less to say about work and health, except for the military work environment, probably because of the denigration of manual labour in ancient Greece. In the Roman age, Galen (ca. 129-200) wrote about visits to mines and recorded his observations of workers who were exposed to acid mists (3). Paracelsus and Agricola – two prominent figures of the 16<sup>th</sup> century – both had an interest in mining and health. Agricola (aka Georgius Bauer, 1494-1555) is best known as the author of *De Re Metallica*. Paracelsus (aka Theophrastus Bombastus von Hohenheim, 1493-1541) describes dyspnoea and cachexia from mining in his monograph on the occupational diseases of miners and other workers, *Von den Bergsucht und andere Bergkrankheiten* ('Phthisis and Other Diseases of Miners').

Bernardo Ramazzini (1633-1714) is often recognized as the father of occupational medicine and is quintessentially known for the admonition to physicians to ask one more question in addition to those recommended by Hippocrates: 'What is your occupation' (3). Ramazzini visited workers and workplaces and assembled his observations in a book *De Morbis Artificum Diatriba*, which was first published in 1700 and revised in 1713, shortly before his death.

The emergence of public health movements in several Western countries in the 18<sup>th</sup> and 19<sup>th</sup> centuries focused attention on the abominable conditions in many factories and on the living conditions, poor nutrition, high stress, poverty and ill health of the new factory working class. In the 19<sup>th</sup> and 20<sup>th</sup> centuries, social legislation and economic progress led to substantial improvements in living and working conditions in Western societies. Whereas the old sectors of mining and industry predominantly caused such classic occupational diseases as poisoning, in the last decades of the 20<sup>th</sup> century a growing number of people went to work in the services provision sector, which led to other patterns of occupational diseases such as musculoskeletal diseases and mental health disorders.

## **Occupational diseases: the magnitude of the problem**

The annual number of employees with a non-fatal occupational disease – such as occupational asthma, noise-induced hearing loss or low-back pain resulting from heavy lifting – has been estimated to be 160 million at a global scale (4). Furthermore, it is estimated that each year some 2 million men and women lose their lives through occupational accidents and work-related diseases, such as occupational cancer and pneumoconiosis (4). This burden could be substantially reduced through the application of evidence-based risk-prevention strategies (5).

Although the working conditions in the Western and Central European region (the research area for this thesis) are fairly good compared to other regions of the world, mortality and morbidity rates due to occupational risk factors are still high. For example, the burden of disease due to occupational exposure to airborne particulates in Europe has been calculated as 259,000 DALYs, which is comparable to other parts of the world (6). Occupational diseases often result in serious personal suffering and the social consequences can range from sickness absence, unemployment, loss of income for the worker and the family, and the disturbance of family relations, to psychological and physical problems (7). In addition, the economic impact of occupational diseases is enormous, on both the company and the national level. Estimates of the economic costs of occupational diseases for the EU countries in 1999 range from 2.6% to 3.8% of GNP. This indicates a total cost of between €185 billion and €270 billion for the EU as a whole (8).

The EU has made the ongoing reduction in the incidence of occupational illnesses one of the prime objectives of the Community strategy on health and safety for the period 2007-2012 (9). Several countries have drafted national strategies to reduce the incidence of occupational diseases. For example, the UK government formulated a ten-year strategy – the so-called government health and safety targets – to reduce the incidence of occupational diseases and injuries (10). A national strategy requires a reliable monitoring system to evaluate the incidence and distribution of occupational diseases over time in order to develop well-targeted prevention programmes and to evaluate their effectiveness. Moreover, according to ILO Convention C155 (1981), all countries should maintain a registration system that is capable of providing information to policy makers (11). Before discussing the use of registries for preventive policy, however, we shall discuss the role of several stakeholders in the prevention of occupational diseases.

## **Prevention of occupational diseases: different stakeholders**

As both the incidence and the prevalence of occupational diseases are still high, there are strong health, social and economic reasons to improve prevention. However, there are several difficulties in developing and implementing preventive policies. One important complication lies in the fact that there are different stakeholders – employers, employees, occupational health services, governmental bodies, insurance companies, etc. – which necessitates discussions about which party should take the initiative for preventive activities or which party should pay for the different aspects of prevention or for the financial consequences of occupational diseases. In the first instance, employers are held responsible for working conditions; however, employees can be considered more or less responsible for their own behaviour when working in hazardous situations. Sometimes the risks are shifted to insurance companies. The government has the responsibility for legal regulations with respect to working conditions and workers' compensation schemes, whereas occupational health professionals are responsible for giving appropriate advice to companies and employees. As can be expected, these interests do not always match. For example, whereas employers are interested in preventing liability claims in order to reduce their costs, organizations that represent the interests of employees can have an interest in liability claims in order to put the prevention of occupational diseases on the political agenda.

According to Verma et al., the prevention of occupational diseases can take place at the societal level and the workplace level, and the information needs of these two levels are different (12). At the societal or national level, control measures are usually implemented through regulatory actions and national policy. Information is needed about the incidence of occupational diseases in branches and occupations, about the consequences and costs, and about new risks. At the workplace level, information is needed about the nature of the hazard, where it is likely to be encountered, and the available options for risk assessment and risk control. In this thesis, the focus is on information on a societal level and it is investigated whether registries could provide relevant information to the stakeholders in prevention and how registries can be improved or enhanced for this purpose.

## Registries of occupational diseases

Most industrialized countries have one or more registries of occupational diseases. These national registries are often linked to a financial compensation system for occupational diseases that is embedded in the country's social security system (13,14). They are mostly maintained by governmental bodies or insurance companies, depending on whether compensation is a private or a public matter. At the same time, statistics from these compensation systems are intended to provide policy information for the prevention of occupational diseases (15,16). In addition to these national registries, some countries have other registries of occupational diseases, such as surveillance schemes for occupational asthma or occupational skin diseases (17-19). In several other countries, there are additional registration activities for specific regions or industrial sectors.

Despite the importance of national occupational registries for compensation and prevention, the reliability of these monitoring systems for occupational diseases in the EU countries is regarded as poor. In general, there is large underreporting and there are substantial differences between countries in diagnostic guidelines and criteria for notification, and, more generally, in culture, legislation and social security regulations (15,16). These observations call for an evaluation of the various monitoring systems.

Another reason to evaluate existing monitoring systems in the industrialized world is the changing pattern of occupational diseases (20). Whereas diseases caused by chemical and physical exposures were at the top of the occupational diseases statistics for many decades, work-related musculoskeletal diseases and mental illness now account for a major part of the work-related burden of diseases in most industrial sectors. From a technical and a social perspective, working life in Europe is changing rapidly, creating new risk areas and requiring new management systems to control these risks (21). This changing pattern of occupational diseases implies the need to study the appropriateness of the present monitoring systems. Although work-related musculoskeletal diseases and mental illness are the most common occupational diseases (22), in many countries these categories are not even on the list of occupational diseases. Another problem is that many registries are not suitable for tracing newly occurring occupational diseases, as they maintain a rather rigid list of diseases that was developed long ago. An extra complication is that these lists are based not only on scientific investigations but also on social-political negotiations. A further cause for the difficulties

encountered in working with lists of occupational diseases is that the definition of occupational disease is not unambiguous. This is the subject of the following section.

## **The definition of occupational disease**

In the *ILO Encyclopaedia of Occupational Health and Safety*, Lesage distinguishes three categories of occupational diseases with respect to the strength of the causal relation (23). Classic occupational diseases are characterized by a clear, often practically monocausal relation to a specific exposure, for example mesothelioma caused by asbestos, or asthma caused by a specific chemical substance like methylene diphenyl diisocyanate (MDI). If the relation is less obvious, the disease is indicated as work-related. Most musculoskeletal diseases and mental health disorders are judged as belonging to this category. Most work-related diseases are considered as multicausal and include work as one of the factors that play a role in the aetiology. Following this line of reasoning, there is a recognizable relation between the working condition and the disease on the individual level (for example, between repetitive movements and shoulder complaints), but it is often not clear whether the working conditions are the decisive factor in the development of the disease. Finally, a third group of diseases is distinguished in which a relation between working conditions and health effects can be demonstrated only on a population level. The incidence or prevalence of these diseases is higher in specific occupational groups, but it is difficult to substantiate the nature of the causal relation in, for example, biological terms. One reason may be the lack of specific signs to identify them as work-related. For example, cardiovascular diseases caused by shift work belong to this category (24).

Many countries, as well as international organizations like the EU and ILO, have drafted definitions and accompanying lists of occupational diseases. Lists of occupational diseases that are maintained for social security purposes mainly contain the classic occupational diseases defined by Lesage. A recent trend is for countries to include work-related diseases in their national lists of occupational diseases. An example is the inclusion of upper-extremity disorders on the French list of occupational diseases, whereupon this category of diseases became the most reported one in France. (25).

For most of the classic occupational diseases, there is ample evidence for the work-relatedness and they can be attributed to work with confidence in individual patients. For the category of work-related diseases, there is much more discussion regarding causal inference on the individual level (26). Criteria for the latter category of diseases should preferably be based on evidence from epidemiological research. Examples are criteria developed for work-related upper-extremity musculoskeletal disorders (27) and for work-related low-back pain (28). Lesage's third category does not differ in essence from the second category, but the odds ratios or relative risks found in epidemiological studies are lower.

To summarize the preceding sections there are strong health, social and economic reasons to prevent occupational diseases. However, the unclear division of roles and responsibilities between the various stakeholders complicates prevention. Moreover, existing registries often do not provide appropriate information for preventive policy. These observations led to the objectives of this thesis, which are formulated in the following section.

## **Objectives and outline of the thesis**

The first objective is to develop an inventory of the information needs of the stakeholders involved in the prevention of occupational diseases, and an overview of instruments and strategies to best meet these needs. The second objective is to investigate whether and, if so, how registries of occupational diseases can be used to fulfil these information needs. The third objective is to investigate how registries can be improved or enhanced in order to provide high-quality information for preventive policy.

In **Chapter 2** we explore the information needs of employers, employees, policy makers and other stakeholders with respect to the prevention of occupational diseases. We also present the opinions of experts about how these information needs can best be met.

In **Chapter 3**, we describe the development of quality indicators that can be used as an audit tool for the quality assessment of registries of occupational diseases in relation to preventive policy on



a national level. In **Chapter 4**, we evaluate registries of occupational diseases in six European countries for their ability to provide appropriate information for preventive policy with the aid of the audit tool.

In Chapters 5, 6 and 7, we present a number of studies that were aimed at the quality improvement and enhancement of registries in relation to preventive policy purposes. **Chapter 5** focuses on whether and, if so, on which aspects a sentinel surveillance project comprising motivated and supported occupational physicians would provide higher quality information than a national registry for preventive policy. In **Chapter 6** we assess the need for quality improvement of diagnosing and reporting of noise-induced occupational hearing loss and occupational adjustment disorder (nervous exhaustion). **Chapter 7** presents an exploration of whether the role of registries of occupational diseases for preventive policy can be extended by creating longitudinal data in sample projects. Here, the particular focus is on the course and consequences of work-related upper-extremity disorders as recorded in the registry of the Netherlands Center for Occupational Diseases.

We present the main findings in the general discussion in **Chapter 8**. We also discuss the methodological considerations, implications for practice and suggestions for further research.

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