Registries of occupational diseases and their use for preventive policy
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Summary and Conclusions
The central theme of this thesis is the use of registries of occupational diseases for preventive policy. The first objective of the study on which this thesis is based was to develop an inventory of the stakeholders’ information needs and an overview of the instruments and strategies to use in order to best meet these needs. The second objective was to investigate whether and, if so, how registries of occupational diseases can be used to fulfil these information needs. The third objective was to investigate how registries can be enhanced in order to provide high-quality information.

In Chapter 2 an inventory was made of the information needs of the stakeholders in the prevention of occupational diseases and how these information needs can best be met. For this, a survey consisting of two rounds of interviews was performed. The first round comprised interviews with eleven representatives of key stakeholders, namely employer organizations, employee organizations, the government, the labour inspectorate, the EU authorities and the Netherlands society of occupational physicians. In the second round, fourteen experts on the registration of diseases from six EU countries were asked to comment on the results of the first round and to give their opinion on how these information needs could best be met.

From the first round of interviews, five categories of information needs of stakeholders were deduced: 1. time trends of occupational diseases for setting policy priorities, 2. cases of new occupational diseases for early preventive action, 3. disease patterns in specific occupational groups for focused prevention measures, 4. the consequences of occupational diseases and resulting measures for policy evaluation purposes, and 5. blind spots that reveal in which areas further investigation is needed. The round of interviews with the experts revealed that it is wise to rely on several instruments and findings in order to meet the comprehensive information needs of the stakeholders, such as national registries, sentinel surveillance, epidemiological studies and case studies. The experts recommended to maintain an ongoing dialogue between the providers of figures and the stakeholders to better link registration to prevention.

The aim of the study presented in Chapter 3 was to develop quality indicators and corresponding criteria that can be used for quality assessment of registries of occupational diseases in relation to preventive policy on a national level. For this, a literature search was performed to assess which output of registries can be considered appropriate for preventive policy and to develop a set of preliminary indicators and criteria. Second, final indicators and criteria were assessed; their content
validity was tested in a Delphi study, in which experts from the 25 EU Member States were invited to participate. The literature search revealed two different types of information output to be appropriate for preventive policy, namely monitor information and alert information. Based on the experts' comments, we developed nine indicators: completeness of the notification form, coverage of registration, guidelines or criteria for notification, education and training of reporting physicians, completeness of registration, statistical methods used (only for monitoring), investigation of special cases (only for alerting), specified monitor information, and specified alert information. Except for the indicator 'coverage of registration' for the alert function, all the indicators met the predetermined requirements of content validity. Together, the indicators form a tool – ODIT – that can be used for the quality improvement of registries of occupational diseases.

Chapter 4 reports on the use of the audit tool (ODIT) to evaluate registries of occupational diseases in six EU countries for their ability to provide appropriate information for preventive policy. First, the contact persons of the six national registries were interviewed. The objectives of the six registries were compensation, provision of statistics, prevention or research. Next, the items of the audit tool were independently rated by two reviewers based on verified audit reports, and an average quality score (0-10) was assessed. The average quality was rated 3.2 (out of 10) for monitoring occupational diseases and 5.3 (out of 10) for tracing new risks (alert function). Reasons for poor quality were the inadequate education and training of physicians with respect to occupational diseases and the poor participation of notifying physicians. After the audit, the six contact persons were asked to evaluate the usefulness of ODIT: three considered it helpful for future quality improvement of the registry in relation to prevention, while three were of the opinion that ODIT should first be improved. It was concluded that registries in the EU countries can provide valuable information, but have major shortcomings in adequately monitoring the occurrence of occupational diseases and in tracing newly occurring occupational diseases. We consider improvement and harmonization as urgently needed.

The aim of the study presented in Chapter 5 was to evaluate whether a sentinel surveillance project comprising motivated and guided occupational physicians would provide higher quality information for a policy to prevent occupational diseases than would a national registry. A group of 45 occupational physicians participated in a sentinel surveillance project for two years. All other
occupational physicians (n=1,729) in the national registry were chosen as the reference group. The number of notifications per occupational physician, the proportion of incorrect notifications and the overall reported incidence of occupational diseases were compared. The median number of notifications per occupational physician during the project was 13.0 (IQR 4.5-31.5) in the sentinel group versus 1.0 (IQR 0.0-5.0) in the reference group (p<0.001). The proportion of incorrect notifications was 3.3% in the sentinel group and 8.9% in the reference group (p<0.001). The overall reported incidence was seven times higher (RR 6.9, 95%CI: 6.5-7.4) in the sentinel group (466 notifications per 100,000 employee years) than in the reference group (67 notifications per 100,000 employee years). Thus, the conclusion is that a sentinel surveillance group comprising motivated and guided occupational physicians will provide higher incidence rates and fewer incorrect notifications than will a national registry.

Chapter 6 presents an assessment of the need for quality improvement of diagnosing and reporting of noise-induced occupational hearing loss and occupational adjustment disorder within the Dutch national registry. The assessment comprised several steps. First, performance indicators and criteria for the quality of diagnosing and reporting were developed. Next, self-assessment questionnaires were sent to 1705 occupational physicians. The performance of these physicians was then assessed by separate scores per performance indicator and by a total quality score. The mean quality score for diagnosing and reporting was 6.0 (SD: 1.4) for noise-induced occupational hearing loss and 7.9 (SD: 1.5) for occupational adjustment disorder, both on a scale of 0 to 10. For noise-induced occupational hearing loss, there was a need for quality improvement of the aspects of medical history taking, audiometric measurement, clinical diagnosis of the disease, and reporting. For occupational adjustment disorder, the assessment of other competing causes needed improvement. It was concluded that the quality of diagnosing and reporting can be improved for noise-induced occupational hearing loss and occupational adjustment disorders. Information, education and practical tools were proposed for quality improvements.

The focus in Chapter 7 was on the course and consequences of work-related upper extremity disorders that had been notified to the Netherlands Center for Occupational Diseases (NCOD). A secondary aim of this study was to investigate which factors might have a prognostic value for the
course and consequences of the disorder. Therefore, a follow-up study during one year was performed in cases of work-related upper extremity disorders notified to the NCOD. Perceived severity, quality of life, functional impairment and sickness absence were measured directly after notification and after 3, 6 and 12 months. A linear mixed model was used to compare these parameters at the different measurement moments and to assess the predictive value of several factors on baseline for the course of these parameters. The perceived severity of the disorder and functional impairment declined during one year of follow-up after notification, while quality of life improved substantially. Sickness absence decreased during the follow-up period. Workers above the age of 45 had worse scores on perceived severity of the disease, functional impairment and quality of life than did younger employees. It was concluded that the role of registries of occupational diseases for preventive policy can be extended by creating longitudinal sample projects that inform us about prognostic factors and various consequences of the diseases notified.

Chapter 8 addressed the main findings of this thesis and elaborated on the following methodological issues: case definitions and the need for completeness and full coverage of the registration, and the linkage of registration to prevention. Next, implications for practice and further research were discussed. As a final conclusion we stated that national registries of occupational diseases are useful, but have also major shortcomings for the provision of information for preventive policy. The changing pattern of occupational diseases requires traditional registries to become more flexible and dynamic systems. For monitoring occupational diseases for preventive aims a set of instruments is needed. In addition to a number of registries, projects linked to these registries can be executed in order to, for example, obtain more information on exposure patterns or the course and consequences of occupational diseases. Tracing new risks and newly occurring occupational diseases require different methods, for which lessons can be learned from the methods used in pharmacovigilance. Clear preventive strategies and an ongoing dialogue between the providers of figures and the stakeholders in prevention is a prerequisite for achieving results in prevention.
Conclusions

1. Stakeholders have various and widely different information needs; thus, not one but various methods and instruments are needed to meet these demands, such as national registries, sentinel surveillance, follow-up studies and case finding. These various methods and instruments have to be selected dependent not only on the information needs of stakeholders, but also on the characteristics of diseases and risk factors and the available budget.

2. Current registries of occupational diseases are valuable for preventive policy but they have also major shortcomings for the provision of information for preventive policy. The quality of national registries can be assessed on nine aspects by a newly developed audit tool, namely ODIT. The results can be used for quality improvement. This instrument was applied to the national registries in six European countries, and revealed various aspects that need improvement, such as the education and participation of physicians.

3. Performance indicators showed that the quality of diagnosing and reporting in the Dutch national registry requires substantial improvement.

4. Sentinel surveillance projects that include a sample of motivated and guided occupational physicians can produce substantially better data than can national registries.

5. The course and consequences of occupational diseases can be studied by longitudinal sample studies within a national registry. Thus, basic facilities can be used efficiently to provide important new information on occupational diseases.

6. Crucial for the prevention of occupational diseases is the commitment of stakeholders on various levels, namely the workplace, the industrial sector and the national level. An ongoing dialogue with stakeholders is needed in order to strengthen the linkage between registration and prevention.

7. Special attention should be paid to the alert function for the detection of new risks at the workplace. There is an urgent need to develop appropriate methods and instruments.

8. We strongly recommend stimulating international collaboration to improve the quality of information on the incidence and prevalence of occupational diseases in Europe. At this moment activities of the European Foundation for the Improvement of Working and Living Conditions in Dublin and the European Agency for Occupational Safety and Health in Bilbao.
provide data especially on working conditions. Sentinel surveillance projects, including
evidence based case definitions, can be started in a number of countries to provide
supplementary reliable data on the adverse effects of working conditions. These data can be
used for benchmarking and preventive policy.