Registries of occupational diseases and their use for preventive policy
Spreeuwers, D.

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Chapter 8

General Discussion
This chapter first presents the main findings related to the research questions: 1. What are the information needs of stakeholders who are involved in the prevention of occupational diseases and how can these needs best be met? 2. Can registries of occupational diseases be used to provide information for prevention? 3. How can registries be improved or enhanced in order to provide high-quality information for preventive policy? Next, methodological considerations, implications for practice and suggestions for further research will be presented.

Main Findings

Information needs of stakeholders and how best to meet them

In Chapter 2 we presented the qualitative survey we carried out in order to make an inventory of the information needs of stakeholders involved in the prevention of occupational diseases and to investigate how best to meet these information needs. Five categories of information needs were deduced from interviews with representatives of key stakeholders: 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. an overview of consequences of occupational diseases and resulting measures for policy evaluation purposes and 5. a description of blind spots, that reveal in which areas further investigation is needed. Not all stakeholders are equally interested in these issues, for example the government is more interested in the time trends of various occupational diseases than is an employer in the construction industry. This employer might be more interested in a decrease in contact eczema and low back pain in bricklayers related to new work processes and materials, and in a consequent decrease in sickness absence both in the branch and in his company.

Experts on registries were then asked how these information needs can best be met. An important conclusion was that registries alone cannot satisfy the information needs of stakeholders. The advice of the experts was to use several additional sources of information, such as epidemiological studies, surveys in companies and focused projects. Furthermore, tracing new and
emerging risks requires different methods and instruments than does the monitoring of occupational
diseases. For monitoring a rather stable group of reporting physicians is to be preferred, as are clear
case definitions. In this way, both comparisons between branches of industry or occupations and
comparisons over time can be made. On the other hand it is clear that detailed specified case
definitions can hamper the notification of suspect cases. Moreover, if we do want to receive signals of
possible newly occurring occupational diseases it would be advantageous to organize a report system
that includes every physician (and perhaps even other groups, such as employees and employers)
rather than a stable group of well trained professional reporters. The experts consulted in this study
recommended to develop a low threshold for the notification of suspect cases followed by a more
detailed examination as a second step in the procedure. Other recommendations were to organize
periodic literature searches and data mining in existing databases for the provision of alert information.

The interviews with experts also revealed that we need specific monitor methods for each
category of occupational diseases. For diseases that are nearly exclusively occupational -such as
occupational asthma or post traumatic stress disorders that originate in a work setting- it is sufficient to
count prevalent or incident cases. For example, in the case of occupational asthma, prevention can be
focused on the reported causes and preventive policy can be evaluated by following trends over time
in the number of cases and reported causes. For disorders with a low relative risk related to work (e.g.
lung cancer related to exposure at work to polycyclic aromatic hydrocarbons at work), a better
approach is to apply epidemiological methods to assess the attributed proportion of the total morbidity
related to various causes. In general, such factors as the length of the latency period (the time period
between the exposure and the detection of the disease) the course of the disease and the strength of
the causal relationship determine the preferred monitoring method. For preventive purposes
information about trends in disease incidences alone is not sufficient to evaluate policy interventions.
Especially for diseases with long latency periods monitoring of exposure or intermediate variables is
advocated. For example, to evaluate the effect of measures for the prevention of noise-induced
hearing loss, information about the increase in the use of hearing protection or about the
implementation of noise reducing interventions at the workplace will give an earlier indication of
effective preventive measures than will a decrease in the incidence of the disease.

The experts stated that frequent communication with stakeholders is a key issue in linking
figures on occupational diseases to actual prevention. The involvement of stakeholders in the
registries makes it easier to put occupational diseases on their agenda and can also increase their willingness to take preventive measures. Furthermore, discussions with stakeholders can initiate and guide decisions for projects or studies that are linked to registries. Obviously, the dissemination of relevant results of the registries to workplaces, labour safety authorities and other stakeholders is decisive for an effective use of the information for prevention. Consequently, in order to effectively link registration activities to prevention it is recommended to use a set of instruments and methods (instead of a single registry) for monitoring occupational diseases and for tracing new risks, and to maintain an ongoing dialogue with the stakeholders.

The use of registries of occupational diseases to provide information for prevention

Chapter 3 described the development of indicators for the quality assessment of registries of occupational diseases in relation to preventive policy. A literature search revealed two different types of information output that are appropriate for preventive policy: monitor information and alert information (1). Monitor information concerns the nature, magnitude and distribution of recognized occupational diseases over time, related to branches of industries, occupational groups, gender and age categories. This information is essential in order to estimate the magnitude of the problem and to establish trends over time, which is useful in setting priorities for preventive policy and in evaluating the effectiveness of preventive policy measures. In contrast, alert information refers to the discovery of newly occurring occupational diseases that result from new risk factors or the discovery of new associations between a well-known occupational risk factor and disease that is not yet suspected, or of an increased awareness of the impact of already known associations. Based on the comments of the experts who participated in the Delphi study presented in Chapter 3, nine indicators for the evaluation of the quality of registries of occupational diseases were assessed: completeness of the notification form, coverage of the working population by the registry, present guidelines or criteria for notification, realization of education and training of reporting physicians, completeness of registration, presentation of statistical methods used, the option to investigate special cases, presence of specified monitor information and of specified alert information. Except for the indicator ‘coverage of registration’ for the alert function, all the indicators met the predetermined requirements of content validity, which means that the experts considered the indicators relevant for the assessment of the quality of a
registry of occupational diseases. These indicators led to the development of an audit instrument - ODIT - for the evaluation of registries of occupational diseases in relation to preventive policy.

We presented in Chapter 4 the results of a study that applied the ODIT instrument to evaluate the registries of six countries, namely those of Austria, Belgium, the Czech Republic, France, Finland and the UK. Registries in these countries report having various objectives, for example compensation, the provision of statistics, prevention or research. Registries linked to compensation systems are mostly aimed at administrative support of the financial completion of the claim proceedings, therefore the provision of statistics for preventive or research activities is a secondary aim. Furthermore, there are differences between countries regarding who is entitled to report to the registry. In some countries, employers or employees themselves can apply for compensation, but in most countries a physician’s certificate is needed for reporting. All compensation systems have an acknowledgement procedure that is executed by physicians who have special expertise in occupational diseases. In some countries registers are linked to the compensation process (e.g. as an administrative database), whereas in Finland and the Czech Republic the registry records are derived from notifications for compensation, even though the registry itself is not linked to the compensation process. The UK registry has no links at all to the compensation process.

For the six registries we audited, the average quality was rated 3.2 (SD 2.2) out of 10 for monitoring occupational diseases and 5.3 (SD1.4) out of 10 for alerting to new risks. The main reasons for the low scores were the inadequate education and training of physicians and the poor participation of notifying physicians. All contact persons agreed that the registries need improvement in relation to prevention. Three of the six contact persons considered the audit tool helpful for future quality improvement of the registry in relation to prevention, whereas the other contact persons were of the opinion that the tool should first be improved.

Enhancement of registries in order to provide high-quality information for preventive policy

In Chapter 5 we presented an evaluation of whether a sentinel surveillance project comprising motivated and guided occupational physicians would provide higher quality information than would a national registry for a policy to prevent occupational diseases. The median number of notifications per
occupational physician was 13 in the sentinel group versus 1 in the reference group. The number of incorrect notifications in the sentinel group was three times lower than in the reference group. Compared to the two preceding years, the sentinel group and the reference group did not notify significantly more cases. However, the quality of notification improved significantly in the sentinel group but not in the reference group. The overall incidence of occupational diseases as reported by the sentinel group was about seven times higher than that reported by the reference group. For diseases of the upper limb, the difference was even larger, suggesting a differentiation in underreporting in the national registry. On the basis of these results, it was concluded that a sentinel surveillance group comprising motivated and guided occupational physicians reported a substantially higher occupational disease incidence and a lower proportion of incorrect notifications than did a national registry.

The focus of Chapter 6 was on the quality of diagnosing and reporting in the Netherlands for two diseases, namely noise-induced occupational hearing loss and occupational adjustment disorder (nervous breakdown, burnout). For this, we had formulated performance indicators and criteria. The indicators were medical history taking (considering which complaints were essential to inquire about), diagnosis, exposure, other competing causes, conclusion and reporting. For noise-induced occupational hearing loss we added the indicator “audiogram” and developed criteria for the quality of performance. The mean quality score for diagnosing and reporting was 6.0 (SD: 1.4) out of 10 for noise-induced occupational hearing loss and 7.9 (SD: 1.5) out of 10 for occupational adjustment disorder. For noise-induced occupational hearing loss, there was a need for quality improvement on the aspects of medical history taking, audiometric measurement, the clinical diagnosis of the disease and the quality of the reporting. For occupational adjustment disorder the aspect of determining non-work-related competing causes needed improvement.

The incidence rate is not the only information that can be derived from the data. Additional information on the severity and consequences of the diseases is important for decision-making in preventive policy, as it is for setting priorities. Unfortunately, most registries of occupational diseases do not provide this type of information at the moment. In Chapter 7 we discussed the possibility of extending the role of registries of occupational diseases by creating longitudinal sample studies. This
Discussion was based on a longitudinal sample study on work-related upper extremity disorders that we had carried out in our national registry. We found that, in general, such disorders had a favourable course. However, 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 registries of occupational diseases can be used as a basic facility that can be extended to produce various kinds of information for preventive policy.

Methodological considerations

The methodological strengths and limitations of the studies included in this thesis have been discussed in the previous chapters. However, three substantial methodological issues deserve further consideration: the issue of the differences in case definitions of occupational diseases, the need for completeness and full coverage of the registration, and the linking of registration to prevention.

Case definitions

In practice, the development of case definitions for occupational diseases is based not only on scientific evidence but also on socio-political negotiations. A related problem is that every registry uses its own criteria or guidelines for diagnosing and reporting. Even for noise-induced hearing loss - a disease that is easy to assess and in which the causal relation with occupational exposure is obvious - a wide variation of criteria and guidelines can be noted. Questions like how severe a medical condition must be to define a case as being an occupational disease are answered differently. Criteria differ on which exposures belong to the realm of occupational health, for example the acceptance of combined stress caused by work and home life as a work-related risk factor. The same holds for such issues as to what degree an occupational factor among other causal and conditional determinants contribute to the origin of a disease in an individual. Therefore, the concept ‘occupational disease’ and its subsequent operationalization are complicated. Furthermore, one might argue the inclusion of individual susceptibility and coping capacity towards exposure as important elements of the definition.
Applying criteria in the assessment of occupational diseases for compensation purposes mostly leads to a simple yes or no to the question whether a disease is work-related. In our view, however, causal relationships are nearly always a matter of probabilities. Therefore, guidelines that include a measure for the probability of a causal relationship do more justice to the existing relationship than the mere conclusion that a disease or is not occupational.

There are also different opinions about the occupational causes of diseases amongst physicians (2), employers, employees and other relevant parties (3). As a result, some physicians are more hesitant than others to ascribe a medical condition to work. Along the lines, the presuppositions of employers and employees about causal inference are highly relevant, as these determine whether they regard health problems as work-related and thus bring them to the attention of a physician.

Completeness of registration and coverage

A limitation of this thesis is that it focused only on registries of occupational diseases. Consequently, workers who have serious work-related health complaints or diseases but do not have access to or do not attend a physician will not be taken into account. In general, a major shortcoming of registries of occupational diseases is the incompleteness of the coverage. Several causes of underreporting and several levels of causation can be distinguished: 1. workers do not or cannot turn to a physician with their work-related health complaints and diseases, 2. occupational diseases are not recognized and diagnosed by physicians, 3. occupational diseases are recognized but not reported to the registry and 4. occupational diseases are reported but not registered due to the limitations of the prescribed case definition (e.g. if an occupational disease is not on the national list). There is little knowledge particularly about the first level of underreporting. Registries represent only recognized cases and the recognition rate of occupational diseases depends on the access of workers to a reporting (occupational) physician, and on the quality of health care in general and of occupational health care in particular. If surveillance programmes for workers at risk exist, for example in the case of exposure to high noise levels, the degree of underreporting will be limited, depending on the coverage of these surveillance programmes. In monitoring for time trends, it does not matter if there is some under-ascertainment of cases, provided that the level of under-ascertainment remains fairly constant over time. To estimate the burden of occupational diseases it is better to rely on a high-

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quality sample of reporting physicians who notify cases and the source population of workers more reliably than can be realized in national registries, as described in Chapter 5 of this thesis.

Another relevant issue for the completeness of information is the observation that patients follow different pathways in the health care system, whether or not the system includes occupational health care. In addition they may follow different routes in the assessment procedure for compensation. A patient with occupational hand dermatitis can be treated by a GP, or the GP can refer the patient to a dermatologist. The patient might also visit an occupational physician, or even an occupational dermatologist, whether for treatment, rehabilitation or in an assessment procedure of an occupational disease. If the registry collects cases from dermatologists, only some of the cases of occupational hand dermatitis will be captured, whereas if the registry collects cases from occupational physicians, other cases will be captured. Triangulation, that is aimed at more reliable incidence figures can be done by reporting cases on different positions in the health care system. Next, if the same cases appear in different registries, capture-recapture techniques can be used to make a reliable estimate of incidences (4).

Linking of registration to prevention

The studies presented in this thesis looked at registries from the perspective of their use for preventive policy. As explained in Chapter 4, registries can have different objectives, for example compensation, the provision of statistics, prevention or research – and this can lead to methodological dilemmas.

It is not easy to describe the prevention of occupational diseases in one model. There are various stakeholders with a diversity of interests, motives and information needs. Prevention can take place at the individual, the workplace, the national or even the international level. Prevention in an industrial environment, with its principally physical and chemical exposures, requires an approach that is different from that applied in the services sector. Although registries of occupational diseases can play an important role in the prevention process, they certainly do not guarantee preventive actions and the role of registries in actual prevention is mostly unclear.

An interesting possibility is to enhance registries with projects, for example follow-up of cases to study the course and consequences of occupational diseases, or to investigate exposure and the
effectiveness of protective measures more thoroughly. Another option to strengthen the link with actual prevention is the organization of or participation in campaigns to promote the reporting of specific occupational diseases aiming at better prevention, or reporting projects within industrial branches or occupational groups in order to put occupational diseases high on the agenda. These extensions and projects make registries more dynamic and more focused on prevention. However, one must realize that it might also have an impact on the figures of the registry itself. For example, if one decides to organize a campaign with the aim of obtaining more reports of occupational asthma in a certain year, these figures have to be interpreted in the light of the campaign. Another point for deliberation is that prevention might be contentious in compensation systems, because although insurance companies benefit from prevention, they might hesitate or even refuse to invest in, for example, a campaign for prevention that draws employees' attention to occupational diseases. They might be afraid to foster new claims or be concerned about the increase in their administrative workload.

**Implications for practice**

This thesis has demonstrated that providing relevant information to the various stakeholders requires a set of methods rather than a single registry. The composition of a set of methods and instruments will depend on the strategic goals of the registry, the information needs of the stakeholders, the characteristics of the disease and the risk factors, the requirements concerning the quality of data and of course the available budget. Based on the information needs of the stakeholders table 1 presents a limited number of appropriate methods for data collection, corresponding sources of data, methods of analysis and the related output information that can be used in composing a tailor-made set of methods aimed at providing information for prevention of occupational diseases.

Registries are just one of the instruments that can be used to provide information for prevention. Although they are mostly authoritative sources, various aspects would benefit from quality improvement, as presented in Chapters 3 and 4. Furthermore, registries can be enhanced by extensions or linked projects. In this section, we first discuss the set of methods aimed at providing information for prevention of occupational diseases, departing from the five information needs of
stakeholders. We then provide some leads for quality improvement of registries and examples of extensions and linked projects.

A set of instruments

In table 1 a set of instruments is presented departing from the five information needs: time trends, new occupational diseases, disease patterns, consequences of occupational diseases and detection of blind spots.

Table 1: Instruments for the provision of information for preventive policy

<table>
<thead>
<tr>
<th>Information needs</th>
<th>Methods for data collection (case capture)</th>
<th>Who provides the data (source of data)</th>
<th>Methods of analysis</th>
<th>Output information</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Time-trends of occupational diseases for setting policy priorities</td>
<td>Administrative registry</td>
<td>Dependent on the organization of the registry (mostly physicians, sometimes employers, employees)</td>
<td>Calculation of incidence rates Comparisons of incidence rates between subgroups (relative risks)</td>
<td>Nature, magnitude and distribution of occupational diseases over time, related to branches of industries, occupational groups, gender and age categories.</td>
</tr>
<tr>
<td>Sentinel surveillance</td>
<td>(Sample of) well trained and motivated physicians</td>
<td></td>
<td>Time series Calculation of work-attributable proportion of the total incidence rate of a disease</td>
<td></td>
</tr>
<tr>
<td>Periodic survey of a population of workers</td>
<td>Workers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Analysis of workers’ health surveillance data (possible only if occupation is registered)</td>
<td>Health surveillance data provided by workers and OH professionals</td>
<td></td>
<td>Work-attributable proportion of the incidence rate of a disease</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Cases of new occupational diseases for early preventive action</th>
<th>Reporting of special cases or clusters</th>
<th>All physicians (and possibly others, e.g. employers and employees, other experts: occupational hygienists, nurses, psychologists, etc.)</th>
<th>Clinical and technical investigations of special cases or clusters</th>
<th>Indications of new associations between occupational exposures and diseases; indications of new risks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data mining in existing registries</td>
<td>Existing registries</td>
<td>Several epidemiological</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### 3. Disease patterns in specific occupational groups for focused prevention measures

<table>
<thead>
<tr>
<th>Techniques</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administrative registry</td>
<td>Dependent on the organization of the registry (e.g. employers, employees, physicians)</td>
</tr>
<tr>
<td>Sentinel surveillance in a specific occupational group</td>
<td>Sample of well trained physicians working in a specific occupational group</td>
</tr>
<tr>
<td>Survey in a specific occupational group (amongst workers, employers and experts)</td>
<td>Workers, employers and experts</td>
</tr>
</tbody>
</table>

### 4. Consequences of occupational diseases and resulting measures for policy evaluation purposes

<table>
<thead>
<tr>
<th>Techniques</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sentinel surveillance or administrative registries extended with follow-up studies</td>
<td>Follow-up data can be provided by workers (notified cases) or their physicians</td>
</tr>
<tr>
<td>Record linking (possible only in the case of unique identifiers)</td>
<td>Existing registries that can linked to registries of occupational diseases</td>
</tr>
<tr>
<td>Other epidemiological studies (cohort or case control studies) and qualitative studies</td>
<td>Depending on the nature of the study</td>
</tr>
</tbody>
</table>

### 5. Blind spots that reveal in which areas further investigation is needed

<table>
<thead>
<tr>
<th>Techniques</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Projects of active case-finding in prescribed industries or occupational groups; especially useful for underprivileged groups such as workers in the informal sector</td>
<td>Dependent on the nature of the project</td>
</tr>
</tbody>
</table>

| Interpretation of figures linked to developments in the industrial branche or occupational group |

| Patterns of occupational diseases in specific occupational groups |

**Methods for the analysis of longitudinal data and qualitative studies**

**Information on the consequences of occupational diseases in terms of sickness absence and disability pensions, medical and social consequences and economic costs, as well as information on measurements taken and their results.**
1. Time trends of occupational diseases for setting policy priorities

The time trends of occupational diseases can be derived from annual incidence figures on the basis of administrative registries or sentinel surveillance schemes. Time trends can also be studied by comparing repeated surveys of a population of workers. To estimate the occurrence of disorders that have low relative risks, that are difficult to assess on an individual level, it is better to estimate the excess of illness that is attributable to work based on well-designed epidemiological studies than to count the number of cases (5). This has the merit that it directly represents the impact of occupation on health at a population level. If the occupation is recorded in health surveillances projects, these data can be used to estimate the relative risk and the work-attributed proportion of the total incidence rate of a disease and to study time trends of both measures.

Problems in monitoring time trends can occur in chronic diseases (e.g. occupational hearing loss) and in episodic diseases with exacerbations and remissions (e.g. occupational dermatitis). If cases are reported anonymously, chronic occupational diseases might be reported more than once, for example if an employee changes his or her job. In episodic diseases it is important to decide whether to register episodes or the underlying chronic medical condition. For example, dermatitis caused by wet work can occur as an occupational disease, then dissipate only to flare up again when working conditions change. From the perspective of evaluation of the effectiveness of prevention one could argue that this second episode is as relevant to note as the first one, as both show that prevention has failed. The consequent conclusion is that from a perspective of prevention, both events or episodes have to be registered as a separate case of occupational disease. If unique identifiers are used in the registry, the episodes can be traced back to the individual worker.

2. Cases of new occupational diseases for early preventive action

Cases of new occupational diseases can be traced by the reporting of special cases or clusters, followed by clinical and technical investigations. Examples of activities specifically focused on tracing newly occurring occupational diseases are the THOR Extra project in the UK (6) and the Health Hazard Evaluation in the USA (7). Furthermore, data mining in existing registries can reveal new associations between new or existing occupational risk factors and diseases. An example is the study by Bonneterre, who advocated the use of pharmacovigilance methods (e.g. the reporting of special cases or clusters and data mining in existing registries) for tracing new occupational risks (8).
Performing periodic literature reviews is another method to find new risks. Establishing networks as communities of experts sharing knowledge and evaluating new findings can be an advanced approach in the discovery and evaluation of new and emerging risks, as can be concluded from experiences in the Netherlands (Ten years experience of an expert network on Allergy and Work) (9) and from the EU (e.g. the Expert forecasts on emerging physical, biological en psychosocial risks) (10-12).

3. Disease patterns in specific occupational groups for focused prevention measures

Disease patterns in specific occupational groups can be derived from administrative registries or sentinel surveillance schemes. Data can also be collected by surveys amongst employers or employees. Consequently, the data must be linked to developments in the industrial branche or occupational group so that focused prevention measures can be taken.

4. Consequences of occupational diseases and of resulting measures useful for policy evaluation

The consequences of occupational diseases and the resulting measures can be investigated by standard epidemiological methods, such as cohort or case control studies. However, these studies are both expensive and time-consuming. Therefore, it is recommendable to extend registries (administrative registries and sentinel surveillance schemes) by creating longitudinal data to provide this kind of information. This can be done either by record linkage of existing data or by sample projects linked to registries. Record linkage is possible only if the occupational disease registry records unique identifiers that can be linked to other databases. An example of a project aimed at collecting longitudinal data was described in Chapter 7. Another option is to develop a qualitative study using the notifications to the register.

5. Blind spots that reveal in which areas further investigation is needed

The tracing of blind spots that can reveal in which areas further investigation is needed requires projects of active case-finding in industrial branches or occupational groups. Options are studies of the patient files of occupational health services or hospitals, or surveys in specific occupational groups. Special attention has to be paid to underserved and vulnerable populations which have poor access to (occupational) health care, such as workers in the informal sector and in branches of industry where many migrant and illegal workers are working.
Chapter 2 showed that the output of registries can be divided into monitor information and alert information. Although national registries had a better score on the ability to provide alert information than on the ability to provide monitor information, additional facilities are still needed for tracing newly occurring occupational diseases. Therefore, the alert function is discussed in the following section as an extension of a registry. In this paragraph a limited number of possible quality improvements of registries aiming at providing monitor information for prevention will be discussed.

As a starting point, good quality registration requires a minimal data set. According to the results of the study discussed in Chapter 3, for the monitor function the minimal data set should comprise diagnosis, exposure, occupation, industrial branche, probability of the causal relation, age and sex of the worker, and potential other causes. We would like to promote the international standardization and use of classification systems for the items in the minimal data set in order to be able to compare registries from various countries.

The assessment of the coverage of registration is relevant to the determination of the denominator in the case of the calculation of incidence rates. Besides presenting the gross figures, the calculation of incidence rates is important because they indicate the size of the problem in an industrial branche or occupational group. For example, a few notifications in a small industrial branche might correspond with a high incidence rate, probably indicating a serious problem in the branche.

Clear, concise and preferably international case definitions are essential for the monitoring function of a registry. The quality of case definitions can be improved by developing evidence based guidelines for the assessment. We can use the opportunity to develop evidence-based case definitions as a product of international consensus projects. Successful examples are the guidelines for silicosis (13,14) and occupational asthma (15). Examples of guidelines for work-related diseases with a lower relative risk are those of work-relatedness of musculoskeletal disorders of the upper limb (16) and of occupational low back pain (17).

The reporting performance of physicians can be improved by education and training (18). The study presented in Chapter 5 demonstrated that education and training can improve the quality of notifications, while that in Chapter 6 showed that education and training should be focused on specific
issues. For example, for noise-induced occupational hearing loss, occupational physicians need education and training in medical history, audiometric measurement, clinical diagnosis of the disease and reporting. For occupational adjustment disorder education and training should be focused on estimating the relevance of occupational and non-occupational factors.

An imperative demand for registries of occupational diseases is the presence of a document that accounts for the statistical methods used. Besides the calculation of incidences, several other techniques could be used to enhance the information provided by registries. Record linkage, if possible with unique identifiers that can be linked to other databases, can provide information about the consequences of occupational diseases, for example unemployment, sickness absence or permanent work disability. If more than one registry is used to represent occupational diseases (triangulation), capture-recapture techniques can be used to make a better estimate of the incidence rate.

Extensions of registries and linked projects

Although most registries are not primarily set up as an instrument for tracing new risks, they can be enhanced to give them the ability to meet the conditions needed. An essential condition is that the registry is open not only for clear-cut cases that meet prescribed criteria, but also for unclear cases that are only suspected. In a next step after reporting exchange of more detailed information on the disease and exposure between the reporting physician and the personnel of the registry is crucial. Furthermore, it is important that all physicians are entitled and encouraged to report suspected cases to the registry. But also others, e.g. occupational health nurses, occupational hygienists and psychologists can be entitled and encouraged to report as they might be the first who may notice new unexpected health events that might be caused by conditions at work. A helpdesk can be useful to stimulate contact with an expert. It is important that potential reporters are widely and repeatedly informed that the registry exists. Next, there must be means to validate the signals of new risks or newly occurring occupational diseases and to disseminate the information to relevant groups.

Better incidence figures can be obtained by organizing sentinel surveillance projects with a group of motivated and intensively guided reporters. These projects can have the purpose to function
as a representative sample for the working population or can focus on specific occupational diseases, specific industrial branches or occupational groups. As demonstrated in Chapter 5 these projects can be embedded in a national registry or be set up separately.

Another possible extension of registries can be follow-up studies of reported cases, in order to obtain information about the course and consequences of occupational diseases, as described in Chapter 6. In addition, campaigns can be organized to promote reporting and prevention; such campaigns can be focused on specific occupational risks and diseases, specific industrial branches or occupational groups. However, the results of campaigns to promote reporting or prevention were not investigated for this thesis.

Furthermore, registries offer the possibility for case studies, in which, for example, the exposure or the use and effect of protective measures are investigated. Critical incidence analysis, in which incidents with a significant contribution to, for example, the occurrence of an occupational disease are determined and observed, can provide a better understanding of the development of occupational disease and give leads to preventive strategies (19). Obviously, there are more possible extensions of registries. We recommend enhancing the national registry of a country with several projects that will lead to the development of a dynamic set of instruments that will provide more comprehensive and relevant information for prevention.

Implications for further research

We recommend further study on the following issues: 1. quality improvement of existing registries, 2. alerting to newly occurring occupational diseases, 3. extension of registries and 4. better linking of registration to prevention.

1. Quality improvement of existing registries

National registries should collaborate in international projects to develop common case definitions based on scientific and professional evidence. In addition evidence-based guidelines are needed for the assessment of occupational diseases. There is no other way to provide reliable and international comparable figures on occupational diseases. As most registries are embedded in the
social security system(s) and legislation of a country and political negotiations play an important role in the development of these systems, this is not an easy operation and this will take a long period of time.

Development of evidence-based case definitions, aiming at the determination of the probability of causal inference on the individual level, is essential to record the right cases. A challenge is to explore the role of individual susceptibility, and the incorporation in case definitions. Next, the issue of how to assess the denominator is important for estimating incidence figures. The quality of diagnostics in practice and the task to improve the diagnostic skills of reporters is another area for improvement and evaluation study, as is the decision process of reporters and their attitudes and beliefs towards occupational diseases.

On the short run national registries can be used, for example, to study national trends in occupational diseases. In addition, they are important to keep occupational diseases on the social and political agenda and moreover, they offer many opportunities to extend the basic functions of the registry with projects that can offer unique relevant information tailor-made for preventive applications. Therefore, in spite of the limitations, we have recommended several options for quality improvement of existing registries. Further study is needed on the feasibility of these quality improvement options and their contribution to better quality information.

2. Alerting to newly occurring occupational diseases

In Chapter 2 it was suggested that methods used in pharmacovigilance systems to discover new adverse effects of drugs can be applied in tracing new occupational risks (20,21). Examples of methods used in pharmacovigilance are data mining in registry databases and sentinel reports from patients or physicians. Examples from the field of occupational medicine are the THOR Extra project in the UK (6), the Health Hazard Evaluation in the USA (7) and the European Agency for Safety and Health at Work reports containing expert forecasts on emerging physical, biological and psychosocial risks (10-12). To discover newly occurring occupational diseases active and passive methods can be distinguished. In passive methods existing health surveillance data are searched to find indications for possible new relationships between occupational causes and medical conditions. In active methods suspicious cases are reported and investigated. Further research is needed on how these methods can be applied to discover newly occurring occupational diseases. The discovery of possible newly
occurring occupational diseases has to be followed by strengthening and validating the evidence of causal inference. This can be done, for example, by consulting experts or specific research. Further research is needed to find appropriate and efficient strategies for strengthening and validating indications of newly occurring occupational diseases.

3. Extensions of registries

In Chapter 6 we demonstrated that the role of registries of occupational diseases for preventive policy can be extended by creating longitudinal data in sample projects. A great advantage of using registries as a study base is the flexibility and efficiency of linked sample studies, whereas primary studies often are expensive and take more time. On the other hand, the reliability of registries can be lower than that of primary studies. We recommend carrying out studies that compare data from registries with data from primary studies.

Further possible extensions of registries are sentinel surveillance, campaigns and case studies. We strongly recommend international collaboration in the setting up and evaluation of these projects. There is a clear need to start a number of sentinel surveillance projects in different countries as part of an international collaborative project, for two purposes. First these projects, using the same definitions and assessment guidelines, can provide more reliable incidence rates useful for comparisons as benchmarks between countries. In this way e.g. in the EU complementary information can be provided that can supplement the data of the European working conditions surveys of the European Foundation for the Improvement of living and Working Conditions (22). Second, these sentinel surveillance projects are important as examples for the national registries, EU authorities, national governments and social partners, showing the feasibility and advantages of international collaboration. These examples can also be regarded as the first steps toward a new, more evidence-based international harmonised system, useful not only for compensation but also more appropriate for prevention.

4. Better linking of registration to prevention

The studies presented in this thesis looked at registries of occupational diseases from the perspective of their use for prevention. It was proposed in Chapter 2 to distinguish several levels at which information can be provided for prevention: the workplace level, the sector or branch level, the
national level and the supranational level. On each level there is a need for information useful for prevention. The results of a qualitative study on the information needs of the various stakeholders have been presented in this thesis. Registries can provide this information only partially and additional sources of information are needed. Further research is needed on the role of registries in the process of prevention and on how quality improvement and extensions of registries can contribute to the obtention of more relevant information for preventive policy.

Recent developments

In the future we expect major quality improvements of the following projects in the Netherlands for the development of a set of instrument for monitoring occupational diseases and alerting to newly occurring occupational diseases.

1. A sentinel surveillance project in collaboration with a motivated group of occupational physicians to obtain better quality incidence figures and monitor information.

2. Quality improvement projects for the national registry of the Netherlands and for the registries of occupational skin diseases and respiratory diseases

3. A study aimed at developing methods for alerting to newly occurring occupational diseases.

4. A number of projects in collaboration with industrial branches to obtain better information about occupational diseases in these branches and to provide good practices for prevention

5. A study aimed at developing methods for case finding in areas of the labour market that are not covered by the present registry, such as contingent workers and the self-employed.

At the European level, several European centres for registration of occupational diseases, recently started collaboration in a project called Modernet that aims to improve instruments and methods for monitoring occupational diseases and for alerting to newly occurring occupational diseases. With
sufficient support of the EU authorities this can be the start of the improvement of the European registries of occupational diseases.

**Final conclusion and recommendations**

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 studies. 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 international collaboration to improve the quality of information on the incidence and prevalence of occupational diseases in Europe and on a global scale. 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.
References


