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

Citation for published version (APA):

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: http://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.
Chapter 2:

Time trends and blind spots: What employers, employees and policymakers want to know about occupational diseases

Abstract

**Background** - Occupational illness and accidents at work impose a heavy burden on both workers and employers and represent enormous economic costs. This burden could be substantially reduced through preventive measures. The objective of the study was to investigate what information employers, employees, policymakers and other stakeholders need in order to prevent occupational diseases and how these information needs can best be met.

**Methods** - We performed a survey, consisting of two rounds of interviews. In the first round, we interviewed eleven key stakeholder persons from employer organizations, employee organizations, the government, the Labour Inspectorate, the EU authorities and the society of occupational physicians. In the second round, we asked fourteen experts on the registration of diseases to comment on the results of the first round and to give their opinion on how these information needs could best be met. Between them, the experts represented six countries.

**Results** - From the first round of interviews we deduced five categories of information needs of 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. consequences of occupational diseases and resulting measures for policy evaluation purposes and 5. blind spots to reveal in which areas further investigation is needed.

The round of interviews with experts revealed that it is wise to rely on several instruments and findings to meet the comprehensive information needs of the stakeholders, such as sentinel surveillance, epidemiological studies and case tracing. In addition, the experts indicated that linking registration to prevention requires closer communication between providers of occupational diseases figures and stakeholders.

**Conclusions** - Five categories of information needs of stakeholders could be specified. A single registry of occupational diseases alone cannot satisfy all needs of the stakeholders. It is recommended to use several additional instruments and to maintain an ongoing dialogue between providers of figures and stakeholders.
Background

Occupational illness and accidents at work impose a heavy burden on both workers and employers and represent enormous economic costs (1) (2). The WHO states in its Global Plan of Action on Worker’s Health 2008-2017 that national approaches to the prevention of occupational disease and injuries should be developed according to each country’s priorities and in concert with WHO’s global campaigns (3). The EU has made the ongoing, sustainable and uniform reduction in the number of accidents at work and the incidence of occupational illnesses as the prime objective of the Community strategy on health and safety for the period 2007-2012 (4). In several EU countries, the government has set its own targets on reducing occupational illness and accidents at work. One example is the ‘Securing Health Together’ ten-year occupational health and safety strategy in the UK, which aims at achieving a reduction of 20% in the incidence of work-related ill health by 2010 (5). Both NIOSH in the USA and CCOHS in Canada indicate as one of their strategic goals the reduction in workplace illness and injuries (6) (7).

In order to evaluate whether targets of reduction in occupational illnesses have been achieved by policy measures, we must be able to monitor occupational diseases in a valid and reliable way. Valid monitoring presupposes clear case definitions of occupational diseases and valid instruments for assessment. Furthermore, for reliable monitoring the case capturing process and the data recording process have to meet certain requirements (8). For good comparability of figures between countries, it is necessary to harmonize definitions and methods concerning the registration of occupational diseases (9).

At present, various systems are used to monitor occupational diseases (10) (11). Besides national registries, several countries have additional schemes for the surveillance of occupational diseases (11). For example, many countries have set up registries of cases of occupational asthma, for example SWORD (Surveillance of Work-related & Occupational Respiratory Disease) in the UK (12) and SENSOR (Sentinel Event Notification Systems for Occupational Risks) in the USA (13) (14) (15) (16) (17) (18). Most national registries were set up in the context of a financial compensation system for occupational diseases and are embedded in the country’s social security system. At the same time, such systems are intended to provide policy information for the prevention of occupational diseases.
Although almost everyone acknowledges the importance of a preventive policy towards occupational diseases, there are diverging interests between the various stakeholders concerning how we should deal with this issue (19) (20). The parties that have to pay for the prevention of occupational diseases or to compensate for them - for example employers and insurers - will probably propose higher demands concerning the evidence of a causal relationship than workers and their representatives. Workers who perceive a disease as clearly work-related and who can claim for financial compensation, might try to facilitate the assessment of a causal relationship. On the other hand, workers and their organizations do not always feel that it is in their interest to detect occupational diseases, for example if there is a threat that they will lose their jobs either as individuals or as members of a collective of workers in a high-risk sector of industry.

These diverging interests have to be taken into account in formulating preventive policy on occupational diseases. Moreover, if we want to promote concrete preventive activities we also have to take into account the specific interests and needs of the stakeholders. This led us to our first research question, namely ‘What are the information needs on occupational diseases of the various stakeholders: employers, employees, national governments, the EU, labour inspectorates and occupational health professionals?’ Consequently, the second research question was: ‘How can these information needs best be met?’

Methods

Study design

To answer the research questions we performed a survey, consisting of two rounds of interviews with key stakeholder persons and experts. The interviews were carried out by three researchers who have long-standing international experience in the field of occupational health.
Interviews with stakeholders (first round)

To answer the first research question ('What are the information needs of the various stakeholders?'), we interviewed key persons from various stakeholder groups. As the project was executed under the assignment of the Netherlands Ministry of Social Affairs and Employment, which was mainly interested in the national situation, all the interviewees were Dutch. To select the key persons, the project group drafted a list of persons from the following stakeholder groups: employers, employees, the Ministry of Social Affairs and Employment, the Ministry of Health, the Labour Inspectorate and occupational health professionals. We consulted the researchers and occupational physicians of the Department of Occupational Health of our institute about the list and offered them the opportunity to add new names. The project group decided on the final list of key persons to be interviewed. We then asked the selected persons whether they were prepared to be interviewed. If they did not wish to be interviewed, we asked for their motivation and whether they could suggest another key stakeholder person. We informed the key stakeholder persons by letter or email about the aim of the project, the method to be used and the interview questions.

The project group formulated six open questions in order to structure the interview (see box 1). After the project group had drafted the interview questions, researchers and occupational physicians of the Department of Occupational Health of our institute were asked to comment on them. The project group decided on the final questionnaire. The interviews were open: the interviewees not only answered the questions but also expressed their opinions freely.

The interviews were recorded on tape and documented in a report, which was sent to the interviewees for verification. After processing the report on the basis of the comments of and additions by the interviewees, the report was filed in its final version.

Interviews with experts (second round)

We interviewed international experts on disease registration in general and on the registration and epidemiology of occupational diseases in particular, and asked them to comment on the results of the first round of interviews and to answer the second research question ('How can the information needs of the stakeholders best be met?'). To select the experts, the project group drafted a list of
persons who either had published on or were known to be occupied with the registration of occupational diseases or with disease registration in general. As in the first round, we consulted the researchers and occupational physicians of the Department of Occupational Health of our institute about the list and offered them the opportunity to add new names. The project group decided on the final list of experts to be interviewed. The procedure used to approach the experts was the same as that used to approach the key stakeholder persons.

The questions in the second round were based on the results of the first round. Both the procedure used to develop the questions and the way in which we carried out the interviews were the same as in the first round. The questions asked in the first and the second interview round are presented in box 1.

**Box 1: Questions asked in the interviews in the first and the second round**

<table>
<thead>
<tr>
<th>First round: stakeholders</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. In your opinion, what information is needed for policy concerning the monitoring and prevention of occupational diseases?</td>
</tr>
<tr>
<td>2. Can you rank according to their importance the issues you mentioned in your answer to the first question?</td>
</tr>
<tr>
<td>3. What is the required level of specification for the issues?</td>
</tr>
<tr>
<td>4. If the information you want were to become available, for what purpose would you use it?</td>
</tr>
<tr>
<td>5. Can you estimate the economic value of the information you want? (In other words: how much are you willing to pay for it?)</td>
</tr>
<tr>
<td>6. Do you feel a need for information on specific groups? If so, which groups and what information do you want on those groups?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Second round: experts</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Which types of medical registration systems have you worked with?</td>
</tr>
<tr>
<td>2. Can you indicate the pros and cons of each type of registration system (practicability, response, yield, interpretation, required manpower, costs, etc.)?</td>
</tr>
<tr>
<td>3. Did you encounter any bottlenecks when working with these registration systems, and if so, what were they? What solutions were tried and what was the result?</td>
</tr>
</tbody>
</table>
| 4. When it comes to collecting general information on occupational diseases (overviews), what would
be the most suitable type/types of registration system/systems? Are there any conditions that would need to be met before implementing this type/these types of registration system/systems?

5. When it comes to collecting detailed, specific information on occupational diseases (numbers and overviews per profession or branch, etc.), what would be the most suitable type/types of registration system/systems? Are there any conditions that would need to be met before implementing this type/these types of registration system/systems?

6. How could additional information (duration, severity, absenteeism, incapacity for work, reintegration, etc.) on occupational diseases be collected? Can this be done by using a registration system or would other methods of analysis be more appropriate? Can you mention any preconditions related to the application of a registration method or other similar system?

Analysis of the interviews

To analyse the interview reports of the first and the second round, we used several methods for quality assurance as recommended by Ploch and van Zwieten (21). The reports of the interviews were studied by all five members of the project group. We then discussed the material in project group meetings and pursued getting agreement on the answers to the research questions. Minutes were taken at the meetings, and later the members of the project group had the opportunity to comment on them. The results of the project were presented at a departmental meeting in which researchers and occupational health experts commented on the conclusions of the project group and the methods used. The project group decided on the final formulation of the results and the conclusions.

Results

In the first round we interviewed eleven key persons in nine interviews. We interviewed two officials of the Netherlands Ministry of Social Affairs and Employment together in one interview; four officials of three employee organizations in three interviews; three officials of three employer organizations in separate interviews; an official of the Labour Inspectorate; and a representative of the Dutch society of occupational physicians.
In the second round we interviewed five Dutch experts, four experts from the UK, two from Finland, and one each from France, Belgium and Germany. The Dutch experts were acquainted with disease registrations in fields varying from disease registration by GPs, registration of sickness absence, adverse effects of drugs, intensive care registration, registration in cardiac surgery, renal substitution therapy, perinatal registration and mortality statistics. The Belgian expert was involved in the registration of needle stick injuries. The other experts were primarily acquainted with various registries of occupational diseases. One of the experts was an official from Eurostat.

*Information needs of stakeholders*

All stakeholders stressed the need to improve the linking of figures from registries with the prevention of occupational diseases. Hereunder, we list in five categories the information needs of stakeholders. The value that stakeholders attached to these categories varied, as did the desired quality of the information. Some striking statements taken from the stakeholder interviews are presented in box 2.

Stakeholders want the information for differing purposes. Employers want detailed information on causal inferences to use for liability purposes. The unions’ representatives considered the information important for collective labour agreement negotiations. Employers and employees are both interested in figures to benchmark between industries. The government wants to use the figures to stimulate and evaluate employers’ and employees’ preventive activities. The Labour Inspectorate wants to use the information for its audit and enforcement strategy, while occupational health professionals would like to use the information for quality improvement of the care and facilities offered. Other possible stakeholders - such as insurance companies, GPs and medical specialists - were suggested during the interviews.

All of the interviewed key stakeholder persons estimated the economic costs of occupational diseases to be in the order of several billion euros on a national level. Therefore, all stakeholders considered reliable information on occupational diseases as highly relevant. However, they did not agree on the financial responsibility to collect, analyse and disseminate information on occupational diseases.
Stakeholders were interested in specific topics, such as effects of chemical exposure, mental health disorders and groups at special risk (e.g. pregnant women, and young and elderly employees).

Finally, we formulated five categories of information needs of relevant stakeholders.

1. **Time trends of occupational diseases for setting policy priorities:** figures of occupational diseases divided by sectors or occupational groups, especially suitable for monitoring trends in time and for priority setting on a macro level. Particularly the Ministry of Social Affairs and Employment and the Labour Inspectorate were interested in reliable statistical figures and subdivisions into personal characteristics such as sex, age, education and ethnicity. Provision of these figures can trace high-risk groups for which special efforts are needed on prevention and control. In some cases figures can induce research to clarify unknown reasons for a specific high risk. Employers and employees were not so much interested in detailed figures as in rough indications of where problems could be expected. Although they were less interested in detailed statistics, employers and employees stressed the importance of good quality assessment in individual cases.

2. **Cases of new occupational diseases for early preventive action:** specific and detailed information on new or rare diseases, unusual patterns of already known or common diseases, and suspicious exposure-disease associations at the individual level. All stakeholders characterized this information as being of the utmost importance. The representative of the Labour Inspectorate indicated that ‘tracing new occupational risks is a spearhead in national policy’. An employers’ representative indicated the importance of the early detection of new risks, referring to the unfortunate history of asbestos and solvent exposure.

3. **Disease patterns in specific occupational groups for focused prevention measures:** both employers and employees were particularly interested in specific and detailed information that can be applied for preventive activities. One of the employees’ representatives stated that ‘data on occupational diseases should be translated into concrete preventive measures’. Employers’ representatives stressed that it is important ‘to describe very precisely the various occupations with their specific risks’ and the ‘need for risk estimates of occupational diseases related to small companies’. One of the employer’s representatives said that it would be interesting to know whether there is diversity in occupational disease patterns considering large companies and small and medium-sized enterprises. Operational management and possibilities for prevention in small and
medium-sized enterprises might differ from those in large companies. For example, regulations for machine safety are often framed from the perspective of large companies, whereas small enterprises sometimes cannot afford the investments for the required adjustments.

4. Consequences of occupational diseases and resulting measures for policy evaluation purposes: this includes information on the circumstances in which occupational diseases occur, preventive and control measures taken, adverse consequences of the disease, medical treatment applied and rehabilitation. Particularly the Ministry of Social Affairs and Employment and the Labour Inspectorate were interested in information on the whole course from origin to social consequences of occupational diseases. Employers and employees were mainly interested in sickness absence rates related to occupational diseases.

5. Blind spots to reveal in which areas further investigation is needed: in general there is large-scale underreporting in all registries of occupational diseases, and some sectors or occupational groups are hardly represented in the official statistics. There might be several reasons why these cases do not appear in the registries, for example administrative barriers, employees’ fear of conflict or of losing their jobs, or a lack of knowledge or motivation on the part of physicians to report. Consequently, opportunities for prevention are missed. All stakeholders were interested in information on these blind spots and the reasons behind them. One of the employees’ representatives urged the necessity of an analysis of the whole process from health complaints to interventions. It was suggested that employees could be empowered to insist on the examination and reporting of possible work-related complaints and that diagnosing and reporting of occupational diseases should have a high priority for physicians.

Box 2: Striking statements taken from the stakeholder interviews

<table>
<thead>
<tr>
<th>Employees’ representatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘Figures on occupational diseases could be important ammunition in labour agreement negotiations.’</td>
</tr>
<tr>
<td>‘Occupational physicians should be prosecuted if they do not report an occupational disease.’</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employers’ representatives</th>
</tr>
</thead>
<tbody>
<tr>
<td>‘For employers, sickness absence is the most important perspective with regard to occupational diseases.’</td>
</tr>
<tr>
<td>‘The administrative burden on employers must not be increased.’</td>
</tr>
</tbody>
</table>
Government representatives

‘Prevention of occupational diseases is primarily an employers’ and employees’ responsibility.’

Labour Inspectorate representative

‘Tracing new occupational risks has to be a spearhead in national policy.’

Occupational health professionals’ representative

‘Notification of occupational diseases should be less free of obligations.’
‘Figures on occupational diseases can provide information for priority setting in the development of new professional guidelines.’

How can the information needs be met best?

All experts emphasized that there is no single answer to the question how the information needs of stakeholders can be met optimally. A clear policy of the government can support prevention. For example, in 2000 the UK government formulated a ten-year strategy - the government health and safety targets - to reduce occupational diseases and injuries (5). Information from registries can be used to evaluate the objectives set. However, the reliability of the figures on occupational diseases provided by registries is often poor. Quality improvement of registries is needed to justify their use for preventive policy.

The presence of a financial compensation system is a crucial element in the socio-political context. A compensation system offers legal security to at least a group of workers with an occupational disease and will prevent often long-lasting lawsuits. An advantage of a compensation system may be the availability of clear case-definitions and a high quality of the acknowledgement of cases. Consequently, figures over years can be well comparable, allowing trend analysis within a country. A major disadvantage is that the only diseases that are registered are those that have undergone a long process of socio-political negotiations before being acknowledged as compensable occupational diseases. A large part of occupational morbidity - such as work-related mental illnesses, cardiovascular diseases and a number of musculoskeletal diseases - is not registered at all in many registries that are embedded in a compensation system. In addition, there can be obstacles to reporting, such as fear of job loss or fear of conflicts with employers.
1. **Time trends of occupational diseases for setting policy priorities**

Statistics on occupational diseases can be extracted from several sources, such as epidemiological studies, employee surveys or registries. Confining ourselves to registries, several experts stated that the distinction between administrative registries and notification systems is important. In administrative registries, personal data are not collected for statistics in the first instance, but for example for social security purposes. In notification systems cases are reported, mostly anonymously, directly for statistical aims. The advantages of administrative registries are the mostly superior possibilities for analyses over time and for data linkage with other data and registries.

Experts shared the opinion that specific occupational diseases need specific monitoring methods. One of the experts stated that ‘in the case of diseases that are nearly exclusively occupational, such as silicosis or asbestosis, it is sufficient to count cases. This can be done from death certificates if the disease has a high mortality rate. For disorders with low relative risks, for example back pain related to heavy occupational lifting or lung cancer related to exposure to polycyclic aromatic hydrocarbons, a better approach is to assess the attributed proportion of the total morbidity related to various causes by epidemiological methods.’ In general, such factors as clinical features of the disease (e.g. latency or course) and the strength of the causal relationship determine the preferred monitoring method. Accurately assessing the absolute burden of disease attributable to work can require more complex and accurate methods than monitoring for trends. In monitoring for trends, it might not matter if there is some under-ascertainment of cases, provided the level of under-ascertainment remains fairly constant over time.

The experts indicated the importance of combining techniques for data analysis in order to get a more accurate result, for example a combination of trend analysis, the use of several data sources (triangulation), record linking or application of correction factors. They also stressed that a better insight into the denominator of the population at risk is needed in order to estimate incidences of occupational diseases. Some experts advised limiting the number of notifiable diseases and minimizing the required data set in order to enhance reporting and acquire data of better quality.

2. **Cases of new occupational diseases for early preventive action**

According to one of the experts: ‘a real challenge is to identify new and emerging risks.’ Tracing new and emerging risks requires another approach than monitoring occupational diseases.
Communication with potential reporters (physicians, as well as insurers, companies and employees) and validation of the signals through further clinical examination of patients and workplace visits, followed by the adequate dissemination of the information to the target groups, were considered high priorities. The experts added that performing periodic literature reviews and establishing networks of experts can contribute to the discovery of new and emerging risks. Furthermore, it was suggested that methods used in pharmacovigilance systems to discover new adverse effects of drugs, could be applied in tracing new occupational risks. Examples of methods used in pharmacovigilance are data mining in register databases and sentinel reports from patients or physicians.

Examples of systems that are aimed at tracing new and emerging risks based on sentinel reports are the THOR-Extra project in the UK - in which all physicians can report interesting cases or suspected novel causes - and the Health Hazard Evaluation in the USA, in which a request by three employees is sufficient to launch an investigation into work-related diseases. For example, several years ago the HHE revealed the popcorn workers lung based on a patient's report of lung complaints after exposure to diacetyl.

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

One expert mentioned the example of the registration of needle stick injuries in her country. Every needle stick injury is registered in the hospital's database. Hospitals all over the country use the same database system. The notification of an accident in a database is the start of a follow-up procedure. On a national level, the information in the various hospital databases is gathered for preventive policy aims.

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

In order to monitor the whole course of occupational diseases from cause to final consequences, other methods than just reporting cases are required. Course monitoring requires the formulation of clear targets and the choice of characteristics that can be followed over time. For example, in order to assess the effect of preventive measures in health care workers on latex sensitization, one can monitor the ultimate response (cases of latex sensitization), but one can also monitor indicators of intermediates, such as the use of latex-free gloves at the workplace.
5. Blind spots to reveal in which areas further investigation is needed

Active tracing of cases can reveal the occurrence of occupational diseases in sectors or occupational groups that have a high degree of underreporting. Some experts mentioned projects whose aim is to reveal hidden occupational diseases. A possible approach is to examine the files of patients who have diseases that might be occupational but are not yet reported. The files of these patients could be examined for information about occupation or past exposures.

Another way to get an insight into the blind spots might be surveys, in which employees are asked to report work-related diseases and health complaints. A disadvantage of surveys might be the poor validity of the assessment of the work-relatedness of a disease. Figures of occupational diseases, derived from self-reporting by employees, tend to be much higher than the figures derived from compensation schemes or reporting by physicians. However, one of the experts stated that ‘a great advantage of self-reporting by patients is that you get information that has not been filtered by physicians’.

**Box 3: Striking statements taken from the expert interviews**

| Time trends of occupational diseases for setting policy priorities: | ‘The focus for the future should be on building monitoring systems for work-related diseases, such as cardiovascular diseases.’ |
| Cases of new occupational diseases for early preventive action: | ‘A real challenge is to identify new risks. This will be partly possible within existing reporting systems. Communication is very important here.’ |
| Disease patterns in specific occupational groups for focused prevention measure: | ‘We organize meetings with all the stakeholder groups’. |
| Consequences of occupational diseases and resulting measures for policy evaluation purposes: | ‘Course monitoring requires formulation of clear targets and the choice of characteristics that can be followed over time to monitor the process.’ |
| Blind spots to reveal in which areas further investigation is needed: | ‘A great advantage of self-reporting by patients is that you get information that has not been filtered by physicians.’ |
Discussion

We interviewed key stakeholder persons in prevention to chart the information they need in order to improve the registration of occupational diseases and to better link registration to prevention. From these interviews we deduced five categories of information needs: 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 measure, 4. consequences of occupational diseases and resulting measures for policy evaluation purposes, and 5. blind spots to reveal in which areas further investigation is needed.

There is no single answer to the question how these information needs can best be met. The advice of experts is to use several sources of information for the monitoring of occupational diseases, including registries and the results of epidemiological studies, surveys and focused projects. Tracing of new and emerging risks requires other methods and instruments, including sentinel surveillance, periodic literature searches and data mining. Close communication with stakeholders and reporters is of paramount importance to effectively link registration to prevention. Active tracing of cases can reveal the occurrence of occupational diseases in sectors or occupational groups that have a high degree of underreporting (blind spots).

A strength of this study is that we first asked stakeholders about their information needs, because they are the actors responsible for preventive policy and activities. This approach can result in leads to tailor-made registrations related to preventive activities. Subsequently, experts on registration can advise about the best methods to gather the needed information, taking into consideration the information yield, the costs and the information quality.

Another strength of our study is the division into clear categories of information needs and the indication how stakeholders value these categories of information. This knowledge can support the decision process for setting up monitoring systems in terms of fitting the information to the target group. Furthermore, experts’ recommendations can indicate which factors should be taken into account when setting up or maintaining monitoring systems for occupational diseases.
A limitation of the study is that not all stakeholders were involved. For example, we did not interview representatives of insurance companies or claim settlement agencies, or lawyers, GPs or medical specialists.

Another limitation is that we did not explore motives or practice in depth. Stakeholders might not have much interest in active monitoring, for example because preventive activities are expensive or because revealing better figures might disturb established relationships between employers and employees. Moreover, occupational physicians are sometimes hesitant to report occupational diseases because they do not want to risk damaging their relationship with the employer. Regarded from this perspective, in some cases socially desirable answers might have been given by the stakeholders.

A further limitation, one that is probably inherent to the subject, is that although the information provided by the interviews with the experts is detailed and balanced, it does not give a clear answer to the question how the information needs of stakeholders can best be met. The development of a set of methods and instruments to satisfy the needs of the various stakeholders requires an iterative method with continuous innovation and frequent evaluation. Of course, this way of proceeding can only succeed in close communication with the stakeholders. The result might be a set of various instruments and methods.

To make the general picture provided by this study manageable for registration and prevention practice, we propose the development of scenarios for monitoring occupational diseases on several levels. Verma et al. (22) stated that the development of control strategies for occupational hazards takes place at the societal and the local workplace level. These two levels have differing information needs. At the societal level, control measures are usually through regulatory actions on the national level or the industrial sector level. Information is then needed on possible exposure-effect relationships as well as on workplace demographics. At the local workplace level, information is needed on the nature of the hazard, where it is likely to be encountered and the available options for risk reduction. We propose to develop scenarios on three levels: a national scenario, a scenario for branch or sector approaches, and a scenario for the company level. The basic idea is that monitoring should be linked to preventive measures.
On the national level, reliable information is needed about exposure-effect relationships, the extent of the problem and the costs. Information should be monitored over time in order to evaluate whether preventive policy is effective. The information can be used as input for decisions on legislation and government policy. Furthermore, monitoring activities can support public campaigns focused on prevention and can be used for evaluating such campaigns (23) (24).

On the branch or sector level, more detailed information is needed on hazards and exposure-effect relationships within the branch or sector, where possible within specific occupations, with a clear reference to a range of solutions. Reliable figures of disease incidences in the sector and the occupational level can be used for benchmarking. Special attention should be given to work-related problems that are specific to the sector, such as reproductive hazards in the health care sector (which has a high number of young female employees).

On the workplace level, information is needed on the nature of the hazard and where it is likely to be encountered, and on the risk of occurrence of occupational diseases and the available options for risk reduction. This information can be derived from monitoring systems as well as from surveys or scientific literature (25) (26). Knowledge should be disseminated on demand rather than by periodic reports.

Information on the economic costs of work-related ill health and the economic benefits of occupational health interventions is important for drafting national health strategies (27). Economic data are useful on a company level to develop a health and safety strategy (28). On a supranational level, there is a need to develop and harmonize national indicators in order to be able to compare countries and to exchange experiences (29). To put the issue on the political agenda, it is crucial to assess the burden of occupational disease (2) (30).

As stated, we did not explore in depth the motives of the stakeholders or the practice of registration. Further research is needed into the social context and the role and position of the stakeholders involved in preventing and compensating for occupational diseases. This type of research can provide information for the development of strategies for the prevention of and compensation for occupational diseases. Furthermore, cost-effect studies concerning preventive measures are very much needed. All the stakeholders we interviewed estimated the costs of the
consequences of occupational diseases to be in the order of several billion euros on a national level, but there is hardly any information on the opportunity costs of preventive measures.

Various aspects of the practical implementation of the registration of occupational diseases need further study. The themes provided by the experts can give leads to quality improvement projects and evaluation studies. Examples are a Dutch study of the quality of diagnosing and reporting by occupational physicians (31) and a study of physicians’ beliefs in the assessment of work attribution when reporting musculoskeletal disorders (32).

Our study reveals that discovering new occupational risks needs a different approach from that used to monitor occupational diseases. Methods for tracing, validating and disseminating information about new risks need to be explored and evaluated. Promising examples are the THOR-Extra project in the UK (33), the activities of the European Risk Observatory (34) and case investigations in the Health Hazard Evaluation (HHE) in the USA (35). The consecutive steps used in pharmacovigilance - namely signal discovery, strengthening, confirmation and dissemination - seem applicable also for the discovery of new occupational risks (36) (37). The study of Bonneterre (38) is an example of the application of pharmacovigilance methods to occupational diseases databases, in which unknown associations were traced by data mining.

Blind spots - areas of the labour market that have hidden occupational diseases - are a matter of concern to the various stakeholders. The experts we interviewed recommended the development of methods for charting these blind spots. Projects of active case finding in certain sectors or occupational groups are advocated to uncover blind spots.

Conclusion

Identifying stakeholders’ information needs on occupational diseases can result in leads to tailor-made registrations related to preventive activities. Five categories of information needs of stakeholders could be specified. A single registry of occupational diseases alone cannot satisfy all needs of the stakeholders. It is recommended to use several additional instruments and to maintain an ongoing dialogue between providers of figures and stakeholders.
Acknowledgements

We should like to thank all the key stakeholder persons and the experts who were prepared to be interviewed for this study.
References


