

Four stages when developing an Occupational Diseases Surveillance program

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What are the stages that you have to follow when developing a good quality, relevant occupational diseases surveillance program? It might be wise that you pass a number of stages of development in order not to miss essential considerations and decisions that you have to take.

We prefer to explore various considerations openly and to take the decisions transparently after considering various alternatives and consequences of each decision, instead of making choices based on limited examples and sometimes not even knowing that you have decided to take one road or another. Following an elaborated decision scheme supports the quality and finally the evidence-base of the surveillance system developed.

Four stages

We propose to distinguish four stages in the process of developing a good Occupational Diseases Surveillance program

1. The stage **conceptualization** of **what** you want to assess, **in which population, during which period of time** and using a specific **surveillance design**.
2. The stage of **instrumentalization** in which stage you decide **how to assess** what you want to know. The measurement instrument and procedure chosen can be related to a chosen **occupational disease classification system**, if you decided that you want to make use of such a system.
3. The stage of **analysis** during which data coming from the surveillance are transformed in valid and relevant information that you want to have.
4. The stage of formulating **conclusions and recommendations** and making choices for the **dissemination** of these.

The chosen **aims and specific objectives** of the surveillance are leading in a number of decisions during the development process. Quality aspects have to be considered for all stages. To improve the quality you will need education especially of the health care workers or others who are doing the surveillance in practice, information for all involved, support and referral options to be used mostly by the professionals or volunteers who are doing the surveillance, in case of complex cases or situations.

Conceptualisation

During this stage you will make decisions based on the aims and objectives, the local background and the literature, about:

- **What** you want to assess
 - Occupational diseases as notified related to a **social security system** in a country or as notified to promote **prevention**
 - Only 'occupational diseases' or also including '**work-related diseases**'
 - Inclusion of occupational **injuries** such as eye and head injuries and acute musculoskeletal disorders
 - **Incidence** figures and/or **prevalence** figures
 - Inclusion or not of **aggravation of an existing occupational disease**
 - Is the focus on well-known occupational diseases (**monitoring system**) or on not-well-known, so new or emerging potential occupational diseases (**alert system**)
 - Is the focus on **all occupational diseases** in a population or on **one occupational disease** or one group of occupational diseases
 - Is the focus on **all risk factors** in a population and related occupational diseases; or on **one or one group of risk factors**
 - The severity of a disease as inclusion criterion for a case
 - How sure do you (mostly health care professional) have to be about the causal relationship with work as inclusion criterion for a case
- **Which population** do you select for the assessments?
 - An **open population** in a region e.g. all adults in one region; or all workers in one region; or only all salaried employees in one region
 - A population of **workers** belonging to one **occupational group** (welders)
 - A population of **workers being exposed** to one risk (welding)
 - A population of **patients with all kind of diseases or with only one disease**
 - A population of patients in the **primary health care** and/or **community health care** and/or **occupational health care** and/or **hospital patients**
 - Do you want to study the whole population or a **sample** of that population and if yes what kind of sample?
 - Do you decide to do an **active surveillance** minimizing non-response, or a **passive surveillance** (wait and see)?
- **During which time period** do you want to measure ,and what **study design** is chosen
 - During one year or five years counting **new cases in a chosen population (cross-sectional design)**
 - Follow-up of a defined cohort of workers during a period of one or five year (**cohort design**). Do you make a choice for a **prospective** or **retrospective surveillance design**?

Instrumentalisation

During this stage, based on aims and objectives, the local context and literature, you will make decisions about:

- The kind and quality of **diagnostic instruments and related protocols** to assess a case
- The kind and quality of **health care personnel** that decides about the inclusion of cases after making a diagnosis; e.g. only medical doctors will do so who are well-trained in occupational diseases? Are self-reports of workers or patients included without doctor-confirmation?
- Instruments and protocols can be related to a chosen **Occupational Diseases registration system** such as **ICD-10 or ICD-11**, or the **EU registration and notification system**; or the **ILO system**, or a **national OD registration/notification system**. Such wide-scope OD registration systems are most relevant for the surveillance of a wide range of ODs. For specific occupational groups and for specific occupational diseases, **a large variety of specific instruments and protocols have been developed tailor-made** for (1) an occupational group, (2) a risk factor, (3) a specific occupational disease even in an early phase, or (4) for a specific health care personnel group as lung specialists or occupational physicians. You have to decide which system or specific instruments to use.
- **What will be registered:** kind of occupational disease, related risk factors (work-related or other) or occupations, susceptibility factors, strength of the association with work , ..

Analysis

During this stage, based on practical and epidemiologic experience and literature, you have to decide about:

- If and how to **adjust for bias (errors, mistakes)** caused by
 - **Selection**, e.g. the population that is contacting/responding can be more healthy or more ill; participants can be relatively high exposed or the opposite: low exposed. Ill workers may avoid contact because of anxiety for job loss. A healthy worker effect may be strong: most ill workers have already left the job or even never entered high-risk jobs
 - **Information bias** in workers and/or in health care personnel caused by lack of awareness, poor knowledge, failing information system, poor support, lack of referral options; all stakeholders can have reasons to avoiding the association of a disease with work
 - **Confounding** bias e.g. adjusting for non-work related risk factors e.g. smoking ?
 - **Low coverage** of the ill workers by health care personnel may be a serious issue: ask how many contacts there are in a year
 - **Scaling up** from a sample to the whole population ? Only after adjustments?
 - Using **statistics** such as confidence intervals, trend analysis over years, before-after evaluation statistics, sensitivity analysis, etc.

Conclusions, recommendations and dissemination

During this stage, mainly based on your aims and objectives, you will decide about:

- To which **target groups you want to report**: workers and professionals involved in the surveillance, workers' and employers' associations, government, insurers, international bodies, scientific journals, colleagues in congresses, others
- **What** you will report, e.g. only own figures; or your own figures in the **context of other national or international figures and/or studies** on the occurrence of occupational diseases
- Including considerations or figures on general **economic and social consequences** of ODs, **personal consequences** for workers: work disability or job loss, etc.
- Focus on disease figures, or also including **recommendations on preventive measures** or **evaluating preventive measures** that were taken
- Including considerations about **high-risk workers and susceptible groups** (pregnant workers, ageing workers, young workers, migrants, informal workers, etc)
- Including **comments on the quality and coverage** of your own work: the surveillance process including the quality of the own data and information generated
- Having an active or a passive **dissemination policy**
- Database is **free accessible** for public, or only for other researchers, or not accessible?